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Review

Natural Language Processing and Machine Learning Techniques for Analyzing Conversations About Nutritional Yeasts in the United States and France: Retrospective Social Media Listening Study

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Abstract

Background: Nutritional yeast, an inactive form of *Saccharomyces cerevisiae*, has recently become increasingly popular as a food supplement and healthy ingredient, especially among individuals following plant-based diets. It is valued for its health benefits and high content of B vitamins, minerals, and protein. Social media has enabled people to share information and personal experiences at an unprecedented level, further amplifying conversations around health and nutrition. With the rise of social media, data mining techniques like natural language processing and machine learning are increasingly used for analyzing the large amounts of information generated on these platforms.

Objective: This study aimed to analyze social media data from the United States and France to identify the most frequently discussed topics among nutritional yeast consumers. The objective was to fill gaps in our understanding of the perceptions, experiences, and usage trends related to nutritional yeast.

Methods: This study was retrospective, using social media data geolocated in the United States and France, posted by users discussing nutritional yeast between December 2017 and September 2023. Data cleaning and filtering were done using natural language processing methods and specific algorithms. Biterm topic modeling was applied to identify the most frequently discussed topics.

Results: A total of 36,642 posts written by 28,069 users discussing nutritional yeast were identified across 1039 publicly available online sources. This included 34,292 posts from the United States (26,154 users across 994 sources) and 2350 from France (n=1915 users across 45 sources). Twitter was the most commonly used platform in both countries, accounting for 39.6% of posts in the United States (13,587/34,292) and 84.3% in France (1982/2350). In the United States, conversations centered around the role of nutritional yeast role as a vegan nutrient source (n=12,345, 36.0%). Several users highlighted its culinary versatility as a natural seasoning (n=8093, 23.6%) and its health and skin benefits (n=6173, 18.0%). In France, discussions frequently focused on nutritional yeast's use in dietary supplement routines in various forms (n=1177, 50.1%), emphasizing its benefits alongside other supplements such as castor oil, particularly noted for effects on nails and hair (n=928, 39.5%).

Conclusions: This social media listening study identified the perceptions and preferences of nutritional yeast users in France and the United States. Researchers and health care professionals can reflect on these findings to investigate the potential health benefits of nutritional yeast for specific groups and its long-term impact on different diets and lifestyles. Marketers may also use this information to create customized strategies that better align with the preferences and needs of each market.

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KEYWORDS

nutritional yeast; social media listening; natural language processing; machine learning; infodemiology study

Introduction

For thousands of years, yeast has been used in the preparation of food and beverages due to its fermentation properties in baking and brewing. Nutritional yeast, an inactive form of *Saccharomyces cerevisiae* [1], has been consumed for its health benefits since the early 20th century. More recently, it has become popular as a food supplement and cooking ingredient. Nutritional yeast—also known as brewer's yeast—is rich in B vitamins, minerals, and protein, making it both nutritious and flavorful [2,3]. In today's world, where healthy living is a priority for many, it has become an important part of vegan and vegetarian diets. Individuals following a raw vegan diet and experiencing B12 deficiency showed significant improvement after supplementing with nutritional yeast and sublingual B12 tablets, whereas probiotic supplements did not yield similar benefits [4]. Additionally, a randomized double-blind clinical trial involving adults with type 2 diabetes mellitus found that brewer's yeast supplementation improved blood pressure [5]. Another study reported beneficial effects on serum triacylglycerol and glucose tolerance [6]. Nutritional yeast has also been shown to support the immune and gastrointestinal systems; it includes probiotics and postbiotics that help in immune modulation, strengthening the body's defense against pathogens [7,8]. Furthermore, it contributes to the balance and growth of gut microbiota, promoting gastrointestinal health and overall well-being [9,10]. As awareness of healthy nutrition continues to grow, nutritional yeast is gaining popularity among a broader population looking for healthier food options or to modify their shopping, cooking, and eating habits as a whole [3,11].

As consumers become more health conscious and search for information about food supplements, they are increasingly turning to social media to gain knowledge about health and nutrition [12]. Users engage online for various purposes, including sharing information and personal experiences, participating in medical education [13], gaining awareness around health campaigns [14,15], and becoming members of online communities [16]. Twitter, Facebook, and health-related forums are increasingly used for information about nutrition, dietary supplements, and related topics [17-19], especially among younger individuals [20].

Given the vast volume of data generated through social media, data mining is being applied to analyze user-generated content [21]. This artificial intelligence technique includes natural language processing, which allows machines to analyze textual data to comprehend human language [22], and machine learning, which creates algorithms that recognize patterns in data and produce predictions [23], both of which are progressively used within this framework [24]. As a result, public perceptions, trends, and behaviors can be identified.

Although nutritional yeast is gaining popularity, knowledge about public opinions and usage patterns is still limited. While previous research has explored its health benefits, little is known about the discussions surrounding it, particularly on social media. Moreover, comparative analyses between different cultural and geographical contexts, such as the United States and France, are scarce. This study, which focuses on online discussions in the United States and France, aims to fill this gap by exploring how nutritional yeast is discussed, used, and perceived. Through data mining, we aim to identify the main topics of discussion on social media among consumers of nutritional yeast.

Methods

Study Design and Population

The present study is retrospective, using data from social media posts by nutritional yeast users geolocated in the United States and France.

Data Extraction

Between December 2017 and September 2023, messages were retrieved from general, publicly accessed sites (eg, Twitter, Reddit) and health-related forums (eg, Doctissimo in France and HealthUnlocked [25] in the United States). Due to restricted data access and closed groups, Facebook and WhatsApp were excluded from this study. An extraction query featuring relevant keywords was first developed to identify pertinent messages. Keywords associated with nutritional yeast were included in English (eg, brewer's yeast, nutritional yeast) and French (eg, levure de bière, *Saccharomyces cerevisiae*). The complete list of keywords was subsequently used in the extraction query (Multimedia Appendix 1).

Using the Brandwatch extractor (Cision Ltd.) [26], we identified and gathered all publicly available posts that contained one of the required keywords, along with their associated metadata (eg, author, publication date). Posts were also geolocated using Brandwatch. When applicable, various spellings of a keyword were considered in the extraction query. For example, the word bière was inserted as biere, bierre, and bier and the words brewer's yeast were included as brewer's yeast and brewer yeast. This approach allowed us to increase exhaustivity by including the various ways an internet user might spell a keyword.

Data Cleaning

First, messages were harmonized to ensure consistency across the dataset. We switched all characters in the messages to lowercase format and removed all accents and apostrophes from words; this approach helped achieve a smoother cleaning, and eliminating duplicates.

The cleaning process then established a list of exclusion criteria, removing messages from sources deemed unsafe or irrelevant (eg, advertising websites, forums related to cars, pets, or animals), duplicate posts, messages containing five words or less, and posts exceeding 10,000 characters. Generally, a message with fewer than five words does not contain enough information to be effectively exploitable and interpreted. Messages exceeding 10,000 characters are rare and nevertheless, are excluded from the analysis dataset due to excessive processing time.

To determine the number of messages for each keyword, we applied a "presence" step. This involved automatically searching the dataset for keywords and identifying the messages that contained them. Not all messages mentioning nutritional yeast were from people who had consumed it—some may have been discussing it without personal use. To address this, we applied a supervised machine learning algorithm [27] to identify messages specifically from nutritional yeast users. This algorithm classified each message by determining whether the user had taken the mentioned "treatment" (nutritional yeast), assigning a value of 0 for no intake and 1 for intake. It analyzed language to make predictions, including first-person pronouns to detect personal use, sentiment words to understand the emotional context, verb tenses for timing, negation words, and possessive pronouns to detect whether a statement denied or confirmed use. The algorithm was trained and tested on a sample of 1563 messages that spanned a range of pathologies. Its ability to detect whether a treatment was taken generated the following performance results: accuracy, 72%; F_1-score, 74%; sensibility, 78%; specificity, 66%; and precision, 70%. To extend its application to English-language messages, we translated these into French before applying the algorithm, which was initially developed and optimized for French. We then separated the messages into French and US datasets based on the language of the original messages.

Multiple human annotators annotated random samples of messages to further validate the algorithm's output. This step ensured that the algorithm's results were pertinent and accurate.

Topics of Discussion

The main discussion themes among nutritional yeast consumers were identified using Biterm Topic Modeling (BTM). BTM is a natural language processing approach that analyzes large volumes of text and clusters similar text based on common topics [28]. BTM automatically groups messages into different categories—each representing a specific topic—in descending order of frequency. For each category, BTM provides a list of the most recurring words, which helps understand the general focus of each topic. For example, a BTM result about breast cancer may include:

Topic 1 | Proportion of messages = x | List of most frequently mentioned words: body, image, confidence, scars, mastectomy, hair loss, appearance, self-esteem, femininity.

These words suggest a focus on body image issues, which can be further validated when reviewing the messages associated with Topic 1. This allows us to assign a title to the topic, such as *Impact of breast cancer on body image.*

In this study, we applied BTM separately to the US and French datasets without prior knowledge of the topics. For each country, BTM generated distinct categories, providing a list of the most recurrent keywords and the messages associated with each category. Based on the list of keywords, we obtained an initial understanding of each topic. We then reviewed the messages in each category to validate and refine our understanding. This allowed us to assign appropriate titles to the topics.

Ethical Considerations

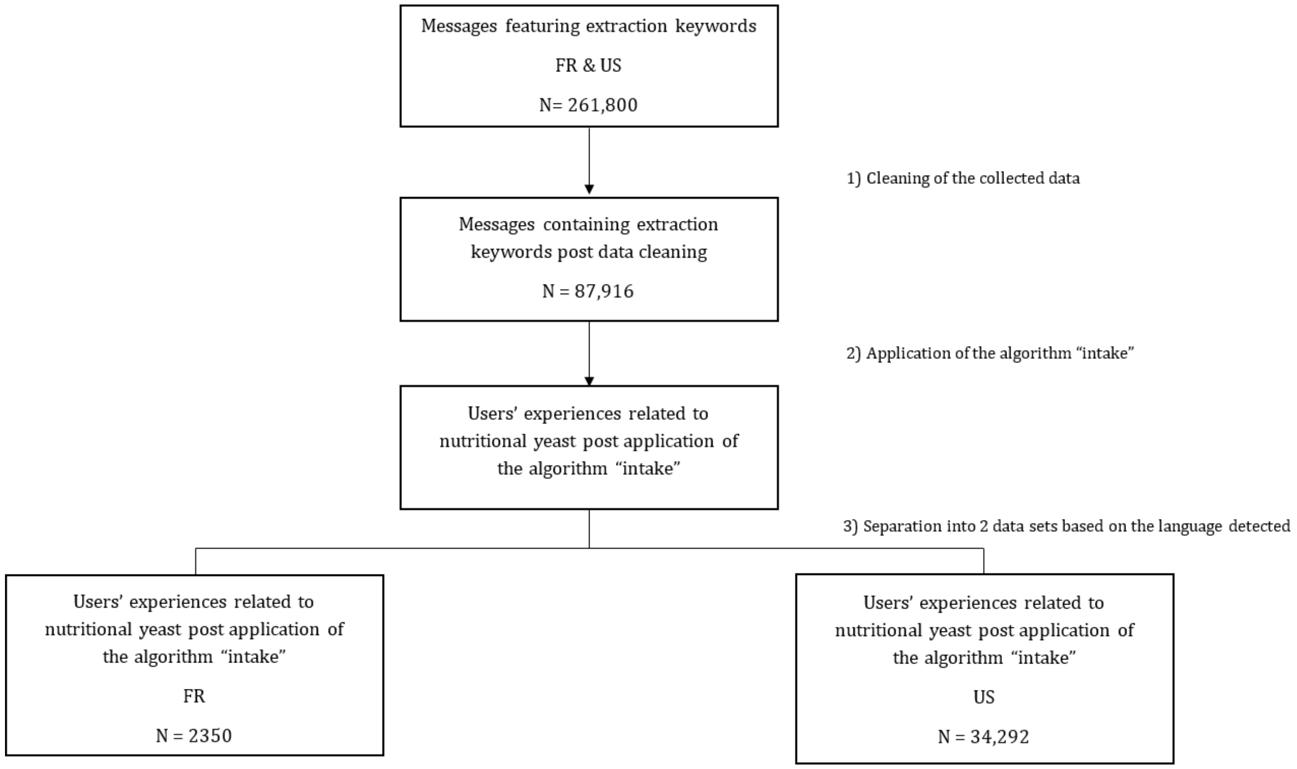
This study used only data from publicly available sources, excluding private groups, forums, and web pages. Given that users posting on public platforms automatically agree to the reuse of their information, we did not seek formal consent for this study. The findings are reported in aggregate, without personally identifiable details such as names, usernames, specific locations, or sensitive information, were deliberately removed.

Results

Population and Posts

A total of 261,800 posts were initially retrieved, written by internet users discussing nutritional yeast in the United States and France. Data cleaning and processing allowed us to identify internet users who had consumed nutritional yeast. As a result, the analysis dataset contained a total of 34,292 posts in the United States written by 26,154 users and 2350 posts in France written by 1915 users (Figure 1).

Figure 1. Flowchart of the data cleaning and sample selection processes showing the number of messages (N) and users discussing nutritional yeast in the United States and France between 2017-2023.



Data Sources and Temporal Evolution

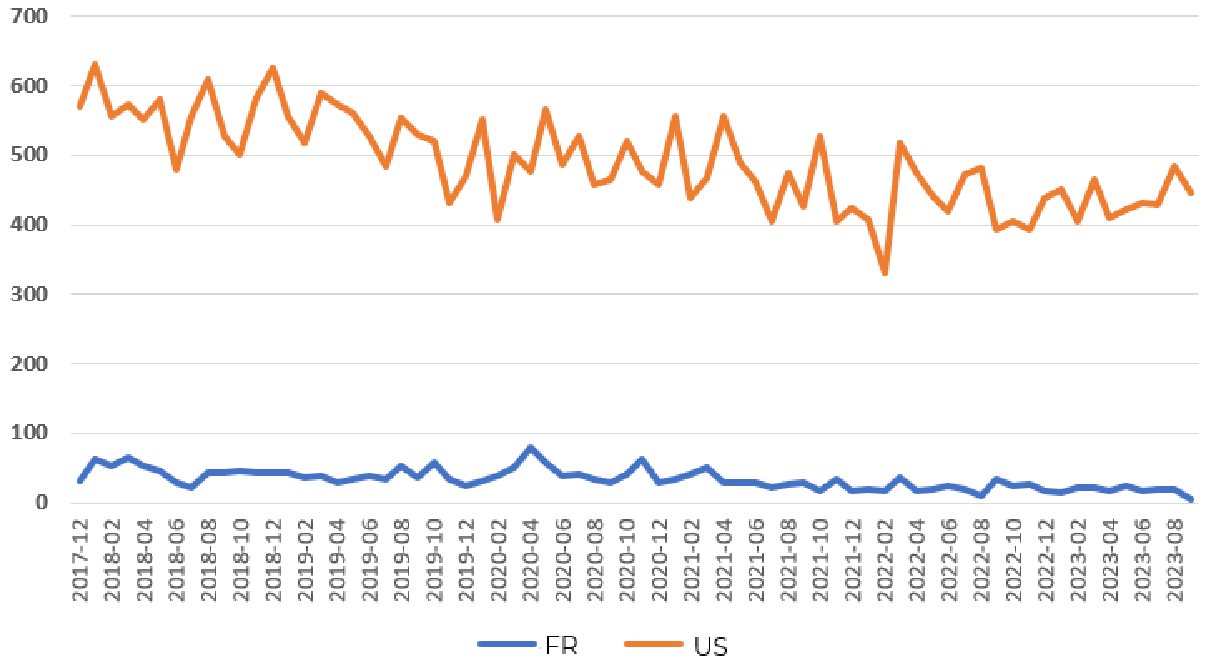
Posts originated from 995 social media platforms in the United States and 45 in France. In the United States, Twitter was the main source of data (13,587/34,292; 39.6%) of posts, followed by Reddit.com (n=5333; 15.6%), and Instagram.com (n=4398, 12.8%). In France, Twitter was also the main source of data (1,982/2,350; 84.3%), followed by jeux vidéo.com (125; 5.3%) and babycenter.fr (n=93; 4.0%) (Table 1). The complete list of sources is found in Multimedia Appendix 2.

During the analysis period, the number of posts was higher in the United States (n=34,292) than in France (n=2350). Figure 2 shows the temporal evolution of the posts extracted in United States and France.

Table . Top 10 geolocated data sources in the United States and France for messages about nutritional yeast posted between 2017-2023 .

Forum/Social media	Posts, n (%)
United States	
Twitter	13,587 (39.6)
Reddit.com	5333 (15.6)
Instagram.com	4398 (12.8)
Whattoexpect.com	1134 (3.3)
Myproana.com	819 (2.4)
Babycenter.com	773 (2.3)
4channel.org	649 (1.9)
Myfitnesspal.com	483 (1.4)
Edsupportforum.com	307 (0.9)
Shroomery.org	276 (0.8)
France	
Twitter	1982 (84.3)
Jeux vidéos.com	125 (5.3)
Babycenter.fr	93 (4.0)
Instagram.com	32 (1.4)
Sports-sante.com	16 (0.7)
Hardware.fr	15 (0.6)
Au Feminin	14 (0.6)
Beauté test	7 (0.3)
Madmoizelle.com	5 (0.2)
Magic maman	5 (0.2)

Figure 2. Temporal trend in the number of posts on nutritional yeast extracted between December 2017 and September 2023 from social media geolocated in the United States and France.



Topics of Discussion

After applying the BTM, various discussion topics were identified through human interpretation of the most associated terms. It is worth noting that a single message can contain multiple topics. The main revealed topics are shown in Table 2.

Table . Proportions of messages featuring the most frequently discussed topics.

Topics	Posts, n (%)
United States	
Vegan vitamin source	12,345 (36.0)
Seasoning for various recipes	8093 (23.6)
Health and Skin benefits	6173 (18.0)
Taste of cheese	4218 (12.3)
Fermented products	2160 (6.3)
Protein and calorie balance	1269 (3.7%)
France	
Dietary supplement regimens in various forms	1177 (50.1)
Castor oil for nails and hair	928 (39.5)
Personal experience, diet, and taste	223 (9.5)
Reduction of hair loss, effectiveness, and duration	115 (4.9)
Yeast, a dietary supplement rich in vitamins	96 (4.1)
Organic products (purchase and diet)	31 (1.3%)

Main Topics of Discussion in the United States

The most discussed theme in the United States was nutritional yeast as a vegan vitamin source (12,345/34,292; 36.0%). Users from the vegan community mentioned it as a source of vitamins, particularly B vitamins including B12—a nutrient that is challenging to obtain from a diet lacking animal products. Users also shared their experiences of how to incorporate nutritional yeast into their daily lives, such as sprinkling it on meals or blending it into smoothies. An example message reads:

Yesterday's lunch was a salty (and spicy ... Def went too far on the red bell pepper) and hit the spot! Nutritional yeast may sound a bit odd, but it's a great source of B vitamins for eaters (translation to French in Multimedia Appendix 3)

Additionally, online discussions revealed that cooking enthusiasts have used nutritional yeast as a natural and nutritious seasoning (n=8093; 23.6%). Users posted their recipes using it as a flavor enhancer in pasta and casseroles, sharing that it added taste and creaminess without the need for dairy products. For example:

I bought a big carton of egg whites, what I did with the tofu scrabble was to add nutritional yeast, turmeric for color and black pepper, which makes it taste whole and with whole egg and egg white too. (translation to French in Multimedia Appendix 3*)*

Users frequently mentioned the health and skin benefits of nutritional yeast (n=6173; 18.0%) messages, with users highlighting its positive effects on skin health, particularly in managing fungal infections. They also discussed its ability to strengthen nails and improve hair health.

Nutritional yeast was also used as a cheese alternative (n=4218 messages; 12.3%). It was especially popular among vegans and individuals with lactose-intolerant, who praised it as a nutritious, plant-based option that can add flavor to dairy-free diets. Several users described it as both palatable and versatile, therefore important to include in one's balanced diet.

Another topic of discussion was the use of nutritional yeast in home fermentation processes (n=2160; 6.3% messages) such as brewing beer, making bread, and other fermented products. However, since nutritional yeast is an inactive form of *Saccharomyces cerevisiae*, it lacks the enzymes required for fermentation. This means that the conversations discussing fermentation have mistakenly mentioned the use of nutritional yeast.

The high protein content and low-calorie count also made nutritional yeast appealing within fitness and wellness communities (n=1269; 3.7%) messages. Users noted its importance as a complete protein, ie, containing all nine essential amino acids, which is beneficial for muscle development and maintenance.

Main Topics of Discussion in France

In France, internet users primarily discussed the use of nutritional yeast in food supplement routines (1177/2350; 50.1%). Users mentioned how they included brewer's yeast into their routines, sharing the different ways they consumed it in the form of capsules or pills. They reported using it for overall health or for specific concerns like hair loss and mood improvement. One user described their experience with brewer's yeast in the following message:

Personally, brewer's yeast worked really well, no side effects, I also tried Oenobiol, which wasn't bad, and now I'm starting Forcapil, apparently it's a wonder. I can't wait to have Rapunzel's hair (*translated from French, in Multimedia Appendix 3*).

Another frequently discussed topic was the use of castor oil for improving nail and hair health (n=928; 39.5%). Many users paired castor oil with brewer's yeast, highlighting their combined benefits in strengthening and stimulating the growth of hair and nails. Users also shared specific routines, such as applying castor oil directly to their hair or nails and taking brewer's yeast tablets as supplements. An example of a message is shown below:

I used to lose handfuls of them too, that's why they're so damaged, you need to make frequent oil masks that you leave on overnight, rinse them with cold water and take brewer's yeast to strengthen them ☺ (*translated from French, in Multimedia Appendix 3*).

Discussions also focused on personal experience, diet, and sensory attributes of brewer's yeast (n=223; 9.5%). Some users described its texture and taste, while others shared their recipes and methods for incorporating brewer's yeast into their diets. Feedback regarding its taste was generally positive, as shown in the following message:

No problem with taking care of oneself with all kinds of oils (jojoba, coconut, castor) natural shampoo like Liperol, and brewer's yeast in capsules and powder form (I like the taste) (*translated from French, in Multimedia Appendix 3*).

Other messages revolved around the effect of nutritional yeast in reducing hair loss (n=115; 4.9%), as well as its role as a food supplement rich in vitamins (n=96; 4.1%), particularly the B complex. Although less commonly discussed, some users expressed a preference for organic products (n=31; 1.3%), specifically organic brewer's yeast.

Discussion

Principal Findings

The objective of the study was to identify the predominant themes in conversations among internet users discussing nutritional yeast.

A total of 36,642 messages posted by 28,069 users were included in this study. Twitter emerged as the main source of discussion in both countries, accounting for 39.6% of the US dataset with 13,487 posts and 84.3% of the French dataset with 1982 posts. Additional key platforms included Reddit and Instagram in the United States, and jeux vidéo.com and babycenter.fr in France. In the US, discussions mainly focused on its role as a nutrient source for individuals following a vegan diet (36.0% of posts). Many users reported using it as a natural seasoning (23.6%) and for its benefits for health and skin (18.0%). Users also discussed cheese alternatives (12.3%), specifically using nutritional yeast as a substitute for cheese. In France, nutritional yeast was part of supplement regimens in various forms (50.1% of posts) and was used with other supplements such as castor oil, mainly to improve nail and hair health (39.5%). Additional themes included personal experiences regarding dietary habits and flavor preferences (9.5%), the role of nutritional yeast in preventing hair loss (4.9%), and its high vitamin content (4.1%).

Our findings are consistent with previous studies highlighting the role of plant-based foods in today's diets. In the United States, nutritional yeast was already recognized as an important component in vegan nutrition, with a rapid transition to plant-based diets. In fact, veganism in the United States increased by 600% between 2014 and 2018 [29], motivated by health concerns, environmental sustainability, ethical considerations regarding animal welfare, and media influence [29-31]. Additionally, the plant-based foods market increased by 29% from 2017 to 2019 [32], highlighting the rising demand for plant-based foods among American consumers [33].

Conversely, nutritional yeast was mostly considered a dietary supplement in France, which is consistent with the French tendency to favor holistic health solutions. According to data from the Second Individual and National Study on Food Consumption (INCA), 22% of French adults consume dietary supplements on a regular basis [34], especially women, individuals aged 18 to 44, and those with higher education levels [34]. Although most adults still buy supplements from pharmacies, online purchases have significantly increased from 1% in 2015 to 11% in 2019—a clear shift in consumer habits [34]. In 2022, more than two-thirds of the French population had used dietary supplements at least once, with 32% reporting use in the past three months [35]. The market for nutritional supplements has grown to €2.6 billion and had a+3% yearly growth rate between 2021 and 2022 [36].

Our results align with previous research emphasizing the value of social media in understanding health and nutrition. With the help of data mining, social media has become a powerful source of real-world data, providing insights that traditional research methods such as clinical trials may fail to obtain. It also bypasses some of the limitations of conventional research such as lengthy timelines and complicated participant recruitment processes, making it a useful complementary tool for health research [37-39]. Infodemiological studies allow for the identification of various aspects, including specific populations, their discussion topics, the impact of health on their quality of life, as well as user perceptions and challenges [40-43]. They offer significant data, with 5.35 billion internet users and 5.04 billion actively using social media platforms in 2024 [44]. Consistent with our findings, previous studies have also identified Twitter as an essential source of data and a valuable platform for health-related discussions [38,45-48].

This study may help shape marketing strategies for each country's unique preferences. In France, where consumers were focused on improving their overall health and well-being, marketing strategies could emphasize the holistic benefits of nutritional yeast—perhaps including it as part of multisupplement regimens. In the United States, the growing population of health-conscious, plant-based consumers presents an opportunity to focus on nutritional yeast's role in vegan diets and its versatility in cooking, particularly as a natural flavor enhancer. Strategies could include creating educational content, collaborating with culinary experts, and launching targeted social media campaigns to effectively promote nutritional yeast's benefits in both regions.

Limitations

We recognize several limitations to our study. Our analysis only included openly accessible online sources; private sources such as WhatsApp, private forums, or invitation-only groups were excluded. Furthermore, the level of detail that we obtained and our understanding of the messages' context depended on the information shared by users. Our study included a potential recall bias, as it was based on users' self-reported data, their memory, and subjective interpretation. Additionally, individuals posting on social media may represent certain socioeconomic backgrounds and literacy capacities, which could affect the representativeness of our findings. It is also possible that relevant discussions were incorrectly removed during data cleaning. Another limitation is the variation in the number of users from each country, which may affect data representation. Additionally, since not all social media posts include geolocation data, accurately determining their country of origin can be challenging.

Despite these limitations, this study provides valuable insights into the discussions and perceptions about nutritional yeast.

Conclusions

Nutritional yeast is a natural ingredient valued for its health benefits and culinary versatility by users in France and the United States. Social media allowed us to gain insights into consumer perspectives, experiences, and usage trends related to nutritional yeast. It also allowed the identification of the unique preferences of each country, providing more information about the health-focused French consumers and the growing American vegan population. Future research could include clinical studies to better understand the health benefits of nutritional yeast for specific groups, such as vegans or people interested in natural beauty solutions. Studies could also explore its long-term effects on various diets and wellness habits. Additionally, marketing strategies could be improved by creating tailored communication and messaging that connect more effectively with the preferences and needs of various consumer groups.

Data Availability

The datasets generated or analyzed during this study are not publicly available due to the proprietary nature of the algorithms and data used, which are the intellectual property of Kap Code, and in order to comply with the General Data Protection Regulation (Regulation [EU] 2016/679).

Authors' Contributions

Conceptualization: JFJ, JM, AV, FM, MT
Methodology: JFJ, JM, AV, FM, MT
Data curation: MT
Formal analysis: JFJ, JM, AV, FM, MT

Writing – original draft: JM
Writing – review & editing: JFJ, AV, FM, MT

Conflicts of Interest

JM, MT, and SS are employed by Kap Code. JFJ, AV, and FM are employees of Lesaffre.

Multimedia Appendix 1
Extraction query used for Brandwatch.
[DOCX File, 14 KB - infodemiology_v5i1e60528_app1.docx]

Multimedia Appendix 2
List of sources.
[DOCX File, 35 KB - infodemiology_v5i1e60528_app2.docx]

Multimedia Appendix 3
Examples of messages in English and French.
[DOCX File, 16 KB - infodemiology_v5i1e60528_app3.docx]

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Abbreviations

BTM: Biterm Topic Modeling

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Understanding Patient Experiences of Vulvodynia Through Reddit: Qualitative Analysis

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Abstract

Background: Vulvodynia is a chronic vulvar pain condition affecting up to 25% of the US population. However, diagnosis and effective treatment remain elusive. Many individuals with vulvodynia face stigma and medical uncertainty, leading them to seek information and web-based support. Reddit is a popular social media platform where patients share health concerns and experiences. The anonymity and accessibility of this platform make it a valuable source of real-world patient perspectives that are often overlooked in clinical settings.

Objective: This study evaluated Reddit content related to vulvodynia to explore how individuals with vulvodynia describe their symptoms, treatments, and personal experiences.

Methods: The subreddits “r/vulvodynia” and “r/vestibulodynia” were selected for analysis in May 2023. Threads were sorted from the most popular to least popular, with “popularity” measured by upvotes. Opening threads from the top 70 posts in each subreddit were extracted and analyzed using inductive qualitative analysis to identify themes and sentiment analysis to evaluate attitudes.

Results: In May 2023, the “r/vulvodynia” and “r/vestibulodynia” subreddits had a total of 7930 members (7245 and 685 members, respectively). Out of 140 analyzed threads, 77 (55%) contained negative attitudes. A total of 50 (35.7%) threads were seeking information or advice and 90 (64.3%) included some form of peer support. Inductive thematic analysis identified 6 core themes: symptoms (n=86, 61.4%), treatments (n=83, 59.3%), sexuality (n=47, 33.6%), erasure or disbelief (n=38, 27.1%), representation or media (n=17, 12.1%), and humor (n=15, 10.7%). Threads that discussed treatments (48/83, 57.8%), sexual experiences (25/47, 53.2%), and representation (14/17, 82.4%) had the highest proportions of positive attitudes, while threads that touched on erasure (21/38, 55.3%), symptoms (51/86, 59.3%), and humor (12/15, 80%), had the highest proportion of negative attitudes. A multivariable logistic regression of valence on the themes revealed that posts referring to treatments (odds ratio 12.5, 95% CI 3.7-42.2; $P<.001$) or representation (odds ratio 21.2, 95% CI 4.2-106.0; $P<.001$) were associated with significantly increased odds of positive valence. Furthermore, it was noted that 3 of the 5 most frequently discussed treatments aligned with clinical guidelines from the American College of Obstetricians and Gynecologists, American Urological Association, and International Society for the Study of Vulvovaginal Disease. Despite this alignment, threads frequently mentioned alternative remedies and frustration with medical professionals related to diagnostic delays and perceived lack of understanding.

Conclusions: This is the first study of Reddit discussions about vulvodynia. Findings suggest a gap between patient experiences and provider understanding, underscoring the need for improved patient education and greater clinician awareness of psychosocial factors in vulvodynia care. While limited by its sample size and lack of demographic data, this study highlights how web-based communities can help identify ways health care providers can better meet patient needs and how patients mutually support each other.

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KEYWORDS

sexual health; health literacy; vulvodynia; vestibulodynia; pelvic pain; Reddit

Introduction

Vulvodynia is defined as vulvar pain lasting for at least 3 months without an identifiable cause. Vulvodynia is characterized by the location of pain (eg, localized or generalized), triggers (provoked, spontaneous, or mixed), onset (eg, primary or secondary), and temporal nature (eg, intermittent, constant, or delayed) [1,2]. The most common subtype of vulvodynia is vestibulodynia, which is pain isolated to the vulvar vestibule [2].

Vulvodynia is prevalent, affecting up to 1 in 4 women in the United States [3,4]. However, the majority of people living with vulvar pain remain undiagnosed and inadequately treated. It is reported that nearly 40% of people with chronic vulvar pain do not seek treatment, and of those that do, 60% consult at least 3 physicians before receiving a diagnosis, if they receive one at all [3]. Factors contributing to this gap in care may include a lack of knowledge on the part of medical providers, inadequate medical education related to vulvar anatomy and physiology, longstanding dismissal of female pain, and stigma surrounding female reproductive organs and sexuality [5-7].

Since the advent of the internet, individuals have sought web-based medical information, often before consulting health care professionals [8,9]. For individuals with understudied health conditions, digital health forums can be essential sources of information and peer support [10]. Moreover, web-based platforms may allow individuals with chronic diseases to connect with one another and build a social identity that extends beyond the disease itself [11].

Reddit, a popular website with 1.5 billion registered users and over 52 million daily users is a notable platform for exchange and anonymized information-sharing [12]. By design, Reddit facilitates open discussion across various topics, allowing for global information exchange that is not as readily facilitated on other platforms such as Instagram or Facebook. Reddit is organized into various subreddits, which are discussion-based communities devoted to an identified topic or theme. Within a typical subreddit, a user makes a post expressing an opinion or sharing information. Other users can evaluate that post by "upvoting" or "downvoting" it. Users can reply to the initial post or others who have replied to the post. Together, the post and subsequent comments are known as a "thread."

The anonymous nature of Reddit may be beneficial because it lends itself to open and often vulnerable exchanges. Prior studies have explored Reddit content related to substance use, chronic pain, sexual dysfunction, and mental health, providing key insights into the lived experiences of those who may feel shame [13-17]. Despite relatively extensive investigation of these topics with varied analytic techniques, there is little research on Reddit content related to female sexual dysfunction. Existing studies primarily focus on reproductive conditions, changes in libido, or abortion [18-22]. To date, there has been no study examining how Reddit may be used by patients to obtain or share information about vulvodynia.

While population-level data on patient experiences of vulvodynia exists, patient-centered studies that capture the experiences of individuals living with vulvodynia are rare [23-25]. This study therefore seeks to qualitatively assess patient experiences of vulvodynia as discussed on Reddit, amplifying person-centered perspectives and gauging gaps in medical care for those affected by vulvodynia. By capturing these narratives, this study highlights the importance of understanding patient experiences beyond the clinical setting, which can inform more empathetic and effective health care strategies.

Methods

Subreddit Selection

To evaluate Reddit forum content related to vulvodynia, this study used a cross-sectional design, analyzing publicly available data from "r/vulvodynia" and "r/vestibulodynia," in May 2023 [26,27]. The "r/vestibulodynia" subreddit was included to provide a more comprehensive understanding of patient experiences, as vestibulodynia is a specific form of vulvodynia.

For each subreddit, threads were sorted from the most popular to the least popular. A thread becomes popular based on the number of upvotes, comments, and overall engagement it receives from others in the Reddit community. We collected and analyzed the most popular 70 threads from each subreddit, as they were deemed most representative of key topics in the community. Comments from other users on each thread were excluded from the analysis.

Thematic and Sentiment Analysis

Quantitative and qualitative data, including the number of upvotes and comments, the post title, and a brief description of the post, were collected by accessing the Reddit website directly and navigating subreddits directly through the site. Data were collected using Google Chrome (version 113) and Safari (version 16.5) web browsers under default settings (cache and cookies enabled, no use of privacy or incognito mode) to simulate a typical user experience. The data were directly downloaded and preserved in an Excel (version 16.82; Microsoft Corp) spreadsheet on May 7, 2023, at approximately 6 PM EST. Four team members (SP, EM, KS, and AP), located in New York, Ventura, Memphis, and Glen Head, served as coders. Extracted data were coded between May 7, 2023, and May 15, 2023. These coders independently assessed all 140 threads, using a thematic analysis approach. All posts were manually annotated, and the themes were derived through iterative review and comparison. Codes were revised as necessary based on commonly identified themes, following established qualitative analysis procedures and an inductive approach in which the analysis is guided by the data itself, allowing for themes to emerge organically [28-30]. Each thread was assigned 1 or multiple themes. Threads were also evaluated for tonal expression. We defined "positive" attitudes to be any expression of optimism, relief, or joy, as well as references to "cures," and observational or light humor. "Negative" attitudes were defined as any expression of frustration, despair, fear, or isolation, as well as mentions of pain, pessimism, exhaustion, or unresolved symptoms, and dark humor with elements of bitterness or the macabre or morbid.

Any discrepancies in themes and attitudes based on individual coding were identified by AJG who was not involved in coding. All instances of coding discrepancy were resolved by group consensus, a practice used in qualitative research to constructively arrive at a consistent understanding of the data [31,32]. For example, in cases where coding defined the post as negative because of a user's description of vulvodynia as "terrible," but also noted that the post was "positive" because it used "humor" together, the coding team engaged in a discussion of whether the post should be coded as "negative" due to the word "terrible," or as "positive" because the presence of humor suggested a more complex emotional response, such as a coping mechanism. Examples of representative threads by theme and valence are provided in Multimedia Appendix 1.

A multivariable logistic regression of valence on the 6 identified themes was conducted using STATA/BE (version 18.0; StataCorp LLC). Each post was assigned a binary code for positive or negative valence and the presence or absence of a particular theme. A 2-sided significance level was defined at α=.05.

Any mention of treatments in the subreddit was recorded and compared with guidelines from the American College of Obstetricians and Gynecologists (ACOG), American Urological Association (AUA), and International Society for the Study of Vulvovaginal Disease (ISSVD), as they are viewed as the primary sources of information about managing vulvar pain.

Ethical Considerations

The study was deemed exempt by the Institutional Review Board of the University of California San Diego and Johns Hopkins Institutional Review Board due to its observational nature and analysis of public web-based content. The original data were collected in compliance with Reddit's public content policy, which informs users that researchers can access Reddit's public content for research purposes. All Reddit usernames and any potentially identifiable information were deidentified to protect user privacy. Furthermore, no direct user interactions or private messages were included in the analysis. Only publicly accessible forum posts were analyzed, and efforts were made to ensure that the data could not be traced back to individual users through reverse searchability. In consideration of the potential ethical concerns related to social media–based research, the authors acknowledge the need to engage in ongoing academic debates regarding internet research ethics. While Reddit users agree to the public visibility of their posts, the authors recognize that these ethical discussions, such as those put forth by the Association of Internet Researchers, underscore the need to balance public data use with user privacy in research contexts.

Results

At the time of analysis, the "r/vulvodynia" and "r/vestibulodynia" subreddits had a combined total of 7930 members (7245 and 685 members, respectively). A total of 140 posts were analyzed; these posts received an aggregate of 4166 upvotes. Out of all 140 analyzed threads, 50 (35.7%) were deemed to be seeking information or advice and 90 (64.3%) were deemed to involve peer support discussions of personal experiences related to vulvodynia.

Six core themes emerged from the qualitative analysis: (1) Reddit users' subjective sense of being disbelieved about symptoms or erasure more generally; (2) difficulty managing symptoms; (3) the condition's impact on sexuality and sexual experiences; (4) representation or media; (5) humor as a coping technique or a response to the condition; and (6) treatments sought or tried.

Out of the 140 threads, the most frequently observed themes were symptoms (n=86, 61.4%) and treatments (n=83, 59.3%), followed by sexuality (n=47, 33.6%), erasure or disbelief (n=38, 27.1%), representation or media (n=17, 12.1%), and humor (n=15, 10.7%). Of all 140 analyzed threads, 45% (n=63) of threads were coded as reflecting positive attitudes, and 55% (n=77) of threads were coded as reflecting negative attitudes. The core themes of treatments (48/83, 57.8%), sexual experiences (25/47, 53.2%), and representation (14/17, 82.4%) had the highest proportions of positive attitudes in analyzed threads. The themes of humor (12/15, 80%), erasure or disbelief (21/38, 55.3%), and symptoms (51/86, 59.3%) had the highest proportions of negative attitude threads. Fleiss κ for coded valence was 0.54. The distribution of positive and negative attitudes across themes is illustrated in Table 1.

Results from the multivariable logistic regression revealed that only treatments (odds ratio [OR] 12.5, 95% CI 3.7-42.2; *P*<.001) and representation (OR 21.2, 95% CI 4.2-106.0; *P*<.001) were associated with significantly increased odds of positive valence. Nonsignificant associations were found for themes erasure (OR 1.25, 95% CI 0.5-3.0; *P*=.60), symptoms (OR 0.47, 95% CI 0.2-1.2; *P*=.11), and sexuality (OR 2.2, 95% CI 0.9-5.1; *P*=.07).

There were 119 instances of treatment discussions across the 140 analyzed threads. The most commonly mentioned treatments included topical medications (n=22, 18.5%), physical therapy (n=22, 18.5%), surgery (n=16, 13.4%), dilators (n=14, 11.8%), and stopping oral contraceptive pills (n=11, 9.2%). Three of the 5 most discussed treatments—physical therapy, topical medications, and surgery—aligned with clinical guidelines from ACOG, AUA, and ISSVD.

Table . Positive and negative attitudes by theme.

Theme	Positive	Negative	Total
Erasure or disbelief	17	21	38
Symptoms	35	51	86
Treatments	48	35	83
Sexuality	25	22	47
Representation or media	14	3	17
Humor	3	12	15

Discussion

Principal Findings

This is the first study to analyze Reddit posts about vulvodynia. On Reddit, individuals with vulvodynia shared personal experiences, provided advice, and found communal support. From the qualitative and sentiment analyses, 6 core themes with unique valence distributions were identified, providing insight into the experiences, priorities, and needs of individuals living with vulvodynia.

Reflections on Erasure and Being Disbelieved

A published study exploring the experience of women with vulvodynia in the United Kingdom found that health care professionals often dismiss patients' expressions of concern or physicians lack knowledge about the condition [33]. The substantial percentage of posts mentioning not being taken seriously by a health care provider, which was coded as "erasure and disbelief" indicates health care's inadequate support for patients with vulvodynia, which may explain the prevalence of negative attitude posts. Discussions of erasure and being disbelieved were present in many of the opening threads, and many users described needing to increase self-advocacy in medical settings. Such reports highlight the persistent marginalization and sense of being disbelieved during health care interactions, thereby necessitating substantial self-advocacy. Reddit users shared their disappointment with providers' behavior, attitudes, and expertise: one user shared that her doctor bluntly asked if the patient had tried lubricant, revealing a gap in understanding and empathy about vulvodynia's etiology and treatment. In aggregate, the prevalence of posts mentioning erasure and being disbelieved underscores the critical need for improved medical education and patient-centered care, 2 weaknesses of health care professionals at all levels of training [5,6,34-36].

Physical Symptoms and the Impact on Daily Functioning

Symptoms were the most prevalent theme, and many posts emphasized the wide-ranging impact of symptoms on overall health. Symptom-related posts predominantly had a negative attitude, reflecting the disruptive nature of physical discomfort in all facets of daily life. It is essential to acknowledge, however, that participants posting in these threads may not all have a formal diagnosis of vulvodynia. It is impossible to verify the truth of the contents of any of the posts. Despite this limitation, however, there were notable parallels in the dataset between user-reported symptoms and clinical diagnostic criteria for vulvodynia. Currently, there is no exclusive classification for vulvodynia; rather, a diagnosis is characterized by the description of pain [1,2,16].

Pain was the most discussed symptom, underscoring the debilitating and all-consuming nature of vulvar pain [37]. Reddit users described experiences of burning pain, pain with tampon insertion, pain during sexual intercourse, and irritation from clothing. Some symptoms mentioned, such as swollen tissue associated with tampon insertion, pain with urination, and pelvic floor tightness, do not align with established diagnostic criteria, suggesting current diagnostic tools may not capture the full range of experiences of individuals living with vulvodynia [2].

Vulvodynia can interfere with day-to-day functioning; one user noted vulvar pain made it difficult to ride a bike. Others found it challenging to stay active due to pain. Difficulties related to vulvodynia extended beyond physical discomfort; one user described how finding comfortable and wearable underwear became an unexpected source of financial stress. The heterogeneity of pain associated with vulvodynia suggests that further research is needed to better understand its etiology and develop more effective treatment strategies.

In addition to pain, the subreddit posts included expressions of anger, frustration, anxiety, depression, and even trauma, highlighting the connection between mental health and chronic pain. Although few studies have investigated mental health outcomes in individuals with vulvodynia, current evidence suggests that vulvodynia symptoms contribute to worse quality of life and many individuals living with vulvodynia have comorbid anxiety or depression [38-40]. While further research is needed, comprehensive care for vulvodynia should consider both physical and mental health to improve patient well-being.

Treatment Approaches: Navigating Options and Uncertainty

Treatment-related discussions highlight the range of difficulties individuals face in managing chronic health conditions. Participants exchanged information about various treatment modalities, sharing insights into effectiveness, side effects, and accessibility. Of posts discussing treatments, the higher proportion of positive opening threads suggests that individuals in this Reddit community often shared experiences of treatment that were effective. Three of the 5 most mentioned treatments in the Reddit threads—physical therapy, topical medications, and surgery—aligned with guidelines from ACOG, AUA, and ISSVD. To be sure, not all discussions of these treatments were positive. However, these discussions indicate that users in this web-based forum are aware of and discuss clinically recommended treatments.

Physical therapy and vaginal creams were the top 2 treatment modalities discussed. While physical therapy is widely recognized as an effective approach for vulvodynia, vaginal creams such as baclofen and amitriptyline, though effective, are still considered novel remedies [41-43]. Surgery and discontinuing oral contraceptives were also commonly discussed. Surgery is considered for cases where conservative methods fail [1,44]. Procedures such as vestibulectomy or neuromodulation aim to alleviate pain by removing affected tissue or modifying nerve signals. Although controversial, the AUA and ACOG recommend discontinuing hormonal contraceptive treatments, as these may worsen symptoms. The literature on this topic is divided, however. Some researchers argue that long-term oral contraceptive pills may contribute to vestibulitis, while others provide evidence that refutes this connection [45,46].

Another notable challenge discussed by Reddit users is the wide variation in rates of treatment success, an observation that is well-documented in the literature [2,3,37]. Success rates for medical interventions are reported to range from 13% to 67% [47]. Note that the AUA, ACOG, and ISSVD provide slightly differing guidelines for treating vulvar pain. This may complicate care for providers already navigating serious time constraints in health care. In light of Reddit users' self-reported challenges in obtaining successful treatment for vulvodynia, harmonizing treatment guidelines would likely benefit clinicians and patients alike.

Sexuality and Relationships: Coping With Intimacy Challenges

It is not surprising that sexual experiences also emerged as a prevalent theme in these subreddit threads, given that vulvodynia directly affects individuals' intimate lives and sexual health [48]. One user shared that vulvar pain complicated their interest in sexual intimacy, demonstrating how the connection between experiences of pain, desire, pleasure, and sexual experiences may be altered by vulvodynia. Some users detailed the frustrations and challenges of finding an understanding partner, while others shared success stories of supportive and accommodating partners. Further research is needed to understand how vulvodynia impacts relationships and sexuality. In subsequent studies, qualitative interviewing would be one way to center the voices of individuals with vulvodynia.

Media Representation and Visibility

The low percentage of posts discussing representation and media highlights the invisibility of vulvodynia to the public. The prevalence of positivity in such posts underscores the urgent need for increased awareness, which can be transformative for an individual's sense of self and confidence. One user shared that representation in media made them feel less isolated in their experience. In this way, media may represent an unexpectedly positive domain in which individuals with vulvodynia can find support and recognition of their experience. Health care providers should be aware of the power of representation to positively impact individuals with vulvodynia who may feel overlooked by the medical system. For others, media can be a reminder of the difficulties associated with pain, sexuality, and daily functioning. Overall, representation was associated with significantly increased odds of positive valence, illustrating the value and importance of representation for individuals with vulvodynia.

Humor as a Coping Strategy

Humor is well-recognized as an adaptive tool for coping with stressful situations. For individuals with chronic pain, in particular, humor has been shown to reduce pain intensity and improve quality of life [49]. Explicit humor therapy, in which individuals engage with materials they find entertaining, is associated with decreased pain and feelings of loneliness [50]. In this way, humor represents a nonpharmacological approach for addressing and even ameliorating pain. Humorous interpersonal interactions have also been noted as a way for individuals with chronic pain to engage with one another and even improve clinical outcomes [51]. Members of the vulvodynia community on Reddit creatively reframed their experiences through memes and conversational threads. Users generated memes and made jokes about symptoms and interactions with doctors; in this way, the separation of body and mind may be a method of relief. Humor therefore represents a unique approach for managing experiences of vulvodynia, and it is one means by which members of the Reddit community express themselves and connect with others.

Limitations

A notable limitation of this study is the lack of access to user demographics due to the anonymous nature of Reddit. As a result, we were unable to interpret the possible effects of factors including race, age, health literacy, socioeconomic status, location, transportation, and access to health care which may have impacted the experiences mentioned by each user. Although we cannot determine whether any user had an official diagnosis or indeed met diagnostic criteria for vulvodynia, the Reddit contributors were driven to the platform for specific reasons. Furthermore, as a cross-sectional study, these results are only representative of the time in which data were collected. Results are not generalizable and should be understood as a snapshot of what anonymous Reddit users reported about vulvodynia.

Conclusions

This study aimed to better understand patient experiences of vulvodynia by analyzing web-based discussions on Reddit. Findings highlight that Reddit serves as a vital platform for sharing personal experiences, accessing peer-to-peer support, and seeking health care–related information. These web-based discussions provide valuable anecdotal evidence underscoring a need for health care providers to be trained on the management of vulvodynia, guided by consensus from professional associations. Such training would help ensure patients receive accurate diagnoses and effective care. By prioritizing and centering the patient perspective, health care providers can gain a deeper understanding of the multifaceted challenges faced by individuals living with vulvodynia. This study contributes to existing literature by offering insights directly from those affected by vulvodynia or who are experiencing vulvodynia-like symptoms.

Data Availability

The datasets analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

LAB is a consultant for Locus Biosciences and reports funding from the National Institutes of Health. MU is the founder of VULVAi. At the time of this study, VULVAi has not received funding or engaged in commercial activities. This affiliation did not influence the design, execution, or interpretation of the research presented in this manuscript.

Multimedia Appendix 1
Example paraphrased threads by theme and valence.
[PNG File, 38 KB - infodemiology_v5i1e63072_app1.png]

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Abbreviations

ACOG: American College of Obstetricians and Gynecologists
AUA: American Urological Association
ISSVD: International Society for the Study of Vulvovaginal Disease
OR: odds ratio

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Original Paper

How Patients With Cancer Use the Internet to Search for Health Information: Scenario-Based Think-Aloud Study

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Abstract

Background: Patients with cancer increasingly use the internet to seek health information. However, thus far, research treats web-based health information seeking (WHIS) behavior in a rather dichotomous manner (ie, approaching or avoiding) and fails to capture the dynamic nature and evolving motivations that patients experience when engaging in WHIS throughout their disease trajectory. Insights can be used to support effective patient-provider communication about WHIS and can lead to better designed web-based health platforms.

Objective: This study explored patterns of motivations and emotions behind the web-based information seeking of patients with cancer at various stages of their disease trajectory, as well as the cognitive and emotional responses evoked by WHIS via a scenario-based, think-aloud approach.

Methods: In total, 15 analog patients were recruited, representing patients with cancer, survivors, and informal caregivers. Imagining themselves in 3 scenarios—prediagnosis phase (5/15, 33%), treatment phase (5/15, 33%), and survivor phase (5/15, 33%)—patients were asked to search for web-based health information while being prompted to verbalize their thoughts. In total, 2 researchers independently coded the sessions, categorizing the codes into broader themes to comprehend analog patients' experiences during WHIS.

Results: Overarching motives for WHIS included reducing uncertainty, seeking reassurance, and gaining empowerment. At the beginning of the disease trajectory, patients mainly showed cognitive needs, whereas this shifted more toward affective needs in the subsequent disease stages. Analog patients' WHIS approaches varied from exploratory to focused or a combination of both. They adapted their search strategy when faced with challenging cognitive or emotional content. WHIS triggered diverse emotions, fluctuating throughout the search. Complex, confrontational, and unexpected information mainly induced negative emotions.

Conclusions: This study provides valuable insights into the motivations of patients with cancer underlying WHIS and the emotions experienced at various stages of the disease trajectory. Understanding patients' search patterns is pivotal in optimizing web-based health platforms to cater to specific needs. In addition, these findings can guide clinicians in accommodating patients' specific needs and directing patients toward reliable sources of web-based health information.

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KEYWORDS

web-based health information seeking; think aloud; scenario based; cancer; patient evaluation; information seeking; web-based information; health information; internet; pattern; motivation; cognitive; emotional; response; patient; survivor; caregiver; interview; scenario; women; men

Introduction

Background

Patients with cancer increasingly use web-based platforms to seek information about their diagnosis, treatment, and implications thereof in the short and long term. In the Netherlands, 85% of patients with cancer use the internet [1,2], a rate comparable to that in most Asian countries [3] and other European countries [4,5]. The internet offers a wealth of information that can be readily accessed. It provides practically limitless opportunities for finding health information and support from both lay and expert perspectives, making it a highly popular source of information for many patients.

Within the context of cancer, patients' web-based health information seeking (WHIS) behaviors have been explained through theories of coping behavior. Most often, cancer literature on information-seeking patterns revolves around coping behaviors such as monitoring and blunting. Studies suggest that most patients manage health threats by proactively seeking information, a behavior referred to as monitoring coping style, whereas others choose to avoid information and opt for distraction, known as blunting coping style [6,7]. However, some studies indicate that the WHIS behaviors of patients with cancer could be explained via a broader range of approaches than merely through theories of coping behavior [8-10]. For instance, patients with cancer could also differ in their choices regarding the kind, quantity, and origins of the sought information, as well as the strategies used for information management. These approaches are based on patients' perceptions of self-care, which means that patients vary in their WHIS based on what they need to adequately take care of themselves [10]. In addition, the reasons behind seeking information and emotional support on the web are contingent on how patients use the internet [9].

Another factor that could explain variations in how people use the internet is patients' disease and treatment stage—which may predict different needs concerning the type and amount of information [11,12]. However, studies investigating WHIS and particularly the motives to engage in WHIS often treat the behavior as a one-time event. By treating WHIS as a one-time event, researchers tend to overlook the dynamic nature of health information needs and fail to capture the evolving motivations that patients experience throughout their disease trajectory. Considering that searching for health information is a rather longitudinal behavior, especially for patients moving through different stages of the disease trajectory, a longitudinal lens is required when studying WHIS [11].

In addition to the different phases in the disease trajectory influencing how patients use the internet, WHIS may also vary depending on patients' *motives* for going on the web. For example, patients may do so to address their cognitive (ie, the need for understanding) and affective (ie, the need to be understood) needs [13]. Cognitive needs (eg, engaging with the internet to enhance preparedness and comprehension of the information provided during a consultation or to validate or challenge the information offered by the provider) will lead to diverse forms of WHIS compared to affective needs (eg, using the internet for peer interaction). In other words, patients' specific goals regarding information seeking could also impact their search queries [13]. However, these motives are often not sufficiently taken into account when studying WHIS behavior.

Finally, in the period between diagnosis and cure or remission, patients often experience a range of emotions, including (but not limited to) uncertainty, hope, fear, and anxiety. These feelings and emotions are important motivators for many patients to seek out information to cope with their illness [14]. For example, when just diagnosed with cancer, individuals might be concerned about the unpredictable aspects of the disease, leading them to search for information to better manage and cope with their newly discovered illness. Apart from instigating patients' WHIS behavior, these emotions may also influence decisions to continue, expand, or terminate WHIS [10,14-16]. Earlier qualitative studies have identified various WHIS patterns and the emotions associated with them, ranging from intense to guarded information seeking [10,16,17]. While all participants in these studies expressed a desire for basic information about their diagnosis, they also exhibited diversity in their motivations for seeking cancer information; the emotions experienced; and the nature, quantity, and sources of the sought information, along with the strategies used to manage this information. However, interviews rely on patients' subjective, retrospective reporting and, therefore, do not provide a comprehensive overview of WHIS behavior.

Hence, it is thus far largely unknown how various motives and emotions guide WHIS behavior in various phases of the cancer disease trajectory, whereas such insights can lead to better designed web-based health platforms catering to patients' changing requirements and supporting them effectively throughout their health journey. In addition, having a comprehensive understanding of how patients navigate information acquisition on the internet is crucial for establishing effective patient-provider communication that accommodates patients' specific needs. These insights may also make health care providers aware of the potential impact that WHIS has on patients and, consequently, on the consultation.

Objectives

Studying the impact of motives and emotions on information-seeking behavior during the disease trajectory poses several challenges that have not been taken into account in previous studies. First, as most WHIS occurs in private settings, such as at home, most of these studies use data collection methods that rely on patients' subjective, retrospective reporting, such as surveys, focus groups, and interviews. Using these retrospective methods presents significant drawbacks, including recall bias, which may lead to inaccurate results [18]. In particular, information collected before or during diagnosis is considered challenging as this often entails a short and stressful period for many patients [19]. New research methods such as the think-aloud method enable participants to verbalize what they are thinking and doing while performing a certain task [20]; this allows researchers to observe patients' WHIS more precisely. This includes assessing attention to web-based information, choices made while selecting information, and people's thoughts and feelings evoked during exposure to information [21]. When combining the think-aloud method with vignettes representing different scenarios at various stages of the disease trajectory, research has the potential to provide a more comprehensive and naturalistic view on the WHIS of patients with cancer. Therefore, this study aimed to explore patterns of motivations and emotions behind the web-based information seeking of patients with cancer at different stages of their disease trajectory, as well as the cognitive and emotional responses evoked via a scenario-based, think-aloud approach. This study adopted a unique explorative approach by observing analog patients (ie, patients or healthy participants putting themselves in the position of a patient [22]) as they engaged in WHIS during different phases of their disease trajectory.

Methods

Study Design, Setting, and Population

We used a scenario-based, think-aloud approach followed by a semistructured interview to obtain more in-depth information regarding analog patients' search strategy, their reasoning and emotions behind this strategy (ie, motives), and the emotions experienced throughout. To increase feasibility and for ethical reasons, we decided to rely on analog patients (patients or healthy participants who are asked to imagine themselves in the role of the patients), who are considered valid proxies for clinical patients [23,24]. The COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines were used to report the methods (Multimedia Appendix 1).

Analog patients were recruited from a local panel of patients with cancer, survivors, and their informal caregivers who were willing to participate in scientific research on patient-provider communication and health information provision [25]. In this way, we ensured that the analog patients had some personal experience with cancer. Via email, panel members were informed about the study purpose and invited to complete a screening questionnaire to establish their eligibility, that is, whether they were aged ≥18 years, had previously used the internet to search for health information, and owned a computer or laptop with internet connection. The screening questionnaire also included panel members' age, gender, and educational attainment to allow for purposive sampling based on these characteristics as research shows that individuals differing in these characteristics navigate the web differently and differ in information needs [26]. In addition, we strived for diversity in relation to cancer experience (eg, “I have (had) cancer” or “My partner has (had) cancer”), cancer type, and frequency of using the internet for health information in the previous year (eg, “1-5 times,” “6-10 times,” “11-30 times,” or “more than 30 times”).

In total, 75 panel members indicated an interest in participating. Of these 75 members, we invited 34 (45%) individuals based on purposive sampling to take part in the scenario-based, think-aloud study. Eventually, of the 34 individuals, 5 (15%) participated in the pilot study, and 15 (44%) participated in the think-aloud sessions, 5 (33%) for each scenario. Among the 34 individuals, there were 9 (26%) nonresponses, 1 (3%) failed recording, and 4 (12%) who opted out.

Procedure

The scenario-based, think-aloud sessions were conducted between May 2021 and December 2021 by 3 researchers (PK, FH, and an undergraduate student). PK and the student have a health communication background, and FH has a health science and health care management background. PK is trained in qualitative research. Due to the COVID-19 pandemic, the sessions were held on the web using videoconferencing software (ie, Zoom [Zoom Video Communications] or Microsoft Teams [Microsoft Corp]) and were recorded with video. Analog patients could participate in the sessions from the comfort of their home while using their own devices, thereby enhancing ecological validity.

We used a protocol for the scenario-based, think-aloud sessions, including a semistructured interview guide. This protocol was pilot-tested with 15% (5/34) of the analog patients. On the basis of the pilot, we decided to develop a video tutorial explaining the think-aloud procedure and a written manual explaining the use of the videoconferencing software (eg, “How do I share my screen?”). We also adapted the interview guide by adding questions focusing on analog patients' explanations of and reflections on their WHIS behavior (Multimedia Appendix 2). Participating analog patients received an email including an information letter and the video tutorial.

At the start of each session, the researcher explained the nature of the scenario-based, think-aloud method to the analog patients and asked for their personal experience with WHIS. Then, to become familiar with the process of thinking aloud, the analog patients were presented with a practical task (ie, to find a recipe for a pie or a cake containing apples) [27].

After familiarizing the analog patients with the think-aloud procedure, the researcher asked them to imagine themselves in one of the three following scenarios: (1) being an individual who experienced symptoms that could point toward non-Hodgkin lymphoma (NHL), hereinafter referred to as analog prediagnostic patient; (2) being a patient who is about to receive treatment for NHL, hereinafter referred to as analog patient with cancer; or (3) being a survivor of NHL 2 months after having finished treatment, hereinafter referred to as analog survivor of cancer (Multimedia Appendix 3). We use the general term *analog patients* when referring to 2 or 3 scenarios.

Each scenario was based on real patient experiences that were reported in blogs and discussion groups of the largest cancer-related website in the Netherlands [28] and was reviewed by a survivor of cancer to optimize external validity [29]. Analog patients were assigned to the scenario that was most appropriate given their health status and relationship to cancer.

To enhance identification, analog patients were asked to report in their own words what they had just heard in the scenario. In addition, the researcher asked analog patients to discuss any thoughts or feelings that were evoked by the scenario and score their stress, anxiety, worries about cancer, hope, and uncertainty on an 11-point thermometer-style scale (0=*not at all*; 10=*an extreme amount*). Next, analog patients were asked to go on the web imagining themselves as the described patient in the scenario. While performing the various tasks, analog patients were asked to share their screen. The researcher instructed analog patients to indicate when they wanted to stop their web-based search. If analog patients fell silent during the session, the researcher reminded them to voice their thoughts.

After the think-aloud process, a short semistructured interview was conducted in which the researchers probed for analog patients' motives (eg, what made them choose particular search terms or why they decided to end their search) and their satisfaction with the content (Multimedia Appendix 2). Each interview session ended with a questionnaire assessing the analog patients' coping style (Dutch Threatening Medical Situations Inventory [30,31]), uncertainty intolerance (Dutch version of the short Intolerance of Uncertainty Scale [32]), information needs [33], and eHealth literacy (Dutch eHealth Literacy Scale [34]). These measures were used to be able to describe the sample.

Data Analysis

In total, 2 coders (FH and PK) first familiarized themselves with the data by watching the recordings and reading the interviewer field notes. Second, they independently selected and transcribed parts of each recording that seemed relevant to the research questions (eg, motives and emotions related to WHIS and search strategies). During the analysis, they focused on the analog patients' actions (observations), their verbalized thoughts during the scenario-based, think-aloud process (what they did vs what they said), and their reflections (interview). What was considered relevant was first discussed with a third team member (AL). Third, the coders independently double coded all relevant fragments. Fragments were coded inductively based on the sensitizing concepts as discussed in the introduction (ie, emotions and motives to seek web-based health information, search strategy used, and type of emotions evoked). During the observations, the coders closely examined the search terms used by the analog patients and the content viewed to deduce the analog patients' underlying motives. Fourth, the coders met and discussed their codes after each session to reach an agreement on the coding scheme together with a third team member (AL). Fifth, after completion of the coding process, the codes were aggregated into potential overarching themes and subthemes through comparisons and discussion between the coders. To improve reliability, validity, and generalizability, the results were substantiated using vivid quotes, and a continuous process of reflection and discussion among the coauthors (FH, PK, AL, and ES) was used. To improve the readability of the overall analysis (N=15), we decided to use the term *most* when the analysis applied to >10 analog patients, *several* when it applied to between 5 and 10 analog patients, and *some* when the analysis applied to <5 analog patients. For scenario-specific analysis (5/15, 33%), we decided to use the term *most* when the analysis applied to 3 or 4 analog patients and the term *some* when the analysis applied to 2 analog patients.

Ethical Considerations

The Amsterdam School of Communication Research Ethical Review Board approved this study at the University of Amsterdam (ethics approval code: 2021-PC-13493). Informed consent was verbally obtained from analog patients at the start of the scenario-based, think-aloud session. Analog patients could withdraw their consent at any time. The data could not be anonymized as the think-aloud interviews were video recorded. The data are saved on a secured drive of the Amsterdam University Medical Center. No compensation was provided to the participants.

Results

Sample Characteristics

Among the 15 participating analog patients (n=9, 60% women and n=6, 40% men), the ages ranged from 28 to 72 years (mean 56.9, SD 12.5 years). Most were former patients with cancer and reported having used the internet for seeking health information >6 times in the foregoing year. In total, the sessions lasted between 25 and 70 minutes, and the web-based search lasted between approximately 6 and 26 minutes. The number of web pages visited ranged from 3 to 15 per session, and changes in search terms ranged from 1 to 16 per session. Table 1 shows the sample characteristics, and Tables 2-4 provide descriptions of the individual search sessions.

Table 1. Analog patient characteristics (N=15).

	Prediagnosis stage (n=5)	Treatment stage (n=5)	Survivor stage (n=5)	Total
Age (y), mean (SD; range)	59.6 (8.1; 51-72)	54.6 (14.9; 28-63)	56.4 (15.7; 29-66)	56.9 (12.5; 28-72)
Gender, n (%)				
Woman	3 (60)	3 (60)	3 (60)	9 (60)
Man	2 (40)	2 (40)	2 (40)	6 (40)
Educational level, n (%)[a]				
Low	1 (20)	1 (20)	1 (20)	3 (20)
Middle	0 (0)	1 (20)	2 (40)	3 (20)
High	4 (80)	3 (60)	2 (40)	9 (60)
Relationship to cancer, n (%)				
Having cancer	0 (0)	2 (40)	1 (20)	3 (20)
Having had cancer	2 (40)	3 (60)	4 (80)	9 (60)
Having a relative with cancer	3 (60)	0 (0)	0 (0)	3 (20)
Frequency of web-based health information seeking in the previous year, n (%)				
1-5 times	3 (60)	2 (40)	1 (20)	6 (40)
6-10 times	1 (20)	0 (0)	2 (40)	3 (20)
11-30 times	0 (0)	3 (60)	1 (20)	4 (27)
>30 times	1 (20)	0 (0)	1 (20)	2 (13)
Uncertainty intolerance score, mean (SD; range)	36.2 (7.9; 25-46)	31.8 (9.4; 24-47)	25.6 (7.4; 15-36)	31.2 (8.9; 15-47)
eHEALS[b] score, mean (SD; range)	34.6 (3.8; 31-40)	34.0 (5.3; 27-40)	36.6 (2.1; 34-39)	35.1 (3.8; 27-40)
Monitoring coping style score, mean (SD; range)	11.8 (2.6; 8-15)	13.0 (2.3; 10-15)	8.2 (1.3; 6-9)	11.0 (2.9; 6-15)
Information preference, n (%)				
"I want to know as much as possible, both positive and negative information."	4 (80)	4 (80)	3 (60)	11 (73)
"I want to know as much as possible, both positive and negative information, but in a dosed way (little by little)."	1 (20)	1 (20)	1 (20)	3 (20)
"I want mainly positive information."	0 (0)	0 (0)	1 (20)	1 (7)
"I don't need to know that much."	0 (0)	0 (0)	0 (0)	0 (0)

[a]Low: secondary education; middle: senior general secondary education, secondary vocational education, and preuniversity education; high: college or university.

[b]eHEALS: eHealth Literacy Scale.

Table 2. Characteristics of the participants and search sessions in the prediagnosis phase.

	Participant S01	Participant S05	Participant S06	Participant S08	Participant S10	Values, mean (SD)
Age (y)	61	51	54	60	72	59.6 (8.1)
Gender	Man	Woman	Man	Woman	Woman	—[a]
Educational level[b]	High	High	High	Low	High	—
Search time	15 min 52 s	8 min 57 s	16 min 51 s	6 min 11 s	7 min 55 s	11 min 9 s (4 min 51 s)
Times changing search terms, N	9	4	8	4	1	5.2 (3.3)
Search engine used	Google	Google	Google	Google	Google	—
Total web pages visited, N	5	9	9	3	5	6.2 (2.7)
Uncertainty intolerance score[c]	35	34	41	46	25	36.2 (7.9)
eHealth literacy score[d]	33	32	37	31	40	34.6 (3.8)
Monitoring coping style score[e]	11	8	15	12	13	11.8 (2.6)
Thermometer score[f]						
Feelings of stress and anxiety	7	6.5	8	7	5	6.7 (1.1)
Worries about cancer	7	7.5	6	5.5	5	6.2 (1.0)
Hope	—	—	—	—	—	—
Uncertainty	7	7.5	8	6	10	7.7 (1.5)

[a]Not applicable.

[b]Low: secondary education; middle: senior general secondary education, secondary vocational education, and preuniversity education; high: college or university.

[c]Uncertainty intolerance was measured using the Intolerance of Uncertainty Scale. Total sum scores can range from 12 to 60. A higher score indicates a higher level of intolerance of uncertainty.

[d]Self-perceived eHealth literacy was measured using the eHealth Literacy Scale (eHEALS). Scores on the eHEALS are summed and can range from 8 to 40, with higher scores representing higher self-perceived eHealth literacy.

[e]Monitoring coping style was measured using the Threatening Medical Situations Inventory. Scores are based on the sum of items and can range from 3 to 16. A higher score means a higher monitoring coping style.

[f]Analog patients were asked before the search session to score feelings of stress and anxiety (thermometer 1), worries about cancer (only for the first scenario), hope (only for the second and third scenarios; thermometer 2), and uncertainty (thermometer 3) on an 11-point thermometer-style scale (*0=not at all*; *10=an extreme amount*).

Table 3. Characteristics of the participants and search sessions in the treatment phase.

	Participant S23	Participant S24	Participant S25	Participant S27	Participant S28	Values, mean (SD)
Age (years)	61	62	63	59	28	54.6 (14.9)
Gender	Woman	Man	Woman	Woman	Man	—[a]
Educational level[b]	Low	High	High	Middle	High	—
Search time	9 min 55 s	13 min 40 s	16 min 34 s	24 min 55 s	16 min 35 s	16 min 19 s (5 min 31 s)
Times changing search terms, N	5	5	9	11	9	7.8 (2.7)
Search engines used	Google	Google and Microsoft Bing	Google, Firefox, and Norton Safe Search	Google	Google	—
Total web pages visited, N	5	3	10	11	9	7.6 (3.4)
Uncertainty intolerance score[c]	32	32	24	47	24	31.8 (9.4)
eHealth literacy score[d]	36	40	30	36	27	34 (5.3)
Monitoring coping style score[e]	15	15	10	14	11	13 (2.3)
Thermometer score[f]						
Feelings of stress and anxiety	7	8	7	9	8	7.8 (0.8)
Worries about cancer	—	—	—	—	—	—
Hope	9	3	9.5	4	4.5	6 (3.0)
Uncertainty	8	8.5	2	9	5.5	6.6 (2.9)

[a]Not applicable.

[b]Low: secondary education; middle: senior general secondary education, secondary vocational education, and preuniversity education; high: college or university.

[c]Uncertainty intolerance was measured using the Intolerance of Uncertainty Scale. Total sum scores can range from 12 to 60. A higher score indicates a higher level of intolerance of uncertainty.

[d]Self-perceived eHealth literacy was measured using the eHealth Literacy Scale (eHEALS). Scores on the eHEALS are summed and can range from 8 to 40, with higher scores representing higher self-perceived eHealth literacy.

[e]Monitoring coping style was measured using the Threatening Medical Situations Inventory. Scores are based on the sum of items and can range from 3 to 16. A higher score means a higher monitoring coping style.

[f]Analog patients were asked before the search session to score feelings of stress and anxiety (thermometer 1), worries about cancer (only for the first scenario), hope (only for the second and third scenarios; thermometer 2), and uncertainty (thermometer 3) on an 11-point thermometer-style scale (0=*not at all*; 10=*an extreme amount*).

Table 4. Characteristics of the participants and search sessions in the survivor phase.

	Participant S32	Participant S34	Participant S35	Participant S36	Participant S37	Values, mean (SD)
Age (y)	66	63	66	29	58	56.4 (15.7)
Gender	Woman	Man	Man	Woman	Woman	—[a]
Educational level[b]	Low	High	High	Middle	Middle	—
Search time	15 min 11 s	21 min 40 s	8 min 40 s	25 min 55 s	23 min 35 s	19 min 00 s (7 min 01 s)
Times changing search terms, N	6	16	4	13	8	9.4 (5.0)
Search engines used	Microsoft Bing	Google and Microsoft Bing	Google	Microsoft Bing	Google	—
Total web pages visited, N	8	13	4	15	12	10.4 (4.4)
Uncertainty intolerance score[c]	25	26	15	26	36	25.6 (7.4)
eHealth literacy score[d]	38	39	34	37	35	36.6 (2.1)
Monitoring coping style score[e]	9	6	9	9	8	8.2 (1.3)
Thermometer score[f]						
Feelings of stress and anxiety	5	8	6	3.5	8	6.1 (1.9)
Worries about cancer	—	—	—	—	—	—
Hope	3	6.5	8	10	8	7.1 (2.6)
Uncertainty	7.5	6	0	5	9	5.5 (3.4)

[a]Not applicable.

[b]Low: secondary education; middle: senior general secondary education, secondary vocational education, and preuniversity education; high: college or university.

[c]Uncertainty intolerance was measured using the Intolerance of Uncertainty Scale. Total sum scores can range from 12 to 60. A higher score indicates a higher level of intolerance of uncertainty.

[d]Self-perceived eHealth literacy was measured using the eHealth Literacy Scale (eHEALS). Scores on the eHEALS are summed and can range from 8 to 40, with higher scores representing higher self-perceived eHealth literacy.

[e]Monitoring coping style was measured using the Threatening Medical Situations Inventory. Scores are based on the sum of items and can range from 3 to 16. A higher score means a higher monitoring coping style.

[f]Analog patients were asked before the search session to score feelings of stress and anxiety (thermometer 1), worries about cancer (only for the first scenario), hope (only for the second and third scenarios; thermometer 2), and uncertainty (thermometer 3) on an 11-point thermometer-style scale (0=*not at all*; 10=*an extreme amount*).

Start of the Search Session

Analog patients reported starting their search session with various associations and reactions evoked by the scenario. For example, in the scenario in which they were experiencing symptoms, analog prediagnostic patients were immediately worried about cancer or felt alarmed by specific symptoms. This was reflected in their search terms, showing a predominant focus on searching for information about these symptoms. This was also reflected in their thoughts as patients expressed concern about the symptoms. Whenever the general practitioner in the scenario showed concern, analog patients more often showed signs of feeling distressed:

> *The word tumor immediately pops into my mind. This is serious. These are symptoms I would not trust.* [S01; analog prediagnostic patient]

> *You do not immediately think the best, especially sweating attacks and weight loss are warning signs.* [S05; analog prediagnostic patient]

Most analog patients with cancer assigned to the scenario of undergoing cancer treatment started their search by expressing fear about the upcoming challenges, particularly the apprehension of chemotherapy, and harboring doubts about the effectiveness of the treatment. The aggressive nature of NHL added to their anxiety, with a lack of optimistic information causing visible distress and confusion about the treatment process:

> *I am scared of what's coming and scared of the chemo. And I am not so hopeful because of my doubt whether the treatment will work.* [S27; analog patient with cancer]

Despite these negative emotions, some analog patients with cancer still remained combative or hopeful:

> *Damn, I have cancer again, now I have to have another treatment, but well I am going for it, because I am far from finished living.* [S25; analog patient with cancer]

This fear was also reflected in their search, with all analog patients with cancer being prone to mainly focus on using search words that were used in the scenario (*(aggressive) non-Hodgkin* and *R-CHOP* [rituximab, cyclophosphamide, hydroxydaunorubicin, oncovin, and prednisone regimen]).

Finally, those who were allocated to the survivor case ("analog survivors of cancer") generally voiced uncertainty at the beginning of the search about whether the cancer was definitely gone. They showed concerns about cancer recurrence and recovery and were somewhat skeptical about recovery:

> *Should I really be happy with being cancer-free? What if it comes back? Before this, I had not felt anything. Now, I do not know what I should and should not feel anymore.* [S32; analog survivor of cancer]

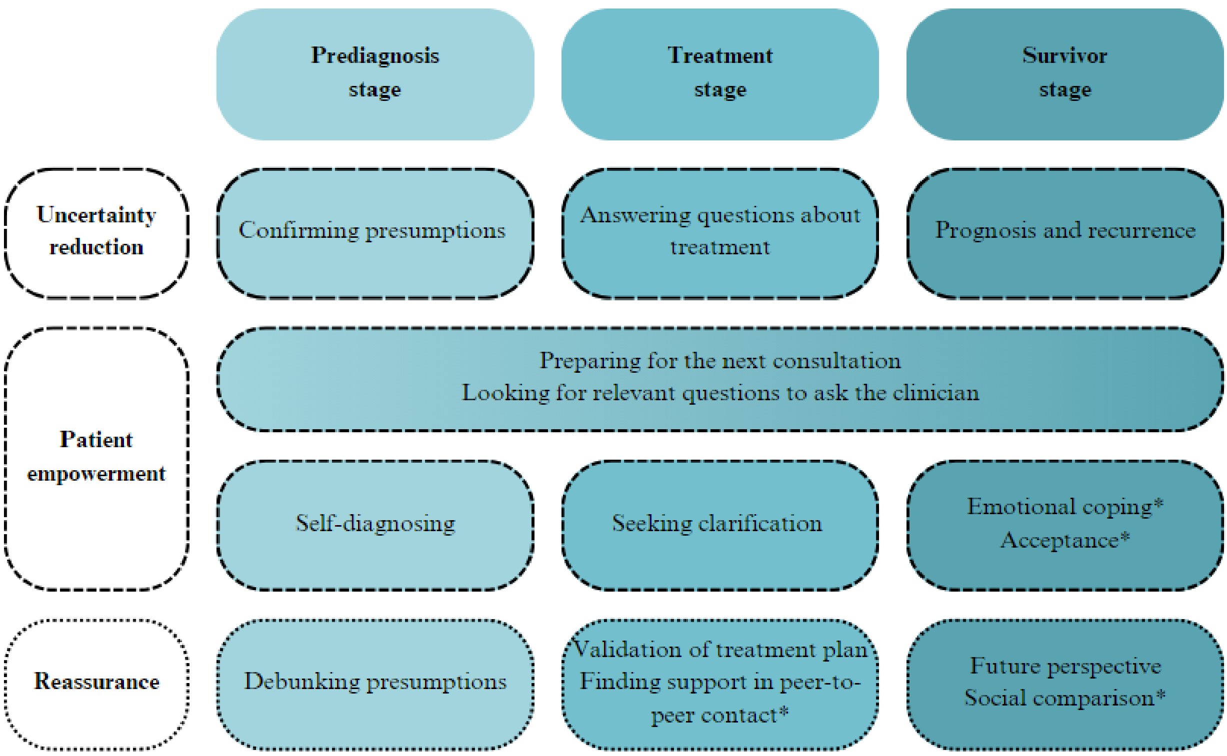
Analog survivors of cancer voiced that, most of all, they wanted to return to their normal lives before the diagnosis and, accordingly, started with search terms related to this desire to get back to the normality of their lives (eg, *out of cancer treatment, what now?*).

Search Motives

Overview

On the basis of the search strategies observed and the thoughts voiced, we were able to distinguish 3 overarching motives guiding patients' WHIS. These overarching motives were prevalent regardless of the allocated stage in the disease trajectory. Each overarching motive was expressed differently throughout the various disease stages (Figure 1). The first motive was *uncertainty reduction* to cope with the anxiety and health threats as most analog patients started their search by expressing uncertainty about what was going to happen to them. The second motive was *empowerment* (ie, "the process of increasing the capacity of individuals (or groups) to make choices and to transform those choices into desired actions and outcomes" [35]) as most analog patients searched content to pursue an active role in their own care process, for example, by actively preparing for the next consultation and looking for relevant questions to ask the clinician. The third motive was *finding reassurance* as analog patients wished to find content that would give them some hope. The 3 overarching motives were not mutually exclusive; they could go hand in hand.

Figure 1. Expressions of the 3 overarching motives for web-based health information seeking—uncertainty reduction, patient empowerment, and reassurance—within the 3 disease stages (prediagnosis stage, treatment stage, and survivor stage). *Affective needs (ie, need to be understood).



Motives in the Prediagnosis Stage

Analog prediagnostic patients wanted to diminish their anxiety and reduce their uncertainty by starting their search with confirming their presumptions. One analog prediagnostic patient immediately used the search term *characteristics cancer*, looked on different websites to compare symptoms, and said the following at search onset:

> *You do not know anything for sure...Apart from the fact that I initially think it is cancer, I still want to confirm that by searching the internet.* [S10; analog prediagnostic patient]

Furthermore, they mostly used the internet to empower themselves by attempting to self-diagnose and prepare for the next consultation. When trying to self-diagnose, they used symptom-related search terms, such as *fatigue*, *swollen glands*, *(unexplained) weight loss*, and *night sweats*. After encountering content about possible diagnoses, some changed their search terms to *symptoms of non-Hodgkin* and *symptoms of cancer* while simultaneously explaining this change:

> *I am actually finding several causes now and cancer is also mentioned. However, I am not quite happy with the information I'm getting yet. But since cancer has come up a few times, I am going to search for symptoms of cancer, so I'm turning it [the search terms] around now [searches for: symptoms of cancer].* [S06; analog prediagnostic patient]

The motive *empowerment* was apparent in one analog prediagnostic patient who used the search terms *preparing consult internist* and read the text *What can you do to prepare for the first visit with an internist?*:

> *What I would do now, because I am going to the hospital, is that I am going to prepare. So, I am now going to search on prepare consult internist. I think I am going to an internist, but obviously I'm not sure yet. [reads text on how to prepare for a visit] I would also like to know, what are useful questions? [clicks on other website] Okay, I have pretty much got everything now I need to consider, only I have to go through the 3 good questions again which I can ask the internist [opens the online brochure about 3 good questions].* [S06; analog prediagnostic patient]

The extent to which analog prediagnostic patients in this phase narrowed down their search to know their exact (possible) diagnosis differed. Some searched various options related to the symptoms, one settled for the likely diagnosis "cancer," whereas others continued their search until they had a specific idea about the type of cancer. Those who searched for various possible diagnoses wanted to be reassured that the symptoms could be anything other than a serious illness such as cancer. They tried to debunk their presumptions, as reflected in the following observation and quote:

> *[reads content about causes of swollen lymph nodes] Infection, which could also be, that makes sense. Then I see here swollen nodes due to a systemic disease. Then I am thinking about Lyme disease, okay. That is different from a tumor. Autoimmune disease is potentially on the table. I already see that swollen nodes can be caused by many factors, which is somewhat reassuring.* [S01; analog prediagnostic patient]

Motives in the Treatment Stage

Analog patients with cancer mostly appeared to use the internet to answer their remaining questions to reduce uncertainty. Reducing uncertainty seemed to be combined with increasing their feeling of empowerment as they appeared to seek for more clarification about diagnosis and treatment. Both uncertainty reduction and empowerment were reflected in search terms such as *What is non-Hodgkin lymphoma?*, *R-CHOP*, *side effects*, and *immunotherapy* (ie, cognitive needs). While searching these terms, they said the following:

> *More than 50% of patients with an aggressive non-Hodgkin lymphoma in an advanced stage are cured after treatment with R-CHOP. Okay, that is quite a lot. But, hmm, yes, the other half does not. It is not clear to me whether the half that does not recover remains chronically ill or simply succumbs to death. I would like to know that in that sense.* [S28; analog patient with cancer]

The motive to obtain reassurance via web-based information was reflected in analog patients with cancer using the internet to validate whether the treatment (as being proposed in the scenario) was indeed the right treatment for them. They specifically searched for websites and information that would convince them of this treatment being the best option:

> *And I would definitely, before starting that treatment, request a second opinion from another institution to ensure that I...um...yes, receive the correct diagnosis or the right treatment [searches for other hospitals].* [S24; analog patient with cancer]

One analog patient with cancer also seemed to use the internet to obtain reassurance via socioemotional content. This was reflected in the search term *experiences with R CHOP*. Of note, none of the analog patients with cancer used search terms indicating a need to know more about the prognosis of NHL.

Motives in the Survivor Stage

Analog survivors of cancer seemed to use the internet to reduce uncertainty only to a limited extent. When they used the internet for that purpose, they wanted to know more about prognosis and recurrence, as reflected in search terms such as *prognosis*, *late effects*, and *what to expect*. While using these search terms, they said the following:

> *Yes, you are quite uncertain about how everything will unfold. There are still quite a few questions, and that diminishes over time, but especially in the beginning after that hospital period, you still have quite a lot of questions.* [S37; analog survivor of cancer]

Analog survivors of cancer mainly used the internet to search for socioemotional content related to pursuing an active role in their own recovery (ie, patient empowerment). This was reflected in search terms regarding feelings, experiences, and emotions (eg, *uncertainty after cancer* and *feelings after non-Hodgkin treatment*). Pursuing an active role in their own recovery mainly encompassed (emotional) coping and finding acceptance (eg, returning to their normal life before diagnosis). Apparently, to satisfy these motives, they often visited blogs of survivors of cancer writing about feelings and experiences and providing advice on coping with survivorship (eg, *how to deal with emotions/fatigue/work/daily life*). Some searched for psychologists or for recovery programs offered by patient organizations or hospitals, which could also be seen as an expression of empowerment:

> *Not because I do not trust my own hospital, but I just want to look further. What do other hospitals offer their patients? Is there anything I can take advantage of?* [S32; analog survivor of cancer]

To a lesser extent, analog survivors of cancer went on the web to seek reassurance about their future. They seemed to be reassured when encountering people with similar experiences. For example, one survivor stated the following:

> *Okay, I found something here, there are more people like me. Shared sorrow is half sorrow.* [S34; analog survivor of cancer]

Overall WHIS Patterns

The web-based source that analog patients eventually selected seemed to depend on their cancer-specific knowledge, cancer-related experience, and search experience. The use of cancer-specific knowledge and experience was reflected in selecting familiar and well-known websites about cancer. The use of search experience was reflected in analog patients using strategies that they reported to prefer (eg, preferring to use the search bar on specific websites instead of the regular search engine or the other way around). Analog patients mentioned different reasons for selecting content. The most prevalent reasons were familiarity with a website or organization (eg, the Dutch Cancer Society) or previous experience with a website. Some also mentioned that they selected certain websites as part of habitual behavior rather than for specific reasons. Notably, analog patients also visited websites while voicing doubt about their trustworthiness. It seemed that those analog patients thought that it was more important to find information relevant to fulfill their motives than looking for trustworthy information.

WHIS Approaches

In total, 2 overarching WHIS approaches could be identified: explorative and focused. Explorative approaches consisted of spontaneously selecting information seemingly without having an explicit information need. Analog patients who used this explorative approach mainly guided their searches by clicking on referral links and using suggestions made by search features on Google, such as the *autocomplete* (a feature within Google Search that makes it faster to complete searches that users start to type. Google’s automated systems generate predictions that help users save time by allowing them to quickly complete the search they already intended to do) and *people also ask* (a feature within Google Search that provides users with additional questions related to their original search query and quick answers to them) functions. Analog patients were considered to use a focused approach when they seemed to search more purposefully (ie, mainly selecting information aligned with their verbally expressed specific information needs). For instance, an analog prediagnostic patient searched *symptoms of cancer* and exclusively selected content related to these search terms.

Unlike analog patients using an explorative approach, patients using a focused approach only made use of Google features when these explicitly helped them meet their self-reported information needs. For example, an analog patient with cancer searched for and read information about R-CHOP and subsequently encountered the following suggestions from the Google feature *people also ask*: *What does R-CHOP mean?* and *What is a CHOP cure?*

Several analog patients used both explorative and focused approaches. Some started with a clearly focused search strategy based on an information need but appeared to become emotionally distracted by the encountered content and started to use a more explorative approach. Others started with an explorative approach and were triggered by specific content that led them to adopt a new, more focused approach (eg, understanding difficult, complex words or confirming assumptions). In other words, information needs evolved while searching. WHIS approaches seemed independent of the disease stage that analog patients were allocated to.

Dissatisfying Content

All analog patients came across dissatisfying content while searching (in other words, content that did not satisfy the wishes of the patients). Examples of dissatisfying content were difficulty navigating systems on websites, cookies, or information not being in line with search motives. When this dissatisfying content was encountered, analog patients most often changed their search terms or quickly moved on to other web pages (the number of web pages visited ranged from 3 to 15 per session). Search terms were frequently changed during a search session (range 1-16 times per session), mostly because of dissatisfying content:

> *So, I’m not getting anywhere with this either, because I don’t need to know what the cancer looks like...So I guess I’m not getting anywhere with this search term, with the search things. Uhm how am I going to do that?* [S35; analog survivor of cancer]

Impact of WHIS on Emotions and Dealing With Content

Emotions

Regardless of the stage of the disease, emotions were present throughout the entire search process, ranging from anxiety and worry to hope. These emotions fluctuated, and negative emotions were often induced when confrontational, complex, or unwanted information was found. Confrontational content included information on symptoms suggesting cancer or thyroid problems, information on treatment side effects such as hair loss and nausea, or a confronting picture:

> *I am not happy with the image I see here. That photo confirms the nightmare I have about chemotherapy. This is someone surrounded by nurses, being injected, and she has no hair, so that picture embodies for me everything that is wrong with this disease in one image. They have succeeded very skillfully in capturing all of that in one photo, but I do not think that was the intention of the person who took the photo. However, that is how it comes across at me: the embodiment of a mountain of misery.* [S27; analog patient with cancer]

Complex information included content containing medical jargon, such as *malignancies*; *cachexia*; or drug names such as *rituximab*, *cyclophosphamide*, and *hydroxydaunorubicin*. Most analog patients seemed to be affected by complex words:

> *This is getting annoying because I already see a word here that I do not know at all. I'm getting a lot of medical terms here that do not mean much to me...* [S06; analog prediagnostic patient]

Sometimes, positive emotions emerged from information that gave hope (eg, indolent NHL more often has a chance of recurrence than aggressive NHL). Moreover, analog patients who doubted their own navigation skills while searching on the web reported high levels of distress. Some of the analog patients also experienced cognitive dissonance (ie, a mental state of having conflicting beliefs, thoughts, values, or attitudes), as reflected in the following quote:

> *Everything in you says that it is better not to click on it, because you don't want to know it. But if you see the option then you just need to click on it.* [S27; analog patient with cancer]

Dealing With Emotionally Difficult Content

When encountering cognitively or emotionally difficult (or unwanted) information, analog patients with cancer dealt with the content in various ways. They adapted their search strategy, ignored the information by quickly clicking away from it and shifting toward other information, or stopped searching:

> *I immediately find myself with types of cancer, um...all the hits are related to Hodgkin; [scrolling back and forth through search results on the first Google page, but not clicking on anything]. Yes, I find this difficult; I think I will check the next Google pages to see what else comes up, what comes after Hodgkin.* [S01; analog prediagnostic patient]

Several analog patients also mentioned that they would normally seek information multiple times briefly or seek a distraction from the confronting information, such as watching Netflix or having some tea.

End of the Search

As mentioned previously, one of the reasons to stop searching was encountering cognitively or emotionally difficult information (confronting, upsetting, or confusing). This was mostly the case for analog prediagnostic patients and analog patients with cancer. The following quote illustrates this "overload":

> *Nothing [information found] makes me happy. Yeah, you can find information, but I believe I would make a cup of coffee now. I cannot say I'm a lot wiser now.* [S25; analog patient with cancer]

Another reason to stop searching was that analog patients saw their health care provider as a gatekeeper and their primary source of information about their disease and treatment. During the interview, they indicated that they preferred to talk with their clinician to clarify the encountered information instead of looking for more web-based information:

> *I believe that this information is quite overwhelming me right now, so I would put it away for a while. And I would talk it through first at a subsequent consultation with my doctor before I start worrying and assuming things that are not an issue at all...So, I think I will stop looking for now until I have spoken to the doctor again. It is a lot of information, and it is also complicated. So, I want to consult the doctor first.* [S23; analog patient with cancer]

All analog patients with cancer indicated ending their search sessions with many unanswered questions and an increase in uncertainty (compared to the start of the search). Unlike analog patients with cancer, analog prediagnostic patients and analog survivors of cancer ended their search more often with their information needs being fulfilled, as reflected in the following quote during the interview:

> *I do think it is very true. I'm at a point now where I do think: yeah, I'm reading this now, I'm not really getting very comfortable with this. I do not think there is any point in continuing to search now. I think I am now on a trustworthy site, and I find this a very upsetting story now that I see this. I cannot do much but wait and see. I don't know if I'm happy I've figured this out now...* [S01; analog prediagnostic patient]

Compared to analog patients in other disease stages, analog survivors of cancer ended their search most often satisfied and with more positive emotions; they felt less uncertain and found useful (practical) information on ways to cope with the future:

> *I definitely did become a bit wiser, because I can move on: I can go to physio, psychologist and I have a phone line which I can call.* [S36; analog survivor of cancer]

Discussion

Principal Findings

Using a comprehensive scenario-based, think-aloud approach, we were able to show that (1) patients' overarching motives for WHIS were mainly to reduce uncertainty, obtain reassurance, and increase empowerment; (2) these motives differed depending on the disease stage (at the beginning of the disease trajectory, patients mainly showed cognitive needs, whereas this shifted more toward affective needs in the subsequent disease stages); (3) analog patients' WHIS approaches varied from exploratory to focused to a combination of both; and (4) positive (hope and reassurance) and negative (anxiety and worry) emotional responses played an important role in patients' search strategies.

We found 3 overarching motives (ie, reducing uncertainty, obtaining reassurance, and increasing empowerment) for patients to search on the web. With these findings, we not only confirm the problem-solving model in the context of patient motivations to go on the web throughout their illness journey but also extend this model. According to Wilson [36], the process of problem-solving is the result of patients' wishes to reduce uncertainty. Patients' uncertainty at either the prediagnosis or treatment phase concerned various topics, clearly showing that these motives change over time. However, we also discovered 2 other important motives for patients to engage in a problem-solving process, namely, reassurance and empowerment [36]. In addition, the study's findings revealed a potential conflict between patient empowerment and uncertainty reduction in the context of WHIS. When patients seek web-based information to empower themselves, they gain a better understanding of their situation, which could enable them to ask informed questions to their clinicians. However, this increased knowledge may also give rise to new questions and uncertainties, leading to a potential challenge in fulfilling the motive of uncertainty reduction.

Moreover, our findings provide insights into the search behavior of patients with cancer at various stages of their disease trajectory and how these behaviors vary. In the initial phase of prediagnosis, patients often engaged in self-diagnosis. The results of this study extend those of previous research [9] by showing that patients prepare for a consultation by using the internet not only to help them formulate questions but also to self-diagnose. Despite the popularity of this search approach, research on self-diagnosing remains limited. In the context of web-based self-diagnosis for minor ailments, research shows that using the internet for self-diagnosis can be helpful as 44% of participants achieved accurate final diagnoses after searching the internet compared to 11% before searching the internet [37]. Another study shows that web-based self-diagnosing has the potential to empower patients in appraising and challenging clinicians' advice and requesting further diagnostic procedures [38]. However, web-based self-diagnosis can also be counterproductive if the patient misdiagnoses themselves, leading to unnecessary concerns. In addition, problems may occur if patients visit their clinician with a preconceived diagnosis, potentially causing disagreements about their condition [39]. During the treatment phase, the search strategy of patients with cancer focused on cognitive needs by seeking clarification, gathering more information, and preparing. However, we only observed a shift in search strategies toward affective needs by seeking emotional coping resources for dealing with the disease after patients completed treatments and were declared cancer free. In other words, at the beginning of the disease trajectory, analog patients had mainly cognitive needs, whereas analog survivors also showed affective needs and used the internet for emotional support. The change from more cognitive needs to more affective needs could be explained using the social-cognitive processing model. According to this model, seeking emotional support may facilitate emotional adjustment to traumatic experiences, such as cancer diagnosis and treatment [40]. Potentially, survivors have more mental space to cope with the situation and reflect on what has happened in the past months.

Our results further show that patients tend to use different search strategies: explorative, focused, or a combination of both. Previous research has demonstrated that individuals who are more exploratory seekers tend to tackle unfamiliar problems by using a broader search strategy (symptom exploration), resulting in a broader range of new information [37]. By encountering a broad range of information, patients are possibly confronted with new and unknown content, which could increase their level of uncertainty [41]. Our results also suggest that an exploratory search strategy increased the risk of being confronted with unwanted information. On the other hand, those who are more focused seekers tend to have a clear idea and a specific plan, leading them to research within a limited set of results (hypothesis testing) [37]. Such hypothesis testing can be problematic because it skews the way in which patients process information and distorts their perception of reality—a phenomenon known as confirmation bias [42]. It occurs when patients seek, interpret, or favor information that confirms their existing beliefs while ignoring or downplaying evidence that contradicts those beliefs [43]. Pang et al [41] argue that seekers within one internet visit alternate between exploratory and focused search strategies as new, unknown topics often lead to more exploratory searches. If the topic to be searched becomes clearer, the seeker may use a more focused approach. Our results confirm those of this previous study by showing that patients used both explorative and focused approaches. Some started with a focused search but became emotionally distracted and switched to an explorative approach. Others began exploratively and shifted to a focused search after encountering specific content.

Furthermore, our findings show that positive (hope and reassurance) and negative (anxiety and worry) emotional responses were present before, during, and after the search sessions. On the basis of patients' voiced thoughts and observed behavior, we conclude that these emotions impacted their search behavior. This is in line with the functionalist perspective of emotions, which argues that emotional responses may motivate people to behave in particular ways [44-46]. For instance, hope is seen as a motivating force that helps individuals move toward desired outcomes even in the face of uncertainty [47]. It is a future-oriented emotion as it involves visualization of positive future situations [48], and thus, hope could explain why patients are motivated to seek reassurance. Worry, on the other hand, is seen as an uncertainty-associated emotion and can increase a patient's desire for obtaining additional information [15]. Studies show a positive relationship between worry and the perceived need for additional information [49-51], and thus, worry could explain why patients are motivated to reduce uncertainty by searching for additional information. However, we also observed that patients who were worried ignored or avoided specific information. A possible explanation is that hope and worry are intertwined during WHIS [16]. Confronting or complex information poses a threat to hope, and thus, ignoring certain information may serve as a self-protective behavior to stay hopeful [16].

In our study, patients in the treatment phase were most worried after their search session. This is in contrast to existing literature indicating that perceived knowledge through web-based information seeking decreased patients' worry [15]. WHIS has also been found to help searchers fill information voids and enhance their coping abilities [52]. Although we did find some comparable results for the prediagnosis and survivor phases regarding decrease in worry and enhancing coping abilities, we did not find this for patients in the treatment phase. A possible explanation is that complex or confrontational information (eg, jargon for medicines and treatments and intense side effects) may have induced worries in analog patients in this phase. This inconsistency with the existing literature could further be explained by our design, which involved one search session only at one specific moment rather than multiple search sessions by one individual patient. Possibly, patients who search for more information at multiple times will eventually be less worried as they become more familiar with the difficult and complex information. Therefore, future research should investigate the longitudinal search behaviors of individual patients during their disease trajectory and the effects of multiple shorter search sessions within a particular disease phase.

Limitations and Strengths

First, a strength of our approach is that we not only observed patients' WHIS behaviors but simultaneously gained insights into their thoughts. During the interview, the interviewer made use of techniques such as paraphrasing and checking to clarify the meaning of the interviewee, thereby enhancing the validity of our findings. This innovative, comprehensive scenario-based, think-aloud approach exhibits strength in its consideration of the intuitive nature of web-based searching while overcoming challenges such as recall bias in retrospective methods. However, certain limitations should be considered. Some remarks suggested that participants may have felt limited in their choice of search engine and might have perceived an obligation to use a specific search platform, such as Google. Furthermore, during the think-aloud sessions, participants did not explore the use of social media channels (eg, Facebook, Instagram, or Twitter [subsequently rebranded X]). Use of social media may have been limited as participants could perceive it as an intrusion into their personal lives. Another reason could be that these communication channels may represent more spontaneous ways through which patients acquire unplanned or unexpected web-based health information while scrolling through their social media timeline [53]. The scenario-based, think-aloud approach as used in this study does not provide any insights in how social media has an effect on patients' WHIS strategies, motives, and emotions. Furthermore, the relatively small sample size used in this study calls for caution when generalizing the findings. It is important to account for variations in patients' (eHealth) literacy, education, and cultural backgrounds [54]. Although previous research demonstrates overlap in WHIS among patients from different countries, it also identifies distinct country-specific differences even when the countries have comparable welfare and health status [5]. As this study was an explorative qualitative study, and despite our relatively small sample size, we believe we achieved thematic saturation during the iterative process as no new codes emerged toward the end of our analysis. Moreover, it is important to bear in mind when interpreting the findings that our sample consisted of analog patients who were presented with a scenario. This may have biased our results as using analog patients is different from using patients with NHL. However, participants in this study possessed preexisting familiarity with cancer; our sample consisted of patients with cancer (other than NHL), survivors of cancer, and informal caregivers of patients with cancer. Thus, this sample's strength lies in their ability to strongly identify with the scenarios presented, which is also reflected in their quotes, the emotions showed during the think-aloud process, and their scores on the thermometers [24]. Furthermore, participants possessed experience in web-based cancer information seeking. Many of them were acquainted with patient advocacy organizations, and a subset even served as administrators for certain web-based platforms dedicated to cancer information and peer support groups. In addition, they had previously encountered medical terminology in the context of their own medical conditions, thus acquiring a degree of familiarity with medical jargon. Consequently, our sample likely possessed a higher level of proficiency in navigating the internet for cancer-related information compared to the average patient with cancer. Despite their advanced familiarity with the subject, the results still indicated that patients encountered difficulties in navigating the internet and understanding medical jargon.

Practical Implications

Knowing how patients with cancer search for web-based health information is a first step toward optimizing web-based health platforms such that patients with cancer can (more) easily find and navigate through information that fits their needs. On the basis of the study results, there are various implications for the development of cancer websites. First, web-based health platforms could use less complex words and show content warnings about confrontational prognostic or side effect–related information on web pages. The latter could warn searchers about unwanted information, which is especially relevant for exploratory searchers. Second, websites should enable users to self-pace and allow for user-initiated tailoring (ie, allowing users to tailor the information themselves based on their information needs). For example, information should be minimalized, with the possibility to read more if wanted (eg, with the use of hyperlinks). Third, it should also be clear to the user whether platforms are expert generated or peer generated as these platforms differ in content focusing on cognitive needs (addressing the needs of analog prediagnostic patients and analog patients with cancer) and affective needs (addressing the needs of analog survivors of cancer) [13]. In the Netherlands, multiple cancer platforms already make use of such features, which patients in our sample experienced as convenient. In addition to these implications for websites, another important finding is that patients see their health care providers as their primary source of information when it comes to their disease and treatment. Patients indicated that they had various remaining questions and considerable uncertainty after their search, which they wanted to resolve during their interaction with their health care provider. Therefore, it is important that, within consultations, there is room for questions arising from WHIS. Furthermore, health care providers can guide patients in the search process by giving tips and tricks on how (not) to use the internet to search for health information and how to cope with any uncertainty that may result from such a search.

Conclusions

This study provides valuable insights into the real-time WHIS strategies of patients with cancer, the motivations behind seeking web-based health information, and the emotions experienced at various stages of the disease trajectory. Understanding patients' search patterns is pivotal in optimizing web-based health platforms to cater to their specific needs. In addition, these findings can guide clinicians in directing patients toward reliable sources of web-based health information.

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Data Availability

The datasets generated during and analyzed during this study are not publicly available due to the anonymity of the participants but are available from the corresponding author on reasonable request.

Authors' Contributions

The conceptualization of the study was carried out by ES, MH, JvW, and AL. ES acquired funding for this project. FH and PK gathered and analyzed the data, and AL was responsible for the validation process. The original draft of the manuscript was prepared by FH and AL. All authors reviewed the protocols, contributed to conceptualization and methodology, and reviewed the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist.
[DOCX File , 18 KB - infodemiology_v5i1e59625_app1.docx]

Multimedia Appendix 2
Final think-aloud protocol, including semistructured interview guide.
[DOCX File , 15 KB - infodemiology_v5i1e59625_app2.docx]

Multimedia Appendix 3
Think-aloud scenarios.
[DOCX File , 15 KB - infodemiology_v5i1e59625_app3.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
NHL: non-Hodgkin lymphoma
R-CHOP: rituximab, cyclophosphamide, hydroxydaunorubicin, oncovin, and prednisone
WHIS: web-based health information seeking

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Original Paper

Assessment of Reliability and Validity of Celiac Disease–Related YouTube Videos: Content Analysis

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Abstract

Background: YouTube is an increasingly used platform for medical information. However, the reliability and validity of health-related information on celiac disease (CD) on YouTube have not been determined.

Objective: This study aimed to analyze the reliability and validity of CD-related YouTube videos.

Methods: On November 15, 2023, a search was performed on YouTube using the keyword "celiac disease." This search resulted in a selection of videos, which were then reviewed by 2 separate evaluators for content, origin, and specific features. The evaluators assessed the reliability and quality of these videos using a modified DISCERN (mDISCERN) score, the *Journal of the American Medical Association* (*JAMA*) benchmark criteria score, the usefulness score, video power index (VPI), and the Global Quality Scale (GQS) score.

Results: In the analysis of 120 initially screened CD videos, 85 met the criteria for inclusion in the study after certain videos were excluded based on predefined criteria. While the duration of the videos uploaded by health care professionals was significantly longer than the other group (*P*=.009), it was concluded that the median scores for mDISCERN (4, IQR 4-5 vs 2, IQR 2-3; *P*<.001), GQS (4, IQR 4-5 vs 3, IQR 2-3; *P*<.001), *JAMA* (4, IQR 3-4 vs 2, IQR 2-3; *P*<.001), and usefulness (8, IQR 7-9 vs 6, IQR 3-6; *P*<.001) of the videos from this group were significantly higher than those from non–health care professionals. Video interaction parameters, including the median number of views, views per day, likes, dislikes, comments, and VPI, demonstrated no significant difference between the 2 groups.

Conclusions: This study showed that YouTube videos about CD vary significantly in reliability and quality depending on their source. Increasing the production of reliable videos by health care professionals may help to improve patient education and make YouTube a more reliable resource.

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KEYWORDS

gastroenterology; celiac; YouTube; internet-based information; medical information; health-related; reliability; validity; quality; videos; celiac sprue; sprue; gluten enteropathy; cross-sectional

Introduction

Celiac disease (CD) is an autoimmune disorder that occurs in genetically predisposed individuals as a result of the immune reaction to gluten, primarily affecting the small intestine [1]. Symptoms range from asymptomatic to digestive problems and nutritional deficiencies due to malabsorption of nutrients. Treatment includes a gluten-free diet [1]. Over the past few decades, CD has been estimated to affect around 1% of the world's population [2]. Despite the increasing prevalence of

CD, the majority of the patients with CD remain undiagnosed [1].

In recent years, the internet has become an important source of health information for the public. It has been reported that 80% of internet users use social media (SM) platforms to get information about their disease. Patients with chronic diseases in particular are increasingly relying on SM platforms to manage their conditions [3]. In a recent study investigating the use of SM by patients with CD and parents of patients with CD, it was reported that 96% of participants used SM for disease management [4]. YouTube (Google), is one of the world's most popular video-sharing platforms. Currently, YouTube has more than 1 billion registered users, and billions of videos are watched every day, about 30 million of which are health-related. Health-related videos can be uploaded by anyone, but the content of these videos may contain inaccurate or misleading information without being reviewed by health care professionals.

There are studies in the literature evaluating the reliability and quality of YouTube videos for many diseases [5,6]. There are few studies evaluating CD-related YouTube videos [7,8]. However, one of these studies evaluated non-English language videos [8]. The other study did not measure CD-related YouTube videos with the tests developed for these studies and did not include videometric parameters (such as the number of likes and dislikes) in the evaluation [7]. Unlike previous studies, which either focused on non-English videos or lacked comprehensive quality metrics, this research provides a more robust and comparative analysis of CD-related video content on YouTube.

We could not find any studies in the literature that evaluated the reliability and validity of YouTube videos about CD. This study aims to evaluate the quality and reliability of YouTube videos about CD using validated scoring tools and detailed content analysis.

Methods

Study Design

In this cross-sectional study, videos were collected using the keyword "Celiac Disease" in YouTube's search engine on November 15, 2023. The search was conducted in a Google Chrome browser in incognito mode, logged out of any user account, and using a standard IP address in Turkey. This was chosen because it is the most common keyword that holistically assesses all aspects of the disease, such as clinical, pathogenesis, diet, and nutrition. YouTube's default relevance mode was used to simulate the average consumer's search habits. It is recognized that most viewers rarely venture beyond the first few pages of results. Therefore, the first 120 videos about CD were selected, similar to previous studies. Based on the search results, a total of 120 videos were saved for further analysis, ranging from the most viewed video to the least viewed video. Video sampling criteria were determined with reference to similar studies [5,9].

The following factors were considered as exclusion criteria in the research: (1) videos in languages other than English, (2) videos with muted or poor picture quality, (3) videos containing advertisements, (4) videos with content unrelated to CD, and (5) videos with repetitive content.

Data Review

Data such as video type (real and animation), video length (min), time since upload (d), number of views, number of daily views (number of views/d since upload), number of likes, number of daily likes (number of likes/d since upload), number of dislikes, and number of comments were recorded. In our study, we categorized video sources into two groups: educational content of health care professionals (doctors, academic institutions or professional organizations, and health-related websites) and personal narratives of non–health care professionals (patients, independent users). The videos were independently analyzed by 2 raters (YHP and REC) and coded according to the themes of "Educational content" and "Personal narratives." Discrepancies in coding were resolved through repetitive discussions and consensus, ensuring a reliable and consistent categorization process. This method of assessment has been used in similar studies of other diseases [10].

Video Usefulness

The usefulness score is a usefulness scale defined by Lee et al [11]. Each video is rated with a score between 0 and 10 depending on the content of the video, such as causes, symptoms, diagnosis, diagnosis, and recovery status. According to the total score obtained, it is categorized as follows: 0=not useful, 1-3=less useful, 4-7=useful, and 8-10=very useful.

Video Popularity

The video power index (VPI) developed by Erdem et al [12] shows the popularity of videos and has been used in many studies [9]. The VPI calculation is as follows: VPI=(×100/[number of likes+number of dislikes]) × (number of views/number of d since upload)/100.

Quality and Reliability Evaluation

The Global Quality Scale (GQS) assesses the quality by providing the interpretation and usefulness of the videos for patients based on the flow of information. GQS has a 5-point Likert structure according to the quality, flow, and ease of use of the analyzed videos [13]. As used in similar studies, scores 1-2 were considered as low quality (inadequate in terms of patient information, contains incomplete information), 3 as medium quality (video flow is poor, some information is available but important issues are not addressed), and 4-5 (contains sufficient and useful information for patients) as high quality [14].

The quality assessment included the *Journal of the American Medical Association* (*JAMA*) benchmark criteria for determining authorship, attribution, disclosure, and currency. Each of these criteria was given a score of 1, with a maximum score of 4 [15].

The mDISCERN scale developed by Charnock et al [16] and later adapted to YouTube videos by Singh et al [17] was used to assess the reliability of the videos. The mDISCERN scale consists of 5 questions and is a questionnaire about information sources, purpose, reliability, bias, additional sources, and areas of uncertainty. Each question can be answered yes or no. Each yes answer is worth 1 point and 5 points represent the highest quality.

The video content was evaluated and graded according to the most recent American College of Gastroenterology guidelines for the management of CD [18]. These guidelines emphasize accurate symptom identification, diagnostic criteria, and effective dietary management strategies. Videos were scored for reliability, usefulness, and consistency with evidence-based practice.

Statistical Analyses

The SPSS (version 25.0 for Windows; IBM Corp) package program was used. Continuous variables were evaluated using the Shapiro-Wilk test to determine whether they were normally distributed. Continuous variables are reported as median and IQR, while categorical variables are presented as counts and percentages. Chi-square tests were used to analyze categorical variables and Mann-Whitney *U* test for numerical variables. The significance level was set at P=.05 for all analyses.

Ethical Considerations

The study adhered to the ethical standards outlined in the Helsinki Declaration and complied with national regulations in the respective field. Since the study did not involve the use of human or animal data, ethics committee approval was not necessary. This study analyzed publicly available YouTube videos. No identifiable personal data was used, and all results are presented in aggregate. Therefore, formal ethics approval was not required.

Results

Main Characteristics of Videos and Video Analysis

In total, 120 videos were analyzed and 85 videos met the study criteria and were included. A total of 35 videos were excluded from the study, including 2 non-English language videos, 13 videos with repetitive content, 12 videos with advertising content, and 8 videos with poor picture and sound quality. Most (22/85, 25.9%) were published by universities and other organizations, and most (50/85, 59%) were uploaded by health care professionals. A total of 68.2% (58/85) of the videos consisted of real images. Descriptive statistics of the above characteristics and other variables are shown in Table 1.

Table 1. Main characteristics of the analyzed videos. Categorical variables are expressed as n (%), and numerical variables are expressed as median (Q1-Q3).

Characteristics	Values
Source, n (%)	
Physicians	12 (14
Universities and professional organizations	22 (26)
Health information websites	16 (19)
Independent users	16 (19)
Patient	19 (22)
Source, n (%)	
Health care professionals	50 (59)
Non–health care professionals	35 (41)
Image type	
Real image, n (%)	58 (68)
Animation, n (%)	27 (32)
Number of views, median (IQR)	17,026 (2860-46,358)
Number of likes, median (IQR)	306 (45-820)
Number of dislikes, median (IQR)	6 (1-20)
Duration (min), median (IQR)	6.3 (3.4-12.1)
Days on YouTube, median (IQR)	1381 (572-2290)
Number of comments, median (IQR)	27 (5-130)
Views per day, median (IQR)	13.1 (4-33.2)
Likes per day, median (IQR)	0.2 (0.1-0.7)

Content Analysis and Source Evaluation of Videos

In the health care professional group, most (37/85, 43.1%) of the videos were uploaded by universities and other organizations, whereas in the non–health care professional group, most (19/34, 55.9%) of the videos were uploaded by "patients" (P<.001). While the duration of the videos uploaded by health care professionals was significantly longer than the other group (*P*=.009), it was concluded that the median scores for mDISCERN (4, IQR 4-5 vs 2, IQR 2-3; *P*<.01), GQS (4, IQR 4-5 vs 3, IQR 2-3; *P*<.001), *JAMA* (4, IQR 3-4 vs 2, IQR 2-3; *P*<.001), and usefulness (8, IQR 7-9 vs 6, IQR 3-6; *P*<.001) of the videos from this group were significantly higher than those from non–health care professionals. (Tables 2 and 3)

Table 2. The average scales of the analyzed videos.

Video scales	Values, median (IQR)
mDISCERN[a]	3 (3-4)
GQS[b]	4 (3-4)
JAMA [c]	3 (2-4)
VPI[d]	12.8 (4-33)
Usefulness	7 (5-9)

[a]mDISCERN: modified DISCERN score.
[b]GQS: Global Quality Scale score.
[c]*JAMA*: Journal of the American Medical Association.
[d]VPI: video power index.

Table 3. Comparison of videos according to source status. Categorical variables are expressed as n (%), and numerical variables as median (Q1-Q3).

Variables	Source		*P* value
	Health care professionals	Non–health care professionals	
Image			
Real image, n (%)	31 (62)	27 (77.1)	.21
Animation, n (%)	19 (38)	8 (22.9)	
Number of views, median (IQR)	16,657 (4858-57,896)	17,851.5 (1907-43,310)	.87
Number of likes, median (IQR)	297 (52-774)	373 (22-846)	.67
Number of dislikes, median (IQR)	6 (1-24)	8.5 (0-18)	.92
Duration (min), median (IQR)	7.4 (4.2-16.4)	3.9 (2.5-8.2)	.009
Days on YouTube, median (IQR)	1291 (516-2290)	1467.5 (832-2470)	.64
Number of comments, median (IQR)	21 (6-79)	67 (3-170)	.52
View per day, median (IQR)	12.8 (4.6-40.9)	15.6 (2.1-33.2)	.50
Like per day, median (IQR)	0.23 (0.07-1)	0.18 (0.03-0.73)	.39
mDISCERN[a], median (IQR)	4 (4-5)	2 (2-3)	<.001
GQS[b], median (IQR)	4 (4-5)	3 (2-3)	<.001
JAMA[c], median (IQR)	4 (3-4)	2 (2-2)	<.001
VPI[d], median (IQR)	12.3 (4.6-41)	15.3 (2.1-33)	.72
Usefulness, median (IQR)	8 (7-9)	5 (3-6)	<.001

[a]mDISCERN: modified DISCERN score.
[b]GQS: Global Quality Scale score.
[c]*JAMA: Journal of the American Medical Association.*
[d]VPI: video power index.

Themes Identified in Videos

From the 85 included videos, two major themes were identified.

Educational Content

These videos, primarily created by health care professionals, provided detailed information about CD symptoms, diagnosis, treatment, and long-term management. This category accounted for 59% (50/85) of all videos and demonstrated significantly higher scores in quality and reliability metrics (mDISCERN, GQS, *JAMA*, and Usefulness; *P*<.001).

Personal Narratives

Uploaded by patients or non–health care professionals, these videos focused on personal journeys, sharing challenges, and tips for living with CD. They received moderate interaction metrics (likes, comments) but were lower in quality and reliability scores (*P*<.001).

Discussion

Principal Findings

In this study, we analyzed YouTube videos about CD, an important disease that can occur at any age. We found that CD videos uploaded by health care professionals were significantly more reliable, adequate, useful, and quality information sources than those uploaded by non–health care professionals. Another striking result of the study was that there was no difference in video interaction parameters between those with and without health care professionals as video sources.

Recently, SM has become a popular way to access medical information and knowledge. Patients with many chronic diseases, including CD, have been reported to use SM as a source of information since adolescence [19]. Especially YouTube, a video sharing website, has become an important source of information in the field of health. In a recent nationally based survey study, it was reported that younger patient groups and patients with chronic diseases such as hypertension, diabetes mellitus, and chronic lung disease were more likely to watch YouTube videos as a source of health-related information [20].

As in other chronic diseases, SM use among patients with CD and their families has become widespread in recent years [4]. When we consider the importance of increasing adherence to a gluten-free diet as well as the diagnosis, risk factors, and clinical presentation of the disease, access to real and adequate information through SM becomes even more important. In a recent survey of patients with CD, two-thirds of the patients used SM every day for an average of 60 minutes per day. The 3 most common reasons for using SM were researching gluten-free diet products, obtaining information about diet, and CD. In the study, it was stated that the most frequently used platform was WhatsApp (Meta), and it was suggested that YouTube usage was 4% [4]. Although this rate may vary according to regional and cultural differences, it is still a relatively low rate and suggests that the use of YouTube may be higher than this data. In another similar survey study conducted in Japan, 27% of more than 2000 participants with chronic diseases stated that they used the YouTube platform related to their disease [20].

One of the studies evaluating YouTube videos on CD was a study in which 100 videos were evaluated in 2019. In this study, it was examined whether there was a difference between sources in 31 different topics such as etiology, symptoms, diagnosis, and treatment of the disease, and it was stated that there was no significant difference in terms of content in all remaining topics except 3 [7]. However, none of the video reliability-efficacy tests used in our study were used in this study. Nevertheless, it differs from our study because it claims that there is mostly no significant difference between videos whose source is health care professionals and other videos in terms of topics. Another study in the literature evaluated Polish-language videos, so it does not seem possible to make a comparison with our study [8].

Among the videos analyzed in our study, the fact that the reliability, usefulness, and quality scores of the videos of health care professionals were significantly higher than those of non–health care professionals was also observed in similar studies evaluating other diseases [21]. One of the most remarkable findings of our study is that there was no significant difference between the groups in terms of views, likes, dislikes, and VPI. There are many factors that can contribute to this, such as the visual presentation of the video, the demographic and cultural make-up of the viewers, the video's viral status, and the influencer's effect [22,23]. In a recent study investigating the influencer effect on SM related to dermatology, it was shown that dermatologists without competence and certification had as high a level of interaction as those with competence and certification [23]. This finding shows us that videos that may be insufficient as a source of information may also have high interaction and accordingly may cause misinformation and negative effects on patients and their families.

Based on these findings, we believe that in order for YouTube to be an accurate source of information about CD, many organizations and institutions, such as professional associations and universities, should provide training for health care professionals to produce high-quality videos that can provide more interaction and raise awareness among health care professionals about this issue. On the other hand, it is also important to raise patient awareness of the possibility that patients may be exposed to misinformation when using YouTube. We think that more use of YouTube and other SM platforms by health care professionals and peer review of health-related video content may reduce misinformation.

Limitations

There were some limitations in our study. The first 120 videos searched with the keyword "Celiac disease'" in the search results were analyzed and the other videos were not analyzed. In addition, since YouTube is a dynamic SM platform, video interaction parameters such as daily views, likes, and dislikes can change every day. Finally, the fact that only English videos were analyzed in our study can be considered among the limitations.

Conclusions

This study showed that YouTube videos about CD vary significantly in reliability and quality depending on their source. Increasing the production of reliable videos by health care professionals may help to improve patient education and make YouTube a more reliable resource.

Authors' Contributions

REC and YHP contributed to conceptualization, resources, data curation, writing (original draft preparation and review & editing), formal analysis, project administration, software, validation, and visualization. REC was responsible for developing the methodology, conducting the statistical analyses, and investigating and supervising the project.

Conflicts of Interest

None declared.

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Abbreviations

CD: celiac disease
GQS: Global Quality Scale
***JAMA*:** *Journal of the American Medical Association*
mDISCERN: modified DISCERN
SM: social media
VPI: video power index

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Original Paper

Unveiling Topics and Emotions in Arabic Tweets Surrounding the COVID-19 Pandemic: Topic Modeling and Sentiment Analysis Approach

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Abstract

Background: The worldwide effects of the COVID-19 pandemic have been profound, and the Arab world has not been exempt from its wide-ranging consequences. Within this context, social media platforms such as Twitter have become essential for sharing information and expressing public opinions during this global crisis. Careful investigation of Arabic tweets related to COVID-19 can provide invaluable insights into the common topics and underlying sentiments that shape discussions about the COVID-19 pandemic.

Objective: This study aimed to understand the concerns and feelings of Twitter users in Arabic-speaking countries about the COVID-19 pandemic. This was accomplished through analyzing the themes and sentiments that were expressed in Arabic tweets about the COVID-19 pandemic.

Methods: In this study, 1 million Arabic tweets about COVID-19 posted between March 1 and March 31, 2020, were analyzed. Machine learning techniques, such as topic modeling and sentiment analysis, were applied to understand the main topics and emotions that were expressed in these tweets.

Results: The analysis of Arabic tweets revealed several prominent topics related to COVID-19. The analysis identified and grouped 16 different conversation topics that were organized into eight themes: (1) preventive measures and safety, (2) medical and health care aspects, (3) government and social measures, (4) impact and numbers, (5) vaccine development and research, (6) COVID-19 and religious practices, (7) global impact of COVID-19 on sports and countries, and (8) COVID-19 and national efforts. Across all the topics identified, the prevailing sentiments regarding the spread of COVID-19 were primarily centered around anger, followed by disgust, joy, and anticipation. Notably, when conversations revolved around new COVID-19 cases and fatalities, public tweets revealed a notably heightened sense of anger in comparison to other subjects.

Conclusions: The study offers valuable insights into the topics and emotions expressed in Arabic tweets related to COVID-19. It demonstrates the significance of social media platforms, particularly Twitter, in capturing the Arabic-speaking community's concerns and sentiments during the COVID-19 pandemic. The findings contribute to a deeper understanding of the prevailing discourse, enabling stakeholders to tailor effective communication strategies and address specific public concerns. This study underscores the importance of monitoring social media conversations in Arabic to support public health efforts and crisis management during the COVID-19 pandemic.

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KEYWORDS
topic modeling; sentiment analysis; COVID-19; social media; Twitter; public discussion

Introduction

Background

Throughout history, humanity has faced numerous outbreaks of infectious diseases that have resulted in significant loss of life and economic impact. Toward the end of 2019, the World Health Organization reported a series of pneumonia cases in Wuhan, which were later identified as COVID-19. As a novel infectious disease transmitted through respiratory droplets and contact, COVID-19 quickly spread across the globe, leading to an unprecedented impact on global public health, businesses, and economies. As of February 7, 2023, there have been >676 million confirmed cases and 500,000 reported deaths in >200 countries [1]. Social media platforms, particularly Twitter, have emerged as valuable sources of information for understanding and predicting disease outbreaks. Text mining techniques allow for the extraction of relevant health information from user-generated content on social media platforms. Twitter, in particular, provides researchers with vast amounts of real-time data, enabling early response strategies and enhancing situational awareness. Analyzing Twitter data has become a crucial area of focus in medical informatics research [2,3].

COVID-19 emerged as a prominent and sustained topic on Twitter starting from January 2020, and its discussion has persisted uninterrupted up to the present day [4]. With quarantine measures implemented worldwide, individuals increasingly relied on social media to access news and express their opinions. Twitter data offer valuable insights into public discussions, sentiments, and real-time updates during global pandemics [2,5]. Using Twitter as a data source enables infodemiology studies, providing health authorities with opinions and concerns to inform their responses [6].

Since the outset of the COVID-19 outbreak, an escalating number of studies have been harnessing Twitter data to delve into the public's reactions and discussions surrounding the COVID-19 pandemic. In their respective studies, researchers used distinct methodologies to explore COVID-19–related discussions and sentiments. For instance, Xue et al [4,7] used latent Dirichlet allocation (LDA) for topic identification. Similarly, a study by Alharbi and Alkhateeb [8] investigated the sentiment of the Arabic public on Twitter, using natural language processing (NLP) and machine learning techniques, finding that the long short-term memory model outperformed the naive Bayes model with an accuracy rate of 99% [8]. Another study focused on Arabic sentiment analysis for vaccine-related COVID-19 tweets, introducing the first and largest human-annotated dataset in Arabic for this purpose; it used advanced models such as the stacked gated recurrent unit and AraBERT, achieving a 7% accuracy enhancement [9]. During the COVID-19 pandemic, a separate study analyzed online learning–related tweets in Arabic, using various classification algorithms and achieving a maximum accuracy of approximately 89.6% using the Support Vector Machine classifier to analyze public perceptions of the coronavirus [10].

In addition, research conducted in Saudi Arabia showed a significant increase in negative sentiments during the COVID-19 pandemic, with deep learning algorithms achieving high accuracy rates [11]. Other studies explored sentiment differences between countries and in response to events, using topic modeling and sentiment analysis to reveal previously unreported patterns [12]. Furthermore, a study from Morocco compared different machine learning algorithms for tweet classification, finding logistic regression to yield the best sentiment predictions [13].

Recent advancements in NLP have shown significant potential in transforming various aspects of health care, including clinical decision support, patient management, and automated analysis of health records. Recent studies, such as the one by Tamang et al [14], highlight the use of NLP for optimizing patient outcome predictions and identifying disease patterns through electronic health record data. Similarly, a study by Elbattah et al [15] explores the role of NLP in extracting actionable insights from unstructured medical texts, further underscoring the growing relevance of NLP in enhancing the health care decision-making processes.

COVID-19 remains a scientifically and medically novel disease that requires in-depth and consistent research. Leveraging social media data, particularly from platforms such as Twitter, is essential for syndromic surveillance and understanding public health–related concerns. Twitter, as a prominent communication modality during disease outbreaks, offers valuable insights into public awareness and provides real-time reflections of public sentiment. Despite extensive research on COVID-19, limited studies have used social media data, specifically Twitter, to address conclusive themes and sentiment analysis in Arab regions during the early stages of the COVID-19 pandemic.

While numerous studies have investigated similar themes in different languages and contexts, there remains a notable gap in the analysis of Arabic tweets [16-22]. The Arabic-speaking population plays a significant role in the global discourse on COVID-19, and their perspectives and sentiments warrant dedicated exploration. Building on previous research, and to bridge this gap, our study used a combination of topic modeling techniques, specifically LDA, and sentiment analysis methods to uncover the predominant topics of discussion and the prevailing emotional tones within this corpus.

This Study

This study aims to analyze Twitter posts during the early stages of the COVID-19 pandemic in Arab regions to provide valuable insights into public sentiment, concerns, and awareness regarding COVID-19 in Arab communities. To achieve this, >1 million tweets posted between March 1 and March 31, 2020, were collected and analyzed. Through this analysis, we hope to assist policy makers in making informed decisions, enhancing public health communication, and implementing effective interventions to mitigate the impact of future outbreaks.

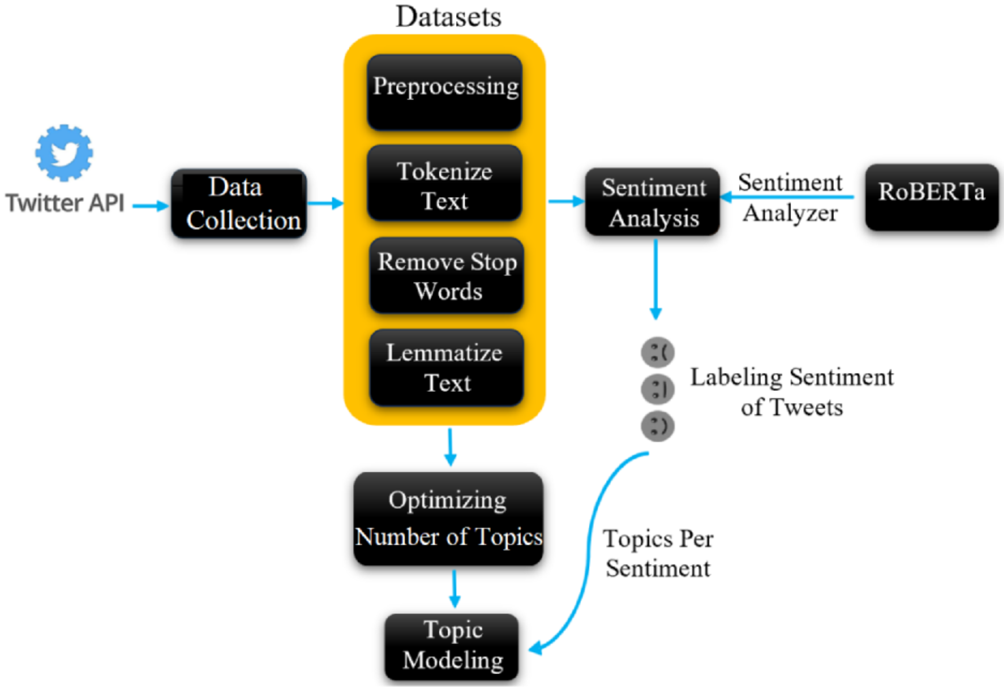
Although this study was conducted during the COVID-19 pandemic, its scope extends beyond the immediate implications of the COVID-19 pandemic. The primary goal of this research is to enhance health care planning and resource allocation in Jordan, which remains a critical issue regardless of pandemic conditions. The findings are designed to inform strategies that could be beneficial in various health care scenarios, whether in routine health care management or in response to other emergent public health challenges. Therefore, the study's relevance persists even in a postpandemic context, making it valuable for long-term health care system improvements.

Methods

Research Design

This study uses LDA for topic modeling and a sentiment analysis emotion detection tool to uncover topics and emotions in Twitter data related to COVID-19 in the Arab region. The methodological flowchart is depicted in Figure 1. Our approach to mining Twitter data adheres to the following 4 primary steps: data collection, data preprocessing, sentiment analysis, and topic modeling. The flowchart in Figure 1 illustrates how these steps are interconnected and carried out in our data analysis pipeline. Through these methods, we aim to gain valuable insights into the topics of discussion and the emotional responses of individuals in the Arab region concerning the COVID-19 pandemic.

Figure 1. Twitter data mining pipeline. API: application programming interface.



Data Collection

In our research, we harnessed the GeoCoV19 dataset, a multilingual COVID-19 Twitter dataset that spans a significant period of 90 days, from February 1, 2020, to May 1, 2020. This extensive dataset comprises hundreds of millions of tweets and is enriched with a diverse set of multilingual hashtags and keywords to ensure its comprehensiveness [23]. The dataset primarily provides tweet IDs, which presented us with the task of retrieving the actual tweet text associated with these IDs. To accomplish this, we made effective use of the Twarc application programming interface (API), a robust and efficient tool explicitly designed for this purpose [24]. The Twarc library was chosen due to its robustness in handling large-scale data collection, effective management of Twitter's API rate limits, seamless integration with existing data pipelines, and support for extended tweet metadata, making it an ideal tool for ensuring the integrity and completeness of the dataset required for this study. The Twarc API streamlined the process of collecting tweet texts corresponding to the tweet IDs provided. As we gathered all the tweets, we applied a language filter to focus exclusively on Arabic tweets. This selective filtering step was crucial for tailoring the dataset to our specific analysis, concentrating on tweets in the Arabic language.

Data Preprocessing

Data preprocessing plays a pivotal role in text mining, and it serves as a fundamental step in this domain. The purpose of this preprocessing is 2-fold: it optimizes the efficiency of prediction algorithms by eliminating potentially detrimental words, and it conserves storage space, contributing to improved computational performance [25]. In our analysis, we worked with Arabic text data, which requires thorough preprocessing to filter out any noise or irrelevant elements. The initial raw Arabic text underwent a series of transformations as part of this preprocessing effort. These transformations involved tokenization and the removal of various elements such as white spaces, punctuation marks, special characters, emojis, and URLs.

To accomplish this, we used a set of established methods for Arabic text preprocessing, including the use of Farasa [26]. Farasa proved invaluable in normalizing Arabic characters, stripping away diacritics, erasing punctuation marks, and eliminating repetitive characters, collectively enhancing the quality and relevance of the text data for our analysis.

Sentiment Analysis

Overview

To classify the primary sentiments expressed in Twitter messages, such as fear and joy, we used sentiment analysis, an NLP technique [27]. Our approach involved deploying the RoBERTa-base model, meticulously trained on a vast corpus of approximately 58 million tweets and further fine-tuned for precise emotion recognition leveraging the TweetEval benchmark [28]. This specific model, known as Twitter-RoBERTa-Base-Emotion [29], has been purposefully tailored for the nuanced task of emotion recognition within Twitter text data. It adeptly classifies text into various emotion categories, including joy, sadness, anger, fear, surprise, disgust, anticipation, and trust. Our sentiment analysis process unfolded in a sequence of four distinct steps, described in the following sections.

Step 1: Translation to English

As a reliable Arabic emotion detection API was not readily available, we initiated the process by translating Arabic tweets to English. To accomplish this, we leveraged the Google Translation API. We established an account and procured the necessary translation service. It is worth noting that the cost associated with using the Google Translation API amounts to US $20 per 1 million characters. Given that we were dealing with a substantial volume of data, encompassing 5.1 million Arabic tweets with a staggering 970,801,329 characters, the estimated cost tallied up to US $19,420. Consequently, we opted to translate 1 entire month of tweets. March was selected as the ideal candidate for translation, primarily due to its status as the month with the highest tweet volume. In addition, March witnessed several pivotal events, including Trump's declaration of COVID-19 as a national emergency, the implementation of travel bans on non-US citizens traveling from Europe, and the World Health Organization's formal declaration of the coronavirus as a global pandemic. To verify the quality of the translations, a sample of 5000 tweets was randomly selected and evaluated both before and after translation. Bilingual experts reviewed these tweets, comparing the original Arabic content with the translated English text. This review process focused on ensuring that the translations accurately conveyed the original meaning, context, and sentiment. On the basis of their feedback, we confirmed that the translations were of high quality, making them suitable for further analysis.

Step 2: English Text Preprocessing

Once the translation was complete, we embarked on preprocessing the English text. This entailed removing common stop words such as "and," "the," and "to."

Step 3: Stemming

To further refine the text data, we applied a stemming process, which involves eliminating predefined prefixes and suffixes. This step aids in reducing words to their root form. For instance, it transforms "running" into "run" through stemming.

Step 4: Emotion Determination

The final step involved determining the emotion expressed in the tweets using Twitter-RoBERTa-Base-Emotion.

Table 1 illustrates the distribution of emotions across the analyzed tweets, providing valuable insights into the prevailing sentiments during the specified time frame.

Table 1. Number of tweets per emotion.

Emotion	Tweets, n
Anger	182,105
Disgust	150,022
Joy	141,446
Anticipation	60,449
Sadness	44,591
Surprise	30,666
Fear	28,439

Topic Modeling Using LDA

In our analysis, we harnessed the power of LDA as a formidable tool for uncovering latent topics within our extensive dataset. LDA, a generative probabilistic model, proves exceptionally useful for extracting these hidden themes from a vast collection of documents. Its underlying mechanism involves representing documents as random combinations of latent topics and characterizing each topic as a distribution of words [30]. This framework of the LDA model adheres to a 3-level Bayesian approach to effectively capture the generative process. However, before delving into the application of LDA or any other probabilistic topic modeling techniques, a critical step is to determine and define the number of topics often denoted as "k" [31]. This crucial decision significantly impacts the outcomes of the topic modeling process.

Qualitative Analysis

To strengthen the reliability of our findings obtained through the LDA model, we integrated a qualitative method focused on gaining a more profound insight into the identified themes. In particular, we followed the established 6-step thematic analysis framework outlined by Braun and Clarke [32] and successfully used by Xue et al [33]. This framework includes the following steps: (1) familiarizing ourselves with the keyword data and reviewing the most representative tweets for each topic, (2) generating initial codes to summarize key themes, (3) searching for thematic patterns by grouping similar topics, (4) reviewing and refining these potential themes to ensure coherence and consistency, (5) defining and naming themes based on their overall significance and contribution to the research question, and (6) reporting and documenting the final themes. This process was iterative and reflexive, involving multiple rounds of discussion and reassessment. Two researchers with extensive experience in social media analysis and public health independently reviewed and documented the initial codes. These codes were then examined by 2 additional researchers to refine the themes, ensuring that they accurately captured the essence of the topics.

Ethical Considerations

This study analyzed publicly available data collected from Twitter. The dataset consisted of tweet IDs, and no personally identifiable information was included in the analysis. All tweet texts were retrieved in compliance with Twitter's terms of service. Ethics approval was not sought, as the study used publicly accessible data, ensuring that no identifiable personal information was involved. To maintain the highest ethical standards, all results are presented in aggregate, guaranteeing the anonymity and privacy of individuals represented in the dataset.

Results

Descriptive Results

A total of 637,718 tweets were included in the final dataset after processing raw data. The analysis focused on identifying the most frequently tweeted bigrams (pairs of words) related to COVID-19. Bigrams are 2 consecutive words, regardless of their grammar structure or semantic meaning. They may not be self-explanatory, as in the case of the bigram "social distancing," which does not convey the meaning of either word on its own. Such an approach was adopted by Xue et al [4], and it was proved that bigrams can be a useful way to identify the most prominent topics and themes in Twitter conversations. The identified bigrams included pairs of words such as "virus corona," "stay home," "home order," "travel curfew," "new coronavirus," "spread virus," "home quarantine," "health quarantine," "coronavirus pandemic," "new infected," and "new case." Among the popular unigrams were words such as "coronavirus," "virus," "home," "new," "health," "world," "visit," "pandemic," "stay," "case," "quarantine," and "curfew." Most common unigrams and bigrams related to COVID-19, and pertinent details are listed in Table 2 (original Arabic tweets are provided in Multimedia Appendix 1).

Table 2. Top 50 unigrams and bigrams and their distributions.

	Values (%)
Top 50 unigrams	
Coronavirus	6.558451
Virus	2.350919
Home	0.921041
New	0.857981
Health	0.614924
Kuwait	0.576566
Condition	0.551307
Saudi Arabia	0.503562
World	0.491143
Country	0.487031
Visit	0.392251
Pandemic	0.391468
Curfew	0.359459
Stay	0.359077
Country	0.352204
Spread	0.34872
Infected	0.340486
Quarantine	0.339662
Case	0.335292
Disease	0.331376
Infected	0.328934
Urgent	0.314949
Egypt	0.313753
Virus	0.288958
People	0.272675
Minister	0.263771
People	0.257506
Health	0.244108
China	0.243201
Good	0.241965
Travel	0.241181
Citizen	0.239945
COVID	0.238966
King	0.238255
New	0.220993
Procedure	0.213274
Lebanon	0.211883
Wanted	0.209183
Confrontation	0.205782
Education	0.205174
In	0.198331

	Values (%)
Infection	0.193302
Thanks	0.187623
Announced	0.186263
Prevention	0.185222
Nation	0.184861
Iran	0.180255
House	0.178111
Italy	0.174504
In house	0.172979
Top 50 bigrams	
Virus, coronavirus	2.029932
Coronavirus, new	0.526419
Stay home	0.325347
Coronavirus, coronavirus	0.302665
Visit, health	0.263658
Virus, coronavirus	0.19593
Coronavirus, Kuwait	0.194992
Coronavirus, new	0.192446
Curfew, travel	0.18009
Spread, virus	0.155542
Coronavirus, virus	0.146133
Quarantine, home	0.138868
Quarantine, health	0.123512
New, virus	0.122492
Coronavirus, Lebanon	0.108992
Pandemic, coronavirus	0.108868
Home, coronavirus	0.107683
Coronavirus, Saudi Arabia	0.105704
Coronavirus, Egypt	0.103818
Infected, virus	0.102376
New, case	0.09342
Coronavirus, COVID	0.091503
Kuwait, coronavirus	0.089236
New, coronavirus	0.088587
Health, global	0.08464
Stay, home	0.083898
Minister, health	0.083743
Crisis, coronavirus	0.083589
Coronavirus, stay	0.076416
Organizer, health	0.073128
Confrontation, coronavirus	0.068563
Condition, in	0.06845
Saudi Arabia, coronavirus	0.064812

	Values (%)
Coronavirus, wanted	0.061967
Coronavirus, urgent	0.060535
Recording, case	0.055537
Confrontation, virus	0.054918
Spread, virus	0.053424
Spread, coronavirus	0.053187
Coronavirus, curfew	0.050755
Curfew, curfew	0.04958
Procedure, precautionary	0.049426
United, State	0.048818
Staying, home	0.048519
Disease, coronavirus	0.047993
Infected, coronavirus	0.047849
Citizen, resident	0.047684
Servant, holy mosque	0.04552
Prevention, travel	0.045458
Coronavirus, visit	0.044582

COVID-19–Related Topics

In our study, we used the LDA technique to identify and categorize frequently co-occurring words associated with COVID-19. The LDA algorithm allowed us to manually determine the number of topics we wanted to generate. In this study, we used 2 widely recognized metrics, CaoJuan2009 and Deveaud2014, available through the R package (R Foundation for Statistical Computing), to determine the optimal number of topics for our dataset. These metrics provided a robust framework for evaluating the coherence and distinctiveness of the topics, ensuring that the final model best captured the underlying structure of the data. The CaoJuan2009 measure is minimized when the number of topics aligns with the data's intrinsic structure, while the Deveaud2014 measure is maximized to indicate topic coherence and separation. These metrics were used to assess and validate the number of topics to ensure they reflect the data's diversity and relevance. By leveraging these 2 complementary metrics, we ensured that the selected number of topics provided meaningful insights and reduced the risk of overfitting. The number of topics was determined when these metrics stabilized, indicating a consistent result.

Upon evaluating the metrics, it was found that the CaoJuan2009 score converged at its minimum value with 16 topics, while the Deveaud2014 score peaked at its maximum value with the same number of topics. On the basis of this, we concluded that the optimal number of topics, denoted as "k," is 16, as shown in Figure 2.

In addition, we calculated the topic distance and visualized the intertopic relationships using a 2D plane [34]. Each circle in the plot represents a distinct topic, ranging from topic 1 to topic k. The positioning of these circles reflects the calculated distances between topics, offering a visual representation of their relationships.

It is also worth noting that cross-validation is less commonly applied in topic modeling for several reasons. These include computational challenges associated with applying cross-validation to unsupervised models, the interpretive nature of topic models, and the emphasis on qualitative coherence over predictive performance. Most studies on LDA and related techniques do not apply cross-validation, as the focus of topic modeling is on the interpretability and coherence of the topics rather than on predictive performance. Instead, topic models are typically evaluated using internal coherence and stability measures, such as the CaoJuan2009 and Deveaud2014 metrics, which prioritize the coherence of the topics and the consistency of the results across multiple runs. This approach is consistent with what is found in most related work on LDA. For example, Blei et al [30] introduced LDA and highlighted that the evaluation of topic models is traditionally done using measures such as coherence scores.

In Table 3 (original Arabic tweets are provided in Multimedia Appendix 2), we present the findings of the 16 LDA topics, revealing the most frequently occurring words within each topic along with the percentage of tweets falling under each respective topic. Among all 16 topics, topic 5 stands out with the highest percentage (9.98%) of tweets associated with it. In topic 5, we observed a significant co-occurrence of specific words, including "coronavirus," "increase," "health," "new," "infected," "death," "recovery," and "case." This combination of words indicates an escalation in the number of COVID-19 infections, leading to unfortunate fatalities and the emergence of new cases. Moreover, the presence of the term "recovery" implies that some individuals who were previously infected are now undergoing healing and improvement. Furthermore, we calculated the topic distance and illustrated the intertopic distance [35] in a 2D plane, as depicted in Figure 3. Each circle on the plot corresponds to a topic, ranging from topic 1 to topic 16 in this study. The positions of these circles were determined based on the calculated distances between the topics. Notably, in the visualization, the circles were not overlapping, which served as a validation of the 16 topics.

Figure 2. Metrics for estimating the optimal number of topics, ranging from 2 to 25 topics.

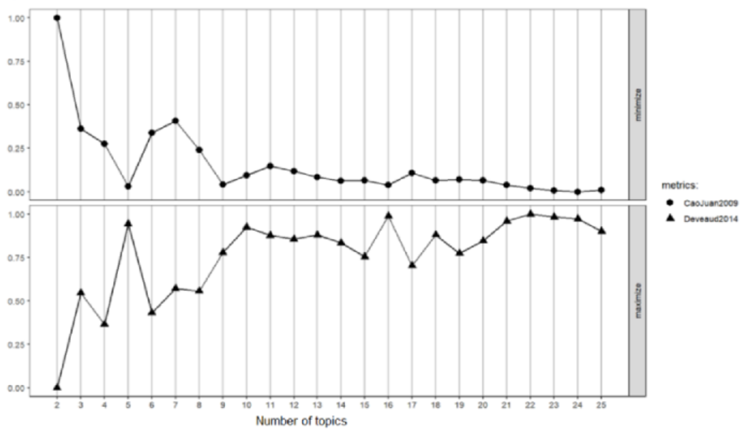
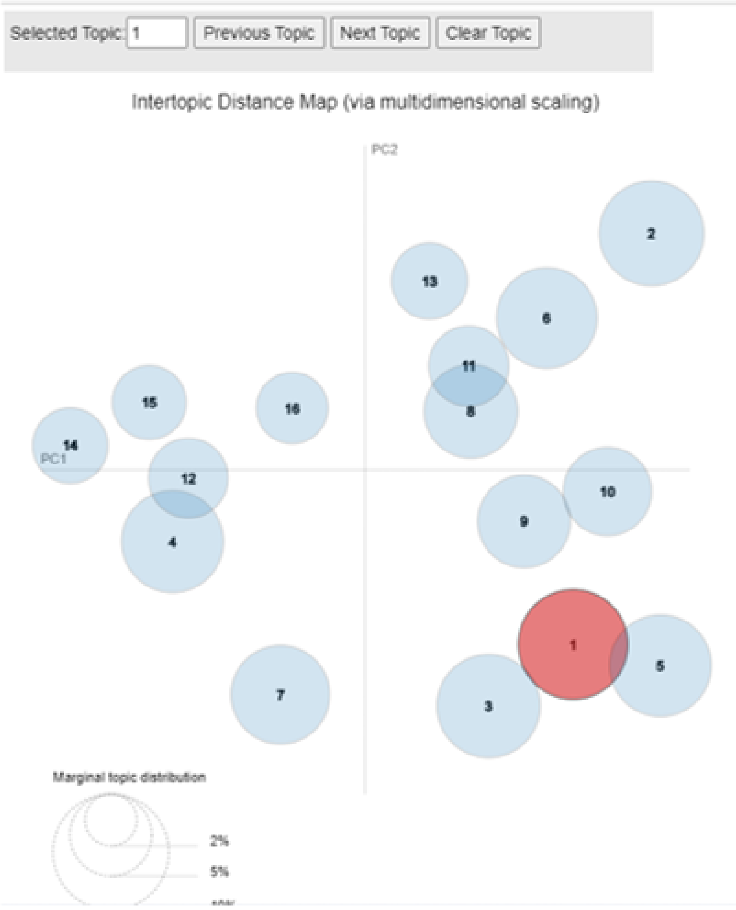


Table 3. Topic, words, and percentage of tweets.

Topic	Words	Values (%)
0	country, corona, Kuwait, praise, protection, gratitude to god, blessing, people, protect, people or nation, state, goodness, world, Saudi Arabia, Muslim, illness, thanks, pandemic, virus, Egypt	6.31
1	corona, affliction, pandemic, goodness, virus, Muslim, mercy, supplication/prayer, new, mind, world, lift or remove, great, illness, heart, raise, evil, people, mercy, Earth	8.5
2	corona, hand, virus, mask, washing, people, new, water, sanitizer, way, discount, knowledge, world, wear, person, soap, usage, glove, mask, beautiful	4.69
3	corona, virus, illness, Iran, medical, infected, hospital, doctor, treatment, Iraq, examination or test, health, person, device, hospital, Bahrain, infected, transmission, Italy, system	7.28
4	corona, virus, Kuwait, Egypt, new, emerging, COVID, health, visited, suspension, Saudi Arabia, corona, statement, Kuwaiti, confrontation, Emirate, study, crew, state, prevention	6.09
5	corona, virus, condition, new, case, infected, health, infected, died, infection, urgent, recording, death, announced, visited, increase, recovery, recorded, total, rose	9.98
6	corona, virus, education, visited, minister, confrontation, support, private, health, student, bank, spread, sector, state, responsible, crisis, communication, community, request, home	8.16
7	corona, China, state, virus, world, pandemic, union, Italy, hate, Europe, league, America, new, spread, presented, condition, European, action, player, east	4.13
8	corona, virus, house, scene, protect, country, Algeria, Egypt, died, rest, detail, video, lead, people, young man, Morocco, new, image, wanted, film	3.83
9	house, corona, stay, curfew, quarantine, wandering, home based, virus, new, Saudi Arabia, home, Kuwait, responsible, effectiveness, roaming, health, wanted, complete, goodness, Zoom	7.18
10	corona, virus, world, Trump, Oman, new, vaccine, president, faced, America, China, treatment, wanted, news, Chinese, partnership, vaccine, COVID, American, Palestine	4.68
11	corona, virus, spread, health, state, pandemic, prevention, illness, enemy, awareness, danger, way, gathering, must, home, country, avoidance, citizen, world, prevention	5.86
12	corona, virus, spread, health, state, pandemic, prevention, illness, enemy, awareness, danger, way, gathering, must, home, country, avoidance, citizen, world, prevention	5.86
13	corona, China, state, virus, world, pandemic, union, Italy, hate, Europe, league, America, new, spread, presented, condition, European, action, player, east	4.13
14	corona, Saudi Arabia, thanks, Kuwait, king, health, protection, country, homeland, virus, citizen, people or nation, visited, effort, state, sanctuary, praise, Salman, pandemic, protect	7.35
15	corona, Lebanon, people, one, age, went out, quarantine, meant, topic, condition, house, what, virus, safety, health, Egypt, people or nation, world	4.98

Figure 3. Latent Dirichlet allocation—intertopic distance.



COVID-19–Related Themes

Through the process of thematic analysis, we were able to categorize the identified topics, bigrams, and representative tweet samples into distinct themes, as shown in Table 4 (original Arabic tweets are provided in Multimedia Appendix 3).

The sample tweets provided in Table 4 are excerpts taken from the original tweets. These 16 topics have been categorized into eight overarching themes, summarized below.

1. Preventive measures and safety (“public health measures”): this theme focuses on various measures to prevent the spread of COVID-19, such as wearing masks, washing hands, using sanitizers, and practicing social distancing.
2. Medical and health care aspects: this theme encompasses topics related to the medical and health care aspects of COVID-19, including hospitals, doctors, treatments, testing, and recovery.
3. Government and social measures: this theme covers government actions, social measures, and policies implemented to address the COVID-19 pandemic, including lockdowns, travel restrictions, home orders, suspending schools, avoiding gatherings, closing shops, staying at home, and support measures.
4. Impact and numbers: this theme involves discussions about the impact of COVID-19, including the number of cases, deaths, recoveries, and updates on the situation.
5. Vaccine development and research: this theme revolves around vaccine development, clinical trials, and scientific research related to finding a solution to COVID-19.
6. COVID-19 and religious practices: this topic discusses how COVID-19 has impacted religious practices and gatherings. It mentions places of worship ( ) and the importance of adhering to prayers ( ) and religious guidelines ( ) during the COVID-19 pandemic, especially during occasions such as Ramadan ( ). The theme also includes expressions of gratitude and good wishes for nations and people (, ,).
7. Global impact of COVID-19 on sports and countries: this topic discusses the spread of COVID-19 in different countries, including China, Italy, and the United States, and its impact on various aspects, such as sports events and leagues in Europe and the Middle East. It also mentions the virus as a global pandemic and its effects on athletes and players ( ) as well as its presence in different regions around the world.
8. COVID-19 and national efforts: this theme focuses on the efforts of different nations, including Saudi Arabia and Kuwait, in combating COVID-19. It mentions leaders (, ,) and their efforts to protect the health and well-being of their citizens (,). The theme includes expressions of gratitude for the nation’s efforts in managing the COVID-19 pandemic ( ) and highlights the importance of public health ( ). Textbox 1 provides a comprehensive list of topics, thoughtfully translated into English for better clarity and accessibility.

Table 4. Themes based on topic classification, bigrams, and sample tweets.

Theme and topic	Bigrams	Sample tweets
Preventive measures and safety		
Face mask	Wear mask	A note for your safety from the new coronavirus infection: Avoid social gatherings with more than 1 person. Avoid crowded areas or places where you might interact with individuals who are sick. Avoid handshakes as they are among the primary causes of virus transmission. Wear a mask whenever possible.
Hands	Wash hands, use sanitizers	Avoid gatherings, closed spaces, and crowded areas, along with regularly washing your hands with water and soap or sanitizing them with alcohol-based disinfectants. By God's will, you will be protected from contracting the new coronavirus.
Social distancing	Social distancing	Social distancing means staying away from gatherings and crowded places. If you must leave your home, maintain a distance of at least 2 meters from the people around you. Source: Cleveland Clinic, COVID-19.
Medical and health care aspects		
Health authorities	Precautionary measures, followed the instructions	Home quarantine protects against the risk of a person spreading the coronavirus without showing symptoms, making them a potential source of transmission to various groups. Preventive measures against COVID-19 ease the burden on health care providers, enabling them to fulfill their roles in treating other illnesses and performing preventive tasks, including COVID-19 detection. Voice of the physician.
Recovery	Case recovery	Breaking: The Ministry of Health announces the recovery of the first coronavirus case in the kingdom. This concerns the young man who returned from Italy and was previously announced as the first imported case of the virus in Morocco. COVID-19, Morocco, Recovery, Ministry of Health.
Treatment	Treating the infected	The Minister of Health announces the initiation of treating patients with COVID-19 with the chloroquine vaccine.
Treatment	New drug	The *Washington Post* reports that Chinese experts and physicians have successfully fought COVID-19 using chloroquine, a drug primarily used to treat malaria, and Kaletra, an HIV medication that combines lopinavir and ritonavir. Emirati physician Omar Al Hammadi shares the success of this trial.
Hospital	Field hospital	Starting Sunday, a physician will accompany every ambulance, and a field hospital will be established inside the trade unions complex. Dr Ali Al-Abous, President of the Jordanian Medical Association, comments on the nationwide curfew in Jordan due to the COVID-19 pandemic.
Government and social measures		
Lockdowns and suspending	Closing shops, suspending schools	Precautionary measures in Kuwait against COVID-19: suspension of studies and work, cancellation of weddings, closure of mosques, closure of malls, closure of salons, partial curfew, extension of the suspension of studies, regulation of work in central markets, closure of shops, postponement of installments.
Travel restrictions	Travel ban	Saudi Arabia: Saudi Arabia suspended studies, banned cafes and shisha, prohibited sports gatherings and cinemas, halted entertainment activities, stopped Umrah and travel, and conducted intensive testing to search for patients. All for your benefit—help your government overcome these circumstances with minimal losses.
Home orders	Stay home	Stay home and protect your family from coronavirus. Prevention guidelines. Stay home.
Curfew	Curfew	Breaking: Al Jazeera correspondent reports the sounding of alarm sirens across Jordan as the nationwide curfew begins to combat the spread of COVID-19.
Remote	Remote work	It is everyone's duty to follow the precautionary measures taken by our government, may God protect them, to prevent the spread of COVID-19. At our facility, we have informed the success team to work remotely from their homes until further notice.
Impact and numbers		
New cases	Confirmed cases, increase in cases	The Kuwaiti Ministry of Health has reported new cases of the novel coronavirus, and the total number of patients that have exited quarantine is 20.
Deaths	Coronavirus deaths	A new death has been recorded in Jordan due to COVID-19, bringing the total number of deaths to 5.
Vaccine development and research		
Religious guidelines	Prayer, supplication	Breaking: The Senior Scholars Authority calls on everyone to adhere to the instructions, guidelines, and regulations, to fear God, and to resort to prayer and supplication. COVID-19, Saudi Arabia.

Theme and topic	Bigrams	Sample tweets
Umrah	Suspension of Umrah	It was discovered during the COVID-19 crisis that preserving life is one of the most important objectives of Sharia, and everything is subordinated to it. The suspension of Umrah and prayer in mosques reflects the greatness of Islam and the depth of Sharia's objectives.
Global impact of COVID-19 on sports and countries		
Postponement of matches	Postponement of matches	The Union of European Football Association has decided to postpone all matches scheduled for next week. Sports, COVID-19.
Italy	The situation in Italy	Terrifying numbers in Italy and Iran; a video shows the spread of the coronavirus outside China until March.
COVID-19 and national efforts		
King Salman	Royal support	King Salman bin Abdulaziz and Crown Prince Mohammed bin Salman. The Saudi Arabian Monetary Authority announces support for the private sector with 1 billion Saudi riyals to face the expected financial and economic impacts of the coronavirus.
Thanks	Government gratitude	We thank God for the blessing of Islam and the blessing of Salman. Every Saudi has the right to be proud and boast about Saudi Arabia. May God protect its government and people from all harm. Saudi Arabia. COVID-19. Stay at home.

Textbox 1. Topic and words (English translations) used in the study.

- Topic 0: country, corona, Kuwait, Hamad, preserve, Alhamdulillah, blessing, people, preserve, people, state, good, world, Saudi Arabia, Muslim, disease, thanks, epidemic, virus, and Egypt
- Topic 1: corona, calamity, epidemic, good, virus, Muslim, mercy, prayer, new, by, world, lift, great, disease, heart, raise, evil, people, mercy, and land
- Topic 2: corona, hand, virus, mask, wash, people, new, water, sanitizer, road, discount, know, world, wear, person, soap, use, gloves, mask, and beautiful
- Topic 3: corona, virus, disease, Iran, medical, infected, hospital, doctor, treatment, Iraq, test, health, person, device, hospital, Bahrain, infected, transfer, Italy, and system
- Topic 4: corona, virus, Kuwait, Egypt, new, novel, Covid, health, visit, suspension, Saudi Arabia, core, statement, Kuwaiti, confront, Emirate, study, cure, country, and protection
- Topic 5: corona, virus, condition, new, condition, infected, health, infected, and, infection, urgent, registration, death, announce, visit, rise, recovery, register, total, and rise
- Topic 6: corona, virus, education, visit, minister, confront, support, special, health, student, bank, publish, sector, state, official, crisis, contact, community, request, house
- Topic 7: corona, China, country, virus, world, epidemic, union, Italy, football, Europe, league, America, new, spread, foot, player, and east
- Topic 8: corona, virus, home, scene, protect, country, Algeria, Egypt, die, wind, detail, video, top, people, young, Morocco, new, picture, wanted, and film
- Topic 9: home, corona, stay, ban, quarantine, circulation, homely, virus, new, Saudi Arabia, home, Kuwait, official, activity, circulation, health, wanted, complete, good, and old
- Topic 10: corona, virus, world, Trump, Oman, new, vaccine, president, confront, America, China, treatment, wanted, news, Chinese, company, vaccine, coveted, American, and Palestine
- Topic 11: corona, virus, spread, health, state, epidemic, protection, disease, enemy, awareness, threat, road, gathering, mandatory, country, avoid, citizen, world, and protection
- Topic 12: corona, mosque, people, gathering, prayer, congregation, Lebanon, condition, Ramadan, virus, prayer, I mean, talk, cover, world, Egypt, great, good, people, and peace
- Topic 13: corona, virus, procedure, spread, prevention, decision, sanitization, closure, local, logic, visit, urgent, Saudi Arabia, new, governor, application, shop, Riyadh, precautionary, and system
- Topic 14: corona, Saudi Arabia, thanks, Kuwait, king, health, preserve, country, homeland, virus, citizen, people, visit, effort, state, crisis, blessing, Salman, epidemic, and preserve
- Topic 15: corona, Lebanon, people, and, age, came out, quarantine, from me, subject, condition, house, and, mean, virus, peace, health, Egypt, people, world, and damn

Sentiment Analysis

We conducted sentiment analysis for each of the 16 topics and presented the results in Figure 4 and Table 5. Figure 4 visualized 7 emotions: anger, disgust, joy, anticipation, sadness, surprise, and fear. Across all 16 topics, anger (represented by the red line) was the dominant emotion in 16 topics, followed by disgust (green line), joy (blue line), and anticipation (orange line). To delve deeper into the emotional aspects of the data, we provide a breakdown of the number of tweets associated with each emotion across different topics in Table 5. For example, in topic 5, a substantial number of tweets (n=17,848) expressed anger, reflecting a strong sentiment regarding the need for essential measures and precautions. This high prevalence of anger in topic 5 stands out in comparison to the other topics. It is worth noting that excessive anger, if left unmanaged, can lead to a range of medical problems. Managing emotions such as anger is crucial not only for mental well-being but also for overall physical health.

Figure 4. Sentiment analysis for each of the 16 latent topics.

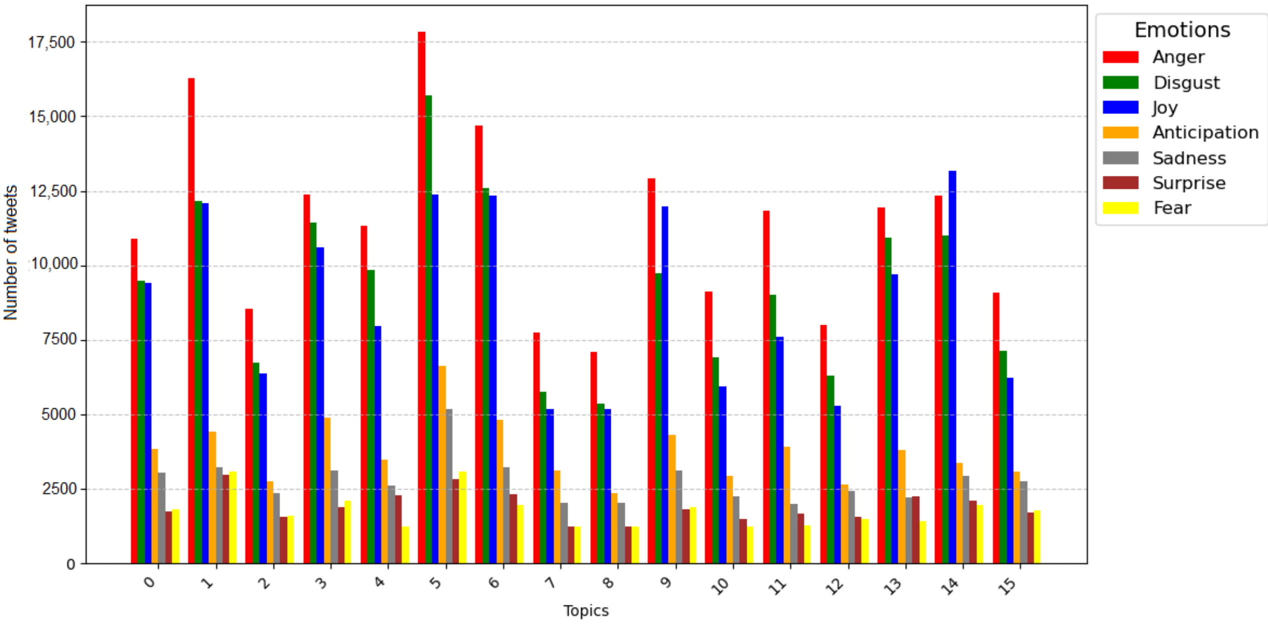


Table 5. The number of tweets for 7 emotions across 16 topics.

Topic	Anger	Anticipation	Disgust	Fear	Joy	Sadness	Surprise
0	10,896	3834	9475	1835	9428	3040	1757
1	16,295	4434	12,164	3079	12,083	3217	2965
2	8559	2772	6729	1585	6366	2346	1554
3	12,391	4894	11,424	2110	10,602	3113	1876
4	11,345	3493	9838	1246	7969	2624	2295
5	17,848	6630	15,688	3078	12,375	5192	2847
6	14,702	4820	12,601	1979	12,329	3239	2342
7	7757	3130	5752	1224	5189	2031	1230
8	7082	2367	5344	1222	5168	2035	1228
9	12,926	4321	9742	1896	11,989	3132	1802
10	9113	2948	6901	1225	5953	2245	1486
11	11,836	3915	9027	1288	7606	2015	1656
12	7988	2646	6286	1494	5282	2416	1547
13	11,942	3801	10,928	1437	9717	2231	2241
14	12,328	3357	11,007	1962	13,172	2953	2124
15	9097	3087	7116	1779	6218	2762	1716

Discussion

Principal Findings

This study delved into public discussion and emotional expressions related to COVID-19 using Arabic Twitter messages. Twitter users engaged in discussions encompassing 8 primary themes regarding COVID-19. Using topic modeling on the tweets proved valuable in uncovering insights into COVID-19–related topics and concerns. The outcomes highlighted several crucial observations.

This analysis concentrates on tweets from March 2020, a pivotal phase in the COVID-19 pandemic's unfolding narrative. During this period, the second stage of the COVID-19 pandemic emerged prominently, marked by a significant milestone as Arabic countries reported their initial cases of COVID-19. Subsequently, a cascade of vital health measures ensued, encompassing the enforcement of quarantine protocols, the temporary cessation of air travel, and the inevitable postponement or cancelation of various events. This time frame aligns logically with the peak frequency of tweets, as previously observed by Taneja et al [22] and Haouari et al [34].

Amidst the array of all 16 topics, a discernible pattern surfaced, characterized by the recurring presence of specific keywords such as "coronavirus," "increase," "health," "new," "infected," "death," "recovery," and "case." This linguistic cluster strongly implies a surge in COVID-19 infections, accompanied by lamentable loss of life and the emergence of new cases during the ongoing COVID-19 pandemic. It is imperative to emphasize that our chosen time frame aligns precisely with the onset of the COVID-19 pandemic's second phase, coinciding with heightened global concern. The substantial spike in COVID-19 cases in Italy during this period ignited a profound sense of alarm on a global scale. This surge in worldwide apprehension may have contributed to the observed increase in tweet frequency, corroborating findings from multiple studies [22,34].

Furthermore, substantial discussions revolving around the COVID-19 pandemic within diverse Arabic nations have drawn significant interest. These conversations are marked by a prevailing sense of indignation. Moreover, public sentiments concerning the spread of COVID-19 unveiled an underlying sense of anticipation toward prospective measures. These sentiments were accompanied by a mix of emotions, including anger and fear; a notable undercurrent of fear was predominant in discussions revolving around the COVID-19 crisis and the resulting fatalities. This trend aligns with global sentiments, as documented by Lwin et al [36], wherein public emotions underwent a noticeable shift from fear to anger throughout the COVID-19 pandemic, with traces of sadness and joy also emerging.

Noteworthy, the appearance of dialogues concerning COVID-19 and religious practices introduced a fresh subject not previously detected in prior research. This indicates a developing connection between COVID-19 and religious matters on the Twitter platform. This is particularly apparent due to the substantial influence of religious identity on attitudes and actions concerning the COVID-19 pandemic and vaccination efforts; the COVID-19 pandemic has significantly reshaped communal worship and gatherings as measures to curb the virus's transmission [37]. Furthermore, religious leaders have assumed a central role in championing COVID-19 vaccination campaigns, effectively addressing and mitigating vaccine hesitancy [38].

In-Depth Analysis of Findings

The application of topic modeling and sentiment analysis in this study provided several valuable insights into public sentiment and thematic discussions during the early stages of the COVID-19 pandemic in Arab regions. The findings largely align with anticipated outcomes, such as the focus on preventive measures and safety and medical and health care aspects, both of which were expected topics given the nature of the COVID-19 pandemic.

However, the emergence of discussions on COVID-19 and religious practices was a unique finding that adds depth to the understanding of public discourse in Arab communities. This theme highlights the intersection of the COVID-19 pandemic with cultural and religious practices, which had not been as thoroughly explored in previous research. It underscores the significant impact that COVID-19 had on religious identity, communal worship, and adherence to religious guidelines during pivotal periods such as Ramadan.

Another notable aspect was the attention given to the global impact of COVID-19 on sports and countries, reflecting the broad international concern and how global events, especially sports, were affected. This indicates that the COVID-19 pandemic's influence went beyond public health and extended into societal and cultural dimensions, impacting activities that are deeply integrated into daily life.

In addition, the sentiment analysis revealed a nuanced distribution of emotions, with a significant proportion of tweets expressing anger and disgust, as expected, given the uncertainty surrounding the COVID-19 pandemic. However, there was also a notable presence of positive emotions, such as hope and solidarity, particularly in tweets discussing community support and coping mechanisms. This suggests that, despite the overwhelming nature of the crisis, many users turned to social media not only to express negative emotions but also to share supportive messages and encourage others.

Overall, the identified themes and their respective discussions provide a comprehensive view of public sentiment, concerns, and priorities during the early COVID-19 pandemic period. These insights not only reflect the immediate response to the health crisis but also highlight the diverse and context-specific aspects that shaped public discourse. Such findings offer a foundation for more effective public health communication and intervention strategies, particularly in culturally sensitive contexts.

Strengths

This study provided valuable insights into the sentiments and concerns of Arabic-speaking Twitter users during the COVID-19 pandemic, underscoring the significance of social media as a means of understanding and addressing public health issues in the digital era. First, the analysis encompassed a substantial dataset of 1 million Arabic tweets, offering a comprehensive view of the sentiments and topics expressed by Twitter users in Arabic-speaking countries during a specific period of the COVID-19 pandemic. Besides, the study used a combination of machine learning techniques, including topic modeling and sentiment analysis, to uncover and categorize themes and emotions within the dataset, providing a holistic understanding of the data. By identifying and categorizing 16 conversation topics into 8 themes, the study offered a structured view of the discussions surrounding COVID-19 in the Arab region, making it easier to interpret and use the findings. Finally, the inclusion of emotion analysis adds depth to the study, revealing how Twitter users in the Arab world emotionally responded to various aspects of the COVID-19 pandemic.

Limitations

First, at the forefront of our approach, we meticulously aimed to unravel the complexities embedded within the COVID-19 pandemic's second phase. Our focus was sharp and exclusive, centered on harnessing tweets originating exclusively from March 2020. The motivation behind this specific time frame stemmed from our intention to subject translated tweets to a comprehensive sentiment analysis. This intricate process relied upon the Google API translation service, which, although effective, is accompanied by a substantial cost factor. The financial implication associated with translating the entirety of the datasets using this service was a noteworthy consideration that prompted us to make strategic choices in our analysis approach.

Second, it is crucial to recognize that Arabic is a linguistically intricate language characterized by a rich array of dialects and intricate cultural nuances. These unique linguistic qualities can present substantial challenges for automated sentiment analysis tools. While we attempted to apply automated sentiment analysis to Arabic tweets, we encountered difficulties in precisely capturing the subtleties of emotions. Automated tools often grappled with interpreting nuanced sentiments, such as sarcasm, irony, and contextual shifts in sentiment that frequently permeate social media conversations.

Third, a strategic decision was made to exclude non-Arabic tweets from our analyses. As a result, our findings were inherently confined to users who exclusively communicated in Arabic. It is essential to underscore that the fundamental objective of our research revolves around gaining insights into the opinions and reactions of Arabic countries in relation to COVID-19.

Furthermore, while our study leveraged social media data as a proxy for public sentiment, it is essential to recognize the inherent biases associated with using Twitter data. For instance, social media users may not be representative of the general population, as certain demographics might be underrepresented on platforms such as Twitter. A study by Padilla et al [39] has shown that social media content can be biased based on whether individuals are local residents or visitors and the types of activities they engage in throughout the day. Similarly, Gore et al [40] highlighted that the sentiment of tweets is often correlated with the geographical area in which they were composed, suggesting that local context and specific events may have a significant impact on sentiment analysis results. Frank et al [41] also found that emotional expressions, such as happiness, vary significantly by location, further reinforcing the influence of geographic factors on sentiment.

In addition, it is plausible that individual personality traits or political affiliations, as suggested by Auer and Elena [42], could influence whether a user expresses positive or negative sentiments. This raises an open question about the extent to which sentiment reflects variance in psychological traits versus the situational context in which those traits are expressed. These factors could contribute to biases in our dataset and should be considered as potential sources of influence on the study's outcomes.

Future Work

Regarding future studies focusing on COVID-19, first, there arises a noteworthy avenue for exploration comparing the sentiments and opinions of Arabic-speaking populations with those of individuals expressing themselves in other languages. A comprehensive approach might encompass languages such as English, Italian, French, German, and Spanish. Such comparative analyses have the potential to yield valuable insights into the cross-linguistic dynamics of perceptions and responses to the COVID-19 pandemic.

Second, another promising avenue for future research involves conducting a comparative analysis between sentiment analysis using human-labeled data and automated tools specifically tailored for Arabic languages. This comparative study should aim to ascertain the feasibility of leveraging these automated tools as an alternative to translation APIs. By meticulously comparing the results obtained from human-labeled sentiment analysis and those generated by automated tools, researchers can gauge the efficacy, accuracy, and reliability of automated sentiment analysis for Arabic tweets. The outcomes of this research hold the potential for far-reaching implications, potentially presenting a cost-effective and streamlined avenue for sentiment analysis that eliminates the reliance on costly translation APIs.

By providing an accurate and efficient mechanism for measuring sentiments in Arabic tweets, researchers and mental health professionals could identify patterns of emotional distress or psychological well-being. This could be especially pertinent during times of crises, enabling timely interventions and support for individuals experiencing heightened emotional responses. Importantly, the ability to effectively harness sentiment analysis for understanding emotional states has the potential to empower the broader field of mental health research and intervention as well as enhance our understanding of collective emotional dynamics within Arabic-speaking communities.

Third, there is an imminent need for research to unravel the stem of fabricated tweets that emerge during a pandemic. Given that Twitter users experience a heightened sense of fear, which might be exacerbated by the proliferation of misinformation, it becomes a critical endeavor to investigate the prevalence and impact of false tweets. Subsequent studies could significantly benefit from spotlighting the issue of misinformation, with a specific focus on understanding how government officials and international organizations can effectively manage the dissemination of deceptive messages targeting the public. By comprehensively addressing the challenges posed by misleading content, we can enhance our collective understanding of navigating information dissemination during such critical periods.

Conclusions

This study delves deep into the intricate web of topics and emotions found in Arabic tweets about COVID-19. It highlights how platforms such as Twitter, especially during times of global change, are crucial for capturing the diverse feelings and concerns of Arabic speakers. Through a mix of topic modeling and sentiment analysis, we revealed the basic human emotions in user responses to COVID-19 tweets from March 2020.

We used 2 methods together: topic modeling (specifically LDA) and sentiment analysis tools. These helped us uncover the main themes and feelings within the tweets. Anger was the prominent emotion tied to COVID-19 topics, accompanied by other emotions. Joy was linked to vaccine and education discussions, while authority and politics stirred up anger. Sadness emerged from topics about cases, deaths, and the impacts on families and mental health.

This study connects social media, emotions, and the global scene. It sheds light on the emotional layers of digital conversations, offering insights into COVID-19–related tweets. These findings guide better communication strategies and compassionate responses, strengthening our collective resilience in the face of challenges.

Moreover, the results and workflow of this study present actionable insights for the medical and public health communities. By integrating our findings into official government documentation or public health research, authorities can tailor their communication strategies based on public concerns and emotions. This, in turn, helps in shaping more effective educational campaigns and policy interventions. Our methodology also serves as a robust tool for continuous monitoring of public sentiment in real time, allowing policy makers to stay informed and adapt their strategies accordingly. This approach ensures that responses are not only timely but also grounded in the actual sentiments and needs of the population.

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Data Availability

The data sets generated and analyzed during this study are available in the GitHub repository [43].

Conflicts of Interest

None declared.

Multimedia Appendix 1
Original Arabic versions of tweets shown in Table 2.
[DOCX File , 20 KB - infodemiology_v5i1e53434_app1.docx]

Multimedia Appendix 2
Original Arabic versions of tweets shown in Table 3.
[DOCX File , 18 KB - infodemiology_v5i1e53434_app2.docx]

Multimedia Appendix 3
Original Arabic versions of tweets shown in Table 4.
[DOCX File , 25 KB - infodemiology_v5i1e53434_app3.docx]

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Abbreviations

API: application programming interface
LDA: latent Dirichlet allocation
NLP: natural language processing

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Original Paper

Visualizing YouTube Commenters' Conceptions of the US Health Care System: Semantic Network Analysis Method for Evidence-Based Policy Making

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Abstract

Background: The challenge of extracting meaningful patterns from the overwhelming noise of social media to guide decision-makers remains largely unresolved.

Objective: This study aimed to evaluate the application of a semantic network method for creating an interactive visualization of social media discourse surrounding the US health care system.

Methods: Building upon bibliometric approaches to conducting health studies, we repurposed the VOSviewer software program to analyze 179,193 YouTube comments about the US health care system. Using the overlay-enhanced semantic network method, we mapped the contents and structure of the commentary evoked by 53 YouTube videos uploaded in 2014 to 2023 by right-wing, left-wing, and centrist media outlets. The videos included newscasts, full-length documentaries, political satire, and stand-up comedy. We analyzed term co-occurrence network clusters, contextualized with custom-built information layers called overlays, and performed tests of the semantic network's robustness, representativeness, structural relevance, semantic accuracy, and usefulness for decision support. We examined how the comments mentioning 4 health system design concepts—universal health care, Medicare for All, single payer, and socialized medicine—were distributed across the network terms.

Results: Grounded in the textual data, the macrolevel network representation unveiled complex discussions about illness and wellness; health services; ideology and society; the politics of health care agendas and reforms, market regulation, and health insurance; the health care workforce; dental care; and wait times. We observed thematic alignment between the network terms, extracted from YouTube comments, and the videos that elicited these comments. Discussions about illness and wellness persisted across time, as well as international comparisons of costs of ambulances, specialist care, prescriptions, and appointment wait times. The international comparisons were linked to commentaries with a higher concentration of British-spelled words, underscoring the global nature of the US health care discussion, which attracted domestic and global YouTube commenters. Shortages of nurses, nurse burnout, and their contributing factors (eg, shift work, nurse-to-patient staffing ratios, and corporate greed) were covered in comments with many likes. Comments about universal health care had much higher use of ideological terms than comments about single-payer health systems.

Conclusions: YouTube users addressed issues of societal and policy relevance: social determinants of health, concerns for populations considered vulnerable, health equity, racism, health care quality, and access to essential health services. Versatile and applicable to health policy studies, the method presented and evaluated in our study supports evidence-based decision-making and contextualized understanding of diverse viewpoints. Interactive visualizations can help to uncover large-scale patterns and guide strategic use of analytical resources to perform qualitative research.

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KEYWORDS

social media; semantic network; health system; health policy; ideology; VOSviewer; health care reform; health services; health care workforce; health insurance

Introduction

Background

The US health care system, characterized by high costs [1] and perceived to fall "far short of its potential" [2], has been a focal point for media attention and public commentary over the past decade. Discussions have revolved around topics such as the repeal of Obamacare, presidential health care agendas, the exorbitant costs of health care, comparisons to systems in other nations, and postpandemic health care personnel shortages. Throughout this period, conservative, moderate, and liberal media outlets have produced a variety of content, including newscasts, full-length documentaries, political satire, and stand-up comedy, all centered on the intricacies of the US health care system [3-6]. When disseminated through YouTube (Google Inc), the most popular platform among US social media users [7], select videos have generated millions of views and tens of thousands of comments. To the best of our knowledge, the perspectives of YouTube commenters on the US health care system and its reform, despite their considerable value for policy analysis, remain unexplored.

Objectives

Social media discussions are abundant, but they are often chaotic, noisy, indignant, and hateful [8-11]. There is a need for a method that effectively visualizes large volumes of commentary, filters out the noise, and highlights key patterns, making the information more digestible for stakeholders. The current state of social media research falls short of efficiently and clearly disseminating scientific outputs to diverse audiences. In quantitative social media studies, the constraints are statistical and graphical outputs with low idea density or high decoding requirements, which often require specialized knowledge. In qualitative studies, researchers communicate analytical outputs as summaries of themes and subthemes with representative quotes; however, they are based on limited data samples.

To address these challenges, we propose a mixed methods approach of mapping social media commentary. This approach combines automation and human judgment to create a visual representation of social media comments' contents and structure, presenting them as a semantic network [12]. This methodology is particularly relevant for researchers, policy makers, and the wider public seeking a better understanding of complex social media narratives. We repurpose VOSviewer (Centre for Science and Technology Studies at Leiden University), a user-friendly bibliometric tool, to analyze tens of thousands of social media comments on YouTube regarding the US health care system. In this study, semantic networks are graphical representations of social media comment meanings. Nodes represent terms frequently mentioned in YouTube comments, linked and grouped into clusters based on their co-occurrence.

Since their introduction in 2010, VOSviewer algorithms have been extensively applied to build term co-occurrence networks from the text of article titles and abstracts [13-20]. Visualization of nonbibliometric textual data as semantic networks in VOSviewer was proposed in 2011 [21], followed by early visualizations of Twitter and YouTube discussions ([22-25]). Subsequent explorations of VOSviewer's applications to social media comments and hashtags primarily led to cluster mapping ([26-35]). Notably, some scholars enhanced their cluster maps with informational layers called custom overlays to reveal patterns not visible in the base network [36-38].

Previous research compared VOSviewer semantic networks to networks generated from manually coded Twitter text [26]. However, there have been few systematic evaluations of VOSviewer-generated semantic networks derived from social media data. Consequently, our overarching goal is to evaluate VOSviewer's application to social media data: Can it produce credible semantic networks to be used as analytical and communication tools? We test VOSviewer's term co-occurrence map with custom-built overlays by posing 3 research questions:

1. How well does the VOSviewer network capture the content, context, and structure of social media comments?
2. What does it reveal about a decade-long online public discussion of the US health care system?
3. What is the policy analysis value of VOSviewer visualizations?

Methods

Semantic Network Construction

VOSviewer generates a custom semantic network by processing a corpus text file featuring social media comments. Our corpus comprised the text of primary comments and first-level replies to 53 videos shared by 17 US-based media outlets on their respective YouTube platforms between 2014 and 2023. The videos were sourced from news outlets such as Consumer News and Business Channel, Cable News Network, Fox News, and Public Broadcasting Service Frontline. Detailed criteria for video selection and video characteristics are outlined in the Tables S1 and S2 in Multimedia Appendix 1 [39]. After eliminating 5575 duplicate comments from the initial dataset of primary comments at first-level responses, our final corpus encompassed a total of 179,193 unique comments.

VOSviewer processes YouTube comments by detecting sentences, applying the Apache Software Foundation's OpenNLP library algorithm for part-of-speech tagging, identifying terms as nouns and the longest noun phrases, and unifying terms through various methods [17,18]. From an initial pool of 1948 terms appearing in at least 60 comments, a subset of 323 (16.58%) terms related to the US health care system, such as Obamacare, prescription, and wait time, was selected for the final semantic network. A detailed term selection process, including manual screening and thesaurus construction, is described in Multimedia Appendix 1.

By distilling 179,193 comments into a network with several hundred nodes, a macro model of YouTube video commentaries was created, providing insight into social media users' discussions on US health care. In this network, terms are interconnected and organized into distinct, nonoverlapping clusters [15,19,20]. A cluster is a group of terms tightly linked within the group and loosely connected with terms outside it. If >1 term was extracted from the text of the comment, it is possible for the same comment to be represented by multiple nodes in multiple clusters. We did a thematic analysis of clusters to gain insights about the US health system discourse.

We addressed limitations observed in previously published semantic networks by enhancing the network's informational value. First, we added custom overlays to VOSviewer's map, which displays the color of network nodes based on selected attributes. To build overlays, we coded each comment to reflect the theme of its YouTube video and added these codes, along with other comment characteristics (eg, comment date), to a scores file, which was uploaded to the VOSviewer together with our corpus file that contained YouTube comments (for more information on building corpus and scores files, refer to Multimedia Appendix 1). Second, we presented findings with hyperlinks to VOSviewer Online for broader accessibility and interactive engagement with our semantic network.

Network Interpretation and Evaluation

The evaluation of the US health care system's semantic network and its overlays was structured as follows. A comparison of 2 networks, before and after the deletion of repeated comments, served as a test of network robustness. Thematic alignment between the network terms, extracted from YouTube comments, and the videos that elicited these comments was a test of network's content representation.

To examine structural relevance, we asked if network relationships reflected the underlying meanings evident in YouTube comments. We examined clusters: Do terms in the same cluster have more similar meanings than terms in different clusters? We also examined pairs and groups of interconnected terms: Are they used together in the source data? Do their relationships align with existing knowledge? A comprehensive analysis of all pairs or term groups is outside of the scope of this study. For practical reasons, we engaged in close reading of a limited number of comments, focusing mainly on smaller nodes. When the number of comments exceeded 200, we randomly sampled 200 comments to cover discussions of different videos, taking care to sample more than once when we encountered heterogeneous ideas that required careful interpretation. When ≥2 nodes were examined, we used close reading of comments that mentioned all selected terms. Following the approach by Eve [40], network visualizations were used to locate "points of interest, which are then resynthesized into close readings."

In addition, we performed tests of semantic accuracy through raw data verification. Specifically, we cross-checked ambiguous or unexpected terms in our network against the comments that mentioned them. The analysis involved multiple readings of each comment to capture nuances of how individuals articulate their experiences or opinions of the US health care system, focusing on the words that were extracted as terms, their meaning, and context. On several occasions, for example, when performing a close reading for ideology, we offered brief summaries of the main ideas expressed by the commenters. Our validation of semantic network findings against extant comments adhered to the principles for quantitative text analysis outlined by Grimmer and Stewart [41].

Finally, we tested the usefulness of semantic network analysis for generating policy-relevant insights. We picked 4 health system design concepts—universal health care, Medicare for All, single payer, and socialized medicine—and examined how the comments mentioning these concepts were distributed across the terms we mapped. For insights into the policy ramifications of public perceptions of health system design, we focused on ideological terms and those with the highest share of comments referring to each concept.

Ethical Considerations

Ethics approval for this study was sought from Central Michigan University's Institutional Review Board (project 2023-1021-Mt. P). The study did not meet the definition of human participant research under the purview of the institutional review board according to federal regulations. The study used publicly accessible user-generated YouTube comments. The data were deidentified and aggregated before analysis. As the results are presented in an aggregate form, individual commenters cannot be identified. Informed consent has not been obtained. No compensation was provided to comment contributors.

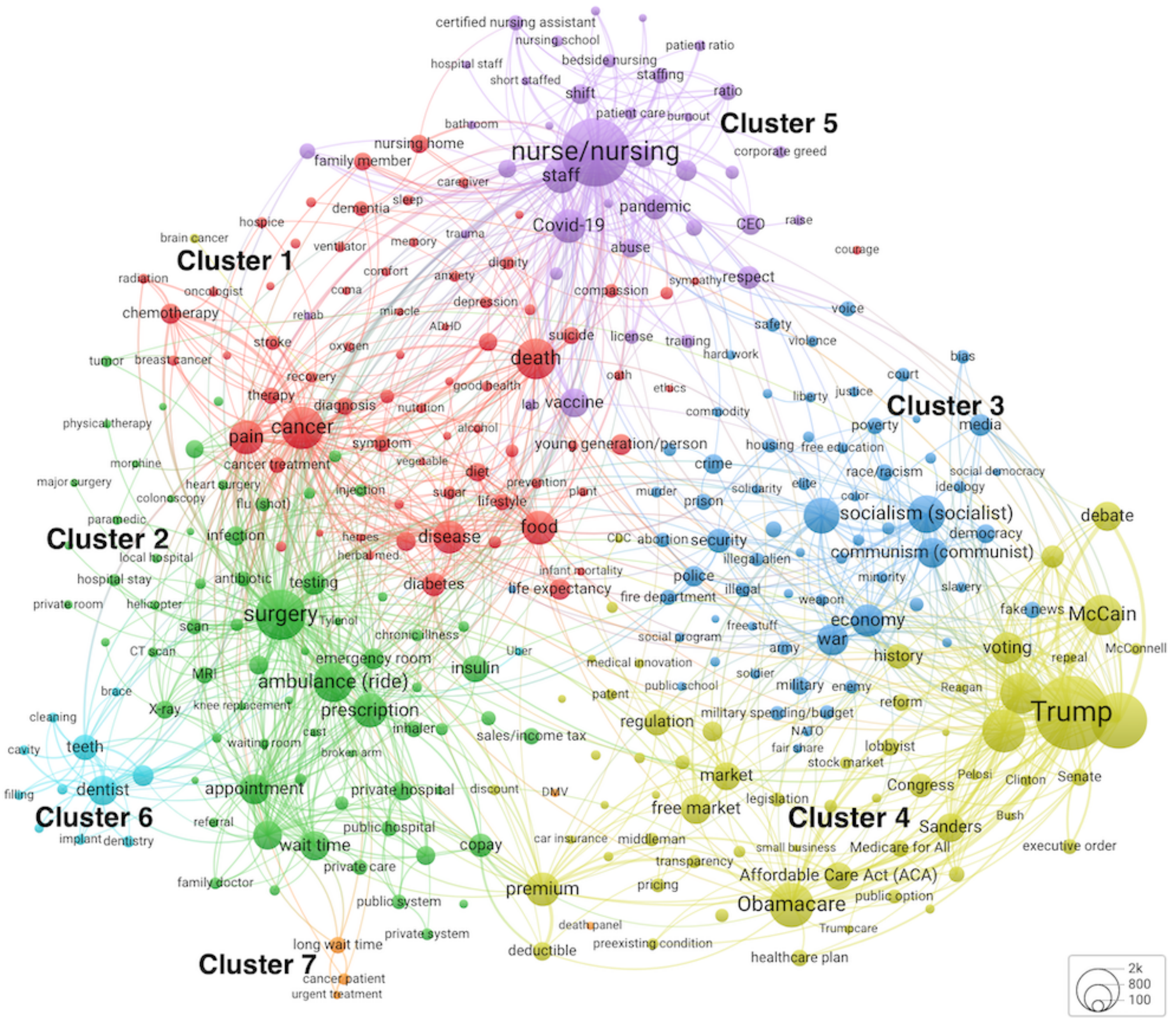
Results

A Semantic Network of Term Co-Occurrence and Clustering

From a manually screened list of 539 terms occurring in our corpus at least 60 times, VOSviewer's algorithm assisted in the selection of 323 (59.9%) most relevant terms [19]. Figure 1 [42] shows a 7-cluster solution for a term co-occurrence network.

On average, each term represented 357.74 (SD 606.88; median 163, IQR 104-321) comments. The longer the comment, the greater the likelihood that multiple terms were extracted from it. VOSviewer assigns cluster numbers based on the quantity of nodes; the same cluster numbers appear in our online interactive maps (URLs are provided in the notes of Figure 1).

Figure 1. A co-occurrence network (cluster map) of terms extracted from the comments on 53 YouTube videos about the US health care system. Binary-counted terms that occurred ≥60 times were mapped. An interactive map is available from Leiden University's VOSviewer app.



Cluster 1 (red) emerged as the largest group of nodes, covering chronic diseases, treatment, pain, and death. Its diverse terms also included topics related to disease prevention (*diet, exercise,* and *smoking*), mental health (*ADHD* [attention-deficit/hyperactivity disorder,] *anxiety*, and *depression*), and end-of-life issues (*hospice, euthanasia*, and *do-not-resuscitate*). Below it, cluster 2 (green) terms covered services, encompassing surgeries, emergency medical services, procedures, diagnostics, wait times, and discussions about public versus private health organizations and prescription medications. On the right, cluster 3 (dark blue) had terms about political ideologies, economic, societal, and cultural issues, surrounded by nodes from cluster 4 (yellow) related to political actors, institutions, the 2010 Patient Protection and *Affordable Care Act* (*ACA* or *Obamacare*), market regulation, and insurance terminology. The top of the map displayed a group of terms (cluster 5, purple) dedicated to health worker shortages, nurse-to-patient ratios, and nurses' burnout. Dental care terms formed a group on the lower left (cluster 6, light blue). Finally, a 5-node group (cluster 7, orange) at the bottom of the map had terms related to long wait times by patients with cancer who required urgent treatments, as well as further away terms *DMV* (Department of Motor Vehicles) and *death panel*.

The network displayed a rather coherent collection of terms, the meaning of which could be intuitively understood within the context of the US health care, with a few exceptions. For instance, as we manually selected terms for map inclusion, we checked the use of an ambiguous term *DMV* in YouTube users' comments. *DMV* was mentioned as a metaphor in a debate of government-managed health care efficiency. It was retained due to its relevance to the health care discourse.

The interpretive value of our network extended beyond a simple list of terms. The network specified links between terms that were often mentioned together, for example, *pricing* and *transparency* in cluster 4. Meaning extraction was further aided by the analysis of spatial proximity, cluster assignment, and cluster boundaries. For example, *preexisting condition*, as a term of interest, was directly and most strongly linked to *Obamacare* and *ACA*, which were mentioned with *preexisting condition* in multiple comments. This finding was consistent with a key ACA provision: insurance companies cannot use applicants' medical history to deny coverage or charge higher premiums based on their preexisting conditions [43]. Network structure's alignment with existing knowledge speaks to its structural relevance. *Preexisting condition* is located close to *premium,deductible, pricing,* market-related terms, and *government regulation* from cluster 4 about politics, as well as to *private health insurance* and *copay* on the far right of cluster 2, which is mostly dedicated to health care services. Therefore, when YouTubers discussed the US health care system, they used a noun phrase *preexisting condition* at the semantic intersection of health care politics and legislation, insurance pricing, and health services access.

In summary, the 323 networked terms, identified as most relevant by VOSviewer, unveiled discussions about illness and wellness; health services; ideology and society; the politics of health care agendas and reforms, market regulation, and health insurance; health care workforce; dental care; and concerns such as long wait times.

Before we removed 5575 duplicate comments, our original cluster map (Figure S1 in Multimedia Appendix 1) was quite similar to the cluster map in Figure 1. Our inquiry into the medical debt cluster comments uncovered repeated comments by a single YouTube user. After deletion, this cluster disappeared, but the network's overall structure largely remained intact, demonstrating its robustness.

Next, we examined clusters and nodes using overlays that reflected 2 aspects of the YouTube platform: the videos that elicited comments and the commentary itself. We assessed the usefulness of custom overlays as contextualization tools: Do they improve our understanding of nodes, node groups, and clusters? While we presented data on both video attributes and comment attributes, our analysis prioritized overlays depicting comment characteristics because they are more valuable for understanding digital publics' discussion of the US health care system.

Distribution of Video Groups Across Network Clusters

Thematic alignment between the video content that elicited the commentary and the commentary itself speaks to the content representativeness of the VOSviewer term co-occurrence network. The distribution of comments from 10 thematically diverse YouTube video groups across our term network is shown in overlays in Figure S2 in Multimedia Appendix 1. Our main findings are summarized in Table 1.

We observed substantial thematic congruence between video content and cluster terms. Nodes with above-average concentrations of comments related to the health care workforce were closely grouped in cluster 5, encompassing terms about nurses, staffing shortages, and management. Unlike most nodes in cluster 5, which were associated with health care workforce videos, the term *respect* had an above-average share of comments related to ACA and Obamacare reform videos. Our analysis of comments indicated that commenters mentioned respect for nurses, which explained the placement of *respect* in cluster 5. In addition, many comments on ACA and Obamacare reform videos expressed respect for Senator John McCain, which explained the connection between the term *respect* and *McCain*. *Respect*'s placement within cluster 5 but at its outer boundary, in the direction of node McCain, coupled with video overlay evidence, suggested semantic accuracy and structural relevance of our network.

Videos from 2 groups (health care policies, politics, ACA, and Obamacare reform) generated comments in cluster 4, which consisted of numerous political and reform-related terms. In addition, videos about health costs, one of which was titled "Dollars and Dentists," elicited discussions of dental care (cluster 6). Comments on videos about health care systems in different countries produced terms that appeared in multiple clusters but mostly in cluster 2 about health services and cluster 7 about long wait time concerns. At the same time, a Home Box Office video "Medicare for All" featuring John Oliver and a Netflix video featuring stand-up comedians making jokes about the US health care produced comments in nodes scattered across the map. The Netflix video showcased many comedians and topics, one of whom, Wanda Sykes, spoke about opioids from the perspective of racial and ethnic minority people. A commentary on this topic appeared in nodes *pain* and *prescription* (left side of the map) and *race/racism*, *Black person*, and *White person* (right side of the map), where commenters debated racial disparities in pain medicine access. For race-related nodes, the share of comments on the Netflix video (comedy on the US health care) varied between 1% and 8%, indicating that it was not the only video prompting the discussion. This finding is not unique; it was common for terms to represent commentaries to a wide variety of videos or video groups.

Across all video group overlay legends, the highest scale midpoint was 0.25 for videos about health care costs and financial issues. It means that, on average, 25% (SD 14%) of comments within a term come from that video group. Across 323 map terms and 10 video theme overlays, there were only 11 (0.34%) instances (out of 3230 possible instances) where terms represented >90% of comments from a single video group.

Table 1. Characteristics of videos that elicited comments related to cluster-specific terms.

Cluster number (color)	Topical areas	Cluster's 10 largest terms	Video groups that elicited comments related to most, some, or specific terms within a cluster
1 (red)	Illness and wellness, including mental health and end of life	*Cancer, death, pain, food, disease, diabetes, young generation/person, life expectancy, chemotherapy,* and *cure*	• Children's health care (some terms) • End-of-life health care (some terms) • Health care systems in different countries (*young generation/person* and *life expectancy*) • Comedy on the US health care (*pain*) • Medicare for All video by John Oliver (*pain*)
2 (green)	Health services	*Surgery, ambulance (ride), prescription, appointment, wait time, specialist, insulin, testing, copay,* and *emergency room*	• Health care systems in different countries (most terms) • Medicare for All video by John Oliver (most terms) • Comedy on the US health care (*prescription*)
3 (dark blue)	Ideology and society	*Socialism (socialist), capitalism (capitalist), economy, war, communism (communist), security, media, police, crime,* and *democracy*	• Single-payer health care (most terms) • Health care systems in different countries (some terms) • Medicare for All video by John Oliver (some terms) • Health care costs and financial issues (*capitalism*) • Comedy on the US health care (*race/racism, Black person,* and *White person*) • ACA[a]/Obamacare reform (*race/racism, Black person,* and *White person*)
4 (yellow)	Health care politics, reform, market regulation, and insurance	*Trump, Biden, Obamacare, Republican, Democrat, McCain, premium, voting, free market,* and *debate*	• Health care policies and politics (most terms) • ACA/Obamacare reform (most terms) • Medicare for All video by John Oliver (some terms) • Single-payer health care (some terms) • Health care costs and financial issues (market regulation terms)
5 (purple)	Health care workforce	*Nurse/nursing, staff, Covid-19, vaccine, pandemic, respect, shortage, management, CEO*[b], and *shift*	• Health care workforce (most terms) • Health care systems in different countries (vaccine) • ACA/Obamacare reform (*respect*)
6 (light blue)	Dental care	*Dentist, teeth, dental care, dentistry, implant, dental insurance, cleaning, cavity, filling,* and *brace*	• Health care costs and financial issues (most terms)
7 (orange)	Concerns	*Long wait time, cancer patient, DMV*[c], *urgent treatment,* and *death panel*	• Health care systems in different countries (most terms) • Single-payer health care (*DMV*)

[a]ACA: Affordable Care Act.

[b]CEO: chief executive officer.

[c]DMV: Department of Motor Vehicles.

Comment Date and Ongoing Discussions

When considering the timing of comments, the overall mean for all nodes was December 2020 (mean 2020.99, SD 0.81; range: from early 2018 for *repeal*, referring to the Trump administration and Republican lawmakers' efforts to repeal the ACA, to early 2023 for *do-not-resuscitate*). Clusters 1, 5, and 6 have terms with more recent comments than other clusters (Figure 2, left [42]), which is likely a function of when a video was uploaded on YouTube.

Also shown in Figure 2 are ongoing discussions, conceptualized at the term level as mean posting time since the first comment in the respective video. We calculated time for each comment, based on the video it came from, then averaged across all comments behind each term. The terms that scored above the midpoint of 0.49 years (approximately 6 months) highlighted areas on the map where YouTube users continued to contribute comments long after the videos were posted, serving as a proxy for ongoing interest and engagement. Comment scores were calculated in 2 ways: without standardization, expressed as a fraction of a year (Figure S3 in Multimedia Appendix 1), and with standardization, using the base-10 logarithm to adjust for skewed data. The standardized scores were then normalized so that the mean is 0 and the scale points represent SDs (Figure 2, right).

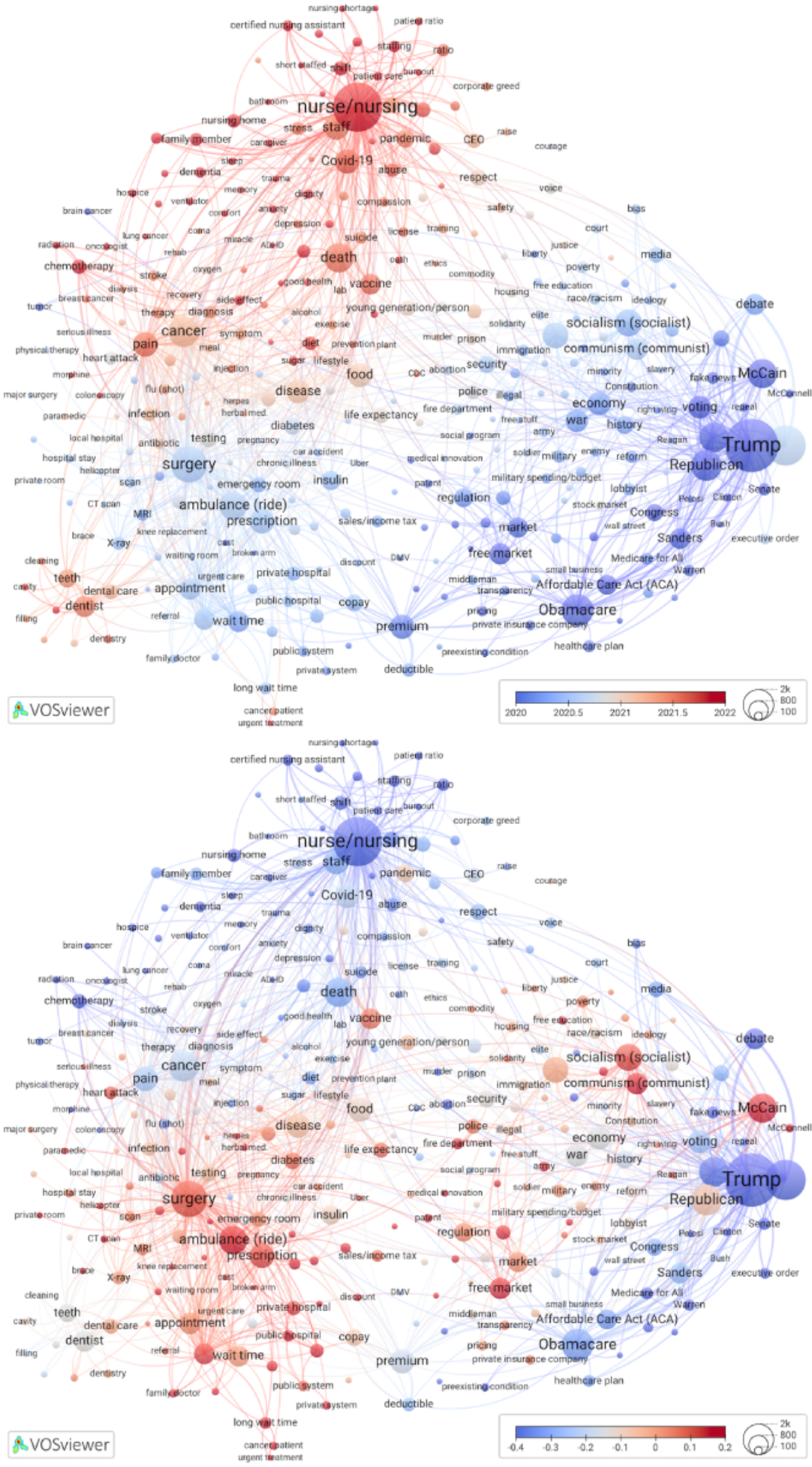
Ongoing discussions in cluster 1, “illness and wellness,” were about cure (*herbal medicine* and *herpes*), *diabetes*, and life expectancy, and young people persisted, on average, for 11 months. In cluster 2, “health services,” ongoing discussions revolved around ambulances, specialist care, prescriptions, appointment wait times, copays, and private (vs public) health insurance or services, roughly covering the same area as high-scoring nodes in an overlay for videos about health care systems in different countries. YouTube commenters demonstrated continued interest in these topics. On average, cluster 2 terms that scored above the mean came from comments posted approximately 9 months after the first comment on a given video.

In cluster 3, “ideology and society,” YouTube users’ comments on political ideologies, police, and military were typically added around the 8-month mark, on average. To better understand an unexpectedly salient group of ideological terms in our map, we analyzed hundreds of comments about communism, socialism, and capitalism. Our analysis confirmed node size and interconnectedness. The discussion of the US health care system was highly politicized, with ideological battles that revolved around dichotomies, such as socialism versus capitalism. Individuals who self-identified as capitalist, conservative, libertarian, or Republican outright rejected any government involvement in health care, calling it socialism, which was often equated with communism (thus confirming node proximity), social democracy, inefficiency, economic decline, and excessive control. Commenters who self-identified as progressive, liberal, social democrat, or left leaning pointed out that health care in the United States was already a mix of capitalism and socialism: publicly funded US police and army were essentially socialized law enforcement, similar to socialized medicine in other countries. They saw no logical reason to reject socialized medicine.

Moreover, several non-US commenters and US residents living abroad shared their positive experiences with health systems in Europe and elsewhere, pointing out that they were affordable to residents with low-income status. Commenters questioned the following: Why do Americans accept *GoFundMe* fundraising to cover medical expenses but not universal health care? Those who defended capitalism praised it for *medical innovation* and high quality of health care but often added that it must be properly regulated. Application of capitalist principles to the US health care system was also discussed in connection to greed, lack of access to health care services, inequities, and poor outcomes. Multiple comments suggested that every economy needed a mix of socialism (relating it to public good or public welfare) and regulated capitalism to counterbalance corporate interests.

Finally, in cluster 4, “health care politics, reform, market regulation, and insurance,” we observed ongoing discussions about market-related topics (*monopoly, regulation,* and *market*) and especially the role of John McCain during Obamacare repeal.

Figure 2. Overlays to Figure 1 for mean comment date (top) and ongoing discussions (standardized scores, bottom). High-resolution versions are available in Multimedia Appendix 1 (Figures S4 and S5).



Comment Likes

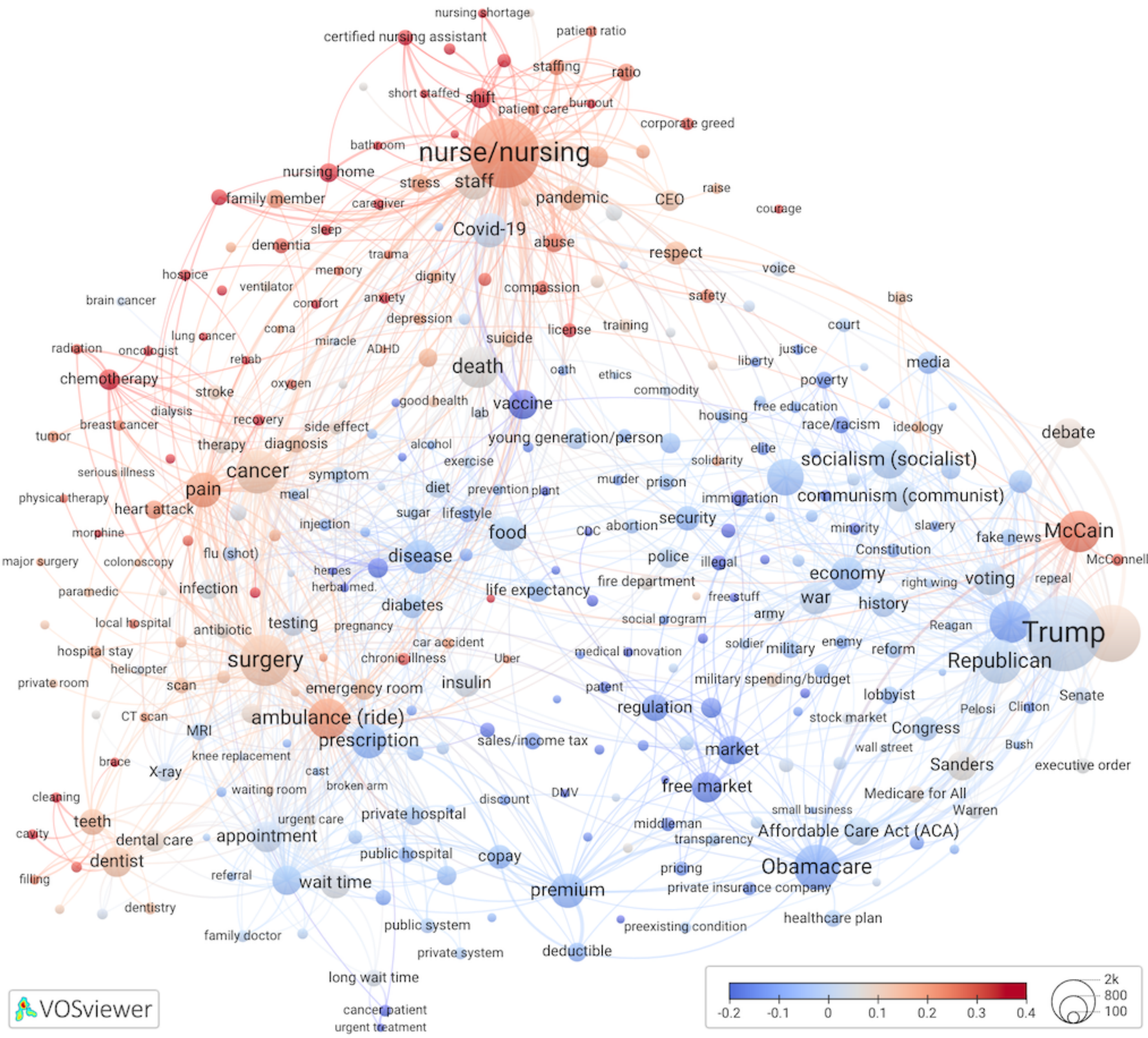
Comment likes were standardized using the same method as for ongoing discussions. We examined overlays for cluster-specific concentrations of terms that scored above the mean, identified dyads of linked terms that scored high, and summarized the most-liked comments from a specific cluster or term.

In Figure 3 [42], the largest concentrations of above-average liked comments were mostly cluster specific (clusters 1, 2, 5, and 6). Most-liked cluster 5 terms came from comments about shortage of nurses and nurse burnout as well as factors contributing to it (*shift*, *short staffed*, *corporate greed*, *patient ratios*, *abuse*, and *management*). We checked an unexpected connection between *shift* (0.58 SD above the mean for all terms) and *bathroom* (0.48 SD above the mean), which represented highly liked comments. A total of 20 unique commenters shared stories of extreme job demands, describing how nurses worked long shifts, endured heavy workloads, faced high patient-to-nurse ratios, and had to wait for breaks to address their physiological needs. All but 3 commenters self-revealed their profession. They were experienced nurses, practicing or retired, or nursing students on clinical rotations. Their detail-rich comments described burnout antecedents, such as profits over staffing, mistreatment of nurses, and mandatory overtime, and outcomes, for example, reduced patient care quality and medication errors.

In cluster 1, cancer-related terms, the term *sleep*, and end-of-life terms such as *do-not-resuscitate* were extracted from comments with many likes. Individuals who mentioned "do not resuscitate" (DNR; 0.42) expressed deeply personal desires for autonomy and the avoidance of prolonged distress at the end of life. The commenters identified themselves as older adults, patient advocates, veterans, or health care workers. They discussed the implications of DNR orders, sometimes expressing doubts that an overburdened health care system could handle their implementation in a patient-centered way. Nevertheless, some nurses who witnessed slow deaths of patients without DNR orders chose to create their own advance directives.

Comments about *sleep* were also well liked (0.43) but, unlike the DNR discussion, referred to many different contexts: caregivers, including nurses, experiencing stressors and sleeplessness; sleep as a precondition to wellness; and in the context of passing away peacefully in one's sleep. The placement of *sleep* within our network, on the boundary of cluster 1 terms (*dementia*, *family member*, *nursing home*, and *caregiver*) and cluster 5 terms (*stress*, *trauma*, and a direct link to *nurse/nursing)*, matched these observations and provided evidence of semantic accuracy and structural relevance.

Figure 3. A mean comment likes (standardized) overlay to Figure 1.



Among dental treatment nodes in cluster 6, *cavity* scored the highest (0.48) on comments with likes. Cavity-related comments came from individuals who revealed the following self-identifications: residence (mostly the United States but also US residents living abroad and foreign nationals from multiple continents), low income (jobless or poor), and medical tourists (eg, US residents receiving dental treatments in Mexico). Commenters particularly liked quotes of low dental costs in Australia, France, Mexico, and other countries; stories of cost savings after buying airfare and paying for dental treatments abroad; personal accounts of dentists recommending unnecessary procedures; and oral health tips, such as reducing sugar intake. Comments specified systemic problems with US dental care: financial strains, even with dental insurance; potentially superfluous, according to second opinions, or unnecessarily extensive procedures (eg, on baby teeth); worsened conditions due to cost-related treatment delays; and processed sugar industry's influence on consumption of foods, leading to dental decay.

Other clusters also had node groups that were well liked. We explored 2 dyads of linked nodes that scored high on likes: *McCain–McConnell* (0.31-0.34, cluster 4) and *ambulance (ride)–Uber* (0.26 for both, cluster 2), with above-average likes. In first dyad comments, most commenters applauded McCain's vote that helped prevent the repeal of ACA and criticized McConnell and other Republicans. Comments from the second dyad, *ambulance* and *Uber,* were by YouTuber users who expressed concerns about the cost of US ambulances and Americans' reluctance to use specialized emergency transportation. To avoid unpredictable costs, some US commenters planned to use nonmedical transport, such as ride-sharing services like Uber, during health emergencies.

Comments With Select British Spellings

Figure S6 in Multimedia Appendix 1 displays an overlay that approximates contributions from commenters whose backgrounds are associated with regions where British spelling conventions are more common than in the United States. Such spelling was detected in multiple clusters, but the highest-scoring terms were in cluster 2 (*national insurance*, *government hospital*, and *private system*) and cluster 3 (*free education*, *unemployment*, and *justice*).

Commonly Mentioned Health Care Concepts: System Design Ideas

Our last set of overlays demonstrates the distribution of comments that mention policy-relevant ideas on health care system design: universal health care, Medicare for All, a single-payer system, and socialized medicine (Table 2). VOSviewer Online offers a modifiable legend with an option to normalize term scores by subtracting mean and dividing by SD. When term scores are normalized, we can directly compare multiple overlays (Figures 4 and 5 [42]) to identify map areas with terms that are extracted from a high (vs low) share of comments mentioning specific system design ideas. Unlike the standardization of comment scores, normalization is performed at the term level.

Table 2. Mentions of health care system design ideas.

Attributes	Design idea overlay[a]			
	Universal health care	Medicare for All	Single payer	Socialized medicine
Definition[b]	A system where all citizens have access to health care services without financial hardship	A proposed system to expand the US Medicare program to cover all individuals, eliminating private insurance	A system where a single entity (usually the government) pays for all health care costs	A system where the government not only funds but also provides the health care services
Comments, N	3638; "universal health" or "universal healthcare"	2909; M4A or "medicare for all"	1474; "single payer" or "single-payer"	716; "socialized medicine" or "socialised medicine"
Prevalence of comments that mention each design idea within a term-specific comment collection				
Highest-scoring term on a corresponding overlay	*Private room* (12/95, 12.6% of comments also mention universal health care)	*Warren* (116/276, 42% of comments also mention Medicare for All)	*Administrative cost* (16/108, 14.8% of comments also mention single payer)	*Medical innovation* (5/108, 4.6% of comments also mention socialized medicine)
Share of comments within ideological terms[c]				
Socialism/socialist	+1.44 SD	+0.04 SD	−0.16 SD	+0.64 SD
Communism/communist	+3.06 SD	−0.18 SD	−0.65 SD	+0.45 SD
Capitalism/capitalist	−0.33 SD	−0.28 SD	−0.49 SD	−0.53 SD

[a]Interactive overlays are available from the left panel (view>items>color >) [42].

[b]Commenters defined health system design ideas in different ways and sometimes used them interchangeably. For example, some commenters talked generally about a state-managed health care system in reference to both single payer and socialized medicine.

[c]Normalized health system design idea overlay scores for 3 ideology nodes are shown relative to all nodes' mean share of comments mentioning that specific health system design idea. Plus or minus signs refer to above or below all terms' mean share, expressed in SD units, within each health system design idea overlay.

Figure 4. Overlays to Figure 1 depicting the distributions of comments that mention “universal health” (top) and “Medicare for All” (bottom). High-resolution versions are available in Multimedia Appendix 1 (Figures S7 and S8).

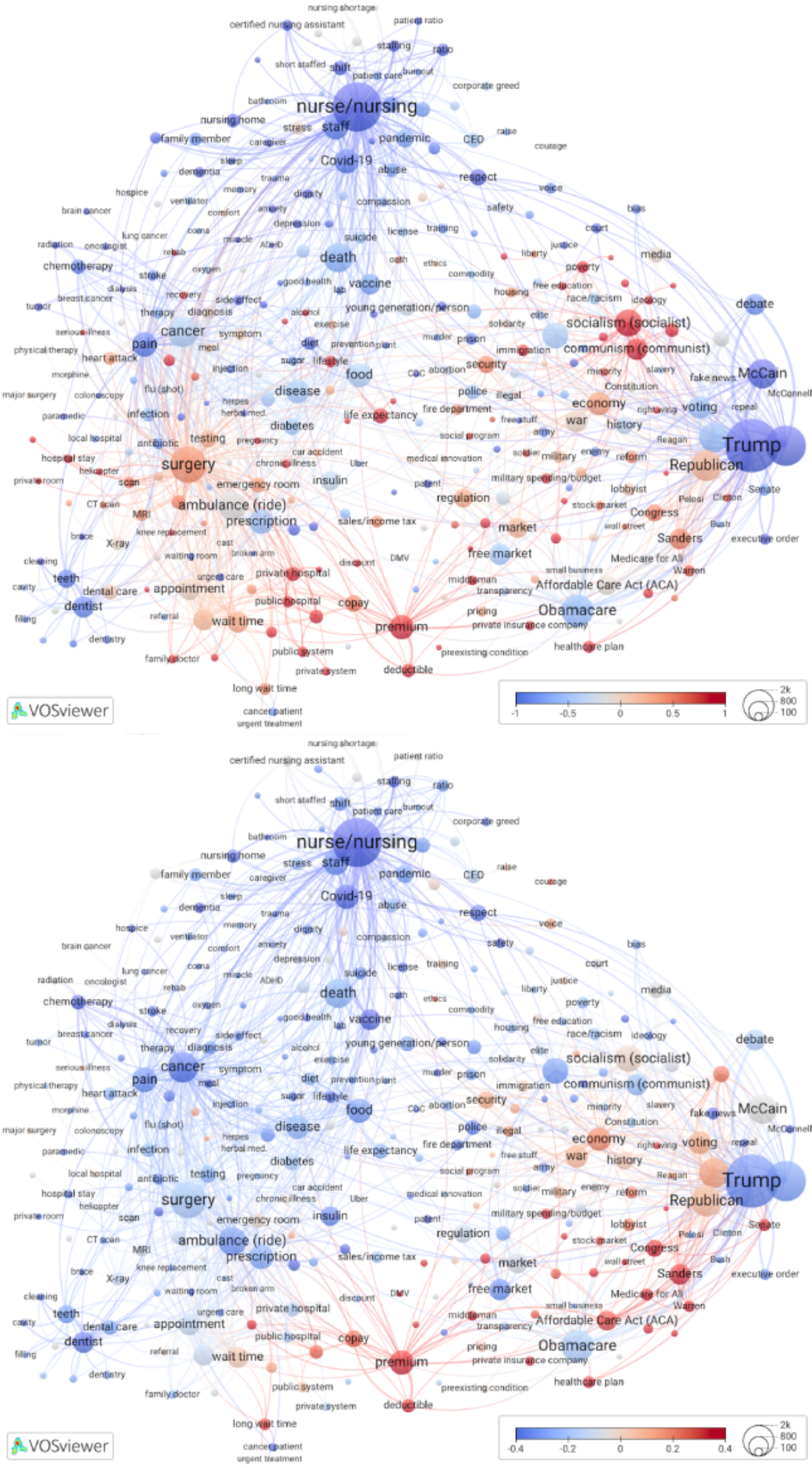
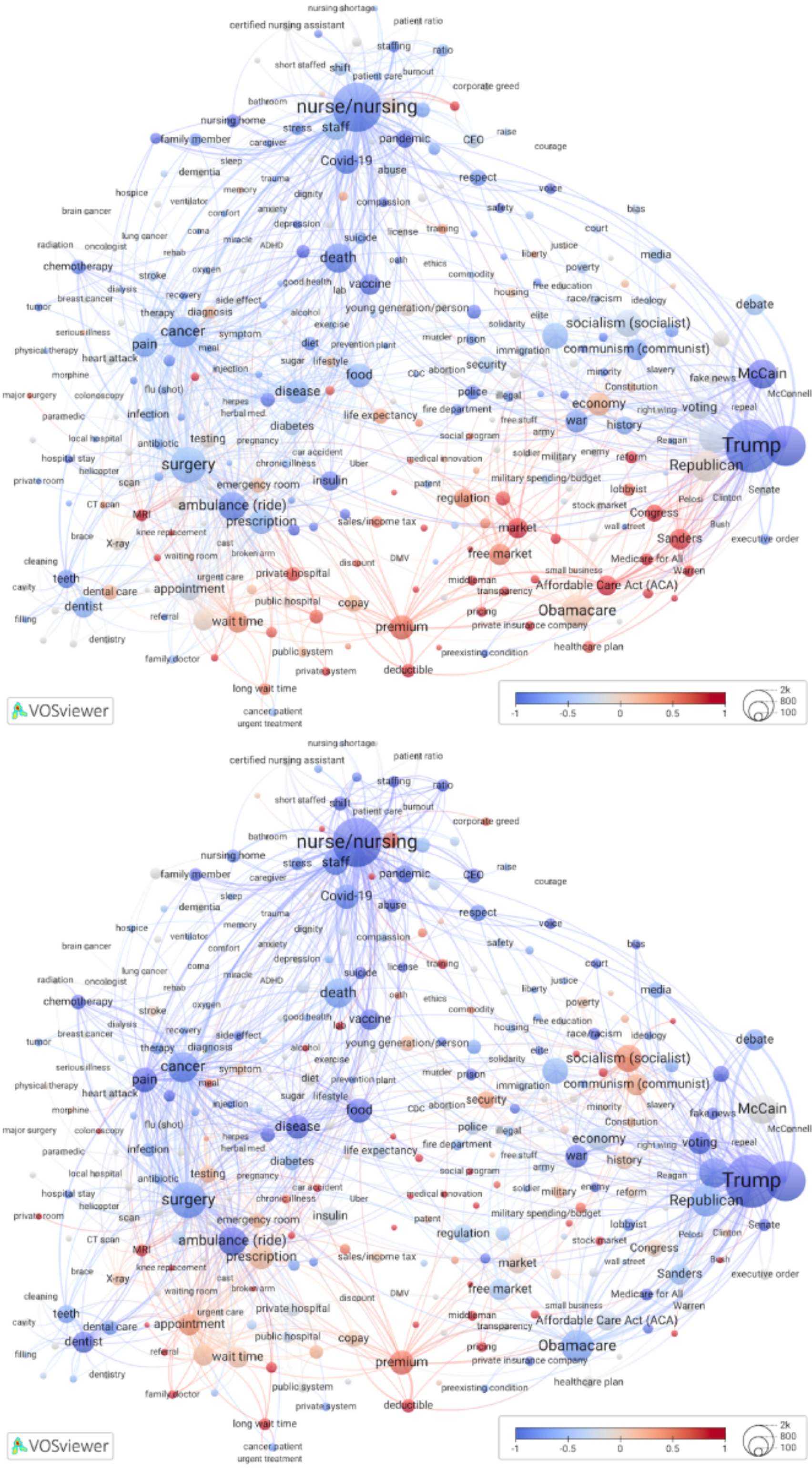


Figure 5. Overlays to Figure 1 depicting the distributions of comments that mention “single-payer” (top) and “socialized medicine” (bottom). High-resolution versions are available in Multimedia Appendix 1 (Figures S9 and S10).



As shown in Table 2, the most frequently mentioned health system design idea in our comments—universal health care—was discussed in connection to *private room*, the highest-scoring term on the universal health overlay. The term *private room* also had above-average share (3/95, 3%) of comments, with at least 1 (6%) of 18 British-spelled words. US residents and foreign nationals discussed semiprivate and private hospital rooms as a desirable high standard for hospital stays.

Commenters with experience in universal health systems explained that such systems serve everyone but may not provide extra luxuries unless a patient is also covered by private insurance or pays out of pocket. Several comments expressed preferences for universal health care systems with balanced public and private health care. Private rooms, marble floors, and hotel-like amenities in US hospitals were discussed as luxuries available to the rich, while care was being denied to the poor.

At the bottom of Table 2, we show 3 ideological terms and compare the extent to which they are linked to each health system design idea. For universal health overlay, the data address the following question: In node *socialism/socialist*, what is the share of comments that mentioned universal health and how far is this share, in SD units, away from the universal health care overlay's mean for all nodes? Compared to 3 other concepts (Medicare for All, a single-payer system, and socialized medicine), universal health care was most strongly linked to discussions of communism and socialism. Specifically, the share of universal health care comments in the node *socialism/socialist* was much greater than that in most other nodes (1.44 SD above all terms' mean). It was even higher for the node *communism/communist* (3.06 SD above the mean).

While discussing Medicare for All in early 2020, YouTube commenters were concerned that it was insufficiently supported by Elizabeth Warren, as compared to Bernie Sanders, which explains why *Warren* was the highest-scoring term in the Medicare for All overlay. In addition to questioning the political viability of Medicare for All, commenters expressed concerns about its funding and tax increases, possible loss of preferred private insurance, unemployment among health insurance workers, increased wait times, diminished quality of care, and fluctuating government or political control over reproductive health.

The highest-scoring term on the single-payer overlay, *administrative cost*, was often mentioned with a term *middleman*, an unnecessary intermediary, for example, private insurance companies and for-profit corporate interests. Discussions of single payer, administrative costs, and middlemen turned into debates. Advocates cited the potential for significant savings and increased efficiency by eliminating the profit-driven insurance model. They pointed to Medicare's low overhead as evidence that a single-payer system could reduce administrative costs. By cutting out middlemen, single-payer systems bring down administrative costs and simultaneously simplify system navigation and transactions for patients, restrain profiteering, reduce health care fraud, and open health care systems to cost control. Critics, however, expressed skepticism about the efficiency of government-run systems, cautioning that replacing one bureaucratic structure with another may not achieve the expected reductions in administrative costs.

Finally, the term *medical innovation* had the highest share of comments that mentioned socialized medicine. The comments often referred to the United States's top position in producing medical innovations. Several US commenters suggested that countries with socialized medicine rely upon US innovations without contributing comparable advancements in new treatments or medical technologies. US medical innovations, according to their comments, come at high cost but also contribute to high quality of care. Others expressed disagreement, saying the United States ranked fourth on medical innovation, behind Switzerland, Germany, and the Netherlands. In addition, hopes were expressed that rising costs of US health care could be controlled through medical innovations, especially in older adult care.

Of the 4 health system design ideas we analyzed, the concept of single-payer health system had the lowest use of ideological terms. The distribution of scores across the single-payer overlay shows that single-payer discussions were less prevalent in ideological terms (*socialism/socialist*, *communism/communist*, and *capitalism/capitalist)* than in other terms we mapped. In the *socialism/socialist* node, an above mean share of comments about Medicare for All (+0.04 SD), socialized medicine (+0.64 SD), and especially universal health care (+1.44 SD) indicated greater use of ideological terms, as compared to single-payer discussions (–0.16 SD). In addition, the universal health care discussion was much more centered around communism or communist (+3.06 SD) compared to the single-payer discussion (–0.65 SD).

Discussion

Overview

We discuss 2 sets of findings. First, we summarize our evaluation of the semantic network. We elaborate on the implications of repurposing VOSviewer to subsequent social media studies and anticipate scientific advances that may result from its broad application. Second, we summarize our US health system insights and discuss their policy implications, pointing out limitations.

VOSviewer Term Co-Occurrence Network as a Social Media Analysis Method

VOSviewer is one of several programs available to researchers for conducting semantic network analysis. For example, previous studies have used the Fruchterman-Reingold algorithm [44], Gephi [45], and R [46] to build semantic networks. At the same time, VOSviewer's user-friendly interface is suitable for users without advanced technical skills. Regardless of the tools used in their construction, semantic networks promise to represent knowledge, while their interconnected nodes likely capture meaning [12], as demonstrated by this analysis.

We used VOSviewer as a data visualization tool to respond to the critical need to decrypt chaotic and extensive social media discussions on a socially important topic. Our analysis suggests that VOSviewer produces visualizations with high information density, interactivity, and interpretive richness. In addition, we obtained evidence regarding the following characteristics of the VOSviewer-generated network: (1) robustness or resilience to variations in data, (2) content representativeness of the diversity of issues related to the US health system, (3) structural relevance defined as meaningful network relationships, and (4) semantic accuracy defined as accurate representation of comment meaning. Our evaluation of the network's decision support usefulness is discussed in the US Health System Insights and Their Policy Implications section.

First, our limited test of robustness confirmed the network's resilience to the removal of approximately 3% of repeated comments from our corpus. If such comments were retained, identical comments by just 1 social media user would have produced a user-specific map cluster about medical debt and bankruptcy. Striving to build a network reflective of broad conversations, we chose to remove it, but the comments we removed were relevant to the US health system. The person who posted them might have tried to express desperation or draw attention to the seriousness of medical debt.

Second, the network comprehensively covered 10 thematic video groups, representing the entire diversity of video content about the US health care system. In other words, comments from all video groups were represented within the network nodes. Third, we observed a meaningful cluster layout that, overall, could be intuitively interpreted. Structural relevance was confirmed by spatial arrangement of nodes in the network, where the proximity of nodes corresponded to the co-occurring nature of the semantic relationships observed in the text from which the nodes were derived. Moreover, the network's structure aligned with existing knowledge, for example, ACA provisions. Forth, multiple checks confirmed that the mapped terms, including unexpected or ambiguous ones, captured the meanings of posts as well as their context.

Anticipated Scientific Advances of the VOSviewer Application to Social Media Analyses

The VOSviewer's term co-occurrence mapping method and their custom overlays can advance computational social sciences through informative, contextualized semantic networks. Natural language processing enables unbiased extraction of relevant terms, with an option of manual term screening. Revealing large patterns in extensive source data, VOSviewer "visual narratives" [47] can guide researchers to efficiently allocate their analytical resources as they explore salient patterns of societal importance embedded in "context or domain-specific knowledge" [48]. As such patterns involve network terms—nouns and noun phrases that occur in comments—researchers can strategically focus on the most promising subsets of extant data. In addition, VOSviewer-enabled semantic networks bring to light the interdisciplinary nature of social media studies. According to our cluster map, an in-depth analysis of public perceptions of the US health system calls for input from scholars in fields such as communication, economics, health care management, medicine, political science, public health, and others.

Clusters model thematic structure at a macro scale; overlays provide interpretive richness. The method we demonstrated here offers a valuable way for researchers to experience relationships embedded in source data, some of which are hard to document using conventional analyses. Chronological overlays that show video dates, comment dates, and lags in time between the first and the nth comment offer clues on how the discussion progressed over time, enabling a study of unfolding discourses. This is particularly relevant for data from social media platforms, which are "inherently longitudinal" [48]. With additional automation, it would be possible to create dynamic network visualizations that are updated in near–real time as new comments are posted.

Another benefit of semantic map overlays is that they foster cluster exploration and hypothesis testing by combining different data sources. For the YouTube platform, overlays may reflect characteristics of comments, YouTube video channels, videos themselves, or social media users' channels. Therefore, visual overlays represent many opportunities for innovation and experimentation. For example, information excluded during term selection can be brought back in overlays. In this study, we removed geographical references from the cluster model's nodes but created an overlay to highlight discussions with British spelling.

The method we demonstrated in this study can also enhance the value of qualitative research. Resource-intensive qualitative methods can be deployed strategically, guided by the grasp of larger patterns evident in semantic networks. Semantic networks can be contextualized and nuanced through qualitative coding. The qualitative codes can then be incorporated into custom-designed overlays, leading to new hypotheses and qualitative analyses. This iterative approach enables visualization-assisted qualitative inquiry.

Given these methodological strengths, we believe that VOSviewer-enabled semantic network analyses of social media data can advance social science research in the digital era. Thinking even broader, the proposed method can be applied across a variety of contexts and data sources, not limited to social media, and across different disciplines, such as computational humanities.

US Health System Insights and Their Policy Implications

Overview

Health care debates unfold in both in real life and online spheres. We examined digital publics' discourse about the US health care system in response to YouTube videos from right, center, and left media outlets. The YouTube platform allows purposeful selection of videos by varied media outlets on different aspects of an issue. We provided evidence that thematic diversity of videos was passed on to the commentary, opening a door to the policy-relevant analysis of diverse viewpoints. The YouTube platform has emerged as a space for heated debates, thoughtful ideas, misconceptions, and personal narratives in response to the US health care system.

Understanding the viewpoints by social media users provides valuable input for policy makers, health care professionals, and advocates aiming to shape effective reforms. The insights gleaned from the VOSviewer semantic network carry significant implications, which we grouped into 3 categories (concerns about the health care system, domestic and global interconnections in health care discussions, and informing change through key health care discourse insights).

Concerns About the Health Care System

The clusters shed light on a wide range of areas of concern within the US health care system, including those that are likely to be voiced by the public when politicians mention universal health care, Medicare for All, a single-payer system, and socialized medicine. The network analysis was helpful in estimating the use of ideological terms in discussions of various health system design ideas and identifying related concerns, for instance, about continued medical innovation or patients' access to private hospital rooms. The ideology and society cluster terms, derived from politicized comments, reflect the entrenched ideological conflicts and capitalism-socialism dichotomies within the YouTube discourse about the US health care system.

We observed that comments in the health care workforce cluster, particularly those about staff shortages and burnout, received many likes. This pattern points to a widely shared perception of the urgent need to address challenges faced by nurses and other health professionals. If corroborated across time and other data sources, this sentiment may translate into public support for health care reforms that enhance workforce well-being, improve nurse-to-patient ratios, and support the essential role of health care workers in the system.

Online discussions also highlight ongoing debates about the balance between public and private health care services. Policy makers can use these insights to formulate strategies that optimize the strengths of both sectors, ensuring accessibility, affordability, and quality of care. In sum, a VOSviewer-generated semantic network with overlays shows promise as a decision support tool for policy makers.

Domestic and Global Interconnections in Health Care Discussions

Health care reforms should consider the broader societal and political context of the country to build sustainable and politically viable solutions. The health care discourse we described incorporated widespread debates about political ideologies, societal issues such as racism, and economic considerations. While many of these issues were domestic, there was also a significant international component. Terms such as *national insurance*, *government hospital*, *private system*, *free education*, *unemployment*, and *justice* represented 6% to 8% of comments with at least 1 British-spelled word from our list. In much smaller concentrations (2.5%-4%), British-spelled comments appeared in the wellness discussion (*nutrition*, *vegetable*, and *memory*) and conversations about tax break (or cut), social health care, and private insurance companies. Adding evidence in support of semantic accuracy, several terms extracted from a nonzero share of British-spelled comments (*national insurance* and *social health care*) described societies outside of the United States.

The presence of British-spelled words in our data indicated the global nature of US health care discussions, which is evident in international comparisons of prices and patient experiences. YouTube discussions offered opportunities for US social media users to learn about foreign health systems and explore their benefits, trade-offs, and foundational values. The information was conveyed not by experts or politicians but by laypeople who had encountered foreign systems as taxpayers and patients. Some informants lived in several countries and could compare multiple systems. Informed by global perspectives, the US public may shift its expectations, prompting politicians to incorporate best practices, for example, affordable drugs and predictable costs of emergency patient transportation, into reform initiatives. At the same time, both the public and policy makers stand to benefit from reexamining their own misconceptions and rigid ideological beliefs in light of successful health care models and practices in other countries.

Informing Change Through Key Health Care Discourse Insights

Our semantic network analysis provides insights into the topics that garner the most attention and engagement in ongoing discussions. Health care reforms can be supported by targeted public education and awareness campaigns addressing these key themes, fostering informed public discourse and encouraging active participation in the reform process. Accordingly, policy makers should continuously monitor public sentiments on platforms such as YouTube to inform dynamic, responsive health care policies that adapt to changing societal needs and concerns. Finally, leveraging user engagement patterns, particularly standardized likes and ongoing discussions, can establish effective feedback loops between policy makers and the public. Understanding which aspects of the discourse resonate most strongly with the public allows for the refinement of reform strategies. We provided empirical evidence of links between specific public opinions on health system designs and ideological discourse; comments about universal health care had a much higher use of ideological terms than discussions of single-payer health systems. Overall, the key takeaways drawn from the VOSviewer-generated semantic network analysis provide actionable insights for shaping reforms in health care, which are responsive, inclusive, and aligned with the diverse perspectives expressed by the public on digital platforms.

Finally, we share 2 observations on how VOSviewer maps may support evidence-based policy making and communicating with stakeholders. One consideration is the empirical rootedness of the information we mapped. Decision makers are more likely to accept and act upon information perceived as "evidence based" [48], for example, maps that display intuitively interpretable terms grounded in actual text. In the study by van der Voort et al [47] on big data, decision makers "wanted 'stories to tell' to feed public debate and highlight problems and opportunities," favoring reports at higher resolutions. In our study, clusters communicated broad narratives about the public discourse of the US health system, while overlays enriched and contextualized interpretation of narratives, adding complexity and specificity.

How well decision makers with different levels of education can decode VOSviewer data visualizations remains to be tested. We anticipate that for most decision makers, the learning curve of interpreting maps will be less steep than that for statistical outputs with comparable informational value. While overlays provide a multidimensional understanding of the discourse, they may be harder to decode than clusters. At the same time, the interactive nature of VOSviewer Online is likely to add interest and user engagement, helping to translate research findings into informed decision-making and actionable policy measures.

Limitations

While VOSviewer offers a powerful tool for visualizing and analyzing co-occurrence networks, the algorithm's effectiveness is contingent on the initial selection of terms. The manual screening of a list of terms introduces a potential bias. In addition, the study is limited to English language YouTube comments, which may not fully capture the broader public discourse on health care.

Further research is warranted to validate and expand upon our results. Future studies could use other advanced natural language processing techniques to enhance the accuracy of term selection and clustering. Moreover, a multiplatform analysis that includes other social media platforms and online forums would provide a more comprehensive understanding of public sentiment and discourse surrounding health care.

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Data Availability

All data are available in the main text or Multimedia Appendix 1. Map files can be downloaded from map URLs provided in Multimedia Appendix 1. Original YouTube comments (initial comments and first-level replies) can be accessed through YouTube using the video descriptions provided in Multimedia Appendix 1.

Authors' Contributions

LVI conceptualized the study, curated the data, conducted the formal analysis, created the visualizations, provided supervision, and managed the project administration. LVI and EE collaborated on writing the original draft, methodology, investigation, validation of the findings, and contributed to the writing, review, and editing of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary information on video and comment analysis.
[DOC File , 50822 KB - infodemiology_v5i1e58227_app1.doc]

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Abbreviations

ACA: Affordable Care Act
DMV: Department of Motor Vehicles
DNR: do not resuscitate

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Original Paper

Characterizing Experiences With Hikikomori Syndrome on Twitter Among Japanese-Language Users: Qualitative Infodemiology Content Analysis

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Abstract

Background: *Hikikomori* syndrome is a form of severe social withdrawal prevalent in Japan but is also a worldwide psychiatric issue. Twitter (subsequently rebranded X) offers valuable insights into personal experiences with mental health conditions, particularly among isolated individuals or hard-to-reach populations.

Objective: This study aimed to examine trends in firsthand and secondhand experiences reported on Twitter between 2021 and 2023 in the Japanese language.

Methods: Tweets were collected using the Twitter academic research application programming interface filtered for the following keywords: "#引きこもり," "#ひきこもり," "#hikikomori," "#ニート," "#脱ひきこもり," "#不登校," and "#自宅警備員." The Bidirectional Encoder Representations From Transformers language model was used to analyze all Japanese-language posts collected. Themes and subthemes were then inductively coded for in-depth exploration of topic clusters relevant to first- and secondhand experiences with *hikikomori* syndrome.

Results: We collected 2,018,822 tweets, which were narrowed down to 379,265 (18.79%) tweets in Japanese from January 2021 to January 2023. After examining the topic clusters output by the Bidirectional Encoder Representations From Transformers model, 4 topics were determined to be relevant to the study aims. A total of 400 of the most highly interacted with tweets from these topic clusters were manually annotated for inclusion and exclusion, of which 148 (37%) tweets from 89 unique users were identified as relevant to *hikikomori* experiences. Of these 148 relevant tweets, 71 (48%) were identified as firsthand accounts, and 77 (52%) were identified as secondhand accounts. Within firsthand reports, the themes identified included seeking social support, personal anecdotes, debunking misconceptions, and emotional ranting. Within secondhand reports, themes included seeking social support, personal anecdotes, seeking and giving advice, and advocacy against the negative stigma of *hikikomori*.

Conclusions: This study provides new insights into experiences reported by web-based users regarding *hikikomori* syndrome specific to Japanese-speaking populations. Although not yet found in diagnostic manuals classifying mental disorders, the rise of web-based lifestyles as a consequence of the COVID-19 pandemic has increased the importance of discussions regarding *hikikomori* syndrome in web-based spaces. The results indicate that social media platforms may represent a web-based space for those experiencing *hikikomori* syndrome to engage in social interaction, advocacy against stigmatization, and participation in a community that can be maintained through a web-based barrier and minimized sense of social anxiety.

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KEYWORDS

hikikomori; social withdrawal; hikikomori syndrome; mental health; social isolation

Introduction

Background

Hikikomori syndrome, a form of severe social withdrawal largely characterized as experienced among adolescents and young adults in Japan, has recently gained increased attention as a global mental health concern [1]. Importantly, variability in reported *hikikomori* prevalence in countries and regions such as China, Hong Kong, South Korea, Singapore, Nigeria, the United States, and Taiwan may reflect different cultural distinctions of *hikikomori* inclusion criteria, study-specific assessments, and study-specific enrollment methods [2,3]. Nevertheless, increasing prevalence continues to challenge the notion that *hikikomori* is specific to the Japanese context and provides emerging evidence that this phenomenon is widespread cross-nationally [2,4]. Importantly, this form of extreme and persistent social isolation and withdrawal can be viewed as a complex sociocultural mental health phenomenon influenced by a variety of factors, such as economic and employment conditions, social norms and expectations, technology access and use, and changing attitudes toward acceptable social interaction (such as changes in interpersonal dynamics caused by the social isolation experienced during the COVID-19 pandemic) [5,6].

Hikikomori (derived from the verb *hik* [引き], which means to withdraw, and *komori* [籠り], which means to be inside) was originally coined by Japanese psychologist Tamaki Saito in 1998. The term was originally operationalized to refer to an individual who has stopped going to school (*futoukou* [不登校]) or work (*neeto* [ニート]) and has remained at home for a duration of >6 months [7]. A consensus on a standardized definition of *hikikomori* has not been reached, contributing to challenges in measuring the phenomenon, but a commonly used set of criteria was created in 2003 by the Japanese Ministry of Health, Labor, and Welfare (JMHLW) [1,4]. The JMHLW criteria have since been updated with the most recent 2010 definition, which describes *hikikomori* as a result of various factors, such as avoiding social participation (such as schooling, including compulsory education; employment, including part-time jobs; and other interactions outside the home), which in principle has continued under the condition of being housebound for a period of >6 months (this may include leaving the home while still avoiding interactions with others [8]). A later definition in 2020 by Kato et al [9] proposed updated diagnostic criteria for *hikikomori* as a pathological social withdrawal or social isolation in which the essential feature is physical isolation in one's home and for which the person needs to meet the criteria of (1) marked social isolation in one's home, (2) duration of continuous social isolation of at least 6 months, and (3) significant functional impairment or distress associated with the social isolation. Furthermore, many studies have found that patients with *hikikomori* syndrome often had experiences with bullying, peer rejection, or dysfunctional family life and were prone to internet addiction [10,11].

However, until recently, *hikikomori* was understood as a culture-bound phenomenon unique to Japan, reported to affect an estimated 1.2% of the population and over a quarter of students based on household survey data [2,12,13]. Although the causes and risk factors for *hikikomori* are not completely known, many studies have highlighted aspects of Japanese society and culture that enable *hikikomori* features and may account for the especially high number of *hikikomori* cases reported in Japan. Sociocultural factors such as *amae* (甘え), the Japanese term for codependency in parent-child relationships; the tendency of overprotection and indulgence of children by parents; the high-pressure environment created by the Japanese educational system; the need to conform to others and norms; and the challenging job search process for young adults often leading to identity distress have all been hypothesized to be causes of or risk factors for *hikikomori* [14-16]. Furthermore, the idea of isolation has been prominent in Japanese society for centuries. It has been seen as a way of life commonly represented in history with tales of mysterious mountain recluses and hermits [17]. However, numerous *hikikomori*-like situations and the lack of standardized diagnostic methods have made identifying *hikikomori* challenging in Japan [1].

Previous studies have attempted to carry out clinical interviews with families or study individuals who have sought help from public health centers for *hikikomori* syndrome, but the underlining challenges of social reclusion have also made *hikikomori* research and recruitment difficult [12]. Those who experience social and geographic isolation often feel unable to discuss mental illness openly due to the fears of stigma and may feel more comfortable sharing their experiences on the web [18,19]. In response, researchers have leveraged social media platforms as a source of self-reported health information that can be analyzed for stigmatizing issues and topics discussed among hard-to-reach populations, including generating insights specific to certain demographics and geographies [20,21]. Despite this possible application to *hikikomori* research, existing studies using web-based sources of data are limited and have primarily focused on exploring *hikikomori* through Western tweets outside of Japan and tweets in Japanese with limited keywords or have studied *hikikomori* alongside other mental health phenomena [22-24].

Objectives

Importantly, *hikikomori* has evolved since its introduction and original classification in 2003. While initially classified as a cultural syndrome in the 2019 version of the *Diagnostic and Statistical Manual of Mental Disorders*, it has since been included in the appendix of the 2022 *Diagnostic and Statistical Manual of Mental Disorders*, indicating that it will become a formal addition to the volume [25]. These changes may be a result of increasing public awareness, increased willingness to discuss mental health topics, and destigmatization yet can cause an expansion or inflation of the clinical meaning of *hikikomori* [26]. In response, this exploratory study sought to expand knowledge on *hikikomori* syndrome with a focus on

Japanese-language social media posts from Twitter (now known as X), a platform that is popular among Japanese web-based users. Furthermore, no study, to the best of our knowledge, has examined *hikikomori*-related data after 2020 (the start of the COVID-19 pandemic) despite the pandemic contributing to a rise in social isolation due to public health measures mediated by increased use of social media for social interactions [27,28]. We also sought to source more diverse data and web-based discussions by including additional keywords in Japanese, such as more casual terms, closely related words, and synonyms related to *hikikomori*. Finally, this study focused on firsthand and secondhand experiences self-reported by Twitter users and how those experiencing or who have had experience with *hikikomori* interact on the platform. The results of this study can provide insights into how the Japanese *hikikomori* population and their caregivers use social media to discuss this condition and promote a better understanding of primary concerns and behaviors that can help destigmatize this growing condition.

Methods

Data Collection

We first conducted manual searches of *hikikomori* posts on Twitter to identify keywords and hashtags associated with *hikikomori* conversations and mentions in the Japanese language. From this initial search, we identified a set of *hikikomori* keywords that Japanese-language Twitter users commonly used in web-based discussions regarding *hikikomori* syndrome (Multimedia Appendix 1). This initial set of keywords included nonspecific *hikikomori* keywords such as stopping going to school (*futoukou* ["不登校"]) or work (*neeto* ["ニート"]) and staying at home ("自宅警備員"), all terms that are considered a similar social phenomenon to *hikikomori* and often exhibit similar characteristics of social isolation as those included in the definition of *hikikomori* by the JMHLW. This approach was also supplemented by conducting an analysis of Google Trends data for related topics and queries associated with the Japanese-language spelling of *hikikomori* ("引きこもり") from 2004 to the present, which identified additional related topic keywords used in this study.

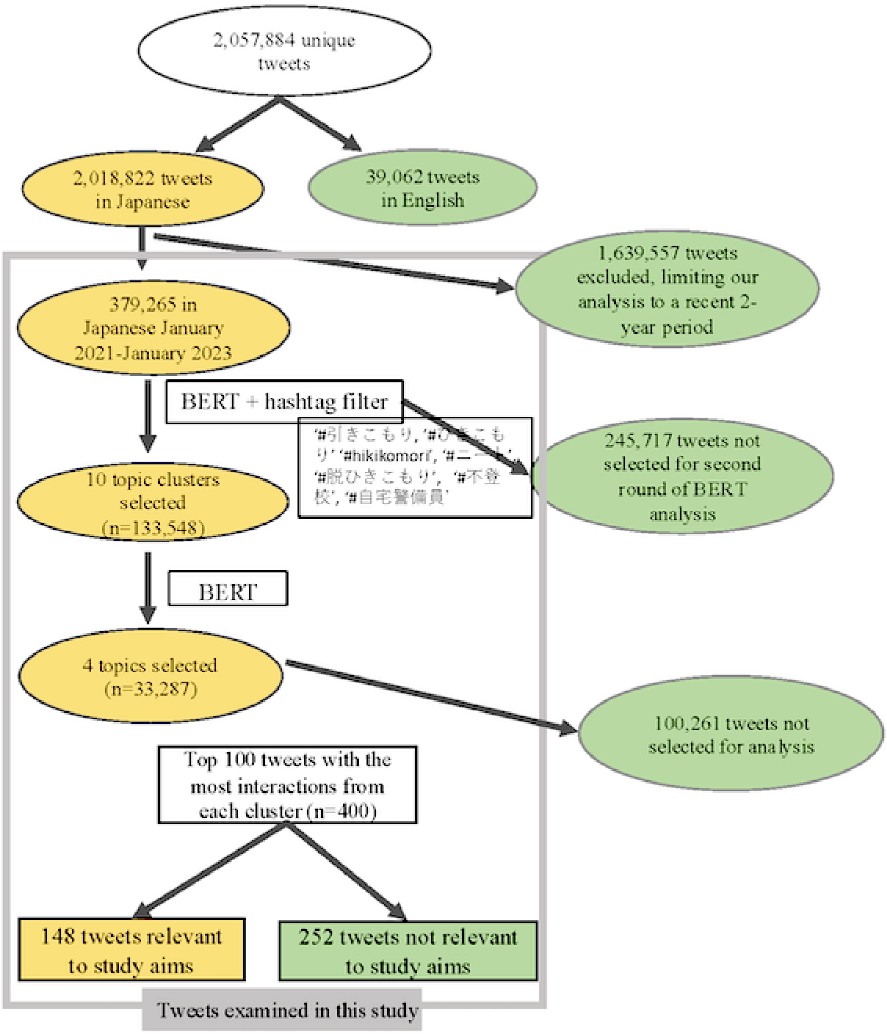
After the study keywords were finalized, the Twitter application programming interface (API) was used to collect all Twitter posts (ie, tweets) in 50 languages, including Japanese and English. We then limited the data to the Japanese language only (ie, filtered data in the JSON language field *LANG* for the *JA* [Japanese] attribute); removed all retweets; and only included data over a 2-year time frame from January 1, 2021, to January 1, 2023. For the academic API data collection, the API had a limit of 300 queries per a 15-minute window, so the *next_token* feature was used to collect data continually between all queries to ensure that all available data in the given period were collected based on the API settings. The Twitter data field categories analyzed for this study primarily consisted of text, including the following fields: text, link, ID associated with the tweet, username (deidentified and not disclosed in this study), user link, author ID, API type, geolocation (latitude and longitude, if available), and tweet creation time and date. Data collection took place in June 2023.

Topic Modeling

Before topic modeling, any retweeted tweets were removed, and only unique tweets with a unique Twitter ID were analyzed. Due to the relatively large volume of data collected, we applied a natural language processing approach to group tweets into relevant thematic clusters. For this corpus of tweets, we used BERTopic, which is a topic modeling technique that leverages Bidirectional Encoder Representations From Transformers (BERT), and class-based term frequency–inverse document frequency, a statistical measure of the importance of words to a particular group of text, to create dense clusters allowing for easily interpretable topics while keeping important words in the topic descriptions. BERTopic then produced an output of data using the k-means algorithm, which includes the sum of the posts into a predetermined number of k clusters (k=10) based on the posts' semantic similarities and groups text containing the same word-related themes into the same clusters. BERTopic was selected due to its use in previous work that has analyzed large-scale Twitter data, its general utility in analyzing unexplored themes that lack existing training data, and utility for the overall exploratory nature of this study's aims [29,30]. Importantly, when compared against other traditional topic models, BERTopic has resulted in a better performance on both topic coherence and topic diversity on Twitter data [31]. Hence, BERTopic methodically has better utility to group tweets that are specifically relevant to *hikikomori* while reducing the potential for noise in selected clusters by providing more accurate and contextually relevant tweet conversational groupings. This study used BERTopic version 0.6.0 with Python version 3.7 (Python Software Foundation).

For the purposes of analyzing tweets specific to the aims of this study, BERTopic was executed in 2 phases: an initial round on the full dataset after data cleaning followed by a second round of focused analysis on relevant, selected topics. Data cleaning performed before the BERTopic analysis included removing punctuation and stop words in posts for optimized BERTopic grouping output. For the initial BERTopic analysis, we ran both 1- and 2-gram analyses on the same dataset to obtain the most visibility of content in our dataset. From both results, we selected 10 clusters in total for review. From those 10 clusters, we limited the data to the following hashtags—"#引きこもり" ("*hikikomori*"), "#hikikomori," "#ニート" ("*neeto*"), "#脱ひきこもり" ("stopping *hikikomori* lifestyle"), "#不登校" ("prolonged absence from school"), and "#自宅警備員" ("home security guard")—to further reduce the data size (see Figure 1 for a summary of the study methodology). With results from these data, a second round of BERTopic analysis was run on the initial 10 topics using a 2-gram BERTopic analysis, and the output topic clusters were reviewed for a final set of 4 clusters that were selected due to their high relevance to *hikikomori* topics. Before manual annotation, we reverted the cleaned posts to their original text with punctuation and stop words to ensure complete comprehension of each post as initially posted. The top 100 tweets with the most interactions from users within the 4 relevant clusters were then selected for manual annotation.

Figure 1. Inclusion criteria and study methodology. BERT: Bidirectional Encoder Representations From Transformers.



Qualitative Content Analysis

The objective of this study was to conduct an in-depth analysis of themes associated with self-reported firsthand and secondhand experiences with *hikikomori* as expressed by Japanese-language Twitter users. For the purpose of study analysis, we relied solely on self-reported *hikikomori* experiences perceived by users and those who observed or interacted with individuals who perceived that they were experiencing *hikikomori* rather than reported verified clinical diagnoses. Hence, there may be variation in the clinical definition of *hikikomori* and self-reported *hikikomori* experiences detected in this study. Our content analysis focused on detecting themes related to firsthand or secondhand knowledge, attitudes, and experiences related to *hikikomori* syndrome or associated characteristics of severe social withdrawal. To classify the content of the collected tweets following topic modeling and topic cluster selection, 2 coders who were native Japanese speakers (the first and second authors, MAU and HB) first independently used a binary coding approach to identify tweets that were relevant to the study aims and excluded tweets that did not fall under the criteria of *hikikomori* syndrome knowledge, attitudes, or experiences self-reported by Twitter users (eg, discussions related to other health or psychological conditions, news articles, statistics or opinions about *hikikomori*, and other topics that used the *hikikomori* term but were not related to the syndrome, hereinafter referred to as *noise*). The primary focus of this study was to identify tweets that met the following conditions: (1) were posted by a Twitter account that appeared to be an individual account (eg, not an organizational, news, or botlike account); (2) self-reported firsthand knowledge of, attitudes toward, or experiences with *hikikomori* syndrome; or (3) self-reported secondhand knowledge of a friend, family member, caregiver, or other social contact that experienced *hikikomori* syndrome.

Discussion of *hikikomori* syndrome or related topics (such as "不登校" or "ニート," which translate to prolonged absence from school or work in English) in the post content, along with pronouns (such as "僕," "私," and "俺," which translate to *I* or first-person pronouns in English, or "彼," "彼女," and "あの子/子供," which translate to *him* or *her*, *that* or *my child*, or second-person pronouns in English) or other form of reference to the user themselves, signaled relevance as a firsthand or secondhand account. After applying this binary coding scheme for inclusion and exclusion, we then used a general inductive coding approach to conduct in-depth qualitative coding of all relevant tweets selected (hereinafter referred to as *signal tweets*). First, a sample of signal tweets were inductively coded by MAU and HB, and notes were taken on the general themes of posts, from which an initial code list was created focusing on specific *hikikomori* experiences, behaviors, and societal factors associated with *hikikomori* syndrome. Next, formal coding of all signal tweets was conducted using refined codes and developed subcodes. Finally, MAU and HB reviewed the final coded dataset, and the authors reconciled differences in code definitions and application with senior author TKM, also a native Japanese speaker. MAU and HB coded all posts independently and achieved high intercoder reliability for Twitter thematic classification (Cohen κ=0.95).

On the basis of the content of the collected tweets, all detected themes were classified into three major themes: (1) clinical symptoms, with anxiety (“不安障害” and “パニック障害”), social isolation (“社会的孤立” and “ぼっち”), depression (“うつ病”), self-harm (“死にたい,” “リスカ,” and “自殺”), and developmental and learning disorders (“発達障害” and “学習障害”) as subthemes; (2) social determinants, with school (“不登校”) and work (“ニート”) as subthemes; and (3) awareness, with 1 subtheme detected, education. Descriptive statistics of data characteristics and distribution of the volume of topics coded were also carried out.

Topic Interaction Analysis

To further analyze the levels of user interactivity with different topics related to *hikikomori* experiences self-reported by Japanese-speaking Twitter users, we also examined the volume of users’ interaction behavior for all signal tweets. The interactivity with tweets was determined using the number of likes, retweets, comments, and favorites for the tweets analyzed.

Ethical Considerations

This study was exempt from institutional review board approval in accordance with the Common Rule as all data were publicly available and any user-generated data did not include individually identifiable information, and the results are paraphrased and deidentified.

Results

Overview

A total of 2,057,884 tweets were collected from Twitter from February 13, 2009, to June 23, 2023 (n=2,018,822, 98.1% tweets in Japanese and n=39,062, 1.9% tweets in English), based on the method of data collection used. After the exclusion of English-language tweets and limiting our analysis to a recent 2-year period (to examine the more recent discourse concerning *hikikomori* and discussions centered on the general time frame of the COVID-19 pandemic), 18.43% (379,265/2,057,884) of the tweets in Japanese from January 2021 to January 2023 were included for full analysis. Our results are organized into a description of the output topics selected and the qualitative content analysis of specific tweets in each selected cluster.

Topic Selection and Features

The initial 10 topics selected after the first round of BERT analysis all had overlapping themes of mental health and withdrawal from society and high frequency of *hikikomori*-related terms. Frequently mentioned terms included a variation of the term *hikikomori* (“ひきこもり” or “引きこもり”); words associated with mental health conditions such as depression (“うつ病”); and other related terms associated with being socially isolated, such as not being able to go to school (“不登校”) or work (“ニート”), which provided a preliminary indication that the cluster included conversational groupings related to *hikikomori* behavior and user perceptions. Other terms identified included *hikikomori*-related services or lifestyle, such as unconventional schooling methods (“free school” [“フリースクール”]), or topics such as gaming, gaming livestreams (“ゲーム 実況”), or web-based platforms (eg, “YouTube”) that were suspected as also indicating a *hikikomori* lifestyle. In addition, the presence of more colloquial or casual terms was thought to be more associated with firsthand and secondhand accounts. Following the second round of BERTopic analysis, all *hikikomori*-related themes appeared to be categorized into 1 of the 4 topic clusters selected for the final analysis (topic 1, topic 7, topic 11, and topic 14).

Final Topics for Manual Annotation

The first topic selected as output using BERTopic (topic 1) was selected due the frequency of words such as “お悩み相談” (“consulting for advice”), “話したい” (“want to talk”), and “不登校さんとがりたい” (“seeking connection with someone unable to go to school”), which indicate that tweets in the cluster had a focus on seeking help or connections within the community of those with similar experiences. Phrases such as “必ず返信します” (“I will definitely reply”) suggest the practical uses of Twitter as a platform to encourage and facilitate user interaction. Words such as “フリースクール” (schools dedicated to children who fail to fit into conventional school systems in Japan) and “カウンセリング” (“counseling” or “therapy”) allude to discussion of the services that are available for those experiencing *hikikomori*, including “精神疾患” (“psychological disorder”) and “発達障害” (“developmental disorder”), which further suggests that there is discussion of related disorders and *hikikomori*’s associated impacts. Although there were many possible subtopics in the cluster, there was an overall emphasis on seeking help and exchange of information about the syndrome.

Our second topic selected (topic 7) was focused on mental health, containing topics such as depression (“うつ病”) and suicide (“'死にたい”), as well as other words or ideas that are closely related, such as bullying (“いじめ”) or feelings of uncertainty or mental instability (“不安”). Words in the cluster were collectively pessimistic or had negative connotations. Phrases such as “どうでもいい報告をする” (“will report something of no use”) may indicate that Twitter users in this cluster of tweets feel as if their words have little impact or may be meaningless, which is in concordance with the overall topic of depression and mental health. This cluster contained tweets related to escaping reality and searching for a place to cope, which indicates that platforms such as Twitter may serve as a conversation space for those who are experiencing *hikikomori* syndrome and other related mental health disorders.

The third topic selected (topic 11) centered on secondhand accounts of *hikikomori* experience, most of which came from parents or guardians of youths or minors experiencing “不登校

の親" ("parents of child unable to go to school or hikikomori"). Words in the cluster such as "いじめ" ("bullying") and "子育て" ("raising children") indicate caregivers' concerns about their children regarding their experiences. This cluster is also characterized by a large portion of keywords related to an unwillingness of youth experiencing *hikikomori* to go to school ("学校行きたくない"), which aligns with the social isolation factor that characterizes *hikikomori* syndrome, suggesting the very closely interlinked ideas of *hikikomori* syndrome and "不登校" ("inability to go to school"). More general terms such as "中学生" ("middle schooler") or "小学生" ("elementary schooler") that were included in the cluster suggest that education and school are main topics of discussion and indicate at what grade levels children may be first experiencing *hikikomori* syndrome.

The final topic selected (topic 14) was similar to topic 11 in that it also had a focus on caregivers of youth experiencing *hikikomori*. Many similar words, such as "不登校の親" ("parent of a child unable to go to school") and "子育て" ("raising children"), were also included in this cluster. However, topic 14 had a more specific focus on solutions to struggles, including alternatives to public school—indicated by words such as "フリースクール" (schools dedicated to children who fail to fit into conventional school systems in Japan) and "家庭教師" ("home or private tutoring"). In addition, words such as "メンタルヘルス" ("mental health") suggested more discussion and awareness associated with *hikikomori* syndrome. Overall, this cluster highlighted the caregivers' crucial role as the connection between those with *hikikomori* syndrome and the outside world through platforms such as Twitter, discussion and advocacy, and seeking of opportunities for support and services.

Content Analysis

After the initial round of BERTopic analysis, 10 topic clusters (n=133,548 tweets) were selected as relevant to the study aims and underwent an additional round of BERTopic analysis. Following the second round of running BERTopic, 4 topic clusters (n=33,287 tweets from 6403 unique users) were determined to be relevant to the study aims. From these, the top 100 tweets with the most engagement (measured using the sum of the likes, comments, and retweets) from each of the relevant 4 topics (n=400) were extracted and manually annotated for inclusion or exclusion, of which 37% (148/400) of tweets from 89 unique users were identified as relevant to *hikikomori* experiences. Of these 148 relevant tweets, 71 (48%) were identified as firsthand accounts (eg, individuals who currently had or had recently had direct experience with *hikikomori* syndrome), and 77 (52%) were identified as secondhand accounts (eg, parents or guardians of individuals with *hikikomori* syndrome who often lived in the same household). Our qualitative analysis and inductive coding approach derived 8 topics based on our 3 parent categories. All the detected topics were first classified into the 3 parent domains: clinical symptoms (58/148, 39.2%), social determinants (111/148, 75%), and awareness (33/148, 22.3%; see Table 1 for a description and example tweets of the themes and subthemes).

Posts identified within the clinical symptoms domain were characterized by discussions related to explicit or implicit descriptions or mentions of mental health conditions or symptoms related to *hikikomori* syndrome, including both firsthand accounts (52/58, 90%) and secondhand accounts (6/58, 10%). Within this parent domain, frequently discussed symptoms included anxiety (2/58, 3%), social isolation (32/58, 55%), and depression (24/58, 41%). These subthemes represent symptomology most commonly associated with *hikikomori* syndrome. However, additional subthemes within this domain included self-harm (7/58, 12%) and developmental and learning disorders (3/58, 5%) mentioned and discussed alongside *hikikomori* syndrome, suggesting that these other disorders and symptoms may be additional or emerging symptoms associated with *hikikomori*. Frequent examples of posts within the social isolation subtheme included a stated desire for community support, friends, or others with similar experiences on the platform alongside mentions of their physical and social isolation (eg, isolating within their home). For example, users sought friendships with like-minded individuals, often asking to connect with those within a specific age range (eg, "中学生" ["middle schooler"]) or someone with a particular experience (eg, "不登校" ["someone unable to go to school"]). Within the subtheme of depression, individuals often used the platform to rant or openly vent about their depressive symptoms and as a place of expression. Tweets within this subtheme were more of a snapshot of an individual's emotions rather than a recollection of an event or informational content. These tweets often included the hashtag "#うつ病" ("depression"). Self-harm had overlap with our depression subtheme but diverged in its explicit mentions of self-harm through suicide or wrist cutting. Tweets frequently included the hashtag "#死にたい" ("want to die"). Our final subtheme, developmental and learning disorders, was frequently mentioned specifically by caregivers. Disorders were cited as factors that led to the *hikikomori* lifestyle or the inability to go to school as conditions accompanying *hikikomori* syndrome or as hindrances to daily life. Other disorders that are diagnostically unrelated were also mentioned alongside *hikikomori* syndrome. Tweets within this subtheme frequently included the hashtags "＃発達障害" ("developmental disorder") and "#学習障害" ("learning disability").

Table 1. Explanation and paraphrased examples of the identified hikikomori parent domains and topic subcodes detected on Twitter generated from content analysis (N=148).

Parent domain and subtheme	Subtheme description	Example tweet (original+translation)	Tweets, n (%)
Clinical symptoms			58 (39.2)
Anxiety	Content that describes anxious tendencies or uses terms that relate to them (ie, 不安 or “anxious”)	• 不安が増す。(“Anxious thoughts are increasing.”) • 何に追われてるのかわからないが、 • お金、将来、健康 (“I don’t know what is stressing me out, but money, future, health”) • 家にじっとしているともういてもたってもいられなくなる。。(“If I stay at home, I won’t be able to sit still.”) • 読書やテレビを観ても頭に入らない。(“I can’t focus when I read or watch TV.”) • 参ってます。(“I’m exhausted.”) • #鬱 #うつ病 #適応障害 #パニック障害 #不安障害 #不安 #人間関係 #心療内科 #孤独 #ひきこもり #休職 #会社関係 (“#Depressed #Depression #Adjustment disorder #Panic disorder #Anxiety disorder #Anxiety #Human relations #Psychotherapy #Loneliness #Hikikomori #Leave of employment #Co-worker relations”)	2 (1.4)
Social isolation	Content that describes social isolation as part of the user’s lifestyle	• 休職して孤独な年末年始を目前に(“Taking a leave of absence and facing the lonely New Year holidays”) • 家のものを断捨離した (“I got rid of things at home”) • 少しスッキリした社宅の中 (“Inside the slightly empty company housing”) • 少し気分が晴れた (“I feel a little better”)	32 (21.6)
Depression	Content that displays depressive thoughts or episodes that reflect a nonprogressive and pessimistic mindset of the user	• 買いたいもの、欲しいものなんて買えないし、バイトする気力は無いし、そもそも生きたい理由もないから、何もできない。(“I can’t buy anything I want, I don’t have the energy to work part-time, and I have no reason to want to live in the first place, so I can’t do anything.”) • 生きているだけで惨めな思いをする。(“Just being alive makes me feel miserable.”) • 頑張れないし、苦しいし、生きていても迷惑かけるだけだから死にたいって思うのは「甘え」なのだろうか。(“Am I acting like a spoiled child to think that I want to die because I can’t do my best, it’s painful, and even if I live I’ll only cause trouble?”) • #ニート #ひきこもり #死にたい (“#Not in Education, Employment, or Training (NEET) #Hikikomori #Want to die”)	24 (16.2)
Self-harm	Content that includes mentions or descriptions of self-harm and suicide	• 新品のカミソリ気持ちよすぎだろ (“The brand-new razor blade feels so good ”) • 新品しか勝たん. (“New blades for the win .”) • #自傷行為 #不登校 #od (“#Self-harm #Not going to school #od”) • #不登校と繋がりたい (“#I want to connect with school truants”) • #リスカ #アムカ #レグカ (“#Wrist cutting #Arm cutting #Leg cutting”) • #病み垢 #病み垢女子 (“#Account characterized by mental sickness #Girl with account characterized by mental sickness”) • #病み垢女子さんと繋がりたい (“#Want to connect with girls with accounts characterized by mental sickness”) • #病み垢さんと繋がりたい (“#Want to connect with people with accounts characterized by mental sickness”)	7 (4.7)
Developmental and learning disorders	Content that includes the mention of other developmental and learning disorders alongside “hikikomori” syndrome	• #不登校 なのにも動じないで普通に接してくれるのはとても有難いんだけど #非同期発達 の事は、特に勉強面に関しては言い辛いから一寸困る。こちらは正直に話しても良いんだけどホントに時々態度急変する人が居るから面倒臭くて試す気にはなれない。 • “I’m very grateful that you don’t get upset and treat me normally even though I’m not going to school, but it’s a bit difficult to talk about #asynchronous development, especially when it comes to studying. I can be honest about this, but there are some people whose behavior changes suddenly after finding out, so I find it annoying and I don’t feel like risking it.”	3 (2)

Parent domain and subtheme	Subtheme description	Example tweet (original+translation)	Tweets, n (%)
Social determinants			111 (75)
School	Content that includes mentions of school and education, often through the act of missing school or unconventional alternatives to public school	• 娘がチャレンジの問題でつまずいて癇癪。学校行ってる子達と比べたら圧倒的に解いてる問題数が違うからすぐにつまずく。適室での勉強も家庭教師も拒否。今自室で『自分だけの力でやってみせる』ってヤケになって勉強しに行った。もう限界でしょうよ . どうすりゃいいの . (“My daughter stumbles over a challenging problem and has a tantrum. Compared to kids who go to school, the number of problems she solves is greatly less, so it’s easy to get stuck. She refuses to study in a proper room or have a private tutor. She just said, ‘I’ll do it on my own’ and went to study in her room. It’s probably at its limit . What should I do .”) • #不登校 #不登校の親 (“#Not going to school #Parents of children not going to school”)	103 (69.6)
Work	Content that includes mentions of work, often through the act of missing or quitting work	• 親から「ウーバーイーツでも何でもやれ」「死に物狂いでやるしかないだろう」と言われた。(“My parents told me, ‘Find a job, work for Uber Eats if you need to’ and ‘Work as if your life depends on it.’”) • 仕事するために”死に物狂い”になる必要がある状況って何だろう。(“In what situation would you need to be ‘desperate’ to do your job”) • 仕事するために生きているわけでもないし。(“I don’t live to work.”) • 親から何か言われるたび、死んだほうがマシだとしか思えない。(“Every time my parents say something to me, all I can think is that I would be better off dead.”) • #ニート #ひきこもり #死にたい (“#NEET #hikikomori #Want to die”)	8 (5.4)
Awareness			33 (22.3)
Education	Content that includes active forms of providing education about “hikikomori” syndrome to the public or active advocacy	• #不登校#ひきこもり#ニート今振り返れば。今の自分なら。そう言えるくらいに全部の経験が今に繋がる。今どこかで悩んでいるおかあさんへ。当事者さんへ。あなたは大丈夫。ひとりじゃない。あなたはあなた。他の誰かは他の誰か。みんな違っていいんだよ。 • “#Not going to school #Hikikomori #NEET Looking back now, I can say that all of my experiences have led me to where I am today. Dear mothers and other people who are worried right now. You are ok. You are not alone. You are you. Someone else is someone else. It’s okay for everyone to be different.”	3 (2)

The social determinants parent domain was mentioned in 75% (111/148) of the tweets relevant to *hikikomori* experiences. Mentions of school or being “不登校” (“not going to school”) were common (103/111, 92.8%), reflecting the younger demographic of those posting about or experiencing *hikikomori* syndrome on Twitter. Although the age of users is difficult to determine, many individuals who sought out a human connection or social interaction on the platform requested relationships within an age range (eg, middle schoolers or high schoolers). Topics such as the lack of friendship due to their isolated lifestyle or their inability to go to school were discussed. Caregivers on Twitter discussing *hikikomori* syndrome were mainly parents of youth who were also “不登校” (“not going to school”). In addition, these caregivers displayed a sense of responsibility to improve their children’s lives or ease their difficulties and pain, observed through their active participation in seeking help. As a result, there were many secondhand experiences or caregiver community users detected in these tweets (71/111, 64%). Topics discussed included alternative education opportunities (eg, “フリースクール” [schools dedicated to children who fail to fit into conventional school systems in Japan] or “家庭教師” [“home or private tutoring”]), parenting philosophies, and specific experiences and advice regarding *hikikomori* syndrome. Less common were mentions of work and *hikikomori* (8/111, 7.2%). Tweets identified within this subtheme expressed an even greater disconnect from society and personal accounts of struggling to come to terms with lack of financial independence. Overall, within this parent domain, we found that *hikikomori* syndrome is heavily intertwined with the ideas of “ニート” (“not going to work”) and “不登校” (“not going to school”) in Japanese society. Even when tweet content alluded to a *hikikomori* lifestyle, many preferred the terms “ニート” and “不登校” (“not going to work” and “not going to school”) when self-identifying over explicitly identifying themselves as having *hikikomori* syndrome. The hashtags "#ニート" and "#不登校" were observed frequently with or even synonymously to *hikikomori* ("#引きこもり" or "＃ひきこもり").

Within the awareness parent domain, individuals sought to reduce stigma regarding *hikikomori* syndrome by spreading awareness about the condition (33/148, 22.3%). Users spread awareness through Twitter primarily in 2 ways. Some tweets portrayed the syndrome positively by clearing misconceptions that previously created apprehensiveness toward *hikikomori* syndrome or by drawing attention to the benefits of the lifestyle (eg, having less disputes between family members and, consequently, having a more peaceful and connected family life in certain circumstances). Other tweets highlighted the negative attitudes toward the syndrome and aimed to reduce stigma by portraying stigmatization of *hikikomori* in a negative context (eg, explaining how a friend's negative comments were morally unacceptable). This was frequently observed through users recalling an experience in which an individual experiencing *hikikomori* syndrome or their caregivers faced shame for their condition. Tweets were not always targeted toward the public and, instead, aimed to reduce internal shame of the syndrome by addressing users with similar experiences. Tweets within the education subtheme (3/33, 9%) were characterized by users providing knowledge to the public through digital flyers, meetings, or other active forms of creating awareness, directly addressing their audience in the process. Tweets within this subtheme were only posted by caregivers and in secondhand accounts as explicit advocacy and education often requires contact with the public. Although it was uncommon, some caregivers used the platform to educate and act in the role of mediator between the isolated population and the uninformed public.

In general, those experiencing *hikikomori* and their caregivers used Twitter to either share experiences and opinions with the public through 1-way communication (personal anecdotes, emotional ranting, and advocacy) or increase social interaction and discussion through 2-way communication (seeking social support and seeking and giving advice). Through 1-way communication, those experiencing *hikikomori* disclosed important and often personal information on their lifestyle or used the platform as a means to discuss and cope with their struggles. Caregivers often shared their own experiences with family members with *hikikomori* syndrome and also worked to directly reduce stigma. Through 2-way communication, those experiencing *hikikomori* found like-minded individuals on the web to connect with. Caregivers also exchanged advice and information to better support individuals experiencing *hikikomori*. We found more 1-way communication (53/71, 75% of firsthand accounts and 54/77, 70% of secondhand accounts) than 2-way communication in the tweets analyzed. However, the audience and motive of the tweets were often unspecified.

Discussion

Principal Findings

This study collected and analyzed 2,018,822 tweets with terms related to *hikikomori* syndrome, a form of severe social withdrawal prevalent in Japan, and after conducting data filtering for more recent posts posted between January 2021 and January 2023 and topic modeling for detection of prevalent themes, we found both first- and secondhand experiences reported among Japanese-language tweets (148/2,018,822, 0.01%) from 89 unique users. Among our sample, we found that 48% (71/148) of tweets discussing their experiences with *hikikomori* syndrome were firsthand accounts of the challenges associated with their daily lives, whereas 52% (77/148) were identified as secondhand accounts mainly from caregivers. Within both first- and secondhand reports, the parent categories identified were clinical symptoms, social determinants, and awareness.

Within the 3 parent domains, we found 8 subthemes, which included users describing firsthand and secondhand experiences with *hikikomori* symptoms, including anxiety, depression, social isolation, self-harm, and developmental disorders, as well as discussion related to missing school or work, a commonly reported manifestation of *hikikomori* [1]. Twitter users in this study also shared advocacy and educational awareness related to the syndrome and sought out connections with other web-based users. Similarly to previous research, this study found a variety of topics. Common use of personal anecdotes and other detected topics such as social support, exchange of advice, and stigma are in line with and further support existing research findings, emphasizing the potential value of social listening–related *hikikomori* discourse on social media platforms where *hikikomori* communities interact [22]. Our findings provide additional novel context by focusing on first- and secondhand experiences of the syndrome to better characterize lived experiences with *hikikomori*. Previous studies have identified topics such as marketing, employment and educational opportunities, and medical and science topics related to the syndrome, which were excluded from this study [22,23].

This study provides additional context to the *hikikomori* literature and provides the first social media–based study to characterize web-based discussions from both the first- and secondhand perspectives in the Japanese language, specifically following the COVID-19 pandemic. Of the social media studies that have characterized lived experiences with *hikikomori*, some have focused on *hikikomori* in Western societies, including European countries, in which individuals who directly experience *hikikomori* were the most active users, in contrast to this study, in which secondhand posts were the most commonly detected overall (eg, caregivers or friends of those with *hikikomori* syndrome) [32]. While COVID-19 restrictions resulted in mandated social isolation to different degrees for people worldwide, there may have been more visibility of *hikikomori* symptoms by caregivers that may not have been otherwise observed before many of the public health restrictions during the pandemic. In turn, caregivers may have turned to social media to connect with others, seek advice about *hikikomori*, or spread awareness of the syndrome.

While our study found more secondhand experiences with *hikikomori* overall, within our clinical symptoms parent topic, we found an overwhelming majority of firsthand reporting of *hikikomori* (52/58, 90%). These findings may indicate that, when an individual is struggling with *hikikomori*, they are more likely to self-report their struggles with the syndrome and its associated symptoms on the web. Concerningly, as detected in this study, individuals may take to web-based platforms to report more severe symptoms and mental health struggles, such as suicidal ideation [33]. However, social media has increasingly represented a valuable way to detect depression and suicidal ideation and can provide rapid data for policy-level decisions, especially given the rise of mental health conditions during and after the pandemic [33]. As such, this finding may also represent shifting ideas and definitions regarding *hikikomori*, especially after the COVID-19 pandemic, a period characterized by social isolation, remote education, and increasing mental health concerns [26]. Furthermore, firsthand users detected in this study may take to web-based platforms as a way to discuss their own experiences and self-report *hikikomori*-related symptoms but appear to engage in less education, advocacy, or awareness raising compared to those with secondhand experiences based on our observations.

Platforms such as Twitter may be an advantageous and comfortable way for those with *hikikomori* syndrome to interact with others while in a lifestyle that lacks social interaction, especially during the mandated social distancing measures that aligned with the study period. Simultaneously, the results provide updated insights into the lives of those with *hikikomori* syndrome and others who support them, as well as into direct advocacy by those who are affected. The findings indicate that access to information on this syndrome through social media platforms can increase access to other individuals and broader online communities experiencing the syndrome, possibly facilitated by semianonymous and web-based conversations, which may otherwise be inhibited by physical barriers due to the isolating nature of *hikikomori*. By leveraging platforms such as Twitter, greater interactions within the community can potentially reduce internal stigma and shame, whereas greater interactions with the public can reduce external stigma toward the syndrome as a whole [34]. In addition, open discussion about experiences and resources available, both within the community and through interactions with the public, could lead to greater accessibility to those resources and more awareness and acceptance.

Limitations

This study has certain limitations. First, it only evaluated data from publicly available content on Twitter and limited the analysis to Japanese-language tweets and tweets that were in both Japanese and English, which is not representative of general social media *hikikomori*-related discourse, including that occurring on other platforms such as Facebook, Reddit, TikTok, and Instagram. Hence, this study may fail to capture posts from individuals who have additional privacy settings or engage in conversations via private or direct messages due to the stigmatization of mental health issues. Furthermore, this study only analyzed tweets posted by users and not comments or other interactions between Twitter users in response to a tweet, which could have yielded additional discussion related to *hikikomori*. In addition, our period of data collection and analysis coincided with the COVID-19 pandemic, which significantly impacted individuals' way of life and required social isolation. Hence, the volume and nature of *hikikomori* discussions on the web may have also been driven by the COVID-19 restrictions during the study period. This study likely underreported the total amount of *hikikomori*-related content within the dataset as we only coded tweets that were the most highly engaged with within selected topic clusters. This approach streamlines manual coding and allows for more efficient detection of relevant conversations but may exclude tweets that have low engagement. Furthermore, this study may have oversampled what is considered clinical *hikikomori* discussions due to variation in the colloquial meaning of *hikikomori*, the potential expansion of *hikikomori* to refer to less severe symptoms, and the reliance on self-reported accounts from web-based users and their perception of their or someone else's experience with *hikikomori*. Hence, it is crucial to acknowledge that this study's findings are specific to a subset of *hikikomori* accounts and content—those who consider themselves as experiencing *hikikomori* first- or secondhand. As such, it may not capture the diversity of *hikikomori* behaviors and attitudes and lacks generalizability to the overall population of those who experience it. In addition, although Twitter offers users a significant degree of anonymity through features such as customizable usernames and the option to create throwaway accounts for sensitive discussions, self-reported measures remain susceptible to recall bias and social desirability bias, which could lead to over- or underreporting of behaviors. Thus, tweets coded as *hikikomori* may in some instances be less representative of the clinical condition and more associated with the casual use of the term to describe non-*hikikomori* symptoms or may more broadly reflect the collective understanding of *hikikomori* as a concept in Japanese culture by those who do not actually have the condition from a clinical context. Future studies should explore multi-platform analysis for *hikikomori*-related discussions, combine social media data with other data sources (eg, focus groups and surveys), and use other data science approaches (eg, supervised machine learning and large language models) to better characterize *hikikomori* changes over a longer period both before and after the pandemic.

Conclusions

Understanding culturally specific self-reported symptomology through social media studies may offer insights into the convergence and divergence of cross-national *hikikomori* experiences. In addition, commonalities in experiences and rhetoric provide insights into the Japanese public's view of *hikikomori* and its prevalence in Japanese society. The findings of this study also have potential clinical implications. As *hikikomori* is increasingly recognized as a global concern, clinicians may look to web-based platforms and discussion forums to understand modern manifestations of the syndrome and the collective understanding of the concept in different cultural contexts (both in Japan and other cultures experiencing *hikikomori*), especially as a standardized definition and criteria are evolving [4]. This study may also provide additional evidence that online support groups may be well received among those with *hikikomori* and could provide clues on how to help relieve adverse experiences associated with social withdrawal as well as provide social support for those caring for someone with *hikikomori* [32]. These results may also justify the need to increase telehealth consultations in the post–COVID-19 era regarding *hikikomori* screening and possible diagnosis. However, increasing participation in digital care and support opportunities for patients with *hikikomori* syndrome should be afforded careful consideration to ensure that that same technology does not facilitate further social isolation if not used correctly or in a culturally appropriate manner [35,36].

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

This manuscript has been seen by all authors, who have approved of its content.

Conflicts of Interest

T McMann, ZL, and T Mackey are employees of the start-up company S-3 Research LLC. S-3 Research is a start-up funded with previous and current funding from the National Institutes of Health National Institute on Drug Abuse through a Small Business Innovation Research program for social media research and technology commercialization. T Mackey also holds equity in the start-up company S-3 Research LLC and is the Editor-in-Chief of *JMIR Infodemiology*.

Multimedia Appendix 1
Study keyword selection and rationale for use of the keywords.
[DOCX File , 15 KB - infodemiology_v5i1e65610_app1.docx]

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Abbreviations

API: application programming interface
BERT: Bidirectional Encoder Representations From Transformers
JMHLW: Japanese Ministry of Health, Labor, and Welfare

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Original Paper

Exploring the Use of Social Media for Medical Problem Solving by Analyzing the Subreddit r/medical_advice: Quantitative Analysis

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Abstract

Background: The advent of the internet has transformed the landscape of health information acquisition and sharing. Reddit has become a hub for such activities, such as the subreddit r/medical_advice, affecting patients' knowledge and decision-making. While the popularity of these platforms is recognized, research into the interactions and content within these communities remains sparse. Understanding the dynamics of these platforms is crucial for improving online health information quality.

Objective: This study aims to quantitatively analyze the subreddit r/medical_advice to characterize the medical questions posed and the demographics of individuals providing answers. Insights into the subreddit's user engagement, information-seeking behavior, and the quality of shared information will contribute to the existing body of literature on health information seeking in the digital era.

Methods: A cross-sectional study was conducted, examining all posts and top comments from r/medical_advice since its creation on October 1, 2011. Data were collected on March 2, 2023, from pushhift.io, and the analysis included post and author flairs, scores, and engagement metrics. Statistical analyses were performed using RStudio and GraphPad Prism 9.0.

Results: From October 2011 to March 2023, a total of 201,680 posts and 721,882 comments were analyzed. After excluding autogenerated posts and comments, 194,678 posts and 528,383 comments remained for analysis. A total of 41% (77,529/194,678) of posts had no user flairs, while only 0.1% (108/194,678) of posts were made by verified medical professionals. The average engagement per post was a score of 2 (SD 7.03) and 3.32 (SD 4.89) comments. In period 2, urgent questions and those with level-10 pain reported higher engagement, with significant differences in scores and comments based on flair type (*P*<.001). Period 3 saw the highest engagement in posts related to pregnancy and the lowest in posts about bones, joints, or ligaments. Media inclusion significantly increased engagement, with video posts receiving the highest interaction (*P*<.001).

Conclusions: The study reveals a significant engagement with r/medical_advice, with user interactions influenced by the type of query and the inclusion of visual media. High engagement with posts about pregnancy and urgent medical queries reflects a focused public interest and the subreddit's role as a preliminary health information resource. The predominance of nonverified medical professionals providing information highlights a shift toward community-based knowledge exchange, though it raises questions about the reliability of the information. Future research should explore cross-platform behaviors and the impact of misinformation on public health. Effective moderation and the involvement of verified medical professionals are recommended to enhance the subreddit's role as a reliable health information resource.

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KEYWORDS

online health information; medical advice; Reddit; r/medical_advice; health information–seeking behavior; user-generated content; subreddits; patient education; virtual environments; information quality; social media; medical problem; quantitative analyses; cross-sectional study; user interactions; online health; decision-making; social news; health information

Introduction

The internet has significantly impacted how individuals access and share health-related information. Online health information–seeking behavior has been a growing area of interest in the medical literature, given its potential impact on patient knowledge, decision-making, and outcomes [1]. As a result, the quality and accuracy of health information shared on the internet have been the subject of numerous studies, which have identified both benefits and risks for users [2,3].

Reddit, a social news forum and discussion website, has emerged as a popular platform for health information sharing [4]. Among its topic-specific communities called “subreddits,” r/medical_advice has become a prominent online community where users seek and provide advice related to medical conditions, symptoms, and treatments [5]. r/medical_advice stands out not only for its popularity but also for its extensive user engagement compared with other similar online communities. Despite its popularity, there has been limited research examining the content and user interactions within this online community [6]. As the demand for patient education in internet-based environments continues to grow, it is essential to understand the topics discussed on this subreddit to assess the quality of the information provided, as well as the challenges associated with providing accurate and reliable health information in online spaces.

We define information-seeking behavior as the deliberate pursuit of health-related knowledge by individuals, which differs from information sharing (actively providing knowledge to others) and more general health communication (exchanging health-related messages with various purposes). By focusing on r/medical_advice, we specifically examine users seeking preliminary guidance or reassurance before consulting health care professionals. This study addresses three main research questions: (1) What types of medical questions are asked on r/medical_advice? (2) How do different post flairs, pain levels, and inclusion of media relate to user engagement? and (3) How do verified and nonverified medical professionals contribute to the information ecology of r/medical_advice? The findings of this study will contribute to the growing body of literature on health information–seeking behavior in the digital age and help inform potential strategies for improving the quality and utility of online health information.

Methods

Study Design and Data Collection

This cross-sectional study systematically characterized all posts and their top comments from the r/medical_advice subreddit since its inception on October 1, 2011. Data for this investigation were collected on March 2, 2023, using a public resource created by Jason Baumgartner of pushshift.io [7]. Metadata fields collected for posts included subreddit, post ID, title, self-text, post flair, comment score, post score, author, author flair, URL, image, time stamp, and date (Table 1). Flairs are a feature that allows users to add a label or tag to their posts or usernames. Post flairs categorize post content, while user flairs (also referred to as author flairs) can indicate qualifications or expertise in a specific subject. For comments, the collected metadata fields included subreddit, comment content, score, author, author flair, post ID, URL, image, time stamp, and date. Before analysis, we applied data cleaning steps to remove non–user-generated content and posts that did not represent genuine user inquiries such as automated moderation posts, duplicate entries, or advertisements. We used similar criteria for comments to ensure that both posts and comments represented organic user activity.

Table 1. Definition of metadata fields. This table provides definitions for the common metadata fields encountered in the pushshift.io database.

Metadata field	Definition
Subreddit	The name of the specific Reddit community where the post is made
Post ID	A unique identifier assigned to each post in a subreddit
Title	The heading or title of the Reddit post
Self-text	The main body text of the Reddit post
Post flair	A category or tag assigned to a post to indicate its content or topic
Comment score	A numerical value representing the net upvotes and downvotes a comment receives
Post score	A numerical value representing the net upvotes and downvotes a post receives
Author	The username of the individual who created the post
Author flair	A tag or label next to a user's name that indicates their role, expertise, or affiliation
URL	A direct link to the specific Reddit post
Image	Visual content (photo or graphic) attached to a Reddit post
Time stamp	The exact date and time when the post or comment was made
Date	The date when the post was made, formatted as year-month-day

Subreddit Time Periods and Flair Analysis

The analysis of posts was divided into 3 distinct time periods: October 1, 2011, to March 5, 2019 (period 1); March 6, 2019, to July 31, 2022 (period 2); and August 1, 2022, to March 2, 2023 (period 3). This categorization was necessary due to the varying availability of flairs during these periods. Period 1 had no available flairs, whereas period 2 offered flair options based on pain level or question type. In period 3, flairs were organized using a systems-based approach.

The analysis of author flairs was conducted between May 7, 2019, and March 2, 2023, which corresponds to the implementation of author flairs. Throughout the entire time period, user flair options remained consistent. Flairs related to each post, the account that submitted the post, and comments were analyzed.

Definition of Scores

Scores were defined as the net result of upvotes subtracted by downvotes, with a lower limit set at 0. Upvotes and downvotes on Reddit signify agreement, relevance, or perceived quality of a post or comment. A higher score typically indicates greater community acceptance.

Statistical Analysis and Data Visualization

RStudio (Posit) was used for all statistical analyses, while data visualization was conducted using GraphPad Prism 9.0 (Insight Partners).

Data Analysis

The data analysis process involved the calculation of averages and SDs for posts across the 3 time periods. To comprehensively examine the engagement of the subreddit community with the posts, the study considered several factors, including post flair; the presence of images, galleries (multiple images), or videos; and the combined engagement, which was defined as the sum of scores and comments.

A detailed examination of post flair engagement was conducted, comparing engagement across flairs in periods 2 and 3. The Kruskal-Wallis test was initially applied to assess differences in combined engagement, followed by the Dunn test for pairwise comparisons. During period 2, the analysis was segregated into question type (general, urgent, or other) and pain level (no pain, 1-3, 4-6, 7-9, and 10). Since each post could only be assigned a single flair, posts were exclusively categorized based on either question type or pain level.

In period 3, a similar statistical approach was used to compare combined engagement by the type of medical problem. The analysis in this period focused on the systems-based categorization of post flairs, enabling a more targeted investigation of engagement patterns.

Ethical Considerations

Project data were collected from a publicly accessible online forum. No direct interaction with users occurred, and no personally identifiable information was included in the dataset. In accordance with ethical guidelines for internet research, efforts were made to ensure privacy and confidentiality by excluding usernames and any personally identifiable content from the analysis. The use of Reddit data complies with the platform's terms of service, which allow the analysis of public content for research purposes. Institutional review board approval was not required, as this study exclusively analyzed publicly available, anonymized data and did not involve human participant interventions.

Results

Demographics and Flair Distribution

A total of 201,680 posts (Figure 1A) and 721,882 comments (Figure 1B) were collected from October 2011, the inception of the subreddit, through March 2023. After data cleaning to remove nonmedical inquiries and responses, 194,678 posts and 528,383 comments remained for analysis. The top flairs of periods 2 and 3 are shown in Tables 2 and 3, respectively.

Figure 1. Quarterly trends in posts and comments in r/medical_advice. This bar graph displays the (A) number of posts and (B) comments in the r/medical_advice subreddit over time, with each bar representing a quarter of a year on the x-axis. Qtr: quarter.

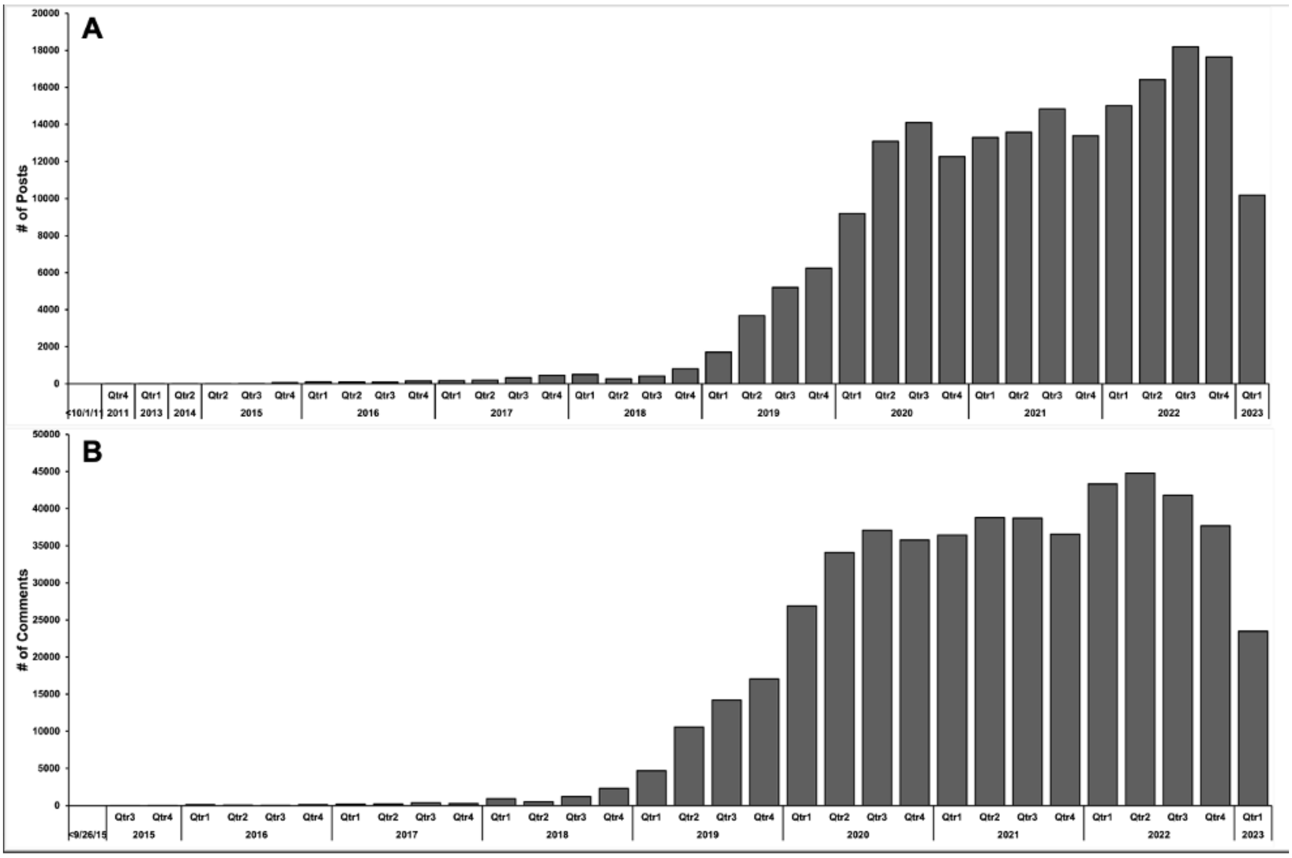


Table 2. Distribution of post flairs in period 2. The table shows the frequency and percentage of post flairs categorized by question type and pain level, illustrating the prevalence of various types of medical questions and reported pain levels in the subreddit during this period.

Post flair type	Post flairs (n=136,486), n (%)
Question type	
General question	50,671 (37.4)
Urgent question	17,739 (13.1)
Other question	6612 (4.9)
Pain level	
No pain	23,844 (17.6)
Levels 1-3	18,337 (13.5)
Levels 4-6	12,252 (9)
Levels 7-9	6055 (4.5)
Level 10	976 (0.7)

Table 3. Distribution of post flairs in period 3. This table presents the frequency and percentage of post flairs across different medical topics during period 3, highlighting the most discussed health issues in the subreddit during this period.

Post flair	Values (n=27,661), n (%)
Skin issues or rashes or freckles or moles	6505 (23.5)
Mouth or gums or throat or cheeks	2648 (9.6)
Genitalia	2486 (9)
Injury	2447 (8.8)
Bones or joints or ligaments	2198 (7.9)
Digestion or stomach or bowels	2179 (7.9)
Illness	2033 (7.3)
Wound care	2015 (7.3)
Medication	1758 (6.4)
Cardiac	1230 (4.4)
Eyes	903 (3.3)
Mental health	741 (2.7)
Parasite concern	264 (1)
Pregnancy	254 (0.9)

User Flair Analysis

Across all time periods, 41% (77,529/194,678) of posts were made by users without user flairs, 42% (81,607/194,678) of posts were made by users who were not verified medical professionals, 18% (35,434/194,678) of posts were made by users who were not verified, and 0.1% (108/194,678) of posts were made by verified medical professionals. The verification process on the subreddit requires the user to upload a picture of their employment badge next to their handwritten username. In other words, 99.9% (194,886/194,691) of the posts were made by Redditors who were not verified medical professionals.

With respect to comments across all three periods, 50% (232,274/528,383) of the comments were made by users tagged "Not a Verified Medical Professional," 39% (183,470/528,383) of the comments were made by users tagged "Users Not Verified," and 12% (55,296/528,383) of the comments were made by medical professionals. Table 4 illustrates the breakdown of medical professionals by profession.

Table 4. Breakdown of medical professionals in comments.

Medical profession	Values (n=55,296), n (%)
Nurses[a]	29,838 (54)
Physicians	11,204 (20.3)
Students[b]	6615 (12)
Emergency medical services personnel[c]	1496 (2.7)
Allied health professionals[d]	962 (1.7)
Medical assistants	468 (0.8)
Midlevel providers[e]	215 (0.4)
Nursing support staff[f]	89 (0.2)
Other (moderators, etc)	4409 (8)

[a]Nurses encompass registered nurses, licensed practical nurses, and licensed vocational nurses.

[b]Students involve medical, nursing, and allied health students.

[c]Emergency medical services personnel consist of paramedics and emergency medical technicians.

[d]Allied health professionals include roles such as respiratory therapists, occupational therapists, physical therapists, and radiologic technologists.

[e]Midlevel providers include nurse practitioners and physician assistants.

[f]Nursing support staff includes certified nursing assistants.

Engagement Analysis

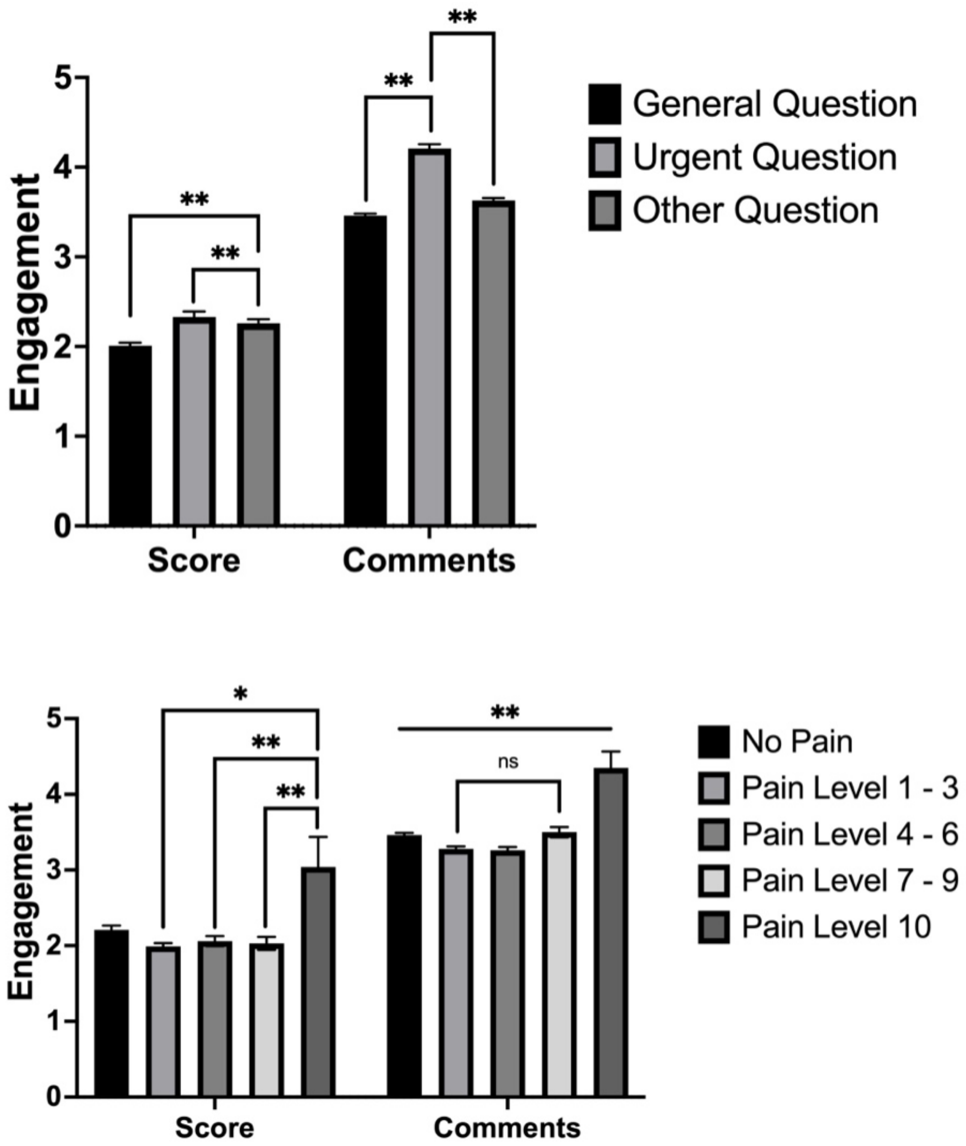
Across all posts and time periods on the subreddit, on average, each post received a score of 2 (SD 7.03; range 0-687) and 3.32 (SD 4.89; range: 0-338) comments. To account for the total engagement level of the subreddit over time, the following averages were calculated for each period: (1) score of 1.38 (SD 0.98) and 2.17 (SD 2.87) comments in period 1; (2) score of 2.14 (SD 7.71) and 3.56 (SD 5.05) comments in period 2; and (3) score of 1.48 (SD 3.83) and 2.50 (SD 4.30) comments in period 3.

In period 3, posts were divided into system-based flairs. A total of 11,772 posts were removed from the analysis due to the lack of problem-based flairs, leaving 27,661 posts for flair analysis. Engagement, broken down by flair for period 3 is highlighted, is given in Table 5. Posts related to pregnancy had the highest engagement in period 3, while those about bones, joints, or ligaments had the lowest engagement (Figure 2). This pattern was reflected when examining both scores and comments.

Table 5. Engagement by post flair in period 3. This table presents the mean (SD) values of combined engagement (score and comments) for each post flair category during period 3, highlighting the varying levels of engagement across different medical topics within the r/medical_advice subreddit.

Post flair	Combined engagement, mean (SD)	Score, mean (SD)	Comments, mean (SD)
Pregnancy	6.16 (9.18)	1.93 (4.34)	4.23 (5.9)
Wound care	4.60 (9.12)	1.74 (5.53)	2.86 (4.59)
Injury	4.59 (9.97)	1.88 (5.86)	2.71 (5.1)
Parasite concern	4.36 (6.31)	1.51 (2.93)	2.85 (4.23)
Skin issues, rashes, freckles, or moles	4.17 (8.93)	1.60 (4.89)	2.57 (4.58)
Genitalia	4.05 (6.89)	1.42 (3.18)	2.63 (4.32)
Cardiac	3.86 (6.65)	1.34 (2.03)	2.53 (5.01)
Mouth, gums, throat, or cheeks	3.86 (8.13)	1.47 (3.98)	2.40 (4.62)
Illness	3.80 (6.67)	1.39 (2.89)	2.41 (4.46)
Eyes	3.76 (7.41)	1.48 (3.62)	2.28 (4.28)
Mental health	3.65 (5.25)	1.35 (2.66)	2.30 (3.33)
Medication	3.58 (5.09)	1.28 (2.71)	2.30 (3.06)
Digestion, stomach, or bowels	3.45 (4.73)	1.24 (1.97)	2.21 (3.34)
Bones, joints, or ligaments	3.13 (4.34)	1.25 (1.90)	1.88 (2.85)

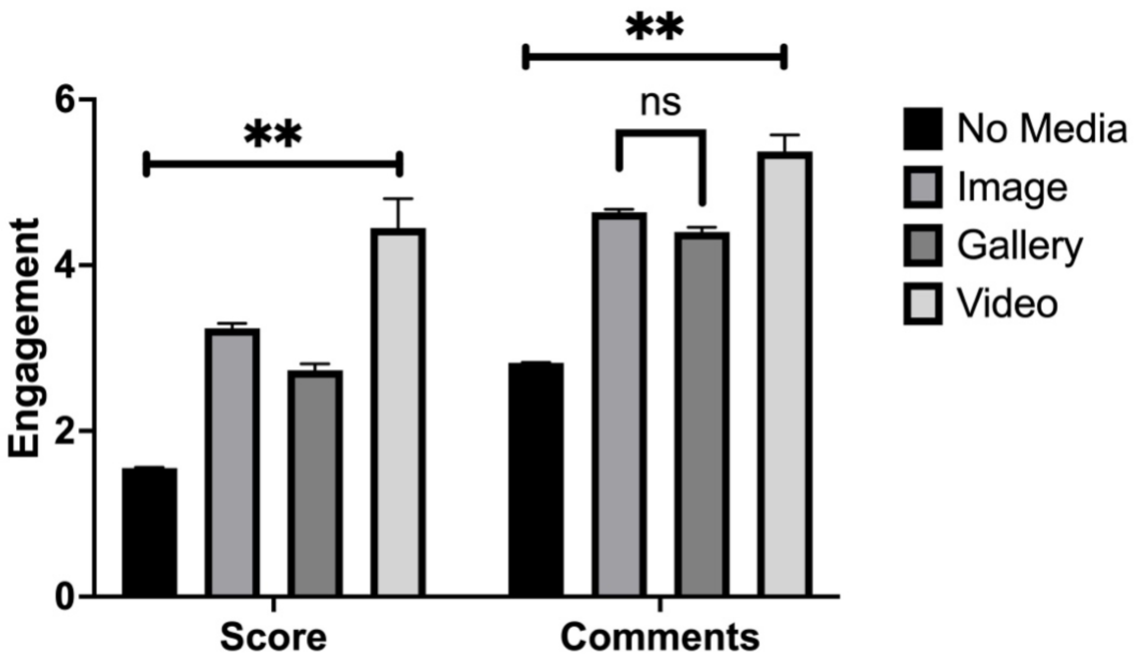
Figure 2. Engagement analysis by question type and pain level in period 2. This figure presents two separate bar graphs, illustrating the engagement patterns in r/medical_advice during period 2. The top graph displays the engagement by question type, including general question, urgent question, and other question, while the bottom graph shows the engagement by pain level categories (no pain, levels 1-3, levels 4-6, levels 7-9, and level 10). Error bars represent the SEM. Asterisks indicate the level of statistical significance (**P*<.05 and ***P*<.01), with all comparisons in the bottom graph being significant except for the one marked as nonsignificant. These graphs highlight the differences in engagement across various question types and pain levels, shedding light on the patterns of user interaction in the subreddit during period 2. ns: nonsignificant.



Engagement by Media Inclusion

A total of 28% (56,533/201,904) of posts contained media in the form of images or videos. Of these, 20% (39,776/198,830) included a single image, 8% (15,149/189,363) included multiple images, 0.8% (1608) included a video, and 72% (145,147/201,000) did not include any media. Posts that included a single image received, on average, a score of 3.24 (SD 12.03) and 4.64 (SD 6.91) comments. Posts with multiple images received, on average, a score of 2.73 (SD 9.18) and 4.40 (SD 6.80) comments. Posts with a video received, on average, a score of 4.45 (SD 14.10) and 5.37 (SD 7.98) comments (Figure 3).

Figure 3. Engagement by inclusion of media. This bar graph illustrates the engagement of posts based on the type of media the posts include in r/medical_advice during all periods. Gallery means multiple images are included as part of the post. Error bars represent the SEM. Asterisks indicate the level of statistical significance (**P*<.05 and ***P*<.01). ns: nonsignificant.



Posts with any media received, on average, a score of 3.14 (SD 11.41) and 4.60 (SD 6.92) comments, compared with a score 1.55 (SD 4.15) and 2.82 (SD 3.70) comments for posts without any media. Compared with posts without media, those with media received higher engagement (Dunn test; scores *P*<.001, comments *P*<.001). There was a significant difference between engagement of videos, multiple images, and a single image (Dunn test; scores *P*<.001; comments *P*<.001). Posts with videos received the highest engagement, followed by posts with images, and posts with no media received the least. Furthermore, posts with multiple images received lower scores (*P*<.001) but a greater number of comments (*P*<.001) compared with posts with a single image.

Discussion

Principal Findings

Our study provides an in-depth examination of user dynamics within the subreddit r/medical_advice, illuminating the intricacies of online health information–seeking behaviors. Our findings align with established medical literature on online medical information seeking. Online health forums have been shown to frequently serve as primary sources for addressing nonurgent and less severe medical concerns [8]. The high volume of posts on noncritical health issues suggests a common use of these platforms. It is reasonable to think that users are seeking preliminary advice, or perhaps just reassurance, before consulting a health care professional due to the ease of access to online medical information. Of note, the high level of engagement with pregnancy-related posts is a trend mirroring other online health communities [9], highlighting a consistent public interest in reproductive health.

In addition, our study explored the engagement dynamics of posts containing visual media, an area of study that is lacking in current medical literature. Our results show that posts featuring images or videos, especially concerning dermatological issues such as skin rashes or moles, have attracted higher levels of engagement. This observation not only underscores the effectiveness of visual aids in communicating complex medical information but also hints at a growing user preference for multimedia content [10]. With the rise of telemedicine and digital health communication in the post–COVID-19 era, the importance of visual aids in enhancing both diagnosis and patient understanding cannot be overstated.

Another intriguing aspect of our study is the significant contribution of nonverified medical professionals in providing advice. Our results show that r/medical_advice relies heavily on contributions from laypersons. This may be due to the lack of a robust verification process on the platform as it relies on the user to self-identify. This trend reflects a broader shift in the digital health information landscape, where community-based knowledge exchange is becoming increasingly predominant over traditional expert-driven models. While this democratization of health information has its advantages, it also inevitably raises concerns about the accuracy and reliability of the advice shared—challenges that have been extensively documented [11].

A key limitation of this study is that 41% of posts lacked user flairs, which leaves a significant portion of users' backgrounds unclear. We acknowledge this as a potential source of bias and recommend future investigations using natural language processing or other linguistic analysis methods to characterize these flairless users, which could enhance our understanding of their information-seeking patterns. In addition, by focusing solely on a single subreddit, we acknowledge that our findings may not fully represent online health-seeking behaviors across various platforms and communities. The unique characteristics of r/medical_advice—including its user demographics, content moderation practices, and engagement patterns—may not perfectly mirror those of other online health forums. Furthermore, the study's reliance on user-generated categorizations for post flairs and the self-identification of medical professionals introduces potential biases and inaccuracies, which could affect our interpretation of the data [12].

In terms of future directions, numerous opportunities for further research present themselves. Comparative studies across various social media platforms could examine unique trends and user behaviors, offering a more comprehensive picture of online health-seeking patterns. Further investigation into the truthfulness and impact of advice provided by online users remains a critical area of exploration [13]. In addition, understanding the motivations behind patients turning to social media for medical advice, and the consequences of acting on potentially incorrect information, is important to assess these platforms' impact on public health and health care costs.

Conclusion

Our investigation into r/medical_advice uncovers a complex and evolving landscape where online platforms serve as significant avenues for medical inquiry and information exchange. This study highlights the role of both professional and nonprofessional users in shaping these interactions and emphasizes the value they bring. While these platforms may offer invaluable opportunities for information sharing and support, the variable quality and reliability of the advice provided require careful consideration from the professional medical community. There is a clear need for increased participation from verified medical professionals and the implementation of effective moderation policies to ensure that online health forums function as reliable and supportive communities for individuals seeking medical guidance. Such measures are vital to mitigate the risks of misinformation and foster a safer, more informed online health ecosystem.

Conflicts of Interest

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Original Paper

Appropriateness of Web-Based Resources for Home Blood Pressure Measurement and Their Alignment With Guideline Recommendations, Readability, and End User Involvement: Environmental Scan of Web-Based Resources

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Abstract

Background: High blood pressure (≥140/90 mm Hg) is the most prominent mortality risk factor worldwide. Home blood pressure measurement (HBPM) is recommended for blood pressure (BP) management. HBPM is most effective to improve BP management when delivered with patient education. It is unknown whether web-based resources are appropriate for patient education for HBPM. Patient education should provide accurate, evidence-based information, communicate at an eighth grade reading level, and involve end users in development to meet the needs of adults of all health literacy levels. Using these criteria, this study aimed to determine the appropriateness of web-based HBPM resources.

Objective: This study aimed to determine whether web-based resources are appropriate for HBPM education based on three research questions: (1) Do web-based resources provide evidence-based information that aligns with guideline recommendations? (2) Do they communicate at an appropriate reading level? (3) Do they involve end users in their development?

Methods: An environmental scan of web-based resources for HBPM was conducted on Google (October 2022) using search terms developed with consumers (n=6). Resources were included if they were identified on the first page of the search findings, not paywalled, and in English. Resource appropriateness was appraised based on three criteria: (1) alignment of resource content to 23 recommendations for HBPM from 6 international guidelines, (2) being at an appropriate grade reading level as determined by a health literacy assessment software, and (3) having evidence of end user involvement in resource development.

Results: None of the identified resources (n=24) aligned with all 23 of the guideline recommendations. All resources aligned with the recommendation to measure BP when seated, while few aligned with the recommendation to use a validated BP device (n=9, 38%). All resources exceeded the recommended eighth grade reading level (mean 11.8, range 8.8-17.0) and none reported evidence of patient end user involvement in development.

Conclusions: None of the web-based resources met the criteria for appropriate education to support adults to measure BP at home. Resources should be developed with end users using health literacy tools and multimodal communication methods to ensure they are appropriate to meet the needs of patients.

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KEYWORDS

readability; online resources; blood pressure guidelines; end user; home blood pressure measurement; patient education; educational resource; self-education; hypertension

Introduction

High blood pressure (BP; hypertension: BP≥140/90 mm Hg) is the leading risk factor for death worldwide [1,2]. High BP can be controlled (<140/90 mm Hg) via medication and lifestyle changes to reduce the risk of heart attack and stroke [3]. Home BP measurement (HBPM) is widely recommended to inform hypertension diagnosis and to monitor the control and ongoing management of BP [4-7]. HBPM provides accurate, standardized BP readings, which have greater prognostic value for cardiovascular disease when performed according to guideline recommendations [8]. Adults who measure BP at home are more engaged in BP management and achieve greater BP control [9]. Further, several studies, including a recent meta-analysis, highlight that HBPM is only effective for improving BP management when accompanied by appropriate patient education on how to measure HBPM accurately and act on BP readings [7,10,11]. However, there is a lack of guidance and standardized resources to provide effective education for HBPM in clinical settings [11,12].

In the absence of effective in-clinic education and with the increased use of telehealth, web-based resources are commonly used by adults who seek health-related information for self-education [13]. In addition, recent work in Australia has shown that >35% of adults would prefer to access information about high BP on the web [14]. With this evolution of health care and patient education delivery, government bodies have emphasized the need for web-based resources to provide health information that is evidence-based and understandable [15]. More specifically, several systematic reviews on eHealth, mobile health, and other digital strategies to improve BP management also suggest a growing need to ensure that appropriate education is available on the web to support adults to undertake HBPM [16-18].

Web-based educational resources that are appropriate to support adults to perform HBPM should deliver evidence-based information in a manner that meets the health literacy and learning needs of most adults. To do this, information should be presented at an eighth grade reading level, with the use of visual aids such as graphics to support understandability [19,20]. The use of co-design methods involving target end users during resource development is an effective method to ensure that resources meet the needs of end users for effective patient education [21-24]. However, previous research has shown that web-based educational resources for cardiovascular disease risk management do not provide appropriate information or meet the usability or readability needs of adults [18,25-29], and co-design involving end users (such as community members and medical professionals) is an underused method during resource development [24]. Due to the importance of patient education for HBPM to achieve improved BP control and patient self-efficacy in BP management, patient education resources for HBPM should be appropriate for use by adults who self-monitor BP.

The aim of this study was to determine whether web-based resources are appropriate for HBPM patient education based on three research questions: (1) Do web-based resources provide evidence-based information that aligns with guideline recommendations? (2) Do they communicate at an appropriate reading level? (3) Do they involve end users in their development?

Methods

Study Design

An environmental scan of web-based resources on HBPM was conducted through a Google search designed to emulate the approach taken by adults with lived experience of HBPM when seeking web-based material about HBPM [27]. The resources were characterized according to basic identifying features such as publishing organization and year. Resources were assessed for alignment with 23 recommendations common across 6 international guidelines that encompass HBPM activities including acquiring the BP measurement device, scheduling and preparing for HBPM, selecting and fitting the cuff, BP measurement conditions, and recording and reporting BP readings (Textbox 1 and Multimedia Appendix 1) [6,30-34]. The grade reading level of the content of the resources was determined using the health literacy assessment software Sydney Health Literacy Lab Editor (SHeLL Editor) [19,35,36]. The recommended reading level for maximum comprehension for adults is eighth grade or below [19]. Involvement of community member and/or medical professional end users in resource development was assessed according to whether this was reported within each resource. Data extraction and resource appraisal were undertaken by 2 independent researchers (EC and SC) using a coding framework hosted on the secure web-based platform REDCap (Research Electronic Data Capture; Vanderbilt University) [37].

Textbox 1. Twenty-three key guideline recommendations for home blood pressure measurement.

Acquiring the blood pressure (BP) measurement device:

- Use a validated BP measurement device for home BP measurement (HBPM).
- Finger cuff BP measurement devices should not be used for HBPM.

Scheduling HBPM:

- On a day that HBPM is being conducted, BP should be measured in the morning and the evening.

Preparing for HBPM:

- Do not measure BP if uncomfortable, stressed, or in pain.
- Measure BP before medication.
- Measure BP before eating or 30 minutes or 2 hours after eating.
- Measure BP after emptying the bladder.
- Measure BP before exercise or 30 minutes after exercise.
- Measure BP before consuming caffeine or after 30 minutes or 1 hour of consuming caffeine.
- Measure BP before smoking or 30 minutes or 1 hour after smoking.
- Have 5 minutes, or at least 5 minutes, of seated rest before measuring BP.

Selecting and fitting the cuff:

- Use an appropriately sized arm cuff for HBPM.
- The arm cuff should fit the arm within the accepted range indicated on the cuff.
- Fit the upper arm BP cuff to a bare arm.

Measurement conditions:

- Measure BP in a room at a comfortable temperature.
- Measure BP with the arm fitted with the cuff supported or supported at the heart level.
- Measure BP in a seated position.
- Measure BP with both feet flat on the floor.
- Measure BP with legs uncrossed.
- Measure BP with back supported.
- Take 2 readings 1 minute apart at each HBPM sitting.

Recording and reporting BP:

- Average the BP readings taken over a 7-day period, discarding the first day.
- Take a copy of home BP readings to a doctor.

Search Strategy

The search engine Google Australia was used to identify web-based resources addressing HBPM. Seven search terms were developed with trained research consumer advisors who have lived experience of BP management and using Google Trends (Multimedia Appendix 2). Consumer advisors (n=6) identified the search engine and the top 5 search terms they would use to find information about HBPM on the web. Google Trends was used to identify the search queries related to the term "home blood pressure measurement," which had the highest probability of use worldwide on Google from January 1, 2012, to October 7, 2022. Search terms suggested by consumer advisors, which also had high probability of use on Google according to Google Trends and were relevant to HBPM were used. Search terms included the following: "How to take your blood pressure," "How to check blood pressure at home," "How to take blood pressure at home," "Home blood pressure monitoring," "How to measure blood pressure at home," "How to monitor blood pressure at home," and "Home blood pressure measurement."

Data Extraction From Web-Based Resources

Data extraction was undertaken independently by 2 investigators (EC and SC) on October 17, 2022 (duplicate search). To avoid potential bias attached to the reviewers' Google history, each reviewer conducted the search using default Google search settings within the incognito browser of Google Chrome and cleared the cache before each search. The results obtained with each search term, which were present on the first page of the search findings on Google, were exported, excluding advertisements. After completing all searches, the resources extracted by each reviewer across all search terms were combined, and duplicate resources were removed (ie, resources identified across >1 search term).

Inclusion Criteria for Web-Based Resources

HBPM resources were included if they met the following inclusion criteria: (1) they were free to access by the public (eg, no paywalls), (2) they were available in English, and (3) they contained content relevant to HBPM (eg, resource mentions "home blood pressure measurement" or "self-measured blood pressure"; Multimedia Appendix 3). The resources extracted from Google were independently analyzed against inclusion criteria by EC and SC, and discrepancies were resolved by third and fourth independent reviewers based on the same criteria (NC and DP). All resources that met the inclusion criteria were included for analysis. Resources were not excluded due to criteria regarding publication date, publication location, or resource format (ie, video, graphic, or blog).

Appraisal of Web-Based Resources

A coding framework hosted on REDCap was used by EC and SC to independently and systematically appraise resources according to three criteria: (1) alignment of resource information with HBPM guideline recommendations, (2) grade reading level of the content of the resources, and (3) end user involvement in resource development. The REDCap appraisal framework captured resource characteristics (type of publishing organization, authorship, year of publication or last review, and location of publication and languages), communication methods used (categorized as written text, visual, video, or audio), the alignment of resource content against HBPM recommendations, and the grade reading level of the content of the resources (Multimedia Appendix 3). Independent reviewers were trained on how to undertake the search, extract data, and appraise resources. During training, the appraisal data of a subset of resources (n=3) were compared to ensure that the correct process was undertaken by both independent reviewers. All data were captured in a framework housed on REDCap. All content (including audio, text, video, and graphical content) included within each HBPM resource was appraised according to 3 main criteria detailed below. Any discrepancies in appraisal were resolved in adjudication sessions where blinded discrepancies were presented to adjudicators (NC and DP) and resolved via discussion until consensus was reached.

Alignment of Resource Information With HBPM Guideline Recommendations

Twenty-three recommendations that encompass activities for HBPM from 6 international guidelines were used to determine the alignment of resource content to the guidelines (Textbox 1) [6,30-34]. Resource content was marked against each recommendation and categorized as "aligned with" if the resource correctly stated the recommendation, "incorrectly stated" if the resource incorrectly or incompletely stated the recommendation, or "not mentioned" if the resource did not include the recommendation (Multimedia Appendix 3). Where resources "incorrectly stated" a guideline recommendation, the incorrect information provided by the resource was recorded on REDCap (Multimedia Appendix 4).

Grade Reading Level of Resource Text

The grade reading level of each resource was calculated using the SHeLL Editor, which is a health literacy assessment tool that calculates the school grade reading score of text according to the Simple Measure of Gobbledygook, and reports other measures such as complex language, uncommon English words, and the use of passive voice [19,35,36]. All text presented within each resource (including written text, image captions, and audio and video transcripts when available) was entered into the SHeLL Editor and the grade reading level, and associated measures were recorded in the REDCap framework (Multimedia Appendix 3).

End User Involvement in Resource Development

End user involvement in resource development was recorded in the REDCap framework as stated within the resource. End users were defined as adults who seek information to measure BP at home (eg, patient, health consumer, service user, carer, or community advisor) or medical professionals due to their role in delivering education for HBPM to adults or directing adults to educational resources for HBPM [38,39].

Data Analysis

Data were analyzed using Stata (version 17; StataCorp). Resources were assigned an identifying number for analysis and the presentation of results (Multimedia Appendix 5). Categorical data are presented as n (%) values.

Results

Resource Characteristics

Twenty-four resources were included in the study (Multimedia Appendices 5 and 6). Not-for-profit organizations (such as the National Heart Foundation) were the most common type of publishing organization (n=6, 25%) followed by websites (such as Healthline), academic journals, and scientific societies (Table 1). Most resources were communicated via a combination of written text, visual (eg, images), and audio and video communication methods (n=17, 71%), and the remaining resources were communicated by written text only (n=7, 29%; Table 1). Most resources were published in Australia (n=10, 42%) or North America (n=9, 38%), and only 3 (13%) were available in languages other than English.

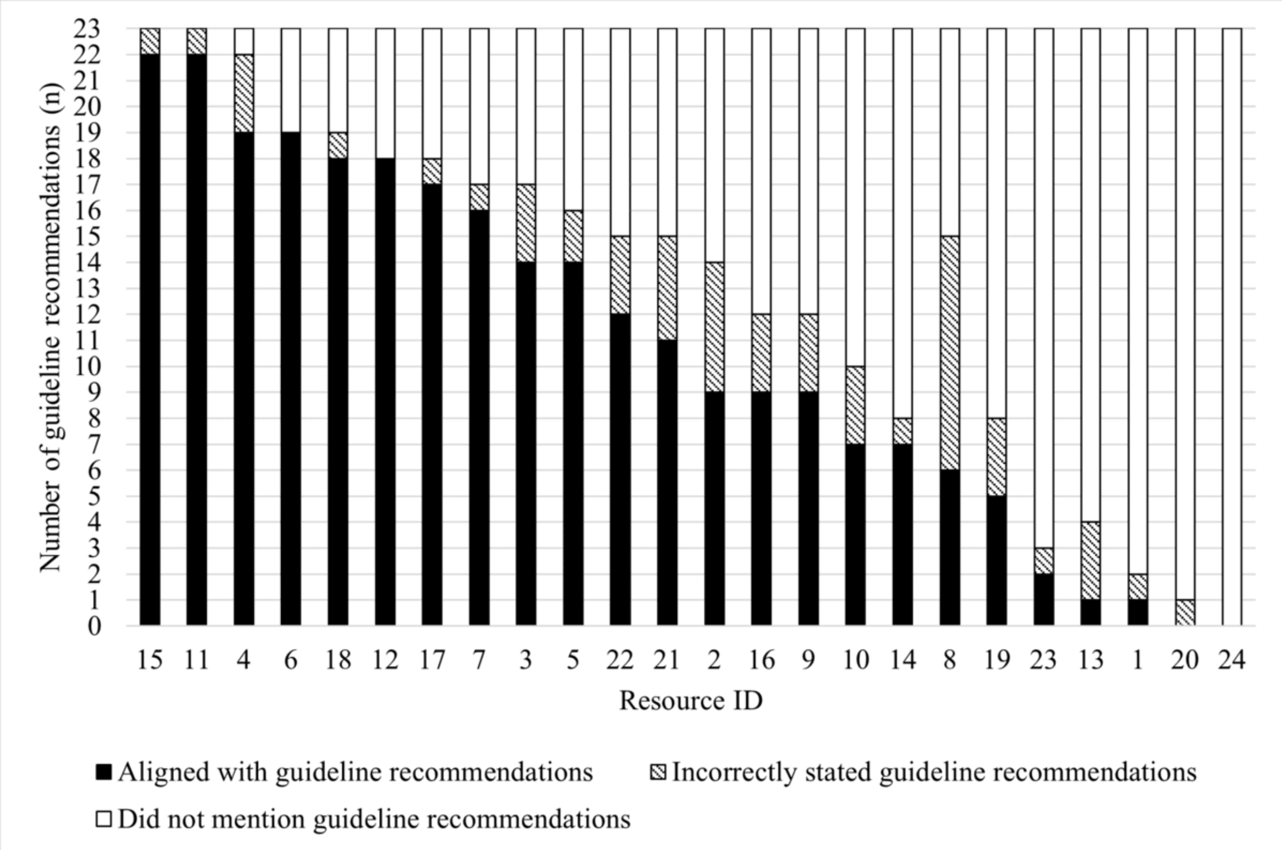
Table 1. Characteristics of the included resources.

Characteristic	Resources, n (%)
Type of publishing organization	
Commercial entity	3 (12)
Scientific journal	4 (17)
Government body	1 (4)
Not-for-profit organization	5 (21)
Scientific society	5 (21)
Website	4 (17)
Medical research institute	2 (8)
Date of publication or last review	
Last 12 months	3 (13)
1-2 years ago	3 (13)
2-3 years ago	2 (8)
3-4 years ago	1 (4)
4-5 years ago	1 (4)
>5 years ago	4 (16)
Not stated	10 (42)
Location of publication	
Australia	10 (42)
North America	9 (37)
Europe	5 (21)
Communication method	
Written text only	7 (29)
Written text and visual	9 (37)
Written text and video	4 (17)
Written text, visual, and video	3 (12)
Written text, audio, and visual	1 (4)
Languages	
English only	21 (88)
English, Mandarin, and Spanish	1 (4)
English and Spanish	2 (8)

Resource Alignment With HBPM Guideline Recommendations

As shown in Figure 1, none of the resources aligned with all 23 guideline recommendations for HBPM. Almost all (n=22, 92%) of the resources incorrectly stated at least one guideline recommendation. Two (8%) resources did not align with any of the 23 guideline recommendations for HBPM. The alignment of resources with each guideline recommendation is shown in Figure 2, indicating whether the recommendation was "aligned with," "incorrectly stated," and "not mentioned" in each resource. Time- or frequency-bound recommendations were often incorrect within resources. For example, to rest for 5 minutes before measuring BP was incorrectly stated in 25% (n=6) of resources and to take 2 BP readings 1 minute apart at each sitting was incorrect in 46% (n=11) of resources (Figure 2).

Figure 1. Alignment of each resource to 23 guideline recommendations for home blood pressure measurement. Resource content either "aligned with" the HBPM guideline recommendations (black bars), "incorrectly stated" the guideline recommendations (patterned bars), or "did not mention" the guideline recommendations (white bars). The y-axis indicates each of the 23 guideline recommendations, and the x-axis indicates the number of resources (n=24 resources).



Resources incorrectly stated guideline recommendations because their content was not specific enough to capture the meaning of the guideline recommendation, provided contradictory advice, or stated an alternate rest period, number of measurements, frequency, duration, or other numeric parameters to the guideline recommendations (Multimedia Appendix 4). For example, rather than stating the recommendation to “have five minutes [or at least five minutes] of seated rest before measuring BP,” resources that incorrectly stated this recommendation said to “rest for 15 minutes” (resource ID 10) or “rest quietly and wait about one to two minutes before taking another measurement” (resource ID 19). In addition, rather than stating the recommendation to “take two readings one minute apart at each HBPM sitting,” a resource that incorrectly stated this recommendation said “if you get a reading that is slightly or moderately higher than normal, take your blood pressure a few more times” (resource ID 6).

Resource alignment to guideline recommendations according to the publishing organization is outlined in Figure 3. Resources published by scientific journals, scientific societies, and not-for-profit organizations aligned with a higher number of HBPM guideline recommendations (14 resources; median 16.5, range 2-22 recommendations) than resources published by websites, commercial entities, and medical research institutes (9 resources; median 6.5, range 0-12 recommendations; Figure 3).

Figure 2. Alignment of all resources to each of the 23 guideline recommendations for key home blood pressure measurement (HBPM) activities. Resource content either "aligned with" the HBPM guideline recommendations (black bars), "incorrectly stated" the guideline recommendations (patterned bars), or "did not mention" the guideline recommendations (white bars). The x-axis indicates the number of HBPM resources. BP: blood pressure.

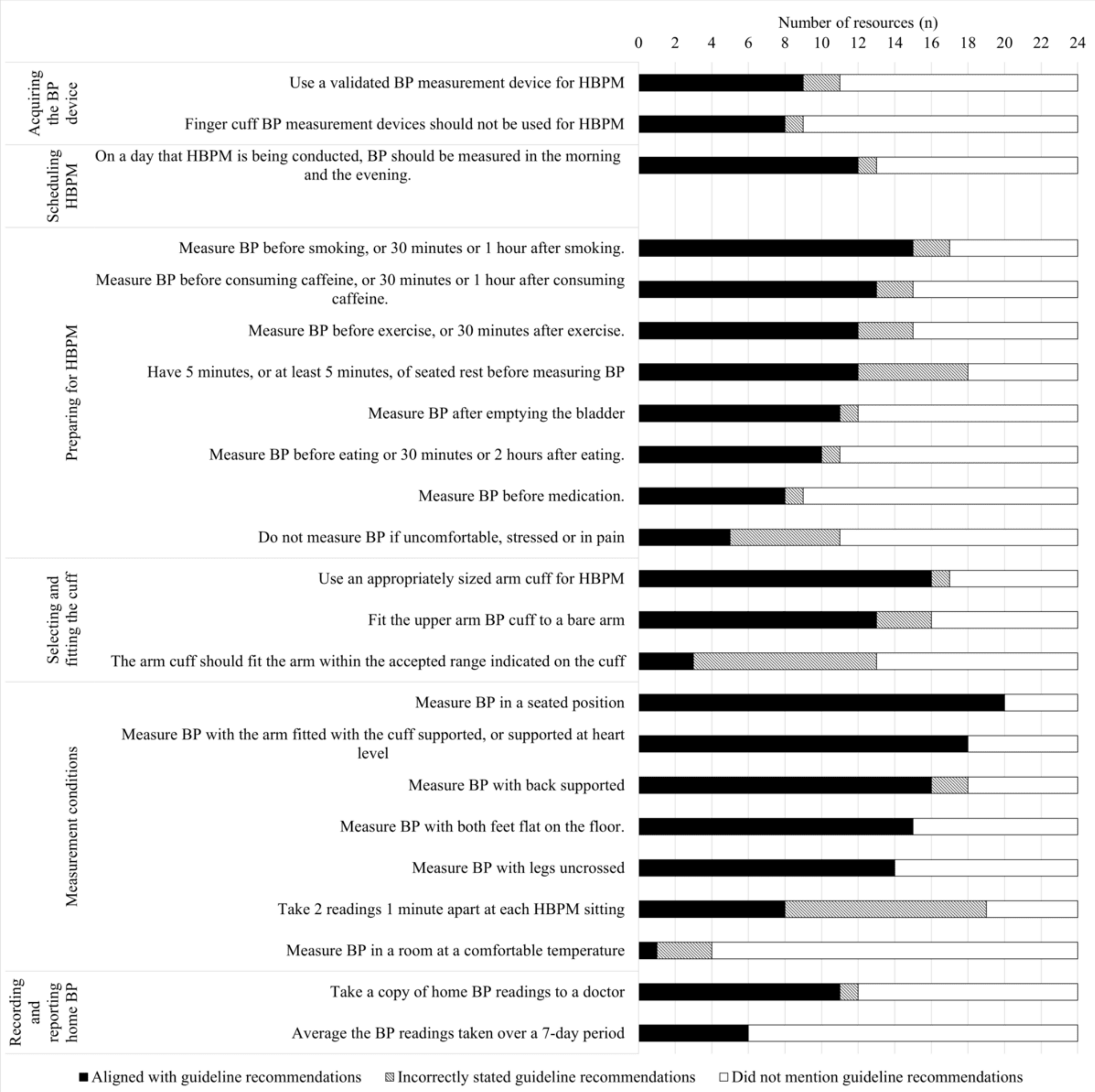
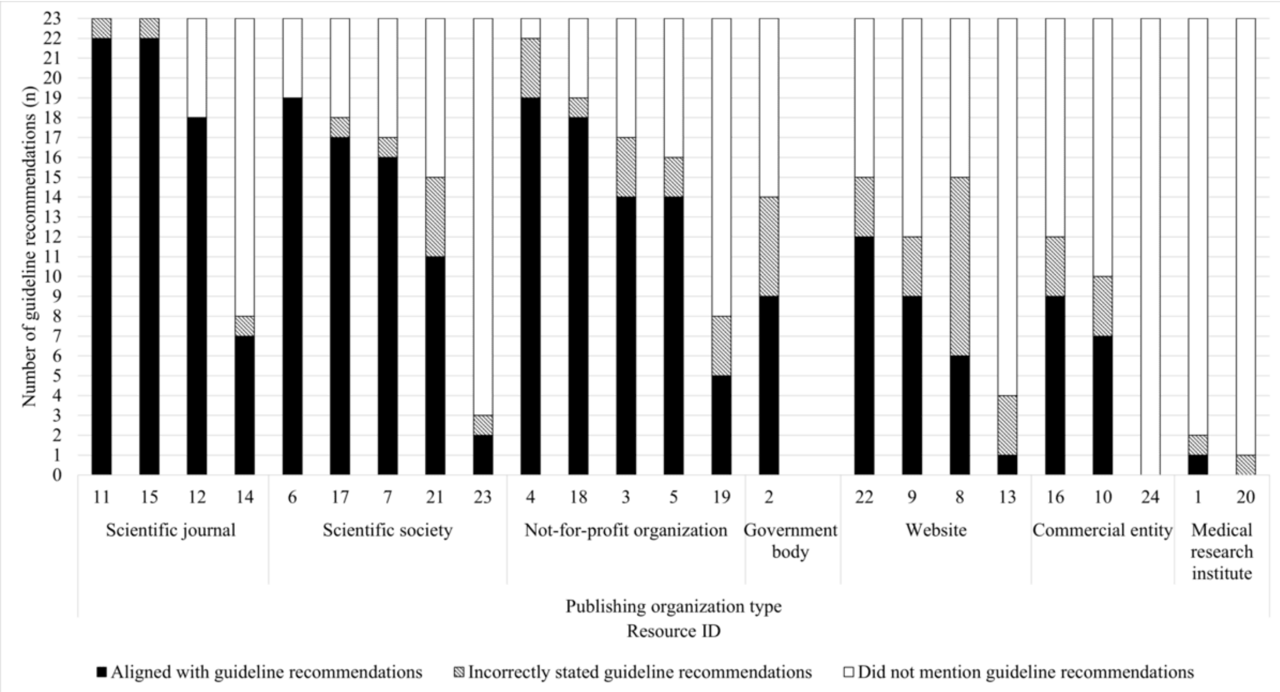


Figure 3. Resource alignment to home blood pressure measurement (HBPM) guideline recommendations according to the type of publishing organization. Resource alignment was determined by appraising resource content against 23 guideline recommendations of core HBPM activities. Resource content either "aligned with" the HBPM guideline recommendations (black bars), "incorrectly stated" the guideline recommendations (patterned bars), or "did not mention" the guideline recommendations (white bars).



Grade Reading Level of Resource Text

All resources exceeded the recommended eighth grade reading level (grade reading level: mean 11.8, range: 8.8-17.0; Figure 4). The grade reading level of resources did not differ according to the level of alignment with HBPM guideline recommendations or communication methods used (Figures 4 and 5). Resources presented through written text only (n=7) had the highest average grade reading level (grade reading level: mean 12.9, range 10.5-16.4; Figure 5). Resources published by scientific journals had the highest average grade reading level (n=4; grade reading level: mean 16.5, range 11.9-17), compared to government bodies (n=1; grade reading level: mean 8.8) and not-for-profit organizations (n=5; grade reading level: mean 10.2, range 9-10.9; Figure 6), which had the lowest average grade reading levels. Multimedia Appendix 7 shows the characteristics of the resource text that contributed to the grade reading level score.

Figure 4. Grade reading level of web-based home blood pressure measurement (HBPM) resources. Resource grade reading level (y-axis) is presented in the order of resources from the highest (left) to the lowest alignment (right) with HBPM guideline recommendations. The grade reading level (y-axis) of resource content was calculated by inputting all resource content into the Sydney Health Literacy Lab Editor.

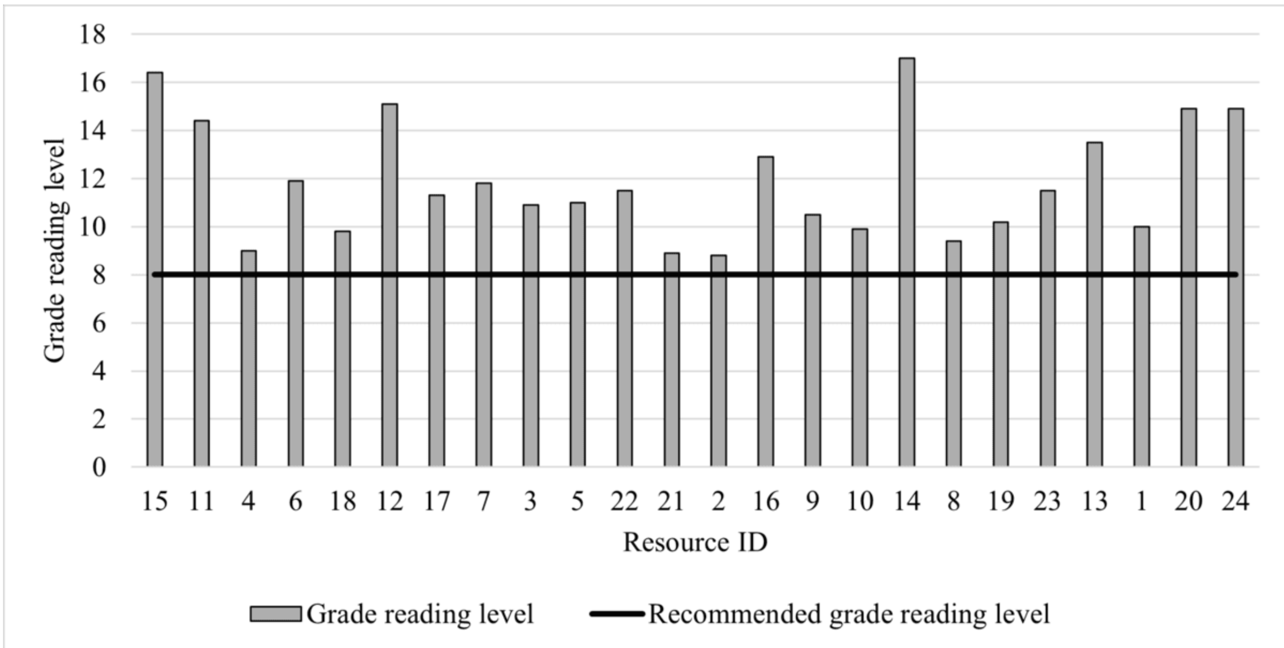


Figure 5. Resource grade reading level according to the communication method. The average grade reading level (y-axis) of resources according to communication methods used in the resource (x-axis). The grade reading level (y-axis) of resource content was calculated by inputting all resource content into the Sydney Health Literacy Lab Editor.

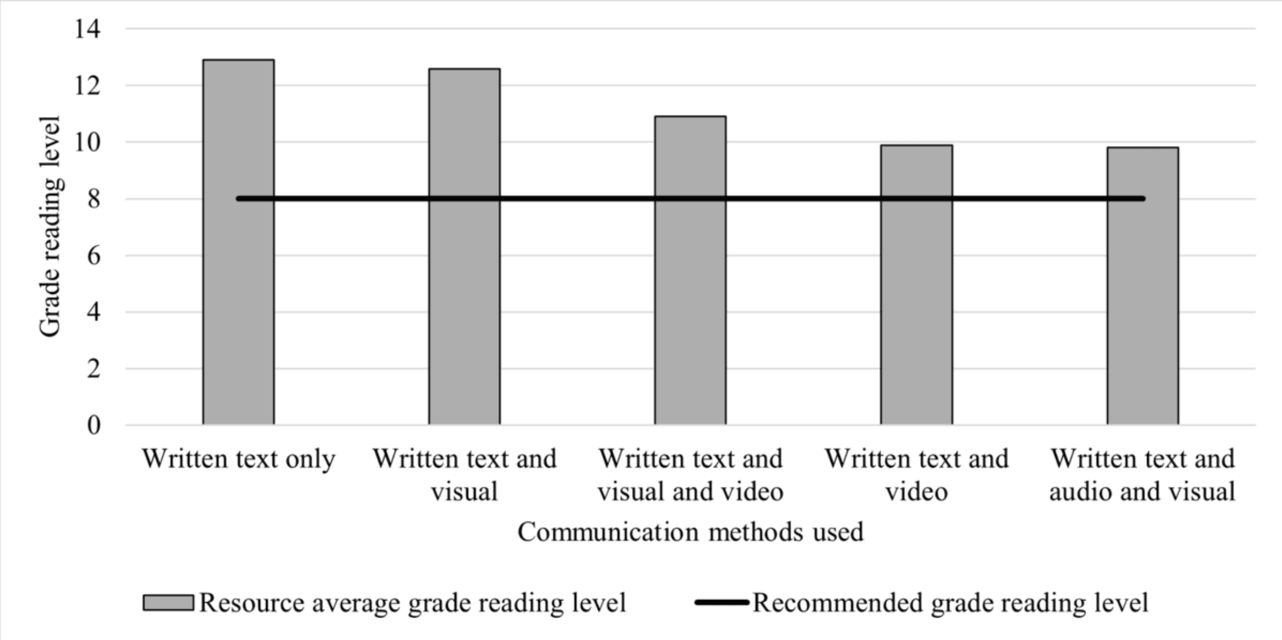
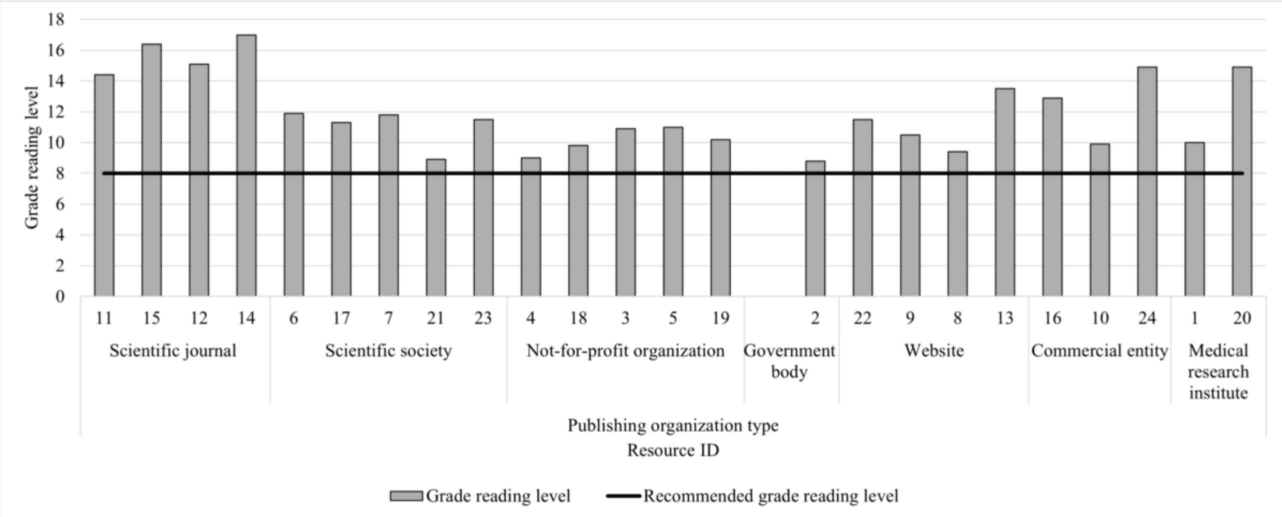


Figure 6. Resource grade reading level according to the type of publishing organization. Grade reading level was calculated by inputting all resource content into the Sydney Health Literacy Lab Editor.



End User Involvement in Resource Development

None of the resources reported involving adults (such as patients, health consumers, or carers) during resource development. Medical professional involvement was reported in 5 (21%) resources. Resources with and those without medical professional involvement during development had similar alignment with HBPM guideline recommendations and grade reading levels (Figures 7 and 8).

Figure 7. Resource alignment to guideline home blood pressure measurement (HBPM) recommendations according to medical professional involvement during resource development. Resource alignment was determined by appraising resource content against 23 guideline recommendations of core HBPM activities. Resource content either "aligned with" the HBPM guideline recommendations (black bars), "incorrectly stated" the guideline recommendations (patterned bars), or "did not mention" the guideline recommendations (white bars).

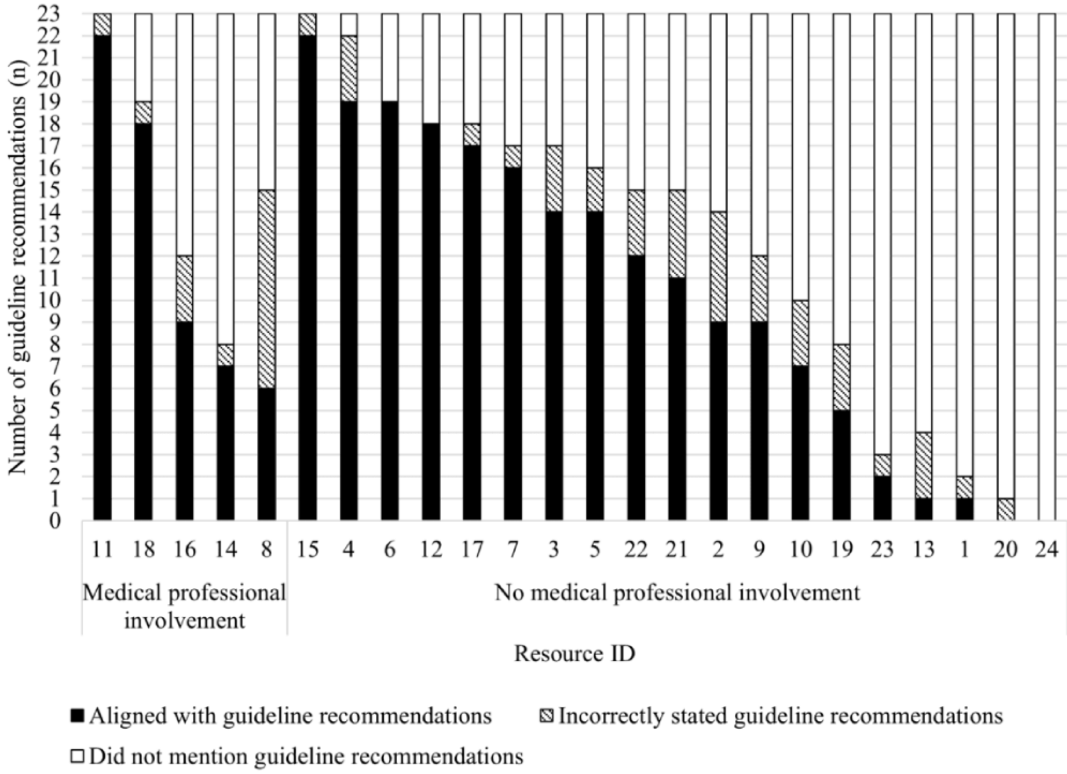
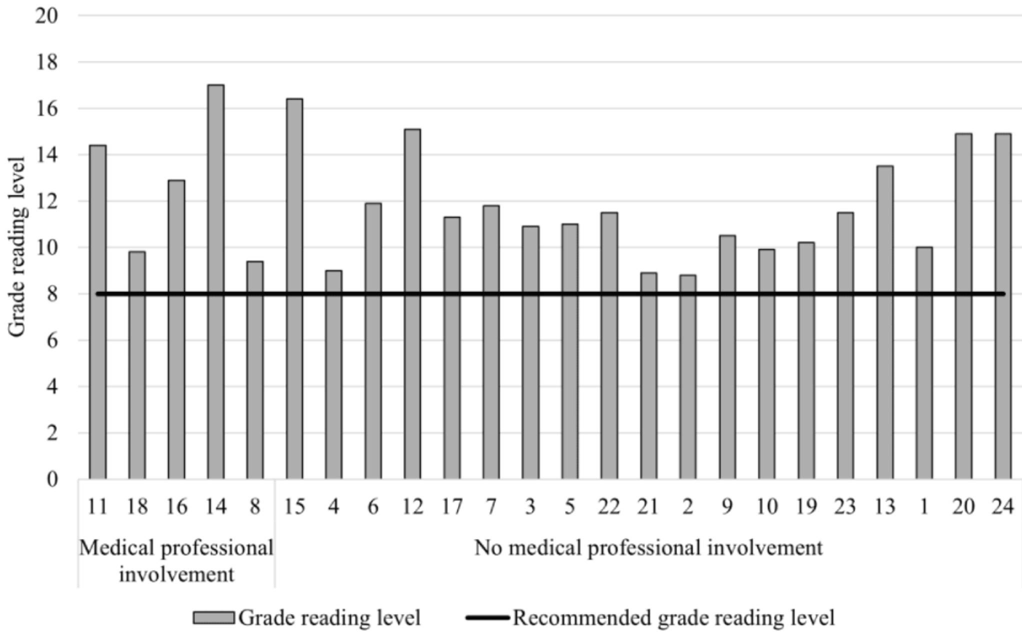


Figure 8. Resource grade reading level according to medical professional involvement during resource development. Grade reading level was calculated by inputting all resource content into the Sydney Health Literacy Lab Editor. Resources are presented in order of the highest (left) to the lowest alignment (right) to home blood pressure measurement guideline recommendations.



Discussion

Principal Findings

This study has demonstrated that web-based resources may not be appropriate to fully support adults to undertake high-quality HBPM because none of them provided sufficient guideline information or communicated at an appropriate reading level. Using methodology that emulated the search strategy of adults with lived experience of HBPM to identify web-based resources, we identified that none of the resources correctly stated all key guideline recommendations for HBPM, and most resources included information that was incorrect according to guideline recommendations due to incorrectly stating time- and frequency-bound recommendations. The findings of this study highlight the need to design educational materials for key BP management behaviors such as HBPM, which are appropriate for adults who self-monitor BP.

Calls to action on hypertension in the United States and Australia highlight the importance of empowering patients who perform HBPM to improve and monitor BP control [40,41]. At a global level, the World Heart Federation Hypertension Roadmap highlighted that appropriate patient education is an important strategy to improve BP control [20]. Existing research supports this by illustrating that patient education delivered with HBPM improves BP control outcomes [10] and adherence to recommendations for HBPM [11,42]. However, the results of this study suggest that web-based resources may not be appropriate to educate adults about HBPM as the identified resources did not provide guideline aligning information required to support HBPM in a manner that met adult reading needs.

This study found that time- and frequency-based HBPM recommendations, such as the number of BP measurements to take per sitting and the associated rest periods, were incorrectly stated within the most resources, while the recommendation to measure BP when seated was accurately communicated in the most resources. Interestingly, a recent study on BP guideline recommendations followed by adults who measure BP at home found that time-bound recommendations were adhered to by the lowest number of adults, while the recommendation to measure BP when seated was performed by the highest number of adults. Additionally, adults who reported to have previously sought information to support HBPM did so via web-based sources; however, these adults did not perform higher-quality HBPM than those who had not used web-based information to support HBPM [43]. Altogether, these findings highlight that current educational resources are not appropriate to support adults to measure BP at home as recommended by guidelines and illustrate a possible synergy between the inaccurate information delivered within web-based HBPM resources and the practice of adults when measuring BP at home. This emphasizes the need for web-based HBPM resources to accurately and clearly deliver guideline recommendations to enable proper HBPM practice among adults, which is an important behavior for BP management.

This study found that resources published in scientific journals, scientific societies, and not-for-profit organizations stated more guideline recommendations correctly than resources published by websites, commercial entities, and medical research institutes. This suggests that some organizations and resource developers may have low awareness of or access to guideline recommendations for HBPM and may not recognize the importance of standardized BP measurement practices for achieving and maintaining BP control. International BP guidelines should consider the importance of using consistent, unambiguous, and plain language for HBPM recommendations to support the accurate translation of recommendations into educational resources for HBPM. To ensure that guideline information is disseminated to the general public, guideline developers should share guidelines with organizations that publish health information on the web and partner with peak organizations to enable resource developers from outside of the scientific and clinical community to create guideline-informed, evidence-based resources.

Apart from correctly delivering evidence-based guideline information, HBPM resources must deliver information in a format accessible for adults to achieve effective education. Previous evidence has shown that web-based health information is not appropriate to inform patient decisions surrounding cardiovascular disease because the reading level is too high and the information is not adapted to meet the learning needs of adult patients [17,26,27,44]. This is consistent with the findings of our study where all resources were at a reading level that was too high (≥8 grade) for adult comprehension and over a quarter (n=7, 29%) of resources only presented information via written text only.

Strategies to deliver patient education that meet the literacy levels of adult patients should be implemented to ensure that educational resources can support adults to perform key cardiovascular disease risk management behaviors such as HBPM. As highlighted by the World Heart Federation Hypertension Roadmap, the delivery of education via graphical means is a more appropriate communication method to meet the needs of those with lower health literacy levels [20]. This is supported by the findings of this study, where web-based resources with multimodal communication methods achieved a lower average grade reading level than those that communicated via written text alone. Supporting audiovisuals, such as graphs, diagrams, images, videos, and the read-aloud function should be used to aid understandability, comprehensibility, and actionability of web-based health information. Additionally, the use of readability and grammar editing tools when developing resources may help to ensure that resource information is presented at a grade reading level that is appropriate to all adults, and resources such as the Agency for Healthcare Research and Quality's Health Literacy Universal Precautions Toolkit may provide actionable methods to maximize the understandability of patient education strategies [45]. Finally, artificial intelligence (AI) could be used to tailor web-based information to meet patient literacy needs, selectively deliver information most relevant to the unique information needs of patients, and support chat box functions enabling adults to ask clarifying questions [46]. However, although AI-generated content is accurate and retains key meaning, caution should be exercised to ensure that information used by AI generators is sourced from guidelines.

Direct end user involvement in resource development is an increasingly well-recognized strategy to ensure that health products and services, including health information, meet end user needs to deliver quality care and education [21-24]. However, end user involvement is not commonplace in resource development [24], which is consistent with the findings of our study. Although some resources of this study involved medical professionals in their development, this did not improve the resource grade reading level or the number of correctly stated guideline recommendations. While medical professionals play a central role in patient education, they may not be aware or have sufficient resources to meet the health literacy needs of all patients [47-49]. Additionally, some medical professionals have general distrust in BP guidelines [50] and do not use current guidelines recommendations for HBPM in clinical practice, such as the recommendation to use different cutoffs for a hypertension diagnosis using in-clinic versus at-home BP readings [12,51]. This further highlights the need for adults with lived experience of BP management to be involved in resource development to identify unfamiliar medical jargon, recommend culturally and linguistically sensitive adaptations, and advise on the appropriate use of images. For existing resources, such as those identified in this study, adults could be involved in appraising these resources to identify how they could better meet the needs of adults seeking information on HBPM. Implementing the strategies suggested would ensure that information provided by web-based resources is suitable for use by all end users to support high-quality HBPM among adults.

Strengths and Limitations

A strength of this study was the involvement of consumer advisors in the development of the search strategy to emulate the experience of adults seeking information for HBPM. In addition, a rigorous framework analysis approach was used by 2 independent researchers for resource identification and appraisal. This study was strengthened by the guideline-informed appraisal process; however, guideline recommendations included in this analysis were not exhaustive of all recommendations for HBPM due to inconsistency in recommendations across guidelines. The incognito mode was used to eliminate the impact of cookies and search history unique to the reviewer. However, as a result of using default Google search engine settings and including only the first page of search results, some web-based HBPM resources would have been missed. The location at which this study was conducted has likely impacted the search results, as 42% of included resources were from Australia. This suggests that the resources that an adult seeking HBPM information is exposed to depends on the location from which the search is conducted. This method should be replicated in other locations to assess resources that may not have been identified in this study. The scope of this study was narrow, with highly specific appraisal criteria used to evaluate resources. Other important considerations of web-based resources such as ease of access and usability should be included in future studies for a more complete understanding of resource appropriateness to support HBPM. Further, given the proliferation in use of AI, mobile health, and eHealth for health interventions and patient education, HBPM resources found on these information sources should also be appraised for appropriateness.

Conclusion

This study found that the web-based resources identified herein are not appropriate to fully support adults to measure their BP at home according to HBPM guideline recommendations. None of the resources identified provided sufficient guideline information to support adults to perform high-quality HBPM, were presented at an appropriate reading level, or involved end users in their design. Resources that deliver health information should use strategies such as the use of multimodal communication methods, literacy editor tools, and co-design methods with adult end users to ensure that the information delivered is appropriate to support adults. Due to the recognized importance of effective education in achieving standardized HBPM and improving BP control, creating appropriate educational resources for key BP management behaviors such as HBPM should be considered a priority.

Acknowledgments

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Data Availability

The data that support the findings of this study are available from the corresponding author (NC) upon reasonable request. NC had full access to all data in the study and takes responsibility for its integrity and the data analysis.

Conflicts of Interest

CB is a director of Health Literacy Solutions, a company set up to fund the future development of the SHeLL Editor.

Multimedia Appendix 1

The guideline recommendations used for resource appraisal.

[DOCX File , 18 KB - infodemiology_v5i1e55248_app1.docx]

Multimedia Appendix 2

Development of the search strategy. Consumer advisors (n=6) and Google Trends data were used to develop the search strategy to identify web-based home blood pressure measurement resources. Search terms suggested by consumer advisors that also had a high probability of use on Google (January 1, 2012, to October 7, 2022) were used.

[DOCX File , 20 KB - infodemiology_v5i1e55248_app2.docx]

Multimedia Appendix 3
Home blood pressure measurement (HBPM) resource eligibility and appraisal form. HBPM resources were appraised for eligibility and appraised for alignment to HBPM guidelines, grade reading level, and end user involvement in development according to the questions in the form house on REDCap (Research Electronic Data Capture).
[DOCX File , 27 KB - infodemiology_v5i1e55248_app3.docx]

Multimedia Appendix 4
Incorrectly stated guideline recommendations. Resource information marked as "incorrectly stated" during resource appraisal "step 1 alignment to guideline recommendations" was recorded in the REDCap (Research Electronic Data Capture) appraisal framework.
[DOCX File , 22 KB - infodemiology_v5i1e55248_app4.docx]

Multimedia Appendix 5
Resources included in the study.
[DOCX File , 18 KB - infodemiology_v5i1e55248_app5.docx]

Multimedia Appendix 6
Search strategy and results.
[DOCX File , 27 KB - infodemiology_v5i1e55248_app6.docx]

Multimedia Appendix 7
Sydney Health Literacy Lab Editor results of home blood pressure measurement resources. All text within resources, including written text and transcripts of audio and video material, was input to the Sydney Health Literacy Lab Editor. Grade reading level was calculated using the Simple Measure of Gobbledygook method.
[DOCX File , 21 KB - infodemiology_v5i1e55248_app7.docx]

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Abbreviations

AI: artificial intelligence
BP: blood pressure
HBPM: home blood pressure measurement
REDCap: Research Electronic Data Capture
SHeLL Editor: Health Literacy Lab Editor

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Original Paper

Online Information About Side Effects and Safety Concerns of Semaglutide: Mixed Methods Study of YouTube Videos

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Abstract

Background: Social media has been extensively used by the public to seek information and share views on health issues. Recently, the proper and off-label use of semaglutide drugs for weight loss has attracted huge media attention and led to temporary supply shortages.

Objective: The aim of this study was to perform a content analysis on English YouTube (Google) videos related to semaglutide.

Methods: YouTube was searched with the words semaglutide, Ozempic, Wegovy, and Rybelsus. The first 30 full-length videos (videos without a time limit) and 30 shorts (videos that are no longer than 1 minute) resulting from each search word were recorded. After discounting duplicates resulting from multiple searches, a total of 96 full-length videos and 93 shorts were analyzed. Video content was evaluated by 3 tools, that is, a custom checklist, a Global Quality Score (GQS), and Modified DISCERN. Readability and sentiment of the transcripts were also assessed.

Results: There was no significant difference in the mean number of views between full-length videos and shorts (mean 288,563.1, SD 513,598.3 vs mean 188,465.2, SD 780,376.2, *P*=.30). The former had better content quality in terms of GQS, Modified DISCERN, and the number of mentioned points from the custom checklist (all *P*<.001). The transcript readability of both types of videos was at a fairly easy level and mainly had a neutral tone. Full-length videos from health sources had a higher content quality in terms of GQS and Modified DISCERN (both *P*<.001) than their counterparts.

Conclusions: The analyzed videos lacked coverage of several important aspects, including the lack of long-term data, the persistence of side effects due to the long half-life of semaglutide, and the risk of counterfeit drugs. It is crucial for the public to be aware that videos cannot replace consultations with physicians.

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KEYWORDS

YouTube; semaglutide; social media; Ozempic; Wegovy; Rybelsus; safety; knowledge exchange; side effects; online information; online; videos; health issues; drugs; weight loss; assessment; long-term data; consultation

Introduction

Public health information has traditionally been disseminated through printed media. However, with the rise of online social media platforms [1], the internet has become increasingly influential in spreading information and misinformation, notably during the COVID-19 pandemic [2-5]. Safety concerns in health care are frequently discussed on social media platforms such as YouTube (Google) [2,6].

Currently, obesity and being overweight are urgent health issues that reduce quality of life and increase the risk of cardiovascular diseases, type 2 diabetes mellitus, cancers, and reproductive system disorders, among others [7]. While lifestyle changes are essential for managing obesity, many people struggle with adherence [8]. Consequently, medical organizations are developing clinical guidelines for the long-term use of pharmacological therapy for obesity in adults. For instance, the American Gastroenterological Association recommends the use of pharmacological agents (strong recommendation, moderate certainty evidence) for adults with obesity or overweight who have insufficient results from lifestyle changes [8].

Unfortunately, some patients take their own antiobesity medication based on social media information, which can be dangerous without professional guidance. In particular, many people have watched YouTube videos on weight loss. It was found that the 98 most viewed weight loss videos on YouTube were viewed more than 365 million times in total [9]. In recent years, the injectable antidiabetic drug with weight loss property, branded Ozempic, has gained significant attention on platforms such as TikTok (ByteDance) and YouTube. Between 2018 and 2023, online searches for Ozempic surged in the United States [10]. Celebrity endorsements have driven its popularity, with 100 TikTok videos garnering over 70 million views [11]. However, this trend is concerning as many social media posts focused on the off-label use of Ozempic for weight loss, ignoring the potential health hazards [12]. Analyses of Reddit posts and social media comments have revealed discussions about off-label uses, struggles with insurance coverage, interest in compounded formulations, and unwanted side effects such as insomnia, anxiety, and depression [13,14].

Semaglutide, the active ingredient in Ozempic, was developed in 2012 to treat type 2 diabetes [15]. It is a glucagon-like peptide-1 (GLP-1) receptor agonist. GLP-1 receptors are expressed in many organs (pancreas, gastrointestinal tract, heart, brain, kidneys, lungs, and thyroid). This is associated with the pleiotropy and benefits of semaglutide in type 2 diabetes mellitus, weight loss, and cardioprotection. It can lower blood sugar levels through numerous means, including increasing insulin production, inhibiting glucagon secretion, and slowing gastric emptying [16]. Semaglutide is marketed as Ozempic and Rybelsus for treating diabetes and as Wegovy for chronic weight management. Ozempic and Wegovy are injectable, whereas Rybelsus is an oral tablet.

In 2017, the SUSTAIN (Semaglutide Unabated Sustainability in Treatment of Type 2 Diabetes) 1 trial demonstrated that weekly injections of semaglutide significantly improved body weight as well as glycated hemoglobin (HbA_{1c}) levels in type 2 diabetes patients [17]. The STEP (Semaglutide Treatment Effect in People with obesity) 1 trial published in 2021 showed that semaglutide, combined with lifestyle changes, significantly reduced body weight in overweight or obese nondiabetic patients [18]. These trials and their subsequent trials facilitated the United States Food and Drug Administration (FDA) to approve injectable semaglutide for treating diabetes and weight management. Besides, semaglutide was also approved in Europe [19]. Meanwhile, the PIONEER (Peptide Innovation for Early Diabetes Treatment) 1 trial published in 2019 found that daily oral semaglutide, versus placebo, significantly improved HbA_{1c} levels in type 2 diabetes patients managed by diet and exercise [20]. This supported the FDA approval of oral semaglutide to treat diabetes.

During the development of semaglutide (*la semaine* in translation from French, "week"), researchers sought to increase its duration of action. The half-life of oral semaglutide is approximately 1 week [21]. Ozempic (in strengths of 2 mg/1.5 mL, 2 mg/3 mL, 4 mg/3 mL, and 8 mg/3 mL), Rybelsus (3, 7, and 14 mg), and Wegovy (0.25 mg/0.5 mL, 0.5 mg/0.5 mL, 1 mg/0.5 mL, 1.7 mg/0.75 mL, and 2.4 mg/0.75 mL) have different dosages depending on the treatment purposes and patient characteristics. Ozempic, Rybelsus, and Wegovy are prescription medicines [22]. Common side effects include a slowdown in the digestive process from the stomach, nausea, and vomiting, which can be mitigated by gradually increasing the dose. Semaglutide is associated with increased risks of pancreatitis, gallbladder disease, and retinopathy, including vitreous hemorrhage and vision loss [8,23]. Besides, the rapid decrease in glucose levels can also worsen retinopathy in type 1 diabetes patients. Semaglutide is contraindicated in patients with a personal or family history of medullary or multiple thyroid cancer or endocrine neoplasia syndrome type 2. Serious side effects include abdominal pain, constipation, diarrhea, nausea, vomiting, dizziness, cholelithiasis, cholecystitis, acute myocardial infarction, gastroenteritis, and suicidal ideation [8].

The use of semaglutide, particularly the famous Ozempic, by nonsevere overweight individuals might pose safety issues [24]. Off-label drug use is legal and common, though it means a drug is being used for an unapproved indication or population, at an unapproved dosage, or via an unapproved route of administration [24,25]. Off-label users may have a higher safety risk if they obtain semaglutide via online vendors or beauty spas without a proper medical consultation [26]. With this background, this study aimed to investigate whether YouTube videos mentioned or discussed the side effects and safety concerns of semaglutide. It was hypothesized that full-length videos should be more informative than shorts (limited to 1 minute) and that full-length videos uploaded by YouTube-verified health source channels should be more informative than their counterparts. For readers' information, a video coming from YouTube-verified health source channels would have an information panel underneath the video stating that it comes "from a channel with a licensed doctor (or health professional)" in a particular country, such as the United States.

Methods

Data Source and Search Strategy

On January 5, 2024, a search was performed on YouTube for semaglutide videos in English. Using Google Chrome with Incognito mode, YouTube was searched with the words semaglutide, Ozempic, Wegovy, and Rybelsus, respectively. For each search word, the first 30 full-length videos (videos without a time limit) and 30 shorts (videos that are no longer than 1 minute) resulting from the search, sorted by relevance, were recorded. The number of 30 videos was chosen according to a recent study, which claimed that very few YouTube users searched beyond the 33rd video [27]. After discounting duplicates and excluding unsuitable videos, a total of 96 full-length videos and 93 shorts were analyzed.

Outcome Measures

We recorded the basic video metrics, such as the duration, number of views, number of comments, number of likes, number of channel subscribers, and the age of the video since upload (number of days until March 14, 2024). The readability and sentiment of the video transcripts were assessed. The quality of video content was evaluated. Further details are described in further sections.

Data Extraction

To evaluate the readability and overall sentiment, video transcripts were generated and analyzed. To evaluate the quality of video content, the entire videos were watched and analyzed.

The video transcripts were generated by Whisper (with the "large" version, edition 20231117), an artificial intelligence automatic speech recognition system developed by OpenAI [28]. It has been used in previous research to transcribe educational videos [29] and had the best performance compared with similar automatic transcription tools [30]. The readability of the transcripts was evaluated by the Flesch Reading Ease (FRE) score [31], calculated via an online platform (Readability Formulas website). In brief, the score ranged from 0 to 100, with 90 to 100 being very easy, 0 to 29 being very difficult, and 60 to 69 being standard. Meanwhile, the sentiment of the transcripts was evaluated by ChatGPT 3.5, an artificial intelligence large language model developed by OpenAI that has been demonstrated to be very effective in sentiment analysis across multiple languages [32]. Referring to the method by Fu et al [32], the prompt was set as "Is the sentiment of this text positive, neutral, or negative? Respond with the sentiment label only." The "temperature" of the ChatGPT model was set at 0 to ensure the consistency of the answers with the least creativity. Temperature is a variable that changes the degree of randomness of the output generated by the model [33].

Next, the quality of video content was evaluated by 3 tools, Global Quality Score (GQS) [34], Modified DISCERN [35], and a custom checklist. Manual evaluations were independently performed by two authors (AWKY and AGA). Disagreements were resolved through mutual discussion. During these evaluations, the overall audiovisual content of the videos, not merely limited to verbal narrative, was examined. The GQS is a 5-point Likert scale designed to evaluate online health information. A score of 1 means "poor quality, poor flow, most information missing, not at all useful for patients," whereas a score of 5 means excellence and high usefulness for patients [34]. Meanwhile, the Modified DISCERN contains 5 evaluative items and gives 1 point for every positive answer and 0 points for negative answer. It was designed to evaluate YouTube videos on health care information [35]. The 5 items are as follows: (1) Are the aims clear and achieved? (2) Are reliable sources of information used? (3) Is the information presented balanced and unbiased? (4) Are additional sources of information listed for patient reference? (5) Are areas of uncertainty mentioned? For readers' information, the Modified DISCERN is based on an original version of DISCERN, which was designed to evaluate written health information and used a 5-point Likert scale to answer 15 questions plus an overall rating [36]. Since GQS and Modified DISCERN could only give a more general evaluation of the videos, a custom 12-point checklist was devised to evaluate the video content based on some specific aspects of side effects and safety concerns related specifically to semaglutide.

The custom 12-point checklist was compiled by the authors' team with reference to Smits and Van Raalte [37]. It recorded whether the following contents were mentioned in the videos or not: (1) form of application (injection, exception: oral for Rybelsus); (2) safe dosage; (3) need for long-term usage, or change in lifestyle and eating habits to avoid rebound back to original weight after drug cessation; (4) serious side effects (eg, retinopathy and pancreatitis); (5) gastrointestinal symptoms (eg, nausea, diarrhea, vomiting, gastric reflux, and gastritis); (6) prevalence or frequency of such side effects; (7) increased risk of aspiration during the induction of anesthesia; (8) contraindications; (9) long half-life (7 days) so that potential side effects persist for multiple days after drug cessation; (10) lack of long-term data; (11) potential alternatives (eg, diet and bariatric surgery); and (12) risk of counterfeit drugs.

Statistical Analysis

Following descriptive analysis of the video contents, 2-sample t tests were performed were performed to evaluate if there were significant differences between the full-length videos and shorts in terms of the mean FRE, GQS, and Modified DISCERN scores, as well as the mean number of mentioned points from the custom checklist. To supplement, the same tests were performed among the full-length videos, to evaluate if there were differences between those uploaded by YouTube-verified health source channels and those without this verification.

Ethical Considerations

Ethical approval was not applicable, as this study only analyzed publicly available data from existing datasets, and results were presented in aggregate that did not contain any identifiable information.

Results

The viewing metrics and content quality between full-length videos and shorts are compared in Table 1. All 189 videos (Figure 1) were collectively viewed 45,040,855 times. There was no significant difference in the mean number of views between full-length videos and shorts (288,563.1 vs 188,465.2, *P*=.30). However, full-length videos received thrice the number of comments than shorts on average (669.6 vs 200.4, *P*=.003). Full-length videos were usually older (ie, uploaded earlier) than shorts (468.0 vs 350.0, *P*=.01). The former had better content quality in terms of GQS, Modified DISCERN, and number of mentioned points from the custom checklist than the latter (all *P*<.001). The readability of the transcripts of the 2 types of videos did not significantly differ and both were at the fairly easy level. Meanwhile, 1 full-length video did not have a narration, whereas 16 shorts played music without a narration (Figure 2). Besides, sentiment analysis showed that full-length videos mainly had a neutral tone (n=59), followed by positive (n=24) and negative (n=12) tones. One full-length video did not have a verbal narrative. Meanwhile, shorts mainly had a neutral tone (n=40), rather than positive (n=19) and negative (n=18) tones. There were 16 shorts without a verbal narrative.

Among the full-length videos, those from YouTube-verified health source channels had a higher average view count than their counterparts (Table 2), though the difference did not reach statistical significance (401,867.2 vs 258,746.3, *P*=.41). Readability analysis suggested that the transcripts from health source videos were generally less readable than their counterparts (63.7 vs 73.8, ie, standard vs fairly easy, *P*<.001). However, health source videos had a higher content quality in terms of GQS and Modified DISCERN (both *P*<.001). On average, they also contained a larger number of mentioned points from the custom checklist than their counterparts, though that difference was not significant (3.5 vs 2.7, *P*=.17)

Next, the reporting of the points from the custom checklist was examined. As stated in previous sections, full-length videos were generally more informative than the shorts. Gastrointestinal symptoms and form of application were the 2 mostly reported points among the full-length videos as well as the shorts (Figure 3). Among full-length videos, the most deficient aspect was the lack of mention about an increased risk of aspiration during the induction of anesthesia associated with the use of semaglutide. Only 1 full-length video (1/96) warned the audience about this potential side-effect. Less neglected aspects were the persistence of side effects due to the long half-life of semaglutide (4/96, 4%) and the risk of counterfeit drugs (4/96, 4%). On the other hand, the shorts had generally omitted several important aspects. Apart from the increased risk of aspiration during the induction of anesthesia (1/93), none of the shorts mentioned the prevalence or frequency of side effects, persistence of side effects due to the long half-life, lack of long-term data, and risk of counterfeit drugs.

Table 1. Viewing metrics and content quality between full-length videos and shorts.

Metric	Mean (SD)		*P* value
	Full-length videos	Shorts	
Duration (s)	610.5 (542.6)	39.0 (17.2)	<.001
View count	288,563.1 (513,598.3)	188,465.2 (780,376.2)	.30
Comment count	669.6 (1281.0)	200.4 (571.4)	.003
Like count	5363.2 (11,842.7)	7412.4 (39,692.8)	.63
Channel subscriber count	1,721,826.1 (3,500,160.1)	531,761.7 (1,783,695.8)	.004
Video age (days)	468.0 (411.4)	350.0 (152.4)	.01
Flesch Reading Ease score	71.7 (11.6)	72.9 (14.3)	.54
GQS[a] score	2.6 (0.8)	1.1 (0.4)	<.001
Modified DISCERN	2.3 (0.8)	1.1 (0.2)	<.001
Number of content points from custom checklist	2.9 (1.7)	0.7 (0.9)	<.001

[a]GQS: Global Quality Score.

Figure 1. The screening process of YouTube videos on semaglutide.

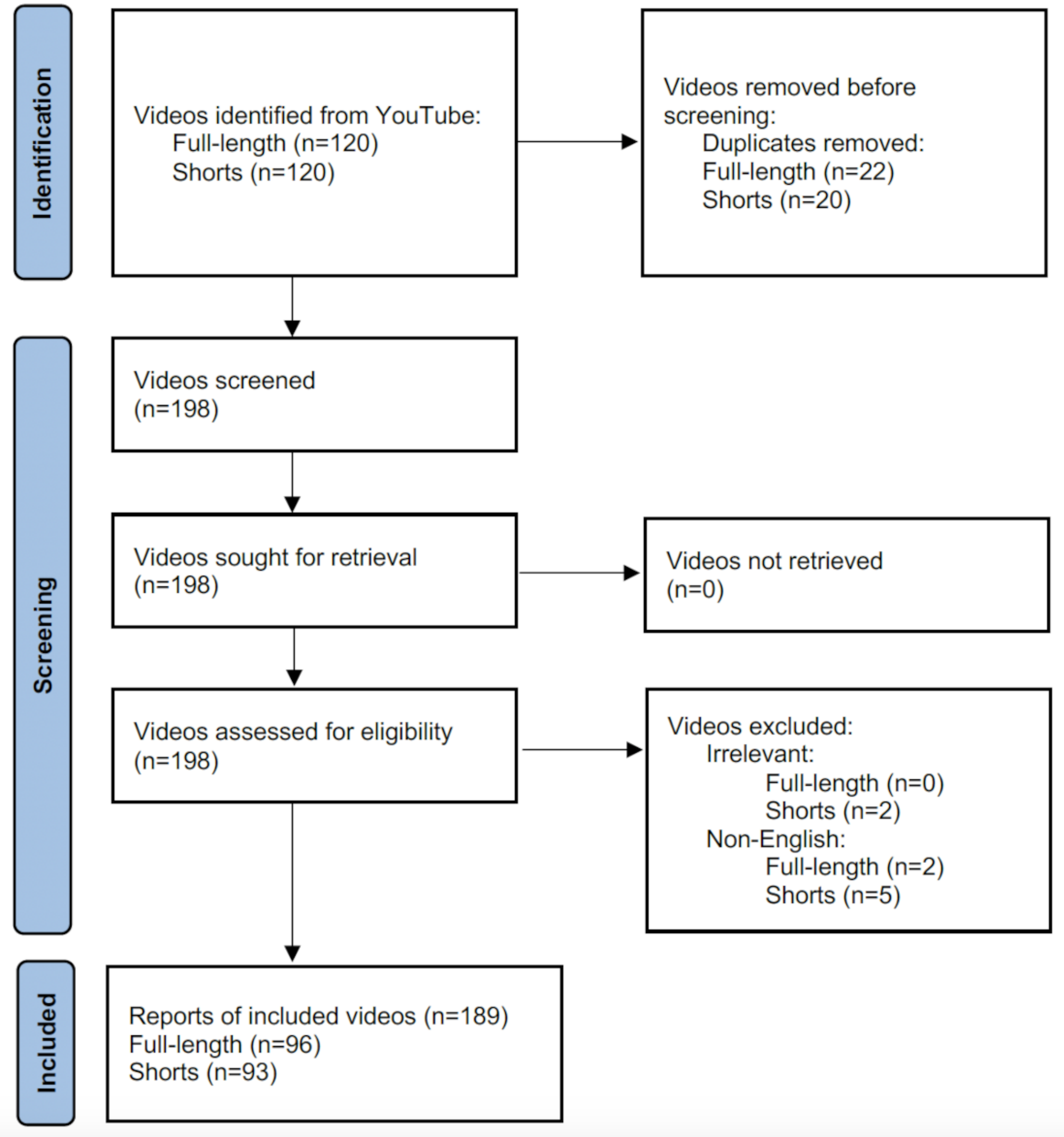


Figure 2. Percentage of full-length videos and shorts with a narration.

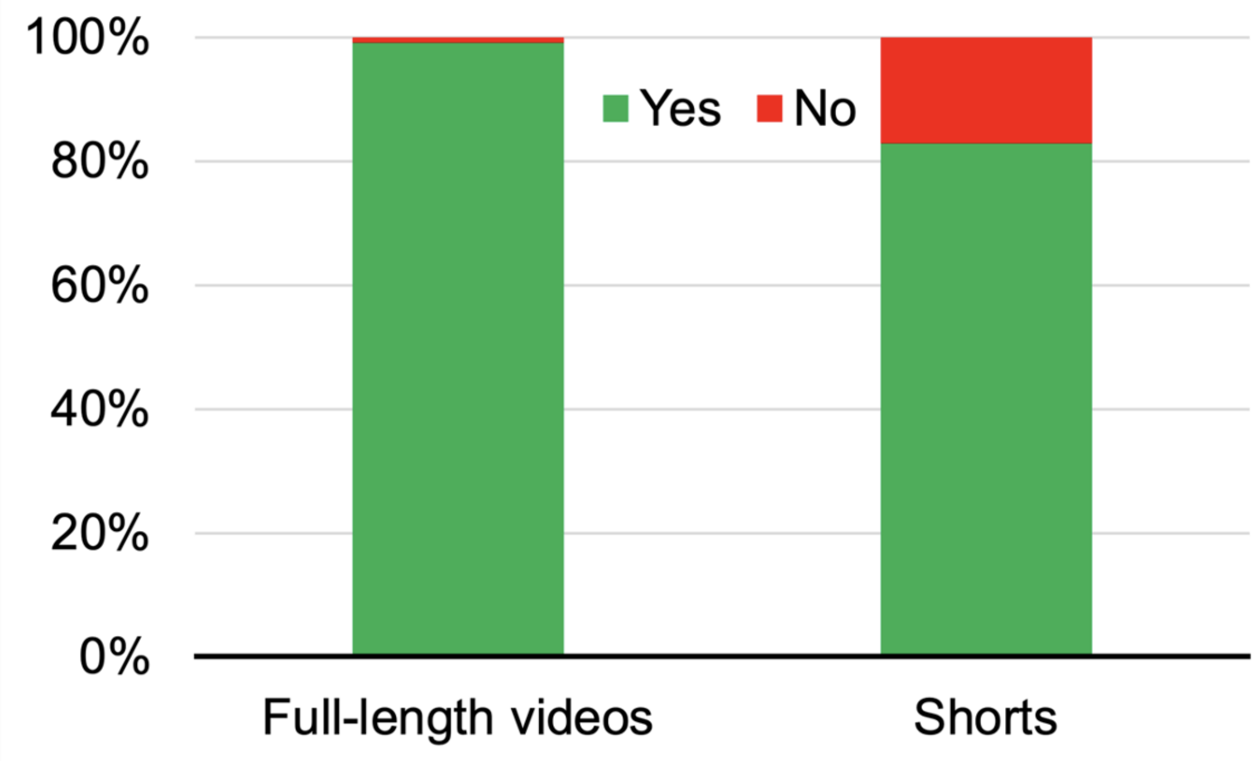
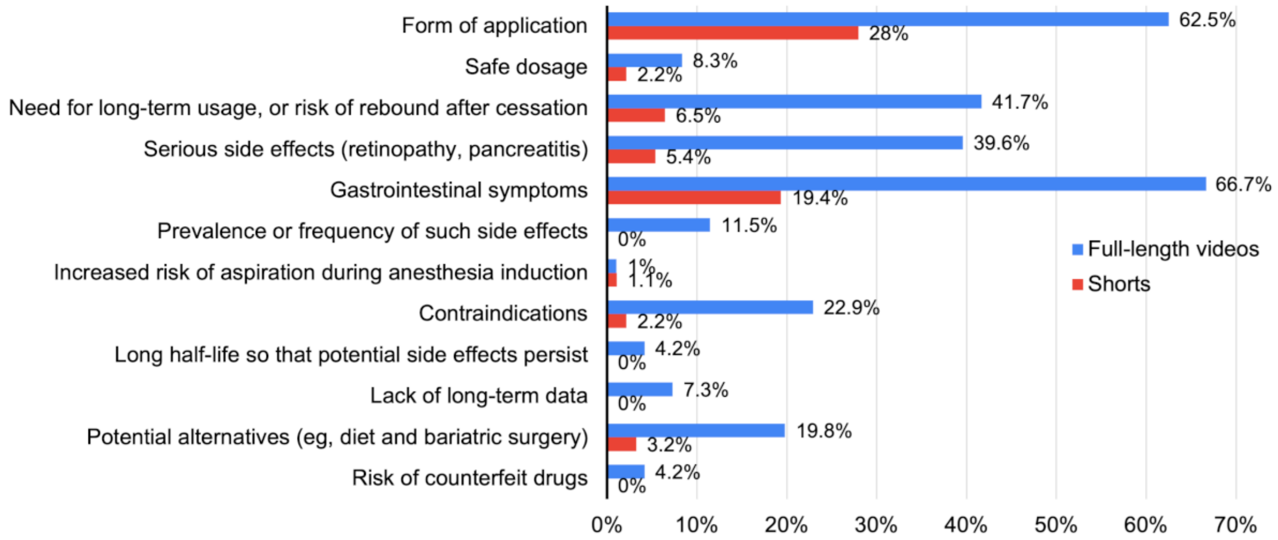


Table 2. Viewing metrics and content quality between full-length videos uploaded by YouTube-verified health source channels and other channels.

Metric	Mean (SD)		*P* value
	Health sources	Other channels	
Duration (s)	587.7 (664.0)	616.6 (510.9)	.83
View count	401,867.2 (733,982.5)	258,746.3 (439,684.8)	.41
Comment count	990.2 (1,631.5)	580.1 (1,163.6)	.32
Like count	10,371.5 (20,053.2)	4009.6 (8079.6)	.18
Channel subscriber count	1,873,152.0 (3,581,554.9)	1,682,003.5 (3,501,532.6)	.83
Video age (days)	630.7 (614.9)	425.1 (331.2)	.16
Flesch Reading Ease score	63.7 (13.3)	73.8 (10.2)	<.001
GQS[a] score	3.3 (0.6)	2.4 (0.8)	<.001
Modified DISCERN	3.1 (0.6)	2.1 (0.7)	<.001
Number of content points from custom checklist	3.5 (2.3)	2.7 (1.5)	.17

[a]GQS: Global Quality Score.

Figure 3. Percentage of full-length videos and shorts that covered the points from the custom checklist regarding the side effects and safety concerns of semaglutide.



Discussion

Principal Findings

This study found that semaglutide videos on YouTube have reached a broad audience. The 189 analyzed videos had a total view count of over 45 million. For comparison, the 98 most viewed YouTube videos on diabetic retinopathy were collectively viewed 1 million times [38]. It implied that these videos might potentially affect the perception and even health care decisions of the general public regarding the use of semaglutide. As expected, full-length videos were generally more informative than shorts. For patient education, shorts would serve better to grab the attention of the patients or make them aware of 1 or 2 particular issues related to semaglutide; whereas selected full-length videos might be more suitable to be incorporated as part of a panel discussion or public forum.

Alarmingly, the videos seldom covered the risk of counterfeit drugs. For instance, the antidiabetic drug, Ozempic, contains semaglutide that is synthesized by yeast fermentation and subsequent synthetic modification [39]. Without proper quality control of the synthetic processes, some falsified Ozempic products were found to contain contaminants such as glass particles and filler substances [39]. Meanwhile, some pharmacies would produce compounded versions of semaglutide to circumvent the patent issue. The high demand, high cost, and limited supply have led to a period of time when some patients and drug providers switched to compounded semaglutide [10]. Subsequently, the FDA stated that the compounded drugs, such as semaglutide sodium and semaglutide acetate, do not have their approval due to lack of testing, may not possess the same drug effect as semaglutide, and may even cause adverse effects (unspecified) [40,41]. Another safety issue of using compounded semaglutide is an increased risk of overdose due to suboptimal drug packaging. A recent case series reported that compounded semaglutide might be dispensed in vials instead of prefilled manufactured injection pens such as those by Ozempic and Wegovy [42]. Vials that contain large volumes of semaglutide and vials dispensed together with subpar syringes might allow for overdose much more easily during self-administration [42]. There seemed to be yet a case series on the overdose of oral semaglutide, but it would be reasoned that compounded semaglutide in the form of tablets for oral intake could have the same increased risk if each tablet did not conform to the amount of semaglutide contained in approved branded semaglutide products such as Rybelsus.

Another not uncommon risk of taking semaglutide that was often neglected by the videos was the risk of aspiration during the induction of anesthesia. One effect of semaglutide is gastroparesis, that is, reduced bowel motility and gastric emptying without any physical obstruction. This would increase the gastric volume and increase the risk of regurgitation and pulmonary aspiration of gastric contents even with the usual recommended fasting time before anesthesia [43,44]. According to a recent study, aspiration of gastric contents accounted for 5% of closed anesthesia malpractice claims in the United States during 2000-2014 [45]. Among these claim cases related to aspiration, 57% (66/115) of patients died and another 14% (16/115) suffered from permanent severe injury [45]. It implied that aspiration during anesthesia was not uncommon, and it could lead to very serious consequences. While medical organizations develop recommendations regarding the use of GLP-1 receptor agonists before operations, the optimal approach to patient data management is still being specified [46,47]. Hence, it is important for researchers and clinicians to conduct subsequent studies to optimize the fasting time and airway management strategy for patients on semaglutide who need to undergo anesthesia.

Although there have been many clinical trials on the efficacy and safety of semaglutide, most of them (if not all) had a study period of up to 2 years (104 weeks) only, such as the STEP, SUSTAIN, and PIONEER trials [37,48]. Since the use of semaglutide could last beyond 2 years and there could be a possibility of life-long usage, a lack of long-term data could mean potential risks yet to be elucidated, such as the discovery of more side effects, and potential development of drug dependence or drug resistance [49,50]. The COVID-19 vaccines may illustrate the situation of lack of long-term data. After the COVID-19 pandemic began near the end of 2019, pharmaceutical companies put huge efforts into creating vaccines that could lower the infection rate and reduce the symptoms or morbidity. By the end of 2020, at least 10 vaccines have already been introduced into the global market and authorized by governments for emergency use [51]. After several years in use, millions of people vaccinated and billions of doses administered, data have accumulated. By analyzing the retrospective data, researchers have recently found 2 new rare but potentially severe side effects of COVID-19 vaccines, namely acute disseminated encephalomyelitis and transverse myelitis [52]. This new finding may influence the decision-making of some people in the public on whether they should be vaccinated, take a booster, or choose which type of available vaccines to use. In the case of semaglutide, more data besides its weight loss and antidiabetic properties would facilitate better-informed decisions from clinicians and patients. For instance, there were cases reported on the development or recurrence of depression 1 month after taking semaglutide, which was subsequently relieved after discontinuing the drug [53]. On the other hand, a retrospective study that covered over 1.5 million patient records reported that semaglutide users had a lower risk of incident and recurrent suicidal ideation [54]. At the same time, an analysis of over 40,000 user comments posted on social media platforms has found that users of GLP-1 receptor agonists (including semaglutide) felt that the drugs have mixed effects on their mood, anxiety, and insomnia conditions [14]. Patients should be aware of the fact that many weight-loss drugs, mainly appetite suppressants, were withdrawn from the market in the past due to adverse drug reactions [55]. Therefore, in the future when long-term data become available, the safety and side effects of semaglutide could be better assessed and established.

Findings from this study echoed previous studies on Reddit content on Ozempic or semaglutide, in the sense that there is generally a lack of discussion or elaboration on the potential health risks and hazards associated with the use of Ozempic, not to mention its off-label use [12,13]. However, the risks and hazards indeed exist, such as concerns with depression and anxiety raised by social media users on YouTube and TikTok [14]. Therefore, actionable recommendations included better public health awareness campaigns to educate the public on the proper use of Ozempic or semaglutide including the potential side effects and how to manage them. Pharmaceutical companies, governments, and health authorities can organize exhibitions in shopping malls, provide easy-to-understand information on their web pages, and develop user-friendly mobile apps to engage members of the public who are interested. Future research should evaluate the effects of such activities on the knowledge level of the public on semaglutide.

This study has several limitations. First, only the first 30 full-length videos and 30 shorts were initially screened for each search word, rendering a final analysis of 189 videos. This might only represent a small proportion of the entire relevant video collection. Second, only videos in English were analyzed. The themes and foci could be different for videos produced in other languages. Third, errors might exist during computational and manual evaluations. Besides, there was not a detailed analysis of video sources, which might further enhance the findings, for example, whether videos produced by clinicians were more informative than those from general influencers. It was said that there was a tendency for the YouTube algorithm to place more "reliable" videos at the top of the search results [56], hence the presented results in this study might be biased.

Conclusions

The 189 analyzed YouTube videos on semaglutide have attracted more than 45 million views. Full-length videos were much more informative than shorts in terms of side effects and safety issues. The analyzed videos lacked coverage of several important aspects, including the increased risk of aspiration during the induction of anesthesia, the persistence of side effects due to the long half-life of semaglutide, the risk of counterfeit drugs, and the lack of long-term data. Patients should be aware that these videos may not be comprehensive enough even if they were uploaded by YouTube-verified health source channels, and hence cannot replace the consultation from the physician, who may make tailor-made recommendations and treatment plans for each patient.

Conflicts of Interest

None declared.

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Abbreviations

FDA: United States Food and Drug Administration
FRE: Flesch Reading Ease
GLP-1: glucagon-like peptide-1
GQS: Global Quality Score
HbA$_{1c}$: glycated hemoglobin
PIONEER: Peptide Innovation for Early Diabetes Treatment
STEP: Semaglutide Treatment Effect in People with obesity
SUSTAIN: Semaglutide Unabated Sustainability in Treatment of Type 2 Diabetes

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Original Paper

Evolutionary Trend of Dental Health Care Information on Chinese Social Media Platforms During 2018-2022: Retrospective Observational Study

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Abstract

Background: Social media holds an increasingly significant position in contemporary society, wherein evolving public perspectives are mirrored by changing information. However, there remains a lack of comprehensive analysis regarding the nature and evolution of dental health care information on Chinese social media platforms (SMPs) despite extensive user engagement and voluminous content.

Objective: This study aimed to probe into the nature and evolution of dental health care information on Chinese SMPs from 2018 to 2022, providing valuable insights into the evolving digital public perception of dental health for dental practitioners, investigators, and educators.

Methods: This study was conducted on 3 major Chinese SMPs: Weibo, WeChat, and Zhihu. Data from March 1 to 31 in 2018, 2020, and 2022 were sampled to construct a social media original database (ODB), from which the most popular long-text posts (N=180) were selected to create an analysis database (ADB). Natural language processing (NLP) tools were used to assist tracking topic trends, and word frequencies were analyzed. The DISCERN health information quality assessment questionnaire was used for information quality evaluation.

Results: The number of Weibo posts in the ODB increased approximately fourfold during the observation period, with discussion of orthodontic topics showing the fastest growth, surpassing that of general dentistry after 2020. In the ADB, the engagement of content on Weibo and Zhihu also displayed an upward trend. The overall information quality of long-text posts on the 3 platforms was moderate or low. Of the long-text posts, 143 (79.4%) were written by nonprofessionals, and 105 (58.3%) shared personal medical experiences. On Weibo and WeChat, long-text posts authored by health care professionals had higher DISCERN scores (Weibo P=.04; WeChat P=.02), but there was a negative correlation between engagement and DISCERN scores (Weibo tau-b [τb]=–0.45, P=.01; WeChat τb=–0.30, P=.02).

Conclusions: There was a significant increase in the dissemination and evolution of public interest in dental health care information on Chinese social media during 2018-2022. However, the quality of the most popular long-text posts was rated as moderate or low, which may mislead patients and the public.

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KEYWORDS

social media; dental health education; natural language processing; information quality assessment; dental care; dental hygiene; dentistry; orthodontic; health care information; retrospective study; observational study; user engagement; Chinese; dental practitioner; WeChat; health information; preventive care

Introduction

Social media usage has been extensively integrated into modern life. As of early April 2024, there were 5.1 billion social media users around the world, equating to 62.6% of the worldwide population [1]. As for Mainland China, active social media users numbered approximately 1.1 billion in January 2024, constituting 74.2% of its total population [2]. Social media provides a platform for everyone to disseminate health knowledge, demonstrate cases, and promote themselves [3]. The general public, especially patients, increasingly turns to social media to obtain health information and join communities that exchange medical experiences [4]. A survey conducted in China revealed that 71.9% of participants obtained health education through the internet, with 30.0% of them frequently seeking health information online [5]. The internet is the most important source of information for patients with cancer, and 80% of them use social media to communicate with others about their condition [6]. The content related to health on social media creates a rich repository of information, dynamically reflecting the public's health perceptions in real time.

The growing reliance on social media for health information is a double-edged sword. On the one hand, social media offers a wealth of readily accessible information and a platform for sharing experiences, enhancing public knowledge and communication. On the other hand, studies have shown that the quality of health information on these platforms is highly variable, which may mislead the public, including patients, and potentially cause adverse outcomes [7,8]. The National Institutes of Health explicitly encourages medical professionals to share accurate health information and curb the spread of misinformation online [9].

Social media as a library for real-world studies has garnered attention from academia. Existing studies have focused on tracking topic trends, analyzing group emotions [10,11], searching for health care development directions, predicting disease spread [12], evaluating network information quality, and highlighting the harm of misinformation dissemination [13,14].

Despite the extensive user engagement and voluminous content in Chinese social media, there remains a conspicuous gap in methodical investigations into dental health care information. This gap is particularly pronounced, given China's unique digital landscape, which is dominated by platforms such as Weibo, WeChat, and Douyin (TikTok) [8,15]. Investigating the information on these platforms could fill this void and provide Eastern insights into contemporary public perceptions and concerns regarding dental health. Although a few studies have surveyed COVID-19–related dental posts on Weibo, primarily focusing on the impact of the pandemic on patients [16,17], there is a lack of comprehensive analyses of information quality and topic trends, possibly due to limitations in research tools.

The application of artificial intelligence (AI) tools has made it possible to analyze and monitor the massive amount of information on social media [18]. Among them, natural language processing (NLP), an important branch of AI, is useful for analyzing social media content for text mining purposes [19]. Another burgeoning branch, sentiment analysis tools, can be used for public opinion analysis, such as epidemic trends [20], willingness for vaccination [10], and even presidential elections [21]. Since the emergence of Chat Generative Pretrained Transformer (ChatGPT), it has also been applied to social media research, such as popular hashtag generation algorithms [22] and the construction of lexica for online pharmacovigilance [23]. AI advancements have increased the popularity of social media research in various industries and provided guidance for their development [3,12].

This study was designed to leverage AI tools to shed light upon the changing patterns and standards of dental health care information on mainstream Chinese social media platforms (SMPs). The collected data were meticulously analyzed to identify evolving trends and assess the quality of information pertaining to dental health care. Additionally, this study probed into the determinants of audience engagement and the influence of social media information, aspiring to trace the shifting contours of public perception and the demand for dental health care. The ultimate goal was to furnish dental health care professionals with actionable insights and strategies to enhance their clinical practice and the quality of doctor-patient interactions.

Methods

Data Sources

This study was conducted on 3 major text-based SMPs in China: Weibo, WeChat, and Zhihu. Data from Match 1 to 31 in 2018, 2020, and 2022 were sampled. Weibo is a microblogging website. The WeChat public platform is a self-media platform based on the short-message service application WeChat. Zhihu is a knowledge question-and-answer (Q&A) community, as well as an original content platform.

Data Extraction

To extract relevant data for this study, a social media scraping program was developed using Python's Selenium module. The inclusion criteria specifically focused on 3 key elements: platform, time, and keywords. The time periods were divided into 3 distinct intervals: March 1-31, 2018; March 1-31, 2020; and March 1-31, 2022. The search for data extraction was conducted using a series of Chinese keywords on April 1, 2023. The translated keywords are presented in Boolean logic format in Table 1 and were divided into 3 predetermined themes (general dentistry, orthodontics, and prosthodontics) based on established classifications of subspecialties within the field of dentistry. The general dentistry section included "dental fillings," "dental cleaning," "tooth extraction," "root canal treatment," and "teeth whitening." The orthodontics section included "orthodontics," "teeth straightening," "orthodontic treatment," "braces," "dental braces," "get braces," and "retainers." The prosthodontics section included "dental crown," "overlay," "porcelain tooth," "dental implant," "implanted tooth," "tooth veneer," and "porcelain veneer." The bilingual translation table is provided in Table S1 in Multimedia Appendix 1, and the translation was based on Chinese official textbooks and the Chinese edition of authoritative English textbooks [24-26]. These keywords covered a broad spectrum of nearly all commonly used Chinese expressions related to dental practices across various specialties, ensuring that the search was comprehensive and inclusive. Notably, all posts meeting the inclusion criteria were included, irrespective of authorship or topic and without manual intervention. When a post was retrieved, it was automatically assigned to the relevant theme based on the search term. For instance, posts retrieved using the keyword "dental fillings" were classified under the general dentistry theme.

Table 1. Keywords for searching posts (translated from Chinese).

Theme	Keywords
General dentistry	"dental fillings" OR "dental cleaning" OR "tooth extraction" OR "root canal treatment" OR "teeth whitening"
Orthodontics	"orthodontics" OR "teeth straightening" OR "orthodontic treatment" OR "braces" OR "dental braces" OR "get brace" OR "retainer"
Prosthodontics	"dental crown" OR "overlay" OR "porcelain tooth" OR "dental implant" OR "implanted tooth" OR "tooth veneer" OR "porcelain veneer"

Weibo's open application programming interface (API) allowed access to all content that met the inclusion criteria. In contrast, for WeChat and Zhihu, we could rely only on the built-in search functions, which do not provide access to all the data. Zhihu required searches based on time conditions within the website. For the WeChat public platform, Sogou's WeChat search was conducted to retrieve the top 10 pages of posts based on the website's own sorting logic, representing the content that people were most likely exposed to.

The exclusion criteria were primarily based on 4 aspects. "Duplicated" content referred to posts that were entirely identical due to duplicate publication, plagiarism, or other similar reasons. Only the earliest published post was retained, and the others were removed. "Irrelevant" content referred to posts in which dental-related keywords were mentioned only briefly, while the main content focused on unrelated subjects. "Unavailable" content referred to posts where the title or abstract was accessible but the full text was no longer available, possibly due to voluntary removal or deletion by the platform. Finally, "meaningless" content included posts that were composed of incoherent or garbled text consisting of nonsensical strings of words or symbols without any thematic relevance. Upon data collection, the content from the 3 SMPs was rigorously screened according to the exclusion criteria. Posts that could potentially disrupt the integrity of the subsequent analysis were removed, and the remaining posts were included to construct a social media original database (ODB).

Database Construction

Following data collection and screening based on the inclusion and exclusion criteria, the ODB was constructed. Posts with 600 characters or more were defined as "long-text posts." Previous studies suggest that long-text posts tend to provide more comprehensive information and exhibit higher engagement levels [27]. The top 20 long-text posts with the highest level of popularity each month on the three platforms were selected to establish an analysis database (ADB) for lexical analysis with NLP tools and information quality assessment.

Evaluation Strategy

Preliminary analysis of the ODB data involved capturing author information and popularity indicators for each platform, including the number of likes or reads. The metric for popularity varied by platform. For Weibo and Zhihu, the number of likes was used. For WeChat, the number of reads was used, as WeChat users tend to use "like" functions less frequently. The top 20 long-text posts with the highest levels of popularity during each observation period were selected from each platform, totaling 180 posts constituting the ADB for text mining and information quality evaluation. The classification of author account types followed subsequently and was based primarily on usernames. Specifically, accounts with names containing medical-related terms, such as "doctor," "dentist," "hospital," or "clinic," were classified as health care professionals, whereas those without such identifiers were categorized as non–health care professionals.

Text mining analysis and information quality evaluation were conducted on the ADB. NLP tools were used for text mining analysis. Using the Jieba segmentation tool, the first step involved cleaning the text data by removing punctuation, converting all text to lowercase, and eliminating common Chinese stop words, such as "of." The cleaned text was then tokenized into individual words, or tokens, to facilitate the analysis of word frequency across the entire ADB. Python's Counter module was used to compile a frequency distribution of the keywords. The most frequently mentioned words were visualized as word clouds, and the frequencies of the top 30 words for each period or platform were visualized as heatmaps. The font size of the word cloud and the color depth of the heatmap represented the frequency of word occurrence, providing a clear representation of the prevalent topics and their temporal variation. For information quality evaluation, the DISCERN questionnaire (Multimedia Appendix 2), which is widely used in research on the quality of health material information online [28,29], was used to assess the reliability of health material and the quality of information for treatment plan selection. The DISCERN score was rated on a 5-point Likert scale, with 1 indicating low quality, 5 indicating high quality, and 3 indicating moderate quality [30]. To ensure the objectivity of evaluation, all posts were anonymized during the review and quality assessment process. The determination of account type was conducted separately from the quality scoring, ensuring that the account type did not influence the quality assessment. Given the greater complexity of the DISCERN information quality assessment, this work was conducted by 2 practicing dental professionals following the Cohen kappa consistency test. Among the 180 long-text posts in the ADB, 18 (10%) were randomly selected for independent assessment by 2 evaluators, resulting in a Cohen kappa coefficient of 0.84, indicating reliable consistency between the results of the 2 evaluators.

Statistical Analysis

Statistical analysis was performed using SPSS software version 25 (IBM Corp). Descriptive results are presented as the median (25th-75th percentile) for quantitative data. The Shapiro-Wilks test and the Levene test were performed to determine the normality and homogeneity of variance, respectively. The Mann-Whitney U test and the Kruskal-Wallis test, followed by Bonferroni correction, were used to compare nonparametric data among the groups. The Kendall tau-b (τb) correlation coefficient was calculated to evaluate the potential relationships between the parameters. The significance level was set at $P<.05$.

Ethical Considerations

This study did not seek ethical approval, as it exclusively analyzed publicly available data from SMPs, which were voluntarily shared by users in the public domain. All data has been deidentified; account information collected was used solely for research analysis, and relevant results are presented in aggregate to ensure that no personally identifiable information is disclosed.

Results

Post Details

The research methodology is depicted in Figure 1. According to the search keywords, we retrieved a total of 220,869 Weibo posts. After applying the exclusion criteria, 64,039 (29%) posts were deleted, and the remaining 156,830 (71%) posts were included in the ODB. Among Weibo posts, 2458 (1.6%) were long-text posts. The distribution and proportion of posts and long-text posts for each theme in each observation period are shown in Table S2 in Multimedia Appendix 1. Results showed that over time, there has been significant growth in the content related to dental health care on Weibo, with the number of posts increasing by more than 4 times (Figure 2A). In terms of themes, in 2018, there was a greater proportion of posts and long-text posts discussing general dentistry–related topics, accounting for 49.5% (n=7952) and 55.7% (n=305) of the total, respectively. In 2022, 52.5% (n=42,701) of the posts and 47.5% (n=563) of the long-text posts discussed orthodontics topics (Figure 2D), surpassing the proportion of general dentistry topics. In addition, 543 (0.34%) posts from WeChat and 210 (0.13%) posts from Zhihu were included in the ODB.

Figure 1. Overview of data-processing flowchart. ADB: analysis database; NLP: natural language processing; ODB: original database.

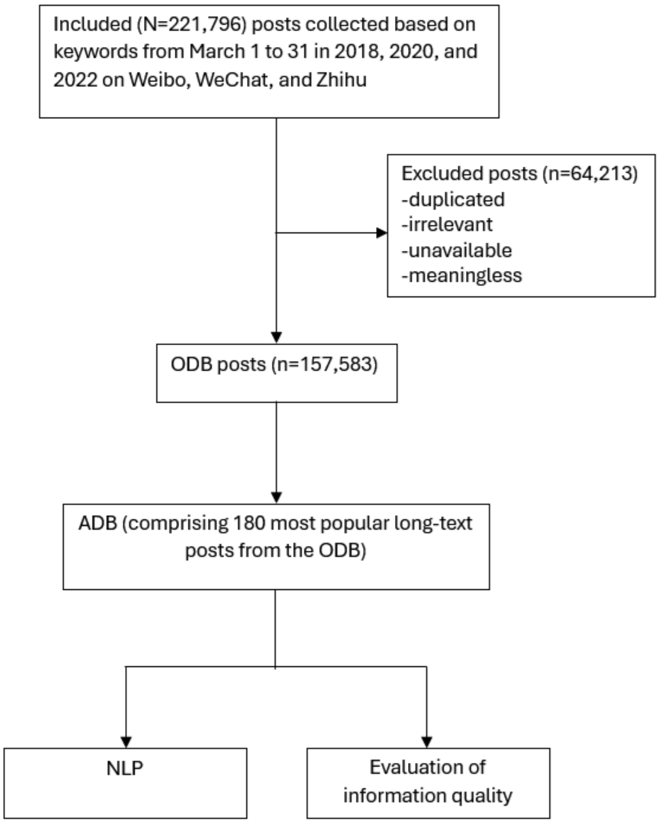
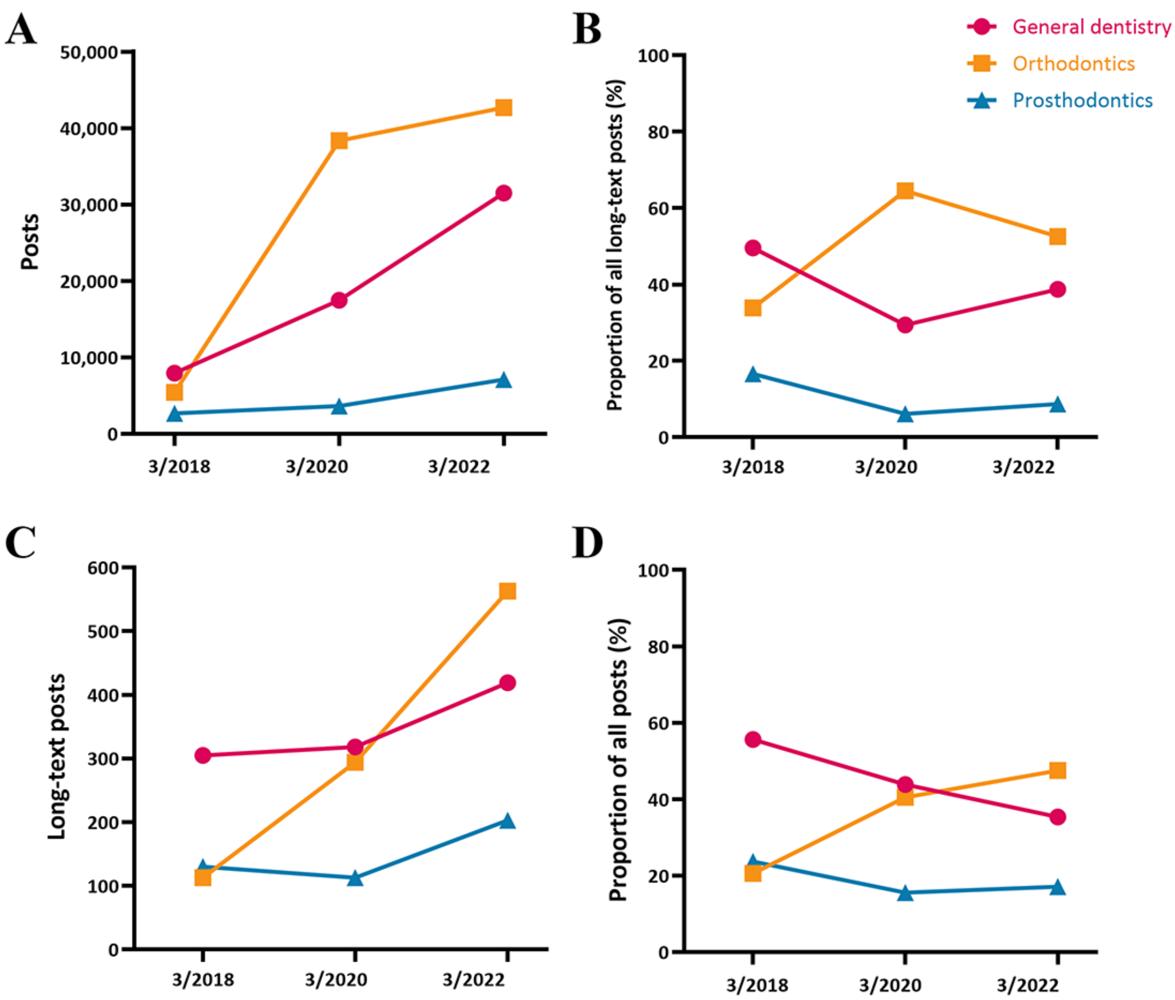


Figure 2. Numbers and proportions of Weibo posts (A, B) and long-text Weibo posts (C, D) on each theme in March 2018, 2020, and 2022.



The ADB comprised 180 most popular long-text posts (n=60, 33.3%, posts from each platform) during the observation period. There were significant differences in the engagement of long-text posts published on Weibo, WeChat, and Zhihu between March 2018, 2020, and 2022 (*P*<.001; Figure 3 and Table S3 in Multimedia Appendix 1). The median (IQR) of likes on Weibo increased from 5.5 (IQR 3.25-12.5) in 2018 to 149.5 (IQR 87.75-454.75) in 2022. Similarly, the median number of likes on Zhihu increased from 63 (IQR 29.25-161.25) in 2018 to 214 (IQR 126-435.5) in 2022. In contrast, the median (IQR) of WeChat reads was 30,000 (IQR 20,000-54,250) in 2018, decreased to 13,000 (IQR 11,000-18,000) in 2020, and then increased to 25,500 (IQR 15,250-48,000) in 2022. Interestingly, 143 (79.4%) long-text posts were written by non–health care professionals, including patients and some medical self-media accounts. In terms of topics, there were 105 (58.3%) posts about personal medical experiences, a number significantly greater than the content of health education and popular science provided by dental health care professionals.

In the ADB, the median (IQR) of the DISCERN score for WeChat long-text posts was 3 (IQR 2-4), that for Weibo was 2 (IQR 2-3), and that for Zhihu was 2 (IQR 2-3). There was a significant difference in the DISCERN scores between WeChat and Weibo (*P*=.03; Figure 4 and Table S4 in Multimedia Appendix 1). The scores for each question in the DISCERN questionnaire corresponding to each platform are presented in Table S5 in Multimedia Appendix 1. Among the 180 long-text posts in the ADB, only 37 (20.6%) were authored by dental health care professionals, while the DISCERN scores of these long-text posts on Weibo and WeChat were significantly higher than those of long-text posts written by non–health care professionals. Specifically, for Weibo the median (IQR) of the DISCERN score of health care professionals' long-text posts was 3 (2.5-3.5), while that of non-health care professionals' was 2 (2-3); for WeChat the median (IQR) of the DISCERN score for health care professionals' long-text posts on WeChat was 4 (IQR 4-4), while that for non–health care professionals was 3 (IQR 2-3). The difference was statistically significant (Weibo *P*=.04; WeChat *P*=.02). Furthermore, there was a significant negative correlation between information quality (DISCERN score) and engagement (Weibo τb=–0.45, *P*=.01; WeChat τb=–0.30, *P*=.02). No similar significant negative correlation was observed for the Zhihu long-text posts.

Figure 3. Violin plots of engagement indicators for long-text posts on Weibo (A), WeChat (B), and Zhihu (C) in March 2018, 2020, and 2022.

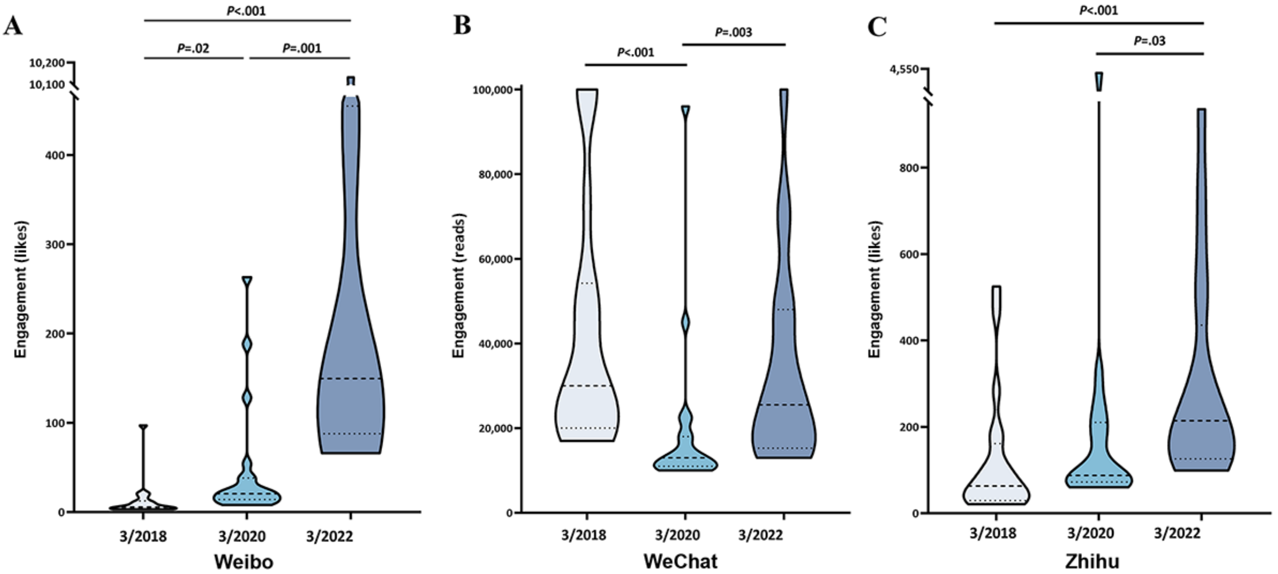
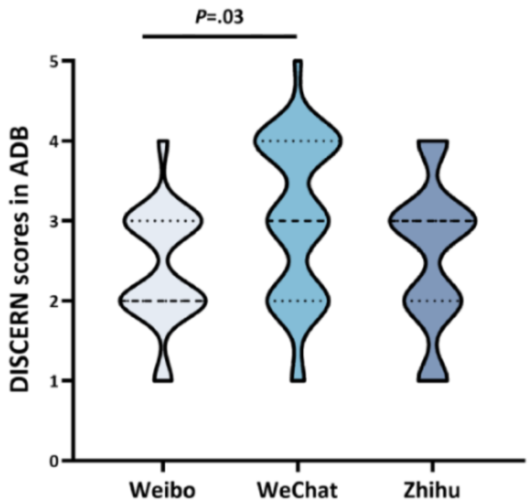


Figure 4. Violin plot of the DISCERN scores of long-text posts on the 3 SMPs in the ADB during the observation period. ADB: analysis database; SMP: social media platform.



Text mining analysis of the ADB using NLP tools was visualized as word clouds and heatmaps of the 3 observation periods (Figure 5) and the 3 platforms (Figure 6). For optimal readability, the bilingual word cloud figures are shown in Multimedia Appendices 3 and 4. The frequencies of the top 30 words in each time period and platform are presented in Tables S6 and S7, respectively, in Multimedia Appendix 1. In the word clouds, “teeth” and “doctor” were the most frequently mentioned core keywords. The most prominent terms in the 2018 word cloud were “straightening,” “braces,” “orthodontics,” “prosthodontics,” “tooth extraction,” “root canal,” “health,” and “metal” (crown). In the 2020 word cloud, the most prominent terms were “straightening,” “orthodontics,” “braces,” “tooth extraction,” “invisible,” “deciduous teeth,” “follow-up visit,” and “retention.” In the 2022 word cloud, the most prominent terms were “straightening,” “orthodontics,” “feeling,” “brush teeth,” “gums,” “tooth extraction,” “implant,” and “dental cleaning.” This trajectory suggested that over time, orthodontics and tooth extraction have consistently been the most mentioned terms in Chinese social media in regard to dental health care. However, it could be seen from the word clouds and heatmaps that there was a shift from topics such as root canal treatments and metal crown restoration, which were discussed more often in 2018, to topics such as teeth brushing, gingival health, and dental cleaning by 2022, indicating the concentration on periodontal health and early prevention of dental diseases. There was also an increase in discussions related to dental implantation and orthognathic surgery. The most prominent terms in the Weibo word cloud were “straightening,” “orthodontics,” “wisdom tooth,” “tooth extraction,” and “gum.” The most prominent terms in the WeChat word cloud were “straightening,” “brush teeth,” “health,” “deciduous teeth,” “orthodontics,” and “gum.” In Zhihu, the most prominent terms were “orthodontics,” “braces,” “feeling,” “straightening,” “tooth extraction,” and “follow-up visit.”

Figure 5. Heatmap of the frequencies of the top 30 words of dental health care information in the ADB in March 2018, 2020, and 2022. Orthodontics and tooth extraction have consistently been the most mentioned terms in Chinese SMPs in regard to dental health care. However, there was a shift from topics such as root canal treatments and metal crown restoration, which were discussed more often in 2018, to topics such as teeth brushing, gingival health, and dental cleaning by 2022. ADB: analysis database; SMP: social media platform.

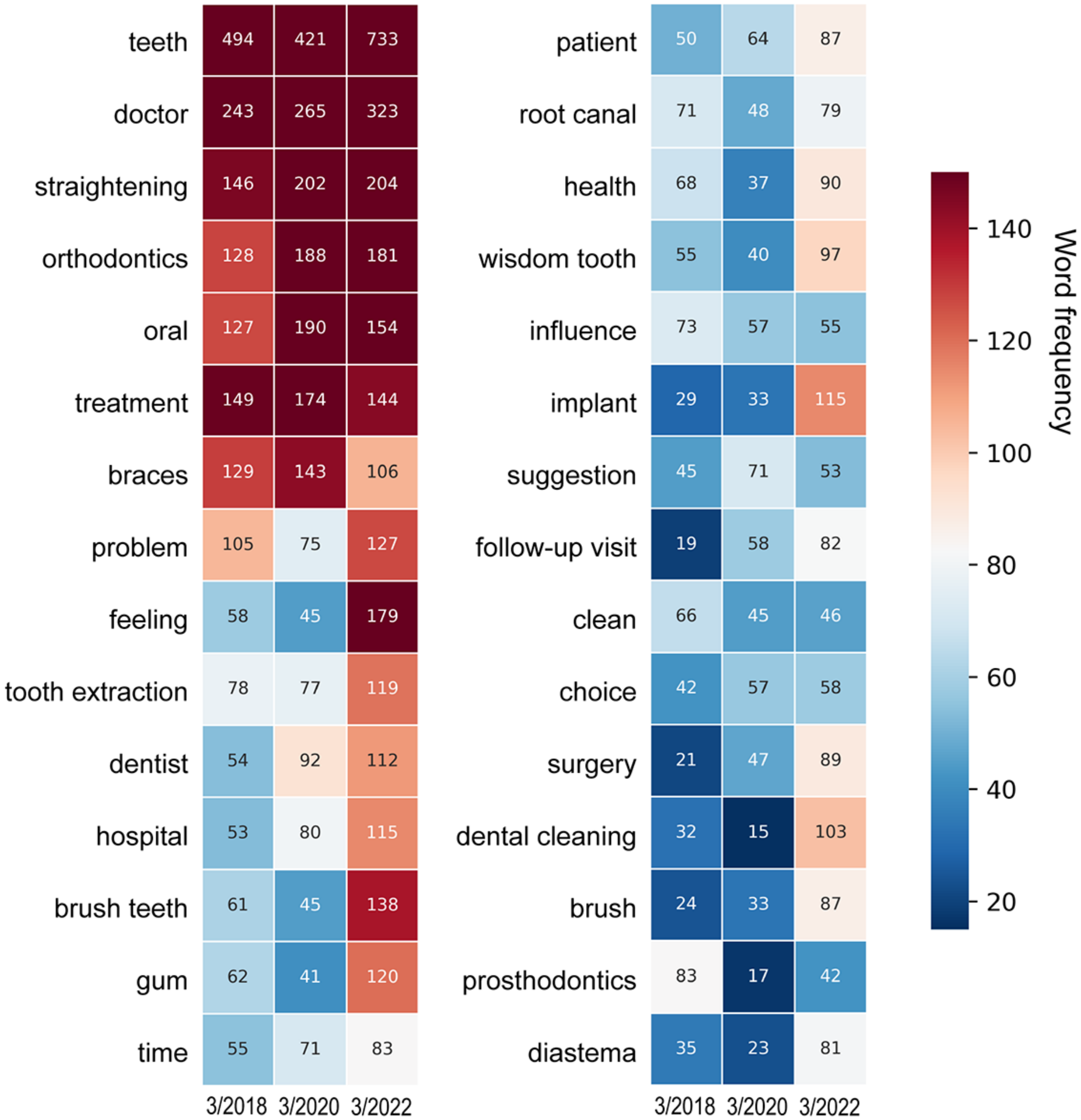
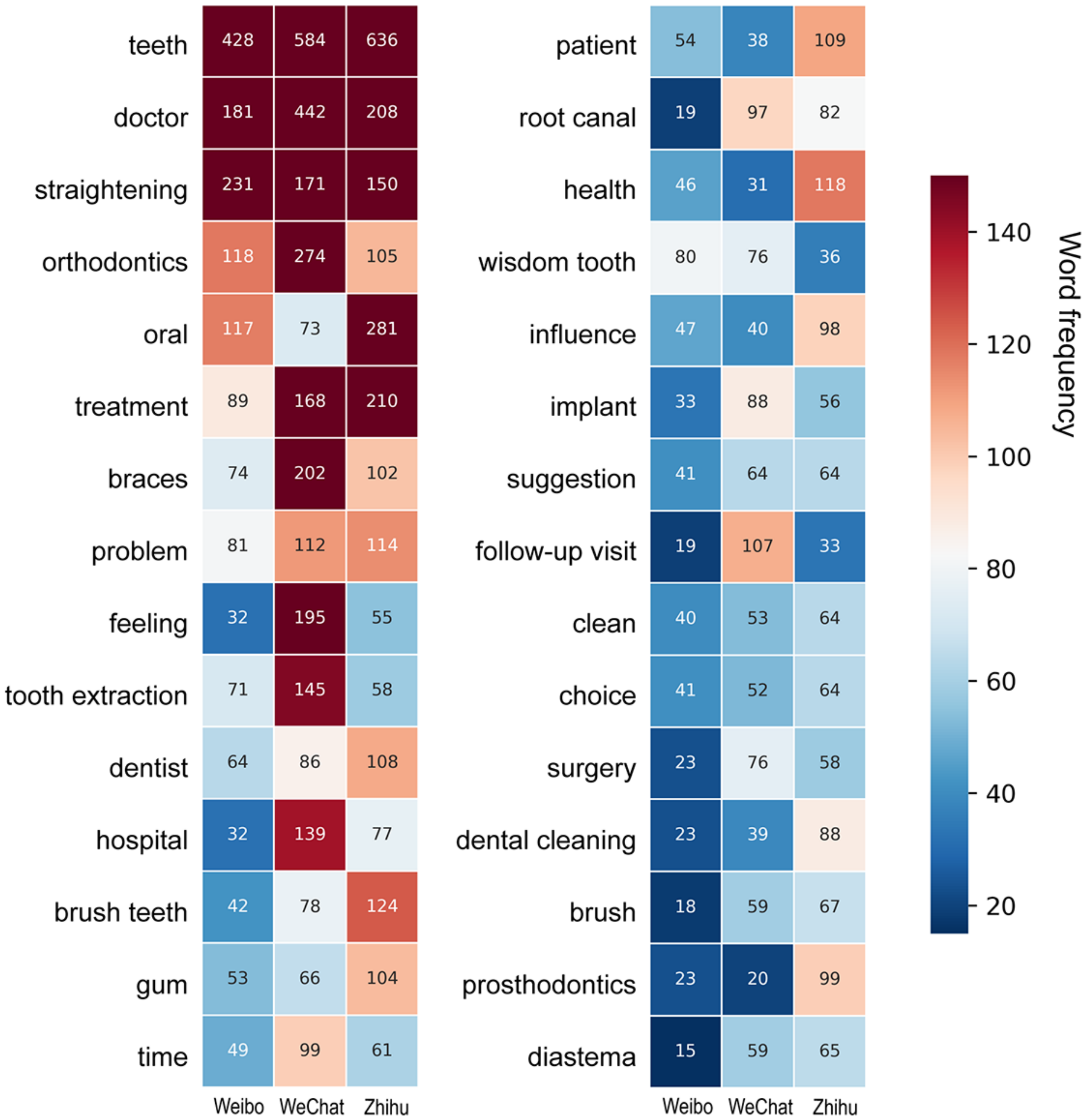


Figure 6. Heatmap of the frequencies of the top 30 words of dental health care information across the 3 SMPs in the ADB. ADB: analysis database; SMP: social media platform.



Discussion

Principal Findings

This study extracted dental health care-related content from Weibo, WeChat, and Zhihu for March 2018, 2020, and 2022 and constructed an ODB. We also constructed an ADB consisting of the most popular long-text posts on each platform. By analyzing the nature, themes, public engagement, information quality, and word frequency, this study tracked the evolution of Chinese social media content related to dental health care. In the field of dentistry, previous studies have investigated SMPs, such as Facebook, Instagram, and YouTube, analyzing topic trends and evaluating the adequacy of these platforms as patient sources of information or education [31-33]. Graf et al [32] explored the nature and potential attitude differences in German orthodontic content on Twitter and Instagram, finding “getting braces” and “getting braces removed” to be the most crucial events for orthodontic patients, and Instagram contained more posts with positive emotions. Yahya et al [34] studied the 63 most viewed videos on YouTube related to miniscrew anchorage and found that the information quality of videos uploaded by dental professionals is not perfect, especially in terms of treatment duration, maintenance, and costs. Similarly, Samur et al [35] reported that the reliability and information quality of content related to facial trauma on SMPs are generally low, highlighting the need for caution when recommending SMPs as a source of facial trauma–related information. To the best of our knowledge, similar systematic research on dental health care information on Chinese SMPs has not been reported in the literature.

Our findings revealed significant growth, by more than 4 times, in Weibo posts concerning dental health care from 2018 to 2022, with the fastest increase observed in the discussion of orthodontics, surpassing general dentistry content since 2020. The long-text posts with the highest engagement on Weibo and Zhihu platforms in the ADB also displayed an upward trend. SMPs plays a progressively significant role in people's lives [36], and our data confirmed that the amount of dental health care–related content on Chinese SMPs is also steadily increasing. Yang et al [37] reported that Instagram accounts created by oral and maxillofacial surgery residency programs increased exponentially from the period of the 7 months from June to December 2020 compared to the 18 months from December 2018 to May 2020. This indirectly reflected the increasing trend of dental health care information on US SMPs, which is consistent with our results.

In the ADB, which consisted of the most popular content on the 3 SMPs, 79.4% of the long-text posts were written by individuals without a health care background, and 58.3% shared personal medical experiences. This finding was consistent with the study by Samur et al [35], who found that personal experience–based content posted by laypersons receives more interactions. This phenomenon aligns with the theories of cognitive dissonance and selective exposure: people are inclined to consume content that is more similar and relatable to them [38,39]. It is worth noting that long-text posts authored by health care professionals received significantly higher DISCERN scores, indicating superior information quality. Nonetheless, these long-text posts were not rewarded with the same level of engagement as those written by nonprofessionals. Furthermore, there was a negative correlation between the DISCERN scores and engagement observed on Weibo and WeChat, suggesting that high-quality information may not generate a larger audience. Similar trends were observed in the study by Hegarty et al [40], who found that the most viewed YouTube videos are less helpful. However, a study by Kovalski et al [41] on oral leukoplakia–related content showed that more reliable videos of higher quality receive more likes and have higher viewing rates and interaction indices. Studies indicate that misinformation often features sensational headlines that are easy to understand without deep engagement or critical thinking. These posts quickly capture attention, eliciting strong emotional responses that prompt users to like, comment, and share [9,42]. The positive feedback loop of social media algorithms amplifies the spread of low-quality content, indirectly suppressing accurate, evidence-based, high-quality information and creating information silos [43].

Peek et al's [44] guidelines for mental health education and advocacy noted that using language that is more accessible to the public instead of medical jargon can make popular science even more popular. However, in the study by Yahya et al [34] on 31 videos uploaded by dental professionals about miniscrew anchorage on YouTube, only 2 videos avoided using technical terms. The remaining videos all used them, with 80.7% failing to provide explanations. The excessive use of technical terms, obscure and complicated principles, and stagnant formatting in health education materials may meet the requirements of the DISCERN questionnaire and thus can elicit high information quality scores. However, several studies have revealed that this may result in a loss of readers' interest and psychological resonance [35,39]. Conversely, using psychologically assisted writing techniques that foster affinity may prove more effective in attracting readers and achieving better health education outcomes. To effectively disseminate health care knowledge, dental professionals should improve writing methodologies, while ensuring the accuracy and high quality of the evidence-based information conveyed. For instance, incorporating patient-centered medical experiences and visual materials can attract more readers and stimulate discussions. This could ultimately make a greater impact and benefit a larger audience. In addition to health care professionals, governments and health departments should take measures to promote the dissemination of high-quality health information online, while enhancing the public's critical-thinking skills to discern true from false information and make informed decisions [9,13]. Technology platforms should transparentize and optimize recommendation algorithms and regulate the quality of health [9,42].

Oliveira et al [45] performed 2 searches on Twitter using the keywords "dentist" and "teeth" and generated a word cloud based on the collected tweets, finding that the most commonly used terms are "third molar" and "orthodontic appliance." On this basis, they determined that the most common dental needs during the COVID-19 pandemic were pain, urgencies, and orthodontic follow-ups. Graf et al [32] showcased word clouds of orthodontically posts with different sentiments. Positive posts revolved around the effectiveness of orthodontic treatment and the excitement of wearing or removing braces, while negative posts covered complaints about appointments, waiting times, pain, and side effects during orthodontic treatment. In this study, word clouds were generated for 3 SMPs during the observation period. We found that "teeth" and "doctors" are consistently the core subjects in the field of dental health care on Chinese SMPs. In line with the findings of Oliveira et al [45], orthodontics and tooth extraction have been the most discussed topics across different years and platforms, suggesting that the most prevalent keywords on Chinese SMPs are similar to those in other languages. Moreover, there has been a noticeable shift from topics such as endodontic treatment or dental crown restoration in 2018 to a stronger emphasis on topics such as periodontal maintenance and early prevention by 2022. This is indicated by the increased discussions around teeth brushing, gingival health, and dental cleaning. Additionally, topics such as dental implantation and orthognathic surgery have gradually gained popularity in the word clouds, suggesting that concepts in these areas are becoming more universally accepted by the public. Patients interest has gradually evolved from basic dental treatments to functional dentofacial aesthetics and preventative care.

This study demonstrates the increase in the quantity and engagement of dental health information on Chinese social media from 2018 to 2022, emphasizing the importance of offering high-quality information online in the digital age. Additionally, we explored changes in public interest in dental topics, providing insights into the evolving awareness of patients. This highlights the need for dental health care providers to supplement evidence-based information, particularly on topics of interest to the general public. They should take measures to improve the popularity of online scientific materials and mitigate the impact of low-quality information.

Limitations

This study has a few limitations. First, there are constrained capabilities of NLP tools when evaluating complex indicators, such as DISCERN scores, across large datasets, as well as identifying meaningless content, such as bot-generated text. Consequently, this task was performed manually as a substitute, which inevitably restricted the scale of relevant data analysis, necessitating the use of sampling methods rather than analyzing the entire dataset. Second, platforms such as WeChat and Zhihu do not provide a straightforward way to access comprehensive data, prompting us to use alternative strategies for collecting a representative sample. We also note that including data from 2019 and 2021 could have resulted in more continuous and reliable sampling points. Third, this study was retrospective in design, while, given the dynamic nature of social media, some users may have hidden or deleted previously published posts, potentially introducing bias into the findings. Finally, expanding the scope of this study to include data from additional sources, such as government agencies or dental associations, would facilitate a comparative analysis. Future research could focus on these aspects.

Conclusion

During 2018-2022, despite the increase in the dissemination and evolution of public interest in dental health care information on Chinese social media, the quality of the most popular long-text posts was rated as moderate or low, which may mislead patients and the public. These findings could yield insights for dental practitioners, investigators, and educators into patients' evolving perceptions and interests in the era of social media. We also emphasize the importance of enhancing the provision of high-quality and popular health information on Chinese SMPs.

Acknowledgments

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Data Availability

The databases generated and analyzed in this work are available from the corresponding author upon reasonable request.

Authors' Contributions

ZZ and ZY contributed equally to this work. BF, LX, and ZL also contributed equally to this work. ZZ was responsible for conceptualization, methodology, formal analysis, investigation, and writing—original draft; ZY for conceptualization, methodology, and investigation; QW for software, investigation, data curation, and writing—review; RL for investigation, visualization, writing—review, and supervision; HL for conceptualization and methodology; WG for formal analysis and writing—review; ZL for writing—review and project administration; LX for methodology, writing—review, and supervision; and BF for conceptualization, writing—review and editing, supervision, and funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Chinese keywords for searching posts and their corresponding English translation; distribution of the number and proportion of Weibo and long-text posts on different themes in the ODB; engagement of long-text posts on Weibo, WeChat, and Zhihu in the ADB; DISCERN scores of long-text posts on the 3 SMPs in the ADB during the observation period; DISCERN scores of each question of long-text posts on the 3 SMPs in the ADB during the observation period; frequencies of the top 30 words in the ADB in March 2018, 2020, and 2022 and on Weibo, WeChat, and Zhihu. ADB: analysis database; ODB: original database; SMP: social media platform.

[DOCX File , 35 KB - infodemiology_v5i1e55065_app1.docx]

Multimedia Appendix 2

DISCERN health information quality assessment questionnaire.

[DOCX File , 19 KB - infodemiology_v5i1e55065_app2.docx]

Multimedia Appendix 3

Word clouds in English.
[PDF File (Adobe PDF File), 24432 KB - infodemiology_v5i1e55065_app3.pdf]

Multimedia Appendix 4
Word clouds in Chinese.
[PDF File (Adobe PDF File), 12340 KB - infodemiology_v5i1e55065_app4.pdf]

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Abbreviations

ADB: analysis database
AI: artificial intelligence
NLP: natural language processing
ODB: social media original database
SMP: social media platform

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Original Paper

Large-Scale Deep Learning–Enabled Infodemiological Analysis of Substance Use Patterns on Social Media: Insights From the COVID-19 Pandemic

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Abstract

Background: The COVID-19 pandemic intensified the challenges associated with mental health and substance use (SU), with societal and economic upheavals leading to heightened stress and increased reliance on drugs as a coping mechanism. Centers for Disease Control and Prevention data from June 2020 showed that 13% of Americans used substances more frequently due to pandemic-related stress, accompanied by an 18% rise in drug overdoses early in the year. Simultaneously, a significant increase in social media engagement provided unique insights into these trends. Our study analyzed social media data from January 2019 to December 2021 to identify changes in SU patterns across the pandemic timeline, aiming to inform effective public health interventions.

Objective: This study aims to analyze SU from large-scale social media data during the COVID-19 pandemic, including the prepandemic and postpandemic periods as baseline and consequence periods. The objective was to examine the patterns related to a broader spectrum of drug types with underlying themes, aiming to provide a more comprehensive understanding of SU trends during the COVID-19 pandemic.

Methods: We leveraged a deep learning model, Robustly Optimized Bidirectional Encoder Representations from Transformers Pretraining Approach (RoBERTa), to analyze 1.13 billion Twitter (subsequently rebranded X) posts from January 2019 to December 2021, aiming to identify SU posts. The model's performance was enhanced by a human-in-the-loop strategy that subsequently enriched the annotated data used during the fine-tuning phase. To gain insights into SU trends over the study period, we applied a range of statistical techniques, including trend analysis, k-means clustering, topic modeling, and thematic analysis. In addition, we integrated the system into a real-time application designed for monitoring and preventing SU within specific geographic locations.

Results: Our research identified 9 million SU posts in the studied period. Compared to 2019 and 2021, the most substantial display of SU-related posts occurred in 2020, with a sharp 21% increase within 3 days of the global COVID-19 pandemic declaration. Alcohol and cannabinoids remained the most discussed substances throughout the research period. The pandemic particularly influenced the rise in nonillicit substances, such as alcohol, prescription medication, and cannabinoids. In addition, thematic analysis highlighted COVID-19, mental health, and economic stress as the leading issues that contributed to the influx of substance-related posts during the study period.

Conclusions: This study demonstrates the potential of leveraging social media data for real-time detection of SU trends during global crises. By uncovering how factors such as mental health and economic stress drive SU spikes, particularly in alcohol and prescription medication, we offer crucial insights for public health strategies. Our approach paves the way for proactive, data-driven interventions that will help mitigate the impact of future crises on vulnerable populations.

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KEYWORDS

substance use; social media; deep learning; Robustly Optimized Bidirectional Encoder Representations from Transformers Pretraining Approach; human-in-the-loop; COVID-19

Introduction

Overview

Substance use (SU) is a pressing public health issue in the United States, with 58.7% of Americans aged ≥12 years using tobacco, alcohol, or illicit drugs in 2020, with an annual increase of 3.8% [1]. This includes 50% alcohol users, 18.7% tobacco users, and 13.5% illicit drug users [1]. The consequences of SU, such as deteriorating health and increased crime, have led to a significant rise in drug overdose deaths, reaching >91,000 in 2020 and >106,000 in 2021 [2]. The economic cost is substantial, with an estimated US $249 billion for alcohol misuse and >US $193 billion for illicit drug use annually [3]. The financial and health repercussions of SU demand a strategic focus on prevention research. Allocating resources to explore and counteract the causes of drug use can lead us toward a healthier and more economically resilient society.

Background

The year 2020, commonly referred to as the COVID-19 year, holds historical significance for health care researchers due to the emergence of the deadly coronavirus. The COVID-19 pandemic exhibited a profound connection with preexisting SU and mental health issues [4-6]. Various consequences, such as economic instability, social isolation, bereavement, and restricted access to health care services, escalated anxiety and stress levels among the population [7-10]. According to the Centers for Disease Control and Prevention, data as of June 2020 revealed that 13% of Americans reported initiating or intensifying SU as a means of coping with stress or emotions related to COVID-19 [11]. The Overdose Detection Mapping Application Program reports indicated an 18% rise in drug overdoses in the early months of the pandemic compared to the same period in 2019 [12]. Several other studies [13-15] also highlighted that changes in drug availability contributed to a rise in deaths related to illicit opioid use; for instance, if heroin became less accessible, individuals might resort to the more potent fentanyl.

Simultaneously, the COVID-19 pandemic led to internet use of up to 70% [16], leading to a record 11.1% growth in Twitter's (subsequently rebranded X) user base in 2020. This surge in social media engagement, while providing a vital connection for many, has also been directly linked to an increase in SU [17]. Research studies [18-22] have indicated the negative impacts of social media on mental health, including increased anxiety, depressive symptoms, and psychological burdens related to COVID-19, which have been correspondingly linked to an increase in SU as individuals seek coping mechanisms. Notably, previous studies [23-27] have also shown a strong correlation between social media use and SU, with evidence of users being influenced to use substances by their peers' behavior, such as tagging their social connections in their posts [26,27]. A few research studies [23,25] provide evidence that higher levels of exposure to substance-related content tend to develop positive norms and attitudes toward alcohol and drug use. Likewise, a study also showed that adolescents who are regularly active on social media have a greater likelihood of subsequent tobacco or cannabis use initiation [24]. In our research, we aim to identify these gaps in the knowledge of SU during the COVID-19 pandemic by analyzing social media content and making a comparison with pre- and postpandemic years. We achieve this through a deep learning model alongside various statistical methods. By comprehending the findings, the ultimate goal is to support public health sectors to develop more effective prevention and intervention strategies to control and prevent SU during global crises.

Related Studies

The onset of the COVID-19 pandemic has notably intensified global research on drug crises. Numerous studies [6,7,28-50] have examined the intersection of drug use and the pandemic's societal impacts. These investigations commonly revealed a significant correlation between the pandemic and shifts in SU patterns, impacting both people with or without SU disorder (SUD). Various studies [6,28,36,37] evidenced that the disruption in health care services during the COVID-19 pandemic period primarily impacted people with SUD and was thus linked to higher abuse of substances. However, many of those research studies relied on data from small cohorts [18,22,29,30] that predominantly used methodologies such as surveys or interviews for data collection. Few studies [30,35,39-41,47,48,51] have used social media data to explore SU during the pandemic. However, the scope of such studies often remains limited to peak pandemic periods and typically focuses on specific types of drugs, such as alcohol, tobacco, or opioids. Only 2 of the studies [14,52] accounted for multiple drug types (that are mostly consumed) to study the correlation between COVID-19 and use of substances, but they still did not consider other drug types (that are less widely used) to check if the use was altered during the global crisis. Likewise, most research only accounted for the peak pandemic period to study the SU trend during COVID-19. Only the study by Omare et al [47] accounted for the prepandemic period (2016-2020) as the baseline to compare the SU trend before the COVID-19 pandemic. Essentially, it established 2 prepandemic baselines, that is, 2016 to 2018 and 2018 to 2019, and compared SU trends over the studied period. However, it did not account for the postpandemic period or whether the SU was altered due to the consequences of COVID-19. This highlights a gap in the literature, underscoring the need for more expansive research that covers various substance types and multiple time frames to better understand the long-term impacts of the pandemic on drug use patterns.

Prominent national agencies such as the National Survey on Drug Use and Health [1], the National Institute on Drug Abuse

(NIDA) [Centers for Disease Control and Prevention [2], and the Substance Abuse and Mental Health Services Administration [50] routinely perform national-level analyses of drug use. Traditionally, these reports are based on survey methodologies, which may involve a relatively limited participant pool. The COVID-19 pandemic further complicated these efforts, limiting face-to-face data collection and necessitating a shift toward online surveys. This change compromised the depth and reliability of data in 2020; for example, the 2020 National Survey on Drug Use and Health report only includes data from the first quarter and used web-based methods for the fourth quarter [1]. In addition, the transition from *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* to *The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* during this period introduced challenges in comparing the new data with those from previous years due to methodological changes.

The existing studies were limited to fewer drug types and demographics of smaller cohorts that mainly focused on the peak pandemic period and did not account for trends before and after the pandemic. Thus, in our research, we have aimed to use large-scale social media data to examine a broader spectrum of drug types, aiming to provide a more comprehensive understanding of drug use trends during the COVID-19 pandemic.

Previous research on social media often used keyword-based and traditional machine learning approaches to analyze drug-related content. Notably, studies [52,53] have identified potential SU incidents using keyword-based methods, that is, by detecting specific drug names such as Adderall, oxycodone, quetiapine, metformin, cocaine, marijuana, weed, methamphetamine, tranquilizer, etc. However, these keyword-based methods are limited, as they often fail to discern the context in which terms are used, resulting in significant ambiguities [54]. Users frequently use slang and metaphorical language that these models cannot adequately interpret. In addition, other studies [53,55-57] have used traditional machine learning classifiers such as naive Bayes, support vector machines, and decision trees. While enhancements such as word2vec for word embedding have been applied, these methods typically struggle with the subtleties of language used in social media. Despite some advancements in sequence-based models, such as long short-term memory or convolutional neural networks [54,58], these approaches still fall short of fully understanding contextual meanings, a challenge effectively addressed by the attention mechanism [59]. Thus, in our research, we have adopted the Robustly Optimized Bidirectional Encoder Representations from Transformers Pretraining Approach (RoBERTa) [60] model, which leverages an advanced attention mechanism to overcome these limitations. This implementation represents a novel application in the analysis of large-scale social media data for drug use studies. Despite the challenges posed by limited annotated data availability, we have incorporated an iterative learning process inspired by human-in-the-loop (HITL) [61] and active learning techniques [62] to further enhance the accuracy of our model. This approach not only refines the model with each iteration but also focuses on learning from the most informative data points, streamlining the data annotation process.

In summary, in this research, we sought to study a large amount of data from Twitter spanning a 3-year period, including the prepandemic (2019) and postpandemic (2020) periods as baseline and consequence periods, to identify the patterns of drug use using a deep learning model (RoBERTa) and various other statistical methods (trend analysis, k-means clustering, topic analysis, and thematic analysis), which are explained in the Methods section in detail. In addition to this, we also aim to analyze different types of drugs and themes in the SU discourse. Specifically, we aim to answer the research questions presented in Textbox 1.

Textbox 1. Research questions.

1. How did the discourse on substance use (SU) evolve on Twitter (subsequently rebranded X) from 2019 to 2021, and what variations existed in the distribution of different substances during this time?
2. Following the announcement of the pandemic, what were the primary substance types that garnered significant discussion, and what were the themes of these dialogues?
3. How did the prevalence of the studied theme influence various types of substances during the underlying study period?
4. How did the identified themes correlate with the substance types?
5. What primary discussion topics arise from k-means analysis, specifically during the study period?
6. To what degree does the classifier's effectiveness in pinpointing SU-related tweets during the pandemic align with or differ from GPT-3?
7. How has the overall system contributed to the real-time tracking of SU, as evidenced by the research?

Contributions

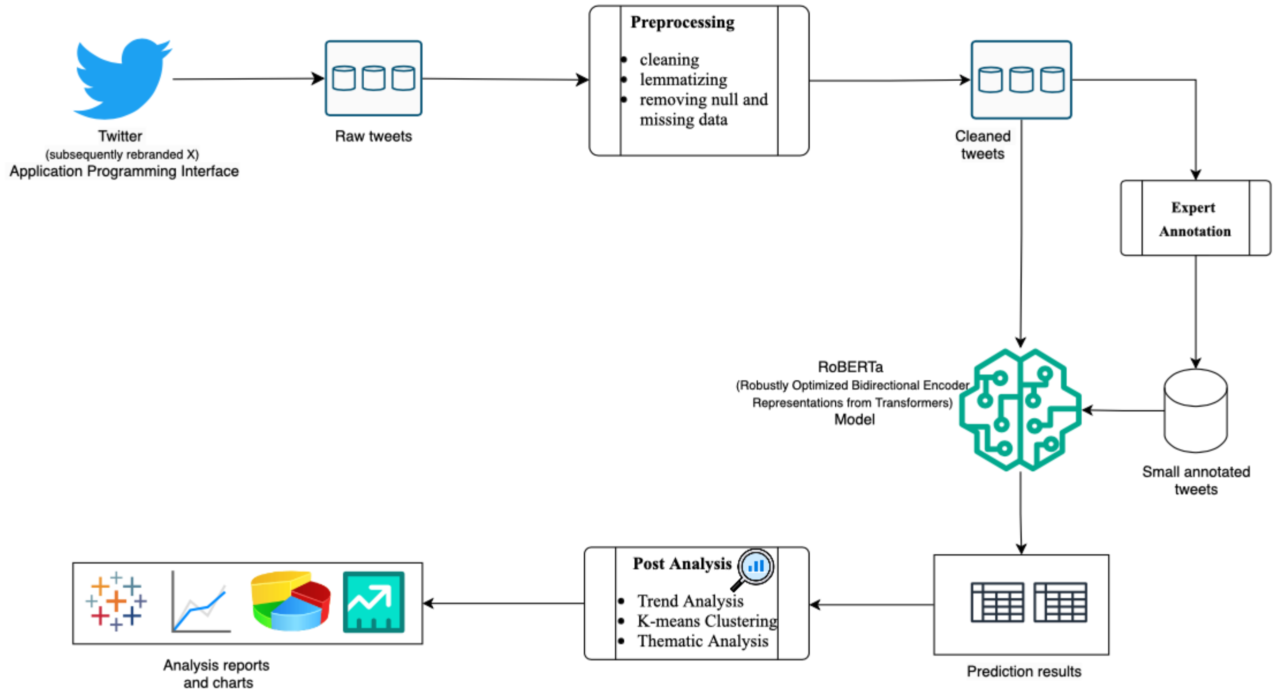
The study's main contributions are as follows:

1. A large-scale SU behavior tweet collection system with expert-annotated tweets for supervised learning
2. A customized pretrained language model based on social media data (Twitter) and an iterative supervised deep learning algorithm for detecting SU posts
3. Insightful statistical analysis of the identified SU posts
4. A real-time search engine–based application for monitoring SU in temporal and spatial dimensions

Methods

Figure 1 shows the overall methodology used in the research. All the steps mentioned in the flow diagram are described subsequently.

Figure 1. Comprehensive research overview flowchart. API: application programming interface; BERT: Bidirectional Encoder Representations from Transformers; NA: not available; RoBERTa: Robustly Optimized Bidirectional Encoder Representations from Transformers Pretraining Approach.



Data Collection

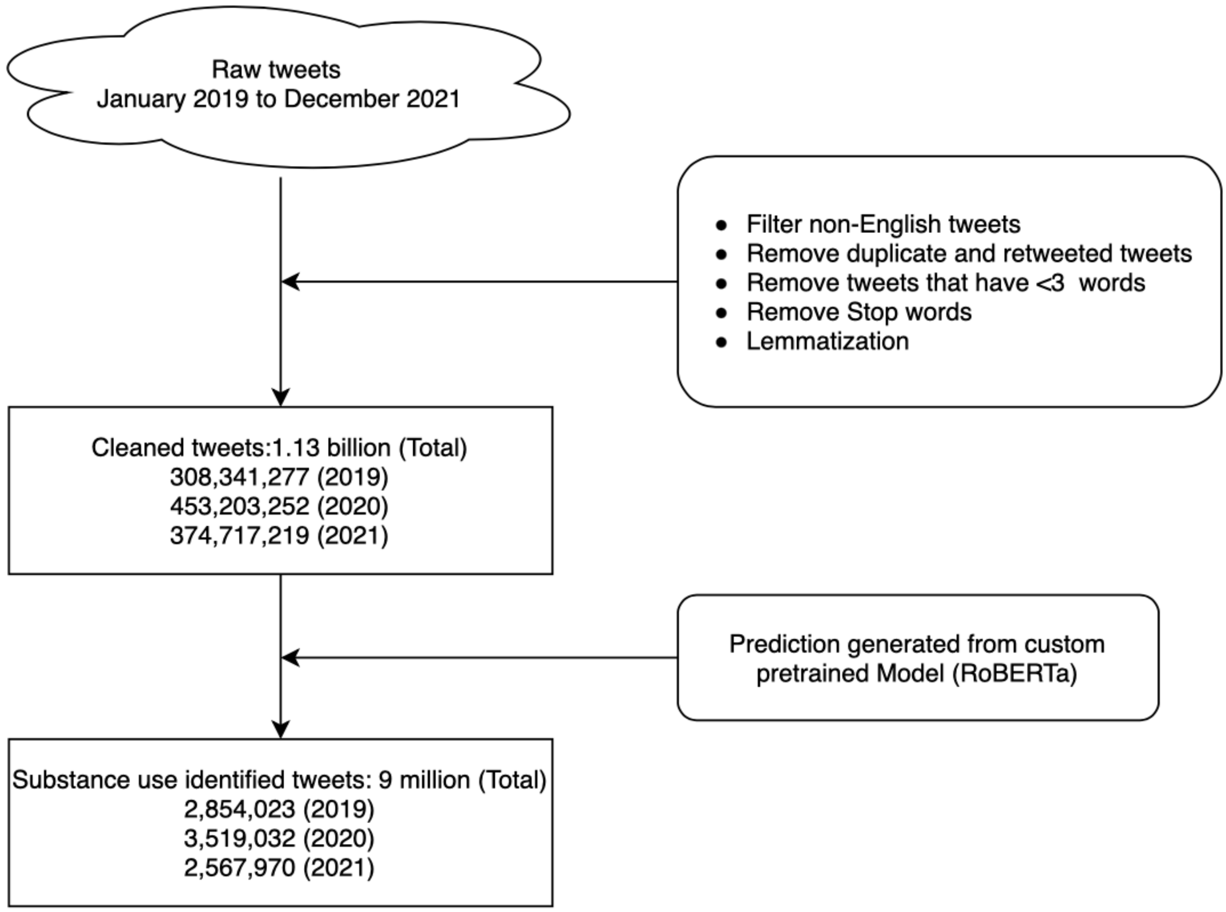
For this research, historical Twitter data were obtained from the Internet Archive [63], a digital library committed to providing free access to a wide array of digital information, including web pages, texts, audio, and videos. This nonprofit organization archives digital content to preserve it and make it accessible for future research. Among its many resources, the Internet Archive includes collections of Twitter data, which consist of tweets captured until July 2023. In our research, we downloaded the raw tweet data covering the period from January 2019 to December 2021. Initially, the data downloaded from this source were in compressed JSON formats, consisting of a large set of files for each day. A pipeline script was developed to extract these files and consolidate them into single-day JSON files. During the extraction process, we retrieved only the time stamp and the actual text of the posts for our analysis. It is important to note that the raw tweets for some days were missing in the data source, specifically in February 2020, January 2021, and April 2021. This absence resulted in skewed time series plots in these months, as discussed in the Results section.

Data Preprocessing

The preprocessing of raw tweets was a crucial initial step to ensure the quality and relevance of the data for further analysis. To efficiently preprocess the large-size files, we divided each daily JSON file into smaller chunks, loaded them in memory, processed each chunk individually, and then merged them back into a single file. The preprocessing steps are described subsequently.

Initially, we filtered out all non-US tweets and duplicate or retweeted tweets to focus our research on English-language tweet posts and reduce redundancy, respectively. Then, we cleaned the text data by removing punctuation and stop words using the Nature Language ToolKit (*NLTK*) package and converted all characters to lowercase to maintain uniformity and prevent discrepancies caused by case sensitivity. Subsequently, we also replaced all the usernames, URLs, and hashtags in the post with the keywords “USER,” “HTTPURL,” and “HASHTAG” to hide the users’ identity and ease semantic understanding. Then, we performed lemmatization using the *NLTK* package to reduce words to their base form (eg, “drinking” to “drink”) to standardize text and improve consistency. Finally, we removed tweets containing <3 words, as these were deemed too brief to provide substantive insights. This comprehensive preprocessing approach resulted in a refined dataset of 1.13 billion cleaned tweets (n=308,341,277, 26.84% in 2019; n=453,203,252, 40.05% in 2020; and n=374,717,219, 33.11% in 2021) poised for further analysis, as depicted in Figure 2.

Figure 2. Flowchart of tweet processing. RoBERTa: Robustly Optimized Bidirectional Encoder Representations from Transformers Pretraining Approach.



Feature Extraction and Data Annotation

Overview

Three specialized domain experts in mental health, SU, and public health performed the data annotation process. The main purpose of annotating data was to serve as a seeding dataset to train our deep learning RoBERTa model. Furthermore, as we intended to identify the SU posts in natural language social media data (where users might not clearly mention the drugs but still talk about SU), our goal was to collect and annotate data that were based on context rather than just keyword-based posts. Thus, we first outlined the context of SU based on 3 main criteria, namely *Types of Substance*, *Uses of Substances*, and *Intent to Use a Substance*.

Types of Substance

Substance type posts usually indicated either direct mention of drug names (that could be slang or street names) or described consuming them with or without actual drug names by specifying slang. The detailed list of such drug names, along with the street names and slang, are outlined in Table S1 in Multimedia Appendix 1. For instance, the tweet, "Man, just chill and smoke weed" had a direct mention of the substance "weed" with a clear meaning of SU. Likewise, "Just smoked a joint after work" had an indication of cannabis use hinted by the keyword *joint* even though the post had not specified the actual drug name. We acknowledge that Table S1 in Multimedia Appendix 1 contains a wide range of keywords or slang that might not have a direct association with SU. Hence, careful consideration has been made while annotating posts that contain slang but do not refer to SU. One counterexample of this would be "His joints and bones ache and his muscles seize up." Here, the post does not have any context with SU even though it contains the keyword *joint*. Hence, it is labeled as a non-SU post.

Uses of Substances

SU posts were identified as posts that described the context of the use of substances, including experiences, effects, or consequences of consumption. The description usually covered personal anecdotes, stories, testimonials, promotions, advice, or recommendations about consumption, and information on obtaining substances. Examples included posts such as, "Feeling relaxed and happy after taking my meds—Xanax does wonders" and "Anyone needs advice on chilling out? I swear by CBD gummies." In both examples, the post specified the consequence of consuming substances without mentioning the actual names of the substances.

Intent to Use a Substance

Substance intent posts were posts that exhibited actions or behaviors suggesting preparation for specific plans to engage in or a desire for SU and were classified as indicative of SU. Examples included "Planning to get some crystal tonight, can't wait" and "Thinking about getting high this weekend to unwind." These examples indicated the actual plan of consuming the substance without clearly mentioning the substance type.

Once the context of SU had been outlined, we proceeded with collecting tweets to annotate. We collected a subset of raw tweets (ie, without cleaning or preprocessing) from January 2020 through April 2020 and asked each domain expert to independently review and annotate a batch of collected tweets under the previously defined criteria. The annotation for each single post was confirmed only if at least 2 annotators voted the same. Upon discrepancies, the annotators further convened to discuss and repeated the process until a consensus was met. This iterative process ensured high reliability and validity in identifying instances of SU. The final annotation resulted in a corpus of 4011 posts. Sample examples of annotated SU and non-SU tweets are included in Table S2 in Multimedia Appendix 1. This thorough annotation process aided in creating a reliable training dataset for fine-tuning our SU classifier.

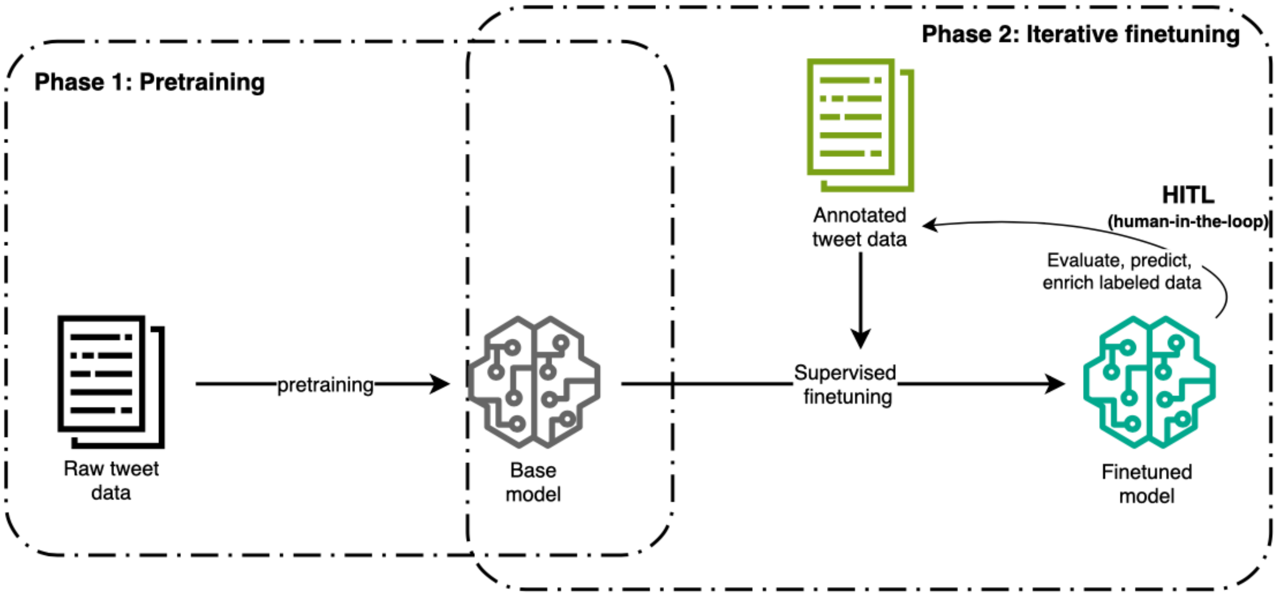
RoBERTa Model for Tweet Classification

Overview

In our research, we used the RoBERTa model [60], an advanced iteration of the Bidirectional Encoder Representations from Transformers (BERT) model [64], which itself marked a significant breakthrough in natural language processing. Developed by Google, BERT harnesses the power of the transformer architecture [59], notable for its innovative attention mechanism. This mechanism generates word embedding that captures deep contextual meanings within the text by enabling the model to consider each word in the context of all other words in a sentence rather than in isolation. The BERT model is structured to undergo 2 training phases, a pretraining phase and a fine-tuning phase, which is advantageous when adapting to specific tasks with limited available data. During the pretraining phase, the model learns general language patterns from a large text corpus through the masked language model (MLM) and next sentence prediction (NSP). MLM encourages the model to predict missing words based only on their context, enhancing its understanding of language nuances. NSP trains the model to understand the relationships between consecutive sentences, which is vital for tasks that require an appreciation of text flow. The fine-tuning phase then specifically adapts the pretrained model to nuanced tasks using smaller, specialized datasets, ensuring that the model maintains robust performance by refining the comprehensive linguistic capabilities developed during pretraining. Our objective could have been achieved by the BERT model; however, the elimination of the NSP task in the RoBERTa model simplifies the architecture, thereby making it the best fit for our use case. Unlike in BERT, RoBERTa only focuses on capturing contextual meaning (on the MLM task) rather than sentence relationships (on the NSP task), which is more relevant to tweet dataset context because tweet data are usually short sentences that do not require sentence relationship information. This modification makes RoBERTa more robust without compromising all the key features of BERT.

In the subsequent subsections, we explain the pretraining and fine-tuning phases carried out in our research, as depicted in Figure 3.

Figure 3. Illustration of training 2 phases Robustly Optimized Bidirectional Encoder Representations from Transformers Pretraining Approach model for substance use tweet classification. HITL: human-in-the-loop.



Pretraining From Scratch

The specific linguistic challenges of our Twitter dataset necessitated a training-from-scratch approach to avoid biases from generic training datasets. In our method, we primarily adopted this customized approach to learn the language understanding of social media data from 33 million raw Tweet posts as shown in the phase 1 of Figure 3.

Initially, we performed tokenization using ByteLevelBPETokenizer. Essentially, this sub–word-level tokenizer broke down words into subword units, allowing it to handle out-of-vocabulary words and rare words more effectively than word-level tokenizers, thus enabling more coverages and generalizations in domains with specialized terminology such as ours. We used 8192 vocab_size and min_frequency 2 as hyperparameters, along with [“<s>”, “<pad>”, “</s>,” “<unk>”, “mask>”] special tokens to indicate the start of the sentence token, padded token, end of the sentence token, unknown token, and masked token, respectively. Additional parameters are provided in Tables S3 and S4 in Multimedia Appendix 1.

After tokenization, we split the original dataset into 2 splits: as the training set (n=29.7 million, 90%), the testing set and (n=3.3 million, 10%). Then, we started training with the MLM objective, where a fraction of tokens (n=4.45 million, 0.15%) in each input sequence were masked, and the model learned to predict them based on contextual information. Training proceeded iteratively using stochastic gradient descent, with hyperparameters tuned based on validation performance. The model achieved a perplexity of 3.84 on the test data, which served as a baseline evaluation of the model. We ensured our language model was efficient by further evaluation after the fine-tuning step.

Iterative Fine-Tuning

Overview

After our model successfully deciphered language understanding in social media data, our next objective was to leverage this knowledge to distinguish posts related to SU. We achieved this by incorporating an additional binary classification layer into the existing model and retraining it with a newly labeled dataset, as depicted in the phase 2 of Figure 3. As with the unsupervised pretraining, we divided the dataset into training, validation, and test splits. We then retrained (fine-tuned) the newly annotated dataset, adjusting the model’s weights by calculating the error between the predictions and the actual labels using an optimization algorithm.

However, to prevent overfitting due to the limited size of the initially labeled data, we adopted an iterative fine-tuning approach inspired by HITL [61]. HITL is a collaborative technique that integrates human input at various stages of model development, such as training, testing, feedback, and decision-making [61]. In our case, we used HITL in only the training phase. We used human reviewers to only assess the model’s prediction results, which were then used to further train the model in successive rounds. Specifically, the process began with training the model on a seed-labeled dataset, followed by generating predictions for unseen data. Furthermore, these predictions were reviewed by human experts to refine and enrich the annotated dataset, which was used for subsequent training. This iterative cycle of training, prediction, and human review continuously improved the model’s performance by enhancing the quality of the training data.

The overall steps in our fine-tuning phase are detailed in the algorithm mentioned subsequently.

Step 1: Data Split

Before training the model, we split our 4011 annotated dataset into 3 sets: the training set (n=3208, 80%), the testing set (n=402, 10%), and the validation set (n=401, 10%).

Step 2: Initial Fine-Tuning and Cross-Validation

The initial parameters from the pretrained model were initialized. Then, the model was fine-tuned with the training dataset for 32 epochs on a batch size of 16 and a learning rate of 2e-5. A dropout layer was added to prevent overfitting, and the model was evaluated using a separate held-out dataset to ensure unbiased parameter tuning.

Step 3: HITL for Generating a New Labeled Dataset

Overview

Our ultimate objective at this step was to leverage human experts to pinpoint crucial data points that could enrich the annotated dataset and refine the model’s accuracy. Human experts reviewed the model’s predictions on unseen data and then identified and corrected errors. This feedback (corrected data) was then used to train the model in the next iteration.

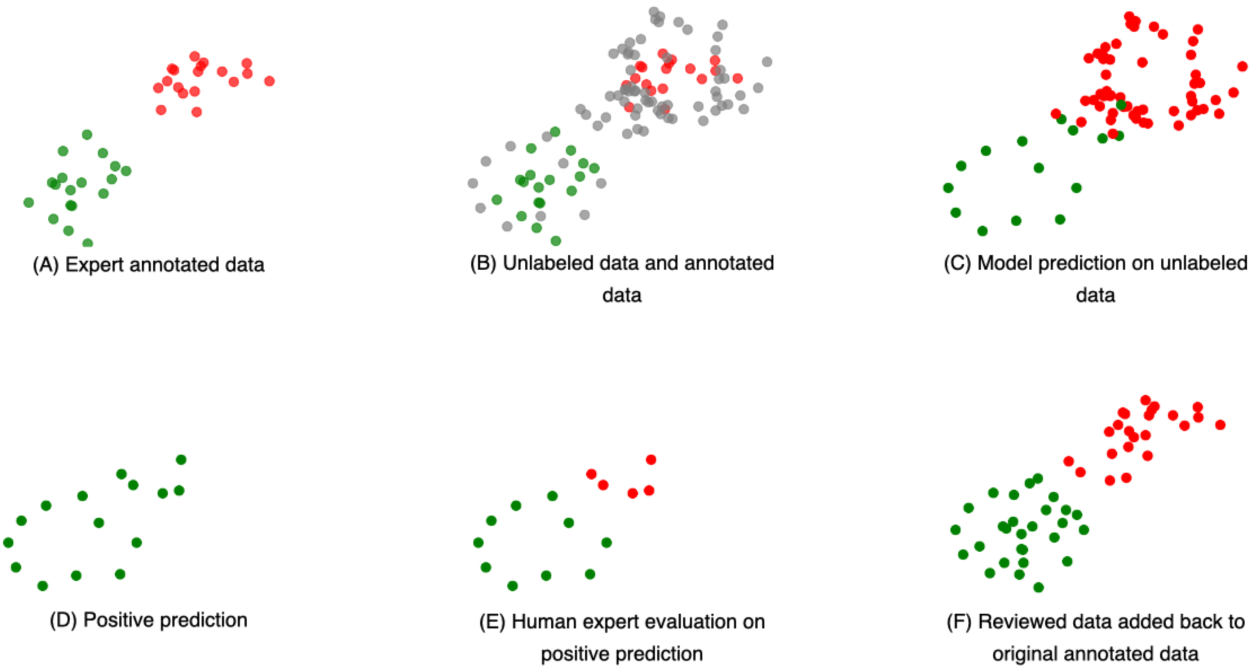
Step 3.1: Prediction of Unseen Data

We used the refined model from step 2 to generate predictions of new, unseen data.

Step 3.2: Expert Review on Positive Predictions

Due to the severe imbalance in the dataset (0.05 positive, 0.95 negative), as shown in Figure 4, we focused exclusively on reviewing positive predictions. Concentrating on positives and making corrections to false negatives allowed us to directly improve the model’s sensitivity and precision. This approach ensured that the model better recognized the critical but infrequent true positive cases, thus enhancing overall accuracy and robustness.

Figure 4. Illustration of datasets in different stages used in the iterative fine-tuning phase. SU: substance use.



Step 3.3: Annotation

We leveraged our expert knowledge to annotate misclassified positives (false negatives) as negatives and correctly identified positives (true positives) as positives.

Step 3.4: Bias Reduction

To address potential bias by specifically focusing on positive predictions, we selectively reviewed a subset of complex positive predictions, which were likely to be misclassified as negatives. For example, posts using metaphoric language or slang, such as "riding the white horse," to indicate heroin use, required nuanced interpretation beyond simple keywords. By targeting these complex positives, we aimed to reduce the bias of not reviewing negative predictions. This careful attention to positive predictions ensured that we minimized the risk of failing to identify true instances of SU hidden within the data labeled as negative.

Step 3.5: Outcome

The final subset of true positives from Bias Reduction and misclassified positives from Annotation were considered as newly annotated data. In each iteration, we made sure the outcome contained 100 positive and 100 negative posts.

Step 4: Expansion of the Original Annotated Dataset

The outcomes from step 3 were added to the original annotated dataset.

Step 5: Evaluation and Iteration (Repeating Steps 1, 2, 3, and 4)

The fine-tuning was carried out for 20 iterations, expanding the annotated dataset in each iteration up to 6400 entries. At each round, we evaluated the model's accuracy on the test set and repeated the process until we achieved the desired accuracy of 80%.

In addition to achieving 80% accuracy, the model demonstrated strong performance across other metrics, with a recall of 79%, a precision of 85%, and an F_1-score of 81%. These scores indicated that the classifier effectively identified most SU instances while maintaining a low rate of false positives, ensuring balanced overall performance.

Substance Definitions and Their Types

A substance encompasses any psychoactive compound that can be legal, illegal, or medically prescribed, with potential impacts on health and society, including the risk of addiction. In our study, we classified substances into 10 primary categories based on their pharmacological and behavioral effects, following the categorization provided by the NIDA [65] and the Drug Enforcement Administration [66].

These categories are presented in Textbox 2.

The specifics for each substance category, including associated keywords, are detailed in Table S1 in Multimedia Appendix 1.

Textbox 2. Classification of substances into 10 primary categories based on their pharmacological and behavioral effects.

1. Tobacco: includes cigarettes, vapor cigarettes, cigars, chewing tobacco, and snuff
2. Alcohol: covers all forms of beer, wine, and distilled spirits
3. Cannabinoids: encompasses marijuana, hashish, hash oil, and edibles containing cannabinoids
4. Opioids: includes drugs such as heroin, methadone, buprenorphine, oxycodone, Vicodin, and Lortab
5. Stimulants: includes cocaine, amphetamines, methamphetamine, methylphenidate (eg, Ritalin), and atomoxetine (eg, Strattera)
6. Club drugs: includes 3,4 methylenedioxymethamphetamine (MDMA) or ecstasy and gamma hydroxybutyrate (GHB)
7. Hallucinogens: lysergic acid diethylamide (LSD), psilocybin, mescaline, and dimethyltryptamine
8. Dissociative drugs: ketamine, phenyl cyclohexyl piperidine (PCP), and dextromethorphan
9. Prescription medications: a broad category that includes antibiotics, analgesics, statins, antidepressants, antihypertensives, hormonal contraceptives, and anticoagulants
10. Other compounds: features synthetic cannabinoids (eg, K2 or spice), anabolic steroids, inhalants, and synthetic cathinone (eg, mephedrone and methylenedioxypyrovalerone [MDPV])

Baseline Themes

The relationship between COVID-19 and SU patterns has garnered significant attention, with the COVID-19 pandemic serving as a critical case study. Previous research [4-6,14,15,31,36,37,67-70] highlighted various thematic areas that significantly influence SU, including stress and concerns related to COVID-19, economic instability, social dynamics, mental health issues, and disruptions in drug supply and health care services. Our study encompassed 6 key themes—COVID-19, economic factors, social influences, mental health, supply chain disruptions, and health care disruptions, as presented in Table 1. A short description of each theme and the impacted individuals (target population), along with study references, are listed in Table 1. To identify the themes in our dataset, we performed latent Dirichlet allocation (LDA) topic analysis to extract the tokens associated with each theme. Then, we refined the list of these tokens with the help of our experts. The complete list of tokens for each theme is detailed in Table S5 in Multimedia Appendix 1.

Table 1. Six major themes that impacted substance use during the global COVID-19 pandemic.

Themes	Description	Target	Studies
COVID-19	Worry or fear related to the virus and lockdown	All people with or without SUD[a]	[4,5,31,36,67]
Economic	Financial instability, job stress, housing, and food insecurity	All people with or without SUD	[5,68-70]
Social	Stress caused by the COVID-19 lockdown, social distancing policies, and change in daily routine	All people with or without SUD	[5,36,37,68,70]
Mental health	Anxiety and depression before COVID-19	Especially people with SUD	[4-6,36,37,68,70]
Supply disruption	Drug market disruptions	Especially people with SUD	[4,13-15]
Medical disruption	Decreased access to substance use treatment, harm reduction, and emergency services	Especially people with SUD	[4-6,68,70]

[a]SUD: substance use disorder.

Trend Analysis

Overview

Trend analysis is the most common technique for identifying patterns over time. In our study, trend analysis involved tracking and analyzing changes in types, discussion patterns, and themes associated with identified SU posts. We mainly used substance-type trend analysis, theme trend analysis, and k-means clustering analysis. At first, we identified the substance type, themes, and discussion pattern for each post by the keyword analysis based on Tables S1 and S5 in Multimedia Appendix 1, LDA topic analysis, and k-means clustering, respectively. Then, the subsequent trend analysis was performed.

Substance-Type Trend Analysis

To identify the substance type in the post, we first formulated a list of street names and slang words associated with the substance and labeled it with corresponding types, such as labeling post 1 for tobacco type if it contained any terms related to tobacco substance. The samples of posts, along with the identified substance type, are presented in Table S6 in Multimedia Appendix 1. Following identification, we aggregated the posts according to type and visualized the time series and histogram plot to identify and compare the growing trends in each substance type.

Theme Trend Analysis via LDA Topic Modeling

Theme trend analysis is a methodological approach that combines elements of theme analysis and trend analysis to understand how specific themes or topics evolve within a dataset. In order to understand key topics of discussion, we used LDA topic modeling [71], a powerful unsupervised machine learning technique, to discover abstract topics within a collection of documents. We used this to answer question 2 (Textbox 1) specifically, where we generated the top 10 topics with the top 10 keywords and categorized the topics based on the identified baseline themes.

k-Means Clustering Analysis

k-means clustering is an unsupervised machine learning algorithm used to partition a dataset into k distinct, nonoverlapping clusters based on the similarity of data points by minimizing the variance within each cluster and maximizing the variance between different clusters [72]. The algorithm iteratively assigns data points to one of the k clusters based on the closest mean (centroid) of the cluster until the positions of the centroids stabilize. In our case, we used the scikit-learn library to perform the k-means clustering, where we used the term frequency-inverse document frequency scheme to create vectorization and considered the elbow method to identify the value of k for performing the clustering.

Thematic Analysis

Thematic analysis is used in qualitative research to analyze and interpret theme patterns within qualitative data. In our study, we used heat map analysis and factor analysis [73-75] to visually explore the relationship between identified themes and types of substances and to identify latent factors (patterns) from the observed themes, respectively.

Integration in Real-Time Application

We also integrated the trained model into a real-time application to monitor SU using the Elastic Logstash Kibana stack. We set up a search engine framework—using search database [76] and logstash [77]. Elasticsearch is an open-source, distributed, RESTful, JSON-based search engine originally based on Lucene (Solr) search that stores the document or the JSON object in an inverted index structure and allows the fastest full-text search. Logstash is a server-side data processing pipeline that usually sources or sinks data to and from multiple sources. In our work, we leveraged this pipeline to ingest the document and tweets from MongoDB [78], transformed the document by adding a custom call to generate a prediction result from the trained model, and finally wrote the document in Elasticsearch. The final document was a JSON comprising a tweet body with an additional prediction field from the trained model. Meanwhile, the Elastic Logstash Kibana stack had a built-in visualization tool to generate different trending charts based on real-time data during the development phase. We developed a full-fledged application in AngularJS and ReactJS frameworks for the client's real-time purposes. The snapshots demonstrating the chart showing the temporal and spatial analysis based on different filters are presented in the *Results* section.

Comparison With GPT-3

The advent of large language models, particularly GPT-3 [79], seemed to have raised questions regarding the efficiency and validity of custom models such as ours. Thus, we compared the reliability of our RoBERTa model and GPT-3 model in identifying SU posts. For this, we randomly sampled 3150 positive predictions from our customized model and queried GPT-3. Essentially, we designed a GPT-3 prompt, "Is this tweet <a real tweet post> related to substance use: Yes or No?" and queried for all sampled posts. Then, the predictions made by our model and GPT-3 were evaluated by our human experts.

Ethical Considerations

To ensure the privacy and confidentiality of individuals whose data were analyzed, all study data underwent a rigorous deidentification process before analysis. The data for this study were sourced from publicly available platforms [63] containing no personally identifiable information. In addition, all the sample posts were preprocessed, removing user IDs, emails, URLs, numbers, stop words, and lemmatizing, making the resulting tokens impossible to identify users' information. Thus, there was no personal information, including author names or any other private information, in the dataset. By addressing these ethical considerations, we conducted insightful research on SU patterns using social media content. In addition to this, our research was supported by the Substance Abuse and Mental Health Services Administration Strategic Prevention Framework-19 (grant 6H79SP081502), which was approved by the institutional review board at Kent State University (IRB20-182).

Results

Overview

Our primary objective was to comprehensively analyze the trends and patterns of SU over 3 years. To identify SU posts, we developed a self-trained deep learning model that achieved a precision rate of approximately 80%. This model was then used to detect SU tweets. The yearly breakdown of identified posts revealed 2,854,023 posts in 2019; 3,519,032 in 2020; and 2,567,970 in 2021. The identified data underwent various quantitative and qualitative analyses, such as trend analysis, k-means cluster analysis, topic and theme analysis, and factor analysis. To enhance the robustness of our findings, we validated our results by comparing them with those obtained from a GPT-3 model [79]. In the final section of our results, we present the outcomes of our integrated real-time application, showcasing the practical implications of our analyses.

Trend Analysis (Question 1: How Did the Discourse on SU Evolve on Twitter From 2019 to 2021, and What Variations Existed in the Distribution of Different Substances During This Time?)

We began our research by conducting a time series analysis to understand the SU trend in the following 3 periods: the prepandemic period, the pandemic period, and the postpandemic period. We aggregated identified SU posts monthly to plot in the chart. Figure 5 shows the average number of SU posts for the entire study period. The proportional representation of the same chart can be found in Figure S1 in Multimedia Appendix 1. While the trend in average number seems substantially high in 2020 in comparison to pre- and postpandemic periods (Figure 5), the proportion of posts for the same data is observed to decline from 2019 to 2021.

In addition, we also plotted a time series for 10 different substance categories to learn the trend of substances by categories. Thus, at first, we categorized each of the posts by applying a keyword-based method by referring to standard keywords from the NIDA [65], as outlined in Table S1 in Multimedia Appendix 1. For instance, we marked the post as alcohol if it contained any keywords associated with it and so forth. After the classification, we plotted the distribution for each substance type to visually understand the trend of each substance type in the study period, as shown in Figure 6.

Figure 5. Substance use distribution from 2019 to 2021.

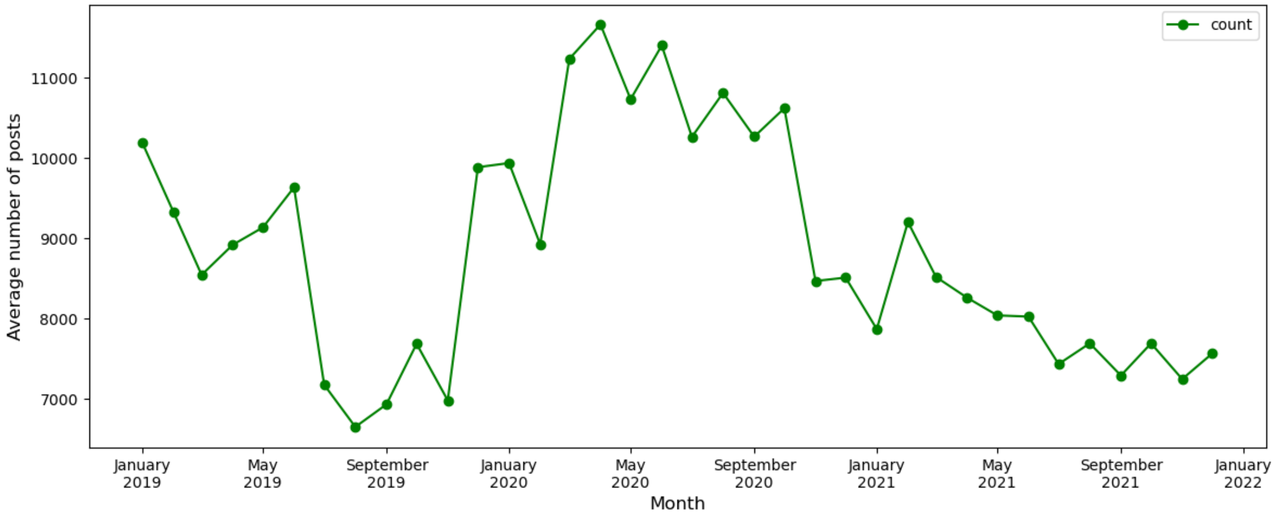
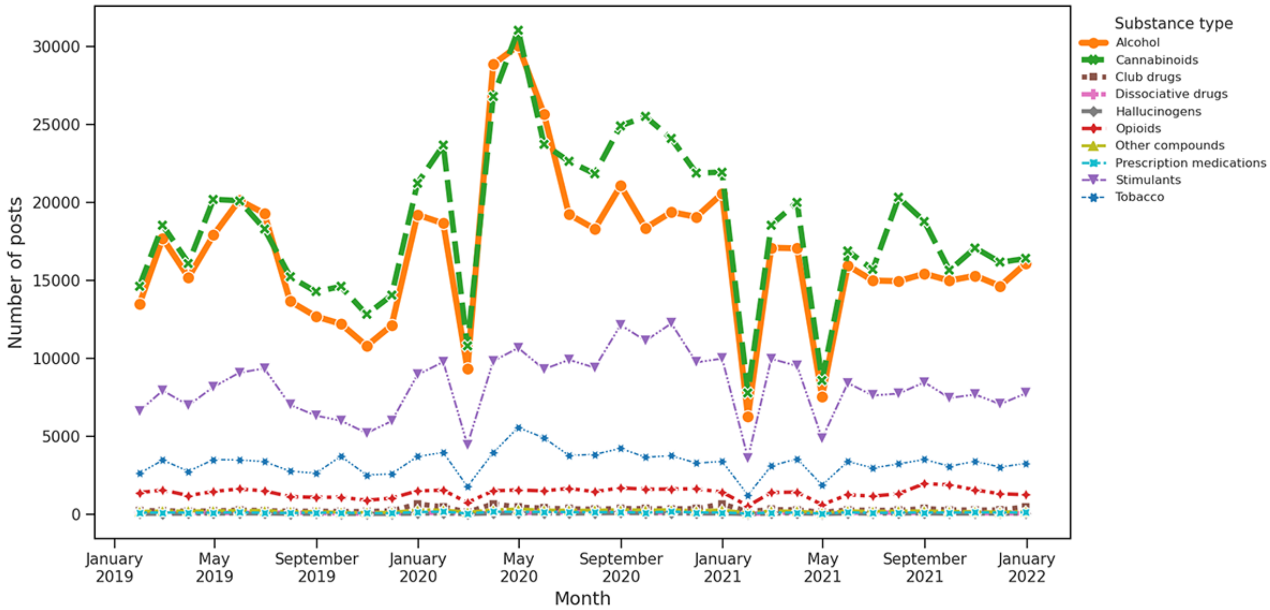


Figure 6. Substance type distribution from 2019 to 2021.



LDA Topic Analysis (Question 2: Following the Announcement of the Pandemic, What Were the Primary Substance Types That Garnered Significant Discussion, and What Were the Themes of These Dialogues?)

Drug Distribution 7 Days Before and After the Pandemic Declaration Day

Following the announcement of the pandemic on March 15, 2020, by Donald Trump, our result evidenced a significant 21% surge in the mentions of SU in tweets in just 3 days. Thus, understanding the change in pattern during that period was essential. We selected data from 7 days before and after March 15 to learn the impact of the pandemic declaration date on the trends. Thus, we aggregated the post count by each substance type 7 days before and after March 15, as shown in Table 2. The time series plot for the same period is also provided in Figure S3 in Multimedia Appendix 1.

Table 2. Substance type distribution 7 days before and after the pandemic declaration day.

Period and substance type	Proportion of posts, n (%)
Seven days before March 15, 2020 (n=54,671)	
Tobacco	2165 (3.96)
Alcohol	15,620 (28.57)
Cannabinoids	23,837 (43.6)
Opioids	1345 (2.46)
Stimulants	10,241 (18.74)
Club drugs	1000 (1.83)
Dissociative drugs	98 (0.18)
Hallucinogens	87 (0.16)
Other compounds	470 (0.86)
Prescription medications	98 (0.18)
Seven days after March 15, 2020 (n=56,773)	
Tobacco	1936 (3.41)
Alcohol	19,661 (34.63)
Cannabinoids	21,341 (37.59)
Opioids	835 (1.47)
Stimulants	7914 (13.94)
Club drugs	613 (1.08)
Dissociative drugs	131 (0.23)
Hallucinogens	57 (0.1)
Other compounds	199 (0.35)
Prescription medications	2606 (4.59)

LDA Topic Analysis

Furthermore, to comprehend the nuances of keywords and topics discussed following the declaration of the pandemic, we conducted an LDA topic analysis on these periods, 7 days before and after the official declaration. As shown in Tables 3 and 4, we highlighted the 10 main topics along with the distribution of the posts across each topic. Also, each topic consisted of the topmost terms that were extracted, excluding stop words.

Table 3. Top 10 terms of 10 latent Dirichlet allocation topics (7 days before the pandemic declaration day).

Topic	Top 10 terms	Distribution (n=54,671), n (%)
0	wine, buy, smoking, glass, everyone, water, red, drink, taste, beer	2733 (5)
1	alcohol, virus, corona, people, cigarette, leave, amp, covid, roll, hit	2733 (5)
2	beer, know, thing, fuck, try, man, cancel, cold, drink, problem	2733 (5)
3	drunk, bar, get drunk, blunt, pain, hold, kill, tonight, sick, coronavirus	2733 (5)
4	liquor, high, store, week, without, bitch, right, keep, always, low	2733 (5)
5	use, coke, would, call, drink, put, lmao, shot, really, enjoy, alcoholic	30,069 (55)
6	smoke, drink, drinking, sleep, drug, coffee, bro, work, fire, outside	2733 (5)
7	crack, night, love, last, stay, damn, smoke, cocaine, end, next	2733 (5)
8	weed, good, need, come, tequila, shit, smoke, drink, day, first	2733 (5)
9	nose, alcohol, bottle, year, please, beer, well, drink, hope, time	2733 (5)

Table 4. Top 10 terms of 10 latent Dirichlet allocation topics (7 days after the pandemic declaration day).

Topic	Top 10 terms	Distribution (n=56,773), n (%)
0	come, smoking, back, man, alcoholic, street, eye, way, chinese, sell	1947 (3.43)
1	drink, drinking, beer, bottle, sleep, tequila, good, drive, tonight, nose	1947 (3.43)
2	liquor, stop, alcohol, store, order, close, bar, help, essential, turn	1947 (3.43)
3	drink, cigarette, smoke, eat, tell, weed, food, hold, even, talk	1947 (3.43)
4	fuck, virus, coke, year, high, shot, corona, covid, people, kill	1947 (3.43)
5	high, last, blunt, night, please, lit, amp, loudlycryingface, thought, die	1947 (3.43)
6	smoke, shit, start, open, feel, find, lmfao, woozyface, asf, miss, fire	1947 (3.43)
7	quarantine, pain, crack, really, use, cocaine, damn, bitch, drug, liquid	39,196 (69.04)
8	wine, would, weed, see, glass, need, someone, lmao, drunk	1947 (3.43)
9	drunk, get, love, friend, house, home, free, eat, wine, stay	1947 (3.43)

Theme Trend Analysis (Question 3: How Did the Prevalence of the Studied Theme Influence Various Types of Substances Used During the Studied Period?)

The theme in any subjective study is either a topic or a related subject name that best describes the group of the data. In our context, we wanted to identify such themes in the SU posts so that we could analyze the pattern and further investigate a correlation with different substances. Thus, we derived 6 major themes, namely COVID-19, economic, social, mental health, supply disruption, and medical disruption, as discussed in the Baseline Themes section in the Methods section. Subsequently, we plotted a time series for each substance type for all themes, as depicted in Figures 7-12. Our research yielded valuable insights through a trend analysis focused on the impact of prevalent themes on SU.

Figure 7. Substance distribution based on keywords associated with COVID-19.

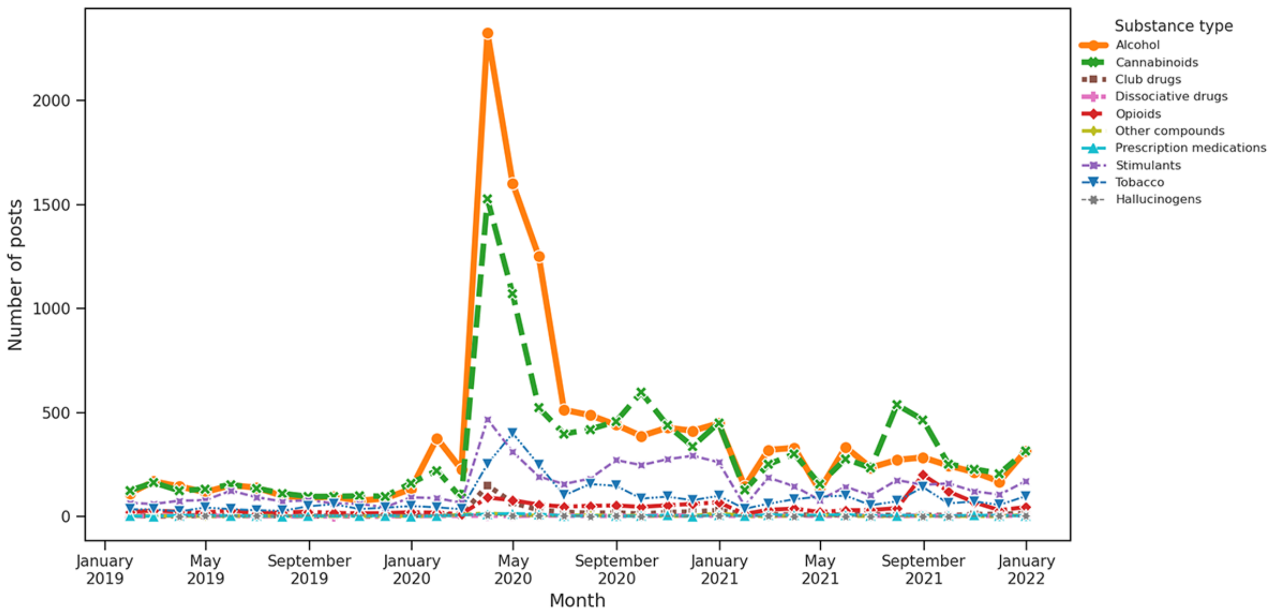


Figure 8. Substance distribution based on keywords associated with economic stress.

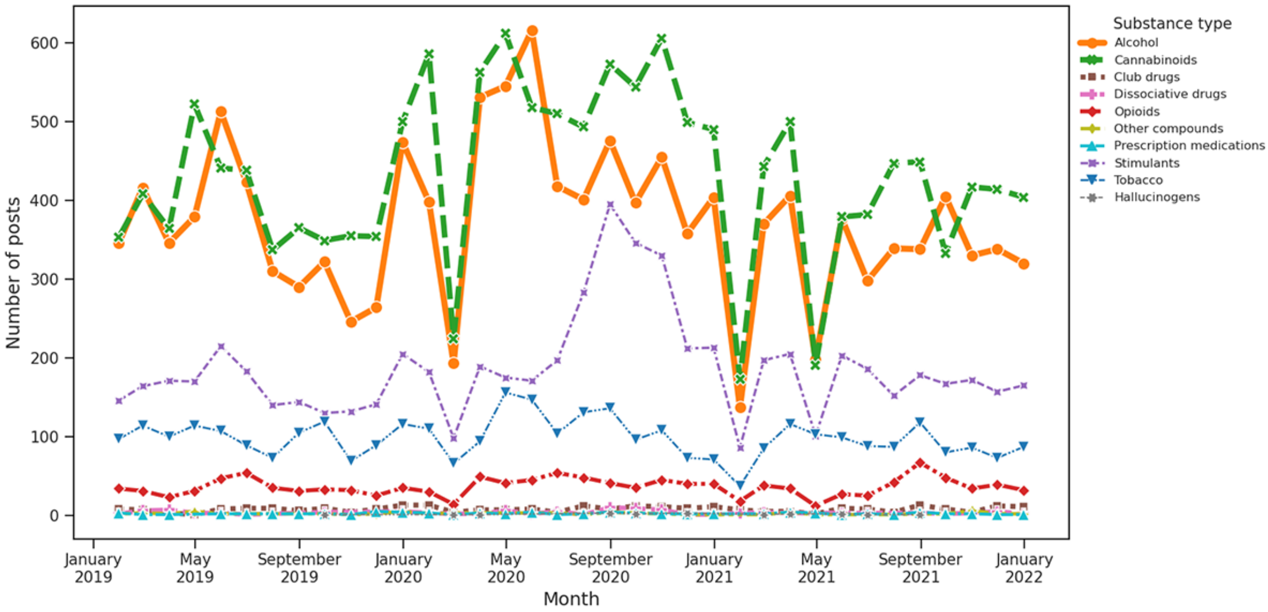


Figure 9. Substance distribution based on keywords associated with social stress.

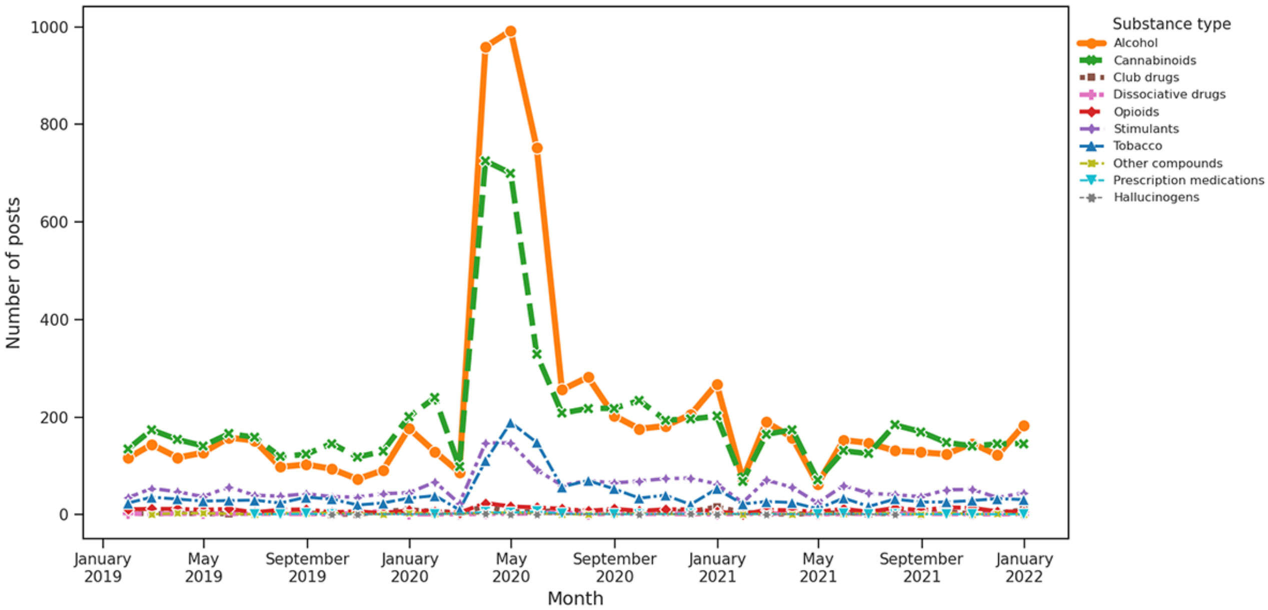


Figure 10. Substance distribution based on keywords associated with mental health.

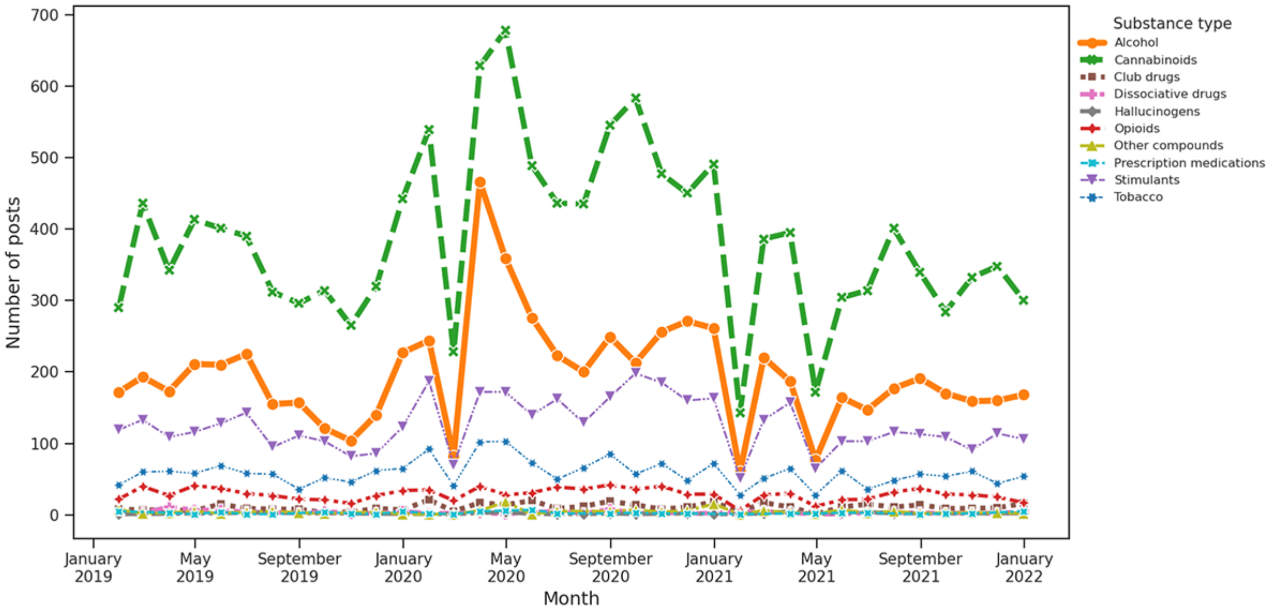


Figure 11. Substance distribution based on keywords associated with supply disruption.

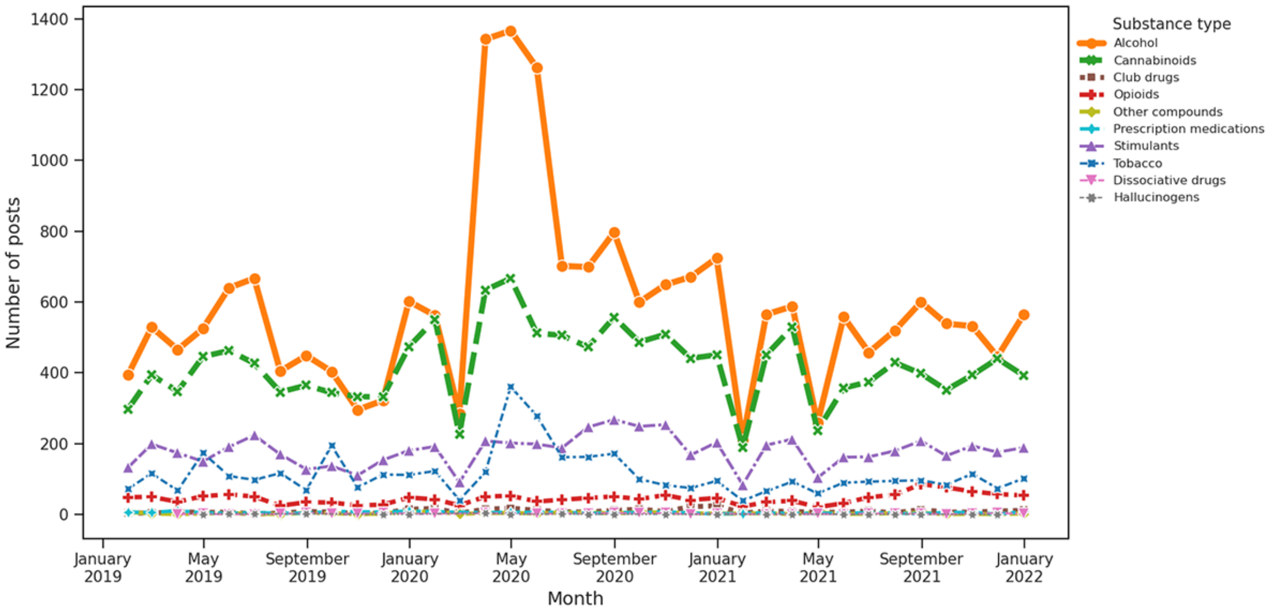
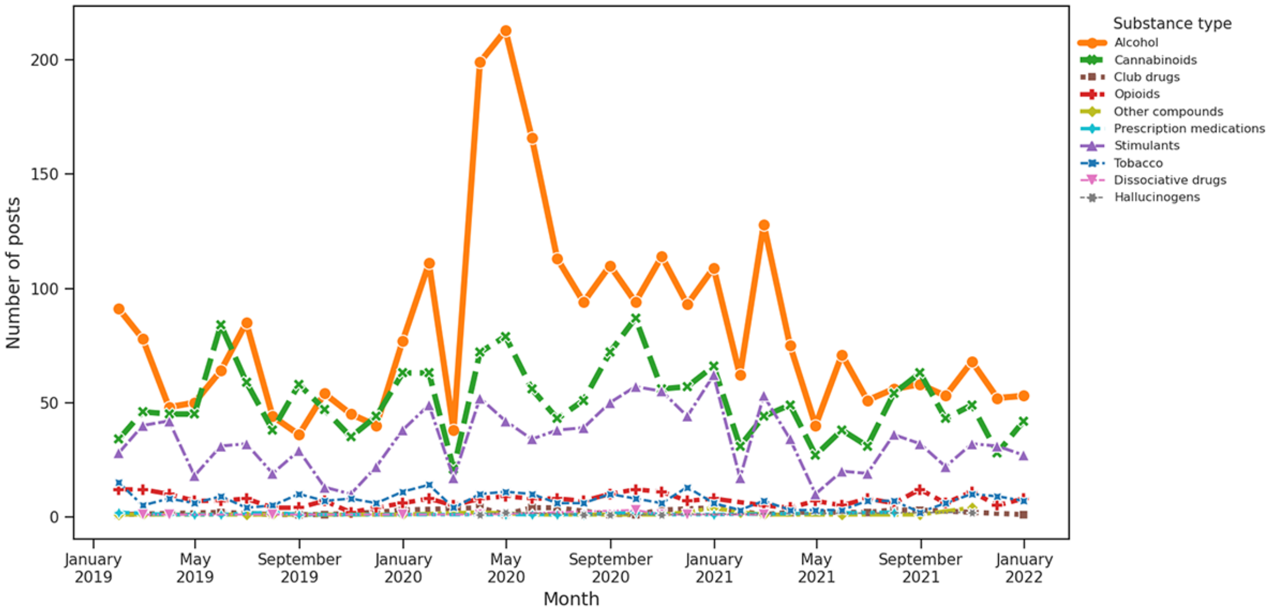


Figure 12. Substance distribution based on keywords associated with medical disruption.



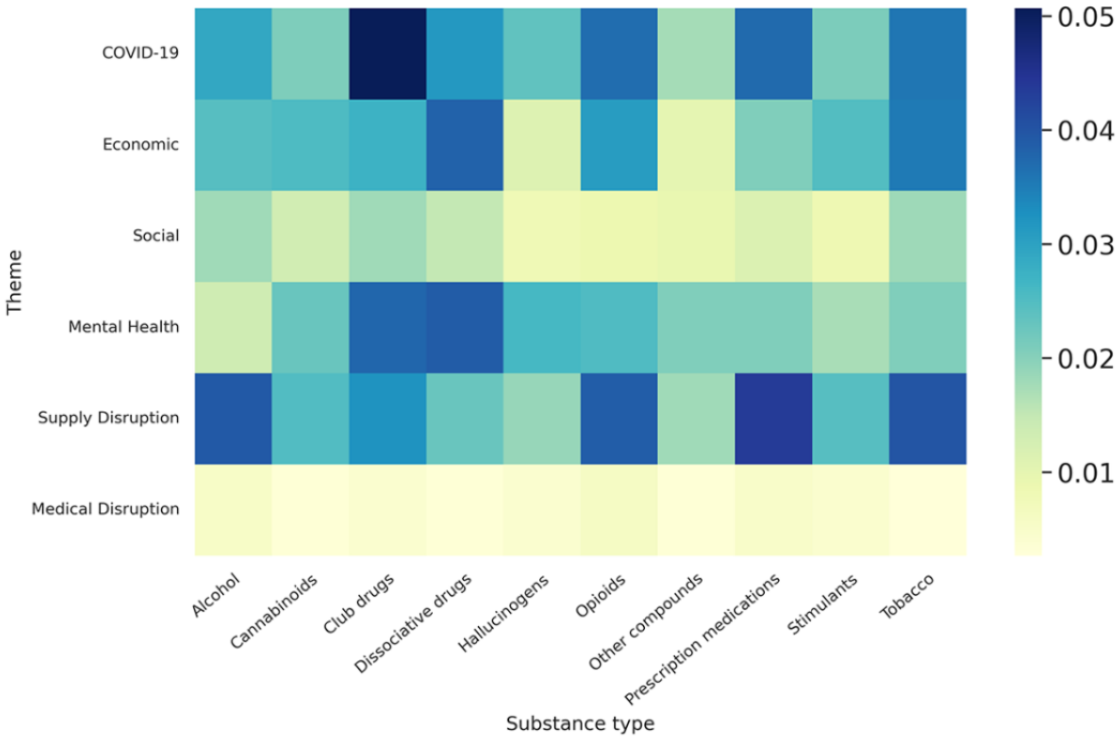
Thematic Analysis (Question 4: How Did the Identified Themes Correlate With the Substance Types?)

We performed heat map analysis and factor analysis to explore the correlation between identified themes.

Heat Map Analysis

In our study, we further used a heat map to visually analyze the relationships between identified themes (COVID-19, economic, social, mental health, supply disruption, and medical disruption) and substance types (alcohol, cannabinoids, club drugs, dissociative drugs, hallucinogens, opioids, other compounds, prescription medications, stimulants, and tobacco). The correlation plot is shown in Figure 13, where themes are represented on the y-axis and substances are represented on the x-axis. Each cell within the grid corresponds to a unique pairing of theme and substance type, with the color intensity indicating the strength of the association between them, and the color scale positioned along the right side of the vertical axis represents the intensity of association between these variables. Here, deeper shades of blue signify stronger associations, while lighter shades, reminiscent of lime, indicate weaker associations.

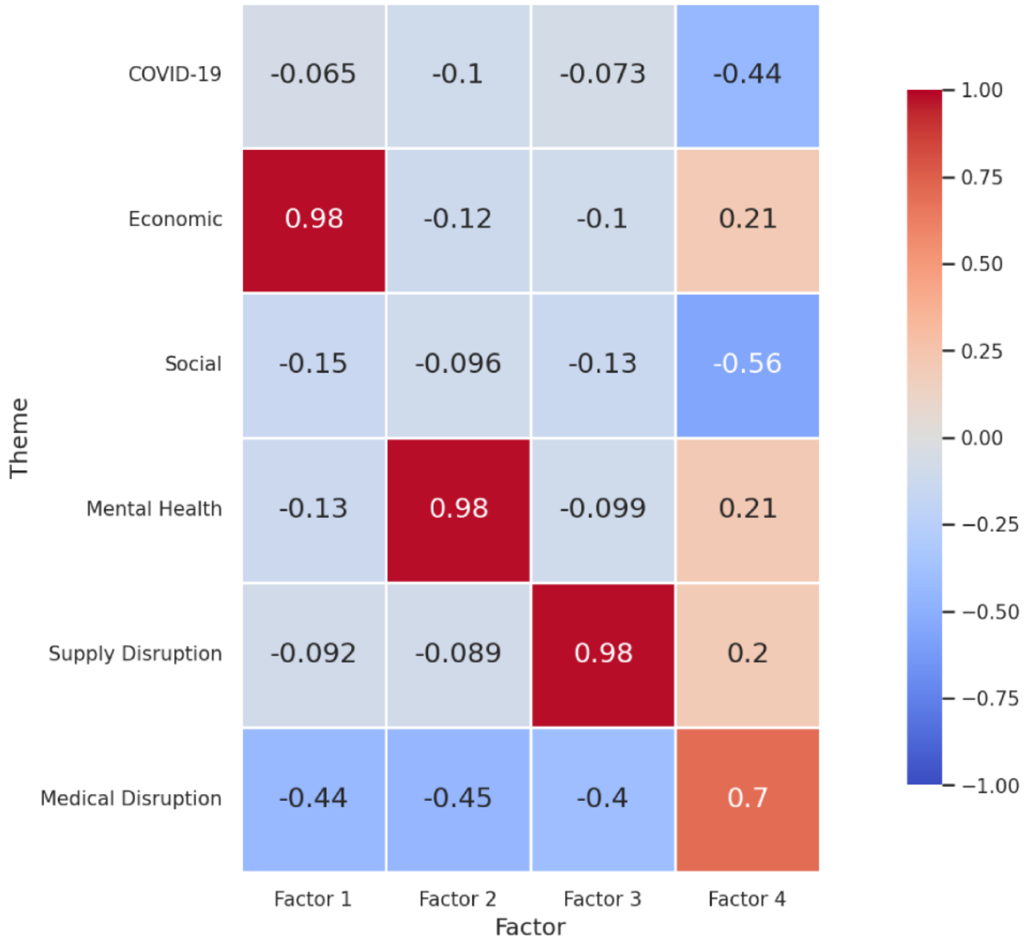
Figure 13. Heat map between themes and substance types.



Factor Analysis

We performed factor analysis to examine the variability among the selected themes, aiming to distill these into a smaller set of unobserved, underlying variables known as factors. We determined the optimal number of factors to be 4 based on the Kaiser criterion, a decision further substantiated by the scree plot analysis, which revealed a distinct elbow point (Figure S5 in Multimedia Appendix 1). This analysis was facilitated by the *factor_analyzer* package within the Python application programming interface [45], which calculated the eigenvalues for each factor corresponding to the identified themes. The resultant factor loading heat map is shown in Figure 14. This heat map illustrates the relationships between factors and themes; negative values signify an inverse relationship, while positive values denote a direct relationship. The intensity of the relationship is indicated by values approaching 1 or –1 for strong relationships and values near 0 for weak ones. The heat map uses a color gradient where red shades indicate positive associations and blue shades indicate negative associations, providing a clear visual representation of these relationships.

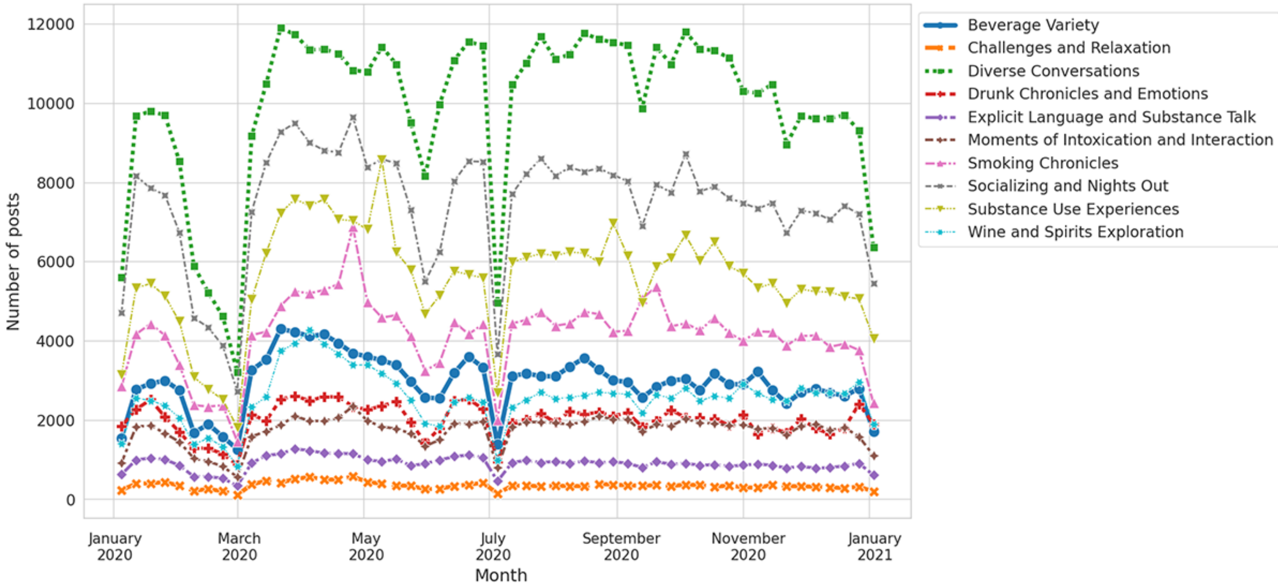
Figure 14. Factor loading heat map.



k-Means Clustering Analysis (Question 5: What Primary Discussion Topics Arise From k-Means Analysis, Specifically During the Pandemic Year?)

In addition, we also performed k-means clustering on SU posts from 2020 to identify the relevant groups or clusters by leveraging the similar distance algorithm inbuilt in the k-means clustering method [72]. Essentially, we started by applying the elbow method to determine an optimal cluster size, which turned out to be 19 for our data. The elbow diagram is depicted in Figure S4 in Multimedia Appendix 1. Furthermore, we applied k-means clustering to generate 19 clusters. However, due to redundant cluster keywords, we merged the relevant clusters, resulting in 10 main clusters, as shown in Figure 15. The cluster keywords and their respective details are presented in Table S8 and Figure S4 in Multimedia Appendix 1, respectively. Initially, information from each cluster was gathered and categorized into interaction, discussion, feelings, and perceptions. In addition, correlated clusters were amalgamated, such as cluster 0 and 13 labeled as raw conversations—explicit language and substance talk; cluster 1 and 6 as smoking chronicles—weed and cigarettes; cluster 2 and 12 as wine and spirits exploration; cluster 4 and 9 as social highs—moments of intoxication and interaction; cluster 5 and 16 as socializing and nights out—drinks and smokes; cluster 7 and 8 as beverage variety—beers, alcohol, and voting; cluster 10 and 14 as SU experiences—smoking, drugs, and liquor; and cluster 15 and 18 as challenges and relaxation—tiredness, and blunts. Cluster 3, encompassing diverse experiences and activities, was named diverse conversation.

Figure 15. K-means cluster analysis of substance use posts in 2020.



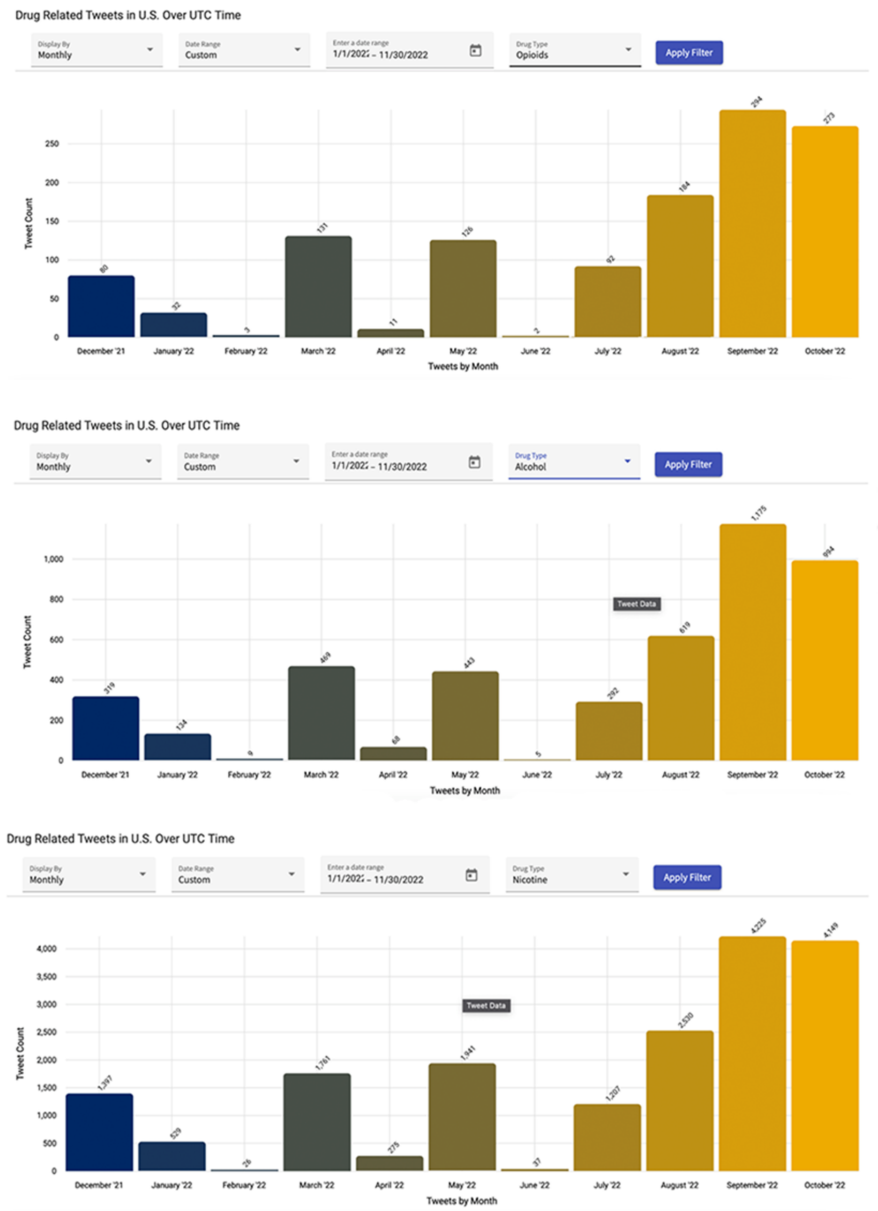
Comparison With GPT-3 (Question 6: To What Degree Does the Classifier's Effectiveness in Pinpointing SU-Related Tweets During the Pandemic Align With or Differ From GPT-3?)

We also compared our results with the GPT-3 model by asking the model to classify tweets using GPT application programming interface [79]. We used a prompt, "Is this tweet '<a real tweet post>' related to substance use: Yes or No?" For this, we randomly sampled 3150 predicted positive results from our customized model and cross verified with the human (experts) and a machine (GPT-3). The human-verified 95.23% (3000/3150) of these predicted positive tweets were accurate, while GPT-3 only verified 53.73% (1693/3150) of the tweets as accurate. From this result, we concluded that generic powerful models such as GPT-3 do not necessarily generate true results when identifying hidden contexts in domain-specific data. This necessitates the need for domain-specific models for accurate results.

Real-Time Application (Question 7: How Has the Overall System Contributed to the Real-Time Tracking of SU, as Evidenced by Research?)

We further deployed our model to provide a real-time service in an application, Northeast Ohio Tri-County Prevention Infrastructure [80], specifically within the social media section designed for Ohio state. Primarily, the aim of the application was to serve as a monitoring and prevention dashboard for the state from static data. However, the real-time nature of social media data gave the application true power to monitor patterns of SU across areas of interest. Figure 16 provides snapshots of the application, illustrating how the stakeholders can dynamically monitor the SU segmented by time and substance type.

Figure 16. Snapshots of integrated real-time application. UTC: Universal Time Coordinated.



Discussion

We used our custom deep learning model and several statistical methods to perform this analysis to get insights into the trends and impacts of COVID-19 related to SU. The subsequent sections elaborate on the results in detail.

Trend Analysis

Time to Event Analysis and Substance Distribution for Question 1

The analysis of time to event reveals a significant increase in SU tweets in 2020, surpassing the counts for 2019 and 2021 by 17.6% and 22.35%, respectively (Figure 5). Notably, March 2020, April 2020, and June 2020 emerged as the focal months for SU discussions, with frequencies 16.55%, 21.18%, and 18.19% higher than other months in 2020. The elevated trend persisted until October 2020, likely coinciding with the availability of vaccines, highlighting a limitation in our study.

The examination of substance discussions over a 3-year time frame revealed a consistent focus on alcohol and cannabinoids, emerging as the predominant topics throughout the study. An intriguing observation during the pandemic period was the discernible surge in discussions surrounding alcohol, cannabinoids, and stimulant drugs, distinguishing them with an upward trend. In contrast, other substances did not exhibit substantial shifts in discourse.

It is crucial to exercise caution when interpreting the data for February 2020, January 2021, and April 2021, as the graph may be skewed due to limited available tweets in the Twitter source during those specific months. Despite this limitation, the broader insights gleaned from the study underscore the enduring prominence of alcohol and cannabinoids in public discourse.

The pandemic period, marked by unprecedented global challenges, evidently influenced a notable increase in discussions surrounding these substances and stimulant drugs, indicative of evolving societal dynamics and coping mechanisms. These findings prompt further exploration into the nuanced factors shaping substance-related discussions, offering valuable insights for public health considerations and policy implications.

Topic Analysis and Substance Distribution for Question 2

In order to observe the impact of the declaration of the global COVID-19 pandemic declaration day on March 15, we analyzed the posts by each substance type 7 days before and after March 15. The aggregated posts in these 2 weeks had distinct changes in each substance type. Notably, discourse in only 2 substance types, alcohol and prescription medication, were observed significantly increasing, while discourse in all other substance types were observed slightly declining. The trend can also be visualized in Figure S3 in Multimedia Appendix 1. The increased trend of alcohol discussion was likely due to the effect of COVID-19, particularly due to closed schools, social isolation, boredom, and various types of mental stress and anxiety, which is also supported by some studies [15,35,36]. A study by Farhoudian et al [15] that conducted a survey in May highlighted the increment in alcohol, prescription medication, and cannabinoids. However, in our study, cannabinoids showed a slight decrement in a 7-day period while it remained significantly discussed during the entire study period.

Moreover, our topic analysis for the same period indicated a shift in substance-related discourse. In general, during the prepandemic period, references to substances were casual in almost all the 10 topics, as depicted in Table 3. Although topic 5 had the highest proportion of keywords (30,069/54,671, 55%), the terms referred to casual keywords, insignificant to any particular substances or behavior. However, topics in the postpandemic period included keywords that concerned quarantine and SU as seen in topics 4 (1947/56,773, 3.43%) and 7 (39,196/56,773, 69.04%) in Table 4. The mention of keywords (such as *nose*, *coronavirus*, and *covid*) during the first period suggested that COVID-19 has been interlinked with few substance discussion; however, there were no negative words indicating stress or bad impact on mental health. By contrast, the topics in the second period included negative keywords (such as *pain*, *die*, *stress*, and *fuck*) along with SU keywords. This shift suggests a nuanced decline in mental health after the pandemic declaration day. Likewise, topics 1, 2, 8, and 9 in the second week contained more alcohol- and liquor-related keywords (such as *drink*, *beer*, *bottle*, *liquor*, *store*, and *drunk*), suggesting use of alcohol as the main substance during this period. Nevertheless, there were no major terms in the topic analysis that could support prescription medication use in the second week.

In conclusion, our detailed analysis on 7 days before and after the pandemic declaration day highlights the immediate impact on the use of substances, particularly alcohol and prescription medication.

Theme Trend Analysis and Substance Distribution for Question 3

As per our keyword-based theme analysis, COVID-19 had a notably significant impact on the discussion of SU. The early pandemic period showed a significant rise in alcohol and cannabinoids associated with 2 main themes as follows: COVID-19 and social isolation. This surge was most evident at the onset of the pandemic in early 2020, likely reflecting a response to the stress, uncertainty, and lifestyle changes imposed by the health crisis. The data indicated that these increases were particularly influenced by COVID-19–related factors, with social and economic aspects also playing a role. In contrast, factors related to supply and medical disruptions did not drastically affect use patterns. This concentrated spike in alcohol and cannabinoid use during challenging periods highlights the broader impact of the pandemic on SU behaviors.

k-Means Clustering Analysis for Question 5

From the k-means clustering, we identified 10 main clusters as an indication of what was discussed in the pandemic year as follows: beverage variety, challenges and relaxation, drunk chronicles and emotions, explicit language and substance talk, moments of intoxication and interaction, smoking chronicles, socializing and nights out, SU experiences, wine and spirits exploration, and diverse conversations. The diverse conversation cluster includes all the remaining tweets that do not belong to particular clusters. Hence, the number of posts in it has the highest counts. Excluding this cluster, SU-associated posts were mostly seen in socializing and nights out, followed by SU experiences and smoking chronicles as the 3 main top discussions.

Thematic Analysis for Question 4

Heat Map Analysis

The heat map analysis provided insightful revelations regarding the factors influencing SU discourse, highlighting COVID-19, economic stress, mental health concerns, and alterations in drug supply as the principal elements. Specifically, there is a stronger correlation between the "COVID-19" theme and cannabinoid use, possibly signifying an increase in this substance's consumption as a direct response to the pandemic's stressors. The "economic" theme shows a somewhat lower yet noticeable correlation with alcohol, which might reflect economic uncertainty's impact on alcohol consumption. The "social" theme has a less pronounced correlation across all substance types, implying that social factors had a milder influence on SU during this period. "mental health" has a moderate correlation with both cannabinoids and alcohol, highlighting these as coping mechanisms during mentally challenging times. "supply disruption" shows a varied correlation but is not significantly linked with any substance, suggesting that supply issues did not drastically alter consumption patterns. Finally, "medical disruption" seems to have the least correlation with SU, suggesting that medical service disruptions during the pandemic had minimal influence on the consumption of these substances. Overall, the heat map indicates that COVID-19–related factors had the most significant correlation with changes in SU, with economic and mental health factors also being relevant but to a lesser extent.

Factor Analysis

The factor analysis gave insights into a combination of themes that had an impact on SU. Factor 1 indicated that mental health was the leading factor. Factor 2 was strongly and positively associated with the economic theme, suggesting that this factor could represent financial stress or economic consequences of the pandemic. The social theme had a moderate negative loading on factor 2, implying that social aspects may decrease in relevance as economic concerns increase or vice versa. Factor 3 showed a very strong negative loading with the medical disruption theme, indicating that this factor was significantly influenced by disruptions in medical services. This could represent the strain on health care systems and the impact of health care access on the population. Mental health and supply disruption themes had a strong positive loading on factor 4, implying that this factor may represent the psychological impact of the pandemic and its influence on drug supply chains.

In summary, the factor analysis suggested that economic and mental health themes were major dimensions of the pandemic's impact, with medical disruptions also playing a significant but negatively associated role.

Comparison With GPT-3 for Question 6

Our comparative analysis with the GPT-3 model yielded valuable insights into the effectiveness of powerful generic models in identifying hidden contexts in domain-specific data, particularly related to drug use in tweets. The experiment involved using a prompt to classify tweets as either related or unrelated to SU. The results demonstrated a substantial discrepancy in accuracy between human verification and GPT-3. When comparing the randomly sampled predicted positive tweets, human experts confirmed the accuracy of 95.23%, whereas GPT-3 verified only 53.73% of the tweets as accurate. This notable difference underscores the limitations of generic models such as GPT-3 in accurately discerning domain-specific nuances. Although we have not performed a detailed analysis to find out the reason behind this discrepancy, we anticipate the limitation of contextual awareness as a primary reason for this, as indicated in the studies by Ray [81] and Moradi et al [82]. For instance, Moradi et al [82] highlighted similar cases where GPT-3 underperformed in the biomedical corpora in comparison to domain-specific pretrained model BioBERT [82]. By contrast, generic pretrained models such as ours can provide rich contextual understanding as they are pretrained solely on social media data, making them powerful in understanding slang-like languages. Thus, the limitation in GPT-3 is well addressed by our custom model pretrained on domain-specific data.

Real-Time Integration for Question 7

The successful integration of our trained model into the practical application Tri County Prevention Infrastructure [80], particularly within the social media section tailored for Ohio, marks a significant achievement. This integration empowers real-time users by allowing them to visually explore the distribution of substance-use posts in both temporal and spatial dimensions. For instance, the users can explore and analyze the trend of any substance (eg, alcohol) in real time and take immediate actions to mitigate the use in the areas of interest. In addition, the applicability of our models' integration is promising during crisis periods such as the COVID-19 pandemic, when physical intervention is unfeasible.

Limitations

Our study has several limitations. Initially, data inconsistencies in certain months were due to incomplete datasets from the sources [63]. Moreover, our analysis was confined to English-language posts, potentially excluding non-English speaking users and thus not reflecting the full spectrum of users during the study period. The initial annotated data used for the training model were collected from a specific time frame (January 2020 through April 2020). The selection of data from this particular time frame could have introduced some bias in the SU identification process. In addition, the consideration of precision as our primary evaluation metric during iterative fine-tuning steps could have missed real SU posts, limiting to the small spectrum of patterns learned by the model and leading to overfitting. Also, the overall accuracy of the classifier reached 80%, which could have led to non-SU posts being identified as SU posts and vice versa. Consequently, this could actually deviate the count of SU posts identified in our study, thus deviating from trend studies. Although the choice of classifier, RoBERTa, seems to have performed better, the identification of SU tweet posts for multiple sequences could have been misclassified. Likewise, the limited labeled dataset during fine-tuning could have underfitted the performance in the initial rounds. While we used HITL [61] in our iterative fine-tuning approach to enrich the annotated data, the human reviewers involved in the process were only tasked with reviewing model predictions without providing feedback. This lack of active human feedback may have limited the model's capacity for improvement as corrections to errors and mispredictions or rewarding accurate predictions could have enhanced its performance further. In the future, incorporating a full HITL at different stages of model development could significantly improve accuracy and model refinement. Finally, the scope of keywords used in processing tweet data may have been too narrow, possibly leading to an overrepresentation of certain themes and factors in our results.

Future Work

This study only considered text data for the identification of SU. Future research could use multimedia, such as images and videos, to enhance the accuracy of the identification of SU. Furthermore, our iterative fine-tuning approach could be enhanced through active learning [62], where the most critical samples are selected for annotation in each iteration, optimizing model performance. Another potential improvement involves incorporating full HITL feedback [61], allowing human reviewers not only to review but also to correct errors or reward accurate predictions. This approach could significantly refine model accuracy. In addition, a user-level analysis could be conducted to investigate factors influencing the intention and purpose behind substance misuse. In addition to this, demographic factors such as age, gender, race, emotion, socioeconomic status, personality trait, and mental and physical health status could be considered for investigation to understand the most impacted cohort during the pandemic. By understanding these cohorts and factors, we can develop strategies and interventions to prevent and control SU during global crises.

Conclusions

In this study, we conducted an extensive infodemiology analysis of Twitter posts from 2019 to 2021, focusing on SU patterns during the COVID-19 pandemic. Using a deep learning model (RoBERTa) alongside techniques with human involvement in iterative fine-tuning, our classifier achieved an optimal accuracy of 80%, even with limited resources. This performance is notable as even a powerful state-of-the-art model such as GPT-3 struggled with domain-specific data such as SU.

In summary, the results from our study showed the key patterns in SU trends during both the pandemic and overall study periods. The analysis of the pandemic period has shown that COVID-19 had a huge impact on the influx of SU. As indicated by trend analysis, the numbers were higher during the peak pandemic period, mainly between March and October 2020. Furthermore, the theme analysis showed a higher association of SU posts with COVID-19 and social themes in comparison to other themes during the pandemic period. In addition to this, the immediate declaration of the pandemic introduced stress and anxiety in public, as evidenced by our LDA topic analysis, causing a significant rise in SU (21% in just 3 days), primarily in readily available substances such as alcohol and prescription medication. These findings suggest that the authorities should pay attention to key factors such as social isolation, stress, and anxiety, and focus on strengthening regulations around the sale of accessible substances such as alcohol, prescription medications, and cannabinoids (though not legal in all areas) to have control the SU during the global COVID-19 pandemic crises. By contrast, economic, mental health, and supply disruptions seem to be the major contributing factors for SU throughout the study period, as indicated by our factor analysis, with cannabinoids, alcohol, and stimulants as dominating substances. Thus, public health agencies should focus on controlling the economic and mental health of global citizens as key actions, alongside surveilling drug supplies, in order to control global SU.

In summary, our study demonstrates the applicability of social media data used along with a deep learning model to analyze trends in global issues such as SU. The findings and methodology from this study can help public health sectors develop real-time strategies and prevent SU during future crises.

Acknowledgments

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Data Availability

The data and code supporting this study are publicly available on GitHub [83].

Authors' Contributions

JM contributed to the conceptualization, methodology, investigation, formal analysis, model development, and writing of the original draft. RJ assisted in conceptualization and supervised the study. JZ provided feedback on the analyses, while JK contributed to data curation and validation. All authors reviewed and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Additional dataset details, classified tweet samples, and analysis figures to support this paper’s investigation.

[DOCX File , 3734 KB - infodemiology_v5i1e59076_app1.docx]

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Abbreviations

BERT: bidirectional encoder representations from transformers
HITL: human-in-the-loop
LDA: latent Dirichlet allocation
MLM: masked language model
NIDA: national institute on drug abuse
NLTK: Nature Language ToolKit
NSP: next sentence prediction
RoBERTa: robustly optimized bidirectional encoder representations from transformers pretraining approach
SU: substance use
SUD: substance use disorder

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Original Paper

Exploring the Use of Social Media for Activism by Mexican Nongovernmental Organizations Using Posts From the 16 Days of Activism Against Gender-Based Violence Campaign: Thematic Content Analysis

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Abstract

Background: In the past decade, *hashtag feminism* has emerged in Mexico as a prevalent strategy to build social movements against gender-based violence (GBV). For example, during the global "16 Days of Activism Against GBV" campaign held between November 25 and December 10 each year, Mexico-based nongovernmental organizations (NGOs) turn to X (formerly known as Twitter) to share messages. Despite this prevalence, there is limited research on the type of information shared by these NGO activists on social media and the public's engagement with these messages.

Objective: This study aims to explore the themes covered by Mexican NGOs on X and examine what types of messages related to GBV potentially resonated more with the public.

Methods: We collated and reviewed posts (commonly known as tweets) published in Spanish on the platform X by Mexico-based NGOs between November 25 and December 10 of 2020, 2021, and 2022, a period when digital interactions increased during the COVID-19 pandemic. We then extracted posts using the following 4 hashtags: #16días, #16DiasdeActivismo, or #16DíasdeActivismo; #25N or #25Noviembre; #DiaNaranja or #DíaNaranja; and #PintaElMundoDeNaranja. We subsequently assessed the number of likes each post had and retained the top 200 posts from each year with the highest number of likes. We used the iterative content analysis process and the inductive 6-step qualitative thematic analysis method in NVivo software to code and analyze the final 600 posts.

Results: Five themes emerged from the 16 Days of Activism Against GBV campaigns, covering both knowledge-sharing and activism-generating messages as follows: (1) activism and how to be an activist, (2) types of GBV most commonly highlighted in posts, (3) changing public discourse surrounding GBV, (4) GBV as a violation of human rights, and (5) the COVID-19 pandemic's impact on GBV. Most of the messages on these posts exclusively mentioned women and younger girls, while a few included adolescents. Gaps in the representation of vulnerable populations were also found.

Conclusions: The posts from this campaign that were highly liked by the public reflect some of the most significant societal issues currently present in the country. Our results could help guide further GBV campaigns. Still, further research related to hashtag feminism by Mexico-based NGOs on GBV is needed to understand the population that NGOs reach and how the messages shared on these campaigns translate into activism on online and offline social media platforms.

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KEYWORDS

gender-based violence; Mexico; hashtag activism; feminist social activism; hashtag feminism; Twitter; X; nongovernmental organization; social media

Introduction

Background

Violence against women and girls, also commonly referred to as gender-based violence (GBV), is one of the world's most persistent forms of human rights violations and a major problem in the public health and clinical health arenas [1,2]. Specifically, GBV continues to be a serious problem in Mexico, as 70% of the women aged ≥15 years have experienced at least one incidence of GBV throughout their lives [3]. GBV takes many forms, with the most prevalent forms in Mexican society being psychological and sexual violence [3]. Disappearances and femicide, which is the intentional murder of a girl or woman because of her gender, are also common forms of violence in Mexico, with approximately 25% of women, adolescent girls, and young girls experiencing these forms of violence [4,5]. The COVID-19 pandemic increased the risk of violence against women, adolescents, and girls; women in North America, Central America, and South America were disproportionately affected by GBV during the pandemic [6]. Particularly in Mexico, domestic violence increased by more than 15% between 2020 and 2021 [7]. In 2020, the number of emergency calls related to violence against women increased by >30%, and the requests for support due to GBV increased by 40% [8,9]. Forms of structural GBV, such as violence at the social and economic levels, were also impacted during the COVID-19 pandemic in Mexico, for example, by the continuous increase in unpaid domestic and care work [10]. In addition, digital violence, which involves gender-based acts of violence through communication technology or digital media, such as image-based abuse, cyberstalking, blackmailing, and online harassment, increased in visibility in Mexico in the years surrounding the limitations of social interactions [10-13].

In Mexico, government institutions provide some forms of social support in the fight against the various forms of GBV, although important gaps in coverage are addressed by nongovernmental organizations (NGOs). Specifically, NGOs provide health care, psychosocial support, and legal aid for women, adolescents, and girls experiencing this type of violence [14]. As GBV and gender inequality became more visible during the COVID-19 pandemic, feminist movements, such as hashtag activism, feminist social activism, and hashtag feminism, in which NGOs actively collaborate, also became more visible [15]. Hashtag activism can facilitate social change, policy formation, and the provision of resources for the public [16]. Feminist social activism, popular since the late 2000s and present in Mexico since 2011, involves feminist individuals and organizations using social media for online civic engagement to denounce GBV and related aspects (such as sexism and gender discrimination); initiate social movements; and connect to share experiences, support, and resources, to name a few [17].

Online engagement to denounce GBV and other forms of gender-inequitable practices includes the initiation of social movements by connecting individuals to share their experiences, provide support, and offer sources of support. Hashtag feminism is a form of activism that combines hashtag activism with feminist social activism using specific hashtags across different digital platforms to call for action by sharing information and stories, connecting people, and organizing and mobilizing events against gender inequities [18-20]. NGOs have played a significant role in catalyzing hashtag feminist movements on GBV worldwide and in Mexico by engaging stakeholders and the general public through dialogue and community-building practices, mainly through Facebook and X (formerly known as Twitter; X Corp) [21-29]. An example of this is the 16 Days of Activism Against GBV, an annual international campaign led by civil society that runs from November 25, the International Day for the Elimination of Violence Against Women, to December 10, Human Rights Day [30,31]. The intention of this global campaign is to call for the prevention and elimination of violence against girls, adolescents, and women in all its different forms, including child marriage, sexual harassment, and intimate partner violence, to name a few [31,32].

Hashtag feminist movements stand to make a great impact in Mexican society, as social media use is widespread. In 2021, 89.2% of the internet users in Mexico connected to the internet daily, and 89.8% used it to access social media [33]. As of January 2022, Mexico ranked ninth in the world for most X users, with 13.9 million users [34]. Similar to what happened in other countries, digital interactions increased during the COVID-19 pandemic in Mexico, and the use of social media to promote strategies against violence, such as support groups, helplines, and screening for violence, became more popular [35-37]. Despite the prevalent use of X in the world and in Mexico, research is limited in regard to hashtag activism and hashtag feminism through X on GBV, specifically on interpersonal and sexual violence [22,38-40]. To our knowledge, only a few publications exist on feminist social activism in Mexico that are specific to GBV at the local level [17,41]. Furthermore, the X content from campaigns that address the umbrella of different types of GBV by Mexico-based NGOs has not previously been explored. Understanding the public's engagement on the GBV hashtag feminist campaigns is critical, as this can inform future GBV campaigns and provide valuable information to NGOs, governments, and researchers for tailored online and offline GBV prevention and intervention strategies.

This Study

To fill this gap, this research aimed to describe the range of GBV themes that Mexican NGOs posted on X during the annual 16 Days of Activism Against GBV campaign during the COVID-19 pandemic (from 2020 to 2022) and elucidate what types of messages related to GBV the public engaged with the most across and between the 3 different years. It is important to specify that while in Mexico the more specific term "violence against women" is commonly used, as it is the term described in the General Law on Women's Access to a Life Free from Violence first published in 2007 [3], this research followed the term GBV, as it is an umbrella term commonly used interchangeably [42] with violence against women and is the term used in the global campaign that is the focus of our investigation. We sought to describe the GBV themes raised by Mexico-based NGOs on X during these global campaigns and, based on the public's engagement, how the main content themes of posts (commonly known as tweets) compare between the 3 different years. Our findings can provide information on how these campaigns and the public's engagement could modify the agenda against GBV at different societal levels that was weakened during the COVID-19 pandemic [43] by contributing information on the topics that are generating the attention of the public, providing voice to certain communities, and adapting these results into current or future political or legal initiatives.

Methods

Study Design and Data Collection

Our research methodology followed a thematic content analysis of posts posted by Mexico-based NGOs during the annual 16 Days of Activism Against GBV campaign from 2020 to 2022. The following four hashtags chosen for this analysis were based on informal exploration on X of relevant hashtags used by Mexico-based NGOs during the campaign in 2020, 2021, and 2022: (1) the overall name of the campaign and its variations, namely #16días, #16DiasdeActivismo, or #16DíasdeActivismo (#16daysofactivism); (2) the first day of the campaign and the International Day for the Elimination of Violence Against Women (November 25), namely #25N or #25deNoviembre; (3) Orange Day, which occurs on the 25th of each month to create awareness and prevent violence toward girls and women, namely #DiaNaranja and #DíaNaranja (#OrangeDay); and (4) a related but broader hashtag, namely #PintaElMundoDeNaranja (#PaintTheWorldOrange). Given that the hashtag #10D, referring to December 10, the last day of the campaign and Human Rights Day, is also used annually in Argentina for democratic campaigns, we excluded it from analysis as a strategy to ensure data focused on the GBV campaign.

During data collection, the advanced search option from X was used to filter data based on the following study inclusion criteria: (1) only original content (no reposts or retweets); (2) included one of the hashtags used by Mexico-based NGOs during the campaign that were selected for this analysis (#16días, #16DiasdeActivismo, #16DíasdeActivismo, #25N, #25deNoviembre, #DiaNaranja, #DíaNaranja, or #PintaElMundoDeNaranja); (3) published in Spanish; (4) posted by a public X user with "non-governmental and nonprofit organization" as the professional category in order to only collect posts from local, state, national, or global NGOs; (5) the location of the X user marked as Mexico or a city or state in it; and (6) posted between November 25 and December 10 of 2020, 2021, and 2022, to align with the dates the campaign occurred. We used the Zeeschuimer and the 4CAT research tools to capture and download data from X. Zeeschuimer is a browser extension that collects data from social media sites, such as Instagram, TikTok, and X, while 4CAT is a research tool that can be connected to Zeeschuimer to store and download the data collected by the browser extension [44].

Data Cleaning

Posts posted between November 25 and December 10 of 2020, 2021, and 2022 were downloaded from 4CAT to a Microsoft Excel spreadsheet in August 2023. Posts that included videos (<1 min) and informational graphics were also included in the analysis. A total of 1914 posts (n=662, 34.59% for 2020; n=654, 34.17% for 2021; and n=598, 31.24% for 2022) were collected for the hashtags and the selected time period. To avoid duplicates, identical posts published during the same campaign year were collapsed and considered as one individual post. The collected posts were reviewed to ensure they met the inclusion criteria (only posts in Spanish, X user being an NGO, and location of the X user in Mexico).

We used the number of likes received by a post as the metric to determine the public's interest in and engagement with a post [45]. The frequency of likes has been previously used in the literature, including studies on GBV and feminist activism, to measure the public's engagement [21,39,46-50]. Reposts, which have been considered another form of public engagement in which the public contributes and creates content through reposting or forwarding a post [22], were not included in the analysis in order to focus on an original and representative set of posts posted by Mexico-based NGOs that participated in the 16 Days of Activism Against GBV campaigns.

We limited the analysis to the top 200 posts per year with the most likes (N=600 total posts) to assess the messages that generated the most engagement from the public. This analytic decision was based on previously published literature that has demonstrated that at least 500 posts are sufficient to identify themes and understand how individuals engage in health behaviors on X [51,52]. In the event of identical posts from different NGOs, we collapsed the number of likes.

Data Coding and Analysis

After obtaining and cleaning the data, the final list of 600 posts was uploaded into NVivo (version 14; Lumivero) for coding and analysis in the original language. We retained the original language of the posts to more accurately capture the cultural connotations and local meaning of the messages [53]. We completed an iterative content analysis process and a 6-step inductive thematic content analysis to identify and categorize the content of the posts into themes and explore socially produced and reproduced experiences [21,22,54]. These systematic approaches to interpreting qualitative research data have been used by other researchers when conducting thematic content analysis of social media data, including X hashtags in GBV campaigns [38,55-59]. The thematic process involved familiarization with the data, selection of keywords, coding, theme development, interpretation of themes, and development of a conceptual model [55]. An iterative inductive content analysis approach [60] was followed for the creation of the codebook by the first author and 2 research assistants (Yxchel Tejeda and Julia Godinez), as code categorization and subcategorization were extracted from the posts. Both research assistants were bilingual and were trained in thematic content analysis. Regular debriefing meetings between the primary author and the 2 research assistants took place during the coding and analysis process to refine the working codebook, discuss findings and emergent themes, resolve any coding discrepancies, and address any potential questions. The research team used NVivo (version 14) for coding and analysis. After the initial analysis, data were translated from Spanish to English by the first author (MM), who is bilingual.

Ethical Considerations

This study used publicly available, deidentified posts and did not directly involve human participants. Per the US Department of Health and Human Services' regulations for the protection of human subjects in research (45 CFR 46), approval from a research ethics committee was therefore not required or obtained. However, we adhered to ethical guidelines for handling and analyzing publicly available data, ensuring user anonymity and data privacy throughout the research process, including findings reported in this study.

Results

Overview

The 600 posts included in the final sample came from 61 different Mexico-based organizations. The number of likes for each post ranged from 9 to 2095. As shown in Table 1, the hashtag using the campaign's name (16 Days of Activism Against GBV) was the most frequently used hashtag in all 3 campaign years.

Table 1. Frequency of hashtags mentioned on most liked posts per campaign year by Mexico-based nongovernmental organizations.

Hashtag	2020, n (%)	2021, n (%)	2022, n (%)	Total, n (%)
#25N or #25Noviembre (n=216)	56 (25.9)	58 (26.9)	102 (47.2)	216 (100)
#DiaNaranja or #DíaNaranja (n=283)	113 (39.9)	111 (39.2)	59 (20.8)	283 (100)
#16días, #16DiasdeActivismo, or #16DíasdeActivismo (n=528)	167 (31.6)	204 (38.6)	157 (29.7)	528 (100)
#PintaElMundoDeNaranja (n=76)	49 (64.5)	22 (28.9)	5 (6.6)	76 (100)

The following five themes emerged across the 3 campaign years: (1) activism and how to be an activist, (2) types of GBV most commonly highlighted in posts, (3) changing public discourse surrounding GBV, (4) GBV as a violation of human rights, and (5) the impact of the COVID-19 pandemic on GBV. Within some of these themes, we also identified several cross-cutting subthemes, as described subsequently.

Theme 1: Activism and How to Be an Activist

The most common theme among the highly liked posts covered descriptions of what the 16 Days of Activism Against GBV campaign is, along with what activism is and how to be an activist (Table 2). Many of these posts were invitations to join the campaign or be activists. Other posts stressed that activism to support the rights of women and girls does not stop when the campaign stops but should be practiced on a regular basis. Invitations, live updates, and links to different types of events, such as marches, podcasts, and webinars organized during the campaigns, were also shared in these posts.

Table 2. Representative quotes from theme 1 (activism and how to be an activist).

Subthemes	Examples (posts translated into English)	Examples (posts in original language)
Description of the campaign	• "During these #16Días and all year long, stand in solidarity with women's rights activists and support feminist movements to resist the rollback of women's and girls' rights. #Únete #25N" [2022 campaign] • "What are the #16Días de activismo? It is a call to action and a reminder that violence against women and girls is the most widespread human rights violation around the world. #DíaNaranja Take action to end violence against women and girls." [2022 campaign]	• "Durante estos #16Días y todo el año, solidarízate con las activistas de los derechos de las mujeres y apoya a los movimientos feministas para resistir el retroceso de los derechos de las mujeres y las niñas. #Únete #25N" [Campaña 2022] • "¿Qué son los #16Días de activismo? Es un llamado a la acción y un recordatorio de que la violencia contra las mujeres y las niñas es la violación de derechos humanos más extendida en todo el mundo. #DíaNaranja Actúa para poner fin a la violencia contra las mujeres y las niñas." [Campaña 2022]
Campaign events	• "Women musicians, visual artists, activists, journalists, photographers and filmmakers join their voices to create #25NMás16, a sound, visual and informative piece promoted by the Initiative #SpotlightMX #DíaNaranja #Únete #16Días" [2020 campaign]	• "Mujeres músicas, artistas visuales, activistas, periodistas, fotógrafas y cineastas unen sus voces para crear #25NMás16, una pieza sonora, visual e informativa impulsada por la Iniciativa #SpotlightMX #DíaNaranja #Únete #16Días" [Campaña 2020]
Geographical examples	• "#25N| This is a fight for all women 'Neither in Tijuana, nor in Chiapas, nor in this city, NOT ONE MORE MURDERED' #NiUnaMenos #VivasNosQueremos" [2020 campaign]	• #25N| Esta es una lucha de todas las mujeres "Ni en Tijuana, ni en Chiapas, ni en esta ciudad, NI UNA ASESINADA MÁS" #NiUnaMenos #VivasNosQueremos" [Campaña 2020]

Different NGOs used different types of communication materials to explain the campaign's purpose and why and how to be an activist, including songs, short videos, and celebrity involvement. Particularly in the 2021 campaign, posts included images and quotes related to the campaign from musicians, politicians, ambassadors, NGO directors and representatives, and leaders in industry and sport. Figure 1 shows examples of visuals used in highly liked posts for the 16 Days of Activism Against GBV campaigns in 2020, 2021, and 2022.

Figure 1. Examples of visuals used by Mexico-based nongovernmental organizations in the frequently liked X (formerly known as Twitter) posts for the 16 Days of Activism Against Gender-Based Violence campaigns in 2020, 2021, and 2022.

Posts' messages on activism and how to be an activist were mainly generalized to the national level or provided data at a country level, although some included specific activities and examples of GBV cases from different municipalities, states, and, in 3 instances, other countries.

Theme 2: Types of GBV Most Commonly Highlighted in Posts

Many posts consisted of information about a specific type of violence (Table 3). Sexual violence was the most common type of violence found in these posts, followed by messages related to trafficking, disappearances, and femicide. These types of posts included data on the number of femicides or women and girls who have disappeared in the country and advice on what needs to change to prevent trafficking. Specific examples of women who have experienced GBV, particularly sexual violence and torture, were also included. Violence at home and physical violence were other forms of GBV that were also commonly present in these posts. Posts about digital violence were present in the data as well, particularly in 2020, at the start of the COVID-19 pandemic.

Table 3. Representative quotes from theme 2 (types of gender-based violence most commonly highlighted in posts).

Subthemes	Examples (posts translated into English)	Examples (posts in original language)
Sexual violence	• "Let us join forces against those who attempt to blur the boundaries of sexual consent, blame victims, and excuse perpetrators. During the #16Days of Activism, let's say it loud and clear: NO IS NO. #Únete #DíaNaranja" [2020 campaign]	• "Unamos nuestros esfuerzos contra quienes intenten desdibujar los límites del consentimiento sexual, culpar a las víctimas y excusar a los agresores. Durante los #16Días de Activismo, digámoslo alto y claro: NO ES NO. #Únete #DíaNaranja" [Campaña 2020]
Femicides and trafficking	• "Mexico closes the year with the terrible number of 27 thousand missing girls and women. Within the framework of #16Días of Activism, it is essential to demand differentiated strategies with a gender perspective to find them all" [2022 campaign] • "In Mexico, 11 femicides occur DAILY. Today #25N International Day for the Elimination of Violence against Women, we raise our voices for freedom, security, justice and sisterhood for all girls and women in Mexico. #NiUnaMas #VivasNosQueremos #DiaNaranja" [2020 campaign]	• "México cierra el año con la terrible cifra de 27 mil niñas y mujeres desaparecidas. En el marco de #16Días de activismo es fundamental exigir estrategias diferenciadas con perspectiva de género para encontrarlas a todas" [Campaña 2022] • "En México ocurren 11 feminicidios DIARIOS. Hoy #25N Día Internacional de la Eliminación de la Violencia contra la Mujer, alzamos la voz por la libertad, seguridad, justicia y sororidad para con todas las niñas y mujeres en México. #NiUnaMas #VivasNosQueremos #DiaNaranja" [Campaña 2020]
Violence at home	• "Women, girls and adolescents need to have peace of mind in their home and feel that their home is a safe and reliable space. Their home is NOT a space of #violence. Let's make families and homes #EspaciosSeguros! #25N #PintaElMundoDeNaranja #16Días" [2021 campaign]	• "Las mujeres, niñas y adolescentes necesitan tener tranquilidad en su hogar y sentir que su casa es un espacio seguro y confiable. Su hogar NO es un espacio de #violencia. ¡Hagamos de las familias y los hogares #EspaciosSeguros! #25N #PintaElMundoDeNaranja #16Días" [Campaña 2021]
Digital violence	• "The increase in internet use during #COVID19 has made women and girls targets of online violence. In these #16Días of Activism, #pintaelmundodenaranja using your networks to raise awareness and promote solidarity. #DíaNaranja #Únete" [2020 campaign]	• "El incremento del uso de internet durante #COVID19 ha convertido a mujeres y niñas en blanco de violencias en línea. En estos #16Días de Activismo, #pintaelmundodenaranja usando tus redes para concientizar y fomentar la solidaridad. #DíaNaranja #Únete" [Campaña 2020]
Physical violence	• " Did you know that 1 in 3 women in the world has suffered physical or sexual violence throughout their lives? Share this post and #Únete the #16días of activism to end this global pandemic. #25N" [2021 campaign]	• " ¿Sabías que 1 de cada 3 mujeres en el mundo ha sufrido violencia física o sexual a lo largo de su vida? Comparte este post y #Únete a los #16días de activismo para acabar con esta pandemia mundial. #25N" [Campaña 2021]

Other forms of violence, such as the lack of access to sexual and reproductive resources, obstetric violence, vicarious violence, and precarious work, were present in posts, but they were not as common as sexual violence, femicide, and digital violence. Violence against women in the form of harassment in specific locations, such as school and at work, was also highlighted by the campaign but to a lesser extent.

Theme 3: Changing Public Discourse Surrounding GBV

Posts in this theme centered on changing current narratives in Mexican society surrounding GBV that blame and silence survivors and normalize violence (Table 4). The posts provided examples of how to change the narrative, such as believing the victim, not excusing the perpetrator, and reporting any form of violence. The actors responsible for making these changes included both individuals and institutions. At the individual level, most posts were not targeted at a specific gender; however, some did aim toward male individuals and their role in eradicating GBV. Some highly liked posts were focused on female individuals, while other posts were specific to inviting both men and women to become activists and eradicate GBV. Throughout the 3 campaign years, the highly liked posts provided specific information about GBV toward women or women and younger girls. A few highly liked posts included adolescents in the messages, and, when included, these posts were about violence against younger girls and adolescents or against younger girls, adolescents, and women. At the institutional level, posts provided reasons for the importance of these groups in combating GBV, such as health and government personnel providing help to women after experiencing some form of GBV, while also providing examples of what these institutions can do, such as treating survivors of GBV with dignity and defending the rights of women, adolescents, and girls.

Table 4. Representative quotes from theme 3 (changing public discourse surrounding gender-based violence).

Subthemes	Examples (posts translated into English)	Examples (posts in original language)
Believe survivors	• "Every time a woman talks about her experience of sexual violence and we don't believe her, rape culture grows stronger. Every time you hear a survivor's story: 1-Listen. 2-Believe. 3-Support. #DíaNaranja #16Días #Únete" [2020 campaign]	• "Cada vez que una mujer habla de su experiencia de violencia sexual y no le creemos, la cultura de la violación se hace más fuerte. Cada vez que escuches la historia de una sobreviviente: 1-Escucha. 2-Cree. 3-Apoya. #DíaNaranja #16Días #Únete" [Campaña 2020]
End the silence	• "If you face violence, don't be silent, raise your voice. Call 911 for help immediately and tell your trusted people. #16Días #DíaNaranja" [2021 campaign] • "Report when you see: Abuse Harassment on the street Sexist jokes Unwanted behavior Inappropriate sexual comments Sexual harassment is never acceptable. #16Días #Únete #DíaNaranja" [2020 campaign]	• "Si enfrentas violencia, no te calles, alza la voz. Pide ayuda inmediatamente al 911 y cuéntalo a tus personas de confianza. #16Días #DíaNaranja" [Campaña 2021] • "Denuncia cuando veas: Abuso Acoso en la calle Bromas sexistas Comportamiento no deseado Comentarios sexuales inapropiados El acoso sexual nunca es aceptable. #16Días #Únete #DíaNaranja" [Campaña 2020]
Call out perpetrators' actions	• "Don't be an accomplice to those who commit violence, don't look the other way. Speak up, intervene and show your support for survivors during the #16Días, and every day. #Únete #DíaNaranja" [2020 campaign]	• "No seas cómplice de quien ejerce violencia, no mires a otro lado. Habla, interviene y muestra tu apoyo a las sobrevivientes durante los #16Días, y todos los días. #Únete #DíaNaranja" [Campaña 2020]
Engage men	• "As men we have to reflect, question ourselves, inform ourselves and act. #25N Let's build relationships of respect, peace and equality! " [2022 campaign]	• "Como hombres nos toca reflexionar, cuestionarnos, informarnos y actuar. #25N ¡Construyamos relaciones de respeto, paz e igualdad! " [Campaña 2022]
Focus on women and younger girls	• "Eliminating violence against girls and adolescents is everyone's task. Get informed and learn about different ways in which you can prevent gender violence. #16Días #DíaNaranja" [2021 campaign] • "Violence will affect 1 in 3 girls and women throughout their lives. This must stop! #PintaElMundoDeNaranja and unite against violence." [2020 campaign]	• "Eliminar la violencia contra las niñas y las adolescentes es tarea de todas y todos. Infórmate y conoce diversas formas en que tú puedes prevenir la violencia de género. #16Días #DíaNaranja" [Campaña 2021] • "La violencia afectará a 1 de cada 3 niñas y mujeres a lo largo de su vida. ¡Esto debe parar! #PintaElMundoDeNaranja y únete contra la violencia." [Campaña 2020]
Responsibility of societal institutions	• "People in leadership must implement prevention measures that address inequalities in power relations between genders, which are at the root of violence against women and girls #16Días #DíaNaranja" [2021 campaign] • "Health providers can also defend the life and health of girls who have been forced to become mothers. Taking care of the health of survivors also involves having the ability to treat them humanely and with dignity. They are #GirlsNotMothers. #25N" [2021 campaign]	• "Las personas en liderazgo, deben poner en marcha medidas de prevención que hagan frente a las desigualdades en las relaciones de poder entre los géneros, que se encuentran en la raíz de la violencia contra las mujeres y las niñas. #16Días #DíaNaranja" [Campaña 2021] • "Las personas proveedoras de salud también pueden defender la vida y la salud de las niñas que han sido forzadas a ser madres. Cuidar la salud de las sobrevivientes también pasa por tener la capacidad de darles un trato humano y digno. Son #NiñasNoMadres. #25N" [Campaña 2021]

Theme 4: GBV as a Violation of Human Rights

Posts related to GBV as a human rights concern rooted in gender inequalities and power imbalances were also common in the 3 campaign years (Table 5). These posts that stated the importance of challenging inequitable gender norms to promote equity and justice for girls and women were highly liked during the 3 campaign years. Particularly, for posts from 2020 related to justice and equity, many highly liked posts described real-life events of women in Mexico who had experienced sexual violence, wrongful convictions, and unjust incarcerations.

The focus on inequities did not stop at gender inequities. Posts also focused on violence toward specific vulnerable groups, such as people with disabilities, migrants, and sexual minority groups, and they were also found in the highly liked posts for the 3 campaign years, especially in 2021 and 2022. The two most common messages among posts related to vulnerable groups were (1) events to visualize the GBV that migrants experience in Mexico and (2) information on vulnerable populations being at a higher risk of experiencing GBV.

Table 5. Representative quotes from theme 4 (gender-based violence as a violation of human rights).

Subthemes	Examples (posts translated into English)	Examples (posts in original language)
Human rights violation	" Violence against women is the most widespread violation of human rights in the world and the latest UN data show that the greatest threat to women and girls lies in the people in their immediate environment. #16Días #YaEsYa #DíaNaranja #Únete" [2022 campaign]	" La violencia contras las mujeres es la violación más generalizada de los derechos humanos en el mundo y los últimos datos de ONU demuestran que la mayor amenaza para las mujeres y las niñas reside en las personas de su entorno más cercano. #16Días #YaEsYa #DíaNaranja #Únete" [Campaña 2022]
Origins in gender inequity	"The origin of violence is discrimination and gender inequality, as well as gender stereotypes and harmful masculinities still in force in our societies. #16Días #DíaNaranja #Únete" [2021 campaign]	"El origen de la violencia es la discriminación y la desigualdad de género, así como los estereotipos de género y las masculinidades nocivas aún vigentes en nuestras sociedades. #16Días #DíaNaranja #Únete" [Campaña 2021]
Violence toward vulnerable groups	"Inequality, poverty, ethnic origin, disability, immigration status, among others, increase the vulnerability of women and girls. Let's end violence against women and girls NOW! #16Días #DíaNaranja" [2021 campaign]	"La desigualdad, la pobreza, el origen étnico, la discapacidad, el estatus #migratorio, entre otros, aumentan la vulnerabilidad de las mujeres y las niñas. ¡Pongamos fin a la violencia contra las mujeres y las niñas YA! #16Días #DíaNaranja" [Campaña 2021]

Theme 5: The Impact of the COVID-19 Pandemic on GBV

Finally, a common theme among posts from 2020 (but not common in the 2021 and 2022 campaign posts) was the impact of the COVID-19 pandemic on GBV in Mexico. Posts in this theme highlighted the importance of the resources for GBV victims during this time and shared data or examples of how the pandemic increased GBV during the lockdown period in Mexico. Posts also cautioned that inaction could lead to setbacks in progress made toward gender equity. Table 6 presents selected quotations representing this theme.

Table 6. Representative quotes from theme 5 (the impact of the COVID-19 pandemic on gender-based violence).

Examples (posts translated into English)	Examples (posts in original language)
"We have stayed at home to avoid risks of contagion by #COVID19 but what happens if the risk is at home? Violence against women in the home has increased during the pandemic, but we can all help victims. #DíaNaranja #16Días #Únete" [2020 campaign]	"Nos hemos quedado en casa para evitar riesgos de contagio por #COVID19 pero ¿qué pasa si el riesgo está en casa? La violencia contra las mujeres en el hogar ha aumentado durante la pandemia, pero toda/os podemos ayudar a las víctimas. #DíaNaranja #16Días #Únete" [Campaña 2020]
" Shelters Helplines Advice Services for survivors are essential. Any type of support for victims of violence must be available to anyone who needs it, even during the #COVID19 pandemic. #DíaNaranja #16Días #Únete" [2020 campaign]	" Refugios Líneas telefónicas de ayuda Asesoramiento Los servicios para las sobrevivientes son esenciales. Cualquier tipo de apoyo a las víctimas de violencia debe estar disponible para quien lo necesite, incluso durante la pandemia de #COVID19. #DíaNaranja #16Días #Únete" [Campaña 2020]
"The pandemic is being particularly painful for women. If no action is taken, the progress in gender equality made over the last 25 years will be lost. #16Días #DíaNaranja #Únete" [2020 campaign]	"La pandemia está siendo particularmente dolorosa para las mujeres. Si no se adoptan medidas, los avances en la igualdad de género logrados en los últimos 25 años se perderán. #16Días #DíaNaranja #Únete" [Campaña 2020]

Discussion

Principal Findings

Using data from 3 years of social media activism by Mexican NGOs on X, we found that messaging surrounding the 16 Days of Activism Against GBV centered on the following: (1) activism and how to be an activist, (2) types of GBV, (3) changing the public discourse surrounding GBV, (4) GBV as a human rights violation, and (5) the impact of the COVID-19 pandemic on GBV. The posts from this campaign that were highly liked by the public reflect some of the biggest societal issues currently present in Mexico. In total, 3 of the 5 main themes identified—the types of GBV, activism and how to be an activist, and changing public discourse surrounding GBV—were present across the 3 campaign years. The impact of the COVID-19 pandemic on GBV and GBV as a violation of human rights were the more prevalent themes in 2020 and 2021 and 2022, respectively. Subsequent research on future campaigns could help better understand how these themes evolve in Mexican society over time.

Activism and how to be an activist was the most common theme among the posts analyzed during the 16 Days of Activism against GBV campaigns from 2020 to 2022. The activism in this annual campaign educates the public on GBV through posts that show the information in different ways, such as videos, songs, data, infographics, and citing influential people, to name a few. Similar to what other studies have found related to digital activism, the posts from this campaign provide information that makes the problem of GBV visible, which helps destigmatize GBV in Mexico [61,62]. A mixed methods study published in 2018 analyzed whether GBV activism through Facebook creates sisterhood among followers and found that the sisterhood created on Facebook through the interaction and creation of groups and communities was translated into activism online and offline; this study noted that the lack of groups and communities on X does not allow this sisterhood to be created among X users [28]. However, we suggest that further analysis on X is needed to understand the potential of activism developing a sisterhood on this social media platform through reposts, replies, and other communication tools present on this platform.

Related to the different forms of GBV, sexual violence was the main form of violence highlighted in the analyzed posts. This resonates with the prevalence of sexual violence among the Mexican population, as this type of violence is the second most common form of GBV in Mexico [3]. Sexual violence prevalence among women aged ≥15 years increased from 41.3% in 2016 to 49.7% in 2021 [3]. Digital violence was another form of violence featured in the campaign posts. Digital violence soared in 2020 as a consequence of the COVID-19 pandemic [63]. This type of violence has continued to increase after the pandemic and affects girls and adolescent girls more than their male counterparts. Between 2021 and 2022, more than 33% of girls and adolescent girls in Mexico with access to a phone or internet experienced some form of digital violence, compared to 12% to 18% of Mexican boys and male adolescents [64]. As both forms of GBV continue to increase, the 16 Days of Activism against GBV campaign as well as other NGO- and non–NGO-based campaigns and prevention and intervention strategies should focus on sexual and digital violence in girls, adolescents, and women in Mexico.

We found that less commonly discussed forms of violence, such as economic violence, vicarious violence, lack of access to sexual and reproductive resources, and obstetric violence [65-69] were covered in the posts for these campaigns. Although other more commonly known forms of violence, such as sexual violence and intimate partner violence, were more commonly highlighted in these posts, having information on less commonly discussed forms of GBV within the campaign educated the public and provided tools to identify more types of violence. Indeed, although these forms of GBV are less commonly known by the public, it does not necessarily mean that these forms of violence are less prevalent. For example, Mexican national data have found that economic violence, which is not a well-known form of GBV in the country compared to physical, psychological, and sexual violence, is the most common form of GBV in the workplace [70].

A notable finding from theme 3, changing the narrative surrounding GBV, is that those called upon for change were not only individuals and the general public but also those in the public sector, including people in government leadership positions and health care providers. For the latter, the highly liked posts from the 3 campaign years acknowledged health care professionals as pillars of society for eradicating GBV in Mexico, one of the few countries with laws for the health care sector to address GBV at different prevention levels [71]. However, limited research has examined whether the Mexican health care sector is addressing GBV with their patients or working in other ways toward prevention. For example, a study completed among health care professionals in the states of Quintana Roo, Coahuila, and Mexico City found that while health care professionals were willing to address the issue of domestic violence with their patients, the care and attention needed for this specific type of violence was insufficient [72]. The awareness provided by the NGOs' posts and the engagement of the public on the vital role of these medical professionals in preventing and eliminating GBV could lead to the health care sector and other types of leadership organizations finally taking ownership of their role in reducing GBV.

A current social issue represented as a subtheme under theme 4, GBV as a human rights violation, was the violence experienced by vulnerable groups in Mexico, including migrant girls, adolescents, and women. Since 2018, caravans of migrants from Central and South America have traveled to Mexico in order to reach the United States, with girls, adolescents, and women being particularly vulnerable to different forms of GBV through their travels in Mexico [73,74]. According to the literature, migrants are more likely to be the victims of human trafficking [73], another form of GBV also present in highly liked posts for the 3 campaign years. However, the posts analyzed did not provide resources that could help prevent human trafficking, as these posts only had data on the prevalence of this GBV. Specific resources, such as phone numbers, may be more instrumental, particularly in states such as Chiapas, where migrants tend to stay longer and where it has been shown that GBV is more prevalent for this group [73]. A vulnerable group not mentioned in the highly liked posts that were analyzed was of Indigenous girls, adolescents, and women, even though they have consistently experienced GBV, structural violence, and institutional violence [75,76]. It is unknown if posts with fewer likes and thus not included in these analyses specifically mentioned this vulnerable group in posts by NGOs during the 3 campaign years. Future research on this topic is suggested to not only better understand the public's interest or awareness but also to identify different vulnerable groups that are not represented or addressed in nation-based campaigns or are not receiving broader support through recognition (likes).

Our results found that most of the messages on these posts exclusively mentioned women and younger girls, while only a few included adolescents. However, in Mexico, 60% of the adolescents aged between 15 and 17 years have experienced some type of GBV, and 40% have experienced sexual violence, while 80% of the minors aged <18 years who have disappeared in this country were adolescent girls aged between 12 and 17 years [4,77]. In addition, different studies have found a high prevalence of GBV in Mexican adolescent girls. For example, a study in the northern city of Tijuana found that most adolescent girls have experienced some form of intimate partner violence, more specifically, emotional, sexual, or physical abuse [78]. It is imperative for Mexico-based NGOs involved in future campaigns for 16 Days of Activism against GBV to be more inclusive of adolescent girls in their posts and have specific messages toward this age group, as they are vulnerable and in need of information to combat GBV, and to take account of the influence of social media toward adolescents. It is also important to state that the messages from most highly liked posts followed a collective voice, as these were written from a collective point of view in order to express ideas about GBV and activism against GBV through group unity, shared responsibility, and changes as a group. This characteristic of the highly liked posts from Mexican NGOs is in line with existing literature, which has previously identified that Latin American feminist movements are distinguished by a collective voice compared to non-Latin American campaigns that have been framed through an individualized lens, such as the #MeToo movement [79].

Research using social media data to learn more about hashtag activism and hashtag feminism has grown in the last decade. Particularly, published literature on X data to analyze activism against GBV in the world has focused on hashtags in English [38,80], and most of it has been related to sexual violence [22,39,40,81]. Previous examples of hashtag feminism in Mexico include the #MeToo movement in 2017; #SiMeMatan (#IfTheyKillMe), used by women in response to the media and authority's secondary victimization of femicide victims; and #MiPrimerAcoso (#MyFirstAssault) in 2016, related to childhood sexual abuse, to name a few [82]. Some of these hashtags have been previously analyzed; however, to the best of our knowledge, we believe this research is one of the first studies to focus on Mexico-based NGOs, different campaign years, and more than 1 hashtag. This study provides important information on the types of messages that Mexico-based NGOs focused on in the prevention and elimination of GBV as well as what types of messages are potentially of more interest to the public. Future studies could further expand the limited knowledge on hashtag feminism against GBV in Mexico. For example, analyzing the demographics of the X users who liked these posts would provide context for understanding the population that follows this campaign. Analyzing other campaigns on GBV as well as the messages published and liked on other popular social media platforms in Mexico, such as Facebook, TikTok, and Instagram, is worth pursuing in future studies to further explore and better understand topics related to the prevention and elimination of GBV. Moreover, future research that quantifies post volume and interactive users through in-depth social network and semantic network analysis could provide more information on our findings by further exploring the level of user engagement and the evolution of discussions on GBV and activism over time. This tone of voice emerged across the 5 themes.

Finally, due to the inductive nature of this research, our study did not follow a theoretical framework. Nonetheless, our results lay the groundwork for future research that could benefit from the use of theoretical frameworks, such as the intersectionality framework [83], to further understand the intersecting identities of the public engaging in GBV campaigns and the feminist theory [84] to further study one of the main themes for this research, GBV as a violation of human rights, including gender inequities.

Strengths and Limitations

As noted earlier, to the best of our knowledge, this study is the first of its kind to conduct a comprehensive thematic content analysis using X data to examine GBV activism across Mexico at a national level. It delivers a groundbreaking perspective on the powerful impact of hashtag activism and feminist movements, offering an unprecedented understanding of social activism in the country. The research brings valuable insights into the topics related to GBV and the messages from this activist campaign that the public engages with the most. This high-level synthesis provides an overview of priorities and topics that can help NGOs and other types of organizations be more strategic in their social media campaigns and messages to combat GBV. For example, we note a gap in the provision of specific resources for those facing GBV; this may be a key area for future campaigns to build on. Despite these strengths, we recognize the inherent limitations in working with X data. First, the text content of posts is limited to up to 280 characters. This particular characteristic of X could hinder the amount of content that can be shared with the public. While some posts analyzed in this study included videos or infographics that could further expand the message shared by the NGO, most posts were messages of <280 characters with concise and specific yet limited information. First, we chose to use X data for analysis instead of another platform such as Facebook, as X offers a diverse dataset and has been one of the main channels used for hashtag feminism [39]. Second, while we collected and analyzed all the text present in the highly liked posts, we only analyzed the visual elements from the posts in the form of pictures and short videos (<1 min), losing the potential for more emerging themes to come from longer videos. Third, our study is limited to posts posted by NGOs that participated in the 16 Days of Activism against GBV campaigns. The results are not generalizable to other types of users (such as government agencies and celebrities) or to other hashtags related to the campaign that were not analyzed in this research. Fourth, this analysis was specific to NGOs based in Mexico and posts published in Spanish, so our results might not be generalizable to the campaign in other countries. Fifth, we focused our research on 4 hashtags (and their variations) specific to this campaign; therefore, it is possible that our research missed capturing other themes from other hashtags (such as #10D, #niunamenos [#notonemore], #niunaasesinadamás [#notonemoremurdered]) related to the 2020, 2021, and 2022 campaigns. Sixth, because of the limited number of posts (N=600) analyzed in this research, themes could have been missed; however, a sample size of 500 posts has been demonstrated to be sufficient to identify themes and understand the public's engagement [52,85]. Finally, the posts chosen for this analysis were based on the number of likes at the time of data collection. The number of likes on a post changes through time; therefore, the messages from these posts that generated the most attention and engagement from the public at the time of the campaign could have changed by the time the data were collected and might not reflect the engagement of the public with the different topics related to GBV. However, this is unlikely, as research has found that most likes on a post are given within 24 hours after the post is posted on X [86].

Conclusions

Our findings reveal that the highly liked posts for the 16 Days of Activism against GBV campaigns posted by Mexico-based NGOs in 2020, 2021, and 2022 are a reflection of the forms of violence and social issues that currently occur in the country. According to our results, informational posts about the types of GBV, the role of activism, and changing public discourse surrounding GBV are the types of messages that seem to engage the public the most. Our results could help inform and guide future GBV campaigns while also informing the NGOs of the lack of representation in their messages about GBV toward important vulnerable populations, such as adolescents and Indigenous groups. Nevertheless, further research related to hashtag feminism by Mexico-based NGOs on GBV, such as the demographics of X users who engage on these posts and the types of activism interactions among X users on other social media platforms, is vital to understand the population that NGOs reach and how the messages shared on these campaigns translate into activism online and offline.

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Conflicts of Interest

None declared.

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Abbreviations

GBV: gender-based violence
NGO: nongovernmental organization

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Original Paper

Exploring Topics, Emotions, and Sentiments in Health Organization Posts and Public Responses on Instagram: Content Analysis

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Abstract

Background: Social media is a vital tool for health organizations, enabling them to share evidence-based information, educate the public, correct misinformation, and support a more informed and healthier society.

Objective: This study aimed to categorize health organizations' content on social media into topics; examine public engagement, sentiment, and emotional responses to these topics; and identify gaps in fear between health organizations' messages and the public response.

Methods: Real data were collected from the official Instagram accounts of health organizations worldwide. The BERTopic algorithm for topic modeling was used to categorize health organizations' posts into distinct topics. For each identified topic, we analyzed the engagement metrics (number of comments and likes) of posts categorized under the same topic, calculating the average engagement received. We examined the sentiment and emotional content of both posts and responses within the same topic, providing insights into the distributions of sentiment and emotions for each topic. Special attention was given to identifying emotions, such as fear, expressed in the posts and responses. In addition, a linguistic analysis and an analysis of sentiments and emotions over time were conducted.

Results: A total of 6082 posts and 82,982 comments were collected from the official Instagram accounts of 8 health organizations. The study revealed that topics related to COVID-19, vaccines, and humanitarian crises (such as the Ukraine conflict and the war in Gaza) generated the highest engagement. Our sentiment analysis of the responses to health organizations' posts showed that topics related to vaccines and monkeypox generated the highest percentage of negative responses. Fear was the dominant emotion expressed in the posts' text, while the public's responses showed more varied emotions, with anger notably high in discussions around vaccines. Gaps were observed between the level of fear conveyed in posts published by health organizations and in the fear conveyed in the public's responses to such posts, especially regarding mask wearing during COVID-19 and the influenza vaccine.

Conclusions: This study underscores the importance of transparent communication that considers the emotional and sentiment-driven responses of the public on social media, particularly regarding vaccines. Understanding the psychological and social dynamics associated with public interaction with health information online can help health organizations achieve public health goals, fostering trust, countering misinformation, and promoting informed health behavior.

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KEYWORDS

emotion analysis; fear; health communication; health care; Instagram; official health organizations; sentiment analysis; social media; vaccines

Introduction

Background

Social networks are used by billions of people around the world, making them an effective platform for reaching a wide range of audiences. Health organizations, such as the World Health Organization (WHO), use social networks to disseminate important health-related information [1-5]; provide real-time updates, news, and emergency guidelines [6]; and promote awareness of diseases [7] and mental health [8]. Health organizations also promote vaccination compliance by disseminating information regarding vaccination importance, safety, and disease severity [9].

In contrast to the content published by social network users unaffiliated with health organizations, who can spread a large amount of inaccurate, false, and misleading information about health-related issues [10,11], the health-related content published on social networks by official health organizations enables the public to have access to reliable and useful information [12-14]. Therefore, health organizations are important actors in social media as reliable sources, providing evidence-based and authoritative information [15]. Through their efforts, these organizations educate the public, dispel myths, and help the community become healthier and more informed [16].

In addition to serving as a means of disseminating health-related information, social networks provide the public with the opportunity to participate in discussions and conversations with health organizations [17] by posting comments, sharing posts, and liking posts. Members of the public can also ask questions about the health issue being discussed, and the organizations that disseminate the information can respond. Active public participation can enhance individuals' understanding of health-related content [18,19] and can foster public trust in and appreciation for science [20]. In addition, health organizations are able to pinpoint concerns related to specific health topics, gain insight into public opinion [17-25], and identify topics that result in misinformation [26].

However, health-related messages disseminated by health organizations can provoke negative public reactions [27]. When combined with contradictory messages from unaffiliated social media users, this can lead to undesired health behaviors, such as vaccine hesitancy, noncompliance with health directives, and diminished trust in the reliability of health organizations [28-30].

Understanding public emotions in response to information disseminated by health organizations on social media is important for assessing the effectiveness of health communication strategies [31]. Sentiment and emotion analysis are widely used for determining sentiment polarity and detecting specific emotions expressed in textual data [32]. Sentiment analysis categorizes a text as positive, negative, or neutral, while emotion analysis identifies specific emotions expressed within a text [32]. Fundamental emotions, such as happiness, sadness, anger, disgust, surprise, and fear, can be detected, along with more nuanced emotions such as confusion and trust [33,34]. Among these emotions, fear is an important factor in health communication, as it can influence public perception, engagement, and behavioral responses [35].

Various theoretical models, such as the extended parallel process model [36], have explored how fear is used in public health messaging to encourage protective behaviors. This model suggests that individuals respond to fear-based messages depending on their perceived threat level and their sense of efficacy in managing the threat. According to this model, when perceived risk is high and the message also offers a clear solution, individuals are more likely to engage positively and adopt protective behaviors. However, if either condition is not met, responses may be negative, leading to outcomes such as avoidance or denial [36]. Therefore, fear is a crucial factor to consider in public health communication.

Despite the need to examine how the public emotionally responds to information shared by health organizations on social media, studies examining the topics communicated by these organizations and the corresponding responses from the public are sparse. The aim of this study is to analyze and characterize the content disseminated by health organizations on social media into topics, as well as social media users' responses to this content and the engagement, sentiment, and emotions induced by this content. In addition, we aim to identify gaps in fear between health organizations' messages and public responses.

Related Work

In this section, we provide an overview of various studies associated with health-related content and the topic modeling and sentiment analysis of such content.

Sentiment Analysis of Health-Related Social Media Content

Many studies examined the sentiment and public opinion surrounding the COVID-19 vaccine on Twitter [21,23,24,37-53]. For example, an analysis of Twitter data was conducted by Niu et al [24] to examine public opinion and sentiment before and during the administration of the COVID-19 vaccines in Japan. They found that negative sentiment toward the vaccines dominated positive sentiment in Japan, and concerns about side effects may have outweighed fears of infection at the beginning of the vaccination process.

Numerous studies leveraged machine learning techniques to classify tweets as positive, negative, or neutral sentiment toward vaccines, enabling the identification of vaccine hesitancy among communities and social media users [35,54-68]. Most of these studies collected data from Twitter using keywords or hashtags related to vaccinations. Chakraborty et al [56] used deep learning to analyze 226,668 COVID-19 tweets from December 2019 to May 2020, achieving 81% accuracy. Most tweets showed positive or neutral sentiment, while highly retweeted posts were predominantly neutral or negative.

Topic Modeling for Health-Related Social Media Content

Several studies have used topic modeling to examine health-related discussions on social media, focusing on topics such as blood donation [69], cancer-related content [70], and vaccine-related conversations [71]. Paul and Dredze [72] proposed the ailment topic aspect model to identify health topics on Twitter. Analyzing 144 million tweets, they identified 13 topics linked to seasonal influenza, allergies, temporal surveillance, and obesity-related geographic data in the United States.

Seltzer et al [73] analyzed 500 Instagram (Meta Platforms, Inc) images tagged #zika from May to August 2016, analyzing them by sentiment, content, and engagement. A total of 299 images were related to health, while 193 focused on topics of public interest. Sentiments and emotion analysis revealed that fear and negative emotions were linked to Zika transmission and response uncertainty. The study highlighted Instagram's value in understanding public sentiment and addressing gaps in health communication. Furthermore, Muralidhara and Paul [74] analyzed 96,426 Instagram posts collected between September and October 2016, using 269 health-related hashtags. Polylingual topic modeling approach was used to identify 47 health-related topics spanning 10 broad categories: acute illness, alternative medicine, chronic illness and pain, diet, exercise, health care and medicine, mental health, musculoskeletal health and dermatology, sleep, and substance abuse. Kim et al [75] analyzed 96,302 Instagram photos and 513,694 comments with antivaccination hashtags, focusing on photo features, engagement, and sentiment. Most photos (52.24%) were categorized as "text." "Food" and "plant" photos received the most positive comments, while "text" photos, despite high engagement, received fewer positive responses.

Other studies focused on dividing vaccine content on social networks into topics [40,41,43,45,52,53,76]. The study by Kwok et al [76] examined tweets of Australian users regarding COVID-19 vaccination on Twitter. Using a latent Dirichlet allocation topic model, they identified 3 commonly discussed topics: attitudes toward COVID-19 and vaccination, advocacy for infection control measures against COVID-19, and misconceptions and complaints regarding COVID-19. Similarly, Lyu et al [40] used latent Dirichlet allocation to analyze COVID-19 vaccine discussions on Twitter, identifying 16 topics grouped into 5 themes. Vaccination opinions were the most discussed topic. Emotion analysis showed trust as the dominant emotion, followed by anticipation, fear, and sadness. In addition, Chandrasekaran et al [43] used the correlation explanation topic modeling algorithm to examine COVID-19 vaccine–related tweets. The authors identified 16 topics in the COVID-19 vaccination tweets, which were grouped into 6 broader themes. Most tweets regarding COVID-19 vaccination centered on vaccine policy, vaccine hesitancy, and postvaccination symptoms and side effects.

Analysis of Health Care Providers' Content and Public Responses on Social Media

Several studies have examined content published on social networks by health care providers. Among them, Kim and Kim [77] analyzed 1545 Instagram photos published by the US Centers for Disease Control and Prevention (CDC) and public comments using Microsoft Azure Cognitive Services. Their findings showed that most images featured text or people, but those with larger faces or flashy elements tended to receive less engagement. Happiness and neutral emotions in comments were negatively correlated with interaction levels. Pinto et al [78] analyzed 632 Instagram posts from Portugal's National Health Service (NHS) and Brazil's Ministry of Health (MH) in 2019, mapping 53 topics for the NHS and 63 for the MH. The NHS emphasized healthy eating and blood donation, while the MH focused on vaccination campaigns, dengue prevention, and HIV awareness.

Mello et al [79] analyzed 726 Instagram posts from the WHO and CDC in 2020 to explore how these organizations communicated COVID-19 risks. Their study focused on messaging related to threat and efficacy, cues to action, and indicators of credibility. According to the findings, efficacy messages, such as those promoting preventive behaviors, were more prevalent, while threat messages addressing the susceptibility and severity of COVID-19 were less common. The study concluded that improving credibility cues, using compelling visuals, tailoring content for diverse audiences, and leveraging Instagram's interactive features could enhance public health communication, boosting engagement, trust, and impact.

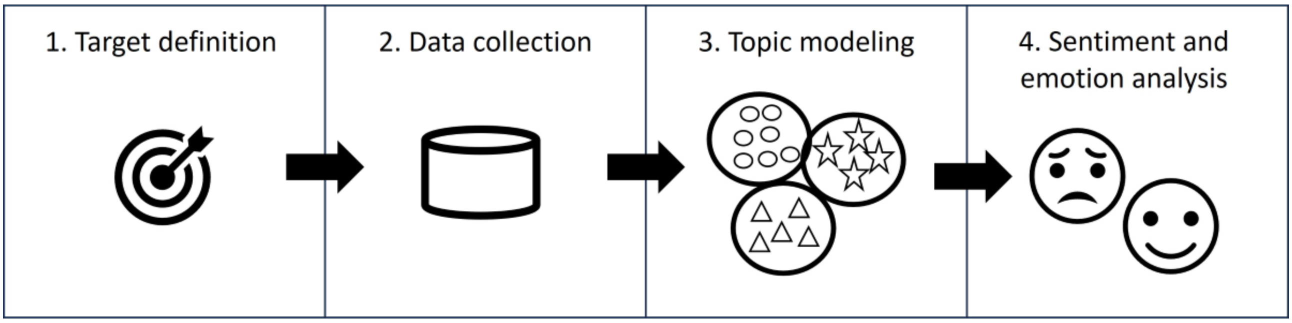
Vaghefi et al [80] analyzed health care providers' messages on Twitter from May 2018 to May 2019 using machine learning, including Bidirectional Encoder Representations from Transformers (BERT)–based models, to classify tweets as professional communications or health-related information, further categorizing them as fear based or hope based. Results showed that fear-based messages were widely shared by the public but were less effective at motivating constructive health actions, while hope-based messages resonated more with health care providers. While this study [80] examined health care providers' content and the fear evoked by their messages on Twitter, our study focuses on categorizing health care providers' posts into distinct topics; analyzing engagement metrics, sentiment, and emotional content within each topic; and identifying the gaps between the fear expressed in messages from health organizations and the fear observed in public responses to such content. In contrast, Vaghefi et al [80] did not analyze the public comments to measure fear in relation to health care providers' messages; instead, they focused on public interactions, such as retweets and replies, to study information propagation.

Methods

Overview

This section outlines the proposed methodology, which consists of four main phases, as illustrated in Figure 1: (1) defining the targeted health organizations, (2) gathering data from the selected health organization accounts, (3) performing topic modeling on health organization content, and (4) analyzing the sentiment and emotion associated with each topic and the public's response to it.

Figure 1. An overview of the methodology's main phases.



Detailed descriptions of each phase are provided in the subsections that follow.

Target Definition

The first phase of our methodology was to define the group of health organizations to be examined. These organizations were selected based on their status as official government entities or government-supported health agencies responsible for public health policies, research, and regulations, ensuring that the study focused on authoritative sources [81-88]. In addition, a minimum threshold of 10,000 followers was set for health organization accounts to ensure sufficient activity and public engagement.

A brief description of each organization is provided in Textbox 1.

Textbox 1. Description of the health organizations included in this study.

Description

1. The World Health Organization (WHO): the WHO is the United Nations agency tasked with connecting nations around the world to promote health, keep the world safe, and serve populations considered vulnerable [81]. The organization's official Instagram account is named WHO.
2. Department of Health and Human Services (HHS): the HHS aims to enhance the health and well-being of the residents or citizens of the United States by providing effective health and human services and fostering sound, sustained advances in the sciences underlying medicine, public health, and social services [82]. HHSgov is the official Instagram account of the HHS.
3. The Office of Minority Health (OMH): the OMH is part of the HHS dedicated to improving the health of racial and ethnic minority groups. The OMH fulfills its commitment to improving the health of racial and ethnic minority groups in large part by developing health policies and programs that help eliminate health disparities [83]. MINORITYHEALTH is the official Instagram account of the OMH.
4. National Institutes of Health (NIH): the NIH is the leading federal agency in the United States responsible for conducting and supporting medical research. The NIH, which is part of the HHS, is one of the world's most prominent centers for medical research. Its mission is to enhance human health by advancing research across a wide range of scientific disciplines [84]. The organization's official Instagram account is named NIHgov.
5. The National Institute of Mental Health (NIMH): the NIMH is the US agency responsible for research on mental health. Its primary objective is to understand, treat, and prevent mental illness by conducting basic and clinical research. The NIMH is one of the 27 institutes and centers that comprise the NIH, which is part of the HHS [85]. NIMHgov is the official Instagram account of the NIMH.
6. The US Centers for Disease Control and Prevention (CDC): the CDC is a science-based, data-driven organization that leads the United States' efforts to protect the public's health. The CDC is one of the major components of the HHS, and it aims to protect the residents of the United States from health, safety, and security threats, both foreign and domestic [86]. CDCgov is the official Instagram account of the CDC.
7. The UK National Health Service (NHS): the NHS was established as the public health care system of the United Kingdom. It is one of the largest and most comprehensive health care systems in the world. The NHS provides various types of services, including mental health services, general practitioners, hospitals, and treatment facilities. The NHS is dedicated to improving the overall health of the population by promoting public health initiatives, health education, vaccination programs, and disease prevention campaigns [87]. The organization's official Instagram account is named NHS.
8. The US Food and Drug Administration (FDA): the FDA is a governmental regulatory agency responsible for protecting public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices [88]. The organization's official Instagram account is named FDA.

It is important to note that, because we selected health organizations with a high number of followers, the resulting sample skewed toward US-based organizations. Most accounts originated from the United States, with 1 from the United Kingdom and 1 global organization (WHO). This concentration may affect the generalizability of the findings, as both the published content and the public responses are likely influenced by US-specific health priorities and cultural context.

Data Collection

We chose Instagram as the social media platform for its visual and interactive nature, which allows health organizations to share information and engage with the public effectively [89]. We searched for the official Instagram accounts of health care organizations using Instagram's search box. Table 1 provides the name of each official Instagram account for the organizations, along with the total number of posts published since the account's creation and the number of followers, as recorded in August 2024. As can be seen in Table 1, the CDC, WHO, and Office of Minority Health are the organizations that publish the most posts. The WHO's account has the largest number of followers.

To collect the health organizations' Instagram posts, we connected with the Instagram application programming interface (API) using the RapidAPI website. This website is a large API hub that allows to connect with tens of thousands of public Representational State Transfer APIs over the internet.

The posts were collected between April 7, 2017, and November 17, 2023. Each Instagram post included the publication date, the number of likes, the number of comments, text, and a photo. For each post, we collected the comments, including the publication date, the comment text, and the number of likes. A total of 6082 posts and 82,982 comments were collected using the Instagram API. All retrieved posts and comments were included in the analysis. Table 2 presents the relevant statistics for the collected posts and comments for each health organization's Instagram account. We analyzed all the posts that the API allowed us to retrieve, without applying selection criteria or filtering specific posts. Comments were collected only from the original posts, excluding replies to comments.

Table 1. Statistics for the health organizations' Instagram accounts, ranked by number of followers (highest to lowest).

Organization name	Instagram account name	Published posts, n	Followers, n
Centers for Disease Control	CDCGOV	6359	2.5 million
World Health Organization	WHO	3893	12 million
National Health Service	NHS	695	564,000
Department of Health and Human Services	HHSGOV	3269	202,000
Food and Drug Administration	FDA	801	122,000
National Institute of Mental Health	NIMHGOV	674	64,100
National Institutes of Health	NIHGOV	1867	279,000
Office of Minority Health	MINORITYHEALTH	3909	15,400

Table 2. Statistics for the collected posts and comments of each health organization's Instagram account.

Name of health organization	Collected posts, n	Collected comments, n	Number of likes, mean (SD)
Centers for Disease Control	4298	58,471	2725.341 (3870.086)
World Health Organization	527	15,448	18349.774 (28197.828)
National Health Service	277	3826	1443.018 (1386.701)
Department of Health and Human Services	116	896	207.836 (270.549)
Food and Drug Administration	85	565	203.259 (183.758)
National Institute of Mental Health	301	1096	185.920 (142.871)
National Institutes of Health	253	1987	723.447 (709.083)
Office of Minority Health	225	603	34.124 (31.448)

Ethical Considerations

The data collection process and analysis were approved by the Emek Yezreel College Ethical Review Board (2023-81 YVC EMEK).

As the research relied solely on publicly available social media data and did not involve direct interaction with individuals, informed consent was not applicable. No compensation was offered or provided, as the study did not involve direct participation of human participants.

No identifiable private user information was collected or analyzed. All data used in the analysis were publicly available and did not contain personally identifiable information.

Topic Modeling

Text from the posts published by health organization accounts was analyzed using BERTopic [90]. Note that we removed the names of the health organizations and their abbreviations from the text to avoid creating topics around each organization. Stop words were also removed from the text.

We used the C_V coherence score to evaluate the quality and interpretability of the topics produced by the model. This measure combines the indirect cosine measure with normalized pointwise mutual information and a Boolean sliding window [91]. The coherence score indicates how closely related and coherent the words are in a topic. Using the average coherence metric, which is the average of the coherence metrics within each topic, we measured the model's ability to generate coherent and meaningful topics. This score enabled us to evaluate the overall effectiveness of the model in producing topics with a high degree of semantic similarity.

We performed 6 steps in BERTopic to analyze the posts (Textbox 2).

Textbox 2. Six-step BERTopic analysis of posts.

1. Embedding tweets: in this step, the text in the posts was converted into numerical representations using a sentence-transformers model named All-MiniLM-L6-v2 [92].
2. Dimensionality reduction: uniform manifold approximation and projection [93] was used to reduce the dimensionality of the embedded text, with the following parameters: _neighbors=15, n_components=3, min_dist=0, and metric = 'cosine.'
3. Cluster tweets: the text was grouped into clusters using the hierarchical density-based spatial clustering of applications with noise density-based clustering technique [94], with the following parameters: min_cluster_size=40, metric="Euclidean," and cluster_selection_method='eom.'
4. Word frequency analysis in clusters: the frequency of each word in each cluster was determined at the cluster level.
5. Topic representation: to represent the topics in the Instagram posts and responses, term frequency–inverse document frequency (TF-IDF) was adapted to work on a cluster or topic level instead of a tweet level. A new TF-IDF representation was used called class-based TF-IDF (c-TF-IDF).
6. Outlier reduction: hierarchical density-based spatial clustering of applications with noise identified texts that were outliers, meaning they did not belong to any of the established topics. To address this, we calculated the c-TF-IDF representation for each outlier text and compared its cosine similarity with the c-TF-IDF representations of the existing topics. By associating outlier texts with the closest matching topic based on similarity, we minimized the number of texts classified as outliers.

Sentiment and Emotion Analysis

Having categorized the health organizations' posts into topics, we analyzed the emotions and sentiment of each post and comment associated with a particular topic. Sentiment analysis was conducted using *distilbert - base - multilingual - cased - sentiments - student*, which achieved an average accuracy of 0.808 on the test set [95]. This is a distilled version of a zero-shot classification pipeline trained on the multilingual sentiment dataset. Zero-shot classification is a machine learning technique that allows models to classify data into categories they have never encountered during training without requiring labeled examples to be provided. It accomplishes this by leveraging contextual understanding and semantic relationships between seen and unseen classes, often using embeddings or natural language models [96]. In this case, a larger "teacher" model, *MoritzLaurer/mDeBERTa-v3-base-mnli-xnli*, was used to train a smaller "student" model, *distilbert-base-multilingual-cased*. Using this distillation process, the student model maintains high classification performance while being more efficient and lightweight. According to the training log, the student model achieved an impressive agreement rate of 88.29% with its teacher model.

Emotion analysis of 6 basic emotions (fear, anger, disgust, joy, sadness, and surprise) was conducted using a fine-tuned checkpoint of the DistilRoBERTa-base model called *j-hartmann/emotion-english-distilroberta-base*. The model was trained on 6 diverse datasets [97]. The model was trained on a balanced subset from several datasets of nearly 20,000 observations in total. In total, 80% of this balanced subset was used for training and 20% for evaluation. The evaluation accuracy was 66%.

To ensure the accuracy of the models in identifying sentiments and emotions, we randomly selected 100 posts and comments. We manually classified them based on their dominant sentiment and dominant emotion. The results showed that the sentiment model achieved 92% accuracy, while the emotion model demonstrated 84% accuracy. Considering sentiment models predict binary classification and emotion models face greater complexity due to emotions' multidimensional nature, the results are logical. Therefore, applying the models to the data was expected to provide sufficiently reliable outcomes.

Each post and posts' comments received a sentiment score of positive, negative, or neutral, as well as an emotion score of fear, anger, disgust, joy, sadness, or surprise.

For each topic, we calculated the following:

- Average number of comments (the average number of comments for all posts in the topic).
- Average number of likes (the average number of likes for all posts in the topic).
- Average post sentiment scores (the average positive, negative, and neutral sentiment scores for all posts in the topic).
- Average post emotion scores (the average fear, anger, disgust, joy, sadness, and surprise scores for all posts in the topic).
- Average comment sentiment scores (the average positive, negative, and neutral sentiment scores for all post comments in the topic).
- Average comment emotion scores (average fear, anger, disgust, joy, sadness, and surprise scores were calculated for all post comments in the topic).
- Gap (the difference between the average fear score of the posts and the average fear score of the comments).

Linguistic Analysis

The objective of this analysis was to identify the most significant phrases used by health organizations in posts that resonated more positively with the public (ie, associated with higher positive sentiment in comments) compared to those that elicited more negative reactions (higher negative sentiment in comments).

For this purpose, we calculated the average sentiment score (positive and negative) of all comments related to each post. Posts were then categorized based on the dominant sentiment (positive or negative) derived from these average sentiment scores in comments, resulting in 2 groups: posts with predominantly positive comments and posts with predominantly negative comments.

For each group of posts, we extracted the top 50 most significant phrases, including single words (unigrams), 2-word phrases (bigrams), 3-word phrases (trigrams), and 4-word phrases (four-grams). The preprocessing involved removing hashtags from the text, eliminating stopwords, and calculating term importance using TF-IDF. TF-IDF estimates the significance of terms within a group of posts based on their frequency within each post as compared to the frequency across all posts in the group. The cumulative TF-IDF scores for each term were calculated by summing across all posts in the group, enabling the identification of the most significant phrases for each group of posts.

Time Analysis

In the time analysis section, we examined the average positive and negative sentiment in both comments and posts over the years. In addition, we analyzed the average levels of various emotions, including fear and anger, expressed in both posts and comments throughout the data collection period. Furthermore, we decided to calculate additional emotions of trust, disappointment, and confusion. The purpose of including these emotions was to extend the analysis beyond the 6 basic emotions, providing a broader range of emotional insights.

To calculate trust, we used the *ayoubkirouane/BERT-Emotions-Classifier* model [98], a fine-tuned BERT-based model designed for multilabel emotion classification. This model was trained on the sem_eval_2018_task_1 dataset. This model includes a wide range of emotions, such as anger, anticipation, disgust, fear, joy, love, optimism, pessimism, sadness, surprise, and trust.

For confusion and disappointment emotions, we used the *SamLowe/roberta-base-go_emotions* model [99], which is trained on the go_emotions dataset for multilabel classification. The go_emotions dataset, based on Reddit (Reddit, Inc) data, contains 28 emotion labels. The model achieved high performance in identifying confusion (with an accuracy of 0.972) and disappointment (with an accuracy of 0.974).

As part of the temporal analysis, we incorporated weekly COVID-19 mortality data in the United States using a publicly available dataset published by the National Center for Health Statistics [100]. The analysis included calculating a “COVID-19 death ratio,” which represents the proportion of US COVID-19–related deaths to the total number of US deaths. We applied a rolling average smoothing technique across a 10-week window to reduce noise and variability in the data, allowing us to identify patterns over time. This approach allowed us to combine the mortality data alongside our sentiment and emotional analyses, providing valuable insights into the alignment between public responses and real-world outcomes.

Results

Topic Modeling

Using BERTopic, 36 topics were identified for the posts of the 8 health organization Instagram accounts. The average coherence score was 0.7374. A health expert reviewed the list of topics and suggested that we combine related topics.

Therefore, the following topics were combined: 7 topics related to COVID-19 were grouped together, 2 topics related to vaccines for children were grouped together, 2 topics related to monkeypox were grouped together, and 2 topics related to booster vaccines were combined. Combining the topics resulted in 25 topics, with an average coherence score of 0.7298. The health expert assigned a representative name to each topic. The topic names were assigned by analyzing the 10 most significant words for each topic, as determined by the c-TF-IDF scores (refer to the Methods section for more information about c-TF-IDF) from the BERTopic algorithm and cross-referencing them with example posts related to that topic. Each topic was automatically assigned a unique number starting from 0, following the default numbering convention used by the BERTopic algorithm. Table 3 lists the topics, indicating their number, name, and number of posts. Refer to Multimedia Appendix 1 for the 5 words with the highest c-TF-IDF for each topic.

Table 3. The number, name, and size of each topic.

Topic number	Topic name	Topic size, n
0	COVID-19	1446
1	Mental health	752
2	Children and vaccines	496
3	COVID-19 booster vaccine	288
4	Pregnant	246
5	Foodborne	235
6	Research	226
7	Community health	223
8	Flu	216
9	Cancer	198
10	Monkeypox	197
11	Cardiovascular diseases	193
12	Public health	183
13	Climate	148
14	Sepsis	141
15	Masks	127
16	Vector	122
17	Health equity	108
18	Antibiotics	108
19	Ebola	92
20	Humanitarian	91
21	Smoking	85
22	RSV[a]	59
23	Sun damage	52
24	Noise damage	50

[a]RSV: respiratory syncytial virus.

Engagement Analysis

Our dataset includes engagement metrics for each post, specifically the number of likes and user comments.

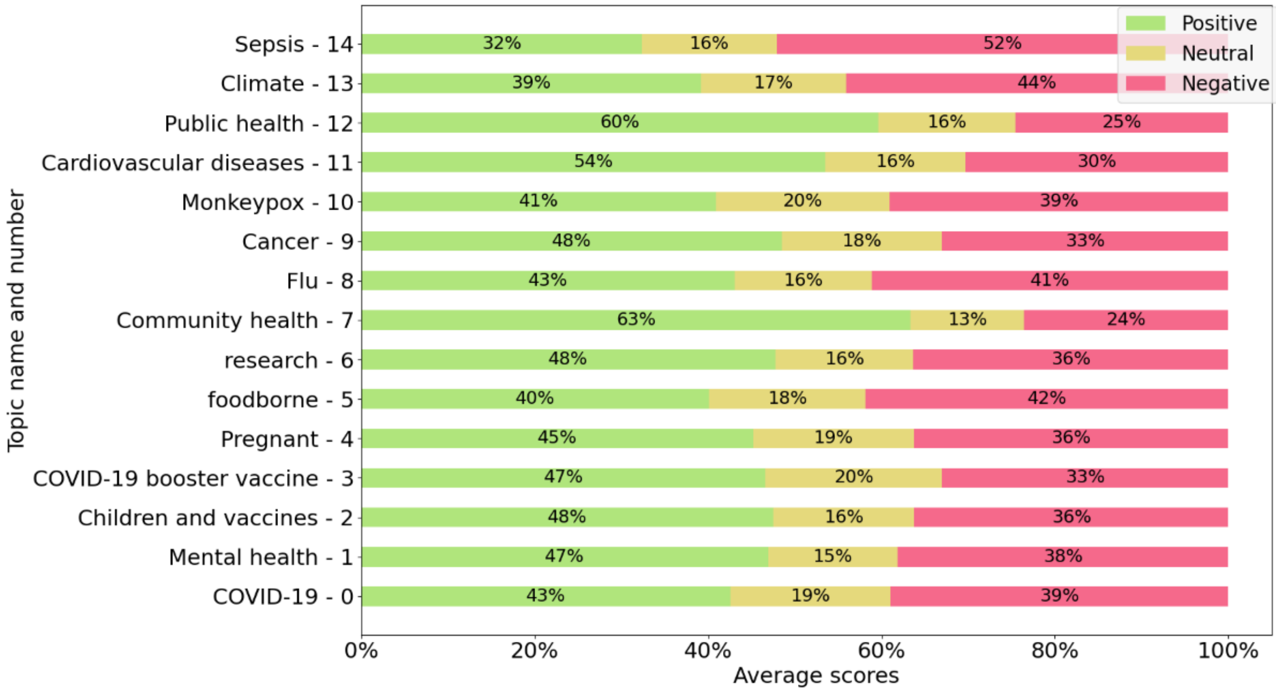
We calculated the average number of comments and likes for all posts in each topic. Multimedia Appendix 2 presents the average number of comments received per topic, while Multimedia Appendix 3 displays the average number of likes. Among the topics, those with the highest user engagement based on the average number of post comments were humanitarian issues, masks, and COVID-19. In terms of engagement measured by the average number of post likes, the leading topics were humanitarian issues, masks, and cancer. Multimedia Appendices 2 and 3 also show increased engagement for topics related to vaccines and COVID-19.

Sentiment Analysis

We analyzed the sentiment in the text of the posts and comments and calculated the sentiment scores of the posts and comments, as described in the Methods section.

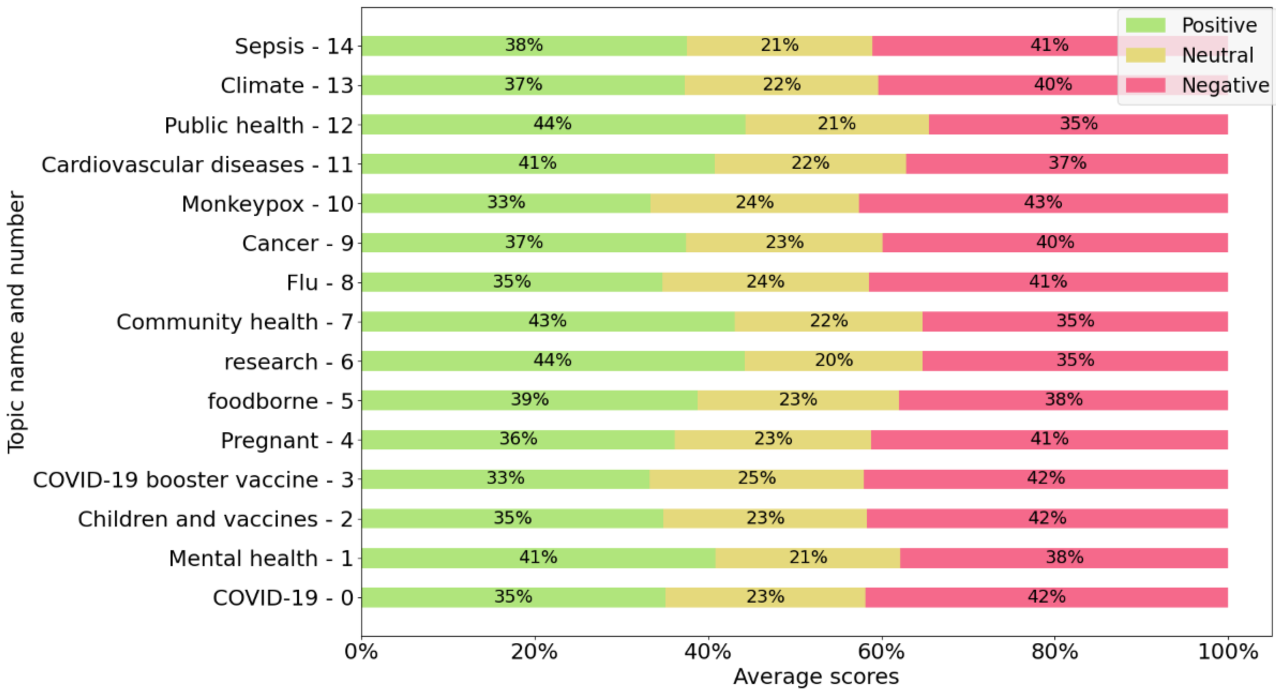
Figures 2 and 3 present the average sentiment scores for health organizations' posts and comments, respectively. In Figures 2 and 3, we selected only the 15 largest topics (those containing the greatest number of posts). Figure 2 shows that in certain topics, such as sepsis, climate, and foodborne illnesses, negative sentiment is the most prominent in the health organizations' posts. However, in Figure 3, which presents the scores for the comments to the health organizations' posts, we see that there are more topics where negative sentiment is dominant than in Figure 2, with the greatest negative sentiment found in the comments for posts about vaccines, specifically for posts in the COVID-19, children and vaccines, booster vaccines, and monkeypox topics.

Figure 2. Sentiment scores of posts (average positive, neutral, and negative) for each topic.



While certain topics showed a dominant positive sentiment in the posts published by health organizations (as illustrated in Figure 2), this does not necessarily reflect how the public responds to those posts. The dominance of positive sentiment in these topics was based on the average sentiment scores, where the positive score was higher than both the negative and neutral scores. This indicated that these subjects were presented mostly positively by the organizations. However, when examining the sentiment expressed in user comments (Figure 3), we observed a contrasting response. In topics such as COVID-19, children and vaccines, and the COVID-19 booster vaccine, the comments exhibited predominantly negative sentiment, even though the organizations framed these topics positively. In these cases, the average negative score in the comments was higher than both the positive and neutral scores. In other words, while the organizations tried to communicate these topics in a positive light, the public's reaction to them was largely negative.

Figure 3. Sentiment scores of comments (average positive, neutral, and negative) for each topic.



Emotion Analysis

We analyzed the emotion in the text of the posts and comments and calculated the emotion scores of the posts and comments, as described in the Methods section.

The emotions present were anger, disgust, fear, joy, neutral, sadness, and surprise. Figure 4 presents the average emotion scores for the posts, and Figure 5 displays the average emotion scores for the comments. In Figures 4 and 5, we selected only the 15 largest topics (those containing the greatest number of posts).

As seen in Figure 4, the dominant emotion in all topics was fear, and its scores were higher than those of all the other emotions in the posts. In other words, the text in the health organization posts was characterized by a very high level of fear. Among the topics with the highest fear emotion were sepsis, monkeypox, cancer, and flu.

Figure 4. Emotion scores of posts (average anger, disgust, fear, joy, neutral, sadness, and surprise) for each topic.

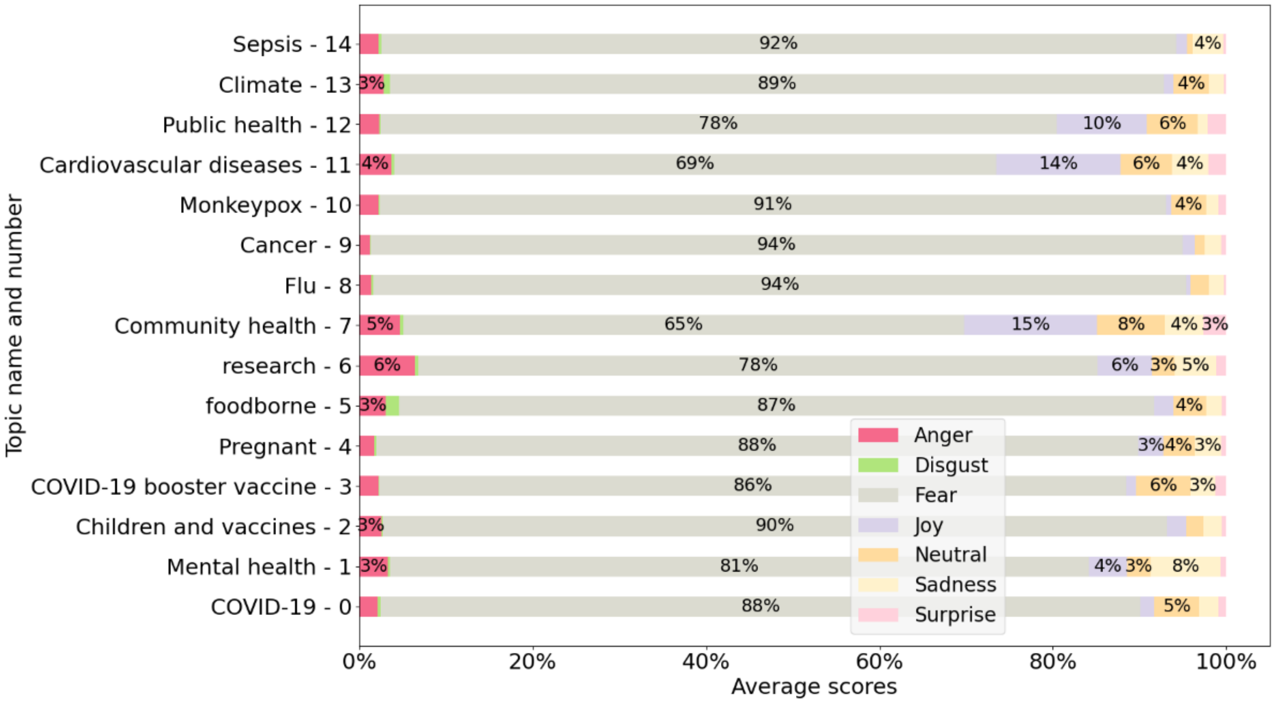
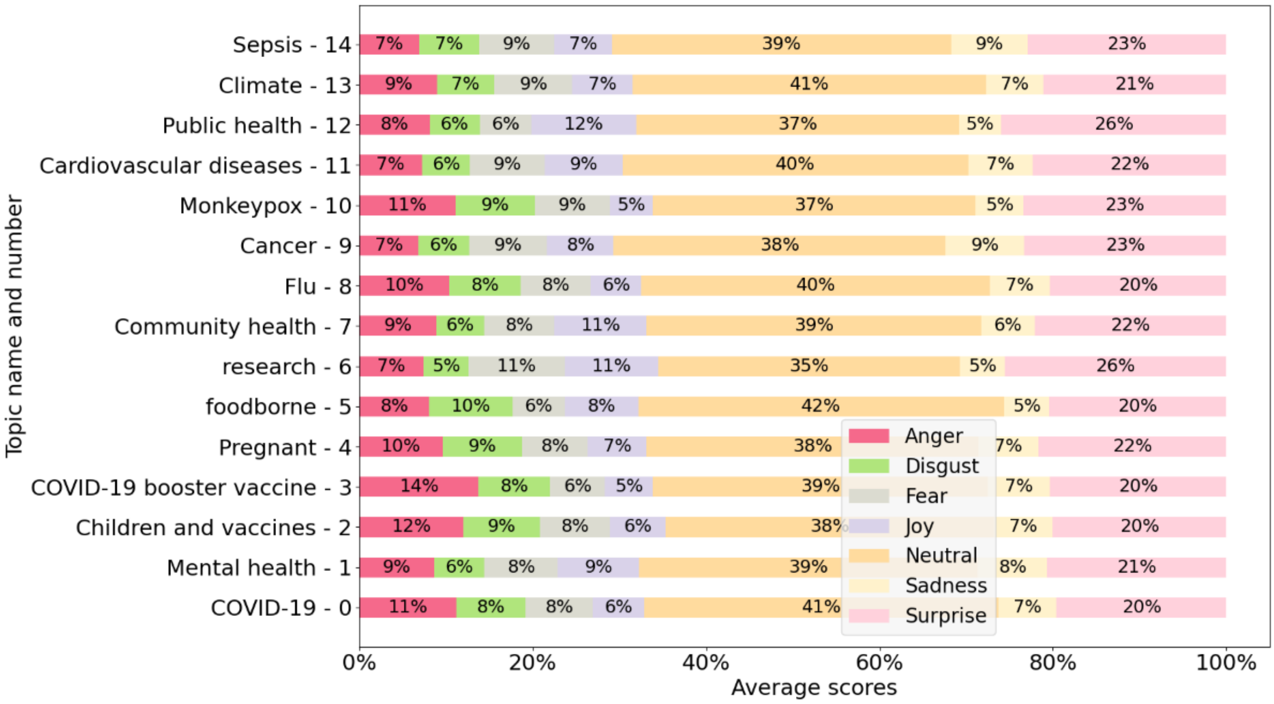


Figure 5. Emotion scores of comments (average anger, disgust, fear, joy, neutral, sadness, and surprise) for each topic.



However, as shown in Figure 5, fear is not the dominant emotion; instead, neutral responses prevail. This suggests a disconnect between what health organizations consider fear-inducing issues and how the public actually responds, displaying less fear. When examining other emotions in Figure 5, we see that the topic generating the most anger is vaccines, with the COVID-19 booster vaccine specifically eliciting the highest levels of anger. In terms of sadness, cancer and sepsis were the topics that evoked the strongest feelings of sadness.

Gap Analysis

Given the difference observed between the high average fear in the health organizations' posts compared to the very low fear in the public's responses to the posts, we examined the topics with the largest gap between the 2 average fears as revealed in the emotion analysis. For each topic, Table 4 presents the average fear in the posts of health organizations, the average fear in the comments, and the difference between the two. As can be seen in Table 4, the topics with the highest gap are masks and flu.

Table 4. Each topic's average scores for fear in post and comments and the gap.

Topic name	Topic number	Fear in posts, mean (SD)	Fear in comments, mean (SD)	Gap
Masks	15	0.958 (0.072)	0.092 (0.166)	0.881
Flu	8	0.938 (0.156)	0.066 (0.180)	0.857
Vector	16	0.931 (0.090)	0.101 (0.196)	0.846
Cancer	9	0.936 (0.126)	0.062 (0.191)	0.846
Sepsis	14	0.917 (0.124)	0.106 (0.191)	0.831
Children and vaccines	2	0.904 (0.152)	0.086 (0.181)	0.823
Noise damage	24	0.913 (0.150)	0.084 (0.198)	0.821
Monkeypox	10	0.906 (0.138)	0.061 (0.197)	0.819
Ebola	19	0.898 (0.170)	0.085 (0.193)	0.812
Foodborne	5	0.870 (0.198)	0.077 (0.155)	0.810
Pregnant	4	0.879 (0.192)	0.086 (0.172)	0.803
Climate	13	0.893 (0.208)	0.090 (0.197)	0.803
COVID-19	0	0.876 (0.201)	0.060 (0.181)	0.799
COVID-19 booster vaccine	3	0.861 (0.178)	0.086 (0.155)	0.798
RSV[a]	22	0.897 (0.161)	0.087 (0.222)	0.796
Health equity	17	0.815 (0.223)	0.091 (0.147)	0.754
Antibiotics	18	0.835 (0.274)	0.081 (0.192)	0.751
Sun damage	23	0.800 (0.272)	0.081 (0.169)	0.734
Mental health	1	0.806 (0.283)	0.111 (0.188)	0.722
Public health	12	0.780 (0.281)	0.060 (0.152)	0.720
Smoking	21	0.777 (0.254)	0.076 (0.143)	0.715
Research	6	0.783 (0.218)	0.064 (0.240)	0.672
Humanitarian	20	0.724 (0.341)	0.081 (0.207)	0.618
Cardiovascular diseases	11	0.694 (0.332)	0.084 (0.192)	0.608
Community health	7	0.646 (0.331)	0.077 (0.178)	0.565

[a]RSV: respiratory syncytial virus.

Linguistic Analysis

The linguistic analysis results are presented in Multimedia Appendix 4. It contains the top 50 phrases for unigrams, bigrams, trigrams, and four-grams in posts receiving predominantly positive or negative responses, along with their TF-IDF scores.

Results revealed that phrases associated with positive public responses promote public health awareness, vaccination benefits, and preventive measures. As an example, the phrases that were only included in the top 50 phrases of the health organizations' posts that received positive responses included "stay healthy" "awareness month," "signs symptoms," "raise awareness," "save lives," "help slow spread," "health care provider," and "better health better understanding." In contrast, phrases associated with negative sentiment related to vaccination efforts, outcomes, policy mandates, and health monitoring include terms such as "data tracker," "vaccinated covid," "dose vaccine," "severe illness hospitalization,” “illness hospitalization death,” and “covid 19 vaccine booster.”

Time Analysis

Figures 6-8 illustrate sentiment and emotional shifts in posts and comments from 2018 to 2023 along with the COVID-19 death ratio. The numbers 1 to 5 in Figures 6-8 represent 5 significant milestones during the COVID-19 pandemic. These include the following: (1) first report of COVID-19 in late 2019, (2) the declaration of COVID-19 as a global pandemic by the WHO in March 2020, (3) the administration of the first COVID-19 vaccine in December 2020 in the United Kingdom, (4) the peak of the Omicron wave in early 2022, and (5) the WHO’s declaration in May 2023 that COVID-19 was no longer a global health emergency.

Figure 6. Evolution of sentiment (average positive and negative scores) in posts and comments over the years, combined with the COVID-19 death ratio.

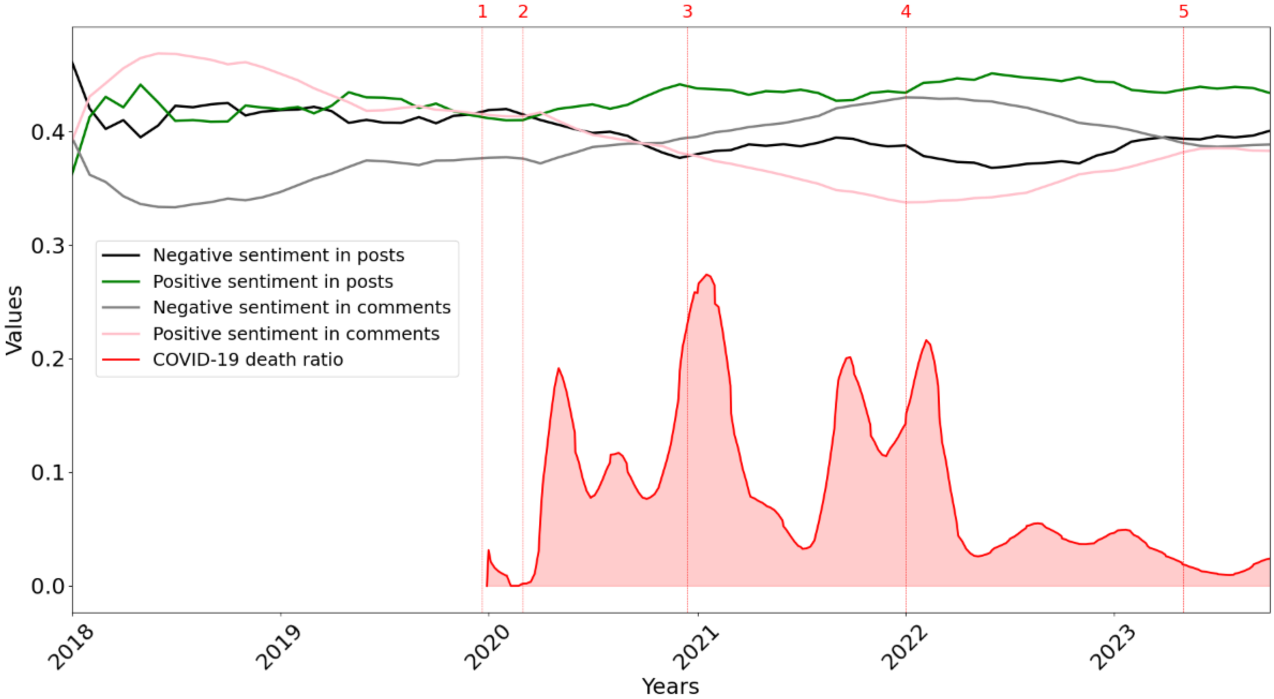


Figure 6 presents the average positive and negative sentiment expressed in posts and comments over time. The negative sentiment in comments increased over time and then began to decrease after the peak of the Omicron wave. Positive sentiment in comments showed a similar but opposite pattern, as it decreased and then increased after the peak of the Omicron wave. Regarding the sentiment of posts, it appeared that positivity in posts increased slightly over the years, while negativity decreased. The peaks of the COVID-19 death ratio aligned with increased negative sentiment in comments.

Figure 7 explores the average levels of emotions—fear, trust, disappointment, anger, and confusion—in posts. Fear consistently dominated posts and remained relatively steady until it declined, coinciding with a significant reduction in the death ratio. Trust, anger, and disappointment remained relatively steady throughout the years. Confusion gradually increased following the declaration of the pandemic.

Figure 7. Evolution of emotion (average scores for trust, fear, anger, confusion, and disappointment) in posts over the years, combined with the COVID-19 death ratio.

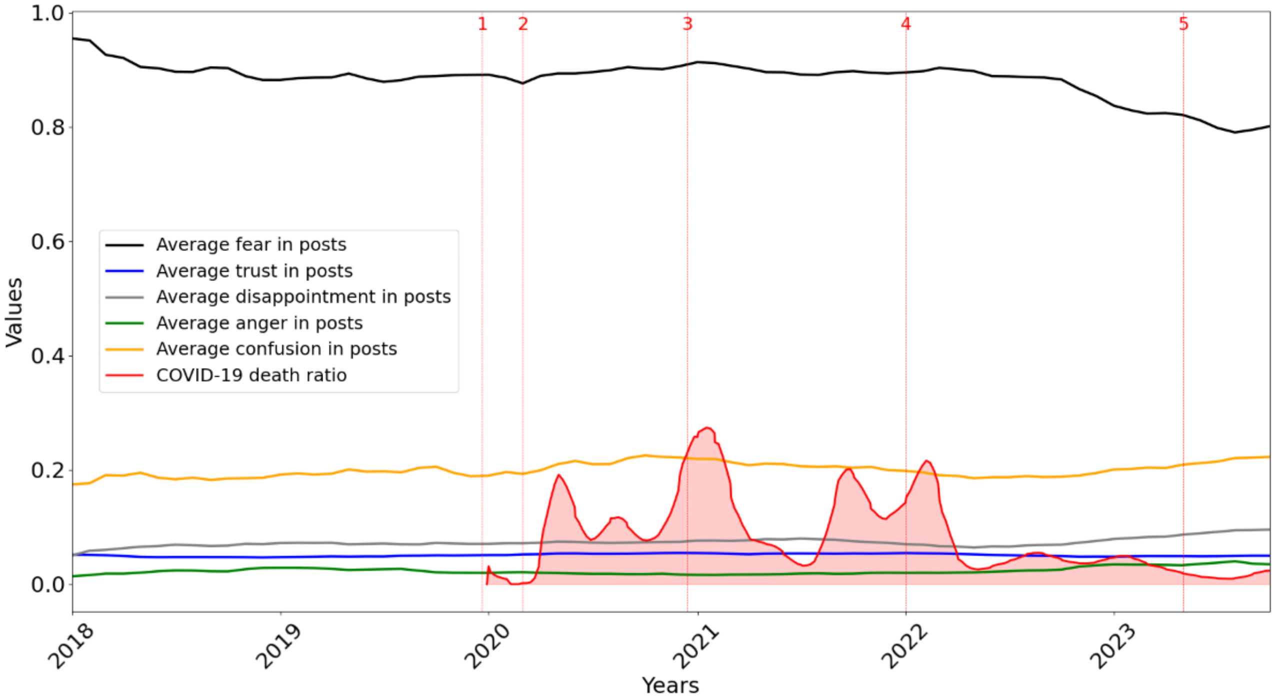
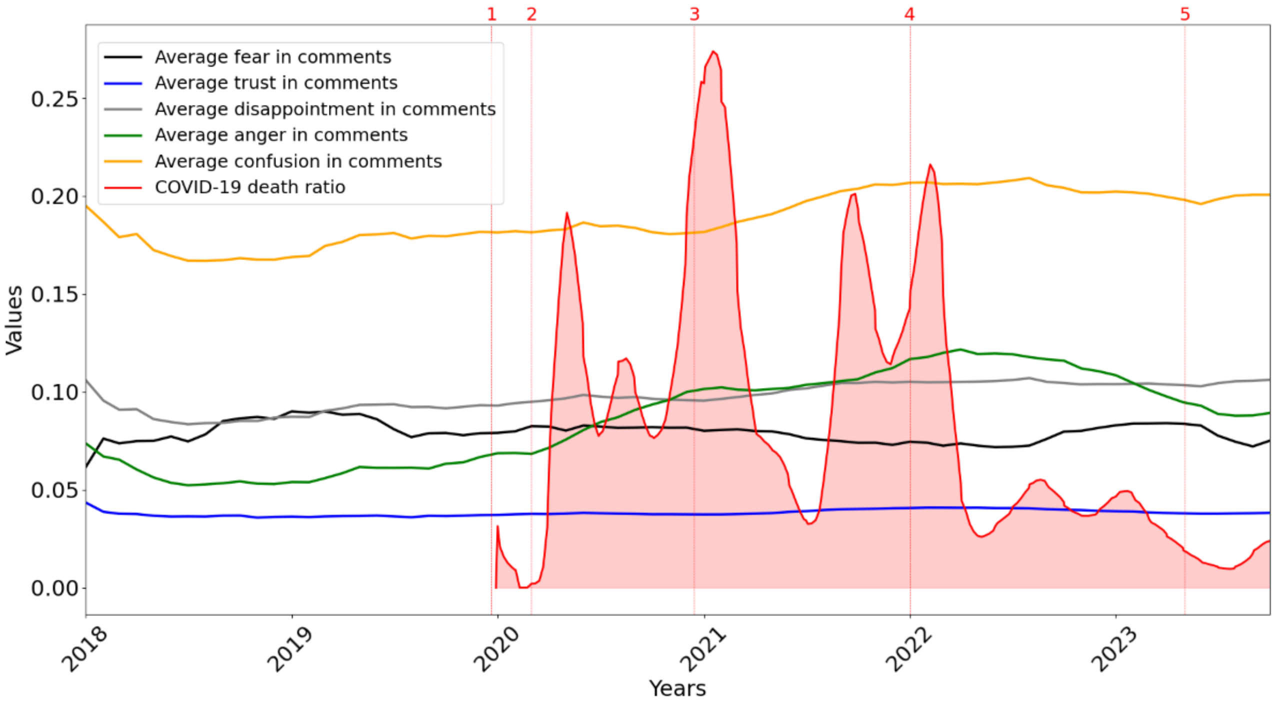


Figure 8 shows the average levels of emotions—fear, trust, disappointment, anger, and confusion—in comments over the same period. Emotions of fear and trust remained relatively steady throughout the years. Anger and disappointment increased around death ratio peaks and, overall, showed a general upward pattern over the years. However, anger began to decline slightly after the Omicron peak and the subsequent decrease in the death ratio.

Figure 8. Evolution of emotion (average scores for trust, fear, anger, confusion, and disappointment) in comments over the years, combined with the COVID-19 death ratio.



Discussion

Principal Findings

The findings of this study should be interpreted with consideration of the dataset's geographic composition. As most of the health organizations analyzed are based in the United States, the topics emphasized may reflect US-specific health priorities, and the patterns of public engagement, sentiment, and emotional responses to these topics may also be shaped by US cultural and social contexts. The selected health organizations have a high number of followers on the platform, hold substantial influence, and reach audiences beyond national boundaries. Still, the framing and intensity of reactions observed in this study may not be fully generalizable to health organizations in other countries or regions, particularly because the characteristics of the users engaging with the content (such as their geographic location or demographics) are unknown.

Our findings on engagement analysis show that humanitarian issues, including the Ukraine war and the war in Gaza, and the COVID-19 pandemic received the greatest response from the public. This supports prior research, which has shown that those disasters, including humanitarian crises, such as nature-related crises and wars, are a major concern of the public and policy makers [101]. In recent years, conflicts, such as the ongoing Ukraine war and the war in Gaza, have had a significant impact on international stability, affecting economies, migration patterns, and security measures, particularly in Europe [102]. These conflicts have not only disrupted local societies but have also prompted reevaluation of humanitarian aid and intervention strategies globally. The connection between humanitarian conflicts and adverse health outcomes is well documented. Studies have shown increased incidence of mental health disorders, infectious disease outbreaks, and chronic health conditions in conflict-affected areas [103]. As a result, health organizations worldwide have recognized the urgent need to develop comprehensive strategies for emergency preparedness. This includes enhancing public health response capabilities, improving prehospital care, and integrating disaster medicine in public health frameworks to better address humanitarian crises [104,105].

The COVID-19 pandemic has fundamentally altered global perceptions and practices across various sectors, revealing both strengths and weaknesses in systems and policies worldwide [106]. During the COVID-19 pandemic, the public turned to health organization websites and social media channels to receive timely updates on infection rates, government guidelines, and evolving safety protocols [107,108]. Trust in organizations such as the WHO and CDC was crucial, as these bodies communicated essential information, adapting advice as new data emerged about the virus's spread and impact. The results of this study further highlight that a significant portion of posts shared by health organizations focused on the topic of COVID-19. In addition, these posts generated substantial public engagement, demonstrating the public's heightened interest and concern regarding COVID-19–related information. Given the profound impact of COVID-19, the public remains extremely interested in these insights, recognizing that understanding what was done well and what failed can better prepare societies for future health crises. Consequently, the ongoing dialogue among scientists, policy makers, and the public about these findings continues to shape postpandemic recovery strategies and fortify global health preparedness [109].

Our sentiment and emotion analysis of responses to health organizations' posts showed that the highest percentage of negative scores was in topics related to vaccines and monkeypox. Moreover, our results show that the highest level of anger was observed in topics related to the COVID-19 booster and children's vaccination in general. The high anger and negative sentiment can be attributed to vaccine hesitancy.

Vaccine hesitancy and antivaccine movements have long posed significant challenges to public health [110], particularly in communities with historically low trust in government and pharmaceutical institutions [111]. The analysis of topics associated with high anger emotions, such as COVID-19 vaccines, can be enriched by examining the emotional characteristics and motivations of specific user groups with vaccine hesitancy. For instance, women are generally more likely to exhibit vaccine hesitancy than men [112]. Alternatively, older individuals tend to display lower levels of hesitancy, likely due to their awareness of their vulnerability to COVID-19 complications, which may alleviate their fear or anger [112]. Vaccine hesitancy is also more prevalent among individuals with lower economic security [112]. Trust also shapes emotional and cognitive characteristics. Higher trust in health care providers, scientists, and global health organizations such as the WHO correlates with reduced vaccine hesitancy [112]. Conversely, in some contexts, higher trust in religious leaders is linked to increased hesitancy [112].

The COVID-19 pandemic has increased skepticism toward routine immunizations and increased hesitancy even among those previously compliant with vaccination schedules. The rapid development of COVID-19 vaccines, coupled with widely publicized adverse effects, heightened fears and deepened mistrust [113]. In addition, misinformation and conflicting narratives on social media further fueled fear, anger, and uncertainty, particularly in communities already skeptical of public health authorities. Our findings reflect these trends, showing increases in public negativity, anger, and disappointment over time.

Our linguistic analysis highlights that messages emphasizing safety, prevention, and public health benefits tend to elicit positive sentiments, while messages emphasizing vaccination efforts, outcomes, policy mandates, and health monitoring tend to elicit negative sentiments. This underscores the need for health organizations to refine communication strategies, focusing on clear, trust-building messaging to address concerns and counteract negative sentiments effectively.

Our analysis also reveals a gap between the fear conveyed in posts by health organizations and the public's responses to these posts, particularly regarding the influenza vaccine and face masks during the COVID-19 pandemic. While health organizations intended to convey urgency, public comments did not reflect the same fear. Addressing skepticism and ambivalence about influenza vaccine and mask use is critical.

Face masks are a critical tool in pandemic response [114], and enhancing public understanding of their effectiveness is essential for improving adherence and compliance during future outbreaks.

The difference in fear responses between the influenza vaccine and face masks can be understood by examining the interplay of social, psychological, and cultural factors [114]. One factor is psychological reactance, which occurs when individuals perceive mandates, such as mask requirements, as threats to their autonomy. This perception, combined with beliefs that masks are ineffective and an aversion to being forced to wear them, can trigger anger and counterarguments. Individuals with strong psychological reactance are particularly likely to exhibit these responses, reinforcing and intensifying their antimask attitudes [115,116]. Such resistance is further exacerbated by personality traits, which not only strengthen antimask sentiments but also link to broader vaccine skepticism, exaggeration of COVID-19 risks, and resistance to social distancing, often influenced by political conservatism [117].

Social and cultural dynamics also shape mask perceptions. For example, in many Western societies, masks are seen as extraordinary artifacts associated with emergency, while in Asian cultures, they are normalized as part of daily life [118]. In collectivist cultures, mask wearing aligns with a sense of duty to protect the community [116]. In addition, stigma, appearance concerns, and fears of being perceived as overly cautious further hinder acceptance [119].

Policy decisions and public health campaigns significantly influence perceptions. During the COVID-19 pandemic, inconsistent messaging from health authorities and varying guidance on mask use between countries and organizations contributed to public confusion and skepticism regarding their efficacy [120], despite substantial scientific evidence supporting their role in reducing transmission rates [120,121]. Therefore, consistent messaging and targeted communication strategies should focus on populations with antimask perceptions, aiming to reduce stigmas and address the underlying factors driving these attitudes.

Historically, the influenza vaccine has engendered significant hesitancy and objection from segments of the general public, a trend particularly evident among health care workers, who are critical in promoting vaccination [122]. Factors contributing to this hesitancy include misconceptions about vaccine efficacy, fears of adverse effects, and a perceived lack of urgency surrounding influenza, particularly when compared to more severe illnesses such as COVID-19 [123,124]. The emergence of the COVID-19 pandemic exacerbated this situation. During the COVID-19 pandemic, public focus shifted intensely toward COVID-19 vaccination campaigns, leading to a diversion of attention and resources from influenza vaccination efforts [125]. The flood of information regarding COVID-19 vaccines overshadowed the long-standing influenza vaccine campaigns. As a result, many individuals prioritized the COVID-19 vaccine over the seasonal influenza vaccine [125]. Data indicating that compliance with the influenza vaccine plummeted in several countries during 2023 and 2024 compared to prepandemic years highlight the ongoing challenges faced by public health authorities [125].

Despite the availability of the influenza vaccine, social media misinformation and evolving health narratives regarding influenza and COVID-19 have led to an atmosphere of uncertainty. For instance, some individuals may mistakenly believe that if COVID-19 variants pose health risks, the influenza virus may be less significant or that acquiring one vaccine negates the need for others. This shift necessitates a reassessment of public health strategies to reengage communities with the importance of influenza vaccination. Health organizations must develop targeted messaging that addresses misconceptions, enhances understanding of the influenza virus's potential impact, and reinforces the protective benefits of vaccination, even during times when attention is focused on other diseases.

To summarize, in this study, we analyzed the quality of disseminated messages along 2 dimensions: public responses to topics and the emotions and sentiments expressed in those responses. Mapping these reactions to messages posted by health organizations is important for evaluating public engagement with specific health-related issues. Identifying emotional gaps can also help assess the effectiveness of health-related messages, revealing potential discrepancies between the importance health organizations assign to certain topics and the public's perceived importance.

Our findings highlight gaps in fear responses regarding the influenza vaccine and wearing face masks during the COVID-19 pandemic, underscoring the need for transparent communication from health authorities and comprehensive education campaigns to address misconceptions and reassure the public. Understanding the psychological and social factors driving vaccine hesitancy after the pandemic is essential for tailoring effective public health strategies. Efforts must focus on fostering trust through consistent and clear messaging, transparency about vaccine development processes, and open forums for addressing public concerns. By doing so, it will be possible to mitigate misinformation, reduce fear, enhance public compliance, and improve vaccine uptake across populations.

Limitations

Our study may have some limitations. We collected data from Instagram, and therefore, our results and conclusions are based on the posts and interactions on this social media platform. Our data did not include specific information about the users who commented on the health organizations' posts. However, according to general information about Instagram users by Statista [126], Instagram had 2 billion monthly active users in 2024, with India leading the platform's user base at approximately 360 million, followed by the United States with 169 million and Brazil with 134 million users. Younger users dominate the platform, with the 18- to 24-year age group being the largest demographic, followed by the 25- to 34-year age group. Participation declines significantly among older age groups, particularly those aged ≥55 years, who represent only a small fraction of the audience. Moreover, most users in the 18- to 34-year age group are men, while most users >34 years are women.

The absence of detailed user characteristics in our dataset may limit the generalizability of our findings, as biases could arise due to age, gender, educational level, or other demographic factors that influence engagement and sentiment patterns. Certain user groups may be overrepresented or underrepresented in the data, potentially shaping the interpretation of public responses. Future research should aim to systematically characterize respondents' profiles, leveraging available metadata or incorporating external surveys to gain a clearer understanding of the audience engaging with health-related content.

The study also has limitations regarding the influence of social media algorithms on post visibility and engagement. The social media algorithms prioritize content based on user interactions, interests, and platform-specific ranking mechanisms, potentially introducing bias in public sentiment patterns. Nevertheless, the decision as to whether to engage and how to respond is left to the users. Therefore, although engagement data may not fully represent the broader public, it still offers insights into those actively participating in discussions. To mitigate bias, we ensured a diverse dataset by including a substantial number of posts from multiple health organizations.

It is important to acknowledge that the models used in this study may have limitations. Although BERTopic is an effective topic modeling technique, it assumes that each document (in our case, each post) is associated with a single dominant topic, which does not always reflect reality. As posts can discuss a variety of interconnected topics, it is often difficult to classify them accurately under a single theme. Furthermore, topic separation relies on clustering techniques, which may not always produce clear or optimal topic divisions, resulting in the merging of distinct topics or the fragmentation of related discussions, reducing interpretability.

Similarly, the sentiment and emotion models may inherit biases from their training datasets, influencing detection. These models are not always fully accurate and often struggle to capture context-dependent sentiment shifts, irony, and implicit emotional expressions, which may result in misinterpretations.

In addition, as previously mentioned, the health organizations in this study are predominantly US based, with limited representation from other countries. This concentration may influence the topics represented in the dataset, reflecting US-specific health priorities and cultural dynamics, as well as the public sentiment, emotional responses, and engagement observed in relation to those topics. Future research could incorporate data from a more geographically diverse set of health organizations, enabling cross-cultural comparisons and providing a broader understanding of global public health communication and audience responses.

Conclusions

This study demonstrates the value of our methodology in assessing public responses and emotions expressed regarding health-related messages. By identifying emotional gaps, particularly fear, we were able to uncover discrepancies between the fear health organizations assign to issues and the fear that the public expresses in response. The greatest gaps were revealed with regard to influenza vaccines and face masks during COVID-19.

These findings emphasize the need for transparent communication and trust-building strategies that consider the emotional and sentiment-driven responses of the public on social media. By understanding the psychological and social dynamics of public interaction with health information, particularly regarding vaccine resistance, organizations can support public health goals, foster trust and efficient engagement, counter misinformation, and encourage informed health behaviors.

In future research, we plan to apply our topic modeling and sentiment and emotion analysis approach on other social media platforms to gain a more comprehensive view of the public's response to the posts of health organizations across various digital platforms. In addition, we aim to extend our analysis beyond social media to offline settings, such as newspapers and television campaigns. Because public responses are essential to our method, we will also incorporate surveys to assess audience reactions and engagement with these campaigns. Investigating how fear-based messaging and public emotional responses manifest in both online and offline environments will provide deeper insights into the broader impact of health communication strategies. In addition, we plan to investigate misinformation within the comments on health organization posts and identify the topics where inaccuracies are prevalent.

Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

APV contributed to the study's conceptualization, software, methodology, data curation, formal analysis, visualization, and writing. AM contributed to the study design, methodology, and writing. All authors approved the final version of this manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The number, name, size, and top-5 most significant words of each topic.
[XLSX File (Microsoft Excel File), 11 KB - infodemiology_v5i1e70576_app1.xlsx]

Multimedia Appendix 2
Average number of post comments per topic. RSV: respiratory syncytial virus.
[PNG File , 92 KB - infodemiology_v5i1e70576_app2.png]

Multimedia Appendix 3
Average number of post likes per topic. RSV: respiratory syncytial virus.
[PNG File , 101 KB - infodemiology_v5i1e70576_app3.png]

Multimedia Appendix 4
Top-50 phrases for unigrams, bigrams, trigrams, and four-grams in posts receiving predominantly positive or negative responses with corresponding term frequency–inverse document frequency scores.
[XLSX File (Microsoft Excel File), 23 KB - infodemiology_v5i1e70576_app4.xlsx]

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Abbreviations

API: application programming interface
BERT: Bidirectional Encoder Representations from Transformers
CDC: Centers for Disease Control and Prevention
c-TF-IDF: class-based term frequency–inverse document frequency
MH: Ministry of Health
NHS: National Health Service
TF-IDF: term frequency–inverse document frequency
WHO: World Health Organization

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Understanding Interventions to Address Infodemics Through Epidemiological, Socioecological, and Environmental Health Models: Framework Analysis

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Abstract

Background: The COVID-19 pandemic was accompanied by a barrage of false, misleading, and manipulated information that inhibited effective pandemic response and led to thousands of preventable deaths. Recognition of the urgent public health threat posed by this infodemic led to the development of numerous infodemic management interventions by a wide range of actors. The need to respond rapidly and with limited information sometimes came at the expense of strategy and conceptual rigor. Given limited funding for public health communication and growing politicization of countermisinformation efforts, responses to future infodemics should be informed by a systematic and conceptually grounded evaluation of the successes and shortcomings of existing interventions to ensure credibility of the field and evidence-based action.

Objectives: This study sought to identify gaps and opportunities in existing infodemic management interventions and to assess the use of public health frameworks to structure responses to infodemics.

Methods: We expanded a previously developed dataset of infodemic management interventions, spanning guidelines, policies, and tools from governments, academic institutions, nonprofits, media companies, and other organizations, with 379 interventions included in total. We applied framework analysis to describe and interpret patterns within these interventions through their alignment with codes derived from 3 frameworks selected for their prominence in public health and infodemic-related scholarly discourse: the epidemiological model, the socioecological model, and the environmental health framework.

Results: The epidemiological model revealed the need for rigorous, transparent risk assessments to triage misinformation. The socioecological model demonstrated an opportunity for greater coordination across levels of influence, with only 11% of interventions receiving multiple socioecological codes, and more robust partnerships with existing organizations. The environmental health framework showed that sustained approaches that comprehensively address all influences on the information environment are needed, representing only 19% of the dataset.

Conclusions: Responses to future infodemics would benefit from cross-sector coordination, adoption of measurable and meaningful goals, and alignment with public health frameworks, which provide critical conceptual grounding for infodemic response approaches and ensure comprehensiveness of approach. Beyond individual interventions, a funded coordination mechanism can provide overarching strategic direction and promote collaboration.

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KEYWORDS

infodemics; misinformation; disinformation; Covid-19; infodemic management; health communication; pandemic preparedness

Introduction

Background

The COVID-19 pandemic entailed an outbreak not only of viral illness but also of viral rumors. This so-called infodemic, defined by the World Health Organization as an overabundance of accurate and inaccurate information [1], had tangible public health consequences. As of April 2022, 24% of COVID-19 mortality, or 234,000 deaths, was vaccine-preventable [2], and misinformation and disinformation cost the United States between US $50,000,000 and US $300,000,000 each day during the pandemic in health care spending and economic losses [3].

These impacts demonstrated the necessity of addressing misinformation as part of public health responses [4].

A wide range of stakeholders globally including governments, nongovernmental organizations, academic institutions, professional societies, and technology companies rapidly developed and deployed a large number of interventions to mitigate the perceived harms of the infodemic. These interventions varied substantially in their foci and impacts and addressed both the infodemic itself and the social problems related to the infodemic, such as vaccine hesitancy and institutional distrust. For example, in the New York City Department of Health and Mental Hygiene, the misinformation response unit disseminated culturally specific communication materials in response to emerging web-based COVID-19 rumors through partnerships with community organizations [4]. YouTube and Google also prioritized credible health information sources in search results based on criteria developed by organizations including the World Health Organization, the National Academy of Medicine, and the Council of Medical Specialty Societies [5,6].

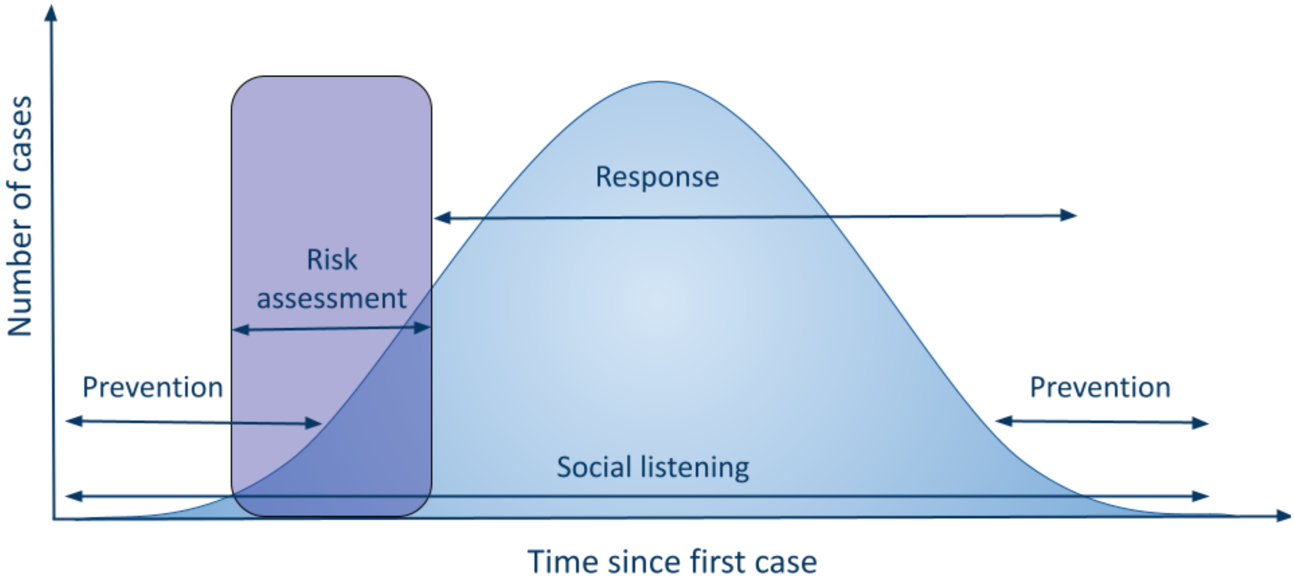
Given the inevitability and growing threat of future infodemics, it is critical to learn from the successes and shortcomings of the growing body of infodemic management interventions. Prior studies have evaluated the effectiveness of these interventions, their fundamental characteristics, and the psychological concepts underlying them [7-9]. However, these studies were limited in the scope of interventions examined, only considered 1 framework, or focused on individual-level factors. Little research has explored the areas of emphasis, both intended and unintended, and strategies revealed and gaps left by these interventions in aggregate. Such an analysis is needed to provide funders, government agencies, public health leaders, and other stakeholders that set priorities for infodemic responses with insights to inform proactive, sustainable, and coordinated efforts that effectively use limited resources. Given increasing politicized attacks on public health and misinformation research in recent years, it is particularly important to avoid infodemic management practices that lead to or exacerbate public mistrust. For example, in the United States, Republicans are disproportionately likely to consider the removal of false articles on social media, a key component of Facebook's COVID-19 misinformation policy [10], to be censorship [11].

In public health, conceptual frameworks serve as lenses that systematically illuminate gaps, patterns, and opportunities in programs and policies [12-14]. Frameworks are not exhaustive or mutually exclusive, and multiple frameworks are necessary to comprehensively interrogate complex topics. Applying public health frameworks to infodemic interventions offers an opportunity to explore their theoretical foundations and inform the design of future interventions. Certain public health metaphors, particularly analogies to epidemics of disease, are frequently invoked in and often dominate discussions of misinformation in academia and public media. However, the use of these frameworks and the validity of their underlying assumptions in this setting have yet to be rigorously evaluated [15]. As a result, other promising mechanisms of impact supported by alternative paradigms may be overlooked [15]. In the following sections, we outline the 3 frameworks applied in this study and their applications to infodemics. These frameworks were selected because they are well established in public health or are often referenced, implicitly or explicitly, in infodemic-related discourse. Public health frameworks were prioritized to reflect the growing application of public health perspectives to address misinformation during the pandemic.

Epidemiological Model

Epidemiological models describe the spread of disease over time within a population. The epidemiological model frames misinformation as a contagion (Figure 1) [16]. As the epidemiological model is currently a dominant paradigm in discourse about misinformation [15], it is critical to assess how well suited previously developed interventions are to this model. Areas of engagement in the information ecosystem are drawn analogously from responses based on public health approaches to infectious diseases: social listening, risk assessment, response, and prevention [17]. Risk assessment can take place either as a one-time evaluation or a continuous assessment at various points along the epidemiological curve.

Figure 1. Epidemiological model.



Socioecological Model

The socioecological model illustrates the health impacts of various components of society and the environment (Figure 2) [18]. Given its widespread application in health promotion and public health [19-22], it is important to evaluate its use in health misinformation. Counterinfodemic activities fit within this paradigm as the information environment is an increasingly recognized determinant of health influenced at multiple levels, from clinical interactions to social media regulation [23]. This perspective indicates a need to comprehensively target misinformation throughout the socioecological spectrum [8], reflected in the US Surgeon General's "whole of society" response to misinformation [24,25] and reports from the World Health Organization and other public health experts [26,27].

Figure 2. Socioecological model.

Environmental Health Framework

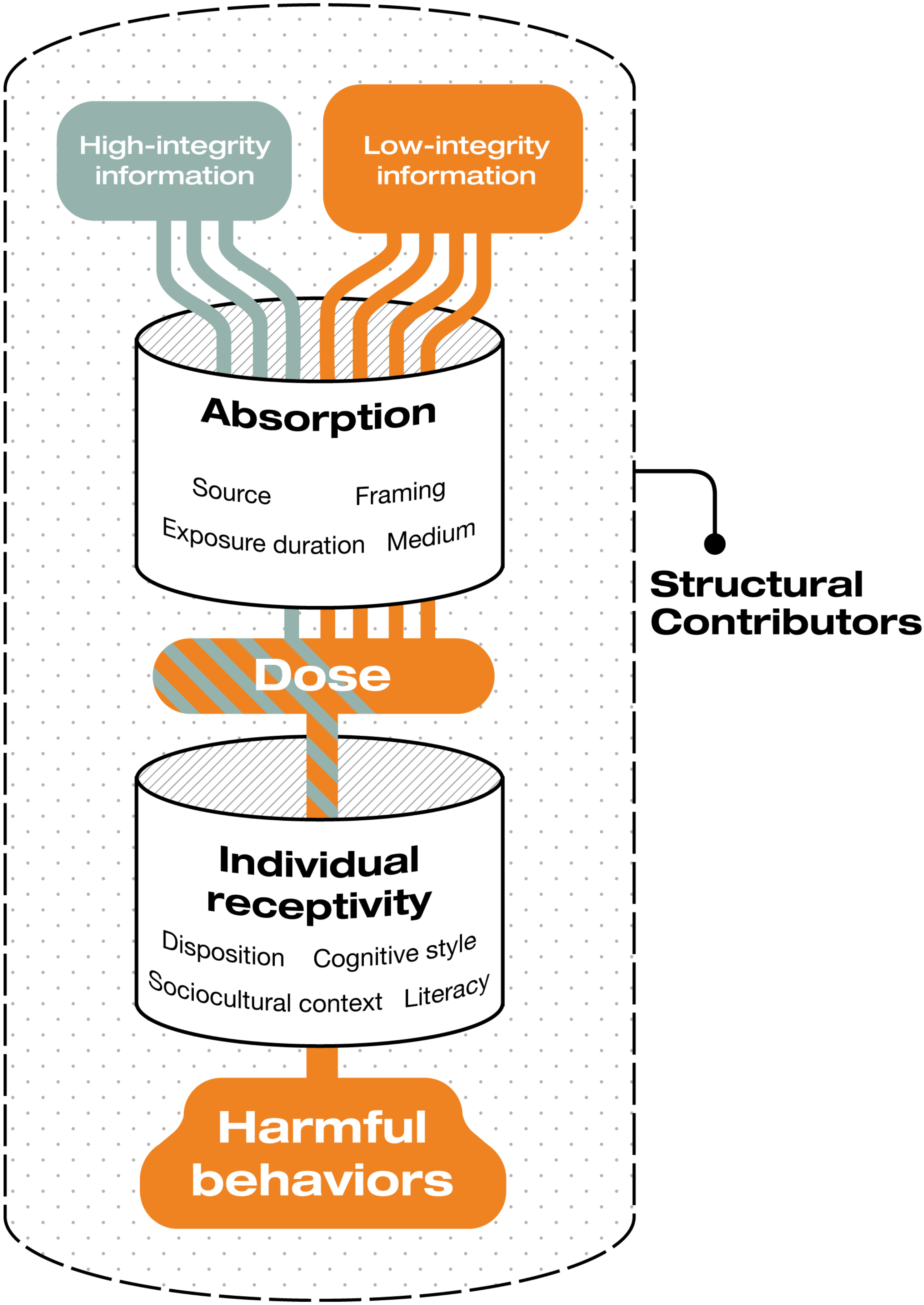
Environmental health is an area of public health focused on the health impacts of the natural and built environment. Despite its decades of use, the term "information environment," previously defined as the space where people receive and process information to make sense of the world [28,29], has only recently been applied to misinformation. In national defense, it was conceptualized to facilitate (often clandestine) information operations [30]. Political science literature has examined to what extent the information environment is conducive to political knowledge, civil discourse, and other democracy-relevant outcomes [31]. In both instances, the implied orientation of the information environment is toward information producers, rather than information consumers.

Environmental analogies about health-related information challenges have expanded, as scholars have alluded to the toxic effects of a polluted media environment [32,33]. In 2021, the US Surgeon General included the subtitle “Building a Healthy Information Environment” in his special advisory on misinformation [24]. The New York City Commissioner of Public Health, Ashwin Vasan, and the New York City Mayor, Eric Adams, recently urged public health authorities to “treat social media as a toxin, ever present in our daily environments” [34]. Here, the implied orientation is toward information consumers.

Despite the use of environmental metaphors, environmental health frameworks have been underused to understand public health–related information challenges. From a public health perspective, the information environment has been defined as an adaptive space that includes content from traditional and web-based media and in-person sources and technology to access and process this content [35]. This paradigm highlights several mechanisms of misinformation spread and corresponding opportunities for intervention: altering the dose of information of variable integrity to which an individual is exposed, influencing an individual’s receptivity to toxic misinformation, assessing the threat posed by a claim or narrative (referred to as hazard identification), and mitigating the harms of information hazards through multipronged approaches (hazard management) (Figure 3). Detailed definitions and examples of each of these intervention types are provided in the “Methods” section.

By applying these 3 models, this study sought to identify gaps and opportunities in an aggregate view of pandemic-related infodemic management interventions and to assess the use of public health frameworks to broadly structure and strategize responses to infodemics.

Figure 3. Environmental health framework.



Methods

Data Collection

This analysis drew on a dataset of infodemic management interventions aiming to address the effects and spread of misinformation that was previously developed as part of a report commissioned by the National Academies of Sciences, Engineering, and Medicine, which ultimately led to a peer-reviewed publication [8,36,37]. These interventions, which were identified between October 2022 and January 2023, include guidelines, policies, and tools from local and federal governments, public health departments, nonprofits, universities, technology and media companies, and other organizations [8]. The original authors identified these interventions through searches of the following sources: academic literature about infodemics and infodemic management; gray literature from organizations including federal agencies, nongovernmental organizations, and technology companies; and websites from state and local health departments [8,36]. Interviews with key informants were used by the original authors to identify additional interventions [36]. We expanded this dataset to include additional interventions lacking from the original dataset, focusing on interventions performed by professional societies that were identified through a similar search strategy, and reviewing the websites and resources of medical and scientific societies. As many societies' interventions were undertaken without either a publication or a description of such interventions on the societies' websites, the goal with this expansion was to be illustrative of these interventions and not exhaustive. The final dataset consisted of 379 interventions and can be made available upon request.

Data Analysis

We used framework analysis, a form of qualitative content analysis useful for applied health policy research [12,13]. Framework analysis provides a comprehensive and systematic approach to describe, interpret, and identify patterns in policies and procedures [12,14]. Codes based on thematic frameworks are applied to cases, allowing data to be compared across and within cases [13]. Through applying frameworks to a given topic, framework analysis can assess the relevance of public health analogies that are frequently applied to health infodemics but have yet to be rigorously defined in this context. Studying multiple frameworks allows for a more comprehensive lens to examine the many dimensions to an issue such as misinformation [13].

Five steps are involved in framework analysis: (1) familiarization, in which the researchers become immersed in the data and reflect on patterns; (2) identifying the thematic framework, based on emerging themes; (3) indexing, or coding components of the data that correspond to themes; (4) charting, which involves rearranging data based on themes; and (5) mapping and interpretation, when themes are analyzed through the charts [12]. We first familiarized ourselves with the data by reviewing the intervention descriptions and websites in the dataset. The thematic frameworks were identified based on prior literature cited in the introduction that provide a range of perspectives to conceptualize misinformation. We developed a coding scheme of deductive codes drawn a priori from the components of the frameworks. This coding scheme accommodated additional inductive codes that emerged through the coding process.

The epidemiological model included the following codes: prevention, social listening, risk assessment, and response. Prevention activities proactively protect populations and information networks from the adverse effects of an infodemic. Social listening activities identify and track harmful (web-based) narratives [38]. Risk assessments determine which narratives require intervention based on factors such as its spread over time, the channels in which it is disseminated, and the communities it affects, with the goal of avoiding expending limited resources on or giving oxygen to low-impact narratives [38]. For example, narratives about vaccines causing infertility that are disseminated widely in the press and on social media during a pandemic would be considered high risk [38]. Finally, rapid responses curtail the spread of harmful information.

The codes derived from the socioecological model included individual, interpersonal, community, organization, and public policy, referring to the societal level at which influence was exerted on the information environment [19]. A public policy intervention was considered to be "a choice made by government to undertake some course of action" involving goals and means of reaching them [39].

The following codes were applied for the environmental health model: dose (which could be further specified as increasing high-integrity information exposure, decreasing low-integrity information exposure, or influencing absorption), receptivity, hazard identification, and hazard management. Drawing from toxicology, "dose" refers to the concentration of low-integrity information compared with high-integrity information, defined as information that is "trustworthy; distinguishes fact from fiction, opinion, and inference; acknowledges uncertainties; and is transparent about its level of vetting," [40] and the degree of absorption of this content [41]. Hazard identification and management are conducted by organizational and governmental entities engaged in infodemic management and information integrity protection. Analogously to toxicology approaches, hazard identification refers to assessing the health effects of an information toxin [42]; hazard management describes multipronged approaches to evaluating and mitigating the threats posed by such a toxin. While structural determinants (eg, health care access or socioeconomic marginalization) influence the information environment, we did not code for this domain in order to focus on the individual components of the information environment that are specific to this model. Examples of each of these codes are given in Table 1.

Table . Example interventions corresponding to each environmental health code.

Code	Examples	Examples
Dose	InVID assists journalists in assessing the reliability of videos on social media, thus facilitating the sharing of high-integrity videos while inhibiting the further spread of low-integrity videos.	[43]
Receptivity	Interland is a game developed by Google that teaches young children to distinguish truths from misinformation on the web.	[44]
Hazard identification	Logically tracks misinformation campaigns to understand threats to national security, corporations, nonprofits, and elections.	[45]
Hazard management	CrossCheck, a program run by First Draft, promotes collaboration and resource sharing for journalists responding to misinformation. The Vaccination Community Navigator Program similarly takes a multipronged approach in educating community health workers to boost vaccine confidence.	[46]

Coding was conducted in an iterative, discursive process. One author (JNJ) coded the entire dataset in batches, documenting evolving code definitions and interpretations of the data, where relevant, multiple codes were applied to the same intervention. After each batch, 2 of the authors met to discuss uncertainties and insights that arose, such as ambiguities in the code definitions and emerging patterns in the data. Coding was conducted iteratively, until thematic saturation was reached [47]. Then, DS independently coded a random sample of approximately 20% of the dataset. Codes were reviewed to ensure alignment and discrepancies were resolved through discussions between both authors.

Results

Overview

Overall, 379 interventions were included in the final analysis, including 14 interventions from professional societies that were identified through the expanded search. The 3 frameworks lended distinct insights into the functions and capacities of the interventions (Table 2). The applications of each of the frameworks are described in detail in the subsequent sections. For further details on the coding results and representative interventions, see Multimedia Appendix 1.

Table . Insights from the 3 frameworks.

Key finding	Framework	Supporting evidence	Infodemic management recommendations
Risk assessments are often value-based or poorly defined.	Epidemiological framework	Vague or absent language about how risk assessments are conducted.	Risk assessments should be rigorous, objective, and transparent about how community values are incorporated into decision-making.
Interventions are skewed toward acting at the individual level and often focus on only 1 level of influence.	Socioecological model	Most interventions were focused on either individuals alone or individual members of organizations, rather than implementing structural change with community, interpersonal, organizational, or policy interventions. Only 11% of interventions received more than 1 socioecological code.	Interventions acting at the interpersonal, community, organizational, and policy levels should be explored, and structural barriers to implementing interventions at these levels should be identified and overcome. Collaborations should involve interventions targeting multiple levels of the socioecological spectrum.
Interventions often lack mechanisms to reach their intended audiences (ie, the Field of Dreams Fallacy) [48].	Socioecological model	Abundance of resources and tools that lacked connections to established workflows and organizations within the socioecological spectrum.	Interventions should be developed in partnerships with the organizations that are intended to use them.
Interventions place a greater emphasis on increasing high-integrity information rather than decreasing low-integrity information.	Environmental health framework	More than 3 times as many interventions address high-integrity as low-integrity content.	Interventions that decrease the spread of low-integrity information should be developed.
Demographic factors are emphasized when addressing receptivity to misinformation, while psychological factors are overlooked.	Environmental health framework	Focus on targeting racial, cultural, or age-related communities.	Interventions should consider approaches to segmenting audiences based on personas and psychobehavioral factors.
Interventions that address receptivity tend to involve a one-time action rather than longitudinal education.	Environmental health framework	Prevalence of self-contained courses, games, handouts, etc, that lack mechanisms to reinforce instruction over time.	Media literacy initiatives should incorporate mechanisms for longitudinal instruction on detecting and responding to misinformation.
Few organizations are equipped to implement hazard management approaches, despite increasing awareness that such approaches are critical.	Environmental health framework	Overrepresentation of tool kits, handbooks, and other resources lacking direct action in the hazard management category.	Media, public health, and government agencies should adopt hazard management approaches.

Epidemiological Framework

By distinguishing between the stages of an infodemic, the epidemiological framework highlighted critical distinctions in the foci of interventions that emerged in response to a specific ongoing or predicted infodemic. This framework was less relevant to interventions that addressed general components of misinformation that were agnostic of a particular crisis, such as tools providing assessments of the credibility of information sources. The framework also did not apply to interventions that lacked a clear audience or mechanism of impact.

In total, 50% (189/379) of interventions were engaged in activities intended to prevent an infodemic itself, in contrast to preventing an individual from falling for misinformation amid an ongoing infodemic. Prevention activities were most prominent when the amount of misinformation was low. Moreover, 19% (73/379) of interventions conducted social listening, monitoring conversations, concerns, claims, and news, online or offline [49]. Social listening tools most often analyzed social media feeds and datasets. The degree of analysis varied widely, from tracking misinformation with artificial intelligence to descriptive statistics on rumor spread. Seven percent (28/379) were risk assessment interventions that assessed the severity or status of an infodemic to inform whether and to what extent a response was needed. These interventions not only provided data that could be relevant to a risk assessment, such as the amount of spread of a rumor, but conducted the risk assessment itself. Most interventions (286/379, 76%) responded to an ongoing infodemic, primarily through fact-checking, debunking, and amplifying reliable information and sources. They also conducted prebunking to address topics for which misinformation is already widespread.

Socioecological Model

The socioecological model allowed for a better understanding of the key groups and audiences that are affected by or are in a position to address misinformation. Applying this framework revealed a skew toward interventions that acted at the individual level, rather than the interpersonal or community levels. While most interventions were directed toward organizations, they required exposure or uptake by individual members, rather than spurring structural change within the organization overall. In addition, interventions often lacked a clearly defined target group and means of reaching this audience. By revealing these shortcomings, the socioecological model shed light on opportunities to align valuable resources with the groups with the greatest capacity to leverage them.

We identified 150 (40%) interventions that acted at the individual level. These interventions included media literacy and prebunking initiatives, repositories of reliable information, fact-checks and debunks, and tools evaluating the credibility of claims and sources, when these tools were intended for use by the general public. Interventions acting at the interpersonal level, such as an app that provides guidance about discussing vaccines with friends, were the least common, representing only 2% (9/379) of this dataset. Eleven percent (42/379) of interventions were community-level, targeting groups based on educational systems, geographic regions, and racial or ethnic identities, as well as social networks. The interventions often included content or dissemination strategies tailored to a community's needs. The 178 (47%) organization-level interventions primarily provided resources and tools that were intended for members of a profession, such as journalists, researchers, physicians, teachers, librarians, policy makers, or organizational bodies. These resources included infodemic management tool kits, communication materials, social listening platforms, media literacy curricula, reporting guidelines, and social media policies. There were 39 (10%) public policy interventions. Most of these policies were developed by federal governments. Two came from the United States; other regions included Singapore, Australia, the United Kingdom, France, Egypt, Germany, and the European Union.

Environmental Health Framework

The environmental health framework allowed for a more nuanced perspective on the mechanisms through which interventions interacted with the information environment. By outlining a variety of components that contribute to the information environment, this framework underscored the importance of contextualizing misinformation within information networks and audiences.

Most interventions (244/379, 64%) targeted the dose of high- and low-integrity information. More interventions increased the amount of high-integrity information (155/379, 41%) rather than decreasing the volume of low-integrity information (44/379, 12%). We identified 61 (16%) interventions that addressed receptivity to misinformation. Most of these interventions involved media literacy education, including curricula, games, infographics, and web-based courses. Seventeen percent (65/379) of interventions conducted hazard identification by assessing the dose or toxicity of misinformation. These interventions were primarily resources and tools for professionals, particularly infodemic managers, public health communicators, and journalists. The interventions involved content verification, social listening, credibility assessments, and fact-checking. Seventy (19%) hazard management interventions took a comprehensive and higher-level approach to addressing misinformation that went beyond any 1 particular intervention. They often took the form of tool kits, handbooks, field guides, and frameworks intended to inform professional hazard management activities, rather than conducting hazard management themselves.

Crosscutting Insights

We identified several findings that suggest opportunities for future interventions relating to the use of technology, coordination, and sustainability that surfaced from a combination of all 3 frameworks (Table 3). For example, some interventions such as artificial intelligence–powered chatbots suggested an overzealous application of new technologies that lacked grounding in user needs. Perhaps owing to the urgent and unprecedented nature of the COVID-19 pandemic, interventions were often duplicative and short-lived.

Table . Crosscutting insights.

Key finding	Supporting evidence	Infodemic management recommendations
Greater strategic direction to align theories of change with desired impact is needed.	Unclear distinctions between efforts to address acute compared with endemic misinformation as well as efforts engaged in prevention versus response. The intended audiences of interventions also tended to be poorly defined.	Interventions should specify the nature of the infodemics they are intended to address, intentionally select a guiding framework, and address the unmet needs of a specific audience.
Technological tools are often built and used without adequate need finding.	Prominence of tools such as chatbots enabled by technology that do not clearly fill a well-defined need.	The design process for interventions should center around identified needs rather than the tool.
Lack of coordination or pervasive duplication of efforts.	Very few initiatives included cross-sector collaboration; those that did were not sustainably funded to persist beyond the pandemic. A number of initiatives duplicate work and effort (eg, see "tool kits").	Sustainable cross-disciplinary or sector coordination mechanisms may be required to support effective and ethical infodemic management initiatives [50].
Short-term funding opportunities early on in the COVID-19 pandemic were not conducive to long-term sustainability.	Many interventions had concluded or had websites that had not been recently updated.	Sustainability given funding trends should be a key consideration when developing interventions. Funding programs should include support to sustain efforts beyond immediate crises and collect longitudinal data.
The role of incidental information exposure compared with intentional information consumption was rarely accounted for.	Interventions frequently made unsupported assumptions about the degree of agency individuals have in the information they encounter.	Future frameworks should incorporate the distinction between incidental information exposure and intentional consumption.

Discussion

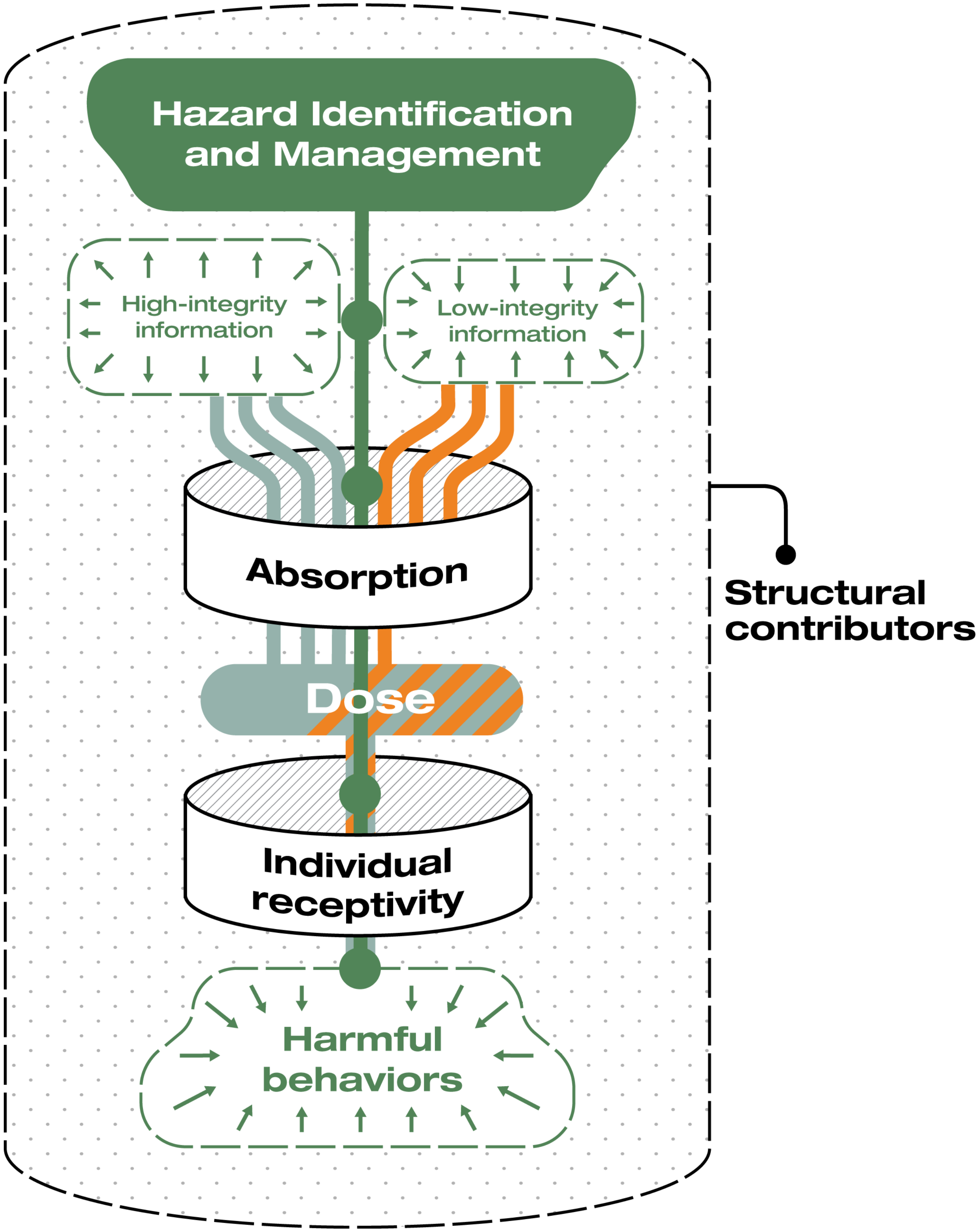
In our analysis, the epidemiological, socioecological, and environmental health frameworks shed light on trends, gaps, and opportunities among counterinfodemic interventions. The epidemiological framework revealed an opportunity to implement more robust and transparent risk assessment measures in partnership with communities to triage rumors and allocate resources, particularly as more evidence emerges on the threats posed by various claims and narratives. By relying on value judgments, the risk assessments in the interventions in this dataset risk undermining trust and expending limited resources on low-impact efforts. Instead, the World Health Organization recommends developing risk assessment matrices that synthesize considerations such as the timing of a narrative, its spread on various platforms, and the impacted communities to categorize narratives as high, moderate, or low risk, and positive sentiment [38].

The socioecological framework demonstrated the need to target higher levels of influence through collaborations spanning multiple levels, reinforcing a finding from the original analysis of this dataset [8]. Scholars have recently argued that the outsized attention given to individually framed behavioral interventions “pollutes” the discourse and diverts attention from structural interventions [51,52]. This trend was replicated in our dataset, where structural change through public policy or enduring platform adjustments was rarely the priority. As with other complex public health challenges such as diabetes or drug overdoses, structural-level interventions coordinated with efforts acting at other levels of the socioecological spectrum are likely to be more effective and sustainable than individual-level efforts in the case of infodemic management. Policy efforts to protect children from social media–related harms have garnered significant attention, most notably in the US Surgeon General’s recommendation to display warning labels on social media [53]. Despite their limitations, related legislation, such as the Stop Addictive Feeds Exploitation [54], offers potential models for analogous efforts to mitigate the harms of digital infodemicshttps://www.zotero.org/google-docs/?FlRQ40

The socioecological framework additionally revealed the importance of avoiding the Field of Dreams Fallacy [48], as many interventions neglected to specify mechanisms to reach their intended audiences. While the speed of a response is often prioritized in an emergency, the resulting lack of alignment with existing efforts may prove harmful in infodemic management due to the resource and trust barriers to maintaining strong relationships with community partners. Sustaining proactively developed partnerships is needed to increase the uptake and sustainability of infodemic interventions, particularly the tool kits and other resources that were often deployed independently of established partnerships in this dataset.

The environmental health framework provided a structure for systems-level, multipronged approaches that influence the information environment as a whole (Figure 4). A key finding was that reducing exposure to low-integrity information, which digital platforms can implement through content moderation, deplatforming, and algorithmic adjustments, was a notable gap. Amid the growing politicization of content moderation, many social media platforms have recently rolled back these efforts [11,55]. Differing perceptions of trustworthiness and integrity may also reduce the efficacy of content moderation or even lead to further polarization [6,56]. Regulating algorithmic recommendation and amplification may encourage platforms to prioritize high-integrity content while protecting First Amendment rights [57]. While the answer to bad speech was once considered to be “more speech” [58], in the social media era, it is now recognized that freedom of speech does not equate to freedom of reach [59]. Current revenue models incentivize platform architectures and algorithms that promote content that provokes negative emotional reactions, particularly anger [60].

Figure 4. Opportunities for intervention based on the environmental health framework. Points of intervention within this framework are represented by green nodes; for example, interventions can modify individual receptivity to misinformation. The shift in the composition of the information environment toward high-integrity information and subsequent reduction in harmful behaviors as a result of these interventions is indicated with green arrows. Structural contributors influence these dynamics but were not a focus of the present analysis.



While many interventions used demographic characteristics to target the information environments of particular communities, psychobehavioral segmenting may allow for more precise tailoring of messages to individuals uniquely receptive to misinformation (eg, those who engage in absolutist thinking) [61,62]. An information environment perspective additionally suggests that initiatives based on inoculation theory could expand their impact through longitudinal rather than one-time modes of engagement and by reaching a saturation point that displaces low-integrity information. Hazard management approaches are critical to address an issue as pervasive as an infodemic. Such approaches were uncommon in our dataset, however, likely due to the funding, coordination, and sustainability challenges. Strong governance and financial support are needed to enable key stakeholders, including media, public health, environmental scientists, and government, to create and sustain hazard management approaches, potentially following models such as the Elections Infrastructure Information Sharing and Analysis Center [50].

Several key crosscutting considerations emerged (Table 3). Infodemic management interventions could benefit from greater strategic direction regarding the theories of change applied in various settings. The intended mechanism and audience of an intervention should be informed by a framework that aligns with the relevant type of information distortion. For example, while misinformation is often considered as part of acute infodemics, endemic misinformation unrelated to particular health events may require different theories of change, use of alternate frameworks (eg, socioecologic or environmental), and corresponding interventions. Too often, the development of tools using novel technologies such as generative artificial intelligence centered the technology itself, rather than a need they are intended to address. Need-finding processes must be incorporated into the design of technologically enabled interventions to maximize their potential impact. Design-thinking principles, for example, provide an approach to explore stakeholders' needs and develop tailored solutions [63].

Funders and stakeholders involved in the interventions were often fragmented and uncoordinated, leading to duplication and unstrategic allocation of resources. Well-governed and funded coordination mechanisms, perhaps modeled on Elections Infrastructure Information Sharing and Analysis Center, offer an opportunity to streamline resources while diversifying efforts. Since many efforts to counter the COVID-19 infodemic were not sustained after the immediate threat of the pandemic subsided, funding structures that support longitudinal and crisis-agnostic efforts are needed. Interventions rarely accounted for the distinction between incidental exposure and intentional information consumption. While a consumptive lens suggests that individuals make conscious decisions about the information they encounter, from an exposure-based perspective, individuals are subject to influence by information within their environments. Incorporating this distinction into future frameworks may illuminate new approaches for interventions.

Overall, by testing these frameworks in our dataset, we identified their strengths and weaknesses, allowing for iterative adaptation to the infodemic management context.

Our analysis was limited in that not all components of the interventions that we considered, such as reach and distribution, were typically reported. As a result, it was sometimes necessary to make inferences about goals and impacts. Many interventions lacked information about time and scale, which resulted in organizing the data in a way that gave the same prominence to small- and large-scale initiatives. This lack of information biased the data toward smaller-scale initiatives, although large-scale initiatives likely had a broader impact. Many of the codes we applied were subjective, not mutually exclusive, and reliant on interpretation, a limitation that was exacerbated when details of an intervention were not available. For example, for the epidemiological framework, prevention and response entail critically distinct activities, but we were unable to distinguish between these 2 foci when information about the stage of the infodemic at which an intervention was deployed was not provided. There was also at times overlap in the insights derived from each framework; our analysis attempted to focus on the dominant framework that surfaced a given insight. The dataset used in this study is not exhaustive; notably, given the focus on terms such as "infodemic management," a term that emerged during the COVID-19 pandemic, interventions that predate the pandemic may have been underrepresented. Our study was designed to be illustrative, not exhaustive, so it did not use systematic search criteria. This study considered only 3 frameworks, which were chosen based on their prominence in public health and misinformation discourse; future work should consider additional frameworks to illuminate further findings. For example, recent work has adapted a public health prevention framework to infodemic management [64]. Finally, we acknowledge that the feasibility of our recommendations may be limited given resource constraints and an evolving evidence base.

In this study, we used a framework analysis using 3 public health frameworks to illuminate emphases and gaps in interventions to address the COVID-19 infodemic. While many opportunities to expand the reach and impact of interventions were identified, it was also clear that the landscape of infodemic management approaches lacks an overarching strategy and entity responsible for coordinating and evaluating activities. In preparation for future infodemics, emphasis should be placed on multisector collaboration, alignment with measurable and meaningful goals, and top-down approaches to determining and implementing strategies.

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Conflicts of Interest

JNJ is an employee of Roon. SG and DS have no conflicts of interest to disclose.

Multimedia Appendix 1
Example interventions.
[DOCX File, 10 KB - infodemiology_v5i1e67119_app1.docx]

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Original Paper

Geosocial Media's Early Warning Capabilities Across US County-Level Political Clusters: Observational Study

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Abstract

Background: The novel coronavirus disease (COVID-19) sparked significant health concerns worldwide, prompting policy makers and health care experts to implement nonpharmaceutical public health interventions, such as stay-at-home orders and mask mandates, to slow the spread of the virus. While these interventions proved essential in controlling transmission, they also caused substantial economic and societal costs and should therefore be used strategically, particularly when disease activity is on the rise. In this context, geosocial media posts (posts with an explicit georeference) have been shown to provide a promising tool for anticipating moments of potential health care crises. However, previous studies on the early warning capabilities of geosocial media data have largely been constrained by coarse spatial resolutions or short temporal scopes, with limited understanding of how local political beliefs may influence these capabilities.

Objective: This study aimed to assess how the epidemiological early warning capabilities of geosocial media posts for COVID-19 vary over time and across US counties with differing political beliefs.

Methods: We classified US counties into 3 political clusters, democrat, republican, and swing counties, based on voting data from the last 6 federal election cycles. In these clusters, we analyzed the early warning capabilities of geosocial media posts across 6 consecutive COVID-19 waves (February 2020-April 2022). We specifically examined the temporal lag between geosocial media signals and surges in COVID-19 cases, measuring both the number of days by which the geosocial media signals preceded the surges in COVID-19 cases (temporal lag) and the correlation between their respective time series.

Results: The early warning capabilities of geosocial media data differed across political clusters and COVID-19 waves. On average, geosocial media posts preceded COVID-19 cases by 21 days in republican counties compared with 14.6 days in democrat counties and 24.2 days in swing counties. In general, geosocial media posts were preceding COVID-19 cases in 5 out of 6 waves across all political clusters. However, we observed a decrease over time in the number of days that posts preceded COVID-19 cases, particularly in democrat and republican counties. Furthermore, a decline in signal strength and the impact of trending topics presented challenges for the reliability of the early warning signals.

Conclusions: This study provides valuable insights into the strengths and limitations of geosocial media data as an epidemiological early warning tool, particularly highlighting how they can change across county-level political clusters. Thus, these findings indicate that future geosocial media based epidemiological early warning systems might benefit from accounting for political beliefs. In addition, the impact of declining geosocial media signal strength over time and the role of trending topics for signal reliability in early warning systems need to be assessed in future research.

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KEYWORDS

spatiotemporal epidemiology; geo-social media data; digital disease surveillance; political polarization; epidemiological early warning; digital early warning

Introduction

On March 12, 2020, the World Health Organization (WHO) declared the novel coronavirus disease COVID-19 a pandemic [1]. Its high infectiousness and severity posed a great threat to large populations worldwide, ultimately causing an estimated 15.9 million pandemic-related deaths [2], challenging health care professionals, hospitals, and authorities alike. Thus, decision makers around the world sought to unravel and predict the spreading dynamics of this novel coronavirus. Consequently, researchers explored various ways of adjusting and improving existing epidemiological early warning systems, with complementary internet-based data sources being one such method to better monitor and anticipate how this new disease would affect different geographies around the world [3-5].

Multiple studies have already emphasized the role of geosocial media data in improving early warning of epidemiological phenomena. For instance, geosocial media data were used to improve real-time reporting on diseases like Zika and Ebola [6] or to enhance the prediction of dengue fever [7]. Accordingly, various recent examples further emphasize the ability of geosocial media data for real-time surveillance and early warning in the context of COVID-19 [8,9]. In this regard, Kogan et al [10] observed that in the beginning of the pandemic, increases in geosocial media activity, among other digital data sources, preceded surges in COVID-19 cases by 2 to 3 weeks on state level. Similarly, Zhang et al [11] used geosocial media posts in a linear regression model to predict COVID-19 signals on state-level. Yet, an increasing trend in epidemiological analysis focuses on ever finer spatial scales in the hopes of gaining a more distinct understanding of infection patterns. In this regard, Stolerman et al [12] investigated the value of X posts (formerly known as Twitter) for COVID-19 early warning on a representative subset of US counties. However, the authors only investigated a comparably small sample of counties (n=97), raising questions with respect to the generalizability of the presented results. Thus, in this study, we extended their investigation on the early warning capabilities of geosocial media data to all US counties.

Furthermore, geosocial media data garnered notable attention across various fields to answer research questions related to mental health or public attitudes, during the COVID-19 pandemic [13]. For instance, researchers investigated how language in Reddit posts reflected real-world pandemic-driven events like lockdowns, revealing significant psychological shifts among users which coincided with tendencies toward decreased analytical thinking [14]. Similarly, Swain et al [15] developed a machine learning model leveraging geosocial media data to predict disruptions in mental well-being caused by the COVID-19 pandemic. Beyond that, researchers explored geosocial media users' attitudes and concerns toward COVID-19 vaccines for the United States and the United Kingdom [16]. They observed that geosocial media derived results correlated broadly with nationwide surveys. In essence, the previous results suggest that geosocial media exchange during the COVID-19 pandemic was likely influenced by real-world public attitudes and even users' mental health. Similarly, a variety of studies indicate that the language used and the topics of interest of geosocial media users vary based on political beliefs [17-19]. This further supports our underlying assumption that differences in political beliefs are likely to be reflected in geosocial media behavior, which could, in turn, correspond to differences in geosocial media's early warning capabilities for COVID-19 cases.

However, even before the surge of the COVID-19 pandemic, researchers observed the emergence of echo chambers when analyzing pro and antivaccination attitudes on Facebook (Meta), which in their opinion might have caused further polarization [20]. In this regard, Howard et al [21] found that X was particularly prone to misinformation and polarizing content compared with professionally produced news during the 2016 presidential election. They even found more misinformation being prevalent in swing states. Such spread of misinformation and emerging political polarization on geosocial media should be of further concern for health experts and policy makers. In particular, since many researchers illustrated that diverging political beliefs can not only influence exchange on geosocial media [17-19], but also real-world individual behavior such as vaccine up-take [22] or the usage of nonpharmaceutical interventions such as mask wearing [23]. This is in line with previous findings [24], which highlight significant variation between individuals with different political beliefs with respect to self-estimated COVID-19 risks, self-reported adherence to COVID-19 health care measures, and expectations on the future course of the pandemic. In addition, researchers observed that US counties that voted in favor of the republican presidential candidate in the 2016 election, experienced up to 3 times higher mortality due to COVID-19 during the winter of 2020 [25].

Hence, in essence it can be assumed that individuals may respond differently on geosocial media to a swiftly politicized epidemic event like the COVID-19 pandemic [26], corresponding to their political beliefs. Evidence further suggests that differences in political beliefs do not only influence online and offline behavior, but they might indeed coincide with higher COVID-19 cases and death rates [25,27,28]. In summary, these results highlight the need to understand and adjust geosocial media based early warning systems with respect to political beliefs. Thus, within the scope of this paper, we seek to answer the following 2 research questions with a particular focus on geosocial media posts:

1. How do the early warning capabilities of geosocial media data change across consecutive epidemiological waves of COVID-19 cases?
2. What differences across US county-level political clusters can be observed with respect to geosocial media's early warning capabilities for COVID-19 cases?

To explore the early warning capabilities of geosocial media data, we determined the correlation between geosocial media posts and COVID-19 cases and the number of days by which signals in geosocial media data preceded actual COVID-19 cases (temporal lag). Furthermore, we specifically examined the temporal lag and the correlation in the context of political clusters based on US county voting data and over the course of 6 consecutive waves of COVID-19 cases.

Methods

Data Collection

We used 2 main data sources in this study. First, we gathered official data on confirmed COVID-19 cases in the United States and we obtained geolocated posts (Tweets) from the geosocial media network X. The time frame for which we collected our data ranges from February 28, 2020, the beginning of the pandemic in the United States, to April 27, 2022, which denotes the end of the first major Omicron wave that began in November 2021 [29]. This time frame covers the main COVID-19 waves, time periods before and after the availability of vaccines, and was selected based on retrospective knowledge on the course of the pandemic. The contiguous United States was chosen as our study area. Furthermore, to gain a more refined understanding of the underlying spatial patterns, we decided to use US counties as our finest spatial analysis resolution, on which we identified politically similar clusters, advancing previous research that was mostly performed on national or state levels.

COVID-19 Case Data

We downloaded officially confirmed COVID-19 cases for the United States in csv format from the not-for-profit public data aggregator USAFacts [30]. The COVID-19 cases csv file contained daily cumulated COVID-19 cases, which we transformed into daily incidence data. In addition, we applied a 14-day moving average to account for possible reporting delays and differing update cycles across states.

Geosocial Media Data

Furthermore, we collected geolocated posts from the geosocial media network X through their official application programming interfaces (APIs) during our investigation time frame [10,12], when academic access for researchers was still available. In particular, we used the Twitter REST and Streaming API access points to gather about 727 million geosocial media posts. The REST API allowed us to retrieve posts from the previous 7 days, with a limit of 450 requests per 15-minute window. In contrast, the Streaming API provided a continuous, real-time stream of posts. For both API endpoints we applied filters to capture only posts containing a geolocation. Thus, each collected geosocial media post includes a geolocation, which can either be the Global Navigation Satellite System position of the device through which the post was shared, or a user-defined location. Furthermore, locations can consist of polygons (eg, city, state level polygons) or point locations. We excluded geosocial media posts with polygon or point geometries that were not located within the county-level geometries, which left us with 242 million posts.

Next, to obtain geosocial media posts that are relevant to the analysis of COVID-19, we performed keyword filtering on the remaining 242 million posts located within county geometries. Therefore, we defined keywords based on the knowledge of geosocial media and health experts, with the goal to properly capture geosocial media trends relevant to the COVID-19 pandemic (Textbox 1). For some keywords only their word stem was used to allow for different variations of the word to be detected.

Textbox 1. Keywords used for relevant post extraction.

COVID-19 keywords:

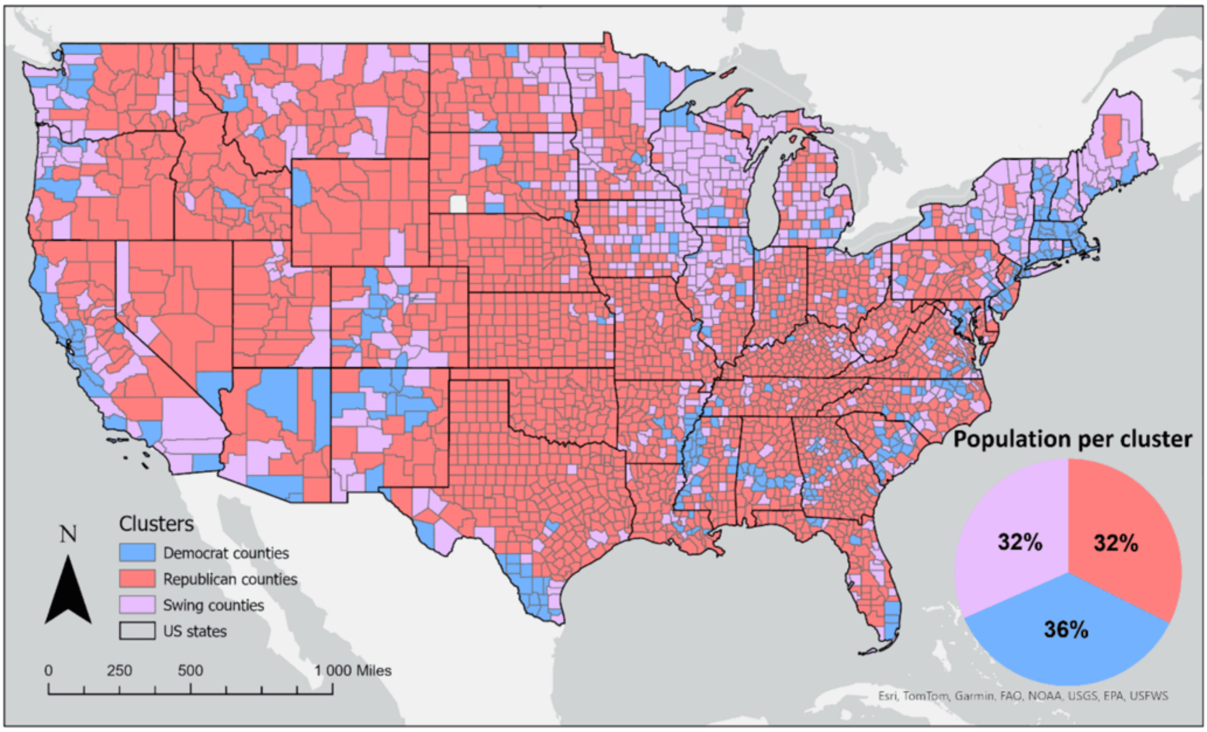
covid, corona, sarscov, sars-cov, sars, epidemic, pandemic, influenza, virus, viral, infect, spread, 2019-ncov, Delta variant, Omicron, H1N1, H3N2, Wuhan, sickness, transmission, contagio, Illness, outbreak, super spread, incubation, quarantine, lockdown, vaccin, fever, cough, headache, fatigue, body aches, loss of taste, loss of smell, no smell, no taste, respirator, face mask, masks.

After the keyword extraction, the posts were aggregated on US county-level and a 14-day moving average was applied. Finally, to cope with differing amounts of geosocial media posts over time and space, we normalized the amount of relevant filtered geosocial media posts over the amount of all geosocial media posts on county level. In the remainder of this study, we solely used this ratio, that is, the proportion of relevant posts over all posts per county. This allows us to account for spatially clustered population and post density. In total, the semantic filtering procedure left us with 3.3 million relevant posts.

Political Clusters

To examine the differences between the various political beliefs, we based our analysis on voting data from the last 6 US presidential elections. The voting data were obtained from the Harvard Dataverse [31]. We classified US counties into 3 different clusters depending on their historical vote share for either the republican or the democrat party. In the political sciences literature, swing states are traditionally defined through a variety of quantitative and qualitative indicators. However, most of these definitions such as the bellwether status of a state [32], or it being perceived as a battleground [32], are not directly transferable to county-level analysis. Thus, we decided to base the classification into republican, democrat, or swing county clusters, on the so-called flippability of a county [32]. We chose to assess the flippability of a county on its last 6 federal election cycles. Concretely, we classified a county as belonging to a specific party, if said party had won at least 5 consecutive elections in the last 6 elections cycles. All other counties were considered as flipping between political parties and thus classified as swing counties. This division yielded political clusters, each of which representing approximately one third of the US population (Figure 1).

Figure 1. Geospatial distribution of political belief clusters on county level based on the last 6 election cycles.

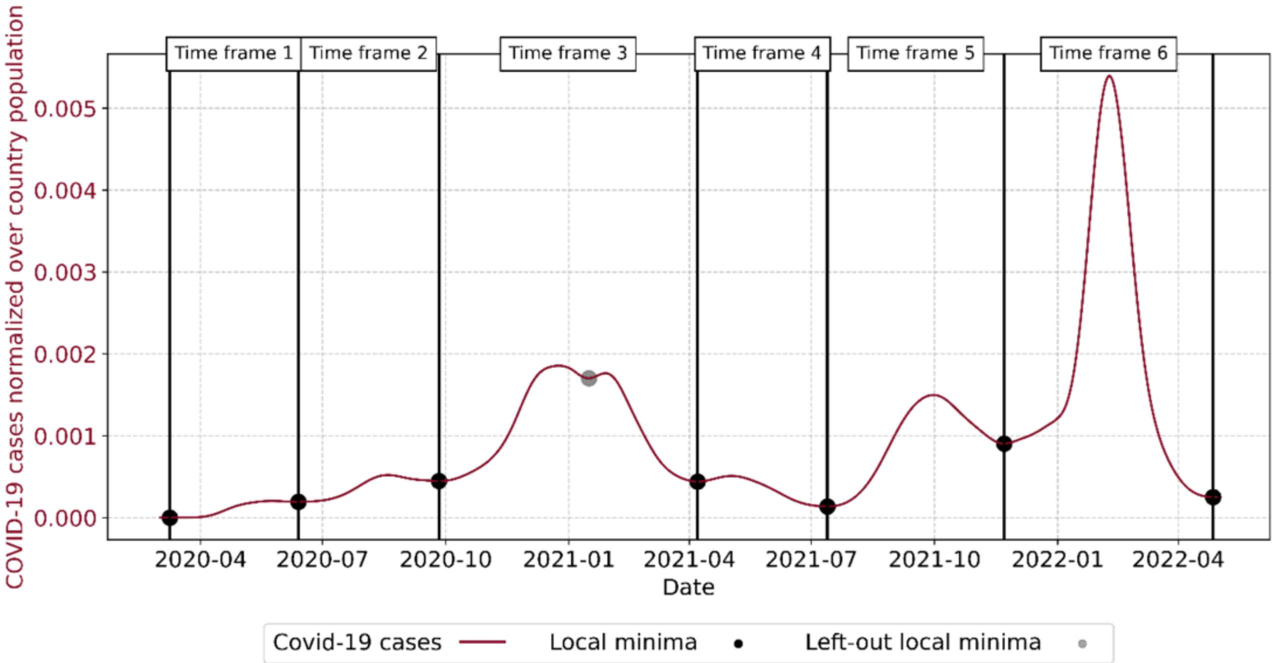


Defining COVID-19 Waves

We split the COVID-19 cases time series into smaller time frames, to capture individual epidemiological waves. However, there exist multiple approaches to define epidemic waves ranging from statistical methods using, for instance, exponential growth [10,33] or the effective reproduction number R [12,34]. In contrast, other authors tried to identify statistics and guiding principles on the duration of COVID-19 waves based on empirical data [35]. Nevertheless, all these approaches are based on strong assumptions and subjective definitions on what thresholds characterize an epidemic wave. Thus, similarly to [35], we based our definition of COVID-19 waves on a rule-based approach using the local minima on a 21-day moving average of the COVID-19 cases, which was informed through retrospective knowledge on the course of the pandemic.

We defined these time frames based on COVID-19 cases for the entire United States, rather than defining them individually for each political cluster. Furthermore, our procedure yielded 7 different time frames (Figure 2). Nonetheless, these 7 time frames did not accurately reflect all epidemic waves. In particular, the wave ranging roughly from October 2020 to April 2021, was split into 2. As a result, we decided to combine the original time frames 3 and 4 into 1 epidemic wave, which left us with 6 epidemic waves in total. This decision enabled us to capture the epidemic waves more accurately (Figure 2).

Figure 2. COVID-19 case waves for the entire US primarily defined through local minima.



Early Warning Capabilities

Finally, we quantified the early warning capabilities separately for each of the epidemic waves. We defined early warning capabilities twofold: (1) as the Pearson correlation between the time series of COVID-19 related geosocial media posts and COVID-19 cases, and (2) the number of days by which geosocial media posts preceded COVID-19 cases. However, the more important measure for early warning is the correlation between the 2 time series. Put differently, this means that if the temporal lag is high, however a correlation close to zero is present, it is obviously not reasonable to attribute any early warning capabilities to geosocial media data.

Furthermore, to identify the maximal correlation and the corresponding temporal lag, we shifted the geosocial media posts time series between 7 and 42 days into the future to determine the highest possible early warning capabilities. This procedure is repeated for each individual political cluster and epidemic wave, respectively. The decision to investigate a temporal lag between 7 and 42 days into the future was based on previous results [12], in which an early warning model, using, among others, geosocial media data, was able to predict COVID-19 cases between 1 and 6 weeks in advance.

Ethical Considerations

The study was carried out in accordance with the Declaration of Helsinki and with the ethical regulations in place at the Paris Lodron University of Salzburg, and complies with the General Data Protection Regulation legislation of the European Union. We only used publicly available data, which were collected in accordance with the terms of service of the respective geosocial media platform X at the time of data collection. Furthermore, no identifiable information was revealed in this study. Specifically, the user-provided geographic locations and semantic content were spatially aggregated to ensure user privacy and anonymity. Thus, we did not need to seek ethical approval from our institution for this study.

Results

Democrat Counties

Figure 3 depicts the Pearson correlation for different temporal lags between the time series of COVID-19 cases and geosocial media posts in democrat counties. In particular, the y-axis represents the individual waves of COVID-19 cases as introduced in Figure 2, while the x-axis denotes the number of days the posts time series was shifted into the future. The coloring of individual windows reflects the Pearson correlation between COVID-19 cases and the shifted posts time series. Furthermore, Figure 4 illustrates the corresponding COVID-19 cases, the post time series and the post time series shifted by the correlation maximizing temporal lag for each individual epidemic wave.

Figure 3. Depicting the Pearson correlation between COVID-19 cases and geosocial media post time series for each epidemiological wave when stepwise shifting the geosocial media post time series into the future for democrat counties.

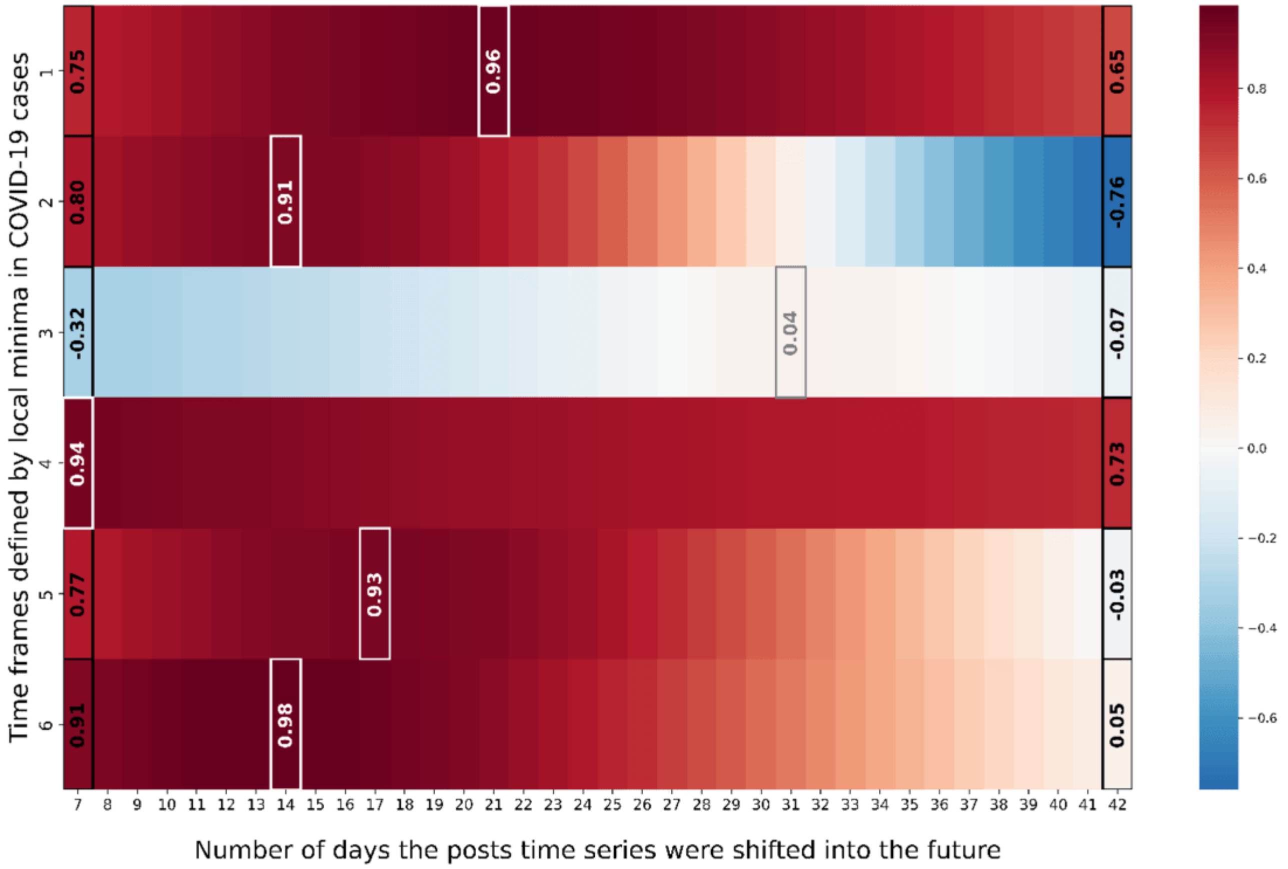
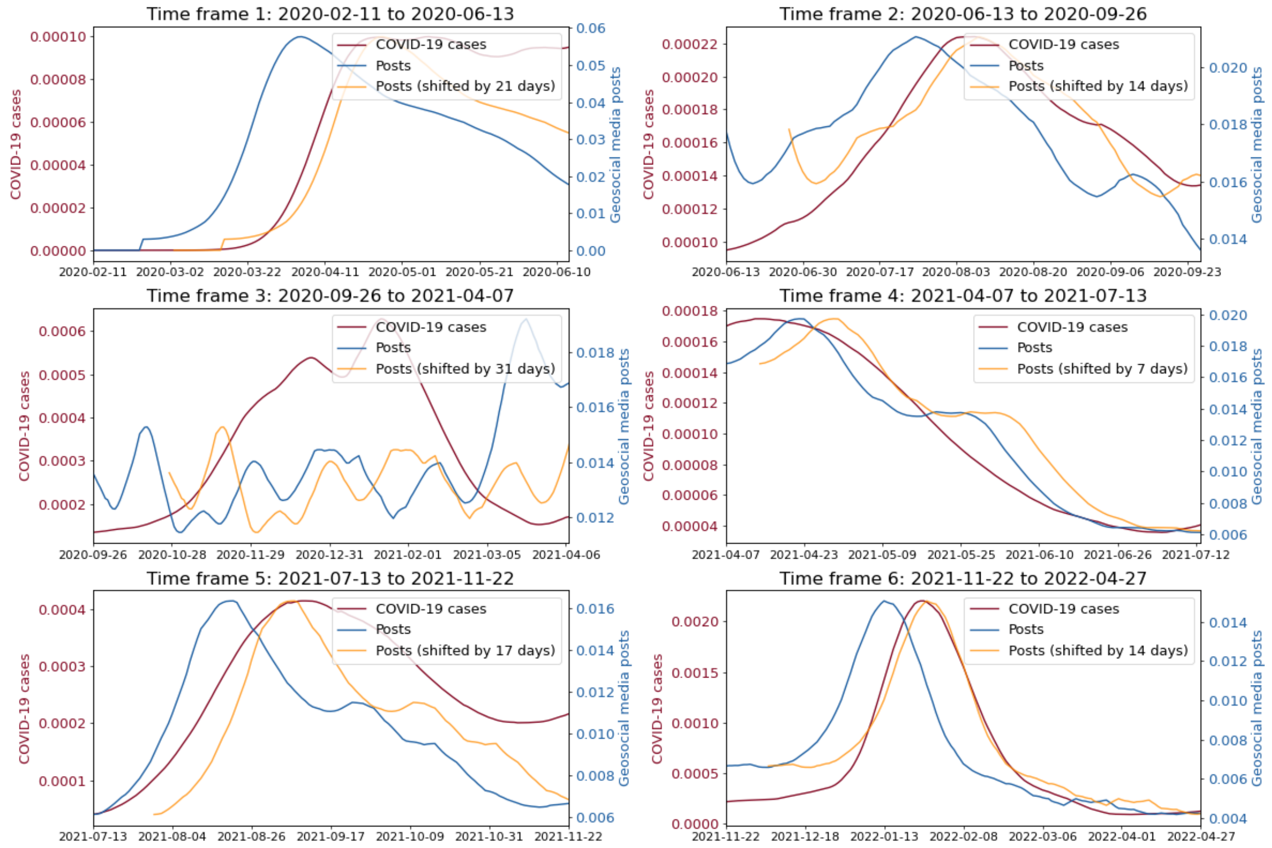


Figure 4. Depicting COVID-19 cases and the geosocial media posts time series and the shifted geosocial media posts time series across individual epidemic waves for democrat counties.



The results for democrat counties in Figure 3 indicate the highest Pearson correlations between posts and COVID-19 cases time series in 5 out of 6 epidemic waves, for a shift of 7 to 21 days (time frames 1, 2 and 4-6). For the same 5-time frames, the Pearson correlations ranged between 0.91 to 0.98. Furthermore, Figures 3 and 4 suggest that only for time frames 1, 2 and 4-6, geosocial media data exhibited actual early warning capabilities. For these time frames, signals in COVID-19 cases were clearly preceded by signals in X data, while for time frame 3 no clear early warning signal in geosocial media data was apparent. Nevertheless, in the beginning of the pandemic (time frames 1 and 2) geosocial media posts showcased a clear increase up to 21 (time frame 1) and 14 days (time frame 2) ahead increases in COVID-19 infections, with Pearson correlations of 0.96 and 0.91. In addition, the COVID-19 wave from mid of July 2021 to the end of November 2021 (time frame 5) was reflected in geosocial media posts up to 17 days earlier than an increase in COVID-19 cases, with a Pearson correlation of 0.93. Also, the Omicron wave (time frame 6) starting in mid of November 2021 [29] was accurately reflected 14 days in advance in the geosocial media time series (Pearson correlation of 0.98). Beyond that, Figure 4 clearly illustrates that the ratio of geosocial media posts related to COVID-19 decreased significantly over the course of the pandemic. Specifically, the percentage of relevant geosocial media posts gradually decreased from 5.7% at its peak in the first time frame, to 1.5% in the last time frame.

Republican Counties

Figure 5 illustrates for the republican counties that in 5 out of 6 time frames the post time series exhibited the highest Pearson correlation with the COVID-19 cases 7 to 38 days ahead of time (time frames 1, 2, and 4-6). Furthermore, for these time frames the Pearson correlations between posts shifted 7 to 38 days into the future and COVID-19 cases were between 0.74 and 0.97. Furthermore, Figure 6 showcases that for republican counties, early warning signals in geosocial media posts could be observed for time frames 1, 2 and 4-6. Similarly to the democrat county cluster, the COVID-19 cases wave in time frame 3 was not captured in advance by the geosocial media time series. The fact that all time frames besides time frame 3, lend themselves for early warning is also consistent with the results for the democrat counties. Furthermore, it appears that in the republican counties, geosocial media data preceded COVID-19 cases time series a few days more in advance. On average over all 5 time frames for which we attest early warning capabilities (time frames 1, 2, and 4-6), the mean temporal lag in democrat counties is 14.6 days (average correlation 0.94) and for 21 days republican counties (average correlation 0.9). Furthermore, it appears that the ratio of relevant posts decreased over time for republican counties from roughly about 5.3% to 0.9%.

Figure 5. Depicting the Pearson correlation between COVID-19 cases and geosocial media post time series for each epidemiological wave when stepwise shifting the geosocial media post time series into the future for republican counties.

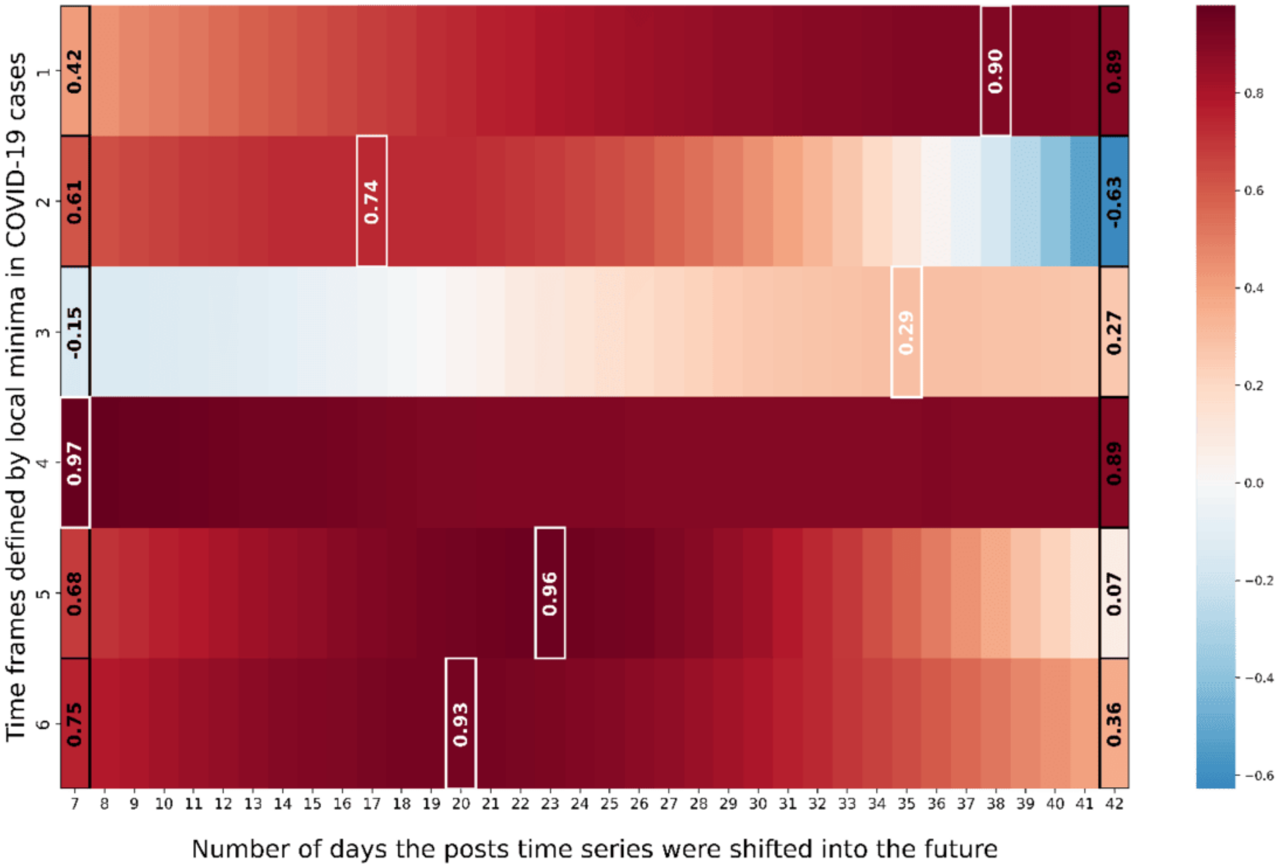
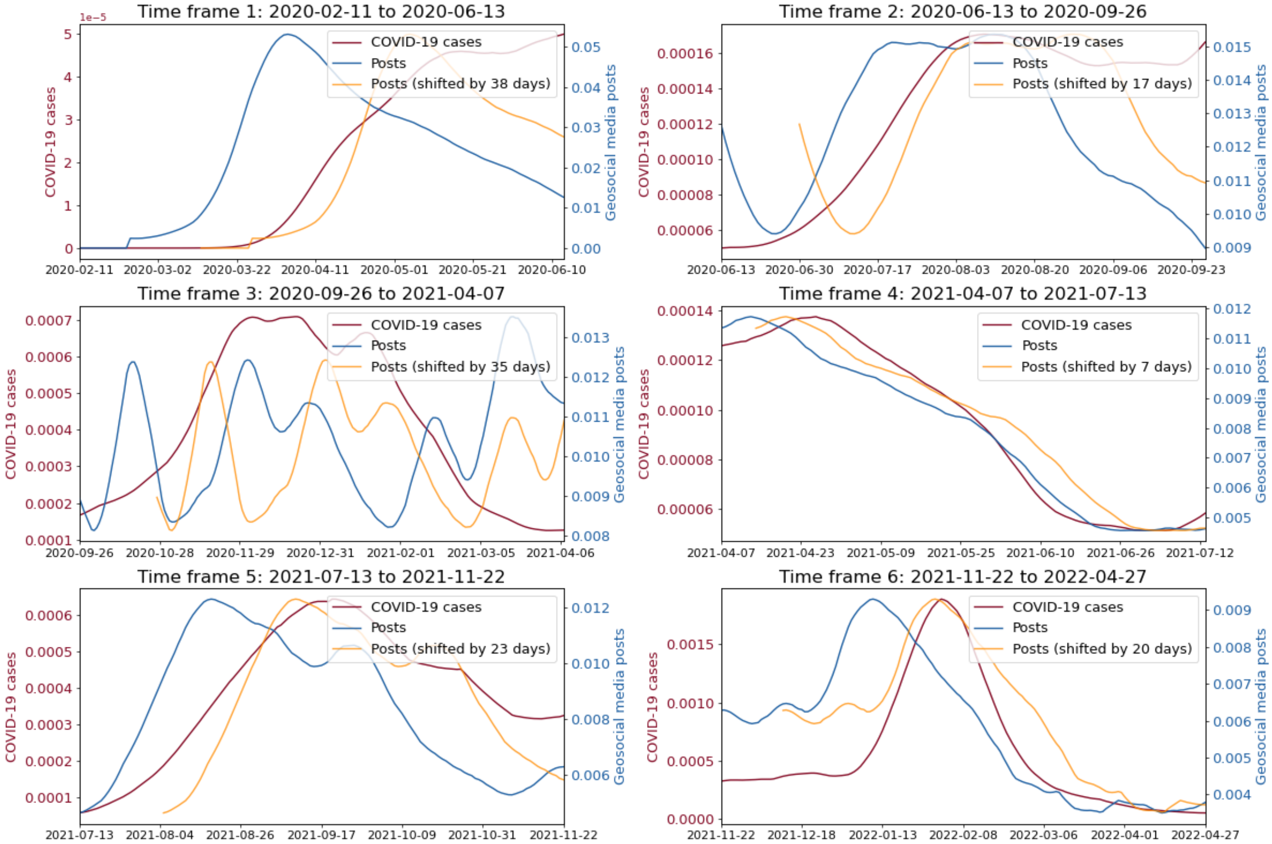


Figure 6. Depicting COVID-19 cases and the geosocial media posts time series and the shifted geosocial media posts time series across individual epidemic waves for republican counties.



Swing Counties

Figure 7 illustrates for swing counties that shifting the posts time series between 7 and 37 days into the future achieved the highest correlation for all time frames. Furthermore, for all time frames the maximal Pearson correlations between geosocial media posts and COVID-19 cases ranged between 0.52 and 0.96. Beyond that, Figure 8 shows that the time frames 1, 2 and 4-6 exhibited clear early warning signals in geosocial media data ahead increases in COVID-19 cases. Similarly to the republican and democrat counties, the COVID-19 wave in time frame 3 was not clearly captured in advance by geosocial media data. However, similar, to republican counties, Figure 8 showcases for swing counties that there actually existed a signal in geosocial media data which is in line with the COVID-19 data in time frame 3. Nevertheless, the actual early warning capabilities are still limited due to noise in the signal which coincides with the COVID-19 infection of former President Donald Trump. Overall, the posts time series preceded COVID-19 cases in swing counties across all time frames, excluding the third, on average by 24.2 days. Also, the intensity with which geosocial media data appears to precede COVID-19 waves clearly decreased for swing counties over the course of the pandemic (from 5.6% to 1.1%).

Figure 7. Depicting the Pearson correlation between COVID-19 cases and geosocial media post time series for each epidemiological wave when stepwise shifting the geosocial media post time series into the future for swing counties.

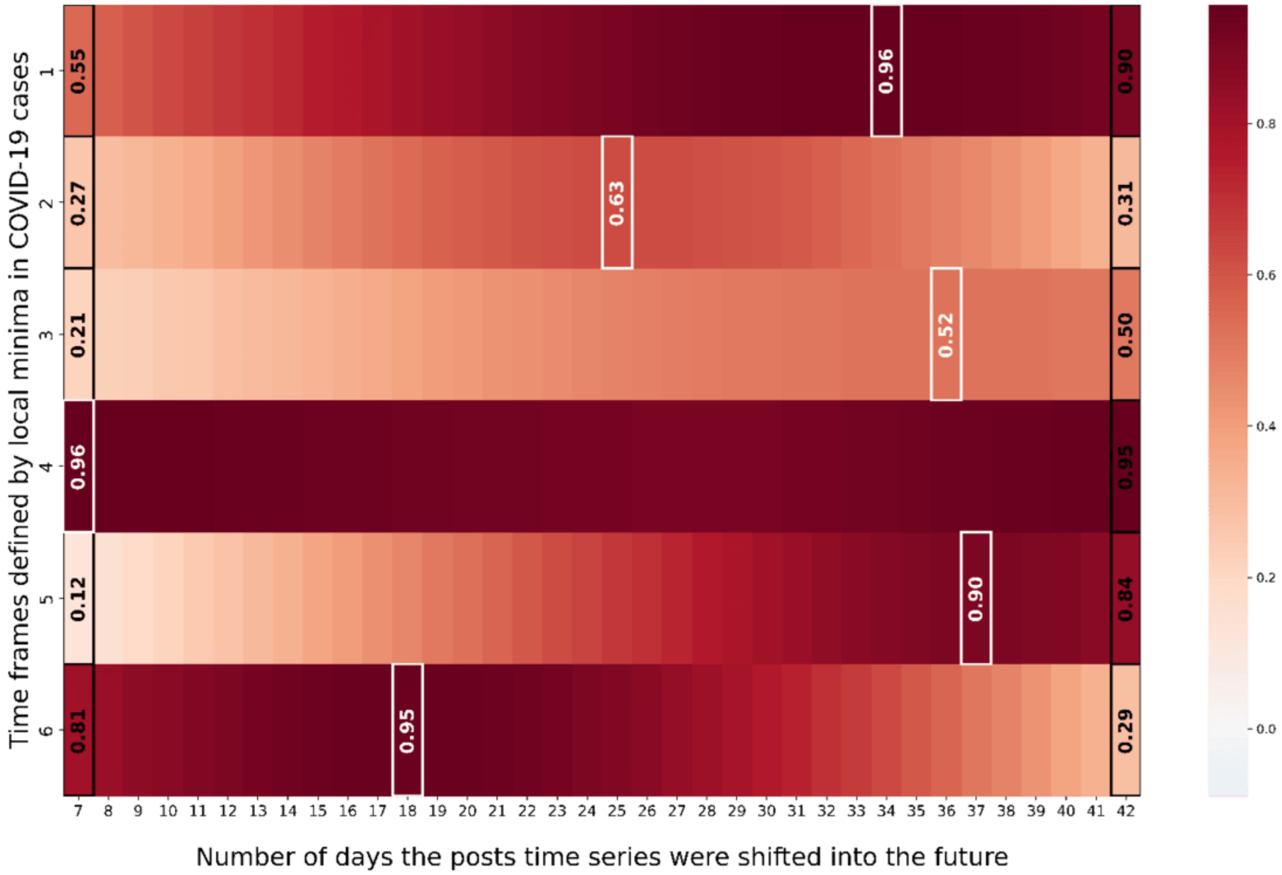
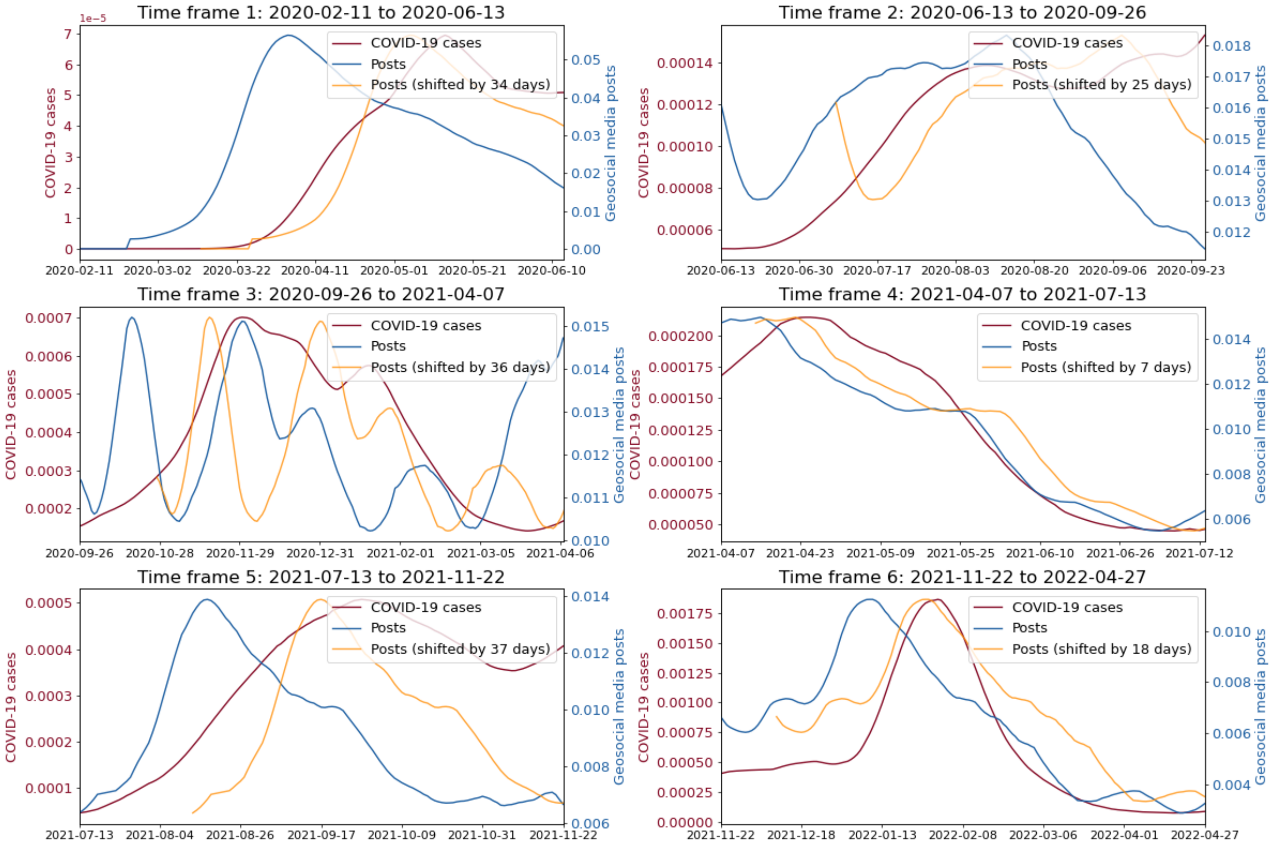


Figure 8. Depicting COVID-19 cases and the geosocial media posts time series and the shifted geosocial media posts time series across individual epidemic waves for swing counties.



Discussion

Principal Findings

The results of this study highlight how a deeper understanding of the relationship between COVID-19–related geosocial media data and confirmed COVID-19 cases, across politically distinct geographies, may help improve epidemiological early warning systems. Specifically, our analysis confirmed and expanded previous findings on the use of geosocial media posts as early indicators of disease activity [8-10,12]. However, we observed strong differences in the early warning capability of geosocial media data across different epidemiological waves. For example, geosocial media data were unable to reliably anticipate the third major COVID-19 wave, September 2020 to April 10, 2021 (time frame 3), across all political clusters. After significantly high COVID-19–related engagement on geosocial media in the first wave, it appears that the geosocial media signal lost some of its sensitivity in the third wave. The only event clearly detectable in COVID-19–related geosocial media posts in the third time frame is the COVID-19 infection of the former President Donald Trump in October 2020. The significance of this event might have reduced the sensitivity of the geosocial media users toward an increase in COVID-19 symptoms and infections. The reaction signal to this event was particularly visible in the republican and swing county clusters, while the democrat counties only registered a minor increase in geosocial media posts coinciding with the COVID-19 infection of President Trump. This further highlights how susceptible geosocial media data can be to politically charged trending topics and how these topics of interest might differ across political clusters. This is also in line with previous findings that the topics geosocial media users engage with and the language they use can differ depending on political beliefs [17-19]. Thus, we hypothesize that it might be key to identify different sets of keywords related to political beliefs and resulting trending topics, to capture geosocial media signals more accurately across political clusters. Therefore, future research should explore the influence of different geosocial media topics on early warning capabilities across political clusters and how such topics might change over time.

Furthermore, the findings of this study illustrate differences in the early warning capabilities of geosocial media posts for COVID-19 cases across counties with diverging political beliefs. This is particularly true for the number of days that geosocial media posts precede COVID-19 cases (temporal lag) and the Pearson correlation between these 2 time series for republican and democrat counties. For instance, geosocial media posts appear to anticipate COVID-19 cases in republican counties (21 days) on average 6.4 days earlier than in democrat counties (14.6 days). This difference in temporal lag might partly be caused by varying population densities between democrat and republican counties. In less densely populated republican counties [36], infection transmission might be slower [37], which could lead to a higher temporal lag between the onset of COVID-19 symptoms being observed and shared on geosocial media, to the eventual peak of infections in that region. However, it remains beyond the scope of this study to substantiate the actual underlying mechanisms which might cause these observed differences in early warning capability between political clusters. Despite that, the results of this study clearly emphasize the need to account for political beliefs in epidemiological early warning systems using geosocial media data. Nevertheless, the precise methodology to integrate political beliefs into real-time geosocial media-based early warning models remains the subject of future research.

The psychological effects of public health measures, such as lockdowns, might offer another explanation for the observed differences in early warning capabilities of geosocial media data across political clusters. These effects may be connected to the fact that public health measures were implemented and suspended at different points in time across political administrative areas. In this regard, Pettersen et al [38] associated more stringent public health and quarantine measures with increased mental distress in adults in Norway. Similarly, Ferwana and Varshney [39] observed a significant increase in visits to mental health facilities during the 2020 lockdown periods in the United States. While Ashokkumar and Pennebaker [14] even reported drops in analytical thinking and shifts in the emotional states of Reddit users coinciding with the start of lockdowns. Hence, it might be the case that the varying timing of public health measures across political regions caused various psychological effects, manifesting in changes of geosocial media behavior. However, our findings do not sufficiently verify this hypothesis. Although numerous studies have explored the psychological effects of public health measures, future research should focus on how these effects might influence the early warning capabilities of geosocial media data across the political spectrum.

In addition, we also found a clear decrease in the number of days with which geosocial media posts preceded COVID-19 cases and in the strength of the geosocial media post signal over time. Interestingly, yet to be explained, the decrease in temporal lag appears to be less pronounced in republican and swing counties. Nonetheless, this overall phenomenon might be caused by some sort of geosocial media and emotional COVID-19 fatigue. The association between self-reported depression symptoms and geosocial media usage [40], alongside potential factors contributing to social media fatigue [41-43] have already been explored in the context of the COVID-19 pandemic. For instance, recent findings by Li et al [43] indicate a direct relationship between social media overload during the COVID-19 pandemic and increased anxiety. Similarly, Sun and Lee [44] observe that COVID-19 information overload on social media directly contributes to fatigue toward pandemic related messages. Nevertheless, it remains beyond the scope of this study to substantiate whether the observed decreasing strength of the geosocial media post signal and temporal lag are robust and attributable to some form of geosocial media or COVID-19 fatigue. However, based on our observations, we advise caution, as the epidemiological early warning capabilities of geosocial media appear to change over time and depending on prevailing political beliefs. In this regard, it remains the task of future research to develop geosocial media-based early warning approaches, which can account for decreasing signal strength over time.

Furthermore, Howard et al [21] observed varying levels of misinformation and thus topics of interest, across states with different political beliefs. Interestingly, they found the highest rates of misinformation occurring in swing states. This is particularly noteworthy, as we found geosocial media data to be highly capable for early epidemiological warning in swing counties. Specifically, the average temporal lag of 24.2 days over all time frames in which we observed the highest early warning capabilities for swing counties, while mostly achieving high correlations (average correlation over all time frames with early warning capabilities 0.88). Thus, concluding from Howard et al [21] and our findings, it appears that it might not be the quality or factual correctness of the shared information on geosocial media that warrants its value for early warning purposes. Nevertheless, future research needs to further validate these findings in the context of different countries and their political ramifications as they might influence the relevance of shared information quality and factual correctness for epidemiological early warning capability.

Data and Methods

We acknowledge that using a simple linear correlation measure might not always reflect the actual similarity between time series accurately. However, in preliminary analysis we also used different nonlinear correlation measures, which yielded only neglectable differences in the actual results. In addition, we also tested more advanced time series matching algorithms such as dynamic time warping [45], the Fréchet distance [46], or mutual information [47]. Nevertheless, neither nonlinear correlation measures nor more advanced comparison algorithms outperformed conventional linear correlation measures for most of our analyses. We evaluated the performance of these different methods in their ability to match the peaks and onsets of geosocial media signals and COVID-19 cases. Nonetheless, we acknowledge that the alignment of peaks and onsets is not always feasible, as the time it takes from the onset to the peak may vary between geosocial media signals and COVID-19 cases. As a result, for some epidemic waves the determined temporal lag might not reflect the actual real-world early warning capabilities of geosocial media data. Despite that, our main objective in this study was not to assess the exact temporal lag and correlations, but rather to provide an algorithmic way to compare the early warning capabilities of geosocial media data across political clusters.

In addition, there is a need to discuss the definition of epidemiological waves based on COVID-19 cases of the entire United States as one might argue that this decision might potentially have caused the observed variations in the number of days and the correlation between the geosocial media and the COVID-19 cases time series. The reason for this is that the COVID-19 waves can have different starting points and intensities across states [48] and as our results show also across political clusters (Figures 4, 6, and 8). Therefore, it might appear reasonable to assume that variation in the starting points and intensities caused the underlying observed differences in temporal lag and correlation between geosocial media posts and COVID-19 cases across political clusters. However, upon testing this hypothesis by defining COVID-19 waves individually for each political cluster, the fundamental results of our study remained unchanged. Although minor discrepancies were present in the temporal lag (primarily ranging from 1-2 days) and the correlations between COVID-19 cases and geosocial media posts, their differences persisted across political clusters and time frames in a similar manner. For example, republican counties still exhibited on average a higher temporal lag than democratic counties and the decrease in geosocial media signals was also still prevalent across political clusters.

In addition, it is important to consider the choice of keywords used for our analysis, as they strongly influence the observed results. One might argue that some keywords relevant to the discourse related to the COVID-19 pandemic were left out. However, in this analysis we mainly focused on gathering less polarized keywords, topics, and hashtags. The reason for this is that certain words, topics and hashtags were predominantly used by 1 political faction [17,18], which might indeed introduce bias into the final comparison between early warning capabilities across political clusters from the start. Concretely, keywords used predominantly in republican counties and less in democrat counties might directly influence differences in early warning capability across political clusters. Therefore, we decided to use a condensed set of keywords, which was to our knowledge mostly not inherently politically charged or biased.

Furthermore, we acknowledge that some keywords which we used in the semantic filtering process of the geosocial media posts, might not be only COVID-19 specific. However, we argue that for most words there exists a baseline signal of how often these words are being used. Therefore, our underlying assumption is that a real-world epidemiological event causes a significant spike in the usage of relevant keywords. Indeed, our results confirmed this assumption. We observed a baseline fluctuation in geosocial media posts and significant spikes in filtered posts, which in most cases preceded COVID-19 cases.

We also tried to improve the semantic filtering by leveraging machine learning approaches such as BERTopic or Latent Dirichlet Allocation [49,50]. However, due to performance issues with our large dataset (600+ GB) and based on the insufficient results for subsample experiments, we decided to stick to traditional keyword filtering. Nevertheless, in future work large language models [51] might be a possibility to improve the process of identifying relevant geosocial media posts.

Limitations

The main limitation of this study stems from its retrospective nature. Our findings, while insightful for the past pandemic, may not be directly transferable to future epidemiological events. This limitation is partly due to the unpredictable nature of political polarization. Specifically, it is inherently difficult to predict whether a topic will become politically charged and, as a result, be discussed differently on social media across geographies with diverging political beliefs. In addition, social media behavior itself is influenced by various dynamic factors, for instance platform algorithms [52] or changing governance structures, which affect public engagement [53], all of which may differ significantly across social media platforms, future epidemiological events, and national borders. Although our study revealed differences in the epidemiological early warning capabilities of geosocial media data across US county-level political clusters, these results should be treated with caution when considering future-use cases.

Conclusion

Our results confirmed the findings of previous research [9,10,12], demonstrating that geosocial media data can improve epidemiological early warning for consecutive waves of COVID-19 cases. In addition, we expand the existing literature by showing that the early warning capabilities of geosocial media data vary across US county clusters with differing political beliefs. For instance, geosocial media posts in republican counties (21 days) tend to precede increases in COVID-19 cases on average about 6.4 days earlier than in democrat counties (14.6 days). We hypothesize that this discrepancy in temporal lag between the geosocial media signal and the COVID-19 cases may stem from differences in the adoption of public health measures or population density variations across regions. In addition, we observed that the early warning capabilities of geosocial media data can be mitigated due to its susceptibility to a shift in trending topics and a decrease in signal strength over time.

Based on our findings, we would recommend that policy makers and researchers enhance and further investigate real-time geosocial media monitoring capabilities to improve epidemiological early warning systems. In addition, our findings suggest that it could be particularly beneficial for such systems to account for political beliefs prevalent across finer spatial scales such as county-level, given their potential to impact the early warning capabilities of geosocial media signals. Furthermore, since our results clearly highlight the value of geosocial media data for epidemiological early warning, we strongly encourage social media companies to grant researchers access to their data. Furthermore, future research should examine the early warning capabilities of different geosocial media topics specific to regional political beliefs and assess the transferability of our findings to other countries with different political environments. Furthermore, investigating the role of political communication strategies and potential improvements to social media algorithms to mitigate political polarization could enhance our understanding of how geosocial media data can be leveraged for future epidemiological events.

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Conflicts of Interest

MS has received institutional research funds from the Johnson and Johnson foundation, from Janssen global public health, and Pfizer. All other authors declare no conflicts of interest.

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Abbreviations

API: application programming interface
WHO: World Health Organization

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Original Paper

Mental Health and Coping Strategies of Health Communicators Who Faced Online Abuse During the COVID-19 Pandemic: Mixed Methods Study

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Abstract

Background: During the COVID-19 pandemic, health experts used social media platforms to share information and advocate for policies. Many of them faced online abuse, which some reported took a toll on their mental health and well-being. Variation in the impacts of online abuse on mental health, well-being, and professional efficacy suggest that health communicators may differ in their coping strategies and ultimately their resilience to such abuse.

Objective: We aimed to explore the impacts of online abuse on health communicators' mental health and well-being as well as their emotion- and problem-focused coping strategies.

Methods: We recruited health communicators (public health officials, medical practitioners, and university-based researchers) in Canada who engaged in professional online communication during the COVID-19 pandemic. In phase 1, semistructured interviews were conducted with 35 health communicators. In phase 2, online questionnaires were completed by 34 individuals before participating in workshops. Purposive recruitment resulted in significant inclusion of those who self-identified as racialized or women. Interview and workshop data were subjected to inductive and deductive coding techniques to generate themes. Descriptive statistics were calculated for selected questionnaire questions.

Results: In total, 94% (33/35) of interviewees and 82% (28/34) of questionnaire respondents reported experiencing online abuse during the study period (2020-2022). Most health communicators mentioned facing an emotional and psychological toll, including symptoms of depression and anxiety. Racialized and women health communicators faced abuse that emphasized their ethnicity, gender identity, and physical appearance. Health communicators' most common emotion-focused coping strategies were withdrawing from social media platforms, avoiding social media platforms altogether, and accepting online abuse as unavoidable. Common problem-focused coping strategies included blocking or unfriending hostile accounts, changing online behavior, formal help-seeking, and seeking peer support. Due to the impacts of online abuse on participants' mental health and well-being, 41% (14/34) of the questionnaire respondents seriously contemplated quitting health communication, while 53% (18/34) reduced or suspended their online presence. Our findings suggest that health communicators who used problem-focused coping strategies were more likely to remain active online, demonstrating significant professional resilience.

Conclusions: Although health communicators in our study implemented various emotion- and problem-focused coping strategies, they still faced challenges in dealing with the impacts of online abuse. Our findings reveal the limitations of individual coping strategies, suggesting the need for effective formal organizational policies to support those who receive online abuse and to sanction those who perpetrate it. Organizational policies could improve long-term outcomes for health communicators' mental health and well-being by mitigating online abuse and supporting its targets. Such policies would bolster professional resilience, ensuring that important health information can still reach the public and is not silenced by online abuse. More research is needed to determine whether gender, race, or other factors shape coping strategies and their effectiveness.

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KEYWORDS

mental health; online harassment; online abuse; coping strategies; resilience; social media; online advocacy; public health communication; health communication

Introduction

Background

From the start of the COVID-19 pandemic, public health officials, medical practitioners, university-based researchers, health journalists, and other health experts played a crucial role in shaping public opinions and behaviors. To inform publics and counter poor-quality information, many health experts increased their use of social media platforms: frontline health care workers creating TikTok videos [1], medical professionals countering misinformation on Twitter [2], and physicians and researchers posting on Facebook, Instagram, and Twitter [3,4]. These health communicators could be considered an emergent community of practice, meaning they encountered many similar opportunities and challenges of engaging audiences through social media platforms.

Many health communicators were exposed to online harassment and abuse, ranging from trivial criticisms to sexual harassment and violent threats [5,6]. This abuse was faced by those communicating as individuals or on behalf of institutions. Health communicators were typically unprepared for the abuse that often follows online advocacy [7], which was exacerbated by a lack of existing institutional protections and supports [7,8].

Exposure to Online Abuse

In a survey conducted from February 2019 to March 2019, 23% of 464 physicians in the United States reported being personally attacked on social media, primarily for advocacy on topics such as vaccines, gun control, and abortion [9]. Research suggests that the online harassment experienced by health communicators worsened during the COVID-19 pandemic [10,11]. In a 2022 survey of 359 physicians, biomedical scientists, and trainees in the United States, 228 (64%) reported harassment on social media related to comments they had made about the COVID-19 pandemic [12]. Similarly, more than two-thirds of 321 scientists responding to a *Nature* survey in 2021, predominantly located in the United States, the United Kingdom, and Germany, reported negative experiences because of their media interviews or social media comments regarding COVID-19 [10]. In total, 22% of these respondents had received threats of physical or sexual violence, and 15% had received death threats [10]. Threats of violence illustrate that online abuse is not merely confined to the internet [13]. Escalating violence against health care workers in Canada during the COVID-19 pandemic prompted the Canadian Medical Association to call for legislation in 2021 that would protect health care workers from aggressive patients and protesters, both online *and* in-person [14].

Forms of online abuse may differ with individuals' gender identity, race or ethnicity, professional role, and other factors. For instance, women health communicators and journalists have faced more gendered or sexualized abuse than men [6,9,15].

Impacts of Online Abuse

Research suggests that online abuse can have serious negative consequences for health communicators' mental health and well-being: individuals who have experienced online harassment consistently report emotional distress and fear [2,9]. In a prepandemic survey, 62.4% (63/101) of prominent medical science communicators reported some negative mental health impacts, including depression, anxiety, and stress because of public engagement [6]. While most mental health impacts they reported were minor, 15% of them reported considerable or significant mental health ramifications [6]. Mental health consequences of online abuse can be disproportionately experienced due to gender, race or ethnicity, and other sociodemographic factors [15]. Throughout the COVID-19 pandemic, many health communicators have spoken out about the toll that negative comments and personal attacks have taken on their mental health [5,11]. In the *Nature* survey, more than 40% of 321 scientists reported experiencing emotional or psychological distress after commenting about the COVID-19 pandemic in traditional media interviews or on social media [10].

Some health communicators have expressed a desire to reduce or stop their online advocacy [6,10,12]. Thus, online abuse and its mental health consequences may undermine individuals' professional capacity, reducing the amount of engagement within the communication sector. If certain voices (eg, women and racialized individuals) are pushed out [16], then the diversity of perspectives within this sector will be in jeopardy.

Coping and Other Responses to Online Abuse

Variation in the impacts of online abuse on mental health, well-being, and professional efficacy suggests that health communicators differed in their coping strategies and ultimately their resilience to such abuse. A person who has experienced harassment will tend to adopt one or more strategies to "cope with it" [16]. Lazarus and Folkman [17] developed a seminal model to understand coping as either emotion- or problem-focused. Emotion-focused coping strategies help regulate emotional responses to a stressful situation, whereas problem-focused coping strategies aim to manage or alter the situation itself [17]. The effectiveness of emotion- and problem-focused coping strategies has been debated, but those who rely predominantly on emotion-focused coping strategies report significant negative emotions and poor mental health outcomes, such as depression [18].

Research on the coping strategies used by individuals who receive online abuse has primarily been conducted with journalists, scholars, and students [16,18-20], rather than health communicators. Many studies have further stratified emotion- and problem-focused coping strategies. For example, Scarduzio et al [21] put forth 11 "types" of emotion-focused strategies (eg, ignoring negative comments) and 5 "types" of problem-focused strategies (eg, blocking hostile users) used by university students in response to online sexual harassment. In this study, we leveraged the model developed by Lazarus and Folkman as well as the examples of digital coping strategies given by Scarduzio et al to examine how health communicators responded to online abuse.

Objectives

Despite the broad adoption of social media by health care providers, scientists, and public health officials and the increasing recognition of online abuse they have received, no study has focused on the mental health consequences of *online* harassment for health communicators during the COVID-19 pandemic. Thus, our study aimed to explore (1) the impacts of online abuse on health communicators' mental health and well-being during the COVID-19 pandemic and (2) the emotion- and problem-focused coping strategies health communicators used to manage online abuse.

Methods

Study Design

This study is part of a larger participatory action research project on an emergent community of practice of health communicators. Relationships with health communicators were developed through direct outreach and through a partnership with ScienceUpFirst, a Canadian initiative that works with science and health experts to address misinformation. We used mixed methods, including semistructured interviews, an online questionnaire, and 2 workshops to examine the impacts of online abuse on Canadian health communicators during the COVID-19 pandemic.

Participant Recruitment

Health communicators for the larger participatory action research project were purposively recruited in 2 phases, emphasizing significant inclusion of those who self-identified as women or racialized. We use the term "racialized" rather than "visible minority groups" or the terms "Black," "Indigenous," and "people of color," following recommendations to use the former term by the Canadian government [22] and academics [23], arguing that race "does not exist as a biological concept to distinguish between human beings, but that social processes of racialization are inherently linked to major forms of historical, social, economic, and cultural oppression, including slavery and colonialism" [23].

During the first phase, research team members monitored traditional and social media platforms to identify people in Canada who were actively discussing public health measures online during the COVID-19 pandemic. Team members contacted a subset of these individuals by email, seeking participation from health communicators of diverse gender identities, ethnicities, and professional roles (eg, public health officials, health care professionals, university-based or civil society health experts, and health journalists). Health communicators who replied (N=35) were invited to participate in a virtual one-on-one semistructured interview, after informed consent was obtained.

During the second phase, team members recruited health communicators to participate in 2 workshops. Participants were recruited through #ScienceUpFirst affiliate groups and the authors' professional networks, seeking similar forms of diversity to the first phase. Journalists were intentionally excluded from the second phase because exploratory conversations with journalists and other health communicators suggested that combining these groups might put participants in awkward professional predicaments and because there has already been extensive research on online abuse of journalists [15,19,24]. In this phase, health communicators (N=34) first completed an online questionnaire to collect data on sociodemographic characteristics, communication activities, and experiences of harassment. Then, they participated in 1 of 2 virtual small-group 2-hour workshops. Observations from these workshops were taken from the research team members' notes because no audio-recordings or transcripts of the discussions were made.

Data Collection and Analysis

Quantitative Data

Given that there are no validated scales for online abuse of individuals in their professional capacities, we developed a questionnaire by drawing on existing questionnaires [13], including one previously created by the research team members [25] and another created by Ipsos to survey journalists' experiences of online harm [24]. Alongside the frequency, causes, and sources of online abuse, our questionnaire assessed how participants responded to online harm and how they changed their personal and professional work as health communicators due to online abuse. Simple descriptive statistics were calculated for specific questions using Microsoft Excel. All data were anonymized to protect participant confidentiality and were stored in a secure electronic database.

Qualitative Data

One-on-one interviews (N=35) were conducted by a research team member and recorded over Zoom (Zoom Communications, Inc) between December 2021 and June 2023. Each interview lasted between 40 and 90 minutes. A semistructured interview guide was used to conduct the interviews, which allowed researchers to compare participants' responses to set questions within the guide and explore other insights based on responses. Questions addressed issues, including the form and frequency of online abuse, professional and mental health impacts, and the online and offline actions that individuals took to respond to abuse. Zoom audio-recordings were transcribed verbatim.

For the first round of coding, our principal researcher created an initial list of deductive codes from literature on online harassment of politicians and journalists [16,25]. Three team members then coded approximately 15% (5/35) of the interview transcripts using this list, meeting regularly to discuss whether deductive codes and their definitions should be modified and whether new inductive codes should be added to the list. A revised codebook was created, and the remaining interview transcripts were independently coded using ATLAS.ti (Lumivero) software. Team members continued to discuss coding during this process to ensure their shared fidelity to the revised codebook.

A second round of coding was undertaken to examine interview data about health communicators' mental health and well-being in more detail. One team member coded all interview excerpts that had been tagged with the "Impact: Mental health" code during the first round of coding. Inductive coding techniques were used to generate themes around mental health and resilience. Deductive coding techniques were used to identify emotion- and problem-focused coping strategies from the model developed by Lazarus and Folkman [17] and the study by Scarduzio et al [21]. Patterns across the excerpts were noted, and our team met 4 times to collectively categorize and interpret themes.

Ethical Considerations

This study was reviewed and approved by the University of British Columbia Behavioural Research Ethics Board (H21-01503 and #H22-01816). For one-on-one interviews, all participants received a consent statement outlining the study, potential risks and benefits, and measures to protect their personal information. The interviewer reviewed these details at the start of the interview and obtained verbal consent before proceeding. For individuals who completed surveys and participated in workshops, all participants signed a consent form that described the study, potential risks and benefits, and measures to protect their personal information.

Discussing online abuse can be difficult. Both the consent statement and consent form emphasized that participation was entirely voluntary, that individuals could stop participating in the interview or focus group at any time, and that they could withdraw from the study at any point. During interviews, if a participant expressed or displayed discomfort, the interviewer offered to pause, end the interview, or move to another question. For workshops, all participants received a community guidelines document in advance to ensure that group discussions were conducted safely and inclusively.

Data from this project are stored on password-protected hard drives and University of British Columbia–managed cloud storage, accessible only to core research team members registered as part of our research ethics board certification.

Results

Participant Characteristics

Table 1 outlines the sociodemographic characteristics of the interviewees (N=35) and questionnaire respondents (N=34). Most participants were living and working in either British Columbia or Ontario, Canada's 2 most populous English-speaking provinces. More women participated in both phases of this study than men, but both phases had an equal number of self-identified racialized and White participants.

Table 1. Sociodemographic characteristics of the participants from individual interviews and questionnaires.

Characteristics	Phase 1: Interviews (N=35), n (%)	Phase 2: Questionnaires (N=34), n (%)
Self-identified gender		
Woman	20 (57)	21 (62)
Man	15 (43)	13 (38)
Nonbinary	0 (0)	0 (0)
Prefer not to answer	0 (0)	0 (0)
Self-identified ethnicity		
Racialized	17 (49)	17 (50)
White	18 (51)	16 (47)
Prefer not to answer	0 (0)	1 (3)
Province of residence		
Alberta	5 (14)	1 (3)
British Columbia	15 (43)	11 (32)
Ontario	11 (31)	20 (59)
Quebec	3 (9)	1 (3)
Yukon	1 (3)	0 (0)
Other	0 (0)	1 (3)
Primary professional role[a]		
Public health official[b]	8 (23)	9 (26)
Medical professional	10 (29)	9 (26)
Health journalist	9 (26)	0 (0)
University-based or civil society expert	8 (23)	6 (18)
Other[c]	0 (0)	10 (29)

[a]While several participants belong to more than one category (eg, medical professional *and* university-based expert), we categorized participants based on their *primary* professional role.

[b]Employed by a public health agency, provincial government, or federal government.

[c]Employed by a nonprofit organization, research institute, community health center, science center, or self-employed.

Impacts of Online Harassment on Health Communicators' Mental Health and Well-Being

In the first phase, 94% (33/35) of the interviewees reported facing some form of online abuse since the pandemic began. Of the 2 interviewees who had not faced online abuse, one managed a health agency's general accounts and the other primarily relied on staff to manage her accounts. In the second phase, we asked the participants more detailed questions about the frequency of online harassment they experienced in the last 6 months. In total, 82% (28/34) of the questionnaire respondents received online threats, harassment, or false claims on multiple occasions in the last 6 months.

About 38% (13/34) of the questionnaire respondents claimed that their nationality or ethnic background was the reason they were targeted with online harassment. Racialized interviewees described how the online abuse they encountered differed from their White colleagues. For instance, a racialized woman stated:

> *There are random people out there that don't like you just because of who you are. Not necessarily because of what you say... I have female colleagues who are White... who say the same thing and don't get the reaction that I get.* [Civil society expert]

These sentiments were repeated by multiple racialized workshop participants.

In total, 18% (6/34) of the questionnaire respondents asserted that their gender identity or appearance was the reason they were targeted. Several women described how the abuse they received tended to emphasize their identity, including references to sexualized acts and derogatory remarks about their professional capabilities based on their gender. One woman explained how she inadvertently put her "whole self" online for scrutiny and, consequently, received many messages laced with "fatphobia and body shaming" (White woman, health journalist). She further explained, "It feels pretty vulnerable to be attacked that way as a young woman... I think it's really been probably the most intense misogyny I've ever faced in my life."

When interviewees recounted the online harassment they experienced, they often described negative emotions (Figure 1). Similarly, 41% (14/34) of the questionnaire respondents experienced strong negative feelings in response to online harassment (Table 2).

Most health communicators mentioned multiple negative emotions around online abuse. Interviewees commonly mentioned feeling simultaneously frustrated and exhausted when they received a “constant barrage” of online harassment (White woman, public health official). Health communicators were “being fed this stream of negativity and abuse through...your phone all day” (White man, health journalist), and some felt that “even the best possible...person can’t deal with an assault of hostility 24-7” (White woman, public health official).

An interviewee reflected on how online harassers were misrepresenting his opinion on certain health topics:

> *That really does sting, and you find it frustrating and you waste...cognitive energy worrying about it.* [White man, university-based expert]

Several health communicators explicitly mentioned the “psychological toll” and “psychological exhaustion” of receiving and reading countless negative, hostile, and threatening e-mails (White man, university-based expert).

Interviewees also frequently expressed feeling sad and scared in the same instance:

> *When I get a hateful message, a...message that threatens violence against me, it makes me feel sad. ...it does scare me. It instills fear in me, and...it makes me feel really sad to know that this person...has taken time out of their day to...send me that message with the hope of hurting me somehow.* [Racialized woman, civil society expert]

While some of the interviewees described symptoms of depression, such as “not wanting to get out of bed...[in the] morning” (Racialized woman, civil society expert), others described symptoms of anxiety, such as difficulty “trying to unplug” (White woman, health journalist). Another interviewee, who received an email with “a message from someone...saying they hope that I get blood clots and like, basically die,” explained how these types of messages are anxiety-inducing: “sometimes it keeps you up at night, makes you very worried and concerned” (White woman, health journalist).

Racialized and women health communicators across interviews and workshops discussed how negative comments about their ethnicity, ancestry, and physical appearance impacted their mental health and well-being:

> *When it actually ends up being personal attacks on you as a person, on how you look, on the colour of your skin, where you’re originally from...It takes a toll on you.* [Racialized woman, civil society expert]

Interestingly, only 18% (6/34) of the questionnaire respondents claimed to be “struggling with mental health issues” (Table 2), whereas the interviewees repeatedly mentioned how their mental health and well-being had been impacted by health communication and subsequent harassment during the pandemic. This variation in the severity of mental health impacts reported suggests that certain participants implemented strategies to mitigate some of the mental health consequences of online abuse.

Figure 1. Examples of negative emotions expressed by interviewees because of online abuse.

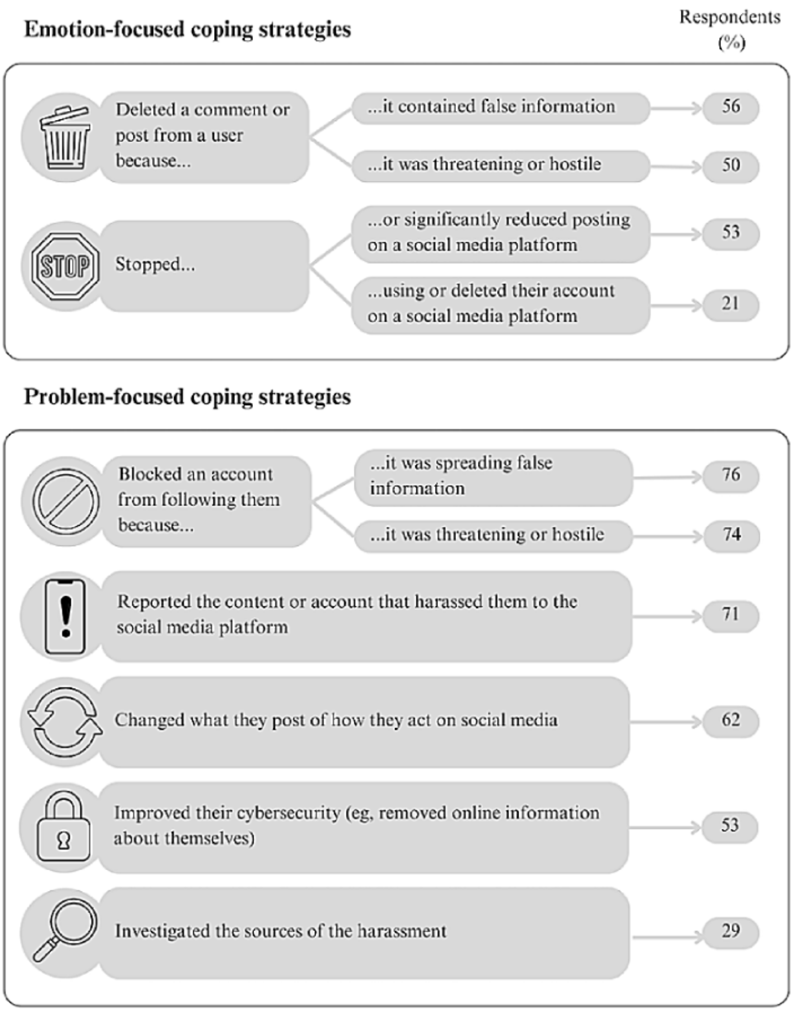
Table 2. Impacts of online harassment on questionnaire respondents.

	Questionnaire respondents (N=34), n (%)
Personal impacts	
Experienced strong negative feelings (eg, fear, horror, anger, guilt, or shame)	14 (41)
Felt scared for the safety of their family and friends	8 (24)
Felt scared for their physical safety	7 (21)
Struggled with mental health issues	6 (18)
Felt jumpy or easily startled	6 (18)
Experienced strong negative beliefs about themselves or other people	6 (18)
Repeated, disturbing dreams of the stressful experience	3 (9)
Professional impacts	
Avoided publicly addressing certain topics	21 (62)
Seriously considered quitting health communication	14 (41)
Requested a change in their professional role	5 (15)
Took a greater number of sick days than usual	2 (6)

Coping Strategies Implemented by Health Communicators

When health communicators experienced online harassment, they used a variety of coping strategies (Figure 2).

Figure 2. Responses to online harassment implemented by questionnaire respondents (N=34).



Emotion-Focused Coping Strategies

Health communicators' most common emotion-focused coping strategies were (1) withdrawing from social media planforms, (2) avoiding social media platforms altogether, and (3) accepting online harassment and abuse as unavoidable.

First, many participants withdrew from online public health communication because of harassment. In total, 53% (18/34) of questionnaire respondents noted that they significantly reduced or stopped posting on a social media platform (Figure 2). Interviewees mentioned that they "used to...be very active on Twitter," (White woman, health journalist) but they "made a conscious choice to distance myself from Twitter as a professional" due to persistent online harassment (White man, health journalist).

Second, 21% (7/34) of questionnaire respondents claimed that they have stopped using or deleted their account on a social media platform (Figure 2). Several health communicators explicitly stated that they avoided social media platforms to safeguard their mental health and well-being. "I felt for my mental well-being, I am avoiding this because it is like a triggering response to see all those notifications coming in again and again and again" (White woman, health journalist). One interviewee said he had "to turn if off" for his "own peace of mind...because there's been an overwhelming amount of negativity," (White man, public health official), and another firmly stated she was "not on Twitter for...[her] mental health" (White woman, public health official).

Several interviewees justified these emotion-focused coping strategies by explaining how sharing public health information was not part of their job descriptions, so they were "not paid to be on Twitter" (Racialized man, medical professional). A racialized civil society expert noted, "It's not as though this is my job...I'm not getting paid for any of this work...[and] on top of that, I get vitriol."

Third, several interviewees seemed to accept the possibility of receiving online harassment. One health communicator conceded that "because of the way that things are now, whatever you share, anything you post...you do open yourself up to some degree of abuse" (White man, health journalist). Another felt disheartened that she was "going to have to be dealing with [online harassment]...for a long time," particularly if she wanted to continue publishing in major outlets and working on "more polarizing" topics (White woman, health journalist).

Health communicators may have relied on emotion-focused coping strategies because they were unaware of problem-focused coping strategies or unable to implement them. One woman asserted that she did not "know how to get back on Twitter without...facing all this same garbage again" (Health journalist). Another admitted that she felt "ill-equipped to...be on the site anymore" (White woman, health journalist).

Problem-Focused Coping Strategies

Scarduzio et al [21] proposed 5 specific "types" of problem-focused coping strategies, including blocking or unfriending, changing online behavior, formal help-seeking, peer intervention, and confronting. Health communicators in our study implemented all 5 of these digital coping strategies to mitigate further online harassment and abuse.

In total, 74% (25/34) of the questionnaire respondents blocked a threatening or hostile account from following them, and 53% (18/34) of respondents improved their cybersecurity (Figure 2). Several interviewees explained the exact steps they took to improve their cybersecurity, such as "taking my face off of my Twitter profile" (White man, health journalist). One interviewee explained how making her "account private" helped her create "a bit of a safer space" online (Racialized woman, civil society expert).

In total, 62% (21/34) of the questionnaire respondents (Figure 2) and many interviewees changed what they posted and how they behaved online. One participant started making an extremely conscious effort to refrain from posting personal information online:

> *It has just made me more cognizant of what I share in general about my life...I never tweet about where I am. I never tweet about the neighbourhood I live in...I didn't want malicious people [to] have that information about me.* [White woman, health journalist]

Other health communicators refrained from sharing public health information because they were "worried about it becoming somehow a lightning rod for hate or harassment or just unwanted negative attention" (White woman, health journalist). For example, some interviewees explained how they no longer shared opinions on "controversial and important topics" (White woman, health journalist), and they "don't advocate outwardly for...[COVID-19] restrictions" (Racialized man, medical professional). Similarly, 62% (21/34) of the questionnaire respondents avoided publicly addressing certain topics (Table 2). As more health communicators resorted to self-censorship, crucial health information became less available to publics.

Other participants described setting boundaries on how they used social media platforms, not as a form of self-censorship but to balance personal well-being with professional efficacy. For instance, when online abuse made his social media engagements particularly stressful, a health official took time away from the platform to develop new strategies for how he would use it:

> *I just reactivated [my account] after a few weeks...Coming back with a few rules in mind, I felt much better.* [Racialized man, public health official]

Some health communicators sought assistance to manage online abuse by reporting the harassment directly via social networking sites' reporting mechanisms. In our study, 71% (24/34) of questionnaire respondents engaged in "formal help-seeking" by reporting the content or account that harassed them to the social media platform (Figure 2). Several interviewees stated that this action did not have a reliable effect, since in some situations the posts or accounts remained on platforms long after the health communicator had reported them. Our interviewees did not discuss how inconsistent action by social media platforms shaped their assessment of the efficacy of this problem-focused coping strategy.

In total, 41% (14/34) of the questionnaire respondents reported acts of online harassment to a supervisor or employer, and 18% (6/34) of respondents sought help from a supervisor or employer (Table 3). Two health journalists found support and directives from their employers to be effective. One journalist explained how the independent news website she writes for “has been really supportive and proactive” by clarifying “the conditions that my work is expected to continue under” (White woman, health journalist). The other journalist described how the mental health supports that her employers have provided were beneficial:

> *Both organizations that I’ve worked for have really been putting an emphasis on...getting mental health support. I think some big changes that were made structurally to benefits that were being offered in terms of how much mental health support was being covered made a really big difference.* [Racialized woman, health journalist]

These findings suggest that health journalists received more support from their employers than health communicators in other professions.

Other health communicators relied on colleagues and family members to help manage online abuse and stop harassers (ie, “peer intervention”). In response to online harassment, more than half of the questionnaire respondents (18/34, 53%) asked a colleague for help, and 47% (16/34) of respondents asked a friend or a family member for help (Table 3). For instance, members of a public health agency team regularly checked in with each other to provide emotional support, often in the form of humor, and to review potentially abusive messages.

If someone else, such as an employee, colleague, or significant other, could oversee their social media accounts, then health communicators would not have to read negative comments and messages themselves:

> *I was...telling with my campaign team that I actually want to hand...over the keys [to my social media accounts]...because I actually don’t want to see it anymore.* [Racialized man, university-based expert]

One public health official described how her “partner joined Twitter partly because he took on the job [of] monitoring my account,” but she acknowledged “there’s a toll... when you read angry tweets about your partner every day” (White woman, public health official).

Confronting online harassers was not a popular problem-focused coping strategy used by health communicators. Only one interviewee explained that she wanted to engage with perpetrators of online harassment “because criticism and conflict eats at” her, and it was “empowering” to try to connect with those who were unnecessarily hostile (White woman, university-based expert). She noted that, “I’ve engaged twice, by phone and it actually worked.”

Table 3. Sources of reporting and support for questionnaire respondents who experienced online harassment.

	Questionnaire respondents (N=34), n (%)
To whom did you report the acts of online harassment?	
Social media platforms	22 (65)
Supervisor or employer	14 (41)
Professional association or governing body	6 (18)
Police	4 (12)
Government or political representative	1 (3)
Unions	1 (3)
I did not report any acts of harassment	5 (15)
From whom did you seek support?	
Asked a colleague for help	18 (53)
Asked a friend or family member for help	16 (47)
Spoken publicly about the experience of being harassed, having your reputation attacked, or the sources of harassment	13 (38)
Looked for online resources to protect yourself or cope with harassment	9 (26)
Asked my supervisor, employer, or organization for help	6 (18)
Sought help from a professional organization or other civil society group	5 (15)
Sought legal advice	5 (15)
Sought medical or psychological help	4 (12)
I did not look for support	3 (9)

Continuation of Online Health Communication

Health communicators' experiences of online abuse prompted them to reflect on their long-term use of social media to engage publics. We identified 2 broad groups: those who felt the negative impacts of online harassment on their mental health and well-being outweighed the potential benefits of public health advocacy and those who expressed a desire to continue sharing relevant public health information despite online harassment. Health communicators discussed the internal conflict between reducing their engagement to protect their mental health and continuing their advocacy. One interviewee, after being targeted on Twitter for discussing abuse she and other journalists faced, stopped engaging with those issues online:

> *That was honestly really frustrating because I felt that at a time that I really needed to be vocal about these things, I couldn't without compromising my safety and my mental well-being. It kind of felt like there was no good option: either stay silent about what had been done or speak out and perhaps welcome more harm.* [White woman, health journalist]

Those in the first group generally reduced their online engagement to prioritize their mental health and well-being:

> *My mental health and well-being are more important than the hope that maybe...these people will learn...because they're not going to learn.* [Racialized man, medical professional]

Similarly, a participant who used online platforms to remain engaged with health issues reported that he began to believe those benefits are being outweighed by "the risks to my mental health and well-being...and the threats to my productivity" (Racialized man, university-based expert).

In total, 41% (14/34) of questionnaire respondents seriously considered quitting health communication (Table 2). An interviewee explained how burnout prompted him to take a step back from his profession during the pandemic:

> *I was just kind of tired, I guess...I certainly felt burnt out from reporting on the pandemic...There are still COVID stories that are important to tell and there's important journalism to be done, but I felt as if I didn't want it to be done by me anymore.* [White man, health journalist]

Conversely, interviewees in the second group explained why and how they would continue to engage in online health communication despite the challenges:

> *I do feel upset for a little bit (after experiencing online abuse), but it has never gotten to a point where I would think to myself, "I'm not going to do this ever again." I know of people who have given up, who've taken time off or just completely stopped engaging, but...at least for now, I haven't reached that point.* [Racialized woman, civil society expert]

Several participants emphasized that they continued to advocate online because they believed in the public benefit of sharing health information:

> *I'm just trying to tell (people) the facts. And to be targeted for being the messenger of those facts is not very fun. There have been times because of the backlash that I've thought, well, maybe I won't tweet as much. And I definitely had that thought a few times during the course of the pandemic. I really had to weigh...(is) me getting a few messages that are annoying more important than me trying to get information out to people? And for me, getting information out is always more important.* [Racialized woman, health journalist]

Although most health communicators implemented a variety of problem-focused and emotion-focused coping strategies (Figure 2), only some demonstrated a strong willingness to continue their online engagement, whereas others contemplated quitting public health communication. In the face of persistent online abuse, *continuing* to post online could be understood as an act of "professional resilience." Health communicators who faced challenges overcoming the mental health and well-being impacts of online abuse were more likely to reduce or abandon their online advocacy efforts.

Discussion

Impacts of Online Abuse

Throughout the COVID-19 pandemic, many health care providers, researchers, public health officials, and health journalists put extraordinary effort into engaging publics online, which often exposed them to unwanted harassment and abuse [10]. Although online harassment is often dismissed because it occurs in virtual environments, the consequences of such harassment can be very real, including psychological stress and burnout [13]. Among our questionnaire respondents, 82% (28/34) faced online harassment or abuse. Therefore, most participants reported negative emotions, including feeling fatigued, sad, distressed, and angry. Some participants shared symptoms of anxiety and depression, and some explicitly reported that they had been struggling with mental health issues. This emotional distress caused by online harassment has exacerbated the widespread burnout experienced by medical professionals during the COVID-19 pandemic [26].

Coping Strategies for Online Abuse

Participants in this study mentioned a variety of strategies to cope with the mental health impacts of online harassment. Drawing on the framework proposed by Lazarus and Folkman [17], we categorized these as emotion-focused and problem-focused coping strategies [21,27,28].

Participants' most common emotion-focused coping strategies were enduring or ignoring online harassment and disengaging or withdrawing from social media platforms. Several interviewees seemed to accept online harassment as something that came with the territory, rather than something that could be mitigated with problem-focused coping strategies. This sentiment aligns with other research findings that many scientists who publicly commented on the COVID-19 pandemic said they learned to cope with online harassment by "accepting it as an unpleasant but expected side effect of getting information to the public" [10]. Furthermore, research suggests that many health communicators have purposefully ignored and not responded to social media trolls [10,11,29], since "engagement is their oxygen" [5]. Other emotion-focused coping strategies for online abuse reported by health communicators in our study and the literature include deleting negative comments, reducing engagement on social media platforms, avoiding certain social media platforms, and deleting social media accounts altogether [5,10,29]. Although self-blame has been identified as an emotion-focused coping strategy in other studies [16], no health communicator in our study described blaming themself for the online harassment they received.

Health communicators also used many problem-focused coping strategies to respond to online abuse. As opposed to reactive emotion-focused strategies, such as deleting negative comments, problem-focused strategies tend to be more proactive, such as blocking or reporting hostile users. For example, by preventing such users from sending messages directly to the communicator or seeking to have social media platforms enforce their terms of service against online harassment, health communicators have tried to limit the number of negative or threatening messages they will receive *in the future*. One academic told other researchers that she even blocked her abuser's followers to make it harder for them to target her [10]. Health communicators in our study and in the literature have taken several proactive steps to avoid receiving online abuse, including refining cybersecurity settings by making accounts private [11,29] and removing contact information from public websites [5].

Furthermore, rather than avoiding posting on social media platforms *entirely*, many health advocates became "more careful about how...[they] use" social media [10], making conscious efforts to strategically avoid posting about *specific* topics online. In fact, 63.5% (228/359) of the physicians, biomedical scientists, and trainees in the United States who reported experiencing any online harassment during the pandemic claimed that they have *changed* how they use social media [12]. Many health communicators, in the literature and our study, have begun compartmentalizing professional and personal identities online, avoiding "making comments that might be perceived as political" or controversial [10], or refusing to correct misinformation online [29].

When we examined help-seeking behaviors among our participants, we found a distinction between *reporting* online harassment and *seeking support* for such harassment. While almost three-quarters of questionnaire respondents (24/34, 71%) formally reported online harassment directly to social media platforms, when the same respondents recorded who they asked for help, colleagues (18/34, 53%) and friends and family members (16/34, 47%) were the most common sources of support. Several interviewees explained how their employees or loved ones helped them manage online abuse, limiting the number of negative comments and direct messages they read about themselves. Similarly, Hodson et al [30] reported that women scholars who experienced online harassment were most likely to try to deal with the problem by enlisting the help of spouses, close family members, or friends to help manage their online presence. Social media platforms allow users to report and block hostile users [31], but taking these actions may not be as effective in improving health communicators' mental health and well-being as receiving assistance and emotional support from friends and family members [30]. However, our study focused on health communicators' perspectives on the efficiency of various coping strategies, rather than examining social media platform activity. Thus, we cannot directly assess whether health communicators' reports of hostile users were acted on by platforms or whether these platform responses shaped health communicators' assessments on the efficacy of this strategy.

Some scholars have discussed how emotion- and problem-focused coping strategies can be difficult to discern, and we also found some overlap between the 2 categories. For example, Scarduzio et al [21] described asking friends and family members "for support and advice" as an active emotion-focused coping strategy yet asking friends and family members "to help stop the harasser" as a problem-focused coping strategy. Thus, we acknowledge that some coping strategies may fall into a "gray zone" between emotion-focused and problem-focused.

Although confrontation was an unpopular problem-focused coping strategy among health communicators in our study, some participants expressed a desire to have productive dialogues with their harassers. One physician said she occasionally responded to comments or messages but not when she was upset or angry [10]. However, confronting perpetrators may pose a risk of further abuse and negative mental health consequences [32], which could be one reason most health communicators in our study and the literature relied on other coping strategies.

We found some problem-focused coping strategies were individual in nature, while other strategies involved support through personal and professional relationships or official organizational policies. Individual strategies, like blocking hostile accounts, can lessen exposure to online abuse and, consequently, lessen the impacts of such abuse on mental health and well-being. Another strategy to lessen exposure is sharing the burden of monitoring and responding to hostile content with friends, loved ones, or colleagues. Beyond reducing exposure to online abuse, social and organizational support can strengthen a health communicator's ability to emotionally process abuse and rebuild mental health. For example, 2 journalists in our study, who demonstrated a willingness to continue their professional advocacy, highlighted the importance of access to expanded employee benefits, which enabled them to take time off work and receive counseling after experiencing online abuse. In the workshops, several public health officials described how their teams routinely discussed the hostility they received to address any sense of isolation or personal responsibility for these reactions and to share coping strategies. Conversely, health communicators in our study who worked as freelancers or in individual medical practices noted that a sense of isolation and lack of workplace support had exacerbated the mental health consequences of online abuse.

Professional Resilience Among Health Communicators

There are several opinions about the effectiveness of emotion- and problem-focused coping strategies, but many scholars argue that problem-focused strategies are more beneficial in the long-term [17,33]. Our findings suggest that health communicators who used problem-focused coping strategies were more likely to continue their advocacy than health communicators who used emotion-focused coping strategies. In the face of persistent online harassment and abuse, Veletsianos et al [16] reported that women scholars who continued working and teaching "required determination and resilience." Thus, simply continuing their professional obligations became an act of resistance [16]. Similarly, we put forth that health communicators who remained "active" online demonstrated significant professional resilience, compared to those who censored or otherwise minimized their online presence. Several communicators in our study noted their commitment to sharing important health information broadly with publics was one reason for this resilience. Some of the clearest expressions of professional resilience were shared by racialized health communicators in our study, which warrants further investigation.

Importantly, we do not define professional resilience as an individual quality or character trait. An individual's capacity to continue using online spaces to inform and advocate publics is significantly shaped by the forms and intensity of online abuse they face as well as the interpersonal and institutional support they receive. Moreover, the extraordinarily high levels of online engagement by health communicators during the COVID-19 pandemic required many health experts to take on burdens that went beyond their job descriptions or were otherwise unsustainable.

Online and in-person abuse has contributed to burnout and high turnover among health communicators, particularly medical professionals and health journalists [11]. Many participants in our study contemplated reducing or ceasing their online health communication activities. This decision could have negative professional consequences, such as a reduction in opportunities to network and collaborate with other scholars [9]. These consequences were especially pronounced for women and racialized individuals, who have historically been excluded from academia. Women who have reported considerable online harassment, especially sexual harassment, have frequently responded by reducing and censoring their online participation as well as deleting their accounts on social media platforms [9,16,34], further limiting their opportunities for professional development.

There are also broader social consequences if health communicators reduce their engagement online. Notably, misinformation and disinformation may be left unchecked by those most qualified to counter it [12]. Experts who were attacked online said they were less likely to participate in future media interviews, highlighting the effectiveness of these attacks [7]. Similarly, scientists who reported the highest frequency of trolling in the *Nature* survey were most likely to report that their experiences have greatly affected their willingness to speak to the media in the future [10]. At a time when "we've never needed them so badly" [10], many health communicators are avoiding certain topics on social media or withdrawing from these platforms entirely. Furthermore, given the alarming amount of abuse reported by senior public health officials, it seems likely that the hostile online environment could dissuade up-and-coming health communicators from fully engaging in important discussions [6]. Consequently, we may see a reduction in the diversity of thoughts and opinions shared within academia and public discourse, especially if women and racialized academics are disproportionately pushed out of online spaces [16].

Policy Recommendations

Health communicators in our study implemented various emotion- and problem-focused coping strategies, many of which they implemented as individuals. Future studies should investigate the effectiveness of these digital coping strategies for health communicators' mental health, well-being, professional efficacy, and professional resilience, especially those who belong to gender and racial minorities.

Our findings also highlight the limitations of individual coping strategies, necessitating the development of organizational policies to support those who receive online abuse and sanction those who perpetrate it. While health communicators have taken many steps to mitigate the frequency and severity of harassment they experience on social media platforms, advocates argue that individuals should not have to "cope on their own" [10].

Advocates have asserted that there is much that institutions can do to assist scientists who are receiving online abuse [10]. Studies have suggested several actions for institutions that employ health communicators: creating formal policies to guide health communicators' digital interactions [19], hosting trainings for health communicators on how to engage with the media and what to expect from online trolls [5,10], and enlisting organizations' information technology departments to block consistent abusive emailers and report incidents to social media platforms and police [10]. These organizational efforts should address the potential for different forms of abuse based on individuals' gender identity, race or ethnicity, ancestry, and other sociodemographic characteristics. In our study, the strongest examples of organizational policies were provided by health journalists and communicators at public health agencies. These examples include (1) clear recognition from superiors that online abuse is a serious problem that requires action and (2) institutional programs providing psychological therapy, cybersecurity assistance, and peer support. This finding warrants an exploration of organizational polices across industries to ascertain and promote best practices. Programs are also needed to support health communicators who are not full-time employees of large organizations, such as family doctors, free-lance journalists, and others.

While individual actions may have immediate short-term outcomes, institutional policies and practices could have sustained long-term outcomes for health communicators' mental health and well-being by preventing online harassment or, at least, mitigating it. Organizational policies would support professional resilience, ensuring that important health information is "not silenced" by online abuse and can still reach publics [10].

Limitations

There are several limitations to this study. Our purposive sampling of health communicators who were highly engaged in online health communication provided findings from an important population but not necessarily a representative one. Our study was conducted in English, which might have precluded insights from Canada's significant French-speaking population. Moreover, because of the small sample size of our study, we could not quantitatively compare exposure to online harassment by gender identity, ethnicity, or professional role. A more comprehensive sample of health communicators across institution types, professional roles, and sociodemographic characteristics could identify broader patterns and gaps in our findings as well as greater insights into the experiences and coping strategies of members from marginalized populations. Finally, this study focuses on health communicators in Canada and their experiences during the first few years of the COVID-19 pandemic, when uncertainty and fear were heightened. Further comparative studies across countries are needed to measure the long-term impacts of online abuse and coping strategies on health communicators in different political and health care contexts.

Conclusions

This study elucidates the significant impacts of online abuse on health communicators during the COVID-19 pandemic, highlighting both mental health and professional consequences. Despite the variety of individual coping strategies used by health communicators, there remains a pressing need for organizational efforts that offer comprehensive protection against online abuse and support for those who receive it. Institutions must acknowledge that the burden of coping with online abuse should not fall solely on individuals and that they should be supported by formal organizational policies and practices that safeguard the mental health, well-being, and professional efficacy of health communicators. These efforts will support individuals at the forefront of public health communication to share critical information.

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Authors' Contributions

CT, SH, and HT conceptualized the study. CT collected interview and survey data. CT and a research assistant coded the qualitative data. LW analyzed the quantitative and qualitative data with support from SH and CT. LW drafted the manuscript. CT, SH, and HT reviewed and edited the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Original Paper

Unraveling the Use of Disinformation Hashtags by Social Bots During the COVID-19 Pandemic: Social Networks Analysis

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Abstract

Background: During the COVID-19 pandemic, social media platforms have been a venue for the exchange of messages, including those related to fake news. There are also accounts programmed to disseminate and amplify specific messages, which can affect individual decision-making and present new challenges for public health.

Objective: This study aimed to analyze how social bots use hashtags compared to human users on topics related to misinformation during the outbreak of the COVID-19 pandemic.

Methods: We selected posts on specific topics related to infodemics such as vaccines, hydroxychloroquine, military, conspiracy, laboratory, Bill Gates, 5G, and UV. We built a network based on the co-occurrence of hashtags and classified the posts based on their source. Using network analysis and community detection algorithms, we identified hashtags that tend to appear together in messages. For each topic, we extracted the most relevant subtopic communities, which are groups of interconnected hashtags.

Results: The distribution of bots and nonbots in each of these communities was uneven, with some sets of hashtags being more common among accounts classified as bots or nonbots. Hashtags related to the Trump and QAnon social movements were common among bots, and specific hashtags with anti-Asian sentiments were also identified. In the subcommunities most populated by bots in the case of vaccines, the group of hashtags including #billgates, #pandemic, and #china was among the most common.

Conclusions: The use of certain hashtags varies depending on the source, and some hashtags are used for different purposes. Understanding these patterns may help address the spread of health misinformation on social media networks.

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KEYWORDS

social media; misinformation; COVID-19; bot; hashtags; disinformation; network analysis; community detection; dissemination; decision-making; social bot; infodemics; tweets; social media network

Introduction

From the swine influenza (H1N1) pandemic in 2009 to the subsequent outbreak of the H7N9 virus, also known as bird flu, in 2013, Twitter (subsequently rebranded as X) has increasingly become a popular platform for sharing health information [1,2]. Using posts, users can express their thoughts and opinions on many health topics. That is why specific interaction tasks have attracted the attention of researchers. This research can inform public policy by encouraging governments and health care professionals to allocate necessary resources, act, and plan accordingly [3,4]. These social media platforms have played a crucial role in providing information to the public during the COVID-19 pandemic. However, there was an increase in low-quality information, as well as the infodemic phenomenon. The infodemic, defined as an excess of information that makes it difficult for people to find reliable sources [5], can have harmful consequences [6].

The COVID-19 pandemic triggered mandatory lockdowns, social distancing, quarantines, and SARS-CoV-2–protective measures that would give rise to all sorts of opinions and behaviors [7]. During the COVID-19 pandemic, mandatory lockouts drastically altered people's daily routines (work, travel, and leisure activities) to levels never before experienced by the populations of the different countries affected by the new disease [8]. The state of uncertainty in the face of an invisible threat would transform previously normal situations into situations of risk. Direct social interaction with people outside the nuclear family, attending a concert, meeting for dinner with friends and family, shaking hands with someone, and even hugging or kissing became exceptional situations during the most uncertain periods of the pandemic—situations that, as has been observed retrospectively, would have a significant impact on the mental health of the population [9]. Likewise, the health crisis gave rise to the infodemic that, through social media platforms, opened the door to fake news, misconceptions, hoaxes, and anecdotal evidence about the origin of the pandemic, the social agents to blame for the situation, and the possible measures to be taken at a time of maximum uncertainty [10].

To understand how during the new context of health emergency misinformation spreads on these platforms, studies analyzed different elements, including the quality of information sources through URL analysis; identification of topics that generate misinformation; and analysis of online communities that spread misinformation, such as the antivaccine movement [11-14]. Others focused on the use of hashtags to describe the organization of the debate around the COVID-19–related topics. Researchers examined the frequency of use and the topic analysis of hashtags, and emphasized their main role in certain conversations [15,16]. By analyzing specific hashtags, studies also demonstrated how antivaccine communities, the proliferation of racist sentiments, or the spread of conspiracy theories are articulated on social media [17-19]. Some studies paid particular attention to how hashtags were used or combined in online conversations about the COVID-19 pandemic, using clustering techniques to describe the themes and combining hashtags with semantic text analysis and natural language processing (NLP) methods to improve topic modeling [20-22]. In addition, social network analysis (SNA) became useful to examine the co-occurrence of hashtags [23]. These studies demonstrate how the combination of different approach is useful to analyze online conversations more thoroughly.

Recently, the role of social bots has contributed to the spread of misinformation on social media platforms in various ways [24]. This issue garnered more attention as fake news and misinformation were significant factors during the COVID-19 pandemic. In this sense, some studies analyzed the role of bots regarding the spread of misinformation in general, while others have focused specifically on topics such as vaccines, conspiracy theories, hate speech, or reactions to other political actions [25-31]. However, a small amount of research compared the behavior of bots and humans [32,33].

To better understand the influence of bots on social media conversations, a previous study used topic modeling to segment the Twitter conversation and compare differences between accounts [34]. Nevertheless, the analysis did not focus on the usage of hashtags, which is the primary focus of this study. We aim to identify patterns and trends in hashtag usage to describe how bots and nonbots differ in their use of hashtags.

Only a few studies analyzed how social media bots use hashtags compared to humans. Most studies in this field examine specific hashtags [17-19,35-37]. To address this knowledge gap, we explore how social bots use hashtags specifically in connection with certain infodemic topics, issues that contribute to the generation or spread of fake news, misinformation, or discriminatory narratives. By analyzing how frequently hashtags co-occur, we aim to understand how they appear in the conversation and how they are combined. Besides, we also considered the context in which hashtags are used. They can be used ironically or convey disagreement. Our goal is to address three key questions: (1) What are the most common hashtag co-occurrences? (2) What are the differences in hashtag usage between bots and nonbots? and (3) Do bots and nonbots use certain hashtags in different ways?

Methods

Data Collection

Data collection for this study took place from March 16 to June 15, 2020, using the Twitter Streaming application programming interface (API). The hashtags #covid_19, #covid19, #covid, and #coronavirus were used to capture conversations about the first wave of COVID-19 pandemic, and only English-language posts were selected.

Based on previous research, we created a list of topics that were commonly associated with fake news or misinformation. This list includes ozone, laboratory, 5G, conspiracy, Bill Gates, milk, military, and UV. Vaccines were also identified as a controversial topic in multiple studies, so we added them to the list [38-40].

Ethical Considerations

The present study was approved by the Ethics Committee of the University of Cadiz (005_2024).

Bot Classification

To identify whether accounts on Twitter were bots or not, we used Botometer by OsoMe (formerly known as BotOrNot) [41]. This publicly available application uses over a thousand criteria to determine how closely a Twitter account matches the typical characteristics of social bots.

To create a binary classification (bot or nonbot) and prioritize identifying true positives over true negatives, we set a threshold value of 0.8 [34]. Using this threshold, we classified approximately 14.8% of the accounts as bots, which is in line with the findings of other research that found bot levels to be between 9% and 15% of the total number of Twitter accounts [42].

Botometer also provides rankings for 6 main types of bots, including echo-chamber, fake follower, financial, self-declared, spammer, and others, in addition to the overall likelihood of being a bot. In this study, we focused on analyzing the behavior of social bot accounts, particularly those that were not identified as automated accounts. These types of accounts are often associated with press agencies, companies, newspapers, or journals, and their primary purpose is to automatically publish information about a specific topic. These accounts may indicate that they are automated, for example, by including the word “bot” in their screen name or being identified as bots on Botwiki [41]. Therefore, we chose to exclude self-declared bots from our analysis due to their different characteristics compared with other social bots [41].

For this study, we classified accounts as nonbots if their probability of being a bot was less than 0.8, as self-declared bots if their probability of being a self-declared bot was greater than 0.8, and as bots if their probability of being a bot was greater than 0.8 and their probability of being a self-declared bot was less than 0.8. We then filtered out self-declared bots and considered both bots and nonbots for analysis.

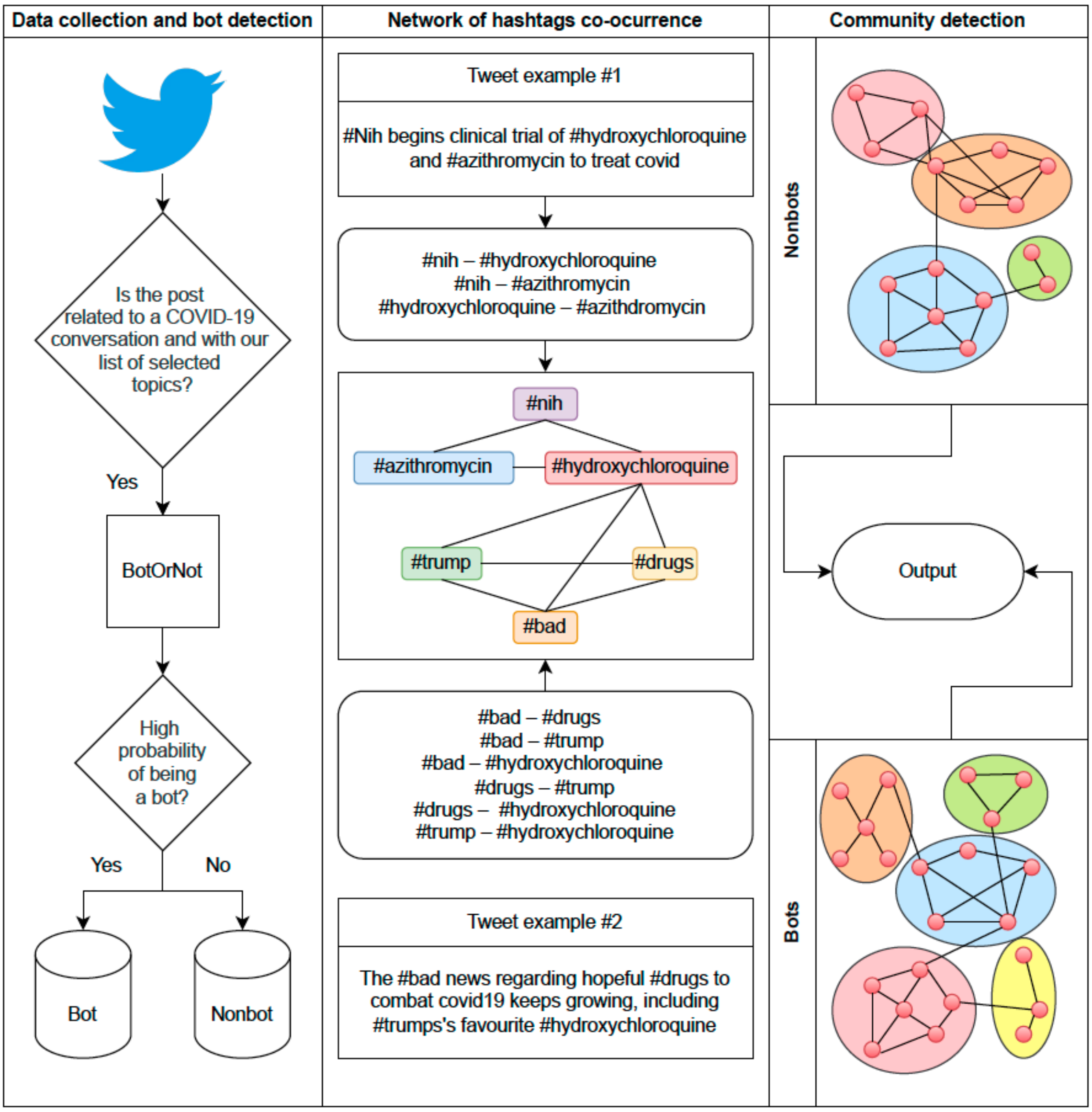
Network Analysis

To identify patterns in the usage of hashtags, we applied network analysis. We constructed a network by analyzing the co-occurrence of hashtags in posts and comparing the use of hashtags by bots and nonbots. In the network, hashtags were represented as nodes, and they were connected if they appeared in the same post. The weight of the connection between 2 hashtags was determined by the number of times they co-occurred.

We also calculated various metrics of connection, distribution, and segmentation of the hashtag network. We used the PageRank algorithm to identify the most important nodes in the network and the degree value, which represents the number of connections each hashtag has [43]. We also used the betweenness metric, which measures centrality [44]. In addition, we used the Louvain algorithm to detect the most important communities in the network. This algorithm maximizes a modularity score for each community, where the modularity measures the quality of the assignment of nodes to communities. This allowed us to identify hashtags that often co-occur together. We computed each metric separately considering whether the hashtags appear in posts posted by a bot or a nonbot. Figure 1 contains a flow diagram for the entire process.

In the following section, we first present the results for the entire network. In the following subsections, 1 for each topic, we segment the overall network of hashtag co-occurrences by extracting posts that specifically mention words related to each topic. For example, the network for vaccines will show the co-occurrences of all hashtags that appeared in posts about vaccines.

Figure 1. Flowchart from data collection to analysis.



Results

Overview

In total, we extracted around 107,173 posts from March to July 2020 that were related to the topics on our list. Most of these posts were about vaccines (59,090/107,173, 55.1%), hydroxychloroquine (17,731/107,173, 16.5%), or the military (12,548/107,173, 11.5%). Out of all the accounts analyzed, 85.2% (91,311/107,173) were identified with a low likely of being bots, that is, nonbots. Approximately 14.8% (15,862/107,173) of the posts were classified as likely being from bot accounts. As shown in Figure 2, the number of posts related to vaccines was consistently higher throughout the period, except for 2 specific moments. The first of these coincides with a message from US President Donald Trump recommending the use of hydroxychloroquine, an unproven drug. The second date also coincides with a message from Trump suggesting the injection of disinfectant to beat COVID-19 pandemic.

We created a graph of the full network of hashtags. For clarity, we selected a random sample from the entire collection of posts and depicted it in Figure 3. We also applied color to the Louvain communities and highlighted some hashtags that represent the topics analyzed in the study. This process is like the one we used for each topic in the list.

Figure 2. Bot and nonbot distribution by topic and date.

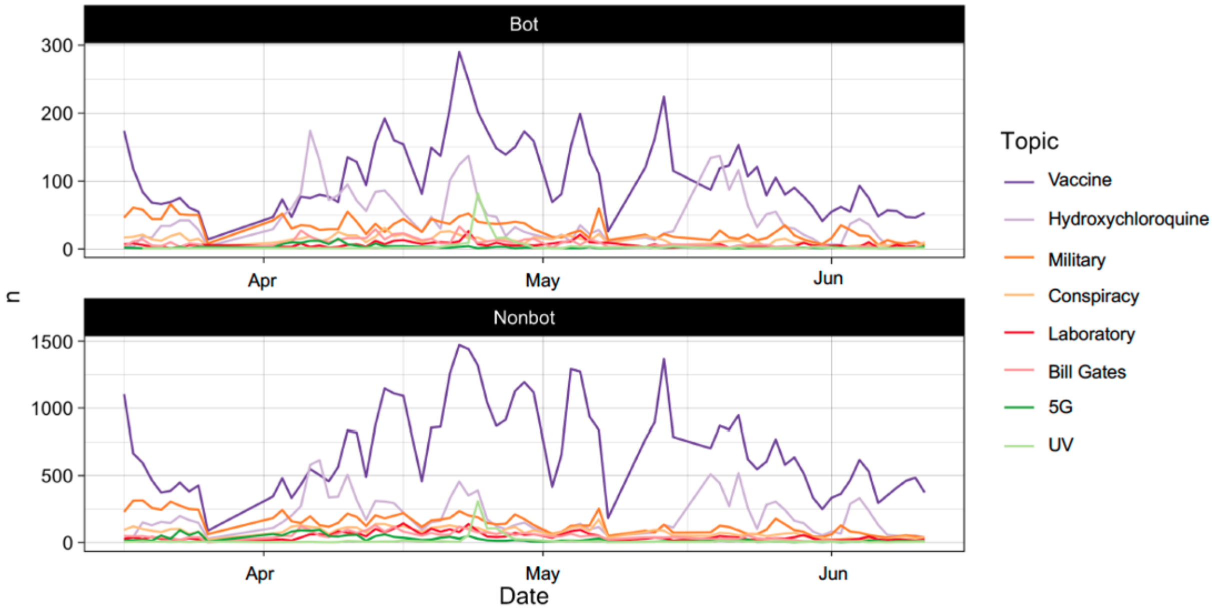
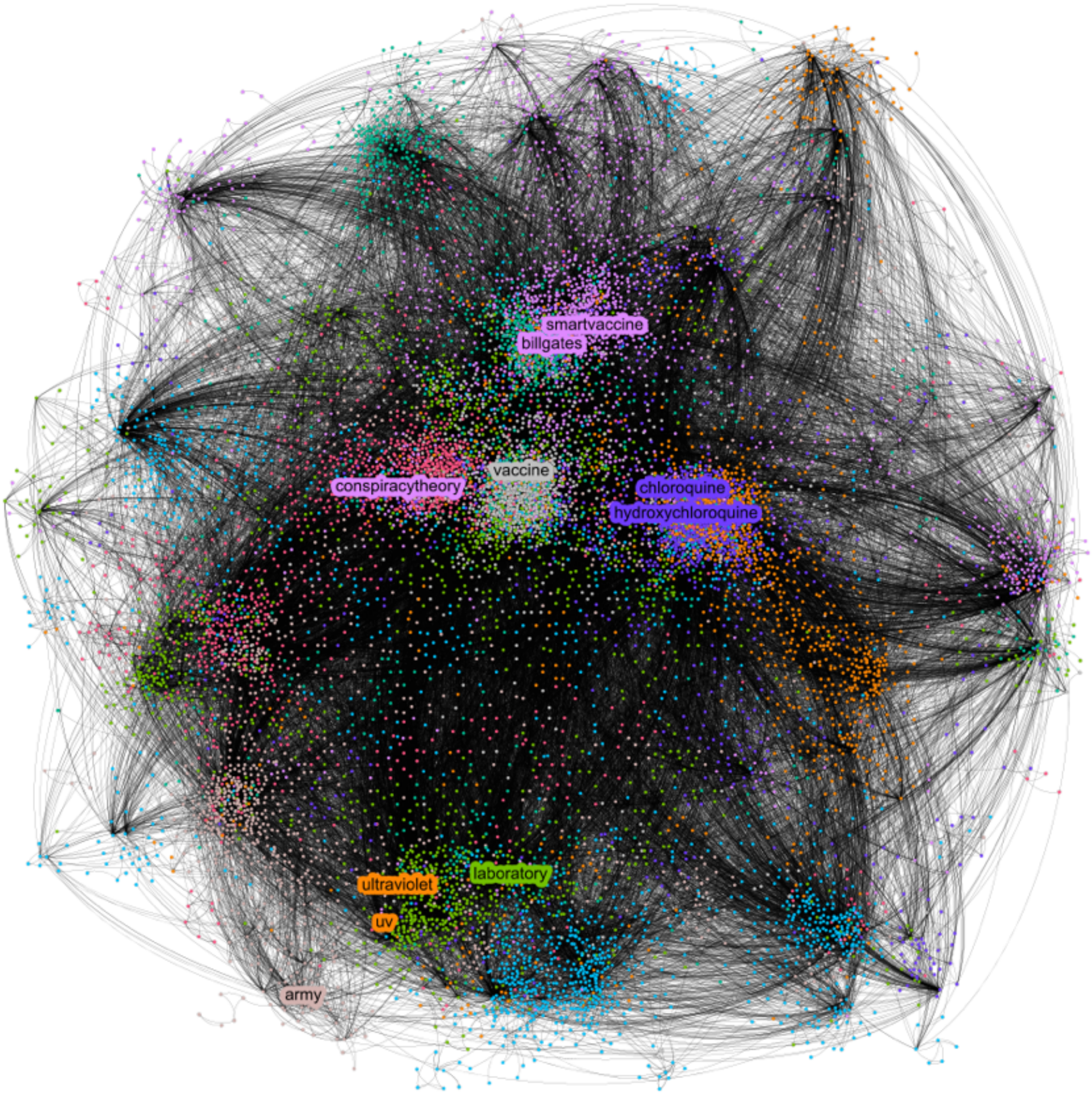


Figure 3. Hashtag network.



In Table 1, we present statistics for the overall hashtags network to provide a broad overview. As mentioned earlier, we calculated the metrics separately for each type of account. There are some differences in the most used hashtags between the 2 groups. For example, hashtags such as #Trump, #China, and #BillGates appear in both groups. However, the hashtag #vaccineswork is one of the most used by nonbots, while the hashtag #lka (which is the country code for Sri Lanka) is more frequently used by bots.

Table 1. Most common co-occurrences by bot and nonbot.

Hashtags	Posts, n (%)
Bots (n=3459)	
#chloroquine - #hydroxychloroquine	537 (15.52)
#hydroxychloroquine - #trump	490 (14.17)
#africaisnotalaboratory - #changeyourworld	437 (12.63)
#azithromycin - #hydroxychloroquine	345 (9.97)
#coronavirushoax - #prisonearth	280 (8.09)
#digitalvirus - #policestate	280 (8.09)
#digitalvirus - #prisonearth	280 (8.09)
#policestate - #prisonearth	280 (8.09)
#coronaviruslockdown - #lockdownextension	267 (7.72)
#changeyourworld - #coronacrisisuk	263 (7.6)
Nonbots (n=665)	
#hydroxychloroquine - #trump	133 (20)
#climatechange - #sustainability	106 (15.94)
#lka - #srilanka	86 (12.93)
#chloroquine - #hydroxychloroquine	84 (12.63)
#azithromycin - #hydroxychloroquine	72 (10.83)
#kag - #maga	53 (7.97)
#pandemic - #vaccine	35 (5.26)
#billgates - #vaccines	33 (4.96)
#kag - #qanon	33 (4.96)
#china - #vaccine	30 (4.51)

There are also some similarities in the co-occurrence of hashtags between the 2 groups. For example, hashtags #hydroxychloroquine and #trump appear in the same posts with higher frequency in both cases, at 14.17% (490/3459) and 20% (133/665), respectively. However, other hashtag pairs such as #kag-#maga, #billgates-#vaccines, or #kag-#qanon are common among bots. “KAG” stands for “Keep America Great,” which was President Trump’s campaign slogan in 2020, while “MAGA” stands for “Make America Great Again,” which was his campaign slogan in 2016. Both slogans have been associated with American nationalism, and the hashtag #MAGA has sometimes been used by white supremacist groups and Trump supporters.

On the other hand, nonbots tend to use other hashtag pairs such as #coronavirushoax-#prisionearth, #digitalvirus-#policestate, and #digitalvirus-#prisionearth. These hashtags, especially “#prisionearth,” were often used ironically to mock false rumors or exaggerations that were circulated online.

Vaccines

The most common co-occurrent hashtags used by nonbots regarding vaccines are #uk-#usa, #research-#science, #vaccineswork-#worldimmunizationweek. However, the most common hashtags in those posts posted by bots are #trump-#votebluetosaveamerica, #healthcare-#ppe, or even #healthcare-#ventilators. In addition, these last mentioned are exclusive of bots. That is, they only co-occur in posts from accounts classified as bots. Besides, it is worth mentioning that #billgates, along with #pandemic or #china, are the hashtags with the highest degree of connections, as seen in Table 2.

Table 2. Most important hashtags by topic.

Hashtags	Degree	PageRank	Betweenness
Vaccine			
billgates	44	0.025	22,728
pandemic	39	0.019	26,196
china	35	0.019	12,380
usa	30	0.013	7,375
vaccineswork	28	0.019	8,833
trump	28	0.015	15,704
stayhome	22	0.011	4,583
uk	21	0.010	2,703
science	21	0.011	5,048
france	19	0.008	2,064
Military			
trump	34	0.042	8,032
china	27	0.030	3,733
usa	22	0.026	5,561
italy	16	0.023	4,219
us	16	0.019	1,667
iran	15	0.020	1,938
russia	11	0.015	1,353
maga	10	0.012	620
wuhan	10	0.012	497
breaking	9	0.012	2,372
Laboratory			
wuhan	36	0.045	8,422
laboratory	26	0.033	11,660
africaisnotalaboratory	21	0.041	4,641
china	20	0.023	3,470
staysafe	11	0.017	7,566
stayhome	10	0.013	9,242
us	8	0.009	476
pandemic	8	0.009	8,614
coronaviruslockdown	7	0.011	1,676
healthcare	7	0.009	1,331
5G			
china	42	0.020	31,413
pandemic	27	0.012	25,136
wuhan	19	0.009	13,463
iot	18	0.008	11,045
qanon	17	0.008	6,437
bigdata	17	0.007	7,446
technology	17	0.008	8,731
ai	14	0.007	4,819

Hashtags	Degree	PageRank	Betweenness
tech	14	0.006	4,455
fakenews	14	0.007	8,353
Hydroxychloroquine			
trump	54	0.074	10,106
chloroquine	20	0.028	2,538
coronaviruspandemic	15	0.020	1,515
kag	14	0.017	897
maga	13	0.017	2,197
coronavirusoutbreak	12	0.016	1,089
india	12	0.017	855
hcq	12	0.020	1,468
usa	12	0.015	2,095
gop	11	0.014	636
Conspiracy			
conspiracy	35	0.084	1,872
conspiracytheory	25	0.054	2,111
conspiracytheories	16	0.037	686
pandemic	16	0.033	878
china	15	0.032	785
trump	12	0.030	732
disinformation	10	0.022	77
fakenews	10	0.023	321
usa	10	0.024	778
us	9	0.020	213
Bill Gates			
billgates	68	0.056	17,637
qanon	29	0.023	4,043
pandemic	27	0.024	7,341
maga	23	0.017	1,650
vaccines	19	0.016	5,232
stopbillgates	15	0.011	862
kag	13	0.009	104
trump	13	0.011	1,049
microsoft	13	0.010	1,978
usa	13	0.010	1,173
UV			
ai	14	0.041	839
trump	11	0.044	1,427
health	8	0.025	491
innovation	8	0.024	171
pandemic	8	0.029	428
uvlight	8	0.028	1,617
robots	7	0.023	754

Hashtags	Degree	PageRank	Betweenness
artificialintelligence	6	0.018	112
lysol	5	0.018	122
machinelearning	5	0.016	255

The algorithm extracted 5 different communities (Multimedia Appendix 1). We found significant differences in the hashtags that made up the Louvain communities. The first community contains hashtags related to news (#breaking, #usnews, and #breakingnews); countries (#canada, #france, #japan, #spain, and #africa); and others related to fake news like #wuhanvirus, #ccpvirus, #bioweapon, #hiddenhand, #psychopaths, #chinaisassho, and #madeinchina. This community is the most populated by bots, and the difference between bots and nonbots is the highest.

The second community contains hashtags related to famous people (#billgates, #anthonyfauci, and #georgesoros). These include people like Bill Gates and Anthony Fauci who played a leading role by holding provaccine positions. As in the previous case, we also found some hashtags related to fake news or conspiracy theories such as #billgatesisevil, #billgatesvaccine, #vaccinemafia, or #newworldorder. In this community, the quantity of nonbots is slightly higher than the number of bots.

On the other hand, the number of bots is also higher in the third community. In this case, the hashtags mention politics, such as #trump, #biden, and #borisjohnson. In addition, there were also some hashtags related to measures to curb the pandemic, such as #stayhome, #socialdistancing, or #lockdown. Only a few infodemic-related hashtags were found: #methanemouth, #pussygrabber, or #bananarepublic. The number of nonbots is higher in the other 2 communities. The fourth and fifth communities contain hashtags related to research and vaccines (#research, #health, and #medicine) or diseases and public health campaigns (#vaccineswork, #measles, #endpolio, and #healthforall), respectively. In particular, #vaccineswork is a hashtag used by health institutions such as the World Health Organization. Conversations on these hashtags were related to second waves and the importance of vaccines to fight against the COVID-19 pandemic.

Hydroxychloroquine

Hashtags related to Trump and the Republican movement were common in the case of hydroxychloroquine. These hashtags, such as #kag, #maga, #gop, #qanon, and #tcot, were more common in bot posts. Although #trump also appears in the case of nonbots, there were other hashtags related to news: #breaking-#breakingnew and #chinavirus-#wuhanvirus. Consequently, #trump has the highest degree of connection and the one with the highest betweenness. This hashtag, along with #chloroquine or #coronaviruspandemic, is the hashtag with the highest number of connections. There is a big difference between the first and the rest of the hashtags shown in Table 2. This difference indicates the leading role that #trump plays in the conversation about hydroxychloroquine.

We identified 8 different communities (Multimedia Appendix 1). Regarding the composition of the communities, it is worth mentioning the difference between the 2 most important ones. On the one hand, the first contains hashtags related to drugs, vaccines, or the pharmaceutical industry: #azithromycin, #biotech, #chloroquine, #lupus, #malaria, #cdc, or #hcq. In the same line, in the fourth community, the predominance of nonbots is noticeable. This time the hashtags mention countries (#uk, #us, #coronavirusuk, #france, #italy, and #germany), news (#worldnews and #usnews), TV series (#greysanatomy and #littlefireseverywhere), and supporting hashtags (#inthistogether).

On the other hand, in the second community, most of the hashtags are related to Trump or social movements related to him (#trump, #gop, #maga, and #donaldtrump). Nonetheless, some are against him (#notaleader, #worstpresidentinhistory, and #putinpuppet). In addition, the number of bots is higher than the number of nonbots, contrary to what happens in the first one.

Military

In this case, hashtags are related to specific countries that were mentioned during the pandemic. For nonbots, those most mentioned are #china-#us, #italy-#russia, and #lka-#srilanka. The latter is the most common among bots, followed in fourth place by #italy-#russia. Among the sets that do not mention countries, we find hashtags related to Trump (#gop-#trump, #kag-#maga, and #kag-#qanon).

These hashtags have similarities to those of hydroxychloroquine. The bots' unique hashtags are related to the Trump movement or Republican movements (#gop, #kag, and #qanon). In addition, #trump has the highest degree of connectivity and betweenness. This situation is also present in the communities (Multimedia Appendix 1). The first community detected contains hashtags related to Trump, and the second is related to military and veterans (#usmc, #veterans, or #usairforce). In both cases, these relationships take place in posts posted by bots.

Conspiracy

In this group, we found some hashtags related to conspiracy theories (or misinformation) and others related to countries. Regarding bots, the most common hashtags are #fakenews-#technology, #conspiracytheories-#socialmedia, and #donthecon-#trumplies. In line with this, for the nonbots, the most common hashtags are #conspiracytheory-#woke. The hashtags used only by bots are also related to racism (#racism-#sinophobia) or the economic system (#capitalismfails-#socialismworks).

Of the 6 most prominent communities (Multimedia Appendix 1), 3 of them have only nonbots. Topics in these communities are about minority groups (#blackpeople, #lgbt, and #amerikkka), about Trump (#maga, #bananarepublic, and #qanon), and about the pandemic (#coronavirusoutbreak,

#coronaviruspandemic, and #pandemictech). Of the other 3, in the first one, the number of nonbots is slightly higher than the number of bots. Some of the hashtags have to do with conspiracy theories (#conspiracytheory, #disinformation, and #propaganda), media (#qanonnfoxnews, #propaganda, and #fakenews), and others in a derogatory tone (#covidiot, #plandemic, and #plandemicdocumentary). On the other hand, in the second and fifth communities, the numbers of bots are higher. In this case, the most common hashtags are related to countries (#china, #us, and #iran), Iran specifically (#irancovidtruth and #iranregimechange), or against right-wing political parties (#rightwingignorance).

Laboratory

In this case, there are apparent differences in the geographical areas of the most used hashtags. On the one hand, nonbots mostly use #africaisnotalaboratory, while bots use #srilanka and #lka (country code for Sri Lanka). The hashtag #indiafightscorona is also common for bots. The hashtags #china-#wuhan are very common in both cases. This explains why #wuhan is the hashtag with the highest PageRank value and the highest degree of connection (Table 2), followed by #laboratory in second place and #africaisnotalaboratory in third place.

The differences between hashtags and the type of account that wrote the message were very clear in this case. On the one hand, in the first and fourth communities, the presence of bots is higher than nonbots (Multimedia Appendix 1). The first is focused on China, with some examples such as #ccpvirus, #chinamustexplain, or #chinaliedpeopedied, and the second is focused on Southeast Asia, such as #armenia, #abudhabi, or #masdarcity.

Bill Gates

The data from the Bill Gates conversation are similar to those obtained in the case of hydroxychloroquine. Trump-related hashtags were very common (#kag, #maga, and #qanon) in both bots and nonbots. The centrality and degree values are among the highest, as can be seen in Table 2. There were also new hashtags related to this type of political movement that only appears in this conversation, such as #crimesagainsthumanity, #gatesofhell, or #greatawakening. In addition, hashtags disparaging the figure of Bill Gates are also common, such as #saynotobillgates or #billgatesisevil.

We identified 5 communities of hashtags (Multimedia Appendix 1). Among the 3 largest communities, the number of bots is higher than the number of nonbots in the second one. In this community, the most frequent hashtags are #trump, #depopulationagenda, #eugenetics, #repubicans, #auspol, #qanon, and #americafirst. The hashtags, as mentioned above, are related to Trump or against some figures who have publicly supported vaccines. Examples are #trump, #americafirst, or #faucifraud. These hashtags can also be found in the first community, where the percentage of both account types is similar. However, in this community, the number of bots is not higher than that of nonbots. In the third community, the number of nonbots is higher than bots. Most hashtags in this community mention COVID-19 (#coronaviruschallenge, #coronavirusbill, #coronaviruschina, and #coronavirusnewyork), but other hashtags such as #hoaxvirus, #tedconnnect, #freedomovefear, or #trumpisevil also appear.

5G

Regarding 5G, hashtags related to technology or news were the predominant ones in the case of nonbots, such as #techwar-#tradewar or #bbcaq-#itvnews. On the other hand, in the case of bots, the hashtags continue to mention geographical areas: #america-#china and #america-#lka. There are other hashtags with higher intensity, for example, #chinesecoronavirus-#democratshateamerica or #conspiracytheories-#technology. As can be seen in Table 2, the #china hashtag gets the highest PageRank value, followed by #pandemic and #wuhan. In addition, #china has 42 degrees of connectivity, doubling the value of the second, which is #pandemic with 27 connections. But above all, these values indicate the central place these hashtags take in the conversation. On the one hand, the high degree indicates they co-occur with many different hashtags. On the other hand, a high betweenness value indicates a central place in the network.

This time, the algorithm found 5 different communities of hashtags (Multimedia Appendix 1). The presence of bots is higher than nonbots in the first 3. The first is related to #tech, #bigdata, #cibersecurity, and so on. The second one is focused on #conspiracytheories, #digitalskynet, and #misinformation. The third is focused on China, with hashtags such as #batflu, #chinesevirus, and #huaweithis. The last 2 communities, where the level of nonbots is higher, are formed by varied hashtags. The fourth community is formed by hashtags such as #kag or #maga. The fifth one contains hashtags mentioning rumors or disinformation: #fakenews, #disinformation, and #democrathoax. In this community, it is worth mentioning the appearance of hashtags related to #blacklivesmatter, such as #racism, #blacklivesmatteraustralia, or #policebrutality.

UV

In this case, the appearance of technology-related hashtags (#ai and #healthtech) is even more noticeable, especially in the case of bots (Table 2). On the other hand, the most common hashtags are #batflu-#quarantine in the case of nonbots. Concerning the 6 communities we found (Multimedia Appendix 1), in the first 3, the number of nonbots is higher. The subject matter of these communities is related to politicians (#trump, #joebiden, and #berniesanders), technology (#artificialintelligence, #bioinformatics, and #machinelearning), or more specifically to technological innovation (#health, #innovation, #coronavirusnewyorkty, and #smartcities).

Discussion

Principal Findings

This study examined the use of hashtags by social bots on Twitter during the early stages of the COVID-19 pandemic. By analyzing the co-occurrence of hashtags, we were able to identify differences between accounts classified as bots and nonbots. We used Louvain communities to further classify these co-occurrences and found consistent differences in hashtag usage between the 2 groups. We used social network analysis based on the co-occurrence of hashtags to take advantage of hashtags as key elements of online texts and understand how different users tag posts.

The analysis of hashtags provided several key insights into attitudes toward the COVID-19 pandemic and related behaviors. We consistently observed differences between bots and nonbots. In the case of bots, it was more common to find co-occurrences of hashtags related to political movements, particularly those on the right wing and related to Trump. This is consistent with findings in the literature showing a higher presence of conservatives in topics related to misinformation about COVID-19 pandemic [45].

In the conversation about vaccines, we observed that bots used hashtags related to fake news, such as #billgates and #china, more frequently. This analysis also identified specific uninformative hashtags (#ccpvirus and #chinesevirus) associated with anti-Asian sentiment [18]. Other hashtags expressed different opinions, such as criticism (#billgateisevil) or hate (#chinaliedpeopledied). It is worth noting that most of the tweets posted by nonbot users came from official accounts of institutions such as the World Health Organization, ministries of health, or entities related to public health. These messages focused on reporting on the evolution of the pandemic; the number of deaths; infection rates; and the health measures implemented, such as lockdowns and vaccination campaigns to contain the spread of the virus.

In our analysis of the conversation related to hydroxychloroquine, we identified 2 distinct communities of hashtags. One group was related to public health or medicine, while the other group was related to political movements and associated with Trump. Other studies have also found that Trump was involved in this conversation [46,47]. However, we also found that some of the hashtags in the conversation about hydroxychloroquine related to scientific facts. These differences suggest a highly polarized conversation with scientific arguments pitted against controversial political campaigns.

According to one of these studies [47], accounts with a higher impact on topics related to hydroxychloroquine disinformation were more likely to support President Trump. In addition, these types of content had a higher volume of tweets, longer duration in time, and greater echo. Our findings on the number of bots in these communities with politicized hashtags would partly explain the permanence over time and high echo values. Bots amplify these debates and increase the impact of the messages they disseminate [29,48,49]. However, our results also identify communities with anti–President Trump hashtags and higher numbers of bots. Liberals also engage in these conversations, although to a lesser extent than Conservatives [45].

These findings are extensible to topics such as the military or Bill Gates, where the conversation has been highly politicized and permeated with fake news. According to the results obtained, Trump occupied a leading role in the Twitter conversations during the period analyzed. This fact has also been noted in other previous works. Trump publicly supported the use of hydroxychloroquine and other drugs to combat the advance of the COVID-19 pandemic, with its corresponding impact on increased searches [50]. In addition, Bill Gates is often the protagonist in conspiracy theories [51].

Limitations and Strengths

There are several factors to consider when categorizing accounts as nonbot or bot. Botometer is backed by a large volume of research, but its effectiveness has been debated. It is important to remember that Botometer only provides a probability that an account is a bot, not a definitive classification. To get the most accurate results, it is recommended to compare probability distribution. However, in some cases it may be necessary to establish a binary classification for research purposes. In such cases, previous research has shown that using a cutoff value and comparing the results is a successful strategy [52].

It is important to consider the language constraint of this study. Only selecting tweets written in English may limit the focus to actors and events from English-speaking countries. In addition, no geographic limitations were placed on the collection of tweets, which allows for a larger volume of data but may also make it difficult to interpret results. It is also worth noting that the tweets analyzed in this study were from the early stages of the pandemic, and conversations and topics may have evolved over time.

Conclusion

Our analysis of hashtag usage on Twitter showed that there were differences in the patterns of use between bot and nonbot accounts. By grouping hashtags based on co-occurrence, we were able to identify distinct patterns in the usage of hashtags. On controversial or highly polarized issues, the hashtags used often pertained to the campaign or movement being promoted, with a significant portion related to Trump. In some cases, hashtags opposing these movements were also identified. On less polarized topics, hashtag usage was more diverse and included references to specific geographic locations or social groups. This analysis method can be useful in detecting hashtags that may be linked to fake news or misinformation, or in tracing the spread of such content on social media platforms.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Bot distribution by topic.

[PNG File , 104 KB - infodemiology_v5i1e50021_app1.png]

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Abbreviations

API: application programming interface
NLP: natural language processing
SNA: social network analysis

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Original Paper

Identifying Misinformation About Unproven Cancer Treatments on Social Media Using User-Friendly Linguistic Characteristics: Content Analysis

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Abstract

Background: Health misinformation, prevalent in social media, poses a significant threat to individuals, particularly those dealing with serious illnesses such as cancer. The current recommendations for users on how to avoid cancer misinformation are challenging because they require users to have research skills.

Objective: This study addresses this problem by identifying user-friendly characteristics of misinformation that could be easily observed by users to help them flag misinformation on social media.

Methods: Using a structured review of the literature on algorithmic misinformation detection across political, social, and computer science, we assembled linguistic characteristics associated with misinformation. We then collected datasets by mining X (previously known as Twitter) posts using keywords related to unproven cancer therapies and cancer center usernames. This search, coupled with manual labeling, allowed us to create a dataset with misinformation and 2 control datasets. We used natural language processing to model linguistic characteristics within these datasets. Two experiments with 2 control datasets used predictive modeling and Lasso regression to evaluate the effectiveness of linguistic characteristics in identifying misinformation.

Results: User-friendly linguistic characteristics were extracted from 88 papers. The short-listed characteristics did not yield optimal results in the first experiment but predicted misinformation with an accuracy of 73% in the second experiment, in which posts with misinformation were compared with posts from health care systems. The linguistic characteristics that consistently negatively predicted misinformation included tentative language, location, URLs, and hashtags, while numbers, absolute language, and certainty expressions consistently predicted misinformation positively.

Conclusions: This analysis resulted in user-friendly recommendations, such as exercising caution when encountering social media posts featuring unwavering assurances or specific numbers lacking references. Future studies should test the efficacy of the recommendations among information users.

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KEYWORDS

linguistic characteristics; linguistic features; cancer; Linguistic Inquiry and Word Count; misinformation; X; Twitter; cancer; alternative therapy; oncology; social media; natural language processing; machine learning; synthesis; review methodology; search; literature review

Introduction

Approximately 16% of people reported using social media to inform their medical decisions [1]. This percentage, based on estimates from the National Cancer Center, equates to 37 million adults in the United States. A recent systematic review estimated that up to 40% of health-related social media posts contain misinformation [2]. Misinformation could cause more harm to individuals with serious conditions such as cancer. Patients who believe in misinformation and use unproven therapies in parallel or in place of cancer treatment tend to be less adherent to evidence-based treatment [3-5]. Moreover, patients with cancer might choose to delay or reject evidence-based treatment and instead pursue unproven and potentially toxic therapies, which, for some patients, results in up to 2.5 times shorter life expectancy [6]. Approximately 30% of cancer-related social media posts on Facebook, Reddit, Pinterest, and X (previously known as Twitter) contain misinformation, and a staggering 77% of these posts have the potential to encourage patients to pursue futile and toxic therapies, resulting in physical, psychological, and logistical burdens [7]. Cancer misinformation persists across various cancer types and is more pervasive in more prevalent cancers. Across various social media platforms, two-thirds of the most shared posts about prostate cancer contain misinformation [8]. Researchers identified misinformation in 59% of posts related to breast cancer prevention and treatment [9] and 30% of posts related to gynecological cancer [10]. When surveyed, 70% of patients with cancer reported encountering misinformation about cancer on social media, with 71% believing that some of this misinformation was accurate [11].

There is a growing need to protect health information users from misinformation, especially those who are affected by serious conditions such as cancer. Multiple recommendations have been developed to assist individuals in their search for reliable health information [12-14]. However, many of the recommendations are complex, as they require individuals to possess a certain level of scientific knowledge and skills. For instance, recommendations frequently suggest taking steps such as identifying authors and their credentials, evaluating potential conflicts of interest, understanding funding sources, and assessing the original sources of scientific information. Considering the time and expertise required, expecting individuals to perform these tasks routinely is unrealistic. Moreover, these guidelines often fall short when it comes to addressing the challenges posed by social media platforms. Those who post may not disclose their real names or sources of findings, which makes some recommended steps not possible.

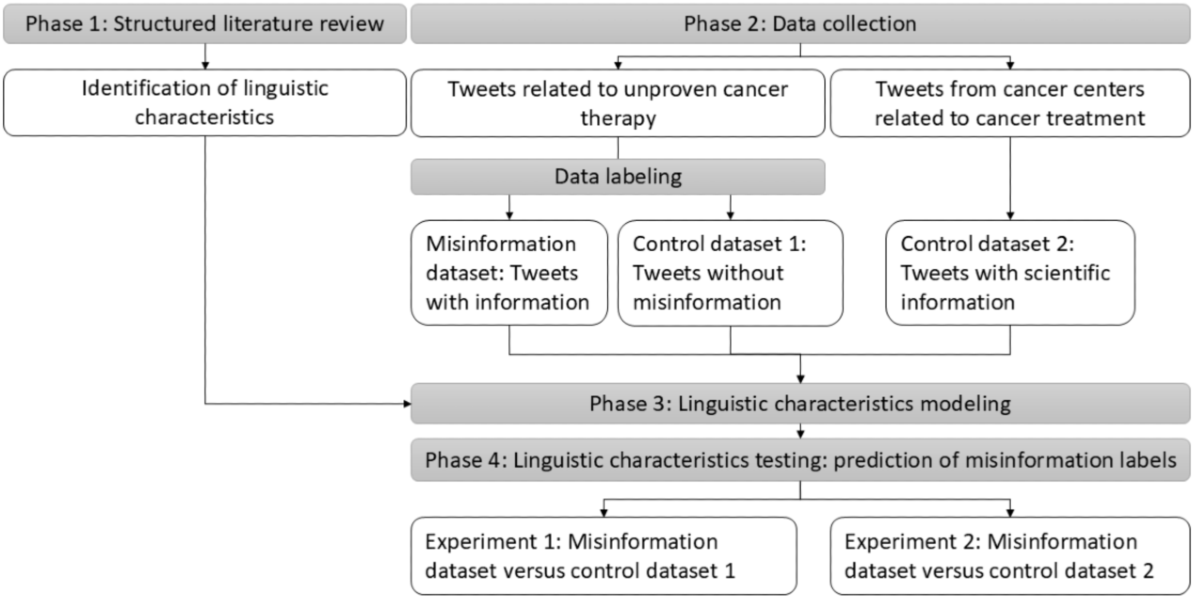
In this work, our goal is to identify user-friendly recommendations for addressing the high rate of misinformation on social media. We began by exploring literature on the algorithmic detection of misinformation. The algorithmic approach often involves the analysis of linguistic characteristics that differentiate between factual information and misinformation [15]. Linguistic characteristics describe a body of text in an abstract manner regardless of context and may include counts of words and word parts such as nouns, verbs, adjectives, and negations, as well as specific symbols such as URLs, hashtags, and question marks. An additional category of linguistic characteristics includes words associated with the psychological state of an author [16], which includes words related to emotions, expressions of certainty, tentativeness, insight, persuasion, and gratitude. To date, linguistic characteristics have been used by algorithms only. However, some of these characteristics are observable and could be used by individuals when they need to evaluate the credibility of the text. While individuals are unlikely to count words in social media posts regularly, they may routinely note other linguistic characteristics, such as emotions, URLs, and a strong degree of certainty. Linguistic characteristics have been shown to be effective in distinguishing misinformation from factual information across multiple contexts. However, it is unknown (1) whether the linguistic characteristics are effective in cancer-related context and (2) which subset of user-friendly linguistic characteristics could effectively distinguish misinformation. In this work, we identify the linguistic characteristics specific to the context of cancer. These characteristics will be recommended as guidelines for health information users when browsing social media.

Methods

Study Design

The main sequence of study procedures is illustrated in Figure 1 and includes (1) a structured literature review, in which we assemble linguistic characteristics that were used in algorithms for distinguishing factual information and misinformation (phase 1); (2) data collection, which encompasses assembling cancer-related posts using the X application programming interface (API) and labeling them as misinformation and non-misinformation (phase 2); (3) identification of the linguistic characteristics in collected datasets using natural language processing tools (phase 3); and (4) conducting predictive modeling analysis to evaluate the effectiveness of linguistic characteristics in distinguishing social media posts with cancer misinformation (phase 4).

Figure 1. Summary of the study procedures.



Ethical Considerations

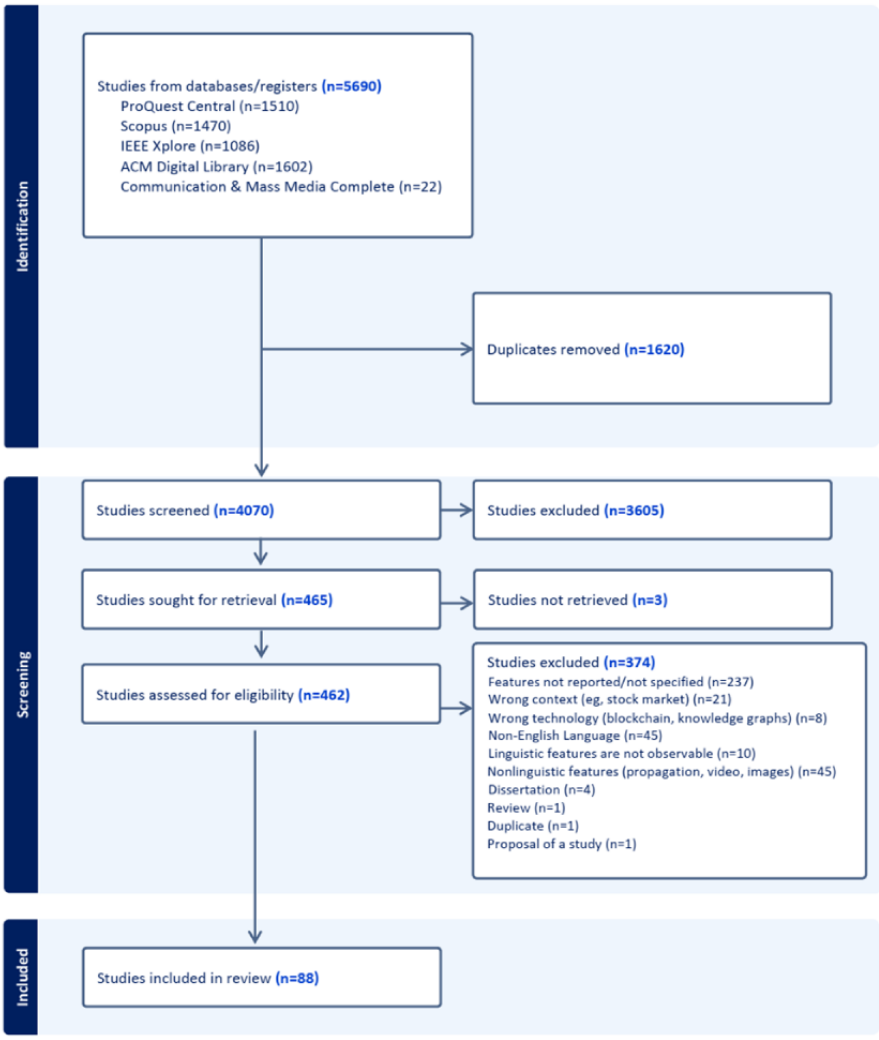
The study was institutional review board–approved by the University of North Carolina (IRB#21-2861). This was an analysis of publicly available data. As such, participants were not compensated and did not need to provide consent for the study, because the study did not involve any prospective data collection. To protect the confidentiality and anonymity of participants in this secondary data analysis, we reworded reported posts from X.

Structured Literature Review

To identify linguistic characteristics, we developed a literature review protocol that included the search strategy and keywords. This process was informed by a collaboration with a health sciences librarian (CBS), who suggested an initial set of keywords referenced in several relevant reviews [17-21]. She also created an expanded title, abstract, and keyword search strategies for each of the following concepts: (1) text as a unit of analysis, (2) misinformation, (3) algorithms, (4) internet, and (5) linguistic features or characteristics. After the search was peer reviewed by a second health sciences librarian (CB), 5 databases were searched: ProQuest Central (ProQuest), which includes the arXiv repository; Scopus (Elsevier); IEEE Xplore (Institute of Electrical and Electronics Engineers); ACM Digital Library (Association for Computing Machinery); and Communication & Mass Media Complete (EBSCOhost). The keywords and search strategies are reported in Multimedia Appendix 1. Results were limited to citations published between January 2012 and December 2022. Within databases, results were limited to journal papers, conference proceedings, working papers, and book chapters.

Two reviewers (IF and DB) independently coded titles and abstracts in Covidence software (Veritas Health Innovation) [22] and resolved conflict in codes during research meetings. Papers were included if they focused on detecting misinformation and contained a “Methods” section describing an approach for algorithmically detecting misinformation (eg, reviews and viewpoints were excluded). Examples of the algorithms included supervised and semisupervised machine learning (eg, Bidirectional Encoder Representations from Transformers [BERT] classification) that was built on linguistic characteristics. Papers were excluded if they did not report specific linguistic characteristics, focused on misinformation in any language other than English, or used human coding but not algorithms. The detailed inclusion-exclusion criteria and PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram are reported in Figure 2.

Figure 2. Flowchart of paper identification and extraction.



Identification of Linguistic Characteristics

Upon identifying eligible papers, 2 team members (IF and DB) reviewed the full text and extracted the linguistic characteristics. Around 11% (10/90) of papers underwent double-coding. After reviewers reached an agreement, we continued with single coding. The linguistic characteristics were extracted based on the following criteria: observability, applicability, and generalizability. The observability criterion was related to whether readers could easily observe the linguistic characteristics within the text; for example, positive emotions could be easily observed while morale or cognitive language styles may be difficult to distinguish. The applicability criterion distinguished linguistic characteristics that readers could easily apply while reading the text. For instance, common characteristics such as the number of words required substantial effort from readers to evaluate and, therefore, were deemed nonapplicable. In contrast, readers could easily use citations and hashtags in their post evaluations as the mere presence of these characteristics was determined to be helpful in identifying misinformation. The third criterion, generalizability, was chosen to ensure that linguistic characteristics were not related to a specific context but could be applied across various contexts. Thus, characteristics that were based on specific words such as "COVID-19," or "cure" were excluded.

Data Collection: Unproven Therapy

Overview

To test how extracted linguistic characteristics could distinguish social media posts from misinformation and factual information, we collected social media posts from X. Misinformation was operationalized here *as information that promoted cancer treatment that was known as ineffective or information that suggested cancer causes not supported by current scientific evidence* [23]. This definition focused our investigation on misinformation that could be harmful to patients with cancer or cancer survivors. Based on this operationalization, we searched existing resources that summarized unproven cancer therapy, such as "List of unproven cancer therapy" [24], a list of "Illegally sold cancer drugs" [25], and previous literature [23,26]. We extracted keywords and constructed 176 queries associated with unproven cancer treatments (Multimedia Appendix 2). Using these queries, we randomly selected up to 500 posts per query from social media. We used R software (R Foundation for Statistical Computing) to access the Academic X API. The data were manually evaluated to determine their relevance to the cancer context and unproven therapies. Queries were edited to ensure relevance. Upon corrections, the data collection was implemented on a schedule every other week between July 2022 and August 2023. After data collection was completed, the duplicate posts were removed.

Data Labeling

To distinguish posts with misinformation from other discussions, 2 reviewers (IF and CR) double-coded a randomly chosen subset of 1064 posts, achieving an acceptable interrater agreement of 0.68 measured with Krippendorff a [27]. Since the agreement was rather on a lower bound, we followed the current recommendations [28] and resolved disagreements between coders during research meetings, reaching consensus case by case. The initial criterion for coding misinformation was developed deductively based on the definition of misinformation used in this study. A post was coded as containing misinformation if it promoted an unproven therapy as a cancer-directed treatment. For example, a post claiming that an alkaline diet can eliminate cancer would be classified as misinformation: "Cure for cancer is an alkaline diet and lots of alkaline water." As reviewers worked with the data, they developed additional criteria based on observed patterns. Specifically, posts were labeled as containing misinformation if they discussed unproven approaches to prevent cancer, for example, "Pygeum Bark is nature's defense against prostate cancer." Furthermore, if a post contained a combination of factual and false information it was labeled as "misinformation."

Posts that were labeled as non-misinformation fell into 4 distinct categories. First, posts mentioned complementary and alternative medicine but did not promote it as a cancer treatment, for example, "Acupuncture and acupressure seem to be helpful in reducing pain and anxiety in patients having surgery." Second, posts that used sarcasm and actively debunked misinformation related to cancer were in the non-misinformation category, for example, "If what you stated is true, then Gerson treatment for cancer is false." The third category included posts that discussed complementary and alternative therapies but not in the context of promotion of cancer treatment, for instance, "Grapes can help protect you from the sun! Who knew?" Finally, posts that presented information with ambiguity, lack of clarity, or insufficient context were categorized as non-misinformation, for instance, "As a pancreatic cancer patient providing myself with all the additional holistic care practices made all the difference." The author did not specify whether his symptoms were alleviated or cancer progression was slowed down because of holistic practices. Therefore, the post was coded as non-misinformation.

Once a subset of the database was labeled by 2 reviewers (IF and RC), we applied an algorithm to populate labels to the entire database. We worked with BERT [29], a machine learning model for natural language processing. The BERT model was chosen because it (1) worked well with short, informal text [30]; (2) was shown to be applicable to medical text extracted from X [31]; and (3) was successfully used in previous research to identify misinformation on X [32]. The BERT model was implemented with the programming language Python (Python Software Foundation). The manually prelabeled subset served as training data for the BERT model. Such semisupervised approaches are commonly used in similar classification tasks [33]. After training, BERT used its understanding of the language and context learned from the large corpus it was originally trained on and the specific examples from the manually prelabeled dataset. BERT predicted labels for each post in the rest of the data (unlabeled dataset), determining whether each was likely to contain misinformation or not based on the patterns and features it learned from the manually coded dataset.

After BERT algorithm assigned labels to the posts, a researcher (IF), blinded to the model's results, manually coded a random subset of the posts (n=960) using the same "misinformation" and "non-misinformation" labels, adhering to the same criteria that were used to prelabel the data. When compared with manual coding, the algorithm identified misinformation with an accuracy of 83%, with a higher 86% specificity, and a slightly lower sensitivity of 82%. Upon labeling, 2 datasets were created and used in the first experiment: the misinformation dataset included only posts with misinformation, and control BERT dataset 1 included only posts with non-misinformation (Figure 1).

Data Collection: Posts From Cancer Centers

Following the definition of misinformation as "information not supported by scientific evidence or expert consensus" [34] and the definition used for this research, we assumed that posts originating from cancer centers reflect scientific evidence and expert consensus. To collect posts with factual information, we retrieved X data posted by cancer centers. Cancer centers often shared internal announcements and organizational news on X. To make posts comparable between the dataset with misinformation and control datasets, we used the keywords "cancer," "treatment," "chemotherapy," "healing," and other words related to treating cancer or controlling cancer progress. With the help of R software, we sampled 300 posts per cancer center between June 2011 and November 2022. A researcher (IF) manually checked randomly chosen (n=100) posts. As expected, no misinformation was found in the posts originating from cancer centers. The dataset, therefore, was assumed to consist of non-misinformation posts from cancer centers and was designated as control dataset 2, which was used in the second experiment alongside the misinformation dataset.

Linguistic Characteristics Modeling

Upon data collection and labeling, we used algorithmic approaches to model linguistic characteristics. First, we used an automated text search using regular expressions in Python [35] to capture digital numbers, hashtags, and URLs in the text.

Second, we used the Linguistic Inquiry and Word Count (LIWC) software [36]. LIWC calculates the proportion of the words in the posts associated with distinct psychological dimensions [37]. In this study, LIWC identified when authors of posts used certain, absolute, or tentative language.

Third, we leveraged the natural language processing tool, Name Entity Recognition [38], which was trained on human-labeled datasets to extract names from unstructured text. Using Name Entity Recognition, we were able to identify which posts contained personal names, organizational names, or locations identified from text.

Fourth, we experimented with several models for sentiment analysis and identified the DistilBERT algorithm as an optimal approach for its accuracy in handling health-related X data [39]. DistilBERT is a black-box algorithm that is trained on a large corpus of data and is based on multiple deep stack layers. The DistilBERT algorithm identified positive, negative, and neutral tones present in the posts. To evaluate the algorithm's performance, we manually labeled 300 posts across the databases. On average, the DistilBERT algorithm achieved an 83% accuracy (82% for misinformation and 84% for the control database) in detecting the emotional tone within the posts.

Linguistic Characteristics Testing: Prediction of Misinformation Labels

Identified linguistic characteristics were used in an algorithm to test whether these could distinguish misinformation in posts. As shown in Figure 1, we conducted 2 experiments using *tidymodels* package in R software [40]. Using linguistic characteristics as predictors, we forecast the "misinformation" and "non-misinformation" labels in the datasets semimanually coded by researchers and BERT classification algorithm. Data were split 60:40 to enable evaluation of the predictive power of the model and reported the accuracy as a ratio of correctly classified posts to the total number of posts. We also reported area under the curve (AUC), which accounted for both false-positive and false-negative predictions. AUC value ranged from 0 to 1, where 0.5 indicated that the model performs no better than a random chance, and 1 was a perfect prediction. The model was built on the basis of Lasso ("Least Absolute Shrinkage and Selection Operator") regression, which allowed variable selection by shrinking the coefficients of less important predictors to zero [41]. Bootstrapping procedure was applied to optimize and stabilize the selection of variables [42]. Lasso was chosen to address multicollinearity and overfitting issues in the regression model. More importantly, Lasso regression helped identify a set of linguistic characteristics that effectively distinguished posts containing misinformation. To evaluate the significance of specific linguistic characteristics, we computed importance scores, with higher scores indicating greater relevance in distinguishing posts containing misinformation. Importance scores, a common measure in predictive modeling, indicates to what extent individual predictors contribute to the overall model performance. The assessment involves permutating the characteristic values through shuffling and measuring the subsequent decline in model performance, effectively revealing the critical factors influencing predictions. Finally, we conducted a permutation statistical test (with 1000 permutations) to determine whether models with linguistic characteristics significantly outperformed random chance.

Results

Structured Literature Review

A total of 5677 citations were initially identified across all databases. After removing 1598 duplicates, we screened 4070 unique citations in Covidence. Subsequently, 3605 were excluded during the title and abstract review phase, leaving 464 papers for full-text review. Ultimately, we extracted linguistic characteristics from 88 full-text papers. These papers featured algorithmic approaches for identifying misinformation through automated text analysis, spanning various contexts, including politics, social issues, and computer science. Exclusion reasons are detailed in Figure 2, and additional information about the included papers can be found in Multimedia Appendix 3.

Identified Linguistic Characteristics

The extracted linguistic characteristics and corresponding literature are detailed in Table 1. Representative examples that contain each linguistic characteristic were chosen by selecting posts from the misinformation dataset. We used results from linguistic characteristic modeling to identify such posts. The first category of characteristics pertains to the sentiment and emotional expression in the text and includes positive, negative emotions, and neutral sentiments (absence of either). Some papers delved into more nuanced emotions such as anger, fear, surprise, and others. We excluded these emotions due to the potential difficulty for readers to detect nuanced emotions reliably in the text.

The next category comprises linguistic characteristics that pertain to psychological concepts. It is worth noting that some psychological concepts consist of a combination of linguistic characteristics, such as social processes including references to family, friends, other people, and verbs indicating interactions. Although algorithms frequently use such combinations, we decided to exclude the following psychological concepts that consisted of combinations of linguistic characteristics such as cognitive, perceptual, social processes, and morality or deception. The rationale behind this exclusion is that users are unlikely able to observe and combine linguistic characteristics for evaluations of the posts. We also excluded characteristics mentioned in fewer than 4 studies, such as gratitude, insight, causation, and persuasion. Following our 3 criteria, we included negations, tentativeness, profanity (as a proxy of informality), and words associated with absolutes and certainty.

Other categories that met our inclusion criteria were linguistic characteristics such as names of individuals, locations, and organizations, as well as categories related to the presence of URLs, hashtags, personal pronouns, and numbers. Readers can identify these characteristics without additional efforts (observability criterion) and use them for evaluation of the text (applicability) because the presence of these characteristics in social media has historically been a distinguishable factor in detecting misinformation. Furthermore, these characteristics were not context-dependent and, therefore, satisfy the generalizability criterion.

Table 1. Linguistic characteristics and examples of misinformation.

Characteristics	Examples of linguistic characteristics and posts with misinformation[a]	Studies using characteristics for misinformation detection
Sentiment[b]		[43-93]
Negative emotions	• Chemo is costly and very painful. It seems to worsen illness and hasten life's end. • Sad this happened, to overcome cancer, consider utilizing cannabis oil in combination with vitamin B17. • Feeling frustrated that insurance doesn't cover certain treatments I believe in. Wish there were more options beyond the conventional cut, burn, and poison approach.	
Positive emotions	• Cure for cancer that works holistically, Vitamin B17, very good! • Please do some heavy doses of medical organic marijuana if possible let it eat that cancer. Wishing you healing and joy and comfort. • Wonderful treatment! Discover the incredible benefits of ProstateRelax, a natural herbal treatment for prostate cancer. ProstateRelax effectively treats and prevents the progression of prostate cancer.	
Neutral emotions	• Anyone with cancer. Check your body's pH level. Drink alkaline water, eat alkaline foods, and avoid acidic sugary treats and dairy. • Cancer cells thrive in low oxygen environments. B17, found in apricot seeds, can help. • Antineoplastons, a protein suppressed by cancer, could hold the key to a potential cure.	
Psycholinguistic		
Negation	• Unlock the potential of Acupuncture to modulate immunity and create an environment where cancer cannot thrive. Discover the holistic power of this ancient practice in bolstering your body's defenses against cancer. • I wonder why aren't we utilizing hyperbaric chambers for Cancer? Ask your doctor about the incredible potential of pure oxygen in rejuvenating and generating new cells to combat this disease. • Don't consume sugar (as cancer thrives on it), minimize or eliminate carb-rich foods like bread and pasta, and limit alcohol intake. Embrace the power of fasting to allow your body to heal itself.	[46,49,53,70,79,81,94-96]
Tentativeness	• 3 women with similar cancer, undergoing comparable treatments—2 passed away, but 1 is thriving Possible factor? She incorporated mistletoe & other non-pharma medicines into her regimen. • Concerns about [standard treatment] as a cancer solution persist, with claims of it being a harmful creation backed by influential medical forces. If it truly worked, wouldn't it have been banned long ago like Laetrile? • Listen or not: Vitamin B17, found in Apricot seeds and sold online as a "health supplement," has caught my attention as a potential cancer cure.	[49,51,59,61,62,66,81,94,96-100]
Absolute language or certainty	• I take sea buckthorn pills! They are an absolute lifesaver. • Vitamin B17 has definitely prevented my cancer from spreading. It's been a while, and there has been no growth. • During my time in a chemo clinic, alternative treatments were never allowed to be discussed or promoted. I left and started studying herbal medicine.	[43,51,59,61,94,97-101]
Profanity	• Create an alkaline environment that cancer can't thrive in! Incorporate herbs, vitamins, and minerals to support your healing journey. You are going to heal and beat that s*** • Go to a poor country and you get real tea with real ginger. Go to a rich country and you will get chemical b**** that will give you cancer • It damages healthy cells, no surefire cancer cure. It's like a c*** shoot for survival & recurrence. But I choose a different path: starving cancerous cells with therapeutic fasting & lifestyle shifts.	[48,57,62,63,66,69,81,89,96,98,102]

Characteristics	Examples of linguistic characteristics and posts with misinformation[a]	Studies using characteristics for misinformation detection
Named entities		[44,49,51,60,64,69,79,93,103-109]
Names	• I watched the documentary of Dr. B [name] on YouTube. He cured stage 4 cancer with no chemotherapy and no radiation.	
Location	• Fascinating, study from M [name of State]! Certain sound frequencies may aid the body in fighting cancer. Pair this with an alkaline diet - and the world is cured!	
Organization	• Must-watch documentary on YouTube! Unveiling a shocking cancer cure cover-up for over 40 years! B [name]: The Cancer Cure Cover-Up—Full documentary available now!	
URL	• Insights from Dr. N [name]! Learn how to transform the cancer terrain, boost immunity, and create an inhospitable environment for cancer using Acupuncture, Chinese herbal medicines, and food therapies. Check out the discussion here: [link provided].	[45,51,52,54,55,62,69,78,79 ,86-88,92,93,98,99,101,104,107-117]
Numeric data	• Cancer is nearly 100% curable but beware of certain hospital treatments. Explore alternative options for better outcomes.	[44,49,51,57,65,67,70,72,73,79,81,94,98,101,105]
Pronouns	• I love your positivity and your fight against cancer. Keep up the fight and adhere to Alkaline Diet for a healthier journey. • Your cancer can be cured by #fasting paired with no sugar alkaline diet. • A pro basketball player revealed how organic Wheatgrass healed his close friend from blood cancer. A testament to the power of natural remedies!	[61,66,68,72,78,79,93,97,99,103,106,108,112,118-121]
Hashtag	• #TualangHoney helps against skin Cancer with no side effects.	[43,44,47,52-55,59,64,66,77-79,82,87, 92,96,98,101,104,107,108,111,115,119,122,123]

[a]All posts were paraphrased to protect the author's anonymity.

[b]In sentiment analysis, emotions are identified by a "black box" model (DistilBERT). While we report here examples and highlight "negative/positive" words in the sentence, we must acknowledge that the algorithm may or may not use these words for detecting emotions.

Collected Data From X

We collected a total of 45,791 posts related to unproven cancer therapies. Among these, 13,046 posts were labeled as misinformation (forming the misinformation dataset), while 32,745 posts were categorized as non-misinformation (comprising control dataset 1). Furthermore, we gathered 6782 posts from the profiles of comprehensive cancer centers, which were used as control dataset 2, as shown in Figure 1. The content description of both the misinformation dataset and the control dataset 1 is shown in Table 2. To illustrate the dataset in this study, we categorized the X posts into 9 distinct categories. The examples of the posts with misinformation are shown in Table 1.

Table 2. Relevant prevalence of therapy categories within posts about unproven cancer therapy.

Categories of therapies	Total posts, n	Posts with misinformation, n (%)[a]	Examples of unproven cancer therapy
Diet based	5179	3069 (59)	Antioxidant, fasting, and alkaline diet
Alternative health system	7036	2250 (32)	Herbal therapy and ayurveda
Plant- and fungus-based	13,851	4386 (32)	Mushrooms
Synthetic substances	8471	2637 (31)	Antineoplastic Brudzinski and vitamin C
Spiritual and mental healing	2347	272 (12)	Meditation, praying, and tai chi
Electromagnetic and energy-based	2825	283 (10)	Polarity therapy and magnetic
Physical procedures	1144	49 (4)	Acupuncture
Other	4938	100 (2)	N/A[b]
Total	45,791	13,046 (28)	N/A

[a]Out of the total number of posts.

[b]N/A: not applicable.

Linguistic Characteristics Testing: Prediction of Misinformation Labels

As shown in Table 3, experiment 1 demonstrated that linguistic characteristics predicted misinformation with 60% accuracy. In experiment 2, they exhibited even stronger predictive power, achieving an accuracy of 77%. The importance scores for each linguistic characteristic are shown in Table 4.

Next, we selected linguistic characteristics with an impact score 0.05 and consistent predictive performance across experiments 1 and 2. These short-listed characteristics underwent further testing within the same experiments. In experiment 1, the short-listed characteristics achieved an accuracy rate of 50%, which did not significantly differ from random chance (P>.90). However, in experiment 2, these characteristics predicted misinformation with an accuracy rate of 73% and an AUC of 83. This performance was significantly better than random chance (McNemar $^2{}_1$=5.7 ×10^7; P<.001). The importance scores for the short-listed characteristics are shown in Table 4. For a more detailed breakdown of the importance scores, we have summarized the percentage of posts containing these short-listed characteristics by dataset in Table 4 and the complete list in Multimedia Appendix 4.

Table 3. Lasso regression performance.

Name of the dataset	Total posts, n	Posts with misinformation, n	Accuracy, %
Experiment 1: misinformation dataset and control dataset 1	45,791	13,046	60
Experiment 2: misinformation dataset and control dataset 2	19,828	13,046	77

Table 4. Importance scores.

Linguistic characteristics	Experiment with control group 1		Experiment with control group 2		Experiment with short-listed characteristics (control group 2)	
	Predictors		Predictors		Predictors	
	Negative	Positive	Negative	Positive	Negative	Positive
Absolute language	—[a]	*0.11* [b]	—	*0.69*	—	*0.84*
Certainty	—	*0.21*	—	*1.13*	—	*1.02*
First-person pronoun	0.27	—	—	1.31	—	—
Hashtags	*0.56*	—	*1.55*	—	*1.6*	—
Location	*0.27*	—	*0.27*	—	*0.46*	—
Name	—	0.08	0.91	—	—	—
Negation	0.53	—	—	0.73	—	—
Negative emotions	0.24	—	0	—	—	—
Neutral emotions	0	—	—	0.07	—	—
Number	—	*0.17*	—	*0.29*	—	*0.28*
Organization	—	0.02	0.63	—	—	—
Positive emotions	—	0.31	0.46	—	—	—
Profanity	0.92	—	—	1.99	—	—
Second-person pronoun	0.02	—	0.45	—	—	—
Tentativeness	*0.08*	—	*0.16*	—	*0.08*	—
Third-person pronoun	0	—	0.23	—	—	—
URL	*0.3*	—	*2.28*	—	*2.47*	—

[a]Not applicable.

[b]Italicized values represent short-listed characteristics.

Table 5. The percentage of posts with short-listed linguistic characteristics.

Linguistic characteristics	Misinformation dataset (n=13,046), n (%)	Control dataset 1 (n=32,745), n (%)	Control dataset 2 (n=6782), n (%)
Positive predictors			
Certainty	1579 (12)	3044 (9)	208 (3)
Absolute	2741 (21)	7294 (22)[a]	630 (9)
Number	6358 (49)	14,360 (44)	2497 (37)
Negative predictors			
URL	6978 (53)	19,591 (60)	6560 (97)
Hashtags	2296 (18)	8512 (26)	4343 (64)
Location	1212 (9)	3373 (12)	975 (14)
Tentativeness	4154 (32)	11,171 (34)	1835 (27)[a]

[a]Valence of predictions is inferred from the model, which includes all characteristics simultaneously.

Discussion

Principal Findings

We have identified linguistic characteristics that can help people affected by cancer detect cancer misinformation on social media platforms such as X. Linguistic characteristics that were *likely* to be present in posts with misinformation were related to certain, absolute language, and numbers. Certain language included phrases that reflected a "degree of bravado" or "boasting of certainty." Examples of certain languages could be "I really believe," "it is definitely helpful," and similar others [36]. The absolute language referred to phrases that reflect black-and-white thinking and included words such as "none," "all," "never," and others [36]. The number category encompassed any information reported with digits such as percentages, count of any units, years, and priorities. Notably, all 3 linguistic characteristics could be united under the umbrella of definite, confident language. Linguistic characteristics that were *unlikely* to be present in posts with misinformation encompassed URLs, hashtags, and location mentions. Each of these attributes could be considered as a form of citation or reference. URLs offered direct links to the original source or further information, hashtags connected posts to broader relevant discussions, while locations mentioned in posts provided context and a sense of origin to the information shared. Our findings are consistent with some of the suggestions provided by previous guidelines for identifying misinformation. For instance, the Food and Drug Administration recommends being vigilant if patients read confident statements such as a drug definitely "cures cancer" or "guarantees results" [124]. Other guidelines encouraged users to search for references and original sources of health-related information [12-14].

While consistent with previous recommendations, our findings make a unique contribution. Previous work has based the guidelines on theoretical assumptions, while our study is one of the first to provide some empirical evidence based on a large dataset to support the recommendations for users. Another contribution is that we outlined ineffective linguistic characteristics for detecting cancer misinformation. Despite a substantial body of research showing that social media posts with sentiments predicted fake news, we did not find these relationships. A potential explanation could be the algorithm's limited efficiency in identifying emotions within cancer-related contexts. Furthermore, it is possible that authors express a limited range of emotions in cancer-related conversations, typically negative emotions toward cancer and both positive and negative emotions toward various treatments, including those that are unproven. These emotions may vary little across posts containing valid and nonvalid information, making emotions an unreliable factor for distinguishing misinformation.

Our work accumulates knowledge about misinformation detection from the literature covering a wide range of contexts—including political, social, and computer science—and translates this knowledge to the cancer context. The findings highlighted promising avenues for future research and could expedite the development of automated and augmented methods for identifying and verifying cancer-related misinformation on social media platforms. Finally, the robust labeled datasets developed by our research team are available to other researchers upon request to the corresponding author, thereby further supporting research on misinformation within the context of cancer and social media.

In practice, our work is at the forefront of customizing recommendations and contextualizing them for social network users. Our exploratory findings suggest a promising direction for studying linguistic characteristics that information users might apply when making quick judgments while scrolling through X feeds. Empowering users to stay vigilant in their initial evaluations could help reduce the spread of misinformation and the formation of erroneous beliefs. This is a crucial area for future research, which should explore how these findings apply in different cancer-related contexts and across various social networks.

Limitations

All the studies included in our analysis exclusively originate from peer-reviewed journals and conference proceedings; however, we must exercise caution when considering the potential for publication bias. Furthermore, in accordance with our selection criteria for linguistic characteristics, we included only those papers that focused on text and excluded other forms of social media content, such as videos and images. We recommend that future research comprehensively explore social media, including multimedia content, as it could potentially provide additional insights for user-friendly recommendations.

In selecting linguistic characteristics, we prioritized observability, applicability, and generalizability. However, alternative criteria may be considered when users are open to a more thorough exploration of a post's validity. For example, future research should explore the use of metadata, link content analysis, and hashtag meanings. As misinformation evolves and its authors adjust to societal changes, the linguistic characteristics that identify misinformation may also shift. A longitudinal analysis is necessary to understand how linguistic characteristics perform in predicting misinformation over time.

Algorithms used in our analysis operate with a certain level of accuracy. Specifically, the accuracy of label identification in the dataset reached 83%, indicating that approximately 17% of posts were labeled incorrectly. This means that in experiment 1 some proportion of misinformation is included in the non-misinformation group and vice versa, making further exploration less accurate in experiment 1. This degree of uncertainty is common in algorithmic performance. Therefore, it is important to interpret our results in light of the inherent imperfections in algorithmic performance.

Furthermore, we encountered that the short-listed linguistic characteristics did not significantly outperform random chance in identifying misinformation in experiment 1. This outcome underscores a potential boundary condition of the effectiveness of the linguistic characteristics. Notably, experiment 1 encompassed more homogeneous data in contrast to experiment 2. Based on these findings, it becomes plausible to speculate that linguistic characteristics might provide limited help when a reader assesses posts within a closely knit community.

In experiment 2, the control dataset 2 consisted of posts shared by cancer centers and was compared with the misinformation dataset comprising random posts. To address this limitation, we collected posts from cancer centers that contain words related to cancer therapies. This step was taken to ensure a similar context of discussion as the posts with unproven therapy. Next, we exclude linguistic characteristics that are likely displayed differences between datasets due to the distinct nature of the information within control dataset 2. For example, linguistic traits such as "the use of profanity" or "first-person pronouns" were discarded. Furthermore, we decided to focus our analysis solely on the text within the posts and omitted other accompanying metainformation that users might observe, such as the user's name, location of the author, and posting time. This approach allowed us to assume that posts shared by cancer centers might be perceived more broadly, for instance, as posts shared by researchers, physicians, administrators, and patient advocates. Because of these measures, we anticipate that the linguistic characteristics identified in this research may help differentiate between health misinformation and factual posts on social media, irrespective of their sources. Despite our precautionary measures, we cannot fully guarantee that identified linguistics characteristics certainly distinguish between posts with misinformation and non-misinformation versus posts produced by the general public and posts by health experts from health care systems. However, there are factors that support the first conclusion more than the second. First, our findings are consistent with the previous theoretical and practical recommendations for identifying misinformation [12-14]. Second, the associated with misinformation linguistic characteristics, such as numbers and assertive language, are expected to be used by health experts. For instance, providers use numbers more confidently than the general public [125]. Professional guidelines for health providers encourage them to use numbers over verbal descriptions [126] as well as the use of assertive language in communication with patients [127,128]. Yet, our study associated these characteristics with misinformation shared by the general public on social media, which suggests that we might be finding more than just a mere distinction between the general public language and the health professional language. One study in and of itself is not yet a comprehensive body of evidence. Our findings will need to be validated and built upon via additional studies—including those that use posts from other types of entities and comparison groups.

Finally, our data were collected only on a single social network X. Many characteristics and customs of X are transferable to other social networks and our recommendations are likely to go beyond application on X, as demonstrated by the consistency of our recommendations with the recommendations of other researchers [12-14]. Given this limitation, our results need to be generalized cautiously, and further similar research is needed for different platforms (eg, Facebook, Pinterest, etc).

Conclusions

Our structured review synthesized knowledge from studies that used algorithmic approaches for text analysis to detect misinformation in social media. From this literature, we identified user-friendly linguistic characteristics that can assist individuals in distinguishing misinformation when they seek health-related information on social media. The linguistic characteristics, such as certainty, absolute language, and numbers, were positively associated with misinformation, while characteristics such as URLs, hashtags, and location mentions were negatively predictive of misinformation. Based on these findings, we suggested that users should be cautious of social media posts containing confident promises or specific numbers without proper references to the original information. According to our analysis, we expect that this approach will allow users to filter out two-thirds of posts with cancer-related misinformation. Yet, before drawing a definitive conclusion, further testing with different datasets is required.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Strategy for literature review.
[DOCX File , 29 KB - infodemiology_v5i1e62703_app1.docx]

Multimedia Appendix 2
List of unproven therapy.
[DOCX File , 25 KB - infodemiology_v5i1e62703_app2.docx]

Multimedia Appendix 3
Summary of the literature.
[DOCX File , 47 KB - infodemiology_v5i1e62703_app3.docx]

Multimedia Appendix 4
Summary of linguistic characteristics.
[XLSX File (Microsoft Excel File), 10 KB - infodemiology_v5i1e62703_app4.xlsx]

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Abbreviations

API: application programming interface
AUC: area under the curve
BERT: Bidirectional Encoder Representations from Transformers
LIWC: Linguistic Inquiry and Word Count
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Original Paper

A Model of Trust in Online COVID-19 Information and Advice: Cross-Sectional Questionnaire Study

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Abstract

Background: During the COVID-19 pandemic, many people sought information from websites and social media. Understanding the extent to which these sources were trusted is important in relation to health communication.

Objective: This study aims to identify the key factors influencing UK citizens' trust and intention to act on advice about COVID-19 found via digital resources and to test whether an existing model of trust in eHealth provided a good fit for COVID-19–related information seeking online. We also wished to identify any differences between the evaluation of general information and information relating specifically to COVID-19 vaccines.

Methods: In total, 525 people completed an online survey in January 2022 encompassing a general web trust questionnaire, measures of information corroboration, coping perceptions, and intention to act. Data were analyzed using principal component analysis and structural equation modeling. The evaluation responses of general information and COVID-19 vaccine information were also compared.

Results: The principal component analysis revealed 5 trust factors: (1) credibility and impartiality, (2) familiarity, (3) privacy, (4) usability, and (5) personal experiences. In the final structural equation modeling model, trust had a significant direct effect on intention to act (β=.65; *P*<.001). Of the trust factors, credibility and impartiality had a significant positive direct effect on trust (β=.82; *P*<.001). People searching for vaccination information felt less at risk, less anxious, and more optimistic after reading the information. We noted that most people sought information from "official" sources. Finally, in the context of COVID-19, "credibility and impartiality" remain a key predictor of trust in eHealth resources, but in comparison with previous models of trust in online health information, checking and corroborating information did not form a significant part of trust evaluations.

Conclusions: In times of uncertainty, when faced with a global emergent health concern, people place their trust in familiar websites and rely on the perceived credibility and impartiality of those digital sources above other trust factors.

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KEYWORDS

eHealth; electronic health; digital intervention; trust; online information seeking; scientific credibility; digital resources; COVID-19; SARS-CoV-2; respiratory; infectious; pulmonary; pandemic; public health; health information; global health; surveys; social media

Introduction

Background

The COVID-19 pandemic understandably led to an increase in "official" sources of information and advice from politicians, public health officials, clinicians, and scientists. This public-facing information was communicated via the mainstream press, through live-streamed press briefings, and online. However, "unofficial" sources of information were also circulated, primarily via social media. For individuals, access to good quality information during the pandemic was critical, not least because official messaging was constantly being updated in relation to recommended or mandated behaviors such as social distancing, mask-wearing, and self-isolation.

During this time, many people sought their information online [1] through websites, social media, and mobile apps. People looked for information on the signs and symptoms of the virus, measures to avoid catching and spreading the virus, self-care once infected, and vaccination information. In addition to health advice, people also sought related information on rules and guidance regarding self-isolating, masks, and social distancing.

Accurate and appropriate health communication is an important tool in tackling any pandemic and it can directly influence individuals' affective and behavioral responses to a crisis [2]. In relation to the COVID-19 pandemic, studies have shown that access to a larger and more diverse set of information sources led to increased worry [1,3] and greater confusion, in part because of the infodemic of misinformation and rumors that were promoted about the pandemic [4]. The UK Government's approach to tackling COVID-19 relied upon broad public trust, but issues with inconsistent and unclear messaging, as well as general political mistrust, were apparent [5]. In short, it sometimes became difficult for people to know who to trust in relation to taking appropriate actions to reduce the spread of COVID-19 and minimize personal risk.

Against this backdrop, the aim of this study was to understand more about the digital resources people in the United Kingdom used for COVID-19–related information and the extent to which they trusted these resources. Although we know that online health formed a key source of information for many people during the pandemic, we do not know how people evaluated these digital sources and what factors were important in trusting the information, the source, and ultimately deciding whether or not to act on the advice given. We also wished to test whether an existing model of trust in eHealth provided a good fit for COVID-19–related information seeking online. We begin by briefly reviewing the literature on trust and eHealth before introducing the COVID-19 context and outlining the study objectives.

Trust in Online Health Information

Over the last 20 years, research has consistently pointed to the importance of both the design and the content of websites in terms of establishing trustworthiness [6,7]. Commonly reported indicators of trust and credibility include site owners or sponsors; consensus among multiple sources; characteristics of writing and language; advertisements; content authorship; and interface design [8]. Related studies have looked at the quality of web-based health information and have highlighted navigability, aesthetics, and ease of understanding as important factors [9]. As digital resources for health have developed and diversified, we have seen a move away from government and medically driven sources towards more charity and patient-led sites [10] and the use of social media [11,12] meaning that shared patient experience has also become a critical factor in determining trust and appropriateness of online advice [13].

Despite concerns about the quality and reliability of some digital sources [14], they are often well-used and well-liked. Interestingly, they are not necessarily trusted and the advice they contain is not always acted upon. In part, this may relate to a dislike in the United Kingdom for commercial funding models underpinning health websites [10]. A recent model of trust in eHealth [15] found that credibility and impartiality are the key predictors of trust in eHealth websites and noted that websites containing patients' experiences can have a positive impact on trust but only if those sources have been checked against other sources first. The authors also noted that the need to corroborate digital information sources may be reduced in cases where there is strong familiarity with a well-used website.

COVID-19 Context

The COVID-19 pandemic led to a global surge in information seeking online in relation to the spread of the virus, best means of protection, access to health care, local rules and guidance, and, subsequently, information about COVID-19 vaccines, tracing apps and COVID-19 passports [16]. While official sources moved quickly to try and fill these information gaps, social media platforms provided a space for information and misinformation to circulate widely [17]. Conspiracy theories and rumors in relation to the virus and the vaccine were prevalent online as was poor-quality information [18-20]. The unique situation increased attention on governments as a source of information however historically government and official health sources have been subject to mistrust and their health messages resisted especially concerning vaccinations for example in the case of the Measles Mumps Rubella vaccination and the H1N1 (swine flu) vaccination program [21,22]. In these cases, trust in nonofficial information sources and the media is often higher.

United Kingdom Context

In response to the global pandemic, the UK prime minister announced a national lockdown on March 23rd, 2023 [23]. Daily press briefings followed, led by politicians and National Health Service (NHS) leaders providing coordinated information on COVID-19 legislation and guidance, health advice, and subsequently the vaccine rollout.

Survey data indicates there was a slight increase in political trust in the United Kingdom as the lockdown commenced [24] and most people supported the government enforcement of behavior in the early months [5] with positive views on government decision-making related to response transparency. Although people looked to government and health leaders for information and guidance these officials were not immune from criticism. Politicians and advisors often found themselves at the center of news stories that challenged perceptions of trust [24], and of privacy and security, for example in relation to the rollout of contact tracing apps [25] and COVID-19 passports. Low trust in scientists and medics was also associated with COVID-19 vaccine hesitancy [26].

The sudden onset of COVID-19 and its impact not just on UK citizens but worldwide highlighted the public's need for information. Understanding how individuals sought information from digital sources and whether they trusted this information is the focus of this study. Note that this distinct aim is different from many of the studies of information-seeking behavior during the pandemic that were more focused on the motives that drive online interrogation. Typically, these searches adopted the Risk Information Seeking and Processing model [27] which sees risk information seeking as driven by factors such as information insufficiency, subjective norms, and relevant channel beliefs. Although the Risk Information Seeking and Processing model has been used effectively to model information-seeking behaviors in relation to COVID-19 [28,29] it says relatively little about the extent to which people decide whether to trust the information they are exposed to.

Other studies have examined overall levels of trust in traditional information sources concerning COVID-19 by comparing television, radio, and newspapers with websites [30] but to our knowledge, this is the first study that examines trust and the antecedents of trust in different digital resources in relation to COVID-19. Focusing on the antecedents of trust at this time alongside individuals' behavioral and attitudinal responses to the information they found is key for our future understanding of trusted health communication during health emergencies.

Rationale for This Study

The revised model of trust in eHealth [15] indicates a number of antecedents for trust in online health information and advice and for intention to act on that advice. This study builds upon that work by asking whether existing trust models are a good fit for COVID-19 information-seeking online. The uncertainty provided by the COVID-19 pandemic provides a unique opportunity to examine how people search for, evaluate, and make trust decisions about health information and advice.

The COVID-19 pandemic provides an opportunity to examine in more depth the type of health information seeking that has been taking place. As described previously, people's information needs vary including information on symptoms and symptom management, self-isolation, and vaccination. Vaccination in particular presents a unique opportunity to explore health information seeking within the context of heightened uncertainty and self-reported behavioral outcomes.

It may be that the global nature of the pandemic and people's desire for information exchange fueled social media sources of health information and increased visibility of patient experiences. On the other hand, information corroboration is effortful, and in times of heightened stress and uncertainty, it may not be appropriate or lead to better coping outcomes. Relying on a single source of information may be more straightforward but trust in government or health professionals may impact trust perceptions around such information sources.

Therefore, the study has three aims: (1) to examine whether an existing trust model is a good fit for COVID-19–related information seeking online, (2) to examine differences in affective responses to digital resources about COVID-19 vaccination versus general information about COVID-19, and (3) to examine whether searching had a self-reported impact on vaccination decisions or attitude toward COVID-19 passports.

Methods

Design

A cross-sectional survey was conducted in January 2022. At this time in the United Kingdom, the Omicron variant wave had just peaked, mask use was still advised but no longer compulsory in indoor settings, and self-isolation after a positive test result was still a legal requirement. We collected quantitative data from eHealth users regarding their use of health websites in relation to COVID-19. We used Prolific to recruit a representative UK sample.

Participants

A total of 600 people completed the survey. In total, 525 participants indicated they had looked for COVID-19 information online. Of these 85.3% (448/525) had looked for more general information and advice about COVID-19 while 14.7% (77/525) had looked for information specifically on the vaccine. Full details of participant demographics can be found in Table 1.

Participants were asked whether they had gone online to look for health advice and information about COVID-19. Those answering "yes" were asked to indicate whether they had been searching for general health advice about COVID-19 or whether they had been searching for health advice about COVID-19 vaccinations. Participants then completed a series of questions relating to the last time they searched for health advice about COVID-19 online. Specifically, they were asked to "think about any one digital source that you visited during that search" and to answer the remaining questions with respect to that source. They answered questions relating to the impact of health advice on their coping perceptions and intention to act on the advice, the degree to which they trusted the information and the digital source, their attitude toward COVID passports, for example, the NHS app that shows proof of vaccination and demographic information.

Table 1. Participant demographics (of those who reported looking for COVID-19 information, N=525). All participants were from the United Kingdom.

Characteristics	Values, n (%)
Age group (years)	
18-25	54 (10.3)
26-34	85 (16.2)
35-54	197 (37.5)
55-64	123 (23.4)
65 years or older	66 (12.6)
Sex	
Male	249 (47.4)
Female	273 (52)
Transgender	2 (0.4)
Other	1 (0.2)
Ethnicity	
Caucasian	430 (81.9)
Latino or Hispanic	3 (0.6)
Middle Eastern	5 (1)
African	11 (2.1)
Caribbean	10 (1.9)
South Asian	31 (5.9)
East Asian	11 (2.1)
Mixed	12 (2.3)
Other	7 (1.3)
Prefer not to say	5 (1)
Education level	
Less than secondary school	2 (0.4)
Secondary school	68 (13)
Further education (eg, college, A-level)	177 (33.7)
Bachelor’s degree	194 (37)
Postgraduate degree (eg, MSc, PhD, MD)	82 (15.6)
Prefer not to say	2 (0.4)
Employment	
Full time	254 (48.4)
Part time	87 (16.4)
Retired	85 (16.2)
Unemployed	60 (11.4)
Student	29 (5.5)
Prefer not to say	10 (1.9)
Relationship status	
Single	143 (27.2)
Married or civil partnership or cohabiting	333 (63.4)
Divorced	30 (5.6)
Widowed	10 (1.9)
Prefer not to say	9 (1.7)

Measures

Unless stated otherwise, participants answered the following measures on a 5-point Likert scale (1=strongly disagree to 5=strongly agree).

General Web Trust Questionnaire

The general web trust questionnaire contained 36 items from the study by Sillence et al [15] alongside measures of coping, information corroboration, and affective responses also taken from Sillence et al [15]. Specifically, coping was measured by asking participants to respond to the following stem and variables "After I read the information about COVID-19 I felt…" (1) in control and (2) optimistic using a 5-point scale with the labels: 1=less, 2=slightly less, 3=no different, 4=slightly more, and 5=more (Cronbach α=.84.). Additional affective responses, worried, reassured, at risk, confused and anxious were measured using the same format.

Information corroboration with other sources of information was measured with the following 4 items: (1) "I checked other websites," (2) "I checked other sources," (3) I found the advice consistent across other websites or apps, and (4) I found the advice consistent across other sources (Cronbach α=.87).

Impact on vaccination decision was measured using a single item developed for this study: "To what extent did the information and advice you read online impact your decision regarding COVID vaccinations?" Responses were given on a 5-point scale from "1=It did not influence at all" to "5=It influenced to a very large degree."

Attitude toward COVID-19 passports was measured using a single item developed for this study, that is, "I think COVID passports are a good idea" (1=strongly disagree to 5=strongly agree).

Outcome Measures

Trust was measured following Sillence et al [15], using the mean response to the following 2 items: (1) "I trusted the site" and (2) "I felt I could trust the information on the site" (Cronbach α=.95). Intention to act was an outcome measure, assessed with 1 item "I intended to act upon the advice." This item was taken from Sillence et al [15].

Ethical Considerations

The study received full ethical approval from Northumbria University ethics committee (REF:33639). The survey was hosted on Qualtrics and all data was anonymized. The first page provided participants with information detailing the aim, length, data storage, contact details, and withdrawal process of the study. They were then asked to provide informed consent. Participants received £1.25 (€1.49; US $1.66) for taking part in the study and the average completion time was around 7 minutes.

Results

Overview

We first explored the general web trust questionnaire by performing principal component analysis (PCA). We then explored the relationship between the factor structure and outcomes by testing its fit to the sampled data using structural equation modeling (SEM).

Properties of the General Web Trust Questionnaire

The 36 items of the scale were entered into the PCA. All items loaded onto the extracted components but any items with factor loadings lower than 0.30 were suppressed (Table 2). The analysis indicated that 5 components possessed eigenvalues greater than 1 and together explained 68.7% of the variance in keeping with accepted conventions for successful PCA [31]. The Familiarity factor is the weakest of those extracted although it does meet the minimum threshold of comprising three items [32].

Table 2. Factor loadings for each item (factor loadings lower than .30 are suppressed).

Item	Rotation factor loadings				
	Personal experience (PEx)	Credibility and impartiality	Usability	Privacy	Familiarity
The language made it easy to understand	—[a]	—	.69	—	—
It helped me understand the issue better	—	—	.70	—	—
It was easy to use	—	—	.77	—	—
It told me most of what I needed to know	—	—	.59	—	—
The layout was consistent with other digital sources	—	—	.61	—	—
The advice appeared to be prepared by an expert	—	.69	—	—	—
The advice seemed to be offered in my best interests	—	.73	—	—	—
The advice came from a knowledgeable source	—	.73	—	—	—
The advice seemed credible	—	.80	—	—	—
It was owned by a well-known organization	—	—	—	—	.73
It featured familiar logos	—	—	—	—	.78
It had a professional design	—	—	—	—	.64
It had an attractive design	—	—	.47	—	—
It provided reassurances about my privacy	—	—	—	.66	—
It gave the option to post anonymously	—	—	—	.45	—
It gave reassurances about how they used your information	—	—	—	.78	—
It had a privacy policy	—	—	—	.82	—
It explained their use of cookies	—	—	—	.75	—
It contained accounts of other people's experiences	.87	—	—	—	—
There was a chance to share my experiences	.90	—	—	—	—
There were opportunities to interact with other people on the digital source	.87	—	—	—	—
I saw a wide range of experiences rather different to mine	.88	—	—	—	—
It offered powerful accounts of health experiences	.85	—	—	—	—
It felt like the advice was tailored to me personally	.62	—	—	—	—
I was offered the chance to see experiences from people just like me	.91	—	—	—	—
It contained contributions from likeminded people	.92	—	—	—	—
I was able to contribute to content on the digital source	.88	—	—	—	—
The personal accounts on the digital source were written by people similar to me	.91	—	—	—	—
I found personal accounts that reflected my own experience	.92	—	—	—	—
I found personal accounts that were relevant to my condition	.93	—	—	—	—
There were opportunities to gather information from the personal accounts on the digital source	.91	—	—	—	—
The personal accounts contained advice for readers	.91	—	—	—	—
The personal accounts provided social or emotional support	.89	—	—	—	—
The advice appeared to be impartial and independent	—	.78	—	—	—

Item	Rotation factor loadings				
	Personal experience (PEx)	Credibility and impartiality	Usability	Privacy	Familiarity
The advice seemed objective (ie, no hidden agenda)	—	.81	—	—	—
It was free from advertisements		.54	—	—	—
Eigenvalues	11.8	4.7	3.2	3.0	2.1
Variance explained (%)	32.7	13.1	8.9	8.2	5.8

[a]Not available.

Exploring the Relationship Between the Trust Questionnaire and Self-Reported Behavioral Outcomes

The data were further analyzed using SEM performed in analysis of moment structures using the maximum likelihood estimation method on the item covariance matrix. The specified model was based on Sillence et al [15] and modified to incorporate the new 5-factor structure. The goodness of fit indices supports the specified model. The chi-square value indicated poor fit (χ^2_{773}=1265.5; P<.001). However, this test is considered too sensitive for samples over 200 and here the sample size is 448.

The Cmin/*df* value of 1.64 indicates a good fit. The goodness of fit and adjusted goodness of fit values of .89 and .86 respectively indicate adequate fit [33]. The comparative fit index value of .97 indicates good fit [34], as does the root mean square of approximation value of .04, 90% CI .034-.041 [35].

The model accounted for 64.7% of the variance in trust, 8.7% in coping, 9.7% in information corroboration, and 40.3% in intention to act. All beta path coefficients including those in Figure 1 and those that were not significant were inspected in evaluating the predictive power of the model and are presented for completeness in Table 3.

Figure 1. The trust model with significant standardized path coefficients.

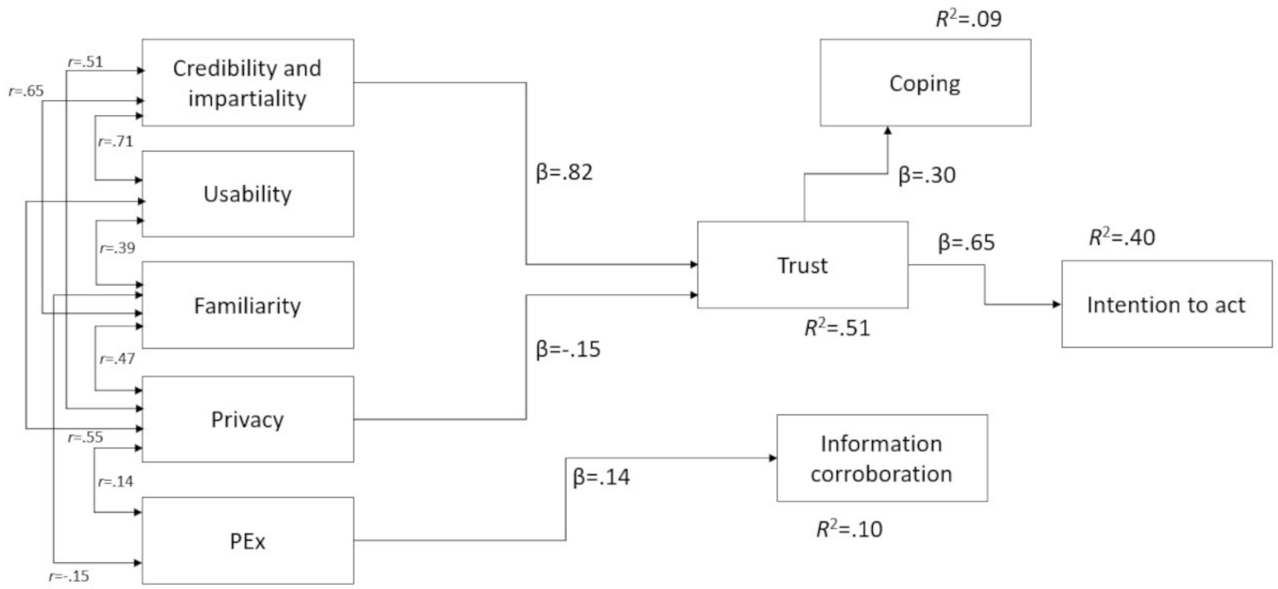

Table 3. The unstandardized path weights and critical ratio (ie, *z* score) values for the main effects of the hypothesized full model.

Parameter	Unstandardized path coefficient	Critical ratio	*P* value
Credibility and impartiality			
Trust	.93	9.79	<.001
Information corroboration	.17	1.07	.29
Usability			
Trust	–.05	–.36	.72
Information corroboration	.39	1.56	.12
Familiarity			
Trust	–.04	–.64	.52
Information corroboration	.12	.98	.33
Privacy			
Trust	–.19	–2.43	.02
Information corroboration	.06	.41	.68
Personal experience			
Trust	–.001	–.03	.98
Information corroboration	.09	2.78	.01
Trust			
Coping	.27	4.89	<.001
Intention to act	.80	15.23	<.001
Coping–intention to act	–.04	–.67	.50
Information corroboration			
Trust	.001	.03	.98
Intention to act	–.02	–.61	.54

Only Credibility and Impartiality were found to possess a significant positive path to Trust. Privacy had a weaker yet significant negative path, meaning privacy assurances were associated with lower trust. Familiarity, usability, and personal experience (PEx) were not significantly predictive of Trust. Only Trust was found to significantly predict the intention to act on the advice. In addition, Trust significantly predicted Coping, suggesting that trustworthy websites heighten individuals' coping perceptions, making them feel more in control and optimistic. PEx significantly predicts Information Corroboration, suggesting that people are exploring a little further than the original digital source; however, this corroboration process does not appear to be affecting their level of trust or intention to act.

Comparison of Two Populations

Although the relatively small sample size for the vaccine information group meant that a comparable SEM model could not be reliably tested a series of independent samples *t* tests were used to compare the two groups on the key variables of interest (Tables 4 and 5).

Table 4. Mean (SD) values for key outcome variables.

Group	Trust	Intention to act	Corroboration	Impact on the decision regarding vaccination	Attitude toward COVID-19 passports
Searching for information on vaccinations (N=77)	4.22 (.91)	4.10 (1.05)	3.49 (1.24)	2.90 (1.21)	3.38 (1.51)
Searching for information on COVID-19 (N=448)	4.33 (.74)	4.13 (.89)	3.49 (1.06)	2.74 (1.39)	3.51 (1.36)

Table 5. Mean (SD) values for "after I read the information" variables.

Group	Worried	Reassured	At risk	Confused	Anxious	Optimistic	In control
Searching for information on vaccinations (N=77)	2.27 (1.11)	3.84 (.95)	2.40 (.98)	2.14 (1.13)	2.42 (1.20)	3.66 (1.11)	3.57 (1.13)
Searching for information on COVID-19 (N=448)	2.48 (.88)	3.68 (.77)	2.84 (.88)	2.15 (.98)	2.76 (.97)	3.27 (.81)	3.42 (.85)

Independent Sample *t* tests

There was no significant difference between groups for trust (t_{523}=–1.169; *P*=.24; Cohen *d*=–.14, 95% CI –.386 to .098), intention to act (t_{523}=–.187; *P*=.85; Cohen *d*=–.02, 95% CI –.265 to .219), corroboration (t_{523}=–.038; *P*=.97; Cohen *d*=–.01, 95% CI –.247 to .237), impact on decision regarding vaccination (t_{523}=.934; *P*=.35; Cohen *d*=.115, 95% CI –.127 to .357), or COVID-19 passports (t_{523}=–.773; *P*=.44; Cohen *d*=–.095, 95% CI –.337 to .146).

Those searching for information on vaccinations (mean 2.40) felt significantly less at risk than those searching for general information on COVID-19 (mean 2.84; t_{523}=3.988; *P*<.001; Cohen *d*=–49, 95% CI –.735 to –.2348) and felt significantly less anxious (mean 2.42) than those searching for general information on COVID-19 (mean 2.76; t_{523}=–2.758; *P*=.003; Cohen *d*=–.34, 95% CI –.583 to –.097). Those searching for information on vaccinations (mean=3.66) felt significantly more optimistic than those searching for general information on COVID-19 (mean=3.27; t_{523}=3.760; *P*<.001; Cohen *d*=.464, 95% CI .220-.707).

There was no significant difference for the variable "In Control" (t_{523}=1.335; *P*=.18; Cohen *d*=–.165, 95% CI –.077 to .407) or for "Confused" (t_{523}=–.054; *P*=.96; Cohen *d*=–.007, 95% CI –.248 to .235). Finally, the variables "Worried" and "Reassured" approached but did not reach statistical significance (t_{523}=–1.813; *P*=.07; Cohen *d*=–.224, 95% CI –.466 to .019 and t_{523}=1.712; *P*=.09; Cohen *d*=.211, 95% CI –.031 to .453, respectively).

Digital Sources of Information

Table 6 shows the digital sources used. The majority of participants used either the NHS health care sources or the governmental sources for both general information and vaccine-specific information.

Digital sources were categorized as: (1) Governmental sources: official UK government website (Gov.uk), World Health Organization, Office of National Statistics, and Centre for Disease Control. (2) NHS health care sources: any page hosted on the NHS website (nhs.uk). (3) Other health care sources: any non-NHS health care website. This included The Mayo Clinic, WedMD, patient.co.uk, and the Health Check podcast. (4) News websites: any of the mainstream news providers, the majority of those reported were the BBC. (5) Search engines: where participants did not go to one source but reported explicitly using search engines, such as Google, to intentionally search for COVID-19–related information, rather than, for example, visiting a particular source (perhaps a source perceived as authoritative or trusted), such as the NHS, government, or BBC websites, and browsing the content from there. (6) Scientific journal: any peer-reviewed journal publishing academic research. (7) Specific health condition websites: any website dedicated to a specified health condition rather than a general health website, including asthma.org and Crohn's & Colitis UK. (8) Social media and forums: any online forum or social networking platform defined as user-driven and facilitating sharing of content, dialogue creation, and communication by and between users (in keeping with Kapoor et al, 2018 [36]). (9) Other: all instances where resources were not explicitly specified or where participants reported visiting multiple sources. All other resources are named individually in Table 6.

Table 6. Digital sources used.

Source	General information (N=448), n (%)	Vaccine specific information (N=77), n (%)
National Health Service health care sources	262 (58.48)	39 (50.65)
Governmental sources	64 (14.30)	11 (14.29)
Multiple resources or unspecific	37 (8.30)	13 (16.88)
News websites	30 (6.70)	3 (3.90)
Other health care sources	6 (1.34)	1 (1.30)
Social media and forums	20 (4.46)	2 (2.60)
Search engines	19 (4.24)	7 (9.09)
Zoe COVID-19 study	6 (1.34)	0 (0)
Scientific journals	1 (0.22)	0 (0)
Specific health condition websites	2 (0.45)	0 (0)
Wikipedia	1 (0.22)	0 (0)
TripAdvisor	0 (0)	1 (1.30)

Discussion

Principal Results

Trust continues to significantly influence self-reported intention to act on health information. In terms of trust predictors, only credibility and impartiality have a significant, direct, and positive relationship with trust. Privacy has a significant negative relationship with trust. Other predictors (familiarity, usability, and PEx) may be indirect and mediated through other trust variables. The variable PEx had a significant direct effect on information corroboration and trust was found to significantly relate to coping perceptions. The findings suggest a number of important discussion points.

First, the Sillence et al [15] trust model provides a reasonable fit for COVID-19–related health information online. Trust continues to predict intention and the credibility and impartiality of the digital source remains the strongest predictor of trust in digital health sources. However, compared to the 2019 model, the picture here is of a simpler trust process in which the credibility and impartiality factor does the “heavy lifting” in relation to trust compared to the other variables. Another key difference is the lack of a relationship between corroboration and trust. In earlier models, health information seekers looked to verify the information they found online by cross-checking with other digital and nondigital sources. Here we see only a direct relationship between the credibility and impartiality of the website and trust. One reason for this, given the predominance of the NHS as the most popular site for information and advice, is that our health information seekers are simply taking the website at face value providing it appears sufficiently credible and impartial. However, it is interesting that in an American sample, information seekers relied heavily upon often unreliable social media sources for information and advice, yet still engaged in relatively low levels of fact-checking [37] and so we must consider the possibility that people are being bombarded with so much information in relation to the pandemic that they simply switch off.

The role of PEx within digital sources is interesting here. While PEx significantly predicts information corroboration there was no subsequent relationship with trust. In the 2019 model [15] it was suggested that patient experiences can positively influence trust but only if users first corroborate the information through other sources. In our study, we suggest that people are checking up on these patient stories and experiences simply out of interest rather than as a way of assessing the trustworthiness of the information. When faced with a high degree of uncertainty and with limited detailed information, assessments of risk may be emotion-based [38], and people may well seek out other people’s personal accounts of their COVID-19 experiences. Personal accounts are often engaging and are seen as more relatable than statistical information when it comes to decision-making [39]. While PEx is now embedded within a diverse range of digital resources, those more closely associated with personal content, for example, social media platforms or individual blogs, were generally underrepresented in the data we collected. Instead, we observed a reliance on official digital sources, in particular, the NHS website and government sources. In terms of pandemic or emergency, reliance on official sources may be more commonplace. Sillence et al [15] found that the majority of UK respondents cited the NHS website as their source of health information, and McNeill, Harris, and Briggs [40] noted that the main UK source to be retweeted during the H1N1 pandemic was NHS Choices. In this study, there was little reported use of social media, which is perhaps surprising and contrasts with other recent health pandemics in which social media use and misinformation have been prevalent [37,41,42] as well as in earlier studies examining the COVID-19 pandemic and the facilitation of conspiracy theories [43,44].

Despite generally high levels of mistrust in the government’s overall handling of the pandemic [5], UK citizens still sought information from government sites. Moreover, we see a reliance on health professionals and public health information. In a time of limited information, there may be fewer options available to information seekers and individuals may be satisfied with seeking official sources of information even if they contain basic knowledge as opposed to more detailed, specific information. This contrasts with earlier work on trust in digital health information in which personalization or tailoring is seen as important to trust. People with long-term experience of a particular health condition often become experts by experience and may seek more specific, tailored digital resources to support their health conditions. This involves making more fine-grained assessments of the personal relevance of the information before deciding to trust or act upon the advice it contains [10,45] and is especially true where the condition is rare or less well known [46]. In the case of COVID-19, a worldwide pandemic affecting all age groups, it might be that generic information applicable to all sufficed in this case. There was little sense that people were checking COVID-19 information in relation to their other, pre-existing health conditions and specific health websites may not have had that information readily available. In light of research that shows how health information overload may lead to increased anxiety [47], our participants’ reliance on relatively few, authoritative websites seems like a reasonable strategy. Too much, possibly conflicting, information about COVID-19 can leave an individual feeling overwhelmed and will ultimately lead to “information avoidance,” which is clearly a poor outcome in the face of a global pandemic.

Unlike Sillence et al’s [15] 2019 model, we note that privacy has a weak negative relationship with trust. The topic of privacy was raised repeatedly in relation to the discussion of contact tracing apps and COVID-19 passports and so while not directly related to the digital source being used it may be that being asked to think about the privacy features of sources stimulates a wider consideration of privacy and mistrust. Rather than privacy policies etc. being seen as an example of good practice, the very fact that these options were present on digital sources may have served as a reminder that data are being collected, processed, and often shared. Privacy nudges may well remind people of the need to be mindful of privacy but can also raise awareness of the data that is available for collection [48,49].

Second, trust significantly predicted coping suggesting that trustworthy websites heighten individuals’ coping perceptions, making them feel able to cope. Interestingly, Wang et al [1] did not find an association between the use of the internet as an information source on COVID-19 and self-confidence in coping with COVID-19 but did not focus on trusted websites.

Looking at the affective variables in more detail for the two groups (general information seeking and vaccination information), we see that those searching for vaccination information felt more positive—specifically, they felt less at risk, less anxious, and more optimistic after reading the information. Wang et al [1] found that vaccination information sources have different effects on students' coping appraisal of COVID-19 with information from medical personnel leading to greater knowledge about the mechanism of vaccination and greater response efficacy of vaccination compared to information from coworkers or colleagues. In terms of coping, during the H1N1 pandemic, those people who adopted a more problem-focused coping strategy including seeking out information to help solve problems were more likely to indicate they would be vaccinated [22]. In our data, those individuals who have gone looking for information about vaccination feel better for having done so.

Zheng et al [50] noted that vaccine information seeking is related to vaccination intention and suggested that health information seeking can be viewed as a coping behavior when people do not have sufficient knowledge of a particular health topic. Although seeking vaccine-related information online was also positively related to perceived vaccine information overload [50], it may be that sticking with a single trusted source is preferable for improved coping. Finally, there were no differences in terms of trust, intention to act on information, or attitude toward COVID-19 passports between participants who were searching for general COVID-19 health information versus those who had searched for vaccination information. This is unsurprising given the similarity of digital sources used.

In summary, people searching for general COVID-19 information as well as those searching for COVID-19 vaccine-specific information sought out official sources of information online. In terms of uncertainty when faced with a global emergent health concern people place their trust in familiar websites and rely on the perceived credibility and impartiality of those digital sources.

Limitations

It is important to note that data was purposely not collected during a period of national lockdown in the United Kingdom. The vaccination program was already well underway and COVID-19 passports were very much still on the agenda. People may have sought information from alternative digital sources had data collection taken place during a period of lockdown. Focusing on the United Kingdom made sense given the local regulations and practices in place, but it would be interesting to make comparisons with other countries going forward. The reliance on the NHS website in the United Kingdom would be interesting to compare with countries where different funding models exist for example where health insurance schemes mean there is no single free at the point of service system. Vaccine hesitancy is relatively low in the U and has declined since the start of the vaccination rollout program from 10% to 3% in September 2021 [51]. Other countries, for example, France, have much higher levels of vaccine hesitancy [52], and comparisons here in relation to trust around digital health resources would warrant further investigation. Finally, it is interesting to note that although we have used a one-shot cross-sectional methodology, we mirror findings from Zhang et al [53], who examined trust over several waves earlier in the pandemic and noted a decrease in the use of social media over time and an increase in trust in government information.

Conclusion

In conclusion, in the context of COVID-19, "credibility and impartiality" remain a key predictor of trust in eHealth resources but in comparison with previous models of trust in online health information, checking and corroborating information did not form a significant part of trust evaluations. In times of uncertainty when faced with a global emergent health concern, people placed their trust in familiar websites and relied on the perceived credibility and impartiality of those digital sources.

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Data Availability

The datasets generated and analyzed during this study are available in the Open Science Framework repository [54].

Conflicts of Interest

None declared.

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Abbreviations

NHS: National Health Service
PCA: principal component analysis
PEx: personal experience
SEM: structural equation modeling

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Original Paper

Transformer-Based Tool for Automated Fact-Checking of Online Health Information: Development Study

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Abstract

Background: Many people seek health-related information online. The significance of reliable information became particularly evident due to the potential dangers of misinformation. Therefore, discerning true and reliable information from false information has become increasingly challenging.

Objective: This study aimed to present a pilot study in which we introduced a novel approach to automate the fact-checking process, leveraging PubMed resources as a source of truth using natural language processing transformer models to enhance the process.

Methods: A total of 538 health-related web pages, covering 7 different disease subjects, were manually selected by Factually Health Company. The process included the following steps: (1) using transformer models of bidirectional encoder representations from transformers (BERT), BioBERT, and SciBERT, and traditional models of random forests and support vector machines, to classify the contents of web pages into 3 thematic categories (semiology, epidemiology, and management), (2) for each category in the web pages, a PubMed query was automatically produced using a combination of the "WellcomeBertMesh" and "KeyBERT" models, (3) top 20 related literatures were automatically extracted from PubMed, and finally, (4) the similarity checking techniques of cosine similarity and Jaccard distance were applied to compare the content of extracted literature and web pages.

Results: The BERT model for the categorization of web page contents had good performance, with F_1-scores and recall of 93% and 94% for semiology and epidemiology, respectively, and 96% for both the recall and F_1-score for management. For each of the 3 categories in a web page, 1 PubMed query was generated and with each query, the 20 most related, open access articles within the category of systematic reviews and meta-analyses were extracted. Less than 10% of the extracted literature was irrelevant; those were deleted. For each web page, an average of 23% of the sentences were found to be very similar to the literature. Moreover, during the evaluation, it was found that cosine similarity outperformed the Jaccard distance measure when comparing the similarity between sentences from web pages and academic papers vectorized by BERT. However, there was a significant issue with false positives in the retrieved sentences when compared with accurate similarities, as some sentences had a similarity score exceeding 80%, but they could not be considered similar sentences.

Conclusions: In this pilot study, we have proposed an approach to automate the fact-checking of health-related online information. Incorporating content from PubMed or other scientific article databases as trustworthy resources can automate the discovery of similarly credible information in the health domain.

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KEYWORDS

fact-checking automation; transformers; infodemic; credible health information; machine learning; automated; online health information; misinformation; natural language processing; epidemiology; health domain

Introduction

With rapid progressions in the digital age, and the vast dissemination of textual information available online, the likelihood of coming across misinformation has surged [1,2]. Misinformation refers to information that is untrue, incorrect, or deceptive in nature [3]. It is prevalent across various domains, with social media being a particularly prominent source [4]. Indeed, many people seek health-related topics on modern platforms and websites available online [5]. Inaccurate health-related information, however, poses an even greater risk, as it can directly impact lives [6,7]. Health misinformation is considered "a health-related claim or information which is not correct due to a lack of scientific evidence or knowledge" [4,8]. The importance of trustworthy online health information became particularly clear during the COVID-19 pandemic, which triggered a new crisis known as the COVID-19 infodemic. An infodemic refers to the excessive spread of false or misleading information across both digital and physical spaces [9] causing confusion and detrimental outcomes, as it underscores the potential risks posed by inaccurate or deceptive information to individuals [3,10]. The infodemic often manifests across 4 key areas: scientific research, policy and health care practice, news outlets, and social media platforms [11]. As a result, distinguishing between true and reliable information and falsehoods has become increasingly challenging. The labor-intensive process of manually verifying information specifically in health-related fields demands expert oversight and consumes significant time [4,9,12]. Therefore, it is crucial to establish an automated fact-checking process to help users identify the accuracy of health-related information available online.

The fact-checking process involves evaluating the truthfulness of information and consists of 3 key tasks: claim detection, evidence retrieval, and claim verification [12]. The first 2 tasks can be considered as factual verification, while the third focuses on assessing the accuracy of claims, which involves distinguishing reliable information from falsehoods to establish their factual validity [13].

Several studies have explored automating the fact-checking process, primarily focusing on misinformation in the form of fake news on websites [4,14,15] or social media [2,7,16-18]. These studies have generated synthetic datasets as the gold standard to facilitate the automation of evidence-based fact-checking. Thus, they compiled datasets comprising information or claims along with their corresponding evidence from trusted sources. Models were then trained using these datasets to automate the fact-checking process [7,10,15,17-20]. To create a database of verified claims, they used methods such as modifying phrases from Wikipedia [20], manual selection of quotation sentences and handpicking of claims from health news sites [14,15,21], and automatic selection of verified claims that were manually done by experts of journalists from fact-checking websites [10]. For example, the FEVER dataset, generated by modifying sentences taken from Wikipedia, consisted of 185,400 claims [22]. PUBHEALTH is another dataset containing false, true, unproven, and a mixture of health-related claims. The dataset also had a column containing journalist-crafted, gold-standard explanations designed to substantiate the fact-check labels assigned to each claim [6,18]. While synthetic datasets provide valuable contributions to advancing automatic fact-checking efforts, they cannot fully address real-world challenges, particularly the need for real-time, dynamic information [23]. Therefore, there is a need that claims and their associated evidence to be automatically extracted [24]. A study [25] developed a Large Language Model called TrumorGPT, which addresses limitations in fact-checking by incorporating retrieval-augmented generation and using continually updated knowledge graphs. This approach uses few-shot learning, knowledge graph construction, and semantic reasoning, which enhances the model's ability to handle fact-checking tasks effectively. Another recent survey [12] explored automated techniques for predicting the veracity of claims, relying on natural language processing, knowledge representation, and databases. This study identified common challenges in fact-checking research and emphasized the importance of information retrieval and knowledge representation, particularly due to the rapid emergence of new claims.

Therefore, a key element of fact-checking involves identifying credible sources, and for health information, leveraging up-to-date scientific literature is essential as it is widely regarded as 1 of the most trustworthy references [26]. Indeed, numerous platforms and databases provide access to health-related and scientific literature, including Google Scholar, PubMed, ScienceDirect, and Web of Science, among others. These databases can be used as a reliable source for the automation of all the processes.

Numerous organizations have established guidelines to aid users in identifying trustworthy claims [27,28] where time-consuming manual recognition plays an important role in the process. In this pilot study, we proposed a novel automated evidence-based fact-checking approach that aims to identify and confirm accurate, truthful information using scientific literature and research databases as sources of truth. This exploratory evaluation highlights how using this approach may help users measure the extent of confidence in a web page and make informed decisions about accepting the health-related information of a website. Thus, the objective was to assess the truthfulness of health-related information through an evidence-based approach, without creating a synthetic database of claims-evidence but leveraging PubMed as a reliable source of fine-grained and up-to-date health-related information.

Methods

Approximately 1000 web pages were provided by Factually Health company on January 31, 2023. This company specializes in identifying reliable health-content websites [29]. The web pages were selected through random sampling within various disease categories to ensure a balanced dataset while minimizing the risk of overrepresentation of any single category. This approach accounted for variations in the number of available websites across disease categories. The web pages then underwent manual cleaning. Redundant pages were removed, and those unsuitable for research were excluded based on the following criteria: pages primarily featuring video content, pages related to clinical studies, pages resembling anecdotes rather than factual health information, or pages that restricted data extraction by Python (Python Software Foundation) libraries.

After this process, a dataset comprising 538 web pages was finalized. These web pages represented a diverse range of diseases, including arthritis (81 pages), chronic obstructive pulmonary disease (79 pages), COVID-19 (66 pages), hypertension (66 pages), lung cancer (70 pages), prostate cancer (66 pages), and diabetes (110 pages).

The selection of diverse disease categories was intended to minimize potential bias in the analysis. However, our previous study demonstrated that the selected diseases did not significantly impact classification results [29]. Using the URLs of each web page, the content was extracted as text files using the "justext" library in Python, to remove additional links and extraneous content from websites, such as navigation links, headers, and footers.

The process included the following three steps: (1) Classification of web page content into 3 thematic categories, semiology, epidemiology, and management by evaluating various transformer models, including bidirectional encoder representations from transformers (BERT), SciBERT, and BioBERT, as well as traditional models such as random forest (RF) and support vector machine (SVM), (2) automating the creation of PubMed queries combining "WellcomeBertMesh" and "KeyBERT" models, (3) automatic extraction of top 20 related literatures from PubMed, and (4) applying similarity checking techniques of cosine similarity and Jaccard distance to compare the content of extracted literature and web pages vectorized using BERT tokenizer. As a reliable source of truth, PubMed was a suitable choice to find evidence for health-related claims. PubMed, an open-source platform dedicated to facilitating searches and retrieval of health-related literature, encompasses over 36 million papers [30].

Classification of Web Page Contents

One of the necessary stages before determining the veracity of a claim or information is to detect the sentences that need to be verified [31]. These claims are crucial to the content's main point but require verification through an annotation schema and developing a benchmark for automated claim detection [14,31]. To detect sentences that need to be verified, two major steps were taken: (1) the identification of 3 thematic categories of content and (2) the classification of web page content according to these categories.

The Content Categories

To compare web page content with materials from the scientific literature database, it was essential to categorize the content, ensuring that comparisons were made within the relevant subject. Three distinct thematic categories have been identified for analysis: epidemiology, semiology, and management. In the epidemiology category, we included all sentences related to the statistics of a disease, the population, the frequencies, the causes, the risk assessment of the disease, and all public health-related information about the disease (eg, as of 2014, the global prevalence rate of rheumatoid arthritis was about 0.24%). In the semiology category, we considered all sentences related to signs (eg, high blood pressure is another sign of the disease) and symptoms (eg, this disease has symptoms such as pain, discomfort, weakness, fatigue). Finally, for the management category, we considered all the sentences linked to therapeutic approach (eg, drug treatment and surgical intervention, prevention, and the element of paraclinical diagnosis of diseases (eg, a complete medical examination carried out by a doctor can better determine if a person has chronic obstructive pulmonary disease and the degree of severity of the disease).

Manual Annotation and Model Development

Two authors (AB and AA) independently annotated 200 web pages on a sentence-by-sentence basis considering the 3 categories of epidemiology, semiology, management, and neutral until reaching a roughly balanced amount of data across all classes [32]. We used the Cohen κ score to assess the agreement between the 2 reviewers AB and AA). Any discrepancies were resolved by the third author (JNN).

Neutral sentences were those that did not correspond to any of the defined thematic categories. Table 1 shows the distribution of sentences for each category. The portable serverless text annotation tool of MedTator-1.3-11 [33] was used for the annotation process. A total of 3 transformer models of BERT, SciBERT, and BioBERT were used to classify the sentences into the 4 mentioned categories. The BERT model has demonstrated superior performance in several text classification tasks [29,34,35]. SciBERT is an extension of BERT and is trained on a vast corpus of scientific literature spanning multiple domains [36] and BioBERT is pretrained using an extensive corpus comprising PubMed abstracts (PubMed) and full-text articles from PubMed Central [37]. We have also conducted a performance comparison between the transformer models and 2 traditional machine learning models: RF and SVM.

Table 1. The distribution of classes.

Category	Number of sentences
Neutral	3162
Semiology	851
Epidemiology	1171
Management	1066

The “BertTokenizer” library has been used to tokenize the incoming sentences, with the following parameters: We applied a maximum sequence length of 128 to standardize the size of each input sentence. To optimize the model's hyperparameters, we applied the Bayesian optimization approach using the ‘BayesianOptimization’ library in Python. The hyperparameter tuning spaces are detailed in Table 2.

Table 2. Hyper-parameter tuning search space.

Hyper-parameters	Range	Best trial
Learning rate	10^{-7}, 10^{-2}	3×10^{-5}
Weight decay	10^{-5}, 10^{-1}	10^{-3}
Number of epochs	(1:5)	3
Batch size	(8,16,32,64)	32

Automating PubMed Query Generation

Overview

Literature extraction involved identifying scientific articles within PubMed to support the process. To achieve this, the approach requires the formulation of a query by combining keywords and Medical Subject Headings (MeSH) terms, which can be extracted from web page content. This process included three steps: (1) Automating PubMed subquery creation from MeSH terms and creating a subquery using the “WellcomeBertMesh” model, (2) Automating PubMed subquery creation from keywords using KeyBert model and creating a subquery, and (3) Construction of the final query by combining the different subqueries.

Automating PubMed Subquery Creation Using MeSH Terms Extracted by Transformers

All the MeSH terms were extracted from the text using a pretrained model of “WellcomeBertMesh,” which takes its inspiration from “BertMesh,” which undergoes the pretraining using the entire text of biomedical publications and is built upon the foundation of the BioBert pretrained model [38]. Given that our evidence for the websites primarily comprised health-related articles from PubMed, we selected this model. Its architecture is rooted in the latest advancements in the biomedical field, prominently featuring Microsoft’s cutting-edge “PubMedBert” as its core framework [38].

To enhance the accuracy of the subquery, the identified MeSH terms were initially organized according to their MeSH categories to construct subsubqueries. The MeSH has a tree structure that is organized hierarchically, visually presenting descriptors in broader and narrower relationships. The top tier of the MeSH tree structure encompasses 19 comprehensive categories. While these terms are not included in MeSH data maintenance and distribution, they can be used to search PubMed by using the search term “category” [39]. Therefore, we have considered the MeSH terms under each head category together using the “OR” operator in this subsubquery. Then, we constructed the subquery using the “AND” operator between extracted MeSH terms in different categories. The pseudo-code for this step is presented in Figure 1.

Figure 1. MeSH (medical subject heading) subquery builder.

```
Input: A list of sentences belonging to a web page S = [s1, s2, …] for a specific category
Input: category to consider ∈ {Epidemiology, Semiology, Management}
Output: A PubMed query extracted from the web page
model ←Load the "WellcomeBertMesh" pre-trained model
/* iterating through sentences to compute their vector representation then extracting the MeSH terms corresponding
to each sentence: */
for i ← 1, n do:
        vi ← model_vector (si)
        meshi ← model (vi)
end for
/* identifying the head categories for each MeSH term extracted*/
for j ← 1, length(mesh) do:
        categoryj ← extract_mesh_head_category(meshj)
end for
/* creating subqueries based on the MeSH terms belonging to the same or different categories */
for i ← 1, n do:
        for k ← 1, K do:
            sub-subquery1, sub-subquery2 ← null
        /* put OR for mesh terms in the same category, put AND for different categories*/
                if meshi belong to same categoryk then
                    sub-subquery1 ← (meshi OR sub-subquery1)
                Else
                  sub-subquery2 ← (meshi AND sub-subquery2)
                end if
            MeSH-sub_query ← (sub-subquery1 AND sub-subquery2)
        end for
end for
```

Automating PubMed Subquery Creation Using Key Phrases Extracted by Transformers

The key phrases from web page contents have been extracted using the transformer model "KeyBERT" library, which is described in previous literature as having the best performance in extracting the key phrases [40], especially for long texts [41], which aligns with our need of extracting the key phrases of the scientific papers. The extracted keywords were combined with the "AND" operator to create a subquery.

Figure 2 shows the proposed pseudo-code to extract the keywords for the creation of the subquery.

Figure 2. Key phrase extractor and subquery builder.

Input: A list of sentences belonging to a web page $S = [s_1, s_2, \ldots]$ for a specific category

Input: *category* to consider ∈ {*Epidemiology, Semiology, Management*}

Output: A PubMed query extracted from the web page

model ←***Load*** the "KeyBERT" pre-trained model

/* computing a vector representation and extracting the key phrases corresponding to each sentence */

for $i \leftarrow 1, n$ **do**

$v_i \leftarrow$ model_vector (s_i)

$keyphrase_i \leftarrow$ model (v_i)

end for

/* creating key phrase subquery tailored to the specified categories */

keyphrase_query ← *null*

for i ← *1, length(keyphrases)* **do**

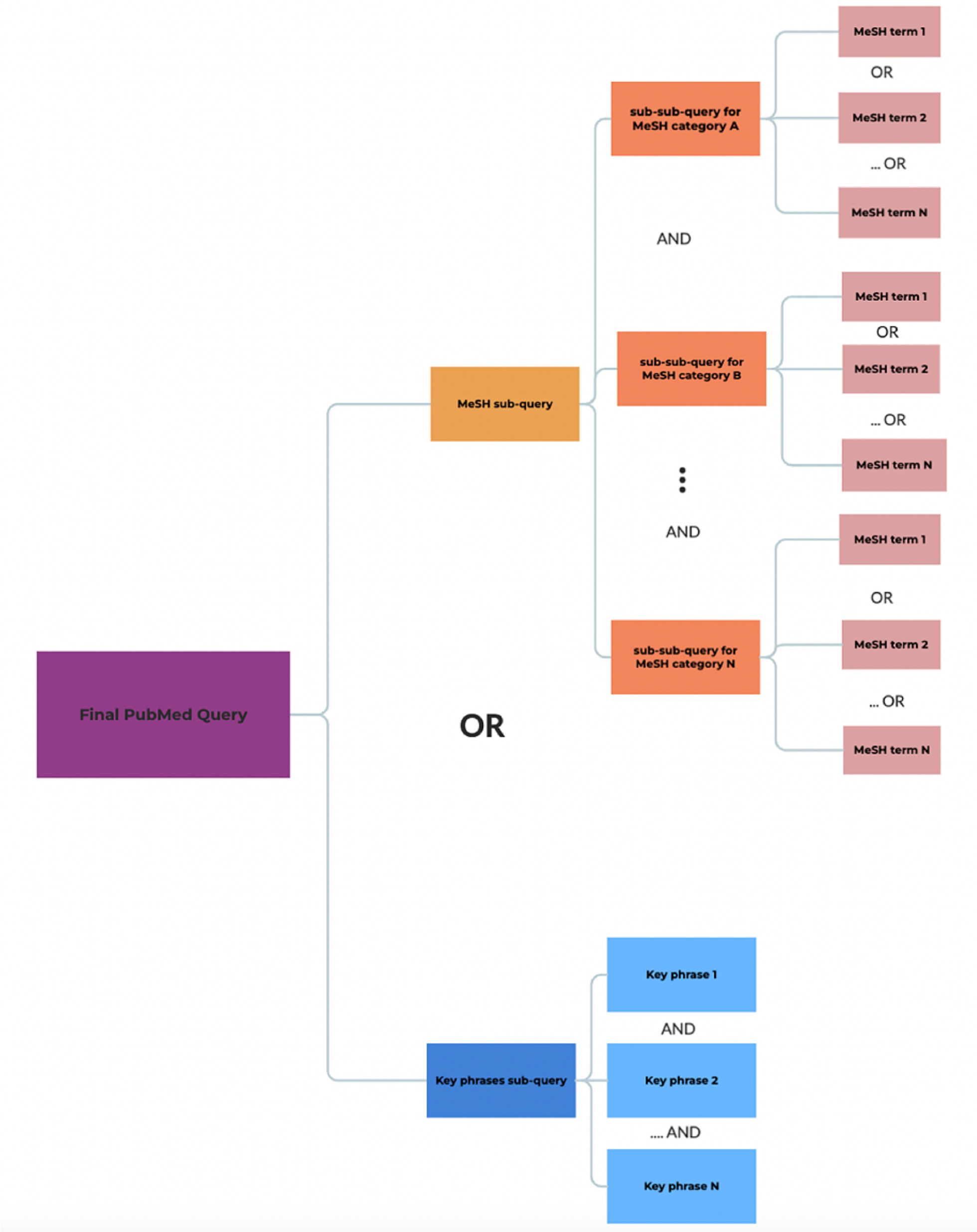
keyphrase_query ← (*keyphrase_query* AND $keyphrase_i$)

end for

Construction of the Final Query

The subqueries extracted from the preceding processes were combined using the "OR" operator to construct the final query. Figure 3 presents a comprehensive overview of the process used to construct the final PubMed query, summarizing the structure and strategy behind its creation.

Figure 3. Detailed process diagram for the development of the comprehensive final PubMed query.



Automating Related Literature Extraction

The final query was used to retrieve a compilation of articles, from which the top open access 20 resulting papers were extracted. The "PMC_ids" of papers were extracted using the "Entrez" library of Python that provides integrated access to PubMed Medline [42]. To evaluate the quality of our query results, we conducted a comprehensive review of the obtained full-text papers. In our assessment of the extracted papers in PubMed, those subjected to filtering within the systematic reviews and meta-analysis category exhibited more related papers to the subject of the research, compared with papers that were not subject to such filtering. Consequently, we selected them to encompass a wider range of relevant articles.

Finally, the automatically extracted papers were manually checked to be pertinent considering the title of the papers, the irrelevant papers were removed and excluded from the final process.

Similarity Detection and Fact-Checking

For the process of computing the similarity measure between different sentences, for each disease, we randomly selected 5 web pages in our dataset. For each of the 3 predefined thematic categories in a web page, 1 PubMed query was generated and with each query, the 20 most related, open access articles within the type of systematic reviews and meta-analysis were extracted. The following steps were then carried out: (1) Categorizing the extracted related literature content based on the 3 thematic categories. This was necessary to analyze sentences (from websites and scientific articles) that are relevant to the same topics. (2) Comparing by thematic category, the content from scientific articles and web pages to identify similar sentences.

Finally, after conducting a manual evaluation of the identified similar sentences, we calculated the average number of categorized sentences for each randomly selected web page, as well as the average number of credible sentences detected. Credible sentences refer to those in the related literature that demonstrated similarity with the sentences from the web pages.

Categorizing the Extracted Literature

The more performant fine-tuned model on the web page contents was used to categorize literature contents into 3 thematic categories. This approach enabled us to facilitate a direct comparison between sentences sharing the same thematic context.

Comparing the Content From Literature and Web Pages to Identify Similar Sentences

For the sentence comparison, we used the BERT vectorizer to transform the texts into vectors. This allowed us to encode the semantic significance of sentences as numerical values, facilitating the application of different similarity detection algorithms [43].

Both scientific articles and web page sentences were transformed into vector representations, taking into account their respective thematic categories. Subsequently, each web page sentence was compared with scientific article sentences of the same category using the cosine similarity and Jaccard technique. A similarity threshold of 87% was chosen to determine sentence selection, ensuring that sentences with over 87% similarity were chosen.

Figure 4 shows the proposed pseudo-code for the similarity-checking part.

Figure 4. Paper similarity detection.

Input: A list of sentences belonging to a web page and papers $S = [s_1, s_2, \ldots]$, $P = [p1, p2, \ldots]$

Input: *category* to check ∈ {*Epidemiology, Semiology, Management*}, *similarity_threshold*

Output: percentage of similarity between two contents

model ←***Load*** the "bert_base_uncase" pre-trained model

/* computing vector representation of paper sentences */

for $i \leftarrow 1, n$ **do:**

v_i , v'_i← model_vector (s_i, p_i)

end for

/* computing the percentage of similarity between the contents of the web page and the papers*/

for $k \leftarrow 1$, *length* (v_i) **do**

/* if the similarity between web page and the paper sentences be more than threshold*/

if *Cosine_similarity* ($v_i, v'_j \in_{(1...n)}$) > *similarity_threshold* **then**

print (corresponding sentences of (v_i, v'_j))

end if

end for

compute similarity percentage

For each disease, we randomly selected 5 web pages and extracted both their related papers and similar sentences. It was due to the inherent variability and specificity of medical information related to each disease. Diseases often exhibit unique characteristics, nuances, and clinical considerations. By prioritizing diseases, we aimed to provide a more granular and clinically relevant assessment of the similarity between the sentences. The outcomes, comprising sentences from the web pages and their corresponding similar sentences, underwent a manual verification by the authors to ensure semantic similarity between them. Subsequently, the proportion of semantically similar sentences between a web page and its related reference papers was calculated.

Ethical Considerations

This research relied solely on publicly accessible data and did not involve any human or animal participants, making it exempt from the need for ethical approval. The study strictly adheres to established data privacy norms to prevent any compromise of confidentiality or privacy. In addition, the project does not include any direct involvement or interactions with individuals, thereby minimizing potential ethical issues. The University of

Montreal's Research Committee has carefully examined our methodology and affirmed that this study falls outside the scope of Medical Research Involving.

Results

This section elaborates on the results of each part of the proposed pseudo-codes.

Classification of Web Page Contents

The annotation process for web page contents achieved a Cohen κ score of 87% among the 2 annotators (AA and AB), indicating high agreement between the annotators and ensuring the reliability of the data used for model evaluation.

The performance of transformer-based models (BERT, BioBERT, and SciBERT) was compared to traditional machine learning models (RF and SVM) for categorizing web page content into four categories. BERT emerged as the most effective model, consistently achieving superior precision, recall, and F_1-scores across all categories. Traditional models, in contrast, demonstrated lower performance, particularly in terms of F_1-scores, indicating limitations in balancing precision and recall effectively.

Table 3 illustrates the performance of the classification models used to classify the content of web pages. The performance matrix includes metrics such as precision, recall, and F_1-score.

Table 3. Performance evaluation of the BERT (Bidirectional Encoder Representations from Transformers) and machine learning models for web page content classification across considered categories.

	BERT[a]			BioBERT			SciBERT			RF[b]			SVM[c]		
Classes	Precision	Recall	F_1-score	Precision	Recall	F_1-score	Precision	Recall	F_1-score	Precision	Recall	F_1-score	Precision	Recall	F_1-score
Neutral	0.96	0.93	0.95	0.88	0.83	0.85	0.85	0.81	0.83	0.51	0.92	0.66	0.72	0.81	0.77
Semiology	0.91	0.94	0.93	0.81	0.81	0.81	0.77	0.79	0.78	0.96	0.05	0.09	0.71	0.59	0.64
Epidemiology	0.92	0.94	0.93	0.80	0.76	0.76	0.75	0.74	0.75	0.8	0.1	0.1	0.69	0.62	0.65
Management	0.95	0.96	0.96	0.83	0.89	0.89	0.83	0.87	0.85	0.59	0.58	0.59	0.74	0.73	0.74

[a]BERT: Bidirectional Encoder Representations from Transformers.

[b]RF: random forests.

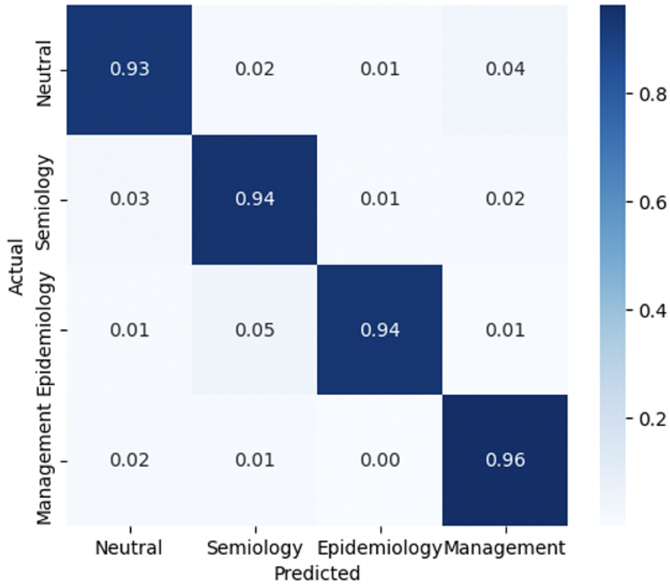
[c]SVM: support vector machines.

According to Table 3, among the transformer models, the BERT model had a promising performance with more than 93% recall for neutral sentences, 94% for semiology and epidemiology, and 96% for the management category. The model had an F_1-score of 95% for neutral sentences, 93% for semiology and epidemiology, and 96% for management. The model had 96% precision for neutral sentences, 91% for semiology, 92% for epidemiology, and 95% for management. Also, traditional models did not have high performance, the precision values for both RF and SVM were relatively low in some classes, indicating a high rate of false positives. Also, the F_1-scores for both RF and SVM were generally lower compared with the BERT model, indicating that they may not achieve a good balance between precision and recall. Therefore, the BERT model was selected for the classification of the web page contents.

The confusion matrix for the BERT model is shown in Figure 5, providing a detailed visualization of its classification performance across the different categories.

Figure 5 shows the confusion matrix for the BERT classifier, which correctly classified 0.93 of the neutral sentences, 0.94 for both the semiology and epidemiology sentences, and 0.96 for management sentences as true positives.

Figure 5. Bidirectional encoder representations from transformers model performance: confusion matrix for the classification of web page sentences into 3 thematic categories.



Automating PubMed Query Generation

To extract relevant literature for the web pages categorized thematically, a PubMed query was generated for each of the 7 diseases. Each query retrieved the 20 most related papers. The titles of the retrieved papers were manually evaluated, and less than 10% were deemed irrelevant, demonstrating the effectiveness of the generated queries. These irrelevant articles were excluded from further analysis.

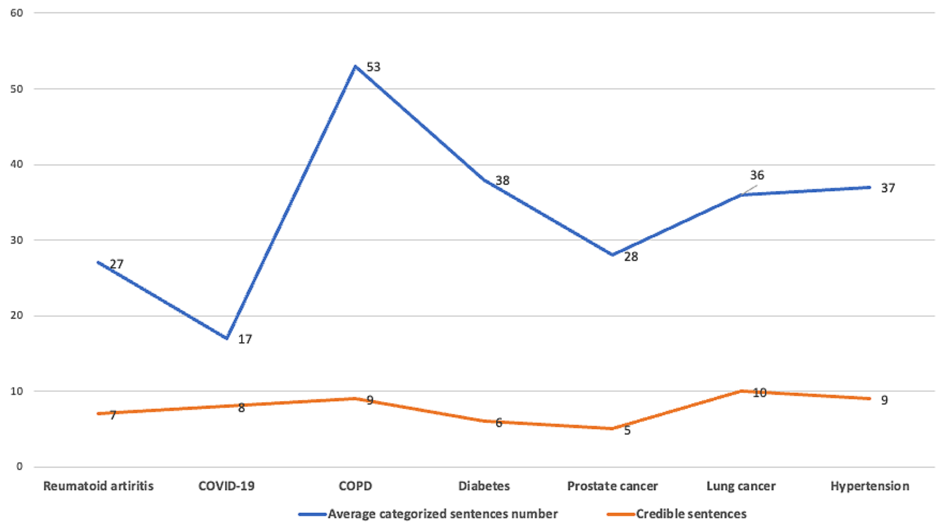
This result highlights the utility of using MeSH terms and key phrases in constructing PubMed queries, which efficiently yielded pertinent literature. The generated weblinks for accessing the papers followed the format: “https://pubmed.ncbi.nlm.nih.gov/PMID/,” with PMIDs obtained directly from the PubMed queries.

Similarity Detection and Fact-Checking

Figure 6 illustrates the average percentage of credible information found in the 5 randomly selected web pages categorized by related diseases. Credible information is defined as sentences in the web pages that were successfully matched with corresponding sentences in PubMed articles.

On average, 23% of the sentences on each web page were identified as similar to statements in the scientific literature. While this demonstrates the potential of the system to detect credible content, a significant challenge arose with false positives. Some sentences achieved a similarity score exceeding 80% but were semantically dissimilar upon closer inspection.

Figure 6. The average number of credible sentences on web pages (red line) versus the average number of all sentences on each web page (blue line). COPD: chronic obstructive pulmonary disease.



For instance, the following sentences from an extracted paper and a web page had a similarity score of 88% yet conveyed different meanings:

1. “Previous studies have documented residual symptoms that continue 12 weeks after the onset of acute COVID-19, known as post-acute or long COVID-19.”

2. “The acute phase of COVID itself can last for up to 14 days.”

This highlights the need for more sophisticated approaches to accurately distinguish between syntactic similarity and genuine semantic alignment.

As an illustrative example, for the rheumatoid arthritis category, we randomly selected 5 web pages, each containing an average of 27 sentences distributed across 3 thematic categories: epidemiology, semiology, and management (represented by the blue line). Among these, an average of 7 sentences per web page were deemed credible and successfully matched to corresponding statements in the scientific literature (depicted by the red line).

Discussion

Principal Findings

In the present pilot study, our objective was to automate aspects of the fact-checking process for online health information. While previous research [21,26] has explored automation in various stages of fact-checking, such as evidence retrieval or claim identification, this pilot serves as an initial step toward achieving full automation in the fact-checking process. Our approach includes the automation of identifying verifiable sentences through a classification process. Notably, our study used a fine-tuned BERT model, which exhibited notable efficacy in categorizing health-related sentences. Although BioBERT and SciBERT models have been reported to outperform BERT in various downstream tasks [36,37], in our investigation, the BERT model demonstrated superior performance. This discrepancy could be attributed to BERT training on general-purpose texts, such as Wikipedia or Book Corpus [35], which align more closely with the content of websites targeted at general populations. In contrast, BioBERT and SciBERT are trained on more specialized texts, such as scientific publications [36,37].

Previous research [14,31,44] has shown that the identification of claim-worthy sentences or the recognition of key information needing verification from reliable sources is a fundamental first step in automating the fact-checking process akin to our approach. This process is commonly structured as a text classification task. The previous studies used human annotators [44] or crowdsourcing [31] to tag claim-worthy sentences and trained machine learning models to classify them. A previous study [14] focused on detecting claims within news and public information, assigning each sentence a likelihood score for containing significant factual claims. Also, automating the fact-checking process is far from straightforward, as it necessitates the utilization of artificial intelligence tools to struggle with the complexity of text and context [10]. Studies often considered the problem as a binary classification to split the contents into credible or non-credible information, however, the decision is more complex since there may be several ambiguities in the sentences. In addition, several parts of the process depend on human judgment, which needs further research in the area. Building on this groundwork, our study applied a BERT-based classification approach to detect health information requiring verification and automatically proposing a sentence for this process. Previous studies relied on reviewer selections to develop claim and evidence datasets, lacking attempts to automate claim identification with real-world resources [17,18,45].

In addition, rather than constructing a manual reference dataset as the evidence for verifiable sentences, we leveraged the PubMed database as our source of truth. We automated the detection of evidence for claims made on web pages in an unsupervised approach, streamlining the verification process. This aligns with previous studies [21,26] that used PubMed publications as evidence, using transformer models to generate queries and retrieve documents from PubMed. We demonstrated the effectiveness of using transformer models to extract MeSH terms and key phrases from web page content, enabling the efficient generation of PubMed queries. This approach facilitated the retrieval of related articles from scientific references without requiring supervision. According to a previous study [14], to verify the veracity of the claims, it is crucial to translate them into queries against the reference databases. However, other studies [6,20,22] created a knowledge database as the references to compare with the claims. Notably, Sarrouti et al [6] introduced a dataset comprising evidence-claim pairs, manually annotated as SUPPORT, REFUTE, and NEUTRAL. They used BERT-based models to create a realistic testing ground for evidence-based fact-checking systems.

To assess the alignment between claim sentences and extracted references, we measured their similarity, a practice supported by [46]. This study underscores the necessity for a model in claim verification to measure the semantic similarity between claims and verified factual knowledge or references. To compare the semantic similarity, we used a transformer-based representation that converted the textual content into vectorial representation, allowing us to capture the contextual nuances of each sentence consistent with previous approaches [19,43,47]. This approach is more efficient and produces semantically richer sentence representations than simply averaging the vectors of words that appear in each sentence, and facilitates the similarity detection for the algorithms [48]. We successfully identified factual evidence for 23% of the health-related information extracted from web pages, indicating the complexity inherent in health information. Further research is required to enhance contextual comparison between claims and verified references. Also, the cosine similarity outperformed the Jaccard distance measure for comparing the claims and evidence in this study, which is different from the previous study [4], as they reported that the Jaccard distance was better at the similarity selection measure. The reason may be due to differences in the nature of the datasets in the 2 studies.

Limitations

This study had several limitations. First, we faced a challenge in identifying sentences within the papers that closely matched the content of the web pages. Numerous methods have been devised to tackle this issue [19,43,46]; however, a comprehensive consideration of the complete meaning of sentences requires further investigation. In addition, 77% of the sentences did not have matching counterparts in the academic literature that we retrieved. Regarding this proportion, 2 possible assumptions can be made: either the sentences themselves were not valid or the algorithm was unable to locate their related counterparts. Another potential reason could be that the sentences, though addressing a common subject such as the same medical condition, exhibited variations in meaning or contextual interpretation. Consequently, it would be premature to assert that these unmatched sentences are inherently not credible, given the vast volume of published papers that renders comprehensive verification computationally infeasible. Expanding the number of selected papers for comparison could therefore increase the likelihood of identifying additional relevant sentences in the literature. Nonetheless, quantifying the proportion of credible sentences offers valuable insights to aid users in their trust assessment.

It is worth acknowledging that authors in the realm of health-related data often simplify and rephrase content to cater to their target audience, making it more challenging to identify credible references for their statements. Therefore, the researchers propose exploring other models such as text generation models as potential solutions to address this particular challenge including WordNet or sequence-to-sequence (Seq2Seq) models.

A second limitation was the sample size of the academic papers used in the comparison. Due to the extensive volume of health-related publications, the assessment was limited to a selection of 20 papers. Expanding this scope to include more papers per content type could enhance the discovery of factual evidence in PubMed publications. Thus, further investigation into paper retrieval approaches is recommended.

A third limitation was that, although the thematic categorization of web page content, such as epidemiology, semiology, and management, ensured that the generated PubMed queries were more precise and contextually relevant, the need for quality assessment of the extracted PubMed articles remains evident. While our method provides users with essential information to assess the accuracy of health information, the ultimate determination of its truthfulness may depend on individual judgment, expert evaluation, source credibility, scientific article quality (eg, journal quality, impact factor for the domain) and the contemporaneity of the information (eg, date of publication, retracted).

The retrieved articles may vary in quality, ranging from high-impact studies to potentially outdated or retracted articles that could influence the reliability of the fact-checking process and the conclusions drawn from matched content. Addressing these characteristics within an automated process remains a key challenge. In our previous research, the credibility of the sources was automatically assessed [29]. In this study, while we evaluate comparability with scientific articles, developing a credibility scoring strategy for these articles is also necessary. Combining an algorithm that evaluates website credibility and assigns a credibility score to scientific articles with 1 that determines truthfulness could significantly enhance the effectiveness of fact-checking. These models can change the structure of sentences and may improve the possibility of finding more similar sentences. Finally, while the process could not be automated entirely since each step needed human supervision for the results, the suggested techniques have the potential to substantially alleviate the human effort required to locate valid information.

Conclusions

Our approach aimed to empower users in the decision-making process regarding the truthfulness of information by providing relevant evidence and enabling informed judgments. As a pilot, this research serves as an initial step toward exploring the feasibility of automating fact-checking processes in health information. Specifically, the methods presented here could be applied to create tailored fact-checking workflows for specific disease areas, such as diabetes, arthritis, or cancer, which were among the categories included in this study. For instance, thematic categorization (eg, management and epidemiology) could improve the precision and relevance of fact-checking tools in health care contexts. Using state-of-the-art models such as transformers may improve the performance of the model since the BERT embedding captures the meaning of the sentences [49]. The investigation also revealed that incorporating PubMed publications as a trustworthy resource can enhance the discovery of similar credible information as evidence. Finally, while the process could not be entirely automated and required human supervision, the suggested techniques demonstrate significant potential for integration into fact-checking tools. This integration could reduce the effort required to validate health information, ultimately increasing accessibility and reliability for end-users. Future work should focus on expanding the dataset and testing the approach in real-world scenarios to further refine its applicability across various health domains.

Acknowledgments

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Data Availability

The datasets generated and analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

This research was funded by the Mitacs acceleration program in partnership with Factually Health Company, and the IVADO Funding for Collaborative Research in Data Science to Serve Sustainable Development.

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Abbreviations

BERT: bidirectional encoder representations from transformers
MeSH: medical subject heading
RF: random forest
SVM: support vector machines

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Original Paper

Beliefs in Misinformation About COVID-19 and the Russian Invasion of Ukraine Are Linked: Evidence From a Nationally Representative Survey Study

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Abstract

Background: Detrimental effects of misinformation were observed during the COVID-19 pandemic. Presently, amid Russia's military aggression in Ukraine, another wave of misinformation is spreading on the web and impacting our daily lives, with many citizens and politicians embracing Russian propaganda narratives. Despite the lack of an objective connection between these 2 societal issues, anecdotal observations suggest that supporters of misinformation regarding COVID-19 (BM-C) have also adopted misinformation about the war in Ukraine (BM-U) while sharing similar media use patterns and political attitudes.

Objective: The aim of this study was to determine whether there is a link between respondents' endorsement of the 2 sets of misinformation narratives, and whether some of the selected factors (media use, political trust, vaccine hesitancy, and belief rigidity) are associated with both BM-C and BM-U.

Methods: We conducted a survey on a nationally representative sample of 1623 individuals in the Czech Republic. Spearman correlation analysis was performed to identify the relationship between BM-C and BM-U. In addition, multiple linear regression was used to determine associations between the examined factors and both sets of misinformation.

Results: We discovered that BM-C and BM-U were moderately correlated (Spearman ρ=0.57; P<.001). Furthermore, increased trust in Russia and decreased trust in the local government, public media, and Western allies of the Czech Republic predicted both BM-C and BM-U. Media use indicating frustration with and avoidance of public or mainstream media, consumption of alternative information sources, and participation in web-based discussions indicative of epistemic bubbles predicted beliefs in misinformation narratives. COVID-19 vaccine refusal predicted only BM-C but not BM-U. However, vaccine refusers were overrepresented in the BM-U supporters (64/161, 39.8%) and undecided (128/505, 25.3%) individuals. Both beliefs were associated with belief rigidity.

Conclusions: Our study provides empirical evidence that supporters of COVID-19 misinformation were susceptible to ideological misinformation aligning with Russian propaganda. Supporters of both sets of misinformation narratives were primarily linked by their shared trust or distrust in the same geopolitical actors and their distrust in the local government.

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KEYWORDS

misinformation; COVID-19; war in Ukraine; political trust; digital media; belief rigidity; vaccine hesitancy; war; political; trust; belief; survey; questionnaire; national; false; association; correlation; correlation analysis; public opinion; media; news; health information; public health; COVID; misinformation; propaganda

Introduction

During the COVID-19 pandemic, many countries worldwide have experienced an increase and acceleration in the spread of conspiracies, hoaxes, misinformation, and intentionally disseminated disinformation [1,2]. A large body of scientific research has demonstrated the detrimental effects of the infodemic on vaccine hesitancy worldwide [3,4], hateful and divisive rhetoric [5], politicization of the issue [6], and radicalization [7].

Social epistemic structures known as echo chambers, which primarily emerge in web-based communities where members reinforce their shared views while actively discrediting other relevant voices [8], have been frequently identified as primary digital channels reinforcing beliefs in misinformation and fueling radicalization [9,10]. Similarly, in the Czech Republic, misinformation narratives have been monitored in web-based communities [11], as well as in chain emails, that have been massively forwarded [12,13]. The main COVID-19 misinformation narratives encompassed a wide range of claims, including the pandemic being a hoax, the assertion that the virus is not dangerous or was artificially developed, and the belief that vaccines are harmful, while PCR tests, face masks, and other preventive measures against COVID-19 pandemic are ineffective [14].

Apart from the spread of misinformation—false information disseminated without the intent to deceive—fueled by the uncertainty of pandemic developments and negative emotions on social media [15], it has been suggested that the issue of COVID-19 pandemic has also been "hijacked" and used by disinformation campaigns conducted for monetary [16] or political purposes [17]. Previous studies have indicated that worries about the harmful effects of vaccination and distrust in Western pharmaceutical companies and politicians have been exploited and reinforced by Russian disinformation campaigns, aiming to undermine public support for state authorities [18]. The Czech Security Information Service reported that pro-Russian activists, promoting antivaccination attitudes and pro-Russian narratives, used COVID-19 pandemic as a useful topic for spreading conspiracies and disinformation [13]. These activists operated largely in symbiosis with the anti–COVID-19 measures movement, particularly on Czech language fringe news websites [13] labeled "disinformation" or "antisystem" websites by media experts [12].

Another massive wave of infodemic began to spread after the Russian invasion of Ukraine in February 2022 [19]. The war has become a new global threat, dominating media coverage and social media attention. Consequently, the focus on COVID-19 pandemic has receded, along with COVID-19 misinformation in the web-based environment [20]. In the Czech Republic, misinformation, including pro-Russian narratives about the conflict in Ukraine and hostile targeting Ukrainian refugees, has spread on "antisystem" websites [21]. These narratives also proliferated via chain emails, which have steeply increased in number after the invasion [20], in social media communities [22], as well as in web-based discussions under web news articles, where increased troll and bot activity has been observed [20,21]. A direct comparison of fact-checking publications revealed that while hoaxes related to both COVID-19 pandemic and the Ukraine war were predominantly disseminated via social media, they differed in their preferred format. Fabricated content was more common in pandemic-related hoaxes, whereas out-of-context images were prevalent in disinformation surrounding the Russia-Ukraine war [23]. The flood of web-based disinformation during both COVID-19 pandemic and the Russian invasion of Ukraine galvanized fact-checking and verification efforts [24-26].

While previous research has shown that individuals who believed in COVID-19 conspiracy theories were more prone to believe in other unrelated, broader conspiracies [27-29], it remains an open question whether those who believe in misinformation about COVID-19 pandemic are also more susceptible to believe politically ideological misinformation. This question has become pressing since the onset of the Russian invasion of Ukraine and the massive spread of disinformation aligned with Russian propaganda. Such disinformation mixes elements of strategic narratives rooted in historical revisionism, imperial mythology, and war memories with factual lies and misinterpretations, aiming to manipulate public opinion and influence political decisions in European Union (EU) and North Atlantic Treaty Organization (NATO) member states [30]. Comparisons have been drawn between the disinformation narratives related to COVID-19 pandemic and those related to the Russia-Ukraine war [14,23]. Anecdotal observations suggest that individuals sharing rigid beliefs in misinformation narratives about COVID-19 pandemic (BM-C) may have also adopted beliefs in misinformation about the Russian invasion of Ukraine (BM-U), and that they tend to use specific digital media channels while avoiding public and mainstream media and share antisystem attitudes and political orientation toward Russia [21]. However, no empirical research has examined this social phenomenon population-wide. Therefore, to validate or refute these observations, we conducted a nationwide representative cross-sectional survey of the Czech Republic.

The first aim of this study was to determine whether there is an association between respondents' endorsement of the 2 sets of misinformation narratives (BM-C and BM-U).

- Hypothesis 1: There is a correlation between BM-C and BM-U.

The second aim was to examine associations between beliefs in the 2 sets of misinformation (BM-C and BM-U) and factors anecdotally observed or suggested in both contexts. Media monitoring and official reports have indicated that both sets of misinformation have been spreading through specific digital media channels, such as web-based discussions and web-based bubbles or echo chambers, political chain emails, and antisystem websites with political leanings toward Russia [13,21]. However, it remains unknown whether users of these channels are significantly more likely to believe the misinformation and to trust specific geopolitical powers on a nationwide scale. Therefore, we examined associations between (2a) political trust and the 2 sets of misinformation, as well as associations between (2b) media use factors and the 2 sets of misinformation.

- Hypothesis 2a: Distrust in the Czech government's decisions and public media, trust in Russia, and distrust in Russia's geopolitical opponents and Western allies of the Czech Republic (US, EU, and NATO) are shared factors that explain both BM-C and BM-U.
- Hypothesis 2b: The use of antisystem websites, emails, and social media as information sources, along with participation in web-based discussions and engagement in web-based bubbles, explains BM-C and BM-U.

The third aim of this study was to examine whether BM-C and BM-U are connected to COVID-19 vaccine refusal. Determining that this factor explains not only BM-C but also BM-U would indicate that this specific health-related behavior significantly reflects the politicization of the COVID-19 issue to such an extent that it increased susceptibility to ideological misinformation.

- Hypothesis 3: COVID-19 vaccine refusal explains both BM-C and BM-U.

In addition, we aimed to test whether beliefs in the 2 categories of misinformation are associated with belief rigidity. The underlying assumption is that individuals who endorse misinformation place greater emphasis on the importance of these beliefs, as they often provide complex collective narratives and transcend mere opinions on specific health, societal, or political issues. Rather, they may become a belief system infused with moral convictions, which tends to be fixed and rigid [31,32]. Belief rigidity has been connected to echo chambers [8,33], conspiracy thinking [34], and polarization [31,35,36].

- Hypothesis 4: Belief rigidity explains both BM-C and BM-U.

Methods

Procedure

The data were collected from April 25 to May 5, 2022, at the time when COVID-19 pandemic had subsided and 2 months after the start of the Russian invasion of Ukraine. The cross-sectional survey was completed by members of the Czech National Panel [37] as a part of a longitudinal study [38], using the standardized computer-assisted web interviewing method. Participation was voluntary, with financial compensation. The mean completion time of the survey was approximately 11 minutes, and participants were informed in advance about the length. The survey included sociodemographic data (gender, age, level of education, region of residence, and household income), as well as questions about beliefs in misinformation regarding COVID-19 pandemic and the Russian invasion of Ukraine, media use, political trust, belief rigidity, and whether and how many times they have been vaccinated against COVID-19. Only self-reported measures were used. To ensure the protection of personal information, all collected data were securely stored in an encrypted, password-protected institutional database hosted on National Institute of Mental Health servers. Only authorized personnel had access to the data. Any personal identifiers were anonymized during data processing to prevent unauthorized access or identification of participants.

Participants

Participants of the longitudinal study [38] were invited to participate in this study. We received responses from 1623 respondents (return rate: 55% of 2950 invited; 839/1623, 51.7% women) aged between 20 and 91 years (mean 55.04, SD 15.55). The proportions of participants' attained educational levels were as follows: 4.6% (76/1623) elementary school education, 29.1% (472/1623) certificate of apprenticeship, 36.2% (587/1623) high school education, and 30.2% (490/1623) university degree. The sample was constructed to be quota-representative of the adult population of the Czech Republic. To ensure repeated participation of various sociodemographic groups, it was necessary to adjust the current sample through poststratification weighting. This adjustment was based on current population distributions (using data from the Czech Statistical Office) for the following characteristics: gender, age, education, size of place of residence, region, crosscutting of age and education, crosscutting of age and gender, and employment status. The inclusion criteria were knowledge of the Czech language and being older than 18 years.

Measures

Beliefs in Misinformation Narratives

To measure BM-C and BM-U, we developed 2 questionnaires. The questionnaires were constructed based on the main misinformation related to COVID-19 published by the Center Against Hybrid Threats within the Ministry of the Interior of the Czech Republic [39]. The Ministry reported that such narratives had been spread in an attempt to exploit societal issues in accordance with the interests of foreign powers. We reduced the number of items from the original 15 to 6 based on results from our pilot study (N=423), excluding items according to item analysis, exploratory factor analysis (EFA), and the results of the Cronbach α coefficient. BM-C items are shown in Textbox 1. Similarly, the BM-U questionnaire was constructed, using the prevalent misinformation narratives related to the Russian invasion in Ukraine at the time of the study [40]. We selected 4 items from the original 8 based on pilot data according to the same procedure as in BM-C. BM-U items are shown in Textbox 1. Both questionnaires showed good internal consistency in both the pilot study (BM-C: Cronbach α=0.953; BM-U: Cronbach α=0.932) and in this study (BM-C: Cronbach α=0.846; BM-U: Cronbach α=0.891). Participants rated the items on a 5-point scale (1: "I do not agree at all"—5: "I completely agree").

Textbox 1. Items for beliefs in misinformation narratives (beliefs in misinformation narratives about COVID-19 pandemic [BM-C] and beliefs in misinformation about the Russian invasion of Ukraine [BM-U]).

Evaluate the extent to which you agree or disagree with the following statements.

BM-C

- "Western pharmacological vaccine companies are untrustworthy."
- "Vaccines are dangerous for the vaccinated."
- "The discrimination against Russian and Chinese vaccines is largely driven by political reasons."
- "The coronavirus was developed artificially, perhaps as a biological weapon."
- "The epidemic is fake, the situation has never been so serious."
- "Epidemic measures were ineffective and were counterproductive."

BM-U

- "The demilitarisation and de-Nazification of Ukraine is a legitimate objective for the Russian military operation in Ukraine."
- "The civilian casualties on the Ukrainian side are deliberately exaggerated by the European media."
- "Ukraine is developing banned biological weapons on its territory."
- "NATO and Western countries are exploiting Ukraine to serve their own interests."

COVID-19 Vaccination

Participants were asked whether and how many times they had been vaccinated against COVID-19 (0, 1, 2, or 3 times). It should be noted that at the time of the survey, the Ministry of Health of the Czech Republic recommended 3 doses of the vaccine.

Media Use

We used an adapted version of the media use questionnaire [41]. We omitted some items and included additional ones, while also rewording some items to better suit the research objectives of measuring media behavior and media effects that may be indicative of or contribute to the spread of misinformation. To compare responses to the 2 societal issues, we used identical wording for questions related to the COVID-19 pandemic (C), and the Russian invasion of Ukraine (U), with only a difference in the topic and time frame being questioned (eg, “How often did you search for news regarding COVID-19 at the height of the pandemic?” or “How often did you search for news on the Russian invasion of Ukraine last month?”). The mirrored items were placed in different locations within the questionnaire and never in sequence. The newly developed measures were tested in a pilot survey conducted via Facebook in April 2022 (N=423; response rate: 51.8% of 817 invited). Respondents were asked about their frequency of use of media channels categorized as public media, mainstream news websites [42], and those that have been previously connected to spreading misinformation: emails as a source of information (possibly indicating political chain emails), YouTube, social media, and “anti-system websites” that have been identified as such by various media experts [12,42]. However, at the time of our survey, in reaction to the Russian invasion of Ukraine and the uncertain development of the situation, most of the antisystem websites were evaluated as a threat to national security and were officially banned in the Czech Republic due to their open promotion of Russian disinformation narratives. Only 1 functioning, moderate news website, remained in our survey. Participants were also asked about their engagement in web-based discussions and web-based bubbles related to C/U. Furthermore, we decided to examine several other aspects of media use—searching and sharing the news (C/U), respondents’ interest in the 2 topics (C/U), and their frustration with public and mainstream media.

Political Trust

Perceptions of trust in the (1) Czech government and (2) public media were assessed in relation to both issues (C/U). Due to the high correlation of items 1 (C) and 2 (C) (r=0.783, n=1623; P<.001), as well as items 1 (U) and 2 (U) (r=0.849, n=1623; P<.001), we summed the items in 1 score for each topic: trust in the Czech government and public media regarding COVID-19 (*Trust in CZ-C*); trust in the Czech government and public media regarding Russian invasion of Ukraine (*Trust in CZ-U*). In addition, distrust in foreign geopolitical actors (Russia, United States, China, EU, and NATO) and belief rigidity was assessed. Detailed descriptions of the survey items and response scales for media use, political trust, and belief rigidity are shown in Multimedia Appendix 1.

Statistical Analysis

All data were analyzed using R software (R Core Team). The significance level was set at P≤.05. Poststratification weighting was applied using a quadratic programming algorithm based on current population distributions of the following characteristics: gender, age, education, region, residence size, job status, interaction between age and education, and interaction between age and gender. Descriptive statistics were used for demographic description. Shapiro-Wilk test did not confirm the normal distribution of BM-C and BM-U. EFA was conducted on both BM-C and BM-U items to uncover the latent structure based on interdependence between the items. The primary aim of the EFA was to clearly differentiate COVID-related and ideological items, ensuring that the correlation between BM-C and BM-U scales is not influenced by the ideological items possibly present in BM-C.

As the data were nonparametric, we used Spearman correlation to determine the relationship between BM-C and BM-U (Hypothesis 1). Multiple linear regression models were used to reveal the relationships between the examined factors according to Hypotheses 2-4 (COVID-19 vaccine refusal, media use, political trust, and belief rigidity) and beliefs in BM-C and BM-U. For the multiple linear regression models, we used normalization of nonparametric right-skewed data by square root. Two distinct models were constructed, 1 for BM-C and 1 for BM-U (dependent variables), with COVID-19 vaccine refusal, media use, political trust, and belief rigidity as independent variables. We also controlled for demographic characteristics (age, gender, education, and income). To compare the predictive power of the independent variables, we used a feature scaling approach. Specifically, we used normalization to standardize all continuous input variables to a uniform range of 1-5. This step guarantees comparability and stability in the regression analysis, establishing a standardized input space for the model and enabling the evaluation of the effect of each variable. However, categorical variables were maintained in their original scale to preserve their interpretability and intrinsic categorical distinctions.

Ethical Considerations

The procedure performed in this study was in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments. The study was approved by the ethics committee of the National Institute of Mental Health, Czech Republic (reference no. 181/21). The data were anonymized. Respondents were compensated by the Czech National Panel at a standard rate of 1 CZK (US $0.041) per minute for completing the questionnaire. The compensation was provided as credit, which could be transferred to a bank account, redeemed for a material reward, or donated to charity. In addition, 2 randomly selected participants had the chance to win a tablet. All participants provided informed consent. They were informed about the purpose of the study. Furthermore, they were informed that the data would be accessible only to authorized research staff and the principal investigator, whose name and contact information were provided for any follow-up questions or concerns. Participants were assured that their participation was voluntary.

Results

Exploratory Factor Analysis

EFA was conducted using parallel analysis to identify the underlying structure of the BM-C and BM-U items. Two factors were extracted, explaining 58.7% of the total variance, with factor 1 accounting for 32.4% of the variance and factor 2 accounting for 26.3%. The overall Kaiser-Meyer-Olkin measure of sampling adequacy was 0.91, indicating that the data were highly suitable for factor analysis. The Bartlett sphericity test (χ^2_{45}=9338; *P*<.001) further confirmed the appropriateness of conducting EFA. An Oblimin rotation was applied to enhance interpretability, allowing for correlations between factors. The first factor, labeled "Ideological," included all BM-U items and BM-C item 3 ("The discrimination against Russian and Chinese vaccines is largely driven by political reasons"). The second factor, labeled "COVID," comprised all remaining BM-C items (except item 3). Due to its significant loading on the ideological factor and theoretical considerations, BM-C item 3 was excluded from further analysis. Factor loadings are shown in Multimedia Appendix 2.

Correlation Between BM-C and BM-U and Descriptive Statistics for BM-C and BM-U

A moderate positive correlation was found between BM-C and BM-U (Spearman ρ=0.57; *P*<.001). For a more straightforward description of BM-C and BM-U, we considered 4 points ("I rather agree") and 5 points ("I completely agree") as an indication of belief in misinformation (*supporters*). Those who rated 3 points ("I neither agree nor disagree") were considered undecided whether they believe in misinformation or not (*undecided*). Those who rated 1 ("I completely disagree") or 2 ("I rather disagree") were considered *opponents* who do not endorse misinformation narratives. According to this grouping based on cumulative scores, the prevalence of BM-C supporters was 13.4% (217/1623), and the prevalence of BM-U supporters was 9.9% (161/1623). There were 50% (812/1623) of undecided respondents for BM-C and 31.1% (505/1623) for BM-U. The demographic description showed that supporters in BM-C were most represented in apprenticeship education degree (88/217, 41%), followed by high school degree (77/217, 36%) and university education level (42/217, 19%), with lowest numbers in elementary education level (10/217, 5%). BM-C opponents were most prevalent in the university education level (243/594, 40.9%). Supporters of BM-U were most prevalent in apprenticeship education level (60/505, 37%), followed by high school degree (54/161, 34%) and university degree (39/141, 24%). BM-U opponents were most prevalent in high school (357/957, 37.3%) and university education (342/957, 35.7%), followed by apprenticeship education (223/957, 23.3%). Overall, supporters and undecided both for BM-C and BM-C were less prevalent in the university education level and more in the apprenticeship education level compared with nonsupporters. Regarding household income, supporters and undecided (both for BM-C and BM-C) were represented less in the high-income group and more in the below poverty line income group compared with opponents. In terms of gender, noticeable differences were found in the undecided groups, particularly in BM-U, with female participants representing a higher proportion (304/505, 60.2%). Conversely, male participants were more prevalent among BM-U supporters (98/161, 61%). Differences in age compared with an average of the whole sample (mean 55.04, SD 15.56) were observed only in BM-U supporters, who were older (60.9 years), and BM-U opponents, who were younger (49.3 years). Vaccine refusers were minimally represented in BM-C opponents (33/594, 6%), more in BM-C undecided (146/812, 18%), and most in BM-C supporters (142/217, 65%). Moreover, 34.6% (75/217) of BM-C supporters were vaccinated despite their beliefs. Regarding BM-U, vaccine refusers were most represented in BM-U supporters (64/161, 40%), followed by BM-U undecided (128/505, 25.3%), with the lowest numbers in BM-U opponents (129/957, 13.5%; Figure 1). The descriptive statistics are shown in Table 1.

Figure 1. Distribution of unvaccinated (shown in red) and vaccinated (shown in cyan) against COVID-19 pandemic in relation to beliefs in misinformation regarding COVID-19 (BM-C) and the war in Ukraine (BM-U). The x-axis represents BM-C total score, and the y-axis represents BM-U total score.

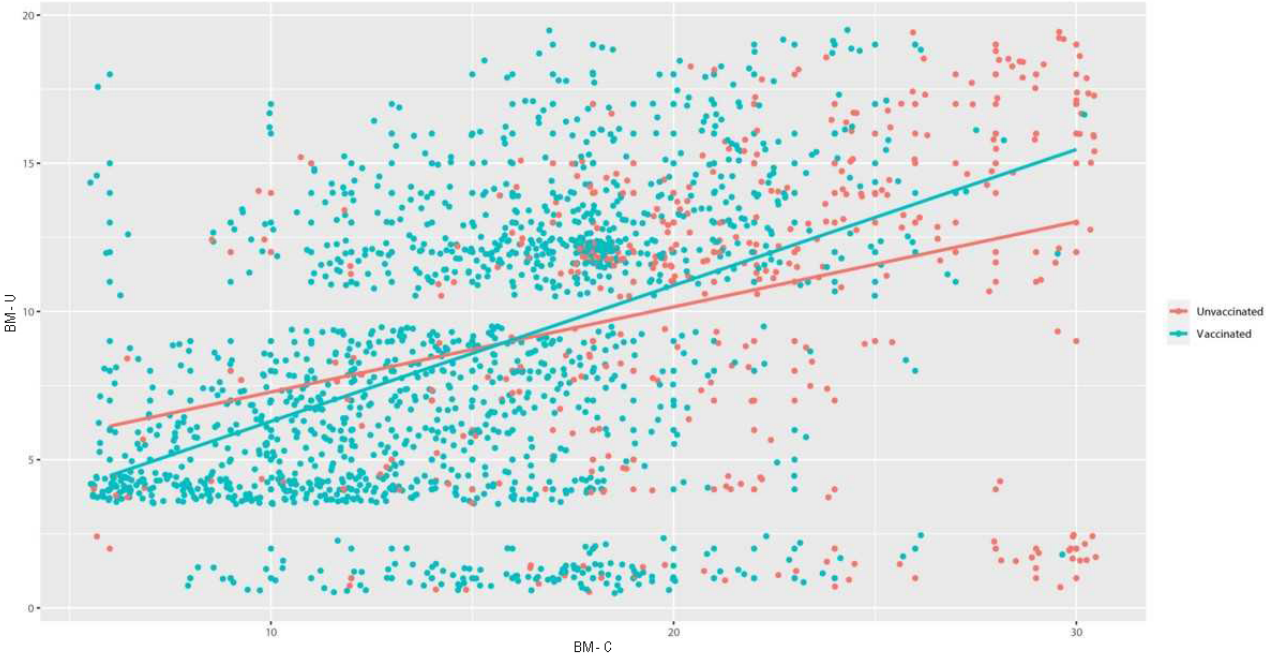

Table 1. Sociodemographic characteristics of BM-C[a] and BM-U[b].

Sociodemographic variables	Opponents BM-C	Undecided BM-C	Supporters BM-C	Opponents BM-U	Undecided BM-U	Supporters BM-U
Male + female, n (%)	594 (36.6)	812 (50)	217 (13.4)	957 (59)	505 (31.1)	161 (9.9)
Female, n (%)	267 (44.9)	459 (56.5)	113 (52.1)	472 (49.3)	304 (60.2)	63 (39.1)
Male, n (%)	327 (55.1)	353 (43.5)	104 (47.9)	485 (50.7)	201 (39.8)	98 (60.9)
Age (years), mean (SD)	55.02 (16.62)	55.25 (15.11)	54.31 (14.16)	53.25 (15.19)	56.58 (14.89)	60.80 (13.28)
Elementary education, n (%)	17 (2.9)	47 (5.8)	10 (4.6)	35 (3.7)	31 (6.1)	8 (5)
Apprenticeship education, n (%)	119 (20)	265 (32.6)	88 (40.6)	223 (23.3)	189 (37.4)	60 (37.3)
High school education, n (%)	215 (36.2)	295 (36.3)	77 (35.5)	357 (37.3)	176 (34.9)	54 (33.5)
University education, n (%)	243 (40.9)	205 (25.2)	42 (19.4)	342 (35.7)	109 (21.6)	39 (24.2)
Income 1[c], n (%)	32 (5.4)	57 (7)	26 (12)	55 (5.7)	41 (8.1)	19 (11.8)
Income 2[d], n (%)	164 (27.6)	268 (33)	81 (37.3)	289 (30.2)	175 (34.7)	49 (30.4)
Income 3[e], n (%)	231 (38.9)	325 (40)	88 (40.6)	369 (38.6)	211 (41.8)	64 (39.8)
Income 4[f], n (%)	167 (28.1)	162 (20)	22 (10.1)	244 (25.5)	78 (15.4)	29 (18)
Vaccinated, n (%)	561 (94.4)	666 (82)	75 (34.6)	828 (86.5)	377 (74.7)	97 (60.2)
Unvaccinated, n (%)	33 (5.6)	146 (18)	142 (65.4)	129 (13.5)	128 (25.3)	64 (39.8)

[a]BM-C: beliefs in misinformation narratives about COVID-19 pandemic.
[b]BM-U: beliefs in misinformation about the Russian invasion of Ukraine.
[c]Below poverty line income (below 60% of the median).
[d]Low income (below the median).
[e]Upper middle income (up to 1.5 times the median).
[f]High income (above 1.5 times the median).

Factors Explaining BM-C

The multiple linear regression model explained 44.92% of the individual differences in BM-C ($F_{30,1592}$=45.1; adjusted R^2=0.45; P<.001). Descriptions of variables used in the BM-C model are shown in Multimedia Appendix 3. The results showed significant relationships between the 12 examined factors as the independent variables and BM-C total score as the dependent variable (Table 2). Trust in the Czech government and public media, vaccination against COVID-19 pandemic, distrust in Russia, searching for news on COVID-19 pandemic, and participation in web-based discussions predicted lower levels of BM-C. Distrust in the United States, distrust in the EU, frustration from public and mainstream news, rigid beliefs, use of emails as a source of information, sharing COVID-19 news, and engagement in web-based bubbles predicted higher levels of BM-C. Regarding demographic factors, upper middle income (compared with high income), as well as elementary, apprenticeship, and high school education levels (compared with university education level) were associated with increased BM-C. The below poverty line income group (compared with high income) predicted lower levels of BM-C.

Table 2. The results of multiple linear regression models for BM-C[a] and BM-U[b,c].

Explaining variable	BM-C, coefficient (SE)	BM-C, *t* test (*df*)	BM-C, *P* value	BM-U, coefficient (SE)	BM-U, *t* test (*df*)	BM-U, *P* value
Intercept	2.11 (0.25)	8.48 (1592)	*<.001*	2.30 (0.28)	8.24 (1592)	*<.001*
COVID-19 vaccination	–0.17 (0.01)	–12.93 (1592)	*<.001*	–0.02 (0.01)	–1.55 (1592)	.12
Information from emails	0.04 (0.02)	2.05 (1592)	*.04*	0.04 (0.02)	2.13 (1592)	*.03*
YouTube	0.03 (0.02)	1.79 (1592)	*.07*	–0.02 (0.02)	–1.26 (1592)	.21
Antisystem websites	0.03 (0.02)	1.50 (1592)	.13	0.06 (0.02)	2.92 (1592)	*.004*
Public media	0.03 (0.02)	1.84 (1592)	.07	–0.02 (0.01)	–1.37 (1592)	.17
Mainstream websites	0.02 (0.02)	0.97 (1592)	.33	–0.04 (0.02)	–2.52 (1592)	*.01*
Exposure to social media	–0.03 (0.06)	–0.56 (1592)	.58	–0.07 (0.05)	–1.42 (1592)	.16
Social media information source	–0.001 (0.02)	–0.06 (1592)	.95	0.03 (0.02)	2.01 (1592)	*.045*
Discussions under news	0.02 (0.02)	1.06 (1592)	.29	0.05 (0.02)	2.68 (XX)	*.007*
Discussions on social media	0.32 (0.10)	3.18 (1592)	*.002*	–0.02 (0.15)	–0.12 (1592)	.90
Web-based bubbles	0.17 (0.06)	3.10 (1592)	*.002*	0.03 (0.07)	0.42 (1592)	.68
Search for news	–0.1 (0.03)	–3.81 (1592)	*<.001*	–0.06 (0.02)	–2.30 (1592)	*.02*
Sharing news	0.07 (0.03)	2.47 (1592)	*.01*	0.01 (0.03)	0.48 (1592)	.63
Interest in news	0.01 (0.02)	0.76 (1592)	.45	–0.03 (0.02)	–1.59 (1592)	.11
Frustration from media	0.12 (0.02)	6.27 (1592)	*<.001*	0.10 (0.02)	5.42 (1592)	*<.001*
Trust in Czech government	–0.22 (0.02)	–10.34 (1592)	*<.001*	–0.23 (0.02)	–11.81 (1592)	*<.001*
Distrust in Russia	–0.07 (0.02)	–2.94 (1592)	*.003*	–0.24 (0.02)	–10.26 (1592)	*<.001*
Distrust in United States	0.08 (0.03)	2.33 (1592)	*.02*	0.20 (0.03)	6.63 (1592)	*<.001*
Distrust in EU[d]	0.12 (0.04)	2.86 (1592)	*.004*	0.10 (0.04)	2.65 (1592)	*.008*
Distrust in China	0.02 (0.03)	0.82 (1592)	.41	–0.05 (0.02)	–0.22 (1592)	.82
Distrust in NATO[e]	–0.05 (0.04)	–1.20 (1592)	.23	0.07 (0.04)	1.81 (1592)	.07
Rigid beliefs	0.09 (0.02)	5.07 (1592)	*<.001*	0.08 (0.02)	4.99 (1592)	*<.001*
Income 1 (below poverty line)[f]	–0.18 (0.08)	–2.35 (1592)	*.02*	0.14 (0.07)	2.00 (1592)	*.046*
Income 2 (low)[f]	0.09(0.05)	1.75 (1592)	.08	0.07 (0.05)	1.42 (1592)	.16
Income 3 (upper middle)[f]	0.10 (0.05)	2.04 (1592)	*.04*	0.07 (0.05)	1.48 (1592)	.14
Elementary education[g]	0.31 (0.07)	4.37 (1592)	*<.001*	0.20 (0.07)	3.00 (1592)	*.003*
Apprenticeship education[g]	0.22 (0.05)	3.97 (1592)	*<.001*	0.06 (0.05)	1.14 (1592)	.25
High school education[g]	0.17 (0.05)	3.40 (1592)	*<.001*	0.02 (0.05)	0.32 (1592)	.75
Gender (female)[h]	–0.03 (0.04)	–0.89 (1592)	.37	–0.03 (0.04)	–0.81 (1592)	.42
Age (year)	0.001 (0.001)	1.01 (1592)	.31	0.07 (0.02)	3.23 (1592)	*<.001*

[a]BM-C: beliefs in misinformation narratives about COVID-19 pandemic.
[b]BM-U: beliefs in misinformation about the Russian invasion of Ukraine.
[c]Significant values are italicized.
[d]EU: European Union.
[e]NATO: North Atlantic Treaty Organization.
[f]Contrasted to high-income group.
[g]Contrasted to university degree.
[h]Contrasted to male.

Factors Explaining BM-U

The multiple regression model explained 62.21% of the variance in BM-U ($F_{30,1591}$=90.01; adjusted R^2=0.62; P<.001). Descriptions of variables used in the BM-U model are shown in Multimedia Appendix 3. We found significant relationships between the 12 examined factors as independent variables and BM-U total score as the dependent variable (Table 2). Trust in the Czech government and public media, distrust in Russia, consumption of mainstream news websites, and searching for news about the war in Ukraine predicted lower levels of BM-U. Conversely, distrust in the United States, distrust in the EU, frustration from public and mainstream news, consumption of "antisystem websites," use of emails as a source of information, use of social media as an information source, reading discussions under web news articles, and belief rigidity predicted higher levels of BM-U. Regarding demographic factors, below poverty line income (compared with high income), elementary education level (compared with university education level), and older age were associated with higher levels of BM-U.

Discussion

Principal Findings

Our study provides evidence of a connection between beliefs in COVID-19 misinformation (BM-C) and misinformation regarding the Russian invasion of Ukraine (BM-U) by identifying a correlation between these 2 sets of beliefs and several shared factors. Regarding political trust, higher trust in Russia and lower trust in local government, public media, and Western allies of the Czech Republic (the EU and the United States) were revealed as strong predictors of both BM-C and BM-U. In addition, frustration with public and mainstream media, using emails as a source of information—possibly indicating chain emails—and reduced frequency in searching for news related to COVID-19 pandemic or war in Ukraine, predicted both BM-C and BM-U. We also identified media use patterns commonly associated with the spread of misinformation, which predicted either BM-C or BM-U. These included participation in web-based bubbles, engagement in discussions under web news articles, use of antisystem websites, avoidance of mainstream media, use of social media as an information source, and sharing news. In addition, belief rigidity was a significant predictor for both BM-C and BM-U.

Correlation Between BM-C and BM-U

A moderate positive correlation discovered between BM-C and BM-U supports our hypothesis, indicating that a significant number of individuals believing in COVID-19 misinformation have also adopted ideological misinformation regarding the Russian invasion of Ukraine. This extends previous findings that beliefs in COVID-19 conspiracies correlate with beliefs in other, broader and unrelated conspiracies [27,28] to the politicized side of COVID-19 misinformation, which increased susceptibility to ideological misinformation aligning with Russian propaganda. Our finding provides further evidence for the so-called "conspiracy singularity" [43] suggesting the tendency of actors to spread and interconnect various conspiracy theories [44,45]. For instance, the same actors who spread COVID-19 conspiracies before the Russian invasion of Ukraine later disseminated anti-NATO and pro-Russian narratives in Finland [46] and Slovakia [47]. Our findings thus corroborate similar phenomena observed beyond the context of the Czech Republic and may provide further insights into the mechanisms by identifying underlying factors revealed in our analyses, which are discussed in the sections "Associations of Political Trust and Beliefs in Misinformation," "Associations of Media Use and Beliefs in Misinformation Narratives," "COVID-19 Vaccine Refusal," and "Belief Rigidity."

Associations of Political Trust and Beliefs in Misinformation

Our finding that lowered trust in governmental decisions and public media was associated with both increased BM-C and BM-U supported our hypothesis. Moreover, it was the strongest predictor explaining both BM-C and BM-U. It is in line with previous research linking distrust in public institutions to COVID-19 misinformation beliefs [48-51]. While most previous findings on associations between beliefs in COVID-19 misinformation and political attitudes report that conservatism is associated with increased susceptibility to misinformation [52-54], we did not inquire about partisanship but rather about trust in geopolitical powers. Our results showing increased trust in Russia in higher levels of both BM-C and BM-U indicate a leaning toward this geopolitical power in supporters of both sets of misinformation. In addition, we observed increased distrust toward the Czech Republic's geopolitical allies and Russia's main opponents—the United States and the EU—among individuals with higher levels of both BM-C and BM-U. While this ideological inclination is not surprising regarding BM-U, which openly promotes Russian propaganda, it is not as readily apparent in the case of BM-C. However, our result aligns with previous research that has suggested the role of Russian disinformation campaigns in supporting the antivaccination movement [18,55,56].

Our findings can thus be contextualized in light of the goals of Russia's hybrid war strategy, which aims to continually undermine the trustworthiness and legitimacy of foreign governments in the eyes of the target population by warping their beliefs, thoughts, decisions, and behavior over the long term [57]. The goal of this tactic is to gradually reconstruct the target population's prior beliefs in favor of Russia [58,59]. However, our study cannot establish a causal relationship in terms of direct influence of Russia's disinformation campaigns. The inclination toward Russia may also have deep historical roots, as the Czech Republic—former Czechoslovakia—was part of the Eastern Bloc under the direct influence of the Soviet Union for 4 decades. Increased trust in Russia may also represent an alternative to the current Western orientation of the Czech Republic as a member of the EU and NATO, reflecting a broader, socially driven epistemic mistrust that manifests in the rejection of authoritative information, as suggested by the socioepistemic model of belief in conspiracy theories [60].

Associations of Media Use and Beliefs in Misinformation Narratives

All of the identified media use factors linked to either BM-C or BM-U provided support for our hypothesis regarding media use, formulated based on previous observations and theoretical or empirical associations with the dissemination of misinformation. However, it is noteworthy that not all of the examined factors demonstrated significant relationships with both BM-C and BM-U. The strongest media factor associated with higher levels of both beliefs was identified as frustration with the public and mainstream media. While previous research has established this factor as a predictor of higher anxiety and depression levels during the COVID-19 pandemic [41], our study extends its relevance to the context of misinformation susceptibility. This observation is complemented by another finding, which links less frequent searches for COVID-19 news with higher BM-C levels, and less frequent consumption of mainstream media and searches for the news about the war in Ukraine with BM-U. These findings align with previous research [1,61,62] and suggest that supporters of misinformation narratives engage in avoidance behavior, possibly due to their mistrust in information they perceive as misrepresented in public and mainstream media.

On the other hand, supporters of BM-C and BM-U showed higher engagement with other media channels. Specifically, there was an association between obtaining news information from emails—possibly indicating chain emails—and both BM-C and BM-U. In addition, reading discussions under web news articles and consuming information from antisystem websites was positively associated with BM-U. These findings corroborate observations regarding the role of such media channels in disseminating misinformation content and the susceptibility of their consumers to misinformation [13,20].

Next, the positive relationship between obtaining information from social media and increased BM-U, as well as the association between engagement in web-based bubbles and increased BM-C, indicates that the social media environment contributed to the spread of misinformation and their users' endorsement, as suggested by previous research [1,51,63-66]. While we acknowledge the limitations of the web-based survey method in assessing the phenomenon of web-based (epistemic) bubbles or echo chambers, it is plausible to assume that this phenomenon may have indeed been reflected in our results, as it aligns with prior findings [8-10,64].

Conversely, the negative relationship of engagement in discussions on social media and BM-C, as well as the lack of discernable associations between cumulative exposure to social media and BM-C/BM-U, underscores the reductive conclusions of associating social media platforms solely with the spread of misinformation. Indeed, social media offers users engagement in socializing and discussing a diverse array of content, as well as a broad spectrum of viewpoints on sociopolitical issues. Notably, in the context of nondemocratic regimes, digital media often serves as a primary source of obtaining reliable information. Research in nondemocratic regimes indicates that the use of digital media correlates with diminished adherence to misinformation, contrasting with users reliant solely on official information channels [67].

Our next finding of a positive association between sharing news and heightened levels of BM-C indicates that BM-C supporters demonstrated a propensity for active engagement with digital media. Speculatively, this could be due to heightened arousal triggered by specific content, frustration, or a sense of moral obligation to disseminate the alternative information on social media, perceived as accurate, compared with information reported by public and mainstream media, perceived as misleading or incomplete [68]. This inference is drawn from previous research indicating that the perceived accuracy of content significantly influences the likelihood of its sharing by users [69]. While our study did not directly explore the specific content shared by respondents, it is pertinent to note that previous studies have demonstrated that misinformation tends to be inherently more frequently shared than other types of news [69].

COVID-19 Vaccine Refusal

Our finding that vaccine refusal was a strong factor associated with BM-C supports our hypothesis and aligns with extensive prior research linking exposure to COVID-19 misinformation to COVID-19 vaccine hesitancy [48,62,70-73]. Our finding provides further evidence that COVID-19 vaccine refusal is a behavioral indicator of diverse attitudes that transcend medical concerns. However, it is important to note that 34.6% of BM-C supporters (75/217) reported being vaccinated, indicating a divergence from their beliefs. They may ultimately yield to social pressure and decide to get vaccinated, considering the practical difficulties posed by remaining unvaccinated in their daily lives during the pandemic.

Contrary to our hypothesis, COVID-19 vaccine refusal was not associated with BM-U, suggesting that this health-related behavior is a broader phenomenon that includes vaccine hesitancy due to health reasons, medical concerns, simple reluctance, and other factors. We conclude that vaccine refusal should not lead to the reductionist conclusion that COVID-19 vaccination was entirely politicized. However, we observed a higher prevalence of vaccine refusers in BM-U supporters (64/161, 39.8%), followed by BM-U undecided (128/505, 25.3%), with the lowest numbers in BM-U opponents (129/957, 13.5%). Special attention should be given to the BM-U undecided group, requiring longitudinal monitoring to assess whether they might become new adherents of BM-U.

Belief Rigidity

Our additional finding of a positive association between the rigidity of one's beliefs regarding sociopolitical issues with both BM-C and BM-U indicates that those who adhere to the alternative interpretations of both sociopolitical issues tend to harbor more fixed and rigid opinions than those who do not support such interpretations. Our finding is consistent with previous studies connecting belief rigidity to conspiratorial thinking [34] and beliefs in misinformation propagated through social media [74]. Rigid beliefs have been found to facilitate group cohesion, partisanship, polarization, and extremism [31,35,75]. It is thus plausible that beliefs such as BM-C or BM-U may serve as a group-shared alternative "truth" while being shared through the digital media environment as identified in our analysis. Furthermore, it is in line with our other finding (discussed in the "Associations of Media Use and Beliefs in Misinformation Narratives" section) indicating avoidance of public and mainstream information sources. This pattern is consistent with previous research suggesting that belief rigidity is strengthened when individuals isolate themselves from contradictory information, thus reinforcing their confirmation bias [10].

Conclusions

Our findings support the hypothesis that individuals who endorsed COVID-19 misinformation were more susceptible to ideological misinformation, aligning with Russian propaganda. Supporters of both misinformation narratives shared common traits, including heightened distrust of local government, public media, the United States, and the EU, along with increased trust toward Russia. They also exhibited increased belief rigidity and demonstrated several common media use patterns, previously linked to the spread of misinformation. To gain a deeper understanding of these phenomena, longitudinal monitoring is essential. By tracking the development of BM-C, BM-U, and the examined factors over time, causal relationships can be uncovered.

Limitations

The primary shortcoming of this study was the constraint imposed by the short survey format. Due to time limitations, it was not feasible to use longer standardized questionnaires such as the Belief Rigidity Scale. Instead, we opted for a single statement specifically related to societal issues, such as politics, war, and pandemics, and we considered this finding as supplementary. On the other hand, we chose to investigate media use in more detail with practical implications in mind, aiming to identify specific media channels where misinformation is prevalent for targeted recommendations. However, some aspects of the media environment, such as web-based communities with an echo chamber effect and chain emails, were challenging to assess via survey. Consequently, our findings regarding these information sources should be interpreted with caution. In addition, while we acknowledge the availability of standardized COVID-19 conspiracy or misinformation scales, our objective was to study COVID-19 misinformation prevalent in the local context of the Czech Republic as identified by previous analytical sources.

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Data Availability

The dataset generated during this study is available in the OSF data repository (osf.io/wtuqj).

Conflicts of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Multimedia Appendix 1
Items and response scales for variables on media use, political trust, and belief rigidity.
[DOCX File , 21 KB - infodemiology_v5i1e62913_app1.docx]

Multimedia Appendix 2
Factor loadings of BM-C and BM-U items resulting from exploratory factor analysis.
[DOCX File , 23 KB - infodemiology_v5i1e62913_app2.docx]

Multimedia Appendix 3
Descriptions of variables used in multiple linear regression models for BM-C and BM-U.
[DOCX File , 23 KB - infodemiology_v5i1e62913_app3.docx]

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Abbreviations

BM-C: beliefs in misinformation narratives about COVID-19 pandemic
BM-U: beliefs in misinformation about the Russian invasion of Ukraine
EFA: exploratory factor analysis
EU: European Union
NATO: North Atlantic Treaty Organization

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Breast Cancer Vlogs on YouTube: Descriptive and Content Analyses

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Abstract

Background: Many women with breast cancer document their experiences in YouTube vlogs, which may serve as peer-to-peer and community support.

Objective: This study aimed to determine (1) the forms of content about breast cancer that tend to be discussed in vlogs, (2) the reasons why women choose to vlog their breast cancer experiences, and (3) the potential for breast cancer vlogs to serve as an alternative or complement to peer-to-peer support as well as a site of digital community overall.

Methods: YouTube was searched in incognito mode in November 2023 using the search terms "breast cancer vlog." A maximum of 10 videos/creator were included based on viewership and date created. Video characteristics collected included title; length; number of views, likes, comments; and playlist inclusion. Videos were assessed for sponsorship; presence of explanation and discussion on breast cancer; type of content; and themes. Creator characteristics included age, location, and engagement approaches. Descriptive and content analyses were performed to analyze video content and potential areas where peer-to-peer support may be provided.

Results: Ninety vlogs by 13 creators were included, all from personal accounts. The mean (SD) video length, number of views, and number of comments were 21.4 (9.1) minutes, 266,780 (534,465), and 1485 (3422), respectively. Of the 90 videos, 35 (39%) included hashtags, and 11 (12%) included paid sponsorships. The most common filming location was the home (87/90; 97%), followed by the hospital (28/90; 31%) and car (19/90; 21%). Home vlogs were most often set in the living room (43/90; 44%), bedroom (32/90; 33%), or kitchen (20/90; 21%). Thirty-four of 60 videos (57%) included treatment visuals and physical findings. Creators addressed motivation for vlogging in 44/90 videos (49%); the two most common reasons were wanting to build a community and helping others. In 42/90 videos (47%), creators explicitly expressed emotion. Most common themes were treatment (77/90; 86%), mental health (73/90; 81%), adverse effects (65/90; 72%), appearance (57/90; 63%), and family relationships (33/90; 37%). Patient-directed advice was offered in 52/90 videos (58%), mostly on treatment-related issues. In 51/90 videos (57%), creators provided explicit treatment definitions. Chemotherapy was discussed in 63/90 videos (70%); surgery in 52/90 (58%), primarily mastectomy; radiation in 27/90 (30%); and general adverse effects in 64/90 (71%). Twenty-two of 90 videos (24%) were about a new diagnosis. When mentioned (40/90; 44%), the most common creator location was the United States. When mentioned (27/90; 30%), the most common age was 20 - 29 years.

Conclusions: The dedication to building community support by vlog creators, and the personal nature of their storytelling, may make vlogs a potential resource for peer-to-peer support.

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KEYWORDS

breast cancer vlog; YouTube; social media; experience; video; content analysis; breast; cancer; women; oncology; descriptive analysis

Introduction

Vlogs, or “video blogs,” are personally and individually created experiential videos based on wide-ranging topics, usually posted to YouTube. A popular subset of vlogs are created by women with breast cancer, in which they document their breast cancer experiences in a publicly accessible digital format. As videos that tend to invite viewers into the lives of their creators, vlogs typically receive high levels of engagement and draw audiences who will continue watching in order to keep up with what creators are doing next. Online tools such as these vlogs are important parts of patients’ experience with processing and managing chronic illness [1]. They can help patients find support, community, and information in spaces they may not have access to in real life [2]. Overall, social support is a prominent theme in literature about breast cancer communication on social media [2].

YouTube is growing as a source of “peer-to-peer health information sharing and support” [3]. The importance of peer support across cancer is widely acknowledged [4]. Breast cancer peer support programs have been shown to be effective in enhancing patients’ quality of life [5], particularly regarding the alleviation of depression and anxiety [6]. Moreover, peer programs are similarly shown to be successful in providing emotional and psychosocial support [7]. Patient support groups can fulfill patient needs and improve quality of life [6,8,9]. Peer education was also found to reduce levels of psychological pain [10]. Research demonstrates that women with breast cancer need and expect online support programs, despite platform-related challenges such as inconsistent content moderation and that “well-organized and tailored” peer support is important to enhance their quality of life [11].

While vlogs about breast cancer may have the potential to serve as peer-to-peer support and provide community, their content, quality, and role in the breast cancer experience are understudied. The objectives of this study were to (1) determine what forms of content about breast cancer tend to be discussed in vlogs, (2) inquire into the reasons why women choose to vlog their breast cancer experiences, and (3) consider the potential for breast cancer vlogs to serve as an alternative or complement to peer-to-peer support, as well as a site of digital community overall.

Methods

Study Design

YouTube was searched in incognito mode in November 2023, using the search terms “breast cancer vlog.” Breast cancer vlog creators were identified, and their video characteristics were collected. If the creator produced less than 10 videos, all were included. If they produced more than 10, a maximum of 10 were included, based on viewership and most recent date created. Creators were identified based on whether they produced English-language breast cancer-related videos in the last 5 years. Prior to evaluating the videos in this dataset, reviewers were trained to collect vlog data using a standardized data collection tool. A sample was collected, and data collection quality, as well as procedures for any disagreement in evaluations, were assessed before initiating the formal data collection.

Reviewers collected creator information (ie, age, location, profession, and cancer stage). They collected the video titles; length; date; number of views, likes, and comments; and hashtags; and noted whether the videos were part of a playlist. Reviewers then assessed videos based on consumer details (ie, sponsorships, product recommendations, and endorsements), and the creators’ explanations and discussions of their breast cancer. Engagement levels were considered based on vlog creators’ discussion with their audience, whether they commented on their experience with their audience, or asked the audience to share insights of their own. Types of content (diagnosis, surgery, or other event) were also collected.

Video themes were extracted both deductively and inductively. The themes collected deductively are described in Table 1. Descriptive and content analyses were performed to assess and analyze video content and potential areas where peer-to-peer support may be provided. Reviewers were encouraged to add subthemes inductively in cases where the content exceeded or was more specific than the deductive themes [12]. An additional set of questions was applied to videos that contained advice, in order to characterize the nature, source, and potential validity of the advice provided (Table 2).

Table . Deductive themes.

Theme	Definition
Appearance	Refers to one’s experiences with their appearance, including how it may have changed over the course of treatment
Mental health	Refers to questions of mental health, including stress, anxiety, depression, or other related issues
Fear of recurrence	Refers to fears or anxieties related to the future possibility of a cancer recurrence
Gender identity	Refers to one’s gender identity, particularly in the context of breast surgery or reconstruction choices
Sexuality	Refers to experiences of sexual intimacy, including how these may have changed over the course of treatment
Fertility	Refers to one’s experiences with fertility or infertility, including fertility treatment
Motherhood	Refers to the specific relationship between mother and child, how to disclose to one’s children, as well as wanting to be a mother
Spousal relationship	Refers to the patient’s relationship with their spouse, including stress on the spouse who takes on a caregiving role
Family relationship	Refers to family-based experiences, such as how one may disclose their diagnosis to their family and how a diagnosis shifts the family dynamic
Path to diagnosis	Refers to the story or experience of being diagnosed with breast cancer, such as discovering a breast lump
Treatment	Refers to a wide array of topics, ranging from treatment choices to the experience of receiving treatment
Adverse effects	Refers to specific experiences with adverse effects, whether due to surgery, chemotherapy, or other forms of treatment

Table . Advice assessment.

Characteristic	Definition
Vlog creator verbalizes a reference or source for advice.	Refers to the vlog creator verbally explaining where or from whom they learned about the advice provided.
Vlog creator confirms having tried the advice personally.	Refers to the vlog creator describing their own personal experience by following the advice provided.
Proposed advice recommends adding something (addition) or not doing something (omission).	Refers to whether the vlog creator suggests making some sort of addition to their care or cancer management or ceasing or removing an aspect of their care or cancer management.
Proposed advice involves a product to be applied or consumed.	Refers to whether the proposed advice involves applying or consuming a product.
Proposed advice suggests a modification or reduction in the treatment plan.	Refers to whether the proposed advice suggests some sort of modification to or reduction in one’s cancer care management or treatment plan.
Proposed advice is potentially beneficial, neutral, or potentially harmful.	Refers to whether the advice provided is of potential benefit to a patient, neutral, or of potential harm to a patient.

Ethical Considerations

Institutional ethics review was not required for the completion of the study, as all the data including patient- and disease-specific information and opinions or experiences were volunteered into the public domain by the creators. No patient- or disease-specific information was collected. No identifiable information is published.

Results

A total of 90 vlogs by 13 vlog creators were included in the study, all of which originated from personal YouTube accounts. The mean (SD) video length was 21.4 (9.1) minutes. The mean (SD) number of views was 266,780 (534,465). The mean (SD) number of comments was 1485 (3422). Hashtags—words or phrases preceded by the “#” symbol that serve to categorize social media content—were included in 35 videos (39%), the majority of which were breast cancer-related. Paid sponsorships were present in 11 videos (12%). Creators promoted their own channel in a large majority of videos (80/90; 89%); for instance, by encouraging channel subscriptions. Most creators (88/90; 98%) included a title that effectively summarized the video topic, meaning that the title described the events discussed in the video. Where mentioned, the range of 20 - 29 years was the most common age group (14/27; 52%), followed by 30 - 39 years (10/27; 37%). Where mentioned, the most common creator location was the United States of America (25/40; 62%).

Visuals were present in 60/90 videos (67%); of these 60 videos, 34 (57%) included images or videos of vlog creators undergoing treatment (such as receiving chemotherapy or radiation, or undergoing magnetic resonance imaging) as well as physical features of treatment, including port scars, surgical drains, and breast contour after expander placement. A portion of videos (36/90; 40%) included inserted recorded clips, for instance, playing a recording of a phone call with their pathologist discussing results or footage of entering the radiation machine.

Videos were mainly filmed at home (87/90; 97%), at the hospital (28/90; 31%), or in the car (19/90; 21%). It is possible that vlogs were filmed in more than one setting. When filmed at home, vlogs were most often set in the creator's living room (43/90; 44%), bedroom (32/90; 33%), or kitchen or office (both 20/90; 21%).

In half of the vlogs (45/90, 50%), the creator commented on how their audience makes them feel, and in 44/90 (49%), the creator explained why they decided to make vlogs about their breast cancer experience, the most frequent reasons being: (1) enjoying filming vlogs, (2) wanting to build a community, (3) having a predominantly female viewership, (4) wanting others with cancer to feel less alone, (5) sharing information on surgery, and (6) providing details about signs of their recurrence. For example, one vlog creator described the process of filming and posting vlogs about her metastatic breast cancer as therapeutic "because it feels like she sat and talked to someone about everything on her mind"; this creator also referred to the viewers who have expressed that her vlogs helped them through their own experiences as making her feel like her vlogs have a purpose. It is important to her that her audience—specifically, others facing a similar diagnosis—knows that they are "not alone in this at all." In 42/90 videos (47%), creators expressed emotion in an explicit way; for instance, one vlog creator filmed her last chemotherapy treatment and was emotional while ringing the celebratory bell and thanking her nurses.

Advice was offered in 52/90 (58%) videos, with the most common topics being cold capping, hair regrowth, clothing, nutrition, mental health habits, chemotherapy preparation, saline soaking for radiation burns, wig use, and cancer prevention. References or sources were rarely cited, with advice usually originating from the video creator themselves. In most cases, the creator confirmed the advice was based on their personal experience. Advice overwhelmingly involved making some sort of addition to one's care or cancer management rather than an omission. None of the proposed advice was considered of potential harm to patients. Additional details on videos containing advice are outlined in Table 3.

Table . Advice provided in vlogs.

Characteristic	Frequency (%)	Example
Vlog creator verbalizes a reference or source for advice.	• Yes: 3 (5%) • No: 49 (95%)	Friend, website, or book
Vlog creator confirms having tried the advice personally.	• Yes: 42 (81%) • No: 10 (19%)	N/A[a]
Proposed advice recommends adding something (addition) or not doing something (omission).	• Yes: 51 (98%) • No: 1 (2%)	Cold capping, purchasing products, stretching, attending therapy sessions, using sleep aids, maintaining a positive outlook, or praying
Proposed advice involves a product to be applied or consumed.	• Yes: 15 (20%) • No: 37 (80%)	Vaseline, compression socks, ginger supplement, cold capping equipment, hair or beauty products, blankets, or pajamas
Proposed advice suggests a modification or reduction in the treatment plan.	• Yes: 14 (27%) • No: 38 (73%)	Modifying chemotherapy administration method by using a port-a-cath instead of a peripheral venous infusion
Proposed advice is potentially beneficial, neutral, or potentially harmful.	• Harmful: 0% • Neutral: 24 (46%) • Potentially beneficial: 28 (54%)	Reduced risk of deep vein thrombosis, reduced hair loss, and reduced diarrhea

[a]N/A: not applicable.

Where the cancer stage was mentioned, stage IV was most common (13/90; 14%). Of the 90 videos, 22 (24%) were about a new diagnosis. Chemotherapy was the predominant treatment form discussed in the majority of videos (63/90, 70%); surgery in 58% (52/90), primarily mastectomy (20/52, 38%); and radiation in 30% (27/90). The general adverse effects were discussed in 71% of the videos (64/90). In over half of the videos (50/90; 57%), creators provided a structured definition to some aspect of their treatment.

The most common themes were treatment (77/90; 86%), mental health (73/90; 81%), adverse effects (65/90; 72%), appearance (57/90; 63%), and family relationships (33/90; 37%). Subthemes included young age, finances, the importance of online community support, social life, fear of surgery, egg retrieval, and confidence and redefining beauty standards.

Discussion

Principal Findings and Comparison With Previous Works

This study demonstrates that vlogs by women with breast cancer receive significant levels of engagement and represent an important site of online community for women. However, the nature of their content, their authorship, and the potential to be integrated into care plans are underexplored. Our study shows that most commonly discussed themes in breast cancer vlogs include treatment, mental health, adverse effects, and appearance, but that a wide range of subthemes are also present. Moreover, they are often filmed in a personal home setting. These patient-created videos, which included less paid sponsorship than what researchers have identified in previous analyses [12], included detailed and overt expressions about why creating vlogs about their breast cancer is a valuable experience. The production behind vlogs, combined with the settings in which they are filmed, contribute to the feeling of connection between the creator and the audience. That vlogs are often filmed at home may be important to building a sense of community. The seemingly close and casual environment of filming in one's own living room or bedroom creates a sense of proximity to the vlog creator that is more aligned with the support group model that might not necessarily be present in a professional setting.

There is a rich community-centered aspect to breast cancer vlogs, which may position them as complementary forms of peer-to-peer social support and as unique methods for effective coping. Tailoring peer support to the moments when patients are most in need is crucial [13]. In their study on factors of engagement and patient-reported outcomes in a stage IV breast cancer Facebook group, Kashian and Jacobson [14] conclude, "Optimal social support plays a critical role facilitating engagement in online breast cancer support groups. It is not enough that members exchange social support in online support groups, rather members must exchange the type of support that facilitates effective coping." Power and Hegarty [15] also found that support programs need to be tailored to the needs of women with breast cancer and have identified "the need to allow more informal sharing to occur in facilitated peer support programs." Vlogs are easily findable and watchable. While different peer support models and approaches will have varying outcomes on different patients, web-based support without training and/or moderation should be used with caution [16]. YouTube is heavily engaged with for public health reasons. However, there is a need for higher-quality content [17]. Research evaluating YouTube videos about radiotherapy in breast cancer concludes that while videos were inconsistent in following best practice guidelines, YouTube still has potential toward disseminating health information [18]. Research on YouTube videos about radiotherapy in lung cancer draw similar conclusions [19].

It is possible that informal sharing also happens in online spaces, where patients might feel they have more control over how much they can share and can do so in the format, style, narrative, and medium of their choosing. Ziegler and colleagues [20] have shown a moderate positive association between peer support and psychological improvement in cancer patients. People who post and share about their experiences in online communities are not the only ones who benefit from the peer support in these spaces; research shows that "lurkers," or those who watch or consume content without sharing their own, can also benefit from the advice and insights shared [21]. Many messages in online support groups are requests for information and opinion from those in the same situation and are designed to reach like-minded people [22]. These networks are informal, grow organically, and are accessed when needed.

The use of visuals and additional recorded clips in vlogs, such as the inserted phone recordings or hospital footage, may contribute to a sense of closeness between the creator and their audience. Such instances of additional video editing are indications of vlog creators' platform expertise and demonstrate the production efforts behind vlog creation [23]. However, in the context of documenting one's breast cancer experiences, additional video editing may actually serve to provide even more detail for one's audience: playing a phone recording or showing hospital footage (of, for instance, receiving chemotherapy infusions) allows the audience to see and hear parts of the creator's breast cancer experience that they were not present for, thereby creating a further sense of closeness with the creator. Inviting one's audience into private hospital or clinical encounters also holds implications for standardized practices of medical confidentiality. For these creators, there is something important about sharing what tends to be considered private. The perceived closeness afforded by hospital footage and recorded phone calls, for example, may also serve to demystify these experiences for audience members who might be about to begin their own breast cancer treatment. In this context, typical conceptions of what is considered public or private are blurred, and viewers may begin to develop emotional bonds with vloggers they have never met: a phenomenon not unique to vlogs about breast cancer, but which occurs across different types of social media content and platforms [24]. Scholars have discussed the notion of the microcelebrity, particularly the ways in which celebrity and fame are connected to different media [25]. Given this context, it is plausible that breast cancer vloggers may achieve certain levels of microcelebrity status on YouTube, which may result in a feeling of parasocial closeness—defined as "nonreciprocal socio-emotional connections with media figures such as celebrities or influencers"—on the part of the audience, and which can continue in cases where the video creator dies [26].

Key features of breast cancer vlogs, which include explanations of the diagnosis experience, are associated with receiving empathic support from audiences [27]. The emotionally intense context afforded by the medium of video is demonstrated to lead to community-building and social support among vloggers and their audiences [28]. In their study of breast cancer narratives on social media, Ma and colleagues [29] found, "Stories that were longer, less emotionally intensive, told from the cancer survivor's perspective, with gender identity–related information, describing the act of providing social support, explicitly requesting engagement and/or donation, and using more vivid forms of visuals such as linked images tended to be more engaging." However, while Ma and colleagues [29] found that emotionally intensive stories may be less engaging, social media research suggests, "Crying and anxiety blogs can function as a means of demonstrating vloggers' 'authenticity,' and thus fostering valuable intimacy between vloggers and their audience" [30]. The sense of intimacy shared by vloggers—especially when demonstrating explicit emotion in their vlogs—is valuable in this context because it serves to develop a bond between the creator and the audience, who may decide to begin regularly following the creator's breast cancer trajectory. In our study, creators explicitly expressed emotion in almost half of the videos. Emotion is an important part of the breast cancer stories that vlog creators tell, and it resonates with their audiences: several videos in this dataset, particularly those relating to metastatic disease and end of life, were challenging for reviewers to watch and remained distinctly memorable after data collection was completed. The vulnerability and emotion present in these vlogs—and thus, their relatability—may provide a form of connection between creator and audience that health care professionals cannot provide due to the objectivity they have to maintain in delivering care.

Vlogging about breast cancer may also hold therapeutic value [31]. Creators in this dataset have discussed what they perceive to be the benefits of vlogging, among which is the idea that vlogging is a way to speak about everything on their minds, not unlike sitting and chatting with someone. When creators hear from their audience that watching their vlogs helped them to feel less alone, or helped them in their own journeys, they express that this audience response helps them to feel like their vlogs have a purpose. Vlogs are a source of support and can help patients cope with isolation not only in dealing with cancer, but also with other chronic illnesses such as fibromyalgia, diabetes, and HIV [32-34]. The value of vlogging about breast cancer can extend beyond patient communities to health care settings; one reviewer, a surgical resident, commented that watching the vlogs in this dataset was important to their training experience. For this reviewer, seeing how patients understand the course of their treatment as explained to them by their doctor/surgeon, what they focus on, what they fear, and how they take the information they have received and share it in a digestible way with their viewers was very useful, and would contribute to how they engage with cancer patients going forward. In this way, watching vlogs may also hold value in medical training settings, as examples of voluntarily provided patient experience.

Questions of how to handle the transfer of information in vlogs were considered throughout this study's design. In some cases, reviewers were able to anecdotally or casually identify some vloggers who provided high-quality explanations of their cancer and its treatment, to the point that the reviewer would suggest it to their patients if needed. That being said, it is challenging even for health care professionals to evaluate the quality of information as it is presented intertwined with personal experiences (often indistinguishable) in experience-based videos. Validated tools for evaluating YouTube video quality now exist; however, Gabarron and colleagues [35] demonstrated, in their 2013 review, that as recently as 10 years ago, guidelines for such evaluations were "unclear and not standardized." While standardized instruments such as the DISCERN tool and the Patient Education Materials Assessment Tool can be used to evaluate different forms of media, their applicability is limited in regards to patient-created, experiential content. Vlogs are an experience-based media format grounded in personal storytelling, where it is often difficult to distinguish information from advice or lived experience. As such, the goals behind both creating vlogs and watching them may be more closely related primarily to building and seeking forms of community and connection, rather than imparting information or learning about medical facts. Nevertheless, our assessment revealed that the majority of advice offered in vlogs consisted of patient-centered concerns and personal preferences that were unlikely to affect cancer treatment trajectories. The proposed advice was not found to be of potential harm to patients (even if questionably beneficial) and was largely experiential.

Limitations

The limitations of this study include restrictions based on language and challenges related to collecting demographic data. This study was limited to English-speaking videos, which may influence views or perceptions of the breast cancer experience. In addition, because vloggers may or may not disclose specific information such as their age, nationality, location, profession, or cancer stage, the consistent collection of these data points was not possible. Future research on breast cancer vlogging practices in specific linguistic, geographic, or ethno-cultural communities represents an opportunity to understand the circulation of health information within communities that may not have easy access to mainstream health services. While some of the peer support literature cited in this paper predates the development and widespread use of social media, the authors contend that this earlier foundational literature functions as a precursor to contemporary understandings of the benefits of social media communities, their effects on patients' outlooks, as well as their reasons for participating in them.

Given that the purpose of vlogging is not to educate one's peers but to share experiences and build an online community, the potential for using currently existing standardized tools to assess information quality is limited. In light of the growth of online peer-support communities and the lack of methodology regarding the quality and accuracy of information that is woven into patient experiences reported in the vlog format, there is a need for the development of a methodology that specifically validates the quality of information transferred in these settings. The next phase of our research will address breast cancer vlogs, and other cancer-related media content, created by and from the perspectives of health care professionals where, in contrast, health care professionals have a primary goal of transferring information to support patients. Future research may evaluate the differences in engagement metrics (such as views, likes, or comments) between breast cancer video content created by patients for patients and content created by health care professionals.

Conclusion

This study demonstrated that the awareness of and dedication to building community that vlog creators show in this context, as well as the personal nature of their storytelling, their advice and suggestions, and their discussions of wide-ranging yet specific topics all position vlogs by women with breast cancer as a potential resource for peer-to-peer support in breast cancer. The experiences of both creating and watching breast cancer vlogs hold significant potential benefits for peer-to-peer support in breast cancer care. This study aligns with Kashian and Jacobson's [14] conclusions, which suggest that given the association between optimal social support and community engagement, "Hopefully practitioners will use this information to encourage patients to join quality online support groups for positive experiences." While there are risks associated with consuming online content, the potential benefits of community and support offered by breast cancer vlogs should not be overlooked. Future research will consider patient perspectives and further address how the specific themes discussed in vlogs may be used to improve the cancer care experience for breast cancer and other cancers.

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Conflicts of Interest

None declared.

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#GenderAffirmingHormoneTherapy and Health Information on TikTok: Thematic Content Analysis

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Abstract

Background: Transgender and gender diverse people often turn to online platforms for information and support regarding gender-affirming hormone therapy (GAHT); however, analysis of this social media content remains scarce.

Objective: We characterized GAHT-related videos on TikTok to highlight the implications relevant to GAHT prescribers.

Methods: We used a web scraper to identify TikTok videos posted under the hashtags #genderaffirminghormonetherapy and #genderaffirminghormones as of November 2023. We identified recurrent themes via qualitative content analysis and assessed health education videos with the Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V) scale and a modified Currency, Relevance, Authority, Accuracy, and Purpose (CRAAP) test.

Results: Out of 69 videos extracted, 71% (49/69) were created by GAHT users, 24.6% (17/69) were created by health care workers, and 21.7% (15/69) were created to provide health education. Themes included physical changes on testosterone, GAHT access, and combating misinformation and stigma surrounding GAHT. Health education videos scored highly on PEMAT-A/V items assessing understandability (mean 88.3%, SD 11.3%) and lower on actionability (mean 60.0%, SD 45.8%). On the CRAAP test, videos scored highly on the relevance, authority, and purpose domains but lower on the currency and accuracy domains.

Conclusions: Discussions of GAHT on TikTok build community among transgender and gender diverse users, provide a platform for digital activism and resistance against legislation that limits GAHT access, and foster patient-provider dialogue. Educational videos are highly understandable and are created by reliable sources, but they vary in terms of currency and quality of supporting evidence, and they lack in actionability.

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KEYWORDS

transgender; gender diverse; transgender and gender diverse; TGD; gender fluid; online platform; social media; gender affirming; hormone therapy; gender-affirming hormone therapy; GAHT; social media content; media information; social media analysis; TikTok; web scraper; hashtag; themes; qualitative content analysis; patient education materials assessment; PEMAT; Currency, Relevance, Authority, Accuracy, and Purpose; CRAAP; audiovisual materials; qualitative

Introduction

TikTok (ByteDance) is a short-form video-sharing application that boasts 97.6 million active users in the United States. Since TikTok's spike in popularity in 2020, transgender and gender diverse (TGD) content creators have used the platform as a space to document and share their experiences with others. While TikTok has the potential to disseminate health information and improve access to gender-affirming care, it has come under scrutiny for spreading misinformation, bias, and hate speech [1].

Despite the lack of systematic analysis, the spread of information about gender-affirming care within the TGD TikTok community has been cited as an example of community-engaged knowledge exchange and peer-to-peer support [2]. Furthermore, TikTok has the potential to improve access to health information among communities that experience health inequities as the result of discrimination, because having positive impressions of knowledgeable professionals on social media may help decrease medical mistrust and enhance access to care offline [2]. Lowering medical mistrust among TGD communities is crucial, given that 24% of respondents in the 2022 US Transgender Survey reported avoiding medical care due to fear of mistreatment by a provider [3].

While TikTok videos have the potential to improve access to health information, peer support, and trust in medical professionals, TikTok may also be used to spread misinformation, disinformation, and hateful rhetoric against lesbian, gay, bisexual, transgender, queer, intersex, and all asexually and gender diverse (LGBTQIA+) people on the platform [4]. For example, the use of gender-affirming hormone therapy (GAHT), which involves administering hormones like estrogen and testosterone or puberty blockers to alter gendered physical characteristics among TGD youth, has increasingly been attacked; its controversy has led to online hate speech and, in several instances, threats of violence against hospitals and individual providers online [5,6].

Previous studies have queried TikTok to explore attitudes toward and experiences with other types of medical care, using qualitative methods to determine the content and tone of posts about medical interventions ranging from contraceptive methods to erectile dysfunction treatment [7-9]. Others have focused on analyzing the quality and accuracy of health information reported on the platform [10-15]. Their analyses yielded insights into misconceptions about care, the prevalence of inaccurate factual claims about treatment, and salient elements of individual experiences with care, all of which have the potential to inform how clinicians treat and counsel their patients. However, there have been no analyses of users' attitudes towards, experience with, or knowledge about GAHT.

The aim of this study is to explore popular TikTok content posted under the hashtags #genderaffirminghormones and #genderaffirminghormonetherapy. Using previously validated methods, we (1) describe the demographic characteristics, attitudes, and affiliations of video content creators; (2) perform a qualitative analysis of video content to identify content themes; and (3) assess the understandability, actionability, and reliability of information presented in a subset of educational videos. In doing so, we aim to better understand the degree to which TikTok is a vehicle for sharing valuable information about GAHT and treatment access versus a potentiator of misinformation and harmful biases.

Methods

Data Extraction

We used the web-scraping application Apify (Apify Technologies s.r.o.) TikTok scraper to download all TikTok videos posted publicly under the hashtags #genderaffirminghormonetherapy and #genderaffirminghormones as of November 17, 2023; Apify provided all videos as MP4 files. While videos that fit the inclusion criteria may be available under alternate hashtags, only these two hashtags were selected for this study, as it was infeasible to scrape the vast content created under broader hashtags; additionally, users who are actively seeking information on GAHT would most likely search these two hashtags. The scrape included a total of 86 videos. We applied the following exclusion criteria: (1) non-English language video, (2) country codes in the European Union or China (based on differences in data usage agreements in these regions), (3) GAHT not mentioned in the video, (4) duplicate video, or (5) video posts removed following the scrape.

Descriptive Analysis of the Content

For all eligible videos, we recorded the date posted and video duration, and TikTok engagement statistics, including the number of video views, likes, comments, shares, and number of creator fans. Through discussion and consensus, the first and second authors determined five main categories of videos after reviewing all videos (personal experience, health education, politics, creator opinion, and humor) and categorized each video. The sum, median, and IQR of engagement statistics were calculated for each type of video to best characterize the distribution of engagement; these metrics were selected given that specific videos may go viral on the platform, thereby skewing the data.

The first author then determined content creator demographics, including self-described gender identity and sexual orientation, for each video via the exploration of content creators' public profiles, including the user, bios, current or previous videos, video captions, and comment responses [16]. Only explicitly stated identities from content creators were included to avoid assumptions about their identities; if no such statements were available, we marked the field as "unknown." We selected "not applicable" if the account belonged to an organization rather than an individual. We similarly obtained creators' GAHT user status, health care worker status, and organizational affiliations from information on their public profiles. Finally, the first and second authors individually rated each video on whether the creator displayed a positive (eg, supportive or encouraging), negative (eg, dismissive or transphobic), neutral (eg, purely informative), or ambiguous or mixed attitude (authors could not ascertain or agree on the creator's intentions) toward GAHT. Through discussion, the authors came to a consensus on the final ratings of all videos.

Quality Rating of the Content

We further analyzed a subset of health education videos to assess the understandability, actionability, and reliability of information presented. "Health education" videos contained at least one message about which creators aimed to inform viewers [17,18].

The first and second authors independently used the Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-AV) to assess information understandability (ie, accessibility of the information presented for the layperson, including statements like "The material uses common, everyday language"; items 1 - 13) and actionability (ie, the feasibility of implementing the information presented, including statements like "The material breaks down any action into manageable, explicit steps"; items 14 - 17) of patient educational materials. Each item in the scale is rated as "agree" (1 point), "disagree"

(0 points), or "not applicable." The first and second author then compared each rating they assigned until they came to a consensus on all items. Finally, scores were calculated as a percentage of the possible points obtained for all items, excluding those rated as not applicable. Higher percentages suggest higher levels of understandability and actionability, with a threshold of >75% used to indicate "high quality" [19-21].

The senior author, who is a physician-scientist specialized in gender-affirming care, also used a modified Currency, Relevance, Authority, Accuracy, and Purpose (CRAAP) test to assess the reliability and accuracy of health information presented in educational videos [22]. The CRAAP test is used for the quantitative assessment of digital health information [23-25] by assessing five domains of information reliability: currency, relevance, authority, accuracy, and purpose. We adapted a previously published scale and scoring key by modifying the language and removing several items that were not applicable to audiovisual media [23]. Our adapted scale contained a total of 18 items (3 assessing currency, 4 assessing reliability, 3 assessing authority, 3 assessing accuracy, and 5 assessing purpose).

Overall scores ranged between 0 and 34, with higher scores suggesting higher reliability. Based on previous work using the CRAAP test, we considered a final score of <20% as unreliable, 20 - 46% as reliable with caution, 46 - 80% as good reliability, and >80% as excellent reliability [23]. We used Cronbach α to assess the interitem reliability of the scale (α=.88). The rubric for the modified CRAAP test is provided in Table 1.

Table . Modified Currency, Relevance, Authority, Accuracy, and Purpose (CRAAP)[a] test.

Item	Scoring key			
	0	1	2	3
Currency (3 items, 5 points)				
Date created	>5 y	1 - 5 y	<1 y	N/A[b]
Information outdated or debunked	Yes	No	N/A	N/A
Embedded links or suggested resources still accessible	None listed	No longer accessible	Still accessible	N/A
Relevance (4 items, 4 points)				
Information answers a central question	No	Yes	N/A	N/A
Information identifies an intended audience	No	Yes	N/A	N/A
Information appropriate for the needs of the intended audience	No	Yes	N/A	N/A
Information avoids overgeneralization	No	Yes	N/A	N/A
Authority (3 items, 5 points)				
Identity of the author or source	None identified	Medication user or patient	Expert in the field	N/A
Author's credentials	None	Lived experience	Licensed medical professional	N/A
Author qualified to discuss the topic[c]	No	Yes	N/A	N/A
Accuracy (3 items, 7 points)				
Derivation of information	Unclear	Individual lived experience	Professional experience	Evidence-based review
Is the information supported by evidence[d]	No	Yes	N/A	N/A
What kind of evidence supports the claim	None	Individual lived experience	Expert/consensus opinion	Published evidence-based guidelines
Purpose (5 items, 8 points)				
Purpose of information	Advertisement	Persuading or entertaining	Informing	Teaching
Intentions or purpose clear	No	Yes	N/A	N/A
Nature of information	Propaganda	Opinion	Facts	N/A
Point of view appears objective and impartial	No	Yes	N/A	N/A
Political, ideological, cultural, or religious biases	Yes	No	N/A	N/A

[a]This modified CRAAP Test is developed from the original test by Sarah Blakeslee, which is licensed for adaptations under a Creative Commons Attribution 4.0 International License.

[b]N/A: not applicable

[c]Creators were considered qualified to discuss a topic if they either had confirmed credentials indicating relevant subject matter expertise and licensure relevant to the clinical topic, or lived experience in a patient testimonial.

[d]Information presented in videos was considered supported if contemporary scientific evidence was congruent with the information.

Ethical Considerations

This study involves the analysis of publicly available data from TikTok; data from private accounts were not assessed as part of this project. Investigators only had access to creators' account names while viewing videos during the initial scoring and coding of data. Any identifiable information, including account names, was removed from the data prior to dissemination. This study received a Not Human Subjects Research Determination from the Harvard Longwood Campus Institutional Review Board.

Results

Descriptive Analysis of the Content

Our search identified 84 videos posted between February 2022 (the earliest video searching the TikTok hashtag recalled) and October 2023; while data collection was performed in November 2023, no new videos under the hashtag were posted in November 2023. Fifteen videos were determined ineligible for analysis based on non-English language (n=6), country code in the European Union or China (n=1), GAHT not mentioned in the video (n=6), duplicate (n=1), or video post removed following the scrape (n=1). The remaining 69 videos were included in our analysis. The median (IQR) video duration was 56 (23 - 73) seconds. Video characteristics and creator demographics are summarized in Table 2.

Table . Video characteristics and creator demographics of the 69 TikTok videos analyzed.

Video characteristics	n (%), N=69
Video type	
Personal experience	45 (65.2)
Health education	15 (21.7)
Politics	4 (5.8)
Creator opinion	4 (5.8)
Humor	1 (1.4)
Attitude toward GAHT[a]	
Positive	58 (84.1)
Negative	2 (2.9)
Neutral	5 (7.2)
Mixed or ambiguous	4 (5.8)
Medication referenced	
Testosterone	41 (59.4)
Estrogen	11 (15.9)
Antiandrogens	1 (1.4)
Not specified	17 (24.6)
Creator gender identity	
Nonbinary	29 (42.0)
Cisgender woman	16 (23.2)
Trans masculine	14 (20.3)
Transgender man	9 (13.0)
Transgender woman	6 (8.7)
Trans feminine	1 (1.4)
Unknown	1 (1.4)
N/A[b]	3 (4.3)
Creator sexual orientation	
Bisexual	10 (14.5)
Queer	10 (14.5)
Lesbian	1 (1.4)
Gay	1 (1.4)
Pansexual	1 (1.4)
Unknown	43 (62.3)
N/A	3 (4.3)
Health care professional	
Yes	17 (24.6)
No or unsure	52 (75.4)
GAHT user	
Yes	49 (71.0)
No or unsure	20 (28.9)
Creator affiliation	
None	65 (94.2)

Video characteristics	n (%), N=69
Health care organization	3 (4.3)
Religious organization	1 (1.4)

[a]GAHT: gender-affirming hormone therapy.

[b]N/A: not applicable.

Common themes that appeared in videos are described in Table 3. Self-identified health care workers created 50% of videos about estrogen and antiandrogen regimens, 46% of videos about GAHT access and legality, and 33% of videos about physical changes on testosterone. They created relatively smaller proportions of videos about testosterone regimens (24%), combating misinformation or social stigma around GAHT (11%), and physical changes due to testosterone (10%). None posted antitrans rhetoric.

Table . Content themes and subthemes appearing in the 69 TikTok videos analyzed.

Content themes and subthemes	n (%), N=69
Physical changes on testosterone	29 (42.0)
Voice changes	20 (29.0)
Facial or body hair growth	11 (15.9)
Clitoral growth	7 (10.1)
Skin changes (acne or oiliness)	6 (8.7)
Body odor changes	3 (4.3)
Body composition changes	6 (8.7)
Physical changes on estrogen	2 (2.9)
Breast development	4 (2.9)
Pre-post therapy photo reveal	17 (24.6)
Testosterone regimens	13 (18.8)
Medication formulations and routes of administration	2 (2.9)
Medication safety or monitoring	2 (2.9)
Concomitant use of estrogen-containing medications	6 (8.7)
Estrogen and antiandrogen regimens	4 (5.8)
Medication formulations and routes of administration	3 (4.3)
Medication safety or monitoring	13 (18.8)
GAHT[a] access and legality	6 (8.7)
Reviews new state guidelines or policy proposals	4 (5.8)
Reviews the process of obtaining medical clearance or prescription	3 (4.3)
Promotes a health care practice offering GAHT	1 (1.4)
Solicits advice on obtaining a prescription	1 (1.4)
Offers resources for funding GAHT	9 (13.0)
Combating misinformation and social stigma about GAHT	6 (8.7)
Validates TGD[b] identities	5 (7.2)
Emphasizes mental health benefits of access to GAHT	2 (2.9)
Normalizes the use of GAHT	29 (42.0)

[a]GAHT: gender-affirming hormone therapy.

[b]TGD: transgender and gender diverse.

Regarding engagement, videos had a total of 446,318 views, 43,743 likes, 1184 comments, and 438 shares. The sums, medians, and IQRs of engagement measures across each video type are described in Table 4. The top three most viewed videos each discussed physical changes on testosterone therapy and accounted for 46% of total views, 55 of total likes, 32% of total comments, and 56% of total shares. The single most-viewed video (104,800 views) depicted a nurse practitioner discussing labial changes due to testosterone with the aid of a plastic anatomic model.

Table . Number of views, likes, comments, shares, and creator fans for the 69 TikTok videos analyzed.

Engagement statistics by video type	All, n=69	Personal experience, n=45	Health education, n=15	Politics, n=4	Creator opinion, n=4	Humor, n=1
View count						
Total	440,711	272,602	138,843	18,165	9808	1293
Median (IQR)	847 (283 - 2649)	843 (313 - 2600)	423 (276 - 4315)	1451 (235 - 5758)	2122 (1148 - 3424)	N/A[a]
Like count						
Total	43,743	26,431	12,281	3671	1051	309
Median (IQR)	77 (21 - 248)	77 (28 - 222)	25 (11 - 242)	149 (19 - 1048)	185 (106 - 341)	N/A
Comment count						
Total	1169	585	246	226	96	16
Median (IQR)	6 (1-16)	6 (2-13)	2 (0 - 9)	34 (0 - 91)	23 (19 - 28)	N/A
Share count						
Total	437	198	101	118	20	0
Median (IQR)	0 (0 - 3)	0 (0 - 1)	0 (0 - 6)	8 (0 - 37)	5 (2-9)	N/A
Creator fans						
Total	488,055	185,202	129,321	162,177	10,857	498
Median (IQR)	1871 (593 - 3448)	1871 (759 - 3047)	189 (39 - 16,648)	3429 (2257 - 41,717)	2269 (1924 - 4640)	N/A

[a]N/A: not applicable.

Quality Rating of the Content

Health education videos averaged 88.3% (SD 11.1%; median 85.7%) on PEMAT-A/V understandability items, and 60.0% (SD 45.8%; median 100%) on actionability items. Together, the weighted mean (SD) PEMAT-A/V score for all items was 81.7% (18.7%). Videos averaged 74.5% (SD 18.4%) in total on the CRAAP test, with mean (SD) component scores as follows: currency, 58.7% (19.2%); relevance, 93.3% (SD 20.0%); authority, 82.7% (SD 35.3%); accuracy, 61.0% (SD +29.3%); and purpose 81.7% (SD 14.1%).

Discussion

Principal Findings and Comparison With Previous Works

This study characterized the creators and content of 69 TikTok videos related to GAHT. The most common videos were those made by TGD content creators who shared personal experiences on GAHT. For example, many videos were part of weekly or monthly series in which the creator reviewed the physical effects of their medications or applied or injected medication on camera while providing updates to their followers. Attitudes among users were overwhelmingly positive, with a few instances of ambivalence or mixed attitudes reflecting a preference for one mode of GAHT administration over another.

The large proportion of personal experience videos, which also had high engagement from viewers, reflects the longstanding popularity of TGD video blogs (vlogs) across other social media sites, including Reddit and YouTube [26-28]. As in the current study, prior work has noted an increased frequency of videos created by testosterone users relative to estrogen/anti-androgen users, which may be partially due to the shorter onset time of visible bodily changes with testosterone use [29,30]. Prior YouTube-based ethnographic research suggests these vlogs simultaneously function as opportunities for creators to reflect on and visualize their own gender affirmation journeys, as well as digital diaries to share their narratives with others and engage in broader dialogue [28]. The prevalence of and engagement with personal experience videos in this dataset suggest that TikTok provides a similar space for TGD GAHT users to continually reaffirm their personal identities and engage with the community through digital narrative-sharing.

Our findings suggest that TikTok also functions as a platform for digital activism and resistance. Nearly a third of videos dealt with issues related to GAHT access, newly imposed restrictions on GAHT use, and disinformation about GAHT in the media. In these videos, creators reviewed the process of obtaining a prescription, described sources of funding, or detailed how users could continue to access GAHT despite restrictive legislation passed in Florida and Utah during the timeframe studied. Many used TikTok's duet function to respond directly to disinformation circulating in the media and among politicians. These videos represent a timely means of intracommunity resistance against restrictive legislation by providing GAHT users with steps to continue GAHT. As legislatures in the United States and abroad attempt to ban and restrict access to care, social media platforms including TikTok may play an increasingly important role in community organizing and harm reduction.

Our results suggest that TikTok provides space for dialogue between GAHT users and health care workers, which may help reduce medical mistrust and facilitate the safe administration of GAHT. Content made by health care workers constituted nearly a quarter of all videos and was created with the intention of sharing health information relevant to GAHT users. These videos showed high levels of engagement, and often directly addressed viewers' comments or private messages. The ability for health care providers to respond directly to GAHT users' questions about hormones supports its potential as a space for effective digital knowledge mobilization, as prior work suggests [2]. Furthermore, health care providers also benefit from this interaction by gaining a deeper understanding of common questions and concerns among TGD people interested in GAHT.

Our analysis of health education videos suggests that information contained in educational videos is of high understandability, low actionability, and moderate reliability. An average PEMAT understandability score of 88.3% across educational videos suggests a high level of accessibility to viewers. The lower average actionability score of 60.0% may reflect the fact that the goal of many health education videos was to explain a particular phenomenon (eg, the mechanisms behind expected physical changes due to testosterone) rather than to guide patients' decisions about treatment.

High scores on the relevance, authority, and purpose components of the CRAAP test (>80%) suggest that educational information regarding GAHT is well-suited to the needs of the intended audience, created by reliable sources, and shared with the purpose of informing viewers about their health. The lower scores on the accuracy and currency components of the scale reflect the finding that while many content creators used their professional experience to support their claims, few cited evidence-based guidelines or provided viewers with further reading or updates as new information emerged. While the content analyzed was overall understandable, it did not reliably contain the level or depth of detail present in evidence-based clinical practice guidelines. It may therefore be important for providers to work with patients to contextualize information about GAHT found on the platform.

Clinical Implications

Our findings have several clinical implications. Providers should be aware that patients may use TikTok as a source of health knowledge, and that this information varies in depth and accuracy. GAHT prescribers may consider incorporating routine screening questions about patients' consumption of medication-related social media content and using these to either augment, contextualize, or correct information found online. As much as GAHT users may use TikTok as a space to seek information from health care providers, it can also better inform providers about TGD patients' needs and priorities. These needs are apparent where videos made by providers and users diverge thematically. For instance, providers created a high proportion of videos surrounding drug safety and monitoring, whereas GAHT users focused more on desired medication effects, suggesting a potential need for comprehensive counseling on expected and adverse effects.

Furthermore, videos created by providers also differed from user-created videos in that few of them directly addressed a nonbinary audience, despite nonbinary content creators being the most well-represented demographic in the videos analyzed, suggesting that there may be a lack of awareness surrounding GAHT-related needs of nonbinary people. In fact, only one health education video created by a provider explicitly addressed a nonbinary audience, and nearly a quarter used language that reinforced a binary gender paradigm (eg, "this video is for anyone transitioning male to female"). Thus, TikTok may also offer cisgender providers an opportunity to better understand the unique needs of diverse groups seeking out GAHT, which may allow for a more patient-centered and culturally responsive approach to counseling.

Limitations

There are several limitations to this study. First, the content analyzed is limited to what appears under the specific search terms #genderaffirminghormonetherapy and #genderaffirming hormones. While there is likely broader discourse on TikTok surrounding this topic, broadening the search terms—for example, to #hormonetherapy or #testosterone—would have yielded results that are not specific or relevant to TGD communities. While the videos analyzed were created over a 20-month period, they represent a single snapshot in time within the rapidly changing landscape of social media.

We were unable to compare quantitative statistics between different video types due to the small sample size for some video types and the non-normal distribution of engagement statistics with videos that were outliers with regard to viewership. Future studies should conduct rigorous statistical comparisons on video metrics in a larger sample size.

Additionally, TikTok has been criticized for its tendency toward "collaborative filtering," a method of predicting users' interests based on their previous views and activity in the app. By using physiognomic data, some argue that TikTok is more likely to recommend creators who look like the platform's white and able-bodied top influencers, and less likely to recommend creators who belong to underrepresented minority groups, which can also be referred to as "shadow banning" [31-33]. In this context, it is important to consider that some perspectives may be systematically privileged over others.

Similarly, the collected data may be vulnerable to bias towards more positive experiences. Users may be more willing to share positive experiences given the nature of the community formed under these hashtags; those with negative experiences may be less willing to share their experiences. However, we attempted to mitigate bias in content selection by using a web scraper rather than a TikTok account for data collection.

Our analysis involved collecting self-reported demographic characteristics from public profiles, which can be falsely reported for a variety of reasons, including stigma or safety concerns. Thus, it is possible that the number of TGD content creators and GAHT users within the dataset was underreported. Moreover, we chose to limit our focus to video content to analyze the dialogue between creators and viewers, though future research may also include the comment sections of such videos.

Finally, while an abundance of clinical evidence supports the efficacy of GAHT, there remains debate nationally and internationally on certain aspects of GAHT. Videos were rated based on the contemporary understanding of GAHT, with the authorship team comparing information presented in videos to the majority consensus in the academic field; however, we acknowledge that our ratings are limited by a lack of consensus in the clinical community on certain topics related to GAHT.

Conclusions

This study evaluated the discourse around GAHT on TikTok to better understand the extent to which it is being used as a tool for building community and disseminating health knowledge. Overall, our results suggest that TikTok allows GAHT users to document their experiences, connect with other community members, and advocate for GAHT as legislation restricts access to treatment. TikTok also provides a space for direct user-provider dialogue, whereby users can have questions answered by health professionals with a high level of information understandability. Health professionals should be aware that patients may use TikTok as a source of information and should be ready to explore these sources of knowledge with patients, as they vary in terms of currency and quality of supporting evidence. Health care workers may utilize social media platforms such as TikTok as an opportunity for bidirectional learning and health knowledge dissemination between clinicians and GAHT users.

Conflicts of Interest

ASK declares royalties as editor of a McGraw Hill textbook on transgender and gender diverse health care and of an American Psychiatric Association textbook on gender-affirming psychiatric care. The authors declare no competing financial interests.

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Abbreviations

CRAAP: Currency, Relevance, Authority, Accuracy, and Purpose
GAHT: gender-affirming hormone therapy
LGBTQIA+: lesbian, gay, bisexual, transgender, queer, intersex, and all asexually and gender diverse
PEMAT-A/V: Patient Education Materials Assessment Tool for Audiovisual Materials
TGD: transgender and gender diverse

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Review

Experiences of Public Health Professionals Regarding Crisis Communication During the COVID-19 Pandemic: Systematic Review of Qualitative Studies

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Abstract

Background: The COVID-19 pandemic emerged in the digital age and has been called the first "data-driven pandemic" in human history. The global response demonstrated that many countries had failed to effectively prepare for such an event. Learning through experience in a crisis is one way to improve the crisis management process. As the world has returned to normal after the pandemic, questions about crisis management have been raised in several countries and require careful consideration.

Objective: This review aimed to collect and organize public health professionals' experiences in crisis communication to the public during the COVID-19 pandemic.

Methods: We searched PubMed, MEDLINE, CINAHL, Web of Science, Academic Search Complete, PsycINFO, PsycARTICLES, and Communication Abstracts in February 2024 to locate English-language articles that qualitatively investigated the difficulties and needs experienced by health professionals in their communication activities during the COVID-19 pandemic.

Results: This review included 17 studies. Our analysis identified 7 themes and 20 subthemes. The 7 themes were difficulties in pandemic communication, difficulties caused by the "infodemic," difficulties in partnerships within or outside of public health, difficulties in community engagement, difficulties in effective communication, burnout among communicators, and the need to train communication specialists and establish a permanent organization specializing in communication.

Conclusions: This review identified the gaps between existing crisis communication guidelines and real-world crisis communication in the digital environment and clarified the difficulties and needs that arose from these gaps. Crisis communication strategies and guidelines should be updated with reference to the themes revealed in this review to effectively respond to subsequent public health crises.

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KEYWORDS

COVID-19; health communication; infodemic; misinformation; social media; SARS-CoV-2; pandemic; infectious; digital age; systematic review; internet; public health; government; health professional; crisis communication; qualitative; disinformation; eHealth; digital health; medical informatics

Introduction

The COVID-19 pandemic claimed millions of lives. It resulted in a public health crisis and caused economic and social turmoil worldwide. No country, irrespective of region or wealth, was spared the devastating effects of the COVID-19 pandemic. Given that there were no available drugs or vaccines early in the pandemic, communication was an important means of containing the crisis. Even after vaccines were developed, communication to increase trust in the vaccines was central to ending the crisis. Therefore, communication is essential in dealing with a pandemic [1].

Before the COVID-19 outbreak, crisis communication guidelines had been published by the World Health Organization (WHO) [2-4] and crisis communication strategies had been studied by researchers [5-9]. However, when the COVID-19 pandemic started, public health organizations worldwide acknowledged their lack of preparation and training for effective communication during such chaos [10-15]. Furthermore, the communication technology infrastructure has become increasingly complex over the last few decades. Social media platforms now seamlessly connect people to both accurate and false information, which tends to flow to recipients faster than viruses spread [16]. During the COVID-19 pandemic, public health organizations worldwide experienced difficulties with the "infodemic" of misinformation on social media [17]. Before the pandemic, researchers had recognized the importance of management of misinformation and studied countermeasures [18-21]. However, the COVID-19 pandemic highlighted the inexperience of public health agencies in dealing with the influence of misinformation during an emergency [22,23]. Therefore, the COVID-19 pandemic presented public health agencies with unprecedented challenges and highlighted the need to update existing crisis management communication strategies. A crisis is an important opportunity for learning; learning through experience in a crisis is the only way to improve the crisis management process [24,25]. Now that the world has returned to normal following the pandemic, questions requiring reflection have been raised about the crisis management in each country. Therefore, studies are needed to collect and organize data on public health professionals' experiences in crisis communication worldwide during the COVID-19 pandemic. This work is essential for updating crisis communication strategies to prepare for subsequent public health crises.

We conducted a systematic review of qualitative studies that focused on public health professionals' experiences in crisis communication during the COVID-19 pandemic in diverse countries. We examined the difficulties that public health professionals experienced during the COVID-19 pandemic, the challenges they faced in overcoming those difficulties, and the needs to be met in future public health crises. We also discussed the gaps between existing crisis communication guidelines and real-world experiences in the COVID-19 pandemic that need to be bridged going forward.

Methods

Overview

This systematic review followed the guidelines provided in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [26]. In addition, we referred to the Sample, Phenomenon of Interest, Design, Evaluation, Research type tool for the synthesis of qualitative evidence [27]. The protocol was previously published [28] and registered with the international Prospective Register of Systematic Reviews (registration: CRD42024528975).

Literature Search

We searched the following databases on February 7, 2024: PubMed, MEDLINE, CINAHL, Web of Science, Academic Search Complete, PsycINFO, PsycARTICLES, and Communication Abstracts. We filtered our database searches to include articles published from January 1, 2020, to January 31, 2024. We used a combination of keywords with reference to previous studies to search the abstracts in these databases [29-31]: "((government*) OR (ministr*) OR (department*) OR (office*) OR (municipalit*) OR (prefecture*) OR (province*) OR (state*) OR (count*) OR (organization*) OR (institution*) OR (center*) OR (agenc*) OR (sector*) OR (authorit*)) AND ((covid-19) OR (coronavirus) OR (sars-cov-2)) AND ((interview*) OR (focus group*) OR (questionnaire*) OR (survey*)) AND ((communicat*) OR (messag*) OR (inform*) OR (recommend*) OR (announce*)) AND ((qualitative) OR (mix method))."

Study Selection

We used Rayyan software (Qatar Computing Research Institute) [32] to screen the identified studies and automatically remove duplicates. Study inclusion and exclusion criteria are shown in Textboxes 1 and 2.

Titles and abstracts were independently screened to identify eligible studies using selection criteria established by the first author (TO) and the second author (MT). Then, the full texts of the remaining studies were screened independently by the first and second authors. Any disagreements during the screening process were discussed until consensus was reached, assisted by the third author (HO), as necessary.

Textbox 1. Study inclusion criteria.

- The study aim was to investigate public health professionals' experiences in crisis communication during the COVID-19 pandemic in the digital age with the infodemic of misinformation on social media.
- Regarding study content: qualitative studies of communications from governments and public health agencies to the public focusing on addressing the infodemic of misinformation on social media platforms.
- Regarding design: studies with qualitative data (eg, interviews, documents, and free-text questionnaire responses), those that used content analysis of qualitative data, reviews of qualitative studies, and mixed methods studies with qualitative results that met the study aim.
- Studies on individuals (irrespective of age, gender, ethnicity, or nationality), such as officials, health professionals, and researchers working for governments and public health agencies.
- Gray literature (information produced outside traditional publishing and distribution channels, such as conference proceedings and theses) if sufficient information was provided to confirm its eligibility (ie, full-length descriptions of research objectives, methods, results, discussion, and conclusions).
- Papers written in English and conducted from (and including) January 2020.

Textbox 2. Study exclusion criteria.

- Quantitative studies with quantitative data (eg, observational and interventional studies)
- Studies on journalists in media companies, patients, and the public
- Studies not published in full-text format
- Non–English-language papers
- Studies that did not meet the study aim that public health professionals' experiences in crisis communication during the COVID-19 pandemic in the digital age with the infodemic of misinformation on social media (eg, those on content analysis of media information, information searches by the public, COVID-19 patient management in hospitals, and patient-provider communication)

Quality Assessment

The Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research was used to assess the methodological quality of eligible studies [33,34]. This Joanna Briggs Institute checklist assesses the descriptive, interpretative, theoretical, and evaluative validity of qualitative studies. The 10 items of the checklist are evaluated as "yes," "no," "unclear," or "not applicable." The first (TO) and second (MT) authors independently performed quality assessments of the included studies. Any disagreements were discussed until consensus was reached, assisted by the third author (HO) as necessary.

Data Synthesis

Thematic synthesis was used to synthesize the collected data [35]. Thematic synthesis is recommended as a systematic method for synthesizing qualitative evidence [36]. In the first stage, free line-by-line coding of texts and quotations in the results and discussion sections of the included studies was conducted by TO. Next, 2 reviewers (TO and MT) independently grouped similar codes and generated data-driven descriptive themes. Consensus was reached through discussion, and the third reviewer (HO) was consulted when necessary. Finally, TO developed analytical themes by organizing the descriptive themes generated in the previous stage. This process of developing analytical themes involved repeated discussions among TO, MT, and HO.

Results

Study Characteristics

Figure 1 shows the PRISMA flow diagram of the study selection. We included 17 studies in this review. Table 1 shows the characteristics of the included studies. A total of 5 studies were conducted in the United States, 4 in Canada, 2 in Switzerland, and 2 in Iran, and the other studies included participants from Europe, the Middle East, Asia, South America, and Africa. Participants' occupations included communication specialists, medical professionals, scientists, and officials in public health institutions and local municipalities. The median number of study participants was 20 (IQR 12.5-26), and 367 health professionals were represented overall. The time frame in which the data were collected was from March 2020 to December 2022. The included studies showed an overall good methodological quality; the median number of studies classified as "yes" was 8 (IQR 7-9). Results of the quality appraisal are shown in Multimedia Appendix 1 [11,15,37-51].

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) search process flowchart.

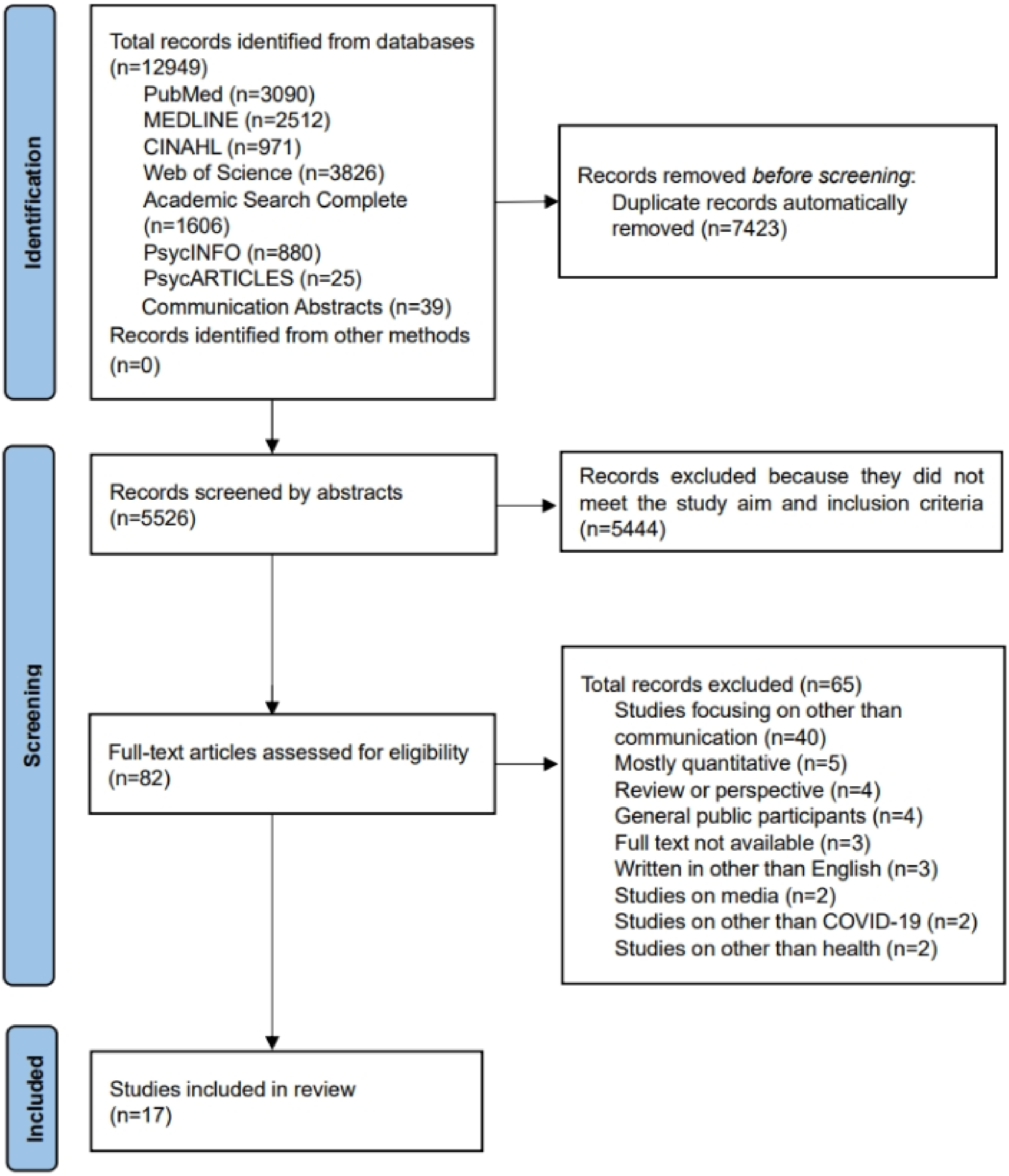


Table 1. Study characteristics of qualitative studies regarding crisis communication during the COVID-19 pandemic.

Study	Country	Settings	Participants, n	Period when the data were collected	Study aim
Atighechian et al [15], 2021	Iran	Universities, governments, and hospitals	Health professionals and experts, including university faculty members, policy makers, physicians, and nurses working in the infectious disease unit (n=19)	March 2020-June 2020	To identify the challenges of COVID-19-related information among people in point of experts' views
Nehushtan et al [41], 2023	Israel	14 municipalities	Officials in local municipalities, including chief executive officers, mayors, and officials responsible for health in emergencies (n=42)	October 2020-February 2021	To explore local municipalities' management of the COVID-19 pandemic
Sears et al [43], 2024	United States	One state	Public health workers, including sanitarian, educator, and administrative positions (n=11)	October 2020-March 2021	To gain an in-depth perspective of public health workers' experiences during the complex and dynamic climate the COVID-19 pandemic
Colman et al [37], 2021	Belgium, the Netherlands, United Kingdom, Sweden, and Germany	Academic or public health research institutions	Scientists with an official government advisory role during the pandemic (n=21)	December 2020-April 2021	To explore the views and experiences of scientists working on government advisory boards
Bravo et al [40], 2023	Paraguay, Uruguay, United States, Canada, Germany, Spain, New Zealand, Australia, and South Korea	Universities, governments, a research center, a health care center, and a non-governmental organization	Experts with experience in health crisis management or risk communication (n=10)	December 2020-March 2021	To identify a framework for risk communication during health crises from the voices of international experts by using the COVID-19 pandemic as a case study
Rubinelli et al [11], 2023	Switzerland	Institutions responsible for communicating with the public at the national and cantonal levels	Individuals responsible for public institutional communication within key public health institutions (n=25)	January 2021-July 2021	To collect individual experiences of communicating the situation and protective measures to the public
Ort and Rohrbach [42], 2024	Switzerland	Key Swiss public health institutions at the federal and cantonal levels	Individuals responsible for public institutional communication within key public health institutions (n=25)	January 2021-July 2021	To explore public health institutions' challenges in implementing their COVID-19–related communication strategies
Pringle et al [50], 2022	Canada	Vancouver, the most diverse area	Communication specialists, medical professionals, officials in community service organizations, and volunteer community advocates (n=27)	May 2021-November 2021	To examine how community leaders, advocates, and public health communication specialists have approached community engagement
Engdawork et al [45], 2024	Ethiopia	A capital city	Stakeholders in the local government and private sectors engaged in social interventions to prevent COVID-19 (n=21)	September 2021-October 2021	To investigate the effectiveness of structural interventions during the earlier period of the pandemic in promoting adoption of preventive actions, challenges encountered during implementation, and draw lessons for future pandemic responses in low- and middle-income settings

Study	Country	Settings	Participants, n	Period when the data were collected	Study aim
Dubé et al [38], 2022	Canada	One province	Communication specialists in charge of developing health authorities' COVID-19 communication and health care professionals actively engaged in public discussion in traditional and social media (n=11)	September 2021-December 2021	To explore how communication specialists working in health and governmental institutions and health care professionals have communicated about COVID-19
Lowe et al [39], 2022	Canada	11 jurisdictions	Public health officials, frontline health care workers, health scholars (social, epidemiological, policy, and clinical researchers), and health care worker union leaders (n=34)	September 2021-December 2021	To assess COVID-19 pandemic public health messaging for its potential to encourage or undermine public trust and adherence
Ittefaq [44], 2023	United States	Three states	Communication officials working in local health departments (n=14)	February 2022-April 2022	To explore challenges in information dissemination on social media, and factors contributing to burnout among communication officials
Kamruzzaman et al [49], 2023	Bangladesh	Three divisions that reported the highest COVID-19 cases	Health professionals, including district-level health education officers, residential medical officers, and pertinent national specialists (n=14)	February 2022-May 2022	To understand how the social context influences risk communication and community response during the COVID-19 pandemic
Bates et al [46], 2023	United States	One county	Public health professionals working at city health departments and a county health department (n=7)	March 2022-May 2022	To determine how public health officials perceived misinformation and political polarization during the pandemic, and to learn more about strategies county health officials used to combat misinformation
Strand et al [48], 2023	United States	Midwestern states	Public health professionals in local and state public health departments, universities, and health care organizations (n=48)	Summer of 2022	To describe the lived experiences of public health professionals working during the COVID-19 pandemic and to provide lessons learned and best practices to inform preparation for a future infectious disease pandemic
Bazrafshan et al [47], 2023	Iran	Provincial and national public health institutions	Public health professionals across provincial and national health authorities (n=20)	October 2022-December 2022	To develop a conceptual framework for health risk communication and infodemic management during epidemics and health emergencies
Johnston et al [51], 2024	South Africa and Zambia	18 community health organizations	Individuals working in community health organizations with engagement in health education and information services (n=18)	Not mentioned	To investigate the strategies, challenges, and needs of community health organizations involved in public COVID-19 education to understand their role in public health crises in relation to communicating health information

Data Synthesis

Our analysis identified 242 free codes, which were organized into 41 descriptive themes: 7 analytical themes and 20 subthemes. Multimedia Appendix 2 [11,15,37-51] shows the analytical themes and subthemes, the studies that contributed to those themes, and direct quotations from the included studies to support those themes.

Difficulties in Pandemic Communication

Gap Between Scientific Uncertainty and Expectations of Certainty

The COVID-19 pandemic revealed a gap between the normal reality of scientific uncertainty and political and public expectations of certainty, which made public health communication difficult [11,37-40]. The traditional scientific method of generating, evaluating, and acting on evidence was incompatible with the urgency of the pandemic [11,37]. However, participants were required by policy makers and citizens to provide rapid, definitive conclusions and explanations based on uncertain evidence in an uncertain situation [11,37,38] (quotation 1). This demand contrasted with the "slowness" of science [37]. Changes were unfolding rapidly in terms of scientific knowledge, the spread of the infection, and political, economic, and social conditions, and this required several changes in public health policies over a short time [37,38] (quotation 2). The gap between the uncertainty of science and unrealistic expectations of certainty resulted in public criticism of public health professionals and difficulties in public health communication [11,37-40] (quotation 3).

Communication Challenges in a "Slow Disaster"

Participants described the characteristics of the COVID-19 pandemic as a "slow disaster" [40]. Most disasters are short-lived, but the nature of the COVID-19 pandemic meant that they had to continuously deal with changing circumstances [11,40,41]. In the early stages of the pandemic, citizens cooperated with public health recommendations [11]. However, over time, their patience waned, their trust in public health professionals declined, and compliance worsened [11,40,41] (quotation 4). In addition, health professionals experienced difficulty in using communication to encourage citizens to adopt preventive behaviors amid fatigue from a pandemic with no seeming end in sight [11,40-42] (quotation 5).

Difficulties Caused by the Infodemic

Difficulties in Public Health Activities Due to Misinformation

Misinformation about the severity and mortality of COVID-19 and the safety of vaccines spread on social media, and affected citizens' attitudes and behaviors [11,15,42-47] (quotations 6 and 7). Participants were forced to devote significant resources to identifying and correcting misinformation [11,15] (quotations 8 and 9) but did not have effective measures to counter the sensational communication strategies used by purveyors of misinformation [11,39,43] (quotation 10). It was also more difficult to persuade people who had acquired a skeptical attitude through misinformation than it was to simply convey correct information [11,42,43,45].

Countering Misinformation

During the COVID-19 pandemic, participants learned several strategies to deal with misinformation. The first was the importance of timely communication; it was crucial that participants disseminated messages before misinformation spread [11,15,47] (quotation 11). Second, participants recognized that social listening improved their understanding of citizens' psychosocial aspects and information needs, as well as the quality of information they provided [11] (quotations 12 and 13). Third, participants had to recognize and address fear and anxiety among citizens [39] (quotation 14). Finally, participants recognized the importance of actively using social media to disseminate accurate information and guide people to reliable information sources [11,38,39,46,47] (quotation 15). However, the lack of human resources with expertise in using social media made it difficult to counter misinformation using these platforms [11] (quotation 16).

Difficulties in Partnerships Within and Outside Public Health

Tensions Within the Community of Public Health Experts

Participants recognized the importance of public health agencies partnering with epidemiologists, data scientists, sociologists, communication scholars, and other professionals with unique expertise for developing and implementing pandemic communication strategies [11,15,37,38,40,42,47-49]. This was because pandemic communication had to incorporate consideration of the social, economic, and political context that unfolded along with the health crisis [15,37,40,47-49] (quotation 17). However, there were coordination difficulties, especially in the early stages of the pandemic. Expert committees tended to be dominated by biomedical and virological researchers and often excluded sociologists and anthropologists [37] (quotation 18). A reason cited for the limited effectiveness of communication to citizens was that the strategies used lacked an understanding of people's sociocultural beliefs [38,49].

Tensions Between Public Health and Politics

The conflict of interest between health care and the economy was a major factor that characterized the communication difficulties during the COVID-19 pandemic [11,15,37-39,42,43,46,48,49] (quotation 19). The conflict between safeguarding public health and maintaining the economy abrogated the coherence of policy decisions and messages to the public and led to public confusion and distrust of public health [15,37-39,48]. This conflict of interest between health care and the economy also created tensions between public health professionals and political leaders who wanted to maintain their political popularity [37,48]. At the policy-making level, some political leaders did not accept or use the scientific evidence provided by public health experts [37,39,48,49]. Moreover, political leaders sometimes used and abused public health professionals to evade their own responsibilities in communicating with the public [37,46] (quotation 20). At the policy practice level, public health professionals were sometimes obstructed by political leaders from recommending preventive behaviors and vaccination for citizens, rather than receiving political support [43,46] (quotations 21 and 22).

Difficulties in Coordination Between Public Health and Mass Media

Participants recognized the importance of close collaboration with the mass media [11,15,37,42,43,47]. They understood the influence of mass media in shaping public opinion and journalists' commitment to scientifically accurate and balanced reporting [15,37,47]. However, they recognized that during the COVID-19 pandemic, the mass media often engaged in misleading reporting, as well as pitting public health professionals against each other and politicians against public health professionals, quoting out of context, and linking public health professionals to specific political decisions [11,37,42,43]. In addition, some participants perceived that the biased discussion and criticism of public health activities in mass media coverage led to a decline in people's trust in public health [43] (quotations 23 and 24).

Difficulties in Community Engagement

Need to Tailor Communication to Community Realities

Some participants recognized that many of the COVID-19 recommendations were not consistent with community realities [45,50,51]. For example, small living quarters, large families, and essential travel by public transportation to buy food and work affected compliance with preventive behaviors such as social distancing [45,51]. Some citizens had to prioritize other essential living activities over infection prevention behaviors. For example, people of lower economic status had to go out to earn their living even during lockdown periods [45,51] (quotations 25 and 26). Compliance with COVID-19 prevention recommendations meant that many citizens faced economic hardship, food insecurity, domestic violence, and mental health problems [45].

Need to Consider Local Cultural Factors

Cultural factors such as a given community's dominant religion could also pose a barrier to compliance with the COVID-19 prevention recommendations [38,39,45,50] (quotations 27 and 28). However, participants recognized that cultural factors could act as both facilitators and inhibitors of public health activities [50]. They adapted their communication strategies to reflect community-specific sociocultural factors and incorporated ideas such as using culturally significant meeting places (eg, local religious centers) [45,50] (quotations 29 and 30).

Need for Bottom-Up and 2-Way Communication

Participants identified that the effectiveness of communication from health professionals to communities was inhibited by its 1-way nature [45,47,49,51] (quotation 31). Community groups and leaders were involved in implementing infection prevention programs; however, they had little involvement in planning and designing feasible programs [45]. Community participation tended to be lower when information was distributed from public health agencies to communities in a top-down manner. These top-down communication strategies, which lacked collaboration with the community, inhibited acceptance of recommendations for preventive behaviors [45,47,49]. This suggested that bottom-up and 2-way communication that involved the community were required to foster community engagement [45,47,49] (quotation 32).

Need to Build Trust With Communities

Participants generally responded that a trusting relationship between public health and the community was a factor in increasing community engagement [39,40,45,46,48,50,51]. They noted the importance of building trust with local political, religious, business, and agricultural leaders, along with schools, newspapers, radio stations, and other local organizations [40,48,50,51] (quotations 33 and 34). Existing local networks were especially important in developing grassroots communication activities [46] (quotation 35). In addition to trusting relationships with organizations, participants stated the importance of one-on-one trust relationships between health professionals and local residents [39,46] (quotation 36). However, in areas where public health outreach services had been reduced in the years before the pandemic, it was difficult to quickly rebuild trust between public health professionals and the community during the pandemic [50].

Need for Communication Through Community Channels

Communication through community-specific communication channels, such as local television and radio stations, social media platforms, and connections with trusted individuals, were emphasized as ways to increase community engagement [11,38,40,41,44-46,49-51] (quotation 37). Formal and informal communications were developed, including traditional media campaigns and disseminating messages via social media [11,40,41,45,50,51] (quotation 38). Participants noted that the key communication channels, including newspapers, radio, and social media, varied by community resident group [11,40,44,45,50,51] (quotation 39). For those groups using social media in particular, attempts were made to increase their engagement by encouraging their participation in communication activities [45,46] (quotation 40).

Difficulties in Effective Communication

Need for Uniformity and Promptness in Communication

Participants identified the absence of reliable sources of information known to citizens as an impediment to effective communication [11,15] (quotation 41). The plethora of available information sources, including mass media and social media, created confusion among citizens [11,15,43] (quotation 42). Furthermore, the importance of rapid information dissemination was crucial in communication regarding a hitherto unknown infectious disease [11,15,39,44,47] (quotations 43 and 44). However, participants faced a dilemma whereby prioritizing the speed of communication did not allow sufficient time to create effective messages. For example, translation into multiple languages was time-consuming [11,44] (quotations 45 and 46). In addition, it took time to crunch the vast amount of information and create concise, clear messages [11,44,45] (quotation 47).

Need for Understandable and Persuasive Communication

Participants emphasized the importance of efforts to ensure the public understood messages [11,37-40,42,45,48] (quotation 48).

These messages needed to have a clear purpose, use plain language and illustrations, and be persuasive to be easily understood and accepted by all citizens [11,38-40,45,48]. However, participants experienced difficulties in creating messages that addressed the various levels of citizens' individual health literacy [38,39,42,45] (quotation 49). Understandable communication was also important for politicians and policy makers who did not necessarily have basic scientific knowledge [37].

Need for Communication to Empower People

Participants noted the harms associated with health authorities generating stigma for certain populations [38-40]. For example, they accused young adults of often failing to follow recommendations for social distancing, and therefore, transmitting the virus, or of prolonging the pandemic by not being vaccinated [38,39] (quotation 50). They stressed that effective communication strategies should emphasize helping people make better informed decisions rather than punishing them with blame or fear or offering temporary reassurance [38,40] (quotations 51 and 52).

Burnout Among Communicators

Difficulties With Information Overload and Requests

Participants indicated that they felt like they were drowning in an overwhelming influx of information related to COVID-19 [11,41,51]. They tried to extract relevant information from this torrent; however, they did not know how to do so [51] (quotation 53). In addition, they were under intense pressure from the community to share the latest information about the novel virus [11,44] (quotation 54). Furthermore, public health professionals were expected to respond to constant media requests for updated information [11] (quotation 55).

Lack of Trust in Public Health

Participants experienced a lack of public trust, which led to communication difficulties [11,15,39,40,44,48,51]. A major contributing factor to this was discrepancies in the information disseminated by the government, municipalities, public health agencies, and professionals [15,39,48] (quotations 56 and 57). The confusion caused by these discrepancies increased people's distrust and decreased their willingness to accept infection prevention recommendations [15,40,44] (quotations 58 and 59).

Attacks on Public Health Professionals by Citizens

Participants experienced criticism and attacks from citizens despite their best efforts to overcome the aforementioned difficulties [11,37,43,44,46,48] (quotation 60). Daily criticism and attacks from citizens through social media, email, and community face-to-face meetings accelerated burnout among participants [11,43,44,46,48] (quotations 61 and 62). Accordingly, they sought ways to prevent burnout, including learning to set emotional boundaries for criticism [43] (quotation 63). They noted that rare words of gratitude from citizens empowered them [37,43] (quotation 64).

Need to Train Communication Specialists and Establish a Permanent Organization

Need to Train Communication Specialists

There was a notable lack of human resources with communication expertise during the COVID-19 pandemic [11,42,44,45,47]. In the early stages of the pandemic, public health agencies made efforts to increase the number of communications personnel by reorganizing their human resources [11]. However, securing a sufficient number of communications personnel, relative to the overwhelming volume of information that needed to be addressed, was difficult [11,42,45,47] (quotation 65). Personnel who had been moved to communications duties from other departments often lacked basic communication skills and competencies [11,42,45]. In addition, even those who had been previously trained in communications lacked the experience and ability to communicate effectively in the emergency pandemic situation [11,42] (quotation 66).

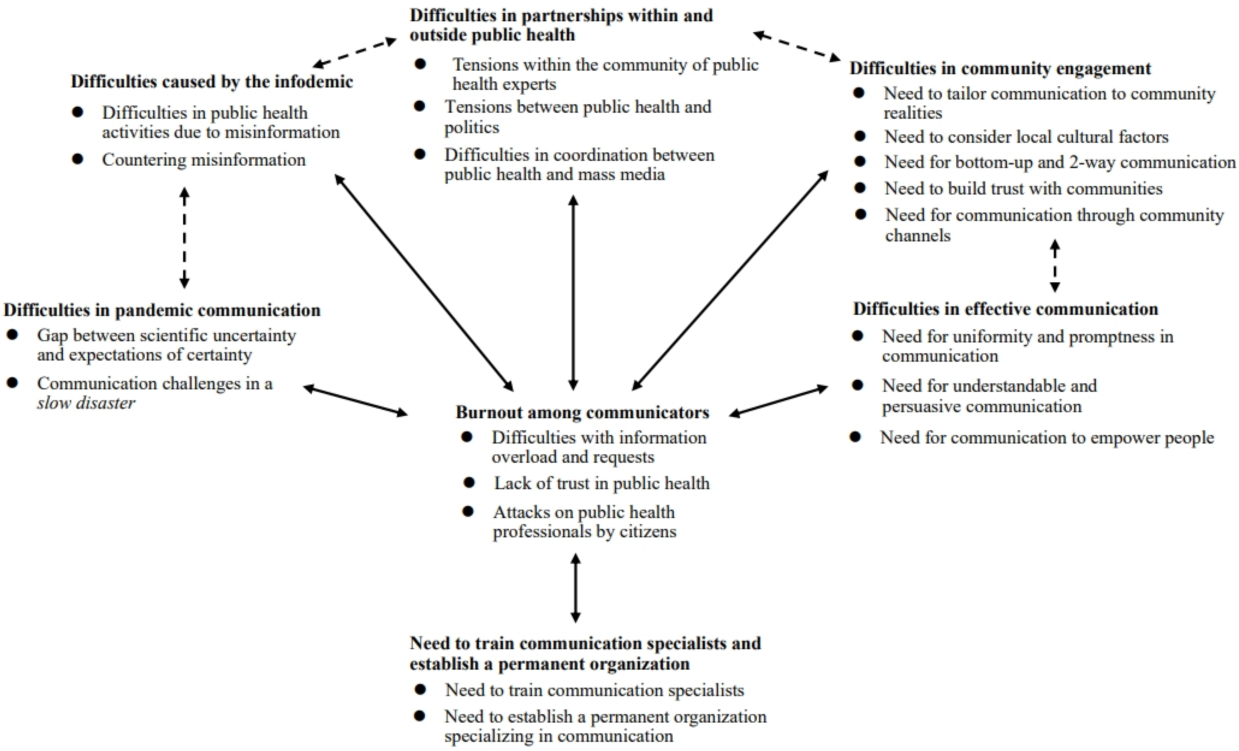
Need to Establish a Permanent Organization Specializing in Communication

Participants identified the rigidity within existing organizational structures as a problem. They emphasized that the many procedures, time-consuming approval processes, and inflexible and rigid protocols in the organizations inhibited rapid and effective public health communication [11,50]. They agreed on the importance of establishing a permanent organization specializing in public health communication [40,41] and noted that such an organization should train communication specialists, accumulate methods for effective communication strategies, build cross-functional partnerships with other organizations, and establish a structure to respond quickly in further public health crises [47] (quotation 67).

Conceptual Model

Figure 2 shows the conceptual model developed from the above results. Themes 3.2.1 to 3.2.5 were interrelated, and the difficulties experienced by communicators resulted in their burnout (theme 3.2.6). The difficulties and needs indicated in themes 3.2.1 to 3.2.6 indicated the need for future training of communication specialists and establishing a permanent organization specializing in communication (theme 3.2.7). It was assumed that training experts and establishing organizations would reduce difficulties and enable effective communication in subsequent public health crises.

Figure 2. Conceptual model developed from qualitative studies regarding crisis communication during the COVID-19 pandemic.



Discussion

Principal Findings

This systematic review of qualitative studies examined the difficulties, challenges, and needs experienced by public health professionals during the COVID-19 pandemic and identified 7 themes. The theme of difficulties in pandemic communication encompassed difficulties stemming from scientific uncertainty and the "slow disaster." Public health crisis communication inherently involves uncertainty [52,53], and the WHO and the Centers for Disease Control and Prevention (CDC) recommended explicitly communicating information about uncertainties [1,54,55]. Researchers in crisis communication argued that communicating uncertainty increased rather than decreased public trust [56,57]. However, this systematic review revealed that risk communication in the real world is not as simple as the above recommendation suggests. Uncertainty reduction theory indicates that humans are intrinsically motivated to reduce uncertainty [58]. Therefore, communicating uncertainty creates a conflict with people's demand for certainty. However, when people's trust in their government and communicators is stronger, they tend to more successfully accept uncertainty [59]. People's trust in government and public health agencies may offer a clue to resolving communication difficulties associated with uncertainty. Furthermore, neither the WHO nor CDC guidelines contained details on how to deal with communication difficulties stemming from a slow disaster [1,54,55]. Coping with pandemic fatigue was one of the difficulties stemming from the slow disaster. Although previous studies have examined factors associated with pandemic fatigue during the COVID-19 pandemic [60,61], much remains unknown about pandemic fatigue. Further research should consider effective communication strategies for a slow disaster.

The communication difficulties in the COVID-19 pandemic were characterized by the destructive impact of the infodemic. A survey conducted in the United Kingdom in 2020 showed that 46% of the public had been exposed to fake news about COVID-19 and 40% said they could not tell the difference between truth and lies [62]. Previous studies have examined effective debunking methods for misinformation [18-21]. The CDC also developed public health infodemic surveillance systems in the wake of the COVID-19 pandemic [63]. Furthermore, there are more than 100 laws against disseminating misinformation in different countries worldwide [64]. A multifaceted approach is needed to prepare for future public health infodemics, including surveillance, communication, and legal regulation.

The WHO guidelines to address COVID-19 emphasized the importance of collaboration within public health agencies and with external partners [55]. However, this systematic review found that, in reality, tensions in and outside of public health agencies hindered an effective crisis response. During noncrisis periods, governments, public health agencies, researchers, and media are often siloed, making crisis-related coordination and information sharing difficult [65]. In addition, political and economic interests that conflict with public health policies hinder an effective pandemic response [66]. Such partnership failures, which were experienced in past epidemics and pandemics, were repeated in the COVID-19 pandemic. Addressing this is a crucial challenge going forward.

Existing public health organization guidelines emphasized the importance of community engagement strategies [1,54,55].

Many studies have shown that community-based cultural factors were related to preventive behaviors and mortality rates during the COVID-19 pandemic [67-70]. Furthermore, language and cultural barriers prevented access to information, understanding of messages, and compliance with recommendations during the pandemic [71,72]. This systematic review showed that top-down, 1-way communication to the community hindered effective pandemic responses, despite the importance of a bottom-up approach that involves community stakeholders and residents in decision-making having been officially emphasized [73]. Communication in public health crises requires adapting communication strategies to the cultural, social, and demographic background of the local community to gain support among the target population [74]. To achieve this, it is important to break away from top-down, 1-way communication and adopt a 2-way, bottom-up approach that includes dialogue with the community [75].

During epidemics and pandemics, it is important that information from public health agencies is not overtaken by competing misinformation [25]. The first message that an audience receives shapes their subsequent attitudes [76]. Therefore, quick dissemination of information based on partial evidence is better than delayed dissemination of information based on complete evidence [1,55,77] because prompt communication is an essential principle of risk communication [54]. However, this systematic review revealed that the speed of communication hindered the effectiveness of communication during the COVID-19 pandemic. Public health professionals experienced difficulty in securing time for translation, pretesting, and creating easy-to-understand messages as they were under pressure to communicate quickly. The COVID-19 pandemic highlighted the difficulty of following existing crisis communication guidelines in a real-world crisis response.

Many public health professionals experienced burnout during the course of the pandemic. The main factors contributing to burnout were information overload that exceeded limited human resources, along with criticism and attacks on public health professionals from the public. The lack of public trust in public health also contributed to attacks against health professionals. The degree of trust in public institutions was associated with the rate of COVID-19 infection and the associated mortality rate [78]. A 2022 report by the Organisation for Economic Co-operation and Development highlighted that public trust was a key insight from the evaluation of responses to the pandemic, which pointed to the importance of building trust over a long period before a crisis occurs [73]. Building public trust and preventing burnout among public health professionals are essential for preparing for future public health crises.

The aforementioned 6 themes suggested the seventh theme, the need to train communication specialists and establish permanent organizations specializing in communication. These measures are necessary to address the aforementioned issues brought to light by the COVID-19 pandemic. COVID-19 showed that many countries had failed to learn the lessons of past global infections (eg, severe acute respiratory syndrome and influenza A virus subtype) and had failed to prepare for a future public health crisis [73,79]. Even now, many countries are still not prepared for future public health crises [80]. Another public health crisis occurring is not a matter of "if" but of "when" [81]. The best way to manage a crisis is to prevent one [25], and the second-best way to manage a crisis is to prepare for one [82]. All public health institutions and professionals must learn from the difficulties, challenges, and needs identified in this systematic review and update their strategies and guidelines to implement more effective communication in the next public health crisis.

Future Directions for Practitioners

The results of this systematic review suggest the following practice implications, which may help to prepare for the next public health crisis. (1) The scientific process is accompanied by uncertainty; however, politicians and citizens seek certainty. It is necessary to increase trust in public health organizations and address the communication difficulties associated with uncertainty, to address pandemic fatigue, and to develop effective communication strategies for future slow-onset disasters. (2) More research and practice are needed to manage misinformation in public health crises, including surveillance and communication strategies for "prebunking" and debunking information. (3) Partnerships between stakeholders at both the policy-making and communication practice levels are needed to manage public health crises. Such partnerships are important for enabling the creation and transmission of consistent messages, and avoiding confusion among citizens and distrust in public health. (4) It is necessary to build trusting relationships between public health organizations and communities before a crisis occurs and to enable bottom-up communication during crises. (5) It is also necessary to address the trade-off between communication promptness and effectiveness and conduct communication with the aim of empowerment. (6) Measures are needed to prevent burnout among health professionals during a crisis. (7) To address these issues and support an effective response to future public health crises, it is necessary to train more communications specialists, establish permanent organizations specializing in communication, and update strategies and guidelines.

Limitations

This systematic review had several limitations. First, we conducted a rigorous literature search and qualitative synthesis with 2 or more reviewers. However, we could not completely rule out the possibility that some relevant literature had not been included. Second, we did not weight the interpretation of study results according to the quality appraisal of the included studies; however, the included studies showed an overall good methodological quality. Third, because this was a systematic review of previous studies, our interpretations were limited by the data that were reported in the included studies. Fourth, participants in the included studies had various occupational backgrounds such as policy makers, officials in local municipalities, frontline health care workers, and scientists. A strength of this review was that it reflected the experiences of participants from diverse backgrounds; however, it was also limited by not differentiating experiences at the policy-making level from those at the policy implementation level on the front line. Fifth, another strength was that we included studies from various countries in Europe, the Middle East, Asia, Africa, and

North and South America; however, a limitation was that we did not make any economic or cultural distinctions. Finally, because all crises are novel and involve contextual differences, the generalizability of the findings and implications of this study to future crises is limited. Despite these limitations, this review has the important implications mentioned earlier, in that it identified the gaps between existing crisis communication guidelines and real-world crisis communication and the difficulties and needs that arise from those gaps.

Conclusions

This systematic review of qualitative studies identified the following issues that need to be addressed to prepare for subsequent public health crises. Despite the importance of collaboration within and outside public health and community engagement being highlighted in existing crisis communication guidelines, there was insufficient preparation and response to the COVID-19 pandemic. Although prompt communication is an essential principle for crisis response, the trade-off between promptness and the effectiveness of communication should be addressed. Difficulties specific to "slow disasters" and "infodemics" characterized the challenges encountered during the COVID-19 pandemic. Information overload, a shortage of human resources, and a lack of trust in public health contributed to burnout among health professionals. Public health professionals need to address the difficulties and needs identified in this systematic review by training communication specialists and establishing permanent organizations specializing in communication. One health professional described the difficulties resulting from the lack of preparation during the COVID-19 pandemic as "we are building the plane while we are flying" [44]. Of course, airplanes must be built before they fly, and in the case of a public health crisis, preparations must be made before the crisis arises.

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Data Availability

Data sharing is not applicable to this paper as no datasets were generated or analyzed in this study protocol.

Authors' Contributions

TO was responsible for the conceptualization, methodology, data analysis, writing of the original draft, and funding acquisition. MT, HO, and RY were responsible for data analysis. TK was responsible for supervision. All authors contributed to reviewing and editing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Quality appraisal of included studies.

[DOC File , 54 KB - infodemiology_v5i1e66524_app1.doc]

Multimedia Appendix 2

Themes and illustrative quotes from qualitative studies regarding crisis communication during the COVID-19 pandemic.

[DOCX File , 32 KB - infodemiology_v5i1e66524_app2.docx]

Multimedia Appendix 3

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.

[PDF File (Adobe PDF File), 34 KB - infodemiology_v5i1e66524_app3.pdf]

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Abbreviations

CDC: Centers for Disease Control and Prevention
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
WHO: World Health Organization

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Original Paper

Evaluating the Content and Quality of Videos Related to Hypertrophic Scarring on TikTok in China: Cross-Sectional Study

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Abstract

Background: Hypertrophic scars (HTSs) are a predominant condition after burns and trauma, and it causes severe physiological and psychological problems. TikTok (Douyin in Chinese), a popular platform for sharing short videos, has shown the potential to spread health information, including information related to HTSs. Educating the public to obtain correct information is important to reduce the incidence of physiological and psychological problems caused by HTSs. However, the quality and reliability of HTS-related video content on TikTok in mainland China have not been thoroughly studied.

Objective: This study aims to evaluate the content and quality of short videos related to HTSs on the Chinese version of TikTok (Douyin) and explore the factors related to their quality, providing valuable insights for health information dissemination.

Methods: We collected a sample of 153 TikTok videos in Chinese related to HTSs and categorized them according to video source and content. We evaluated the video content using a coding schema, and a hexagonal radar schema was used to intuitively display the spotlight and weight of each aspect of the videos. We evaluated quality using 4 standardized tools: the modified DISCERN (mDISCERN) questionnaire, the *Journal of the American Medical Association*, the Global Quality Scale (GQS), and the Health on the Net Foundation Code of Conduct. We also explored the potential relationship between video quality and characteristics.

Results: The analysis showed that health care professionals uploaded all videos about treating HTSs, which matched the hexagonal radar model analysis findings. The quality assessment scores for the *Journal of the American Medical Association*, GQS, mDISCERN, and the Health on the Net Foundation Code of Conduct had median values of 1 (IQR 1-2), 2 (IQR 2-3), 2 (IQR 2-3), and 3 (IQR 3-4), respectively, indicating a need to improve the quality and reliability of videos on HTSs. In addition, high-quality videos were more popular, based on metrics such as likes, comments, favorites, and shares (P<.001). Interestingly, the time when the videos were uploaded positively correlated with GQS and mDISCERN scores (r=0.393; P<.001 and r=0.273; P<.001), while the video length did not significantly correlate with evaluation scores (P=.78, P=.20, P=.07, and P=.04).

Conclusions: The quality of TikTok videos related to HTSs is generally moderate. Users should exercise caution when seeking information on HTSs from TikTok. It is advisable to choose videos uploaded by health care professionals from the burn department and the burn plastic surgery department, and in the Chinese context, those produced in first-tier cities and emerging first-tier cities.

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KEYWORDS

hypertrophic scars; health education; TikTok; social media; information quality

Introduction

Background

Hypertrophic scars (HTSs) are a common fibrotic skin condition that can develop from various sources, including acute or chronic wounds, deep burns, and surgical incisions [1]. The overall incidence of HTSs ranges from 4% to 16%, but among patients with burns, the prevalence can be as high as 70% [1,2]. A study of Chinese college students reported an incidence rate of HTSs at 5.2% [3]. In high-income countries, around 100 million individuals are affected by HTSs [4]. HTSs can negatively impact a person's appearance and lead to impaired skin function, joint deformities, and decreased mobility, significantly affecting mental and physical well-being [5]. The annual global cost for HTS care is estimated at nearly US $20.8 billion, with the United States spending about US $4 billion on treatment yearly [6]. The market for HTS and keloid scar treatments is projected to grow, potentially reaching US $37.9 billion by 2026, with a compound annual growth rate of 9.9% [7]. Making lifestyle changes, such as minimizing intense physical labor, avoiding spicy foods, reducing alcohol consumption, and limiting time spent in hot baths, may help lower the risk of developing HTSs [2]. Early detection, diagnosis, and effective treatment are essential for improving patient outcomes and addressing the physiological and psychological issues related to HTSs. Therefore, educating the public about accurate and reliable health information is crucial in reducing the incidence of problems associated with HTSs.

Health Information in the Digital Era

The rapid advancement of internet technology has transformed how we share and communicate health information [8,9]. Remarkably, around 80% of individuals worldwide rely on online resources to inform themselves about health matters [10,11]. This shift enhances health communication and unprecedentedly empowers patients in their education and decision-making [12]. With easy access to information online, patients are no longer passive recipients; they have become proactive seekers, fully engaged in their health outcomes [13]. In recent years, health education videos designed to inform viewers, individually or collectively, have surged in popularity [14]. Unlike traditional text, videos on social media platforms present information more digestibly and effectively motivate users toward healthier behaviors through compelling visuals [15,16]. Short video platforms have the potential to spread health education widely, but patients may encounter challenges in using these technologies. Patients' primary concern when searching for online health information is the quality of the information [17]. The rise of numerous content creators and the lack of regulation on these platforms often lead to concerns about the trustworthiness of the medical information shared [18]. When searching for online health information, the quality of the information is a primary concern for patients [17]. For many nonprofessionals, evaluating the quality of online health information sources, especially for patients with lower health literacy levels, is not easy [19]. Due to the varying quality of short video content, patients often struggle to distinguish between true and false information. This can lead to the spread of misleading information, potentially impacting patients' understanding of their own medical conditions [20]. It is important to recognize that the content creators on video platforms could be (1) patients themselves or (2) health professionals. Experience sharing by patients who have experienced similar conditions can be a handy educational mechanism for other patients or their caregivers [21]. Health professionals, experts in their fields, can also offer helpful advice. However, more must be done to verify the authenticity of the sources (patients or health professionals) producing these videos. This is one of the primary reasons why a lot of misinformation or unverified health information is propagated on social media and video platforms. Therefore, establishing robust oversight of online health videos is crucial to ensure that patients receive reliable and accurate health information.

This Study

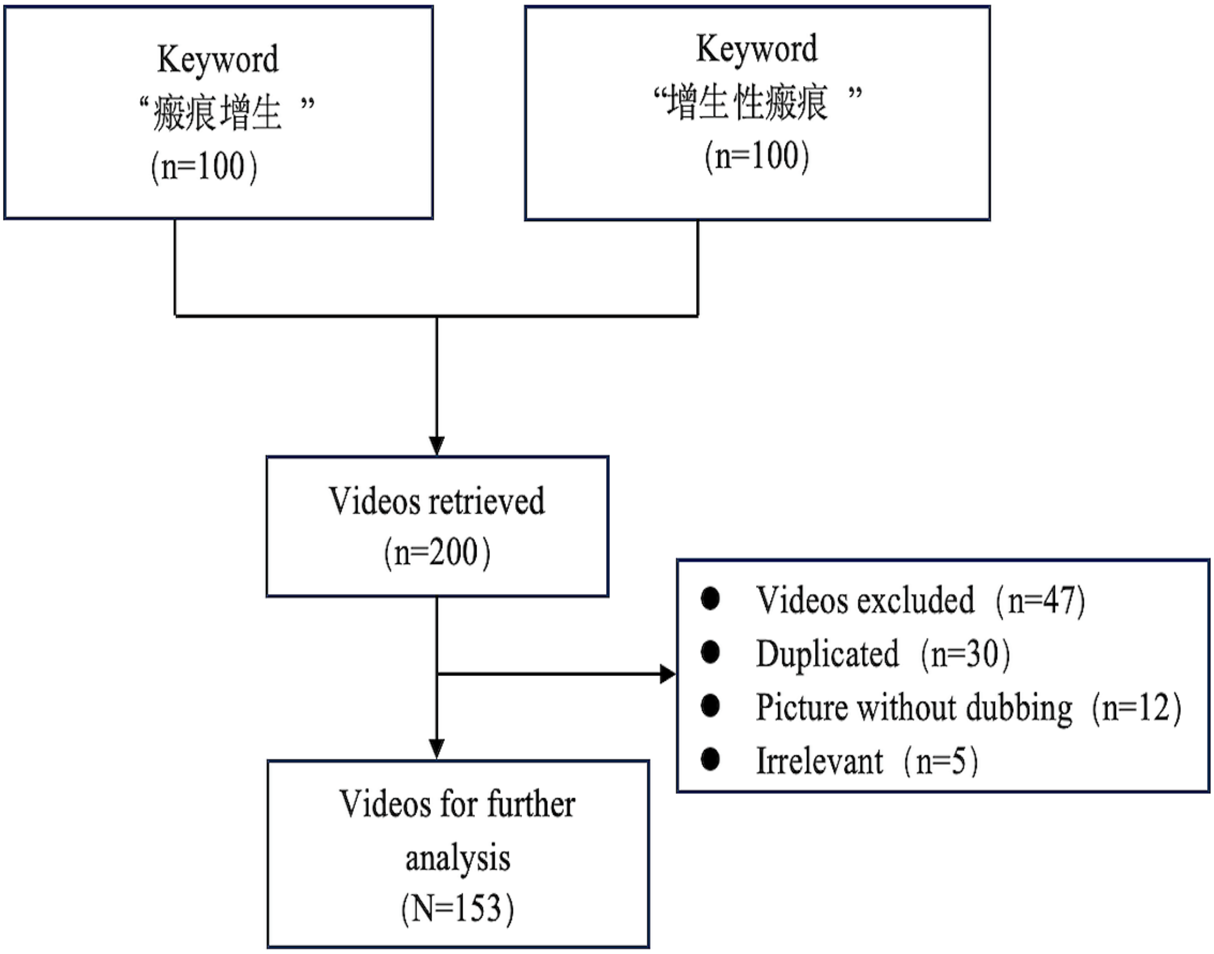
TikTok (ByteDance), or Douyin, its Chinese name, is the leading video social media app in China, captivating a vast audience. Focusing on diverse content, such as food, travel, and education, it has attracted over 750 million daily active users, making it a vital platform for engagement and discovery [22]. During the COVID-19 pandemic, TikTok videos about the SARS-CoV-2 garnered 93.1 billion views by July 2020 [17,19]. In addition, videos tagged with #cancer have amassed over 1.1 billion views worldwide [23]. As a platform for disseminating health information, social media has significant differences in video quality and information accuracy. Previous studies have shown that videos published by health care professionals typically have higher scientific validity and credibility [24]. However, the popularity of these videos is often limited by the social influence of the publishers. Videos posted by social media influencers with many followers may attract more viewers and interactions, even if they lack professionalism. In addition, Ming et al [25] found that erroneous information is commonly present in health education videos released by for-profit organizations. This further highlights the necessity of evaluating video quality and authenticity. Previous research has examined the quality of videos on various themes on TikTok, revealing differences in video quality. For instance, videos about *Helicobacter pylori* infection [11], breast cancer [26], liver cancer [20], and inflammatory bowel disease [27] are generally considered unsatisfactory in quality. In contrast, videos related to plastic surgery are deemed satisfactory in quality and reliability [28]. We found many videos about HTSs on Douyin, the Chinese version of TikTok, but the quality of the information presented is yet to be evaluated. To address this research gap, we assessed the content, quality, and reliability of HTS-related videos on TikTok. We examined the relationship between the quality of video content and audience engagement, focusing specifically on interactive indicators, such as likes, comments, favorites, and shares.

Methods

Search Strategy and Data Extraction

In this cross-sectional study, we used the keywords "瘢痕增生" ("scar hyperplasia" in Chinese) and "增生性瘢痕" ("hypertrophic scars" in Chinese) to search on the Chinese version of TikTok ("Douyin") on February 28, 2024, with the default sorting option of “overall ranking.” To avoid bias caused by personalized recommendations, we used newly registered accounts to conduct searches. We did not apply any filtering conditions to restrict the search. Consumers seeking general health videos typically do not scroll very far when searching online; they usually browse only the first few pages of search results. Furthermore, videos that rank low in the search results of the “overall ranking” mode often have little relevance to the topic [29]. Considering the aforementioned situation, we selected the top 100 videos for further analysis of the search results. Subsequently, we excluded non-Chinese, irrelevant, repetitive, and silent videos, resulting in 153 videos selected for the final data analysis (Figure 1).

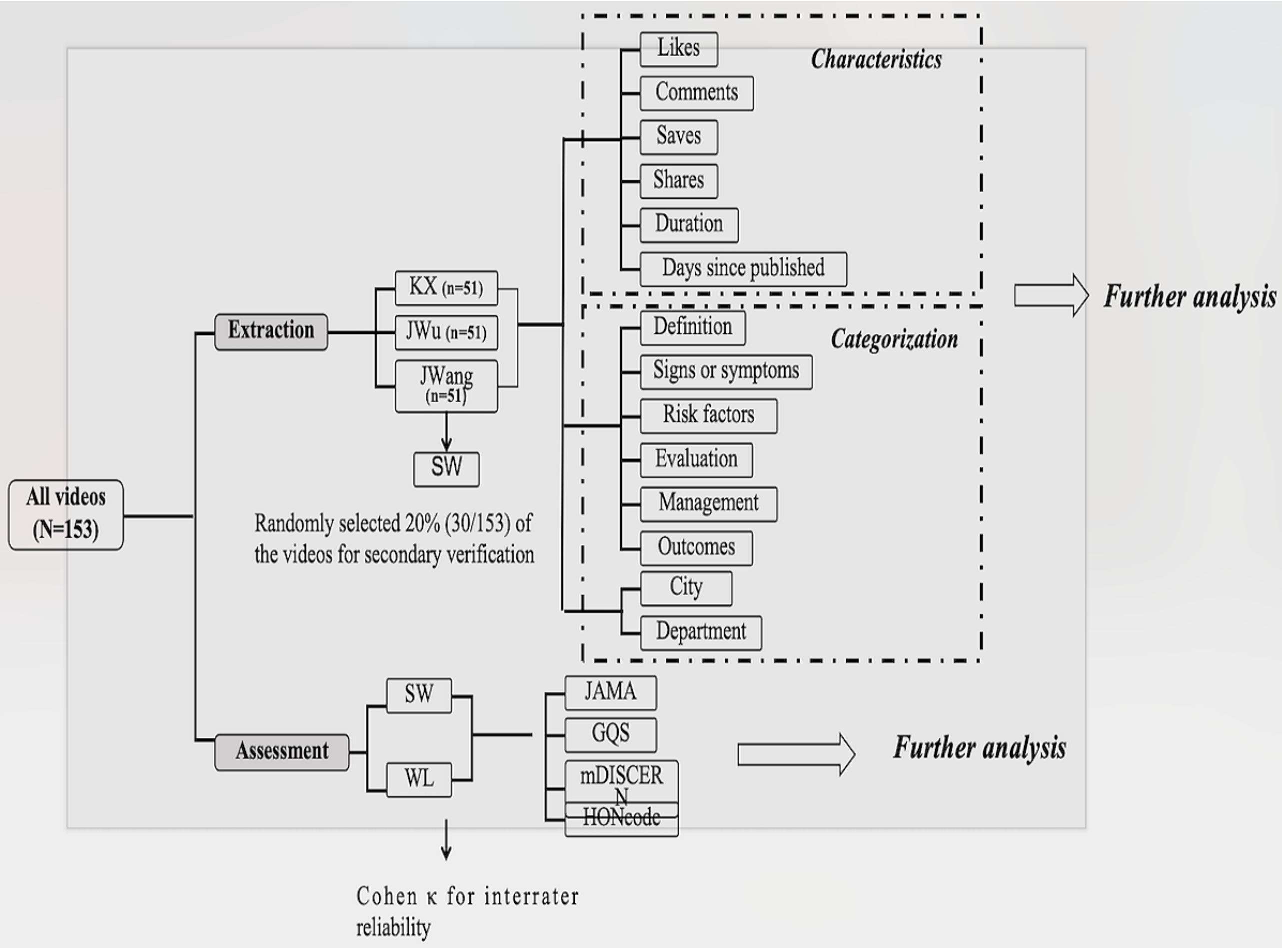
Figure 1. Search strategy for short videos on hypertrophic scars.



Exclusion criteria were non-Chinese videos and repetitive videos—which refers to videos with the same content but different sources; we based our judgments on the video descriptions and main content. We excluded silent videos, which are defined as content that consists only of images or text, with no voice or background sound. We determined whether a video was silent by overseeing each clip to ensure no audio. Moreover, we excluded irrelevant videos, which refers to videos that do not pertain to the themes of “scar hyperplasia” or “hypertrophic scars.” Examples included advertisements, entertainment videos, or content related to other health topics. We based our judgments on the video descriptions and main content.

We extracted data directly from the public information provided by the TikTok platform, as it lacks a bulk data export function. Consequently, we manually recorded the relevant data for each video. Team members used browser tools, including screenshots and text-copying functions, to transfer video information into Microsoft Excel spreadsheets for further classification and analysis. Three team members (J Wu, KX, and J Wang) completed the data extraction, each responsible for a specific portion of the videos. To ensure the accuracy of the data entry, we developed a unified operations manual, and cross-checking was conducted by another team member (SW) after the data entry was finished. In addition, we randomly selected 20% (30/153) of the videos for secondary verification, which resulted in a data consistency rate of over 95% (Figure 2).

Figure 2. Flowchart for data extraction and analysis. GQS: Global Quality Scale; HONcode: Health on the Net Foundation Code of Conduct; *JAMA*: *Journal of the American Medical Association*; mDISCERN: modified DISCERN.



Video Classification

The content of the videos was classified through manual review. Three authors (J Wu, KX, and J Wang) independently watched each video and categorized it into 1 of the following 6 groups based on its content: the definition, signs and symptoms, risk factors, evaluation, management, or outcomes. All videos were provided by health care professionals; we further classified them according to department categories, specifically including plastic and aesthetic surgery, dermatology, burn care, burn and plastic surgery, and a general category termed "other departments," which includes various departments, such as traditional Chinese medicine and pediatric surgery. In addition, to comprehensively consider the distribution of video resources, we categorized the videos based on city administrative levels, including first-tier cities, emerging first-tier cities, second-tier cities, third-tier cities, and fourth-tier cities, to reflect regional differences more accurately (Figures 2 and 3, Tables 1 and 2) [30].

Figure 3. Percentage of videos on health care professionals from different departments and city tiers.

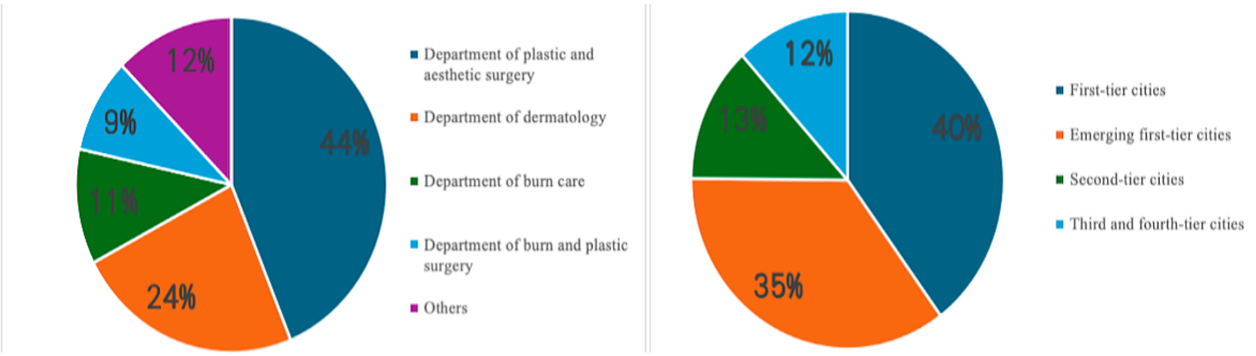


Table 1. Scoring criteria and weight for categorization of cities.

Scoring criteria	Weight
Commercial resource concentration	0.19
Big Brand Favorability Index	0.32
Commercial Core Index	0.40
Commercial support maturity	0.28
Urban hub connectivity	0.2
Transportation connectivity	0.33
Talent Mobility Index	0.27
Industry Synergy Index	0.20
Commercial resource regional centrality	0.2
Urban population activity	0.22
Consumption activity	0.38
Social activity	0.31
Nighttime activity	0.31
New economy competitiveness	0.20
Corporate leadership	0.36
New Consumption Index	0.32
Industry Chain Ecosystem Index	0.32
Future flexibility	0.19
Innovation Atmosphere Index	0.32
Talent Attraction Index	0.39
City Size Index	0.29

Table 2. The 2024 China city classification rankings.

City classification	List of cities
First-tier cities	Shanghai, Beijing, Shenzhen, and Guangzhou
Emerging first-tier cities	Chengdu, Hangzhou, Chongqing, Suzhou, Wuhan, Xi'an, Nanjing, Changsha, Tianjin, Zhengzhou, Dongguan, Wuxi, Ningbo, Qingdao, and Hefei
Second-tier cities	Foshan, Shenyang, Kunming, Jinan, Xiamen, Fuzhou, Wenzhou, Changzhou, Dalian, Shijiazhuang, Nanning, Harbin, Jinhua, Nanchang, Changchun, Nantong, Quanzhou, Guiyang, Jiaxing, Taiyuan, etc.
Third-tier cities	Urumqi, Linyi, Haikou, Huzhou, Yangzhou, Yancheng, Luoyang, Tangshan, Jining, Langfang, Taizhou, Ganzhou, Hohhot, Zhenjiang, Wuhu, Shantou, Handan, Jiangmen, Zibo, Yinchuan, etc.
Fourth-tier cities	Zhoushan, Qingyuan, Quzhou, Zhumadian, Deyang, Yibin, Longyan, Rizhao, Hongzhi, Anshan, Maoming, Binzhou, Qinhuangdao, Jilin, Kaifeng, etc.

The weights of the primary and secondary dimensions of the ranking were determined through scoring by the expert committee of the New First-Tier Cities Research Institute, while the indicators mentioned after the secondary dimensions were calculated using the principal component analysis method. The indicators for each subdimension of the ranking were primarily derived from data collected throughout 2023 or up to early 2024.

In this study, to determine the geographic location of video creators, we mainly obtained relevant information through 2 channels. First channel was user profile information, where the TikTok account profile of the video uploader usually voluntarily disclosed location information, such as city name or workplace. We manually checked the account home page of each uploader and recorded the geographic location mentioned in their profile (such as a hospital in Beijing). The second channel was the certification identification and employer information, where the TikTok platform usually included the publisher's employer and department information for certified accounts. For example, the authentication information may have included "burn and plastic surgery department of a hospital in Shanghai" or "dermatology department of a hospital in Guangzhou," based on which we could determine the geographic location of the uploader.

Assessment of Video Content, Quality, and Reliability

We used the 6 questions developed by Goobie et al [31] to assess video content, focusing on disease definition, signs and symptoms, risk factors, evaluation, management, and outcomes. The hexagonal radar chart is a unique statistical tool that can display data from 6 different fields at the same time. Each dataset is mapped onto a separate axis, and the data points on each axis are connected by continuous lines to form a hexagonal outline. The main goal of this chart design is to visually represent the focus and impact weight of a specific subject, such as video content, across 6 core dimensions [19]. By doing so, the hexagonal radar chart simplifies the comprehension of complex data and provides a clear and user-friendly visual representation for both users and researchers [12,32].

The videos' reliability and quality were assessed using 4 standardized evaluation tools: modified DISCERN (mDISCERN; Table 3), Global Quality Scale (GQS; Table 4), the *Journal of the American Medical Association* (*JAMA*; Table 5), and the Health on the Net Foundation Code of Conduct (HONcode; Table 6). We used a multifaceted approach to assess the quality and reliability of the educational content of the videos collected, mainly based on the following considerations:

- Each benchmark focuses on different dimensions. mDISCERN assesses the information quality, GQS evaluates overall content quality, *JAMA* evaluates the reliability of the video, and the HONcode examines the ethics and credibility of health information.
- By integrating multiple benchmarks, it is possible to more comprehensively capture the differences in quality and reliability dimensions in short videos.
- The multibenchmark method improves the objectivity of evaluation and avoids bias that may arise from a single benchmark.

Table 3. Description of modified DISCERN (mDISCERN) for evaluating the quality of the videos with information on hypertrophic scars.

mDISCERN	Scores (1 point is given for every yes and 0 points for no)
Is the video clear, concise, and understandable?	0-1
Are reliable sources of information used? (ie, publication cited and speaker is a specialist)	0-1
Is the information presented balanced and unbiased?	0-1
Are additional sources of information listed for patient reference?	0-1
Are areas of uncertainty or controversy mentioned?	0-1

Table 4. Description of the Global Quality Scale (GQS) for evaluating the quality of the videos with hypertrophic scars information.

GQS	Scores (range from 1=poor quality to 5=excellent flow and quality)
The information is of poor quality, and the flow of the site is poor. Most information is missing and not useful for patients at all.	1
The information is generally of poor quality and flow. Some information is listed, but many important topics are missing, and it is of very limited use to patients.	2
Moderate quality and suboptimal flow: Some vital information is adequately discussed, but other topics are poorly discussed and somewhat useful for patients.	3
Good quality and flow: Most relevant information is listed, but some topics still need to be covered. It is useful for patients.	4
The information is of excellent quality and has excellent flow. It is beneficial for patients.	5

Table 5. Description of the *Journal of the American Medical Association (JAMA)* for evaluating the quality of the videos with hypertrophic scar information.

JAMA benchmark criteria	1 point for each criterion, with a total score of 4 points
Authorship	Author and contributor credentials and their affiliations should be provided.
Attribution	All copyright information should be clearly listed, and references and sources for content should be stated.
Currency	The initial date of posted content and subsequent updates to the content should be provided.
Disclosure	Conflicts of interest, funding, sponsorship, advertising, support, and video ownership should be fully disclosed.

Table 6. Description of the Health on the Net Foundation Code of Conduct (HONcode) for evaluating the quality of videos with information about hypertrophic scars.

HONcode	Detail
Authority	Any medical or health advice given in the video must come from a qualified health professional unless it is clearly stated that the information does not come from a qualified health source.
Complementarity	The information provided in the video must be designed to support the patient's HTS[a] self-management, but it is not meant to replace the patient-physician relationship.
Privacy policy	The information in the video maintains the right to confidentiality and respect of the individual patient featured.
Referenced and dated	Each video contains references to source data on information presented or contains a specific HTML link to source information.
Justifiability	Each video containing claims on the benefits or performance of specific skills and behaviors, interventions, treatments, products, etc must be supported by evidence through references or HTML links.
Transparency	The video must provide the viewer with contact information or a URL to more information.
Financial disclosure	Any individual or organization that contributes funds, services, or material in the posted video must be clearly identified in the video or video description.
Advertising policy	If an advertisement supports funding to the video or the video's developers, it must be clearly stated. Included advertising must be clearly differentiable to the viewer. There should be a clear difference between the advertising material and the educational material in the video.

[a]HTS: hypertrophic scar.

mDISCERN is the most commonly used quality research tool [33]. This method has been widely used to evaluate information quality on video-sharing platforms [34]. Considering that the video studied belongs to the medical category, mDISCERN is based on the following 5 aspects: clarity, relevance, traceability, robustness, and fairness. The mDISCERN has 5 questions that need answers as "yes" or "no." A score of 1 indicates yes, 0 indicates no, and the maximum score is 5 [35].

GQS was used to assess the overall content quality of the videos in this study. The GQS is a commonly used 5-point scale comprising 5 criteria ranging from 1 to 5, with higher scores indicating better quality [36-38].

JAMA was used to evaluate the reliability of the video [39]. The rating is according to the 4 predetermined issues: authorship, attribution, currency, and disclosure. There is 1 point for each criterion, with a total score of 4 points [40].

The HONcode consists of 8 issues that are predetermined for the rating: authority, complementarity, privacy policy, reference and date, justifiability, transparency, financial disclosure, and advertising policy [41,42]. The details of the scoring criteria are mentioned subsequently. First, any medical or health advice given in the video must come from a qualified health professional unless it is clearly stated that the information does not come from a qualified health source. Second, the information provided in the video must be designed to support the patient's HTS self-management, but it is not meant to replace the patient-physician relationship. Third, the information in the video maintains the right to confidentiality and respect of the individual patient featured. Fourth, each video contains references to source data on the information presented or contains a specific HTML link to source information. Fifth, each video containing claims on the benefits or performance of specific skills or behaviors, interventions, treatments, products, etc must be supported by evidence through references or HTML links. Sixth, the video must provide the viewer with contact information or a URL to more information. Seventh, any individual or organization that contributes funds, services, or material in the posted video must be clearly identified in the video or video description. Eighth, if an advertisement supports funding to the video or the video's developers, it must be clearly stated. Included advertising must be differentiable to the viewer: There should be a clear difference between the advertising material and the educational material in the video. There is 1 point for each criterion, with a total score of 8 points.

Although *JAMA* and HONcode are commonly used to evaluate formal or long-format medical content (such as websites, journals, or organizational publications), their application has been extended to user-generated content on the TikTok short video platform [43]. In this study, we had a detailed discussion on the benchmark before scoring and adjusted the scope of application of the scoring criteria. For the "disclosure" rating item, we focused on whether the video identified the publisher's identity and affiliation rather than detailing funding sources or advertising disclosures. Regarding the "citation source" standard, many videos did not provide explicit references and often used vague terms, such as "research shows" or "experts say." To tackle this issue, we reached the following consensus: (1) videos that do not provide any source explanation will receive a score of 0; (2) content that mentions vague references (like "research shows") but fails to specify the source will receive a score of 0.5, indicating a partially satisfied score; and (3) videos that list their sources or include relevant reference information in the video description will receive a score of 1. We also focused on evaluating whether the core medical information of the video was accurately conveyed based on the video duration limit rather than comprehensive coverage. In addition, during the rating process, we considered the background information of the video creator (such as certification marks or institutional affiliations) to help evaluate the credibility of the references.

The videos were evaluated by 2 qualified physicians (SW and WL) who have extensive experience in scar treatment. Before scoring the videos, the 2 evaluators reviewed the mDISCERN, GQS, *JAMA*, and HONcode scoring guidelines and conducted detailed discussions to prevent cognitive bias. The final score for each video was calculated by averaging the scores given by the 2 evaluators. If there was a significant difference between the scores of the 2 experts, the final score was determined through discussion with the third arbitrator (KX; Figure 2). In the evaluation process of 153 videos, Cohen κ values rated by experts showed high consistency (κ>0.80). Therefore, no case involved the third arbitrator.

Ethical Considerations

All information used in this study came from publicly published TikTok (Douyin in Chinese) videos. This study did not involve clinical data, human specimens, or animal experiments, nor did it involve personal privacy. No personal data identifying the uploader's identity, such as username or profile picture, were recorded or stored during the research process. Data analysis only focused on video content and interaction metrics (such as likes, comments, and shares). The study strictly abided by the terms of use of the TikTok platform and did not obtain the platform's undisclosed data through any technical means. The research content did not involve any potential harm to user interests or platform rules and was only used for academic purposes. Therefore, this study did not require an ethics review.

Statistical Analyses

The data were analyzed using SPSS Statistics (version 29; IBM Corp). Continuous variables were presented as medians with IQRs, while categorical variables were presented in terms of numbers and percentages. Cohen κ was used to measure interrater reliability between the 2 evaluators. According to the criteria set by Landis and Koch [44], a κ value > 0.8 indicates almost perfect agreement, a value between 0.6 and 0.8 indicates substantial agreement, a value between 0.4 and 0.6 indicates moderate agreement, and a value <0.4 indicates poor agreement. Spearman correlation analysis was conducted to assess the relationships between quantitative variables. A significance level of $P<.001$ was considered statistically significant.

Results

Video Characteristics

A total of 153 videos about scar hyperplasia and HTSs were found on Chinese TikTok, all posted by health care professionals. In terms of departmental distribution of video uploads, professionals from the department of plastic and aesthetic surgery contributed the highest proportion of video content, accounting for 67 videos (43.8%), followed by dermatology (n=36, 23.5%), burn care (n=17, 11.1%), burn and reconstructive surgery (n=14, 9.2%), and "other departments," which included traditional Chinese medicine and pediatric surgery (n=19, 12.4%). Further analysis by city tier revealed significant differences in video publication volume. Health care professionals in first-tier cities were the most active, accounting for 61 (39.9%) of the video uploads, followed by new first-tier cities (n=54, 35.3%), second-tier cities (n=20, 13.1%), and third- and fourth-tier cities (n=18, 11.8%; Figure 3). The general characteristics of the videos are presented in Tables 7-9.

The median time since upload was 212 (IQR 54-321) days, and the average video duration was 43 (IQR 33-58, SD 36) seconds. All videos received a maximum of 21,000 likes (median 72, IQR 31-189), 1230 comments (median 9, IQR 4-32), 7580 favorites (median 21, IQR 7-66), and 2292 shares (median 20, IQR 9-63). Table 8 describes the critical features of the videos uploaded by health care professionals from different departments. Notably, videos posted by dermatologists stood out in several engagement metrics, specifically with higher numbers of likes (median 112.5, IQR 44.5-254), comments (median 12, IQR 5.75-46.25), saves (median 36.5, IQR 13.75-94.75), and shares (median 29, IQR 11.75-70.75). This phenomenon may reflect the public's interest and preference for educational dermatology videos. Further analysis (Table 9), which focused on the essential characteristics of videos uploaded by health care professionals from different city tiers, revealed a notable phenomenon. Although some cities may not have the overall resource advantage, emerging first-tier cities' videos showed unique appeal in user engagement. The median numbers of likes, comments, saves, and shares were 94 (IQR 37.75-183), 12 (IQR 5-55.5), 24.5 (IQR 8-78.75), and 26.5 (IQR 10.25-66), respectively. This finding suggested that video content dissemination strategies should focus more on regional characteristics and alignment with user needs. In addition, the shortest video was 13 seconds long, the longest was 282 seconds long, and the first video was uploaded 1047 days before our search. In contrast, the most recent video was uploaded the day before data collection.

Table 7. Characteristics of hypertrophic scar videos (N=153).

Parameters	Values
Video source, n (%)	
Health care professionals	153 (100)
Department classification, n (%)	
Department of plastic and aesthetic surgery	67 (43.8)
Department of dermatology	36 (23.5)
Department of burn care	17 (11.1)
Department of burn and plastic surgery	14 (9.2)
Other departments	19 (12.4)
City classification, n (%)	
First-tier cities	61 (39.9)
Emerging first-tier cities	54 (35.3)
Second-tier cities	20 (13.1)
Third- and fourth-tier cities	18 (11.8)
Likes, median (IQR)	22 (31-189)
Comments, median (IQR)	9 (4-32)
Saves, median (IQR)	21 (7-6)
Shares, median (IQR)	20 (9-3)
Duration (s), median (IQR)	44 (33-8)
Days since published, median (IQR)	159 (54-21)
JAMA[a] score, median (IQR)	1 (1-2)
GQS[b] score, median (IQR)	2 (2-3)
mDISCERN[c] score, median (IQR)	2 (2-3)
HONcode[d] score, median (IQR)	3 (3-4)

[a]*JAMA*: *Journal of the American Medical Association*.
[b]GQS: Global Quality Scale.
[c]mDISCERN: modified DISCERN.
[d]HONcode: Health on the Net Foundation Code of Conduct.

Table 8. Characteristics of hypertrophic scars in videos across different departments.

Variable	Department of plastic and aesthetic surgery (n=67), median (IQR)	Department of dermatology (n=36), median (IQR)	Department of burn care (n=17), median (IQR)	Department of burn and plastic surgery (n=14), median (IQR)	Others (n=19), median (IQR)	Overall (n=153), median (IQR)
Likes	52 (30.5-61.5)	112.5 (44.5-254)	70 (34-189)	62 (37.25-146.25)	96 (18.5-234)	22 (31-189)
Comments	8 (4-19)	12 (5.75-46.25)	7 (2-33)	8.5 (3-27)	10 (3.5-40)	9 (4-32)
Saves	17 (8-56.5)	36.5 (13.75-94.75)	22 (6-50)	14.5 (7-35.25)	45 (5-97.5)	21 (7-66)
Shares	14 (8-55.5)	29 (11.75-70.75)	22 (6-50)	16.5 (7.75-47)	32 (8.5-96.5)	20 (9-63)
Duration (s)	45 (33.5-59)	41.5 (30-55.25)	45 (5-97.5)	43.5 (29.5-55.75)	53 (42.5-58.5)	44 (33-58)
Days since published	16.5 (39.5-334)	143.5 (71.5-281)	162 (88-196)	258 (69.25-464)	145 (28-260)	159 (54-321)
JAMA[a] score	1 (1-1.5)	1.75 (1-2)	1.5 (1-2)	1 (1-1)	1 (1-1.5)	1 (1-2)
GQS[b] score	2 (2-3)	2 (2-3)	2 (2-2.5)	2 (2-2.75)	2 (2-3)	2 (2-3)
mDISCERN[c] score	2 (2-3)	2 (2-3)	3 (2-3)	2 (2-3)	2 (2-2)	2 (2-3)
HONcode[d] score	3 (3-4)	3 (3-3)	3 (3-4)	3.25 (3-4)	3 (3-3.5)	3 (3-3.75)

[a]*JAMA*: *Journal of the American Medical Association*.
[b]GQS: Global Quality Scale.
[c]mDISCERN: modified DISCERN.
[d]HONcode: Health on the Net Foundation Code of Conduct.

Table 9. Characteristics of hypertrophic scars in videos across different city tiers.

Variable	First-tier cities (n=61), median (IQR)	Emerging first-tier cities (n=54), median (IQR)	Second-tier cities (n=20), median (IQR)	Third- and fourth-tier cities (n=18), median (IQR)	Overall (n=153), median (IQR)
Likes	79 (34-220)	94 (37.75-183)	53.5 (29.5-108.75)	51.5 (24-144.25)	22 (31-189)
Comments	8 (4-33)	12 (5-45.5)	10.5 (3-15)	10.5 (4-16.5)	9 (4-32)
Saves	22 (8-76)	24.5 (8-78.75)	9 (4-52.5)	13 (8-46)	21 (7-66)
Shares	20 (9-63)	26.5 (10.25-66)	18 (7.75-47.25)	10 (7-40)	20 (9-63)
Duration (s)	41 (31-55)	43 (30.25-54.5)	50 (38.25-60.5)	58 (37-102)	44 (33-58)
Days since published	188 (80-317)	119.5 (54.75-325.5)	156.5 (76.75-329)	25 (14-168)	159 (54-321)
JAMA[a] score	1 (1-2)	1 (1-2)	1 (1-1)	1.25 (1-2)	1 (1-2)
GQS[b] score	2 (2-3)	2 (2-3)	2 (2-2)	2 (2-3)	2 (2-3)
mDISCERN[c] score	2 (2-3)	2 (1-3)	2 (2-3)	2.5 (2-3)	2 (2-3)
HONcode[d] score	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)	3 (3-4)

[a]*JAMA*: *Journal of the American Medical Association*.
[b]GQS: Global Quality Scale.
[c]mDISCERN: modified DISCERN.
[d]HONcode: Health on the Net Foundation Code of Conduct.

Analysis of Video Content

According to the hexagonal radar chart, the most frequently discussed topic in all videos was managing HTSs, which appeared in approximately 72.5% (111/153) of the videos. This was followed by the symptoms and definitions of HTSs mentioned in 47.7% (73/153) and 24.2% (37/153) of the videos. However, the outcomes and risk factors of HTSs should have been addressed, with only 11.8% (18/153) and 19.6% (30/153) of the videos discussing these aspects. The least mentioned topic was the evaluation of HTSs, with only 9.2% (14/153) of the videos adequately covering evaluation, while 90.8% (139/153) of the videos provided little to no information on this aspect (Figure 4). An in-depth analysis of the hexagonal radar chart structures presented by various city tiers revealed a common phenomenon—regardless of city tier, the video content predominantly focused on managing HTSs, while the evaluation of HTSs was notably less addressed (Figure 5). This finding aligned with our overall evaluation of the video content, further confirming the distribution bias of video resources toward specific topics.

Figure 4. Hexagonal radar charts of the content of videos on hypertrophic scars.

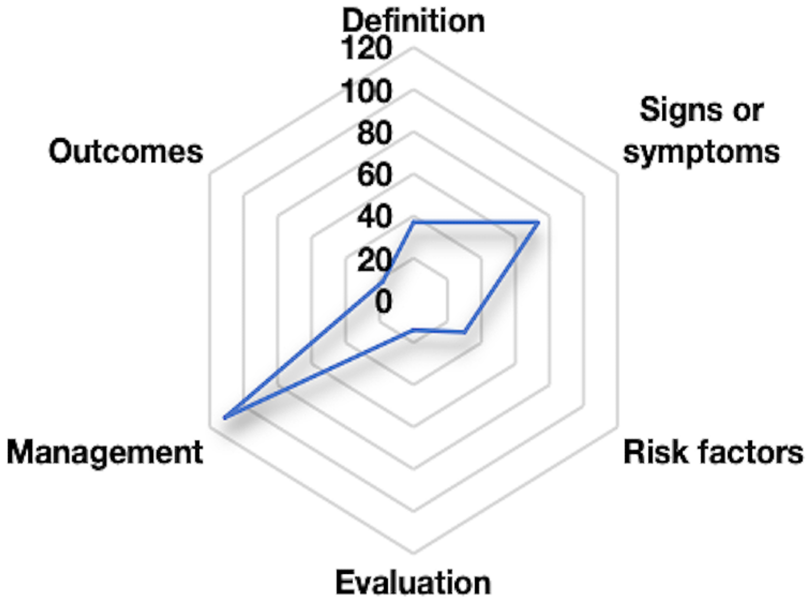
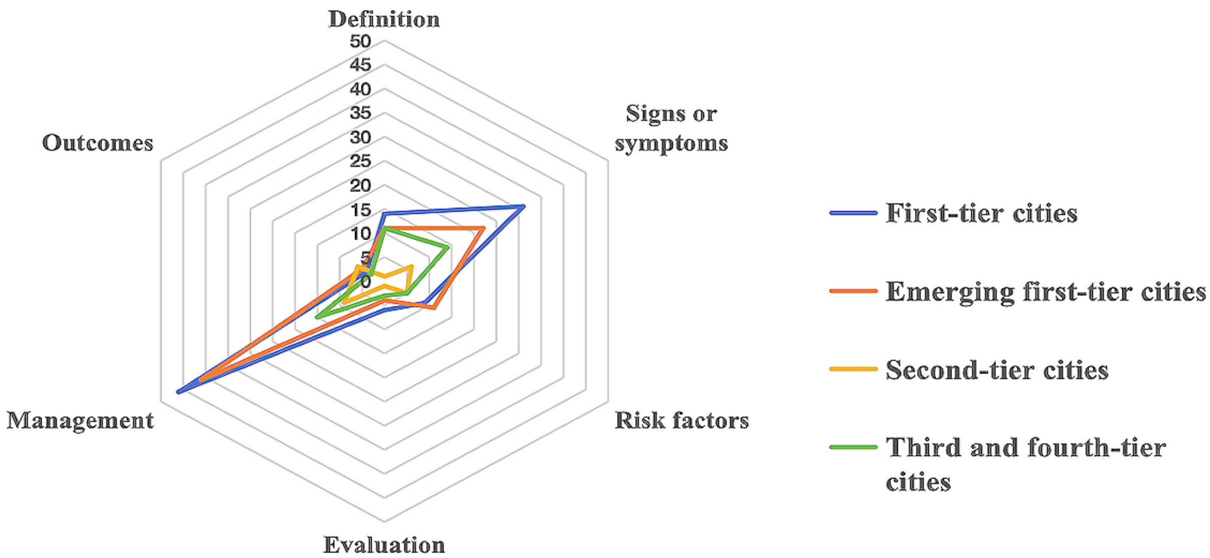


Figure 5. Hexagonal radar charts of the content of different city-tier videos on hypertrophic scars.



Assessment of Video Quality

We found that the median *JAMA* score for all uploaded TikTok videos was 1 (IQR 1-2). When we used the mDISCERN score to assess the usability and reliability of the videos, the median score was 2 (IQR 2-3). Specifically, the median GQS score for the overall quality of the TikTok videos was 2 (IQR 2-3), while the median HONcode score was 3 (IQR 3-4).

To explore whether health care professionals from different departments and cities influenced the quality and reliability of videos, we conducted a detailed categorization based on departmental affiliations and city tiers. The results showed slight differences in the quality scores, specifically *JAMA*, GQS, mDISCERN, and HONcode, among videos uploaded from 1 to 3(IQR 1.75-2.25), indicating an overall low quality of the videos. There was little variation in video quality ratings among different city levels; HONcode ratings were primarily concentrated at 3 (IQR 3-4) points, suggesting moderate overall content quality. Further analysis revealed that videos related to burn plastic surgery and burn surgery had relatively high-quality ratings, with HONcode score of 3.25 and an mDISCERN rating of 3. These departments exhibited stronger professionalism and scientific content. However, the videos suffered from insufficient interactivity, indicated by fewer likes and shares, resulting in a lower dissemination effect compared to dermatology videos.

For new first-tier cities, the video quality ratings (GQS: 2 and mDISCERN: 2) were comparable to those in first-tier cities. In addition, the median upload time for these videos was shorter (119.5 days compared to 188 days), indicating that the content was timelier. In contrast, videos from third- and fourth-tier cities achieved HONcode ratings of 3 and mDISCERN ratings of 2, showing no significant disadvantage in terms of quality. However, these cities had lower upload volumes and interaction metrics, averaging 51.5 likes and 10.5 comments. This could be attributed to limited medical resources and a smaller number of creators in those areas.

Correlation Analysis

The nonnormal distribution of the data led us to use Pearson correlation analysis to investigate the relationships between different video variables and all evaluation scores (Table 10). We found that each video variable positively correlated with the scores obtained from the 4 evaluation methods. Notably, likes, comments, favorites, and shares were the only variables that showed significant correlations with all evaluation scores (P<.001), indicating that higher-quality videos tended to be more appreciated by viewers. Specifically, the number of days since video upload was significantly positively correlated only with GQS scores (r=0.393; P<.001) and mDISCERN scores (r=0.273; P<.001). In contrast, video duration did not significantly correlate with the evaluation scores (Table 10).

Table 10. Pearson correlation analysis between the video variables and all evaluation scores.

Variables	*JAMA* [a]	GQS[b]	mDISCERN[c]	HONcode[d]
Likes				
r	0.514[e]	0.740[e]	0.394[e]	0.287[e]
P value	<.001	<.001	<.001	<.001
Comments				
r	0.403[e]	0.613[e]	0.438[e]	0.426[e]
P value	<.001	<.001	<.001	<.001
Saves				
r	0.504[e]	0.736[e]	0.424[e]	0.293[e]
P value	<.001	<.001	<.001	<.001
Shares				
r	0.470[e]	0.701[e]	0.413[e]	0.301[e]
P value	<.001	<.001	<.001	<.001
Days since published				
r	0.123	0.393[e]	0.273[e]	0.098
P value	.11	<.001	<.001	.23
Duration				
r	0.023	0.105	0.149	0.169
P value	.78	.20	.07	.04

[a]*JAMA*: *Journal of the American Medical Association*.

[b]GQS: Global Quality Scale.

[c]mDISCERN: modified DISCERN.

[d]HONcode: Health on the Net Foundation Code of Conduct.

[e]The correlation is significant at a significance level of .01 (2-tailed).

In addition, we used Spearman correlation analysis to reveal the relationships between different video variables. We observed a positive correlation between the following variables: likes and comments (ρ=0.777; P<.001), likes and saves (ρ=0.941; P<.001), likes and shares (ρ=0.904; P<.001), likes and uploads (ρ=0.534; P<.001), comments and saves (ρ=0.781; P<.001), comments and shares (ρ=0.820; P<.001), comments and uploads (ρ=0.404; P<.001), saves and shares (ρ=0.897; P<.001), saves and uploads (ρ=0.499; P<.001), and shares and uploads (ρ=0.564; P<.001). Meanwhile, there was no significant relationship between video duration and other variables (Table 11).

Table 11. Spearman correlation analysis between the video variable.

Variable	Likes	Comments	Saves	Shares	Days since published	Duration
Likes						
ρ	1	0.777[a]	0.941[a]	0.904[a]	0.534[a]	0.072
P value	—[b]	<.001	<.001	<.001	<.001	.38
Comments						
ρ	0.777[a]	1	0.781[a]	0.820 [a]	0.404 [a]	0.122
P value	<.001	—	<.001	<.001	<.001	.13
Saves						
ρ	0.941[a]	0.781[a]	1	0.897[a]	0.499[a]	0.105
P value	<.001	<.001	—	<.001	<.001	.20
Shares						
ρ	0.904[a]	0.820[a]	0.897[a]	1	0.564[a]	0.072
P value	<.001	<.001	<.001	—	<.001	.38
Days since published						
ρ	0.534[a]	0.404[a]	0.499[a]	0.564[a]	1	0.020
P value	<.001	<.001	<.001	<.001	—	.80
Duration						
ρ	0.072	0.122	0.105	0.072	0.020	1
P value	.38	.13	.20	.38	.80	—

[a]The correlation is significant at a significance level of .01 (2-tailed).

[b]Not applicable.

Discussion

Principal Findings

Health problems are crucial and need daily attention, accurate assessment, and timely intervention. With the increasing popularity of the mobile internet, it has become one of the most popular ways to obtain health and medical information. A survey shows that 70% of internet users rely on the internet as their primary source of health information [45]. In this cross-sectional study, we used *JAMA* GQS, mDISCERN, and HONcode tools to evaluate the quality and reliability of HTS-related videos on the Chinese version of TikTok (Douyin). The results showed that the quality and reliability of HTS-related videos from TikTok were generally moderate. From the perspective of video sources, HTS-related videos were mainly released by health professionals. TikTok has strict verification rules to protect users' interests, information security, and content reliability, and it requires only certified institutions or individuals to share medical-related videos on the platform [46]. In terms of video content, the video integrity was insufficient. Most (111/153, 72.5%) of the videos were related to HTS management. From the perspective of video classification, compared with other departments and cities, the videos uploaded by health professionals in burn departments and burn plastic-surgery departments, and videos produced in first-tier and emerging first-tier cities, were of slightly higher quality.

Users should exercise caution when seeking information on HTSs from TikTok. It is advisable to choose videos uploaded by health care professionals from burn departments and burn plastic surgery departments, and in the Chinese context, those produced in first-tier and emerging first-tier cities.

Analysis of Overall Video Quality and Correlation

Our research uncovered an interesting phenomenon—only a few (1/153, 0.7%) videos thoroughly covered all aspects of HTSs, offering authoritative and practical guidance. Most (111/153, 72.5%) videos focused mainly on treatment methods, with symptom descriptions coming next and preventive measures mentioned less frequently. This may be related to the format of the TikTok platform, where video lengths vary; however, according to the latest statistics, the average length of popular videos is about 40 seconds [47]. This characteristic requires creators to present health information within a limited time frame, thereby affecting the depth and coverage of the video, and encourages users to create multiple videos on the same topic, each focusing on different aspects [48]. Our findings support this observation. Because a single video cannot cover all 6 core aspects of HTSs due to time constraints, users tend to split these into multiple videos presented as a series [46]. However, social media platforms usually recommend videos based on algorithms or randomness, making it difficult for users to access comprehensive health information systematically [49].

In the evaluation process of 153 videos, *JAMA*, GQS, mDISCERN, and HONcode scale values rated by experts showed high consistency (Cohen κ>0.80). Most videos on this platform did not receive high scores based on evaluations using *JAMA*, GQS, mDISCERN, and HONcode scales. This suggests that short videos about HTSs have poor quality and reliability. According to the recommendation algorithm of TikTok, people may primarily watch recently uploaded videos, and longer videos might cause viewers to lose patience and interest, leading to video skips. In addition, this mechanism determines that videos with more likes are more likely to be recommended; therefore, popular videos with lower quality have become more popular, further exacerbating the gap between video quality and popularity. We also found that videos from third- and fourth-tier cities received higher scores; however, this result only partially reflects the quality and reliability of their video content. The main reason is the relatively limited sample size from third- and fourth-tier cities, which may introduce some statistical bias. Therefore, caution is needed when interpreting these scores to avoid misinterpretation or misleading conclusions. To address this issue, we recommend that short video platforms introduce professional certification for experts and use unique markers to improve the trustworthiness of medical video content and reduce the spread of misinformation. The review standards for content uploaders on short video platforms are not yet comprehensive and strict. A significant number of nonprofessionals are still posting medical and scientific videos, which, to some extent, affects the accuracy and authority of the content [19]. Therefore, platforms should improve their verification and management procedures to ensure the professionalism and reliability of medical videos.

Our research discovered a potential link between video attributes and evaluation scores. We found a positive relationship between video length and evaluation scores, indicating that longer videos may improve quality by offering more informative content. However, this correlation was not statistically significant (P>.05). Previous studies have suggested that high-quality videos are often longer, which is consistent with our findings [50,51]. Excessively long videos might decrease viewer interest, resulting in fewer views, likes, and user engagement. This decrease in interest may stem from reduced viewer motivation despite the comprehensive content [52]. Therefore, publishers should consider video length carefully to maintain viewer interest and effectiveness of dissemination while upholding content quality. In addition, metrics, such as likes, comments, favorites, and shares, can gauge video popularity. Our analysis found significant positive correlations (P<.001) between these metrics and evaluation scores, indicating that high-quality videos are more likely to receive viewer approval. This finding aligns with the research conducted by Kong et al [12], which evaluated the quality of TikTok videos focused on diabetes health education. Their study found that higher-quality videos tend to receive greater recognition from audiences, evidenced by increased praise and sharing rates. In addition, our research revealed a positive correlation between the upload time of videos and their quality ratings, such as the GQS and mDISCERN scores (P<.001). This suggests that audiences prefer more timely and relevant content. Similar to the findings by Kong et al [12], we observed that the upload timing of videos is positively correlated with user engagement. However, in contrast to the work of Kong et al [12] and other studies that examined YouTube videos as sources of health information, our research found that TikTok videos received lower overall quality ratings. Specifically, in this study, the median *JAMA* score for TikTok videos was 1 (IQR 1-2), while YouTube videos typically received higher ratings in comparable studies (Kong et al [12] reported a median score of 2.5). This disparity may be attributed to the distinct characteristics of each platform. The short video format of TikTok, usually limited to 40 seconds, restricts the depth of content, whereas YouTube allows for longer videos that are more likely to adhere to *JAMA* and HONcode standards for comprehensive information. Furthermore, we found that interaction metrics for TikTok videos, such as likes and shares, were significantly correlated with GQS and mDISCERN ratings (r=0.740 and r=0.394, respectively; P<.001). This supports the conclusion made by Kong et al [12] that high-quality videos tend to engage audiences more actively. In addition, our study revealed variations in interaction metrics among medical professionals from different departments and cities, with videos uploaded from first-tier cities showing higher rates of likes and shares (P<.05). This finding has not been extensively explored in research on other platforms, suggesting that user behavior on TikTok may be influenced by unique regional and professional factors.

Analysis of Evaluation Tools

This study comprehensively used *JAMA*, GQS, mDISCERN, and HONcode to evaluate the quality and reliability of TikTok short videos, mainly based on the considerations mentioned subsequently. First, each benchmark focuses on different dimensions. *JAMA* evaluates authorship and transparency, GQS evaluates overall content quality, mDISCERN focuses on information reliability, and the HONcode examines the ethics and credibility of health information. Second, by integrating multiple benchmarks, it is possible to more comprehensively capture the differences in quality and reliability dimensions in short videos. Third, the multibenchmark method improves the objectivity of evaluation and avoids bias that may arise from a single benchmark. However, we also recognize that these benchmarks were not originally designed for short videos and may pose applicability challenges. For example, *JAMA* and HONcode standards are commonly used to evaluate formal or long-format medical content (websites, journals, or organizational publications). However, this study attempts to extend their application to user-generated content on the TikTok short video platform. These videos mainly focus on visual effects and have a duration between 33 and 58 seconds, so they may not fully meet the requirements of *JAMA* standards for content depth and information transparency. To overcome this challenge, 2 scoring experts had a detailed discussion on the benchmark before scoring and adjusted the scope of application of the scoring criteria. For example, the "disclosure" rating item focuses on whether the video identifies the publisher's identity and affiliation rather than detailing funding sources or advertising disclosures. The rating experts also focus on evaluating whether the core medical information of the video is accurately conveyed based on the video duration limit rather than comprehensive coverage. By adjusting the scope of application of these benchmarks (such as simplifying citation source standards), they still have reference value in evaluating the accuracy and credibility of core medical information in short videos. In addition, the review study by Li et al [53] indicates that mDISCERN is the most commonly used evaluation tool for health information videos. However, the review mainly focuses on long-format health education content and needs to explore the applicability of mDISCERN, specifically on short video platforms. Secondly, mDISCERN's single benchmark may need to be able to cover the multidimensional quality assessment needs in short videos. Therefore, our study attempts to compensate for the dimensions that a single benchmark may overlook, such as video transparency and overall content quality, by combining other benchmarks, such as *JAMA* and GQS. Therefore, this study chooses to comprehensively use multiple benchmarks to evaluate the quality and reliability of short videos from different perspectives. Future research should further optimize and develop evaluation tools for short videos to enhance their applicability and scientific validity.

Limitations and Future Directions

This research is the first to use 4 evaluation tools (*JAMA*, GQS, mDISCERN, and HONcode) to comprehensively evaluate the quality and reliability of high-frequency videos about HTSs on the TikTok platform. The study also includes an in-depth analysis of the relationship between video characteristics (likes, comments, favorites, and shares) and video quality. However, there are limitations to this study. First, the sample is limited to videos uploaded on the Chinese TikTok platform, which may limit the generalizability of the findings to other languages (such as English) and platforms (such as BiliBili). Despite focusing on Chinese TikTok, the research aligns with studies on videos from various platforms. Given the prevalence of HTS as a health issue, the findings may offer insights for video content in other languages and platforms (such as international versions of TikTok and YouTube). Second, there is a lack of standardized methods for evaluating health information video content on TikTok [46]. The study used 4 standardized evaluation tools due to their proven effectiveness in assessing video quality on media platforms and their previous use in studies evaluating TikTok video quality [54,55]. However, these assessments are somewhat subjective. Despite 2 raters confirming the scores and using Cohen κ to quantify interrater reliability, subjective differences cannot be ignored [20]. This highlights the need for the development of more suitable scoring standards. Third, limiting the analysis scope to verified accounts may result in certain limitations, such as not including videos published by ordinary users (such as patients) or unverified accounts. These videos may contain patients' firsthand experiences or other nonprofessional information, which can impact the comprehensiveness of research conclusions. Future research should consider expanding the scope of analysis and adopting broader validation criteria to cover a more diverse range of video sources. Fourth, although we only selected videos uploaded by medical professionals certified by the platform, we cannot completely rule out the ambiguity of the author's identity information. For example, some uploaders may not be the video's actual creators or information providers but may only participate in video publishing. This uncertainty may affect the accuracy of *JAMA*'s benchmark "authorship" score, potentially leading to bias in research results. Fifth, there are inherent issues with viewing TikTok as a platform for disseminating health information. TikTok's recommendation algorithm tends to push videos that easily attract attention rather than the most scientifically sound ones. This mechanism may lead to the dissemination of misleading or incomplete information. The subject of this study is limited to short videos related to HTSs on the TikTok platform, and all videos are uploaded by medical professionals. Although this choice ensures the scientific and credible nature of the video content, it also limits the generalizability of the research results. Videos related to HTSs uploaded by other groups, such as ordinary users or unverified health influencers, were not included in the analysis, which may limit the applicability of the research results to the broader dissemination of short videos related to health. In addition, the data source of this study is limited to Chinese TikTok (Douyin). The platform culture, user behavior, and regulatory policy may differ from the international version of TikTok or other social media platforms. Therefore, the research results may not directly apply to short video platforms in other countries or regions. In addition, TikTok's video duration limit (usually within 40 s) poses a challenge to the comprehensiveness of health information. Although short videos on the platform can attract viewers to understand a topic quickly, their structure and depth often need to be improved, which may not meet the audience's needs for complex health issues. Therefore, the effectiveness and limitations of TikTok as a tool for disseminating health information need to be further explored.

In addition, there are other evaluation criteria, such as the Video Popularity Index, that can be considered for assessing the quality of health-related information [56]. We recommend that future research incorporate various evaluation methods and platforms to assess the quality of video information more accurately.

The rapid advancement of internet technology and the rising health standards have led to the growing popularity of internet-based health promotion methods. Patients have shifted from being passive recipients to seeking health information actively [20]. With the widespread use of electronic devices, such as smartphones, and the flourishing multimedia technology, visual social media has become a crucial channel for accessing health information. However, the quality of video content varies greatly, leading to significant challenges. Some videos are misleading and provide inaccurate information to viewers, prompting professionals to advocate for stricter regulations. The Chinese government recently issued guidelines for media platforms to publish scientifically accurate health information, a move with global implications [57]. Enhancing the quality of health promotion videos has become a pressing issue requiring all stakeholders' attention. A high-quality health promotion video should be scientifically accurate, appeal to a broad audience, and be easily understandable while eliminating any misleading content. Therefore, rigorous evaluation of video quality is essential to ensure the dissemination of reliable information. Future research should focus on constructing and optimizing platforms to better cater to the public's health information needs.

Conclusions

This research gathered 153 videos about HTSs from TikTok, a popular short video–sharing social media platform in China, and comprehensively evaluated their information quality. The findings revealed that the videos lacked reliable sources and content quality. Overall, videos on the topic of HTSs produced by health care professionals from the burn department and burn plastic surgery department as well as those from first-tier and emerging first-tier Chinese cities demonstrated more significant insights regarding quality and reliability. They provide audiences with more reliable medical information. Therefore, people may prefer content from these departments and cities when seeking information about HTSs. As video-sharing platforms become increasingly popular sources of health information, it is essential to improve regulation and quality control. Users should be cautious when seeking health care management information on short video platforms. To ensure access to accurate information on hypertrophic scarring, we recommend referring to professional and authoritative sources and platforms to safeguard health effectively.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

SW and KX developed and planned the study. SW and WL conducted video reviews and provided ratings. J Wu, KX, and J Wang collected and analyzed the data. J Wang initially drafted the manuscript, which was then reviewed and edited by J Wu. SW and WQ revised the manuscript for content. All authors contributed to writing, revising, and editing the manuscript and approved the final draft for submission.

Conflicts of Interest

None declared.

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Abbreviations

GQS: Global Quality Scale
HONcode: Health on the Net Foundation Code of Conduct
HTS: hypertrophic scar
***JAMA*:** *Journal of the American Medical Association*
mDISCERN: modified DISCERN

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Original Paper

Using Natural Language Processing Methods to Build the Hypersexuality in Bipolar Reddit Corpus: Infodemiology Study of Reddit

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Abstract

Background: Bipolar is a severe mental health condition affecting at least 2% of the global population, with clinical observations suggesting that individuals experiencing elevated mood states, such as mania or hypomania, may have an increased propensity for engaging in risk-taking behaviors, including hypersexuality. Hypersexuality has historically been stigmatized in society and in health care provision, which makes it more difficult for service users to talk about their behaviors. There is a need for greater understanding of hypersexuality to develop better evidence-based treatment, support, and training for health professionals.

Objective: This study aimed to develop and assess effective methodologies for identifying posts on Reddit related to hypersexuality posted by people with a self-reported bipolar diagnosis. Using natural language processing techniques, this research presents a specialized dataset, the Talking About Bipolar on Reddit Corpus (TABoRC). We used various computational tools to filter and categorize posts that mentioned hypersexuality, forming the Hypersexuality in Bipolar Reddit Corpus (HiB-RC). This paper introduces a novel methodology for detecting hypersexuality-related conversations on Reddit and offers both methodological insights and preliminary findings, laying the groundwork for further research in this emerging field.

Methods: A toolbox of computational linguistic methods was used to create the corpora and infer demographic variables for the Redditors in the dataset. The key psychological domains in the corpus were measured using Linguistic Inquiry and Word Count, and a topic model was built using BERTopic to identify salient language clusters. This paper also discusses ethical considerations associated with this type of analysis.

Results: The TABoRC is a corpus of 6,679,485 posts from 5177 Redditors, and the HiB-RC is a corpus totaling 2146 posts from 816 Redditors. The results demonstrate that, between 2012 and 2021, there was a 91.65% average yearly increase in posts in the HiB-RC (SD 119.6%) compared to 48.14% in the TABoRC (SD 51.2%) and an 86.97% average yearly increase in users (SD 93.8%) compared to 27.17% in the TABoRC (SD 38.7%). These statistics suggest that there was an increase in posting activity related to hypersexuality that exceeded the increase in general Reddit use over the same period. Several key psychological domains were identified as significant in the HiB-RC (P<.001), including more negative tone, more discussion of sex, and less discussion of wellness compared to the TABoRC. Finally, BERTopic was used to identify 9 key topics from the dataset.

Conclusions: Hypersexuality is an important symptom that is discussed by people with bipolar on Reddit and needs to be systematically recognized as a symptom of this illness. This research demonstrates the utility of a computational linguistic

framework and offers a high-level overview of hypersexuality in bipolar, providing empirical evidence that paves the way for a deeper understanding of hypersexuality from a lived experience perspective.

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KEYWORDS

bipolar; hypersexuality; natural language processing; Linguistic Inquiry and Word Count; LIWC; BERTopic; topic modeling; computational linguistics

Introduction

Background

Bipolar is a severe mental health condition characterized by recurring episodes of high mood and low mood that is thought to affect at least 2% of the global population [1]. Clinical observations suggest that individuals with bipolar face difficulties regulating emotions and impairments to their cognitive processing, which can contribute to an association with high-risk behaviors [2], and research has demonstrated that these behaviors are often associated with a period of elevated mood [3-5]. Most of the existing research in this area has focused on trying to isolate the biological and behavioral mechanisms that drive risky behavior in people living with bipolar [2,6-14], whereas how these behaviors are exhibited in reality has been comparatively underresearched. Existing research presents a preliminary classification system for the types of risk-taking behavior that people living with bipolar may engage in [3], and through this study, we hope to contribute a more nuanced understanding of one facet of risk-taking behavior, the presentation of hypersexuality, based on large-scale social media data.

This research approaches hypersexuality through the lens of risk-taking behavior and as a symptom of bipolar, focusing on its potential to harm personal safety. However, hypersexuality is a complex concept lacking a universal definition and is shaped by cultural, individual, and situational factors. Perrotta [15] describes it as “a psychological and behavioural alteration as a result of which sexually motivated stimuli are sought in inappropriate ways and often experienced in a way that is not completely satisfactory” and further highlights that hypersexuality is challenging to diagnose due to the lack of established criteria and the impracticality of rigid diagnostic standards in addressing the subjective emotional universe of individuals. Walton et al [16] emphasize that diagnosing hypersexuality requires observable symptoms, subjective perceptions, adverse consequences, and distress. While it is included in the *International Classification of Diseases, 11th Revision*, as compulsive sexual behavior, the rejection of hypersexuality as a distinct diagnosis from the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, underscores ongoing debates about its classification, reflecting concerns about stigmatization and definitional challenges. The term *hypersexuality* may be used by some individuals to articulate personal experiences without negative consequences, and while these self-descriptions may not align with the definition adopted in this paper, they represent meaningful aspects of lived experience.

There are only a limited number of studies that have focused on the topic of hypersexuality and sexual risk taking in bipolar, and the literature on hypersexuality is sparse and not systematically defined [4,17-19]. Krantz et al [5] found that hypomania often precedes risky sexual behavior, with two-thirds of sexually active youth with bipolar engaging in behaviors categorized as above minimal risk and one-third reporting pregnancy, and Mazza et al [19] observed increased sexual interest in women with bipolar type I compared to bipolar type II. Raja and Azzoni [20] noted high awareness of sexually transmitted infection risks but prevalent risky sexual behaviors among individuals with bipolar, schizophrenia, or schizoaffective disorder, and Marengo et al [21,22] found a link between unplanned pregnancies and hypersexuality in manic episodes, also finding higher rates of casual and nonmonogamous sex among women with bipolar, including during euthymia. Krogh et al [4] explored the impact of mood swings on sexuality in bipolar through qualitative interviews, identifying 5 key themes: sexual drive, behavior, thoughts, intimate relationships, and identity. Their results suggest that elevated mood states increased sexual drive and interactions and that mood-related shifts had significant relational impacts. Observing the existing literature critically, a number of studies that have investigated hypersexuality in bipolar are >30 years old [23-25], making it “subject to the biases of sexual and gender norms” of those times [17]. There is also evidence of stigma attached to hypersexuality and the discussion of sexual experiences from health care professionals [26], as well as a lack of qualitative research into the sexual behaviors of people living with bipolar [4,27].

In this paper, we present a toolbox of computational linguistic techniques, including pretrained machine learning models for demographic inference, the extraction of key psychological domains using the 2022 version of Linguistic Inquiry and Word Count (LIWC-22; Pennebaker Conglomerates, Inc) [28], and unsupervised topic modeling using BERTopic [29], to provide an understanding of what kinds of topics are talked about in discussions regarding hypersexuality. This is the first study to use such methods on data that relate to hypersexuality in general and specifically to bipolar and demonstrates the utility of large-scale language analysis in health research. We acknowledge that there are serious ethical implications associated with the collection of such sensitive information but believe that the benefit of improved understanding and awareness that can be obtained using Reddit (Reddit, Inc) posts is of significant value to people who experience the symptom of hypersexuality as part of their diagnosis of bipolar. We provide a comprehensive outline of our ethical considerations, including consultation with lived experience experts, in the Methods section.

This research aimed to form the foundation for future work in the area by developing a dataset of qualitative information, addressing a significant gap in the field, and presenting key themes. The objective was not to provide an exhaustive analysis of all posts in the dataset as this lies beyond the scope of this study. Instead, the focus of this study was on the methodology used to construct the corpus and on foregrounding this topic as a critical area of scientific interest. We hope that this study supports calls for novel research to "address sexual symptomatology in bipolar within the context of current sexual, cultural, and gender norms" [27]. Our research questions are defined in the following section.

Research Questions

The research questions for this study were as follows:

- Is hypersexuality talked about on Reddit?
  - How can we recognize Redditors who post about hypersexuality on Reddit?
  - What are these Redditors' posting behaviors?
- How can computational linguistic methods be used for exploratory analysis of the Hypersexuality in Bipolar Reddit Corpus (HiB-RC)? This includes the following:
  - Psychological domains
  - Topic modeling

Methods

The Talking About Bipolar on Reddit Corpus

Application Programming Interface Data Collection

The posts in this dataset were collected using the Pushshift and PRAW application programming interfaces (APIs) in July 2022 through adaptation of existing code [30]. The 2 subreddits related to bipolar with the highest number of followers—r/bipolar and r/BipolarReddit (approximately 300,000 users)—were scraped to include data posted between July 2017 and July 2022. Applying a similar framework to those in the studies by Coppersmith et al [31], Sekulic et al [32], Cohan et al [33], and Jagfeld et al [34], we then used pattern-matching methods on this corpus to detect Redditors who self-reported a clinical diagnosis of bipolar using a framework implemented by Jagfeld et al [34,35]. We adapted this framework to identify self-reported diagnosis patterns from Reddit posts and comments that (1) contained at least one condition term for bipolar, (2) matched at least one inclusion pattern (ie, bipolar diagnosis of any type by a professional), and (3) did not match any exclusion pattern (eg, self-diagnosis).

After identifying posts from Redditors who had self-reported a diagnosis, we then collected the entire posting history for these users across all subreddits using a custom Python script (Python Software Foundation). This script collected the following information for each comment or submission made by a user: (1) post ID, (2) text body, (3) username, (4) subreddit, (5) post title (for main submissions and not for comments), and (6) time stamp.

We note that there are limitations to using self-reported diagnoses as these have not been clinically verified within the dataset.

Demographic Inference

Overview

To develop a more comprehensive understanding of the Redditors in our dataset, we used a number of methods for demographic inference (age, gender, and location) presented originally in the work by Jagfeld et al [34], Tigunova et al [36], and Harrigian [37]. While we acknowledge that these methods do not necessarily implement state-of-the-art technologies such as large language models, they are to date the only publicly available models for this type of demographic inference within the Reddit domain. Ethical considerations associated with using inference models are presented in the Ethical Considerations section.

Age and Gender

First, we manually identified self-reported instances of age and gender using the pattern-matching code provided in the work by Jagfeld et al [34]. These patterns identify self-reported instances of age and gender from submission titles, which are captured between square brackets as is typical notation on Reddit, for example, "I {28f} am posting here for the first time." Age was calculated using a function that estimates date of birth based on the age provided in the submission title compared to the submission posting date. Labels for gender were assigned using manual extraction for 675 users, and labels for age were assigned using manual extraction for 643 users. We then used pretrained models to determine age and gender for the remaining users in the dataset for whom a self-reported age or gender could not be determined. The pretrained models used for automated age and gender inference were developed by Tigunova et al [36], who presented a hidden attribute model using a convolutional neural network with attention mechanism architecture to develop representations of demographic information based on language use. The models were trained on similar domain data using the posts from >350,000 Redditors included in the RedDust dataset [36]. The reported accuracies for the age and gender algorithms are an area under the receiver operating characteristic curve of 0.88 for age and an area under the receiver operating characteristic curve of 0.91 and accuracy of 0.86 for gender [36]. Using a subset of gold truth labels that were manually extracted from the dataset for age and gender (675 users for gender and 643 users for age), we manually calculated a weighted F_1 accuracy of 0.8 for gender and 0.6 for age for our dataset. The text used as input to the models was preprocessed before being used as input, which involved cleaning the data to remove hyperlinks and non–English-language words and converting the text to the vector representation format expected by the model (adapting the scripts provided by Tigunova et al [36,38]). Both submissions and comments were used as input to the model provided that the content was between 10 and 100 words in length and that users had at least 10 posts that matched these criteria and using only the most recent 100 posts for each Redditor as input. The inference methods for gender that were used in this study were designed only to detect binary genders (man and woman), the implications of which are discussed further in the Discussion section.

Geolocation

We used a pretrained model presented by Harrigian [37] to infer location identifiers for each user in the dataset at the country level. This model was trained using the distribution of words, posts per subreddit, and posts per hour of the day for Reddit users. When applying this model to our data, we included only users with >50 posts and up to 250 posts as specified in the documentation for the package to improve the accuracy of predictions [39]. The global model provided by Harrigian [37] was used, which achieves 35.6% accuracy, and as reported by Jagfeld et al [34], the accuracy is generally higher for users with more training data (95.1% for the United States, 65.1% for Canada, 82.8% for the United Kingdom, 44.1% for Australia, and 41.1% for Germany).

Developing the HiB-RC

After implementing the inference models, any users whose posting history did not satisfy the criteria for the pretrained models were removed from the dataset. This resulted in a snapshot corpus that contains data that span 13 years, with the earliest post dating back to June 2009 and the latest submission date in August 2022.

To detect posts with content related to hypersexuality, we created an initial set of seed terms to generate a subcorpus (the HiB-RC) of users with a self-reported history of hypersexuality. To develop this vocabulary of seed terms, we identified the keywords and phrases related to hypersexuality from a previous study that used lived experience interview data [3] and trained both word2vec (Google AI) [40] and fastText (Facebook's Artificial Intelligence Research laboratory) [41] embedding models on the Talking About Bipolar on Reddit Corpus (TABoRC) to find synonyms (words and phrases) and misspellings of these keywords and phrases. The fastText algorithm produces character-level embeddings that find numeric representations of words by looking at their character-level compositions, thus enabling us to detect common typographical errors for the hypersexuality seed terms. Traditional word- and character-level embeddings were deemed to be sufficient for this task as the embeddings were not being used as part of a predictive algorithm and, thus, there was a cost benefit in terms of lower computational and environmental cost for training these simpler models versus fine-tuning a contextual large language model. The final list of seed terms used to collect posts related to hypersexuality is presented in Textbox 1.

Textbox 1. Hypersexuality keywords used to create the Hypersexuality in Bipolar Reddit Corpus. These keywords were generated by finding the most similar terms to the input keywords using word2vec (Google AI) and fastText (Facebook's Artificial Intelligence Research laboratory) embeddings trained on the Talking About Bipolar on Reddit Corpus.

Input keyword to the word2vec and fastText models

- "Hypersexual"
- "Hypersexuality"
- "Hyper-sexual"
- "Hyper_sexual"

Output—*most similar* keywords

- "Hypersexual"
- "Hyper sexual"
- "Hypersexuallity"
- "Hypersex"
- "Hyper sexualised"
- "Hyper sexuality"
- "Oversexual"
- "Hyposexual"
- "Hyper sexualized"
- "Hypersexualized"
- "Overly sexual"
- "Hyper sexualization"
- "Hypersexualization"
- "Hyposexuality"
- "Hypersexuality"

At the early stages of data collection, we used a much longer list of seed terms to search for posts related to hypersexuality, including phrases such as “hook up with strangers,” “high sex drive,” and “threesomes.” This list of vocabulary was generated using the same word embedding methodology but included a more diverse set of keywords as input when using the models to search for similar words and phrases. This resulted in a much noisier dataset where it was apparent after manual inspection that a large number of the posts were not written in the context of experiencing hypersexuality as a symptom but rather in the context of people sharing and discussing sexual experiences. Due to the infancy of this field of work and to avoid compounding the stigma regarding sex or incorrectly categorizing diverse sexual experiences as hypersexuality, we chose to refine the keyword list used as input to the word embedding models to words and phrases that directly related to the notion of “hypersexuality.” We considered it more ethical to collect data from instances in which individuals self-reported the symptom of hypersexuality rather than inferring hypersexuality through more nuanced descriptions of sexual behavior. The result was that there was less ambiguity and greater reliability in the dataset of posts, with the disadvantage that we filtered out an unknown amount of data related to hypersexuality that talked about the topic in more nuanced ways. We refer in this paper to the concept of a corpus being “acceptably representative,” whereby “we have to make do with studying merely a sample of the language use, or variety, as a whole” due to restrictions on time and resources and, in this case, ethical considerations [42].

After we had generated the final seed list of hypersexuality terms, we created a filter and applied this to the TABoRC. After preprocessing the returned posts to remove duplicates and only include posts that were >30 words in length, we manually annotated this dataset using the doccano tool to verify a post’s inclusion in the corpus, with the posts annotated as confirming a hypersexuality report forming the HiB-RC. The corpus was annotated in full by DH, and circa 10% of the corpus (300 posts) was annotated by second and third annotators (SJ and PR). Interannotator agreement achieved a Krippendorff α score of 0.77 [43], and majority voting was used to solve annotator disagreements. Disagreements primarily occurred in cases in which an experience of hypersexuality was described but there was ambiguity on whether the author of the post was the one who had experienced the symptom. The annotation guidelines are presented in Multimedia Appendix 1.

Analysis Methodology

Interpreting the HiB-RC

To begin the exploratory analysis of our dataset, we produced descriptive statistics to detail the user and posting characteristics of the corpus. These analyses were conducted using Python, and the results are presented in the Results section to show demographic characteristics, the number of new users posting in the HiB-RC each year and the number of new posts referencing hypersexuality each year (using the TABoRC as a comparison dataset), and the top subreddits to which posts about hypersexuality were posted.

Linguistic Inquiry and Word Count

After exploring the Redditor characteristics of our dataset, we used LIWC-22 [28] to understand the key psychological domains within the HiB-RC.

LIWC-22 is a text analysis application that maps psychosocial constructs to words, phrases, and linguistic constructions [28]. Linguistic Inquiry and Word Count (LIWC) processes text using software and a dictionary, where the dictionary contains groups of words that relate to a particular domain (eg, positive or negative tone). Documents of interest (the input text) are analyzed by the software to map the domains to the text, calculating the percentage of each document that comprises words in these dictionary domains. LIWC was designed on the premise that the words that people use tell us about “their psychological states: their beliefs, emotions, thinking habits, lived experiences, social relationships, and personalities” [28]. The LIWC-22 dictionary is based on >12,000 words, phrases, and emoticons, and the authors describe that “in the advent of more powerful analytic methods and more diverse language samples, we have been able to build more internally consistent language dictionaries with enhanced psychometric properties” in this latest release of the software [28]. Modern text analysis has been influenced by >100 years of psychological research [44], and previous research has demonstrated how language analysis can provide insights into cognitive mechanisms, with “an increasing number of studies [which] demonstrate, [that] the ways in which people use words is reliable over time” [45].

LIWC domains have been used in various existing studies that explore how language is used by people living with bipolar, including as input for prediction and classification models [31-33,46-53] and exploratory analysis of mental health datasets [54,55]. In this research, we used LIWC to identify psychological domains that appear significantly more or less by comparing the HiB-RC to a control corpus formed of the same users’ entire posting history across Reddit.

Modeling Hypersexuality

Egger and Yu [56] describe that social media data have opened up new pathways for scientific research but that the short and unstructured nature of the documents within social media datasets can cause methodological issues for analysis. The authors describe that topic modeling has increasingly been applied to the topic of social science, where topic models are defined as “probabilistic models for uncovering the underlying semantic structure of a document collection” [57].

Topic models seek to identify patterns between similar documents to add structure to an otherwise unstructured collection of text to facilitate exploration and understanding. Latent Dirichlet allocation (LDA) is one of the most widely used traditional methods for topic modeling and is a generative statistical model introduced by Blei et al [58]. Despite the popularity of LDA, the reliability and validity of the results have been criticized because there is no definitive method of model evaluation and there is a lack of guidance related to fine-tuning. The efficacy of LDA for analyzing social media data has been further criticized because the noisy and sparse datasets generated in social science research often do not contain enough features for statistical learning [56].

More recent topic-modeling algorithms that have been implemented as an alternative to LDA [56] include embedding models [29,59] that rely on the vectorization of text data to locate semantically similar words and documents. BERTopic [29] is an algorithm that uses pretrained embedding models to create word and document embeddings so that documents that occupy similar vector space can be grouped together to form topics. By default, BERTopic incorporates Bidirectional Encoder Representations From Transformers embeddings and a term frequency–inverse document frequency algorithm, which compares the importance of terms within a cluster and creates term representation based on this [60]. This means that the higher the value is for a term, the more representative it is of its topic. Due to the sparse nature of social media data, BERTopic also includes a default module for dimension reduction using uniform manifold approximation and projection, which enables these dimensions to be reduced to the extent that hierarchical density-based spatial clustering of applications with noise can be used to identify dense regions in the documents [56,59].

On the basis of the comparison of topic-modeling methods presented in the work by Egger and Yu [56], BERTopic presents a number of advantages that influenced our decision to use this method in our research. These include its ability to perform well across multiple domains due to the use of pretrained embeddings and the fact that little to no preprocessing of text is required before training. There still remain limitations, which are described in the Discussion section.

BERTopic Setup

BERTopic was adapted for this study from the code provided by Grootendorst [61]. The parameters that had a significant impact on the topic output included the following:

First, KeyBERTInspired as the main representation input to the model. KeyBERTInspired [62] extracts representative keywords for topics using word embeddings, ensuring more context-aware representations. First, document embeddings are generated to capture the overall meaning of a document. Word embeddings are then created for N-gram words and phrases. Finally, cosine similarity is used to identify the words and phrases that are most similar to the document embedding. Textbox 2 shows the difference in representations produced using the default term frequency–inverse document frequency and KeyBERTInspired representation models.

Second, the use of *mxbai-embed-large-v1* sentence embeddings [63] as the pretrained embeddings for the model, which demonstrate very high performance for low memory use (ranked 13 in the Massive Text Embedding Benchmark leaderboard at the time of writing). We also tested topic generation using MentalBERT embeddings that have been trained on Reddit data within the mental health domain, but the resulting topic representations were less defined and noisier [64].

Third, a custom list of stop words were provided to the CountVectorizer module and, thus, excluded from clusters after training. This list included generic English stop words (eg, “and,” “or,” “this,” and “was”) as well as frequently occurring words such as “hypersex*” and “bipolar”—keywords that appeared in nearly every post due to the seed list of vocabulary used to generate the corpus or the topic domain.

Textbox 2. Default versus KeyBERTInspired representation of the example topics generated by BERTopic.

Default representation

- “Ve,” “manic,” “feel,” “really,” “don,” “mania,” “time,” “people,” “sleep,” and “know”
- “Age,” “years,” “sexual,” “older,” “csa,” “remember,” “trauma,” “know,” “young,” and “happened”

KeyBERTInspired representation

- “Hypomanic,” “manic,” “mania,” “depressed,” “depressive,” “depression,” “disorder,” “psychiatrist,” and “mood”
- “Abuser,” “abused,” “abuse,” “sexual,” “trauma,” “memories,” “rape,” “therapy,” “touched,” and “older”

After our model setup had been finalized, we manually merged similar topics after inspecting the posts included within each topic using the *merge_topic()* method of the model. Finally, we manually assigned topic labels for our topics to be used in visualizations and saved the model as a pickle file for future analysis. As noted when describing the limitations of BERTopic, the topics produced by the model may change each time the model is run. After altering the parameters of the model, implementing *mxbai-embed-large-v1* as the sentence embedding model, and using KeyBERTInspired as the main representation model, we found the generation of topics to be relatively stable with each iteration.

Ethical Considerations

We recognize the importance of developing an ethical framework when working with sensitive data that describe personal lived experience, especially when collecting data from a public site such as Reddit. We outline in this section our considerations regarding consent, anonymization, the right to be forgotten, and dataset retention. Our framework was informed by multiple sources, including institutional resources from the British Psychological Society, the British Sociological Association, and the UK government [65-67] as well as sources from academic research and guidelines [34,68-72]. This study was conducted as part of a PhD thesis on the topic of risk-taking behaviors in bipolar, and we consulted a panel of lived experience advisors through Lancaster University Spectrum Connect at the early stages of design. We also engaged with

Bipolar UK on a webinar on hypersexuality in 2024 [73] and sought invaluable guidance from lived experience researchers who coauthored this paper. Ethics approval was granted for the project by Lancaster University in December 2021 (FHMREC21042).

Reddit is colloquially known as “the front page of the internet,” with >50 million daily users and 100,000 *active* subreddits in 2024 [74,75], and research has shown that the anonymity afforded by social media sites enables users to self-disclose on sensitive topics that they may otherwise find difficult to talk about [76]. As researchers, we wholly acknowledge that the Reddit posts used in our study contain sensitive information and that the forum users were not aware that their discussions would be used for research. We did not seek informed consent from the Redditors whose posts we collected due to the impractical nature of this task considering that the posts of >5000 Redditors were included in the TABoRC, but we note that Reddit users are made aware that their posts are publicly accessible through Reddit’s terms and conditions. From a legal perspective, although Reddit is by nature an anonymous platform, we cannot know that Redditors do not use the same username across other social media sites or platforms, and therefore, we treat the information collected from the site as personal data. In accordance with the Data Protection Act 2018 and General Data Protection Regulation, an exemption for conducting research for “special purposes” would be relevant for nonconsent as we intend to publish our research and are confident that the publication of any research associated with the collection of these Reddit data “would be in the public interest” [67]. Further to the legal grounding of work conducted in the public interest, the motivation for this study was to learn more about experiences of a typically stigmatized symptom to identify how people experiencing hypersexuality could be better supported. There is existing evidence from lived experience suggesting that data on this topic can be difficult to access within a health care setting, so we acknowledge the limitations of using data sourced from the web but also recognize the unique insights that the analysis of such data can provide [3,27,77].

Following previous guidance [65,68,69], as we did not rely on consent for this study, we masked the usernames in this dataset (created alternative alphanumeric usernames for each Redditor in the dataset) and have only included paraphrased and depersonalized quotes in research outputs. We have also minimized the amount of qualitative data reported by using computational methods such as topic modeling and LIWC, which enable us to present key themes and insights from the data in an aggregate format without needing to rely heavily on quotes. Where we presented paraphrased quotes, we verified that Redditors could not be reidentified based on an internet search of the reworded quotes. Using these methods, we strived to maintain the privacy of the Redditors included in our corpus as much as possible.

We would also like to draw attention to the demographic inference methods that we used. Performing inference of such data enables us to offer predicted demographic information about the study population, which may allow for comparison to other domains, for example, clinical populations. Reporting on aspects such as gender also contributes toward more ethical natural language processing data collection as these predictions can suggest how experimental results might be generalized and also highlights where the data include bias [78]. However, inferring demographic information adds an extra level of personal data to the corpus, and we acknowledge that this comes with its own risks. The demographic data that we inferred are not intended to be used for identification or targeting of users in any way, and we understand that these inferred statistics are not 100% accurate, nor have they been used as features in any predictive models. The demographic data were only reported in aggregate format and will not be publicly released, although the code used is available open source. We would also like to strongly emphasize that any analysis reported using the demographic data indicates correlation and not causality.

Using Reddit as a primary data source is not “wholly problematic or must be ceased,” but “careful handling and anonymization of such materials is of paramount importance for maximising ethical research practice going forward” [71]. We have decided to only publish redacted versions of both the TABoRC and HiB-RC with the UK Data Service, as requested by the funder of this research (the Economic and Social Research Council). The redacted versions of the datasets will include only the IDs for the posts that form the corpora. The corpora will be disseminated upon request on a case-by-case basis to researchers with an institutional email address, and future researchers will be required to access the content of the posts using an API. This complies with Article 17 of the UK General Data Protection Regulation and an individual’s rights to data erasure because any content that has been removed since the creation of our datasets will appear as “[removed]” upon retrieving the post ID using an API.

Results

Posting Characteristics on Reddit

The TABoRC comprises 6,679,485 posts from 5177 users, and the HiB-RC comprises 2146 posts from 816 users. The demographic statistics for the TABoRC and HiB-RC corpora are presented in Table 1. The data suggest that >15% (816/5177, 15.76%) of the users in the TABoRC reported experiences of hypersexuality.

Table 1. Demographic information for the Hypersexuality in Bipolar Reddit Corpus (HiB-RC), the Talking About Bipolar on Reddit Corpus (TABoRC), and the benchmarking dataset [34].

	Proportion of users
TABoRC (n=5177), n (%)	
Age (y)[a]	
14-23 (teenagers and young adults)	1385 (26.8)
24-45 (adults)	3371 (65.1)
46-65 (middle-aged adults)	389 (7.5)
66-100 (older adults)	32 (0.6)
Gender	
Female	3668 (70.8)
Male	1509 (29.1)
Country	
United States	3970 (76.7)
United Kingdom	366 (7.1)
Canada	337 (6.5)
Germany	108 (2.1)
Australia	100 (1.9)
Sweden	58 (1.1)
Other countries	238 (4.6)
HiB-RC (n=816), n (%)	
Age (y)[a]	
14-23 (teenagers and young adults)	207 (25.4)
24-45 (adults)	531 (65.1)
46-65 (middle-aged adults)	74 (9.1)
66-100 (older adults)	4 (0.5)
Gender	
Female	626 (76.7)
Male	190 (23.3)
Country	
United States	600 (73.5)
United Kingdom	62 (7.6)
Canada	61 (7.5)
Germany	21 (2.6)
Australia	24 (2.9)
Sweden	12 (1.5)
Other countries	36 (4.4)
Benchmarking dataset [1][b], %	
Mean age (y)	
13-17	16.1
18-29	29.8
30-49	47.5
50-64	6.6
≥65	0

	Proportion of users
Gender	
Female	52.2
Male	47.8
Country	
United States	81.9
United Kingdom	5.6
Canada	4.9
Germany	1.4
Australia	1.7
Sweden	—[c]
Other countries	4.5

[a]The pretrained model [2] included an additional age category of 0 to 13 years (child). For any users who were manually or automatically included within this age group, we removed their data from the dataset as Reddit requires a minimum sign-up age of 13 years.

[b]Original data values were not provided with the dataset, so we have only presented percentages in this section.

[c]Not available.

Figure 1 compares the number of new users between 2012 and 2021 in the HiB-RC and the TABoRC, with an average yearly increase of 86.97% (SD 93.8%) and 27.17% (SD 38.7%), respectively. Figure 2 compares the number of new posts between 2012 and 2021 in the HiB-RC and the TABoRC, with an average yearly increase of 91.65% (SD 119.6%) and 48.14% (SD 51.2%), respectively. The bars represent the raw number of posts and the labels demonstrate the yearly percentage increase compared to the previous year. Table 2 shows how many posts that reference hypersexuality are made by each user.

Table 3 shows the top subreddits where posts related to hypersexuality were made within the HiB-RC (where >5 posts were made to the same subreddit), with the most visited subreddits including r/bipolar, r/BipolarReddit, r/bipolar2, r/AskReddit, and r/BipolarSOs.

Figure 1. Comparing the number of new users each year in the Hypersexuality in Bipolar Reddit Corpus (HiB-RC) and the Talking About Bipolar on Reddit Corpus (TABoRC). There is no percentage increase reported for the HiB-RC in 2012 because the first post in the HiB-RC was reported in 2012. Data collection ended in July 2022, so the observed trend in user growth may not fully reflect subsequent changes.

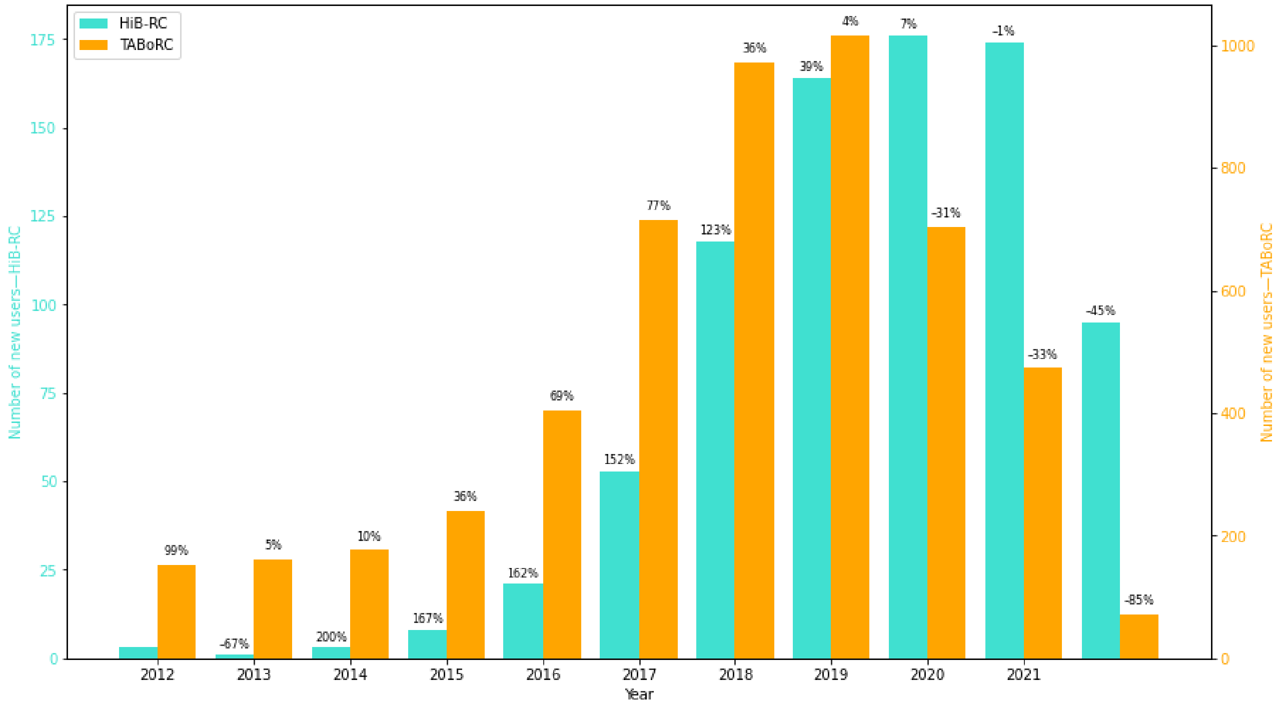


Figure 2. Comparing the number of new posts each year in the Hypersexuality in Bipolar Reddit Corpus (HiB-RC) and the Talking About Bipolar on Reddit Corpus (TABoRC). There is no percentage increase reported for the HiB-RC in 2012 because the first post in the HiB-RC was reported in 2012. Data collection ended in July 2022, so the observed trend in post growth may not fully reflect subsequent changes.

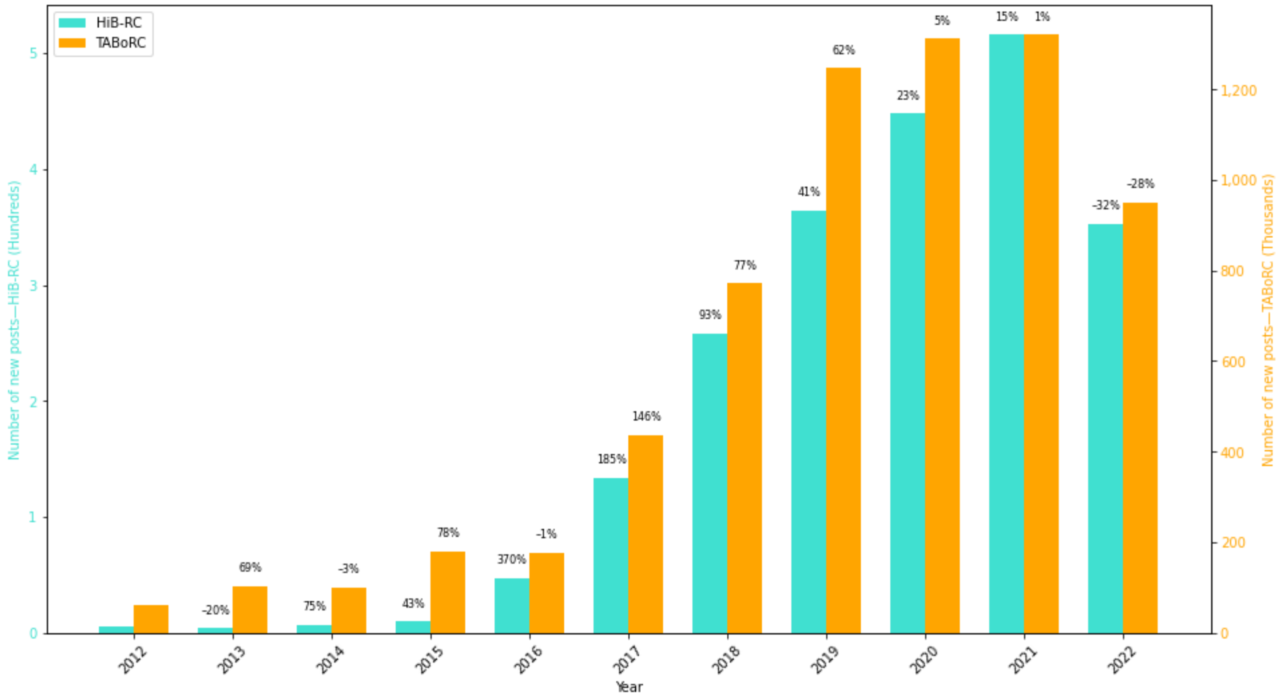


Table 2. Number of posts per user referencing hypersexuality (N=816).

Number of posts per user referencing hypersexuality	Users, n (%)
1	453 (55.5)
≥1 to <5	270 (33.1)
≥5 to ≤10	65 (8)
>10	28 (3.4)

Table 3. Top subreddits for posts related to hypersexuality (where >5 posts were made to the same subreddit; N=2146).

Subreddit	Posts, n (%)
r/bipolar	1027 (47.86)
r/BipolarReddit	421 (19.62)
r/bipolar2	169 (7.88)
r/AskReddit	53 (2.47)
r/BipolarSOs	43 (2)
r/polyamory	28 (1.3)
r/BPD	28 (1.3)
r/hypersexuality	26 (1.21)
r/sex	16 (0.75)
r/adultsurvivors	13 (0.61)
r/ADHD	11 (0.51)
r/BDSMAdvice	10 (0.47)
r/CPTSD	10 (0.47)
r/relationship_advice	9 (0.42)
r/AskRedditAfterDark	9 (0.42)
r/demisexuality	8 (0.37)
r/relationships	7 (0.33)
r/AskMen	6 (0.28)
r/BorderlinePDisorder	6 (0.28)
r/depression	6 (0.28)
r/mentalillness	6 (0.28)

LIWC Results

Table 4 presents a selection of LIWC domains that were statistically significant when comparing the HiB-RC to a control corpus from the same users. The control corpus contains all posting history from each user in the HiB-RC across Reddit after removing the posts that are included in the HiB-RC. The total word count of the HiB-RC is 344,786, and the total word count of the control corpus is 69,495,570. We built the control corpus based on the hypothesis that these data would be representative of more general language use across Reddit by the same group of users based on manual inspection of a sample of the data. After identifying a nonnormal distribution in most LIWC domains based on paired scores using the Shapiro-Wilk test [79], we determined statistical significance using a paired Wilcoxon signed rank test [80] to identify significant differences in domain scores between the control and hypersexuality corpora. All domains included in Table 4 are significant at a *P* value of <.001. The table presents the Wilcoxon score and associated *P* value together with the effect size (Cohen *d*, with directionality represented by the minus sign [–]), which ranges between small (0.01 to 0.2) and huge (≥2) [81]. The methodology for the LIWC analysis was adapted from the work by Cohan et al [33].

Table 4. Significant Linguistic Inquiry and Word Count domains in the Hypersexuality in Bipolar Reddit Corpus (HiB-RC) compared to a control corpus of Reddit posts from the same set of users.

Domain	Description or most frequently used exemplars (from LIWC-22[a] dictionary)	Direction of significance[b]	Wilcoxon signed rank score	*P* value	Cohen *d*
Linguistic dimensions					
First person singular	"I," "me," "my," and "myself"	Positive	34,402.0	<.001	0.37
First person plural	"We," "our," "us," and "lets"	Negative	66,744.0	<.001	−1.14
Second person	"You," "your," "u," and "yourself"	Negative	52,244.5	<.001	−0.55
Third person singular	"He," "she," "her," and "his"	Negative	71,742.5	<.001	−0.55
Third person plural	"They," "their," "them," and "themsel*"	Negative	49,597.5	<.001	−1.57
Psychological processes					
Achievement	"Work," "better," "best," and "working"	Negative	91,466.0	<.001	−0.61
Power	"Own," "order," "allow," and "power"	Negative	111,908.5	<.001	−0.34
Cognition	"Is," "was," "but," and "are	Positive	126,646.5	<.001	0.09
Cognitive processes	"But," "not," "if," "or," and "know"	Positive	126,921.0	<.001	0.09
Insight	"Know," "how," "think," and "feel"	Positive	138,386.0	<.001	0.17
Positive tone	"Good," "well," "new," and "love"	Negative	95,852.5	<.001	−0.36
Negative tone	"Bad," "wrong," "too much," and "hate"	Positive	119,137.5	<.001	0.27
Emotion	"Good," "love," "happy," and "hope"	Positive	132,424.5	<.001	0.24
Positive emotion	"Good," "love," "happy," and "hope"	Negative	131,386.0	<.001	−0.12
Negative emotion	"Bad," "hate," "hurt," and "tired"	Positive	30,310.0	<.001	0.34
Social behavior	"Said," "love," "say," and "care"	Negative	121,529.5	<.001	−0.16
Prosocial behavior	"Care," "help," "thank," and "please"	Negative	107,645.5	<.001	−0.22
Politeness	"Thank," "please," "thanks," and "good morning"	Negative	64,811.0	<.001	−1.63
Communication	"Said," "say," "tell," and "thank*"	Negative	105,069.0	<.001	−0.42
Social referents	"You," "we," "he," and "she"	Negative	46,417.5	<.001	−0.39
Family	"Parent*," "mother*," "father*," and "baby"	Negative	98,628.5	<.001	−0.31
Female references	"She," "her," "girl," and "woman"	Negative	84,008.5	<.001	−0.37
Male references	"He," "his," "him," and "man"	Negative	96,669.5	<.001	−0.29
Expanded LIWC-22 dictionary					
Lifestyle	"Work," "home," "school," and "working"	Negative	53,011.0	<.001	−0.69
Leisure	"Game*," "fun," "play," and "party*"	Negative	82,334.0	<.001	−0.74
Home	"Home," "house," "room," and "bed"	Negative	66,942.5	<.001	−1.52
Work	"Work," "school," "working," and "class"	Negative	57,181.0	<.001	−0.96
Money	"Business*," "pay*," "price*," and "market*"	Negative	94,900.5	<.001	−0.51
Religion	"God," "hell," "christmas*," and "church"	Negative	78,149.5	<.001	−0.47
Physical	"Medic*," "food*," "patients," and "eye*"	Positive	64,808.5	<.001	0.38
Health	"Medic*," "patients," "physician*," and "health"	Positive	97,079.0	<.001	0.31
Wellness	"Healthy," "gym*," "supported," and "diet"	Negative	50,662.5	<.001	−2.35
Mental health	"Mental health," "depressed," "suicid*," and "trauma*"	Positive	73,266.5	<.001	0.58
Substances	"Beer*," "wine," "drunk," and "cigar*"	Negative	73,783.0	<.001	−0.29

Domain	Description or most frequently used exemplars (from LIWC-22[a] dictionary)	Direction of significance[b]	Wilcoxon signed rank score	*P* value	Cohen *d*
Sexual	"Sex," "gay," "pregnan*," and "dick"	Positive	40,559.5	<.001	0.78
Reward	"Opportun*," "win," "gain*," and "benefit*"	Negative	52,059.0	<.001	−2.45
Time	"When," "now," "then," and "day"	Positive	106,340.5	<.001	0.22
Past focus	"Was," "had," "were," and "been"	Positive	125,182.5	<.001	0.14
Future focus	"Will," "going to," "have to," and "may"	Negative	72,929.0	<.001	−0.90

[a]LIWC-22: 2022 version of Linguistic Inquiry and Word Count

[b]Positive direction indicates that the domain is more prevalent in the HiB-RC than the control corpus. Negative direction indicates that the domain is less prevalent in the HiB-RC than the control corpus.

BERTopic Results

Our implementation of BERTopic initially yielded 14 topics and 1 outlier class (which contained posts that were determined to be too noisy to accurately cluster into one of the topics by the algorithm). After manual analysis of these topics, we merged a number of similar clusters using the inbuilt function in BERTopic to produce 9 final topics (shown in Table 5).

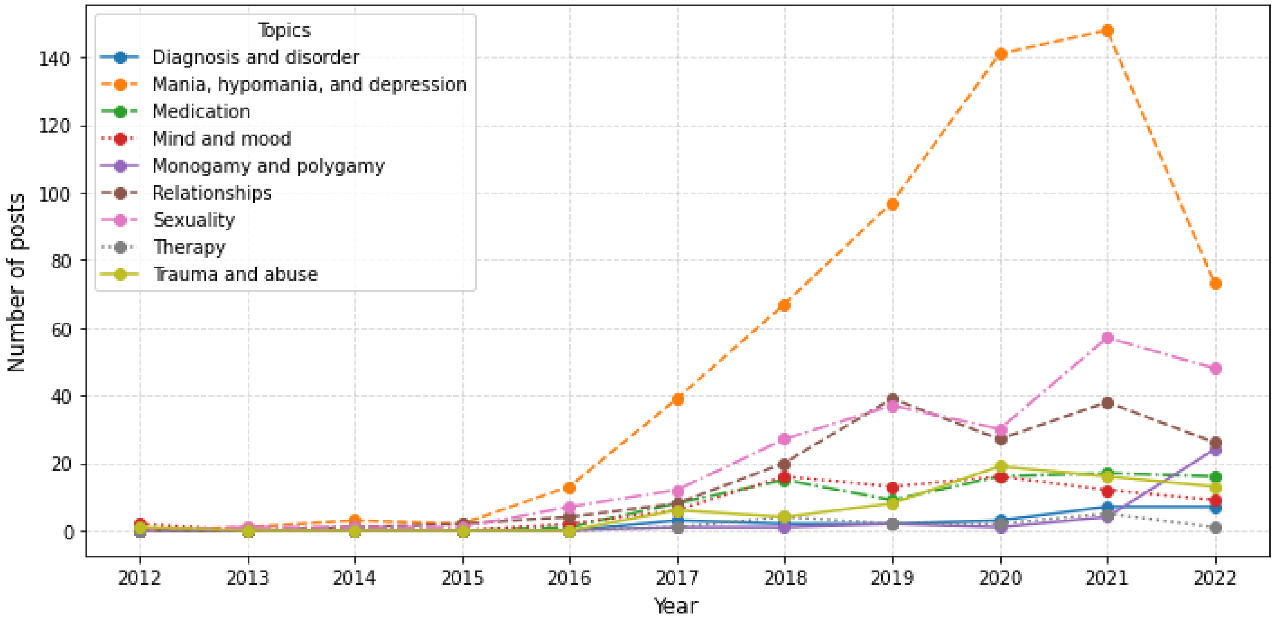
Figure 3 shows how the representation of hypersexuality topics has changed over time, with all topics showing an increase in representation since the inception of the dataset.

Table 5. Topics produced by BERTopic (with the manually inferred topic name), the top 10 keywords for each cluster, and paraphrased excerpts from the most representative post for each topic. Additional examples for each topic are provided in Multimedia Appendix 1 (n=2146).

Topic name (inferred)	Posts, n (%)	Top 10 keywords in the cluster	Extract from the most representative post for each topic (paraphrased)
—[a]	878 (40.91)	Outliers	—
Mania, hypomania, and depression	584 (27.21)	"Hypomanic," "hypomania," "manic," "mania," "disorder," "depressive," "depressed," "depression," "diagnosed," and "psychiatrist"	"Over 3-4 months, I left home, almost divorced, and indulged in reckless sexual encounters due to hypersexuality, hurting my family and behaving poorly. Reflecting on my manic episode, I now see the embarrassment and realize it's a common experience for many. As I came down, I recognized my strange behavior."
Sexuality	221 (10.3)	"Sexuality," "sexually," "sexual," "relationship," "feelings," "manic," "bisexual," "aroused," "feeling," and "boyfriend"	"I define myself as demisexual because I only experience attraction towards those I'm emotionally connected to, none of whom share the sentiment. Despite this, I have a strong sexual drive, feeling intense arousal monthly, and occasionally endure extended periods of hypersexuality lasting days or weeks."
Relationships	165 (7.69)	"Relationship," "relationships," "manic," "boyfriend," "disorder," "sexuality," "mania," "dating," "mental," and "diagnosed"	"I'm a challenging partner due to my manic episodes, leading to outbursts, bouts of hypersexuality (increasing the temptation to cheat), excessive drinking, and impulsive life-altering choices. Also, I believe I haven't completely healed from my previous abusive relationship."
Medication	83 (3.87)	"Hypomanic," "hypomania," "lamictal," "manic," "wellbutrin," "seroquel," "antipsychotic," "lithium," "zoloft," and "psychiatrist"	"In the last two months of taking it, there's been no improvement. Even after a week on 200mg, I'm still stuck in a severe mixed episode. I'm overwhelmed with hypersexuality, impulsivity, late nights, and a complete lack of motivation. My mood appears to be cycling rapidly, possibly even faster than before."
Mind and mood	76 (3.54)	"Hypomanic," "manic," "mood," "mania," "lithium," "feeling," "anxiety," "days," "thoughts," and "mind"	"I'm beginning to understand that although I experience cycling, my episodes often extend beyond a few days. Recent weeks of mood tracking reveal durations of a week or even two, with my current mood episode already lasting four days. In this most recent episode I've been feeling hypersexual, and like my head is full of thoughts. I'm also anxious and I've been focusing a lot on work."
Trauma and abuse	67 (3.12)	"Abuser," "abused," "abuse," "sexual," "raped," "trauma," "feelings," "memories," "therapy," and "touched"	"I started having cyber-sex with men in their 20s when I was 13, I would have online sex with anyone who was there, I wasn't thinking about their age. After this hypersexuality, I became very anxious and scared of men, and now I become very triggered when the topic of sexual abuse comes up."
Monogamy and polygamy	33 (1.54)	"Polyamory," "polyamorous," "monogamy," "monogamous," "relationship," "relationships," "poly," "married," "spouse," and "boyfriend"	"Following almost two decades of monogamous marriage, I divorced due to manic hypersexuality from bipolar, finding monogamy challenging. For five years, I explored different non-monogamous arrangements, aiming to find a new partner for monogamy. However, after another failed attempt, I encountered a married polyamorous man and chose to explore that avenue instead."
Diagnosis and disorder	24 (1.12)	"Disorder," "sexually," "sexual," "addiction," "manic," "adolescence," "mania," "psychological," "addicts," and "diagnosed"	"At 32, I was diagnosed with BP2, prompting reflection on missed signs in my childhood and adolescence. Back then, mental health wasn't a focus in my large family, and I concealed much of my struggles. With a BPD diagnosis too, distinguishing between disorders complicates understanding my experiences and symptoms. I completely relate to the hypersexuality. I have been very sexual since my early teens with a boyfriend who was years older than me."
Therapy	15 (0.7)	"Therapist," "therapy," "therapists," "counseling," "psychologist," "relationship," "intimacy," "psych," "helped," and "talking"	"I always remember them saying to never underestimate libido although that may not be the best advice for someone who's hypersexual."

[a]This is the outlier category that is automatically created by BERTopic to filter posts that are ambiguous and cannot be clustered into one of the topics.

Figure 3. Graph representing the dynamic topic modeling over time. Data collection ended in July 2022, so the observed trends may not fully reflect subsequent changes.



Discussion

Posting Behaviors

The results demonstrate that natural language processing methods were successfully used to create a corpus of Reddit posts from users who had self-reported a diagnosis of bipolar and who created content that relates to hypersexuality. There were 816 users in the dataset who posted to Reddit about hypersexuality, forming a corpus of >2000 posts. While most of the users (453/816, 55.5%) in the HiB-RC had only posted about hypersexuality once (within the data that we collected), 44.5% (363/816) of the Redditors did post repeatedly about hypersexuality—which could indicate repeat episodes of hypersexuality or sharing the same experience across multiple threads. The data demonstrate that there has been a substantial increase in the discussion of hypersexuality in terms of both the number of posts and the number of users when comparing the HiB-RC posts to the TABoRC, suggesting that this is a salient topic being discussed on Reddit.

The data suggest that the HiB-RC encompasses approximately 15% of the Redditors from the TABoRC (816/5177, 15.76%), although the number of Reddit users who talk about hypersexuality more widely on Reddit is likely to be much higher than this. We make this assumption based on the fact that we used a restrictive set of keywords and phrases to retrieve posts related to hypersexuality, as discussed in the Methods section, and based on reports that 63% of women in a recent survey on experiences of bipolar reported hypersexuality as a symptom of bipolar [27,82]. Our dataset relied on Redditors who had self-reported a diagnosis and were already aware of the terminology of “hypersexuality,” but we recognize that there is a large number of people who may be sharing their hypersexual experiences on the web before receiving a diagnosis using nonclinical terminology without knowing that this is a symptom of bipolar [27,77,82]. This is an important area of exploration for future research.

When comparing the demographic inference of the HiB-RC to data from a study that profiled Reddit users with a self-reported diagnosis of bipolar [34], our statistics for age and geolocation correlate. Most Redditors in the HiB-RC were based in the United States, the United Kingdom, Canada, Germany, and Australia (768/816, 94.1%) and were between the ages of 24 and 45 years (531/816, 65.1%). However, the inferred gender data for the TABoRC suggest that most Redditors were women (3668/5177, 70.85%), which is an interesting observation compared to findings that most Reddit users in general are men [83] and previous research on bipolar that identified a more equitable distribution of Redditors who present as men and women [34]. One interpretation could stem from different methodologies of data collection; we initially sourced our Redditors from subreddits that were specific to bipolar, whereas Jagfeld et al [34] sourced Redditors across Reddit from the outset. This notion correlates with research that Redditors who present as women are 33% more likely to post in mental health–related subreddits than Redditors who present as men [55] and, thus, we would assume are also more likely to self-report a diagnosis of bipolar in these subreddits. This gender inequality is further conflated in the HiB-RC (626/816, 76.7% of the dataset presented as women). While the interpretation of this statistic requires consideration of a number of sociological perspectives and a full understanding of this topic is beyond the scope of this study, existing research reports on the “sexual double standard” [84,85]. It is well documented that “behaviours associated with high sexual activity [are] expected more and evaluated more positively” [84] in men than in women, and therefore, it is conceivable that women could feel more stigmatized about hypersexual experiences and may be more likely to post in an online “safer” space [76]: “women must strike the right balance between what society deems to be too much sex or not enough; men suffer from the pressure of performance" [77].

Finally, when considering where Redditors in the HiB-RC posted, we can observe that 77.82% (1670/2146) of the content was posted in subreddits associated with bipolar (r/bipolar, r/BipolarReddit, r/bipolar2, and r/BipolarSOs), suggesting that most of the Redditors in the dataset were aware that this is a symptom that is linked to bipolar. As described previously, this corpus is unlikely to be fully representative of the multiple and nuanced ways in which hypersexuality could be described on the web, and therefore, we should not misrepresent this statistic and assume that the wider population of people with a diagnosis of bipolar are aware of hypersexuality as a symptom. We also note that 7.88% (169/2146) of the posts appeared in the r/bipolar2 subreddit, which has typically been ignored in academic literature related to hypersexuality in bipolar [27,86].

LIWC Analysis

The significant LIWC domains presented in the HiB-RC yielded a number of interesting insights, of which we will only discuss the most salient in this section.

With reference to the *cognition* domains, posts in the HiB-RC were more likely to demonstrate *negative tone* and *negative emotion* and less likely to present *positive tone* and *positive emotion*. This is logical when we consider the potential impact that the symptom of hypersexuality can have on a person's life and correlates with the significantly higher presence of the *mental health* domain, which matches words such as *depressed*, *suicide*, and *trauma*. It is also logical that the *sexual* domain was significantly more frequent in the HiB-RC, where Redditors focused on sharing sexual experiences. For the domains of *reward* and *wellness*, we observed huge effect sizes of >−2, indicating that words such as *healthy*, *supported*, *gain*, and *benefit* (from the LIWC-22 dictionary) were significantly less prevalent in the HiB-RC, suggesting that Redditors do not view hypersexuality as a rewarding behavior. Finally, the domain of *past focus* was significantly more prevalent in the HiB-RC, whereby manual analysis of posts suggests that Redditors were primarily recounting histories and past experiences of hypersexuality. The significantly lower presence of the *future focus* domain correlates with this finding, as well as signifying the impulsive nature of hypersexuality that has been documented in the literature [77,86].

BERTopic Analysis

The clusters produced by BERTopic included 9 topics and 1 outlier class, and each topic was presented alongside a text excerpt from the most representative post (determined by BERTopic). Holistically, the model provided what we consider to be fairly distinct and identifiable topics, which is impressive considering the relatively small corpus and the niche domain of the dataset. Although topic modeling is not capable of capturing every nuance of the data, the model output provides a good starting point for understanding the data without needing to train a supervised model. The number of posts that were clustered into each topic by the model does not mean that these were the only posts that referenced a specific topic as some posts talked about more than one topic, and it is also likely that insightful data may have inadvertently been clustered into the outlier category. We can see that there was an increasing trend for all identified topics since 2017, which was especially pronounced for the topics of *sexuality* and *monogamy and polygamy* since 2020.

Evidence from the existing literature correlates with some of the topics identified by the automated model, including the onset of hypersexuality during an elevated mood [4,5,86], sexuality and sexual orientation [4,87], managing hypersexuality within a relationship [4,17], hypersexuality and medication [88-90], the role of child sexual abuse in hypersexuality [91-93], and vulnerability to sexual assault due to hypersexuality [27,77,82].

The Utility of a Computational Linguistic Framework

Current evidence from lived experience underscores the severe and multifaceted consequences of hypersexuality. These include risks such as sexual assault, unplanned pregnancies, vulnerability to sexually transmitted infections, traumatic abortions, and significant disruptions in personal relationships [82]. Findings from a Bipolar Commission survey involving >1500 individuals reveal that 88% of respondents experienced hypersexual behaviors, highlighting the symptom's prevalence and potential to impact thousands of people across the United Kingdom [27,94]. Over half of the participants reported experiencing ≥8 episodes of hypersexuality during their lifetime. Furthermore, 54% reported putting themselves in dangerous situations, 54% experienced relationship breakdowns, and 22% reported being raped during a period of hypersexuality. In total, 1 in 5 respondents attempted suicide due to hypersexual behavior or its consequences, aligning with previous findings that link hypersexuality in bipolar to increased suicidal ideation [95]. The data reveal a troubling gap in clinical practice, with 60% of respondents reporting that health care professionals had not addressed hypersexuality as part of their care [82]. This disconnect between the prevalence of hypersexuality and its clinical recognition underscores an urgent need for a more comprehensive understanding of hypersexual behaviors, particularly from the perspective of those with lived experience. The development of the HiB-RC and exploratory analysis using computational linguistic methods highlights the potential of this framework in advancing our understanding of hypersexuality as a symptom experienced by individuals with bipolar. The HiB-RC represents a significant resource for future research, enabling deeper exploration of the complex relationship between hypersexuality and bipolar to help bridge the gap between clinical knowledge and practice. The use of Reddit as a data source provides unique advantages, offering insights from real-time, user-generated narratives that are free from the constraints of predefined categories typically observed in self-report questionnaires or controlled laboratory settings [76]. This approach captures an authentic and dynamic perspective, reflecting the lived experiences of individuals as they occur. Future research using this dataset will use a corpus-assisted discourse analysis to explore key thematic concepts discussed by Reddit users and describe how these findings can inform and improve clinical practice for people with bipolar.

Additional avenues for future research could build on the exploratory nature of this study using alternative methodologies to verify the findings and deepen insights. For instance, ethnographic or participatory studies could provide a more immersive understanding, whereas large-scale qualitative studies using interviews could triangulate the results. Applying the same computational methods to clinical datasets would offer valuable cross-validation. Collecting more detailed demographic information, such as relationship status, could also shed light on how hypersexuality manifests across different life contexts, enriching our understanding of this complex symptom.

Strengths and Limitations

This study offered a unique insight into the presentation of hypersexuality within a Reddit population who self-reported a professional diagnosis of bipolar. This is the first study to observe hypersexuality in such a population, and we endeavored to not only contribute to the literature on hypersexuality but also provide a rigorous and ethical framework for doing this. We used novel computational methods to identify salient patterns in the language used by Redditors, which signpost to common experiences shared by people who experience the symptom of hypersexuality. It is also important to consider the limitations of research conducted using social media data and predictive models, and these are outlined in this section.

First, as referenced in the Methods section, we relied on self-reported diagnoses of bipolar. As is the risk with any analysis conducted using social media data, we are assuming that the posts within our corpus are truthful. As described by Coppersmith et al [49], due to "the stigma often associated with mental illness," it seems unlikely that Redditors would post about symptoms of a mental health condition that they do not have. We also tried to reduce false-positive reports of a bipolar diagnosis in the dataset by using pattern matching to capture self-reported diagnoses by Redditors.

Second, we also acknowledge limitations associated with demographic inference. The first limitation is that the gender inference model was restricted to the binary prediction of men and women as there is no tool currently available that predicts beyond these two genders, and this is a limitation of the demographic predictions. A tangential avenue for further research could involve the development of a multiclass predictive model to avoid binary classification. Future research that involves the collection of primary lived experience data (eg, through interviews) should also focus on inclusive data collection to encompass a broader set of gender identities. The second demographic limitation that we would like to address is that most of the inferred geolocations were based in America, and although the data that we report are consistent with existing literature on hypersexuality and bipolar, we cannot assume that these findings will be fully representative of international experiences. For example, Redditors worldwide are likely to be affected differently by varying health care provisions, which could have an impact on experiences with access to psychosocial support and medication costs.

Third, there are a number of limitations associated with using an unsupervised topic model, including the generation of a large number of outliers and a lack of objective evaluation metrics (which is consistent across topic-modeling methodologies). The interpretation of the topic models generated by BERTopic also still relies on human interpretation and domain knowledge, but BERTopic does provide an option to use an "auto" parameter in the setup of the model, which reduces the number of topics by merging similar clusters after the model has been trained to produce the "optimum" number of topics (as opposed to defining *k* number of topics in LDA). Finally, due to the stochastic nature of uniform manifold approximation and projection (the dimension reduction algorithm used by BERTopic), the resulting topics produced by the BERTopic model may differ when running the same code multiple times [29].

Finally, as we have acknowledged throughout this paper, we used a restrictive set of keywords to search for posts that contained references to hypersexuality, and therefore, the data presented in this paper are not definitively representative of all experiences and understandings of hypersexuality in bipolar across Reddit. Future research could use word embeddings on the HiB-RC to identify words and phrases that appear in a similar context to variants of the lemma *hypersexual* and then search for these words in the TABoRC to return a large corpus of posts that potentially describe hypersexuality. To avoid confusing hypersexuality with experiences of increased sex drive or discussion of nonnormophilic sexuality [16], these posts would need to be manually verified for inclusion, and strict coding guidelines would need to be developed.

Conclusions

This paper has presented a novel methodology for generating a corpus of data related to experiences of hypersexuality in bipolar—inferring demographic information for these data—and 2 computational linguistic methods for exploratory analysis. We demonstrated that hypersexuality is an important symptom that is discussed by people living with bipolar, with significant associated factors suggested by the topic model, including the impact on relationships, discussion of medication, sexual assault, and correlation with an elevated mood. Our LIWC analysis demonstrated that posts describing hypersexuality were significantly more likely to include language that denoted mental illness and negative emotions, and we signposted to areas of further research that could be informative in guiding future clinical interventions. This study not only fills a critical gap by providing a dataset of experiences of hypersexuality within the context of bipolar but also highlights the potential of computational linguistic methods in mental health research. The findings underscore the importance of using innovative methodologies to bridge the gap between anecdotal experiences and empirical evidence, providing data that can help develop more informed and impactful psychosocial interventions in the future.

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Data Availability

A redacted version of both the Talking About Bipolar on Reddit Corpus and Hypersexuality in Bipolar Reddit Corpus are available from the UK Data Service.

Authors' Contributions

DH designed this study, collected the Reddit data, and conducted the analysis. SJ, PR, FL, JP-C, CD, and AC provided comments and guidance throughout this study and provided valuable insights for the manuscript draft. PR and SJ performed second annotations for 10% of the Hypersexuality in Bipolar Reddit Corpus, and all the authors approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Annotation guidelines.
[DOCX File , 17 KB - infodemiology_v5i1e65632_app1.docx]

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Abbreviations

API: application programming interface
HiB-RC: Hypersexuality in Bipolar Reddit Corpus
LDA: latent Dirichlet allocation
LIWC: Linguistic Inquiry and Word Count
LIWC-22: 2022 version of Linguistic Inquiry and Word Count
TABoRC: Talking About Bipolar on Reddit Corpus

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