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Dynamic Associations Between Centers for Disease Control and Prevention Social Media Contents and Epidemic Measures During COVID-19: Infoveillance Study

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Abstract

Background: Health agencies have been widely adopting social media to disseminate important information, educate the public on emerging health issues, and understand public opinions. The Centers for Disease Control and Prevention (CDC) widely used social media platforms during the COVID-19 pandemic to communicate with the public and mitigate the disease in the United States. It is crucial to understand the relationships between the CDC’s social media communications and the actual epidemic metrics to improve public health agencies’ communication strategies during health emergencies.

Objective: This study aimed to identify key topics in tweets posted by the CDC during the pandemic, investigate the temporal dynamics between these key topics and the actual COVID-19 epidemic measures, and make recommendations for the CDC’s digital health communication strategies for future health emergencies.

Methods: Two types of data were collected: (1) a total of 17,524 COVID-19–related English tweets posted by the CDC between December 7, 2019, and January 15, 2022, and (2) COVID-19 epidemic measures in the United States from the public GitHub repository of Johns Hopkins University from January 2020 to July 2022. Latent Dirichlet allocation topic modeling was applied to identify key topics from all COVID-19–related tweets posted by the CDC, and the final topics were determined by domain experts. Various multivariate time series analysis techniques were applied between each of the identified key topics and actual COVID-19 epidemic measures to quantify the dynamic associations between these 2 types of time series data.

Results: Four major topics from the CDC’s COVID-19 tweets were identified: (1) information on the prevention of health outcomes of COVID-19; (2) pediatric intervention and family safety; (3) updates of the epidemic situation of COVID-19; and (4) research and community engagement to curb COVID-19. Multivariate analyses showed that there were significant variabilities of progression between the CDC’s topics and the actual COVID-19 epidemic measures. Some CDC topics showed substantial associations with the COVID-19 measures over different time spans throughout the pandemic, expressing similar temporal dynamics between these 2 types of time series data.

Conclusions: Our study is the first to comprehensively investigate the dynamic associations between topics discussed by the CDC on Twitter and the COVID-19 epidemic measures in the United States. We identified 4 major topic themes via topic modeling and explored how each of these topics was associated with each major epidemic measure by performing various multivariate time series analyses. We recommend that it is critical for public health agencies, such as the CDC, to update and disseminate timely and accurate information to the public and align major topics with key epidemic measures over time. We suggest that social media can help public health agencies to inform the public on health emergencies and to mitigate them effectively.

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KEYWORDS

infoveillance; social media; COVID-19; US Centers for Disease Control and Prevention; CDC; topic modeling; multivariate time series analysis
Introduction

The COVID-19 pandemic caused more than 760 million cases and 6.8 million deaths globally as of April 2023 [1]. Therefore, it is crucial for public health agencies, such as the US Centers for Disease Control and Prevention (CDC), to quickly and effectively disseminate up-to-date and reliable health information to the public to curb the pandemic. Over the past years, social media has been widely used by various public health agencies to make announcements, disseminate information, and deliver guidelines of effective interventions to the public. The CDC is among the early adopters of social media to engage with the public, increase health literacy in the society, and promote healthy behaviors [2]. Moreover, the CDC’s social media team has developed the Health Communicator’s Social Media Toolkit to efficiently use social media platforms; map health strategies; listen to health concerns from the public; and deliver evidence-based, credible, and timely health communications in multiple formats such as texts, images, and videos. The CDC’s digital health communication efforts have been especially established on various social media platforms such as Twitter, Facebook, and Instagram.

Building successful interactions with the public relies on people understanding the content and raising awareness of it. The CDC has been heavily engaging in social media presence [3]. For example, during the COVID-19 pandemic since 2019, it has been responsive and proactive on Twitter to continuously tweet about reliable health-related messages and quickly diffuse public engagement by responding to user comments, retweeting credible sources, and monitoring online conversations in real time. Hence, it is meaningful to recognize the COVID-19 pandemic information disseminated by the CDC on social media, characterize various contents and topics, and evaluate posting patterns with regard to the actual epidemic dynamics. Monitoring the content, topics, and trends will help identify current issues or interests and the levels of interventions. It is critical to evaluate the associations between various COVID-19 content topics tweeted by the CDC and the actual COVID-19 epidemic measures (eg, cases, deaths, testing, and vaccination records). Knowing the underlying associations between the CDC’s digital health communication contents on social media and the actual COVID-19 epidemics will help in understanding and evaluating the CDC’s tweeting patterns with changes in the epidemic, and will further help in recommending more effective social media communication strategies for public health agencies accordingly.

Infodemiology and infoveillance studies tackle health challenges, generate insights, and predict patterns and trends of diseases using previously neglected online data. Infodemiology, which is the conjunction of “information” and “epidemiology,” defined by Gunther Eysenbach, is the field of distribution and determinants of information of a population through the internet or other electronic media [4]. Infoveillance takes surveillance as the primary aim and generates automated analysis from massive online data. It employs innovative computational approaches to mine and analyze unstructured online text information, such as analyzing patterns and trends, predicting potential outbreaks, and addressing current issues of public health. Unlike traditional epidemiological surveillance systems, which include cohort studies, disease registries, population surveys, and health care records, infoveillance studies discover a wide range of health topics, monitor health issues including outbreaks and pandemics, and forecast epidemiological trends in real time. A large amount of anonymous online data can be obtained in a more timely manner with these approaches than with traditional surveillance systems, and this will help researchers and public health agencies to prepare for and tackle public health emergencies and issues more efficiently and effectively.

Social media platforms have been having impacts on the community education of COVID-19 and delivering various health information about the disease. Many studies have also incorporated the concept of infoveillance by analyzing unstructured textual data obtained from social media. Liu et al [5] collected and analyzed media reports and news articles on COVID-19 to derive topics and useful information. They aimed to investigate the relationship between media reports and the COVID-19 outbreak, and the patterns of health communication on the coronavirus through mass media to the general audience. They obtained media reports and articles related to the pandemic and studied prevalent topics. There had been prevalent public discussions of attitudes and perspectives on mask-wearing on social media. Therefore, it is important for public health agencies to disseminate the supporting evidence and benefits of masking to mitigate the spread of COVID-19. Al-Ramahi et al [6] studied the topics associated with the public discourse against wearing masks in the United States on Twitter. They identified and categorized different topics in their models. These studies all applied infoveillance to investigate the potential impacts of diseases, health behaviors, or interventions on target populations, communities, and the society. However, mass media and social media are also prone to the spreading of misinformation and conspiracy theories, especially from unreliable sources [7]. Hence, the sources of information obtained from social media are crucial as misinformation could potentially create bias, mislead public perceptions, and provoke negative emotions. Official accounts of public health agencies are usually sources of unbiased and reliable health information. Although there have been several studies that collectively explored the topics discussed by the general public on social media during the pandemic, no investigations have been performed so far to identify various topics from health agencies, such as the CDC, during a large health emergency.

Furthermore, information discrepancies and delays could occur between topics posted by health agencies and real-time epidemic trends. Such discrepancies could cause confusion among the public on interventions for health emergencies. Therefore, quantifying their associations is important to reduce knowledge gaps. Chen et al [8] studied correlations between the Zika epidemic in 2016 and the CDC’s responses on Twitter. They obtained media reports and articles related to the pandemic and studied prevalent topics. There had been prevalent public discussions of attitudes and perspectives on mask-wearing on social media. Therefore, it is important for public health agencies to disseminate the supporting evidence and benefits of masking to mitigate the spread of COVID-19. Al-Ramahi et al [6] studied the topics associated with the public discourse against wearing masks in the United States on Twitter. They identified and categorized different topics in their models. These studies all applied infoveillance to investigate the potential impacts of diseases, health behaviors, or interventions on target populations, communities, and the society. However, mass media and social media are also prone to the spreading of misinformation and conspiracy theories, especially from unreliable sources [7]. Hence, the sources of information obtained from social media are crucial as misinformation could potentially create bias, mislead public perceptions, and provoke negative emotions. Official accounts of public health agencies are usually sources of unbiased and reliable health information. Although there have been several studies that collectively explored the topics discussed by the general public on social media during the pandemic, no investigations have been performed so far to identify various topics from health agencies, such as the CDC, during a large health emergency.
associations, more specifically, the CDC’s COVID-19 content topic tweeting patterns and the actual COVID-19 epidemic metrics.

While still being investigated, it is imperative to understand the dynamic associations between various content topics on social media and actual epidemic outcome metrics, which will guide health agencies to identify driving factors between the 2 and help in disseminating helpful knowledge to the public accordingly. In this study, we aimed to discover the underlying COVID-related topics posted by the CDC during different phases of the COVID-19 pandemic. We also aimed to further quantify and evaluate the dynamic associations between content topics of the pandemic and multiple COVID-19 epidemic metrics. The findings of this study will significantly increase our knowledge about the efficiency of the CDC’s health communications during the pandemic and help make further recommendations for the CDC’s social media communication strategies with the public in the future.

Methods

Data Acquisition and Preprocessing

Using the Twitter academic API (application programming interface) and search query (see search query in Multimedia Appendix 1), we retrieved a total of 17,524 English tweets posted by 7 official CDC-affiliated Twitter accounts up to January 15, 2022 (for the detailed acquisition process for CDC tweets, see Multimedia Appendix 1). We also acquired the COVID-19 epidemic metric data in the United States from the Johns Hopkins University – Center for Systems Science and Engineering (CSSE) public GitHub repository [9-11]. Four sets of important COVID-19 time series data were retrieved, including daily cumulative confirmed cases, deaths, testing, and vaccination. The data were all at the US national level. The 4 sets of original COVID-19 time series data consisted of dates and their cumulative targeted measurements. The case series set included the daily cumulative number of confirmed COVID-19 reported cases, and it had 751 records, ranging from January 22, 2020, to February 10, 2022. The death series set reported the daily cumulative number of confirmed COVID-19 death cases, and it had 908 records, ranging from January 22, 2020, to July 17, 2022. The testing data set reported the daily cumulative number of completed polymerase chain reaction (PCR) tests or other approved nucleic acid amplification tests, and it had 760 records, ranging from January 13, 2020, to February 10, 2022. The vaccination data set included the daily cumulative number of people who received a complete primary series of vaccine doses from the CDC Vaccine Tracker, and it had 428 records, ranging from December 10, 2020, to February 10, 2022.

For consistency in subsequent analyses, all CDC tweet time series and US COVID-19 variable time series were standardized to the same time span in this study, ranging from the start date of reported case data (January 22, 2020) to the end date of CDC tweet collection (January 15, 2022), with a total of 725 records for each data type. Since vaccination data were not available until late 2020, missing values were filled with zeros. In summary, we had 4 time series from 4 different COVID-19 US epidemic metrics and another time series of number of tweets from all 7 CDC-associated Twitter accounts.

Natural Language Processing

In order to identify major topics in the CDC’s COVID-19 tweets, we performed various natural language processing (NLP) steps. NLP, especially topic modeling, provides granular characterization of textual inputs such as the CDC’s COVID-19 communications.

Regular expressions were first applied to process tweet texts by removing @mentions, hashtags, special characters, emails, punctuations, URLs, and hyperlinks. Tokenization was performed to break down sentences into individual tokens, which can be individual words or punctuations. For example, the sentence “As COVID19 continues to spread, we must remain vigilant” becomes tokens of “As,” “COVID19,” “continues,” “to,” “spread,” “,” “we,” “must,” “remain,” and “vigilant” after tokenization. Next, lemmatization, a structural transformation where each word or token is turned to its base or dictionary form of the morphological information, was performed. For example, for words “studies” and “studying,” the base form, or lemma, was the same “study.” In addition to stop word removal via the Python NLTK library, we created our own list of stop words and removed them from the texts (see the stop words list in Multimedia Appendix 1). With help from domain experts, we excluded stop words that did not contribute to topic mapping.

N-grams, phrases with n words, were developed with a threshold value of 1 to form phrases from tweets. Phrase-level n-grams were applied here because phrases offer more semantic information than individual words [12]. A higher threshold value resulted in fewer phrases to be formed. The texts were mapped into a dictionary of word representations, which was a list of unique words, and it was then used to create bag-of-words presentations of the texts. A term frequency-inverse document frequency (TF-IDF) model was implemented to evaluate the importance and relevancy of the words to a document. It was calculated by multiplying term frequency, which is the relative frequency of a word within a document, with inverse document frequency, which measures how common or rare a word is across a corpus. A higher TF-IDF value indicates that the word is more relevant to the document it is in [13,14]. Words that were missing and lower than the threshold value of 0.005 from the TF-IDF model were excluded. Table 1 shows the process of data collection and preprocessing, and Table 2 shows the steps of subsequent NLP and statistical analyses.
Table 1. Data collection and preprocessing.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Data collection</th>
<th>Data preprocessing</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDC&lt;sup&gt;a&lt;/sup&gt; tweets</td>
<td>• Twitter API&lt;sup&gt;b&lt;/sup&gt; using a search query</td>
<td>• Remove @mentions, hashtags, special characters, emails, punctuations, URLs, and hyperlinks</td>
</tr>
<tr>
<td></td>
<td>• 17,524 English tweets by January 15, 2022</td>
<td>• Tokenization: break down sentences into individual tokens</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Lemmatization: each word or token is turned to its base or dictionary form</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Remove a list of stop words created by research experts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• N-grams: form phrases from the tweets</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Modify the date range: January 22, 2020 (the start date of reported case data) to January 15, 2022 (the end date of CDC tweets)</td>
</tr>
<tr>
<td>COVID-19 epidemic metrics</td>
<td>• Public GitHub repository of the CSSE&lt;sup&gt;c&lt;/sup&gt; at Johns Hopkins University</td>
<td>• Standardize metric time series to be the same as that of CDC tweets</td>
</tr>
<tr>
<td></td>
<td>• Confirmed case count: 751 records; January 22, 2020, to February 10, 2022</td>
<td>• Fill missing values in the vaccination data with zeros</td>
</tr>
<tr>
<td></td>
<td>• Death count: 908 records; January 22, 2020, to July 17, 2022</td>
<td>• 725 records for each of the 4 metric series</td>
</tr>
<tr>
<td></td>
<td>• Completed COVID-19 tests: 760 records; January 13, 2020, to February 10, 2022</td>
<td>• Turn cumulative records to daily records</td>
</tr>
<tr>
<td></td>
<td>• Complete vaccination: 428 records; December 10, 2020, to February 10, 2022</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>CDC: Centers for Disease Control and Prevention.
<sup>b</sup>API: application programming interface.
<sup>c</sup>CSSE: Center for Systems Science and Engineering.

Table 2. Subsequent analyses.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Topic modeling</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDC&lt;sup&gt;a&lt;/sup&gt; tweets and COVID-19 metrics</td>
<td>• Construct an LDA&lt;sup&gt;b&lt;/sup&gt; topic model using CDC tweets assigning 4 topics</td>
<td>• Domain experts examine topic keywords with randomly sampled tweets in iteration</td>
</tr>
<tr>
<td></td>
<td>• Extract generated topics with their top 10 unique associated keywords</td>
<td>• Domain experts determine the theme of each topic</td>
</tr>
<tr>
<td></td>
<td>• Produce interactive visualizations using pyLDAvis</td>
<td>• Perform multivariate time series analyses between each topic time series and each COVID-19 metric time series:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. Visualization</td>
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<tr>
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<td>2. Cross-correlation function (CCF)</td>
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<td>3. Mutual information (MI)</td>
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<td></td>
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<td>4. Autoregressive integrated moving average with external variable (ARIMAX) model</td>
</tr>
</tbody>
</table>

<sup>a</sup>CDC: Centers for Disease Control and Prevention.
<sup>b</sup>LDA: latent Dirichlet allocation.

**Topic Modeling With Latent Dirichlet Allocation**

To identify more specific topics from all the COVID-19 tweets posted by the CDC, we performed topic modeling via latent Dirichlet allocation (LDA). LDA automatically generates nonoverlapping clusters of words (ie, clusters of words based on their distributions in their corresponding topics) that represent different topics based on probabilistic distributions across the whole corpus (ie, all CDC tweets in this study). LDA was developed to find latent, hidden topics from a collection of unstructured documents or a corpus consisting of multiple documents. The details of LDA and topic models are provided in Multimedia Appendix 1. We investigated and compared across 3 to 8 potential topics and determined the optimal number of topics based on both topic model evaluation and domain expert interpretations of the identified topic clusters.

Model perplexity and topic coherence scores were calculated as performance metrics of LDA. Perplexity is a decreasing “held-out log-likelihood” function that assesses LDA performance using a set of training documents. The trained LDA model is then used to test documents (held-out set). The perplexity of a probability model $q$ on how well it predicts a set of samples $x_1, x_2, ..., x_N$ drawn from an unknown probability distribution $p$, is defined as follows [15]:

$$
\text{Perplexity} = 2^\frac{\sum_{i=1}^{N} \log q(x_i)}{N}
$$

An ideal $q$ should have high probabilities $q(x_i)$ for the new data. Perplexity decreases as the likelihood of the words in new data...
increases. Therefore, lower perplexity indicates better predictability of an LDA model.

Topic coherence assesses the quality of the topics, which is measured as the understandability and semantic similarities between high scoring words (ie, the words that have a high probability of occurring within a particular topic) in topics generated by LDA [16]. We used the UMass coherence score [17], which accounts for the order of a word appearing among the top words in a topic. It is defined as follows [18]:

$$P(w_i, w_j) = \frac{P(w_i, w_j)}{P(w_i)P(w_j)}$$

where \( N \) is the number of top words of a topic of a sliding window, \( P(w_i) \) is the probability of the \( i \)th word \( w \) appearing in the sliding window that moves over a corpus to form documents, and \( P(w_i, w_j) \) is the probability of words \( w_i \) and \( w_j \) appearing together in the sliding window. According to the study from UMass, coherence decreases initially and becomes stationary as the number of topics increases [16].

Representations of all topics were presented in word-probability pairs for the most relevant words grouped by the topics. Interactive visualizations were produced using the pyLDAvis package in Python 3.7 to examine the topics generated by LDA and their respective associated keywords. A data frame of all dominant key topics was created. The original unprocessed full texts of the CDC tweets, IDs, and posting dates were combined into a data frame along with their corresponding key topic number labels and topic keywords. In addition, the daily percentage of each topic from LDA was calculated for further time series analysis. For instance, vaccine/vaccination is an identified key topic, so the percentage of vaccine-related CDC tweets on each day was calculated for the entire study period to construct the vaccine/vaccination-specific topic time series.

Since LDA is technically an unsupervised clustering method, after the topics or clusters of word distributions from the CDC’s tweets were generated using LDA, domain experts were involved to further label and interpret the content of the topics using domain knowledge. We randomly generated 20 sample tweets from each topic using Python for domain experts to examine, analyze, and determine the themes of the topics. For each topic, LDA provided a list of the top keywords associated with that topic, and we selected the top 10 keywords. We examined these keywords and referred to the 20 sample tweets, and then derived a theme or context that encompasses these keywords and the original tweets through further discussions, which was important for understanding the context in which these words were used. The final agreement on the interpretation of LDA-generated topics was reached after multiple iterations and discussions of the above process.

**Multivariate Time Series Analyses Between Identified CDC Tweet Topics and COVID-19 Epidemic Metrics**

**Data Preparation**

Key topic time series data were derived from the previous NLP and LDA processes. We constructed a multivariate data frame with posting dates and number of tweets for each key topic at a daily resolution. Since LDA identified 4 key topics, a total of 4 CDC key topic time series were developed. There were also 4 US COVID-19 epidemic metric time series: daily cumulative reported cases, cumulative confirmed deaths, cumulative number of completed PCR tests or other approved nucleic acid amplification tests, and cumulative number of people who received a complete primary series of vaccines. These 4 sets of COVID-19 epidemic metric time series were then converted to daily measures via first order differencing. Multivariate time series analyses were implemented to investigate the associations between time series of key CDC tweet topics and US COVID-19 epidemic metrics.

**Visualizations**

Both types of time series, CDC key topics and COVID-19 metrics, were visually inspected in the same plot on double y-axes, with the left y-axis displaying the daily COVID-19 metric and right y-axis displaying the daily CDC tweet topic count. In addition, each plot was further divided based on COVID-19 phases with different dominant variants: the original, Alpha, Delta, and Omicron variants, with their corresponding starting dates: March 11, 2020; December 29, 2020; June 15, 2021; and November 30, 2021, respectively. This helps further observe and identify dynamic changes of time series and their associations during different phases of the pandemic.

**Cross-Correlation Function**

Between 2 time series (also known as signals \( X \) and \( Y \)), the cross-correlation function (CCF) [19] quantifies their levels of similarities (ie, how similar the 2 series are at different times), their associations (ie, how values in one series can provide information about the other series), and when they occur [20]. The CCF takes the sum of the product for each of the \( x \) and \( y \) data points at time lag \( l \), defined as follows [19]:

$$\text{CCF} = \sum_{i=1}^{N} x_i y_{i-l}$$

where \( N \) is the number of observations in each time series, and \( x_i \) and \( y_i \) are the observations at the \( i \)th time step in each of the time series. The CCF ranges from –1 to 1, and a larger absolute value of the CCF is related to a greater association shared by the 2 time series at a given time lag \( l \) [21]. In this study, each of the 4 CDC tweet topic time series was compared with each of the 4 COVID-19 epidemic metric time series to calculate their respective CCFs. All CCF values were calculated with a maximum lag of 30 days, as we assumed that the real-world epidemic could not influence online discussions for more than a month and vice versa.

**Mutual Information**

Mutual information (MI) was calculated by computing the entropy of the empirical probability distribution to further quantify the association between each of the 4 key CDC tweet topics and each of the 4 US COVID-19 epidemic metrics. MI measures the amount of mutual dependence or average dependency between 2 random variables \( X \) and \( Y \). It is defined as follows [22]:

$$\text{MI}(X, Y) = \sum_{i} \sum_{j} P(x_i, y_j) \log \frac{P(x_i, y_j)}{P(x_i)P(y_j)}$$

where \( x_i \) and \( y_i \) are the \( i \)th elements of the variables \( X \) and \( Y \), respectively. When applied to time series data, \( X \) and \( Y \) are 2
individual time series and \( x_t \) and \( y_t \) are their respective observations at the \( t \)th time step. Note that MI is a single value instead of a function over lag \( l \) as in the CCF. A larger MI value indicates a higher shared mutual dependency between the 2 time series.

**Autoregressive Integrated Moving Average With External Variable**

Neither the CCF nor MI differentiate dependent and independent variables, that is, the formula was symmetric with regard to \( X \) and \( Y \) variables. We further evaluated whether the CDC tweeting topics were influenced by real-world COVID-19 epidemic outcomes. An autoregressive integrated moving average with external variable (ARIMAX) model was constructed to fit each of the 4 CDC topics with each of the 4 COVID-19 epidemic metrics during the entire study period. A univariate autoregressive integrated moving average (ARIMA) model fits and forecasts time series data with the integration of an autoregressive (AR) component and a moving average (MA) component with their respective orders/lags (see Multimedia Appendix 1 for detailed information about the AR model). The ARIMA model consists of both AR\((p)\) and MA\((q)\) as well as an order \( d \) differencing term, resulting in the following ARIMA \((p, d, q)\) model [23, 24]:

\[
(1 - B)^d y_t = \phi_1 (1 - B)^p x_t + \theta_1 \epsilon_t + \epsilon_t
\]

or in backward shift operator form:

\[
\epsilon_t - \theta_1 \epsilon_{t-1} = \phi_1 \epsilon_{t-p} + (1 - B)^p x_t
\]

See Multimedia Appendix 1 for details on the parameters.

The ARIMAX model further extends ARIMA to the multivariate time series by incorporating at least one exogenous independent variable \( x_r \). ARIMAX \((p, d, q)\) is specified as follows [25]:

\[
(1 - B)^d y_t = \phi_1 (1 - B)^p x_t + \theta_1 \epsilon_t + \epsilon_t
\]

or in backward shift operator form [26]:

\[
\epsilon_t - \theta_1 \epsilon_{t-1} = \phi_1 \epsilon_{t-p} + (1 - B)^p x_t
\]

where \( \phi_1 \) contributes to the exogeneous independent variable that could potentially influence the dependent variable \( y_t \).

In this study, ARIMAX was developed to evaluate how real-world epidemic metrics, modeled as exogeneous variables, impact CDC tweet topic dynamics as dependent variables. Each of the 4 CDC tweet topics was modeled as a dependent variable \( (y_t) \) and each of the 4 COVID-19 epidemic measures was an independent exogeneous variable \( (x_i) \). The optimal ARIMA and ARIMAX model parameter set \((p, d, q)\) was determined by the \( R \) ARIMA model package.

In addition to reporting the values of the ARIMAX model parameter set \((p, d, q)\), difference in Akaike information criterion (dAIC), root mean square error (RMSE), and mean absolute error (MAE) were also computed to compare different ARIMAX performances. The optimal model was the one with the lowest AIC score. dAIC was computed in between 2 models (see Multimedia Appendix 1 for detailed information on AIC). We had an ARIMA model of a single topic time series and an ARIMAX model of that topic time series with an exogeneous variable. Negative dAIC values indicated that the ARIMAX model showed improvement in model performance over the ARIMA counterpart that did not include an exogeneous variable.

The commonly used RMSE and MAE were adopted as performance metrics. They are defined as follows [27]:

\[
RMSE = \sqrt{\frac{1}{n} \sum_{i=1}^{n} (y_i - \hat{y}_i)^2}
\]

\[
MAE = \frac{1}{n} \sum_{i=1}^{n} |y_i - \hat{y}_i|
\]

where \( n \) is the number of data points in a sample \( (y_i, \) where \( i=1, 2, \ldots, n \). RMSE and MAE are Euclidean distance and Manhattan distance in high-dimensional space, respectively.

**Results**

**Topic Modeling and Content Results**

A total of 17,524 English tweets posted by the CDC were retrieved and analyzed. Four key topics were generated via LDA based on evaluation metrics including perplexity and coherence score. These topics were then examined and categorized to themes by domain experts (Textbox 1 with example tweets with their respective topics). The themes of the topics and their top 10 unique associated keywords are presented in Table 3.

Topics were plotted as circles and displayed on the left panel; the most relevant terms or associated keywords with their corresponding topics were displayed in frequency bars on the right panel, which showed each term’s frequency from each topic across the corpus (ie, all CDC COVID-19 tweets sampled) [28] (see Multimedia Appendix 1 for more detailed information about visualizations in the pyLDAvis package). The size of the circle indicated the prevalence of that topic in the corpus. Visualizations for all topics, displayed in circles on the left panel, and their top 15 corresponding relevant terms or associated keywords, displayed in frequency bars on the right panel, are provided in Figures S1-S5 in Multimedia Appendix 1. Based on the LDA visualization results, these 4 identified key topics had the largest distances and minimal dimensional overlap in the reduced 2D plane. From a public health perspective, the CDC’s online health communication of COVID-19, the largest health emergency in the 21st century, has been relatively cohesive and comprehensive. Therefore, the 4 key topics identified via LDA were not completely mutually exclusive. In addition, the 4-topic model had the balance of separation of topics from a computational perspective and clear interpretability from a health perspective. Increasing the number of topics yields a substantial amount of topic overlap, which was also challenging to provide explicit and clear interpretations. Figure 1 illustrates an example of topic 4 [29,30]. A list of associated terms of topic 4 and the overall frequency of the terms in the corpus have been displayed in the right panel. The 5 key terms from topic 4 based on overall frequency across all tweets were “booster,” “school,” “increase,” “parent,” and “country.”
Textbox 1. Example tweets from each topic theme.

**Topic 1: General vaccination information and education, especially preventing adverse health outcomes of COVID-19**
- “Even as the world’s attention is focused on #COVID19, this week we are taking time to highlight how #VaccinesWork and to thank the heroes who help develop and deliver lifesaving vaccines. #WorldImmunizationWeek message”
- “CDC’s #COVID19 Vaccine Webinar Series is a great place to start learning about a variety of topics around COVID-19 vaccination.”
- “The #DeltaVariant of the virus that causes #COVID19 is more than two times as contagious as the original strain. Wear a mask indoors in public, even if vaccinated and in an area of substantial or high transmission. Get vaccinated as soon as you can.”

**Topic 2: Pediatric intervention, pediatric vaccination information, family safety, and school and community protection**
- “Make #handwashing a family activity! Explain to children that handwashing can keep them healthy. Be a good role model—if you wash your hands often, your children are more likely to do the same. #COVID19”
- “Parents: During #COVID19, well-child visits are especially important for children under 2. Schedule your child’s routine visit, so the healthcare provider can check your child’s development & provide recommended vaccines.”
- “It is critically important for our public health to open schools this fall. CDC resources will help parents, teachers and administrators make practical, safety-focused decisions as this school year begins.”

**Topic 3: Updates on COVID-19 testing, case, and death data, and relevant information of the disease**
- “CDC tracks 12 different forecasting models of possible #COVID19 deaths in the US. As of May 11, all forecast an increase in deaths in the coming weeks and a cumulative total exceeding 100,000 by June 1. See national & state forecasts.”
- “The latest CDC #COVIDView report shows that the percentage of #COVID19-associated deaths has been on the rise in the United States since October and has now surpassed the highest percentage seen during summer.”
- “#COVID19 cases are going up dramatically. This increase is not due to more testing. As the number of cases rise, so does the percentage of tests coming back positive, which shows that COVID-19 is spreading.”

**Topic 4: Research, study, health care, and community engagement to curb COVID-19**
- “Our Nation’s medical community has been vigilant and their help in identifying confirmed cases of #COVID19 in the United States to date has been critical to containing the spread of this virus.”
- “In a new report using data from Colombia, scientists found that pregnant women with symptomatic #COVID19 were at higher risk of hospitalization & death than nonpregnant women with symptomatic COVID-19. HCPs can inform pregnant women about how to stay safe.”
- “A new study finds masking and fewer encounters or less time close to persons with #COVID19 can limit the spread in university settings. #MaskUp when inside indoor public places regardless of vaccination status.”

Table 3. Identified key topics of Centers for Disease Control and Prevention tweets with unique focal keywords.

<table>
<thead>
<tr>
<th>Key topics</th>
<th>Top 10 unique keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General vaccination information and education, especially preventing adverse health outcomes of COVID-19 (including cases, severe conditions/hospitalization, and death)</td>
<td>learn, time, safe, fully vaccinate, prevent, child age, old, share, flu, month</td>
</tr>
<tr>
<td>2. Pediatric intervention, pediatric vaccination information, family safety, and school and community protection</td>
<td>work, school, datum, test, infection, family, free, home, public, check</td>
</tr>
<tr>
<td>3. Updates on COVID-19 testing, case, and death data, and relevant information of the disease</td>
<td>patient, update, booster, cause, recommend, increase, day, program, important, read</td>
</tr>
<tr>
<td>4. Research, study, health care, and community engagement to curb COVID-19</td>
<td>vaccination, vaccinate, child, protect, protection, report, visit, risk, community, travel</td>
</tr>
</tbody>
</table>
Multivariate Time Series Analysis Results

CCF Results

The time series of CDC tweet topics and COVID-19 metrics were plotted to visually examine patterns and potential associations. A total of 16 time series plots (4 topics × 4 COVID-19 epidemic metrics) were generated (Figures S14-S29 in Multimedia Appendix 1). CCFs were computed to quantify the dynamic association between each CDC key topic series and each of the 4 COVID-19 epidemic metrics. Quantitative results have been presented (Tables S3-S6 in Multimedia Appendix 1). Visualizations (Figures S30-S44 in Multimedia Appendix 1) illustrated CCFs between both types of time series. CCF values and plots showed that the CDC’s key COVID-19 tweet topic series was not substantially correlated with the confirmed COVID-19 case count series. As an example, there were no specific patterns between topic 2 and daily confirmed COVID-19 cases (Figure 2A).

COVID-19 confirmed cases and the death time series had very similar dynamic patterns in the United States across the time span (Figure 2B). Consequently, they also showed similar CCFs with the CDC key topic series (Figure S45 in Multimedia Appendix 1). COVID-19 deaths had no substantial correlations with any of the 4 CDC key topics (Figures S18-S21 in Multimedia Appendix 1) based on CCFs. There were no substantial correlations between any of the 4 key topics and the COVID-19 testing series as well as the fully vaccinated rate series. Examples showed the CCFs between those and topic 2 (Figures 3 and 4). These results indicated a potential discrepancy between the CDC’s health communication focus and the actual COVID-19 epidemic dynamics in the United States during the pandemic.
**Figure 2.** Time series of topic 2 against 2 COVID-19 metrics: (A) case counts, (B) death counts. CDC: Centers for Disease Control and Prevention; US: United States.

**Figure 3.** Cross-correlation function (CCF) between the completed COVID-19 test series and topic 2 tweets. (A) Trends of CDC tweet topics and number of completed tests; (B) CCF between COVID-19 confirmed cases and topic 2 tweets. CDC: Centers for Disease Control and Prevention.
MI Results
MI values between each CDC tweet topic and each COVID-19 metric were calculated, and they are shown in Table 4. Confirmed case counts and topic 4 (research, health care, and community engagement to restrain COVID-19) had the highest MI value (3.21), indicating there was a strong dependency in COVID-19 cases and topic 4. On the other hand, the vaccination rate and topic 3 had the lowest MI value (0.56), indicating almost independence between the 2 series. Among all 4 key topics, topic 4 showed the highest MI values (3.21, 3.02, 3.21, and 1.65) with the 4 COVID-19 metrics. Topic 2 (pediatric intervention, family safety, and school and community protection) had consistently lower MI values with the COVID-19 metric than topic 4. The MI of topic 1 (information on COVID-19 vaccination and education on preventing its adverse health outcomes) and topic 3 (updates on COVID-19 testing, case, and death metrics, and relevant information of the disease) showed similar values with all 4 COVID-19 metrics, although the MI values of topic 1 were slightly higher. Vaccination and educational information on the adverse health outcomes of COVID-19 appeared to not be substantially correlated with COVID-19 epidemic metrics, including testing, cases, and deaths. We speculated that the CDC considered both vaccination and preventing adverse health outcomes of COVID-19 critical to public health and disseminated these topics regardless of the current COVID-19 situation at the time of posting.

In addition, MI values between all pairs of CDC topics were calculated (Table S7 in Multimedia Appendix 1). The resulting MI values, ranked from the largest to smallest, were for topics 2 and 4, topics 3 and 4, topics 1 and 2, topics 2 and 3, topics 1 and 4, and topics 1 and 3. Based on the CDC’s COVID-19 tweeting patterns, pediatric intervention and family and community safety were strongly associated with health care research studies and public engagement to curb the spread of COVID-19.

Table 4. Mutual information values between Centers for Disease Control and Prevention key topics and COVID-19 metrics in the United States.

<table>
<thead>
<tr>
<th>COVID-19 daily measurements in the United States</th>
<th>Topic 1a</th>
<th>Topic 2b</th>
<th>Topic 3c</th>
<th>Topic 4d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirmed case counts</td>
<td>1.25</td>
<td>2.93</td>
<td>1.18</td>
<td>3.21</td>
</tr>
<tr>
<td>Death counts</td>
<td>1.12</td>
<td>2.74</td>
<td>1.06</td>
<td>3.02</td>
</tr>
<tr>
<td>Completed COVID-19 test counts</td>
<td>1.24</td>
<td>2.91</td>
<td>1.18</td>
<td>3.21</td>
</tr>
<tr>
<td>Fully vaccinated counts</td>
<td>0.60</td>
<td>1.49</td>
<td>0.56</td>
<td>1.65</td>
</tr>
</tbody>
</table>

aTopic 1: General vaccination information and education, especially preventing adverse health outcomes of COVID-19.
bTopic 2: Pediatric intervention, pediatric vaccination information, family safety, and school and community protection.
cTopic 3: Updates on COVID-19 testing, case, and death data, and relevant information of the disease.
dTopic 4: Research, study, health care, and community engagement to curb COVID-19.

ARIMAX Results
ARIMAX performance measures, including values of ARIMAX parameters (p, d, q), dAIC, RMSE, and MAE, are reported in Table 5. As an external input, the vaccination rate time series significantly improved the performances of the original ARIMA models for all CDC key topics (dAIC = −108.15, −69.79, −90.54, and −91.53 for topics 1 to 4, respectively). This was the largest increase in model performance across all topics with the exogeneous variable in the ARIMAX model. The COVID-19 case series improved the ARIMA model performance for CDC topics 1 and 3 (dAIC = −104.76 and −1.53 for topics 1 and 3, respectively). Including the death or testing series did not result in substantial improvements to the ARIMA model performance for all CDC key topics.

ARIMAX models with lower RMSE and MAE values indicated higher accuracy of the time series models (Table 5). Overall, ARIMAX models for topics 1 and 3 with all COVID-19 metrics delivered the smallest RMSE values (lowest [1.10] for topic 3 with death counts and highest [1.21] for topic 1 with full vaccination records), while those of topic 4 delivered the largest
RMSE values (lowest [6.25] with death counts and highest [6.93] with full vaccination records). Similarly, MAE values were the lowest for ARIMAX models for topics 1 and 3 with the epidemic metrics (lowest [0.82] for topic 3 with death counts and highest [0.91] for topic 1 with full vaccination records), and they were the largest for topic 4 with the epidemic metrics (lowest [4.97] with death counts and highest [5.56] with full vaccination records). These ARIMAX performance results showed significant variabilities between the 2 types of time series (CDC key tweet topics and actual COVID-19 metrics in the United States).

We performed an exhaustive search to identify the optimal ARIMAX parameters ($p, d, q$). For example, topic 1 with death counts and completed testing records had the same parameter set ($p, d, q=2, 1, 3$), indicating that the optimal ARIMAX model between these time series needed first-order differencing ($d=1$) to achieve stationarity and minimal AIC values, its AR time lag was 2 ($p=2$), and its MA time lag was 3 ($q=3$). The topic 1 series with case counts and complete vaccination had the same parameter values ($p, d, q=5, 1, 0$), indicating that the model was simply an AR model ($q=0$ with no MA terms) with a time lag of 5 ($p=5$) after first-order differencing ($d=1$). The complete ARIMAX parameters are shown in Table 5. All ARIMAX models needed first-order differencing ($d=1$) to be stationary and to minimize AIC values.
Table 5. Autoregressive integrated moving average with external variable performance measures of each Centers for Disease Control and Prevention topic and COVID-19 epidemic metric pair.

<table>
<thead>
<tr>
<th>COVID-19 epidemic measures and ARIMAX metrics</th>
<th>Topic 1b</th>
<th>Topic 2c</th>
<th>Topic 3d</th>
<th>Topic 4e</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case counts</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ARIMAX parameters (p, d, q)</td>
<td>(5, 1, 0)</td>
<td>(4, 1, 1)</td>
<td>(2, 1, 1)</td>
<td>(3, 1, 2)</td>
</tr>
<tr>
<td>dAIC</td>
<td>-108.15b (2240.19, 2348.34)</td>
<td>0.45 (4304.09, 4303.64)</td>
<td>-90.54b (2227.59, 2318.13)</td>
<td>-91.53b (4785.89, 4877.42)</td>
</tr>
<tr>
<td>RMSE</td>
<td>1.21</td>
<td>4.66</td>
<td>1.12</td>
<td>6.45</td>
</tr>
<tr>
<td>MAE</td>
<td>0.91</td>
<td>3.66</td>
<td>0.86</td>
<td>5.10</td>
</tr>
<tr>
<td><strong>Death counts</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ARIMAX parameters (p, d, q)</td>
<td>(2, 1, 3)</td>
<td>(4, 1, 1)</td>
<td>(2, 1, 1)</td>
<td>(3, 1, 2)</td>
</tr>
<tr>
<td>dAIC</td>
<td>6.72 (2240.19, 2233.47)</td>
<td>36.60 (4304.09, 4267.49)</td>
<td>19.56 (2227.59, 2225.76)</td>
<td>36.97 (4785.89, 4748.92)</td>
</tr>
<tr>
<td>RMSE</td>
<td>1.12</td>
<td>4.56</td>
<td>1.10</td>
<td>6.25</td>
</tr>
<tr>
<td>MAE</td>
<td>0.84</td>
<td>3.57</td>
<td>0.82</td>
<td>4.97</td>
</tr>
<tr>
<td><strong>Testing</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ARIMAX parameters (p, d, q)</td>
<td>(2, 1, 3)</td>
<td>(4, 1, 1)</td>
<td>(0, 1, 2)</td>
<td>(3, 1, 2)</td>
</tr>
<tr>
<td>dAIC</td>
<td>0.13 (2240.19, 2240.06)</td>
<td>19.56 (4304.09, 4284.53)</td>
<td>1.13 (2227.59, 2225.76)</td>
<td>36.97 (4785.89, 4748.92)</td>
</tr>
<tr>
<td>RMSE</td>
<td>1.13</td>
<td>4.60</td>
<td>1.11</td>
<td>6.34</td>
</tr>
<tr>
<td>MAE</td>
<td>0.84</td>
<td>3.61</td>
<td>0.85</td>
<td>4.99</td>
</tr>
<tr>
<td><strong>Vaccination</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ARIMAX parameters (p, d, q)</td>
<td>(5, 1, 0)</td>
<td>(5, 1, 0)</td>
<td>(5, 1, 0)</td>
<td>(5, 1, 0)</td>
</tr>
<tr>
<td>dAIC</td>
<td>-108.15b (2240.19, 2348.34)</td>
<td>-69.79b (4304.09, 4373.88)</td>
<td>-90.54b (2227.59, 2318.13)</td>
<td>-91.53b (4785.89, 4877.42)</td>
</tr>
<tr>
<td>RMSE</td>
<td>1.21</td>
<td>4.90</td>
<td>1.18</td>
<td>6.93</td>
</tr>
<tr>
<td>MAE</td>
<td>0.91</td>
<td>3.81</td>
<td>0.89</td>
<td>5.56</td>
</tr>
</tbody>
</table>

aARIMAX: autoregressive integrated moving average with external variable.
bTopic 1: General vaccination information and education, especially preventing adverse health outcomes of COVID-19.
cTopic 2: Pediatric intervention, pediatric vaccination information, family safety, and school and community protection.
dTopic 3: Updates on COVID-19 testing, case, and death data, and relevant information of the disease.
eTopic 4: Research, study, health care, and community engagement to curb COVID-19.
fARIMAX parameters (p, d, q).
gdAIC: delta Akaike information criterion (AIC) or difference in AIC.
hNegative dAIC: indicates improvement of performance in the ARIMAX model compared with its autoregressive integrated moving average (ARIMA) model.
iAIC values of ARIMA and its corresponding ARIMAX models.
jRMSE: root mean square error.
kMAE: mean absolute error.

Discussion

Principal Findings

In this study, we systematically investigated and comprehensively identified the CDC’s key topics, COVID-19 epidemic metrics, and dynamic associations between the 2 types of data series based on 17,524 COVID-related English tweets from the CDC since January 2022. The LDA topic model was built to characterize and identify the dynamic shifts of topics in the CDC’s COVID-19 communication over a period of more than 2 years. For the first time, we were able to identify the following 4 key topics: (1) general vaccination information and education; (2) pediatric intervention that also involved family and school safety; (3) updates on the COVID-19 epidemic situation, such as numbers of cases, deaths, etc; and (4) research studies that were able to curb the pandemic.

Our study took a unique approach of infoveillance by identifying potential associations between COVID-19 epidemic outcome metrics in the United States and the CDC’s key topic dynamics during different stages of the pandemic. This innovative
framework significantly expanded the original infoveillance approach that generally relied on the number of posts (ie, posting dynamics) without further extracting more detailed and meaningful content topics and sentiments from the textual data. Our study was able to further provide practical and useful health communication strategies for public health agencies to effectively communicate timely and accurate information to the public. It is important to investigate the dynamic associations between the CDC’s tweets on COVID-19 and the progression of the pandemic for several reasons:

1. Understanding their relationship can reveal how public health messaging impacts public perception and engagement at different stages of a major health emergency. A strong association between the CDC’s tweets and epidemic measures indicates that public health messaging is effective. Weak associations might indicate that messaging from the CDC to the public over time is not effective; however, it will lead us to further explore the influential factors and provide health communication strategies for public health agencies.

2. It can also show if the CDC’s messaging on Twitter is proactive or reactive to the actual epidemic, informing strategies for future public health communication.

3. It helps public health agencies better allocate resources. For example, if tweets related to educating the public on monitoring COVID-19 symptoms and updating certain metrics lead to an increase in the number of people trying to get COVID tests, then resources could be directed toward opening testing centers and sending free test kits to homes.

Our study is the first of its kind to comprehensively evaluate the impact of online public health communication, especially on Twitter, which is one of the major social media platforms, during different phases of a large health emergency. We studied the overall daily volume of COVID-19–related tweets posted by the CDC over time as a baseline (Figure 5), and the volume of tweets was higher in the early phase of the pandemic, indicating a strong effort at the CDC to disseminate important information to the public. We did not observe visually clear patterns of an association with COVID-19 epidemic measures. We further applied novel NLP to significantly reduce the gap of previous studies that overlooked the dynamic association between detailed topics discussed by public health agencies on social media and real-world epidemic metrics.

We then examined the dynamic associations between the 4 identified key topics and 4 COVID-19 epidemic outcome metrics. Among the 4 major topics, topic 1, which covered information on vaccination and adverse health outcomes of COVID-19, had substantially strong associations with death counts and testing records during the Alpha phase (December 29, 2020, to June 14, 2021). We found that during this phase, when the overall vaccination-related CDC tweets were decreasing, the daily vaccination rate (number of people who received a complete primary series of the COVID-19 vaccine based on the CDC Vaccine Tracker) was increasing, which aligned with the CDC’s effort in emphasizing the importance of vaccination to the public on social media. When discussions from the CDC about vaccination were increasing after the Alpha phase, the vaccination rate started to decrease. The reasons could be but are not limited to the following:

1. Ineffective messaging from the CDC on social media to the public during later stages of the pandemic.
2. Lack of engagement from the public, since not everyone follows or engages with official accounts and might miss or overlook them amidst other content.
3. Fatigue from information overload where frequent data updates on social media platforms can lead to desensitization, making it less likely for users to pay attention over time and act on the information.
4. Temporal delays create time lag, which can impact the associations between the topics and the real epidemic measures.
5. Political factors such as antivaccination groups.

Therefore, with all possible influential factors, the CDC could not fully impact the public’s responses and actions on getting vaccinated even though they had been making efforts on sharing educational information about vaccination. This finding showed that the CDC had been making efforts to emphasize the importance of vaccination on Twitter, but the public response was weak. Thus, it is important to further study the influential factors for the CDC’s social media strategies. Topic 3, which provided updates on 3 of the COVID-19 measures (testing, cases, and deaths) and their relevant information, aligned better with the case series during the Delta phase (June 15, 2021, to November 29, 2021). It also matched with the death series during the declared pandemic phase (original variant: March 11, 2020, to December 28, 2020) and Delta phase, classified by the World Health Organization on May 11, 2021. Furthermore, even though topic 3 did not demonstrate a visible association with the testing series, timely communication from the CDC was actually strongly associated with the testing time series over the entire study period based on the multivariate time series analysis.

According to these key findings, we suggest that aligning the content topics of health communication from public health agencies with the temporal dynamics of COVID-19 or other emerging public health emergencies (eg, major epidemic outcome metrics) can help provide more timely and relevant information to the public. Therefore, we recommend that the CDC and other public health agencies monitor the epidemic outcome metrics in real time. Health agencies can then post timely updates about the emergency, most recent findings, and interventions on social media according to the dynamic changes of these outcome metrics. Public health agencies can regain trust from the public by not only helping the public better understand the complex dynamics of the health emergency, but also informing the public with evidence-based guidance and recommendations more effectively.
Limitations and Future Work

There are several limitations in this infodemiology study that could be improved in future work. First, while we focused on probabilistic-based LDA for topic modeling, there are other alternative NLP approaches such as deep learning–based bidirectional encoder representations from transformers (BERT). Hence, we will explore BERT and other state-of-the-art NLP techniques for content topic modeling and sentiment analysis in the future. Second, given the complexity of this study, we will incorporate subthemes to further help contextualize the clusters in future work. Third, the CDC does not have the sole power of controlling people’s responses and actions over time (eg, getting tested and receiving full vaccine doses), even with consistent effort on Twitter to educate the public and mitigate the pandemic. There are other factors that could affect the associations between the CDC’s messages and the COVID-19 measures:

1. Time lags: What is posted might not reflect real-time situations, which can impact the association strength between the posted measures and real-world metrics; thus, we suggest aligning the content topics of health communication with up-to-date epidemic outcome metrics.

2. Discrepancies in posting methods: The CDC simplifies the data in their posts to make the information more comprehensible for the audience, which might not align with the detailed epidemic metrics posted from other sources with different interpretations of the reported metrics.

3. Variability in the data source: The data open to the public might come from sources and reporting standards that are different from the CDC’s protocol, which could weaken potential associations.

4. Audience: As a government health agency, the CDC prioritizes certain data for social media to cater to the public for relevancy. For example, posting daily epidemic measures could lead to strong associations with COVID-19 metrics, but an association does not mean causality, and we assume that the CDC does not generate their tweets with the intention to improve associations of any kind and their priority is to present a variety of reliable information to the public.

5. Fatigue from information overload: Frequent data updates on social media can lead to desensitization, making it less likely for users to pay attention and react to the information over time, for example, tweeting about daily epidemic measures decreases the public’s attention over time.

6. Political and societal factors, for example, antivaccination groups and conspiracy theories about the pandemic.

In addition, it is important for us to continue to examine the validity of the underlying assumption that the CDC’s health communication makes an impact during a pandemic. In this infodemiology study, we focused on the national effects of these tweets. Future studies should further examine geospatial factors and other confounding factors to help understand whether and how much the CDC’s tweets impact pandemic outcomes.

Lastly, public engagement (ie, retweets, likes, replies, etc) of the CDC’s health communication is an important indicator of the effectiveness of online health communication efforts. There have been studies that analyzed public sentiments and attitudes toward various health-related topics. However, very few studies have investigated the associations of public sentiment shifts along disease-related metrics. In addition, public sentiments and attitudes are heavily influenced by health agencies’ messages and should not be misled by misinformation. Public opinions also influence health practices and interventions, which have a significant impact on the actual epidemic outcomes (eg, case, death, vaccination, etc). Thus, it is important to further investigate the underlying association between public health communication topics and actual epidemic measures. The insights can help public health agencies develop better social media strategies to address public concerns at different stages of the emergency. Therefore, we suggest that examining the dynamics and patterns of public responses to health agencies’ original communications can provide valuable insights on public perceptions and attitudes around various issues during the
pandemic, such as pharmaceutical interventions (eg, vaccination) and nonpharmaceutical interventions. Detailed content analysis can be applied to explicitly identify public concerns in response to the CDC’s health communications. In addition, sentiment analysis can be applied to extract public sentiments (ie, positive, neutral, or negative) toward the CDC’s health communications, and further help identify public attitudes and reactions to various content topics that the CDC has communicated. Public attitudes will ultimately determine individual health behavior and decision-making, such as vaccination acceptance and compliance with nonpharmaceutical interventions, which in turn drive the overall epidemic dynamics. Therefore, it is critical to investigate real-time public engagement, such as retweeting or replying on social media, toward public health agencies’ communications to better inform health agencies about prioritizing their communications and addressing public concerns about specific content topics.

Conclusions
This study investigated the dynamic associations between the CDC’s detailed COVID-19 communication topics on Twitter and epidemic metrics in the United States for almost 2 years during the pandemic. Using LDA topic modeling, we were the first to comprehensively identify and explore various COVID-related topics tweeted by the federal public health agency during the pandemic. We also collected daily COVID-19 epidemic metrics (confirmed case counts, death counts, completed tests records, and fully vaccinated records) and performed various multivariate time series analyses to unravel the temporal patterns and associations with the CDC’s COVID-19 communication patterns (ie, investigated the dynamic associations between the time series of each topic generated by the LDA model and the time series of each epidemic metric). The results suggested that some topics were strongly associated with certain COVID-19 epidemic metrics, indicating that advanced social media analytics (eg, NLP) could be a valuable tool for effective infoveillance. Based on our findings, we recommend that the CDC, along with other public health agencies, could further optimize their health communications on social media platforms by posting contents and topics that align with the temporal dynamics of key epidemic metrics. While the CDC had been making efforts to share information on social media platforms to educate the public throughout the pandemic, the public responses to these messages were relatively weak. It is important to further explore the potential factors that played a role in the effectiveness of the CDC’s social media performance in future studies. As such, we suggest increasing online health communication on health practices and interventions during high-level epidemic periods with large numbers of cases and deaths. Our findings also highlighted the importance of health communication on social media platforms to better respond to and tackle future health emergencies and issues.

Acknowledgments
We thank Naomi Nikita Thammadi, former graduate student of the University of North Carolina at Charlotte, who helped with data collection through the Twitter application programming interface and initial data preprocessing. This project was partially supported by the Models of Infectious Disease Agent Study (MIDAS) Network grant MIDASUP-05 to SC.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Supplementary information.
[PDF File (Adobe PDF File), 3131 KB - infodemiology_v4i1e49756_app1.pdf ]

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Abbreviations

AIC: Akaike information criterion  
AR: autoregressive  
ARIMA: autoregressive integrated moving average  
ARIMAX: autoregressive integrated moving average with external variable  
BERT: bidirectional encoder representations from transformers  
CCF: cross-correlation function  
CDC: Centers for Disease Control and Prevention  
daAIC: difference in Akaike information criterion  
LDA: latent Dirichlet allocation  
MA: moving average  
MAE: mean absolute error  
MI: mutual information  
NLP: natural language processing  
PCR: polymerase chain reaction  
RMSE: root mean square error  
TF-IDF: term frequency-inverse document frequency

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Verification in the Early Stages of the COVID-19 Pandemic: Sentiment Analysis of Japanese Twitter Users

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Related Article:
This is a corrected version. See correction statement: https://infodemiology.jmir.org/2024/1/e57880

Abstract

Background: The COVID-19 pandemic prompted global behavioral restrictions, impacting public mental health. Sentiment analysis, a tool for assessing individual and public emotions from text data, gained importance amid the pandemic. This study focuses on Japan’s early public health interventions during COVID-19, utilizing sentiment analysis in infodemiology to gauge public sentiment on social media regarding these interventions.

Objective: This study aims to investigate shifts in public emotions and sentiments before and after the first state of emergency was declared in Japan. By analyzing both user-generated tweets and retweets, we aim to discern patterns in emotional responses during this critical period.

Methods: We conducted a day-by-day analysis of Twitter (now known as X) data using 4,894,009 tweets containing the keywords “corona,” “COVID-19,” and “new pneumonia” from March 23 to April 21, 2020, approximately 2 weeks before and after the first declaration of a state of emergency in Japan. We also processed tweet data into vectors for each word, employing the Fuzzy-C-Means (FCM) method, a type of cluster analysis, for the words in the sentiment dictionary. We set up 7 sentiment clusters (negative: anger, sadness, surprise, disgust; neutral: anxiety; positive: trust and joy) and conducted sentiment analysis of the tweet groups and retweet groups.

Results: The analysis revealed a mix of positive and negative sentiments, with “joy” significantly increasing in the retweet group after the state of emergency declaration. Negative emotions, such as “worry” and “disgust,” were prevalent in both tweet and retweet groups. Furthermore, the retweet group had a tendency to share more negative content compared to the tweet group.

Conclusions: This study conducted sentiment analysis of Japanese tweets and retweets to explore public sentiments during the early stages of COVID-19 in Japan, spanning 2 weeks before and after the first state of emergency declaration. The analysis revealed a mix of positive (joy) and negative (anxiety, disgust) emotions. Notably, joy increased in the retweet group after the emergency declaration, but this group also tended to share more negative content than the tweet group. This study suggests that the state of emergency heightened positive sentiments due to expectations for infection prevention measures, yet negative information also gained traction. The findings propose the potential for further exploration through network analysis.

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KEYWORDS
COVID-19; sentiment analysis; Twitter; infodemiology; NLP; Natural Language Processing
Introduction

Background

The COVID-19 outbreak that occurred in December 2019 in Wuhan, Hubei Province, China, spread rapidly in other countries after January 2020. Lockdowns were implemented primarily in Europe after March 2020 as infection prevention measures. The use of lockdowns as a quarantine measure varied from country to country; however, in the United States, the United Kingdom, France, and other countries, strict measures to regulate behavior were implemented, such as curfews and total school closures, with penalties imposed for violations.

COVID-19 spread rapidly in Japan after the first infection was confirmed on January 16, 2020, with incidents such as the mass infection on the Diamond Princess cruise ship in early February [1]. On April 7, the Japanese government declared a state of emergency in 7 prefectures—Tokyo, Kanagawa, Saitama, Chiba, Osaka, Hyogo, and Fukuoka—owing to the rapid spread of the infection by mass infection in medical facilities and elsewhere [2]. Although the restrictions imposed by the emergency declaration (eg, requests to remain inside and limitations on large-scale events) were less enforceable than those imposed by the lockdown, they did result in a significant decrease in travel rates throughout Japan. However, previous studies have shown that such strong behavioral restrictions may have a negative psychological impact on the public [3]. The emergency declaration was extended to all prefectures, and the restrictions imposed by the emergency declaration were subsequently lifted on May 25. Table 1 summarizes the major developments in the early stages of the COVID-19 outbreak in Japan in chronological order.

Table 1. Japan’s response to the initial spread of COVID-19.

<table>
<thead>
<tr>
<th>Date</th>
<th>Events</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020/1/16</td>
<td>The first case of COVID-19 infection is confirmed in Kanagawa Prefecture, Japan.</td>
<td>[4]</td>
</tr>
<tr>
<td>2020/2/4</td>
<td>COVID-19 infection is confirmed in passengers on the Diamond Princess, a large cruise ship, returning to Hong Kong.</td>
<td>[1]</td>
</tr>
<tr>
<td>2020/2/27</td>
<td>The Japanese government requests the temporary closure of all elementary schools, junior high schools, and high schools in Japan from March 2 to spring break.</td>
<td>[5]</td>
</tr>
<tr>
<td>2020/3/10</td>
<td>The Japanese government declares the new coronavirus infection a historical emergency.</td>
<td>[6]</td>
</tr>
<tr>
<td>2020/3/13</td>
<td>The prime minister can now declare a “state of emergency.”</td>
<td>[7]</td>
</tr>
<tr>
<td>2020/3/26</td>
<td>The prime minister also orders the establishment of a government task force based on the act on special measures.</td>
<td>[8]</td>
</tr>
<tr>
<td>2020/4/7</td>
<td>The Japanese government declares a state of emergency. Seven prefectures (Tokyo, Kanagawa, Saitama, Chiba, Osaka, Hyogo, and Fukuoka), including the Tokyo metropolitan area, are designated as target areas.</td>
<td>[9]</td>
</tr>
<tr>
<td>2020/4/16</td>
<td>An emergency declaration is extended to cover all prefectures until May 6.</td>
<td>[10]</td>
</tr>
<tr>
<td>2020/5/4</td>
<td>A decision is made to extend the period of the state of emergency until May 31.</td>
<td>[9]</td>
</tr>
<tr>
<td>2020/5/14</td>
<td>The Japanese government decides to lift the state of emergency for 39 prefectures, excluding 8 prefectures on special alert (Tokyo, Kanagawa, Saitama, Chiba, Hokkaido, Kyoto, Osaka, and Hyogo).</td>
<td>[9]</td>
</tr>
<tr>
<td>2020/5/21</td>
<td>The Japanese government decides to lift the state of emergency for Kyoto, Osaka, and Hyogo.</td>
<td>[9]</td>
</tr>
<tr>
<td>2020/5/25</td>
<td>The Japanese government decides to lift the state of emergency for all prefectures.</td>
<td>[9]</td>
</tr>
</tbody>
</table>

Prior Work in Infodemiology

Following the spread of COVID-19, social networking services (SNSs) were used to transmit information about the virus, accelerating activity in the field of infodemiology, which utilizes this data. Infodemiology is a relatively new research field that combines health informatics and public health with data analysis. It is a scientific discipline that studies the distribution of information and its determinants in information media, particularly the internet, to provide reliable information on public health [11]. Infodemiology became widely known after the World Health Organization (WHO) used the term at the first WHO Infodemiology Conference in response to the spread of COVID-19 and stated the need to promote research activities in this field worldwide [12]. In a previous study, Su et al [13] used sentimental analysis of text information from SNS data to reflect public concerns and psychological changes in individuals, providing information to promote public health. In particular, a sentiment analysis of the Italian region of Lombardy, where the lockdown was enforced, indicated that the number of SNS users with feelings of “anxiety” decreased after the lockdown. In addition, Heras-Pedrosa et al [14] observed through sentiment analysis that “anxiety” and “anger” toward government policies were the top feelings in Spain in the early stages of the infection. Furthermore, in Japan, Niu et al [15] conducted a sentiment analysis from SNS text data on the reasons for the delay in COVID-19 vaccine uptake compared to other countries, suggesting that concerns about side effects may have outweighed the fear of infection in the initial vaccination process. Thus, social media–based analysis reflects the psychological changes in individuals and enables the provision of real-time information to the government enacting public health policies and infection prevention measures.

SNS Usage in Japan

The importance of social media has been increasing in Japan as well, with social media being utilized in public health countermeasures against recent pandemics. The usage rate of SNSs in Japan is still on the rise, with the Ministry of Internal Affairs and Communications’ 2020 Survey on Communications...
Usage Trends [16] showing that the percentage of people using SNSs was 73.8%, an increase of 4.8% from the previous year. It also points out that the growth is particularly large in the age groups comprising people 19 years and below and 60 years and above, indicating that the usage rate of SNSs by age group is increasing for all generations. In terms of the purpose of use, the second-highest percentage of respondents chose “to search for information I want to know,” followed by “to communicate with acquaintances,” suggesting that social media is used by all generations in Japan as an important means of obtaining information. However, while the research field of infodemiology is being actively promoted, there are limited reports on infodemiology in Japan, even though social media is used by a wide range of generations.

**Study Purpose**

In this study, we investigated psychological changes in individuals after the initial spread of COVID-19 in Japan and public sentiment changes following state-of-emergency declarations by conducting sentiment analysis using SNS data in infodemiology.

**Methods**

**Research Data**

We extracted geocoded Twitter data using “Nazuki no Oto,” a service provided by NTT Data Corporation [17]. The target period was from midnight on March 23, 2020, 2 weeks before the first declaration of a state of emergency in Japan, to April 21, 2020. We selected tweets containing the keywords “コロナ (corona),” “COVID-19,” and “新型肺炎 (new pneumonia)” by random sampling of 4,997,353 tweets. In addition, the data used in this study include retweets, a function that allows users to repost other users’ or their own tweets. Duplicate tweets were removed from the Twitter data extracted for this study, and only unique Twitter data were used.

**Data Preprocessing**

Before conducting the sentiment analysis on the extracted Twitter data, we preprocessed the data. For preprocessing, we deleted Twitter data that contained symbols that could not be analyzed by morphological analysis, hashtags (eg, #COVID-19), and URLs only. Consequently, a total of 4,965,100 tweets were used as the target data for sentiment analysis.

**Morphological Analysis**

In contrast to structured and quantitative data, which can be easily analyzed by a computer, qualitative text data, which are often used in sentiment analysis, require processing to extract the data objectively. Therefore, unstructured data are analyzed to convert them from qualitative to quantitative data. However, thus far, analyzing qualitative data in Japanese has been considered a difficult task. One reason for this is that Japanese grammar is more complex than English and other languages [18]. However, with the recent development of natural language processing, it is possible to separate sentences naturally and convert them into quantitative data on a practical level by preparing Japanese dictionary functions for Japanese text data. Morphological analysis determines the smallest grammatically meaningful unit that constitutes a sentence by demarcating the boundaries of words and phrases in the text data. Following decomposition, the part of speech and the type of conjugation are determined by referring to a registered dictionary. In this study, we used a morphological analyzer, MeCab (version 0.996; Kyoto University).

The International Phonetic Alphabet (IPA) dictionary, integrated within the Japanese morphological analysis system Chasen, is widely used for performing morphological analysis in MeCab [19]. However, conventional IPA dictionaries are limited in their ability to support conventional Japanese words and phrases and do not support neologisms and phrases unique to Japanese. To solve this problem, a new system dictionary called mecab-ipadic-NEologd was introduced [20]. This dictionary is updated every Monday and Sunday and can be automatically updated and registered from websites, such as news sites and social media. Therefore, the dictionary can handle text data on the web where unique expressions and new words are frequently used. In this study, we registered mecab-ipadic-NEologd and performed morphological analysis on text data from the SNS Twitter because many unique expressions and new words are used there.

**Japanese Sentiment Dictionary**

We utilized the Japanese Linguistic Inquiry and Word Count (JIWC) dictionary (Nara Institute of Science and Technology) for the sentiment analysis, employing cloud sourcing to access the latest corpus. This Japanese emotional dictionary was used for determining emotions in sentiment analysis, encompassing 7 categories: “anger,” “concern,” “disgust,” “sadness,” “surprise,” “trust,” and “joy” [21]. Examples of words in the Japanese emotion expression dictionary are shown in Table 2. Among the emotions, “trust” and “joy” were selected as positive emotions, and “anger,” “anxiety,” “disgust,” and “sadness” were selected as negative emotions based on previous studies [22].
Table 2. Examples of words included in the JIWC dictionary.

<table>
<thead>
<tr>
<th>Sentiment</th>
<th>Examples of words</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger</td>
<td>怒った (angry), 怒り (rage), 悪い (bad), 嫌がらせ (harassment), イライラ (irritation), うるさい (noisy), ゴミ (garbage), 暴言 (rant), 噛み (aggravation), 理不尽な (unreasonable), 駄音 (noise), 迷惑 (annoyance), 被害 (damage), 虐待 (abuse), 裏切り (betrayal)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>不安 (anxious), 不安だ (worrying), 不安な (anxiety), 病 (illness), 症状 (symptom), このまま (at this rate), この先 (from now on), 考える (thinking)</td>
</tr>
<tr>
<td>Disgust</td>
<td>嫌な (dislike), 嫌がらせ (harass), 嫌な (disgust), うるさい (loud), テロ (terror), 犯罪 (crime), 犯人 (criminal), ひどい (terrible), 悪 (evil), 悪かった (bad), 批判 (criticize), 無い (no), 無し (none), 無視 (ignore), 嘆 (lie), 炎 (dirty)</td>
</tr>
<tr>
<td>Sad</td>
<td>悲しい (sad), 悲観 (pessimistic), 悲愁 (melancholy), 悔感 (sorrowful), 悲傷 (piteous), 泣き (weeping), 泣き叫ぶ (wailing), 嘆き (lamenting), 涙 (tears), 涙声 (tearful), 追悼 (mourning), 痛嘆 (painful), センチメンタル (sentimental)</td>
</tr>
<tr>
<td>Surprise</td>
<td>いきなり (suddenly), サプライズ (surprise), びっくり (surprised), 偶然 (accidentally), 知った (learned), 知って (knew), 解散 (dissolved), 詐欺 (fraud), 発見 (discovered)</td>
</tr>
<tr>
<td>Trust</td>
<td>仲間 (companion), 任せ (entrust), 依頼 (request), 信用 (trust), 頼り (rely), 頼んで (ask), 助け (help), 売って (sell), 親友 (friend), 親身に (friendly), 関係 (relationship), サポート (support), フォロー (follow)</td>
</tr>
<tr>
<td>Joy</td>
<td>遊び (play), 遊んで (playing), 楽しい (fun), 出かけた (went out), おいしい (delicious), 食事 (meal), できた (could), 会って (meet), 会話 (conversation), 笑い (laugh), 笑顔 (smile), 好きな (like)</td>
</tr>
</tbody>
</table>


Data Clustering

The sentiment analysis conducted in this study involved determining emotions in Twitter data by comparing the words in the text with those found in the JIWC dictionary. However, since the words after the morphological analysis were unstructured data, it was not possible to perform numerical calculations to assess their similarity to the words in the dictionary. To address this issue, we used Word2Vec processing to vectorize the text data for both Twitter data and the Japanese emotional dictionary.

Word2Vec is a model proposed by Mikolov et al [23,34] that represents word meanings using low-dimensional vectors, enabling semantic calculations in natural language processing. When vectorizing a large amount of text data, as in this study, individually vectorizing each word can result in an enormous number of dimensions, making it impractical in terms of computation time. Therefore, Word2Vec enables the vectorization of large text data through an inference-based approach using neural networks. Inference-based methods involve making predictions about what goes into a word when given its context (the surrounding words in a sentence). For example, when given the sentence “You ??? goodbye, and I say hello,” we can easily infer that the missing word is “say.” In this case, the context for “????” consists of 2 words: “you” and “goodbye.” The challenge is to infer what fits into that word based on the surrounding context, and thus learn word occurrence patterns. This approach is based on the distributional hypothesis, which suggests that word meanings are formed by the context of the surrounding words rather than inherent in the words themselves. Word2Vec includes 2 models, namely, the continuous bag-of-words (CBOW) model and the skip-gram model, to solve this inference issue. Generally, the skip-gram model is considered to have higher model accuracy after training, but it incurs higher computational costs since it needs to calculate losses for each context. This study’s text data comprises millions of individual pieces, and due to the added morphological analysis, a higher number of words per sentence was anticipated. Therefore, we anticipated that the computational cost for predictions would become immense. As a result, we employed the CBOW model for word embedding processing. After the data collected from Twitter and the terms registered from each Japanese sentiment dictionary were vectorized, Fuzzy-C-Means (FCM) was used to cluster each of the 7 sentiments.

The FCM method is a nonhierarchical soft clustering technique based on fuzzy logic theory. Fuzzy logic theory, originating from the concept of fuzzy sets proposed by LA Zadeh in 1965, provides a framework for quantitatively handling uncertainty and ambiguity in human subjective thinking and decision-making. FCM is a soft clustering method that applies fuzzy logic theory to cluster data [25]. In traditional hard clustering, data are assigned to clusters by being represented as either belonging (1) or not belonging (0) to a specific cluster. In contrast, because FCM is a soft clustering method, it allows data to partially belong to multiple clusters, such as 0.8 belonging to one cluster and 0.2 belonging to another. FCM clustering is carried out using the following algorithm. The membership values, representing the degree to which data points belong to different clusters, are considered:

![image]

In this case, the following conditions are satisfied:

![image]

The matrix $U$, denoted as $[u_{it}]$, represents an $n 	imes c$ matrix with the membership value $u_{it}$ as an element. Meanwhile, the matrix $V$, represented as $[v_{tj}]$, is an $n 	imes c$ matrix with cluster center $v_{tj}$ as an element. Bezdok proposed the following formula for the FCM model that minimizes the objective function by the weighted sum of the Euclidean squared distances between each data and the center of each cluster under the condition of (1) [26]:

![image]
Here, $m$ is a fuzzy coefficient parameter ($m > 1$) that adjusts the strength of ambiguity. When $m = 1$, the FCM model corresponds to the hard clustering k-means model. In this case, the objective function $J(U, V)$ is linearized with respect to $u_{it}$, eliminating soft clustering. FCM clustering is carried out through the following steps. First, given a data set $\{x_1, \ldots, x_n\}$, we determine the number of clusters $t$ ($2 \leq t \leq c$) and the parameter $m \in (1, \infty)$. Next, we initialize the membership values $u_{it}$ with $U^0 = \{u_{it}^0\}$ randomly. We provide a sufficiently small positive number $\varepsilon$ to determine the termination of the loop. Second, we use the current membership values $u_{it}$ to calculate the cluster centers $v_t^p$ using the following formula:

$$v_t^p = \frac{\sum_{i=1}^{n} u_{it}^p x_i}{\sum_{i=1}^{n} u_{it}^p}$$

Third, we update the membership values from $u_{it}^p$ to $u_{it}^{(p+1)}$ using the following formula:

$$u_{it}^{(p+1)} = \frac{1}{\sum_{j=1}^{c} \left( \frac{d(x_i, v_j^p)}{d(x_i, v_j^{(p-1)})} \right)^{2/(m-1)}}$$

Finally, if $\|u_{it}^{(p+1)} - u_{it}^p\| < \varepsilon$ holds for all $i$ and $t$, we terminate the loop. Otherwise, we increment $p$ by 1 and return to the second step. Once the loop terminates, we obtain the center points for each cluster and the membership values for each sample data, completing the clustering process. In this study, FCM was used on text data to reduce the number of words included in an emotion dictionary and construct the emotion dictionary, allowing for more accurate sentiment analysis of the text data due to the influence of a single word on multiple emotions. Both tweets and retweets of Twitter data were used, and quoted retweets, which are retweets of others’ posts with additional comments, were also included.

After vectorization using Word2Vec and clustering using the FCM method, the distance between the vector coordinates of each tweet and the center-of-gravity vector of each written sentiment was calculated. Next, the value with the shortest vector distance was determined as the sentiment of that tweet. The entire sentiment analysis in this study was performed using the Python programming language (version 3.9.4). A path diagram of the overall sentiment analysis is shown in Figure 1, and a summary diagram of the sentiment determination method is shown in Figure 2.

**Figure 1.** Sentiment analysis flowchart.
Examining Sentiment Changes Before and After the State of Emergency Declaration

The Twitter data were categorized into 2 groups: the tweet group and the retweet group. The study period was divided into "before the declaration of a state of emergency," which ranged from midnight on March 23, 2020, until PM 11:59:59 on April 6, 2020, and "after the declaration of a state of emergency," which ranged from midnight on April 7, 2020, to PM 11:59:59 until April 21, 2020. We calculated the proportion of emotions before and after the declaration of a state of emergency in both the tweet and retweet groups. The sentiment analysis results were validated using 2 methods. The first method involved comparing emotions using a between-group comparison of 7 emotions over approximately 2 weeks before and after the declaration of a state of emergency. This comparison was based on daily average values for each emotion. The second method involved dividing the data into two groups: (1) the tweet group, consisting of posts made by the users themselves, and (2) the retweet group, consisting of posts shared for the purpose of dissemination. Sentiment analysis results were aggregated daily, classifying the data as either positive ("trust" and "joy") or negative ("anger," "concern," "disgust," and "sadness") and then comparing the tweet and retweet groups. Both methods conducted a median difference examination using the Mann-Whitney U test, with statistical significance set at $P < .05$, utilizing the statistical software JMP (version 16.0; SAS).

Ethical Considerations

This study was conducted while adhering to strict ethical considerations and did not require ethics approval. To avoid identification of personal information, the Twitter data used were limited to the type of post (tweet or retweet), text, and the date and time of the post for data analysis. The data used did not contain any personally identifiable information. In addition, efforts were made to ensure transparency throughout the design and conduct of this study.

Results

Research Data

We were able to judge sentiment through the sentiment analysis in 4,884,297 (97.74%) cases out of a total of 4,997,353 cases. In addition, the number of tweets was 1,374,025 (28.13%), and the number of retweets was 3,510,272 (71.87%). The number of tweets and retweets per day is shown in Table 3, and the daily trends for the data from March 23, 2020, to April 21, 2020, are shown in Multimedia Appendix 1.
Table 3. Daily tweet and retweet counts.

<table>
<thead>
<tr>
<th>Date</th>
<th>Tweets (n=1,374,025), n (%)</th>
<th>Retweets (n=3,510,272), n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020/3/23</td>
<td>4666 (0.34)</td>
<td>13,643 (0.39)</td>
</tr>
<tr>
<td>2020/3/24</td>
<td>25,067 (1.82)</td>
<td>71,040 (2.02)</td>
</tr>
<tr>
<td>2020/3/25</td>
<td>33,759 (2.46)</td>
<td>87,476 (2.49)</td>
</tr>
<tr>
<td>2020/3/26</td>
<td>41,944 (3.05)</td>
<td>115,842 (3.30)</td>
</tr>
<tr>
<td>2020/3/27</td>
<td>39,433 (2.87)</td>
<td>103,798 (2.96)</td>
</tr>
<tr>
<td>2020/3/28</td>
<td>37,160 (2.70)</td>
<td>106,915 (3.05)</td>
</tr>
<tr>
<td>2020/3/29</td>
<td>37,804 (2.75)</td>
<td>108,868 (3.10)</td>
</tr>
<tr>
<td>2020/3/30</td>
<td>74,353 (5.41)</td>
<td>209,297 (5.96)</td>
</tr>
<tr>
<td>2020/3/31</td>
<td>51,765 (3.77)</td>
<td>144,594 (4.12)</td>
</tr>
<tr>
<td>2020/4/1</td>
<td>48,902 (3.56)</td>
<td>121,864 (3.47)</td>
</tr>
<tr>
<td>2020/4/2</td>
<td>48,127 (3.50)</td>
<td>119,259 (3.40)</td>
</tr>
<tr>
<td>2020/4/3</td>
<td>52,918 (3.85)</td>
<td>123,835 (3.53)</td>
</tr>
<tr>
<td>2020/4/4</td>
<td>48,470 (3.53)</td>
<td>113,346 (3.23)</td>
</tr>
<tr>
<td>2020/4/5</td>
<td>54,358 (3.96)</td>
<td>115,172 (3.28)</td>
</tr>
<tr>
<td>2020/4/6</td>
<td>75,831 (5.52)</td>
<td>175,918 (5.01)</td>
</tr>
<tr>
<td>2020/4/7</td>
<td>76,184 (5.54)</td>
<td>195,158 (5.56)</td>
</tr>
<tr>
<td>2020/4/8</td>
<td>60,645 (4.41)</td>
<td>179,707 (5.12)</td>
</tr>
<tr>
<td>2020/4/9</td>
<td>55,231 (4.02)</td>
<td>156,760 (4.47)</td>
</tr>
<tr>
<td>2020/4/10</td>
<td>51,078 (3.72)</td>
<td>134,393 (3.83)</td>
</tr>
<tr>
<td>2020/4/11</td>
<td>44,901 (3.27)</td>
<td>111,213 (3.17)</td>
</tr>
<tr>
<td>2020/4/12</td>
<td>42,403 (3.09)</td>
<td>96,575 (2.75)</td>
</tr>
<tr>
<td>2020/4/13</td>
<td>42,117 (3.07)</td>
<td>107,539 (3.06)</td>
</tr>
<tr>
<td>2020/4/14</td>
<td>42,800 (3.11)</td>
<td>105,344 (3)</td>
</tr>
<tr>
<td>2020/4/15</td>
<td>44,185 (3.22)</td>
<td>118,456 (3.37)</td>
</tr>
<tr>
<td>2020/4/16</td>
<td>48,618 (3.54)</td>
<td>122,458 (3.49)</td>
</tr>
<tr>
<td>2020/4/17</td>
<td>44,494 (3.24)</td>
<td>132,009 (3.76)</td>
</tr>
<tr>
<td>2020/4/18</td>
<td>38,270 (2.79)</td>
<td>111,351 (3.17)</td>
</tr>
<tr>
<td>2020/4/19</td>
<td>38,872 (2.83)</td>
<td>110,308 (3.14)</td>
</tr>
<tr>
<td>2020/4/20</td>
<td>39,611 (2.88)</td>
<td>116,187 (3.31)</td>
</tr>
<tr>
<td>2020/4/21</td>
<td>30,059 (2.19)</td>
<td>78,522 (2.24)</td>
</tr>
</tbody>
</table>

Percentage of Emotions in the Sentiment Analysis

The results of the sentiment analysis on the tweet and retweet groups for the period between midnight on March 23, 2020, to 23:59:59 on April 6, 2020 (before the declaration of the state of emergency) are shown in Figure 3. The results for the period between midnight on April 7, 2020, and 23:59:59 on April 21, 2020 (after the declaration of the state of emergency) are shown in Figure 4. In the tweet group, the positive emotion “joy” was highest both before and after the state of emergency declaration at 40.5% (n=272,879) and 31% (n=217,074), respectively, while in the retweet group, the negative sentiment of “worry” was 34% (n=587,540), and “disgust” was 18.6% (n=322,462) during the period before the state of emergency declaration. These percentages were higher than those for the other emotions.
Changes in Sentiment Before and After the Declaration of a State of Emergency

Table 4 shows the results of the sentiment analysis yielding the proportions of the 7 emotion types before and after the declaration of the state of emergency. The Mann-Whitney U test comparison of differences in median values revealed that the sentiment of joy significantly increased in the retweet group\(^{*}\) (\(P<0.05\)). However, no significant differences were observed for the other emotions.

Table 5 and Figure 5 show the results of testing the change of positive and negative content between the tweet group and retweet groups. In the 2 weeks before and after the emergency declaration, the retweet group tended to post more negative content than the tweet group (before \(r=0.29\), \(P=.02\); after \(r=0.40\), \(P=.002\)). However, there was no difference between the tweet and retweet groups in the percentage of positive responses.
### Table 4. Sentiment changes before and after the state of emergency declarationa.

<table>
<thead>
<tr>
<th>Sentiments</th>
<th>Before (n=15)</th>
<th>After (n=15)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>SD</td>
<td>Median</td>
</tr>
<tr>
<td>Anger tweet</td>
<td>0.042</td>
<td>0.061</td>
<td>0.024</td>
</tr>
<tr>
<td>Anger retweet</td>
<td>0.042</td>
<td>0.051</td>
<td>0.063</td>
</tr>
<tr>
<td>Anxiety tweet</td>
<td>0.063</td>
<td>0.078</td>
<td>0.050</td>
</tr>
<tr>
<td>Anxiety retweet</td>
<td>0.210</td>
<td>0.307</td>
<td>0.054</td>
</tr>
<tr>
<td>Disgust tweet</td>
<td>0.023</td>
<td>0.293</td>
<td>0.021</td>
</tr>
<tr>
<td>Disgust retweet</td>
<td>0.073</td>
<td>0.136</td>
<td>0.127</td>
</tr>
<tr>
<td>Sadness tweet</td>
<td>0.041</td>
<td>0.025</td>
<td>0.035</td>
</tr>
<tr>
<td>Sadness retweet</td>
<td>0.041</td>
<td>0.045</td>
<td>0.055</td>
</tr>
<tr>
<td>Surprise tweet</td>
<td>0.038</td>
<td>0.090</td>
<td>0.016</td>
</tr>
<tr>
<td>Surprise retweet</td>
<td>0.051</td>
<td>0.023</td>
<td>0.035</td>
</tr>
<tr>
<td>Trust tweet</td>
<td>0.035</td>
<td>0.033</td>
<td>0.038</td>
</tr>
<tr>
<td>Trust retweet</td>
<td>0.059</td>
<td>0.032</td>
<td>0.061</td>
</tr>
<tr>
<td>Joy tweet</td>
<td>0.390</td>
<td>0.258</td>
<td>0.281</td>
</tr>
<tr>
<td>Joy retweet</td>
<td>0.041</td>
<td>0.057</td>
<td>0.191</td>
</tr>
</tbody>
</table>

aBefore refers to the period from midnight on March 23, 2020, until 11:59:59 PM on April 6, 2020, while after refers to the period from midnight on April 7, 2020, until 11:59:59 PM on April 21, 2020.

### Table 5. Comparison results of positive and negative changes between the tweet and retweet groups.

<table>
<thead>
<tr>
<th>Sentiment</th>
<th>Tweet Median</th>
<th>SD</th>
<th>Retweet Median</th>
<th>SD</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive (n=30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>0.089</td>
<td>0.286</td>
<td>0.054</td>
<td>0.174</td>
<td>.22</td>
</tr>
<tr>
<td>After</td>
<td>0.099</td>
<td>0.290</td>
<td>0.108</td>
<td>0.123</td>
<td>.34</td>
</tr>
<tr>
<td>Negative (n=60)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>0.040</td>
<td>0.161</td>
<td>0.066</td>
<td>0.236</td>
<td>.02</td>
</tr>
<tr>
<td>After</td>
<td>0.038</td>
<td>0.202</td>
<td>0.063</td>
<td>0.173</td>
<td>.002</td>
</tr>
</tbody>
</table>
Discussion

Principal Findings

The Japanese language sentiment analysis conducted during this study’s target period, both before and after the declaration of the state of emergency, revealed that “joy,” associated with a “positive” sentiment, accounted for high proportions within the tweet group at 40.5% (n=272,879) before and 31% (n=217,074) after. On the other hand, “anxiety” and “disgust,” which express “negative” feelings, accounted for high percentages in both the tweet and retweet groups, especially in the retweet group, where “anxiety” accounted for 34% (n=587,540) and “disgust” accounted for 18.6% (n=322,464) of the total retweets before the state of emergency was declared. The self-restraint approach regulating behavior during the declaration of a state of emergency in Japan allowed movement across prefectures. This may have been a contributing factor to the widespread negative posts related to movements from the target area. This surge in negative sentiment was countered by the anticipation of infection prevention following the state of emergency declaration. During the early stages of the COVID-19 spread in other countries, feelings of anxiety may have been expressed on social media, as well as expectations for strong countermeasures, such as behavioral restrictions. In contrast, the results of the sentiment analysis of English-language tweets corresponding to the same period showed that negative and positive emotions accounted for approximately the same proportions by late March, the end of the period covered in this study. Notably, the negative emotion “fear” occupied a higher percentage than other emotions around January and February [27]. In China and European countries, the first cases of infection were confirmed earlier than in Japan (where the initial expansion of the outbreak occurred in late March). Thus, the earlier spread of infection in those nations may have a significant impact on the sentiment analysis.

Comparative Study Between the Tweet and Retweet Groups

When comparing the tweet and retweet groups, the retweet group tended to post more negative sentiments. In this regard, a previous study revealed that in the early stage of the COVID-19 outbreak among English-speaking users, many tweets had a positive sentiment, while many retweets had a negative sentiment [28]. It is clear that much of the information users wished to disseminate was negative in nature. As for the difference between groups in this study, there is a research report
that focuses on virality, one of the characteristics of sentiment analysis using social media [29] Virality is an explosive spread of attention and information through social media and word-of-mouth on the internet. Virality is derived from “viral”—as in a virus. Previous research indicates that negative posts increase virality, while positive posts decrease virality. Therefore, for topics that attract substantial public attention, such as COVID-19, the topic of this study, there is a tendency to spread negative content in retweets, consequently increasing virality. This suggests a noteworthy contrast between the tweet and retweet groups.

Limitations

There are a few key limitations of this study. First, the social media platform Twitter, which was used for the sentiment analysis in this study, had an age bias. According to a survey conducted by the Ministry of Internal Affairs and Communications in 2020, the Twitter usage rate is highest among teenagers (67.6%) and twentysomethings (79.8%) [30]. Additionally, data from the Ministry of Internal Affairs and Communications indicate that the usage rate declines with increasing age, especially among individuals aged 40 years and older. This suggests that the younger generation is the predominant user of Twitter as a whole. This suggests that the younger generation predominantly constitutes the main users of Twitter overall. Therefore, the results of the sentiment analysis in this study are not necessarily representative of the entire nation. In addition, the Twitter data used in this study were limited to Japanese-language content. We did not use location-based information or conduct analyses based on geographical data. As such, this data may originate from disproportionate samples depending on the prefecture. During Japan’s initial state of emergency declaration in 2020, the target areas comprised 7 prefectures: Tokyo, Kanagawa, Chiba, Saitama, Osaka, Kobe, and Fukuoka. Subsequently, on April 16, 2020, the target area was expanded to the entire country [9]. Throughout the study period covered, only some of the target areas were declared as emergency areas; therefore, emotional variations in Twitter usage may exist depending on the location of the users.

Second, the sentiment analysis categorized each tweet into one of 7 predefined sentiment types, limiting its ability to capture multiple sentiments, such as “anger” and “surprise,” within a single tweet or account for cases where the selected sentiments might not apply.

The Twitter data utilized in this study underwent random sampling for both tweets and retweets. Twitter incorporates a function known as “bot,” which automatically generates tweets in response to specified times and keywords. Numerous accounts, commonly referred to as “bot accounts,” are responsible for automatic posting. Shi et al [31] conducted a sentiment analysis on Twitter focusing on the #coronavirus hashtag from January 2020 to March 2020, including human and bot-generated tweets. Their findings revealed that bot-posted tweets had more negative sentiments compared to those posted by humans concerning the topic of COVID-19. This suggests that the bot feature intentionally promotes negative public opinion and sentiment. Consequently, it is plausible that the inclusion of a substantial amount of data posted by bot accounts in this study may have influenced the results of the sentiment analysis. Unfortunately, we were unable to preprocess the data to account for this aspect. For our future research, we anticipate that carrying out a network analysis using the results of this study will provide a deeper understanding of the specific subjects that capture public interest. In terms of social network analysis, Seungil [32] investigated how Twitter users in the United States accessed COVID-19–related information based on their posted data. The investigation revealed that during the initial outbreak period, users expressed significant concerns about the number of infections. Additionally, the study highlighted that users were more likely to obtain COVID-19 information from news channel accounts and the official accounts of the president. Sakun et al [22] conducted a network analysis to uncover topics associated with different emotions based on the results of a sentiment analysis using Twitter text data. They found that words like “pneumonia,” “influenza,” “infectious disease,” and “quarantine” were frequently linked to the emotion of “fear.” In addition, words like “pandemic,” “disease,” and “hospital” were associated with the emotion “sadness.” These results suggest that Twitter data can be used to understand the public’s awareness of and emotions toward pandemics, providing valuable insights for governmental responses. Hence, the results of the sentiment analysis should be used for further exploration in infodemiology, specifically by conducting a network analysis focusing on the topics associated with each sentiment identified in this study.

Conclusions

In this study, we conducted a sentiment analysis using Japanese tweet and retweet text data spanning approximately 2 weeks before and after the first state of emergency declaration in Japan to assess public sentiments toward the initial spread of COVID-19. We observed a combination of positive sentiments (“joy”) and negative sentiments (“anxiety” and “disgust”) during the target period. The results of the Mann-Whitney U test indicated that feelings of joy significantly increased in the retweet group before and after the state of emergency declaration. However, there was a significant tendency for the retweet group to post more negative content compared to the tweet group. After the first state of emergency declaration, the anticipation regarding infection prevention measures due to this declaration contributed to an increase in positive sentiments. Moreover, it appears that information, including negative content, was more likely to be disseminated on the topic of COVID-19. Based on the results of this study, we believe that further development through network analysis is possible.

Acknowledgments

We express our gratitude to all individuals who cooperated in the progression of this study.
Conflicts of Interest
None declared.

Multimedia Appendix 1
Total number of tweets and retweets per day. [PNG File, 180 KB - infodemiology_v4i1e37881_app1.png]

References


Abbreviations

CBOW: continuous bag-of-words
FCM: Fuzzy-C-Means
IPA: International Phonetic Alphabet
JIWC: Japanese Linguistic Inquiry and Word Count
SNS: social networking service
WHO: World Health Organization

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The Journey of Engaging With Web-Based Self-Harm and Suicide Content: Longitudinal Qualitative Study

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Abstract

Background: Self-harm and suicide are major public health concerns worldwide, with attention focused on the web environment as a helpful or harmful influence. Longitudinal research on self-harm and suicide–related internet use is limited, highlighting a paucity of evidence on long-term patterns and effects of engaging with such content.

Objective: This study explores the experiences of people engaging with self-harm or suicide content over a 6-month period.

Methods: This study used qualitative and digital ethnographic methods longitudinally, including one-to-one interviews at 3 time points to explore individual narratives. A trajectory analysis approach involving 4 steps was used to interpret the data.

Results: The findings from 14 participants established the web-based journey of people who engage with self-harm or suicide content. In total, 5 themes were identified: initial interactions with self-harm or suicide content, changes in what self-harm or suicide content people engage with and where, changes in experiences of self-harm or suicide behaviors associated with web-based self-harm or suicide content engagement, the disengagement-reengagement cycle, and future perspectives on web-based self-harm or suicide content engagement. Initial engagements were driven by participants seeking help, often when offline support had been unavailable. Some participants’ exposure to self-harm and suicide content led to their own self-harm and suicide behaviors, with varying patterns of change over time. Notably, disengagement from web-based self-harm and suicide spaces served as a protective measure for all participants, but the pull of familiar content resulted in only brief periods of disconnection. Participants also expressed future intentions to continue returning to these self-harm and suicide web-based spaces, acknowledging the nonlinear nature of their own recovery journey and aiming to support others in the community. Within the themes identified in this study, narratives revealed that participants’ behavior was shaped by cognitive flexibility and rigidity, metacognitive abilities, and digital expertise. Opportunities for behavior change arose during periods of cognitive flexibility prompted by life events, stressors, and shifts in mental health. Participants sought diverse and potentially harmful content during challenging times but moved toward recovery-oriented engagements in positive circumstances. Metacognitive and digital efficacy skills also played a pivotal role in participants’ control of web-based interactions, enabling more effective management of content or platforms or sites that posed potential harms.

Conclusions: This study demonstrated the complexity of web-based interactions, with beneficial and harmful content intertwined. Participants who demonstrated metacognition and digital efficacy had better control over web-based engagements. Some attributed these skills to study processes, including taking part in reflective diaries, showing the potential of upskilling users. This study
also highlighted how participants remained vulnerable by engaging with familiar web-based spaces, emphasizing the responsibility of web-based industry leaders to develop tools that empower users to enhance their web-based safety.

(Keywords: suicide; self-harm; online; longitudinal; qualitative)

Introduction

Background

Self-harm and suicide are major global public health concerns, with >700,000 people worldwide dying by suicide each year [1]. Attention has increasingly focused on the role of the web environment in triggering, exacerbating, or normalizing self-harm and suicide [2-4]. The amount of suicide-related information accessible on the web has grown [5], and graphic content describing self-harm is increasingly available on social networking platforms [6]. Research shows that self-harm and suicide-related internet use is common among young people [7], particularly those who are under psychiatric care [8] and who go on to die by suicide [9].

There is a range of self-focused and social motivations for engaging with web-based self-harm and suicide content. These include accessing ongoing peer support or immediate help during a crisis [2,10,11], documenting recovery from self-harm [1,8], and researching suicide methods [12]. Moreover, research has shown that the ways in which people interact with web-based self-harm and suicide content vary depending on their level of distress [11,13].

The diversity in self-harm and suicide material complicates the experiences of content engagement. Research has identified these content interactions as being both a public health concern and a possible preventative measure [3,14], and studies have recognized the potential for engagement to have both benefits and costs [15]. Content with the potential to harm includes information on high-lethality suicide methods [16], prosuicide websites that may encourage suicide [13], and content describing novel methods of self-harm [17]. Benefits associated with accessing content include the role of the online community in peer support, validation and acceptance of one’s own self-harm experiences of content engagement. Research has identified their level of distress [11,13].

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The review also identified only 4 longitudinal studies on the impact of self-harm and suicide-related internet use. Of these studies, 2 identified preventative effects of suicide prevention websites and web-based health forums on suicidal ideation [21,22]. One study showed minimal effects of search engine helpline notices on future suicide queries [23], and another study found that exposure to self-harm on Instagram predicted suicidal ideation and self-harm–related outcomes [17]. However, none of these studies used qualitative methods with their participants, emphasizing the current paucity of evidence on how self-harm and suicide–related web-based behavior evolves and the long-term effects and experiences of engaging with such content from the user’s perspective, including whether these are brief or permanent.

Objectives

The aim of this study was to explore the motivations for and consequences of viewing, searching for, and posting web-based self-harm or suicide content over a longitudinal period. Specifically, this study builds on existing knowledge by using qualitative and digital ethnographic methods to explore individual narratives of web-based engagement. Exploration of “significant moments” and points of transition within the web journey could also have substantial implications for the prevention of suicide and reduction of self-harm [24].

Methods

Design

This was a 6-month qualitative ethnographic study that investigated the stability and change in engagement with web-based self-harm and suicide content. This involved 3 one-to-one interviews and daily diary completion by participants over the study duration. We selected a 6-month time frame to ensure that we could observe changes over time in web-based engagement and associated behaviors [25,26] while also remaining mindful of the considerable commitment required for this ethnographic approach to maintain retention of participants.

Ethical Considerations

Ethics approval was obtained from the University of Bristol Faculty of Health Sciences ethics committee (reference: 117491). All participants provided written informed consent before participation, and were informed that they could withdraw from the study (including data withdrawal up to the time of analysis), without giving a reason. During consent, participants were assigned a participant ID used to identify their data and ensure anonymity. They were also informed that their data would be held confidentially and securely by the University of Bristol according to its duties and obligations under GDPR and the Data Protection Act. All participants were also compensated for their time, receiving a total of up to £75 (US $94.79) for full study completion.

Sampling and Recruitment

UK residents aged ≥16 years who were able to communicate in English and had experience engaging with web-based self-harm or suicide content were eligible. This included posting...
images, videos, memes, forum posts, blog posts, recovery posts, or comments related to self-harm or suicide or engaging with others’ self-harm or suicide–related content through reposting and reblogging, quoting, liking, sharing, saving, subscribing to, or commenting. They did not need to have previous experience with self-harm or suicidal thoughts or behaviors.

Potential participants responded to advertisements posted between November 2021 and April 2022 on social media platforms (Facebook, Twitter [subsequently rebranded as X], and Reddit subreddits “[r]/AdultSelfHarm,” “[r]/StopSelfHarm,” “[r]/BPD,” “[r]/MentalHealthUK,” and “[r]/malementalhealth”), via Tellmi—a UK-based young person mental health app), and through charity websites and newsletters (Samaritans, SMaRtE, The McPin Foundation, and MQ Mental Health Research). Advertisements were posted once to platforms or sites until the end of recruitment in April 2022; however, due to web-based posting and reposting, it is possible that they were also shared elsewhere by others. Permission was sought from moderators or administrators before posting. Advertisements included a link to an expression of interest form in which participants consented via completion to the collection of brief demographic information, if and when the person last self-harmed, the way they were engaging with web-based self-harm or suicide content, and what platforms they used. All respondents had engaged with web-based self-harm or suicide content in some way.

This information was used to sample a diverse range of participants from those who expressed interest and target recruitment advertisements. Potential participants were sent the study information sheet via email, and those who were still interested in participating completed a consent form. Interviews were then arranged via email. The demographic data of those who did not participate were deleted. Once 14 baseline interviews had been conducted, the study team considered that there was good participant diversity in ethnicity and sufficient gender diversity. In addition, we had a broad range of platforms and apps represented in participant use. The authors also identified high-quality dialogue data sufficient for analysis and consistent themes to address the research aims. This resulted in the data achieving good information power [27], and therefore, recruitment was terminated. Information power was used as an alternative to data saturation in this study as the diverse nature of participant narratives meant that we were unlikely to reach a point of saturation.

**Data Collection**

Written consent to participate was provided by participants before entering the study. Participants were also required to complete a mandatory safety plan, including contact details for someone who could support them, their general practitioner’s details (in case serious safety concerns arose), and a self-care plan that was individually designed by each participant to suit their needs (Multimedia Appendix 1). Study information was sent to the parents or guardians of those aged 16 to 18 years as a transparency measure. However, formal parental or guardian consent was not deemed a requirement by the ethics committee given the ages of the participants involved. As part of the study, a distress protocol was developed with a clinician to manage the risk of worsening mental health or increased self-harm or suicidal thoughts as a result of participation in the study. According to the protocol, participants would first be referred to their own safety plan if their mental health declined as a result of the study. A hierarchy of responses was specified in cases of more serious distress, including the options of offering follow-up support from UK suicide charity “Samaritans” or calling upon the advice of a named senior clinician. However, study-induced distress was not reported by participants during the study, and therefore, such responses were not actioned by researchers.

One-to-one interviews were conducted at baseline and the 3- and 6-month time points via Zoom (Zoom Video Communications) with just the researcher and participant present. The interviews were open-ended and flexible, using probing techniques where appropriate, and structured loosely using a topic guide. The main topics explored were “history of self-harm and suicide feelings”; “current and historic web-based activity related to self-harm and suicide content”; “patterns, motivations, and impact of web-based content engagement”; “critical moments in the web-based content engagement journey”; “keeping safe on the web”; and “experiences of web-based moderation and blocking.” The topic guides were originally refined using feedback from 2 lived-experience experts. Throughout the study, the topic guides continued to be iteratively adapted between interviews, grounding question modifications in the study data. The interviews were conducted by ZH, LK, or LB and lasted between 35 and 80 minutes (with baseline interviews averaging 65 [SD 8.55] min and follow-up interviews averaging 45 [SD 2.87] min). They were audio recorded using an encrypted device and then transcribed.

**Diaries**

Participants completed daily diaries independently between interviews. These diaries served as an ethnographic tool and were introduced at the end of the baseline interview. Blank digital templates were then provided periodically via email. Each covered a 4-week period and had 3 main components (daily recording of content engagement, mood ratings, and a weekly reflection of content impact). Each participant was asked to complete 5 diaries in total. Entries were used to formulate personalized follow-up interview schedules in which further information or clarifications could be sought from participants.

**Measures**

Self-reported mental well-being data were collected from participants at baseline and monthly intervals to coincide with diary data collection. This was done via surveys on SurveyMonkey and included validated measures for assessing anxiety, depression, and psychological well-being (Multimedia Appendix 2 [28-31]). These data were used to characterize the sample and identify whether changes in mental health and mood reported by participants during the study interviews and in the diary data were reflected in outcome measure scores.

**Data Analysis**

**Descriptive Analysis**

Participant baseline demographic characteristics were reported as proportions or frequencies, as appropriate. Individual
trajectories for well-being measures were represented visually using line graphs.

**Qualitative Analysis**

A trajectory analysis approach [32] was undertaken to interpret interview data temporally using the following steps:

1. Baseline interviews were transcribed, and then, through coding, themes were derived deductively from topic guide questions and inductively from the data themselves. ZH, LK, and LB separately listed preliminary themes and then refined and revised them collaboratively (Table S1 in Multimedia Appendix 2).

2. Initial matrices were produced for each participant, which included data from the baseline and the 3- and 6-month interviews. These were ordered so that each row was dedicated to a theme established in the previous step. Time points were then assigned to each column. Web-based engagement time points included “initiation,” “historic,” “current,” “never,” and periods of “disengagement and reengagement.” These time points were adapted from the original trajectory approach [31] to preserve the “chronological flow” of the data collected during this study. This allowed us to acknowledge historical content engagement and the nonlinear flow of participant journeys as the levels of engagement fluctuated, ceased, and restarted. This also enabled the inclusion of participants who were only interviewed at baseline (due to dropout) as their data included information about past experiences. Data were formatted according to a “key” using text color to denote the site or platform used and highlighting whether it was related to a significant web event. An event was deemed to be “significant” if the participant recalled it as such or if the researchers found evidence within the narrative that it had a significant impact on the participant’s thinking or behavior. Matrices were developed by extracting relevant quotes or context summaries for 2 participants by ZH, LK, and LB, and once consistency in interpretation was achieved, ZH and LK separately constructed the remaining initial matrices, with ongoing discussion between the researchers to ensure that all the data were captured.

3. Second matrices were then constructed for each participant. These were ordered with the initial themes as column headings. Each row represented an web-based platform or site used by the individual and included condensed versions of the “journey” that participants had experienced for each theme. The comparison allowed us to explore possible patterns in theme content by platforms or sites used. Second matrices were created by ZH for each participant and reviewed by LK and LB.

4. With all matrices complete, ZH, LK, and LB met to discuss similarities and differences across participant trajectories, noting trends, patterns, and outliers. Member checking of transcripts did not occur in this study due to funding and time constraints. During qualitative meeting discussions, overarching longitudinal themes were finalized.

**Results**

**Participant Flow**

The participant flow through the study is shown in Figure 1. There were 92 expressions of interest. Of the 77 individuals who were sampled and sent study information, 63 (82%) did not respond and 14 (18%) took part. Data from the expression of interest forms showed that participants were less likely to respond to the research invite if they were younger (aged 16-24 years), had never hurt themselves on purpose, or had self-harmed in the last week.

Of the 14 participants who completed a baseline interview, 8 (57%) completed a midpoint interview, and 7 (50%) also completed the end-point interview. On the basis of preliminary observations of demographic characteristic data from the final sample, it appears that participants of non-British ethnicity may have had a lower likelihood of completing the study compared with those of British ethnicity. However, it should be noted that this observation was not tested statistically (Table S2 in Multimedia Appendix 2). Throughout the study, participants regularly completed their diaries, with study completers returning 77% (27/35) of the distributed diaries.
Participant Characteristics

The characteristics of those who completed the baseline interviews (N=14) are displayed in Table 1. Of the 14 participants, 4 (29%) self-identified as male and 10 (71%) self-identified as female. Their ages ranged from 16 to 52 years, with 18 to 24 years being the most prevalent age group represented. There was a range of ethnicities, with almost half (6/14, 43%) of the participants being from global majority groups. Participants had engaged with self-harm or suicide-related content on a wide variety of sites and platforms.
Table 1. Participant characteristics at baseline (N=14).

<table>
<thead>
<tr>
<th>Demographic variables</th>
<th>Participants, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Man</td>
<td>4 (29)</td>
</tr>
<tr>
<td>Woman</td>
<td>10 (71)</td>
</tr>
<tr>
<td>Nonbinary</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Asian British</td>
<td>2 (14)</td>
</tr>
<tr>
<td>Asian other</td>
<td>2 (14)</td>
</tr>
<tr>
<td>Black British</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Black other</td>
<td>0 (0)</td>
</tr>
<tr>
<td>White British</td>
<td>7 (50)</td>
</tr>
<tr>
<td>White other</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Mixed</td>
<td>1 (7)</td>
</tr>
<tr>
<td><strong>Age (y)</strong></td>
<td></td>
</tr>
<tr>
<td>16-17</td>
<td>1 (7)</td>
</tr>
<tr>
<td>18-24</td>
<td>7 (50)</td>
</tr>
<tr>
<td>25-35</td>
<td>0 (0)</td>
</tr>
<tr>
<td>36-45</td>
<td>4 (29)</td>
</tr>
<tr>
<td>46-54</td>
<td>2 (14)</td>
</tr>
<tr>
<td>≥55</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Have you ever hurt yourself on purpose?</strong></td>
<td>14 (100)</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Website or platform used to access content</strong>a</td>
<td></td>
</tr>
<tr>
<td>Instagram</td>
<td>3 (21)</td>
</tr>
<tr>
<td>Facebook</td>
<td>5 (36)</td>
</tr>
<tr>
<td>TikTok</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Twitter</td>
<td>6 (43)</td>
</tr>
<tr>
<td>Tumblr</td>
<td>3 (21)</td>
</tr>
<tr>
<td>Weibo</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Discord</td>
<td>1 (7)</td>
</tr>
<tr>
<td>WhatsApp</td>
<td>1 (7)</td>
</tr>
<tr>
<td>YouTube</td>
<td>3 (21)</td>
</tr>
<tr>
<td>Suicide forums</td>
<td>3 (21)</td>
</tr>
</tbody>
</table>

aParticipants were able to select more than one option.

**Participant IDs**

Participant IDs were assigned during the consent process to ensure anonymity. As participants were aware of their assigned IDs, these were changed in the manuscript (see further details in Multimedia Appendix 2).

**Descriptive Analysis Results**

Individual line graphs for each well-being measure demonstrated fluctuations in mental health throughout the 6-month study period that reflected participant journeys recalled through interviews (Multimedia Appendix 2). One participant, IDB, scored poorer at 6 months on the Entrapment Scale–Short Form (which measures feelings of entrapment in a concise manner) than at baseline; however, the decline was minimal. All other study participants (13/14, 93%) improved from baseline or had no change in total score at the study end point in all quantitative measures, although no statistical analysis of change was undertaken.
Longitudinal Qualitative Analysis

Overview

The themes developed following trajectory analysis included (1) initial engagements with web-based self-harm or suicide content, (2) changes in what self-harm or suicide content people engage with and where, (3) changes in self-harm or suicide behaviors associated with web-based self-harm or suicide content engagement, (4) the disengagement-reengagement cycle, and (5) future perspectives on self-harm and suicide content engagement. The themes and their constituent subthemes are summarized inTextbox 1.

Within these themes, fluctuations in mental health and control were identified as significant factors impacting behavioral and emotional responses to web-based content and, therefore, will be further explored in the following sections.

Textbox 1. Themes and subthemes.

<table>
<thead>
<tr>
<th>Initial engagement with web-based self-harm or suicide content</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Motivations for initial web-based self-harm or suicide content engagement</td>
</tr>
<tr>
<td>• Experience of engaging with self-harm or suicide content for the first time</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Changes in what self-harm or suicide content people engage with and where</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Changes in types of web-based self-harm or suicide content engagement over time</td>
</tr>
<tr>
<td>• Balancing curiosity and control</td>
</tr>
<tr>
<td>• Changes in posting web-based self-harm or suicide content over time</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Changes in self-harm or suicide behaviors associated with web-based self-harm or suicide content engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Personal risk associated with web-based self-harm or suicide content engagement</td>
</tr>
<tr>
<td>• The precipitative and protective effects of engagement with self-harm or suicide content on self-harm or suicide behavior</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The disengagement-reengagement cycle</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Disengagement from web-based self-harm and suicide content</td>
</tr>
<tr>
<td>• Reengagement with web-based self-harm and suicide content</td>
</tr>
<tr>
<td>• Longer periods of disengagement</td>
</tr>
<tr>
<td>• Limiting content engagement: strategies</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Future perspectives on self-harm and suicide content engagement</th>
</tr>
</thead>
</table>

Initial Engagement With Web-Based Self-Harm or Suicide Content

Motivations for Initial Web-Based Self-Harm or Suicide Content Engagement

Our first theme captured historical accounts of engaging with web-based self-harm and suicide content. Participants in this study, most of whom (12/14, 86%) had already self-harmed, initially engaged with web-based self-harm or suicide content following attempts to seek help offline during mental health declines. Those who attended mental health services and received new or changes in diagnoses generally reported leaving unsatisfied, citing reasons that included lack of support, inadequate availability, or feelings of being “dismissed” (IDH; baseline interview) due to a perception of low risk. Some were unable to access services at all or felt that attending was not worthwhile. These mental health declines alongside gaps in service provision were the common catalysts for initial web-based searches for self-harm and suicide content. While some of these searches were motivated by a desire to seek help, they varied among participants, with some also seeking information on self-harm and suicide methods:

So, I’d been to the doctors...I’d already tried looking for help. I was waiting for a referral to the CMHT [Community Mental Health Team]. And then within a couple of days I’d started lightly [cutting] on my hand then I moved up to my arm, and then I was looking for support groups online, just general support groups. [IDB; baseline interview]

Experience of Engaging With Self-Harm or Suicide Content for the First Time

The experience of initially encountering self-harm or suicide content on the web is captured through the participant responses in Table 2. Only 14% (2/14) of the participants recalled first coming across content unintentionally, with most (12/14, 86%) describing purposeful searches to access material. While most of these searches were for help and support, 14% (2/14) of the participants reported seeking information about methods for self-harm or suicide, and 7% (1/14) of the participants were uncertain about what they were hoping to find but acknowledged that support-focused sites were unhelpful to them at that point.
Table 2. Quotations related to the experience of first encountering web-based self-harm or suicide content.

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Description</th>
<th>Quotations</th>
</tr>
</thead>
</table>
| Negative   | First engagement with web-based self-harm or suicide content produced a negative response.     | • “That’s not what I was looking for [support sites], I didn’t want help, at that point I was beyond help.” [IDH; baseline interview]  
• “…I was researching [a suicide method]...what’s required and the best way to manage [that]...It was scary. It’d have been really easy just to have thought, well, actually, I know more about it now and I can do that.” [IDC; baseline interview]  
• “I received a picture on WhatsApp of someone, of a friend at the time who was self-harming and she basically just sent me a picture of her scars. I think that that image has stayed with me until today, and I think it’s one of the reasons why I’m so careful because it’s not something that I want to see again.” [IDI; baseline interview] |
| Mixed      | Participants experienced both positive and negative responses to the first engagement with web-based self-harm or suicide content. | • “...because people were experiencing very similar things to what you were experiencing you wanted to have more of that. It was a good environment in one respect, but it was a very toxic environment in the next because you were listening and you were going, ‘Oh, I’ve been through that.’ But it wasn’t helping. It was actually pushing you down a bit because you were getting ideas [about how to self-harm].” [IDG; baseline interview]  
• “I think I was just surprised that there was so much content out there. And yeah, that they haven’t been removed, and I think...I guess a sort of comfort knowing that there were others out there who were also going through tough times...And I think, I guess also shocked at how severe some [images of self-harm] are yeah.” [IDL; baseline interview] |
| Positive   | First engagement with web-based self-harm or suicide content produced a positive response.     | • “I applied to go onto that [Facebook] group just so that I could reach out to people and find out more from survivor-led experiences. And people offered support to each other, and I felt that was quite a good thing to do.” [IDA; midpoint interview]  
• “It made me feel a lot less alone just knowing, even if they were anonymous people out on the internet that could be wherever in the world, that there were other people, and I wasn’t the only person feeling like this. It was so beneficial, especially as a young teen.” [IDF; baseline interview] |

Some participants sought support-related content, and others not intending to access self-harm or suicide content at all unintentionally came across graphic content (eg, images of fresh self-harm) or suicide method descriptions during their first engagements. Those whose initial interactions were with this type of self-harm or suicide content described feelings of distress even when this was the content they were seeking out. Some of these participants (2/14, 14%) recognized that this content could inadvertently validate and trigger their own self-harm and suicide feelings and behaviors, making them feel more at risk. In cases in which participants first engaged with web-based self-harm or suicide content in a discussion forum or peer support group, they were more likely to respond positively, describing how they felt less alone and were able to share experiences with others. However, some participants (2/14, 14%) had mixed emotions—it was comforting to know similar others existed, but processing extreme content was challenging and subjected them to information about novel self-harm and suicide methods, revealing their lack of control over what they were exposed to.

Changes in What Self-Harm or Suicide Content People Engage With and Where

Changes in Types of Web-Based Self-Harm or Suicide Content Engagement Over Time

All participants continued interacting with online self-harm or suicide content after their initial encounter even if it had been a negative experience. In cases in which they had positive initial engagements, participants continued to use the same platforms to access self-harm or suicide content in the long term. When those platforms or sites became obsolete, they sought out equivalent content in other web locations. Participants who had negative initial interactions accessed different platforms or sites searching for self-harm or suicide material that resonated with them.

Although participants had self-harm and suicide content that they accessed in a stable and routine manner, many also described occasions when they would change what they were accessing. Most participants (12/14, 86%) explained that different content satisfied different needs depending on their current mental state or mood. Examples of this can be found in Textbox 2.
Dips in mental health often resulted in changes in the way participants engaged on the web, such as posting their own self-harm or suicide material rather than just interacting with others’ content. In cases in which participants experienced sustained episodes of poorer mental health, self-harm and suicide content was also seemingly accessed more frequently and sometimes uncontrollably through “habit” (IDG) or “addiction” (IDC and IDH), with 21% (3/14) of the participants describing it as falling down a “rabbit hole” (IDI, IDL, and IDF). In total, 7% (1/14) of the participants reported how this compulsive engagement with self-harm or suicide content interrupted elements of their usual social and occupational functioning:

Even through work time I would take ten minutes and just read some of it. [IDI; baseline interview]

Directly questioning participants about web-based engagement when feeling “actively suicidal” elicited similar reported changes in behavior. A couple of participants described engaging with different content—notably turning to web-based suicide organizations and charities or friends and family members offline when they needed support for suicidal thoughts rather than their usual web-based resources for self-harm or suicide content. However, another 21% (3/14) of the participants described how prominent suicidal thoughts were more likely to result in them returning to prosuicide forums, where they would seek or check resources for their own suicide plans.

Improvements in mental health saw participants more likely to transition to web content of a recovery-based nature while often sticking to the same web-based locations. Some participants (3/14, 21%) also attempted to limit web engagement with greater use of offline resources such as community help centers or sometimes uncontrollably through “habit” (IDG) or “addiction” (IDC and IDH), with 21% (3/14) of the participants describing it as falling down a “rabbit hole” (IDI, IDL, and IDF). In total, 7% (1/14) of the participants reported how this compulsive engagement with self-harm or suicide content interrupted elements of their usual social and occupational functioning:

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Balancing Curiosity and Control

Other participants came across content unexpectedly in their web journey or seemed to spontaneously seek out different self-harm or suicide content due to “curiosity.” Some described the ability to negotiate novel self-harm and suicide content with a developed sense of control over time, skipping over or avoiding engaging with content that was undesirable to them:

Being able to scroll past content with trigger warnings of self-harm pics has been quite a new thing. Like in the last year-ish, before then I wouldn’t have been able to have done that. I’d have looked. [IDJ; baseline interview]

However, others described tensions between curiosity and control and how that curiosity led them to seek out different self-harm or suicide content. For example, 14% (2/14) of the participants, who read a news article on a person’s death by suicide that referenced web-based prosuicide forums, went on to search for them:

...I saw it [article on death-by-suicide of person who used pro-suicide forums] in the news. When you see something in the news, especially on the BBC website you know...it’s quite serious stuff. So, then you end up looking further. Now sometimes you have to be careful because you get drawn into it and I think you have to sort of say to yourself, “I’m only going to spend a few minutes doing this...” [IDE; midpoint interview]

The functions of social media sites (eg, hashtags or algorithms) could also enable unintentional content encounters, making control over engagements less feasible:

I guess sometimes that like tags on social media and...it’s usually by chance, I don’t actively go and seek them, but sometimes it appears and then I kind of just go down a rabbit hole of looking at more of such content. Even though I didn’t do it intentionally. [IDL; baseline interview]

Another participant explained that, in transitioning from self-harm and suicide content that no longer resonated, they had less control over what they engaged with:

I think recently, it’s like I don’t know what I’m looking for, but it’s like I know that I haven’t been able to

Textbox 2. Web-based self-harm and suicide content accessed during mental health changes.
find it...So, I think it’s normally looking through my explore page instead of searching for anything in particular... [IDI; midpoint interview]

Changes in Posting Web-Based Self-Harm or Suicide Content Over Time

For some participants (5/14, 36%), posting content seeking help and support regarding self-harm or suicide feelings or looking for ways to stay safe while self-harming was an early action in their web journey (IDA, IDB, IDC, IDD, and IDG). Others also posted detailed descriptions of suicide methods they were considering on discussion forums (IDH, IDK, and IDD), blog posts detailing their own self-harm and suicide feelings (IDN), and images of quotes on Instagram with captions about their mental health (IDI). One participant sent images of their own self-harm via direct messaging after other users requested them (IDK).

A total of 21% (3/14) of the participants in the study refrained from publishing their own content publicly (IDF, IDL, and IDJ). Of these 3 participants, 2 (67%) posted content privately (meaning that it was posted on the web but was only visible to them). Both participants described this as their way to “vent” (IDF) or “rant” (IDL) when upset and an opportunity to document their journey.

Notably, all 3 “observation-only” participants mentioned valuing their anonymity in the web space and refraining from online community interactions. They also emphasized that the potential for posts to negatively affect others deterred them from posting self-harm or suicide content publicly:

I always felt quite conflicted about reposting other people’s content related to it [photos or videos of fresh self-harm]. I feel like it’s one thing for me to look at it because they’ve posted it...versus me reblogging it to my own blog. I don’t know. It’s odd to explain it but it just felt weird. [IDF; baseline interview]

Another participant reported posting content in one context (asking for support on a Facebook group) but not posting “graphic images” (IDC) due to fear that it may cause harm to children. This particular concern for young people viewing content was echoed by IDF, IDH, and IDK.

IDN, who initially described making public blog posts about their own self-harm, later made these private due to a realization that the material may negatively affect others as well as an attempt to maintain anonymity. IDI also reported a change in posting behavior during and as a result of taking part in the study. After initially posting about their experiences in an attempt to raise mental health awareness, they reflected on their tendency to put a “positive spin” (IDI) on content, and by the 6-month follow-up interview, they had reduced the frequency of their posts as they began to question their own authenticity. They considered that, if they posted about their negative experiences, it would likely have a harmful effect on others, and so they refrained from posting.

Finally, one participant also noted that access to psychological therapy reduced their need to post on the web for support:

[I haven’t posted] for quite some time actually. I can’t remember the last time I did that. It would be over a month ago easily. Yeah, I haven’t needed to really. [IDA; final interview]

Why do you think that is? [Interviewer; final interview]

Because I could handle whatever I was thinking probably on my own or bring it to the next...because I’m having weekly sessions with my psychologist... [IDA; final interview]

Changes in Self-Harm or Suicide Behaviors Associated With Web-Based Self-Harm or Suicide Content Engagement

Personal Risk Associated With Web-Based Self-Harm or Suicide Content Engagement

As described previously, some participants identified risks after their initial exposure to web-based self-harm or suicide content (Table 2). Others recognized potentially harmful consequences after longer periods of engagement. Some thought that the content they engaged with gave them implicit “permission” to carry out similar self-harm or suicide behaviors (IDG, IDH, IDJ, IDK, and IDN):

It makes it [completing suicide] feel less scary and like being able to hear people talk about what happened to them, them saying it’s not that bad, like it wasn’t...It just felt like nothing, it makes it feel a lot easier to do it if you know what I mean? [IDK; baseline interview]

Some found that their own self-harm or suicidal behaviors were influenced by self-harm and suicide information they had gathered on the web (IDJ, IDK, IDL, and IDB):

...there were some posts which would link to other websites where you could get resources [information on overdose statistics]. I’d say definitely at the start of my mental health journey that was quite a turning point for me. Because it was just an idea and then it became a possible thing to do. [IDJ; baseline interview]

Another participant experienced feelings of jealousy over the self-harm people had engaged in, which resulted in them feeling the need to escalate their self-harm behaviors:

I think that was that self-comparison to myself...maybe I’m being too scared or I’m not trying hard enough... [IDL; baseline interview]

The Precipitative and Protective Effects of Engagement With Self-Harm or Suicide Content on Self-Harm and Suicide Behavior

The feelings and behaviors that participants experienced following engagement with web-based self-harm or suicide content are shown in Table 3. Content could be precipitative or protective for participants depending on when they encountered it in their journey. Several participants (5/14, 36%) recalled engaging in self-harm and suicide behavior as a result of engaging with web-based content. A few of these participants
Most participants (8/14, 57%) reported entering a cycle of disengagement and reengagement during their web-based self-harm and suicide content journey. Disengagement was usually temporary, with participants choosing to have “no phone days,” deleting their accounts, finding offline activities to take part in, or being forced to disengage due to lack of internet access.

Most often, disengagement was purposeful but impulsive. It usually occurred during periods of compulsive engagement with self-harm and suicide content. For some, there was less consistency regarding whether disengagements with self-harm and suicide content would result in helpful or harmful circumstances. This was exemplified by one participant who stated that their searches were usually protective and kept them occupied when their suicidal thoughts were most intense:

“I think there is a part of me that does it [conduces searches for self-harm and suicide content] to buy time. [IDB; final interview]”

However, this participant also reported attempting a new form of self-harm at the midpoint interview after learning about it through a peer support group on Facebook.

Table 3. Precipitative and protective effects of web-based self-harm or suicide content engagement identified by participants.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Description</th>
<th>Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Precipitative factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-harm or suicide behavior</td>
<td>a consequence of engaging with web-based self-harm and suicide content</td>
<td>“It could also be really detrimental because many times, I would just come away feeling much more triggered than previously and then would engage in the behaviour [self-harm].” [IDF; baseline interview]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“One of the [posts] got taken out of a group [by me] because it was talking about bloodletting and since then, I’ve bought syringes and needles to try and do it myself.” [IDB; midpoint interview]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“How did you then cope with the fallout of what you’d seen [distressing self-harm and suicide content]?” [Interviewer; baseline interview]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I coped by self-harming. Yeah, and I write lots as well. So yeah, writing about how I feel and what I saw.” [IDC; baseline interview]</td>
</tr>
<tr>
<td>Vicarious experiences through</td>
<td>self-harm or suicide content</td>
<td>“It would mainly be trying to vicariously live out things through other people. So, I had a particular urge but wasn’t in a position where I felt like I could self-harm or necessarily wanted to and almost living those experiences through somebody else’s experience which was one of the ways that it [viewing self-harm material] could be really beneficial for me because it could almost meet that urge without me having to engage in the behaviour.” [IDF; baseline interview]</td>
</tr>
<tr>
<td>Delaying or stopping own self-</td>
<td>harm or suicide behavior</td>
<td>“I don’t really need to research it [suicide method] anymore. Sometimes, I do it anyway and I just re-research, re-read it and re-check my facts but it can be a way of preventing me from doing anything.” [IDB; final interview]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“How do you mean?” [Interviewer; final interview]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“It’s like there are levels to it, aren’t there? That’s what I find anyway. It starts with thoughts, then it turns to urges and once you get to that urge stage, you need to feel like you’re doing something, whereas, re-searching it [suicide method] is better than actually putting the tablets in your mouth. It gives you that extra step before you get to that point, if you see what I mean.” [IDB; final interview]</td>
</tr>
<tr>
<td>Calming effect</td>
<td></td>
<td>“How did you feel [coming across images of self-harm]?” [Interviewer; midpoint interview]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Quite relaxed because that’s what I do [self-harm], so I could identify with them, those people who’d done things like that.” [IDC; midpoint interview]</td>
</tr>
</tbody>
</table>

**Disengagement-Reengagement Cycle**

**Disengagement From Web-Based Self-Harm and Suicide Content**

Most participants (8/14, 57%) reported entering a cycle of disengagement and reengagement during their web-based self-harm and suicide content journey. Disengagement was usually temporary, with participants choosing to have “no phone days,” deleting their accounts, finding offline activities to take part in, or being forced to disengage due to lack of internet access.

Most often, disengagement was purposeful but impulsive. It would usually occur during periods of compulsive engagement when participants recognized a lapse in their control or as a reaction to a significant life event that resulted in mental health decline. Life events that occurred during this study included suicide bereavement, hospitalization, bullying or victimization, and experiences of exam- or work-related stress. The act of intentionally disengaging from self-harm or suicide content was...
usually a conscious decision to reclaim control over their web-based actions.

A total of 14% (2/14) of the participants reflected on changes in their disengagement behavior while in the study (IDC and IDI). Previously, similar to other participants, they reported a tendency to compulsively access content during periods of poorer mental health followed by impulsive disengagement. However, at the 6-month interview, both participants described an improved ability to recognize their patterns of web-based behavior (Table 4). This understanding and insight empowered the participants to purposefully disengage during declining mental health episodes as a strategic means of regaining control over their behavior.

**Table 4. Reasons for disengagement from web-based self-harm or suicide content—from final interviews.**

<table>
<thead>
<tr>
<th>Participant ID and reason for disengagement</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IDC</strong></td>
<td></td>
</tr>
<tr>
<td>Mental well-being</td>
<td>“It felt like I needed to look after myself and that I needed that break to try and keep myself safe. One of the things that this research has taught me and helped me understand, it’s helped me understand more about how social media impacts upon me. So, I think social media can be a source for good. I think you also need to recognise that sometimes you need a break.”</td>
</tr>
<tr>
<td>Regaining control</td>
<td>“I really crashed down, and it scared me because I’d had a lovely weekend. Things are generally a lot better, and it scared me in that I can still crash down and fluster myself. I didn’t trust myself to be researching suicide, self-harm...And there was a part of me that knew that I wanted to live, there was a part of me that knew I could spiral out of control, and I didn’t want to spiral out of control. And I’ve alluded to the fact that I’ve learnt personally a lot about myself during the six month’s research and how I use social media. And for me that Monday when I made that decision [to disengage from self-harm content] it was really positive.”</td>
</tr>
<tr>
<td><strong>IDF</strong></td>
<td></td>
</tr>
<tr>
<td>Regaining control</td>
<td>“I think just to prevent myself from falling down a rabbit hole and looking at content that I know wasn’t good for me. And just feeling like so I’ve always been one of those people that I sort of like to sort of physically remove myself from things and remove things from me. So that’s one of the reasons why I do that.”</td>
</tr>
<tr>
<td>Mental well-being</td>
<td>“So, I think it was about a month ago now and someone who was quite active in Twitter (X) and the mental health recovery community passed away from what I feel was suicide. That’s not been confirmed but when all of that happened, I did take a couple of days off the internet just to, I guess, process things there.”</td>
</tr>
</tbody>
</table>

**Reengagement With Web-Based Self-Harm and Suicide Content**

Participants described various reasons for reengagement with web-based self-harm and suicide content, including a “fear of missing out” with the community (IDA, IDC, IDM, and IDK), wanting to use the site or platform to access other types of content (IDE, IDF, and IDI), procrastination or boredom (IDI and IDK), and the need to perform web-based responsibilities (eg, work or moderating roles within self-harm and suicide communities; IDI, IDA, and IDB). Some participants (5/14, 36%) claimed that they weighed the advantages and disadvantages of web-based content engagement before reengaging. Several participants (3/14, 21%) felt that the benefits of reengaging with self-harm and suicide content, such as feeling part of a community, were enough to justify the potential risks. As this participant noted, while the experience could be upsetting at times, it was still considered useful in light of the rewards of engagement:

> With Twitter [X], I deleted that as well, but I felt like actually I missed the community and felt out of touch with people, so I actually found that useful [reengaging], as much as sometimes it’s upsetting, it was useful. [IDK; baseline interview]

There were also differing accounts of reengagement due to mental health improvements and declines. One participant described feeling more in control once their mental health was stable:

> I think I was in a better place emotionally and with my mental health...And I just felt stronger, I genuinely felt stronger and more positive. It’s a better time of year for me...I’ve started some new medication...So, I think that’s a factor as well and me feeling stronger to go back online. I just felt ready. [IDC; final interview]

Similarly, another participant felt that they were more able to view and contribute to self-harm and suicide content in a positive way when their mental health improved:

> When my mental state is better, and I can go back on. I feel like I can share, and I can help someone. [IDM]

Alternatively, some participants (2/14, 14%) described past reengagement with self-harm and suicide content to “punish”...
Despite this, they also reported beginning to reengage with Twitter toward the end of the study:

I think just because I feel a bit better, I wanted to check-in on other things on there on my newsfeed, wall thing. [IDC; final interview]

However, they reengaged shortly after this event after wanting to check whether “they [the site] put the resources [suicide methods literature] back” (IDH; baseline interview) following their removal after the media article publication.

At the midpoint interview, IDH had again disengaged from and reengaged with the forum following the death by suicide of a relative. On describing their reengagement, they reported that “it was to check [that] the sources of getting stuff [suicide materials]...are still available” (IDH; midpoint interview) as they were aware of scams related to sourcing materials and wanted to verify that their plans would still be viable.

Limiting Content Engagement: Strategies

After spending time engaging with web-based self-harm and suicide content, half (7/14, 50%) of the participants began to develop strategies to limit their content engagement. These included less “arbitrary ‘liking’” to curate their feeds (IDI), clearing search histories to “remove temptation” (IDJ), “blocking” or “muting” certain terms or phrases—such as “suicide” and “self-harm” (IDC, IDF, and IDK)—closing their direct messages so that other users were unable to message them (IDI and IDH), “self-banning” so that they were unable to post methods literature—back” (IDH; baseline interview) following their removal after the media article publication.

However, these participants described differences in their reengagements over time. IDI reported how their reengagement behavior changed during the study. When feeling low, they now went on the web and sought out non–self-harm or suicide content.

Other participants also described attempts to engage with self-harm or suicide content differently during the reengagement period with the aim of regaining control. This included observing interactions rather than actively participating or limiting engagements with specific content on platforms or sites:

Recently I’ve just been viewing [prosuicide threads] and I’ve got to fight the urges [to interact]. [IDI; baseline interview]

However, most participants who disengaged briefly would return to their usual use of web-based content. This reengagement process highlighted weaknesses in participants’ ability to exercise control over web-based actions, leaving users vulnerable to reencountering triggering content on the web and beginning the disengagement-reengagement cycle again:

I basically quit Tik Tok for three weeks because I was like I just can’t deal with it anymore because it’s just so hard to block everything and I was also thinking is it actually good for my mental health and it’s not... [IDK; baseline interview]

...but you are back on TikTok now, is that right? [Interviewer; baseline interview]

I think I was just bored really, and I thought do you know what I’ll just download it for the afternoon, and... [IDK; baseline interview]

Longer Periods of Disengagement

In total, 14% (2/14) of the participants in this study disengaged for up to a month before reengaging with specific platforms. One of these participants disengaged after a second death by suicide in their Twitter community. Notably, an earlier death by suicide of another member of the same community had increased their frequency of accessing the platform.

During their Twitter disengagement, the participant continued their engagement with a self-harm support group on Facebook, where they felt less connected:

I think because I haven’t known them [Facebook users] so long and there’s certain people [on Twitter, subsequently rebranded as X]...who post frequently, several times possibly in a day...I think the more you get to know people and recognise the handles, I know it sounds bizarre, but you feel yourself becoming closer to them. [IDC; final interview]

Despite this, they also reported beginning to reengage with Twitter toward the end of the study:
to disengage. Some also described a sense of comfort and reassurance knowing that content continued to exist on the web:

> It’s a cushion for people who need that. [IDA; midpoint interview]

In addition, others reported a desire to “give back” and described having a peer support role themselves as a future goal following their recovery (IDI, IDM, and IDB):

> I’m looking forward to where I improve myself, and maybe be able to talk to more people and if possible, reach out to them, and offer that help. [IDM; final interview]

> I’m also very passionate about sharing stuff I’ve learnt. When people are in that place that I remember being in and you can see it from their posts, I think, “I’ve just learnt about something that will help them. I’ll pass that on to them.” It’s helping to build that confidence back up to do those posts and say those things on there. [IDB; final interview]

Some participants in this study (3/14, 21%) also highlighted that they were unable to find alternative web-based or offline spaces that satisfied their current needs. One participant mentioned that disengaging from their current preferred site or platform could be detrimental and so expressed no wish to “move on”:

> What I’m trying to say is that there is nowhere for people when they come off that website. There’s no safe space. There’s nowhere. If you’ve been on that particular site [prosuicide forum] for the reason of wanting to die and you didn’t, there’s nowhere. You’ll go on something and just get these silly comments or things where there’s lack of understanding that just escalates a situation. [IDH; midpoint interview]

A few participants in this study (3/14, 21%) did recognize the potential costs associated with continuing to engage in web-based spaces with self-harm and suicide content but compromised, stating that “I do feel that the benefits outweigh the risks” (IDC; baseline interview). For these individuals, the draw of the positive aspects of such content was strong enough to justify the potential negative consequences. Other participants (2/14, 14%) struggled to weigh the risks and benefits of engaging with self-harm and suicide content as they felt that the positive and negative aspects of engaging with content were more intertwined, making it difficult to control what they were exposed to:

> I’d say that online is very complicated, depending on what you feed your mind, because it has both positive and negative information, so sometimes it’s good to your mind, and sometimes not. Also, if you are coming across lots of negative things in a group, that can be harmful, like self-harm pictures. But it’s also good to look in those groups for people who are offering help for those things, so that you are learning how to help yourself. [IDM; final interview]

Ultimately, this resulted in both sets of participants remaining vulnerable to the negative effects of harmful content as they continued to engage with web-based self-harm and suicide material.

**Discussion**

This study showed that those engaging with web-based self-harm and suicide content experienced nonlinear journeys that were characterized by 5 key themes: “initial engagements with web-based self-harm or suicide content,” “changes in what self-harm or suicide content people engage with and where,” “changes in self-harm or suicide behaviors associated with web-based self-harm or suicide content engagement,” “the disengagement-reengagement cycle,” and “future perspectives on web-based self-harm and suicide content engagement.”

**Cognitive Flexibility Versus Cognitive Rigidity**

Constructs that may explain behavior change and maintenance within these themes are cognitive flexibility and its counterpart, cognitive rigidity [33]. Cognitive flexibility refers to an openness in thinking and behavior, which allows an individual to consider alternative perspectives and approaches. In contrast, cognitive rigidity is the tendency to adhere to specific thought and behavior patterns, making it challenging to change one’s mindset or actions [33]. Previous research has identified a relationship between cognitive rigidity and suicidal ideation [34] and between cognitive rigidity and self-harm [35]. Another study showed that cognitive flexibility can result in engagement in multiple methods of self-harm [36]. This indicates that the construct of cognitive flexibility may provide important insights into the behavior changes over time associated with web-based self-harm and suicide content engagement. This discussion will explore the ways in which cognitive flexibility was impacted by participants’ mental health and control over decision-making and how this influenced their web journeys.

Previous research has identified gaps in clinical support as a key motivator for web-based self-harm and suicide content engagement [2]. The causes for initial engagement in this study were consistent with this, with participants reporting a lack of support but also a reluctance to engage with clinical services due to previous experiences. This suggests a high level of cognitive flexibility among participants during their first engagement with web-based content, with mental distress and a lack of alternative resources potentially triggering participants to be more open to web-based options. This emphasizes the critical need for accessible offline options during the early stages of mental health decline, preventing vulnerable people from resorting to web-based avenues where they may lack the control or knowledge to engage safely.

When participants were unable to find content that was immediately desirable to them, they explored different self-harm or suicide–related material on the web. Often, this led to spontaneous browsing of self-harm and suicide–related links or hashtags, a behavior characterized as “pessimistic browsing” [13]. While this reflects a high level of cognitive flexibility among participants, it also indicates what might be a lack of behavioral control, making participants vulnerable to potentially harmful encounters. Later on in web journeys, when browsing routines had been established, some reported similar bouts of...
“pessimistic browsing” and harmful behaviors that they considered spontaneous. These episodes of cognitive flexibility were usually triggered by unexpected exposure to web-based self-harm or suicide content, where impulsive tendencies resulted in exploring this novel content further or, in one case, in trying a new self-harm method. This indicates that unexpected engagements with self-harm or suicide content may act as a stimulus for activating cognitive flexibility, resulting in changes in behavior [37]. When experiencing poor control, this cognitive flexibility may lead to a willingness to engage in potentially unhelpful or harmful behaviors when engaging with self-harm or suicide content [38].

Outside of episodes of cognitive flexibility, participants largely accessed web-based self-harm or suicide content in a routine pattern while also reporting a greater feeling of behavioral control. This cognitive rigidity often worked as a coping mechanism allowing for regular engagement with resources of help and support. However, in instances in which content included images or videos of “fresh self-harm,” suicide, or self-harm and suicide method information, repeated engagements were more likely to have negative effects on participant well-being and sometimes led to increased severity of harm to themselves. This shows that, while some perceived their cognitive rigidity as a form of control, it may ultimately have diminished their ability to make decisions to protect themselves and seek alternative positive coping mechanisms [39].

Similarly, participants reported increased engagement with self-harm or suicide content during dips in their mental health, which were prevalent in this study, as indicated by fluctuations in their well-being measure outcomes over time. These engagements, recalled as “habitual” or “addictive,” highlighted a loss of control during these mental health dips. Previous research has shown a relationship between cognitive inflexibility and addictionlike behaviors [40,41], and a more recent study [42] has indicated that distress-driven impulsivity, in which a person is likely to make rash decisions due to a negative mental state, alongside cognitive rigidity, can lead to addictionlike eating behavior. This emphasizes the potential risk of overreliance on web-based self-harm and suicide content as a coping strategy, particularly during periods of mental health decline, when participants may become more vulnerable to the content they are engaging with. The addictive nature of this behavior also has the potential to negatively impact other important aspects of people’s lives, such as social or occupational functioning [43].

**Disengaging and Reengaging**

Key to self-preservation during the web journey was participants’ ability to disengage from web-based spaces. Most participants recorded disengagements in their web journeys in response to life experiences or stressors, such as work stress, bereavement, or a rapid deterioration in mental health. This indicates a resurgence of cognitive flexibility, which reflects previous research showing that individuals become more open to alternative solutions when their perspective is challenged by a significant life event [44]. Although participants demonstrated disengagement attempts from the content during these times, they were usually temporary. This represents a brief state of cognitive flexibility, with reengagement often occurring within days. When disengagement was longer, it tended to coincide with more significant life events such as bereavements, which may indicate more prolonged changes to behavior following extreme circumstances and mental health declines.

Participants also reported that their mental state dictated whether they returned to more helpful or harmful content during the reengagement period. Participants experiencing poorer mental health were more likely to reengage with content they described as “negative” as a type of self-punishment or as a preventative measure against potentially worsening self-harm or suicide behavior. They were also more likely to post their own content, which included help-seeking comments, suicide method inquiries, and “depressive” blog posts. This showed that, although some participants attempted to use their online communities for help during mental health dips, others could find themselves returning to potentially unhelpful or harmful situations. This reflects previous research showing that “active” suicidal ideation is associated with greater cognitive rigidity compared to “passive” suicidal ideation [45]. Often, when reengaging during mental health declines, use would also regress to “addictive” or “habitual” engagements. However, when experiencing mental health improvements during reengagement periods, those who had previously engaged with more “positive” or “recovery-based” content would be more likely to return to this material. This indicates that cognitive rigidity is influenced by mental health state and that, when experiencing mental health changes, participants’ well-being is reliant on earlier web-based encounters with self-harm and suicide content.

**Upskilling Users**

Despite this, some participants did experience lasting adaptations to the ways in which they interacted with the content. These more enduring changes were attributable to the skills that participants reported developing in digital efficacy and metacognition. Digital efficacy skills include the ability to use web-based safety mechanisms such as muting, blocking, and self-banning. Participants with digital efficacy skills in the study felt safer and more protected, which acted as a preventative measure against cognitive rigidity. In this study, these participants were likely to be younger, which reflects research showing that digital literacy skills are significantly better in younger cohorts [46]. Despite this, evidence also shows that digital literacy skills can be built over time [47]. This is consistent with the experiences of some participants in this study who reported that their web experiences prompted them to organically develop digital skills and strategies to stay safe over time. This finding has important implications for industry leaders, who should be encouraged to consider ways in which they can empower users by improving accessibility to safety mechanisms on their platforms and sites.

Metacognition skills, or the ability to reflect on one’s own thoughts and behaviors to change one’s responses, were evident in some of the participants [48]. Specific metacognitive abilities such as self-awareness and self-regulation resulted in greater control over their cognitive flexibility. Some described gaining metacognition skills such as self-awareness before their
participation in the study, which allowed them to recall changing their responses to content from self-harm behavior to vicarious viewing of material. Others identified metacognitive skills gained through therapeutic input as well as through monitoring web-based behavior and reflecting on it during the study. This may reflect a Hawthorne effect [49] in which participant behavior shifts due to their awareness of being observed in a study. Several diary and ecological momentary assessment interventions have resulted in improved metacognitive skills [50] (Haime, Z, unpublished data, January 2024), and it is possible that metacognition was acquired in this study as a result of completing the research diary. In cases in which participants’ metacognition developed during the study, they noted improvements in their mental health, also indicated by improvements in their well-being outcomes over time. This resulted in the type of self-harm and suicide material they engaged or reengaged with changing from “negative” or “depressive” to “recovery-based” or “positive” in nature. This shows that self-awareness and control while experiencing mental health improvements lead to positive content engagement during periods of cognitive flexibility in this population and has important implications for the development of future target metacognitive interventions.

**Remaining Vulnerable on the Web**

However, shifts toward recovery-based content did not necessarily mean that participants were able to fully disengage from their previous self-harm and suicide material. Sometimes, as recovery-based content coexisted alongside more harmful content in web spaces, there was no alternative place in which to access it. On the other hand, some participants expressed a strong connection with the communities they had previously engaged with and reported intentions to remain active in these spaces with a desire to provide support to others. While this altruistic act had benefits, including the ability to continue drawing on support when needed, it left them vulnerable to potentially triggering content. These findings emphasize the strength of web-based self-harm and suicide spaces as a source of comfort and security, which is consistent with previous research on engagement motivators [2,7,10]. Thus, although participants became more aware of the negative outcomes of engaging with web-based self-harm and suicide content and were better able to manage them, the perceived benefits of being involved in a community of like-minded individuals with similar experiences often outweighed the potential costs.

**Limitations**

Participants in this study used a diverse range of web-based platforms to access self-harm and suicide content, meaning that attempts to identify patterns in behavior related to the sites used were challenging. However, as common behaviors were observed across participants, it was possible to draw conclusions more broadly about how people engage with web-based self-harm and suicide content over time. Diaries in this study were completed daily by participants, but many had missing entries or were filled out retrospectively. This diluted the advantages of “in-the-moment” diary data capture and resulted in some interview topic guides being less informed by participant data. Despite this, participants reported finding the diaries largely acceptable, and some reported additional benefits to their metacognitive ability related to their completion [51]. While visually observing quantitative data allowed us to identify patterns consistent with participant-reported mental health fluctuations and slight improvements toward the end of the study, our inability to conduct statistical analyses prevented us from identifying any significant differences in participant well-being changes. However, the rich qualitative data and trajectory analysis provided valuable insights into the individual pathways and factors influencing web-based engagement.

In terms of participant characteristics, this study had an underrepresentation of male individuals. Although steps were taken to target male-orientated web spaces for recruitment, uptake remained poor. Furthermore, responses to recruitment were limited, which resulted in possible selection bias and may have affected the representativeness of the sample. In addition, we did not collect data on the educational level or socioeconomic status of the participants involved, limiting our understanding of how demographic characteristics may affect web-based experiences. Half of those recruited at baseline were also lost to follow-up. Strategies were undertaken to limit attrition, including at least 3 attempts to communicate with participants before they were considered lost to follow-up. High attrition rates are consistent with longitudinal studies of self-harm and may represent a selection bias among study completers [52]. Finally, although cognitive flexibility provides a useful framework with which to interpret our findings, it is important to acknowledge that there may be alternative explanations.

**Future Implications**

The findings of this study have shown that there are ongoing challenges in navigating the web environment for those engaging with self-harm and suicide content. A key priority for future research should be to establish how engaging with web-based content can be better managed in this population. Consequently, the following should be considered:

1. Inaccessibility to offline support was a significant motivator for participants’ willingness to explore web-based self-harm and suicide–related resources. Therefore, the availability of offline help and support is necessary to limit or moderate initial web-based engagements.
2. This study offers evidence that greater metacognition and digital efficacy can positively influence web-based behavioral control. As individuals are unlikely to completely disengage from web-based content, it is important to prioritize upskilling users. Therefore, interventions should be developed focusing on improving digital literacy and metacognitive skills, such as the diary-based reflections used in this study.
3. A deeper examination of the perceived benefits of web-based engagement is necessary to ensure that these needs can be met in a safer manner both on the web and offline. In addition, it is crucial to critically evaluate the helpfulness of these perceived benefits, such as the impact of “vicarious living” through observing others self-harm.
4. Web-based industry leaders need to produce more tools that empower individuals to regain control of their
web-based engagement and improve the safety of web-based spaces where self-harm and suicide content is available. This may include changes to the functions of social media, such as providing further control and management options to users over algorithms and hashtags.

Conclusions
A balance between cognitive flexibility and rigidity seems necessary to protect individuals when engaging with self-harm and suicide content on the web. While cognitive flexibility may be helpful in certain situations such as exploring new coping strategies, it can also leave individuals vulnerable to harmful content. On the other hand, cognitive rigidity, or the tendency to repeatedly engage with the same type of content, can lead to desensitization, potential impairments in functioning, and an increased severity of harm to oneself. Cognitive rigidity can also prevent people from engaging in harmful behaviors and allow them to consistently engage with content that is helpful and positive. Although life events and changes in mental health state could trigger cognitive flexibility resulting in behavior changes, these were unlikely to become permanent unless participants developed skills such as digital efficacy and metacognition that gave them greater control over their behavior. Despite this, even with improved skills for recognizing and managing web-based risks, individuals still perceived that the benefits of web spaces outweighed the costs, making it difficult to fully disengage.

Data Availability
The data sets generated and analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Supplementary material including data confidentiality statement, additional tables, and descriptive analysis line graphs. [DOCX File, 43 KB - infodemiology_v4i1e47699_app1.docx]

Multimedia Appendix 2
Example safety plan. [DOCX File, 64 KB - infodemiology_v4i1e47699_app2.docx]

References


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PMID:
The Use of Social Media to Express and Manage Medical Uncertainty in Dyskeratosis Congenita: Content Analysis

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Abstract

Background: Social media has the potential to provide social support for rare disease communities; however, little is known about the use of social media for the expression of medical uncertainty, a common feature of rare diseases.

Objective: This study aims to evaluate the expression of medical uncertainty on social media in the context of dyskeratosis congenita, a rare cancer-prone inherited bone marrow failure and telomere biology disorder (TBD).

Methods: We performed a content analysis of uncertainty-related posts on Facebook and Twitter managed by Team Telomere, a patient advocacy group for this rare disease. We assessed the frequency of uncertainty-related posts, uncertainty sources, issues, and management and associations between uncertainty and social support.

Results: Across all TBD social media platforms, 45.98% (1269/2760) of posts were uncertainty related. Uncertainty-related posts authored by Team Telomere on Twitter focused on scientific (306/434, 70.5%) or personal (230/434, 53%) issues and reflected uncertainty arising from probability, ambiguity, or complexity. Uncertainty-related posts in conversations among patients and caregivers in the Facebook community group focused on scientific (429/511, 84%), personal (157/511, 30.7%), and practical (114/511, 22.3%) issues, many of which were related to prognostic unknowns. Both platforms suggested uncertainty management strategies that focused on information sharing and community building. Posts reflecting response-focused uncertainty management strategies (eg, emotional regulation) were more frequent on Twitter compared with the Facebook community group ($\chi^2_{1}=3.9; P=.05$), whereas posts reflecting uncertainty-focused management strategies (eg, ordering information) were more frequent in the Facebook community group compared with Twitter ($\chi^2_{1}=55.1; P<.001$). In the Facebook community group, only 36% (184/511) of members created posts during the study period, and those who created posts did so with a low frequency (median 3, IQR 1-7 posts). Analysis of post creator characteristics suggested that most users of TBD social media are White, female, and parents of patients with dyskeratosis congenita.

Conclusions: Although uncertainty is a pervasive and multifactorial issue in TBDs, our findings suggest that the discussion of medical uncertainty on TBD social media is largely limited to brief exchanges about scientific, personal, or practical issues rather than ongoing supportive conversation. The nature of uncertainty-related conversations also varied by user group: patients and caregivers used social media primarily to discuss scientific uncertainties (eg, regarding prognosis), form social connections, or exchange advice on accessing and organizing medical care, whereas Team Telomere used social media to express scientific and...
personal issues of uncertainty and to address the emotional impact of uncertainty. The higher involvement of female parents on TBD social media suggests a potentially greater burden of uncertainty management among mothers compared with other groups. Further research is needed to understand the dynamics of social media engagement to manage medical uncertainty in the TBD community.

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**KEYWORDS**
social media; medical uncertainty; telomere biology disorder; dyskeratosis congenita; social support

**Introduction**

**Background**

Medical uncertainty is a common experience in rare diseases and may combine with limited scientific knowledge and access to peer groups to impede a patient’s ability to seek and adhere to medical treatments [1] and intensify health-related anxiety, decreasing quality of life for patients and their caregivers [2,3]. Dyskeratosis congenita (DC) is a rare telomere biology disorder (TBD) associated with very high risks of bone marrow failure, pulmonary and liver disease, cancer, and other medical conditions. Diagnosis is challenging because of its wide phenotypic spectrum, including the classic DC triad (nail dystrophy, abnormal skin pigmentation, and oral leukoplakia) with pediatric bone marrow failure, middle-age presentation with pulmonary failure or aplastic anemia, abnormally short telomere length, or detection of pathogenic germline variants in >18 different genes [4]. Although age of onset is variable, DC often presents in childhood and adolescence, with most patients experiencing their first symptoms before the age of 20 years [5]. Diagnosis frequently results in a lifetime commitment to screening to detect progressive clinical manifestations of DC, including cancers across multiple organ systems [5]. Owing to the complexity and rarity of DC and related TBDs, patients and their families often have long diagnostic journeys, face complicated health decision-making, and frequently do not have access to medical professionals and supportive peers who are familiar with their condition. This situation likely creates a substantial burden of medical uncertainty for patients with TBDs and their families. Although medical uncertainty has been associated with increased anxiety and difficulty with decision-making in rare diseases and cancer occurrence and recurrence [6-11], to date, no research has addressed the experience or management of medical uncertainty in the TBD context.

As outlined in a previously published taxonomy developed by Han [12], uncertainty in medicine arises from multiple sources (eg, probability, ambiguity, and complexity) and focuses on scientific, personal, and practical issues. These situations activate a variety of management strategies to address uncertainty, which are primarily cognitive, emotional, and relational in nature. Uncertainty management strategies may target ≥1 sources or issues of uncertainty and are defined as belonging to ≥1 of the following approaches: seeking information to fill knowledge gaps (“ignorance-focused”), reducing or increasing attention to unknowns (“uncertainty-focused”), ameliorating adverse psychological effects of uncertainty (“response-focused”), and fostering interpersonal relationships to engage with uncertainty as a shared experience (“person-focused”). In situations where uncertainty cannot be reduced, these strategies may mitigate its negative mental health impact and help individuals achieve an adaptive, optimal balance of responses to uncertainty (uncertainty tolerance).

The rarity of TBDs suggests a potential role for internet-based platforms to deliver social support by bridging geographic, knowledge, and community network limitations. Social support, a complex concept encompassing a variety of helping social interactions [13], includes four main types: (1) expression of empathy and care (emotional), (2) provision of tangible assistance (instrumental), (3) provision of knowledge or facts (informational), and (4) evaluative feedback about task performance or personal qualities (appraisal) [14]. Research suggests that social support decreases the experience of stress, anxiety, and depression and improves the overall quality of life in populations experiencing medical uncertainty [8,10,15-17]. The benefit of social support has been demonstrated in patients with Li-Fraumeni syndrome, a rare genetic cancer predisposition, where informational, tangible, spiritual, and emotional support from in-person sources enhanced positive coping capacities [18]. Social media platforms such as Facebook and Twitter have been identified as important resources for social support in rare disease contexts [19-24], and disease-specific social media support has been recommended in oncology [25], rare genetic disease [26-28], and other stigmatized or rare diseases [29-31]. In addition to increasing access to information and social networks, continued participation in socially supportive internet-based communities may also build capacities for uncertainty tolerance [10,17,32-38]. Although social media has the potential to bridge geographic or social boundaries, its use is often concentrated in select populations, limiting its reach and potentially inhibiting its use by some groups [39,40]. In addition, dynamics observed on social media posts may not reflect real-life experiences and are limited in depth and detail, increasing the potential for misinterpretation [39]. Social media can also spread misinformation with damaging consequences, especially in high-uncertainty health contexts [41-43].

**Objectives**

Although extensive research has investigated the psychosocial benefits of internet-based health forums for patients and their caregivers [23,28,29,44-51], there is still a need to evaluate the use of social media to express or manage medical uncertainty in rare diseases. Specifically, we need to examine social media use for expressing and managing medical uncertainty in TBDs to understand the experience of medical uncertainty in this...
context and to build evidence to improve health communication and uncertainty management interventions [52]. This exploratory study aims to review social media posts created by and targeted at patients with TBDs and their caregivers to (1) measure the frequency of uncertainty-related posts; (2) catalog the issues, sources, and types of uncertainty and uncertainty management strategies; (3) measure user engagement with different post types; and (4) explore the relationship between uncertainty and social support. To achieve these aims, we reviewed all publicly available social media sites owned and maintained by Team Telomere (previously DC Outreach, Inc), the oldest and largest patient advocacy organization for individuals, caregivers, and families affected by TBDs worldwide [53]. The social media of Team Telomere constitutes the most expansive and accessible body of internet-based TBD-related content, inclusive of a variety of user perspectives. The variety of posts by users with diverse connections to TBDs (eg, medical providers, patients, caregivers, and health advocacy nonprofits) makes Team Telomere’s social media an ideal data source for understanding the range and dynamics of medical uncertainty communication and social support exchange in the TBD context.

Methods

Ethical Considerations

Data collection was undertaken in partnership with Team Telomere following best practices guidelines for social media research [54] and was approved by the National Institutes of Health Institutional Review Board (IRB 000722).

Data Source

The source of data for this study was all publicly available social media owned and maintained by Team Telomere. These sites included the Team Telomere Twitter page [55], the Facebook main page [56], and a public Facebook community group [57] (Table 1). All the sites were open to the public and had no eligibility requirements for membership. Content across all platforms was monitored by Team Telomere to ensure appropriate adherence to community guidelines, and Team Telomere’s staff removed posts with offensive or scientifically inaccurate content. The Facebook main page and Twitter accounts were created to promote the work of Team Telomere “supporting families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders” [56]. The Facebook community group was created in response to social isolation following the COVID-19 pandemic as “a place to share our everyday lives in the spirit of promoting and maintaining connections among our Team Telomere/Dyskeratosis Congenita/Telomere Biology disorder community” [57].

Table 1. Data source characteristics at the time of the study.

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Facebook community group</th>
<th>Facebook main page</th>
<th>Twitter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creation date (y)</td>
<td>2020</td>
<td>2010</td>
<td>2010</td>
</tr>
<tr>
<td>Followers, n</td>
<td>187</td>
<td>1637</td>
<td>1933</td>
</tr>
<tr>
<td>Posts, n</td>
<td>511</td>
<td>1815</td>
<td>434</td>
</tr>
</tbody>
</table>

aRepresents posts captured during the study period (June 2019 to December 2021).

Inclusion

All posts made on Team Telomere’s social media (Facebook main page: n=1818, Facebook community group: n=518, and Twitter: n=441) between June 2019 and December 2021 were eligible for inclusion. This time frame encompasses the period starting 1 year before the Facebook community group. This group was created in June 2020 as a platform for social connection during the COVID-19 pandemic. Posts were excluded from the analysis if they were (1) removed by the user or Team Telomere (n=5), (2) duplicate posts with identical content from the same day (n=2), or (3) posts without image or text content (n=7). This resulted in a total of 2760 posts, with both primary posts and comments considered unique. The post was used as the unit of analysis and included all content visible to a passive social media user. Additional post content that required clicking links to external sites or embedded audiovisual materials was not included in this study.

Data Extraction and Quality Control

We met with Team Telomere’s leadership (eg, executive director and board) before conducting the study and cocreated a community-based research contract outlining parameters. Although all data were publicly available and Facebook data were manually extracted by the authors, Team Telomere facilitated data extraction from Twitter by sharing downloaded images and text files made available to them as account owners. We used the post (original or responses), rather than post creator, as the unit of measurement and did not collect identifying information of the social media users or interact directly with users.

Data were extracted directly from each social media site manually through (1) screenshots saved as deidentified image files and (2) cut-and-paste of post text into an Excel (Microsoft Corporation) spreadsheet. For the Facebook community group, we assigned unique ID numbers to post creators using public data (usernames) to calculate how many unique users engaged in conversation threads, and we viewed the publicly available profile images to assess observed sex and race. Posts were assigned a unique ID number within Excel, and additional data were manually extracted for each post to capture the post popularity (number of likes, shares, and comments), post type (primary post or comment), and types of emojis present. Demographics of post creators (observed gender and race) were assessed through an independent review of profile images and
profile names by 3 coders (EP, HR, and NE). Quality control for data extraction was performed on a subset of the data \( n=100 \) posts by NE, and intercoder reliability was assessed during the multiple-reviewer coding process.

**Coding and Analysis**

We used a combined content analysis mixed methods approach to analyze the social media data [58]. This involved qualitative analysis (coding by multiple independent reviewers) and quantitative analysis (frequency and chi-square testing). Constructs were defined through codebook development using deductive (theory driven) approaches, whereas qualitative themes were identified through inductive (data driven) discussion, as described in greater detail in the Methods section. The analysis was performed separately for each social media source, 2 Facebook pages (the Team Telomere main page and a separate community group page established in 2020) and the Team Telomere Twitter feed, resulting in the creation of 3 separate data sets (Facebook main page: \( n=1815 \), Facebook community group: \( n=511 \), and Twitter: \( n=434 \)). A subset of Facebook community group posts \( n=77 \) (12 primary posts and 65 comments) was reviewed by 3 coders and used to inform uncertainty inclusion criteria (Multimedia Appendix 1) and the codebook (Multimedia Appendix 2) developed to deductively identify the presence or absence of uncertainty and social support constructs defined in the Han Taxonomy of Medical Uncertainty [12] and the Social Support Framework [14]. Then, all posts were coded for uncertainty and social support by 3 independent coders (EP, HR, and PKJH), with all disagreements in coding resolved through discussion and consensus. Posts identified as uncertainty related in the Facebook community group \( n=156 \) and Twitter \( n=210 \) were then independently subcoded (EP, HR, and PKJH) for uncertainty issues, sources, and management strategies according to the codebook definitions detailed in the Measures section. Data were then arranged by subcode and reviewed qualitatively to detect themes that emerged from the data and were refined through discussion between coders.

**Measures**

**Intercoder Reliability**

Intercoder reliability among the 3 coders was measured across all social media types for the initial coding of dichotomous social support and uncertainty variables using Cohen \( \kappa \). The analysis found acceptable reliability of independent coders in assessing the presence or absence of any social support \( (\kappa \text{ value range across all platforms}, 0.79-0.95) \) and uncertainty \( (\kappa \text{ value range across all platforms}, 0.58-0.93) \) across all social media platforms. Regardless, all discrepancies were mutually resolved through coder consensus.

**Post Creator Characteristics**

Post creator characteristics were visible from profile images and usernames that appeared alongside each post. Posts from Team Telomere’s organizational account were created by staff members, often identified in the post context (eg, executive director, communications director, or board member). We did not scrutinize user profiles to detect the activity of nonhuman bots; however, in the context of the small population with this rare disease, most users could be positively identified as human beings from the context of their posts and history of participation in organizational events. Post creator characteristics, including observed gender and race, were assessed by 3 independent coders’ perceptions of publicly available usernames and profile images. Disagreements between coders resulted in the characteristic being coded as “unknown.”

**Uncertainty Issues, Sources, and Management Strategies**

Posts were coded as uncertainty related according to 1 of the following types: (1) uncertainty-related primary posts, (2) uncertainty-related comments, and (3) non–uncertainty-related posts captured within a thread where 1 or more other post was uncertainty related. For the Facebook community group and Twitter, posts identified as uncertainty-related primary posts or comments were further analyzed to determine the presence or absence of sources (ambiguity, complexity, and probability), issues (scientific, personal, and practical), and attributes of uncertainty management strategies (ignorance focused, uncertainty focused, response focused, and person focused). We defined sources of uncertainty as insufficient, unreliable, or contradictory information (ambiguity); information features, such as multiple or interacting causes and effects that make a phenomenon difficult to understand (complexity); and fundamental randomness or indeterminacy of a phenomenon that makes outcomes unpredictable (probability). We defined issues of uncertainty as pertaining to the causes, diagnosis, prognosis, or management of disease (scientific); the impact of disease on aspects of personal life (personal); and logistical issues related to health care or disease management (practical). Although the data did not allow assessment of intent to manage uncertainty, we searched posts to identify evidence of management strategies with \( \geq 1 \) of the following attributes: (1) providing or seeking information to fill knowledge gaps (ignorance focused), (2) reducing or increasing attention to unknowns to gain or relinquish a sense of control (uncertainty focused), (3) ameliorating the adverse psychological effects of uncertainty (response focused), and (4) fostering interpersonal relationships to engage with uncertainty as a shared experience (person focused).

**Social Support**

Posts were categorized as containing social support through qualitative coding by 3 independent reviewers (EP, HR, and PKJH) following definitions developed over decades of research in social support theory [14,59,60]. Dichotomous variables were assigned to indicate the presence or absence of social support and the presence or absence of specific types of support within 4 domains (appraisal, emotional, informational, and instrumental). These domains were defined as (1) giving or receiving evaluative feedback (appraisal); (2) giving or receiving indicators of care, love, appreciation, empathy, or sympathy (emotional); (3) giving or receiving knowledge (informational); and (4) giving or receiving tangible support (instrumental), as recently formulated by Holt-Lunstad and Uchino [14]. Assignment to social support domains was not mutually exclusive.
Relationship Between Social Support and Uncertainty

We examined the relationship between social support and uncertainty by comparing frequencies and chi-square tests. Posts were coded as dichotomous variables for uncertainty (uncertainty related, non–uncertainty related), uncertainty subtypes (presence or absence), and social support subtypes (presence or absence). We examined the frequencies of social support subtypes in uncertainty-related posts overall, by social media platform (Facebook community group and Twitter) and by post type (primary post or comment). We performed chi-square tests to determine the strength of the relationship between uncertainty-related posts and social support across platforms and for uncertainty-related posts by post type (primary post, comment, thread) and issue subtype (scientific, personal, practical).

Popularity and Engagement

Popularity on the Facebook community group, Facebook main page, and Twitter was defined as the sum of comments, likes, and shares. Engagement was defined separately for social media types (Facebook community group and Facebook main page vs Twitter) owing to differences in user tracking approaches between Facebook and Twitter platforms. Facebook engagement was defined as the sum of conversations (number of responses generated by a post or comment), voices (number of unique users responding to a post or comment), and depth (number of back-and-forth responses). Engagement on Twitter was defined as the sum of detail expands (clicks to view more of the post), profile visits, link clicks, and video views. Engagement was also measured for the Facebook community group by examining the proportion of users who contributed posts and post frequencies by author.

Sentiment

Sentiment analysis was performed through manual annotation by 2 independent coders, with differences resolved through consensus. Posts were assigned categorical sentiment variables according to the (1) frequency and (2) presence or absence of keywords and emojis. Unambiguous emotion words (eg, “happy” and “sad”) were chosen as keywords to indicate emotional valence, as described in other studies [61,62]. The emotional valence of emojis was assigned based on the emoji definition in internet-based emoji dictionaries and validated by a coder review of the emoji within the post context (Multimedia Appendix 3).

Results

Post Characteristics

A total of 2760 posts created on all platforms between June 2019 and December 2021 were included in this study. Across all platforms, most posts were created either by the executive director of Team Telomere or by individual users who were primarily identified as White, female, and parents of children affected by TBDs. Post characteristics differed by platform: on Twitter, most posts (368/434, 84.8%) were primary posts, most of which (384/434, 88.5%) were generated by the executive director of Team Telomere; Facebook main page posts were either primary posts (800/1815, 44.08%) or first-level comments (1014/1815, 55.87%) created by Team Telomere (860/1815, 47.38%) or individual users (955/1815, 52.62%); and on the Facebook community group, most posts (403/511, 78.9%) were comments to primary posts, in sometimes lengthy (up to 8 level) conversation threads created by 67 individual users (502/511, 98.2%). Posts across all platforms were written almost exclusively in English (Table 2).
| Table 2. Characteristics of posts on Team Telomere’s social media from June 2019 to December 2021 (N=2760). |
|---------------------------------|-------------------------------------------------|-------------------------------------------------|
| **Post type**                  | **Facebook community group (n=511), n (%)**     | **Facebook main page (n=1815), n (%)**          | **Twitter (n=434), n (%)**                      |
| Primary post                   | 108 (21.1)                                      | 800 (44.1)                                      | 368 (84.8)                                     |
| Comment                        | 403 (78.9)                                      | 1015 (55.9)                                     | 66 (15.2)                                      |
| **Language**                   |                                                 |                                                 |                                               |
| English                        | 487 (95.3)                                      | 1807 (99.6)                                     | 434 (100)                                      |
| Othera                         | 4 (0.8)                                         | 8 (0.4)                                         | 0 (0)                                          |
| Image only                     | 17 (3.3)                                        | 0 (0)                                           | 0 (0)                                          |
| **Creator type**               |                                                 |                                                 |                                               |
| Team telomere                  | 8 (1.6)                                         | 861 (47.4)                                      | 385 (88.7)                                     |
| Individual                     | 503 (98.4)                                      | 954 (52.6)                                      | 49 (11)                                        |
| **Observed creator sex**b      |                                                 |                                                 |                                               |
| Male                           | 25 (5)                                          | 69 (7.2)                                        | 5 (10)                                         |
| Female                         | 478 (95)                                        | 885 (92.8)                                      | 41 (83.7)                                      |
| Unknown                        | 0 (0)                                           | 1 (0.1)                                         | 3 (6.1)                                        |
| **Observed creator race**b     |                                                 |                                                 |                                               |
| White                          | 443 (88.1)                                      | 766 (80.3)                                      | 40 (81.6)                                      |
| Otherc                         | 46 (9.1)                                        | 30 (3.1)                                        | 6 (12.2)                                       |
| Unknown                        | 14 (2.8)                                        | 158 (16.6)                                      | 3 (6.1)                                        |
| **Observed creator telomere biology disorder relationship**bd | | | |
| Patient                        | 65 (12.9)                                       | 42 (4.4)                                        | 1 (2)                                          |
| Parent                         | 428 (85.1)                                      | 384 (40.3)                                      | 14 (28.6)                                      |
| Medical provider               | 3 (0.6)                                         | 31 (3.2)                                        | 10 (20.4)                                      |
| Othere                         | 5 (1)                                           | 59 (6.2)                                        | 22 (44.9)                                      |
| Unknown                        | 40 (8)                                          | 495 (51.9)                                      | 2 (4.1)                                        |
| Multiple                       | 129 (25.6)                                      | 126 (13.2)                                      | 0 (0)                                          |

aRespectively by platform (Facebook community group, Facebook main page, and Twitter), “other” language included Spanish (0.2%, 0.2%, and 0%), French (0.4%, 0.1%, and 0%). In the Facebook community group the following languages also appeared: Hebrew (0.1%), Italian (0.1%), Swedish (0.1%), and Māori (0.2%).

bIncludes frequencies for individual creator types only; does not include Team Telomere organization (Facebook community group: n=503, Facebook main page: n=954, and Twitter: n=49).

cRespectively by platform (Facebook community group, Facebook main page, and Twitter), “other” identified creator race and ethnicity included Latinx (7.7%, 1.5%, and 1.4%) and Arab or Middle Eastern (1.4%, 11%, and 0%).

dFrequency does not total to 100% because of some individuals occupying multiple categories.

eRespectively by platform (Facebook community group, Facebook main page, and Twitter), “other” creator telomere biology disorder relationship included grandparent (0%, 0.2%, and 0%), sibling (0.4%, 0.9%, and 0%), spouse (0%, 0.2%, and 0%), other advocacy organization representative (not Team Telomere; 0%, 0%, and 40.8%), and clinical or pharmaceutical industry representative (0%, 0.1%, and 4.1%).

**Qualitative Findings**

Qualitative analysis of posts revealed multiple uncertainty issues, sources, and management indicators. Issues included diagnostic, prognostic, therapeutic, and causal uncertainties (scientific); assembly of medical care teams, geographic or financial constraints, and limitations to research funding and dissemination (practical); and building “rare” identity, communicating complex health information to children, and reframing educational or developmental goals (personal). Sources of uncertainty included confusing symptoms and lack of clarity in medical advice (ambiguity); the TBD impact of TBD on multiple organ systems, managing medications or screening regimens, emotional confusion, and achieving scientific literacy across different medical specialties (complexity); and prognostic outcomes, behavioral health risks, or genetic inheritance (probability). Attributes of uncertainty management strategies included (1) information seeking, participation in research, and connection to trusted information sources and care providers (ignorance focused); (2) ordering...
multiple uncertainties through categorization, prioritization, and sequential narratives, including counting of survival days since transplant (uncertainty focused); (3) sharing positive emotions, portraying TBD experience as a source of strength, and encouraging relaxation (response focused); and (4) promoting a TBD community identity by creating a community mascot (a unicorn named “Tillymere”), recognizing community-specific celebrations (TBD month and transplant anniversaries), providing TBD-pride identifiers (T-shirts and swag), and making reference to Team Telomere as a “family” (person focused; Table 3).
Table 3. Uncertainty in telomere biology disorder (TBD) social media.

<table>
<thead>
<tr>
<th>Post text</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sources of uncertainty</td>
<td></td>
</tr>
<tr>
<td>Ambiguity</td>
<td></td>
</tr>
<tr>
<td>• “This is a tough one! One of those maybe/maybe not symptoms...I often ask myself the same questions about my daughter’s more obscure symptoms.” [FBCG218304.21.07.30]</td>
<td></td>
</tr>
<tr>
<td>• “Pre-lung # transplantation patients with # pulmonary # fibrosis who have short # telomeres may need different # clinical care...” [TWT180100.19.06.11]</td>
<td></td>
</tr>
<tr>
<td>Complexity</td>
<td></td>
</tr>
<tr>
<td>• “[Name] is having kidney, heart, and lung problems. Oh, and who can forget the liver? This week has been too long at the hospital” [FBCG2110000.21.11.23]</td>
<td></td>
</tr>
<tr>
<td>• “# DYK Those with # telomere biology disorders may be especially vulnerable to the effects of taking multiple medicines at the same time and may respond to medications differently.” [TWT186700.19.11.14]</td>
<td></td>
</tr>
<tr>
<td>Probability</td>
<td></td>
</tr>
<tr>
<td>• “80% of patients diagnosed with dyskeratosis congenita will experience bone marrow failure.” [TWT185500.19.11.04]</td>
<td></td>
</tr>
<tr>
<td>• “5 out of 6 of the cell lines tested were less than 1%. And when that’s the case, patients have a 10-20% chance of getting cancer...” [FBCG203500.20.09.08]</td>
<td></td>
</tr>
<tr>
<td>• “A recent publication advises against an elective eye surgery in patients with DC due to higher long-term risks caused by delayed healing...” [TWT182100.19.08.25]</td>
<td></td>
</tr>
<tr>
<td>Issues of uncertainty</td>
<td></td>
</tr>
<tr>
<td>Scientific</td>
<td></td>
</tr>
<tr>
<td>• “Has anybody experienced hearing loss with connection to short telomere length?” [FBCG218300.21.07.30]</td>
<td></td>
</tr>
<tr>
<td>• “Has anyone had kidney problems outside of BMT? Are there any articles anyone has seen on kidneys and short telomeres?” [FBCG2110000.21.11.23]</td>
<td></td>
</tr>
<tr>
<td>Practical</td>
<td></td>
</tr>
<tr>
<td>• “At the moment [Name] has 1-2 appointments each week. Add to that emails to/from paediatrician, calls from hospital to change/confirm appointments...It’s overwhelming some weeks. And I’m usually doing all this from work. We are also applying for different supports...so lots of forms, phone calls and emails!” [FBCG204305-8.20.10.13]</td>
<td></td>
</tr>
<tr>
<td>Personal</td>
<td></td>
</tr>
<tr>
<td>• “It’s # PFMonth, and we want you to know you have a team surrounding you...” [TWT1816000.20.09.04]</td>
<td></td>
</tr>
<tr>
<td>• “TBDs are not just a pediatric disease.Affected adults with a # raredisease, you are NOT ALONE!” [TWT183100.19.09.21]</td>
<td></td>
</tr>
<tr>
<td>• “Another milestone reached. This time five years ago as we celebrated [Name]’s 5th birthday we were also getting ready to go to transplant two weeks later. Yesterday we celebrated the big 10...” [FBCG201300.20.06.27]</td>
<td></td>
</tr>
<tr>
<td>Focus of uncertainty management</td>
<td></td>
</tr>
<tr>
<td>Ignorance</td>
<td></td>
</tr>
<tr>
<td>• “Wondering if anyone with DC had a dental implant post-transplant...? And did your medical team have any concerns or recommendations?” [FBCG215500.21.01.05]</td>
<td></td>
</tr>
<tr>
<td>• “Hello—any contraindications to getting COVID 19 vaccine if you have DC?” [FBCG217100.21.04.04]</td>
<td></td>
</tr>
<tr>
<td>• “Do you have a copy of the clinical guidelines?” [FBCG203509.20.09.08]</td>
<td></td>
</tr>
<tr>
<td>• “Take time to learn more about #Telomere Biology Disorders through our informational video!” [TWT1822100.21.11.04]</td>
<td></td>
</tr>
<tr>
<td>Uncertainty</td>
<td></td>
</tr>
<tr>
<td>• “Each Family Story is set up so you can find a connection via gene or experience.” [FBCG204400.20.10.29]</td>
<td></td>
</tr>
<tr>
<td>• “My daughter has yearly bone marrow biopsies, lung and liver screenings. ENT and skin checks for cancer.” [FBCG203513.20.09.08]</td>
<td></td>
</tr>
<tr>
<td>• “I’ve been preparing something for the new school trying to give them what her medical challenges are.” [FBCG219900.21.11.16]</td>
<td></td>
</tr>
<tr>
<td>Response</td>
<td></td>
</tr>
<tr>
<td>• “Our family is celebrating today! [Name]’s Happy 8th bone marrow transplant anniversary!” [FBCG203300.20.08.24]</td>
<td></td>
</tr>
<tr>
<td>• “Fitting for us all: it wasn’t the trauma that made you strong, kinder, and more compassionate. It’s how you handled it. That credit is yours.” [FBCG216200.21.02.28]</td>
<td></td>
</tr>
<tr>
<td>• “Join@sixnwstevies as she teaches yoga for research...” [TWT1822600.21.03.16]</td>
<td></td>
</tr>
<tr>
<td>Person</td>
<td></td>
</tr>
<tr>
<td>• “Thank goodness for social media otherwise it would be very isolating.” [FBCG203821.20.09.25]</td>
<td></td>
</tr>
<tr>
<td>• “Don’t forget to register for our Young Adult Meetup...” [TWT1814300.20.06.23]</td>
<td></td>
</tr>
<tr>
<td>• “[Name] it’s never ending, I hope you find a way to take care of you” [FBCG204307.20.10.13]</td>
<td></td>
</tr>
<tr>
<td>• “You are in great hands but always happy to connect with [Provider Name]” [FBCG203504.20.09.08]</td>
<td></td>
</tr>
<tr>
<td>• “Check out # tillymere! All # sparkly and ready for # TBDmonth!” [TWT185400.19.11.04]</td>
<td></td>
</tr>
<tr>
<td>• “We have all known the long loneliness and we have learned that the only solution is love and that love comes with community. – Dorothy Day” [TWT1816300.20.09.12]</td>
<td></td>
</tr>
</tbody>
</table>
Uncertainty Issues, Sources, and Management Strategies

Content analysis revealed that 45.98% (1269/2760) of posts overall were uncertainty related, although the frequency differed by platform (Facebook main page: 691/1715, 40.29%; Facebook community group: 155/511, 30.3%; and Twitter: 210/434, 48.4%). Most uncertainty-related posts on Facebook community group and Twitter were generated by Team Telomere’s organizational profile (332/511, 65% and 353/434, 81.3%, respectively) and were often similar in topic, wording, and image content. In the Facebook community group, all uncertainty-related posts were generated by individual users, including a portion (119/511, 23.3%) posted by Team Telomere–affiliated volunteer group moderators.

Owing to low frequency of community-generated uncertainty content on the Facebook community group and Twitter, compared with the Facebook community group, we decided to code uncertainty subtypes only within the Facebook community group and Twitter to compare how medical uncertainty was expressed on social media by 2 contrasting content creator groups (community members vs advocacy organization).

Scientific uncertainty was the most common issue on both platforms (305/434, 70.3% to 429/511, 84%). On Twitter, personal uncertainty was more frequently discussed, whereas in the Facebook community group, practical uncertainty was more frequent. Across platforms, most posts (1713/2760, 62.07%) had multiple sources of uncertainty, and a substantial number of posts (1126/2760, 40.8%) were coded as emerging from the combined information features of probability, complexity, and ambiguity.

The most common attributes of uncertainty management styles detected on both platforms were requests or offers of information to fill knowledge gaps (ignorance focused) and offers of emotional support or community building (person focused). Response-focused management style attributes (eg, yoga and meditation classes) were marginally more frequent on Twitter compared with the Facebook community group ($\chi^2=3.9; P=.05$), but on the Facebook community group, indicators of uncertainty-focused management (eg, strategies for organization of care logistics) were more frequent compared with Twitter ($\chi^2=55.1; P<.001$; Table 4).

Table 4. Characteristics and frequency of uncertainty-related posts on Team Telomere’s Facebook community group and Twitter (N=2760).

<table>
<thead>
<tr>
<th>Issue</th>
<th>Facebook community group (n=156), n (%)</th>
<th>Twitter (n=210), n (%)</th>
<th>Chi-square (df)$^a$</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal</td>
<td>48 (30.8)</td>
<td>111 (52.9)</td>
<td>16.6 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Practical</td>
<td>35 (22.4)</td>
<td>23 (11)</td>
<td>9.2 (1)</td>
<td>.002</td>
</tr>
<tr>
<td>Scientific</td>
<td>131 (84)</td>
<td>148 (70.5)</td>
<td>11.4 (1)</td>
<td>.007</td>
</tr>
<tr>
<td>Multiple</td>
<td>53 (34)</td>
<td>59 (28.1)</td>
<td>—$^a$</td>
<td>—</td>
</tr>
<tr>
<td>Source</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ambiguity</td>
<td>81 (51.9)</td>
<td>80 (38.1)</td>
<td>17.6 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Complexity</td>
<td>81 (51.9)</td>
<td>75 (35.7)</td>
<td>20.8 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Probability</td>
<td>112 (71.8)</td>
<td>81 (38.6)</td>
<td>71.3 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Multiple</td>
<td>88 (56.4)</td>
<td>77 (36.7)</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Management attributes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ignorance focused</td>
<td>124 (79.5)</td>
<td>156 (74.3)</td>
<td>1.9 (1)</td>
<td>.16</td>
</tr>
<tr>
<td>Person focused</td>
<td>106 (67.9)</td>
<td>125 (59.5)</td>
<td>3.6 (1)</td>
<td>.06</td>
</tr>
<tr>
<td>Response focused</td>
<td>57 (36.5)</td>
<td>100 (47.6)</td>
<td>3.9 (1)</td>
<td>.05</td>
</tr>
<tr>
<td>Uncertainty focused$^b$</td>
<td>53 (34)</td>
<td>10 (4.8)</td>
<td>55.1 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Multiple</td>
<td>106 (67.9)</td>
<td>131 (62.4)</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

$^a$Chi-square tests were not performed for issues, sources, or management attributes assigned to multiple categories.

$^b$Uncertainty thread includes non–uncertainty-related posts captured in a thread where ≥1 other posts were uncertainty related.

Facebook Social Support and Uncertainty

Frequent overlap of social support and uncertainty was found across all platforms, with uncertainty-related posts being more likely to contain social support compared with non–uncertainty-related posts ($\chi^2=70.7; P<.001$). However, within social support subtypes, only informational support remained significantly more frequent within uncertainty-related posts ($\chi^2=486.0; P<.001$), whereas emotional support was significantly less frequent in uncertainty-related posts ($\chi^2=66.5; P<.001$) compared with non–uncertainty-related posts. The relationship between informational support and uncertainty remained significant for all social media types, but the relationship between emotional support and uncertainty differed by platform (Multimedia Appendix 4). Emotional support was significantly more frequent in uncertainty-related posts for the
Facebook community group ($\chi^2 = 7.8; P = .005$), was significantly less frequent in uncertainty-related posts on the Facebook main page ($\chi^2 = 79.5; P < .001$), and had no relationship with uncertainty-related posts on Twitter ($\chi^2 = 0.5; P = .47$).

On all platforms, uncertainty-related posts were more frequently offers of support than requests. When requests occurred, they were more likely to appear on the Facebook community group compared with Twitter ($\chi^2 = 12.7; P < .001$). Posts that were not uncertainty related but appeared in an uncertainty-related thread frequently contained offers of emotional support.

Given the greater variation in types and direction (offer vs request) of social support in the Facebook community group, we decided to focus on subsequent analyses of the relationship between social support and uncertainty subtypes on this platform. Analysis of social support in the Facebook community group posts by uncertainty issue found that informational support was offered more frequently in response to scientific and practical uncertainty posts compared with personal uncertainty posts. Informational support was also the most frequent type of support requested and offered across uncertainty source types in the Facebook community group; however, uncertainty posts emerging from probability concerns had similar frequencies of emotional and informational support (320/511, 62.6% and 511/836, 61.1%, respectively). This was particularly true in the case where a post had multiple uncertainty sources, which were more likely to be coded as informational support offers or requests compared with posts with only a single uncertainty source ($\chi^2 = 90.4; P < .001$).

**Popularity and Engagement**

Popularity and engagement were positively skewed toward lower values across all social media types. Popularity was highest for posts on Twitter (Facebook community group: median 1, range 0-55, mean 4, SD 7.5; Facebook main page: range 0-151, median 1, mean 5.9, SD 13.3; and Twitter: range 0-1147, median 13, mean 28.8, SD 76.6). However, engagement was higher in the Facebook community group than on the Facebook main page or Twitter (Facebook community group: range 0-29.6, median 0.54, mean 2.15, SD 4.0; Facebook main page: median 0.0006, range 0-0.09, mean 0.004, SD 0.008; and Twitter: median 0.007, range 0-0.56, mean 0.02, SD 0.04). Most uncertainty-related posts were categorized as having below-median popularity and engagement. The uncertainty-related post with the highest engagement was a question about kidney issues and telomere length posted on Facebook community group by a parent of a child with TBDs, which generated 12 comments from 6 unique users, including a self-identified medical expert. The nonnormal distribution combined with low (<20) frequency in cross-tabulation groups made it ineffective to analyze the relationships between the presence of social support and popularity or engagement (Multimedia Appendix 5).

In the Facebook community group, posts were created by 67 unique individuals, representing 35.8% (183/511) of all group members. Frequency per user was positively skewed toward lower numbers (range 1-94 posts and median 3 posts), and the majority of post creators (343/511, 67.1%) generated ≤5 posts. Although Team Telomere rarely posted directly on the Facebook community group (8/511, 1.6% posts), the top 2 post creators (156/511, 30.5% posts) were identified as White, female, parents of children affected by DC who were also group moderators for Team Telomere. After removing the moderators, the remaining median post frequency was 3 posts per user, with 22.3% (114/511) of the users creating only a single post.

**Sentiment**

The majority of posts (2208/2760, 80%) on all social media types were categorized as positive sentiment. Negative sentiment was rarely expressed and was more likely to be expressed on Facebook compared with Twitter ($\chi^2 = 45.4; P < .001$). Uncertainty-related posts demonstrated a similarly high frequency of positive sentiment across all social media types (Facebook community group: 433/511, 84.7%; Facebook main page: 1495/1815, 82.37%; and Twitter: 328/434, 75.6%; Multimedia Appendix 6).

**Discussion**

**Principal Findings**

In this study, we explored the use of TBD social media to express health-related uncertainty. We found that uncertainty was a frequent focus of TBD social media across platforms but was primarily limited to scientific issues, requests for informational support, and offers of emotional support, with most posts generated by White, female, English-speaking parents of children with TBDs. These findings are in keeping with other research on rare disease internet-based communities, which found that post content focused on biomedical questions and emotional support provision [63] and was frequently created by White, female users [40,63-65].

The high frequency of uncertainty-related posts on TBD social media created by female caregivers suggests a potentially higher burden of uncertainty management among mothers, which is in agreement with the extensive literature documenting the psychosocial burden of childhood illness on female caregivers [66-68]. However, the observed demographics of TBD social media users may also be an artifact of greater social media engagement among this group, as previous research suggests that female users frequently rely on internet-based communities for navigating uncertainty related to motherhood and other sex-specific health topics [69,70]. Additional research is needed to investigate the relative burden of medical uncertainty among female care providers and to understand the potential barriers to internet-based community formation for users outside this identity group.

Despite the multiplicity of identified uncertainty sources, issues, management, and social support strategies, we found that scientific uncertainty, informational support, and emotional support were the predominant features of uncertainty-related posts on TBD social media. The high frequency of scientific uncertainty issues across platforms suggests that limited scientific and medical knowledge is a salient concern for the TBD community. Gaps in scientific knowledge likely contribute to the focus on probability as a source of uncertainty in TBD...
social media posts, especially concerning matters such as prognosis, diagnosis, and symptom experiences. Informational support was the most common form of social support in uncertainty-related posts overall, which is in line with other studies showing information seeking as the principal motivator for participation in disease-specific social media [24,26,71-73]. The high frequency of emotional support suggests the potential for TBD social media to enable uncertainty management through person-focused strategies, such as community building, networking, and relationship formation, as seen in other rare disease contexts [24,72]. In addition, evidence of positive asynchronous internet-based communication as a form of “cybertherapy” [32,44] suggests that the emotionally supportive culture of TBD social media may provide psychological benefits for peers, even without explicit conversations about the personal burden of uncertainty. In addition, items coded as emotional support (eg, emoji hearts) that appeared in response to a variety of uncertainty-related content may have communicated multiple forms of support (eg, care, approval, agreement, or affinity) and may be a common reaction to intractable sources of uncertainty, such as probabilistic and scientific unknowns surrounding TBDs. Further exploration of the complex, dynamic, and potentially interactive relationships between social support and uncertainty on social media may be a fruitful area of investigation for future studies.

Given the evidence of the high psychosocial burden of personal uncertainty in similar rare disease contexts [18,36,74,75], it is surprising that the mental and emotional impacts of uncertainty appeared infrequently in TBD social media discussions. When these topics did arise, they were more likely to appear on Twitter content generated by Team Telomere, as opposed to within the conversations of individual users. In the Facebook community group, the impact of uncertainty on personal life was commonly presented in terms of practical issues and focused on ordering uncertainty, such as providing lists of symptoms, organizing information and screening schedules, and triaging problems. This suggests that despite the frequent focus on personal uncertainty issues by Team Telomere, most individual users engaged with TBD social media to troubleshoot and strategize practical issues, rather than to discuss the impact of uncertainty on personal identity, goals, or values. This is also reflected in the positive sentiment valence and rare expression of negative emotion on TBD social media, which suggest that social media may not be perceived as a “safe space” for exploring personal topics beyond surface-level stressors [23]. Future research is needed to investigate the shortcomings of social media for expressing personal uncertainty and painful emotions and may highlight a need for psychosocial support to fill this gap in TBD community resources.

Our finding that uncertainty-related support varied by platform could be explained by differences in the structure and expectations of engagement inherent to Twitter compared with the Facebook community group. The predominance of emotional support and greater overall user engagement in the Facebook community group suggests that internet-based platforms structured for mutual conversational exchange may have the most utility for psychosocial support delivery. In addition, the Facebook community group may have encouraged more community participation owing to user familiarity with the platform and its explicit creation for supportive internet-based connection in the context of COVID-19 isolation. Similarly, the nature of the Twitter platform, which is limited to one-way communication streams, suggests that uncertainty management and social support on Twitter would be limited to information provision. However, recent research indicates that Twitter retweets and endorsements may be effective methods for receiving and providing emotional support [76]. The formation of the Facebook community group and the use of Twitter to encourage community activities (eg, webinars and internet-based meetups) underscores the potential of these platforms in person-focused uncertainty management, but additional research is required to evaluate the capacity of TBD social media to build health-promoting personal relationships.

Although we found substantial potential for social media to deliver support for uncertainty management, analysis of engagement rates demonstrated that the primary function of TBD social media was a “drop-in” source of information. Although the Facebook community group included some multilevel, ongoing conversations, an analysis of posts within this group revealed that most user engagement was limited to single posts, suggesting quick check-ins or requests for answers to targeted questions, not ongoing social connection. Although low engagement may suggest limited supportive utility of TBD social media, findings from previous research with young adults with cancer showed that support delivered via social media benefited a variety of users, including those actively seeking deep connections, those seeking information only, and those who do not actively participate but frequently observe the conversation of others (eg, “lurkers”) [77]. As suggested by other research, any benefit from engagement with social media likely varies over time and may be most pronounced during experiences of novelty or discrepancy in diagnosis, treatment, or prognosis [28,48,63]. The uncertainty-related post that generated the highest engagement involved the participation of a medical expert, suggesting a desire among TBD social media users to engage with clinicians on internet-based platforms that facilitate reciprocal information exchange, including both synchronous (eg, internet-based group meetings) and asynchronous (eg, post exchanges) formats. Further research is needed to understand the motivations, perceived benefits, and perceived barriers to participation in TBD internet-based support platforms, including the perspectives of patients, caregivers, and medical providers.

Limitations

The limitations of our study include the use of social media data, which biases our sample toward active social media users who may have higher levels of distress [64], greater disenchantment with medical care [78], or lower perceived social support [79] compared with patients with TBDs and their families who do not actively use social media. Demographic analysis revealed that our sample of posts was generated primarily by White females, parents of patients with TBDs, or representatives of Team Telomere. This limited the generalizability of our findings. In addition, our use of social media posts, rather than content creators, as the unit of analysis...
precludes the observation of the longitudinal impacts of social media participation on uncertainty management. Furthermore, our findings allow us to infer the presence of uncertainty management strategies on social media but not the motivations for or effects of these activities.

In addition, our data were limited to social media that was actively moderated by Team Telomere. This moderation activity, which included removing posts that were inappropriate or scientifically inaccurate, likely decreased the presence of medical misinformation compared with unmoderated social media content. The moderation of posts by Team Telomere could also have impacted the range and authenticity of social and emotional expression owing to social desirability bias. This is in keeping with recent research challenging the assumption that the privacy and anonymity of internet-based environments decreases the likelihood of social desirability compared with in-person interactions [80,81]. In addition, we did not access the private Facebook community group maintained by Team Telomere described as “where we share detailed and private medical information” [57], which may contain additional uncertainty-related posts and a wider range of social and emotional expression. Limiting ourselves to social media owned and maintained by Team Telomere also prevented us from discerning the perspectives of individuals affected by TBD who lacked knowledge of or who chose not to engage with Team Telomere.

Finally, our study was limited by the occurrence of the COVID-19 pandemic, first mentioned in Team Telomere social media on February 28, 2020, which may have changed the nature of uncertainty-related conversations or social support in that portion of our data timeline (June 6, 2019, to December 7, 2021). To test the impact of this, we included available posts (Twitter and Facebook main page) from 1 year before the pandemic and tested the difference. Greater frequencies of uncertainty-related posts after COVID-19 suggest that the pandemic may have increased the expression of uncertainty on TBD-related social media, thus limiting the applicability of our findings to other time points (Multimedia Appendix 7).

Conclusions
This study found the frequent use of disease-specific social media for the discussion and management of uncertainty in TBDs. Uncertainty-related posts appeared across all TBD social media platforms and communicated a burden of multiple, often interacting sources and issues of uncertainty, particularly focused on scientific knowledge gaps and the desire to predict health outcomes. Posts also indicated multiple uncertainty management attributes, with a focus on information-seeking and community-building approaches. Uncertainty-related posts frequently co-occurred with social support, primarily emotional and informational. Female parents were most often the creators of uncertainty-related posts on TBD social media, suggesting a potentially higher burden of uncertainty management in this population. Overall, social media provided access to a positive emotional environment and frequent information exchange but was limited in the type and depth of uncertainty-related discussions. Despite these limitations, our findings suggest that social media is a useful lens for researching and understanding the experience of uncertainty in TBDs and holds potential as a tool for uncertainty management. Future research is needed to further explore the experience of medical uncertainty in TBDs and to determine the usefulness of TBD-related social media as a tool for improving mental health and quality of life outcomes in this context.

Acknowledgments
This study was supported by the Intramural Research Program of the Division of Cancer Epidemiology and Genetics, National Cancer Institute. Katherine Stevens from Team Telomere facilitated our access to the publicly available social media data.

Data Availability
In compliance with the National Institutes of Health data management and sharing policy, data, analysis code, and research materials are available upon reasonable request from the corresponding author.

Authors' Contributions
EP contributed to the study design, formative research, data collection, data analysis, codebook development, coding, and manuscript preparation; HR contributed to data collection, codebook development, and coding; PKJH contributed to the study design, codebook development, coding, and manuscript preparation; MBG, KMR, and AJL contributed to the study design, codebook development, and manuscript preparation; SAS contributed to manuscript preparation, study primary investigator, and National Institutes of Health; and NE contributed to data quality control and coding.

Conflicts of Interest
SAS and HR are members of Team Telomere Advisory Boards.

Multimedia Appendix 1
Criteria for identification of posts for inclusion in qualitative uncertainty analysis.

[DOCX File, 21 KB - infodemiology_v4i1e46693_app1.docx ]
Multimedia Appendix 2
Social media study codebook.
[DOCX File, 20 KB - infodemiology_v4i1e46693_app2.docx]

Multimedia Appendix 3
Emoji dictionary.
[DOCX File, 26 KB - infodemiology_v4i1e46693_app3.docx]

Multimedia Appendix 4
Frequency of social support by support type and direction.
[DOCX File, 262 KB - infodemiology_v4i1e46693_app4.docx]

Multimedia Appendix 5
Engagement and popularity by platform.
[DOCX File, 14 KB - infodemiology_v4i1e46693_app5.docx]

Multimedia Appendix 6
Sentiment by post type.
[DOCX File, 16 KB - infodemiology_v4i1e46693_app6.docx]

Multimedia Appendix 7
COVID-19 impact summary.
[DOCX File, 13 KB - infodemiology_v4i1e46693_app7.docx]

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Abbreviations

DC: dyskeratosis congenita
TBD: telomere biology disorder
The Role of Social Media in Knowledge, Perceptions, and Self-Reported Adherence Toward COVID-19 Prevention Guidelines: Cross-Sectional Study

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Abstract

Background: Throughout the COVID-19 pandemic, social media has served as a channel of communication, a venue for entertainment, and a mechanism for information dissemination.

Objective: This study aims to assess the associations between social media use patterns; demographics; and knowledge, perceptions, and self-reported adherence toward COVID-19 prevention guidelines, due to growing and evolving social media use.

Methods: Quota-sampled data were collected through a web-based survey of US adults through the Qualtrics platform, from March 15, 2022, to March 23, 2022, to assess covariates (eg, demographics, vaccination, and political affiliation), frequency of social media use, social media sources of COVID-19 information, as well as knowledge, perceptions, and self-reported adherence toward COVID-19 prevention guidelines. Three linear regression models were used for data analysis.

Results: A total of 1043 participants responded to the survey, with an average age of 45.3 years, among which 49.61% (n=515) of participants were men, 66.79% (n=696) were White, 11.61% (n=121) were Black or African American, 13.15% (n=137) were Hispanic or Latino, 37.71% (n=382) were Democrat, 30.21% (n=306) were Republican, and 25% (n=260) were not vaccinated. After controlling for covariates, users of TikTok ($β=-.29$, 95% CI $-0.58$ to $-0.004$; $P=.047$) were associated with lower knowledge of COVID-19 guidelines, users of Instagram ($β=-.40$, 95% CI $-0.68$ to $-0.12$; $P=.005$) and Twitter ($β=-.33$, 95% CI $-0.58$ to $-0.08$; $P=.01$) were associated with perceiving guidelines as strict, and users of Facebook ($β=-.23$, 95% CI $-0.42$ to $-0.043$; $P=.02$) and TikTok ($β=-.25$, 95% CI $-0.5$ to $-0.009$; $P=.04$) were associated with lower adherence to the guidelines ($R^2=0.06$-$0.23$).

Conclusions: These results allude to the complex interactions between online and physical environments. Future interventions should be tailored to subpopulations based on their demographics and social media site use. Efforts to mitigate misinformation and implement digital public health policy must account for the impact of the digital landscape on knowledge, perceptions, and level of adherence toward prevention guidelines for effective pandemic control.

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KEYWORDS
COVID-19; digital media; social media; TikTok; Instagram; Twitter; Facebook; prevention guidelines
**Introduction**

In March 2020, the infectious disease SARS-CoV-2, more commonly known as COVID-19, was classified as a pandemic [1,2]. As the virus is transmitted through the respiratory systems of individuals in close contact, preventative measures include wearing a facial mask, social distancing, and receiving recommended COVID-19 vaccinations [3]. Over the course of the pandemic, prevention recommendations changed in response to emerging scientific evidence. Initially, a 14-day quarantine and isolation were recommended, which was then shortened to 10 days, and was once more shortened to 5 days [3]. As of March 2022, masks were still recommended in indoor spaces, COVID-19 vaccinations and boosters were widely available, and rapid self-testing was advised in response to exposure or symptom onset [3]. In the United States, as of November 2, 2022, there have been over 97 million confirmed cases and over 1 million total deaths due to COVID-19 [4]. Despite these prevention recommendations, case numbers continued to rise, necessitating research into prevention efforts.

In response to social distancing recommendations, many aspects of life shifted from physical to online environments. Adapting to this change, most US adults (ie, 90%) indicated that digital media was either essential or important for them throughout the pandemic [5]. Digital media encapsulates social media as the platforms that enable human connection in the online environment, with varying degrees of privacy [6]. On social media, individuals encounter and consume information, government announcements, and reactions from other users as they work, learn, connect, and are entertained online [7]. Popular social media sites include Facebook, Twitter, Instagram, Snapchat, TikTok, Pinterest, Reddit, and LinkedIn, among others. As of 2021, a total of 72% of adults in the United States report using at least 1 social media site, representing a 3% increase since 2018 [8]. When stratified by age, 84% of US adults aged 18-29 years indicate using at least 1 social media site [8]. Of those who use Facebook, Snapchat, and Instagram, a majority indicate visiting the platform at least once a day [9]. In considering news consumption on social media, when stratified by age, 42% of users aged 18-29 years indicate social media as their primary source of news [9].

With an increasing proportion of individuals active on social media, thereby encountering COVID-19 news and information online, there are concerns about information accuracy, where unsourced or false information that is widely distributed threatens the dissemination of scientifically accurate information [7,10]. The modalities of social media (eg, concise, organized content formats, and sharing capabilities) allow information to quickly trend as a result of high engagement. The visibility of trending content on social media is determined by engagement and is often based on sensationalism rather than factual accuracy [7]. Sensational misinformation risks reducing the visibility and reach of reputable information [7]. Due to the saturation of misinformation online, the United States is understood to be in a syndemic, denoting the interactions between the COVID-19 pandemic and the infodemic. Social media, therefore, has the capacity to serve both as a tool and a hindrance to health communication.

Despite motivations for use, social media users are subject to unintentionally overconsuming content related to COVID-19 due to the saturation of pandemic information online. Social media has been preliminarily found to negatively contribute to COVID-19 prevention guideline adherence [11]. Among US adults, 53.3% indicate that the amount of information on COVID-19 is overwhelming to the effect that 54.7% indicate that it has led to their avoidance of consuming information about COVID-19 [12]. Resembling emerging trends in the United States, a study in Turkey indicated that 34.4% of respondents follow COVID-19 guidelines less in the present than at the beginning of the pandemic [13]. Fluctuations in pandemic prevention perceptions and adherence over time can be expected, but negative trends, regardless of their cause, necessitate investigation and intervention to bolster commitment to prevention guidelines to limit further pandemic-related exposures [13]. Although a complicated mechanism with additionally probable explanations (eg, milder virus mutations, vaccination availability, mental health burdens, and pandemic fatigue), these downward patterns of adherence are thought to be partially explained by social media use (eg, misinformation and overconsumption). The effective dissemination of scientific, evidence-based health communication must be prioritized in stark opposition to skepticism and disbelief, as sustained by misinformation.

There exists a limited understanding of the associations between demographics and frequency of social media site use and engagement with pandemic prevention behaviors, despite the significant risks to public health. Therefore, there is a present and pressing need to address the field’s limited understanding of pandemic-related knowledge, perceptions, and adherence, as impacted online, to design effective health behavior and communication interventions. As the emerging literature demonstrates that content consumption impacts perceptions and, subsequently, health behaviors, the field of health communication must understand the compounding effects of the online environment on COVID-19 prevention efforts [7]. This study therefore aims to investigate the associations between the social media platforms from which individuals consume pandemic-related information as well as their frequency of use and their knowledge of, perceptions of, and adherence to COVID-19 prevention guidelines.

**Methods**

**Survey Development and Data Collection**

Preliminary development of the survey involved compiling constructs related to the topics of interest. Survey items were then drafted to measure participant knowledge, perceptions, and adherence toward COVID-19 prevention guidelines. The items were then reviewed by an expert to evaluate and ensure adherence toward COVID-19 prevention guidelines to limit further pandemic-related exposures. The data were collected from March 15, 2022, to March 23, 2022.

**Ethical Considerations**

The University of South Carolina’s Institutional Review Board exempted the study (Pro00119512) from Human Research
Subject Regulations based on its minimal risk to participants in providing web-based survey responses. Informed consent was obtained from all participants prior to survey completion. All participants were compensated for their time and efforts in completing the survey (ie, US $6).

Sample
All adults in the United States were eligible for participation, given that they were 18 years or older at the time of survey response. Responses that were deemed low quality based on response speed, lack of variability in selection, or repetitive attempts were removed before analysis to ensure data quality. Qualtrics used quota sampling methods to ensure the collection of a sample proportionate to that of the United States by way of gender, age, income, race, ethnicity, and education level. The final sample size included 1043 viable responses.

Measures

Demographics
Participant demographics collected included age, gender identity, race or ethnicity, education, employment, income, political affiliation, and COVID-19 vaccination status. Due to limited representation, the American Indian or Alaska Native and Native Hawaiian or Pacific Islander categories were collapsed into 1 category. Age, education, employment, and income were used as continuous variables in the regression models. Gender identity, race or ethnicity, political affiliation, and COVID-19 vaccination status were used as categorical variables in the regression models.

Frequency of Social Media Use
Participants’ frequency of any social media use was measured through the item: “About how often do you use social media sites?” Response options ranged from several times a day, once per day, a few times per week, once per week, less than once per week, to never.

Social Media Sources of COVID-19 Information
Participants were asked to check all that apply to the question, “Which of these social media sites have you used to get information about COVID-19?” with the possible response options of Facebook, Twitter, Instagram, Snapchat, Pinterest, TikTok, Reddit, LinkedIn, and another social media site. The social media sites available as response options were chosen due to their popularity and presentation of short-form, user-generated content. Although there exist additional social media platforms (eg, YouTube), those chosen to be included here have active engagement and content sharing capabilities. Demographic profiles of the included social media sites were not accounted for in participant sampling procedures, as it is assumed that user bases may have fluctuated during the pandemic. The selections of these sites were operationalized as categorical predictors in the regression models.

Knowledge of COVID-19 Guidelines
Set forth by the Centers for Disease Control and Prevention, as of March 2022, relevant COVID-19 guidelines were used in crafting 4 items to assess participant pandemic-related knowledge. The assessment evaluated respondents’ knowledge of calculating exposure date, the minimum length of isolation after an exposure or positive test, the percentage of alcohol in hand sanitizer required to kill COVID-19, and what a negative rapid test result indicates. Participants were asked to indicate what they believe the current, official recommendations to be, at the time of survey administration, rather than what they may prefer them to be. These 4 items were then compiled for a final score out of 100%. Knowledge scores of the COVID-19 prevention guidelines were used continuously in the regression models.

Perceptions of COVID-19 Guidelines
Participants were asked to indicate the degree to which they perceived COVID-19 prevention guidelines to be relaxed or strict. The terminology “strict” was operationalized through concurrent dimensions that encapsulate participant responses to legal and scientific guidelines as well as enforcement. As perceptions of COVID-19 guidelines were assessed after the knowledge assessment, the guidelines were not explicitly defined but rather assumed to encapsulate mask-wearing, gathering size limitations, hygiene measures, as well as quarantine and isolation timelines. This ordering provided participants with context as to what the term “guidelines” referred to. Participants were asked: “Do you consider the current COVID-19 guidelines as...” with the response options ranging from too strict, a little too strict, about right, a little too relaxed, to too relaxed.

Adherence to COVID-19 Guidelines
Adherence to COVID-19 guidelines was evaluated by asking participants if they generally follow the official COVID-19 prevention guidelines, with the available response options of strongly, sometimes, rarely, and never follow the guidelines. This item provided an average, typical measure of self-reported participant adherence to COVID-19 guidelines, broadly. Given the state of the pandemic, this item was reliant upon participant understanding of guidelines in the organizations and institutions to which they belong (ie, schools and workplaces).

Statistical Analysis
All statistical analyses were conducted using the statistical analysis software, SAS (version 9.4; SAS Institute). Descriptive analyses were conducted for key predictors. All data were screened for outliers, missing data, and normality. As all data used in this study was collected through discrete response options, excluding age, their distributions were considered to assess the presence of outliers. This was done by considering the frequency of responses within available options through histograms and box plots, as applicable. Those categories that were lower in response volume were collapsed (eg, race or ethnicity response of American Indian or Alaska Native and Native Hawaiian or Pacific Islander) or excluded from the analysis before modeling (eg, gender identity response option of nonbinary). Data quality was ensured as Qualtrics excluded participants who did not complete the survey in a single session, who were not continuously and carefully responding, who missed embedded attention checks, or who completed the survey in less than a third or more than 3 times the median time it took other participants to complete the survey. Due to the use of...
these features, respondents who did not complete the survey were not tracked. No systematic patterns of missing data within the data collected, or between variables, were observed. There is limited item nonresponse. Bivariate associations were assessed through ANOVA and Pearson correlation tests, as appropriate. Three generalized linear regressions, using a maximum likelihood estimation procedure, were conducted, independently, to explore associations between social media use and demographics and knowledge, perceptions, and self-reported adherence toward prevention guidelines, respectively. Although the 3 outcomes of knowledge, perceptions, and self-reported adherence were run independently, their theoretically dependent nature led us to consider implementing a correction (ie, Bonferroni), but as it resulted in a minimal impact on our findings, the traditional $\alpha$ level of .05 was here used to evaluate our findings.

**Results**

**Overview**

Of the 1043 participants, the median age of participants was 45.3 years (Table 1). The distribution of the gender identity of the participants was split approximately equally between men (515/1032, 49.9%) and women (513/1032, 49.71%), with few participants indicating being nonbinary or transgender. The race or ethnicity of participants was primarily White (696/1042, 66.79%), followed by Latino or Hispanic (137/1042, 13.15%) and Black or African American (121/1042, 11.61%). A quarter (253/1042, 24.28%) of participants held a bachelor’s degree and approximately a quarter (269/1042, 25.82%) of participants indicated earning US $50,000-US $79,999 annually. Finally, almost half (498/1040, 47.88%) of the participants had received a full vaccination series and booster against COVID-19.
Table 1. Demographic characteristics of study participants (N=1043).

<table>
<thead>
<tr>
<th>Variables</th>
<th>Values, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years; 1 participant’s data are missing), mean (SD)</td>
<td>45.3 (16.94)</td>
</tr>
<tr>
<td><strong>Gender (11 participants’ data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>515 (49.9)</td>
</tr>
<tr>
<td>Women</td>
<td>513 (49.71)</td>
</tr>
<tr>
<td>Nonbinary or other</td>
<td>4 (0.39)</td>
</tr>
<tr>
<td><strong>Race or ethnicity (check all that apply; 1 participant’s data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>121 (11.61)</td>
</tr>
<tr>
<td>Latino or Hispanic</td>
<td>137 (13.15)</td>
</tr>
<tr>
<td>American Indian or Alaska Native and Native Hawaiian or Pacific Islander</td>
<td>22 (2.11)</td>
</tr>
<tr>
<td>White</td>
<td>696 (66.79)</td>
</tr>
<tr>
<td>Other</td>
<td>66 (6.33)</td>
</tr>
<tr>
<td><strong>Education (1 participant’s data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school degree</td>
<td>25 (2.4)</td>
</tr>
<tr>
<td>High school graduate or equivalent</td>
<td>248 (23.8)</td>
</tr>
<tr>
<td>Some college but no degree</td>
<td>248 (23.8)</td>
</tr>
<tr>
<td>Associate degree</td>
<td>123 (11.8)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>253 (24.28)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>112 (10.75)</td>
</tr>
<tr>
<td>Doctoral or professional degree (JD, MD, or PhD)</td>
<td>33 (3.17)</td>
</tr>
<tr>
<td><strong>Employment status over the last 3 months (6 participant’s data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>Working full-time</td>
<td>499 (48.12)</td>
</tr>
<tr>
<td>Working part-time</td>
<td>132 (12.73)</td>
</tr>
<tr>
<td>Unemployed and looking for work</td>
<td>74 (7.14)</td>
</tr>
<tr>
<td>Homemaker or stay-at-home parent</td>
<td>70 (6.75)</td>
</tr>
<tr>
<td>Student</td>
<td>35 (3.38)</td>
</tr>
<tr>
<td>Retired</td>
<td>200 (19.29)</td>
</tr>
<tr>
<td>Other</td>
<td>27 (2.6)</td>
</tr>
<tr>
<td><strong>Previous year income (US $; 1 participant’s data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 10,000</td>
<td>56 (5.37)</td>
</tr>
<tr>
<td>10,000-19,999</td>
<td>58 (5.57)</td>
</tr>
<tr>
<td>20,000-29,999</td>
<td>96 (9.21)</td>
</tr>
<tr>
<td>30,000-39,999</td>
<td>87 (8.35)</td>
</tr>
<tr>
<td>40,000-49,999</td>
<td>70 (6.72)</td>
</tr>
<tr>
<td>50,000-59,000</td>
<td>117 (11.23)</td>
</tr>
<tr>
<td>60,000-69,999</td>
<td>70 (6.72)</td>
</tr>
<tr>
<td>70,000-79,999</td>
<td>82 (7.87)</td>
</tr>
<tr>
<td>80,000-89,999</td>
<td>47 (4.51)</td>
</tr>
<tr>
<td>90,000-99,999</td>
<td>51 (4.89)</td>
</tr>
<tr>
<td>100,000-149,999</td>
<td>215 (20.63)</td>
</tr>
<tr>
<td>150,000 or more</td>
<td>93 (8.93)</td>
</tr>
<tr>
<td><strong>Political affiliation (30 participants’ data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>Republican</td>
<td>306 (30.21)</td>
</tr>
</tbody>
</table>
### Table 2: Voter Registration Status and COVID-19 Vaccination Status

<table>
<thead>
<tr>
<th>Variables</th>
<th>Values, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Democrat</td>
<td>382 (37.71)</td>
</tr>
<tr>
<td>Independent</td>
<td>325 (32.08)</td>
</tr>
<tr>
<td><strong>COVID-19 vaccination status (3 participant's data are missing)</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>260 (25)</td>
</tr>
<tr>
<td>Yes, but no booster</td>
<td>282 (27.12)</td>
</tr>
<tr>
<td>Yes, including booster</td>
<td>498 (47.88)</td>
</tr>
</tbody>
</table>

### Social Media Site Use

Participants reported using, generally or for any reason, the social media sites Facebook (835/1042, 80.13%), Twitter (396/1042, 38%), Instagram (586/1042, 56.24%), Snapchat (329/1042, 31.57%), Pinterest (320/1042, 30.71%), TikTok (401/1042, 38.48%), Reddit (208/1042, 19.96%), LinkedIn (254/1042, 24.38%), or another social media site (69/1042, 6.62%). Further, participants reported accessing COVID-19 information using the social media sites Facebook (604/1042, 57.97%), Twitter (220/1042, 21.11%), Instagram (258/1042, 24.76%), Snapchat (85/1042, 8.16%), Pinterest (59/1042, 5.66%), TikTok (129/1042, 12.38%), Reddit (84/1042, 8.06%), LinkedIn (72/1042, 6.91%), and another social media site (42/1042, 4.03%).

Table 2 presents the results of the bivariate analyses. Pearson correlations suggest that the demographic variables of age, education, and income were correlated with the prevention mitigation outcomes of guideline knowledge, perceptions, and self-reported adherence. The ANOVA suggests that political affiliation was correlated with all 3 outcomes while gender, race or ethnicity, and COVID-19 vaccination status were correlated with prevention guideline perceptions and self-reported adherence. Social media sites used to consume COVID-19 news were correlated with self-reported adherence. Employment and regularity of social media use were not correlated with the outcomes of interest.
### Table 2. Bivariate analysis results.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Outcomes</th>
<th>Knowledge</th>
<th>Perceptions</th>
<th>Self-reported adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>r</td>
<td>P value</td>
<td>r</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td>0.09</td>
<td>.006</td>
<td>-0.14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td>0.11</td>
<td>&lt;.001</td>
<td>0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td>0.02</td>
<td>.48</td>
<td>-0.03</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td>0.15</td>
<td>&lt;.001</td>
<td>-0.08</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td>0.38</td>
<td>.54</td>
<td>6.43</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Race or ethnicity</strong></td>
<td></td>
<td>2.36</td>
<td>.051</td>
<td>12.66</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Political affiliation</strong></td>
<td></td>
<td>6.23</td>
<td>.002</td>
<td>94.13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>COVID-19 vaccination status</strong></td>
<td></td>
<td>2.7</td>
<td>.07</td>
<td>23.88</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Site for COVID-19 news</strong></td>
<td></td>
<td>2.07</td>
<td>.07</td>
<td>1.64</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P value</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Regularity of social media use</strong></td>
<td></td>
<td>0.53</td>
<td>.75</td>
<td>1.21</td>
</tr>
</tbody>
</table>

**Knowledge of COVID-19 Guidelines**

Indicating the level of knowledge related to COVID-19 prevention guidelines, the possible scores participants could receive included 100% (n=14, 1.4%), 75% (n=112, 10.9%), 50% (n=429, 41.7%), 25% (n=368, 35.7%), or 0% (n=107, 10.4%) correct. Model 1 (Table 3) suggests that income, Democratic political affiliation, and use of the social media platform TikTok were associated with COVID-19 prevention guideline knowledge. Specifically, as income ($\beta$=.03, 95% CI 0.005-0.05; $P$=.02) increased, it was found to be associated with a higher level of knowledge of COVID-19 guidelines. Democratic political affiliation ($\beta$=–.21, 95% CI –0.37 to –0.057; $P$=.008) was found to be negatively associated with guideline knowledge. Using TikTok as a source of COVID-19 information ($\beta$=–.29, 95% CI –0.58 to –0.004; $P$=.047) was associated with a lower level of knowledge. This model explained 6% of the variance in knowledge of COVID-19 guidelines.
Table 3. Regression results for knowledge, perceptions, and self-reported adherence.

<table>
<thead>
<tr>
<th>Independent variables (reference)</th>
<th>Model 1: knowledge&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Model 2: perceptions&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Model 3: self-reported adherence&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β (95% CI)</td>
<td>P value</td>
<td>β (95% CI)</td>
</tr>
<tr>
<td>Age</td>
<td>.002 (–0.003 to 0.007)</td>
<td>.51</td>
<td>–0.007 (–0.01 to –0.002)</td>
</tr>
<tr>
<td>Gender (men)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>.026 (–0.1 to 0.15)</td>
<td>.69</td>
<td>.16 (0.02 to 0.3)</td>
</tr>
<tr>
<td>Race or ethnicity (White)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>–.048 (–0.26 to 0.16)</td>
<td>.66</td>
<td>.14 (–0.09 to 0.36)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>–.079 (–0.27 to 0.11)</td>
<td>.41</td>
<td>.28 (0.08 to 0.49)</td>
</tr>
<tr>
<td>American Indian or Alaska Native and Native Hawaiian or Pacific Islander</td>
<td>.072 (–0.45 to 0.6)</td>
<td>.79</td>
<td>.92 (0.35 to 1.49)</td>
</tr>
<tr>
<td>Other</td>
<td>–.09 (–0.35 to 0.17)</td>
<td>.49</td>
<td>.07 (–0.21 to 0.34)</td>
</tr>
<tr>
<td>Education level</td>
<td>.03 (–0.014 to 0.079)</td>
<td>.17</td>
<td>–.015 (–0.065 to 0.036)</td>
</tr>
<tr>
<td>Employment</td>
<td>.029 (–0.008 to 0.066)</td>
<td>.13</td>
<td>–.001 (–0.04 to 0.038)</td>
</tr>
<tr>
<td>Income</td>
<td>.03 (0.005 to 0.05)</td>
<td>.02</td>
<td>–.03 (–0.053 to –0.005)</td>
</tr>
<tr>
<td>Political affiliation (independent)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Republican</td>
<td>–.12 (–0.28 to 0.04)</td>
<td>.15</td>
<td>–.5 (–0.67 to –0.33)</td>
</tr>
<tr>
<td>Democrat</td>
<td>–.21 (–0.37 to –0.057)</td>
<td>.008</td>
<td>.34 (0.17 to 0.5)</td>
</tr>
<tr>
<td>COVID-19 vaccination status (yes, but no booster)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>.00 (–0.17 to 0.17)</td>
<td>.99</td>
<td>–.22 (–0.4 to –0.04)</td>
</tr>
<tr>
<td>Yes, including booster</td>
<td>.02 (–0.13 to 0.18)</td>
<td>.78</td>
<td>.31 (0.15 to 0.48)</td>
</tr>
<tr>
<td>Site for COVID-19 news (Reddit)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facebook</td>
<td>–.086 (–0.31 to 0.14)</td>
<td>.45</td>
<td>–.23 (–0.47 to 0.009)</td>
</tr>
<tr>
<td>Instagram</td>
<td>–.026 (–0.28 to 0.23)</td>
<td>.84</td>
<td>–.40 (–0.68 to –0.12)</td>
</tr>
<tr>
<td>Snapchat</td>
<td>.21 (0.26 to 0.68)</td>
<td>.38</td>
<td>–.17 (–0.66 to 0.31)</td>
</tr>
<tr>
<td>TikTok</td>
<td>–.29 (–0.58 to –0.0044)</td>
<td>.047</td>
<td>–.29 (–0.6 to 0.016)</td>
</tr>
<tr>
<td>Twitter</td>
<td>.015 (–0.22 to 0.25)</td>
<td>.90</td>
<td>–.33 (–0.58 to –0.08)</td>
</tr>
<tr>
<td>Regularity of social media use (less than once per week)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Several times per day</td>
<td>.27 (–0.18 to 0.71)</td>
<td>.24</td>
<td>–.22 (–0.71 to 0.27)</td>
</tr>
<tr>
<td>Once per day</td>
<td>.16 (–0.32 to 0.63)</td>
<td>.52</td>
<td>–.12 (–0.63 to 0.4)</td>
</tr>
<tr>
<td>A few times per week</td>
<td>.2 (–0.29 to 0.69)</td>
<td>.43</td>
<td>–.03 (–0.57 to 0.5)</td>
</tr>
</tbody>
</table>
Perceptions of COVID-19 Guidelines

Model 2 (Table 3) suggests that age, gender, Hispanic or Latino populations, American Indian or Alaska Native populations, income, political affiliation, COVID-19 vaccination status, and the use of the social media sites Instagram and Twitter were associated with perceptions of COVID-19 prevention guidelines. As age (β = –0.007, 95% CI –0.01 to –0.002; P = 0.007) increased, it was found to be associated with a perception of the guidelines as strict. Women (β = 0.16, 95% CI 0.02-0.3; P = 0.02) were associated with perceiving the guidelines as relaxed. Hispanic or Latino (β = 0.28, 95% CI 0.08-0.49; P = 0.007) and American Indian or Alaska Native and Native Hawaiian or Pacific Islander (β = 0.92, 95% CI 0.35-1.49; P = 0.002) populations were found to be associated with perceiving the guidelines as relaxed. As income (β = –0.03, 95% CI –0.05 to –0.005; P = 0.02) increases, it was found to be associated with stricter perceptions of the guidelines. Republican political affiliation (β = –0.5, 95% CI –0.67 to –0.33; P < 0.001) was found to be associated with perceiving the guidelines as strict, while Democratic political affiliation (β = 0.34, 95% CI 0.17-0.5; P < 0.001) was found to be associated with perceiving them as relaxed. Receiving the full vaccination series and booster (β = 0.31, 95% CI 0.15-0.48; P < 0.001) was found to be associated with perceiving the guidelines as relaxed, while receiving no COVID-19 vaccinations (β = –0.22, 95% CI –0.4 to –0.04; P = 0.02) was associated with perceiving them as strict. Instagram (β = –0.4, 95% CI –0.68 to –0.12; P = 0.005) and Twitter (β = –0.33, 95% CI –0.58 to –0.08; P = 0.01) were found to be associated with stricter perceptions of the COVID-19 prevention guidelines. This model explained 23% of the variance in perceptions of COVID-19 guidelines.

Adherence to COVID-19 Guidelines

As related to self-reported COVID-19 guideline adherence, model 3 (Table 3) suggests that women, Black or African American populations, Hispanic or Latino populations, political affiliation, COVID-19 vaccination status, and the use of Facebook and TikTok were associated with adherence to the COVID-19 prevention guidelines. Women (β = 0.15, 95% CI 0.04-0.26; P = 0.008) were found to be positively associated with adherence to the COVID-19 prevention guidelines. Black or African American (β = 0.21, 95% CI 0.03-0.39; P = 0.02) and Hispanic or Latino (β = 0.27, 95% CI 0.11-0.43; P = 0.001) populations were found to be positively associated with adherence to the guidelines. Republican political affiliation (β = –0.23, 95% CI –0.37 to –0.09; P = 0.001) was negatively associated with adherence to prevention guidelines, while Democratic political affiliation (β = 0.17, 95% CI 0.04 to 0.31; P = 0.01) was positively associated with adherence. Receiving the full vaccination series and booster (β = 0.32, 95% CI 0.19-0.45; P < 0.001) was positively associated with adherence to the COVID-19 prevention guidelines, while receiving no COVID-19 vaccinations (β = –0.22, 95% CI –0.36 to –0.07; P = 0.003) was negatively associated with adherence. Facebook (β = 0.23, 95% CI –0.42 to –0.043; P = 0.02) and TikTok (β = –0.25, 95% CI –0.5 to –0.009; P = 0.04) were found to be negatively associated with self-reported adherence to COVID-19 prevention guidelines. This model explained 19% of the variance in adherence to COVID-19 guidelines.

Discussion

Principal Findings

This study suggests that knowledge, perceptions, and self-reported adherence toward COVID-19 prevention guidelines differ by demographics and social media site use. Notably, marginalized populations (eg, older adults, women, and racial or ethnic minority individuals) were found to perceive the COVID-19 prevention guidelines as relaxed, in addition to their positive association with adherence. Political affiliation and COVID-19 vaccination status mirror assumptions about perceptions and adherence, where those identifying as Republican and reporting no vaccination were associated with perceiving the guidelines as too strict and adhering to a lesser degree, respectively. The popular social media sites TikTok, Instagram, Facebook, and Twitter were found to negatively impact pandemic prevention efforts as they were differentially associated with lower levels of knowledge, perceiving guidelines as strict, and lower self-reported adherence. The findings of this work, while demonstrating complicated interactions between guideline knowledge, perceptions, and adherence, serve to inform tailored public health interventions (ie, on the basis of demographic subgroups and social media site use), platform policies (eg, misinformation prevention), and digital public health policy more broadly.

Demographics and Knowledge, Perceptions, and Adherence Toward Guidelines

When considering the associations between the demographic correlates of income, age, and gender with knowledge, perceptions, and adherence toward prevention guidelines, the findings suggest a complex pandemic landscape. Whereas education and employment were not associated with guideline knowledge, it can be assumed that income reflects a layer of privilege afforded to those of higher income throughout the pandemic. In the case of this study, income may be acting as a proxy for pandemic privilege rather than solely socioeconomic status. Pandemic privilege can be understood here as the role of income in altering the pandemic environment, where those with additional resources are more likely to have access to...
prevention methods (eg, working from home, personal protective equipment, vaccination appointment flexibility, transportation, residential privilege, limited disruptions to services and care, and financial buffer for burdens of lost employment and wages) [14,15]. Despite possessing increased knowledge of the guidelines, perceptions of the prevention guidelines as strict reflect privileged protections afforded through increased income. Concordant with the existing literature, among older adults, a higher level of adherence to prevention guidelines, despite perceptions of them as strict, is likely due to the higher risk of severe illness from COVID-19 associated with increased age [16,17]. Gendered differences in perceptions of the guidelines as relaxed with a higher level of adherence reflect disproportionate pandemic burdens experienced by women (eg, occupational exposure, incidence, and post–COVID-19 condition [long COVID]).

The present findings are in accordance with the existing literature that demonstrates the impact of political affiliation on knowledge, perceptions, and adherence toward prevention guidelines. Partisan differences in perceptions of COVID-19 guidelines have been theorized to be explained by differential risk perceptions as influenced by news sources and media consumption [18-21]. Republican political affiliation has been found to be aligned with a preference for reducing the imposition of guidelines, while Democratic political affiliation is aligned with a preference for maintaining guidelines [22]. In accordance with the literature, political affiliation may play a decisive role in impacting knowledge-seeking and comprehension, perceptions, and adherence toward prevention guidelines. Health communication efforts may bolster prevention efforts through the characteristics inherent to partisan politics (eg, collectivism, inequity perceptions, perceived risk, skepticism, and media influence) and their influence on health behaviors [22-24]. The emerging literature attests that although political affiliation may demonstrate explanatory differences in pandemic prevention outcomes, there is a call for public health efforts that extend beyond interventions targeted based on political affiliation, implementing bipartisan efforts that also further consider demographics and individual differences influencing the operationalization of information from news and social media sites in the interest of COVID-19 prevention [18,23].

Social Media Sites and Knowledge, Perceptions, and Adherence Toward Guidelines

The use of the social media sites TikTok, Instagram, Twitter, and Facebook was found to be associated with lower knowledge, stricter perceptions, and lesser adherence toward COVID-19 prevention guidelines. Despite operating under distinct algorithms, all 4 platforms share commonalities in their functions for photo, video, audio, and text sharing, as well as social networking structures. A reliance on user-generated content creates difficulty in regulating the presence and spread of misinformation on social media. All 4 sites implemented, to various degrees, efforts to mitigate misinformation through informational banners on videos discussing the pandemic with off-site links to additional information. Despite these soft moderation efforts to address misinformation by TikTok, Instagram, Twitter, and Facebook, all have been found to contribute to the dissemination of misinformation [25-28]. Therefore, there is a need for improved mechanisms on these social media sites to limit the spread of misinformation due to its negative impacts on COVID-19 prevention guideline knowledge, perceptions, and adherence in the physical environment.

One key consideration of this study is the discrepancy between the demographic profiles of the included social media sites and the study sample. The user base of TikTok (ie, 48% users aged 18-29 years, 22% users aged 30-49 years, 14% users aged 50-64 years, and 4% users aged 65 years and older), Twitter (ie, 42% users aged 18-29 years, 27% users aged 30-49 years, 18% users aged 50-64 years, and 7% users aged 65 years and older), and Instagram (ie, 71% users aged 18-29 years, 48% users aged 30-49 years, 29% users aged 50-64 years, and 13% users aged 65 years and older) tends to be younger than that of Facebook (ie, 70% users aged 18-29 years, 77% users aged 30-49 years, 73% users aged 50-64 years, and 50% users aged 65 years and older) [8]. Although the average age of the study sample is older, it aligns with profiles of users of a similar age range who are active online (ie, 22% users on TikTok, 27% users on Twitter, 48% users on Instagram, and 77% users on Facebook) [8]. Although social media sites have unique demographic user profiles, it is necessary to consider that all individuals are able to access their platforms. Understanding the scope of a platform’s typical and atypical users is necessary to systematically address misinformation online, where those who do not align with the average user experience an assumedly differential interaction with the platform and its content.

Public Health Implications

This research is uniquely situated within the COVID-19 pandemic and serves to inform tailored public health interventions, social media platform strategies, and policies. The key implications of this research include addressing knowledge gaps in the literature regarding the impact of social media use and demographic characteristics on COVID-19 prevention guideline knowledge, perceptions, and adherence. Public health interventions should be tailored to relevant platforms to address the impacts of social media sites on prevention guideline knowledge, perceptions, and adherence. Additionally, interventions targeting demographic subgroups may be operationalized on social media platforms with a user base that aligns with the target subgroup (eg, age, income, and political affiliation). In this context, platform functionality should be considered when designing interventions, regulations, and misinformation mitigation policies to alleviate the negative impacts of social media use on COVID-19 prevention efforts. Finally, these findings are necessary to be operationalized within public health interventions to tailor interventions to increase pandemic-related knowledge while enhancing supportive perceptions of the guidelines, aiming to increase and maintain sufficient adherence among subpopulations to mitigate the effects of the pandemic.

Strengths, Limitations, and Future Studies

This study has the strengths of using a country-wide, quota-based sample to investigate emerging trends during the pandemic as related to knowledge of, perceptions of, and adherence to COVID-19 prevention guidelines. Although there
is likely some inherent difference in those who are online and able to participate in the survey as compared with those who are not, this concern may be mitigated in the context of this work, as it centers those active in the online environment. With the goal of identifying the role of social media on the target population, the exclusion of those not online is warranted. The findings should be cautiously interpreted and generalized as selection bias may affect the representativeness of the sample. When interpreting the study’s findings, low statistical significance does not imply the absence of a certain phenomenon. One limitation that could persist, as the results are reliant on a self-report measure of prevention guidelines adherence, is participants’ ability to approximate habits (eg, wearing a mask and using a social media site). A key limitation of this study is the discrepancy between the demographics of the study sample and the demographic profiles of the users of the various social media sites included. Finally, as a cross-sectional study, where some potential but key confounders may not have been included, there is the inability to obtain causal inference. Further, work accounting for the interrelations between factors should be conducted to provide a comprehensive assessment of confounders [22]. Future work should consider focusing on the validation of measures to assess knowledge, perceptions, and adherence. Additional research would benefit from an expanded survey considering a variety of potential, influential factors (eg, health literacy and location). Longitudinal explorations of the influence of social media use, knowledge levels, and declining perceptions should be prioritized in efforts to examine their impacts on prevention guideline adherence over time. Future directions for health communication should prioritize implementing programmatic interventions on social media platforms to address misinformation and information oversaturation in a manner that optimizes each platform’s social networking functions, algorithms, and user base.

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Authors' Contributions
CG developed survey materials, analyzed data, and led manuscript development. SQ collaborated on the development and provided significant contributions in manuscript refinement. XL provided significant contributions to manuscript refinement.

Conflicts of Interest
None declared.

References


Government-Nongovernmental Organization (NGO) Collaboration in Macao’s COVID-19 Vaccine Promotion: Social Media Case Study

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Abstract

Background: The COVID-19 pandemic triggered unprecedented global vaccination efforts, with social media being a popular tool for vaccine promotion.

Objective: This study probes into Macao’s COVID-19 vaccine communication dynamics, with a focus on the multifaceted impacts of government agendas on social media.

Methods: We scrutinized 22,986 vaccine-related Facebook posts from January 2020 to August 2022 in Macao. Using automated content analysis and advanced statistical methods, we unveiled intricate agenda dynamics between government and nongovernment entities.

Results: “Vaccine importance” and “COVID-19 risk” were the most prominent topics co-occurring in the overall vaccine communication. The government tended to emphasize “COVID-19 risk” and “vaccine effectiveness,” while regular users prioritized vaccine safety and distribution, indicating a discrepancy in these agendas. Nonetheless, the government has limited impact on regular users in the aspects of vaccine importance, accessibility, affordability, and trust in experts. The agendas of government and nongovernment users intertwined, illustrating complex interactions.

Conclusions: This study reveals the influence of government agendas on public discourse, impacting environmental awareness, public health education, and the social dynamics of inclusive communication during health crises. Inclusive strategies, accommodating public concerns, and involving diverse stakeholders are paramount for effective social media communication during health crises.

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KEYWORDS
COVID-19; government; vaccine; automated content analysis; Granger causality test; network agenda setting; QAP; social media

Introduction

As of December 2022, the global COVID-19 pandemic had resulted in 669 million confirmed cases and 6.8 million deaths [1]. Environmental factors were a key determinant significantly influencing the pandemic [2], through airborne viral infectivity impacted by air pollution and seasonality effects [3,4]. Vaccination was crucial to contain the spread of virus [5], although complex factors such as the Peltzman effect, emerging viral variants, and socioeconomic conditions also affected
pandemic diffusion [6]. Determining an optimal level of vaccination is complex and multifaceted, requiring a balance to avoid undermining democratic values and triggering larger socioeconomic problems than the pandemic [7,8]. Nonetheless, the willingness to vaccinate hinges on various factors, including safety concerns, sociodemographic characteristics, and individual behaviors and attitudes [9,10]. Other determinants including lack of knowledge, government distrust, skepticism about vaccine development, efficacy concerns, exposure experience, coronaphobia, and workplace mandates also predict vaccine uptake [11-13]. As social media becomes increasingly significant for public communication, social media adaptivity, information availability, and health care infrastructure capabilities are also influential for vaccination decisions [14]. Vaccine communication plays a vital role in addressing public concerns, building trust, and encouraging vaccine uptake. Specifically, effective strategies including trusted sources, health provider guidance, a reasonable quantity of information, cultural tailoring, information contextualization, and cultural sensitivity have the potential to significantly increase vaccination intent [15-17]. Despite the notable antagonism in the discourse surrounding immunization on social media [18], it is worth noting that social media campaigns initiated by health organizations have proven to be effective in increasing public awareness about vaccination [19].

Governance mechanisms are another crucial factor for expediting vaccine distribution and mitigating pandemic-related socioeconomic effects [20]. Evidence has shown that clear, consistent, and transparent communication from governmental bodies engendered higher levels of public compliance and trust [21,22]. Given the major impact of the pandemic on public health and society, involvement of the government in vaccine communication becomes a vital research area.

Governments worldwide have adopted diverse approaches to encourage COVID-19 vaccination. For instance, the New Zealand government promoted vaccination among young people by highlighting community factors such as “protecting others” and “striving for herd immunity” [23]. By promoting the scientific notion that there are more advantages than disadvantages to COVID-19 vaccination, the Chinese government has strengthened risk communication to increase the public’s awareness of the benefits of vaccines [24]. Although COVID-19 vaccine communication has received increasing attention, particularly from the research community, scientific evidence focusing specifically on low-risk regions, such as Macao, is scarce. This suggests that the existing literature does not sufficiently reflect the concerns of the Macao population as related to COVID-19 vaccination. As one of the world’s most densely populated cities, Macao has maintained a record of relatively low risk of infection and high coverage of COVID-19 vaccines [25]. Throughout the pandemic before June 2022, Macau had only recorded 17 confirmed cases of local infection (with a rate of 2.5 cases per 100,000 population) with no fatalities. By June 19, 2022, the vaccine coverage rate within the entire population in Macao was 85.6% for at least 2 doses and 40.5% for 3 doses [26]. The low prevalence of COVID-19 is believed to be the result of the close connection between Macao and mainland China. Since the outbreak of the pandemic, Macao has implemented anti-epidemic measures following the “dynamic zero-COVID-19 policy” established by mainland China, with some adaptations based on local socioeconomic circumstances [27]. Given the close link between these entities, it is important to understand how the Macao Government communicated with citizens to drive their demand for vaccinations and the impact of this communication. Researchers have long investigated how governments develop policy agendas and whether a policy agenda is led by the government or the public [28]. However, literature on the role of the government in public health agenda setting, specifically related to vaccine promotion in the COVID-19 context, is limited. The primary goal of this study was to reveal the patterns of vaccine communication on social media during the COVID-19 pandemic as well as the role of the government in advancing vaccination through a case study of Macao, the special administrative region of China. By conducting this research, we aimed to contribute to the existing knowledge on vaccine communication and provide implications for policymakers to improve health promotion communication strategies for preparedness against future pandemics.

The theory of agenda setting suggests that the media has the ability to influence the public agenda by making a specific issue prevalent and salient [29]. Agenda setting is a competition among issue proponents to gain the attention of media professionals, the public, and policy elites [30]. Recently, research about agenda setting has been extended by incorporating the concept of social networks and the associative network of memory, which has been proposed by Guo [31] as the network agenda setting model (NAS). The NAS underlines the associations between topics or attributes presented in the agenda: The more frequently 2 attributes are correlated in news coverage, the more likely the public will perceive them to be interrelated [32]. The NAS can be used to identify the interconnections between public, media, organizational, and government topics on social media. For instance, a study conducted by Chen et al [33] utilized the NAS to investigate the correlation between individual users and organizational accounts on Weibo in terms of their focus on nationalist concerns. The NAS emphasizes the relationship between topics or attributes in constructed agendas. Hou et al [34] analyzed posts mentioning COVID-19 vaccines on Twitter and found that topics related to COVID-19 vaccines can be divided into the following 9 categories: (1) vaccine importance, (2) vaccine effectiveness, (3) vaccine safety, (4) trust in governments, (5) trust in experts, (6) COVID-19 risk, (7) vaccine accessibility, (8) vaccine distribution, (9) vaccine affordability. Additionally, recent studies examined the concerns of all users, including parents, regarding COVID-19 vaccines (eg, [35]). However, these studies did not distinguish between regular accounts (ie, ordinary individual users), government accounts, organization accounts, and media accounts. This distinction is important to understand the nuances of vaccine promotion engaged by different entities. Governments, for instance, influence public discourse through policymaking [24,28], whereas organizations play a significant role in agenda setting via funding, lobbying, and advertising activities [36]. The public, media, and government may construct different
associations among topics in their respective agendas and impact each other. Our research questions (RQ) thus ask the following:

- **RQ1**: What are the most prevalent agenda attributes emphasized in the communication of vaccination on Facebook during the COVID-19 outbreak in Macao?
- **RQ2**: How do the attributes interact in the vaccine agendas of governmental and nongovernmental entities?
- **RQ3**: What are the associations between the vaccine agenda networks constructed by government and nongovernmental users?
- **RQ4**: How do government and nongovernment users impact each other’s vaccine agenda on Facebook?

**Methods**

**Sample and Data**

This study retrieved data relevant to COVID-19 vaccines in Macao from January 1, 2020, when the SARS-CoV-2 virus was initially detected in China, to August 31, 2022, when the number of newly reported cases had sharply declined [1]. Facebook was selected as the main source of data to analyze the dynamics of vaccine communication in Macao. Being one of the most widely used social media platforms globally, Facebook accounts for a more dominant market share (65.05%) than other sources (eg, Pinterest: 11.47%; Twitter: 10.54%) in Macao [37,38]. The widespread usage of Facebook suggests that it has a significant impact on the population’s perceptions, attitudes, and behaviors, making it an essential platform to study to understand the public agenda. In addition, Facebook’s archival nature allows for tracking the evolution of vaccine-related discussions over time, capturing the core dynamics of vaccine communication online.

A combination of the keywords “COVID-19” and “vaccine” as well as their synonyms (ie, 29 synonyms of COVID-19–related terms and 10 synonyms of vaccine-related terms) in Chinese were used to detect and collect relevant posts (see Multimedia Appendix 1). Information was also compiled on the various labels given to users on Facebook, such as labels of government, media, and organization accounts. Following the collection of raw data from Facebook, data screening was performed to remove duplicate and irrelevant posts. The preprocessing of data including the removal of stop words (eg, “an,” “the,” “etc.”, punctuation, symbols, and numbers) and word segmentation was implemented using the DivoMiner platform.

**Ethics Approval**

This research strictly adheres to ethical guidelines by ensuring complete anonymity and de-identification of all data sources. To preserve the confidentiality and privacy of all sources involved, no identifiable information about individual users, their IDs, or direct, non-paraphrased posts are included in the main manuscript or any supplementary materials.

**Clarification**

All identifiers in the data set (eg, names of the senders) were removed and replaced with a code to mask the information about each sender, ensuring the anonymization of our data. Data were only collected from publicly available posts that were returned based on the structured keyword search criteria.

**Measures of Variables**

This study investigated the dynamics of agenda setting between government and nongovernment users on Facebook. To achieve this, we categorized users into the following different categories, drawing from prior research [39,40]: (1) media, (2) civil organizations, (3) regular users, (4) government.

The media functions as information gatekeepers and holds potential influence over people’s decision-making [29,32]. To account for significant differences in content, news culture, and viewpoints, the media category in this study was further divided into professional media and alternative media for a thorough investigation [41]. Professional media includes those traditional mass media outlets responsible for information dissemination and public awareness, such as newspapers, radio, and television, while alternative media includes independent and electronic media, which is in contrast to mainstream mass media. By referencing relevant media research [42], this study annotated professional media accounts, alongside alternative media accounts.

Civil organizations, also called civil society organizations, include those organizations or associations that are established by individuals or groups with a common purpose or interest and operate in the community, differing from the government and corporations. Civil organizations work alongside the government and other stakeholders to contribute to public discourse, policy development, and social change [43].

Regular users were defined in this study as individuals who interact with Facebook on a personal basis, without representing any official capacity, media, or organizations. Therefore, regular users can be considered as representatives of the public in this study.

The government in this study was defined as all authorities. We did not categorize the specific levels, instead treating all government authorities as a single entity, to gain a clear understanding of the overall position of the Macao Government in vaccine communication. This was also a practice adopted by previous research (eg, [44]).

The classification of Facebook users into 5 distinct categories was conducted based on the information gathered from users’ short biographical profiles and the user identity labels provided by Facebook. We assigned 2 coders to classify the users contributing relevant posts. Any confusion that might have occurred during classification was resolved through discussion. This approach allowed for the categorization of users into specific groups, enabling a systematic analysis of user communication and interactions within the Facebook platform [44].

To investigate the dynamics of vaccine communication, 9 predefined categories that indicate elements influencing vaccine acceptance were established based on a coding framework adapted from prior studies (eg, [34,45,46]). These categories included the following topics: importance of vaccines, effectiveness of vaccines, safety of vaccines, trust in...
governments, trust in experts, risk of the COVID-19 pandemic, and vaccine convenience (ie, accessibility, distribution, and affordability). Details of the coding categories are shown in Multimedia Appendix 2.

Data Analysis Procedures

Automated Content Analysis

In this study, an automated content analysis method was used to identify and categorize posts into the predefined categories. Each post could belong to one or more categories or none at all. The effectiveness of automated coding depends on the design of the keywords. To develop accurate keywords, this study followed the approach outlined by Chang et al [37] using the Word2vec word embedding toolkit from the Python 3.7.4 Gensim module [47]. Word2vec, a word embedding technique powered by neural networks, allows the identification of words with similar meanings by analyzing word associations in a large text corpus [48]. Due to the intricacies of the Chinese language, the synonyms suggested by Word2vec were further checked by assessing their relevance to the context. On this basis, the Chinese thesaurus and relevant literature [49] were further consulted for the inclusion of additional synonyms. The list of keywords for machine coding can be found in Multimedia Appendix 3.

DivoMiner, a text mining and automated content analysis platform driven by machine learning algorithms, was used to facilitate the automated content coding task. This platform integrates automated content analysis with traditional content analysis methods and has been widely utilized in health and communication studies [37,30,51]. Following automated coding, manual verification was conducted to ensure the accuracy and reliability of the machine-generated outcomes. To achieve this, 2 coders, both native Cantonese speakers, were recruited and underwent 36 hours of training to independently code 300 messages. Each variable was coded as either present or absent. Discrepancies between the coders were resolved through discussions, with the author intervening only when consensus could not be reached between the coders. The overall intercoder reliability, measured using Krippendorff alpha, demonstrated satisfactory levels across all examined variables, with coefficients ranging from .77 to .82. The consistency between machine coding and manual coding reached an acceptable level, with an average score of 74%. This score aligns with previous studies, in which a threshold value of 70% was considered rational [49-51].

Statistical Analysis

The conventional statistical analysis in this study involved the use of SPSS (version 23; IBM Corp) for analysis. Categorical variables were summarized using counts and percentages. The chi-square test of independence was used, and post hoc comparisons with Bonferroni corrections were further implemented to precisely identify the specific significant differences between user categories and vaccine-related topics and avoid the likelihood of generating false-positive outcomes (type I errors).

Co-Occurrence Network Analysis

Co-occurrence matrices, which represent the strength of ties between 2 topics engaged by different users, were generated as dyadic data sets. Based on the co-occurrence data, this study established undirected and weighted topic co-occurrence networks. Each network represents the co-occurrence relations of the attributes of a certain user category. To clarify, if a particular category of user mentions topic “i” and topic “j,” a band will link “i” and “j.” The width of the band indicates the frequencies of the pair of topics discussed by a user type [52,53]. For example, in the professional media user category’s topic co-occurrence network, if a professional media news report mentions the topics of “vaccine importance” and “vaccine effectiveness” together, the topics will be linked in the network by a band. The more frequently these topics co-occur, the thicker the band becomes. The visualization of topic co-occurrence is presented in a chord diagram by Echarts (The Apache Software Foundation), as indicated by Wang et al [52].

Quadratic Assignment Procedure for Network Analysis

In this study, the quadratic assignment procedure (QAP) method was applied to understand the correlation between the Macao Government’s agenda network and that of other Facebook users, via analysis of the co-occurrence matrices. QAP is a common method in social network or agenda network studies [40,54]. QAP correlation analysis can be used to assess the correlation between 2 matrices with the Pearson correlation coefficient, while QAP regression analysis can determine whether an explanatory variable can predict an outcome variable when the 2 matrices are significantly correlated [55]. In this study, the QAP method used UCINET 6.730 to test whether the Macao Government’s vaccine agenda network has impacted that of nongovernment Facebook users, particularly regular type users, during the COVID-19 pandemic.

Vector Autoregression Modeling

The vector autoregression (VAR) approach was used to examine the dynamic of agenda attributes between government and nongovernment users. This approach evaluates the effect of an observed variable by considering its lagged effect in the earlier period and that of other predictors in previous time points, without presuming the associations between the variables [56]. The VAR modeling technique is widely used in the economic field and, in recent years, has been increasingly applied in research on health science, sociology, neuroimaging, and meteorology (eg, [54,57-59]).

VAR modeling is ideal for measuring the dynamic performance response and interaction between performance and marketing communication variables. A study applied VAR models to construct the dynamic response relationship between news stories and public attention using a combination of survey and news content ranging from 2009 to 2013 [60]. The VAR models captured the dynamic feedback system and gave estimates for the short-term effects of TV news coverage on public perception by demonstrating a unidirectional process wherein changes in news salience led to significant changes in public salience. In addition, VAR models have also been used to investigate the dynamic mapping relationship between the diffusion of political
messages and emotional expression in public messages during the COVID-19 pandemic [61]. The increased diffusion of political messages positively predicted changes in emotional expression among citizens, and the VAR model was able to explain the interdependencies among variables based on the lag values of multiple time series. Overall, the VAR model proves to be an insightful tool for analyzing complex relationships in communication studies, providing insights into the short-term and long-term effects of various factors on outcomes of interest. Hence, using the VAR technique allows the exploration of temporal dynamics and associations between different agenda attributes in this study. For example, the approach enables a better understanding of whether the agenda attributes propagated by the government (AG) at time (t-n) impacts the agenda attributes of nongovernment users (AN) including professional media, alternative media, civil organizations, and regular users. The VAR model was generated as follows:

\[
\alpha_i, \beta_i, \rho, \epsilon_i
\]

Within this model, \(\alpha_i\) and \(\beta_i\) are the estimated coefficients, \(\rho\) represents the optimal number of lags for the model, and \(\epsilon_i\) indicates the error term. AG\(_{t-i}\) and AN\(_{t-i}\) represent the respective variable at the earlier periods. For instance, AG\(_{t-1}\) indicates the first lag of AG. The lag length for the VAR model was selected as per the Akaike information criterion. The augmented Dickey-Fuller test was applied to examine the stationarity of the time series. For nonstationary series, differencing at the first or higher level was performed to achieve stationarity [62]. When both time series were stationary at the same level, this study proceeded with the Johansen maximum eigenvalue and trace tests based on the estimation of VAR models to determine whether the time series were cointegrated and suitable for Granger causality tests. Granger causality posits that causes lead to effects and happen before their effects [40]. In this sense, using prior values of a time series can statistically forecast the future status of another time series.

In this study, the Granger causality test was used to provide greater insight into the statistical causal relationship between the government’s agenda and the nongovernment users’ agenda. To estimate VAR models and enable Granger causality tests, this study transformed the collected data in the form of time series by dividing the data into 32 monthly periods (from January 2020 to August 2022), and each monthly period was treated as an independent unit for analysis. EViews 12 software was used for statistical analysis.

**Results**

**Results of Content Analysis**

This research initially collected a sample of 24,089 Facebook posts with relevance to COVID-19 vaccines. Data screening was further performed on the sample to remove duplicated, irrelevant, and unclear messages, resulting in 23,577 unique and relevant posts. Finally, the results of machine coding presented a total of 22,986 posts that include the examined vaccine topics.

In answering RQ1, we calculated the frequency of the vaccine topics and found that the majority of posts in the sample related to the importance of COVID-19 vaccination (7358/22,986, 32.01%), followed by posts that indicated the high risk of contracting COVID-19 (6877/22,986, 29.92%) and highlighted trust in experts (4320/22,986, 18.79%). In addition, a considerable number of posts mentioned vaccine effectiveness (4163/22,986, 18.11%), safety (3358/22,986, 14.61%), accessibility (2683/22,986, 11.67%), distribution (2492/22,986, 10.84%), and affordability (1685/22,986, 7.33%), while posts related to trust in government were less frequent (1593/22,986, 6.93%). In addition, in the overall vaccine-related discussion, nongovernment users comprised a substantial majority of the posts, at 76.85% (17,665/22,986). When examining the nongovernment user segment at a more granular level, professional media accounted for a significant proportion of the posts, at 33.87% (7555/22,986), followed by alternative media, at 12.24% (2814/22,986); civil organizations, at 3.99% (918/22,986); and regular users, at 27.74% (6377/22,986). The topics associated with vaccine agenda attributes by government and nongovernment users are shown in Table 1.

The chi-square test indicated that the distributions of vaccine-related topics were significantly different across the user categories (\(\chi^2_{32}=1579.469, P<.001\)). The outcomes of the post hoc comparisons suggested that the government was more concerned with topics of vaccine effectiveness (1003/5322, 18.85%; \(P<.001\)), COVID-19 risk (1805/5322, 33.92%; \(P<.001\)), vaccine accessibility (1010/5322, 18.98%; \(P<.001\)), and vaccine affordability (605/5322, 11.37%; \(P<.001\)), while discussion of vaccine safety (393/5322, 7.38%; \(P<.001\)), government trust (1035/5322, 19.32%; \(P<.001\)), and vaccine distribution (341/5322, 6.41%; \(P<.001\)) occurred to a less extent than for other users. In comparison, professional media contributed more to the topics of government trust (752/7555, 9.95%; \(P<.001\)) and expert trust (1985/7555, 25.08%; \(P<.001\)). Alternative media, however, were less inclined to discuss vaccine affordability (128/2814, 4.55%; \(P<.001\)) than other categories of users. Regular users were primarily concerned about vaccine safety (1092/6377, 17.12%; \(P<.001\)) and vaccine distribution (724/6377, 11.35%; \(P<.001\)) and were less concerned about vaccine effectiveness (937/6377, 14.69%; \(P<.001\)), COVID-19 risk (1529/6377, 23.98%; \(P<.001\)), and vaccine accessibility (416/6377, 6.52%; \(P<.001\)) than other users. The outcomes of the post hoc tests with details are shown in Multimedia Appendix 4.
<table>
<thead>
<tr>
<th>Vaccine topic</th>
<th>Government users, n (%)</th>
<th>Nongovernment users, n (%)</th>
<th>Total, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Professional media</td>
<td>Alternative media</td>
<td>Civil organizations</td>
</tr>
<tr>
<td>All posts</td>
<td>5322 (23.15)</td>
<td>7555 (32.87)</td>
<td>2814 (12.24)</td>
</tr>
<tr>
<td>Importance</td>
<td>1616 (30.36)</td>
<td>2931 (38.80)</td>
<td>697 (24.77)</td>
</tr>
<tr>
<td>Effectiveness</td>
<td>1003 (18.85)</td>
<td>1638 (21.68)</td>
<td>404 (14.36)</td>
</tr>
<tr>
<td>Safety</td>
<td>393 (7.38)</td>
<td>1374 (18.19)</td>
<td>359 (12.76)</td>
</tr>
<tr>
<td>Trust in government</td>
<td>133 (2.5)</td>
<td>752 (9.95)</td>
<td>175 (6.22)</td>
</tr>
<tr>
<td>Trust in experts</td>
<td>518 (9.73)</td>
<td>1895 (25.08)</td>
<td>593 (21.07)</td>
</tr>
<tr>
<td>COVID-19 risk</td>
<td>1805 (33.92)</td>
<td>2651 (35.09)</td>
<td>681 (24.2)</td>
</tr>
<tr>
<td>Accessibility</td>
<td>1010 (18.98)</td>
<td>981 (12.98)</td>
<td>196 (6.97)</td>
</tr>
<tr>
<td>Distribution</td>
<td>341 (6.41)</td>
<td>1005 (13.3)</td>
<td>309 (10.98)</td>
</tr>
<tr>
<td>Affordability</td>
<td>605 (11.37)</td>
<td>529 (7)</td>
<td>128 (4.55)</td>
</tr>
</tbody>
</table>

**Trend in Facebook Activities**

To reveal the dynamics of different attributes of the vaccine agenda, this study mapped trends of these attributes during the investigated period. All vaccine-relevant content remained at a relatively low volume in 2020 and increased significantly in 2021. The volume of content regarding "vaccine distribution" began to grow at the start of 2021 and showed an observable spike in February of the same year. This was followed by a sharp acceleration in content regarding the high risk of COVID-19 reaching its peak in June 2021. The highest peak in vaccine-relevant content occurred in September 2021 related to the topic of vaccine importance. Between June 2021 and October 2021, the most debate centered around themes relating to COVID-19 vaccines. Overall, variations in the volume of vaccine communication were observed over time. Figure 1 shows the dynamic of vaccine discussion showing the monthly volume of posts.
Figure 1. Temporal changes in the vaccine agenda attributes (January 2020–August 2022): (A) vaccine importance, (B) vaccine effectiveness, (C) risk of COVID-19, (D) government trust, (E) expert trust, (F) vaccine safety, (G) vaccine affordability, (H) vaccine distribution, (I) vaccine accessibility.

Interactions Between Agenda Attributes in Vaccine Communication

To answer RQ2, this study computed the interrelationships between agenda attributes by the government and nongovernment users by constructing co-occurrence matrices. Results showed that “vaccine importance,” “vaccine effectiveness,” and “COVID-19 risk” were the most prominent attributes interacting with each other in the agendas of government and nongovernment users, except for the regular users’ agenda in which “vaccine safety” (n=2503) rather than “vaccine effectiveness” (n=2161) had more established connections overall with other attributes. Specifically, the government agenda featured strong connections between “vaccine importance” and “COVID-19 risk” (n=1505), followed by “vaccine importance” and “vaccine effectiveness” (n=945), “vaccine importance” and “accessibility” (n=940), and “COVID-19 risk” and “accessibility” (n=816). As for the agenda of professional media, the strongest link was established between “vaccine importance” and “COVID-19 risk” (n=1528), followed by the link between “vaccine importance” and “vaccine effectiveness” (n=1327) and the link between “vaccine importance” and “trust in experts” (n=1220). In terms of regular users, their agenda highlighted the relationships between “vaccine importance” and “COVID-19 risk” (n=931), “vaccine importance” and “vaccine effectiveness” (n=655), “vaccine importance” and “vaccine safety” (n=644), “vaccine importance” and “trust in experts” (n=536), and “vaccine safety” and “COVID-19 risk” (n=469). Using chord diagrams, this study visualized the interrelationships of agenda attributes by different user categories. The arc in the outer ring represents the attributes of the vaccination agenda and is differentiated by color. The arc length indicates the total number of associations an attribute maintains with other attributes when communicated by users in a specific category. The band within the ring represents the connected relationship between 2 topics, with the thickness of the band indicating the magnitude of the connection. A set of chord diagrams revealing agenda attribute interactions in the agendas with comparison of different users is presented in Figure 2.
To assess the evolution of links between attributes over time, this study also divided the co-occurrence dynamics of intragroup agenda attributes into 3 distinct periods: 2020, 2021, and 2022. Our findings revealed that the connections between agenda attributes varied by both the time period and the categories of Facebook users. Notably, in the government agenda, the link between “vaccine effectiveness” and “vaccine affordability” exhibited an increase in strength during 2022 (795/4150, 19.16%), compared with 2020 (18/223, 8.25%) and 2021 (690/4744, 14.54%). Conversely, the connection between “vaccine importance” and “expert trust” within the agenda of regular users demonstrated a decline in frequency over the 3-year span (2020: 119/1165, 10.21%; 2021: 282/3417, 8.25%; 2022: 118/1779, 6.63%). More information about the co-occurrence dynamics of the intragroup agenda attributes over time can be found in Multimedia Appendix 5.

**Agenda Network Analysis**

In answering RQ3, the results of the QAP tests demonstrated significantly positive and strong correlations between the agenda network of the government and those of professional media ($r=0.745$, $P=.005$) and civil organizations ($r=0.632$, $P=.02$). However, the correlations between the government’s agenda network and the network of alternative media ($r=0.462$, $P=.08$) and regular users ($r=.451$, $P=.07$) were not statistically significant.

The subsequent QAP linear regression analysis tested whether the agenda network of the Macao government can predict that of nongovernment users. For example, by using the government as a predictor and different types of nongovernment users as outcome variables, the results demonstrated that the government has an impact on the agenda network of professional media ($b=0.703$, $P=.006$) and civil organizations ($b=0.051$, $P=.02$). The adjusted $R^2$ value for professional media indicated that government accounts for around 54% of the variance in the professional media’s agenda network, while government only accounts for 38% of the variance in the agenda network of civil organizations. The results of the QAP linear regression analysis with the government as a predictor are shown in Table 2.

In the QAP linear regression model predicting the agenda of regular users, the results revealed significant impacts of alternative media ($b=2.46$, $P=.001$), professional media ($b=0.52$, $P=.001$), and civil organizations ($b=6.16$, $P=.001$) on the agenda of regular users. The adjusted $R^2$ value for professional media, civil organizations, and alternative media ranged from 0.81 to 0.86, suggesting that all 3 categories of users can explain 81%-86% of the variance in the regular users’ agenda network. The results of the QAP linear regression analysis with regular users as the outcome variable are shown in Table 3.
Table 2. Quadratic assignment procedure regression analysis with government as the predictor.

<table>
<thead>
<tr>
<th>User category</th>
<th>Unstandardized coefficient</th>
<th>P value</th>
<th>R^2 value</th>
<th>Adjusted R^2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Civil organizations</td>
<td>0.051</td>
<td>.02</td>
<td>0.399</td>
<td>0.382</td>
</tr>
<tr>
<td>Professional media</td>
<td>0.703</td>
<td>.006</td>
<td>0.556</td>
<td>0.543</td>
</tr>
<tr>
<td>Alternative media</td>
<td>0.095</td>
<td>.10</td>
<td>0.214</td>
<td>0.191</td>
</tr>
<tr>
<td>Regular users</td>
<td>0.246</td>
<td>.12</td>
<td>0.204</td>
<td>0.180</td>
</tr>
</tbody>
</table>

Outcomes were considered statistically significant at P<.05.

Table 3. Quadratic assignment procedure regression analysis with regular users as the outcome variable.

<table>
<thead>
<tr>
<th>User category</th>
<th>Unstandardized coefficient</th>
<th>P value</th>
<th>R^2 value</th>
<th>Adjusted R^2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>0.246</td>
<td>.12</td>
<td>0.204</td>
<td>0.180</td>
</tr>
<tr>
<td>Alternative media</td>
<td>2.462</td>
<td>.001</td>
<td>0.868</td>
<td>0.864</td>
</tr>
<tr>
<td>Professional media</td>
<td>0.521</td>
<td>.001</td>
<td>0.811</td>
<td>0.805</td>
</tr>
<tr>
<td>Civil organizations</td>
<td>6.164</td>
<td>.001</td>
<td>0.832</td>
<td>0.827</td>
</tr>
</tbody>
</table>

Outcomes were considered statistically significant at P<.05.

Impacts of Government and Nongovernment Users on Each Other’s Vaccine Agenda

To answer RQ4, the Granger causality test was further performed to examine whether the 9 attributes in the government’s agenda statistically predicted the future intensity of topics discussed by different categories of users and vice versa. Specifically, the results showed that attributes such as “vaccine safety” ($F_{3,13}=3.817; P=.04$) and “trust in experts” ($F_{3,11}=3.916; P=.03$) in the government’s agenda significantly affected such attributes in the agenda of nongovernment users, while the attributes associated with “trust in government” ($F_{3,13}=4.590; P=.02$) and “vaccine affordability” ($F_{3,13}=3.851; P=.04$) in the agenda of nongovernment users affected these attributes in the agenda of the government at the significance level of $P<.05$.

By classifying nongovernment users into different user categories, the results suggested a unidirectional trend in the attribute of “vaccine safety” flowing from the government’s agenda to that of professional media ($F_{3,15}=3.247; P=.03$), while professional media affected the agenda of the government unilaterally through the attributes of “vaccine importance” ($F_{3,12}=7.192; P=.003$), “vaccine effectiveness” ($F_{3,13}=4.391; P=.02$), “COVID-19 risk” ($F_{3,13}=5.173; P=.006$), and “vaccine affordability” ($F_{3,13}=4.754; P=.02$). Additionally, alternative media affected the government by setting the agenda with attributes such as “COVID-19 risk” ($F_{3,15}=8.769; P<.001$) and “vaccine accessibility” ($F_{3,13}=2.963; P=.047$), while there was no temporal causation from the government to alternative media for the attributes identified.

Regarding civil organizations, the government predicted the agenda of civil organizations through the attributes of “vaccine importance” ($F_{3,15}=4.111; P=.01$), “vaccine effectiveness” ($F_{3,13}=6.264; P=.007$), and “trust in experts” ($F_{3,9}=15.877; P=.001$), while the causation from civil organizations to the government was absent for all attributes except “vaccine safety” ($F_{3,12}=4.405; P=.03$). Most notably, the Granger causality analysis revealed that the government had a significant impact on the agenda of regular users through the attributes of “vaccine importance” ($F_{3,15}=3.809; P=.02$), “trust in experts” ($F_{3,15}=16.639; P<.001$), “vaccine accessibility” ($F_{3,15}=3.343; P=.03$), and “vaccine affordability” ($F_{3,13}=6.012; P=.008$). Despite the absence of Granger causality from regular users to the government for most attributes, there was a reciprocal relationship between the government and regular users in the attribute of “vaccine affordability.” The results of the Granger causality tests between the government and other types of users are shown in Table 4.
### Table 4. Granger causality tests between government users and other types of users for each vaccine attribute.

<table>
<thead>
<tr>
<th>Vaccine attribute</th>
<th>Nongovernment users</th>
<th>Professional media</th>
<th>Alternative media</th>
<th>Civil societal organizations</th>
<th>Regular users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>1.410 (2,20)</td>
<td>1.209 (2,20)</td>
<td>1.413 (5,20)</td>
<td>7.192 (5,12)</td>
<td>2.412 (5,15)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.26</td>
<td>.32</td>
<td>.26</td>
<td>.003</td>
<td>.09</td>
</tr>
<tr>
<td>Effectiveness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>0.449 (2,30)</td>
<td>3.029 (3,13)</td>
<td>0.133 (2,30)</td>
<td>4.391 (3,13)</td>
<td>0.293 (3,13)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.64</td>
<td>.07</td>
<td>.88</td>
<td>.02</td>
<td>.83</td>
</tr>
<tr>
<td>Safety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>3.817 (3,13)</td>
<td>3.222 (3,13)</td>
<td>3.247 (5,15)</td>
<td>2.565 (5,15)</td>
<td>0.706 (1,15)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.04</td>
<td>.057</td>
<td>.03</td>
<td>.07</td>
<td>.41</td>
</tr>
<tr>
<td>Trust in government</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>2.017 (3,15)</td>
<td>4.590 (3,13)</td>
<td>3.270 (3,13)</td>
<td>3.924 (3,13)</td>
<td>1.228 (2,20)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.15</td>
<td>.02</td>
<td>.055</td>
<td>.03</td>
<td>.31</td>
</tr>
<tr>
<td>Trust in experts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>3.916 (3,13)</td>
<td>0.402 (2,20)</td>
<td>3.753 (2,10)</td>
<td>1.437 (5,30)</td>
<td>0.401 (2,20)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.03</td>
<td>.67</td>
<td>.06</td>
<td>.24</td>
<td>.67</td>
</tr>
<tr>
<td>COVID-19 risk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>0.255 (2,9)</td>
<td>1.124 (2,30)</td>
<td>1.890 (2,30)</td>
<td>5.173 (5,15)</td>
<td>0.665 (3,3)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.78</td>
<td>.34</td>
<td>.16</td>
<td>.006</td>
<td>.63</td>
</tr>
<tr>
<td>Accessibility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>0.248 (2,15)</td>
<td>2.781 (3,13)</td>
<td>0.045 (2,10)</td>
<td>1.362 (5,20)</td>
<td>1.461 (5,15)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.78</td>
<td>.08</td>
<td>.96</td>
<td>.28</td>
<td>.26</td>
</tr>
<tr>
<td>Distribution</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>0.756 (2,20)</td>
<td>0.104 (2,20)</td>
<td>0.596 (2,20)</td>
<td>0.283 (2,20)</td>
<td>0.147 (1,25)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.48</td>
<td>.90</td>
<td>.56</td>
<td>.76</td>
<td>.70</td>
</tr>
<tr>
<td>Affordability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$F$ value (df)</td>
<td>2.500 (3,13)</td>
<td>3.851 (3,13)</td>
<td>0.745 (2,20)</td>
<td>4.754 (3,13)</td>
<td>0.479 (2,20)</td>
</tr>
<tr>
<td>$P$ value</td>
<td>.10</td>
<td>.04</td>
<td>.49</td>
<td>.02</td>
<td>.63</td>
</tr>
</tbody>
</table>

### Discussion

**Principal Findings**

This study examined the dynamics and patterns of vaccine communication on Facebook in Macao during the COVID-19 pandemic. The principal findings demonstrated that “vaccine importance” was the most prevalent attribute in the vaccination agenda on Facebook, followed by the attributes of “COVID-19 risk” and “trust in experts.” The overall vaccination agenda revealed the highest co-occurrences were between “vaccine importance” and “COVID-19 risk.” Differences existed in agenda priorities between the government and regular users. The government primarily focused on the risks of COVID-19 and the effectiveness of vaccines, whereas regular users were more concerned with the safety and distribution of vaccines. The Macao government played a role in shaping the agenda for...
regular users by highlighting vaccine importance (Granger causality result: $F_{5,15}=3.809; P=.02$), trust in experts (Granger causality result: $F_{5,15}=16.639; P<.001$), and vaccine accessibility (Granger causality result: $F_{5,15}=3.343; P=.03$) and affordability (Granger causality result: $F_{3,11}=6.012; P=.008$), while its impact on the agenda network of regular users remained insignificant (QAP result: $b=0.246; P=.12$). Both government and nongovernment users (eg, professional media, alternative media, civil organizations, and regular users) had intertwined agendas with mutual influence.

Unlike previous studies that predominantly focused on single aspects of vaccine communication (eg, [17,34]), this study used a more holistic approach to reveal the role of various actors including the government, professional media, alternative media, civil organizations, and regular users in promoting vaccination agendas and the interplay of diverse actors in the vaccine agenda setting process. The results of this study suggest that professional media acts as more than simple information providers to the government but rather effectively pushed agenda setting as a supplementary process to vaccine promotion by raising salient topics that the government fails to identify due to lack of information and experience. The government, however, is more likely to respond to professional media to receive timely feedback on vaccination issues for the purpose of learning and improvement. This can be observed from the impact that professional media has on the government in the agenda setting process through topics of “vaccine importance” (Granger causality results: $F_{5,12}=7.192; P=.003$), “vaccine effectiveness” (Granger causality results: $F_{3,13}=4.391; P=.02$), “trust in government” (Granger causality results: $F_{5,13}=3.924; P=.03$), “COVID-19 risk” (Granger causality results: $F_{5,15}=5.173; P=.006$), and vaccine affordability (Granger causality results: $F_{5,13}=4.754; P=.02$).

Who Leads the Vaccine Agenda of Whom?

Despite a significant correlation between the government agenda network and the agenda network of nongovernment users, the government had a limited impact on the agenda attributes of different Facebook user categories and vice versa. As Facebook is an open platform where information from a wide variety of sources freely circulates and interacts, it is difficult to determine the driving force behind the vaccine promotion agenda on the platform [55]. In other words, nongovernment users’ vaccine promotion agendas may have been impacted by other sources, such as the World Health Organization or other health professionals, which indicates a multidirectional effect.

As such, it appears that the government did not unilaterally set the agenda of nongovernment users. Instead, there is a “2-way” interaction between government and nongovernment user agendas. Due to their mutual effect, neither the government nor nongovernment users lead the agenda on social media. It is likely that the government and different types of nongovernment users pay attention to the agendas of one another and interact with one another to build the overall vaccine agenda network on Facebook. This corresponds with the argument by Finset et al [63] that, amid the near-chaotic flow of information, every individual, in different roles and with varied responsibilities, can contribute to the development of the information flow and agenda on COVID-19. A plausible explanation for this outcome could be the unprecedented nature of the health crisis. The lack of up-to-date crisis communication planning and experience with coping with a novel crisis may challenge the government’s agenda-setting process, particularly in terms of vaccine promotion.

Comparison With Prior Work

Previous agenda setting research found that changes in the government agenda led to changes in the public agenda [64]. However, during the COVID-19 pandemic, the public was no longer passive consumers of social media. Our results indicating the different concerns of vaccination between the government and regular users corroborate previous findings by Zhou and Zheng [44] who found that, during the COVID-19 pandemic, the government’s Weibo account exhibited a more propaganda-oriented approach, whereas public accounts were more attentive to issues that directly pertained to self-interest, such as protective measures against the virus and minimizing financial losses. Unlike other political issues, the government may have less impact on shaping public agenda due to the more collected information possessed by the public. This is partly consistent with some recent research indicating that shaping public opinion in a fragmented digital environment such as social media is challenging [54,65]. Additionally, the case of Macao also indicates selective public responsiveness on topics that are clear and straightforward, which partially verifies the observation by Kim [66] that individuals are more receptive to topics that are unambiguous and do not demand extensive background knowledge as they may not have enough background information with which to fully process any new information on complex topics.

Practical Implications

Our study provides several implications to inform the management of future pandemics. First, given the disparity between the government and public agenda networks, it is crucial to bridge the gap to enable effective vaccine communication. Policymakers should strive for alignment between government messaging and public concerns, addressing issues that are prominent within the public discourse. Social media listening activities are invaluable tools for understanding public health concerns. By monitoring public conversation through social media listening, policymakers can develop targeted messaging and communication strategies that effectively address public concerns and provide accurate information to dispel misconceptions.

Second, the low responsiveness of the public agenda to the government agenda indicates the need to enhance the government impact on the public agenda. Governments can streamline their messaging by using plain language, which helps individuals with different levels of knowledge understand information easily. Clear and concise presentation avoids unnecessary complexity. Visual aids and interactive media can also be used to improve public involvement and responsiveness, overcoming barriers caused by limited background information.
Third, policymakers’ efforts to convince the public to receive vaccines in response to potential health risks have been shown in our study to lead to a spillover of media attention that significantly drives the vaccination agenda among the public. Collaboration with influential media, including professional and alternative media, thus offers a powerful means to facilitate vaccination policy and improve public health. Governments can utilize the extensive reach and persuasive power of media outlets to actively involve and inform the public about specific issues that should receive priority attention, thereby advancing the government’s crisis management initiatives.

Fourth, civil organizations’ ability to shape public attention toward vaccination issues by influencing the public agenda network suggests that their impact on shaping the vaccination agenda may be underestimated or overlooked. Driven by social responsibility, civil organizations often dedicate their efforts to promoting public health by increasing awareness and advocating for public health policies [43]. The close ties to communities enable them to be trusted sources of information for the public. Therefore, through partnerships with civil organizations, governments can leverage their networks, expertise, and community trust to effectively promote vaccination initiatives.

Limitations
Several limitations warrant consideration. First, broadening the scope beyond vaccines to encompass diverse policies could offer a more comprehensive understanding of public attention allocation mechanisms. Researchers are encouraged to explore various policies to enhance generalizability. Second, although Facebook data provided valuable insights, the findings are platform-specific and may not apply universally. Future studies should incorporate a diverse set of social media platforms and combine quantitative data with surveys and interviews for a more nuanced perspective. Third, although this study explored temporal agenda dynamics, it did not delve into the determinants driving public attention intensity, such as government transparency and issue salience. Investigating these factors could provide valuable insights into the agenda setting process at the government level.

Conclusions
This study investigated the communication dynamics of COVID-19 vaccines in Macao, with a specific focus on how government agendas impact other entities on Facebook. Our results reveal that the Macao Government’s efforts to set the vaccination agenda on Facebook have shown limited effectiveness in shaping the public’s discourse and priorities regarding vaccines. Such findings have profound implications for shaping government responses to future pandemics. Authorities, in their endeavor to legitimize policies, must recognize the intricate interplay between their agendas and public reception. Although agenda setting serves as a strategic tool to promote vaccination, it also exhibits limitations. This requires a shift toward more nuanced, strategy-focused research. This study offers indispensable insights in the area of crisis communication, underscoring the urgent necessity of bridging the gap between government and public agendas. Furthermore, it illuminates the potential of collaborations with influential media outlets and civil organizations as formidable channels to augment the reach and influence of vaccination agendas set by the government.

Authors’ Contributions
XX conceptualized the study, curated the data, wrote the original manuscript draft, and created the visualizations. XX and AC performed the formal analysis. XX and RJN validated the data. AC and RJN reviewed and edited the manuscript. AC supervised the study and served as project administrator. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Keywords for vaccine-related data acquisition.
[DOCX File, 16 KB - infodemiology_v4i1e51113_app1.docx ]

Multimedia Appendix 2
Coding framework for COVID-19 vaccine posts on Facebook.
[DOCX File, 21 KB - infodemiology_v4i1e51113_app2.docx ]

Multimedia Appendix 3
Keywords for machine coding of vaccine-related topics.
[DOCX File, 19 KB - infodemiology_v4i1e51113_app3.docx ]

Multimedia Appendix 4
Outcomes of post hoc tests on the significant difference between user categories and vaccine-related topics.
[DOCX File, 21 KB - infodemiology_v4i1e51113_app4.docx ]
Multimedia Appendix 5
Intra-group co-occurrences dynamic of agenda shifts for the years of 2020, 2021, and 2022.

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64. Luo Y. The Internet and agenda setting in China: The influence of online public opinion on media coverage and government policy. International Journal of Communication 2014;8:1289-1312 [FREE Full text]


Abbreviations

NAS: network agenda setting model  
QAP: quadratic assignment procedure  
RQ: research question  
VAR: vector autoregression

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Development of a Medical Social Media Ethics Scale and Assessment of #IRad, #CardioTwitter, and #MedTwitter Posts: Mixed Methods Study

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Abstract

Background: Social media posts by clinicians are not bound by the same rules as peer-reviewed publications, raising ethical concerns that have not been extensively characterized or quantified.

Objective: We aim to develop a scale to assess ethical issues on medical social media (SoMe) and use it to determine the prevalence of these issues among posts with 3 different hashtags: #MedTwitter, #IRad, and #CardioTwitter.

Methods: A scale was developed based on previous descriptions of professionalism and validated via semistructured cognitive interviewing with a sample of 11 clinicians and trainees, interrater agreement, and correlation of 100 posts. The final scale assessed social media posts in 6 domains. This was used to analyze 1500 Twitter posts, 500 each from the 3 hashtags. Analysis of posts was limited to original Twitter posts in English made by health care professionals in North America. The prevalence of potential issues was determined using descriptive statistics and compared across hashtags using the Fisher exact and χ² tests with Yates correction.

Results: The final scale was considered reflective of potential ethical issues of SoMe by participants. There was good interrater agreement (Cohen κ=0.620, P<.01) and moderate to strong positive interrater correlation (r=0.602, P<.001). The 6 scale domains showed minimal to no interrelation (Cronbach α=0.206). Ethical concerns across all hashtags had a prevalence of 1.5% or less except the conflict of interest concerns on #IRad, which had a prevalence of 3.6% (n=18). Compared to #MedTwitter, posts with specialty-specific hashtags had more patient privacy and conflict of interest concerns.

Conclusions: The SoMe professionalism scale we developed reliably reflects potential ethical issues. Ethical issues on SoMe are rare but important and vary in prevalence across medical communities.

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KEYWORDS
ethics; social media; conflict of interest; interventional radiology; X; Twitter; cardiology; privacy; ethical issues; medical social media; prevalence; professional; professionalism

Introduction

The digital footprint of clinicians on social media has increased over the past 10 years with an estimated 90% and 65% of clinicians using social media for personal and professional purposes, respectively [1]. Medical social media (SoMe) has blossomed, offering clinicians opportunities to collaborate across distances, debate treatment approaches for challenging cases,
and engage in public health advocacy [2-4]. However, this rapid integration of social media in health care has outpaced guidance that counsels on how to avoid ethical concerns that can occur with SoMe [2].

The risks of SoMe have not gone unnoticed. Several professional organizations have released statements outlining guiding principles for online clinician behavior, including the American Medical Association and the Federation of State Medical Boards [5,6]. There have also been opinion pieces and recommendations published within various specialties such as neurology, dermatology, and vascular surgery [7-9]. Guidelines and opinion pieces are helpful starting points but may not address subtle but important breaches in professionalism [10] and may fail to resonate with the majority of users’ experiences and values [2].

A few studies have assessed the prevalence of issues such as violations of the HIPAA (Health Insurance Portability and Accountability Act) [10]. However, the potential issues are much broader than explicit patient privacy violations [10,11]. This study sought to develop a more complete scale of ethical issues related to medical SoMe to provide empirical data on these issues. The authors hypothesized that a scale could be developed that captures the most salient ethical issues with good interrater agreement and correlation. The authors also hypothesized that applying such a scale would find that the prevalence of issues was small and varied across different professional groups.

**Methods**

**Scale Development**

This study was approved by the Stanford University Institutional Review Board (eProtocol 60351). An initial draft of the scale was developed based on medical professionalism in the new millennium: a physician charter created by the American Board of Internal Medicine Foundation, American College of Physicians Foundation, and the European Federation of Internal Medicine as well as a study by Chandratilake et al [12] assessing definitions of medical professionalism across cultures [13]. These sources were selected to attempt to define medical SoMe ethics that would be reflective of common definitions of medical professionalism. The initial draft consisted of 5 criteria rated on a 3-point scale: no ethical concern (0), potential ethical concern (1), and clear ethical concern (2). The 3-point scale was selected to reflect a concept raised by both initial sources that ethical issues occur on a continuum, allowing the scale to also capture less overt violations of professionalism.

The initial scale was then vetted for validity via semistructured cognitive interviewing with a group of clinicians and trainees [14]. Interviewees were recruited via email and were primarily a convenience sample at the authors’ institutions. They were invited to provide feedback on a draft of the scale, which included fabricated posts and example scoring for demonstration. Purposeful recruiting was used to ensure that interviewees were diverse in terms of specialty, training level, and gender identity. Iterative adjustments were made to the initial scale based on interviewee feedback until additional interviews continued suggesting that the scale was reflective of interviewee perceptions of potential ethical issues related to medical SoMe. This occurred after 11 interviews with interviewees from 6 different specialties whose demographics are shown in Table 1.
Table 1. Demographic characteristics of interviewees (N=11).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Interviewees, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Training level</strong></td>
<td></td>
</tr>
<tr>
<td>1st-year MDa</td>
<td>2 (18)</td>
</tr>
<tr>
<td>2nd-year MD</td>
<td>0 (0)</td>
</tr>
<tr>
<td>3rd-year MD</td>
<td>2 (18)</td>
</tr>
<tr>
<td>4th+ year MD</td>
<td>1 (9)</td>
</tr>
<tr>
<td>1st-year resident</td>
<td>0 (0)</td>
</tr>
<tr>
<td>2nd-year resident</td>
<td>1 (9)</td>
</tr>
<tr>
<td>3rd+ year resident</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Attending</td>
<td>4 (36)</td>
</tr>
<tr>
<td><strong>Institution</strong></td>
<td></td>
</tr>
<tr>
<td>Stanford University School of Medicine</td>
<td>8 (73)</td>
</tr>
<tr>
<td>University of California San Diego</td>
<td>1 (9)</td>
</tr>
<tr>
<td>University of Kansas Medical Center</td>
<td>2 (18)</td>
</tr>
<tr>
<td><strong>Specialty</strong></td>
<td></td>
</tr>
<tr>
<td>Anesthesiology</td>
<td>2 (18)</td>
</tr>
<tr>
<td>DRb/IRc</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Emergency medicine</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Primary care</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Otolaryngology</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Undeclared</td>
<td>4 (36)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7 (64)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (36)</td>
</tr>
</tbody>
</table>

aMD: Doctor of Medicine.
bDR: Diagnostic Radiology.
cIR: Interventional Radiology.

The vetted scale scored posts on 6 domains, using the same 3-point scale (Table 2). Scale item interrelation as well as scale interrater agreement and correlation were assessed by having 2 researchers use the scale to independently rate 50 random posts each from #MedTwitter between June 15, 2021, and August 15, 2021, with an overlap of 10 tweets. Posts were identified using the Healthcare Hashtag Project (Symplur, LLC). The interrelation of scale items was assessed via Cronbach \( \alpha \). Interrater agreement was assessed via Cohen \( \kappa \) and interrater correlation was assessed via Spearman correlation coefficient, assuming a nonlinear relationship. An \( \alpha \) of <.05 was predefined as statistical significance.
Table 2. Medical social media professionalism scale.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Score</th>
<th>1=minor concern</th>
<th>2=major concern</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient privacy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the post maintain patient privacy by applying appropriate safeguards for patient information and removing patient identifiers?</td>
<td>Post omits HIPAA identifiers and any other details that in combination would enable patient identification.</td>
<td>Post omits HIPAA identifiers but uses information that could potentially allow for patient identification, particularly when combined with the author’s known practice location, medical specialty, or rarity of medical condition.</td>
<td>Post uses one or more HIPAA identifiers that allows for easy identification.</td>
</tr>
<tr>
<td><strong>Patient dignity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the post treat patients with respect and avoid the use of degrading language or images?</td>
<td>Post treats patients as individuals worthy of respect and does not demean the patient in any way.</td>
<td>Post contains references, images, or language that could be negatively construed such that some may take offense.</td>
<td>Post is objectifying or dehumanizing, treating patients as being of lesser intelligence or caliber.</td>
</tr>
<tr>
<td><strong>Information accuracy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the information medically accurate with no counterfactual, exaggerated, or otherwise misleading content?</td>
<td>Information in the post is reasonably supported by current evidence and does not make superlative claims.</td>
<td>Information in the post is ambiguous or exaggerated in a manner that could lead to misinterpretation.</td>
<td>Information in the post is overtly sensational and makes baseless claims.</td>
</tr>
<tr>
<td><strong>Conflict of interest</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the post unduly influenced by ulterior motives for private gain without proper acknowledgment or disclosure in a way that could affect information accuracy?</td>
<td>The post does not promote or endorse products or services without an appropriate declaration of any associated financial ties.</td>
<td>The post promotes or endorses products or services without a declaration of conflicts, however, it does not make authoritative claims about these products.</td>
<td>The post promotes or endorses products or services without a proper declaration of conflicts and also makes authoritative claims about these products.</td>
</tr>
<tr>
<td><strong>Justice and equity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the text or images in the post discriminatory based on race, gender, socioeconomic status, ethnicity, religion, sexual orientation, or any other social category and does the post promote further inequities in health care?</td>
<td>The post does not express or imply any discriminatory sentiments or propagate a stance that either sustains or widens inequities in health care.</td>
<td>The post contains ideas associated with stereotypes or broad generalizations without suggesting the differential treatment of individuals based on these stereotypes.</td>
<td>The post explicitly expresses sentiments that are discriminatory and is a proponent for the differential treatment of individuals based on these prejudiced notions.</td>
</tr>
<tr>
<td><strong>Interprofessional respect</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the post treat colleagues and other health care professionals with respect and avoid the use of stereotypes, mockery, and incivility?</td>
<td>Post treats colleagues and other health care professionals with esteem and does not demean them in any way.</td>
<td>Post contains references, images, or language that could be negatively construed by other colleagues as offensive.</td>
<td>Post clearly mocks or disrespects colleagues, portraying them as inferior or of lesser intelligence or caliber.</td>
</tr>
</tbody>
</table>

*aHIPAA: Health Insurance Portability and Accountability Act.*

**Evaluation of Posts**

The validated scale was then used to assess the prevalence of ethical issues among posts using 3 distinct hashtags: #MedTwitter, #IRad, and #CardioTwitter. These were selected as they are the most frequently used hashtags among the general medical community, interventional radiologists, and cardiologists, respectively, as indicated by the number of posts per day for each hashtag on the Symplur software. Interventional Radiology (IR) and cardiology were selected to provide examples of more specialty-specific posts to contrast with #MedTwitter as they are primarily used by physician specialists in those fields to discuss more expert medical content compared to #MedTwitter. Posts were limited to those in English posted by individuals (rather than societies or bots) who are clinicians or health care trainees in North America between December 10, 2021, and January 10, 2022. Retweets were also excluded. A total of 1500 posts were analyzed, 500 from each hashtag. Data were analyzed using descriptive statistics as well as Fisher exact tests and \( \chi^2 \) tests with Yates correction to compare the prevalence of ethical issues across hashtags. These statistical tests were selected to adjust for the low rates of ethical issues. All statistical analyses were performed using SPSS software (IBM, Inc).

**Ethical Considerations**

All procedures were approved by the Stanford University Institutional Review Board (IRB#: 60351) and were per the legal and ethical standards of the responsible committee on human experimentation institutionally. Additionally, we adhered to local, national, regional, and international laws and regulations regarding the protection of personal information, privacy, and human rights.
Results

Scale Development
Cognitive interviewing supported the validity of the initial 5 domains. However, the initial interviewees felt the initial scale did not address interspecialty and inter–health care professional cyberbullying, leading to the addition of interprofessional respect as a 6th domain. Interviewees also suggested the addition of language to better delineate a minor concern (1) rating from a major concern (2) rating. Subsequent interviews confirmed that the 6-domain scale, each rated from 0 to 2, was reflective of their perceptions of SoMe ethics.

The scale demonstrated good interrater agreement (Cohen \( \kappa =0.620, \ P<.01 \)) and moderate to strong positive correlation between the scores given by the independent raters (Spearman correlation coefficient=0.602, 95% CI 0.515-0.677; \( P<.001 \)). The scale domains showed minimal to no interrelation (Cronbach \( \alpha =0.206 \)).

Evaluation of Posts
Application of the scale to 1500 Twitter posts showed that ethical concerns across all 6 domains were infrequent with the majority in the range of 0.2% (n=1) to 1.2% (n=6). Further, 1 exception was a minor conflict of interest concern among posts using #IRad, which demonstrated a prevalence of 3.6% (n=18).

Relative to posts using #MedTwitter, posts using #IRad or #CardioTwitter were more likely to have patient privacy concerns (n=7, 1.4% vs 0%, \( P=.02 \); n=6, 1.2% vs 0%, \( P=.04 \); respectively). Posts using #IRad were also more likely to have conflicts of interest concerns relative to #MedTwitter and #CardioTwitter (n=18, 3.6% vs n=3, 0.6%, \( P<.001 \); n=18, 3.6% vs n=4, 0.8%, \( P=.005 \); respectively). Issues related to interprofessional respect were also more prevalent in #IRad posts than #CardioTwitter (n=8, 1.6% vs n=1, 0.2%, \( P=.04 \)) but similar to #MedTwitter (n=8, 1.6% vs n=6, 1.2%, \( P=.79 \)). As a result, across all domains, #IRad posts had the greatest overall prevalence of ethical concerns. Table 3 summarizes the prevalence of ethical concerns by hashtag and domain and Tables 4-6 summarize comparisons between hashtags.

Table 3. Prevalence of ethical concerns on medical social media by hashtag (N=500).

<table>
<thead>
<tr>
<th>Domain</th>
<th>No issue (0), n (%)</th>
<th>Minor concern (1), n (%)</th>
<th>Major concern (2), n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MedTwitter prevalence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient privacy</td>
<td>500 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>495 (99)</td>
<td>3 (0.6)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>Information accuracy</td>
<td>497 (99.4)</td>
<td>2 (0.4)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>500 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Justice and equity</td>
<td>499 (99.8)</td>
<td>1 (0.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Interprofessional respect</td>
<td>494 (98.8)</td>
<td>4 (0.8)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>IR(^a) prevalence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient privacy</td>
<td>493 (98.6)</td>
<td>6 (1.2)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>497 (99.4)</td>
<td>1 (0.2)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>Information accuracy</td>
<td>497 (99.4)</td>
<td>2 (0.4)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>482 (96.4)</td>
<td>18 (3.6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Justice and equity</td>
<td>500 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Interprofessional respect</td>
<td>492 (98.4)</td>
<td>7 (1.4)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Cardiology prevalence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient privacy</td>
<td>494 (98.8)</td>
<td>6 (1.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>499 (99.8)</td>
<td>1 (0.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Information accuracy</td>
<td>500 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>496 (99.2)</td>
<td>2 (0.4)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>Justice and equity</td>
<td>500 (100)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Interprofessional respect</td>
<td>499 (99.8)</td>
<td>1 (0.2)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

\(^a\)IR: Interventional Radiology.

https://infodemiology.jmir.org/2024/1/e47770

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(page number not for citation purposes)
Table 4. Comparison of ethical concerns on medical social media by hashtag: #IRad vs #MedTwitter.

<table>
<thead>
<tr>
<th></th>
<th>#IRad, n (%)</th>
<th>#MedTwitter, n (%)</th>
<th>Fisher exact P value</th>
<th>Chi-squared with Yates correction P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient privacy</td>
<td>7 (1.4)b</td>
<td>0 (0)b</td>
<td>.02b</td>
<td>.02b</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>3 (0.6)</td>
<td>5 (1)</td>
<td>.73</td>
<td>.72</td>
</tr>
<tr>
<td>Information accuracy</td>
<td>3 (0.6)</td>
<td>3 (0.6)</td>
<td>≥.99</td>
<td>≥.99</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>18 (3.6)b</td>
<td>0 (0)b</td>
<td>&lt;.001b</td>
<td>&lt;.001b</td>
</tr>
<tr>
<td>Justice and equity</td>
<td>0 (0)</td>
<td>1 (0.2)</td>
<td>≥.99</td>
<td>.32</td>
</tr>
<tr>
<td>Interprofessional respect</td>
<td>8 (1.6)</td>
<td>6 (1.2)</td>
<td>.79</td>
<td>.79</td>
</tr>
</tbody>
</table>

aComparisons reflect the composite of major and minor concerns for each scale criterion. P<.05 on a 2-tailed analysis was considered significant.
bComparisons that are significant.

Table 5. Comparison of ethical concerns on medical social media by hashtag: #CardioTwitter vs #MedTwitter.

<table>
<thead>
<tr>
<th></th>
<th>#CardioTwitter, n (%)</th>
<th>#MedTwitter, n (%)</th>
<th>Fisher exact P value</th>
<th>Chi-squared with Yates correction P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient privacy</td>
<td>6 (1.2)b</td>
<td>0 (0)b</td>
<td>.03b</td>
<td>.04b</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>1 (0.2)</td>
<td>5 (1)</td>
<td>.22</td>
<td>.22</td>
</tr>
<tr>
<td>Information accuracy</td>
<td>0 (0)</td>
<td>3 (0.6)</td>
<td>.37</td>
<td>.62</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>4 (0.8)</td>
<td>0 (0)</td>
<td>.22</td>
<td>.37</td>
</tr>
<tr>
<td>Justice and equity</td>
<td>0 (0)</td>
<td>1 (0.2)</td>
<td>≥.99</td>
<td>.32</td>
</tr>
<tr>
<td>Interprofessional respect</td>
<td>1 (0.2)</td>
<td>6 (1.2)</td>
<td>.12</td>
<td>.13</td>
</tr>
</tbody>
</table>

aComparisons reflect the composite of major and minor concerns for each scale criterion. P<.05 on a 2-tailed analysis was considered significant.
bComparisons that are significant.

Table 6. Comparison of ethical concerns on medical social media by hashtag: #IRad vs #CardioTwitter.

<table>
<thead>
<tr>
<th></th>
<th>#IRad, n (%)</th>
<th>#CardioTwitter, n (%)</th>
<th>Fisher exact P value</th>
<th>Chi-squared with Yates correction P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient privacy</td>
<td>7 (1.4)</td>
<td>6 (1.2)</td>
<td>≥.99</td>
<td>.78</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>3 (0.6)</td>
<td>1 (0.2)</td>
<td>.62</td>
<td>.62</td>
</tr>
<tr>
<td>Information accuracy</td>
<td>3 (0.6)</td>
<td>0 (0)</td>
<td>.37</td>
<td>.62</td>
</tr>
<tr>
<td>Conflict of interest</td>
<td>18 (3.6)b</td>
<td>4 (0.8)b</td>
<td>.004b</td>
<td>.005b</td>
</tr>
<tr>
<td>Justice and equity</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>≥.99</td>
<td>≥.99</td>
</tr>
<tr>
<td>Interprofessional respect</td>
<td>8 (1.6)b</td>
<td>1 (0.2)b</td>
<td>.04b</td>
<td>.04b</td>
</tr>
</tbody>
</table>

aComparisons reflect the composite of major and minor concerns for each scale criterion. P<.05 on a 2-tailed analysis was considered significant.
bComparisons that are significant.

Discussion

Principal Results

This study sought to develop a scale to characterize and quantitate ethical issues on SoMe and then apply the scale to 3 different SoMe communities based on Twitter hashtags. Although some guidelines and opinion pieces exist describing potential ethical issues on SoMe, to the best of the authors’ knowledge, no scales had been created, making it difficult to assess the prevalence of ethical issues and guide efforts to mitigate potential harm [10]. This is important not only because of legal implications, but this behavior can exacerbate existing hierarchies and damage mutual trust.

The scale proposed in this study was developed via a structured deductive and inductive approach. Key domains were identified based on literature review as well as qualitative interviews,
consistent with best practices in scale development [15,16]. This helped ensure that the scale was comprehensive and perceived as valid. Interrater agreement and correlation were good but likely limited by the qualitative nature of these assessments. The lack of interrelation between domains is not unexpected. A post with a patient privacy concern would not necessarily be more likely to have a conflict of interest as well.

Application of the scale to Twitter posts with #MedTwitter, #CardioTwitter, and #IRad yielded a couple of important observations. First, the prevalence of ethical concerns is low, often around 1% (n=5) across domains. However, such a number is not insignificant. According to Symplur software, there are approximately 5000 to 8000 posts per day made using #MedTwitter, equating to approximately 50-80 ethically concerning posts per day. These findings are similar to a 2011 study of over 5000 general tweets from health care providers, which found 3% of tweets were unprofessional and 0.7% were concerning for breaches in patient privacy [17].

A second interesting observation was how the prevalence of ethical concerns varied across the 3 groups of posts analyzed. For example, posts with the specialty-specific hashtags #CardioTwitter and #IRad had more patient privacy and conflict of interest concerns than general #MedTwitter posts. This may be due to a higher likelihood of posting specific patient cases in specialty-specific communities to illustrate an approach or solicit recommendations compared to the general #MedTwitter community. Posts with conflict of interest were also most prevalent in #IRad posts, which may be due to IR being a more procedural specialty than cardiology in general, and a specialty whose professional identity is closely tied to specific procedures and devices rather than patient populations [18]. Previous authors have observed similar variations in posts across specialties. The dominating content among IR posts tends to be images of an intervention performed on a patient to share new techniques or gather recommendations for superior approaches [19]. In contrast, cardiology posts are dominated by short synopses of trending research papers with reactive commentary [20]. However, interventional cardiology posts can share similar traits to IR [20,21], likely accounting for some of the overlap in the ethical issues among these posts.

Practical Implications
The persistence of posts with ethical issues among medical professionals and trainees invites evaluation of current social media training programs. The domains in the scale offer a useful framework with validated language and examples to offer caution against ethical concerns that go beyond HIPAA violations. The framework can also foster a mental model to assist in evaluating personal tweets before publishing a post. This is important as once a post is made; it is difficult to retract it completely before it is shared or copied by other users.

The results from this study also provide a foundation for evidence-based social media guidelines by professional bodies and specialty-specific societies. As demonstrated by differences in the prevalence of ethical concerns between #CardioTwitter and #IRad, not all ethical issues are equally problematic, and with this data, guidelines can be tailored to the target group. This scale can be applied to hashtags used by other specialists to uncover trends in ethical issues and address those weak points more specifically. For example, social media statements for interventional radiologists may include more specific and detailed guidance on avoiding conflict of interest concerns.

From an academic perspective, the scale and methodology described in this study offer a way to assess the efficacy of interventions aimed at reducing the frequency of ethical issues on SoMe. Previously, there were limited ways to quantify and characterize the landscape of SoMe professionalism. However, now it is possible to perform pre- and poststudies with a specific intervention of interest.

Although this study focused on the application of the professionalism scale to Twitter posts as a proof of concept, the principles could be translated to other platforms as they do not include any evaluation metric that is inherent to Twitter, since the development of the scale was independent of any specific platform. From a validation perspective, this translation would be easiest for platforms that mimic Twitter by using a combination of texts and images, such as Facebook and Instagram posts. Importantly, videos were not assessed in this study, which would be of interest in analyzing Reels, TikTok, and YouTube videos. However, the methodology of this study can be applied to these different social media contexts to assess the generalizability of the scale.

Limitations and Future Directions
This study had important limitations. The scale provides a good estimate of the prevalence of ethical issues, but it is not a thorough investigation of whether a given issue definitively exists especially for domains like conflict of interest that are challenging to verify without collateral information. Although the scale development incorporated input from a diverse group of clinicians and trainees in terms of training level, specialty, and gender identity, the sample was a small convenience sample from academic settings that could have missed important input from other clinicians in different contexts, for example, private practice. The sample was limited to posts in English from North America due to language restrictions and greater cultural familiarity. However, this may limit the external validity of the scale and results in other cultures. The authors relied on self-described Twitter biographies to limit posts to health care professionals, which could have been inaccurate.

To address some of these limitations, future steps to continue improving the scale would include expanding the sample to include more physicians and trainees from private practice, community hospitals, and primary care so that these additional perspectives can further refine the scale. Additionally, although the Cohen κ for interrater reliability already suggests good agreement, there may be domains with greater discrepancies than others. The language of these domains can be made more precise or explicit based on a bigger sample feedback to potentially improve consistency. Lastly, a comparison among different platforms would help directly assess if scale validity transcends social media contexts.

Conclusions
The developed SoMe ethics scale is reliable, relevant, and concisely captures the myriad ethical tensions that can arise on
these platforms. Ethical issues are present in a small but meaningful percentage of posts among health care professionals, which vary in important ways across different specialties and professional groups. The authors hope this scale will allow researchers to better characterize and assess the prevalence of ethical issues on SoMe while guiding more targeted interventions to mitigate these issues.

Conflicts of Interest
None declared.

References


Abbreviations

HIPAA: Health Insurance Portability and Accountability Act
IR: Interventional Radiology
SoMe: medical social media
Corrigenda and Addenda

Correction: Verification in the Early Stages of the COVID-19 Pandemic: Sentiment Analysis of Japanese Twitter Users

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1. The authorship list was previously listed as:
Ryuichiro Ueda, MA; Feng Han, MA; Hongjian Zhang, MD; Tomohiro Aoki, MA; Katsuhiko Ogasawara, Prof Dr
And has now been changed to:
Ryuichiro Ueda, MHA; Feng Han, MHA; Hongjian Zhang, PhD; Tomohiro Aoki, MHA; Katsuhiko Ogasawara, MBA, PhD

2. Author Feng Han’s affiliation was originally:
Faculty of Health Sciences, Hokkaido University, Sapporo, Japan
And was changed to:
Graduate School of Medicine, Hokkaido University, Sapporo, Japan

3. The phone number listed for the corresponding author was originally:
81 011 716 2111
And was changed to:
81 11 706 3409

The correction will appear in the online version of the paper on the JMIR Publications website on March 14, 2024 together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Using Social Listening for Digital Public Health Surveillance of Human Papillomavirus Vaccine Misinformation Online: Exploratory Study

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Abstract

Despite challenges related to the data quality, representativeness, and accuracy of artificial intelligence–driven tools, commercially available social listening platforms have many of the attributes needed to be used for digital public health surveillance of human papillomavirus vaccination misinformation in the online ecosystem.

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KEYWORDS

human papillomavirus; HPV; vaccine; vaccines; vaccination; vaccinations; sexually transmitted infection; STI; sexually transmitted disease; STD; sexual transmission; sexually transmitted; social media; social listening; cancer; surveillance; health communication; misinformation; artificial intelligence; AI; infodemiology; infoveillance; oncology

Introduction

The COVID-19 pandemic accelerated the spread of misinformation online, creating an “infodemic” that had profound effects on health behavior [1]. The breadth and depth of COVID-19 misinformation expanded to include all vaccinations, such as human papillomavirus (HPV) vaccination, depressing already suboptimal vaccination uptake in the United States [1,2]. As HPV vaccination is critical to the prevention of various cancers, this could pose significant cancer control challenges in the future [2]. There is an urgent need to address HPV vaccination misinformation to increase HPV vaccination uptake [2]. Behavioral interventions can counter misinformation online, but they are typically limited to a single social media platform without geographic specificity [3].

Public health surveillance (PHS) is defined by the Centers for Disease Control and Prevention (CDC) as “the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health” [4]. Digital PHS (DPHS) uses data from online sources, often collected outside of traditional PHS, for similar purposes [5]. There has been debate as to the ethics of using publicly available online data for DPHS [5]. However, the pandemic illustrated the need for user-friendly, timely, interactive digital tools to drive health-related intervention [6].

Social listening (SL) is the process of aggregating data from across online channels to collect real-time measures of emotions, opinions, and themes, typically through platform algorithms that rely on machine learning and artificial intelligence (AI) [7]. While SL platforms’ AI-driven tools for emotion and sentiment detection can be unreliable, machine learning provides an opportunity to “train” SL platforms for greater accuracy over time in the automated recognition of emotions and sentiments [8]. The World Health Organization Early AI-Supported Response With Social Listening Platform (WHO EARS) uses...
an SL dashboard to provide health professionals access to information from across the internet to assist in the development of timely responses to COVID-19 narratives that occur online at the global and country levels, highlighting the growing acceptance of such tools in public health [7].

The purpose of this exploratory study was to assess the feasibility of using a commercially available SL platform to monitor HPV vaccination misinformation online at the national (ie, within the United States overall) and state (ie, within Mississippi and Rhode Island) levels.

**Methods**

**Ethical Considerations**

This study received institutional review board exemption from West Virginia University (protocol #00152755).

**Study Design**

Brandwatch was the commercially available SL platform selected for this exploratory study. It was selected after reviewing functionalities of leading SL platforms and having conversations about capabilities with representatives from Agorapulse, Brandwatch, Hootsuite, and Sprout Social. While most platforms had similar functionalities and data access, Brandwatch was selected based on opportunities to build queries with greater geographic specificity. While there is limited research on SL platform functionality within public health, Brandwatch was previously studied for the accuracy of AI-driven analyses [8]. The previously cited limitations of Brandwatch AI-driven tools informed the study team’s systematic, routine approach to training.

The research team received onboarding from Brandwatch through 5 structured, live training sessions. Two research team members completed a self-paced online training certificate. After onboarding was complete, the research team’s SL lead analyst (AS) built an HPV vaccination query within Brandwatch, using keywords and phrases identified through previous research and with research team consensus [9]. From this query, AS, with support from Brandwatch developers, created a dashboard to monitor online conversations within the United States overall and in 2 states—Mississippi, the US state with the lowest HPV vaccination rate, and Rhode Island, the US state with the highest vaccination rate. The research team regularly reviewed the query keywords and updated them as needed for increased relevancy and accuracy.

Brandwatch AI-driven tools were trained to recognize sentiments and emotions related to HPV vaccination. Sentiment categories for this study were different from the ones provided automatically by Brandwatch within the platform and were determined by the research team based on previous research [9]. Sentiment categories included “fact-based information,” “pro-vaccine opinions,” “misinformation,” “anti-vaccine opinions,” and “neutral comments.” These sentiment categories were built into the dashboard by a Brandwatch developer in conjunction with AS. The initial AI-driven recognition of these sentiment categories was initially incorrect and required routine training by AS to improve accuracy.

Once the SL platform was built, the research team evaluated the dashboard, query, and implementation process notes to assess the feasibility of using a commercially available SL platform for HPV vaccination misinformation DPHS. This assessment was completed by using an adaptation of the CDC’s attributes for an effective PHS system [4]. The attributes adapted in this study were identified from CDC iterations published since 1988 [10]. The adaption of attributes involved the inclusion of consistent elements and associated definitions from across these CDC iterations; the addition of “cost” as a potential challenge to scaling; and the removal of “predictive value positive,” as the proposed DPSh approach would assess online narratives as opposed to a specific health condition. Consensus on each attribute was reached among the research team members.

**Results**

Table 1 details each adapted PHS system attribute and the opportunities and limitations with regard to using a commercially available SL platform for HPV vaccination misinformation DPSh. Opportunities include user-friendly dashboards with real-time data monitoring and platform adaptability. For example, from June 21 to 24, 2023, the research team was able follow the spread of misinformation through social media posts related to a lawsuit filed by the Children’s Health Defense Fund, an organization led by prominent antivaccine activist Robert Kennedy Jr. However, while the SL platform dashboards are user-friendly, it took significant staff time, expertise, and routine maintenance to keep them relevant and as accurate as possible. Brandwatch was also found to be adaptable to the ever-changing online information ecosystem; however, the quality of this information was dependent on data access agreements with individual social media companies, which could change at any time. Additional challenges to using an SL platform for DPSh include concerns with data quality, representativeness, and the accuracy of AI-driven tools. There are limited ways to validate data within the SL platform itself. Data may be downloaded from Brandwatch and externally analyzed for sentiments and emotions, but this process would remove the AI-driven, automated nature of the SL platform and reduce the effectiveness of real-time monitoring in DPSh.
Table 1. Feasibility of using a commercial social listening platform for human papillomavirus vaccination misinformation digital public health surveillance. This was assessed based on attributes of public health surveillance systems adapted from the Centers of Disease Control and Prevention [4].

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Attribute description</th>
<th>Social listening opportunities</th>
<th>Social listening limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usefulness</td>
<td>Contribution to prevention and control of misinformation</td>
<td>Events that may trigger misinformation spread can be identified in real time, providing an opportunity to target intervention</td>
<td>Unclear if targeted interventions can effectively shift online narratives</td>
</tr>
<tr>
<td>Simplicity</td>
<td>Simplicity of structure and ease of use</td>
<td>Dashboards can automate monitoring and provide easy-to-use tools to dig deeper into observable trends</td>
<td>Building effective queries requires a specialized skill set, including content area knowledge and experience with social media and online ecosystems</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Adaptable to changing information and conditions</td>
<td>Queries can be adapted to new information and trends by changing keywords and phrases</td>
<td>Requires consistent monitoring by skilled personnel to ensure queries are reflective of current conditions</td>
</tr>
<tr>
<td>Data quality</td>
<td>Validity and completeness of data</td>
<td>Queries can include data beyond social media, providing a window into narratives in online public spaces</td>
<td>Data are limited by access provided by specific social media companies and the effectiveness of the query, along with a current lack of external data validation</td>
</tr>
<tr>
<td>Representativeness</td>
<td>Accurately describes flow of health information over time and distribution by place and person</td>
<td>Queries can monitor conversation trends over time, such as trends among audience panels and in various locations, which provide insights into demographics and geographic boundaries</td>
<td>Demographic and geographic information is imprecise and is limited based on availability</td>
</tr>
<tr>
<td>Timeliness</td>
<td>Lapse of time between misinformation and intervention</td>
<td>Conversations can be monitored in real time, providing opportunities for quick responses to misinformation</td>
<td>Lack of evidence-based responses to counter misinformation spread</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>Ability to identify true cases and detect misinformation</td>
<td>Dashboard algorithms can be trained to detect changes in sentiments and emotions, providing an opportunity to respond to trends</td>
<td>Effectively training algorithms to detect sentiments and emotions is time-consuming and requires a specialized skill set</td>
</tr>
<tr>
<td>Stability</td>
<td>System is resilient to change</td>
<td>Can collect new sources of online data as they emerge to remain relevant in the shifting social media and online ecosystem</td>
<td>Changes to social media company policies can affect access to data sources</td>
</tr>
<tr>
<td>Acceptability</td>
<td>Willingness of persons and organizations to participate</td>
<td>Data collection is passive and does not burden participants with active data requests</td>
<td>Ethical concerns with online public data collection</td>
</tr>
<tr>
<td>Portability</td>
<td>Duplication of system in another setting</td>
<td>Social listening platforms can be purchased and adapted to different settings and health conditions, with no specialized hardware required for operation</td>
<td>Effectiveness of the queries may be limited by the personnel developing them and the sophistication of the selected social listening platform</td>
</tr>
<tr>
<td>Costs</td>
<td>Cost-effectiveness of the system</td>
<td>Online services can vary in price (≥US $2500 annually) based on the services needed for social listening</td>
<td>Sophisticated social listening platforms are more costly, although they provide greater access to data and tools</td>
</tr>
</tbody>
</table>

While Brandwatch was selected due to opportunities for greater geographic specificity, this functionality was limited in scope to only certain social media platforms, such as X (formerly Twitter). Furthermore, geographic specificity was limited based on whether social media users used geolocation functionalities and whether locations were mentioned in profiles or posts. Despite this, the research team identified and monitored different narratives in misinformation within the two states included in this exploratory study—Rhode Island and Mississippi—suggesting the potential importance of assessing online misinformation narratives based on geographic location. For example, on the same day in January 2024, the top trending story for Rhode Island focused on the Children’s Health Defense Fund lawsuit, while in Mississippi, the top story focused on childhood injury due to vaccination.

Discussion

Our findings suggest that there are opportunities and challenges associated with using commercially available SL platforms to monitor HPV vaccination misinformation online at the national and state levels. While there were strengths across all PHS system attributes, there were also significant weaknesses. These weaknesses, particularly those related to data quality, representativeness, and the accuracy of AI-driven tools, reflect limitations to using current SL platforms for DPHS. If these challenges are addressed over time however, this level of DPHS could provide the foundation for different intervention opportunities, such as using skilled infodemiologists to counter online misinformation [11]. While the research team identified challenges with the accuracy of Brandwatch AI-driven tools, which matched previously published research [8], building DPHS capabilities now could provide critical infrastructure if
and when such tools improve over time. If found to be effective in monitoring HPV vaccine misinformation, commercially available SL platforms may be adapted to other fields and health conditions. Findings may differ based on the SL platform used and vendor access agreements with social media companies. Future research should focus on increasing the specificity of geographic location, studying strategies to increase the accuracy of SL platform AI-driven tools, and testing targeted interventions using SL platforms.

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Authors' Contributions

DB, AA, and SKR contributed to the conception of this work. DB designed this work. AS acquired the data. DB and AS contributed to the analysis of data. DB, AS, LA, and ZJ contributed to the interpretation of data. All authors contributed to drafting the manuscript, and DB approved the final version for publication.

Conflicts of Interest

None declared.

References


Abbreviations

AI: artificial intelligence
CDC: Centers for Disease Control and Prevention
DPHS: digital public health surveillance
HPV: human papillomavirus
PHS: public health surveillance
SL: social listening
WHO EARS: World Health Organization Early AI-Supported Response With Social Listening Platform