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

\(^a\)CDC: Centers for Disease Control and Prevention.  
\(^b\)API: application programming interface.  
\(^c\)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>
</table>
| CDC\(^a\) tweets and COVID-19 metrics | • Construct an LDA\(^b\) topic model using CDC tweets assigning 4 topics  
• Extract generated topics with their top 10 unique associated keywords  
• Produce interactive visualizations using pyLDAvis | • Domain experts examine topic keywords with randomly sampled tweets in iteration  
• Domain experts determine the theme of each topic  
• Perform multivariate time series analyses between each topic time series and each COVID-19 metric time series:  
  1. Visualization  
  2. Cross-correlation function (CCF)  
  3. Mutual information (MI)  
  4. Autoregressive integrated moving average with external variable (ARIMAX) model |

\(^a\)CDC: Centers for Disease Control and Prevention.  
\(^b\)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]:

\[
\text{Perplexity} = 2^{\text{Perplexity}'}
\]

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 (i.e., 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]:

\[ P(i, j) = \frac{N}{\sum_{w \in T} \min(i, j)} \]

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 (i.e., how similar the 2 series are at different times), their associations (i.e., 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]:

\[ r_{x,y}(l) = \frac{\sum_{t=1}^{N-l} (x_t - \bar{x})(y_{t+l} - \bar{y})}{\sqrt{\sum_{t=1}^{N} (x_t - \bar{x})^2 \sum_{t=1}^{N} (y_t - \bar{y})^2}} \]

where \( N \) is the number of observations in each time series, and \( x_t \) and \( y_t \) are the observations at the \( t \)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]:

\[ I(X;Y) = \sum_{x \in X} \sum_{y \in Y} P(x,y) \log \frac{P(x,y)}{P(x)P(y)} \]

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 $x_i$ and $y_i$ are their respective observations at the $i$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]:

\[ (1 - B)^d x_t = (1 - B)^d v_t, \]

or in backward shift operator form:

\[ (1 + B)^d x_t = (1 + B)^d v_t, \]

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 $x_i$. ARIMAX ($p$, $d$, $q$) is specified as follows [25]:

\[ (1 - B)^d x_t = (1 - B)^d v_t + \sum_{i=1}^n \beta_i y_{t-i}, \]

or in backward shift operator form [26]:

\[ (1 + B)^d x_t = (1 + B)^d v_t + \sum_{i=1}^n \beta_i y_{t-i}, \]

where $\beta_i$ contributes to the exogeneous independent variable that could potentially influence the dependent variable $y_i$.

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 ($y_i$) 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]:

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

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

where $n$ is the number of data points in a sample $y (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 topic’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.
Figure 4. Cross-correlation function (CCF) between the completed COVID-19 vaccination series and topic 2 tweets. (A) Trends of CDC tweet topics and vaccination records; (B) CCF between records of fully vaccinated people 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 that 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 1&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Topic 2&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Topic 3&lt;sup&gt;c&lt;/sup&gt;</th>
<th>Topic 4&lt;sup&gt;d&lt;/sup&gt;</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>

<sup>a</sup>Topic 1: General vaccination information and education, especially preventing adverse health outcomes of COVID-19.

<sup>b</sup>Topic 2: Pediatric intervention, pediatric vaccination information, family safety, and school and community protection.

<sup>c</sup>Topic 3: Updates on COVID-19 testing, case, and death data, and relevant information of the disease.

<sup>d</sup>Topic 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 1</th>
<th>Topic 2</th>
<th>Topic 3</th>
<th>Topic 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case counts</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ARIMAX par</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>−104.76 (2240.19, 2344.95)</td>
<td>0.45 (4304.09, 4303.64)</td>
<td>−1.53 (2227.59, 2229.12)</td>
<td>11.97 (4785.89, 4773.92)</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>0.90</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 par</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>20.43 (2227.59, 2207.16)</td>
<td>60.14 (4785.89, 4725.75)</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 par</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>1.83 (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 par</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>−108.15 (2240.19, 2348.34)</td>
<td>−69.79 (4304.09, 4373.88)</td>
<td>−90.54 (2227.59, 2318.13)</td>
<td>−91.53 (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>

---

**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 protection; (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 infodveillance 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.
Figure 5. Time series of the daily number of Centers for Disease Control and Prevention (CDC) tweets and COVID-19 case counts. US: United States.

Limitations and Future Work

There are several limitations in this infoveillance 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 [31-34] 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.
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
daIC: 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.

(JMIR Infodemiology 2024;4:e37881) doi:10.2196/37881

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 2020. 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 that “anxiety” and “anger” toward government policies were the top feelings in Spain in the early stages of the infection. Thus, in Japan, the prime minister can now declare a “state of emergency.”

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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>

References

[1] 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.

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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, McCab (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 McCab [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 (JLWC) 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].
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:

\[
\begin{bmatrix}
    u_1 & \cdots & u_n
\end{bmatrix},
\]

\[
\begin{bmatrix}
    v_1 & \cdots & v_n
\end{bmatrix}
\]

In this case, the following conditions are satisfied:

\[
\begin{bmatrix}
    \sum_{i=1}^{n} u_{i} & \sum_{i=1}^{n} v_{i}
\end{bmatrix}
\]

The matrix \(U\), denoted as \(u_{i}\), represents an n \times c matrix with the membership value \(u_{i}u_{j}\) as an element. Meanwhile, the matrix \(V\), represented as \(v_{i}\), is an n \times c matrix with cluster center \(v_{i}\) as an element.

Bezdek proposed the following formula for the FCM model that minimizes the objective function by the weighted sum of clustering, data are assigned to clusters by being represented as either belonging (1) or not belonging (0) to a specific cluster.

\[
\sum_{i=1}^{n} \sum_{j=1}^{c} u_{ij} v_{ij}^{2}.
\]

\[
\sum_{i=1}^{n} \sum_{j=1}^{c} u_{ij} v_{ij}^{2}.
\]
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:

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

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 $P < 0.05$, 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 (3.55)</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>
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<td>2020/4/15</td>
<td>44,185 (3.22)</td>
<td>118,456 (3.37)</td>
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<td>2020/4/16</td>
<td>48,618 (3.54)</td>
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<td>2020/4/17</td>
<td>44,494 (3.24)</td>
<td>132,009 (3.76)</td>
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<td>2020/4/18</td>
<td>38,270 (2.79)</td>
<td>111,351 (3.17)</td>
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<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 declaration.

<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>

Before 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>Tweet SD</th>
<th>Retweet Median</th>
<th>Retweet 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 a simultaneous rise in positive emotions, attributed to the anticipation of infection prevention following the state of emergency declaration. During the early stages of the COVID-19 spread in other countries, a previous study on English-speaking users indicated elevated levels of positive emotions linked to anticipations for potential policies [22]. A generally similar emotional response was apparent among the public in other countries. In the early stages of the spread of infection, when no vaccine or other countermeasures had been implemented, 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 twentiesomethings (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 hashtag from January 2020 to March 2020, including human and bot-generated tweets. Their findings revealed that bot-generated 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.

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
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 dysplasia, 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 cognitively, affectively, and relationally 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>

*Represents 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, (2) duplicate posts with identical content from the same day, (3) posts without image or text content, or (4) posts without image or text content. This resulted in a total of 2,760 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 co-created 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

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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 κ. The analysis found acceptable reliability of independent coders in assessing the presence or absence of any social support (κ value range across all platforms, κ=0.79-0.95) and uncertainty (κ value range across all platforms, κ=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 ≥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.

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**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).

<table>
<thead>
<tr>
<th></th>
<th>Facebook community group (n=511), n (%)</th>
<th>Facebook main page (n=1815), n (%)</th>
<th>Twitter (n=434), n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Post type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary post</td>
<td>108 (21.1)</td>
<td>800 (44.1)</td>
<td>368 (84.8)</td>
</tr>
<tr>
<td>Comment</td>
<td>403 (78.9)</td>
<td>1015 (55.9)</td>
<td>66 (15.2)</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>487 (95.3)</td>
<td>1807 (99.6)</td>
<td>434 (100)</td>
</tr>
<tr>
<td>Other&lt;sup&gt;a&lt;/sup&gt;</td>
<td>4 (0.8)</td>
<td>8 (0.4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Image only</td>
<td>17 (3.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Creator type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Team telomere</td>
<td>8 (1.6)</td>
<td>861 (47.4)</td>
<td>385 (88.7)</td>
</tr>
<tr>
<td>Individual</td>
<td>503 (98.4)</td>
<td>954 (52.6)</td>
<td>49 (11)</td>
</tr>
<tr>
<td><strong>Observed creator sex</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>25 (5)</td>
<td>69 (7.2)</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Female</td>
<td>478 (95)</td>
<td>885 (92.8)</td>
<td>41 (83.7)</td>
</tr>
<tr>
<td>Unknown</td>
<td>0 (0)</td>
<td>1 (0.1)</td>
<td>3 (6.1)</td>
</tr>
<tr>
<td><strong>Observed creator race</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>443 (88.1)</td>
<td>766 (80.3)</td>
<td>40 (81.6)</td>
</tr>
<tr>
<td>Other&lt;sup&gt;c&lt;/sup&gt;</td>
<td>46 (9.1)</td>
<td>30 (3.1)</td>
<td>6 (12.2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>14 (2.8)</td>
<td>158 (16.6)</td>
<td>3 (6.1)</td>
</tr>
<tr>
<td><strong>Observed creator telomere biology disorder relationship</strong>&lt;sup&gt;b,d&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>65 (12.9)</td>
<td>42 (4.4)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Parent</td>
<td>428 (85.1)</td>
<td>384 (40.3)</td>
<td>14 (28.6)</td>
</tr>
<tr>
<td>Medical provider</td>
<td>3 (0.6)</td>
<td>31 (3.2)</td>
<td>10 (20.4)</td>
</tr>
<tr>
<td>Other&lt;sup&gt;e&lt;/sup&gt;</td>
<td>5 (1)</td>
<td>59 (6.2)</td>
<td>22 (44.9)</td>
</tr>
<tr>
<td>Unknown</td>
<td>40 (8)</td>
<td>495 (51.9)</td>
<td>2 (4.1)</td>
</tr>
<tr>
<td>Multiple</td>
<td>129 (25.6)</td>
<td>126 (13.2)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Respectively 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%).

<sup>b</sup>Includes 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).

<sup>c</sup>Respectively 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%).

<sup>d</sup>Frequency does not total to 100% because of some individuals occupying multiple categories.

<sup>e</sup>Respectively 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>
<thead>
<tr>
<th>Table 3. Uncertainty in telomere biology disorder (TBD) social media.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Post text</strong></td>
</tr>
<tr>
<td><strong>Sources of uncertainty</strong></td>
</tr>
<tr>
<td><strong>Ambiguity</strong></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>
</tr>
<tr>
<td>• “Pre-lung # transplantation patients with # pulmonary # fibrosis who have short # telomeres may need different # clinical care...” [TWT180100.19.06.11]</td>
</tr>
<tr>
<td><strong>Complexity</strong></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>
</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>
</tr>
<tr>
<td><strong>Probability</strong></td>
</tr>
<tr>
<td>• “80% of patients diagnosed with dyskeratosis congenita will experience bone marrow failure.” [TWT185500.19.11.04]</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>
</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>
</tr>
<tr>
<td><strong>Issues of uncertainty</strong></td>
</tr>
<tr>
<td><strong>Scientific</strong></td>
</tr>
<tr>
<td>• “Has anybody experienced hearing loss with connection to short telomere length?” [FBCG218300.21.07.30]</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>
</tr>
<tr>
<td><strong>Practical</strong></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>
</tr>
<tr>
<td><strong>Personal</strong></td>
</tr>
<tr>
<td>• “It’s # PFMonth, and we want you to know you have a team surrounding you...” [TWT1816000.20.09.04]</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>
</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>
</tr>
<tr>
<td><strong>Focus of uncertainty management</strong></td>
</tr>
<tr>
<td><strong>Ignorance</strong></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>
</tr>
<tr>
<td>• “Hello—any contraindications to getting COVID 19 vaccine if you have DC?” [FBCG217100.21.04.04]</td>
</tr>
<tr>
<td>• “Do you have a copy of the clinical guidelines?” [FBCG203509.20.09.08]</td>
</tr>
<tr>
<td>• “Take time to learn more about #Telomere Biology Disorders through our informational video!” [TWT1822100.21.11.04]</td>
</tr>
<tr>
<td><strong>Uncertainty</strong></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>
</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>
</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>
</tr>
<tr>
<td><strong>Response</strong></td>
</tr>
<tr>
<td>• “Our family is celebrating today! [Name]’s Happy 8th bone marrow transplant anniversary!” [FBCG203300.20.08.24]</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>
</tr>
<tr>
<td>• “Join@sixnwstevies as she teaches yoga for research...” [TWT1822600.21.03.16]</td>
</tr>
<tr>
<td><strong>Person</strong></td>
</tr>
<tr>
<td>• “Thank goodness for social media otherwise it would be very isolating.” [FBCG203821.20.09.25]</td>
</tr>
<tr>
<td>• “Don’t forget to register for our Young Adult Meetup...” [TWT1814300.20.06.23]</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>
</tr>
<tr>
<td>• “You are in great hands but always happy to connect with [Provider Name]” [FBCG203504.20.09.08]</td>
</tr>
<tr>
<td>• “Check out # tilmere! All # sparkly and ready for # TBDmonth!” [TWT185400.19.11.04]</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>
</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 ($\chi^2_1=3.9; P=.05$), 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>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 ($\chi^2_1=70.7; P<.001$). However, within social support subtypes, only informational support remained significantly more frequent within uncertainty-related posts ($\chi^2_1=486.0; P<.001$), whereas emotional support was significantly less frequent in uncertainty-related posts ($\chi^2_1=66.5; P<.001$) 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 or 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_appl.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 ($\beta$=−.29, 95% CI −0.58 to −0.004; $P$=.047) were associated with lower knowledge of COVID-19 guidelines, users of Instagram ($\beta$=−.40, 95% CI −0.68 to −0.12; $P$=.005) and Twitter ($\beta$=−.33, 95% CI −0.58 to −0.08; $P$=.01) were associated with perceiving guidelines as strict, and users of Facebook ($\beta$=−.23, 95% CI −0.42 to −0.043; $P$=.02) and TikTok ($\beta$=−.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.

**Ethical Considerations**

The University of South Carolina’s Institutional Review Board exempted the study (Pro00119512) from Human Research Ethics Considerations.
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><strong>Age (years; 1 participant’s data are missing), mean (SD)</strong></td>
<td>45.3 (16.94)</td>
</tr>
<tr>
<td><strong>Gender (11 participants’ data are missing)</strong></td>
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</tr>
<tr>
<td>Men</td>
<td>515 (49.9)</td>
</tr>
<tr>
<td>Women</td>
<td>513 (49.71)</td>
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<td>Nonbinary or other</td>
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<td>Black or African American</td>
<td>121 (11.61)</td>
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<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>
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<tr>
<td><strong>Education (1 participant’s data are missing)</strong></td>
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<tr>
<td>Less than high school degree</td>
<td>25 (2.4)</td>
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<tr>
<td>High school graduate or equivalent</td>
<td>248 (23.8)</td>
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<tr>
<td>Some college but no degree</td>
<td>248 (23.8)</td>
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<tr>
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<td>123 (11.8)</td>
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<tr>
<td>Bachelor’s degree</td>
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<td>Doctoral or professional degree (JD, MD, or PhD)</td>
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<td><strong>Employment status over the last 3 months (6 participant’s data are missing)</strong></td>
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<tr>
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<td>Working part-time</td>
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<td>Unemployed and looking for work</td>
<td>74 (7.14)</td>
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<td>Homemaker or stay-at-home parent</td>
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<td>Student</td>
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<tr>
<td>Retired</td>
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</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><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.09</td>
<td>-0.14</td>
<td>0.08</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.006</td>
<td>&lt;.001</td>
<td>.01</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.11</td>
<td>0.001</td>
<td>0.11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&lt;.001</td>
<td>.97</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.02</td>
<td>-0.03</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.48</td>
<td>.27</td>
<td>.21</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.15</td>
<td>-0.08</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&lt;.001</td>
<td>.007</td>
<td>.17</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td>0.38</td>
<td>6.43</td>
<td>5.27</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.54</td>
<td>.01</td>
<td>.02</td>
</tr>
<tr>
<td><strong>Race or ethnicity</strong></td>
<td></td>
<td>2.36</td>
<td>12.66</td>
<td>3.85</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.051</td>
<td>&lt;.001</td>
<td>.004</td>
</tr>
<tr>
<td><strong>Political affiliation</strong></td>
<td></td>
<td>6.23</td>
<td>94.13</td>
<td>49.87</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.002</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>COVID-19 vaccination status</strong></td>
<td></td>
<td>2.7</td>
<td>23.88</td>
<td>69.85</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.07</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Site for COVID-19 news</strong></td>
<td></td>
<td>2.07</td>
<td>1.64</td>
<td>2.89</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.07</td>
<td>.15</td>
<td>.01</td>
</tr>
<tr>
<td><strong>Regularity of social media use</strong></td>
<td></td>
<td>0.53</td>
<td>1.21</td>
<td>1.23</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.75</td>
<td>.30</td>
<td>.29</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 ($\beta=0.03$, 95% CI 0.005-0.05; $P=0.02$) increased, it was found to be associated with a higher level of knowledge of COVID-19 guidelines. Democratic political affiliation ($\beta=-0.21$, 95% CI $-0.37$ to $-0.057$; $P=0.008$) was found to be negatively associated with guideline knowledge. Using TikTok as a source of COVID-19 information ($\beta=-0.29$, 95% CI $-0.58$ to $-0.004$; $P=0.047$) 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(^a)</th>
<th>Model 2: perceptions(^a)</th>
<th>Model 3: self-reported adherence(^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(\beta (95% CI))</td>
<td>(P) value</td>
<td>(\beta (95% CI))</td>
</tr>
<tr>
<td>Age</td>
<td>.002 (–0.003 to 0.007)</td>
<td>.51</td>
<td>–.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</td>
<td>.072 (–0.45 to 0.6)</td>
<td>.79</td>
<td>.92 (0.35 to 1.49)</td>
</tr>
<tr>
<td>Hawaiian or Native Pacific Islander</td>
<td></td>
<td></td>
<td></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(^b)</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(^b)</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 –0.004)</td>
<td>.047(^b)</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=0.26, 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. Facebook (β=0.4, 95% CI −0.68 to −0.12; P=0.005) and Twitter (β=−3.3, 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 19% of the variance in adherence to 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 (e.g., 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 (e.g., 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


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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 vaccination 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 nongovernment 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 (e.g., Pinterest: 11.47%; Twitter: 10.54%) in Macao [37,38]. The wide 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 (e.g., 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 (e.g., “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 (e.g., 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 (e.g., [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 (e.g., [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 [37,50,51]. 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:

\[
\alpha_i \beta_i \rho \varepsilon
\]

Within this model, \(\alpha_i\) and \(\beta_i\) are the estimated coefficients, \(\rho\) represents the optimal number of lags for the model, and \(\varepsilon\) 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 (133/5322, 2.5%; \(P<.001\), expert trust (518/5322, 9.73%; \(P<.001\)), 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 (1895/7555, 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 1. Overview of the vaccine agenda attributes by government and nongovernment users in Macau from January 1, 2020, to August 31, 2022.

<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.
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.
Figure 2. Comparison of agenda attribute interactions by different users: (A) government, (B) professional media, (C) alternative media, (D) civil societal organizations, (E) regular users. Acce.: vaccine accessibility, Afford.: vaccine affordability, Distri.: vaccine distribution, Eff.: vaccine effectiveness, E.T.: expert trust, G.T.: government trust, Import.: vaccine importance, Risk: risk of COVID-19, Saf.: vaccine safety.

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$^a$</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>

$^a$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$^a$</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>

$^a$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” ($F_{3,12}=4.590; P=.02$) 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” ($F_{3,13}=4.391; P=.02$), “COVID-19 risk” ($F_{3,15}=5.173; P=.006$), 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” ($F_{3,12}=2.963; P=.047$), 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” ($F_{3,9}=4.111; P=.01$), “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” ($F_{3,12}=6.012; P=.008$). 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></td>
<td>Outcome variable</td>
<td>Antecedent variable</td>
<td>Outcome variable</td>
<td>Antecedent variable</td>
<td>Outcome variable</td>
</tr>
<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 (2,20)</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>
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<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>
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<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: $F_{5,15}=3.809; P=0.02$), trust in experts (Granger causality result: $F_{5,15}=16.639; P<0.001$), and vaccine accessibility (Granger causality result: $F_{5,15}=3.343; P=0.03$) and affordability (Granger causality result: $F_{3,13}=6.012; P=0.008$), while its impact on the agenda network of regular users remained insignificant (QAP result: $b=0.246; P=0.12$). 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: $F_{3,13}=7.192; P=0.003$), “vaccine effectiveness” (Granger causality results: $F_{3,13}=4.391; P=0.02$), “trust in government” (Granger causality results: $F_{3,13}=3.924; P=0.03$), “COVID-19 risk” (Granger causality results: $F_{5,15}=5.173; P=0.006$), and vaccine affordability (Granger causality results: $F_{3,13}=4.754; P=0.02$).

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 non-government users pay attention to the agendas of 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 dynamics of agenda attributes for the years of 2020, 2021, and 2022.

[DOCX File .2025 KB - infodemiology_v4i1e51113_app5.docx ]

References


Abbreviations

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

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

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Related Article:
Correction of: https://infodemiology.jmir.org/2024/1/e37881
doi:10.2196/57880


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 inaccurate. For example, all content that mentioned “cancer” was automatically considered negative by the SL platform AI. AS trained the AI-driven sentiment tool to recognize the intended content by reviewing aggregated social media comments, as well as other online articles and posts within Brandwatch, and adding them to the appropriate categories to spur AI recognition. During this AI training process, another sentiment category—“irrelevant”—was added, as content that used similar language but was not directly related to HPV was identified. The Brandwatch AI-driven sentiment tool was trained by AS routinely over a 6-month period to enhance the recognition of categories. This routine training significantly improved category recognition within the SL platform but was not completely accurate upon periodic spot reviews by the research team. The AI-driven tool for recognizing emotions automatically included categories such as “anger,” “disgust,” “fear,” “joy,” “sadness,” and “surprise.” Like the AI-driven sentiment tool, the identification of correct emotion 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 DPHS 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 DPHS. 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 DPHS 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 DPHS.
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>Representiveness</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 ($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.

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