Digital hemophilia: insights into the use of social media for hemophilia care, research, and advocacy

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Abstract

Introduction: The hemophilia community on Twitter is diverse, consisting of advocacy groups, patients, physicians, researchers, and other users. However, the scope of this community is uncharacterized, and limited data are available regarding effective participation in this community.

Aim: To assess the types of users active in the hemophilia community on Twitter, as well as major themes present in hemophilia-related tweets.

Methods: 49,512 tweets between September 2019 and September 2021 were classified using regular expressions. A subset of the classified tweets was manually analyzed to identify prevalent discussion themes.

Results: Among the top 250 users by post count, the largest categories of users were support and advocacy groups, people with bleeding disorders, and healthcare providers. The largest thematic categories of tweets were gene therapy, contaminated hemophilia blood products, hemophilia research, clinical management of hemophilia, and COVID-19. While misinformation was rare, negative and incorrect perceptions of hemophilia were present among the general public.

Conclusion: Our results demonstrate patterns of effective Twitter usage for patient care, research, and advocacy purposes among the hemophilia community.

Keywords

hemophilia; education; social media; text classification; natural language processing; data science

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Introduction

The global proliferation of social media has important implications for healthcare. More than 40% of healthcare consumers report using social media to obtain healthcare information[1], and a growing number of physicians and researchers are using social media for professional purposes, including hematologists[2–4]. Concurrently, disease advocacy groups use social media as an education and promotion platform[5].

The use of social media usage among chronic disease communities has been studied in the context of multiple chronic diseases, including cancer[6], diabetes[7], and hearing loss[8]. The use of social media for chronic disease has been found to have positive social- and emotional support-related outcomes[9–11] and to promote adaptive health behaviors, such as increased physical activity[12]. Conversely, the prevalence of inaccurate or biased information on these platforms may have a negative impact on patient education[13]. However, little is known about the use of social media within the hemophilia community or the use of the term "hemophilia" on social media.

Our study addresses these questions in three ways. Firstly, we classify the individuals driving the hemophilia conversation on Twitter, one of the largest social media platforms worldwide. Secondly, we categorize the major themes present in hemophilia-related tweets, the temporality of these tweets, and the sentiments they express. Finally, we investigate public perceptions of hemophilia as well as misinformation among hemophilia-related tweets. Based on the results, we identify strategies for better engagement and reveal unmet needs where the community needs to better educate the public.

Methods

We used Twitter API v2 to retrieve all non-retweet, English-language tweets containing either "hemophilia" or "haemophilia" published between September 1, 2019 and September 1, 2021, yielding 57,027 tweets (Figure 1). We performed quality filtering by removing duplicate tweets (n = 6,159) and tweets containing stock tickers (1,356). To quantify user interaction with tweets, we calculated an engagement score for each tweet, defined as the sum of likes, retweets, and replies.

To classify tweets, we selected 181 topic-differentiating regular expressions from three sources: 1) frequent n-grams identified by the Python Natural Language Toolkit[14]; 2) topic keywords identified by Latent Dirichlet Allocation using the Python ktrain library[15]; 3) and author-contributed keywords not identified by the two automated methods. We used 44 of the 181 expressions to identify tweets containing non-medical references to hemophilia (Supplemental Table 1), such as hemophilia presence in royal families. Non-medical references were used for the public perceptions analysis. The other 137 expressions were medically relevant and grouped into 11 categories (Supplemental Table 2), individually checked for specificity, and applied to the remaining 45,590 tweets. The 200 tweets with the most engagement within each category were independently screened by two authors to identify common discussion themes. Two authors also independently screened

the 1,000 tweets with most engagement among the medically relevant tweets to identify misinformation.

To analyze the categories of users responsible for hemophilia tweets, we first identified 250 users with the most authorships among the 45,590 tweets. The descriptions, usernames, and most recent tweets of these users were independently screened and categorized by two authors into 12 categories with 97.2% agreement; the remaining 7 users were arbitrated by the third author.

To perform sentiment analysis of tweets, we used the VADER (Valence Aware Dictionary and Sentiment Reasoner) package, which is available open source (https://github.com/cjhutto/vaderSentiment). VADER is a social media sentiment analysis tool that has previously been used to analyze tweets in medical contexts[16,17]. The output of VADER is a compound score normalized between −1 (most negative) and +1 (most positive), with scores below −0.05 classified as negative, scores between −0.05 and 0.05 classified as neutral, and scores above 0.05 classified as positive.

All data analysis was conducted in Python. Heatmaps and violin plots were generated using the Seaborn and Matplotlib libraries. The Wilcoxson rank-sum test was performed using the SciPy library, and Bonferroni correction was applied using the statsmodels library.

Results

User account classification analysis

From September 2019 to September 2021, we identified 16,392 unique users who posted at least one tweet containing either "hemophilia" or "haemophilia." Within this period, 12,952 users posted only one such tweet, while the most active user posted 968 hemophilia-related tweets. We manually classified the 250 most active accounts into 12 major categories based on primary self-identification (Table 1; Supplemental Table 3). These accounts represented 16 countries (Supplemental Figure 1), including the USA (60), UK (32), and India (9).

70 of the most active accounts belonged to organizations or individuals participating in support and advocacy for hemophilia, such as the National Hemophilia Foundation (747) and The Haemophilia Society UK (688). 35 people with bleeding disorders (PwBDs), primarily hemophilia A, hemophilia B, and Von Willebrand disease, were also among the 250 most active accounts, eighteen of whom self-identified as bleeding disorder advocates. Healthcare providers, including 19 physicians and nine non-physician providers, were also present.

Examining the popularity of tweets, we calculated a user-averaged engagement score, defined as the sum of likes, retweets, and replies, for each category. Despite support and advocacy groups having the most activity, taken as a whole, they had an average engagement score of 5.82 per post (Table 1). In contrast, non-physician providers had the highest score of 12.69, followed by PwBDs (12.51), pharmaceutical organizations (11.58), and researchers (11.11).

The sentiment of tweets posted by most categories of users ranged from neutral to highly positive (Figure 2). However, only tweets made by non-physician providers and support and advocacy groups had a statistically significantly higher compound sentiment than tweets made by all other users (Supplemental Table 4).

Additionally, 135 of the most active accounts belonged to organizations, while 115 belonged to individuals. Organization accounts were more likely than individual users to explicitly state their focus on hemophilia in their username or description, making them more accessible for non-specialists interested in hemophilia content on Twitter.

Major themes of content

We classified 20,316 of the 45,590 (44.6%) tweets into at least one of 11 categories with gene therapy and blood product contamination being the most frequent (Figure 3). Certain categories had a high incidence of co-occurrence; for example, 1,060 tweets related to gene therapy and 339 tweets related to hemophilia management also contained research keywords.

The major themes present in tweets varied by user type (Supplemental Figure 2). Analysis of the 250 most active users demonstrated that among the 11 thematic categories, the average patient most often tweeted about contaminated blood products. In comparison, physicians and researchers most often tweeted about gene therapy, research, and hemophilia management. Support and advocacy users most often tweeted about World Hemophilia Day and awareness, contaminated blood products, and hemophilia management.

Tweets in the athletics, World Hemophilia Day, management, and research categories had a statistically significantly higher compound sentiment than all other tweets (Figure 4; Supplemental Table 5). Tweets discussing athletics had the highest median compound sentiment score and discussed the ability of people with hemophilia to participate in physical activities, as well as notable athletes with hemophilia. Tweets discussing World Hemophilia Day were generally positive and aimed to improve patient quality of life and hemophilia awareness. Conversely, tweets in the gene therapy, inhibitors, mental health, symptoms, and contamination categories had a statistically significantly lower compound sentiment than all other tweets. Only one topic category, contamination, had a median negative sentiment.

Gene therapy tweets: This was the largest identified category. These tweets were primarily informational, delivering updates regarding the development process of therapeutics. Many tweets named a specific pharmaceutical company, such as BioMarin (719), Spark Therapeutics (138), and Sangamo (122), and/or its gene therapy product, such as Valrox (170) or AMT-061 (75). Several gene therapy trial participants also shared their experiences of gene therapy, both for hemophilia A and hemophilia B; these accounted for the posts with the second and fifth most engagement in the gene therapy category. While most tweets had a positive outlook of gene therapy, some raised concerns regarding the durability of gene therapy, long-term risks, and adverse events. 99 tweets also raised concerns regarding the financial accessibility of gene therapy, many in response to the anticipated 2–3 million dollar cost of BioMarin's product[18].

Contaminated hemophilia blood product tweets: This was the second largest category and the most prominent theme for patients. 1,964 of these mentioned human immunodeficiency virus or acquired immunodeficiency syndrome, while 276 tweets mentioned hepatitis C. Many tweets criticized the mishandling of the crisis and lack of accountability by the UK's National Health Service (97), paralleling the ongoing Infected Blood Inquiry in the United Kingdom[19]. Other tweets criticized pharmaceutical companies and prominent politicians for their roles in the crisis. Some users also discussed their own experiences with the contaminated blood scandal, either as a person with hemophilia or as a friend or family member of someone affected by the crisis.

Hemophilia research tweets: Researchers from many fields actively use Twitter for professional purposes, including asking for advice, disseminating their research, seeking collaborations, and announcing open positions[20], and the hemophilia community is no exception. Hemophilia researchers used Twitter to announce publications (212), abstracts (108), successful acquisition of funding (47), preprints (5), and open research positions (4). Tweets contained both translational and clinical research topics, such as novel hemophilia therapies, hemophilia management and patient care (339), and clinical trials (536). Some tweets explicitly referenced scientific conferences, including American Society for Hematology (376), International Society on Thrombosis Hemostasis (321), and American Society for Gene and Cell Therapy (14).

Hemophilia management tweets: This topic included non-gene therapy therapeutics, such as emicizumab/Hemlibra (410) and efmoroctocog alfa/Eloctate (13), approaches to prophylaxis for hemophilia A (443), and clinical practice guidelines (286). 51 tweets mentioning emicizumab, including the post with the seventh most engagement in this category, raised concerns on its adverse effects, namely thrombotic microangiopathy, thrombosis, and death.

Tweets mentioning COVID-19: While this category covered a diverse range of topics, only a subset of these tweets made a meaningful connection between COVID-19 and hemophilia. Some users expressed concern over hemophilia care during COVID, with one user posting that they were hesitant to take their child with hemophilia to the hospital because of high rates of COVID cases in their area. At least 6 posts expressed concern over shortages of hemophilia medication and blood donations. Clinicians, researchers, and professional groups used Twitter to discuss the intersection of COVID-19 and hemophilia care, such as managing COVID-19 coagulopathy in hemophilia A patients (14), the use of telemedicine (11), and the impact of COVID-19 on hemophilia treatment centers (9). Additionally, 622 posts explicitly mentioned vaccines; while a small number of users expressed concern regarding SARS-CoV-2 vaccination in individuals with hemophilia, many support and advocacy groups and providers provided guidance that those with bleeding disorders should still receive the vaccine. There were also 24 posts discussing reported incidences of acquired hemophilia A post SARS-CoV-2 vaccination.

Temporal analysis

The rate of hemophilia-related tweets remained stable between September 2019 and September 2021, as did the number of unique users per month. This is consistent with stagnation of growth of Twitter as a whole since 2015[21]. In both metrics, there were major spikes on April 17 corresponding to World Hemophilia Day, and minor spikes corresponding to other notable events (Figure 5). For example, the peak in August 2020 can be attributed to the FDA BioMarin rejection on August 18, 2020, which prompted more than 300 gene-therapy related posts in the same week. Tweets related to COVID-19 peaked in March and April 2020 and declined thereafter, although conversations regarding COVID-19 vaccination grew rapidly between November 2020 and January 2021, when vaccination efforts commenced.

Minor spikes were also detected whose timing corresponded to hematology research conferences. For example, 274 posts tagged with "ASH" (including "ASH19" and "ASH20"), 288 posts tagged with "ISTH" (including "ISTH20" and "ISTH21"), and 218 posts tagged with "WFHVirtualSummit" appeared primarily during the week of the respective conference. These spikes are in part due to targeted interventions by conference organizers to increase tweets, impressions, and engagements; in fact, ISTH appointed "Twitter Ambassadors" for both the 2020 and 2021 conferences (including author BSJ for 2021)[22]. However, we identified some hemophilia-related tweets that do not explicitly say "hemophilia," making them difficult to identify by search (Supplemental Table 6).

In every month between September 2019 and September 2021, the median tweet had either a positive or neutral compound score, and very few tweets had a compound negative score. Although there was a slight decline in the median compound sentiment in March 2020, the sentiment distribution of all tweets did not change in a significant manner between the months before, during, and after the initial onset of COVID-19 (Supplemental Figure 3), and tweets mentioning both hemophilia and COVID-19 had a median positive sentiment.

Public perceptions of hemophilia

Unexpectedly, we found 5,278 posts referencing hemophilia in a non-medical context. For example, 134 tweets used hemophilia as an analogy to refute claims that the COVID-19 death count was inflated by including people with comorbidities. The general argument of these tweets was that if a person with hemophilia dies due to an external event causing blood loss, the cause of death is the external event rather than hemophilia. Similar references to hemophilia in argument from analogy were also made in 44 posts mentioning the case of the State of Minnesota v. Officer Derek Chauvin, for the death of George Floyd. Here again, hemophilia was used in analogy for an underlying condition in arguments regarding the primary cause of this event. The use of hemophilia in these analogies suggests that many people are unaware of modern prophylaxis therapy in hemophilia.

Since hemophilia is sometimes referred to as the "royal disease," many people associate hemophilia with royal families (2293). Some tweets discussed two recent television series, "The Irregulars" (16) and "The Last Czars" (4), that reference hemophilia in royal family members. There were also associations of hemophilia with inbreeding (448), sometimes in

the context of royal families. While the effects of these associations have not been studied, they may reflect unawareness of hemophilia's prevalence across ethnicities, as well as negative perceptions of people with hemophilia.

Misinformation

The spread of misinformation on social media adversely affects public health. Among the 1,000 tweets with the most engagement, tweets with explicit misinformation were rare, with five posts describing 'miracle cures' for hemophilia, one post inaccurately describing plasma as the only treatment for hemophilia, and one post exaggerating the severity of hemophilia (Supplemental Table 7). There were also a significant number of patient-directed informational posts, some from well-known hemophilia advocacy groups. While these posts were not necessarily misinformation, they may provide health advice that is irrelevant or harmful for a specific patient (Supplemental Table 8). Considering this data, healthcare providers should be aware of the misinformation and irrelevant healthcare advice prevalent online, and the potential for their patients to engage with this content.

Discussion

This study investigated the scope of the hemophilia community on Twitter, specifically the types of users involved, major themes and sentiments present in tweets, and the prevalence of misinformation. Among the 250 most active accounts, which originate from 16 countries, the largest category are organizations and individuals participating in hemophilia support and advocacy. These accounts also have the most followers and generate posts with high engagement, and thus exert significant influence on hemophilia-related discourse on Twitter. While PwBDs, providers, and researchers have less representation among the 250 most active accounts, they generate more engagement per post than the average support or advocacy account, suggesting their perspectives are in high demand. These findings highlight the potential for individual PwBDs, providers, and researchers to increase engagement in the hemophilia Twitter community.

We also classified 44.6% of all tweets into at least one of 11 major categories. The largest categories were gene therapies and contaminated hemophilia blood products, with several highly active accounts dedicated to these topics. Other large categories included World Hemophilia Day, research, hemophilia management, and COVID-19. Of note, contaminated blood products represented a higher proportion of tweets from patient users than other user categories, suggesting a potential disconnect between the concerns of patients and other members of the hemophilia community. Likewise, we note that tweets regarding adverse events receive substantial engagement, highlighting the ongoing interest of safety consideration in hemophilia therapies.

World Hemophilia Day appears to be a highly effective mechanism for social media engagement around hemophilia, with marked spikes in the temporal analysis in both years studied. Our results strongly support the continued promotion of this event. Interestingly, despite explicit social media outreach by ISTH[22], ISTH and ASH appear to generate comparably few tweets mentioning hemophilia; we recommend that tweet authors tag all hemophilia-related tweets with "#hemophilia" to improve searchability. Our results also

demonstrate the utility of social media for the rapid dissemination of information to the hemophilia community; this is illustrated by the tweets mentioning COVID-19 as well as the temporal spike around the FDA's ruling on Biomarin's Valrox in 2020.

It is unsurprising that hemophilia, the most well-known bleeding disorder, is widely referenced outside of the hemophilia community. While tweets containing explicit misinformation were rare (seven among the 1,000 tweets with the most engagement), our results reveal a high prevalence of negative perceptions of hemophilia, including the false and highly stigmatizing association with inbreeding. We are also surprised about the use of hemophilia in rhetorical arguments by analogy over divisive controversial social issues. Our findings suggest that negative connotations of those with hemophilia persist among the public, despite highly active awareness campaigns on social media. Educating the public about hemophilia remains an unmet need.

Limitations of this study primarily concern inaccuracies in tweet thematic categorization. While regular expressions used for classification were selected to be as specific as possible, misclassification of some tweets is unavoidable. Furthermore, although hemophilia is a global phenomenon, we limited our study to English-speaking populations and did not examine differences in perspectives on hemophilia-related issues among these regions.

In conclusion, the results of our comprehensive analysis of the hemophilia community on Twitter demonstrate the importance of social media for disseminating information associated with hemophilia, highlight effective engagement strategies, and identify the need for better hemophilia education among the public.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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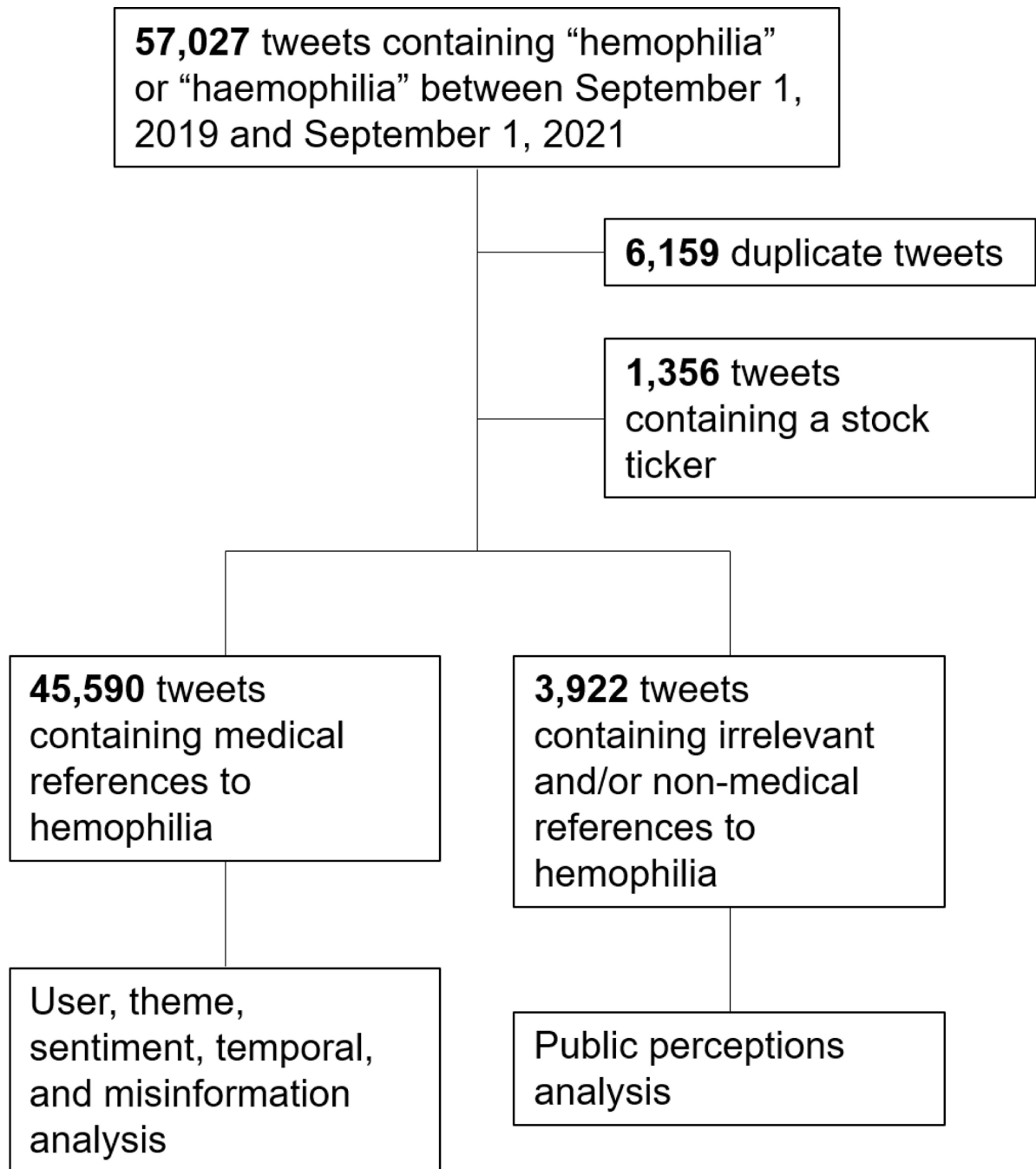
57,027 tweets containing "hemophilia" or "haemophilia" between September 1, 2019 and September 1, 2021

6,159 duplicate tweets

1,356 tweets containing a stock ticker

45,590 tweets containing medical references to hemophilia

3,922 tweets containing irrelevant and/or non-medical references to hemophilia

User, theme, sentiment, temporal, and misinformation analysis

Public perceptions analysis

Figure 1.
Workflow for the quality filtering and classification of tweets. After removing duplicate tweets (n = 6,159) and tweets with stock tickers (1,356), regular expression matching was used to classify the remaining 49,512 tweets as medically relevant (45,590) or non-medically relevant (3,922). Medically relevant tweets were used for user account classification analysis, major content theme analysis, temporal analysis, sentiment analysis, and misinformation analysis, while non-medically relevant tweets were used to analyze public perceptions of hemophilia.
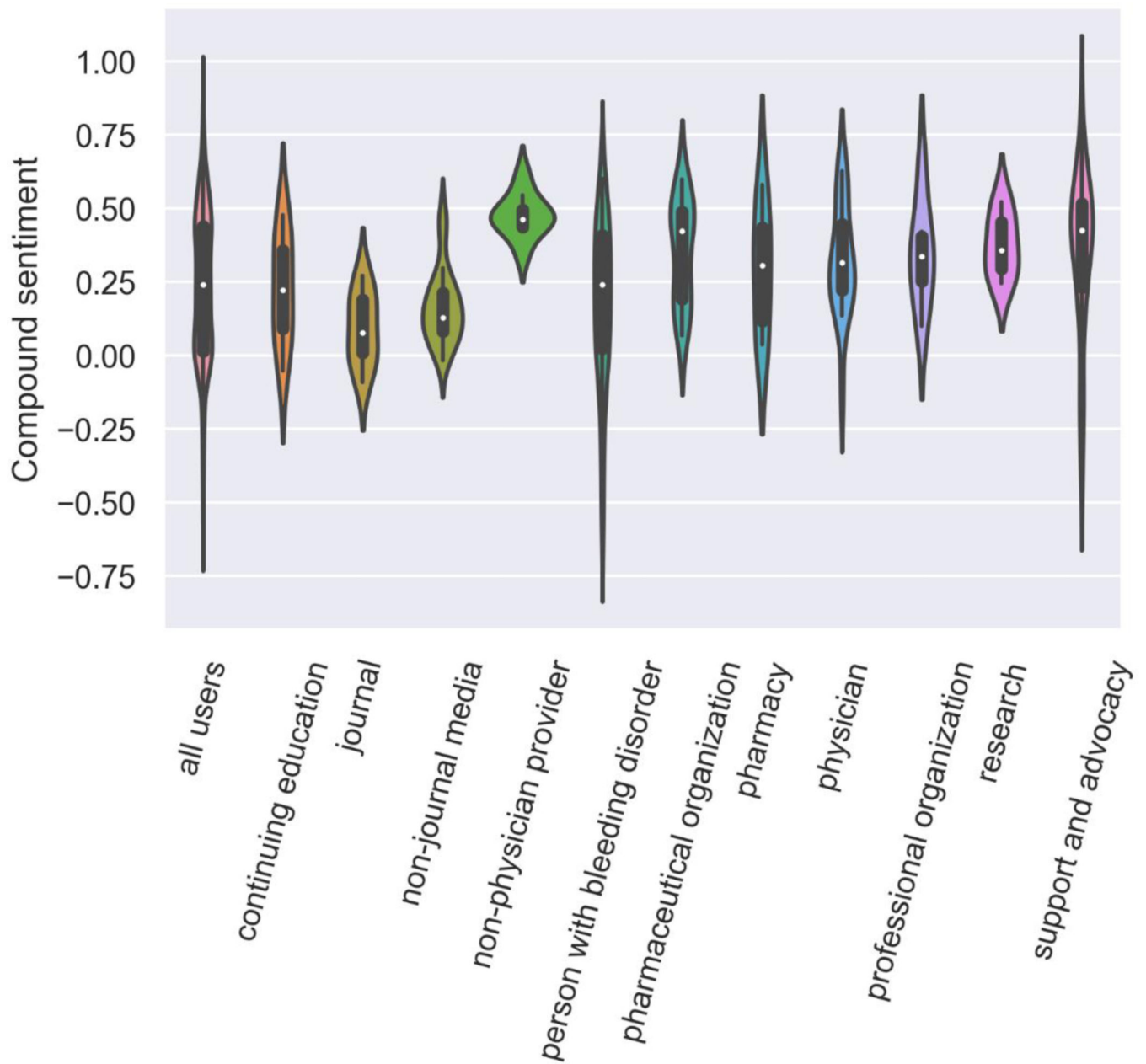
Figure 2.
Violin plot of the average compound sentiment of tweets from the average user, within each
of 11 user categories. The category of hospitals and treatment centers was omitted due to
low user count (n = 2). A compound sentiment below −0.05 indicates a compound negative
sentiment, a score between −0.05 and 0.05 indicates a compound neutral sentiment, and
a score above 0.05 indicates a compound positive sentiment. *PwBD, people with bleeding
disorders.*

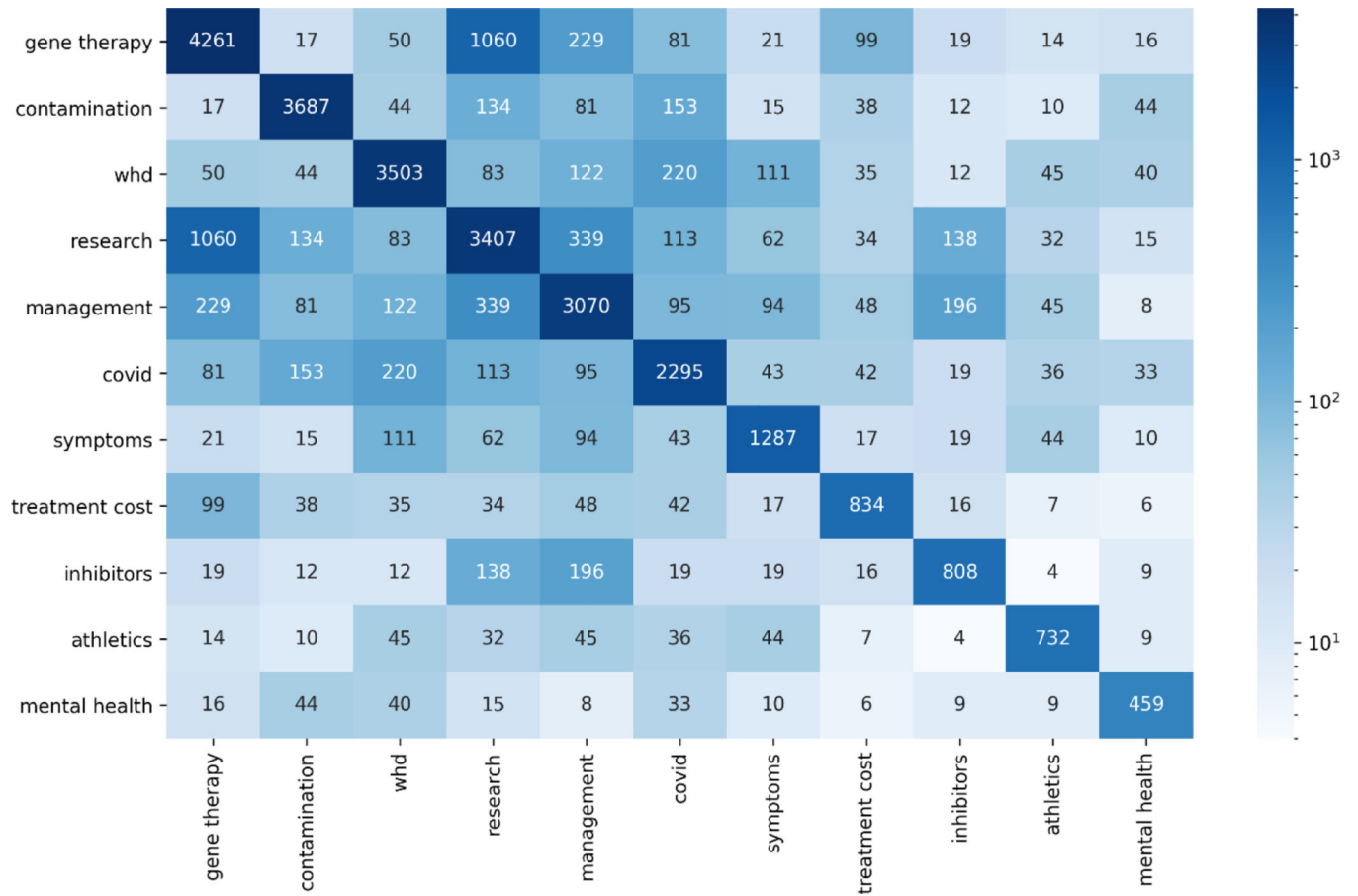**Figure 3.**
Heatmap indicating the frequency of 11 major themes among filtered tweets. More than one theme may be assigned to a single tweet. Boxes on the main diagonal indicate the frequency of each theme in isolation; other boxes indicate the co-occurrence frequency of two themes.
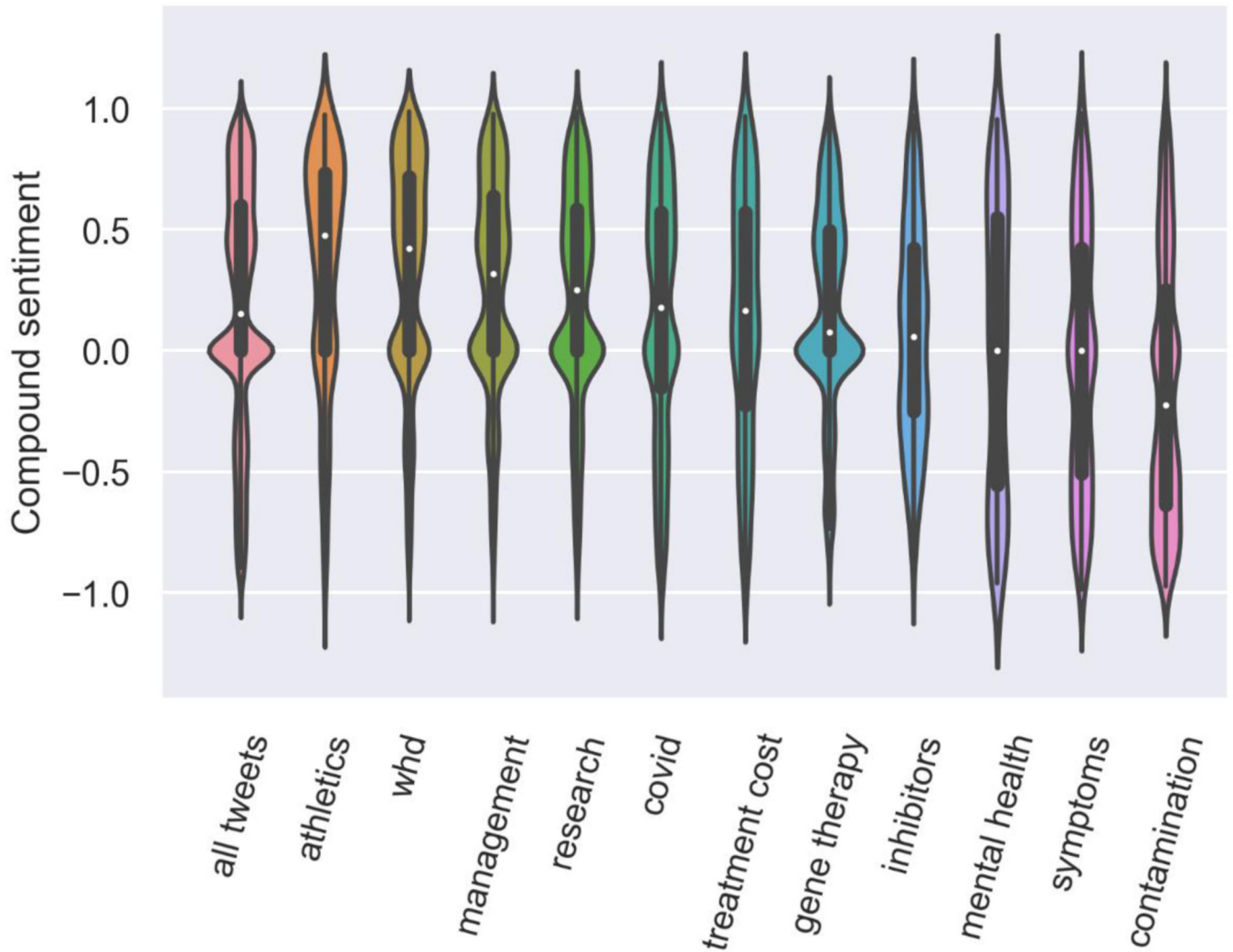
Figure 4.
Violin plot of the average compound sentiment of all tweets, as well as each of 12 thematic categories of tweets. *whd, World Hemophilia Day.*
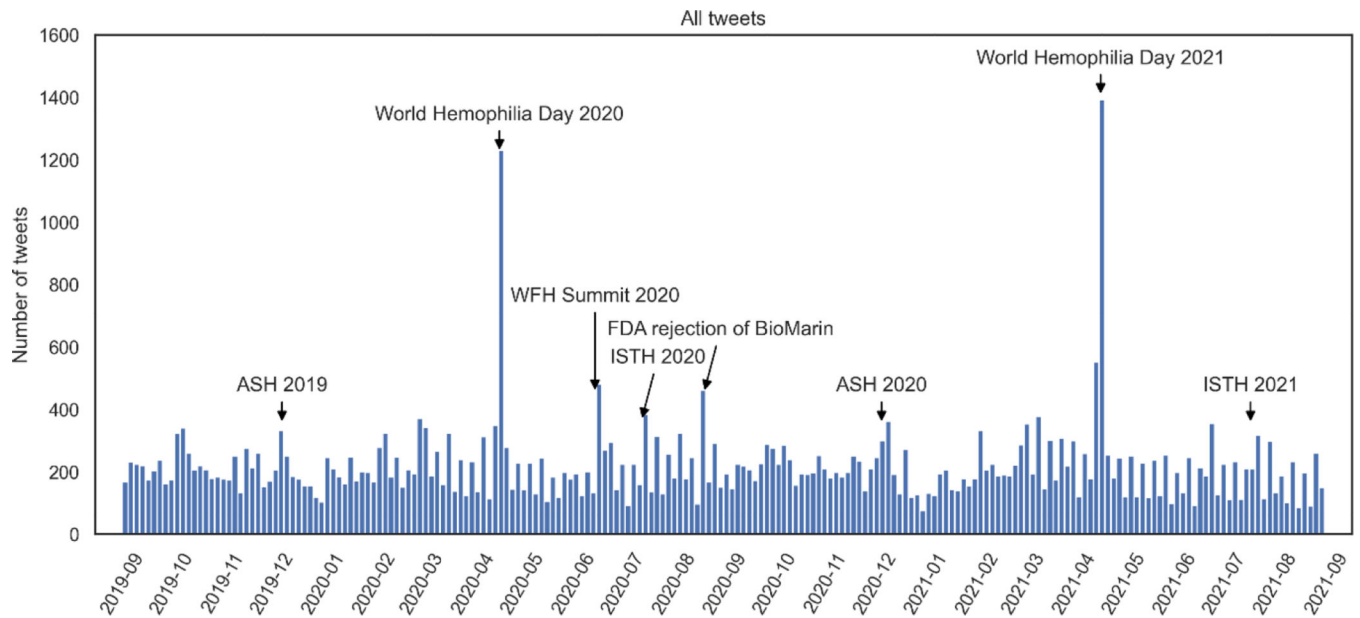
Figure 5.
Temporal analysis of hemophilia-related tweets between September 2019 and September 2021. Each bar in the graph represents one week. Weeks with significant hemophilia-related events are labeled.

Table 1:

User type analysis of the 250 most active accounts.

Category	User count	Average engagement per post
support and advocacy	70	5.82
person with bleeding disorder	35	12.51
non-journal media	30	1.55
physician	19	9.02
pharmaceutical organization	16	11.58
non-physician provider	9	12.69
journal	8	9.13
continuing education	8	2.89
professional organization	6	10.79
pharmacy	6	1.02
research	5	11.11
hospitals and treatment centers	2	1.06
unidentifiable	36	5.52

214 users were classified into one of 12 major categories, while 36 users could not be classified. The category "support and advocacy" is defined as individuals or groups supporting or advocating for patients with bleeding disorders or other rare diseases, while the category "non-journal media" is defined as non-journal accounts posting or affiliated with news, blogs, podcasts, and magazines. In cases where users had multiple roles (e.g., physicians who also performed research), categories were assigned based on the following priority: person with bleeding disorder, physician, research, non-physician provider, support and advocacy.