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Health Information Communication and Advocacy in the Haemophilia Community: An X-Based Analysis

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Abstract

Purpose: This study evaluates the network characteristics of the haemophilia community on X (previously known as Twitter) and identifies prevalent themes in their conversations, informed by the Uses and Gratifications (U&G) theory, within the broader context of information systems and communication studies.

Design/methodology/approach: The study analyzed 50,859 posts from 16,737 users over six months in 2022. Social network analysis and LDA-assisted qualitative techniques were applied to explore the network dynamics and prevalent thematic discourses within the haemophilia community on X.

Findings: The research explores the significant role of social media platforms like X as essential tools for healthcare communication and advocacy, specifically for the haemophilia patient community. The study emphasizes X's value in supporting patient care, sharing research, and driving advocacy efforts.

Originality/value: These findings can provide useful insights for healthcare professionals, system designers, and researchers, showing how X can help improve patient engagement, healthcare services, and advocacy efforts. The study also shows how social media can be an important resource for people with chronic and rare diseases, offering them a space to share experiences, find emotional support, and access health information. This is especially important for those with rare conditions as haemophilia, where traditional support networks might not be as easily available.

Keywords: healthcare communication, social media, Twitter, X, social network analysis, Uses and Gratifications (U&G) theory

Paper Type: Research Paper

Introduction

Haemophilia, an inherited genetic disorder affecting approximately one male in every 7,500 births, is characterised by the body's inability to produce enough clotting factors, leading to excessive bleeding in joints, muscles, and internal organs (Curry *et al.*, 2022). Despite advancements in medical treatment, including the use of clotting factors as preventive or on-demand therapy, individuals with haemophilia and their caregivers face ongoing challenges in managing this condition. Social media platforms, particularly X, have emerged as potentially valuable tools for people with haemophilia to connect with others who share similar experiences, access reliable health information, and receive moral support (Lin and Kishore, 2021; Moorhead *et al.*, 2013; Frey et al., 2022).

Consider the case of a young adult with haemophilia who has recently turned to social media for support. While they found a welcoming community, they also encountered harmful stereotypes and misinformation shared by influential users, highlighting the need for critical evaluation of online health information. A recent study of individuals with haemophilia revealed that many feel isolated and misunderstood (Hakimi *et al.*, 2024). Social media platforms offer a potential avenue for connection and support, but it remains unclear how these platforms are actually being used to address these needs. While previous research has examined the use of social media by individuals with chronic illnesses (Sendra *et al.*, 2020), few studies have focused specifically on the experiences of people with haemophilia. This gap in the literature highlights the need for further investigation into the unique challenges and opportunities presented by social media for this population.

This study critically analyses the use of X for health support and information sharing among people with haemophilia, their caregivers, and others interested in personal health matters related to the disease. By framing our analysis within the lens of Uses and Gratifications (U&G) theory, we aim to explore the specific motivations and needs that drive individuals to engage with X for health-related purposes. This theoretical perspective allows us to delve deeper into the unique dynamics of the haemophilia community on X, shedding light on how individuals utilize the platform for health communication and advocacy.

Since the late 1970s, health communication has increasingly relied on digital platforms, providing new opportunities for both patients and healthcare professionals to interact. In the case of haemophilia, social media not only serves as a space for sharing medical information but also plays a critical role in fostering advocacy and community support. X, in particular, allows users to actively seek out information that fulfils their specific needs and interests. According to U&G theory, individuals are motivated to use media, such as X, to satisfy various needs, including social interaction, information seeking, entertainment, and personal identity (see Katz 1974). In the context of the haemophilia community, X offers a platform to connect with others who share similar experiences, seek emotional support, and gain access to up-to-date health information. By examining how X is utilized by the haemophilia community to disseminate health-related information, advocate for improved healthcare, and provide mutual support, we can gain valuable insights into the diverse ways in which individuals use social media for health-related purposes.

Individuals with haemophilia rely on a network of support systems to manage their condition effectively. Clinical practice guidelines provide evidence-based recommendations for diagnosis, treatment, and management, offering crucial medical information. However, these guidelines, while authoritative, can be dense and technical, often focusing on clinical management and potentially overlooking the day-to-day challenges faced by patients.

Haemophilia support organizations, such as the World Federation of Hemophilia[1] and national Bleeding Disorders Foundation[2], and The Heamophilia Society[3] play a crucial role in complementing clinical care. These organizations offer a range of services, including:

- Information and resources on haemophilia.
- Support groups, both in-person and online, facilitating peer connections and emotional support.
- Advocacy efforts to raise awareness and improve access to care.
- Educational programs for patients, families, and healthcare professionals.

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[1] https://wfh.org/
[2] https://www.bleeding.org/
[3] https://haemophilia.org.uk/

In contrast to clinical guidelines, these organizations often focus on the lived experience of haemophilia, providing practical advice and addressing psychosocial needs.

Social media platforms like X offer a complementary space for individuals with haemophilia to connect, share information, and find support (see Chen et al. 2022). These platforms offer advantages such as accessibility, real-time communication, and opportunities for peer interaction. Patients can share personal experiences, exchange tips on managing daily challenges, and find emotional support from others who understand their condition (Virole et al. 2025). However, it's crucial to acknowledge the potential disadvantages of social media, including the risk of misinformation, privacy concerns, and the need for users to critically evaluate online information. Social media should be viewed as an additional resource that can enhance, rather than replace, traditional support systems (Sezgin et al. 2025; McLaughlin et al. 2022). By providing access to peer support, practical advice, and information on managing daily life, social media can contribute to reduced stress and improved coping mechanisms, potentially leading to better health outcomes for individuals with haemophilia. Our study considers the benefits, drawbacks, and ethical considerations of using social media for healthcare purposes, providing practical recommendations for healthcare professionals and individuals with chronic health conditions.

The insights gained from our focused analysis extend beyond the haemophilia community, offering valuable lessons for healthcare communication and advocacy across diverse patient populations. By understanding how individuals utilize social media to fulfil their specific needs and gratifications, as outlined by U&G theory, healthcare providers and policymakers can, we argue, leverage these platforms to improve health outcomes and promote well-being.

Literature Review

Social media has transformed healthcare communication, offering new avenues for patient engagement and information sharing. Here, we consider the intricate dynamics of X usage among individuals with haemophilia, examining its potential impact on their physical and emotional well-being. To understand the motivations and benefits that drive X adoption within this specific patient population, we employ U&G theory as our primary theoretical lens. By applying U&G, we explore how individuals actively seek to fulfil specific needs and gratifications through their engagement with X, such as social connection, information seeking, and emotional support. Drawing upon Alvesson and Sandberg's (2011) problematisation framework, we critically examine the often idealized and oversimplified narratives surrounding social media's transformative potential in healthcare. Through this lens, we aim to uncover the complex interplay between social, technological, and individual factors that shape the experiences of individuals with haemophilia on X. By combining U&G theory with a critical, problematizing approach, we aim to move beyond idealized depictions of social media as a purely positive force and explore its potential for both empowerment and marginalization.

While U&G theory provides a valuable framework for understanding user motivations and behaviours on social media platforms like X - particularly in the search for health information (Malik *et al.,* 2023; Khursheed *et al.*, 2024), it may not fully capture the complexities of health communication in the digital age, particularly with the intersection of modifying identities such as gender (Drtilová *et al.*, 2022)**,** age (Sheldon *et al.*, 2021; Magsamen-Conrad *et al.*, 2015). Recent research has highlighted the potential for misinformation and disinformation to proliferate on social media, particularly in health-related contexts (Okoro et al. 2024; Swire-Thompson and Lazer 2020). As such, it is crucial to consider the role of information-advocacy (Naveh and Bronstein, 2019), digital literacy (Mackert *et al.,* 2016), and fact-checking (Lee and Ramazan 2021) in mitigating the negative consequences of online health information.

Furthermore, the issue of privacy and security is a significant concern for individuals sharing personal health information online (Abdelhamid *et al.*, 2017; Alipour *et al.*, 2023). While U&G can help us understand why people might disclose personal health information, it is essential to acknowledge the potential risks associated with such sharing, including identity theft, discrimination, and social stigma (see Ranjit *et al.*, 2024). In addition to the challenges posed by misinformation and privacy concerns, the influence of authoritative figures, such as medical professionals and public health officials, on social media can be both beneficial and harmful (Hong *et al.*, 2021; Chen *et al.*, 2020). While these individuals can provide valuable information and guidance, they may also inadvertently contribute to the spread of misinformation or promote harmful stereotypes. To explore these complexities and build on existing research gaps (Moorhead *et al.*, 2013), we consider three key areas, integrating U&G theory throughout:

I. The Role of Social Media in Health Communication

II. The Haemophilia Community and Social Media

III. X as a Platform for Health Communication

First, we explore the broader landscape of social media use in healthcare, highlighting the potential benefits and challenges associated with online engagement.

I. The Role of Social Media in Health Communication

Social media support groups are one type of resource that care givers and individuals with chronic illnesses may use. People with similar health challenges are able to meet and build relationships in this environment. Social media also help users to find online health forums and communities that provide patients with quick and easy access to a wealth of information, advice, and services (Pershad *et al.*, 2018). Here, users can openly discuss alternatives to conventional medicine and stress-management techniques and provide emotional support. In this context, U&G theory suggests that individuals globally, both in the global North (Langstedt and Hunt 2022) and global South (Hong *et al.*, 2021) are motivated to use social media to fulfil a range of health information needs, including social support and advocacy through interaction, information seeking, and emotional support.

Social media platforms like X offer unique affordances, which are the perceived and actual properties of the platform that enable specific actions by users (Mirbabaie & Marx, 2020). These affordances shape how individuals interact, communicate, and seek information. For example, X's affordances include the ability to share brief messages quickly, use hashtags to categorize content, and engage in real-time conversations. These features can facilitate information seeking, community building, and advocacy efforts among individuals looking for health information and support for chronic conditions - see Senyel et al. (2025) seminal work here concerning support for women with endometriosis.

Our study uses Uses and Gratifications (U&G) theory to understand how individuals are motivated to use X for health content and processes (López-Carril et al. 2025). In addition to understanding user motivations, it is crucial to examine how individuals interpret and make sense of the information they find on social media (Kuo and Chen 2025). Sensemaking theory offers a valuable lens for examining how individuals interpret and make sense of information within social media contexts - as demonstrated by Kahlawi et al (2025)make in their study of public opinions related to COVID-19. Sensemaking theory offers a valuable lens for examining how individuals interpret and make sense of information within social media contexts, an approach Wu et al. (2023) adopt in their research on virtual communities and collective health conversations around pregnancy studies have demonstrated the value of sensemaking theory for examining social media use. Mirbabaie et al. (2022) applied sensemaking theory to the study of rumour debunking in social media, highlighting the importance of distinguishing between connective action and collective action in online health communities.

By sharing their experiences through social media, individuals with chronic illnesses can potentially use social media to fulfil a range of U&G needs. They can connect with others who share similar experiences, building a sense of community and reducing feelings of isolation (Aboelmaged, 2018). Additionally, these platforms provide opportunities to access up-to-date information about their condition, treatment options, and self-management strategies. Sharing personal experiences and insights can also contribute to a collective understanding of the illness, empowering individuals to advocate for their needs and challenge societal misconceptions - see Gomez-Vasquez *et al.*'s (2024) research about Huntington's Disease. Moreover, these groups offer a safe space to share thoughts, feelings, and challenges without fear of judgment or stigma, providing valuable emotional support.

Previous research (Sannon et al., 2019) has examined how people with invisible chronic illnesses (ICIs) use social media platforms such as Facebook (including closed groups), Instagram and Twitter. The authors noted that these social media platforms were a useful distraction for people with ICIs and allowed users to converse about their journey. However, the study did find that almost all of the participants did encounter some form of negativity online which may take away from their experiences. Interestingly, however, in their study published in 2019, Twitter, Tumblr and Instagram, were found to be more light-hearted. They provide the example of a user joking about "breaking up" with their pharmacist as a type of humorous content that might be shared on Twitter. The study found that participants would experience the most negativity on Facebook. They provide an example of a user noting how they'd often see humour and positivity whereas on Facebook they note how it would be a stream of depressing content. These reflections on platforms may be driven by the technological affordances afforded by then, for instance, Twitter has a restriction on length and Instagram is image based. Facebook allows longer posts and also consists of closed-groups. This suggests that this information can be used to develop more effective patient education materials, improve care delivery, and advocate for policy changes.

Online platforms can provide a valuable space for individuals to connect with others who share similar experiences, reducing feelings of isolation and providing emotional support - see Johnson et al.'s (2022) research on support for people living with dementia. This aligns with broader insights into how vulnerable populations navigate complex health information environments, with peer support playing a critical role (Panaite et al. 2024).

Sensemaking, in this context, refers to the process of interpreting and understanding information, particularly in complex and ambiguous situations (e.g. Wannheden et al. 2023). In healthcare, sensemaking involves individuals actively constructing meaning from various sources of information, such as medical professionals, online communities, and personal experiences (e.g. Kahlawi et al. 2025). For individuals with chronic illnesses, sensemaking is crucial for navigating complex health information environments. Naveh and Bronstein (2019) utilized sense-making in their analysis of how individuals navigate these environments. It's important to distinguish this application of sensemaking from 'organizational sensemaking,' which focuses on how organizations interpret and respond to internal and external changes. For example, Wu et al. (2023) research has explored using virtual health communities sponsored by healthcare organizations to provide support to specific patient populations, such as pregnant women before and after birth.

Research on health communication has also explored the role of 'assertive speech acts' and 'connective sensemaking' on platforms like X_(e.g. Varanasi et al. 2023), with more recent work capturing the intersection of human-AI health collaboration (Daly et al. 2025). Our analysis of X-posts revealed a range of communication styles. While some instances involved information broadcasting, indicative of connective sensemaking, there was also evidence of interactive discussions and engagement, demonstrating a more collaborative approach to meaning-making. We argue that by understanding these sensemaking processes, organizations can develop more effective strategies to support individuals with chronic illnesses and improve health outcomes. To this end, in the next section, we examine the specific use of social media by individuals with haemophilia, focusing on how they utilize platforms and online communities for health information seeking, social support, and advocacy.

II. The Haemophilia Community and Social Media

Recent research shows that social media can help patients with haemophilia fulfil specific U&G needs, such as accessing reliable health information, connecting with others who share similar experiences, and advocating for their needs (Perolla and Kalaja 2024) Indeed, the availability and variety of content available for patients with haemophilia has empowered individuals to take an active role in managing their condition and advocating for their needs (Sterling *et al.*, 2012). For example, a cross-country study conducted in 2020 found that over half (56%) of the people with haemophilia obtained information about their condition regularly from internet sites and social media (Banchev *et al.*, 2021). Previous U&G studies on conventional media identified two primary incentives for media use: information and entertainment (see Korgaonkar and Wolin 1999; Katz 1974; Stafford, Stafford, and Schkade 2004; Ruggiero 2000)

In the health sciences literature, previous studies have found great potential for patients with haemophilia, especially adolescents, to use social networks as a means of expression, network with their colleagues, and acquire meaningful and important information (Khair *et al.*, 2013, Khair *et al.*, 2012). Chen *et al.* analysed the use of X in the haemophilia community (Chen *et al.*, 2022). They identified major themes, such as gene therapy, blood product contamination, haemophilia management, research, World Haemophilia Day, inhibitors, mental health, symptoms, athletics, and misinformation. Gene therapy was the most prevalent theme among the study samples. Although this topic is considered new to the haemophilia community, this aligns with U&G theory where individuals actively may actively seek out information about new treatments to fulfill their need for health-related information and improve their quality of life (see Zhang *et al.*, 2021; Holtz *et al.*, 2015). As discussed, social media platforms have played a crucial role in raising awareness about the latest treatments, such as gene therapy, and fostering discussions among the haemophilia community (Chen, *et al.,* 2022*;* Fletcher *et al.*, 2021). This increased attention has the potential to accelerate research and development efforts, leading to the development of more effective therapies and the creation of supportive online communities (Lewandowska *et al.,* 2022). Pinto (2018) highlights the elevated risk of depression among individuals with haemophilia, attributing this to factors such as chronic illness, pain, and social isolation. The chronic nature of haemophilia, coupled with factors such as pain, social isolation, and limitations in daily life, can significantly impact the mental health of individuals with this condition, increasing their risk of depression (Witkop *et al.*, 2019). Moreover, individuals with haemophilia with lower levels of social support were more likely to experience depression. Sezgin *et al.* (2021)

X **as a Platform for Health Communication**

Examining the structure and dynamics of online networks can shed light on the specific information needs, social support preferences, and advocacy priorities of the haemophilia community. Patients with haemophilia often seek advice from those who have been there before because of the condition's uniqueness and intricacy (Azar and Gopal 2023). X can be an excellent resource for people with haemophilia to find and connect with others with haemophilia so that they can learn from and be supported by them (Chen *et al.*, 2022). Talking to others who have experienced similar situations may help them gain a perspective and feel belonging in their community (McLaughlin *et al.*, 2022). As Cassis *et al.* (2012) argued, patients emotional and physical well-being may benefit from many aspects of community life. The popularity and accessibility of social media for health management and support has drastically changed the relationship between doctors and patients (Eekelaar, 2023). X, with its large user base and real-time capabilities, has emerged as a powerful tool for sharing health information, raising awareness about specific health issues, and encouraging healthy behaviours (see Roy and Malloy 2023). People seeking healthcare information have access to reliable resources (Aboelmaged, 2018). Furthermore, using hashtags, X users may find and follow conversations on health and wellness topics and find others who share their interests and experiences (Ahmed *et al.,* 2022). For example, studies on mental health information needs among Chinese university students emphasize the dynamic and sometimes private nature of health information-seeking behaviours (Li *et al.*, 2023). These findings point to the importance of platforms like X in addressing specific, often sensitive health concerns, allowing users to seek tailored information while maintaining a level of anonymity. The predecessor to X, Twitter, was used as a tool for public health research including for the real-time monitoring of public health related issues (Sinnenberg et al. 2017; Kostkova et al. 2014; Tavoschi et al. 2020; Karafillakis et al. 2021). However, as Edinger et al. (2023) and many other researchers assert there is strong potential for misinformation and trolling where X content is designed to push trending issues, rather than provide reliable health information. Researchers and policymakers may be notified of emerging health issues in specific places using trending themes, sentiment analysis, and geographical data (e.g. Berry *et al.,* 2017). Notably, X has potential as a health management tool; however, users should exercise caution. The rapid spread of rumours and erroneous information can lead to disastrous results - an issue recently highlighted by WHO (2023). Making informed judgments about one's health requires assessing the credibility and trustworthiness of the available information (Pershad *et al.*, 2018). In the COVID-19 pandemic, for instance, a wide range of medical, vaccine, and general health conspiracies were found to have been widely shared (Skafle et al. 2022).

X facilitates communication and sharing between individuals with chronic illnesses, fulfilling U&G needs for social connection and support (Zhang *et al.*, 2021). By joining online communities, users can connect with others who share similar experiences, reducing feelings of isolation and providing emotional support (Hardey, 2022). X's real-time nature and brief messaging format align with U&G theory's emphasis on immediacy and convenience (see Gilbert, 2016). Additionally, X can be used to seek and share health information, addressing the information needs of users. As we have argued, the platform's hierarchical structure, with influential users and opinion leaders, can be leveraged to promote health literacy and counter misinformation (see Do Nascimento *et al.*, 2022). The lack of social support and the need for individualised medical treatment are two problems people face with chronic diseases.

Individuals looking for people who understand their experiences may find X a great resource (Kamal *et al.,* 2010). By participating in online communities catering to specific conditions or conducting focused searches using relevant hashtags, people diagnosed with haemophilia can access various resources, including educational materials, practical utilities, and psychological support (Asogwa, 2017).

Those diagnosed with haemophilia may use the web to push for better care and a deeper understanding of the disorder (Walker, 2015). Prejudices against people with chronic health disorders can be reduced if those affected can make their voices heard, share relevant information, or engage in open discourse. The U&G theory explains why it is essential for people with haemophilia to be on X to provide a variety of gratifications (e.g., emotional needs, information needs and entertainment). Even though the U&G theory has undergone significant adaptations over the years, particularly in response to new technologies (Chang *et al.*, 2022, Pelletier *et al.*, 2020), one can still identify four main categories of the theory. Concerning online health information, four prominent relevant uses of social media platforms and their gratifications (Table 1) might be suggested as follows.

Table 1. Operational definition of Uses and Gratifications (Chang *et al.*, 2022)

Dimension	**Example and Usage**
Cognitive Gratifications	Patients can use social media in order to have a better understanding of their condition and improve their care.
Affective Gratifications	Patients can use social media to create entertaining and joyful moments.
Personal Integrative Gratifications	Patients can use social media to build confidence and self-esteem.
Social Integrative Gratifications	Patients can use social media to reach out to fellow patients and their community online to build and create online connections.

Notes: The U&G theory is further discussed in the context of the study's results within the discussion section.

Clarifying the various approaches that social media platforms take toward their users is a crucial addition to the U&G theory (Pelletier et al., 2020). By considering the diverse approaches taken by different platforms, we can gain a deeper understanding of how individuals use social media to meet their specific needs and gratifications. This leads us to our problem statement, formulated using Alvesson and Sandberg's (2011) problematisation approach where we seek to explore:

RQ1: How do individuals with haemophilia utilize X to fulfil their information and social needs, and how does this engagement shape their understanding of the condition and their experiences with healthcare?
This RQ directly connects to the U&G theory by exploring the specific motivations behind using X for health purposes.

RQ2: How do network structures and thematic discourses on X facilitate health information dissemination, patient advocacy efforts, and peer support within the haemophilia community?
This RQ broadens the scope by examining how the platform itself (network structure) and the content shared (thematic discourse) contribute to the U&G identified needs. It also builds on information systems concepts by looking at the platform as a tool for communication.

RQ3: How can the understanding of U&G motivations for using X within the haemophilia community inform healthcare professionals, system designers, and researchers to improve health communication, advocacy strategies, and patient engagement?
This RQ emphasizes the potential impact of our study. It explores how U&G insights can be used to improve communication and information systems for better healthcare delivery.

By adopting a problematizing approach, building on Alvesson and Sandberg's (2011) framework, this study aims to challenge conventional assumptions and identify critical gaps in the existing literature on social media and health. Specifically, we seek to problematize the role of social media in shaping the experiences and well-being of individuals with haemophilia. By critically examining the dominant discourses and practices within the haemophilia community on X, we aim to uncover hidden assumptions and identify areas for potential intervention. Understanding the topics that resonate most deeply with the community can inform the development of tailored interventions and support services that address the specific needs and concerns of individuals with haemophilia.

Methods

The study used the X academic track Application Programming Interface (API) and retrieved data over six months from January 2022 to June 2022. The keywords' Haemophilia OR haemophilia' were used to retrieve data, and X's language field was used only to retain English-language X-posts. These X-posts were then entered into NodeXL for further analysis; the dataset consisted of 16,737 X users who had posted 50,859 X-posts.

Social Network Analysis

Drawing upon NodeXL, social network analysis was applied to analyse the data. Social Network Analysis (SNA) is a research methodology that maps and measures relationships and flows and can be used for people, groups, organisations and social media data. In our analysis, we produce a social network visualisation where the graph is directed, and its nodes are organised into clusters (i.e., groups) using the Clauset-Newman-Moore clustering algorithm (Clauset *et al.*, 2005), and the graph is laid out using the Harel-Koren Fast Multiscale layout algorithm (Koren and Harel, 2004). Being used in several areas of advocacy, social network analysis (SNA) is considered an emerging instrument for extracting important data about the connection between people, communities and social groups (Kothari *et al.*, 2014). The use of social network analysis to improve advocacy efforts is advantageous due to its ability to interrogate the unique relationship between technology and virtual communities. Examination of social contexts can be easily conducted through SNA. Moreover, it substantially impacts decision-making, helps in the identification of influential individuals and filters communication approaches. It enhances focused visibility, hence, presenting a crucial tool to firms that attempt to explore and impact the intricate web of social interactions (Kent *et al.*, 2016). Including both somatic and cognitive health, several cases have underlined the beneficial effect of SNA. Due to its characteristics to promote intensive care of ailments, searching essential treatment spots in virtual sites as well as deciphering patterns about approaching healthcare. Nicaise et al. employed social network analysis to estimate the provision of care (Nicaise *et al.*, 2012) in the interplay between mental health and social care facilities at the systemic level. Barnett et al. evaluated the level of networking among staff of a mental healthcare service located in Tasmania and their coordination in promoting student learning (Barnett *et al.*, 2015).

SNA will highlight the significance of members of these organisations emphasising the importance of exchanging ideas and social networks. Through SNA, comprehension of Haemophilia societies may enable tailored support, boosted connection and personal care (Kothari *et al.*, 2014).

LDA-Assisted Qualitative Analysis

The study also drew upon Latent Dirichlet Allocation (LDA) (Blei *et al.*, 2003) assisted qualitative analysis. This is a statistical method used for text analysis that analyses co-occurrences of words. LDA will group words that appear together within our dataset of X posts. These collections of words are referred to as as 'topics'.

In our study we first used the LDA method was used to identify the topics which is simply a collection most commonly occurring clusters of words. These were then contextualised with the X-posts content and discussed within the team to develop a richer set of contextualised thematic overviews of each theme. This allowed us to provide detailed themes and interpretations to each group. This is further described below.

Collective Sensemaking

To analyze the LDA groups and identify key themes and patterns within the data, our study adopts a collaborative approach to sensemaking, also known as interprofessional sensemaking (Cunningham et al. 2023), This collaborative approach involves a systematic process of interpretation, drawing on the expertise of both researchers and members of the haemophilia community. It is important to distinguish this approach from other forms of sensemaking that are often used interchangeably: Connective sensemaking often involves more individual actions facilitated by technology (see Mesgari and Okoli 2019), whereas collective sensemaking implies a more coordinated effort towards a shared understanding (see Reed et al. 2025). Collaborative sensemaking, as applied here, emphasizes the interactive and social construction of meaning through explicit collaboration between researchers and community members, a distinction highlighted by Urqhart et al. (2025).

While sensemaking is a valuable tool for interpreting complex social phenomena, it is important to acknowledge its limitations. The subjective nature of interpretation can lead to different understandings of the same data, and researcher bias may influence the selection and interpretation of information. Moreover, some data from X can also lack context. To mitigate these limitations, we employed a rigorous methodological approach, including inter-reliability checks and triangulation of our data sources. Additionally, we sought feedback from medical professionals, members of the haemophilia community, and those supporting people with haemophilia to ensure that our interpretations were grounded in their lived experiences. The preliminary findings from this research were presented at our local haemophilia chapter symposium last year, where they were very well-received and affirmed.

Results

Social Network Analysis Results

This section details the results of the social network analysis, and Figure 1 provides a visual overview of the network. Each circle within the network visualisation represents an X user, and lines between users represent connections between different users such as a reply, repost, quote etc. As noted in our methodology, based on these interactions users are further grouped based on who they interact with the most. Users with no interactions are placed in their own group (Group 1). When taken in aggregate these connections reveal interesting patterns and shapes that can be further interpreted. Readers new to interpreting social network visualisations may benefit from reference to (Smith *et al.*, 2014) who define a typology for interpreting social network visualisations such 'isolate' and 'broadcast groups' that will be referred to in our analysis.

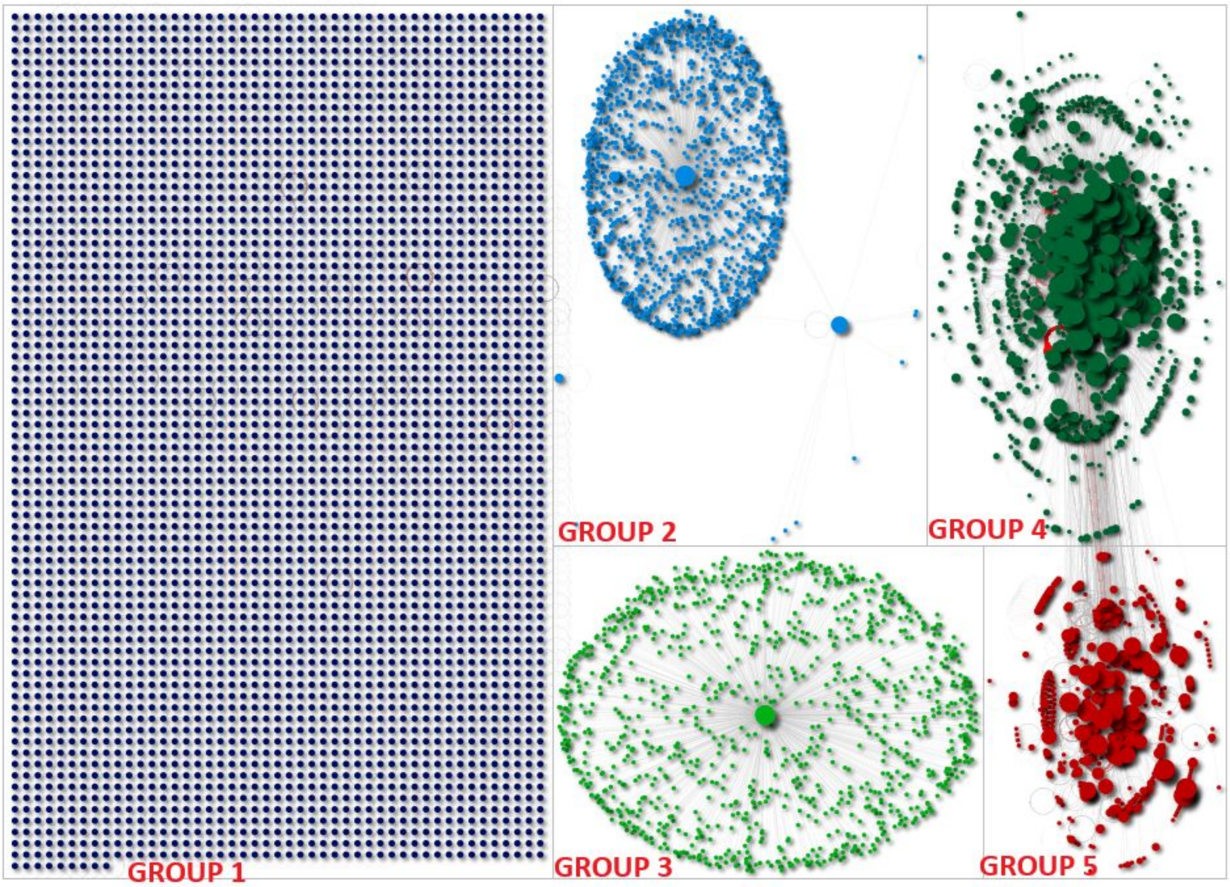

Figure 1. Social Network Visualisation of the Haemophilia Community on X

Group 1: Isolates

First, Group 1, consisting of 3534 users, is identified as an 'isolates' group. In this group, users mostly broadcast information by sending individual X-posts but without mentioning or directly engaging with anyone else. This indicates the dissemination of information that lacks direct interpersonal interaction and highlights a missed opportunity for community-building within this segment of users. This group of users may be less likely to be aware of important policy issues affecting haemophiliacs. They may also be less likely to be involved in advocacy efforts. To reach this group, it is important to use channels that they are likely to see, such as targeted campaigns and bringing users into key debates and issues across other groups via direct messaging of relevant X-posts.

Group 2: Broadcast group

Secondly, Group 2 is characterised as a 'broadcast group' with 1488 users. It is centred around an influential user who acts as a hub of information. Other users in this group primarily X-post content from this central account. The dynamics of this group suggest that the influential user holds significant sway, likely disseminating authoritative or valued information to a broad audience. This group of users may be more likely to be aware of important policy issues affecting haemophiliacs. They may also be more likely to be involved in advocacy efforts. The broadcast group can be a powerful tool for raising awareness of policy issues and mobilising support for advocacy efforts.

Group 3: Densely connected network

Group 3 is a more complex, 'densely connected' network of 1192 users. Unlike the first two groups, it features several influential users who are actively engaged in conversations, indicated by frequent replies and X-posts. This group is well-connected internally and has extensive connections to other groups, making it a potentially vital bridge within the broader network. Its structure suggests a higher level of discourse and collaboration, which could be critical for community engagement and information exchange. This group of users may be well-informed about policy issues affecting haemophiliacs. They may also be involved in advocacy efforts. The densely connected network can be a valuable resource for policymakers and advocates. They can provide insights into the experiences of haemophiliacs and help identify solutions to their challenges.

Group 4: Interactive broadcast network

The fourth group, with 1051 users, mirrors the 'broadcast network' shape found in Group 2 but with a slight twist. Here, the central user is not just disseminating information but is also receiving X-posts from the network. This might imply a more interactive form of broadcasting, possibly encouraging feedback and dialogue. This group of users may be more likely to be engaged in posting policy related content. They may also be more likely to provide feedback to policymakers. To engage this group, creating opportunities for them to participate in policy related posts is important. It is also important to listen to their feedback and consider their suggestions.

Group 5: Densely connected cluster

Lastly, Group 5 is a smaller but 'densely connected' cluster of 592 users. This group stands out for its multiple influential users and a notable level of cross-collaboration among them. Unlike the larger, densely connected Group 3, this smaller group may offer more specialised or niche interactions, possibly fostering more profound relationships and targeted engagement with certain users.

Each group offers unique opportunities and challenges for engaging with the haemophilia community on X. Understanding these dynamics can inform better communication, advocacy, and information dissemination strategies. This group of users may be well-informed about the specific challenges facing haemophiliacs in their community. They may also be involved in advocacy efforts at the local level. The densely connected cluster can be a valuable resource for policymakers and advocates. They can provide insights into the challenges facing haemophiliacs in specific communities and help identify solutions tailored to those needs.

Table 2 provides insight into the network characteristics indicated by the types of X-posts users were sending.

Table 2. Network characteristics

X-post **Type**	**Count**	**Percentage**
Repeated X-post	17981	35.34%
Mentions In Repeated X-post	13032	25.61%
Mentions	7891	15.51%
Replies to	1153	2.27%
X-post	10802	21.24%

As shown in Table 2, X-posts were most frequent, with a total count of 17,981, demonstrating that the majority of the activity centred around resharing existing content. Following Re X-posts, original X-posts comprised the second largest category, with 10,802 instances. Mentions embedded within Repeated X-posts came in third, amounting to 13,032 occurrences, indicating a high level of engagement that combines both mentioning and resharing. Direct Mentions were less frequent but still notable, accumulating to 7,891 instances. The category with the least activity was Replies, with only 1,153 cases. These results shed light on how users primarily interact through Repeated X-posts and original X-posts, while other forms of engagement, including Mentions and Replies, are less common.

Table 3 provides an overview of the popular hashtags within the network. The hashtag #Hemophilia was the most frequently occurring with 5,495 instances. The alternate British spelling, #Haemophilia, was also prominently featured, tallying 3,786 mentions. Beyond the primary focus, other health-related hashtags appeared, including #HIV with 1,363 mentions, #Cancer at 1,274, and #AIDS with 1,227 instances. Specific campaigns and observances were not left out; the hashtag #WorldHemophiliaDay was mentioned 1,136 times. Other general health and medical issues like #Hepatitis and #Physical were also part of the discussion, appearing 1,104 and 1,028 times, respectively. Even broader scientific themes were represented, with the hashtags #Science and #WHD2022 being mentioned 1,006 and 942 times, respectively. These data offer a view of the digital conversation surrounding haemophilia, highlighting the primary focus on the condition itself and its intersection with other significant health and scientific topics.

Table 3. Popular hashtags and frequency

Hashtag	**Count**
hemophilia	5495
haemophilia	3786
hiv	1363
cancer	1274
aids	1227

worldhemophiliaday	1136
hepatitis	1104
physical	1028
science	1006
whd2022	942

Table 4 below provides an overview of the top 5 users within the network.

Table 4. Top five users within the network

Rank	Type	User	Betweenness Centrality	User Bio
1	Media Personality with a Medical Background	Anonymised	23517008.9	Anonymised
2	Haemophilia organisation	nhf_hemophilia	17467512.61	NHF is dedicated to finding better treatments/cures for inheritable blood disorders & preventing related complications via education, advocacy, & research. □
3	Haemophilia organisation	haemosocuk	11597716.02	We are a community that makes each other feel stronger every day. Membership is completely free and everyone affected by a bleeding disorder is welcome.
4	Haemophilia organisation	wfhemophilia	8705106.498	The World Federation of Haemophilia improves and sustains care for people with inherited bleeding disorders around the world.
5	Individual user	Anonymised	8526698.949	Anonymised

The most influential user within the network is a media personality with a medical background. Their bio notes that they are a physician, author, and news commentator, and they are known to have disseminated misinformation in the past, in particular during the COVID-19 pandemic.

The second most influential user was the Idaho Chapter of the NHF (National Haemophilia Foundation), which focuses on finding better treatments and cures for inheritable blood disorders. They also work on preventing related complications through education, advocacy, and research.

The third most influential user is a Haemophilia Community Organization, which emphasises creating a supportive community for those affected by bleeding disorders. Their mission centres around emotional and social support, providing a platform for individuals impacted by haemophilia to connect and share experiences.

The fourth most influential user is the World Federation of Haemophilia, an international organisation with a global scope. They aim to improve and sustain care for people suffering from inherited bleeding disorders worldwide, making them an important voice in global healthcare policies and initiatives.

The fifth most influential user is an Anonymised Individual User. Though not a public figure, this user plays a significant role in the conversations surrounding haemophilia. The account appears to amplify misinformation and conspiracy theories and would be a low-quality contributor to the discussion.

When examining whether accounts were still active, at the time of writing (February 2025), four of the five accounts were still active with the Idaho Chapter of the NHF becoming inactive and only having last posted in March 2022. Many of the haemophilia organisations were found to also be on other social media platforms such as Instagram and Facebook.

LDA-Assisted Qualitative Analysis Results

This section details the results of the LDA-assisted qualitative thematic classification, and Table 5 provides an overview of the key themes. Overall, nine separate topics were found in answer to the research questions for this study. The chosen themes demonstrate a keen interest and dedication towards online support networks, with each topic focusing on certain parts of the disease and the underlying reasons for seeking help. Significantly, each topic encompasses discussion points about the involvement of medical specialists, opinions, and the importance of clinical diagnosis. Many of the key themes included posts by patients, health professionals, and patient support groups with more official organisations posting general awareness raising information.

Table 5. Overview of Key Themes

No.	Topic Name	Thematic Overview
1	Alternative Healing Methods	Explores the intersection of spiritual healing with diseases including haemophilia.
2	Haemophilia Awareness & Orgs	Conversations related to various haemophilia organisations, their regional presence, and awareness campaigns.
3	Haemophilia Clinical Aspects	A focus on bleeding disorders, clotting issues, and raising awareness about inherited bleeding disorders.
4	Haemophilia Healthcare	Posts around health, blood, treatment factors, and official healthcare resources related to haemophilia.
5	Haemophilia Treatment	Posts around treatments, therapies, patient experiences, and community resources for haemophilia.
6	Blood Contamination Scandals	Addressing contaminated blood issues, inquiries, cover-ups, and scandals.
7	Medical Case Analysis	Posts around interpretation pitfalls and approach to medical cases of haemophilia.
8	Russian Royal History	Touching on Rasputin and the Russian royal family, likely to be in the context of Tsarevich Alexei's haemophilia.
9	Miscellaneous Views & Opinions	A range of X-posts expressing other views and opinions unrelated to the central theme of haemophilia.

Aligned with Alvesson and Jonsson's (2022) emphasis on sensemaking, we explore the shared meanings constructed about health by patients and their loved ones using social media. At the same time, this direction has been addressed in the context of patient groups, communities, subcultures, and health organisational units e.g., (Choukou *et al.*, 2022, Atanasova *et al.*, 2018), it has received less attention in dominant approaches to health organisation studies, particularly those focusing on organisational culture, identity, and sensemaking. Our subsequent nine themes highlight the context of shared meanings, as these are often taken for granted among patients in online community groups and within the theories and domains of health organisation studies. We open up this meaning generation to greater scrutiny, aligning with Alvesson and Sandberg's (2011) emphasis on problematisation and assumption-challenging as critical elements of our research. The nine key themes are further described and discussed below.

Theme 1: Alternative Healing Methods

Users within this theme explored using spiritual healing, such as prayer, meditation, and yoga, to treat haemophilia. Users would discuss the potential benefits and risks of these methods and share their experiences using them.

For example, one X-post noted:

> *'Siddha yoga, claims to relieve various conditions like stress, anxiety, and even chronic diseases such as haemophilia through meditation. #HolisticHealing #Meditation #AlternativeTherapy'*

The X-post suggests that Siddha yoga, a form of meditation, can offer alternative healing for conditions including haemophilia. While the prospect of using meditation to manage symptoms of chronic diseases like haemophilia may provide hope, it's crucial to cautiously approach such claims. Although meditation and other holistic practices may offer supplemental benefits such as stress reduction and improved mental well-being, the scientific evidence to support their efficacy in treating chronic medical conditions like haemophilia is currently limited. The hashtags used in the X-post highlight the desire for non-pharmacological interventions to treat haemophilia.

The work of Lambing et al., underscores the importance of alternative therapies for people with haemophilia (Lambing *et al.*, 2019), particularly in light of the current climate of opioid risk in some parts of the world. Mulders et al., conducted a comprehensive investigation into several alternative therapies for pain management and explored the potential for healthcare practitioners to prioritise this facet of patient care (Mulders *et al.*, 2020). The analysis of social media information indicates that providing support for individuals with haemophilia is a significant area of concern, which lacks a clear definition within the existing academic literature.

Theme 2: Haemophilia Awareness & Organisations

Users within this theme would converse about haemophilia awareness and advocacy and the different haemophilia organisations worldwide and their work. X-posts included conversations around the role of these organisations in raising awareness and supporting people with haemophilia.

For example, one X-post noted:

> *'Exciting news! The number of registrations for the upcoming Haemophilia Congress in Montreal gives us reason to be optimistic. #HemophiliaAwareness @wfhemophilia'.*

The X-post highlights the role of haemophilia organisations in advocacy and raising awareness by mentioning the upcoming Haemophilia Congress in Montreal and referencing a global organisation (@wfhemophilia). The enthusiasm expressed within the X-post over the number of registrations reflects the growing interest and attention towards haemophilia, which is crucial for advocacy efforts. Organisations dedicated to haemophilia are pivotal in increasing the visibility of the condition by disseminating valuable information and supporting research to lobbying policymakers and offering platforms for care-givers.

In their investigation of X-posts about haemophilia, Chen observed that social media content were predominantly influenced by professional and pharmaceutical organisations aiming to promote the subject matter (Chen *et al.*, 2022). These accounts are more inclined to utilise tags in their profile and explicitly mention their concentration on haemophilia in their account description, enhancing their visibility among other users interested in haemophilia-related material. In the future, health organisations may need regular risk assessments to ensure their information is up-to-date and accurate. This is especially important as the volume and sophistication of health misinformation on social media continue to grow (Ahmed *et al.*, 2023).

Theme 3: Haemophilia Clinical Aspects

Users in this theme focused on the clinical aspects, and posts included the causes of haemophilia and how it is inherited, as well as the diagnosis and treatment of haemophilia. Some users also conversed about the long-term complications of haemophilia.

For example, one X-post noted:

> *'A breakthrough in gene therapy for Haemophilia A! Genes from a virus were used to produce the missing clotting factors in patients, achieving disease reduction or removal in 88% of cases. #Science #HemophiliaTreatment'*

The X-post highlights a potential milestone in treating Haemophilia A by referring to the potential of gene therapy. It states that 88% of patients in a group saw a reduction or even elimination of their disease after being treated with a gene therapy technique. The X-post highlights the medical advancements in understanding and treating haemophilia at a clinical level.

Understanding haemophilia from a clinical standpoint is vital for managing the condition effectively. Haemophilia A and B are the most common types, differentiated by the specific clotting factors they are deficient in. The approach to therapy has largely been supportive, mainly involving the replacement of missing clotting factors. However, gene therapy, as indicated in the X-post, is a frontier that could drastically alter the prognosis for those living with haemophilia.

The X-post also implicitly raises awareness about the inheritance pattern of haemophilia, which is usually X-linked recessive and emphasises the significance of diagnosis and targeted treatment. Although gene therapy is still an area of active research, its promise, as mentioned in the X-post, signals a potential game-changer in managing long-term complications associated with haemophilia. Sezgin and Uğur's study of haemophilia social media communities in Turkey highlights the importance of online communities for access to information and discussion about innovations in treatment (Sezgin and Ugur, 2021), such as the latest gene therapies.

Theme 4: Haemophilia Healthcare

This theme examines healthcare providers' role in caring for people with haemophilia. Users would discuss the different treatment options available for haemophilia and the challenges of accessing it. Users would also converse about the importance of patient education and self-management for people with haemophilia.

For example, one X-post noted:

'Excited to see our paper on informed consent for haemophilia gene therapy discussed in a great talk on supporting autonomous choices for healthy living. #HaemophiliaHealthcare #EAHAD2022'

This X-post emphasises the pivotal role healthcare providers play in treating haemophilia. It highlights a paper discussing informed consent for gene therapy, a treatment option for haemophilia. The topic of informed consent is critical, as it embodies the ethical practice of patient education and autonomy, key components of effective healthcare provision.

Treating haemophilia involves a multidisciplinary approach, often requiring specialised healthcare providers, such as haematologists, to guide treatment options, ranging from factor replacement therapy to emerging options like gene therapy. Healthcare providers are responsible for delivering treatment and educating patients about the risks and benefits of various treatment options, as exemplified by the X-post's focus on 'informed consent'.

Access to these advanced treatment options can be challenging, especially in regions with limited healthcare infrastructure. Though not explicitly stating so, the X-post indirectly draws attention to the need for universal access to such treatments. Patient education and self-management are also crucial in this aspect, as informed patients are better equipped to navigate the complexities of healthcare systems and make choices best suited to their condition. The significance of incorporating new competencies into professional practice was highlighted by Pollard, who emphasises the important role of healthcare workers, such as nurses, in coordinating care delivery (Pollard *et al.*, 2020).

By spotlighting the role of healthcare providers and the ethical considerations of treatment, the X-post captures the essence of what haemophilia healthcare should aspire to be: comprehensive, ethical, and patient-centred. The theme strengthens the early argument made by Colvin for the implementation of comprehensive care plans and aiding healthcare professionals in their efforts to provide patient-centred care (Colvin *et al.*, 2008).

Theme 5: Haemophilia Treatment

Users in this theme conversed about the different treatments available for haemophilia. Users would discuss the effectiveness of different treatments for haemophilia and the side effects of different treatments for haemophilia. Users would also explore the cost of haemophilia treatment.

For example, one X-post noted:

> *'Managing #haemophilia is not one-size-fits-all. We've got clotting factor treatments, gene therapy, and more, but it's crucial to weigh effectiveness, side effects, and costs. Personalised care is key. # TreatmentOptions'*

This X-post encapsulates the core elements of the theme, 'Haemophilia Treatment', by discussing the multifaceted approach to treating haemophilia. It underlines the importance of tailored care, considering not just the effectiveness of various treatment options like clotting factor treatments and gene therapy but also their side effects and costs.

The phrase 'not one-size-fits-all' immediately signals that haemophilia treatment is complex and needs to be individualised. This is critical because it emphasises that what works for one person may not necessarily work for another. Individual circumstances, such as the severity of the disorder, the presence of other health conditions, and even financial considerations, can significantly influence the best course of treatment.

The X-post also touches upon the cost of haemophilia treatment, which can be a significant burden for many patients and their families. This economic aspect can often determine the accessibility of specific treatments and is crucial in managing the disorder effectively.

By using the hashtag' #TreatmentOptions', the X-post invites further discussion and exploration on the topic, likely encouraging others to share their experiences or knowledge about different treatments, their efficacy, and their costs. This community sharing can provide invaluable insights for those affected by the condition and healthcare providers and policymakers who could use such real-world evidence to improve care pathways and perhaps even advocate for more equitable access to treatments. Furthermore, the X-post serves as an overview of the *'Haemophilia Treatment'* theme, urging us to think critically about the various treatment options available, their effectiveness, side effects, and economic implications. It promotes a dialogue that could be vital in shaping future research and healthcare policies for haemophilia.

The theme reinforces Samelson-Jones and George's observation that the only constant for haemophilia care is constant change (Samelson-Jones and George, 2021). Discourses of uncertainty are common on social media, such as the conspiracy theories that were popular during the COVID-19 pandemic. Topics concerning patient treatment options show engagement and growing awareness of the expanding pharmaceutical markets and the general commodification of healthcare.

Theme 6: Blood Contamination Scandals

Users in this theme discussed the history of blood contamination scandals involving haemophilia, the impact of blood contamination scandals on people with haemophilia, and the lessons learned from these scandals.

For example, one X-post noted:

> *'Confirmation that a blood donor had AIDS in 1984 led to a recall of factor VIII vials from haemophilia centers. Of the 485 issued, 187 were recovered'.*

The X-post discusses a historical blood contamination scandal involving people with haemophilia, specifically regarding the contamination of factor VIII vials with HIV/AIDS in the 1980s. This topic is incredibly sensitive and has left an indelible mark on the haemophilia community, as it led to many infections and, in some instances, loss of life.

Blood contamination scandals like this have profoundly impacted public trust in blood donation and transfusion systems. They have necessitated rigorous screening processes and surveillance mechanisms to ensure the safety of blood products. These measures are especially critical for people with haemophilia, who often require frequent transfusions or infusions of clotting factors, making them particularly susceptible to bloodborne pathogens.

Despite the significant improvements in screening and safety, the scars from past contamination scandals continue to affect the haemophilia community. These incidents have led to more stringent regulations but have also highlighted the importance of transparency and accountability in healthcare systems. Lessons learned from these scandals emphasise the need for constant vigilance in screening and testing procedures to prevent any future lapses in safety.

This X-post serves as a stark reminder of the serious consequences of contaminated blood products and the need for ongoing vigilance in preventing such tragedies in the future. The theme builds on a large body of work on the impact of contaminated blood products on the morbidity and mortality of patients with haemophilia. More recent concerns have become popular topics on social media, where clinical practice is openly discussed, and questions about the lack of familiarity with the condition can lead to misdiagnosis or delayed diagnosis (Chen *et al.*, 2022).

Theme 7: Medical Case Analysis

Users would discuss the challenges of diagnosing and treating haemophilia. They would also emphasise the importance of accurate diagnosis and treatment approaches. Some users also explored the outcomes of different treatments for haemophilia.

For example, one X-post noted:

> *'More bad news. Autoimmune disorder creates a syndrome similar to Haemophilia with pathologic bleeding (tongue, joints). Can begin several months after taking it. Lesson learned is to be vigilant on both thrombosis and bleeding'.*

This X-post highlights the complexity of diagnosing and treating haemophilia, particularly when other medical conditions like autoimmune disorders confound it. The X-post indicates that an autoimmune disorder can manifest symptoms mimicking those of haemophilia, such as pathological bleeding in different parts of the body. This can make the diagnosis and treatment of haemophilia significantly more complicated, as healthcare providers must differentiate between various potential underlying causes.

The X-post also stresses the need for vigilance in monitoring both thrombosis (clot formation) and bleeding, showing that the balance of treatment can be precarious. A wrong diagnosis or inadequate treatment can lead to excessive bleeding or dangerous clot formation, which can be life-threatening for a patient with haemophilia.

Therefore, accurate diagnosis is crucial for effective treatment. With advancements in medical technology, diagnostic kits and more targeted therapies have been developed to better manage haemophilia and similar disorders. However, as the X-post points out, medical professionals need to be continuously vigilant, especially when patients present with symptoms that multiple underlying conditions might cause.

This X-post serves to emphasise the complexity of diagnosing and treating haemophilia and the need for ongoing research and clinical education to improve patient outcomes. Research in this area has raised similar concerns about the medical review of female patients with haemophilia (Farej *et al.*, 2020) and regional and national comparisons of how different countries diagnose and treat the condition (Mulla *et al.*, 2021). The purpose of social media topics is complex, which challenges researchers, patients, professionals, and students to derive meaning from extracted data like X-posts. We gain a sense of this complexity in this theme, where users' self-selection for certain topics about haemophilia may introduce biases or enhance misinformation. Interpreting such content raises additional questions for the clinical experience of haemophilia: Where do users get their information? What misinformation do they see? What impact does such information have on individuals diagnosed or seeking a diagnosis for haemophilia?

The impact of these questions varies from person to person, making it impossible to fully understand every individual's experience of social media information about health and the effect on diagnosis. However, this theme highlights the importance of medical case analysis and the role that health professionals have to play in ensuring clearly communicated health information, not only at the point of diagnosis but also throughout treatment and the patient's lifelong journey (Lewandowska *et al.*, 2022).

Theme 8: Russian Royal History

Users in this theme conversed about the role of haemophilia in the Russian royal family. Users would discuss the life of Tsarevich Alexei, who had haemophilia, and the impact of haemophilia on the Russian royal family. Users would also explore the legacy of haemophilia in the Russian royal family.

For example, one X-post noted:

> *'Just watched a docu about Tsarevich Alexei of Russia. His haemophilia wasn't just a personal struggle; it profoundly influenced Russian history and eventually led to the fall of the Romanovs. #RussianRoyals #Haemophilia'*

This X-post summarizes the impact that haemophilia had on the life of Tsarevich Alexei. Tsarevich Alexei was the only son of Tsar Nicholas II, the last Emperor of Russia. Diagnosed with haemophilia he is known to have lived a life of fragility, experiencing frequent and agonising pain. According to the X-post, Haemophilia, therefore, had wide-reaching implications in shaping political decisions, public opinion, and the legacy of the Romanov family.

Theme 9: Miscellaneous Views & Opinions

Users in this theme had a wide range of views and opinions on haemophilia, from the personal to the political. Users would also discuss challenges and opportunities facing people with haemophilia and the future of haemophilia treatment and care. For example, one X-post noted:

> *'So many angles to consider when talking about #haemophilia - from alternative therapies and historical insights to modern medical approaches and future innovations. It's not just a medical issue; it's a complex tapestry of human experience. #holisticview'*

The X-post captures the essence of the theme by highlighting the multifaceted nature of haemophilia. It suggests that understanding and treating haemophilia isn't just about focusing on the clinical aspects; it's also about looking at the condition from personal, historical, and social angles to get a full picture.

The hashtag' #holisticview' in the X-post underlines the importance of a comprehensive approach to understanding haemophilia, which could potentially open up new avenues for research and treatment. The theme further strengthens Boccalandro calls for multidisciplinary management (Boccalandro *et al.*, 2023) and echoes Skinner criticism of the lack of health equity for patients with haemophilia (Skinner *et al.*, 2020).

Discussion

Given that social media platforms are designed to be social, it is not unexpected that hashtags such as #heamophilia and #haemophilia have fostered a range of tagging and posting behaviours that promote social interactions. These practices are significant in examining health boundaries and professional contexts and disseminating accurate guidance and misleading information. As discussed by Pershad *et al.* (2018), social media's immediacy often amplifies both valid information and misinformation, a dual nature also highlighted in our findings**.** This abundance of information, coupled with the inherent ambiguity of online sources, creates a challenging environment for individuals seeking to make sense of health-related content. Users are faced with a deluge of information, often from sources with varying levels of credibility, making it difficult to determine what is accurate and reliable. This situation reflects Weick's (Weick, 2004) concept of "equivocality," where multiple interpretations of the same information are possible, leading to confusion and uncertainty. In response to this information overload and ambiguity, users may employ various sensemaking strategies. For instance, they might rely on trusted sources, such as established medical organizations or healthcare professionals, to filter information. They may also seek confirmation from others within the online community, engaging in posts that clarify information and build shared understandings. Chen et al. observe digital haemophilia practices as part of social media communities that foster social and emotional support (Chen et al., 2022). Parallel to their primary support function, these online forums also provide a platform for users to discuss disputed and sensitive social problems surrounding the unfavourable perception of haemophilia.

The potential for anyone to become an influential user and peddle misinformation is a serious concern. This was also reflected in our findings as the most influential user was known to have shared dangerous misinformation during the COVID-19 pandemic, putting their credibility in doubt. And the fifth most influential user also appeared to be an account that was amplifying misinformation. -Social interaction plays a crucial role in sensemaking on X. Users do not just passively consume information; they actively engage with each other to make sense of it. Posts within the haemophilia community can serve several important functions. They provide a platform for users to clarify ambiguous information, ask questions, and share their interpretations (Moorhead *et al.*, 2013) . They also allow users to challenge misinformation and offer counter-arguments (Starbird, Arif, and Wilson 2019). Through these interactions, users can collectively construct a shared understanding of health-related issues (Weick and Weick, 1995). Shared narratives can emerge within the community, providing a framework for interpreting information and experiences related to haemophilia (Gunning and Koenig Kellas 2024).This collective sensemaking process can be particularly important in the context of health, where individuals often rely on others for support and guidance (Mamykina, Smaldone, and Bakken 2015) For example, users might discuss the latest research on haemophilia treatment, sharing their perspectives and experiences to arrive at a shared understanding of its implications. Or, they might debate the merits of different health policies, using online content to build consensus and advocate for change. Here, moderators can play a crucial role in verifying information, removing false or misleading posts, and directing users towards reliable sources (Petrakaki and Kornelakis 2025). This proactive approach can create a safer and more trustworthy online environment for health-related discussions, helping to protect vulnerable individuals from the potential harms of misinformation and disinformation.

Our study provides a comprehensive analysis of the X community associated with haemophilia, revealing a heterogeneous population exhibiting varying degrees of involvement and inclination towards numerous aspects such as health information, sources of health information, and health policy. The Groups 1-5 identified in the SNA can be effectively utilised to enhance knowledge regarding policy matters, mobilise support for advocacy initiatives, and get valuable insights into the lives of individuals affected by haemophilia. By understanding the different groups within the haemophiliac community and how they interact with each other on social media platforms, we can better tailor outreach efforts to reach them effectively. This can lead to stronger relationships with the community and improved policy outcomes that benefit people with haemophilia. While we acknowledge the potential positive impact of personal experiences and insights, we will also highlight the importance of critical evaluation and fact-checking, especially in the context of health information. By understanding these diverse groups and their interactions, healthcare providers and organizations can tailor their outreach efforts to provide accurate and timely information, address misinformation, and support the needs of individuals with haemophilia.

When we analyse our findings through the lens of the U&G theory, we can observe that certain uses and gratifications are more prominent than others among haemophilia patients on X (Pelletier et al., 2020). For instance, X is frequently employed by patients to reinforce cognitive gratifications, particularly by combating misconceptions, addressing misinformation, and enriching their general knowledge about the disease. This is consistent with findings by Walker (2015), who identified the cognitive benefits of patient support groups for rare diseases. Additionally, given X's nature as a social medium, it is not surprising that social integrative gratifications are achieved using hashtags, fostering a sense of support and community. Finally, effective gratifications are obtained through the use of online memes and other forms of humour, providing enjoyment, serving as a pastime, and potentially offering a form of escapism (Chang *et al.*, 2022).

It is important to note that X was known as Twitter prior to a rebrand that took place on July 23, 2023, due to Elon Musk's purchase of the platform on October 28th, 2022. This has led to changes in features, design, and also lead to some organisations leaving the platform in its entirety (Mallett 2024), we found that there is still a sizeable community of users and healthcare professionals conversing about haemophilia. Four out of the five influential users identified were still very active on the platform.

Implications for Healthcare Professionals and Policy

Our findings have significant implications for healthcare providers, policymakers, and researchers. Understanding the diverse needs and behaviors of individuals with haemophilia enables healthcare professionals to tailor interventions and support services to meet this population's specific requirements. For instance, healthcare providers can utilize social media platforms to disseminate accurate information, address misinformation, and provide timely updates on research and treatment advancements, provided they have sufficient support and training.

However, it's important to acknowledge that healthcare workers possess varying levels of social media expertise and confidence, and developing social media and communication skills and effective strategies for engaging with patient populations is time-consuming (Lunkka et al. 2025). To mitigate the spread of misinformation on social media and online forums, moderators, who may be healthcare professionals or trained individuals, can play a key role in ensuring that shared information is accurate and evidence-based. By directing patients toward these moderated spaces, health professionals can offer a safer alternative to platforms like X, where misinformation can spread more easily. Here, policymakers can play a crucial role by assisting healthcare workers in interpreting social media data, particularly when informing health policy decisions and allocating resources. Additionally, ensuring that digital health tools are accessible and inclusive for individuals with varying levels of technological literacy is essential, as accessibility plays a critical role in patient engagement and health communication (Hardey, 2022).

Conclusion

This study has demonstrated the significant role of X in facilitating health communication and advocacy within the haemophilia community. By analyzing a large dataset of tweets, we have identified key themes and patterns of interaction among community members. Our findings highlight the potential of social media to support patient empowerment, knowledge sharing, and social support. However, it is crucial to acknowledge the challenges and risks associated with social media, such as the spread of misinformation and the potential for harmful online interactions. Future research should explore the long-term impact of social media on health outcomes and well-being, as well as the development of strategies to mitigate the negative consequences of online engagement.

While U&G theory provides a valuable framework for understanding user motivations and behaviors, it may not fully capture the complexities of social media use in health contexts. U&G can help us understand why individuals might share personal health information online, however, it may not fully address the potential risks and consequences of such sharing, particularly in relation to privacy and security. Indeed, as social media platforms like X continue to evolve, it is essential to consider the potential impact of these changes on the haemophilia community. Future research should explore how platform modifications, such as algorithm changes or policy updates, may influence information sharing, community building, and advocacy efforts within this group.

The insights gained from this study on the haemophilia community on X can, we argue, be applied to other patient communities facing similar challenges, such as those with rare diseases, chronic illnesses, and mental health conditions. Social media platforms have the potential to foster strong, supportive communities, facilitate information sharing, and empower patients to advocate for their needs. By understanding the dynamics of online health communities, healthcare providers, policymakers, and researchers can develop strategies to improve patient care, health outcomes, and public health. Indeed, as social media platforms continue to evolve, it is essential to explore their potential for healthcare communication and advocacy. These platforms can be used to disseminate accurate health information, connect patients with healthcare providers, and mobilize communities to advocate for policy change. However, it is crucial to address the challenges associated with social media, such as the spread of misinformation and the potential for online harassment.

Limitations and Future Research

While this study provides valuable insights into the use of X by individuals with haemophilia, it is important to acknowledge its limitations. As with any social media research, there is a risk of selection bias, as not all individuals with haemophilia may be active on the platform. Additionally, the rapid evolution of social media platforms can impact the findings of this study.

Future research should explore the long-term impact of social media on the health and well-being of individuals with haemophilia. It is also important to investigate the role of social media in facilitating access to healthcare services, particularly in low-resource settings. By addressing these research questions, we can gain a deeper understanding of the potential benefits and risks of social media use in the context of chronic illness. Furthermore, as the digital landscape continues to evolve, it is essential to consider the ethical implications of social media use in healthcare. Researchers and policymakers should work together to develop guidelines and regulations that protect the privacy and security of individuals while promoting the positive use of social media for health and well-being. To address these limitations, future research should explore the intersection of U&G theory with other theoretical frameworks, such as social cognitive theory and the health belief model. By incorporating these additional perspectives, we can gain a more comprehensive understanding of the factors that influence health-related behaviours on social media. Additionally, qualitative research methods, such as interviews and focus groups, can be used to delve deeper into the experiences and perceptions of individuals with chronic illnesses who use social media.

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