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Impact of Chronic Graft-versus-Host Disease on Patient and Caregiver Experiences in the United States: A Retrospective Social Media Analysis

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A B S T R A C T

Social media listening (SML) offers a unique approach to understanding the lived experiences of patients with chronic graft-versus-host disease (GVHD) and encompasses diverse voices from various socio-economic backgrounds. The objective of this study is to use SML to better understand the lived experiences of patients with chronic GVHD and their caregivers in the United States. A search syntax identified relevant posts from public social media platforms (X [formerly Twitter], TikTok, Instagram, Reddit, Facebook, YouTube, podcasts, forums, and blogs) in the United States between September 1, 2022, and September 1, 2024. A core analytic set about chronic GVHD was identified after removing posts from nonrelevant stakeholders and those containing exclusionary terms or overt acute GVHD mentions. This isolated set of posts was analyzed for descriptive information on chronic GVHD content. A smaller subset of posts was randomly selected and manually coded to create the qualitative analysis set, which was interpreted by natural language processing through an AI-driven qualitative research tool and a netnographic method to identify themes. A total of 12,476 relevant posts were captured during the study period, of which 5051 and 1278 were included in the core analytic set and the qualitative analysis set, respectively. Overall, 71% of posts in the qualitative analysis set were from patients, 15% from caregivers of pediatric patients, and 4% from caregivers of adult patients. Four key themes were identified: physical, mental, and emotional burden; treatment experiences; ways of coping; and burden on caregivers. The most common (39%) source of posts in the core analytic set was X. Skin was the most mentioned organ, and trauma, defined as traumatic experiences or feelings, was the type of emotional burden most commonly cited in conjunction with an organ or specific treatment. There were multiple physical, mental, and emotional burdens of chronic GVHD, with dry eyes, feelings of anxiousness, and struggles with the sense of self being the most common in each respective category. Overall, tacrolimus and ruxolitinib were the most frequently

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mentioned treatments. GVHD treatments were challenging for patients and caregivers due to variable efficacy, side effects, time consumption, and/or high costs. Patients sought specialized care from their health care professionals and often used online communities for support. Caregivers described feeling burdened by their role, experiencing emotional distress, and needing to balance the demands of caregiving with other responsibilities. Using SML, we have gathered unique insights into the burden and impact of chronic GVHD onto the physical and mental health of patients. Currently, there is a need for improved access to more effective treatments to decrease patient and caregiver burden and improve their quality of life.

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INTRODUCTION

Chronic graft-versus-host disease (GVHD) is a common complication after allogeneic hematopoietic cell transplantation (HCT), historically affecting 28% to 42% of HCT recipients [1]. In the last decade, the use of post-transplant cyclophosphamide as GVHD prophylaxis has increased due to its efficacy in preventing both acute and chronic GVHD [2,3]. However, many patients who undergo HCT still live with chronic GVHD, and post-HCT cyclophosphamide does not completely eliminate this risk [4]. There is still a need to understand the impact of the disease on patients and caregivers in order to develop better treatments and mitigation strategies. Chronic GVHD adversely impacts patients in terms of clinical outcomes, psychological distress, and quality of life [5,6] and can still be fatal despite recent advancements in treatment [7,8].

Chronic GVHD is a systemic disease characterized by its multi-organ involvement and high symptom burden in moderate-to-severe cases [9,10]. In addition to the physical burden of the disease, patients with chronic GVHD may experience psychological distress, including depression and anxiety [11], which is linked to a higher symptom burden, lower survival [12], and a diminished quality of life [13]. Moreover, chronic GVHD negatively affects patients' socio-economic status, with many experiencing increased use of disability leave, higher medical costs, and medical leave–associated productivity loss, making it impossible for some patients to regain the same quality of life they had prior to transplantation [14,15].

The recommended first-line treatment for chronic GVHD is to administer systemic steroids, often in conjunction with a calcineurin inhibitor or sirolimus as steroid-sparing agents [16]. However, approximately 50% of patients become steroid-resistant or -dependent and require a second-line treatment [17]. Currently, ruxolitinib [18] and ibrutinib [19] are the only US Food and Drug Administration–approved agents for the second-line treatment of chronic GVHD, with belumosudil [20] and axatilimab [21] approved as third-line treatments [16]. Due to the chronic nature of the disease, nearly all patients receive long-term immunosuppression, which may negatively impact their quality of life [22] and increase susceptibility to infections, malignancies, renal dysfunction, and metabolic and musculoskeletal complications [23,24]. An understanding of the real-world burden of chronic GVHD is crucial for addressing unmet needs and improving patient outcomes, especially since patient-reported outcomes are not consistently included in clinical trials of chronic GVHD [25].

Social media has become a platform where patients and caregivers openly share authentic experiences about disease management [26,27], creating an opportunity to capture real-world data that traditional research methods often miss [28]. Social media listening (SML) studies can thus analyze largely unfiltered data to provide insights into the lived experiences of patients and caregivers [28,29], in contrast with other qualitative methodologies, which may be limited by the amount of data that can be gathered in a time-effective manner [30,31]. SML methodologies have previously been used to better understand the lived experiences of patients with different diseases, including metastatic breast cancer [32], advanced bladder cancer [33], and GVHD (in a European patient population) [34]. Against this backdrop, this study uses SML to highlight the real-world voices of patients and caregivers living with chronic GVHD in the United States.

MATERIALS AND METHODS

Study Design

This was a retrospective observational SML study conducted in the United States. Online conversations related to chronic GVHD and its treatment were captured across publicly accessible social media and digital channels, including news, forums, X (formerly Twitter), blogs, Reddit,

Content Warning

This article discusses deeply sensitive issues including sexuality, self-harm, and suicidal thoughts in the context of GVHD. If you or someone you know is thinking about suicide, in the United States call or text 988 or chat via 988lifeline.org. For resources outside the United States, see the International Association for Suicide Prevention directory or local health services.

Facebook public pages, YouTube, Instagram, and TikTok, from September 1, 2022, to September 1, 2024, using the SML platform Talkwalker (Talkwalker Inc., Luxembourg). A word search term syntax was refined using a pilot to ensure the relevance and quality of posts and online conversations. The syntax consisted of keywords, hashtags, public health forum website addresses, and public social media support groups or influencer addresses, and it was developed to identify posts and conversations relevant to chronic GVHD (Supplementary Table 1).

To more accurately reflect the patient and caregiver discussion, posts from the following groups were excluded from the total chronic GVHD data set to create the core analytic set (Figure 1): nonpatient sources, such as news outlets, medical associations, and clinics; those where the authors were deemed to be health care professionals or part of patient advocacy groups; and those that contained exclusion terms such as "acute GVHD." A flow chart of the SML methodology is presented in Supplementary Figure 1.

To facilitate the qualitative analysis and perform a manual review of social media posts to identify themes, a randomly selected subpopulation of posts was created from the core analytic set, referred to as the qualitative analysis set. Posts from the core analytic set were excluded from further qualitative analysis based on their content, length, and potential mentions of acute GVHD as assessed from the contextual language of the post. Fictionalized examples of language that may have led to the exclusion of posts from further analysis because of their content, length, or a potential mention of acute GVHD included the following: "I had GVHD for a few weeks following my transplant" (example of post excluded due to potential acute GVHD) or "GVHD is bad" (example of post excluded due to content or length). Focus was placed on identifying posts from patients sharing experiences with having and/or being treated for chronic GVHD, or caregivers of patients with chronic GVHD. Posts deemed to be from noncaregiver friends or family were not included as part of the qualitative analysis. Anonymous posts from public forums were assessed to determine if they were from patients or caregivers by examining the post content and other relevant context. Treatment-related posts were grouped by treatment category, and all posts mentioning relevant brand names, abbreviations, and generic drug names were grouped. To differentiate between chronic GVHD symptoms and treatment side effects, posts related to side effects must have included specific terms (e.g., "side effect," "adverse event," "safety"); however, miscategorization of posts could not be ruled out, and side effects could not be attributed to specific treatments. Posts were categorized by different mental and emotional burdens based on specific keywords that must be included (Supplementary Table 2).

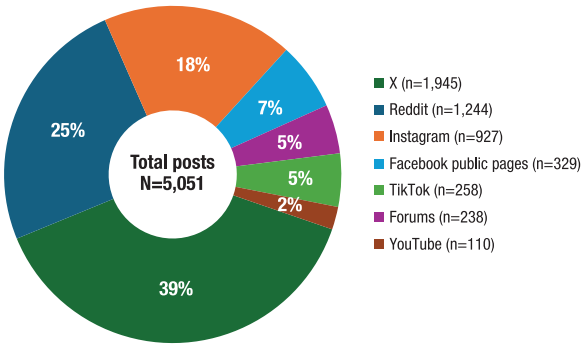

Figure 1. Core analytic set by post type. Values have been rounded to the nearest integer and totals may be less or more than 100%.

Data Analysis

SML data were analyzed using a combination of machine analytics, natural language processing, and a netnographic method. Machine analytics were used to summarize social media content to detect any trends and understand the number of chronic GVHD mentions within the study period. The netnographic method is an interpretive research methodology that adapts traditional ethnographic research techniques to online communities [35,36]. This method was used to interpret the collected social media data by a human-led narrative analysis to capture relevant patient and caregiver posts, tracing conversation threads back in time to map the full historical journey and disease experience. These post histories were then mapped on top of one another, where possible, to identify key triggers, decisions, and pain points that impact the relationship to treatment and management of their condition.

Due to the anonymization and removal of all metadata from social media posts included in the qualitative analysis, the core analytic set was analyzed for additional descriptive information of the social media content. Data on the number of unique authors were only available from the TalkWalker platform, and any identifying information was removed once the data were extracted and anonymized. In the qualitative analysis set, posts were analyzed by natural language processing through an AI-driven qualitative research tool (QRT) and a netnographic method to identify key themes and topics relating to the patient and caregiver experience. The QRT was refined with relevant social media data to improve topic and thematic clustering and increase accuracy by training with a set of predefined themes related to chronic GVHD (such as emotional burden, physical symptoms, treatment side effects, and quality of life impacts). Themes within conversations were identified by top-down and bottom-up analyses (Supplementary Methods) of the core analytic set, qualitative analysis data sets were used to identify themes, and any results were consolidated to establish key findings.

Ethics

Ethical approval exemption was granted by the Western Copernicus Group International Review Board on September 3, 2024, due to the use of publicly available identifiable information.

Glossary

A glossary of key terms associated with the SML methodology is provided in the Supplementary Methods.

RESULTS

Total Population Posts

A total of 12,476 posts related to chronic GVHD were identified over the data extraction period. After excluding posts based on the criteria mentioned in the Methods section, 40% (n/N = 5051/12,476) of posts from 2920 unique authors were included in the core analytic set (Supplementary Figure 2). To ensure that there was no substantial contamination from posts related to acute GVHD, an analysis of implicit acute mentions was conducted, and only 1% (n/N = 53/5051) of posts with implicit acute mentions was found in the core analytic set. The most common source of posts was X (n/N = 1945/5051 [39%]), followed by Reddit (n/N = 1244/5051 [25%]), and Instagram (n/N = 927/5051 [18%]) (Figure 1). The number of posts remained broadly consistent over the data extraction period, with peaks associated with key congresses and disease-related awareness days (Supplementary Figure 3).

Descriptive Results of the Core Analytic Set (N = 5051)

From the 5051 posts (2920 unique authors) extracted in the core analytic set, the physical, emotional, and mental burden of GVHD was mentioned in 28% (n/N = 1437/5051), 6% (n/N = 283/5051), and 5% (n/N = 253/5051) of posts, respectively.

Posts Related to Specific Organ Involvement

Specific organ manifestations were mentioned in 43% (n/N = 2169/5051) of posts, of which 50% (n/N = 1076/2169) highlighted only a single organ, 43% (n/N = 926/2169) mentioned 2 organs, and 8% (n/N = 167/2169) mentioned 3 or more organs. The most commonly highlighted manifestations in single-organ posts were skin rashes and dry eyes (Figure 2A). Skin was the most commonly mentioned organ alongside another organ (Figure 2B).

The emotional burden of chronic GVHD in relation to specific organ manifestations was described in 6% (n/N = 283/5051) of posts. The distribution of posts describing feelings of hopelessness, trauma, uncertainty, and isolation by organ manifestations is shown in Figure 2C.

Posts Related to Specific Treatments

Specific treatments were mentioned in 24% (n/N = 1207/5051) of posts. The most commonly mentioned treatment was steroids (Figure 3A). A relationship between a drug class and any emotional burden was described in 4% (n/N = 182/5051) of posts. Trauma was the most common type of emotional burden mentioned for the majority of treatments, with other posts highlighting hopelessness, uncertainty/fear, isolation, frustration, anxiousness, and stigma with similar frequency (Figure 3B).

The logistical and financial burden of different therapies was described in 7% (n/N = 369/5051) of posts. The inability to work was the most frequently mentioned logistical or financial burden across all therapies (Figure 3C).

Qualitative Analysis of Chronic GVHD Online Discussion (N = 1278)

From the 5051 posts in the core analytic set, a random sample of 25% (n/N = 1278/5051) of posts from 378 unique authors was included in the qualitative analysis set (Supplementary Figure 2). Posts from patients represented 71% (n/N = 907/1278) of posts (Supplementary Figure 4), while 15% (n/N = 196/1278) and 4% (n/N = 48/1278) of posts were from caregivers of pediatric and adult patients, respectively. Posts from relatives and friends of patients with chronic GVHD made up 10% (n/N = 127/1278) of the sample; these were excluded from the qualitative analysis. Following the QRT and netnographic analyses, the following themes were identified: physical, mental, and emotional burden; treatment experiences; ways of coping; and caregiver burden.

Physical, Mental, and Emotional Burden

Patients and caregivers discussed the physical, mental, and emotional burden of chronic GVHD in 78% (n/N = 997/1278) of posts. Physical burden was mentioned in 50% (n/N = 643/1278) of posts, most of which cited dry eyes (Figure 4). Most commonly, patients described specific organ manifestations affecting the eyes, skin, and gastrointestinal system (Supplementary Figure 5). The physical burden of chronic GVHD increased patients' dependence on others for basic tasks, which sometimes strained relationships. Caregivers of pediatric patients more commonly mentioned respiratory manifestations, dry eyes, digestive issues, and liver issues (Supplementary Figure 5).

Patients and caregivers described the mental and emotional burden of chronic GVHD in 23% (n/N = 297/1278) and 21% (n/N = 266/1278) of posts, respectively. Feelings of anxiousness (n/N = 255/1278 [20%]) and loss of their sense of self (n/

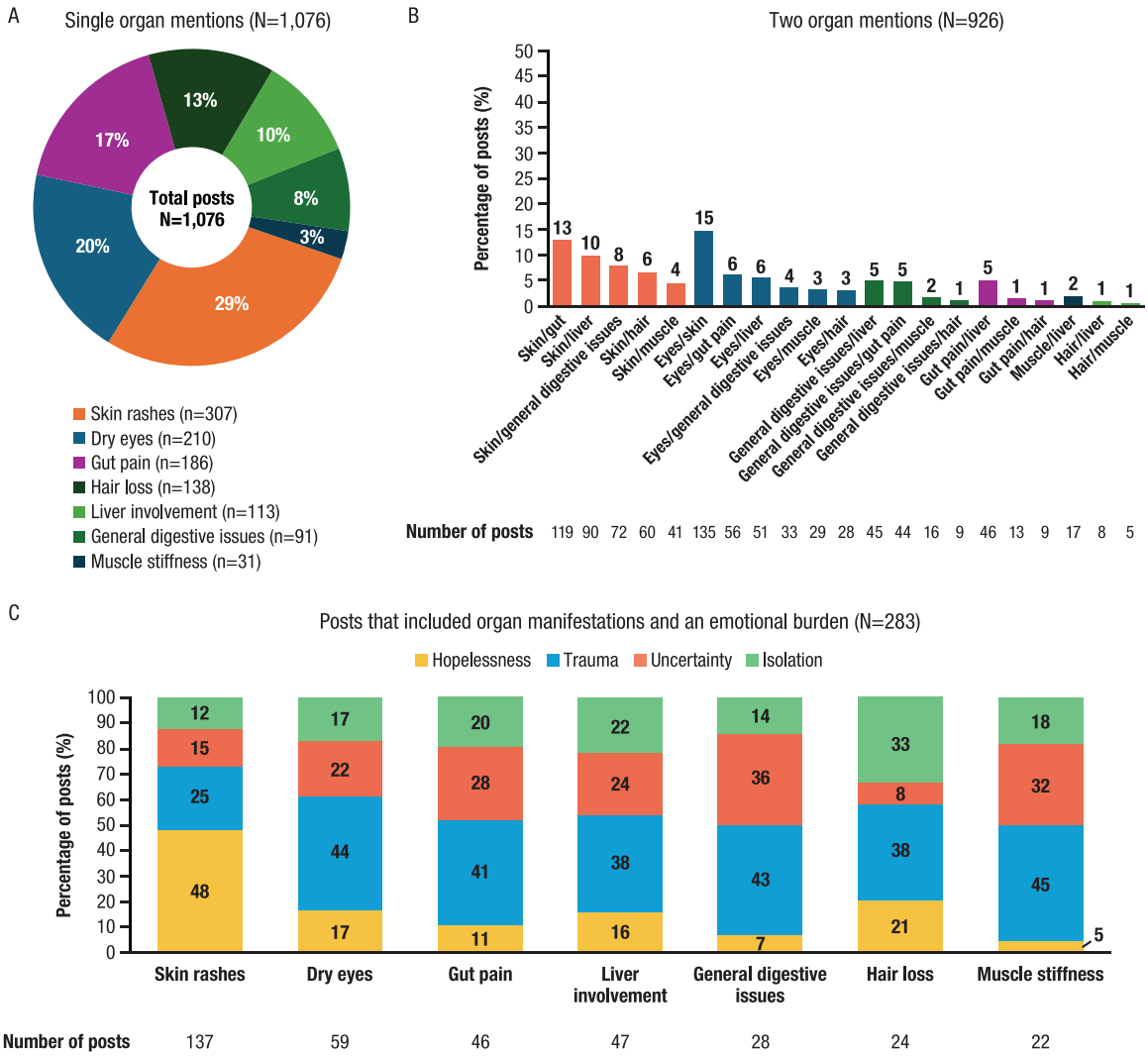

Figure 2. Single organ mentions (A), 2 organ mentions (B), and the relationship between organ manifestations and emotional burden (C) in the core analytic set (N = 5051). Percentages in panels A and B were calculated from their respective subpopulations, and percentages in panel C were calculated from the total number of posts for each treatment type. Single organ mentions (N = 1076), 2 organ mentions (N = 926), and posts that included organ manifestations and an emotional burden (N = 283) were subpopulations of the core analytic set (N = 5051). Values have been rounded to the nearest integer and totals may be less or more than 100%. Column length indicates the exact percentage.

N = 170/1278 [13%]) were the most reported types of mental and emotional burden, respectively (Figure 4). Caregivers of adult patients struggled more with their sense of self compared with pediatric patients/caregivers of pediatric patients (Supplementary Figure 5). In total, 11% (n/N = 139/1278) of posts described that health care provider expertise and compassion contributed positively to patients' overall well-being.

Patients emphasized that the physical burden of chronic GVHD negatively affected their mental health, leading to feelings of anxiousness and hopelessness. The compounding of mental and emotional burden with physical burden was described in 8% (n/N = 107/1278) of posts. Patients and caregivers described contemplating suicide in 15 posts due to the physical and subsequent psychological burden of chronic GVHD. Ten posts mentioned how the physical and emotional burden of chronic GVHD impacted their sex life and sense of self. Patients and caregivers discussed seeing psychiatrists and GVHD-specific therapists to manage the mental and emotional burden of chronic GVHD, as well as taking antidepressants (11 posts), which helped with the feelings of hopelessness. The immunocompromised status of patients with chronic GVHD further contributed to their social isolation and loneliness. This, in addition to the physical burden of chronic GVHD, including severe fatigue, pain, dry eyes, and pulmonary issues, contributed to an inability to work and a loss of income, as was described in 6 posts.

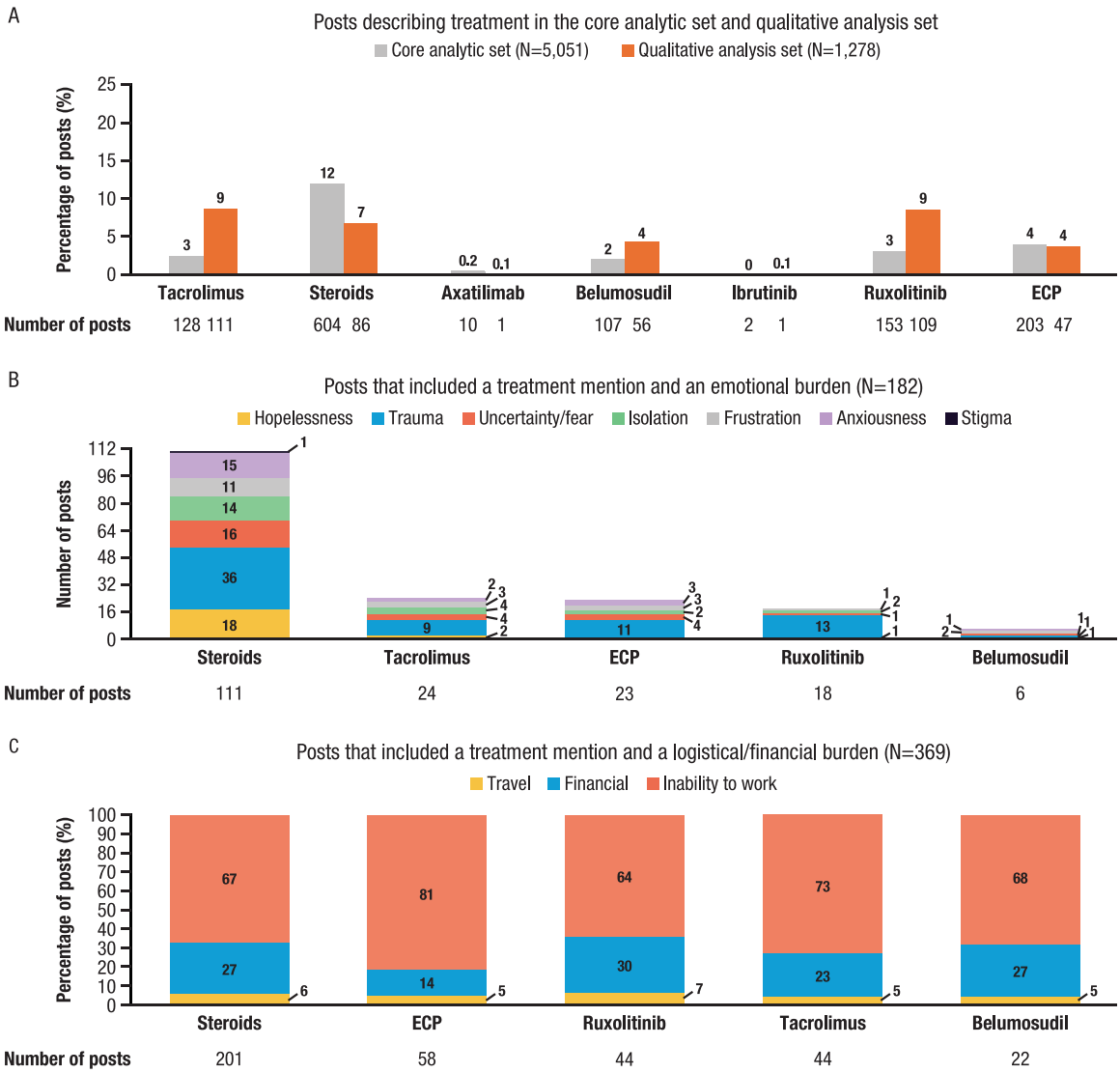

Figure 3. Total number of posts describing treatment in the core analytic set (N = 5051) and qualitative analysis set (N = 1278) (A), the number of posts describing treatment and emotional burden (B), and the logistical and financial burden of different drug classes (C) in the core analytic set (N = 5051). Percentages in panel A were calculated from the total posts in the core analytic set (N = 5051) and qualitative analysis set (N = 1278). The percentages in panels B and C were calculated from the total number of posts for each treatment type. Posts that included a treatment mention and an emotion burden (N = 182) and a treatment mention and a logistical/financial burden (N = 369) were subpopulations of the core analytic set (N = 5051). Values have been rounded to the nearest integer. Column length indicates the exact percentage. ECP, extracorporeal photopheresis.

Treatment Experiences

A total of 42% (n/N = 542/1278) of posts were related to specific treatments for chronic GVHD. The most common treatments mentioned were tacrolimus and ruxolitinib (Figure 3A).

Ways of Coping

Online conversations in 13% (n/N = 172/1278) of posts documented how patients and caregivers coped with the unpredictable nature of chronic GVHD.

Patients and caregivers described connecting to other peers through online support groups, communities, and social media platforms in 18 posts. Patients sought guidance on navigating the complexities of the medical system and government programs, as well as becoming active participants in their treatment. These posts (n/N = 68/1278 [5%]) included discussions around disability, long-term unemployment, government medical insurance, and how to apply for financial assistance. Part of the patient-to-patient conversation mentioned the importance of finding health care professionals with chronic GVHD experience due to the uniqueness of the disease. These posts included GVHD specialists (n/N = 75/1278 [6%]), bone marrow transplantation physicians and nurses (n/N = 38/1278 [3%]), and other specialists

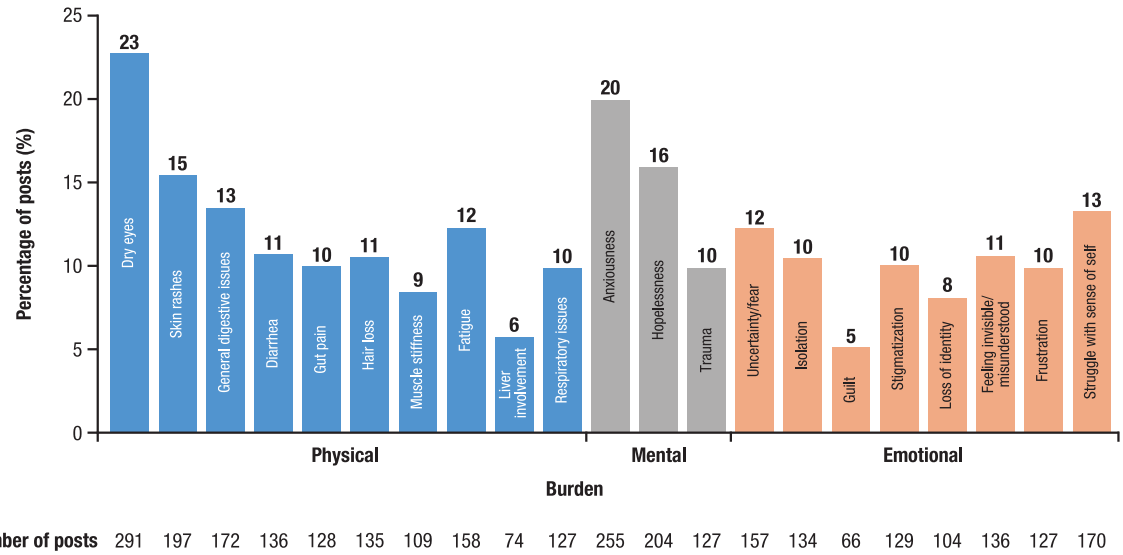

Figure 4. The physical, mental, and emotional burden of chronic GVHD in the qualitative analysis set (N = 1278). Reported burdens include symptoms of chronic GVHD and possible side effects due to chronic GVHD treatment. Posts could mention more than 1 symptom or type of burden. Values have been rounded to the nearest integer. Column length indicates the exact percentage. GVHD, graft-versus-host disease.

such as dermatologists (n/N = 93/1278 [7%]), gastroenterologists (n/N = 85/1278 [7%]), endocrinologists (n/N = 59/1278 [5%]), and ophthalmologists (18 posts) to deal with the specific issues related to chronic GVHD. Two posts specifically mentioned multi-disciplinary clinics being very helpful in their care.

Caregiver Burden

Caregiver burden was mentioned in 4% (n/N = 56/1278) of posts and brought attention to how different caregivers faced unique challenges. As the number of posts included in this theme was low, the output was identified through manual qualitative analysis of the caregiver conversation.

Adults who have parents with chronic GVHD described witnessing their parents in a state of weakness and vulnerability, which led to anxious feelings, emotional distress, and a sense of instability. As a result, these caregivers described how they suppressed their emotions to avoid burdening their parents, further contributing to internalized stress and difficulty processing their feelings. Similarly, young adults (20 to 40 years of age) were burdened by their caregiver role due to assisting parents with GVHD with household tasks, providing emotional support, and helping with medical care, which disrupted their social lives.

Overall, spouses and partners of adults with chronic GVHD often became primary caregivers. This role included managing facets of their medical care and advocating for their partner's needs. Furthermore, chronic GVHD impacted their physical intimacy and affected relationship dynamics. Spouses and partners also experienced the spectrum of emotions alongside their partner. There were differences between caregivers of adult and pediatric patients, with social media posts from the parents and guardians of children with chronic GVHD emphasizing how they advocated for their children, sought expert opinions, and researched their disease by focusing on treatment options. Parents and guardians also mentioned the need to balance the demands of caring for a child with chronic GVHD with other household and work responsibilities.

General Safety Summary

Patients and caregivers described the general impact of side effects in 27% (n/N = 351/1278) of posts. The side effects that may have been associated with chronic GVHD treatment included osteoporosis, nausea and vomiting, diarrhea, mouth sores, joint damage, changes in appearance, and mood or personality changes. Due to the nature of the analysis, specific side effects cannot be attributed to individual treatments, and it may be difficult to differentiate between side effects of treatment and symptoms of GVHD. Patients described how side effects were a challenging part of their treatment and experience with chronic GVHD. However, patients and caregivers viewed side effects as a necessary part of their treatment and actively sought ways to mitigate

them through medication adjustments, lifestyle changes, and supportive care.

DISCUSSION

This retrospective SML study evaluated the lived experiences of patients with chronic GVHD and their caregivers in the United States, capturing their unique perspectives on the challenges and unmet needs that may have been overlooked by structured clinical assessments and traditional research methodologies. A combined netnographic and qualitative analysis revealed 4 recurring themes: the burden of chronic GVHD, treatment experiences, ways of coping, and the burden of caregivers.

This study provided a unique patient and caregiver perspective on the substantial physical, mental, and emotional burden of chronic GVHD. Patient and caregiver posts on social media reflected the multi-organ effects of the disease [10], with dry eyes and skin rashes the most common physical burden. Patients and caregivers also posted about their relevant mental and emotional symptoms [11], and how the physical burden of chronic GVHD diminished patients' quality of life, which was consistent with other qualitative studies [34,37].

Posts indicated that chronic GVHD causes emotional distress, with feelings of anxiousness commonly mentioned, which was consistent with another study [38]. Overall, these findings highlight that patients may need further support through specialist care and mental health services to address the psychosocial challenges associated with chronic GVHD, in line with the results of a recent European Lymphoma Coalition and Eurograft advisory board and review [39,40].

While the socio-economic impact of chronic GVHD has been previously described [14,15], in this study, patients and caregivers commented directly on the financial burden of chronic GVHD. In addition, they gave insight into difficulties they may face while navigating financial support, which emerged as a relatively novel finding, in line with a previous report that approximately one-third of patients with chronic GVHD had insurance claims for treatment and laboratory tests rejected [41].

Steroids were the most commonly discussed treatment, which was in line with a previous GVHD SML study [34]. Several side effects were highlighted, but any results related to side effects should be interpreted cautiously as side effects could not be attributed to specific treatments. Trauma was the most commonly mentioned emotional burden in treatment-related posts. Overall, these results highlight the need for enhanced supportive care and therapeutic options that aim to alleviate the disease and/or treatment burden of patients, which was in line with previous reports [34].

Social media can help connect patients who are geographically distant [42]. Patients and caregivers actively sought support from online communities to cope with the unpredictability of chronic GVHD and navigate the complexities of the medical system and government programs. Posts mentioned the importance of finding doctors who are familiar with the unique challenges of chronic GVHD. In line with this, the benefits of managing chronic GVHD through a multi-disciplinary team have been previously described [30].

Nearly 20% of all posts included in the qualitative analysis set were from caregivers. However, only 4% referred specifically to caregiver burden. These posts emphasized their challenges, both emotional and social, and described the financial strain, isolation, and emotional exhaustion related to their caregiver role, which was consistent with what has been previously described [43]. While these insights help further characterize the caregiver experience, posts related to caregiver burden only represented a small proportion of posts in the chronic GVHD online discussion, and future caregiver-focused SML studies may provide more analytical insights.

Strengths and Limitations

The population of this study was limited to patients and caregivers with social media posts in the United States, which affects the study's generalizability as it only represents a sample of patients with chronic GVHD who used social media during the time frame of the study. Due to the study design and nature of the SML methodology, there are limited demographic and clinical data that can be collected, which impacts the ability to stratify findings or assess whether certain populations (e.g., older patients, non-English speaking patients or those who do not have social media) were underrepresented or not captured.

It was not possible to confirm whether the symptoms mentioned in the posts were from side effects of treatment or organ-specific chronic GVHD manifestations. Notably, no posts explicitly referenced urogenital manifestations of chronic GVHD, despite their known clinical relevance [44]. Some posts discussed the impact of chronic GVHD on patients' sex lives and relationships; however, specific symptoms were not discussed

at length, perhaps reflecting stigma or privacy concerns that discourage discussion on social media. Pulmonary manifestations accounted for 8% of posts in the qualitative analysis set. Chronic pulmonary GVHD is associated with significant morbidity [45,46], which suggests that patients with pulmonary involvement may have been limited in their ability to engage in online discussions. This may also reflect the retrospective nature of the study design, where only patients who survived long enough to post during the study time frame would have been captured, whereas insights from patients with more severe disease trajectories would not have been captured. Additionally, there may have been a lack of recognition that pulmonary symptoms were related to GVHD. In contrast, skin and eye symptoms were the most frequently mentioned, likely because they are more visible, easier to describe, or more commonly discussed in public forums. This may have affected the thematic analysis toward these organ systems. Overall, this study is limited by the social media posting patterns of patients with chronic GVHD and their caregivers which does not capture the full chronic GVHD experience.

The study methodology was limited by the fact that only publicly available posts were analyzed. Different discussions and issues may have been highlighted by patients and caregivers in private groups and posts, as highlighted above, and Facebook groups for patients with specific conditions have been reported to contribute to peer-to-peer support [47]. Due to adherence to privacy regulations, it was not possible to determine if specific posts were made by a single individual or multiple unique individuals, particularly in the qualitative analysis set where some insights were generated from a small ($<$20) number of posts. The presence of a single individual making multiple posts may have confounded these results. In addition, the search syntax used may have excluded relevant posts from the data set. Expanding the search syntax to include terms such as “shortness of breath,” “bronchiolitis obliterans,” “urinary issues,” or “vaginal dryness” may improve thematic coverage. Furthermore, as posts were manually coded to determine whether they were authored by patients or caregivers, some misclassification may have affected the accuracy of thematic attribution. Moreover, since the AI-driven QRT was trained on predefined themes, it may have failed to detect or cluster symptom domains not included in the training set. Finally, using contextual cues to assess whether a post was related to acute GVHD may have resulted in the inclusion of posts with ambiguous contexts. Future studies may benefit from using a combination of SML methodology and qualitative interviews with patients and their caregivers to obtain a more comprehensive understanding of their emotions, including sentiments that may not have been expressed in a public manner such as social media. The use of multiple data sources would also act to verify some of the themes identified through SML. Furthermore, additional publications on more recent social media data would capture updated trends in social media use and changes in the patient and caregiver posting behavior as their disease experience changes or is affected by other factors such as new treatments.

CONCLUSION

This study captured the opinions of patients with chronic GVHD and their caregivers, providing a unique perspective into the profound challenges and unmet needs faced by patients and their caregivers that are not recorded through traditional patient-reported outcome measures and clinical trial endpoints. There is a need for improved access to more effective treatments and support systems to decrease the burden of chronic GVHD in both patients and caregivers and improve their quality of life.

DECLARATION OF GENERATIVE AI AND AI-ASSISTED TECHNOLOGIES IN THE MANUSCRIPT PREPARATION PROCESS

The authors acknowledge the use of AI for data analysis. A closed, privately owned, and secure generative AI platform was used in addition to NVivo™ qualitative data analysis software to conduct the SML. The authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

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SUPPLEMENTARY MATERIALS

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