Received: 29 January 2024 | Revised: 25 April 2024 | Accepted: 7 May 2024

DOI: 10.1002/mgg3.2467

Molecular Genetics & Genomic Medicine Open Access WILEY

ORIGINAL ARTICLE

Social media use by patients with hypermobile Ehlers–Danlos syndrome

Colin M. E. Halverson[1,2,3,4,5] | **Tom A. Doyle**[1] | **Samantha Vershaw**[1]

[1]Department of Medicine, Center for Bioethics, Indiana University School of Medicine, Indianapolis, Indiana, USA

[2]Department of Medicine, Indiana University School of Medicine, Indianapolis, Indiana, USA

[3]Department of Anthropology, Indiana University, Indianapolis, Indiana, USA

[4]Regenstrief Institute, Indianapolis, Indiana, USA

[5]Charles Warren Fairbanks Center for Medical Ethics, Indianapolis, Indiana, USA

Correspondence
Colin M. E. Halverson, Department of Medicine, Center for Bioethics, Indiana University School of Medicine, Indianapolis, IN, USA.
Email: chalver@iu.edu

Funding information
National Human Genome Research Institute

Abstract

Background: Patients with uncommon genetic conditions often face limited in-person resources for social and informational support. Hypermobile Ehlers–Danlos syndrome (hEDS) is a rare or underdiagnosed hereditary disorder of the connective tissue, and like those with similar diseases, patients with hEDS have begun to turn to social media in search of care and community. The aims of our study were to understand the usage habits and perceptions of utility of social media use for patients with hEDS in order to formulate suggestions for how clinicians may best engage these and similar patient populations about this topic.

Methods: We conducted both a quantitative survey and qualitative interviews with patients who had received a robust clinical diagnosis of hEDS.

Results: Twenty-four individuals completed the initial survey, and a subset of 21 of those participants completed an interview. Through thematic analysis, we identified four primary themes related to their experience with social media: (1) befriending others with their disease, (2) seeking and vetting information, (3) the risks and downsides of social media use, and (4) the desire for clinicians to discuss this topic with them.

Conclusion: We conclude by proposing five suggestions that emerge empirically from our data. These proposals will help clinicians engage their patients regarding social media use in order to promote its potential benefits and circumvent its potential harms as they pursue support for their hereditary condition.

KEYWORDS

Ehlers–Danlos syndromes, patient perspective, qualitative research, social media

1 | INTRODUCTION

Hypermobile Ehlers–Danlos syndrome (hEDS) is a hereditary disorder of connective tissue and is characterized most prominently by chronic musculoskeletal pain and fatigue as well as joint subluxations and dislocations (Malfait et al., 2017). While it has traditionally been considered a rare disease, others have suggested it may simply be underdiagnosed (Aubry-Rozier et al., 2021; Castori, 2012; Demmler et al., 2019). Like patients with other similar diseases, patients with hEDS encounter a lack of information about their diagnosis, minimal local

clinicians with relevant expertise, and few possibilities for in-person community-building (Halverson et al., 2021). This population additionally experiences a particularly long diagnostic odyssey, even relative to patients with rare diseases (EURODIS, 2007; Halverson et al., 2021; Kalisch et al., 2020), and often encounters antagonistic relationships with their clinicians (Bennett et al., 2019; Halverson, Penwell, & Francomano, 2023; Langhinrichsen-Rohling et al., 2021), making their experiences in seeking healthcare particularly challenging. Moreover, symptoms of the condition may impose barriers to patients' physical ability to attend in-person support groups or scientific conferences (Halverson, 2024), further limiting their access to information necessary for promoting their health.

Faced with a lack of knowledgeable local clinicians or patient communities, individuals with rare diseases are increasingly turning to social media (SoMe) to make use of global networks of care and information (Yabumoto et al., 2022). These platforms have the potential to provide informational, social, and medical support for populations that are otherwise too small and dispersed to have such access (Barton et al., 2019; Deuitch et al., 2021; Van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008). However, they may also be unregulated in terms of validity and utility, and their use therefore also entails potential risk for patients (Deuitch et al., 2021). Due to their protracted diagnostic odysseys and often physically limiting symptoms, patients with hEDS may be particularly positioned to turn to SoMe.

It is especially concerning, then, that studies have found that clinicians rarely discuss SoMe use with their patients (DeLuca et al., 2012; Deuitch et al., 2021), even though they desire training in how to do so appropriately (Bautista et al., 2021). The only other published study on SoMe use among patients with EDS (Ashtari & Taylor, 2022) likewise found that clinicians do not provide the guidance this population needs to make use of online resources effectively, appropriately, and safely. For that reason, we undertook a pre-survey and an in-depth, qualitative interview study to understand how these patients utilize SoMe, and what barriers and risks they encounter in these online spaces. In what follows, we analyze the results of that study and provide suggestions for clinicians on how best to undertake such critical discussions with their patients.

2 | METHODS

2.1 | Ethical compliance

This qualitative study was conducted with the approval of the Indiana University Institutional Review Board. Participants were required to provide both written and verbal informed consent before their involvement in the study.

2.2 | Participants and procedures

The study was conducted between April and August 2023 and involved individuals recruited from the Indiana University Ehlers–Danlos Clinic. To be included in the study, participants had to meet specific criteria, including having a robust clinical diagnosis of hEDS, a minimum age of 18 years, and proficiency in the English language. All eligible candidates from the clinic who had agreed to be contacted regarding research were invited to participate in the pre-survey. Pre-surveys were meant to provide support for the construction and interpretation of the subsequent qualitative interviews and were not intended to reach a number relevant for statistical validity.

Interviewees were selected from pre-survey respondents through convenience sampling, which was carried out irrespective of SoMe utilization statistics. This method ensured that both individuals who intensively utilized these platforms and those who did not were included in the study. As appropriate to qualitative research of this nature, the sample size was not pre-determined (Saunders et al., 2018), and instead, recruitment from the pre-survey cohort was closed when thematic saturation was achieved (Strauss & Corbin, 1998).

2.3 | Instruments

The pre-survey encompassed various aspects of participants' SoMe engagement. It collected information about the SoMe platforms participants actively used, the frequency of their usage, their attitudes toward these platforms, their perception of the platforms' impact on mental health, the role of SoMe in encountering misinformation and conducting research, as well as the influence of online social life and networking. Questions for the pre-surveys were selected after an extensive review of the literature. The pre-survey instrument is available in the Data S2.

The interview guide was structured into sections to explore participants' experiences and perspectives regarding their SoMe usage. It explored how they utilized SoMe, their emotional and cognitive responses to such usage, the ways in which SoMe influenced their perceptions and understanding of EDS, its impact on their social lives and advocacy efforts, and their interactions in online support groups and communities. These questions were likewise derived from our literature review and informed by the pre-survey responses,

addressing salient issues highlighted by previous research into SoMe and rare-disease communities (Koinig & Diehl, 2020; Morgan & Subbiah, 2023; Yabumoto et al., 2022; Zhu et al., 2021). The interview guide is available in the Data S2.

Interviews were conducted over the phone by one researcher (CMEH), who is a medical anthropologist and bioethicist and has doctoral-level training in qualitative research methods. During the interviews, the interviewer took detailed field notes. Additionally, each interview was audio-recorded and transcribed by MacWhisper, a HIPAA-compliant, AI-based transcription program. Researchers uploaded transcripts to Dedoose, a mixed-methods analysis tool (Dedoose Version 9.2.007; Los Angeles, CA). Thematic analysis based on the flexible, recursive phases outlined by Braun and Clarke (2006) was selected as the best method to investigate these interviews qualitatively and systematically (Braun & Clarke, 2023; Campbell et al., 2021; Holstein & Gubrium, 1997). This method allows the search across interviews for patterns of meaning. We began by reviewing the interview transcripts and familiarizing ourselves with similarities and potential points of interest. Then, we generated an initial coding tree, which we refined through discussion. As this is a recursive method, we moved back and forth between coding and reviewing. We then sorted the codes into themes, which we named, reviewed, and defined as a group. We finally produced the write-up of the report.

3 | RESULTS

3.1 | Sample description

Surveys were completed by 24 individuals, 21 of whom went on to complete a subsequent interview. The average interview length was 49 minutes, with a range of 21 to 83 minutes. The average age of participants was 39, with a range of 19 to 63 years. The majority identified as cis-female and White. Other participant demographics are summarized in Table 1.

In the interviews, we identified four primary themes. (1) We found that SoMe was a major source for meeting and befriending others with hEDS. (2) Participants also used SoMe to seek information about their condition, though they paid special attention to vetting information encountered in these virtual spaces. (3) They detailed the risks and downsides of SoMe use from their own experience. And finally, (4) they stated that clinicians did not discuss SoMe use with them despite the perceived utility of such conversations. We provide a deeper analysis of these themes in the remainder of this section. Personal details have been redacted, but a unique number has been assigned to each participant and is given after respective quotations.

TABLE 1 Participant demographics.

	Survey participants ($N = 24$)	Interview participants ($N = 21$)
Gender		
Female	20 (83%)	18 (86%)
Nonbinary	3 (13%)	2 (10%)
Male	1 (4%)	1 (5%)
Age		
Average	40	39
Range	19–63	19–63
Race		
Non-Hispanic White	22 (92%)	20 (86%)
Hispanic	1 (4%)	0
More than one race	1 (4%)	1 (5%)
Education		
High school	4 (17%)	4 (19%)
Some college or associate degree	4 (17%)	3 (14%)
Bachelor's degree	10 (42%)	9 (43%)
Graduate degree	6 (25%)	5 (24%)

3.2 | Usage statistics

The majority of survey respondents reported opening a SoMe site or application two or fewer times per day (67%). Additionally, nearly half of survey respondents (48%) reported spending less than an hour per day using SoMe, and none reported using it more than 4 h per day. The slight majority of our interviewees felt that the amount of time they spent on SoMe was appropriate for them personally (53%), while the remainder felt that it was "too much" (47%). (None felt that it was too little or wished they would spend more time using these platforms.) Most survey respondents (71%) said they try to limit their time on SoMe. The majority (62%) were members of two or fewer online groups related to hEDS. A noteworthy minority, however, reported much higher utilization: 14% were members of 12 or more hEDS groups, and 10% reported checking SoMe 11 or more times per day.

Accounts on Facebook and Instagram were the most common among our interviewees. On average, they had 3.4 active accounts on different SoMe platforms. For more information on platform usage, see Table 2. Participants used Facebook to become members of private and public groups related to EDS. Their use of these groups is

TABLE 2 Five most common social media accounts.

1. Facebook	20 (95%)
2. Instagram	15 (75%)
3. TikTok	7 (33%)
3. Twitter/X	7 (33%)
5. Snapchat	4 (19%)

discussed in more detail below. On Instagram, TikTok, and Twitter/X, they followed clinicians and researchers to learn more about their condition. One quarter said they followed hEDS influencers, that is, people who use SoMe in a professional or semi-professional manner as a means to disseminate information and promote products and services related to hEDS. Twitter/X in particular was seen as a place to find "highly curated information" related to their condition (06), including scientific and academic news relevant to hEDS.

3.3 | Theme 1: Social benefits of life online

The majority of our interviewees (90%) reported that their symptoms affected their ability to socialize as they desired. One woman turned to SoMe "when I was completely disabled," since it remained enjoyable for her even when she was too weak to hold up a book to read (20). Another reported, "Usually, you're sitting around because you can't do anything, so you can still be on social media" (03). "It was a huge place of escapism when I got really sick with EDS," acknowledged one young woman (04). Similarly, one woman stated that she primarily uses SoMe when "I'm having a really bad day" in terms of her chronic pain, because she is physically unable do anything else at that time (08).

The majority of survey respondents reported that they somewhat or fully enjoy checking their SoMe accounts (76%), finding it a satisfying or rewarding activity. SoMe use was a source of pleasant diversion. Several participants mentioned the Facebook group "EDS Zebra Memes," a community whose purpose is to post funny images addressing issues faced by this patient population.

However, SoMe provided more than just escapism. Many participants also noted its value in raising awareness of EDS. For instance, several interviews took place during EDS and hypermobility spectrum disorders (HSD) awareness month (May), and participants described both scrolling through and contributing to that month's influx of posts related to the experience of having one of these conditions. The ability to disseminate and consume this information and at this scale was seen as a significant benefit of these global communities.

The rarity of our participants' condition meant that many of them had not encountered another person with the same clinical diagnosis in their offline life. "With something like EDS," one woman (04) explained, "you don't typically just run into someone on the street." SoMe, thus, was a major way for our participants to connect with others who shared their condition, and the majority (76%) felt that it had helped them meet other people with hEDS.

Moreover, the slight majority of our participants (56%) described befriending other patients through SoMe: "There are people who I would consider very, very good friends – best friends – who I've met through [Facebook] support groups" (04). One woman, feeling overwhelmed after her diagnosis, joined just such a group. She subsequently met with another member for lunch, and afterward, they started an in-person, local support group together (11). However, only 37% said that they had used SoMe for the explicit purpose of improving their social lives; virtually mediated friendships were primarily spontaneous and serendipitous, albeit relatively common. "I do have friends that I have on social media that I've never met in person, but it wasn't like I went on social media just looking for [new friendships]" (05). One woman said of another patient, "We met at one of our [EDS] conferences or something and became Facebook friends, and closer friends as the years [went] on" (21). When asked whether SoMe played an important role in their relationships, there was an even split among participants, with 48% agreeing, 48% disagreeing, and the remaining 4% equivocating.

Seeing and interacting with others with the same condition was a psychosocially significant experience for our participants. For many, this was positive: As one young woman explained, SoMe had given her "a place where I can know people like me. [...] You can accept yourself more because you don't always feel like you're the person who has something wrong with you. When you're in a room full of other zebras, you're normal" (05). "It's nice to be able to say to a friend, 'My rib slipped out again,' and then the friend can say, 'I am so sorry. I know exactly how you feel,'" stated a young woman (04). Another young woman described validation in seeing that she was not alone in experiencing disabling symptoms and that "other people are struggling with this, too" (07). "If you don't know people with illness in real life, even just reading that other people are going through the same thing or having the same symptoms [...] is nice," another participant explained (01). One interviewee said that she believed this aspect of SoMe had been useful for her son, who also has an hEDS diagnosis: "It helps him realize that the symptoms he experiences are real and treatments that people have given him are also beneficial, because I see him a lot of times not taking care of himself as much as he should"

(08). One woman who has slowly withdrawn herself from SoMe stated that even though "I don't actively participate in it, I think that knowing that people are being seen and they're finding each other and they're finding support in each other, that's a great thing" (12).

Nonetheless, participants persisted in placing greater weight on relationships that featured an offline component. "Those I have never [met], I do feel that it puts them in an outer circle," one woman (21) explained: "Maybe it's my gray hair showing, [but] I'm just feeling closer to somebody if I've actually had an in-person conversation and done things with [them]." In particular, participants found platforms on which people use pseudonyms (such as Reddit or Inspire) to be less conducive to developing meaningful relationships.

Many participants stated that, ideally, they would use SoMe merely to complement their offline social life. One participant said she used SoMe to "supplement, not necessarily improve" her social life (13). "I do think it has a place, but I think it definitely shouldn't be your first choice," another woman explained (20). Some values of "offline" life were seen as irreplaceable: "It's always nice to be able to give someone a hug," another woman noted (04). However, due to chronic pain-related disability (as discussed above), participants sometimes viewed SoMe as the only possible source for maintaining a social life.

3.4 | Theme 2: Information seeking and vetting

Participants frequently turned to SoMe in pursuit of information about their condition. Eighty-nine percent said that they had used these online resources to research their condition and its potential care. Interviewees described SoMe as providing accessible, wide-ranging information about care and experiences of other patients, as well as the potential for more empathetic spaces for sensitive conversations than they had come to expect from the healthcare system. However, they tempered this enthusiasm with significant concerns about the reliability of the information they encountered on these platforms.

Five participants stated that they first learned of hEDS through SoMe. They experienced it as a sort of "eureka" moment: "I had never heard of [hEDS] before," one participant said, but the way it was described on a TikTok video matched a lot of their symptoms (19). They subsequently brought the possible diagnosis to their primary care physician and were given a clinical diagnosis. Similarly, another interviewee had used a SoMe platform to solicit the community to suggest diagnoses for her symptoms, and "in less than 72 h," hEDS had been identified as the appropriate label for her condition (15). She likewise brought this candidate diagnosis to a clinician for confirmation. One woman held SoMe in particular esteem for the same reason: "It was lifesaving [...] If there was no Facebook or social media, I don't know that I would be in as good of shape as I am" (11).

Seeking information online was seen as particularly beneficial for some patients who had "a deep discomfort with doctors" after repeated negative encounters (04). Getting advice from others online was therefore preferable to asking a clinician, since it allowed participants to avoid anxious and potentially retraumatizing hospital visits. It also provided anonymity in asking about sensitive topics that might make patients feel uncomfortable were they to seek this information in person: "Social media has been able to help with stuff that's more stigmatized," one participant explained (19). Topics in this category included advice about safe sexual practice for patients with symptomatic hypermobility and the use of complementary and alternative therapies to manage chronic pain.

However, participants also harbored prominent skepticism about the information they encountered in virtual spaces. Users need to take all information with "a grain of salt every time, maybe a full pile of salt" (04), many participants insisted. "Take everything with a grain of salt and do your own homework," stated another (11). While participants overwhelming (90%) believed they could judge the reliability of information they found on SoMe, the majority (64%) chose not to rebut other users who posted information they found dubious. Instead, our interviewees relied on moderators in EDS groups to address such potential misinformation. "This isn't science-backed," moderators would reportedly caution (05). Moderators were seen to prevent users from saying things like, "I take turmeric and it helps with inflammation" (03). Some interviewees regarded moderators as essential for the proper vetting of information, but they worried that other patients—especially those newly diagnosed—did not have the requisite health literacy to recognize misinformation: "There has to be a specific base level of education that you have to have to be able to weed out the trash" (20).

The spreading of misinformation was seen not as arising "from a nefarious place," as one interviewee put it (21), but rather from the lack of the necessary "educational level to understand the information that is in reliable sources to be able to give accurate information in their answers. But they want to help, so they're very quick to answer." Another woman stated that emotions related to diagnosis and disability play a role in other users' spread of misinformation: "I know that the child is probably sick, and the mom is probably overwhelmed with grief and has information mixed up," she said (14). She treats these posters with care: "I tread lightly because I know that this woman is probably floundering and grasping at straws."

3.5 | Theme 3: Risks of social media use

Only a third (33%) of survey respondents felt that using SoMe was a waste of time, but its ultimate role in patients' lives was complicated. The majority equivocated (76%) as to SoMe's impact on their emotions after logging off, reflecting overall ambivalence toward these platforms. (Only 14% reported feeling better and 10% feeling worse after using SoMe.) Participants identified several reasons beyond merely the dubious information available in these groups for this more complicated perspective, including bad-faith and overtly bad actors, witnessing the struggles of living with hEDS, and what they viewed as the damaging online self-presentation of some other patients.

Only four interviewees (21%) stated that they had encountered a "troll," or someone who intentionally disrupts and undermines civil discourse, in one of these groups. For instance, one participant described a user who had joined a group apparently with the sole purpose of mocking patients with EDS: "Oh, I need this mobility aid. I'm so sick; I'm so dainty," the troll reportedly wrote (19): "Oh, you're just faking your illness." "I just doubt myself a lot more, because a lot of people [on SoMe] just don't think it's real" said one woman (16).

While trolls were reportedly rare, participants nonetheless encountered others online whom they felt were ill-intentioned. As a particular source of such harassment and distress online, several participants mentioned a specific subreddit, or discussion forum organized around a shared interest on the immensely popular website Reddit. Users of this specific subreddit, called r/illnessfakers, publicly post information about and images of influencers as well as private individuals who discuss their chronic illnesses on SoMe. In particular, our interviewees noted attacks on individuals who had stated online that they have hEDS. "They say they're making things up and they're just flexible," one participant explained, stating that the users of the subreddit go on to dox and harass these people and their families (16): "It's intensely sick. I can't think of something more troubling." One interviewee noted that people targeted by this subreddit have reportedly committed suicide as a result of the influx of abuse.

It was not just outsiders to the hEDS community who caused stress for our interviewees. Some features of EDS groups themselves felt stressful and burdensome to participants. While seeing others with similar symptoms and diagnoses was often validating and even reassuring, as discussed above, dwelling in these spaces and witnessing others' struggles in such a condensed fashion can be scary and worrisome, they told us. "I feel like I cannot separate myself from other people's baggage," one woman explained (20), "I take on their emotional stress, and it ends up being more work than it is support for me." Another interviewee described this precarious balance as: "Posts about EDS were really validating in a way that I was like, 'See, I'm not making it up!' [but] when you see other people throwing in the towel, that can be frustrating" (10). Another participant stated that for this reason, she has actively limited her use of SoMe: "In the beginning, I thought I needed to be a part of every group and [then] realized that I don't" (18).

One young woman said that she did not believe that people intended to be overwhelming or misrepresent their conditions in their posts, but "I think they are maybe making things a little bit more dramatic than they are. I think people get online when they're in a flare-up or get online when something bad has happened and they're emotionally driven" (07). Participants identified this problem as unique to the dynamics of SoMe and its engagement algorithms.

> When you're only posting yourself sick, it becomes kind of a hopeless situation for everybody [...] That's what gets the most views. You're not going to post when you were able to go outside and go on a nice walk. [...] Then your chronic illness is not only an illness, but it's a job. (19)

In a similar vein, interviewees mentioned a worry that hEDS influencers performed "party tricks" on video-sharing platforms like Instagram and TikTok. These SoMe personalities take advantage of their hypermobility and bend on camera in ways that are considered dangerous for patients with connective tissue disorders, in order to garner greater engagement. Our participants worried that such behaviors inspired others to risk their own health for internet fame.

Another concern participants expressed was the "fear of missing out," or "FOMO" as several interviewees dubbed it, witnessing lives not constrained by chronic illness. "I just look at other people who are having all these great experiences, and I'm like, that would be awesome if I could do that, but I can't," one young adult explained (02). Witnessing such positive experiences was also seen as a potential stressor of SoMe use.

3.6 | Theme 4: Conversations with clinicians about social media

Many participants noted that it would have been helpful for a clinician to address SoMe use early into their diagnostic odyssey or directly after their diagnosis. Importantly, the vast majority of participants (78%) said that no clinician had discussed SoMe with them at any point. Of the minority who had experienced such

conversations, they were reportedly either cursory or a brusque directive not to get involved in these online communities. One interviewee who found SoMe support groups incredibly valuable said that at the time of her diagnosis, she "didn't even realize something like that [SoMe support groups] existed" (03). She felt that she would have benefited from knowing about them immediately rather than waiting to "stumble across" them. She wished that at that critical and anxious period following her diagnosis, she had had access to the psychosocial support she has since found in these groups. Another woman indicated that it would be useful for patients to be able to discuss with clinicians the information they find on SoMe. She hoped clinicians would be "open to talking about anything that the patient learns on social media" so that they could "point them in a couple of directions [the clinicians] trust" (10). Additionally, one woman wished a clinician would have warned her about the potential dangers of SoMe and told her that "even though [SoMe] can be helpful, [...] having that information overloading a person can be overwhelming" (17).

4 | DISCUSSION

Previous studies have examined SoMe use among patients with rare disease broadly (Yabumoto et al., 2022), among their guardians (Barton et al., 2019; DeLuca et al., 2012; Deuitch et al., 2021), and among rare-disease researchers and advocates (Morgan & Subbiah, 2023; Reason et al., 2021; Walker, 2013). However, our study is one of the first qualitative studies to explore the role of SoMe in the lives of patients with hEDS (Ashtari & Taylor, 2022). Critically, it is also among the first to investigate such patients' perspectives on how clinicians should address this topic with patients. Understanding the views and use habits of patients with hEDS is particularly important given the notoriously difficult diagnostic odysseys they face (Bennett et al., 2019; Halverson et al., 2021) and the potential for SoMe to provide this population with unique opportunities for networking and research.

Our interviews have revealed four primary themes: (1) the importance of SoMe in socializing, (2) knowledge seeking and vetting practices, as well as (3) the risks of SoMe use. Finally, our interviewees have provided their perspectives on (4) the value of discussing SoMe with their clinicians. Our results offer clinicians guidance for how best to address the topic with patients living with hEDS and similar conditions.

Many of our participants had not encountered another person with hEDS, a relatively rare or at least uncommonly diagnosed disorder, before turning to SoMe. While family and friends are important emotional and social resources, patients with such diseases receive a unique benefit from interacting with others who have intimate experience with shared symptoms and diagnoses (Rosenthal et al., 2001; Van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008). Such interactions can be incredibly beneficial, both psychologically and medically (Deuitch et al., 2021), with one study even finding a 67% decrease in disease-related anxiety after participation in an online support community (Attai et al., 2015). Given that the rare-disease experience is often characterized by social isolation (Currie & Szabo, 2020), SoMe can also help in networking and organizing to promote research and activism (Morgan & Subbiah, 2023; Reason et al., 2021). Specific groups and accounts can also simply provide a pleasant diversion and sense of communitas (Turner, 1969), sharing humorous images and quips with others in a rare moment of comradery with those who share similar disease experiences. Support group participation, even online, has been shown to empower patients and improve their sense of well-being (Van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008).

The vast majority of our interviewees (90%) reported being limited by the symptoms of hEDS in their ability to socialize in-person as they desired. Such barriers to accessing in-person emotional and educational support have been reported by previous studies on other conditions as well (Stephen et al., 2013; Ussher et al., 2008). While essential anonymity and abstraction may underscore all sociality (Simmel, 1972), our participants identified that a limitation of SoMe-mediated relations was a lack of personal closeness. Sites that allowed for or required less anonymity (for example, by providing actual names or photographs, or at least screen names and avatars) were seen as more useful in promoting social support. Thus, while placing a greater weight on in-person relationships overall, SoMe served a vital role in enabling our participants to maintain a social life despite chronic pain and other disabling symptoms. While not a theme that emerged from our interviews, attention to privacy in sharing personal information and experiences has been reported by other studies as a critical concern (Deuitch et al., 2021; Rocha et al., 2018).

The majority (89%) of our participants had used SoMe to improve their understanding of their condition and its management. A lack of local clinicians with expertise in—or even exposure to—rare or underdiagnosed diseases dramatically increases the importance and value of global, online resources in the development of patients' self-understanding and self-advocacy. In point of fact, some of our interviewees even credited online research with informing them about hEDS in the first place. The democratization of health information and the ability to

crowdsource solutions to complex medical cases may be an exceptional boon offered by SoMe. However, even after receiving a correct diagnosis, these patients continue to face limited reliable and readily accessible local resources for the management of their conditions (Stoller, 2018), suggesting the enduring utility for information-seeking online.

While our participants were adamant that information encountered on SoMe be taken with "a grain of salt," they felt confident that they could judge its reliability. They typically preferred to rely on group moderators to prevent the spread of misinformation rather than to correct other users themselves. This may be due to fears of cyberbullying and other web-based harassment, which have been found to prevent clinicians from correcting misinformation when they encounter it online as well (Bautista et al., 2021). Other work suggests that reliance on moderators may not be sufficient, as health misinformation is particularly prevalent on SoMe (Wang et al., 2019).

Our participants saw the use of these platforms as contributing not only to their individual awareness of hEDS but also to the awareness of the general public. Some participants felt empowered with the ability to access a wider audience, and campaigns such as EDS and HSD Awareness Month were felt to reduce stigma, influence public perception, and even direct health policy. Relatedly, one study found that nearly three-quarters of survey respondents reported plans to increase their advocacy efforts after participation in an online support community (Attai et al., 2015).

For some of our participants, turning to SoMe for hEDS-related information felt safer and less judgmental, even while such information was not seen as equally valid on its face as consulting a clinician in person. In part, this was due to "a deep discomfort with doctors" resulting from the lasting, trauma-like symptoms of repeated negative encounters with clinicians, something characteristic of the experience of patients with hEDS (Halverson, Penwell, & Francomano, 2023). Additionally, researching sensitive topics such as safe sex practices for individuals living with symptomatic hypermobility as well as complementary and alternative pain management techniques were mentioned, echoing previous work demonstrating a level of distress in discussing these topics with healthcare providers (Doyle & Halverson, 2022).

Interviewees expressed that overall, the people they encountered in hEDS SoMe groups were well-intentioned and well-behaved. However, participants harbored a fundamental ambivalence toward SoMe arising from witnessing others with similar health-related experiences. While it was often at first radically validating, spending too much time reading about or observing others' struggles could become highly upsetting. Participants saw particular features of the online ecosystem as promoting the production of these distressing images and text—it is "what gets the most views"—incentives that are not present in the same way in in-person social dynamics. This duality of witnessing has been expressed by rare-disease patients regarding their encounters online as well (Deuitch et al., 2021). Relatedly, SoMe's use of engagement algorithms was blamed for encouraging unsafe behaviors related to the display of hypermobility as a sort of "party trick" and thus endangering impressionable users. This aligns with findings from other studies which identified algorithmic curation as potentially harmful for users (Harriger et al., 2022; Milton et al., 2023).

Finally, it is important to underscore that our findings contradict certain stereotypes about SoMe use of people living with hEDS. In fact, even some of our interviewees expressed stereotypes of this patient population as overly active and potentially incautious users of these platforms. However, thanks to our sampling strategy, we managed to capture the voices and experiences of individuals from across the usage spectrum, and we found that our participants do not utilize SoMe with exceptional frequency relative to the general population. Moreover, they were thoughtful about their SoMe habits and critical of the information they encountered online. Therefore, we suggest that impressions of this population's SoMe habits are influenced by a sort of overrepresentation bias in which the most active posters become the most visible. This leads observers to the erroneous belief that the posts they see are representative of a majority of the community. Our study found that these highly active users do not necessarily reflect the attitudes and opinions of the majority of the hEDS SoMe community. The majority of our participants preferred to "lurk" rather than post, potentially leading them to be less visible in the broader SoMe discourse on hEDS. That said, "lurkers" have nonetheless been shown to benefit from SoMe use in the same ways as more active users (Van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008), even while not impacting public perceptions of the community to the same extent.

4.1 | Limitations

Our participants' demographics were representative of what is known of the overall population that has managed to receive an hEDS diagnosis. However, the fact that there is a significant gender skew may mean that our data are limited in terms of the diversity of views captured, as SoMe use has been shown to vary based on that dimension of personal identity (Muscanell & Guadagno, 2012).

4.2 | Suggestions for clinicians

Our data demonstrate both clear benefits and challenges of SoMe use for patients with hEDS. Clinicians appear not to be discussing these important online resources, leaving their patients to navigate this tenuous balance alone. How should clinicians counsel patients with hEDS on the appropriate, effective, and safe use of these virtual spaces? Five suggestions emerge directly from the results of this study, supported by the explicit input of our interviewees, and may aid clinicians who commonly diagnose hEDS, such as geneticists and rheumatologists (Halverson, Penwell, Perkins, & Francomano, 2023), as well as primary care providers who provide supportive and follow-up care.

First, it is crucial for clinicians to *establish an open and non-judgmental space for conversation*. Patients should feel comfortable raising and discussing their SoMe experiences, questions, and concerns, including information that they have encountered in these online communities. We suggest that clinicians begin conversations regarding SoMe by establishing its potential usefulness and acknowledging its possible importance: "I've learned that social media can be a useful resource for patients with EDS. Would you like to discuss social media with me today as a part of your visit?"

Such openness is critical given that the information found online may not be evidence- or even consensus-based (Yabumoto et al., 2022). Therefore, our second suggestion is for clinicians to encourage *patients to engage in skepticism and critical thinking when using SoMe*. The reliability and relevance of information found in these spaces must be taken "with a grain of salt," as several of our participants noted. Relatedly, patients should be counseled not to use SoMe to seek cures but rather to help develop effective coping strategies and improve their quality of life, and they should be encouraged to bring these suggestions to their clinicians. A helpful way a clinician can reinforce this skepticism and critical thinking is by allowing patients to vet certain information they find on social media with them: *"There can be a lot of confusing information on social media. Have you encountered anything that you wanted to run by me or get my opinion on?"* Furthermore, clinicians should acknowledge the variability of hEDS presentations across individuals. What patients see on SoMe will not necessarily align with their own present and future experiences.

Third, if patients describe previous negative encounters with other clinicians, they may be counseled that *SoMe can help identify local and regional experts* who are both knowledgeable about and sensitive to hEDS care: "Social media can be a good place to find good clinicians who understand the unique challenges that patients with hEDS face."

Networking and friendship opportunities enabled by online spaces can be rewarding. They offer a platform for humor, socialization, and emotional support. But social support buffers taxing life circumstances—such as living with a rare or underdiagnosed disease—only insofar as it does not itself add inordinate stress and conflict (Lakey & Cohen, 2000). Thus, our fourth suggestion is that *if patients feel overwhelmed, they should reflect on which groups and what content they believe genuinely benefit their well-being* and interact only with them. Clinicians should inform their patients that SoMe use also has the potential to cause psychological distress and exhaustion: "I've read that social media can sometimes be overwhelming. It might be helpful to consider which groups and content are the most helpful and which might be better to unfollow or avoid." "Just keep scrolling," as one participant phrased it (01).

Finally, it is essential for clinicians to stress that *SoMe should complement rather than replace their offline social connections and support systems* insofar as possible. Patients should be encouraged to maintain strong relationships with friends, family, and clinicians where feasible: "We've learned that it is best when social media supplements in-person activities and relationships. What in-person activities and relationships can you pursue in addition to those on social media?" While such conversations may add time to the clinic visit, they have the potential to improve patients' appropriate and successful utilization of SoMe. By consulting these suggestions, clinicians can help patients to harness the distinctive benefits afforded by SoMe while minimizing potential risks and challenges.

AUTHOR CONTRIBUTIONS

Colin M. E. Halverson, Tom A. Doyle, and Samantha Vershaw each contributed to the conceptualization, analysis, drafting, and reviewing of this article. Colin M. E. Halverson additionally provided funding and conducting the interviews.

ACKNOWLEDGMENTS

The authors thank the study participants for sharing their experiences. We would also like to thank Dr. Clair Francomano for her support in our ongoing work on the lived experiences of patients with EDS. The research detailed in this publication was supported by the National Human Genome Research Institute of the National Institutes of Health (NIH) under award number 1K01HG012408. However, its content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

FUNDING INFORMATION

Research detailed in this publication was supported by the National Human Genome Research Institute of the National Institutes of Health under award number 1K01HG012408. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

The data underlying this article are qualitative in nature and consist of confidential interview transcripts. Due to the sensitive nature of the information shared by participants and ethical considerations, the data will not be made publicly available. This decision is in line with the principles of confidentiality and privacy outlined in the research ethics approval obtained for this study. Access to the data may be granted under specific circumstances and with explicit permission from the researchers. Researchers interested in accessing the data for further analysis or collaboration are encouraged to contact the corresponding author for inquiries regarding data access and sharing agreements. The authors are committed to ensuring the protection of participants' privacy and maintaining the confidentiality of the information gathered during the course of this study.

REFERENCES

Ashtari, S., & Taylor, A. D. (2022). The internet knows more than my physician: Qualitative interview study of people with rare diseases and how they use online support groups. *Journal of Medical Internet Research*, *24*, e39172.

Attai, D. J., Cowher, M. S., Al-Hamadani, M., Schoger, J. M., Staley, A. C., & Landercasper, J. (2015). Twitter social media is an effective tool for breast cancer patient education and support: Patient-reported outcomes by survey. *Journal of Medical Internet Research*, *17*, e188.

Aubry-Rozier, B., Schwitzguebel, A., Valerio, F., Tanniger, J., Paquier, C., Berna, C., Hügle, T., & Benaim, C. (2021). Are patients with hypermobile Ehlers–Danlos syndrome or hypermobility spectrum disorder so different? *Rheumatology International*, *41*, 1785–1794.

Barton, K. S., Wingerson, A., Barzilay, J. R., & Tabor, H. K. (2019). "Before Facebook and before social media...we did not know anybody else that had this": Parent perspectives on internet and social media use during the pediatric clinical genetic testing process. *Journal of Community Genetics*, *10*, 375–383.

Bautista, J. R., Zhang, Y., & Gwizdka, J. (2021). US Physicians' and Nurses' motivations, barriers, and recommendations for correcting health misinformation on social media: Qualitative interview study. *JMIR Public Health and Surveillance*, *7*, e27715.

Bennett, S. E., Walsh, N., Moss, T., & Palmer, S. (2019). The lived experience of joint hypermobility and Ehlers-Danlos syndromes: A systematic review and thematic synthesis. *The Physical Therapy Review*, *24*, 12–28.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.

Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a *knowing* researcher. *International Journal of Transgender Health*, *24*, 1–6.

Campbell, K., Orr, E., Durepos, P., Nguyen, L., Li, L., Whitmore, C., Gehrke, P., Graham, L., & Jack, S. M. (2021). Reflexive thematic analysis for applied qualitative Health Research. *The Qualitative Report*, *26*, 2011–2028. https://nsuworks.nova.edu/tqr/vol26/iss6/24/

Castori, M. (2012). Ehlers-Danlos syndrome, hypermobility type: An underdiagnosed hereditary connective tissue disorder with mucocutaneous, articular, and systemic manifestations. *ISRN Dermatology*, *2012*, 1–22.

Currie, G., & Szabo, J. (2020). Social isolation and exclusion: The parents' experience of caring for children with rare neurodevelopmental disorders. *International Journal of Qualitative Studies on Health and Well-Being*, *15*, 1725362.

DeLuca, J. M., Kearney, M. H., Norton, S. A., & Arnold, G. L. (2012). Internet use by parents of infants with positive newborn screens. *Journal of Inherited Metabolic Disease*, *35*, 879–884.

Demmler, J. C., Atkinson, M. D., Reinhold, E. J., Choy, E., Lyons, R. A., & Brophy, S. T. (2019). Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: A national electronic cohort study and case–control comparison. *BMJ Open*, *9*, e031365.

Deuitch, N. T., Beckman, E., Halley, M. C., Young, J. L., Reuter, C. M., Kohler, J., Bernstein, J. A., Wheeler, M. T., Undiagnosed Diseases Network, Ormond, K. E., & Tabor, H. K. (2021). "Doctors can read about it, they can know about it, but they've never lived with it": How parents use social media throughout the diagnostic odyssey. *Journal of Genetic Counseling*, *30*, 1707–1718.

Doyle, T. A., & Halverson, C. M. E. (2022). Use of complementary and alternative medicine by patients with hypermobile Ehlers–Danlos syndrome: A qualitative study. *Frontiers in Medicine*, *9*, 1056438.

EURODIS. (2007). Survey of the delay in diagnosis for 8 rare diseases in Europe (EurordisCare2).

Halverson, C. M. E. (2024). Social isolation: Physical symptoms leading to the erosion of a support network. In C. A. Francomano, A. J. Hakim, L. Henderson, et al. (Eds.), *Symptomatic: The symptom-based handbook for Ehlers-Danlos syndromes and hypermobility Spectrum disorders* (pp. 145–149). Elsevier.

Halverson, C. M. E., Clayton, E. W., Garcia Sierra, A., & Francomano, C. (2021). Patients with Ehlers-Danlos syndrome on the diagnostic odyssey: Rethinking complexity and difficulty as a hero's journey. *American Journal of Medical Genetics*, *187*, 416–424.

Halverson, C. M. E., Penwell, H. L., & Francomano, C. A. (2023). Clinician-associated traumatization from difficult medical encounters: Results from a qualitative interview study on the Ehlers-Danlos syndromes. *SSM—Qualitative Research in Health*, *3*, 100237.

Halverson, C. M. E., Penwell, H. L., Perkins, S. M., & Francomano, C. A. (2023). Comorbidity, misdiagnoses, and the diagnostic odyssey in patients with hypermobile Ehlers-Danlos syndrome. *Genetics in Medicine Open*, *1*, 1–8.

Harriger, J. A., Evans, J. A., Thompson, J. K., & Tylka, T. L. (2022). The dangers of the rabbit hole: Reflections on social media as a portal into a distorted world of edited bodies and eating disorder risk and the role of algorithms. *Body Image*, *41*, 292–297.

Holstein, J. A., & Gubrium, J. F. (1997). *Active interviewing. Qualitative research: Theory, method and practice* (pp. 113–129). Sage Publications.

Kalisch, L., Hamonet, C., Bourdon, C., Montalescot, L., de Cazotte, C., & Baeza-Velasco, C. (2020). Predictors of pain and mobility disability in the hypermobile Ehlers-Danlos syndrome. *Disability and Rehabilitation*, *42*, 3679–3686.

Koinig, I., & Diehl, S. (2020). Designing sustainable social media health communication campaigns for promoting rare diseases. In L. V. Costa & S. Oliveira (Eds.), *Advances in medical technologies and clinical practice* (pp. 113–153). IGI Global. https://doi.org/10.4018/978-1-7998-2088-8.ch003

Lakey, B., & Cohen, S. (2000). Social support theory and measurement. In S. Cohen, L. G. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 29–52). Oxford University Press.

Langhinrichsen-Rohling, J., Lewis, C. L., McCabe, S., Lathan, E. C., Agnew, G. A., Selwyn, C. N., & Gigler, M. E. (2021). They've been BITTEN: Reports of institutional and provider betrayal and links with Ehlers-Danlos syndrome patients' current symptoms, unmet needs and healthcare expectations. *Therapeutic Advances in Rare Disease*, *2*, 263300402110220.

Malfait, F., Francomano, C., Byers, P., Belmont, J., Berglund, B., Black, J., Bloom, L., Bowen, J. M., Brady, A. F., Burrows, N. P., Castori, M., Cohen, H., Colombi, M., Demirdas, S., de Backer, J., de Paepe, A., Fournel-Gigleux, S., Frank, M., Ghali, N., … Tinkle, B. (2017). The 2017 international classification of the Ehlers-Danlos syndromes. *American Journal of Medical Genetics*, *175*, 8–26.

Milton, A., Ajmani, L., DeVito, M. A., & Chancellor, S. (2023). "I see me here": Mental health content, community, and algorithmic curation on TikTok. In *Proceedings of the 2023 CHI conference on human factors in computing systems* (ACM p. 1–17). https://dl.acm.org/doi/10.1145/3544548.3581489

Morgan, G., & Subbiah, V. (2023). Rare disease research powered by empowered patients: Solving the zebra puzzle through social media. *Cancer*, *129*, 2128–2131.

Muscanell, N. L., & Guadagno, R. E. (2012). Make new friends or keep the old: Gender and personality differences in social networking use. *Computers in Human Behavior*, *28*, 107–112.

Reason, S. L., Løkken, N., & Voermans, N. (2021). International patient group harnesses social media to help inform rare disease research: Use of a low carbohydrate ketogenic diet in McArdle disease. *Current Opinion in Endocrinology, Diabetes, and Obesity*, *28*, 441–445.

Rocha, H. M., Savatt, J. M., Riggs, E. R., Wagner, J. K., Faucett, W. A., & Martin, C. L. (2018). Incorporating social media into your support tool box: Points to consider from genetics-based communities. *Journal of Genetic Counseling*, *27*, 470–480.

Rosenthal, E. T., Biesecker, L. G., & Biesecker, B. B. (2001). Parental attitudes toward a diagnosis in children with unidentified multiple congenital anomaly syndromes. *American Journal of Medical Genetics*, *103*, 106–114.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality and Quantity*, *52*, 1893–1907.

Simmel, G. (1972). The stranger. In D. N. Levine (Ed.), *Georg Simmel on individuality and social forms: Selected writings* (pp. 143–149). University of Chicago Press.

Stephen, J., Rojubally, A., MacGregor, K., McLeod, D., Speca, M., Taylor–Brown, J., Fergus, K., Collie, K., Turner, J., Sellick, S., & Mackenzie, G. (2013). Evaluation of CancerChatCanada: A program of online support for Canadians affected by cancer. *Current Oncology*, *20*, 39–47.

Stoller, J. K. (2018). The challenge of rare diseases. *Chest*, *153*, 1309–1314.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Sage Publications.

Turner, V. (1969). *The ritual process: Structure and anti-structure*. Aldine.

Ussher, J. M., Kirsten, L., Butow, P., & Sandoval, M. (2008). A qualitative analysis of reasons for leaving, or not attending, a cancer support group. *Social Work in Health Care*, *47*, 14–29.

Van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Seydel, E. R., & van de Laar, M. A. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research*, *10*, e18.

Van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research*, *18*, 405–417.

Walker, K. K. (2013). Rare disease-specific social media sites: An opportunity for collaboration. *Journal of Communication in Healthcare*, *6*, 71–76.

Wang, Y., McKee, M., Torbica, A., & Stuckler, D. (2019). Systematic literature review on the spread of health-related misinformation on social media. *Social Science & Medicine*, *240*, 112552.

Yabumoto, M., Miller, E., Rao, A., Tabor, H. K., Ormond, K. E., & Halley, M. C. (2022). Perspectives of rare disease social media group participants on engaging with genetic counselors: Mixed methods study. *Journal of Medical Internet Research*, *24*, e42084.

Zhu, Q., Sundstrom, E., & Xu, Y. (2021). Better understand rare disease patients' needs by analyzing social media data – A case study of cystic fibrosis. In *2021 IEEE international conference on bioinformatics and biomedicine (BIBM)* (pp. 2618–2621). IEEE. https://ieeexplore.ieee.org/document/9669842/

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Halverson, C. M. E., Doyle, T. A., & Vershaw, S. (2024). Social media use by patients with hypermobile Ehlers–Danlos syndrome. *Molecular Genetics & Genomic Medicine*, *12*, e2467. https://doi.org/10.1002/mgg3.2467