

"I was really, really nervous posting it": Communicating about Invisible Chronic Illnesses across Social Media Platforms

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ABSTRACT

People with invisible chronic illnesses (ICIs) can use social media to seek both informational and emotional support, but these individuals also face social and health-related challenges in posting about their often-stigmatized conditions online. To understand how they evaluate different platforms for disclosure, we interviewed 19 people with ICIs who post on general social media about their illnesses, such as Facebook, Instagram, and Twitter. We present a cross-platform analysis of how platforms varied in their suitability to achieve participants' goals, as well as the challenges posed by each platform. We also found that as participants' ICIs progressed, their goals, challenges, and social media use similarly evolved over time. Our findings highlight how people with ICIs select platforms from a broader ecology of social media and suggest a general need to understand shifts in social media use for populations with chronic but changing health concerns.

CCS CONCEPTS

• **Human-centered computing** → **Collaborative and social computing**;

KEYWORDS

Health; social media; media ecology; invisible chronic illness

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1 INTRODUCTION

Invisible chronic illnesses (ICIs) are illnesses that cause chronic physical impairments that are not visibly apparent, such as Lyme disease, lupus, and fibromyalgia [14]. An estimated 10% of all adults in the United States have an ICI [56], which means they often face two challenges that compound each other. First, since their health conditions are *chronic* rather than temporary, people with ICIs have to come to terms with a new self-identity that involves living with illness [14]. Second, ICIs are *invisible* – that is, the symptoms cannot be easily seen and verified by others, and thus can be delegitimized. Consequently, people with ICIs face both physiological and social challenges because of their illnesses [26].

As a result, people with ICIs can struggle with a "dilemma of disclosure": talking about their ICIs with others can risk stigmatization, but concealing their ICIs can harm their psychological well-being [60]. Social media can provide a valuable way to communicate about ICIs with a variety of audiences for a range of goals, such as receiving informational and emotional support [12, 40]. ICI-related communication not only occurs on illness-specific forums, such as Patients-LikeMe [64], but also on general social media platforms including Facebook [25] and Tumblr [23].

In this study, we are interested in how people disclose about their ICIs across multiple social media platforms and how the particular goals and challenges of ICIs influence their choice of platform. Prior work establishes that, in general, people use many platforms in everyday life, where each

platform is part of a broader social media ecosystem [66]; consequently, disclosure choices reflect what a given platform has to offer within the context of other available options [65]. We suspect that the social and health-related challenges around ICIs influence how people select platforms to disclose about their ICIs. To this end, we conducted semi-structured interviews with 19 people who use social media to talk about their ICIs. Our participants were diagnosed with a range of ICIs and used an average of three social media platforms to talk about them. We were therefore able to conduct a cross-comparative analysis of how they made ICI-related disclosures across many platforms, including Facebook, Instagram, Tumblr, Twitter, and personal blogs.

We found that people with ICIs select platforms based on an evaluation of various platforms' suitability to fulfill specific ICI-related goals (such as information-seeking) and the ICI-related challenges on each platform (such as cognitive burden). Moreover, we saw how people's goals and social media use change over time as their illness progresses. We discuss how ICI-related goals and challenges map onto different platforms, how time is a useful lens through which to understand the social media use of people with chronic but changing health issues, and how ICI-related challenges on social media might be mitigated through technology design.

2 RELATED WORK

ICI as an Evolving but Chronic Identity

Living with an ICI is often an evolving process marked by several milestones in a broader *illness trajectory* [10]: accepting the illness, renegotiating one's self-concept, and reframing one's identity [37]. This process has a fundamentally social component because the meaning people assign to their ICIs is based on how they are viewed by others [22]. The acquired social meaning of the ICI then shapes how people negotiate their identity and the strategies they use to either disclose or conceal their ICIs. Thus, living with an ICI goes beyond management of a clinical condition; it involves changes in one's self-concept and identity as people accept and integrate their illnesses into their daily lives [14].

According to Goffman [21], people actively construct their identities and social worlds through interaction. Today, online spaces introduce additional contexts for interaction and can provide psychosocial benefits by giving more control and flexibility over how people with ICIs present themselves [41]. This is similar in many ways to the experiences of other groups that leverage social media to navigate identity transitions. For example, people who undergo gender transitions use social media to explore their new identity in a safe space [27]. Similarly, students transitioning into college life from disadvantaged backgrounds use social media to receive social support to help affirm their new identities as college students

[43]. Social media can also be a way to raise awareness during a person's transition, as well as to find camaraderie with peers and a safe space to vent, as seen in research on military veterans transitioning into civilian life [52].

People undergoing transitions also face many challenges when assessing benefits and risks around disclosure. For example, navigating a gender transition on Facebook is complicated by the digital traces of one's previous gender identity (e.g., name, pictures) that persist after the transition [28]. Impression management also plays a role in posting about transitions; for example, some disadvantaged and low-income students transitioning into college life avoid asking for college advice on social media because they do not want to be judged by their social network [43].

While identity transition is challenging for all of these and other populations, it takes on a slightly different form for people with ICIs. Instead of managing a painful past (as in gender transitions, e.g., [28]), the transition for people with ICIs is about reconciling a healthy past with a current and future self that lives with illness, and requires evolving, long-term management [14]. To pursue these evolving needs, people with ICIs may select different social media platforms at different stages of their illness, and a cross-comparative study of platforms is needed to understand how participants map the various goals and challenges that emerge as part of the identity transition process onto different platforms in their broader social media ecology.

Communicating about ICIs on Social Media

ICIs fall in the class of stigmatizing chronic conditions because they become central to one's identity but have symptoms that others find hard to interpret, and cause long-term social consequences [19]. The stigma around ICIs is further complicated by the fact that healthy people can also temporarily experience some of the symptoms of ICIs, such as fatigue or headaches. As discussed by Lonardi [37], this creates dominant stereotypes about these symptoms – e.g., that headaches are mild and temporary. Such thinking can discredit people with ICIs who experience more severe forms of these symptoms and can render their ICIs as even more invisible. This stands in contrast to well-known health conditions (e.g., cancer), which are not experienced by healthy people. Some ICIs, such as chronic fatigue syndrome and fibromyalgia, are also "contested illnesses"—that is, both physicians and the public often question the validity of these illnesses, which further stigmatizes people's illness experience [9]. Consequently, stigma around ICIs can hold people back from seeking support from their social networks [29]. The stress from dealing with a stigmatized health condition can be particularly burdensome, as it can cause individuals to develop other stress-related illnesses, as well as worsen clinical outcomes and make it harder to live a "regular" life [35].

The Internet can facilitate communication and education around stigmatized illnesses [5] and provide visibility to invisible illnesses [8]. People with ICIs can use social media to integrate illness into their lives and to feel 'normal' by socializing with others [36]. People with ICIs can also reframe their illnesses through humor, for example by drawing on chronic illness memes on Tumblr [23]. The visual nature of some social media platforms, such as Flickr, can make ordinarily invisible pain visible, and elicit empathy from others by depicting daily life with an ICI [24]. Similarly, people can find blogging about ICIs therapeutic, as it allows them to share and reflect on their illness experience [49]. Finally, forums such as PatientsLikeMe can provide an invaluable source of informational support, which in some cases can lead to less inpatient care [64].

However, stigma complicates identity negotiation and poses additional risks for disclosures in social media because people with stigmatized identities fear being misunderstood, stereotyped, blamed, and rejected [38, 55]. People mitigate these risks by engaging in various impression management strategies, for example, by making ambiguous and indirect disclosures on social media [2]. Furthermore, those with ICIs can feel hesitant to share negative health-related disclosures given the prevalent norm to post positive content on social network sites [48], and they can even receive hateful comments when they do decide to disclose [30]. These challenges may be more problematic on some platforms rather than others; for example, Facebook is commonly perceived to pose impression management concerns in general [3]. It remains to be seen how the many motivations and challenges around posting about ICIs on social media vary by platform and how this variation drives platform choice.

Considering Multiple Platforms for ICIs

Many people use multiple social media platforms, and they choose them by evaluating their options within a broader social media ecology [66]. Such platform choices are influenced by a person's sense of how well a site's characteristics might satisfy their intended goals [51] in comparison to other available communication resources. When a platform is not conducive to achieving a particular goal, people switch to alternative media that may be a better match [53]. Presented with various platform choices, people simultaneously consider content (what to share) and audience (with whom to share) when choosing a platform for disclosure [66]. People also choose communicative media based on the degree to which they need to constrain the privacy boundaries of their communication [18]. In order to reduce risks of disclosure (e.g., social rejection), people may also switch to other communication media that afford more targeted audiences, such as email over Facebook [61].

Navigating a broad ecology of social media and selecting platforms based on their suitability for disclosure goals is likely to be particularly complicated for people with ICIs compared to the general population, since they have to balance the need to disclose for emotional well-being with the challenges of managing a chronic, stigmatized identity. However, existing work on ICIs has focused on specific platforms (e.g., [23]); it remains to be understood how people with ICIs choose platforms for their disclosures, as well as how their social media use changes with the evolving needs of their ICIs. Moreover, focusing on only one platform at a time obscures the many combinations in which people might be using different social media platforms to talk about various aspects of their ICIs. Therefore, we pose these two research questions:

RQ1: How do people's various motivations to post about their ICIs online affect how they choose social media platforms for disclosure?

RQ2: How do the challenges people face in posting about ICIs vary by social media platform, and how do they navigate these challenges?

3 METHOD

Recruitment and Procedure

We conducted semi-structured interviews with 19 people who use social media to talk about their ICIs. We recruited participants by posting advertisements on Twitter, Instagram, and Tumblr that contained two popular ICI-related hashtags, #chronicpain and #spoonies [23]. Participation was restricted to people over 18 years of age who had an ICI. The advertisements included a link to a Qualtrics form for potential participants to sign up for an interview. We chose to recruit on these three public platforms so as not to intrude on the community's safe spaces, such as closed Facebook groups.

Interviews focused on participants' experiences living with an ICI and their use of various social media to talk about and manage their ICIs. We began by asking participants about their age, employment status, health condition(s), the length of time since diagnosis and symptom onset, the perceived severity of symptoms, and the daily life challenges they face due to ICI. We used participants' terms for their illnesses, taking care to avoid stigmatizing or negative terminology. Next, we asked about participants' goals in talking about ICI on various platforms, and the challenges they encountered. While some participants looked through their social media posts during the interviews, we made a conscious decision not to personally access and analyze their content to respect their privacy, particularly since they were already sharing such sensitive stories with us. Two coauthors met regularly to discuss emerging findings, and we conducted interviews until data saturation.

Table 1: Participant Demographics

ID	Age	ICI Diagnosis	Employment	Social Media ^a
P1	41	Cauda Equina Syndrome	Part-time	FB, TW, TB, B
P2	18	Ulcerative Colitis	Part-time	TW(2), TB
P3	36	Myalgic Encephalomyelitis, Chronic Fatigue Syn.	Self-employed	FB, IN, TW
P4	40	Mixed Connective Tissue Disease	Full-time	FB, IN(2)
P5	27	Endometriosis	Full-time	FB, IN
P6	32	Lyme disease, Fibromyalgia, Chronic headaches	Unable to work	TW(2), FB, IN
P7	24	Endometriosis	Unable to work	FB, IN, TW
P8	46	Klippel Feil Syndrome	Unable to work	FB, TW, YT, IN, B
P9	55	Rheumatoid Arthritis	Full-time	FB, P, IN
P10	39	Sciatica, Fibromyalgia, Depression, Anxiety	Unemployed	IN(3), FB, TW, P, B
P11	23	Lyme disease	Unable to work	IN, B, TW, FB
P12	24	Fibromyalgia	Unable to work	IN, TB, R
P13	24	Lyme disease, Fibromyalgia, Chronic Fatigue Syn.	Unable to work	IN, FB, B
P14	24	Crohn’s Disease, Celiac Disease, Bronchiectasis	Part-time	TB, FB, IN
P15	25	Lupus, Spondylitis, Fibromyalgia	Self-employed	IN, TW, FB
P16	30	Postural Orthostatic Tachycardia Syndrome	Full-time	IN(2), YT, TW, FB
P17	25	Ehlers-Danlos Syndrome	Full-time	FB, IN, YT
P18	28	Lupus, Fibromyalgia, Heart palpitations	Self-employed	IN, FB
P19	36	Fibromyalgia, Degenerative Disc Disease	Full-time	IN(2), TW

^aFacebook (FB), Instagram (IN), Twitter (TW), Tumblr (TB), Reddit (R), Blog (B), YouTube (YT), Pinterest (P); numbers in parentheses denote multiple accounts.

All interviews were audio-only to protect our participants’ privacy. With consent, we recorded interviews; one participant did not consent to be recorded, and we instead took extensive notes. On average, interviews lasted 73 minutes, and participants received \$20 USD (or equivalent) for their time. No identifying data was collected, and email addresses were not stored or connected to the data. All procedures were approved by Cornell University’s Institutional Review Board.

Analysis

We conducted a thematic analysis of our interview transcripts [6]. Two authors read all the transcripts and conducted all the analyses. First, both authors independently assigned open codes to half of the transcripts and then met to discuss emergent codes. Similar concepts were grouped to understand the themes in our data. For example, codes related to online negativity and impression management were both categorized as challenges in posting about ICIs. Based on these groupings, we developed a codebook that both authors used to recode the entire dataset. Throughout the development and analysis of codes and themes, both authors met in a series of face-to-face meetings to address questions. After both authors coded half of the final dataset each, they reviewed and discussed the entire coded dataset,

identifying and resolving points of disagreement and ensuring consistent agreement over every applied code. This functioned as a systematic check on the process, as advocated by Lincoln and Guba [34].

Limitations

Our study has several limitations that we outline here to help contextualize and interpret our findings. First, our sample is limited to people with ICIs who were comfortable being interviewed, who also use common social media platforms to talk about their ICIs. Our participants also did not use illness-specific forums, though extensive research has covered these venues (e.g., [42, 64]), and we were primarily interested in the use of general social media platforms for ICI-related communication. In terms of demographics, ICIs disproportionately affect women [20], and we were only able to interview one male participant. While this participant’s responses were similar to the rest, other men with ICIs may experience concerns that we could not uncover. Similarly, while we did not restrict our sample by location, the majority of our participants were from North America; we did not find cultural differences within our sample.

4 RESULTS

After describing our participants, we present our findings, which are organized into three categories: 1) the goals people

had for posting about ICIs online and how these influenced their choice of social platform, 2) the challenges posed by each platform and how these drove platform choice, and 3) how participants' social media use evolved as the goals and challenges around their ICIs changed over time.

Participants

Participants ranged in age from 18 to 55 years; 18 of our 19 participants were female. They were located in the U.S. (14), Canada (3), the U.K. (1), and South Africa (1). They had experienced ICI-related symptoms for a median time of 10 years and posted about their ICIs on an average of 3 platforms; 32% had multiple accounts on the same platform. The majority posted about their ICIs on Instagram (89%), Facebook (including closed and secret groups) (84%), and Twitter (58%). A few also used Tumblr (16%), Pinterest (11%), YouTube (16%), and blogs like WordPress (21%). Participants did not regularly use illness-specific forums: some had discovered forums early into their diagnoses but found the amount of available information to be overwhelming, while others preferred to use social media they were already familiar with. Participant demographics are shown in Table 1, along with the social media platforms they used to post about ICIs.

Matching Motivations to Platforms

In this section, we present participants' reasoning for selecting one platform over another in service of three common types of goals: 1) finding informational support, 2) finding emotional support, and 3) distraction and reminiscence.

Finding Informational Support. Almost all participants used social media to find information about their ICIs, in terms of diagnoses, medications, and strategies for condition management. Facebook groups were perceived as particularly useful for information-seeking, as they provided access to others' rich experiential knowledge about ICIs: *"There's women who have had surgery after surgery. There's women that are going to the best specialist in the world, and so it's really great to be able to throw out, 'Hey, this is what's happening to me. Anyone else have this?' Or, 'What did you do?'"* (P7).

Moreover, Facebook allowed for more detailed discussions compared to other popular platforms, such as Instagram: *"Even though I post a lot on Instagram in terms of pictures, when I'm talking or discussing anything Fibro, that's always on Facebook"* (P10). Facebook was perceived as aiding more organized discussion compared to other platforms: *"with my Lyme disease group I talk to more on Facebook [...], it's hard to tweet about that many different things if they're all talking at once"* (P6).

However in some cases, the content delivery styles of media-heavy, hashtag-oriented sites like Instagram were appreciated over Facebook, as they enabled participants to

quickly skim through and ingest greater amounts of information: *"the different hashtags on Instagram seem to have a lot more information. So I've been searching a lot on things like functional impairment or physiotherapy, and Instagram has diagrams and video tutorials that you can usually watch while you're scrolling through instead of clicking on links, so that was a more intuitive and interactive platform"* (P19).

While the more elaborate, threaded conversations on Facebook and Reddit could be a strength over sites like Instagram or Twitter, sometimes participants desired informational feedback from a more intimate network than a large, seemingly impersonal Facebook group or Reddit thread. In such cases, they turned to platforms that felt more personal, such as Instagram: *"I feel like Instagram is a little more intimate, and the people you follow and the people who follow you maybe have a better idea of who you are and what your life is in general, and they might be able to say, 'Oh, well, you did such and such the other day, and maybe that made an impact.' If I post something like that on Reddit, that person doesn't know necessarily unless we talked before"* (P12). This is in line with prior work on social media that suggests that receiving more intimate comments on posts is associated with higher user satisfaction [50].

Balancing informational and emotional needs could also influence *intra*-platform selection choices, such as deciding between different types of Facebook groups: *"With Lyme disease, there's just so much documentation that you need. So I'll go into the [Lyme-specific] groups when I need that stuff. But if I am more so looking for tips on how to cope and that kind of thing, I would 9 times out of 10 rather go to a generalized group, because people are less focused on the negative and more focused on healing solutions"* (P13).

In general, when participants wanted to gain information through a detailed discussion, they sought out platforms that enabled such threaded conversations (such as Reddit or Facebook), and when they wanted to skim large amounts of information, they often preferred platforms that delivered information in short or media-heavy formats (such as Instagram). Platform choice could also be influenced by network composition, such as when participants wanted information from a more intimate or familiar network (such as a smaller Facebook group, or Instagram).

Finding Emotional Support. Participants connected with others with ICIs for emotional support and community-building on many platforms. Instagram, Twitter, and Tumblr were all considered good platforms to find new people with ICIs and to tap into a broader community by using popular hashtags: *"I am able to find so many different people on Instagram by either going on the search or via hashtag...while Facebook is often people you know. I'm just able to find more people on Instagram"* (P3).

Once they had established these networks, it was easier to build an emotional connection using platforms that allowed for greater disclosure: *"The 140 character limit on Twitter can be kind of limiting to getting to know someone. So I think Tumblr is more personal...Twitter is better for quick updates of people you have already gotten to know through this kind of thing"* (P2). Similarly, P19 perceived Instagram to be more intimate because of its visual nature: *"the images [on Instagram] also do help to maybe make it feel a bit closer... It's the same as Twitter in terms of connectivity but it feels more relatable."*

Even though Twitter limited lengthy disclosures due to its character constraints, participants found value in using hashtags to socialize with the platform's ICI community. Prior work finds that illness-related hashtags can allow people to interact and bond with unstructured illness communities on Twitter [44]. Similarly, while our participants did not see Twitter as well-suited for deep conversations, they used it to interact with others with ICIs over shared recreational events. For example, P6 described using hashtags on Twitter as a way to organize an informal community event and foster needed emotional engagement: *"A lot of us unintentionally became isolated, because you don't have the energy to do stuff. So I started a movie night where we would all watch Netflix at the same time and live-tweet about it together"*.

Finally, an affective connection was also easier to build with like-minded peers, with participants' demographics influencing the community with whom they felt an affinity. For example, P17 primarily used Instagram over Facebook because she perceived Instagram to have a younger base of users: *"A lot of the people in the support groups are my mom's age, in their forties, which is fine, but in terms of being able to communicate with someone who's my age, who's going through the same things I am at the same time, it's very difficult on Facebook. Then once I got into Instagram, I'm finding a lot of people who are in their early twenties [like me]"* (P17).

In general, participants described developing strong emotional connections with people on most social media platforms. Some platforms were seen as particularly well-suited for connecting with new people because of features such as hashtag searches (e.g., Twitter), while platforms that enabled greater disclosure were seen as better for developing a deeper relationship (e.g., Tumblr or Facebook). Finally, where one sought emotional support was influenced by perceptions of audience, as participants preferred to get support from people who were similar to themselves.

Distraction and Reminiscence. Using social media was also a way to stay entertained when sick, and simply browsing others' ICI-related content could serve as a distraction: *"There were some days where...if I was in a really, really bad spot, I*

wouldn't post it—I would kind of just browse through Instagram and read other people's stories and see how they're doing and kind of take my mind off of what I'm feeling" (P16). This type of increased passive engagement on social media during periods of sickness is consistent with social media use patterns in the general population during declines in mental and physical health [7].

Prior work finds that video logs can be a way to document ICIs and help others [30]; we find that other platforms can also serve as a tool for documentation and reminiscence. Instagram was seen as especially valuable in creating a visual narrative of the journey with ICI: *"[Instagram] is mainly just like a picture diary for me. To look back and [say] 'look at how much I've overcome'"* (P18). In contrast, participants did not use Facebook for such journaling, given they felt a greater need to curate ICI-related content on Facebook as compared to Instagram or blogs: *"On YouTube, you know, I can do a vlog describing what my day is like with dysautonomia and things like that. Facebook, since I have a lot more family on there, I kind of don't want to worry people on there."* (P16).

Overall, social media served as an effective way for participants to distract themselves from their ICIs and to reminisce about their journey with the ICI, though participants preferred platforms with lower impression management concerns when using social media as an ICI journal. Apart from impression management concerns, participants were relatively audience-agnostic with distraction and reminiscence goals because achieving these goals was less tied to specific audiences as compared to goals around informational and emotional support.

Challenges Across Platforms

Participants perceived four main types of challenges in posting about their ICIs on social media: constraints posed by their health conditions, negativity within the ICI community, impression management to manage audiences without ICI, and concerns about privacy and risk. In this section, we discuss how these challenges varied by platform, and consequently influenced platform selection.

Health Considerations. Our participants experienced several physical constraints or cognitive impairments due to their ICIs, and their social media activity was influenced by the severity of their symptoms. Some platforms were seen as time- and labor-intensive, such as text or video blogs. Participants noted these platforms' utility for sharing more in-depth content, but often limited their use because of their health challenges: *"I really struggle with the reading and writing from day to day. And then even if I can [post on my blog], you know, I kind of have a couple hour maximum and then that's it. And then I'm done for a couple days after. And I'm done in a way*

that I'm lost in my own house kind of thing. So I have to be careful not to do too much" (P13).

Instead, a platform's ease and convenience could enhance its appeal. Some platforms were perceived as requiring very little effort, such as Instagram: *"I like to take a nice photograph and put how I'm feeling on that image and share it on Instagram...That's a quick social media thing that I can do that makes me feel better, to create" (P8).* Twitter was also easier to use in the face of health challenges because of its limited character count, which was seen as a less burdensome way to receive social support: *"When I got ill, [Twitter] was nice because it was short and you didn't have to interact as much" (P3).* Despite the low effort involved in such posts, this type of social media activity can be rewarding and lead to a sense of empowerment, as noted by previous research on online participation by people with chronic illnesses [59].

The ease of such platforms allowed participants to use them even during symptom flare-ups. For example, P13 was able to use Instagram even when she was experiencing cognitive impairment, compared to Facebook and blogs: *"[Instagram] is the easiest of the three, just because if I post an image, even if the words – like on brain fog days – even if my words aren't really making sense, it's okay, because all I'm doing is a small hashtag" (P13).*

Overall, we found that the decision to use social media to improve emotional well-being had to be balanced with the tolls it could take on physical wellness. In general, time- and labor-intensive platforms (e.g., blogs) posed cognitive and health burdens for people with ICIs, compared to platforms that required little effort (e.g., Instagram).

Negativity Within the ICI Community. Almost all of our participants had encountered some form of negativity within the ICI community online, which could detract from their experience. They described these disagreements as occurring most often in Facebook groups, where there could be *"a weird sense of competition... the whole 'who has it worse' situation" (P2)* or that some members were *"just coming [into the Facebook group] to dump or purge their issue" (P8).*

These negative interactions were less common on platforms such as Twitter, Tumblr, and Instagram, which were seen as well-suited for lighthearted content: *"[My] Twitter [posts] will be more of a joke. 'Before moving to LA, I had to break up with my CVS pharmacist' - jokes like that" (P15).* This is consistent with findings from a content analysis of cancer-related hashtags on Twitter that positive emotions like hope were more frequently expressed than negative emotions like fear [44].

Instead, participants felt that negativity was most common on Facebook: *"You never see negative stuff on Instagram, you find humor and you find pictures of stuff. Facebook on the other hand is where the talons come out, I say. You can open*

up your page in the morning or you go onto your landing page and it's just one depressing thing after another" (P10). In general, social media users see Facebook as most appropriate for sharing negative emotions, followed by Twitter, and then Instagram [63]; we find this holds true for people with ICIs.

The differences in tone on Facebook compared to other platforms may be due to the level of interactivity afforded by the platform, given it allows extensive conversations, which may become heated: *"There is just a lot of negativity on Facebook, and I found Instagram was... it's a picture, and you can like it or you can move on, or you can like it and comment. It doesn't have to be a big discussion, which I find Facebook turns into" (P3).* Moreover, participants felt that they could be more selective about their audiences on Instagram versus in Facebook groups, thus avoiding conflict: *"If it's a Facebook group that has a ton of people in it, like thousands, then everyone's going to have differing opinions on what's good and what's not. Instagram not as much, because it's not such a public platform, it's a little more personal. You don't follow people on Instagram that you don't really agree with usually" (P11).*

However, Facebook groups can be invaluable in meeting both informational and emotional needs [4], and participants did use them despite the negativity. For example, P17 stated *"[Instagram] just seems really positive. I don't get the negative kind of judgmental response that I would in a Facebook group."* Yet, she also stated, *"there have been some times where I won't Instagram as much because I feel like I really need to just sit and talk to someone, so I'll go into a Facebook group and post something and that will result in a two hour threaded conversation."* In this way, the benefits of extensive discussions in Facebook groups could outweigh their challenges.

Impression Management. While participants wanted to share about their ICIs online, impression management was a key concern for them. This was particularly true on Facebook, as this was where most participants connected with offline friends and family, creating a situation of context collapse [39]: *"My boyfriend is on my Facebook, of course, and my close friends and my political community... so that's why I try not to be like 'oh, woe is me' every day. It's just preserving my image because I know people don't want to read me complaining about my pain every day" (P7).* This is in line with prior work that finds that Facebook functions as a place for people to socialize with their network and feel "normal", rather than to discuss their illnesses [58].

To post unfiltered content about ICI, participants gravitated towards spaces where they had less overlap between their offline and online worlds. For example, the majority of participants sought out closed Facebook groups with controlled access, and were careful to ensure that content did not spill into their personal Facebook Timeline. One participant

was a moderator for a closed Facebook group for ICI, and received many messages about the visibility of content from members: *"When you post in a private [Facebook] group, it comes up on your feed. So it looks to you like everyone can see it...then [they] send me a note saying 'This showed up on my feed? Can my whole family see this?'"*(P8)

For most participants, impression management was less of a concern on platforms like Twitter and Instagram, where they were less likely to be connected to people they knew offline. This was partly due to the widespread practice of maintaining several accounts on Instagram [15], with one account being designated for ICI communication: *"[I] have multiple Twitter accounts, and I have one that is more like people I've known from high school and personal friends like that, so I don't really talk about [ICI] much on [that account]"* (P2). As explained by Duffy and Chang [16], people have alternative accounts on the same platform as a way to manage connections to their identities; accounts with pseudonyms – unlinked from one's real persona – are used for sharing a less filtered version of daily life with a select group of people. Likewise, for our participants, having a separate account for ICI content allowed them to be more open, in a similar way to other populations undergoing transitions [27]: *"Most people have a personal Instagram account, and then they'll have the chronic pain account just to connect with other chronic illness people, and they can be very real, which is nice to see the unscripted version of how people actually feel and what they're actually going through"* (P11).

However, some participants found using multiple accounts to be burdensome: *"Ideally, I would have two [Instagram accounts]...I don't know though, it's stressful having more than one account, and I don't want to overwhelm myself with technology"* (P11). In contrast, these participants liked that Facebook provided them with more granular control in sharing individual posts, as compared to Instagram and Twitter: *"You either have to have a private [Instagram] account, or a public account. It would be really nice to be able to post certain things and just have them private, so it's just me that can see them... On Facebook, for example, I do the same thing where occasionally I'll post something, or repost something, that I want to read later, but I can set it as private to just myself"* (P17).

Overall, platforms posed less of a challenge for impression management when they allowed participants to separate their audiences, such as their online and offline networks (e.g., through Facebook's privacy settings). While participants still used platforms that did not allow for nuanced content control (such as Instagram), the workarounds they developed were often seen as less than ideal solutions.

Privacy and Risk. Given participants were posting sensitive health-related content, they were concerned about maintaining their privacy online. As they wanted to communicate

with the broader ICI community, they mostly set their Instagram and Twitter accounts as public; however, this raised issues about who could view their content: *"I'm scared of stalkers...you just find your inbox full of really creepy men. They would see a post about how much pain you're in and they'd be like, 'Hi, I saw your post. I'm so sorry you're in pain.' Then the next thing you knew it was, 'Oh, can I get your number? Can I meet you?'"* That was really creepy" (P10).

In contrast, closed Facebook groups could provide a safe space for participants, where they could discuss sensitive health information without certain risks, such as being stalked. However, Facebook groups could also be risky, since they could be infiltrated by outsiders: *"We had a situation where a woman saw that a bunch of us were on a site...for a fetish of women wearing [neck] braces... several of us, myself included, had been posted. Our photos had been taken from that [closed Facebook] group and posted on this awful site"* (P8).

In the face of these risks, participants engaged in different strategies to protect themselves, based on the platform. Since they wanted to have public accounts on Instagram and Twitter to reach new ICI connections, they restricted the amount of personal information (especially their full names) on their public profiles: *"I already have Facebook which is obviously very personal, so all of the other websites that I have, especially that I don't have a lot of people that I actually know, [those details were] just never something that I really needed to include for any reason"* (P2).

Since people used their full names on Facebook (and by extension, in closed or secret Facebook groups), participants used alternate strategies to stay safe. These groups were often policed by moderators and vigilantly restricted access to outsiders to protect members from harm: *"We're pretty strict about letting people in. Some of them you may have to answer a question or some of them just an admin will message you first. They like to keep it to only women who have been diagnosed with endometriosis"* (P7). Prior work finds that Facebook groups contain informational and emotional support for health conditions, but that there is also a lot of personal data in these groups [25]. We find that people are aware of the risks that come with disclosing sensitive information in such groups, but that they use strategies to mitigate risks, such as strict moderation.

Evolving Goals, Challenges, and Social Media Use

We found that participants' goals, and the challenges they faced, changed over time as their ICIs progressed. We also saw several transitions in their social media use that aligned with their illness trajectories. When first diagnosed with an ICI, the majority of participants turned to social media with the goal of seeking information, as opposed to connecting with others. Their initial strategy was to do so by using platforms they were already using for other purposes, primarily

because of their comfort level with those systems: *"It's just kind of easy to take those [sites] that I'm using already and extend them to that aspect of my life [ICI]"* (P2).

However, on platforms where they were connected with offline contacts (such as Facebook), they chose not to post about their conditions: *"I didn't want anybody to know. I was actually kind of in denial when I was first diagnosed"* (P16). Prior work finds that people with ICIs attempt to avoid stigma from their social networks [29]; we found that this led participants to seek spaces disconnected from their existing network of contacts: *"When I sought out to use Twitter, I knew that is what I wanted to use it for... I wanted to use it for that purpose [finding an ICI community], especially away from my normal social circles"* (P19).

With time, several participants *"started to make peace with [ICI]"* (P19) and became more open in their online communication, though overcoming their instinct to self-censor was initially difficult. For example, P15 recalled the first time she posted something negative about her ICI online that was visible to people she knew offline, saying: *"I used to be super, super positive about it and act like it was no big deal to people. It was the first time I was just very open and candid about it. I was really, really nervous posting it. I didn't want to share it."* In this way, participants made a conscious decision to self-disclose once their need to be open about their ICIs outweighed their impression management concerns.

As participants came to terms with their illnesses, they also became more open in making ICI disclosures in general: *"This is all part of that journey for me, with me reclaiming feeling comfortable about discussing my condition, being open about things.... It's all about my journey"* (P17). In parallel, participants' goals commonly turned more externally facing, transitioning from satisfying their own informational needs to supporting others: *"First when I was diagnosed with [my condition], I didn't really know what was going on, so I did use Instagram to search the hashtag for [my condition] and what spoonie meant and chronic illness... When I was really okay with accepting the condition, that's when I was in that state where I was like, 'Okay, I want to help people'"* (P16).

Participants would select platforms based on perceptions of how each could facilitate this supportive work, noting for instance that closed Facebook groups help individuals with ICI *"be very open about some of our really tough experiences and talk about things like that"* (P6), that hashtag features on Instagram and Twitter aid targeted sharing and discussion of ICI-related content, and that Tumblr works well to *"spread fun things and lighten things up - to make humor of the illness"* (P14). Thus, as their identities and social needs evolved, participants navigated the broader ecology of social media to match their changing goals, which often involved a comparison of different platforms' benefits and constraints.

5 DISCUSSION

Our work sheds light on how people with ICIs select social media platforms to satisfy ICI-related needs by considering the benefits and constraints of various platforms within a broader ecology of social media. In this section, we discuss how our work contributes to understandings of how social media use changes over time for people with shifting health needs. We then discuss how the ICI-related challenges in posting on social media may be mitigated through design.

Changes and Transitions in Social Media Use and ICI

We found that the ways people with ICIs used social media changed with time, which is consistent with prior platform-specific work that shows that the content of ICI blogs changes with the progression of people's conditions [32], and that people who blog about ICIs can experience a shift in motivations from information-seeking to social support and advocacy over time [49]. In addition to understanding how these shifts in ICI communication take place on specific platforms, our study sheds light on how people navigate a broader ecology of social media to pursue these evolving goals.

When they first experienced symptoms or were diagnosed with an ICI, participants turned to their existing platforms to explore information about their ICIs. Thus, for some participants, this meant turning to platforms that are not illness-specific sites, such as Twitter. Prior work finds that people often turn to search engines to learn about health conditions that involve social stigma, but use public social media platforms such as Twitter to learn about benign conditions [13]. Our work finds that people can still turn to public platforms to learn about stigmatized health conditions, particularly if they were using these prior to the development of their ICIs.

Once people with ICIs have met these informational needs and have gained more experience with their conditions, prior work suggests that their use of the social media decreases [54]. However, our cross-platform analysis suggests that people simply migrate to other platforms in the pursuit of new ICI-related needs that emerge as their condition progresses, such as the desire to provide and receive emotional support and connect with others with ICIs.

In the early stages of dealing with their ICIs, our participants were also careful to manage their content in spaces where they were connected with friends and family, aligning with prior work that impression management is a concern for identities in transition. For example, [28] found that people undergoing gender transition can maintain two accounts to separate their new gender identity from their old one; eventually, their new account becomes their main account, and they distance themselves from their old network and identity. A key difference with ICI is that people do not aim to distance themselves from their previous healthy selves;

rather, they are motivated to eventually decompartmentalize the ICI and non-ICI components of their identities.

As time progressed, we saw a trend towards participants becoming more comfortable disclosing about their ICIs. Prior work finds that people's privacy attitudes can change in response to changes in their illnesses [45] and that they can become more comfortable with sharing personal health information the more they use illness-related forums [64]. This increase in comfort also influenced participants' platform selection, since they gradually began to talk about their ICIs on platforms with existing social ties, such as Facebook.

These findings align with research that over time, veterans and people who experience pregnancy loss also become more comfortable disclosing their struggles on social media, often transitioning from anonymous platforms to identified platforms with familiar social contacts [1, 52]. For example, Andalibi and Forte found that disclosing on anonymous sites (e.g., by using throwaways on Reddit) can make people become more comfortable with posting on identified sites, such as Facebook [1]. We find that identified sites, such as Twitter, can also play this role in making people become more comfortable, provided that they are separate from people's social networks. Moreover, we find that holding pseudonymous accounts on typically identified sites, such as alternate Instagram or Twitter accounts, can also help participants become more comfortable about making such disclosures. This may be due to the fact that, in contrast to anonymous accounts (such as Reddit throwaways), such pseudonymous accounts allow people to build connections and exchange social support with others with ICIs, while also not being identified by their existing social networks.

Temporal changes in impression management concerns and social media use may be understood through the lens of Goffman's dramaturgical analysis [21]. That is, different social media platforms serve different ICI-related purposes borne out of impression management concerns (e.g., closed Facebook groups function as back-stage spaces for unfiltered ICI content, whereas the newsfeed serves as a front-stage with more carefully curated content). This separation between front-stage and back-stage platforms is especially evident in the initial stages of dealing with ICIs, as people often choose to use platforms without existing social ties when they are first dealing with ICI and require backstage communication. In this sense, entire platforms can serve as either front- or back-stage, depending on where people are in their health trajectory. As their ICIs progress and they become more comfortable with their new identities, some of this backstage communication transitions to front-stage. The malleability of perceived disclosure goals and risks for people with ICIs underscores the importance of a temporal perspective to understanding disclosure decisions as outlined

in disclosure theories, such as the disclosure decision model [47].

Overall, we see a need for technologies to aid change and progression in populations that experience health-related transitions. In the case of ICIs, adaptive content delivery features might provide filtering settings to highlight content that aligns with current goals (e.g., to provide predominantly informational resources for personal consumption in one's early post-diagnosis phases, or once motivations have shifted, to provide opportunities for providing social support, such as by highlighting posts by other users that indicate vulnerability). Such tailoring could match individuals' needs based on where they are in their illness trajectories.

Social media could also be harnessed to support people's changing health needs by facilitating desired social connections. Current platforms allow people to connect through ICI-related hashtags or groups, but participants wanted to connect with people with similar experiences within this broader community. For example, some participants chose Instagram to connect with users of a similar age at the expense of having more detailed threaded conversations, as afforded by Facebook groups, since these were perceived as having older users. A solution would be to make it easier for people with ICIs to connect with others who are at similar points of the ICI trajectory, or of similar ages, across social media. Moreover, given participants' goals eventually changed from seeking information to providing social support, it would be helpful to design ways newcomers to the community could be matched with people who have successfully transitioned for advice and mentorship.

Mitigating ICI-related Challenges on Social Media

We found that the challenges participants faced in posting about social media were often uniquely driven by their ICI experience. In this section, we discuss the challenges that emerged on various platforms and how they might be addressed through design.

Health Considerations. While communicating about ICI on social media helped participants find information and receive social support, their usage could be constrained by the health challenges of their ICIs. In particular, participants chose social media platforms not only based on specific communicative goals, but also on how much energy – both mental and physical – they had at the time. For example, Instagram was seen as requiring very little effort, since posting a picture did not involve much writing and could be done quickly. Thus, we found that the amount of effort a platform requires is an important consideration in platform choices among people with ICI. This factor was particularly salient when participants' symptoms were flaring up, and it helps in making sense of how and when participants use high-effort versus

low-effort platforms for ICI-related disclosures. For example, according to Ressler et al. [49], blogging about ICI allows people to share information about their ICIs with a broad audience in a less time-intensive way than telling individual people directly; however, we find that blogs can also have a large cost in time and energy. Thus, while some of our participants used blogs to communicate and gain social support, we found that there were many times that they selected less effort-intensive platforms (e.g., Twitter or Instagram) to communicate about their ICIs due to health considerations.

Moreover, during symptom flare-ups, participants sometimes desired to stay connected but through limited interaction, in order to conserve cognitive and emotional energy. At times like this, some preferred to passively look through their past posts, aligning with research that reminiscence can be therapeutic [29]. Our findings therefore provide support for building tools such as Pensieve [11] that facilitate remembrance on social media, particularly for populations that could benefit from pleasant memory-laden content to augment positive emotions. These findings also support the development of customizable health-related tools and apps, such as My Journey Compass [31], which can aid relaxation while also catering to changing health needs.

Negativity in ICI-Related Communities. While existing work on ICI-related forums and Facebook groups for health management shows that they offer invaluable social support, we found that such spaces can also foster negativity and hamper participation. Waterloo and colleagues [63] state that platform modality (whether the platform uses text, visuals, or audio) is one of the mechanisms that influences how people judge platform appropriateness for expressing negative emotions. Platform modality also came up in many of our interviews, but in relation to encountering negative interactions. For example, participants stated that long, involved conversations on Facebook could easily lead to heated fights. Building on O’Leary et al.’s [46] suggestion that training can improve peer support for mental health, systems could similarly identify pro-social and supportive content along with the users who make positive posts, who could be prompted to help intervene when negative interactions or conflicts arise. Finally, since too much negative ICI-related content can be triggering or overwhelming—particularly for newcomers to the community—a system could provide content-filtering features to enable users to select a preferred “negativity exposure level”, which would automatically remove content deemed by the system to exceed this user-defined threshold.

Impression Management and Privacy Risks. While all participants reported publicly sharing ICI-related content on general social media platforms, we found that these disclosures did not reflect a lack of concern for privacy or self-presentation. Prior research suggests that people in general

make disclosure decisions based on a privacy calculus, weighing the benefits and costs of the disclosure [33]. In the case of ICI, the benefits of disclosing about ICI can often outweigh the risks of such disclosures, and thus, sharing sensitive health-related content is a rational decision to achieve specific informational or emotional goals. Since disclosures about ICI can provide many psychosocial benefits [60], we see a clear need to facilitate these disclosures on social media while mitigating potential risks around making them.

In their own attempts to manage these risks, participants took care to create compartmentalized, anonymous identities that were separate from their offline selves. This strategy makes people feel less vulnerable about making sensitive self-disclosures [57] because they can enact different parts of their identity in online spaces unlinked from one another or their offline identity [17]. However, due to their ICIs, some of our participants found this to be a cognitive strain. A potential design solution could reduce the burden of maintaining separate accounts; for example, a social media management application might make it easier for people to see all their accounts in one place and to select a platform for disclosure based on any given communicative goal.

Our participants also did not want to make their social network uncomfortable with extensive or frequent health updates, in a similar way to other populations undergoing identity change [43]. Participants’ disclosures were further influenced by the norm to post positive content on social media [48, 63]. Thus, audience considerations played a large role in how and where people chose to disclose about their ICIs, and some participants made multiple accounts or migrated to different platforms altogether in order to segment their audiences. These difficulties highlight a clear need to provide people with more granular levels of contextual control over their content across platforms, and to develop interventions that can help them avoid making disclosures to unintended audiences (such as privacy “nudges” that prompt users to reconsider the content in their posts prior to disclosure by showing them the potential audiences of their posts [62]).

6 CONCLUSION

This study contributes a multi-platform comparative analysis of how individuals with ICIs select social media platforms in the pursuit of multifaceted goals, and in light of varying challenges. We illustrate how people’s social media use can evolve alongside their chronic but changing health needs, and identify several social media challenges that are specific to ICIs that could be potentially mitigated through design.

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