

## Feeling less alone online: patients' ambivalent engagements with digital media

Alan Petersen, Sociology, School of Social Sciences, Monash University, Australia

Allegra Schermuly, Sociology, School of Social Sciences, Monash University, Australia

Alison Anderson, Sociology, School of Law, Criminology and Government, University of Plymouth,  
UK

### Abstract

Digital media offer the chronically ill, especially those who experience related isolation, unparalleled opportunities to connect with others. This article asks, how do these individuals ascribe meaning to and use these media to manage their condition and related isolation? Using the concepts of affordance and emotional community, and drawing on the findings from an Australian study on patients' use of digital media, we examine individuals' ambivalent ascriptions of media, which are both feared and distrusted for the risks they present and embraced as invaluable tools of social connection. We argue that this ambivalence is explicable in terms of the communities to which the chronically ill belong which are founded on strong emotional bonds. In a context in which individuals tend to feel isolated through pain and/or stigmatization, digital media may offer powerful means for sharing and affirming their experiences, the subjective benefits of which may outweigh the perceived risks. The article discusses the functions and features of digital media that the chronically ill value and distrust and concludes by considering the implications of our analysis for strategies to address the needs of people who feel isolated as a consequence of their condition.

### Keywords

Digital media, Facebook, patients, patient experience, chronic illness, social isolation, loneliness, affordance, emotional community

## **Introduction**

Of the many promises attached to digital media, the potential to establish contact with others from virtually anywhere at any time is paramount. In our contemporary hyper-connected world, it is widely assumed that one should never feel alone. For those who suffer the isolations of illness, which very often entail chronic pain and stigma, these media may hold especially strong appeal.

This article examines the role played by digital media in the lives of those who experience chronic illness-related social isolation. Digital media, comprising the internet, social media, and webcams and other online video and audio platforms, offer chronically ill individuals and their advocates novel options for sociality. These include connecting with others to create and share stories on specific conditions and treatments, building new communities and working with others such as professionals to influence research priorities or change policies (e.g. 'compassionate access' to unapproved therapies), and crowdsourcing for funds to support these activities (e.g. Petersen, et al., 2017; Rabeharisoa et al. 2014; Sosnowy 2014; Vicari and Cappai 2016). For chronically ill patients, isolation is often related to their severe ongoing pain, and sharing their experiences with others may be crucial for 'normalising' and making visible their experiences and feeling that they are not alone (e.g. Gonzalez-Polledo 2016; Mazanderani and Papparini 2015). However, while patients and patient advocates from different condition-specific communities have extensively exploited digital technologies to connect with others, as we show, this does not mean that they are uncritical of what digital media offer.

Employing the concepts of affordance and emotional community and drawing on interview data from an Australian sociological study on patients' use of digital media, we explore chronically ill individuals' complex ascriptions of the digital media that they use to manage their conditions and related feelings of isolation. We argue that patients' ambivalent assessments of the options offered by digital media can be understood in light of the priorities and values of the communities

to which they belong, which are bound by strong affective bonds and shape outlooks and actions in profound ways. In a context in which individuals feel isolated and marginalised and have few options for sociality, digital media may be seen to offer one of the few or only available means for them to share and affirm their experiences with others, the subjective benefits of which may outweigh the perceived risks. In the article we identify the functions and features of digital media that the chronically ill both value and distrust and consider the implications of our analysis for strategies to address lonely patients' needs. To begin, we offer some observations on the chronic illness experience in an age of growing digital connections, before introducing the concepts that underpin our analysis and turning to the details of our methods and findings.

### **Chronic illness and digital media**

The experiences of the chronically ill have been of interest to health sociologists now for more than four decades (e.g. Charmaz 1987; Larsson and Grassman 2012; Ytre-Arne 2019). As this body of work reveals, the impacts of chronic illness go beyond managing the condition itself and influence all aspects of affected individuals' lives, including their identity and sense of continuity and normalcy. Patients are compelled to grapple with what are often-debilitating symptoms and the side effects of treatment and are unable to maintain ongoing paid work and relationships outside the home. Consequently, chronic illness is characterised by 'biographical disruption' or disturbance to one's sense of continuity (Bury 1982), which often predisposes feelings of isolation. The nature of this disruption and the extent of isolation will be shaped by the nature of the condition, the options for treatment, and community responses, among other factors. For those living with HIV/AIDS and other stigmatised or rare conditions, patients may be especially susceptible to feeling isolated and this may, in turn, impact their health (Cherry and Smith 1993: 184). Irrespective of the condition, however, patients typically respond by seeking to re-establish a

sense of social connection and continuity through the telling of stories, or 'illness narratives' (Bury 2001; Kleinman 1988).

As Becker (1997) observes, the narratives that individuals tell about disruption, whether of chronic illness or other life-altering events (e.g. forced migration, divorce, loss of employment) are inescapably moral accounts that draw on a language specific to the sociocultural context and time to help them make sense of their experiences. Narratives enable one to attain a feeling of normalcy that has been brought into question by the disruption. Metaphors are crucial in the interpretation of events, in creating linkages between the past, present and envisaged future. While in all societies the course of life is structured by expectations about the future and its unfolding, Western societies tend to view life as 'a predictable, continuous flow' (Becker 1997: 7). One's life course is envisaged as moving forward in a linear, largely expected manner. Unpredictability is generally negatively viewed and order and certainty highly valued (1997: 6-8). However, as Becker notes, this perspective on disruption is shifting, and technological and other developments shape both how people make sense of irregular events and their impacts and also what they view as the possibilities for the future; that is, what they may hope for.

Increasingly, the digital imaginary shapes views of disruption and its impacts and options for action. While one may question whether the impacts of digital media are as profound as implied by the frequent use of the term 'disruption', there is no doubt that digitalisation is helping to recast how citizens communicate about issues of significance to them, including health and illness. The seminal contributions to the chronic illness literature were made before or in the very early years of the internet. They predate the launch in 1998 of Google, which is now the most widely used web-based search engine, and the advent of Facebook, which since 2004 has become established as the predominant digital platform around the world (Statcounter 2020). These and other platforms, including smartphone apps, social media and other online communications (e.g. Skype, Zoom) enable experiences of chronic illness to be mediated in novel ways. This is not to

suggest that pre-digital communications were unmediated or less mediated than they are now. Whether individuals interact face-to-face or use non-digital technologies, such as print media, communications are always culturally inflected (Miller and Sinanan 2014: 6-7). Nonetheless, digital media offer users new means for self-expression and unprecedented scope for controlling what and how much they reveal about themselves to others via their narrations. In the 'network society' individual patients and patient activists or advocates can engage in 'mass self-communication', and digital health technologies reposition them as co-creators (Castells 2011; Saukko, 2018).

There is a small but growing body of literature that examines how patients use digital technologies to create narratives about their conditions. An important theme is that of storytelling (e.g. Orgad 2005). Most studies have tended to focus on communicating chronic pain through blogs (e.g. Sosnowy 2014; Iannarino 2018; Rains and Keating 2011; Ressler et al. 2012). With the growing proliferation of media platforms, other studies have focused on platforms that contain images or memes. For example, Gonzalez-Polledo and Tarr (2016) analyse chronic pain narratives via social media networks Flickr (images) as well as Tumblr (blog posts).

### *Affordance*

In seeking to understand how the chronically ill engage with digital media, we have found the concept of 'affordance' (sometimes called 'sociotechnical affordance'), applied in analyses of technology-user engagements, to be useful. The concept of affordance was first used by James Gibson in his ecological approach to visual perception, to highlight what 'the environment *offers* the animal, what it *provides* or *furnishes*, either for good or ill' (2015: 119; orig. 1979; emphases in original). Gibson sought to emphasise the complementarity of organisms and the environments, in that while the latter offers options for action, different animals, including humans, modify their world in their own ways to suit their particular purposes (2015: 122). The value of the concept of

affordance is that it draws attention to the agency of users and their perception of what environments enable (2015: 126).

In elaborating on the utility of the concept for science and technology studies, Hutchby observes that this field of scholarship has been dominated by the notion that ‘technologies should be treated as “texts” that are “written” in certain ways by their developers, producers and markers, and have to be “read” by their users or consumers’ (2001: 6). However, the technology as text metaphor leads to an over-emphasis on the question of how technologies are represented and leads one to overlook the fact that different technologies possess different possibilities for action, which ‘constrain the ways that they can possibly be “written” or “read”’ (2001: 9). These affordances both enable *and* constrain action and assume and invite certain uses and users (2001: 11).

The concept, which draws attention to reciprocal interactions between the application of a technology, users’ responses and the social context, has found application in several areas of scholarship, including studies of communication and digital media (e.g. Jensen and Dyrby 2013; Nagy and Neff 2015; Schrock 2015). As this work makes clear, while producers may design technologies with particular users and uses in mind, the meanings that they are ascribed and the applications that they find will be shaped by the priorities and values of users *and* the contexts of their use. There are many examples of technologies finding applications that are different from those envisaged by their designers because their users have adapted them to suit their own purposes or used only certain of their functions or features, depending on the context. The use of airplanes as weapons, as occurred with the 9/11 attacks, and the use of digital technologies to influence elections and undertake extortion, identity theft and hacking are some noteworthy examples.

*Emotional communities*

The users in whom we are interested, namely the chronically ill, belong to communities whose members share a broadly similar range of emotional experiences and expressions. We propose that these communities shape assessments of digital media and the affordances they offer in significant ways. The stories of the chronically ill are typically ones of suffering, injustice and outrage—for being afflicted with a severe life-limiting illness and/or there being little or no research on their condition and/or being denied access to what are seen as life-saving therapies—and expressions of hope for improved lives in the future (Petersen, et al., 2013; Petersen, et al., 2017). Views on the character of the disease or condition, and how they should be managed, are forged within these communities, which may be the primary or only source of information for the chronically ill and their carers or family members. Following Rosenwein, these communities may be described as emotional communities whose ‘members adhere to the same valuations of emotion and their expression’ (2010: 1; see also Rosenwein and Cristiani 2018: 39-45).

Emotional communities are distinguished by distinct norms of feeling, or ‘feeling rules’ (Hochschild 1983) that prescribe the modes of emotional expression that members expect, encourage, tolerate, and deplore and the value and harm posed by particular emotions (Rosenwein 2010: 11). As Rosenwein explains, emotional communities are largely the same as social communities, whether neighbourhoods, families, academic institutions, or factories, and may vary in size and be an ‘imagined community’ (Anderson 1983); however, the researcher focuses first and foremost on the systems of feeling that the communities define as valuable or harmful to them, the nature of the affective bonds that bind people, and the modes of emotional expression that are expected, tolerated, and deplored (2010: 11). It is within these emotional communities that stories are created, embellished and circulated via various media, including increasingly social media.

Patients and their carers often use social media and weblogs to post stories about the day-to-day hardships and struggles that they or those whom they care for endure, using personal or

family photos to highlight their plight. These stories and images are circulated via a digitally networked architecture that shapes not just interactions and flows of information but the very identities of its users (Boyd and Ellison 2008). As Boyd and Ellison note, social network sites, in particular, are characterised by a combination of features that enable users to control their public profile within a bounded system, to make it public to defined users with whom they establish a connection, and to view and traverse their own connections and those established by others (2008). The performative self may establish a level of 'impression management' that would be difficult, if at all possible, offline, where speech and body language may reveal a great deal about one's thoughts and feelings. This affordance has been harnessed by patients and their families to connect with other patients with similar conditions, along with carers, researchers, health professionals, and businesses, to achieve goals that would have been extremely difficult before the internet. By combining social media and traditional print and electronic media, individual patients may produce their own knowledge, enhance the public profile of 'their' condition and promote particular treatments and/or providers (Petersen, et al., 2016).

The concepts of affordance and emotional community, we suggest, can be used to help explain why chronically ill individuals assess and engage with digital media as they do. In particular, they can help account for the powerful appeal of these media and why individuals may to continue to use them even when they recognise the significant risks that they carry. We believe our analysis has important implications for interventions oriented to those who experience chronic illness-related isolation and have few options for interactions in public life.

## **Methods**

Our article draws upon research that explored patients' use of digital media to access treatments, involving patients (sometimes also carers), and patient activists/advocates in Australia who represent particular patient communities: breast cancer, HIV/AIDS, and those living with



neurodegenerative conditions. Our study involved a combination of online surveys (n=302) and qualitative, semi-structured interviews (n=50) exploring how those from the above major condition-specific communities use digital media to shape research agendas and gain access to treatments. In this paper, we focus on the findings from the interviews since these provide in-depth insight into individuals' perceptions and experiences. Indeed, it was during the interviews that participants discussed their experiences of isolation and the connection afforded by digital technologies. By focusing on key areas where patients have influenced or sought to influence research agendas, and the development and availability of treatments (e.g. community awareness, fundraising, and the creation of information sources, databases and forums), we aim to reveal the sociocultural factors that shape individuals' use of digital media—and thereby characterise patients' use of digital media and its impact across different patient communities.

Our interview participants were principally recruited via the online survey, which attracted mostly female respondents (79 percent of the 166 participants who completed the survey and identified their gender) with the majority overall being between the ages of 35 and 74. To target the condition-specific communities we were interested in, we contacted Australian organisations representing these communities for assistance in publicising our call for survey respondents on their social media pages, email lists and newsletters. Given its self-selective nature, our final sample comprised those living with a range of conditions, including neurodegenerative diseases, stroke, HIV/AIDS, Parkinson's disease, spinal cord injury and spinocerebellar ataxia, and those who work on behalf of individuals living with these conditions (as self-identified activists or advocates), who were often also patients themselves.

The interviews were conducted face to face or by telephone and subsequently audiotaped and transcribed for ease of analysis. The interview transcripts were loaded into NVivo. Each transcript was read several times and the text coded thematically by each member of the research team, to increase consensus on the themes arising from the interview data. Once this process was

complete for all the interviews, the topics discussed by participants in response to open questions and topics they raised themselves were represented by eight main themes or 'nodes'. Each main node contained several sub-themes and sometimes sub-sub-themes, depending on the popularity of the topic. The ultimate list of main nodes comprised the themes: celebrity involvement; characteristics of digital media platforms; connection; defining 'activism' online; equality of access and opportunity; health information seeking; isolation/loneliness and navigating the online health space. Some of the themes, such as 'connection', were expected given its prominence in previous studies (e.g. Iannarino 2018; Orgad 2005; Rains and Keating 2011). Other themes, such as that regarding definitions of activism, were more unexpected and emerged from participants' initial reactions in interviews to being described as an 'activist'. Therefore, the process of arriving at the themes or findings was both an inductive and deductive one. The nodes represented the most common themes of discussion by participants in interviews, the issues that mattered most to them in relation to digital media use as patient activists and advocates. The data comprising the nodes 'isolation'/'loneliness' and 'connection' provide much of the evidence base for this paper. Furthermore, the node 'characteristics of digital media platforms', encompassed discussion of why participants used the platforms they did for various online health activities. It was from these discussions that it was possible to determine that Facebook was the most commonly used platform for patient activism. The online surveys revealed that over two-thirds of the sample were using this platform.

The nodes also represented an exploration of issues arising from the surveys, such as the way that digital activism aligned with patients' broader illness narratives and perceptions of the practice of online engagement including negotiating the risks and exploiting the benefits of particular technologies. Our participant's use of particular metaphors, words and terms conveyed how they construct their realities, and bring order to seemingly unconnected events, and we were able to gain valuable insights into the moral ascriptions that individuals attached to their actions.

## Findings

As noted, our research aimed to explore patients' use of digital media to access treatments and the sociocultural factors that shape this use. We did not set out to explore a particular hypothesis and our questions were wide ranging. Therefore, our finding that patients often feel isolated or lonely as a consequence of their condition was unexpected. While we acknowledge that our self-selected sample may include respondents who felt especially lonely and perhaps saw the interview as an opportunity to share their experiences, their spontaneous expressions of feeling isolated or lonely is noteworthy, and confirms previous research on the experiences of those living with chronic illness (Meek et al. 2018; Petite et al. 2015). The chronically ill may feel lonely as a consequence of the disruption to their social lives that frequently accompanies the onset of illness. A recent cross-national survey revealed that people who experience loneliness disproportionately report having a debilitating chronic illness, acquired disability or injury or other negative life events (DiJulio et al. 2018).

Participants explicitly or implicitly linked such feelings to the nature of the condition itself, which in some instances was felt to carry stigma, or to the symptoms (e.g. extreme pain or tiredness), which made it difficult to fully participate in social activities outside the home. While only one of our respondents used the term 'loneliness' in their account of digital media use, others used phrases such as 'feeling alone' or 'isolated and alone' or 'I'm actually very isolated', or references to the fact that 'chronic illness is very isolating', and the like.

In recounting these feelings, they often mentioned that the internet (most commonly email and Google) and social media, and Facebook in particular, were important to them or other patients in making connections and exchanging stories. The words 'connecting' and 'sharing' figured prominently in their descriptions of the benefits derived from these media. This sharing and connecting entailed more than a straightforward exchange of information regarding the

nature of the condition itself and treatments, but the tendering of confirmatory evidence that one's feelings are valid. And it is here that digital media have come to provide a ready-to-hand means for affirming the uniquely isolating experience of pain and, for some, knowing that there existed the security of diagnostic confirmation. Yet, as our respondents' accounts made clear, they were not uncritical in their use of digital media.

While recounting the various benefits of digital media, a number of respondents also mentioned, without prompting, that such media contained various risks, including the potential for surveillance, harmful conduct and 'misinformation'. Concerns were expressed about social media in general and Facebook specifically, with comments suggesting wariness, scepticism and/or distrust of this platform's functions or features.

### *De-humanising impacts*

Cam, who co-founded and coordinated a 'private online community' representing people with HIV/AIDS, mentioned the 'de-humanising aspect' of their online connections that 'combined with the incredibly human experience of living with HIV'. Mary, whose condition, fibromyalgia (which causes generalised pain and muscle stiffness throughout the body), qualified her generally positive assessment of digital media, and specifically Facebook, with: 'I would never join Facebook normally' and that 'it's just another marketing tool as far as I'm concerned...and I've got my own little conspiracy theories', but joined 'because it was a way of showing my friends what I was doing....' In elaborating on her views, Mary referred to early (1980s) attempts to introduce an Australia Card—a national identification card proposed in 1985 and abandoned in 1987, following much public controversy, as well as George Orwell's dystopian novels 'Animal Farm and 1984'—in effect, tendering evidence of the potential for surveillance posed by digital technologies.

### *Trolling, inappropriate postings and impersonation*

Cheryl, who recounted the benefits of digital media for the socially isolated, raised a series of concerns. She observed that 'you can get terribly trolled' [on social media], commenting that 'there's still people who are behind a keyboard, warriors who can sit there and write underneath a photograph of somebody who is clearly visibly disabled, 'you should have been killed at birth'. Adding: 'That sort of thing happens a lot.' She also said that it was 'too easy just to put up a Facebook page' and that 'you don't have to answer any questions', which, for her, helped explain why 'fake news' had spread. Elsewhere in the interview she talked about a particular online experience involving impersonation on her patient group's Facebook page. She commented that 'you can impersonate anyone on social media. And I think there are people who are vulnerable to that and suggestible, which is awful, but they are there.' Cheryl, a patient activist who worked on behalf of a support group for people with neurodegenerative conditions, also expressed doubt about the potential to regulate Facebook because, she indicated, the company made themselves difficult to contact, which she saw as a way of avoiding responsibility.

#### *Inaccurate, untrustworthy or biased information*

Other respondents expressed fears about the potential for other users to reveal information about a person's health condition that could be detrimental to their health, or about people making comments about a condition they do not have or understand. Some raised concerns about the trustworthiness of sources or information on social media. For example, Barbara, who said that digital media assisted her to share her experiences of episodic ataxia, commented that people may accept information as 'the be-all and end-all, without any...research that goes with it'. She cited the case of another patient who, in her view, had made an inaccurate assessment of the severity of their episodic ataxia based on information provided by someone online. In her view, the patient was led to believe that they had the 'lesser' rather than the 'greater' [more severe] version of their condition and that their prognosis was in fact 'the worst one'. She noted that it

was difficult to say anything online. Barbara also observed that patients were comparing quotes for the cost of undertaking genetic testing, which, she felt 'could be quite disappointing if you're a person who can't afford to have the highly-expensive genetic testing that has to be sent overseas'.

Lucy, a breast cancer survivor and activist who said she found it difficult to discuss 'anxiety and death' with her family and described the 'life changing' impact of Facebook, especially with being able to 'interact in your own time when you're ready', also referred to the 'downsides' of social media, including 'poor or incorrect information'. She indicated that she was 'not particularly internet savvy' and, while she used Facebook prior to her diagnosis she was 'not super-active' and 'didn't think I would enjoy or get much benefit from online support because I'm a bit of a face-to-face person'. Yet, while recounting the benefits of digital media for her now, she also mentioned the generation of anxiety in those newly diagnosed with conditions that access 'overwhelmingly negative information', especially from those online users with strong views who had been diagnosed in the past and saw themselves as 'king of the hill'. In Lucy's view, the operation of 'complex algorithms' may lead to users being 'very cocooned'. She referred to the impact of 'anti-science' postings and the 'hostile' messages that are sometimes found on Facebook.

Despite these frequently expressed reservations and evident fears about digital media, it is noteworthy that none of our respondents questioned their overall benefits for individual patients or patient communities. Rather, they tended to take the view that, despite the risks they presented, digital technologies provide valuable tools of connection and that they had improved their own or other patients' lives. This generally positive assessment of digital media may reflect the self-selected nature of our sample, with more critical consumers perhaps avoiding using these media and hence not volunteering to be interviewed. But it is noteworthy that, despite respondents' evident awareness of and concerns about the limitations and risks of digital media, they were prepared to overlook these in order to exploit the benefits they were seen to afford—especially the potential to feel part of a community of those sharing common experiences.

### *Feeling part of a community*

Cheryl, the patient activist who worked on behalf of a support group for people with neurodegenerative conditions, recounted the benefits of social media: 'There is definitely good things about it for people who are isolated, I think. And it's that sense of belonging or finding common interest ... or reinforcing a friendship group.' Vicki, a breast cancer advocate, said that social media allowed her to maintain more regular contact with other affected women she had linked up with online:

I can't duck and see her all the time and say, 'how are you going' but I can send her a message or something and say, 'Look, just thinking about you today and I hope you are ok'. And just for her to know that there's someone there that is caring about her...that still remembers her is really important.'

For Mary, whose condition, fibromyalgia left her unable to move and feeling that 'my brain is going to explode from pain', the connections she established online enabled her to determine that her symptoms were 'normal'.

'I could feel it sort of crawling inside me and ... you would ache from the inside out. And I found a lot of women all over the world that say, "Is this a symptom of fibro?" And I can tell, from my experience, it was certainly a symptom of mine.'

In many cases, 'sharing' entailed expressing empathy; that is, showing oneself to be concerned with and understanding the experience of others. The connection enabled by digital media is evidently a deeply emotional one, providing confirmation that one's feelings are both valid and acknowledged by others within one's community. As Rosenwein argues, while one can learn much about emotional communities from individual stories, since they are addressed to a public, they imply a wider group; by having several different voices one can more easily discern where the

commonalities of emotional experience lie (2010: 12). As a number of our participants explained, it was important for them to know that someone was available when needed and, as one expressed it, ‘talking to other people with similar issues’. By enabling them to compare and ‘affirm’ their experiences, digital media made them *feel* ‘less alone’.

A few described their use of digital media in terms that conveyed that the impacts were personally transformative or empowering. For example, one participant commented that ‘I’m just such a different person thanks to being able to have access to all of these different genres through finding them online and working with them online.’ The comments of some other respondents, on the other hand, indicated that they made a more pragmatic, albeit personally significant assessment of the benefits of digital media. For example, they indicated that digital media enabled them to ‘keep abreast of issues’, reach a large audience, and spread awareness of their or their community’s disease or condition—the latter being especially valued by those who through their advocacy roles sought to improve the lives of fellow patients.

### *Controlling interactions*

The functionality and features of Facebook made it a popular choice for our respondents—reflecting the findings of our survey (see Methods). Crucially, Facebook enabled users to manage the extent, manner and timing of their interactions. As some respondents noted, they could choose to simply observe rather than participate in communications if they so desired, according to the issues and personalities involved, or make their profile only ‘semi-public’ using Facebook’s privacy settings.

Cam, the aforementioned HIV/AIDS activist, spoke of the valuable features of Facebook, namely ‘privacy settings’ that performed a dual function, serving both as a tool for advertising the aims of the group (‘to promote the movement, share news and information about HIV in general’) and as a means of preserving participants’ confidentiality, which was deemed crucial. As he



explained, 'You can start with an open group and make it closed...[or] You can turn a closed group into a private group.' He noted, 'People join with an assumption of a degree of confidentiality. Now the reality, of course, is that, whilst we have the highest confidentiality privacy settings on Facebook...actual confidentiality of the groups is the responsibility of all the members.' In his responses, Cam was careful to distinguish between the Facebook platform itself, which he described as 'a marketing tool' and 'the private group [of users which] is the actual movement'. As he explained, the online community 'needs to have a confidential space because the community is not quite ready to have that information fully available to anyone who could stumble upon it....And the benefits...of having a private Facebook community is that, if you are a member of that group, it doesn't show up on your profile and it doesn't get into other people's newsfeeds unless they're also members of the group.'

The value of the privacy settings offered by Facebook became evident as he elaborated on the history of the community. Cam and the other co-founder originally met at a weekend workshop where 'we decided to start something', which was an 'email group based pretty much on the members of that workshop.' However, after further meetings and growth in the community's membership, 'I quickly realised that a social movement for people living with HIV that ignored social media at that point in history was folly, so we created the private on-line community via Facebook called [name of organisation]'. As he noted, the online community had initially been conceived for gay men and men who have sex with men who were newly diagnosed with HIV. However, the group founders soon realised how important it was 'to ensure that it was inclusive of women and non-binary people, etc.' in terms of providing an online resource for people living with HIV. This provided 'the extraordinary opportunity for the majority of the members who are gay men or men who have sex with men to...hear the perspectives of women with HIV...so it was a big turning point.' Another inclusive aspect of this online community was the

ability of members to start a conversation at any time of the day. Cam commented, his community 'is essentially a digital drop-in centre that's open 24 hours, seven days a week'.

The potential of Facebook in particular and digital media in general to enable control over the *timing* of one's interactions was also mentioned by other respondents. Pete, from the Parkinson's disease community, commented that the '24-hour cycle' meant that someone posting a question in one part of the world could wake up next morning with an answer from another part of the world. This affordance is one that makes Facebook a highly attractive tool for patients and helps explain why many patient communities have quickly adopted the platform for both routine communications and to advance collective goals. In a study of hospice patients, for example, it was found that people 're-purposed' Facebook so as to allow them to establish their relationships at a desired distance (Miller 2017).

Facebook allows users a level of control over interactions that would be difficult if at all possible offline, which, our research confirms, greatly appeals to users. The functions and features of social media in general and Facebook in particular enable users to 'curate' their selves, including emotional expressions, via the 'backstage' work of carefully crafting messages and images to achieve desired online persona and impressions. The ability to control interactions online was considered crucial by those from communities that suffer stigmatising conditions, such as HIV/AIDS, or who are prone to harassment. Patients within these communities can selectively reveal or conceal aspects of themselves in a way that would be difficult offline. A number of respondents mentioned that social media allowed them to moderate their interactions when feeling drawn in to serving others' needs to the neglect of their own. These individuals noted that they could just observe and contribute to the extent that they felt this met their needs (see also Maslen and Lupton 2019).

*Sharing experiences of pain*

For some of our respondents, the experience of isolation was inextricably linked to their severe ongoing pain. Anna, an advocate for people with neurodegenerative conditions, noted that ‘I’m out in the desert alone a lot of the time with chronic pain’, adding that digital media allowed her ‘connection and...sharing...stories and feeling less isolated by having that available to me.’ For her, the internet was her ‘first port of call a lot of the time, especially when I’m diagnosed with something else.’ This use of digital media to share stories of pain was very common and often served to evoke expressions of empathy from others.

It was commonly noted that it was difficult to share experiences of pain and other isolating aspects of one’s illness, even with one’s intimate partners, and that this was where digital media’s potential to enable users to exchange experiences was welcomed.

As Zoe, who was recovering from stroke, explained:

‘It’s an uphill marathon, stroke recovery, and extremely lonely because so few people understand just how hard it is. Even people, you know, from their intimate partners, will feel they don’t quite understand even if they’re an amazing person. And so, the other people saying, “I felt like that too. I experienced that too”, is incredibly powerful.’

Zoe, like many others we interviewed, valued the convenience of social media. She found it ‘very difficult to access face-to-face support when you’re working and parenting because they’re [other stroke patients] primarily...retirees meeting in the daytime.’ Consequently, she ‘started looking at online stroke groups on Facebook’ and found one that involved mainly women of working age who were discussing parenting issues and ‘I found lots and lots...of validation.’ As our participants’ accounts conveyed, the internet helps those affected by chronic illness overcome the limitations of their condition and potentially—as with Zoe—the constraints posed by the demands of their family or work roles, allowing them to feel part of a community of others with similar experiences.

As Bill, a patient activist who represents people with neurodegenerative conditions, expressed it:

“People need to talk and people need to... be able to get some support from each other.

Look, human beings were never meant to be isolated and yet, unfortunately, chronic pain isolates all of us completely. It’s the new leprosy - you look good on the outside.”

Bill’s use of the term ‘leprosy’ strongly conveys the stigmatising aspect of chronic pain mentioned explicitly or obliquely by many of our respondents. His comment conveys the invisibility of pain—its lack of evident symptoms—sometimes referred to by those whom we interviewed (see Scambler 2009). As explained by Denise, who lives with chronic pain and depression linked to her neurodegenerative condition: ‘[I]t’s not like I know anyone else in my situation...so it’s really good to get out there and...talk about some of the things that go on and the struggles that you have day-to-day, they also have it...so, you don’t feel as alone.’

Mary, who suffered from fibromyalgia and other chronic conditions, and was active in various Facebook-based support groups, also commented that ‘chronic illness is very isolating’. As she went on to say, chronic pain is ‘such an isolator’ that ‘does send you crazy’ and that ‘there’s nothing worse than being backed into a corner and knowing that you’re gonna drown’. In accounting for her use of digital media, she indicated that it provided ‘a sort of lifeline, at least you feel as if you’ve got an alternative’. She noted, ‘the internet enables me to stay in touch with people and...watch movies or whatever’, and that ‘when you’ve not got the strength to go out, it’s helpful to be able to order your groceries’. Similar to a number of others, she indicated that she had not been able to discuss her feelings of desperation with family members and that consequently ‘the Internet had been very freeing for someone like me’. Also like others, for her, the valued affordances of digital media encompassed a number of dimensions: a kind of escape hatch when things proved difficult (a ‘lifeline’), a means for regular contact with others (‘stay[ing] in touch with people’), and everyday practical activities, including entertainment and ordering

groceries. By offering these options, digital media enabled her to feel connected and less isolated dealing with her chronic pain.

The isolation of pain, a number of respondents said, went beyond the physical suffering associated with their condition to include all aspects of life—confirming research on the profound disruption experiences of those living with chronic illness, noted earlier. This was evident from the comments of Irma, who used medicinal marijuana to relieve the symptoms of her pain which she had suffered for ‘the better part of 25 years’, related to her neurodegenerative condition. As she explained, ‘It affects your sexual life...your house duties, if you are a housewife.’ Consequently, being able to share one’s experiences, ‘to tell people who understand and can give you that empathy that you’re looking for...is really important to me, personally.’ She has used the internet for about 20 years, especially since the advent of Facebook, which allowed her the empathetic encounters that she would otherwise be lacking. As she noted, ‘we need to talk about it, to feel like we’re not alone and having the outlet of others to all come together for being able to be someone who will listen and understand...are really, really big, especially for people like me.’

In short, among our respondents, feelings of isolation were common and, for a number, an integral aspect of their identity as a person with chronic illness. For these individuals, digital media was of crucial importance in their lives, enabling them to share and ‘validate’ their experiences and know that there are others available who will listen and offer support, while allowing them to control the extent and timing of their interactions. As noted, this sharing and validation enabled them to achieve a ‘sense of belonging’ and feel that they are part of a community defined by a common interest—which was especially valued by those suffering the isolation of pain and stigma.

### **Discussion and conclusion**

Our findings underscore patients’ ambivalence regarding the options enabled by digital media. On the one hand, these media, especially Facebook, offer them affordances that they highly value.

These include the potential to conveniently and easily connect with others outside their immediate family and to control the timing and extent of interactions. This connectivity enables individuals to *feel* part of a community, to know that others are readily available when needed with whom they can share and affirm their experiences or provide information or advice—which is clearly of crucial importance to those isolated by illness. Yet, respondents' concerns, spontaneously expressed during interviews, convey wariness and distrust of digitally mediated communications, with Facebook—the greatly valued platform—being mentioned as presenting various risks. These include the potential for impersonation, misrepresentation and trolling, the distribution of fake news, marketing, hostile postings and anti-science views, and the creation of disappointed expectations. Of course, we have no way of knowing how widely these views are held across the great diversity of patient communities and whether individuals' media practices are consistent with their expressed views. Nevertheless, the findings suggest a complex picture of patient-user interactions, and more so than that conveyed by much of the scholarly and policy literature, which tends to emphasise the potential for individual patients and patients communities to be 'empowered' by the use of digital media (e.g. Gillett 2003; Ziebland and Wyke 2012).

Our findings confirm those from a growing body of research revealing citizens' ambivalent relationship with digital technologies, which are experienced as neither consistently positive nor consistently negative on all dimensions of what they offer (e.g. connectivity, instantaneity) (Marent et al. 2018: 139; see also Davis 2012). As this work highlights, users may embrace or reject features or functions of technologies depending on the context in which they are used, and perceptions of their risks. These assessments, in turn, are likely to depend on users' previous experiences and established practices of using technologies (Marent et al. 2018: 136). However, we suggest that ambivalence is likely to be especially pronounced among those who experience chronic illness-related isolation, given the emotional communities to which they belong. Members

of these communities have shared experiences of disruption in their lives and are required to grapple with often severe ongoing symptoms, including chronic pain, and uncertainties about their future, accompanied by feelings of social disconnection and vulnerability (Petersen, et al., 2017). In a context in which individuals' participation in public life is severely restricted, digital media promise the experience of human immediacy and intimacy—the sharing and affirming of one's experiences of which our respondents spoke—that healthy citizens may take for granted. Indeed, as our respondents' comments make clear, for some patients (e.g. those living with HIV/AIDS), digital media offers affordances that are assessed to be *uniquely attuned to their needs*, namely the ability to contact others at one's convenience and use functions such as privacy settings in order to preserve anonymity. Yet, as our respondents themselves recognised, these same affordances call for an investment of trust in technologies whose operations are opaque and enable forms of sociality that carry significant risks. Our respondents' evident wariness and distrust of digital technologies is understandable in light of the particular circumstances these individuals and their communities confront and their reliance on technologies that carry potential harms. The implications of this for initiatives addressed to chronically ill patients who feel isolated are important to acknowledge in light of recent loneliness policies.

In a number of countries, including the UK, Australia and the US, policymakers and commentators have recently voiced concerns about a widely reported 'epidemic of loneliness' which is perceived to disproportionately impact particular groups, including the chronically ill (Cigna 2018; IPSOS 2018; Co-Op/British Red Cross 2016; ONS 2018). In response, authorities and service organisations have developed or recommended the use of digital technologies and platforms to meet lonely individuals' needs; for example, Good Karma Network, One Good Street, Gather my crew.org, Forever Alone Together! However, our findings lead us to conclude that optimism for loneliness interventions involving digital technologies needs to be tempered by caution regarding the likely benefits for individuals, given the various risks that technologies pose. The desire for

intimate sociality is a fundamental human need that may in some cases be assisted by the use of digital technologies of communication. But when these technologies erode trust and generate wariness and unease among users one needs to question their benefits and ask whether growing reliance on them ultimately serves to make their users feel more rather than less alone.

### **Acknowledgement**

We wish to acknowledge the support offered by all our participants who kindly offered their time and generously shared their experiences. We would also like to acknowledge the support offered by the Australian Research Council (DP170100402), which funded the project upon which the paper draws. Finally, we would like to thank Dr Kiran Pienaar who provided valuable feedback on an earlier version of this paper.

### **Address for correspondence**

Alan Petersen, Sociology, School of Social Sciences, Monash University, Clayton 3800, Victoria, Australia. Email: Alan.petersen@monash.edu

### **References**

- Anderson, B. (1983) *Imagined Communities: Reflections on the Origin and Spread of Nationalism*. London: Verso.
- Becker, G. (1997) *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley, CA: University of California Press.
- Boyd, D. and Ellison, N. B. (2008) Social network sites: definition, history, and scholarship, *Journal of Computer-Mediated Communication*, 13, 210-230
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, 2: 167-182



- Bury, M. (2001) Illness narratives: fact or fiction?, *Sociology of Health and Illness*, 23, 3: 263-285
- Castells, M. (2011) *The Rise of the Network Society: The Information Age: Economy, Society and Culture*, Chichester, West Sussex; Malden, MA: Wiley-Blackwell.
- Charmaz, K. (1987) 'Struggling for a Self: Identity Levels of the Chronically Ill', *Research in the Sociology of Health Care*, 6, 283-321
- Cherry, K. and Smith, D. H. (1993) Sometimes I Cry: The Experience of Loneliness for Men with AIDS, *Health Communication*, 5, 3: 181-208
- Cigna (2018) Cigna US Loneliness Index, [https://www.multivu.com/players/English/8294451-cigna-us-loneliness-survey/docs/IndexReport\\_1524069371598-173525450.pdf](https://www.multivu.com/players/English/8294451-cigna-us-loneliness-survey/docs/IndexReport_1524069371598-173525450.pdf)
- Co-Op/British Red Cross (2016) Trapped in a Bubble: An Investigation into Triggers for Loneliness in the UK, <https://www.co-operative.coop/campaigning/loneliness>
- Davis, J. (2012) Social media and experiential ambivalence, *Future Internet*, 4: 955-970.
- DiJulio, B., Hamel, L., Muñana, C. and Brodie, M. (2018) Loneliness and Social Isolation in the United States, the United Kingdom, and Japan: An International Survey. The Henry J. Kaiser Family Foundation: San Francisco, CA.
- Gibson, J. J. (2015; orig. 1979) *The Ecological Approach to Visual Perception*. Classic Edition. New York and London: Psychology Press.
- Gillett, J. (2003) Media activism and internet use by people with HIV/AIDS, *Sociology of Health and Illness*, 25, 6: 608-24
- Gonzalez-Polledo, E. (2016) Chronic Media Worlds: Social Media and the Problem of Pain Communication on Tumblr, *Social Media and Society*, January-March: 1-11. DOI: 10.1177/2056305116628887
- Gonzalez-Polledo, E. and Tarr, J. (2016) The thing about pain: The remaking of illness narratives in chronic pain expressions on social media, *New Media and Society*, 18, 8: 1455-1472

- Hochschild, A. R. (1983) *The Managed Heart: The Commercialization of Human Feeling*. Berkeley, CA: University of California Press.
- Hutchby, I. (2001) Technologies, texts and affordances, *Sociology*, 35, 441-456
- Iannarino, N. T. (2018) "My Insides Feel Like Keith Richards' Face": A narrative analysis of humor and biographical disruption in young adults' cancer blogs, *Health Communication* 33,10: 1233-1242
- IPSOS (2018) Over Half of Americans Report Feeling Like No One Knows Them Well.  
<https://www.ipsos.com/en-us/news-polls/us-loneliness-index-report>
- Jensen, T. B. and Dyrby, S. (2013) Exploring affordances of Facebook as a social media platform in political campaigning, *Proceedings of the 21<sup>st</sup> European Conference on Information Systems', Completed Research*, 40. [https://aisel.aisnet.org/ecis2013\\_cr/40](https://aisel.aisnet.org/ecis2013_cr/40)
- Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. London: Hachette.
- Larsson A.T. and Grassman E.J. (2012) Bodily changes among people living with physical impairments and chronic illnesses: Biographical disruption or normal illness?, *Sociology of Health and Illness*, 38, 8: 1156–1169
- Marent, B., Henwood, F., Darking, M., on behalf of the EmEmerge Consortium (2018) Ambivalence in digital health: co-designing an mHealth platform for HIV care, *Social Science & Medicine*, 215: 133-141.
- Maslen, S. and Lupton, D. (2019) Keeping it real: women's enactments of lay health knowledges and expertise on Facebook, *Sociology of Health and Illness*, <https://doi.org/10.1111/1467-9566.12982>
- Mazanderani, F. and Papparini, S. (2015) The stories we tell: qualitative research interviews, talking technologies and the "normalisation" of life with HIV, *Social Science and Medicine*, 131: 66-73
- Meek, P., Bergeron, D., Towne, D., Ahn, S., Ory, G. and Smith, L. (2018) Restricted

- social engagement among adults living with chronic conditions, *International Journal of Environmental Research and Public Health*, 15, 1, e158. DOI: 10.3390/ijerph15010158
- Miller, D. (2017) *The Comfort of People*. Cambridge: Polity Press.
- Miller, D. and Sinanan, J. (2014) *Webcam*. Cambridge: Polity Press.
- Nagy, P. and Neff, G. (2015) Imagined affordance: reconstructing a keyword for communication theory, *Social Media and Society*, July-December, 1-9. DOI: 10.1177/2056305115603385
- Office for National Statistics (2018) What Characteristics and Circumstances are Associated with Feeling Lonely? <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/lonelinesswhatcharacteristicsandcircumstancesareassociatedwithfeelinglonely/2018-04-10>
- Orgad, S. (2005) *Storytelling Online: Talking Breast Cancer on the Internet*. New York: Peter Lang.
- Petersen, A., Munsie, M., Tanner, C., MacGregor, C. and Brophy, J. (2017) *Stem Cell Tourism and the Political Economy of Hope*. Palgrave Macmillan: London.
- Petersen, A., MacGregor, C. and Munsie, M. (2016) 'Stem cell miracles and Russian Roulette?: patients' use of digital media to campaign for access to clinically unproven treatments', *Health, Risk & Society*, 17, 7-8: 592-604
- Petersen, A., Seear, K. and Munsie, M. (2013) 'Therapeutic journeys: the hopeful travails of stem cell tourists', *Sociology of Health & Illness*, 36, 5: 670-685.
- Petitte, T., Mallow, J., Barnes, E., Petrone, A., Barr, T. and Theeke, L. (2015) A systematic review of loneliness and common chronic physical conditions in adults, *Open Psychology*, 8 (Suppl 2), 113–132
- Rabeharisoa, V., Moreira, T. and Akrich, M. (2014) Evidence-based activism: Patients', users' and activists' groups in knowledge society. *Biosocieties*, 9, 2, 111–128

- Rains, S. A., and Keating, D. M. (2011) The social dimension of blogging about health: Health blogging, social support, and well-being, *Communication Monographs*, 78, 511–534
- Ressler, P. K., Bradshaw, Y. S., Gualtieri, L. and Chui, K. K. (2012) Communicating the experience of chronic pain and illness through blogging, *Journal of Medical Internet Research*, 14, e143
- Rosenwein, B. H. (2010) Problems and methods in the history of emotions, *International Journal for the History and Theory of Emotions*, 1, 1-33
- Rosenwein, B. H. and Cristiani, R. (2018) *What is the History of Emotions?* Cambridge: Polity Press.
- Saukko, P. (2018) Digital health – a new medical cosmology? The case of 23andMe online genetic testing platform, *Sociology of Health and Illness*, 40, 8: 1312–1326
- Scambler, G. (2009) Health-related stigma, *Sociology of Health and Illness*, 31, 3: 441-455
- Schrock, A. R. (2015) Communicative affordances of mobile media: portability, availability, locatability, and multimediality', *International Journal of Communication*, 9; 1229-1246
- Sosnowy, C. (2014) Practicing patienthood online: Social media, chronic illness, and lay expertise, *Societies* 4, 2: 316-329
- Statcounter (2020) *Social Media Stats Worldwide Feb 2019 to Feb 2020*.  
<https://gs.statcounter.com/social-media-stats> Accessed 10 March.
- Vicari, S. and Cappai, F. (2016) Health activism and the logic of connective action: A case study of rare disease patient organisations. *Information, Communication and Society*, 19, 1653–1671
- Ytre-Arne, B. (2019) Media use in changing everyday life: How biographical disruption could destabilize media repertoires and public connection, *European Journal of Communication*, 34, 5: 488–502
- Ziebland, S. and Wyke, S. (2012) Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health?, *The Milbank Quarterly*, 90, 2: 219-249

