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‘A platform for goodness, not for badness’: the heuristics of hope in patients’ evaluations of online health information

Abstract

Patient advocates and activists are increasingly relying on online health information that can assist them to manage their health condition. Yet once online, they will confront diverse information whose veracity and utility are difficult to determine. This article offers a sociological analysis of the practical methods, or heuristics, that patient advocates and activists use when making judgements about the credibility and utility of online information. Drawing on the findings from interviews with fifty Australian patient advocates and activists, it is argued that individuals’ use of these heuristics reflects their hopes that information can help them manage their condition which may, in some cases, override fears and uncertainties that arise during searches. The article identifies the common ‘rules-of-thumb’—or what we call the ‘heuristics of hope’—that patient advocates/activists may use to make judgements and highlights the dangers of over-reliance on them, especially regarding clinically unproven, potentially unsafe treatments. Analyses of the heuristics of hope, we conclude, can assist in understanding the dynamics of decision-making and the role that affect plays in online patient communities which is crucial in an age characterised by the rapid circulation of emotionally charged messages, often based on hope.

Key words

Patient advocates/activists, online health information, heuristics of hope, credibility assessments, digital health, affective decision making

Introduction

For patients, the internet is now a major source for information on managing their health (Bujnowska-Fedak, et al., 2019). While individuals' informational needs will vary according to the nature, severity, and stage of the illness, all will be seeking information that they can trust and rely on for health decisions. Many patients are highly vulnerable: they may suffer severe ongoing pain, restricted mobility, feel lonely and/or marginalised, and have insufficient support for their ongoing needs (Authors). They belong to 'emotional communities' (Rosenwein and Cristiani, 2018) bound by common experiences of pain, distress and the frustrations of restriction on their lives and the hope that the information they acquire will assist them to manage often complex conditions. However, once online, individuals will encounter a surfeit of information whose credibility and utility will be difficult to determine (Swire-Thompson and Lazer, 2020).

Making reference to data from a study involving interviews with fifty Australian patients who self-identify as activists or advocates and carers from various disease- or condition-specific communities about their use of digital media to access treatments, we examine the practical methods, or heuristics, individuals use to make judgements about the credibility and utility of online health information. Heuristics are generalisations or 'rules-of-thumb' that help simplify judgements in situations of complexity or uncertainty and draw on past experiences (e.g. familiarity with certain situations or settings), shared cultural knowledge (e.g. stereotypes), trust in certain authorities or expertise, and subjective impressions. As we argue, individuals' use of heuristics reflect their hope that online information will help them manage their condition which may override fears and uncertainties that arise during searches. We discuss how these heuristics—or what we call the heuristics of hope—guide individuals' selection and evaluation of information. As we conclude, reliance on these heuristics may lead individuals to make decisions based on incomplete, faulty, or confusing information which may lead to outcomes that are not optimal

for their health. We conclude that greater attention needs to be given to researching the heuristics of hope whose implications for those making decisions in the high stakes context of health information may be far-reaching. To begin, we summarise the relevant literature and outline our guiding concepts and assumptions and outline the study from which our data draws, before turning to our findings and considering the implications.

Patients and online information

The question of how patients navigate and evaluate online health information sources has been of interest to social scientists and other researchers for more than twenty years (Authors; Beck, et al., 2014; Lupton, 2013; Sillence, et al., 2007; Nettleton, et al., 2005; Zeibland, 2004; Henwood, et al., 2003; [Eysenbach and Köhler, 2002](#); Cline and Haines, 2001). This research, which has been undertaken against a background of a growing emphasis on self-responsibility for health and individuals' use of technologies for self-care, reveals patients' complex, often ambivalent engagements with online information. It underlines the limitations of the 'rational actor' model and the assumption underpinning many discussions of digital health that access to online sources necessarily 'empowers' patients (Author). As Henwood and her colleagues observed nearly two decades ago in their study of women's 'information practices', people may not want to take responsibility for their own health or acquire information themselves for various reasons and, if they do, their research may be unsystematic and pay little attention to the sources that publish the information being accessed (2003: 604-605). The 'digitally engaged patient' may use technologies to varying degrees according to their own needs and emotional investments (Lupton, 2013: 262-263). Some patients use the internet to simply gain information, while others may actively engage by posting messages, sharing information, commenting on health-related issues, or joining or developing web-based communities (Madrigal and Escoffery, 2019). Patients' use of the

internet is likely be contingent on their condition and health needs, and they may complement information derived from the internet with that gained from other sources, including formal healthcare settings (Nettleton, et al., 2005: 974).

Since the launch of Facebook in 2004 and other social media platforms, patient communities have been able to create and share information to an extent not previously possible. Many patients now integrate science-based, or credentialed expert knowledge and ‘experiential knowledge’ to undertake ‘evidence-based activism’ (Rabeharisoa, et al., 2014). This involves working within biomedicine and in collaboration with credentialled experts, including scientists, clinicians, and the pharmaceutical industry (McCoy, et al., 2017; Moynihan and Bero, 2017). To achieve their goals, patients use social media and online blogs to extend traditional ‘illness narratives’ by combining humour and narrative immediacy to make their experiences (for example, of chronic pain) visible, to evoke sympathy and empathy, and build community (e.g. Gonzalez-Polledo and Tarr, 2016; Iannarino, et al., 2018; Sosnowy, 2014). These narratives change over time as patients refashion their identities through telling stories, and typically comprise expressions of hope for promising treatments or cures (e.g. DePalma, et al., 2021; Soundy, et al., 2011). These hopes are sustained and circulate in online communities and are exploited by providers who use the internet to advertise clinically unproven treatments (Authors).

The role of heuristics

While the significance of hope for patients and their families is well understood, little is known about how hope shapes patients’ methods for evaluating the credibility of online information. As noted, many patients living with a chronic illness are vulnerable, and this may predispose them to hopeful messages regarding new treatments or cures, and perhaps disregard or downplay complexities and uncertainties of information, for example, regarding

the development of the science or the side-effects of interventions. An extensive literature exploring how patients assess the credibility, trustworthiness, or ‘believability’ of information online, including via internet forums and social media, underlines that patients’ methods for assessing the veracity of online information are ‘messy’ and convoluted, and shaped by subjective factors such as personal experiences, trust, and the perceived characteristics of the source/s (e.g. Hirvonen, et al., 2018; Keeling, et al., 2013; Klawitter and Hargitti, 2018a; Thai, et al., 2018). In evaluating information, individuals are likely to use ‘short-cut’ methods, or heuristics, to help simplify decisions. Heuristics are colloquially known as ‘educated guesses’ or ‘rules-of-thumb’ that are used to make judgements in complex situations and involve various ‘trade-offs’ which, while not always optimal for the individuals concerned, are nevertheless sufficient for achieving a short-term goal. Individuals may, for example, draw on familiar circumstances to make sense of a situation (what has been dubbed the ‘familiarity heuristic’), or examples that readily come to mind (‘availability heuristic’), or act on the first piece of information received prior to making a decision (‘anchoring heuristic’) (e.g. Gilovich, et al., 2002; Tversky and Kahneman, 1973; Tversky and Kahneman, 1974). Heuristic scholars (who are predominantly psychologists) have developed many ‘informal models of heuristics’ to help explain dimensions of human decisions and judgements, including in relation to online information *in general* (e.g. Metzger, et al., 2010; Metzger and Flanagin, 2013; Zyl, et al., 2020). Because heuristics involve snap judgements regarding the relative importance of different options that may lead individuals to ignore or overvalue certain information they may have far-reaching consequences in the high stakes context of health information.

Research shows that internet users rely on various criteria to evaluate the credibility of online information, including source expertise, professionalism of design, the search context, reputation, consistency of information (e.g. information appearing on multiple

websites), and familiarity with information (e.g. Banning and Sweetser, 2007; Hargittai, et al., 2010; Metzger, et al., 2010; Pan, et al., 2007). Individuals have been found to use these heuristics to assess specifically online *health* information (Rieh, 2014), including that gained via health apps (Kanthawala, et al., 2019) and news sources (Maggio, et al., 2020). One study found that users rely heavily on multiple complementary heuristics to evaluate the credibility of online health information rather than employ intensive systematic processing of information (Klawitter and Harittai, 2018b). Studies to date, however, exhibit a strong *cognitive* bias. As Slovic and his colleagues argue, people’s decisions and judgements are likely to be based on subjective impressions and rely extensively on what they call ‘the affect heuristic’ (Slovic, et al., 2007). This heuristic serves as a mental short-cut providing an affective impression of an otherwise complex situation that calls for consideration of many aspects (Slovic, et al., 2007: 1136). Research has found that posts on social media with a high emotional charge are much more likely to be shared than those that are not (Döveling, et al., 2018; Myrick, et al., 2016; Salgado and Bobba, 2019). Sillence et al. (2007) found that emotion-based heuristics play a crucial role in the initial rapid screening of the large numbers of internet sites accessed via search engines. This research shows that internet users may form an ‘initial trust impression’ based upon more salient and easily processed information (e.g. ‘look and feel’ of a site) to help them navigate a large number of poor quality sites to reach what they consider to be high-quality advice (2007: 1854).

Our study advances understanding of how patients deploy these heuristics—or more specifically what we call the heuristics of hope—to evaluate the credibility and/or utility of online health information, and how this may shape outcomes for those who self-manage their health. We argue that the risks posed by individuals’ reliance on these heuristics are likely to be significant including individuals making decisions based on faulty or incomplete information (for example, about the state of the science), incorrectly self-diagnosing their

condition, and/or submitting themselves to health interventions, such as clinically unproven and hence potentially unsafe therapies. Understanding the sociological implications of heuristics, we conclude, is crucial in an age when many people turn to the internet for information that they can trust and rely upon for their health decisions.

Methodology

For this article, we draw on material from a larger Australian study undertaken between 2017 and 2020 which examined patient advocates/activists¹ use of digital media to engage with health information. The aim of the project was to identify the sociocultural characteristics of patient activists' use of digital media, thus charting the impact of online health tools across patient communities. This was with a view to discovering the motivations behind the evolving online practices and unpacking the practical methods undertaken to search for the information. The health communities included patient activists and advocates from breast cancer, HIV and neuro-degenerative condition-specific communities, which included conditions such as stroke, Parkinson's disease, spinal cord injury, spinocerebellar ataxias as well as HIV, breast cancer and chronic pain syndromes. These communities were chosen because HIV/AIDS and breast cancer have well-documented histories of activism and advocacy dating well before the availability of the internet as a tool. We were interested to discover how the emergence of online resources had been incorporated by these groups. The broad category of neuro-degenerative communities has a less well-known activist past, but was chosen as it encompasses diverse conditions impacting many people both in Australia and globally and is growing a strong, contemporary online presence. All the themes that

¹ The authors have published another paper from this study discussing the use of the terms 'activist' and 'advocate' by our participants. Details withheld for anonymity at this stage.

emerged from the study are presented in Table 1, where we have focused on the themes that provided material for this article.

Data collection

The study was conducted via an online survey (n = 302) containing a mix of quantitative and qualitative questions, followed up with semi-structured, in-depth interviews (n = 50) with a proportion of the survey respondents. The majority of the survey respondents identified as female (79% of the 166 participants who identified their gender). Most survey respondents were between the ages of 35 and 74. To disseminate the online survey, we contacted patient and disease advocacy organisations in Australia, many of whom agreed to publicise the survey link with a brief description on their websites, social media pages and in newsletters and mailing lists. The survey concluded with an invitation to undergo a follow up interview and contact details of the researchers were supplied. Therefore, the online survey doubled as a recruitment tool for the interviews. We acknowledge that our recruitment methods bias the sample towards those who enthusiastically use the internet in their health travails, although we did have contact with individuals who were online reluctantly - as it had become the only way to continue their health advocacy work. However, as self-identified activists/advocates, all respondents were well-placed to describe and explain how digital media were useful to them, the difference they perceived them to make and how they related to hopeful personal illness journeys and narratives. At the commencement of each interview, the study was introduced to the participants by first eliciting the story of how and why each participant became involved with their area of health activism/advocacy, which was in every case due to a personal or close family health crisis in one of the illness areas we focused on. Follow up interview questions included: Do you use the internet and social media such as Facebook or Twitter, for activities to advance patient activist or advocacy goals?; In your opinion, are

there any disadvantages with using the internet and/or social media for patient activism or advocacy?; and Would you like to raise any other issues you see as relevant in relation to internet and social media use for patient activism or advocacy?

Interviews were conducted face to face or over the telephone by a member of the research team who is a sociologist and registered nurse. This is relevant because hearing of the interviewer's background in nursing appeared to allow some of the participants to discuss more candidly their experiences of illness than they might otherwise have done and, thus, assisted with promptly establishing a relationship between interviewer and subject.

Interviews lasted between 30 minutes and 2 hours, with most approximately 1 hour in duration. Our article is crafted from this interview data as the interviews provided the forum for participants, who have been given pseudonyms, to describe their illness experiences and online practices in detail, including framing their online practices as a journey of hope for improvement in their illness situation by way of attaining information that may assist in that. The researchers took an interpretivist approach to the interviews (Willis, 2007) which meant that the data were treated as individual narratives that both described and framed the practices that the activists were undertaking but also served to make sense of those practices according to the context in which each participant was located, in relation to their individual health situation. This approach, therefore, aimed to explain the phenomenon of online health activism/advocacy via the perspectives of those involved.

Analysis of interview data

The interviews were audiotaped, transcribed and loaded into NVivo to assist the process of thematic coding. Coding was initially carried out by one member of the research team (the interviewer). Two other team members then read all the transcripts, coded them manually and combined the results of this process with the initial NVivo codes to create a master codebook

that all the researchers agreed accurately reflected the interview data. The codebook consisted of eight main nodes (themes) which are shown below with examples and annotations demonstrating the heuristics of hope embedded in our participants' online practices.

Table 1

Main nodes (themes)	Sub-themes	Data examples: Building heuristics of hope
Health information seeking	Critical thinking; Credibility of information online ; Shifting patient/doctor relationship; Amount of information online; Why individuals turn to online methods for health ; Using social media to change perceptions about different diseases	<p>'...hope is one of the biggest aspects of any illness about keeping...hope and hearing about those stories, and getting the right information.' (Int. 9, social media manager for a large pharmaceutical company who self-identified as a patient's advocate) - pharmas on board with the potential power of hope when designing their patient facing pages and information</p> <p>'There's not any one source I find where there is likely to be, if it's an opinion, there's just so many views and you've gotta hope. Hope that you pick the right opinion and the right view.' (Int. 6) - illustrates the 'heuristics of hope' in action</p> <p>'I try to educate myself all the time. And if my doctor prescribes a certain medication for me, I go to our government website to make sure that I fully understand what I'm taking and why, and side effects – this is another thing for people to be aware of as well. So, those are things that I try to educate myself with and hopefully getting enough information to better my knowledge or keep myself on an even keel and not get any worse.' (Int. 18) - hope at the core of this advocate's online searches for information about their condition</p>
Navigating the online health space	Bad experiences online; Creating unrealistic expectations & false hope ; Risk vs benefit; Regulation, rules & guidelines for online health information and fora	<p>'...they were talking about genetic testing today on the Facebook page, and various people were giving quotes on how much it cost them to have their genetic testing. And that 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.' (Int. 5) - online health information can dash hopes as well</p>
Characteristics of digital media platforms	Commercial involvement; Dark side of social media; Frequency of use; Overwhelming	'Pink Hope ' (Int. 45) - some digital spaces even epitomise 'hope' in their names

	nature of online communications; Pitfalls; Trust; Use of different platforms	
Connection	Connecting with others in same position; Empowerment; Experiential evidence; Rare conditions; Personal narratives; Lay knowledge	'It wasn't until I went to a professor who had operated on my head for migraines many years before and I was desperate, and I said, "Can you please help me out?" And he said to me, "Sarah, Tarlov cysts do not cause any problems." And I cried. I broke down and cried because he was my last hope .' (Int. 31) - heartfelt demonstration of the importance of hope in chronic disease journeys
Defining online activism & advocacy	Dynamic process of information gathering, dissemination & support; Embodied activism; 'activist' vs 'advocate'; Reasons for becoming involved in activism	'...in 2004 I thought there was just no hope for me to get out of the chronic pain that I was in, I just did not know how I was going to move forward with all my chronic injuries. And I chose, I don't know how I found the internal strength, but I chose to take the high road and, yeah, jump on the internet, and be proactive...' (Int. 17) - hope associated with a narrative of progress and online health information seen as one of the means to achieve that 'Activism, I think it's just contributing with your opinion and ideas that hopefully have a good outcome for whatever you're fighting for.' (Int. 37) - hope as an integral component of activism
Isolation/Loneliness	Financial hardship; Identity & belonging; Regional, rural & remote experiences; Isolation of chronic illness experience; Some experiences of illness are more isolating than others	(Sarah's quote above from Interview 31 was coded under this node as well)
Equality of access and opportunity	Digital literacy; Enabling choice; Connectivity issues	
Celebrity involvement	No sub-themes	

As the table shows, this article is based on interview excerpts that were coded under the nodes 'Health information seeking', 'Navigating the online health space', 'Characteristics of digital media platforms', Connection, Defining online activism & advocacy and Isolation/Loneliness, together with the sub-themes shown in bold text in the table. These nodes capture participants' descriptions of their heuristic practices in terms of how they pragmatically used digital media for their health activism, mostly to look for and disseminate information and support to better manage chronic conditions, with the result that they could

retain a more hopeful outlook health-wise than they may otherwise be able to. Some extracts mention hope directly, whereas in others we have drawn out the mechanisms of the heuristics of hope as we demonstrate in the findings sections that follow. As with any similar qualitative research, we would caution against our findings being generalisable beyond the communities and individuals involved with our study. However, we believe that the themes we draw out in the next section contribute to the wider conversation about managing individual health and how patients are using digital media in that context.

Findings

Confirming previous research on the experiences of patients with many types of diagnoses, our research reveals that hope is an important strategy for individuals in coping with their condition and managing its symptoms (e.g. Griggs and Walker, 2016; Ling, et al., 2021; Raleigh, 1992; Schiavon, et al., 2017; von Scheven, et al., 2021). The language of hope was sometimes used by our respondents when describing their goals, such as Irma, who suffered with and advocated for those suffering chronic pain: ‘I try to educate myself with and hopefully getting [sic] enough information to better my knowledge to keep myself on an even keel and not get any worse’. Individuals’ hopes were for positive outcomes from their activism or advocacy efforts, as was expressed by Anna, who was living with and working on behalf of people with chronic pain: ‘Activism, I think it’s just contributing your opinion and ideas that hopefully have a good outcome for whatever you’re fighting for’. Hope was manifest in our respondents’ persistent searches for information that they believed could help them better manage their condition, as well as their constant alertness to medical breakthroughs such as new treatments and other developments of perceived relevance and their efforts to share the information they acquired with others in their communities who had similar conditions. In line with previous related research, this hope tends to attach to the

definitive diagnosis and to treatments and cures (Jonasson, et al., 2022; Perrotta and Hamper, 2021). Yet, often, hope remained unfulfilled, leading to feelings of frustration and despair—evident in the case of Sarah, an advocate for people with chronic pain and had Tarlov Cysts (which typically cause no symptoms), who said she ‘broke down and cried’ when told by her physician that the cysts ‘do not cause any problems’ ‘because he was my last hope’.

During interviews, our respondents generally presented themselves as committed, methodical researchers who used a range of criteria to evaluate information, which for them was often of uncertain value or conflicting or potentially inaccurate. Individuals relied extensively on Google and Facebook to undertake their searches, with some mentioning that they belonged or contributed to several online groups or forums or subscribed to newsletters posted to them via email. They described in varying levels of detail the methods they used for investigating and evaluating information using search engines and/or particular platforms.

Diane, a breast cancer survivor who was also an advocate for her community, explained:

If something comes up or if someone has a diagnosis that I’m not familiar with, I might look that up, Google it or, if I get something myself that I’m not sure about, little odds and ends, I’ll look it up. I’ve got a tablet and I use that quite a bit to look something up.

Dave, who experienced chronic pain, asserted:

Anybody who’s not got onto the technical bandwagon...if they’re not up to date with a PC or through apps and so forth on the phones, if they’re not up to date with those then, they’re caught out there. They’re missing out on all that information.

Comments such as these conveyed individuals’ belief they *should* use this information to manage their own health—consistent with the responsibilisation that is a hallmark of contemporary, neoliberal healthcare (O’Malley, 2009). If they were not familiar with something they came across, it is *they* who should ‘look it up’. If they are not ‘up to date’

with the digital technologies, then *they* will miss opportunities ('they're caught out'). Some respondents implied that access to internet-based information should be a *right*. Taryn, who was living with chronic pain, for example, commented 'if people don't have the minimum level of internet access, they're not going to be able to manage their health properly.'

Yet, while individuals presented themselves as responsible citizens who methodically undertook their online searches, their accounts showed their reliance on various heuristic short-cuts to help simplify decisions especially when confronted with diverse, conflicting information. For example, Charlie, who was living with and advocating for patients with Parkinson's Disease commented that he consulted various sources, including the peak patient organisation in his state, a GP and a physiotherapist, and online sources, and 'there's just so many views and you've gotta hope...hope that you pick the right opinion and the right view'. He continued: 'I don't have a choice around so much information and I often encounter conflicts with other information that I'm given, and often I have to look at differing information from different sources for different subject matter and come up with something in the middle that sounds about right'. The hope that Charlie articulates in his account of his method of evaluating different sources—namely that he had 'pick[ed] up the right opinion and right view'—was implicit in many of our respondents' accounts of how they searched for and evaluated information. Charlie's comments, like those of other respondents, indicate that his evaluations involved what might be described as 'educated guesses' such as 'sounds about right' in making judgements about online information. Other respondents recounted the often-arduous process of trawling through and sorting a large amount of information but then relying on what seemed to us to be cursory observations or subjective impressions to make judgements. This was evident with Monique, a mental health advocate in the chronic pain community.

As Monique explained, if someone told her about the name of a new disease ‘I’ll go looking, I’ll Google it’. Monique described her method of evaluating information:

There are little sites that you can go to. A lot of them American. But then, to get the information you want, you’ve gotta sign up for newsletters and that. I’d be spending half the night clicking on the newsletters to put them in the spam folder or delete them or something before I’d actually get any information. This spam business is over the top. That’s why, if I’m going to look at [health] information, I look at two or three different sources, maybe more. And out of that, if it’s all very similar, you can say, well, it’s reasonably safe and okay.

It is interesting to note Monique’s account of her approach to collecting, sorting, and filing information. Much like a scientist, she presents herself as dogged in her determined search of sources, especially newsletters, remaining constantly alert to developments in her field. Using a method akin to Charlie’s, she says she examines different sources to confirm her observations and delaying judgement that information is ‘reasonably safe and okay’ only after she has detected a pattern. Yet, despite what appears to be her use of a systematic, science-like approach for evaluating sources, she ultimately relies on a subjective judgement regarding the similarity of information—what heuristic scholars call a ‘similarity heuristic’ (e.g. Read and Grushka-Cockayne, 2011).

Research-based information

Given that our respondents are patient activists or advocates who use science-based knowledge to advance their community’s goals, it is perhaps not surprising that they tended to exhibit some degree of familiarity with the technical aspects of specific diseases or conditions. Some individuals said they were involved in scientific research projects or that they try to gain access to research papers, and so may be especially familiar with related

knowledge and evidence. Some individuals mentioned that they sought to read research papers about their disease or condition. Taryn mentioned ‘trying to get hold of pertinent research papers’, while Vicky, a breast cancer survivor, indicated ‘you’ve got to look at more than one paper or look at more than one thing...to try and help you to get an educated opinion as to what the general consensus is’. Regardless of the disease or condition, our respondents strongly pinned their hopes to science and the promise of biomedical treatments, with their comments suggesting they placed considerable trust in science- or research-based sources. Consistent with this, their searches were guided by the tacit rule that information should be based on ‘science’, ‘evidence’ and/or ‘research’—what has been described as an ‘expertise heuristic’ (Meinert and Krämer, 2022).

We were unable to confirm whether those whom we interviewed *did* in fact use original, science-based sources, and if they did so, *how* they evaluated the information they found. Judgements may have been influenced by source cues such as information appearing in reputable journals or science organisations. Previous research on social media communication has found that lay persons may make use of these ‘credibility cues’ when deciding which articles to read (Winter and Cramer, 2014); for blogs, user comments are likely to be persuasive (Winter and Cramer, 2016). Some of the information respondents referred may have been reported in news media or other outlets or appeared as summary versions in the newsletters of the patient organisations to which they belonged, and then circulated through social media networks—thus shaping how the information was framed and understood (Kamenova, et al., 2014).

Some individuals presented themselves as *critical* consumers of expert information and expressed confidence in their ability to distinguish between credible and non-credible information. But the methods they used for making this distinction was mostly unclear. Taryn, who said she had been using ‘low-dose opioids for over twenty years because I have a

number of very painful conditions’ was critical of the advice offered by ‘a lot of GPs’ that people suffering opioid addiction ‘go and see these so-called “pain specialists”’. She wondered whether such specialists even existed, explaining that:

I was able, because of access to a certain amount of information...to build my own case and then, when it was my turn to be forced to a pain specialist, I was able to give a rational argument in my favour whereas a lot of people who may not know how to use the internet properly or don’t know how to research, and don’t know how to choose, you know...the correct facts from the bullshit.

While evidently self-confident in her judgements, Taryn seemed to rely exclusively on her own lay knowledge to evaluate the credibility of online information. Yet, as other respondents noted, sorting through and evaluating an abundance of information is far from a straightforward matter.

Who or what to trust online?

Our respondents reported struggling with the *deluge* of information, whose credibility was difficult to assess. Marg, who had spinocerebellar ataxia observed, ‘It is off-putting when there is so much information. Wading through lots to find something specific is off-putting.’ One way in which respondents sought to deal with this was to confirm their findings with expert advice gained offline. Marg went on to say that ‘health information online is great as an introduction but I like to follow up so my situation can be addressed’, adding:

Recently I had a health concern, so I searched online. It is very informative, but I hate relying on that. I followed up with my doctor rather than relying solely on the internet.

General information is good but then I still want my unique situation addressed.

Some individuals mentioned that they did not rely solely on the internet, but sought other people’s, particularly doctors’, views following their online search—although Diane pointed

out that ‘doctors don’t like you going into their surgery and telling them what you found on Google’. Julie, a breast cancer activist, said that if ‘If I want information about any medications... from drug companies, I go to my local pharmacist who I have a fairly good rapport with...and he will print off whatever comes out of their printout.’ She added: ‘It’s... about accessing reliable information.’ We are unable to confirm whether the respondents who do not rely solely on the internet consistently consulted a doctor or other health professional. Diane’s comments suggest that some may be reluctant to do this. However, recent research found that those who consume online health information are more likely to seek information from their doctors; for example, by bringing a list of questions or concerns to them (Xiang and Stanley, 2017).

To help ensure quality control, many of our respondents emphasised that it was important to exercise care in the use of sites or sources. Rose, a breast cancer advocate and health consumer representative, commented that ‘You’ve really got to be careful what sites you go on’, and ‘at the end of the day, if you’ve got a problem, you go to your GP, you go to your specialist...you find out from...reputable places.’ Adding: ‘There’s so many people spruiking so much stuff online’ and ‘if you’re facing cancer...some of those things might be all right as an extra, but you’ve got to be so careful about how things relate to each other and...what might work for somebody is not going to be right for somebody else.’

Individuals showed acute awareness of the dangers they confronted when going online, including: reading information that might be distressing, others learning about one’s private life, dealing with information ‘overload’ or information that is ‘completely false’ or ‘incorrect’, being vulnerable to exploitation by ‘a lot of crooks’, ‘people that make jokes’ at their expense, having no ‘gatekeepers’, being vulnerable to ‘scammers’, and falling prey to companies ‘spruiking’ products or to ‘imposter, so-called drug companies’. Our respondents expressed wariness and caution about who or what to trust, as well as fear. As individuals

noted, knowing how to identify credible and/or useful sources from the mass of available information was crucial. As Irma put it: ‘you have to weed through the rubbish to get to the good stuff’.

However, despite holding these concerns, respondents often ‘threw caution to the wind’, with Rose, for example, reasoning in relation to Facebook: ‘I think, if you’re a reasonable, normal... respectful person, you’ve either gotta decide that it’s... a platform for goodness, not for badness, and some people are always going to maybe try and use the badness that a social media platform might have. But most people are out there just sharing information’. In this case, Rose seemed to combine the trust heuristic (placing trust in the platform) and the representativeness heuristic (making judgements about the probability an event under uncertainty) in arriving at her judgement (Cummings, 2014; Kahneman & Tversky, 1972). In Rose’s view, Facebook was ‘phenomenal’, and allowed her access to the kind of information that was not available to her when she was in her teens.

Use of Facebook to share experiences

Some individuals indicated that they belonged to several Facebook groups where stories are shared, as was the case with Irma who, as noted earlier, suffered chronic back pain and sought to educate herself about potential treatments:

I belong to a few Facebook groups, I have a couple of friends that have chronic pain as well. We compare notes and support each other and just pick each other up when we’ve fallen down. And, yeah, just checking information from others and sharing so that we can try and do the best that we can for our particular circumstances.

Mary, who had fibromyalgia, said that:

I joined Facebook and I just put in fibromyalgia, and a whole, oh, there’s a plethora of chronic illness groups and all sorts of groups. So, I’m a member of several. And...I’ve

never asked a question but I...do know a bit about fibro [fibromyalgia]. So ... People ask stupid questions. But, you know, I believe in sharing information because that's powerful.

As these and other respondents' accounts make clear, Facebook is valued for sharing experiences and learning about conditions. The platform's accessibility and ease of use lends itself to the kind of 'effort reduction' that is typical of heuristic decision-making and credibility judgements on social media (Meinert and Krämer, 2022). Stories of illness experiences have been found to provide an important resource for patients in offering them a sense of control and opportunity to re-frame past events and thereby become 'experts by experience' (Jones and Pietilä, 2020). They enable patients to overcome feelings of isolation or loneliness and experience being part of a community (Authors). Yet, it is potentially also a mechanism for reinforcing certain views and distribute information without first confirming its reliability.

As Claire, who had a rare chronic illness explained to us during her interview: 'You go, "Okay, that one's interesting to me. I'm going to share it." All of a sudden you've shared it with 200 friends and then it only takes one more of those people to share it and that's that social media spread.' Claire's confidence in the power of information, it seemed, meant that she simply trusted that the information she found would be useful to others in her community. Rose, a breast cancer survivor and advocate said she used Instagram to 'share snapshots relevant to my life' and said she has 'now got a page that I...put all sorts of bits of information on it...I put, yeh, motivational stuff on there'. The kind of sharing of which Claire and Rose spoke, involving the circulation of 'interesting' titbits of information via Facebook or Instagram arguably contributes to the 'echo chamber' effect, which may actually serve to 'disempower' others by restricting the range of information available to them (Bruns, 2019).

In short, our respondents seemed to accept that the various dangers posed by their use of digital media were largely unavoidable. In making their judgements about online information, they relied variously on third-party assessments, personal experiences, culturally shared knowledge, a 'leap of trust', and the belief that the platform delivering the information is essentially a 'platform for goodness'. Yet, reliance on heuristic short-cuts to expedite decisions and on Facebook to share information are likely to bias their selection and assessment of information, which may have far-reaching consequences for individuals' health, as we will explain.

Discussion and conclusion

Our article, which draws on data from a study exploring how patient activists or advocates and carers from various disease- or condition-specific communities use digital media, reveals how 'the heuristics of hope' shape individuals' evaluations of online health information. These heuristics, we have argued, provide a far from reliable basis for judgements and may lead to decisions that prove harmful. While individuals expressed commitment to science and research-based information and sought to present themselves as methodical and rigorous in their selection and evaluation of sources, their accounts revealed their strong reliance on a range of subjective criteria in making judgements using lay knowledge and experiences exchanged within their online communities. Further, while they showed acute awareness of the risks they faced online and of the need to exercise care in using sites or sources, including seeking to confirm information via offline sources, their concerns tended to be set aside in the conviction that digital media were essentially beneficent tools.

As Mattingly (2010) observes, hope has a paradoxical character, in that it involves trying to keep one's life worth living in the context of suffering and uncertainty. It calls for both resistance and adaption to current circumstances, and this inevitably involves risks;

namely pursuing unrealistic futures that may lead to despair (Perrotta and Hamper, 2021: 2). This includes the pursuit of ‘false hopes’—hopes based on promising but clinically unproven interventions, such as stem cell treatments, that may deliver no benefit or produce harm (Authors; Rettig, et al., 2007). As noted, patients belong to emotional communities that share a hopeful narrative of progress towards cures or treatments that profoundly shape their engagements with online information. However, reliance on affective responses for making judgements and decisions can misguide individuals and make them vulnerable to manipulation by others who wish to control their behaviour (Slovic, et al., 2007). The online advertising of unproven health products is rife on the internet and exploits people’s hopes by employing techniques such as persuasive testimonials recounting experiences of miraculous recovery following interventions (Authors). Advertisers and ‘user experience’ companies use the findings from studies of heuristics to develop their digital design practices to attract audiences and keep them engaged. For example, they use techniques to enable users to ‘feel in control’, provide rapid feedback on prior interactions, help minimise recall when moving from one part of the interface to another, and enhance the aesthetic appeal of platform interfaces (e.g. Nielson Norman Group, 2021). These practices are then enhanced by algorithm-driven systems that deliver personalised messages ‘offering hope’, based on patients’ previous searches, including for treatments. These messages are likely to resonate with those who are especially vulnerable due to their condition and have limited options for treatment and care. It is in this context, individuals may make hasty, heuristic-based decisions based on incomplete, faulty, or confusing information that may mislead them, and perhaps predispose them to embarking on treatments that are expensive, ineffective, or cause financial or physical harm.

Analyses of the heuristics of hope, we suggest, can assist in understanding the dynamics of decision-making and the role that affect plays in online patient communities

which is crucial in an age characterised by the rapid circulation of emotionally charged messages, often based on hope. Sociologists have been slow to embrace the concept of heuristics or applied the ideas from this broad field of research, perhaps because studies of heuristics to date have tended to eliminate or de-emphasise the impacts of social environments, which reduces their obvious relevance to scholars (Bruch and Feinberg, 2017). However, as Bruch and Feinberg argue, sociologists could develop more contextually sensitive, less cognitivist, analyses of heuristics, with more attention given to the core concerns of their discipline. In an age when many people turn to the internet for health information, it is critical to understand how the heuristics of hope shape health-related decisions the implications of which may be profound.

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