Engaging With Online Patient Experiences: Exploring Differences Between Health Groups

Claire Hardy, Elizabeth Sillence, Pamela Briggs

Department of Psychology, Northumbria University
Newcastle-upon-Tyne, UK
e-mail: claire2.hardy@northumbria.ac.uk,
elizabeth.sillence@northumbria.ac.uk,
p.briggs@northumbria.ac.uk

Peter Harris

Department of Psychology
University of Sheffield
Sheffield, UK
e-mail: p.harris@sheffield.ac.uk

Abstract— **In this paper, data from qualitative investigations with three discrete health groups were pooled in order to identify factors that affect engagement with online material. A total sample of 74 participants (29 asthma sufferers, 25 smokers considering quitting, and 20 personal carers of people with multiple sclerosis (MS)) took part in a study in which they examined and commented on e-health information, including shared patient experiences available online. The findings suggest that engagement is influenced by the availability of off-line information, the ability to cure or control the health condition, and the daily impact the of health condition. Some health conditions (e.g., individuals with MS and their carers) may be more likely than others to engage with websites containing patient experiences, therefore targeting such groups with e-health initiatives could be advantageous.**

Keywords-online patient experiences; engagement; secondary analysis; asthma; smoking cessation; multiple sclerosis carers

I. INTRODUCTION

It is widely acknowledged that the Internet is a commonly used resource for health information. In the UK, a survey by Ellins and Coulter [1] found that second to the doctor, the Internet is a key resource for those seeking health information. Using the Internet as a health information resource has been steadily increasing over the past decade, and is often used as an initial information source before turning to other methods [2]. One form of health information that is sought is other patients' experiences.

Preece [3] noted that "Physicians can provide the facts, but other patients can tell you what it really feels like and what to expect next, in a way that only someone with personal experience can" (p. 63). Other patient experiences of a disease, condition, or treatment can provide information otherwise inaccessible from other sources of health information. From the 2011 Pew Internet Survey, 34% of the Internet users had read someone else's experience or commentary about health or medical issues [4]. Such shared online patient experiences can come from forums, blogs, case studies and testimonials, which can be viewed as text, audio, and video. A recent review of such peer-to-peer online patient experiences suggests their impact can be potentially positive and negative, including providing information, improving health service use, affecting real world relationships, and changing behavior [5]. Empirical studies in this area have focused on a variety of health conditions, but particularly on those considered relatively rare, life threatening, or chronic (e.g., breast cancer [6]; HIV/AIDS [7], arthritis and fibromyalgia [8]). Such investigations have typically focused on a single health condition, and/or multiple conditions considered similar (e.g., degenerative neurological diseases, [9], [10]). Whilst such research is important and insightful, the narrowed focus limits the degree to which comparisons can be made across different types of health conditions.

A large National Institute for Health Research (NIHR) program is currently seeking to explore the role of online patient experience for health decision making in three different kinds of health groups: asthma sufferers, smokers wanting to quit, and carers of someone with multiple sclerosis (MS). These three patient groups were chosen to reflect different types of health conditions (i.e., patients with a chronic health condition, individuals looking for a health behavior change, and individuals who are responsible for someone with a serious life threatening health condition). Whilst collecting data from the groups in three studies, the researchers noticed engagement disparity with the online health information and patient experiences. This was observed in terms of reaction and interest in the materials shown during the study, participant's engagement with similar material before and after the study, and whether they thought online patient experiences were useful. Of the three groups, the MS carers were the most engaged, with the asthma group and then the smokers showing the least engagement.

Although not primary research questions of the program, it became evident to the researchers during their analyses that recurring themes were present across the data, which may contribute to understanding the observed variations. Therefore, the aim of the present paper is to present evidence for three potential factors: 1) availability of off-line information; 2) control over or cure for the health condition; and 3) the daily impact of the health condition.

The remainder of the paper is structured in the following way. Firstly, the method(s) and analysis strategy are briefly outlined, before going on to present the findings of the study. The results are presented in three sections reflecting the three proposed factors that may influence online patient experience engagement. These results are then discussed in relation to other relevant research, before highlighting

implications and limitations of the study. The paper concludes with some lessons learnt, and suggestions for future research in light of the paper's findings.

II. METHOD

This paper is based on secondary analysis of data from three studies conducted in the UK between 2011 and 2012 by the authors. The studies employed multiple methods and involved asking participants to look at and comment on websites containing health information, and shared patient experiences. For this study, qualitative data from focus groups and interviews (including follow-up telephone interview in studies two and three) were used. In total, the pooled-sample comprised of 74 participants, including 29 asthma sufferers, 25 smokers considering quitting, and 20 personal carers of people with MS. The analysis was carried out using a similar approach to those adopted by other secondary analyses published within the field (e.g., [9]; [10]), largely derived from guidelines suggested by Heaton [11], and West and Oldfather [12]. Selected data was pooled from the verbatim transcripts to provide relevant material on the selected themes, which had been identified in previously analyses but not relevant to the primary research questions. This process of 'data sorting' [11] was carried out by the primary researcher (CH), who contained a bank of knowledge and 'participatory knowing' [13] of the data, allowing a deeper contextual understanding of the sampled data [12]. The data and themes across the health groups was explored and discussed with the second author (ES, whom was also very familiar with the full transcripts) to ensure interpretations were shared and agreed. Final interpretations were then presented to the remaining two authors (PB, PH), who considered the interpretations of based on their own familiarity with the data.

III. RESULTS

Each theme from the analysis will be presented in turn, including separate sub-sections for each health group to illustrate variations. These findings are illustrated with quotations, using St1, St2, or St3 to indicate the study quotes were derived, and FG (focus group), INT (interview), or FINT (follow-up interview) to indicate which method.

A. Availability of Off-line Information

The present data suggests that if information is widely available off-line or already known by the individual (either through previous information search enquires or general public exposure), then using the Internet and the experiences shared online as a health and decision-making resource may not be utilized or valued.

1) Asthma

For the asthma sufferers, information about the condition was unanimously provided by the individual's physician. Participants felt very confident their physician had given them all the information they needed and in turn, understood the condition well enough.

"I got given an information pack from the doctor that was from the NHS, but have not really looked online. Because they just gave me the pack, so I thought that would have all of the information that I needed" (St3, INT, Participant 7)

Some participants also commented on the input from their family. The condition's heritability meant they were exposed to it from other sufferers and could speak to them off-line for any help or advice.

"I suppose what most information that I got was from my dad…[…]…people in that family who suffer from asthma, and they can offer you some advice"(St2, FG, Participant 3)

Some Internet searches had been carried out by some of the asthma sufferers. However, participants commented that the information they retrieved then, and what they saw during the Internet sessions in the study was generally what they already knew and/or what an off-line source (e.g., physician or nurse) had provided.

"I'd say that I probably have initially in the past when I was kind of first diagnosed and particularly times when I've been ill, more ill with it than I have over times I've maybe looked to see if there's anything I can kind of do but I've never found anything more so I'd say what the asthma nurses told me" (St2, FG, Participant 2)

2) Smokers

From the discussion with smokers, there was a consensus that health information about smoking and quitting can be found from various sources without the need to go looking online.

Participant 3: *"I don't think you need to look for on the Internet. It's on buses. It's on the TV. You don't need to go looking for it they tell you every time stop smoking it's bad for you…"*

Participant 4: *"It's kind of told to you. A lot of people just tell it to you."*

Participant 5: *"You just know it. You don't have to look for it."*

Participant 3: *"It's everywhere like at the doctors on buses metros it's in bus stops. It's just everywhere."*

Participant 4: *"Everything you find on the Internet you know already." (St1, FG)*

Health information on this topic is even available when the smoker is not looking for it. Smokers wanting to find out information about quitting have gone to their physician, pharmacists, or spoken to friends. They have access to many off-line resources and feel that the information they receive online is typically what they already know or can obtain easily from these other off-line resources.

"Yeah first I found some facts I didn't know about which is good, but then they started to get repetitive, for all the websites I looked at, but yeah, I did found out something I

didn't know so it was kind of helpful and in terms of the advice page I looked at, didn't really help. Well, you see them on TV all the time and you know, I don't know, just kind of I knew already." (St1, FG, Participant 9)

3) MS Carers

The perceived amount of information provided by off-line sources, such as physicians, was markedly inferior in this group relative to the other health groups studied.

"Yes, I've used the Internet when he, when we first had the diagnosis, we looked on some of the MS sites to find out some information because we'd had very little information from the hospital…[…]…The only other help we've had is actually once a year contact with the [hospital name] but that dropped out because it wasn't any use." (St3, INT, Participant 3)

Information had been obtained from charities and support groups, through magazines and meetings, but was still felt to be limited. Participants acknowledged that this was in part due to the unknowns surrounding the condition itself.

"No, not the doctor, he was as much use as a chocolate fire guard…[…]… There we are ' I took various Sativex documents to my GP for her to read and decide if I was a good candidate for the drug. When I handed them over she said 'is this this cannabis spray' In other words she didn't know, in other words the GP didn't know. 'I said yes, what do you think' before I could finish that short question, she put her hands up in front of her and backed up quickly, banging into the table. Anyone watching would have thought I was handing her an envelope with anthrax'. And that's the sort of attitude we've got but by people putting this sort of thing up and say look I know this is what the doctors think but this is available to us. And you ought to read up. And we used to get two copies of MS Matters, which is the in house magazine from the MS Society… And so I used to send one down to the doctors surgery and it has improved her appreciation of the illness. But that was the case pretty much." (St3, INT, Participant 7)

Due to professional off-line help seemingly limited across this health group, these participants often felt like information from the Internet was useful (or potentially useful) and the first port of call for finding out about symptoms of the conditions and other people's experiences.

"Yeah, yeah I think nowadays it [the Internet] tends to be kinda a first port of call. I think we kind of resolved that we, the experience we get at the yearly consultants appointment. Usually a 10-15minute conversation with the consultant where she basically tells them what their symptoms have been so far and give it another year. We don't get any more information" (St3, FINT, Participant 1)

B. Control Over or Cure for the Condition

Each group talked about the level of control they felt they had over their or their loved one's health condition, or whether or not it was curable. In this respect, the three health groups varied and this in turn influenced whether they were interested in, or saw value in, the experiences of other patients posted online.

1) Asthma

For the majority of these participants, they perceived their asthma to be well controlled. Many had lived with it for a long time and knew the triggers that could worsen their condition.

"Well I've had it since I was about thirteen so I would say twenty year ago erm ... erm ... I've never really had a ... had it really bad. Only in the winter when I get a cold or something like that. That's the only time it's really bad. But apart from that it's really well controlled." (St3, INT, Participant 6)

When participants had experienced something in relation to their asthma (such as an asthma attack) then they had engaged with the Internet and were more receptive to some of the experiences shared on the websites they examined during the Internet session.

"Just kind of like, like symptoms, whether they're normal or if there's anything like, I used to have a lot of difficulties sleeping so if there's any techniques or anything I could do on a night to make me sleep better, just things like that." (St2, FG, Participant 6)

However, participants had regular check-ups with their physician and generally felt that unless they had a problem, they did not feel the need to look online or act on any information or advice given online. They and their physician or other health professional were able to help control their condition.

2) Smokers

For these smokers, participants believed that quitting was down to them. Participants were aware that whilst smoking is bad for their health and there are quitting aids available, it is entirely their own personal drive that could accomplish cessation.

"I think if you want to quit smoking it's mostly about will power rather than reading about what could happen to you. Everyone knows the facts everyone knows what will happen" (St1, FG, Participant 2)

Participants were not typically engaged with online information of experiences because no one else could do it for them; they themselves have full control of this health issue.

"I think as well you kind of know in your head if you want to quit, so if you want to quit, the chances are like you'll go around yourself, I don't think you need other people's advice, you really want to quit you gonna do it… I think" (St1, FG, Participant 14)

Participants sometimes liked hearing that others found quitting difficult and welcomed any novel tips or advice. However, ultimately, they felt their health condition was entirely under their control and knowing that others could do it may be helpful in terms of inspiration but not a strong reason to return to patient experiences online.

3) MS Carers

Resoundingly, carers commented on the fact that there was yet to be a cure for MS. Research was being carried out, but nothing concretely acknowledged as a drug or therapy had been produced for use within the NHS.

"He [PARTNER] won't admit he got it. He thinks he's gonna get better. Even now he thinks he's gonna get better…[…]… you really realise that you're clutching at straws. There isn't anything out there to help" (St2, FU, Participant 7)

Carers experienced frustration toward the disease because of its variability across different people, which contribute to the difficulty of treating and controlling the condition. The one certainty participants acknowledged was that the condition would get worse and this was beyond their control.

"You know things aren't going to get any better. They're only just going to go downhill." (St2, FINT, Participant 8)

Due to this variability and lack of knowledge of the condition, carers felt that using the Internet to share experiences and learn from one another had significant potential benefits for people living with a health condition.

"I think I think particularly for MS because it's one of those things which's such a broad spectrum…[…]…that a lot time it is that kind of personal information that does make a big difference" (St2, FG, Participant 2)

C. Daily Impact

The daily impact of the condition was another observed theme across the three health groups. Responses highlight a positive relationship between level of daily impact and engagement with online information and experiences.

1) Asthma

For most of the asthma sufferers, this health condition was not regarded as something that had a huge impact on their life and to some, was not even considered a health problem.

"With asthma I don't even think of it as an illness or anything like that it's you know a bit of an irritation that I totally forget once I've taken my inhaler I don't think about it really so I don't search the Internet for anything." (St3, INT, Participant 1)

Asthma was regarded as something these individuals were aware of and took the necessary precautions to ensure it was managed (i.e., take their inhalers). However, once they had done that, the condition could on the whole be forgotten about as it did not impact on their daily life. Some

sufferers did think that perhaps they would be more interested in online information and experiences if their asthma was more severe, but otherwise it was something easily controllable with the help of their physician and medication, which in turn means little significant impact on their daily life.

"I mean if I felt kind of more, in a house bound of asthma really affect me I would seek other people's experiences or opinions online but since it didn't seem to be very part of my life I certainly wouldn't use the forums, it work different maybe, more appealing." (ST2, FG, Participant 3)

2) Smokers

The only highlighted daily impact of stopping smoking was attempting to deal with craving. The Internet and reading others experiences online was suggested by one participant as having the potential to be beneficial in this respect.

"I think actually if you just got craving, like I think if you did have a craving for the day, these websites, just maybe kind of distract yourself going onto the website, I think it can help you get pass that initial craving and you go for the next jerk, like half hour to an hour before you start thinking about it, yeah."(St2, FG, Participant 6)

However, largely participants did not see smoking cessation as something that had a daily impact, at least not in a negative way. Therefore, there was little need to engage with online resources.

3) MS Carers

The daily impact of caring for someone with MS was pronounced in this group.

"From my end obviously I've not suffered with the illness but I still, there's an impact on me, there's an impact on the relationship." (St2, FINT, P2)

During the later stages of MS, carers often have to give up employment because the impact of the condition increases to the point where the patient needs full time care.

"Yes, 96, my husband was diagnosed. Erm actually became a non employed carer after 2000. I gave up work then…[…]…and it's just increased the workload, has increased from erm assistance around the house, assistance with getting dressed to erm full 24/7, just about covering every physical need." (St3, INT, Participant 3)

Carers saw the value of using the Internet for information and seeing other people's experiences as it could help them understand their own position as a carer and how they can cope with the progressive impact of the condition on their own daily life.

Interviewer: *"Do you think websites with personal experiences on them are useful?"*

Participant 2: *"Yes. I do. Say I think particularly in the early stages. Just as an ongoing basis...I think that's what's missing sometimes a lot of the more clinical stuff on the websites, there's a limit to the amount of information you can be told about MS. There's a limit to what's known. But there's a lot underneath that. I mean a lot of the questions people ask are 'how's this gonna impact me? Is it gonna break up my life? How am I gonna cope with it?...[...]...This kind of thing. Most of the time the only people who can tell you that are the people who suffer form MS themselves. Em, so yeah I think there is a lot of value in that."* (St2, FINT)

IV. DISCUSSION

The increasing use of the Internet for health information, and in particular, the experiences of others with a specific health condition has spurred researchers from various disciplines to explore this phenomenon. However, evidence from the present research indicates that people with certain health conditions or problems may be more likely to engage with online patient experiences than others. This paper suggests that individuals living with a health condition where: a) little off-line information about the condition is available (e.g., from their physician; b) is non-curable or non-controllable; and/or c) has a high impact of the individual's daily life, are more likely to seek out and engage with shared online patient experiences.

These findings are consistent with other findings that individuals with chronic or debilitating conditions (or their carers) are likely to seek information online [4; 14]. Other research has also shown that the Internet is a preferred resource for health information when patients felt dissatisfied with the patient-physician interaction, particularly when needs (e.g., the provision of information) have not been met [15]. Research has revealed that households would often use the Internet to find out information for their needs regarding health issues that were affecting everyday routines [16]. The present study's proposed factors could explain these higher levels of online engagement in terms of unsatisfactory off-line information (e.g., from a physician) and having a health problem with a daily impact, which is not under the individual's.

In other research, however, Tian and Robinson [17] found that adult cancer patients who visited their doctors more frequently were more likely to pay attention to health information from other mediums (e.g., magazines and on the Internet), even after controlling for condition severity. The researchers proposed that these findings supported the complimentary theory of media use (i.e., use of one media increases the likelihood of using another). More recently, other research has also shown that online support group members, who believed they had high control over their illness, were also more likely to use online resources [18]. These studies seem to contradict the present study's findings.

However, interestingly, in another study on breast cancer patients Sandaunet [20] found that online support group members withdrew from online participation when they no longer felt 'ill enough' or when they were at a particular phase of the illness which felt manageable. It may therefore be the case that these cancer patients felt in control of their condition, and that the daily impact on their lives was insufficient to warrant continued engagement with an online support group. Therefore, it could be that complementary use of media resources are more likely to result when low levels of control and/or daily impact is high, which may vary over time. In addition, utilizing the additional resource of online support groups may contribute to perceived control over the health condition.

These research findings, together with the present paper, suggest that understanding engagement with online health resources is a complex phenomenon, and further research is needed. Of course, even within health conditions there may be individual or dispositional variations in the likelihood to engage with the Internet and seek other online patient experiences (e.g., [20]). However, the present research suggests it may be possible to predict why some health groups may be more likely than others to use the Internet and look for others who are experiencing similar health issues. These findings could have important implications for policy makers, investors, and health providers in terms of future ehealth initiatives. For example, it is often advocated that physicians have a list of recommended websites for referring patients to so they can seek out such information in relation to their condition. However, the present study suggests that it may not be necessary for physicians to do this for every patient they see. Not all patients with health conditions may be equally interested in websites related to their condition. It may only be useful for certain conditions where physicians know there is a limited amount of information or help they can provide to the patient, and/or where they know the impact on the patient's daily life will be high.

For policy makers and investors, these results also suggest where a society or population may already know or be exposed to a lot about a health condition, individuals may feel saturated or de-sensitized to attempts to change their behaviors or decisions in relation to their health condition. Therefore, ehealth policies and strategies aimed at such conditions may provide a smaller return on investment than less well known conditions, conditions that cannot be cured/controlled, and/or may have a significant impact on the individual's daily lives. This is a particularly significant implication when there are limited time and resources available for such ehealth initiatives.

Despite such useful insights from the present study, it is not without its limitations. The data collected represents a UK sample. Other countries have different health care services and provisions, and cultural variations may affect engagement factors. Whilst representing a variety of types of health user, it may be that the health conditions examined

do not cover all the possible levels of engagement with patient experiences. It is also important to note that for practical and ethical reasons, our sample did not contain any very severe health cases. These limitations impose some restrictions on the generalizability of the results. However, they give rise to important suggestions for future research and collaborations on this topic.

V.   CONCLUSION AND FUTURE WORK

From this study, we have learnt that different health conditions may vary in terms of the levels of engagement with online health information and shared patient experiences. In particular, engagement appears to be influenced by the level of off-line information, the ability to cure or control the health issue, and the daily impact the condition. These lessons provide some important implications for policy makers, investors, and service providers on ehealth initiatives, as well as highlighting the potential value that this line of research. Continuing this research across a broader range of health topics would therefore be worthwhile. Future research could also examine the degree of influence of each factor, and whether higher levels in just one factor (e.g., daily impact) would still result in engagement when there are lower perceived levels in the other factors (e.g., off-line information and control/cure of health condition). Longitudinal research would also allow researchers to see how and if engagement varies over time in relation to the proposed factors. Finally, the paper highlights the potential of using innovative methods of recycling existing data. We therefore encourage future pooled case comparisons of existing data to help explore online patient experience engagement, ehealth, and health in general.

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