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Publisher citation:

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Patients' learning in cyberspace: a thematic analysis of patient-patient discussions in a chronic illness Facebook page

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Abstract: Online support groups play an increasingly important role in patients' lived experience of chronic illness. The objective of this study was to explore how learning takes place from patients' interactions in an online chronic illness support group. Qualitative data consisted of 1,478 messages posted to a publicly accessible non-illness specific Facebook support page. Data was analysed using inductive thematic analysis. Four themes were identified from the analysis. This paper presents two themes, information sharing and dis(trust). Employing Wenger's communities of practice theoretical framework (Wenger, 1998), themes are discussed in terms of learning, participation in practices and identity. Online support groups can be pivotal to learning in illness. Patients' online information sharing provides them with opportunities for informal learning about their condition to take place. These online interactions lead to patients developing trust for one another and distrust for the medical care system.

Keywords: patient interactions; illness community; chronic illness; online support groups, communities of practice; learning.

Reference to this paper should be made as follows: Stevens, G., O'Donnell, V.L. and Williams, L. (xxxx) 'Patients' learning in cyberspace: a thematic analysis of patient-patient discussions in a chronic illness Facebook page', *Int. J. Web Based Communities*, Vol. X, No. Y, pp.xxx-xxx.

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This paper is a revised and expanded version of a paper entitled 'The impact of learning in cyberspace on chronic illness: identity, coping and the psychosocial experience', presented at the Division of Health Psychology Conference for the British Psychological Society, York, UK, September 2014.

1 Introduction

A plethora of research has investigated the lived experience of chronic illness. For example, research has explored illness identities, self-management and coping mechanisms in chronic illness (Flensner et al., 2003; Whitehead, 2006). However, there remains a great deal that is unknown about the lived experience of chronic illness, including the way in which learning contributes to that experience. A growing body of research indicates some benefits of learning to the illness experience and associated health outcomes, suggesting an important role for learning for those diagnosed with ill health. Informal learning is the unstructured learning which results from naturally occurring opportunities for learning in everyday life by applying strategies such as questioning, listening, observing and reflection (Cseh et al., 1999; Marsick and Watkins, 1990). Incidental learning is the unintended outcome of such informal learning (Watkins and Marsick, 1992). Previous research has shown that informal and incidental learning lead to better meaning-making in the illness experience and result in better self-management in renal failure patients (Keeping et al., 2001).

Self-directed learning (SDL) is central to adult learning and is a process whereby individuals take control of their own learning about a particular topic, formulate goals, identify resources and select appropriate strategies (Knowles, 1975). SDL by women with breast cancer led to greater feelings of empowerment, connectedness, and ability to cope in the illness experience (Rager, 2004). Men with prostate cancer demonstrate a preference for engaging in SDL by gathering information from the internet and information leaflets, over speaking to others (Rager, 2006). However, there is a gap in the literature regarding how such learning occurs in illness and about the processes involved.

Online support groups have become an invaluable source of information, advice, and support for individuals living with a range of health conditions. With social media growing in popularity as a 'meeting place' for those with shared interests, and across traditional geographic boundaries, the last decade has seen an increased interest in online

activity as a means of understanding contemporary aspects of chronic illness (Attard and Coulson, 2012). Research exploring online social support in a Huntington's disease forum found that exchanging informational and emotional support was the key purpose of the forum (Coulson et al., 2007). Another study investigated the psychological effects of online support group use on patients living with HIV/AIDS (Mo and Coulson, 2013). Patients with higher levels of participation in the online support group were found to have higher levels of optimism and lower levels of loneliness and depression, compared to those with lower levels of participation in the online support group. In addition to the positive aspects of online participation in illness, research has identified negative aspects of patients' online participation including a lack of replies, misunderstandings and disagreements, information overload, misinformation and inappropriate behaviour (Attard and Coulson, 2012; Mo and Coulson, 2013). Despite this research suggesting an important role for social media in the illness experience, there is a lack of research which investigates how learning occurs within an online context for chronic illness patients.

Sociocultural perspectives on learning suggest that the best way to understand the learning process in those living with chronic illness would be in terms of their social interactions, due to the inseparability of learning from its social context (Arthur et al., 2010; Vygotsky, 1978). For example, Lave and Wenger's (1991) communities of practice theory presents learning as encompassing aspects of identity, situational context, and participation. A community of practice consists of a group of people who share a common interest and want to 'deepen their knowledge and expertise' in a particular area of interest and learn to do tasks better as they interact regularly (Wenger et al., 2002). These explanations of learning imply a learning process, however what that process entails in an illness context is unclear. In braided learning theory, Preston (2008) suggests that professionals' frequent participation in an online community of practice can result in collaborative learning, leading to them acquiring knowledge, a new status, and a new identity. Currently there is little known about whether patients' online interactions lead to learning, or indeed about the processes involved in such learning. To address this gap in knowledge, the present study aims to explore patients' participation in an online illness community to understand how learning occurs in this context and the processes involved.

The research will be guided by the following two research questions:

- 1 How does learning occur from patients' online interactions in a chronic illness Facebook page, and what are the processes involved in such learning?
- 2 What is the impact of learning taking place via the Facebook page on the experience of living with chronic illness?

2 Methods

2.1 Sample

Facebook is a social media platform where users can access several group interest and support group pages. It is the most popular social networking site worldwide and it is reported that 68% of the USA population use Facebook (Pew Research Center, 2018). A publicly accessible chronic illness Facebook page was identified for the purpose of the study. Chronic illness support groups were identified on the social networking site Facebook using search terms 'chronic illness', 'chronic disease' and 'illness support

groups'. Initially, six Facebook chronic illness pages were identified. The selected page was chosen due to the frequency of its use, and the volume of messages posted, allowing for a sizeable dataset for analysis. Although a convenience sample, it was purposive to access the online participation and interactions of those with chronic illness. The messages were publicly available to anyone with access to the internet. However, individuals posting messages must be registered members of Facebook. The page selected for analysis was frequently used, averaging 446 messages per month.

The Facebook page was a non-illness specific support page, and provided patients of any chronic illness a 'meeting place' to discuss their illness experience and to give or receive information. Although the page was open to all types of chronic illness, it was largely used by patients of autoimmune diseases such as multiple sclerosis (MS), lupus and myalgic encephalomyelitis (ME). The majority of online contributors who provided their locations came from the USA and the UK.

2.2 *Data collection*

Although messages within the selected Facebook page were plentiful, it was important to gather a manageable dataset, whilst being consistent with the volume of messages that previous online studies have used for their datasets (Attard and Coulson, 2012; Coulson et al., 2007; Gooden and Winefield, 2007; Ravert et al., 2004). To that end, the dataset consisted of messages posted between April 2013 and June 2013, as these were the most recent messages available at that time. Extending the timeframe beyond three months resulted in an unmanageably large dataset. All threads posted by chronic illness patients during these months were analysed. This ensured that threads were not subjectively selected for analysis to suit research questions.

Before the analysis began, there was a process of downloading messages and 'cleaning' the data (see Figure 1). In total, 224 threads containing 1,478 messages were analysed. A total of 1,005 unique users were identified from these messages; of which 54 were male, 904 were female, 21 were other support pages and for 26 of the users, their gender was unknown.

2.3 *Ethical considerations*

The study was approved by the University of the West of Scotland Ethics Committee and adhered to the British Psychological Society's guidelines for internet-mediated research (British Psychological Society, 2007, 2013). Those interested in the detailed ethical considerations of the current study are referred to our paper outlining our approach to developing an ethically robust online study (Stevens et al., 2015).

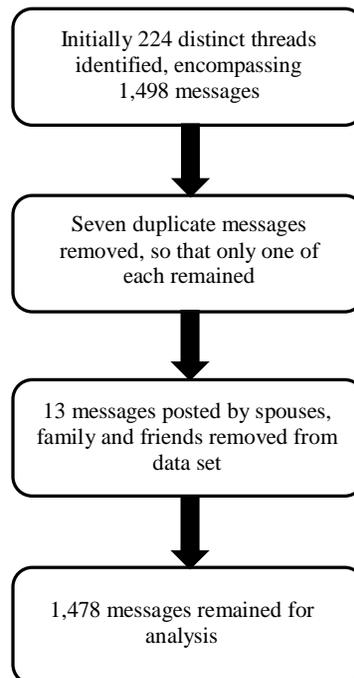
The principal ethical issues related to protecting the data and ensuring confidentiality and anonymity. All identifiable information, including names, was removed from the data and replaced with pseudonyms and all data was stored securely. A process of scrutiny was applied to quotes used in the analysis to ensure they could not be traceable through search engines, compromising patients' identities.

2.4 *Data analysis*

Thematic analysis was used to examine the interaction and messages between patients due to its flexibility in identifying and reporting themes (Braun and Clarke, 2006). The

analysis took an inductive approach to identifying patterns in the data which allowed for themes identified to be strongly linked to the data, coding data without trying to fit it into a pre-existing coding frame (Braun and Clarke, 2006). During the analysis, themes were identified at a semantic level and did not seek to go beyond what had been explicitly written in the messages (Boyatzis, 1998). Themes were considered based on the prevalence of meaning across the entire dataset in relation to the topics under discussion, and based on patterns relating to learning, until the point of saturation (Morse, 2000).

Figure 1 Flowchart displaying process of arriving at messages used for analysis



The analysis was conducted manually using a hard copy of the data, and was later uploaded into NVivo 10 software for organising (Ryan, 2009; Cousins and McIntosh, 2005). The analysis adhered to the guidelines set out by Braun and Clarke (2006):

- Phase 1 becoming familiarised with the data
- Phase 2 generating initial codes
- Phase 3 searching for themes
- Phase 4 reviewing themes
- Phase 5 defining and naming themes
- Phase 6 producing the report.

To ensure credibility, transferability, dependability and confirmability of the study's findings and conclusions, a number of measures were taken. For credibility and

transferability, findings were shared with a similar patient group in an offline support group context and were positively received and regarded as true for those patients in this similar setting. For dependability the researchers ensured the study's research questions were clear and that the research design was congruent with them. In addition, an audit trail was kept consisting of the research steps taken from the start of the research, to the identification of findings and their links to one another, and to external theory. For confirmability the first author engaged in a reflexive process of going between identified themes and sub-themes and the data to ensure that each theme and sub-theme could be well supported with the data and that the theoretical framework employed had explanatory power (Lincoln and Guba, 1985; Yilmaz, 2013).

3 Findings

Four major themes were identified from the analysis, each with respective sub-themes. Two of the major themes specifically relate to the influence of learning taking place online on the psychosocial experience of illness, whilst the other two relate to learning taking place online and the day-to-day lived experience of illness. In the interest of ensuring that the depth of each theme is fully conveyed, only the latter two themes will be presented here. These are information sharing and (dis)trust. These two themes will be presented in this section, before a more detailed discussion and analysis of these themes in Section 4.

3.1 Information sharing

Patients using the Facebook page regularly exchanged personal stories and experiences, gave tips and provided links to information about chronic conditions. This information sharing presented opportunities for informal learning to take place. Through discussions with other site users, patients made sense of their own illness, which they may have struggled to negotiate without this online collaboration. Information sharing online represents participation in an online illness community of practice (Wenger, 1998), and fosters learning in chronic illness. Information sharing, and thus learning, impacted the experience of living with chronic illness and influenced specific health behaviours. Within this theme, four sub-themes were identified (journey, perceived control, awareness and self-management), which will now be presented in turn.

3.1.1 Journey

Patients at all stages in their illness journey (e.g., pre-diagnosis, immediately post diagnosis and several years post diagnosis) sought guidance and advice from fellow patients by posting questions and comments to the Facebook page about specific issues related to their illness or about chronic illness more generally. However, patients predominantly at the start of their illness journey relied on the advice and guidance of patients further into their illness journey, with experienced patients relying on the site moderator for advice. At the start of her chronic illness journey, Gina described her appreciation for the Facebook page, explicitly referring to her expectations to learn from her online participation:

Gina: "I was just recently diagnosed with systemic lupus erythematosus, as well as kidney issues caused by something still unknown. I found your website through a friend. It's encouraging reading and seeing your posts... I'm looking forward to following you and learning more."

The sharing of information also contributed to the illness journey by allowing patients an opportunity to 'hear' the experiences of others and realising that what they feel is 'normal'. Sharon described the difficult time she had been experiencing, and how it helped to learn that what she was feeling was normal:

Sharon: "Thanks. I really needed to read this and now. I'm going through a really difficult time. I'm in pain all the time. It's all a mess. It helps to know it's normal to feel this way. Sometimes it doesn't matter how sensitive or close someone is, unless they have walked a mile in your pinching shoes, they have no clue."

3.1.2 Perceived control

Information sharing between patients had some influence on perceived control. In the case of chronic illness, perceived control refers to the patients' belief that they have the ability to control or influence some aspect of their condition, and their lives more generally (Wallston et al., 1978). Anna explained how her learning from the illness community had led her to take control of her condition:

Anna: "I want to say a big thank you to your page. I have learned much and decided to 'take control' of my illnesses, at least as much as possible."

However, other interactions had negative consequences for patients' perceived control, as some interactions reinforced a lack of patient responsibility, attributing responsibility instead to factors beyond the patients' control. Many patients used the page to share their belief that only God can control aspects of their condition. Claire described how she believed only a greater force had the answers to her condition:

Claire: "I don't know. But I know the One who has the answers, so I will pray for the peace and wisdom that only He can give."

3.1.3 Awareness

The sharing of experiences between patients provided a rich resource for learning to take place. Patients' online interactions, and thus learning, emphasised the importance of raising awareness about chronic illness among the healthy population. Shirley hinted towards a collective chronic illness identity, with patients dealing with more than just physical challenges in the illness experience. She suggested that raising awareness to highlight these challenges is important:

Shirley: "...it's not just the physical challenges we face, but the emotional and mental ones that are often the worse [sic], this is why awareness is SOO important."

Through their online participation in the Facebook support page, patients learned that raising awareness is a practice which is valued by the illness community (Wenger, 1998), resulting in patients frequently discussing their efforts to raise awareness. Pamela shared her attempts to raise awareness about her autoimmune disease (a diagnosis that is shared by a large number of patients using the Facebook page):

Pamela: "I woke up this am to see every news anchor in our area wearing yellow for cancer, probably THE most feared and well known disease. I emailed these same stations last year about Lupus awareness day. Oh well."

3.1.4 *Self-management*

The sharing of information influenced patients' self-management, and allowed them to consider their self-management strategies. Self-management in chronic illness is a necessary component of illness care (Griffiths et al., 2007), and has a positive influence on health outcomes (Clark, 2003). Patients exchanging information and practical tips on issues such as pain management and diet were engaging in and promoting self-management. Jill described how the information sharing of the community had led to her successfully self-managing her condition whilst sitting university exams. Therefore, Jill was learning from the experiential knowledge of fellow patients on how to manage aspects of her condition (Mazanderani et al., 2012):

Jill: "...thanks, everyone. I've just done my first exam of the year using some pain management tips I received in a detailed private message, and it went very well. I haven't tried hypnotherapy, but perhaps I should! I've tried meditation, which is close..."

Nancy, on the other hand, was keen to tap into the experiential knowledge of fellow patients online as she sought their experience on dietary issues:

Nancy: "I've heard people with autoimmune and other inflammatory diseases having success with going gluten free. I haven't tried it yet myself, has anyone done so and felt better???"

3.2 *(Dis)trust*

Several patients discussed the lack of trust others have in them about the nature of their illness, and their distrust for research and the medical profession. This contrasted with their implicit trust in the illness community and fellow patients. Discussions about these experiences reinforced patients' trust in the illness community and strengthened patients' identities. Whilst the 'information sharing' theme mostly presents positive outcomes of the learning taking place between patients online such as learning how to self-manage their condition, not all learning resulted in positive outcomes. This theme identifies a potentially negative aspect of learning taking place between patients online. That is, learning that may be detrimental to the illness experience. Within this theme, four sub-themes were identified, which are now presented in turn (scepticism, research, fellow patients and medical care system).

3.2.1 *Scepticism*

Patients often discussed the scepticism they experience from others regarding their illness, largely due to the 'invisible' nature of their conditions. Patients experience doubt and distrust relating to the limitations they have as a result of their illness. This distrust comes from the healthy section of society, and reinforces a sense of unity and belonging between patients by allowing them a sense of shared experience within their community which also serves to justify their exclusion of healthy people as 'outsiders'. Louise described the distrust she experienced when parking in disabled parking spaces:

Louise: "I think this is one of the worst things about MS [multiple sclerosis]... When I park in a handicap space, I sure get nasty looks... All handicaps are not visible [sic]."

The scepticism that patients experience extends to the media, as the legitimacy of certain chronic illnesses is doubted:

Molly: "Funny how every time there's a new biological breakthrough, the media uses the same old headline, that 'finally' there is proof it isn't all in our heads."

These online interactions between patients provide an opportunity for patients to learn that other patients experience a similar scepticism, and serve to reinforce the division between the chronically ill and healthy sections of the community.

3.2.2 Research

Many patients were explicit about their distrust for research on medical developments. Patients shared links to the latest research articles, and were often pessimistic about the motivations for the research. Overall, there was a general dissatisfaction with findings offered by medical research. This presents an interesting contrast with patients' apparent desire for cures or better treatments, and for raising awareness.

Patients' distrust for research resulted from the drastic measures suggested by research and the unknown long-term side-effects of medication developments. Judith expressed her concerns about the logic of medical research:

Judith: "The headline seems like a godsend, the article less so. Killing neurons to deaden pain seems like cutting off your hand because your finger hurts – it'll work but maybe it's too drastic of a measure? Gotta see how it works in the long term."

Patients' discussions about distrust for medical research led to some considering and sharing their own personal experiences of taking part in drug trialling. Janice reinforced the notion of distrust for the medical profession by describing the negative consequences she experienced:

Janice: "I've been a guinea pig twice now with drastic results... I got the medicated BS stent put in me, one month after it coming out and had a heart attack six months later. Another was a new back surgery that has left me in more pain."

These interactions between patients about the negatives of research served as a catalyst for distrust for medical research, with the view that the costs outweigh the potential benefits. These exchanges clearly generated negative feeling towards medical research, and may prevent patients from opting for certain medical treatment options available to them.

3.2.3 Fellow patients

Several patients sought medical advice from the illness community, demonstrating their trust in fellow patients. Patients have learned that the online illness community consists of patients they can trust and can learn from. Valerie described her dependence on the information from the online support group:

Valerie: “Online support groups are a tremendous help and I’ve come to depend on them for so many things, particularly advice about supplements, etc.”

Valerie has negotiated the meaning of her participation, and learned that participation in the illness community is of benefit to her living with a chronic condition.

Some patients had greater trust for information received from fellow patients than for information from their own medical professionals. Annabel valued the experiential learning (Kolb, 1984) and experiential knowledge (Mazanderani et al., 2012) of her fellow patients for medication advice over and above the formal training of her doctors:

Annabel: “So anyone on Imuran? How has this affected you? Good or Bad? My doc wants me to start on it for Crohn’s but I am really hesitant due to all the side effects.”

3.2.4 *Medical care system*

Throughout the data, distrust and dissatisfaction were expressed towards the medical care system. This distrust ranged from GPs and illness specialists, to pharmacies and legislation governing medication guidelines. Joyce described her frustration with the medical care system, and the mutual distrust between doctors and patients; whilst doctors distrust the credibility of patients’ symptoms, patients distrust doctors’ competence in identifying the cause of their symptoms:

Joyce: “So there seems to be some merit to the report... Hopefully it will at least change the minds of a few more in the medical ‘profession’ who continue to label us malingerers. It’s a mystery to me how suspicions about our veracity still linger in the minds of many who were smart enough to earn a medical license, despite the fact that there are reportedly 10 million of us (with a lot more probably still undiagnosed). How many will it take to convince them? 25 million? 100 million? If they actually *cared* about their patients, they’d believe them, thus saving the afflicted the additional stress of not being taken seriously and having to spend so much more time unnecessarily suffering while they go from doctor to doctor, trying to find someone who recognizes their symptoms and prescribes some relief.”

Other patients expressed their distrust for the medical profession when it comes to obtaining an accurate diagnosis. Holly felt she had been let down by the medical care system, suggesting medical professionals take a reductionist approach to diagnosing chronic illness, over a more holistic approach and often get it wrong as a result:

Holly: “And how many doctors have suspected I have a thyroid problem, but immediately rejected the idea when my tests came back normal? I’m 72, and have suffered with little to no help for far too many years from inadequate medical care. When my fibromyalgia symptoms started... I, like so many others, went from doctor to doctor looking for just a diagnosis, only to be told, when even a neurologist couldn’t get to the bottom of it, that I needed to consider seeing a psychiatrist! And we all know how *that* feels, right?!”

The exchange of personal experiences about medical distrust contributed to patients’ illness identity. Participating in such discussions allowed patients to realise that medical distrust is a shared concern of the illness community, which fellow patients also have to deal with. In this sense, then, patients’ identities are reinforced by participation in the online illness community. Together the patients co-construct meaning of what it is like to live with a chronic illness (Wilkinson, 1998).

4 Discussions and conclusions

4.1 Discussions

To date, no research has explored how patients' participation and interactions in an online illness community might result in learning, the learning processes involved or the impact of this learning on the day-to-day lived experience of illness. The present study analysed messages posted to a chronic illness Facebook support page and identified four themes (two of which have been presented here) which relate to learning and the experience of living with illness.

These themes revealed that, in an online context, learning occurs in an illness community of practice within which certain practices are valued (Wenger, 1998), such as information sharing. Throughout the themes identified, the data showed that learning was taking place at the level of experience of chronic illness. Patients' information sharing contributed to their learning in the illness experience, with patients further ahead in the illness journey providing advice and guidance to newly diagnosed patients. This aligns with Vygotsky's (1978) sociocultural theory, in which learning is a collaborative process; with patients developing in collaboration with more experienced others. Patients' positions within the online illness community can be understood in terms of Lave and Wenger's (1991) full and peripheral participation. Full participants in a given community of practice have the power to set and change the practices that are valued within it (Lave and Wenger, 1991). Peripheral participants do not hold such power, but contribute to the community by participating in simple tasks which contribute to the goals of the community, as set by the full participants (Wenger, 1998). Experienced patients constitute full participants, with less experienced and newly diagnosed patients constituting peripheral participants in the community, learning about the valued practices from the side-lines of the community and the illness experience from more experienced patients. Patients learning from the side-lines of the illness community engaged in, and thus upheld, practices within the community. By engaging in the valued practices and sharing the practices with other newcomers, they play an important role in the goals of the community. Through interaction with full participants, peripheral members develop knowledge of the community's practices, which consists of learning how to participate online. It is from engagement in these practices which lead to learning and shifts in patients' identity. Therefore, learning from the side-lines of the community is far from passive participation.

The information sharing taking place online played an important role in patients' learning in the illness experience. The diagnosis of chronic illness is said to involve psychological and social consequences that require significant psychological adjustment (Stanton et al., 2007). Patients valued the opportunity to 'hear' that how they feel due to their condition is 'normal' and to learn that other patients feel the same as they do, contributing to the illness journey as a source of social support. This finding parallels previous research which suggests that failure to recognise patient-patient interactions as a source of social support can negatively impact on post-diagnosis adjustment and patients' illness identity (Dickson et al., 2011).

The learning taking place online was informal in nature, as it resulted from naturally occurring opportunities for learning in everyday life (Cseh et al., 1999), and resulted in incidental learning in patients and influenced patients' perceived control. While learning in the illness community facilitated some patients to take control of their condition, not

all interactions positively impacted on perceived control. Some attributed responsibility for patients' conditions to external factors such as divine power. Attributing responsibility for life events to external factors, over internal and individual behaviour factors, represents an external locus of control (Cobb-Clark et al., 2014), and has been associated with poorer health outcomes (Van der Linden et al., 2000; Dec, 2006). Learning occurs and identity is constructed from the practices we engage in, in collaboration with more experienced others (Wenger, 1998; Vygotsky, 1978). Therefore, the practice of attributing responsibility to external issues can lead to patients learning and constructing their identities on others being responsible for their condition. This understanding presents learning as being a social phenomenon, with learning capable of shaping identity. It is this shift in identity which in turn impacts on patients' behaviour.

Not all learning taking place online was incidental. Some patients had specific learning objectives and could be considered as goal-oriented learners (Houle, 1961), engaging in SDL through the Facebook page in a deliberate attempt to foster their learning about their condition. The majority of these patients had no desire to become full participants in the community. Their participation was less frequent than full participants' and was geared solely towards finding solutions to their challenges. In this sense, these patients' participation remained deliberately peripheral. Patients recognised the importance of the online illness community's information sharing to their learning experience, supporting the utility of sociocultural perspectives for understanding learning in illness.

Patients united with one another in their distrust for medical research and the medical care system more generally. This finding supports previous research that patients using online support groups develop a sense of unity with fellow members (Attard and Coulson, 2012; Coulson et al., 2007). From these interactions, patients construct an understanding that medical research and the healthcare system should not be trusted. This aspect of patients' online learning can have negative implications for patients. Medical mistrust has been linked with a lack of utilising healthcare services (LaVeist et al., 2009; Musa et al., 2009) and poor adherence to medical recommendations (Thom et al., 2004). Therefore, one potentially negative aspect of learning to distrust the medical care system is the possibility that patients might be less likely to seek medical care when needed. Furthermore, if this medical distrust is perpetuated through the inculcation into such practices of generation after generation of new participants in the community, then it is unlikely to change. In this sense there would be no new learning taking place, just a 'passing down' of received wisdom.

Whilst the present study provided an important insight into the learning taking place between patients online and the impact of such learning in the illness experience, there are some limitations which should be considered. Firstly, more females posted messages to the Facebook page than males. As a result, more data came from females than males, which may have influenced the themes identified in the study. Secondly, the majority of contributors to the page were patients of autoimmune diseases. It is possible that the online learning experiences of patients with different conditions may be different to those reported in the current study. Future research should investigate the learning taking place within different chronic conditions and its impact on illness-specific conditions.

4.2 Conclusions

The findings of this study suggest that in an online context, learning occurs within an illness community of practice, whereby less experienced patients learn from more experienced patients. The learning taking place is informal in nature, resulting from naturally occurring opportunities for learning in everyday life. Some patients demonstrated deliberate learning efforts to manage some aspect of their condition, while learning by other patients was the serendipitous outcome of their online interactions with fellow patients. Patients' online learning has potentially positive and negative influences on the everyday lived experiences of patients of chronic illness. Overall, these findings offer support to sociocultural learning theories, whereby social interactions play a fundamental role in learning in illness.

4.3 Practical implications

Online support groups can be pivotal to learning in illness, fostering increased perceived control and self-management in patients. Through patient-patient interaction, patients negotiate an understanding of what it means to be a chronic illness patient. Medical professionals should recognise the value that patients place on experiential lived experience knowledge, highlighting the importance of access to patient-patient interactions. However, the findings also identify potentially negative aspects of learning taking place within the online illness community. These findings provide a unique and contemporary way of thinking about learning in illness which may be of interest to health professionals and health educators.

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