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Gemma Stevens[a]*, Victoria L. O'Donnell[b] and Lynn Williams[c]

[a]School of Education, University of the West of Scotland, Paisley, Scotland, UK; [b]University of the West of Scotland, Paisley, Scotland, UK; [c]School of Media, Culture & Society, University of the West of Scotland, Paisley, UK

This paper discusses the ethical issues faced in undertaking research about the role of learning in the subjective experience of chronic illness, where data were taken from social media. Drawing on psychology and education, this paper discusses the ways in which authors from these disciplines are laying the groundwork for legitimate online research by actively debating the public versus private nature of online spaces. The paper explains how this debate informed the development of an ethical approach to research. Relevant ethical guidelines and previous research are used to support the argument that individuals' informed consent is not necessary in online contexts where data exist within the public domain, and where risk of harm to users is low. This paper provides an insight into one educational researcher's journey through the process of doing ethical social media research, and suggests ways forward for others embarking upon that same journey.

Keywords: social media research; online ethics; public domain; private data; cyberspace

Background and introduction

This paper discusses how ethical issues influenced and shaped an inter-disciplinary research project aimed at developing an understanding of the role of learning in the subjective experience of chronic illness. To achieve this aim, the project drew from the fields of education and health psychology.

Chronic illnesses are increasing in prevalence and are among the leading causes of death in the UK and globally (World Health Organisation, 2013). Interest in the phenomenon of chronic illness has grown considerably, and the lived experience of illness has been well documented (Berghammer, Dellborg, & Ekman, 2006; Newman, Steed, & Mulligan, 2004). It is recognised that the psychosocial consequences of chronic illness (reduced quality of life and the struggle to cope) may be equally, if not more, challenging for the individual living with chronic illness than the physical condition itself (Berghammer et al., 2006; Dijkers, 1999). Interest in factors contributing to the illness experience has also grown considerably. Literature on living with chronic illness has explored a range of issues, such as identity, sense of control, self-management, and coping mechanisms

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*Corresponding author. Email: gemma.stevens@uws.ac.uk

when suggesting what it might be like to live with a chronic illness, and the impact this may have on an individual's well-being (Flensner, Ek, & Soderhamn, 2003; Whitebread, 2006).

However, there remains a great deal that is unknown about the lived experience of chronic illness, including the way in which learning might contribute to the experience. Some form of learning, on the sufferer's part, appears to contribute significantly to the experience of living with chronic illness, and the associated health outcomes. Previous authors have contended that informal and incidental learning leads to better meaning-making in the illness experience and results in better self-management in renal failure patients, while self-directed learning in women with breast cancer led to greater feelings of empowerment, connectedness, and ability to cope (Keeping, English, & Fleming-Courts, 2001; Rager, 2004). The form of learning that fosters a positive lived experience and the consequences for the individual remain unclear. The limited body of research in this area comes from nursing and education perspectives, yet factors that have emerged from the lived experience literature have a psychological underpinning (identity, self-efficacy, and coping). The current study was motivated to understand how learning occurs in chronic illness, and its impact on the psychosocial experience of illness. The project drew from literature in health psychology (exploring the psychosocial experience of chronic illness) and literature from education (explaining how and why learning occurs) in order to start thinking about how learning might "fit" with the experience of chronic illness.

Sociocultural perspectives have identified learning as resulting from social interactions (Arthur, Grainger, & Wray, 2010). Vygotsky's (1978) theory stresses that development appears on two levels: first, between people on a social level (interpsychological) and second, on an individual level (intrapsychological). Such ideas represent the foundation of sociocultural learning theory, in that all higher functions appear first as relationships between individuals. This view of learning suggests that the best way to understand the learning processes in those living with a chronic illness is in terms of their social interactions.

Situated learning offers another sociocultural perspective on learning. Lave and Wenger's (1991) communities of practice theory presents learning as encompassing aspects of identity, situational context, and participation. A community of practice develops around a group of people who share a common concern or 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, McDermott, & Snyder, 2002, p. 4). Wenger (1998) argues that communities of practice learn from social participation and emphasises the importance of active group learning and collaboration in the real-world practice environment. Wenger explained that a community of practice can exist online as the internet has extended interactions beyond the geographical limitations of traditional communities. Guided by sociocultural perspectives on learning, the dynamics of interaction between chronic illness patients became a focus for the current study, to allow prominent issues in the illness experience to be identified.

The decision to use social media to understand learning in chronic illness

Due to the growing body of information about health and illness which now exists online, it became apparent that the internet would be important for answering the project's questions about the role of learning in the experience of chronic illness. The UK Government's review of informal adult learning (Department for Innovation, Universities and Skills, 2008) recognises the importance of information and communication technologies (ICT) in self-directed

learning. Given the amount of information about health and illness which is now available via the internet and social networking sites (Borzekowski & Rickert, 2001; Househ, 2011; Xiao, Sharman, Rao, & Upadhyaya, 2014), the role of ICT in self-directed learning about chronic illness became central to the project.

Attributable to increases in the incidence of chronic illness, online support groups have become an invaluable source of information, advice, and support (Attard & Coulson, 2012). With social media growing in popularity as a "meeting place" for those with shared interests, and across the 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 & Coulson, 2012). Research utilising online support groups has focused on illness-specific conditions, such as Huntington's disease, when seeking to understand the nature of online social support structures within virtual support groups (Coulson, Buchanan, & Aubeeluck, 2007). Other research has explored the positive and negative elements of online discussions in a Parkinson's disease forum (Attard & Coulson, 2012). In addition, with the internet becoming a growing source of health information, research has analysed messages posted to online support forums for Type I diabetes, irritable bowel syndrome, and breast and prostate cancer (Coulson, 2005; Gooden & Winefield, 2007; Ravert, Hancock, & Ingersoll, 2004;). These studies have identified that site users gain access to social support and health information advice.

It became clear that the internet, and specifically social media, is playing a pivotal role in the subjective experience of chronic illness in contemporary Western society. In line with sociocultural perspectives on learning, and previous research on the interactions between chronic illness patients, the current study sought to access online interactions between sufferers. More importantly, the study sought to gain insight into the nature and topics of conversation (Chen, Hall, & Johns, 2004), as they occurred naturally. It was recognised that such research objectives could not be achieved by traditional online research methods, for example, online surveys, online interviewing, or focus groups. Therefore, the current project sought to analyse data from online chronic illness discussion forums posted by sufferers. To this end, social media was selected as the vehicle to understanding learning in the illness experience. Ethical and legal concerns over notions of "private" and copyrighted messages posted to illness discussion boards led to the decision to collect data from the social networking site, Facebook. This decision is explained fully in a later section of this paper (Ethical challenges in planning the research project).

Examining posts to Facebook discussion forums would provide an important insight into the experiences of chronic illness; but importantly, the posts would also provide an insight into the interactions between sufferers, allowing us to identify which sociocultural perspectives on learning are key to the learning process for this group. It was envisioned that access to sufferers' online interactions would provide an understanding of their informal learning – that which results from naturally occurring opportunities for learning in everyday life (Cseh, Watkins, & Marsick, 1999). Most learning results from learners applying their own personal strategies such as questioning, listening, observing, and reflecting on their own situations or environments (Marsick & Watkins, 1990), and thus informal learning is arguably the most important form of learning (Tough, 1971).

The current study represents the first in a series of three studies on the topic of learning in chronic illness. It was anticipated that an analysis of online data would inform the development of interview questions for a later phase of the research. Therefore, online interactions and discourses, as well as being of interest in their own right, would play a crucial role in laying the foundations for the rest of the project. A further advantage of using online discussion forums is that the data would provide access to the experiences

of chronic illness sufferers that may not otherwise be available. For example, face-to-face support groups cannot be offered to sufferers with certain chronic conditions (e.g., cystic fibrosis) due to the risk of infection. Furthermore, the health psychology literature shows that individuals vary in their coping strategies to manage the demands of illness (Moos & Schaefer, 1984). Some individuals may seek emotional support from fellow sufferers, while others may be more interested in finding information about their illness. Therefore, the analysis of online messages would provide access to the experiences of individuals with a broad range of conditions and with varied coping strategies.

The ethics of research using online data

Having taken the decision to analyse data posted to social media, it was important to explore the methodological and ethical issues which would shape the design of the project. Within the higher education institution where the research was undertaken, ethical approval is required from either a school-level or university-level ethics committee, for any research which involves "human participants". It immediately became apparent that within the institution there was a lack of consensus about whether individuals who have posted messages to the internet should be considered "participants" in the research, or whether such research should be viewed as involving the analysis of secondary data that already existed in the public domain. Other researchers who have carried out analyses of online messages (e.g., Attard & Coulson, 2012; Coulson et al., 2007) have deemed the data to be in the public domain, yet have sought ethical approval from within their own institutions anyway. This practice seems contradictory, yet is in line with the British Psychological Society's (BPS, 2007) guidelines for ethical practice in psychological research online.

Selecting the most appropriate guidelines to guide the research posed another challenge to the researchers. Watson, Jones, and Burns (2007) suggest that it is impractical to suppose any single set of guidelines could address all ethical issues concerning online research, due to the diversity of online spaces. Hair and Clark (2007) state that what might be considered as ethical research conduct in one online community might not be considered as ethical in others. Therefore, in designing the present study, it was recognised that many guidelines for ethical online research would need to be consulted, and careful consideration paid to what could legitimately be considered ethical online conduct within the illness community.

The British Educational Research Association's (BERA, 2011) guidelines for ethical educational research do not provide any specific advice for internet-mediated research. Education researchers have addressed significant methodological challenges involved in online interviewing, and identified the evolving ethical issues associated with research of this nature (James & Busher, 2006, 2009). However, for the current project, specific advice involving the retrieval and analysis of online discussion forum messages was sought. A review of literature from the field of education did not provide clear guidelines specifically aimed at how to approach the ethical design of research involving the retrieval of pre-existing online messages for analysis, so literature from other disciplines was consulted.

Guidelines aimed at supporting ethical decision making in online research have been published by the Association of Internet Researchers (AoIR, 2002, 2012) and the BPS (2007). The original AoIR (2002) guidelines discuss issues pertaining to informed consent and the ethical expectations of online users. Their more recent guidelines (AoIR, 2012) draw particular attention to three areas of tension to be negotiated: the concept of "human subjects", public/private online spaces, and data/persons. However, these

guidelines do not prescribe a set of "dos and don'ts" to guide online research. Instead, they recommend researchers consider a series of questions when thinking about the ethics of their study.

The BPS (2007) guidelines for ethical practice in psychological research online stipulate what ought to be deemed as ethical online research, discussing issues of public/private domain and informed consent. Although the AoIR (2012) guidelines provide useful support to many of the significant dilemmas faced when undertaking research of an online nature, the BPS (2007) guidelines are more explicit about their recommendations for ethical online research. For example, on issues relating to protecting individuals' identity, the BPS' (2007) guidelines state "Researchers should avoid using quotes that are traceable to an individual's posting via a search engine unless the participant has fully understood and consented to this" (p. 4). Referring to the same point, the AoIR (2012) ask "Does the connection between one's online data and his or her physical person enable psychological, economic, or physical, harm?" (p. 7). Therefore, the AoIR (2012) guidelines require more interpretative work on the researcher's part. This is no criticism of the AoIR (2012) guidelines, since they clearly state that they are designed to focus on general principles, highlighting processes for decision-making and raising questions that researchers can apply to ever-changing online contexts (AoIR, 2012). However, as novice online researchers, more directive guidelines were helpful in providing clarity regarding the ethical conduct of online research.

To this end, the BPS (2007) guidelines were selected to inform the development of the current study. These guidelines were intended to supplement the Code of Ethics and Conduct (BPS, 2006). However, at the time this research was being undertaken, the most recent Code of Ethics and Conduct was the 2009 edition (BPS, 2009). Negotiating the use of BPS (2007) guidelines in relation to the most recent Code of Ethics and Conduct (2009) was a difficult task. In the end, the BPS (2007) guidelines, in conjunction with the Code of Ethics and Conduct (BPS, 2009) and Code of Human Research Ethics (BPS, 2011) informed the ethical conduct of the current study, as they offered the most appropriate and direct advice on tackling research of this nature. It was recognised that consulting various sources of guidance would contribute to informing an ethical online study (Watson et al., 2007). At the time the project was undertaken, the BPS (2007) guidelines represented the most up-to-date guidance that was provided by the BPS, as the revised guidelines (BPS, 2013) that we refer to later in this paper had not yet been published. However, we refer to these more recent and comprehensive guidelines to indicate more contemporary views on ethical online research that those embarking on a similar research journey might find useful.

Despite the differences between the various sources of guidance in the conduct of online research, it became clear that three main challenges would have to be addressed in order to ensure that the current research plan represented ethical practice. These were the distinction between the public and private spaces of the internet, issues of informed consent, and protecting the data to ensure confidentiality and anonymity.

The distinction between public and private data spaces of the internet

What constitutes public or private online space has been debated for almost 20 years (Sudweeks & Rafaeli, 1996), and yet, whether public discourse should be considered public or private domain remains a controversial topic. The Code of Ethics and Conduct (BPS, 2009) states that if research is to take place without informed consent, observations involving human subjects must take place in public situations where those observed "would expect

to be observed by strangers" (p. 25). But this raises questions about the expectations of those who are being observed.

For the present project, it was important to consider how the Code of Ethics and Conduct (BPS, 2009) applied within a "virtual" public space. Rafaeli (1992, as cited by Sudweeks & Rafaeli, 1996) argues that public discourse, in the form of messages posted online, is exactly that: public. Rafaeli suggests that the study of public discourse is no different to the study of tombstone epitaphs or graffiti. Here, Rafaeli makes the distinction between the personal and the private, stating that while some discourse might be personal, that does not necessarily make it private. More recently, the BPS (2013) have suggested that the difficulty in distinguishing between public and private spaces in an online context is that discourse can take place both privately (whilst at home) and publicly (in an online discussion forum) concurrently. Furthermore, they recognise that it is not easy to decipher what online spaces people perceive to be "private" or "public", or whether individuals would be happy with their discourse being used for research purposes (BPS, 2013). The AoIR (2012) recommend that researchers consider "If access to an online context is publicly available, do members/participants/authors perceive the context to be public?" (p. 8).

Previous authors have concluded that where data can be accessed without site membership, such data can be considered as public domain (Attard & Coulson, 2012; Haigh & Jones, 2005; Sudweeks & Rafaeli, 1996; Whitehead, 2010). Therefore, if data can be accessed by anyone, without website registration, it would be reasonable to consider the data to exist within the public domain of the internet. There appears to be agreement that password-protected data or websites that require registration should be considered as private domain (Haigh & Jones, 2005). Users posting in password-protected websites are likely to have expectations of privacy. In addition, websites that require registration are largely copyrighted, which raises the legal issue of ownership of the data, and whether these messages may be legally or ethically used for research purposes (BPS, 2013; Haigh & Jones, 2005). Hair and Clark (2007) warn researchers not to assume that online communities are accepting of their discussions being observed. Others contend that although publicly available online interactions exist within the public domain of the internet, members may view them as private (AoIR, 2012; Holmes, 2009). So, while the members may be aware that their online contributions are posted to public online spaces, they may have no expectation that their contributions will be used for research purposes.

Others have argued that publicly available online data carry no expectation of privacy (Whitehead, 2010). The AoIR (2002) guidelines suggest that one way researchers may interpret members' expectation of privacy is to check whether the site of interest has a policy establishing users' expectations. For example, where sites advise that members' contributions may be accessible to anyone online, expectations of privacy could not be supported. Where there is ambiguity regarding whether accessible data may be considered public or private, the BPS (2013) suggest some ethical principles to guide ethical online research. These principles (discussed fully later) were not set out in the BPS (2007) guidelines which informed the current project, and therefore, there was no such clarity available. In order to progress the current research project, a judgement was needed about whether the data to be analysed existed in the public or the private domain, and whether messages in the public domain carried any expectation of privacy. The ethical conduct of the research would be dependent upon having a clear and justifiable position in relation to these questions. This judgement would have implications for whether those individuals responsible for contributing the data to be analysed would have to be approached to provide informed consent.

Informed consent

Informed consent refers to the process by which individuals explicitly agree to be participants in a research project, based on a comprehensive understanding of what will be required of them, what data the researcher will be collecting, and what will happen to those data. It also involves the provision of information for participants about their rights to withdraw from the research. Previous authors have argued that no informed consent is necessary in online contexts where data exist within the public domain and are publicly accessible online (Eysenbach & Till, 2001; Sudweeks & Rafaeli, 1996). The BPS (2013) also indicates that informed consent is not necessary where "scientific/social value/research validity considerations are deemed to justify undisclosed observation" (p. 7). These guidelines are consistent with the practices of previous empirical research using online messages for research purposes (Attard & Coulson, 2012; Coulson et al., 2007; Whitehead, 2010). Therefore, where it cannot legitimately be argued that data exist within the public domain, or where data do exist within the public domain but are protected by copyright laws, explicit consent to use such data for research purposes must be sought (BPS, 2013).

In the context of the present research, it was demonstrated that the data legitimately existed within the public domain, and thus could progress without any need for informed consent (Eysenbach & Till, 2001). Depending on what is of interest to researchers, obtaining informed consent may be unproblematic to their research. However, in cases where the focus of interest may be disrupted or altered in some way as a result of obtaining informed consent, relevant guidelines must be engaged with and an ethical judgement made on the researcher's part. Where online data are deemed to exist within the public domain and where informed consent is therefore not necessary, as was the case in the current study, there still remain ethical considerations that relate to the treatment of the data. Consideration of these remaining issues is essential if the research is to ensure the confidentiality and anonymity of the individuals who contributed the online data (BPS, 2007, 2013).

Protecting the data

Ensuring confidentiality and anonymity falls within the principle of "respect for autonomy and dignity of persons" set out by the Code of Human Research Ethics (BPS, 2011), and the BPS (2013) guidelines draw particular attention to this principle for protecting data collected by researchers. This means that any identifiable information should be removed from the data, and that data should be stored and used in a way that will ensure the confidentiality and anonymity of any persons. Empirical research has focused on the protection of the online data in a similar way (Attard & Coulson, 2012). The BPS (2007) guidelines advise that researchers should take care when using quotations, so that these do not compromise individuals' confidentiality and anonymity by being traceable through search engines. Therefore, in the current study, an on-going process of scrutiny was applied to ensure no persons could be identifiable from internet searches of quotes, and users' names were replaced with pseudonyms (AoIR, 2002).

Ethical challenges in planning the research project

It was not the initial plan to collect data from Facebook. A search of the internet returned details of many chronic illness forums where website registration was required to view the online messages. In accordance with the guidelines set out by the BPS (2007) and others (Eysenbach & Till, 2001; Hair & Clark, 2007; Holmes, 2009), ethical issues concerning

privacy, and the extent to which these forums could reasonably be considered "public" domain, it was judged important to avoid "private", copyrighted online sources of discourse. However, since the research project was driven to access a forum which was not specific to any particular illness, it proved challenging to find any open, non-password-protected discussion forums. This was unsurprising given the sensitive nature of chronic illness, and led instead to a search of the social networking site, Facebook. No known previous research had investigated the activity and nature of communications within designated chronic illness Facebook pages.

The search of Facebook returned several non-illness-specific support group pages that were unlocked and could be accessed publicly by anyone. Individuals wishing to post messages to a Facebook support group must be members of Facebook. Membership is available to anyone. Therefore, it was reasonable to consider these pages as "public" domain since they were public pages, and arguably no users could legitimately expect to consider their participation in the discussions as "private" (BPS, 2007; Whitehead, 2010). Of the publicly accessible Facebook pages revealed in the search, some lay dormant or had little activity. The present project sought an active, current source of data. Reviewing the pages that met these criteria, one was selected due to its frequency of use and the volume of messages available for analysis. This was consistent with how other empirical researchers have selected existing online messages for analysis (Attard & Coulson, 2012). The Facebook page was a non-illness-specific support page, and provides patients with any chronic illness a virtual "meeting place" to discuss their illness experiences and to give and receive information.

Since this Facebook page existed within the public domain of the internet, it was agreed within the project team that informed consent would not be necessary. In fact, many ethical issues that would normally be considered when planning research with human participants were not applicable, since it was judged to consist of an analysis of secondary data already in the public domain. Despite this, it was decided (in line with previous research and ethics guidelines) that ethical approval would still be sought from the home institution's School Ethics Committee (e.g., Attard & Coulson, 2012; BPS, 2007; Coulson et al., 2007)

Gaining ethical approval

Although the proposed project adhered to the guidelines set out by the BPS (2007), and was in line with similar empirical research using online messages for research purposes (Attard & Coulson, 2012; Coulson et al., 2007; Whitehead, 2010), the ethics application submitted was initially rejected. The rejection reflected the ethical arguments discussed previously (e.g., Sudweeks & Rafaeli, 1996). The Ethics Committee raised concerns about whether individuals' consent should be sought, and how their privacy could be protected. This rejection was frustrating for the research team, given that the application adhered to the BPS guidelines (2007, 2009, 2011) and since the research design was in accordance with similar online research.

The Ethics Committee suggested obtaining informed consent on some level, either by announcing the presence of the researcher online within the Facebook page, by seeking approval from the Facebook page "moderator" or by "trialling" the project's plan with other chronic illness support groups to obtain their perspective on the conduct of the research. The project team were concerned that seeking explicit consent from users online would require announcing our presence online, and could disrupt the flow and naturalism of conversations. Not disclosing our presence online could be considered lurking, where the researcher acts as a passive observer in an online discussion group, with a view to

collecting data (Griffiths & Whitty, 2010). While some have argued that lurking is necessary for gaining an understanding of the topics and tones of online exchanges (Chen et al., 2004, as cited by Madge, 2007), others argue that researchers lurking in online communities is intrusive, thus causing damage to that community (Eysenbach & Till, 2001). We were keen not to disrupt the natural flow of online conversations, not solely because these were the focus of interest in the research and hence we were keen to protect the naturalism, but also to avoid any unnecessary harm to online users (discussed later).

Dr Neil Coulson (University of Nottingham) is an internationally recognised expert in the role of peer support online communities, and much of his work was cited in the original ethics application for the project (e.g., Attard & Coulson, 2012; Coulson, 2005; Coulson et al., 2007). Since the focus of his research is primarily on online communities, his advice was sought about obtaining ethical approval for research of this nature. It emerged that Coulson was co-author of the revised Guidelines for Internet-mediated Research for the British Psychological Society (BPS, 2013), which were not yet published at the time this project was carried out. Coulson highlighted four ethical principles in the Code of Human Research Ethics (BPS, 2011), that should be considered when justifying a project without informed consent. These principles are: respect for the autonomy and dignity of persons, scientific value, social responsibility, maximising benefits, and minimising harm. These ethical principles have since been incorporated into the BPS (2013) revised guidelines for internet-mediated research. But at the time, the project team had to engage with these principles without explicit guidance linking them to online research, in order to address the concerns of the Ethics Committee.

Applying the ethical principles

The principle of "respect for the autonomy and dignity of persons" encompasses issues of valid consent, confidentiality, and rights for privacy (BPS, 2011). As mentioned, the BPS (2009) guidelines state that observational research without consent may only be justifiable in public situations where individuals would expect to be observed by strangers. In the present project, it was argued that people could not reasonably perceive their online activity to be "private" domain, meaning that informed consent was not necessary. Furthermore, users of the Facebook site had accepted the terms and conditions of use. These include an acknowledgement that if they choose to make messages "public" (an active choice, made by users when broadcasting a Facebook message), then those messages can be accessed by anyone – including those without Facebook accounts. Facebook warns users that "choosing to make your information public is exactly what it sounds like: anyone, including people off of Facebook, will be able to see it". Therefore, users of the Facebook page selected for the project had arguably already provided tacit consent to their messages being accessed and used for purposes other than to be read by other sufferers, with no expectation of privacy (AoIR, 2002; Whitehead, 2010).

Nonetheless, the principle of "respect for the autonomy and dignity of persons" led the project team to give further consideration to the recommendation of the Ethics Committee to obtain the perspective of other chronic illness sufferers on the proposed research. Rather than alerting online users to the presence of a researcher, two other chronic illness support groups were approached and consulted about the planned research. Positive feedback was received from members of both groups. One chronic illness sufferer said, "I wouldn't put anything on Facebook that I didn't feel comfortable with everyone seeing – if it's private, I would send a 'private' message, not a 'public' message". Another said, "It is well known that if you post messages publicly on Facebook, then anyone can access them". Based on

this feedback and the position set out by the relevant guidelines and previous authors, the researchers chose to pursue the original plan not to obtain informed consent.

The second principle of "scientific value" states that research should be "designed, reviewed and conducted in a way that ensures its quality, integrity and contribution to the development of knowledge and understanding" (BPS, 2011, p. 9). The research project sought to make a significant original contribution to the field, given the current lack of understanding of the role of learning in the subjective experience of chronic illness. Therefore, the potential societal benefits of augmenting understandings in the area were greater than the risk of harm resulting from non-disclosure of the presence of a researcher online.

Although Chen et al. (2004, as cited by Madge, 2007) identify lurking as important for accessing the topics and tone of online exchanges, they claim that group moderators disapprove of the notion of lurking as a data collection method, and thus conclude that observation without participation would be unethical research practice. However, the third principle of "social responsibility" states that ethical research has an obligation to acknowledge "social structures in relation to societal need and to be respectful of such structures" (BPS, 2011, p. 10). It continues that "unwarranted or unnecessary disruption should be avoided unless the intervention outweighs the cost of such disruption" (p. 10). In the context of the current research project, disclosing the presence of a researcher online may have disrupted the dynamics and social structures within the illness community, causing more harm to users than non-disclosure of presence, and thus counter-productive. This principle of "social responsibility" suggests that ethical research must be generated for beneficial purposes, and may be defined as contributing to the "common good" as well as individuals' dignity and integrity. The potential benefits of the project outweighed the risk of harm to the Facebook users, thus the study sought to do good over harm by understanding the subjective nature of chronic illness. Similarly, the fourth and final principle of "maximising benefit and minimising harm" was given consideration. It was judged that non-disclosure of the presence of a researcher would maximise benefit by providing much needed understandings of learning in illness; and would minimise harm by avoiding disruption of the online source of social support for chronic illness sufferers, which has been identified as important to the illness experience (Coulson et al., 2007).

Responding to the ethics committee

By addressing these principles from the Code of Human Research Ethics (BPS, 2011) and by drawing attention to the discussions taking place in relevant guidelines and previous empirical research, a detailed response was made to the Ethics Committee. The support for the project from chronic illness sufferers and their perspective on the need for informed consent was presented. It was argued that the data should legitimately be considered to exist in the public domain, and that obtaining informed consent was not only unnecessary but could disrupt the social environment and support provided to users within the Facebook page. Given all of this, it was argued that the risks and ethical concerns of the project related principally to confidentiality and anonymity. To ensure these concerns were addressed, it was agreed that neither individuals' names nor the user IDs of those posting messages to the Facebook page would be disclosed. In addition, a numbered coding system would be employed at the first stage of downloading the messages for analysis, to protect usernames by replacing them with a number, and later assigned a pseudonym for the write-up of the findings.

Confidentiality and anonymity would further be protected by adhering to the BPS (2007) guidelines, ensuring that authors of quotations used in the analysis could not be identified by a search engine. In line with these guidelines, the name of the Facebook page used would not be disclosed in any publications. Instead, later in the research process, a pseudonym would be assigned to quotes used. At the request of the Ethics Committee, an on-going process of scrutiny would be applied to the data to ensure that direct quotes used in any publications would not be traceable to the Facebook page or to any individual through Facebook or through search engines generally. Only information regarding the type of chronic illness the messages related to would be disclosed.

Following the consultation with Dr Coulson, he provided a supporting statement that the plan not to seek informed consent was justifiable. This was included with the response to the Ethics Committee, which also included a detailed explanation of the project's adherence to the ethical principles discussed above. On the basis of this additional material, ethical approval for the project to progress was granted.

Discussion

In undertaking this research project, the aim of which was to develop an understanding of the role of learning in the subjective experience of chronic illness, the initial intention of the project team was not to become well versed in the ethics of conducting research involving online spaces. Embarking on research of an online nature for the first time requires researchers to be familiar with the most up-to-date and relevant guidelines for ethical practice. By engaging with the ethics of online research, it became clear that the issues extend well beyond just the question of what is "public" and "private" domain. The expectation of privacy must also be considered. Once these issues have been addressed, it is vital to consider issues of informed consent. In the present research, non-disclosure of the presence of a researcher to users online was judged to be justifiable, as was the decision not to obtain informed consent. The risk of harm to online users was low, and the scientific value of the project was enhanced by non-disclosure. For this study, disclosure posed more risk to the social support structures for individuals, and disruption to the naturalism of interactions, than non-disclosure.

In the early stages of designing the study, the usefulness of negotiating ethical guidelines, and the value of the data remained to be seen. However, with the analysis now complete, it is clear that the richness of the online data justified the time taken to obtain ethical approval for the study. The efforts involved in identifying relevant ethical guidelines, and applying ethical principles to the current project, were worthwhile. The process permitted us access to the discourses of the contemporary illness community as they took place naturally through interactions between chronic illness sufferers.

Consistent with sociocultural perspectives on learning, the present study identified learning as occurring within an online illness community of practice (Wenger, 1998), with sufferers' exchanges about managing their condition representing the curriculum of the community. Themes from the online data were understood in terms of learning, participation in practices, and identity. Themes of identity, information sharing, coping, and distrust emerged from these rich data, revealing that the online learning allowed for participation in a new community of practice, which serves to support shifts towards new illness identities that are stronger and support better coping in the illness experience.

With the present study now complete, the beneficence of using lurking as a data collection method can be considered. Lurking provided access to the social interactions between chronic illness sufferers as they occurred naturally, adding an online dimension to our

understanding of the role learning serves in the subjective experience of chronic illness. The findings of the study provide a unique way of thinking about learning in chronic illness, and contribute to understanding the use of online support groups by sufferers. This is particularly relevant within contemporary research about learning, given the increase in social media use. Understanding the online "illness community" is crucial to understanding learning in chronic illness; by providing an insight into the information available to sufferers online and how they use this information within their everyday experiences of living with a chronic condition. To date, no research has attempted to understand how the use of social network sites, such as Facebook, may provide sufferers with a "platform to learning", resulting from the opportunity to "hear" the experiences of other sufferers, to share information, and to contribute to an "illness community" more generally. It was anticipated that the current study would begin to bridge these gaps in the literature, and have potential implications for several groups: health professionals, health educators, adult educators, and policy makers. Therefore, the invaluable insight gained about learning in the illness experience and the potential implications of the findings justified lurking as an acceptable procedure.

Through the ethical challenges of planning this project, the value of networking with more experienced researchers in different disciplines and institutions has been highlighted. The development of the project was a collaborative learning process for the research team, in which an expert in online research offered assistance to the project team. Networking with a researcher more experienced in online research contributed to negotiating the BPS guidelines to arrive at an ethical approach to online research.

It seems clear that there are no "one-size-fits-all" guidelines available to inform an ethical approach to internet-mediated research, and it would be unrealistic to expect this from any one set of guidelines (Watson et al., 2007). Instead, research of an online nature demands the use of standard guidelines for ethical practice in conjunction with recommendations specifically for online research (Jones, 2011). The negotiation of multiple guidelines is likely to be required of online researchers, to arrive at a study ethics committees will approve. Within the ever growing social space of the internet, online research methods can contribute to augmenting understandings of many social phenomena that exist in online contexts. In the current study, accessing such phenomena justified the efforts involved in negotiating these guidelines.

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