Understanding appropriation of a social media technology to manage chronic illness: The Facebook case

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Abstract

With the rapid increase of social media appropriation globally, there has been a surge in the number of chronically ill adults who leverage social media tools as part of their illness management practice. While numerous studies discuss the potential benefits of appropriation there seem to be limited studies that have explored appropriation of social media by investigating how and why these technologies have been appropriated by these patients. This paper applies an interpretive case study with mixed methods to examine appropriation of Facebook by these cohorts. Our results highlight the patterns of social media appropriation: lurking as passive learning; liking and reacting to show support and; borderless appropriation of multiple social media tools. Among a range of influences, crafting a positive illness identity, communal filtering of misinformation were found to be positive influences and barriers like emotional overload were found to influence appropriation for chronically ill adults on social media.

Keywords technology appropriation, social media appropriation, chronic illness management, social support.

1 Introduction

Social media technologies have infiltrated all facets of modern life and their use has grown significantly over the last decade, with users numbering roughly around 2,789 billion globally. These technologies have had considerable impact on society: as platforms for activism; as support for new business models; to organize people around common causes such as health (Rozenblum and Bates 2013). Accordingly, a growing number of chronically ill adults make use of social media technologies to better understand and manage their illness. Social media appropriation by patients could be considered a facet of the global e-health initiatives which comprises the use of digital technologies to assist the healthcare system (Agarwal et al. 2010; Fernández-Luque and Bau 2015; Fichman et al. 2011; Hajli 2014). Although numerous studies highlight the benefits and implications of social media to support chronic illness management practices, few studies have investigated the appropriation process in this context (Fernández-Luque and Bau 2015; Fichman et al. 2011). It appears that studies conducted in social media communities for health are focused on motivation mechanisms, i.e. influences on health-related outcomes in these settings (Merolli et al. 2013). There seems to be a limited amount of attention paid to appropriation of social media technologies within the public context to manage one's health and wellbeing (Isika et al. 2016). Further, the role of emotions within the appropriation context seems to have attracted minimal scholarly attention, although appropriation is influenced by and influences the emotions of individuals who interact with the technology artefact (Beaudry and Pinsonneault 2010). Particularly in the case of chronically ill cohorts, who experience psychological and emotional distress while coming to terms with and managing their illness (Merolli et al. 2013). Previous studies have cited the number of people with chronic illness in Australia at 7 million and yearly spending on their health management comes to around 60 billion dollars (Georgeff 2014). Appropriation of social media technologies by chronically ill adults could serve as a cost effective component in self-management of chronic illness as proposed in the chronic care model which serves as a guide for stakeholders such as general practitioners and other healthcare service providers to improve patient involvement and empowerment (Wagner 1998; Yach et al. 2004). To this affect, there is a need for further studies in this domain to understand influences on social media appropriation by these cohorts and how these technologies are applied in the context of chronic illness management.

Some scholars have conceptualized appropriation as the psychological processes and interventions that a user carries out to make a space their own, i.e., to personalize it (Mifsud et al. 2015). Others state that appropriation encapsulates the activities that a user carries out to bring a technology into their routines, thus, creating their own sense of the technology (DeSanctis and Poole 1994; Mifsud et al. 2015). In this paper, we define appropriation as *"the way that users evaluate and adopt, adapt and integrate a technology into their everyday practices"* (Mendoza et al. 2010). Recent studies indicate that appropriation is influenced by emotions experienced by the users as a result, while their patterns of appropriation are context specific (Beaudry and Pinsonneault 2010; Mendoza et al. 2013).

This study is part of larger investigation that examines appropriation of four different social media technologies by chronically ill adults for illness management. In this paper, we aim to gain empirical understanding of how adults with chronic illness engage with and appropriate social media technologies as part of their illness management practices, focusing specifically on Facebook. Hence we apply a practice lens that combines social support theory (Lakey and Cohen 2000; Shumaker et al. 1984) and technology appropriation (Mendoza et al. 2010) as a sensitizing lens to explore influences and patterns of appropriation within this context. Therefore, the research question of this study is: *How do chronically ill adults appropriate Facebook as part of their illness management practices?* with the following sub-questions:

- What are the patterns of appropriation of chronically ill adults while engaging with similar others on Facebook?

- Why do chronically ill adults appropriate Facebook in their illness management practices?

This paper is demarcated as follows: The next section gives theoretical background of this study followed by an outline of the research method. We then present the findings from our investigation followed by a discussion. The paper concludes by highlighting contributions of the study, its limitations and a roadmap for future research.

2 Theoretical background

Social media technologies are a set of internet based tools that facilitate creation and exchange of user generated content (Kaplan and Haenlein 2010). Users participate, produce and consume content while

interacting with their peers through a technologically mediated environment, forming connections which may not be limited by geographical location or boundaries (Urquhart and Vaast 2012; Yoo 2010).

2.1   Patients and social media

Traditionally, chronic illness management has been hierarchical in nature, with majority of control and power in the hands of the healthcare practitioners (Fichman et al. 2011; Pousti et al. 2014). However, scholars in the medical field have noted that self-management and patient engagement lead to improved quality of care for chronically ill cohorts. This is critical because scholars have reported increased incidents of chronic illness globally because of increased sedentary living, an ageing population and other lifestyle factors (Bodenheimer 2002; Pousti et al. 2014). Moreover, previous studies suggest that technologies like social media could augment health management practices of chronically ill cohorts by providing an opportunity for patients to self-manage their illness (Merolli et al. 2013). These technologies present chronically ill users with an opportunity to gain information and engage in interactions that have ramifications on their physical and mental health (Fernández-Luque and Bau 2015). Because healthcare services and providers typically provide episodic care for illness therefore, developing an illness-management practice is essential for chronically ill adults (Liang and Xue 2013). Previous studies suggest that the move to digitization of healthcare efforts through mechanisms like social media could result in reduced overall individual and public-sector spending on managing illness and maintaining an individual's well-being (Hajli 2014). Furthermore, these technologies could alleviate the cost and burden of illness management while also improving the healthcare service quality from both an individual and healthcare sector perspective (Agarwal et al. 2010; Fichman et al. 2011). The majority of studies in this domain have been conducted on the predecessors of social media although an increasing number of users utilize social media tools such as Facebook and others for health related goals (Agarwal et al. 2010; Merolli et al. 2013). While there have been numerous studies that have explored motivations and implementation of online support groups for chronically ill adults, little is known about appropriation patterns of these technologies (Agarwal et al. 2010; Chung 2014). It seems that the actual patterns of appropriation and influences that encourage or discourage appropriation of social media technologies are largely overlooked by scholars, particularly in the context of chronic illness management.

2.2   Technology appropriation

Scholars have suggested that appropriation is an emergent process influenced by the user, their social environment and needs/goals (Beaudry and Pinsonneault 2010; Mendoza et al. 2010). Appropriation is considered contextual and may be faithful or unfaithful depending on user needs of a given technology artefact. Social influences, norms, explicit and implicit rules are present within any social setting so influence and are influenced by the introduction of technology (Jeyaraj and Sabherwal 2008). Previous scholars have applied: Uses and gratifications theory; social capital theory; social cognitive theory; technology acceptance model; unified theory of technology acceptance and use; theory of planned behaviour and process theories such as structuration, adaptive structuration and situated action to examine influences on appropriation outcomes across various contexts (Bandura 1991; DeSanctis and Poole 1994; Giddens 1984; Suchman 1985; Venkatesh et al. 2003). These theories suggest that the locus of appropriation starts individually and is then influenced by contextual characteristics of the appropriation practice (Orlikowski 2000). This indicates that appropriation and its outcomes are context specific, subject to their individual attributes and collective interpretation by the community that adopts a technology artefact (Fulk and Gould 2009; Orlikowski 2000). Also, some recent studies have illustrated that the choices involved in appropriation are often motivated by the user's emotions during this process (Mendoza et al. 2013). However, given the contextual nature of appropriation, there have been limited studies on appropriation within the public context as most studies in this area are conducted within an enterprise setting. The majority of appropriation studies within IS are conducted within organizational settings and a similar focus is present in the ongoing discourse on social media appropriation which has largely focused on enterprise social media applications (Isika et al. 2016; Yoo 2010). Further, there appears to be a current bias in literature which suggests that social media appropriation results in positive outcomes, with few studies examining the potential risks/ drawbacks that could arise from appropriation of these technologies in wellbeing management (Gibbs et al. 2013). In their study, Gibbs et al (2013) showed that workers develop strategic patterns of appropriation to protect their self-interest. Some recent studies indicate that appropriation of social media could have a detrimental effect on users, causing negative emotions such as guilt or envy (Maier et al. 2015). Therefore, we extend work of these scholars by examining the influences and appropriation patterns of social media tools by chronically ill adults, to better understand and manage their illness.

2.3 Conceptual Model: Social support and technology appropriation

Given that chronic illness requires continued management efforts and exerts physical, psychological and emotional impact on sufferers, it is essential to consider emotions during investigation of appropriation among these cohorts. Considering these issues, we apply a combination of social support theory and technology appropriation as a practice lens to guide our study (see Figure 1). Social support theory (SST–B in Figure 1) suggests that social connections may be leveraged to alleviate the effects of stress and improve illness management outcomes for chronically ill cohorts (Shumaker et al. 1984; Wang et al. 2017). SST is commonly operationalized through concepts of emotional, social, informational and tangible support to achieve positive illness management outcomes. Accordingly, SST has been applied to examine influences on engagement with social media by scholars with mixed results. E.g. some scholars found that social media provides users with positive illness management outcomes through the dimensions of emotional and informational support (Chung 2014; Wang et al. 2017). Some others have suggested there may be negative aspects involved in the exchange of social support, such as envy or emotional overload (Maier et al. 2015). However, social support theory does not account for patterns involved in appropriation, particularly in an online environment although it is suggested that deriving an understanding of this aspect could be useful for research and practice. Therefore, to examine patterns of appropriation of social media among chronically ill adults, we use a model of technology appropriation (A in Figure 1 to augment the examination of influences and patterns of technology use within the context of social media appropriation by chronically ill cohorts. Variations of MTA have previously been applied to investigate technology appropriation by various cohorts across varied contexts and so the flexibility of this model in investigating appropriation across various contexts influenced it's selection for this study (Carroll et al. 2007; Mendoza et al. 2010). However, previous iterations of MTA account for emotional or psychological influences on appropriation by these vulnerable cohort in limited ways (Mendoza et al 2013). Therefore, to gain deeper insights into how people use social media for managing chronic illness, we apply a combination of technology appropriation and social support theories as practice lens to frame our examination of the appropriation of Facebook by chronically ill cohorts.
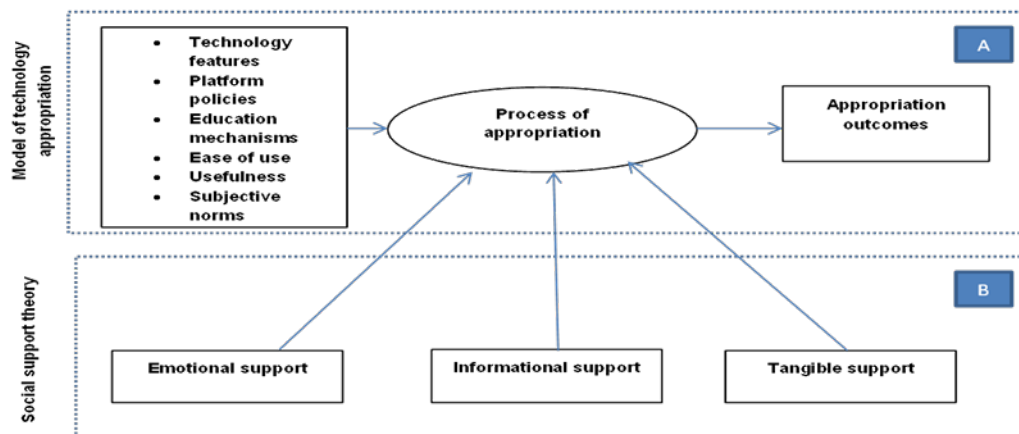

Figure 1 Practice lens of the study

3 Research method

We used an interpretive case study with mixed-methods approach and purposive sampling to guide our case selection (Eisenhardt 1989; Onwuegbuzie and Leech 2007). Facebook was selected because previous researchers (Pew research institute) reported it has the highest number of registered users globally (Smith and Anderson 2018). Our research approach aimed to develop a complete understanding of appropriation through triangulation of qualitative and quantitative strands in this study (Venkatesh et al. 2013). Using data mining techniques (topic modelling) in combination with a mixed methods case study approach provided the theoretical grounding for the noisy and often hard-to-interpret textual datasets that were extracted from our case study platform (McKenna et al. 2017). We interpreted our findings as theoretical dimensions which also integrated the data analytics results (Gioia et al. 2013; Walsham 1995).

3.1 Case description

Facebook - a social networking site, comprises a user profile, newsfeed, friends, real time instant messaging, entertainment features, universal login, groups, pages, events and other features that allow users to connect with friends, family and similar others globally. Our study focused on Facebook communities for adults with fibromyalgia - a debilitating chronic pain disease characterized by tender points, pain episodes (flares), chronic fatigue, emotional and mental distress (Wolfe et al. 1990). We chose fibromyalgia because it is a chronic illness that requires ongoing monitoring and self-care activities from its sufferers.

3.2 Data collection and analysis

Prior to conducting the study, ethics approval was obtained from the university of Melbourne human research ethics community at the school of engineering. The strategy for informant recruitment/data collection was: (1) conducting a search on Facebook for "fibromyalgia" or "fibro"; (2) sending out messages to the profiles, groups or pages informing them about the study and obtaining consent to (3) join these social media groups to monitor their activities and; 4) conducting semi-structured interviews lasting between 60-90 minutes. We recruited 12 key informants, 9 women and 3 men to participate. During the interviews, informants were asked: (1) how they started using Facebook, (2) why they use the platform in general, (3) why they use the tool to discuss their illness, (4) what role the tool plays in their illness management practices, (5) emotional impact and /value of using the tool, and (6) how informants engage with other chronically ill patients. We anonymized the collected data and assigned pseudonyms to our informants in accordance with the order the interviews were conducted in, for instance: Facebook01 and so on. Our thematic analysis of the empirical data helped to organize, cluster and interpret our analysis themes (Strauss and Corbin 2008; Yin 2013).

In keeping with the data collection protocol, the quantitative strand commenced with the search for: "fibromyalgia" or "fibro" on Facebook.com which returned 270 groups and 492 pages connected with fibromyalgia. One Facebook page was selected because its pages are open to access and we acquired permission by the page owner (also an informant) of the group. Posts from 1st January 2015 until 13th September 2017 were collected using the Netvizz browser plugin, which automatically anonymizes the collected data. Using this dataset, one of the researchers commenced with data cleaning, removing all content that seemed to be spam/not in English. From the resulting cleaned dataset, 700 text posts were sampled for further data analysis in this study. To make sense of the noisy and hard to interpret dataset, we also employed data analytic tools such as Natural language toolkit (NLTK) and topic modelling using latent dirichlet allocation (LDA) to extract topic clusters from the text corpus. Finally, these were also interpreted and integrated with the qualitative data using our practice lens as a scaffold.

4 Findings

Our findings are presented in two parts (1) Patterns of appropriating Facebook for illness management and; (2) Influences on appropriation of Facebook for chronic illness management.

4.1 Patterns of appropriating Facebook for illness management

The selected Facebook page had 90,635 followers from 45 countries. Majority of its followers were from United States (59.12%), followed by Great Britain (26.42%) and Canada (4.7%). From the Facebook group, the total number of posts over the observation period was 782, with 4,233 comments, 29,287 views and 14,286 reactions. Similar to the Facebook group, the Facebook page sample contained 7,933 comments, 24,401 reactions and 1,048 shares and the total number of followers of the page was 90,635. This community comprised a group of active members who react, post and comment on each other's content yet it appears that a larger proportion of members read the contents on the community, but don't interact beyond that as one key informants explained: *"There is a core group of active members, who comment on each other's posts and really make an effort to support each other in a positive way. There is also a larger group of silent members, who rarely comment, but like to read everything that is going on in the group."* (Facebook02). Five appropriation patterns were observed: (1) lurking as passive learning (tentative/cautious); (2) liking and reacting to show support (moderate engagement); (3) posting and commenting to exchange information (proactive); (4) borderless technology appropriation; and (5) daily interaction with group to stay informed.

a) Lurking as passive learning: Newcomers practiced lurking initially, reading through posts to familiarize themselves with community norms. Lurkers passively consume content to learn about the community norms while preserving a level of privacy and anonymity. A common statement made by these cohorts when they make the transition from lurking to posting or commenting is "*first time poster,*

long time lurker". Some cohorts explain: "*I read everything if I'm online and if I don't have anything to say I don't emoticon it or post to the thread.*" (Facebook05). Lurkers often preferred interaction through other less visible mechanisms e.g. private messaging: "*Some prefer to personal message an admin with a question, others interact on the page*" (Facebook04).

b)   Liking and reacting to show support: Majority of our informants (7 out of 12) preferred interaction with the community through the liking and reacting feature of Facebook. Hence, liking or reacting was used to participate within the community while retaining some privacy, while also showed support to others in the group. One informant explained the value of a like*: "Likes are also important, people like their posts to be liked because many are nervous about sharing*" (Facebook09).

c)   Posting and commenting to exchange information: Around half of our informants posted seldom but regularly followed up with comments or questions to the community as one informant noted: "*I've made one post thus far, but I comment if I know something or have a suggestion or share experiences or I have a question.*" (Facebook06). Posts made served two main reasons: to encourage interactions on the group and posing questions that were not already discussed in the community. Commenting seemed also a means of sharing personal experiences with peers: "*Well I like commenting because I like sharing my thoughts about the topic in the post as it relates to me or my experiences.*" (Facebook09).

d)   Borderless technology appropriation: Majority of these cohorts appropriated several other social media technologies along with Facebook to augment their illness management needs, such as using the Facebook group to track symptoms and progression of their illness and some other technologies. One informant confirmed this: "*I'm on Instagram, my space, oovoo, tango, and snap chat. [The] Facebook [fibromyalgia group] is the one I'm on the most.*"(Facebook01). Three others didn't have the time to learn new technologies due to limited time to spend online due to life situations and other obligations as one informant explained: "*I don't have the time or the energy for any other social media sites.*" (Facebook02).

e)   Daily interaction to stay informed: Facebook clearly became an important part of participants' daily lives, with some spending most of their day on Facebook. Majority of our informants shared that they were consistently notified about new posts, comments on the group but mostly interacted daily to be aware of events that occurred in the group as one informant explained: "*Well I try to check daily and I only post if I have some knowledge or I have a question really.*" (Facebook05). However, for our informants in an administrative role, this daily interaction was a necessary part of their role but was considered part of the expected workload as an administrator. One of our informants who is an admin explains: "*I seem to be spending all day on FB at times but at present I am training some people which adds to the workload.*" (Facebook05).

4.2   Influences on appropriation of Facebook for chronic illness management

Using topic modelling's latent dirichlet allocation (LDA) algorithm the 50 most salient topics extracted from the text corpus were represented through 10 terms per topic. From those, the emergent themes extracted from the topics were: informational support (84%), emotional support (10%), community (4%), and identity (2%). Table 1 below demonstrates a subset of the 50 topics derived from LDA.

Table 1. Topic modelling results latent dirichlet allocation

Sample sentence from Facebook dataset	Sample topic group from LDA	Theme	Number of topics	Percentage
"Hi everyone, I'm new to the group and recently diagnosed with fibromyalgia. I'm 28 and I guess I'm wondering if my symptoms are 'normal' for fibromyalgia.......Does anyone else get that? And what do you do to help it?...."	fibromyalgia hello thyroid medicine lately arthritis cause eye disease annoying	Information Support	42	84
"...gentle hugs to all my awesome fibro friends x"	pour page hug normal mri extra infection pas pulled feel	Emotional Support	5	10
"Can u message me please I'm having problems with members group page"	late head close group person ankle reply letter school really	Community	2	4
"Hi fellow fibro warriors....."	spoonie post hip planter warrior starting want tuesday flare sky	Identity	1	2
		Total	**50**	100

To get a deeper understanding of the extracted themes we examined the qualitative data presented in the following section in the form of three main themes and their associated subthemes discovered during our analysis.

a) Information support: Making sense of fibromyalgia and raising awareness

Participants use Facebook to learn more how to better manage the day-to-day impact of fibromyalgia on their lives. Some shared information about holistic remedies while others are more concerned with medications, their effects and correct diagnosis. Cohorts engage in collective sense-making of their illness symptoms to obtain appropriate care. In addition, more experienced users often assist newly diagnosed/yet undiagnosed participants with coping strategies and inform them what to expect as the illness progresses. Issues include topics such as medications, symptoms, gaining government support for disability or legislative issues: *"I was approved the first time around for my disability, so I offer insight from a nursing perspective and documentation to help people"* (Facebook07). The following sections discuss the subthemes that arise from the information support theme:

Subthemes that arose from the information support theme were:
- **Increased understanding and illness advocacy**: Facebook groups and pages give these cohorts an opportunity to educate their peers and members of the public on fibromyalgia. Particularly since fibromyalgia is through a process of elimination, termed by sufferers as an "invisible illness", not well supported by the medical community and so, they face huge obstacles to obtaining support. These pages/groups makes the invisible illness visible, which may help sufferers obtain information that will aid them in advocating for themselves to receive care and support as one our informants explained: *"I participate so that I can advocate for myself with doctors with the new info I may get from the group."* (Facebook09)
- **Communal filtering through misinformation/spam**: Although groups attempt to monitor shared content, they had to cope with misinformation and spam challenges as one informant explained: *"Misinformation is also something (to be aware of) as there are so many cures out there. One member tried to sell miracle water via personal message she was blocked and posted about on the site but this is an extreme measure."* (Facebook04). Additionally, spammers attempted to phish data about group members through the urls posted linking these to sites with malware and viruses: *"There is a company in Pakistan that does that. There are also those doing it (phishing attacks) giving away iPhones to gain information and the ones with pop up ads telling you your computer or phone is infected ring this number."* (Facebook04). These actions negatively impacted appropriation, causing members to leave these groups to protect themselves.

b) Emotional support exchanges: coping with the burden of fibromyalgia

A major theme apparent was that these cohorts were motivated to appropriate Facebook to obtain and give emotional support to similar others. Facebook appropriation had a mixed impact on the emotional well-being of these cohorts: some reports obtained indicated positive emotional experiences from being in these communities; a sense of belonging, exchanged empathy and fulfillment helping others through shared experiences. However, they also experienced depression at times because some could read into posts the huge emotional and psychological toll this illness has on it's sufferers. Often member posts expressed suicidal feeling and were negative emotionally charged group posts. Consequently, some members struggled with the barrage of negative posts and stories shared as an informant confirms: "*All I see is negative posts and I think why I bother even being in a support group if everyone is so negative."* Additionally, trolling contributed to the negative emotional impact from appropriating these technologies as one informant indicated*: "The guy just went bonkers and yeah I ended up deleting my post, my mum even saw it and all quite disheartening I cried for a few days after deleting the thread."* (Facebook03). These subthemes are discussed below:
- **Dealing with illness stigma as a community:** Fibromyalgia often manifests with no visible symptoms and there are no specific medical tests that may be used to conclusively offer a diagnosis. Hence, rheumatologists often carry out diagnoses but getting diagnosed and obtaining an effective treatment options seems to be challenging. An informant explains: *"[we are] a disenfranchised group of chronically ill people whose medical condition is misunderstood and often ridiculed by many in the medical profession and the society as a whole."* (Facebook02). This premise played out during daily activities when informants were limited by fibro flares from actively participating in family activities or chores. Other members of the group related to this experience and posted with supporting comments, reactions and gifs to show support to a fellow "fibro-warrior".

- ***Crafting an illness Identity:*** As part of emotional support these cohorts used communities to form illness identities using these social media. E.g., fibromyalgia's unofficial image representing users who suffer from this illness is the fibromyalgia butterfly. We also observed that some form of this logo/badge on their group information. Some participants also had tattoos of these fibromyalgia identifiers/symbols. Some terms used in creating this identity were: "spoonie; fibro fighters; fibro warriors; fibromites" as one explained this sense of identity within the group: *"Yep...it's our unofficial chart, just like the Spoon Theory. Not official (it's not) 100% accurate just like the stages (of fibromyalgia)"* (Facebook09). The excerpt refers to "the spoon theory" refers to a blogpost adopted by chronically ill individuals on social media. This theory that uses the metaphor on spoons to discuss energy limitations chronically ill adults face when dealing with daily life. These terms bring a measure of shared understanding for this cohort as the illness is not well understood by their GPs or family.

- ***Building relationships (giving and receiving social support):*** Participants connections enacted through these technologies served as a: buffer against isolation from living with a physically debilitating chronic illness and the shame of sharing daily challenges faced with friends/family members who might not understand their conditions. The community gave users an opportunity to gain emotional support from peers who understand their physical, mental and emotional condition. Several relationships transcending the virtual space developed through these groups became intimate relationships e.g. friendships and romantic relationships. Some online friendships formed in the groups led to offline interactions e.g. face-to face meetings, becoming pen pals and even sending and receiving gifts from those met online*: "I send birthday cards, letters of encouragement, and talk with people (I met through the group) on the phone"* (Facebook07). Some connections became romantic: *"This group has given me friends, the love of my life, inspiration, and has reminded me to keep going even when I feel like giving up."*(Facebook09).

c) A perpetual supportive environment

These cohorts created safe spaces online which have their own rules, norms and language for developing a shared understanding between members engaging in and appropriating Facebook as part of their illness management. E.g., groups and pages describe rules of conduct pinned to posts. The environment facilitated by Facebook also allowed the selective admission of cohorts into these communities, while also screening prospective members, ensuring they have legitimate profiles and intentions to join. This is moderated to some extent by features built into Facebook, as an informant explains: *"When it comes to being closed members need to be approved but nowadays (scammers) are getting smarter, they make their selling posts friends only and send out 5 - 10 friends requests a day." (Facebook04).* Conversely, the Facebook page is free to view and follow for anyone with a Facebook account. However, posts/comments from followers are monitored and must be approved by page owners to remain on the page without being deleted. The relevant sub-themes are discussed below:

- ***Ubiquitous technology appropriation (Ease of use):*** Facebook features did not seem visible to participants, especially those who had used Facebook for longer. Nonetheless, the role of technology could be seen through their actions such as reading others posts, reacting, sharing, commenting and saving posts. Most of our informants were unable to say which technology features they used most often; however, they found them valuable because of what they could accomplish through appropriation*: "Facebook is a medium available to everyone with basic Internet skills, so is known about and is readily accessible for most people." (Facebook02).*

- ***Community of similar others:*** A major motivation for appropriating Facebook for chronic illness management involved the opportunity to access a global community of similar others. In addition, membership to these communities involves rigorous screening, to enable only genuine profiles access to these communities**.** Members have roles which evolve over time and members who contribute to building a positive group atmosphere are often asked to join the team's administrative group*.* In some instances, members volunteer if they believe current administrative processes of the group could be improved as one informant shared his experience: *"Original role, reader, the other admin who did most of the posting has gotten busy so I messaged her and became one of the admins. Current role, leader, I would describe myself as one of the admins." (Facebook04).* Group administrators (admins) establish norms or owners set the tone for the group. However, as community membership grows, norms are imposed by community themselves who report violations to the admins. We also noticed incidents where members of this community left to form their own, in some cases, groups splintered, and members left forming their own groups, often taking along other group members. We noticed new splintered group attempts to draw on prior community members as

new ones, as one informant explained: *"There have been other new groups start up and branch off but they have a narrower focus (like religion) that I'm not interested in." (Facebook05).*

5 Discussion

This paper aimed to examine and gain deeper insights into the patterns of appropriation of social media technologies by chronically ill adults to better understand and manage their illness. Accordingly, we present two aspects: i) patterns of appropriation by these cohorts to understand how appropriation occurs in this context and; ii) influences on appropriation to understand why these technologies area appropriated for illness management. The following section discusses our findings.

Patterns of appropriating Facebook for illness management by chronically ill cohorts

First, appropriation in this context was voluntary and in line with the primary purpose of Facebook i.e. networking with friends and family. However, joining specific fibromyalgia communities on the site was triggered either by being diagnosed with fibromyalgia or; suspecting a fibromyalgia diagnosis. Each of these patterns of appropriation for illness management has a purpose within these individual's illness management practices: Lurking gives these cohorts an opportunity to familiarize themselves with their community, learn norms and gain information from others' posts while retaining a semblance of privacy. Lurkers formed a larger majority of the members of the community and this action seemed to allow these cohorts engage with the community while requiring minimal effort. This finding confirms previous scholars assessment of lurking as an active learning phase allowing users to passively gain information support while retaining privacy (Han et al. 2014). Perhaps in the context of chronic illness, lurking may be helpful for these cohorts who also experience emotional distress and chronic fatigue because of fibromyalgia. Some users may progress past the lurking phase and become more active members of the community, but a larger number choose to passively participate in these communities through lurking. Furthermore, our findings also demonstrate that users may vacillate between lurking and active participation depending on their needs and emotional capacity at the time. Liking and reacting gave these cohorts an opportunity to demonstrate support using those emotive features. This finding supports previous studies that suggest liking and reacting serves to demonstrate support and acknowledgement of posts (Wohn et al. 2016). Furthermore, as indicated in the *"Liking and reacting to show support"* subtheme, this action is important to the community because it serves to reassure posters and encourage continued interaction within the community. Posting and commenting were used for either seeking treatment information options, to 'rant' or to share emotionally charged experiences. In general, most of the posts were made as an opportunity to vent about the lack of understanding these cohorts faced in their real lives. This was interesting because during the study, we had asked our informants to what extent they discussed fibromyalgia on their personal profiles, majority indicated that they did not discuss this on their profiles because they did not want to seem to be constantly complaining. Some of the posts were also aimed to better understand how to manage their symptoms better or to validate their symptoms by comparing with others. For example, some members would make posts asking about the side effects of some of the medication they were taking for their illness and make decisions on continued use of these prescribed medications based on others experiences which were submitted as comments. Because these technologies are free to use and accessible, they are often adopted in tandem, in contrast to previous studies on appropriation which suggest that users may adopt/use one technology for one task. Some of our informants also used other social media technologies based on their different capabilities, treating these as part of a toolkit to better understand and manage their illness. Borderless appropriation of social media tools serves as an example of how individuals' social media practices in the public space differs from the norm reported in previous studies (Yoo 2010). It seems that the free access and availability of numerous social media technologies allows users to appropriate various technologies using them as part of a toolkit to achieve various aspects of their goal.

Influences on Facebook appropriation for chronic illness management

Our findings align with earlier research on the influences on social media appropriation for chronic illness: information support exchanges; emotional support appear to exert influence on appropriation of Facebook by our key informants (Bodenheimer 2002; Merolli et al. 2013b; Pousti et al. 2014).

Findings indicate that information support exchanges had significantly influenced health-related decisions made by these cohorts as indicated in the information support subtheme. Because they often discussed their current treatment regimens through posting and offered honest evaluations of their experiences on various medications, this served to educate other members. Also, findings demonstrate through the information support theme that our informants enabled better understanding of illness which enabled individuals to advocate for themselves with general practitioners and others. For

example, some of the information shared also included tactics and hints to successfully apply for disability pension, especially since most of these cohorts were unable to work full-time because of fibromyalgia. This finding supports claims that social media technologies such as Facebook could serve as viable sources of health-related information (Rozenblum and Bates 2013). Our study also revealed that although the community collectively attempted to protect themselves from misinformation, they still had numerous encounters with spammers and scammers who tried to take advantage of this vulnerable community. Combating these tactics proved challenging for the administrators/moderators of the group because members were emotionally fragile due to the daily challenge of living with fibromyalgia and the spammers also made use of private messaging and other facebook features such as limiting the audience of the post to members who they had already become friends with, therefore admins were only aware of these activities when members reported to them.

Similar to previous studies, our informants had experienced emotional benefits from appropriation of Facebook and considered it as a safe place to interact with a group of similar others (Merolli et al. 2013). Through the exchange of emotional support, members were able to feel safe, understood and validated. These exchanges took place virtually at first, through posting, commenting, messaging and so on. Furthermore, for some cohorts, the exchange of emotional support helped them gain friends and romantic partners which was challenging in the real world due to the physical limitations of fibromyalgia. Yet, while exchanges of emotional support could serve as a positive influence that encouraged building relationships and dealing with illness stigma, it also negatively impacted these cohorts due to the barrage of emotionally charged posts in this community. Our study showed that some of the posts were rants about difficulties other members were facing such as conflicts and relationship breakdowns with family, friends and their GPs due to not being believed or understood about the symptoms they were experiencing. Some other posts were even more disturbing- for example there were multiple posts about potential suicides asking for emotional help or posting to say goodbye. The facebook notification and newsfeed served to constantly display all the most recent posts made in these groups leading to constant streams of negative emotional content which caused others in the community who read these posts to feel depressed and overwhelmed. Consequently, emotional support could result in emotional overload serving as a barrier to appropriation (Maier et al. 2015). Especially since these cohorts already experience emotional effects from fibromyalgia like depression and anxiety due to their illness. Overall, these influences led to variations in the patterns of appropriation as some members responded by posting and commenting to request that others be more positive, liking and reacting to the posts to show either support or annoyance (using the angry face emoticon), or in some cases members either changed the notifications they got from the group, effectively putting the group on mute to take a break from the barrage of posts.

When asked which features of Facebook they used and how, some of these informants stated that they did not make use of any, which was directly contradictory to our observations; especially since our semi-structured interviews were conducted through Facebook messenger. A possible explanation for this "feature-blindness" could be that Facebook features had disappeared from view as a result of familiarity with the site and similar social media technologies. This finding aligns with technology appropriation literature which suggests that after encountering a technology, it disappears from view as users engages more frequently with it (Mendoza et al. 2010). Previous studies also suggest familiarity with similar technologies could result in users developing mental frames that influence their appropriation outcomes due to an inherited understanding of similar technology artefacts and their use (Treem et al. 2015). Moreover, Facebook became a virtual safe place for these cohorts enabling interactions with peers who understood them in a separate space from their profile pages (Mendoza et al. 2010; Riemer and Johnston 2012). They could take refuge in these spaces with similar others to participate in these spaces either passively through lurking, tentatively through liking and reacting or more actively through posting and commenting without fear of stigma. Through community membership, these cohorts could develop a positive illness identity and so gain a more positive outlook on their illness. This shared 'fibro-warrior' identity encouraged a sense of control, empowerment and belonging, in addition to created shared understanding for coping with their illness through concepts like: spoon theory; fibro butterfly, stages of fibro. Overall, findings indicate that membership, policies, norms and roles were informally negotiated by members of the community and in a constant state of flux. Moreover, these groups were not stable; with changes in group policies or disagreements in the community causing members to leave to form their own groups centred on their personal beliefs or disappropriate those spaces entirely.

6   Conclusion and future directions

One of the main motivations of the study was the lack of empirical evidence that demonstrated how social media technologies are appropriated for chronic illness management. Thus, the practical

contribution of this study is the provision of empirical evidence to inform stakeholders such as: healthcare service providers, general practitioners and chronically ill adults on the nature, influences and outcomes of social media appropriation for chronic illness management. Second, general practitioners/healthcare practitioners could take note of how participation on social media could have both negative and positive influences on provision of suitable care to these cohorts. Care should be taken in participating in these communities to protect against issues such as: misinformation; trolling and over-exposure to negative emotional content. Our study is limited in the following ways: the number of participants recruited for the interviews and qualitative portion of the study. Another limitation of the study is that cross-sectional nature of our research; we were only able to receive retrospective accounts on issues that may be better examined during appropriation process, as all our key informants were already familiar with Facebook and had accounts on it. A possible direction for future research would be to conduct a long-term study on social media appropriation by these cohorts, capturing phases from adoption of Facebook to longer term use in a similar community.

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