“BECAUSE PEOPLE CAN SEE ME”: APPROPRIATION OF YOUTUBE FOR CHRONIC ILLNESS MANAGEMENT

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“BECAUSE PEOPLE CAN SEE ME”: APPROPRIATION OF YOUTUBE FOR CHRONIC ILLNESS MANAGEMENT

Research paper

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Abstract

With the rapid increase of social media adoption globally, there has been a surge in the number of chronically ill adults who utilize social media tools as part of their illness management practice. While there have been numerous conceptual papers discussing the potential benefits of appropriation in this context, there seem to be limited studies that have explored the appropriation of social media platforms by this cohort. This paper addresses this gap in knowledge through a case study with a mixed method approach to examine the appropriation of YouTube by chronically ill adults to better understand and manage their Fibromyalgia illness. Our results highlight the process of social media appropriation which include: viewing to vlogging; implementing workarounds and; borderless appropriation of social media tools. In addition, self-presentation, building transactive relationships, engagement in illness advocacy and technology features were found to influence appropriation outcomes for chronically ill adults on social media.

Keywords: Technology Appropriation, Social media appropriation, Mixed methods analysis, Chronic illness
1 Introduction

Social media technologies have had considerable impact on society: as platforms for activism; as support for new business models and; 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. Recent studies have highlighted the growing global burden of chronic disease such as diabetes and similar chronic illness due to biological and preventable lifestyle factors such as increased sedentary living and an ageing population (Bodenheimer 2002; Georgeff 2014). Further, a recent report by the World Health Organization (WHO) states that currently 60% of deaths globally are due to chronic disease and these figures are expected to rise to 73% of all deaths regardless of socio-economic class by 2020; while in developing nations the projected increase is 79% of all deaths (Department of Health & Human Services 2016; WHO 2016). Hence, scholars have suggested that technologies such as social media could serve as a cost effective tool in self-management of chronic illness as proposed in variations of the chronic care model which act as a guide for stakeholders such as general practitioners and other healthcare service providers to improve patient involvement and empowerment in managing chronic conditions (Kreindler 2009; Wagner 1998; Yach et al. 2004). It appears that studies conducted on social media for health are focused on motivation mechanisms, i.e. influences on health-related outcomes in these settings and have overlooked the processes of appropriation of social media tools within the public context to manage one’s health and wellbeing (Agarwal et al. 2010; Fichman et al. 2011; Isika et al. 2016; Merolli et al. 2013a). To this effect, while the potential benefits of social media tools for self-management of chronic illness have been highlighted, there has been limited empirical investigation into how social media technologies are utilized by these individuals, to better understand and manage their illness. It is necessary to understand how these tools are used in order to gain a deeper understanding of potential benefits or drawbacks of social media in the context of chronic illness self-management.

Some scholars have conceptualized appropriation as 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). While other studies have defined appropriation as “the way that users evaluate and adopt, adapt and integrate a technology into their everyday practices” (Mendoza et al. 2010). In this study, we take a holistic view of appropriation that includes the environment provided by technology, the goals of the user and the processes undertaken by the user to achieve their goals within this technologically mediated environment. Hence, the aim of this study is to gain deeper insights on how adults with chronic illness engage with and appropriate Social Media Tools (SMT) as part of their illness management practices, focusing specifically on YouTube. Therefore, the research question of this study is: How and to what extent does appropriation of a video sharing social media tool support chronically ill adults to better understand and manage their illness? With the following sub-questions:

- What are the processes involved in appropriation of YouTube by chronically ill adults to better understand and manage their illness?
- Why do chronically ill adults appropriate YouTube in their illness management practices?

Further, 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 sensitizing lens to explore influences and processes of appropriation within this context. This study is part of larger investigation that examines appropriation of four different SMTs by chronically ill adults for illness management. In particular, this study focuses on adults with fibromyalgia - a chronic disease which presents with chronic pain, fatigue and may also involve mental health issues such as depression or anxiety (Russell 2001; Wolfe et al. 1990, 2011). In this paper we report findings from the case study on a video based SMT, YouTube. The remainder of the paper is structured as follows: the next sections
introduce the theoretical foundation for the study, followed by the outline of the methodology adopted to conduct the study. Next, we present our findings and close the paper with a discussion of key insights from the study.

2 Theoretical Background

Social Media Tools (SMTs) are socio-technical systems which have attracted significant research interest from scholars across various disciplines and have been defined as: ‘‘a group of Internet-based technologies that allows users to easily create, edit, evaluate and/or link to content or other creators of content’’ (Kaplan and Haenlein 2010; Kietzmann et al. 2011). SMTs enable users to participate, produce and consume content while interacting with their peers through a technologically mediated environment, to form connections which may not be limited by geographical location or boundaries (Urquhart and Vaast 2012; Yoo 2010). Previous studies have reported numerous influences on appropriation such as: familiarity, ease of use, usefulness, altruism, demographic factors such as gender/age, hedonic factors such as enjoyment, self-presentation and many others (Ellison et al. 2010; Riemer and Johnston 2012; Subramaniam et al. 2013; Treem et al. 2015). For instance, Rauniar et al (2014) applied the Technology Acceptance Model (TAM) to investigate the adoption of Facebook among student cohorts using a survey methodology. That study found that use of Facebook correlated with utilitarian constructs such as perceived usefulness; perceived trustworthiness, perceived ease of use and hedonic constructs such as perceived playfulness could determine intention to use and actual use behaviour among their respondents. Conversely, Hsu and Lin (2008) found that perceived usefulness was not significantly related to use intention, rather, hedonic factors such as enjoyment, ease of use and individual factors such as altruism influenced acceptance and continued use of blogging social media tools (Hsu and Lin 2008).

In contrast to the numerous studies on influences on appropriation, comparatively few studies have examined the process of appropriation of these social media tools as this is typically examined through variance theories which historically view use intention in lieu of actual interactions with IT (McKenna et al. 2017; Urquhart and Vaast 2012). Consequently, there have been varying conceptualizations on the interactions between human and technology artefacts in the social media appropriation context. Some scholars suggest that during appropriation of social media, users may perform embodied identity (Schultze 2014; Schultze and Orlikowski 2010), co-produce value (Alaimo and Kallinikos 2017) and others. Other scholars have taken the stance of examining the process of appropriation as occurring in phases, in a bottom-up manner; for instance, Riemer and Johnston (2012) examined the appropriation of an Enterprise Social Media (ESM)-Yammer using Genre analysis with data scraped from the site. They suggested that appropriation of an ESM is phased, bottom-up and involved collective sense-making by users in that context (Riemer et al. 2012; Riemer and Johnston 2012). However, that study did not solicit primary data from users of these sites and so did not further unpack the process of appropriation.

2.1 Related social media studies in healthcare

Chronic diseases are complex incurable medical conditions with prolonged implications on sufferers and their communities (Pousti and Burstein 2014). Effective chronic illness management requires the patient to engage in daily practices in order to achieve better physical and psychological health (Bodenheimer 2002; Schulman-Green et al. 2012). Cohort studies indicate that these social media technologies have strong appropriation mechanisms such as exchange of emotional, physical and informational support in the health context, particularly among chronically ill cohorts (Fichman et al. 2011; Wang et al. 2017). As a result other scholars have examined: therapeutic affordances (Coulson et al. 2017; Merolli et al. 2013a); trust formation (Fan et al. 2014); motivations mechanisms (Ba and Wang 2013); creation of social value (Goh et al. 2016) and outcomes in terms of social support (Coulson 2005; Guo and Goh 2014; Mo and Coulson 2010; Wang et al. 2017). Taken together, these 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 (Bender et al. 2013; Hajli 2014; Merollí et al. 2013). Since healthcare services and providers typically provide episodic care for illness; developing an illness-management practice is essential for chronically ill adults and social media technologies could be considered a useful set of tools available to these cohorts for self-management of their illness (Liang and Xue 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). Yet, although there have been numerous studies that have explored motivations and implementation of online support groups for chronically ill adults, little is known about the processes of appropriation of SMTs for chronic illness management (Agarwal et al. 2010; Chung 2014).

2.2 Practice lens -Social support and technology appropriation

Considering the issues discussed above, we apply a combination of social support theory and technology appropriation as a practice lens to guide our study. Social support theory (SST) 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), while 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). Still, SST does not account for the processes involved in appropriation, although it is suggested that deriving an understanding of this aspect could be useful for research and practice. Therefore, to gain deeper insights into how people use social media for managing chronic illness, we apply a combination of technology appropriation and SST as practice lens to frame our examination of the appropriation of YouTube by chronically ill cohorts.

3 Research Methodology

In order to address the research questions, we designed the study as an interpretive case study and applied theoretical sampling to guide our case selection. We therefore, selected YouTube as the site for the study (Eisenhardt 1989; Onwuegbuzie and Leech 2007; Yin 2013). We chose YouTube, a video sharing SMT, because it is the most used videos based SMT globally. Further, YouTube was observed to have large numbers of chronically ill users (Huh et al. 2014; Smith and Anderson 2018). Further, the study selected adults who have been diagnosed with fibromyalgia (self-reportedly diagnosed). Fibromyalgia was chosen because it involves long-term constant self-management by sufferers to manage their condition. Sufferers describe it as an invisible illness because it typically does not present a discrete set of symptoms that may be used for diagnosis and this adds complexity to the experiences of adults diagnosed with this condition. To derive a complete understanding of social media appropriation and leverage the types of data available through social media, this study used a mixed methods strategy (Creswell and Clark 2007; McKenna et al. 2017). The purpose of mixing methods in this study was to augment the data analytic findings with the qualitative findings as a form of methodological triangulation (Bryman 2009; Denzin 2012). Therefore, we used data mining techniques (topic modelling) with a mixed methods approach to provide 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). The data analytic aspect allowed the researchers to make sense of the large quantities of data available on YouTube SMT, derive insights on topics through the analytic method applied to the text corpus, Latent Dirichlet Allocation (LDA). The researchers also considered interaction metrics returned in that dataset in terms of likes, comments, views and favourite counts per videos to gain a high-level view of appropriation of YouTube by this cohort. Additionally, for the data analytic aspect; the unit of analysis is the central text from chronically ill individuals with fibromyalgia retrieved from
the YouTube Application Programming Interface (API) (Urquhart and Vaast 2012). The unit of analysis for the qualitative aspect of this study is the individual living with a chronic condition who is using social media in their illness management practice. Finally, we interpreted our findings as theoretical dimensions which also integrated the data analytics results (Gioia et al. 2013; Walsham 1995).

3.1 Case description

Since its inception in 2005, YouTube has been one of the most active video-sharing sites and has spawned billions of user generated videos which have facilitated the creation of ad-hoc content-centred communities (Dallas et al. 2012; Konijn et al. 2013). Some of the key features of YouTube include: video publications; user account/channel; subscriptions; content recommendation; hashtagging; comments; private messaging and; a creator studio. YouTube serves as a social media tool containing videos posted by users of the site, commonly denoted as YouTubers. YouTuber is a term that is used to denote YouTube users who share and appear in videos on the site. Accordingly, there are several chronically ill YouTubers who make uploads to share their experiences with managing their illness as well as to share their day to day lives with others who may have the same illness. Further, these uploads also attract others who may have the same illness to view, comment and interact with the chronically ill YouTuber, as seen in the comment section of their uploaded videos.

3.2 Data collection and analysis

Prior to conducting the study, ethics approval was obtained. Qualitative data collection commenced through a search using on YouTube with the keywords of “fibromyalgia” and “fibro” to identify uploaded videos containing those keywords. Next, we carefully examined the profile information of the uploaders, selecting only channels confirming that the YouTuber has fibromyalgia. Subsequently, messages were sent using either the YouTube chat feature or through social media contact details posted on the channel information page. In total, messages were sent to 40 YouTubers, soliciting their participation in the study and 13 individuals responded; some (3) were unable to schedule a suitable time due to their illness; 1 user was excluded due ethics concerns related to her age as she was younger than 18 at the time of data collection, while 9 users who confirmed that they had been diagnosed with fibromyalgia participated in the semi-structured interviews. These informants’ demographic information is provided in table 1 below.

<table>
<thead>
<tr>
<th>Key informant</th>
<th>Gender</th>
<th>Age Group</th>
<th>Location</th>
<th>Join date</th>
<th>First upload</th>
<th>Overall count for channel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youtuber01</td>
<td>Female</td>
<td>30-35</td>
<td>Spain</td>
<td>13-3-2016</td>
<td>13-03-2016</td>
<td>11,911</td>
</tr>
<tr>
<td>Youtuber02</td>
<td>Female</td>
<td>30-35</td>
<td>Canada</td>
<td>24-11-2014</td>
<td>13-12-2014</td>
<td>217,282</td>
</tr>
<tr>
<td>Youtuber03</td>
<td>Female</td>
<td>20-25</td>
<td>United states</td>
<td>2-03-2015</td>
<td>5-02-2016</td>
<td>52,402</td>
</tr>
<tr>
<td>Youtuber04</td>
<td>Male</td>
<td>20-25</td>
<td>United states</td>
<td>4-06-2013</td>
<td>28-6-2016</td>
<td>2,419</td>
</tr>
<tr>
<td>Youtuber05</td>
<td>Female</td>
<td>20-25</td>
<td>United states</td>
<td>19-11-2016</td>
<td>19-11-2016</td>
<td>25,982</td>
</tr>
<tr>
<td>Youtuber06</td>
<td>Female</td>
<td>35-40</td>
<td>United states</td>
<td>4-8-2011</td>
<td>1-04-2016</td>
<td>63,125</td>
</tr>
<tr>
<td>Youtuber07</td>
<td>Female</td>
<td>40-45</td>
<td>United states</td>
<td>19-2-2017</td>
<td>19-2-2017</td>
<td>1,957</td>
</tr>
<tr>
<td>Youtuber08</td>
<td>Female</td>
<td>40-45</td>
<td>United states</td>
<td>24-9-2012</td>
<td>5-3-2018</td>
<td>10,529</td>
</tr>
<tr>
<td>Youtuber09</td>
<td>Female</td>
<td>30-35</td>
<td>United states</td>
<td>14-12-2017</td>
<td>2-1-2018</td>
<td>976</td>
</tr>
</tbody>
</table>

Table 1: Background summary of key informants for the qualitative portion of the YouTube case

The interview questions were focused on issues pertaining to appropriation, which included: individual reasons to adopt and use YouTube SMT, the influence of YouTube on personal chronic illness practices, process of appropriating YouTube; effects of the environment provided by YouTube on appropriation and other issues that had emerged during the interview process. For the analytics portion of
data collection; the researcher made use of Netvizz data extraction tools for YouTube and conducted a search using the terms: “fibromyalgia” and “fibro”, this search query returned a csv flat file containing data about videos that matched the keywords inclusive of category, description, title and interaction metrics (likes, dislikes, views etc). Next, one of the researchers conducted data cleaning to remove duplicate items, entries that were not in English and entries that were not about fibromyalgia. Analysis was restricted to textual content in the captions/descriptions of the submitted videos and associated comments to ensure compatibility with the data analytics methods used for the study (Blei et al. 2003; Debortoli et al. 2016). The search returned 2,157 videos in total published between 1st January 2016 and 8th August 2017. After further cleaning, these were randomly sampled using Python Pandas sampling function to 700 posts for analysis. The following section is demarcated in terms of themes and sub-themes with related data analytic and qualitative findings.

4 Findings

The findings from the YouTube case study are demarcated under three broad theme categories: 1) Individual incentives for adoption and continued use of YouTube; 2) process of appropriation of YouTube and; 3) Influences of the YouTube environment on appropriation.

4.1 Individual incentives for adoption and continued use of YouTube

First, we conducted topic modelling using LDA to extract more meaningful topic clusters. This LDA extracted the 50 most salient topics from the text corpus which were represented through 10 terms per topic, from 5 core themes were interpreted based on the analysis method described. These extracted themes are presented in table 2 below and were about: 1) information giving (58%); 2) Seeking donations (22%); 3) invitations to connect on other social media tools (8%); 4) identifying with others (6%); 5) soliciting community formation (4%) and; 6) offering to share emotional validation (2%).

<table>
<thead>
<tr>
<th>Themes/Definition</th>
<th>Sample sentence from the YouTube text corpus</th>
<th>Sample topic group from LDA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information giving: refers to topic clusters that are about giving or receiving information about illness</td>
<td>“Hi guys and welcome to my third Fibromyalgia video! In this one I discuss some of the common symptoms of Fibromyalgia that I suffer with and share a few of my tips on how to deal with them</td>
<td>cancer author sharing video experience process illness disease day fibromyalgia</td>
</tr>
<tr>
<td>Seeking donations from others: Denotes topic clusters concerned with obtaining or giving monetary or similar resources</td>
<td>Just a friendly video- To keep the videos coming – contribute at <a href="https://www.gofundme.com/removed">https://www.gofundme.com/removed</a> and also my brother, at <a href="https://www.gofundme.com/removed">https://www.gofundme.com/removed</a></td>
<td>amazon ref email book osteoporosis question revolution utf keywords qid</td>
</tr>
<tr>
<td>Invitations to connect on other social media tools: refers to topic clusters that discuss other social media sites or the specific action or features of YouTube</td>
<td>Sorry the lighting sucks, that's what happens when you film at night Come be my friend on: Facebook, Twitter, Instagram, Pinterest</td>
<td>Twitter Instagram Facebook Painfree-kitchen Pinterest Day Tumblr Laser Fibromyalgia Video</td>
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<td>amazon ref email book osteoporosis question revolution utf keywords qid</td>
</tr>
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<td>Twitter Instagram Facebook Painfree-kitchen Pinterest Day Tumblr Laser Fibromyalgia Video</td>
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</table>

Table 2: Selected examples of identified topics from LDA

The qualitative themes below were extracted from interviews with key informants and their commenters and are presented in further detail below:

4.1.1 Information support exchanges to make sense of fibromyalgia and raise awareness

A major theme that was induced from semi-structured interviews was that these key informants, engaged in information support exchanges with similar others to make sense of their illness (both other YouTubers and their commenters). Informants also shared that the process of managing fibromyalgia
was challenging because there was “no one size fits all” solution for managing symptoms: “Not one of us is exactly like the other. There are overlapping similarities, but even our med tolerances are vastly different. What works for one of us, may or may not work for the other. I try to stress that with everyone, as well as reminding them about talking to their Dr, before trying some new med/herb/gadget, etc.” (YouTuber09)

The information support exchanges theme is comprised of the following subthemes:

1) **Collective sensemaking to learn about coping with fibromyalgia**: It was observed that through interactions with other YouTubers, informants could self-diagnose their chronic illness in collaboration with their peers on YouTube. Once they had sufficient information, they took evidence to their general practitioner or rheumatologists to help them in receiving a definitive diagnosis or to clarify the cause of fibromyalgia related symptoms. One of the key informants confirms this observation by sharing her experience: “I spent a few months watching a YouTuber (fibro-vlogger) who had done some videos on her condition and living with a chronic illness. I related to a lot of what they were saying and looked up both fibro and M.E. on the Mayo Clinic’s website, just to see on a basic level what the symptoms were. That was when I went to see my doctor. And it’s funny, because I also expected her to say, no, that’s not it, all your tests are normal and you’re fine, but instead she agreed that fibromyalgia is the most likely thing that we were dealing with.” (YouTuber06).

2) **Applying shared coping mechanisms**: It was also observed that apart from discussing major fibromyalgia symptoms, these informants also exchanged advice to help management of secondary symptoms. Key informants confirmed the value of these coping strategies and shared that they regularly apply the tips and suggestions in videos from peers into their daily illness management practices, one informant elaborates on this, stating: “Through just watching random vlogs (about fibromyalgia), videos and interactions with other people on YouTube I’ve learned a lot about coping with fibro in general and working on my mental health..” (YouTuber02).

3) **Advocating for more visibility by raising awareness**: A recurring theme that was discussed by these informants was the lack of understanding by their general practitioners concerning the ramifications of fibromyalgia. Therefore, YouTube channels and videos offer these cohorts the opportunity to create content that raises awareness about fibromyalgia with their physicians: “I want to reach more Physicians who treat Fibromyalgia to implore them to do more research on Fibromyalgia, and not just go along with what exactly they learned in school. Clearly their way is not helping the Fibro community. I want Doctors to show more empathy to their patients who suffer and not dismiss how they feel.” (YouTuber08).

4.1.2 **Emotional support exchanges: YouTube as a safe space**

All key informants explained that YouTube had generally provided them with positive emotional exchanges, as an informant explained: “That’s how this all began. The positive response I receive from a post about my Fibro experience. It was incredible and enlightening to see the love and support that poured out from that post. Hence why my channel was born. It gave people courage and hope. I was flooded with heartfelt responses!” (YouTuber09). This theme is comprised of the following subthemes: fighting stigma and giving legitimacy to the "trash can disease"; crafting an illness identity; self-presentation as therapy; building transactive relationships and; coping with the isolation of chronic illness.

1) **Fighting stigma and giving legitimacy to the "trash can disease"**: A recurring theme shared by all key informants concerned giving legitimacy to the experience of having an invisible illness like fibromyalgia. Key informants shared that they aimed to help give visibility and legitimacy to their experiences of fibromyalgia. An informant shares: “My vision is to make Fibro known in its entirety. No more stigmas of the "trash can disease", but real knowledge.” (YouTuber09). Another Informant confirms and states further: “We are treated
like drug addicts seeking our next high, when really all we want it the pain to stop. We want help. We want understanding, we want respect, we want our lives back! We want people who don’t have this illness to better understand what we go through every day.” (YouTuber08).

2) Crafting an illness identity: Key informants indicated that a diagnosis of fibromyalgia initially comes as a relief because it provides a concrete explanation for the chronic pain, fatigue and other symptoms they had been going through for several years. One way that these cohorts formed a more positive identity of their illness was through identifying which celebrities are rumoured to also suffer from fibromyalgia. Among the celebrities who often appear in these contexts are: Avril Lavigne (singer), Lady gaga (singer) and Morgan Freeman (Actor). In fact, the concept of identity formation was so strong that one informant regularly dyed her hair purple (the unofficial colour for fibromyalgia). When asked what this represented to her, she explains her broader intention and concept behind her spoo- nie identity, saying: “I generally keep my hair purple, knowing that people usually comment on it, so that opens up the dialog to discuss that my hair is purple for Fibro Awareness.” (YouTube09).

3) Self-presentation as therapy: It seemed that a motivation for our key informants who were all YouTubers/vloggers was self-presentation: “Anyone who says they don’t care at all if people watch is either lying or fooling themselves. If I didn’t care if people watched I’d stick to blogging or writing in a journal” (YouTuber06). It was observed that through presenting themselves on YouTube, these cohorts derived a sense of psychological relief, as an informant explains: “I find posting to YouTube oddly therapeutic; it helps to communicate with others and know I am not alone. I find there to be something very liberating about talking to the public on YouTube – like a better version of therapy!” (YouTuber03).

4) Building transactive relationships: Key informants shared they formed relationships with other YouTubers which are transactive in nature where subscriptions are traded by YouTubers to increase the visibility and impact of their channels. One informant reveals: “I follow over 200 channels, but I probably only actively engage with about half of that. Most of those are channels who also subscribe to me, so those are the people I’ve connected with. I watch some more than others; I tend to be better about watching the YouTubers who watch me regularly as well. There’s a mutual support there. I’ve unsubscribed to some, those who clearly weren’t watching me anymore, but that’s been pretty rare.” (YouTuber06).

5) Coping with the isolation of chronic illness: It was also observed that for most of the study informants (8), the emotional exchanges on YouTube served to offer an escape from loneliness as one informant confirmed, saying: “Between grad school and the fibro I’m pretty isolated sometimes. On days when I’m stuck working at home or stuck in bed with pain and/or fatigue, I can still connect with people on YouTube. I can escape into their videos, see familiar and comforting faces, read their comments, etc. It makes me feel less alone some days” (YouTuber05).

4.1.3 Materialistic benefits: Building a brand and monetization

The potential of gaining monetary benefits from appropriation an added incentive for these informants particularly because some of them (7 out of 9) had limited employment options due to fibromyalgia’s effects on their ability to maintain a job or because they were retirees. Even informants who were employed or currently enrolled at a college, revealed that they were hopeful for the opportunity to turn YouTubing practice into their main income source. One informant (YouTuber01) had already attempted to create a brand and product around the concept of chronic illness identity, through t-shirts and mugs on Facebook with limited success and then she moved to YouTube to increase her viewership and reach a wider audience. Another Informant (YouTuber07) used her channel to market the eBook she wrote and was selling on amazon about the effects of fibromyalgia on pregnancy. A major challenge experienced by these cohorts is that vlogging about fibromyalgia is by default, a niche market. Therefore, they have smaller channels and find it more challenging to meet the monetization policy.
setup by YouTube which requires that a channel have 1000 subscribers and 4000 hour of watch time (annually) in total to qualify for their partnership program.

1) **Monetization:** Key informants revealed that although YouTube provides monetization mechanisms through the partnership programs and advertising options, these paths were not available to all key informants as they did not qualify for the monetization policy set up by YouTube. A key informant explains: “It’s really hard to grow a YouTube channel, that’s based on health and on my life and stuff with barely any funds because I can’t work and I’m trying to make money through Patreon but no one listened to the end of my videos and stuff” (YouTuber04).

2) **Building a brand:** Some of the key informants indicate that vlogging about fibromyalgia is one component of their brand promotion strategies. Three informants were also cross-promoting their videos on other social media sites, selling customized content such as t-shirts, mugs, books. This cross promotion was used to notify followers about new video uploads. An informant explains this, stating: “This is one area where my background in media studies, social media, technical writing, etc. has been helpful. I may not have understood the technological side of YouTube when I started but I did understand the promotion and marketing side of things.” (YouTuber06). Additionally, it was observed that these cohorts maintained the same/similar usernames on all platforms to ensure consistency.

4.2 **Process of appropriating YouTube for illness management**

At its core, YouTube is comprised of a group of vloggers who create content and share with peers, but a significant majority of users are viewers who may or may not have accounts on the site, the next level of users is those who actively engage with the content posted through liking, disliking and commenting, within that group are the subscribers to a channel. It appears that all key informants started their appropriation journey through viewing and then transitioned to vlogging over time. It seems that the most common activity on the YouTube website is viewing/watching content. The following section outlines the subthemes that emerged under appropriation processes which are: 1) viewing to vlogging; 2) building workarounds for technology features; 3) borderless appropriation/YouTube as part of a toolkit and; 4) frequency of engagement with YouTube.

4.2.1 **Viewing to vlogging**

On average, the informants for the study had 1.6 years between creating accounts and making their first video uploads. The range varied significantly, with YouTuber01 creating an account and making her first upload in the same day while YouTuber08 had 6 years between the initial account creation and creating their first video upload. The majority of study informants shared that they had joined YouTube several years ago as viewers and commenters before becoming vloggers. Initially, they had been subscribed to similar channels before they were motivated to create their own content and share their own experiences. One informant explains: “I had watched YouTube videos for many years and always enjoyed the Vlogger community. A university flatmate introduced me to the platform in 2007. I joined YouTube as I wanted to voice my own opinions and experiences in dealing with chronic health issues.” (YouTuber03).

4.2.2 **Building workarounds for technology**

It was observed that the difficulties that are experienced by the study’s key informants while using the YouTube system caused adoption of other technologies to augment their experiences on YouTube and overcome its perceived shortcomings. Thus, key informants construct workarounds to overcome shortcomings of YouTube. One informants explains: “The YouTube subscription box system is notoriously glitchy. Videos get delayed or don’t make it into sub boxes at all. People get unsubscribed from
channels without knowing. So, giving people a way to follow me outside of YouTube is just a good idea in general.” (YouTuber06).

### 4.2.3 Borderless appropriation/YouTube as part of a toolkit

It was observed that key informants appear to also adopt a suite of social media tools to expand their reach and promote their content across the varied social media audiences that are active on various platforms. One informant explains further: “Social media is a great way of sharing your story across platforms. I’ve found some YouTubers through Twitter or Instagram. Someone might stumble on a tweet of mine and follow the link there back to my channel. So, it helps promote your channel to a wider audience than those already on YouTube.” (YouTuber06).

### 4.2.4 Frequency of engagement with YouTube

It seemed that YouTube had become such a significant aspect of the lives of these cohorts that they made sure to interact with the site daily. Although their interaction was affected by the challenges of their chronic health conditions, these cohorts made an effort to log in daily because they wanted to interact with commenters and monitor performance of their videos, and related activities on the site. One informant explains: “It really sort of depends on the week as my depression can really change how much I interact but I try to get on there at least once a day and respond to comments or watch someone else videos - on a really good day I will respond to as many as many 5 or 6 videos and 5 to 10 comments on my own videos - on bad days though I will only ever look around and maybe click on random content but not interact at all... when thinking about how often I have bad days (approximately 3 or 4 times a week)” (YouTuber02).

### 4.3 Influences of YouTube as an environment

Each YouTube user has a channel/profile which has a description which provides the background information of the YouTuber for subscribers. In this context, these descriptions were used by key informants to inform their subscribers of their connection to fibromyalgia, i.e. that they have received a formal diagnosis. Further, the structure of YouTube appears to enable these cohorts to create ad-hoc communities around channels and videos. YouTubers (vloggers) form the core of the community, where they share videos and interact with subscribers and their peers through the platform. This theme is further subdivided into two themes: 1) Effects of YouTube technology features and policies and; 2) Ad-hoc community formation.

#### 4.3.1 Effects of YouTube technology features and policies

The majority of key informants were quite conscious of the limitations of YouTube technology with some indicating that the various features such as the notification systems, subscription system and chats were well known to be faulty. Yet, key informants shared that the YouTube site was seen to be very beneficial to them because is allowed the process of exchanging experiences without the limitations of other mediums such as text or images. It was observed that video medium allows verbal and non-verbal cues to be used to connect with and communicate with other chronically ill cohorts. One informant explains: “I actually picked YouTube because I’m not very good with words and don’t feel I would be able to convey myself as clearly and articulately through just a blog (also, most of my pain is in my hands and arms, so sometimes typing can get to be too much, and thus, video is more accommodating to my pain)” (YouTuber02). Aside from the video component, other features such as video tagging were used by majority of key informants to promote content: “I use tags to help my videos pop up when people are searching, I also see what is trending” (YouTuber05).

1) **Ease of learning YouTube:** According to key informants, uploading a video at first seems uncomplicated, but there were several other issues they encountered as they got more experienced. The key informants also shared that issues such as tagging and optimizing channels
were not immediately obvious to them. Therefore, more experienced vloggers often publish help videos to serve as a guide for other aspiring vloggers. A key informant explains: “I have struggled with the camera. My first camera that I used didn't have a flip out screen, so I couldn't see myself or if I was in focus. I knew there was a way to tether it to my laptop so I could use my laptop as a monitor, but it took me a few hours of Googling a solution before I finally got it to work. But Google, and YouTube, was a huge help. There are a lot of YouTubers who have made videos on how to start a channel and things they wish they'd known and advice they have.” (YouTuber05).

2) Technology policies: While these cohorts indicated that they were free to create content on YouTube without restriction, some informants (3) indicated that it was important for them to comply with the terms of service of YouTube, as explained by an informant: “As far as the creative studio goes, I use the music, and I've read the policies on monetizing and stuff, but I don't really use the help section to search for solutions. I only look up things on YouTube if it's a policy/rules question because I want to make sure I'm within the guidelines.” (YouTuber06).

4.3.2 Ad-hoc community formation

The structure of YouTube seems to support ad-hoc community formation around content. It appears that the source of the community is the YouTuber who posts a video, which attracts some viewers, who may choose to subscribe to the channel and gather in a virtual community through the comment section. In keeping with the community aspect of vlogging, it appears that there are some unspoken expectations within the community such as: to remain a central part of the community, the YouTuber is expected to continue to participate through frequent upload of content. One of the key informants explains further: “At its heart YouTube is a social networking site like Twitter or Instagram or Facebook, but we communicate through videos rather than tweets or photos. So, if you want to stay a central part of that community you have to continue to participate through uploading your videos and commenting on other creator's videos.” (YouTuber03).

1) Community norms and scheduling video uploads: It was observed that these cohorts were expected by their community to adhere to some implicit rules for instance: The YouTubers were expected to provide content in a timely and predictable manner, so that their community has an established schedule to expect new content. One informant explains her posting schedule and it’s importance: “I post every week. My schedule was a bit off in December and January because I was trying to crank out all the travel vlogs (January) and I participated in Vlogmas. But I'm now back to my usual 3 uploads a week. It's very important to be consistent with uploads. It gives your viewers a sense of routine. They know they can count on you to produce new content. My viewers know that on Tuesday they can expect a new video from me.” (YouTuber06).

5 Discussion

So how have our findings contributed to existing research on technology appropriation, particularly in the context of chronic illness self-management? First, the influences which we have found are in line with and further unpack prior theory on the processes and influences on appropriation (Mendoza et al. 2010; Merolli et al. 2015; Wang et al. 2017). Our findings also extend previous research on the role and effects of social media in the context of chronic illness (Goh et al. 2016; Liu and Pratt 2015; Merolli et al. 2013a, 2015; Wang et al. 2017). These findings suggest that: information exchanges aid with the task related aspect of chronic illness management because it allows these informants to obtain information needed to better manage and cope with fibromyalgia. It seemed that the key informants’ appropriate YouTube because the experience of chronic illness was said to vary between individuals, therefore they were motivated to seek access to others treatment plans, crucial behavioural changes and coping information from videos uploaded by peers to YouTube. This finding is in line with previous scholars who had suggested that participation on social media in general could have positive influ-
ences on illness management by chronically ill cohorts by leading to patient empowerment (Househ et al. 2014; Rozenblum and Bates 2013). Our findings also revealed that information obtained from YouTube was often incorporated to varying degrees within the overall context of their individual illness management practices. Furthermore, appropriation of YouTube gave these informants an outlet to raise awareness about invisible illness and fight the associated stigma of chronic illness, empowering them to advocate for themselves in their care and with others who may not understand their illness.

Also, findings suggest that emotional exchanges with others in the community was an important motivation for these cohorts because these emotional exchanges allowed these cohorts to feel validated, accepted, protects them from isolation and serves to shield them from the stigma of an invisible, chronic disease. Accordingly, in line with previous studies that have examined the therapeutic effects of social media for self-presentation in general and chronic illness in particular (Coulson et al. 2017; Merolli et al. 2015; Schultze 2014), it was found that presenting oneself through YouTube videos was cathartic for these vulnerable cohorts because they were able to honestly express their experiences in an accepting community of others who could relate to their daily challenges. Furthermore, in the context of chronically ill YouTubers, it was observed that authenticity, honesty and vulnerability were of value due to the nature of chronic illness. While social support was observed through the friendships created through YouTube, appeared that among YouTubers, it was transactive in nature based on tacit agreements to follow and engage with each other’s content. Further, these friendships emerged, as a sub-component of emotional support because for these vulnerable, isolated users there is an emotional need for companionship and understanding that is being satisfied through membership in the community. Our study also found that key informants tended to pursue material benefits, making use of mechanisms like YouTube’s analytics/monetization features to gain monetary benefits to sustain themselves.

Secondly concerning the process of appropriation, diagnosis seemed to act as a trigger to initiate a distinctive set of appropriation actions for these informants. All the study informants shared that they had made the decision to become video bloggers after they had gotten diagnosed with fibromyalgia to create awareness. Yet, because of the niche nature of chronic illness these informants faced challenges with regards to meeting the monetization criteria set up by YouTube. Therefore, these cohorts applied workarounds by using third-party applications like patreon.com, gofundme.com and others to circumvent the policies set by YouTube and allow their subscribers directly donate funds to them. This finding is in line with previous studies that suggest that users may conduct workarounds to conform an IT artefact to their needs (Barrett 2018; Choudrie and Zamani 2016), in addition this finding aligns with previous studies that state that appropriation is a goal oriented process (Grange and Benbasat 2011; Lamb and Kling 2003; Leonardi 2011).

Despite the challenges involved in appropriating YouTube, the inherent value of YouTube for these informants caused them to augment this technology through workarounds, indicating that YouTube’s usefulness was a significant influence on their continued use of the SMT(Davis 1989; Mendoza et al. 2010). For example, Informants had to conduct multiple workarounds to engage in YouTubing: 1) Integrating external technologies to create useful video clips (cameras, film production setup); 2) editing tools (software packages) to enhance the presentation of this content and; 3) integration of other SMTs to allow them to message others in their community.

Findings also suggest that these informants engage in borderless appropriation of SMTs involved appropriation of a suite of technologies alongside each other to complement their illness management practices and to support their efforts to build a brand as a chronic illness personality. Hence, these key informants reported having multiple SMT accounts across a range of technologies including: Tumblr.com, Pinterest.com, YouNow.com and numerous others in addition to the SMT account they had for the case study. Some informants also suggested that they had accounts on illness specific sites such as mdjunction.com- but interacted with those less because they were not as active or complete as YouTube that allows them to appropriate for numerous tasks and not just illness management. Additionally, YouTube allows videos from the site to be embedded in other SMTs which allowed cross platform promotion of uploaded videos which was seen as essential by these informants because it
could serve as a way to drive up subscriptions and view counts which would impact monetization outcomes. In line with this concept, these informants maintain the same profile name across social media sites to increase their visibility and maintain brand consistency. This finding adds to previous research on complementary use of media for different aspects of the same goal (Jung and Lyytinen 2014). These appropriation processes could be due some positive qualities of the site such as the openness, global access and ease of integration into other social media sites. Our findings show that the effects of the technology features of YouTube allows anyone with internet access to view created content without requiring an account to consume created content. This characteristic of YouTube was useful for these informants because they were able to drive up the view counts of their videos through cross-platform promotion and gain more visibility despite being a niche community on YouTube. Taken together, these characteristics seemed to mitigate the restrictions of YouTube such as the monetization threshold rules, copyright policies and ineffective communication features which served to constrain the extent to which it’s users could create content without risking account deletion.

6 Conclusion

In sum, this study examined appropriation of YouTube in the illness management context from the perspective of YouTubers. The appropriation of social media by chronically ill cohorts remains an area that deserves continued research interest by information systems scholars as they have the potential to aid self-management practices of chronically ill cohorts. Our findings are consistent with previous research on social media role in chronic disease management, but also reveals processes specific to video social media tools. Our findings show that through appropriation of YouTube these informants were able to obtain benefits related to managing their illness which ranged from information related benefits which helped to better understand and manage their illness. Additionally, emotional benefits were experienced by these cohorts which led to self-reported therapeutic benefits in addition to friendships formed through appropriation of this SMT. This study makes several contributions to both theory and practice: First, our findings expose the individual incentives for appropriation of a video based social media tool. In addition, our study unpacked the processes involved in appropriation of YouTube and explains the holistic connection between individual motivations, the processes of appropriation and the enabling or disruptive effects of YouTube on this practice. Further, this case study contributes to the literature by providing a detailed empirical case on appropriation as a rich illustration of the process of appropriation.

In addition, 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. Also, general practitioners/healthcare practitioners could take note of how YouTube may play a role in augmenting self-management of chronic disease. Chronically ill cohorts could derive potential benefits from these videos posted by their peers leading to positive illness management outcomes, yet care should be taken in applying this information. Rather, information obtained from YouTube should be discussed with general practitioners to prevent harm from potential misinformation. A limitation of the study was the focus on YouTubers as sources of information, perhaps future studies could include other users of YouTube such as commenters or viewers to gain a more holistic perspective on appropriation of a video based social media tool.

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