Exploring the Role of Social Media in Chronic Care Management

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Exploring the Role of Social Media in Chronic Care Management:

A Sociomaterial Approach

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Abstract. This paper examines how social media can support communities of patients with chronic illness and their care givers. This study is a qualitative case study and is informed by grounded theory. Sociomateriality is adopted as a theoretical lens to understand and explain the key findings. Our findings suggest that there is a dynamic relation between the contrary roles that social media in chronic care management and this is not only attributed to the functionalities of these technologies but to the attributes of patients and their states of health. We were also able to observe how these technologies are bounded up with human activities in the ways that separating them is not possible. What we learnt from our findings is that the ways patients and carers use of social media can change their perceptions about their conditions, and influence how they understand and approach the management process.

Keywords: social media · community · sociomateriality

1   Introduction

This paper examines how social media can support communities of patients with chronic illness and their care givers. Chronic disease are long term universal disorders, characterized as complex and non-curable conditions with prolonged impacts on individuals and communities [51]. It is argued that the complex process of chronic care management is challenging the wealth and functionalities of many individuals and communities by putting extra demands and pressure on the scarce healthcare and other communal resources [35]. However, studies suggest that information and communication technology can alleviate the adverse impact of chronic disease by supporting many aspects of the management process and potentially improve its outcomes [34, 42].

Recent studies show that there is a growing trend of using social media in the process of chronic care management [49], to the extent that some researchers believe this trend is transforming the process from a clinical-based activities to a more self-managed and community dependent process [25, 73].

While more empirical evidence is being reported regarding the different aspects of such a transformation [e.g. 66, 76], there is still little known on how these new technologies can influence or support the communities of patients and carers that form around chronic care management. This is because social media afford new types of behaviors that were previously difficult or even impossible to achieve before these new technologies being adopted by patients and carers [53, 58].

The lack of solid scholarly knowledge to explain the empirical patterns of use of social media in healthcare activities, calls for a deeper understanding of how social media can support patients and carers who take parts of the management process online. Further, there is a need to explore how the online activities that occur through social media can influence the offline process of the chronic care management and its outcomes.

In light of these motivations, the purpose of this study is to explore and unpack the potential role of social media in supporting community of patients and carers involved in chronic care management. It also aims to deepen our understanding of how such roles may arise from users' perceptions about the affordances and constraints of social media. As such, the question this study aims to answer is:

> *What roles can social media play in supporting chronic care management, and how the characteristics of social media influence such supporting roles?*

This study is a qualitative case study [27, 86], and is informed by grounded theory as its method of exploration and analysis [32]. Sociomateriality is adopted as a theoretical lens to understand and explain the key findings of this study [70]. By offering a relational perspective, this theoretical lens enables this study to highlight the unique and distinctive roles and capabilities of social media in chronic care management that exist beyond the material features of these technologies and the agency of their users, alone.

The paper proceeds as follows. The next section gives an overview of the wide range of literature on the use of social media in healthcare settings. We then discuss the sociomaterial lens used for this study in section 3. In section 4, we explain our methodology, including the grounded theory approach used in the study. Section 5 contains our findings about the role of social media in chronic care management. In Section 6, we engage our findings with the existing literature and our theoretical lens for the purposes of a discussion. Our final section comes to some conclusions about the role of social media in chronic healthcare management.

2 Literature Review

Literature about the application of social media in healthcare highlights the significance of these technologies in creating new opportunities for interactions and conversations between people who are involved in healthcare activities [56]. In particular, the literature points to the promising potential of social media in chronic care management, as well as the ways these technologies may challenges the process [52]. Recently, there

has been also a growing body of literature that highlights the means by which social media is transforming the process of chronic care management from a more clinical practice to a more community-based activity [25, 66].

In identifying the influence of social media in chronic care management, some researchers [e.g. 17] focus on social networking sites to highlight how these type of social media platforms can assist patients and caregivers to make better informed decisions and improve the quality of their lives. Wicks et al. [88] also highlight how Facebook, and other social networking communities can be built around data-sharing platforms, where patients share different types of information about their medical and social conditions.

The role of social media in facilitating the interaction between practitioners and patients is also highlighted in some of the studies that are concerned with chronic care management. For example a study by Jain [41] highlights how social networking sites are used by general practitioners who deliberately decided to become friends or connect with their patients to engage patients and also become more approachable. However, Keckley and Hoffmann [44] suggest that there is a complexity around this type of interaction and they cast doubts on the effectiveness of such approaches.

Stellefson et al. [76] present an analytical comparison between the traditional methods of providing health related information to patients with chronic disease, and the new trend of using social media. They argue that in the traditional methods of information provision, public health experts were providing chronic disease information in static form through Web 1.0, which primarily make written and audio materials available online. However, the rapid growth in adoption of social media has provided opportunities for participatory Internet interventions, to help individuals with chronic diseases become actively engaged in their own health care and become both the producers and consumers of information they need [61, 74].

More studies also highlight other aspects of chronic care management that could be influenced by the use of social media. For instance, Mo and Coulson [59] shows how social media can empower patients to become more active participants in the management of their conditions. Setoyama et al. [75] highlight the supporting role of social media facilitating the formation of online support groups, and Hara and Hew [38] shows how these technologies support information and knowledge sharing process.

Most of these studies examine or measure the influence of social media on the outcome of chronic care management [64]. Their approach is mostly to measure some medical or psychological parameter against certain features and functionalities that are designed into social media platforms [15]. One area that these studies leave almost untouched is how the use of social media by patients and carers can change the perception of these groups about their health conditions and how that in turn would influence the ways they use social media. This calls for further investigation on the relation between technological aspects of social media and the social and human aspects chronic care management.

In the field of IS, in the recent years, IS scholars have shown an increasing interest in studying social media [82]. The importance of social media, and the significance of studying them as new technological innovations, have been widely discussed by IS

scholars. The topic has been approached from variety of perspectives, including affordances of social media [e.g. 53, 79], their implications for virtual teams and communities [e.g. 89], their operational implications for organisations [e.g. 20], and their implications for social change [e.g. 5].

However, as Fichman et al. [26] argue, there is a need for more research from the IS community into the opportunities and challenges that social media can offer in the area of health IT issues. Agarwal et al. [3] contend that the importance of technologies such as social media in healthcare is increasing, as these technologies are playing more influential roles in making healthcare services more affordable and more reachable. They argue that the significant role of IT in modern healthcare warrants more attention from IS researchers, especially in the areas that pertain to the expansion of online health communities.

3   Theoretical Lens

Sociomateriality is a theoretical framework that conceptualizes the social world through the relations between material agency of artifacts and the social agency of human [70]. The sociomaterial perspective attempts to explain the social world as the enactment of meanings and materiality in everyday practices [69]. In doing so, this perspective focuses on the performativity of a 'social object' – the term that what was initially coined by Berger and Luckmann [13] – and its relation to its material features [90]; rather than representing this object through language and numbers [8].

Agency is at the heart of sociomateriality. However, this view makes a distinctive move away from seeing agencies of both people and artifacts, as primarily independent and self-contained entities that influence each other, either through impacts (deterministic approach) or interactions (constructivist approach) [10]. Instead, the focus is on agencies that have so thoroughly saturated each other in a way that boundaries between them are dissolved.

In this perspective materiality refers to the constituent features of a technological artifact that are available to all users in the same way [48]. However, as Majchrzak and Markus [54] put, because people come to materiality with diverse goals and perceptions, an artifact can afford distinct possibilities or limitations for particular actions. This because the material out of which an object is made can provide multiple affordances and it is possible that one object can produce multiple outcomes [79]. Therefore, although materiality exists independent of people, but affordances do not.

From the sociomaterial perspective, the affordances of a technology are a set of potential possibilities that emerges through interactions between people and technology in practice, rather than as properties of either people or technology [40]. In other words, affordances depend not only on the material and functionalities that characterize an artifact, also on the expertise, processes, and people's understandings of what the artifact can afford.

Looking at social media artifacts through the lens of affordances provides several advantages. The main advantage, according to Treem and Leonardi [79], is that focus-

ing on the entangled relationship between users and the material features of social media enables researchers to avoid privileging social determinism in explaining the patterns of social media use by users and ignoring the properties of the technology itself. The implication of this perspective for research is that the researchers need to base their analysis on the entangled and symbiotic relationships between the actions to be taken in a specific context and the capabilities of these technologies [53].

4 Methodology

This study takes a qualitative case study approach [27]. Taking a qualitative approach was essential, as gaining an understanding of the role of social media in chronic care management and how these technologies can influence the dynamics of this process are deeply embedded in the actors' subjective understanding of the applications and roles of these technologies in chronic care management [62].

Data collection and data analysis of the study was informed by grounded theory [32, 80]. The choice of grounded theory approach was entirely appropriate because very limited theoretical studies exist in this area and further exploration was essential [68]. The use of grounded theory as powerful exploratory approach was fruitful. Its flexible coding process enabled the investigation to focus on the contextual elements of the use of social media and unpack the underlying assumptions that would inform the actions and decisions of the key players in using these technologies for the management purposes.

While grounded theory provided this study with unique capabilities, we acknowledge that the findings of studies that are based on grounded theory can be very detailed and context bounded [47, 81]. To address this concern, we concur with Orlikowski [68] and Walsham [86] and argue that the detailed findings of this study can be scaled up to generate more abstract and general explanations through the process of 'analytic generalization'. This means that the findings will be explained with insights from the extant literature, and in the light of the existing formal theory [81], in our case, sociomateriality.

4.1 Data Collection

Informed by the grounded theory method, the data collection of the study was designed in three stages of exploration of the subject matter, conceptualization of the phenomenon, and theorization [32]. Each stage was informed by the analysis of data from previous stages.

At the exploratory stage, a focus group was conducted to explore the preliminary dimensions of the research problem, as well as the initial constructs that could inform the processes of constant comparison and theoretical sampling. The focus group was comprised of 10 participants, and all the participants were patients with arthritis and their carers. The session took two and half hours and was mediated by a professional mediator. The choice of arthritis was well justified as it is the most prevalent chronic

disease in many developed countries [71], and it is one of the most widespread chronic conditions around the world [6].

This stage revealed a number of key findings. First, it revealed the preliminary concepts related to role of social media in chronic care management. Second, it showed that although social media have promising potential for supporting chronic care management, there are a number of areas that were marked by significant uncertainties around social media use. Third, it suggested that many of the characteristics and applications of social media mentioned by the participants were related to or influenced by the material aspects of social media. The latter findings suggested, in Strauss's [77] language, that sociomateriality is a proper theoretical lens 'to grapple' with in order to explain the phenomenon under investigation.

Followed by the focus group, data was collected from social media sources, and complemented with semi-structured interviews. The initial concepts that emerged through the analysis of the focus group guided the process of collection, coding, and analysis of the data that came from social media resources. Major data came from variety of online patient forums and other social media platforms such as Facebook and Twitter. Forums used for this study were open to the public and researchers and were sponsored and maintained by health authorities, support organizations, and universities. The stories posted on the forums came from participants with different backgrounds and were generally from patients and carers, however, patients' family members, doctors, and other health professionals were also active members in those forums.

Forums were categorized into 17 categories based on the disease type they were representing. From the 17 different categories, the top five categories that represented the most prevalent chronic disease [71] were chosen and forums with the highest volumes of posts were selected for the study. We observed that there was a correlation between the prevalence of a disease and the volume of interactions in forums. The collected data were examined through the process of constant comparison. This process enabled us to sharpen our thinking about the emerging concepts by writing theoretical memos, and enrich our understandings of their complexities.

For the purpose of theoretical sampling, a set of keywords (e.g. Facebook, forum, or online) that could help to identify messages and stories that were pointing to the use of social media were used. The result returned with 633 stories, mainly from people who were involved in the management of arthritis, diabetes, autism, asthma, and breast cancer. The 633 stories/messages were reviewed and 223 of them identified as relevant items based on the activity they represented (i.e. use of social media), the purpose of the activities (i.e. chronic care management), and the relevancy of the stories to the research question.

This stage of data collection spanned over a three months period, followed by interviews with some of the key participants in the forums. In total, nine semi-structured interviews were conducted for the deeper investigation of the emerging themes and for the purpose of reaching more theoretical saturation. The complementary sources of data provided valuable insight into the practices of social media by patients and carers, and also assisted in reaching theoretical saturation. In general, the iterative process of coding and analysis through constant comparison enabled the study to search out for contrasts and negative evidence while becoming sensitive to any new emerging concepts

with possible alternative explanations [22]. Table 1 presents detailed information about the data sources used in this study.

It is noteworthy that the use of social media resources provided this study with unique possibilities. For example, with regard to the analytical processes of coding, social media resources provided interesting benefits to this study by making it more convenient to collect new data, deeper exploration of the dimensions of the phenomenon, and to better contrast the findings with the previous observations within the study.

Table 1. An overview of the data collection and data sources

Data source	Number of items/ participants	Type of stories/participants	Stage
Focus group	10 participants	10 arthritis patients	Exploration
Arthritis forum	68 stories	31 patients, 25 carers, 9 nurses, 2 physiotherapists, 1 rheumatologist	Conceptualisation
Diabetics forum	64 stories	36 patients, 13 carers, 9 nurses, 1 GP, 4 social workers, 1 allied health	
Depression forum	29 stories	21 patients, 8 carers	
Asthma forum	28 stories	21 patients, 5 carers, 2 nurses	
Breast cancer forum	34 stories	23 patients, 5 family members, 4 nurses, 2 allied health	
Interviews	9 participants	5 practitioners, 2 patients, 2 carers	Theorising/ corroboration

4.2   Data Analysis

Informed by the grounded theory, a rigorous Glaserian [31] approach to coding was taken in this study. Therefore, coding took place through three stages of open, selective, and theoretical coding. The approach enabled to explore the major constructs and their dimensions pertaining to the use of social media in chronic care management. The coding approach also helped the researcher to ensure that theoretical saturation of the emergent categories was reached.

The data analysis proceeded with close reading and coding of the stories and messages extracted from the online forums, as well as the transcripts of the focus group and interviews. Particular attention was given to the perspectives of the patients and carers, as the major actors, in order to understand how and why they would use, or avoid using, forums or other social media platforms for managing their conditions. Figure 1 presents an overview of the analytical development of the emerged concepts.
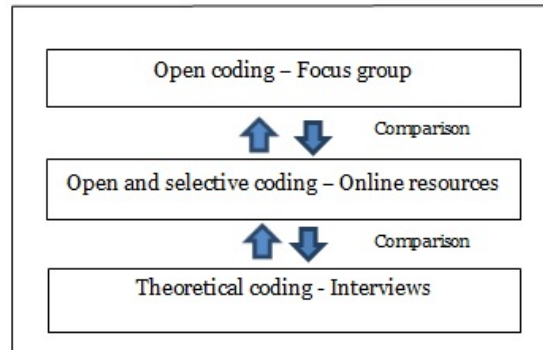
Fig. 1. Overview of the coding process

5   Findings

This section presents the findings as they were built up in the coding process. We present five categories that contribute to the theme of Role of Social Media: Building sense of community, Emotional support, Empowerment, Use of information, and Barriers. The composition of the theme is shown in the Figure 2. We also provide a chain of evidence for each category, so readers can see sample quotes for each category and the basis of that category in open coding.

5.1   Building Sense of Community

This selective code illustrates the means that social media can supports the creation of a sense of community as the patients and carers interact with each other. It shows how social media can help to bridge some of the social gaps that may result from issues such as differences in age, gender, or health conditions. This category shows social media supports the creation of *a sense of community* in chronic care management by *building rapport* among patients and carers (e.g. connecting people with different languages, or connecting people with different life experiences), supporting *diversity* (e.g. connecting people with different cultural backgrounds or in different age groups), facilitating peer and *social support* (e.g. supports social networks), facilitating *learning* (e.g. sharing experiences), and supporting *communication* (e.g. supporting multiple channels and methods of communication)

5.2   Emotional Support

This selective code represents how the use of social media can assist patients and carers to get *emotional support* as they engage in the process of chronic care management. Management of chronic disease is usually with many uncertainties and surprises, creating many emotional difficulties for patients and care givers and therefore, in long

term, getting *emotional support* becomes an important aspect of chronic care management [37]. In the light of this important aspect of the management process, the findings of this study revealed that social media can provide *emotional support* to the patients, carers, and their families by being a source of *emotional comfort* (e.g. helps to show sympathy or showing patients that they are not the only ones who have health problems), and by giving them access to the resources or interactions that can help them *to raise their hopes* for a better future (e.g. supports sharing positive experiences, or spreading encouraging words).
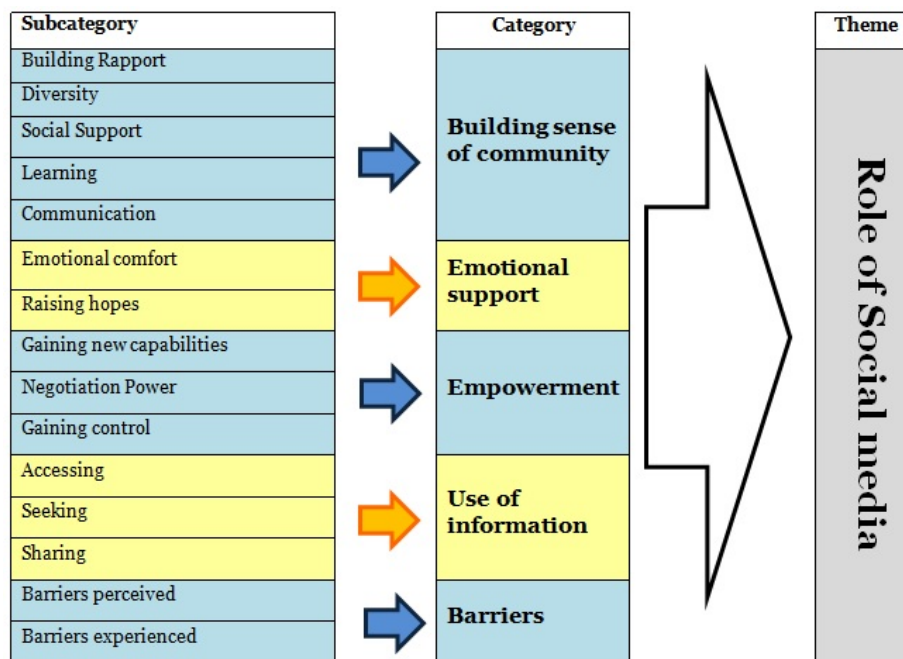
Subcategory	Category	Theme
Building Rapport		
Diversity		
Social Support	Building sense of community	
Learning		
Communication		
Emotional comfort	Emotional support	Role of Social media
Raising hopes		
Gaining new capabilities		
Negotiation Power	Empowerment	
Gaining control		
Accessing		
Seeking	Use of information	
Sharing		
Barriers perceived	Barriers	
Barriers experienced		

Fig. 2. An overview of the development of the Role of Social Media theme

5.3 Empowerment

Traditionally chronic care management is a paternalistic process where the power of decision making and directing the management process mainly rest in the hands of practitioners [12, 28]. The finding of this study disclosed that social media can change this balance of power by enabling the patients and carers to *gain new capabilities* to support the management process (e.g. overcoming communication barriers), giving them more *control* over the management affairs (e.g. helps patients to become proactive), and equip them with *resources* (e.g. knowledge about existing local facilities) that enables them to *negotiate* healthcare and issues related to the management of their conditions (e.g. asking for better resources or alternative treatments).

5.4 Information Use

Chronic care management is an information intensive process [24]. This selective code represents how social media can support different information processes pertaining to chronic care management. The category of information use highlights the role that social media can play in facilitating the processes of information seeking (e.g. looking for information about their diseases or seeking information about the implications of the treatments they receive), information accessing (e.g. talking to people with similar condition), and information sharing (e.g. sharing their experiences with healthcare systems).

5.5 Barriers

The category of *barriers* illustrates the major uncertainties, concerns, and *barriers* against the adoption and use of social media in the management of chronic disease. While many studies suggest that social media have the potential to transcend the social and spatial *barriers* of chronic care management [9, 83]; the findings of this study suggests that this is not always the case. Therefore, it is important to understand what the *barriers* of using social media in chronic care management are and how they can debilitate the potential of social media for supporting chronic care management. Such an understanding can also assist to obviate these *barriers* or alleviate their impacts. Evidence indicated that there are two major groups of 'experienced' (e.g. source of bad news, or information quality can be poor) and 'perceived' (e.g. lack of confidence in using technology, or uncertainties around the legal issues of using social media) *barriers* to the use of social media in chronic care management.

Table 2 provides sample quotes for each category, and shows the chain of evidence based in the open codes that make up each category.

6 Discussion

This section discusses the key findings of this study in the light of the existing literature, and also discusses these findings through the lens of *affordances* perspective.

6.1 Grounding the Key Findings Within the Extant Literature

In general, the findings of this study are congruent with earlier observations by Wellman et al. [87], Ellison et al. [23] and Kane et al. [43] that show the use of social media have become an important aspect of social life within communities and a growing resource for communication and interaction between their members. In particular, the findings from this study are consistent with the existing literature [e.g. 15, 46] suggesting that the use of social media can be beneficial to the chronic care management process, especially in providing *emotional support* to patients and carers and *empowering* them.

Table 2. Examples of supporting evidence of the key findings

Open code	Sample quote	Sub-category	Category
Source of comfort	*It's been more of a source of comfort actually than a lot of the other resources which I found on the Internet*	Emotional comfort	Emotional support
Sympathy	*When I feel I want some sympathy and want to talk to somebody, I will be very tempted to go on the forum and talk to people there*		
Giving vent to feelings	*Thanks for allowing me to vent. Today has been tough and very depressing*		
Sharing positive experiences	*One of the best moments was when someone wrote how the person who couldn't get from the kitchen to the bathroom without a cane finally overcame it*		
Encouragement	*There was a lot of patting on the back trying*		
Accessing new resources	*Social media have opened up a whole lot of different avenues and new resources for us*	Gaining new capabilities	Empowerment
Overcoming communication barriers	*He is not able to speak anymore but still he can communicates with our children and friends through Facebook*		
Understanding of the conditions	*I think I'm learning gradually that the OA symptoms deteriorate in the cold*	Negotiation power	
Negotiation for resources	*You know, having to learn about the healthcare system, they develop some sense of what it is about and how to negotiate it*		
Knowledge acquisition	*Knowledge is power really.*		
Being proactive	*I often look up for information there to find out what services are available in my area and where I need to go and ask for them*	Gaining control	
Prevent surprises	*Nothing was anymore going to be a surprise or a shock for me about the procedure.*		
Choice	*I think when you have the right information you will feel easier with any decision that you make*		
Seeking information about diseases	*Patients these days go online or use social media mainly for information seeking*	Seek	Use of Information
Seeking information for implications of treatments	*I did talk about the possible drugs that I could use*		
Accessing relevant information	*Some information that is not actually relevant to them*	Access	
Accessing information for decision making	*It is a very compelling sort of way of using technology to help and support patients to make decision about what they want to do*		

Accessing to information for education	*They can actually educate you by offering you relevant information*	Sharing	
Sharing contents	*Only took me 8 weeks and 2 days to get this [photo of a drug]*		
Sharing experiences	*He blogs about his experiences of living with RA*		
Common language	*So, we kind of dumped it down with spoons and made up our own way of talking about it.*	Building rapport	Building a sense of community
Same age group	*I have been looking for support groups for younger people like myself (30).*		
Same gender	*We encourages young women with arthritis*		
Individuality	*It's such an individual thing*	Diversity	
Difference of geographical location	*When you talk to different people, somebody in far north or in America*		
Spectrum of a disease type	*We are all different because it is a spectrum*		
Social inclusion	*For some isolated and lonely people, that it opens up a new world to them*	Social support	
Social interaction	*It is really good that he is able to stay in touch with other people*		
Social network	*You can have a network of people to support you*		
Sharing experiences	*People are talking about their own experiences*	Learning	
Sharing knowledge	*I think most people that go on the forum are extremely knowledgeable and well prepared to teach you*		
Learning from feelings	*I know exactly how your husband feels and I can actually tell you why*		
Communication with individuals	*It gives you the opportunity to actually communicate with other patients*	Communication	
Communication with the community	*There's Facebook, there's Twitter and there are other amazing stuff out there have made it much easier for us to communicate with other people*		
Source of bad news	*You don't hear the good news on there. You just hear the bad news*	Barrier experienced	Barrier
Depressive	*I stopped using the forum as it made me feel depressed*		
Information relevancy	*The biggest challenge for us is the information we have on our Facebook are relevant*		
Lack of control over the content	*The risk is that we will have little or no control over the content of Facebook*		
Reliability of sources	*The forum will give you a lot, but again I find, you're better off talking to somebody who is expert rather than getting it from unreliable sources*		

		Barrier Perceived	
Social isolation	*My friends only communicate with me on Facebook*		
Social gap	*People who use social media are in different social state from those who don't use technology*		
Confidentiality concerns	*We are bound by laws that say we cannot talk to other people about our patients*		
Lack of regulations	*In terms of Facebook, there is no regulation for doing social media-based consultations*		
Age dependency	*Because arthritis patient are all older we couldn't communicate with them through Facebook*		
Computer literacy deficit	*I don't understand what any of that is because I was a swimming instructor*		
Language barriers	*Something that we haven't done well at all in the past with our ethnics groups with none English background*		

Our findings show that an important aspect of using social media for chronic care management is that it can provide valuable emotional support to the patients and care givers. This finding is consistent with Frost and Massagli [29], Nakayama et al. [63], Setoyama et al. [75], suggesting that the use of different social media platforms can create positive emotional feelings for the patients and carers.

Emotional comfort found as a major dimension of *emotional support*. This finding is supported by Chung and Kim [18] study of social media that shows the use of social media technologies such as blogs can generate a sense of emotional gratification and satisfaction among patients with chronic care. Vilhauer [85] also highlights instillation of hope, and catharsis, as two major benefits of social media mediated support groups. This is in accordant with the finding of this study suggesting *raising hope* as a major aspect of *emotional support* attainable through the use of social media.

The *empowering* role of social media has been widely discussed within the literature [59, 91]. In the context of healthcare and especially chronic care management, the role of social media in *empowering* patients and carers is also highlighted frequently [e.g. 25, 52]. In our findings we showed that one of the aspects of *empowerment* is the patients' feelings that they have more *control* over the management process. This finding is consistent with Van Uden-Kraan et al. [84] as their study of online support groups for patients with chronic illness reveal that sharing experiences through social media can *empower* patients by leading them to a feeling of regaining *control* over their personal lives and their future.

In our findings we also highlighted how social media can contribute into patients' and carers' *empowerment* through provisions of *new capabilities* such as accessing to new resources and expanding the scope and range of *communication*. These findings tally with the earlier research by Bartlett and Coulson [11] that shows the significant role of social media in expanding *communication capabilities*; also a study by O'Connor [65] highlights how social media technologies provides *access to new resources* that are beneficial to chronic care management.

We also explored social media support patients' and carers' *empowerment* by giving them more *negotiation power*. This aspect is not explicitly identified in the literature, but Van Uden-Kraan et al. [84] implicitly point to this aspect, by showing how the use of social media can help patients to feel confident in their relationships with their physicians. So, we believe our finding with regard to *negotiation power* extends the current literature about the *empowering* role of social media in healthcare.

The extant literature also supports the findings from this study that highlights the *barriers* of using social media for chronic care management. Studies by O'Keeffe and Clarke-Pearson [67] show that the use of social media can create distress and *emotional discomfort* for patients as they frequently read unpleasant news about their friends or other patients with similar conditions. Issues related to poor *information quality* and the *reliability of information* accessible through social media are also widely discussed by researchers [1, 57]. Also, the different aspects of the social concerns related to the use of using social media by patients and carers are highlighted by Dutta-Bergman [21].

Although not all the identified concerns about the *legal dimensions* of the *barriers* are discussed within the literature, *confidentiality* and *privacy* have been highlighted strongly within the literature [1, 7]. Evidence from literature also supports our findings regarding the *lack of self-efficacy* as a *barrier* of using social media for chronic care management. For example, findings from Nakayama et al. [63] show that *age* and *lack of confidence* contributes in patients' avoidance to the use of social media. However, we suggest that our findings about *the lack of computer literacy* and *language barriers* can extend the literature in this area by adding new dimensions to these constructs (e.g. how the technological features of social media such as user interfaces couple up with users' health conditions and enact as a barrier) that were previously unexplored .

6.2   Viewing Our Findings Through the Lens of Sociomateriality

One way to explain the increasingly symbiotic relationship between social media and healthcare activities is through the lens of affordances. We adopt Majchrzak et al. [53] definition of affordance and define technology affordances as the mutuality of actors' intentions and technology capabilities that provide the potential for particular actions.

In the light of this definition, a preliminary exploration of the use social media in chronic care management, shows that the ways the capabilities and limitations of these technologies are perceived by the patients and carers are highly influenced by the material aspects of social media platforms [72]. Also, findings from other studies [e.g. 58] show that many of the actors involved in chronic care management, specially patients and carers, often could enact new practices or achieve outcomes such as mobilizing social resources or fast and timely dissemination of sensitive information, that would not be possible without the use of social media and engaging with material features of these technologies. As such, informed by Gibson [30] and Hutchby [40], we contend that our empirical findings lend themselves to analysis from an affordance perspective.

The relational concept of technology affordances suggests that social media have no inherent properties, boundaries or meaning but, as Barad [8] suggests, these technologies are bound up with the specific material-discursive practice that constitute their

characteristics and affordances. As Zammuto et al. [90] point out, based on the affordances perspective, technological possibilities of action are not given but they depend on the intent and perception of the actors enacting them.

Using an affordance lens suggests that although social media and the social features of chronic care management may exist independently of each other, their value for explaining the role of social media in the management process comes from how their agencies enact together.

This means, although social media and chronic care management process may have their own potentials and constraints, but as Zammuto et al. [90] argue, an affordance perspective recognizes that a technological object has some recognized functionality but needs to be recognized as a social object. In other words, the influence of social media, as social objects – a term first coined by Barley [10] – on the management process cannot be separated from, for example, patients' status of health, their technology literacy, their communities, or any other social features pertaining to the management process. We therefore suggest a number of key affordances of social media in the context of chronic care management.

Emotional Support Affordance. The emotional support affordance is defined as a potential of social media to provide patients and carers with emotional support through emotional comfort and instillation of hopes. This affordance is enacted by the assemblage of material features of social media (e.g. hardware, software, or interfaces) and social features of chronic care management (e.g. friendship, or peer support).

Technologically, interactive environments such as online forums that enable synchronous and asynchronous interactions are needed to have the basic capabilities and elements of emotional support in place [2]. In addition, databases, usually supplied through a service provider coupled with physical storage environments and other hardware are needed to store the history of interaction and give the capability of retrieving data to patients and carers [34]. Further, algorithms are generally essential for authentication and protection of users' privacy and confidentiality [14] as many of the online participants seek support while staying anonymous [63] or only interested to communicate with certain people [34].

These technological features of social media need to be coupled with important social features of the management process to enact the affordance. These social features can include the type of the medium [36], the chronic disease types [58], the participants' demographics [19], the culture of the online forum [55], and the participants' attitudes and communication skills [60].

The emotional support affordance assists to understand and explain the role of social media in the outcome of chronic care management in ways that examining either social media or the management process separately does not. By investigating how social media can be used by different actors to provide emotional support to patients and carers, interdependencies and potential sources of support can be more easily identified. Also, features of social media that are more useful to the provision of such support and those that are less attractive can be more accurately pinpointed.

Empowerment Affordance. We define this affordance as the potential of social media in empowering patients and carers. The empowerment affordance is enacted through the relationship between the material features of social media (e.g. information representation, multiple format support, and information sharing spaces) and social features of chronic care management (e.g. knowledge acquisition, interaction with service providers, or decision making).

Technologically, several technological features are needed to enable this affordance. Technologies such as wikis, blogs, and online forums that enable users to produce, share, and access information are needed to support capabilities lead to patients and carers empowerment [74, 83]. In addition, technologies that support the representation of information in different formats such as text, video, and audio are needed to help the patients and carers understand the different dimensions of an issue and acquire knowledge with more depth about the issues related to the management of their disease [91]. These technical and material features of social media need to be conjoined with some of the significant aspects of chronic care management to make the empowerment affordance possible.

Several chronic care management features are needed as well to enable empowerment affordance. Features such as making decisions about different aspects of treatments [15], negotiating work place related issue [45], educating friends and families [56], and taking part in social activities [33], are just a few to name.

The affordance of empowerment assists to explain the role of social media in identifying the roles and relation between the actors involved in chronic care management. By examining how social media can give patients and carers a stronger voice and enable them playing a more central role in the management process, we can get a clearer understanding of how social media can support them to become more independent from healthcare services and engage in a more effective and fruitful self-management process. Also, by examining the empowerment affordance across different actors, it is possible to identify inter-power-relationships and inter-power-dependencies, which in turn could assist to get a deeper understanding of the technological and social features that, could more effectively support empowerment capabilities.

Barriers Constraint. While the concept of affordance mainly represents potential capabilities for actions, as Hutchby [40] explains, an artifact's affordances and constraints are similar in nature. The notion of constraints emerges from an artifact's affordances and how people perceive an artifact can put constraints on their possibilities for action based on its affordances [54]. Accordingly it is useful to consider how constraints might play out in using social media in chronic care management. Participants did independently identify constraints, which underlines why the theoretical lens is so helpful when considering this research problem.

The barriers constraint in our study is defined as the potential harm of using social media in chronic care management. This constraint is enacted through the dynamic relationship between the material agency of social media (e.g. security, confidentiality, and meta-information) and social agency (e.g. regulations, online relationships, information reliability) of chronic care management.

Several technological features of social media contribute in enactment of this constraint. Features like accessibility of depressive or concerning information [63], poor filtering features [4], complex interfaces and process [39], lack of methods or algorithms to evaluate the quality of imparted information [57], and insufficient level of confidentiality [4] are a number of material features of social media that contribute in the barriers constraints.

These technological features need to be coupled with some important social aspects of chronic care management to enact as barriers. Social features such as legal issues [78], health literacy [16], and age [19] can influence users' perceptions about the capabilities of social media, and the ways they could assist or harm patients and carers during the management process.

The barriers constraint helps to explain the potential harm that the use of social media can cause of patients and carers. By examining this constraint(s) across diverse actors, it should be possible to identify features or functionalities of social media that are potentially insignificant or damaging to patients and carers and may adversely impact chronic care management. Also, it helps to understand the social concerns that the causes that improvises or diminishes the potential values of applications of social media in chronic care management.

It is noteworthy that these barriers and affordances are not permanent, but they are dynamic as the relations between the material agency of social media, and the social agency of the patients and carers can change [8]. In fact these affordances (constraints) that enact through such a relationship can also be a factor in changing the perceptions of users about the affordances of social media and therefore, the nature of users' perception about the affordances and constraints of social media can change over time. This change of perception, however, is yet influenced by users' new understandings of the material aspects of social media and how they can enact in a dynamic relationship with the social aspects chronic care management.

7   Conclusion

The question we aimed to answer in this study was: *How can social media support communities of patients and carers that form around the complex process of chronic care management?* Our investigation revealed that social media can play a supporting role in a number of ways including enabling patients and carers to *build a sense of community*, provide *emotional support* to each other, *empower* one another, and also assist each other to *access, share, and search for the information* they need. We also observed that social media did not always play a supporting role, and could create concerns around their potential harm to patients and carers.

By focusing on its key findings of *emotional support, empowerment,* and *barriers*, this study also highlighted how these three aspects of social media use can influence the process of chronic care management. In explaining these key findings, we adopted an affordance perspective. This approach furnished us with a set of analytical concepts that put stress on inseparability of technological and social aspects of social media. The affordance perspective also allowed us to base our understandings on our participants'

perceptions about the potentials of social media, emancipated us from framing and packaging their views within pre-defined concepts and constructs that attempt to establish superiority of either technology or social over the other. Our finding show that social media does not always play supporting roles to chronic care management but they may sometimes act as obstacles and barriers to the management process. These roles, however, are not permanent and fixed but can change as patients and carers learn more about themselves and the capabilities of social media. Our findings suggest that there is a dynamic relation between the contrary roles that social media can play in chronic care management and this is not only attributed to the functionalities of these technologies but to the attributes of patients and their states of health. This socio-material characteristic of social media can have implications for the design of these technologies as well as for their applications in healthcare communities.

By focusing on the role of social media in the context of chronic care management, we were able to observe how these technologies are bounded up with human activities in the ways that separating them is not possible. What we learnt from our findings (for example, how empowerment or barriers are perceived) is that the ways patients and carers use of social media can change their perceptions about their conditions, and also influence how they understand and approach the management process. In other words, social media is not seen just as technological artifacts, but as an aspect of the management process that constructs the every experiences of having chronic disease for patients and carers. At the same time, these experiences identify how social media can support or prevent the outcomes of the management process to be achieved.

We believe this study makes two major contributions. First, it expands our analysis and knowledge of the role of social media in supporting healthcare communities in ways that investigating either social media or healthcare communities alone does not. Second, this study provides insights into how social media can assists the future design of possible toolkits aim to help the patients and carers to build their own self-managed communities. For instance, our identification of certain barriers would imply that any self-managed community would have to be prepared to help and support patients to minimize the possible emotional discomforts or the social pressures that may occur by the use of social media. As another instance, considerations have taken into account by the community to make sure that patients felt comfortable with legal issues. We also argue that the findings of this study are transformable to communities within similar social context [50].

Communities are dynamic social entities. So, we believe the findings of this study can be used to conduct further research on how the use of social media can influence the dynamics and attributes of communities (e.g. resilience, sustainability, or adaptability), especially those that exist or form in complex and uncertain environments.

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