The Impact of Online Health Communities on Patients' Health Self-Management

Short Paper

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Abstract

Online health communities offer unprecedented opportunities of empowering patients to take care of their own health and reducing the pressure of chronic diseases on the health service. Given the importance of knowledge for the empowerment of patients, the objective of this study is to understand the impact of knowledge sharing in online health communities on various aspects of health self-management. We develop a model to investigate 1) the factors that influence the level of community engagement in online communities and 2) the impact of engagement in online communities on members’ cognitive, behavioral, and emotional experiences of health self-management. We will empirically test our model through an online survey with the users of Diabetes.co.uk's forum. The study aims to provide a holistic perspective on the impact of a properly managed online health community on patients’ wellbeing.

**Keywords:** Online health communities, health self-management, knowledge sharing, diabetes

# Introduction

Social media, such as Twitter, Facebook and discussion forums, have enabled the formation of online health communities, whose members interact, communicate, and exchange information about their medical condition and treatment (Josefsson 2005). Various studies suggest that online health communities are a source of peer-support and can have a therapeutic effect on patients’ wellbeing (e.g., Bernardi 2016; Nambisan 2011). This study is motivated by the opportunities that online health communities offer to their members to manage their own health, which can potentially reduce the pressure of chronic diseases such as diabetes on healthcare systems. By empowering patients to take better care of their health, online health communities can bring cost-savings to the healthcare system, for example by reducing medical consultations. In particular, community members can tap into the collective knowledge of people with a similar medical condition, which increases their confidence in making informed health decisions (Hall et al. 2015; Willis 2016). Knowledge shared in online communities also empowers their members in navigating healthcare systems and interacting with medical professionals and institutions (Foster 2016).

So far research has focused on the factors affecting knowledge contribution in online health communities (Zhao et al. 2013; Zhao et al. 2015). Less is known about the implications of knowledge sharing in an online community for health self-management. Our study recognizes the complexity of managing a chronic disease due to its different experiential dimensions: cognitive, behavioral, and emotional. Graffigna et al. (2014) suggest that these three experiential dimensions are equally important in patients’ health self-management, i.e., their will and ability to make treatment and health behavior decisions. In order to manage different experiences with their condition, online community members need to share different types of knowledge such as medical knowledge about treatments, useful practical tips on how to use medical equipment or even emotions and feelings to cope with pain and distress (Nambisan 2011; Willis and Royne 2016). Therefore, the objective of our study is to analyze the impact of knowledge sharing in online communities on the three experiential dimensions (cognitive, behavioral, and emotional) of health self-management. The focus on these three experiential dimensions is important because it allows us to fully appreciate how online communities can help patients to cope with the management of a chronic condition.

Given the value of patients’ knowledge for health self-management (O’Grady et al. 2008; Zhao et al. 2013), a key contribution of this study is to unearth the significant role of online health communities in knowledge sharing and knowledge co-creation. Our argument is that patients’ empowerment in managing their own health arises from knowledge shared in online communities. Such knowledge can influence patients’ decisions about their own health management, which, eventually, has an impact on the utilization of health service resources (e.g. medical consultations, medical treatments, etc.). Our conceptual model builds on existing research about knowledge contribution in health (Zhao et al. 2013) and non-health online communities (Chiu et al. 2006; Ray et al. 2014). From the literature, we identify antecedents to community engagement and propose that community engagement affects the cognitive, behavioral, and emotional experiential dimensions of health self-management. We will empirically test the model on one of the largest diabetes online communities in Europe. Our two research questions are:

*1) What factors influence the level of community engagement in online health communities?*

*2) How does engaging in online health communities affect members’ cognitive, behavioral and emotional experiences of health self-management?*

# The Impact of Online Health Communities on Patients’ Wellbeing

The impact of participation in online health communities on wellbeing has been mainly studied in relation to the informational and emotional support that members receive from their community and the positive impact that such support has on their health condition (Leimeister et al. 2008; Nambisan 2011; Yan and Tan 2014). Community members provide and receive informational support by sharing practical information that can help them manage their own health condition. Emotional support involves community members’ seeking mutual understanding and comfort by sharing their story about how it can be frustrating and painful to live with a health condition (Merolli et al. 2013; Nambisan 2011; Yan and Tan 2014).

A number of factors may moderate the relationship between participation to online health communities and wellbeing. For example, perception of emotional support and its relationship with wellbeing may be relevant for peer-support groups rather than online communities of health organizations (Nambisan 2011). Community members’ health status and psychological state of mind are other factors that influence the impact of participation to an online community on their wellbeing (Batenburg and Das 2015; Yan and Tan 2014). These findings highlight the complexity of measuring the impact of online health communities on wellbeing. Related to this is the limited understanding of the impact of participation to online health communities on better health outcomes. As a matter of fact, positive impact on factors that facilitates healing and recovery, such as informational and emotional support (Nambisan 2011), does not necessarily translate into improved health outcomes (Taiminen 2016). Even though research has found that peer-support can lead to better health conditions (Yan and Tan 2014), we can only assume but not argue with certainty that such improvement is due to changes in medical treatments and health behaviors that are consequent to members’ engagement with an online community. We argue that a clear understanding of the impact of online health communities on patients’ wellbeing and health outcomes is difficult to achieve because community members do not make sense of and use the community’s knowledge in the same way.

According to Kazmer et al. (2014) there are three types of knowledge: distributed knowledge, undiscovered knowledge, authoritative knowledge. Knowledge is “distributed”, that is, it is not owned by an individual but is built and owned by a group of individuals such as carers, doctors, and patients. Such knowledge is of no use until it is discovered and becomes of public domain. For example, the relationship between a type of treatment and its side effects might be known but still undiscovered. Authoritativeknowledgeis the knowledge that is legitimized and accepted by the community and, therefore, influences decisions about treatment and health management behavior.

Community members construct authoritative knowledge by navigating among the medical literature, healthcare professional advice, their own and their peers’ lived experience and use it in different ways. For example, peer-knowledge takes precedence over medical advice (Kazmer et al. 2014) if it reflects the lived experience of “disease veterans” and multiple members (Willis 2016). Members would draw on medical literature or expert knowledge when causes and treatment of a disease are uncertain and, therefore, shared lived experience alone cannot satisfy their knowledge gap (Kazmer et al. 2014). Therefore, community members might have different perceptions of the validity and authority of their community’s knowledge, which, ultimately, influences community members’ self-efficacy, i.e., their confidence of making independent informed decisions about their health (Hall et al. 2015).Thus, one way to better understand the impact of online health communities on patients’ wellbeing is to look at the influence of the community’s knowledge on members’ ability and will to manage their own medical condition.In particular, we gain such understanding through the three experiential dimensions – cognitive, behavioral and emotional – thatrelate to how patients make sense of their medical condition and, therefore, their level of engagement in managing their health (Graffigna et al. 2014). The cognitive dimension relates to the patient’s knowledge and understanding of a medical condition and its treatment. The behavioral dimension is connected to all the activities necessary to manage and live with a condition. The emotional dimension is about the psychological and emotional need to manage and accept a medical condition and adapt to a new way of life.

# Hypotheses and Research Model

## Online Community Engagement and the Emotional, Cognitive and Behavioral Experiential Dimensions of Health Management

Online health communities are a source of information and support thanks to the active participation and engagement of their members (Zhao et al. 2015). Even though recent research has found that lurkers can benefit from the information posted by others (Petrovčič and Petrič 2014), other studies suggest that posters perceive greater emotional and psychological support by sharing useful tips and information (Bernardi 2016; Batenburg and Das 2015). Hence, one of the therapeutic effects of online communities is the increased sense of empathy that members feel by contributing medical and experiential knowledge to the community (Zhao et al. 2013). Such sense of empathy is positively related to patients’ psychological state, which helps patients to improve their health status (Nambisan 2011). Therefore, engagement is an important element that drives members’ knowledge contribution because they consider it “socially important” and “personally meaningful” (Ray et al. 2014). In particular, members can engage with their community and provide medical facts and knowledge about the symptoms, treatment, and monitoring of a disease (Graffigna et al. 2014). Members need to make sense of this information and use it for managing their own condition. For example, in the case of the diabetes online community analyzed in this study, members need to know about the effect of certain type of food on their glucose level. Such knowledge is part of the cognitive experiential dimension of managing diabetes. Therefore, we hypothesize that community engagement drives members’ contribution and understanding of medical knowledge, which helps members to cope with the cognitive experiential dimension of managing chronic diseases:

*H1: Online community engagement is positively related to community members’ medical knowledge (cognitive experiential dimension).*

Engagement in health self-management is often associated with self-efficacy (Holman and Lorig 2004). Self-efficacy is people’s beliefs of their ability to perform certain behaviors (Bandura 1977a). Thus, self-efficacy is not an indicator of skills, but rather a measure of people’s confidence in their ability to achieve a goal. A person will not engage in a specific behavior, unless he or she believes in the success of his or her actions. Recent research has found that participation to an online community increases patients’ perceptions of self-efficacy, which gives them the confidence of practicing health self-management behaviors (Willis 2016). Active engagement with an online community is fundamental to boost confidence in health self-management. Experience of living with a disease improves the knowledge of its symptoms and self-efficacy in health management. New community members would normally ask more experienced members for help. By engaging in conversations with “disease veterans” of an online community, new members do not only learn what works and does not work in managing a health condition, but they also receive moral support, which increases their perception of self-efficacy (Willis 2016). With reference to the online diabetes community in this study, we hypothesize that the knowledge acquired through active engagement with the community increases members’ confidence of performing the actions needed to manage diabetes including the ability of putting doctors’ recommendations into practice. Such actions are part of the behavioral experiential dimension of managing diabetes:

*H2: Online community engagement is positively related to community members’ health management self-efficacy (behavioral experiential dimension).*

Another way in which members engage with their community is by telling stories about their experience with a medical condition. Through narration community members support each other and find relief in knowing that they are not alone in experiencing the difficulties of a medical condition (Bernardi 2016; Merolli et al. 2014). Thus, through narration, community engagement reduces the emotional burden attached to everyday living with a condition, such as pain and anxiety derived from testing and treatment, little support and sympathy from family and friends (Yan and Tan 2014). Community members’ stories constitute a source of knowledge through which members better cope with the bad feelings that a medical condition might induce. We thus hypothesize that community engagement can reduce the emotional burden of living with diabetes and help patients to better cope with the emotional experiential dimension of managing diabetes:

*H3: Online community engagement helps reduce members’ emotional burden of living with a disease (emotional experiential dimension).*

## Offline Social Support

One of the reasons patients join an online community is that they can receive greater support from people that experience living with the same medical condition than from family and friends (Bernardi 2016). Therefore, engagement with an online community may be less needed when family and friends are supportive. As suggested in recent research, perceived support from family and friends outside the online environment can reduce the effect of participation in an online community on perceived wellbeing (Batenburg and Das 2015). Encouragement from family and friends can increase patients' confidence in their ability to achieve specific health management goals. In addition, social support and sympathy from family and friends can help patients reduce their sense of anxiety and distress of living with a medical condition. Therefore, we posit that offline social support (from family and friends) can moderate the effect of online community engagement on health management self-efficacy and emotional burden. Community members that receive high support from family and friends can better cope with the behavioral and experiential dimensions of managing diabetes, which means that the effect of community engagement on these two dimensions will be attenuated:

*H4: Offline support attenuates the positive relationship between online community engagement and health management self-efficacy.*

*H5: Offline support attenuates the negative relationship between online community engagement and emotional burden of living with a disease.*

## Antecedents of Community Engagement

Following our hypotheses of the positive impact of online health community engagement on health self-management, it is important to understand the factors that motivate users to engage with an online community. Recent studies suggest that online health communities are social circles where members interact and share their opinions and facts about a medical condition to receive information and social support (Kallinikos and Tempini 2014; Merolli et al. 2013; Nambisan 2011). Members engage in discussions with an online community because they hope to find useful information and increase their knowledge about how to manage their medical condition (Nambisan 2011; Rupert et al. 2016). Perception of knowledge quality reduces members’ perception of risk of participating to an online community (Shiue et al. 2010). Therefore, knowledge quality is one factor that drives users’ engagement with an online community. In addition, members feel motivated to actively participate in an online community to receive but also to give help. It is this feeling of mutual exchange and reciprocity that can strengthen social network ties (Myers et al. 2014) and create a stronger sense of engagement (Bernardi 2016). Knowledge self-efficacy, i.e., the sense of confidence about the value of one’s knowledge is another factor that influences knowledge contribution to the community and, therefore, community engagement (Ray et al. 2014). Finally, sense of community, i.e., the perception of being part of the same community and sharing the same values, can motivate members to actively participate to the community’s discussions (Chiu et al. 2006; Ray et al. 2014; Zhao et al. 2013). Therefore, we posit that knowledge quality, reciprocity, knowledge self-efficacy, and sense of community are important antecedents of community engagement.

### Knowledge Quality

Knowledge quality indicates the quality of content shared in an online health community and drives knowledge sharing in an online community (Yoo et al. 2002). Knowledge quality is subjective and depends on community members’ perception of its utility in addressing their needs. The greater the perception that the community’s knowledge can satisfy their needs, the higher the likelihood that members will continue to engage with the community and share knowledge (Chiu et al. 2011). High knowledge quality also reduces the perception of risk of contributing to an online community. Risk is associated with the feeling that participation in an online community can lead to loss of time and opportunities. Therefore, knowledge quality increases the perception of knowledge sharing as a rewarding rather than risky activity increasing the intention to actively participate in an online community (Shiue et al. 2010). The process of validating and producing knowledge quality also drives members’ engagement with an online health community. Community members are aware of the anecdotal nature of peer-information and the need to contrast it with their own and other members’ experience and medical advice (Rupert et al. 2016). Through this process of validation, members participate in the construction of knowledge that is accepted by the community as legitimate (Kazmer et al. 2014). Hence, our hypothesis is that perceived knowledge quality is an important factor that motivates engagement with an online health community:

*H6: Perceived knowledge quality is positively related to online community engagement.*

### Reciprocity

In the context of online knowledge sharing, reciprocity refers to the belief that sharing knowledge will lead to future requests for knowledge being met (Chang et al. 2015; Kankanhalli et al. 2005). That is, a person who has helped others expects a return of favor when he or she needs it. With direct reciprocation, the exchange of favor happens between two actors in a restricted, tit-for-tat exchange. When more than two parties are involved, there is a possibility of indirect reciprocity where A gives to B and eventually receives a return from someone other than B (Bearman 1997; Lévi-Strauss 1969). Johnson et al. (2014) argue that exchange patterns in online communities are shaped by both direct and indirect reciprocity. Nevertheless, like many other social sciences researchers, IS researchers are generally more interested in indirect or generalized reciprocity. After all, the norm of direct reciprocity is difficult to maintain online due to uneven distribution of knowledge (Faraj and Johnson 2011) and/or high turnover rate of online communities (Wasko et al. 2009). Instead, people contribute knowledge online without expecting immediate reciprocation, although there exists a generalized sense of mutual indebtedness which drives continuous engagement.

A number of studies have examined the relationship between the norm of reciprocity and online community engagement. In Wasko and Faraj’s (2000) study of Usenet newsgroups, “giving back to the community in return for help” was the most cited reason for knowledge contribution. Chou and He (2011) examine expertise integration in Open Source Software (OSS) communities and find that a strong norm of reciprocity creates a strong sense of fairness and trust, which in turn increase people’s willingness to build on each other’s perspectives and expertise. Similarly, Chai et al. (2011) find that reciprocity encourages knowledge sharing in blogosphere and leads to strong and trusting social relationships. More recently, Ray et al. (2014) argue that reciprocity is a key social norm that derives from satisfaction with social interaction, which in turn encourages further social engagement. Based on this stream of literature, we hypothesize:

*H7: Reciprocity is positively related to online community engagement.*

### Knowledge Self-efficacy

Knowledge self-efficacy is the perception and confidence that one has about his or her expertise and knowledge contribution. Past studies have found the positive effect of knowledge self-efficacy on knowledge contribution behavior in online spaces (Kankanhalli et al. 2005). Cheung et al. (2013) argue that being able to help other members in a community confirms knowledge self-efficacy, which in turn encourages continued community involvement. Ray et al. (2014) also show that highly efficacious members of an online community are more likely to be psychologically engaging with the community. In a recent study about a diabetes online community, Bernardi (2016) argues that more experienced members of an online health community would show high knowledge self-efficacy and invest more effort in sharing knowledge with their peers. This is because by experiencing community relationships, members realize the limits of their own knowledge and understand what they can teach and learn within the community. Therefore, we postulated that knowledge self-efficacy is an important factor that drives online community engagement.

*H8: Knowledge self-efficacy is positively related to online community engagement.*

### Sense of Community

Sense of community has been defined by community psychologists as “a feeling that members have of belonging” (McMillan and Chavis 1986, p. 294). This sense of belonging entails, among other things, identification with and affective commitment to the social group (Ellemers et al. 1999). IS researchers have discussed whether and how sense of community in the physical world also comes about in virtual communities (Blanchard and Markus 2004; Rotman and Wu 2014). While research on sense of community as an antecedent to community engagement has been limited, a few studies have examined similar concepts. For example, in Chiu et al. (2006) “emotional identification” refers to “an individual's sense of belonging and positive feeling toward a virtual community” (p. 1877), which partly explains one’s engagement with a virtual community. Their empirical findings show a positive relationship between identification and quantity of knowledge sharing in the community. Adopting an organizational commitment framework, Bateman et al. (2011) find that “affective community commitment” drives deeper and continued engagement in an online discussion community. Affective community commitment in members is based on their strong emotional attachment to that community. In particular, this affective attachment not only positively affects posting replies, but also has a powerful effect on informal discussion moderating behaviors. Hsu and Liao (2014) treat sense of community as a variable moderating the relationship between information accessibility and microblog stickiness, and they argue that when sense of community is strong, microblog users are more motivated to engage in processing information and remain involved in the microblog community.

*H9: Sense of community is positively related to online community engagement.*

Our research model is illustrated in Figure 1.

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| Figure 1. Research Model |

# Research Method

## Participants and Data Collection

To empirically test our model, we conduct an online survey with the users of Diabetes.co.uk's forum. Active since 2007, Diabetes.co.uk (www.diabetes.co.uk) is the largest community of People with Diabetes (PwD) with 526,790 members at the time of this writing. Diabetes.co.uk is part of Diabetes Digital Media, a private organization that reinvests the community's profit into educational programs, contents, digital tools, and apps for managing diabetes. With the support of the forum managers, we plan to first recruit a small number of forum participants (around 150) via email in a pilot study to assess the survey instrument and solicit qualitative feedback on the questionnaire design. We then analyze the pilot study data for measurement quality using exploratory and confirmatory factor analysis. The main survey invitation will be posted on Diabetes.co.uk’s forum. The forum’s senior management team has been actively participating in designing and deploying the empirical study. Two senior executives reviewed the questionnaire and made suggestions to improve factual accuracy and appropriateness of wording in some of the questions. The researchers also worked with the management team to determine when and how to distribute the survey invitations to the community. It is worth noting that the researchers have remained independent throughout the process, with no compromise made in the survey design.

## Measurements

There are three constructs that measure the cognitive, behavioral, and emotional experiential dimensions of managing diabetes. For the cognitive dimension, we measure the respondents' knowledge of diabetes based on 10 items selected with the senior management team of Diabetes.co.uk from the Diabetes Knowledge Test of Michigan Diabetes Research Centre[[1]](#footnote-1) (Fitzgerald et al. 2016). The behavioral dimension concerns participants' self-efficacy in managing diabetes, which we measure with items from the Diabetes Self-Efficacy Scale by Lorig et al. (2009). The emotional dimension identifies the emotional burden (e.g. sense of anxiety and stress) of living with diabetes. We measure this construct with items adapted from the Diabetes Distress Scale of Polonsky et al. (2005).

The scales for online community engagement and its antecedents are adapted mainly from the IS literature. To measure the level of community engagement of an individual forum user, we collect data on their tenure of membership, frequency of visiting the site, number of posts, and whether they have read/started/replied to forum posts in the last 30 days (Batenburg and Das 2015). To measure perceived *knowledge quality*, we use items from the knowledge quality scale of Chiu et al. (2006). These items measure whether the knowledge shared by other members of the online community is relevant, readily, usable, credible, reliable, up to date, and timely. We adopt items for *reciprocity* from Kankanhalli et al. (2005) and Wasko and Faraj (2005), and *knowledge self-efficacy* from Ray et al. (2014). The measures for *sense of community* are adapted from items measuring identification (Chiu et al. 2006) and affective community commitment (Ray et al. 2014). These items reflect sense of belonging, feeling of togetherness, positive feeling, sense of pride, emotional attachment, and personal meaning associated with being a member of the online community.

The moderating variable *offline social support* is measured with items from Batenburg and Das (2015), which are part of the Interpersonal Distress Scale (Polonski et al. 2005). In addition to demographics such as age, sex, and education level, we also control type of diabetes (e.g., Type 1, Type 2, etc.), years of having diabetes, HbA1c level (glucose level), and methods of managing diabetes (e.g. insulin, pills, etc.).

As all measures are collected in the same survey instrument, there is the possibility of common method bias (CMB). We adopt several procedures recommended by Podsakoff et al. (2003) to control CMB. First, the respondents are completely anonymous, which reduces the potential influence of social desirability and leniency biases. Second, we use the survey software to randomize the order of the measurement of the antecedents and dependent variables, which will help control biases related to where a question is embedded in the questionnaire. Finally, we will test CMB in Harman’s single-factor test using a confirmatory factor analysis (CFA) approach. If the covariance among measures is mainly due to CMB, a one-factor CFA model would fit better than the measurement model.

# Conclusion

This study adds to existing research about the impact of online health communities on patients’ wellbeing (Nambisan 2011; Yan and Tan 2014). In particular, we contribute to a greater understanding of the impact of the knowledge sharing in online health communities on patients’ health self-management, i.e., their confidence in managing their own health. For this purpose, we aim to measure the impact of engagement in an online health community on three experiential dimensions of living with a medical condition: cognitive, behavioral, and emotional (Graffigna et al. 2014).

This study aims to make the following theoretical contributions. First, by focusing on the three experiential dimensions of health management, we expect to provide a holistic perspective on the impact of online health communities on members’ will and ability to manage their own health. So far research in online communities has analyzed knowledge contribution as a monolithic construct (Chiu et al. 2006; Zhao et al. 2015). We believe that an adequate understanding of the implications of online communities on “social learning” (Bandura 1977b) needs to consider the contribution of different types of knowledge. The differentiation among types of knowledge contributions is particularly important in health management since the knowledge needed to cope with a disease is not confined to treatments and symptoms but encompasses health behaviors and the emotions associated with a bad health status. Second, we aim to shed light on the factors influencing engagement in online health communities. Apart from little research on knowledge contribution in online health communities (Zhao et al. 2015), so far engagement has been studied in relation to non-health online communities only (Ray et al. 2014). Given the different dynamics of patients’ aggregation in online health communities (Bernardi 2016), there is need for a proper understanding of the factors that influence engagement in online health communities.

We also expect to provide useful practical implications. There has been debate among healthcare professionals regarding the quality of information shared online (Wilson 2002), as well as unintended consequences of health self-management (Sillence et al. 2007), particularly among those with low health literacy (Chinn 2011). We will collect feedback from Diabetes.co.uk community members regarding the quality of shared knowledge and their use of this knowledge. Hence, we expect to contribute to the debate by offering evidence of positive health benefits of participating in a properly managed online health community. Such evidence would encourage other stakeholders such as policy makers to systematically assess the value of online health communities and to investigate ways of integrating websites like Diabetes.co.uk in their provision of healthcare. Health community managers may also find insights in this study on how to maximize the impact of their communities on patients’ health self-management.

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1. <http://diabetesresearch.med.umich.edu/Tools_SurveyInstruments.php> [↑](#footnote-ref-1)