Knowledge Contribution in Online Health Communities:
An Exploratory Examination

Research-in-Progress

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ABSTRACT

In recent years online health communities have emerged as an alternate source of health information for patients. By allowing patients to connect directly with each other these communities provide an easier and more readily accessible means for attaining health information. Yet the continued growth and prosperity of online health communities is contingent on their members being open and willing to share their personal information. Given the sensitive nature of health information it is important to understand the mechanisms supporting the sharing of such information in online health communities. In this paper we present a conceptual model of knowledge contribution in online health communities drawing upon three primary factors: individual personality, context, and structural features of the community. We also propose a study to test the model and discuss the development of a survey instrument.

Keywords

Online Communities, Online Health Communities, Healthcare, Knowledge Contribution, Personality.

INTRODUCTION

In recent years, online communities – internet based social networks where groups of people linked by a common goal or interest congregate to transmit, exchange or share information (Preece & Maloney-Krichmar, 2002) - have become extremely popular. In particular, the online health communities have seen tremendous growth. Web technologies and social media have fostered new ways of communication and collaboration among caregivers, physicians and patients, leading to emergence of a wide variety of online health communities. In addition to healthcare professionals, many other individuals use the internet to share information on medical conditions, symptoms, diseases, treatments and medication. A recent pew Internet Study (Fox, 2011) found that eighty percent of internet users engaged in some form of online search for health information. A study by Deloitte Consulting found that fifty five percent of surveyed individuals got information about a therapy or health condition online. In addition to seeking health information individuals use online health communities to find others with similar conditions for emotional support. One in every five internet users go online to find others with similar medical concerns (Fox, 2011).

Given the tremendous growth in user base for online health information, a large number online health communities have arisen to meet the demand. However, not all of these sites have been successful, with some even being forced to shut down. A highly publicized example is Trusera.com. Founded by a former Amazon executive, Trusera was forced to close after it could no longer obtain funding, due in part to its inability to attract and retain members (Rao, 2009). Arguably the most important factor in the success of any online community is an active member base. Without active members communities fail to generate content and without content they are unable to attract and retain users resulting in a downward spiral, the end result of which is the failure of the community. Thus it is important to understand the dynamics underlying information sharing in online health communities.

While there has been a tremendous amount of research conducted on traditional online communities, the online health community presents a unique scenario which warrants separate examination. The nature of health information makes it inherently sensitive in nature. This is demonstrated through the extensive laws, such as HIPAA, that have been enacted to protect the privacy of an individual’s medical information. Being sensitive in nature, one would expect individuals to not openly share their personal health information with others. However the growth of online health communities is indicative of exactly the opposite. Online health communities are experiencing tremendous growth driven in no small part by the willingness of the members to openly share their personal health information including treatments, medication, physical conditions, clinical information and the entire health experience on the sites. This discrepancy creates an online health information privacy paradox – where sensitive health information which is largely considered private is shared online with a
larger membership. This paradoxical behavior is partly encouraged by the online medium that offers the ability to share information under an anonymous or partly-anonymous identity. However, examination of online communities like patientslikeme.com shows that many users are willing to share sensitive health information without anonymizing or masking their real identities. The goal of this research is get a deeper understanding of knowledge contribution in online health communities in an attempt to explain the contradiction between an individual's privacy concern and their willingness to provide their medical information in an open forum. To do so we present a conceptual model to explore how different factors act as potential drivers of knowledge contribution in online health communities.

The remainder of this paper contains a brief overview of online health communities and a literature review of prior research. This is followed by the development of a conceptual model and hypotheses related to knowledge contribution in online health communities. Finally a proposed study is discussed along with directions for future research.

Online Health Communities

In the most general terms, an online health community is a virtual venue on the web where individuals can come together to share information about various health issues. Online health communities offer a space for members to access, share and contribute knowledge on varied health issues ranging from health conditions, treatments, and information on physicians, hospitals and health centers. Online health communities also offer a platform for members to identify others with similar conditions or problems. Further, online health communities offer a forum for interaction and communication that could pave way for mental and emotional support. (Swan, 2009) Many online communities many also serve as a repository of archival knowledge exchanged by members. Therefore, these communities provide members with opportunity to gain access to information, expertise or ideas that may not be readily available locally. (Oh, 2012)

RESEARCH REVIEW

An online health community is a virtual venue on the web where individuals can come together to share information about varied health conditions, treatments and outcomes. Despite the sensitive nature of health information, the membership and knowledge sharing in many online health communities has been flourishing and growing. Building upon social-psychological perspectives, past research has identified several motivators for knowledge sharing in online communities. These motives include expectations of extrinsic benefits such as economic rewards or performance expectancy, or intrinsic benefits such as self-worth, social norms, social capital and reputation. An early study by Constant et al (1996) on use of email to offer assistance to other fellow members found that citizenship behavior and desire to benefit to be major motivators for knowledge contributions. Studying an online community of legal professionals, Wasko and Faraj (2005) suggest community interest, reputation, altruistic tendency, and reciprocity to be key motivators for knowledge sharing. In another study of electronic repositories, Kankanhalli et al. (2005) identify both extrinsic benefits such as organizational reward and reciprocity, as well as intrinsic benefits such as self-efficacy and enjoyment in helping others to motivate knowledge sharing behavior. In addition to these motivators, self-expression, online reputation, affiliation, sense of belonging, and social capital have been suggested to be key motivators for online knowledge contribution (Chiu et al., 2006; Ma & Agarwal, 2007).

Knowledge sharing behavior in online health communities is quite distinct from those in other communities for at least three important reasons. First, it involves providing very personal and sensitive information. Unlike other general communities where information need not be tied to individual or specific experiences, health communities typically have members who share very sensitive and detailed health information. Second, privacy assumes additional importance in online health communities as the information shared can potentially create several challenges for the members sharing such information. Third, revelation of sensitive health information could potentially create problems such as social stigma, estrangement or alienation. Hence, members can be expected to conceal their identities and/or adopt other ways to avoid these problems, yet participate due to the larger benefits.

DEVELOPMENT OF A CONCEPTUAL MODEL

Knowledge contribution in online communities has been studied extensively however literature surrounding knowledge contribution within the healthcare context is sparse. This is not surprising given that the rise in popularity of online health communities has been fairly recent. In this paper existing literature on knowledge contribution in traditional
online communities is utilized and expanded to create a model for knowledge contribution in the healthcare context. The model contains three categories of drivers that are predicted to influence knowledge contribution: individual, contextual, and structural. The outcomes of knowledge contribution are also considered.

Figure 1. Conceptual Model

**Individual**

In any online community the primary source of content is the member base of the community. Individual characteristics of particular members can play a large role in shaping their decision on whether or not to participate in the community. Specifically, an individual's personality is theorized to have an influence on their willingness to participate in an online health community. Previous research has demonstrated that personality can play a large role in online communications and can be objectively measured using the Five Factor model. (Chen & Caropreso, 2004) The Five Factor model has been widely used as a measure of personality and breaks an individual's personality into five components: extraversion, neuroticism, agreeableness, conscientiousness, and openness. Each of the five factors is characterized below:

- **Extraversion** – sociable, cheerful, optimistic
- **Neuroticism** – fearful, sad, emotionally unstable
- **Agreeableness** – sympathetic, cooperative, forgiving
- **Conscientiousness** – deliberate, reliable, strong-willed
- **Openness** – curious, imaginative, adventurous

Previous research has shown mixed results on which dimensions of personality have an impact on knowledge contribution. In different studies each of the factors has been shown to have a positive influence on knowledge sharing, however the particular factors shown to have influence vary from study to study. (Cabrera et al, 2006; Flynn et al, 2006; Korzaan and Boswell, 2008; Hsieh and Kao, 2010; Picazo-Vela et al, 2011; Teh et al, 2011) Additionally, agreeableness and conscientiousness have been shown to have no effect and neuroticism has been shown to have a negative effect. (Cabrera et al, 2006; Picazo-Vela et al, 2010) Given the lack of consensus the following hypothesis is presented:

**Personality factors will have an influence on knowledge sharing in online health communities.**

In addition to personality another individual specific factor which has the potential to influence knowledge contribution is an individual's health information privacy concerns. Health information privacy refers to an individual’s sensitivity to potential violations of their personal health information. General Internet information privacy concerns can be broken into three components: collection, unauthorized use, and improper access. (Malhorta et. al, 2004) Additionally, in the healthcare context it has been shown that the identity of the recipient, level of anonymity, and type of information being shared have an impact on privacy concerns. (Whiddeet et. al, 2006) It has also been shown that general levels of privacy concern are higher with healthcare information than other types of information. (Rohm & Milne, 2004) Based on this the following hypothesis is proposed:
Higher levels of health information privacy concern will lead to lower levels of knowledge sharing in online health communities.

**Contextual**

Contextual factors are defined as those related to the particular circumstances under which information is being shared. In the case of health information a significant contextual factor is the condition about which information is being shared. (Whiddett et al, 2006; Flynn et al, 2006) Specifically, the stigma associated with that condition. Stigma is the result of discrimination against an individual or group based on social judgments about them. (Weiss and Ramakrishna, 2001) Perceived stigma refers to the fear of being discriminated against. Stigma can vary greatly across different types of medical conditions, and the levels of perceived stigma an individual associates with their particular medical condition can have a profound impact on their willingness to openly provide information about their condition.

Higher levels of perceived stigma for the condition about which information is being shared will lead to lower levels of knowledge sharing in online health communities

**Structural**

Structural factors are those related to the design of the community. Ma & Agarwal demonstrated that the use of certain features within online communities had an impact on an individual’s decision to share information within that community. (Ma & Agarwal, 2007) In their model knowledge sharing is influenced by perceived identity verification, the extent to which one member of the community feels that their identity is expressed to other members of the community, which they do through the use of different structural components of the community. They identify four different features of online communities which enable users to communicate their identity to others: virtual co-presence, persistent labeling, self-presentation, and deep profiling. These features manifest as artifacts whose presence and use within a community can be actively measured. Virtual co-presence refers to artifacts which create the sense of being with others within the environment. These artifacts are those which allow for synchronous communication, such as chat rooms and instant messengers, as well as any other tools which allow for real time feedback. Persistent labeling is the use of a single method of identifying a user within the community. This manifests as user IDs which remain constant. Self-presentation refers to the ability for an individual to present themselves to other members of the community. Examples of self-presentation artifacts include signatures, avatars, profiles, and nicknames. Additionally, any method of personalization which allows a user to make themselves distinct from other members falls under self-presentation. Deep profiling is the ability for community members to provide and seek out information about other users. This can come in the form of reputation or ranking mechanisms as well as member directories and archived searching.

The use of structural features will be positively correlated with knowledge sharing in online health communities.

**PROPOSED STUDY**

Prior to any data collection an appropriate target community must first be selected. A large number of online health communities exist from which to choose however not all of them would be ideal for data collection. For the purposes of this study only patient to patient communities will be considered as they are the most predominant type of online health community. This also serves to reduce the amount of variability in the motivations for participation in the community. Additionally a subset of specific conditions within the focal community will be selected for analysis. This will allow for control expected levels of stigma as conditions can be selected to represent high and low levels. Finally, communities of insufficient size will be removed from consideration to ensure adequate response rates. Based on the outlined criteria the most likely candidate for analysis is the community www.medhelp.org.

To collect the data a self-reported questionnaire will be utilized. Participants will be randomly sampled from the selected condition groups and asked to participate via email. The survey instrument has been adapted wherever possible from existing scales which have been previously tested for their validity. The instrument can be found in Appendix A.

**DISCUSSION**

Online health communities represent an important tool for the medical field in the Internet age. Not only do they represent an easily accessible source for individuals seeking to gain both information and emotional support for their medical conditions but some research has even demonstrated that the benefits of online health communities can manifest as actual physical outcomes. (Hwang et al, 2011) However, their success appears to be in direct contradiction to traditional ideas regarding the privacy of medical information. Given the importance of these communities it is crucial to understand the
mechanics that make them successful in order for them to realize their full potential. This research seeks to address one component of the success of online health communities by providing a better understanding of knowledge contribution within them.

This research helps to address a gap in the existing literature surrounding online health communities. Previous work has yet to provide a model of knowledge contribution in online health communities which takes into account multiple dimensions of knowledge contribution drivers. This more comprehensive model will help shed light on how these different determinants work together as well as which ones might be the most significant. From a practitioner perspective this research represents an opportunity to improve existing online health communities by providing and understanding of which factors are most important to encouraging knowledge contribution. With this information online health communities can be better designed and managed to optimize member participation and contribution, which is critical to the success of any online community.

Clearly there are many different factors which can influence knowledge contribution in online health communities, and while this model is more comprehensive than others previously proposed it is by no means all encompassing. One particular element which has not been included is how the roles different actors within online health communities influence knowledge contribution. This research intentionally excludes communities where non-patient actors, such as doctors and medical students, are incorporated. Not only could motivations for knowledge contribution vary greatly between patients and doctors but also the mere presence of another group could influence decisions to contribute knowledge to a community. Future research can examine how these additional actors and motivations affect knowledge contribution in online health communities.

Additionally, while survey methodology is useful in obtaining intentions and perceptions from users regarding their knowledge sharing behavior, it cannot guarantee that those intentions match actual behavior within the community. However, the design of most online communities allow for the collection of actual user behavior over time. As such, the next phase of this research is to incorporate data mining techniques to ascertain if stated intentions for knowledge sharing match actual user behavior.

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