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Antecedents of privacy calculus components in virtual health communities



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ABSTRACT

Over the past decade, social media technologies have become effective tools not only for entertainment, but also for online health communications. In virtual health communities (VHCs), the members often share their personal health information (PHI) with other members. These information exchanges provide benefits to both the information providers as well as the recipients. The PHI disclosure, however, may entail privacy concerns. Our study used the privacy calculus model to examine the trade-off between individuals' expected benefits and privacy concerns when disclosing PHI in social media environments. Our results showed that age, health status, and affective commitment influence the balance between the information disclosure drivers and barriers in the privacy calculus model. More specifically, we found that among members of VHCs, healthier people expect to receive fewer personal benefits of communicating PHI in social media environments. Moreover, individuals who are emotionally attached to online communities expect to both receive and provide more benefits while communicating PHI in those communities. We also observed that individuals who are familiar with but not members of VHCs, especially those who are young and healthy, are more concerned about their PHI privacy in online communities.

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1. Introduction

With the rapid growth of social media technologies over the past decade, social networking websites that revolve around health and wellness topics are being increasingly adopted by individuals for health communications. For example, MedHelp.org with 17 million unique users per month, and DailyStrength.org with more than 500 support groups such as those related to cancer, diabetes, and depression, are among the major health-related websites in the United States. These health-specific online communities, called virtual health communities (VHCs), (Welbourne, Blanchard, & Wadsworth, 2013) or health online social networks (Sadovykh, Sundaram, & Piramuthu, 2015), provide users with various communication platforms such as physician-rating, medicine-rating, ask-an-expert, and discussion boards (Kordzadeh & Warren, 2013). Discussion boards, for instance, enable individuals to initiate discussion threads by posting questions concerning health and wellness topics. Users of these websites post replies to the threads

and share their relevant knowledge and experience with the thread initiators, as well as other users who join the threads. Thus, health consumers such as patients and their families, friends, and caregivers exchange information and emotional support with each other in a convenient yet inexpensive way (Chou, Lin, & Huang, 2016).

The results of recent national surveys have confirmed the growing adoption of social media platforms for health communications. A survey conducted by the Pew Research Center (Fox & Duggan, 2013) revealed that 26% of adult internet users in that study had gone online to look at someone else's health-related experience in the past year. Additionally, 16% of the respondents indicated that they looked online for other individuals with similar medical conditions to theirs. The results also demonstrated that 40% of the respondents had shared their health-related experiences in online environments (Fox & Duggan, 2013). Accordingly, the user-generated health-related knowledge shared in VHCs helps the community members learn from others' experiences to make informed health decisions such as what doctor to choose, what medication to take, and how to cope with medical conditions (e.g., cancer and alcoholism) effectively (Sadovykh et al., 2015).

A major aspect of health communications via social media platforms is communicating personal health information (PHI) such

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as information related to one's medical procedures, diagnosis, symptoms, medications, test results, and one's feelings about their medical conditions. People engage in this form of PHI disclosure because of the benefits that this behavior may provide to them (Welbourne et al., 2013). Expecting to receive better support from the community, feeling emotionally relieved, and providing more useful information to the community are among the perceived benefits of PHI disclosure in online environments (Rodgers & Chen 2005; Welbourne et al., 2013). However, sharing PHI in publicly available social media environments may entail privacy risks and concerns for information providers. For example, disclosing information about one's medical conditions may lead to social stigma, job loss, or even criminal prosecutions in the cases such as drug abuse (Anderson & Agarwal, 2011; Beckerman & Foundation, 2008).

The trade-off between the expected outcomes and privacy concerns associated with communicating PHI in social media platforms are elucidated by the privacy calculus model (Culnan & Armstrong, 1999; Diney & Hart, 2006). The two opposing factors in this theoretical model determines whether or not an individual engages in PHI disclosure behaviors. The privacy calculus balance between the drivers and barriers to PHI disclosure by individuals may vary. Those who are less concerned about their PHI privacy and expect to receive more benefits of PHI sharing may participate actively and share PHI more prevalently in online discussions. Whereas, those who exhibit a greater level of privacy concern may participate at a minimum level. The former group will help the community to prosper and succeed; while, the latter group may not contribute to the growth of the community. Thus, in order for community developers and providers to be able to boost user participation and enhance community growth, they need to understand the factors that impact the two opposing sides of the privacy calculus model in the context of health social media. In this research, we address this issue and investigate the potential determinants of the privacy calculus components. In particular, we examine the role of age, health status, and affective commitment.

The remainder of this article is structured as follows. The second section discusses the theoretical background of this research. The third section presents the research model and hypotheses. The fourth section describes the method. The fifth section discusses the results of our data analysis. Finally, the last two sections summarize the results and their implications, and also provide suggestions for future research.

2. Theoretical background: privacy calculus model

Westin (1967) defines privacy as "the claim of individuals...to determine for themselves when, how, and to what extent information about them is communicated to others. (p. 7)" The potential risks associated with personal information disclosure in different contexts makes people concerned about their privacy. However, people may still engage in personal information disclosure to gain some benefits, although they are aware of the potential risks of that. As mentioned earlier, these contrary beliefs and behaviors constitute the privacy calculus model. This theoretical notion was first introduced and discussed by Culnan and her colleagues (Culnan & Armstrong, 1999; Culnan & Bies, 2003). They argued that when faced with a privacy loss situation, individuals perform a psychological privacy calculus to decide on letting or not letting their personal information be disclosed. This perspective was later adopted in the contexts of e-commerce (Dinev & Hart, 2006), location-based services (Xu, Teo, Tan, & Agarwal, 2009), health care (Anderson & Agarwal, 2011), and online social networks (Krasnova and Veltri, 2010), to help to understand individuals' privacy-related perceptions and behaviors in those information-intensive domains, Fig. 1 depicts a generic privacy calculus model, which we have devel-

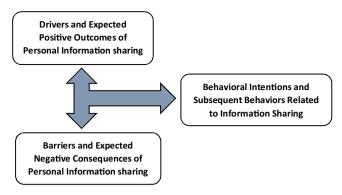


Fig. 1. Generic Privacy Calculus Model.

oped based on the extant literature (e.g., Culnan & Armstrong, 1999; Culnan & Bies, 2003; Dinev & Hart, 2006).

The privacy calculus model may also be adopted in the context of health social media. Health information is often sensitive information, whose revelation may expose people to privacy risks, and entail negative consequences for them (Moorhead et al., 2013; Rohm & Milne, 2004). For example, discussing one's prior experiences of being sexually abused in VHCs may make one socially stigmatized and embarrassed, especially if they believe that there is a chance that their identity may be disclosed to the public (Angst & Agarwal, 2009). In a survey conducted by Antheunis, Tates, and Nieboer (2013), privacy concern was found to be the patients' first barrier to health-related social media use.

If one intends to seek and provide social support in virtual environments, they may need to share health-related personal information in order to make their health communications more meaningful to others, and to gain richer benefits, such as improved health-related behaviors (Wickramasinghe, Teoh, Durst, & Viol, 2013) and psychological well-being (Batenburg & Das, 2014; Tanis, Das, & Fortgens-Sillmann, 2011). Sharing health-related information and knowledge in social media environments while publicly communicating with others will benefit the community as well. Oh (2012), found that altruism is a major driver for individuals' replies on others' posts in health-related social media environments. Chung (2011) found that people join VHCs and contribute within them mainly to help others, although this helping behavior will also provide personal benefits for the information provider, such as feelings of importance and self-satisfaction. Thus, privacy concerns and expected outcomes of sharing PHI in online environments for the purpose of gaining and providing help and benefits can shape the privacy calculus model in health social media.

What remains to be answered is: what are the factors that impact the privacy calculus trade-off in health social media? More specifically, what factors can decrease or increase one's privacy concerns and/or expected outcomes of health communications via public health-related discussions? Addressing this question will advance our understanding of why some people ultimately share a large extent of PHI in virtual environments, whereas, others prefer to protect their PHI by not sharing them with others, even though they may be aware of the benefits of sharing that information.

In this study, we examine three potential antecedents of the privacy calculus trade-off including age, health status, and affective commitment. The reason for choosing these three are because they are important factors in shaping individuals' beliefs and communication behaviors in privacy-intensive environments.

Disease-specific online communities may be used by people at different ranges of age or health status. For example, Parkinson's disease and Alzheimer's disease are common chronic conditions of the elderly. Whereas, obesity and sports injuries are more prevalent with younger people. Thus, understanding the differences

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