Communicating Personal Health Information in Virtual Health Communities: A Theoretical Framework

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Abstract

The use of social media technologies and platforms for health communications has grown dramatically over the past decade. Health consumers such as patients and caregivers join virtual health communities and exchange social support with other users on these websites. Communicating personal health information (PHI) in public discussions is a part of these support exchange activities. Despite the benefits that sharing PHI in this context can offer for both information owner and community, it may entail privacy risks and concerns for individuals, which may ultimately hamper user participation. Thus, drawing on the notion of privacy calculus, we propose a theoretical framework to address the simultaneous impacts of privacy concerns and expected outcomes of information sharing on communicating PHI in public discussions within virtual health communities. Moreover, we propose that emotional attachment to an online community, namely affective commitment, can have direct and moderating effects on PHI sharing within these virtual environments.

1. Introduction

The use of social media technologies and platforms for health communications has grown dramatically over the past decade. A major reason for this growth is that people are more and more relying on the Internet to find answers for their medical questions and engage in health-related discussions. The results of a survey conducted by Pew International Center revealed that 80% of the participants use the Internet to seek health information online [24].

In line with this trend, hundreds of socially-integrated health-specific websites that offer collaboration platforms for health consumers (e.g., patients and caregivers) have been developed. People visit these virtual health communities (VHCs) to seek and provide social support in collaboration with other individuals and make one-to-one social ties with them [19, 27]. DailyStrength.org, PatientsLikeMe.com, and MedHelp.org are among the most frequently visited VHCs in the United States [28]. For instance, MedHelp.org states that this website "empowers more than 12 million people each month to take control of their health and find answers to their medical questions" [36].

VHCs present various collaboration mechanisms and platforms for their users to communicate. These platforms include health blogs, discussion boards, and physician-rating mechanisms [28, 42]. People can join VHCs, create profile pages, and post their personal images and information such as name, age, gender, and health conditions on these pages. Discussion boards are among the most widely used collaboration platforms on VHCs [15]. These platforms, also known as forums, enable users to initiate discussion topics, seek support from the whole community with respect to specific health issues, questions, conditions, and post comments to others' topics [23, 46]. Discussion boards are typically organized based on health conditions or support groups (e.g., cancer, depression, migraines, and eating disorders). DailyStrength.org, for example, provides more than 500 support groups within which users can participate by initiating discussion threads and/or responding to the threads initiated by other community members.

Sharing personal health information (PHI) is a part of participation activities in public discussions within VHCs. PHI includes information about one's diseases, health conditions, symptoms, treatments, medications, test results, and health-related experiences and emotions. Disclosing PHI in this context can potentially offer benefits both to the contributor and to the community. For example, if community members know about an individual's specific health conditions and symptoms, they can offer better informational aid to that individual. Moreover, by contributing PHI in the form of health-related knowledge and experience, the value and usefulness of the social support that individuals provide to the community is enhanced.

Despite the benefits of communicating PHI in these virtual environments, this form of information sharing can produce privacy risks and concerns for users [19, 28]. These privacy concerns "span the gamut from financial anxiety (e.g., I don't want to be put into a

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high risk, high premium insurance plan), to embarrassment (e.g., I'm ashamed to tell [others] about my past risky behaviors), to job security (e.g., my employer might fire me if they know I have had a history of mental illness), to control (e.g., I don't want pharmaceutical companies marketing new drugs to me)" [4] (p.348). Consequently, these privacy concerns can hamper user participation and knowledge/information sharing in VHCs. This is important because a low level of user participation can threaten the overall vibrancy, growth, and success of any VHC [27].

Given the perceived benefits and privacy costs of communicating PHI in VHCs, users of VHCs who intend to engage in support exchange activities in these virtual environments are faced with decisions between sharing and not sharing PHI in communications with others. On the one hand, community members are willing to disclose their health information to the community to receive supportive comments and messages and also to help others in the community to whom this information can be useful. One the other hand, sharing PHI and publicizing it on these websites can result in unforeseen negative results for the information owner. In order to provide insights into this paradoxical behavior, we propose a theoretical framework. In this framework we address the simultaneous impacts of perceived benefits and privacy costs on one's intentions to share PHI while communicating within VHCs.

Furthermore, the results of recent studies show that affective commitment to online communities can influence individuals' participations in these environments. Accordingly, those who feel more attached to an online community participate more actively in that community [5, 7]. In the context of VHCs, affective commitment can also impact users' intentions for communicating PHI to other individuals. Because affect and emotions play a major role in peer-to-peer relationships and support exchange activities within these virtual environments. In the proposed framework, we also address the effects of affective commitment on sharing PHI in VHCs.

Thus, the two research questions that we seek to address in this study are as follows.

RQ1: How do expected outcomes and privacy concerns associated with PHI disclosure influence communicating PHI in VHCs?

RQ2: How does affective commitment influence communicating PHI in VHCs?

The theoretical framework proposed in this article can offer contributions to the literature on information privacy, health informatics, and information disclosure in social media. Moreover, the proposed framework can be used as a basis for empirical research to better understand privacy-intensive health communications through VHCs. This understanding will provide benefits for the providers of these online communities, the healthcare providers and organizations that embark on social media strategies, and the governmental agencies that enforce health information privacy acts and regulations.

2. Theoretical background

In order to address the research questions and develop our conceptual model, we draw on two theoretical notions including privacy calculus model and affective commitment. Thus, in this section, we will discuss the theoretical foundations of this study and briefly review the relevant literature.

2.1. Privacy Calculus Model

The privacy calculus model was first coined by Culnan and Armstrong [16] and further elaborated by Culnan and Bies [17] to examine the impacts of the contrary beliefs including expected benefits and privacy risks (or concerns) associated with revealing personal information on information disclosure intentions and behaviors within different contexts. This theoretical notion suggests that individuals disclose their personal information and continue to do that if they perceive this disclosure provides benefits (we use the term outcomes) for them, that exceed the current and future risks of the disclosure brought to them [17].

Privacy calculus is built on the notion of calculus of behaviors. According to the calculus of behaviors, institutional norms, anticipated benefits, and unpredictable consequences lead to an individual's decision on disclosing personal information [33]. Privacy calculus is also consistent with a widely used economic technique called cost/benefit analysis [17]. Cost/benefit analysis is used for evaluating the costs and benefits of a course of action in monetary terms to decide on whether to follow that course of action or not. This technique has also been extended to non-monetary contexts and adopted in other disciplines [44]. Expectancy theory is another theory that is consistent with the notion of privacy calculus [21]. This theory postulates that people engage in a behavior if the expected positive outcomes of the behavior overweigh the expected negative outcomes [39, 47].

Researchers in different disciplines have adopted the privacy calculus model to study information disclosure in the contexts ranging from location-based services [49] to e-commerce transactions [20, 21], and general-purpose online social networks (OSNs) such as Facebook [29, 30, 31]. In the context of e-commerce, for instance, Dinev and Hart [21] adopted the privacy

calculus model to examine the antecedents to behavioral intentions of personal information disclosure in online transactions such as those related to online purchasing (goods, services, or information) and online registration on a website. Their findings demonstrated the impact of contrary beliefs (privacy concern and privacy risks as the inhibitors and personal Internet interest as the driver) on customers' willingness to disclose personal information such as identifiers, home addresses, and credit card information over the Internet.

In the context of OSNs, Krasnova et al. [29] discussed privacy concern as the cost, and perceived enjoyment as the benefits of information disclosure, which influenced the amount of self-disclosure on Facebook. In another study, Debatin, Lovejoy, Horn, & Hughes [18] found that the perceived benefits of using Facebook exceeded the privacy concerns of information disclosure. Additionally, Krasnova, Spiekermann, Koroleva, and Hildebrand [30] highlighted the role of perceived benefits of self-disclosure as the driver and perceived privacy risk as the impediment to self-disclosure in OSNs.

VHCs are a specific form of OSNs. Therefore, privacy concerns and expected outcomes of communicating personal information can affect this sharing behavior. People, however, join VHCs to exchange social support in the forms of emotional and information aids with other members of community [15, 27]. These online communities help patients make social ties with individuals who are suffering from, or have undergone similar medical conditions [15]. This helps patients learn from others' experiences [27], feel less isolated [40], and cope with their medical conditions more effectively [26]. In a recent study, Chung [15] conducted an online survey to investigate individuals' motivations to join and participate in VHCs. The results of this study demonstrated that the major motivations for using discussion boards within these virtual environments included seeking information, helping others, meeting others, and maintaining offline relationships.

On the other hand, privacy concerns associated with using VHCs and communicating PHI within them may negatively influence user participation in these online environments. Individuals are concerned that the PHI they disclose on VHCs may be collected, used, and disseminated in an unauthorized and unanticipated manner [48]. Therefore, they may not be willing to let others know about their health conditions or disease information such as those relevant to mental illnesses, substance abuse, or genetic traits [2, 4, 6]. Disclosing this information may potentially lead to social stigma, discrimination, criminal prosecution, and even job loss [3, 9].

Prior research has emphasized the role of privacy concerns in this context as a barrier to participation and information disclosure. Bansal and Zahedi [6] conducted an experimental study to understand the precedents of intention to disclose health information to health-related websites. The findings of this study showed that the Internet level health information privacy concerns negatively affected intention to disclose personal information online. Similarly, Ambrose and Basu [2] proposed that perceived privacy concerns influence the use of online healthcare information systems such as VHCs. They also theorized that attributes such as age, experience, and gender can moderate the relation between perceived privacy concerns and use of these online healthcare information systems.

In another study, LaCoursiere, Knobf, and McCorkle [32] examined the attitudes of cancer patients who use the Internet to seek social support toward using and participating in VHCs. The results of this research revealed that cancer patients showed a level of skepticism in sharing PHI within VHCs. Nevertheless, these patients were willing to disclose PHI in these online environments in exchange for individualized information that the website can provide for them. The findings of this study were in line with the core concept of privacy calculus suggesting that perceived outcomes and privacy concerns associated with sharing PHI in VHCs should be investigated in order to better understand individuals' participation and sharing behaviors in this context.

Collectively, prior research demonstrated the rigor and relevance of the privacy calculus model in investigating and understanding the simultaneous impacts of drivers and barriers to information disclosure within information-intensive contexts. Moreover, the extant literature highlighted the need for further investigation of individuals' perceptions, attitudes, beliefs, and behaviors concerning PHI disclosure as well as the trade-off between privacy concerns and perceived benefits of this disclosure in the context of VHCs. Thus, we draw on the theoretical notion of privacy calculus to develop our conceptual model that addresses communicating PHI in public discussions within VHCs.

2.2. Affective commitment

Affective commitment is another factor that can potentially influence participation and information disclosure in any form of online community. Affective commitment pertains to emotional attachment to a group, community, or organization [22, 37]. It is a theoretical concept that has become a focus of research primarily in the fields of organizational behavior,

social psychology, as well as community and group sociology over the past few decades.

Despite its relatively clear definition, affective commitment is termed and conceptualized differently in different theories, models, and disciplines. Organizational studies tend to use affective commitment as a component of organizational commitment [37]. Research rooted in social psychology or group sociology views affective commitment as a component of social identity [10, 22], a component of sense of community and termed as sense of belonging [11, 35], a component of social capital and termed as identification [14] or a distinct construct, termed as attachment [41].

The proliferation of online communities have also motivated IS researchers to adopt the organizational and affective commitment concepts and use them in the context of online communities. This motivation lies partly in the inherent similarities between online communities and traditional organizations in terms of social structure and social behaviors displayed by the members. Bateman et al. [7] define affective community commitment as "a bond between a member and a particular community that is based on the member's strong emotional attachment to that community" (p. 843). They found that this construct has a significant relation with posting comments and moderating online discussions within online communities. Other researchers have also confirmed that affective commitment, regardless of the way it is termed and conceptualized, has a positive relation with usage of online communities [11, 45] as well as participation and knowledge contribution within these virtual environments [13, 50, 52].

In summary, prior research has emphasized the impact of affective commitment on user participation in different types of online communities [7, 15]. We believe that this construct can also play a major role in user participation in the form of PHI sharing within VHCs. Therefore, we extend our theoretical model by incorporating affective commitment into the generic privacy calculus model. In the next section, the proposed theoretical model will be elaborated more in detail.

3. Theoretical framework

In general, people join VHCs to seek and provide informational and emotional social support in communication with other individuals. To do so, people may engage in PHI sharing activities while communicating with others through discussion boards. A potential driver for communicating PHI in these environments is the immediate outcomes that this form of PHI revelation can provide for the contributors. For instance, people may perceive that if they talk about their PHI on discussion boards, they will more likely find others with similar health conditions or experiences. Consequently, they can make social ties and exchange knowledge on the medical issues of interest or concern to them.

Moreover, people may believe that communicating PHI on discussion boards may provide a sense of relief for them. This can be more important for patients suffering from mental conditions such as depression and anxiety [26]. A sense of importance and helpfulness can be another perceived outcome of communicating PHI for the purpose of supporting others in the community. In line with privacy calculus model, we expect that the more people believe that communicating PHI can provide outcomes for them, the more likely they will engage in personal information sharing behaviors. Thus, we hypothesize:

Hypothesis 1. *Expected personal outcomes will increase willingness to communicate PHI in public VHC discussions.*

Prior studies demonstrated that providing support and being helpful to community members is a prominent motivation for joining and contributing to online communities [14]. This can also apply to VHCs. Individuals participate in discussion topics and talk about their PHI such as experiences of undergoing medical tests and treatments in order to help other community members with similar health conditions or concerns [23, 26]. Moreover, the information shared in discussion boards usually persists as long as the community website exists. Therefore, this information can also be accessible and useful for individuals who are not the members of the community at the time the information is posted, but join the community in the future. Thus, we argue that if people believe that the PHI they communicate to the community provides helpful outcomes for the community, they will more likely engage in these sharing behaviors. Therefore, we hypothesize:

Hypothesis 2. *Expected community-related outcomes will increase willingness to communicate PHI in public VHC discussions.*

Privacy concerns are shown to be major barriers to personal information disclosure in online communities [8, 29]. It is also demonstrated that people are less willing to share PHI through traditional healthcare information systems [3] and online healthcare websites [6], if they believe that this disclosure can threaten their privacy. Privacy concerns associated with communicating PHI in public discussion boards can also make people less inclined to contribute PHI in these online discussions. The information shared in discussion boards is publicly visible. In other words, individuals do not control the level of public

accessibility to the information revealed through these collaboration platforms. Thus, communicating PHI in public discussions can potentially produce high levels of privacy concerns for individuals. We believe that these concerns may decrease individuals' willingness to share PHI within these virtual environments while communicating with others. Thus, we hypothesize:

Hypothesis 3. *PHI privacy concern will decrease willingness to communicate PHI in public VHC discussions.*

In the context of virtual communities, affective commitment reflects the emotional bonds between individuals and these communities. The extant literature demonstrates that from the perspectives of organizational commitment [7], social identity [5], sense of community [45, 50, 13, 51], and social capital theory [52] affective commitment has a significant relation with participation in virtual communities. Moreover, prior studies highlighted the emotional aspect of social support [12, 38] and support exchange activities within VHCs [23, 27]. This can make the role of affective commitment in these online environments more salient. Therefore, we expect that affective commitment drives participation in terms of communicating PHI within VHCs. We believe that individuals who feel a stronger sense of belonging to VHCs will be more willing to disclose PHI in order to contribute to public discussions. Therefore, we hypothesize:

Hypothesis 4. *Affective commitment will increase willingness to communicate PHI in public VHC discussions.*

Affective commitment lies in the emotional attachment of individuals to communities. This emotionally-oriented attachment can make people rely more on feelings when participating within VHCs. We believe that these feelings can make people more willing to sacrifice their privacy concern in favor of communicating PHI to the public discussions within VHCs. In other words, we expect that the negative relation between privacy concern and willingness to communicate PHI in this context is mitigated when people have a high level of affective commitment to a VHC. Thus, privacy concern plays a more significant impact on willingness to communicate PHI for people with lower levels of affective commitment to a VHC. We hypothesize:

Hypothesis 5. *High affective commitment reduces the impact of PHI privacy concern on willingness to communicate PHI in public VHC discussions.*

Affective commitment has its roots in sense of community [51]. Thus, it can intensify the role of community-related factors in individuals' intentions and behaviors in online communities. Accordingly, in the context of VHCs, we argue that the impact of perceived community-related outcomes on willingness to communicate PHI to VHCs is more significant for the community members with higher levels of affective commitment. Conversely, the PHI sharing intentions of individuals with lower levels of affective commitment are expected to be less influenced by their perceptions of community-related benefits of communicating PHI to the community. Hence, we hypothesize:

Hypothesis 6. *High affective commitment increases the impact of community-related outcomes on willingness to communicate PHI in public VHC discussions.*

Moreover, age and gender are constantly suggested by the existing literature as the two influential factors on information disclosure and privacy perceptions and behaviors [1, 3]. For instance, Acquisti and Gross [1] found that compared with males, females showed higher levels of privacy concerns. Thus, we incorporate these demographic factors as control variables in our model.

The definitions of the theoretical constructs in our model are provided in Table 1. Furthermore, the conceptual framework that depicts Hypotheses 1 through 6 is illustrated in Figure 1.

Table 1.Theoretical constructs

Construct	Reference	Construct Definition
Willingness to Communicate PHI	[6]	The extent to which one is willing to disclose PHI in public discussions within VHCs.
PHI Privacy Concern	[3]	The extent to which one feels concerned about sharing his/her PHI in the public discussions within VHCs.
Expected Personal Outcomes of Communicating PHI	[14]	One's judgment of likely beneficial consequences that his/her PHI communication in public discussions will produce to him/her.
Expected Community-Related Outcomes of Communicating PHI	[14]	One's judgment of likely beneficial consequences that his/her PHI communication in public discussions will produce to that online community.
Affective Commitment	[7]	Identification with, involvement in, and emotional attachment to a VHC.

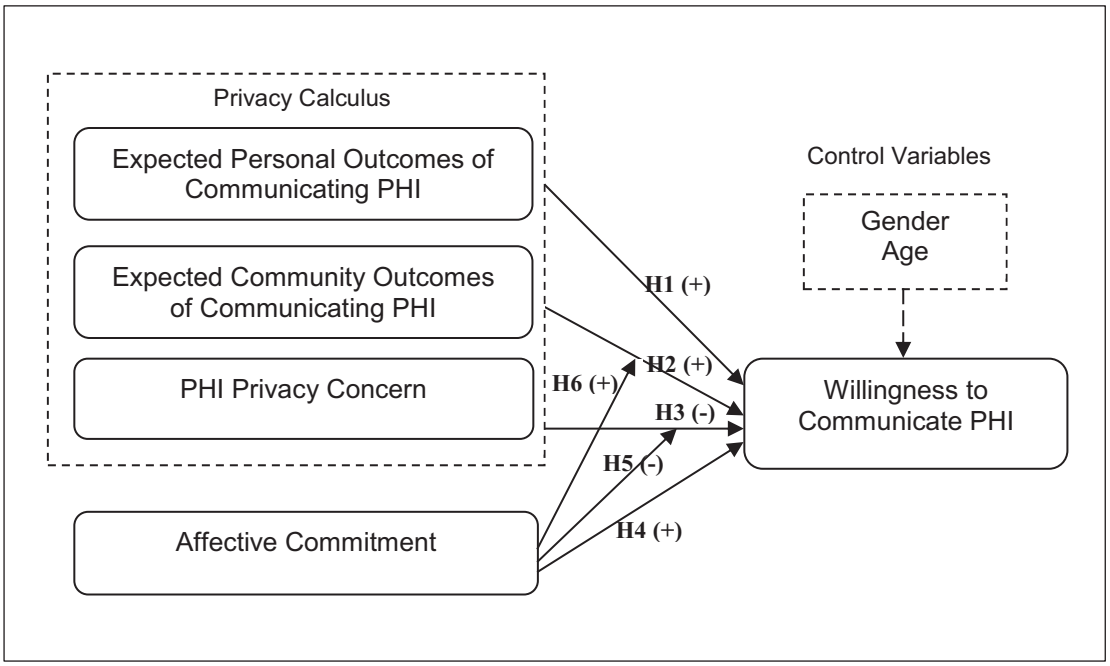

Figure 1. Research framework and hypotheses

4. Discussion

The diffusion of virtual communities and social media platforms and technologies in healthcare has revolutionized peer-to-peer health communications. Stakeholders in the healthcare industry that include health consumers (e.g., patients and caregivers) use social media such as VHCs and discussion boards for health information exchanges. These communities facilitate the making of social ties and the establishing of partnerships with other health consumers on these websites. The partnerships created enable individuals to exchange health-related knowledge and experience as well as emotional support. The social support exchange activities aid people with their healthcare processes and help them cope with their medical conditions more effectively. Moreover, these virtual environments provide access to a wide range of health information that would otherwise be costly to people if they sought this information from traditional channels such as health professionals. This is particularly important in the areas throughout the world where quality health information is not conveniently accessible to individuals. Thus, providing reliable and viable health social media such as VHCs and promoting the adoption of these platforms by health consumers can be important at different levels, from an individual level to society at large.

In order to leverage these emerging computer-mediated collaboration channels effectively, developers, administrators, and providers of these online communities need to better understand user behaviors and concerns within these virtual environments. Thus, in the theoretical model developed in this study, we aimed at understanding PHI sharing intentions in this context.

We proposed that sharing PHI while communicating with other individuals within VHCs can be simultaneously affected by user's beliefs and perceptions regarding the expected outcomes and privacy costs of this sharing behavior. This is consistent with privacy calculus model as well as calculus of behaviors, cost/benefit analysis, and expectancy theory, which were all discussed earlier. Moreover, our model suggests that affective commitment can directly and indirectly influence willingness to communicate PHI in the context of this study. This is also consistent with the theories in the areas of organizational behavior, social psychology, and community sociology and the results of the existing literature in online communities.

From the theoretical perspective, the conceptual framework proposed in this study extends the privacy calculus model by incorporating affective commitment into the model and fitting the extended model into the context of peer-to-peer health communications within VHCs. Our model will offer contributions to the literature in three main research streams: 1) information privacy, 2) health informatics, and 3) participation and self-disclosure in OSNs. We summarize the theoretical implications of this study along three dimensions of context, content, and process of personal information disclosure.

Prior studies that employed the privacy calculus model to study personal information revelations confined their research contexts to such areas as e-commerce transactions, location-based services, and general-purpose OSNs. However, relatively few studies focus on privacy and PHI disclosure in the context of VHCs. In our theoretical framework, we applied an extended privacy calculus model to this context.

Another gap in the literature is that prior research on personal information disclosure in OSNs does not distinguish health-related content from other types of personal information such as phone numbers, relationship statuses, and financial information [1, 25]. In this model we fill this gap by focusing specifically on the PHI privacy and sharing intentions in online environments.

The extant literature generally addresses sharing personal information through the process of online shopping [21] or creating and updating personal profile pages in OSNs [25]. Given that the primary mission of VHCs is to facilitate computer-mediated communications among health consumers, we focused on the process of disclosing PHI while communicating through public discussions within VHCs.

Understanding the determinants of PHI disclosure within VHCs can help community providers address individual privacy concerns, improve perceived outcomes of communicating PHI in public discussions, and promote active participation within VHCs. This participation can ultimately lead to the growth, vibrancy, and success of these virtual communities. Furthermore, developers and providers of traditional healthcare information systems (e.g., electronic medical records) that have incorporated or plan to incorporate socially-enabled features and community platforms into those healthcare information systems can better understand privacy behaviors of users of these systems.

Our model can also provide benefits for governmental organizations such as the U.S. Department of Health and Human Services, which enforces privacy regulations such as The Health Insurance Portability and Accountability Act (HIPPA). Understanding privacy concerns and behaviors within virtual environments can help these organizations extend the privacy rules and regulations to help protect individuals' PHI that are shared within these environments.

In order to empirically validate the proposed research framework, we plan to collect data from actual and potential users of VHCs. We designed a survey instrument to measure the focal constructs in the framework. After collecting data, we will analyze it using various statistical techniques including Pearson's correlation analysis and regression models with interaction. This will enable us to test the direct and moderating effects of the variables in the hypotheses proposed in our model. The results of the data analysis will then be reported and discussed in a future article.

5. Limitations and future research

The theoretical framework proposed in this article has limitations. The model has been theoretically developed, but needs to be validated. Thus, as mentioned earlier, we are in the process of data collection and analysis to empirically test the model and demonstrate its applicability in the context of VHCs. Furthermore, in order to maintain the simplicity and testability of the model, other privacy-related theoretical constructs that can potentially impact individuals' information sharing intentions and behaviors are not included in the proposed model. Trust, control, and privacy risks are among these constructs, which can be considered by researchers in future studies to further extend this model.

Moreover, privacy concern in our model is conceptualized as a high-level one-dimensional factor. However, in future models, the dimensions of privacy concern such as those proposed by Smith, Milberg, and Burke [43] (collection, error, unauthorized secondary use, and improper access to personal information) or those suggested by Malhotra, Kim, and Agarwal [34] (collection, control, and awareness of privacy practices) can be included in the model. We also suggest that researchers in future studies extend the theoretical model to the context of consumer-to-professional communications within VHCs (e.g., patients to doctors), which is discussed and elaborated by Kordzadeh and Warren [28].

Another potential direction for future research is the use of different research methods to empirically validate the model proposed in this study. Researchers, for instance, can employ experimental designs to test the proposed hypotheses. They can initiate experimental discussion threads on specific topics within a particular VHC and ask subjects to contribute relevant knowledge, experience, and PHI to those threads, if they are willing to. The subjects can then complete a questionnaire that measures their perceptions and attitudes relevant to the theoretical constructs in the model. By doing this, they will be able to observe and examine individuals' actual PHI sharing behaviors, which will help them test an extended theoretical model that may focus on individuals' actual PHI sharing behaviors. This can further enrich the findings and advance our understanding on individuals' privacy-intensive behaviors in the context of VHCs.

6. Conclusion

In this study, we leveraged the privacy calculus model and the notion of affective commitment to propose a theoretical framework that examines the antecedents to willingness to communicating PHI within VHCs.

Consistent with the core concept of privacy calculus, we consider privacy concern as the barriers side and expected outcomes of communicating PHI, both for the individual and community, as the drivers side of information sharing in this context. Affective commitment is also hypothesized to have direct and moderating effects in the model. The model can be empirically examined in future research.

7. Reference

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