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WHY THEY SELF-DISCLOSE ? EXAMINING FACTORS INFLUENCING PEOPLE'S PERSONAL INFORMATION DISCLOSURE IN ONLINE HEALTHCARE COMMUNITIES

RESEARCH-IN-PROGRESS

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Abstract

Online healthcare communities (OHCs) encourage people to disclose their personal information with others to seek support and to accelerate research and help create better treatments. However, disclosing personal information might cause privacy disclosure and some risks. This paper aims to explore what factors and how those factors affect people's personal information disclosure intention in OHCs. Based on "risk-motivation" perspective, we identify perceived usefulness as extrinsic motivation and social support as intrinsic motivation, and distinguish four kinds of risks to test those motivation and risk factors' effects on people's personal information disclose intention in OHCs. As two constructs describing the characteristics of OHCs, expected disease severe extent and common identity are supposed having moderating effects' on motivation and risk factors' effects. The theoretical contribution of this paper is offering a model to explain people's personal information disclose intention in OHCs and integrate constructs to describe the characteristic of OHCs; the practical implications is providing insight on OHC managers' operation for communities' viability and people's privacy protection. Finally, limitations and future works also are presented.

Keywords: Privacy Concern, e-Health, Personal Information Disclosure, Online Healthcare Community.

1   INTRODUCTION

In the contemporary society, people has become increasingly concerned about their life quality and daily healthcare especially in developing countries such as China (Consulting 2009; Guo et al. 2012). However, things seem not as optimistic as expected: the status quo of healthcare in China is serious. On one hand, the pressure on China's healthcare resources is increasing rising during past recent years, e.g., 458.7 billion RMB was spent on healthcare in 2000, 1 453.5 billion RMB in 2008, and even 2 434.6 billion RMB in 2011, exerting much pressure on China's economic development. On the other hand, the health literacy of Chinese citizens is very low according to the first survey on China citizens' health literacy released by China's Ministry of Health in 2009. According to this survey, the rate of people having qualified health literacy in China is only 6.48%. Since the above reasons, exploring innovative public healthcare service patterns has been considered as a potential effective way to tackle the above severe situation in China (Wu & Dang 2013).

As the popularity of online healthcare communities (OHCs), using OHCs to support people's healthcare information and knowledge sharing seems an effective way to mitigate the severity of healthcare (Maloney-Krichmar & Preece 2002; Romanow et al. 2012; Sunday 2000). The concept of OHCs originates from virtual communities (VCs) (Rheingold 1993), referring to a public online platform for emotional support, social networking, and information and knowledge sharing among different participators (Porter et al. 2013). The most significant characteristics of OHCs include social networking, participation, apomediation, collaboration, and openness (Eysenbach 2008). There are many famous OHCs as we know, e.g., PatientsLikeMe.com in USA, haodf.com in China, which not only provide healthcare information to people, but also encourage them to share their therapy experience or disease record to other people or the community in order to promote healthcare knowledge sharing, social support exchange, research, and better treatment creation (PatientsLikeMe, 2014).

The viability of networked communities depends on the creation and disclosure of user-generated content and the frequency of user visitation (Chang & Chen 2014; Zhou et al. 2014). So are those OHCs. There are different bodies of participators in OHCs, such as professionals (doctors or nurses), patients, third-party institutes, nursing homes, and medicine factories. One of the major content-generating sources in OHCs is those patients and common users which is the focus of this paper. The data those people shared in OHCs is significantly important and valuable, because personalized web services and business intelligence software require the collection and mining of unprecedented amounts of personally identifying information (Li & Sarkar 2006). The data people shared in OHCs is not only useful for those people suffering from the same disease, but also can accelerate research and help create better treatments.

Sharing personal information might cause privacy disclosure, making people being at a vulnerable position. As we know, in order to improve information quality, people should provide more details such as what happens, symptoms, or treatments they have experienced. The more detailed the information is, the higher quality the information will be. But, the potential problem is that the more information one disclose, the more possible their privacy will be disclosed. In other words, pursuing information or knowledge quality might cause privacy disclosure in OHCs which is similar with the so called "personalization-privacy" paradox (Guo et al. 2012; Sutanto et al. 2013).

Although having privacy discl0ure risks, there are still lots of people self-disclose their personal information in OHCs. Thus, we are curious about what factors and how those factors influence people's personal information disclosure in those OHCs? The expected results will provide insight on people's information sharing behavior, online privacy protection, and healthcare knowledge sharing promotion in OHCs. The remains of this paper are organized as following. The second part is theoretical background and hypotheses development, and then is methdology. The last section is discussions, implications, limitations, and future work.

2   THEORETICAL BACKGROUND AND HYPOTHESES

2.1   "Risk-Motivation" Perspective and Conceptual Model

What describes, derives, or decides human actions is an interesting theme which has been attracting scholars' attention (Steel & König 2006). One result of this endeavor is motivation theory, which is a basic theory to explain human behavior. According to this theory, motivation is a psychological feature that induces an organism to act towards a desired goal and elicits, controls, and sustains certain goal-directed behaviors. Since its power in explaining human behavior, motivation theory has been accepted by many disciplines. Taking information systems (IS) for example, motivation was adopted as two dimensions (extrinsic and intrinsic motivation) to explain why people use a technology in those seminal papers (Davis et al. 1992; Venkatesh 1999), and then was treated as driving factors to explain people's online behavior or behavior intention, e.g., knowledge sharing in VCs or open source communities (Chiu et al. 2006; Ke & Zhang 2010; Wasko & Faraj 2005).

Besides of driving factors, an increasing body of papers in IS also pay lots of attention to those hampering factors, e.g., perceived risks accompanying technology usage are considered as important factors affecting consumers' opinions, evaluations, and adoption intentions negatively (Featherman et al. 2010; Featherman & Pavlou 2003; Featherman & Wells 2004). Especially in e-commerce context, perceived risk is recognized as an issue, especially due to product intangibility and to the lack of information when making purchase decisions which are even more acute in the services market (Cocosila et al. 2009). People not only consider the motivating factors, but also evaluate the potential risks when deciding whether conducting a certain behavior or not; it's necessary to analyze why people conduct certain behavior from the perspective of "risk-motivation" (Cocosila et al. 2009). Therefore, we adopt the "risk-motivation" perspective to analyze why people self-disclose their personal information in OHCs.

Research in IS on e-health could be divided into four kinds, IS only, IS-healthcare, healthcare-IS, and healthcare only (Chiasson & Davidson 2004; Romanow et al. 2012). We category this paper as the third"healthcare-IS" that directly incorporate healthcare contextual influences to inform the analysis of the empirical results and to extend IS theory or concepts. Directed by this principle, we identify three kinds of factors, i.e., motivation factors and risk factors which exert main effects, and moderating factors which moderate the two above kinds of factors' effects (as shown in figure 1). Obviously, the risk factors and two moderating variables highlight the charachtersctics of healthcare context.
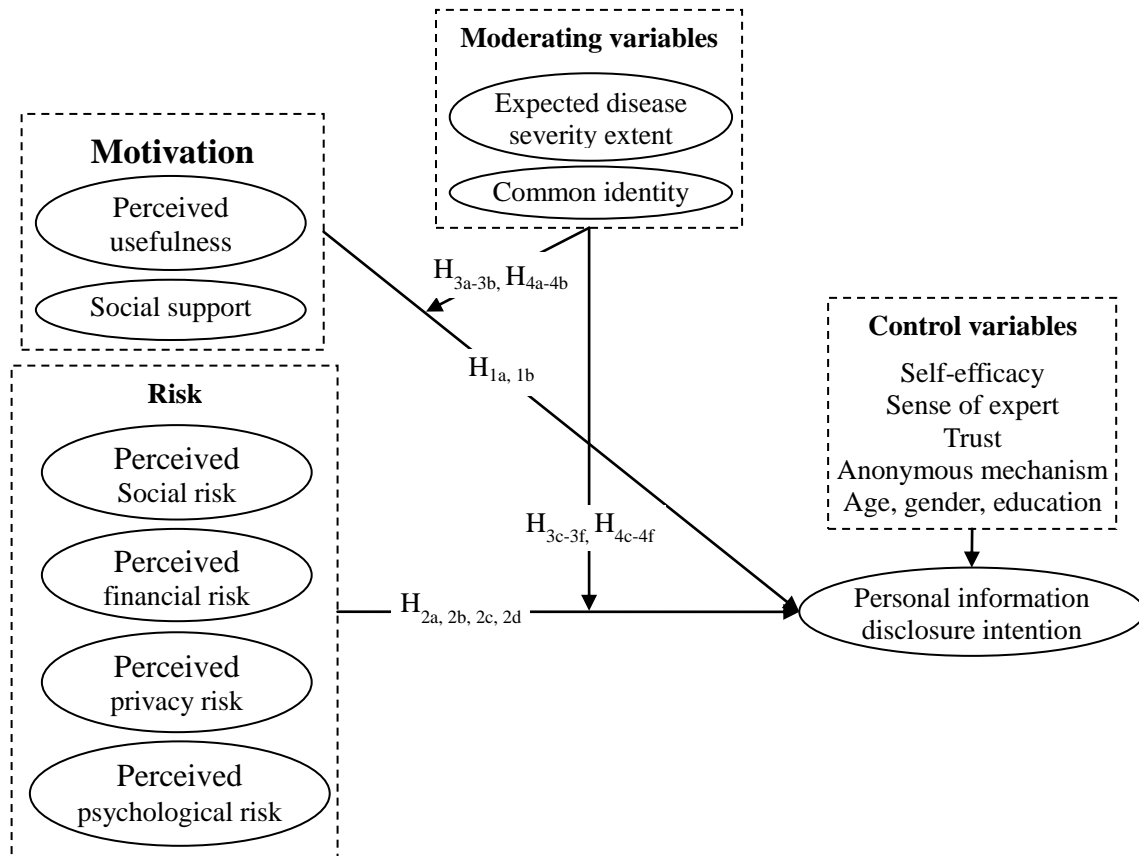
Moderating variables

Expected disease severity extent

Common identity

Motivation

Perceived usefulness

Social support

Risk

Perceived Social risk

Perceived financial risk

Perceived privacy risk

Perceived psychological risk

H_{3a-3b}, H_{4a-4b}

$H_{1a, 1b}$

H_{3c-3f}, H_{4c-4f}

$H_{2a, 2b, 2c, 2d}$

Control variables

Self-efficacy
Sense of expert
Trust
Anonymous mechanism
Age, gender, education

Personal information disclosure intention

Figure 1.   Hypotheses and Conceptual Model

2.2   Extrinsic and Intrinsic Motivation

Extrinsic motivation is a construct that pertains whenever an activity is done in order to attain some separable revenue (Ryan & Deci 2000). Prior research shows online communities could provide people useful information (Wasko & Faraj 2005). So is OHCs. When participating in healthcare information sharing activities, people are aiming to seek useful information or help from others. They disclose their personal information because they believe disclosure could help others to better understand their situation and then offer practical suggestions which is useful. We use perceived usefulness as the extrinsic motivation to explain why people disclose their personal information in OHCs, and propose,

H_{1a}: perceived usefulness as the extrinsic motivation positively affects people's personal information disclosure intention

Intrinsic motivation represents doing of an activity for its inherent satisfactions rather than for some separable consequence (Ryan & Deci 2000). Prior research shows using VCs could help people obtain social support, maintaining their social networks, and getting new friends (Fichman et al. 2011; Maloney-Krichmar & Preece 2005). For those people in OHCs, suffering diseases is not a good experience, and sharing this experience with others could help them find those patients like them, reduce the psychological distance, and obtain new friends. We use the construct social support as the intrinsic motivation to explain why people disclose their personal information in OHCs, and propose,

H_{1b}: social support as the intrinsic motivation positively affects people's personal information disclosure intention

2.3 Perceived Risks

There are some potential risks accompanying people's personal information disclosure in OHCs. We identify four kinds of risk as following. First, some health information is sensitive, e.g., types of disease, especially those mental diseases and infectious diseases; disclosing those sensitive information might cause others' misunderstanding and bring back social risk. Second, there is a long value chain relative with people's privacy information in OHCs. For example, people's information on financial state, demography, or contact channels might be used by some unintended purposes, e.g., marketing, which might cause financial risk. Since people's personal information might be used by unintended purpose, people want more control over the use of their information when it is for profit-generating purpose (Willison et al. 2009); therefore, the third is privacy risk which refers to people's uncertainty or fear that online businesses may use inappropriately customer personal information (Cocosila et al. 2009; Featherman & Pavlou 2003). The last one is psychological risk which refers to the potential mental anxiety associated with privacy disclosure. These risks above firstly are considered affecting consumers' intention to pay for online services or goods (Cocosila et al. 2009; Laroche et al. 2004; Lim 2003), and we apply those conclusions into the OHC context in this paper, and propose,

H_{2a}: perceived social risk negatively affect people's personal information disclosure intention

H_{2b}: perceived financial risk negatively affect people's personal information disclosure intention

H_{2c}: perceived privacy risk negatively affect people's personal information disclosure intention

H_{2d}: perceived psychological risk negatively affect people's personal information disclosure intention

2.4 The Moderating Effect

Prior research suggests that people tend to be more emotional and exhibit greater risk-seeking behavior when faced with a life–death choice than with problems in other life domains such as personal finances or public property (Anderson & Agarwal 2011; Druckman & McDermott 2008). When people fight for their life or death, they may overestimate the potential revenue and neglect the potential risks' effect. Therefore, the effects of motivation and risks on people's intention to disclose are strongly relevant with people's expected disease severity extent. So, we propose,

H_{3a-3b}: expected disease severity extent will positively moderate the relationship between extrinsic (H_{3a}) and intrinsic (H_{3b}) motivation and people's personal information disclosure intention

H_{3c-3f}: expected disease severity extent will weaken the relationship between perceived social risk (H_{3c}), financial risk (H_{3d}), psychological risk (H_{3e}), and privacy risk (H_{3f}) and people's personal information disclosure intention

For those people suffering from the same disease, they usually have the similar feeling: we all are patients, and we have the common identity. Common identity is an internal feeling: people who have common identity like the group as a whole – identity-based attachment; when people feel identity-based attachment to a group, they tend to perceive others in the group as interchangeable, even though they don't know each other (Ren et al. 2007). From the perspective of common identity, people are willing to disclose their personal information because they find other people in the same OHC are all patients like them, and common identity could guarantee their potential revenue and mitigate the potential risks accompanying personal information disclosure. So, we propose,

H_{4a-4b}: common identity will positively moderate the relationship between extrinsic (H_{4a}) and intrinsic (H_{4b}) motivation and people's personal information disclosure intention

H_{4c-4f}: common identity will weaken the relationship between perceived social risk (H_{4c}), financial risk (H_{4d}), psychological risk (H_{4e}), and privacy risk (H_{4f}) and people's personal information disclosure intention

2.5 Control Variables

Besides of the main effects and the moderating effects, we also identify several control variables, i.e., self-efficacy, sense of expert, trust, and demographics (age, gender, and education). Self-efficacy, sense of expert, and trust are supposed and tested having positive effects on users' knowledge sharing behavior or intention in VCs (Hsu et al. 2007; Wasko & Faraj 2005). Many VCs including OHCs adopt anonymous mechanism in order to reduce people's worrying about their privacy disclosure, so we treat it as control variables. Furthermore, people's demographics such as age, gender, and education are also integrated as control variables.

3 METHDOLOGY

A mixed-methodology approach composed of content analysis and structural equation model (SEM) will be adopted in this paper. During the past three years, we are keeping using and collecting chatting data from an OHC (a QQ discussion group for rectal cancer communication). Based on those data, participation observation and content analysis will be used to further analyze the potential motivation factors and risks in OHCs for construct developing, hypotheses testing, and cause-and-effect relationship testing (Jorgensen 1989). SEM will be used to further test the hypotheses and conceptual model based on the data collected by questionnaire.

4 DISCUSSIONS, IMPLICATIONS, AND FUTURE RESEARCH

4.1 Theoretical Implication

Drawing on the "risk-motivation" perspective, this study offers a theoretical framework to explain why people self-disclose their privacy information in OHCs. We identify perceived usefulness as extrinsic motivation and social support as intrinsic motivation, and perceived social risk, financial risk, privacy risk, and psychological risk as risk factors, treat expected disease severity extent and common identity as moderating variables, and plan to test those factors' effects.

This paper has two potential theoretical implications. First, our work will offer a model to explain why people self-disclose their personal information in OHCs, which is a potential contribution to current e-health research in IS. Second, we integrate several constructs, e.g., four kinds of risks, expected disease severity extent, and common identity to describe the characteristics accompanying personal information disclosure in OHCs, which is an address to the call of highlighting the unique characteristics of healthcare environment when doing healthcare-IS research (Romanow et al. 2012).

4.2 Practical Implication

Our findings will identify factors influencing people's personal information disclosure in OHCs, and shall help OHC managers to better operate their communities. From a managerial perspective, our study provides evidence that 1) what potential risks people care about when disclosing and what they managers can do to protect people's privacy security in OHCs; 2) motivating factors driving people's information sharing and how they managers promote those people participation in OHCs; and 3) factors mitigating risks' effect and how they managers enhance motivation factors' positive effects and weaken risk factors' negative effects in OHCs.

4.3 Limitations and Future Research Directions

Some limitations of this study should be mentioned. First, alought we identify four kinds of risks, we don't distinguish the types of information as Anderson and Agarwal (2011) do, which might weaken the power of our conclusions. Second, rules on online e-health such as diagnose and privacy protection in China is not as strict as western countries; we have observed those differences but have not integrated them into the model. As a research-in-progress paper, we have enough time to remedy these limitations in our future work.

References

Anderson, C. L. and Agarwal, R. (2011). The digitization of healthcare: boundary risks, emotion, and consumer willingness to disclose personal health information. Information Systems Research, 22(3), 469-490.

Chang, L. and Chen, J. V. (2014). Aligning principal and agent's incentives: A principal–agent perspective of social networking sites. Expert Systems with Applications, 41(6), 3091-3104.

Chiasson, M. W. and Davidson, E. (2004). Pushing the contextual envelope: developing and diffusing IS theory for health information systems research. Information and Organization, 14(3), 155-188.

Chiu, C. M., Hsu, M. H. and Wang, E. T. G. (2006). Understanding knowledge sharing in virtual communities: An integration of social capital and social cognitive theories. Decision Support Systems, 42(3), 1872-1888.

Cocosila, M., Archer, N. and Yuan, Y. (2009). Early investigation of new information technology acceptance: A perceived risk-motivation model. Communications of the Association for Information Systems, 25(article 30), 339-358.

Consulting, V. W. (2009). mHealth for development: the opportunity of mobile technology for healthcare in the developing world. Washington Dc and Berkshire, UK.

Davis, F. D., Bagozzi, R. P. and Warshaw, P. R. (1992). Extrinsic and intrinsic motivation to use computers in the workplace1. Journal of Applied Social Psychology, 22(14), 1111-1132.

Druckman, J. N. and McDermott, R. (2008). Emotion and the framing of risky choice. Political Behavior, 30(3), 297-321.

Eysenbach, G. (2008). Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness. Journal of Medical Internet Research, 10(3), e22.

Featherman, M. S. and Pavlou, P. A. (2003). Predicting e-services adoption: a perceived risk facets perspective. International Journal of Human-Computer Studies, 59(4), 451-474.

Featherman, M. S., Miyazaki, A. D. and Sprott, D. E. (2010). Reducing online privacy risk to facilitate e-service adoption: the influence of perceived ease of use and corporate credibility. Journal of Services Marketing, 24(3), 219-229.

Featherman, M. and Wells, J. D. (2004). *The Intangibility of E-Services: Effects on Artificiality, Perceived Risk, and Adoption.* Paper presented at the HICSS.

Fichman, R. G., Kohli, R. and Krishnan, R. (2011). Editorial overview-the role of information systems in healthcare: Current research and future trends. Information Systems Research, 22(3), 419-428.

Guo, X., Sun, Y., Yan, Z. and Wang, N. (2012). Privacy-personalization paradox in adoption of mobile health Service: The Mediating Role of Trust. Paper presented at the PACIS.

Hsu, M. H., Ju, T. L., Yen, C. H. and Chang, C. M. (2007). Knowledge sharing behavior in virtual communities: The relationship between trust, self-efficacy, and outcome expectations. International Journal of Human-Computer Studies, 65(2), 153-169.

Jorgensen, D. L. (1989). *Participant observation: A methodology for human studies* (Vol. 15). Sage Publications, Incorporated.

Ke, W. and Zhang, P. (2010). The effects of extrinsic motivations and satisfaction in open source software development. Journal of the Association for Information Systems, 11(12), 784-808.

Laroche, M., McDougall, G. H., Bergeron, J. and Yang, Z. (2004). Exploring how intangibility affects perceived risk. Journal of Service Research, 6(4), 373-389.

Li, X. and Sarkar, S. (2006). Privacy protection in data mining: A perturbation approach for

categorical data. Information Systems Research, 17(3), 254-270.

Lim, N. (2003). Consumers' perceived risk: Sources versus consequences. Electronic Commerce Research and Applications, 2(3), 216-228.

Maloney-Krichmar, D. and Preece, J. (2002). *The meaning of an online health community in the lives of its members: Roles, relationships and group dynamics.* Paper presented at the International Symposium on Technology and Society (ISTAS'02).

Maloney-Krichmar, D. and Preece, J. (2005). A multilevel analysis of sociability, usability, and community dynamics in an online health community. ACM Transactions On Computer-Human Interaction, 12(2), 201-232.

Porter, C. E., Devaraj, S. and Sun, D. (2013). A Test of Two Models of Value Creation in Virtual Communities. Journal of Management Information Systems, 30(1), 261-292.

Ren, Y., Kraut, R. and Kiesler, S. (2007). Applying common identity and bond theory to design of online communities. Organization Studies, 28(3), 377-408.

Rheingold, H. (1993). *The virtual community: Homesteading on the electronic frontier*: Addison Wesley Publishing Company.

Romanow, D., Cho, S. and Straub, D. (2012). Editor's comments: riding the wave: past trends and future directions for health IT research. MIS Quarterly, 36(3), A18.

Ryan, R. M. and Deci, E. L. (2000). Intrinsic and extrinsic motivations: Classic definitions and new directions. Contemporary Educational Psychology, 25(1), 54-67.

Steel, P. and König, C. J. (2006). Integrating theories of motivation. Academy of Management Review, 31(4), 889-913.

Sunday, N. (2000). The online health care revolution: How the Web helps Americans take better care of themselves. Pew Internet & American Life Project.

Sutanto, J., Palme, E., Tan, C. and Phang, C. W. (2013). Addressing the personalization–privacy paradox an empirical assessment from a field experiment on smartphone users. MIS Quarterly, 37(4), 1151-1164.

Venkatesh, V. (1999). Creation of favorable user perceptions: exploring the role of intrinsic motivation. MIS Quarterly, 23(2), 239-260.

Wasko, M. M. L. and Faraj, S. (2005). Why should I share? Examining social capital and knowledge contribution in electronic networks of practice. MIS Quarterly, 29(1), 35-57.

Willison, D. J., et al. (2009). Consent for use of personal information for health research: Do people with potentially stigmatizing health conditions and the general public differ in their opinions? Bmc Medical Ethics, 10(1), 10.

Wu, Y. and Dang, J. (2013). *Blue Book of Aging: China Report of the Development on Aging Cause (2013)*. Beijing: Social Sciences Academic Press.

Zhou, J., Zuo, M., Yu, Y. and Chai, W. (2014). How Fundamental and Supplemental Interactions Affect Users' Knowledge Sharing in Virtual Communities? A Social Cognitive Perspective. Internet Research, 24(5), forthcoming.