HHS Public Access

Author manuscript

Proc Hum Factors Ergon Soc Annu Meet. Author manuscript; available in PMC 2014 October 25.

Published in final edited form as:

Proc Hum Factors Ergon Soc Annu Meet. 2008 September ; 52(22): 1785–1789. doi:

10.1177/154193120805202201

Privacy Concerns and Disclosure Behavior in a Health Setting

Kelly E. Caine, Kaylee E. Burnham, Arthur D. Fisk, and Wendy A. Rogers

Georgia Institute of Technology, Atlanta, GA

Abstract

Health care practitioners need complete and accurate information to provide quality care to their patients. However, health information is considered to be highly private. Patients may have concerns about disclosing such information, especially if asked to provide this information using technology. The goal of this study was to investigate how participants' experience with a technology affect their level of disclosure in a health setting. Specifically, we were interested in understanding how the use of a health database system influences the disclosure of private health information. We asked 12 younger and 12 older adults to interact with a computerized health data entry system and then to rate the completeness and accuracy of their intended disclosures. Results indicate that, for the most part, participants would provide complete and accurate information using such a system. Younger adults were less likely than older adults to intend to disclose sensitive information, suggesting that additional information gathering may be appropriate for younger adults. The importance of providing a reason for the request of each piece of health information is discussed in relation to the setting where information is gathered.

INTRODUCTION

Information is an important tool for health care practitioners. It is used to assess, diagnose, and treat all manner of health issues. Often, information about a patient's condition must be disclosed by the patient to the health care provider. However, health information is considered to be particularly private (Metzger, 2004; Olson, Grudin & Horvitz, 2005) and thus may be less likely to be disclosed than other types of information due to increased privacy concerns.

As an added complication, the adoption of electronic medical records (EMR) poses major implications for more stringent privacy policies and regulations. Widespread adoption of EMR and other information technologies purportedly allows for improved patient care and convenience, but efforts to implement these systems have been hindered due to privacy concerns (Miller & Tucker, 2007). An important step in improving patient care and convenience is to understand what aspects of a technology relate to privacy concerns so that effective EMR may be developed.

Privacy and health are intimately related. On the one hand, a lack of perceived privacy has been shown to be related to an increase in potentially unhealthy stress, including an increased incidence of psychosomatic stress (Webb, 1978). On the other hand, understanding people's perceptions about privacy—specifically, the conditions under which they disclose information about themselves—is of critical importance to the full range of users of such data, including patients, health care providers, and public health officials.

For patients, the decision to disclose information and any subsequent concern over the security of disclosed information can be a stressful experience. Patients may have difficulty determining the optimal level of information to disclose, may be unaware of the full range of information that is useful to a health care provider, or may be unwilling to volunteer information that they believe is unrelated to the condition at hand. In some cases, patients may fear the social or financial consequences of disclosure. For example, they may fear that their insurance company will find out about certain conditions they have (Westin, 1981) and subsequently alter their rates. Patients may also fear that their condition will associate them with a stigmatized group (Dindia, 1998) and that they may be subsequently overlooked for job opportunities or promotions. In other cases, patients may simply not understand that information that seems unrelated or unimportant is actually related to a condition at hand, or one that may develop in the future. For example, if a patient is visiting a dentist for a routine root canal, the patient may not see the need to disclose his or her health status, yet this information may be critical in determining time needed to heal after such a procedure.

For health care providers, understanding that patients may not always fully disclose, and having an understanding of the situations where this is most likely to occur is of critical importance. Additionally, if health care providers can be given tools to help them know what can be done to prevent or discourage this behavior they may be better able to help their patients.

For public health officials, as with health care providers, it is important to understand the variables that lead to disclosure, and to understand the how to encourage patients to provide accurate data. Public health deals primarily with information provided by patients and health care providers. If the information they receive is incorrect or incomplete, public health officials are unable to fully analyze a situation, leading to incorrect conclusions. For example, if multiple people who are suffering from a stigmatized condition, such as HIV, are providing incorrect information as to their (potentially embarrassing) sexual history public health officials may be led astray as to their analysis of the situation.

In this study, we were interested in how experience with a novel system for gathering health information would affect participants' willingness to disclose health information. Participants interacted with a computer system designed to gather health information and were asked to rate their willingness to disclose pieces of health information to this system. We measured both the completeness and accuracy of the information each participant reported intending to disclose.

METHOD

Participants

Participants were 12 younger adults (8 males and 4 females) ranging in age from 18 to 22 years ($M = 19.67$, $SD = 1.435$), and 12 older adults (7 males and 5 females) ranging in age from 65 to 74 years ($M = 70.00$, $SD = 3.104$). Younger adult participants were recruited from the psychology student participant pool at the Georgia Institute of Technology and were awarded course credit for their participation. Older adults were recruited from a pre-existing database of adults living in the Atlanta area and were compensated \$10/hour for

their participation. All participants had completed, at minimum, a high school education, and most had completed at least some college coursework. The sample was ethnically diverse; among the younger adult sample, 17% were African American, 8% were Asian, 75% were Caucasian and 6% identified as 'other' whereas among the older adult sample, 25% were African American, 67% were Caucasian and 8% identified as 'other'. Self-reports of health status are presented in Table 1.

Design

The experimental design was a 2 (age) $\times$ 2 (reason) $\times$ 2 (sensitivity) mixed design. Reason provided for information request (present or absent) was a between participants manipulation with 6 younger and 6 older adults receiving each condition. Level of question sensitivity: 'less sensitive' or 'more sensitive', was assessed within participants, *post hoc*. That is, the mean level of sensitivity for each question was assessed using a health item sensitivity questionnaire (Burnham, 2008). Items were divided into the 10 'most sensitive' and 10 'least sensitive' for each age group. Age was a grouping variable.

Measures

Completeness—Participants rated the completeness of the answers they would provide to the computer system for each health-related question on a scale from 1: "I would skip this question (not enter any information)," to 5: "I would answer this question to the fullest extent possible." This scale was presented on the computer display concurrently with the each health question.

Accuracy—Participants rated the accuracy of the answers they would provide to the computer system for each health-related question on a scale from 1: "I would provide information that was completely inaccurate," to 5: "I would provide information that was completely accurate." This scale was presented immediately following the completeness rating. Participants were not given a question relating to accuracy if they responded 1: "I would skip this question, not enter any information" on the completeness scale. A response of zero (not applicable) for accuracy was reported in this case. Zero responses were removed prior to analysis.

Sensitivity—Participants rated the sensitivity of each health-related question on a scale from 1: "Least sensitive," to 5: "Most sensitive" after completing the experimental portion of the study. Ratings of item sensitivity for each health question were averaged across participants, and the 10 'least sensitive' and the 10 'most sensitive' items were identified for both younger and older adult age groups.

An example of a question that was rated as more sensitive for younger adults is "Over the last 2 weeks, how often have you been bothered by feeling bad about yourself or that you are a failure or have let yourself or your family down?" An example of a question that was rated more sensitive for older adults was "During the last 4 weeks, how much have you been bothered by constipation, loose bowels, or diarrhea?"

Procedure

The study was conducted in the Human Factors and Aging Laboratory at the Georgia Institute of Technology. Following consent, participants completed demographics, technology experience, and a Privacy Questionnaire adapted from Jensen, Potts and Jensen (2005), and Westin (Harris, 2003).

Next, participants were seated at a desktop computer and instructed about the nature of the task. Participants were informed that their task would be to complete a questionnaire about their health using a computerized data entry system (See Figure 1). During the task, participants were asked to imagine they were at a physician's office were told to imagine that their physician would have access their responses at a later time.

Participants were instructed to read each question as well as any other relevant information on the computer screen and to formulate the answer they would provide in the given situation. However, because we were not interested in the health information *per se*, participants were not asked to actually disclose any information to the system. Instead, after they read each question and considered their answer they were presented with two Likert-type scales assessing the completeness and accuracy of the response they had formulated.

Items in the questionnaire were adapted from the CREATE health questionnaire (Czaja, et al, 2006), a questionnaire designed to assess the health of older adults, and the Patient Health Questionnaire (Spitzer, Williams, & Kroenke, 1999).

Following participants' interaction with the data entry system, they were given a health item sensitivity questionnaire that presented all of the health question items again. This time, participants were asked to indicate, on a Likert-type scale, the sensitivity of each question.

Finally, participants took part in a short exit interview where they were asked about the process they used to formulate their answers and the nature of their interaction with the system. In addition, they were asked if they had ever used any type of computer system to input personal health information. At the conclusion of the study participants were fully debriefed.

RESULTS

Description of Disclosure Intentions

Across age groups participants reported that they would answer health questions presented to them on a computer system to the fullest extent possible almost 80% of the time. Only rarely would a participant skip a question or provide only minimal information to their physician when asked to provide this information using a computer system (See Figure 2).

In addition, across age groups participants reported that, when they would answer a question presented to them using a computer system designed to gather health information, most of the information they would provide information that was somewhat or totally accurate. Only rarely participants reported that they would skip a question or not enter any information (See Figure 3).

Analysis of Disclosure Intentions

To test the hypothesis that responses of completeness and accuracy would vary based on age and condition of reason-absent or reason-present across varying levels of question sensitivity, a mixed design ANOVA was conducted for the independent between subjects factors of age and condition, and the within subjects factor of question sensitivity. The two dependent variables of interest were participants' responses of completeness and accuracy.

Completeness—For the 'completeness of answer' data, there was no interaction of age $\times$ condition $\times$ question sensitivity ($p = 1.00$). Further analysis yielded no interactions for condition $\times$ question sensitivity ($p = .31$), or for age $\times$ question sensitivity ($p = .06$). A significant main effect of question sensitivity was found $F(1, 22) = 10.427$, $p < 0.05$, such that participants reported that they were more willing to answer more completely on questions of lower sensitivity compared to questions of higher sensitivity.

Accuracy—For accuracy ratings, there was also no interaction of age $\times$ condition $\times$ question sensitivity ($p = .83$), nor was there an interaction between condition $\times$ question sensitivity ($p = .83$). There was a significant main effect of question sensitivity $F(1, 22) = 10.06$, $p < 0.05$, such that participants reported that they were willing to answer more accurately on questions of lower sensitivity compared to questions of higher sensitivity. However, there was a significant interaction of age $\times$ question sensitivity on $F(1, 22) = 5.81$, $p < 0.05$, such that younger adults reported they would respond more accurately to less sensitive questions than more sensitive questions, whereas older adults did not differ their responses between less and more sensitive items.

DISCUSSION

Across age groups, participants reported that they were willing to disclose accurate and complete health information using a computerized system in their physician's office. Thus, implementing in-office EMR entry systems may be a viable way for health care practitioners to gather health information from their patients. However, participants in both age groups reported that they would provide more complete answers to questions of lower sensitivity than questions of higher sensitivity. This suggests that physicians may need to verify the completeness of responses to particularly sensitive health questions gathered via an in-office data entry system across patients of all ages.

In addition, because of age differences in the way each group of participants reported they would interact with the system, health care providers may need to take special precautions to ensure that the data younger adults provide to them is accurate. This may be especially important when they are asking for information younger adults consider sensitive because younger adults reported that they would give more accurate answers to less sensitive questions than more sensitive questions. Older adults, on the other hand, did not report that they would significantly alter the accuracy of their responses based on question sensitivity.

Although neither younger nor older adults altered their reports about level of disclosure in reaction to the distribution of a reason about the purpose of each item asked, this finding must be interpreted in light of the task instructions. All participants were told to imagine

they were in a physician's office and that this information would primarily be for their physician's use. During the exit interview, participants mentioned that they would not want to withhold information from their doctor or lie to their doctor. Two participants explicitly cited trust for a physician as a reason for intending to enter all relevant information that was requested. These statements provide support for the claim made by Wheless and Grotz (1977) that trust is associated with a greater amount of disclosure. However, if patients do not trust their health care provider, or the system the health care provider asks them to use, level of disclosure may differ based on the reason the information is requested.

In addition to trust, the context of instances of disclosure is important in the assessment of privacy concerns (Antaki, Barnes, & Leudar, 2005). Among the data collected about the relationship of technology and disclosure using methods such as content analysis and self-report, lack of context is often cited as a limitation of the research (Antaki, Barnes, & Leudar, 2005; Joinson & Paine, 2006). In this study we asked users to imagine themselves in the context of a physician's office. Statements from the exit interview indicate that participants did actively imagine this context during the study. Younger adults mentioned that there was nothing they would not want their physician to know about them because "doctors are there to help." Older adults reported that when health is involved they would want to provide all information possible to prevent misdiagnosis or any other problems, even if it had to be through a computer. Two participants even referenced their personal health, saying that they would not want to hide any of their many health problems from their doctors.

In this setting, both younger and older adults indicated that they were willing to disclose a large amount of health information using a computer system. However, outside of the setting of the physician's office participants may have different disclosure preferences. An important next step will be to examine privacy concerns and disclosure behavior outside the setting of a physician's office. For example, disclosure behavior may differ if participants are asked to disclose using a system from their home instead of at their physician's office.

Acknowledgments

This research was supported in part by the National Institutes of Health (National Institute on Aging): Grant P01 AG17211 under the auspices of the Center for Research and Education on Aging and Technology enhancement (CREATE). This article is based on a thesis submitted by the second author as partial fulfillment of the Bachelor of Science degree at Georgia Institute of Technology. We are grateful to Michelle Kwasny for feedback throughout the project and to Kurt Luther for copy editing.

References

- Ackerman, MS., Cranor, LF., Reagle, J. Privacy in e-commerce: examining user scenarios and privacy preferences. Proceedings of the 1st ACM conference on Electronic commerce; 1999.
- Altman, I. The environment and social behavior : privacy, personal space, territory, crowding. Monterey, California: Brooks/Cole Publishing Company; 1975.
- Altman, I., Taylor, DA. Social Penetration: The Development of Interpersonal Relationships. New York: Holt, Rinehart and Winston, Inc; 1973.
- Antaki C, Barnes R, Leudar I. Self-disclosure as a situated interactional practice. British Journal of Social Psychology. 2005; 44:181–199. [PubMed: 16004645]

- Burnham, KE. Unpublished Senior Thesis. Georgia Institute of Technology; Atlanta, GA: 2008. The effects of experience with a technology on privacy concerns and disclosure of health information.
- Buchanan T, Paine C, Joinson AN, Reips UD. Development of measures of online privacy concern, and protection for use on the internet. *Journal of the American Society for Information Science and Technology*. 2007; 58:157–165.
- Czaja, SJ., Charness, N., Dijkstra, K., Fisk, AD., Rogers, WA., Sharit, J. CREATE Common Core Battery of Measures. CREATE Technical Rep. CREATE-2006-01. 2006. Available online at www.create-center.org/tools.htm
- Damschroder LJ, Pritts JL, Neblo MA, Kalarickal RJ, Creswell JW, Hayward RA. Patients, privacy, and trust: Patients' willingness to allow researchers to access their medical record. *Social Science & Medicine*. 2007; 64:223–235. [PubMed: 17045717]
- Dindia, K. "Going into and coming out of the closet": The dialectics of stigma disclosure. In: Montgomery, BM., Baxter, LA., editors. *Dialectical Approaches to Studying Personal Relationships*. Mahwah, New Jersey: Lawrence Erlbaum Associates; 1998.
- Harris Interactive. The Harris Poll #17: Most people are 'privacy pragmatists' who, while concerned about privacy, will sometimes trade it off for other benefits. 2003. Online: http://www.harrisinteractive.com/harris_poll/index.asp?PID=365
- Jensen C, Potts C, Jensen C. Privacy practices of internet users: Self-reports versus observed behavior. *International Journal of Human-Computer Studies*. 2005; 63:1–2. 203–227.
- Joinson AN. Self-disclosure in computer-mediated communication: The role of self-awareness and visual anonymity. *European Journal of Social Psychology*. 2001; 31:177–192.
- Joinson, AN., Paine, CB. Self-disclosure, privacy and the internet. In: Joinson, AN., McKenna, K., Postmes, T., Reips, U-D., editors. *Oxford Handbook of Internet Psychology*. Oxford University Press; 2006.
- Jupiter Research. Security and privacy data. Presentation to the Federal Trade Commission Consumer Information Security Workshop; 2002. Available: <http://www.ftc.gov/bcp/workshops/0205201leathern.pdf>
- Kobsa A. Privacy-Enhanced Personalization. *Communications of the ACM*. 2007; 50(8):24–33.
- Karat, J., Karat, C-M., Brodie, C. Human-computer interaction viewed from the intersection of privacy, security, and trust. In: Sears, A., Jacko, JA., editors. *The Human-Computer Interaction Handbook: Fundamentals, Emerging Technologies and Emerging Applications*. 2. New York, NY: Lawrence Erlbaum Associates; 2008.
- Miller, AR., Tucker, CE. Privacy protection and technology diffusion: The case of electronic medical records. Paper presented at the Workshop on the Economics of Information Security; Pittsburgh, PA. June, 2007; 2007. Available: <http://www.weis2007.econinfosec.org/program.htm>
- Metzger M. Privacy, Trust, and Disclosure: Exploring Barriers to Electronic Commerce. *Journal of Computer-Mediated Communication*. 2004; 9(4)
- Pew Internet and American Life Project. The mainstreaming of online life. 2005. Retrieved June 20, 2005, from http://www.pewinternet.org/pdfs/internet_status_2005.pdf
- Olson, JS., Grudin, J., Horvitz, E. Toward Understanding Preferences for Sharing and Privacy (MSR-TR-2004-138). 2004. Retrieved from Microsoft Research: <http://research.microsoft.com/research/pubs/view.aspx?type=Technical%20Report&id=843>
- Olson, JS., Grudin, J., Horvitz, E. CHI '05 extended abstracts on Human factors in computing systems. 2005. A study of preferences for sharing and privacy.
- Spitzer RL, Williams JBW, Kroenke K. Validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. *JAMA*. 1999; 282:1737–1744. [PubMed: 10568646]
- Vail, M., Earp, J., Anton, A. An empirical study of consumer perceptions and comprehension of website privacy policies. 2007.
- Westin, AF. Privacy and Freedom. New York: Atheneum; 1967.
- Westin, AF. The Dimensions of Privacy: A National Opinion Research Survey of Attitudes Toward Privacy. New York & London: Garland Publishing; 1981.
- Wheless LR, Grotz J. The measurement of trust and its relationship to self-disclosure. *Human Communication Research*. 1977; 3:250–257.

Knowing the medications you are taking will allow your doctor to properly assess the symptoms you have and choose appropriate treatments.

With the answer to the question you were just asked in mind, please rate the completeness of information you would provide.

1 ☐	2 ☐	3 ☒	4 ☐	5 ☐	<input type="button" value="ok"/>
I would skip this question (not enter any information)	I would provide an answer, but I would only provide minimal information	I would provide an answer, but I would only provide some information	I would provide an answer, but I would only provide most information	I would answer this question to the fullest extent possible	

With the answer to the question you were just asked in mind, please rate the accuracy of the information you would provide.

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	<input type="button" value="ok"/>
I would enter information that was totally inaccurate	I would provide information that was somewhat inaccurate	I would provide some information that was accurate, and some that was inaccurate	I would provide information that was mostly accurate	I would provide information that was completely accurate	

Figure 1.
Screen shot of health information entry system.

Figure 2.
Amount of disclosure.

Figure 3.
Accuracy of disclosure.

Table 1**Health Characteristics**

	Younger adults	Older adults
N	12	12
General health		
Excellent	33%	17%
Very good	50%	33%
Good	17%	25%
Fair	0%	25%
Health compared with other people of same age		
Excellent	42%	17%
Very good	17%	33%
Good	42%	33%
Fair	0%	17%
Satisfaction with present health		
Extremely satisfied	25%	33%
Somewhat satisfied	67%	42%
Not very satisfied	8%	17%
Not at all satisfied	0%	8%
Health problem limited activities		
Never	42%	25%
Seldom	58%	50%
Sometimes	0%	17%
Often	0%	8%

Note: Self-report.