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Pouyan Esmaeilzadeh
Florida International University, pesmaeil@fiu.edu

Tala Mirzaei
Florida International University, tmirzaei@fiu.edu

Spurthy Dharanikota
Florida International University, sdhar006@fiu.edu

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Completed Research

Pouyan Esmaeilzadeh
Florida International University
pesmaeil@fiu.edu

Tala Mirzaei
Florida International University
tmirzaei@fiu.edu

Spurthy Dharanikota
Florida International University
sdhar006@fiu.edu

Abstract

The quality of the patient health information databases determines the success of health information exchange (HIE) networks. Data entry interfaces are suggested as an important factor affecting the quality of information. However, little is known about whether individuals with different diseases (mental and physical) care for the data entry structure in sharing health information. We conduct four experiments to examine the impact of different health problems (mental vs. physical) and types of data entry interfaces (structured vs. unstructured) on individuals' willingness to share health information. Findings demonstrate that the disease type and degree of data entry structure significantly influence individuals' perceptions of psychological risk, privacy concern, stigma, and willingness to share health information. This study suggests that the best level of structure for data entry interfaces could be designed at the point of care with respect to patients' type of diseases in order to improve the success of HIE networks.

Keywords

HIE; information quality; data entry structure; physical diseases; mental disorders

Introduction

Federal incentive programs such as Health Information Technology for Economic and Clinical Health Act (HITECH) resulted in large scale digitization of health information in the form of electronic health records (EHRs). These EHRs further enable the sharing of personal health information (PHI) via the federally defined standards of Continuity of Care Record, Continuity of Care Document (CCD), and the Federal Health Insurance Portability and Accountability Act (HIPAA) to facilitate health information exchange (HIE) (Fontaine et al. 2010). These initiatives empower patients to access their PHI, which includes demographic information, medical history, as well as test and laboratory results (Walker et al. 2017). There are multiple stakeholders in the healthcare landscape, such as patients, healthcare providers, and healthcare organizations. Secure information sharing or data exchange among different stakeholders helps facilitate coordinated and quality patient care by reducing healthcare costs (Adjerid et al. 2018), minimizing medical errors, enhancing patient engagement, and avoiding duplicate medical tests (Adjerid et al. 2016; Ayabakan et al. 2017). The lack of active information-sharing initiatives among multiple disparate healthcare entities is recognized to be a likely cause of redundant tests, delayed medical procedures, and erroneous care planning (LaBorde et al. 2011).

Effective and efficient PHI sharing among healthcare entities can only be possible if the patient is primarily willing to share his/her information. Researchers have examined the factors influencing the attitudes of the general public towards the sharing of their health information (Dimitropoulos et al. 2011; Simon et al. 2009) for health care and research purposes (Barrett et al. 2006; Bell et al. 2014; Platt and Kardia 2015). Privacy and security concerns were identified as significant factors influencing intentions to share PHI (Abdelhamid

et al. 2017; Ancker et al. 2012). Moreover, prior studies investigated the impact of individuals' health status on their PHI sharing decisions and behaviors. Lafky and Horan Lafky and Horan (2011 categorized the health status into well, unwell, and disabled and defined disabled as "physically disabled, maybe chronically ill" but no reference was made to mental disability. Additionally, their study provided evidence that people with disabilities and chronic illnesses expressed lower level of concern than those without these problems toward health information management.

To date, the majority of the studies in health information management were generally conducted on healthy individuals. Furthermore, very few studies have investigated the information sharing attitudes of individuals suffering from mental disorders or physical illnesses. For example, Willison et al. (2009 conducted a study investigating the consent choices to disclose health information of individuals with seven health conditions, namely hypertension, diabetes, alcoholism, depression, HIV, breast cancer, and lung cancer (ordered in the increasing order of stigma). Teixeira et al. (2011) investigated HIV patients' willingness to share PHI electronically and found that the majority of the HIV patients were willing to share PHI with clinical staff only for care purposes rather than with non-clinical staff. A qualitative study was conducted to understand the privacy perspectives of patients with mental health conditions or sensitive health information toward health information sharing (Shen et al. 2019). They discovered that patients with mental health conditions support HIE initiatives if they believe that the benefits, they can obtain by sharing their PHI prevail the privacy concerns and risks associated with the sharing activities. It is necessary to understand the attitudes of individuals with mental disorders and physical diseases towards health information sharing as these individuals are arguably the most at risk from PHI sharing, such as HIE efforts (Lafky and Horan 2011). Their health information could be of great use for medical practice and research, and at the same time, their disclosure of health information could result in their exposure to discrimination, making them undesirable for obtaining employment, insurance, and loans (Willison et al. 2009). Sharing sensitive PHI may further make vulnerable individuals with stigmatizing disabilities experience embarrassment, humiliation, shame, anxiety, and depression (Rothstein and Talbott 2006) and decide to forego medical care resulting in undesirable healthcare consequences. These conditions and feelings may either discourage individuals with chronic physical illness or mental disorder to actively participate in information sharing and HIE initiatives or prompt them to partially share their health information with providers and healthcare organizations, which may have negative impacts on the quality of the health information being collected and exchanged.

The potential benefits of health information sharing via large scale HIE projects, to enhance the quality of care, could be mainly dependent on the quality of data being collected, stored, and shared in this data-driven healthcare landscape. Wang and Strong (1996 defined data quality as "fitness for use." Poor data quality could pervasively influence almost all the organizations and industries (such as healthcare) which use integrated information systems and are mostly driven by data (Côrte-Real et al. 2020). The consequences of poor data quality could be devastating, particularly in the healthcare industry, as one wrong medical decision based on inadequate data inputs could significantly affect the lives of people involved (Hasan and Padman 2006; Stein et al. 2000).

Previously, a study proposed a data quality framework where the structure of data was presented as an essential measure of data quality Cai and Zhu (2015. Another study suggested that people are more likely to disclose sensitive information using online, highly structured data collection methods (such as web-based self-report surveys) (Milton et al. 2017). Additionally, recent research highlighted the effects of data entry structure on the quality of information collected by healthcare providers (Esmaeilzadeh et al. (2020. With the increasing importance of data quality in the healthcare industry, we contend that the structure and format of data during the data entry stage may influence the PHI sharing perceptions and behaviors of the patients. Health information is primarily stored in two types of data forms – structured and unstructured data (Abhyankar et al. 2014; Baars and Kemper 2008; Park and Song 2011). Structured data entry refers to a format where data is assigned to dedicated fields and will be coded accordingly, and unstructured data entry can be seen as self-contained content items (Baars and Kemper 2008) where data is usually text-heavy and is not organized in a pre-defined data model. We propose that the data entry structure may significantly shape individuals' health information sharing behaviors as patients under different health conditions may exhibit various capabilities, vulnerabilities, and perceptions in recording information. For example, an individual sharing data in a structured format could think of providing the treating physicians and relevant healthcare entities with an overall picture of his/her health status through disclosing requested information. However, an unstructured data entry, mostly in text format, may be preferred by individuals

who desire to share their illness in detail by describing the chief complaints, emotional facets of the disease, and side-effects of the treatment in their point of view.

A number of previous studies addressed the issues associated with PHI sharing and HIE initiatives. Though, to the best of our knowledge, no experimental research has investigated the differences in the perceptions of individuals suffering from chronic physical illnesses and mental disorders toward data entry format and health information quality. This assessment is practical because these patients are in greater need of information exchange between different healthcare organizations and providers. Additionally, research on the patients' attitudes toward using structured and unstructured data entry format is quite sparse, specifically in the information quality and HIE studies. These reasons explain the need for detailed investigation to not only address the gaps in the literature but also inform the practitioners in the healthcare industry of the need for adaptable data collection mechanisms. Thus, the main objective of this study is to examine the influence of structured and unstructured data entry format on the perceptions of individuals with mental disorders and physical diseases about PHI sharing.

In the current information-sharing era, HIE can play an essential role in facilitating data sharing and cooperation among healthcare providers, which helps to improve the quality of care and efficiency of the healthcare system (De Pietro and Francetic 2017). Through HIE projects, healthcare organizations gain access to a great source of patient medical records and are able to mine such big data to generate actionable information and patterns (Dimitrov 2016). However, HIE efforts will not be successful without valid and reliable databases that store complete, accurate, and timely patient health information. Therefore, data collection procedures are considered as a critical foundation of effective HIE projects, and data collection interfaces could affect patients' perceptions of privacy, risks, and willingness to share such personal records. Healthcare providers mainly collect patients' information during their visit and consultation with them. In this context, it is very critical to provide users with an interface that could gain users' trust and also result in higher-quality content. Since patients suffering from mental disorders and physical diseases may not exhibit the same information sharing propensities, we suggest that healthcare organizations should tailor the structure degree of a data collection interface to accommodate patients' expectations in the data creation process.

Material and Method

To identify the differences in individuals' perceptions of data entry interfaces, we designed an experiment with four scenarios separately for individuals with physical illness and mental disorders. In our preliminary study, we collected more than 50 respondents per scenario. In this study, we consider the interface for data collection to follow either a structured or unstructured format. Structured interfaces by design use specific forms of dedicated fields to record requested information; however, this format limits the respondents' possibility to explain their responses.

For scenarios with the structured data interface, we provide a fixed number of multiple-choice questions in an online survey to the respondents to enter the requested health information. For the scenarios with the unstructured data interface, we provide an open data entry box for respondents to type in and describe their health information and experiences. Whereas, for the physical ailments, we ask participants to reflect on their records such as signs and symptoms, past medical history, treatments, progress notes, medications, allergies, genetic information, laboratory results, patients' problem lists about the chronic physical disease they are suffering from (such as heart diseases, diabetes, arthritis, injuries, kidney disease, cancer, chronic back pain, and Parkinson's disease). For the mental disorder scenarios, we ask respondents to report their signs and symptoms, past medical history, treatments, progress notes, medications about the chronic mental disorder they are suffering from (such as clinical depression, chronic anxiety, post-traumatic stress disorder, bipolar disorder, mood disorder, dementia, panic disorder, and social phobia).

Then, we use a questionnaire to compare respondent's perceptions of psychological risk, stigma, privacy concern, and willingness to share information across four proposed scenarios. Perceived risk is defined as the extent to which individuals perceive that the information (collected and shared) gives them a feeling of unwanted anxiety and psychological discomfort (Forsythe and Shi 2003). Perceived stigma is defined as the extent to which individuals perceive that the information (collected and shared) can cause unfair reactions to them and carry a social stigma (King et al. 2007; Pyne et al. 2004). Perceived privacy concern is defined as the extent to which individuals concern about how organizations collect, access, use, and

protect their personal information (Stewart and Segars 2002). Perceived privacy concern is used to measure individuals' concerns about four factors: collection, error, unauthorized access, and secondary use (Van Slyke et al. 2006). Finally, the willingness to share health information is defined as the extent to which individuals are willing to disclose their health information to healthcare providers. Table 1 shows the details of the design of the number of participants per scenario.

Degree of interface structure / Type of disease	Structured data	Unstructured data
Physical illness	Scenario 1 (n = 64)	Scenario 2 (n = 63)
Mental disorder	Scenario 3 (n = 59)	Scenario 4 (n = 56)

Table 1. Research Design Diagram

Each experiment has four sections: 1. Scenario, which explains the purpose of each experiment (i.e., data collection and information sharing with other providers). 2. Then, respondents are asked to fill out their reflections about their illness (via structure or unstructured data collection methods) 3. Next, a set of questions is asked to assess participants' perceptions of the given data entry structure. 4. Finally, demographic questions are asked.

Data Collection

We initially collected a sample of about 70 respondents per scenario in January 2020, through Amazon's Mechanical Turk (MTurk). MTurk is a survey tool that has been used in several studies as an acceptable means to collect individual-level data from the general population of interest (Paolacci et al. 2010). We posted the surveys for each scenario and limited the respondents' location to the United States. We used a randomizer function to assign respondents randomly to the four scenarios to minimize the likelihood of one respondent participating in more than one experiment. We encoded a microcode in the survey to prevent individuals from taking each experiment more than once. Finally, all experiments were also double-checked using the generated respondent ID and IP address to ensure that the respondents were unique between experiments. The incentive for participation was a monetary reward. The range of average completion time for the four experimental groups was between 5:12 and 7:26 min that implied acceptable responses in terms of timing. To avoid random responses and haphazard questions, we incorporated captcha questions in the instrument as a reverse Turing test. We removed insufficient answers and dropped responses that failed the response quality questions. We also discarded answers if the type of disease entered by a respondent was inconsistent with the intended health status defined by the respective scenario. For instance, the response is removed if the scenario is intended to capture answers from an individual suffering from a mental disorder, but the participant entered a physical problem instead. The final set of useable and valid samples after data cleansing included between 56 and 64 responses per experiment, presented in Table 1.

We used matching scores across four groups to avoid the potential problem of individual differences between groups. In total, 44% of the participants are male. About 70% of the participants are between 20 and 40 years of age. About 52% of the respondents reported an annual income of less than $50,000, while 23% reported between $50,000 and $75,000. The majority of the respondents are White (79%), followed by African Americans (8%) and Asian (6%). 42% of the participants completed a bachelors' degree, while 31% completed some college degrees. The majority of the participants are full-time employees (64%), followed by part-time employees (20%). Almost all participants are native English speakers. Results of the chi-square tests in terms of demographic characteristics across all four groups provide enough evidence to assume that there are no significant differences between the groups in terms of demographics, and matched groups were used in this study.

Results

We adapted the items from previously validated instruments to measure each of the outcome variables, perceived psychological risk, stigma, privacy concern, and willingness to share information. All items were

measured on a five-point Likert-type scale with 1 indicating "strongly disagree," and 5 indicating "strongly agree." We calculated unweighted sum scores of items for each variable to create the aggregates of outcome variables. Then, we used the t-test to compare respondents' perceptions about the proposed outcome variables when given a structured versus unstructured data interface, separately for physical illnesses and mental disorders. The results presented in Table 2 show the significant differences between scenarios. For scenarios that involved physical illnesses (i.e., scenarios 1 and 2), we found significant differences in their willingness to share health information given a structured interface versus unstructured. Respondents with chronic physical diseases were more willing to share information when a structured interface was presented to them (t=2.094, p=.038). Next, we compared scenarios where the respondents were asked to reflect on sharing information about mental disorders given different data interface structures (i.e., scenarios 3 and 4). For patients suffering from mental disorders, we found a significantly higher perception of psychological risk (t=-3.383, p<.001), and privacy concern (t=-1.995, p=.048) when a highly unstructured data interface was used. Moreover, patients with mental disorders exhibited a significantly higher willingness to share information when given a structured data interface (t=1.842, p=.042). Further, for scenarios where unstructured interfaces provided, we compared the scenario that reflected physical illnesses (i.e., scenario 2) versus the scenario that reflected mental disorders (i.e., scenario 4). We found that patients with mental disorders perceived significantly more concerns about risks of information sharing (t=-3.217, p=.002), stigma (t=-2.571, p=.011), and privacy (t=-2.881, p=.005) compared to patients with physical illnesses. We did not find any significant differences between respondents' perceptions when structured interfaces were used for sharing information about physical illnesses (i.e., scenario 1) and mental disorders (i.e., scenario 3). Detailed results of all significant tests are presented in Table 2.

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Physical Structure-Physical Unstructured					
Willingness to share health information	2.094	125	0.038	1.283	.613
Mental Structured-Mental Unstructured					
Perceived Psychological risk	-3.383	113	0.001	-2.96	0.87
Perceived Privacy Concern	-1.995	113	0.048	-2.01	1.02
Willingness to share health information	2.052	113	0.042	1.24	0.67
Physical Unstructured - Mental Unstructured					
Perceived Psychological risk	-3.217	117	0.002	-2.885	0.897
Perceived Stigma	-2.571	117	0.011	-1.887	0.734
Perceived Privacy Concern	-2.881	117	0.005	-2.859	0.993

Table 2. Comparison of outcome variable between four proposed scenarios
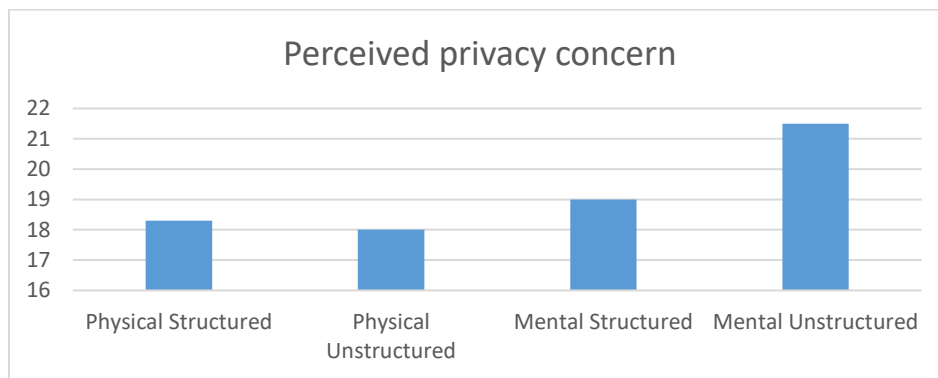
The following figures (Figures 1-4) display the differences in the means of outcome variables across four scenarios.
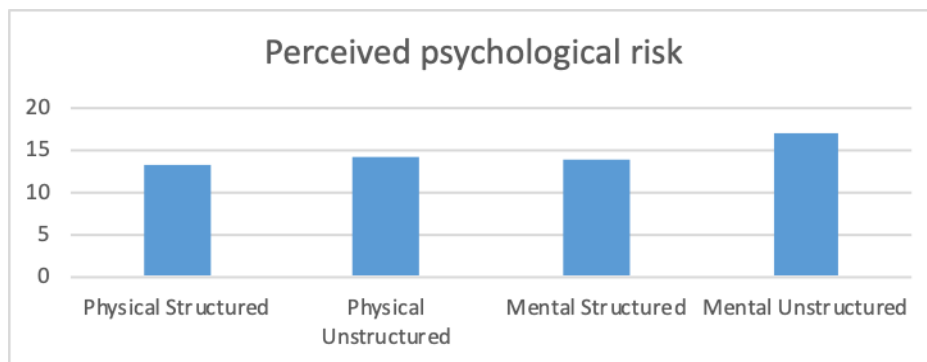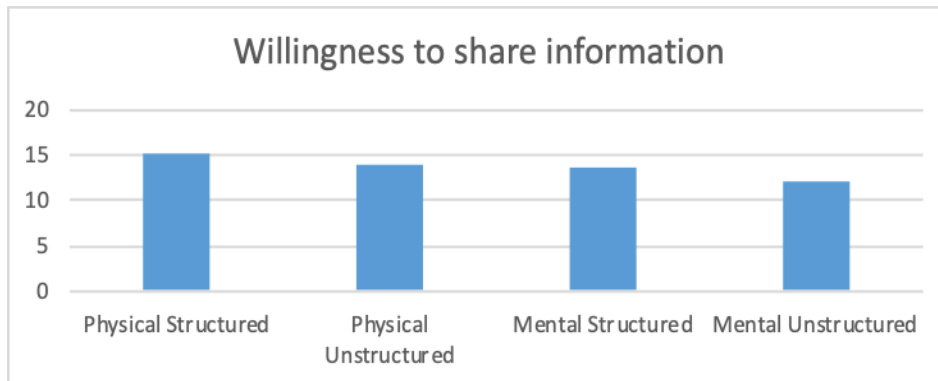

Figure 1. Differences in means of perceived psychological risk
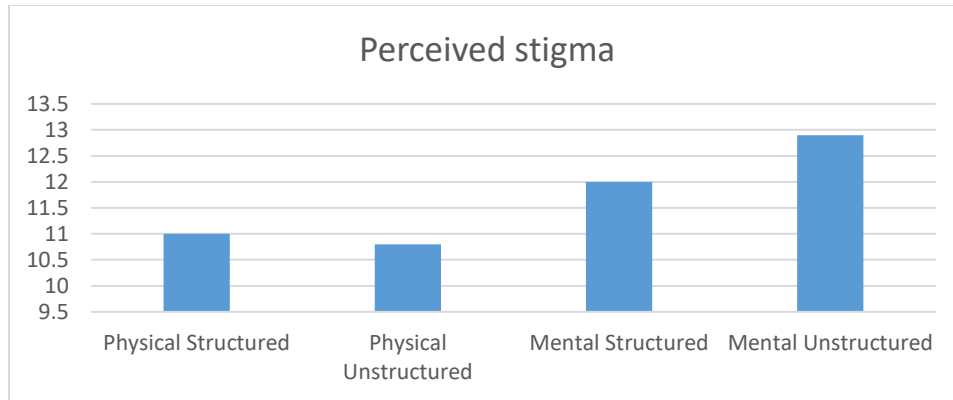
Figure 2. Differences in means of perceived stigma

Figure 3. Differences in means of perceived privacy concern

Figure 4. Differences in means of willingness to share information

Discussion

The findings demonstrate that patients with mental disorders prefer structured data interfaces as they perceive that a high degree of data entry structure can protect their privacy and mitigate stigma and psychological risk more than unstructured interfaces. Patients suffering from physical diseases are more likely to share their information when a highly structured data entry interface is used, and patients with mental disorders are less likely to disclose their information when providers collect health records using an unstructured data entry interface. Our results show significant evidence that patients (with chronic physical problems and mental disorders) are more willing to share their health information if structured data

interfaces are provided to them. Specifically, for patients with mental disorders, the interface design is more important as it reflects the patients' concerns of privacy and stigmatization. There are fewer psychological risks associated with structured data interfaces for patients with mental disorders. This may occur because a structured interface provides individuals with mental disorders greater peace of mind as they do not need to spend much time speculating how to draft some paragraphs about their sensitive mental issues, which are sufficient for treatment purposes. This result is in agreement with other studies (Grando et al. 2020) that show individuals with mental disorders are increasingly reluctant to share their sensitive data unless they feel they have more control over data collection procedures (i.e., what type of data is requested and how such records are collected). Thus, it highlights the importance of the data input structure for people suffering from mental diseases during data collection for healthcare purposes. The structured interface, usually with fixed scales, such as structured or itemized rating adopting a variety of Likert scales (Dellarocas et al. 2010), may impose the notion of more control over data collection practices and, therefore, less risk for the respondents about what will happen further on with the data. Therefore, to ensure the collection of complete and reliable personal health information, the developers of HIE need to consider the patient's concerns and reflect that in the design of data entry interfaces.

Individuals with mental disorders perceive higher levels of psychological risks, privacy concerns, and stigma compared to those of physically infirm individuals when they are asked to write about their signs, symptoms, medications, and overall health status using an open box (i.e., unstructured format). This result is in line with recent studies on mental health (Grando et al. 2020), which propose that individuals suffering from mental disorders are not willing to describe and share their health information due to fear of facing stigma, discrimination, and prejudice in personal life, healthcare, and work settings. Moreover, prior studies identify that the writing quality of individuals with mental illnesses (such as schizophrenia, depression, and bipolar disorder) was significantly lower than individuals with no reported mental disorders (Park and Conway 2018). These studies further indicate that individuals with mental disorders consider tasks, such as writing to express thoughts, to be more difficult when compared to effortless and automated tasks that require less attention. Our study sheds more light on this point by suggesting that choice of data entry interface for individuals with mental disorders may vary based on their feeling of unwanted anxiety, fear of social stigma, and uncertainty associated with less structured information sharing initiatives.

Most of the researchers studying HIE design and development have focused on the data consumer (i.e., healthcare organizations and healthcare providers) (Everson et al. 2017). Our study attempts to examine the data creators /providers' (i.e., patients) perceptions about the data interface structure and how their choice influences their health information sharing behaviors. Exploring the attitudes and perspectives of patients toward HIE and PHI sharing behaviors can facilitate the regional and federal initiatives of HIE for the successful transfer of electronic health information between healthcare organizations to ensure the use of right information in the concise form to prevent duplicate and redundant tests, avoid medical errors, and make timely medical decisions (Menachemi et al. 2018).

Our study also contributes several practical implications to HIE designers and developers. It is important to consider developing different types of interfaces (i.e., structured or unstructured) depending on the health status of individuals, to make sure the information being collected is accurate, complete, concise, and suitable to improve data-driven medical decision-making processes. The other major implication of this study is to inform healthcare professionals, data entry designers, and developers that individuals differ in their choice of data entry structure to input information based on their mental disorder or physical illness. We suggest that more attention is required in designing the data structure format for patients with a mental disorder. In general, patients with a mental disorder are more concerned about their health information privacy, and they are more prone to physiological risk and stigmatization. Our results show that patients with a mental disorder desire a high level of interface structure to protect their privacy, reduce social stigma, and decrease the psychological risk associated with health information sharing over unstructured interfaces. Several studies indicated the therapeutic effect of writing for patients with mental disorders and reflected on the impact of writing on keeping track of mood changes, medication side effects, and possible triggers that could be causing specific symptoms (Smyth et al. 2008). However, for information exchange purposes where patients consider exposing their information to other parties, using a well-structured format helps them reserve their privacy and avoid stigma by limiting the information to what is only required in the data collection forms.

Limitations and future research

Our research has some limitations that call for additional studies. First, our study used an online survey to recruit participants digitally. Thus, we considered only individuals who could access the Internet and were healthy enough to participate in the online survey. Future researchers can use other data collection means and sampling strategies to reach out to a sample that is generalizable to a wide range of healthcare consumers. For instance, future research can recruit patients with mental and physical problems who are directly referred by their treating providers. Second, other designs may offer different data-collection features or a combination of some, such as semi-structured data entry interface. In this research, we assume two extreme conditions of the data structure spectrum, namely, a highly structured and unstructured format. Using a semi-structured interface can help data creators answer a set of questions by selecting given choices and record the requested content in a text area box. Another promising area of research is expanding this study by investigating the effects of semi-structured data collection on information quality perceptions of patients with chronic health problems. Third, we investigated the perspectives of individuals with physical illness or mental disorder separately in our study. Future research could focus on individuals who have both mental disorders and physical diseases and study their data entry interface preferences for health information sharing.

Conclusion

There is a need to encourage patients with physical and mental disorders to share their personal health information with providers in order to enhance the care process of patients. The two interface designs (i.e., structured and unstructured) are different in many ways, and each has certain advantages and disadvantages. However, we argue that each interface gives data creators (such as patients) different perceptions, capabilities, and willingness to disclose health information. In other words, when patients with chronic problems are given a data entry interface with a certain level of structure, their risk perceptions and sharing capabilities are influenced by that particular interface. It is imperative for both theoretical and practical reasons to understand what degree of data structure can match the expectations of patients with different types of diseases (i.e., mental or physical) in order to design an appropriate data entry platform for HIE projects. The results demonstrate that individuals suffering from a physical problem prefer a highly structured data entry interface. Moreover, patients with mental disorders are more likely to use well-structured interfaces for sharing PHI mainly because of lower perceived psychological risks and privacy concerns. Furthermore, individuals with mental disorders perceive greater stigmatization attached to unstructured data entry formats compared to people suffering from physical problems. The findings of this study provide insights into the phenomenon of information quality assessment and add to the literature on HIE, patient behavior, and health informatics. Hence, healthcare providers and data entry designers may need to improve the designs of data collection platforms by addressing the expectations and needs of patients with different types of diseases. Theoretical and practical contributions of this study are noticeable since they could result in a deeper understanding of what degree of interface structure would be desirable to collect complete, accurate, and reliable health information to facilitate the successful implementation and realization of large scale HIE efforts.

REFERENCES

Abdelhamid, M., Gaia, J., and Sanders, G. L. 2017. "Putting the Focus Back on the Patient: How Privacy Concerns Affect Personal Health Information Sharing Intentions," Journal of medical Internet research (19:9), p. e169.

Abhyankar, S., Demner-Fushman, D., Callaghan, F. M., and McDonald, C. J. 2014. "Combining Structured and Unstructured Data to Identify a Cohort of Icu Patients Who Received Dialysis," Journal of the American Medical Informatics Association (21:5), pp. 801-807.

Adjerid, I., Acquisti, A., Telang, R., Padman, R., and Adler-Milstein, J. 2016. "The Impact of Privacy Regulation and Technology Incentives: The Case of Health Information Exchanges," Management Science (62:4), pp. 1042-1063.

Adjerid, I., Adler-Milstein, J., and Angst, C. 2018. "Reducing Medicare Spending through Electronic Health Information Exchange: The Role of Incentives and Exchange Maturity," Information Systems Research (29:2), pp. 341-361.

Ancker, J. S., Edwards, A. M., Miller, M. C., and Kaushal, R. 2012. "Consumer Perceptions of Electronic Health Information Exchange," American journal of preventive medicine (43:1), pp. 76-80.

Ayabakan, S., Bardhan, I., Zheng, Z., and Kirksey, K. 2017. "The Impact of Health Information Sharing on Duplicate Testing," MIS Quarterly (41:4).

Baars, H., and Kemper, H.-G. 2008. "Management Support with Structured and Unstructured Data—an Integrated Business Intelligence Framework," Information Systems Management (25:2), pp. 132-148.

Barrett, G., Cassell, J. A., Peacock, J. L., and Coleman, M. P. 2006. "National Survey of British Public's Views on Use of Identifiable Medical Data by the National Cancer Registry," bmj (332:7549), pp. 1068-1072.

Bell, E. A., Ohno-Machado, L., and Grando, M. A. 2014. "Sharing My Health Data: A Survey of Data Sharing Preferences of Healthy Individuals," AMIA Annual Symposium Proceedings: American Medical Informatics Association, p. 1699.

Cai, L., and Zhu, Y. 2015. "The Challenges of Data Quality and Data Quality Assessment in the Big Data Era," Data science journal (14).

Côrte-Real, N., Ruivo, P., and Oliveira, T. 2020. "Leveraging Internet of Things and Big Data Analytics Initiatives in European and American Firms: Is Data Quality a Way to Extract Business Value?," Information & Management (57:1), p. 103141.

De Pietro, C., and Francetic, I. 2017. "E-Health in Switzerland: The Laborious Adoption of the Federal Law on Electronic Health Records (Ehr) and Health Information Exchange (Hie) Networks," Health Policy).

Dellarocas, C., Gao, G., and Narayan, R. 2010. "Are Consumers More Likely to Contribute Online Reviews for Hit or Niche Products?," Journal of Management Information Systems (27:2), pp. 127-158.

Dimitropoulos, L., Patel, V., Scheffler, S., and Posnack, S. 2011. "Public Attitudes toward Health Information Exchange: Perceived Benefits and Concerns," The American journal of managed care (17:12 Spec No.), pp. SP111-116.

Dimitrov, D. V. 2016. "Medical Internet of Things and Big Data in Healthcare," Healthcare informatics research (22:3), pp. 156-163.

Esmaeilzadeh, P., Mirzaei, T., and Maddah, M. 2020. "The Effects of Data Entry Structure on Patients' Perceptions of Information Quality in Health Information Exchange (Hie)," International Journal of Medical Informatics (135), p. 104058.

Everson, J., Kocher, K. E., and Adler-Milstein, J. 2017. "Health Information Exchange Associated with Improved Emergency Department Care through Faster Accessing of Patient Information from Outside Organizations," Journal of the American Medical Informatics Association (24:e1), pp. e103-e110.

Fontaine, P., Ross, S. E., Zink, T., and Schilling, L. M. 2010. "Systematic Review of Health Information Exchange in Primary Care Practices," The Journal of the American Board of Family Medicine (23:5), pp. 655-670.

Forsythe, S. M., and Shi, B. 2003. "Consumer Patronage and Risk Perceptions in Internet Shopping," Journal of Business research (56:11), pp. 867-875.

Grando, A., Ivanova, J., Hiestand, M., Soni, H., Murcko, A., Saks, M., Kaufman, D., Whitfield, M. J., Dye, C., and Chern, D. 2020. "Mental Health Professional Perspectives on Health Data Sharing: Mixed Methods Study," Health Informatics Journal), p. 1460458219893848.

Hasan, S., and Padman, R. 2006. "Analyzing the Effect of Data Quality on the Accuracy of Clinical Decision Support Systems: A Computer Simulation Approach," AMIA annual symposium proceedings: American Medical Informatics Association, p. 324.

King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Passetti, F., Weich, S., and Serfaty, M. 2007. "The Stigma Scale: Development of a Standardised Measure of the Stigma of Mental Illness," The British Journal of Psychiatry (190:3), pp. 248-254.

LaBorde, D. V., Griffin, J. A., Smalley, H. K., Keskinocak, P., and Mathew, G. 2011. "A Framework for Assessing Patient Crossover and Health Information Exchange Value," Journal of the American Medical Informatics Association (18:5), pp. 698-703.

Lafky, D. B., and Horan, T. A. 2011. "Personal Health Records: Consumer Attitudes toward Privacy and Security of Their Personal Health Information," Health Informatics Journal (17:1), pp. 63-71.

Menachemi, N., Rahurkar, S., Harle, C. A., and Vest, J. R. 2018. "The Benefits of Health Information Exchange: An Updated Systematic Review," Journal of the American Medical Informatics Association (25:9), pp. 1259-1265.

Park, A., and Conway, M. 2018. "Harnessing Reddit to Understand the Written-Communication Challenges Experienced by Individuals with Mental Health Disorders: Analysis of Texts from Mental Health Communities," Journal of medical Internet research (20:4), p. e121.

Park, B.-K., and Song, I.-Y. 2011. "Toward Total Business Intelligence Incorporating Structured and Unstructured Data," Proceedings of the 2nd International Workshop on Business intelligencE and the WEB, pp. 12-19.

Platt, J., and Kardia, S. 2015. "Public Trust in Health Information Sharing: Implications for Biobanking and Electronic Health Record Systems," Journal of personalized medicine (5:1), pp. 3-21.

Pyne, J. M., Kuc, E. J., Schroeder, P. J., Fortney, J. C., Edlund, M., and Sullivan, G. 2004. "Relationship between Perceived Stigma and Depression Severity," The Journal of nervous and mental disease (192:4), pp. 278-283.

Rothstein, M. A., and Talbott, M. K. 2006. "Compelled Disclosure of Health Information: Protecting against the Greatest Potential Threat to Privacy," Jama (295:24), pp. 2882-2885.

Shen, N., Sequeira, L., Silver, M. P., Carter-Langford, A., Strauss, J., and Wiljer, D. 2019. "Patient Privacy Perspectives on Health Information Exchange in a Mental Health Context: Qualitative Study," JMIR mental health (6:11), p. e13306.

Simon, S., Evans, J. S., Benjamin, A., Delano, D., and Bates, D. 2009. "Patients' Attitudes toward Electronic Health Information Exchange: Qualitative Study," Journal of medical Internet research (11:3), p. e30.

Smyth, J. M., Hockemeyer, J. R., and Tulloch, H. 2008. "Expressive Writing and Post-Traumatic Stress Disorder: Effects on Trauma Symptoms, Mood States, and Cortisol Reactivity," British Journal of Health Psychology (13:1), pp. 85-93.

Stein, H. D., Nadkarni, P., Erdos, J., and Miller, P. L. 2000. "Exploring the Degree of Concordance of Coded and Textual Data in Answering Clinical Queries from a Clinical Data Repository," Journal of the American Medical Informatics Association (7:1), pp. 42-54.

Stewart, K. A., and Segars, A. H. 2002. "An Empirical Examination of the Concern for Information Privacy Instrument," Information Systems Research (13:1), pp. 36-49.

Teixeira, P. A., Gordon, P., Camhi, E., and Bakken, S. 2011. "Hiv Patients' Willingness to Share Personal Health Information Electronically," Patient education and counseling (84:2), pp. e9-e12.

Van Slyke, C., Shim, J., Johnson, R., and Jiang, J. J. 2006. "Concern for Information Privacy and Online Consumer Purchasing," Journal of the Association for Information Systems (7:6), pp. 415-444.

Walker, D. M., Johnson, T., Ford, E. W., and Huerta, T. R. 2017. "Trust Me, I' ma Doctor: Examining Changes in How Privacy Concerns Affect Patient Withholding Behavior," Journal of medical Internet research (19:1), p. e2.

Wang, R. Y., and Strong, D. M. 1996. "Beyond Accuracy: What Data Quality Means to Data Consumers," Journal of management information systems (12:4), pp. 5-33.

Willison, D. J., Steeves, V., Charles, C., Schwartz, L., Ranford, J., Agarwal, G., Cheng, J., and Thabane, L. 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), p. 10.