Mobile Health Privacy Concerns – A Systematic Review

Completed Research

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Abstract

Mobile health technologies have great potential to improve healthcare delivery. However, adoption of mobile applications raise many privacy concerns, and these issues must be addressed in order to facilitate technology adoption. We conducted a systematic review of the extant research literature to understand privacy concerns of patients and providers when they use mobile health applications. An extensive search of various databases including Web of Science, CINAHL, Cochrane Library, Embase, MEDLINE, PsycINFO, PubMed, ScienceDirect, and JMI identified 37 unique articles on this topic. We analyzed these articles using a 3x3 framework with user type and usage type as the two dimensions. Our findings revealed that patient’s privacy concerns are heightened in the presence of certain disease types that carry a social stigma. Providers on the other hand are anxious about staying compliant with privacy regulations. Limitations of the study and directions for future research are discussed.

Keywords

Privacy concerns, mobile health, m-health, systematic review.

Introduction

Mobile technologies have found widespread use in business and society in recent times. In spite of their potential benefits, their adoption in the health sector is somewhat dampened. There are several reasons for this slow adoption of mobile technologies among healthcare providers and patients. One reason is the traditionalism of physicians, who want to maintain the status quo in technology use and are unwilling to adopt a new technology (Venkatesh et al. 2011; Walter and Lopez 2008). Another important reason that impedes wider adoption of these technologies among physicians and patients alike is privacy concerns raised by mobile technology use in the health sector (Sunyaev et al. 2015). As a matter of fact, medicine requires confidentiality due to the seriousness of patients’ conditions. Consequently, the potential for personal health information being leaked into the public domain due to the use of mobile devices seems to worry both patients and providers. Considering the significant potential benefit of mobile technology use in the health sector and the privacy concerns that could deter rapid adoption of this technology, it is critical that we study this important issue. Our goal in this report is to conduct a systematic review of extant research of privacy concerns regarding the use of mobile technologies in healthcare both from the perspective of physicians and patients. Such a study would enable us to make recommendations to facilitate mobile technology adoption in healthcare.

Systematic reviews are widely used in the health literature to analyze the extant body of research in a specific area and to draw conclusions. Following this methodology, we conducted a comprehensive analysis of privacy concerns in mobile health care. Our analysis covered the perspectives of patients as well as providers. It also encompassed mobile health applications of three different categories: design, non-intervention, and intervention. Thus we believe that our review provides a holistic view of privacy concerns.
in mobile healthcare that enriches our understanding of this critical issue and can help advance mobile health technology adoption in the health sector. The next section provides a brief review of the research literature. It is followed by a description of our research methodology. The results are then discussed and conclusions are drawn.

**Literature Review**

Systematic reviews have been playing an important role in healthcare literature (Liberati et al. 2009; Moher et al. 2010). The summaries and reviews conducted through this process generate rich insights for researchers, and help them understand the limitations and gaps in the current body of research and plan future research projects to fill these gaps. The Cochrane Collaboration, which sets the standards for systematic review defines it as “a comprehensive high-level summary of primary research on a specific research question that attempts to identify, select, synthesize, and appraise all high-quality evidence relevant to that question to answer it (Harris et al. 2014).”

Several systematic reviews have been conducted to understand different aspects of mobile health. Some dealt with smartphones applications and their usability (Arnhold et al. 2014; Fernández-Alemán et al. 2015); others studied text messaging as an intervention mechanism to help patients control their disease symptoms (Déglise et al. 2012; Herbert et al. 2013) and improve their health behavior (Free et al. 2013; Militello et al. 2012). In the case of mobile health privacy, most of the systematic reviews published so far have addressed both security and privacy together (Fernández-Alemán et al. 2013) and made recommendations on security and privacy guidelines, protocols, and regulations about the design of mobile health care application (Martínez-Pérez et al. 2015).

While a number of systematic reviews exist in this area, none of these offer a comprehensive analysis of this phenomenon. Our study extends this body of literature by offering a comprehensive review of privacy concerns both from the perspectives of patients and providers, and by analyzing privacy issues at three stages of mobile technology adoption and use, namely, intervention, adoption/non-intervention, and design.

**Methodology**

We followed the PRISMA guidelines (Harris et al. 2014)) to identify and screen articles suitable for this study. This is a well-established and widely used procedure for article selection for systematic review studies.

Our goal was to identify all articles addressing privacy concerns in the domain of mobile health. To accomplish this, we used the following query: ("m-health" OR "mhealth" OR "mobile health") AND privacy. This query was run on the following databases: Web of Science, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane Library, Embase (Excerpta Medica Database), MEDLINE (Medical Literature Analysis and Retrieval System Online), PsycINFO, PubMed, ScienceDirect, and JMIR (Journal of Medical Internet Research).

<table>
<thead>
<tr>
<th>Query</th>
<th>Restrictions</th>
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<tr>
<td>(&quot;m-health&quot; OR &quot;mhealth&quot; OR &quot;mobile health&quot;) AND privacy.</td>
<td>Language: English</td>
</tr>
<tr>
<td>Content type: Journal articles</td>
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<td>Discipline: Any</td>
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**Table 1: Search Query**

We limited our search to journal articles written in English. Since these databases curate only healthcare journals, no disciplinary restriction was imposed. The search resulted in an initial list of 2413 articles. After removing duplicates, we applied inclusion/exclusion criteria. We included only research papers that discussed both mobile healthcare and privacy, and were published in English language journals. Thus, papers published in conference proceedings, abstracts, and non-English reports were excluded. Also, articles that didn’t meet the keyword search query listed in Table 1 were excluded. Our final list comprised of 37 articles.
Figure 1: Article Selection Process

Our article selection process is summarized in Figure 1. The 37 articles were analyzed and the results are presented in the following section.

Results

Study characteristics

The 37 articles included in this study were published between 2011 and 2016, and used diverse research methods. While some articles relied on a single research method, others used mixed methods. 11 of those studies used survey (Boulos et al. 2014; Dehling et al. 2015; Henseler et al. 2012; Kharrazi et al. 2012; Kuhlmann et al. 2014; Lee and Kwon 2015; McGillicuddy et al. 2013; Schooey et al. 2016; Shareef et al. 2014; Sun and Rau 2015; Sunyaev et al. 2015). Interviews were used in 4 articles (Garg et al. 2016; Mergel 2014; Ranney et al. 2014; Whittaker 2012). Focus groups were used in 3 articles (Gkatzidou et al. 2015; Pineros-Leano et al. 2015; Weaver et al. 2015). 2 articles only used review (Eng and Lee 2013; Fischer et al. 2014). 8 articles were conceptual and descriptive in nature. These did not use any research method (Harvey and Harvey 2014; Luxton et al. 2011; Mancuso et al. 2014; Meier et al. 2013; Morgan and Agee 2012; Ray and Biswas 2014; Tate et al. 2013; Varshney 2014). 8 articles used multiple research methods; 3 using both focus groups and interview (Murray et al. 2015; Ramanathan et al. 2013; Willcox et al. 2015), 2 relying on both focus groups and survey (McClure et al. 2016; Schoenberger et al. 2013), 2 using both focus groups and experiments (Broaddus et al. 2015; Siedner et al. 2015), and 1 based on both experiments and interviews (Shaw et al. 2013). Only 1 article used meetings among participants (Mercer et al. 2015).

Based on the health condition of interest, the articles fall into 3 categories: chronic diseases, mental health, and wellness. While mental health is a chronic condition, we wanted to treat it separately due to its unique status in healthcare and society. The articles in the various categories are (1) wellness (Lee and Kwon 2015; McClure et al. 2016; Shaw et al. 2013; Sunyaev et al. 2015; Willcox et al. 2015), (2) mental health (Harvey and Harvey 2014; Luxton et al. 2011; Pineros-Leano et al. 2015; Shareef et al. 2014), and (3) chronic diseases (Broaddus et al. 2015; Dehling et al. 2015; Eng and Lee 2013; Fischer et al. 2014; Garg et al. 2016; Gkatzidou et al. 2015; Harvey and Harvey 2014; Henseler et al. 2012; Kharrazi et al. 2012; Luxton et al. 2011; Mancuso et al. 2014; Meier et al. 2013; Mercer et al. 2015; Morgan and Agee 2012; Ramanathan et al. 2013;
Schoenberger et al. 2013; Shareef et al. 2014; Siedner et al. 2015; Sun and Rau 2015; Varshney 2014; Weaver et al. 2015).

Figure 2. Disease Category
As shown in figure 2, about 72% of the articles addressed mobile technology use in managing chronic diseases including diabetes, sexually transmitted diseases (STDs), cancer, heart disease, asthma, arthritis, autism, dyslexia, pulmonary diseases, and others. Since effective management of chronic conditions leads to improved quality of life for the patient as well as lowering of healthcare costs, it is not surprising that these diseases are a primary target of mobile technologies. Chronic illness management using mobile technologies also raise many privacy concerns from the patient's perspective due to perceived social stigma associated with some of them. For example, patients suffering from HIV/AIDS feel strongly about maintaining privacy of their conditions and cancer patients experiencing debilitating conditions are concerned about being treated differently, if their conditions become known to others. About 10% of the articles dealt with mental illness, and privacy is a big concern in this domain due to well-known social stigma associated with mental illness in our society. About 17% of the articles were focused on wellness, and dealt with issues such as weight loss and fitness. Privacy concerns are somewhat less prevalent in this category.

We categorized the articles using 2 dimensions: technology user perspective and technology usage type. The primary user groups of mobile healthcare are patients and providers. Thus, based on which user group is the focus of the study, the articles fell into three clusters: some dealt with the patient perspective, others addressed the provider perspective, and few others elicited both patient and provider perspectives. Depending on the nature of the mobile technology applications, the articles were categorized into 3 groups: intervention, adoption/non-intervention, and design. Articles in the intervention category focused on applications that involved mobile technology based health interventions such as enabling the patient to monitor his/her health conditions, providing reminders to enhance adherence to prescribed treatment regimen, viz., taking medication on time etc. The second group of articles under this dimension primarily focused on adoption issues, but did not include any interventions. We named that group adoption/non-intervention. Finally, those articles that dealt with design features were put under the design category. Table 2 lists the article count based on this 3x3 classification. As can be seen from Table 2, a large number of articles focus on privacy concerns from the patient’s perspective; which seems logical as patients are the primary beneficiaries of mobile health care.

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<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Adoption/Non-Intervention</th>
<th>Design</th>
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<tbody>
<tr>
<td>Patient perspective</td>
<td>6 articles</td>
<td>5 articles</td>
<td>9 articles</td>
</tr>
<tr>
<td>Provider perspective</td>
<td>4 articles</td>
<td>4 articles</td>
<td>1 article</td>
</tr>
<tr>
<td>Both patient and provider perspectives</td>
<td>1 article</td>
<td>None</td>
<td>7 articles</td>
</tr>
<tr>
<td>Total</td>
<td>11 articles</td>
<td>9 articles</td>
<td>17 articles</td>
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Table 2 Article Count by User Category and Usage Type
Intervention – Patient perspective

Six articles studied privacy concerns related to mobile health interventions from the patient’s perspective (Broaddus et al. 2015; Meier et al. 2013; Ranney et al. 2014; Shaw et al. 2013; Siedner et al. 2015; Weaver et al. 2015). Text messaging was found to be a simple and economical intervention tool for weight loss management. The authors of that article mentioned that privacy concern was the main factor in the development of that tool (Shaw et al. 2013). Another article investigated and compared the benefits and risks of text-messaging in sexual health intervention (Broaddus et al. 2015). The authors of that article noticed from their experiment that participants showed some privacy concerns for text messages compared to group-based intervention. Another study looked at the preventive intervention of text messages from acceptability/feasibility, structural, and language perspectives. Participants raised privacy concerns from the language perspective. They feared that their information might be read by others if they did not delete them regularly (Ranney et al. 2014). Another article studied the use of mobile health intervention in smoking cessation and found it to be an effective intervention tool but the users expressed reservations regarding privacy violations (Meier et al. 2013). (Siedner et al. 2015) evaluated the antecedents of making use of mobile health application by HIV patients in Uganda. The authors found that reading abilities and the use of text message were crucial antecedents of the patients’ responses to mobile health applications messages. (Weaver et al. 2015) studied text message-based intervention in screening for colorectal cancer and found that older patients were willing to receive screening messages from their health care providers, whereas younger patients with sufficient health literacy raised privacy concerns due to unauthorized access and security breach.

Intervention – Provider perspective

Four articles studied privacy concerns of interventions from the provider’s perspective (Garg et al. 2016; Kuhlmann et al. 2014; Murray et al. 2015; Schoenberger et al. 2013). One investigated text message exchange between providers and patients and found that many physicians were concerned about potential for violation of privacy laws (Kuhlmann et al. 2014). The second study investigated the use of mobile phones in sending text messages to low income patients and found governmental regulations protecting patient privacy to be a critical barrier (Garg et al. 2016). The third article dealt with text message intervention seen by health care providers (HCP) in the case of HIV-positive individuals (Murray et al. 2015). Before the interventions, HCPs evoked the issue of privacy. They were concerned about sharing their personal cell phone numbers with patients. The fourth article evaluated various means of accessing health information by Community Health Advisors (Schoenberger et al. 2013). The participants of a focus group asserted that text messaging was helpful in rapid information distribution while maintaining privacy of communication.

Intervention – Both patient and provider perspectives

Only one article explored intervention from the perspectives of both providers and patients (Willcox et al. 2015). It studied the use of mobile health devices by pregnant women and found that both the patients and the health professionals acknowledged the usefulness and helpfulness of mobile health information sources and interventions. However, there were mixed results on privacy concerns. Some health professionals felt that social networks offered the potential for privacy breach whereas others felt that people active in social networks were aware of such risks and were willing to accept them.

Adoption/non-intervention – Patient perspective

Five articles addressed patients’ privacy concerns about adoption/non-intervention of mobile health (Fischer et al. 2014; Mancuso et al. 2014; McGillicuddy et al. 2013; Shareef et al. 2014; Sun and Rau 2015). One article showed the promising benefits of mobile health monitoring systems on kidney transplant patients, many of whom were willing to be monitored via mobile technology and felt confident that their privacy would be protected (McGillicuddy et al. 2013). However, those who had less positive attitude toward remote monitoring were more skeptical regarding the privacy protection aspect of this technology. A second article investigated the acceptance of health care information technology by elderly patients and found privacy concerns to be the primary obstacle impacting technology adoption (Fischer et al. 2014). A third article studied the adoption of personal health devices by chronic patients. The authors found privacy issues to be a major concern influencing user acceptance of these devices (Sun and Rau 2015). (Shareef et al. 2014)
propose a mobile health adoption model based on the technology acceptance model of (Davis et al. 1989) and found that patients who perceived the system to be secure and private were more likely to adopt mobile health technology. Finally, (Mancuso et al. 2014) discussed the challenges, benefits, and privacy issues as well as psychological and physiological parameters of fitness devices for clinical use. They showed that patients differed in their understanding of privacy of data collected via these devices.

**Adoption/non-intervention – Provider perspective**

Four articles examined providers’ privacy concerns about adoption/non-intervention (Henseler et al. 2012; Pineros-Leano et al. 2015; Schooley et al. 2016; Whittaker 2012). One of those articles showed that health care providers’ perception of the common issues in policy and regulation of mobile health implementation included privacy and data security, FDA regulation of mobile health, medical practice with respect to clinical practice roles, and bandwidth or spectrum availability (Whittaker 2012). A second article dealt with physicians’ intention to adopt mobile health monitoring systems, particularly those related to diabetes. It found that privacy and security concerns did not have significant effect on intention to use mobile diabetes monitoring (Henseler et al. 2012). A third study investigated depression screening using tablets and found that providers felt this process to enhance client privacy (Pineros-Leano et al. 2015). Another study involving tablet use by health care providers (Schooley et al. 2016) also found no privacy concerns related to the use of these tablets. Thus, providers seem to have less privacy concerns in adopting mobile health technologies.

**Design – Patient perspective**

Our analysis revealed that patients expressed significant privacy concerns about design features of mobile healthcare applications. Some were worried about information leak and its consequence. They desired their health information to be secure and private (Boulos et al. 2014; Dehling et al. 2015). Other users emphasized the need for developers to take into consideration HIPAA regulations and transparency while building these applications (Harvey and Harvey 2014; Sunyaev et al. 2015). Regarding HIPAA regulations, a particular article dealt with the proposition of a mobile health care system that followed the HIPAA standards about privacy and security (Ray and Biswas 2014). One of the studies revealed that HIV positive patients were concerned about the application tracking their location (Ramanathan et al. 2013). They also expressed unwillingness to answer questions regarding their alcohol or drug use. Multi-level authentication was also proposed as a means to improve privacy. It was suggested to have passwords both at the system level and the mPHR (mobile PHR) application level (Kharrazi et al. 2012). A study involving young people suggesting requirements for the design of mobile health application for sexually transmitted infection (STI) was conducted. Other than privacy and security; some issues were brought up; those of credibility; support; and the fit between task and technology (Gkatzidou et al. 2015). Moreover, an approach to manage patients’ act of giving their private information away while keeping it private was proposed (Lee and Kwon 2015).

**Design – Provider perspective**

Only one article dealt with obstacles to implementation and adoption of mobile health in federal agencies in USA (Mergel 2014). It found four barriers to the adoption of mobile apps. These are legal terms of use, accessibility and compliance, data privacy, and security. The users of these applications also feared that the agencies would have access to their direct and personal information during the use of the applications.

**Design – Both patient and provider perspectives**

Some of the articles covering both patient and provider perspectives discussed obstacles to mobile health care adoption; among which were both data privacy and data security (Luxton et al. 2011). The problem of regulations was also enunciated. As a matter of fact, it was pointed out that there were no regulations for patients and that HIPAA’s rules were only for providers, hospitals, and payers (Morgan and Agee 2012). Design recommendations for mobile health applications included standardized data encryption and security of open architecture (Tate et al. 2013); using application features to keep smoking information private (McClure et al. 2016). Not only were there recommendations, but also propositions to improve mobile health applications through quality of devices, privacy and security (Mercer et al. 2015). Furthermore, health care applications for endocrine diseases were examined. It was stated that there were
more and more privacy threats and concerns in mobile health care (Eng and Lee 2013). In addition to those findings specified, another is that there was a need of trade-off between benefits of access and privacy in the context of proposing a framework for mobile health. It was also suggested that more research was needed to improve privacy in the context of mobile health applications (Varshney 2014).

Discussion

Our analysis shows that privacy concerns permeate all aspects of mobile health care, and affects both patients and providers. Patient concerns emanate from the fear of health information being leaked out by mobile health applications. These concerns are heightened in the presence of diseases carrying social stigma. Provider concern lies in being compliant with the regulatory environment, such as HIPAA regulations. Provider concern also reflected patient needs as perceived by them. The most recurrent theme revealed by the study is the need to enhance privacy protection in mobile applications and make them compliant with the regulatory requirements so as to satisfy the expectations of both the patient and provider communities. These findings lead to the following recommendations. First, application designers need to ensure that their software is HIPAA compliant. Second, application designers creating software for use in the context of diseases that carry a social stigma must take extra care in enhancing privacy to mitigate the privacy concerns of patients. Finally, providers need training to ensure that they maintain patient privacy while using mobile applications.

Conclusion

We conducted a systematic review of mobile health literature to understand privacy concerns from both patient and provider perspectives. An extensive search of literature identified 37 unique journal articles that address privacy concerns. Our analysis revealed the importance of taking patient privacy into consideration in developing mobile health applications. Our results must be considered keeping in mind the limitations of the study. Our review targeted only journal articles published in the English language. It is possible that we might have missed some key insights that appeared in conference proceedings or in a different language publication. However, considering the fact that journals are archival resources we hope that all important conference papers eventually make into a journal. We limited our analysis to only patients and providers. One may extend this study by taking into consideration the perspectives of healthcare organizations, and the software development community. This will provide a holistic view by encompassing the perspectives of all stakeholders.

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Privacy Concerns in Mobile Health


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