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Understanding the Impact of Perceived Negative Consequences on Personal Health Information Disclosure: The Case of Ghana

Research Idea

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Abstract

In developing countries increased investments in electronic health record (EHR) systems are fueling efforts to digitize personal health information (PHI). However, in countries where widespread diseases such as HIV/AIDS are heavily stigmatized, people may not want to disclose their health information fearing that digitization may lead to privacy loss and negative consequences should unintended others know about their infection. Drawing on the privacy calculus, this study will use a scenario-based survey approach to examine the impacts of particular negative consequences (i.e. emotional, economic, social consequences) alongside trust and privacy concerns on individuals' PHI disclosure decisions in digitized settings. The results are expected to provide insights into the impact of negative consequences and yield recommendations to practice on addressing such concerns about the privacy management of people's PHI.

Keywords: privacy concerns, electronic health record, personal health information, healthcare, perceived negative consequences.

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Research Idea

Introduction

Recent years have seen significant investments in electronic health record (EHR) systems in developing countries, with expectations that increased efficiencies in the collection and management of personal health information (PHI) will improve the quality of healthcare and help address the epidemics that plague these countries (Oluabunwa et al. 2016). However, many of these epidemics, like Ebola and HIV/AIDS, are heavily stigmatized. As a result some persons hide their illness to avoid negative consequences that may occur should others know about their infection (Dapaah and Senah 2016; Kwansa 2013). With this, are concerns that PHI when stored electronically, may become known to unintended others (Bedeley and Palvia 2014; Karwatzki et al., 2017; Willyard 2010) increasing further, people's unwillingness to share their PHI with healthcare providers. Thus, it is important to understand the impacts of negative consequences of PHI disclosure on individuals' disclosure decisions in digitized settings.

To date, IS privacy research has largely used the privacy calculus perspective to explain consumer disclosure of personal information (Anderson and Agarwal 2011; Dinev and Hart 2006). This perspective, applied to healthcare, suggests individuals' decisions to disclose PHI result from an analysis of the risks and benefits of disclosure (Dinev and Hart 2006). One conceptualization of risk focuses on the negative outcomes (or potential losses) that may arise with personal information disclosure (Karwatzki et al., 2017; Malhotra et al. 2004). While some of these consequences (e.g., social, material, and physical) have been identified in prior research (Karwatzki et al. 2017; Smith et al. 2011), their impact in relation to PHI disclosure in online environments has received little attention. Addressing this gap as well as calls for further study of the diversity of privacy harms (Kokolakis, 2015), this study examines the impact of perceived negative consequences on individuals' willingness to reveal their PHI to healthcare providers where the information is digitized.

Theoretical Foundation and Conceptual Model

Prior research based on the privacy calculus (Anderson and Agarwal 2011; Dinev and Hart 2006) shows concerns about privacy of electronic information and trust in the electronic medium are key variables that individuals consider when evaluating the risks and benefits of information disclosure. Indeed, research suggests that privacy concerns and trust will impact PHI disclosure, where privacy concerns will lower disclosure of PHI while trust beliefs would enhance PHI disclosure (Anderson and Agarwal 2011). In addition, we expect that perceived negative consequences will impact individuals' willingness to disclose PHI (Karwatzki et al. 2017) especially in sensitive settings where such information will be digitized. Taken altogether, these expectations about the impacts of privacy concerns, trust and negative consequences on PHI disclosure decisions are summarised in Figure 1 (Appendix). Next we examine more closely, perceived negative consequences of PHI disclosure, and argue that these will lessen individuals' PHI disclosure.

Perceived Negative Consequences of PHI disclosure.

Following Karwatzki et al. (2017), we define *perceived negative consequences* of PHI disclosure as the adverse consequences that individuals believe may result from PHI disclosure. A review of the health informatics literature (Kordzadeh and Warren 2017; Laric et al. 2009; Rindfleisch 1997), suggests these negative consequences can be broadly classified as emotional, economic, and social consequences. Though all types of PHI are sensitive, some PHI are considered more sensitive than others as evident by the legal protection offered to some PHI such as sexual health information (Anderson and Agarwal 2011). The negative consequences of a given disclosure will thus vary depending on PHI sensitivity. In this study we explore the potential for emotional, economic, and social consequences of disclosing HIV-related PHI.

Indeed, HIV is especially relevant with 36.7 million people worldwide living with HIV at the end of 2016, and 75% knowing their status (UNAIDS, 2018). The epidemic is most pronounced in Africa where 25.5 million people live with HIV. The situation is exacerbated further as HIV is heavily stigmatized especially in Sub-Saharan Africa. For example in Ghana, Kwansa (2013) found that some HIV infected individuals avoid treatment because they dread the negative consequences that may result from the disclosure of their status when they seek care; eventually, these persons may commit suicide or die from living secretly with the disease. Although these studies were based on paper-based healthcare environment (Kwansa 2013), given peoples' beliefs of the likelihood of privacy loss being greater with digitizing PHI (Fichman et al. 2011), we propose that negative consequences of PHI disclosure will adversely influence individuals' willingness to disclose their PHI in a digitized healthcare environment. Next we explore examples of these consequences.

In relation to HIV several **emotional consequences** may arise from PHI disclosure. One example is *perceived inferiority*; it is an important dimension of shame and refers to beliefs about the negative evaluation of the self by others (Goss et al. 1994). Adapted to this study, *perceived inferiority* reflects beliefs about the negative evaluation of the self by others that can result from PHI disclosure. In Ghana, studies show people have negative attitudes toward HIV positives subjecting them to adverse treatments and discrimination (Anafi et al. 2014; Kwansa 2013). For instance, people may avoid HIV positives, refuse to share clothes or eat with them (Anafi et al. 2014). These ill-treatments can damage one's sense of worth. Fearing these consequences people do not readily disclose their illness (Dapaah and Senah 2016).

Economic consequences reflect the potential for impaired economic opportunities e.g. to make a living or income (Laric et al. 2009). *Employment discrimination* is an example of economic consequences (Karwatzki et al. 2017; Ulasi et al. 2009), and refers to beliefs about the potential for impaired employment opportunities (e.g., job loss, denial of employment or promotion) that can result from PHI disclosure. Sprague et al. (2011) found high levels of employment discrimination based on HIV status in all African sub-regions. These include refusal to hire or promote, and employment termination for people with HIV. To avoid these employment risks, HIV positives conceal their illness (Sprague et al. 2011).

Social consequences refer to potential damage to social relationships (Karwatzki et al. 2017), such as *family rejection* (Kwansa 2013). *Family rejection* in this study reflects beliefs about the potential neglect by one's family that can result from PHI disclosure. In many African countries, the *shame* of HIV positives is felt also by their families because of the disease's association with norm-violating behaviours such as promiscuity (Dapaah and Senah 2016). To prevent stigma by association, some families abandon HIV positive members and evict them from their homes (Kahn 2004).

Research Method

In general, individuals are said to be more willing to disclose their PHI when care is needed to improve their health (Anderson and Agarwal 2011). However, this may be challenged when persons consider the negative consequences that could arise if their PHI were exposed to others. The study uses a scenario-based survey approach to explore the impact of perceived negative consequences on willingness to disclose PHI to a healthcare provider where this information will be digitised. Data will be collected from individuals living in Ghana (a Sub-Saharan African country). Participants will be presented with a scenario involving an HIV patient, Kwame, who is contemplating whether to disclose information about his HIV status to a healthcare provider who will store Kwame's HIV treatment information electronically. Currently, Kwame's HIV status is not known to anyone. Given this scenario, participants will answer questions regarding (i) willingness to disclose their HIV status in order to receive the needed care if they were in Kwame's position, and (ii) negative consequences (i.e. perceived inferiority, family rejection, and employment discrimination) that Kwame could face should his HIV status be exposed. This approach can help address issues such as social desirability bias as participants would not report on personal intentions, but on how they might respond if presented with the described scenario (Johnston et al. 2016). Questions about trust in the technology, trust in the institution (i.e. healthcare provider), and privacy concerns are also presented.

The results are expected to yield recommendations to practice on addressing individuals' concerns about the privacy management of their PHI (Karwatzki et al. 2017). The findings are also expected to provide insights in to negative consequences, and addressing calls for further research on specific privacy harms (Kokolakis, 2015). Future research can build on these findings and explore other categories/examples of negative consequences (e.g. resource loss, mental discomfort) (Karwatzki et al. 2017), in other countries where views about the digitization of PHI and consequences may differ.

Appendix

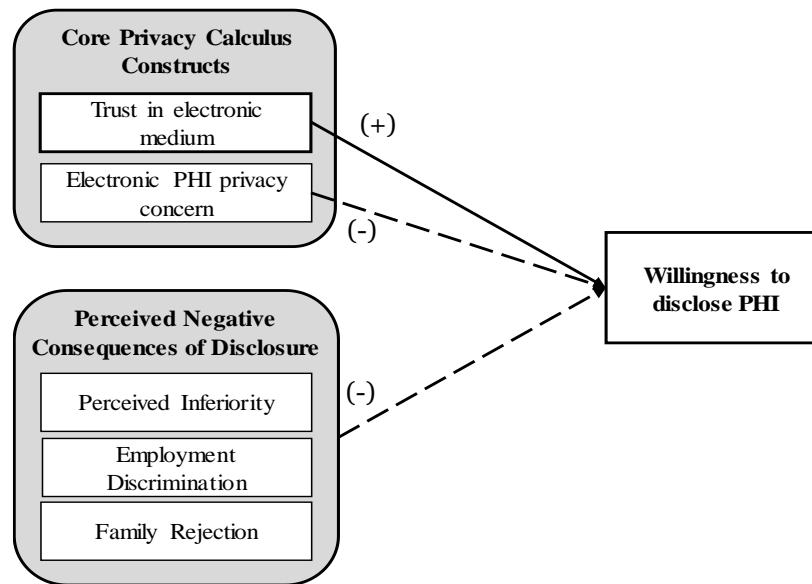


Figure 1: Research Model

Notes about Figure 1:

1. Dashed line indicates negative relationship, whereas solid line represents positive relationship
2. Trust in electronic medium refers to individuals' belief that electronic medium is safe and reliable for the storage of PHI, and their belief that the electronic storage format has the necessary components to facilitate the storage of PHI (Anderson and Agarwal 2011).
3. Electronic PHI privacy concern refers to individuals' concerns regarding opportunistic behaviour related to their digitized PHI (Dinev and Hart 2006).

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