Modelling and Analysis of Identity Personally Identifiable Information and Human Values in Patient Portals:

A Systematic Review of Older Adult-Oriented Studies

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Abstract

This paper reports preliminary findings from a systematic literature review on patient portals, focusing on the values invoked in those papers. We used content analysis to identify values, building on an earlier thematic analysis of a related (but distinct) corpus. We found that each of the 52 articles in the corpus included invocations of at least one value, with security being the most frequently invoked value and confidentiality being the least frequently invoked value. We discuss the implications and future directions.

Introduction

As health information increasingly moves online, it is critical to consider the usability of health information systems such as patient portals. These online systems can allow patients to view their personal health records, see test results, check scheduled appointments, and access educational resources. However, merely ensuring that these systems are usable is not sufficient. There is little point in designing a highly usable system that does not meet the needs of users. Typically, we think about needs such as tasks and requirements, but technologies such as patient portals also have to be sensitive to users’ values.

Patient portals are web-based portals that enable patients to access their personal health information, communicate with providers, and use various self-management tools (Otte-Trojel, de Bont, van de Klundert, & Rundall, 2014). In most cases, patient portals are tethered to health care institutions’ existing electronic health record (EHR) systems. That is, the data in a patient portal are owned and managed by the health care organizations. The recent years saw a rapid adoption of patient portals among health care organizations, suggesting that they may soon become a standard part of care (Sarkar & Bates, 2014). At the same time, preliminary evidence about positive impacts of patient portals on health outcomes has started to emerge, particularly for patients with chronic conditions. For example, a survey of 1871 US veterans infected with HIV found that the use of the VA patient portals was associated with 90% or greater adherence to antiretroviral therapy (McInnes et al., 2013).

However, whether or not patient portals are effective in empowering patients and improving quality of care remains largely inconclusive (Kruse, Argueta, Lopez, & Nair, 2015). A major challenge is that the adoption rate of patient portals is still low. In most studies, the adoption rate was less than 50%. Some were even lower (Yamin et al., 2011). Many reasons contribute to this low adoption rate, including users’ demographic and socioeconomic status (e.g., old age, low education and income, and low health literacy), system usability, and a lack of awareness among patients (Lyles, López, Pasick, & Sarkar, 2013; Ronda, Dijkhorst-Oei, & Rutten, 2014).

Theory

This research connects two distinct strands of theory within our field: human values and usability. Human values can be defined as “what a person or group of people consider important in life” (Friedman, Kahn, & Borning, 2006). Values are trans-situational (Hitlin and Piliavin, 2004), insofar as they apply to many aspects of life. Human values can be used to explain sentiment, which is individuals’ positive and negative reactions to individuals, groups, or concepts (Fleischmann, 2014). This paper focuses on six values identified in a prior thematic analysis of values in personal health records (Fleischmann, Zhang, & Xie, 2015): privacy, confidentiality, security, trust, transparency, and agency (all defined below).
Usability can be defined as “the ease with which the target user of a product can successfully complete appropriate tasks with that product” (Collins & O'Brien, 2011, p. 501). For a product to be successful, however, good usability is not sufficient; the design must also satisfy users’ emotional needs (e.g., to be desirable, valuable, and credible) (Garrett, 2010). These feelings, in many cases, are fueled by human values. As Friedman and Kahn (2008) argue, “some HCI designers, however, have a tendency to conflate usability with human values with ethical import” (p. 1244). Values and usability can come into conflict in some cases; for example, a highly usable system for hackers can undermine security. Values can also impair usability, as with the tedium of cookie management in surfing the web. Values and usability may be independent, or they can work in tandem to provide the best possible user experience.

**Research Questions**

RQ1: To what extent and in what ways have existing studies of patient portals considered the importance of protecting the PII of patients?

RQ2: To what extent and in what ways have existing studies of patient portals considered the role of human values such as privacy, confidentiality, security, agency, trust, and transparency in protecting the PII of patients?

RQ3: To what extent and in what ways have existing studies of patient portals considered the role of human values in protecting the PII of older adults with low eHealth literacy?

**Research Methods**

To achieve a comprehensive understanding of how patients use patient portals, we performed a systematic literature review of user studies of patient portals. A systematic review is a literature review that focuses on identifying and appraising research evidence about a topic in an exhaustive manner, and summarizing what is known about the topic (Crowther, Lim, & Crowther, 2010). Our systematic review followed the following steps:

Step 1: Database Search
Databases were selected from the electronic journal databases available through the authors’ institution. Given the focus of this literature review, databases were selected from the following eight fields: Communication, Communication Sciences and Disorders, Communication Studies, Consumer Health, Library and Information Science, Medicine, Nursing, and Psychology. To be included, a database must:

1. Contain journals that publish peer-reviewed articles. Databases that only contain dissertations, e-books, book reviews, video/audio, encyclopedias, images, factual data, regulations/laws, citations, or directories were excluded.
2. Allow keyword search in the title or abstract.
3. Be relevant to the scope of the present review.
4. Contain articles with full text written in English.

Based on these criteria, a total of nine databases were selected (the year coverage of each database listed below was the coverage available through the library of the authors’ institution). These included:

1. ACM Digital Library (1985 - present);
2. PubMed/Medline (1950 - present);
3. Communication & Mass Media Complete (CMMC, 1920 - present);
4. Cumulative Index to Nursing & Allied Health (CINAHL) Plus with Full Text (1937 - present);
5. PsycINFO (1887 - present);
6. Sociological Abstracts (1952 - present);
7. Cochrane Library (Dates of coverage vary);
8. Health Source: Nursing/Academic Edition (Dates of coverage vary);

Additionally, to ensure a broad coverage, we also searched Google Scholar, resulting in a total of ten databases.

**Step 2: Keyword Search**

In June 2015, using the search term “patient portal*,” one of the authors performed keyword searches in the Title and Abstract of the nine databases selected from the library’s resources and searches in Title in Google Scholar. The following inclusion/exclusion criteria were used for this round of the searches:

1. Only included papers from peer-reviewed journals or conference proceedings.
2. Only included papers with full text written in English.

After removing duplicates, a total of 253 unique records were identified. The title and abstract of these articles were downloaded to a reference management tool, Zotero, for further screening.

**Step 3: Title/Abstract Screening – First Round**

The following inclusion/exclusion criteria were used for this round of screening:

- Included publications reporting original research findings.
- Excluded non-empirical publications (e.g., abstracts, editorials, commentaries, book reviews, viewpoints, opinions).

One coder used this criterion to code the articles, and a total of 72 articles were excluded, leaving 181 articles for further analysis.

**Step 4: Title/Abstract Screening – Second Round**

The remaining 181 articles were examined by two independent coders (two of the authors) using the following criteria:

1. To be included, papers must focus on empirical results from user studies of patient portals, involving patients as end users, that is, reporting patients’ use of patient portals. This included both studies of patients’ actual use of patient portals and studies of user perceptions, needs and requirements.
2. Only included papers with full-text, not just abstract.
3. Papers that only reported background information about patient portals such as the adoption rate of patient portals or the characteristics of adopters were excluded.
4. Papers that only analyzed messages in patient portals were excluded.
5. Papers that only reported the use of patient portals by clinicians or clinicians’ attitudes and preferences towards patient portals were excluded.

Three of the authors discussed these criteria and used them to independently code the first 20 records. After further discussion, we reached a consensus. The inclusion/exclusion criteria and notes about the coding decisions and rationale for the first 20 records formed the material to train a graduate research assistant (GRA) to screen the rest of the records. The GRA, following the examples of records 1-20, practiced coding records 21-40. Meanwhile, one of the authors also independently coded these same 20 records, and we compared the coding results from these two independent coders. The comparison shows that the raw agreement between these two independent coders was 85% (17/20 in agreement). However, to factor in the chance that the two results might agree randomly, especially in a case where there is a binary classification, we used Cohen’s (1960) Kappa, a standard measure of inter-rater reliability. The
resulting Kappa was 0.5. Based on Landis and Koch’s (1977) benchmarks, this represents moderate agreement, which is an encouraging preliminary result.

All authors then discussed the three items that the two coders disagreed on, consulted the full text of these items, and then reached a consensus (which included tweaking the criteria for clarity and consistency). The two coders then coded the remaining records. In total, 125 records were excluded, leaving 56 records in the final dataset.

Step 5: Data Extraction
For the preliminary analysis, one of the authors reviewed the citation records of the 56 included articles and coded the following information concerning each article in Excel: year of publication, journal where the article was published, participants involved, aspects of use of patient portals studied, and research methods. (In further analysis in the future, we will identify the characteristics of the use of patient portals, including usage patterns, barriers and facilitators to the use, and users’ expectations.)

Step 6: Content Analysis of Human Values
While the literature on human values has primarily employed surveys, surveys are not practical in a wide range of situations, and carry inherent biases (Fleischmann et al., 2009). This study followed other content analyses found in the literature (e.g., Cheng, 1994; Cheng et al., 2012; Fleischmann & Wallace, 2010; Koepfler & Fleischmann, 2013, 2014; Rokeach, 1973). Our value inventory was based on a previous thematic analysis of a related, but non-overlapping (by design), set of articles on personal health records (Fleischmann, Zhang, & Xie, 2015). The six values in the inventory were:

1. Privacy (how patients control access to their own records and personal health information)
2. Confidentiality (how practitioners and others restrict others’ access to patient records)
3. Security (preventing unauthorized access to patients’ records and personal health information)
4. Transparency (ensuring patients understand the systems and the information provided therein)
5. Trust (ensuring patients have confidence in the systems and the information provided therein)
6. Agency (ensuring patients feel empowered to make their own decisions about their records)

The prior thematic analysis was conducted by one of the authors, who selected quotes to use as training data. The inventory and training data were then used to train another author to also conduct the content analysis of this corpus. The two coders worked independently to identify if a particular value was invoked within the text of a particular paper in our dataset. We initially computed inter-annotator agreement using Krippendorff’s (2012) alpha, after which we discussed each of the disputed value codes to achieve consensus. We used these consensus results for all quantitative and qualitative analyses reported here.

Results
The 56 articles in the final sample were published between 2005 and 2015. The number of publications between 2005 and 2011 was stable, ranging from one to four each year. 2012 saw an increase of attention to this topic, with 9 (16.1%) articles being published. The peak appeared in 2014, with 16 (28.6%) articles being published in this year. The level of attention to this topic continues to develop. The year 2015 so far (early June when the search was performed) has already yielded eight articles.

The 56 articles were published in 34 unique journals and conference proceedings. Journals that published the most number of articles were the Journal of Medical Internet Research (10 articles) and Journal of American Medical Informatics Association (9 articles). The most common conference venue was the American Medical Informatics Association Annual Symposium (3 articles).
The purpose of this systematic review was to examine patients’ use of patient portals to inform the design of effective patient portals. The included articles examined a number of different aspects of patients’ use of patient portals. These include patients’ use of specific functions of patient portals (e.g., accessing radiological reports, managing medications, and using electronic messaging to communicate with healthcare providers), patterns of usage, patients’ perceptions of and attitudes towards patient portals, barriers to using patient portals, and disparities in the use of patient portals among underserved user groups (e.g., older adults, patients with low education levels, and patients with low English proficiency and literacy levels).

In the included articles, the participants were predominately patients associated with specific hospitals or clinics. Only one article reported studying general health consumers, and four articles included parents or primary caregivers. Most patient portals target patients with chronic conditions, led by diabetes, with 12 articles reporting studies related to patients living with diabetes. Other commonly studied chronic conditions included HIV/AIDS (1 article), lung cancer (1), multiple sclerosis (1), and asthma (1).

A number of research methods were used to study patients’ use of patient portals. The most popular methods were survey (19 articles), transaction log analysis (12 articles), randomized controlled trial (8 articles), observation of users using specific systems (8 articles), focus group (7 articles), various forms of interview (including in-depth, semi-structured, and structured telephone interviews, 5 articles), and review of patients’ medical records (3 articles). In about a dozen articles, several different methods were used. The most common pairing of methods was between transaction log analysis and either the review of patients’ EHRs or survey, particularly when the purpose of the article was to examine the relationship between patients’ characteristics or the use of portals and health outcomes.

Following independent coding of the articles for values by the two expert coders, we began by measuring the reliability of the coding based on the frequency of their agreement. By comparing the results using Krippendorff’s (2012) alpha, we found that one value, privacy, had high enough agreement to use for meaningful analysis; another value, confidentiality, had high enough agreement to use for drawing tentative conclusions. Based on this result, we used a process of consensus to achieve the final set of results.

<table>
<thead>
<tr>
<th>Value</th>
<th>Privacy</th>
<th>Confidentiality</th>
<th>Security</th>
<th>Transparency</th>
<th>Trust</th>
<th>Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha</td>
<td>0.89</td>
<td>0.71</td>
<td>0.20</td>
<td>-0.27</td>
<td>0.61</td>
<td>-0.16</td>
</tr>
</tbody>
</table>

Table 1. Inter-Annotator Agreement (Krippendorff’s Alpha)

How frequently did the values occur in studies of patients’ perceptions and use of patient portals? As Table 2 illustrates, the most frequently occurring value was security (67%), followed by transparency (54%), agency (52%), trust (46%), privacy (46%), and confidentiality (23%).

How many papers included invocations of multiple values? All 52 papers included invocations of at least one of the six values. Of the 52 papers in the corpus, 4 (8%) of the papers included invocations of all six values; 7 (13%) included invocations of five of the values; 9 (17%) included invocations of four of the values; 14 (27%) included invocations of three of the values; 8 (15%) included invocations of two of the values, and 10 (19%) included the invocation of only one value.

How frequently did the values co-occur? The most frequent pairing was between security and agency (50%), followed by transparency and agency (44%), and privacy and security (42%). Security was the most frequently co-occurring value for privacy, confidentiality, and agency, while agency was the most frequently co-occurring value for security, transparency, and trust (Table 2).
Table 2. Frequency of Values and Value Pairs

<table>
<thead>
<tr>
<th></th>
<th>Privacy</th>
<th>Confidentiality</th>
<th>Security</th>
<th>Transparency</th>
<th>Trust</th>
<th>Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Privacy</td>
<td>46%</td>
<td>19%</td>
<td>42%</td>
<td>27%</td>
<td>27%</td>
<td>38%</td>
</tr>
<tr>
<td>Confidence</td>
<td>23%</td>
<td>21%</td>
<td>17%</td>
<td>13%</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Security</td>
<td></td>
<td></td>
<td>67%</td>
<td>35%</td>
<td>33%</td>
<td>50%</td>
</tr>
<tr>
<td>Transparency</td>
<td></td>
<td></td>
<td></td>
<td>54%</td>
<td>27%</td>
<td>44%</td>
</tr>
<tr>
<td>Trust</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>46%</td>
<td>38%</td>
</tr>
<tr>
<td>Agency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>52%</td>
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</tbody>
</table>

**Analysis**

**Privacy.** Discussions relating to privacy invoked a few specific ideas and examples: concerns of exposing or accessing personal contact information (such as email accounts and/or telephone numbers) or demographic information to various parties (including sensitive and “detailed personal information about patients’ medical, social, and family histories” (Vodicka et al., 2013); a preference for “sending psychosocial messages by portal because it affords privacy and distance” (Lin et al., 2005); “respect for personal boundaries” (Osborn et al., 2011); concerns related to accessing the portal in a public space, including because a home computer was not available; and HIPAA compliance.

**Confidentiality.** Confidentiality was closely linked with both privacy and security; it was not coded in a single document without one or the other (and usually both) also appearing. Authors invoking confidentiality described ideas related to using secure online messaging as a means of “communicating sensitive information (eg, depression/anxiety symptoms, sexual dysfunction)” (Wade-Vuturo et al., 2013); HIPAA compliance; issues of open visit notes and patients’ “sharing their visit notes with others, including other doctors” (Walker et al., 2011); tired access levels to the portals and health information (non-family specific); and issues of access and information availability between family members or patients and caregivers—particularly between parents and children or teenagers. Zarcaadoolas et al. (2013) describe “the issue of parental access to an adolescent’s online health records” as “complicated to resolve;” Bergman et al. (2008) similarly note that “there would have to be ground rules around confidentiality and disclosure of important health issues that would have to be negotiated by each family.”

**Security.** Detailed discussions of security within the documents included several different facets of digital and information security, including: specifics of the login process for the portal and/or the authentication process; the ramifications and complications caused by sharing passwords between patients and their surrogates or others; the importance of the login process and the necessity of having secure passwords; the (often unspecified) dangers of unauthorized individuals (including other personnel or staff involved in the patient’s care or in portal design and maintenance, total strangers, or family members and past or present acquaintances) accessing patient data; “hacking” and identity theft; data encryption features (such as SSL); and the avoidance of “insecure” mediums of communication for sensitive information.

**Transparency.** We identified two main themes: the transparency of the ICT itself and the transparency of the information presented. Discussions related to the transparency of the ICT itself were closely related to issues with accessing and understanding the portal features, including: user interface design, HCI, and usability issues related to fundamental access of patient-desired information; unclear expectations from either the patient or physician; lack of clarity regarding specific practices or criteria of the portal, including a desire for increased “transparency of confidentiality policies in play” (McNamara et al., 2014).

**Trust.** We found some distinction between the concepts of having trust in the system (the patient portal and how it operates), as opposed to trusting the health information contained and presented within the patient portal (including general disease and health information, patient records entered by the medical
care centers, and patient-recorded information). The former case often involved “privacy” and “security” issues or issues relating to the constancy and reliability of access and maintenance of the portal, including concerns that “information was not made available in the portal or the portal was not up-to-date” (Giardina et al., 2015). Examples of the latter case would include patients’ preference for a “direct link to accurate and trustworthy health information (via search engine or hospital-based website)” (Dhanireddy et al., 2014), or a participant’s assertion that “I am not quite sure who maintains the information. If someone else does it, I don’t trust it 100%” (Chou et al., 2010). Authors also discussed trust in relation to perceptions of and relationships with medical professionals involved in care; doctor/physician endorsement of the portal; general distrust of technology and/or a lack of prior access to digital technologies (e.g., digital divide issues); unfamiliarity with the particular portal, previous negative experiences with similar technology; and perceived reputation of originating agencies and sources.

Agency. When discussing the concept of agency, document authors often focused on issues of empowerment, management (including self-management), engagement, autonomy, control, and active (including proactive) or collaborative involvement with the patient’s health or health information. The potential difficulty in adequately and accurately invoking agency was also addressed specifically by Giardina et al. (2015), who argue that “though a recent review of controlled trials found insufficient evidence to support increased empowerment, it may be an issue of how empowerment is conceptualized (i.e.; self-efficacy, control, activation). Despite patient empowerment being ubiquitous, in the literature related to health information technology, there is no consensus on the definition” (Giardina et al., 2015).

Discussion

Patient portals, a new health information technology with the promise to improve patients’ access to their clinical data, have received great attention from policy makers, health care organizations, and patients themselves. However, the adoption rate is still low. This systematic review intends to review the current research evidence concerning patients’ use of patient portals to shed light on the design of effective patient portals to encourage user adoption and use. The preliminary analysis uncovered a number of aspects from which the use of patient portals has been studied in the literature. As this preliminary analysis is a part of a larger study, in further analysis in the future, we will identify specific usage patterns, barriers and facilitators to the use of patient portals, as well as users’ expectations.

The preliminary results also indicate that most of the selected studies were conducted in clinical settings and published in health-focused journals. Only one article was published in an information science journal, Journal of the Association for Information Science and Technology. This finding invites information science researchers to contribute more actively to the study of patients’ use of patient portals from a human information behavior perspective.

Our analyses show that security, transparency, and agency occurred most frequently, with each of them found in more than half of the papers in the corpus. While trust and privacy were each invoked in nearly half of the publications, confidentiality occurred in only 23%. This low occurrence of confidentiality was a surprise, given that this value (which considers how anyone who has legitimate access to patient records also has the responsibility to fully protect patients’ personal information in the portals) is strictly mandated by federal and state regulations (e.g., HIPAA, HITECH). This finding perhaps reflects a more technology-centric view of patient portals in the current conversations about these systems, as security often lies more at the technological level. However, confidentiality involves a more subtle balance of relationships among different stakeholders and different types of information. The lack of emphasis on confidentiality in the majority of the papers may also be due to our focus on user studies by patients, instead of providers.
Interestingly, while we did not limit our searches to patient portal studies involving values (i.e., we did not use the keyword “value” or any of the six values in our searches), it still turned out that all publications in our final sample invoked at least one value. This result is a promising sign that patient portal researchers and designers are already sensitive to value-related issues, although more attention on various combinations of multiple values – and particularly their interactions or design tradeoffs – is still much needed. For instance, in a small practice where two or three physicians regularly cover for each other (i.e., “share” their patients) while their colleagues are out of the office for any reason, confidentiality might be less important than security. However, in a large hospital with over 30 different units employing hundreds of providers that typically have little need to share patient information in their care of the patients, confidentiality may just be as important as security.

Our study findings have important implications for patient portal researchers and designers as well as healthcare providers. First, researchers need to pay more serious attention to the potential effects of human values on the adoption and use of patient portals (among patients and healthcare providers alike). Second, designers should always have a good understanding of the target users’ values and strive to achieve the best balance that can accommodate the values of target users, who may prioritize different values and whose prioritized values may even change over time under evolving circumstances. Finally, in order to improve the adoption rate of patient portals among patients with diverse characteristics, healthcare providers need a good understanding of the values that a specific portal may implicitly or explicitly promote (or, alternatively, may suppress, both intentionally and unintentionally), and assess whether or not a portal matches patients’ values.

Due to time and space constraints, we were unable to delve into depth in this preliminary report regarding several important issues, which we plan to address in our future work. These include:
• Does a specific value invocation reflect the authors’ perceptions or those of the end users?
• Do patient portal designers and healthcare providers fully understand the differences – and design tradeoffs – between different values (e.g., security and confidentiality)?
• Our analyses suggest that noticeable percentages of – and different combinations of – values co-occur in patient portal studies. It would be interesting to examine if and how designers might have intentionally considered multiple values simultaneously, and if and how the final product might have achieved what they intended to (e.g., when designers intentionally invoke both security and confidentiality in the design); would the final product be more likely than otherwise to ensure both?
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