ICT-Enabled Self-Management of Chronic Diseases: Literature Review & Analysis Using Value-Sensitive Design

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Abstract

Increasing number of older population and patients with chronic diseases, demand a new healthcare model in which patients take more responsibility in their disease management and actively collaborate with their health professionals, known as self-management (SM). SM is defined as a patient’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and life style changes that are germane to living with a chronic disease. The use of ICT-enabled SM systems have shown promising benefits for the patients with chronic diseases. However it is not clear in the literature if the human values important to the patients are implicated in the SM systems. In this paper, building on Value-Sensitive Design (VSD) perspective and Information Systems Design Theory (ISDT), we have conducted a literature review and analysis to uncover SM human values, to explicate the extent to which those values are implicated in the SM systems, and to illustrate the ways values can be supported in the SM systems.

1. Introduction

Increasing number of older population and patients with chronic diseases such as diabetes, asthma, and arthritis [2, 3, 7, 15, 18, 19, 33] coupled with limited resources and increasing healthcare costs [6, 26], demand a new healthcare model. In this shifting paradigm, patients are expected to take more responsibility of their disease management and actively collaborate with their health professionals in the treatment of their conditions [3]. In this new ‘collaborative care’ paradigm, empowered patients are their own caregivers and healthcare professionals are their consultants [3, 13]. SM, compared to standard care, has shown promising benefits for the patients with chronic diseases by improving their anthropometrics, physical activity, diet, medical, and psychosocial outcomes [2, 3, 6, 7, 10, 15, 19].

Chronic diseases, which are increasing in the developed countries [22], can be very disruptive to individuals’ everyday lives [31]. SM, which is defined as a patient’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes that are germane to living with chronic disease [2], has reduced health-related costs and assisted patients to develop skills and techniques to enhance their self-care and improve their health outcomes [25]. Mobile technologies through their pervasiveness, for example, have the potential to reshape the nature of disease monitoring and SM [28]. SM enabled by the Information and Communication Technologies (ICTs) has several advantages over other approaches, such as higher, easier, and faster access regardless of time and location [22, 23], real time feedback [29], error detection and frequent data collection [16], and improved communication [38]. Although, the impact of information systems on SM of chronic diseases has been studied [8, 24], the designs of such systems have not been critically evaluated. In this study we premise that there is a need to assess the degree to which human values that are important to the patients with chronic diseases are implicated in the SM systems.

Our review suggests that researchers in the SM area have continued to primarily focus on enhancing medical control of chronic diseases to the exclusion of patient-based outcomes that support a more holistic view of patient function, longevity, quality of life, and human values [26]. El-Gayar et al. [8], for example, in their review of diabetes SM briefly discuss the value-added benefits realized from ICT-enabled SM. However, they surmise that more research is needed to understand how such support can be further improved [8].

There is an increasing interest in considering human values in the design, development, and use of information technology and systems [for example, 17, 32, 40]. Human values should be investigated in relation to how they are supported, augmented, or constrained by technological developments [32]. Most information systems theories draw on functionalist assumptions neglecting or compromising human values of end users [17]. IS researchers and practitioners need
to consider a broad array of issues while designing information systems. The relevance of human values in IS, is that information systems influence human lives and system designers have an obligation to implicate desirable values in the systems [5]. This is particularly true in the context of SM of chronic diseases that emphasizes on human-centered approaches that can result in prosperous living experiences. Therefore, the objective of this paper is to conduct a systematic review of the literature using VSD perspective to address the following question - How and to what extent human values are implicated in the design of the ICT-enabled SM systems for patients with chronic diseases?

Drawing on VSD methodology, we examine current literature on SM of chronic diseases to assess the implication and instantiation of human values in SM systems. Our findings can provide guidelines for supporting human values in the ICT-enabled SM systems for patients with chronic diseases.

The paper is organized as follows. In the next section, we will discuss theoretical background of ICT-enabled SM and relevant literature. Next, we will discuss method and will present findings and analysis. We will conclude with discussion, limitations, and conclusion.

2. Theoretical Background

In the following sections we summarize the relevant literature, introduce VSD, ISDT, and an Integrated Framework.

2.1. ICT-enabled self-management

In the shifting healthcare paradigm, the patients are no longer passive recipients of the care but active participants in their chronic disease management [2]. SM is planned and conducted in a variety of ways and by using diverse techniques, such as educational interventions, self-reported care strategies, peer-supported goal-setting and action planning, multi-modal interventions, and ICT-enabled interventions. In the last approach, SM techniques are delivered via ICTs.

Healthcare reform in the US known as Affordable Care Act (ACA) provides a crucial moment to study SM programs. ACA will expand health coverage and patients with chronic conditions are the ones with the highest needs. Yet, health demands of the newly covered people with chronic diseases will outpace the availability of health services and resources. Hence, ACA aims to promote and improve SM for the patients with chronic diseases providing more efficient, cost-effective, and accessible health services [33]. An in-depth understanding of SM programs can inform national policy on the provisioned health reform.

The impact of ICTs on SM of chronic diseases has been studied in prior literature [for example, 8, 24]. There is some evidence to suggest that the values embedded in SM systems are limited to the functionalist medical outcomes and human-based values are often not implicated and communicated in the design of such systems [26]. However, the extent to which human values are supported in the designs of SM systems for the patients with chronic diseases have never been systematically evaluated. In the following sections we will describe the theoretical and methodological perspectives, VSD and ISDT, and an integrated framework, used to examine the literature to investigate human values in the SM information systems.

2.2. Value sensitive design

VSD, a theoretically grounded approach introduced by Friedman et al. [12], provides a comprehensive framework for developing a value-centered research and design agenda [40]. VSD is a design approach “that accounts for human values in a principled and comprehensive manner throughout the design process” [12, p. 70] while building information systems. VSD is based on three investigations, conceptual, empirical, and technical, which are used in an iterative and integrative manner. Since its introduction, VSD has been used in various studies, scarcely used by the IS scholars, for investigating human values such as, privacy [39], universal usability [37], autonomy, [34] and trust [27]. In the following sections the concept of ‘value’ in VSD is elaborated and three pivotal investigations, conceptual, empirical, and technical, are discussed.

2.2.1. Values. Values are not inscribed into ICTs nor do the users of such systems merely hold values [4]. Rather, information system designers impart social and moral values in their works [11]. A system’s design dictates the nature and extent of its use. In other words human activity is constrained by the system features, but not determined by it [11]. Values are classified in three categories, (1) moral, justifications based on justice, fairness, and rights, (2) conventional, social behavioral uniformities promoting better social interactions, and (3) personal, self-centered judgments [11]. When information systems are designed, conflicts arise between these values. While designing information systems, designers make decisions by balancing competing values [11]. Values discussed in VSD refer to what a person or group of people
consider important in life. Values such as privacy, universal usability, trust, freedom from bias, autonomy are examples of universal human values suggested by Friedman et al. [12]. In the context of SM of chronic diseases, common attributes associated with chronic diseases, patients’ needs, benefits of SM, are identified and analyzed to uncover the values important to the patients with chronic diseases. Further discussion is provided in ‘Findings and Analysis’.

2.2.2. Conceptual investigation. It is the philosophical and theoretical grounding of the central constructs and values. It provides theoretical and conceptual criteria for the implementation of core constructs and values [4].

2.2.3. Empirical investigation. It examines the human response to the technical artifact and empirically investigates the technical artifact situated in the human context [12]. The entire range of qualitative and quantitative methods used in social sciences, such as interviews, observations, surveys, are potentially applicable [4].

2.2.4. Technical investigation. It investigates what technologies are suitable for what activities and applications. It examines how existing technological properties and mechanisms support or hinder human values [12].

2.3. Information systems design theory

In this paper, the main focus is on the ICT-enabled SM system, and thus, our analysis employs three main components of ISDT posited by Walls et al. [36]. ISDT is defined as “a prescriptive theory which integrates normative and descriptive theories into design paths intended to produce more effective information systems” [36, p.36]. Design, as articulated in ISDT, can be a product or a process, about principles underlying the form of design and act of implementing the design [14]. ISDT has three main components, kernel theories, meta-requirements, and meta-design. These components are discussed in the following subsections.

2.3.1. Kernel theories. These are theories from natural or social sciences which inform and guide design requirements. For example, Chatterjee et al. [5] have used ethical theories to design a Collaboration Engineering artifact.

2.3.2. Meta requirements. Design requirements are informed by kernel theories. Meta-requirements are class of goals and problems to which the kernel theories apply. For example, Chatterjee et al. [5] draw consistency and accountability driven from ethical theories as meta-requirements in designing Collaboration Engineering artifact.

2.3.3. Meta design. It describes a class of artifacts which meet the goals and problems of the meta-requirements. For example, in the work of Chatterjee et al. [5], a conceptual schema is introduced as an ethical collaboration class which consists of practitioners, facilitators, and participants meeting the requirements of consistency and accountability.

2.4 Integrated Framework

Here we posit an integrative framework by combining VSD and ISDT perspectives which is used to analyze and synthesize the findings in the literature (See Figure 1). This integration facilitates the translation of VSD’s methodological components into design-oriented outcomes. The integration has been done based on the common assumptions between two perspectives. Conceptual investigation in VSD is integrated with kernel theories and meta-requirements in ISDT. These components from VSD and ISDT perspectives serve the same purpose which is providing a theoretical and conceptual foundation for the design of the information systems. Technical investigation in VSD is integrated with meta-design in ISDT. Meta-design and technical investigation describe and identify set of technologies, ICTs in this article, which can be utilized toward meeting design requirements. Detailed discussion of the interrelationships among these components is articulated in section 4.2.

![Figure 1. Integrated framework combining VSD and ISDT perspectives](image-url)

3. Method
The literature review was conducted at the intersection of ICTs, SM, and design literature streams. The articles were identified by conducting a search in Business Source Complete (EBSCO), CINAHL, Complete (EBSCOHost), MEDLINE (EBSCO), HICSS Digital Library, AIS Library/Journals, IEEE Xplore Digital Library, Cochrane Library, Google Scholar, ScienceDirect using keywords self-management, self-care, self-monitoring, information technology/system, information and communication technology, IT-enabled, tele-, mobile, mhealth, health, and social media. In order to extract relevant articles, keywords were searched within each document’s title and abstract. Additional search included bibliographic search of the eligible articles.

Studies with the main focus on SM of chronic diseases were included in the review process. Search results were pooled in two sets. The first set consists of SM articles that did not use ICTs to provision SM. The second set comprised of ICT-enabled SM articles that prominently discussed the use of ICT-enabled systems in delivering SM to the patients with chronic diseases. Human values important to the patients with chronic diseases were identified from the first set. The needs and desires of the patients with chronic diseases, the common attributes of chronic diseases, and benefits of SM intervention and programs were more elaborately discussed in the first set of articles. Therefore, this literature was more conducive to identifying human values. Whereas the ICT artifact was central to the papers in the second set which allowed us to assess the ICT-enabled delivery of SM programs and interventions. The literature review and analysis was conducted using the integrated framework (Figure 1). In the next section we will further discuss the findings and analysis from our literature review.

4. Findings and Analysis

Our initial literature search generated 74 chronic SM articles in which ICTs were not primarily used in delivering SM, and 145 ICT-enabled SM articles. After removing duplicates and irrelevant papers, the first set contained 61 articles and the second set comprised of 113 articles. SM articles were reviewed to uncover human values, while the ICT-enabled SM articles were analyzed to identify human values supported in the ICT-enabled SM systems and to assess how the identified values were implicated in the system design. In the next section we discuss the systematic analysis conducted for identifying human values that are important to the patients with chronic diseases, and investigating ICT-enabled SM systems implicating those values.

4.1. Values

Values were uncovered using a three step process. First, the articles from the first set of papers were analyzed to identify the common attributes across chronic diseases, needs and desires of the patients, and benefits and advantages of using SM interventions and programs. Second, the findings from the first step were clustered into 4 universal human values introduced by Friedman et al. [12] (Table 1). In addition to these four values, one new human value, ‘hope’, emerged from our analysis (see table 1). The clustering in step two was conducted by mapping the findings from step one on to the definitions of the values introduced in the literature. The values are theoretically and empirically investigated and validated in the prior literature [12, 30]. In the third step, visual lexical analysis, generating word clouds after removing confounding search terms, was conducted to study word frequency distributions to validate the value clusters uncovered in the second step. These higher level values revealed in this step were used to judge the nature and the extent to which these human values were implicated in the ICT-enabled SM systems. This analytical process enables us to connect the higher level values (that are theoretically and conceptually grounded) with the lower level values implicated in the systems (that are revealed in design requirements and features). Analysis of the values against ICT-enabled SM systems is discussed in the next section.

4.2. Values implicated in the SM system design

In this section we describe the nature and extent of human values implicated in the design of ICT-enabled SM systems proposed in the literature. The ICT artifact discussed in the second set of papers was the primary unit of analysis. An ICT-enabled SM system explicated in an article was examined against the uncovered values (see table 2). If an ICT-enabled system articulated in the article did not support any major SM task or if the SM system was not described clearly, or if it was not informing the 3 investigations, meta-requirements and meta-design in table 2, then it was eliminated. For example, the SM system using mobile technologies explicated in Wickramasinghe et al. [38] was identified as having a substantial role in delivering SM because it facilitates communication between the patients and health professionals and provides medical and psychosocial feedbacks for the patients, motivates
requirements, such as ‘immediate support’ and (kernel theories) they have generated design conditions. Drawing on behavior change theories been designed for the SM of diabetes chronic use of mobile phone technology (meta-design) has [9], a real-time telemedicine system based around the chronic conditions. In another work by Farmer et al. resources will hold higher hopes in managing his ‘hope’. A patient with higher accessibility to the SM ‘attribute of ‘resource availability’ in the definition of chronic diseases. Immediate support aligns with the providing immediate support for the patients with (of mood experience (kernel theories). Such system is designed in a way that supports the value of ‘hope’ by providing immediate support for the patients with chronic diseases. Immediate support aligns with the attribute of ‘resource availability’ in the definition of ‘hope’. A patient with higher accessibility to the SM resources will hold higher hopes in managing his chronic conditions. In another work by Farmer et al. [9], a real-time telemedicine system based around the use of mobile phone technology (meta-design) has been designed for the SM of diabetes chronic conditions. Drawing on behavior change theories (kernel theories) they have generated design requirements, such as ‘immediate support’ and ‘personalized approaches’ (meta-requirements). These requirements are implicated in the system design by implementing immediate communicative channels for the nurses contacting patients with chronic diseases, using text messages or calling mobile phones and leaving voice messages. In this example, behavior change theories recommend that immediate support can lead to a behavior change. Immediate support reinforces internal motivation in the patient and internal motivation is part of the ‘hope’ definition. In such a system, ‘phone-based diary’ is designed so patients can input additional information while they are self-managing their conditions, for example, when they are monitoring their glucose levels. Additional information input enabled by ‘phone-based diary’ design feature, empowers patients to customize their SM routines, which allows them to be more autonomous. Hence, this supports the value of ‘autonomy’ as it enables patients to plan, decide, and act in ways that they believe will help them to achieve their goals.

Our VSD analysis shows that the values of ‘universal usability’ and ‘trust’ are the least implicated in the SM systems designed for the SM of chronic diseases. The value of ‘human welfare’ on the other hand, which relates to the physical, and psychological

<table>
<thead>
<tr>
<th>Human Values</th>
<th>Definition of the Value</th>
<th>SM Values</th>
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<tbody>
<tr>
<td>Hope</td>
<td>Refers to primarily future orientated expectation (potentially informed by negative experiences such as mental disorder) of attaining personally valued goals which will give meaning, are subjectively considered possible and depend on personal activity or characteristics (e.g. resilience and courage) and/ or external factors (e.g. resource availability)</td>
<td>Problem solving, goal setting, action plan, and achieving health goals; internal motivation; social and peer support; access to resources; decision making; knowledge; feedback; coping with negative emotions; cognitive and attitudinal barriers toward self-management; uncertainty [1, 2, 3, 7, 10, 13, 15, 18]</td>
</tr>
<tr>
<td>Human Welfare</td>
<td>Refers to people’s physical, material, and psychological well-being</td>
<td>Cost-effectiveness of the self-management for the patients; distress and anxiety; improvement in mental and physical health; self-monitoring; depression; changing life-style; Treatment adherence; improved self-management skills; [1, 2, 3, 6, 7, 13, 15, 18, 19, 26, 21, 33]</td>
</tr>
<tr>
<td>Universal Usability</td>
<td>Refers to making all people successful users of information technology</td>
<td>Chronic care models in low income countries; culturally adapted diabetes self-management; racial/ethnic minorities; underserved groups; mostly for the well-educated higher-income white adults; gender and age differences; adjusting one’s lifestyle may conflict with cultural norms; Cultural appropriateness; language tailoring [1, 10, 13, 15, 19, 33]</td>
</tr>
<tr>
<td>Trust</td>
<td>Refers to expectations that exist between people who can experience goodwill, extend goodwill toward others, feel vulnerable, and experience betrayal</td>
<td>Active partnership with professional healthcare providers; participating in treatment decisions; participatory decision making; effective communication with health professionals; [1,2, 3, 18, 19, 33]</td>
</tr>
<tr>
<td>Autonomy</td>
<td>Refers to people’s ability to decide, plan, and act in ways that they believe will help them to achieve their goals</td>
<td>Patient empowerment; increase the skills and confidence of patients in managing; patient takes responsibility for his/her chronic condition ; self-efficacy; patients are experts about their own lives; Allowing patients to define their problems can be eye-opening; Tailoring; responding to patients’ individual needs; limited presence of ‘self’ in self-management ; [1, 2, 3, 6, 7, 15, 18, 19; 26, 30, 33]</td>
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</table>
well-being, is highly implicated in the ICT-enabled SM systems. In fact, it is assumed that SM systems are merely used to improve medical outcomes while other values being compromised. In observing ‘human welfare’ value in the SM system, the material well-being which refers to the affordability of the SM system is also neglected. Patients with chronic diseases face long term expenses in improving their chronic conditions and it is not clear, neither empirically nor in the system design, that if the ICT-enabled SM system will be more economic for the patients compared to other alternatives [18]. Lowering health care costs (human welfare) have not been thoroughly evaluated in the literature particularly for specific cultural and gendered populations (universal usability) [15]. Moreover, active partnership of the patient with health professional is viable in the presence of trust in such collaboration [1, 2, 3, 18, 19, 33]. SM systems should promote trust in the health professional and patient relationship, for example, by providing enhanced secure communicative features in the system and protecting privacy of the patients.

Table 2. A Select ICT-enabled self-management articles against uncovered values

<table>
<thead>
<tr>
<th>Article</th>
<th>Human Values</th>
<th>Conceptual Investigation</th>
<th>Empirical Investigation</th>
<th>Technical Investigation</th>
<th>ICTs</th>
</tr>
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<tbody>
<tr>
<td>[35] (Bipolar Disorder)</td>
<td>Hope</td>
<td>The cognitive behavioral model of mood experience; The recovery model</td>
<td>To provide highly accessible round the clock self-directed support</td>
<td>- Feasibility and acceptability will be assessed by website usage statistics, user satisfaction scales and a series of qualitative interviews.</td>
<td>Internet, web</td>
</tr>
<tr>
<td>[38] (Diabetes)</td>
<td>Autonomy</td>
<td>To enable patient empowerment by way of enhancing self-management</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Trust</td>
<td>To allow patients to become more like partners with their clinicians in the management of their own healthcare</td>
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<td></td>
<td>Human Welfare</td>
<td>Actor Network and Social Network Analysis</td>
<td>To facilitate better self-care and increase levels of healthy medical measures</td>
<td>Rigorous thematic analysis of interview data transcribed with data from internal documents, reports and medical records as well as their own observations,</td>
<td>Mobile Internet (wireless) environment, web-based business model, wireless technology solutions,</td>
</tr>
<tr>
<td></td>
<td>Hope</td>
<td>To provide feedback, examples include complimenting the patient when they make good progress or asking the patient to come for a follow-up appointment when they don’t progress well.</td>
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</table>
5. Discussion

Although ICT-enabled SM has provided benefits for the patients with chronic diseases [8, 22, 23, 24, 38], it is unclear whether the benefits were achieved by supporting human values that are important to the patients. Our value-sensitive review suggests that ICT-enabled SM systems have been designed by focusing primarily on medical control of the chronic diseases while compromising other human values [26]. We have used an integrated framework derived from merging VSD and ISDT perspectives to analyze the extant literature. Our analysis shows that ‘universal usability’ and ‘trust’ values are the least implicated values in the SM systems for chronic diseases. Gender and age differences and adjusting one’s lifestyle may conflict with cultural norms (universal usability) [1, 10, 13, 15, 19, 33]. Such cultural and individual differences call for flexible design requirements drawn from social theories that allow patients with chronic diseases from different cultural, social, and ethnic
groups to fully take advantage of ICT-enabled SM systems. Enhanced communicative channels between patients with chronic diseases and health professionals designed in the SM systems while accommodating privacy and security concerns of the patients, can improve ‘trust’ value in the SM process [18].

We believe that future research in information systems, more particularly in health information systems and technology, would benefit from considering the principles of VSD when designing ICT-enabled artifacts. This work lays a foundation for designing SM systems that are mindful of human values.

6. Limitations

‘Self-management’, ‘self-care’, ‘self-monitoring’, and ‘self-help’ have been interchangeably used in the literature. However, self-care and self-help, for example, can be components of SM [1, 2, 18].
Despite an extensive literature search, it is possible that eligible studies were missed due to inconsistent terminology used in SM research. Our system design analysis using value-sensitive perspective is limited to what is reported in the articles about the systems. Although we eliminated articles with insufficient information, we have been constrained by the information provided in the articles. For example, indirect stakeholders such as family and relatives of the patients, primarily advocated in VSD, were rarely discussed in the articles. Future research can investigate the role of indirect stakeholders in designing ICT-enabled SM systems for patients with chronic diseases.

7. Conclusion

Building on the principles of VSD and components of ISDT, we have reviewed literature for the ICT-enabled SM of chronic diseases. More specifically, we have analyzed ICT-enabled SM systems using integrated framework derived from VSD and ISDT to uncover human values important to the patients with chronic diseases. Our analysis shows how and to what extent such values are implicated in the SM systems. The VSD outcomes are integrated into design-oriented outcomes to facilitate the translation of higher level human values into system’s design features and requirements.

7.1. Theoretical Contribution

We posit a framework grounded in theory which can not only be used to design effective SM systems, but also serves as a catalyst for infusing value-sensitive perspective in the IS design science methodologies which prescribe to a more functionalist perspective. This work also establishes VSD as a powerful and beneficial approach for conducting research in IS and refines and expands upon the VSD methodology.

7.2. Practical Contribution

Our findings provide a basis for implicating human values in the SM systems for the patients with the chronic diseases. The findings analyzed through the integrated ISDT-VSD framework facilitates devising actionable metrics for designing ICT-enabled SM systems. The integrated framework transforms human values into meta-requirements and meta-design, which can inform designers in the process of designing SM systems sensitive to the values important to the patients with chronic diseases.

Our literature review and analysis identifies human values that are relevant to ICT-enabled SM of chronic diseases. Our work informs national policy on promoting value-based health models using ICTs. It also contributes to the collective expertise and scholarship in the IS community to conduct research that can inform policy debates, and to become active participants in the national discourse on healthcare transformation.

7.3. Future work

In future work, we expect to extend the VSD investigations by validating our findings in an empirical study. Our future work will provide a predictive model demonstrating the significance of the relationships among human values, design requirements, and desired outcomes. Finally, we intend to develop a testable prototype of an ICT-enabled SM system for a specific chronic disease (e.g., diabetes or asthma) based on the human values, meta-requirements, and meta-designs uncovered in this work.

8. References


