ICT-ENABLED SELF-MANAGEMENT OF CHRONIC DISEASES
THROUGH VALUE SENSITIVE DESIGN

By
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A dissertation submitted in partial fulfillment of
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Carson College of Business

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To the Faculty of Washington State University:

The members of the Committee appointed to examine the dissertation of MAJID DADGAR find it satisfactory and recommend that it be accepted.

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I would like to thank my advisor Dr. KD Joshi for all her support and help through all these years in the doctoral program. I would also like to thank my committee members Dr. Suprateek Sarker and Dr. Terence Saldanha. I would like to dedicate my work to my mother, father, and brother who have always supported me in life and encouraged me to aspire for higher goals. And, I would like to dedicate this work to all the patients with chronic diseases and their families. I hope that the results of my study will be beneficial to them.
ICT-ENABLED SELF-MANAGEMENT OF CHRONIC DISEASES
THROUGH VALUE SENSITIVE DESIGN

Abstract

by Majid Dadgar, Ph.D.
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This dissertation investigates the values of the patients with chronic diseases and conditions in using technology-enabled self-management (SM) systems through three essays. Self-management, in the healthcare context, is defined as patient’s ability to manage symptoms, psychological consequences, and lifestyle changes imposed by a chronic disease. Our investigation is conducted based on three parts of the value sensitive design (VSD) methodology consisted of conceptual, empirical, and technical investigations. The first essay is a conceptual investigation of values, system features, and SM activities. In the first essay we conduct review of the extant literature to uncover the values important to the patients with chronic diseases and examine how those values are implicated in the system features used to perform SM activities. Our literature review and analysis provides a theoretical understanding for the main concepts in our work, SM, values, and system features.

The second essay is an empirical investigation scoped down to diabetes. In this essay we examine a SM system, a diabetes mobile app, to reveal the values important to the patients-users. We conduct a field study interviews to collect human responses. Interview data collected from 20
diabetic patients is analyzed and coded based on interpretive principles and VSD premises. Our findings show the total of 12 values, 4 categories of system features, and 7 SM activities. We define the relationships between SM activities, values, and system features by providing examples from interview data. We propose a conceptual model that shows how diabetic patients use system features to perform certain SM activities while certain values are fulfilled. Our model is developed based on the work system theory that defines systems within their ecosystem broader than technological features.

The third essay is a technical investigation of the SM systems. In this essay we elaborate on how technological features can hinder or advance SM activities. We propose design principles for designing SM systems based on characteristics of digital technologies. Our theoretically driven principles are guided by the system design methods in design science research and informed by the technological advances of the mobile technologies and platforms.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGMENT</td>
<td>iii</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>xi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xii</td>
</tr>
<tr>
<td>ESSAY ONE: ICT-ENABLED SELF-MANAGEMENT OF CHRONIC DISEASES: LITERATURE REVIEW &amp; ANALYSIS USING VALUE SENSITIVE DESIGN</td>
<td></td>
</tr>
<tr>
<td>1. ABSTRACT</td>
<td>1</td>
</tr>
<tr>
<td>2. INTRODUCTION</td>
<td>2</td>
</tr>
<tr>
<td>3. THEORETICAL BACKGROUND</td>
<td>4</td>
</tr>
<tr>
<td>ICT-enabled self-management</td>
<td>4</td>
</tr>
<tr>
<td>Value sensitive design</td>
<td>5</td>
</tr>
<tr>
<td>Values</td>
<td>6</td>
</tr>
<tr>
<td>Conceptual investigation</td>
<td>7</td>
</tr>
<tr>
<td>Empirical investigation</td>
<td>7</td>
</tr>
<tr>
<td>Technical investigation</td>
<td>7</td>
</tr>
<tr>
<td>Information systems design theory</td>
<td>7</td>
</tr>
<tr>
<td>Kernel theories</td>
<td>8</td>
</tr>
<tr>
<td>Meta-requirements</td>
<td>8</td>
</tr>
<tr>
<td>Meta-design</td>
<td>8</td>
</tr>
<tr>
<td>Integrated framework</td>
<td>8</td>
</tr>
</tbody>
</table>
6. RESEARCH METHODS ........................................................................................................ 38
   Selecting an ICT context .................................................................................................... 39
   Data collection ................................................................................................................ 41
   Data coding and analysis ................................................................................................. 43

7. FINDINGS ......................................................................................................................... 46
   Values ............................................................................................................................... 46
   System features ............................................................................................................... 50
   The Interplay of patients’ values and system features in SM activities ..................... 51
      Symptom management .................................................................................................. 51
      Drug management ........................................................................................................ 53
      Communication ............................................................................................................ 55
      Lifestyle ......................................................................................................................... 56
      Management of psychological consequences ............................................................ 58
      Social support ............................................................................................................... 59
      Information ................................................................................................................... 61
      Discussion - ICT-enabled self-management conceptual model .................................. 62

8. THEORETICAL CONTRIBUTIONS ..................................................................................... 66

9. IMPLICATIONS .................................................................................................................. 68

10. CONCLUSION .................................................................................................................... 71

11. REFERENCES .................................................................................................................. 72

12. APPENDIX ...................................................................................................................... 79
ESSAY THREE: DESIGN PRINCIPLES FOR CHRONIC DISEASES SELF-MANAGEMENT SYSTEMS: A TECHNICAL INVESTIGATION BASED ON CHARACTERISTICS OF DIGITAL TECHNOLOGIES

1. ABSTRACT ........................................................................................................... 85

2. INTRODUCTION .................................................................................................. 86

3. LITERATURE REVIEW .......................................................................................... 88

4. DESIGN SCIENCE METHODOLOGY AND SM SYSTEMS .................................. 92
   Domain theories ...................................................................................................... 93
   Individual and family self-management theory (IFSMT) ........................................ 94
   Digital technologies ................................................................................................ 96
   Principles ............................................................................................................... 97
   Design .................................................................................................................. 104
   Design Principle 1: data integrability ................................................................. 107
   Design Principle 2: system flexibility ................................................................. 109
   Design Principle 3: system externality ............................................................... 111

5. DISCUSSION ...................................................................................................... 113

6. CONTRIBUTION ................................................................................................. 115

7. IMPLICATIONS .................................................................................................. 116
8. CONCLUSION .................................................................................................................. 117

9. REFERENCES .................................................................................................................. 118

CONCLUSION .................................................................................................................. 123
LIST OF TABLES

1. Table 1.1: Select SM Values Uncovered from the SM Literature .................................. 12
2. Table 1.2: A Select ICT-enabled self-management articles against uncovered values 14
3. Table 2.1: Self-Management Activities........................................................................... 30
4. Table 2.2: Examples of Peer-Reviewed Journal Articles Based on VSD
   Methodology.................................................................................................................. 37
5. Table 2.3: Technology Sampling ...................................................................................... 40
6. Table 2.4: Descriptive Statistics of the Sample................................................................. 42
7. Table 2.5: A Sample Matrix Illustrating the Data Coding Process ................................. 46
8. Table 2.6: Revealed Values Relevant to a Diabetes Self-Management System ............ 47
9. Table 2.7: System Feature Categories.............................................................................. 50
10. Table 2.8: Sampling dataset ............................................................................................ 81
11. Table 3.1: Categories of SM systems using digital technologies found in the
    literature............................................................................................................................ 89
12. Table 3.2: Development process of design principles for a SM system with examples
    of system implications................................................................................................. 100
13. Table 3.3: SM activities supported by GB diabetes mobile app ................................... 105
LIST OF FIGURES

1. Figure 1.1: Integrated framework combining VSD and ISDT perspectives .............. 9
2. Figure 2.1: ICT-enabled self-Management as a work system................................ 32
3. Figure 2.2: Conceptual Model of a Self-Management Work System ..................... 63
4. Figure 3.1: Design principles for a SM system are derived from characteristics of
digital technology (Yoo et al. 2010) and SM theory of IFSMT (Ryan and Sawin
2009)........................................................................................................................................ 98
5. Figure 3.2: System architecture of the GB mobile app and its interactions with
user. ........................................................................................................................................... 106
6. Figure 3.3: Use case diagram illustrating design principle 1, data integrability, for a
SM system of diabetes mobile app................................................................. 108
7. Figure 3.4: Use case diagram illustrating design principle 2, system flexibility, for a
SM system of diabetes mobile app................................................................. 110
8. Figure 3.5: Use case diagram illustrating design principle 3, system externality, for a
SM system of diabetes mobile app................................................................. 112
Dedication

For my mother, father, and brother.
ESSAY ONE:
ICT-ENABLED SELF-MANAGEMENT OF CHRONIC DISEASES: LITERATURE REVIEW & ANALYSIS USING VALUE SENSITIVE DESIGN

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 has 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.
INTRODUCTION

Increasing number of older population and patients with chronic diseases such as diabetes, asthma, and arthritis (Barlow et al. 2002; Bodenheimer et al. 2002; Ditewig et al. 2010; Gucciardi et al. 2013; Houle et al. 2013; Koller et al. 2012; Siantz and Aranda 2014) coupled with limited resources and increasing healthcare costs (Chodosh et al. 2005; Norris et al. 2001), 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 (Bodenheimer et al. 2002). In this new “collaborative care” paradigm, empowered patients are their own caregivers and healthcare professionals are their consultants (Bodenheimer et al. 2002; George and Topaz 2013). 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 (Barlow et al. 2002; Bodenheimer et al. 2002; Chodosh et al. 2005; Ditewig et al. 2010; Fitzpatrick et al. 2013; Koller et al. 2012).

Chronic diseases, which are increasing in the developed countries (Marshall et al. 2007), can be very disruptive to individuals’ everyday lives (Schulman-Green et al. 2012). 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 (Barlow et al. 2002), has reduced health-related costs and assisted patients to develop skills and techniques to enhance their self-care and improve their health outcomes (McKinsey & Company 2010). Mobile technologies through their pervasiveness, for example, have the potential to reshape the nature of disease monitoring and SM (Pinnock et al. 2007). 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 (Marshall et al. 2007; Medvedev and Marshall 2008), real time feedback (Quinn et al. 2008), error detection and frequent data collection (Gupta et al. 2011), and improved communication (Wickramasinghe et al. 2011). Although, the impact of information systems on SM of chronic diseases has been studied (El-Gayar et al. 2013a; McDermott and While 2013), 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 (Norris et al. 2001). El-Gayar et al. (2013a), 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 (El-Gayar et al. 2013a).

There is an increasing interest in considering human values in the design, development, and use of information technology and systems (for example, Hirschheim and Klein 1994; Sellen et al. 2009; Xu et al. 2012; Yetim 2011). Human values should be investigated in relation to how they are supported, augmented, or constrained by technological developments (Sellen et al. 2009). Most information systems theories draw on functionalist assumptions neglecting or compromising human values of end users (Hirschheim and Klein 1994). 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 (Chatterjee et al. 2009). 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 and answer the research question that how values can be designed in SM system. 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.

THEORETICAL BACKGROUND

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

**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 (Barlow et al. 2002). 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 (Siantz and Aranda 2014). 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, El-Gayar et al. 2013; McDermott and While 2013). 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 (Norris et al. 2001). 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.

**Value sensitive design**

VSD, a theoretically grounded approach introduced by Friedman et al. (2008), provides a comprehensive framework for developing a value-centered research and design
agenda (Yetim 2011). VSD is a design approach “that accounts for human values in a principled and comprehensive manner throughout the design process” (Friedman et al. 2008, 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 (Xu et al. 2012), universal usability (Walton and Derenzi 2009), and trust (Palen et al. 2003). In the following sections the concept of “value” in VSD is elaborated and three pivotal investigations, conceptual, empirical, and technical, are discussed.

**Values**

Values are not inscribed into ICTs nor do the users of such systems merely hold values (Borning et al. 2005). Rather, information system designers impart social and moral values in their works (Friedman 1997). 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 (Friedman and Kahn 2003). 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 (Friedman 1997). When information systems are designed, conflicts arise between these values. While designing information systems, designers make decisions by balancing competing values (Friedman et al. 2008). 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. (2008).

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.

**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 (Borning et al. 2005).

**Empirical investigation**

It examines the human response to the technical artifact and empirically investigates the technical artifact situated in the human context (Friedman et al. 2008). The entire range of qualitative and quantitative methods used in social sciences, such as interviews, observations, surveys, are potentially applicable (Borning et al. 2005).

**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 (Friedman et al. 2008).

**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. (1992). ISDT is defined as “a prescriptive theory which integrates normative and descriptive theories into design paths intended to produce more effective information systems” (Walls et al. 1992, 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 (Gregor and Jones 2007). ISDT has three main
components, kernel theories, meta-requirements, and meta-design. These components are discussed in the following subsections.

**Kernel theories**

These are theories from natural or social sciences which inform and guide design requirements. For example, Chatterjee et al. (2009) have used ethical theories to design a Collaboration Engineering artifact.

**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. (2009) draw consistency and accountability driven from ethical theories as meta-requirements in designing Collaboration Engineering artifact.

**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. (2009), a conceptual schema is introduced as an ethical collaboration class which consists of practitioners, facilitators, and participants meeting the requirements of consistency and accountability.

**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 1.1). 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 Values implicated in the SM system design.

Figure 1.1: Integrated framework combining VSD and ISDT perspectives
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 1.1). In the next section we will further discuss the findings and analysis from our literature review.
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.

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. (2008) (Table 1.1). In addition to these four values, one new human value, “hope”, emerged from our analysis (see Table 1.1). 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 (Friedman et al. 2008; Schrank et al. 2012). 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.

<table>
<thead>
<tr>
<th>Human Values</th>
<th>Definition of the Value</th>
<th>SM Values</th>
<th>(Extracted from the first set of articles)</th>
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</thead>
<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 (Aantjes 2014; Barlow et al. 2002; Bodenheimer et al. 2002; Ditewig et al. 2010; Fitzpatrick et al. 2013; George and Topaz 2013; Gucciardi et al. 2013; Houle et al. 2013)</td>
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<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 (Aantjes 2014; Barlow et al. 2002; Bodenheimer et al. 2002; Chodosh et al. 2005; Ditewig et al. 2010; George and Topaz 2013; Gucciardi et al. 2013; Houle et al. 2013; Koller et al. 2012; Lorig et al. 1994; Norris et al. 2001; Siantz and Aranda 2014)</td>
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<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 (Aantjes 2014; Fitzpatrick et al. 2013; George and Topaz 2013; Gucciardi et al. 2013; Koller et al. 2012; Siantz and Aranda 2014)</td>
<td></td>
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<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 (Aantjes 2014; Barlow et al. 2002; Bodenheimer et al. 2002; Houle et al. 2013; Koller et al. 2012; Siantz and Aranda 2014)</td>
<td></td>
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</tbody>
</table>
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 1.2). 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 1.2, then it was eliminated. For example, the SM system using mobile technologies explicated in Wickramasinghe et al. (2011) 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 patients to participate in their treatment, and enhances the SM experience for the patients.
<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>
</thead>
<tbody>
<tr>
<td>Bipolar Disorder (Todd et al. 2012)</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. - Effectiveness will be assessed on a range of outcome measures including quality of life, mood symptoms, coping, recovery, and illness beliefs.</td>
<td>Recovery informed web-based self-management intervention</td>
</tr>
<tr>
<td>Diabetes (Wickramasinghe et al. 2011)</td>
<td>Autonomy</td>
<td>Actor Network and Social Network Analysis</td>
<td>To enable patient empowerment by way of enhancing self-management</td>
<td>Rigorous thematic analysis of interview data triangulated with data from internal documents, reports and medical records as well as their own observations;</td>
<td>Pervasive technology enabled solution</td>
</tr>
<tr>
<td>Diabetes (Farmer et al. 2005)</td>
<td>Human Welfare</td>
<td>Behavior change theories</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>
<td>Real-time telemedicine system based around the use of mobile phone technology</td>
<td>Motorola T720i phone and a One Touch Ultra blood glucose meter; java-based programs;</td>
</tr>
<tr>
<td>Hope</td>
<td>To provide immediate support from health professionals (by providing easier and faster communicative channels for the nurses contacting patients)</td>
<td>test the equipment and provide regular feedback on its usability and to suggest changes to the system.</td>
<td>wireless Bluetooth/GPRS connection</td>
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<tr>
<td>Autonomy</td>
<td>- To develop personalized approaches to improve control (by enabling phone-based diary and reminders of overall progress)</td>
<td>- To support interpretation of test results (by providing graphical results)</td>
<td></td>
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<tr>
<td>Chronic widespread pain (Kristjánsdóttir et al. 2011)</td>
<td>Mindfulness-based cognitive behavioral approach</td>
<td>Six women participated and evaluated the experience; Evaluation questionnaires and interviews.</td>
<td>Intervention delivered by a Web-enabled mobile phone to support SM of chronic widespread pain</td>
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<td></td>
<td>To accept, rather than struggle with unwanted thoughts, emotions and symptoms, and to commit to valued behavior (by enabling patient to register and send information to the therapist when in different situations)</td>
<td></td>
<td>Web-enabled mobile phone; internet.</td>
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<td></td>
<td>To encourage self-monitoring of thoughts and feelings (By enabling patients to provide online diaries)</td>
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</table>

Each ICT-enabled study was examined using the posited integrated framework (illustrated in Figure 1.1) (see Table 1.2). The integration of the two perspectives, ISDT and VSD, allows us to translate value sensitive approach into actionable design-based metrics. For example, Todd et al. (2012) designed a recovery informed web-based SM intervention (meta-design). Their web-based SM system provides immediate access to the self-directed support (meta-requirement). Such requirement has emerged from their conceptual investigation drawn
from cognitive behavioral model 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. (2005), 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 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 (Houle et al. 2013). Lowering health care costs (human welfare) have not been thoroughly evaluated in the literature particularly for specific cultural and gendered populations (universal usability) (Gucciardi et al. 2013). Moreover, active partnership of the patient with health professional is viable in the presence of trust in such collaboration (Aantjes 2014; Barlow et al. 2002; Bodenheimer et al. 2002; Houle et al. 2013; Koller et al. 2012; Siantz and Aranda 2014). 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.

**DISCUSSION**

Although ICT-enabled SM has provided benefits for the patients with chronic diseases (El-Gayar et al. 2013a; Marshall et al. 2007; McDermott and While 2013; Medvedev and Marshall 2008; Wickramasinghe et al. 2011), 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 (Norris et al. 2001). 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) (Fitzpatrick et al. 2013; George and Topaz 2013; Gucciardi et al. 2013). 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 (Houle et al. 2013). 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.

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 (Aantjes 2014; Barlow et al. 2002; Houle et al. 2013). 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.

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.

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.

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.

**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-design uncovered in this work.
REFERENCES


ESSAY TWO:
THE ROLE OF INFORMATION AND COMMUNICATION TECHNOLOGY IN
SELF-MANAGEMENT OF CHRONIC DISEASES: AN EMPIRICAL
INVESTIGATION THROUGH VALUE SENSITIVE DESIGN

ABSTRACT

Sensitivity towards patients’ values in the designs of information and communication technologies (ICTs), which can empower them, is the central thesis of this study. ICTs for patient empowerment in healthcare can help in building a “Bright Society.” This study focuses on the role of ICTs in self-management (SM) of diabetes, a chronic disease. Chronic diseases, declared as an “invisible epidemic” by the World Health Organization, causes and perpetuates poverty and impedes the economic development of many countries. As a means of informing the design of ICTs that enable self-management, we draw on value sensitive design (VSD) to conduct an in-depth interpretive field study to reveal the values that are important to diabetic patients. Specifically, we uncover a portfolio of twelve values they share: accessibility, accountability, autonomy, compliance, dignity, empathy, feedback, hope, joy, privacy, sense-making, and trust. From the analysis of the interviews of diabetic patients emerged a conceptual model that explains how these values implicated in ICT features afford or constrain patients’ abilities to self-manage their activities. This study makes multiple theoretical contributions: By granting ICT artifacts a clear theoretical status, it advances the field of SM that has nominally covered ICTs. It extends design research by extending the VSD literature and by introducing a value-centric design perspective to examine a complex socio-technical system. It broadens the work system theory by applying it in the healthcare space. In
addition, this study’s findings have implications for design science researchers, healthcare providers, and policymakers.

INTRODUCTION

Advancing patients’ ability to engage in self-managed health through information and communication technologies (ICTs) is increasingly a top priority (e.g., U.S. Federal Health IT Strategic Plan for 2015-2020 (ONC 2014) and the 2014-2018 plan of The National Health Service in England (NHS England 2013)). Broadly, this study supports this goal by focusing on the design of sociotechnical artifacts (referred to as ICT-enabled SM systems) to improve patients’ health. Despite technological advances in healthcare ICTs that improve care and reduce costs, patients often avoid using them, perhaps because patients are often ignored in their design (Dadgar et al. 2013; El-Gayar et al. 2013a, 2013b; Koch et al. 2004; Vuong et al. 2012; Waite et al. 2013). Thus, on one hand, as indicated in the call for this special issue, ICTs (e.g., mobile revolution) have “improved the “health” in healthcare services, as reflected by the delivery of high-quality patient care at low cost,” (Acquisti, Oh, & Sia, 2016, p. 1) but on the other hand, the design, development, and implementation of ICTs that focus chiefly on patient-centered care is still in its infancy (Jacelon, Gibbs, & Ridgway, 2016; LeRouge, Hevner, & Collins, 2007).

The spirit of “patient-centered care” is reflected in the meaning of “care” manifested in ethics and morals. In order for ICTs to fulfill the true promise of “patient-centered care,” ICT designs must move beyond the clinical, functional, and legal, and deliberately “care” about the beliefs and values that are deeply significant to patients. More importantly, the ICT designers and the patients who use ICTs must guard against succumbing to societal pressures to either relinquish or compromise patients’ beliefs about “care” under the guise of improving
health at low cost. Sensitivity towards patients’ values in the designs of ICTs is the central thesis of this study. We argue that such sensitivity will help establish sociotechnical environments that empower patients to effectively self-manage their health conditions. By examining ICTs for patient empowerment in healthcare, this study illustrates the role ICTs can play in building a “Bright Society” where patients can take control of their illness and wellness. We address the research question that how patients with chronic diseases experience and value using SM systems.

Focusing on diabetic patients, the findings in this paper reveal how the values important to patients are implicated in ICTs, in part, drive them and shape their SM of their illnesses. The findings also illustrate that incorporating patients’ values such as autonomy and privacy in ICTs to manage their diabetes is not simply a matter of preference (Norris, Engelgau, & Narayan, 2001), but also of provisioning care sensitively. We draw on value sensitive design (VSD) (Friedman, Kahn, & Borning, 2008) to conduct an in-depth interpretive field study (Galliers & Land, 1987; Orlikowski & Baroudi, 1991; Walsham, 1995) to, first, reveal the values that are important to diabetic patients and then use work system theory (Alter, 2013b, 2015) to explain how these values implicated in ICT features afford or constrain patients’ abilities to self-manage their activities. Theoretically, we advance the field of SM that has nominally covered ICTs by granting ICT artifacts a clear theoretical status by examining its role in SM of chronic diseases. We extend design research by extending the VSD literature and by introducing a value-centric design perspective to

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1 Although illness and disease often are used interchangeably, here we refer to illness as the feelings and conditions resulting from a chronic disease such as diabetes.
examine a complex socio-technical system. Lastly, this study also advances the work system theory by applying and extending it in the healthcare space.

The remainder of the paper is organized as follows. Next, we describe the research context. We then summarize relevant SM literature followed by a review of VSD. We then describe pertinent research methods before presenting our findings. Then we discuss the conceptual model derived from this work. We then discuss our theoretical contributions and design and practice implications before concluding the paper.

INVESTIGATIVE CONTEXT

In this section we describe the research context of SM of diabetes, a chronic disease, using ICTs. First we define and explain the concept of SM and then we conceptualize the role of ICTs in SM using Alter’s (2008, 2013b) work system framework.

Self-management of chronic diseases

According to the U.S. National Center for Health Statistics, a disease is considered chronic when its course lasts for more than three months (Adams, Kirzinger, & Martinez, 2013). A chronic disease persists an entire life-time and generally cannot be prevented by vaccines or cured by medication. Recurrent illnesses and conditions caused by chronic diseases, if not managed carefully, can not only diminish quality of life, but can also result in health emergencies, complications, and even death. Chronic diseases are the leading cause of mortality in the world, and 80% of chronic disease deaths occur in low and middle income countries (WHO, 2015). The World Health Organization refers to the death rate from chronic diseases as an “invisible epidemic” which causes and perpetuates poverty and impedes the economic development of many countries (WHO, 2015). As a result, the effects of chronic diseases are not confined to individuals but spread to families, communities, and countries.
Therefore, improving the health environments of individuals living with chronic diseases can have a broad, positive societal impact.

Effective SM is a proven way of improving the lives of individuals suffering from chronic diseases (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Bodenheimer, Lorig, Holman, & Grumbach, 2002). SM refers to a care management approach in which patients actively engage in and take responsibility for treating their chronic diseases (Bodenheimer et al., 2002). It is a self-regulating, dynamic, continuous, interactive process (Schulman-Green et al., 2012, Barlow et al., 2002, p. 178) in collaboration with family, community, and healthcare professionals for managing patients’ chronic conditions. SM requires a patient to simultaneously perform and manage several activities medication, treatments, symptoms, psychological consequences, and lifestyle changes (Barlow et al., 2002; Bodenheimer et al., 2002). An effective SM program supports the management of the entire gamut of recurrent symptoms (e.g., fluctuating blood sugar levels) and their psychosocial consequences (e.g., anxiety) to sustain a good quality of life.

A metasynthesis of the SM literature reveals three broad, overlapping, non-sequential, yet distinct, categories: 1) focusing on illness needs, 2) activating resources, and 3) living with a chronic illness (Schulman-Green et al., 2012). "Illness needs,” the first category, refers to activities that are necessary for patients to take care of their bodies and chronic, illness-specific concerns (e.g., a diabetic using an insulin pump). The three main activities managing illness needs are drug management, symptom management, and communication with healthcare providers (Barlow et al., 2002). The second category, activating resources, relates to acquiring and utilizing the human resources (e.g., family members, friends, healthcare providers) and community resources (e.g., spiritual, social, and transportation services)
needed to manage their illness (e.g., navigating the healthcare system, having a social support group). These resources are mobilized to activate social support, promote a healthy lifestyle, and communicate with health providers (Schulman-Green et al., 2012). The last category, living with a chronic illness, includes activities designed to move the focus away from simply meeting illness needs (e.g., taking insulin) to coping with the condition by integrating the disease into the context of the individual’s life (e.g., modifying eating habits to control sugar levels). The activity salient to this category is management of the psychological consequences of living with chronic disease in an effort to adjust to the new life (Barlow et al., 2002). The need for information is common to performing all of the activities. Although acquiring information is implied in the conduct of other activities, we include information usage as a distinct SM activity. The seven SM activities mentioned above are defined in Table 2.1.

<table>
<thead>
<tr>
<th>Table 2.1: Self-Management Activities</th>
<th>Definitions</th>
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<tr>
<td>1. Communication with Healthcare Providers</td>
<td>Communicate needs and problems assertively, and create and maintain relationships with healthcare providers</td>
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<td>2. Drug Management</td>
<td>Practice taking the medication and overcome the barriers to adhering to the schedule</td>
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<tr>
<td>3. Information Usage</td>
<td>Acquire information about the disease and its treatments</td>
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<td>4. Lifestyle Management</td>
<td>Engage in health promotion activities and modify lifestyle to adapt to the disease (such as exercise, nutrition, diet, and leisure activities)</td>
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<td>5. Management of Psychological Consequences</td>
<td>Manage the psychological consequences of the disease such as depression, negative emotions, stress, and anger.</td>
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<tr>
<td>6. Use of Social Support Systems</td>
<td>Obtain and manage social support from family, friends, and community; address social and environmental challenges; and limit isolation</td>
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<tr>
<td>7. Symptom Management</td>
<td>Recognize, monitor, and manage symptoms and side effects of the chronic disease</td>
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The illnesses caused by diabetes are examined in this study. Diabetes is the most common and the costliest among the chronic diseases (Gucciardi, Chan, Manuel, & Sidani, 2013). Use of ICTs, such as mobile apps, to support SM activities is growing. Millions of dollars are invested in designing SM systems and technologies for diabetic patients (El-Gayar
et al., 2013a). Although the need and desire to enable SM with the use of ICTs is growing (Kouris, Mougiakakou, & Scarnato, 2010; Marshall, Medvedev, & Markarian, 2007; McDermott & While, 2013; Pinnock, Slack, Pagliari, Price, & Sheikh, 2007; Tran, Tran, & White, 2012; Turner-McGrievy, Beets, Moore, & Kaczynski, 2013; Wickramasinghe, Tatnall, & Goldberg, 2011), the role of ICTs within the whole assemblage of activities, tools, and people involved in SM needs further conceptualization, a topic to which we now turn.

Framing the role of ICTs in SM: ICT-enabled self-management systems

With the emergence of an abundance of mobile health apps, their use for the SM of chronic diseases is growing (Cummings & Turner, 2009; El-Gayar et al., 2013b; Vuong et al., 2012; Waite et al., 2013; Wickramasinghe et al., 2011). The Federal Drug Administration (FDA) predicted that, by the end of 2015, 500 million individuals would be using mobile health applications (El-Gayar et al., 2013a). We use the work system framework (Alter, 2008, 2013b) to conceptualize how ICTs (such as mobile apps) fit into the SM routines of patients with chronic diseases. The work system framework has been used in the IS discipline to explain IT-enabled business processes (e.g., (Alter, 2010, 2013a; Hamid, Rozan, Deris, & Ibrahim, 2013; Truex, Alter, & Long, 2010; Vartiainen, Aramo-Immonen, Jussila, Pirhonen, & Liikamaa, 2011)). Next we use the elements of this framework to characterize the environment within which SM unfolds for patients with a chronic disease.

The work system framework conceptualizes the role of ICT as a phenomenon (e.g., SM of chronic diseases) within a broader ecosystem (Alter, 2013b); ICT artifacts such as mobile apps are just one part of a larger work system where human and technological components work in concert (Alter, 2008). A work system, defined as “a system in which human participants and/or machines perform work (processes and activities) using
information, technology, and other resources to produce products/services for internal and/or external customers” (Alter, 2013b, p. 82), consists of six main elements (See Figure 2.1): 1) participants, 2) information, 3) technology, 4) processes and activities, 5) products and services, and 6) customers. Participants can be users or non-users of ICT; non-users do not use the work system technologies but participate in performing the work. Any information that is created and used in a work system is part of the information element. For example, both digitized (e.g. electronic health record) and non-digitized (e.g. verbal commitments) content are considered information. Technologies are the tools or the hardware and software that automate the processes. Processes and activities represent pieces of work conducted within the system (e.g. monitoring blood pressure). Products and services are physical goods or actions generated by a work system to benefit customers. Customers can also be participants in a work system (e.g., patients receiving a medical exam). The arrows in the work system framework show that there should be alignment among these elements.

![Figure 2.1: ICT-enabled self-Management as a work system](image)

In this study, we characterize ICT-enabled SM systems as a type of work system in which human participants (such as patients, healthcare providers, and family members)
perform SM activities (such as checking blood sugar levels, providing emotional support, monitoring the calorie intake) using information (such as insulin dosage) and technology (such as a mobile app) to provide SM services to diabetic patients. Diabetic patients self-manage their illness in partnership with their health providers, such as their primary doctor, nurses, dietitians, diabetes educators, and endocrinologists, all of whom are represented as human participants within the ICT-enabled SM system. Patients use various kinds of information, such as insulin dosage, blood sugar levels, food carbs, and calories burned, and a variety of tools such as a diabetes mobile app, wearable gadgets, a wireless scale, an insulin pump, and a meter, which are the technology in an ICT-enabled SM system. Participants use technologies and information to perform SM activities such as symptom management and management of psychological consequences. The SM services available to the diabetic patients represent the product/services. The customer is the diabetic patient.

The study of the SM phenomenon is not new, but our analysis shows that the SM literature has failed to examine the role of IT within the context of patients’ clinical, physical, and social environments.

**LITERATURE REVIEW**

The three disciplines that have examined the phenomenon of SM, management, psychology, and healthcare (e.g., nursing), have failed to fully investigate the ICT artifact. The management literature examines the impact of self-managed teams and employees on different organizational outcomes such as job performance (Frayne & Geringer, 2000), job attendance (Latham & Frayne, 1989), and leadership (Manz & Sims, 1980). The psychology literature examines the role of self-control in SM (Joireman, Balliet, Sprott, Spangenberg, & Schultz, 2008). Healthcare researchers have predominantly studied face-to-face SM
education, intervention, and programs with no use of technology (K. R. Lorig & Holman, 2003; Norris et al., 2001; Ryan & Sawin, 2009; Siantz & Aranda, 2014), with only limited investigation of ICT-enabled management of chronic diseases.

Specifically, studies in this line of research describe the system design process for conditions such as diabetes (Bu, Pan, & Walker, 2007; Farmer, Gibson, & Hayton, 2005; Glasgow, Kurz, King, Dickman, & Faber, 2012; Kouris et al., 2010), asthma (Gupta, Chang, Anyigbo, & Sabharwal, 2011; Pinnock et al., 2007), Parkinson’s (de Barros, Cevada, Bayés, Alcaine, & Mestre, 2013), bipolar disorder (Todd, Solis-Trapala, Jones, & Lobban, 2012), and healthy eating (Turner-McGrievy et al., 2013). These studies investigate a variety of technologies: smartphone and tablet apps (Bailey, Belter, Pandit, & Carpenter, 2013; Belisario, Huckvale, Greenfield, Car, & Gunn, 2013; Dadgar & Joshi, 2015a; El-Gayar et al., 2013b; Fu et al., 2013), telehealth technologies (Davis, Hitch, & Salaam, August), mobile platforms (Dadgar et al., 2013; de Barros et al., 2013; Gupta et al., 2011; Kouris et al., 2010; Pinnock et al., 2007), and internet-based technologies (Glasgow et al., 2012; K. Lorig et al., 2012; Nijland, van Gemert-Pijnen, Kelders, & Seydel, 2009). However, they follow a functionalist and system-based approach to design that often compromises patients’ perspectives. This artifact-oriented system design in the healthcare context has five limitations.

First, although the systems are designed for the patients, they do not fully capture the patients’ needs and desires. If what patients consider important is not designed into the system, they do not use the system and SM becomes ineffective and incomplete (Cummings & Turner, 2009). Second, patients with chronic diseases live with their conditions every day, yet the systems designed for them are alienated from the realities of their daily lives and
ignore their multi-faceted, daily decision making. These systems are designed for one scenario: passively controlling medical conditions. Such systems are not centered on the patient-users (Koch et al., 2004) and lack a holistic view that enhances the patients’ quality of the life (El-Gayar et al., 2013a). Third, the SM systems in the literature are developed for one-dimensional worlds, where patients use the systems in isolation, whereas in reality, patients use different kinds of technologies, in partnership with different individuals, performing a variety of activities in diverse situations and contexts. This broad ecosystem of SM is neglected in the design of the SM systems in the literature. Fourth, indirect stakeholders such as immediate family members and friends are not incorporated into the applications and functionalities of the SM systems. And fifth, the designs of the SM systems are not theoretically driven but are motivated by experimental objectives.

In this paper, we begin to bridge these gaps by capturing patients’ perspectives for the design of ICT-enabled SM systems that consider the entire portfolio of SM activities (i.e., the seven SM activities) in the broader ecosystem (i.e., work system view) within which patients care for their illness, and most importantly, systems that are attentive to patients’ values. Next we turn to the theoretical framework that we draw on to reveal and analyze the diabetic patients’ values implicated in ICTs used for SM activities.

**THEORETICAL FRAMEWORK - VALUE SENSITIVE DESIGN OF ICTS**

Value sensitive design (VSD) seeks to account for human values in a principled, deliberate, and thorough fashion (Borning, Friedman, & Kahn, 2004; Friedman, 2014; Friedman, Kahn, et al., 2008; Friedman, Nathan, & Yoo, 2016; Friedman & Nissenbaum, 1996; Xu, Crossler, & Belanger, 2012). Applied to ICTs, this methodology is used to conceptualize, understand, and reveal values that are important to the users and then
mindfully implicate them into ICT designs. Given our focus on patient-centered care, where the perspective of patients is salient, VSD offers an appropriate theoretical lens through which to examine the values of individuals who are dealing with their illnesses caused by diabetes.

VSD methodology is composed of three integrative investigations that are conducted iteratively: conceptual, empirical, and technical (Friedman, Kahn, et al., 2008). The conceptual investigation identifies human value constructs based on relevant philosophies and theories (Friedman, 1997). In the empirical investigation, the human response to ICT artifacts is obtained (Friedman, Borning, Davis, Gill, & Kahn, 2008). The technical investigation involves outlining design principles and guidelines and building ICT artifacts that support the values identified in the conceptual or empirical investigations (Denning et al., 2010). These three investigations, albeit intertwined, are distinct. One key distinction lies in their unit of analysis. Technical investigations focus on the technology; empirical investigations capture the responses of individuals, groups, or communities that are affected by the technology; and conceptual investigations scrutinize values as theoretical, abstract constructs (Friedman, Kahn, et al., 2008).

A value in VSD is a broad term that captures what is important to the users of the system (Friedman, Kahn, et al., 2008). Values are derived subjectively based on the needs, desires, and interests of human beings (e.g., patients) within a certain social-cultural context, and therefore are not facts (Friedman, 1997). Given the subjective nature of values, they should be revealed empirically before they are used to design or refine systems. Friedman et al. (2008) propose a list of values that are universally important to any system user; however, these values need to be contextualized and culturally situated before they can be designed into an artifact (Borning & Muller, 2012). Consistent with this argument, we conduct an exploratory
study to reveal diabetic patients’ values that can be embodied in the designs of ICT-enabled SM systems. VSD research commonly relies on case studies in conducting empirical investigations. Table 2.2 summarizes illustrative VSD studies.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Technology</th>
<th>Values</th>
<th>Outcomes</th>
</tr>
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<tbody>
<tr>
<td>(Xu et al., 2012)</td>
<td>Privacy-enhancing tools for internet users</td>
<td>Privacy</td>
<td>Privacy Enhancing Support Systems (PESSs) that enhance the interactivity of Internet users' privacy experiences, increase users' control perceptions over their personal information, and reduce their privacy concerns.</td>
</tr>
<tr>
<td>(Chatterjee, Sarker, &amp; Fuller, 2009)</td>
<td>Collaboration engineering for practitioner groups</td>
<td>Participants’ ethical values</td>
<td>A conceptual schema for a fundamental artifact having ethical features derived from the deontological view of ethics. An object-oriented representation of an Ethical Collaboration class is developed that can be instantiated into objects that, in turn, can serve as fundamental building blocks for ethical collaboration.</td>
</tr>
<tr>
<td>(Friedman &amp; Nissenbaum, 1996)</td>
<td>Computer systems</td>
<td>Freedom from bias</td>
<td>A framework is offered for understanding and remedying bias in computer systems. It is suggested that freedom from bias should be judged based on reliability, accuracy, and efficiency.</td>
</tr>
<tr>
<td>(Friedman et al., 2016)</td>
<td>Multi-lifespan information system design</td>
<td>Transitional justice</td>
<td>Design reflections are suggested that pertain to information systems for transitional justice under shifting socio-political and technical conditions.</td>
</tr>
<tr>
<td>(Deng, Joshi, &amp; Galliers, 2016)</td>
<td>Crowdsourcing platforms</td>
<td>Access; Autonomy; Fairness; Transparency; Communication; Security; Accountability; Making an impact; Dignity.</td>
<td>Raising the awareness of worker marginalization in microtask crowdsourcing. Recommendations are offered regarding the ethical use of crowd workers and improving the design of crowdsource platforms.</td>
</tr>
<tr>
<td>(Dadgar &amp; Joshi, 2015b)</td>
<td>Information and communication technologies</td>
<td>Hope; Human welfare; Universal usability; Trust; Autonomy.</td>
<td>Design-based outcomes to facilitate implementation of human values in the SM systems that are used by patients with chronic diseases and conditions; an integrated framework is developed based on value sensitive design and information system design theory to uncover human values for system design and analysis.</td>
</tr>
</tbody>
</table>
Investigating diabetic patients’ responses to an ICT artifact in an effort to identify salient values through an empirical study requires identifying the theoretical and philosophical underpinnings relevant to the context of SM of chronic diseases. Such theoretical underpinnings are provided by the SM activities defined in Table 2.1 and the studies summarized in Table 2.2. Our empirical investigation using the constructs from VSD and SM is detailed in the next section.

**RESEARCH METHODS**

An in-depth, interpretive field study was conducted to reveal from a diabetic patient’s perspective the role ICTs play in the SM of a chronic disease and how the values important to patients are (or need to be) implicated in ICTs. Consistent with interpretive approaches to IS research (e.g., (Orlikowski & Baroudi, 1991; Walsham, 1995)), our research inductively examines how human actors (diabetic patients) use and value ICTs within their environment rather than deductively hypothesizing or testing cause-and-effect relationships. Our empirical study, grounded in design theory, develops an analytical generalization regarding diabetic patients’ values and their experiences with SM systems enabled by ICT. This generalization may prove useful for research on other types of ICT-enabled SM systems designed for patient-centered care. Our approach is consistent with Klein and Myers’ (1999) principle of abstraction and generalization for interpretive field studies and with Lee and Baskerville’s (2003) framework for generalizability (i.e., empirical to theoretical generalization). The ubiquitous nature of health care mobile apps offers an opportunity to collect rich case study data in a setting (e.g., use of mobile apps for SM of diabetes) where the phenomena (ICT-enabled SM activities) we hope to capture are likely to be prevalent (Yin, 1994). Observing how diabetic patients use mobile apps within the context of their SM of their chronic disease
allows us to collect first-hand data as to how technology supports and/or impedes various activities. Our data collection and analysis was based on qualitative research methods articulated by Miles and Huberman (1994): analytical categories informed by prior research, data display matrices, and open coding. The following section describes the selection of ICT for SM, recruitment of diabetic patients, data collection, coding, and analysis.

**Selecting an ICT context**

We chose Glucose Buddy (GB) mobile app as a representative ICT artifact within a patient’s SM system that provokes a human response. The objective of choosing a mobile app is not to evaluate its design but to give our subjects an ICT-enabled SM experience that would elicit their deeply held values as they engage in SM using GB’s features (referred to as system features hereafter). We chose GB in two steps. First we selected the top five mobile apps, Diabetes Diary, GluCoMo, Rapid Calc, Glucose Buddy, and GlucoSUccess, based on two diabetic app reviews (i.e., (El-Gayar et al., 2013b; Waite et al., 2013)) and their popularity on the Apple app store. Popularity was measured by the number of users, number of reviews, average ratings, number of years the app has been in the app store, and whether the app was endorsed by technology magazines such as Wired and by the American Diabetes Association. We limited our technology selection to the Apple app store to avoid the possible differences among devices. Next we evaluated the five apps based on their primary care properties (for example basic features such as tracking blood glucose), secondary properties (such as social network capabilities), and Apple app store characteristics. The ratings for each of the categories and the total scores are shown in Table 2.3. If a property is present in the app, it is rated as 1, and if not, it is rated as 0. For example, the physical exercise property is present only in the GB app; therefore, it received a rating of one while others were rated as zero. The
characteristics of the Apple app store show the history, popularity, and maturity of the app. For example, GB has the highest number of reviews, stands equal with Rapid Calc in average ratings, and its latest version shows that it has the longest development history. The diabetes app with the highest score, Glucose Buddy (GB), was chosen. Since GB is available on Android platforms and several diabetic patients use Android devices, both Android-based GB and iOS-based GB are included in our study. We controlled for the differences in the mobile operating systems (between iOS and Android) and device feature differences (between different mobile devices, such as iPhone and Samsung mobile devices) in our analysis of the interview transcripts by comparing and analyzing whether the differences would affect patients’ values regarding the use of system features to perform SM activities.

<table>
<thead>
<tr>
<th>Category (Waite et al., 2013)</th>
<th>Technology (Diabetes Mobile App)</th>
<th>Technology Sampling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Diabetes Diary</td>
<td>GluCoMo</td>
</tr>
<tr>
<td>Primary Care</td>
<td>Medication</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Blood Glucose</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Monitoring</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Diet Management</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Physical Exercise</td>
<td>0</td>
</tr>
<tr>
<td>Secondary Features</td>
<td>Education</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Weight BMI</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Blood Pressure</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Social Networking</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Integration with PHR</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Alert/Reminders</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Tagging</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Decision Support</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Security</td>
<td>0</td>
</tr>
<tr>
<td>App store Characteristics</td>
<td>iOS/platform</td>
<td>iOS</td>
</tr>
<tr>
<td>Number of ratings</td>
<td>41</td>
<td>83</td>
</tr>
<tr>
<td>Average Rating</td>
<td>~3.5/5</td>
<td>~2/5</td>
</tr>
<tr>
<td>Latest Version</td>
<td>2.0.0</td>
<td>1.0.12</td>
</tr>
<tr>
<td>Cost</td>
<td>$2.99</td>
<td>$0.99</td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Total Score</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>

**Data collection**

Data were collected through face-to-face interviews with diabetic patients. Diabetic patients were recruited by distributing an online and printed recruitment announcement (See Appendix A) to several potential venues, such as local radio channels, the local Chamber of Commerce, diabetes programs within the YMCA branches across the state, local health clinics, local regional hospitals, a university-wide digital newsletter, and the Glucose Buddy (GB) discussion forum.

Once patients completed the online or printed survey (See Appendix B), we contacted them to participate in a training session. Only patients who had pre-diabetes, diabetes type 1, or diabetes type 2 and owned an iPhone or an Android phone were selected for training. Each participant was trained to use the GB diabetes mobile app individually for about 15-30 minutes. Specifically, in the training session, we introduced the app, they installed the app on their iOS or Android smart phone, and we demonstrated the features and functionalities of the app. The participants received a $25 Amazon gift-card for their participation in this study.

We asked the participants to stay engaged with the app and use it on a regular basis. Patients used the app voluntarily on a daily basis to explore and experience its role in their SM activities. The following quotes illustrate that the patients not only took this activity seriously, but that they were engaged and fully immersed in employing this app in their SM activities. For example, after using the app, Shawn says, “It just spurred me to take a look at things. I guess it gives me a feeling of I'm taking better care of myself when I'm looking at the data and responding to it and doing a better job of caring for myself”. Kim says, “It was very
eye opening [to use the GB app]. When I was going through it, I thought, 'You know, I missed being accountable’”.

During the training session the patients were asked to use the GB logbook for blood glucose, medicine, food, activities, and the A1C, the graph feature which shows the logs over time; the discussion forum feature where they can post their questions, read about other patients’ experiences, and share their own experiences; and reminders for taking medication and testing BG. They were also encouraged to take notes while they used the app. These notes were discussed during their interviews. Thirty-seven patients completed the recruitment survey, after which 17 patients dropped out or withdrew. A total of 20 patients participated in the study. Demographic and descriptive information was collected in the recruitment phase using a survey (See Appendix B). All the patients were given a pseudonym. Please see Appendix C for the details of the sampling dataset for each individual case. Descriptive statistics of the sample are provided in Table 2.4.

<table>
<thead>
<tr>
<th>Table 2.4: Descriptive Statistics of the Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Descriptive Item</strong></td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>18-21</td>
</tr>
<tr>
<td>22-30</td>
</tr>
<tr>
<td>31-40</td>
</tr>
<tr>
<td>41-50</td>
</tr>
<tr>
<td>51-60</td>
</tr>
<tr>
<td>Over 60</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>High School</td>
</tr>
<tr>
<td>Professional Degree</td>
</tr>
<tr>
<td>Some College</td>
</tr>
<tr>
<td>Associate Degree</td>
</tr>
<tr>
<td>Bachelor's Degree</td>
</tr>
</tbody>
</table>
After at least one week of using the GB app, we scheduled a one-hour interview with each patient. The interview script is provided in Appendix D. During the interview, we asked open-ended questions to help us understand how they self-manage their condition, what is important to them as they engage in SM activities, and how ICTs accommodate their preferences and values during these activities. The questions were based on the VSD framework (Friedman, Kahn, et al., 2008) and, consistent with VSD methodology and principles, were asked in an iterative and integrative manner. Based on VSD interview principles, if a value or a SM activity derived from the literature review did not emerge during the interview, the interviewer indirectly asked participants about it. The interviews were based on the laddering technique, in which the interviewer asks questions to find out what is important to the interviewees and why (Reynolds & Gutman, 1988). Using the laddering technique helped us design interview scripts and questions to elicit responses from patients to connect the system features to values and the values to SM activities. We audio-recorded all interviews, which were then transcribed. In the next section we discuss the coding and analysis of the interview transcripts.

**Data coding and analysis**

The data coding was conducted in four iterative steps. First, the passages from the interviews that reflect patients’ values, SM activities, and system features were extracted from
the transcripts. In these passages, the patients clearly explain how they use system features to perform various SM activities and describe how their preferences, needs, and desires are fulfilled (or not) by the mobile app.

**Second**, in the initial data coding, we used diabetic patients’ statements to identify values that were expressed in the context of their SM activities. Interview transcripts were coded based on the values found in the VSD literature discussed earlier. This process is consistent with the coding strategies suggested by Miles and Huberman (1994) and analysis based on the principles of interpretive field research suggested by Klein and Myers (1999). The coding scheme based on prior VSD studies (e.g., (Dadgar & Joshi, 2015b; Friedman & Kahn, 2003; Le Dantec & Edwards, 2008)) was used for a pilot coding of one interview. The two researchers then discussed the pilot coding results and refined, extended, and contextualized the coding scheme to capture the context of SM. Appendix E provides examples of coding discrepancies and their resolution. Then, while being aware that new categories of values could continue to emerge, one author followed the agreed-on coding scheme to code the remaining data. In total 516 rows of data were coded. We assigned between 3 and 12 values to each patient (average 5.6 values, median 5 values per patient). This iterative process resulted in 12 value categories, summarized in Table 2.6 in the Findings section.

**Third**, SM activities reflected in the value statements were coded. The coded value statements expressed how a system feature assisted patients in performing one or more of the seven SM activities: Communication with Healthcare Providers, Drug Management, Information Usage, Lifestyle Management, Management of Psychological Consequences, Social Support, and Symptom Management (see section 2 for more details). No new SM
activities were revealed in our study. We assigned between 2 and 7 SM activities to each patient (average 5.75, median 5 SM). Last, the system features used and described by the patients in support of SM were coded. We assigned between 3 and 18 system features to each patient (average 7.3, median 7.5). Four system feature categories revealed in this step are summarized in Table 2.7 in the Findings section.

After completing the four coding steps, the relationships between values, SM activities, and system features were analyzed to explain how the values important to diabetic patients are implicated in system features and the role these features play in driving and shaping the patients’ SM. A granular relationship was coded when the patient explained what was important to them (i.e., a value) while using a specific system feature to perform a certain SM activity. The values important in SM that were not implicated in the system features were also coded. We used data display matrices (Miles & Huberman, 1994) to record concepts and categories and to show patterns (themes) between major constructs (patients’ values, SM activities, and system features). Table 2.5 contains a sample data matrix to illustrate our analytical method.

Building on this analysis, we evaluated how the values expressed are related to SM experiences using the system features. We then combined the value-SM experience-system feature association instances for all the respondents, resulting in 300 instances. Further analysis of these instances revealed four inter-related themes that collectively characterize the complex phenomenon of ICT-enabled SM of diabetes as a work system: 1) The patient value construct is multifaceted and consists of 12 human values implicated in system features; 2) Four broad categories of system features are crucial to SM; 3) The interplay of values implicated in system features supports or impedes one or more SM activities; 4) A conceptual
work system model emerges by connecting all the values, system features, and SM activities. These overarching themes are discussed in the four sections that follow.

<table>
<thead>
<tr>
<th>Value Statements – What a diabetic patient considers important while using ICTs to self-manage diabetes.</th>
<th>Value Revealed</th>
<th>Value Category</th>
<th>Importance of Values Reflected in SM Activity</th>
<th>Values implicated (or not) in Mobil App Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think it's just good reinforcement to get some feedback on what you're doing. Without this type of feedback on a day-to-day basis with apps and other technologies that you use to help manage your chronic conditions, you're basically just going in and seeing your doctor every 3 months. That's really the only feedback you get is when you get that A1C back unless you're paying a lot of attention to your finger sticks and the like.</td>
<td>Receiving constant and continued feedback.</td>
<td>Feedback -- The extent to which patients' self-management abilities are reinforced.</td>
<td>Symptom Management -- Allows patients to recognize, monitor, and manage symptoms and side effects on day-to-day basis</td>
<td>Day-to-day feedback feature – available in the diabetes app complement feedback provided by health providers every 3 months.</td>
</tr>
<tr>
<td>It [The log entries of blood sugar and food intakes] is in writing and I think that's really impactful. Keeping you honest. When you have to sit there and type in ice cream or choose it off of a list, yeah, that's hard, because you know you shouldn't have had it. I think when you have to put in the choices that you made, I think it brings it more to your face and says, okay, you're right, I shouldn't have done that.</td>
<td>Value the act of entering food intakes that forces them to recognize and be responsible for their eating habits that affect blood sugar levels.</td>
<td>Accountability -- Ensures that the patient’s actions are traced back to them which not only keep them aware of their habits but also ameliorates denial behaviors.</td>
<td>Lifestyle -- Allows patients to modify their nutrition and diet to manage their blood sugar levels.</td>
<td>The Log Entries -- Recording and tracking levels of blood sugar and food intakes in the form of numbers and visuals of log entries.</td>
</tr>
</tbody>
</table>

**FINDINGS**

**Values**

Twelve values emerged from the interview data: *accessibility, accountability, autonomy, compliance, dignity, empathy, feedback, hope, joy, privacy, sense-making, and trust*. The definitions and examples of these values are provided in Table 2.6.
Table 2.6: Revealed Values Relevant to a Diabetes Self-Management System

1) **Accessibility** *(Derived from the study):* It refers to the properties of being available when needed. In this study these properties often referred to the system’s being available when needed.

- “There are these different platforms. It’d be fantastic to have one platform where I could integrate all these things and use them together …Then, you can manage everything in one system”.
- “I loved the way it [MyFitnessPal app] allowed me to choose foods, to choose things easier. You could go in and pick foods that was really cool and I was really good at keeping track”.
- “I usually try to keep nuts in my car and stuff like that, but having the mobile app with you, [allows you to] put it in [as soon as you eat] so you don’t forget what you ate”.

2) **Accountability** *(Adapted from Friedman et al. (2008)):* It refers to the properties that ensure that the actions of an entity may be traced uniquely to that entity.

- “Yeah, before [in the absence of an app] I would be in denial, I’d eat what I wanted and go, "I’m not going to check, I’m just going to go to bed and that’s it”.
- “Just probably being more aware of what I’m doing. It is probably something you set for if you’re recording something or writing it down, maybe you make better choices because you don’t want to write the bad thing…being aware of it pushes it to the front of the mind”.

3) **Autonomy** *(Adapted from Friedman et al. (2008)):* It refers to patients’ ability to decide, plan, and act independently in ways that they believe will help them to achieve their goals.

- “I like it [to self-manage on my own] from the standpoint of having more autonomy and not feeling like I’m totally dependent on others for my own care because, by nature, I’m type A, independent. It’s hard for me to reach out for help sometimes, even though it’s important for having type 1 diabetes”.
- “I’ve always tried to be as self-sufficient as I can and try and work things out through things on my own before I ask for help or seek help”.

4) **Compliance** *(Derived from the study):* It refers to adherence to activities (Such as taking drug, using medical device and ICTs for self-care and self-directed exercises).

- “Every iteration, whether it has been smart phone apps or on the computer or in a log book, has been the same. Good intentions at the onset, not being able to, sort of, build it in as a habit very quickly, and then moving … Then just sort of leaving it in the rear-view mirror”.

5) **Dignity** *(Adapted from Deng et al., 2016; Le Dantec & Edwards, 2008):* It refers to a sense of pride in oneself and self-respect. It captures both the positive and negative consequences of preserving dignity. On one hand, good SM provides a sense of pride in controlling chronic problems, and on the other hand, it impedes SM as patients try to withhold information or not seek help in an attempt to preserve their pride.

- “More I’m paying attention to what I’m doing, the better I feel about myself as how I’m basically preventing more diabetes-related problems down the line and certainly you feel better when you take care of yourself”.
- “I tend to, for better or worse, wait until my personal attempts at resolving the issue has failed and then I’ll reach out. … My other hang up is I don’t want to bug them and feel like I’m taking up their valuable time for not really important reasons”.

6) **Empathy** *(Derived from the study):* It refers to the ability to understand and share the feelings of diabetic patients.

- “It’s a little frustrating. My mom would bring it up to her friends especially. She has older friends, and a lot of them have Type 2 diabetes. They’d bring up tips like, “Oh, just eat this, and do this, or exercise. This is what I did, and I don’t have to give myself shots or anything.” It is like, “Thank you, that’s nice for you telling me, but that’s not manageable for me. It’s completely different in that way. “It’s a little frustrating”.

7) **Feedback** *(Derived from the study):* It refers to information about patient’s SM activities used as a basis for reminders, improvement, or positive reinforcement.
“I think it would be very helpful for people who have their blood glucose down just to keep reaffirming what they're doing is the right thing because we all slip a little bit from time to time. You have to recheck your habits, what you're doing and making sure you're taking care of yourself”.

“...may be even a little thing that would pop up and go, “You're eating too much.” ... Yeah, a little alarm like, "Oh, maybe you should take this corrective action." I know that everything right now is positive reinforcement, well I think that's good but I'd rather know what I'm doing wrong”.

“I can set up alarms, and ... To remind me to test my blood sugar or if I've missed a bolus, I can set up an alarm in case I missed a bolus, so it'll tell me that "Hey, maybe you missed a bolus, you should probably check." I usually have the bolus go off every morning because sometimes when I'm getting ready for work I'll have something really quick, and if I'm really rushing I'll just run out the door and I'll forget to check my insulin”.

8) **Hope** *(Adapted from Schrank, Bird, Rudnick, & Slade, 2012)*: It refers to a patient’s motivation to achieve future-oriented expectations and personally valued goals which will give meaning and are subjectively considered possible, and depend on personal activity or characteristics.

“‘There’s this point of when you get a diagnosis like that that's lifelong and it really changes your day-to-day activities. I know a lot of people I work with and certainly was true for myself, it's a point where depression kicks in and it's hard to deal with on the outset’.

“There's no reason that I can come up with that they should have spiked. It is frustration maybe, why is my body not acting the way it's supposed to act, and I can't do anything to fix it”.

9) **Sense-making** *(Derived from the study)*: It refers to the ability to give meaning to data that captures patients’ SM activities and behaviors.

“All these numbers are great and they're great for nutritionists, dietitians, but for the average person it's like, “Well, I don't know what proportions of fat are in my diet, I haven't a clue.” This is avoiding all of that, the number crunching routine, I can see it, and I love it. Great”.

“It's nice to have a variety of graphs to choose from. They have weight and blood pressure graphs. There's a fair amount of customization that I can do. They're set by default, so you're trying to keep your blood sugar below 180. I was able to change those because I want my blood sugar to be below 140”.

10) **Joy** *(Derived from the study)*: It refers to the feeling of pleasure.

“I still want to cook like my parents did, fats, and potatoes, and pasta, and spaghetti every week, no fried foods. I'm having, still to this day, a real hard time resisting that, but I do. I try to behave when I'm cooking and eating. I still have that and say, “Hell, I can do that, I can eat a quart of ice cream, hey, why not?” I guess it's that perpetual struggle with the diabetes”.

11) **Privacy** *(Adapted from Friedman, Kahn, et al., 2008)*: It refers to a claim, an entitlement, or a right of an individual to determine what information about himself or herself (e.g., medical data, taking medication in public, being a diabetic) can be communicated to others.

“When I was on basically insulin pens and the like, absolutely that was a huge barrier. I'd be at a business lunch or something. Last thing I want to do is unbutton my shirt and give an injection but right now, I have my insulin pump. I think most people just assume I'm playing on my cell phone or something”.

“I was not insurable before the Affordable Care Act was passed because of pre-existing conditions and nothing to do with diabetes, but if insurance is contingent on not having a hangnail, which it was before the Affordable Care Act, putting any medical information on the web that anybody could figure out how to track back to you would be dangerous. It could exclude you from getting insurance”.

“This is actually the first condition that I'm finding it harder to talk about, because there is such a stigma associated with diabetes related to weight and because my weight at diagnosis was close to 200 pounds. I've had more embarrassment about talking about my diagnosis with diabetes because, whether or not it's true, the perception will be that I caused it”.

12) **Trust** *(Adapted from Friedman, Kahn, et al., 2008)*: It refers to expectations (Of reliability, truth, and/or ability to do the right thing) that exist between people and/or technology.

“I have to take the information I’m given and research it myself somewhat to understand, make sure okay, this is really what this is and whatever else”.

“I wouldn't trust technology without a doctor working with it. I trust it to give me numbers, but the implications of the numbers are a different thing”.

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Accessibility, which refers to a system’s availability, has a variety of meanings to diabetic patients. Broadly it pertains to a system’s features (such as automatic recording of blood sugar levels, seamless sharing of data across systems and devices, and portability that affords spatial and temporal extensions) that adapt to new situations and conditions (e.g. when patients travel to new places with new food options). Accountability refers to patients’ “self” accountability for their habits and care performance in an effort to ameliorate avoidance and denial by confronting patients with the realities of their disease and driving patients to make good choices. Autonomy is central to SM. It encourages independent behavior and decision making. Autonomous behavior can be related to individual characteristics of patients or it can be learned and developed over time. Compliance helps patients sustain their lifelong SM activities. Living with a chronic condition requires integrating SM activities into patients’ everyday lives. SM experiences and knowledge obtained over time can create compliance barriers as patients develop their own model of SM, which may not comply with best practices.

Diabetic patients perceive a loss of dignity if their SM performance does not produce positive outcomes or if they are unfairly made accountable for their SM performance. Empathy captures patients’ desires to be fully understood by their healthcare providers, family members, and friends. They want others to be aware of diabetes and its intricacies and accept them as who they are. Feedback is valued by the patients because it reinforces SM activities. Responsive SM systems that validate good SM performance and provide suggestions for improving when patients fall short increase patients’ confidence. Hope keeps patients motivated to self-manage and fight negative psychological emotions such as frustration and disappointment. Sense-making facilitates the interpretation of data (e.g. the impact of food
carbs on blood glucose levels) and generates actionable metrics. Diabetes changes lifestyles and imposes constraints. Joy captures the perpetual efforts by diabetic patients to balance living with a chronic condition and enjoying life. Privacy concerns relate to sharing information about their condition, feelings, and treatment outcomes. Patients need to trust the technologies they use and have trust in those who use technologies to provide care. Lack of trust masks the advantage of technology and leads to technology resistance.

**System features**

Four categories of system feature critical to SM emerged from the interview data: connectivity, data analysis, data retrieval, and data storage (See Table 2.7).

<table>
<thead>
<tr>
<th>System Feature Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connectivity</td>
<td>The system features that enable a diabetic patient to interact and share information with healthcare providers, family members, friends, and other diabetic patients. This feature allows patients to develop and/or maintain a network of people who can interact, communicate, and support the practice of SM in and through a digital device.</td>
</tr>
<tr>
<td>Data* Analysis</td>
<td>The system features that enable a diabetic patient to make sense of diabetes data over time. This feature allows patients to manipulate and visualize data (e.g. effective representations of past trends and patterns) that augments the capacity to process and apply insights from data in establishing the dynamic and continual process of self-regulation and adjustment crucial to managing a chronic condition.</td>
</tr>
<tr>
<td>Data Retrieval</td>
<td>The system features that enable a diabetic patient to access data. This feature allows patients to obtain pieces of information to continually monitor their condition in real time to trigger a response (cognitive, emotional, or behavioral) necessary for maintenance of a chronic condition.</td>
</tr>
<tr>
<td>Data Storage</td>
<td>The system features that enable a diabetic patient to store, log, and track the diabetes data. This feature allows patients to enter data that can be retrieved and analyzed in the future.</td>
</tr>
</tbody>
</table>

*Blood glucose, food carbs and calories, activity burned calories, medicine dosage, A1C levels, weight, and blood pressure.*

**Connectivity** features provide one-to-many and many-to-many information exchanges regardless of time and location. Diabetic patients benefit from real-time communication with healthcare providers and health coaches to address their needs, concerns, and questions, while sharing measurement data enables informed decisions, reduces redundancy, and overall, increases the quality of the data. **Data analysis** features enable interpretation of interrelated
data (e.g. calories, carbs, insulin, and glucose). Visualized data showing the history and trends over time reduces the cognitive load on the patients and integrative reports assist care providers. Data retrieval features enable real-time access and use of data. SM decisions are supported by the constant use of data. For example, a comprehensive and automated food database that displays calories and carbs makes it easier for patients to choose healthful foods. Data storage features enable data processing, maintenance, and management. Customizable data fields and attributes that are automatically aggregated and related to other data types are desired by the patients. For example, the ability to store activity duration, burned calories, activity type and condition, and potential impact on blood glucose levels is important for future data analysis.

In summary, the interviews with the diabetic patients reveal a set of twelve values implicated in four system features, which are used to manage their chronic conditions. How system features and values interact to support or undermine SM is discussed next.

The Interplay of patients’ values and system features in SM activities

Patients achieve their goals of managing their chronic diabetic conditions through the interplay among their values and system features only if the values implicated in the system fulfill their needs and preferences; otherwise these interactions impede SM. In this section, we explain how the values embodied in the system’s features drive SM activities.

Symptom management

As patients focus on their illness needs, they seek help from various system features (e.g., data retrieval to monitor their blood sugar levels) to manage their symptoms, which entails recognizing and monitoring the symptoms and their side effects (Schulman-Green et al., 2012). The diabetic patients shared the importance of certain values as they engaged with the
technologies while managing their symptoms. These values are accessibility, accountability, autonomy, interpretation, reinforcement, dignity, compliance, empathy, and privacy. Here we describe how a subset of values, compliance, autonomy, and dignity, fulfill SM expectations as patients interact with system features.

System features such as tracking and logging data can help diabetic patients recognize symptoms, such as levels of blood sugar that are too low or too high. This ability to monitor one’s condition is only effective if the data are entered and tracked over time. For example, Janet (Female, 51-60, white, professional degree, diabetes type 2) monitors her symptoms but her response to the symptoms is not consistent. After a short time of effectively managing her symptoms, she may recognize the symptoms, but may not take the right action to manage them. System features that make it difficult to enter and track data over time limit the system’s potential for symptom management, as expressed by Janet:

If that [the use of system features] was easier, and that's, again, one of my goals for getting the stuff [data about calorie intake, medication dosage] uploaded is [for tracking] the blood glucose levels, so that now all I have to do is go back and take the blood glucose app and the MyFitnessPal and track back what I was eating on a particular day. I'm doing that now, but it's less regular because when I'm really, really motivated at the beginning, I am willing to put in a lot of effort, but over time, I'm three months into it now and I'm already slacking off a little bit on tying the carb tightly to blood sugar, apparently because I [am more aware] when it does, but making compliance easy over time [through good system design] I think is crucial.

Patients track their progress, in conjunction with health professionals and with help from family members, to manage their symptoms. However, patients who depend on their immediate family members, prefer autonomy in the long term. They recognize that certain system features could support their need to eventually be free from relying on their support system. For example, since her diagnosis, Jasmin (Female, 18-21, white, some college, diabetes type 1) has relied on her parents and primary doctor to manage her diabetic
symptoms. She hopes that in the future she will be able to track, recognize, and manage the symptoms on her own:

I eventually want to be able to feel comfortable enough being alone in a house or a hotel room all by myself, not having to worry about any blood sugar issues at all, being confident in my ability to keep track of everything and have everything be healthy. ... [I would also like] to feel confident in my ability to judge certain ratios for insulin, judge and adjust those based on what's occurring, being confident in that ability and not having to go in for an appointment every time I feel like it's [blood glucose] off, just being able to adjust it myself and hopefully get results faster.

Based on the data entered into the system, patients can virtualize and identify the areas, for example blood sugar levels, that should be controlled and managed to self-regulate their symptoms. However, a sense of shame is associated with trends that show poor symptom management, especially if symptoms have to be shared with health professionals. Avoiding the sense of shame, or keeping their sense of dignity, drives patients to more effectively manage their symptoms. This value is captured in Shawn’s (Male, 31-40, white, doctorate degree, type 1) explanation regarding the importance of system features that allow him to regulate and adjust his care by being aware of his daily symptoms:

When you have these kinds of apps where you can see these trends and try and work on them, it helps you I think from the emotional standpoint, too because there’s a sense of shame that people have when they’re going in to their doctor. They say, "Well, here's my data." You don't want to show your doctor that, "Gosh, I've been going 3 months and my morning blood sugars are 200." You want to show them that you're doing a good job. Whether you've been doing this for a long time or you're new to it, you want your health care providers to be proud of you and think you're doing a good job, too. I think these kinds of interfaces where you can work on your care between office visits helps with that sense of wellbeing and self-pride as well.

**Drug management**

Drug management is defined as the practice of taking medication with regularity and overcoming the barriers to drug adherence (Barlow et al., 2002). Different system features can help patients with the administration of medication and adherence to treatment routine. The
values of privacy, interpretation, accessibility, and feedback were mentioned by patients as important in meeting their needs through regular medication. We describe how the values of accessibility and feedback are attained or constrained through the interactions among the system features and drug management activities.

Storing medical data in the diabetes app helps patients adjust their medications by tracking the impact of medical dosages on blood sugar levels over time. It is important for patients to have easy and fast access to the information about the kind and amount of drugs they take every day. They want the process of logging and tracking medical data to be automatic. For example, John (Male, 31-40, white, master’s degree, diabetes type 1), finds the manual logging and tracking of medical data in the GB app cumbersome and frustrating. Inadequate automation hinders one’s future access to information that is crucial to drug administration, as reflected in John’s statement:

It's a small thing, but when adding the meds, one of the things that annoyed me here was that when I get here, I wanted to be able to simply say how much insulin because that's the only ... I only have one type of insulin and it's the only medication I take. There are no others. But instead, what it makes me do is it makes me add a medication, select the only one that's an option, say done, then go in and add the units. It's a minor thing but when I take insulin on the insulin pump probably 15 times a day that adds up. That's an extra three clicks to make that one log, and that's 45 in a day, and that's a bit, I don’t know, frustrating.

The social networking features are beneficial as patients connect with other patients to learn effective drug practices. Connecting with other patients who are taking similar drugs can not only provide good insights but also reinforce the importance of SM. For example, Shawn (Male, 31-40, white, doctorate degree, type 1) finds the discussion forum in GB helpful:

If you can integrate some of that social aspect, it makes it enjoyable and you’re interacting with others but in doing so, you’re also reinforcing your self-care behaviors...you're constantly learning things when you're going through that online
forums] and learning from things other people have experienced. Maybe they're had a
drug started that caused our blood sugar to go up. You're like, "Oh, gosh. I didn't
realize that would happen with that medication.

Communication

The SM activity of communication refers to patients’ sharing their needs and problems
assertively and to building and maintaining relationships with healthcare providers
(Schulman-Green et al., 2012). In using system features to communicate their medical data
and their problems and questions to health professionals, patients express the values of
accessibility, autonomy, dignity, feedback, empathy, trust, and sense-making. Here we
describe the importance of empathy and accessibility.

Patients often share their medical data with their doctors to adjust SM progress.
However, when patients share such information, they feel vulnerable and expect some level of
understanding from their care providers. On one hand, the system allows easy sharing of
patients’ health data, but on the other hand, patients expect that healthcare providers spend
time with them during their scheduled visits to reconcile such decontextualized data. For
example, Kim (Female, over 60, white, bachelor's degree, diabetes type 1) is discouraged by
her doctor’s lack of empathy when she shares the data stored in her app, as he did not try to
contextualize the data by digging deeper into the reasons for her high sugar levels:

The doctor in Richland, I started out seeing him every few months and he knows I
come from a distance ... He's always encouraging. He thinks I’m doing great and he
did recognize [that] last time. He looks at my blood sugars. I take a list that I copy off
from the glucose buddy and he glances through them. [However, last time I was there
he was not very nice.] He said, “You know, your blood sugars are running higher this
time than they’ve been running.” [I wanted to say] “Well, my husband had open heart
surgery two months ago, so the stress level has been up. ...the stress and the lack of
controlled eating [are the reasons for high blood sugar]. The doctors have their 15-
minute, maybe it’s only 12-minute time slot. I don’t know how much they’re allowing.
The connectivity features of a system can not only help with the patient-doctor communication but can also potentially enable communication among all the doctors who are caring for a patient. Many diabetic patients have multiple diseases and have to visit multiple doctors. It is important for the patients that all their doctors be equally informed about their medical information and conditions. For example, Lucy (Female, 41-50, other ethnicity, some college, diabetes type 2) has two diseases in addition to her diabetes and becomes frustrated when she has to update her doctors individually about her medical conditions. The lack of communication between the doctors results in ineffective care, (e.g., medical prescriptions that have adverse effects). As noted below, an integrated access to the medical prescriptions and information, which could be provided through system design, would make it easier for Lucy to communicate with all the doctors:

I like being able to deal with one doctor for everything, because I feel like when you have multiple doctors, not everybody's on the same page. They're not necessarily communicating [with each] other. Sometimes medications are prescribed that I later find out have contradictions with other medications. I've had to tell doctors that you're over-medicating me. One ...prescribed me Methocarbamol muscle relaxer. [when I] tried [the medication] ... I woke up 2 days later. With Dysautonomia [I have] problems with being alert, I can't take anything that's going to make me drowsy. I can't take over-the-counter Benadryl because it puts me to sleep. I [take] too many [medications]. I'm on a pain medication, I'm on Lyrica, and then you want to throw in a muscle relaxer. These are all different doctors prescribing these things.

**Lifestyle**

Lifestyle refers to performing activities (such as exercise, nutrition, diet, and leisure activities) that promote health and assist in adapting to the chronic condition (Barlow et al., 2002; Bodenheimer et al., 2002). Our analysis reveals that as patients use system features to make lifestyle changes, the values of *sense-making, accountability, and accessibility, hope, autonomy, feedback, compliance, empathy, and joy* become important. Here we describe how
the values of sense-making and accountability are reflected in patients’ use of system features to maintain or change their lifestyle.

The system features, if designed well, can support the need of active diabetic patients for a lifestyle that helps them effectively manage their illness. However, designs that do not fully account for patients’ values limit a system’s potential. For example, Jackie (Female, 22-30, white, master's degree, diabetes type 1) needs to know the potential impact of various activities she engages in on her blood sugar levels. However, in the absence of such system capabilities, she cannot store the data at the desired granular level that would allow for deeper analysis and sense-making of the connection between sugar levels and the nature and magnitude of an activity. Jackie shares the importance of a more nuanced, deeper and richer analysis of her lifestyle data:

I liked that you could put in the activity, but ...I couldn't really tell [specifically what and how I did that activity] ... All I could do was just say what the activity was [such as running]. I guess that's fine, but it was hard ...to specify exactly what I did [would be better]. That could potentially be helpful, particularly with active people, like myself, when blood sugars around my activity is the most variable. Knowing exactly what I did, and then how my blood sugar responded to that activity, could help.

Data storage features facilitate making healthful food choices by tracking and monitoring eating habits. For example, Jonathan (Male, 41-50, white, some college, and prediabetes) feels that keeping track of his food intake makes him more aware of what he is eating. Such monitoring features would allow him to recognize his good and bad eating habits and motivate him to adjust his habits. Jonathan explains that using the GB app to log his food carbs tells him the impact of certain foods:

Sometimes a simple logging of what you’ve consumed over the course of the day makes you aware, “Wow, I’ve had four sodas today and I didn’t eat anything until 3:00 in the afternoon.” By tracking that you become a little bit more aware of, “Hey,
that’s probably not good. I didn’t log snacks, breakfast or lunch, I’m just logging at dinner and I’m probably going to have a snack before bed which is not a good time for eating heavier foods.” Just probably being more aware of what I’m doing, [you are more goal oriented] if you’re recording something or writing it down, maybe you make better choices because you don’t want to write the bad thing, right?

**Management of psychological consequences**

During the course of their disease, diabetic patients grapple with a number of psychological states because of negative emotions resulting from diabetes. Management of psychological consequences entails controlling the depression, negative emotions, stress, and anger induced by the persistent nature of chronic conditions (Barlow et al., 2002). Our analysis shows that the values of hope, autonomy, feedback, dignity, accountability, privacy, and empathy are critical to creating a more positive mindset. Here we describe how the values of hope and accountability can be implicated in a system design to achieve the desired psychological outcomes.

Diabetic patients could use can networking and discussion forum features to mitigate their negative emotions after diagnosis. The life changes caused by diabetes are disruptive and intrusive, and patients struggle to understand them and look for ways to fight their negative emotions. When patients learn that others are successfully managing their diabetes, they become motivated to manage their own chronic condition. For example, when Shawn (Male, 31-40, white, doctorate degree, type 1), who suffered from depression post-diagnosis, visits discussion forums and learns that other patients are successfully managing their disease, it helps him fight his negative emotions:

*When I was first diagnosed trying to change the way I did things, everything from physical activity to making sure I was checking my blood sugar frequently enough and eating the right things, I didn’t really use a lot of apps and technology to help me with that but I think it would have been a huge help. Particularly, I know, for myself,*
there's this point of when you get a diagnosis like that's lifelong and it really changes your day-to-day activities. I know a lot of people I work with, and it certainly was true for myself; it's a point where depression kicks in and it's hard to deal with on the outset. I think having that social aspect could help a lot with that, again, just understanding that there's other people being very successful and living well with the disease.

Post-diagnosis, many diabetic patients deny their disease and thus are incapable of self-managing their conditions. Using the system features immediately after diagnosis to connect with health coaches could help alleviate their negative emotions. For example, Mark (Male, 51-60, white, master's degree, diabetes type 1) went into denial after diagnosis. Connecting with a health coach through a feature in the mobile app could have helped Mark communicate with a professional and learn more about diabetes. Mark explains the importance of such assistance by describing the negative consequences on his health of his denial:

When I was first diagnosed, I kind of denied it. My doctor didn't tell me what to do for the first couple weeks. He said, "You're diabetic and we'll start you on medication and come back in a couple of weeks." I had some real good success with low calorie diets, not low calorie, and low carbohydrate diets. I just kind of cut out a bunch of carbohydrates. When I was diagnosed in the doctor's office because I was like, "I'm not diabetic." He says, "Yeah, yes, you are." He took my blood sugar and he said, "Your blood sugar is 355." I was like, "Is that bad?" Because I didn't know. He said, "Well, 100 is normal." I was like, "Oh".

Social support

Connecting with other patients with diabetes, friends, and family members will help patients break the isolating shell around them and remain motivated to manage their disease. Social support is defined as support from family, friends, and community in addressing social and environmental challenges and limiting isolation (Barlow et al., 2002; Schulman-Green et al., 2012). In reaching out for social support, the following values are important:
accountability, autonomy, empathy, feedback, and trust. We provide examples for the importance of trust and empathy.

Specialty discussion forums and boards about diabetes can address patients’ problems and answer their questions. However, sometimes patients do not trust the SM strategies and approaches suggested by other patients on the discussion forums. Jonathan (Male, 41-50, white, some college, and prediabetes) does not use diabetes discussion boards because he doubts the reliability of that source:

[I] never post a question [on a forum/discussion board]. I have to have run out of reputable data sources before I start to probably go through forum type stuff. All people think that it’s right because they want other people to read what they wrote. I don’t know if it’s very accurate so I have to see a lot of people saying the same thing before it’s like, “Okay, maybe there’s some validity to whatever that is.” That’s time consuming. In general, you can find the answers through something more reputable and quicker, not trolling through a bunch of people debating through something in a forum. I think there’s a certain type of person that posts regularly in a forum and so maybe I should try to put some bias towards that one. “Yeah, I don’t know if I want to hear what you have to say, sorry.” A lot of it is extremely opinionated. It’s not accurate. They’re not medical professionals. They’re just other people with something but they state things as factual. They advise other people as if they know. You don’t know. You don’t know what that person’s condition really is. You just know what they’ve told you in one sentence in a post. They’re like, “No, you should never do that?”

Online discussion forums can function as face-to-face diabetes support groups. Sharing experiences with people who have been through the same conditions, makes it easier for diabetic patients to seek support. For example, Sarah (Female, 22-30, white, high school, diabetes type 1), finds online discussion forums a venue for sharing her experiences and relieving the effects of an unpleasant day:

There’s a group called Diabetes Daily that I go to, and they have forums for pretty much about anything for diabetes. They also have live chat. … Yeah, you can just sit there and talk with them. Go on there if you’re having a bad day, just talk, and help them. That’s really nice, I really like that website. … It’s real, since I don’t hang out
with a whole lot of people. Basically, I hang out with my family and my life is working, and then doing whatever else I need to do during the day. If I'm having a bad day, it's nice that my family's there for the support but they just don't always get it. It's easier to talk to a group of people who are going through the exact same things, like the support group basically.

**Information**

Diabetic patients constantly seek information about their disease as they engage in SM activities. Acquiring information is defined as learning about the disease and its treatments (Barlow et al., 2002; Schulman-Green et al., 2012) to accomplish one or more SM activities. Informational resources in the SM systems can support multiple values, such as getting feedback, inspiring hope, and coping with a negative psychological state, that are important to patients' wellbeing. Gaining knowledge reduces patients’ uncertainties and reinforces their understanding of the disease. For example, Sandie (Female, over 60, white, bachelor's degree, diabetes type 2), mitigates her anxiety about hair loss by obtaining relevant information from online informational resources:

*Information is always power. You begin to understand your medications better, how they're helping, what they're doing, why Metformin works, what it does for your body, how it protects your liver and your kidneys and gets sugar out of your bloodstream and increases insulin, so that helps to know how that works. One of the more interesting things I looked up, I have very thin hair, much thinner than it ever was, and there's this rumor out there that Metformin makes you lose hair, but from what I've read people are losing it by the gobs, they're pulling it out by the fistful, which I'm not doing. "Maybe I can get off Metformin and my hair will grow back." That was one thing.*

Our analysis shows that information is used and also produced in SM activities. Next we present a conceptual model of an integrated and unified ICT-enabled SM system that represents all twelve values, the four system features, and the seven SM activities.
Discussion - ICT-enabled self-management conceptual model

Diabetic patients practice self-care by attending to their immediate illness needs (e.g., taking insulin) and coping with the realities of living with a chronic disease (e.g., controlling negative emotions) by harnessing and leveraging the resources (e.g., reaching out for support) available in their ecosystem. The orchestration of these activities in their clinical and non-clinical milieu with the assistance of ICTs that incorporate the values important to patients is represented in a conceptual model which we refer to as ICT-enabled SM. Our conceptual model (Figure 2.2) is derived from the VSD (Friedman, Kahn, et al., 2008) and work system (Alter, 2013b) frameworks described in sections 2 and 4. Our model explains how the values and SM activities are supported by system features within the SM ecosystem. In our model, system feature categories are on the left, along with participants, followed by the values implicated in and through the use of system features in the middle, and SM activities as outcomes on the right. The straight black arrows show the progress of the SM system. Information is represented with recursive arrows that show how information is used and produced among system features, participants, and values, and between values and SM activities. Patients use and produce different types of information as they employ system features to self-manage. Information is both a SM activity and a work system element that fuels the flow of the activities practiced in this system.

The central part of the model is Values, the 12 values that emerged from our value sensitive analysis of interview data. The five support values shown at the bottom of the value box are feedback, sense-making, accessibility, hope, and trust. The support values are essential and positively affect other values and SM activities. These values do not change significantly with changes in other values. A value sensitive design of a SM system calls for
some trade-offs between the values that directly support value sensitive system requirements (Borning et al., 2004; Friedman, Kahn, et al., 2008; Friedman, Kahn, Hagman, Severson, & Gill, 2006). However, we believe that support values should not be traded off in any ICT-enabled SM system, as they are tightly connected to the positive outcomes of the SM activities.

Seven swing values emerged from our study. These values are inversely dependent on other values, that is, fulfillment of one swing value is achieved by compromising other values. We call these values “swing” because they move in opposite directions. Swing values are categorized in three groups: (1) autonomy and compliance, (2) empathy, dignity, and privacy, and 3) joy and accountability. These values present potential conflicts among the values, which creates tensions in an ICT-enabled SM system. The constant tension among the swing values, represented with in-and-out arrows, are described below in greater detail.

![Figure 2.2: Conceptual Model of a Self-Management Work System](image-url)
Our analysis shows that as diabetic patients become more autonomous they become less compliant with SM activities. Over time, patients become experts about diabetes, which is shown in their less-compliant behavior in following regular SM practices. John (Male, 31-40, white, master's degree, diabetes type 1) was advised to log his blood sugar, activities, and the food that he eats, but he has never followed those recommendations with regularity. He has developed his own ways of managing diabetes over time; therefore, he does not log data or use system features but goes with his own instincts, as he explains below:

Okay, I know what the recommendation is but I'm going to do my own thing instead ... It was recommended that I log my blood sugars and, at that time, that meant literally in ...a mini log, you know, log book. I was supposed to log my blood sugars and log my activities and the food that I ate and the insulin that I took, and all that stuff. Honestly, I never ... I don't think I ever adopted that practice for more than a day or two.

Autonomous patients who are noncompliant do not seek support, which results in adverse medical complications. For example, Shawn (Male, 31-40, white, doctorate degree, diabetes type 1) is a type A person who enjoys being independent, which makes it difficult for him to ask for help or advice. He has “run into trouble” and experienced “dangerous” consequences of not asking for help:

I like it [to self-manage on my own] from the standpoint of having more autonomy and not feeling like I'm totally dependent on others for my own care because, by nature, I'm type A, independent. It's hard for me to reach out for help sometimes, even though it's important. On the other side, that can be a negative, too, I guess, wanting to work through things on my own first before I reach out. Sometimes I can run into trouble where I think I have a handle on it but really, I should have reached out for another opinion earlier. It's a double-edged sword ... in some instances, I know enough to be dangerous but I'm learning as time goes on when to reach out for advice and when to try and manage things on my own.
Patients become more private when the values of dignity and empathy are compromised. John (Male, 31-40, white, master's degree, diabetes type 1), for example, likes to keep his diabetes private because others do not understand the reality of his condition. He uses an insulin pump, for example, to disguise his use of medication when he is with his friends. New technologies and system features help John keep his SM private. As John’s friends become less empathetic about his diabetic condition, John becomes more private about his diabetes:

*I would say most of the time it's not so much that I want to keep it private for privacy's sake. It's more that I perceive that most people don't understand diabetes and most of the time ... I don't mind talking about it and explaining it and helping people understand. In fact, I kind of enjoy it but most of the time there's not room for that, or time for that. It's a little bit inconvenient. ... The easier ... Sort of, the path of least resistance is to simply deal with it somewhat privately. What I mean by that is, often if I'm in a group where I would normally check my blood sugar before I eat or if I feel a little high or low, I might choose to not and sort of guess based on how I feel or if I'm going to take insulin ... I now wear an insulin pump and so I can be fairly discrete about it. I can just reach down, push a button and take a little bit more insulin. I'll sometimes do that in the middle of a conversation. ... I'll just reach down, take a little bit of insulin, keep going as if nothing was happening when, in fact, I'm making a pretty major decision about my diabetes management. Not so much because I don't want people to know, I just don't feel like explaining or interrupting what's happening otherwise to have this moment of trying to explain what's going on, and why, etc.*

The values of dignity and privacy have similar tensions. Patients become more private when they perceive they are in danger of losing their dignity. For example, Mike (Male, 41-50, white, bachelor's degree, diabetes type 2) does not share information with his doctor that will show he has done a “poor job” of self-managing his diabetes. Mike maintains his dignity by not sharing his diabetes data even with his doctor:

*I guess, I don't like sharing information [my data stored on Glucose Buddy diabetes app] if I'm doing a poor job, but then again, if I'm doing a poor job and I give it to a doctor or somebody and they say, "Hey, what is this cr**?" then they'll circle back and say, "You need to do a better job," so, no, I don't [share my data that shows poor self-management].*
Diabetic patients seek a balance between their lifestyle management and enjoying life. They desire foods which are not good for diabetics. As they engage in unhealthy habits, they become less accountable toward their SM norms of practicing a healthful lifestyle. For example, Sandie (Female, over 60, white, bachelor's degree, diabetes type 2) struggles to avoid the high carb foods she enjoys. There is a perpetual tension between pleasure and accountability for Sandie:

*I have a lot of trouble with foods ...I really love bread and I really have to ... put the brakes on with bread when I'm out there. It's so easy, because it's on the table, just to keep grabbing pieces. I suppose if I asked anybody anything it would be, "Please don't serve a dinner family style." Have it on a buffet, you have to get up from your chair, take your plate over there, and really make the decision to keep eating.*

Patients can be educated to find the common ground between the value of pleasure and accountability. For example, Sandie learns that by following the portion control technique she learned from the dietitians and other patients, she can enjoy eating foods she likes and being accountable about her diabetes at the same time:

*You can eat anything, ... because all these years I've been hearing, "I can't, I can't, I can't, I can't." Now I have a banana on my table because I love bananas, so I can't eat a whole banana, but I certainly can eat a third of a banana in my cereal, so it's portion control. I can eat anything if I control the portions. That's been a real important piece of information for me, control your portions. When I eat ice cream, I try to control portions. Pasta's still bad, who could eat a third of a cup of pasta? ...but I control my intake of rice, and I'll have a small apple with some protein, but I check my blood sugar in an hour and a half ...*

**THEORETICAL CONTRIBUTIONS**

Our study contributes to theory in three important ways. First, it contributes to SM literature by explicating the role of ICTs in the SM of chronic diseases. Granting ICT artifacts a clear theoretical status through direct and deeper theoretical engagement with system features (i.e., its material properties) is necessary for advancing our understanding of
the role ICTs play in social-technical system (Robey, Raymond, & Anderson, 2012). By engaging ICTs in the conduct of SM, we not only extend SM literature that has nominally covered ICTs (Cummings & Turner, 2009; El-Gayar et al., 2013b; Farmer et al., 2005; McDermott & While, 2013), but also expand it by engaging its theoretical constructs (e.g. SM activities) with ICT artifacts that are commonly used today (such as online communities, mobile apps). Multiple SM models have been posited in the literature (Bodenheimer et al., 2002; K. R. Lorig & Holman, 2003; Ryan & Sawin, 2009). We build on this literature to derive an ICT-enabled SM model that explicated the role of ICT in SM activities to explain how the properties of system features support or impede SM conduct. This model, along with our initial analysis, can be used as a foundation to more deeply explore and theorize how the material properties of ICTs (e.g., portability and multiplicity of devices) exert their agency to facilitate or constrain patients’ SM actions.

Second, it contributes to VSD research in two ways. VSD researchers are demanding a more contextualized and flexible inventory of values and recommending moving away from largely fixed value classifications offered in the past (e.g., (Le Dantec, Poole, & Wyche, 2009)). We extend the VSD literature by empirically identifying patients’ values within the context of SM of chronic diseases, reinforcing the thinking that different patterns of values might emerge from different environments. Specifically, first we contribute by contextualizing values (accountability, autonomy, dignity, privacy, trust), which exist in the VSD literature and are viewed largely as universal. Additionally, we extend existing inventory by adding values that are specific to the SM context (accessibility, compliance, empathy, feedback, hope, sense-making, and joy). We argue that the contribution of such an inventory firmly lies in its use as a portfolio of values for SM that collectively serve as a
design guide and by viewing them simply as individual, discrete and isolated values, limits its impact. This portfolio can be used as a foundation for classifying a body of SM values that can be extended by future design science researchers through an iterative and integrative process defined in VSD’s tripartite investigations involving conceptual, empirical and technical analysis. Second, we expand the scope of VSD by applying it to investigate a complex social-technical system (STS). VSD predominantly focus on the use of micro computational systems such as Web browsers; groupware; simulation system, and RFID (e.g., (Friedman, Kahn, et al., 2008; Millett, Friedman, & Felte, 2001)). By revealing the interplay of values and system features in the conduct of SM, our study explains at a granular level how the values implicated in system features support or impede SM of diabetes.

Third it contributes to the work system research (Alter, 2013b) by applying and extending it in the healthcare space. Specifically, such an application expands the conceptualizations of ICTs beyond isolated technologies to a more holistic and unified view where ICT-enabled SM systems are assemblages of the social (e.g., patient, healthcare providers, family and friends) and the material (e.g., ICTs, insulin pump, wearable gadgets) components influencing and influenced by each other (Orlikowski & Scott, 2008). In doing so, the role of ICTs in structuring SM of chronic diseases is explicated. Such explications can not only help in understanding their role in shaping the conduct of SM (e.g., better provisioning the needs and preferences of patients by supporting the values that are important to them), but also help in guiding how the SM is organized and performed.

**IMPLICATIONS**

Broadly, our study’s findings have implications for design science researchers, healthcare providers, and policy makers.
Implications for Design Science Research: The values explicated in our study through VSD lens help in prioritizing consideration of human values in design. In so doing, it complements the more functionalist approach that focus on usability (i.e., which refers to system properties that make systems work in a functional sense) by adding a more critical interpretive lens in support for patients’ values (Friedman, Kahn, et al., 2008); perhaps it even subverts the functionalist approach by encouraging human value considerations over usability (e.g., designs that disallow healthcare providers to view recent exercise history to preserve patient’s dignity). To this end, the implications of this work for design science researchers are threefold. First, the findings from this work can be used to develop principles for guiding value sensitive ICT-enabled SM system designs. Design principles can enhance the capabilities of the system features such that they are more attentive to patients’ needs and preferences. For example, a set of design principles can be generated that support the value of hope. Such principles could guide in designing features that monitor and bolster patients’ hopefulness. For instance, it is conceivable to analyze the data stored in ICTs used by patients to anticipate situations that engender the feeling of hopelessness (e.g., a patient demonstrating regular commitment to exercising and drug management, but still experiencing high fluctuations in their blood levels could be a harbinger of loss of hope) and provide support to ameliorate such feeling. Second, the portfolio of values uncovered in this work can be used in future research to determine the positive and negative health consequences of implicating (or not implicating) the values in ICTs that support SM. Examining such impact on patient outcomes could help in harmonizing healthcare providers’ priorities of managing symptoms with patients’ concerns for their values. Orchestrating such harmonization could help in developing design features that embody both patients’ values and clinical priorities which
could boost the use of ICTs for SM. Third, we provide a starting point for conducting three kinds of analysis proposed in VSD literature to advance this work (Friedman, Kahn, et al., 2008). One, design researchers could undertake a value-driven investigation on ICT-enabled SM systems where a more detailed conceptual, empirical and technical analysis is conducted on each value uncovered in this study. The other kind of analysis could be driven by SM activities where the focus is on what and how to implicate the revealed values in ICTs in preforming a certain SM activity. The last kind could be a retroactive technical investigations of current healthcare ICTs to recommend improvements in existing designs.

*Implications for Healthcare Providers:* The findings of this work furnish insights to the healthcare providers that they could employ while encouraging the use of ICTs to drive certain healthcare outcomes. For instance, the insight that the practice of portion control is intertwined with the value of joy (i.e., eating food they enjoy) could push healthcare providers to make recommendations regarding the use of ICTs to balance the ill effects of certain food with the benefits of enjoying life as patients learn to live with their chronic conditions.

*Implications for Policymakers:* Our work informs national health policies on using technologies to empower and engage patients in their chronic care. Advancing patient-centered and self-managed health with the use of ICTs is a growing priority (ONC, 2014). The goal is to improve the health and wellbeing of individuals with chronic diseases through the use of technology and health information. For instance, Affordable Care Act (ACA) in the U.S. promotes SM based on strictly objective measures to reduce costs and improve care (Public Law, 2010, p. 296,273). Our work complements such healthcare policies by highlighting the centrality of the patients’ values in achieving health outcomes. Our work
suggests that in order to achieve and sustain objective and meaningful health outcomes in and through ICTs, it is imperative that their designs are attentive and sensitive to patients’ values.

The findings of this research are limited to patients with diabetes but we believe they can be adopted to support values of patient with other kinds of chronic diseases in using SM systems. Technology in this research is illustrated in a diabetes mobile app. Future research can further investigate value-sensitive design and use of other types of technologies individually and collectively being used by the patients in the ecosystem of SM work system.

**CONCLUSION**

Empowering patients in their own care through ICTs is essential to promoting patient-centered healthcare. However, in order for patients to embrace and use ICTs as a part of their SM system, it is imperative that such artifacts recognize and support the values that are important to them. By revealing a portfolio of values that are important to diabetic patients as they use ICTs to self-manage their illnesses, we broaden the intellectual space where investigations of the role of ICTs in healthcare moves beyond just focusing on lowering costs and bettering clinical outcomes.
REFERENCES

Acquisti, A., Oh, W., & Sia, C. L. (2016). Call for Papers for a Special Issue (Journal of the Association for Information Systems) ICT Challenges and Opportunities in Building a “Bright Society.”


NOTE:

You will qualify to participate in this research only if:

- You have Pre-Diabetes or Diabetes type 1 or Diabetes Type 2
- You own an iPhone or an Android phone

How can mobile apps improve our health conditions?

My name is [Anonymized for blind review]. My doctoral research is about the role of information technology (IT) in the management of treatments and symptoms, and promoting healthy lifestyle for the patients with diabetes. Management of treatments and symptoms of chronic diseases is known as self-management. The information technologies that can be used in the self-management range from using text message or phone call reminders to glucose monitoring systems for the diabetic patients and mobile apps. My research focus is on supporting human values important to the patients in designing systems and technologies. The opinions of the patients with chronic diseases are critical to my work and will greatly inform my research.

Upon your interest to participate in this study I will contact you with the details and instructions. You will be provided with an iOS mobile app specifically designed for improving self-management of diabetes. After using the mobile app for one week, we will meet for an in-depth 1-hour long interview. We will audio record and transcribe the interview for the research purposes. No personal information will be used and we will de-identify all the
collected information. Any data and information collected in this study will be used solely for research purposes. **You will be compensated for your participation with $25 Amazon gift card.**

If you are interested to participate in this research, on the next pages, please sign the consent form, provide your contact information, and answer to the following questions. You can complete the digital version of this survey at the following link:

**Survey Link:** [Removed for blind review]

If you have completed the paper copy, please return the completed form to the location where you picked up the form or return it to the person who delivered the form to you:

Should you have any question, you can reach me at [Removed for blind review]

**Appendix B – recruitment survey**

Your contact information (Please provide the most convenient way that we can contact you):

- Email:
- Phone:
- Other:

Demographic questions:

1. Gender:
   a. Male
   b. Female

2. Age:
   a. 18-21
   b. 22-30
   c. 31-40
   d. 41-50
   e. 51-60
   f. Over 60

3. Ethnicity:
   a. White
b. Hispanic or Latino  
c. Black or African American  
d. Native American or American Indian  
e. Asian / Pacific Islander  
f. Other

4. Education:  
a. High school  
b. Some college  
c. Associate degree  
d. Bachelor’s degree  
e. Master’s degree  
f. Professional degree  
g. Doctorate degree

5. Do you have any of the following chronic diseases or conditions? (Please select all that apply)  
a. Pre-diabetes  
b. Diabetes type 1  
c. Diabetes type 2  
d. Asthma  
e. Heart diseases  
f. Others: ________________

6. What is the severity of your chronic disease or condition? (Please mark below)  
   Mild: 1_ 2_ 3_ 4_ 5_ : Severe

7. Do you own an iPhone or an Android smartphone? Yes____ No____

8. Have you ever used or do you currently use any kind of technology in managing your chronic conditions? Yes____ No____  
   Explain:  
   __________________________________________________________________________
   __________

Appendix C – sampling dataset

<table>
<thead>
<tr>
<th>Case</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Education</th>
<th>CDC</th>
<th>Severity</th>
<th>Platform</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Shawn</td>
<td>Male</td>
<td>31-40</td>
<td>White</td>
<td>Doctorate Degree</td>
<td>Diabetes Type 1</td>
<td>3</td>
<td>iPhone</td>
</tr>
</tbody>
</table>
Appendix D – interview questions

The following open-ended questions are and will be covered during the interview and iterative and integrative fashion:

Layer 1 - Chronic Disease:

- Can you describe your diabetic condition?
- How long have you had the chronic condition or disease?
- What are the treatment that you are currently having or you have had for your chronic disease or condition?
Layer 2 - Self-management (SM):

- What do you do to self-manage your condition? When did you start?
- Have you been self-managing your condition? Explain How. Make examples.
- Is it helping? Yes – How; Not - Why or why not? Illustrate thru examples how SM has helped your condition

Layer 3 - Values:

- What do you like/ NOT like about self-managing your condition – explain with examples.
- What is important to you as a patient with diabetes who is self-managing his/her chronic conditions?

Layer 4 - IT Artifact:

- Describe how you used the <GB App>
- What did you like about the app? (What features) And Why? Please illustrate with examples
- What did you NOT like about the app? Why or why not? Please illustrate with examples
- What would you like to change about the app? And Why? Please provide examples
- Would you consider using an App like this to self-manage your condition? Why or why not?
- Overall, how satisfied are you by this app? Why or why not?
- If you do not use Technology/App, how will you or do you self-manage your condition?
Appendix E – Resolving disagreements on coding schema

Two coders coded the transcripts of an interview. Next, they discussed and compared their coded transcripts. Coders discussed their understanding of every item of the coding schema. They resolved their disagreement by discussing how they interpret each item of the coding schema and how it should be applied to the interview text. Coders compared different instances of the codes from the interview transcript to comprehensively agree on the agreeability of the codes, the way they are applied, and how different instances in the interview transcript can be applied to an item of coding schema. The two coders agreed on the scope and clarity of the coding schema. For example, coding item of “communication” under self-management components was initially defined as “communicate your needs and problems assertively, and create and maintain relationships with healthcare providers”. Coder A applied this component to any instance of the communication from the patient in the interview transcript. Coder B viewed “communication” component only applicable to those instances of communication of needs and problems between patients and health providers.

This disagreement was resolved between the coders by reviewing the literature references of “communication” component of self-management. The coders clarified the definition of “communication” component and centered the definition and applicability of communication item only to the instances in the interview transcript that is between patient and healthcare providers. By clarifying the definition of “communication” coders were able to distinguish and differentiate the coding items of “communication” and “social support”. The coders decided that communicative instances between the patient and non-health providers will be applied to the self-management component of “social support”.
ESSAY THREE:

DESIGN PRINCIPLES FOR CHRONIC DISEASES SELF-MANAGEMENT SYSTEMS: A TECHNICAL INVESTIGATION BASED ON CHARACTERISTICS OF DIGITAL TECHNOLOGIES

ABSTRACT

The use and design of digital technologies, such as mobile applications, for the self-management (SM) of chronic diseases are increasing. SM systems designed without theoretically driven design principles are ineffective and inconsistent. In this study we draw on design science methodology to systematically derive design principles from self-management theories for designing SM systems. Our proposed design principles are informed by the characteristics of the digital technologies: (1) the re-programmability, (2) the homogenization of data, and (3) the self-referential nature. We conceptually instantiate our proposed design principles in a diabetes mobile app and illustrate the system implications of the design principles in use case diagrams. We discuss contributions to research and implications for practice.
INTRODUCTION

Miniaturization of the digital technologies and ubiquitous computing are becoming available in everyday artifacts (Yoo 2010). Such artifacts are transforming health management (Waite et al. 2013) by empowering patients with chronic diseases to self-manage their illnesses (Vuong et al. 2012). Chronic diseases, such as diabetes, heart diseases, and asthma, are lifelong, disruptive to the patients’ lives, costly, and not curable (Barlow et al. 2002). In healthcare digital technologies are used by patients with chronic diseases to self-manage their health and improve their quality of care (El-Gayar et al. 2013a). Self-management (SM) refers to a patient-centric management of symptoms, treatments, and emotional consequences of the chronic diseases and conditions in which patients are actively engaged in the care process, play a central role, and collaborate with healthcare providers (Barlow et al. 2002; Bodenheimer et al. 2002). From glucose-monitoring Google glasses to intelligent mobile health apps, tech firms are designing technologies to improve, automate, and streamline health management. There are 165,000 health-related apps designed for Android and iOS platforms with estimation of 1.7 billion downloads by 2017\(^2\). The market share for mobile health apps will be $21.5 billion in 2018\(^1\). These apps could improve management of chronic diseases such as diabetes, asthma, and cardiovascular diseases by providing continuous long-term monitoring capabilities. Tech companies design self-management systems for the patients with chronic diseases to manage their health on a day to day basis. For example, Medtronic, allied with IBM’s Watson, is designing an app which collects and analyzes data from multiple sources such as insulin pumps, glucose monitors, and

activity trackers to predict three hours in advance when a patient will have high or low levels of blood sugar\(^1\). Studies show that for the first time mobile health apps could become the preferred resource over physicians\(^3\).

Advancement in digital artifacts alone is not sufficient for these technologies to act as complementary or supplementary resources for SM. SM demands designing SM systems to empower patients, engage patients in their care, and support behavior changes (Lamprinos et al. 2016; Vuong et al. 2012). Systematic design approaches for investigating and designing e-health systems (Cummings and Turner 2009) and identifying effective digital capabilities for the SM activities (Bailey et al. 2013) such as symptom management, medication management, and management of psychological consequences imposed by the chronic diseases are lacking (Schulman-Green et al. 2012). The main objective of this paper is to propose a set of design principles drawn from SM theories and informed by the unique properties of digital technologies to support patients with chronic diseases in performing their SM activities. First, our design principles support designing health systems to reinforce the conduct of SM activities and recognize the central role of the patient-user (Solomon 2008). Second, the proposed design principles fully integrate the capabilities and functionalities of digital technologies in supporting SM activities (McDermott and While 2013). We do not build or test a SM system but conceptually provide design features based on the characteristics of digital technologies.

The SM systems designed and conceptualized based on digital technologies in the literature have three limitations. First, the system solutions offered in the literature do not fully and granularly engage the digital artifact to leverage the inherent characteristics of digital technologies.

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\(^{1}\) http://www.forbes.com/sites/jenniferelias/2015/12/31/in-2016-users-will-trust-health-apps-more-than-their-doctors/#bc905a82d5f6

87
digital technologies and their potentials for the SM of chronic diseases (McDermott and While 2013). Second, the design and development of the SM systems are not theoretically driven which creates ineffective SM (Jacelon et al. 2016). Third, SM literature fails to offer design principles that could systematically guide the development of SM systems (Jacelon et al. 2016; Lamprinos et al. 2016). We address these gaps in the design of the SM systems by developing design principles that are grounded in theory and have tight coupling with the salient characteristics of the digital technologies and the SM activities they support. More specifically, we follow design science methodology (e.g., Gregor and Hevner 2013; Hevner et al. 2004; Peffers et al. 2007; Walls et al. 1992) to systematically derive design principles (for example, Chaturvedi et al. 2011) from SM theories (Bodenheimer et al. 2002; Jacelon et al. 2016; Ryan and Sawin 2009) and characteristics of digital technologies (Cummings and Turner 2009; Varshney 2014; Vuong et al. 2012; Yoo 2010; Yoo et al. 2010).

This paper is organized as follows. First we will review the relevant literature. Next we will explain our design science methodology followed by explanation and illustration of proposed design principles. Discussion will be presented next. We will conclude with contribution, implication, and conclusion.

**LITERATURE REVIEW**

We have reviewed the literature to display the conceptualizations of the SM systems designed based on digital technologies (Table 3.1). These categories are computer-based systems (Jacelon et al. 2016; McDermott and While 2013), consumer technologies (Or and Tao 2014), digital media (Li et al. 2012), mobile applications (Bailey et al. 2013; El-Gayar et al. 2013a; Waite et al. 2013), mobile platforms (Belisario et al. 2013; Farmer et al. 2005; Lieffers and Hanning 2012; Tatara et al. 2009), and text messaging systems (Deglise et al. 2012).
These categories vary by their main focus on different types of digital platforms in supporting SM (see Table 3.1). The SM systems support different aspects of SM such as disease education (McDermott and While 2013), medication management (Bailey et al. 2013), self-monitoring (Cummings and Turner 2009), and delivering health-related information (Li et al. 2012).

<table>
<thead>
<tr>
<th>Category</th>
<th>Digital Platforms</th>
<th>SM Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer-based systems</td>
<td>Standalone desktop computer, laptop,</td>
<td>- Disease education</td>
</tr>
<tr>
<td></td>
<td>computer kiosk</td>
<td>- Providing feedback</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- User education</td>
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<tr>
<td></td>
<td></td>
<td>- Healthcare provider access</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Enabling use of peripherals (such as blood pressure, glucose monitor, scale)</td>
</tr>
<tr>
<td>Consumer technologies</td>
<td>Interactive consumer web or technology-</td>
<td>- Access diabetes information</td>
</tr>
<tr>
<td></td>
<td>mediated applications</td>
<td>- Decision making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Informational and emotional support</td>
</tr>
<tr>
<td>Digital media</td>
<td>Electronic media such as social</td>
<td>- Deliver health-related information</td>
</tr>
<tr>
<td></td>
<td>networking tools, and online games.</td>
<td></td>
</tr>
<tr>
<td>Mobile applications</td>
<td>Native Mobile apps</td>
<td>- Tracking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Access disease information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Medication management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Decision making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Communication with healthcare providers</td>
</tr>
<tr>
<td>Mobile platforms</td>
<td>Portable handheld devices</td>
<td>- Symptom management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Medication management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Dietary intake assessment</td>
</tr>
<tr>
<td>Text messaging systems</td>
<td>Short message service (SMS)</td>
<td>- Treatment compliance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Communication with healthcare providers</td>
</tr>
</tbody>
</table>

**Computer-based systems** are SM assistive systems that support patients and reduce healthcare costs (Jacelon et al. 2016). Standalone desktop computer, laptop, and computer kiosks are types of computer-based systems that are used to deliver patient education in health supported settings (McDermott and While 2013). **Consumer technologies** are patient-centric and interactive consumer technologies designed to improve patients’ access to information and decision making (Or and Tao 2014). **Digital media** are ubiquitous and flexible electronic
media that deliver health-related information to the patients (Li et al. 2012). *Mobile applications* are native apps that run on mobile devices and perform functions such as recording, visualizing, and communicating data that were limited to personal computers (Bailey et al. 2013; El-Gayar et al. 2013a; Waite et al. 2013). *Mobile platforms* are portable hand-held devices that provide access to internet/email and run different apps that support SM tasks such as tracking and monitoring disease symptoms (Lieffers and Hanning 2012; Tatara et al. 2009). In this category the main focus is on the mobility of the devices and not the apps. *Text messaging systems* are short message services (SMS) that are used for prevention, surveillance, management and treatment compliance (Deglise et al. 2012).

Our review of the SM systems used and designed for the SM of chronic diseases, shows three major caveats. First, the SM systems are developed based on digital technologies such as mobile platforms but they are not motivated by their inherent characteristics. For example, Waite et al. (2013) show that diabetes mobile apps are designed around SM tasks required for the medical control of the diabetes, such as tracking, education, and estimation of carbs intake. Their technical investigation of the apps is limited to the usability evaluations. The design of mobile apps does not fully engage the unique characteristics of the smartphone apps, such as their ubiquity and flexibility, at the early stages of the design (Bailey et al. 2013; Deglise et al. 2012; El-Gayar et al. 2013a; Quinn et al. 2008). The review of the mobile apps shows that more than 90% of the SM apps have system features for medication management, less than 11% have features for education and providing information and knowledge about the medication, drug interactions, and less than 22% of the apps account for multiple users involved in the SM activities. While 75-100 % of the diabetes SM apps, for example, account for blood glucose and medication, only 7-11 % of the apps have used mobile features for
security and social networking. The underlying reasons, rationales, and principles driving this variability are not well understood (Bailey et al. 2013).

Second, the design of the SM systems for the SM of chronic diseases is not theoretically driven. The design and use of the computer-based SM systems (Cummings and Turner 2009; Davis et al. 2010; McDermott and While 2013), for example, are primarily motivated by the goals of medical control and immediate positive health outcomes without sufficient theoretical support. Jacelon et al. (2016) in their extensive review show that only less than 10% of the designs of the SM systems were theoretically driven. Lack of theoretical support for the technology-based SM systems engenders an incongruent and ineffective SM. The absence of integrated theoretical model upon which SM systems are designed will result in fragmented systems that do not support all aspects of SM (Jacelon et al. 2016). Theoretical support in designing systems is important because theories are existing, valid, and relevant (Mandviwalla 2015). Such theories are applied through the experience and problem solving abilities of the researcher (Hevner et al. 2004).

Third, design frameworks and guidelines for SM systems do not fully capture the potentials of digital technologies in supporting SM tasks and activities. The guiding frameworks in the literature are abstract conceptual models that lack clear connections to SM activities and do not explicitly link system features with SM goals (Jacelon et al. 2016; Lamprinos et al. 2016). The existing prescriptive designs are based on clinical guidelines (Lamprinos et al. 2016), limited to a subset of digital technologies (Li et al. 2012), general recommendations without system implications (Cummings and Turner 2009; El-Gayar et al. 2013a), and lack pre-post assessment of the SM systems (Todd et al. 2012; Tran et al. 2012).
In summary the lack of theoretically driven design principles for SM systems, creates ambiguity and inconsistency in designing SM systems. In the next section, we will explain design science methodology and its components upon which we have developed theoretically driven design principles for SM systems.

**DESIGN SCIENCE METHODOLOGY AND SM SYSTEMS**

IS studies have generally failed to fully engage with the material properties of the ICT artifacts and systems in providing technology-enabled solutions or analyzing societal problems (Robey et al. 2012). The lack of engagement results in the methods and approaches that focus merely on how ICT artifacts can be used while being less concerned with the ICT users’ goals and the capabilities through which those goals can be accomplished (Majchrzak et al. 2016). Design of the SM systems is the main focus in this research. Therefore, we use design science methodology to investigate how systems designed based on digital technologies can support SM. Design science paradigm investigates how technical capabilities can be designed in systems to make them more effective (Hevner et al. 2004).

Design science method has three major components: (1) domain theories, (2) principles, and (3) design ⁴(Hevner et al. 2004; Hevner and Chatterjee 2010; Mandviwalla 2015; Peffers et al. 2007; Walls et al. 1992, 2004). Domain theories include natural and social sciences theories and philosophies. These theories form the foundation upon which principles are developed (Walls et al. 1992). Principles are a set of goals and requirements developed based on domain theories. These requirements are used for a class of systems rather than one specific system (Walls et al. 2004). Principles can be implicated in a class of systems that are

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⁴ Known as kernel theories, meta-requirements, and meta-design.
referred to as *design* (Walls et al. 1992). In summary, a class of requirements, *principles*, derived from relevant theories, *domain theories*, are implicated in a class of systems, *design*.

In this study, SM theories (Ryan and Sawin 2009) and characteristics of digital technology (Yoo 2010; Yoo et al. 2010) are used as *domain theories*. SM systems are socio-material phenomena best understood by the separation of their sociality and materiality (Robey et al. 2012). The SM theories capture the sociality and characteristics of digital technologies capture the materiality. *Principles* are salient requirements that guide SM system designs (Peffers et al. 2007). These design principles do not apply to only a specific SM system, such as glucose meter for diabetic people, but can be used to design a class of SM systems developed based on digital technologies. *Design* is represented in schematic use case diagrams that illustrate how *principles* are implicated in a SM system. We choose a mobile diabetes app as an instantiation of SM systems to explain how design principles can be implicated in a system. Design science method has been used in IS studies to derive design principles for ethical collaborations (Chatterjee et al. 2009), privacy enhancing tools in web browsers (Xu et al. 2012), emerging knowledge processes (Markus et al. 2002), virtual environments (Chaturvedi et al. 2011), and document management systems (Dourish 2003). *Domain theories, principles, and design* for building SM systems are discussed in the following sections.

**Domain theories**

We draw on two streams of work, SM theories and characteristics of the digital technologies, to derive design principles for SM systems. Next we describe these theoretical streams.
**Individual and family self-management theory (IFSMT)**

SM is a fluid, iterative, and dynamic process in which patients manage their health conditions (Jacelon et al. 2016; Schulman-Green et al. 2012) to make health behavior changes (Ryan 2009) by conducting activities such as symptom management, medication management, and coping with negative emotions (Barlow et al. 2002). Based on the Individual and Family Self-Management Theory (IFSMT), SM can be enhanced through three major components of the SM process (Ryan and Sawin 2009): (1) knowledge and beliefs, (2) self-regulation skills and abilities, and (3) social facilitation. This theory posits that fostering, increasing, and enhancing these three components drive patients to change their health behaviors and engage in SM behaviors and activities (referred to as proximal outcome) and improve their health (referred to as distant outcome) (Ryan 2009).

During the course of SM, patients focus on their illness needs by acquiring information about their disease, monitoring and managing their symptoms, and changing lifestyle changes (Schulman-Green et al. 2012). They activate their psychological, community, and social resources by communicating their needs effectively, maintaining positive hope, obtaining and managing social support (Barlow et al. 2002). Living with a chronic illness involves dealing with guilt and self-blame, creating meaning in life, reframing expectations, and appreciating life (Schulman-Green et al. 2012).

Within the knowledge and beliefs component of the SM process, patients perform certain activities to produce positive SM outcomes (Ryan and Sawin 2009). Patients with chronic diseases seek out information to gain knowledge about their medication, its side effects, its interaction with other medications, using medical devices, the treatments, and the predicaments of their disease (Schulman-Green et al. 2012). Their knowledge affects their
perception of their disease (Ryan 2009). Fostering knowledge and beliefs of the patients increases their understanding of their condition, their self-efficacy in changing a behavior and performing a SM activity, their abilities in controlling stressful situations imposed by the disease, their confidence in achieving desired results, and mitigates confusion and anxiety around health goals (Ryan 2009).

Within the self-regulation skills and abilities component of the SM process, patients perform a set of activities to generate positive health outcomes. Self-regulation is an integration of the day-to-day processes into the life habits and lifestyle to make a behavior change (Ryan and Sawin 2009). Self-regulation skills and abilities involve supporting SM activities of self-monitoring the symptoms of the disease, decision making in response to certain symptoms, planning goals and acting upon the goals to make lifestyle changes, and reflecting on and self-evaluating the performance in achieving the goals (Schulman-Green et al. 2012). Increasing self-regulation skills and abilities facilitates behavior change and provides positive SM outcomes (Ryan 2009).

Social facilitation includes both social influence and social support. A person with higher knowledge or authority can influence and motivate a patient to engage in activities that result in behavior change (Ryan and Sawin 2009). In SM of chronic diseases, social influence comes from healthcare providers such as physicians, nurses, dietitians, endocrinologists. Social support is provided by emotional help and support from family members, friends, and other patients. Patients with chronic diseases reach out to their friends and family members when they struggle with frustration and depression caused by the exacting chronic symptoms of their illnesses (Lorig et al. 1994). They identify with patients with the same conditions to remain motivated in their SM (Barlow et al. 2002). Patients communicate their needs and
questions with their healthcare providers when they interpret their medical data, manage their symptoms, and make decisions (Lorig and Holman 2003). Enhancing social facilitation engages patients in their SM activities and promotes health behavior change (Ryan 2009).

**Digital technologies**

Digital technologies are transforming patients’ health management (Jacelon et al. 2016) and empowering patients to integrate SM activities into their daily lives (Lamprinos et al. 2016). Emergence of sensing devices and miniaturization of devices transform technologies into powerful tools for the everyday use of the individual patients (Varshney 2014). Certain qualities of digital technologies benefit patients to self-manage their chronic diseases. For example, location tracking, body sensors, flexible and instant wireless communication and access enable patients in their healthcare management (Varshney 2014). There is a growing number of mobile apps designed for the management of chronic diseases (Waite et al. 2013). For example, for diabetic patients, these apps provide tracking and estimation capabilities to manage their blood glucose levels. Personal assistant digital (PDA) devices, for example, are effective tools to sustain patient’s compliance with health behavior changes recommended in the SM of chronic diseases (Vuong et al. 2012).

Digital technologies provide a unique structure in which different technological components function in flexible modules (Yoo et al. 2010). The layered modular architecture of digital technologies yields to novel combinations of technological features that make new digital products “programmable, addressable, sensible, communicable, memorable, traceable, and associable” (Yoo et al. 2010, p. 725). Digital technologies differ from earlier technologies based on their three unique characteristics of (1) the re-programmability, (2) the homogenization of data, and (3) the self-referential nature (Yoo et al. 2010). The Re-
programmability refers to the flexibility of the digital technology within which data is manipulated in infinite number of ways to afford different functionalities such as calculating distances, word processing, and video editing. The Homogenization of data refers to the interoperability and accessibility of the digital data (such as audio, video, and text) generated from disparate sources that can be integrated and synthesized to introduce new services. The self-referential nature refers to the distributed and ubiquitous nature of the digital technologies that makes their contents, features, and capabilities available to anyone. The availability of digital technologies democratizes their use by larger number of people and enables instant and simultaneous use of technological features by multiple users (Yoo et al. 2010). These characteristics of digital technologies create modular design architecture in which different elements of a system can be combined and re-used by the system users to generate new services from digital data (Yoo et al. 2010).

Yoo et al. (2010) suggest future research questions based on the characteristics of the digital technologies. They suggest exploring the design principles of digital technology and the influence of the technical dimensions on those characteristics. Yoo et al. (2010) call for novel research ideas based on digital technologies. In the next section, we address this call by formulating theoretically driven design principles for a SM system.

**Principles**

Design principles are guidelines (Chaturvedi et al. 2011; Xu et al. 2012) with theoretical support (Hevner and Chatterjee 2010) for designing digital technologies (Dourish 2003). Here we derive principles grounded in SM theory and characteristic of digital technologies that can be used to guide the design and development of features in SM systems (Figure 3.1).
IFSMT theory recognizes three main components for the SM of a chronic disease. These components of the SM process are *knowledge and beliefs*, *self-regulation skills and abilities*, and *social facilitation* (Ryan and Sawin 2009). The goals of using technological interventions in supporting SM process are 1) fostering *knowledge and beliefs*, 2) increasing *self-regulation skills and abilities*, and 3) enhancing *social facilitation* (Ryan 2009).

Supporting these goals facilitates producing positive SM outcomes. SM outcomes, based on IFSMT theory, are higher engagement in health behavior change to achieve better quality of life and health status (Ryan and Sawin 2009). In this study we focus on SM systems designed based on digital technologies to support SM process. Digital technologies have three main characteristics that can support three SM goals. These characteristics are *homogenization of data*, *re-programmability*, and *self-referential nature* (Yoo et al. 2010). These characteristics function within a layered modular architecture in which data (content layer) is homogenized, re-programmed, and shared to create new functionalities (service layer) within a network of connected technologies (network layer). These layers are modular which enables them to combine and create technologies in infinite number of ways.

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<tbody>
<tr>
<td>Fostering knowledge and beliefs</td>
<td>Homogenization of Data</td>
<td>DP#1</td>
</tr>
<tr>
<td>Increasing self-regulation skills and abilities</td>
<td>Re-programmability</td>
<td>DP#2</td>
</tr>
<tr>
<td>Enhancing social facilitation</td>
<td>Self-referential Nature</td>
<td>DP#3</td>
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Figure 3.1: Design principles for a SM system are derived from characteristics of digital technology (Yoo et al. 2010) and SM theory of IFSMT (Ryan and Sawin 2009).
In digital technologies, homogenized data is integrated in one system from multiple data sources. Patients with chronic diseases need to collect different kinds of informational data, for example vital signs, blood glucose levels, blood pressure, from multiple peripheral devices, such as scales, blood pressure devices, glucose monitoring systems, and have immediate access data in one system (Bailey et al. 2013). Data integrated in one system fosters knowledge and beliefs of the patients about their disease, treatments, medications, and symptoms. Therefore, in design principle 1, the characteristic of homogenization of data fosters knowledge and beliefs by integrating and homogenizing data from multiple sources and providing immediate access to knowledge and information at any time and location. Re-programmability of a digital technology allows data manipulation and understanding data relationships (Yoo et al. 2010). Patients with chronic diseases need to manipulate data and interpret their meanings and relationships to self-regulate data recording, monitoring, and symptom management into their daily lives (Bu et al. 2007). Therefore, in design principle 2, the characteristic of re-programmability, increases self-regulation skills and abilities by allowing patients to manipulate data, interpret data relationships, and integrate tracking and monitoring abilities into their daily lives. Self-referential nature of digital technology enables users to communicate through a network of multiple users using similar digital technologies (Yoo et al. 2010). Patients with chronic diseases need to communicate with their healthcare providers, family members, and other patients to seek support (Bodenheimer et al. 2002). Therefore, in design principle 3, the characteristic of self-referential nature, enhances social facilitation by creating a network of devices used by patients, healthcare providers, family members and other patients. Design principles are outlined in Table 3.2 and further explained in the following paragraphs.
Table 3.2: Development process of design principles for a SM system with examples of system implications

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<tr>
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<tr>
<td>1) Homogenization of Data: Digital data from heterogeneous sources are combined, integrated, and accessed on digital technologies to deliver diverse services.</td>
<td>1) Fostering knowledge and beliefs: Providing immediate access to relevant and reliable information and knowledge to increase self-efficacy and outcome expectancies in the patients to engage in SM activities and behavior change.</td>
<td>Design Principle #1: Data Integrability: SM systems should be designed to foster knowledge and beliefs of the patients-users by homogenizing data from multiple sources and providing access to informational resources about the disease, its treatments and medication when and where a patient seeks to answer a question or solve a problem during the conduct of SM</td>
<td>- Quick access to informational resources about the disease and its treatments - Informational resources about the chronic diseases medication - Instructional videos on using the medical devices. - Hyperlinks to medical terms and acronyms</td>
</tr>
<tr>
<td>2) Re-programmability: Any kind of data can be manipulated to allow digital technologies to perform wide of array of functions</td>
<td>2) Increasing self-regulation skills and abilities: Incorporating and integrating SM monitoring, planning, and decision making activities in patients’ everyday lives.</td>
<td>Design Principle #2: System Flexibility SM systems should be designed to increase self-regulation skills and abilities of the patients-users by facilitating data manipulation when and where a patient has to make decisions, plan, and self-monitor during the conduct of SM</td>
<td>- Logging and tracking - Reminders - Alarms - Alerts - Feedback - Adding notes to data entries</td>
</tr>
<tr>
<td>3) Self-referential Nature: Ubiquity and availability of digital platforms create a network of technologies with similar capabilities that accelerates information diffusion and sharing in which almost anyone can participate.</td>
<td>3) Enhancing social facilitation: Providing emotional, informational, and motivational support from family, friends and other patients, and improving communication possibilities with healthcare providers.</td>
<td>Design Principle #3: System Externality SM systems should be designed to enhance social facilitation of the patients-users by connecting patients with human support when and where a patient has to communicate, share, and seek social support during the conduct of SM</td>
<td>- (chronic disease specific) Messaging boards and discussion forums with other patients - Communicative features such as email, live chat, live video chat with healthcare providers and family members, friends, - Social networking connections</td>
</tr>
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</table>
Design Principle #1 – Data Integrability: “SM systems should be designed to foster knowledge and beliefs of the patients-users by homogenizing data from multiple sources and providing access to informational resources about the disease, its treatments and medication when and where a patient seeks to answer a question or solve a problem during the conduct of SM.”

The “Homogenization of Data” enables design of technological platforms to integrate data from multiple sources in one system to provide services (Yoo et al. 2010). Systems are integrated within the ecosystem of SM to exchange data. For example, a mobile app, Fitbit, and insulin meter communicate and exchange data in diabetes SM. In the course of SM, especially post diagnosis, patients face many unanswered questions and concerns about their disease and seek answers to their problems (Cummings and Turner 2009). Patients with chronic diseases obtain and use information on a daily basis to manage their symptoms, medication, and feelings (Schulman-Green et al. 2012). A SM system should facilitate obtaining, using, and accessing data between different devices and information sources for the patient. For example, a diabetic patient takes medication to lower his blood glucose levels. First, he needs to obtain readings from his meter that stores blood glucose measurements. Next, the pump that injects insulin doses communicates with meter to estimate the amount of insulin needed for certain levels of blood glucose. As patient stores his medication data for symptom management, he needs to know the side effects of the diabetes drugs or the interaction effects of his diabetes medication with other medications.

Post diagnosis, understanding different medical terms and acronyms is challenging for the patient without any prior experience in self-managing a chronic disease. The medical terms displayed to a patient, should hyperlink to relevant informational resources (e.g., online
Internet resources) that provide more explanations. Using medical devices to self-manage chronic diseases needs practice and patience. Providing instructional videos that show the proper use of the medical devices enhances medication management. Immediate access to information when and where a patient faces a challenge or problem in the conduct of SM fosters patient’s knowledge about the disease and increases understanding and self-efficacy of the patient in achieving SM goals (Ryan and Sawin 2009).

**Design Principle #2 – System Flexibility:** “*SM systems should be designed to increase self-regulation skills and abilities of the patients-users by facilitating data manipulation when and where a patient has to make decisions, plan, and self-monitor during the conduct of SM*”.

The “re-programmability” characteristic of a digital technology enables users to manipulate data in order to perform certain functions such as data calculations and visualizations (Yoo et al. 2010). Patients with chronic diseases constantly monitor their measurement data, for example levels of blood glucose and food calories and carbs, make data-driven decision, and plan for their food and lifestyle changes based on their recorded measurement data (de Barros et al. 2013; Dadgar and Joshi 2015; El-Gayar et al. 2013b; Kouris et al. 2010). Patients with chronic diseases should be able to manipulate and transform data recorded in their SM systems anytime they need to make data-driven decisions and plans.

Clear relationships between different kinds of data points enable patients-users to make autonomous decisions during the conduct of SM. For example, a diabetic patient goes to a restaurant for a dinner. She looks up the calories in the SM system for each kind of food that she will have for dinner. Next, she needs to know if the food calories will affect the levels of her blood sugar. Using digital technologies, such as mobile platforms and apps, she can
calculate food calories, associate calorie data points with glucose levels, visualize them in charts and graphs, and monitor her symptoms before and after the dinner. Flexible digital platforms enable a system user to customize the environment of the system and generate new functionalities (Yoo et al. 2010). For example, using a diabetes mobile app, patients with chronic diseases will be able to customize the normal ranges of blood glucose that best fit their lifestyle and physiological conditions. Patients can set up individualized alarms and reminders if their measurement data exceed certain thresholds. Using reprogrammable and flexible digital technologies for SM systems, patients with chronic diseases can integrate planning, decision making, and monitoring of their symptoms into their daily lives to make necessary behavior changes.

**Design Principle #3 – System Externality:** “*SM systems should be designed to enhance social facilitation of the patients-users by connecting patients with human support when and where a patient has to communicate, share, and seek social support during the conduct of SM*”.

The “*self-referential nature*” of a digital technology enables an instantaneous sharing and communication of the data regardless of the time, location, and platform (Yoo et al. 2010). Any user with a digital technology, for example a smartphone, can communicate with any other user with a smartphone. The digital technologies create a network in which the values and benefits of using those technologies are amplified (Yoo et al. 2010). This network of technologies facilitates democratic use of digital technologies where the barriers and costs of sharing and communicating are lower and the information diffusion rates are higher (Yoo et al. 2010).
Democratized use of digital technologies benefits patients with chronic diseases. They can now seek emotional and motivational support from family, friends, and other patients with the same conditions. They can communicate their needs and questions in real time with their healthcare providers. For example, a patient diagnosed with diabetes, will be struggling with many emotionally intense conditions. The capability of immediate contact and communication with a healthcare provider will be a valuable support to the patient to make meaning out of the new changes caused by her chronic disease. Family members of a patient with a chronic disease, for example, can co-monitor patient’s symptoms and her SM performance by sharing same data views and dashboards among each other. Digital communities of the patients with the same chronic diseases and similar illnesses, for example, are places where they can share their feelings, identify with other patients, and exchange experiences. Using digital technologies in SM systems, patients can have access to human support in real time, control and lessen their negative feelings, and remain motivated in performing SM activities.

**Design**

Diabetes is the most prevalent chronic disease (WHO 2016) and the SM mobile apps designed for diabetic patients abound in the app market place (Bailey et al. 2013; Dadgar and Joshi 2015; El-Gayar et al. 2013a; Waite et al. 2013). Therefore, we choose to analyze a diabetes SM app to illustrate the applicability and efficacy of the three design principles proposed earlier. Table 3.3 shows the SM activities supported by the functionalities designed in the diabetes app of Glucose Buddy (GB). GB is the most popular and the oldest free diabetes mobile app in the Apple and Android app stores with the highest number of users and rating score (as June, 2016, rated ~4.5 with 1,819 reviews). We use GB’s design architecture
as a template to instantiate and represent our proposed design principles of *data integrability*, *system flexibility*, and *system externality*. However, GB’s functionalities and capabilities are extended where they fall short to fully represent our proposed design principles.

<table>
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<tr>
<th>System Implications</th>
<th>Supported SM activities</th>
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| 1) Logbook: recording and tracking measurement date for blood sugar, food carbs, weight, activity, blood pressure, heart rate, medicine, and A1C. | - Symptom management: monitor and manage the symptoms of the chronic disease  
- Lifestyle management: modify lifestyle to adapt to the disease |
| 2) Graph: graphing measurement data over time | - Symptom management: monitor and manage the symptoms of the chronic disease  
- Lifestyle management: modify lifestyle to adapt to the disease  
- Communication: communicate SM progress with healthcare providers |
| 3) Reminders: reminders to take medication or test blood sugar. | - Medication management: take medication and adhere to the medication routines. |
| 4) Forum: posting, replying, and reading about diabetes. | - Management of psychological consequences: manage negative emotions and feelings of the disease  
- Social support: obtain and manage support from family, friends, and other patients. |

A patient with a chronic disease uses logbook to record her measurement data of blood sugar, food carbs and calories. Recording these data points have two benefits for the patient during the conduct of SM. First, it enables patient to monitor ups and downs and ranges of her blood sugar. Second, it encourages and informs patients to make changes in her lifestyle and behavior where, for example, eating foods with high calories and carbs are causing high levels of blood sugar. Graphing measurement data is an effective way to monitor the symptoms and make necessary lifestyle changes. Graphs facilitate communication between patients and healthcare providers when they report their SM progress and results of controlling their blood sugar. Reminders are mainly used to take the medication at the right time. It is tightly connected with symptom management because dosage and type of medicine depends on the levels of blood sugar. Discussion forums are the venues for the patients to relieve their stress.
and anxiety and share their emotions and feelings with other patients with similar conditions. Digital forums enable patients to seek informational and emotional support.

Figure 3.2 illustrates the overall architecture of the GB diabetes app and shows the interactions between patient and the app where different functionalities are activated and used.

The system architecture of the GB diabetes app is consisted of mobile and web-based platforms. Data is synced between these two platforms. The web-based platform provides additional features such as customizable graphs. Logbook, graphs, reminders, and forum are
the main functionalities. Patients add log entries in the logbook. Average of certain measurement data with their highs and lows over time and during the day are graphed on the mobile platform for 2-month periods. On the web platform, there is no time limit for graphing the data points. Data points can be associated with events such as breakfast, dinner, and snack. Patients can set reminders to take medication or test their BG. Patients can visit a discussion forum online and on the web to read and respond to the different categories of topics.

We employ use case diagrams to represent the designs. Use case diagrams are based on unified modelling language (UML) (Dobing and Parsons 2006) and standard and effective ways to visualize and communicate the design of a system (Jacobson et al. 2016). Use case diagrams depict step by step behavior of a system and its functionalities in interaction with users in different scenarios (Würfel et al. 2016). UML diagrams in IS studies have been used to illustrate the design of collaboration engineering (Chatterjee et al. 2009), grounded requirements for software design and development (Würfel et al. 2016), web application architectures (Conallen 1999), system implementation (Al-Msie’deen et al. 2014), and document management processes (Pătraşcu 2014).

We follow the principles recommended by Jacobson et al. (2016) to develop use case diagrams illustrating how design principles can be implicated in an instantiation of a SM system, diabetes mobile app. The following sections illustrate the three design principles of data integrability, system flexibility, and system externality using use-case diagrams.

**Design Principle 1: data integrability**

Figure 3.3 shows the use case diagram illustrating the design principle 1 implicated in a diabetes mobile SM system.
Figure 3.3: Use case diagram illustrating design principle 1, data integrability, for a SM system of diabetes mobile app.

In GB diabetes app, patients can store BG and medicine data. However, these data are not supported with informational and instructional resources. Design principle of data integrability is salient when and where a patient-user of a SM system faces new or unknown situations with uncertainties. Two important situations where a diabetic patient seeks solutions to her problems and concerns during the course of the diabetes SM are testing BG and storing BG data, and taking medicine and storing medicine data (Bu et al. 2007). Choosing the right diabetes medical devices and using them correctly, notably post diagnosis, can become frustrating for the patients (Nijland et al. 2009). Providing immediate and easily accessible informational resources about medical devices and their usage reduces uncertainties and saves patients valuable time in the conduct of SM.
The use case diagram depicted in Figure 3.3 shows patients’ interactions with the diabetes mobile app at storing BG and medicine data. Design principle of *data integrability* is implicated in the system design of the diabetes app where storing BG data is supported by instructional video tutorial so that patients can watch at any time how medical devices are used to test BG. The BG data is synced from insulin pump and integrated and stored in the mobile app. Similarly taking medicine and storing medicine data is supported with immediate and easily accessible informational resources about the most effective medicine doses for controlling BG levels, their side effects, and their possible interactions with other medicines that patients might be using. Medical library and dictionary of medical terms are provided in these informational resources. The data for the doses of insulin used by insulin pump is synced and stored in the app. The information resources for BG and medicine should be constantly updated to inform patients about new techniques, devices, and medication. These reliable informational databases will be controlled and approved by patient’s doctors.

*Design Principle 2: system flexibility*

Figure 3.4 shows the use case diagram illustrating the design principle 2, system flexibility, implicated in a diabetes mobile SM system.
In GB diabetes app, patients can track, manipulate, and visualize BG, food carbs, medicine, and exercise data. They can customize visualized data on the web platform. Patients can create reminders to reinforce their tracking habits. However, data types are not integrated, compared with normal ranges, and data relationships are not predicted. Alerts and feedback are not created for compared and predicted data relationships. Design principle of system flexibility is applied when and where patient-user of a system should make sense of different kinds of data stored in the diabetes app to track and monitor disease symptoms, make decisions in response to certain symptoms evident in the data, and plan for the future to make lifestyle changes that trigger adverse symptoms.

System flexibility principle is implicated in the diabetes app where data-driven tracking of the symptoms is supported by data manipulation functionalities. Data manipulations are the changes and calculations needed by the patients such as integrating all data types, visualizing data, and comparing measurement data with normal ranges of data. Predictive models

Figure 3.4: Use case diagram illustrating design principle 2, system flexibility, for a SM system of diabetes mobile app.
programmed in the mobile app forecast data relationships. For example, the model predicts how much food carbs would affect levels of blood sugar. Patients can make intelligent decisions and purposeful plans for their daily lives based on the predicted data relationships. In the predictive reports, feedback is provided with possible solutions to achieve certain SM goals, such as, keeping BG under certain level in certain number of days, and having a specific diet. Integrated stored data compared against normal data ranges, produces alerts and feedback. Immediate alerts notify patients of abnormalities and feedback recommends possible problems producing abnormalities. For example, for the abnormally high levels of BG, the app will produce a feedback report that highlights possible areas of improvement in diet and exercises. Patients will be able to customize the normal ranges and data visualizations. For example, they can lower the normal ranges of their BG to make them more compatible with their lifestyle. They can customize data graphs by adding and removing dimensions. For example, different data combinations can be graphed such as BG against food carbs over time. Combining data types enables patients to further explore data relationships. Individualized reminders created in the app help patients comply with tracking and monitoring of the measurement data and symptoms in the long term.

*Design Principle 3: system externality*

Figure 3.5 shows the use case diagram illustrating the design principle 3, system externality, implicated in a diabetes mobile SM system.
In GB diabetes app, patients can visit diabetes discussion forums, read, post, and reply to messages. However, they cannot communicate or share data with their healthcare providers or family members. Healthcare providers cannot view and provide feedback on patients’ data. Design principle of *system externality* is used when and where a patient-user of a SM system seeks human support struggling with negative feelings caused by the longevity and intensity of the disease conditions. There will be a shared view of the data stored and manipulated in the app accessed by indirect stakeholders, healthcare providers and family members, in real-time. Real-time access to the measurement data stored and manipulated in the diabetes app enables healthcare providers to timely feedback to the patients. Unattended patients with negative feelings and frustrations can quickly exacerbate SM (Norris et al. 2001). Therefore, it is important to immediately attend to the patients who are struggling with negative thoughts and emotions.

Figure 3.5: Use case diagram illustrating design principle 3, system externality, for a SM system of diabetes mobile app.
One of the main advantages of the mobile platforms is their communicative features. Patients will be able to communicate their healthcare providers and family members via text messages, voice and video calls. Patients with depression and anxiety need more than medical recommendations. Health coaches can communicate with the patients through the communicative capabilities of the mobile platforms at any time and location, to provide supportive guidelines. The negative psychological consequences of the chronic disease are highly intensified at the onset of the disease (Lorig et al. 1994). Therefore, patients after the diagnosis are the most vulnerable to negative emotions and thoughts. Patients with chronic diseases can participate in the digital communities special to their disease to share experiences with other patients with similar conditions. Patients can visit discussion forums and boards on the go to read through different topics related to their disease. They can post their questions or respond to other patients’ questions and concerns. For example, there are different topics in different categories in the discussion forums for patients with type 1, type 1.5, type 2 diabetes and pre-diabetes.

**DISCUSSION**

SM of chronic diseases is a complex multi-facet process (Bailey et al. 2013; Bu et al. 2007; Jacelon et al. 2016; Lamprinos et al. 2016). Patients perform certain activities to achieve their SM goals such as symptom management, medication management, management of lifestyle changes, and management of psychological consequences (Schulman-Green et al. 2012). Technologies support SM activities, effectively facilitate achieving SM goals, and produce positive health outcomes (McDermott and While 2013; Solomon 2008; Vuong et al. 2012). Complex SM activities are supported sufficiently with digital technologies such as mobile technologies (Varshney 2014). Unique characteristics of digital technologies make
them viable choices for designing SM systems (Yoo et al. 2010). Therefore, it is important to conceptualize how SM systems designed based on digital technologies can be designed and utilized in performing SM activities.

We draw on design science methodology to systematically derive principles upon which SM system can be designed (Hevner et al. 2004; Peffers et al. 2007; Walls et al. 1992, 2004). Our proposed design principles are informed by SM theories. Without clear theoretical support in the design of the SM systems, the technological support will be unsuccessful (Jacelon et al. 2016). Design principles proposed in this study are instantiated in a SM system, diabetes mobile app. We have illustrated the implications of the design principles in the diabetes mobile app using use case diagrams (Jacobson et al. 2016). Our proposed design principles leverage the potentials of the digital technologies in designing SM systems. SM systems designed based on our proposed design principles will be flexible offering array of functionalities and capable of being integrated offering diverse services across multiple users.

Complexity of designing SM systems has four aspects: data relationships, integration, indirect stakeholders, and policies and regulations. First, there is an inherent complexity in the way different kinds of data are stored, manipulated, visualized, and shared on SM systems. Reprogrammability and flexibility characteristics of the digital technologies accommodate such complexity that is illustrated, for example, in use case diagram for design principle of system flexibility (see Figure 3.4). Uncontrolled complexity confuses and frustrates patients with chronic diseases. Intelligent capabilities, such as predictive models embedded in flexible and reprogrammable digital platforms, mitigate such confusions and create meaningful understanding of the data. Second, integration of SM systems has two levels: micro and macro. At micro levels, different data types are collected, stored, and integrated within a
system. At macro level, a network of systems and sources of data integrate. The integrability feature of the digital technologies reduces such complexity and creates inter-operable systems at micro and macro levels. The modular layered architecture of digital technologies streamlines integration processes between and within systems (Yoo et al. 2010).

Third, multiple users participate in the SM processes and activities, such as endocrinologists, general practitioners, nurses, dietitians, and family members. Coordination and communication between these indirect stakeholders of the SM is complex. However, the self-referential characteristic of the digital technologies harmonizes the interactions between indirect stakeholders and the patients. Fourth, as the use of digital technologies in SM systems for chronic diseases are proliferated, strict policies are devised to regulate and control their design. Compliance with such constraining policies will add to the complexity of the design and development of the systems. For example, FDA (Food and Drug Administration) announced new policies last year for the mobile health technologies\(^5\). New regulations and policies such as FDA’s will make storage and sharing of patients’ health data even more complex and will raise privacy concerns. Such strict policies on data sharing will make doctors and hospitals reluctant to adopt SM systems designed based on digital technologies.

**CONTRIBUTION**

This study contributes to design science research, digital technologies research, and SM literature. Our work contributes to design science research by conceptually improving design of technology-enabled solutions for SM of chronic diseases (Gregor and Hevner 2013). Our work contributes to descriptive knowledge by explaining conceptualizations and theories.

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related to SM systems and it contributes to prescriptive knowledge by providing representations and instantiations of the features in the SM systems (Gregor and Hevner 2013). Our work contributes to digital technologies research by extending design of SM systems based on digital technologies (Yoo et al. 2010) into the healthcare context and specifically SM of chronic diseases (Barlow et al. 2002; Bodenheimer et al. 2002). We investigate how characteristics of digital technologies, such as mobile platforms, can be designed in the SM systems. Our work contributes to SM literature by proposing a set of three design principles that integrates theory of SM with system features at granular levels. Our theoretically driven design principles unify conceptualizations of the SM systems. We have systematically derived design principles that demonstrate how certain system functionalities can afford certain SM activities.

**IMPLICATIONS**

Our proposed design principles provide guidelines for designing effective SM systems based on digital technologies. System designers can use our design principles and their descriptions to fully utilize material properties of the digital technologies. Our design principles are illustrated and communicated in use case diagrams to show where and when they can be designed in the systems and how they can benefit patients with chronic diseases. Our technical investigation shows how characteristics of digital technologies reduce the complexities inherent in designing SM systems, such as data relationships, integration within and between systems, and coordination and communication between indirect stakeholders. System designers can employ our proposed and illustrated design principles to prioritize system features and predict their consequences in the context of SM of chronic diseases.
This study has few limitations. Design principles recommended in this study are technically instantiated in a diabetes mobile app. Future research can further investigate SM systems and instantiate proposed design principles across different platforms and technologies designed and used for SM of chronic diseases. Increasing the number of technology cases can improve validity and reliability of findings in this research.

CONCLUSION

SM of chronic diseases is a complex and dynamic process in which patients as human agencies interact with intelligent features and technologies. Technology-based SM plays an important role in achieving SM goals and generating positive health outcomes. Certain characteristics of the digital technologies reduce the complexity of SM process. SM systems designed based on digital technologies will be more effective in supporting SM activities. Theoretically driven design principles for SM systems make the conceptualization and development of the systems designed based on digital technologies consistent and congruent.
REFERENCES


CONCLUSION

The increasing number of patients with chronic diseases and conditions, such as diabetes, demands a new care model in which patients are more engaged and active in their care process. Patients with chronic diseases collaborate with their healthcare providers rather than passively receiving treatments. Patient-centered management of the treatments, symptoms, lifestyle changes, and psychological consequences of chronic diseases is known as self-management (SM). Billions of dollars are invested in designing systems for patients with chronic diseases to self-manage their conditions. However, such systems have become inconsistent, incongruent, and insensitive to the values of the patients. The lack of support for the values of the patients in the systems make SM systems ineffective and users reluctant to use the systems.

In this research I have conceptually, empirically, and technically investigated SM systems. I have conceptualized technology-enabled SM in the context of chronic diseases. I have empirically collected human responses in using SM systems to account for their values in their SM systems. I have technically suggested design guidelines and principles for developing SM systems that support SM activities and create positive experience for the patients during the course of SM. My investigations show what patients value in using SM systems to manage their chronic conditions and how those values can be designed in the systems. The findings of my research have shown that technologies are part of a complex SM work system. The complex, iterative and dynamic SM work system involves different stakeholders, and varieties of technologies and different types of information, and several processes and activities. Through this complex ecosystem of SM, values, SM activities, and features of the SM system influence each other. The interplay of these elements show that
system designers and policy makers in healthcare should account for value changes and tradeoffs when patients use SM systems.

Patients use technologies to manage their SM activities while their values are fulfilled. Values of the patients during the course of SM change and swing. Swing values are major finding in this study. For example, a diabetic patient who uses data viewing and sharing features in a SM system to manage her symptoms and take actions to control the symptoms, will trade off between the values of autonomy and compliance. As patient becomes more autonomous and more diligent in using data viewing features, such as graphing blood glucose over time, she could become less compliant with normative medical regiments and procedures necessary to perform SM activities. healthcare providers need to be aware of such interplays when they devise healthcare policies and interact with patients.

System designers should engage patients in the design process of the SM systems at the early stages. SM systems can complement SM activities if value-informed decisions are made by healthcare providers and policy makers in integrating technologies in the SM process. SM systems should empower patients with chronic diseases to customize and adapt system features based on their unique ways of performing SM activities. The future research can further investigate disease and demographic differences in the system implications of the values. In the future research, developing, building, and testing value-sensitive systems and incorporating recommended values and design principles of this study in such systems can further advance knowledge and research in the area of technology-enabled SM of chronic diseases.