



The Role of Information and Communication Technology in Self-Management of Chronic Diseases: An Empirical Investigation through Value Sensitive Design

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Abstract

This paper primarily investigates sensitivity towards patients' values in the designs of the information and communication technologies (ICTs) that are capable of empowering them. We focus on the role of ICTs in self-management (SM) of diabetes, a chronic disease. Chronic diseases, declared an invisible epidemic by the World Health Organization, cause and perpetuate poverty and impede the economic development of many countries. As a means of informing the design of ICTs that facilitate 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 reveal twelve values shared by these patients: accessibility, accountability, autonomy, compliance, dignity, empathy, feedback, hope, joy, privacy, sense-making, and trust. A conceptual model emerged from analyzing interviews with diabetic patients; this model explains how these values, which are integrated into 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 valuecentric design perspective to examine a complex sociotechnical system; and it broadens work system theory by applying it in the healthcare space. The study's findings have implications for design science researchers, healthcare providers, and policymakers.

Keywords: Chronic Diseases, Information and Communication Technology, Diabetes, Self-Management, System Features, Value Sensitive Design, Work System Framework.

Alessandro Acquisti was the accepting editor. This research article was submitted on May 1, 2016 and went through 1 revision.

1 Introduction

Advancing patients' ability to engage in self-managed health through information and communication technologies (ICTs) is increasingly a top health-care priority (e.g., The National Health Service, 2013, The Office of the National Coordinator for Health Information Technology, 2014). Broadly, this study supports this goal by focusing on the design of sociotechnical artifacts to improve patients' self-

management (SM) of their health (hereafter referred to as ICT-enabled SM systems). 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, Samhan, & Joshi, 2013; El-Gayar, Timsina, Nawar, & Eid, 2013a, 2013b; Koch, Jenkin, & Kralik, 2004; Vuong, Ory, Begaye, & Forjuoh, 2012; Waite, Curtis, & Nugrahani, 2013). Thus, on one hand, as indicated in the call for this special issue, ICTs (e.g.,

the 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 development 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 clinical, functional, and legal aspects, to also deliberately care about the beliefs and values that are deeply significant to patients. More importantly, 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. The central focus of this study addresses sensitivity towards patients’ values in the designs of ICTs. By examining ICTs for patient empowerment in healthcare, this study illustrates the role ICTs can play in building a Bright Society (Lee 2015; Association for Information Systems 2015; Eymann, Legner, Prenzel & Kremer, 2015) where patients can take control of their illness and wellness. The notion of an ICT-enabled Bright Society, the focus of this special issue (Acquisti, Oh, & Sia, 2016), is an Association of Information Systems initiative that frames ICT-centric Grand Challenges which, if addressed, will have a broad societal impact (Lee 2015; Association for Information Systems 2015; Eymann et al., 2015). Specifically, this initiative calls to investigate “the problems in societal knowledge infrastructure and to design the vision of an ICT-enabled Bright Society” (Association for Information Systems 2015). Value sensitive ICTs can help mitigate the negative impact of technocentric designs and help protect patients from undesirable consequences resulting from use of the commercialized ICTs proliferating in the healthcare industry.

We draw on value sensitive design (VSD) theory (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 apply work system theory (Alter, 2013b, 2015) to explain how these values that are implicated in ICT features afford or constrain patients’ abilities to self-manage their activities. This study’s findings reveal how the values important to diabetic patients that are embedded in ICT features, in part, (de)motivate the self-management of their illnesses. The findings also illustrate that incorporating patients’ values into ICTs to manage their diabetes is not simply a matter of preference (Norris, Engelgau, & Narayan, 2001), but also a means of provisioning care sensitively. Theoretically, we contribute to design

research through extending the VSD literature by introducing a VSD perspective to examine a complex sociotechnical system. Finally, this study advances work system theory by applying it in the healthcare space.

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

2 Research Context

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

2.1 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). Chronic diseases often persist for an entire lifetime 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 worldwide, and 80% of chronic disease deaths occur in low- and middle-income countries (World Health Organization, 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 (World Health Organization, 2015). Thus, the effects of chronic diseases are not confined to individuals but also affect 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 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), employed in collaboration with family,

community, and healthcare professionals for managing patients' chronic conditions. SM requires a patient to simultaneously address and manage several different elements: 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, nonsequential, yet distinct, categories (Schulman-Green et al., 2012) that include seven major activities. The first category, focusing on illness needs, refers to actions 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 related to 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). These resources are mobilized to activate social support in achieving a healthy lifestyle, and communicating with health providers (Schulman-Green et al., 2012). The third category, living with a chronic illness, includes activities that 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); in other words, management of the psychological consequences of living with a chronic disease and adjusting to the new life (Barlow et al., 2002). The need for information is common to performing all of the activities. Although acquiring information is a component of other activities, we include information usage as the seventh activity. These seven SM activities are defined in Table 1.

Table 1. Self-Management Activities

Activities	Definition
1. Communication with healthcare providers	Communicating needs and problems assertively, and creating and maintaining relationships with healthcare providers.
2. Drug management	Taking the medication and overcoming the barriers to adhering to a schedule.
3. Information usage	Acquiring information about the disease and its treatments
4. Lifestyle management	Engaging in health promotion activities and modifying lifestyle to adapt to the disease (e.g., exercise, nutrition, diet, and leisure activities).
5. Management of psychological consequences	Managing the psychological consequences of the disease, such as depression, negative emotions, stress, and anger.
6. Use of social support systems	Obtaining and managing social support from family, friends, and community; addressing social and environmental challenges; and limiting isolation.
7. Symptom management	Recognizing, monitoring, and managing symptoms and side effects of the chronic disease

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 being 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; McDermott & While, 2013; 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.

2.2 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 increasing. 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 Information Systems (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). We use the elements of this framework to characterize the environment within which SM unfolds for patients with a chronic disease below.

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 1): 1)

participants, 2) information, 3) technology, 4) processes and activities, 5) products and services, and 6) customers. Participants can be users or nonusers of ICT; nonusers 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 records) and nondigitized (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 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.

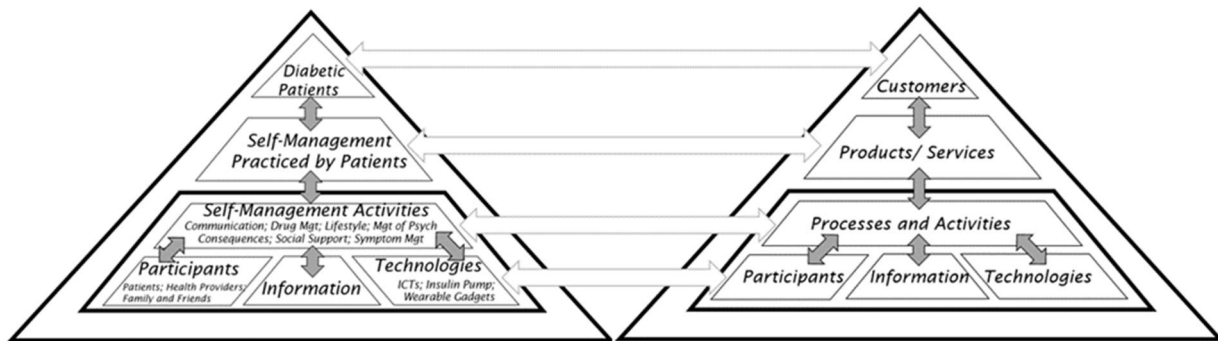


Figure 1. ICT-Enabled Self-Management as a Work System

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, and monitoring 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.

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.

3 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 that do not use 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 healthcare describe the system design process for SM of 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 disease (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, 2010), 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, the design processes follow a functionalist and system-based approach 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 multifaceted, 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 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, and 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 existing SM systems. And fifth, the designs of the existing SM systems are not theoretically driven, but are motivated by experimental objectives.

In this paper, we begin to address these limitations by capturing patients' perspectives for the design of ICT-

enabled SM systems that would consider the entire portfolio of SM activities (i.e., the seven SM activities) within the broader ecosystem (i.e., the work system view) and, most importantly, would be attentive to patients' values. We turn next to the theoretical framework that we draw on to reveal and analyze the diabetic patients' values implicated in ICTs used for SM activities.

4 Theoretical Framework—Value-Sensitive Design of ICTs

VSD seeks to account for human values in a principled, deliberate, and thorough fashion (Friedman, 2014; Friedman, Nathan, & Yoo, 2016; 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 implement 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 diabetic-related illnesses.

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). The empirical investigation elicits the human response to ICT artifacts (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).

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 based on the needs, desires, and interests of human beings (e.g., patients) within a certain sociocultural context, and therefore are not facts (Friedman, 1997). Given the context-sensitive nature of values, they should be revealed empirically before they are used to design or refine systems. Although Friedman et al. (2008) consider their proposed list of values to be human values with ethical and moral import that are important to all system users, other VSD scholars have challenged this notion of universalism by arguing that these values must be contextualized and culturally situated (Borning &

Muller, 2012). We argue that these two views are not orthogonal; while Friedman et al.'s (2008) assertions regarding the universality of human values are grounded in principles of morality, as indicated by their challengers, the specific nature and meaning of these values are best revealed in a diabetic patient's SM milieu. Consistent with this argument, we conduct an exploratory study to reveal the values of diabetic patients that are capable of being integrated into the designs of ICT-enabled SM systems. VSD research commonly relies on case studies in conducting empirical investigations (Chatterjee, Sarker, & Fuller, 2009; Deng, Joshi, & Galliers, 2016; Friedman & Nissenbaum, 1996; Friedman et al., 2016; Xu et al., 2012).

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 1. Our empirical investigation using the constructs from VSD and SM is detailed in the next section.

5 Research Methods

We conducted an in-depth, interpretive field study from a diabetic patient's perspective to reveal the role ICTs play in the SM of a chronic disease and how the values important to patients are (or should 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 the SM of their chronic disease allows us to collect firsthand 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.

5.1 Selecting an ICT Context

We chose the Glucose Buddy mobile app as a representative ICT that provokes a human response. VSD scholars separate the concept of ethically significant human values from the concept of usability by arguing that usability refers to system properties that make a tool work in a functional sense; however, in this sense, usability does not guarantee support for ethical values (Friedman et al. 2008). The VSD approach is useful in bridging the gap between ethics and the efficient design of ICT artifacts by prioritizing consideration of human values in design (Deng et al. 2016). Therefore, the value-centered approach prescribed by VSD requires choosing an app that is functionally adequate. If the app is not sufficiently functional, it will be difficult to uncover the patient's values.

The objective in choosing a mobile app is not to evaluate its design but to give our subjects an ICT-enabled SM experience that elicits deeply held values as they engage with Glucose Buddy's features (referred to hereafter as system features). We chose Glucose Buddy 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 (El-Gayar et al., 2013b; Waite et al., 2013) and their popularity in 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. 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. Details concerning the ratings for each of the categories and the total scores are presented in Appendix A.

5.2 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 to 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 discussion forum. Once patients completed the

recruitment survey (provided upon request) in which their demographic and descriptive information was collected, we contacted them and asked them to participate in a training session. Only patients who had prediabetes, diabetes type 1, or diabetes type 2 and owned an iPhone or an Android phone were selected for training. Participants were trained individually for 15-30 minutes in how to use the Glucose Buddy. Specifically, in the training session, we introduced the app, they installed it on their iOS or Android smart phone, and we demonstrated its features and functionalities. The participants received a \$25 Amazon gift card for participating 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 Glucose Buddy 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 Glucose Buddy 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 blood glucose. They were also encouraged to take notes while they used the app. These notes were discussed in later 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. All the patients were given a pseudonym. The sampling dataset with detailed information for each individual case will be provided upon request. Table 2 contains the descriptive statistics for the sample.

Table 2. Descriptive Statistics of the Sample

Descriptive Item		Percentage
Gender	Male	30%
	Female	70%
Age	18-21	5%
	22-30	15%
	31-40	10%
	41-50	20%
	51-60	20%

Table 2. Descriptive Statistics of the Sample

	Over 60	30%
Ethnicity	White	95%
	Hispanic or Latino	5%
Education	High school	5%
	Professional degree	5%
	Some college	25%
	Associate's degree	10%
	Bachelor's degree	30%
	Master's degree	20%
	Doctorate degree	5%
Chronic Disease	Prediabetes	10%
	Diabetes type 1	50%
	Diabetes type 2	40%
Platform	iPhone	55%
	Android	45%

After at least one week of using the Glucose Buddy app, we scheduled a one-hour interview with each patient (Appendix B). During the interview, we asked open-ended questions to help us understand how the participants 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, they 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.

5.3 Data Coding and Analysis

We conducted the data coding 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 were fulfilled (or not) by the mobile app.

Second, in the initial data coding, we used patients' statements to identify values expressed in the context of their SM activities. We coded interview transcripts 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). We used the coding scheme based on prior VSD studies (e.g., Dadgar & Joshi, 2015b; Friedman & Kahn, 2003; Le Dantec & Edwards, 2008) 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 C provides examples of coding discrepancies and their resolution. One author coded the remaining data following the agreed-on coding scheme. In total, 516 rows of data were coded. Coding revealed between 3 and 12 values per patient (average 5.6 values, median 5 values per patient). This iterative process resulted in 12 value categories, summarized in Table 4 in the Findings section. The value of universal usability, defined as "making all people successful users of information technology" (Friedman et al. 2008), which was used in the initial coding scheme resulted in repetitive and redundant occurrences. The high occurrence of universal usability in the coding is due to our technology sampling based on high usability standards. We did not include this value in the findings to report the values with unique and interesting system implications.

Third, we coded SM activities reflected in the value statements. The coded value statements expressed how a system feature assisted patients in performing one or more of the seven SM activities presented in Section 2 above: communication with healthcare providers, drug management, information usage, lifestyle management, management of psychological consequences, use of social support systems, and symptom management. In the interviews, patients revealed between 2 and 7 SM activities (average 5.75, median 5 per patient). Fourth, we coded the system features used and described by the patients in support of SM. This coding uncovered between 3 and 18 system features per patient (average 7.3, median 7.5 per patient). Four system feature categories revealed in this step are summarized in Table 5 in the Findings section.

After the four coding steps were completed, we analyzed the relationships between values, SM activities, and system features to explain how the values important to diabetic patients are implicated in system features and describe the role these features play in driving and shaping the patients' SM. A granular relationship was coded when patients explained what was important to them (i.e., a value) while using a specific system feature for 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 3 contains a sample data matrix that illustrates our analytical method.

Building on this analysis, we evaluated how the values are related to SM experiences using the system features. We then combined the value-SM experience-system feature-association instances for all respondents, resulting in 300 instances. Further analysis of these instances revealed four interrelated 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 with 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.

6 Findings

6.1 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 4.

Accessibility, a system's availability, has a variety of meanings for 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 them with the realities of their disease and driving them 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.

Table 3. A Sample Matrix Illustrating the Data Coding Process

Value statements—What a diabetic patient considers important while using ICTs to self-manage diabetes.	Value revealed	Value category	Importance of values reflected in SM activity	Values implicated (or not) in mobile app nature
I think <i>it's just good reinforcement to get some feedback on what you're doing</i> . Without this type of <i>feedback on a day-to-day basis</i> with apps and other technologies, you're basically just going in and seeing your doctor every 3 months. That's <i>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</i> .	Receiving constant and continued feedback.	<i>Feedback</i> —The extent to which patients' self-management abilities are reinforced.	<i>Symptom Management</i> —Allows patients to recognize, monitor, and manage symptoms and side effects on day-to-day basis	<i>Day-to-day feedback</i> feature—Available in the diabetes app. Complements feedback provided by health providers every 3 months.
It [The log entries of blood sugar and food intakes] is in writing and I think <i>that's really impactful</i> . 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 <i>it brings it more to your face and says, okay, you're right, I shouldn't have done that</i> .	The act of entering food intakes forces them to recognize and be responsible for their eating habits that affect blood sugar levels.	<i>Accountability</i> —Ensures that the patient's actions are traced back to them, which not only keeps them aware of their habits but also reduces denial behaviors.	<i>Lifestyle</i> —Enables patients to modify their nutrition and diet to manage their blood sugar levels.	<i>The Log Entries</i> —Recording and tracking levels of blood sugar and food intake in the form of <i>numbers and visuals of log entries</i> .

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 to accept them for 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.

Table 4. Revealed Values Relevant to a Diabetes Self-Management System

1) <i>Accessibility</i> (derived from the study): The properties of being available when needed.
<ul style="list-style-type: none"> “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) <i>Accountability</i> (adapted from Friedman et al. [2008]): The properties that ensure that the actions of an entity may be traced uniquely to that entity.
<ul style="list-style-type: none"> “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.”
3) <i>Autonomy</i> (adapted from Friedman et al. [2008]): Patients' ability to decide, plan, and act independently in ways that they believe will help them achieve their goals.

Table 4. Revealed Values Relevant to a Diabetes Self-Management System

<ul style="list-style-type: none"> “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.”
4) <i>Compliance</i> (derived from the study): Adherence to activities such as taking drugs, using medical devices and ICTs for self-care and self-directed exercises.
<ul style="list-style-type: none"> “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) <i>Dignity</i> (adapted from Deng et al., 2016; Le Dantec & Edwards, 2008): 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.
<ul style="list-style-type: none"> “The 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.”
6) <i>Empathy</i> (derived from the study): The ability to understand and share the feelings of diabetic patients.
<ul style="list-style-type: none"> “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) <i>Feedback</i> (derived from the study): Information about patient’s SM activities used as a basis for reminders, improvement, or positive reinforcement.
<ul style="list-style-type: none"> “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.”
8) <i>Hope</i> (adapted from Schrank, Bird, Rudnick, & Slade, 2012): A patient’s motivation to achieve future-oriented expectations and personally valued goals which will give meaning and depend on personal activity or characteristics.
<ul style="list-style-type: none"> “There’s no reason that I can come up with [for a spike in my sugar levels]. 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) <i>Sense-making</i> (derived from the study): The ability to give meaning to data that captures patients’ SM activities and behaviors.
<ul style="list-style-type: none"> “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.”
10) <i>Joy</i> (derived from the study): The feeling of pleasure.
<ul style="list-style-type: none"> “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) <i>Privacy</i> (adapted from Friedman, Kahn, et al., 2008): 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.
<ul style="list-style-type: none"> “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.”
12) <i>Trust</i> (adapted from Friedman, Kahn, et al., 2008): Expectations (of reliability, truth, and/or the ability to do the right thing) that exist between people and/or technology.
<ul style="list-style-type: none"> “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.”

6.2 System Features

Four categories of system features critical to SM emerged from the interview data: connectivity, data analysis, data retrieval, and data storage (See Table 5).

Table 2. System Feature Categories

System Feature Category	Description
Connectivity	<p>The system features that enable a diabetic patient to interact and share information with healthcare providers, family members, friends, and other diabetic patients. This category 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.</p> <p><i>Example:</i> “If you’re having issues, go into certain forums and chat with other people, having similar experiences. I thought that was a really nice touch . . . it helped share experiences.”</p>
Data* Analysis	<p>The system features that enable a diabetic patient to make sense of diabetes data over time. These features allow patients to manipulate and visualize data (e.g., effective representations of past trends and patterns) and augment 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.</p> <p><i>Example:</i> “it would be helpful . . . [to have] the time of day graph so that rather than these [independent data points] it had the blood sugar on one side and then like midnight to midnight instead, so you could see this is the average of past 10 AM or 9 PM.”</p>
Data Retrieval	<p>The system features that enable a diabetic patient to access data. These features allow 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.</p> <p><i>Example:</i> “You can search for foods in here [food database]. You can search for, let’s just do a hamburger and so in here it’ll have different brands of hamburgers. It’ll have like the menu items already in there so it’ll have like the carbohydrate counts.”</p>

Table 2. System Feature Categories

Data Storage	<p>The system features that enable a diabetic patient to store, log, and track the diabetes data.</p> <p><i>Example:</i> “I could maybe just put difficult, average, easy, for a workout. That might be actually a decent idea, for how it challenged me. That way, I don’t have to write everything that I did. Then, I could see how my blood sugar responded from that.”</p>
<p>*Blood glucose, food carbs and calories, activity burned calories, medicine dosage, A1C levels, weight, and blood pressure.</p>	

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 increases the quality of the data overall. *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. Patients desire customizable data fields and attributes that are automatically aggregated and related to other data types. 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 feature categories, which are used to manage their chronic conditions. How system features and values interact to support or undermine SM is discussed next.

6.3 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.

6.3.1 Communication with Healthcare Providers

The SM activity of communication refers to patients' sharing their needs and problems assertively and 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.

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 healthcare providers to spend time with them during their scheduled visits to understand 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, since he did not try to contextualize the data by digging deeper into the reasons for her high sugar levels:

I started out seeing [my doctor] 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. I take a list that I copy off from the Glucose Buddy and he glances through [the list]. [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].

6.3.2 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). System features can help patients with administering medication and adhering to treatment routines. The values of privacy, sense-making, accessibility, and feedback were mentioned by patients as important in meeting their needs through regular medication. We describe how the value of accessibility is 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 Glucose Buddy app cumbersome and frustrating. Inadequate automation hinders 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 . . . I only have one type of insulin and it's the only medication I take. But instead, . . . 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.

6.3.3 Information Usage

Acquiring information is defined as learning about the disease and its treatments (Barlow et al., 2002; Schulman-Green et al., 2012). Diabetic patients frequently seek information to accomplish one or more SM activities. Informational resources in the SM systems can support multiple values that are important to patients' well-being, such as getting feedback, inspiring hope, and coping with a negative psychological state. 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 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, was 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.

Our analysis shows that information is both used and 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 categories, and the seven SM activities.

6.3.4 Lifestyle Management

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, accessibility, hope, autonomy, feedback, compliance, empathy, and joy become important. Here we describe how the value of sense-making is reflected in patients' use of system features.

Well-designed system features 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 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] . . . To specify exactly what I did . . . 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.

6.3.5 Management of Psychological Consequences

During the course of their disease, diabetic patients grapple with a number of psychological states, such as 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 value of hope can be implicated in a system design to achieve the desired psychological outcomes.

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. Networking and discussion forum features can mitigate patients' negative emotions. For example, when Shawn (male, 31-40, white, doctorate degree, type 1), who suffered from depression postdiagnosis, 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 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 it certainly was true for myself; it's a point where depression kicks in and it's hard to deal with at 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.

6.3.6 Use of Social Support Systems

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 to patients: accountability, autonomy, empathy, feedback, and trust. We provide an example of the importance of trust.

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 these forums. Jonathan (male, 41-50, white, some college, and prediabetes) does not use diabetes discussion boards because he doubts their reliability:

[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. A lot of it is extremely opinionated. It's not accurate. They're not medical professionals. They advise other people as if they 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.

6.3.7 Symptom Management

As patients focus on their illness, 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: accessibility, accountability, autonomy, interpretation, reinforcement, dignity, compliance, empathy, and privacy. Here we describe how the values of compliance and dignity fulfill SM expectations as patients interact with system features.

System features such as tracking and logging data can help patients recognize symptoms, such as high or low levels of blood sugar. 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 them but not take the right action to manage them. System features that make it difficult to enter and track data over time limit

When you have these kinds of apps where you can see trends and try and work on them, it helps . . . from [an] emotional standpoint, too, because there's a sense of shame that people have when they're going to their doctor. They say, "Well, here's my data. . . . Gosh, I've been going three months and my morning blood sugars are 200." 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 help with that sense of well-being and self-pride as well.

6.4 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 in their ecosystem (e.g., reaching out for support). The orchestration of these activities in their clinical and nonclinical milieus with the assistance of ICTs that incorporate the values important to patients is represented in a conceptual model which we call the ICT-enabled SM model (Figure 2). It is derived from the VSD (Friedman, Kahn, et al., 2008) and work

the system's potential for symptom management, as expressed by Janet:

I'm doing that [tracking food intake] now, but it's less regular because when I'm 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 on tying the carbs tightly to blood sugar, . . . [so] making compliance easy over time [through good system design] I think is crucial.

Based on the data entered into the system, patients can visualize and identify the areas; for example, blood sugar levels that should be controlled 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. Patients strive to more effectively manage their symptoms in order to avoid feeling a sense of shame, or because they want to their sense of dignity. 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:

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 implemented 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 ICT-enabled SM system. The information value is represented with recursive arrows, which show that information is used and produced among system features, participants, and values, and between values and SM activities. 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 at the bottom of the value box—feedback, sense-making, accessibility, hope, and trust—are essential and positively affect other values and SM activities. They do not change significantly with changes in other values. Value sensitive design in 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. We call these values “swing” because they move in opposite directions. They are inversely dependent on other values; that is, fulfillment of one swing value is achieved by compromising other values. Swing values are categorized in three groups: 1) autonomy and

compliance, 2) empathy, dignity, and privacy, and 3) joy and accountability. The constant tension among the swing values, represented with in-and-out arrows, creates tensions in an ICT-enabled SM system, as described below in greater detail.

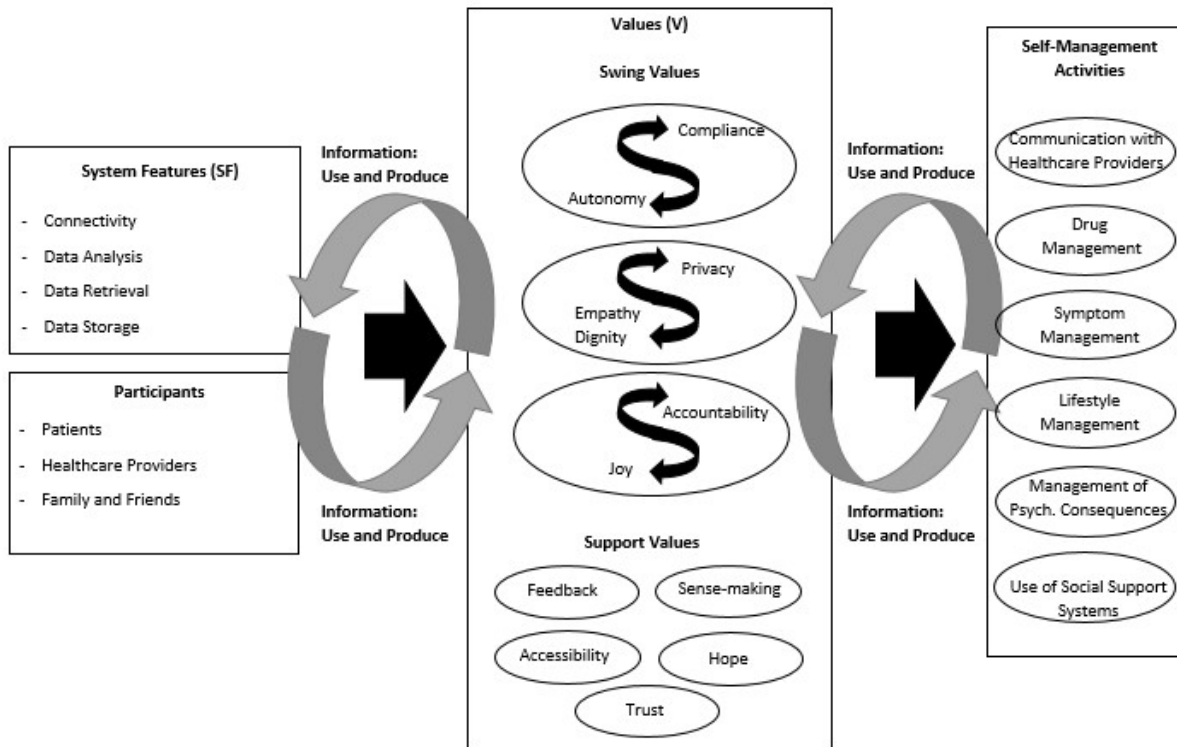


Figure 2. Conceptual Model of a Self-Management Work System

Our analysis shows that the autonomy desired by the diabetic patients drives them to be less compliant with SM activities. As indicated in the following quote, John (male, 31-40, white, master’s degree, diabetes type 1) acted autonomously by not complying with his doctor’s recommendation to log his blood sugar, activities, and the food that he eats:

Okay, I know what the recommendation is, but I’m going to do my own thing instead. 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.

Patients become more private when the values of dignity and empathy are compromised. John, for example, also 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. . . . The easier [path]. . . , the path of least resistance, is to simply deal with it somewhat privately.

The values of dignity and privacy have similar tensions. Patients becomes 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 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 [for a favor] 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.

7 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 their role in sociotechnical systems (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; Lorig & Holman, 2003; Ryan & Sawin, 2009). We build on this literature to derive an ICT-enabled SM model that explicates 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 recommend moving away from the 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 the 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) from the VSD literature and then add new values that emerged from examining the SM context (accessibility, compliance, empathy, feedback, hope, sense-making, and joy). We argue that the contribution of such an inventory lies in its use as a portfolio of values for SM that collectively serve as a design guide and that viewing them simply as individual, discrete, and isolated values, limits their impact. This portfolio can be used as a foundation for classifying and expanding a body of SM values that may emerge in future investigations.

Third, we expand the scope of VSD by applying it to investigate a complex sociotechnical system. VSD focuses predominantly on the use of micro computational systems such as web browsers, groupware, simulation systems, and radio-frequency identification (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 diabetes SM.

Finally, our study contributes to work system research (Alter, 2013b) by applying and extending it to the healthcare space. Specifically, such an application expands the conceptualization of ICTs 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 the SM of chronic diseases is explicated. Such explications can not only help in understanding ICTs' 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.

8 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 a VSD lens help prioritize human values with ethical import in design. In so doing, VSD complements the more functionalist approach that focuses on usability (i.e., properties that make systems functional), an approach that VSD scholars argue does not guarantee support for ethical values (Friedman et al. 2008). The VSD approach, with its deliberate and systematic attention to ethical and moral values, openly stresses an interpretive and critical analysis of ICT designs and privileges a radical humanist research paradigm in contrast to the functionalist approach, with its positivist leaning that focuses on the efficient design of ICT artifacts (Deng et al. 2016). Harmonizing these design approaches could advance the possibility of paradigm pluralism advocated by Goles & Hirschheim (2000).

To this end, the implications of this work for design science researchers are threefold. First, the findings 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 so that they are more attentive to patients' needs and preferences. For example, it is possible to design principles that support the value of hope and that can guide in designing features that monitor and bolster patients' hopefulness. For instance, patients could use the data stored in ICTs to anticipate situations that engender the feeling of hopelessness (e.g., regular commitment to exercising and drug management with continuing high fluctuations in blood glucose levels) and provide support to ameliorate such feelings. Second, future research can use the portfolio of values to determine the positive and negative health consequences of implicating (or not implicating) the values in ICTs that support SM. Examining the impact on patient outcomes could help healthcare providers harmonize priorities in order to manage symptoms in accordance with patients'

concerns for their values. Such harmonization could help develop 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 kind of analysis could involve design researchers engaging in a value-driven investigation of ICT-enabled SM systems, conducting a more detailed conceptual, empirical, and technical analysis on each value revealed in this study. Another 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 performing a specific SM activity. The third kind could be a retroactive technical investigation of current healthcare ICTs in order to recommend improvements to existing designs.

Implications for Healthcare Providers: The findings of this work furnish insights that healthcare providers 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 recommend using ICTs to balance the ill effects of certain foods with the benefits of enjoying life as patients learn to live with their chronic condition.

Implications for Policymakers: Our work informs national health policies on using technologies to empower and engage patients in their own chronic care. Advancing patient-centered and self-managed health with the use of ICTs is a growing health-care priority (ONC, 2014). The goal is to improve the health and well-being of individuals with chronic diseases through the use of technology and health information. For instance, the Affordable Care Act 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 be sensitive to patients' values.

9 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 part of their SM system, such artifacts must support the values that are important to these patients. By revealing values that are important to diabetic patients using ICTs to self-manage their illnesses, we broaden the intellectual space so that investigating the role of

ICTs in healthcare moves beyond focusing only on lowering costs and improving clinical outcomes.

Future research might further investigate users of SM technologies who have stopped using them, in order to inform the design of more effective SM systems. The interplay between a free app and the use of data for

commercial purposes could be examined in data privacy research.

Acknowledgments

We would like to thank the special issue editors and reviewers, and the Philip L. Kays Endowment.

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Appendix A: Technology Sampling

Category (Waite et al., 2013)	System features/characteristics (El-Gayar et al., 2013a)	Technology (Diabetes Mobile App)				
		Diabetes Diary	GluCoMo	Rapid Calc	Glucose Buddy	GlucoSuccess
Primary Care	Medication	1	1	1	1	1
	Blood glucose	1	1	1	1	1
	Monitoring	1	1	1	1	1
	Diet management	1	1	1	1	1
	Physical exercise	0	0	0	1	0
Secondary features	Education	0	1	1	1	0
	Weight BMI	0	0	0	0	1
	Blood pressure	0	0	0	1	0
	Communication	0	1	1	1	0
	Social networking	0	1	0	1	0
	Integration with PHR	0	0	0	0	0
	Alerts/reminders	1	1	1	1	1
	Tagging	1	0	0	0	0
	Decision support	0	0	1	0	0
	Security	0	1	1	0	1
App store characteristics	iOS/platform	iOS	iOS	iOS	iOS	iOS
	Number of ratings	41	83	23	1,627	67
	Average rating	~3.5/5	~2/5	~4.5/5	~4.5/5	~3/5
	Latest version	2.0.0	1.0.12	2.1.2	3.7.0	1
	Cost	\$2.99	\$0.99	\$7.99	Free	Free
Total Score		6	9	9	10	7

Appendix B: 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?; No—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 C: 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.”

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