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A Smart Consumer-empowered Diabetes Education System (SCEDES): Integrating Human Wellbeing and Health Care in the Community Environment

Dr. Sharie Falan
Western Michigan University, sharie.falan@wmich.edu

Dr. Bernard Han
bernard.han@wmich.edu

Dr. Alan Rea
Western Michigan University, alan.rea@wmich.edu

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Dr. Sharie Falan
Bronson School of Nursing
College of Health and Human Services
Western Michigan University
sharie.falan@wmich.edu

Dr. Bernard Han
Dept. of Business Information Systems
Haworth College of Business
Western Michigan University
bernard.han@wmich.edu

Dr. Alan Rea
Dept. of Business Information Systems
Haworth College of Business
Western Michigan University
alan.rea@wmich.edu

Abstract
Uncontrolled diabetes creates an increasing burden on individuals, their families, and the society in the United States. The expected total annual costs of diabetes, including both direct costs and the lost productivity, are expected to be 20% of the Gross Domestic Products by 2016. In this paper, a community-based infrastructure is proposed to provide consumers, both diabetics and pre-diabetics, with a *Smart Consumer-empowered Diabetes Education System* (SCEDES) that will not only build consumer self-efficacy but also promote their self-management, self-learning, and support from peers and health care professionals. The system architecture and key implementation features are addressed. Challenging issues and research directions are also discussed for further investigation.

Key Words
Consumer-centered, Empowerment Paradigm, Diabetes, Health Care, Self-management, Self-efficacy, Smart Health and Wellbeing, Web Services.

INTRODUCTION

Uncontrolled diabetes produces an increased financial, physical, and emotional burden on patients, their families, and society, and it has long been recognized as an epidemic in the United States (Rocchini, 2002). It is the leading cause of kidney failure, non-traumatic lower-limb amputations, and the major cause of heart disease and stroke. Currently, diabetes is the 7th leading cause of death in the country (NDIC, 2011). One recent study released by the Centers for Disease Control and Prevention (CDC, 2011) shows that nearly 26 million Americans have diabetes and another 79 million adults have pre-diabetes. If this trend continues, CDC projects that as many as 1 in 3 U.S. adults could have diabetes by 2050. With respect to the spending, diabetes costs in the United States exceeded more than $174 billion in 2007 and in the coming years, the expenditures are expected to grow at an increasing rate. With the prevalence of diabetes rising, the total cost of health care is expected to reach 20% of the GDP by 2016. If no actions are taken, its potential impacts on the U.S. will be astronomical (Boyle, Thompson, Gregg, Baker, and Williamson, 2010). As projected, by 2030 the global annual cost will be at least 490 billion dollars (Zhang, Zhang, Brown, Vistisen, Sicree, Shaw, Nichols, 2010). Of these costs, the United States (U.S.) is expected to consume 57% of the total global health expenditure for diabetes, whereas other regions with higher incidences of diabetes will spend much less (e.g., India and China). The current status in diabetes care imposes an increasing burden on the worldwide health care system and the global economy.

People with diabetes consume health care resources at a rate three times greater than individuals who do not have the disease (American Diabetes Association, 2008; American Association of Clinical Endocrinologists, 2007). There are two types of diabetes – Type-1 and Type-2, the former is *insulin-dependent* or *juvenile-onset* diabetes, and the latter, *non–insulin-dependent* or *adult-onset* diabetes. Fortunately, Type-2 diabetes is a controllable chronic disease that can also be prevented or eliminated if proper health care interventions are taken by or for the consumers (Diabetes Monitor, 2010). Numerous studies have been conducted to understand how to help health consumers with diabetes to ensure their compliance with health interventions in order to improve or eliminate disease (Anderson and Funnell, 2005). Findings show that limited effects were produced by the acute care delivery approach (Anderson and Funnell, 2002). Rather, there is a new paradigm shift in diabetes patient treatment, i.e., from *acute-care* to *patient empowerment*. Results from this paradigm change are very positive and encouraging. As pointed out by Anderson and Funnell (2005), patient empowerment has not been extensively embedded in health care practice because the traditional acute-care paradigm has been deeply rooted in the mind of most health care professionals. Therefore, little improvements have been made (i.e., patients are not empowered) and, most of all, health care professionals are also frustrated due to limited resources such as the shortage in health care personnel.

In this paper, a *Smart Consumer-empowered Diabetes Education System* (**SCEDES**) is proposed. This system, when implemented, will motivate consumers to maintain an appropriate lifestyle to delay or even prevent the diabetes disease. It also offers self-care strategies that will empower consumers with intelligence by getting support from the system, peers, and health care professionals at their discretion. More details are to be provided in the ***SCEDES Architecture*** section of this paper. In brief, the aims of our proposed SCEDES are to ensure self-efficacy in health management through user friendly devices, provide tools and access to 24/7 information, release critical health care resources and maximize self-learning and education. A detailed review on diabetes care via self-management using the patient empowerment paradigm is given in the next section.

LITERATURE REVIEW

The need for health care consumers to self-manage their diabetes is so critical that Bill H.R. 2425: Medicare Diabetes Self-Management Training Act of 2009 was introduced to the House for consideration (111th United States Congress, 2009). The bill states that diabetes self-management has shown to be effective in reducing risks and complications of diabetes and that lifestyle changes were particularly effective in people aged 60 and older.

Indeed, **d**iabetes **s**elf-**m**anagement **e**ducation (DSME) is the cornerstone of care for all individuals with diabetes who want to achieve successful health-related outcomes (Mensing, Boucher, Cypress, Weinger, Mulcahy, Barta, et al., 2002). Nevertheless, effective diabetes self-management (i.e., lifestyle change) is more than adhering to a medication or physical activity regime. It means that health consumers should take active behavioral involvement in the day-to-day decisions that promote health and wellness. Over the past three decades, hundreds of studies have focused on DSME, in particular, concentrating on the problems of non-compliance/non-adherence of diabetics in conducting self-care (Anderson and Funnell, 2005). As argued by Anderson and Funnell (2005), one fundamental mistake made by the health care professionals is the use of an approach typically helpful for acute diseases rather than chronic diseases. The "problem solver" approach utilized by health care providers, whether intentional or not, did not promote self-management of diabetes. Unlike other acute diseases, Type-2 diabetes can be delayed or prevented by if health consumers change their lifestyle through proper diet selection and regular exercises. Self-management turns out to be effective if empowerment-based interventions are incorporated into the lives of health consumers (Tang, Funnell, Gillard, Nwankwo, and Heisler, 2011). Rather than monitoring to determine if health consumers adhere to their health providers' medication instructions, it may be more helpful to ask patients to bring a record of their glucose readings and discuss them. This type of patient centric intervention will help the health service provider identify patients' knowledge and discovery about the relationship between food eaten and their glucose readings. This redirects the ownership of the chronic disease back to the health consumer.

Of course, the self-management paradigm (i.e., patient empowerment) is hinged on two major factors: *sufficient knowledge* about diabetes and the *self-efficacy* of patients who have the ability and confidence in self-care to accomplish the desired goals (Hurley and Shea, 1992). One recent study shows that self-efficacy does influence patient's self-management behaviors (Mishali, Omer, and Heymann, 2011), and another study indicates that if a patient receives regular primary care, then he/she will have more motivation in attending self-management education (Shah and Booth, 2009). A similar early study also confirms that a structured self-management education program will more likely convince newly diagnosed diabetics to change his/her lifestyle (Skinner, Carey, Cradock, Daly,

Davies, Doherty, et al., 2006). While self-management is a desired skill for health consumers diagnosed with diabetes, studies also confirm that diabetes education and constant support for consumers are very important.

Researchers have conducted numerous studies looking at the impact of using computers and information technologies on the effectiveness of health care interventions for diabetics. For example, one study shows that health consumers with low health literacy and technology skills are less likely to use health information systems to educate themselves or conduct health research (Eng., Maxfield, Patrick, Deering, Ratzan, Gustafson, 1998). Another study finds that health consumers experience lower perceptions of wellbeing and longer recovery times when barriers prevent ready access to information (Arora, Johnson, Gustafson, McTavish, Hawkins, Pingree, 2002). In contrast, when a computerized program is used to support DSME, positive training success was observed, though it was originally designed to attract patients to attend the education program (Nebel, Bluher, Starcke, Muller, Haak, and Paschke, 2002). More positive findings were also reported when (1) the Internet was employed in searching health information (Barnes, Penrod, Neiger, Merrill, Thackery, Eggett, and Thomas, 2003), (2) kiosks were used for information delivery (Kreuter, Black, Friend, Booker, Klump, Bobra, and Holt, 2006), and (3) a community-based information system was used in eliminating disparity among health consumers (Carlson, Neal, Magwood, Jenkins, King, and Hossler, 2006; Piette, 2007). These aforementioned studies reinforce the important role that information technologies have played in support of DSME and health consumer empowerment.

While information technology has benefited many industries (e.g., manufacturing, transportation, etc.), it has not been effectively used in support of health care management, in particular, in a scale that integrates business operations among stakeholders in the community while maximizing the benefits of all participants. To contain the non-stop cost increase in diabetes expenditures and ensure the success of DSME, we propose SCEDES. An infrastructure for SCEDES is presented to highlight how *health care* and *human wellbeing* can be integrated in a community environment. This infrastructure, in fact, was adopted by a local health care project in the Midwest United States. To maintain the confidentiality, identities of local service providers and health care organizations are kept hidden. The major functionalities and features of the proposed smart health system are detailed below.

A FRAMEWORK OF CONSUMER-EMPOWERED DIABETES EDUCATION SYSTEM

Our research originated from a local health care service provider, in which one of its major community missions is to provide DSME to health care consumers who have been diagnosed with Type 2 diabetes or identified as consumers at risk (i.e., pre-diabetes). The health care consumers live in a broad geographical region. The service provider dedicates its resources (e.g., registered nurses, diabetes educators, etc.) as visiting health care professionals (i.e., community services volunteers) to work with church personnel in helping health care consumers who come to the church to receive free services (i.e., support, testing, education). While it is free for health care consumers, this dedicated mission does become an increasing financial burden for the local health care service provider. For this very reason, a smart health system is proposed to empower diabetes consumers while maximizing the productivity of resources dedicated to the defined corporate mission. As shown in Figure 1, a centralized location is used to support the integration of business operations that are needed to support the defined corporate mission – providing best DSME for regional consumers who are either determined to be at risk for diabetes or actually diagnosed with the disease.

The following infrastructure is created based on an information and communication technology (ICT) that interconnects four major stakeholders: *diabetes service providers*, *community services volunteers* (i.e., visiting health care professionals), *church personnel*, and *health care consumers*. SCEDES is equipped with necessary applications and tools that will provide full services to each of these major stakeholder groups. All services provided are to be digitized and stored on dedicated servers for later retrieval, and servers are hosted and managed by a Service/Tech Coordination Center that is to be shared by all parishes in the region. Note that necessary patient information may be provided by the Diabetes Service Provider to enhance service quality with data stored on servers that are dedicated to the community and health care consumers. To ensure the operation convenience, kiosks and other online devices are provided in churches and public facilities (i.e., senior centers, libraries) for health care inquiry and consumer's decision-making support. Periodical workshops will be provided for health care consumers to ensure their self-efficacy and confidence in self-management of diabetes and thus reduce preventable hospitalizations. The details of the proposed research methodology and justification are presented next.

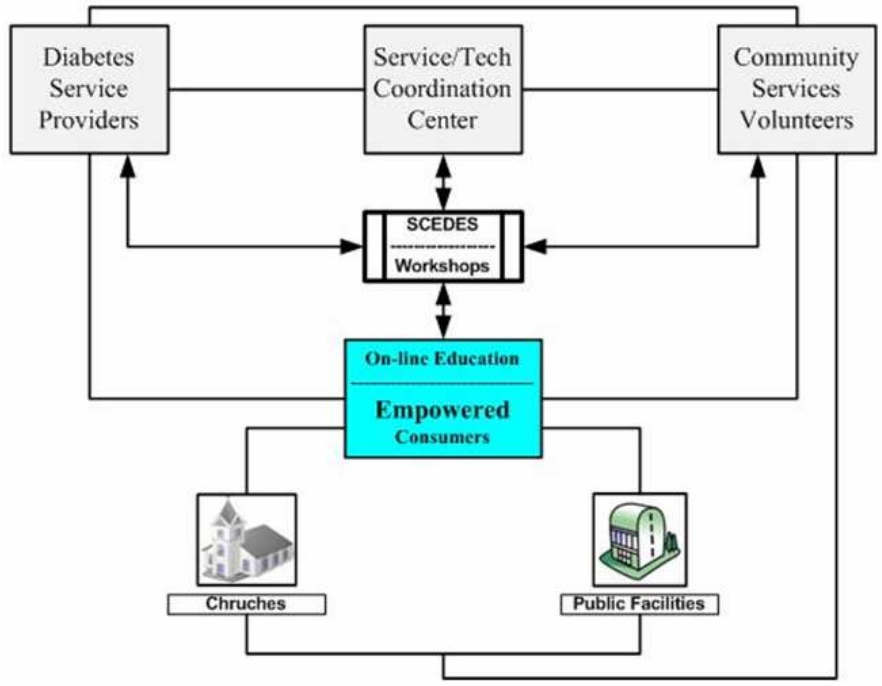

Figure 1. An Infrastructure of Community-based Smart Consumer-empowered Diabetes Education System

RESEARCH METHODOLOGY AND JUSTIFICATION

Our research will conduct multiple cohort studies that will examine the differences in diabetes self-management, lifestyle patterns, and behavioral changes over time to measure the effectiveness of the SCEDES program. A community of experts in diabetes management will be formed to establish a governing body to provide content necessary for SCEDES. In the first phase, both the community and nationally based diabetes programs will be reviewed to determine the most common and salient points that are beneficial for diabetes management in terms of instruction methods and alternative learning strategies. During the second phase, all salient points and strategies will be further investigated through comparison with national care standards. The content of the SCEDES program will be identified and verified based on a needs assessment with consumer and provider focus groups. As the final content is determined, a team of IT and diabetes knowledge experts will be formed to develop SCEDES.

SCEDES Evaluation

A pre/post survey instrument and multiple repeated measures will be used to detect and quantify changes in diabetes self-care management and life style among users of the SCEDES system. Data usage patterns from the SCEDES program will be analyzed to elicit key materials accessed by system users, including incidence of hospitalizations, medical visits, trending of blood glucose levels, incidence of complications, types of data exchanged, the occurrence and duration of downtime, and system responsiveness to a user inquiry. Details of the SCEDES system architecture are presented next.

SCEDES ARCHITECTURE

SCEDES provides both general and personalized diabetes education, support, and monitoring and reporting functionality to a diverse demographic population with varying technical skills and inclinations. SCEDES implements a variety of user interfaces—Web, mobile applications, voice menus, and short messaging service (SMS) to foster community building, educational initiatives, and self-managed care no matter what the consumer's technology use comfort level (See Figure 2).

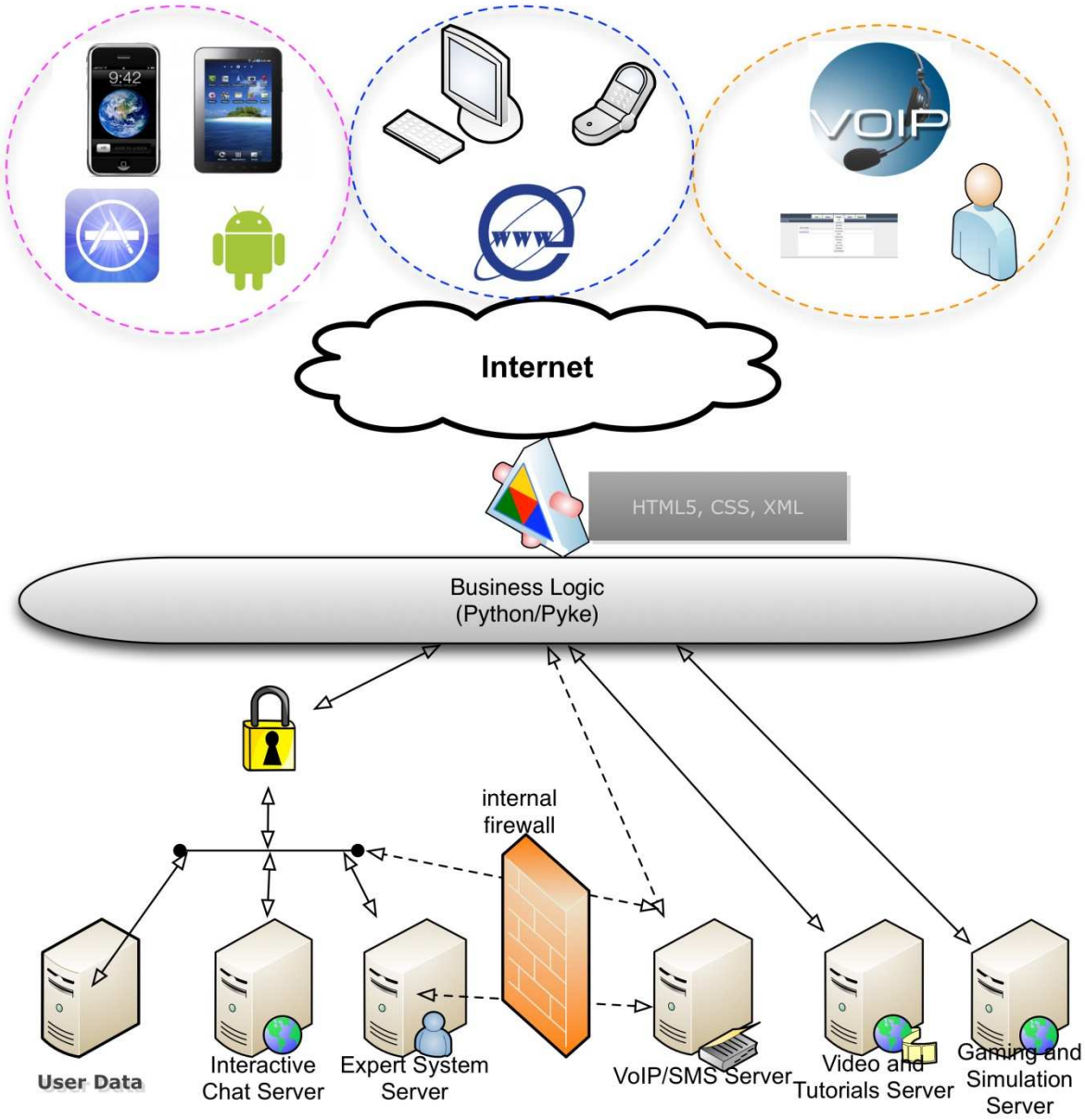

Figure 2: SCEDES System Architecture

Architectural Principles

Much of our preliminary research has demonstrated that readily available, and easy to use technologies are critical to system adoption by healthcare consumers (Barnes, et al., 2003; Carlson, et al., 2006; Kreuter, et al., 2006; Piette, 2007). When developing the SCEDES architecture, we operated under the assumption that most users would be able to use a Web browser to at least access information. Studies have demonstrated an increase in consumers using the Web to collect information relevant to their condition, to include users in older demographics (Cho, Arar, Edelman, Hartwell, Oddone, and Yancy, 2010). However, SCEDES needed to go beyond the generic Web 1.0 technology and incorporate more collaborative Web 2.0 features (Topcu, Mustacoglu, Fox, and Cami, 2007) between providers and consumers, and later among SCEDES users themselves for sharing links and resources (Zheng, Mei, and Hanauer, 2011), as well as more advanced functions such as e-scheduling and messaging found in general healthcare portals (Clingan, 2011).

One of our underlying structures was that the system needed to adhere to open standards (Vittorini, Tarquinio, and di Orio, 2009) so that it could be easily deployed in various environments beyond our geographical boundaries and perhaps our original focus (self-managed diabetes care). In addition, we employ open source technologies as many studies show the impact of open source systems to foster innovation with a lower risk in licensing and technology investment (Ratib, Rosset, and Heuberger, 2011). As we worked to create the architecture, security was foremost in our minds as well since we are dealing with sensitive personal health information. To that end, SCEDES is a distributed SOA system modeled with robust authentication and authorization at its core (Koufi, Malamateniou, Vassilacopoulos, and Papakonstantinou, 2010).

Our choice to deploy via the Web was an easy one. In the past few years there has been a dynamic growth in the use of Web-based systems to facilitate various healthcare operations from training and compliance among healthcare staff (Ribner, Hall, Steinberg, Bornstein, Beasley, Duffell, et al., 2011) to large-scale artificial intelligence driven systems that links patients, providers, and other healthcare stakeholders (Razi, Athappilly, and Rea, 2009). A Web-based architecture for SCEDES is illustrated in Figure 2. As shown, the system is coupled with powerful smart phones and other mobile devices that can be used to access the Web.

SCEDES will be developed using Web-based ICT tools, such as "Diabetes Connect" (Pelletier, Jethwani, Bello, Kvedar, and Grant, 2011) which enables home users to report glucose levels. Moreover, necessary services will be provided to integrate the system that observes Health Level 7 (HL7) standards for future system growth (Huang, Hung, Chiou, Liu, and Liou, 2011). SCEDES also needed to reach a younger population more accustomed to accessing information via mobile devices (Jen, 2010). Furthermore, our research is informed by successful mobile implementations (Hsieh, Hou, Cheng, Tan, Shen, Hsu, et al., 2010), as well as issues with mobile offerings (Harris, Tufano, Le, Rees, Lewis Evert, et al., 2010).

Embedded throughout the entire system are technologies to meet Health Insurance Portability Accountability Act (HIPAA) privacy and data protection regulations where appropriate like secure socket layer (SSL) and transport layer security (TLS). Additionally, granular privacy controls are embedded in the business logic that allow consumers, providers, and physicians to control personal and sensitive information thereby preventing privacy leakage either across system components or into public space. Underlying the entire system architecture is the portability requirement to facilitate SCEDES deployment and usage in multiple community environments.

SCEDES is designed with functionality that supports two overarching goals: 1) Health consumer self-management of the condition and 2) Empowerment of the health consumer. These goals are met by providing not only tailored information to the healthcare consumer but also providing direct connectivity between consumers and health care professionals. With planned features, SCEDES will allow health consumers to take an active role in their well-being.

In order to meet the consumer's educational needs, SCEDES first provides general information supplemented by videos and frequently asked question (FAQ) areas. However, the delivery mechanism for this information differs somewhat as the content can be viewed by the consumer via a Web browser either on a computer or mobile phone (with appropriate capabilities), or via a smart phone with one of the free Android or iPhone apps. SCEDES diverges from the one-way communication paradigm and moves to a tailored two-way customized educational format that includes interactive games and weekly chat sessions with healthcare professionals. To facilitate this shift, consumers will need to register for a free account on the SCEDES system in order to customize the information flow. Depending on personal needs, health consumers will need to provide necessary information to access various functionalities and services.

Consumer Access and Offerings

When registering for an account there are increasing tiers of requested information. At most, a consumer needs to create a user name and password (level 1). This would consist of an e-mail address (for uniqueness) and a validated password. Logins will be protected with standard SSL/TLS sessions. By creating a level 1 account, the user can select certain preferences, such as desired interface theme customizations.

In order to move to the next access tier (level 2), a user must enter demographic and lifestyle information. At this point customization of educational materials begins as research has demonstrated direct links to race, age, and lifestyle to diabetic and pre-diabetic risk factors.

At the final tier of information entry (level 3), the consumer enters healthcare professional information (e.g., primary care physician). At this point, the healthcare provider is notified of their patient's entry into the system and must approve (opt-in) the interaction. Once this level is reached, a new interactivity level is set and additional SCEDES options are activated for the consumer. Consumers can move voluntarily through levels.

SCEDES System Challenges

Although SCEDES is still in the design and prototyping phase, a few forthcoming system challenges are already recognized. For example, there will be those who either do not have extended connectivity or some devices are not available, which will make user access challenging. In addition to training health care providers, health care consumers would also need special training opportunities. Furthermore, SCEDES deals with private patient health data that are potentially accessible over the Internet, and all these sensitive data have to be encrypted for security control. Moreover, all smart health systems must adhere to the industry standards (e.g., HL7, HIPAA) in order to make sure the interoperability between systems for information transmission and sharing by different providers.

CONCLUSIONS: RESEARCH ISSUES AND FUTURE DIRECTIONS

Similar to the occurrences of disease and chronic conditions in countries around the world, the United States healthcare system is facing growing demands from diabetic and pre-diabetic populations. These demands result in an increased need for human resources and financial support that further challenges our over burdened economy. In spite of the widely broadcast issues of obesity and sedentary lifestyles, most popular consequences resulted from these health problems include diabetes and kidney failure, and these antecedents continue to occur. Worse yet, diabetes and its management are further compromised by the shortage of health care resources (e.g., doctors, nurses, and nutritionists). In order to improve the overall health of consumers while encouraging consumer-empowered self-management, the following challenges are identified: (1) Evidence-based expert decision support will need to be integrated into SCEDES to provide access and utilization of current knowledge; (2) Multicultural dimensions, such as cultural diversity and consumer collaborations, are necessary to enhance the applicability of SCEDES to the diverse people who use it; (3) Incorporate care standards to ensure the quality of health care with respect to its delivery, outcomes, and system maintenance. The implementation of the proposed SCEDES represents an investment in both capital and human resource. The successful adoption of SCEDES is an example of a Smart Health and Wellbeing application.

Many challenges have been raised that will require communities, regions, and states to come together for the health care consumers common good as well as for the national interests of controlling costs, conserving resources, and improving care. Most importantly, it is necessary to create an empowered health care consumer that seeks and utilizes evidence-based information and knowledge to take actions to improve and manage their health.

The health care consumer knowledge base will grow and by the very nature of the systems that are used, interdisciplinary collaborative between health care providers and health consumers will evolve. It will be imperative that researchers examine the changes in health knowledge among health care consumers. Health care consumers will develop their own type of health practice that uses knowledge systems and information to improve their health. By understanding what is important to and used by health consumer, system designers can build better tools to inspire consumers to learn. Through empowering strategies, patients will have greater opportunities to make informed decisions about their health, maximize their potential heath, and experience a difference sense of health freedom. All of these areas will require research so we can determine the effects of these changes.

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