

A Holistic Approach to Enhance the Doctor-Patient Relationship for Diabetes Using Social Networking, Personalized Alerts, Reminders, and Recommendations

William WL Yip
University of Hawaii, Manoa
1680 East-West Road,
Honolulu, HI 96822, USA
1-808-956-9988
wyip@hawaii.edu

Luz M. Quiroga
University of Hawaii, Manoa
1680 East-West Road, POST 314B,
Honolulu, HI 96822, USA
1-808-956-9988
lquiroga@hawaii.edu

Abstract

This paper describes an ongoing project that proposes the conceptual design of a decision-support system (DSS) based on patient modeling that enhances the communication and relationship among health care providers and patients with diabetes. This project attempts to answer the following two research questions: 1) What are the challenges in the current relationship between a diabetic patient and his/her health care providers? 2) Can a DSS based on providing motivation support through social networking, personalized alerts, reminders, and recommendations improve objective and subjective factors that affect the overall health outcome of a diabetic patient?

Categories and Subject Descriptors

H.4.2 [Information Systems Applications]: Types of Systems – Decision support (e.g. MIS)

General Terms

Design, Experimentation, Human Factors

Keywords

Compliance, Diabetes, Empowerment, Information Filtering, Personalization, Social Networking

1. Introduction

This paper describes an ongoing project that proposes the conceptual design of a decision-support system (DSS) based on patient modeling that enhances the communication and relationship among health care providers (i.e. physicians and nurses) and patients with diabetes. With more than 23 million Americans suffering from diabetes [3], health care providers and researchers have devised ways to improve diabetic patients' overall health outcome as well as to reduce expensive acute episodes as a result of non-compliant lifestyle activities [14]. In spite of these efforts, there remains a gap in the communication channel among health care providers and diabetic patients. This

gap is attributed by the fact that most health care providers resort to the traditional model of compliance and adherence to treat chronic illnesses like diabetes [2]. This model, which was based on a health care system that provided the majority of its treatment for acute illnesses [1], can have potential damaging effects on the provider-patient relationship. Instead, the empowerment approach emerged in the early 1990's as a new model to promote equal partnership among providers and diabetic patients [7, 9, 12, 17]. A DSS based on patient modeling can potentially facilitate this new approach. Effective communication among health care providers and patients can be facilitated by a DSS that:

For patient:

- Provides motivational support through social networking sites (SNSs).
- Provides alerts and reminders to motivate patient to comply with lifestyle-changing activities.
- Provides personalized recommendations of trusted health-related information based on individual patient's situation.

For health care provider:

- Provides personalized alerts and reminders when his/her patient's physiological parameters (e.g. blood glucose level) are out of range.
- Provides personalized recommendations of treatment options based on evidence-based guidelines.

Situation of each patient is unique. In [13], the study showed the importance of context in users' relevance feedback in information filtering (IF) systems for delivery of personalized consumer health information. The study identified non-topical characteristics such as lifestyle, domain expertise, credibility of information sources, and comprehensibility. To increase patients' motivation to change behavior, providing the right information to the right patient at the right moment is crucial. To achieve this, a holistic model of the patients is required. In the health care domain, many opportunities exist for profiling patients. A holistic model may include:

- Electronic Medical Record (EMR)
- Vital signs and physiological parameters collected from outpatients settings (e.g. blood pressure, blood glucose level)
- Quality-of-Life (QOL) issues (e.g. food intake, exercise)

- Web browsing behavior that includes health-related websites, social networking sites (SNSs), and patient support groups

This information can be fed to an agent-based DSS which in turn provides alerts, reminders, and recommendations to both health care providers and patients.

2. Conceptual Framework

Why do diabetic patients remain non-compliant to lifestyle-changing activities in spite of the physical, psychological, and financial burdens that diabetes place on them? The problem lies in the application of the compliance and adherence model in diabetic care. In chronic diseases like diabetes, this model places the patients in a submissive position obeying authoritative care providers [8]. Health care providers often feel frustrated with their patients' non-compliant activities. Vice versa, patients feel frustrated with their lack of knowledge and understanding of the disease as well as blames from their care providers for their non-compliant activities. What is needed is an approach that: 1) redefines the roles and responsibilities of both patients and care providers; 2) create a relationship that promotes collaboration and partnership [5]. Considerable amount of research has been done to facilitate this approach. Since the early 1990's, there has been a push for patient empowerment that gives control to both patients and care providers [7, 9, 12, 17]. In [5], the authors even downplayed the importance of compliance, claiming that compliance becomes irrelevant if patients are "viewed as collaborators who establish their own goals". In a community-based diabetes self-management education program [6], the study encouraged patients to find their own solutions that fit their psychological and physical needs. In a study conducted with 85 type-2 diabetic patients [12], individuality was identified as one of the five issues that are pivotal to effective management of the disease. It is a patient-centered approach where information delivered to patients is based on their individual needs and concerns.

Diabetic patients need to make informed decisions in order to manage their disease effectively. Informed decisions are based on information provided to patients pertaining to their individual needs and circumstances. Personalized recommendations are provided to diabetic patients in a health information tailoring system called Violet Technology (VT) in [9]. VT is a web portal that performs information filtering and prioritization based on patients' profiles in Diabetes Information Profile (DIP). There are 5 components in DIP:

- Diabetes-related situation: current lifestyle, diabetes education exposure, self blood glucose tests, medications.
- History of information browsing
- Patient information preference
- History of quizzing
- History of agenda generation

The presentation of the information is adapted based on a two-step process. First, information is filtered using a series of rules (e.g. removing female issues for male patients). Then, information is ordered by its significance based on priority assigned to each information item. The patient-modeling approach of VT allows

diabetic patients to access information relevant to their individual situations more efficiently. Furthermore, the agenda service allows patients to generate a list of 5 questions that they can bring to their health care providers during their office visits. Although this research shows the face validity of such information tailoring system for diabetic patients, it falls short of being a comprehensive approach for both diabetic patients and their health care providers. Such approach can help bridge the communication gap and provide an environment of equal partnership among all stakeholders. Research has shown that a decision-support system can help health care providers follow clinical guidelines, which eventually leads to improved care [15].

Motivation is a key component in successful management of diabetes. Self-determination theory distinguishes between autonomous and controlled behaviors [18, 19]. Patients are autonomously motivated when their desire to change behaviors comes from within themselves; while behaviors are controlled when patients are pressured from external forces to change their daily activities. Two separate studies [18, 19] showed that patients' autonomous motivation is strongly correlated to their perception of their providers' autonomous support. It is autonomous motivation that leads to patients' competence in making lifestyle changes, and is therefore an important factor to be considered in reducing the communication gap among diabetic patients and health care providers.

Social networking sites (SNSs), mostly in terms of support groups around health issues, has a long tradition, starting with first generations of social tools of the 1980's exemplified by the "Well" community in Rheingold's book "The Virtual Community" to activities such as Sermo (<http://www.sermo.com/>) - social networking for licensed physicians, NurseConnect (<http://www.nurseconnect.com/>), Nurses' Lounge (<http://www.nurseslounge.com/>), and specific groups (by illness, treatment, therapies, etc). More recently, progress has been made in Second Life (<http://secondlife.com>) with islands such as Health Info Island, Karuna (AIDS), Virtual Ability Island (disabilities), and Rachelville (parents of terminally-ill kids). Virtual events are held to promote "social engagement" such as the recent Helen Keller Day, organized by EASI: Equal Access to Software and Information (<http://easi.cc>), as part of its commitment with students and professionals with disabilities to have the same right to access information technology as everyone else.

In a pilot study [11], five participants were interviewed on their perceptions (both positive and negative aspects) on SNSs and which properties of SNSs can facilitate online support and adherence to health-related regimens. The study found that SNSs were most instrumental in providing emotional (e.g. encouragement from a friend) and informational (e.g. a tip to perform a task) support. Furthermore, users of SNSs tend to build and strengthen existing relationships among family members and friends rather than to meet new friends. This preliminary result suggests that SNSs can potentially have a positive effect for diabetic patients who rely on their close ones for motivation. In the following section, a solution incorporating personalized alerts, reminders, and recommendations, as well as social networking features will be proposed.

3. Solution

This section provides a brief description of each component of the DSS that this project proposes. Figure 1 below illustrates a conceptual diagram of an agent-based DSS that provides personalized alerts, reminders, and recommendations, as well as motivations through social networking.

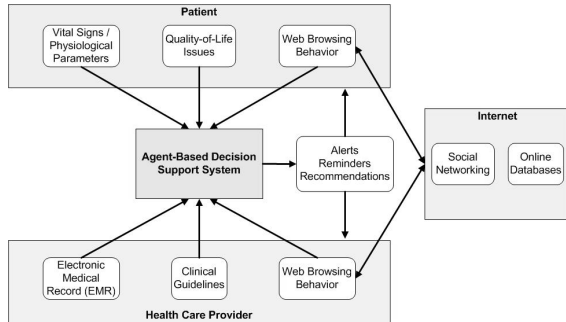


Figure 1 Conceptual Design of a design-support system for diabetic patients and health care providers

Although they provide similar functions, it is important to point out the minor differences between alerts, reminders, and recommendations. The following scenario illustrates the differences:

*John is a 56-year-old man who was diagnosed with diabetes 5 years ago. He monitors his blood glucose level daily using a blood glucose meter provided by his primary care physician. He receives an **alert** from the meter when his blood glucose level is 10% above his acceptable range. He has an office visit with his dietician every 6 months. He creates a **reminder** on Google Calendar to remind himself of the appointments. Lastly, John's brother was recently diagnosed with diabetes so John sent an online article from WebMD about **recommendations** on how to perform foot care on a periodic basis.*

From the patients' perspective, there are 3 primary data sources where profiling information can be collected: 1) vital signs and physiological parameters; 2) QOL issues; and 3) web browsing behaviors. Vital signs and physiological parameters are measurements that are collected periodically by patients themselves in remote settings. Examples are blood glucose level and blood pressure. QOL issues are qualitative indicators of how well patients are managing their disease. QOL issues may be the amount of exercise that a patient is performing daily, or the lifestyle preferences of the patients (e.g. smoker, preference to alternative treatment, their personal goal, plans, strategies, success and impediments regarding their management of the disease). Together, quantitative measurements of vital signs and physiological parameters and qualitative indicators of QOL issues form a unique model of each patient. In an exploratory study [10], they designed the CHAP (Continuous Health Awareness Program) system that engage patients to reflect on their breakdown activities and to build correlations between these activities and the collected data on the patients' blood glucose values. Based on the collected data on an individual's vital signs, physiological parameters, and QOL issues, a DSS can provide personalized alerts, reminders, and recommendations.

Patients' web browsing behaviors provide a clue on what their information needs are. For instance, a patient who often searches for information about a particular drug indicates that he may be prescribed with the drug and in need for additional information (e.g. recent findings on side effects). A DSS can provide personalized recommendation of health-related information from trusted source (e.g. National Library of Medicine, MedlinePlus).

From the health care provider's perspective, patients' clinical data includes demographic information about the patient, clinical test results, history of drug prescriptions, history of vital signs and physiological parameters, and etc. This, typically in the form of Electronic Medical Record (EMR), is an enormous source of information that provides many opportunities for decision-support services based on evidence-based guidelines. Integrating evidence-based guidelines with EMR can help reduce practice variability and improves the overall quality of care for patients.

The last component of the DSS is an online social network for both diabetic patients and health care providers. Diabetic patients, health care providers, family members, and friends participate in a common medium to provide emotional and information support for each other. Members can write messages in public (e.g. a "wall" on Facebook) as well as private areas. Patients can also post updates on their health status. In addition, games and puzzles can be used to educate members, increase participation, and keep members interested over a longer duration.

4. Research Methodology

This ongoing project proposes the following research methodology, which is broken down into 3 phases.

Phase 1 of the project will focus on the relationship among diabetic patients and their respective care providers. The research question of this phase is:

What are the challenges in the current relationship between a diabetic patient and his/her health care providers? Why are diabetic patients non-compliant to lifestyle-changing activities?

To answer this research question, in-depth interview sessions will be conducted with diabetic patient educators and coordinators from various health institutions. Patient educators act as intermediaries between patients and care providers who can provide their unbiased opinions. In a way, they are "human agents" that perform similar functions that a potential DSS could do. The focus of the interview questions will center on the existing communication means (or lack thereof) among diabetic patients and health care providers.

Phase 2 of this project involves the conceptual design of the social networking component of a DSS. The specifications and design of this component will be based on interview results from Phase 1. In Phase 2, the prototyped social networking component will be integrated with an existing DSS called Comprehensive Disease Management Program (CDMP) (<http://www.estenda.com>), which is based on the Chronic Care Model [16]. CDMP, currently operational in more than 70 clinics in the Indian Health Service, allows patients to upload their physiological parameters (e.g. blood glucose) and images. This data is then combined with laboratory results and other patient records to provide decision-support services to patients and health care providers. The social

networking component implemented in this phase will build upon the existing patient profile in CDMP.

The last phase of this project is to evaluate the effectiveness of the social networking component of a DSS implemented in Phase 2. The research question of this phase is:

Can a DSS based on providing motivation support through social networking improve objective and subjective factors that affect the overall health outcome of diabetic patients?

The independent variable of this experimental study is the existence of a social networking component in health care setting; while the dependent variable is the objective and subjective factors that affect a diabetic patient's overall health outcome. The control group is a group of diabetic patients and health care providers who will not be provided with the social networking component; while the experimental group will evaluate the social networking component implemented in Phase 2. About 50 participants will be chosen from existing users of the CDMP into the control and experimental groups, respectively.

Objective factors are facts that can be measured quantitatively (e.g. patient compliance to measuring blood glucose level, number of times a patient is admitted to a hospital because of complications). On the other hand, subjective factors (e.g. motivation to comply with lifestyle-changing activities, patients' perception of the health care system) are more difficult to measure quantitatively. In this phase, both qualitative and quantitative data will be collected. Objective factors will be measured through a self-reported questionnaire comprised of 6 compliance components: exercise, hypoglycaemia, foot care, diet, home monitoring, and drug [4]. Statistical analysis will be performed to measure the effects of the existence of the social networking component. Subjective factors will be evaluated through an interview session with a subset of the experimental group. The focus of the interview session is to determine whether social networking has an effect on diabetic patients' perception on their health care providers. Aspects of the perception of their health care providers include trust, availability, satisfaction, optimism, and etc. These factors correspond to the autonomous support that self-determination theory identifies and have a major effect on patients' ability to comply to lifestyle-changing activities.

5. References

- [1] Anderson, R. M., & Funnell, M. M. (2000). Compliance and adherence are dysfunctional concepts in diabetes care. *The Diabetes Educator*, 26(4), 597.
- [2] Anderson, R. M., & Funnell, M. M. (2005). Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. *Patient Education and Counseling*, 57(2), 153-157.
- [3] Centers for Disease Control and Prevention. (2008). National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.
- [4] Chan, Y. M., & Molassiotis, A. (1999). The relationship between diabetes knowledge and compliance among Chinese with non-insulin dependent diabetes mellitus in Hong Kong. *Journal of Advanced Nursing*, 30(2), 431-438.
- [5] Funnell, M. M., & Anderson, R. M. (2000). The problem with compliance in diabetes. *The Journal of the American Medical Association*, 284(13), 1709.
- [6] Funnell, M. M., & Anderson, R. M. (2002). Working toward the next generation of diabetes self-management education. *American Journal of Preventive Medicine*, 22(4), 3-5.
- [7] Funnell, M. M., & Anderson, R. M. (2003). Patient empowerment: a look back, a look ahead. *Diabetes Educator*, 29(3), 454-464.
- [8] Lutfey, K. E., & Wishner, W. J. (1999). Beyond "compliance" is "adherence". *Diabetes Care*, 22(4), 635-639.
- [9] Ma, C., Warren, J., Phillips, P., & Stanek, J. (2006). Empowering patients with essential information and communication support in the context of diabetes. *International Journal of Medical Informatics*, 75(8), 577-596.
- [10] Mamykina, L., & Mynatt, E. D. (2007). Investigating and supporting health management practices of individuals with diabetes. In *Proceedings of the 1st ACM SIGMOBILE international workshop on Systems and networking support for healthcare and assisted living environments*. San Juan, Puerto Rico: ACM New York.
- [11] Olsen, E., & Kraft, P. (2009). ePsychology: a pilot study on how to enhance social support and adherence in digital interventions by characteristics from social networking sites. In *Proceedings of the 4th International Conference on Persuasive Technology* (pp. 1-6). Claremont, California: ACM New York.
- [12] Pooley, C. G., Gerrard, C., Hollis, S., Morton, S., & Astbury, J. (2001). 'Oh it's a wonderful practice... you can talk to them': a qualitative study of patients' and health professionals' views on the management of type 2 diabetes. *Health & Social Care in the Community*, 9(5), 318-326.
- [13] Quiroga, L. M., & Mostafa, J. (2002). An experiment in building profiles in information filtering: the role of context of user relevance feedback. *Information Processing and Management*, 38(5), 671-694.
- [14] Steinbrook, R. (2006). Facing the diabetes epidemic: Mandatory reporting of glycosylated hemoglobin values in New York City. *New England Journal of Medicine*, 354, 545-548.
- [15] Vashitz, G., Meyer, J., Parmet, Y., Peleg, R., Goldfarb, D., Porath, A., et al. (2009). Defining and measuring physicians' responses to clinical reminders. *Journal of Biomedical Informatics*, 42(2), 317-326.
- [16] Wagner, E. H. (1998). Chronic disease management: what will it take to improve care for chronic illness? *Effective Clinical Practice*, 1, 2-4.
- [17] Weiss, M. A. (2006). Empowerment: a patient's perspective. *Diabetes Spectrum*, 19(2), 116-118.
- [18] Williams, G. C., Freedman, Z. R., & Deci, E. L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care*, 21(10), 1644-1651.
- [19] Williams, G. C., Rodin, G. C., Ryan, R. M., Grolnick, W. S., & Deci, E. L. (1998). Autonomous regulation and long-term medication adherence in adult outpatients. *Health Psychology*, 17, 269-276.