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Chad Anderson
canderson32@gsu.edu

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Chad Anderson
Georgia State University
canderson32@gsu.edu

ABSTRACT

This research-in-progress presents a difficult healthcare problem, namely how to reduce the costs associated with chronic diseases. A comprehensive Web-based disease management system is proposed as a potential solution to help patients with chronic disease more effectively self-manage their disorders. A proposed research agenda is presented using a design science research approach. Theories capable of informing the design of the proposed solution are discussed including social learning theory and the theory of planned behavior. Design parameters are described and potential design ideas are presented.

Keywords

Disease management, design science, healthcare

INTRODUCTION

The World Wide Web has become an integral part of modern life with it uses in business, education, politics, entertainment, healthcare, and so much more that "an unavoidable fact is that the future of human society is now inextricably linked to the future of the Web" (Hendler, Shadbolt, Hall, Berners-Lee, and Weitzner 2008, p. 68). The Web's connections to society and its exponential growth led Berners-Lee, Hall, Hendler, Shadbolt, and Weitzner (2006) to propose Web science, an interdisciplinary approach to studying and understanding the Web that includes the social as well as the technical. An implicit goal of the Web science discipline is for researchers to better understand and engineer the Web to produce desirable social phenomena in order to solve some of society's most intractable problems.

One of those seemingly intractable problems is the effective delivery and management of healthcare. Total spending on healthcare in the United States for 2006 is estimated to have been $2.1 trillion or 16% of our gross domestic product, and based on current trends is projected to be $4.1 trillion by 2016 (Poisal, Truffer, Smith, Sisko, Cowan, Keehan, and Dickensheets 2007). This represents a considerable drain on both our national and individual economic resources. A substantial portion of these costs are due to complications with and exacerbations of chronic diseases like; heart disease, diabetes, asthma, and chronic obstructive pulmonary disorder. For example, the American Diabetes Association reports that there are currently 23.6 million people in the US with diabetes, nearly 8% of the population, and in 2007 the total annual economic cost of diabetes was estimated at $174 billion (ADA 2007). What makes chronic diseases, like diabetes, particularly important in the battle to curb healthcare costs is that much of the cost associated with chronic disease is preventable through lifestyle changes and the implementation and compliance with proper treatment plans. This means that patients with chronic disease need to effectively and consistently self-manage their disorders under the guidance of physician-based treatment regimens to reduce the potential for complications and exacerbations which are so costly.

In order to facilitate this process, the creation of disease management programs has been advocated and over the last couple of decades various types of these programs have been designed and implemented by healthcare organizations around the country (for a list of program providers see, DMAA 2009). The Disease Management Association of America (DMAA) defines disease management as "a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant" (Consensus 2003, p. 123). This is a relatively broad definition and therefore the specific ways in which these programs can be designed and implemented is quite varied. While there is general belief that disease management is effective, the myriad of ways in which these programs have been manifested makes it difficult to easily assess their value individually (Stone 2008). In addition, although "disease management programs have been shown to produce improvements in quality of care, … most of these interventions have been delivered in person and have therefore reached a relatively limited number of patients" (Espinet, Osmick, Ahmed, and Villagra 2005, p. 89). The question this raises is; a*re there better mechanisms for designing and implementing effective disease management programs that can potentially reach more individuals in ways that are more amenable to evaluation?*

The World Wide Web is one possible answer to that question. The Web certainly makes it easier to reach more people in more places than ever before and the observation by Hendler et al. (2008) that the Web is capable of producing emergent properties at the macro level suggests that a scalable Web-based disease management system could produce properties for self-managed disease care that are not possible with existing programs. Healthcare organizations, recognizing the potential value of the Web, have begun including it as a component in their disease management programs and several studies have been conducted on the value of Web-based disease management systems. Dubey (2003) designed and implemented a Web-based diabetes disease management system for use by clinicians at the point of care to improve data collection related to diabetes management. Meigs, Cagliero, Dubey, Murphy-Sheehy, Gildesgame, Chueh, Barry, Singer, and Nathan (2003) tested a clinical decision support tool for diabetes disease management and found that the system improved several evidence-based processes of diabetes care. Many other disease management programs use the Web in various ways, but a scalable comprehensive Web-based disease management system that incorporates all components suggested by the DMAA to constitute a full-service disease management system has not yet been build and evaluated. It is suggested that such a system that can fully leverage the Web's unique characteristics and capacities could be effective in reaching a larger percentage of the population that would benefit from disease management interventions.

Research Objectives

The specific objectives for the proposed research are as follows:

- Build and implement a comprehensive Web-based disease management system in conjunction with a specific healthcare organization.
- Build system architectures and applications for scalability to facilitate potential macro level Web-related emergent properties.
- Evaluate the effectiveness of the system through available metrics for disease management programs and compare these results to other existing programs.

March and Smith suggest that, "design science attempts to create things that serve human purposes. It is technology-oriented. Its products are assessed against criteria of value or utility – does it work? is it an improvement?" (1995, p. 253). They go on to state that, "design science consists of two basic activities, build and evaluate" (March and Smith 1995, p. 254). The objectives for this research, focused on the activities of building and evaluating, constitute the primary activities of design science as defined by March and Smith (1995) and place this work within the design science approach to research.

Vaishnavi and Kuechler (2008) identify five potential outputs of design science; *constructs* (the conceptual vocabulary of a domain), *models* (a set of propositions or statements expressing relationships between constructs), *methods* (a set of steps used to perform a task – how-to knowledge), *instantiations* (the operationalization of constructs, models, and methods), and *better theories* (artifact construction as analogous to experimental natural science). The Web-based disease management system that is the proposed output of this research constitutes an instantiation of design science research.

THEORETICAL BACKGROUND

Disease management programs focus primarily on behavior-based interventions. Therefore theories of psychology are particularly relevant to the development of an effective disease management system.

Social learning theory (Bandura 1971) has relevance for the design of disease management systems. Social learning theory suggests that people learn by observing and modeling the behaviors of others. The likelihood that observed behaviors will be enacted is related to the self-efficacy (i.e. self confidence towards learning) of the individual. Individuals suffering from a chronic disease often begin treatment with a low self-efficacy in regard to their ability to self-manage their disorder. This makes it important to incorporate mechanisms that facilitate increased self-efficacy and adequate opportunities for observing appropriate behavior that can subsequently be modeled. Lieberman (2001) found that computer games designed to teach adolescents self-management skills of chronic conditions were effective in facilitating self-management behaviors by increasing self-efficacy toward those behaviors. For a Web-based system, in addition to self-efficacy toward self-management behaviors, it will also be necessary to take into consideration computer self-efficacy issues.

The theory of planned behavior (TPB) (Ajzen 1991) can also inform the design of disease management systems. TPB posits that human behavior is determined by the combination of; attitude toward the behavior, subjective norm, and perceived behavioral control. Interventions designed to change behavior can be directed at one or more of these determinants. This would suggest that disease management systems should be constructed to facilitate positive attitudes toward self-management behaviors, include family and other important referents in intervention strategies, and make it clear that the patient is in charge of his/her own disease management and capable of performing self-management tasks. Theories of motivation also have significant relevance to the design of disease management systems. Self-determination theory (SDT) is one theory of motivation that has been used in relation to disease management programs. SDT posits that, "human motivation requires a consideration of innate psychological needs for competence, autonomy, and relatedness" (Deci and Ryan 2000, p. 227). Sheldon, Williams, and Joiner suggest that SDT is "perfectly tailored for clinical settings, because it focuses not only on how people in positions of knowledge and influence can best motivate their clients but also on how authorities may sometimes unintentionally undermine their clients' motivation" (2003, p. vii). An SDT process model was used by Williams, McGregor, Zeldman, Freedman, and Deci to study glycemic control in diabetes self-management and found that "self-management behaviors mediated the relation between change in perceived competence and change in glycemic control" (2004, p. 58).

Other relevant theories for disease management include social cognitive theory (SCT), common sense self-regulation model (CS-SRM), operant learning theory (OLT), and implementation intention (II). Eccles, Grimshaw, Johnston, Steen, Pitts, Thomas, Glidewell, Maclennan, Bonetti, and Walker (2007) combined constructs from these theories along with constructs from TPB in a study of the management of upper respiratory tract infections. In predicting behaviors, they found that the explained variance was proportioned at: 31% for TPB, 26% for SCT, 6% for II, and 24% for OLT.

Having an understanding of these theories and applying them in the design process can facilitate the development of a disease management system that complements and enhances the treatment regimens of physicians for self-management of chronic diseases.

BUILD

The build stage centers on the creation of an IT artifact to appropriately address the identified problem; in this case, the lack of substantial gains in the overall reduction of complications and exacerbations of chronic diseases and their associated costs using existing disease management programs. A comprehensive Web-based disease management system that can fully leverage the Web's unique characteristics and capacities is proposed as a potential solution to this problem.

A starting point for designing the various components and modules that would make up the proposed system would come from DMAA specifications for disease management program components. The following list of components is required for a disease management program to be considered full-service as opposed to merely a support service (Consensus 2003): (1) population identification processes; (2) evidence-based practice guidelines; (3) collaborative practice models to include physician and support-service providers; (4) patient self-management education (may include primary prevention, behavior modification programs, and compliance/surveillance); (5) process and outcomes measurement, evaluation, and management; and (6) routine reporting/feedback loop (may include communication with patient, physician, health plan and ancillary providers, and practice profiling).

Each of these components is addressed below with proposed design ideas.

Population identification processes: It is estimated that 24% of the 23.6 million people in the US with diabetes are currently undiagnosed (ADA 2007). This component, leveraging Web capabilities, would incorporate mechanisms for identifying undiagnosed as well as at-risk individuals in the general population. Novel methods to encourage participation in conjunction with online screening tests and customized links to treatment resources would facilitate this process.

Evidence-based practice guidelines: Methodologies have been proposed for evidence-based disease management guidelines (Ellrodt, Cook, Lee, Cho, Hunt, and Weingarten 1997) which could be used to guide the design and development of the portions of the system relating to this component. System design for this component would focus on facilitating the implementation and achievement of these guidelines in practice in novel ways.

Collaborative practice models: Collaborative practice models emphasize joint decision-making between a patient and clinicians. Disease management typically involves an interdisciplinary team of clinicians to develop and guide effective disease management treatments. Therefore, the design of system mechanisms to support this component would incorporate existing collaborative Web tools as well as the development of novel methods of facilitating effective collaboration between patients and clinicians. In addition, there are a limited number of clinicians for a growing number of patients so the design of tools that allow for more efficient collaboration will be particularly important.

Patient self-management education: There are a number of mechanisms for facilitating patient self-management of chronic diseases including informational resources, support groups, and incentive programs along with standard physician directed primary prevention and structured behavior modification programs.

A substantial amount of information about disease management is currently available on the Web, but lacks a mechanism for adequately distilling that information for effective use. Here semantic web tools, proposed by Berners-Lee, Hender, and Lassila (2001) as the next generation of Web technology, could be leveraged to provide patients with a highly customizable resource and information space to better inform them about their condition and provide recommendations on effective methods for self-management of chronic diseases.

Support groups are another useful tool for encouraging appropriate disease management practices and sustaining those practices over time. Zrebiec and Jacobson (2001) found that a professionally moderated Internet diabetes discussion group was actively used by a wide audience and may be an effective method for providing information and support about the disease. Collaborative Web tools could again be leveraged to facilitate more effective online support and discussion groups for disease management.

Incentives are another potentially useful mechanism for encouraging and sustaining appropriate disease management practices. A team of MIT students is currently testing an incentive system for TB medication compliance in Nicaragua that rewards compliance with cell phone minutes (Trafton 2008). This is just one example of how technology could be combined with incentives to improve compliance with treatment plans. Roter, Hall, Merisca, Nordstrom, Cretin, and Svarstad (1998) conducted a meta-analysis of intervention studies to improve patient compliance with medical regimens and found that no single strategy showed a clear advantage, but comprehensive interventions were more effective then single-focus interventions. This would suggest that an intervention component to the proposed system should be multi-faceted and customizable to individuals needs.

Process and outcomes measurement, evaluation, and management: Existing metrics described in the evaluation section below would be used for process management and outcome evaluation. In addition, novel mechanisms developed for other components of the system may require the creation of new metrics to appropriately assess their effectiveness.

Routine reporting/feedback loop: In this component a variety of customizable communication tools would be necessary to facilitate communication between the patient, physician, other clinicians, the health plan and ancillary providers.

The second research objective of building scalability into the system's architectures and applications is a direct response to the suggestion by Hendler et al. (2008) that emergent properties of Web-based applications often occur at the macro level which cannot be easily predicted by analyzing technical and/or social effects on the micro scale. Building for scalability and encouraging expansion could result in useful emergent properties for disease management. For example, it may be that an effective incentives program would emerge at a macro level that was not viable at the micro level.

EVALUATION

An evaluation of the proposed Web-based disease management system could be fulfilled using established metrics. In 2003, the American Healthways and Johns Hopkins Consensus Conference was convened to develop both a set of metrics and a uniform methodology for the evaluation and comparison of disease management programs (Consensus 2003). The methodology proposed included recommendations for components of study design, implementation, evaluation, and analysis. Specific metrics for each disease were established including; biological indicators (e.g. LDL level at target), exam intervals (e.g. dilated retinal exam), and behavioral metrics (e.g. smoking quit rate) that could be used to assess program success.

The DMAA has more recently produced a set of guidelines for measuring disease management outcomes that could also be used for evaluating the proposed system (Market-Wire 2007). These guidelines continue to be updated annually so may better serve as a current best set of metrics for evaluating disease management programs.

In addition to these metrics designed specifically for disease management, Dzewaltowski, Glasgow, Klesges, Estabrooks, and Brock (2004) have developed the RE-AIM framework for use in evidenced-based behavioral medicine. RE-AIM, "emphasizes results along the dimensions of reach; effectiveness (including impact on quality of life and potential negative outcomes); adoption (by representative settings and clinicians); implementation consistency by various staff; and maintenance at both the patient and the setting level" (Glasgow, Nelson, Strycker, and King 2006, p. 68). Because disease management is very much a behavioral oriented practice, the RE-AIM framework could provide an additional set of metrics for evaluating the proposed system.

Based on the existence of established metrics for the evaluation of disease management systems, the "Using Metrics" research pattern (Vaishnavi and Kuechler 2008) will be adopted as the evaluation method for the proposed system. The exact methodology used to apply these metrics would depend on the implementation setting. Appropriate evaluation models might include; time trend analysis, a multiple baseline design, or a regression-discontinuity design. Because the proposed system is being implemented and evaluated in a live environment there are likely to be events that impact outcomes in the target population that are unrelated to the disease management program. It will therefore be necessary to identify any potential environmental factors that may be an influence on the disease management outcomes and include those factors in the discussion of project results.

Design Research Guidelines

Hevner, March, Park, and Ram (2004) proposed seven guidelines for design science research. This proposal is evaluated against those guidelines as follows:

- *Design as an Artifact*: The proposed Web-based disease management system constitutes an instantiation of "a purposeful IT artifact created to address an important organizational problem" (Hevner et al. 2004, p. 82).
- *Problem Relevance*: The proposed Web-based system is designed to facilitate improvement in the management of chronic disease; medical conditions which currently results in billions of dollars in US healthcare costs. According to the National Center for Health Statistics, patients with one or more chronic conditions accounted for fully 50% of the visits to physician offices in 2006 (NCHS 2008).
- *Design Evaluation*: The system will be evaluated against established metrics for disease management and behavioral medicine. The results will be compared to the performance of other disease management programs to determine improvements in effectiveness over existing solutions.
- *Research Contribution*: The Web-based disease management system as a design science research artifact will be the primary contribution as a "solution of heretofore unsolved problems" (Hevner et al. 2004, p. 87). The proposed research would also contribute to the knowledge base of both the information systems and web science disciplines by adding to our understanding of how the World Wide Web can be engineered and leveraged to produce desirable social change. The contribution to practice would be an improvement in the ongoing treatment of chronic diseases with potential cost savings that could be redirected to other healthcare needs.
- *Research Rigor*: Design and construction of the proposed system will utilize patterns suggested by Vaishnavi and Kuechler (2008) and follow best practices for systems development. Evaluation will be based on established metrics for disease management outcomes.
- *Design as a Search Process*: The general design cycle described by Vaishnavi and Kuechler (2008) with its emphasis on iterative circumscription along with their suggested patterns promotes a step by step process of searching for and designing a more effective artifact and the iterative cycles this process typically requires.
- *Communication of Research*: Communication with researchers and practitioners in both the information systems and medical fields will be accomplished through conference/journal publication.

CONCLUSION

This research, while ambitious in scope, has the potential to significantly change the way chronic disease is managed and controlled. The design and evaluation of a comprehensive Web-based disease management system will be a significant contribution to research in both the information systems and healthcare fields. Results of the design process may also add to our understanding of the ways in which the Web can produce emergent properties not evidenced in current systems.

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