A PATIENT-CENTRIC SELF-CARE TELEMEDICINE FOR CHRONIC DISEASE MANAGEMENT

Muhammad A. Razi, Bernard T. Han and J. Michael Tarn
Department of Business Information Systems, Haworth College of Business
Western Michigan University, Kalamazoo, MI 49008-5412, USA
Muhammad.razi@wmich.edu (269)387-5524

ABSTRACT

In this paper, the background of chronic disease management and its findings are provided, followed by a review of telemedicine and its accomplishments in support of home care, in particular, for patients with chronic disease. Some chronic diseases share a common set of leading causes, risk factors, and modifiable health conditions. To enhance the capacity of existing telemedicine, a framework/model is proposed with necessary details to highlight how it can assure the delivery of health care outcomes and financial performance to assure its long-term sustainability.

INTRODUCTION

The United States is facing a population health challenge of unprecedented scope. More than 49 million Americans are uninsured and 133 million (45% of U.S. population) suffer at least one chronic disease (Nash, 2012). Another study (Fontana, 2009) indicates that, due to fast population aging, the number of U.S. senior citizens (i.e., age 65 or older) will be doubled in the next 25 years; among them, 80% will have at least one chronic disease and 50% have at least two chronic diseases. These chronic diseases have become the most important cause of illness and mortality and the leading driver of health care costs (Yach et al., 2004). It is worth noting that the health care spending is not evenly distributed across the population. According to a recent report (CHRT, 2010), using data released by Blue Cross Blue Shield of Michigan, the average annual health care cost for a patient with two chronic diseases is $13,146, which is near five times of the cost spent for a patient with no chronic disease, and the cost amount will be doubled (i.e., $27,763) for a patient with three or more chronic diseases. Therefore, seeking effective and efficient approach to treating patients with chronic diseases becomes the top priority in health care, which will not only reduce the health care spending but also stop the economic loss due to the loss of life as well as extra workforce (e.g., nurses, family members) used to take care of patients.

Among chronic diseases, the top four non-communicable ones are cardiovascular (heart) failure, cancer, asthma, and diabetes (Stuckler, 2008). In the past, patients with chronic diseases were often treated by the acute care approach, i.e., they were admitted to hospital as either outpatients to receive physician/nursing care or inpatients to accept possible surgical and/or intensive care, which in fact consumes critical medical resources that were supposed to be dedicated to patients with urgent care needs (e.g., accident injury, appendicitis). Not until 1990s, more and more health care professionals recognized that different strategies and approaches shall be used to
enhance chronic disease management (CDM). Studies confirm that there are conditions that, with proper early intervention, diet, and exercise, chronic diseases could be prevented, delayed, or minimized (Ambady & Chamukuttan, 2008). In the meantime, many researchers argue that a new approach, with the focus of self-management and patient-empowerment, shall be used to enhance CDM, the so-called paradigm shift from the hospital-based acute care to home-based self-care (Anderson & Funnell, 2005; Costantini, 2006).

In this paper, the background of CDM and its findings are provided, followed by a review of telemedicine (a generic term used herein) and its accomplishments in support of home care, in particular, for patients with either heart failure or diabetes. These two diseases are considered since they share a common set of leading causes, risk factors, and modifiable health conditions (e.g., lifestyle, diet). Then, to enhance the capacity of existing telemedicine, a framework is proposed with necessary details to highlight how it can assure the delivery of health care outcomes and financial performance to assure its long-term sustainability. Next section provides background of the study followed by literature review. Research model is provided next followed by cost justification. Report ends with additional research issues and conclusion.

**BACKGROUND**

Since 1997, the growth of the U.S. national health care spending has overpassed the growth of its GDP (Falan, *et al.*, 2011). As noted earlier, due to the population aging, the health care costs for treating patients with chronic diseases have become the global burden (Yach *et al.*, 2004). In general, it has become the reality that 20% of population with chronic diseases have consumed 80% of the total health care spending (i.e., medical resources) in the U.S. (CHRT, 2010). Since the health care costs of senior citizens in the U.S. are covered by the Medicare fund at the Centers of Medicare and Medicaid (CMS), a prediction was made that this fund will be depleted in 2017 if no actions were taken (Washington Times, 2009). Due to the these urgent needs, many initiatives have been taken by both public and private sectors in the U.S. to seek effective approaches to treating patients with chronic diseases or preventing people at risk from getting them. Over the past two decades, a number of Chronic Diseases Management (CDM) models have been proposed (Wagner *et al.*, 1999; Barlow *et al.*, 2002; Bodenheimer *et al.*, 2002; Willison *et al.*, 2007; Lewis-Washington & Holcomb, 2010).

In brief, CDM involves a process of care, which spans a continuum from primary “disease prevention” for patients at risk to ongoing long-term care for patients with chronic health conditions (e.g., hypertension) or disease (e.g., diabetes). The process should recognize patients’ health conditions, assess their health status, collects data, and determines effective interventions for producing health outcomes that will resume their health condition to the normal status. Rand *et al.*(2006) propose a facilitation model to develop a care plan through CDM, in which it contains five components: (1) medication review; (2) self-care/education, (3) community support, (4) psychological/social assessment, and (5) prevention screening.

As pointed out by Stuckler (2008), most common chronic diseases (e.g., diabetes, heart failure) have a common set of clinical risk factors and, very likely, share a few common behavioral risk factors. The common risk factors for patients with chronic diseases are: (a) unhealthy diet, (b)
physical inactivity, (c) tobacco use, (d) harmful alcohol use. These known risk factors cause the symptoms of most leading chronic diseases such as hypercholesterolemia, hypertension, raised glucose levels, abnormal blood lipids, and obesity. Subsequently, these abnormal symptoms, along with population aging, lead to patient illnesses such as heart failure, diabetes, stroke, and other chronic diseases like asthma or cancers. Fortunately, unlike acute diseases, the risk factors aforementioned are modifiable (Strong et al., 2005). Therefore, with early detection of these risk factors, especially for patients at risk, and early intervention (e.g., patient lifestyle changes such as dieting and exercising), these chronic diseases could be prevented, delayed, or minimized (Ambady & Chamukuttan, 2008). Based on the recent studies of CDM, only when a patient-centric infrastructure is adopted with the following characteristics, will it be possible to expect noticeable health care outcomes and sufficient “potential savings” (Meyer & Smith, 2008). A brief comment is given below for each essential characteristic required for effective and sustainable CDM.

- **Evidence-based Practice.** To ensure correct diagnosis and correct intervention, patient health care conditions and outcomes must be properly assessed with established care plans. All necessary patient data, with different formats, must be organized and stored for easy retrieval and interpretation to assure the continuity and consistency of patient care.

- **Patient Empowerment:** As found out by Gallagher, et al. (2008), one of the key success factors in implementing CDM is patient’s self-efficacy. Therefore, patient empowerment shall be incorporated into the process to ensure necessary training will be provided such that patients will be able to conduct self-care.

- **Patient Engagement:** Effective care of CDM is hinged on patient’s engagement in health care plan, i.e., patients take proactive role in observing interventions provided by health care professionals. Through patient empowerment and patient engagement, self-managed care will become reality and it will truly redirect the ownership of the chronic disease back to the patient. Cost savings and better health care outcomes are to be expected (Pun, et al., 2008).

- **Community-based Health Support.** Knowledge exchange and sharing among patients with the same chronic disease has been recognized as very helpful in achieving effective CDM (Willison, et al., 2007). Essentially, community-based support is very desirable when patients are able to provide collaborative learning and help with one and another, in particular, when they are the center of health care and have the options to consult others (e.g., peers or medical assistants) for shared decision-making.

- **Sufficient Release of Health Care Resources.** From the perspective of patient care, CDM is no different than any other health care service delivery. It success will rely on savings derived from its appropriate implementation with designated investments. The key is to ensure the cost of CDM implementation and maintenance will be paid off by self-generated savings.

**LITERATURE REVIEW**

The second aim of our research is to propose a framework and a decision-making model that will help the development and delivery of home-based patient-centric self-care for patients with chronic diseases. To fulfill this aim, any information technology that is adequate to support remote health care will be considered. Our preliminary literature review found out that “telemedicine” has been extensively used as a synonym for “remote health care,” which carries a
broad sense of health care services provided outside the hospital or clinicians’ office. As pointed out by Bashshur, et al., (2011), a taxonomy of telemedicine will help clarify this burgeoning field in which new technologies and alternatives are added in support of remote health care delivery. In our review telemedicine is used to represent home oriented health care services that are intended for chronic disease management. Our review will be confined to research work in this application domain.

While there are numerous publications could have been classified into telemedicine studies, a recent survey found that less than 20% of papers identified are truly involved in health care service delivery and all of them were dealing with chronic diseases (e.g., asthma, diabetes, heart failures) (DelliFraine & Dansky, 2008). This survey shows that telemedicine has generated positive significant effects on the health care outcomes for some diseases, i.e., heart failures and psychiatric conditions, but not others (e.g., diabetes). Another recent research (Doolittle, et al., 2011) also indicates that, though telemedicine was introduced more than forty years ago, there was not any systematic analysis of the cost effects on health care services. Their study concludes, based on a real case operated between 1995 and 2005, there is significant cost decrease in providing health care via telemedicine. Possible causes could be attributed to the cost drop in technology and the increase number of patients utilizing the telemedicine services. To date, telemedicine research related to CDM can be classified into the following major categories (Jia, et al. 2011; Cho, et al., 2011; Mulvaney, et al., 2012; Maslowsky, et al., 2012; Seng, et al. 2007; Pinsker, et al. 2011; Rollo, et al., 2011; Nikkanen, et al., 2008; Liu, et al. 2011):

- Health care effectiveness.
- Patient follow-up services (after discharge).
- Patient engagement and monitoring.
- Online health consultation and data collection.
- Team-based videoconferencing for health care consultation.

It is clear that the current telemedicine still has room for further enhancement. As addressed in the previous section, a complete CDM will involve a continuous process that will support a variety of functions to ensure patients or patients at risk are the center of the whole process. The current accomplishments in telemedicine literally are simply an enhanced remote health care delivery based on the acute care approach, i.e., clinical professionals are the health care services providers and patients are the recipients. The gap between what have been done by the existing telemedicine and what are to be expected from an effective CDM includes (1) patient empowerment to assure patients’ self-efficacy, (2) community based health care support to provide patients options in seeking best health care advice or resources, and (3) a sustainable setting that will provide sufficient financial saving for the maintenance of CDM. These findings motivate us to develop a framework that will help the development of a sound patient-centric self-care chronic disease management system. Details are presented in the next section
MODEL TO BRIDGE THE GAP IN TELEHEALTH/TELEMEDICINE

In conjunction with emerging and dynamic medical and consumer electronic devices, patient empowerment and engagement have significant potential to increase longevity and reduce healthcare cost of people with chronic conditions. Self-care telemedicine could not only reduce cost by shifting care from high-cost institutional setting to patients’ homes and communities but also alleviate pressure on healthcare systems (Mattke, Klautzer, Mengistu, Garnett, Hu, and Wu, 2010). Chronic conditions that have greatest potential for remote health management include asthma, cancer, coronary artery disease, chronic heart failure (CHF), chronic obstructive pulmonary disease, chronic pain, diabetes, hypertension etc. (Sarasohn-Kahn, 2011).

Remote healthcare approach can be applied to several segments of the population including at-risk group involved in healthy living and prevention programs. Patient segments, remote monitoring functions, and benefits are provided in Table 1 (Adapted from Sarasohn-Kahn, 2011).

<table>
<thead>
<tr>
<th>Patient Segments</th>
<th>Remote Monitoring Functions</th>
<th>Potential Benefits</th>
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<tbody>
<tr>
<td>Chronic Disease Management</td>
<td>• Monitoring of physiological and clinical data</td>
<td>• Reduction of Physician visitation</td>
</tr>
<tr>
<td></td>
<td>• Monitoring of medication administration</td>
<td>• Reduction of hospital readmission</td>
</tr>
<tr>
<td>Post-Acute Care Rehabilitation</td>
<td>• Monitoring of physiological and clinical data</td>
<td>• Reduction of hospital stay</td>
</tr>
<tr>
<td></td>
<td>• Advice patients to perform self-care functions e.g., change medication dose, self-inject medication, change bandage, try particular physical therapy, etc.</td>
<td>• Reduction of hospital readmission</td>
</tr>
<tr>
<td></td>
<td>• Monitoring of medication administration</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Physical or other therapy at home</td>
<td></td>
</tr>
<tr>
<td>Post Hospitalization Rehabilitation</td>
<td>• Monitoring of vital physiological and clinical data</td>
<td>• Reduction of hospital stay</td>
</tr>
<tr>
<td></td>
<td>• Monitoring of medication administration</td>
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<td></td>
<td>• Physical or other therapy at home</td>
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<tr>
<td></td>
<td>• Monitoring of physical activities</td>
<td></td>
</tr>
<tr>
<td>Aging at home</td>
<td>• Monitoring of vital physiological and clinical data</td>
<td>• Reduction of Physician visitation</td>
</tr>
<tr>
<td></td>
<td>• Monitoring of medication administration</td>
<td>• Reduction of hospital stay</td>
</tr>
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</table>

Many different telemedicine approaches have been tested over the years. However, these approaches are generally narrow and mostly involve remote monitoring of patients' vital signs and data transfer. Patient engagement is limited to data entry and/or data transfer to the
physicians system, and empowerment is also applied in a very limited scope. Linking telemedicine to the EHR is seldom discussed in the literature. In this research, we propose a holistic model for remote management of chronic disease.

**Model**
Patient-Centric Self-Care Telemedicine for Chronic Disease Management model consists of three interconnected components; Community Based Health Support (CBHS), Homecare, and Regional EHR.

**Community Based Health Support (CBHS)**
This support is for socially active patients. Community centers such as a ‘Senior Center’ will have a secured section equipped with medical devices appropriate for remote monitoring along with consumer electronics such as computers and/or kiosks. This setup will not only provide remote monitoring advantage but also provide mental, psychological, and peer support.

**Homecare**: Homecare components are medical devices and consumer electronics. Depending on the patients’ requirements this setup may provide physiological, clinical, movement, and other vital data automatically to the appropriate data center.

**Regional Electronic Health Record (EHR)**: Patient-Centric Self-Care Telemedicine for Chronic Disease Management needs to go beyond the health organization that originally collects and compiles the information. Therefore, another component of the model is EHR. This will allow patients’ healthcare providers to share information with other health care providers, such as laboratories and specialists, so they contain information from *all the clinicians involved in the patient’s care*.

**Expected benefits of the** Patient-Centric model are better care through better planning, intra as well as inter office coordination, quick response, better communication, better patient-provider relationship, use of EHR among other benefits.

**Process flow diagram**: Main processes are depicted in Figure 1. Major parties involved in the process are Patients, Government, Employers, Caregivers, Physicians, Hospitals, Insurance Companies, and Pharmaceutical industries. Main principle of this model is patient engagement and empowerment. Patient empowerment requires patients to be knowledgeable and willing to take charge of certain procedures. Patient engagement requires patients to follow the direction meticulously. Brief description of major components and sub-components are explained below:

**Care planning**: Care planning has three components; care planning, device identification, and patient training. Patients’ needs, restrictions, issues are thoroughly analyzed and a care plan for the patient is developed in the first subcomponent of the care plan. Appropriate medical devices are identified, costs calculated, and feasibility is studied in the second subcomponent. Finally, on-site or remote training is arranged for the patient.

**Data collection to action loop**: Data is collected and sent to the EHR. Data collection and transmission procedure may involve automated and semi-automated process. Data analysis may involve automated and semi-automated process as well. Evaluation is done by the appropriate professionals and notification sent to the appropriate recipients.

**Notification Process**: Possible entities to receive results and other relevant information after the evaluation is complete are physicians, patients, hospitals, labs etc. Evaluation is typically done by certified professionals.
**Action Process:** Several actions may be taken based on the notification. In addition to the typical action items such as lab tests, outpatient visit or inpatient visit, patients may be asked to change medication dosage, inject medication, add a device, change a device, or make lifestyle changes. These action items will be dependent on the comfort level of the patient on changing medication dose, understanding risks of overdosing as well as drug interactions when multiple drugs are involved. Patients will also have to be familiar with the medical device and interoperability of medical devices and consumer electronics.

![Process flow diagram of Patient-Centric Self-Care Telemedicine for Chronic Disease Management](image)

**Figure 1.** Process flow diagram of Patient-Centric Self-Care Telemedicine for Chronic Disease Management

Potential legal issue may arise when patients are asked to take responsibility of injecting drugs, changing devices, collecting data, sending data, changing dosage, etc. Therefore, scope of patient empowerment and engagement for self-care of chronic disease needs to be identified and spelled out and appropriate legal protection from unscrupulous law suits is approved.

**JUSTIFICATIONS BY COST SAVINGS**

The Veterans Health Administration (VHA) introduced a national home telehealth program named Care Coordination/Home Telehealth (CCHT) between July 2003 and December 2007. The purpose of the CCHT program was to coordinate the care of veteran patients with chronic conditions and avoid admission to long-term institutional care. The cost of CCHT is $1,600 per patient per annum which is substantially less than other non-institutional care (NIC) programs and nursing home care (Darkins et al., 2008). Analysis of data obtained from a cohort of 17,025
CCHT patients shows the benefits of a 25% reduction in numbers of bed days of care, 19% reduction in numbers of hospital admissions, and mean satisfaction score rating of 86% after enrolment into the program (Darkins et al., 2008). A study by the Central New Jersey health system found that remote monitoring of patients with chronic conditions reduced the patient readmission rate by 10 percent (Sarasohn-Kahn, 2011). Chaudhry et al. (2010) in a research paper published in the New England Journal of Medicine indicated that they found no advantage for remote monitoring of patients with heart failure. Therefore, existing research indicate a possible cost savings for patients with certain kind of chronic disease if remote monitoring is applied. However, all of these research used a narrow approach of technology application rather that a holistic approach. Cost is just one element of the Patient-Centric Self-Care Telemedicine. Quality of life, social impact, psychological impact, legal impact, time savings, impact on resources, etc. also need to be considered while evaluating the advantages and disadvantages of Patient-Centric Self-Care Telemedicine. As VHA study (Darkins et al., 2008) pointed out that reduction of hospital readmission cost due to remote monitoring self-care process could be significant.

RESEARCH ISSUES

In this research, we have not discussed the payment component of the model. Other issues that need thorough analysis are; Network interoperability, software compatibility, collaboration, standards and guidelines, financial sustainability, acceptance by various parties including physicians, challenge of empowerment and engagement, legal implications, etc. We wish to significantly extend our research on Patient-Centric Self-Care Telemedicine for Chronic Disease Management in the near future.

CONCLUSIONS

Our research provides a thorough review on the current accomplishments of telemedicine in treating patients with chronic diseases. Study premises on that fact that health information technology may be used to enable or strengthen the essential components in chronic disease management. A patient-centric model with the emphasis on patient empowerment and engagement is proposed. The model can also be used as a decision-making tool to implement a patient-centric telemedicine system that supports home-based self-care chronic disease management. Since self-care is conditioned on each individual’s independence, our proposed system is confined to patients with capacity in providing self-help, given the necessary assistance by the addition of HIT. It is important to mention that further revision and analysis of the current model is needed to make it financially sustainable and acceptable by all stake holders.
REFERENCES


