Use of Technology in Remote Monitoring and Pain Management for Patients with Sickle Cell Disease

Emergent Research Forum Paper

Joseph Callaghan  
School of Business Administration  
Oakland University  
Rochester, MI 48309  
callagha@oakland.edu

Vijayan Sugumaran  
School of Business Administration  
Oakland University  
Rochester, MI 48309  
sugumara@oakland.edu

Abstract

Sickle Cell Disease (SCD) is a chronic illness disproportionately afflicting, in the US, African Americans. SCD is genetic, degenerative and characterized by episodic pain events, often requiring medical intervention, including hospitalization. The purpose of this proposed study is to examine the associations between remotely acquired measurements using information technology and the incidences of these pain events. Specifically, electronically Patient-Reported Outcomes (ePRO) and Actigraphy (AG) devices will be utilized for randomly selected patients (against a control group) to garner remotely survey-type information, including perceived pain levels; and activity measures, including movement, sleep and location information. The discovered associations between gathered measures and VOC events could lead to more effective treatment modes, through either telemedical intervention or more timely traditional treatments. Patient satisfaction, quality-of-life improvements and possibly reduced costs are additional possible benefits of the use of these information technologies in this clinical setting.

Keywords

Sickle Cell Disease, pain management, telemedicine, vaso-occlusion, patient outcomes, actigraphy.

Introduction

Sickle cell disease (SCD) is a chronic genetic disease that affects, in the United States, primarily African Americans. The hallmark of the disease is pain caused by vaso-occlusion (VOC), reperfusion injury, and hypoxemia events. Although advances in SCD treatment have decreased the pain and prolonged survival, adults with SCD often experience unpredictable painful crises or pain episodes, many requiring multiple and costly visits to healthcare providers, clinics or hospitals. The pathophysiology of SCD is multifactorial (Rees et al, 2010). However, the polymerization of hemoglobin S (HbS), when it is deoxygenated, is the primary event in the molecular pathogenesis of SCD. Additionally, the adherence of sickle red blood cells as well as other cellular elements to endothelial cells or sub-endothelial matrix proteins (Stuart & Nagel, 2004) and hypoxia-reoxygenation injury likely contribute to disease pathophysiology, including pain.

Self-care management is an important part of living with any chronic illness. Recognizing the cues to an evolving SCD-related acute pain episode (i.e. a VOC event) and responding appropriately may be an important part of knowing the body and self-care management. A significant part of learning the body is recognizing the cues to an evolving sickle cell crisis and responding appropriately. A first step may be an understanding the phases of a sickle cell crisis and the role it might play in care-seeking behavior.

Information technology may facilitate self-care management, improve outcomes and reduce costs associated with the treatment of SCD, generally, but specifically regarding the management of chronic pain caused by VOC of this degenerative disease. Since the efficacy of the use of new IT in this healthcare setting
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is presently unknown, this is necessarily an exploratory study. Specifically we will examine the use of electronic Patient-Reported Outcomes (ePRO) and Actigraphy (AG) devices and their impact on SCD patient behavior, outcomes and costs.

This exploratory research is important to IT investment returns, technology adoption and diffusion, and telemedicine theories. The discovery of pertinent variables for the effective practice of medicine for this chronic diseases is the most practical outcome of this research. This will enable further clinical research and design of future controlled experiments.

Literature Survey

Sickle cell disease (SCD) is a chronic disease that has affected life of many patients worldwide. Though FDA has described SCD as rare disease, too many patients are affected by SCD and their life quality is impacted by associated severe pain episodes, hospital admissions and emergency care. Researchers and medical representatives are looking for ways to improve pain management of patients with SCD while concurrently managing treatment costs.

A number of research and studies on effective pain management of SCD have been conducted. Self-care management has been considered as most effective for managing recurring VOC pain events. Patients understanding of their own bodies is very important for self-care management. Research shows that older adults who understands their bodies well in comparison to young adults and adolescents are managing their pains in most effective way. It has been found that young adults and adolescents are overly dependent on the emergency departments, as they transition from pediatric to adult.

SCD crisis can be differentiated into four different phases – (1) pre-pain or prodromal, (2) initial or infarctive, (3) established, (4) resolving, recovery or post crisis phase. Prodromal phase is the phase before onset of severe pain. In this phase, patients will have low pain for 2-4 days on average. Once the pain becomes more severe, then the phase will be considered as in the infarctive phase. In this phase, patients will have decrease activity. The next phase is established where many patients will consider care from emergency departments and are hospitalized as well. The last phase is recovery phase where patients will be under medication and observation.

During established phase, most patients have to visit Emergency Department for pain management. Many times, patients delay their visit to ED for many reasons, e.g. wait time of approximately 4 hours before they are treated. Most of the times care takers/nurses in ED look at patients as mere drug seekers. As a result, the patients often don’t share good rapport with their medical providers. SCD patients have different levels of hospital usage for pain management. Research shows that the attitudes of patients are different when seeking pain management through hospitalization. Low hospital usage patients are self-aware and are ready to interact/discuss their pain medication with medical representatives treating them, while extremely high hospital usage patients use different coping strategies for their pain management.

Many medical institutions practice different medication for treating/managing pain for SCD patients. Majority of patients reporting to ED for pain management are either treated with NSAID, narcotics and combination of both NSAID and narcotics. One study shows that type of initial pain medication provided affects hospitalization. Patients treated with narcotics only are subjected hospitalization in comparison to NSAID along and combination of both.

Overall pain management in SCD may be improved with effective self-care management. But there are SCD patients for whom self-care management is lower priority because they are not confident that practicing self-care management will improve their health. At times, it is difficult to take notes about clues of pain during different phases of SCD crisis. SCD patients have shown desire to have smartphone app to receive visual feedback on their self-care management goals. Noting down clues about managing pain using pencil and paper though effective may be cumbersome. And these notes will not always be with patients. E-Diary making use of latest internet technologies like web interface (platform independent) or cloud can help in improving the experience of SCD patients. At the same time, this will help in getting the right feedback about action to take to improve pain management.

It may be concluded that self-care management with the use of internet technologies like smartphone app or cloud can improve pain management for SCD patients. This will help them not only in learning their own
bodies, clues about pains and actions to be taken but also in inspiring or motivating other SCD patients by sharing their own experiences. This will also enable patients to be socially involved with other SCD patients. Thus, the use of some information technology has been associated with improved disease management. This suggests that the use of emergent, more-targeted, information technologies might improve patient outcomes and reduce costs associated with VOC events of SCD patients.

**Proposed Approach**

The use of technology to monitor patients and their symptoms remotely is at an early stage. One view is that this is merely an extension of monitoring currently and extensively done in traditional health care settings, e.g. hospitals, clinics, doctors’ offices, etc. Monitoring devices may generate measures in discrete or continuous time. Healthcare providers react to these measures presumably using evidence-based standards of care. The measures generated are part of the evidence generated. In this view, remote monitoring permits the telemedicine treatment equivalent of the clinical setting. Possibly more timely and less costly, i.e. more effective, treatment would result. Patient satisfaction might presumably ensue.

Another view on the use of this technology is that preventative medical treatment is enabled. Measures that are precursors to more severe medical interventions (e.g. hospitalizations) are gathered. Less intrusive and costly treatments are thus possibly facilitated. Again, patient satisfaction would seem to follow. In this study on pain management of sickle cell patients, with periodic VOC events, both viewpoints are pursued. That is, improvements in treatment effectiveness may be accomplished either by detecting events earlier and traditionally treating them, or by predicting events and preemptively intervening before an event, through innovative treatment modalities, including telemedical approaches.

The specific technologies involved are electronically Patient-Reported Outcomes (ePRO) and Actigraphy (AG) devices. The former allows patients to journalize their experiences, while the latter passively monitors patient activity (inactivity), sleeping habits and location. ePRO typically reports measures in periodic (usually daily) batches, while AG measures may be either discretely or continuously reported.

**Service System Architecture**

The proposed solution for SCD pain management would require several services. On the client side, actigraphy devices would be used to collect data. Data related to vital signs, medication dispensing etc. would also be collected and the data is sent to the server side. This data is analyzed on a continual basis and coupled with other patient information, preliminary diagnoses can be made which can be reviewed by the physician and additional recommendations can be made as needed. A variety of services may be needed in order to automate this process. Some of the essential services are: data acquisition services, intelligent dashboard services, medication monitoring services, domain knowledge interface services, preliminary diagnostic services, EMR system interface services, and telemedicine or traditional treatment services. In this paper we develop a design for the patient care and SCD pain management system that has direct impact on the patient and supports their overall wellbeing.

Figure 1 depicts the overall architecture of the proposed solution. It shows the various services that are part of the client side and the server side. The following two sub sections briefly describe the processes, the required data, and the communication between various entities.

**Client Side**

The client side is customer facing and focuses on the necessary processes required to facilitate the patient collect the required data such as the vital signs, medication intake etc. and provide it to the server side in an automated manner. Depending upon the level of monitoring required, the client side may include wireless sensor networks, mechanisms for gathering vital signs and medication related data and other special client-side applications. Each of these components is briefly described below.

The user interface and communication service is a major component within the client side that provides various methods needed to interface with the server side. Specifically, it provides the APIs and the interfaces needed for the user to communicate with server side components as well as send and receive data and
relevant information from the various services that are part of the server side. The Actigraphy Devices (AG) measures activity/inactivity time, pedometer information, measuring periodic intensity of activity (steps/number of hours), sleep in hours and minutes.

The vital signs and medication data collection component gathers the vital signs data as well as medication dispensing data at regular intervals and communicates it to the server side, where it is monitored and based on any exceptions, an agent or a physician might recommend specific actions to take. For example, if a patient forgets to take his/her medication, alerts can be sent to the patient in a timely manner. The ePRO device can be programmed to provide both structured, survey-like data, and open-ended journal entry data. In the context of SC pain management, the patient would daily complete a questionnaire whose responses would be scored on a Likert-type scale and provide a daily measure of pain, measured on a scale from zero to ten. An opportunity for the patient to record unstructured comments would also be provided.

**Server Side**

The server side deals with setting up the necessary infrastructure for information sharing as well as the different services needed to support patient care and medication adherence monitoring. It consists of services related to data gathering and monitoring, and diagnostic services. It also consists of a central repository where the patient sensor data is stored. The various services on the server side are shown in Figure 1 and briefly described below.

The Data Acquisition services is responsible for acquiring the patient related data from the client side and storing and managing it in the central Patient Sensor Data Repository. This component has rules and heuristics implemented for determining how frequently to collect the data, how to deal with missing data, and to organize the data in the repository, and how to ensure the quality and the integrity of the patient data. The intelligent dashboard service monitors patient data to ensure that the parameter values are within range. For example, the vital signs data can be proactively monitored and any deviation from the control limits can be automatically identified or flagged and appropriate stake holders can be notified. The dashboards can provide visual clues as to how different parameters are trending within a given time frame. All or a subset of the dashboards can also be made accessible to the patient through appropriate interfaces.

Medication monitoring service monitors the medication intake data provided from the client side component and ensures that appropriate medications are taken by the patient. If there is any discrepancy between the incoming data and the prescribed medication amounts, this component generates an alert and communicates it to the relevant stake holders. The Diagnostic service automates the routine diagnostic activities and generate some initial diagnoses to be provided to the physician or other health care providers. This alleviates the problem of the health care providers having to comb through large amounts of data in...
order to make some routine decisions. The initial diagnoses generated by this component would be used as the starting point for further verification/exploration as warranted. The EMR system interface facilitates immediate access to relevant data that may be distributed within the health care organization. For example, this component provides APIs and appropriate interfaces to gain access to the patient history and other relevant information stored in the EMR system used by the hospital or other health care organizations.

Using the Telemedicine intervention service, a physician would be able to access all the relevant information from his or her computer/mobile device for a given patient and provide the necessary care for that patient remotely. He or she would be able to gain access to the patient vital signs data and trends, medication data, patient history, social data, and relevant domain knowledge to assess the current situation and provide the necessary recommendations for SCD pain management. In short, the server side incorporates a number of services that would improve the communication between the patient and the health care providers. It also facilitate access to the right data as needed in order to proactively monitor and respond to abnormalities in a timely manner so that the patient can receive quality care from his or her health care provider.

**Discussion and Conclusion**

The first phase of the study would gather information from both devices to discover possible associations between the measures gathered and subsequent VOC events requiring traditional treatments. A control group of unmonitored SC patients would also be tracked during this phase both to provide relative treatment measures and to assess possible placebo effects against historical clinical evidence. Particularly, ePRO survey measures as predictors of VOC events will be tested. Additionally, association of AG measures with both VOC events and ePRO measures will be tested. In a follow up phase of this study, statistically significant findings of the first phase will be utilized both to intervene using telemedicine techniques to treat patients earlier or when indicated facilitate traditional treatment modes. Depending on patient outcomes of this second phase, a longer-term treatment strategy would be pursued, resulting in an increase in effectiveness of treatment for SC patients with chronic VOC events.

**REFERENCES**


