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Electronic Personal Health Records and Systems to Improve Care for Vulnerable Populations

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Abstract

The efforts of this research are to educate patients within vulnerable populations in the use of electronic personal health records and health information technologies so that they may better monitor their health, attain desired health goals and manage their health services. Subsequently, this research seeks to improve sustainability and efficiency of patient-centered care to be provided throughout healthcare networks and community clinic partners. Evaluation measures will include facets of self-management of health, patient-physician communication, improvement of health awareness and outcomes, consumer satisfaction with their healthcare provider and assessment of accessibility and usability factors of the personal health record. The project will also include development and implementation of education for patients, care managers and providers in successful adoption of personal health record systems.

Keywords

Personal health records, patient-centered care, patient-physician communication, vulnerable populations

Introduction

This paper outlines preliminary research of a full study to be conducted over the next twelve months. This study will be evaluating the extent to which a personal health record (PHR) system can play a pivotal role in fostering a sense of patient-centeredness within vulnerable populations. We propose that by facilitating patient use of a PHR system that they will feel empowered to take an active role toward managing their chronic illnesses. Instead of letting health needs reach a point of crises, patients will be more inspired to take the steps to achieve long-term health goals, better communicate with care providers and make better use of their health services. It is our expectation that transition to patient-centered care will not only assist in increased health outcomes for patients but decrease the burden on already strained emergency health services.

The intention of this research is to evaluate the ability of a treatment model titled “eSalud”, which encompasses a program that targets frequent, inappropriate usage of health services, and use of the PHR to positively affect the health of a population who are low-income, chronically ill, and predominately Latino. Frequent utilization of high intensity emergency and inpatient services by this population is well documented. Typically, multiple hospitalizations and emergency visits take place that are otherwise preventable, but are the result of sporadic and fragmented treatment of a chronic condition. We propose to analyze key elements of this problem across four dimensions of patient-centered health. The following outlines the four dimensions of care to be analyzed and related hypotheses:

1. Motivation and Awareness of Health - These patients tend to lack the motivation and awareness of their own health conditions to properly take care of their needs.
   a. Patients who use the eSalud system will improve their feeling of control over their own health.
   b. Patients who use the eSalud System will report higher levels of perceived health status.

2. Compliance and Navigation of the Health Care System – Non-compliance of a health program and inability to understand the health system extenuates medical needs and impacts medical services.
   a. Patients who use the eSalud system will show greater compliance with their health program.
   b. Patients who use the eSalud system will show reductions in unnecessary emergency department, inpatient and specialty care services.
3. Health Outcomes Improvement – Nearly all patients from this population suffer from chronic conditions of hypertension and/or diabetes.
   a. Patients with hypertension who use of the eSalud system will improve in measures of blood pressure.
   b. Patients with diabetes who use of the eSalud system will improve in measures of serum hemoglobin.

4. Satisfaction of Health Services – In order for a PHR to be successful within this population it is essential that the information be consumable and effective in addressing their needs.
   a. Patient who use the eSalud system will report increased satisfaction with their healthcare system.
   b. Patients who use the eSalud system will have increased health literacy scores.

The research context for this study is the Los Angeles County + University of Southern California Medical Center (LAC+USC) which sees over 1.5 million visitors a year with over 40% being uninsured. The program this study centers around is called the Camino de Salud Network (CDSN) which was developed by Cope Health Solutions, a non-profit healthcare corporation. CDSN (Figure 1) is a patient care delivery model that integrates private community clinics with the public LAC+USC Healthcare Network’s Medical Center and three comprehensive health centers in order to provide targeted services to patients with chronic medical conditions. Current enrollment includes over 130 patients. CDSN is the program through which the eSalud treatment model takes place.

![Figure 1. Camino de Salud Network Model](image)

**Review of the Literature**

Associated to the goals of this study, relevant research is available that provides background to the concepts these questions explore. Within the four domains outlining this study’s hypotheses tracks of related research were identified that explored the needs and ability of a PHR to assist patients in transitioning from shared care to patient-centered, self-management of chronic conditions and the communication and education protocols within a health care system necessary to achieve these objectives. Equally considered were research findings that explored the emotional characteristics of patients within vulnerable populations and its relation to self-management of chronic illness and predictors for success in decreasing over-utilization of costly emergency department and inpatient services.

**Current research findings**

Considerable attention has been given to the PHR in recent years with most efforts dedicated to parsing out functionality issues, patient adoption, identification of needs and requirements for PHR systems. Kim and Johnson (2002), in evaluating a sample of available PHR for their utility and functionality based on data entry and display criteria, identified that most of the current PHR provided static repositories for medical information. As a clinical tool, the majority of the PHRs assessed failed
to include basic data that would be needed to manage basic problems commonly found in outpatient medicine. It was also determined that most of the records did not provide patients with any type of guidance in abstracting relevant information from prescription data or test reports. However, the Personal Health Working Group of the Markle Foundation (2003) identified that seventy percent of consumers were interested in having a PHR and were interested in activities such as emailing their doctors and checking for mistakes in their health record. The Markle Foundation outlined a set of distinct attributes for the PHR which include patient control, accessibility, transparency of health data and ease of health information exchange between disparate health systems and health professionals.

Next it is essential to determine how then the PHR can best be incorporated into the health care system, especially as it relates to people suffering from chronic illnesses. In response to findings that suggested that patient concerns were not being properly addressed by clinicians and that due to a lack of shared management patients failed to recall care plan instructions, Bergeson and Dean (2006) suggested that there is a need for redesigning systems of care. Outlined were four different objectives that should be considered in redesign: (1) increased access and continuity of care, (2) increased patient participation in the design of their healthcare and increased ease in the ability to provide feedback, (3) development of systems that support self-management of health goals and increase feelings of empowerment that provide the confidence to take control of their health, and (4) development of systems that support coordination across the different care settings encountered by patients. In light of patients who suffer from chronic conditions these suggestions concur with the chronic care model outlined by Bodenheimer, et.al (2002). The chronic care model suggests that care provisions are most successful when a prepared health care system is coupled with an empowered and informed patient. The standard for this model is made up of health care elements of collaborative care and patient self-management education. In other words, successful chronic care exists when there is high communication between patients and physicians and when at the same time patients are able to educate themselves on how to personally manage their illness.

**Gaps in understanding**

The latter elements of research provided us with a base for understanding the issues and requirements for assisting chronically ill patients of vulnerable populations through use of the PHR, but the current question that begs to be answered is how to effectively achieve this objective. Based on the findings and attributes outlined within the PHR, patient-centered care and self-management of chronic conditions, it appears vital then to identify how information system developers, whose goal is to provide patient-centered applications, can develop applications that are actively adopted by these patients. It will be necessary that health care providers incorporate technologies that appropriately empower users. Successful adoption will hinge on the ability of PHR systems to allow patients to directly manage their illness, provide pathways for patient-driven communication and personalization of their health record, and to make the system transparent enough to invoke a notion of trust (Winkelman, 2005). PHRs will not be extensively adopted until they can prove to patients that they are easy to use and learn and that there is some inherent health value associated with them (Tang, 2006). There is a need for research that will help health care providers to better understand how PHRs can best serve patients.

It is equally unidentified how the PHR, once accepted, can then be used to change behavior of people who over-utilize ambulatory services. Patient desire to self-manage their health is not the only reason why these services are utilized. Many patients, especially those uninsured and/or homeless, do not feel as though they can afford healthcare so they put it off until it becomes too great to bear or until they reach a crisis situation which then puts them into the emergency room (Relman, 1985). Additionally, ease of access to care and perception of broad availability of medical services have also been identified as reasons patients seek treatment for less than severe medical problems in the emergency ward (Shesser, 1991). The consequence is that inability to identify with a familiar location of health care decreases a patient’s ability to create positive relationships with care providers and decreases their chance of receiving preventive care measures. These situations of discontinuous care are encountered most often by people of lower socioeconomic status and is consequently often made up of racial and ethnic minorities (AHRQ, 2003). This not only causes an impact on health, but a burden on services. Better understanding of how or if these aspects will be affected by the PHR will support further PHR development efforts.

**Relation to research**

When working with people within vulnerable populations the challenges to adoption increase significantly. Even supposing that the systems developed provide the mechanical ability to assist in effective communication of data and needs and assuming that notions of trust are successfully garnered, it is then likely that the next hurdle will be to overcome some element of access, disability, understanding or literacy. For example, during a consumer empowerment workgroup of the American Health Information Community, Cynthia Baur, a senior health communication and e-health adviser at the U.S. Department of Health and Human Services (HHS), indicated that it is possible that health literacy is a major impediment to successful adoption of PHRs, especially for populations with low health-literacy rates. Baur stated that "extensive consumer research is essential to understand the market before getting to the product-development stage," and that assessment should
be integral to the design process (Conn, 2006). Berland, et al. (2001), note that while readable and usable information is important to English speaking people, that it might be even more important to people whose language barriers make receiving equal levels of healthcare and information more difficult. Also related is that required reading skills for much of the health information provided are quite high as compared to national adult literacy levels and therefore for people of lower education this can cause difficulties in processing needed information. Usability of systems can be tough to measure and there is no standard that applies to all PHR. Trying to compare usability of different systems intended for different situations (people, purposes, etc.) is prone to error. Trying to generalize across an entire system in this manner is difficult and would most likely not be useful for large groups of users (Brooke, 1996). This is especially vital when dealing with a population with very specific and critical needs. Ability to perform iterative evaluation and development of the PHR will likely be essential in determining methods for improving usability.

Assuming that the system is usable or at least responsive to patient needs as they are realized, we previously had identified that the ability to self-manage one’s health is a key element to therapy of chronic illnesses. An important aspect of self-management is the concept of self-efficacy or in other words the confidence that one has the ability to act upon the behavior necessary to reach their goals (Bandura, 1997). If one doesn’t feel as though they are in control of their health then it is likely they are unable to self-manage their health. Health locus of control has been described as the extent to which one attributes his health to his own behavior versus the influence of others or (Ex. health care professionals) or versus some element of chance, luck or fate (Wallston, 1987). Research has shown that people with a high internal locus of control were more likely to take measures to better their health and overall condition of life (Rotter, 1982). Taking this position into consideration it will be important to determine whether the PHR increases or decreases one’s health locus of control.

Finally, while patient satisfaction with health services is reaffirming for physicians and healthcare providers, it has also been found to be tied to success in managing personal health. Greene (2005) reported that people who were satisfied with their providers with respect to self-management support were significantly more confident in managing their asthma or diabetes. Greene found that respondents would perform self-management tasks one half day to one day more often per week if they had highly positive assessments of their health care providers as compared to those who reported negative assessments of their providers. It is obvious from the research that there is no one variable that will describe success in assisting patient with the successful management of their chronic condition. From the development and implementation of the PHR, to its intended use as a tool for increasing patient-centeredness of care, to the potential self-management of a chronic illness, to redefining health care system use behaviors, to the eventual satisfaction of the patient, it is evident that a strategy for treatment fidelity is critical for program success and is the basis for assessing the effectiveness of the PHR across four interrelated segments of health care.

**Preliminary Results**

The first step was to gain an understanding of whether there were patients using the emergency department and inpatient services at LAC+USC Medical Center who could benefit from primary care or preventive care services. Patient data collected in 2003 from LAC+USC Medical Center’s Affinity Health Information System and analyzed by the identified a small number of adult, uninsured patients with disproportionately frequent utilization of high intensity emergency and inpatient services. Analysis of the data concluded that these patients often experience multiple hospitalizations and emergency visits at the LAC+USC Medical Center for preventable conditions that are the result of sporadic and fragmented treatment of a chronic condition. For instance, approximately 6% of the inpatients in 2003 represented a bed utilization of 16% of all bed-days in that year.

Findings indicated that this group of patients lack access to regular, coordinated primary and specialty care services and tends to lack the skills and knowledge to more effectively and appropriately manage their chronic health conditions. Further examination made it clear that this patient population could greatly benefit from community-based case management working in close coordination with a community clinic and the LAC+USC Healthcare Network’s specialty care, diagnostic and hospital resources.

Preliminary program results found that a $10,000 cost avoidance in hospital services could be realized, including utilization of emergency department and inpatient services, for 22 patients assigned to care managers for at least six months. Beginning in July 1, 2007 the CDSN Care Managers will initiate recruitment of LAC+USC Medical Center patients to participate in the research study.
Research Design

The heart of the study is the implementation and assessment of the eSalud model (CDSN Frequent User Program enrollment and use of the PHR), with the aim to positively affect the health of a population who are low-income, chronically ill, and predominately Latino. This study will utilize an experimental design involving random assignment of participants to two groups (eSalud group, control group) in order to evaluate primary outcomes of health locus of control, compliance, health outcomes results and emergency services utilization. Secondary outcomes to be investigated will include health care satisfaction and technology acceptance. The experimental research design will allow for a high degree of internal validity in assessing the study findings. The use of well established measures will ensure a high degree of construct validity in terms of the measures under consideration. The field nature of the experiment will ensure reasonable external validity, in so far the findings can be generalized to urban populations with high ethnic diversity.

According to a recent report ran by LAC+USC’s Information Systems Department, approximately 2,500 patients are eligible to participate in the program on the basis that they have visited the ER at least 5 times in a 12 month period. This information, collected through an analysis of visits to the LAC+USC Emergency Department during the 2005/2006 fiscal year, demonstrates that there is a strong demand for enrollment into the CDSN Frequent User Program. Due to the current enrollment criteria as well as the limited number of CDSN Care Managers available (10 Care Managers), upwards of 1000 patients can be served during a given year. This overflow situation will provide the basis for random assignment to the eSalud system (treatment) or standard referral (control). Within 6 months, it is expected that 600 patients will be enrolled into the research study, with 300 participants participating in the eSalud treatment group and 300 in the standard referral system.

Methodology

This study will utilize a pretest-posttest control group design involving randomized assignment of participants to two groups in order to investigate primary outcomes of health locus of control, compliance, health outcomes and emergency services utilization and secondary outcomes of health care satisfaction and technology acceptance.

Population and random assignment

The population of interest consists of all adult, uninsured patients who have been admitted five or more times within one year to emergency and inpatient services within the LAC+USC Medical Center. In the past year approximately 2500 patients met this criterion. The research sample will consist of 1000 patients, with 500 each in treatment and control groups. Using a conservative estimate of 40% attrition over the 18 months of the study, data from the entire 18-month study period will be available from approximately 600 participants (300 in each group).

CDSN currently cannot serve all eligible patients and is forced to turn away qualified patients throughout the year. The treatment group for this study will consist of randomly chosen patients who voluntarily accept enrollment into the eSalud program. The control group will consist of randomly chosen patients who voluntarily accept enrollment into the program but will not receive the eSalud intervention. This randomization technique, while modifying the current method of selection for enrollment, will not impact the number of patients served by the CDSN.

Subjects will be allocated to the intervention group (eSalud) or the control group using a computer-generated randomization process. The randomization schedule will be prepared with the RANUNI function of SAS software, version 9.0. The random assignments will be sealed in opaque sequentially numbered envelopes. Potential participants will be informed that depending on the randomization, some patients will enter the ‘eSalud’ program, whereas other patients will not be part of the program and will be contacted every 9 months after that. Bilingual research assistants, who will not participate in any aspect of the preparation of the randomization schedules, will open the envelopes in the presence of enrolled participants to inform them of their group assignment. Those allocated to the intervention group immediately will be assigned a case manager and a primary care clinic.

Research data collection

The data on participation in the eSalud system (the independent variable) will be documented by records of meetings with case workers as well as utilization of the eSalud system. For primary analyses of the study hypotheses, a participant will be considered an eSalud participant if he or she attended all three meetings and utilized the eSalud PHR system in cooperation with the case worker. Exploratory analysis will investigate if there may be a continuum of participation that is correlated with intended study outcomes (see also below).
Data of the intended study outcomes (the dependent variables) will principally be obtained through the combined survey instrument that will be administered to both eSalud and control groups on three occasions during a 27 month time period. Survey item data will be collected through the combined survey instrument at three points (baseline, 9 months, 18 months) following assignment to research condition.

Health outcomes measurements for hypertension and diabetes will be gathered at these same periods as a part of normal follow-up procedures and in accordance with established standards for patient care in these two disease conditions. Compliance data will be collected from this same time period as well. At the time of the program’s implementation, the NaviLinx Care Management system (the application behind the PHR) will have entered its third phase, where daily utilization reports from LAC+USC’s Affinity system will be automatically uploaded into the care management tool on a daily basis. Health utilization data for all corresponding periods will be then extracted from this central location with the help of COPE Health Solution’s IT Coordinator collected from LAC+USC utilization reports for all corresponding periods.

The following table links the key survey constructs and measures to each hypothesis. Description of survey measurements and their relation to hypotheses can be reviewed at http://wfs.cgu.edu/bottsn/phr/amcis/2007/nbotts-2007-AMCIS-attachment-measurements.doc.

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<td>Health Literacy Level</td>
<td>8 item test</td>
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**Data analysis**

The first phase of analysis will be data cleaning and description. Variables will be examined for errors and outliers. Errors will be corrected where possible and outliers will be examined and treated appropriately. Highly skewed variables may be transformed to reduce the impact of outliers. Scales will be evaluated for reliability with this population. Once the data have been cleaned, a series of simple regression models will be tested using the assignment group (eSalud) as a predictor and baseline (T1) test scores as covariates in explaining expected health outcomes at follow-up (T2). Following the tests of hypotheses, a series of exploratory analyses will be conducted. Measures such as locus of control, compliance, and satisfaction with healthcare will be used in multiple regression models to assess how well they predict health services utilization together and the unique contribution of each beyond the others. Mediation analyses and structural equation models
(SEM) will be used to test and compare alternative causal models. Additional techniques such as latent growth curve analysis will be used if necessary to bring to the surface specific details of behavioral change.

With a sample of 600 cases (300 in each group), statistical tests using alpha error rate of .01 have power of 80% to detect a population correlation as small as .14 (r squared = .02) and a difference between population means as small as .28 standard deviations. In the context of regression analyses, an R squared change of as small as .02 can be detected with 80% power using alpha of .01. The experimental treatment in this study is expected to produce meaningful effects that are larger than these minimum values on each of the dependent variables.

**Threats and limitations**

Because the basic CDSN has been operational for several months, we are confident that the basic flow of the program will occur, in terms of referrals into the program and then initial participation in the eSalud program. Also, the use of experimental design provides a generally strong analytic framework for assessing impacts of the program. Two important and distinct challenges, however, have been identified within this study.

One challenge is ensuring that the eSalud participants and control group complete the program, including the research element. This population of people is often highly transitory, sometimes homeless and can be difficult to follow-up with. In this regard, it is important to note that each care manager has as his or her primary responsibility to follow-up with a referral. In this sense, there is already a set of practices in place to locate a client, and even this includes physical follow-ups to residences, homeless shelters or other locals.

A second challenge is gearing the program and the assessment to the special conditions of working within the context of a vulnerable population. Because of the low literacy of many patients at these sites, we designed the questionnaire to be readable at a sixth grade level, as assessed by the Flesch-Kincaid test, and we followed layout and design guidelines for developing readable materials. The questionnaires will be administered in English and, at two sites, in Spanish as well. A related aspect of this challenge is the access and use of the PHR system by patients. The PHR is aimed at providing patients access to their own medical information from any Internet enabled location and to allow the patients to take more responsibility for their own health. It is highly noted that computer literacy will entail a great challenge for many of the participants of this study and will have a great effect on its outcome. Part of this concern is addressed to the extent that PHR use by participants will involve a slow, collaborative hand-off from care manager to patient and will certainly involve elements of computer instruction. Equally, many of the patients do not own personal computers or otherwise have access to computer and/or Internet technologies on their own. The initial partner community clinics will therefore provide computer and Internet access to care providers and patients through computer kiosks, including needed training to use the application. The purpose of the kiosks is to enable secure patient access to both personal health records and to health education information through the web-based personal health record system.

**Conclusion**

This study addresses the implications of a PHR-enabled system to produce meaningful improvements in health beliefs, behaviors, outcomes and satisfaction in an important and often overlooked segment of society. While the study is focused on implementation in the greater Los Angeles area, it is believed that the results will be generalizable to other major facilities that deal with use of emergency settings by vulnerable populations. Conduct of the study will provide a research basis to understanding the positive health impacts beyond this important immediate impact.

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