Experiences in mHealth for Chronic Disease Management in 4 Countries

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ABSTRACT
This paper describes mHealth applications to deal with Non Communicable Diseases in North and Latin America: In Chile, a project focused on Diabetes Mellitus type 2; In the United States, Honduras, and Mexico, projects focused in diabetes, heart failure, depression, hypertension, and cancer. Information Technologies used include voice and sms on cell phones and electronic health records systems.

Categories and Subject Descriptors
J.3 [**Computer Applications**]: Life and Medical Sciences - Medical information systems

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Algorithms, Management, Measurement.

Keywords
eHealth, mHealth, Mobile Health, Telemedicine, Telehealth, Telecare, Computer Applications, Electronic Health Records, Electronic Medical Records, OpenMRS, Health, Non Communicable Diseases, Diabetes, Heart Failure, Depression, Hypertension, Cancer Developing Countries

1. INTRODUCTION
In 2008, Non-Communicable Diseases (NCD) such as cardiovascular diseases, cancers, diabetes and chronic lung diseases were responsible for 63% of all deaths worldwide. Eighty percent of NCDs mortality occurs in low and middle income countries, with Africa the only region where infectious diseases are still responsible for more deaths than NCDs [1]. Care for NCDs is a major and growing burden for developed countries, with diabetes-related costs in the United States exceeding $170 billion [2] [3]. In Spain, healthcare cost for type 2 diabetes patients exceeds 2,500€ million per year [4]. As the prevalence of NCDs continues to grow in low and middle income countries, health care cost increases will be unsustainable [5] [6]. Beyond the direct costs, the impact of NCDs on families, social networks, and workers will strain efforts to develop economies and social resources. In the US, costs of treatments and lost productivity associated with NCDs were $1.324 billions in 2003 [7].

Mobile health (mHealth) tools can play an important role in improving the quality of NCDs care while avoiding unsustainable increases in the costs of human resources associated with more traditional delivery modes. In this paper, we describe experiences using mHealth in the management of NCDs from four countries in North and South America, and draw conclusions for how mHealth is currently enabling NCD management and what it could do in the near future.

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2. EXPERIENCES

2.1 The COSMOS model: mHealth for Type 2 diabetes in Chile

2.1.1 Background
In Chile, health care system are required by law to confirm or rule-out type 2 diabetes (DM2) within 45 days of a patient's high blood glucose test. Despite this, roughly 40% of patients with poor glucose control are not diagnosed and 15% of those diagnosed do not initiate treatment. Between 2005-2010, with the support from the National Science Fund (FONDEF D04i1174) and the Chilean Ministry of Health, a team from the School of Nursing at Pontificia Universidad Católica de Chile implemented a practice linked telehealth model of self- management support to promote lifestyle changes and reduce hemoglobin A1c in low income patients with DM2 treated in public primary care centers [8].

Within 15 months of initiating the program, patients receiving telecare support stabilized in their glycemic control as measured by hemoglobin A1C (A1C) while patients in a comparison clinic experienced a clinically significant worsening of their blood sugar control. Emergency room visits were significantly reduced in the intervention group and access to ambulatory care improved.

Despite its demonstrated benefits, the model's dissemination nationally has been limited due to a shortage of qualified nurses – a problem experienced in most low- and middle-income countries. Qualitative evaluation following the initial implementation trial suggested that many of the tele counseling session could be replaced by short message service (SMS) text messages or

automated calls delivered using an interactive voice response (IVR) service.

In 2010, with funding from the Mobile Citizen project of the Inter-American Development Bank, our team developed a mHealth model based on tele counseling, SMS, and IVR for DM2. The specific goals were: (1) Activate individuals with high blood sugar levels to confirm or rule-out the diagnosis of DM2 within 45 days; (2) Improve the efficacy of the diagnostic confirmation process; (3) Improve adherence to pharmacological treatment and lifestyle changes. In 2010, COSMOS was deployed in two health centers and evaluated during an 11-month development period.

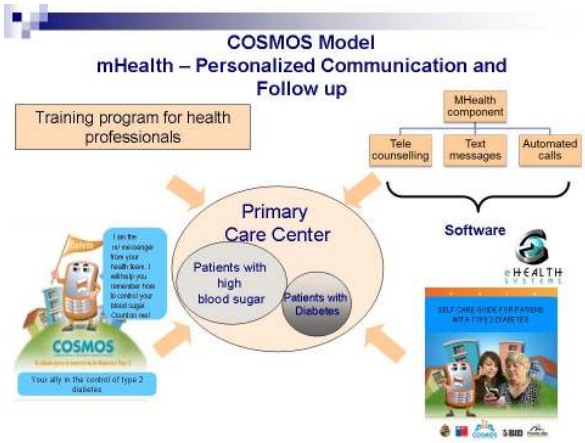

Figure 1: The COSMOS model

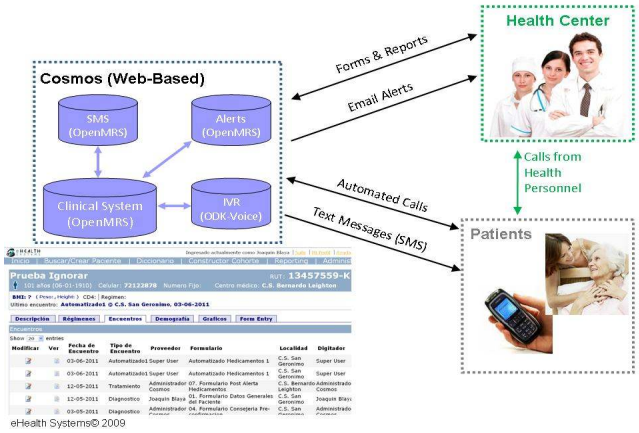

Figure 2: The COSMOS Technical design

2.1.2 Software Platform and Technical Infrastructure

COSMOS is built on OpenMRS, a web-based, open-source Electronic Medical Record (EMR) platform used in over 25 countries. COSMOS links OpenMRS functionality with Open Data Kit Voice (ODK-Voice) to make IVR calls. The central repository of information based on the OpenMRS architecture generates the rules for when an automated call or an SMS should be sent to the patient. The automated calls are seen within OpenMRS in the same way as forms filled out by clinical staff. COSMOS is designed to be easily scaled as the organization grows. Work flows, automated calls and SMS, alerts, searching and reporting are designed to be configurable to fit the unique requirements of individual clinics.

2.1.3 Implementation Challenges

Initial implementation of the system faced several technical and organizational challenges. The first technical challenges were related to sending SMS. The international SMS gateways which had been used in other countries did not work with cell phone providers in Chile, making it impossible to send SMS to all patients with different cell phone providers. In the end these problems were resolved by finding another international SMS gateway which was compatible with SMS delivery to all three cell phone providers in Chile. The second challenge was that ODK-Voice, the IVR system we are using, requires a Voice Over Internet Protocol (VoIP) provider to make the call and it also needs the VoIP call to transmit back the touch tones when a user presses one of the buttons on their cell phone in response to a question. Currently, such a provider has been identified.

By implementing the service within "real-world" practices, we have had to address some of the organizational challenges which are common in primary care. These include: limited provider availability during certain periods such as holidays; variable interest and complex incentive structures for participating clinical staff; and an overall bias against research collaborations which are often seen as limited in their value and a distraction to the day-to-day clinical work. Among patients, we have had to address problems with the accuracy of touch-tone responses resulting from difficulty managing the keypad (e.g., vision problems or decreased dexterity), limited literacy for reading SMS, and occasional confusion regarding the meaning of clinical questions or providing clinically-useful responses.

2.1.4 Evaluation

The ongoing project includes both a formative and summative evaluation using a mixed qualitative plus quantitative approach. Key process measures include: satisfaction and utilization of each of the three main program components: tele counseling, SMS, and IVR. The outcome evaluation will be based on 80 patients with poor glycemic control. Specific endpoints will include: the proportion of patients who received diagnostic confirmation within 45 days; the proportion of patients who receive diagnostic confirmation in one medical visit; and the proportion of patients with confirmed diabetes, who attend the three month follow up in the medical clinic. Qualitative data regarding provider satisfaction and the system's perceived clinical utility will be collected via semi-structured interviews.

2.2 The CarePartner Model: Experience with IVR from the United States, Honduras, and Mexico

2.2.1 Background

Led by Dr. John Piette, the program on Quality Improvement for Complex Chronic Conditions in the University of Michigan develops IVR self-management support programs for patients with chronic illnesses such as diabetes, heart failure, depression, hypertension, and cancer. Here, we report experience from more than 1,500 patients in the United States, Honduras, and Mexico who have completed over 20,000 IVR symptom assessments. In conjunction with the broader literature on IVR, these data provide

evidence for how IVR systems could be used to improve access to quality chronic illness care in developed as well as less developed countries.

2.2.2 System functioning

The CarePartner model is designed to use IVR to improve chronic disease outcomes through three mechanisms of action (figure): (1) tailored self-care information to patients provided during weekly IVR interactions; (2) feedback about urgent issues to patients' clinical team that can be tailored by the provider based on patients' IVR reports, and (3) targeted advice for family members and other informal caregivers provided via email or a structured voicemail service about how to address patient self-care problems and communicate effectively. Patients receive IVR assessment and behavior-change calls at times they designate. Call frequency can vary depending on a predefined schedule, clinicians' preferences, or changes in patients' status. The content for the IVR calls has been developed in conjunction with behavior-change researchers and experts in the target conditions. During assessment calls, patients interact with a structured series of recorded message components, and respond to queries using their touch-tone keypad. Based on their responses, patients receive recorded messages tailored to their individual need

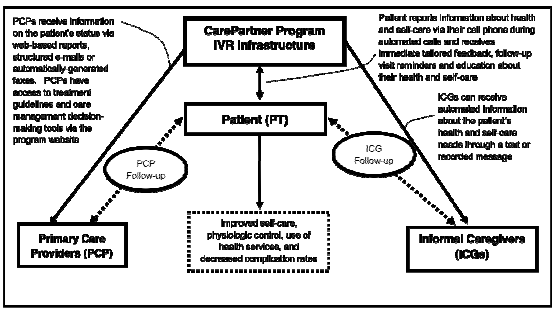

Figure: CarePartner Program Infrastructure.

Figure 1: CarePartner Program Infrastructure

2.2.3 Software Platform and Technical Infrastructure

Technical details for the CarePartner system are available on request. In brief, the system was developed using Asterisk, an open-source telephony language. Asterisk is used to create a communication server for PBX systems, VoIP gateways, and other telephony tasks. Our development efforts have emphasized experience with a variety of international SIP trunk providers and trouble-shooting technical barriers to providing IVR services across national boundaries to low-income communities with limited communication infrastructures [9].

2.2.4 System Feasibility, Satisfaction, and Dissemination in the United States

In two randomized trials, diabetes patients who received weekly IVR calls for one year completed more than 4,000 assessments, representing 71% of all assessment attempts [10]. In a more recent pilot study [11], only 13% of heart failure patients were unable to participate because they did not have an informal caregiver living outside of their household with email access who was willing to be their CarePartner and receive structured feedback based on the patient's IVR calls. In that study, patients completed assessments during 90% of the weeks in which one was attempted with no drop-off in completion rates over the course of patients' participation. Both patients and CarePartners report high levels of satisfaction with the service [12] [13]. More than 1000 U.S. patients with diabetes, heart failure, and depression have used the CarePartner IVR service for between 12 and 52 weeks. Fewer than 2% of patients have chosen to discontinue, and clinicians report that they find the fax reports useful for allocating time to patients with complex needs. The United States Department of Veterans Affairs (VA) healthcare system has adopted the CarePartner program as part of usual care in the Midwest region for the management of diabetes, hypertension, depression, and heart disease. VA currently is exploring ways to use CarePartner with its more than 5 million chronically ill patients nationwide. Programs for patients undergoing cancer chemotherapy, chronic pain management, or other treatment challenges are in development.

2.2.5 Impacts on Health and Self-Care Outcomes

IVR-supported nursing care can improve patients' self-care and health outcomes [14] [15] [16]. In a trial of low-income diabetes patients in the U.S., we found that participants receiving IVR calls had significantly better self-care than control patients at their 12-month follow-up. Intervention patients were substantially less likely than controls to report one or more problems with medication adherence (44% versus 64%, $p < .01$), and more than twice as many intervention patients had acceptable glycemic control at 12 months (18% versus 8%, $p = .01$). Compared to controls, intervention patients reported fewer symptoms of diabetes and depression (both $p < .001$), were more satisfied with their care, had greater perceived access to care, and had more confidence in managing their self-care (all $p < .05$). Outcomes in a second trial were similar [16]. Other studies also have shown that IVR services can improve healthcare and health outcomes of patients with chronic conditions including asthma [17], cardiovascular [18] disease, diabetes [19], childhood obesity [20], tobacco addiction [21], and HIV [22].

2.2.6 CarePartner Development and Testing in Latin America

In 2009, we surveyed 624 chronically-ill patients in Honduras--one of the poorest countries in the western hemisphere [23]. Although more than 25% of respondents were illiterate, 84% reported having either a mobile or "landline" phone. Eighty-eight percent reported that they would be willing to receive IVR telephone reminders about upcoming appointments, 80% were willing to receive IVR health status monitoring for their symptoms and self-care needs, and 81% were willing to participate in automated self-management education. Other studies also have found that Spanish-speaking patients are interested in receiving self-care support via IVR [24] [25] [26].

We recently developed a model for providing IVR disease-management support to low-income countries without a strong technologic infrastructure. The system is maintained on a server at the University of Michigan and can be accessed by clinics in other countries via the Web. Local clinicians can schedule patients' IVR calls, as well as designate where and how follow-up information should be directed to patients' clinical team and informal caregivers. In 2010, 85 diabetes patients were enrolled in an IVR-based disease management program in Honduras [12]. Despite the country's limited resources, patients completed the majority of their weekly IVR assessment calls. Clinicians received

urgent alerts about problems. All but one patient (98%) reported improvements in their health or self care as a result of the program including blood sugar control (56%), diet (66%), medication adherence (64%), and foot care (89%). Mean A1c levels (a measure of glycemic control) decreased from 10.0% at baseline to 8.9% at follow-up ($p<.01$). Ninety-two percent of patients said that if the service were available in their clinic they would use it again. In 2011, 200 patients with hypertension and high blood pressures in Mexico and Honduras were randomized to the CarePartner IVR intervention or usual care. Analyses are underway, but preliminary results suggest that satisfaction was high among patients and clinicians in both countries. Results of both trials will be available in 2012.

2.2.7 Limitations and Conclusions

Some potential patient users and even more health professionals perceive negative connotations of "robo-calls" and see IVR as an attempt to trade-off in-person assistance for a cheap and potentially frustrating alternative. IVR communication alone is insufficient to circumvent the many barriers to disease management in low-resource areas; programs should be designed in conjunction with local stake holders to ensure that the automated recommendations and clinician feedback makes sense given financial constraints on health systems and patients' resources. Despite these caveats, we have found that IVR represents an evidence-based tool for improving access to health information and self-management support in the United States as well as in two countries in Latin America.

3. Conclusions

3.1 Feasibility of Implementations

These case studies demonstrate that mHealth solutions for NCD management are feasible using a variety of widely-accepted informatics tools and with patients that vary in their cultural, socioeconomic level, literacy, and capacity for NCD self-management. In each of the implementation programs described above, mHealth tools increased both the intensity and breadth of information provided to patients regarding their self-care. Systems addressed key clinical functions without increasing workload, including: identifying patients experiencing health and self-care problems between encounters; ensuring appropriate follow-up for patients at the time of diagnosis, and supporting adherence to NCD medications. All these suggest that broader dissemination of these models is possible in many environments within low- and middle-income countries.

Both the COSMOS and CarePartner teams have had to address a variety of technical and organizational challenges to implementation. These barriers to implementation are unavoidable and can only be surmounted through the pain-staking, iterative problem solving efforts conducted in collaboration with clinical teams.

3.2 Clinical and Cost Benefits

These initial experiences show that the adoption of mHealth systems can potentially improve: (1) Patient self-management capabilities; (2) Patient medication adherence; (3) Access to health resources; (4) Access to information; (5) Health education.

These improvements could come with little to no additional burden on clinical personnel, since they could be automated. Though there is little evidence about the costs and savings of these technologies, the major savings could come from reduced transportation, increased efficiency, and finally the improvements of patients' health due to increased monitoring and prevention.

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