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6 Tele-Self-Management Support for Type 2 Diabetes Care

Working through public primary care centers in Santiago, Chile

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Introduction

Type 2 diabetes is a chronic disease and a cardiovascular risk factor of high physical, psycho-social, and economic impact. Like many countries, Chile is experiencing a dramatic increase in rates of diabetes as well as of diabetes risk factors, such as obesity and a sedentary lifestyle. Its prevalence is 9.4 per cent and much higher among people with lower socio-economic status and minimal formal education (Ministerio de Salud de Chile, 2010a). Mortality due to diabetes increased between 1999 and 2007 from 16.8 to 19.7 per 100,000 inhabitants (17 per cent) (Ministerio de Salud de Chile, 2010a).

Since 2005, the Chilean Ministry of Health has made diabetes management a national priority through federal law within the country's 'Plan for Universal Access with Explicit Guarantees' (i.e. the 'AUGE' Plan). This gives the right to any citizen to receive free healthcare access for early detection, treatment, and self-management support (Ministerio de Salud de Chile, 2010b).

A significant concern arose in the primary care clinics nationwide: *how can primary care centers implement these guarantees for patients with diabetes if the physical infrastructure of most centers is already collapsed and their personnel are overloaded?*

We recognized that there was a significant opportunity for our team at the School of Nursing at Pontificia Universidad Católica de Chile to develop, in collaboration with public primary care centers and the Ministry of Health, tele-care support projects. We also conducted feasibility studies to obtain the evidence which decision makers need to incorporate tele-care as a permanent component of chronic disease

management in primary care as a tool to improve chronic disease management without overloading the primary care system.

The purpose of this chapter is to reflect on lessons learned through a sequence of four tele-self-management support projects that the School of Nursing at Pontificia Universidad Católica de Chile (SON) has implemented, between 2004 and 2010, in the commune of Puente Alto, the biggest and one of the poorest communes in Chile. All these projects have had as counterparts the Health Division of the Municipal Corporation of the Commune of Puente Alto, Santiago, and the sponsorship of the Ministry of Health.

I will describe each of these projects because the lessons learned from each one provided information and experience to inform the one that followed. For instance, in our first project we initially did not consider calling cellphones to provide tele-self-management support to patients with type 2 diabetes, as the cost of communication to a cellphone was three times higher than calling a fixed phone. This decision changed very rapidly as we had many inconveniences due to the continuous interruption of the telephone traffic because the copper land lines were stolen, which obliged us to contact our patients through their cellphones. Then we realized that cellphone contacts, although more expensive, were more convenient because we could contact our patients at the first instance at home, at work or in other places outside their home. And that in the long run, the process demanded less professional time, which is scarce and of high cost.

Our effort during these five years has been to develop chronic care strategies for patients with type 2 diabetes, which could be adopted for the care of patients with hypertension and other chronic cardiovascular conditions without overloading the primary care system. In partnership with the health authorities of Puente Alto, we decided to design and try out with patients with type 2 diabetes a tele-self-management support model to improve metabolic control and increase patient satisfaction with the care they receive in primary care centers. The reason we selected diabetes as the prototype chronic disease is that this chronic condition has doubled in Chile in the last ten years. It is also a disease that if not well controlled produces serious health complications, which are of high social and economic impact.

Statistics showed that the prevalence of diabetes in Chile was increasing rapidly from 4.2 per cent in 2005 to 9.2 per cent in 2010. Patients which accessed primary care clinics with high blood glucose levels were not diagnosed in a timely manner nor were they receiving the care they required once it was confirmed that they had diabetes. This is a serious matter because it is known that the early diagnosis of the disease and adequate management reduces the risk of serious complications.

Tele-Self-Management Support: A strategy to improve metabolic control

Several international studies have demonstrated that tele-self-management support, also called tele-care, can contribute to improved metabolic compensation in patients with type 2 diabetes if this strategy is well articulated with face-to-face professional encounters and if telephone protocols and clinical guidelines are used by nurses who are well trained in behavioral change theories (Prochaska and DiClemente, 1984), self-management support strategies and motivational interviewing techniques (Stacey, Noorani, Fisher, Robinson, Joyce, and Pong, 2003; Taylor, Miller, Reilly, Greenwald, Cuning, Deeter, and Abascal, 2003). The tele-self-management support models I describe were selected because they could improve the metabolic control of patients with type 2 diabetes; their satisfaction with care; ability to serve as a natural extension of the traditional primary care model and a desire to identify innovative strategies to use the available human resources without overloading the limited space within the primary care clinics.

We structured and organized the use of tele-self-management support taking into account the characteristics and internal organization of the participating primary care clinics to assure that tele-care would be a natural extension and a supplement to usual care services, which are adequate to treat patients with acute health problems but inadequate to provide care for patients with chronic conditions, such as type 2 diabetes.

The process of refining a tele-care model that would work was accompanied by much frustration for the tele-care nurses of the School of Nursing due to incomplete information in electronic clinical records which was needed to provide personalized and timely self-management support.

It was time to innovate rather than doing more of the same. We agreed with the health authorities of the commune of Puente Alto that we would make every effort to ensure that the pilot initiatives, if successful, would be transformed into institutional programs. This was done to avoid the frequent situation that health centers and patients participate in a chain of isolated pilot projects, which once finished, disappear, because no business plan has been developed as part of the process.

The primary care centers of the commune of Puente Alto have been clinical sites for the students of our School of Nursing for many years. This academic/clinical linkage has been essential. Due to previous community-based projects, our team knew how important it is that the ideas for a project come from the commune rather than from the university. The role of the university is to help to transform these ideas or solutions into a project or research proposal and find the funding for implementation and evaluation. By contrast, with the incorporation of type 2 diabetes in the AUGE

plan, the primary care centers would start to be more overloaded than they already were, because patients had now several legal guarantees which include the right to receive timely diagnosis and continuity of care.

However, it was frequent that patients with diabetes, instead of having three professional face-to-face encounters per year, which is the national recommendation, were often seen once a year or less. The reasons were many: a deficit of physicians, high rotation of healthcare providers, patients who had appointments did not show up or they came without having updated lab examinations which are essential to adjust medication doses or provide nutritional feedback, and difficulties of access to the primary care clinic for patients who work, as the centers are not open for diabetes follow-up in the evenings or weekends.

We thought of designing a practice linked and nurse managed tele-support model as a strategy to improve chronic care in general, and particularly for diabetes care. However, no information was available regarding the use of fixed phones and/or cellphones among these patients nor if they would be interested in receiving self-management support by phone as a complimentary activity to the traditional healthcare provided by the primary care center.

With support of students from the School of Nursing and the Institute of Sociology of our University, we did a baseline needs assessment with patients with type 2 diabetes enrolled in public primary care clinics in the commune of Puente Alto. This study had financial support from the Canadian Institutes of Health Research and the Quality Improvement for Complex Chronic Conditions Program from the University of Michigan.

Results showed that over 96 per cent of the patients had either a fixed phone or cellphone or both, and of those reporting access to a telephone, only 6 per cent said that their telephone service was occasionally discontinued due to an inability to pay bills. Many of these patients unsuccessfully attempted to use the telephone as a means to communicate with clinic staff and 60 per cent were interested in receiving self-management support between face-to-face encounters. Patients who had fewer clinic visits were the most likely to report a willingness to receive phone calls in order to enhance their care (Piette, Lange, Issel, Campos, Bustamante, Sapag, Poblete, Tugwell, and O'Connor, 2006). This study confirmed that tele-support could be a real option to improve self-management for patients with type 2 diabetes enrolled in public primary care clinics.

Project 1: Development of a tele-support model to improve self-management

Based on the results of the baseline needs assessment, in 2005, we received a grant from the National Science Fund to design and implement a telephone-mediated

Figure 6.1 Access to healthcare without tele-care

chronic care model – the ATAS model (**A**poyo **T**ecnológico para el **A**utomanejo de Condiciones Crónicas de **S**alud) – to improve self-management, metabolic compensation, and satisfaction with care of patients with type 2 diabetes enrolled in public cardiovascular health programs, as a contribution to the system of universal access with explicit guarantees (AUGE plan). Our counterparts for this project were the Municipal Corporation of Puente Alto, the Ministry of Health, and ENTEL Call Center. A quasi-experimental design was used to evaluate this project.

The ATAS model promotes active participation of patients and family caregivers in health-related decisions and fosters a permanent relationship between the patients and their health services. Nurses who are trained in self-care, behavioral changes, and motivational interviewing use communication technology (for example, phone and the internet) for counseling in chronic disease management in coordination with the patient's primary healthcare team.

The ATAS model has four components: a training program for the primary care clinicians and tele-care team; the tele-counseling service; the self-management tele-support guide; and the software for self-care information, management and follow up (SIGSAC). The first three components are integral parts of the ATAS model. The SIGSAC was developed to be able to implement the ATAS model in the future in other communes of Chile which do not have access to electronic clinical records which are needed to share relevant information between the traditional primary care team and the tele-care nurses.

Figure 6.2 A healthcare model with tele-care

Figure 6.3 Components of the ATAS Model

1) **The Training Program** introduces the primary healthcare team and tele-counseling nurses to the ATAS model and its conceptual framework. This program includes a self-directed learning module.

2) **The tele-counseling** service is the 'heart' of the ATAS intervention. The tele-nurses have access to the electronic health record used by the primary care centers,

which they can read and complement with biological, psychological, and social information that can help clinicians to provide more effective patient-centered care during the limited time dedicated to the face-to-face encounters. The telephone counseling service uses three types of telephone call protocols: post-clinic visit calls, pre-clinic visit calls, and special event counseling calls.

Post-clinic visit calls: Its purpose is to reinforce the importance of drug adherence, clarify indications of the healthcare providers, when needed, and reinforce self-management behaviors. We know that patients only retain approximately 10 per cent of the information that is provided to them in clinic visits.

Pre-clinic visit calls: One of its purposes is to help the patients and family caregivers organize the information they want to share with the clinicians in the clinic and to help them to structure the questions they want to ask. This is important so that the face-to-face encounter achieves the objectives of the clinician and satisfies the needs of the patient, which often are not the same in order to ensure an effective and satisfactory clinic visit. Another purpose is to remind the patient of the importance of having up-to-date lab tests when attending the Cardiovascular program (CVP) and to remind him or her of the date of the next diabetes follow-up clinic visit.

Special event counseling calls: Patients could call an 800 number to leave a message when they went to the emergency room or had been hospitalized and the tele-care nurse would call back. The information obtained from the patient or family member is incorporated into the electronic clinical record and in parallel an email is sent to the CVP informing of this incident. This is information that primary care centers never receive but which is a critical incident in the patient's life which requires timely follow up.

3) **Self-management Tele-Support Guide for patients with Type 2 diabetes and their Family Caregivers** is a complimentary guide used in all encounters between the patient and the healthcare providers by the patient with the family caregiver and also to strengthen interactions with the tele-nurse during the tele-counseling sessions. The guide includes the clinical guidelines for self-management which are presented using friendly, easy-to-understand language. It contains many drawings and exercises to motivate and help the patient to improve and maintain a healthy lifestyle. The purpose of the guide is to reinforce the topic which is discussed in each counseling session. For instance, if the topic is 'how to take care of the feet', the nurse would ask the patient to open the guide on the page where foot care is discussed. There is also a space for patients to write comments and questions. This guide is used by tele-care nurses, patients, and family caregivers, as well as by professionals in the primary care center.

4) **Software for self-care information, management and follow up (SIGSAC)** was developed by the Universidad Católica de Chile to facilitate self-management

follow up in healthcare services that do not have access to an electronic medical record.

This project showed that the patients who had access to the ATAS model intervention group; (n = 300 patients) stabilized their blood sugar level, measured by hemoglobin A1c (HbA1c) over a period of 15 months. Whereas the conventionally treated group (n = 306 patients) increased their HbA1c by 1.2 per cent during the same timeframe (Lange, Campos, Urrutia, Bustamante, Alcayaga, Tellez, Pérez, Villarroel, Chamorro, O'Connor, and Piette, J, 2010). The one point difference in the increase of HbA1c, between the intervention and the control group, can predict a 25 percent to 30 percent risk reduction in the intervention group of micro-vascular complications such as retinopathy, neuropathy, renal failure, and amputations in a five to ten year time span (Resnick, 2008).

Also, the intervention group had a significantly higher appointment attendance in the CVP and a reduction in emergency room visits when compared with the control group. Studies show that better appointment attendance predicts better glycemic control in people with diabetes.

Another finding was the significant positive impact of the ATAS model on the self-efficacy in the intervention group versus control group. This is very important because self-efficacy is the best predictor of self-management (Sarkar, Fisher and Schillinger, 2006). There was also a significant increase in client satisfaction with overall care in CVP in the intervention group compared with the control group (Lange, 2007).

Although there were no significant differences identified with regard to reported self-care behaviors between the intervention group and the conventionally treated group, the stabilization of the HbA1c in the intervention group could be explained by two factors: 1) the permanent support of tele-health nurses to assure that patients received the required medication from the health center pharmacy and 2) systematic support to help them adhere to medical treatment.

A common theme identified by tele-care nurses was that patients were more honest and open with them than they were with primary care clinicians regarding their adherence to medication and other self-management behaviors. Patients mentioned that they often did not dare saying the truth to the clinicians (in person) about their difficulties in self-management because they were afraid that the health professionals would get angry.

Dissemination of the findings

To disseminate the findings and increase visibility of the importance of tele-care, we organized a yearly seminar with international experts in chronic disease management, decision support, and tele-care where we also presented the state

of advancement of our project. Participants in these seminars includes decision makers from the Ministry of Health, health services, communes, universities, and representatives from the Pan American Health Organization. Faculty members from schools of nursing and medicine, graduate students, clinicians, journalists, representatives from telephone companies and from pharmaceutical laboratories attend these seminars as well. We also facilitated personal interviews between our international experts and the health authorities, which has helped increase interest in our research. The research team also shared its learning and experience through several articles which were published in the main newspapers in Chile. The work and related research has also won the AVONI prize, one of the most prestigious prizes for innovation in Chile, due to its contribution to improve social well-being (Ministerio de Economie 2008).

Project 2: Replication of the ATAS model in Seven primary care centers

Before we had the final results of the ATAS project, the Ministry of Health financed a two-year tele-support implementation project in the seven primary care centers of the commune of Puente Alto. The question the Ministry of Health wanted to answer was if the healthcare providers would be able and willing to make the needed organizational changes to incorporate tele-support as a permanent component of the CVP without increasing resources.

Two thousand patients with type 2 diabetes enrolled in the CVP of these clinics, and benefitted from this model over the course of two years. During this project, we learned that health centers as well as the populations they served had frequent interruptions of their fixed phone services because the copper telephone lines were periodically stolen. Thus, the best way to contact the patients was through mobile phones. The urban population had cellphones with good connectivity that we could use for tele-counseling, even though this is three times more expensive than calling landlines. In the suburban area, the connection of cellphones was of low quality and therefore not appropriate for providing tele-care.

At that point, we had two inconveniences with the use of cellphones for providing tele-counseling: 1) the high cost per minute of traffic and 2) although there was always an appointment set up for tele-counseling, it was not unusual that the patients were not at home at that time but that they answered the phone while shopping, riding in the metro or in other inconvenient places for telephone counseling. After several months, the patients learned that tele-counseling was really helpful for them if they organized themselves to be in a quiet place where they were not interrupted, with their lab results and their tele-support guide. Often family caregivers participated in tele-counseling calls

to learn more how to provide self-management support to their significant other with diabetes.

Project 3: Technology transfer of the ATAS model to the commune of Puente Alto

Due to a positive evaluation from the primary healthcare teams as well as from the patients, in 2009 the Ministry of Health funded a one-year project to train a critical mass of health professionals from the healthcare centers in Puente Alto in tele-counseling with emphasis on patient-centered chronic disease management, motivational interviewing, behavior change, self-care, and decision support strategies. Until then, the tele-care service had been provided by trained nurses from our school of nursing who were physically located in the Entel Call Center. Nurses and nutritionists from the seven primary care centers participated in the training program, as presently the urban as well as the suburban areas of Puente Alto have adequate access to cellphones. After the completion of the training program, two of the health centers incorporated tele-counseling as part of their clinical practice. The rest have not, due to time constraints, lack of physical space in the center to provide the tele-counseling sessions, lack of telephone access in the health center, and no lines for cellphone calls. However, several centers are in the process to request equipment and time from their supervisors to be able to provide tele-care at least to the patients who are not well managed.

As the health authorities of Puente Alto are convinced of the benefits of tele-care, we hope that soon the healthcare centers in Puente Alto will be able to act as demonstration sites, where health teams from other communes can learn how to incorporate the ATAS model in the CVP to improve chronic care for patients with type 2 diabetes or other cardiovascular chronic conditions.

Project 4: Mobile phones: Tools to provide support for early diagnosis and self-management for people with type 2 diabetes

Although our tele-care model was well accepted by the healthcare providers as well as by the patients and their family caregivers, one of the criticisms of the decision makers at institutional and ministerial level was that this model could not be easily replicated because it was very expensive due to the need of well-trained nurses who are a very scarce resource in our country. By contrast, the nurses from the School of Nursing who did the tele-counseling during four years realized that a great part of the information and follow-up needs that the patients had could be solved through automated calls and text messages.

This combination of technology could have many benefits. Cellphones do not need copper lines that can be stolen. To receive calls on a cellphone can be done at no cost for the patient. Agreements can be made with telephone companies to reduce the cost of cellphone traffic. Text messages can be sent and read at any point of the day and they have no cost for the person who receives the messages. Messages can be re-read and shared with the family caregivers. This is very important because many patients, especially those who are sixty years and older, have family cellphones and are not used to reading text messages. We tried messages with patients of low socio-economic background and found that although many patients over sixty-five years of age told us that they did not know how to access a text message, they were very interested in learning (especially the women). They also stated that they could receive help from their children or grandchildren who were experts in the use of text messaging.

We also thought that automated calls could be used as reminders as well as to identify if a patient had a special need (for example a patient who is not taking his medicines because of secondary drug effects). In this case, an email could be sent to the particular healthcare center to ask for a personalized follow-up call. With the addition of text messages and automated calls, the professional counseling calls could be reduced significantly. In this way, the human resources and the budget needed for the implementation of such a model would be much lower than the ATAS model that we developed and implemented in Puente Alto between 2005 and 2009 and the chances of dissemination and sustainability higher. This adaptation of the ATAS model is the COSMOS Model (**M**odelo de **C**omunicación y **S**eguimiento **M**ovil en **S**alud).

The health practitioners from Puente Alto suggested focusing this project on patients with high blood glucose levels to facilitate the process of confirming the diabetes diagnosis in a timely manner. Once a person is diagnosed with type 2 diabetes, she or he will be enrolled in the CVP and will receive self-management support during a three-month period focusing especially on drug adherence, healthy eating, physical activity, and timely clinic visits for diabetes care follow up. The strategies used for self-management support will be telephone counseling, automated calls, text messages, and a tele-support guide for persons recently diagnosed with type 2 diabetes.

The COSMOS project started in August 2010 and was funded for thirteen months by the Mobile Citizen Program of the Inter American Development Bank. We hope that once the whole system is well developed and we have positive evaluations regarding the use of the system as well as its effect on HbA1c, other communes will be able to benefit from this model which will have an open-source software made freely available.

Moving toward national scale

Presently, there are no similar projects in Chile. The only way that a patient can establish contact with the primary care center is by going to the center to get an appointment, and most frequently there will be no appointment available for chronic disease management if she or he has not scheduled two or three months in advance. During the face-to-face encounters very few activities are carried out to activate, empower, and provide self-management support to the patients nor to train the family caregivers. There are several reasons for this, including lack of space, lack of trained health professionals who know how to engage patients with chronic illnesses to increase their perception of self-efficacy, and the fact that healthcare providers are supposed to see a patient with chronic conditions within twenty minutes.

With the technical support of the Pan American Health Organization and the Ministry of Health, our school of nursing recently offered a course, *Evidence Based Chronic Care: a Clinical and Administrative Challenge*. This is an adaptation of the Summer Course Evidence Based Chronic Illness Care offered by PAHO and University of Miami since 2008. Twenty primary healthcare teams (one hundred professionals) working in different areas of Chile were trained. These teams were selected by the Ministry of Health due to their commitment and motivation to improve the care provided to low-income patients with diabetes and hypertension. As a result of this course, each team is designing a project to improve chronic care for their patients, using as their conceptual framework the chronic care model (Wagner, Austin, Davis, Hindmarsh, Schaefer, and Bonomi, 2001). We hope that the primary care centers where these teams work can act as demonstration sites in the future.

Today, the Ministry of Health is working to define the Sanitary Objectives for the next decade (2011–2020). Due to this experience, there is consensus to incorporate eHealth as a component of the chronic care model for patients with diabetes and hypertension. The question is how to prioritize and use the available resources in order to be as efficient as possible without forgetting that ‘no size fits all’. Also, recently, the Ministry of Health has created the concept of a ‘Preventive AUGE Plan’, which gives us the great possibility to provide the COSMOS model to people with pre-diabetes, as a way to prevent type 2 diabetes.

As Chile has implemented in 2006 an excellent national telephone platform called ‘Salud Responde’ to provide advice for symptom management and how to navigate through the healthcare system, our team is working with health authorities to provide mHealth self-management support to patients with diabetes who are recently diagnosed. Salud Responde is mostly an inbound call center which mainly provides orientation to people with acute health episodes and help them

navigate through the healthcare network. Salud Responde has a triage system with administrative personnel, nurses, and midwives and also physicians twenty-four hours a day, seven days a week. However, to provide chronic care which focuses on behavior changes, special professional skills are needed and healthcare processes have to be standardized. An alliance between Salud Responde and our team at the School of Nursing would be a powerful strategy to provide mHealth self-management support to patients with diabetes, hypertension, and other prevalent chronic conditions.

In synthesis, I envision a national chronic care model that uses the '24/7' platform of Salud Responde to provide self-management support and symptom management recommendations to patients with select chronic diseases through inbound and outbound calls, text messages, and automated calls and that these technologies are well articulated with the care provided by the conventional, face-to-face healthcare network. The decision has to be taken by the Ministry of Health. It is our role to present the advantages of such an alliance.

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