ABSTRACT

A FEASIBILITY STUDY OF THE LIKELIHOOD OF USE OF THE SPANISH VERSION OF STANFORD’S CHRONIC DISEASE SELF-MANAGEMENT PROGRAM (CDSMP) BY THE OHIO HISPANIC POPULATION

by Jasleen Kaur Chahal

High prevalence of chronic conditions among Hispanics combined with the aging of the population reinforces the need for preventative programs within this community. Previous studies on Hispanic utilization of prevention programs have been predominantly conducted in the southwestern region of the United States. This research was conducted to determine if the Ohio Hispanic population would be likely to use the Spanish version of Stanford’s Chronic Disease Self-Management Program (CDSMP), and to identify factors associated with successful implementation. The study was divided into two phases (key informant interviews and distribution of surveys to potential clients) and was conducted at a total of four site locations, one in each major metropolitan area of Ohio. Results show that the major factors important for successful implementation of the CDSMP are: building a context of trust for the program, expanding and creating community collaborations, and providing financial and infrastructure support for organizations and their clients.
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DEDICATION

I dedicate this thesis to my family, friends, and the Department of Sociology and Gerontology for their continued support throughout my academic career.
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“My husband’s parents legally migrated from Mexico to the Northwestern Ohio region, where they first were pickers and then settled out. Pop worked in a lime plant and the family still picked and planted whenever that season rolled around... When my father-in-law had heart problems thirty years ago, there were no translators or Spanish speaking people on-staff at hospitals, but luckily my husband and his brothers were totally bilingual.

About five years ago my mother in law was diagnosed with congestive heart failure; slowly her abilities decreased. Soon my brother in law quit his job to become Mom’s fulltime caretaker. Neither of them knew much about how hospitals or social services worked, and there was hostility to outside agencies interfering with their lives.

Mother had difficulty with toileting issues and would get terrible sores that she didn’t mention to her son. When they went to a regular doctor’s visit, the doctor discovered the sores and mother was hospitalized... The doctor was Hispanic so we could communicate with him; however, I believe my brother in law was referred for elder abuse by the hospital staff. I think they were investigated by white people, non-Spanish speaking people, who had no understanding of the culture or what to expect... They were not getting any kind of services that I knew were out there somewhere.

Finally, Mom was put into the hospital and she went on strike. She took out her iv’s, shut her mouth as tight as she could when her meds were brought in, and said she wanted to go home to die... The doctor called in hospice and it was a godsend because someone checked on Mom a couple times a week. Sadly, none of the hospice workers spoke Spanish... From what I am telling you, you can see that, at least in our case, the treatment that my family received was shabby at best.”

This compelling story speaks to many critical issues in our healthcare system: fragmentation, difficulties with access to care, and poor fit between patient needs and care provided. Perhaps the most powerful message is the degree to which all of these problems are exacerbated by the cultural and language issues. This story highlights: the importance for consumers to gain knowledge about community services and health settings, the ability to utilize and trust in a “safe” health environment, the importance for providers to understand cultural differences, the need for more compassion, and the value of listening to those who are struggling to take care of a loved one. Most importantly, the description of what this family went through gives a small glimpse of a common experience for many individuals who are trying to get
appropriate care for their needs. This single narrative provides a reason to not only reevaluate how current services are offered and utilized, but an opportunity to find and create lasting solutions.

With age, the likelihood of being diagnosed with a chronic condition increases. The probability of having a particular chronic disease, such as diabetes, is heightened for various minority groups based on lifestyle and cultural differences. Hispanics, the largest ethnic minority, are one and a half times more likely to have diabetes and more severe related complications (National Hispanic Council on Aging (NHCOA): http://www.nhcoa.org/pdf). This ethnic group is expected to represent 25.4% of the aging population by 2030 (NHCOA: http://www.nhcoa.org/detailNews). Some chronic conditions and associated complications are preventable with simple lifestyle modifications. Therefore, with the increase in prevalence of chronic conditions, as well as the growth in older individuals and minority populations, there is a need for not only chronic disease self-management programs, but programs that have been designed to be culturally appropriate.

The English version of Stanford’s Chronic Disease Self-Management Program (CDSMP) is currently offered in various locations around the United States, including different sites within the state of Ohio. The CDSMP is an evidence-based program which provides participants with tools that enable them to manage their chronic condition. Self-management techniques are not only used to help reduce chronic disease related complications, but more importantly to improve quality of life through training that enhances self-efficacy and patient empowerment. In efforts to reach the growing Hispanic population, a Spanish version of the CDSMP was created by Stanford. The Spanish CDSMP, also known as Tomando Control de su Salud, has been structured in a manner that encourages a healthier lifestyle for the Hispanic population. As Ohio’s population becomes increasingly diverse, the Ohio Department of Aging (ODA) has chosen to prioritize the implementation of Tomando Control de su Salud. This feasibility study will provide ODA with information about venue preferences, referral methods, barriers to, and the likelihood of use among Hispanic Ohioans who meet CDSMP requirements regardless of age.
STATEMENT OF THE PROBLEM

The projected increase in Ohio’s general older population mirrors national trends, growing from 13.3% of the total population in 2000 to 20.4% in 2030 (The U.S. Census: [http://www.census.gov](http://www.census.gov)). As the population ages, there will be an even greater need for chronic disease self-management programs to reduce healthcare costs and improve health communication. The growth of Ohio’s Hispanic population, which has increased by 22.4% since 2000 and has essentially doubled since 1980, places a greater importance on reducing language and cultural barriers to reaching diverse populations (Ohio Department of Development: [http://www.development.ohio.gov](http://www.development.ohio.gov)). As of last year, Ohio’s Healthy U Chronic Disease Self-Management Program is offered in English to over 2,000 Ohioans, according to the Ohio Department of Aging (The Ohio Department of Aging (ODA): [www.goldenbuckeye.com](http://www.goldenbuckeye.com)). The state of Ohio expansion process of the CDSMP for Hispanic communities will encourage Latinos with chronic diseases to live healthier, more active lives. The Spanish CDSMP initiative will be applicable to most age groups, increasing the demand for self-management programs and placing urgency on effective implementation.

The Stanford Chronic Disease Self-Management Program (CDSMP), an evidence-based self-management program, has “demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activity limitations among individuals. [These individuals] also spent fewer days in the hospital and showed a trend towards fewer outpatient visits and hospitalization” (The Stanford Program: [www.patienteducation.stanford.edu](http://www.patienteducation.stanford.edu)). One of the key factors for the program is that one, if not both, of the session leaders suffer from a chronic illness themselves. Having an instructor who also has a chronic condition may add a sense of empathy and enhance the participants’ views of the validity of the program. The value of having session or lay leaders who also share a cultural heritage and a language with participants is also clear.

Similar to the CDSMP, Tomando Control de su Salud was established as means to aid individuals in managing their chronic conditions with a special emphasis on targeting Latinos. Even though Tomando Control de Su Salud is not a direct translation of the English CDSMP, it has been structured to address similar concerns related to living with a chronic disease while also accounting for differences in cultural practices and beliefs. For example, the program takes the
time to explain “the roles and functions of different types of health professionals in the United States, and how to access care” (Lorig, 1999, p.958). An evaluation of Tomando Control de su Salud stated that improvements resulting from participation in the program were still significant after a year; however, just after four months, “the participants, as compared with usual-care control subjects, demonstrated improved health status, health behavior, and self-efficacy, as well as fewer emergency room visits” (The Stanford Program: www.patienteducation.stanford.edu).

A major difference in Tomando Control de su Salud is that the workshops are completed by an instructor entirely in Spanish without the presence of a translator. One-fourth of Hispanic Ohioans are foreign born, and only 35% of these individuals reported that they spoke English “very well”; implementation of the Spanish CDSMP will reach the target population since all workshops are conducted in participants native language (Ohio Department of Development: http://www.development.ohio.gov). The ability to interact with Hispanic participants without a translator is an essential component in effective health communication, but is not commonly practiced within the healthcare field.

One of the goals of the Ohio Department of Aging is that the CDSMP will allow seniors to live independently within the community; in addition to the value of this goal for aging individuals and their families, it is assumed that health promotion measures will also reduce future healthcare costs related to chronic illnesses such as diabetes, arthritis and cardiovascular disease (ODA: www.goldenbuckeye.com). The state is committed to providing equitable access to services for people of all backgrounds. While Stanford has already developed the Spanish version of this program, there is a possibility that the Hispanic communities that reside within Ohio may different preferences and lifestyles than those who live in the Southwestern region of the United States where this version was developed and tested.

To this end, the proposed research will evaluate the feasibility of implementing the Spanish CDSMP or Tomando Control de su Salud in community locations in the major metropolitan areas of Ohio. By evaluating the feasibility of Ohio’s Spanish CDSMP, the research will help ODA to understand how the program should be implemented to benefit the Hispanic Ohioan community and their supporting healthcare networks. In particular, this project will consider the perceptions of key informants and possible participants about the program and the appropriateness of locations, such as community health clinics, that would have maximum outreach to, and connections with, the target population. This project will provide information
that will be useful in implementing Tomando Control de su Salud and could possibly strengthen relationships between the healthcare sector and Ohio’s Latino population.

**BACKGROUND**

**COST VERSUS CARE**

The acute medical model has dominated the healthcare system for many years. Chronic disease management and prevention strategies are often overlooked because some medical professionals do not recognize them as a priority for urgent health care (Glasgow et al., 2001). As a result, health care consumers have not typically been receiving information on how to prevent or manage chronic diseases.

“Although, until recently, primary prevention had not really hit the radar of most governments as a priority matter, and health/wellness promotion had been typically relegated to the individual’s responsibility, this new form of economic analysis has created an intensified appreciation for the hidden costs in failing to prevent predictable negative outcomes, such as those associated with badly managed chronic disease.” (Thorne, 2006, p.6S)

There is a recent attempt to shift the focus of the medical profession from the old acute model to a more innovative preventative model. Hospitals are coming to the realization that by providing such resources to patients and staff, they are saving money because of these “hidden costs.” (Lorig et al, 2005.) “Hidden costs” associated with repeated acute treatment of chronic disease complications has severely impacted the healthcare model at both a macro and micro level. Nationally healthcare spending has increased from 2.2 trillion dollars in 2007 to an expected 3.6 trillion dollars in 2014 and the growth in annual healthcare expenditure is expected to continually increase at a rate of 6.2% until 2018 (Galson, 2009).

Some researchers believe that transforming the current healthcare system “will be faster and far less expensive and confusing” by developing and implementing overall systematic changes to healthcare delivery (Glasgow et al., 2001, p. 580). Simple modifications in medical training, communication between specialties, and incentives to promote prevention versus acute symptom treatment have all been suggestions for adapting the original Chronic Care Model (CCM) by Wagner et al.(1999) in hopes creating a more collaborative approach to medical treatment along the continuum of care (Glasgow et al, 2001). The expanded CCM incorporates not only the role of the patient and physician in caring for chronic conditions, but the importance of support from community resources and public policy.
Figure 1: Expanded Chronic Care Model (CCM)

(Barr et al., 2003, p. 77; http://www.improvingchroniccare.org/index.php)

The Ohio healthcare system for chronic conditions is based on the dominant model of acute care, but is also shifting to person-centered, preventive, and holistic care. A goal of ODA is to help individuals manage their chronic conditions so they may find steady employment in the public or private sectors. (The Stanford Program: http://patienteducation.stanford.edu; ODA: www.goldenbuckeye.com). The Ohio Department Aging continues supporting their objective by providing the English version of the Chronic Disease Self-Management Program in various locations throughout the state. The 2,000 Ohioans currently offered the CDSMP tend to have lower incomes and are over the age of sixty-five. Many of these people are currently working in government subsidized positions. Presumably, those people who have lower incomes will need the assistance of Medicaid sooner than those with higher earnings. This is especially problematic if those who are of lower socioeconomic status have one or more chronic illnesses and have little information on how to care for their condition. By providing a program which educates people about chronic care, there is the good possibility that the state will save money in the long term.

Even in cases where the program experienced unexpected costs, the workshop was so successful that it was deemed “cost-effective” (Lorig et al, 2005). Research comparing healthcare costs at baseline to six months after participating in the CDSMP program, has shown that the estimated healthcare savings would be about $750 per participant for a six month period,
after accounting for only the number of hospital overnight stays and programs costs; savings were estimated to be around ten times the cost for program involvement (Lorig et al, 1999). A similar study that used more conservative estimates of healthcare costs, including both outpatient visits and overnight hospital stays, found the CDSMP program still saved an estimated $520 for each participant every two years (Lorig et al., 2001).

Due to growing healthcare costs, it is likely that the projected amount of saving has increased significantly. If the CDSMP is implemented over multiple years, the community will see a greater benefit which will outweigh the costs Ohio will likely face. One such benefit will be long term cost savings, which could mean that the state will have to spend money in the beginning, but will see an improvement in participant health and life satisfaction, which will result in fewer doctor visits and hospitalizations (The Stanford Program: http://patienteducation.stanford.edu). Health disparities continue to be a challenge for this nation. With a shift from focusing on treating acute illnesses to managing chronic diseases, a focus on prevention and patient self-management has become necessary to reduce complications associated with chronic conditions. Studies by the Center for Disease Control have shown that out of the 2,426,264 deaths nationwide in 2006, there were 631,636 (26%) deaths solely from some form of cardiovascular disease, 72,449 (3.0%) deaths from diabetes, 137,119 (5.7%) deaths from stroke, 124,583 (5.1%) deaths from chronic lower respiratory disease, and 559,888 (23%) deaths from having some form of cancer (Heron, M., 2010, p. 7). Although it may seem as if diabetes represented a slightly smaller percentage of deaths, it was ranked as the sixth highest leading cause of death and is essentially fifth when only looking at the top five preventable chronic diseases related to causes of deaths; thus excluding accidents as the original fifth ranked leading cause of death. In that same year, Hispanics represented 133,004 (5.5%) of the total deaths in the U.S., in which 28,921 (21.7%) deaths resulted from cardiovascular disease, 6,287 (4.7%) from diabetes, 7,005 (5.3%) from stroke, 3,310 (2.5%) from chronic lower respiratory disease, and 26,633 (20%) from malignant tumors (Heron, M., 2010, p. 15). It should also be noted that these numbers only account for deaths and that the values would unimaginably increase if they were adjusted to represent the number of deaths, hospitalizations or physicians visits, and people associated with a chronic condition.
Living with a chronic condition is something that is applicable to all age groups; nonetheless it is especially relevant for older generations. In 2009 it was estimated that 60% of the causes of death for individuals sixty-five and older were due chronic conditions and that 80% of older Americans were currently living with at least one chronic condition (Galson, 2009). Chronic diseases and related complications have become a major factor in both healthcare cost and utilization. Healthcare professionals have realized the importance of shifting from the current acute care model to a more preventative healthcare model as a means to reduce both case loads as well as unnecessary healthcare costs. In efforts to reduce healthcare costs and improve quality of life for all individuals living with a chronic illness, a greater emphasis has been placed on developing prevention programs that help to manage chronic diseases.

To maintain the effectiveness of the vital components found in prevention programs, such as self-management and self-efficacy, it is of utmost importance that the programs are culturally appropriate, and therefore, tailored to the specific values and practices found within a particular culture; as long as the tailored programs maintain the fidelity of the original program. For example, diabetes is a prevalent chronic disease found in Latinos, and it is one of the easiest chronic diseases to manage, which can reduce future preventable complications such as stroke and heart disease. Among individuals with diabetes, two in five have poor cholesterol control, one in three has poor blood pressure control, and one in five has inadequate blood glucose management (The Center for Disease Control (CDC) Website: http://www.cdc.gov). Such simple measures as the re-evaluation of diet and exercise can help to prevent the onset and progression of such chronic illness as cardiovascular disease and diabetes, while also helping to reduce related healthcare cost and utilization. In Ohio alone over 64 %, or 68,504, of the deaths in 2004 were attributed to the five major chronic diseases, with almost 30% associated with cardiovascular disease and diabetes (CDC: http://www.cdc.gov, Leading Cause of Death by state 2006, 2009, p. 19). With the growing Hispanic population, both nationwide and in the state of Ohio, determining simple and effective ways of chronic disease management has become an important concern for reasons of both cost and quality of life.

**Hispanic Healthcare Utilization and Barriers**

Healthcare utilization can be affected by several factors such as access to care, particular health needs, and personal preferences. Reasons that Hispanics resist use of healthcare services can vary from having a lack of trust in the healthcare system, lack of insurance, financial issues,
or cultural beliefs and practices pertaining to appropriate methods of care and the body’s ability to heal itself. A study conducted in 1990 found that Mexican Americans reported barriers in healthcare that were less related to linguistic and cultural barriers and much more related to cost of care, lack of transportation, need for childcare during healthcare visits, long waits in physician offices, problematic office or operational hours, and loss of income due to obtaining care while missing work (Estrada et al.). These finding should be considered when addressing concerns pertaining to lack of healthcare utilization due to accessibility and availability. A lack of cultural understanding could hinder access to healthcare if an individual does not understand the appropriate medical treatments offered to patients or even the patient’s responsibility in care that comprise the American medical culture. Therefore, it is important to note that between patient and healthcare provider, racial similarity and linguistic and cultural competency are imperative factors to consider in regards to offering medical treatments, patient adherence and patient satisfaction related to the quality of healthcare (Liburd et al., 2006; Estrada et al., 1990).

Even with such barriers to healthcare utilization, national averages for 2005-2006 show that Hispanics/Latinos and Mexicans accounted for 35.1% and 39.3% of overall healthcare use, suggesting that Hispanics still have a significant impact on the healthcare system (CDC website: Health, United States 2008: http://www.cdc.gov). Healthcare utilization by Hispanics in the Greater Cincinnati region tends to vary from national averages. In 2005, 79.7% of Latinos in greater Cincinnati, compared to only 58.6% nationwide, felt that they had a primary facility to go to if they needed health advice or care (2005 Greater Cincinnati Hispanic/Latino Health Survey: http://www.healthfoundation.org).

In regards to challenges when attempting to navigate the healthcare system, in Greater Cincinnati alone, 85.6% of participants in the Hispanic/Latino survey stated that they had difficulties when trying to obtain care (The Greater Cincinnati Health Foundation: http://www.healthfoundation.org). Such obstacles can vary from language and cultural barriers to transportation and lack of healthcare coverage. When individuals were asked to choose one obstacle that hindered their ability to access healthcare, the following rankings were noted: “own ability to speak English (21.4%), high cost of care (12.1%), long wait times for an appointment (11.4%), no health insurance (10.5%), and the doctor not speaking their language (6.0%)” (2005 Greater Cincinnati Hispanic/Latino Health Survey: http://www.healthfoundation.org). In order to improve quality of care for Hispanics, it is essential to minimize the previously mentioned
problems; which result in increased emergency healthcare costs and limitations for accessing appropriate healthcare.

There are also differences between national averages and those for the Greater Cincinnati area regarding the type of healthcare utilized. One study conducted by Hong et al. (2007) stated that “Hispanics were most likely to have chosen the ED [emergency department] because they believed they would receive better quality care in the ED than elsewhere”. Beliefs pertaining to quality of care remained a consistent concern in the Greater Cincinnati sample with 55.6% of Hispanics believing that they received lower quality of care. Nonetheless, when participants were asked where they went for care when they were sick, 51.6% of participants reported using a community health center/clinic versus 27.1% utilizing an emergency department (The Greater Cincinnati Health Foundation: http://www.healthfoundation.org).

It is likely that variations in national data, in comparison to Greater Cincinnati, are a result of a preference for a particular geographical region due to the existence of an already established similar Hispanic subgroup in that location. Such regional differences in healthcare utilization can be expected since there are a large number of diverse subgroups, or individuals from different cultural yet Hispanic backgrounds, that collectively make up the American Hispanic community. The diversity within the Hispanic population makes it much more important to analyze barriers and healthcare concerns at a regional versus national level in order to improve overall healthcare outcomes by establishing lasting changes.

**History of Health Promotion**

One possible solution to minimizing barriers associated with the number of hospitalizations resulting from complications associated with chronic conditions, cost for healthcare, healthcare utilization, and access among minorities is by focusing on a more preventative approach similar to Stanford’s Chronic Disease Self-Management Program. The CDSMP is a health program that represents the key ideas of improving care and reducing costs that have been associated with health promotion and prevention; which originated from social cognitive theory. Social cognitive theory focuses on establishing goals and perceived self-efficacy, providing education and resources, and evaluating outcomes and barriers that are associated with the use and cost of services (Bandura, 2004).

It wasn’t until around the 1990s when the CDSMP was seen as an evidence based health promotion program. Bronson et al. stated that evidence based health promotion is considered to
be “the process of planning, implementing, and evaluating programs adapted from tested models or interventions in order to address health issues in an ecological context” (as cited in Whitelaw, N., 2007). In 2002 the Administration on Aging and the CDC began The Aging States Project which emphasized the importance of health promotion by focusing on wellness and prevention and eventually incorporated evidence based promotion programs, such as the CDSMP, in 2004 (www.cdc.gov/aging/states). The Aging States Project provided awareness to the increasing number of chronic conditions that Americans face each year, but also to express a personal responsibility for caring for a condition while also helping to minimize future concerns related to paying for the increasing cost of healthcare associated with caring for chronic conditions.

**SELF-MANAGEMENT**

An important component of health promotion is the concept of self-management. A self-management or self-care movement began around the Vietnam War at which point younger Americans started to challenge authority (Shoor & Lorig, 2002). Throughout the years various researchers have proposed slightly different definitions of self-management, however, Lowell Levin et al. claimed that self-care was “a process whereby a lay person can function effectively on his own behalf in health promotion, and prevention and in disease detection and treatment at the level of primary resource in the health care system” (Shoor & Lorig, 2002, pp. II-41). By this definition, self-management of one’s chronic illness can be seen as an everyday event that requires diligence, an understanding of the disease, and an ability to integrate the conditions that stem from a particular disease into everyday routines (i.e., taking medication regularly, having monthly testing, monitoring your diet and nutrition, appropriate exercise, being comfortable with communicating about problems related to the illness, utilizing healthcare services as needed) (The Stanford Program: [http://patienteducation.stanford.edu](http://patienteducation.stanford.edu)). Programs focusing on self-management education emphasize specific tasks that are associated with developing much needed problem-solving skills, such as identifying and solving problems by creating a general healthcare plan that incorporates the need to set and prioritize goals (Glasgow et al, 2001).

Kate Lorig and Hal Holman (2003) further classified the tasks into three categories associated with “medical management, role management, and emotional management”, and later identified six essential self-management skills: “problem solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring”, that should be emphasized during the program. The idea of self-management might be difficult
to understand especially if a participant of the chronic disease program has been raised with different cultural values. In the Latino population, studies have shown that individuals do not feel as if lifestyle changes are a personal responsibility and often believe that conditions can be managed with only the prolonged use of medication (Becker et al., 1998).

The natural progression of a chronic disease can leave a person feeling powerless and dependent on others when it comes to caring for their own health. However, for Hispanics this sense of dependence or interdependence has been shown to be extremely valued due to the cultural expectation that “the family is responsible for managing the older person’s affairs, including the illness” (Becker et al, 1998, p. 177). In minorities that depend heavily upon extended familial household dynamics and related support systems, such as within the Hispanic community, it is important to emphasize that self-management not only benefits the individual, but also helps their loved ones deal with both the emotional and physical demands associated with caring for a chronic condition (Glasgow et al., 2001). By participating in an effective evidence-based program individuals living in similar conditions can feel empowered to manage their chronic disease in a manner that reduces complications related to their disease while also helping their family cope with transitions associated with the progression of their condition.

A sense of empowerment, as a result of participating in a self-management program, also helps to redefine relationship dynamics between patients and healthcare providers. In the acute care model “health professionals are knowledgeable, and they apply that knowledge to a passive patient”, however, for individuals with a chronic condition it is important that “the patient should be an active partner, applying his or her knowledge continuously to the care process” in order for patients to make lasting healthy lifestyle transition (Holman & Lorig, 2004, p. 240) The change in patient provider relationships creates a new chronic disease model which continues to support the traditional role of patient education through information and training, while incorporating necessary analytical skills that help patients manage their condition and improve their overall quality of life (Bodenheimer et al., 2002).

**The Stanford Program**

The first chronic disease self-management program was created in 1976 by a physician at Stanford university, Hal Holman, who later expanded his idea of self-management to various versions of the CDSMP, group physician visits, and even virtual support systems in which patients and physicians interact via an email discussion (Shoor & Lorig, 2002). The variations of
the Stanford CDSMP, in comparison to other evidence-based programs, are at a higher standard of evidenced-based care management programs, since both the Spanish and English versions are being implemented nationwide. The functions of the courses are built upon the goal of self-management of chronic conditions by enhancing self efficacy.

In the six week workshop, two trained leaders facilitate the program, one or both of whom are non-healthcare professionals who have a chronic disease themselves. From a study done by Lorig and Holman, “we have found that peers, when well trained and given a detailed protocol, teach at least as well as health professionals and possibly better,” (Lorig et al, 2003). The sessions are not limited to people of one specific chronic condition, allowing the training to be expanded by the presence of multiple disease perspectives (such as pain management, arthritis, diabetes, and/or cardiovascular). (The Stanford Program: http://patienteducation.stanford.edu; Lorig et al, 2003.)

Each week both the CDSMP and the Spanish version, Tomando Control de su Salud, cover a different subject. The first session is dedicated to techniques in dealing with problems associated with both physical and psychological factors of chronic illness (i.e., frustration, fatigue, pain, and isolation). The program next outlines appropriate exercises for maintaining and improving strength, flexibility, and endurance. Appropriate use of medications is addressed in the third week. The fourth session stresses the importance of communicating effectively with family, friends, and healthcare professionals. Week five deals with nutrition and healthy eating. The program concludes with teaching participants how to evaluate new treatments. Throughout the course there are measures to ensure success through the entire program:

“Each week, each participant is asked to make a specific action plan for something he or she wants to do in the next week. It must be very specific—not that one will exercise but rather that one will walk two blocks on Monday and Thursday before lunch. After making the plan, we ask each individual about his or her certainty that he or she will complete the plan on a 10-point scale from 10 (very sure) to 1 (not at all sure). (Please note that this is a self-efficacy question.) If the answer is less than 7, we then use problem-solving techniques to adapt or change the plan. The following week, each individual reports on his or her success. If problems arose, then problem solving is used again.” (Lorig et al, 2003, p. 4.)

The program uses materials, written and video, which have been developed specifically for the target regional population. All of these materials have been specially developed for the CDSMP and materials for Tomando Control de su Salud are offered in Spanish. These programs aid
individuals by allowing them to gain the appropriate tools for self-managing their conditions as well as allowing them to remain active in the community. (Lorig et al, 2003.) For additional versions of the CDSMP, the materials and tools are not simply translated into a different language, but are recreated to assure that both cultural and linguistic differences have been incorporated.

**SELF-EFFICACY**

A major component involved with self-management programs and empowering participants is self-efficacy. Self-efficacy, or having the confidence to make needed transformations in order to achieve an objective, originates from social cognitive theory and is extremely important in motivating individuals to initiate and uphold lifestyle changes (Bodenheimer, et al. 2002; Bandura, 2004). Key aspects associated with social cognitive theory have been widely used when discussing health promotion strategies and practices. Health promotion programs have been assessed based on the theory’s key values: perceiving self-efficacy, establishing goals, evaluating outcomes and barriers associated with cost effectiveness and desired transformations, and providing education pertaining to risks and benefits associated with particular healthcare treatments (Bandura, 2004).

The purpose of both the CDSMP and Tomando Control de su Salud is to help those who have a chronic illness learn techniques that will enable them to make better choices regarding their personal health. Each program covers pain management, stress, fatigue, exercise, appropriate medication usage, effective communication with health providers as well as family and friends, and issues associated with the feeling of isolation. Recent literature has supported the importance of self-efficacy, “the capacity to undertake behavior or behaviors that may lead to desired outcomes such as improved health,” (Marks et al, 2005). Self-efficacy has been identified as one of the major methods for improving health status for those in a self-management program. Bandura stated that, “the enhancement of self-efficacy must be considered a key program component,” (as cited in Lorig et al, 2003). To this end, Ohio’s implementation of the Spanish CDSMP will include a lay session leader who will be able to relate to the participants by minimizing language barriers, as well as through personal experience and included program components.

The Stanford English and Spanish CDSMP model incorporates such components as discussion time, open ended questions, and brainstorming sessions, in order to provide valuable
empowerment tools for participants. In this program self-efficacy allows the participants to better adhere to the self-management practices which are recommended during the program, and gives the individual a perceived control of their condition or illness. (National Council on Aging (NCA): https://www.ncoa.org, 2006; Lorig et al, 2003.). Previous research pertaining to the Stanford chronic disease program has shown the importance of gaining a sense of confidence or self-efficacy in relation to improvements in healthcare utilization and overall health. Lorig and her colleagues (2003) found that Hispanic individuals participating in the Spanish CDSMP model four months prior showed significant improvements in regards to self-efficacy, health status and behavior which resulted in a significant decrease in emergency department visits; such results remained consistent after one year from the time of program participation.

Although the CDSMP has been evaluated within the Hispanic community, a majority of these studies have been conducted in the southwestern region of the U.S. As previously noted the Hispanic community of Ohio varies greatly from both the southwestern region and national statistics that tend to be used to represent Hispanics in general. Therefore, prior to implementing the Spanish version of Stanford’s CDSMP, it is extremely important to have a greater understanding of the surrounding Hispanic community by obtaining more information about potential barriers to future implementation, as well as the likelihood of use of the program.

In order to provide information about successful implementation of the Hispanic CDSMP, this study addressed the following specific questions: if the Ohio Hispanic community in general would be likely to use a chronic disease prevention program, who within the Hispanic community would be most likely to use the program, what are the best location, time, and place to both advertise and implement the program, how Hispanics in Ohio currently utilize healthcare services, what types of barriers do they experience when attempting to obtain healthcare, and finally who and where do they trust to obtain information about health services.

**Methodology**

The overarching goal of this study was to identify factors that would improve the likelihood of successfully implementing Ohio’s Spanish CDSMP in different community settings. To achieve this goal, information was gathered from two groups: key informants who are involved in organizations that serve the Hispanic population in four metropolitan areas of the state, and a group that was largely the same as the target population for the CDSMP (18 or above, and previously diagnosed with one or more chronic illnesses). The only additional
requirement for this study was that individuals should be of Hispanic or Latino descent. Key informants were interviewed via telephone, and potential program participants were given a paper survey. All respondents were associated with one of five organizations, selected based on the following criteria: location in a major city in Ohio (and therefore likely to have a relatively large Hispanic population), and currently providing health related services or advice to local Hispanics. Participant sites were chosen in Cincinnati, Columbus, Cleveland, and Toledo, based on population, location, and services. The five site locations collectively consisted of two community centers, two religious affiliated organizations, and one health clinic. Toledo had two sites chosen due to the increased Hispanic population as well as a unique facility that was the only center to offer health activities tailored for seniors. Further details about obtaining site recruitment are provided later.

Unfortunately, at the last minute, two of the original sites (one in Toledo and one in Cleveland) dropped out of the study. The Toledo site offered health services to all ages and had agreed to participate, but was removed from the study due to the inability to reach the key informant after over ten attempts via phone and email. The original Cleveland site voluntarily left the study, explaining that they did not have the staff resources to participate. Leaving the study was primarily due to an organizational change; the original key informant no longer being an employee at the site.

Since there was still a representative site in Toledo greater emphasis was placed on finding an additional site in Cleveland in order to assure that each major city had at least one participating location. An alternate Cleveland site agreed, resulting in a total of four participating sites: one religious affiliated resource center in the Cincinnati area, one health clinic in the Columbus area, one resource/health clinic in the Cleveland area, and one community resource senior center in the Toledo area.

**Instrument Development**

There were two instruments used in the study, the key informant interview guide (Appendix I) and the participant survey materials (Appendix II & III). The key informant interview guide was created by writing questions to gain knowledge about each site location, informants’ opinions about best methods to conduct survey research among the Hispanic population of that city, and their opinions about possible challenges resulting from offering the Hispanic CDSMP. Once the interview guide was presented to various stakeholders, such as staff
at ODA and colleagues at Miami University, changes were made to streamline some questions and to add others that were of particular interest. The final version of the key informant guide was fifteen questions used to obtain a better understanding of each organization and the Hispanic clients that they serve.

The initial draft of the participant survey was forty questions on a variety of topics related to both the CDSMP and healthcare. Some of the questions on the survey came from existing questionnaires that were created by Stanford and shared with the public via the CDSMP website (The Stanford Program: http://patienteducation.stanford.edu). Based on suggestions from stakeholders and key informants, the questionnaire was revised. Changes to the questionnaire provided a clearer focus for the study. The questionnaire was reduced to only incorporate thirty of the original forty questions, which were then placed into the following categories: respondent screening (for eligibility for the CDSMP), program interest, general health, and demographic information. An information sheet for participants to read prior to completing the survey was developed in order to provide a clearer definition of what the study considers to be a chronic condition and a more detailed description of the CDSMP program. When questions related to either a chronic condition or the CDSMP program, notes were placed next to the question in order to help participants remember to refer back to the original information page.

All materials, the consent form, information sheet, and survey were translated into Spanish and later verified. The Spanish materials were translated by a native Spanish speaker prior to the pilot study and checked by the principal investigator, who is fluent in Spanish; the refined instrument was also translated. Both English and Spanish versions were offered at each site in order to accommodate the participants’ preference. If neither Spanish nor English were the primary language of participants, whose predominant language was a regional dialect originating from rural areas, key informants were asked to help these individuals during the survey process.

The materials for the study, including the informed consent, were provided and tested in both English and Spanish. Cognitive interviews were conducted in a site in Cincinnati that met the previously mentioned criteria for choosing participant locations. The site was selected for pilot test of the instrument because of its proximity as well as a larger number of possible participant sites within the city. Cognitive interviewees were representatives of the target population or worked closely with representatives of the study population. Since key informants
had provided extensive initial feedback regarding the materials, only five cognitive interviews were conducted. Volunteers were chosen for the pilot study based on suggestion from a staff member at the site.

Participants were asked to read through the survey material as if they were actually taking the survey. Individuals who volunteered to participate in cognitive interviews did not actually take the surveys. While reading through the participant materials, volunteers did provide feedback about what they felt each question asked them; they also asked questions about the intent of some questions, and expressed their need for further clarification during any part of the survey process. Suggestions were also made in regards to rewording various parts of the participant materials in order to assure all materials were at an appropriate cultural and literacy level. During the cognitive interviews, participants were asked to read all preliminary material for taking the survey and then to read the survey as if they were taking it. During the interview process any pauses, questions, need for clarification, as well as overall understanding of the survey materials was noted. Notes during cognitive interviews were written manually and summarized at the end of each interview in order to assure the comments were recorded correctly. All suggestions from the interviews were used to improve the quality of the existing survey instruments prior to distributing the final version to each participating study location. In order to ensure that the sample size of the study would not be affected by cognitive interview participants, the pilot study location was excluded as a possible site for the data collection phase of the study.

**DATA COLLECTION: KEY INFORMANT INTERVIEWS**

The first phase of the study involved conducting key informant interviews. Key informants holding leadership positions in organizations serving the Hispanic population were interviewed in order to obtain a better understanding of the barriers, benefits, and effective strategies that their organizations had experienced when providing health related services and advice for local Hispanics. Key informants identified within each site were expected to provide valuable information regarding working directly with their Hispanic clients and to identify possible barriers that could be associated with the participant materials or the data collection. The key informants were also essential to the data collection process for survey participants; they were, in effect, research partners who were called upon to direct participants to the survey, which was prominently displayed on a desk in the public area of the agency or handed to participants.
by selected staff members. The key informants also agreed to answer any questions that may arise during data collection phase. All key informants were directors or leaders within their organization and had significant and current experience working with the Hispanic population.

Each key informant was initially contacted over the phone and then later by email. Informants were asked for verbal agreement to participate in the study and later provide an emailed or written signed consent form representing both their participation as a member of that organization and the overall organizations consent as a participant site. When possible, the key informant received an emailed version of the interview questions as well as the participant survey materials. The Cleveland site did not receive an emailed version of the participant survey materials because, as noted earlier, the original site voluntarily left the study resulting in the need to find an alternate location. Due to the short notice, the key informant at another Cleveland site graciously agreed to conduct the key informant interview in person on the same day that the participant survey materials would be delivered to the site. This adaptation to both conducting the key informant interview and asking a slightly different question did not seem to hinder the interview.

The other three interviews were conducted over the phone. Interviews averaged around thirty minutes, and notes were taken during the interviews. During the interviews, informants were asked for their professional insight and opinions about the best methods of recruiting participants, current services being offered, potential barriers to research and participation at the particular site location, as well as personal beliefs on the success of future implementation of the Spanish CDSMP in Ohio. All of the key informants commented on the value that they each placed on being able to offer the CDSMP program and what they felt was necessary in order to implement the program at their site or within their city. An opportunity was also provided for informants to offer important feedback regarding the survey materials and methods to collect data at that particular location as well as any other questions or comments related to the research project. The recorded comments from the interview were typed up within forty-eight hours and emailed back to key informants in order to verify the accuracy of the recorded responses. At this point, key informants were asked to read over the document to make sure there were no errors. If no email was received, it was assumed that all comments presented during the interview were recorded correctly.
Initial issues began to emerge immediately upon completing the first interview; however, final analysis was conducted upon completing all interviews. The interviews were analyzed using open coding in that as soon as all of the key informant interviews were completed the notes from each interview were analyzed by comparing the responses for each question to look for emerging overarching issues. Upon identifying underlying issues, each interview was reread and responses were categorized under the appropriate corresponding issue.

**DATA COLLECTION: PARTICIPANT SURVEYS**

The second phase of the study involved collecting data from surveys of potential CDSMP participants. This phase began after suggestions and comments were taken from the cognitive interviews to create a final version of the participant survey materials. After the survey instrument was refined and finalized, each location received 30 total participant material packets, 15 in English and 15 in Spanish. Key informants were asked to contact the principle investigator if they had any issues with the materials or needed more participant materials in a particular language. The surveys were hand delivered to each site in order to obtain a better understanding of the community and surroundings as well as the actual location in which the surveys would be placed. The site visit also made it easier to make suggestions during the study in regards to where to place surveys and advertisements or better ways to identify participants and hand out surveys.

Participants for the second phase of the study were chosen based on convenience sampling methods. Individuals were asked to voluntarily participate by completing a secure paper-based survey with an attached self-addressed stamped envelope for returning the survey. Surveys were provided at particular locations within each site based on advice provided by that sites key informant. Key informants and staff within each participating facility guided individuals who would likely be in the target population for the CDSMP program to take the surveys; these individuals were recruited when receiving information, resources, or activities related to health and preventative care. Site liaisons were also asked to provide assistance with the survey by directing participants about how to return the surveys, answering questions, as well as communicating with the researcher about any problems or needs regarding the survey instruments.

In efforts to increase the response rate, participation in the study was completely anonymous; there were no identifiers on any of the participant survey materials. Information regarding which site each survey came from and the order in which it was received was obtained
by assigning an automatic number code to all surveys. Each survey was coded with a number which referenced the participating site. Upon receiving completed surveys, an additional number was added based on the order of receiving the survey from that particular site. One week after delivering the participant materials to each site, follow up phone calls were made to each key informant. The calls provided an opportunity to check on any issues upon receiving returned surveys as well as to see if there were any questions about the study or a need for further survey materials. A couple of days after the return deadline noted on the surveys, an additional phone call was made to each key informant in order to obtain their general reaction and each Hispanic community’s reaction to the surveys. At this time each key informant was also asked to estimate the number of surveys that they had given out. This was done to help anticipate the number of returned surveys as well as to determine the next steps of the study based on overall reactions.

RESULTS

KEY INFORMANT INTERVIEWS

The key informants provided valuable insight into their organization, and also helped to elaborate on ways to work with their clients in relationship to the implementation of CDSMP for Ohio’s Hispanic population. The interviews emphasized diverse aspects of each organization, making clear how each site was a unique and valuable resource for their local Hispanic community. Although there were a range of similarities and differences within the interview responses, each key informant did express their personal opinion as to the importance of expanding preventative health services for minorities, and more specifically for Hispanics. The interviews focused on a description of the agency’s services, views about preventative health programming, and ideas about the value of, barriers to, and suggestions for implementation of the CDSMP. In-depth analysis of the key informant responses revealed five general issues that emerged from the interview questions. In keeping with the questions that guided the interview, each key informant discussed: 1) the various services that their organization had offered over the years, 2) their hope to expand current services, 3) their goal of creating new or improving current community collaborations, 4) the barriers, both for the administration and clients, associated with implementing a chronic disease program, and 5) suggestions for supporting the administration and working with their Hispanic clients.
All of the sites offered some form of a health service to the general public; however, each service was also tailored to include the growing Hispanic population. For example, the Columbus site offered interpreters five times a week, and even had the interpreters present at their diabetes education services that are offered once or twice a month. The types of health services ranged from education-related services and screenings at health fairs to nutritional programs and case manager-related services such as helping with healthcare access, obtaining insurance, and counseling. The Columbus site offers summer farmers markets, and the sites in Cleveland and Toledo offer food pantry days. The Toledo site offers a unique nutritional daily lunch in which their Hispanic clients represent about 75% of the total meals provided each day.

Most of the health related screenings were simple measures such as checking glucose and blood pressure. Similar to the types of screening, educational services that were offered were predominately related to diabetes and cardiovascular disease. A unique aspect of the Cincinnati site is that they help their clients find a healthcare provider, follow up with each client in order to make sure they kept their initial appointment, and encourage follow-up appointments as needed. The Cleveland agency was the only site to currently not offer any of the previously mentioned screenings or educational services. However, this organization did offer preventive services in the past. The key informant explained that the site was forced to reconsider the services they would continue to offer due to budgetary concerns and the presence of existing services at other local non-profit organizations.

Each site was looking to expand services, and all respondents thought it was important to offer a program such as the CDSMP for Hispanics. Although all of the sites had between two and three Spanish speaking staff members, the desire to offer the program at that particular site varied among the regions. The Toledo and Cincinnati sites were hoping to have staff members trained to lead the CDSMP program so that they could offer the program at their location. However, the Cleveland and Columbus sites emphasized expanding the services they offered because they were unsure about their ability to offer the program due to financial and staffing constraints. The latter two sites seemed to have a goal of creating more partnerships with other community organizations, while also making sure not to overlap the services offered within the surrounding community. All of the sites were interested in and valued working with and supporting community collaborations; they use this model for some of the services they currently offer. The importance of community collaborations was underscored when all four of the sites
claimed that they would be willing to direct their own clients to another organization if the service needed by their client was offered at that location; they all agreed that this strategy is much preferable to not having the service offered in the area at all.

Responding to questions about expanding services and considering future CDSMP implementation, each key informant mentioned possible barriers that could be encountered (Table 1). Such barriers ranged from key informants acknowledging the importance of wanting to know what their clients need, even though they do not have access or enough resources to obtain the information, to administrative concerns about lack of funding, limited staffing, and possible costs of the program.

**Table 1: Program Implementation Barriers**

<table>
<thead>
<tr>
<th>Administrative</th>
<th>Client</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of staffing</td>
<td>Payment for program</td>
</tr>
<tr>
<td>Cost/ Funding for program, associated staff, and training</td>
<td>Proper advertising</td>
</tr>
<tr>
<td>Need for incentives for training or leading program</td>
<td>Time and day program is offered.</td>
</tr>
<tr>
<td>Need for incentives to obtain participant interest</td>
<td>Lack of incentives</td>
</tr>
<tr>
<td>Not enhancing community collaborations</td>
<td>Trust in location</td>
</tr>
<tr>
<td>Possible overlapping of community services</td>
<td>Trust in program facilitator</td>
</tr>
<tr>
<td></td>
<td>Transportation to program</td>
</tr>
<tr>
<td></td>
<td>Proximity of program location to participants</td>
</tr>
<tr>
<td></td>
<td>Literacy level of all program materials</td>
</tr>
</tbody>
</table>

Even though there was great optimism and hope for offering the program, all four of the sites had several questions regarding administrative and training resources. Each site asked about funding for training of staff members and costs associated with providing the program such as providing educational materials, food, and possibly even childcare for clients. Although the CDSMP does not require that lay leaders be staff members from an organization that is offering the CDSMP, the key informants thought that it was a requirement and later saw it as a benefit to help obtain participants using an existing trusted relationship. There were also concerns as to the availability of pay incentives for staff members that would be trained as lay leaders in addition to their current roles as employees of the organization. The Cleveland and Columbus sites were concerned about the fact that they may not have staff members who would be bilingual, have a chronic condition, and have the time to provide an additional program as a
lay leader. The Columbus site said that it is possible that one of their interpreters may be interested; however, the Cleveland site was unsure of the availability of their current employees to participate in future training as lay leaders. The Toledo and Cincinnati sites felt that they already had staff members that would be interested in being trained even though they still shared concerns about costs associated with training and implementation.

Implementation of the CDSMP is flexible in the sense that administrative costs can vary from location to location by allowing an organization to require a fee for the service. Therefore, in response to the concern about administrative costs, each key informant was asked if requiring a small fee would help with some of the cost. The key informants felt it could help with providing the weekly sessions in regards to cost of providing program materials and incentives such as food. However, each respondent said that even if there was a small fee, less than $20 for the whole program, it would be a potential barrier to getting participants. One key informant stated that “if I’m a client, you don’t know if you spend $15 (not invest, spend) when you are already living with a condition.”

Another issue raised by the agency liaisons related to the fact that the CDSMP is an educational program that will require multiple sessions; the respondents felt that there would be multiple barriers that should be considered when attempting to reach the Hispanic community. A major concern was the requirement that there would be a consistent person that the Hispanic community could trust to run the sessions. There was a great emphasis on the importance of trust; each site respondent felt that the program could only be successful if the Hispanic community trusted the facilitator and the organization that was offering the program. The key informants also mentioned that the program site must not only be trustworthy, but close in proximity to a majority of the participants since transportation is often an issue for their clients in regards to access to community services. The literacy level of all the CDSMP educational materials was also mentioned as an additional concern in regards to access to information provided at each session. One key informant claimed that usually clients verbally learn information at educational programs, and that the literacy level of the written materials becomes a problem because the client cannot refer back to the materials to help them remember what they had once learned.
While the key informants identified key areas of concern for their organization and their clients, their optimism for the future program implementation was manifested in their numerous suggestions for how to minimize the barriers and overcome the obstacles (Table 2). The organizational respondents stressed the necessity of providing staff and monetary resources to the sponsoring organization so that they could support their clients by offering the program and continue to build their relationship with the surrounding Hispanic community. In some cases the recommendations for support involved increasing budgets and staffing at the host organizations; however, other sites recommended creating community collaboration with an existing site that may be a better location for providing the CDSMP program.

Administrative solutions to barriers focused primarily on the need for monetary and staffing support, and need for more information about details associated with possibly offering the program at that particular organization or within the surrounding community. Major recommendations for clients involved providing incentives such as food, and considering appropriate times, days, and the location at which to offer the program. Regarding possible suggestions for helping with program implementation costs and providing an incentive for clients, key informants were asked if they felt participants would bring food or make donations, instead of paying a fee. Each key informant said that it would not hurt to try to ask participants to bring donations if it would help increase participation and reduce costs. Although administrative recommendations varied some, suggestions for providing support and services to future program participants seemed consistent among the site locations.
Table 2: Recommendations for Program Implementation

<table>
<thead>
<tr>
<th>Administrative</th>
<th>Client</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Want staff trained and to offer program or willing to direct clients to a</td>
<td>• Should always provide incentives. (Meal, $10 gas card, bus tickets,</td>
</tr>
<tr>
<td>community organization that offers the program.</td>
<td>childcare, etc.) Possibly have a potluck, “I can’t say it would work or</td>
</tr>
<tr>
<td>• Advertise by word of mouth (best option), also utilize Hispanic grocery</td>
<td>won’t, but it's always worth trying something.”</td>
</tr>
<tr>
<td>stores, Spanish newspapers and radio stations.</td>
<td>• Hardworking culture (shift work) – offer more than one session.</td>
</tr>
<tr>
<td>• Want to expand services and avoid overlapping services</td>
<td>• Provide more than one program on a different days and times.</td>
</tr>
<tr>
<td>• Some need for resources to give pay incentives to current staff, hire new</td>
<td>• Provide program at a trusted location.</td>
</tr>
<tr>
<td>staff or have staff provided. Others don’t think an incentive to train or</td>
<td>• Have trusting and relatable facilitator</td>
</tr>
<tr>
<td>lead program would help- “if they want to do it they’ll do it”.</td>
<td>• Daytime programs important for older females and parents with children</td>
</tr>
<tr>
<td>• Need more information about funding for program and incentives.</td>
<td>• Would like more information about other programs/services that the site</td>
</tr>
<tr>
<td>• Cost of providing incentives to clients and staff.</td>
<td>can offer based on client need/interest.</td>
</tr>
<tr>
<td>• Make sure advertising and materials is at basic literacy level.</td>
<td>• Have program close to where they live.</td>
</tr>
<tr>
<td></td>
<td>• Allow donations or for people to bring payments later.</td>
</tr>
</tbody>
</table>

In addition to the importance of providing food, the key informants felt that it was necessary to offer other incentives such as a public transportation card and more importantly childcare. Some suggestions were to offer the program on Monday through Saturday. The key informants also felt that it would be better to avoid Sundays since most organizations are closed on those days and because a majority of their clients are in church until the afternoon. Since the Hispanic culture is very family-oriented, the key informants suggested that the sites either provide childcare during the CDSMP sessions or have the program at times when children may be at school, such as in the early morning or afternoon. It was recommended to advertise in local Spanish newspapers, on the radio and in grocery stores, however, the key informants stated that a majority of their clients claim that word of mouth is the method in which they heard about a particular service or activity offered at each site. Once again the importance of having a
established trusted organization as well as a long standing trustworthy program facilitator was stressed as a major recommendation for program implementation.

**PARTICIPANT SURVEYS**

The intent of the participant surveys was to get an exploratory sense of the interest and preferences among the population who would be eligible for participation in the CDSMP. Knowing the importance of trust within this particular community, the key informants were asked to distribute and encourage their clients to fill out the survey. Since these agency liaisons are already seen as trustworthy members of an established and trusted organization and the surveys were completely anonymous, this strategy was selected as the optimal way to encourage participation within a limited period of time. The only requirements for study participants were that they were of Hispanic or Latino descent, over the age of eighteen, and have a chronic condition. Returned surveys that did not meet these requirements were excluded from the study. The final response rate was extremely low, only 7.5% (9) of the surveys were returned and only about 4% (5) of the 120 surveys could be used for the study based on meeting all of the previously mentioned requirements. All due diligence was invested in trying to increase the response rate, given the distribution system for the surveys that had already been established.

Key informants were contacted within a few days after the stated deadline for returning the surveys in order to determine issues related to the surveys, and to discuss new approaches for obtaining completed surveys from their clients. Responses from the agency liaisons regarding the survey process varied greatly with each site; most of the surveys were received from the Cincinnati site. The Columbus site offered surveys to about 13 clients that met study requirements as they left physician visits; agency staff asked that participants fill out the survey and mail them in the stamped and addressed envelope that had been provided. By the deadline date the Cleveland key informant stated that they had handed out about 9 surveys, but no surveys had been received from this particular site. The Toledo site had handed out all thirty surveys and had reminded all the participants to mail the surveys midway through the timeframe between distribution and the return deadline; however, only 2 surveys were received.

No surveys were received from the Cleveland site; during the follow up conversation the key informant mentioned that clients stated that they did not want to provide any written information and they would not fill out the survey so it they didn’t feel like they should take the
survey material. The key informant at this location also stated that trust is a general issue with this population and may have been a major issue in handing out written surveys, even though the person passing out the surveys and had been an intern for close to a year. This could imply that the Hispanic community is not interested in attending a prevention program, and therefore, it may not be feasible to implement a Spanish CDSMP in every region of the Ohio. However, since some Hispanics gave a verbal response of interest to key informants, it is more than likely that the survey results have a much deeper implication that the Hispanic community of Ohio is still highly misunderstood and that further research should be conducted in a manner that first elicits trust.

**DISCUSSION**

The key informant interviews helped to determine possible concerns for future implementation of the Spanish version of the CDSMP. Organizations would not only like to improve the services they offer, but they would like to build a stronger collaboration of community resources tailored toward the growing Hispanic community. The study’s findings suggest that trust is the most important issue associated with both interacting with the Hispanic community and providing much needed services. The low response rate is an obvious limitation to the study. Since the study was conducted only in major cities within the state of Ohio, they are not generalizable to more rural areas of Ohio or to the Hispanic population in general. Also, due to the response rate, it is important to understand that the lack of trust among the participants is a major limitation to obtaining information via a voluntary survey. The ability to trust organizations and staff is also something that has been of increased concern for this population with the current political climate associated with passing laws related to providing services to the Hispanic population. A fairly new law, which was passed in Arizona in April, states that in order to provide public services to individuals it would require organizations to verify immigration status for clients receiving any federal, state, or local service (Arizona State Senate : http://www.azleg.gov/legtext). Since this law was passed in the month prior to disseminating the surveys, it is likely that the political change and national media attention associated with topic both affected the response rate by decreasing the client’s willingness to return surveys or even initially participate in the study.

Even though the key informants were seen as trustworthy, their clients did not trust sharing information for the purpose of the study. The site in Cleveland stated that when they
attempted to distribute surveys to an event that had over 100 participants, their Hispanic clients did show an interest in the program. However, these same clients honestly told the staff and key informants that they would not fill out the survey. The lack of participation was mostly likely due to their comfort level with the research area and lack of trust in sharing personal information, with the current political climate, regardless of the anonymity. The key informant in Cleveland suggested that even though their intern was bilingual of Hispanic or Latino descent, and had worked with the Hispanic community for the past year, perhaps she had not gained enough trust within the community to target clients. Therefore, the lack of participation in the study among the Hispanic community shows that having a key informant of Hispanic or Latino descent was not enough to elicit involvement in the survey.

Although the issue of trust proves to be a barrier for the next wave of surveys, there are insights which can be gleaned from the low survey response rate; these observations reiterate many of the findings from the key informant interviews. The surveys showed that Hispanics who returned the survey were more likely to have lived in the U.S. longer, to participate in regular healthcare visits with a primary physician, to go to community centers or clinics for health advice and information, and to participate in and pay a small fee for a preventative program if it would help them manage their condition. Because of their willingness to participate in the survey, these individuals could perhaps help as key informants for further research on this topic. Key informants within each community would not only help to advertise the study, but these individuals would more than likely be a person that the Hispanic community already trusts.

The agency key informants from this study felt it will be necessary to have a program facilitator who will be willing to make a long term commitment to work within the Hispanic community for longer than a year to build the trust of the local Hispanics. In this case future evaluation of the success of program implementation should not occur until after the program has been well established and operating for at least a year. If the program is evaluated after only one year, the program may appear to be unsuccessful solely due to implementation challenges such as low anticipated attendance from the Hispanic community. An evaluation will be more accurate after advertising by word of mouth and a general sense of trust have had time to build the program.

With this being said, the responses from key informant interviews showed that there is a great sense of excitement and optimism about expanding much needed services for the Hispanic
community. Therefore, future research in this project should focus on increasing the amount of
information obtained about program use by the Hispanic community either through focus groups
or a second wave of surveys. Future results from the survey will provide greater insight into the
particular needs of the Ohio Hispanic population while accounting for the presence of needed
adaptations in program implementation based on regional differences. At this stage in the study
it is important to acknowledge the issue of trust as an essential aspect to consider when working
with the Hispanic population; therefore, it may be better to have key informants identify
participants to participate in focus groups.

Further recommendations would include identifying community leaders who could also
help to recruit participants and to find appropriate locations for focus groups to be held. Since the
key informants from this study stressed the importance of providing participants with incentives
it would be vital to consider such things as gas cards, grocery gift cards, transportation tickets, or
even a restaurant voucher or food. If further research involved conducting a second wave of
surveys, the surveys should be distributed so that the survey are filled out and returned
immediately; a trusted community member could administer the survey to each participant,
perhaps even conducting an interview rather than handing out a survey. In this case the new
survey method will need to rely on multiple trusted individuals instead of one key informant.

Those who responded to the survey were individuals who were more likely to visit the
site locations for health advice. These participants only represent a small number of the overall
Hispanic community in Ohio; thus it is essential to have a better understanding of the larger
community that did not participate. The survey response rate shows that in order to obtain a idea
of the larger communities needs, future surveys should be conducted in locations that are not
commonly associated with healthcare, but are sites that are considered trusted and important for
the Hispanic community. Possible locations could be parks and recreation centers, libraries, local
Hispanic grocery stores, authentic restaurants, and churches. Another suggestion would be to
obtain support from the Area Agencies on Aging (AAA) to conduct the surveys during routine
case manager home visits. At this point the case manager could briefly ask the questions to the
participants and then mail the survey or return it to the AAA, encouraging participants to take the
time to fill out the survey. If the survey is distributed by a trusted case manager that has been in
their home before and that person is recognized as someone who already offers care,
compassion, and an understanding of the participants’ health and lifestyle needs, participants may be more likely to complete the survey.

In order to address the needs of the Hispanic community within Ohio, it is important to remember that not all Hispanics will have the same needs; these individuals are a part of a much more diverse Latino community. The Latino community in Ohio not only considers the needs of those who speak Spanish, but also acknowledges the importance of embracing the several subgroups that originate from various other non-Spanish speaking countries when offering services. With this being said, the Spanish version of the CDSMP program would still be much more beneficial to the Latino community, in comparison to the original, since the participants will be able to relate better to the program, thus improving participant adherence and satisfaction with the program. However, since the overall Latino community is comprised of several subgroups it will be important to know which particular subgroups a program site serves and if there are any community leaders within each subgroup that would be interested in being trained as lay leaders. By having lay leaders who are also leaders within their community it will help to elicit trust, meet the needs of their smaller community, and still maintain the fidelity of the original CDSMP program.

The key informant recommendations and future survey or focus group data will also play an integral role in helping to expand community collaborations within each major city simply by further understanding the needs for the clients in each community. Improving partnerships within the community will provide appropriate resources and support systems for implementing a new program, while assuring to avoid budgetary concerns associated with providing overlapping services. Through building a greater support network for Hispanics, the organizations in that area will be able to offer more resources to the community while also helping to increase trust in health related services. The current lack of trust by Hispanics, especially in the healthcare system, has created several barriers to providing adequate and much needed health services. By obtaining more information about the likelihood of using preventative health services by the Ohio Hispanic community it could help to reduce barriers in providing such health services. Minimizing barriers to care will only help to increase access to healthcare information and utilization. Increased utilization and information pertaining to managing health conditions could in turn help to reduce future healthcare costs for both Hispanic residents and the state of Ohio.
APPENDICES

APPENDIX I: KEY INFORMANT MATERIALS

Dear _________________________:

My name is Jasleen Chahal and I am a graduate student in the Department of Gerontology at Miami University. I will be working with Dr. Kunkel, a faculty member within the same department/university, in order to understand the perspective of the current Hispanic community in Ohio.

You are invited to participate in a study regarding the likelihood of use of the Chronic Disease Self-Management Program (CDSMP) among the Hispanic population. I will ask you to complete a short interview about the activities that your organization offers for Hispanics, the best ways to collect survey data in your facility, as well as any overall opinions you have about prevention programs or survey materials. Your interview will help immensely in determining ways in which to collect appropriate data from your Hispanic clients as well as getting your perspective on the possibility for future implementation of Spanish prevention programs. The interview should take approximately 1 hour to complete and I assure you that although your facilities name or regional location may be associated with the results of the collected data, your personal information/name will not. You will not be asked to do anything that exposes you to risks beyond those of everyday life. The results of the study will help us understand more about whether the Ohio Hispanic population will use a health based program, such as the CDSMP, to help manage chronic illnesses as well as the role that your facility can have in future implementation.

If you have further questions about the study, please contact Jasleen Chahal at (chahaljk@muohio.edu). If you have questions about your rights as a research participant, please call the Office of Advancement of Research and Scholarship at 513-529-3600 or email: humansubjects@muohio.edu.

Thank you for your participation. We are very grateful for your help and hope that this will be an interesting session for you. You may keep this portion of the page.

Please cut at the line above and keep the top section for your personal use. Please return this signed bottom section.

By signing this form, or typing my name on the signature line, I agree to participate in the key informant interview as well as am willing to be contacted after the interview as a follow-up to my responses or the actual study. I also authorize the use of my organization as a site location for disseminating surveys/collection research for use in this feasibility study pertaining to the use of the CDSMP by the Hispanic population. I understand my participation is completely voluntary and that my name will not be associated with my responses. By signing below, I also acknowledge that I am 18 years or older and am a representative of my organization.

Interviewee’s signature ________________________________.
Date ____________________________.
INTERVIEW GUIDE

1) Does this facility have particular activities tailored for the Hispanic community or for Hispanics with health conditions such as a chronic disease?

2) What have been some previous services that your organization or local organizations have offered for Hispanics?

3) What advice do you have about involving the Hispanic community in activities? (e.g. day, time, location, advertising)

4) Do you have any upcoming events where you anticipate a large attendance from the Hispanic community or Hispanics with a chronic condition?

5) If so, would it be possible to advertise and have your staff mention the study/survey during these activities?

6) Would you and your staff be willing to also direct individuals to the survey if they fit the study requirements?

7) Is there a particular staff person that participants could go to for help regarding the study?
   a. Would it be possible to speak with this person later to fully explain the study?
   b. Would this person be willing to assist in getting surveys completed?

8) What would be the best location within the facility to place the surveys for people to pick up?

9) Is there a location on site that the participants would be able to mail the sealed envelopes?

10) Would it be okay to follow up with you or another staff member 2 weeks after the surveys are delivered and during/after the study?

11) Do you have any recommendations about questions that should be asked on the survey?

12) Overall, what do you feel would be some barriers in implementing a self-management program for the Hispanic community?

13) What are some things you would want to know that would help you determine ways in which your organization might implement a similar program in the future?

14) A lay leader for CDSMP is someone who is trained to lead the weekly program meetings and usually has been diagnosed with a chronic condition and/or has either taken care of someone with a chronic condition. Can you think of anyone in your facility who would want to be trained as a lay leader for the Spanish CDSMP?
Dear Participant:

My name is Jasleen Chahal and I am a graduate student in the Department of Gerontology at Miami University. I will be working with Dr. Kunkel, a faculty member within the same department/university, in order to understand the perspective of the current Hispanic community in Ohio.

You are invited to participate in a study regarding the likelihood of use of the Chronic Disease Self-Management Program (CDSMP) among the Hispanic population. I hope that you will take the time to fill out the survey if you are Hispanic/Latino, have been told that you may have a chronic condition, and are 18 years or older. I will ask you to complete a short survey about your overall health and if you would use a program to help manage your chronic condition. These will be completely anonymous, as you will receive a reference number prior to submitting your responses. This survey should take approximately 15-20 minutes to complete. Your participation is completely voluntary and you may stop or refuse to answer any questions on the survey that make you uncomfortable. You will not be asked to do anything that exposes you to risks beyond those of everyday life. The results of the study will help us understand more about whether the Ohio Hispanic population will use a health based program, such as the CDSMP, to help manage chronic illnesses.

If you have further questions about the study, please contact Jasleen Chahal at (chahaljk@muohio.edu). If you have questions about your rights as a research participant, please call the Office of Advancement of Research and Scholarship at 513-529-3600 or email: humansubjects@muohio.edu.

Thank you for your participation. We are very grateful for your help and hope that this will be an interesting session for you. You may keep this portion of the page.

By returning the survey you agree to participate in this study about the likelihood of use of the Chronic Disease Self-Management Program for the Hispanic population. Also you understand that your participation is completely voluntary and that your name will not be associated with your responses. By returning the survey, you also acknowledge that you are 18 years or older, are of Hispanic/Latino descent, and have been told by a doctor or nurse that you might have.
Important Information:
The following survey has questions that are related to your current use of healthcare services and your possible use of a chronic disease self management program. Prior to filling out the survey please read the following material about our definition of a chronic disease/condition and more information about the self-management program.

1) For the purpose of the survey a **chronic condition** or **chronic disease** is defined as:
   A health condition or disease that persists for a long period of time, usually lasting longer than three months, by the definition of the U.S. National Center for Health Statistics. These conditions cannot be prevented or cured by using vaccinations or medication; however, they can be cared for and managed by taking appropriate medications and making healthy lifestyles adjustments.

2) **Self-Management Prevention Programs** – the **Chronic Disease Self-Management Program (CDSMP)**:
   Our definition of a self-management prevention program is a program that provides you with resources and tools to manage your chronic health condition(s) by making changes that allow you to actively care for your health. This includes simply asking questions about your health when at the doctor’s office, taking medication and getting medical tests as directed, changes in nutrition and exercise, healthy lifestyle adjustments, and learning ways to cope with stress, depression, pain and fatigue.
   
   A self-management prevention program can help you understand how to make changes to improve your health and affect the quality of your life. The Chronic Disease Self-Management Program (CDSMP) is a program that was created by professionals at Stanford University. The program is for individuals with a chronic disease(s) to help them manage their condition(s), have a better quality of life and reduce complications associated with chronic conditions. This program is currently offered nationwide in both English and Spanish. The Spanish version has been separately developed so that the material and topics are culturally appropriate and not simply a translation.
   
   The CDSMP is a program that is offered once a week, for 2 ½ hours, for 6 weeks. An individual, who is not a healthcare professional, leads the program each week at such locations as community centers, libraries, churches, and healthcare facilities. Each week the leaders of the program cover a different subject.
   
   The Topics include the following: **Week 1** - Techniques to deal with problems such as frustration, fatigue, pain and isolation, **Week 2** - Exercise for maintaining and improving strength, flexibility, and endurance, **Week 3** - Appropriate use of medications, **Week 4** - Communicating effectively with family, friends, and health professionals, **Week 5** - Nutrition/healthy eating, **Week 6** - Appropriate use of the health care system and how to evaluate new treatments.
   
   This provides the opportunity for participants to share their ideas and questions related to the topic, and to discuss how they care for their chronic condition(s).

At the end of the six weeks, leaders hope that each participant will have found additional confidence, resources and tools to help them manage their condition and improve their health and quality of life.

Please continue by completing and returning the following survey by May 31st.
Participant Survey:

1) Are you of Hispanic/Latino origin?
   ___ Yes
   ___ No (STOP – Do not answer anymore questions. Please MAIL your SURVEY in the provided envelope and THANK YOU for your participation.)

2) What month and year were you born?
   MONTH: _______________                             YEAR: _________________

   If you were BORN AFTER APRIL 1992 (Under 18 years old) - PLEASE STOP TAKING THE SURVEY AND Do not answer any more questions. Please MAIL your SURVEY in the provided envelope. THANK YOU for your participation.

3) Has a doctor ever told you that you might have any of the following chronic conditions? (Please mark all that apply) - For the definition of chronic condition please refer to # 1, under Important Information, on the second page.
   ___ Diabetes
   ___ Heart disease/Cardiovascular
   ___ Cancer
   ___ Arthritis
   ___ Asthma/Chronic Bronchitis
   ___ Emphysema or COPD (Chronic Obstructive Pulmonary Disease)
   ___ HIV/AIDS
   ___ I have not been diagnosed, but have been encouraged to see a physician for one of the conditions on this list. Please list the condition: _________________
   ___ None of these (STOP – Do not answer anymore questions. Please MAIL your SURVEY in the provided envelope and THANK YOU for your participation.)
   ___ Other: ____________________

   * For information about the self-management prevention program please refer to # 2, under Important Information, on the second page.

4) Based on the provided information and your personal understanding of prevention programs, how likely do you feel a prevention program would help you better care for your condition?
   ___ Very likely
   ___ Likely
   ___ Possible
   ___ Unlikely
   ___ Very unlikely
5) Did you know that there are currently programs offered in your community that help you address your condition?
   ___ Yes
   ___ No

6) How **likely** is it that you would attend a weekly program, for 6 weeks, **if it helped** you care for your condition?
   ___ Very likely
   ___ Likely
   ___ Possible
   ___ Unlikely
   ___ Very unlikely

7) How **likely** is it that you would attend a separate or additional program that specifically focuses on managing diabetes?
   ___ Very likely
   ___ Likely
   ___ Possible
   ___ Unlikely
   ___ Very unlikely
   ___ Not a diabetic

8) The **major reason(s)** that you **might not** use a prevention program is **(Mark up to 3)**
   ___ Transportation issues
   ___ Hours offered
   ___ Too expensive
   ___ Location of the program
   ___ Not interested in the program
   ___ Other: __________________

9) The person **mostly likely** to tell you about a disease self-management program **(Mark up to 3)**
   ___ Friend
   ___ Nurse
   ___ Physician
   ___ Insurance company
   ___ Community organization staff
   ___ Advertisements (phone,flyer,etc)
   ___ None of the above
   ___ Other: __________________
10) If you **were attending** a self management program, the settings at which you would **most likely attend** are… *(Mark up to 3)*

___ Faith-based facility (ex. Church)
___ Community organization (ex. Community center)
___ Neighborhood health clinic
___ Major medical/healthcare facility (ex. Hospital)
___ None of the above
___ Other: __________________

11) If you were attending a self management program…

11 a) Who would **most likely** accompany you if you could not go alone? *(Mark only one)*

___ One family member or friend every week
___ Multiple family members or friends each week
___ I would most likely go by myself each week

11 b) Would this family member(s) or friend(s) **most likely** be the same or different each week *(Mark only one)*

___ Same
___ Different
___ Not applicable because I would most likely go by myself

12) If you **were attending** a self management program, what days and times would work best for you? *(Please only mark 2 for both part a and b)*

12 a) Days of the Week

___ Monday
___ Tuesday
___ Wednesday
___ Thursday
___ Friday
___ Saturday
___ Sunday

12 b) Time of Day

___ Morning (8am-11am)
___ Afternoon (12pm-2pm)
___ Late Afternoon (3pm-5pm)
___ Evening (6pm-9pm)

13) How **likely** is it that you **would be willing** to participate in the program if it requires a small fee to attend the entire program ($5 - $20 for the whole program)?

___ Very likely
___ Likely
___ Possible
___ Unlikely
___ Very unlikely
14) Does anyone in your family or your household help you take care of your chronic condition?
   ___ Yes
   ___ No

15) In the past year how often has your chronic condition affected your daily life?
   ___ All the time
   ___ Most of the time
   ___ Some of the time
   ___ Rarely
   ___ Never

16) Have any of the following ever stopped you from getting medical care (mark all that apply)?
   ___ Transportation issues
   ___ Lack of insurance
   ___ Worries about paying for care
   ___ Worries about being able to communicate with a nurse or doctor
   ___ Lack of trust in the healthcare system
   ___ Preferences for home or traditional remedies
   ___ Other: ______________________

17) How often do you normally visit the same doctor for your chronic condition?
   (Do not include visits while in the hospital or the hospital emergency department)
   ___ Once a week or more often
   ___ Every month
   ___ About every 3 -6 months
   ___ At least once a year
   ___ No regular visit, only when there is a problem

18) During my visits, I felt that the doctor gave me good advice about how to care for my condition.
   ___ Strongly agree
   ___ Agree
   ___ Neither agree nor disagree
   ___ Disagree
   ___ Strongly disagree
   ___ Not applicable to me; I do not visit a doctor
19) In the **past year, how often** did you seek medical care for your chronic condition from a nurse or doctor **other than** your regular doctor? **Do not include visits while in the hospital or the hospital emergency department**

- ___ None
- ___ 1 time
- ___ 2-3 times
- ___ 4-9 times
- ___ 10-12 times
- ___ 13 or more times

20) In the **past year, how often** did your medical care (for your chronic condition) result in hospitalization or a visit to a hospital emergency room?

- ___ None
- ___ 1 time
- ___ 2-3 times
- ___ 4-9 times
- ___ 10-12 times
- ___ 13 or more times

21) The place you **go to most often** for medical care is

- ___ An emergency department
- ___ Your regular doctor
- ___ A community health clinic
- ___ Other: ______________________

22) The place(s) you **often** get information about your chronic condition **(Mark up to 3)**

- ___ Community organization (ex. Community center)
- ___ Online website
- ___ Community health clinic
- ___ Your doctor’s office
- ___ Major medical/healthcare facility (ex. Hospital)
- ___ Library/books
- ___ Church group

23) The place(s) you would **most likely** look for advertisements about a health program? **(Mark up to 3)**

- ___ Community organization (such as a . Community Center)
- ___ Online website
- ___ Community health clinic
- ___ Your doctor’s office
- ___ Major medical/healthcare facility (such as a hospital)
- ___ Newspaper, TV media
- ___ Library
- ___ Church or temple
- ___ Other: ______________________
24) Are there other resources and information related to your health that you would like to know more about?
   ___ Information about how to pay for healthcare costs
   ___ Help with planning for future health costs (such as long term care)
   ___ Transportation services to medical appointments
   ___ Low or no cost community resources (such as for exercise and nutritional advice)
   ___ Other: __________________

25) How would you rate your overall health? (Mark only one)
   ___ Excellent
   ___ Very good
   ___ Good
   ___ Fair
   ___ Poor

26) What is your gender?
   ___ Male
   ___ Female

27) Are you currently (Mark only one):
   ___ Single
   ___ Married
   ___ Separated
   ___ Divorced
   ___ Widowed

28) Do you live alone?
   ___ Yes
   ___ No

29) Approximately how many years have you lived in the USA?
   ____________ years

30) How many years of education did you complete?
   ___ 0
   ___ 1-6
   ___ 7-12
   ___ 13-16
   ___ 17-22
   ___ 23+

Please return by 05/31/2010 and Thank you for your help!
APPENDIX III: PARTICIPANT SURVEY MATERIALS (SPANISH VERSION)

Carta de consentimiento

Estimado participante:

Mi nombre es Jasleen Chahal y soy estudiante de maestría en el Departamento de Gerontología de Miami University. Voy a estar trabajando con la Dra. Kunkel, miembro del cuerpo docente en el mismo departamento / universidad, con el propósito de conocer la opinión actual de la población Hispana en Ohio.

Usted ha sido elegido para participar en un estudio sobre la posibilidad de uso del Programa de Autocontrol de Enfermedades Crónicas, Tomando el Control de Su Salud (CDSMP, por sus siglas en ingles) entre la población Hispana. Espero que usted vaya participar sí tiene 18 años o más de edad, es usted de origen Hispano o latino y haber sido diagnosticado con una enfermedad crónica. Le pediremos que complete una breve encuesta acerca de su estado general de salud y si usted utilizaría un programa para ayudar a controlar su enfermedad crónica. Las respuestas serán totalmente confidenciales y anónimas, ya que será identificado con un número y no con su nombre. Completar la encuesta le tomará aproximadamente 20 minutos. Su participación es completamente voluntaria y usted puede terminar la encuesta o dejar sin responder cualquier pregunta en la encuesta que lo haga sentir incómodo. No se le pedirá que haga algo que lo exponga a riesgos más allá de la vida cotidiana. Los resultados del estudio ayudarán a entender si la población Hispana de Ohio utilizaría un programa de salud, como el CDSMP, para ayudar a controlar las enfermedades crónicas.

Si tiene preguntas sobre el estudio, por favor póngase en contacto con Jasleen Chahal al (chahaljk@muohio.edu). Si tiene alguna pregunta respecto a los derechos como participante de la investigación, por favor llame a la Oficina de Promoción de Investigación y Becas al 513-529-3600 o a mande un correo electrónico al: humansubjects@muohio.edu.

Gracias por su participación. Estamos muy agradecidos por su ayuda y esperamos que esta sea una experiencia interesante para usted. Puede quedarse con esta página.

Al devolver esta encuesta usted acepta participar en este estudio sobre la posibilidad de uso del Programa de Autocontrol de Enfermedades Crónicas, Tomando el Control de Su Salud, para la población Hispana. También entiende que su participación es totalmente voluntaria y que su nombre no se asociará con sus respuestas. Al devolver la encuesta, usted también reconoce que tiene 18 años o más de edad y haber sido diagnosticado con una enfermedad crónica.
**Información Importante:**

La siguiente encuesta tiene preguntas que están relacionadas con el consumo actual de servicios de salud y la posibilidad de que usted utilice un programa de autocontrol de enfermedades crónicas. Antes de llenar la encuesta, por favor lea el siguiente material sobre nuestra definición de una enfermedad o condición crónica y más información sobre el programa de autocontrol.

1) **Para el propósito de esta encuesta una condición crónica o enfermedad crónica se define como:** Una condición de salud o enfermedad que persiste durante un largo período de tiempo, por lo general dura más de tres meses, según la definición del Centro Nacional de EE.UU. de Estadísticas de Salud (U.S. National Center for Health Statistics). Estas condiciones no pueden ser prevenidas o curadas mediante el uso de vacunas o medicamentos, sin embargo, pueden ser atendidas y controladas tomando los medicamentos apropiados y realizando cambios a un estilo de más vida saludable. (MedicineNet: http://www.medterms.com)

2) **Programas de Prevención - El Programa de Autocontrol de Enfermedades Crónicas (CDSMP):** Nuestra definición de un programa de autocontrol es un programa que le ofrece recursos y herramientas para manejar su(s) condición (es) de salud crónica haciendo cambios que le permiten que participe activamente en el cuidado de su salud. Esto incluye simplemente hacer preguntas sobre su salud cuando está en el consultorio del médico, tomar medicamentos y someterse a exámenes médicos siguiendo las instrucciones, así como cambios en su alimentación y ejercicio en un esfuerzo de realizar los cambios a un estilo de vida más saludable.

Un programa de autocontrol puede ayudarle a entender cómo hacer y seguir los cambios para mejorar su salud y mejorar su calidad de vida. El programa de Autocontrol de Enfermedades Crónicas (CDSMP), *Tomando el Control de Su Salud*, es un programa que fue creado por profesionales de la Universidad de Stanford. El programa está dirigido a personas con una enfermedad (es) crónica con el fin de darle la posibilidad de tomar el control / manejo de su condición(es) para mejorar su calidad de vida y reducir las complicaciones asociadas con enfermedades crónicas. Este programa se ofrece actualmente en todo el país, tanto en inglés y español. La versión en español ha sido desarrollada por separado con el fin de asegurar que el material y los temas fueran apropiados culturalmente y no simplemente una traducción.

El CDSMP es un taller que se ofrece una vez a la semana, durante dos horas y media, por seis semanas. Una persona, que no es profesional de la salud, conduce el programa cada semana en lugares tales como centros comunitarios, bibliotecas, iglesias y centros de salud. Cada semana el líder del programa cubre un tema diferente. Los temas incluyen: **Semana 1:** técnicas para enfrentar problemas como la frustración, la fatiga, el dolor y el aislamiento, **Semana 2:** ejercicios adecuados para mantener y mejorar la fuerza, flexibilidad y resistencia, **Semana 3:** uso apropiado de los medicamentos, **Semana 4:** comunicación efectiva con la familia, amigos y profesionales de la salud, **Semana 5:** alimentación saludable, **Semana 6:** el uso apropiado del sistema de salud, y como evaluar nuevos tratamientos.

 Esto proporciona la oportunidad a los participantes de compartir ideas y hacer preguntas relacionadas con el tema, así como la manera en que cuidan de su condición(es) crónica(s). Al final de la sexta semana, los líderes esperan que cada participante habrá encontrado más recursos y herramientas para ayudarlos a controlar su enfermedad y mejorar su salud y calidad de vida.

Por favor ayúdenos completando la siguiente encuesta por el 31 de Mayo de 2010
Encuesta del Participante:

1) ¿Es usted de origen Hispano o latino?
   ___ Sí
   ___ No (Si contestó que NO, DETENGASE-No conteste más preguntas. Por favor ENVÍE su ENCUESTA en el sobre adjunto y GRACIAS por su participación.)

2) ¿En qué mes y año nació usted?
   MES: _______________: AÑO _________________
   Si usted NACIÓ DESPUÉS DEL MES DE ABRIL DE 1992 (No Tiene 18 años de edad) – DETENGASE, AQUÍ TERMINA LA ENCUESTA, POR FAVOR NO conteste más preguntas. (Por favor ENVÍE su ENCUESTA en el sobre adjunto y GRACIAS por su participación.)

3) ¿Le ha dicho alguna vez un médico que usted puede tener cualquiera de las siguientes enfermedades o afecciones crónicas? (Por favor marque todas las que correspondan) - Para leer la definición de enfermedad crónica por favor consulte el # 1, en la sección de Información Importante, en la segunda página de esta encuesta.
   ___ Diabetes
   ___ Enfermedades del corazón / Cardiovascular
   ___ Cáncer
   ___ Artritis
   ___ Asma / Bronquitis crónica
   ___ Enfisema o EPOC (Enfermedad Pulmonar Obstructiva Crónica)
   ___ VIH / SIDA
   ___ Ninguna (DETENGASE -No conteste más preguntas. (Por favor de ENVÍE su ENCUESTA en el sobre adjunto y GRACIAS por su participación.)
   ___ No he sido diagnosticado con una enfermedad crónica, pero alguien ha dicho que puedo tener alguna(s) de las enfermedades crónicas. Por favor escribe la(s) enfermedad(es): ____________
   ___ Otro: ________________

Interés en el Programa

* Para leer más información sobre el programa de autocontrol, por favor vaya al # 2, en la sección de Información Importante, en la segunda página de esta encuesta.

4) En vaso a la información proporcionada y a su comprensión personal de los programas de prevención, ¿Con qué probabilidad cree que un programa de prevención le ayudaría a cuidar mejor su condición/enfermedad?
   ___ Muy probable
   ___ Probablemente
   ___ Posiblemente
   ___ Poco probable
   ___ Muy poco probable
5) ¿Sabía usted que en la actualidad hay programas que se ofrecen en su comunidad que le ayudan a manejar su enfermedad/condición?
   ___ Sí
   ___ No

6) ¿Qué tan probable es que usted asista a un programa semanal, durante 6 semanas, que le ayuda a cuidar su enfermedad/condición?
   ___ Muy probable
   ___ Probable
   ___ Posible
   ___ Poco probable
   ___ Muy poco probable

7) ¿Qué tan probable es que usted asista a un programa por separado o adicional que se enfoca específicamente en el manejo de la diabetes?
   ___ Muy probable
   ___ Probable
   ___ Posible
   ___ Poco probable
   ___ Muy poco probable
   ___ No soy diabético

8) La(s) razón(es) principal(s) por las que usted no utilizaría un programa de prevención es (son)… (MARQUE SOLAMENTE 3 OPCIONES)
   ___ Problemas de transporte
   ___ Horas ofrecidas
   ___ Demasiado caro
   ___ Ubicación del programa
   ___ No está interesado en el programa
   ___ Otro: ________________

9) Las personas que probablemente le hablarían a usted acerca de un programa de autocontrol de enfermedades (MARQUE SOLAMENTE 3 OPCIONES)
   ___ Amigo/amiga
   ___ Enfermera/Enfermero
   ___ Médico
   ___ Compañía de seguros
   ___ Personal de la organización de la comunidad
   ___ Anuncios (teléfono, volante, etc.)
   ___ Ninguna de las anteriores
   ___ Otro: ________________
10) Si usted asistiera a un programa de autocontrol, los lugares donde es más probable que usted asistiera son... (MARQUE SOLAMENTE 3 OPCIONES)
___ Institución religiosa (por ejemplo, la Iglesia)
___ Organización en la comunidad (por ejemplo, el centro comunitario)
___ Clínica de salud del vecindario
___ Clínica mayor /centros de salud (por ejemplo, Hospital)
___ Ninguna de las anteriores
___ Otro: __________________

11) Si estuviera asistiendo a un programa de autocontrol,
   11 a) ¿Quién sería más probable que lo acompañara si usted no pudiera ir solo o sola?
      (MARQUE SOLAMENTE UNA OPCIÓN)
      ___ Un miembro de la familia o un amigo cada semana
      ___ Más que un miembro de la familia o amigo cada semana
      ___ Lo más probable es que iría por mi cuenta cada semana
   11 b) ¿Sería más probable que esta persona es la misma persona o una persona diferente cada semana?
      ___ Mismo(s) persona(s) cada semana
      ___ Persona(s) diferentes cada semana
      ___ Ninguna de las anteriores, porque lo más probable es que iría por mi cuenta

12) Si usted estuviera asistiendo a un programa de autocontrol, ¿Cuáles son los días y horas que más le convendrían? (Por favor, sólo marque 2 respuestas en cada parte)
   12 a) Días de la semana________
       ___ Lunes
       ___ Martes
       ___ Miércoles
       ___ Jueves
       ___ Viernes
       ___ Sábado
       ___ Domingo
   12 b) Hora del día
       ___ Mañana (8am-11am)
       ___ Por la tarde (12 pm-2 pm)
       ___ Por la tarde (3pm-5pm)
       ___ Noche (6pm - 9pm)

13) ¿Qué tan probable es que estaría usted dispuesto a participar en el programa si el programa requiriera el pago de una pequeña cuota para poder asistir a todo el programa (pagar $5 - $20 por todo el programa)?
   ___ Muy probable
   ___ Probable
   ___ Posible
   ___ Poco probable
   ___ Muy poco probable
14) ¿Hay alguien en su familia o su casa que le ayude a cuidar de su enfermedad crónica?
___ Sí
___ No

15) ¿En el año pasado, con qué frecuencia le afectó su condición/enfermedad crónica en su vida diaria?
___ Todo el tiempo
___ La mayoría del tiempo
___ Parte del tiempo
___ Rara vez
___ Nunca

16) ¿Alguno de los siguientes le ha impedido recibir atención médica? (MARQUE TODOS LOS QUE CORRESPONDA)
___ Problemas de transporte
___ Falta de seguro médico
___ Preocupaciones por pagar por el cuidado médico
___ Preocupaciones acerca de ser capaz de comunicarse con una enfermera/enfermero o un médico
___ Falta de confianza en el sistema médico
___ Preferencias por remedios caseros o remedios tradicionales
___ Otro: ________________

17) ¿Con qué frecuencia visita normalmente al mismo médico para cuidar de su enfermedad crónica? (No incluya las visitas si ha estado hospitalizado/hospitalizada o a los servicios de emergencias del hospital)
___ Una vez por semana o muy seguido
___ Cada mes
___ Cada 3-6 meses
___ Cuando menos una vez al año
___ No visita regularmente, sólo cuando hay un problema

18) Durante mis visitas, sentí que el doctor me dio buenos consejos sobre cómo cuidar de mi condición/enfermedad.
___ Muy de acuerdo
___ De acuerdo
___ Ni de acuerdo o desacuerdo
___ No están de acuerdo
___ Muy en desacuerdo
___ Ninguna de las anteriores; No visita un médico
19) En el año pasado, ¿con qué frecuencia buscó ayuda médica para su condición o enfermedad crónica de una enferma o médico que fue alguien que no sea su médico habitual? - 
No incluya las visitas si estuvo hospitalizado/hospitalizada o a los servicios de emergencias del hospital.

___ Ninguno
___ 1 vez
___ 2-3 veces
___ 4 a 9 veces
___ 10-12 veces
___ 13 veces o más

20) En el año pasado, ¿con qué frecuencia su atención médica (por su condición crónica) resultó en hospitalización o en visita a una sala de emergencias?

___ Ninguno
___ 1 vez
___ 2-3 veces
___ 4 a 9 veces
___ 10-12 veces
___ 13 o más veces

21) Lugar al que acude para recibir atención médica primero (MARQUE SOLAMENTE UNA OPCIÓN)

___ Un servicio de urgencias
___ A su médico habitual
___ Una clínica de salud en la comunidad
___ Otro: ______________________

22) Lugares en los que muchas veces recibe o encuentra información sobre su enfermedad crónica (MARQUE SOLAMENTE 3 OPCIONES)

___ Organización en la comunidad (por ejemplo, el centro comunitario)
___ Sitio en internet
___ Clínica de salud en la comunidad
___ Consultorio de su médico
___ Clínica para mayores/centros de salud (por ejemplo, Hospital)
___ Biblioteca/ libros
___ Grupo de la iglesia
23) Lugares en los que **buscaría anuncios** acerca de un programa de salud *(MARQUE 3 OPCIONES)*
   ___ Organización en la comunidad (por ejemplo, el centro comunitario)
   ___ Sitio en internet
   ___ Clínica de salud en la comunidad
   ___ Consultorio de su médico
   ___ Clínica para mayores /centros de salud (por ejemplo, Hospital)
   ___ Periódico, televisión, medios de comunicación
   ___ Biblioteca
   ___ Iglesia o Templo
   ___ Otro: __________________

24) ¿Quiere usted **saber más** información de otros recursos en su comunidad?
   ___ Información para pagar por el cuidado médico
   ___ Consejos para planear por los otros servicios médicos en el futuro como servicios para los mayores
   ___ Transportación para ir al médico
   ___ Los recursos que son gratis o solamente requiere el pago de una pequeña cuota
     (por ejemplo lugares para hacer ejercicios o recibir consejos sobre nutrición)
   ___ Otro: ______________
   ___ No, no tengo interés en otros recursos

25) ¿Cómo calificaría su salud general? *(MARQUE SOLAMENTE UNA OPCIÓN)*
   ___ Excelente
   ___ Muy buena
   ___ Buena
   ___ Regular
   ___ Mala

26) Sexo:
   ___ Masculino
   ___ Femenino

27) ¿Marque su estado civil? *(MARQUE SOLAMENTE UNA OPCIÓN)*
   ___ Soltero
   ___ Casado
   ___ Separado
   ___ Divorciado
   ___ Viudo

28) ¿Vive solo?
   ___ Sí
   ___ No
29) Aproximadamente, ¿Por cuántos años ha vivido usted en los Estados Unidos de América?

_____________ Número de Años

30) ¿Cuántos años de educación ha completado usted en total?

___ 0
___ 1-6
___ 7-12
___ 13-16
___ 17-22
___ 23 o más

Por favor envié su encuesta en el sobre adjunto por el 31 de Mayo de 2010.

¡GRACIAS POR SU PARTICIPACIÓN!
WORKS CITED


