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An Action Research Approach to Examining Perceptions and Needs in Diabetes Care in a Community in Mexico Using the Innovative Care for Chronic Conditions Framework and Social Capital Theory

Oscar William Garza
University of Iowa

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AN ACTION RESEARCH APPROACH TO EXAMINING PERCEPTIONS AND
NEEDS IN DIABETES CARE IN A COMMUNITY IN MEXICO USING THE
INNOVATIVE CARE FOR CHRONIC CONDITIONS FRAMEWORK AND
SOCIAL CAPITAL THEORY

by

Oscar William Garza

A thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Pharmacy
in the Graduate College of
The University of Iowa

August 2013

Thesis Supervisor: Professor William R. Doucette

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Graduate College
The University of Iowa
Iowa City, Iowa

CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

Oscar William Garza

has been approved by the Examining Committee
for the thesis requirement for the Doctor of Philosophy
degree in Pharmacy at the August 2013 graduation.

Thesis Committee: _____
William R. Doucette, Thesis Supervisor

John M. Brooks

Barry L. Carter

Bernard A. Sorofman

Emily A. Wentzell

To My Family

Warriors are not what you think of as warriors. The warrior is not someone who fights, because no one has the right to take another life. The warrior, for us, is one who sacrifices himself for the good of others. His task is to take care of the elderly, the defenseless, those who cannot provide for themselves, and above all, the children, the future of humanity.

Sitting Bull (c.1831-1890)
Hunkpapa Sioux

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I have always taken comfort in knowing that I have not been alone throughout this journey. First and foremost, I thank my Heavenly Father for this blessed life and for guiding me along His path, even as I have searched to find my own way. I thank Him for being faithful and generous in His many blessings. Through Him I know nothing is impossible!

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ABSTRACT

Background: While there has been a dramatic increase in the prevalence of diabetes in developing countries, such as Mexico, there is a critical need to better understand how the challenges that arise in shifting the focus from acute care to care for chronic conditions manifest at the level of patient care provision in the health care organization and community, especially in rural resource-poor communities. One step in this direction is the exploration of the potential that social capital may provide in improving our understanding of the relationships that exists among patients, health care providers and the broader community.

Objectives: To examine the provision of health care for diabetes, as well as the beliefs, resources and relationships that exist among patients and families, health care teams and community partners that affect treatment for diabetes in a rural resource-poor community in Mexico.

Methods: This study incorporated a qualitative action-research approach and data was collected via community asset mapping, surveys, semi-structured interviews and group discussions. Utilizing an action research model, the study procedures were iterative, whereby results from selected data collection techniques were used to inform subsequent iterations of data collection. Community resources were identified with key informant input and via community exploration, to record existing and potential diabetes-related resources. Surveys were administered to health care providers, patients and general community members. Semi-structured interviews and group discussion topics were informed

by the Innovative Care for Chronic Conditions Framework as well as by prior data collection procedures such as the surveys and preceding interviews. The interviews and group discussions were conducted with health care providers, diabetic patients, and community leaders.

Results: Community asset mapping revealed limited existence of health care resources available to the rural community in Mexico. Three salient themes emerged across health care providers, diabetic patients, and community leaders: (1) Cultural eating behaviors are important drivers in preventing and managing diabetes mellitus; (2) Diabetic patients are currently ill-prepared to adequately manage chronic conditions, such as chronic conditions; (3) Trust is an important facilitator and/or barrier for both patients and health care providers when searching for ways to enhance management of diabetes outside of the health care organization.

Conclusion: An evidence-based understanding of the diabetes-related beliefs, current perceived performance of diabetes care provision, the availability of community resources and social capital can be used to leverage the health care in low-income communities where primary health services are limited in their availability and/or capacity. The informed construction of community-derived initiatives and interventions that integrate community resources and improve the social capital within the community can enhance the care for patients with diabetes by offering both alternative and complementary avenues of accessing care that supports long-term disease management.

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CHAPTER 1: INTRODUCTION

Background:

There has been a dramatic increase in the prevalence of chronic conditions, such as diabetes, in developing countries. Recent evidence shows that diabetes is now the leading cause of mortality in women and the second leading cause of mortality in men in Mexico (Wild et al. 2004; Rull 2005). It has become Mexico's primary cause of limb loss and blindness. Diabetes is one of the top public health problems threatening the security of Mexico's economy, health care systems, and citizens.

Diabetes is a chronic disease that requires life-long treatment and monitoring, as well as, consistent utilization of health care services in order to reduce or delay the onset of related complications, and to prevent premature death from the disease. The Mexican government has recognized diabetes as serious threat for the health services in Mexico and to the economy. It has developed policies aimed at the modernizing of health services, improving diabetes and other chronic disease monitoring, increasing treatment adherence, training physicians, and mobilizing health agencies (Pagan 2005, Sosa-Rubi 2009). Developing a health care system that can efficiently and effectively provide diabetic care for the country's population is especially important as the disease is increasing among young adults, which can compound the already enormous challenge posed to the health care system and the country's economy by the relatively older adult population (Rull 2005).

The current arrangement of the health system in Mexico is in danger of collapse, as it was not designed for the effective delivery of chronic illness care. For developing countries like Mexico, the health system faces the double burden of managing acute care conditions, especially communicable disease, as well as the rapidly increasing rate of chronic diseases like diabetes. In 2001, it was estimated that 10-15% of the adult population in Mexico had diabetes and the incidence of diabetes is expected to double by 2025 (Rull 2005). In 2003, it was estimated that direct and indirect costs associated with diabetes in Mexico was over \$15.1 billion (Jimenez 2004). At the household level, diabetes is also impoverishing families in Mexico. As of 2004, roughly half of the population was uninsured and for those who were insured, 40-60% of the costs associated with diabetic care are paid for out-of-pocket (Pagan 2005).

Compounding the problem of providing care for acute as well as chronic conditions are the systemic inadequacies in the identification and diagnosis of patients that may have diabetes, as well as in access to essential medicines for treatment of the disease. In many countries around the globe, and especially in Mexico, the poor are unable to access important health services (Rull 2005). Medical interventions are offered mainly through the broad public health network and while they do cover diseases like diabetes, they are only available in communities with health units that have a proven capacity in medical resources, personnel and infrastructure to provide health services. These restrictions have severely limited the accessibility to diabetes care by the people of Mexico,

especially those in rural communities (Pagan 2005, Sosa-Rubi 2009). Given these challenges facing Mexico, the purpose of this study was to investigate local factors affecting access to and the provision of diabetes care in one Mexican community. Overcoming these challenges at the community level will require engaging community stakeholders throughout the process in order to develop feasible, community-appropriate strategies for improving diabetes care.

Conceptual Underpinnings for the Study:

Historically, health care systems in developing countries have been organized for treating acute illnesses such as infectious diseases. As the prevalence of chronic illnesses has increased significantly around the world, the health systems in many countries have been able to evolve in response to the changing health care needs of their prospective populations. As this evolution occurred, a variety of models and frameworks for examining and evaluating their performance developed. These models and frameworks have been useful for identifying critical or desirable characteristics of effective health systems and have enabled stakeholders to identify and address some weaknesses in the system. To this day, however, there has not been any consensus approach for identifying core elements that health systems should adopt for effectively and efficiently addressing chronic illnesses. The variability in models and frameworks poses a significant challenge for any effort in evaluating health system performance and health care provision for chronic conditions in many countries, especially within developing countries attempting to address this shift in health care priorities.

Despite this variability, three critically important components can be identified that must be addressed in any framework or model attempting to address care for chronic illnesses: (1) the health care provider/team (2) the patient; (3) the patient's environment (community).

In 2002, the World Health Organization (WHO) released a global report that proposed a comprehensive framework for health systems to address the challenges of the rapidly increasing chronic conditions in developing countries. It is centered around the idea that optimal outcomes occur when a health care triad is formed. This triad is a partnership among patients and families, health care teams, and community partners. It functions at its best when every member is informed, motivated, and prepared to manage chronic conditions, while being able to communicate and collaborate with the others members of the triad. The triad is influenced and is supported by the larger health care organization, the broader community, and the policy environment. This framework is called the "Innovative Care for Chronic Conditions Framework" (ICCCF) and is an iteration of the "Chronic Care Model" (CCM) that was first proposed by Edward Wagner in 1998 (WHO 2000; Wagner 1998). The ICCCF was developed in collaboration between Wagner and the WHO with the explicit intent on adapting the CCM for the national public health systems and primary health care environments of the developing world. In addition to the aforementioned triad, the framework identified eight essential elements for developing strategies to manage chronic illnesses (see Chapter 2), with the concept of integration of action within the triad

forming the critical basis of this framework.

The ICCCF provides a guide for the organization of care for treating and managing chronic conditions within the context of the challenges faced within many developing economies, such as Mexico. However, the ICCCF Framework is limited in its ability to further explain actual mechanisms at work in trying to link broad population based and public health interventions, and more critically within the dynamic relationships of the ICCCF triad of the health care team, patients and families, and community partners. That is, not much is currently known about how these relationships can and/or do function. It is, perhaps, because of this deficit that the promise or potential inherent in implementing the ICCCF to improve care for chronic conditions has largely gone unfulfilled or has not been evaluated empirically.

The focus of this study was primarily on the triad that represents the partnership among patients and families, health care teams, and community partners and how these linkages affect care for diabetes. That is, for this study, we were primarily interested in assessing the performance of the health care organization and its integration with the community from the perspective of the providers, patients and community. This included assessing the ability of the health care system to organize care for chronic conditions like diabetes, which is likely to have a direct effect on the provision of care for patients with diabetes or experiencing diabetic complications. We also assessed the resources available to health care workers and their expertise related to diabetes which are logically

important factors related to the provision of appropriate care for diabetes. Furthermore, we assessed performance in addressing prevention and self-management support of diabetes and other chronic diseases as well as the system's ability to connect with community resources (e.g. domestic non-governmental organizations, traditional medicine practitioners, herbalistas/naturalistas, community support groups, local municipal health care services). Community resources can leverage the health care in low-income communities where primary health services are stretched thin by filling gaps in services which can enhance the care of patients with diabetes by offering an alternative route or avenue of access to care. If these community resources are not present, then access to care and long-term disease management may not be optimal.

Statement of the Problem:

While there has been a dramatic increase in the prevalence of diabetes in developing countries, such as Mexico, a dearth in academic literature exists regarding how these countries have prepared their health systems for addressing the increase in chronic diseases, such as diabetes. The existing literature regarding health care provision within developing countries is centered around discussions of national policy and health care reform or individual patient experiences of health care provision. There is a gap in the literature that addresses health care provision as a product of the intersection of policy, the health care organization and patient experiences. The only discussions of the

strategies addressing the changing state of health and medication access in Mexico have thus far been discussed at the level of national policy and health care reform; thus, it is evident that there is a critical need to better understand how these problems are manifested at the level of patient care provision in the health care organization *and* community. This is especially true of rural resource-poor communities, as the vast majority of health related studies occur in the urban centers within many developing countries, including Mexico. Additionally, research is needed to better understand how the provision of care to patients in the health care organization and the community are affected by the challenges that arise in shifting the focus from acute care to care for chronic conditions, especially in terms of accessibility to care and treatment for diabetes in rural resource-poor communities. One step in this direction was the exploration of the potential that social capital may provide in improving our understanding of the relationships that exists among patients, health care providers and the broader community, especially as countries and communities search for and attempt to apply the various models and frameworks that have been proposed by health services researchers and policy makers alike.

The setting for this study was the rural municipality of Xicotepec de Juarez (Xicotepec). Xicotepec de Juarez is located in the mountainous northern part of the Mexican state of Puebla. The municipality is made up of 100 named settlement communities, whose total combined population is about 75,000 with roughly 35,000 living in the municipality seat (the largest of the settlement

communities) of Xicotepec de Juarez. While the community growth of Xicotepec has accelerated in the last 25 to 30 years, nearly doubling, it is still considered by the international development community as a rural community given its geographic location and access to and development of natural resources (Gomez 2010).

Xicotepec was chosen for this study because of the general receptiveness and increasing interest of local health care providers, government officials and local business leaders for health evaluation activities, as well as, the municipality's tradition of international collaboration for community and economic development. After initial conversations with various stakeholders within the Xicotepec community, it became clear that the disease of diabetes is presently a public health concern that, if left unaddressed, is likely to threaten the economic and social viability of this community. This study sought to address the aforementioned gaps and to inform us about how the community has embraced the challenges that arise in shifting the focus from acute care to care for chronic conditions, especially in terms of accessibility to care and treatment for diabetes. It also provides a basis for developing strategies aimed at improving care for people with diabetes in this rural community in Mexico.

Purpose of the study:

In many countries around the globe, and especially in Mexico, the poor are unable to access important health services. Medical interventions are offered mainly through the broad public health network and while they do cover diseases

like diabetes, they are not readily available to all people in rural communities. (Pagan 2005, Sosa-Rubi 2009).

The purpose of this study was to examine the access to and provision of health care for diabetes, as well as the relationships that exist among patients and families, health care teams, and community partners related to diabetes care in Xicotepec, Mexico. I was interested in assessing patient and health care provider experiences, the health care organization's ability to provide the necessary care for diabetic patients, and its links to the community in doing so. Further, the health-related beliefs associated with diabetes and treatment of various community stakeholders were assessed. That is, the objective of this study was to examine the provision of health care for diabetes, as well as the beliefs and relationships that exist among patients and families, health care teams, and community partners that affect treatment for diabetes in a rural resource-poor community in Mexico. This objective was achieved by answering the following questions:

Main research question: What are the factors that influence the provision of diabetes care in a rural community in Mexico?

Subquestion 1: How do health care providers and patients perceive the accessibility to and current performance of the provision of care for diabetes in the community?

Subquestion 2: What are the diabetes-related health beliefs among patients,

health care providers and community members that could influence care for diabetes?

Subquestion 3: What resources are available within the community and how do patients, health care providers and community members perceive the existing linkages between patients and families, health care teams, and community partners and resources related to care for diabetes?

Subquestion 4: How can the concept of social capital be used to gain a better understanding about the dynamic relationships within the ICCC Triad of health care providers, patients and families, and community partners, in the context of improving access to and provision of care for diabetes?

This study incorporated a systematic qualitative action research approach and data were collected via community mapping, surveys, semi-structured interviews, and a group discussion. Utilizing an action research model, the study procedures were iterative, whereby results from selected data collection techniques were used to inform subsequent iterations of data collection throughout the study.

My rationale for this project was that its successful completion would provide a strong, conceptual, and evidence-based assessment of the factors that influence access to care, the provision of treatment and care, and the subsequent management of diabetes. I believed that incorporating a systematic qualitative action research approach was particularly important, in that more explicit attention was given to providing a readily actionable foundation of

information for the development of strategies to address the needs of the community, as determined by the community.

Summary:

This study was specifically concerned with the topic of diabetes care in the rural community of Xicotepec de Juarez, Mexico. The prevalence of diabetes in Mexico has increased dramatically and poses a significant threat to the public health of the Mexico, its health care system and its economy. Changes in technology, social behavior and cultural practices along with the increases in life expectancy present the health care systems of many developing countries with the double burden of treating life-threatening acute care illnesses as well as increasingly significant chronic care conditions. This can be especially challenging in the rural resource-poor communities of developing countries, such as Mexico, where individuals with the lowest income typically reside and may lack the resources to manage chronic conditions such as diabetes.

There is a dearth in scientific evidence regarding how communities in developing countries envision the looming threat of diabetes as a public health concern and even less evidence has been presented regarding how these communities would attempt to address it. Therefore, this study was designed with the purpose of addressing these gaps by assessing patient and health care provider experiences and health-related beliefs associated with diabetes and treatment, the health care organization's ability to provide the necessary care for diabetic patients, and its links to the community in doing so; thereby providing a

basis of information that can be used to formulate strategies for addressing the needs of the community.

Literature informs us that we should be interested in concepts that previous research in other communities identifies as important factors affecting health care provision. These concepts provide a general outline of the variables we should consider such as: integration and coordination of health and community resources, the flexibility and adaptability of the health care system, health beliefs and behaviors within the community, and family, social and environmental support. These factors will be discussed in a review of the literature in Chapter 2. However, given the limited literature about how these concepts apply to rural resource-poor communities in the developing world, we cannot assume that this literature provides a full understanding of how to approach studying the health situation of the community of Xicotepec, Mexico. This is an especially important consideration as there is very limited evidence regarding the basic understanding of diabetes as a disease within communities in developing countries in general and more specifically in rural Mexico.

Thus, the conceptual framework providing the theoretical basis for this study's approach will also be discussed in Chapter 2. Additionally, the methods that were employed in this study were designed to both investigate the importance of variables that have been previously described in the literature and to explore other variables that may also affect care for chronic diseases such as diabetes in the Xicotepec community. The research design and methods that were used in

this study were largely informed by action research methodology and will be discussed in greater depth in Chapter 3.

CHAPTER 2: REVIEW OF RELATED LITERATURE

Introduction

While there has been a dramatic increase in the prevalence of diabetes in developing countries, such as Mexico, a dearth in academic literature exists regarding how these countries have prepared their health systems for addressing the increase in chronic diseases, such as diabetes. For this study, diabetes will be used as a lens for examining chronic conditions. Diabetes is characterized as a chronic and rather complicated metabolic disorder that if left undiagnosed, untreated and/or poorly managed can have serious long-term complications. Like many chronic illnesses, proper management of diabetes often requires changes in patient behaviors, diet and nutrition, physical activity, medication therapy and consistent use of primary care services.

The existing literature regarding health care provision within developing countries is centered around discussions of national policy and health care reform. The purpose of this study is to examine the provision of health care for diabetes and the inherent relationships that exist among patients and families, health care teams, and community partners related to diabetes care in Xicotepec, Mexico. Given the limited nature of the literature about how these relationships affect care for and management of diabetes in rural resource-poor communities in the developing world, this chapter will provide a discussion of the literature that will be used to inform our approach in studying the health situation of the community of Xicotepec, Mexico. That is, the conceptual framework providing the theoretical basis for this study's approach will be discussed in the context of what

is currently known about the health situation in Mexico. This chapter will examine the organization of health care and the epidemiology of diabetes in Mexico as well as provide a discussion of the theoretical frameworks of health service and health behavior that provide the conceptual underpinnings of the approach that will be undertaken for examining diabetes care in a community in Mexico.

Health Situation: Mexico

The Organization of Health Care in Mexico

The structure of Mexico's current health care system was organized in the 1940's under Mexican President Manuel Avila Camacho, who for the first time in Mexican history attempted to provide universal health care coverage to the populace. On December 30, 1942, the Mexican constitution was amended to include "la Ley del Seguro Social," (Social Security law) and was designed to protect the health care of Mexico's working population. A year later President Camacho created "la Secretaria de Salubridad y Asistencia" by combining two existing departments, "los Jefes de Servicios Sanitarios Coordinados" and "los Rurales y Ejidales" [Heads of Coordinated Health Services and Heads of Rural Development, respectively] which formally established a National Health Secretary position (Lamarque Bastidas, 1993). This decision to consolidate and centralize the health care system was deemed an immediate success as the country observed a decrease in the national mortality rate from 1944 to 1945 (19.8 to 18.7 respectively) as well as an increase in the number of childhood vaccinations provided across the country for diseases such as chicken pox (Lamarque Bastidas, 1993). In a further effort to unify health care delivery and to

enhance the government's ability to provide universal health care to the Mexican population, the "Secretaria de Salubridad y Asistencia" was transformed into the "Secretaria de Salud" (Ministry of Health) in 1988. The Secretaria de Salud, in addition to streamlining health care organization and delivery in Mexico, was now charged with the responsibility of directing and coordinating both public and private health care initiatives (Lamarque Bastidas, 1993). While the consolidation and centralization of the health care organization and delivery resulted in remarkable improvements in the overall health of the Mexican population throughout the latter half of the last century, the persistent and significant disparities in health amongst the Mexican population has led to discussions of how to best approach addressing the evolving health care needs of the country. The recommendation that has gained the most traction has been that of decentralizing health care to local, community and municipal organizations (Lamarque Bastidas, 1993).

The current health care system is a tripartite system that provides health care via three primary vehicles: network of social security agencies, a federal government sector, and a private sector. Under the network of social security agencies, the two primary providers of health care are the Instituto Mexicano de Seguro Social (IMSS) and the Instituto de Seguridad y Servicios de los Trabajadores al Servicio del Estado (ISSSTE).

In 1994 IMSS was established for the salaried labor force working in the urban areas of Mexico and ten years later it was extended to the salaried

agricultural labor force. In 1973 and at present, IMSS is the largest of the social security institutions and is available to any individual who is formally employed including self-employed individuals (Ward, 1987). IMSS services are limited to non-specialist medical care and do not provide coverage for maternity care (Ward, 1987). The ISSSTE was established in 1960 for all state employees and is the second largest social security institution in Mexico (Ward, 1987). The majority of IMSS and ISSSTE beneficiaries come from urban areas and together account for approximately 45 percent of Mexico's population (Nigenda, Lockett, Manca, and Mora, 2001).

Outside of social security, the federal government provides public health care to about 35 percent of the country's population through the Ministry of Health and Welfare (Secretaria de Salud, SSA) and consists of primary health clinics, general hospitals, and specialty hospitals (Nigenda et al., 2001; Ward, 1987). Over the last 30 years, the federal government has sought to develop a variety of health programs in an effort to address the health needs of the country's extreme poor (Nigenda et al., 2001). In 2003, after increasing concern from the country's health officials and mounting popular pressure that too many of the country's citizens either did not have access to the country's health care system or were receiving inadequate health care, a program known as Seguro Popular was implemented. Seguro Popular was developed as a universal health insurance program targeted at citizens who were either unemployed or who would not otherwise qualify for health insurance under the IMSS or ISSSTE (Salud.Com,

2011). Additional requirements for enrolling in Seguro Popular, require that citizens have a valid government identification (e.g. driver's license, voter registration card, or military identification card) and a valid birth certificate.

It is estimated that 10 percent of Mexico's population is served by a private health care sector (Nigenda et al., 2001). The private health care sector is made up of a variety of for-profit hospitals and clinics as well as institutions such as the Cruz Roja (Red Cross) and Cruz Verde (Green Cross), in addition to the private insurance market. The majority of patients must pay out-of-pocket for accessing services in the private market, unless they are covered under a private insurance plan (Nigenda et al, 2001; Ward, 1987). Data from Pan-American Health Organization (PAHO) for 2001 suggests that of the 55.7% of total health expenditures occurring in the private sector, 92.4% were from out-of-pocket payments with only 4.9% being paid out of prepaid plans.

In Mexico, services provided by the private health care sector are not necessarily reserved for the wealthy, as many of the poorer citizens also choose to seek care from private hospitals and clinics. This choice is often motivated by a desire to circumvent the long and unpredictable wait times experienced in the public and social security sectors, or to seek more advanced treatment and care. However, many of the poorer citizens also seek care from private sector providers due to the lack of available public or social security providers in their area (Ward, 1987).

It is estimated that about 10 percent of the Mexican population is not

accounted for under the current health care system and are more likely to be utilizing health care from other sources such as traditional medicine healers or low-cost and free clinics provided by non-profit and non-governmental organizations, as well as practicing various forms of self-care (Nigenda et al., 2001).

In Mexico traditional medicine incorporates the original beliefs and practices of the country's indigenous people along with the beliefs introduced from European settlers as well as modern biomedicine (Nigenda et al, 2001; Trotter, 2001). Traditional medicine in Mexico is generally regarded as a more holistic approach to health and disease than the conventional biomedical approach as it seeks to integrate the social, psychological, physical and spiritual aspects of health and illness (Trotter, 2001).

Traditional medicine is typically provided via curanderismo which is comprised of three primary forms of healing practices (e.g. psychic healing, spiritual healing and spiritualism, and physical treatments and supernatural healing) that is performed by curanderos and has been suggested as an integral part of Mexico's ethnomedical health care delivery system. Treatment is generally provided at a low cost and is thought to be primarily utilized amongst the poor in rural and urban communities where conventional biomedical treatment and services are limited (Ward, 1987; Trotter, 2001). Curanderos have been described as influential community leaders and are generally respected as people of power and authority (Nigenda et al, 2001; Trotter, 2001; Ward, 1987).

It has been estimated that at least 10% of the Mexican population rely on self-care alone or in conjunction with alternative forms of medical care such as traditional medicine, as their primary mechanism for addressing their health care needs. Self-care behaviors and practices can range from incorporating dietary changes, such as using herbal teas and/or eating certain foods or substances to individually purchasing or acquiring over-the-counter or prescription medications from family, friends, colleagues or neighbors in order to treat self-diagnosed illnesses. While these behaviors and practices are generally practiced by all peoples regardless of socioeconomic status, it has been suggested that there is a disproportionate reliance on self-care when other forms of health care (e.g. biomedical care) are either inaccessible or unavailable, especially among poor populations (Leyva-Flores, Kageyama, & Erviti-Erice, 2001).

Additionally, it has been noted that in light of limited access to the formal health care system, self-care behaviors are also increasing as a response to the general population's increase in knowledge of health and medical care that has been influenced by an amalgamation of exposure to mass media, previous contact with the formal health care sector and traditional healers, as well as practices passed on through family and friends (Hernandez Tezoquipa, Arenas Monreal, & Valde Santiago, 2001; Leyva-Flores, et. al., 2001).

In many developing countries non-governmental organizations (NGOs), as well as international non-government organizations (INGOs), have increasingly played an instrumental role in providing support for health care services to poorer

populations where domestic governments have been unable to meet the health care needs of the people (Bradshaw & Schafer, 2000). These organizations have provided support in the form of financial and organizational aid to many developing countries, including Mexico, and in doing so have generated contentious debate about the effectiveness or social desirability of providing support in developing countries, especially among INGOs (Bradshaw & Schafer, 2000).

On one side of the spectrum it is argued that NGOs may hinder the economic development of communities in developing countries by creating a dependency on the information and material resources provided from NGOs and thus these communities have less incentive to invest the energy or resources in their own institutional development (Bradshaw & Schafer, 2000; Postma, 1994; Vegara, 1994). However, at the other end of the spectrum, it has been argued that NGOs have enhanced development by supporting the development of community infrastructure projects increasing access to clean drinking water and sanitation facilities as well as supporting the construction of low-cost housing, schools and health clinics. Additionally, NGOs have provided support for administering vaccinations to children and other health education and promotion programming, thereby bolstering the efforts of government entities lacking the resources to adequately meet the needs of their constituents, especially among the urban and rural poor (Bradshaw & Schafer, 2000).

The Pan American Health Organization (PAHO) suggests that despite efforts

in building a public health system, it is clear that health services do not reach the poorest people and that for whatever reason (e.g. social, political, economic, or cultural) it is the higher income segment of the population that ends up absorbing the majority of the public health resources (PAHO, 2005b). This is especially the case in Mexico, where it is estimated that approximately 27% of the population lives in poorest and mostly rural areas of the country and have very limited to no access to health care services, due in part to the lack of medical equipment, medications, sanitation, and educational programming (Lamarque Bastidas, 1993).

Additionally, despite recent recognition and efforts in decentralizing the structure of the Mexican health care system, much of the existing health care provision occurring within the various branches of the system is still centered around an authoritarian disregard for individual practitioner, patient perspectives, as well as the role that community partners can provide in managing chronic illness (de Keijzer, 1992). This research attempted to address this disconnect by seeking to better understand the experiences, knowledge, and perceptions of community stakeholders (i.e. patients, providers, and community leaders).

Epidemiological Transition and Diabetes in Mexico

Although diabetes has become a global health problem, individuals of developing countries, ethnic minorities, and disadvantaged communities in developed countries disproportionately face the greatest risks of serious long-term complications and thus are said to bear the greatest disease burden (King &

Rewers, 1993; Carolina & Gustavo, 2003; PAHO, 2005b). At the end of the last century, health researchers began to notice an "epidemiological transition", such that chronic-degenerative conditions were increasingly shifting the burden of disease away from acute-infectious diseases (Carolina & Gustavo, 2003; Soberon, Frenk & Sepulveda, 1986). That is, the primary causes of morbidity and mortality in Mexico were increasingly attributed to cardiovascular disease, cancer, and diabetes mellitus as opposed to acute respiratory infections, diarrheas, and fevers (Carolina & Gustavo, 2003; Soberon, Frenk & Sepulveda, 1986).

There is some debate regarding the nature of the "epidemiological transition" that is occurring within Mexico. Some authors have noted that, upon deeper analysis of epidemiological data, this transition is more apparent among the wealthier segments of the population. Whereas, the poorer segments are primarily contending with communicable disease-related mortality (i.e. pneumonia, tuberculosis, parasitic and infectious intestinal disorders and diarrheas, typhoid and salmonella infections) (Soberon, Frenk, & Sepulveda, 1986; Ward 1987). While this may have been true during the early part of the "epidemiological transition" as Mexico's National Health Surveys in the late 1980's and early 1990's as well as data from the PAHO indicated that primary causes of morbidity and mortality were respiratory, musculo-skeletal, and gastrointestinal infections, subsequent data from the PAHO and later National Health Surveys in the late 1990's revealed that three leading causes of were

heart disease, cancer and diabetes mellitus (Carolina & Gustavo, 2003; PAHO, 2006). Complicating the picture, however, is that even as this epidemiological transition is occurring in Mexico and despite the progress that has been made in the reduction of communicable diseases through successful vaccination and immunization campaigns across the country, the rural and urban poor are still experiencing a high incidence of communicable diseases (i.e. infectious respiratory diseases, parasitic and infectious intestinal diseases and tuberculosis) and are even seeing a reemergence of diseases many thought had been eradicated in the country, such as cholera, malaria and dengue (Carolina & Gustavo, 2003).

According to the PAHO, in 1999 diabetes mellitus was the third leading cause of mortality among adults ages 20-59 and the fourth leading cause of mortality among adults 60 years old and over. It is now the primary cause of mortality in the country. Recent evidence shows that diabetes is now the leading cause of mortality in women and the second leading cause of mortality in men in Mexico. It has also become Mexico's primary cause of limb loss and blindness. Diabetes is one of the top public health problems threatening the security of Mexico's economy, health care systems, and citizens. The current arrangement of the health system in Mexico is in danger of collapse, as it was not designed for the effective delivery of chronic illness care. For countries like Mexico, the health system faces the double burden of managing acute care conditions, especially communicable disease, as well as the rapidly increasing rate of chronic diseases

like diabetes. In 2001, it was estimated that 10-15% of the adult population in Mexico had diabetes and the incidence of diabetes is expected to double by 2025. In 2003, it was estimated that direct and indirect costs associated with diabetes in Mexico was over \$15.1 billion. At the household level, diabetes is also impoverishing many families in Mexico. As of 2004, roughly half of the population was uninsured and for those who were insured, 40-60% of the costs associated with diabetic care are paid for out-of-pocket.

Compounding this problem are the systemic inadequacies in the identification and diagnosis of patients that may have diabetes, as well as in access to essential medicines for treatment of the disease. Diabetes is a chronic disease that requires life-long treatment and monitoring, as well as, consistent utilization of health care services in order to reduce or delay the onset of related complications, and to prevent premature death from the disease. The Mexican government has recognized diabetes as serious threat for the health services in Mexico and to the economy and has attempted to develop policies aimed at the modernization of health services, improving diabetes and other chronic disease monitoring, improving treatment adherence, physician training, and the mobilization of health agencies.

Theoretical Frameworks

Over 30 years ago it had been suggested that in order to provide optimal provision of care for treatment and management of chronic illnesses, such as diabetes, there was critical need for reevaluating the widely accepted

"biomedical" model of care. It had been suggested that while the biomedical model may be a critically important approach to the provision of care, it would be better utilized if leveraged with the integration of psychiatric and social science frameworks. This integrative approach was termed the "biopsychosocial model (BPS)" (Engel, 1977; Katon & Kleinman, 1980) and implies that in the context of disease and illness, optimal treatment requires that the health care team address the biological (e.g. physiological functioning), psychological (e.g. beliefs, emotions and behaviors), and social influences (e.g. culture, socioeconomic status, physical environment) on a patient's functioning (Halligan, 2006; Santrock, 2007).

Over the last 15 years, two important and potential useful frameworks have emerged regarding the organization of care for chronic illnesses that have embodied this integrative approach. They are the Chronic Care Model (CCM) and the Innovative Care for Chronic Conditions Framework (ICCC Framework) and will be discussed below.

The Chronic Care Model

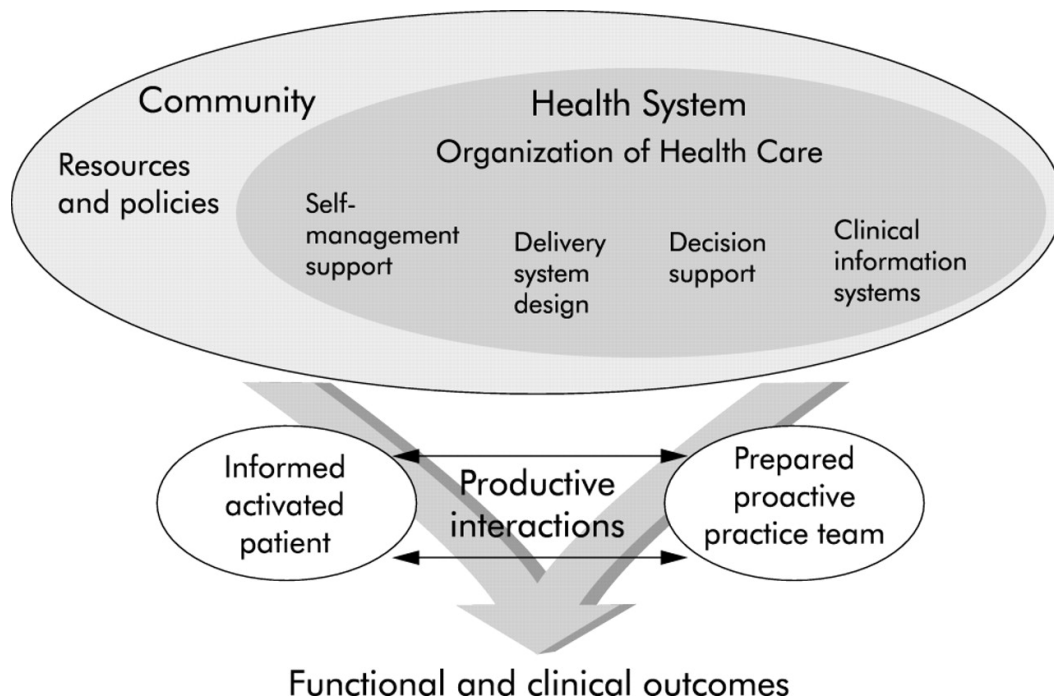
The Chronic Care Model (CCM) is perhaps the most well-known model that has been developed to address the organization of care for chronic illness. The CCM was first conceptualized in 1998 by Edward Wagner and later finalized in 2001 as an evidence-based conceptual framework "designed to help practices improve patient health outcomes by changing the routine delivery of ambulatory care through six interrelated system changes meant to make patient-centered,

evidence-based care easier to accomplish" (Coleman et al., 2009). It was based on an evaluation of the effectiveness of 72 chronic illness management programs, efforts to improve chronic illness management at Group Health Cooperative of Puget Sound in Washington, as well as from the recommendations provided by an advisory panel to Group Health's MacColl Institute for Healthcare Innovation (Wagner, 1998; Bodenheimer et al., 2002).

The CCM suggests that chronic care occurs within the overlapping realms of: (1) the community (i.e. resources as well as public and private policies); (2) the overall health care system; and (3) the provider organization (i.e. integrated delivery system, clinic, or network of physician practices). Within these realms, six essential elements of the CCM have been identified as: (1) community resources and policies; (2) health care organization; (3) self-management support; (4) delivery system design; (5) decision support; and (6) clinical information systems (Bodenheimer et al., 2002). Collectively, these elements were suggested to support developing informed and activated patients as well as prepared and proactive healthcare teams, in which interactions between these two parties would lead to productive and satisfying chronic illness care (Epping-Jordan et al., 2004). See Figure 1. The Chronic Care Model below (CCM).

The first element, Community Resources and Policies, has been defined as the supportive or educational resources that may not be available within the health care system. Thus it is posited that in order to improve the care for chronic

Figure 1. The Chronic Care Model



illnesses, the provider organizations must establish linkages with the community-based resources (e.g. exercise programs, self-help support groups, senior centers) which can be especially helpful for smaller physician offices or provider organizations with limited resources.

The second element, Health Care Organization, has been defined as the broader provider organizational level where its structure, mission, and values in conjunction with its relationships with purchasers, insurers and other providers serve as the backbone from which the remaining 4 elements are comprised. It is posited here that innovation will not take place if chronic care is not a priority set by the organization's goals and leaders. This is largely dependent on reimbursement environment and whether purchasers and insurers are willing to

reward chronic illness care quality and without either improvements in care for chronic illness will not be sustainable.

The third element, Self-management Support, has been defined as assisting patients and their families acquire the knowledge, skills and confidence for managing illness through collaboration within the health care organization. This entails using a collaborative approach to teaching patients and families important elements of managing chronic illness such as diet, exercise, and self-measurement, as well as providing them with self-management tools (e.g. glucometers, specially formulated diets, referrals to community resources) and routine assessment of problems and successes.

The fourth element, Delivery System Design, has been defined as the organization of medical practice that separates acute care from planned management of chronic illness. This involves establishing practice teams based on a clear division of labor where physicians and non-physician team members have clear complementary roles. For example, physicians may treat acute problems, intervening in difficult chronic illness cases, and train other team members; whereas non-physician team members support patient self-management, arrange for routine periodic follow-up assessments (e.g. glucose monitoring, eye and foot examinations) and ensure that patients with more complex conditions or greater needs receive more intensive care from team members and community resources. Planned visits are especially important for ensuring productive interactions between the patient and the health care team.

The fifth element, Decision Support, has been defined as those interventions that have been developed for improving provider knowledge and skills and providing access to the expertise needed to treat patients with complex chronic illnesses. This can occur through the use evidence-based clinical practice guidelines or protocols that establish standards for ensuring that providers are prepared and proactive in administering effective treatments targeted for achieving optimal chronic illness care.

The final element, Clinical Information Systems, has been defined as the information technology that is used to provide timely and useful data on individual patients and populations of patients. This can include written or computerized systems, as long as they employ population based strategies such as outreach or directly observed therapy. An essential component of the clinical information system is the chronic illness/disease registry or database that contains information about the processes and results of care for all patients, such that it provides the health care team with a mechanism for contacting patients with specific need, delivering planned care, receiving feedback on performance, and complying with practice guidelines through the use of a reminder system.

The CCM has been used to guide over 1000 health care organizations, including about 500 community health centers, in their efforts to improve care for chronic illnesses in America (Epping-Jordan et al., 2004). The literature suggests that most of these organizations have achieved measurable improvements in the quality of care and that many of the most successful strategies used for achieving

improvements in chronic illness care have been consistent with the concepts and components outlined by the CCM (Bodenheimer et al., 2002). However, the evidence regarding how the CCM is to be implemented is rather mixed. In a review of various single and meta reviews, Nolte and Mckee (2008) noted that while there is empirical evidence suggesting that individual and/or multiple components of the CCM are associated with improvements in selected care processes and health outcomes, there is little evidence supporting the implementation of the entire model as essential for achieving the same results.

Another meta-analysis found that the majority of the empirical evidence surrounding CCM implementation is primarily focused on four of the CCM components: Self-management support; Delivery system design; Decision support; and Clinical information systems. The role of the other two components: Community resources and policies; and the Health Care Organization (e.g. the organization of health care providers) have not been addressed in the literature (Zwar et al., 2006). This may, however, be a reflection of the fragmentation of health care services that exists in those countries where various aspects of the CCM have been implemented by many health care organizations but have not yet been extended across the broader public health level of the country (Epping-Jordan et al., 2004).

In addition to the mixed evidence surrounding the implementation and overall effectiveness of the CCM, adoption of the model has been limited for a number of proposed reasons. Some suggest that the costs associated with implementing

the CCM are significant as they require extensive training of personnel, the acquisition of newer technologies, and a significant amount of time that leads to reduced patient loads or longer waiting times for patients as health care team members must attend trainings and meetings (Coleman et al., 2009). Others suggest that adoption may be limited because of the "lack of broader based political, financial, and community support" especially in the absence of explicit policy directives for organizing the health care system for the management of chronic illnesses (Epping-Jordan et al., 2004).

On a more a fundamental level, some suggest that partial adoption of the CCM may be due to its lack of patient-centeredness. That is, within the model, individual patients are not necessarily the focus of the surrounding processes of care provision, but rather are active players or recipients of care that must "fit within a clinical pathway or map" of a larger encompassing organization of care (Lubkin and Larsen, 2002).

Recognizing these limitations, especially in the context of the relevance and applicability of the CCM for improving care in developing countries, the Innovative Care for Chronic Conditions Framework (ICCC Framework) was developed to provide a guide for improving the fragmentation of health care services and providing an opportunity to develop or exploit mechanisms that link broader public health interventions (Epping-Jordan et al., 2004).

The Innovative Care for Chronic Conditions Framework

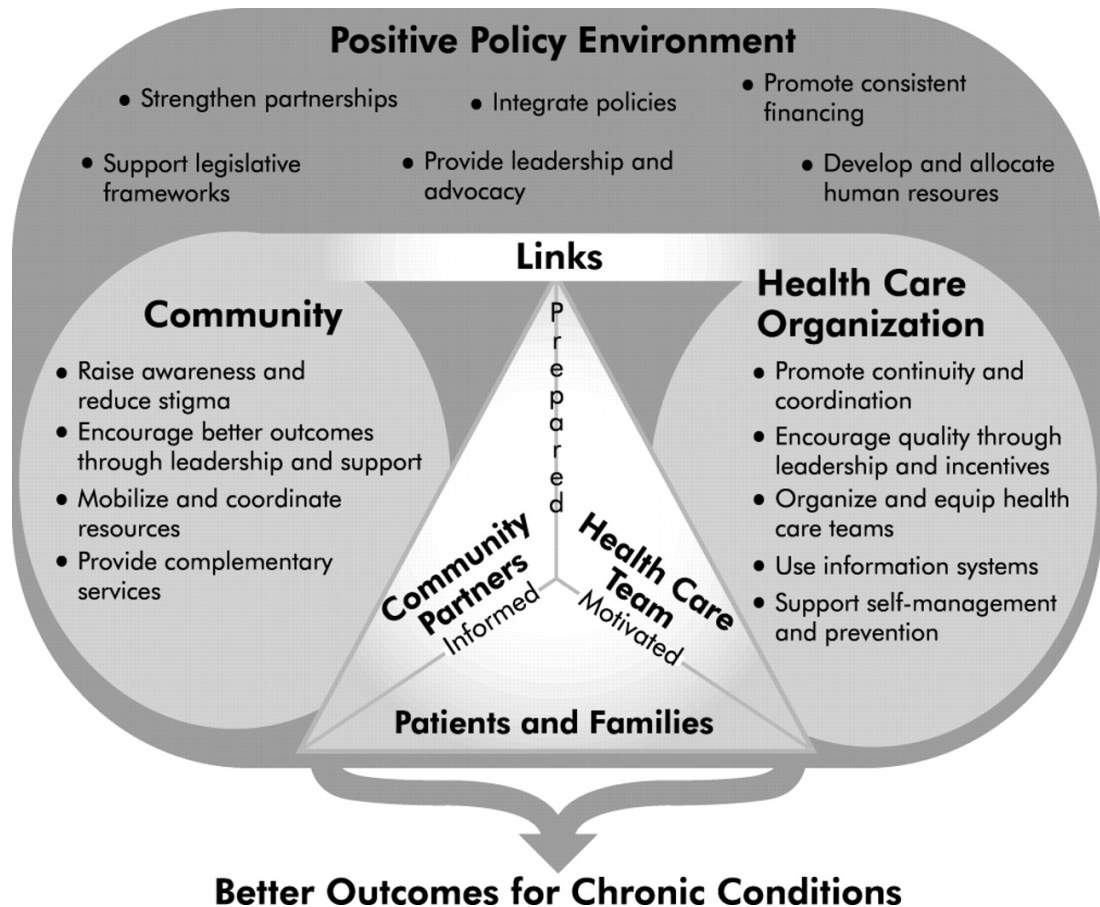
In 2002, the ICCC Framework was introduced by the World Health

Organization (WHO) in an effort to adapt the CCM for policy development and health care system redesign from a global perspective, with special consideration for developing countries. The framework was the result of collaborative efforts of the WHO, health leaders from Africa, Asia, Eastern Europe, Latin America, the MacColl Institute for Healthcare Innovation, and Edward Wagner seeking to revise and expand the CCM in response to the dramatic increase in chronic illnesses, globally, and the need to help countries develop their health care systems accordingly (Epping-Jordan et al., 2004; WHO 2002).

The ICCC Framework is conceptually linked to the CCM, however, unlike the CCM, it places emphasis on different aspects of what is considered to be "good" care for chronic illnesses. That is, it emphasizes the role of community and of policy for improving care while also emphasizing the role patients and their families as "health producers" and recognizing that chronic illnesses may be most effectively managed with the support of their community and their health care teams (WHO 2002; Epping-Jordan et al., 2004). See Figure 2 below.

This change in emphasis places the relationships between patients and their families, the health care team, and community partners at the center of the care process, whereby the CCM dyad (e.g. patients and health care team) becomes the ICCC triad and subsequently comprises the "micro-level" that is influenced by both the overall organization of health care and the broader policy environment and it is the "micro-level" that this study is most concerned with, thus much of the ensuing discussion will be directed toward providing a more concise

Figure 2. The Innovative Care for Chronic Conditions Framework



account of the “micro-level” rather than the entire framework. See Figure 3 below.

By incorporating the community in the health care provision and management processes, there is a greater recognition of the role that community leaders and caregivers can provide for improving how care is accessed and provided within the community. In order for this transformation to be successful, however, there is also an emphasis placed on each member of the ICCC triad being informed, motivated, and prepared; thus enhanced levels of integration are necessary for all members of this partnership to communicate and collaborate efficiently and

Figure 3. ICCC Triad



effectively (WHO 2002).

While incorporating and emphasizing the potential role for community partners presents a significant transformation of the CCM to the ICCC Framework, one of the, arguably, most significant changes is the expansion and recognition of the need for patients and families to be more than “informed and activated” but to be “informed, motivated, and prepared.” This suggests that it is not enough for patients and families to be “activated” but they must also have adequate access to the essential medication and medical equipment, self-monitoring tools, as well as self-management skills. That is, as the WHO (2002) suggests, patients need to be informed about their health condition and any chronic illnesses they have, such as diabetes. However, they must also be

informed about the expected course of treatment, management and potential progression of the illness, along with any expected complications they may encounter. In addition, patients need to know what effective strategies are available for preventing complications and managing symptoms. Patients also need the motivation: to change and maintain health behaviors; to adhere to long-term therapies; and to self-manage their illness. Instrumental to this is the realization and understanding that patients and families must also be prepared with behavioral understanding and skills to effectively manage their illnesses at home. However, in order to do so, patients and families must also have access to the necessary care, medications and medical equipment, as well as the self-monitoring tools and self-management skills to ensure that optimum health outcomes are possible (WHO 2002, Epping-Jordan et al, 2004).

Along with need for patients and families to be more than just “activated,” the ICCC Framework emphasizes the critical need for the health care team to be more than just “prepared” from a professional standpoint. It suggests that the health care team needs to “informed and motivated” as well, requiring a greater degree of integration, collaboration, and accountability to accept the roles and responsibilities for the tasks inherent within their professional strengths and capacities. However, in doing this, each team member must be willing to recognize the need for a flattened hierarchy within the care provision processes as well as accepting that there must be a transition away from physician dominated models, whereby each team member is valued for their unique

contribution to the management of chronic illnesses (WHO 2002).

As described previously, a major transformation from the CCM to the ICCCF Framework is the inclusion of community partners. The emphasis upon inclusion and integration of the community by ICCCF Framework recognizes and reflects the significant roles that communities undertake in many developing countries concerning public health and economic development issues. This emphasis on being “prepared, informed, and motivated” community partners suggests that in order for this inclusion to be effective, community partners must be equipped with the information and skills that are essential for successfully managing chronic illnesses. It recognizes that they provide an “untapped collection of individuals” that can complement and support the care that is provided by the broader health care organization and thus may be able to reduce unnecessary demands for tertiary care or follow-up and monitoring services that in many countries are typically provided by an already over-extended formal health care organization (WHO 2002). That is, community partners can provide a critical bridge in the gap that often exists between the more formal organized clinical care and the real world challenges faced by patients and their families (Epping-Jordan et al., 2004).

The ICCCF was chosen as it incorporates important concepts, theories and models that can be leveraged to study the health situation of communities around the globe and the data generated can inform the development of strategies to improve the public health of these communities that are appropriate at the

community level. Such an application is appropriate, in that it is my hope and intention that the results generated from this research project be used by the community to inform the design and implementation of strategies aimed at improving the care and treatment of people with diabetes and other chronic diseases across the continuum of care (e.g. prevention, diagnosis, treatment, management).

The ICCC Framework provides a guide for the organization of care for treating and managing chronic conditions within the context of the challenges faced within many developing economies, such as Mexico. However, the ICCC Framework is limited in its ability to further explain actual mechanisms at work in trying to link broad population based and public health interventions, and more critically within the dynamic relationships at the micro-level of the ICCC triad of the health care team, patients and families, and community partners. In order to address this shortcoming, especially regarding the ICCC triad, this study examined the perceptions and experiences of each element of the triad using Social Capital Theory.

Social Capital Theory

Social capital has become an increasingly popular construct among health service researchers and development agencies alike, where alternative mechanisms for developing capacity and access to health care and improving the overall health and well-being of communities are being sought, especially in areas experiencing widespread poverty and social inequity. The allure of social

capital theory is that it integrates concepts that have received much attention in health research literature and have been shown to be associated with improved health outcomes. These include the concepts of social support and social networks (Glanz, Rimer, and Lewis, 2002). Glanz, Rimer and Lewis (2002) suggest that with regard to health, social capital can be defined by the horizontal relationships among community members and can be measured through concepts of "trust, reciprocity, and civic engagement such as in voluntary organizations." In the health care literature, social capital has been linked to the transmission of health information, access to health care resources, psychosocial processes such as affective support, establishing and managing health norms, and has been discussed as a mediator between income inequality and health (Glanz et al., 2002; Kawachi and Berkman, 2000; Kim, Subramanian, and Kawachi, 2006; Lin, 2001; Wilkinson, 1996).

The social capital perspective has been used across disciplines to describe and promote economic development, political stability and the health of communities (Portes & Landolt, 1996; Putnam, 1995). Clarke & Foweraker (2001) suggest that primary impetus behind the social capital perspective is "that strongly developed social norms of trust, reciprocity and co-operation are typically accompanied by dense networks of voluntary organizations. These in turn are associated with high levels of civic activity and political participation, which help to produce social integration and co-ordination, create an awareness of the common good, and help society overcome some of the problems of

producing public goods and achieving common goals." Social capital builds upon the conceptualization of capital and is differentiated in its extension beyond the physical and human forms of capital. Coleman (1990) suggests that physical capital consists of tangible, material goods and resources, while human capital consists of intangible resources such as the skills and knowledge that may be acquired by an individual or community. Social capital, however, is defined with regard to its function, such that it is "the value of those aspects of social structure to actors, as resources that can be used by the actors to realize their interests" (Coleman, 1990). The two vital components of the social capital perspective are that of trust and social networks. Within the context of public health and social capital, the concept of trust is instrumental in that it can promote cooperation between individuals in a given community and can thereby enable the community to collectively achieve social goals that may not have otherwise been possible at the individual level (Clarke & Foweraker, 2001). Additionally, the concept of social networks becomes important as they can provide individual social relationships with a structure for generating support that may act as a buffer against the stressors of illness and disease.

The World Bank defines social capital as " the institutions, the relationships, the attitudes and values that govern interactions among people and contribute to economic and social development" (Grootaert & van Bastelaer, 2001). This definition has been suggested to have been heavily influenced by Putnam's definition of social capital, in that it "refers to features of social organization such

as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit" (Putnam, 1995). According to Grootaert & van Bastelaer (2001) the World Bank views social capital as more than a contribution to collective action. That is, social capital can be viewed as an outcome as well, such that social capital can potentially influence the production and utilization of physical and human capital, which in turn can increase the existing social capital in a community. Thus, according to the World Bank's views, developing an understanding of and increasing the existing social capital within communities can play an instrumental role in promoting and ensuring sustainability of economic and community development activities.

Considering the potential value that could be gained through improving the understanding of the social capital possessed by a community and vis a vis, its ability to develop and access other goods and services, the World Bank instituted the "Social Capital Initiative (SCI)" in 1996 (Grootaert & van Bastelaer, 2001). The SCI consisted of three primary objectives: "(1) to assess the impact of social capital on project effectiveness; (2) to identify ways in which outside assistance can help in the process of social capital formation; and (3) to contribute to the development of indicators for monitoring social capital and methodologies for measuring its impact on development" (Grootaert & van Bastelaer, 2001). In pursuit of these objectives, the SCI funded 12 research projects in which six were focused on the role of social capital in improving access to public goods and services as well as increasing household income (Fafchamp & Minten, 1999;

Isham & Kahkonen, 1999; Krishna & Uphoff, 1999; Pargal, Huq, & Gilligan, 1999; Reid & Salmen, 1999; Rose, 1999). Five of the other projects were focused on the effect of policy or donor interventions on the functioning of social capital (e.g. improvement or deterioration of) within various communities (Bates, 1999; Bobbington & Carroll, unpublished; Colleta & Cullen, unpublished; Grootaert & van Bastelaer, 2001; Gugerty & Kremer, 2000; Pantoja, 2000). Using the findings from the previous 11 projects, the final project was charged with developing a tool for assessing social capital (Krishna & Shrader, 2000).

Further analyses of these empirical studies contributed to conceptual framework and methodology that was subsequently developed by the World Bank for assessing social capital. In doing so, the definition of social capital was reevaluated and deconstructed based on what the SCI believed were the three essential characteristics of social capital: the scope, its forms, and channels; thereby facilitating further study for developing and improving the methods for measuring these characteristics and identifying how social capital is enacted and in what ways it affects economic and community development.

The SCI's conceptualization of the scope of social capital is divided among three tiers or levels of analysis that in essence help define the unit of observation: micro, meso, and macro. The conceptualization of the micro level is influenced by the works of Robert Putnam and his analyses of civic association, in that social capital can be thought of as the product of "social organization, such as networks of individuals or households, and the associated norms and values, that

create externalities for the community as a whole," (Grootaert & van Bastelaer, 2001). Thus, the micro level is essentially comprised of the horizontal links that are formed and utilized among both formal (community organizations, group memberships, etc.) and informal (individual, family, friendships, etc.) networks within a community and governed by the shared norms and values inherent within these relationships.

The conceptualization of the meso level is credited as being influenced by the works of Coleman, in that his definition of social capital is aimed at the structural level. That is, social capital is comprised of the vertical and horizontal linkages that "are characterized by hierarchical relationships and an unequal power distribution among members" of a group (Grootaert & van Bastelaer, 2001). Synthesizing these works and expanding further, the conceptualization of the macro level suggests that social capital consists of the "formalized institutional relationships and structures" within a community as well as the horizontal and vertical ties that may exist among its individual members (Grootaert & van Bastelaer, 2001). That is, social capital at the macro level can be analyzed through the nature of the political environment, the laws that govern the community, and the civil liberties afforded to its members.

The second characteristic of social capital, defined by the SCI, is that of the forms of social capital and are divided into two distinct forms that aid in describing/defining how social capital manifests: cognitive and structural. Structural social capital has been noted as the rather objective form in that it

manifests through the sharing of information and collective action that can occur through participation in social networks and associations that are governed by the rules, precedents and roles that have been established by its participants. Whereas, cognitive social capital is noted as the more subjective form, such that it describes the norms, values, attitudes, beliefs and levels of trust that are shared by members of formal as well as informal networks (Grootaert & van Bastelaer, 2001).

The third characteristic, as defined by the World Bank's SCI, is that of the channels of social capital. The channels of social capital are the means through which community development is affected as it occurs across and within the micro, meso, or macro levels. Whether or not it occurs in the structural or cognitive form, it is essentially viewed as a positive attribute that can produce a "stream of benefits," such as those that can be produced by the sharing of information and collective action and decision making (Grootaert & van Bastelaer, 2001).

CHAPTER 3: RESEARCH DESIGN AND METHODS

Introduction

This chapter will revisit elements of the previous two chapters by providing a brief overview of the problem and a re-statement of the proposed research questions. Additionally, this chapter will explore important concepts influencing the research design, the methods used for data collection and field procedures that were employed, and the data analysis process.

Problem Explication

While there has been a dramatic increase in the prevalence of diabetes in developing countries, such as Mexico, a dearth in academic literature exists regarding how these countries have prepared their health systems for addressing the increase in chronic diseases, such as diabetes. The existing literature regarding health care provision within Mexico has thus far discussed the evolution of national policy and health care reform or individual experiences with health care provision. It is evident that there is a critical need to better understand how the challenges posed to the health care system that are associated with the increase in chronic diseases are manifested at the level of patient care provision in the health care organization *and* the community. This is especially true of rural resource-poor communities, as the vast majority of health related studies occur in the urban centers within many developing countries, including Mexico.

Additionally, research is needed to better understand how the dynamic components inherent in the provision of care to patients in the health care

organization and the community are affected by the challenges that arise in shifting the focus from acute care to care for chronic conditions, especially in terms of accessibility to care and treatment for diabetes in rural resource-poor communities. This research aimed to address these issues with the hope that evidence provided by this study would help inform local-level policy decisions about the provision of care for people with chronic conditions, such as diabetes, especially with regard to redesigning, restructuring, and/or improving health care provision with a population focus that can be translated through to the primary care level across both rural and urban health care settings.

Research Questions

The purpose of this study was to use an action research approach and a chronic care model to study access to and provision of care for patients with diabetes in Xicotepec, Mexico. I was interested in assessing patient and health care provider experiences, the health care organization's ability to provide the necessary care for diabetic patients, and its links to the community in doing so; as well as the health-related beliefs associated with diabetes and treatment of various community stakeholders. That is, the objective of this study was to examine the provision of health care for diabetes and the beliefs and relationships that exist among patients and families, health care teams, and community partners that affect treatment and care for diabetes in a rural resource-poor community in Mexico. I expected to achieve this objective by answering the following questions:

Main research question: What are the factors that influence the provision of diabetes care in a rural community in Mexico?

Subquestion 1: How do health care providers and patients perceive the current performance of the provision of care for diabetes in the community?

Subquestion 2: What are the diabetes-related health beliefs among patients, health care providers and community members that could influence care for diabetes?

Subquestion 3: What resources are available within the community and how do patients, health care providers and community members perceive the existing linkages between patients and families, health care teams, and community partners and resources related to care for diabetes?

Subquestion 4: How can the concept of social capital be used to gain a better understanding about the dynamic relationships within the ICCC Triad of health care providers, patients and families, and community partners, in the context of improving access to and provision of care for diabetes?

Research Design

This dissertation was designed as an exploratory multiple case study incorporating a systematic qualitative action research approach. Data were collected via community asset mapping, surveys, semi-structured interviews, and group discussions. Utilizing an action research approach, the study procedures were iterative, whereby results from selected data collection techniques were

used to inform subsequent iterations of data collection throughout the study.

Why an “action research” approach?

Action research has been used within a variety of disciplines, spanning from the social sciences, to business, medicine and education. According to Berg (2004), an action research approach is often called upon by these varying disciplines because action research is considered to be a “highly rigorous, yet reflective or interpretive approach to empirical research” that integrates practical outcomes related to the actual lives of the participants in the research enterprise and is conducted through a “spiraling” of steps in which each step is comprised of some form of planning, action and evaluation. Rapoport (1970) presented, perhaps, one of the most commonly used and understood definitions of this approach in that: “Action research aims to contribute to the practical concerns of people in an immediate problematic situation and to the goals of social science [...]” Years later, action research was described in a more concise way by McKernan (1988) as “a form of self-reflective problem solving, which enables practitioners to better understand and solve pressing problems in social settings.” Greenwood and Levin (1998) would argue, however, that action research is more than practical problem-solving in that it “is a disciplined way of developing valid knowledge and theory while promoting positive social change.”

As the definition of action research has been interpreted and expounded upon over time, Argyris and Schon (1991) have explained the methods and goals of action research as an intellectual tradition where: “Action Research takes its

cues-its questions, puzzles, and problems from the perception of practitioners within particular, local contexts. It builds upon episodes of research according to the boundaries of the local context. It builds descriptions and theories within the practice context itself, and tests them there through intervention experiments-that is, through experiments that bear the double burden of testing hypotheses and effecting some desired change in the situation.” Additionally, as Berg (2004) points out, action research uses many of the traditional data-gathering and investigative techniques, and in doing so, it takes into account the study population’s history, culture, interactive activities, and emotional lives. While this may be very similar to many qualitative traditions, the process that action research utilizes while incorporating these techniques is a differentiating factor. Qualitative research in general is regarded for being responsive to situational contexts and action research embraces this characteristic in an organized spiral, rather than linear, progression of procedures. That is, the action research process involves an iterative spiral consisting of a form of planning or intention, taking an action, and review or critiquing during each cycle of the spiral allowing for flexibility and responsiveness to the environment. The overlapping of action and reflection allows changes in plans for action as people learn from their experiences (Marsick & Gephart, 2003).

In the tradition of the action research approach, this study employed an iterative spiral of data collection (see methods described below) that occurred throughout the study in order to challenge the information and interpretation from

previous cycles as well as provide a gradual refinement in the understanding of the factors that may influence access to and the provision of diabetes care in the Xicotepec community. This is an especially important consideration and characteristic of the action research approach in that the flexibility that was inherent in the approach allowed the researcher to remain responsive to the situation. Maintaining this ability was particularly important given the broad nature of the research questions and methods that were used in this study. However, the iteration process involved in the approach allowed for more refined questions and methods with each turn of the cycle; thereby allowing a convergence toward a more precise, if not at least, deeper understanding of how the triad of stakeholders (patients and their families, the health care team, and community stakeholders) perceive, affect, or are affected by factors that are related to the access to and the provision of care for diabetes.

Why an exploratory case study design?

Case studies have been defined as “an exploration of a ‘bounded system’ of a case or multiple cases over time through detail, in depth data collection involving multiple sources of information rich in context” (Creswell, 1998). Exploratory case studies can be used to provide preliminary investigations for generating ideas, hypotheses and a deeper theoretical understanding of a central phenomenon that can then be empirically tested at later stage. As an exploratory action research study examining the provision of health care for diabetes in Xicotepec, this study sought to facilitate the design of future research,

intervention activities and evaluation studies of diabetes care on a more comprehensive scale as well as continue to develop a theoretical foundation for the Innovative Care for Chronic Conditions Framework. That is, the limited availability of empirical literature describing how the relationships among patients and families, health care teams, and community partners affect the provision of health care for chronic diseases, such as diabetes, necessitated the need for preliminary investigations of the factors that influence care provision, and in this particular case, in rural communities in Mexico. Additionally, this study sought to enrich the ICCC Framework literature by exploring concepts embedded in social capital theory in relation to the principles described in the ICCC Framework for promoting optimal health outcomes. Thus, I believe this dissertation provided a unique opportunity for not only building upon the theoretical foundation that is inherently lacking within the ICCC Framework but that it also provided an opportunity to explore how theory and practice may influence each other.

Case Selection

For this project, the unit of analysis was the “ICCC Triad” that is at the epicenter of diabetes care (as defined previously by the ICCC Framework, see chapter 2) and is made up of 3 embedded subunits: (1) patients with diabetes and their families; (2) the health care team; and (3) community partners. More specifically, while the unit of analysis is somewhat abstract, the embedded subunits served as separate cases that, when used collectively provide an opportunity to gain insight into the central phenomenon being studied (Creswell,

2002; Stake, 2006; Yin, 2003). In this project, cases were selected on an opportunistic and purposive basis, given that access to and provision of care for diabetes is only immediately relevant to a smaller subset of a larger population but with the recognition that broader contextual influences may have also been present. Therefore, selected cases included patients who have been diagnosed with diabetes, patients who have not been diagnosed with diabetes, health care team members (e.g. Physicians, Nurses, Allied Health Professionals, and peripheral health care resources such as Herbalistas and Naturistas), as well as additional community stakeholders (e.g. Municipal government leaders, local Non-Governmental Organization (NGO) leaders, Business leaders). Actual case selection procedures varied by the method of data collection employed as well as through a reflexive consideration of the information being gathered throughout the data collection process. All cases, however, were only selected among people residing in municipality of Xicotepec de Juarez, Puebla, Mexico. More specific case selection procedures will be explained further below (see *Data Collection Methods*).

Triangulation

At the heart of the action research and case study method traditions is the opportunity to utilize many differing sources of evidence. This is known as *triangulation*, and it can take five primary forms: (1) Data Triangulation; (2) Investigator Triangulation; (3) Theory Triangulation; (4) Methodological Triangulation (Denzin, 1970); or (5) Data-Analysis Triangulation (Kimchi et al.,

1991). Triangulation is often used to increase the validity and strengthen the interpretative potential of a study as well as to provide a comprehensive multiperspective view of the phenomena of interest (Denzin, 1970; Boyd, 2000). According to Jick (1979), triangulation: (1) can enhance the confidence in the research data collected; (2) can promote innovative ways for understanding a phenomenon; (3) may uncover unique and/or unexpected findings; (4) can be used to challenge or deepen theories; or (5) may simply provide a clearer conceptualization of an identified problem.

Of particular importance to this project were the concepts of data triangulation and methodological triangulation. Data triangulation involves using different data sources that may vary based on time of data collection, the setting in which data collection occurred, and the persons from whom data were collected (Denzin, 1970; Mitchell, 1986). Fielding and Fielding (1986) suggest that the confidence in the findings is increased when atypical data are revealed or when patterns are identified through variances in people, setting, or time. A particular advantage to using data triangulation lies in the robustness of the data that can be generated for interpretation, especially when multiple sources of data are utilized (Banik, 1993). This is inherent in the multiple case study design that was chosen, whereby multiple sources (or cases) for data will be used to gain a better understanding of the more general dynamics operating within the ICCC Triad related to diabetes care.

Methodological triangulation, on the other hand, refers to the use of multiple

data collection methods and often references qualitative and quantitative methods that can be used to balance the weaknesses of one method with the strengths of another (Goodwin and Goodwin, 1984; Mitchell, 1986). Lincoln and Guba (2000) suggest that utilizing mixed-method approach is not only sensible, but that by doing so the researcher allows the best of qualitative and quantitative worldviews to be represented. This can be especially useful for uncovering meaningful information or unique cases that may not have otherwise been realized with the use of only one data collection technique (Thurmond, 2001). The study also incorporated this form of triangulation in an effort to expose any unique differences in the experiences of the various stakeholders in the community and/or to uncover any rival explanations for any observed phenomena that may have otherwise remained hidden if certain data collection methods were not incorporated.

Gatekeepers

For social science researchers, key informants can serve as gatekeepers to the community of study and can be instrumental in helping the researcher gain access and develop trust within the community. Key informants are often well versed in the social phenomenon being studied and are usually willing to talk at liberty about the phenomenon (Hatch, 2002; Babbie, 2007). Over the last three years, I have collaborated with two key informants whom have been instrumental in the development of this project and were significant collaborators in the field. Relationships with both key informants were developed during prior trips to the

field site, where I travelled with a group from various Iowa Rotary International service clubs, whom had already established a unique relationship with the community.

The two key informants were members of Rotary International (the Mexican counterparts) from the community. Both key informants are physicians practicing in the community, one as a private-practice general medicine physician and the other as an Orthopedic/Trauma Specialist practicing within the Hospital Integral. Both have been very involved in the development of the community through various organizations such as service clubs like Rotary International and are well regarded in the community.

Data Collection Methods

Utilizing an action research approach, the data collection procedures were iterative, whereby results from selected data collection techniques were used to inform subsequent iterations of data collection as the study progressed. While iterative spirals occurred throughout the study, the study was designed across two distinct phases: Phase I and Phase II. Each phase consisted of a 3-4 week field site visit. See Table 1 below.

During Phase I, I engaged in mapping of community assets, the administration of three survey instruments, and semi-structured interviews with community stakeholders. Phase I was to serve as a preliminary “reconnaissance” portion of the study that would allow me to gain initial insight regarding the contextual environment from which care for diabetes is situated in Xicotepec. At

Table 1. Data Collection Methods

Data Collection Methods	
Phase I (Field Site Visit 1: 3- 4 Weeks)	Phase II (Field Site Visit 2: 3-4 Weeks)
Community Asset Mapping	Semi-Structured Interviews
Surveys	Surveys
Semi-Structured Interviews	Group Discussion

the conclusion of Phase I, initial analysis of the data was conducted. This initial analysis was used to inform the data collection methods that were employed during the Phase II portion of the study. For example, an initial analysis of the DKQ-24 suggested that diabetic patients had a limited understanding of how diabetes is developed. The initial semi-structured interview guide did not include this topic, however it seemed like an important topic to learn more about so it was then added to the semi-structured interview guide for diabetic patients.

During Phase II, I administered the remaining surveys and conducted semi-structured interviews and a group discussion utilizing the action research iterative process. While the distinction between Phase I and Phase II illustrated, explicitly, the iterative process that was incorporated, subsequent iterative spirals were less conspicuous throughout Phase II where questions and probes were refined as I maneuvered between surveys, semi-structured interviews with important stakeholders and the group discussion with community leaders.

Phase I

Community Asset Mapping

Community asset mapping was utilized in this study to gain a better understanding of the socio-ecological environmental factors that influence and support the ICCC triad of patients and families, the health care team, and community partners; such as the structure and organization of assets and resources within the broader community, the larger health care system/organization, and the policy environment.

Community asset mapping facilitates a quick comprehension of the spatial location of health care services and other assets in a community that can be helpful in identifying any access issues as well as for providing information on locations or resources that may be important to discuss during later data collection periods. At the basic level, community asset mapping provides information about the resources (tangible and intangible) within a community that can be used to develop or identify possible solutions to community-based problems. Community Asset Mapping is based on the work of Kretzman and McKnight (1993), who are credited with the development of the concept and practice of asset-based community development (ABCD). Mathie and Cunningham (2002) suggest that ABCD is influenced by the recognition of social capital and collaborative economic development models that emphasize using a community's resource base as something to be preserved and enhanced. A community asset map can also influence participatory approaches for strengthening civil society through engaging the community as citizens rather than clients. A community's assets can be operationalized as people, physical

structures, natural resources, institutions, businesses, or informal organizations (Berkowitz and Wadud, 2003). An integral part of the ABCD process involves developing an inventory of assets and capacity, building relationships, leveraging available (internal and external) resources to support action to achieve a community determined vision of the future (Beaulieu 2002). Asset mapping then takes this inventory and depicts the assets in a map, such that it facilitates analysis and communication about community issues, assets, and strategies for addressing community needs and health.

Within the last few years, the field of public health has begun to embrace spatial data and mapping, where public health researchers look for tools that will enable them to better understand critical health issues and the role that community and other environmental factors have on individual health and health disparities (Saalens et al, 2003; Robinson and Sirard, 2005). Public health researchers and health equity advocates have used community mapping and GIS (Geographic Information System) tools to study health disparities as well as develop projects and policy campaigns to improve the health of the community. Notable studies have used GIS and mapping to better understand the implications of local food environments for health (Pothukuchi, 2004), the implications of parks and open spaces on physical and mental health (Schoch, 2007), and the implications of occupational exposure to environmental hazards to health (Steinberg and Steinberg, 2008).

During Phase I of this project, a Community Asset Map of the Xicotepec

community was produced, with a particular emphasis on how the community environment may impact the health of diabetic patients. This method is supported by the extensive literature that has previously examined the effects of neighborhood environments on health (Diez, 2001; Diez et al., 2007; Cohen et al., 2000; Kawachi et al., 2003) and will be adapted based on previous literature that used Google Earth for community mapping Bronx neighborhoods in relation to diabetes and obesity (Lefer et al., 2008). The methods provided by Berkowitz and Wadud (2003) for identifying community assets and resources were used.

Upon arrival to Xicotepec, I utilized the assistance of two primary key informants in the Xicotepec community that have been instrumental with helping develop this study over the last three years. The following describes the procedures that were utilized to develop the community asset map:

(1) Community boundaries were defined and identified on a map (hard copy) printed from Google Maps.

(2) Assets that were included in the community map were specified as they relate to assets that could be leveraged for the treatment and management of diabetes. Input was solicited of key informants to help identify locally relevant assets.

(3) An inventory was created of particular assets to be identified during the mapping/canvassing was carried out in the community. Assets were initially categorized based on one of the six types of assets: (see Table 2 below) (1)

Individual Assets; (2) Institutional Assets; (3) Organizational Assets; (4) Governmental (State and Federal) Assets; (5) Physical and Land Assets; and (6) Cultural Assets.

(4) The previous inventory was then used to create an additional inventory of the groups in the community (these can be within the Organizational, Institutional, Governmental, or Cultural Assets). Input was solicited of key informants to further identify groups within the community that may be resources for those with diabetes.

(5) The groups identified in the inventory were organized and special attention was placed on describing their location, the types of services offered, membership requirements, governance, available resources (material, facilities, staff), as well as their influence and legitimacy in the community.

(6) The community was explored (on foot) and utilizing the inventories that had been created, a GPS receiver was used to record the location/geo-coordinate data that can then be input into Google Maps and Google Earth to organize the assets on the map.

(7) In addition to the wider array of assets that have been discussed and that were inventoried above, this project incorporated the methods used by Lefer et al. (2008) to provide special attention to sources of exercise and food throughout the community, as they are critical aspects related to both the development and

Table 2. Community Assets

General Asset (By Type)	Diabetes-Related Assets	Key Informant Identified Diabetes-Related Assets
Individual Assets Individuals and their: Skills, Talents, Experiences Consider: Professional, Personal, Resources, Leadership, Networks	Health Care Professionals (physicians, specialists, nurses, allied health professionals), Community Leaders, Non- Western health practitioners (Curanderos, Herbalistas, etc) Family, etc.	Examples from previous visits: private and hospital physicians, handful of specialists, nurses, herbalistas, naturistas, homeopathic practitioners, active community leaders
Governmental (State and Federal) Assets City Government, State Capital, Bureau of land management, Economic Development, Dept. Forest Service, Military facilities , School Service Center, Small Business Administration, State Education Agency, Telecommunications agency	Municipal Government, State Government Agencies, Federal Government Agencies	Examples from previous visits: Municipality Seat, DIF(Desarrollo Integral de La Familia/National System for Integral Family Development)
Institutional Assets Churches, Colleges and Universities, Elderly Care Facilities, Fire Department, Hospitals and clinics, Mental health facilities, Libraries, Police Department, Schools, Utilities, Transportation	Churches, Universities, Nursing College, Schools, Hospitals, Clinics, Libraries, Police Department	Examples from previous visits: Nursing college, 2 small universities (1 technical, 1 liberal arts), Hospital Integral, 2-3 sanatoriums, municipal police, state police, federal police, churches, public and private primary and secondary schools
Physical and Land Assets Agriculture, Energy resources, Forest Industrial areas, Lakes, ponds, streams, Mining, Natural resources/landmarks, Parks/ recreation areas Vacant land, Waste resources	Parks/recreation areas, farms, plantations, lakes, river, streams, mining, oil drilling/ pipeline	Examples from previous visits: PEMEX oil pipeline, coffee plantations, Nexaca reservoir
Organizational Assets Community Centers, Radio/TV stations, Small businesses, Large businesses, Home-based enterprises, Religious organizations, Nonprofit organizations, Clubs, Citizen groups, Business associations, Cable and phone companies	Community Centers, media outlets, small businesses, home based businesses, NGO, Community Clubs, religious organizations	Examples from previous visits: Local radio station, local TV station, Local newspaper, Cruz Roja (Red Cross), Rotary International Club, Club de Leones, Knights of Columbus
Cultural Assets Historic/Arts groups Ethnic/Racial diversity Heritage Crafts, skills Cultural traditions	Cultural Arts Center, Artisan studios, cultural celebrations and traditions.	Examples from previous visits: Xochipila shrine/landmark, Cultural arts center

long-term diabetes management of diabetes. This included noting the names, geo-coordinates, and characteristics of the places at which food are available, in addition to the venues of indoor or outdoor exercise. A legend and typology was created for further specifying certain characteristics or categories of business/food source (i.e. Small variety store, restaurant, fast-food, grocery stores, etc.). Sources of food, such as stores were scored based on the availability of produce and nutritious foods. Nutritious foods in this case is operationalized as food other than produce that include whole grains and beans, high fiber/ low sugar breakfast cereals, low-fat dairy, and calcium-fortified orange juice. The scoring system for produce included: “no produce” = 0 produce; “poor variety” = 1-3 different produce available; “Some variety” = 4-7; “good variety” = 8+ produce available (Lefer et al., 2008). Additionally, sources of food were scored upon the availability of nutritious foods where “non-nutritious” = 0-2 of the 5 nutritious food examples and “nutritious” = 3+ of the 5 nutritious food examples.

Surveys/ Questionnaires

Surveys are generally considered to be some of the most cost-effective and common methods of collecting data. Surveys can be conducted by mail, phone, internet or through a personal interview. The first phase of this study utilized surveys to collect some initial data related to provider and patient experiences with the provision of care for diabetes and diabetes-related knowledge.

This section will be divided based on the targeted subunits of analysis: Health Care Team, Patients with diabetes, and Community members without diabetes.

All survey instruments have previously been translated to Spanish, validated and used among Spanish-speaking participants by other researchers outside of this project.

The Health Care Team: The cases from the Health Care Team were selected purposively and include only those health care team members that are involved in the provision of care for diabetes within the Hospital Integral of Xicotepec, Mexico. Based on a preliminary understanding of the health care infrastructure in Xicotepec, the Hospital Integral serves as the primary or usual place of care for the majority of residents in the Xicotepec community. Being the usual or primary source of care for most residents and given the exploratory nature of the study, the Hospital Integral appears to be a logical place for seeking cases for this part of the project. Eligibility inclusion criteria were that health care team members must have been a part of the provision of care process for at least one patient during the last year and the survey will be open to all eligible health care team members, with the expectation of receiving at least 10 responses out of the approximate 20-25 team members on staff at any one time. I have worked with the Assistant Director of the Hospital Integral over the last three years and was granted approval by the state health department of Puebla, Mexico (Secretaria de Salud del Estado de Puebla) and the Director of the Hospital Integral for access to the health care team as part of this study. The Assistant Director served as a key informant within the Hospital Integral and assisted me with identifying health care team subjects. Health care team members were contacted

face-to-face to discuss their participation in the study.

The health care team received a survey instrument that has been previously developed, used and supported in the literature (Bonomi et al., 2002; Si D. Et al. 2005; Solberg, et al., 2006). This instrument is called the Assessment of Chronic Illness Care (ACIC) and was initially developed as a tool to help health care organizational teams identify areas needing improvement in their provision of care for chronic illnesses. It was also intended to measure the level and nature of improvements made in their system (Bonomi et al., 2000) with regard to the overall system of delivery of care and not patient outcomes. The ACIC is based on the Chronic Care Model's (CCM) six areas of system change that have been shown to influence quality of care and thus provides an evaluation of performance in six areas of the CCM: self-management support, decision support, information systems, delivery system design, organization of care and community linkages. See Table 3.

The developers of the ACIC, Bonomi et al. (2002), describe the ACIC as being modeled after a tool that was developed to evaluate the diabetic services within the Indian Health Service and that content of the ACIC was supported by previous interventions and concepts within the Chronic Care Model. For each item in the ACIC, the respondent must choose between four descriptive levels of the implementation of chronic illness care, ranging from offering limited support to incorporating a fully developed chronic illness care and then the respondent will choose one of three ratings about the degree to which the description applies.

Table 3. Operationalization of CCM Components

Chronic Care Model (CCM) Components:	Subcomponents of ACIC
Organization of the health system	<ul style="list-style-type: none"> •General leadership of the organization in chronic illness care •Goals of the organization in chronic illness care •Strategies for Improving chronic illness care •Incentives for and regulations governing chronic illness care •Influential leaders •Benefits
Self-Management and self-monitoring support	<ul style="list-style-type: none"> •Assessment and documentation of needs and self-management activities •Educational programs to support self-management •Support for patients and family members •Interventions for effective behavioral change and mutual support
Community	<ul style="list-style-type: none"> •Patient linkage with community resources •Cooperation agreements with community organizations •Regional and/or local health plans
Delivery system design	<ul style="list-style-type: none"> •Operations of the service delivery team •Leadership of the service delivery team •Multiple monitoring visits •Follow-up appointments •Programmed monitoring visits •Continuity of care
Decision support	<ul style="list-style-type: none"> •Evidence-based medical guidelines/standards •Specialist Involvement in improving first-level care •Education for the service delivery team •Information for patients about medical guidelines/standards
Clinical information system	<ul style="list-style-type: none"> •Records (lists of people with diabetes) •Reminders for the health team •Performance feedback •Relevant information on subgroups of patients requiring special services •Treatment plans
Integration of CCM Components	<ul style="list-style-type: none"> •Informing patients about guidelines •Integration of Information Systems/Registries with patient assessments and self-management goals •Integration of Community Programs with patient treatment plans and self-management progress •Organizational planning for chronic illness care •Routine follow-up for appointments, patient assessments and goal planning •Use of guidelines for chronic illness care

Thus, the respondent will choose a rating between 0-11 where the categories within the scale describe the level of implementation of chronic illness care using the following criteria: 0-2 (limited or no support for chronic illness care), 3-5 (basic or intermediate support for chronic illness care), 6-8 (advanced or reasonably good support for chronic illness care, and 9-11 (optimal or fully developed and integrated care for chronic illnesses) (Bonomi et al., 2002).

The ACIC has been updated and now includes six additional items (making it a 34 item tool) that address how well the organization integrates Chronic Care Model elements, such as how well the organization integrates evidence-based guidelines into self-management programs for chronic conditions. As the CCM and ICCF Framework are conceptually linked, the ACIC can be leveraged for gaining a preliminary understanding of the organization of health care for addressing chronic illnesses in the Xicotepec community and can be assessed in terms of how it is aligned or addresses many of the ICCF Framework guiding principles and building blocks (e.g. Evidence-based decision making, Integration of care, Support for self-management and prevention, etc).

Initial testing suggested that the ACIC was responsive to health care quality-improvement initiatives and that it could be a useful tool for not only guiding quality improvement in chronic illness care but for tracking progress as well. The ACIC is one of the first comprehensive tools designed to evaluate the strengths and weaknesses of a health care system's organization of care for chronic illnesses. The ACIC has been used with health care teams providing care for

patients with illnesses ranging from depression, asthma, and diabetes to congestive heart failure (Bonomi et al., 2002). In 2007 the American College of Physicians included the survey in their comprehensive diabetes toolkit.

The ACIC has also been used in a collaborative project between the Pan American Health Organization (PAHO) and the Ministry of Health in Mexico, known as the Veracruz Initiative for Diabetes Awareness (VIDA) in what was to be a 13-month pilot project between 2003 and 2004. The results of the project showed an improvement in glycosylated hemoglobin levels and foot care, as well as improvements in the inclusion of nutrition support, psychological assessment, and eye and dental check-ups. Not much is known, however, about how these results translated to any additional initiatives to improve the quality of medical care for the rest of the country (PAHO, 2011).

The ACIC tool was chosen for this study as it provides a feasible mechanism for gaining an initial or “baseline” understanding of how well the health care team perceives that the organization has organized care for chronic conditions, such as diabetes. The data generated from the ACIC allow for interpretation to occur based on both subscale scores as well as the average overall score as a way of assessing health care team member feedback. The ability to assess feedback based on the subscale scores allows the researcher to more easily examine individual components of the CCM, especially those that essentially serve as a proxy for the related elements of the ICCF Framework and especially those that are of primary interest for this project such as the linkages to community

resources, self-management support, and decision support. For example, the ACIC tool asks the respondent to rate the extent to which the organization has developed goals for addressing care for chronic conditions, such as diabetes, and in doing so, ask the respondent to first choose the best/closest response that represents their perception related to the development of organizational goals for treating chronic illness and then within this response are asked to rate the intensity level or degree to which they feel the statement applies: (see Figure 4 below)

Figure 4. ACIC Item Excerpt

Organizational Goals for Chronic Care	...do not exist or are limited to one condition.			...exist but are not actively reviewed.			...are measurable and reviewed.			...are measurable, reviewed routinely, and are incorporated into plans for improvement.		
Score	0	1	2	3	4	5	6	7	8	9	10	11

The tool will be self-administered and typically requires 15-30 minutes to complete. It was completed and returned anonymously to a locked drop-box placed within the Hospital Integral.

Patients (With Diabetes): The case selection process for patients with diabetes was purposive and opportunistic and included only those patients between the ages of 18 and 100 who have been previously diagnosed with diabetes and have had at least one visit or exposure to the Hospital Integral for a diabetes related service or problem in Xicotepec, Mexico. Based on a preliminary understanding of the health care infrastructure in Xicotepec, the Hospital Integral serves as the primary or usual place of care for the majority of

residents in the Xicotepec community. Being the usual or primary source of care for most residents and given the exploratory nature of the study, the Hospital Integral appeared to be a logical place for seeking cases for this part of the project. The survey was open to all eligible patients with diabetes meeting the inclusion criteria, with the expectation of receiving at least 5 responses. The challenge was identifying eligible patients within the study timeframe, thus the case selection process was very much opportunistic. A key informant within the Hospital Integral had agreed to work with the P.I in identifying eligible patients and prospective patient subjects were contacted face-to-face during their visit to the Hospital Integral to determine their interest in participating in this study.

Patients received a survey that was comprised of three separate instruments that have previously been developed, used and supported in the literature. These instruments are the Patient Assessment of Chronic Illness Care Survey (PACIC-5As), the Diabetes Knowledge Questionnaire (DKQ-24), and the Short Adapted Social Capital Assessment Tool (SASCAT). The survey instrument was administered by me, and required approximately 30-45 minutes to complete.

The PACIC was designed as a tool to assess the “level of CCM-congruent activities that patients receive” (Glasgow et al., 2005a). As mentioned previously, because the CCM and ICCF Framework are conceptually linked with regard to the organization and provision of care for chronic illnesses, the PACIC was expected to provide a preliminary understanding of the care that is provided to patients with diabetes, from the patient’s perspective, and thus the extent to

which the patient may be informed, motivated and prepared to manage their diabetes (a critical component of the ICCC Triad). The tool was originally designed as a 20-item instrument using a 5-point Likert scale, was to be used to assess the extent to which patients have received CCM-based services over the last six months (Glasgow et al., 2005b). The PACIC was found to have reasonable psychometric properties and could be applicable for use for a variety of chronic conditions. Shortly after releasing the initial results of the PACIC tool, Glasgow et al. (2005a) added six additional items to the instrument, that was evaluated for appropriateness among a larger sample of diabetic patients, Latino patients, and patients receiving care from many providers. The additional six items were items that incorporated the “5As” into the PACIC instrument. The “5As” (ask, advise, agree, assist, and arrange) is a model of behavior change recommended by the U.S. Preventative Services Taskforce that has been empirical evaluated (Whitlock et al., 2002; Goldstein and Whitlock, 2004) and applied to diabetes self-management and quality improvement efforts. It is considered to be congruent with the CCM and has been used to promote better linkages to community resources and enhance the self-management support (Glasgow et al., 2002; Glasgow et al. 2003). Incorporating the 5As, the PACIC became the PACIC-5As version with 26 items that results in 5 subscales for the PACIC portion that represent different aspects of providing patient-centered care congruent with CCM (i.e. Patient Activation, Delivery System/Practice Design, Goal Setting/Tailoring, Problem Solving/Contextual, and Follow-up/Coordination)

in addition to 5 subscales for the 5As (Assess, Advise, Agree, Assist, and Arrange) portion of the tool. The PACIC-5As tool was chosen for this study because it provided the researcher with reasonable mechanism for gaining an initial or “baseline” understanding of patient perceptions regarding how well health care is organized for providing care for chronic conditions such as diabetes. With the addition of the 5As, the tool is an even more attractive choice in that it also facilitated gaining an understanding of how well the organization of care is preparing and/or supporting patients for effective self-management of diabetes and how well patients perceive the care system has linked care to the resources available in the community, which are all important components for achieving optimal health outcomes promoted by the ICCF Framework.

The new tool was shown to possess similar psychometric properties as the original PACIC tool and thus useful for assessing the extent to which care is provided based on CCM activities and principles. In 2008, the PACIC was translated to Spanish and validated, suggesting that it could be reliably used to assess care delivered to a heterogeneous Spanish-speaking population (Aragones et al, 2008).

The second component of the survey instrument, the Diabetes Knowledge Questionnaire (DKQ-24), is a tool that has been developed to assess general diabetes knowledge. Literature suggests that although knowledge about medications, diet, exercise, foot care and treatment modifications alone does not guarantee effective self-management or behavior modification, it has been

demonstrated to be a necessary component for effective self-management of diabetes (Brown, 1988; Brown, 1990; Coates and Boore, 1996; Padgett et al., 1988). Additionally, as Dunn et al. (1984) have suggested, the assessment of diabetes-related knowledge and beliefs is a critical primary approach for designing diabetes education programs and evaluating them. The effective management of diabetes requires careful daily self-care decision-making processes and without a general diabetes-related knowledge, these decisions may not always be made in the best interest of the diabetic patient. The Diabetes Knowledge Questionnaire was developed to address these concerns through the construction of an easy-to-use measure of general diabetes knowledge (Garcia et al., 2001).

The DKQ-24 is a shortened version of the originally 60-item DKQ that has been translated into Spanish and assessed as being a reliable and valid measure of diabetes-related knowledge among people with and without diabetes. The content of the DKQ is based on the content recommendations provided by the National Standards for Diabetes Patient Education Programs (National Diabetes Advisory Board, 1984) and is designed to assess overall diabetes knowledge, such as etiology of the disease, associated risk factors, manifestation of signs and symptoms, diabetes-related complications, as well as self-management. For each question, patients can answer “Yes,” “No,” or “I don’t know.” The tool was chosen for this study based on not only its ease of use but also because of the breadth of the diabetes-related knowledge that it covers. It was expected that the

DKQ-24 portion of the survey for patients with diabetes would provide an understanding of the extent to which patients are informed, motivated and prepared to manage their diabetes.

The third component of the survey instrument, the Short Adapted Social Capital Assessment Tool (SASCAT), was designed for use in studies where social capital is just one element of a broader study (De Silva et al., 2006) in order to measure the social capital of adults quantitatively. It is a shortened version of the instrument that was initially developed by the World Bank, known as the Adapted Social Capital Assessment Tool (A-SCAT) that has been used in Colombia and Sub-Saharan Africa (Harpham et al., 2002; Harpham et al., 2004; Thomas, 2003). The A-SCAT was later modified by Young Lives Project in 2002 for use in Ethiopia, Vietnam, Peru and India to study childhood poverty. The tool was designed to measure the individual social capital of caregivers of children (1-8 years old) in order to explore the relationship between the caregivers' social capital and child well-being (physical and psychological health) as well as educational outcomes (Da Silva et al., 2005).

The SASCAT is comprised of 4 cognitive and 5 structural social capital questions such that within the structural social capital questions are ones that are related to group membership and support, social support from individuals in the community, and participation in citizenship activities while the cognitive social capital questions are related to generalized trust in others in the community, social harmony, sense of belonging and sense of fairness. Additionally, despite

being a much shorter assessment tool than the A-SCAT, SASCAT also includes bonding, bridging and linking social capital which, in addition to structural and cognitive social capital, are all critical concepts within social capital theory (Harpham et al., 2002). Having been designed for use in larger surveys, SASCAT groups together the constructs of emotional, economic and instrumental sources of support as opposed to measuring each separately as is done in the much lengthier A-SCAT. However, it retains face and content validity in that it measures both cognitive and structural social capital, does not measure outcomes associated with social capital and both cognitive and structural social capital are weighted similarly within the instrument. The SASCAT has been translated to Spanish and its psychometric properties suggest that it is a valid tool that reflects the known constructs of social capital theory (Da Silva, 2006). The SASCAT was chosen for this study based on its potential to provide a feasible mechanism for gaining an initial understanding of the relationship between the patient's social capital, general diabetes-related knowledge and patient experiences with the provision of care for chronic conditions, such as diabetes. More specifically, it was expected that this would allow for a preliminary understanding of how social capital may influence and/or support the access and provision of care for diabetes, especially in terms of how the ICCC Triad is connected and influenced by the broader community, health care organization and political environment.

Community Members: (Without Diabetes): Community members received a

survey instrument similar to the instrument provided to patient with diabetes, however, this instrument did not include the PACIC as it is designed specifically for assessing the experiences of patients with diabetes. However, because we were still interested in exploring the general diabetes-related knowledge and individual social capital that exists within the Xicotepec community, the survey instrument was comprised of two separate instruments that have previously been developed, used and supported in the literature. These instruments are the Diabetes Knowledge Questionnaire (DKQ-24) and the Short Adapted Social Capital Assessment Tool (SASCAT), both of which have been discussed above. The survey instrument was administered by me and 2 nursing students from the community/local vocational nursing school. The nursing students were informed and trained on the content of the survey instrument prior to administering to potential community members. The survey instrument was administered face-to-face and required approximately 15-20 minutes to complete. It was expected that the DKQ-24 portion of the survey for community members who do not have diabetes would provide an understanding of the extent to which families and community partners are informed, motivated and prepared to help and/or support those with diabetes manage their illness.

Cases were selected purposively among community members who have not been previously diagnosed with diabetes. Because this survey instrument was only concerned with assessing general diabetes-related knowledge and individual social capital, cases were selected within the broader community and

not necessarily based on the exposure to the care systems organization of care for patients with diabetes. Eligibility inclusion criteria were that community members must not have been previously diagnosed with diabetes and must be between the ages of 18 and 100. The survey was open to all eligible community members meeting the inclusion criteria, with the expectation of receiving at least 5 responses. Although the survey was open to all eligible community members, community members were purposively targeted to include a large proportion of females. That is, I wanted to focus on understanding diabetes knowledge and social capital from the women's perspective. It has long been recognized that women in Latin America are not only the primary household health-related decision-makers but that they also possess significant specialized knowledge about health care behaviors and practices (Murdock et al., 1973; Isely et al., 1983; Browner, 1989). With this in mind, female community members were targeted for participation at a cervical cancer screening event held at the Cruz Roja (Mexican affiliate to the Red Cross) and sponsored by the Xicotepec de Juarez Rotary International service club.

A key informant within the Hospital Integral and community of Xicotepec agreed to work with me in identifying eligible community members and community member subjects were contacted face-to-face to discuss the study and their interest in the participating in the study.

Phase I to Phase II Transition Period

Upon completion of Phase I, the initial data collected were analyzed. The

community asset map was constructed and reviewed, survey data were analyzed, and initial semi-structured interviews were reviewed. I discussed the preliminary analysis with the dissertation advisor and various dissertation committee members in order to make any necessary adjustments or changes to the Phase II protocol. It is important to note that, as this study was designed utilizing a qualitative approach, the data from Phase I was to be analyzed accordingly. That is, although the surveys provided quantitative data, these data were analyzed qualitatively, in that the primary emphasis (or attention) was placed on gaining an understanding of the diversity (e.g. variation, range or breadth) of the responses provided, rather than on the distribution characteristics of the population. The aim of Phase I was not to necessarily describe the frequency of responses nor to establish values for the associated variables within each survey, but rather to examine the diversity of the topics presented in each survey in order to establish relevant dimensions for the topics that can then be used to inform the exploration process used in Phase II. Each survey represented a predetermined set of empirically derived characteristics of the topics of interest in this study, however, a descriptive rather than quantitative analysis of these characteristics would allow for a more informed approach to developing the protocol for Phase II that sought to develop a deeper understanding of the factors that influence the accessibility and provision of care for diabetes in the community.

Phase II

During Phase II, I conducted semi-structured interviews and group discussions utilizing the action research iterative process. As Phase II progressed, questions and probes were refined as I maneuvered between semi-structured interviews and group discussions with important stakeholders in the community. Phase II was informed by the findings from Phase I ensuring flexibility and responsiveness in the pursuit to a better understanding of the dynamic relationships that exist between health care team providers, patients and their families, and community partners related to the care for diabetes. While a set of protocols were initially devised for the data collection techniques used in Phase II, they were amenable to refinement as key concepts and themes emerged from each iteration of the data collection process. The qualitative methods of semi-structured interviews and group discussions were used in this phase of the project, but did not occur linearly. All interviews and group discussions were audio-recorded throughout Phase II.

Semi-Structured Interviews

One of the most important ways of learning about the local situation is to seek the insight of local participants by asking them to share their lived experiences. This study utilized a semi-structured interview format. The semi-structured interview used an interview guide to focus responses toward a particular aspect of the participant's experience but still allowed the participant freedom to answer the open-ended questions in whatever manner they wished and as in-depth as they wanted.

The aim of the semi-structured interview was to elucidate the experiential construction of the world of the participant within a set of topical domains. These topical domains established a structure to the interview guide and questions related to the domains were usually asked in a similar systematic way throughout the study. The interviewer was allowed flexibility, however, to deviate slightly from the guide in order to elicit pertinent information. As Denzin (1989) describes it, conveying equivalence of meaning is more important than providing the exact phrasing to all participants. This, again, allowed the interviewer some flexibility to rephrase or probe further with additional questions in order to get the participant to provide a more elaborate response than may have been initially provided. The topical domains varied based on the category of respondent that was interviewed. That is, topical domains varied depending on whether health care providers, diabetic patients, or community leaders were interviewed. The semi-structured interviews lasted about 20-40 minutes.

The semi-structured interview protocol will be discussed below based on the category of respondent that was interviewed. These three categories of respondents were purposively selected in an effort that attempts to maximize the diversity of responses reflecting the broad range of lived experiences that may exist in the community among this previously defined ICCC Triad of: the health care team, patients and families, and community partners. It is important to note, as well, that additional topical domains were added to the interview guides as the study progresses based on data gathered during previous data collection

iterations, such as during Phase I as well as preceding interviews during Phase II. At least 5 interviews per category of respondents were sought during this phase. The rationale to support this number of interviews for each category was based on recognition of a number of factors, but more importantly that of data saturation. It was recognized that this case study would be situated in a small population and time spent in the field site was an important constraint. However, despite these constraints, it was expected that data saturation could be achieved within each category of respondents after at least 5 interviews for a total of at least 15 interviews. Data saturation occurs when the collection of new data fails to provide any additional discovery of information or shed any further light on the issue being investigated. This seemed particularly reasonable given the various other data gathering techniques that were incorporated in this study, such as the surveys in Phase I and the group discussions that occurred in Phase II.

Health Care Team: The structure of the interview guides for the health care team was largely informed by the principles and building blocks established by the ICCC Framework. When the ICCC Framework was introduced by the WHO, a situation assessment form was included to serve as a guide for creating and/or redesigning the health care system to more effectively manage chronic illnesses. The interviews for the health care team members explored beliefs and experiences that correspond to concepts included in the ICCC Frameworks such as: (a) Evidence-based decision making at the level of the health care organization and the community; (b) prevention focus; (c) integration; and (d)

prepared, informed and motivated health care teams. Additional questions explored diabetes-related processes and outcomes, as well as concepts related to structural and social capital.

Patients (with Diabetes): The structure of the interview guides for patients with diabetes took a rather different route than what is prescribed by the ICCC Framework Assessment, in that it was largely informed by previous literature (Brown and Hanis, 1999; Brown et al., 2002; Brown and Hedges, 1994; Surgenor et al., 2000; Snoek, 2000) on diabetes-related health beliefs. The literature suggests that beliefs about the ability to control diabetes and beliefs about family and social support, as well as perceived barriers and benefits of achieving and managing metabolic control, in relation to actual management of diabetes and contributing to improving diabetes-related health outcomes, are particularly important concepts that warrant further exploration. However, this literature also points out that there is a dearth in research in minority or ethnic non-caucasian peoples. Given this background knowledge, patients with diabetes were interviewed to explore their experiences and beliefs regarding: control over diabetes and management functions, perceived barriers to managing the illness, availability and level of social support, the perceived benefits of proper diabetes self-management, in addition to exploring individual structural and cognitive social capital. While this line of questioning may seem to deviate from the ICCC Framework assessment guide for assessing whether patients and families are prepared, informed and motivated, it is believed that the questions concerning

the concepts above, are still very much in congruence with the overall assessment of ICCC Framework component for patients and families. Examining the perceived beliefs related to control, barriers, social support, and benefits provide for a rich exploration of the extent to which patients and families are prepared, informed and motivated for managing diabetes. Patients were purposively and opportunistically sampled from within the Hospital Integral and the broader community with a goal of recruiting 5 patients with diabetes. The eligibility inclusion criteria and recruitment strategy remained the same as used during the survey administration in Phase I.

Community Partners (Leaders): The structure of the interview guides for community partners reverted to the ICCC Framework Assessment and was geared for exploring the beliefs and experiences of community leaders that correspond to the ICCC Framework such as: (a) Evidence-based decision making at the community level; (b) integration; and (c) prepared, informed and motivated community partners. For the purpose the semi-structured interviews, community partners were a narrowly defined subset of people that included community leaders. Community leaders included those acting in management positions within community organizations (e.g. Municipal government, business leaders, non governmental organization leaders, etc) that are more likely to have a richer understanding of how the community is or can be linked to the health care organization based on their prior and current experiences in community outreach and involvement within their respective organizations. The rationale

behind this purposive sampling was that, exploring the beliefs and perceptions of community leaders would be essential for gauging the capacity and motivation of the broader community to contribute to addressing public health concerns, such as emerging chronic illnesses like diabetes. The two previously mentioned key informants helped in identifying potential community leader participants and I contacted them face-to-face to discuss the study and their interest in participating.

Group Discussion.

The group discussion was similar to traditional focus groups, with the exception that it was less structured and not facilitated by the researcher. Rather, it was moderated by a key informant who served as a guide or facilitator leading the discussion about the topic, as opposed to asking structured questions to be answered and discussed by the group. I worked with and provided the key informant with a discussion guide of topics that the discussion should address. This method is used in Participatory Action Research and Rapid Appraisal efforts by many NGOs (USAID, 2010) and is suggested to allow for rich understanding of specific topics by allowing participants to contribute different experiences and perspectives in a way that allows for fuller participation and a steady flow in the communication of ideas, beliefs and experiences. My role was to observe the discussion and record the details surrounding the interactions and discussions that ensued, paying attention to both verbal and nonverbal communication.

This involved a purposive selection of one groups of about 10 participants.

The group included health care providers (e.g. Physicians and Specialists) who are knowledgeable about diabetes, diabetic care, and health care resources in the community and a broader mix of community stakeholders as representatives from the municipal government (i.e. health secretary or director of the DIF), community development organizations (i.e. Local Rotary member, Club de Leones, etc.), local NGOs (i.e. Cruz Roja), and other community advocates that possess more intimate knowledge about the capacity and motivation of how community partners do or can work together. I worked with key informants to identify prospective participants and contacted them face-to-face to discuss the study and their interest in participating.

The group discussion protocol will be discussed below. This groups of participants was purposively selected in an effort to maximize the diversity of responses reflecting the broad range of lived experiences that exist in the community among this previously defined ICCC Triad of: the health care team, patients and families, and community partners. It is important to note, as well, that additional topical domains were added to the discussion guides as the study progressed based on data gathered during previous data collection iterations, such as during Phase I as well as preceding interviews during Phase II.

Health Care Team: The structure of the discussion guide for the health care team is largely informed by the principles and building blocks established by the ICCC Framework. The discussions for the health care providers explored beliefs and experiences that correspond to concepts included in the ICCC Frameworks

such as: (a) Evidence-based decision making (b) quality focus; (c) integration; (d) prepared, informed and motivated health care teams, community partners and patients and families; (e) flexibility and adaptability of the health care organization; (f) mobilization and coordination of resources; and (g) development and allocation of human resources.

Community Leaders: The structure of the discussion guide for community partners was also informed by the ICCC Framework Assessment and was geared for exploring the beliefs and experiences of community stakeholders that correspond included in the ICCC Framework such as: (a) Leadership and advocacy (b) Raising awareness and reducing stigma; (c) integration; (d) prepared, informed and motivated health care teams, community partners and patients and families; (e) flexibility and adaptability of the health care organization; (f) mobilization and coordination of resources; and (g) development and allocation of human resources.

Analysis

Prior to analysis, all audio-recorded interactions were transcribed into Spanish. Transcription was performed by me, ensuring the preservation of the nuances of spoken communication (i.e. dialect and local colloquialisms) inherent in the local system that may have otherwise been lost through outside translation. This also allowed me to achieve a greater level of acquaintance or familiarity with the data and ensured integrity of the transcription process (Reismann, 1993). Transcription and translation occurred throughout the study period in an effort to

enrich, as much as possible, each successive data collection iteration. This was especially important during the transition period between Phase I and Phase II of the study in that the first phase was intended to inform the second phase of the study.

The logic behind the overall analytic approach that was employed in this project is based on the consideration that quantitative surveys alone are limited in the level of description they can provide in (1) reflecting actual experiences in the quality of care and (2) in capturing important aspects of the quality of service provision that may be uncommon or even marginalized within a care system imbedded in the context of broader societal reality. Thus, because there is ample room for important questions not to be asked or important concepts that cannot otherwise be explored, integrating a qualitative approach can be useful in mitigating these potential pitfalls. These are especially important considerations in exploratory studies where the dynamics of the relationships among the stakeholders, for which care for chronic illnesses has been organized or is being organized, has not been adequately described or remains unknown. Literature in the nursing (Sandelowski, 1996) and mental health profession (Flemming et al., 2008) have come to promote the use of qualitative methods for evaluating evidence-based practice with the intention of improving intervention programs. It is in this vein that the analytic strategies used in this project will be described below.

Thematic Analysis

The purpose of the qualitative analyses was to provide detailed descriptions of health care provider, community partner, and patient and family experiences around access to and provision of care for diabetes. Additionally, it was to capture the broader structure and concepts that further describe factors that may influence how these stakeholders interact and work together to organize and improve the quality of care for diabetes in a way that has not yet been explicitly described. In order to address these aspirations, a thematic analysis approach was utilized. More specifically, as this project used a multiple case study design, data were analyzed case-by-case using a thematic analysis approach and then subjected to a cross-case analysis. That is, the themes that are developed following the case-by-case analysis of the interviews and group discussions were used to conduct the cross-case analysis. With the unit of analysis being the “ICCC Triad” and each component of the triad (e.g. patients and families, health care team, and community partners) serving as a case, three cases were analyzed separately and then subjected to the cross case analyses.

Thematic analysis is a qualitative data analysis method that has been utilized in a variety of disciplines (e.g. Psychology, business, education, sociology, and the health sciences) and has been identified as a tool for providing a much broader perspective than many other qualitative analysis methods (Boyatzis, 1998). It is a method for identifying, analyzing, and reporting patterns or themes within data. Thematic analysis can be used with or without a conceptual framework, and is often used within grounded theory or cultural ethnography

approaches (Braun and Clarke, 2006). However, it is important to note that thematic analysis differs from what is commonly used in grounded theory, in that thematic analysis does not require the implicit theoretical commitment that is required for a grounded theory analysis that is directed toward theory development. Another distinction that must be made is that thematic analysis is not the same as content analysis. Thematic analysis is focused on meaning and thus promotes a rather diffuse interpretation of reality as individual codes can cross-reference multiple themes that have been progressively integrated into higher order themes from systematically identified topics within text. In contrast, content analysis attempts to develop mutually exclusive categories to count the frequency of a theme and in this quantification can be used to statistically test a hypothesis.

In this study, thematic analysis was used to approach the qualitative data with this theoretical freedom in order to provide a “rich and detailed, yet complex account of data” (Braun and Clarke, 2006). Additionally, the flexibility of thematic analysis allowed for the development of a conceptual model with the themes that were developed from the data. This flexibility was especially well-suited for the multiple case study design that was utilized in this study and was expected to yield two levels of information that were described above: (1) rich detailed descriptions of health care provider, community partner, and patient and family experiences that capture predominant, important and/or extremely divergent themes and (2) a more detailed and interpreted set of themes that can be used to

describe the broader structure of factors that may influence how these stakeholders interact and work together to organize and improve the quality of care for diabetes (Boyatzis, 1998; Braun and Clarke, 2006).

In order to conduct the thematic analysis, the six phase/step process outlined by Braun and Clarke (2006) was followed and data management and analysis occurred utilizing Atlas.ti qualitative analysis software. These steps represent a quality standard for researchers to adhere to when conducting thematic analysis and can guide the researcher in order to: (1) Get acquainted with the data through transcription; (2) Generate initial codes that capture meaningful or unique features of the data; (3) Search for initial thematic categories by reviewing each transcript; (4) Review themes for coherence patterns and validate fit of individual themes across entire data set; (5) Define and name themes by identification of the “essence” of what each theme ; and (6) Produce the report (Braun and Clarke, 2006). See Table 4 below.

The Atlas.ti qualitative analysis software was chosen, in particular, for its robust ability to support the coding process as it has the ability to automatically maintain logs of coding changes that allows the researcher to keep track of how the analysis has evolved throughout the study. In addition to allowing the researcher to code data, the researcher can retrieve portions of text using keywords or can rename or merge existing codes without modifying the codes that have already been used and it can help generate visualizations of the

relationships between codes that have been developed from the data (Zhang and Wildemuth, 2009).

Table 4. Thematic Analysis Process

Thematic Analysis Phases	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the code extracts (Level 1) and the entire data set (Level 2), generating clear definitions and names for each theme.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Cross-Case Analysis

As this study was designed as a multiple case study, a cross-case analysis was conducted. The cross-case analysis served as a way to aggregate themes from the thematic analysis across cases as well as make generalizations about the cases (Stake, 2006). Cross-case analysis attempts “to identify process patterns across all the cases, the causes that shape these patterns, and the consequences caused by the patterns” (Radeke, 2010). According to Ragin (1997) cross-case analysis can enhance the capacity to understand relationships among discrete cases as well as aid in refining and developing concepts and thus contributing to theory. Performing the cross-case analysis required that cases be compared for thematic similarities, differences, and conflicts.

CHAPTER 4: RESULTS

Introduction

This chapter will provide a description of the data that were collected using the methodological techniques described in the previous chapter. The data will be integrated and presented among four analytical segments: the ecological context and the 3 selected cases consisting of the diabetic patients, community members and health care providers which make up the individual vertices of the ICCC Triad (e.g. Patients, Community Members, and Health Care Providers). The ecological context will be described through the integration of Community Asset Mapping. The first case, “Diabetic Patients,” integrates data from surveys and semi-structured interviews, while the second case “Community Members,” and the third case “Health Care Providers,” integrate data from surveys, semi-structured interviews and the group discussion.

Ecological Context

Community Asset Mapping

An integral part of the Community Asset Mapping approach is providing a description of the community along with its current and potential assets. The study location was Xicotepec de Juarez, which is known as both a city and municipality, with city functioning as the municipality seat or “la cabecera municipal” [translation: municipality head]. The municipality is comprised of 9 “juntas auxillares”, 21 “rancherías” and 9 “inspectorías” covering a combined area of 302.16 km² (6.62 km² of which is the municipality seat) in the Sierra Norte of the State of Puebla. Although Xicotepec de Juarez is considered a rural and

isolated municipality in the northern mountains in the Mexican state of Puebla, it is the second largest municipality in the northern mountains, with a total population of 75,601 which includes 37,026 within the municipality seat (INEG 2010). Boundaries for the community asset mapping activities were established using key informant input and examination of a variety of maps: electronic via Google Maps; and printed maps available within the community. A description of the activities was provided to the key informants and they subsequently assisted me in defining/demarcating the boundaries of the municipality and municipality seat (i.e. Xicotepec de Juarez proper). It is important to note that consistently developed or accurately composed maps of the municipality were difficult to obtain. In addition to a map provided by Google Maps, 4 maps were obtained in the community that varied in level of detail, accuracy or identification of scale, and comprehensiveness of the entire municipality region.

Xicotepec de Juarez has a rich history that dates back to pre-Colombian times and maintains a culture heavily influenced by 4 major ethnic groups dispersed throughout the municipality: 3 indigenous groups (Totonacos, Nahoas, and Otomis) in addition to the mestizos (Cabrera 2000: Gumesindo Nava Cabrera. "Panoramica de Xicotepec." 3rd edition. Xicotepec. 2000). The following (2) tables provide a socioeconomic profile of the Xicotepec de Juarez Municipality population. See Table 5 and Table 6.

Community Asset Inventory

Developing an inventory of the health-related assets within the Xicotepec de

Table 5. Xicotepec de Juarez Socioeconomic Profile

Xicotepec de Juarez Socioeconomic Profile	
Total Population	75,601
Total Men	36,390
Total Women	39,211
Percentage of Population 15-29 years old	27.50%
Percentage of Population 60+ years old	8.70%
Average household size	4.2
Average level of education (grade)	7.35
Population using social security and social welfare programs	39,013
Literacy rate 15-24 years old	97.97

Source: INEGI (Instituto Nacional de Estadística y Geografía/ National Institute of Statistics and Geography)

Table 6. Xicotepec de Juarez Health Profile

Xicotepec de Juarez Health-Related Socioeconomic Profile	
Total Population	75,601
Population covered by some form of health service/ insurance	27,344
Population not covered by any form of health service/insurance	48,140
Families covered under Seguro Social	14,293
Total Number of Medical Staff	83
Number of Medical Staff in IMSS system	4
Number of Medical Staff in ISSTE system	4
Number of Medical Staff in IMSS-Oportunidades system	31
Number of Medical Staff in Secretaria de Salud del Estado system	40
Average Number of visits per physician per year	1,869.80
Estado system	
Average Number of visits per physician per year	1,869.80

Source: INEGI (Instituto Nacional de Estadística y Geografía/ National Institute of Statistics and Geography)

Juarez Community involved exploring the community on foot and utilizing key informant input to locate and record the location of current and potential health-related resources available in the community. Global Positioning System (GPS) coordinates were recorded and then used with Google Earth to create visual illustrations of the location of health care and food related resources available within the Xicotepec de Juarez community. The following table provides an illustration of the current asset inventory produced through key informant input and exploration of the community. See Table 7.

The asset inventory was categorized based on the type of asset (e.g. Individual, governmental, institutional, physical, and organizational) and whether or not it was currently being used or was available as a resource for diabetic patients in the community. While this produced the basic inventory of assets available in the community, an important part of the community asset mapping process is locating and depicting where many of these assets are located in the community in order to gain a better understanding of where these resources are geographically allocated within the community. The following maps provide an illustration of the location of Health-Care and Nutrition-related (Maps 1, 2, and 3 respectively) assets available to diabetic patients within the Xicotepec de Juarez community.

Map 3 provides a representation of the nutrition-related assets in the community on a larger scale, however, it is important to acknowledge that on a

Table 7. Community Asset Inventory

Asset Inventory (By Type)	Current Diabetes-Related Assets	Potential Assets
Individual Assets	-18 Private physicians clinics -3 specialists: Cardiologist, Orthopedist, Obstetrician -23 pharmacies -7 Ethnomedical practitioners: 2 herbalistas, 2 naturistas, 2 homeopathic practitioners, and 1 curandero	Active community leaders
Governmental (State and Federal) Assets		-Municipal Headquarters -DIF: Municipal and State -1 Federal Military Installation -Telecommunications Agency
Institutional Assets	-1 Hospital Integral	-3 Police stations: Municipal, State, Federal -6 churches -195 public and private schools (preschool – high school) -New Fire Department: not yet operational -3 small universities -1 Nursing vocational school -1 public library
Physical and Land Assets	-1 state sponsored exercise facility	-3 maintained soccer fields -2 maintained parks -1 public indoor/outdoor basketball gymnasium -PEMEX oil pipeline -Numerous coffee plantations - Nexaca reservoir
Organizational Assets	-2 NGOs: Cruz Roja Mexicana, Tik Nime -1 Farmer’s Market -1 mini-supermarket -7 Super markets -1 warehouse supermarket (Wal-mart affiliate)	-1 Local radio station -2 local TV stations -1 Local newspaper, -Adult Social/Service Clubs: Rotary International Club, Club de Leones, Inner Wheel, Damas Vicentinas -Youth Social/Service Clubs: Interact, Rotaract, Futuract, GRAX
Cultural Assets		Xochipila shrine/landmark, Cultural arts center



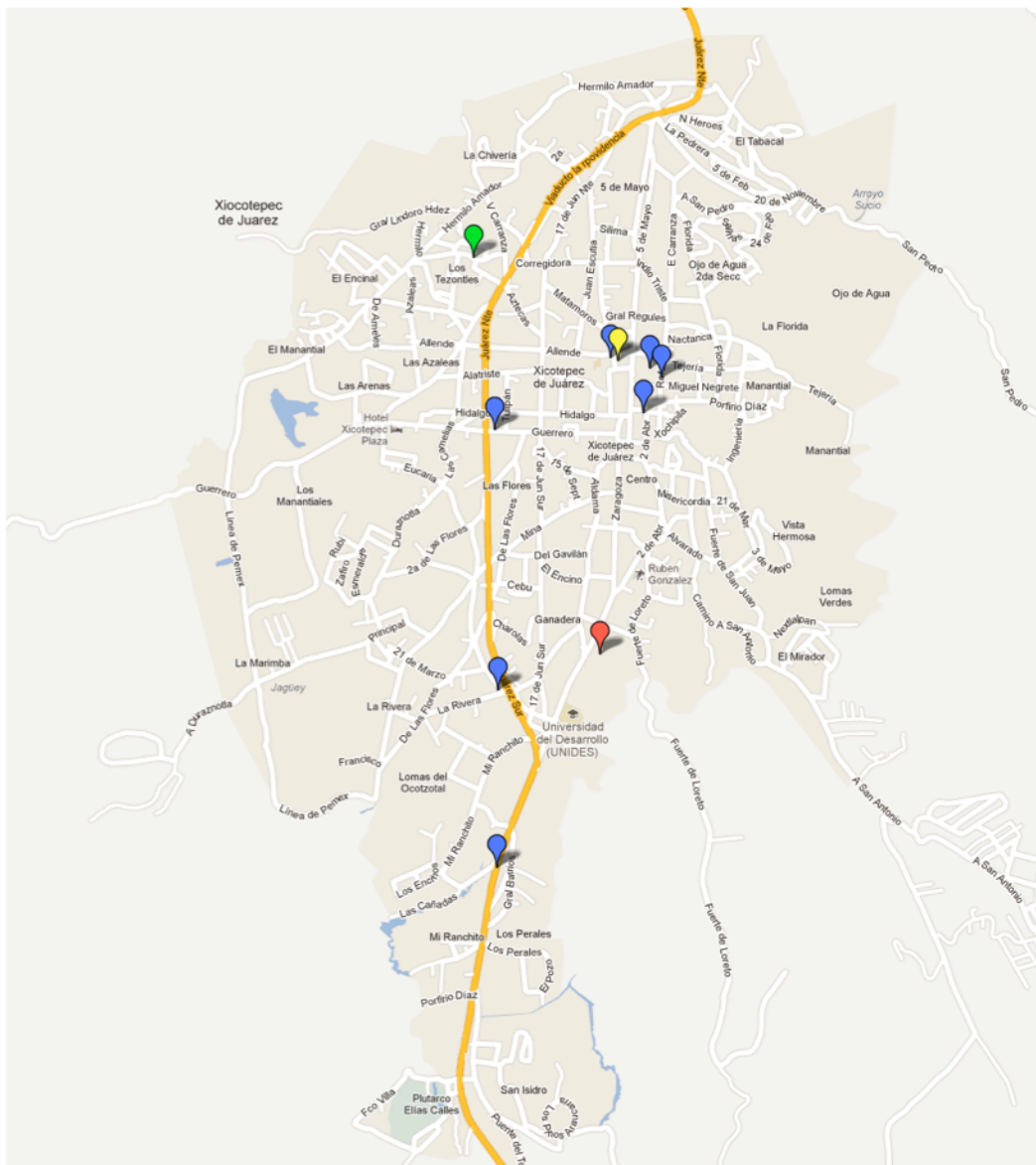
Map 1. Xicotepec de Juarez Municipality Boundary

-
- Xicotepec de Juarez Municipality Size: 302.16 km² (6.62 km² of which is the municipality seat)
 - Total population of 75,601 (37,026 within the municipality seat)



Map 2. Health Care Assets

Legend: Blue=18 Private Clinics; Pink=2 NGO; Yellow=1 Hospital; Red=23 Pharmacies; Green=7 Ethno-medical/Complementary and Alternative Medicine (CAM)



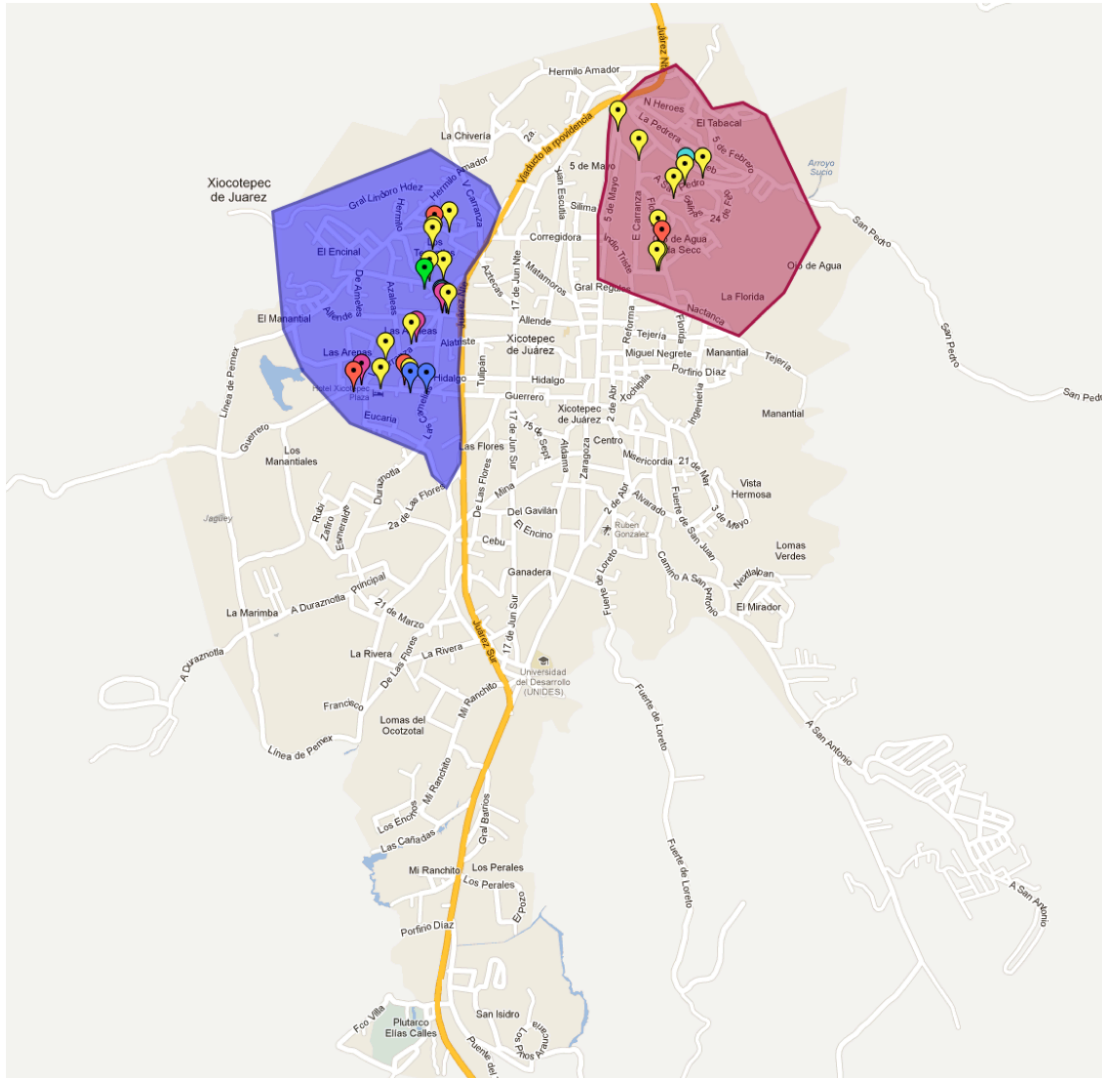
Map 3. Nutrition-related Assets

Legend: Yellow=1 Farmer’s Market; Green=1 Mini-Supermarket; Blue=7 Supermarkets; Red=1 Warehouse Supermarket

smaller scale residents do have a variety of other food outlets available to them in the community. A major source of income for many in the community is generated from operating small “variety store” type shops out of their homes. In many of these store-fronts, a variety of food choices are offered, including chips, candy, bread and even produce in a few. While these types of businesses represent a considerable economic activity for many, they also have an important impact on the overall health of the community. As such, a component of the community asset mapping process involved selecting a few neighborhoods to evaluate the availability of nutritious foods to residents in these neighborhoods. Two (2) neighborhoods were selected with the input from key informants. After discussions with key informants, we agreed that it was important to focus on the neighborhoods that are locally recognized as being the some of the most impoverished of the community, shown in Map 4 below.

In selecting the two neighborhoods, we selected one neighborhood that is generally considered by most in the community as the most impoverished neighborhood (higher concentration of low socioeconomic status residents) within the municipality seat and one that, while it may not be considerably less impoverished, is regarded as having a little more diversity in terms of residents living in varying levels of socioeconomic status (e.g. low-middle socioeconomic status).

Nutritious foods in this case were operationalized as food other than produce that included whole grains and beans, high fiber/ low sugar breakfast



Map 4. Nutritious Food Scoring Neighborhoods

Zone Legend: Pink Zone=Low SES zone; Blue Zone=Low-Middle SES

Marker Legend: Yellow=Small Variety Store; Red=Bakery/Sweet Shop (Panadería, Pastelería, Dulcería); Blue=Tortilla shop (Tortillería); Teal=Butcher (Carnicería); Pink=Restaurant

cereals, low-fat dairy, and calcium-fortified orange juice. The scoring system for produce included: “no produce” = 0 produce; “poor variety” = 1-3 different produce available; “Some variety” = 4-7; “good variety” = 8+ produce available (Lefer et al., 2008). Additionally, sources of food were scored upon the availability of nutritious foods where “non-nutritious” = 0-2 of the 5 nutritious food examples and “nutritious” = 3+ of the 5 nutritious food examples. A summary table comparing the two neighborhoods is provided below (Table 8).

Table 8. Neighborhood Nutrition-related Scoring

Summary Results: Neighborhood Nutrition-Related Scoring		
Scoring Categories	Pink Zone (Low SES)	Blue Zone (Low-Middle SES)
Total number of small businesses offering food	12	22
<u>Business Type</u>		
Small Variety Store	10	9
Butcher (Carniceria)	1	1
Bakery/Confections (Panaderia, Pasteleria, Dulceria)	1	2
Produce Stand	0	1
Restaurant/Fast-Food (Comida Rapida)	0	3
Tortilla Shop (Tortilleria)	0	4
Supermarkets (or Mini-supermarkets)	0	1
<u>Produce Availability</u>		
No Produce (0)	6	11
Poor Variety (1-3)	4	2
Some Variety (4-7)	2	9
Good Variety (8 or more)	0	0
<u>Nutritious Food Source (Nutritious Food Availability)*</u>		
Non-nutritious (0-2)	12	14
Nutritious (3 or more)	0	8

* Based on the availability of 5 food categories: (1)whole grains; (2)beans; (3)High fiber/low sugar breakfast cereals; (4) low-fat dairy; (5)calcium-fortified orange juice

Case I: Patients (with Diabetes)

Survey Results

Diabetes Knowledge Questionnaire (DKQ-24)

In order to gain a better understanding of the diabetes-related knowledge of diabetic patients to serve as a baseline for informing the development of the semi-structured interview guide, the Diabetes Knowledge Questionnaire (DKQ-24) was provided to 9 diabetic patients within the Xicotepec de Juarez Community in and outside of the Hospital Integral. Three (3) diabetic patients were surveyed at the annual Justo-A-Tiempo cervical cancer screening organized by Rotary International and the Cruz Roja Mexicana of Xicotepec de Juarez. Five (5) diabetic patients were surveyed at the Hospital Integral and one (1) diabetic patient was surveyed from within the broader community with assistance from a key informant. All respondents were female and the age of the Diabetic patient group ranged from 33-77 years of age. The DKQ-24 score ranged from 5-19 correct answers (out of 24 questions) with a mean score of 55.55%. A summary table is provided below (Table 9).

Of the 24 questions assessing general diabetes knowledge, there were 11 questions that were answered correctly by more than 50% of the DM respondents and 10 questions that were answered incorrectly by more than 50% of the DM respondents. There were 3 questions that were answered correctly by all 9 diabetic patients: (Possible Responses were: Yes, No, or I don't know; "I

Table 9. Diabetes Knowledge Questionnaire Results: Patients

Summary Results: DM Patient (n=9) Diabetes Knowledge Questionnaire (DKQ-24)	
Category	Results
Respondent Age Range	33-77
DKQ Score Range (Number Correct of 24)	5-19
Mean DKQ Score (% Correct)	55.55%
<i>Question Performance</i>	
# of Questions with >50% Correct Response Rate	11
# of Questions with >75% Correct Response Rate	5
# of Questions with 100% Correct Response Rate	3*
# of Questions with >50% Incorrect Responses Rate	10
# of Questions with >75% Incorrect Responses Rate	7
# of Questions with 100% Incorrect Response Rate	2**

*Items #5, #15, & #18: Untreated DM consequence, Wound healing, Food preparation

**Items #1 & #24: Etiology of DM, Diet

don't know" responses were treated as incorrect responses)

Question #5: In untreated diabetes, the amount of sugar in the blood usually increases.

Question #15: Cuts and abrasions on diabetics heal more slowly.

Question #18: The way I prepare my food is as important as the foods I eat.

There were 2 questions that were answered incorrectly by all 9 diabetic patients:

Question #1: Eating too much sugar and other sweet foods is a cause of diabetes.

Question #24: A diabetic diet consists mostly of special foods.

Patient Assessment of Chronic Illness Care (PACIC-5As)

In order to gain an initial understanding of how diabetic patients perceived the current provision care for chronic diseases, such as diabetes, the Patient Assessment of Chronic Illness Care (PACIC-5As) tool was administered to the same 9 diabetic patients within the Xicotepec de Juarez Community in and outside of the Hospital Integral. The average overall score for the instrument of all nine (9) diabetic patients was a 2.8 out of 5 and ranged from 1.35-4.35. Differentiating between diabetic patients treated for their condition within the Hospital Integral and those under care for their condition outside of the Hospital Integral, the average scores were 3.17 and 2.34 respectively. The PACIC-5As instrument assessed the patient perception of care provision via 5 primary subscales: Patient Activation, Delivery System/Practice Design, Goal Setting/Tailoring, Follow-up/Coordination, and Problem Solving. Additionally, the PACIC-5As instrument offers an assessment of provider behaviors based on the 5As model of behavior counseling (described previously) that is comprised of 5 additional subscales: Assess, Agree, Advise, Assist, and Arrange. A summary table of subscale scores is provided below (Table 10).

Short-Adapted Social Capital Assessment Tool (SASCAT)

In order to gain an initial understanding of how diabetic patients perceived the quality and quantity of their social relationships, the Short Adapted Social Capital Assessment Tool (SASCAT) was also administered to the 9 diabetic

Table 10. Patient Assessment of Chronic Illness Care Results: Patients

Summary Results: DM Patient Assessment of Chronic Illness Care-5As (PACIC-5As)			
PACIC	All DM Patients (n=9)	DM Patients: Community (n=4)	DM Patients: Hospital Integral (n=5)
Overall PACIC Average Score (Range)	2.8 (1.35-4.35)	2.34 (1.35-4.05)	3.17 (2.35-4.35)
PACIC Subscales Average Score (Range)			
Patient Activation	2.81 (1-4)	2.42 (1-3.33)	3.13 (2.3-4)
Delivery system/Practice Design	3.19 (1.67-4.67)	2.83 (2-3.67)	3.47 (1.67-4.67)
Goal Setting/Tailoring	2.62 (1-4.8)	2.15 (1-3.8)	3.0 (1.4-4.8)
Follow-up/Coordination	2.51 (1-5)	2.3 (1-4.6)	2.68 (1-5)
Problem Solving/Contextual	3.08 (1-5)	2.19 (1-4.5)	3.8 (2.75-5)
5As Subscales Average Score (Range)			
Assess	3.24 (1.8-4.6)	2.65 (1.8-4.6)	3.72 (3-4.6)
Agree	2.71 (1-4.6)	2.1 (1-3.6)	3.2 (1.8-4.6)
Advise	2.97 (1.6-4)	2.95 (1.6-4)	3.0 (2.2-4)
Assist	2.42 (1-4.4)	1.95 (1-4.4)	2.8 (2-4.2)
Arrange	2.58 (1-5)	2.0 (1-4.2)	3.04 (1-5)
*Scale: 1=Almost Never, 2=Generally Not, 3=Sometimes, 4=Most of the Time, 5=Almost Always			

patients within the Xicotepec de Juarez Community in and outside of the Hospital Integral.

The average overall scores for the Structural Social Capital and Cognitive Social Capital portions of the instrument for all nine (9) diabetic patients were a 6.44 out of 52 and a 3.11 out of 4, respectively (See Table 11). Differentiating between diabetic patients treated for their condition within the Hospital Integral and those under care for their condition outside of the Hospital Integral, the average scores diabetic patients treated in the broader community were 2.25 for the Structural Social Capital segment and 3.25 for the Cognitive Social Capital segment, while the average scores for diabetic patients receiving care from the Hospital Integral were 9.8 for the Structural Social Capital component and 3.0 for the Cognitive Social Capital component. The SASCAT instrument assessed the

patient perception of the quality and quantity of their social relationships via 5 primary subscales: Group Membership, Support from Groups, Support from Individuals, Citizenship Activities and Cognitive Social Capital (e.g. Trust in the Community). A summary table of subscale scores is provided below: See Table 11.

Table 11. Short-Adapted Social Capital Assessment Tool Results: Patients

Summary Results: DM Patient Short Adapted Social Capital Assessment Tool (SASCAT)			
SASCAT Dimensions	All DM Patients (n=9)	DM Patients: Community (n=4)	DM Patients: Hospital Integral (n=5)
Structural Social Capital (Mean and Range)	6.44 (0-19)	2.25 (0-4)	9.8 (3-19)
<u>Group Membership</u> (Mean and Range)	0.89 (0-2)	0.25 (0-1)	1.4 (0-2)
No Group Membership (%)	44.44%	75%	20%
Member of 1 Group (%)	22.22%	25%	20%
Member of 2 or more Groups (%)	33.33%	0%	60%
<u>Support from Groups</u> (Mean and Range)	2.22 (0-7)	0.25 (0-1)	3.8 (0-10)
No Support Received (%)	44.44%	75%	20%
Support from at least 1 Group (%)	55.56%	25%	80%
<u>Support from Individuals</u> (Mean and Range)	2.78 (0-7)	1.25 (0-3)	2.83 (1-7)
No Support (%)	22.22%	50%	0%
Support from 1 Individual (%)	11.11%	0%	20%
Support from 2 or more Individuals (%)	66.67%	50%	80%
<u>Citizenship Activities</u> (Mean and Range)	0.55 (0-2)	0.50 (0-2)	0.6 (0-1)
No Citizenship Activities (%)	55.56%	75%	40%
1 Citizenship Activity (%)	33.33%	0%	60%
2 Citizenship Activities (%)	11.11%	25%	0%
Cognitive Social Capital (Mean and Range)	3.11 (1-4)	3.25 (3-4)	3.0 (1-4)
Low Cognitive Social Capital (%)	11.11%	0%	20%
High Cognitive Social Capital (%)	88.89%	100%	80%

Semi-Structured Interviews

Patients with diabetes were interviewed to explore their experiences and

beliefs regarding: control over diabetes and self-management functions, perceived barriers to managing the illness, availability and level of social support, the perceived benefits of proper diabetes self-management, in addition to exploring individual structural and cognitive social capital. Six (6) diabetic patients were interviewed; one (1) from the broader community and five (5) were interviewed at the Hospital Integral. Two (2) of the five (5) diabetic patients interviewed at the Hospital Integral were interviewed after being admitted to the Hospital Integral's Intensive Care Unit for diabetic complications. The other three (3) diabetic patients interviewed at the Hospital Integral were interviewed while waiting to be seen by one of the outpatient clinic physicians. All diabetic patients interviewed were female and reported having diabetes, from the time of diagnosis, for 1-35 years. On average, interviews lasted 15 minutes and 47 seconds. Interviews were audiotaped, transcribed in Spanish and then translated and coded in English. A second judge familiar with community assisted developing the initial codes. Thematic analysis of the interviews was conducted and three (3) important themes emerged:

(1) *Diabetes is caused by intense emotional distress.*

The majority of the respondents (4 of 6) said that they believed their condition was the primary result of an intense emotional experience and distress. However, the specific emotional response was mixed among the respondents, where two respondents specifically referenced "fright" or *susto* as the trigger, one respondent specifically referenced "anger" or *corajes*, and one responded

referenced both “fright” and “anger” (or *susto and corajes*). See Table 12 below.

(2) Changing personal habits and making better choices, especially, regarding diet can be very difficult.

The majority of respondents (5 of 6) talked about the difficulty of changing their eating and drinking habits for controlling their condition. While the majority (5 of 6) referenced “diet” as a whole, half of the respondents (3 of 6) also explicitly talked about the difficulty of changing their soda-drinking habits. Two (2) respondents went as far as to refer to drinking soda as a “vice” or *vicio*. See Table 12 below.

(3) Having diabetes can be overwhelming and difficult to manage.

The majority of respondents (4 of 6) also talked about difficulty they have had in managing their condition and reported some level of confusion or inability follow their recommended treatment plan, such as taking their medications or eating a proper diet. This difficulty was also expressed in terms of frustration, worry, or feeling overwhelmed. See Table 12 below.

Case II: Community Members and Partners

Survey Results

Diabetes Knowledge Questionnaire (DKQ-24)

In order to gain a better understanding of the diabetes-related knowledge of the broader community to serve as a baseline for informing the development of the semi-structured interview guide, the Diabetes Knowledge Questionnaire (DKQ-24) was provided to 45 members of the Xicotepec de Juarez Community

Table 12. Emergent Themes among Diabetic Patients

Diabetic Patient: Emergent Themes		
Question(s)/Probe(s)	Themes	Examples (Quotes)
What do you think caused your Diabetes?	Diabetes is caused by intense emotional distress.	
	-Code(s): Fright/Susto	* <i>pues un susto..mi esposo, el papa de mis niños, estaba en el hospital, y cuando le ví que le sacaban así todos los médicos, pos a verlos, me asusté y de allí empecé...</i> [Diabetic patient 3] (well it was “fright”, my husband, the father of my children, was in the hospital and when I saw him, when all the doctors took him out..well when I saw them I was “frightened” and from there it started...)
	-Code(s): Anger/Corajes	* <i>yo siento que fue todo...los corajes...porque yo siempre, hacia corajes con que se me secaba la boca...</i> [Diabetic patient 5] (I feel that it was everything..the anger..because I always, would get so angry that my mouth would dry up...)
Have you felt that you've deviated from your treatment plan? Why do you think this happens? Is there a habit you feel is difficult to change?	Changing personal habits and making better choices, especially regarding diet, can be very difficult.	
	-Code(s): Diet	* <i>...la tortilla..es lo que les dicen a uno..como estan acostumbrado verdad a comer..los primera veces pues me sentí mala..hasta como me voy a morir de mi dieta...mejor que todo de la enfermedad..es defícil por que es una dieta que tenia uno..pero..con tanto que se compongo a uno..</i> [Diabetic patient 2] (the tortilla..it's what they tell an individual..how they are accustomed to eating right..the first few times I felt ill..like I was going to die from my diet..more than everything of the illness..it is difficult because it is a diet someone used to have..but..with everything that one has to adjust to...)
	-Code(s): Soda	* <i>...luego de repente si anda por un refresco..si..pues, como es el vicio..no sea costumbre ya..pero luego me propongo tomar un refresco...</i> [Diabetic patient 3] (then all of a sudden I go find a soda..well, it is a vice..it's not a custom anymore, but then I come through and drink a soda...)
Do you worry or feel overwhelmed by your diabetes? Is there a particular part of your plan that worries you? Do you feel frustrated by the constant effort needed to manage your diabetes?	Having diabetes can be overwhelming and difficult to manage.	
	-Code(s): Difficulty managing	* <i>Pues, la desesperacion..que me altero mucho...hay veces que no me dan ganas de hacer nada...</i> [Diabetic patient 6] (Well, the helplessness, it affects me a lot...there are times when I don't have the motivation to do anything)
	-Code(s): Worry and being overwhelmed	* <i>al principio si lloraba yo todos los días..Uy, si, a mi me afecto mucho, yo estuve como un año pensando..cuando me iba a quedar ciega, cuando me iban a cortar un pie, cuando no...y si me costó mucho aceptar esa enfermedad...este, decia, yo quiero que me quite la diabetes</i> [Diabetic patient 5] (at first I would cry everyday...I affected me a lot...I spent about a year thinking, when am I going to go blind, when are they going to cutoff my foot, when...and yeah it took a lot to accept the condition..I would even say that I wanted the diabetes taken away...)

who had not been diagnosed previously, nor at the time of administration, as having diabetes. All forty-five (45) community members were surveyed at the annual Justo-A-Tiempo cervical cancer screening organized by Rotary International and the Cruz Roja Mexicana of Xicotepec de Juarez. All respondents were female and the age of the Community member group ranged from 19-60 years of age. The DKQ-24 score ranged from 4-19 correct answers (out of 24 questions) with a mean score of 51.75%. A summary table is provided below: See Table 13.

Table 13. Diabetes Knowledge Questionnaire Results: Community Members

Summary Results: Community Members (n=45) Diabetes Knowledge Questionnaire (DKQ-24)	
Category	Community Members (n=45)
Respondent Age Range	19-60
DKQ Score Range (Number Correct of 24)	4-19
Mean DKQ Score (% Correct)	51.75%
<i>Question Performance</i>	
# of Questions with >50% Correct Response Rate	13
# of Questions with >75% Correct Response Rate	8
# of Questions with 100% Correct Response Rate	0
# of Questions with >50% Incorrect Responses Rate	10
# of Questions with >75% Incorrect Responses Rate	8
# of Questions with 100% Incorrect Response Rate	1*

* Item #21: Recognizing Signs High and Low Blood Sugar

Of the 24 questions assessing general diabetes knowledge, there were 13 questions that were answered correctly by more than 50% of the DM

respondents and 10 questions that were answered incorrectly by more than 50% of the DM respondents. There were not any (0) questions that were answered correctly by all 45 Community members. There was one (1) questions that was answered incorrectly by all 45 Community members: (Possible Responses were: Yes, No, or I don't know; "I don't know" responses were treated as incorrect responses)

Question #21: Shaking and sweating are signs of high blood sugar.

Short-Adapted Social Capital Assessment Tool (SASCAT)

In order to gain an initial understanding of how diabetic patients perceived the quality and quantity of their social relationships, the Short Adapted Social Capital Assessment Tool (SASCAT) was also administered to these 45 members of the Xicotepec de Juarez Community who had not been diagnosed previously, nor at the time of administration, as having diabetes. The average overall scores for the Structural Social Capital and Cognitive Social Capital portions of the instrument for all forty-five (45) community members were a 2.13 out of 52 and a 1.71 out of 4, respectively. The SASCAT instrument assessed the patient perception of the quality and quantity of their social relationships via 5 primary subscales: Group Membership, Support from Groups, Support from Individuals, Citizenship Activities and Cognitive Social Capital (e.g. Trust in the Community). A summary table of subscale scores is provided below: See Table 14.

Semi-Structured Interviews

For the purpose the semi-structured interviews, community partners were a

Table 14. Short-Adapted Social Capital Assessment Tool Results: Community Members

Summary Results: Community Member Short Adapted Social Capital Assessment Tool (SASCAT)	
SASCAT Dimensions	Community Members (n=45)
Structural Social Capital (Mean and Range)*	2.13 (0-13)
<u>Group Membership</u> (Mean and Range)	0.49 (0-6)
No Group Membership (%)	73.33%
Member of 1 Group (%)	17.18%
Member of 2 or more Groups (%)	8.89%
<u>Support from Groups</u> (Mean and Range)	0.71 (0-7)
No Support Received (%)	66.67%
Support from at least 1 Group (%)	33.33%
<u>Support from Individuals</u> (Mean and Range)	0.71 (0-4)
No Support (%)	60.0%
Support from 1 Individual (%)	17.78%
Support from 2 or more Individuals (%)	22.22%
<u>Citizenship Activities</u> (Mean and Range)	0.22 (0-2)
No Citizenship Activities (%)	84.44%
1 Citizenship Activity (%)	8.89%
2 Citizenship Activities (%)	6.67%
Cognitive Social Capital (Mean and Range)	1.71 (0-4)
Low Cognitive Social Capital (%)	75.56%
High Cognitive Social Capital (%)	24.44%

more narrowly defined subset of people that included community leaders.

Community leaders included those in managing or leadership positions within community organizations, such as President of the Xicotepec de Juarez Rotary International Club, President of the Club de Leones, and other organizations that

provide valuable services to the community, as they are more likely to have a richer understanding of how the community is or can be linked to the health care organization based on their prior and current experiences in community outreach and involvement within their respective organizations. The rationale behind this purposive sampling is that, exploring the beliefs and perceptions of community leaders is essential for gauging the capacity and motivation of the broader community to contribute to addressing public health concerns, such as emerging chronic illnesses like diabetes. A total of five (5) community leaders were interviewed. On average, interviews lasted 25 minutes and 47 seconds. Interviews were audiotaped, transcribed in Spanish and then translated and coded in English. Thematic analysis of the interviews was conducted and revealed three (3) important themes:

(1) Diabetic patients are not adequately prepared to manage their condition.

All five (5) community leaders expressed to varying degrees the unpreparedness of diabetic patients to manage their condition. During these discussions, this theme was linked to general perceptions that patients lacked the awareness, information and health-related education about the disease and how to properly manage it. See Table 13 below.

(2) Culture is a major barrier to effective care and self-management for patients with diabetes.

All five (5) community leaders, remarked that a larger part of the problem has to do with the culture of the “Mexican people.” This idea of culture

encompassed perceptions about how people value their health and lifestyles and how these seem to be at odds with effectively managing diabetes at both the individual and population levels. See Table 13 below.

(3) Xicotepec de Juarez is a great community with caring people.

All five (5) community leaders expressed that they felt they could trust in the majority of their community. While there were varying degrees hesitancy when responding to the question about being able to trust the majority of the people in their community, each community leader perceived or, at least, promoted their community as a warm and humble community. See Table 15 below.

Case III: The Health Care Team

Survey Results

Assessment of Chronic Illness Care (ACIC)

In order to gain an initial understanding of how health care providers perceived the current provision care for chronic diseases, such as diabetes, the Assessment of Chronic Illness Care (ACIC) tool was administered to ten (10) health care providers within the Xicotepec de Juarez Community, or more specifically within the Hospital Integral. All respondents were either physicians or nurses who had direct contact with or participation in care encounters with diabetic patients. The average overall score for the instrument of all ten (10) providers was a 5.64 out of 11 and ranged from 0.55-8.44. Differentiating between physicians and nurses within the Hospital Integral, the average scores were 7.01 and 4.72 respectively. The ACIC instrument assessed the provider's

Table 15. Emergent Themes among Community Leaders

Community Partners: Emergent Themes		
Question(s)/Probe(s)	Themes	Examples (Quotes)
How do patients receive information or support for reducing health risks or manage conditions like diabetes? Do you think patients are prepared to manage their condition?	Diabetic patients are not adequately prepared to manage their condition.	
	-Code(s): Awareness and Access	<p>* “generalmente...es el, primero que nada el desconocimiento de la enfermedad...muchos pacientes son prediabéticos o diabéticos y no se atienden, simplemente, van sufriendo la enfermedad y viven con ello... nosotros tenemos a la periferia de la cabecera municipal que es Xicotepec, muchas comunidades donde la gente, a la gente le cuesta much trabajo a recibir los servicios de salud...entonces muchos se dejan de atender...” [Community Leader 1] (in general, it is, before anything it’s the unawareness of the disease..many patients are prediabetic or diabetic but don’t seek treatment, they simply go on suffering from the disease and live with it..we have on the periphery of the municipal set that is Xicotepec, many communities where it is a lot of trouble to seek care and so they refrain from seeking care)</p>
	-Code(s): Information and Education	<p>* “las instituciones no les ofrecen información adecuada..o le dan información que no es completa..no esta completa y ellos no llevan el camino que deberían seguirse.” [Community Leader 2] (the institutions [health care system] do not give them adequate information or they give them information that is not complete..it is not complete so they are not able to follow the path that they should..)</p>
What factors do you think affect patients’ ability to follow recommended treatment?	Culture is a major barrier to effective care and self-management.	
	-Code(s): Cultural practices	<p>* “la idiosincrasia la cultura de la gente, le hacen un poquito..la ignorancia hace que no tomen los tratamientos adecuadamente..si no se cerca las instituciones del gobierno..logicamente no reciben tratamiento adecuados, muchos veces son tratamientos como casero..o tratamientos que posiblemente son alternativos a los tratamientos que deberían de llevarse..muchos veces lo detectan despues de diez, quince o veinte años..pero los tratameintos muchas veces, creo que no son llevado adecuadamente..los pacientes no son adherentes por cultura, por religion o otros inconstancias...yo creo la idiosincrasia..la cultura es el enemigo numero un...no hay mas..nada mas importante en Mexico que la cultura...” [Community Leader 2] (it’s the idiosyncrasy of the culture of the people, they are a bit.. their ignorance that makes them not follow their treatment appropriately..if they are not using the government institutions..logically they won’t receive adequate treatment..often times they are using treatments that are homemade or possibly alternative to the treatment they should be using..many times it [diabetes] is not detected until after 10, 15, 20 years..but many times the treatment, I believe is not used appropriately..the patients are not adherent because of the culture, religion or some other reason...I believe this idiosyncrasy..the culture is enemy number one..there is not more..nothing more important in Mexico than the culture...)</p>
	-Code(s): Health behaviors and Values	<p>* “yo creo que mas que nada..que aqui..nosotros..a los Mexicanos..tendramos mucho a no..no cuidar a nuestro salud..desgraciadamente..nosotros somos muy descuidados con nuestro salud..aquí decimos..‘que como la salud nos regalos a Dios, no nos cuesta, no nos preocupamos’. y es cierto..son pocos a las personas que llevan a uno tratamiento y que le siguen...falta de educacion..eso es todo..la mayoría..es falta de educacion..si estuvieramos educados par cuidarnos, para tratarnos, pues no tuvieramos estos problemas...” [Community Leader 3] (I believe that more than anything, that here..we..as Mexicans..we have a history on not taking care of our health..unfortunately..we are careless with our health..we have a saying here ‘As our health is a gift from God, it doesn’t cost us anything so we don’t worry about it.’ and it is true..there are few people who follow their treatment and continue with it..lack of education..that is it..for the most part..it is a lack of education..if we were taught to take care of ourselves to treat ourselves, then we wouldn’t have these problems...)</p>
In general, do you feel that you can trust the majority of the people in this community?	Xicotepec is a great community with caring people.	
	-Code(s): Support	<p>* “la gente de Xicotepec es muy linda...la gente de Xicotepec es solidaria, es muy trabajadora...” [Community Leader 1] (the people of Xicotepec are very nice....the people of Xicotepec are supportive and hard-working...)</p>
	-Code(s): Caring	<p>* “hay muchos ejemplos de gente que esta preocupara por apoyar en una medida o la otra y a un sentido o la otra...” [Community Leader 2] (there are many examples of people who are concerned with helping out in one way or another)</p>

perception of care provision via 7 primary subscales: Organization of the Health Care System, Community Linkages, Self-Management, Decision Support, Delivery System Design, Clinical Information System, and Integration. A summary table of subscale scores is provided below: See Table 16.

Table 16. Assessment of Chronic Illness Care Results: The Health Care Team

Summary Results: Hospital Integral Health Care Provider Assessment of Chronic Illness Care (ACIC)			
ACIC	HC Providers (n=10)	Physicians (n=4)	Nurses (n=6)
Overall ACIC Average Score (Range)	5.64 (0.55-8.44)	7.01 (5.75-7.83)	4.72 (0.55-8.44)
ACIC Subscales Average Score (Range)			
Organization of HC System	6.03 (0.17-9.5)	7.33 (6.83-7.83)	5.17 (0.17-9.5)
Community Linkages	4.97 (0.33-8.33)	7.17 (4.67-8.33)	3.5 (0.33-7)
Self-Management	5.22 (0.25-9.75)	6.31 (4.25-8)	4.5 (0.25-9.75)
Decision Support	5.65 (0.25-9.75)	6.25 (3-9.5)	5.25 (0.25-9.75)
Delivery System Design	6.07 (1-8.5)	7.46 (6.83-8)	5.14 (1-8.5)
Clinical Information System	6.42 (1-9.8)	8.2 (6.8-9.8)	5.23 (1-8.4)
Integration	5.1 (0.83-7.33)	6.38 (4-7.33)	4.25 (0.83-6.17)

ACIC Scoring Scale: Limited Support for Chronic Illness Care= 0-2; Basic Support for Chronic Illness Care= 3-5; Reasonably Good Support for Chronic Illness Care= 6-8; Fully Developed Chronic Illness Care=9-11

Short-Adapted Social Capital Assessment Tool (SASCAT)

In order to gain an initial understanding of how health care providers perceived the quality and quantity of their social relationships, the Short Adapted Social Capital Assessment Tool (SASCAT) was also administered to the ten (10) health care providers from within the Hospital Integral in Xicotepec de Juarez Community. The average overall scores for the Structural Social Capital and

Cognitive Social Capital portions of the instrument for all ten (10) health care providers were a 2.8 out of 52 and a 2.1 out of 4, respectively. Differentiating between physicians and nurses providing care within the Hospital Integral, the average scores for physicians were 1.25 for the Structural Social Capital component and 1.75 for the Cognitive Social Capital component, while the average scores for the nurses were 3.83 for the Structural Social Capital component and 2.33 for the Cognitive Social Capital component. The SASCAT instrument assessed the patient perception of the quality and quantity of their social relationships via 5 primary subscales: Group Membership, Support from Groups, Support from Individuals, Citizenship Activities and Cognitive Social Capital (e.g. Trust in the Community). A summary table of subscale scores is provided below: See Table 17.

Semi-Structured Interviews

The interviews for the health care team members explored beliefs and experiences that correspond to concepts included in the ICCC Frameworks such as: (a) Evidence-based decision making at the level of the health care organization and the community; (b) prevention focus; (c) integration; and (d) prepared, informed and motivated health care teams. Additional questions explored diabetes-related processes and outcomes, as well as structural and social capital. A total of ten (10) health care providers were interviewed and included: two (2) physicians from the Hospital Integral, two (2) nurses from the Hospital Integral, two (2) private practice physicians from the broader community,

Table 17. Short-Adapted Social Capital Assessment Tool Results: The Health Care Team

Summary Results: Hospital Integral Health Care (HC) Provider Short Adapted Social Capital Assessment Tool (SASCAT)			
SASCAT Dimensions	HC Providers: H.I. (n=10)	HC Providers: Physicians (n=4)	HC Providers: Nurses (n=6)
Structural Social Capital (Mean and Range)	2.8 (0-9)	1.25 (0-5)	3.83 (1-9)
<u>Group Membership</u> (Mean and Range)	0.2 (0-1)	0.25 (0-1)	0.17 (0-1)
No Group Membership (%)	80.0%	75%	83.3%
Member of 1 Group (%)	20.0%	25%	16.7%
Member of 2 or more Groups (%)	0.0%	0%	0%
<u>Support from Groups</u> (Mean and Range)	1.2 (0-5)	0 (0-0)	2 (0-5)
No Support Received (%)	70.0%	100%	50%
Support from at least 1 Group (%)	30.0%	0%	50%
<u>Support from Individuals</u> (Mean and Range)	1.1 (0-3)	0.5 (0-2)	1.5 (0-3)
No Support (%)	40.0%	75%	16.7%
Support from 1 Individual (%)	20.0%	0%	33.3%
Support from 2 or more Individuals (%)	40.0%	25%	50%
<u>Citizenship Activities</u> (Mean and Range)	0.3 (0-2)	0.5 (0-2)	0.17 (0-1)
No Citizenship Activities (%)	80.0%	75%	83.3%
1 Citizenship Activity (%)	10.0%	0%	16.7%
2 Citizenship Activities (%)	10.0%	25%	0%
Cognitive Social Capital (Mean and Range)	2.1 (0-4)	1.75 (0-4)	2.33 (1-3)
Low Cognitive Social Capital (%)	50.0%	50%	50%
High Cognitive Social Capital (%)	50.0%	50%	50%

one (1) physician from the community health center outside of the municipality seat, one (1) homeopathic practitioner, one (1) naturista, and one (1) hierbolero. The practitioners have been practicing in the Xicotepec community for 2-32 years (average of 19.7 years). On average, interviews lasted 25 minutes and 38 seconds. Interviews were audiotaped, transcribed in Spanish and then translated and coded in English. Thematic analysis of the interviews was conducted and revealed three (3) salient themes:

(1) Patients need to take more responsibility for managing their diabetes.

The majority of the health care providers (6 of 10) expressed a sentiment that patients are not taking enough responsibility for their management of the disease, with many (4 of 10) expressing that some of this was related to patients inability to accept that they have the condition. See Table 14.

(2) Culture can be a significant issue for diabetic patients, especially concerning food and use of alternative treatment sources such as 'naturistas'.

All ten (10) health care providers remarked in varying instances that culture is a significant issue in developing and managing diabetes. This primarily occurred through references of patients seeking alternative or traditional/ethnomedical courses of treatment for their illness or through patient behavior related to dietary practices or habits. See Table 14 below

(3) Integration, coordination, and cooperation with other health care practitioners can be difficult.

The majority of health care providers (7 of 10) also expressed some frustration in how care was integrated and/or coordinated throughout the community, and how cooperation among other health care professionals could be difficult. Within this theme, health care providers talked about cooperation and solidarity as a medical community as well as issues related to trust and the effect conflicting messages have on patients and their related trust with health care practitioners. See Table 18.

Table 18. Emergent Themes among Health Care Providers

Health Care Providers: Emergent Themes		
Question(s)/Probe(s)	Themes	Examples (Quotes)
How do patients receive information or support for reducing health risks or manage conditions like diabetes? Do you think patients are prepared to manage their condition?	Patients need to take more responsibility for managing their diabetes.	
	-Code(s): Patient responsibility	<p>*".. hay pacientes que no quieren acudir..y que muchos veces ellos no llevan a piel de la letra el tratamiento, aqui es un compromiso de coresponsibilidad..usted paciente, yo medico..le voy a decir sabe que.. tienes que llevar las siguiente medidas..en cuanto el medicamento y a los cuidados que debe tener..pero usted debe administrarse medicamentos, alimentarse como estoy diciendo..y ademas hacer los ejercicios que estoy recomendando..si la parte que le toca hacer la paciente no le lleva acabo no vamos a tener exito..tiene que haber un compromiso de ambas partes para que la participacion puede ser de adelante...que en realmente responsabilizamos.." [HC 5: Physician] (there are patients who do not want to show up..and that many times they will not follow their treatment, here..we have a commitment of co-responsibility..you the patient, me the doctor..I'm going to tell you "you know what? You need to follow these guidelines..concerning your medications and the precautions that you need to take..but you need to take your medications, follow the diet I am giving you and the do the exercises I am recommending..if the patient does not do his/her part then we will not have success..there needs to be a commitment from all parties so that participation can be improved..in reality we all need to take more responsibility.)</p>
	-Code(s): Acceptance of the disease	<p>*"..el paciente en el pais, es defcíl darle inicio por que no aceptan primera de nada la enfermedad y de alli que esta trabajando mucho sobre la..pues la conocimiento de esta de no debe hacer, no dejar su medicacion, hacer ejercicio..pero con el tiempo va concientizar tomar responsibilidad.." [HC 3: Physician] (the patient in this country, it is difficult to start treating because they won't accept, for anything, the illness [diabetes] and then from there you are working hard for the acceptance..but also the awareness of knowing what not to do, not to stop taking your medicine, to exercise..)</p>
What factors do you think affect patients' ability to follow recommended treatment?	Culture can be a significant barrier for diabetic patients, especially concerning food and alternative treatment sources.	
	-Code(s): Cultural practices and Alternative/Traditional medicine	<p>*"..es la cultura no?..dicen que comer nopal, y con hierbitas..y dejan los medicamentos..por los costumbres o buscan medicinas 'magicas'.si..com capsulas de nopal..las este..hay unas vacunas..donde sacan sangre al paciente y una preparado en este.. [gesturing]..en los que vaya..en un frasco que esta preparado..les mezclan sangre..les ponen..este...un vacuna de la misma sangre..es medicina 'magico' para ellos.." [HC 2: Physician] (it is the culture, is it not?..They say to eat 'nopal' (a cactus) and with herbs..and they stop their medications..it is because of the customs or that they look for 'magic' medicines..yeah..with cactus pills..those..vaccines..where they draw blood from the patient and some mixture in this [gesturing]..then they take it..in a container that has something already prepared..they mix the blood..they put..this..a vaccine with the same blood they drew..it is 'magic' medicine for them..)</p>
	-Code(s): Diet	<p>*"..a la mejor..el..pues que puede hacer..no se que podria hacer..porque incluye las verduras son baratas..son mas baratas que comprar pan o que comprar refresco..pero es el costumbre que tenemos de ir por la coca o la fanta..en vez de..oye yo les digo 'cuanto te cuesta un litro de leche, cuanto te cuesta una Coca de 3 litros ..cada vez en cuando que se tome esta bien..pero pues una leche te beneficia mas que el refresco..pues..nuestra nivel cultural yo creo.." [HC 1: Nurse] (the biggest part..well..what could it be?..I'm not sure what it could be because vegetables are cheap, they are cheaper than bread or soda..but it is our custom that we need to go for a Coca-Cola or Fanta..instead..look, sometimes I say 'how much does a liter of milk cost, how much does 3 liters of Coca-Cola cost? You can have soda every now and then and it is ok..but milk will benefit you more than the soda..well I believe that it is our Culture..)</p>
How well do you think each level of the healthcare system works together to improve care for chronic conditions like diabetes? Have you ever encountered any problems working with other health care professionals when managing or treating a patient with diabetes?	Integration, coordination, and cooperation with other health care practitioners can be difficult.	
	-Code(s): Cooperation and Solidarity	<p>*"..pos es defcíl, por que?..por que por desgracia hay mucha envidia..en el medio medico..este incluye los medicos de saludidad [sector de salud]..aunque ellos tienen mas..todo a la mano..pero les falta todavia..este..pues como que me voy a orir mal..pero como que muchos medicos en instituciones..lo que ellos les interesa es ir, cumplir, cobrar y vamos..los falta mucho este..los falta mucha este..solidaridad.." [HC 4: Physician/Homoepathic] (..well it is difficult, why?..because unfortunately there is a lot of envy in the medical community..and it includes the doctors in the public health sector..although they have more..everything in their hands..but they are still lacking..that..well I know I'm going to sound bad, but many of the doctors in the institutions..what interests them is to show up, fulfill, charge and leave..they lack a lot of this..they lack a lot of..solidarity..)</p>
	-Code(s): Trust and Conflicting messages	<p>*"..cada medico tiene un punto de vista en particular y se difiere en algunas cuestiones sobre la dieta, sobre la medicacion y eso en ocasiones el paciente lo pone en cierta desconfianza cual es el mejor tratamiento seguir?..Y eso les puede llevar a que no le den seguimiento a sus invicaciones.." [HC 2: Physician] (..every doctor has his particular point of view and it will be different for some issues about diet, medication..and with that on occasions, the patient will develop a distrust about which is the best treatment to follow..and that can result in them not following your recommendations or instructions..)</p>

CHAPTER 5: DISCUSSION AND CONCLUSION

Introduction

This chapter will provide a discussion of the key results from both phases of the study. However, unlike the preceding chapter where results were presented in the context of the three cases: “Diabetic Patients,” “Community Members,” and “Health Care Providers,” this discussion will be presented in the context of answering the original research question and the four (4) research sub-questions. The chapter will conclude with a more abstract discussion of the merits and challenges of the action research approach used to explore the problem of diabetes in the rural community of Xicotepec de Juarez, Puebla, Mexico.

Problem Explication Revisited

While there has been a dramatic increase in the prevalence of diabetes in developing countries, such as Mexico, a dearth in academic literature exists regarding how these countries have prepared their health systems for addressing the increase in chronic diseases, such as diabetes. The only discussions of the strategies addressing the changing state of health and medication access in Mexico have thus far been discussed at the level of national policy and health care reform. While important, there is little to no evidence that these discussions have been informed by how these problems are manifested at the level of patient care provision in the health care organization and within the community. This is especially true of rural resource-poor communities, as the vast majority of chronic illness related studies occur in the urban centers within many developing

countries, including Mexico. Additionally, research is needed to better understand how the dynamic components inherent in the provision of care to patients in the health care organization and the community impact accessibility to care and treatment for diabetes in rural resource-poor communities.

Answering the Research Questions

The purpose of this study was to examine the provision of health care for diabetes and the inherent relationships that exist among patients and families, health care teams, and community partners related to diabetes care in Xicotepec, Mexico. I was interested in assessing patient and health care provider experiences, the health care organization's ability to provide the necessary care for diabetic patients, and its links to the community in doing so; as well as the health-related beliefs associated with diabetes and treatment of various community stakeholders. That is, the objective of this study was to examine the provision of health care for diabetes and the beliefs and relationships that exist among patients and families, health care teams, and community partners that affect treatment and care for diabetes in a rural resource-poor community in Mexico. I expected to achieve this objective by answering the following questions:

Main research question: What are the factors that influence the provision of diabetes care in a rural community in Mexico?

Subquestion 1: How do health care providers and patients perceive the current performance of the provision of care for diabetes in the community?

Subquestion 2: What are the diabetes-related health beliefs among patients, health care providers and community members that could influence care for diabetes?

Subquestion 3: What resources are available within the community and how do patients, health care providers and community members perceive the existing linkages between patients and families, health care teams, and community partners and resources related to care for diabetes?

Subquestion 4: Is the concept of social capital a suitable tool for characterizing the dynamic relationships within the ICCC Triad of health care providers, patients and families, and community partners, in the context of improving access to and provision of care for diabetes?

The focus of this research was to investigate the factors that influence access to and the provision of diabetes care in a rural community in Mexico. In order to do this, I implemented an action research approach that allowed me to utilize multiple data sources and data collection techniques in order to triangulate the factors that influence access and the provision of care. The action research approach was instrumental for ensuring that the study design incorporated an appropriate amount of rigor and still remained flexible and responsive to the complexities of the ever-changing environment in the municipality of Xicotepec de Juarez, Puebla, Mexico.

The remainder of this chapter will take a closer look at how the proposed research questions were answered and will then conclude with a brief discussion

of the limitations of this study; as well as the implications this work has on theory, research and practice.

Perceptions of Health Care for Chronic Conditions

Subquestion 1: How do health care providers and patients perceive the current performance of the provision of care for diabetes in the community?

Assessing health care provider and patient perceptions of the current performance of the provision of care for diabetes was carried out through surveys and semi-structured interviews amongst both groups. The surveys for both groups were linked to the Chronic Care Model to assess perceptions of the extent to which care for diabetes provided in the community is congruent to Chronic Care Model principles. Within these surveys we were concerned with those components that were especially aligned to the Innovative Care for Chronic Conditions Framework. From the patient survey, the PACIC-5As, we were especially interested in the Patient Activation, Follow-up/Coordination and Arrange scale constructs.

The 'Patient Activation' construct, in general, was related to how well patients feel they are able to take responsibility for their care. Hibbard et al. (2004) defined it as "having the knowledge, skill, and confidence to self-manage and to collaborate with providers." Thus, it provided an assessment of the receipt of patient-centered, self-management support or actions (taken by health care providers) that explicitly solicit patient input and involvement in decision-making that are believed to enhance self-activation (Glasgow, Wagner, et al. 2005).

The 'Follow Up/Coordination' construct, in general, was related to how well

patients feel that their providers were able to coordinate their care with other health care resources. It provided an assessment of actions (taken by health care providers) to arrange care that extends and/or reinforces clinic-based treatment as well as, proactively making contact with patients to assess progress and coordinate care (Glasgow, Wagner, et al. 2005).

Similar to the 'Follow-up/Coordination' construct we were also interested in taking a closer look at the 'Arrange' construct, which is a component of the 5 A's model for behavioral counseling that is related to scheduling follow-ups to provide ongoing assistance and support, including adjusting the treatment plan as needed and making referrals to more intensive or specialize treatment (Whitlock, Orleans, et al. 2002). This construct was particularly concerned with using follow-up contacts to update the behavior change plan, such as diet and exercise for diabetics, as well as supporting relapse prevention for those who have made some significant behavior change.

This present study found that patients reported that provider actions to enhance 'Patient Activation,' to provide 'Follow-up/Coordination,' and 'Arrange' subsequent care based on the patient's efforts, experiences and perspective were generally not occurring. These findings suggest underlying structural and process deficiencies in how care is being organized to address the needs of diabetic patients. Interviews with health care providers are fairly consistent with these findings (with the exception of 'patient activation') and suggest that possible reasons for these deficiencies could include: (1) time constraints placed

on physicians to treat more patients in less time which inhibits adequate patient education and preparation for managing chronic illnesses like diabetes; (2) there may be a limited availability of health care resources for which health care providers can coordinate with, thereby hindering proper coordination and continuity of care (a plausible reason suggested through community asset mapping and patient and community leader interviews); and/or (3) the fact that most health care providers (e.g. physicians, nurses, etc.) receive very little training on behavior modification, an important part of diabetes management. Unfortunately, comparing these results with similar studies could not be accomplished as no other studies utilizing the PACIC within the context of the Mexican health care system and a Mexican population could be identified.

This study also illuminated a rather important finding in that there was a general incongruence regarding expectations of care, between patients and health care providers. This study provided some evidence to this point, in that while patients reported that they were generally not receiving self-management support or support through coordinated care outside the specific clinic site, physicians reported (via the ACIC) that they were providing 'Reasonably Good Support' for developing self-management competencies *and* in linking care to resources outside of the clinic. Interestingly, nurses tempered this message by physicians, as they reported that only 'Basic Support' for these components to care was being provided to patients with diabetes.

In this study we found that the provider perspective, via the ACIC survey,

was somewhat similar to what was found during an interventional study in the Mexican state of Veracruz, conducted as a joint program (VIDA Project) between the Ministry of Health and the Diabetes Declaration of the Americas through the Pan American Health Organization (PAHO)/ World Health Organization. The VIDA Project assessed the status of diabetes care in five urban health centers in Veracruz, Mexico in a one-year intervention between 2003-2004. While the results have not been published, an updated report by the PAHO, provides results of their use of the ACIC. Similar to the current study, the VIDA Project physicians reported that 'Reasonably Good Support' was being provided for developing self-management competencies. However, unlike the current study, the VIDA Project suggests that physicians reported only 'Basic Support' being provided in linking care to additional resources outside of the clinic (PAHO, 2004). This difference is a little surprising given that one could have reasonably hypothesized that performance related to linking to outside resources would have been at least similar to what was reported by Xicotepec health care providers, given that the availability of resources in an urban setting such as Veracruz is much more robust than what are available in Xicotepec. A reason for this difference, however, could be over-reporting of activities by the Xicotepec health care providers. On this note it is important to point out that the impetus for developing the PACIC was to use the patient perspective to temper what many refer to as a systematic tendency for over-reporting by physicians (Glasgow, Wagner, 2005).

Although nurse ACIC results tended to corroborate the patient results from the PACIC, patient and community member results of the Diabetes Knowledge Questionnaire (DKQ-24), patient interviews, and health care provider interviews all provided further evidence that there is a significant need to improve awareness and knowledge about diabetes among patients and the broader community. This also included evidence to support the need to better prepare patients for managing chronic conditions, like diabetes. For example, looking at the results of the DKQ-24 for diabetic patients, there were two concepts (the etiology of diabetes and diet) that revealed the importance of needing to bolster education and awareness. All nine diabetic patients that participated in the survey missed questions related to these concepts. A proper understanding of how diabetes develops and following a proper diet are two critical components for effective diabetes prevention and management.

Patient and health care provider interviews also provided some insight on the current performance of the provision of care for diabetes as they suggested three important themes. From the patient perspective, two important themes emerged: (1) *Changing personal habits and making better choices, especially regarding diet can be very difficult* and (2) *Having diabetes can be overwhelming and difficult to manage*. Together, as patients talked about how difficult it was to follow a proper diet and in expressing how overwhelming managing diabetes could be, the need for improving how patients are prepared to manage their conditions (self-management) is compelling and very much at odds with what

providers reported as 'Reasonably good support' being provided.

From the provider perspective, there was more ambiguity regarding the performance of the provision of care for diabetes. While the results from the ACIC suggest that they believe that they are providing 'Reasonably good support' for chronic illnesses such as diabetes, their responses during the interviews revealed less favorable perceptions. An important theme that emerged from the interviews, *Integration, coordination, and cooperation with other health care practitioners can be difficult*, illustrates this point. Providers expressed a frustration with and reluctance to working with other providers within the community to manage diabetic patients. The reasons ranged from disagreement on diabetes management recommendations, to issues related to "desconfianza" (trust), "envidia" (jealousy and envy), to "nuestra actitud" and "mentalidad" (health care provider attitudes) suggesting a lack of confidence in other health care provider motivations to support adequate care for diabetic patients.

Integration, coordination and cooperation are all critical elements of the Chronic Care Model and if health care providers are finding it difficult to implement or carry out these components of the care process, then it is hard to take their evaluation of 'Reasonably good support' for chronic illness care, at face value. Additionally, at least two of the health care providers expressed their frustration with the overall organization of health care in the country and the bureaucracy that limits it. These providers talked about the variety of programs that get developed by the Ministry of Health at both the national and state levels

that are unable to be carried out efficiently because of the political dynamics at all levels of the health care system and government. They were specifically frustrated with the fact that when administrations change at any level, programs that were implemented or proposed by opposing party officials (or previous administrations) either come to a halt completely, see cuts in funding, or are overhauled to the point that messages are lost or people are confused and become disengaged. I can, personally, attest to the validity of this sentiment as I experienced this firsthand during the study development and approval processes I had to navigate in order to finally carry out this study.

Interestingly, despite these expressions from health care providers another important theme emerged from the interviews that signified a reluctance to be held accountable for the performance of the provision of care for diabetes. That is, health care providers expressed in their frustrations that *patients need to take more responsibility for managing their diabetes*. This signaled a shift from acknowledgment of their role in any deficiencies in the current care process toward transference of the burden of accountability onto the patient.

In summary, in this study, it was found that physicians and patients had differing perceptions regarding the care being provided for diabetes. Physicians within the Hospital Integral were generally more optimistic or positive about the level of care they were providing for diabetic patients. While this type of perception is not particularly surprising, it is interesting that nurses were more in line with patients. In many regards they were acting as a patient advocate, not

afraid of pointing out the problems with the current provision of care and the challenges to providing effective care and support for improving outcomes and the health-related quality of life of their patients. Additionally, the findings also point to fragmentation and lack of integration within the health care system, among other providers within the broader community and with other non-biomedical practitioners. In communities where multiple 'health' systems operate (e.g. biomedical and traditional/alternative medicine) careful consideration for managing chronic illnesses, such as diabetes, is especially important as many patients often utilize multiple sources of care simultaneously. This not only increases the complexity of care and management but it also creates opportunities for enhancing continuity of care and self-management behaviors of patient in communities with limited resources.

Diabetes-Related Health Beliefs in the Community

Subquestion 2: What are the diabetes-related health beliefs among patients, health care providers and community members that could influence care for diabetes?

The survey portion of the study allowed us to gain initial understanding of the perceptions patients and health care providers had regarding the performance of the provision of care for diabetes. However, it was through the interviews that we were able to put those perceptions into context and gain a richer understanding of the diabetes-related health beliefs that could influence care for diabetes in the community.

For example, results from the DKQ-24 instrument suggested that diabetic

patients had limited knowledge of the development of diabetes as an illness, which can have a profound impact on not only accepting the diagnosis but also in adhering to recommended treatment. Thus, during the interviews with the diabetic patients I decided it would be important to understand their beliefs about what caused them to develop diabetes. An important theme emerged from the interviews as the majority of the patients described intense emotional distress as the cause for developing diabetes. This intense emotional distress was described as “*susto*” (fright) and/or as “*corajes*” (intense anger) frequently associated with a traumatic event in the patient’s life. *Susto* and *corajes* have been described frequently in anthropologic and social science literature (Poss et al., 2002). This finding of an intense emotional distress is consistent with other findings about beliefs regarding diabetes among patients in rural Mexico (Valenzuela et al., 2003) and Mexican-American patients in the US (Coronado et al., 2004; Jezewski et al., 2002; Poss et al., 2002).

The literature also suggests that Latinos have different experiences and thought processes about illness and disease compared to other population subgroups and more importantly the physicians who treat them (Coronado et al., 2004; Loewe et al., 2000). Understanding these beliefs and how patients conceptualize causation of diseases has important clinical implications, especially in that research has shown that patients are more likely to take an active role in the management of their disease if they attribute it to some part of their behavior, compared to those who do not (Hunt et al., 1998).

Interestingly, this may provide some context to one of the other important findings that emerged from interviews with health care providers where they expressed frustration with patients, such that *patients needed to take more responsibility for managing their disease*. A part of this frustration was expressed in terms of patients not “accepting” their disease as an illness that can significantly impact their lives. Perhaps this may indeed be partially explained by the research mentioned above that suggests patients and health care providers process and understand diseases and illness differently. However, of particular importance (from the health care provider perspective) is that health care providers were especially concerned with communicating their belief that patients needed to take more responsibility for managing their diabetes. This emerged as a particularly important belief that could affect efforts to improve care and management for diabetes.

This theme regarding patient responsibility for self-management and essentially the desire to shift accountability for health onto the patient alludes to an important issue within the health promotion discipline and literature: victim-blaming. That is, practitioners who have promoted and rallied for individually-oriented behavior change strategies are often said to be supporting a victim-blaming ideology (McLeroy et al., 1988). Tesh (1981) described this ideology as the life-style theory of disease, which “approaches disease as though ill health is the result of personal failure...it ignores the crucial connection between individual behavior and social norms and rewards.” In an even harsher criticism of

individually-oriented behavior change strategies, Crawford suggests that this ideology only serves as a retrenchment from rights and entitlements as it inhibits the understanding of social causation of disease and replaces it instead with an unrealistic model of behavior. In doing so it ignores what is known about human behavior and minimizes the importance of evidence on the effect the environment has in determining individual health (1979).

The individually-oriented behavior change strategy expressed in this study by health care providers has been referred to as a 'Cheap' alternative to quality improvement because it does not call for change in the social environment (Price et al., 1989). One of the central concerns with victim-blaming ideology is that "when individual choice is seen as 'the' cause, individuals already suffering from diseases and/or poor social conditions are made to suffer further from feelings of guilt and failure," (Dougherty, 1993).

In this study, evidence of this occurring emerged from diabetic patients. During one interview a patient was sharing her experience with the difficulty of sticking to the strict diet recommended by her physician and in doing so she referred to her affinity for soda as not merely an unhealthy behavior, but rather it that was a "*vicio*" (vice) she wished she had more control over. Her choice in using the term "vice" to refer to drinking a soda implies that she has come to view her difficulties as a moral failure, which emotionally and psychologically places considerable stress on her, and can ultimately inhibit other healthy behaviors or lead to depression and/or learned helplessness. Additionally, a focus that is

solely on individual behavior tends to promote stereotyping and the hardening of public attitudes toward the unhealthy (Dougherty, 1993). This too was found in the present study during the course of an interview among diabetic patients.

When asked to explain what she was thinking about when she responded to an earlier question about the “majority” of the people in her community (which was a question related to whether she felt that she could trust in the majority of people), this patient responded that she thought about many of the people who wouldn’t believe her and then specifically referred to the fact that sometimes people would treat her like a “drunk” if they saw her with a Coca-Cola in her hands knowing she was diabetic. Interestingly, this patient also referred to drinking soda as being regarded as a “*vicio*” (vice). Thus, this study has provided some evidence of social consequences that are associated with a victim-blaming ideology of diabetes, especially as it may be causing additional suffering to patients and their families.

In summary, the study illuminated some important health/diabetes-related beliefs that can very well affect care for diabetes. It became clear that across all cases (patients, health care providers, and community leaders) there are cultural beliefs that need to be addressed in efforts to improve care people with diabetes. Patients suggested an explanatory model of intense feelings or traumatic stressors as a trigger for the onset of diabetes. Meanwhile health care providers (e.g. physicians) were content on shifting responsibility and accountability onto the patient for self-management behaviors.

These are belief systems that are not only at odds with each other, but they cannot be ignored in the care process. Providers must be willing to change their behaviors to offer more than just prescriptions and superficial recommendations. It is important for providers to understand and be sensitive to the cultural challenges patients face while managing chronic conditions, such as diabetes.

Across all cases there was a general agreement that patients were not prepared to manage their condition, for a variety of reasons. A need for better awareness of diabetes as a disease as well as for better education on self-management is evident and, more importantly, presents an opportunity to address the extent to which these belief systems can affect access to and the provision of care for diabetes. '*Cultura*' (culture) may be the essence of the identity for people in the community, but it must not be dismissed as an explanation for ineffective and inefficient care for chronic illnesses; and especially not as the reason for a lower health-related quality of life that many with chronic illnesses, such as diabetes experience in this community.

Health Care Resources and Community Partners

Subquestion 3: What resources are available within the community and how do patients, health care providers and community members perceive the existing linkages between patients and families, health care teams, and community partners and resources related to care for diabetes?

Identifying the resources available to diabetic patients within the community was accomplished through community asset mapping and interviews with diabetic patients, community leaders and health care providers. The community asset mapping process identified current and potential resources that are or

could be available to people with diabetes. This also included identifying sources of healthy food or nutrition that are available to patients with diabetes within the community. During the interviews patients, health care providers and community leaders were asked to identify resources that may be available in the community for people with diabetes.

Focusing on the health care resources in the Xicotepec de Juarez municipality, one hospital and 18 clinics were identified, which included 3 specialists (1 Cardiologist, 1 Orthopedist, and 1 Obstetrician). The hospital in the municipality is known as the Hospital Integral de Xicotepec de Juarez. In terms of comparison to a US-equivalent hospital, it would be most similar to a critical access hospital with a very limited number of beds (approximately 22 beds, including 8 OB/GYN) and limited availability to sophisticated diagnostic equipment (1 x-ray machine). However, as it primarily serves the uninsured and those participating in the national Seguro Social universal health insurance scheme, and has 6 units/clinics. The units/clinics see patients on an outpatient basis or family care type basis. The Hospital Integral represents the most systematic/structured source of health care that is available to the municipality.

According to the Instituto Nacional de Estadística y Geografía (INEGI, 2011) there are 83 medical professionals in the municipality, which includes physicians, nurses, and other allied professionals. This equates to about 910 residents per medical professional in the municipality. According to the WHO, at the national level it is estimated that there are about 500 residents per physician (WHO,

2012). While I was not able to locate an accurate number of physicians in the municipality, a conservative estimate would be that about 1/3 to 1/2 of the medical professionals in the community are physicians. This would suggest that at the lower end there are about 2,800 residents per physician and at the higher end there are about 1,844 residents per physician. This is a marked difference compared to the national average and provides serious implications on accessibility and availability to appropriate care for those with diabetes.

Community asset mapping also identified 7 traditional or ethnomedical practitioners: 2 hierbalistas (herbs, teas, other intact natural products), 2 naturistas (processed natural products available in pill, powder and suspension forms), 2 homeopathic practitioners and 1 curandero (spiritual healer). Mexico has a long accepted tradition of medical pluralism among its citizens where many seek treatment (often simultaneously) from both their traditional/ethnomedical and biomedical resources. Thus, for the purpose of this study, I have included these practitioners as both current and potential resources for improving the capacity of services for diabetic patients.

Interestingly, among these 7 alternative medical sources, 3 are also licensed allopathic physicians (2 homeopathic practitioners and 1 naturista). While many would consider these as resources with unique potential for diabetic patients, those within the biomedical community in the municipality do not look favorably upon these practices and practitioners. As one biomedical health care provider stated during an interview, these practitioners are dismissed as peddlers

of “*medicina magico*” (magic medicine) and can have detrimental consequences on the health of diabetic patients who seek these treatments. The ‘*cultura*’ (culture) surrounding its use emerged as an important theme for health providers who described it as a significant issue for diabetic patients. However, among the 9 diabetic patients interviewed only 2 reported seeking treatment from a *naturista*, while a third expressed that she thought about it but that they were just as expensive as the ‘regular’ medicine. It must be noted, however, that when asked what other resources outside of the clinic were available to them, none of the diabetic patients included these ethnomedical sources as resources that they could use for their diabetes, it was only after probing and asking specifically that these 3 of the 9 talked about them.

The community asset mapping process also identified 23 pharmacies in the community. The literature has long suggested that pharmacies represent an important health care asset for the communities in developed countries, especially for helping manage chronic conditions such as diabetes. However, in many developing countries, the profession of pharmacy is very much in its infancy. In Mexico, and the Xicotepec de Juarez community, pharmacists rarely work in actual retail/community pharmacy settings. The vast majority of pharmacists work for the private pharmaceutical sector or “industry.” According to the International Pharmaceutical Federation (FIP), 2009, Mexico has an active pharmacist workforce of less than 50,000 and is equivalent to about 5 pharmacists per 10,000 citizens. However, in Xicotepec de Juarez, according to

multiple informants in the community, there are not any practicing pharmacists.

The lack of pharmacists and potential pharmaceutical care services present enormous missed opportunities in the community for providing complementary or alternative services for managing chronic conditions such as diabetes.

Additionally, the lack of pharmacists and the inherent specialized knowledge regarding medication therapy also presents important concerns regarding appropriate, safe and rational medication use for not only those with diabetes, but for the community as a whole. In the United States, as in many developed countries, pharmacists represent an important health care resource and have gained increasing recognition for their ability to bolster management of chronic conditions. For many developing countries, such as Mexico, pharmacists could prove to be an important approach to building the capacity of health services for treating chronic conditions such as diabetes; as well as for improving patient education and community awareness about preventing and managing diabetes.

Diet is an important lifestyle factor in the prevention and management of chronic illnesses, such as diabetes. Thus, as part of the community asset mapping process, it was important to identify the healthy food/nutrition resources available to patients with diabetes. A total of 10 (8 super markets, 1 mini-super market, and 1 farmer's market) were identified. While there are numerous small variety stores run out many of the residents' homes, most do not carry a meaningful variety of fresh meat, fresh produce, milk, or whole grains; but rather they offer '*chatarra*' (junk food) such as candy, chips, prepackaged pastries and

soda. Thus, they were not counted. Given the availability and distribution of these 10 food resources confined to the municipality center, it became evident that there were most likely significant nutritional deficiencies in the community. An argument for the presence of food deserts within the Xicotepec municipality is warranted. The phrase *food desert* has been used to describe neighborhoods or areas without supermarkets or areas that lack affordable and healthy food (Short et al., 2007; Wrigley et al., 2002). As the importance of the local food environment as a social determinant of health has gained traction, studies have provided evidence that increased access to healthy and nutritious food, as well as supermarkets, are associated with lower rates of obesity, an important risk factor for diabetes (Powell et al. 2007; Whelan et al. 2002).

Access to healthy and nutritious food is also especially important to the Xicotepec de Juarez community, given its ethnic composition which is heavily influenced and populated by 3 primary groups of indigenous peoples. Studies have suggested that family history and the genetic make-up of the indigenous populations around the globe have provided insight about the genetic susceptibility to and disproportionate prevalence of diabetes in these populations (Schulz et al., 1995; Baier et al., 2004). Additionally, the “westernization” of lifestyles is also suggested to contribute to the increased prevalence among those in developing countries, especially among the indigenous populations. In one study that compared the traditional environment of an adult Pima Indian population in Mexico to the western environment of an adult Pima Indian

population in the US, it was found that the prevalence of diabetes in the Mexican Pima population (with a traditional/non-western diet and lifestyle) was less than one-fifth that of the US Pima population (whom had adopted a more western diet and lifestyle). As both Pima groups are said to share considerable genetic similarity with other Native Americans throughout the US and Latin America, the westernization of lifestyles (diet and exercise) is of increasing concern for other indigenous groups throughout Latin America experiencing an increase in the westernization of their traditional lifestyles (Schulz et al 2006).

The findings of the present study, suggesting the limited access to healthy and nutritious foods in the Xicotepec de Juarez municipality, are congruent with data provided by the *Consejo Nacional de Evaluacion de la Politica de Desarrollo Social (Coneval)* (translation: National Committee for the Evaluation of Social Development Policies). That is, Mexican president Enrique Peña Nieto announced on January 24th of this year, the formation of the *Cruzada Nacional Contra el Hambre y la Pobreza Extrema (CNCH)* (translation: National Crusade against Hunger and Extreme Poverty) which aims at addressing malnutrition and extreme poverty in 400 of the most impoverished municipalities in the country. According to Coneval, these 400 municipalities account for about 60% of the population living in poverty. Xicotepe de Juarez was identified as one these 400 municipalities in the country (and 1 of 14 in the State of Puebla) facing high levels of malnutrition and extreme poverty (La Jornada, 2013).

While community asset mapping identified important diabetes-related

resources in the community, patients, health care providers and community leaders were also asked to identify resources available to people with diabetes. This revealed an interesting dichotomy in the responses. Neither diabetic patients nor community leaders identified resources outside of the health care clinics that could help support diabetic patients. However, when the health care providers were asked to identify resources available to patients with diabetes, 3 health care providers suggested that a support group or “grupo de ayuda mutua” (GAM) had been established through the Hospital Integral for patients with hypertension, diabetes and obesity. Interestingly, this was something that could not be confirmed by any of the patients or community leaders when asked specifically about the GAM. With my interest piqued, I asked a variety of providers (nurses and physicians) within the Hospital Integral about the existence of this group and only one of five providers acknowledged that the group was functioning. I was given the times the group met and the location (at the satellite ‘old’ Hospital site across town) so that I could potentially talk to the nurse leading this group. The first time I showed up I was able to find the nurse leading the group and she provided me with information on when the group would meet next. When I showed up later that week, this group could not be located and after asking around the hospital, no one (nurses nor physicians) could confirm this group ever meeting. Throughout the remainder of my time in the community, I showed up 3 other times looking for this group and was unsuccessful. Unfortunately, my feeling was that this was a group that existed on paper only, as the formation of

these groups was an initiative highly touted among those in the Ministry of Health, it was most likely one that was not fully implemented at the local level, especially in such a resource-limited community. This feeling was later supported during an interview that occurred with one of the nurses within the hospital, in which she expressed her frustration with the lack of continuity among programs due to lack of resources and support by government officials when political regimes change across all levels of the state and national institutions.

This existence of this GAM group would have served as the only evidence of care for diabetes that could be linked outside of the health clinic. Neither diabetic patients nor community leaders were able to identify existing linkages between the health care center and the community or community partners. This was confirmed among patients in the PACIC where diabetic patients reported that these types of activities (linking to outside resources) generally do not occur and any evidence otherwise was elusive during the study period.

In summary, the findings from this study point to important political and environmental factors that impact the management of diabetes. There is a social and political environment that seemingly marginalizes what could be important potential resources (non-biomedical/alternative medicine practitioners) for diabetics in the community. With a long history of patients utilizing both resources for a variety of illnesses, such as diabetes, potential opportunities for improving coordination, continuity of care and self-management behaviors are being missed by a reluctance to move away from a parallel model of existence and practice.

This parallel model was not only true for the non-biomedical practitioners but also for biomedical providers within the community as there was no evidence any effective linkages (integration or coordination) among providers within and outside the hospital care center.

The study also shed some light on other structural problems such as the limited access to healthy and nutritious food and the influence of the political environment on the continuity of health programs. These are especially important environmental factors that impact access to and the provision of care for diabetes. As the health care system looks for ways of improving the effectiveness and efficiency of the care being provided for chronic illnesses, it must not forget the environmental contexts that also shape patient and health care provider behaviors.

Social Capital and the Innovative Care for Chronic Conditions Framework

Subquestion 4: Is the concept of social capital a suitable tool for characterizing the dynamic relationships within the ICCC Triad of health care providers, patients and families, and community partners, in the context of improving access to and provision of care for diabetes?

The Innovative Care for Chronic Conditions Framework presents a unique approach to improving care for chronic conditions in countries with limited resources by calling for tighter integration of community partners into the care process. However, not much is known about how the dynamic relationships between this triad of actors: patient, health care providers, community partners function. This study proposed examining social capital as a way of gaining a better understanding of how relationships are organized and utilized and how

they could affect care for diabetes. Social capital has, in recent years, received increasing attention as an important social determinant of health (WHO, 2003; Kawachi, 2008). For this study, we were particularly interested in looking at social capital from the perspective of Robert Putnam's definition of social capital, "features of social organization, such as trust, norms and networks that can improve the efficiency of society by facilitating coordinating actions" (Putnam, 1993; De Silva 2006).

Social capital of patients, health care providers, and community members was assessed using the Short Adapted Social Capital Assessment Tool (SASCAT). The SASCAT was created to measure cognitive and structural social capital and was comprised of questions that measured three aspects of structural social (membership of groups, support from individuals and groups in the community, and involvement in citizenship activities), in addition to cognitive social capital (trust, social harmony, perceived fairness, and a sense of belonging (De Silva et al, 2007).

The findings of the survey portion of the study suggest that both structural and cognitive social capital are low among patients, health care providers, and community members. Non-diabetic community members reported the lowest levels of structural and cognitive social capital while diabetic patients reported the highest levels of structural and cognitive social capital. These higher levels of structural and cognitive social capital among diabetic patients were marked by (on average) higher participation in multiple groups, reporting receiving

emotional, economic or help in general from more groups and individuals, as well as higher levels of participation in citizenship activities such as approaching a political leader to address an issue in the community.

A rather interesting finding was that concerning the remarkably low levels of structural social capital reported by health care providers, especially among the physicians. Studies have shown that low social capital is associated with self-rated poor health and that there is a strong link between social capital and subjective well-being, as well as between social capital and happiness (Kawachi et al., 1999; Helliwell and Putnam, 2004; Bjornskov, 2003). It is difficult to imagine that physicians (as a group) would share all of these characterizations.

There may be an alternative explanation for the low levels of social capital being reported by physicians, however. Social capital has been identified as a contributing factor to the quality of the work environment for hospital employees and an intangible asset of hospitals as it encourages cooperation and coordination (Ommen et al., 2009). Studies suggest that the high-risk and stressful environments of hospitals contribute to a negative perception of the quality of work life and job satisfaction among physicians and nurses (Ommen et al. 2009; Pelikan et al. 2001). Studies have also shown that job satisfaction and trust are positively correlated (Gill, 2008; Paille et al., 2010; Rowe et al., 2006). Trust reflects important features of social capital, where trust refers to “the expectation that an individual or institution will act competently, fairly, openly, and considerately (Mohseni et al. 2007; Putnam, 1993). Thus, it may be through

these mechanisms (low levels of trust, negative quality of work life, and job satisfaction) that physicians in this study are reporting only low levels of structural and cognitive social capital. This may also provide an explanation for the why health care providers perceived that integration, coordination, and cooperation with other health care practitioners was difficult.

Additionally, as cognitive social capital is not as tangible as structural social capital, in that it measures individual perceptions of social trust and connectedness to the community, questions related to cognitive social capital or social trust were included during interviews with diabetic patients, community leaders and health care providers. The interviews revealed some rather interesting insights regarding social capital within the community. Unlike the low levels of social capital reported by the broader community responses, during the interviews an important theme emerged: *Xicotepec is a great community with caring people*, as a response to the social trust line of inquiry. This type of response was consistent for every community leader that was interviewed. It may be, however, that as community leaders, as people with true vested interests in the prosperity of the community, they were inherently more trusting to begin with.

From the perspective of the diabetic patient, while on average they reported higher levels of structural and cognitive social capital on the SASCAT, their responses during the interviews were much more varied and cautious. In general, responses tended to be positive but then qualified with somewhat negative connotations. For example, one diabetic patient, when asked if she felt

she could trust the majority of the people in the community, responded with a positive nod and affirmation but then proceeded to qualify her answer: "...I feel that you need to...get a feeling for the person with whom you are interacting and develop trust..because you can't just trust any person...once you get to know a person then you can trust them..." or " ...sometimes there are people that will invite you over for a taco or something, but then you don't know if they are giving it to you with good intentions...I had an uncle that was invited to have a taco with someone, but when he returned, he returned sick...." It is important to note that two of the diabetic patients responded with either a hesitant and uneasy "no" or a stern "no" with visible negative feelings. Neither felt comfortable responding to probing questions and appeared agitated after these questions, perhaps recalling negative experiences or interactions with people in the community.

When health care providers were asked about social trust, some of their responses were perplexing. Admittedly, it may have been an effect of the structuring of the interview or lack of context for this portion of the interview, but nonetheless responses were not very consistent (content wise) but they did follow a similar pattern. This pattern was that of all groups interviewed, health care providers were visibly the most uneasy or unsettled by this line of questioning. It also seemed difficult or unnatural for them to comprehend that the question was a personal one, unrelated to diabetes. Some providers inevitably went back to talking about diabetic patients, for example:

Interviewer: In general, can you trust in the majority of the people in the community?

Health Care Provider 4: [hesitation] well about 75% of the people take responsibility for their condition and for self-managing it...

Interviewer: Can you give me a few examples of how people demonstrate that they can trust in the majority of the people in this community?

Health Care Provider 4: First...that they are taking care of themselves, of their diabetes and that they will make their monthly appointments.

The above exchange happened after further clarifying that I was asking a personal question, outside the topic of diabetes. The health care provider hesitated, became visibly uncomfortable, and then proceeded with the above. This was a similar process for many of the providers at first, until I further clarified my questioning. However, once my question or segue became more clear the majority of responses were positive. They were not as adamant nor as endearing as community leaders in characterizing the community or in trusting the people in it. In some instances they didn't seem as genuine about their answers, given the hesitations and body language that was associated with their response.

Incidentally, immediately after one of the interviews, once the recorder had been turned off, one of the health care providers confided that while she had seen me a few times walking around the community, she probably wouldn't have agreed to do the interview. She told me that had she and others not seen who I was walking around and interacting with (my key informants and their families) she and others may not have been as willing to participate. I feel this is important to point out because it speaks to this concept of social capital and especially to social trust as a feature of social capital.

Overall, I believe the findings of this study suggest that the utility of social capital for describing the relationships at the heart of the Innovative Care for Chronic Conditions Framework, the Innovative Care for Chronic Conditions Triad, is indeed promising. Integrating community partners into the care process creates a new dynamic for both patients and health care providers and the concepts that are fundamental to social capital (social networks, social support, trust and norms) are inherently captured within this dynamic. This new triad in the care for chronic conditions requires a special commitment to the formation and utilization of interpersonal relationships among all three groups (patients and families, health care providers, and community partners) that will be instrumental for integrating and coordinating care for those with chronic diseases. Social capital operates within these interpersonal relationships, explains the positive and negative individual behaviors in communities and encourages cooperation and coordination to derive collective community benefits (Huang et al., 2012).

Implications for Theory, Research and Practice

The findings of this study have important implications for advancing theory, research, and practice related to chronic illness care in rural and resource-poor communities, and even more broadly community development. While I do not want to overstate the results of this study, I do believe that it provides substantial evidence supporting the need for future research on social capital and the Innovative Care for Chronic Conditions Framework, developing innovative and reflexive methods for address social phenomena through the research process

and improving chronic illness care in underserved resource-limited communities.

Theory

When the Innovative Care for Chronic Conditions Framework (ICCCF) was introduced in 2002, it provided countries and health care systems with a framework that could help them reorganize care to address the changing needs of their populations. In doing so, it proposed that better health outcomes could be achieved by integrating community partners into the care process, creating a triad of interested parties. One of the requirements however, was that all three parties (patients and families, community partners, and the health care team) would need to be motivated, informed and prepared to manage chronic diseases. As innovative as this was, it did not provide an understanding of how these 3 parties would or do interact during chronic care processes. While the ICCCF acknowledged that these parties are influenced by the broader health care organization/system and political environments, it did not provide any insight on how these influences shape the dynamic relationships that exists and can exist. These relationships are complex and multidimensional and not yet very well understood.

Thus, this study introduced a potential theory that could help practitioners and policy-makers better understand how the development, organization and norms that govern relationships could be evaluated ensure effective integration of community partners. That is, it provided promising evidence for the use of Social Capital Theory as providing the theoretical backbone or foundation for the

understanding the relationships within the ICCCF that are instrumental for improving care for chronic conditions. It illuminated the importance of establishing both interpersonal and institutional trust (e.g. social trust) among all parties as a prerequisite to effectively integrating community partners into the care process. Social trust has been identified as a valuable component to promoting efficiency and teamwork; and has been found to have a positive influence on improvement in quality of practices of health care organizations (Rowe et al., 2006; Huang et al., 2012). More research is needed to better understand how patients and providers can build and subsequently utilize the social capital when physical, financial and human capital are not readily available.

Research

This study explored a way of evaluating the quantity and quality of the relationships that would be instrumental for integrating community partners in the care process in order to build the capacity of health services in a resource-limited community. While more research is warranted in this regard, this study also introduced a novel way of engaging the community to explore a pressing health concern as well as contribute to the advancement of community-based research of chronic illness care. Demands by community leaders and policy makers for meaningful community participation to address pressing health issues they face has contributed to a significant “renaissance” of community engagement in research (Ahmed et al, 2010).

There has been a significant accumulation of research that points to the

potential benefits of community engagement in research, as it is believed to enhance a community's ability to address the health needs of its citizens while also ensuring that researchers understand the dynamics of community priorities that can ultimately inform policy-making decisions (Cook et al., 2008; Boutin-Foster et al., 2008; Herbert et al., 2009; Rosenstock et al., 2003). However, there is limited guidance and training available for researchers wanting to pursue community engagement in research and even less so for building and sustaining community-academic partnerships that can increase the accountability and equality between partners (Rifkin, 1996; Schulz et al., 1998). This study provides such a framework that can be studied and improved upon by those interested in approaches used to engage the community in the research process.

The impetus behind this study was to serve as a catalyst for positive social change and to develop an approach that could enhance the community's understanding of the issues surrounding the access to and the provision of diabetes care. I strongly believe that the approach used, did in fact accomplish this, even if to a small degree.

Practice

One of the most profound findings of this study, is the illumination of the latent structural violence that predominates health care for diabetes in the community. Structural violence is concerned with the role of unhealthy environments in poor health and premature death (Lane et al., 2004). 'Structural violence' is a term that originated out of Liberation Theology of Latin America

during the 1960s to describe the social arrangements that inhibit individuals, groups, and societies from reaching their full potential (Galtung, 1969). Farmer (2004) suggests that these “arrangement are ‘structural’ because they are embedded in the political and economic organization of our social world; they are ‘violent’ because they cause injury to people.” It is comprised of the economic, political, legal, religious, and cultural forces that influence people’s health (Farmer, 1999). According to Gilligan (1997), structural violence tends to be embedded in “ubiquitous social structures, normalized by stable institutions and regular experience.” It is often seen through “disparate access to resources, political power, education, health care, and legal standing...” (Farmer, 2006).

This is a concept that has been applied to public health and practice issues such as, the spread of HIV/AIDS in Haiti, epidemic tuberculosis in Russia, mental illness and access to healthy food in the US to study social determinants to patterns (Farmer, 2003; Keshavjee et al., 2000; Kelly, 2005; Lane et al., 2007). Studies have shown that social, economic and political forces affect the patterns of susceptibility and exposure to illness, as well as limit the effectiveness of health care systems, including reducing access to health services to those most vulnerable (Kreiger et al., 1993; Farmer, 2003).

Similar to these studies, the present study revealed important social, economic and political factors that hinder development of effective preventative interventions as well as self-management programs for diabetes. That is, this study found that cultural beliefs among patients and providers, prevalence of

extreme poverty and malnutrition, the disparate distribution of healthy and nutritious food resources, and the instability of health programs due to changing political priorities may all account for the ineffectiveness of the health care system to address the growing problem of diabetes in the community. A significant need for more patient education was revealed in this study as well, and I believe the approach used to uncover these issues elucidates the importance of choosing an appropriate approach to improving the care for diabetes in the community.

It will be important for community stakeholders to not only design health education programs that encourage individual responsibility, but to also design health programs that can improve the social environment. Presenting the concept of structural violence here was meant to serve two purposes: (1) to remind stakeholders (e.g. community developers, researchers, community leaders, health care practitioners, policy makers, etc.) of the powerful social forces (i.e. 'structural violence') that act as major determinants of the distribution and outcome of disease ; and (2) to caution public health practitioners and policy-makers to avoid the convenience and allure of developing health promotion programs that primarily focus patients with chronic diseases to take sole responsibility for their health.

Diabetic patients in the community have been urged by their providers and by public service messages to change their eating habits and lifestyles in order to improve their condition. There is no doubt that eating nutritious foods, not

drinking soda and exercising are demonstrably effective in improving the health and quality of life of diabetic patients. In this study diabetic patients understood and wanted to adopt healthier lifestyles. However, while these individual behaviors were important, it also became clear that there were limits to how much each could or was willing to change. These patients are living in a rural and isolated community, surviving on very limited incomes and having limited access (financial, availability, geographically, etc.) to healthy and nutritious foods. Thus, there are significant social forces beyond their control, and placing accountability and responsibility solely on the individual leads to missed opportunities for confronting these social forces.

Interventions that focus on improving health education and self-management behaviors and those that address the cultural, economic and political environment are not mutually exclusive, but rather they are complementary and there is no evidence to suggest otherwise. Therefore, it is our duty as practitioners, scientists, and global citizens to work together to develop strategies and programs for improving the health education, the equitability of health care services, and reducing the effects of structural violence.

Limitations

There are several limitations to this study that must be acknowledged. This study attempted to utilize data and methodological triangulation to better understand the factors that could influence care for diabetes in a rural community in Mexico. In doing so it is important to consider the limitations of each method

used as well as the limitations related to the organization and implementation of the study itself.

The study was designed to take an action research approach that would be iterative and reflexive. With this in mind, it was originally structured to comprise of two distinct phases, Phase I and Phase II, where the data from Phase I would be used to inform Phase II. That is, the community asset mapping and surveys were intended to inform the semi-structured interviews and group discussion in Phase II. Before arriving to the Xicotepec community to commence Phase I approval to conduct the study and access to patients and providers within the Hospital Integral had been granted at the local and state level. Upon arrival to the community during Phase I, I learned that my prior approval was no longer valid as administration within the state Ministry of Health and within the Hospital Integral had changed. This required me to re-apply for approval at both levels while I was in the community, thus there were parts of Phase I that I was not be able to complete until approval had been received, such as the surveys among diabetic patients and health care providers. I had been given local approval to survey the broader community members during Phase I allowing me to at least proceed with that portion of the study. In lieu of administering the surveys to diabetic patients and providers, having permission to interview with people outside of the medical institutions, I began interview providers in the community as well as community leaders. Approval from the state Ministry of Health did come until midway of Phase II. This meant that surveys among the diabetic

patients as well as institutional health care providers occurred after the interviewing had already started. Fortunately, the flexible nature of the approach allowed me to maintain some level of the iterative process as some interviews, community member surveys and community asset mapping did inform later interviews. While this was great, I did want to point out that unfortunately, I do not believe that the process was as effective as it could have been given the shortened time frame.

Utilizing multiple data collections meant that I would need to recognize the limitations of each one despite its strengths. Although I reported on the findings of the community asset mapping, I would classify this as the first half of the community asset mapping process. A considerable strength, characteristic of community asset mapping is that it should be participatory in order to enhance its relevance to the community. While I did utilize key informant input and had was joined by a key informant during much of the mapping process, these results have not yet been shared with stakeholders in the community. Thus, I was only able to really provide evidence on a narrowly-focused aspect of the existing health-related (and food) resources located in the community and could not address the potential resources. Addressing potential resources, and to a lesser extent existing resources, requires a deeper understanding of the lived experiences, especially of diabetic patients in the community. As such, I would consider this the first half of a community asset mapping process that will continue at a later point with greater community participation.

There are also important limitations to consider regarding the survey instruments that were used in the study. Each survey selected for the study had been previously validated for reasonable psychometric properties among Spanish speaking participants, however, with the exception of the ACIC, the other instruments (PACIC-5As, DKQ-24 and SASCAT were validated with populations other than Mexican participants. Thus, translations of the instruments did not consider regional differences that exist in Spanish language usage, especially culturally specific vocabulary and colloquialisms. A related concern and limitation of the instruments was that the Xicotepec de Juarez community has a large indigenous population that includes at least 3 indigenous peoples, each speaking a different language. Given the historical marginalization that has occurred in the country, many are spread out throughout the municipality and do not readily identify themselves as such. While schools with large indigenous concentrations are taught bilingually (Spanish and native language) it was unclear how I should assess mastery/literacy for participation. In order to account for this concern, surveys among diabetic patients and about half of the community members were administered orally. That being said, a considerable limitation remained in whether or not the instruments were culturally competent for the Xicotepec de Juarez population, especially concerning the more abstract concepts included in the SASCAT such as 'support' and 'community'.

A few limitations exist in the sampling technique that was utilized for the surveys, the community members' surveys in particular, as well as the interviews

with diabetic patients. While the sampling technique was purposive, it was also essentially a convenience sample. It was purposive in that I wanted to focus on understanding diabetes knowledge and social capital from the women's perspective. It has long been recognized that women in Latin America are not only the primary household health-related decision-makers but that they also possess significant specialized knowledge about health care behaviors and practices (Murdock et al., 1973; Isely et al., 1983; Browner, 1989) and so I decided to focus on women in this study. Making this decision, I must acknowledge that valuable insight may have been lost by not incorporating men in these parts of the study where the study findings really only speak to women's perceptions and beliefs. Additionally, with regard to social capital, results among the community women respondents may be influenced by cultural and gender specific phenomena not accounted for in the study.

As far as the convenience sampling mentioned earlier, I must also recognize the limitations involved with this decision. Community member women were surveyed at a cervical cancer-screening event hosted by the Cruz Roja (Red Cross) and Rotary International. Picking this event may have created a selection bias in survey results, as these were women that were already concerned about their health and thus health literacy, in general, of this group may not be representative of Xicotepec de Juarez municipality as a whole. A similar limitation exists in the sampling of diabetic patients. The majority of the diabetic patients that were surveyed and interviewed were selected from the

Hospital Integral. This was meant to give us a better understanding of the most standardized and systematic care available for people with diabetes. It also accounts for the largest proportion of care being provided and that is ‘theoretically’ available all residents in the municipality under the country’s *Seguro Popular* universal health insurance scheme. However, concentrating the majority of the surveys and interviews to patients seeking care at this location limits our understanding of care for diabetes being provided in the broader community. This is a particularly important limitation when you consider that an estimated 50% of the municipality population is not covered by any type of health insurance (e.g. Seguro Popular or Social Security: IMSS, ISSTE, PEMEX, SEDENA) which the Hospital Integral requires. Thus, a significant proportion of diabetic patients are either not receiving standard care or are receiving it elsewhere.

Relatedly, by including patients with a self-reported diagnosis of diabetes, this study is unable to account for those that are diabetic and have not yet been diagnosed or for those that perhaps have not accepted a prior diagnosis of the disease. This is an especially important consideration given the prominence of “culture” as a perceived barrier to access and utilization of health care for the disease where many providers believe that patients have a difficult time accepting that they have a disease that must be managed. This is also an important consideration because there may be a larger proportion of the population living with diabetes despite not having been formally diagnosed with

the disease. In many developing countries, as in Mexico, diabetes is often not diagnosed until considerable complications (e.g. limb amputation, renal failure, blindness, etc.) arise requiring more intensive levels of care. Diagnosing diabetes at these later stages pose significant threats to not only the patient's vitality and quality of life, but also to the sustainability of the health care system as a whole with the increased economic pressures complications from diabetes place on an already strained health care system.

Finally, one must acknowledge the limitations associated with the overall design of the study. That is, the limitations of using a qualitative exploratory case study approach. I will refrain from 'classic' polemics of epistemological and ontological perspectives of qualitative case research, instead I think it is important that I acknowledge that a significant limitation in this study may be the bias introduced by the subjectivity of the researcher (me) and those involved in the research (my key informants/co-researchers).

Reflexivity is an important component of ensuring rigor and validity in the qualitative research process as it helps the researcher understand the biases introduced into the study. Part of this reflexivity is an understanding of the role of the qualitative researcher. Adler and Adler (1987) suggest that qualitative researchers can be identified among 3 primary "membership roles": (1) peripheral member researchers (PMR), who do not participate in the core activities of group members; (2) active member researchers (AMR), who become involved with the central activities of the group without fully committing themselves to the

members' values and goals; and (3) complete member researchers (CMR), who are already members of the group or who become fully affiliated during the course of the research.

Naturally, my role was that of a PMR, where I was able to become part of the scene or group but not be completely drawn into it. This allowed me to interact frequently and intensively such that I was recognized by members as an 'insider,' which privileged me with first-hand information and insight. Now let me clarify and identify this group. Although this study is a health-related study, one can think about it from a more holistic stance of community development. It was one that was developed under the auspice of a group of Rotary International club members as well as concerned community stakeholders of Xicotepec de Juarez. In the eyes of the community and the Rotary International group, I was an affiliated member. I attended the club meetings, attended social and service functions, helped plan projects and even developed a diabetes awareness and screening initiative with their support that is now being adopted by another community organization. In fact, I even wore a "name tag" that identified me as an affiliate member and this, seemingly, gave me privileged access to other community leaders as well as the intimate information about the political and social environment in the community. Speaking the language and having an ethnic commonality certainly facilitated my acceptance into the group and the broader community. I believe this allowed some participants to be more willing to share their experiences and beliefs, in a way that may not have been available to

true “outsiders.”

This affiliation was instrumental during my ordeal in getting approval as their influence and clout admittedly expedited the process through the cumbersome bureaucracy that dominates many institutions in the country. I owe them a great deal of gratitude indeed for helping me navigate the process expeditiously.

However, this affiliation also had its disadvantages that are important to acknowledge. This group had a certain reputation among some members of the community, especially as the members of this group are those at the highest socioeconomic levels in the community. That is, they were stereotyped by many, as being a primarily ‘self-serving’ group whose participation was seen as a way of advancing their political and business aspirations. Now granted, whether or not this was true, I was automatically lumped into/accused of sharing these aspirations which colored some of my interactions with the community. Being seen as “one of them” and whatever feelings followed this perception led to interesting off-the-record conversations before and after the interviews that are hard to dismiss. There were absolutely times that I had to clarify my true affiliation and reasons for being in the community during the data collection process. In the end, however, I believe having to do so gave me a deeper understanding of the socio-political environmental determinants to health in the community that are sometimes challenging to uncover as an “outsider.”

I must acknowledge this for three primary reasons: (1) the context in which the interviews were conducted may have influenced responses from patients,

providers and community leaders (affecting face validity of the responses); (2) being affiliated may have influenced access to individuals that would have not been otherwise available (affecting the reproducibility of the study) to the study; and (3) my participation and collaboration in activities intimate to individuals within this group may have influenced my own perceptions and understandings of how I approached the broader issue of diabetes care methodologically and analytically. I must say that throughout the study, I did try to ground myself as much as possible to consider and understand these concerns so that I could maintain an appropriate amount of scientific rigor and objectivity.

Conclusion

This study was specifically concerned with the topic of diabetes in the rural community of Xicotepec de Juarez, Mexico. Changes in technology, social behavior and cultural practices along with the increases in life-expectancy present the health care systems of many developing countries with the double burden of treating significant life-threatening acute care illnesses as well as increasingly significant chronic care conditions. This can be especially challenging in the rural resource-poor communities of developing countries, such as Mexico, where individuals with the lowest income typically reside and as such are disproportionately at higher risk of developing chronic conditions such as diabetes.

I believed that incorporating a systematic qualitative action research approach was particularly important, in that my desire was to move the traditional

approach to assessment beyond presenting evidence of health care needs in a community toward providing a readily actionable foundation of information for the development of strategies to address these needs, as determined by the community. In the tradition of the action research approach, this study employed an iterative spiral of data collection occurred throughout the study in order to challenge the information and interpretation from previous cycles as well as provide a gradual refinement in the understanding of the factors that may influence access to and the provision of diabetes care in the Xicotepec community. This was an especially important consideration, where the action research approach and its inherent flexibility allowed me, the researcher, to remain responsive to the changing environment that could have easily derailed this study. Maintaining this ability was particularly important given the broad nature of the research questions and methods that were being presented in this study. The approach used facilitated a deeper understanding of how the triad of stakeholders (patients and their families, the health care team, and community stakeholders) perceive, affect, or are affected by factors that are related to the access to and the provision of care for diabetes. For example, administering the surveys regarding diabetes knowledge revealed that there was a gap in the knowledge among diabetic patients regarding how the disease develops. Originally, this was not a concept that was included in the semi-structured interview guide. Having the opportunity to reflect on the results of the survey before the semi-structured interviews were conducted allowed me the flexibility to

add a line of questioning to find out more about what diabetic patients believed regarding the cause of their illness. Had this not been possible, I would not have been able to uncover such an important issue that could affect care for diabetes.

Key findings of this study suggest that there is significant need for increased awareness and patient education about diabetes as a disease and the role of self-management in preventing and managing diabetes-related complications. This study also suggests a need to reevaluate the diabetes care processes for developing culturally sensitive and competent diabetes care practices that can facilitate and support long-term self-management of the disease. The ability of individuals to manage their diabetes cannot be disassociated from the community context and support for diabetes care.

Lastly, this study suggests the potential utility and need for developing strategies to improve social capital at the individual and community level as a prerequisite for integrating community partners into the care process. Integration of community partners into the care process offers considerable promise for building capacity to treat and manage chronic illnesses, especially in resource-poor communities. There is ample evidence that community partnerships can enhance cultural relevance and have a positive impact on self-management as well as clinical outcomes (Gerber, 1998; Norris et al., 2002; Cohen et al., 2005). However, without building social trust and social capital in the community, efforts for further integration of community partners will be ineffective and detrimental to future development of health care practices and health promotion programming.

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