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Cultural and Family Challenges in Type Two Diabetes Self-care for Puerto Rican Identified Hispanic Adults

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Cultural and Family Challenges in Type Two Diabetes Self-Care for Puerto Rican Identified Hispanic Adults

A Dissertation Presented
by
JALIL ABDUL JOHNSON

Submitted to the Graduate School of the University of Massachusetts Amherst in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

February 2019

College of Nursing
Cultural and Family Challenges in Type Two Diabetes Self-Care for Puerto Rican Identified Hispanic Adults

A Dissertation Presented

By

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DEDICATION

To my grandparents, parents, my children, and my wife, who taught me that family is the most important part of a life lived well.
It matters not how strait the gate,
How charged with punishments the scroll,
    I am the master of my fate,
    I am the captain of my soul.

-William Ernest Henley
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I would like to thank my committee chair, Stephen Cavanagh, for his many years of thoughtful, patient, support, and gentle-natured guidance throughout this my doctoral work. Additionally, I owe much thanks the two other committee members, Cynthia Jacelon, who advised me quite pointedly throughout each step of my doctoral journey; as well as Lisa Chasan-Taber, for the helpful comments and suggestions.

I want to thank the Mr. and Mrs. Hluchyj and the Hluchyj Fellowship program for funding this research. Thanks to Baystate Medical Center and the staff for allowing me to conduct this research study at one of their outpatient clinics. Thanks to the Holyoke Senior Center for allowing me to recruit subjects from their center. Thank you, Barbara Riegle, for allowing use of the copyrighted materials in this manuscript.

I wish to express my appreciation to all the individuals who volunteered their participation in this project. Importantly, I would like to thank my children and family who have endured many years of my dedication to completing my doctoral studies. A special thank you to all those whose support and friendship helped me to stay focused on this project and who have provided me with the encouragement to continue when the going got tough.
ABSTRACT

CULTURAL CHALLENGES IN TYPE TWO DIABETES SELF-CARE FOR PUERTO RICAN IDENTIFIED HISPANIC ADULTS

FEBRUARY 2019

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Background: Puerto Rican identified Hispanics are disproportionately affected by type 2 diabetes and co-morbid conditions compared to their white counterparts. Culturally tailored interventions improve self-care for Hispanic populations. Interventions should be tailored to the targeted Hispanic subgroup. The intersection of Familism in Puerto Rican culture as it influences type 2 diabetes self-care is not well understood.

Research Aims: The primary aim of this study was to define specific socio-cultural phenomena, Familism as a facilitator or inhibitor of diabetes self-care for Puerto Rican identified Hispanics living in the continental U.S. A secondary aim was to examine how health care professionals may best include the PRiH family in care planning.

Methodology: A qualitative methodology, specifically Case method with an instrumental approach was used. To assess Familism, pre-established definitions
of Familism were compared with the lived experiences of the (n=25) subjects in the study. Four primary sources of data collection were used and included focus groups (n=12 patient subjects), semi structured interviews (n=5 healthcare provider subjects), semi structured interviews (n=5 community member subjects), field notes, and participant observation. Member and nonmember checking (n=3 subjects) was used to confirm the study findings; as well as other validity constructs to ensure credibility, transferability, dependability and conformability. Data analyses was primarily thematic. NVivo software was used to facilitate exploration of the data for themes.

Outcomes: Outcomes of this study were primarily descriptive and provide a greater understanding of the social dynamics affecting diabetes self-care for Puerto Rican identified Hispanics living in the continental U.S. Significant findings from this study include clarification of the substantial impact of Familism dynamics on diabetes self-care for PRiH men and women; and the experiential differences between men and women. Importantly, this data is important for researchers designing culturally tailored studies targeting Puerto Rican identified Hispanic adults.

Key words: Hispanic, Diabetes, Familism, Puerto Rican
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CHAPTER I

BACKGROUND AND SIGNIFICANCE

Introduction

T2DM is an expanding global problem and is one the priorities outlined by the World Health Organization in their targeted plan to prevent and control non-communicable diseases (World Health Organization, 2015). Preventing and treating T2DM is also a national priority as detailed by missions of Healthy People 2020 (Healthy People 2020), and the National Institute of Diabetes and Digestive and Kidney Diseases (National Institute of Diabetes and Digestive and Kidney Diseases, 2015).

T2DM is also a growing problem in the United States (U.S.), where racial and ethnic minorities are disproportionately affected by diabetes (CDC, 2013). Specifically, Hispanic adults are disproportionately affected by T2DM and have poorer health outcomes than their white counterparts (CDC, 2013). The Hispanic diabetes disparity has been well studied in nursing and other disciplines with much of the emphasis focused on individuals of Mexican ancestry. However, understanding why the diabetes prevalence and mortality rates for Puerto Rican identified Hispanic (PRiH) individuals are so much higher than those of other populations is imperative for implementing primary and secondary prevention.
Diabetes

There are two major presentations of diabetes: type 1 (T1DM), or type 2 (T2DM). Gestational diabetes and insulin resistance fall under the category of T2DM. The physiology of diabetes is associated with a diminished or lack of insulin production from the pancreas. T1DM is the result of pancreatic β-cell dysfunction and subsequent deficiency in insulin. T1DM is often diagnosed earlier as patients are usually symptomatic once their pancreas no longer produces insulin. T2DM on the other hand, develops as a result of progressive insulin resistance and or decreased insulin secretion. The insidious nature of T2DM often results in late diagnosis, as patients are not usually symptomatic. As a result, other diabetes associated co-morbid conditions such as retinopathy, heart, and vascular disease, are present once the diagnosis is actually made. Other, co-morbid conditions associated with diabetes include but are not limited to: obesity, hyperlipidemia, heart disease, chronic kidney disease, hypertension, peripheral vascular disease, myocardial infarction and stroke. The pathology of uncontrolled diabetes may impair daily functions. These impairments may include: low limb amputations, vision loss, cognitive changes, and psychological problems.

Diabetes management requires medical and self-management. Medical management may include but is not limited to prescription medications, management of comorbid conditions (blood pressure control, blood lipid management) and frequent health evaluations or screenings (eye exams, blood glucose tests, monitoring kidney function, blood lipid tests etc.) (American
Association of Diabetes Educators 2002). Diabetes self-care (self-management) is a cornerstone of diabetes control. Self-management of diabetes requires adherence, evaluation, and monitoring of several factors in order to achieve blood glucose control (American Association of Diabetes Educators 2002). These factors are heavily dependent on behavior modification. In the case of T2DM, where most affected individuals are adults with well-established patterns of behavior, the recommended behavior modification to control T2DM may be especially difficult. (American Association of Diabetes Educators 2002).

**Hispanic Population**

The term “Hispanic” originated in the 1970s by the U.S. government in their efforts to identify and categories this population of Spanish-speaking individuals living in U.S. (Passel and Taylor, 2009). The Hispanic community, numbering over 50 million, is one of the fastest growing demographic in the U.S. (Census, 2010). Hispanics currently represent 14.8% of the US population and are projected to increase to almost 25% by the year 2050 (Census, 2010). The population of ‘Hispanics’ refers to persons of Mexican, Puerto Rican, Cuban, Central and South American, or of other Spanish culture or origin living in the United States (Marin & VanOss Marin, 1991). Pe’rez- Escamilla (2010) defines Hispanics broadly as individuals living in the United States who come from 20 different Spanish-speaking countries in Latin America and the Caribbean. The U.S. Census (2010) indicates that between 2000 and 2010 the population of Hispanics has varied between subgroups with Hispanics of Mexican ancestry
increasing by 54%, increasing from 20.6 million in 2000 to 31.8 million in 2010. Over the same time frame the population of Hispanics of Puerto Rican ancestry grew by 36%, increasing from 3.4 million to 4.6 million and the Cuban population increased by 44%, growing from 1.2 million in 2000 to 1.8 million in 2010 (Census 2010).

Hispanic subgroups are often combined together in health research and this practice likely conceals important differences between Hispanic subgroups (Aponte 2009; Barcelo et al. 2007; Mainous, et al. 2007; Allison et al. 2008). Generic all-encompassing terms such as “Hispanic” or “Latino”, should be used judiciously when presenting health issues in Hispanic subgroups (Borrell, Crawford, Dallo, and Baquero 2009; Tucker et al. 2010). Disaggregation of Hispanic subgroups is preferred whenever possible when classifying and studying Hispanic populations.

**Diabetes and Hispanics**

Diabetes has a major adverse impact on life years and quality-adjusted life years in all U.S. subpopulations, with an even greater impact among minority individuals including Hispanics (Narayan et al. 2003). Hispanics experience a disproportionate burden of poverty and poor health outcomes including T2DM (Pe’rez-Escamilla 2010). The prevalence of T2DM amongst Hispanics is much higher than non-Hispanic whites (Ezzati, Flegal and Harris, et al.1991; Black, Markides and Ray, 1999). The age-adjusted prevalence of diabetes among Hispanics is significantly higher (9.2%) than non-Hispanic whites (5.9 %) (Center
for Disease Control 2011). Medication non-adherence is also higher among Hispanics with diabetics compared to non-Hispanic white diabetics (Compton, Haack and Phillips, 2010). Hispanics have higher rates of many diabetes complications such as retinopathy, neuropathy, and lower leg amputations than do non-Hispanic whites (Ezzati et al. 1991).

**Diabetes and Puerto Ricans**

Though all of the Hispanic subgroups are affected by the diabetes disparity, there are differences between subgroups as to which risk factors were more prevalent (Aponte, 2009). Additionally, the biophysical effects of diabetes as well as factors for diabetes will vary by Hispanic subgroup (Aponte, 2009). Borrell et al. (2009) found that, compared with non-Hispanic white respondents, Mexican American, Mexican, Puerto Rican, other Hispanic, and non-Hispanic black respondents, PRiHs were more likely than Hispanics of Mexican ancestry to report diabetes. The Council on Scientific Affairs: Hispanic Health in the United States (1991) reports that Puerto Rican identified Hispanics, the second largest Hispanic subgroup representing 9.2% of the Hispanic population, report the worst health status and highest prevalence of several acute and chronic medical conditions when compared with non-Hispanic whites and other Hispanic subgroups.

Several studies (Franzini and Ribble 2001; Carroll et al. 2006; Tucker et al. 2010; Mattei et al. 2010) describe the phenomena of Puerto Rican identified Hispanics in the U.S. experiencing considerable health disparities including
cognitive disability, type 2 diabetes, obesity, depressive symptomatology, hypertension, and self-reported heart disease that exceed those reported for non-Hispanic whites or other Hispanic subgroups, including the more commonly studied Mexican Americans. The age-adjusted prevalence of diagnosed diabetes for PRiHs (10.1%) is comparable to African Americans (9.3%) and Mexican Americans (10.0%), but significantly higher than non-Hispanic whites (5.9%) (CDC, 2011).

Finally, the prevalence of diabetes in the population of PRiH adults not only increases healthcare cost, but also is also burdensome to communities, families as well as individuals within these communities (Whitman, Silva, Shah, 2006). The effects of uncontrolled diabetes are wide spread and not only affect individuals and communities but also present systemic burden on the US healthcare system. For example, Kim (2007) found that avoidable hospitalizations, due to short-term uncontrolled diabetes, were substantial, creating losses of 2.8 billion dollars annually. Schroder et al. (2011), found that the fiscal magnitude of the healthcare burdens an increase medication adherence by 10% among just 10% of the 3.4 million Hispanic individuals with diagnosed diabetes, would equate to increased drug costs of over $30 million, but a net cost savings due disease-related medical costs of $183 million annually.

**Familism and Hispanics**

Despite the increasing number of Hispanic people and associated health disparities, there is limited information regarding factors that may impact the
physical and mental health status and health behaviors of these groups. Socio-cultural variables have been largely implicated as a factor contributing to health disparities in these communities (Perez and Cruess 2014). One particular pathway that warrants investigation is the impact of the Hispanic family and *Familism* values (Perez and Cruess 2014).

*Familism* is essentially the effect of family/community members on an individuals’ health and health related choices (Beck, 2007; Penwell and Larkin, 2010). The “family” is defined broadly and may include an interactive network consisting of a nuclear family as well as extended kin living within a multigenerational household/community. These relationships have the potential facilitate or inhibit family members ability to self-manage chronic disease. *Familism* is a central element of the Hispanic culture and thus may be the impetus behind many of the conflicting findings in the literature regarding Hispanics and their health, especially given the multitude of studies demonstrating a link between social factors and health behaviors (Beck, 2007; Penwell and Larkin, 2010). Please refer to the Review of The Literature, section for a full an in-depth discussion of *Familism*, concepts and constructs.

**Significance for Nursing**

Nursing can be described as the practice and science of optimizing the health of individuals and communities. Uncontrolled diabetes affects individuals as well as communities, and presents a burden on the U.S. healthcare system. Culturally specific interventions improve diabetes self-care, which in turn improve
diabetes outcomes. Family is an important aspect of Hispanic culture. Specifically, regarding Puerto Rican identified Hispanics; the significance of the family’s impact on diabetes self-care is not well known. This study will explore the sociocultural details of Puerto Rican identified Hispanics culture in relation to T2DM self-care.

The Problem

Introduction

Culturally-tailored interventions are needed in order to improve diabetes self-care for all minority populations (Whittemore, R. (2007). Principally, culturally-tailored interventions for PRiH individuals should include community / family diabetes education, culture-specific diet and activity recommendations with practical implications that are appropriate for this population. Additionally, more qualitative research is needed to determine how much of the diabetes disparity affecting the PRiH population is related to lifestyle, healthcare access and utilization, sociocultural, psychological or socioeconomic factors. The primary aim of this study was to illuminate and delineate a specific socio-cultural phenomenon – the effect of Familism on diabetes self-care for Puerto Rican adults with T2DM. This study offers a greater understanding of the role of Familism as it influences to diabetes self-care in the Puerto Rican identified Hispanic population living in the continental U.S.
The Puerto Rican Diabetes Disparity: What is known?

Much of the literature targeting the Hispanic diabetes disparity has targeted the largest subgroup, Hispanics of Mexican ancestry living in the western and southern central United States. Mexican identified Hispanics represent 63% of the Hispanic population. There is little consensus as to whether or not this data is unique to the Mexican ancestry subgroup or if it can be generalized to other Hispanic subgroups (Caban and Walker, 2006).

PRiH individuals are more affected by poverty and are generally less educated compared to non-Hispanic whites (Census, 2010). Many PRiHs live in urban communities comprised of interconnected family systems and are subject to the environmental and psychosocial stressors of urban living (Mattei, et al., 2010). Approximately 53% of all Puerto Rican identified individuals live in the northeastern states, New York, Pennsylvania, New Hampshire, Massachusetts, New York, Connecticut, New Jersey and Rhode Island (Census 2010). The northeastern states have traditionally been more progressive with regards to allowing routes for less fortunate populations to access healthcare. While, all of the north-eastern states do not offer a public healthcare option as of yet, Massachusetts essentially has universal healthcare through Mass health and affiliate programs. The expansive Medicaid legislation and the Affordable Care Act have ensured that access to care is not an issue PRiHs living in Massachusetts.

Generally, PRiH individuals are not significantly disadvantaged regarding access to health care when compared to the general population, have
comparable rates of health insurance coverage and generally have a particular place for receiving medical care. Compared to other Hispanic subgroups, PRiH individuals are more likely to have health insurance coverage (Brodie et al. 2002) and a regular place for care (Schur and Albers 1996). PRiH individuals are disproportionately covered by Medicaid and despite generally adequate health insurance coverage, tended to overuse hospital emergency rooms, outpatient departments, and clinics, where Medicaid-accepting providers were commonly found (Schur and Albers 1996).

Limited English proficiency is an independent predictor for poor glycemic control among insured U.S.-dwelling Hispanic individuals with diabetes, an association not observed when care is provided by language-concordant healthcare providers (Fernandez et. al, 2011). Language barriers are likely to be present, particularly among Spanish-dominant speakers, specifically those who are older and less educated (Hosler and Melnik, 2005). Patients with limited English proficiency treated by language-discordant physicians are more likely than limited English proficiency patients treated by language-concordant physicians to have poorer glycemic control (Hosler and Melnik, 2005). The PRiH subgroup tends to have the highest proportion of native English speakers among Hispanic subgroups, and they are less likely than other Hispanic subgroups to report difficulty communicating with health care providers because of language barriers. Despite comparably higher English language proficiency, PRiH tend to prefer health care providers (physicians & Nurses) who were fluent in Spanish and view these providers as more credible sources of information (Quatromoni et
Importantly, PRiHs prefer to consult with family members about health problems prior to consulting with a healthcare provider (Long, Sowell, Bairan, Holtz and Fogarty 2012). However, the relationship between language proficiency and prioritization of family perspectives over health care providers has not been explored.

Several studies (Arcury et al. 2004; Cherrington et al. 2006; Coranado et al. 2004; Jezewski and Poss 2002) have revealed that some Hispanic subgroups believe that, “susto”, described as negative emotions, stress or emotional trauma; can cause diabetes. While “susto” is a widespread belief amongst some Hispanic subgroups, this belief has not been observed in the Puerto Rican identified subgroup (Concha et al. 2009; Weller et al. 1999). PRiHs, specifically those living on the east coast, generally believe that religion and spiritually play a role in developing or controlling diabetes (Caban and Walker 2006).

Fatalistic thinking or beliefs may be a factor in health perceptions of PRiH individuals with T2DM (Caban and Walker 2006; Smolowitz and Zaldivar 1994; Quatromoni et al. 1994). Caban and Walker (2006) found that fatalistic thoughts, though present in both Hispanics individuals of Mexican ancestry and Puerto Rican ancestry, were contextually different. Mexican identified Hispanics generally expressed fatalistic views regarding denial about the diagnosis of T2DM (Caban and Walker, 2006). Whereas PRiH individuals perceived T2DM as a chronic illness that resulted in complications over time that could not be avoided (Quatromoni et al. 1994; Smolowitz and Zaldivar, 1994). Still, it is
unclear how community and family influences, directly or indirectly, influence fatalistic ideas about T2DM for PRiHs.

PRiH individuals generally have incongruent perceptions of health and illness when compared with their healthcare providers. Anecdotally, these incongruent ideas are the result of learned, community perspectives. Specifically regarding diabetes, the healthcare views of PRiHs and healthcare providers have been found to be incongruent with regards to etiology of diabetes, association of obesity with diabetes, acceptable diabetic diet, appropriate exercise, insulin use, herbal remedies and influence of spirituality or religion (Hatcher and Whittemore, 2007). Additionally, when contrasted with Hispanics individuals of Mexican ancestry, PRiH individuals tend to prefer standard or alternative therapies recommended from a healthcare provider (nurse or physician) rather than traditional or folk remedies (Quatromoni et al. 1994; Smolowitz and Zaldivar 1994).

**The Puerto Rican Diabetes Disparity: What is unknown?**

The best practices for managing diabetes in the general population have been well established. Most of what is unknown about the T2DM disparity affecting PRiH and diabetes self-care pertains to cultural factors. There have been very few studies using interventions that specifically address PRiH culture or family as a component of the intervention (Andres-Hyman, Ortiz, Anez, Paris, Davidson 2006). PRiHs with T2DM generally have incongruent perceptions of health and illness when compared with their healthcare providers and the effects
of root of these perceptions on self-management of diabetes is unclear. Additionally, PRiH individuals generally have higher English language proficiency compared to other Hispanic subgroups. The relationship between predominant Spanish language use and T2DM self-management has been discussed in the literature (Fernandez et. al, 2011; Hosler and Melnik 2005). However, these relationships between PRiH family culture, language and T2DM self-management are not explicit in the literature.

Fatalism is likely widespread amongst PRiH individuals with T2DM and has not been well studied. The effect of community and family influences on fatalistic views and mental health in the PRiH population is unknown. It is well known that co-morbid mental health problems such as anxiety and depression associated with diabetes may also contribute to fatalistic ideas as the relationship between diabetes and depression has been well studied. The current and lifetime prevalence rates of depression amongst individuals with T2DM are nearly twice that of a person without diabetes at 18 vs. 10 % respectively (Ali et al. 2006). Additionally, anxiety is higher in individuals with T2DM compared with those without the disease at 20 vs. 11% percent respectively (Li et al. 2008). A review of the literature did not reveal any studies specifically comparing prevalence of T2DM and co-morbid mental health conditions as they affect PRiH individuals with regards to T2DM self-care. The aforementioned literature suggest that depression and anxiety are a major components of diabetes self-care management in the PRiH population. Understanding this phenomenon specifically as it pertains to community, family and PRiH individuals is pertinent to
patient teaching as well as clinical management; and certainly, warrants further inquiry.

Little is known about spiritual/religious effects on self-care practices in PRiH individuals with T2DM. Caban and Walker (2006) illuminated the void in the literature regarding role of spirituality and religion in self-care for Hispanic subgroups, specifically PRiH individuals. The extent to which these religious/spiritual beliefs affected self-care could not be discerned from this review of the literature. Spirituality and religion affect beliefs, and must be considered when educating and treating patients with T2DM. To date, there are no published studies evaluating or contrasting religious or spiritual differences between community dwelling PRiH men and women and the perceived or lived experience of T2DM self-care management.

T2DM is a complex disease that requires adherence to an array of self-care behaviors, such as monitoring dietary intake and blood glucose levels and increasing physical activity (Concha et al. 2009). Self-management education and behavioral support has been effective at in improving outcomes in adults with T2DM (Gary et al. 2003). Sociocultural factors are important to consider when designing culturally appropriate clinical and behavioral interventions to improve self-care for all “Hispanics” with T2DM (Brown et al. 2002; Caballero 2005; Oomen et al. 1999; Choi et al. 2001; Adams 2003). Additionally, the importance of culturally competent diabetes interventions for the PRiH subgroup has been well established (Whittemore 2007; Latham and Calvillo 2009; Sarkisian, et al. 2003). Some culturally specific interventions aimed at improving
teaching and care of PRiH individuals with diabetes, have produced clinically significant improvements in the average HbA1c and glycemic control (Rosal et al. 2005; Welch et al. 2011; Mauldon, Melkus and Cagganello 2006). However, Caban (2006) found that at the time of their study, only one other study evaluated the “lived” experience of East coast Hispanics individuals with type 2 diabetes. Von Goeler et al. (2003) also discussed the wealth of data and studies relating to Hispanics of Mexican ancestry and contrast them with the limited literature regarding Puerto Rican/Caribbean populations of Hispanics residing in the Northeast.

Knowledge regarding the health status and behaviors of Puerto Rican identified adults with diabetes living in the continental U.S. is (relatively) sparse (Tucker et al. 2010). There are several voids in the literature regarding the role of specific sociocultural aspects of the PRiH lived experience as it influences T2DM self-management. These voids in cultural data include but are not limited to understanding the role of family/community, religion, fatalism, incongruent health perceptions, variations of health perception between men and women. More research is needed to evaluate specific relationships between psychosocial, sociocultural and environmental factors affecting the ability of PRiH individuals to optimize T2DM self-care.

**Implications for Nursing Education, Practice and Research**

The problem, Hispanic adults with uncontrolled diabetes, has been well studied in nursing and other disciplines with much of the emphasis focused on
individuals of Mexican ancestry. However, PRiHs with T2DM, are the second largest Hispanic subgroup and experience similar and in some cases worse diabetes outcomes compared to the more studied Hispanics of Mexican ancestry. This phenomenon is significant for nursing on many levels. Broadly, nursing is a science concerned with promoting and maintaining health in individuals and communities. The effects of uncontrolled diabetes are widespread and not only affect individuals and communities but also present systemic burden on the US healthcare system. While biophysical effects of diabetes must be addressed in this population, understanding and measuring the cultural and psychosocial dimensions of this problem will lead to alternate insights and perspectives of why this disparity persist (Mattei et al. Tucker 2010). The sociocultural forces, specifically Familism and community, influencing the poor diabetes outcomes in the PRiH community are not well understood. Having a better understanding of these forces/factors may help nurses identify and use strategies that use culturally specific education or interventions to improve diabetes outcomes in the PRiH population.

In order for nursing and healthcare professionals to address the diabetes disparity affecting PRiH individuals, we must better understand the overt and subtle cultural forces that affect the day-to-day decisions of the individuals affected. Some factors affecting self-care of diabetes that require investigating include exploring the relationships between family/community and the following: 1) incongruent health perceptions with healthcare providers; 2) effects of English language proficiency; 3) effects of fatalistic thinking; 4) effects of spirituality and
religion; 5) gender variances; sociocultural, psychosocial and environmental factors and 6) general PRiH specific cultural preferences regarding diet choices and exercise. Finally, understanding why T2DM and associated morbidity / mortality rates for PRiH individuals are higher than those of other populations is imperative for implementing primary and secondary prevention.

Specific Aims

The primary aim of this study was to illuminate and delineate a specific socio-cultural phenomenon, specifically *Familism*, as it relates to diabetes self-care in the Puerto Rican identified Hispanic (PRiH) population living in the continental U.S. The hypothesis for this study was that *Familism* may be an inhibitor or facilitator of diabetes self-care for PRiHs. This hypothesis was not tested per se but rather investigated to gain understanding of the problem, thereby creating a basis for further study on the problem.

The first research question was based off of study assumptions 1 and 2.

Assumption 1. *Familism* has an effect on T2DM self-care for PRiH adults.

Assumption 2. PRiH men and women in traditional roles experience the effects of *Familism* differently.

Research Question 1: “What is the effect of Familism on self- management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?”

Six sub-questions, were used to answer the first research question, guide semi-structured interviews and focus groups.
A. What are the positive effects of *Familism* on diabetes self care for PRiH adults?

B. What are the negative effects of *Familism* on diabetes self-care for PRiH adults?

C. In what ways does *Familism* facilitate diabetes self-care for PRiH adults?

D. In what ways does *Familism* inhibit diabetes self-care for PRiH adults?

E. How are PRiH women with T2DM in traditional family roles affected by *Familism*?

F. How are PRiH men with T2DM in traditional family roles affected by *Familism*?

The second research question was based off study assumption 3.

Assumption 3. HCPs do not generally consider *Familism* as a factor in T2DM self-care.

Research question 2: “How can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?”

Two sub-questions were used to answer the second research question, guide semi-structured interviews and focus groups.

A. How can health care providers facilitate the positive effects of *Familism* on T2DM self-care?

B. How do health care providers prevent the negative effects of *Familism* on T2DM self-care?
Summary

T2DM is an expanding global and national problem in the U.S. Hispanics, specifically PRiH adults, are disproportionately affected by T2DM and have poorer health outcomes than their white counterparts (CDC, 2013). Understanding why the diabetes prevalence and mortality rates for Puerto Rican identified Hispanic (PRiH) individuals are so much higher than those of other populations is imperative for implementing primary and secondary prevention. There is limited information regarding factors that may impact the physical and mental health status and health behaviors of Hispanic subgroups.

Familism, the effect of family/community members on a persons’ health and health related choices, has been identified as a central element of the Hispanic culture and thus may be the impetus behind many of the conflicting findings in the literature regarding Hispanic adults and their health outcomes. However, the specific implications and significance of the family’s impact on diabetes self-care is not well known. This study explores the sociocultural details of PRiH culture in relation to diabetes self-care. Moreover, this study delineates Familism as an inhibitor or facilitator of specific diabetes self-care functions and roles within the PRiH community.
CHAPTER II

REVIEW OF THE LITERATURE

Search Methods

Prior to conducting this study, a systematic review was conducted to search for relevant research. The search was based current research that showed PRiHs experienced a diabetes disparity compared to non-Hispanic whites. Initially, the goal of the search was to review the literature for gaps. Thus, the search was narrow, and focused on research that had similar focus in terms of methodology and or qualitative appraisal of PRiHs and T2DM self-management. Through a review of the primary articles, the relationship between PRiHs, self-care and Familism was uncovered as a gap in the literature. A secondary search was conducted to search for studies evaluating Familism in PRiHs and those studies were included. This search was based on the first study assumption, that Familism has an effect on T2DM self-care for PRiHs.

The search was conducted using the following search engines: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Hispanic American Periodical Index (HAPI), Sociological Abstracts, Social Science Abstracts, Google Scholar and Psych Info. Key words included: Puerto Rican, Culture, Diabetes, Type 2 Diabetes, Self-care, Self-Management, Qualitative. The secondary search included Hispanic and Familism as well as the aforementioned key words. For all search engines, aside from Google Scholar, the search was limited to dates 1995 to 2015. Research studies were included that had a primary focus on qualitative appraisal of the experiences of managing
T2DM for adult PRiH populations. Studies that used qualitative methodology to investigate other Hispanic subgroups were also included, as there were similarities and differences between this study and some of those studies. Studies were not reviewed for the following reasons: unidentified sample, genetic or pathology studies; pediatric samples; epidemiological studies investigating incidence or prevalence; pharmacological studies of drug response; unrelated to diabetes; gestational diabetes or type 1 diabetes studies.

**Search Outcome**

A search using PubMed, Psych Info, HAPI and CINAHL generated 93 relevant articles. The abstracts of these articles were reviewed and seven articles were relevant to this study. The search using Google Scholar produced significantly more results (>19,000) using the same search terms as mentioned above. Additional limits were used to reduce the search results to a more relevant sample. Limits included adding key words: Medicine and nursing and psychology, sociology, and Northeast. Additionally, the search on Google Scholar was limited to publications between 2005-2015. The abstracts of approximately 580 articles from the Google search were reviewed. Eighteen publications were included in the review (Caban et al. 2008; Gonzalez 1989; Asgarian 2011; Carbone et al. 2010; Long et al. 2012; Dharma et al. 2013; Orzech et al. 2012; Weitzman et al. 2013; Khan et al. 2012; Hu et al. 2012; Sawyer et al. 2013; Meyer et al. 2013; Hughes et al. 2012; Baig et al. 2012;
Three articles were particularly relevant to this study in that they addressed both *Familism* and the PRiH population (Gonzalez 1989; Carbone et al. 2010; Long et al. 2012). The seven studies that used qualitative methodology to investigate self-care for PRiH were reviewed in depth (Caban et al. 2008; Gonzalez 1989; Carbone et al. 2010; Long et al. 2012; Dharma et al. 2013; Weitzman et al. 2013; Khan et al. 2012). Additionally, eight articles that using qualitative methodology to investigate self-care in other Hispanic subgroups were reviewed (Hu et al. 2010; Sawyer et al. 2013; Meyer et al. 2013; Hughes et al. 2012; Heuer et al. 2006; Aponte et al. 2012). Six of the eighteen articles reviewed addressed some aspect of *Familism* specifically (Gonzalez 1989; Carbone et al. 2010; Long et al. 2012; Orzech et al. 2012; Ramal et al. 2012; Weiler and Crist 2009). Snowball sampling accounted for the additional studies discussed. See Table 2 for a matrix of articles used for this review.

**Search Results**

Researchers have used qualitative methodology to investigate diabetes self-management in Hispanic populations. However, many of these studies were of Mexican identified Hispanics (Hu et al. 2010; Sawyer et al. 2013; Meyer et al. 2013; Hughes et al. 2012; Heuer et al. 2006; or Dominicans (Aponte et al. 2012), and did not specifically address any aspects of *Familism*. There are qualitative studies of PRiHs that investigate diabetes self-care, however they do not
specifically address components of Familism or community as a factor (Khan et al. 2012; Dharma et al. 2013). See Appendix K for details of these studies.

The literature is not completely void regarding the relationship between T2DM, Familism and Hispanics. Baig et al. (2012) conducted a qualitative study using focus group design on a sample of 37 Mexican Americans to assess Latino adults’ preferences for peer-based diabetes self-management interventions and the acceptability of the church setting for these interventions. In this study, participants preferred group-based and telephone based one-to-one peer support programs. While, Familism was not specifically addressed, Mexican Americans’ preference for community involvement in diabetes education was reinforced. Similarly, Ramal et al. (2012) conducted a qualitative study using a focus group design on a sample of 27 Hispanic participants from South West U.S, to identify factors that influence diabetes self-management in Hispanics. In this study, the family’s role as a determinant of diabetes self-management emerged as the underlying subtheme to all of the four emergent themes (access to resources; Struggle with diet; Self-efficacy; social support). The effect of Familism on self-care was implicit, however, the specific impact of the family was not explored. A major limitation was the unidentified Hispanic subgroup, which limits cultural specificity of the findings. Weiler et al. (2009) conducted a qualitative study using grounded theory techniques and in-depth semi structured interviews on a sample of 10 Hispanic (Mexican identified) participants; with a goal to explore the sociocultural influences and social context associated with living with type 2 diabetes. In this study, the family traditions, central to the Mexican culture, had
both positive and negative consequences on diabetes Self-management. Similar to other studies describing *Familism* in Hispanic culture, this study was limited to Mexican identified Hispanics.

There is literature supporting the need for qualitative appraisal of diabetes self-management in the PRiH subgroup. Qualitative studies of T2DM self-care conducted with PRiH participants have highlighted some areas that warrant further investigation. For example, Caban *et al.* (2006) explored psychosocial issues that affect diabetes self-management for Hispanic men and women of primarily Caribbean ancestry and found that PRiHs described experiencing depression, sexual dysfunction, discrimination, and discontinuity in health care services, however the impact of *Familism* on diabetes self-care behaviors specifically was not explored. Asgarian *et al.* (2011) investigated factors that play a role in the practice of health behaviors necessary to manage T2DM and found that PRiHs held problematic beliefs including confusion about the heritability of diabetes and use of subjective feelings as indicators of blood sugar level. The influence of community or family on health behaviors was not addressed or assessed in this study. Weitzman *et al.* (2013) examine body bodily aesthetic ideals in relation to attitudes and T2DM self-care practices. Interestingly, PRiH women in this study preferred a larger than average body size and attractiveness was more closely linked to grooming than body size. Bodily dissatisfaction centered on diabetes-induced skin changes, and fatigue rather than weight. Importantly, social burdens, isolation, and financial stressors were believed to contribute to disease exacerbation. Similar to other studies, *Familism* or effect of
community or diabetes self-management was not specifically investigated or addressed.

**Key Findings**

**Familism concept**

In reviewing research studies, a recurring theme and gap in the literature centered on the relationship between *Familism* in the Hispanic population and chronic disease management. Studies have demonstrated a relationship between social factors and health (Beck, 2007; Penwell and Larkin, 2010). This relates to Hispanic people in that *La familia* (the family) is an important element in the Hispanic culture (Perez and Cruess 2014). The term *Familism* (also referred to as familialism or familismo) has been employed extensively in the literature to highlight the significance of family for Hispanics (Perez and Cruess 2014).

The meaning ascribed to *Familism* has evolved through the years. Early research conceptualized the Hispanic family as a close and interactive network that consisted of some nuclear family and extended kin living within a multigenerational household (Garcia, 1993; Keefe, 1979,1984; Landale and Oropesa, 2007). Other research defines the Hispanic family in terms of its role, which emphasizes close and frequent social interactions, regardless of household size (Garcia, 1993; Kana’iapuni, Donato, Colon-Thompson, and Stainback, 2005; Keefe, 1984; Zinn, 1982).

*Familism* has been operationalized as a construct composed of multiple
sub factors, some of which may yield favorable (e.g., perceived support) or disadvantageous (e.g., perceived obligations) outcomes (Knight and Sayegh, 2010; Losada et al. 2010). The advantages or disadvantages of Familism may take precedence depending on the situation, individual and context (Knight and Sayegh, 2010; Losada et al. 2010).

Hispanics traditionally have identified immediate and extended family members, such as grandparents, aunts and uncles, as part of their exclusive network (De Leon Siantz, 1994; Markides & Krause, 1986). The family system may also include esteemed friends, neighbors and members of their religious community through important religious rituals, such as baptism, communion and marriage (Galanti, 2003; Garcia, 1993; Keefe, 1984; Miller, 1975). These extended family members are reported to assume many of the supporting roles and obligations that are allocated to the more immediate family, especially during times of crises (Kana‘iapuni et al. 2005; Keefe, 1984; Luna et al. 1996). The Hispanic family network is a large, interconnected web that extends beyond familial relationships confined to a single household (Perez and Cruess 2014). Research suggest that the Hispanic family can function as a source of both support and stress for individuals afforded with the responsibility to preserve this network (Perez and Cruess 2014).

Familism has been implicated in the disease experience of Hispanics (Perez and Cruess 2014). Researchers speculate that Familism has both direct and indirect effects on the quality of life and the management of symptoms of Hispanics diagnosed with a chronic illness, thus providing a route by which
Familism can impact the physical health status (Ashing-Giwa et al., 2004; Finnegan et al., 2000; Urizar & Sears, 2006; Valenzuela et al., 2003). Familism values may alter the course of a chronic illness by influencing health behaviors that may be important in managing the condition or by increasing levels of distress (Segerstrom & Miller, 2004). The literature suggests that family variables, in particular, have a considerable influence on the health status of Hispanics (Chesla et al., 2003; Mellin et al., 2004; Weiler and Crist, 2009).

Research also suggests that values regarding family cohesion and family support have a positive influence on the self-care behaviors of Hispanic women with diabetes (Fisher et al., 2000; Hsin, La Greca, Valenzuela, Taylor Moine, & Delamater, 2010; Valenzuela et al., 2003). For example, Hsin et al. (2010) determined that better disease management behaviors were associated with higher levels of familial support in a sample of Hispanic adolescents with diabetes. Whereas, individuals who were less accountable for their diabetes care reported higher levels of familial assistance and demonstrated higher levels of treatment compliance (Hsin et al., 2010). Research also indicates that Hispanic children also help their parents with their diabetes care (Mosavel & Thomas, 2009), including helping with medication reminders, enabling important dietary behavior and encouraging physical activity (Laroche and colleagues, 2009).

Familism and diet

Familism may affect self-care agency when it comes to diabetes self-care. Research by Oomen, Owen, and Suggs (1999) indicate that efforts to care for the family may actually interfere with Hispanic women's compliance with
recommended treatment. Performing self-care routines may also be construed as a violation of the central tenets of *Familism* where familial needs are a priority (Lipton, Losey, Giachello, Mendez, and Girotti, 1998; Oomen *et al*., 1999; Pineda Olvera *et al*., 2007). For example, Adams (2003) conducted a study of PRiH women and found that they felt obliged to prepare and consume meals that were appealing to their family but detrimental to their health. Additionally, these women felt that preparing a separate healthier meal would was alienating and disrespectful (Adams, 2003). Mealtime was also as source of stress as family gatherings centered on traditionally foods (e.g., rice, bean, pasteles) that were typically harmful and family members tended to overlook the individual needs of a person adhering to a therapeutic diet (Adams, 2003). Similarly, Orzech *et al*. (2012) conducted a mixed methods study using survey data from of 297 participants and a subsample of 71 participants completing focus groups, interviews, chronic disease diaries, and home visits. The purpose of this study was to explore the differences in self-reported adherence to diet and exercise plans and self-reported daily diet and exercise practices for non-Hispanic whites, African Americans, and Vietnamese. In this study, the negative effect of *Familism* was described as Hispanic participants described their health care providers’ advice as “conflicting with their traditional diets and forcing them to give up preferred foods or ways of preparing food”. The Hispanic participants experienced this loss most acutely, compared to other ethnic groups in the study, especially those women who prepared food for their family members that they themselves were unable to eat. Specifically, Hispanic participants complained
that friends and family members ate foods in front of them that were restricted from their therapeutic diet and encouraged them to cheat on their diets. A limitation of this study is that findings were not distinguished between groups (ethnicity) and diagnosis (hypertension vs. diabetes), limiting the cultural specificity of the findings. Another major limitation of this study was that the Hispanic subgroup was not identified, however, the sample of patients was collected from an area of the country where there is a large population of Hispanics that identify as Puerto Rican or Dominican.

*Familism* may demonstrate health benefits in regard to diabetes self-care that are related to the support received from their close-knit family relations (Perez and Cruess 2014). While this support may promote positive self-care regimens; these same values may impede self-care behavior when individual needs conflict with family needs (Perez and Cruess 2014). Specifically, for Hispanic women, health and self-care practices are likely impacted by their desire to please the family (Perez and Cruess 2014).

Regarding diabetes self-care specifically, Hispanic family infrastructure may facilitate the adoption of dietary habits amongst family members (Page, 2004). Mellin *et al.* (2004) suggests that high levels of family cohesion are related to poor dietary habits in Hispanic families and familial eating patterns actually contributed to the development of disordered eating in adolescents with T1DM. Other studies indicate that Hispanics are likely to engage in faulty eating behaviors because of concerns over financially burdening their family (Horowitz, Tuzzio, Rojas, Monteith, & Sisk, 2004). Thorton *et al.* (2006) found that, under
financial duress, some Hispanic women purchase foods that their husbands prefer, which are often harmful to their health or not consistent with their recommended therapeutic diet. Ultimately, *Familism* promotes togetherness in daily activities, through which eating preferences and behaviors are modeled (Perez and Cruess 2014). However, the positive or negative effect on therapeutic diet are related to additional variables, including the family’s socio-economic status, financial burden, and knowledge of healthy eating (Perez and Cruess 2014).

**Familism and exercise**

*Familism* may also affect self-care agency when it comes to physical activity. For example, a study by Wen *et al.*, (2004), found that Hispanic participants reported that their motivation to exercise and adhere to therapeutic diet was undermined when family and friends offered them forbidden foods and did not support their efforts to exercise. Other studies have reported more positive effect of *Familism* in that Hispanic people were more likely to exercise regularly when supported by their community (Evenson, Sarmiento, Tawney, Macon, and Ammerman 2003; Dunn, 2008; Mier *et al.*, 2007).

**Familism and healthcare providers**

Healthcare providers working with Hispanic populations will benefit from understanding the role of *Familism* in chronic disease management. Research supports the contention that healthcare providers should consider the values of the family when managing chronic disease in Hispanic populations, and incorporate family members into treatment (Andres-Hyman, Ortiz, Anez, Paris, &
While it has been suggested there are some drawbacks to *Familism*, research has also shown that family is important in providing instrumental and informational support (Miville & Constantine, 2006), helping with the treatment decision-making process (Maly *et al*., 2006) and facilitating compliance with appointments (Kruse, Rohland, and Wu, 2002). *Familism* dynamics can also be a dilemma for providers who hold vastly different and often opposing worldviews, such as a desire to focus on the individual as opposed to the system (Perez and Cruess 2014). Without an understanding of *Familism* dynamics, healthcare providers may become frustrated (Sharma and Kerri, 2002) or pathologies family relations or withhold information about access to services because of beliefs that the family will impose on treatment recommendations (Constantine *et al*., 2005). Culturally competent clinicians should ascertain the level of commitment to *Familism* and examine the unique components that are important to their ongoing situation (Perez and Cruess 2014). Furthermore, components of *Familism* affect health differently across subgroups and within families (Guarnaccia *et al*., 2007; Rivera *et al*., 2008; Scharlach *et al*., 2006; Taylor, Gambourg, Rivera, and Laureano, 2006) and this should be considered as well. Despite this evidence, health care providers need to be cautious about the method in which they include the family, especially since the needs of the individuals can be lost or overpowered by the dynamics of the network (Perez and Cruess 2014).
Importance of Familism

Qualitative studies investigating T2DM self-management in PRiH populations have helped to illuminate some voids in the literature. For instance, in her doctoral dissertation, Gonzalez (1989) conducted a qualitative study using semi-structured interviews on 12 PRiHs, to explore cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida and examine Puerto Ricans' perceptions about their health-care providers. In this study, Familism, traditional gender role expectations, and caregiver burdens were found to be deterrents for participating in care. On the other hand, religiosity and spirituality were found to be coping mechanisms. This study was limited to PRiHs living in the deep southern part of the U.S. It is unclear if these findings are generalizable to PRiHs living in the northeastern U.S. Additionally, focus groups were not segregated by gender. Participants’ responses may differ when in peer groups. In this study, members were segregated by gender in two of the patient focus groups. This is an important difference between this study and Gonzalez’s (1989) study. Another distinction is that healthcare provider’s perceptions regarding Familism were not explored in Gonzalez’s (1989) study but was a key feature of this study. Similarly, Long, et al. (2012) conducted a qualitative study on a sample of 24 Hispanics, using questionnaires and four focus groups to explore similarities and differences in beliefs and attitudes related to health and healthcare practices across four Latino subgroups (Mexican, Colombian, Puerto Rican, and Mayan). The PRiH participants in this study indicated that they preferred to read about the
conditions or problems they faced and take care of it themselves when they could. In terms of Familism, PRiHs were more likely to socialize with other Puerto Ricans; preferred to talk to friends about health before they would go to the doctor or the hospital and would diagnose their own problems when possible. A limitation of this study was underrepresentation by female participants. This study addresses this specifically by recruiting female participants for an all-female focus group. Additionally, this study builds on findings from similar studies by exploring what participants believe will help with the negative effects of Familism on diabetes self-care.

Carbone, Rosal, Idali’ Torres, Goins and Bermudez (2007) conducted a relevant qualitative study on 36 Puerto Rican identified Hispanics, one Columbian and 15 medical practitioners. This study used the data from focus groups with practitioners (assessed perceptions of patients’ knowledge, attitudes, and behaviors) and patients (assessed knowledge, beliefs, practices, barriers, and facilitators) to inform the tailoring of a diabetes self-management program. Findings included knowledge gaps regarding diabetes causation and self-management and negative attitudes towards self-management were common. Key facilitators of diabetes self-management were family support, support of medical practitioners and religious faith. Additionally, there was a noted potential for traditional gender roles to constrain patients’ ability to make healthful lifestyle changes. There was a disconnect in practitioners’ approach to guiding diabetes self-management which emphasized giving instructions and information rather than counseling patients on realistic goals and progressive lifestyle changes.
Notably, in this study, family support was both a facilitator and inhibitor for the adoption of self-management practices. Limitations of this study include limited data collected on the samples literacy, health literacy level, and learning preferences. While the study by Carbone et al. (2010) is similar to this study, the distinguishing factor is that this study focused specifically on Familism. The theoretical underpinning of the study by Carbone et al. (2010) was not discussed. For this study Riegel, Jaarsma and Stromberg’s (2012) Middle Range Theory of Self-Care of Chronic Illness was used to guide the study design and research questions. Importantly, this was study was designed to explore any distinguishing features between male and female perceptions of Familism and its effects. While the study by Carbone et al. (2010) is similar to this study, the distinguishing factor is that this study focuses specifically on Familism.

Additional differences between Carbone et al. (2010) and this study include the use of four patient focus groups used in Carbone et al. (2010), compared to four patient focus groups, one with males only, one with females only, and two focus groups with both male and female subjects. Carbone et al. (2010) describes gender roles as potentially being a factor in family dynamics and health decision-making. The methodology of this study is built on that premise and is designed specifically to addresses the significance of gender roles in the Familism dynamic.

Carbone et al. (2010) selected from a sample of patients that were predominantly PRiH age 39-79. However, not all of the participants identified as PRiH. This study specifically targeted people who identify as PRiH. Geriatric
subjects were generally excluded as the challenges of geriatric populations may
differ from younger and middle age people.

Carbone et al. (2010) also focused patient data collection on diabetes
knowledge, beliefs and attitudes regarding self-management, and self-
management practices. This study includes some of these elements as well as
evaluation of how these specific beliefs affect DM self-management; strategies to
overcome cultural challenges; and best resources for overcoming cultural
challenges. Regarding data collected from providers, Carbone et al. (2010)
focused on diabetes self-management instructional strategies; perceived patient
barriers and facilitators to adopting self-management strategies; experiences
supporting patients’ self-management strategies; beliefs and attitudes regarding
patients’ abilities to manage their diabetes. This study also explores some of
these topics. In addition, the perceived cultural barriers, strategies to overcome
these barriers, best resources for overcoming cultural barriers, as well as
techniques that have worked to overcome cultural challenges were explored.

One advantage that Carbone et al.’s (2010) study has is that the
facilitators were fluent in English and Spanish. Language proficiency can be a
barrier to healthcare. English speaking or bilingual subjects will be recruited for
this study. Initially, the study design and methodology included certified Spanish
interpreters being present during focus groups, however the feasibility of this
design was questioned in light of budget constraints among other factors. This
study was limited in that primarily Spanish speaking subjects were not included
and this could have affected the breadth, depth and quality of the data. Another
limitation of this study was that some meaning may have been lost in translation when participants inadvertently used Spanish during focus groups. An additional methodological difference between Carbone et al. (2010) and this study is that the providers in this study were interviewed prior to the patient focus groups. The provider interviews informed the focus group questions as well as serve as a method of triangulation of data. There are other important methodological differences between this study and Carbone et al. (2010), including strategies to ensure confirmability of study findings. Carbone et al. (2010) used a team of moderators to reach a consensus of findings and conclusions. This study used member checking to ensure confirmability of study findings. Carbone et al. (2010) was able to keep the transcription as close to the original Spanish language by conducting data analysis prior to translation. However, member checking is one of the strengths of this proposed study.

Carbone et al. (2010) triangulated data with field notes, video recordings and moderator guides. This study will use also used audio recordings, however providers will have an opportunity to review the transcripts and summary of conclusions prior to using the data in the study. This is important in that the “case” being evaluated is how culture impacts diabetes self-care. While the cultural impact is the case, the patients and providers are a part of the “community” being evaluated, and thus, their feedback is vital.

Carbone et al. (2010) used multiple people to review data from each focus group to achieve content validity. Lincoln and Guba’s (1985) validity constructs of
credibility, transferability, dependability, and conformability were used to achieve content validity. See Validity Constructs in section IX for details.

Finally, a limitation of Carbone et al. (2010) was the lack of literacy data on the subjects. In this study level of education was collected from subjects (this information was not collected from medical providers). Additionally, providers discussed the lack of training they received to help address *Familism* in their practice.

The degree to which each component of *Familism* influences T2DM self-care behaviors has not been settled in the literature (Knight & Sayegh, 2010; McCallum, Longmire, & Knight, 2007). Possible causes of this variation may be related to the multidimensional nature of *Familism*; the inconsistent ways *Familism* is measured; and important contextual variables (Perez and Cruess 2014). More research is needed on *Familism* as a concept in order to sort this out, however, this study adds to this conversation. Importantly, the bulk of the research on *Familism* and chronic disease management research is disproportionately on Mexican populations (Sheppard *et al.*, 2008), leaving other Hispanic populations (such as PRiHs) underrepresented (Perez and Cruess 2014). In a review of the impact of *Familism* on Hispanic populations, Perez and Cruess (2014) recommend evaluating the impact of caregiving in Hispanic women diagnosed with chronic illness as well as exploring possible gender differences in health outcomes in response to *Familism* practices. Additionally, Perez and Cruess (2014) note that Hispanic women who endorse traditional role expectations may experience higher levels of family caregiver stress associated
with perceived family responsibility in addition to the typical stressors surrounding (chronic disease) treatment (Perez and Cruess 2014).

In conclusion, this study was conducted based on the gaps in the literature regarding the relationships between Familism, PRiHs and T2DM self-care. These gaps were primarily sociocultural and included but were not limited to the role of family/community; religion; fatalism; incongruent health perceptions; and importantly variations of health perception between men and women. Importantly, there was research linking Familism in Hispanic populations to healthcare behaviors. Prior to this study, the degree to which each component of Familism influences self-care behaviors and the differences in Familism related experiences for PRiH men and women had yet to be explored. Aside from this study, there have been no other studies specifically evaluating the aforementioned gaps relating to Familism and the PRiH subgroup. A qualitative method of inquiry was best suited to investigate this phenomenon, as it was not yet well understood. This study was designed specifically to build on previous knowledge and address these gaps in the literature.

**Primary Concepts and Constructs**

**Diabetes self-care/management**

Diabetes self-care management is a cornerstone of diabetes control and is heavily dependent on behavior modification. These behaviors include activities that an individual may initiate and perform on their own behalf in maintaining life, health and wellbeing. Diabetes self-care (self-management) includes adherence
to a low carbohydrate intensive diet; regular exercise; monitoring of blood
glucose; monitoring for symptoms of diabetes; medication adherence; and
attending scheduled appointments with healthcare providers (American
Association of Diabetes Educators 2002).

Familism

Familism as a concept has been defined as an aspect of Hispanic cultural
dynamics in terms of its role, which emphasizes close, frequent, and meaningful
social interactions (Kana'iapuni, et al. 2005). Familism has been operationalized
as a construct composed of sub factors (Knight and Sayegh, 2010; Losada et al.,
2010). Sub factors affect self-care agency and include: favorable influences (e.g.,
perceived support) versus disadvantageous influences (e.g., perceived
obligations).

Summary

Prior to conducting this study, a systematic literature review was used to
review the current research for gaps. In total, eighteen research manuscripts
were reviewed. Of those manuscripts, 3 addressed both Familism and the PRiH
population (Gonzalez 1989; Carbone et al. 2010; Long et al. 2012); 7 studies
used qualitative methodology to investigate self-care for PRiH (Caban et al.
2008; Gonzalez 1989; Carbone et al. 2010; Long et al. 2012; Dharma et al. 2013;
Weitzman et al. 2013; Khan et al. 2012); 8 articles used qualitative methodology
to investigate self-care in other Hispanic subgroups (Hu et al. 2010; Sawyer et al.
and 6 manuscripts addressed some aspect of *Familism* specifically (Gonzalez 1989; Carbone *et al.* 2010; Long *et al.* 2012; Orzech *et al.* 2012; Ramal *et al.* 2012; Weiler and Crist 2009). Many of the studies using qualitative methodology to investigate diabetes self-management in Hispanic populations have investigated Mexican identified Hispanics (Hu *et al.* 2010; Sawyer *et al.* 2013; Meyer *et al.* 2013; Hughes *et al.* 2012; Heuer *et al.* 2006; or Dominicans (Aponte *et al.* 2012), and did not specifically address any aspects of *Familism*. Importantly, the studies of PRiHs that investigate diabetes self-care, did not specifically address components of *Familism* or community as a factor in diabetes self-management (Khan *et al.* 2012; Dharma *et al.* 2013).

Some studies have investigated the relationship between T2DM, *Familism* and Hispanic adults. However, these studies were either focused on Mexican identified Hispanics Baig *et al.* (2012); or did not identify the targeted Hispanic subgroup (Ramal *et al.* 2012, Weiler *et al.* 2009). Still, the literature does highlight the need for further exploration of *Familism*. However, these studies either did not specifically explore the impact of *Familism* on T2DM self-management behaviors (Caban *et al.* 2006); or did not investigate the influence of community or family on health behaviors (Asgarian *et al.* 2011), Weitzman *et al.* 2013).

In reviewing research studies, a recurring theme and gap in the literature centered on the relationship between *Familism* in the Hispanic population and chronic disease management. Importantly, researchers speculate that *Familism*, which emphasizes close and frequent social interactions, has both direct and
indirect effects on the quality of life and the management of symptoms of Hispanics diagnosed with a chronic illness, thus providing a route by which Familism can impact the physical health status (Ashing-Giwa et al. 2004; Finnegan et al., 2000; Urizar & Sears, 2006; Valenzuela et al., 2003). These Familism values may alter the course of a chronic illness by influencing health behaviors that may be important in managing the condition or by increasing levels of distress (Segerstrom & Miller, 2004). Research suggests that for PRiH, Familism may affect the therapeutic diet and meal preparation positively (Perez and Cruess, 2014), negatively Adams (2003), or may contextualize decisions to follow or not follow dietary recommendations (Horowitz, Tuzzio, Rojas, Monteith, & Sisk, 2004). Additionally, Familism may also affect self-care agency when it comes to recommended physical activity (Wen et al., 2004).

Research supports the contention that healthcare providers should consider the values of the family when managing chronic disease in Hispanic populations, and incorporate family members into treatment (Andres-Hyman, Ortiz, Anez, Paris, & Davidson, 2006; Anez et al., 2005; Ingram et al., 2007; Sheppard et al., 2008). Familism dynamics can also be a dilemma for providers who hold vastly different and often opposing worldviews, such as a desire to focus on the individual as opposed to the system (Perez and Cruess 2014). Without an understanding of Familism dynamics, healthcare providers may become frustrated (Sharma and Kerri, 2002) or pathologies family relations or withhold information about access to services because of beliefs that the family will impose on treatment recommendations (Constantine et al., 2005).
A study by Carbone et al. (2007) was similar and relevant to this study. This was a qualitative study with a sample of 36 Puerto Rican identified Hispanics, one Columbian and 15 medical practitioners. There are several methodological differences between the study by Carbone et al. (2007) and this study. The distinguishing factors between Carbone et al.’s (2007) study and this study are that this study focused specifically on Familism; used a theoretical underpinning; and was designed to explore any distinguishing features between male and female perceptions of Familism and its effects on self-care.

Finally, there is research that links linking Familism in Hispanic populations to healthcare behaviors. Prior to this study, the degree to which each component of Familism influences self-care behaviors and the differences in Familism related experiences for PRiH men and women had yet to be explored. Prior to this study, there were few studies specifically evaluating the aforementioned research gaps relating to Familism and the PRiH subgroup; and no studies investigating this problem using the methodology described in Chapter 3.
CHAPTER III

METHODOLOGY

Introduction

The purpose of this chapter is to elaborate on the methodology of this qualitative study. Topics within this chapter include the theoretical framework, study design, research design, setting, sampling, participants, data collection, data management and analysis, trustworthiness, and timeline. A summary of methodological, implementation and execution challenges and recommendations to improve those challenges is provided and expounded upon in chapter 5. Additionally, a brief introduction to the study findings is provided at the conclusion of this chapter.

Methodological Overview

Puerto Rican identified Hispanic (PRiH) adults are disproportionately affected by type 2 diabetes and co-morbid conditions compared to their white counterparts. It is well understood that culturally tailored interventions improve self-care for Hispanic populations. It is also well known that culturally specific interventions should be tailored to the targeted Hispanic subgroup. Importantly, the effect of Familism on T2DM self-care in the PRiH population is not well understood.

The aim of this study was to define specific socio-cultural phenomena, Familism, as a facilitator or inhibitor of diabetes self-care for Puerto Rican
identified Hispanics living in the continental U.S. The cultural phenomena of *Familism* is not well understood, and even preliminary data on *Familism* in PRiH communities is scarce. Therefore, a reductionist methodology was less appropriate as a method of inquiry, and a qualitative methodology was more appropriate. Specifically, Case method was used with an instrumental approach.

To assess the influence of *Familism* on diabetes self-care for PRiH adults, pre-established definitions of *Familism* were compared with the lived experiences of the subjects in the study. Two research questions were asked. The first research question was, “what is the effect of *Familism* on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?” This question was based on the first and second study assumptions; that *Familism* has an effect on T2DM self-care for PRiH adults; and PRiH men and women in traditional roles experience the effects of *Familism* differently, respectively. The second research question was, “how can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?” This question was based on the third study assumption that healthcare providers do not generally consider *Familism* as a factor in T2DM self-care.

The data analyzed from this study was primarily thematic. NVivo software, industry standard for qualitative research, was used to facilitate exploration of the data for themes. Four primary sources of data collection were used and included focus groups (n=12 patient subjects), semi structured interviews (n=5 medical provider subjects), semi structured interviews (n=5 community member subjects) and field notes from participant observation. Member checking and non-member
(n=3 subjects) checking was used to confirm the study findings. Behavioral and demographic surveys were collected. Finally, validity constructs were used to ensure credibility, transferability, dependability and conformability.

**Theoretical Framework**

**Relevant theories**

The premise of this study was based on the evidence that a subgroup (PRiHs) within the general population had worse health outcomes (related to T2DM) compared to the general population; and that these health outcomes were related to self-care behaviors and family dynamics. The first, second and third assumptions for this study were that *Familism* has an effect on T2DM self-care for PRiH adults; healthcare providers do not generally consider *Familism* as a factor in T2DM self-care; and PRiH men and women in traditional roles experience the effects of *Familism* differently. The first and second research questions, as well as their corresponding sub questions, were designed to explore *Familism* as an inhibitor or facilitator of self-care; and to explore how clinicians may use *Familism* dynamics to improve self-care.

Well established nursing theories were considered as theoretical models used to investigate this kind of problem. Orem’s self-care deficit theory (1991) comes to mind most notably. Generally, Orem’s (1991) theory specifies when nursing care is needed. A component of this study was the investigation of “self-care deficits” within a population, however, determining the need for nursing care was not a component of the investigation. Therefore, Orem’s (1991) theory was
not an optimal fit. Additionally, given this study was an exploration of the relationship between self-care and families/communities, one may have proposed to use Johnson’s Behavior System Model (1980) as a theoretical model. However, similar to Orem (1991), Johnson’s (1980) theory is a model of nursing care. This study was not an investigation of nursing care or the need for nursing care, but rather the exploration of a human phenomenon, so Johnson’s (1980) theory wasn’t a good fit either.

Riegel’s (2012) theory

Nursing is a science with its own unique body of knowledge and (nursing) theory is defined as a set of concepts combined uniquely and written at an abstract level to describe, explain, or predict phenomena (Parse, 1997). The theoretical underpinning of this study was based on Riegel, Jaarsma and Stromberg’s (2012) Middle Range Theory of Self-Care of Chronic Illness. The “Middle range theory of Self-care of chronic illness” is a relatively new theory. The usefulness of this theory for nursing science and practice has yet to be determined as this theory has not been evaluated or tested empirically. During time this study was being conducted, a review of the literature did not indicate that this new theory has been tested for congruency with empirical evidence. According to Meleis (2007) a middle-range theory describes a view of reality that deals with specific phenomena and a limited number of variables.

Riegel’s et al. (2012) Middle Range Theory of Self-Care of Chronic Illness is a method of exploring nursing science. Riegel et al. (2004) defines self-care as a process of maintaining health through health promoting practices and
managing illness. Additionally, Riegel et al. (2012) describes self-care in healthy and ill states can be, but are not always, simultaneous processes. In other words, self-care is not the same for all patients nor is it necessarily consistent over time.

Self-care is considered essential in the management of chronic illness. This study is based on the primary assumptions that Familism has an effect on T2DM self-care; and that this effect was different for men and women. Riegel et al.’s (2012) theory was as chosen as framework as it allowed exploration of specific self-care elements used by PRiH adults while managing T2DM self-care. Additionally, Riegel et al.’s (2012) theory provided a framework from which to base the research questions, which explored Familism as an inhibitor or facilitator of T2DM self-care; and specific elements of Familism clinicians could target to facilitate improved diabetes self-care.

**Definition of concepts**

Three key concepts for this theory are: self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance is defined as those behaviors used by patients with a chronic illness to maintain physical and emotional stability. Self-care monitoring refers to the process of observing oneself for changes in signs and symptoms. Self-care management is defined as the response to signs and symptoms when they occur. Riegel et al. (2012) offers that these behaviors and activities will not always take place in the same, linear order and certain steps might be skipped.

**Assumptions**

The assumptions for this theory are as follows:
1. There are differences between general self-care and illness-specific self-care.

2. Decision-making requires the ability to focus attention, to think, sufficient capacity for working memory and the ability to understand and weigh information.

3. Self-care for patients with multiple co-morbid conditions may be conflicting when self-care is considered for each illness separately.

**Propositions**

The propositions for this theory are as follows:

1. There are core similarities in self-care across different chronic illnesses.

2. Previous personal experience with illness or in caring for someone with a similar illness or with similar self-care needs increases the quality of self-care performed.

3. Patients who engage in self-care that is purposive but unreflective are limited in their ability to master self-care in complex situations.

4. Misunderstandings, misconceptions, and lack of knowledge all contribute to insufficient self-care.

5. Mastery of self-care maintenance precedes mastery of self-care management because self-care maintenance is less complex than the decision making required of self-care management.

6. Self-care monitoring for changes in signs or symptoms is necessary for effective self-care management because one cannot make a decision about a change unless it has been noticed and evaluated.

7. Individuals who perform evidence-based self-care have better outcomes than those who perform self-care that is not evidence-based.
Factors Affecting Self-Care

In this theory, the eight factors affecting Self-Care are defined as: experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from others, and access to care. Experience in self-care may allow a person to quickly identify patterns that provide relevant cues, suggest expected outcomes associated with specific responses, and point to reasonable goals and actions in specific types of situations (Klein, 2008). Additionally, experience lends to the acquisition of skill. A degree of skill in self-care is necessary for persons with chronic illness to have the ability to plan, set goals and make decisions (Stromberg, 2005; Dickson and Riegel, 2009).

Motivation in self-care, defined as the force driving humans to achieve their goals (Riegel et al. 2012), is further delineated as either intrinsic or extrinsic. Intrinsic motivation is driven by an internal desire to perform a particular task because that task gives pleasure whereas extrinsic motivation is driven by the desire to change behavior because it leads to a specific predetermined outcome that is desirable for some reason (Riegel et al. 2012). Additionally, Riegel et al. (2012) proposes that self-care may be affected by culture, beliefs and values in that the importance of self-care varies across these social domains. In a similarly variable manner, confidence is not described as part of self-care but rather as important in each stage of the self-care process, heavily influenced by attitudes and beliefs, and determinant as to whether a person has the ability to perform a specific self-care action.
Habits or routines affect self-care in that some people get used to performing self-care behaviors while others struggle with the tasks (Ekman, Ehnfors and Norberg, 2000; Van Der Wal, Jaarsma, Moser, Gilst and Veldhuisen, 2010). Riegel et al. (2012) suggest that those who willingly incorporate self-care into their daily routine may struggle less with self-care than those who resist the behaviors.

Performing self-care behaviors requires requisite functional and cognitive abilities such as adequate hearing, vision, manual dexterity, and general energy. Without such core requisites, it will be difficult for an individual to adequately perform dynamic self-care behaviors. Decreased functional or cognitive abilities may mandate that an individual require assistance with self-care. Riegel et al. (2012) propose that while self-care is performed by the affected individual, many chronically ill individuals require assistance from family and friends—a process referred to as shared care when it involves 2 competent adults (Sebern, 2005). Therefore, social support is considered an influence in a person’s ability to perform self-care. Finally, access to care influences a person’s ability to perform self-care in that without access to trained health care providers, the outcomes associated with chronic illness are typically poor (Merra, Lynd, Esdaile, Kopec and Anis, 2004).

**Decision-making and reflection**

Processes underlying self-care include: Decision making and reflection. Riegel et al. (2012) describes the decision-making process of self-care as naturalistic decision making, which reflects the automatic, impulsive, contextual decisions
that people make in complex real-world situations. The relationships between decision-making and reflection on self-care is illustrated by way of an axis of low-high reflection that intersects the decision-making process. People with chronic illness may be unreflective with sufficient self-care, unreflective with insufficient self-care, reflective with sufficient self-care or reflective with insufficient self-care. For the person with chronic illness, the ideal combination of these ways of reflection are purposive, reflective, sufficient and reasoned self-care.

**Theory critique**

Riegel et al.’s (2012) middle range theory of self-care and chronic illness, depicts a synchronous, iterative, overlapping and intertwined process in which the patient’s illness is the center. Riegel et al.’s (2012) diagram illustrates self-care maintenance, monitoring and management as interconnected and in constant motion in order to maintain health and facilitate management of illness. See Diagram 5 in Appendix L.

This middle range theory offers a method to conceptualize the process of self-care for a person with chronic illness. The key concepts and propositions are explicit and clearly defined, making the theory accessible and ready for empirical testing. However, internal consistency is somewhat lacking in Riegel et al.’s (2012) theory. For example, the use Orem’s self-care theory (1991) is used as the theoretical basis. While, Orem (1991) focuses on patient and nursing actions, Riegel et al.’s (2012) theory focuses on the patients’ process of self-care.

Some of the weaknesses of Riegel et al.’s (2012) theory are that it is illness-centric, passive, and there is limited focus on extra-personal or social
forces that affect the self-care process. Strengths of this theory include an iterative nature, process oriented design, and patient centered and individualized approach. Additionally, the key concepts reflect semantic clarity and consistency in that they are well defined and the conceptual interconnectedness of the terms is presented logically. The succinct nature of this theory lends to an aesthetically pleasing and digestible model.

Theoretical fit and application

Type 2 Diabetes is a complex chronic disease that requires adherence to an array of self-care management behaviors, such as monitoring dietary intake and blood glucose levels and increasing physical activity (Concha et al 2009; American Association of Diabetes Educators, 2002). This theory was relevant to this study in that the study is an exploration of diabetes self-care dynamics as they are affected by Familism. This theory provided a structure from the research questions and interviews could be derived. Additionally, this theory helped to cement the purpose of the study, which is to understand specifically how Familism affects diabetes self-care in PRiH culture.

By using Riegel et al.’s (2012) theory for this study, a broader application of the theory was explored as the extra-personal and social forces that may affect a patient’s self-care process were examined. The premise for using this theory is that the components of self-care (maintenance, monitoring and management) were used as a general framework during the focus groups. The eight components of self-care (experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from
others, and access to care) were used to guide the interview/focus group questions.

The Substruction Model (Diagram 4 in Appendix L) illustrates the relationships between the constructs and concepts being explored in the study. The constructs explored included diabetes self-care, diabetes self-care maintenance, self-care management and self-care monitoring. These constructs are related as diabetes self-care management, maintenance and monitoring are components of diabetes self-care. The concepts explored were *Familism* and diabetes self-care. These concepts are related in that *Familism* is either an inhibitor or Facilitator of diabetes self-care. Empirical indicators were the subjects’ perceptions of *Familism*, Diabetes self-care, and diabetes self-care maintenance, management and monitoring. The product of these perceptions was evaluated through thematic qualitative analysis. Themes emerging from this analysis helped to discern *Familism* is an inhibitor or facilitator of diabetes self-care management, maintenance or monitoring in the PRiH population.

**Research Design**

**Introduction**

Despite the large body of research documenting racial and ethnic and socioeconomic disparities in life expectancy, health care, and health across a wide variety of different conditions, interventions to improve health have lagged behind (Smedley, Stith, Nelson, 2002; Agency for Healthcare Research and Quality, 2006). Scientists and healthcare providers have begun to recognize that
prevention and control of complex conditions, necessitates assessing and addressing the array of nonclinical issues not traditionally in their purview (Horowitz, Robinson, Seifer, 2015). This study was designed to evaluate nonclinical factors, specifically Familism, that impact chronic disease self-management for PRiH adults.

A common approach to research was used: 1) formative stage; 2) study design stage; 3) funding; 4) implementation and analysis; 5) dissemination of findings; 6) translation to practice/policy; and 7) sustaining (Horowitz et al. 2009). This study explores research stages 1-4. The traditional research approach was an appropriate fit for this study as I was building on existing knowledge, with hopes that the data and results may be used to design culturally tailored interventions and improve clinical practice. However, after reviewing the literature, it was determined that in order to plan a study using a Familism-centered intervention, we first needed to gain a better understanding of the problem. The premise of this study was that diabetes self-care is affected by Familism, and that these relationships can be explored by evaluating the peoples lived experiences.

A qualitative method of inquiry, using focus groups (with patients); interviews (with medical providers); individual interviews (with community members) and participant observation data was used to explore the lived experiences of PRiH with T2DM as they relate to Familism. A focus group + individual interview design was used to collect a well-rounded view of the relationship between Familism and diabetes self-care management. Case
methodology was used to frame the research question(s). Riegel’s (2012) Middle-Range Theory of Self-Care of Chronic illness was used to guide the research design as well as structure the interviews and focus groups.

**Qualitative Methodology**

A qualitative method of inquiry was used and included focus groups with patients, interviews with community members, semi-structured interviews with medical providers and participant observation notes. The voids in the literature, highlighted in Chapter 2, demonstrated several areas worthy of investigation, many of which were based on exploration of sociocultural phenomenon. According to Watkins (2012), “When quantitative methods are used alone, or used to acquire more depth about a topic, they are not sufficient. To get the complete picture, it is important to understand and be able to conduct qualitative research—research that traditionally does not include numbers and statistical figures”.

If the specific cultural aspects and effect of *Familism* were better understood, they could be measured and thus a quantitative method of inquiry would be useful. However, the aim of this study was to explore unknown cultural phenomenon, the relationship between *Familism* and diabetes self-management, therefore a reductionist process was less useful. Qualitative methodology allows for a broader/deeper/richer form of inquiry and can expand usual boundaries of understanding (Watkins, 2012). In this instance, where the PRiH community is affected by a diabetes disparity, despite good access to healthcare and strong science of how to optimize diabetes self-care; an in-depth approach was needed.
to understand the subtle and overt effects of *Familism* on diabetes self-care management.

**Case Methodology**

In this study focus groups and semi structured interviews were used to explore the relationship between *Familism* and diabetes self-care management for PRiHs. A Case methodology was used as this approach facilitates exploration of a phenomenon within its context using a variety of data sources (Baxter and Jacks 2008). Using multiple data sources ensures that the issue is not explored through one lens, but rather a variety of lenses, which allows for multiple facets of the phenomenon to be revealed and understood (Baxter and Jacks 2008).

Two distinct approaches to case study methodology are commonly used, Sake (1995) or Yin (2003). While both approaches seek to ensure that a phenomenon is well explored, the approaches are quite different (Baxter and Jacks 2008). Both approaches are based in the constructivist paradigm, which asserts that truth is relative and dependent on one's perspective (Baxter and Jacks 2008). Additionally, the constructivist paradigm “recognizes the importance of the subjective human creation of meaning, but does not reject outright some notion of objectivity (Baxter and Jacks 2008). Pluralism, not relativism, is stressed with focus on the circular dynamic tension of subject and object (Baxter and Jacks 2008). An advantage of this approach is the close collaboration between the researcher and the participant, while enabling participants to tell their stories (Baxter and Jacks 2008). The focus group/structured interview design of this study allowed participants and providers to share their struggles, success,
perspectives and experiences of managing diabetes. Through these stories the
participants are able to describe their views of reality and this enables the
researcher to better understand the participants’ actions (Lather, 1992).

Yin (2003) suggest using case methodology study design should be
considered when: the focus of the study is to answer “how” and “why” questions;
you cannot manipulate the behavior of those involved in the study; you want to
cover contextual conditions because you believe they are relevant to the
phenomenon under study; or the boundaries are not clear between the
phenomenon and context (Baxter and Jacks 2008). The aim of this study was to
explore how *Familism* within Puerto Rican culture intersects with and influences
diabetes self-care behaviors and attitudes as a phenomenon. Thus, the units of
analysis are the focus groups/interviews, with the goal of understanding the
relationship between and effect of *Familism* in PRiH culture and T2DM self-care.
Contrasting the data from medical provider interviews, focus groups, community
members and participant observation ultimately provided richness to the data.

There are different categories of case methodology. Yin (2003) Yin
categorizes case studies as explanatory, exploratory, or descriptive and further
differentiates by single, holistic case studies and multiple-case studies. Sake
(1995) categorizes case methodology as intrinsic, instrumental, or collective. This
study was structured as an instrumental case. Sake (2000) describes an
instrumental case study as the exploration of a particular case with a view to
understanding, or gaining insights about a phenomenon of interest. Additionally,
Sake (1995), recommends an instrumental case study be used when the aims of
the study are to accomplish something other than understanding a particular situation. The researcher conducting an instrumental case study is accessing the phenomena of interest via a case, rather than studying the case itself (Luck et al. 2006a). In doing so, the case is of secondary interest and plays a supportive role by facilitating our understanding of something else (Baxter and Jacks 2008).

The premise of using this methodological approach was that the effect of Familism on diabetes self-care management within the PRiH population was a relatively unknown phenomenon; and that understanding this phenomenon is essential to the development of a cultural based diabetes self-care intervention. Understanding this phenomenon, is paramount to constructing culturally tailored T2DM intervention interventions for PRiH adults. Therefore, the “case” serves a supportive role.

**Sampling and Setting**

**Sampling technique**

A stratified purpose sampling technique was used to recruit medical provider subjects, patient subjects and community member subjects. Four separate focus groups were conducted and comprised of an all-female group, an all-male group, two mix gender groups. The focus groups were segregated by gender based on the second study assumption that PRiH men and women in traditional roles experience the effects of Familism differently. Five individual interviews were conducted with community members and included women and man. The age, gender or practice level (physician or advance practitioner) of the medical providers interviewed was not considered as a factor for recruitment.
**Sample**

A stratified purposive sampling technique was used. This technique was used as the aim of the study was to evaluate a very specific subset of a population. This study sample included four focus groups comprised of patients with diabetes (n=12); individual interviews with community members (n=5); individual interviews with medical providers (n=5); as well as member and non-member checking members (n=3). The total number of subjects participating in the study was n=25.

The HCPs (n= 2 male, n=3 female) interviewed for this study were not stratified in any particular way. Focus groups comprised of one all male group (n=3), one all-female group(n=3) and two mixed gender groups (n=3; n=3). Community member interviews included interviews with women (n=4) and one man (n=1). Segregation of some focus groups by gender was based on the second study assumption that PRiH men and women may experience the effects of Familism differently. Additionally, some subjects may be less comfortable discussing topics surrounding traditional gender roles with members of the opposite gender (Morgan, 1998). Dividing the groups by gender removed this potential barrier and added to the depth of the study findings.

**Setting**

The study was conducted over a 12-month period. Two research sites were used during the three phases of data collection. The first research setting included an urban outpatient clinic at Baystate Medical Center in Springfield Massachusetts (MA) where phase one (medical provider interviews) and phase
two (focus groups with patients) of data collection were conducted. A second research setting, Holyoke Senior Center, was used for phase three of data collection (community member interviews).

**Gaining Access to Research Sites**

**Research site one**

Approval for the study was granted by Baystate IRB via an expedited review. See Appendix A for Baystate approval document. While the study did involve human subjects, the study was considered low risk, thus the proposal received an expedited review. As a Baystate employee, I was allowed to be the PI on the project, which is quite unusual for a large tertiary health center, as this role was primarily reserved for attending physicians. Additionally, the Baystate IRB staff was very helpful in guiding my early proposal revisions and ensuring the study met all of the required IRB standards. It’s worth mentioning that prior to submitting the proposal for this study, I had submitted a separate research proposal to Baystate IRB, and while that study was not executed, I did gain some familiarity with the IRB staff and application process. Surely, cultivating relationships with the Baystate IRB staff was a benefit to some degree, however to what extent is purely anecdotal. It is also worth noting that as a Baystate clinician, with preexisting access to the leadership at the research site, electronic medical records, and importantly a > 6-year history of working with the patient population and clinic staff, there were essentially no initial challenges in navigating the dynamics and structure of the first research site.
**Research site two**

The second research site was at the Holyoke Senior Center in Holyoke Massachusetts. This site was used to recruit community members for individual interviews. Access was granted by the University of Massachusetts Amherst IRB (See Appendix A). This research site was located in a small city that abuts Springfield MA and has a similar demographic. See ‘Setting’ section for details. The attendees at this senior center were more likely to receive their healthcare in the city of Holyoke and less likely to have had clinical contact with any of the research team. Therefore, screening for preexisting clinical contact between the participants and the researcher was not considered a potential conflict or possible influence on participant answers to interview questions.

**Research Site Demographics**

**Research Site One**

It is important to note that Springfield MA is listed, federally, as an underserved medical population, and is generally socioeconomically disadvantaged. The population of Springfield MA is approximately 153,000 (CENSUS 2010); with approximately 30% identifying as Hispanic (CENSUS 2010). Seventy-five percent of Springfield residents report having a high school diploma, 17% have a bachelor degree, 23% are below the poverty line (CENSUS 2010). Springfield MA Per capita income is ~ $18,000; average Household income is ~$34,000; with approximately 30% of residents living below the poverty
line. Though some estimates have suggested Springfield poverty rates may be estimated as high 38% to 50% (CENSUS 2010).

The Health Center where patient focus groups and medical provider interviews were conducted, serviced an area of Springfield MA, Metro Center area, where approximately 43% of the residents identified as Puerto Rican or of Puerto Rican decent (CENSUS 2010). Additionally, 22% of the residents in this area have do not have a High School diploma compared to MA statewide and national average of ~11% and 16% respectively (CENSUS 2010). Unemployment in this area has been estimated at 7.75% compared to Massachusetts and national averages of 4.7 and 4.8 respectively (CENSUS 2010).

The Health Center, was is located in the Metro Center area of Springfield MA. The clinic is staffed by 11 attending physicians; 6 advance practitioners (Nurse Practitioners/Physician Assistants); 14 registered nurses; 16 medical assistants; 6 Spanish interpreters and axillary staff (housekeepers, receptionist, etc.). This research site also served as a training site for 60 internal medicine residents in training.

**Research Site Two**

Phase three of data collection included individual interviews with community members. These interviews were conducted at Holyoke Senior Center. It is important to note that Holyoke MA is similar to Springfield MA in that
many of the residents of Holyoke are considered underserved, and the population is generally socioeconomically disadvantaged.

The Senior Center where subjects were recruited for phase 3 of data collection was located in Holyoke Massachusetts. Holyoke is a small city in Western MA with a population of ~40,000 (CENSUS 2010). Roughly 48% of Holyoke residents identify as Hispanic, with 40% of the population identifying specifically as Puerto Rican (CENSUS 2010). The median household income in Holyoke is ~$36,000 per year; the per capita income is estimated at $22,000; and 28% of the residents live in poverty (CENSUS 2010). Unemployment rates for Holyoke are 6.6, compared to Massachusetts statewide and national averages of 4.7 and 4.8 respectively (CENSUS 2010).

**Special Considerations for Data Collection**

As the PI, and an actively practicing clinician at the Baystate Medical practice where patients were recruited, special care was taken to ensure the research team entered the research setting as researchers and not clinicians. To avoid any unintentional coercion, participants who had previous clinical contact with the PI or Research Assistant (RA) were excluded from participating in the study. Additionally, the medical providers interviewed for this study were colleagues. All of whom were aware what the research topic and aims were. To avoid unintentionally influencing their answers to interview questions, medical provider subjects were not asked any specific questions about the study topic until the actual interview meeting. These subjects were also asked not to share
the content of their discussion with other staff members prior to their interviews being conducted.

**Subject Fees**

Medical providers were not compensated in any way. All other subjects who completed an interview, focus group or member/non-member checking presentation were compensated with a $20.00. This amount was used as compensation for comparable studies conducted with similar populations. Compensation was distributed at the conclusion of each focus group or interview, or presentation. Subjects signed a form to acknowledge receipt of compensation. Compensation was distributed in the form of a debit like card, from which the subjects accessed the funds. Travel costs were not reimbursed. Free patient parking was available at both of the study locations and thus was not included as an expense to the subject. The costs of usual medical care were considered the subject’s responsibility and not included as an expense to the subject. These costs included medical office, medications, medical supplies and health education. Subjects were not responsible for any research-related cost. Finally, subjects were eligible to take part in the study regardless of their insurance status.
Participants

Inclusion and Exclusion Criteria

Medical provider subjects

Medical providers were included in the study if they met the following criteria:

- They were a licensed practicing physicians and or advanced practitioners (Nurse practitioners or physician assistants)
- Providers of outpatient medical/nursing and diabetes care to primarily PRiH populations for > 2 years
- Employed at a Baystate Clinic in an outpatient setting

Medical providers were excluded if they did not wish to participate in the study; did not have clinical experience managing diabetes with the study population; or did not have experience of T2DM management. None of the medical providers recruited into the study were withdrawn from the study.

Patient subjects

Subjects (Patients and community members) were included in the study if they met the following criteria:

- Adults (age 21-65)
- Self-identified as Puerto Rican or of Puerto Rican decent
- Patients at a Baystate outpatient clinic who had been seen in the clinic by a medical provider within the previous 12 months (of recruitment date) OR community members using Holyoke Senior Center
- Diagnosis of Type 2 diabetes > 1 year
• Able to read and speak English

• Living independently in a private home (i.e., not homeless, living in nursing home or assisted living facility)

• Had access to a working telephone and/or cellular phone (to facilitate accessibility)

Patient subjects were excluded from the study for the following reasons:

• Any subject to whom the PI or RA had provided medical care

• Anyone judged not medically fit to participate in the study (i.e., severe medical or psychiatric problems), as per the Primary Care Provider clinical judgment (by direct clinician query)

• Anyone planning to relocate from the area within 6 months of interview/focus group dates (i.e., during study timeframe)

The criteria for withdrawing or terminating subject (patient’s/community members) from the study were as follows:

• If the PI concluded that it was not in the subject’s best interest to participate (i.e., severe medical or psychiatric limitations)

• Subjects who did not follow the study requirements, (i.e., not attending focus groups or interviews)

• If the study is stopped for any reason.

None of the subjects recruited into the study were withdrawn from the study.
Community member subjects

Community member subjects were included in the study if they met the following criteria:

- Adults (age 21-65)
- Self-identified as Puerto Rican or of Puerto Rican decent
- Community members using Holyoke Senior Center
- Diagnosis of Type 2 diabetes > 1 year
- Able to read and speak English
- Living independently in a private home (i.e., not homeless, living in nursing home or assisted living facility)
- Had access to a working telephone and/or cellular phone (to facilitate accessibility)

Community member subjects were excluded from the study for the following reasons:

- Any subject to whom the PI had provided medical care.
- Anyone judged not medically fit to participate in the study (i.e., severe medical or psychiatric problems per observation of the PI).
- Anyone planning to relocate from the area within 6 months of interview (i.e., during study timeframe)

The criteria for withdrawing or terminating community member subjects from the study were as follows:

- If the PI concluded that it was not in the subject’s best interest to participate (i.e., severe medical or psychiatric limitations)
• Subjects who did not follow the study requirements, (i.e., not attending interview)
• If the study is stopped for any reason.

None of the subjects recruited into the study were withdrawn from the study.

Data Collection

Recruitment

Phase one

Recruiting medical providers into the study was relatively uneventful as I had access to the health center staff directories, from which I sent a recruitment email to eligible medical providers working at the research site. See Appendix E Provider Recruitment Letter. Medical providers responded to the email and opted into the study. All of the medical providers working at the research site met inclusion criteria. None of the medical providers were removed from the study prior to completion.

Phase two

As an employee at the Baystate research site and PI, I had access to the patient’s electronic health information. During the recruitment phase of the study, one day each week was dedicated to screening and recruiting patients into the study. A master schedule of medical providers conducting patient care visits on
the research day was reviewed and each provider schedule was screened for eligible patients.

The screening and chart review was conducted one – two hour(s) prior to the beginning of the clinic day. While the patients’ medical records could have been screened prior to their scheduled office visit, given there was a reasonably high probability that the scheduled clinic visits would change on the recruitment day. Therefore, it was decided to actively screen the patient records on the recruitment day only. Screening the medical record included reviewing the following information prior to inviting patients into the study: age, ethnicity, diagnosis/problem list, language spoken, language read, home address and telephone number. Additionally, the patients chart was reviewed to ensure they had not had any clinical contact with the PI or RA.

Once eligible patients were identified, their first name, appointment time and the name of the medical provider they were seeing that day was compiled in a single electronic document (word document). This document was extremely helpful on the recruitment day as there are challenges coordinating times to recruit patients when some of the clinical appointments were scheduled at similar times. See Appendix G for an example of this recruitment document used. These documents were not stored and did not contain any clinical information. In retrospect, the total number of patients who met inclusion criteria versus the number of patients who agreed to participate in the study may have been useful data.
On the recruitment day and prior to or immediately after the patient’s clinical visit, patients were provided with a recruitment letter which explained the study and invited them to participate in the study. See Appendix E Patient Subject Recruitment Letter. Eligible patient subjects had the option to complete the informed consent process during their clinic visit or return for a research visit. The recruitment design did allow for patients opting to be contacted later to receive a phone call from the PI to explain the details of the study and schedule the baseline research visit (See Appendix F for Telephone Script 1). However, all patients who agreed to participate in the study opted to sign the research consent at the time they were recruited. All participants with an interest in participating were recruited into the study.

Additionally, medical providers and were allowed to recommend patients whom have T2DM and meet inclusion criteria. No patients were referred to the study via recommendations from medical providers. On the recruitment day, the medical provider with whom the patient subject was scheduled for an office visit, was consulted prior to recruiting the subject into the study. The reason for this curbside consultation was to inform the medical provider of the nature of the study; inform the provider that the patient met inclusion criteria for the study; and inquire as to whether or not the medical provider had any particular clinical or social information about the patient subject that may influence the decision to involve the patient or not. Throughout phase 2 of recruitment, only one medical provider mentioned that his patient was not appropriate for the study as this
patient had some recent psychiatric and cognitive changes, which he was investigating, but had not been documented in the patients’ record.

**Phase three**

Community members were recruited from a Senior Center in Holyoke MA. A recruitment station was set up near the entrance to the Senior Center, with a sign that read- “Ask me about my research”. Senior Center members who inquired about the research were provided a recruitment letter. Subjects opted into the study by informing the PI that they met the minimal criteria on the recruitment letter and wanted to participate in the study. For community member subjects who opted into the study, the informed consent process, collection of demographic data, collection of contact information, and interview was conducted immediately after they agreed to be involved in the study.

Screening challenges included Spanish speaking requirement; inclusion criteria for age; lack of language proficiency scale/gauge; and the inability to verify diagnosis in community setting. Recruitment challenges included several protocol amendments to adjust in the recruiting strategy. Finally, a transgender subject was recruited into the study. Given, one of the aims of the study was to investigate the influence of PRiH culture on T2DM self-care and specifically clarify gender specific cultural factors that influence T2DM self-care; including this subject posed several challenges. These screening, recruitment and gender related challenges are discussed in depth in Chapter 5.
Subject Participation

Informed Consent Processes

Medical providers completed a written informed consent and demographic questioners immediately prior to being interviewed. Informed consent for focus groups and interviews with community members was obtained using a written informed consent. See Appendix B for informed consent documents.

As the PI, I received informed consent training prior to my doctoral work as well as additionally during my doctoral training; and completed the informed consent process with all of the subjects included in the study. The informed consent process was conducted prior to any of the focus groups or interviews were conducted. To verify that subjects understood the study, the subjects were asked basic questions about the research and procedures prior to signing the consent. Subjects were given up to an hour to ask questions and decide if they would like to give consent. Though, it is notable that none of the subjects required more than 20 minutes to complete the informed consent process.

Research Visits and Questionnaires

As the PI, I conducted all of the recruitment, administered all questionnaires, conducted all focus groups and interviews, as well as presented the final conclusions of the study. The RA who conducted participant observation collected the questionnaires and provided the subjects with writing instruments. The RA also helped to distribute light snacks for subjects that were interested.
**Losses to Attrition**

Many patient subjects that met inclusion criteria and agreed to participate in the study did not show for scheduled research visits (focus group). Of the 21 patient subjects who consented to be in the study, 4 did not return phone calls, and 7 agreed to attend a scheduled research visit but did not come to the scheduled focus group meeting. The challenges associated with losses of attrition are discussed in greater detail in Chapter 5.

**Protection of Human Subjects**

The nature of qualitative inquiry is such that participants are usually not at physical risk due to their participation in the study. However, the participants' rights to self-determination, privacy, autonomy, confidentiality, fair treatment and protection from discomfort and harm must be assured prior to the study and maintained throughout the investigation (Klopper, 2008). The risks of participating in this study were relatively minor, but provisions were made to minimize any forseen risk of the intervention on study subjects. As the PI, I had extensive clinical experience working with the PRiH patient population as a primary care provider. Additionally, I worked directly with my dissertation committee, as well as advisors, mentors and Baystate IRB staff regarding executing the consent process and procedures for conducting the focus groups and or interviews.

The research questionnaires may have included some questions that could have been perceived as sensitive or personal. Subjects were free to skip
any question for any reason. This was explained in plain terms during the consent process.

A loss of confidentiality could have occurred if a hard copy or electronic data were shared with anyone what was not authorized study personnel. Loss of confidentiality was minimized by securing any identifiable data (hard copies) in a locked file drawer at the study locations. Only the PI had access to this file cabinet. At the conclusion of the study, all identifiable data was destroyed.

Patient subjects were recruited from the first research site where I worked as a nurse practitioner. It is possible that patients may have felt some coercion to participate in this study given I was in a position of power over them as a clinician. To minimize this possibility, only patient subjects with whom I had no clinical contact were screened and recruited into the study. Additionally, eligible patients who did want to take part in the study, were reminded prior to consent and prior to the research visit that they may opt out of participation at any time.

Importantly, to ensure the standards for protection of human subjects were met and being followed, the institutional review process was completed for the Baystate Medical Center Institutional Review Board (IRB) as well as the University of Massachusetts Amherst IRB. IRB approval was granted prior to the study being conducted at any of the research sites.

**Conclusion of Recruitment**

This study was designed as such, that recruitment would continue until 25 subjects (n=12 focus group members, n=5 community members, n=5 medical
providers, n=3 nonmembers) agreed to participate in the study; completion of planned focus groups and interviews; and or data saturation occurred. A target of n=40 total subjects was decided as a recruitment goal in anticipation for some loss to attrition, as it was expected that some patients may not complete the study. Additionally, this increased the likelihood that a minimal 25 patients would be available to participate. The samples of patients and medical providers were similar to other studies conducted using this qualitative methodology to investigate this population and problem.

Data collection for phase 1 concluded after five medical providers were interviewed. Data collection for Phase 2 was concluded after four focus groups were conducted. It is important to note that the initial study design included 6 focus groups with patient subjects (2 male groups, 2 female groups, 2 mix gender groups). However, after completing 4 focus groups (1 female group, 1 male group, 2 mix gender groups), it became apparent that no new themes were emerging and data saturation had likely been achieved. Considering this finding, the study design was amended to reflect recruiting 5 medical provider interviews; 4 focus groups with patients; and 5 individual interviews with community members. The addition of the 5 individual interviews from community members was considered an important strength of this study in term of triangulation of study findings within a fairly homogenous sample. Data collection for phase 3 concluded after 5 community members were interviewed and member checking was completed with 5 study members and 3 non-members.
Data saturation

The original study proposal included 6 focus groups (2 mix gender groups, 2 all female groups, 2 all male groups). However, after conducting 4 focus groups, several strong themes emerged, and no new themes or discoveries at the conclusion of the 4 the group. The decision was made to use conduct an additional five individual interviews with n=5 community members. The preliminary themes discovered in the focus groups were used to guide these interview questions, and expound upon newly discovered themes. The methodology, protocol and challenges related to data saturation are expounded upon in Chapter 5.

Data Collection Method

Data collection techniques for this study included questionnaires, focused groups, semi-structured interviews and participant observation. A constant comparison analysis method was used throughout the data collection phases. As new themes emerged, focus groups and interview questions were slightly refocused, amended and or revised.

Medical Provider Interviews

No patient specific or clinical data or health information was collected from medical providers. See Appendix C for an example of semi-structured interview questions. Procedural step for individual provider interview data collection at the
Baystate research site involved 1) medical providers attending a 1-hour interview with the PI conveniently held at the providers’ office.

**Focus Groups**

Focus group data collection from patients at the Baystate site involved 1) selected individuals attending a 1 hour (or less) focus group; 2) the focus groups were held at a Baystate Medical Center outpatient conference room and were captured using an audio recording device; 3) participant observation notes were recorded by the RA during focus groups.

**Community Member Interviews**

Procedural steps for data collection from community members Holyoke Senior Center Senior Center research site were as follows: 1) subjects attended a 20-minute interview at a senior center in a private office; 2) data was captured using an audio recording device.

**Participant Observation**

Participant observation is used as a way to increase the validity of the study, as observations may help the researcher have a better understanding of the context and phenomenon under study (Kawulich, 2005). In this method, the researcher is able to record nonverbal expression of feelings, determine who interacts with whom, grasp how participants communicate with each other, and check for how much time is spent on various activities (topics) (Kawulich, 2005).
An independent RA conducted the participant observation for each focus group. See Appendix H for Participant Observation Training guide. Generally, participant observation included but was not limited to the following:

- Recording actions of individuals, activities, interactions, as well as overall group dynamics.
- Recording key words in conversations to trigger later recollection of the conversation content.
- Observe pertinent remarks and scenes.
- Recording interactions occurring in the setting, including who talks to whom, whose opinions are respected, where participants stand or sit, particularly men versus women (for the mixed gender group).

Specifically, the RA was charged with observing the group and recording: physical appearance of members; verbal behavior and interactions; physical behavior and gestures; personal space; human trafficking; and people who stand out.

Finally, all audio recordings (from focus groups and interviews) were hand delivered to The University of Massachusetts Amherst Translation Center for processing. See Appendix A for Agreement between Baystate IRB and UMass Amherst Translation Center. All of the transcriptions were secured, coded and organized using NVivo software version 11. The raw data was coded and analyzed throughout the data collection and analysis phases of the study. Following each interview or focus group, a time was dedicated to recording
footnotes or Journaling. Findings from the study were shared with the community (non-member checking), prior to any publication or finalization process.

**General Data Collection Procedure**

**Phase One: Medical Provider Interviews**

There were three contacts between the researcher and medical providers.

- The initial contact occurred during recruitment via email (see Appendix E for Medical Provider Recruitment email).
- The second contact was to conduct the informed consent process, collect demographic data (See Appendix D for Medical Provider Demographics) and conduct the research visit (see Medical Provider Research Consent form and Appendix B)
- The third contact was a presentation of the research findings (see Appendix C).

**Phase Two: Patient Subject Focus Groups**

There were four major points of data collection between researchers and subjects recruited to focus groups. Additionally, to reduce losses to attrition, patient subjects were contacted periodically from the time they complete the informed consent until they attended the focus group/interview. See Appendix F Telephone Script 2. No significant data was collected during these phone calls as they were primarily used to check in with the patients and keep them abreast of their scheduled focus group.
The four contacts between the researcher and subjects who participated in focus groups included:

- The initial contact with patients occurred during the patients scheduled clinic visit. The informed consent process was conducted at this time.
- The second contact included recruitment via telephone (See Appendix F Telephone Script 1) to confirm participation, give additional information and schedule the focus group.
- The third contact included collect socio-demographic (See Appendix D for a list of patient subject demographics; and conducting the research visit (focus group) (see Appendix C)
- The fourth contact included a presentation of the research findings (See Appendix C final presentation guide).

Phase Three: Community Member Subject Interviews

There were two contacts between the researcher and subjects who were interviewed in the community.

- The initial contact with subjects occurred while subjects were visiting the Senior Center. The informed consent process (See Appendix C), demographic data (See Appendix C), and interview (See Appendix C) were conducted at this time.
- The second contact was a presentation of the research findings (See Appendix F final presentation guide).
Detailed Data Collection Procedure

**Phase One: Medical provider Interviews**

Specific data collected from medical providers included:

- First Contact: Recruitment Email response recorded.
- Second Contact: Informed consent collected.
- Interview conducted and recorded.
- Collection of practice/clinical data: specialty, number of years practicing, percentage of patients with T2DM, and percentage of PRiH patients served at their practice. (See Appendix D for provider demographic forms).
- Third Contact: Presentation of study findings/intervention. Survey (See Appendix C) data collected.

**Phase Two: Focus Groups**

Specific data collected from patients during focus groups:

- Initial Contact: Recruitment letter given to patients during their scheduled clinic visit. Informed consent was conducted and collected at this time.
- Second Contact: Recruitment Telephone call to confirm participation and schedule baseline research visit and informed consent if needed. Documentation of willingness to participate or not.
- Third Contact: Research visit to conduct and record focus group.
- Complete informed consent process (if needed)
- Collect demographic data:
• Collection of personal data: Name, personal contact information (phone number, address)

• Collection of Behavioral Data: self-reported medication adherence, self-reported blood glucose readings and blood pressure readings (if available).

• Collection of Socio-demographic data: gender, age, race/ethnicity, primary language, secondary language, marital status, employment, education level, family structure and dynamics.

• Check ins: Patients were contacted periodically from the date of completing the informed consent until they participate in a focus group. Aside from willingness to participate in the study, no significant data was collected during these phone calls. See Appendix F Telephone Script 2.

• Fourth Contact: Presentation of research. Optional for all subjects. Survey (See Appendix C) data collected.

Phase Three: Community Member Interviews

Specific data collected from community member interviews:

• Initial Contact: Recruitment letter given to subjects during their visit to the Senior Center. Subjects who opted into the study were recorded.

• Informed consent conducted and collected.

• Interview conducted and recorded.

• Collect demographic data:

• Collection of personal data: Name, personal contact information (phone number, address)
• Collection of Behavioral Data: self-reported medication adherence, self-reported blood glucose readings and blood pressure readings (if available).

• Collection of Socio-demographic data: gender, age, race/ethnicity, primary language, secondary language, marital status, employment, education level, family structure and dynamics.

• Second Contact: Presentation of research. Optional for all subjects.

Member Checking Presentation

All subjects who participated in the study were contacted via a letter informing them of the conclusion of the study and inviting them to attend a presentation of the study results. Additionally, community members were invited to attend the presentation. Community members were invited to each research site via a general announcement email and flyer. After the findings of the study were presented, patients/subjects and medical providers were given an opportunity to provide feedback, critique the study, and confirm or reject the study findings as true.

Other data

Feasibility data was collected throughout the study period and included; proportion of eligible patients who consented vs. those were able to attended focus groups; documentation of problems prior to and during data collection; and the proportion of enrolled patients who completed the study.
Descriptions of Instruments

This section includes abbreviated descriptions of instruments and research questionnaires used in this study. The sub questions for each line of questions are not included here. Refer to Appendix C for full description of interview/moderator guides and questionnaires; Appendix D for behavioral and demographic data sheets; and appendix G for enrollment logs.

Medical Provider Interview Guide

This document was used to guide the four focus groups and was not amended during the study. The content and questions in this interview were not validated. The content for the medical provider interviews included a prepared welcome statement and time allotted for introductions. The medical provider interviews were scheduled for approximately 60 minutes and the following 9 questions were explored:
1. What do you think is the family’s role is in managing chronic illness?
2. Who do you consider to be a member of the Puerto Rican family?
3. Do you include the PR family in the management of a patient’s diabetes?
4. What is your general experience of managing Puerto Rican patients with diabetes?
5. Do you notice any differences when managing Puerto Rican men vs. women with diabetes?
6. What impact you think the PR family has on diabetes self-management?
7. What role does the Puerto Rican family play in your patients’ diabetes self-care maintenance?

8. What role does the Puerto Rican family play in your patients’ diabetes self-care management?

9. What role does the Puerto Rican family play in your patients’ diabetes self-care monitoring?

10. What can healthcare providers do to help families assist their family with diabetes self-care?

11. What can Puerto Rican families do to help patients with diabetes?

12. Is there anything else you’d like to contribute?

**Focus Group Moderator Guide**

This document was used to guide the four focus groups and was not amended during the study. The content and questions in this interview were not validated. The content for the focus groups included a prepared welcome statement and time allotted for introductions. The focus groups were scheduled for 60-90 minutes and the following nine questions were explored:

1. Who do you consider to be a part of your family?

2. What is your role in your family?

3. How does being Puerto Rican affect your diabetes management?

4. How does diabetes affect your role as a man/woman in your family?

5. What role does your family play in your diabetes maintenance?

6. What role does your family play in your diabetes management?
7. What role does your family play in your diabetes monitoring?
8. Should your doctor discuss your diabetes with your family?
9. What can your doctor do to help your family help you with diabetes?

**Community Member Interview Guide**

This document was used to guide the individual interviews with community members and was amended/adapted during the study. The content and questions in this interview were not validated. The content for the individual interviews with community members a prepared welcome statement and time allotted for introductions. The individual interviews with community members were scheduled for 20 minutes and the following 6 questions were explored:
1. Health care provider and family involvement in diabetes care?
2. Family involvement in your diabetes care?
3. Male vs. Female family member involvement in diabetes management?
4. Traditional Foods?
5. Medical providers involving family in diabetes care?
6. Overall, is there anything else we should have asked you?

**Presentation of Research Findings**

This document was used to guide the presentation of research findings to the subjects/community. The content for the presentation included a prepared welcome statement and time allotted for introductions. The presentation was
scheduled for approximately 55 minutes and the following topics were presented and explored with attendees:

- Study Background and Significance (U.S. Hispanic community; the Hispanic diabetes disparity; Puerto Rican identified Hispanics and T2DM)
- Study Description (Design and Methodology)
- Findings from the research
- Conclusions from the research
- Discussion
- Questionnaire

**Presentation Questionnaire**

This document was used to verify the research findings with the subjects and community members who participated in the study. These questions were not validated. The following questions were included in this questionnaire:

1. What is your current role in diabetes self-management?
2. What are your overall impressions of the research findings?
3. What part of the research findings did you MOST identify with?
4. What part of the research findings did you most disagree with?
5. In your opinion is there anything you remember from your meeting with the researcher that is missing from the research findings?
6. Is there anything we should add to the research findings?
7. Is there anything we should remove from the research findings?
Medical Provider Demographics Sheet

This questionnaire was used to collect clinical/practice data from medical providers recruited into the study and was not amended during the study. This questionnaire was not validated. The content for the demographics form included the following 8 questions:

1. What is your clinical role?
2. What is your clinical specialty?
3. How many years have you been practicing in your clinical role?
4. Approximately how many of your patients have diagnosed type 2 diabetes?
5. What percentage of your patients are Hispanic/Latino?
6. How many of your Hispanic/Latino patients identify as Puerto Rican?
7. What is your primary language?
8. Do you speak a second language?

Behavioral Data Sheet

Patient subjects and community member subjects completed this form. These questions were not validated.

1. How many days of the week do perform cardiovascular exercise (walking, biking etc.) for more than 30 minutes each day?
2. How many days of the week do you only eat the foods that are recommended by your doctor/nurse/dietician?
3. How many days of the week do you take ALL of your diabetes medications?
4. How often do you take your other medications (not prescribed for diabetes)?
5. How well controlled is your diabetes?

6. Who do you consider to be your family support? (check all that apply)

7. Who helps you most with managing your diabetes?

Sociodemographic Data Sheet

This form was used for all subjects excluding medical providers.

Part 1. Contact information:

- Name
- Address
- Telephone number

Part 2. These questions were not validated. This section included 17 questions with subcategories as follows:

1. When were you diagnosed with type 2 diabetes?

2. What is your race?

3. What is your ethnicity?

4. What ethnic group do you identify with?

5. What is your current marital status?

6. What is your current work status?

7. What is the highest level of education you have completed?

8. What is the primary language you speak at home?

9. Do you speak a second language?

10. How long have you had diabetes?
Enrollment Log

This tool was used to log subjects who consented to be in the study. No identifiable data was collected. Subjects were assigned a code at the time of consent. Information collected on this form included:

- Assigned code
- Eligibility criteria met
- Date consent obtained
- Version of consent
- Gender
- Ethnicity
- Withdrawal/termination
- Lost to follow up
- Completed research visit

NVivo Software

NVivo Version 11 software was used to organize the data and explore for distinct categories, concepts and themes within the transcript of each interview and focus group as well as between groups.

Research Journal

Journaling was used throughout all phases of the research process. These entries were logged into NVivo and organized by date and time. Journal entries followed interviews, focus groups, or significant change in the study
protocol. Additionally, journal entries were made if and when a notable idea, thought or observation prompted me to do so.

Data Management

Confidentiality and Storage

Only approved study personnel (PI) had access to the data collected. In general, subject data was not linked to their name in any data analysis, or reports, nor were their identifiable data be included in any future publications generated from this study. Any identifiable data collected from this study (contact information) was stored in a file drawer at the study sites and destroyed at the conclusion of the study (shredded). Other identifiable data included consent forms. Consent forms collected from subjects who were interviewed or completed a focus group during phase 1 and 2 of the study are stored at Baystate Medical Center IRB; and consent forms for subjects who completed interviews during phase 3 of data collection are stored at the University of Massachusetts Amherst IRB.

Other de-identified data was stored on a protected hard drive and included transcripts, audio recordings, field notes, and participant demographics. Audio recording devices and any hard-copy study data (e.g., self-administered paper questionnaires) were stored in a locked file drawer at the study sites. Data entry and management was conducted in a private office at the research sites and a private teaching assistant office at the University of Massachusetts Amherst College of Nursing.
Collection of Data

Contact information (home address, phone numbers) were obtained by self-report questionnaires immediately prior to conducting the research visit. There were three points of data collection between researchers and medical provider subjects; four points of data collection between researchers and patient subjects; and two points of data collection between researcher and community member subjects.

Data collected from medical providers included the following:

- First Contact – collected response to recruitment email.
- Second Contact – consent process, collect practice data, and recorded individual interview.
- Consent: written informed consent
- Practice data: specialty, number of years practicing, percentage of patients with T2DM, and percentage of PRiH patients served at their practice. (See Appendix D. for provider demographic forms)
- Research visit: recorded individual interview
- Third Contact – presentation of study findings: collection of questionnaires.
- Questionnaires: member and non-member checking.

Data collected from patient subjects included the following:

- Initial Contact – collected signed informed consent.
- Second Contact – conduct research visit, collect feasibility, behavior and socio-demographic data.
• Research visit: recorded focus group.

• Feasibility Data: Proportion of eligible patients who consented; documentation of problems during prior to and during data collection; and proportion of enrolled patients who completed the study.

• Behavioral Data: self-reported medication adherence, self-reported blood glucose readings and blood pressure control.

• Socio-demographic data: name, gender, age, race/ethnicity, primary language, secondary language, marital status, employment, and education level, family structure and dynamics.

• Third Contact – presentation of study findings: collection of questionnaires.

• Questionnaires: member and non-member checking.

Data collected from community member subjects included the following:

• Initial Contact – informed consent process, conduct research visit, collect feasibility, behavior and socio-demographic data.

• Consent: written informed consent.

• Feasibility Data: Proportion of eligible patients who consented; documentation of problems during prior to and during data collection; and proportion of enrolled patients who completed the study.

• Behavioral Data: self-reported medication adherence, self-reported blood glucose readings and blood pressure control.
• Socio-demographic data: name, gender, age, race/ethnicity, primary language, secondary language, marital status, employment, and education level, family structure and dynamics.

• Research visit: recorded individual interview.

• Second Contact – presentation of study findings: collection of questionnaires.

• Questionnaires: member and non-member checking.

Data Analysis

Data Analysis Overview

Data analysis was used to answer the first and second research questions: 1) In what ways does Familism inhibit or facilitate diabetes self-care for PRiH adults with T2DM, and 2) How can clinicians use Familism to facilitate improved diabetes self-care in Puerto Rican identified Hispanics? The transcripts of individual interviews and focus groups were deconstructed and reorganized for themes specific to each group. These themes were then compared between groups for similarities and contrast. Participant observation notes were reviewed for themes, contrasted and compared to themes generated from focus groups and interviews. Demographic and behavioral data was analyzed using simple percentages and primarily gave context to the sample of subjects.

Data analyses for this study was primarily thematic in nature as no significance testing occurred. Transcribed audio recordings of the focus groups, semi-structured interviews and participant observation notes were the primary data analyzed. A constant comparison analysis method was used. This method
was helpful in guiding the study as themes emerged and the study design was amended to strengthen the methodology as well as further explore new discovery.

The data collected during phase 1 (medical provider interviews) of data collection was analyzed prior to conducting the focus groups. Preliminary analysis of the medical provider interviews provided themes. However, though informative, these themes did not influence the focus group questions per se. The themes uncovered in the analysis of the medical provider interviews corresponded with the original focus group questions.

The data collected during phase 2 of data collection (focus groups) was analyzed after each group was conducted, recorded and were transcripts reviewed. Preliminary analysis of the four focus groups suggested some themes. The data derived from phase 1 and 2 of data collection suggested that there was a strong relationship between family/community support and traditional gender roles. However, no new themes were discovered after conducting four focus groups (1 all male group, 1 all female group, 2 mix gender groups). Having reached apparent data saturation using focus groups, the study design was amended to include 5 individual interviews with community members. The preliminary themes from the focus groups were used to guide the interview questions used to conduct the individual subject interviews. The data collected in phase 3 of data collection was analyzed and compared to findings from medical provider interviews and focus groups.
A research assistant was trained on specific observations of interest and conducted participant observation during focus groups only. A guide was provided for the RA to use while conducting participant observation (Appendix H). Participant observation included taking hand written notes during and after the focus group meetings. These notes were later transcribed into a table to correspond with the training/instructions provided (Appendix H). The RA did not conduct any data analysis or derive any particular themes from the observations.

After the focus groups were analyzed, the participant observation charts were reviewed, deconstructed, reorganized and analyzed for themes. Participant observation notes were analyzed for aggregate group themes as well as in context with each focus group transcription. This data was analyzed post hoc in an attempt to prevent guiding or steering the conclusions derived from focus group analysis.

In essence, the data was analyzed in this order in attempt to let the data from focus groups speak for its self rather and approach the focus group analysis with preconceived conclusions/results/outcomes in mind. Ultimately, the themes derived from participant observation were compared with themes deducted from medical provider interviews, community member interviews and focus group data analysis. Participant observation notes were also compared to field notes/journaling.

**Data Analysis Procedure**

NVivo Version 11 software was used to organize the data and explore for distinct categories, concepts and themes within the transcript of each interview.
and focus group as well as between groups. NVivo software was also used to store footnotes/journaling. Analysis of participant observation notes did not require software.

**Medical Provider Interview Analysis**

Each transcript was coded (i.e. M01 = medical provider number 1; M02 = medical provider number 2). The questions and sub-questions from the semi-structured interview guide were numbered. For example, if question number one had three sub-questions, they would be listed 1, 2, 3, 4; with the 3rd sub question as number four. Question number two would continue and be renumbered as number five, and any sub questions would follow this order. Nodes, or categories were created for each interview question. For example, 4.M = Medical provider question number 4.

Transcripts included both the interview questions and the medical provider responses. Each transcript was loaded into the NVivo ‘internals’ section. As each transcript was reviewed, the response to each question was added to corresponding each node. Each medical provider interview was deconstructed by copying the answer to each question into the corresponding node. Once the responses to the interview questions were compiled in a node, the node was analyzed for themes.

A theme was considered present if more than one medical provider responded to a question with a similar answer. These themes were compiled and compared to themes from focus groups, individual interviews, and what is known
in the literature. Specific examples of these themes or quotes were also compiled in the Raw Data Analysis Documents and included in the findings for each question.

**Focus Group Analysis**

Data analysis for focus groups similar to data analysis of medical provider interviews. Each transcript was coded (i.e. MixFG = mix gender group 1). The questions and sub-questions from the semi-structured interview guide were numbered. Rather than start anew, these numbers were continued from where the medical provider interviews ended. The rationale for this was to help organize the nodes by group and ease the burden of navigating through the NVivo software. For example, if question number twenty had three sub-questions, they would be listed 20, 21, 22, 23, 24; with the 3rd sub question as number twenty-four. On this list, question number twenty-two would continue and be renumbered as number twenty-five, and any sub questions would follow this order. Nodes, or categories were created for each focus group question. For example, 20. MixFG = Mixed Gender focus group question number 20.

Transcripts included both the interview questions and the focus group responses. Each transcript was loaded into the NVivo ‘internals’ section. As each transcript was reviewed, the response to each question was added to each corresponding node. Each focus group was deconstructed by copying the answers to each question into the corresponding node. Once the responses to
the focus group questions were compiled in a node, the node was analyzed for themes.

A theme was considered present if more than one patient subject responded to a question with a similar answer. These themes were compiled and compared to themes medical provider interviews, individual interviews, and what is known in the literature. Specific examples of these themes or quotes were also compiled in the Raw Data Analysis Documents and included in the findings for each question.

Additionally, the themes from the two mix gender focus groups were compared to each other. Similarly, focus group responses from the male and female group were compared to each other. Finally, themes from the mix gender focus groups were compared to the male and female gender groups.

**Community Member Interview Analysis**

Data analysis was similar to focus groups and medical provider interviews. Each transcript was coded (i.e. CM. F01 = Female Interview 1). The questions and sub-questions from the semi-structured interview guide were numbered. Similar to focus group analysis, rather than start anew, these numbers were continued from where the medical provider interviews ended. The rationale for this was to help organize the nodes by group and ease the burden of navigating through the NVivo software. For example, if question number one hundred twenty had three sub-questions, they would be listed 120, 121, 122, 123; with the 3rd sub question as number one hundred twenty-three. On this list, question
number one hundred twenty-four would continue and any sub questions would follow this order. Nodes, or categories were created for community member interview question. For example, 150.CM = community member question number 150.

Each transcript was loaded into the NVivo ‘internals’. Transcripts included both the interview questions and the community member responses. Each interview was deconstructed by copying the answer to each question into the corresponding node. Once all of the interview responses to a question were loaded into the node, the responses were analyzed for themes. A theme was considered present if more than one subject responded to a question with a similar answer. The themes for each question were compiled in a results document. Specific examples of these themes or quotes were also recorded and included in the findings for each question.

Transcripts included both the interview questions and the focus group responses. Each transcript was loaded into the NVivo ‘internals’ section. As each transcript was reviewed, the response to each question was added to each corresponding node. Each community member interview was deconstructed by copying the answers to each question into the corresponding node. Once the responses to the community member interview questions were compiled in a node, the node was analyzed for themes.

A theme was considered present if more than one community member responded to a question with a similar answer. These themes were compiled and compared to themes medical provider interviews, focus groups, and what is
known in the literature. Specific examples of these themes or quotes were also compiled in the Raw Data Analysis Documents and included in the findings for each question.

Data analysis involved comparing themes from male and female community member interviews to each other. Themes from the focus groups and medical provider interviews were compared to themes derived from community member interviews. Similarly, themes from the male and female focus groups were compared to responses to the male and female community member interviews.

**Participant Observation Analysis**

Data collected by the RA, notes, were compiled in a chart, and arranged by category. Analysis of these categories involved deconstructing the raw data from the categories in the table; forming group descriptions (all categories describing the observations of the group), and reorganizing them to compare the findings in each category (i.e. comparing physical appearances of group 1 subjects to group 2 subjects).

**Questionnaires and Feasibility Data Analysis**

Clinical, Socio-demographic and behavioral data collected from patient subjects and community member subjects, was analyzed by computing means for questions from questionnaires; comparing these means within and between groups (focus groups and community members); between genders; as well as to
these what is reported in the literature if applicable/available. Feasibility data analysis involved a report of the proportion of eligible patients who consented versus those who completed the study; study costs and expenditures; as well as a summarization of problems within the study methodology and execution.

Demographic data collected from medical providers was analyzed by computing the means for each of the questions. This information did not undergo a rigorous analysis, as it served to complement and add richness to the study findings. Finally, the follow up presentation was analyzed by computing means and averages for the individual questions, compiling and summarizing the subject responses and non-subject responses, and including this data in the results of the study.

**Trustworthiness**

Validity constructs used to evaluate the strength of quantitative research are not suitable to evaluate qualitative methods of inquiry, as the variables are not always known. In keeping with the aims, to explore the relationship between Familism and T2DM self-care, and the methodology of this qualitative study, Guba and Lincoln’s (1985) validity constructs were used to confirm the trueness of the study findings. These constructs include: credibility, transferability, dependability, and conformability.

**Credibility**

Credibility refers to internal validity and ensures that the results of the research are congruent with the perspective of the participant in the research. To
ensure credibility, a presentation of the research findings and intervention was presented to the study participants before any final conclusions were made and findings were disseminated. Member checking and non-member checking was used to confirm the study findings. Hutchison (1990) suggests, the best way of demonstrating validity is “member checking” or asking the person(s) who are participating to check the report. All subjects (medical providers, patient subjects, community member subjects) were invited to review the study results. Member checking was facilitated by allowing subjects who attended the opportunity to offer feedback and critique of the study and the study findings (see Appendix C). Additionally, non-member checking was facilitated in that the results of the study were presented publicly and those who attended were also allowed to weigh in on the study findings. (see Appendix C). Recommendations or amendments regarding the study results/findings were included in the final study results.

**Transferability**

Transferability refers to external validity, ensures that the results of the study may be transferred or generalized to other context or settings. To ensure transferability, study findings were compared to the known body of literature for congruency. Additionally, sample demographics, all methodology including procedures for recruitment, data collection, and data analysis were documented throughout the study. This information will be published for public record and with the intention of replicating this study with similar or different populations.
**Dependability**

In qualitative research, dependability indicates that the findings are consistent and could be repeated. Dependability is equated to reliability in quantitative research and is strengthened by accounting for changes or unpredicted occurrences in the research process. To ensure dependability all study methodology including procedures for recruitment, data collection, and data analysis were documented throughout the study. Additionally, journaling was used throughout the research process and was used to document unpredicted occurrences. This data is summarized and included within the study findings.

**Confirmability**

Confirmability relates to objectivity of the researcher and ensures the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest. To ensure confirmability, independent researchers (dissertation committee) have reviewed the study methodology, data collection procedures, data analysis procedures, and study findings to ensure there was no researcher bias or distortion throughout the study. Additionally, the institutional review board staff at Baystate Medical Center, served as an independent auditor during phase 1 and 2 of the study. These audits were primarily conducted to ensure the study was being conducted ethically and as planned. However, the researchers conducting the audits also gave written review and methodology critique, prior to the study being approved and throughout the study.
**Triangulation**

Triangulation is a key component in qualitative inquiry and has been defined as the collection of data from multiple sources for analysis in the same study with each source focused upon the phenomenon of interest (Cowman, 1993). Additionally, triangulation increases validity and decreases researcher bias (Cohen & Mamon, 1980). The use of multiple data collection methods and multiple sources provides a more ‘convincing and accurate’ case study (Yin, 1994). For this study, multiple data collection techniques were used: focus groups with patient subjects; semi structured interviews (medical providers and community members); participant observation; and field notes. The multiple sources of data strengthened this study methodology and subsequently increased the trustworthiness of the findings.

**Hermeneutic Cycle**

My prior experience with the study population was certainly a consideration for unwanted investigator bias. The hermeneutic cycle was used to increase validity. The hermeneutic cycle necessitates that the researcher identifies personal fore-understandings, beliefs and assumptions, prior to commencement of the study and then throughout the research process (Dale, 1995). This evaluative process allows the researcher to demonstrate distance and objectivity, and increase the validity of study findings. Prior to conducting this study, my fore-understandings were as follows:
1) I am a novice researcher and will rely on external mentorship throughout the course of the study.

2) I have a sufficient knowledge base and clinical experience with the PRiH population.

3) I serve as a primary care provider for a large Hispanic, primarily PRiH, urban, adult population. This may contribute to preconceived ideas about causes of the diabetes disparity in this community.

4) Significant portions of my clinical encounters are dedicated to managing, teaching, and facilitating self-care of type 2 diabetes.

5) Significant portions of my clinical encounters are dedicated to implementing and or providing primary and secondary prevention of diabetes and its biophysical, social and psychological effects.

6) I also have exposure to some Puerto Rican culture in that I have traveled to Puerto Rico and have some preconceptions regarding cultural food choices in this population. My preconceptions include:

   • Traditional Puerto Rican foods are often carbohydrate intensive and commonly include rice and beans as a dietary staple.

   • Traditional Puerto Rican diets often include foods have high fat and sodium.

   • Traditional Puerto Rican meals do not usually include a large portion of vegetables and primarily consist of starch and meat.

My fore-understandings and clinical expertise did not provide more than anecdotal knowledge about the phenomena of interest. Subjectivity can be a
problem in qualitative research data analysis in that the researcher must navigate through fore understandings; preexisting knowledge of research on the subject matter; and data in the form of ‘answers to questions’, to which some preconceptions may have already been generated. Throughout the research process, these fore understandings were referenced and considered. Often, the question I asked myself was “am I hearing, seeing or writing what I expect to find in the data, or is this truly what the data is showing”. Using multiple data sources to corroborate themes, provided reassurance that the themes and data were true, and not generated from my own experiences, knowledge or ideas.

Timeline and Challenges

Timeline

The timeline from study proposal to completion of data collection was approximately 18 months. The proposal for this study was approved by my dissertation committee 11/2015. The study was approved by Baystate Medical Center IRB 6/28/2016. Phase 1 and 2 of data collection concluded 1/2017. The full study proposal was then submitted to the University of Massachusetts Amherst IRB and approved on 3/7/2017. Phase 3 of data collection began 4/2017 and concluded 6/1/2017. Of note, there was an approximately 3-month delay in data collection due to changing site locations during data collection.
Brief Summary of Methodological Challenges

Amending the study design to include community member interviews (in addition to focus groups with patients and interviews with medical providers) strengthened the study by adding a data set from a different vantage point; allowed true triangulation of the data on the phenomena of interest; and minimized losses to attrition by not requiring subjects to return to the research site to conduct the research meeting. Additionally, the method of screening, recruiting and consenting patient subjects had a relatively high yield of patients agreeing to participate in the study. Despite this relatively smooth recruitment strategy, the rate of return was relatively low. Even when compensating for this known recruitment barrier by scheduling large focus groups (5-7 subjects), the ‘no show’ rate of 33% and 50% overall losses to attrition were remarkably high. This is population is historically difficult to recruit and this should be considered when conducting similar studies in the future.

The population of patients at the first research site had relatively high rates of T2DM. However, most patient subjects were screened out as their age was > 70 years old. Expanding the inclusion criteria or replicating this study with focus on geriatric population may be provide additional insights on this problem and population.

Conducting this study in English proved to be challenging given the population is generally bilingual. Many patient subjects and community member subjects were screened out as they only spoke Spanish. Importantly, English proficiency was not formally tested and some subjects with low English
proficiency may have provided higher quality data in their primary language. It is unclear if this English proficiency affected the outcomes of the study. However, replication of this study in Spanish would help answer that question.

There were several protocol, design and methodological changes throughout this study. These changes did not dramatically changed the outcomes or results of this study. However, researchers conducting similar studies with similar populations should keep in mind that if the study protocol, design or methodology is changed, it is important to consider all of the downstream effects on the implementation of the study, and application to the protocol.

Challenges arise when procuring and securing data for a research study. Some study design changes proved to be very helpful. The constant comparison data analysis method ensured that the data captured throughout the study was stored and analyzed in a relatively timely fashion. Importantly, when the study was closed at the first study site, this data was secure. Surely, losing 2/3 of data near the completion of a study would have been a devastating loss.

The study design did not allow for inquiry about, or provide space for subjects to discuss, note or share their physical and or emotional disability. Nor was there any accommodation for exploration of nontraditional gender expressions; nontraditional gender roles; LGBT experiences as they relate to the problem being explored in the study. Future studies using similar methodology, investigating similar problem or with similar populations, should consider if and how disabilities, nontraditional and LGBTQ experiences should be included in the study design.
Operationalizing Riegel et al.’s (2012) theory was not without challenge. While theoretically distinct, self-care maintenance, management, and monitoring are clinically similar for lay people, researchers and clinicians. Assigning a line of questions that clearly delineates the concepts of self-care maintenance, management and monitoring would be prudent when replicating this study or conducting studies with using this methodology.

Some research questions were very similar. This similarity affected the delivery of some of the research questions. The occasionally clustering a line of questions or a slight adlib of 3-4 research questions did not have any significant effect on the outcomes or themes generated in this study. For researchers conducting qualitative studies and using interview guides, it would be prudent to consistently ask the research questions in the same way every time. Importantly, validating questionnaires prior to conducting a qualitative study may prevent some of this confusion. All of these challenges are discussed in depth in Chapter 5.

**Introduction to Report on Research Findings**

Despite the challenges of executing this study, findings from this study help to illuminate social and cultural forces influencing the poor diabetes outcomes in the PRiH community. Findings from this study suggest that female PRiH family members play an important role in the PRiH community; are an essential factor for T2DM self-care in the PRiH community; and may be generally unsupported in their own T2DM self-care efforts. Importantly, this study suggests that PRiHs men may be generally better supported by a potential array of female
family members. Additionally, findings from this study suggest that T2DM self-care management has an effect on PRiH families.

Results from qualitative studies are descriptive rather than predictive in nature. Therefore, the findings generated from this study should be interpreted in context. Furthermore, the findings warrant additional investigated; and should be replicated prior if used as the basis for an intervention in the PRiH population.
CHAPTER IV
STUDY RESULTS

Methodological Overview

Background

The primary aim of this study was to illuminate and delineate a specific socio-cultural phenomenon – the effect of Familism on diabetes self-care for Puerto Rican adults with T2DM. A secondary aim was to examine how health care professionals may best include the PRiH family in care planning. These aims were used as the first and second research questions respectively, and were based on three assumptions. The first, second and third study assumptions were that Familism has an effect on T2DM self-care for PRiH adults; PRiH men and women in traditional roles experience the effects of Familism differently; and HCPs do not generally consider Familism as a factor in T2DM self-care.

The first research question was, “What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?”. This question, along with six sub questions were based off the first and second study assumptions: Familism has an effect on T2DM self-care for PRiH adults; and PRiH men and women in traditional roles experience the effects of Familism differently. The six sub-questions, were used to guide semi-structured interviews and focus groups were as follows:

A. What are the positive effects of Familism on diabetes self care for PRiH adults?
B. What are the negative effects of *Familism* on diabetes self-care for PRiH adults?

C. In what ways does *Familism* facilitate diabetes self-care for PRiH adults?

D. In what ways does *Familism* inhibit diabetes self-care for PRiH adults?

E. How are PRiH women with T2DM in traditional family roles affected by *Familism*?

F. How are PRiH men with T2DM in traditional family roles affected by *Familism*?

The second research question was, “How can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?”. This question along with two sub questions, as based off of the third study assumption; that HCPs do not generally consider *Familism* as a factor in T2DM self-care. The two sub-questions used to guide semi-structured interviews and focus groups were as follows:

A. How can health care providers facilitate the positive effects of *Familism* on T2DM self-care?

B. How do health care providers prevent the negative effects of *Familism* on T2DM self-care?

**Data Included**

The data in this chapter was analyzed categorically as they apply to answering research question(s) one, or research questions(s) two. The data is also organized and presented according to themes discovered in focus groups or interviews. The study assumptions are discussed and original research questions
are answered in the Conclusions section. A comparison of the study findings to previous and current research; clinical and research significance; study limitations; and recommendations are presented in Chapter 5.

The data analyzed in this chapter includes focus groups, healthcare provider (HCP) interviews, community member interviews, member checking and participant observation notes. Thematic answers to the research questions and sub questions for each cohort (focus groups, HCP interviews, community members) were compiled and compared according to relevance to each other.

**Presentation of data**

Recruitment, and general observations are described first. Data that specifically answered research question one and sub questions A-F are presented next. This data includes qualitative data and quantitative data. Data that specifically answered research question 2 and sub questions G-H are presented next. This data also includes qualitative and quantitative data. These sections are followed by a summary of key findings. Finally, a full and detailed presentation of the findings as they relate to each of the research the questions is provided in the Conclusions section.

**Results**

**Recruitment and sample**

Twelve HCPs were recruited for this study via email. Five HCPs responded to this email, consented to be in the study and were interviewed. Thirty patient subjects were recruited, 21 consented to be included in the study,
and 12 completed a focus group. Fifteen community members were recruited, five consented to be in the study, and 5 completed an interview. Five non-members were recruited to be in the study, 3 consented to be in the study and attended a presentation of the study results. In total, 62 individuals were recruited for this study; 34 consented and agreed to participate; and 25 participated in a research visit. See Diagram 2 in Appendix L for an illustration of subjects recruited and included in this study. An in-depth discussion of recruitment challenges and losses to attrition is included in chapter 5.

**General observations**

Healthcare providers were interviewed in a private office within their outpatient primary care practice. To ensure that they had ample time to conduct the interview, HCPs generally scheduled their interviews during their administrative time or on their day off from clinic work. The atmosphere and mood of the HCP interviews were generally relaxed and casual. Focus groups were conducted at a private conference room within a primary care office. The atmosphere and mood of the focus groups became more relaxed and casual as the groups were conducted. All focus group subjects were aware that both the PI and the research assistant were healthcare providers in the clinical setting where they received care. Some focus group subjects began, nervously or proudly, discussing their personal diabetes management prior to recording the research visit or asking the research questions. Presumably, the mood of the focus groups lightened after the subjects began discussing their personal and cultural experiences as opposed to their actual diabetes management practices.
Interviews with community members were conducted in a private office at Holyoke Senior Center. The atmosphere of these interviews was relaxed and calm. These subjects were aware that the PI was a researcher as well as a clinician, but were not aware of the exact capacity of that clinical work.

All focus group and community member subjects were generally well groomed and neatly dressed. Half of the subjects in focus groups were overweight and 25% were markedly obese. Focus group subjects often nodded to each other, smiled and suggesting a sense of communal pride between when discussing shared cultural values and experiences. Similarly, subjects often nodded in agreement when other subjects described personal or communal difficulties as they related to diabetes management. Generally, female subjects shared lengthier responses to research questions than male subjects. All of the focus group and community member subjects were bilingual and English language proficiency varied greatly. Answers to research questions were sometimes repeated, not answered directly, or had interwoven Spanish terms and phrases.

Research Question One

Question one, “What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?”, as well as corresponding sub questions A-F are answered in this section. This question and corresponding sub questions were based off of the first and second study assumptions, that Familism has an effect on T2DM self-care for PRiH adults; and
PRiH men and women in traditional roles experience the effects of *Familism* differently.

**Sub Questions A and B**

In this section, sub questions A and B are answered. Sub questions A and B were, “What are the positive effects of *Familism* on diabetes self-care for PRiH adults?” and “In what ways does *Familism* facilitate diabetes self-care for PRiH adults?”, respectively. These sub questions were based on the study assumption that *Familism* has an effect on T2DM self-care for PRiH adults.

**Role of PRiH family in T2DM self-care**

Healthcare providers were asked to describe the role of the PRiH family in chronic disease management. All of the HCPs reported that the family has an integral role in chronic disease management for PRiH patients.

“I think the family figures into it a lot personally because oftentimes it’s family members making the meals, if your patient is the primary care giver the family is also putting their likes or dislikes into meals and a lot of families have someone to remind people to take their medication, coordinate doctor’s visits.”

Additionally, HCPs described the synonymous relationship between the PRiH family and community.

“I think there’s a role for the greater community to that I think that the Puerto Rican patients I see also have strong connections in the community and that I guess you could consider family members part of the commune- or community
member is part of the family. In that sense, that maybe it’s a cousin that lives in a different house that also is may have an influential role.”

All HCPs reported instances and potential for family to have a positive impact on diabetes self-care through collective changes in behavior or directly assisting in care. Specifically, the communal effect of shared engagement was reported as helpful for T2DM self-care.

“I see a lot of female care givers, for example daughter’s spouses or granddaughters who are making the male patient take their medication. So, I would say that’s a positive, so filling grandpas pill box or forcing the husband to take his meds at a certain time, or giving the patient insulin that’s the big thing, that a lot of family members are giving the insulin and not the patients themselves. So, I think when the family members are into those things, you know, I’ve seen family members that are really great at caring for their family member, if they’re not or if the patient doesn’t have any family members then they tend to really experience poor control”

Focus group and community members had mixed responses to their family involvement in their diabetes care. Some family members were described as helpers. Others were described as negative forces affecting diabetes self-care and management. However, as discussed later, there were elements of the PRiH family culture that were detrimental or countered recommendations from HCPs. Interestingly, all HCPs agreed that they have not encountered family members intentionally impeding or obstructing care. There was a general consensus from the HCPs that family members were generally involved in helping their patients
manage medication and clinic appointments. These sentiments were echoed by community member subjects. Specifically, community members reported that their families were involved in encouraging diet control - “My granddaughter always checking. Mama- Grandma you cannot eat that. Grandma that’s too much for you. She’s always checking on me”. Several community member subjects also described their family helping with medication adherence - “They help me in a way that they make sure that I take my medication, you know. That I keep everything on track.”

**Female family member as a resource**

All of the HCP subjects reported 1st, 2nd, 3rd degree relatives as well as other community members as PRiH family who may potentially be involved in care for their patients. These answers were congruent with focus group responses. When asked who they considered to be a part of their families, subjects across all focus groups named a variety of supportive family members including spouses, ex-spouses, nieces, nephews, parents, children and friends. However, male subjects included ex-wives and daughters specifically but did not include friends. Female subjects did not include ex-partners, but did include friends as family members.

Four of the five providers mentioned a female family member as a lead decision maker in the PRiH family:

“When I speak with women from families, it becomes - the information is more about: here is what I actually eat, here is what I actually do, here is what I should
be taking with the medicine, or what I shouldn’t be taking. So, when you get
down to the minute care of things, the women pay more attention - seem to talk
about paying more attention to that than the men do.”

When asked whom they trusted to make ‘big’ health decisions, subjects
across all focus groups described themselves, their children, their healthcare
providers (doctors), and parents as people who helped them make big health
decisions. Male subjects described their children, mothers and daughters as the
people who help them with big health decisions. Female subjects reported
themselves and their daughters as the family members who help them with big
health decisions.

Two of the four medical providers described female family members as
the most trusted in family when it comes to health advice. The other medical
providers considered the most trusted family member to be variable: “I think I do
have a fair number of female patients whose mothers seem to be involved in
their care as well. So, spouses and mothers I would say.”

Across all focus groups, subjects reported ex-partners, partners, siblings,
children, self, Healthcare providers (doctors) as those whom they trust for
guidance with health decisions. Male subjects included ex-wives, mothers and
wives. While, female subjects included sisters, daughters, daughter in-laws and
sons. When asked if there whom they trusted for medical advice, some focus
group subjects also described receiving health advice from some non-medical
persons:
“When I was hospitalized with diabetes there was a lady that works at Baystate Hospital, it’s a reverend and she told me about a remedy of mixing water with Brazilian sticks….Yeah and they also told me to mix water with eggplant.”

All of the health care providers reported that family members often gave medical advice. However, there was no consensus or report as to whether or not this advice was helpful or deleterious. Subjects in all focus groups varied in their responses regarding their families soliciting health advice from them. Responses varied from family “sometimes” seeking health advice to not at all. Male subjects reported their families “sometimes” requested advice from them. Nearly all female subjects, reported their family requested advice from them.

**Diet supports**

Two of the five HCPs referenced the collective nature of the family in relation to diet and motivating their PRiH patients adhere to their diet. HCPs described the PRiH family role as being a positive motivator or negative inhibitor:

“I think the biggest role for families in maintenance is motivation. That if the family motivates, they increase the patient’s motivation to do things like eat better and exercise. And if they are not, if the families not motivated then the patient might not be as motivated either.”

“it could be positive, take care of yourself vs negative, saying you haven’t had any of my rice and beans, you’re rejecting my food.”

Across all focus groups none of the subjects mentioned that there were any aspects of being a Puerto Rican that made managing diabetes easier per se.
This topic was explored further in community member interviews. Regarding Puerto Rican cuisine and family members helping them adhere to their diabetic diet, some Community member subjects reported family members helped with diet control by encouraging portion control - “But you know sometimes they do. Yes. And they watch it when I’m eating too much. They will tell me this you know that’s too much for you or too many sweets. And things like that.”

Community member subjects described family support with diabetic diet as “checking in”, and encouraging them not to cook meals that were not a part of their recommended diet - “Well sometimes they tell me not to cook it all the time. Just make it- If I’m gonna make it, make it like once or twice a week. Not make it all the time”. Some community member subjects agreed that family being involved in their diabetes care helped make managing their diabetic diet more manageable. When asked why their family was involved in her diabetes care one subject fear of losing the subject to the illness - “I think because they wanted to have me more- more time around…. I think- I think they want to see me more. See- You know- You know my husband died five years ago.”

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Subjects in the all-male focus group reported they received support with diet, and made specific reference to patriarchy as well as communal environment as the reason for this: “they help me with my diet sometimes, you know. Cause if I gonna eat like that, everybody else has to eat like that. In my house”. One member mentioned his family was not supportive, however he also referenced maternal support in reference to his dietary support: “I just call my mom, she supports me a lot”. Subjects in the all-female focus group reported family members helped them with their diet by preparing healthier meals: “we’re all as a family now trying to eat a little bit healthier because like oil and all that or whatever”. Additionally, subjects in the female focus group reported female family members (sisters) helping with dietary reminders: “Last week I was with my sister and I felt like--I almost fell and I was like “oh, whew, I got dizzy for a minute” ... “did you eat, did you check your sugars?” and
I’m like, “I didn’t eat breakfast”, she was like, “you have to eat breakfast” you know so she--like little things like that, so she makes sure, that’s the only one really my sister”.

PCAs were also mentioned as willing to help with meals - “I have a PCA that--she’s the one who does it. She’s the one who cooks for me, good”. Subjects in the all-female group also mentioned difficulty adhering to diabetic diet, as other family members cook meals that are not in line with their recommended diet - “where I live now which is with my son, I’m staying there a bit...his wife has no idea. She does things that I don’t like or eat. Like lasagna’s bad for me”.

**Exercising support**

HCPs referenced the collective nature of the family in relation to exercise and motivating the patient. Again, they described the family role as possibly being positive as a motivator or negative as an inhibitor. One subject in the mix gender focus group reported he had no family support what so ever when it came to exercising. However, the other subjects, specifically male subjects, reported that their mothers were a source of support and encouragement to exercise - “My mother help me with going to the gym....My mother motivates me”. Subjects in the all-female focus group did not answer the line questions about their family involvement regarding exercise regimens. One subjects in the all-male focus group mentioned familial support from his son, however, he admitted that he did not participate despite this support –
“Well, my son, he play a good roll. But me, I'm the one who don't want to listen. For me to go to the store, I live around 2 blocks from the store. You think I walk? I turn on the car, go and buy it, then back again. I don't walk. I get tired fast when I walk.

**Medication adherence**

Focus group subjects were asked if their families helped them with medication adherence. Some subjects in the mix gender focus groups reported an absence of family support with medication adherence. However, most subjects suggested a family member served as a reminder to take medications. Family members mentioned included adult children, female children, and nephew -

“my kids, and my daughter, they always look out for me….calling me on my phone ….Did you take your medication?”

“I forget to take my medicine, that's why my nephew's always on top of me”.

Subjects in the Male group described familial support with medication adherence, specifically maternal support - “My family helps me a lot. They remind me sometimes to take my medication you know”….“I just call my mom, she supports me a lot.” Subjects in the all-female group described familial support from female family members helping with medication adherence through checking in –

“I eat dinner at my sister’s…between me and her we’re all as a family…and she calls me, “did you take your pills?”; “My daughter does the same thing, she’ll call me to see if I drink my medicine”.

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Healthcare appointments

Healthcare providers were asked to describe the role of the PRiH family regarding helping their patients with follow up healthcare appointments. HCPs described the collective nature of the family as well as the role of the head female care giver-

“I think for the person, people who are not the head female care giver, I think that the role is the head female caregiver tends to remind them of appointments or to make appointments or press them to keep their appointments. I think for the female care giver head of household; they need to be motivated on their own to make those appointments”

Focus group subjects were asked to describe their families’ role in helping them with healthcare appointments. One subject in the mix gender group mentioned having no support with attending his scheduled appointments with his primary care provider. However, the other subjects mentioned spouse, adult children and female children as sources of support –

“I’ve got a lot of help from home. That’s why I made it to this appointment because of my lady. Once I tell her I’ve got an appointment at a certain time she calls me ten minutes before – don’t forget. ….Yeah, my lady helps me a lot with that”

“my kids, and my daughter... every time I tell them about an appointment, and you know, they ask me, two minutes later, calling me on my phone "hey, how’d it go?".”
One subject in the all-male focus group described family support from male adult children - “Yea, my son does. He brings me to my appointments”. However, other members described self-reliance with appointments, with distant maternal support.

“I just do everything for myself right now at like appointments or anything like that. But you know, once I get out of an appointment or I call my mom and say this or this is going on or just everything came out ok. I just call my mom, she supports me a lot”.

Two subjects in the female group described female family members helping them with appointments - “They make me go, she makes me go, my sister, she’s like, and “your appointment’s today”...“My daughter [helps me]”. Others in the all-female group mentioned that they had little support - “I do it myself, but I don’t know, they help me sometimes remind me that I got an appointment”. Or the described not having any family support at all regarding their healthcare appointments - “Not me, my kids don’t”; “Yeah, they can’t help me. They don’t even know the appointments that I have”.

Healthcare providers were also asked to describe the role of the PRiH family regarding helping their patients with follow up specialty healthcare appointments (podiatry, ophthalmology etc.). Similar to the question regarding general healthcare appointments, HCPs described the collective nature of the family as well as the role of the head female care giver. In fact, most HCPs requested to simply use their previous answer about general healthcare provider visits in response to this question about specialty healthcare visits.
Glucose monitoring

There was no consensus amongst providers as to whether or not the PRiH family typically played a role in checking glucose levels. Responses from HCPs varied from "rarely" to "frequently" checking family a member's glucose levels.

When asked about diabetes management and their family helping with checking blood glucose, one female subject in the mix gender group, stated she received no support what so ever from her family with regards to checking her glucose. However, most subjects in the mix gender groups referenced female partners, mothers, female siblings, and nephews (PCA) as family members who helped with checking glucose-

“My mother checks my blood, my sugars “

“In my home my girlfriend, she has even measured my blood sugar while I’m asleep.”

“My wife does it….She check every morning”

“Yeah, when my mother’s here, she’s always on top of me. Because my mother’s diabetic, too. So, you know, she checks me out a lot because I go through these changes with my sugar”

“My sister and my nephew, they check on me every day….Check your sugar, check your sugar, it’s time.”

Most subjects in the all-male group referenced female partners or female adult children as familial support with checking glucose. This support was
described as passive – “They just ask me how much is it”, or active – “Yea, my wife does a lot also and oldest daughter, she’s 17, she sees that I’m not like, like if I’m sitting down and she sees like, if I’m out of it, she’ll tell me, “Are you ok?” and she’ll run and get my meter and stuff like that, and she’ll help me check it out”.

*Monitoring for symptoms of high or low glucose.* Although, one HCP reported that families were more likely to notice extreme changes in glucose as opposed to normal variations of high or low readings – “I think the family would notice the extremes. If grandma can’t see any more I think people would notice, but I don’t think monitoring for vision changes is something people do a lot.”

Subjects in the mix gender groups reported their mothers and female partners as family who helped them by checking them for high or low glucose readings. In this group, only one female family member stated she received no support what so ever from her family with regards to checking for high or symptoms of high or low glucose levels. Subjects in the all-female focus group reported female family members, sister and daughter as support regarding monitoring for symptoms of high or low glucose levels – “my sister because she’s the closest to me…Last week I was with my sister and I felt like–I almost fell and I was like “oh, whew, I got dizzy for a minute” … “did you eat, did you check your sugars?” and I’m like, “I didn’t eat breakfast”, she was like, “you have to eat breakfast” you know so she–like little things like that, so she makes sure, that’s the only one really my sister”.
Subjects in the all-male focus group mostly reported they received assistance from female partners or female adult children as familial support with checking glucose. Support was described as active – “Yea, my wife does a lot also and oldest daughter, she’s 17, she sees that I’m not like, like if I’m sitting down and she sees like, if I’m out of it, she’ll tell me, “Are you ok?” Again, one subject stated he did not receive family support with checking his glucose levels.

*Monitoring for significant glucose reading changes.* Focus group and HCP subjects were asked to describe the PRiH family regarding diabetes monitoring and the family helping assess for significant changes in glucose readings (very high or very low glucose readings). HCPs shared the consensus that families were generally involved in monitoring for very high or low glucose readings. Specifically, elderly patients are involved as well as matriarchal female role in helping offspring with management that may continue despite the patient being well into adulthood.

“I see it more for my elderly patients, their kids will call me”

“If anything, they are too intrusive. So, can be positive or negative If you have a mom whose son has diabetes, that mom she doesn’t care if you’re 49, that mom will say, my little baby, you’ll say how old is he, he’s 50 or he’s an adult. Versus someone who is actually more in their teenage years, the mother or matriarch is always in charge, could be patriarch as well”.

Subjects in the mix gender groups referenced their mothers, adult female children, female siblings, and female partners as sources of familial support with monitoring for significant changes in glucose readings - “My sister and my mom,
when she’s here....when my mom is here she’s kind of sitting on top of me, making sure my sugar's all right”. One subject mentioned that typically family members do not focus on disease management when at family gatherings and this caused some difficulty with monitoring - “When we all get together we’re not thinking about how many shots you took today. We just focus on that moment that is happening”.

The question of monitoring for significant changes in glucose readings was not fully explored in the all-female group. Additionally, there was low response to this question in the all-male group. One subject referenced his adult son as one who monitors him for significant changes in glucose readings - “No, my son, if he see me like I said, like, going out of this world without talking to nobody. Like I'm dizzy, but I don't tell nobody and he see me like I feel bad, he call the ambulance fast, he say, Nope, you’re going to the hospital”.

Monitoring for new/changes in symptoms. Focus group and HCP subjects were asked to describe the PRiH family regarding diabetes monitoring and the family helping assess for new symptoms or changes in diabetes symptoms (dizziness, fatigue, increased urination, thirst or hunger). HCPs shared a consensus that the family is involved to some extent, though variable, with monitoring for changes in symptoms of diabetes. Elderly patients and family members responsible for administering patients’ insulin were mentioned specifically -
“in the extremes. So, I don’t think the family takes a particularly active role in monitoring for mild hypo/hyper symptoms but I think the family does observe when people are extremely hyper or hypoglycemic”.

Subjects in the mix gender groups referenced their mothers, adult female children, female siblings, and female partners as sources of familial support with monitoring for changes in hyper or hypoglycemic symptoms –

“My sister, all the time I’m feeling weak, my sister ask me “are you feeling okay?” She notice, because I’m not able to talk right, I’ll start in and I start mumbling. So, she notice that there’s something wrong with me. So that’s why she’s always around me, always helping me with everything”.

Other subjects in the mix gender group mentioned they were self-reliant and their families were not involved in monitoring them for symptoms of diabetes - “I can do it myself…. something wrong is going on, something wrong is going – I’m getting dizzy, I feel my legs week. That’s how I know my sugars are low”. Responses to this question regarding the family involvement with monitoring for new or changing diabetes symptoms was generally low and was not fully explored in the all-female or all male groups.

**Checking feet**

Three of the five HCPs reported that they did not believe PRiH family members checked their patient’s feet, or that family members often reported they were checking the feet however the provider did not believe this was actually being done.
In response to questions regarding diabetes management and family helping with checking their feet, subjects in the mix gender group reported their mothers and female partners as family support with checking their feet – “When it comes to my feet my girlfriend is the one who checks them. My nails, I make sure I cut my nails the way you’re supposed to cut them”. One female family member stated she received no support what so ever from her family with regards to checking her feet. This question was not explored in the all-female group. Subjects in the all-male group either mentioned no familial support with checking the feet, or mentioned female children as a source of support with checking feet – “My daughter helps me a lot. My daughter, yea. She just, if I tell her to check out whatever I have to, on my feet, my nails, my toenails, yea”.

**Monitoring for pain and discomfort**

Focus group and HCP subjects were asked to describe the PRiH family regarding diabetes monitoring and the family helping monitor for pain and discomfort (neuropathy, paresthesia etc.). HCPs unanimously reported that the PRiH family is generally involved to some extent, though variable, with monitoring for pain symptoms. The elderly and husbands were mentioned specifically as examples of patients whose family typically may advocate for them. There was also mention that male family members may not advocate for family members as often as females - “I think that elderly patient’s kids and husband’s wives, but not the other way around”.
Subjects from the mix gender groups did not describe their families as being directly involved in monitoring them for pain per se. This question, monitoring for pain, was not covered exhaustively in the all-female group. However, one female subject mentioned her female child inquiries about pain, without specific detail about this inquiry. Subjects in the male group mentioned children as familial support for monitoring for pain, with some specific mention of monitoring behaviors -

“\text{I got a lot of pain in my legs and she gives me a massage.}”

“\text{my daughter. She helps me out a lot. She props a pillow under my leg or whatever it is. So, but yea, she helps me out a lot}.”

\textbf{Emotional supports}

Subjects in the all-female group reported that their families were generally aware of their diagnosis without mention of specific emotional support - “\text{they know I have diabetes but they don’t really know how I feel about it because it’s something we don’t talk about, it’s like taboo, I guess. But they know I have it}”. One subject from the all-male focus group reported he did not talk to his family about his feelings regarding diabetes management. However, the other subjects reported that their families were aware of their feelings regarding diabetes management; and described generally being supported, specifically by maternal figures –

“I always talk to them about it sometimes, … I’ll call my mother sometimes and say look, I’m so tired, I don’t want to take my medicine today and this and that.”
But you know she tells me, oh, you gotta take your medicine. I don’t want nothing to happen to you”.

“They understand that I struggle sometimes and “you can a little bit of this, but don’t have too much of that,” you know. Wet your lips or wet your tongue, you know. Whatever you gotta do. But they help me a lot.”.

Throughout this line of questioning, a pattern emerged, with female subjects and male subjects referencing female family members as supports. For example, subjects in the all-female focus group reported they received support from their mothers after they received a T2DM diagnosis - “When I found out I had diabetes….I went right to my mom crying like hysterical crying”. This line of questions regarding the relationship between diabetes self are and gender was explored further in community member interviews. All community member subjects, male and female, reported that they received more support from female family members than they did from male family members - “The female….Yeah, they do it. My niece, they always ask me, you know if I keep my medication, you know. That I make sure that I go to my doctor”. Regarding reasons why they believed female family members offered more support for their diabetes care, community member subjects described “closeness” to female family members; only having support from female family members; female family members seemingly being more concerned; and that female family members share and talk often - “I think females, they are more concerned…Because between women they talk about everything”.

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For those subjects who reported that they did receive support from family members, a nephew was mentioned as a source of support, though he was a PCA worker - “my nephew helps me out a lot. He’s my PCA worker, he’s always in, making sure I’m okay because I pass out a lot”. Additionally, maternal support was mentioned several times as source of support with adhering to recommended diet - “My mother, before she pass away, oh man. She always "hey you’re missing these and missing that be sure you eat right. Don't eat too many things”.

**Family awareness**

Focus group subjects were asked if they knew how aware their families were of their feelings about diabetes management. The all-female focus group primarily reported and discussed maternal support -

“Just my mom and she was always with me at first….she had such a hard time controlling her sugars and when I found out I was like, “my god, mom!” insulin medications she was telling me like, “just do your best” because she wasn’t taking care of herself”.

Giving and receiving paternal support was also mentioned and one subject described interactions with her father who also has diabetes – “he doesn’t like to talk about his health issues, and he cried too. When he found out he was like, “oh no, we both have to take care of ourselves”. He’ll check up on me and I’ll check up on him like “what was your sugar today?”, “well, what was your sugar today?”.
Sub Question C and D

In this section, sub questions C and D are answered. Sub questions C and D were, “What are the negative effects of Familism on diabetes self-care for PRiH adults?” and “In what ways does Familism inhibit diabetes self-care for PRiH”, respectively. These sub questions were also based on the study assumption that Familism has an effect on T2DM self-care for PRiH adults.

Social stressors

While the topic of depression was not a direct inquiry, subjects in the mix gender group also described the relationship between diabetes self-care, social stressors, decreased motivation and depression –

“That also puts a toll on our dieting and taking care of our physical selves if our financials doesn’t help either. The financials don’t help, it causes stress, it causes depression because we want to be healthy, but the only choices that we have are the ones that we can afford.”

“Salads will go stale, bags of spinach go stale because we don’t put the self-motivation there because of all the stress that we have in our lives as trying to stay healthy and also be able to pay the rent, car payments, insurances and all that”.

Financial cost of therapeutic diet

This point is worth noting as many focus group subjects reported that the cost of a “healthy” or diabetic diet was as a source of frustration - “If the doctors want people to eat healthy, but okay when we go to the grocery stores all the diet stuff is so expensive, so expensive”. Given the low socioeconomic status of the community from which the sample of focus group and community members was recruited, it is worth noting that the difficulties expressed by these subjects may differ from those with higher education, income and generally of higher socioeconomic status.

Diet and social gatherings

Focus group members were asked to describe how attending family functions affected their diabetes management. Generally, they described discomfort with having to have a special diet at family gatherings - “If we have family functions, she knows I don’t really drink that much soda no more so she won’t buy much soda.”

“it’s really hard when we have like family reunions and stuff; it’s very hard”.

Additionally, there was discussion regarding frustration with family members taking notice of their chronic condition - “they watch you a lot and they’re afraid I can’t eat the cake, and they’re all eat--happy birthday, singin’ and “oh, we can’t have that cake”; which is aggravating”. Again, female focus group members reported difficulty with preparing food for a non-diabetic spouse –
“I have a difficulty finding something in the house that I could take that’s not gonna be bad for me. You can’t buy two things, you buy something you both could eat”

“because if I buy something for me he can’t be able to eat”.

Specifically regarding dietary recommendations, there was consensus amongst healthcare providers expressing the difficulty of conveying the effect of dietary recommendations on glycemic control. Additionally, there was mention of a noted intent to exercise expressed in office visits, however patients seemed to struggle with follow through with the plan. One provider noted that health literacy may be a particular factor affecting adherence to medical recommendations-

“So I don’t actually have any experience working with well off more upper class Puerto Rican patients, so I’m not sure how they differ in managing their diabetes, but I think that for our patients here, we struggle a lot with first of all understanding what diabetes is, why it happens and what effects it has, I think we struggle a lot the understand of what the dietary recommendations that we’re making impact peoples glycemic control, and I think that we struggle a lot with a lot of social factors around the ability to get all medications all of the time, difficulty with taking medications, adhering to a specific plan, I think there’s a lot of issues around insulin adherence in particular, and I think a lot of that has to do with low health literacy and low literacy of our patients, not necessarily the cultural background”.

When asked if there anything about being Puerto Rican that affected how they managed diabetes, adhering to therapeutic diet was the most mentioned
cultural challenge in all focus groups. All focus groups subjects mentioned the abundance of readily available traditional foods that were not consistent with diet recommendations. The mix gender focus groups discussed specific conflicts between recommended diet and cultural diet -

“when it comes to food and the recommendations that the doctors say for you to have the lower blood sugars is not the one that we follow because like she said fast food or even at home, the rice and beans is always something there”

“The education is great, but the difficult part is when you go home you are the only one that is going to eat like that because everyone else at the table – is like wow, you’re suffering – they feel bad for you. But they are going to eat their fried pork chop and whatever right in front of you. You get to smell it; the smell is amazing”.

Specifically, subjects mentioned the overall lack of healthy options in Puerto Rican eating establishments –

“There is no labels on fried potato balls or anything like that for you to know and they don’t have the manual like they do at McDonalds – this is this many calories, this is heart smart. You don’t get that at our Latino establishments”.

Additionally, focus group subjects described the centrality of Puerto Rican foods in PRiH culture - “Our food is so central to our culture – our culture is centered on the food.”; and the strong nurturing maternal culture that influences family diet - “The mothers are the worst offenders. We want everyone to be
healthy, but it’s the mothers that really need the nutritional information because they’re really the ones that buy the food”.

Subjects in the male only focused group discussed difficulty with refraining from eating at restaurants. However, subjects in the female group focused on difficulty with traditional diet - “I love to eat and because our food it greasy, like, it’s greasy and it’s not the best but that’s what we were brought on-rice all the time”. Subjects in the female group also described feeling obligated to prepare separate meals for family as well as themselves -

“How do you do it when you have a husband that loves to eat? You try to cook two meals and it’s very expensive; cooking two meals. It’s very expensive to eat healthier”

“Our foods are good but they’re not good to eat every day, so, it’s difficult being Puerto Rican because we’re just used to eating what we eat and food is definitely a big part of like obesity and diabetes”.

Additionally, subjects in the female group mentioned the strong relationship between matriarchy and cultural foods-

“the way I was brought up - you ate whatever your mother cooked and that’s it”

“I’m not cooking two meals so if you don’t like fried chicken, peel the skin off and eat it”; that’s the way I was brought up - rice every day”.

The theme of the traditional PRiH diet being a barrier to self-care was further explored in community member subject interviews. All community
member subjects reported that the traditional Puerto Rican cuisine was a barrier to adhering to a diabetic diet. However, subjects also described having self-control and using portion control as a work around to the traditional high carbohydrate diet. “Yes, but like I- I eat it but I don’t eat that big portions….If I eat rice, I eat only a small portion of the rice. … You know. Puerto Rican like to eat”.

Additionally, subjects described knowledge of the effect of Puerto Rican cuisine foods on diabetes control - “Well, you have to be careful about the Spanish food, because sometime Spanish food they are greasy you know, and you, know what you eat and what you not supposed to eat”.

One community member subject described her family as not being supportive, however she reported that she did not believe that this lack of support affected her diabetes management and that ultimately she was responsible for adhering to her diet – “it’s up to me. I do it or no do it”. Other community member subjects described reasons for family members not being involved in diabetes care as lack of caring; denial about their diagnosis; families being unaware of the family members’ illness; or offering counterproductive dietary advice - “They don’t care…Because sometimes they no believe they have it, or not have it. Sometimes nobody tell them thing either, no telling me, no telling them”.

Community member subjects also described ambivalent family attitudes towards diabetes as making their diabetes management difficult. They described common laissez-faire attitudes from family regarding diabetic diet and the prominent idea that "a meal" would not necessarily be harmful for their health -
“They say one- They- one thing I eat no kill me. This they believe. They almost all Latino really.”

“[They say you] got it already but oh [you] can eat this ice cream just for today or [you] need this and that”.

**Attitudes and ambivalence**

Three of five HCPs reported the PRiH family has a direct impact on diabetes self-care. Two of three HCPs reported a perceived normalcy to living with T2DM in the PRiH community - “it’s almost like its normal, so the prevalence is so high that it’s sort of like, welcome to the club type mentality. So, it’s accepted”

Focus group members were asked to describe their feelings about managing diabetes with family members. Subjects in the mix gender groups mentioned the normalcy of diabetes diagnosis in their family/community as many have diagnosed DM. Regarding the family’s awareness of their feelings about diabetes management, subjects in the mix gender group described a lack of caring or involvement from family regarding lifestyle management-

“No, they don’t care”

“Nobody knows or nobody wants to be bothered with you. They got their own situations that sometimes you don’t want to hear either”

“That’s not a topic that would get discussed unless someone was in a health crisis”
Focus group subjects also discussed ambivalence from family regarding their diagnoses -

“We have sayings that people say all the time, they’ll say I don’t want to have any – oh, come on have some, it doesn’t kill you it just makes you a little chubby that’s it. That’s the family adage that they’ve been passing down for generations and also in our culture if you don’t eat mom’s food you have a problem. First of all, if I come home and I cook the meal you better eat it and you better not question what’s in it”.

Denial

When asked what their thoughts were regarding their family’s attitudes about diabetes management, subjects from the all-female group discussed a general sense of denial from their respective families –

“People are in denial, I think.”

“It’s just our culture, we don’t think about, “oh, we’re doing a gathering, let’s do some healthy foods for other people”, no. Like, we’re gonna celebrate, we’re going all out, and if you don’t wanna eat then don’t eat”.

Additionally, when asked to discuss their feelings about diabetes management, subjects in the all-female focus group described their own denial of their diabetes diagnosis -

“…Sucks, I want it go away but…it give me a hard time to do it, to go down and everything”
“Some families, …do like in denial ‘cause when I first found out from being sad, I was in like denial for a little bit, like, “I don't got nothin’” you know? But then when you test them sugars and it comes up three hundred and something, you know, but it like dangerous sometimes you’re like, “oh”. Like my friends, they took longer to accept more than my family because they were like, “oh, come on, let’s go”, you know, the same drinks--sugary drinks, you know it’s like, “no, I can’t…I can’t, I can’t chill like that no more you know, like, I think--“Just one, but they don’t know, just one, jus--seriously”…. “You don’t got nothin’…you’re fine…you don’t got noth—” and I had to like break it down to them, like, “do you know what diabetes is?” you know like--I can’t and that’s it, “either ya’ll love me or respect me or…” and they’re like, “are you serious?” and I had to explain the effect of even sugar drink, juice! It affects it, so like, they were in denial”.

**Deficits in support**

Subjects in the mixed gender group reported difficulty managing diabetes as they experienced a general lack of family/community support -

“The only persons that know what’s going on in my life is my mom and my girlfriend because they’re the ones there”

“I see this other guy eating a half of a chicken, you know, and pork and all of that, and "oh wow, look at that!" I want to eat it but I can’t. So, I feel bad, yeah! I don’t tell everybody, I just keep it to myself.”]
“I feel bad, because they could eat a whole bunch of things that are there that I can't eat. So, it's, like, hard for me to just sit there and just watch everybody eat what I would love to be eating right now, and I can't because of my diet”.

Most subjects reported that their families were not aware of how they were feeling about the burden of diabetes self-management. Only two subjects from the mix gender groups reported that their family members were aware of their feelings about diabetes self-care management -

“With my family, the thing is the gathering are so often that they already know about the choices of food that I would like to eat so when they come over my mom always asks me – is that enough rice or is that too much rice because the thing is right now I've noticed I'm going through when it comes to this free thing”.

When asked to expound on the effect of their family on their feelings about diabetes management, subjects in the all-female group reported difficulty with not having foods from their therapeutic diet available at family gatherings and that their families did not make significant effort to provide therapeutic food options – “it’s very hard when we go to family gatherings because there’s nothing that you can eat there that’s healthy if you don’t bring it yourself, in my family. There are a lot of diabetes in my family but we don’t think about it”.

These subjects also made several references to “cheating” or “cheat days”, on which they would disregard their diabetic diet- “we don’t eat like this every day, so I’m just gonna cheat”. Subjects in the all-male focus group were also asked to expound on the effect of their family on their feelings about
diabetes management. They also described difficulty with limited food choices at family gatherings -

“it's hard sometimes because like, they say, they got a lot of food out there and that's all they think about and you know you can't have this and can't have that. But family gatherings, it's hard, it's a struggle”.

**Emotional tolls**

Several subjects described feelings of social isolation regarding diabetes management –

“I feel bad, because they could eat a whole bunch of things that are there that I can't eat. So, it's, like, hard for me to just sit there and just watch everybody eat what I would love to be eating right now, and I can't because of my diet”.

Sadness. Subjects from the all-female focus group described sadness, fear and despair after being diagnosed with diabetes -

“When I first found out, I literally cried”

“To me, I think of diabetes and I think of somebody cutting off your leg. Just these horrible images would come into my head “I don't want to die young”

“When I found out I had diabetes, ….I went right to my mom crying like hysterical crying”.

Fear. This cohort also described fear of diabetes complications -

“cause my mom had diabetes really bad she had two feet taken out. She died already like 10 years ago. She had--she couldn’t see, her arms...dystrophied...?
“It was, it was like frustrating because at that point that’s when I realized that I want to live, I don’t wanna die. I don’t wanna, you know, be blind. My grandmother was blind because of it; I don’t want to be like that. So, once they got with the program, everything was okay.”

Embarrassment. Subjects described generally feeling “embarrassed” when managing diabetes in public as well as difficulty when navigating family gatherings -

“You can’t buy two things, you buy something you both could eat...’cause if I buy something for me he can’t be able to eat. You have to be with your diabetes compliant, but it’s really hard when we have like family reunions and stuff; it’s very hard”.

Self-esteem and body image. When female subjects were asked how diabetes affected them personally and nearly all of the subjects in the all of the female focus group described low self-esteem related to obesity –

“It’s uncomfortable, I don’t even like to watch myself in the mirror”

“I was feeling not in a good way and because it’s hard for me to walk when I’m big and huge. Even my self-esteem was terrible because I was big and I didn’t feel pretty”

“I used to feel awful look awful just disgusted with myself”.

Finally, depression was mentioned passively as being a factor but not directly in relation to this line of questions.
Mental health

Three of five HCPs mentioned health literacy as a potential negative factor in the PRiH community. Family having a passive negative impact regarding not supporting the patients recommended behavioral changes was mentioned by 2/5 HCPs. Additionally, social isolation was mentioned as a potential factor affecting diabetes self-care. One HCP referenced female patients as struggling in this regard specifically-

“My female patients frequently are more by themselves, or they are - if there’s a family member, it’s a female family member. And frank- my real answer is I feel like I deal with more adherence problems with my female diabetics than I do with my male patients”.

Personal feelings about management

Focus group subjects were asked to discuss their feelings about managing diabetes with their family members. Subjects in the all-male group did not answer the questions directly but referenced their general dislike for recommended diet –

“The only thing I don’t like is when I have to change my diet. Because I’m not a rabbit to be eating carrots and lettuce every day. I like rice and beans and pork chops. It’s hard”.

Female focus group members shared their feelings about the effect of diabetes management freely and this data is presented within categories throughout this section.
**Specialty appointments**

The questions regarding the family role in helping with specialty healthcare provider appointments were answered similarly or not at all in focus groups. In the mix gender groups, the question of family role in helping with specialty appointments was not answered exhaustively. One subject responded that he did not have any support from his family with appointments in general. For the male and female focus groups, the question of specialty appointments was not asked directly. This question of familial support with specialty appointments was not explored as the answer to general help with appointments suggested that family was generally not involved in helping with regular healthcare appointments.

**Checking glucose**

Subjects in the all-female group mentioned that their family members generally did not help with checking their glucose, or family would check if they asked them to or if they were not feeling well. One subject from the all-male focus group stated he did not receive family support with checking his glucose levels.

**Checking for vision changes**

There was no consensus amongst HCPs regarding the role of the family in assessing for vision changes in their diabetic family member. Answers to this line of questions ranged from “rarely” to “yes, absolutely”. Health literacy was
mentioned as a factor. Additionally, one HCP expressed his discomfort with the family being involved with this level of diabetes management when the patient is competent and preference for the patient to be more independent.

In reference to questions about diabetes management and family helping with monitoring for vision changes, subjects in the mix gender group described mothers and female partners as family support with checking vision changes. Again, one female family member stated she received no support what so ever from her family with regards to monitoring for vision changes. Subjects in the all-female group referenced female family members or described no family support regarding monitoring for vision changes. Subjects in the all-male group mentioned no familial support with checking for vision changes or female family member support without specific details.

**Exercise**

HCPs reported that limited exercise may be a factor affecting their PRiH patient’s diabetes care. However, subjects in the all-female group mentioned that PRiH ethnicity or culture was not a factor in their decision not to exercise - “I don’t think it’s like a Puerto Rican thing I think it’s just a personal”…“I’m just lazy”. Instead subjects in the female focus group suggested that they had lack of support as well as general lack of ambition towards exercise - “It was not easy to do that [exercise] so it takes a lot out of me to do it. I have to get a partner that, "come on, let’s go" but I don’t have anybody like that".
Home Remedies

Home remedies were not included in the research questions, nor were they discussed in the all-male or all female focus groups. However, the subject of home remedies came up during the mix gender focus groups. These subjects described their healthcare providers lack of interest in home remedies as well as some culturally based common home remedies –

“It’s an ongoing discussion because we believe in self medicating, everything we was raised with – my mother used to mix cod liver oil with honey. And she used to have big bottles of it and I used to drink it like it was juice”.

One subject reported a brief story of using a supplement and some cultural history that affected his belief that these treatments may be effective –

“She recommended that to us and we searched high and low until we found that tree bark. It wasn’t hard. It was about two bucks for a little pack called Brazilian Bottle and darn it if we don’t think it worked. It became something that he would take before the meal or before bed. I don’t know if it was psychosomatic, but it seemed to work. Then it got to a point – maybe you shouldn’t take that stuff, the sugars really going down so. We do place a lot of cultural emphasis on the home remedies. All our grandmothers back on the island will take the leaves from the orange trees and boil it for ear aches, back aches, colds. It’s all indigenous.”
Sub-question E and F

In this section, sub questions E and F are answered. Sub questions were, “How are PRiH women with T2DM in traditional family roles affected by Familism?” and “How are PRiH men with T2DM in traditional family roles affected by Familism?”, respectively. These sub questions were based on the study assumption that PRiH men and women in traditional roles experience the effects of Familism differently. Quantitative data is presented first, followed by qualitative data.

Quantitative Data

Focus group and community member demographics

To gain context for the experience PRiH men and women, demographic data was collected. This data included race and ethnicity; marital status; employment status; level of education; language proficiency; and duration of diabetes diagnosis. The combining of Hispanic subgroups in research likely conceals important differences between Hispanic subgroups (Aponte 2009; Barcelo et al. 2007; Mainous, et al. 2007; Allison et al. 2008). Race and ethnicity data was collected to confirm that the subjects belonged to the unique PRiH subgroup. Research also shows that PRiHs prefer to consult with family members about health problems (Long, Sowell, Bairan, Holtz and Fogarty 2012). Additionally, the influence of spousal support for diabetes self-care in the study population had not been discussed in the literature. Marital status was collected to give context and help clarify this in the literature.
Research show that PRiH individuals are more affected by poverty and are generally less educated compared to non-Hispanic whites (Census, 2010). Employment status and level of education were collected to give context to the sociocultural environment from which the study population lived. Additionally, the ability to read and speak English was a requisite for subjects to be included in this study. Research shows that limited English proficiency is an independent predictor for poor glycemic control (Fernandez et. al, 2011). People with limited English proficiency treated by language-discordant physicians are more likely than limited English proficiency patients treated by language-concordant physicians to have poorer glycemic control (Hosler and Melnik, 2005). Language preference was assessed to give context to the general discussion surrounding diabetes self-care adherence. Finally, a requisite for inclusion in this study required that subjects were diagnosed with diabetes for greater than one year. The duration of a diabetes diagnosis was assessed to give context to the depth of experience of the samples experience with diabetes self-care.

Race and ethnicity. Focus group and community member subjects were asked to define their “race” and 93% of subjects did not answer this question. Two subjects chose “white” as their race and no subjects chose black, Asian, native Hawaiian, pacific islander, American Indian or Alaskan native. However, in response to their ethnicity, 93% of subjects identified as Hispanic/Latino; (only one subject did not respond to the question) and All subjects (100%) identified as Puerto Rican. This suggests that a line of questions inquiring about “race” may
not necessarily be applicable to the PRiH population and that, perhaps, ethnicity is more relevant.

*Marital status.* For all focus group and community member subjects, 20% reported they were never married, 40% reported they were married / living with a partner, 6% reported they were separated, 26% reported they were divorced, and 6% reported they were widowed. See Graph 1 in Appendix L.

Fourteen percent of male subjects reported they were never married, 42% reported they were married / living with partner, 14% reported they were separated, 28% reported they were divorced, and none reported they were widowed. Twenty-five percent of female subjects reported they were never married; 37% reported they were married / living with a partner, 25% reported they were divorced; 12.5% reported they were widowed, and none reported they were separated. There was no significant difference between the aggregate, male, and female cohorts regarding marital status.

*Employment status.* For all focus group and community member subjects, 6% reported working full-time; 13% reported working part-time; 30% reported they were unemployed; 40% reported they were medically disabled/ unable to work; 20% reported they were retired; and none reported they were students. See Graph 2 in Appendix L. Fourteen percent of male subjects reported they were employed part-time; 14% reported they were unemployed; 57% reported they were medically disabled/ unable to work; 14% reported they were retired; and none reported they were working full time, or were a student. Twelve-point five percent of female subjects reported that they worked full time, 12.5%
reported they worked part time, 25% reported they were unemployed, 25% reported they were medically disabled/unable to work; 25% reported they were retired, and none reported they were students.

This data is limited in that the sample was relatively small. However, the reported data is consistent with the employment rates the region where the study was conducted. Men in this sample were twice as likely to report disability. Otherwise, there were no significant differences between men and women in the sample.

*Level of education.* For all focus group and community member subjects, 13% reported having less than 9th grade education; 20% reported having a 9th-12th grade, but did not graduate; 26% reported having a high school diploma/GED; 26% reported attending some college, but did not graduate; 6% reported having an associate degree; 6% reported having a bachelor degree; and none reported having a graduate or professional degree (master degree, doctorate degree, law degree, etc.). See Graph 3 in Appendix L. Fourteen percent of men in the sample reported having less than 9th education; 28% reported having a 9th-12th grade education but did not graduate; 57% reported having a high school diploma/GED; and none reported having attended some college, an associate’s degree, a bachelor degree or graduate/professional degree (master degree, doctorate degree, law degree, etc.). Twelve-point five percent of female subjects reported having less than 9th grade education; 12.5% reported a 9th-12th grade education but did not graduate; 50% reported attending some college but did not graduate; 12.5% reported having an associate’s degree;
12.5% reported having a bachelor degree; and none reported having a graduate / professional degree, or high school diploma being their highest level of education.

Overall, this sample reported lower education levels compared to the general PRiH population. Puerto Ricans have higher levels of education than the U.S. Hispanic population but lower levels than the total U.S. population. According to the Pew Research Center (2013), 18% of PRiHs ages 25 and older—compared with 14% of all U.S. Hispanics and 30% among the U.S. population—have obtained at least a bachelor’s degree. When comparing male subjects to female subjects, male subjects did not report any secondary education (post high school). Female subjects, on the other hand, reported higher levels of education compared to their male counterparts regarding secondary education. However, rates for having less than a 9th grade education were relatively equivalent between men and women in this sample.

Language proficiency. Seventy three percent of focus group and community member subjects reported that english was the primary language they spoke at home. Interestingly, 71% of male subjects chose English and Spanish as the primary language they spoke at home, while 75% of female subjects chose English and 25% chose Spanish. Forty six percent of subjects reported that they spoke English as a second language and 73% reported that they spoke Spanish as their second language. Again, 71% of male subjects reported English as a second language, while 25% of female subjects reported
English was a second language and 87% reported Spanish as a second language.

This line of questions appeared to be confusing for this sample bilingual subjects. The intent of these questions was to gather information regarding primary and secondary language spoken, and perhaps give some insight into English language proficiency. However, several subjects chose both English and Spanish in response to primary language spoken at home as well as second language spoken. It is possible that these unvalidated questions were worded in such a way that was confusing for subjects. Male subjects, who were reportedly less educated, also seemed to answer the question incorrectly more often than women. It is also plausible that, these questions may be asked in a way that is more recognizable and applicable to bilingual subjects. This line of questions does suggests that nearly all of the subjects were bilingual (Spanish and English) to some degree. However, no other deductions can be made given the obvious ambiguity of the question and the way in which the question was answered.

_Duration of Diabetes Diagnosis._ For all focus group and community member subjects, 6% did not answer the question regarding how long they had been diagnosed with diabetes; 40% reported 1-5 years; 6% reported 5-10 years; 26% reported 10-15 years; 20% reported 15-20 years; and no subjects reported > 20-25. See Graph 4 in Appendix L. Fourteen percent of male subjects did not answer the question regarding how long they had been diagnosed with diabetes; 28% reported 1-5 years; 14% reported 5-10 years; and 42% reported 10-15 years. Fifty percent of female subjects reported they had been diagnosed with
diabetes for 1-5 years; 12.5% reported 10-15 years; and 37% reported 15-20 years.

Comparing male and female subjects in this sample revealed that female subjects (50%) were more likely to report that they had been diagnosed with diabetes between 1-5 years, while male subjects were more likely to report 10-15 years. There were no other significant differences or findings from this question. Given this relatively small sample, and without any truly contrasting findings, no deductions can or should be made from the reported answers to this line of questions.

**Behavioral Data Analysis**

Behavioral data was collected to determine if there were significant differences in self-care behavior between men and women in the sample; as well as provide context to subjects’ reported experiences. Behavioral data included survey questions regarding frequency of exercise, adherence to medications, diabetes control, and family support. The frequency of cardiovascular exercise was evaluated as studies show that *Familism* may also affect self-care agency when it comes to physical activity (Wen *et al.* 2004). Adherence to recommended diet was evaluated given studies show *that* efforts to care for the family may actually interfere with Hispanic adult’s compliance with recommended treatment (Oomen, *et al.* 1999).

Diabetes control and outcomes are directly correlated with self-care behaviors and activities. Adherence to diabetes medications, other medications
and subjective diabetes control was evaluated given studies report Hispanics with T2DM experiencing higher medication non-adherence compared to non-Hispanic white diabetics (Compton, Haack and Phillips, 2010); and have higher rates of diabetes complications (retinopathy, neuropathy, and lower leg amputations) than do non-Hispanic whites (Ezzati et al. 1991). Family Support & Diabetes Management Support was assessed given the literature indicates that *Familism* may demonstrate diabetes self-care benefits related to the support received from their close-knit family relations (Perez and Cruess 2014). Additionally, research suggest that Hispanic families often help with diabetes self-care (Mosavel and Thomas, 2009; Laroche and colleagues 2009).

*Frequency of cardiovascular exercise.* For all focus group and community member subjects 6% of subjects did not answer the question regarding frequency of performing cardiovascular exercise (walking, biking etc.); 20% reported 5/7 days per week; 33% reported 3/7 days per week; 13% reported 2/7 days per week; 6% reported 1/7 days per week; 20% reported they did not exercise; and none reported 7/7 days per week, 6/7 days per week, or 4/7 days per week. See Graph 5 in Appendix L. Fourteen percent of male subjects reported exercising 1/7 days per week, 42% reported 5/7 days per week; 28% reported 3/7 days per week; 14% reported 2/7 days per week and none reported they did not exercise. Thirty-seven percent of female subjects reported they exercised 3/7 days per week; 12.5% reported 2/7 days per week; 12.5% reported 1/7 days per week; and 37% reported they did not exercise. Male and female subjects appear to both report that they exercised 3/7 days per week in relatively
equivalent accounts. However, only female subjects reported that they did not exercise (37%). Otherwise, there no significant deductions could be made from this line of questions.

Adherence to recommended diet. For all focus group and community member subjects, 46% reported that they ate foods recommended by healthcare providers (doctors/nurses/dieticians) 7/7 days per week; 13% reported 5/7 days per week; 6% reported 4/7 days per week; 6% reported 3/7 days per week; 6% reported 1/7 days per week; 33% reported they did not eat their recommended diet; and none reported 6/7 days per week or 2/7 days per week. Graph 6 in Appendix L. Forty two percent of male subjects reported that they ate foods recommended by healthcare providers (doctors/nurses/dieticians) 7/7 days per week; 14% reported 5/7 days per week; 14% reported 3/7 days per week; and 28% reported they did not eat their recommended diet. Twenty five percent of female subjects reported that they ate foods recommended by healthcare providers (doctors/nurses/dieticians) 7/7 days per week; 12.5% reported 5/7 days per week; 12.5% reported 4/7 days per week; 12.5% reported 1/7 days per week; and 37% reported they did not eat their recommended diet.

Approximately one third of focus group and community member subjects reported that they ate their recommended diet 7/7 dys per week. Interestingly, approximately one third of these subjects also reported that they did not eat their recommended diet. Male subjects reported eating recommended diet 7/7 days per week at higher rates than female subjects. Female subjects were slightly more likely to report that they did not eat their recommended diet. Given the
small sample size, these rates are the difference of 1-2 subjects reporting on a given data point, and thus, no statistical significance or weight should be ascribed to this result.

Adherence to diabetes medications. For all focus group and community member subjects, 6% did not answer the question regarding number of days they took all of their diabetes medications; 73% reported 7/7 days per week; 6% reported 6/7 days per week; 13% reported they did not take medications for diabetes; and none reported 5/7 days per week, 4/7 days per week, 3/7 days per week, 2/7 days per week, 1/7 days per week, or that they did not take their prescribed medications. See Graph 7 in Appendix L. Twenty eight percent of male subjects did not answer the question regarding number of days they took all of their diabetes medications; and 85% reported they took their diabetes medications 7/7 days per week. Twelve-point five percent of female subjects did not answer the question regarding number of days they took all of their diabetes medications; 62% reported 7/7 days per week; 12.5% reported 6/7 days per week; and 25% reported they were not prescribed medications for diabetes. Overall, the most subjects in the sample reported they were relatively adherent to taking medications prescribed for diabetes. There were no significant differences between men and women regarding reported diabetes medication adherence.

Adherence to other medications. For all focus group and community member subjects, 6% did not answer the question regarding number of days per week they took all of their other medications (not prescribed for diabetes); 73% reported 7/7 days per week; 6% reported 6/7 days per week; 6% reported 1/7
days per week; 6% reported they were not prescribed any other medications; and none reported 5/7 days per week, 4/7 days per week, 3/7 days per week, 2/7 days per week, 1/7 days per week, or that they did not take other prescribed medications. See Graph 8 in Appendix L. Fourteen percent of male subjects did not answer the question regarding number of days per week they took all of their other medications; 85% reported 7/7 days per week; and 14% reported they were not prescribed any other medications. Sixty two percent of female subjects reported that they took their other medications 7/7 days per week; 12.5% reported 6/7 days per week; and 12.5% reported 1/7 days per week. Overall, the most subjects in the sample reported they were relatively adherent to taking other prescribed medications (not prescribed for diabetes). There were no significant differences between men and women regarding reported other medication adherence.

Diabetes control. For all focus group and community member subjects, 46% reported that their diabetes was well controlled (fasting glucose readings 130-150); 40% reported fair control (fasting glucose readings 130-150); 13% reported uncontrolled (fasting glucose readings 150-200); 13% reported they did not know what their blood glucose readings were; 6% reported they did not check their glucose readings; and none reported they their diabetes was poorly controlled (fasting glucose readings greater than 200). See Graph 9 in Appendix L. Forty two percent of male subjects reported their diabetes was well controlled; 42% reported fair control; 14% reported uncontrolled; and 14% reported they did not know what their glucose readings were. Fifty percent of female subjects
reported their diabetes was well controlled; 37% reported fair control; 12.5% reported uncontrolled; 12.5% reported they did not know their glucose readings; and 12.5% reported they did not check their glucose readings.

Female subjects were slightly more likely to report well controlled or fairly controlled blood glucose levels. Reported glucose control was relatively equivalent between genders. Of note, some subjects chose more than one level of control (i.e. well controlled and uncontrolled). For subjects with poor adherence to recommended diet, blood glucose levels may fluctuate in extremes. It is plausible that subjects’ glucose readings were both controlled at times and uncontrolled at other times; and would explain why some subjects chose more than one level of control. However, in context, there were no significant differences between groups or trends worth noting.

*Family support.* Subjects were asked to check all from a list of community support. For all focus group and community member subjects, 26% reported that they considered parents to be a part of their family support; 26% reported siblings; 26% reported children; 13% reported grandchildren; 6% reported cousins; 13% reported friends; 13% reported extended family; 6% reported neighbors; 6% reported PCAs (personal care assistants); 13% reported they did not have family support; 46% reported their spouse; and none reported in-laws or church members. See Graph 10 in Appendix L. Twenty eight percent of male subjects reported that they considered parents to be a part of their family support; 28% reported siblings; 57% reported children; 14% reported grandchildren; 14% reported cousins; 14% reported friends; 14% reported
extended family; 14% reported neighbors; 14% reported they did not have support; and 57% reported their spouse. Twenty five percent of female subjects reported that they considered parents to be a part of their family support; 25% reported siblings; 37% reported children; 12.5% reported grandchildren; 12.5% reported friends; 12.5% reported extended family; 12.5% reported PCAs; 12.5% reported they did not have any family support; and 37% reported their spouse. Spouses (46%), Siblings (26%) and children (26%) were most frequently reported family support. Male subjects reported their children and spouses at higher rates than female subjects. Otherwise, reported family and community support was relatively uniform between male and female subjects.

*Diabetes management support.* For all focus group and community member subjects, 6% of subjects did not answer who helped them most with managing their diabetes; 26% reported parents; 20% reported siblings; 20% reported children; 6% reported grandchildren; 13% reported friends; 6% reported extended family; 33% reported doctors; 20% reported nurses; 13% reported PCAs; and 46% reported spouses. See Graph 11 in Appendix L. Fourteen percent of male subjects did not answer the question regarding who helped them most with managing their diabetes; 42% reported parents; 28% reported siblings; 28% reported children; 14% reported grandchildren; 28% reported friends; 28% reported doctors; and 58% reported spouse. Twelve-point five percent of female subjects reported that their parents helped them most with diabetes; 12.5% reported siblings; 12.5% reported children; 12.5% reported extended family; 37% reported doctors; 37% reported nurses; 25% reported PCAs; 37% reported
spouse. Both male and female subjects reported parents and spouses as sources of support. Male subjects were somewhat more likely than female subjects to report parents (42% vs 25% respectively) and spouses (58% vs 37% respectively) as a source of support than female subjects. Male subjects were more likely than females to report siblings (28% vs 12.5%), or children (28% vs 12.5%) as sources of support. Female subjects included nurses as a source of support, while male subjects did not.

**Qualitative Data**

*Traditional gender roles*

Focus group subjects were asked to discuss their role in their family in general, as well as in relation to their diabetes management. Responses regarding family role were mixed; with male and female subjects stating they were breadwinners. Interestingly, none of the subjects described themselves as homemakers. It is unclear if this is related to language or if the cohort simply did not have any homemakers. In the all-male focus group, all of the subjects described themselves as being disabled for one reason or another. Additionally, several of the male subjects described themselves as disabled when asked about their family role. Female subjects described specific traditional roles as being the “glue” of their family. One individual in the all-female group, expounded on this point further by discussing her frustration with being dependent on her family to help her with her diabetes as her traditional role was to care for them - “they think they have to take care of me. Which is aggravating to me right now”.

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Subjects in the all-male group overwhelmingly reported that their family status did not affect their diabetes management. Subjects in the all-female group described frustrations with deciding between food preferences for children versus recommended diet - “Well in my case it does because I’m around kids and you know kids like sweets and kids ask for stuff and I’m weak”. They also reported concerns about their illness causing emotional distress for family members - “What does affect them--if I’m sick they’re sad and it affects everybody in my family, you know”. Finally, female focus group members discussed concerns about their ability to make lifestyle changes to prevent their children from developing diabetes - “So like, it helps me in a way, now because I don’t want them to get diabetes when they’re older”.

In response to the effect of traditional roles on diabetes management, female subjects reported difficulty with prioritizing self-care due to family demands as well as disease management generally being a low priority at family gatherings –

“I think about others than myself. With the situation that my husband is he is more important to take care of and be there all the time than taking care of myself. I still do take care of myself, but not as well like I take care of others. Even at work, what I do for my work I take care of the elderly. I think about them more than me”.

When asked if there were certain PRiH cultural beliefs about managing diabetes that conflicted with their healthcare providers’ recommendations, female subjects in the mix gender focus group described conflicting obligations
regarding self-management activities and daily living - “My not checking myself, like in the morning checking my blood sugars and stuff like that. I'm in a rush always and in and out so that's something I have a lot of hard time”.

Subjects in the all-female focus group described difficulty with incorporating recommended diet with traditional food preparation - “we like fry everything it's different our culture's just different that way”. They also described difficulty with their family sometimes encouraging non-therapeutic diet –

“They're the ones that push me, I used to weight more and... they eat unhealthy too, though. They can be that one too, they'll be like, “come on, let's go to Denny's today” and I'm like “ehh, it's too late for that” and they'll be like, “Aw...okay” so they push me but I push them too”.

**Gender and medical management**

When asked directly, there was no consensus amongst medical providers regarding perceived differences in gender as a variable affecting medical management. Two of the five providers did not believe gender was a factor in medical management. One of the five reported that they found female patients and caregiver's/family members more reliable sources regarding their own health or a family member's health.

However, when asked to expound on the effects of gender on diabetes self-care, one medical provider reported women face challenges of trying to “put other people's needs ahead of theirs”, thereby creating a barrier to self-care. Two of four providers reported that the effect of gender on self-care was variable
depending on the family unit and other factors like education. Two of four 
providers reported other confounding factors related to gender and self-care that 
included mental health problems with female patients - 

“What I really think is more of my female patients with diabetes have more 
severe mental health disorders. So, I have a harder time doing their treatment 
because of the mental health barriers. There’s more anxiety or other mental 
health issues that get in the way of the care. The men I take care of, for the most 
part, all have partners who are really helping them with the treatment”.

Two of four providers discussed an increased likelihood that a male 
patient will have additional support from female caregivers - 

“When I’m seeing female patients, they are frequently - it is rare that there’s a 
male member that’s involved with the care. And unless there’s a daughter or 
mother that’s assisting, I have less clarity about what’s actually going on for the 
patient”.

Three of the five providers reported that traditional gender roles regarding 
female family members being in charge of meal preparation directly affects their 
patient’s diabetes self-care - 

“I think in a unit where the women are taking more of sort of cultural female role 
where they are sort of in charge of the cooking and meal perpetration, it can be a 
little more challenging, so if I have the man come in but they are not really doing 
any of the food prep or food shopping or meal preparation then it’s a little hard to 
engage them in their care than if a woman was there”.
Self-care and gender

Focus group subjects were asked about the relationship between their gender and diabetes management. Overall subjects agreed that diabetes did affect them personally. However, there were some differences between genders in these responses. Subjects in the all-male group overtly stated that diabetes did not affect their standing as a male in their family.

Prioritizing family over self

When subjects were asked about the effect of diabetes management on their spousal relationship, female subjects in the mixed gender group described difficulty with prioritizing other family members over themselves - “The thing is you can only be so strong to help everybody else and then they say you skip yourself”. Specifically, female subjects in the mixed gender group described difficulty managing different diets in their homes –

“Yes, because they don't eat some of the things that I eat, so it's hard. I don't... I cook my own food, or I order out, a chicken salad or something. But I don't eat the same things that everybody eats in my house. So, it's, like, hard for me”.

Spousal relationships

Focus group subject were asked to specifically describe the effect of managing diabetes had on their spousal relationship. Subjects in both the male and female groups referenced the effect on sexual function. Subjects in the male group mentioned erectile dysfunction specifically. Subjects in the all-female
group made reference to the effect on sexual problems without mention of specific difficulty. Again, subjects in the female group mentioned feeling torn with regard to preparing food for a non-diabetic spouse - “It does with the eating because if he wants to go out to eat we have to find a place that has something for me to eat. He wants me to eat what he eats”. Additionally, they mentioned difficulty with accommodating a spouse during social activities - “it takes a lot of time to manage diabetes; you have to check it, you can’t leave the house without eating something. It’s not like you can pick up and just leave”. There was also mention of time spent with spouse being affected by diabetes management - “Yeah, because “oh baby let’s go”, “no, I have to sit down and do my breakfast and do this, that”. I think there’s a little effect, yeah it does in many ways”. Finally, they discussed the generally negative perception of burden of diabetes management - “my ex-husband, we didn’t have a good relationship, was like, “oh my god, I have to deal with you” he has diabetes, too, and he has it worse than me”.

**Research Question Two**

Question two, “How can clinicians use Familism to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?”, and corresponding sub questions G and H, were based off of the third study assumption; that HCPs do not generally consider Familism as a factor in T2DM self-care. Sub questions G and H were, “How can health care providers facilitate the positive effects of Familism on T2DM self-care?” and “How do health care providers prevent the
negative effects of *Familism* on T2DM self-care?”, respectively. Quantitative data is presented first, followed by qualitative data.

**Sub-question G and H**

The second research question, “How can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?”, was based on the third study assumption that Healthcare providers do not generally consider *Familism* as a factor in T2DM self-care. To gain context for the HCP experience, demographic data was collected. This data included general experience; experience with the study population; and Spanish language proficiency. Quantitative data is presented first in this section, followed by qualitative data.

**Quantitative data**

**General experience**

Five HCPs were interviewed for this study. Three of the HCPs were physicians and two were advanced practice nurses. No Physician Assistants, nurse educators or Registered Nurses were interviewed. Of the five HCPs interviewed, two specialized in internal medicine, three specialized in primary care and one specialized in family practice/medicine. None of the HCPs were certified as diabetes educators. Two HCPs reported that they had practiced in their clinical role > 10 years, others reported 3-5 years, 7-10 years, and 5-7 years.
**Experience with study population**

One HCP subject reported that 15-20% of her patients were diagnosed with T2DM. The other four HCP subjects reported >20% of their patients were diagnosed with T2DM. Two HCP subjects reported that 60-70% of their patients were Hispanic or Latino. Other HCP subjects reported that their percentage of Hispanic/Latino patients was 40-50%, 70-80%, and 80-90%. Two HCP subjects reported that 60-70% of their Hispanic/Latino patients identified as PRiH. Two HCP subjects reported that 40-50% of their Hispanic/Latino patients identified as of PRiH, and one HCP subject reported that 80-90% of his Hispanic/Latino patients identified as PRiH.

**Spanish language proficiency**

Four of the five HCP subjects spoke English as their primary language and one spoke Spanish as a primary language. Two of the HCP subjects spoke Spanish as a second language. One spoke English and another spoke German. One subject did not answer the question regarding second language.

**Qualitative Data**

**General Experience Managing PRiH with T2DM**

There were no particularly strong themes in the responses from HCPs regarding their general experience managing PRiH patients with T2DM. Regarding aspects of PRiH culture that may affect the management of their patient’s diabetes, HCPs reported traditional diet, limited exercise,
socioeconomic factors, and mental health issues, which they believed were barriers to self-care. One HCP remarked that the line of questioning did not include mental health problems as a potential factor - “You know, what’s not in the list that you said is, are there mental health issues that are also involved here?”

**Traditional PRiH diet**

Healthcare providers reported that the PRiH diet may conflict with medical recommendations. There was no particular consensus amongst providers regarding methods to address cultural factors, displayed by family or patients, that may conflict with their recommendations. Each provider presented an individualized approach to managing cultural conflicts. However, each provider reported that their approach was effective. There were no themes in this regard.

Focus group subjects confirmed this report from HCPs, with several subjects in the mix gender focus group generally reported that their families did not help them adhere to their therapeutic diet. Other subjects reported no support at all or family members not encouraging diet control or actually encouraging non-adherence to diabetic diet - “No they say eat. They say eat. Eat. One day no- no kill you. There’s Latinos like that”

**Should HCPs involve Family in Diabetes Care?**

Focus group subjects were asked if their healthcare providers should talk to their families about their diabetes care. Generally, subjects in the mix gender
focus groups shared that they thought it would be a good idea for healthcare providers to talk with their families about their diabetes –

“Yes, it’s be great. I wouldn’t have a problem at all having my family, my doctor, we’ll all meet together and have a conversation about how hard diabetes – if you we don’t take care of ourselves it’s going to be damaging our lives pretty much because we’ve already seen it throughout my whole family”.

Subjects in the all-female focus group were somewhat split in their response to this question. Some subjects shared that they though it was a good idea for healthcare provider to involve their families in their diabetes care and gave examples of how this was helpful in the past.

“my son came in one day with her--with his girlfriend and said, “my mom is taking too much meds, what is it that she has to do for the diabetes?” and we worked and she cut down a lot of my pills which is great.”

“She can learn a lot about the diabetes, what’s going on, you know, with me and all that, so she could learn more, what to do and all that”.

Subjects in the all-male group were also somewhat split in their response to this question. Some subjects suggested that it was a good idea to involve their family in office visits. Other subjects suggested that HCPs shouldn’t talk to their family members about their diabetes care. When asked to clarify why healthcare providers shouldn’t talk to a patients’ family, one subject in the mix gender group believed that healthcare providers shouldn’t talk to his family as his family did not generally talk to him about his diabetes - “No [they shouldn’t] because if they don’t talk to me – my children, they’re adults. If they don’t talk to me and ask me
– how I’m doing, how I’m feeling – why will I tell my doctor to bother?”. Another subject in this focus group mentioned that having his family involved in his diabetes care would be an invasion of sorts –

“I know it's their problem, but they don't need to know everything about what's going on with me. If I want to tell them, I tell them. If I don't want them to know about it, I don’t have to tell them”.

Some subjects in the all-female group described skepticism of the utility of family involvement in their office visits and hinted at independence –

“I didn't understand it then I wouldn't mind them bringing in, like, “oh, bring your sister or bring whoever” so they can explain it so maybe you can understand it and ultimately, I think, you know, it's up to us to take our meds and do what we’re supposed to do, you know?”.

Additionally, some subjects in the all-male group expressed skepticism about involving family members in their medical care unnecessarily. Female family members were mentioned.

“Only if like an emergency, or anything like that. You like, your wife or your mother, you know”

“they should talk to them, like I said, but, it's let me see, it's if you want him to talk to them, he should ask you if you want that information released to your family. But if it's not life threatening, I think it should not be”.

Community member subjects were asked if they believed that HCPs should include their family members in their diabetes care. All community member subjects reported that they believed HCPs should involve family in their
diabetes care and that this involvement would be helpful - “Yes, because you know, they explain it to me, also they explain it to them you know, so they know what’s going on with my diabetes.”

_Encouraging family involvement diabetes in care_

Healthcare providers were asked how they could best help families provide better care to their patients. (i.e. teaching, appointments, best way to engage family members, and engagement response from families). Two of the five HCPs discussed specific diabetes education points (diet, exercise, symptom recognition, disease pathology) as what they believe the family should gain from appointments. Additionally, two of the five HCPs described the potential usefulness of incorporating family directly into diabetes education for patients. There was consensus amongst HCPs as to their preference for having family members at the visit and they described that they believed this may be helpful. There was no consensus as to whether or not family should attend all visits or selected visits.

_Best ways to engage family members_

Healthcare providers were asked what they believed was the best way to engage family members in their patients' diabetes care. Some HCPs suggested incorporating the PRiH family into visits and discussing medical and behavioral recommendations. Two of five HCPs mentioned expressing empathy and trust as essential to engaging with family during visits. One seasoned physician noted
that his training did not prepare him for incorporating family in disease management.

“I don’t think I’m well trained in how to do that. And I actually think people from nurse practitioners, I think nurse is better trained in how to do that than I am and it’s not part of my skill set to do that. I think what I do which is I can tell you about the disease, I can tell you about the complications, I can tell you about how the treatments are done and all of that. I don’t- I’ve not really been trained in behavioral management for a family”

Most community member subjects suggested inviting family members to appointments as the best way for HCPs to involve their family in their care -

“Maybe when you have an appointment, you know to bring one of the relative for something that is you know to the- to the doctor you know and things like that”. One subject suggested calling family members to inform them of his health, what his management entails, and what they can do to help him - “The best way is Sometimes they call my family and they let them know what’s going on or what I’m supposed to do, or what they’re supposed to help me [with]”.

Projected response to engagement request

There was consensus amongst HCPs that simply asking the family member to engage in care would be sufficient to getting a family to engage. There was also a consensus that request from HCPs to include family members in diabetes care would be received with a positive response from family members.
“I think that’s kind of a no brainer for most of the families that I work with. Like they’re already involved, I think they may feel like it’s a little odd if someone asked them, its and interesting sounding questions, would you like to be involved in your grandfather’s diabetes care because I think the answer for most of our patients is, yes I would like to be involved with his care”.

Focus group subjects were also asked how their families would respond to being asked to be more involved in diabetes care appointments. Most subjects in the mix gender group shared that their families would react positively to being asked to help or be more involved in their diabetes care –

“I think most families you would find at least one family member who would be like involved”

“My family will respond perfectly fine with it, because they know that I have a real bad, hard time with my diabetes. So, my family will love to get more help about my diabetes”.

One subject in the mix gender group shared that it his preference would be to only involve family when he was not doing well with his diabetes control or if he was ill –

“I think that it would be helpful in the critical stages. But if you’re doing good for now, you know, they... the family knows "oh, Dad’s doing good." So... but if in my next month appointment with my doctor, and my doctor says "hey, there’s something wrong with your diabetes, here." You know, that's the one, I would think would be more helpful, like that. The doctor doesn't have to call my
daughter, "hey, yeah, he’s doing good. Oh yeah, we'll check his insulin." I don’t think it has to go that way”.

This question was not discussed in the female focus group. However, subjects in the all-male focus group generally shared that their families would likely be interested in being more involved in their diabetes care - “They would talk to the doctor and I listen to them. They'd see what we can do together to help the person”.

**Best way for families to help patients**

Healthcare providers were asked how the PRiH family could become more engaged in their family members care with respect to appointments and teaching. There was no particular directional response from HCPs regarding how to get families more involved in their family members’ appointments. One HCP suggested the PRiH families should ask about the general diabetes plan of care – “Ask “what the diagnosis is and what the plan is. Medications. Dieting. Exercise. Simple diabetic stuff”. Regarding the best way for the PRiH family to become more engaged in teaching, three of five HCPs suggested the family should try learning about dietary recommendations. One HCP suggested peer to peer learning models for families - “So, there ought to be a way that families could learn from families how to do this. And by the way, patients should learn from patients how to do this. Because they understand things about their homes and their lives that we won’t know…"
Focus group subjects were asked what healthcare providers could do to help teach families to be more helpful with diabetes management. Subjects in the mix gender focus groups suggested that healthcare providers talk to their spouse (wife) and family about their diabetes care -

“they [should] tell my wife, or whatever, my family so that they know what's going on. So, for me, it's very important, the doctor to say to my family what's going on with me. So, that's how I feel”

“it's important for my family to know if there’s anything real bad happening to me. Yes, I would love my doctor to speak to my family about it”

“It's very important they talk, they in communication with my family so they know what's going on with me, though. So, in case something happens, so... my family know what's going on”.

Subjects in the all-male group did not have any suggestions regarding how healthcare providers could teach their family to become more involved in their diabetes care. However, subjects in the all-female group suggested having a nurse assigned to every diabetic patient –

“doctors should have a nurse that with us diabetes or cancer patients, you know, people like that that need a little bit of...extra. They should have a nurse that follows up with us more often, that really cares, more often, 'cause the doctors have like 50,000 patients - all of 'em! But, respect a little more for the nurses, they care a little bit more, just call us, every two weeks maybe, every month”.
Subjects in all focus groups were also given an opportunity to mention any other topics they thought the researchers should have asked. Subjects in the all-male and all female focus groups did not have any suggestions for the study or additional comments.

Subjects in the mix gender group described experiencing their healthcare providers being hyper-focused on one disease (diabetes) –

“Everybody doesn’t understand that so I found with diabetics that also too sometimes the doctors need to see the whole scope. Diabetes is the big diagnosis, but then the thyroid, the cholesterol – how that’s all related. How it marries together”.

There were some suggestions for healthcare providers to better coordinate care and education efforts with each other—

“I know that it’s limited in the amount of time that they have to see you obviously when you’re seeing all these other patients, but maybe it would be helpful to have a specific, maybe once a year – ok, how you doing with these meds? When you introduce new medication the do a really good job here of keeping track of that stuff, like he goes to the weight management – that’s a whole other set of doctors. So, you have two different sets of doctors and you’re getting medication – everybody doesn’t understand how each medication works, they’re called cholesterol medication effects – things that you need to take on an empty stomach. Things like that”.

A recommendation was made regarding specialty healthcare providers, and that they be more aware of other disease processes –
“Yes, I wanted to add that also not just you getting asked the questions, but specialist sometimes they don’t ask questions neither because I have herniated disk on my lower back and I went over and got a cortisone shot and my mom had told me that the cortisone shot raises up your blood sugar so the thing is the doctor went ahead and put the shot – I like to be a smartass sometimes I asked him after he put it. Is it true if I’m diabetic it would raise the blood sugar and he got surprised? He got surprised that I ask the question and he answered – yes, it is true. I said – it’s nothing that I have to worry about, but I want to be…Informed”.

Socioeconomic factors

One healthcare provider who identifies as being “from Puerto Rico”, added an additional comment at the end of his interview. He described the PRiH culture is very complex and suggested that consideration be given to socioeconomic status; generational status in the continental U.S.; and cautioned regarding the Anglo view and bias of the research study -

“I think there’s a lot of variability in terms of what the Puerto Rican community or what the Puerto Rican culture means. It’s complex, if you live in Puerto Rico, which is an island, then you’re going to think like an islander, vs if you were born in the US and then as an American Puerto Rican you’re going to think differently. There is more privileged thinking. It all depends on the school you went to here, so if you went to Holyoke for example and you stayed in the ghetto, you’re going to create inbreeding, so a lot of strong cultural beliefs will stay in that community if you expand the horizons, you’re talking about different mindset and thinking.
It’s very complex. Zero, First generation, and second generation. One thing about this study is that you’re thinking or trying to understand things from the American perspective, from your own bias and you’re dealing with a whole different culture of bias. If you talk to Asians, Asians actually have a similar mentality. Greeks, Italians, Spanish, portages, you know how the Anglo-Saxon calls those? Steaks to picks. The ones who always don’t plan, they get in debt, then they are….it’s two separate mentalities that shaped the world or the millennia. And that’s my own bias”.

Summary of Key Findings

Demographics

All of the HCP subjects had well established professional experience years (>3 to > 10 years). Additionally, HCP subjects reported extensive exposure to T2DM with most reporting that >20% of their patients were diagnosed with T2DM. Similarly, the reported percentage of PRiH patients in the HCPs panels ranged from as low as 40%-50 to 80-90%. Regardless, HCP subjects were amply qualified to provide expert opinions regarding the study questions. HCP subjects reported managing a population of patients with higher rates of T2DM than the national average (9.3% of general population have T2DM); with greater concentration of Hispanic adults than the general population (Hispanics = 16.7% of general population); and higher percentage of PRiH patients than the general population (PRiH = 1.5% of general U.S. population).
Questions regarding “race” may not necessarily be applicable to the PRIH population. Perhaps ethnicity is a more relevant category or descriptor. There were no significant differences between the aggregate, male, and female cohorts regarding marital status.

The reported employment status data was consistent with the employment rates the region where this study was conducted. Men in this sample were twice as likely to report disability. Otherwise, there were no significant differences between men and women in the sample.

Overall, this sample reported lower education levels compared to the general PRIH population. When comparing male subjects to female subjects, male subjects did not report any secondary education (post high school). Female subjects, on the other hand, reported higher levels of education compared to their male counterparts regarding secondary education. However, rates for having less than a 9th grade education were relatively equivalent between men and women in this sample.

Questions regarding primary language showed to be confusing for this sample bilingual subjects. It is possible that these unvalidated questions were worded in such a way that was confusing for subjects. However, answers to this line of questions does suggest that all of the focus group and community member subjects were bilingual (Spanish and English) to some degree. However, no other deductions can be made given the obvious ambiguity of the question and the way in which the question was answered.
Female focus group and community member subjects (50%) were more likely to report that they had been diagnosed with diabetes between 1-5 years. Male subjects were more likely to report they had been diagnosed between 10-15 years. There were no other significant differences or findings from this question.

Finally, this data is limited in that the sample was relatively small. Given this was relatively small sample, and without any truly contrasting findings, few deductions can or should be made from the reported answers to these questions. This data set does, however, give context to the overall discussion.

**Behavioral Data**

Male and female subjects both reported that they performed cardiovascular exercise in relatively equivalent accounts. However, only female subjects reported that they did not exercise. Male subjects reported eating recommended diet 7/7 days per week at higher rates than female subjects. While, female subjects were slightly more likely to report that they did not eat their recommended diet.

Most subjects in the sample reported they were relatively adherant to taking medications prescribed for diabetes as well as other medications not prescribed for diabetes. There were no significant differences between men and women regarding reported diabetes medication adherance. However, female subjects were slightly more likley to report well controlled or fairly controlled blood glucose levels. Reported glucose control was relatively equivalent between
male and female subjects. There were no significant differences between groups or gender.

Spouses, Siblings and children were the most frequently reported family members providing support. Male subjects reported their children and spouses at higher rates than female subjects. Otherwise, general family and community support members were reported at relatively uniform rates between male and female subjects.

Both male and female subjects reported parents and spouses as sources of diabetes management support. However, male subjects were somewhat more likely than female subjects to report parents and spouses as a source of support than female subjects. Male subjects were more likely than females to report siblings or children as sources of support. Female subjects included nurses as a source of support, while male subjects did not.

Given the small sample size, the differences between genders in these reports were sometimes the difference of 1-2 subjects reporting on a given data point, and thus, no statistical significance or weight should be ascribed to these results. No significant deductions can or should be made from this data. However, these questions add context and depth to the discussion on the research topic.

**Experiences with Self-Care**

**General factors**

HCPs reported traditional diet, limited exercise, socioeconomic factors, and mental health issues, and mental health as elements of PRiH culture that
may affect diabetes self-care for PRiHs with T2DM. Additionally, HCPs reported that low health literacy may be a factor affecting diabetes self-care for PRiHs with T2DM. However, focus group and community member subjects were generally aware of the effect of the carbohydrate rich PRiH diet on T2DM. This suggests that lack of understanding or health literacy may not be as strong a factor in decision making.

*Ambivalence*

HCPs describe high prevalence of T2DM and resulting ambivalence about self-care in PRiH community. Community member subjects described lack of caring; denial; and lack of awareness as reasons for lack of positive family involvement. Community member subjects also described ambivalent family attitudes towards diabetes as making their diabetes management difficult.

*Sociocultural stressors*

Focus group subjects did report that they experienced a relationship between diabetes self-care, social stressors, decreased motivation and depression. Specifically, social isolation for female PRiHs may contribute to these social stressors. This social isolation for female subjects will be discussed in subsequent sections within this chapter.

*Traditional diet*

Across all focus groups adhering to a therapeutic diet was the most mentioned cultural challenge when managing T2DM. Focus group and
community member subjects reported abundance of traditional foods that conflicted with diet recommendations; lack of healthy options in PRiH eating establishments; centrality of traditional food within PRiH culture; and strong nurturing maternal culture; as cultural factors affecting diabetes self-care. These struggles with traditional diet were contextually different for male and female focus group subjects. Male focus group subjects mentioned difficulty with navigating diet at PRiH restaurants. Whereas, female subjects reported conflicts with feeling obligated to prepare traditional foods for their family, and traditional matriarchal roles that did not necessarily allow individuality during communal meals.

There was a consensus amongst all subjects (focus groups, HCPs, community members) that the traditional PRiH diet was a central and vital component of PRiH culture. All subjects reported that the PRiH family and traditional diet may conflict with medical recommendations. Healthcare providers unanimously agreed that the PRiH diet played an integral role in chronic disease management for PRiH patients. Importantly, there were no themes from HCP interview suggesting there was a particular method for HCPs to address these cultural conflicts.

**Cost of therapeutic diet**

The cost of a “healthy” or diabetic diet was discussed as a continued source of frustration. However, this sample of PRiH subjects with T2DM generally shared a lower socioeconomic status and education. Some of the
difficulties expressed by these subjects may differ from those with higher education, income and generally of higher socioeconomic status.

**Socioeconomic considerations**

One HCP who identified himself as being “from Puerto Rico”, added an additional comment at the end of his interview, where he reported that the PRiH culture is very complex, and that reports and responses from subjects should be considered in context given the variances in socioeconomic status and education within the general PRiH population. Given the generally lower socioeconomic status and education levels of this sample of PRiHs, all of the reports and findings from this sample may not be generalizable to the PRiH population at large. Socioeconomic considerations will be discussed in greater detail in chapter 5.

**Traditional family role as a factor**

Subjects responses regarding traditional family role were mixed; with male and female subjects stating they were breadwinners; and many of the male subjects reporting they were disabled for one reason or another. Female subjects expressed frustration with being considered a dependent on their family and described themselves as caretakers for their families. Male subjects overwhelmingly reported that their family status did not affect their diabetes management. However, female subjects reported frustrations prioritizing a traditional diet for family versus a therapeutic diet for themselves; concerns that
their illness may cause emotional distress for family members; concerns about their ability to make lifestyle changes; and concerns about preventing their children from developing diabetes. This point was further illustrated as female subjects reported difficulty with prioritizing self-care due to family demands as well as disease management generally being a low priority at family gatherings. Furthermore, female subjects described conflicting obligations regarding self-management activities and daily living; difficulty with incorporating recommended diet with traditional food preparation; and difficulty with their family sometimes encouraging non-therapeutic diet.

HCPs generally reported that they did not believe that gender was a factor in medical management of T2DM. However, HCPs did report that in their experience PRiH female patients tended to prioritize their family's needs over their own. Which is consistent with the shared experiences of female focus group members.

HCPs also suggested that female family members were more likely to be in a caregiving role than male family members, which is also consistent with reports from community members. Finally, HCPs suggested that female family members in traditional roles had a direct effect on their patient's diabetes self-care. Again, this is consistent with the reported experiences from focus group members.

Focus group subjects generally reported that diabetes affected them directly. However, while male focus group subjects reported the disease did not affect their family role, female subjects reported several ways their traditional
roles were affected. Female subjects reported difficulty with prioritizing other family members over themselves; and difficulty managing different diets in their homes. Specifically, they reported difficulty with preparing food for a non-diabetic spouse. This is consistent with the experiences reported by HCPs. One HCP went so far as to say she believed diabetes self-care management may be easier for PRiH patients when there was more than one diabetic person in the home.

Male and female focus group subjects reported that T2DM management negatively affected their sexual function and spousal relationship. Males tended to describe erectile dysfunction. However, females tended to describe negative body image as well as difficulty navigating traditional female roles (food preparation, social activities, time management, and negative perceptions) while self-managing T2DM. All focus group members described discomfort with managing a diabetic diet at family gatherings; and frustration and embarrassment with family members taking notice of them attempting to manage their diet. Focus group members described normalcy and ambivalence of diabetes diagnosis in their family/community. HCPs also described this type of communal ambivalence. Additionally, female focus group members discussed a general sense of denial from their respective families as well as their own denial about their T2DM diagnosis.

Some focus group subjects reported and described their experiences as feeling a general lack of family/community support, and most subjects reported that their families were not aware of how they were feeling about the burden of diabetes self-management. Male and female subjects reported difficulty with not
having foods from their therapeutic diet available at family gatherings; and that their families did not make significant effort to provide therapeutic food options. Several female subjects described “cheat days”, on which they would disregard their diabetic diet when attending family/community gatherings. Interestingly, HCPs did not discuss or mention the cost of adhering to the recommended diabetic diet. However, both male and female subjects discussed their concerns about the cost of recommended diabetic diet.

Several subjects described feelings of social isolation regarding diabetes management. Nearly all female focus group members described sadness, fear and despair after being diagnosed with diabetes. Focus group subjects also reported feeling embarrassed when managing diabetes in public and at family gatherings. Nearly all female subjects reported low self-esteem and negative feelings associated with obesity and diabetes. Depression was mentioned passively as being a factor in these negative feelings. This question was not expounded on. However, HCPs also made mention of concomitant mental health problems as a potential factor in diabetes self-care and management for their PRiH patients.

Generally, focus group subjects reported that their family members were aware of their struggles with diabetes management. Subjects primarily reported female family members as supports. Female subjects reported that their families were generally aware of their diagnosis without mention of specific emotional support. Male subjects reported being generally supported, specifically by maternal figures. Additionally, male and female community member subjects
reported that they received more support from female family members than they
did from male family members. They also reported that they believed both
proximity and relational "closeness" to female family members; female family
members having deeper concern for health; and the tendency for female family
members share and talk often; were reasons why female family members were
more involved in their care.

**Family Role in Self-care Maintenance**

Focus group and HCP subjects were asked questions regarding the PRiH
family role in T2DM self-care maintenance activities – recommended diet,
exercise regimen, medication adherence, and follow up with healthcare
appointments. The following are themes derived from this line of questions.

**Diet**

HCPs described the collective nature of the PRiH family as potentially
being positive motivator or a negative inhibitor regarding adherence to the
recommended diabetic diet. Responses regarding the family role was mixed in
the mixed gender group, with some subjects reporting that they did not receive
any support with their therapeutic diet; and some subjects reporting that they
received some maternal support. Male subjects reported they received familial
help with their recommended diet, and described patriarchy and communal
environment as reasons why they received this support. Male subjects
overwhelmingly reported female or maternal family members as supports.
Female subjects also reported they received some dietary support from their families, and specifically referenced female family members as support. Subjects in the all-female group also mentioned difficulty adhering to diabetic diet, as other family members cook meals that are not in line with their recommended diet.

**Exercise**

HCPs report that limited exercise was a factor affecting diabetes self-care for PRiH patients. Focus group subjects, contrarily, reported that PRiH ethnicity or culture was not a factor in their decision not to exercise and suggested that they had lack of support as well as general lack of ambition towards exercise. Additionally, HCPs referenced the collective nature of the family in relation to exercise and motivating the patient; as well as the family role being potentially positive as a motivator or negative as an inhibitor. Focus groups subjects generally reported maternal support and encouragement to exercise. Female subjects were generally less vocal about their family’s influence on their exercise regimen.

**Medication adherence**

Family assistance with medication adherence was variable. Some female subjects in the mixed gender group reported they received no support, however most subjects reported they received support in the form of reminders to take their schedule medications. Male focus group subjects specifically reported maternal support, while female subjects described check-ins from female family members.


**Healthcare appointments**

Healthcare providers reported that the family was important for the office visit due to the collective nature of the PRiH family. They also described the integral role of the head female care giver. Overall, subjects in all focus groups reported low level family support for both general healthcare provider appointments as well as specialty healthcare provider appointments. Subjects who did report their family helped them with health care appointments reported spouses, adult children and female children as sources of support with attending their appointments. Male focus group subjects primarily described self-reliance or maternal support in helping them with their appointments. Female focus group subjects reported female family members helped them with their appointments, or that they had little to no support with attending appointments.

**Family Role in Self-care Management**

**Checking glucose**

There was no consensus amongst providers as to whether or not the PRiH family typically played a role in checking glucose levels. However, most subjects in the mix gender groups referenced female partners, mothers, female siblings, and nephews (PCA) as family members who helped with checking glucose. Female subjects reported that their family members generally did not help with checking their glucose or only checked if they were not feeling well. This is relatively consistent with the observations and experience reported by one
of the HCPs. Most male subjects reported that female partners or female adult children supported them by actively or passively checking their glucose levels.

**Checking for extreme glucose levels**

Subjects in the mix gender groups reported their mothers and female partners helped them by checking them for high or low glucose readings. One HCP reported that in her observation, PRiH families were likely to monitor their diabetic family members for extremely high or extremely low glucose levels, and female members essentially reported this. However, when asked if their family members checked them for symptoms of high or low glucose, female subjects reported that some female family members, sister and daughter were supportive in this kind of monitoring.

Male subjects mostly reported they received active support and monitoring for high or low glucose from female partners or female family members.

**Checking feet**

Most HCPs reported that they did not believe PRiH family members checked their patients' feet, or that family members often over reported this type of monitoring. Subjects in the mix gender group reported their mothers and female partners provided support with checking their feet. This question was not explored in the all-female group. Subjects in the all-male group either mentioned no familial support with checking the feet, or mentioned female children as a source of support with checking feet.
Checking vision

There was no consensus amongst HCPs regarding the role of the family in assessing for vision changes in their diabetic family member. Subjects in the mix gender group reported mothers and female partners as family support with checking for vision changes. Subjects in the all-female group generally referenced female family members or described no family support regarding monitoring for vision changes. Subjects in the all-male group mentioned no familial support with checking for vision changes or female family member support without specific details of this type of support.

Family Role in Self-care Monitoring

Monitoring for significant glucose reading changes

HCPs reported that the PRiH family were typically involved in monitoring their family members for significant changes in (high or low) glucose readings. Specifically, elderly patients were mentioned. In general, focus group subjects also reported that their families were generally involved in monitoring them for very high or very low glucose readings. Both HCP and focus group subjects mostly reported that female family members were primary sources of support.

Monitoring for new/change in symptoms

HCPs shared a consensus that the family is involved to some extent, though variable, with monitoring for changes in symptoms of diabetes. Again, elderly patients were mentioned specifically. Focus groups subjects reported
variable answers regarding their family involvement in monitoring them for new or changing symptoms of diabetes. Focus group subjects referenced their mothers, adult female children, female siblings, and female partners as sources of familial support with monitoring for changes in hyper or hypoglycemic symptoms. Some of these subjects also reported that they were self-reliant and their families were not involved in monitoring them for symptoms of diabetes.

**Monitoring for pain and discomfort**

HCPs unanimously reported that the PRiH family is generally involved to some extent, though variable, with monitoring for pain symptoms. Once again, the elderly and husbands were mentioned specifically as examples of patients whose family typically may advocate for them. Focus groups generally did not report that their families were directly involved in monitoring them for pain per se.

**Family and community members as resources**

Subjects unanimously agreed that community and family were synonymous in the PRiH community. There was a consensus amongst all subjects that 1st, 2nd, 3rd degree relatives as well as other community members may potentially be involved in the caring for PRiH people with diabetes. Notably, male focus group and community member subjects included ex-wives and daughters specifically, while females did not include ex-partners and did include friends. There was also a theme, amongst all subjects and cohorts, that female family members were generally the lead decision makers and most trusted
regarding health. Interestingly, male focus group subjects included spouses, ex-
spouses, and mothers while female subjects included sisters, daughters,
daughter in-laws and sons. Additionally, while HCPs reported that they believed
that PRiH family members often gave medical advice. Focus group subjects
reported that there was more context to these inquiries. For example, male
subjects reported that their families didn’t ask or “sometimes” asked them for
health advice, and nearly all female subjects reporting that their family asked
them for health advice. In context, these findings suggest that female PRiH family
members are a key community resource, the most trusted for health advice, and
most likely to discuss health decisions. Finally, focus group subjects reported
they received medical advice from non-family, non-medical persons. Additionally,
they reported that using home remedies was a relatively common occurrence,
and generally overlooked by HCPs.

There was also a consensus from HCPs and community members that
PRiH families were generally involved in helping with diabetes self-care. All
HCPs reported the potential of the PRiH family to have a positive impact on
diabetes self-care through collective behavioral changes. Focus group subjects
also reported both positive and negative family forces affecting self-care.
Generally, community member subjects reported family members helped with
diet control by encouraging portion control. Some community member subjects
agreed that family being involved in their diabetes care helped make managing
their diabetic diet more manageable. Interestingly, while HCPs reported they did
not experience family impeding or obstructing diabetes self-care, some
community member subjects reported family members actually encouraging non-adherence to diabetic diet.

Inclusion of PRiH family in self-care

Despite the seeming consensus that the PRiH family was a vital component of diabetes self-care, HCPs reported that their decision to involve the family in diabetes care as an afterthought, rather than a component of the plan of care. Community member subjects were relatively uniform in their reports HCPs did not involve their families in their T2DM care. Responses to this line of questions suggests that HCPs may overestimate to what degree they incorporate the PRiH family in their patients T2DM care.

Should HCPs involve family in diabetes care?

Generally, focus group members reported that they believed HCPs should involve their family in their diabetes care and that this would be helpful. Additionally, all community member subjects reported that they believed HCPs should involve their family in their diabetes care. However, some focus group subjects reported that HCPs should not involve their family in their diabetes care. Male and female focus group members tended to report different reasons for their HCPs to not include their family in their care. Some male focus group members reported that HCPs shouldn’t involve their family members in their care as their family was not involved in their healthcare decisions; there was a risk of an invasion of privacy; and family members were already involved in their care.
Female focus group members who did not think HCPs should involve their family in their care reported that they did not believe that involving their family would be helpful.

*Encouraging family involvement diabetes in care*

All HCPs reported that they would prefer to have family members at diabetes appointments, though they did not specify the frequency of these family visits. Some HCPs reported that incorporating the family into visits was useful. However, HCPs tended to focus on specific diabetes management points as methods of involving the PRiH family in diabetes care appointments.

*Best methods for HCPs to engage family members*

HCPs suggested the best method of including the family in their patient’s diabetes care was to incorporate the family in the visit and discuss medical and behavioral recommendations. They also suggested expressing empathy and developing trust as essential to incorporating the family. Community member subjects also suggested inviting their family members to appointments as the best way for HCPs to involve their family in their care.

*Projected response to engagement request*

Collectively HCPs reported confidence that simply asking PRiH family members to be more involved in their patient’s care would be sufficient to get family members involved. Additionally, they unanimously reported that this
request would be met with a positive response. This was echoed by most focus group subjects, who reported that their families would react positively to being asked to help or be more involved in their diabetes care.

**Best method for families to help patients**

Healthcare providers suggested that family members who would like to be more involved in their family member’s diabetes care should learn about diabetic diet recommendations. Focus group subjects suggested that HCPs talk to their spouse (wife) and family about their diabetes care. Some subjects in the all-female focus group suggested having a nurse assigned to every diabetic patient. Focus group subjects also described frustrations with HCPs hyper-focused disease approach to diabetes management; and a lack of coordination between specialist and other HCPs.

**Conclusions**

**Research Question One**

In this section, the first research question, “What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes”, and sub-questions are answered using the data summarized in the preceding results section. Refer to Diagram 1 in Appendix L, as a guide to research questions and sub questions throughout this section. The following sub-questions are used to answer research question one
Sub-question A: What are the positive effects of *Familism* on diabetes self care for PRiH adults?

Sub-question B: What are the negative effects of *Familism* on diabetes self-care for PRiH adults?

Sub-question C: In what ways does *Familism* facilitate diabetes self-care for PRiH adults?

Sub-question D: In what ways does *Familism* inhibit diabetes self-care for PRiH adults?

Sub-question E: How are PRiH women with T2DM in traditional family roles affected by *Familism*?

Sub-question F: How are PRiH men with T2DM in traditional family roles affected by *Familism*?

**Sub-question A**

What are the positive effects of *Familism* on diabetes self care for PRiH adults? The collective nature of the PRiH family and community may be a potentially positive motivator of diabetes self-care. The positive aspects of *Familism* within the PRiH community appears to center around a strong collective nature. The behavioral data and reports from focus groups suggests that this support network is potentially expansive, and may include 1st, 2nd, 3rd generation relatives, spouses, ex-spouses, non-familial persons, and people who do not work in healthcare.

The PRiH community and family may be synonymous in terms of their integral role in managing chronic disease, and more sepcifically T2DM self-care.
Importantly, PRiH families are generally involved to some degree in helping their family members with T2DM self-care. Community members whose families help with self-care find their diabetes management activities more manageable and less burdensome.

**Sub-question B**

What are the negative effects of *Familism* on diabetes self-care for PRiH adults? The collective nature of the PRiH family and community may be a potentially negative inhibitor of diabetes self-care. The traditional PRiH diet is a central and vital component of PRiH culture. This diet is, in essence, is carbohydrate intensive and generally conflicts with the recommended diabetic diet. Adhering to a recommended diabetic diet is one of the greatest challenges for PRiH managing T2DM. Family support may be absent or contradictory to medical and behavioral recommendations.

Though T2DM is prevalent within the PRiH community there is widespread attitudes of ambivalence and denial regarding the T2DM diagnosis and seriousness of the disease. These attitudes may make self-care, and specifically, dietary adherence more difficult for PRiH adults with T2DM. Importantly, PRiHs with T2DM may experience negative feelings like emotional discomfort, social isolation, frustration, and embarrassment when attempting to manage their diabetic diet at family gatherings. Moreover, while PRiH family members may generally be aware that their family member is attempting to manage their diabetes, family and community members may not be aware of the emotional
burden and depressive symptoms they may be experiencing from managing T2DM. As a result, PRiH families may not make significant effort to accommodate a recommended diabetic diet during family and community gatherings. Importantly, there is a relationship between stressors associated with diabetes self-care and sociocultural stressors (specifically surrounding meals), decreased motivation, and depression. For PRiH with lower socioeconomic status, the financial strain of procuring foods consistent with a diabetic diet may inhibit dietary adherence.

**Sub-question C**

In what ways does *Familism* facilitate diabetes self-care for PRiH adults? The collective community nature within PRiH communities may potentially facilitate communal behavioral changes. This communal behavioral support may facilitate adherence to the therapeutic diet, recommended exercise regimens, medication adherence, and attending healthcare appointments. Finally, female PRiH family members, specifically those in matriarchal roles, tend to be viewed as a reliable source of support for health information, care, and support.

**Sub-question D**

In what ways does *Familism* inhibit diabetes self-care for PRiH adults? The centrality of traditional food within PRiH culture, coupled with the abundance of these traditional foods during family gatherings, and lack of diabetic friendly options in PRiH eating establishments may impede PRiH adults from adhering to
a diabetic diet. Additionally, the strong nurturing matriarchal culture may inhibit diet adherence if these central figures are not supportive of healthier diets. Some family and community members may, in the spirit of the communal gathering which is centered around meals, encourage nonadherence to the recommended diet.

**Sub-question E**

How are PRiH women with T2DM in traditional family roles affected by *Familism*? Results from this study show that for PRiH women there are relationships between *Familism*, T2DM self-care and traditional family roles, traditional diet, intimate partner relationships, and emotional tolls. Additionally, these women engage in diet cheat days to cope with managing a diabetic diet at social gatherings.

*Traditional family role.* Female PRiH family members are a key community resource, often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions. Female PRiH diabetics may feel frustration with being dependent on their family for support when their traditional role expectations may involve them in caretaker roles. Female PRiH adults with T2DM may experience frustrations regarding:

- concerns that their illness may cause emotional distress for family members
- concerns about their ability to make necessary lifestyle changes
- concerns about preventing their children from developing diabetes
• difficulty with prioritizing self-care due to family demands
• disease management generally being a low priority at family gatherings
• conflicting obligations regarding T2DM self-management activities and daily living
• difficulty with their family sometimes encouraging non-therapeutic diet.

*Traditional diet.* Adult PRiH women in traditional roles tend to prioritize their family’s needs over their own. The struggles with traditional diet are contextually different for male and female PRiHs. Managing the diabetic diet presents unique challenges for PRiH women as they may experience conflicts with feeling obligated to prepare traditional foods for their family. Specifically regarding conflicts surrounding preparing traditional foods versus a diabetic diet, PRiH women with T2DM may struggle with:

• feeling conflicted when other family members offer foods they should not eat
• difficulty managing different diets within their homes
• feeling conflicted when preparing foods for a non-diabetic spouse
• difficulty incorporating recommended diet with traditional PRiH foods

*Intimate partner relationships.* Type 2 Diabetes management may affect PRiH women in their intimate relationships and sexual function. These women may also experience:

• negative self-perceptions
• negative body image related to obesity.
• concomitant depressive symptoms related to these negative perceptions.
PRiH women with T2DM in traditional roles may also experience intimate partner relationship strain surrounding accommodating their partner with regards to:

- diet
- social activities
- time management
- negative perceptions.

*Emotional tolls.* Despite their family’s awareness of their diabetes diagnosis, females PRiHs may not receive emotional support from their family. Female PRiHs with T2DM likely experience some degree of:

- depression
- decreased motivation
- social isolation
- sadness
- fear and despair
- low self esteem
- negative feelings associated with obesity and diabetes
- denial about their T2DM diagnosis.

Female PRiHs who do receive support from their family members likely receive this support from female family members. This support may include:

- monitoring for symptoms of high or low glucose
- monitoring for vision changes.

Female PRiHs may receive little or no support from their family regarding:
• encouraging or participating in exercise activities
• medication adherence
• attending their healthcare appointments.

*Cheat days.* Finally, traditional gender role strain, intimate partner relationship strains and the emotional tolls of generally receiving less support may lead to social isolation for PRiH women with T2DM. The communal nature of the PRiH family is largely centered around gatherings, meals and traditional foods. This collective social environment may be largely unsupportive of an individual managing T2DM. To circumvent social isolation, female PRiHs with T2DM may engage in “cheat days”, on which they would disregard their diabetic diet when attending family/community gatherings.

**Sub-question F**

How are PRiH men with T2DM in traditional family roles affected by *Familism*? Results from this study show that PRiH men in traditional roles may be affected positively by *Familism* when managing T2DM, in that they receive support from a variety of female family members. These men may additionally struggle with adhering to the traditional PRiH diet, as well as with intimate partner relationships, though these struggles are contextually different from their female counterparts.

*Female and maternal support.* Male may not recognize that their traditional status and role as a man affects their diabetes management. However,
compared to female PRiHs with T2DM, males may receive more family support from:

- Adult children
- Spouses
- Parents
- Siblings
- Partners
- Ex-partners

Patriarchal roles may insulate male PRiHs from some of the stressors of self-managing diabetes. Male PRiHs may be generally supported by female family members and maternal figures. Male PRiHs may receive maternal support in helping them with:

- medication adherence.
- healthcare appointments.

Male PRiHs may also receive support from female partners or female adult children with:

- actively or passively checking their glucose levels
- monitoring for high or low glucose.

*Traditional diet.* Male PRiHs who struggle with adhering to a diabetic diet may have a tendency to struggle with adhering to their diet at PRiH restaurants and eating establishments. Moreover, they may experience frustration at family gatherings when there are no food options available to accommodate their diabetic diet.
These intimate partner relationships. PRiH men managing T2DM may struggle in their intimate relationships due to sexual dysfunction, specifically erectile dysfunction.

**Research Question Two**

In this section, the second research question, “How can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?” and sub-questions are answered using the data summarized in the preceding results section. Each sub question includes “research finding(s)”; followed by corresponding “recommendation(s)” which are based off of the preceding research finding. Refer to Diagram 1 in Appendix L for a guide to research question 2 and sub questions throughout this section. The following sub-questions are used to answer research question two:

- **Sub-question G** - “How can healthcare providers facilitate the positive effects of *Familism* on T2DM self-care?”

- **Sub-question H** - “How can healthcare providers prevent negative effects of *Familism* on T2DM self-care?” are used to expound on this question.

**Sub-question G**

How can healthcare providers facilitate the positive effects of *Familism* on T2DM self-care? Findings from this study suggest that healthcare providers may facilitate the positive effects of *Familism* by engaging PRiH adults with T2DM through their cultural social collective; and using family supports to improve
medication adherence, glucose monitoring and communal healthcare appointments.

**Facilitating self-care via the social collective**

*Research Finding:* The PRiH family and community may be synonymous and are highly influential in the lives of PRiH adults with T2DM. The collective nature of these social relationships may use to facilitate positive behavioral change (i.e. diet, exercise etc.).

*Recommendation:* Incorporating family and community members into the plan of care may provide a direct pathway to affect behavioral change (i.e. diet, exercise), medical management (i.e. medication adherence) and self-care practices (i.e. monitoring, management, maintenance).

*Research Finding:* Non-healthcare professionals may be a source of health advice in PRiH families and communities.

*Recommendation:* Knowing who these “non-healthcare” supports are and empowering them with accurate evidence based health information may positively affect behavioral changes (i.e. diet, exercise), medical management (i.e. medication adherence) and self-care practices (i.e. monitoring, management, maintenance).
**Research Finding:** PRiH family members and communities may offer traditional and home remedies as treatments for medical problems to their family members.

**Recommendation:** Knowing and clarifying what these traditional treatments and home remedies are, and if they are being used as primary, secondary therapies or adjunctive therapy, may help improve standard self-care practices (i.e. diet, exercise), medical management (i.e. medication adherence) and overall treatment plan adherence.

**Facilitating self-care via family supports**

**Research Finding:** The PRiH family and community offers support for their family members with T2DM. This support may come from 1st, 2nd, 3rd degree relatives. This support most likely comes from female family members that may include spouses, ex-spouses, mothers, sisters, children, grandchildren and other community members.

**Recommendation:** These family and community member supports must be identified, and their roles or functions must be defined in order to include them in the care planning. HCPs may have an opportunity to empower these family members to help their patients with diabetes self care behaviors.

**Research Finding:** Female PRiH family and community members are often a trusted resource for medical and health advice.
Recommendation: These individuals may have a direct effect on self-care behaviors. Empowering these individuals may promote behavioral change.

Research Finding: HCPs should know that male PRiH patients with T2DM very likely have a female family or community member who supports their diabetes self-care; and that their female patients may or may not have the same level of support.

Recommendation: This knowledge should prompt HCPs to inquire as to whom these support persons are, and what their roles are in that support.

Research Finding: Male PRiHs with T2DM may be more likely to receive active support in self-care (i.e. checking glucose levels, checking their feet) from female family members than their female counterparts.

Recommendation: Identifying these family supports, empowering them with the details of the care plan, and including them in healthcare visits may improve self-care activities.

Facilitating medication adherence

Research Finding: PRiHs may receive family and community support with medication adherence. This support is variable. However, male PRiH adults with T2DM may be more likely to receive support than their female counterparts. The support for male PRiHs likely comes from female family and community members.
**Recommendation:** HCPs may improve self-care and medication adherence by determining who these support persons are and empowering those individuals in this function.

**Facilitating glucose monitoring**

**Research Finding:** Though variable, many PRiHs with T2DM have family that support them by actively (physically checking glucose) or passively (inquiring about glucose levels) checking glucose levels.

**Recommendation:** HCPs may empower these family and community members to facilitate more accurate monitoring of blood glucose levels.

**Recommendation:** HCPs may improve their patients’ clinical picture and self-care practices by identifying who these supporting family and community members are, including them in healthcare visits, and understanding how involved they are in monitoring blood glucose levels.

**Facilitating communal healthcare appointments**

**Research Finding:** PRiH patients may prefer for their family or community member supports to be involved in their healthcare appointments.

**Recommendation:** Asking PRiH patients to include their family members in their healthcare appointments may be sufficient method of increasing family member participation in appointments.
Research Finding: PRiH family members who provide diabetes self-care support may receive these requests positively. The preference for family involvement in healthcare appointments may very between individual patients.

Recommendation: Determining the PRiHs patients’ preference for and frequency of involvement from their family and community members in their care may provide a pathway to conversations about social and self-care support.

Recommendation: Involve a family or community member who is instrumental in a patients’ diabetes self-care as this may strengthen the individuals’ self-care practices, empower the supporting family member, and ultimately improve measurable outcomes.

Recommendation: Expressing empathy for the many stressors of diabetes self-care management may foster and improve relationships between clinicians, patients and their families.

Recommendation: Considering the encompassing nature of diabetes self-care, PRiH patients and families may prefer to receive a more holistic approach to diabetes management as opposed to disease specific informational style visits.

Sub-question H

How do HCPs prevent negative effects of Familism on T2DM self-care?

This study shows that healthcare providers may prevent negative effects of Familism on T2DM self-care by addressing sociocultural stressors; offering methods to manage the traditional diet at family gatherings; actively involving
family in care planning; dispelling negative attitudes; addressing emotional tolls; addressing interpersonal relationship strain; as well as addressing variable socioeconomic factors when applicable.

**Addressing sociocultural stressors**

*Research Finding:* PRiH patients with T2DM may be under emotional, financial and social stressors that compete with the behavioral recommendations and medical management (i.e. diet, time management etc.). Female PRiH patients in traditional family roles may be subject to more of these stressors and have subsequent emotional burden than their male counterparts.

*Recommendation:* Understanding and addressing these stressors may help with adherence to behavioral recommendations, self-care and interventions used in medical management.

*Research Finding:* Social and cultural stressors may have a negative effect on diabetes self-care. Some family and community members in PRiH communities may have ambivalent attitudes about diabetes self-care, and may encourage non-adherence to the diabetic diet. For PRiH adults with diabetes, sociocultural stressors coupled with family or community members who obstruct diabetes self-care, may make adhering to the diabetic diet more difficult.

*Recommendation:* HCPs may improve diabetic diet adherence by determining if their PRiH patients experience obstructive behaviors from their
family and community members, and facilitating education to those individuals or providing additional supports for the patients affected.

*Research Finding:* Female PRiH patients with T2DM in traditional gender roles may be charged with caring for other family members. These duties may compete with T2DM self-care and behavioral recommendations.

*Recommendation:* Gaining knowledge of this potentially competing social responsibility may facilitate communications and interventions to remove barriers to self-care and behavioral recommendations.

*Research Finding:* PRiH adults may have lower education levels, employment levels and income compared to the general population. Foods included in the recommended diabetic diet may be more expensive than the traditional Puerto Rican diet. This financial burden may affect adherence to a diabetic diet.

*Recommendation:* HCPs may improve diet adherence by determining if food cost is a barrier to diabetic diet for PRiH patients, and facilitating pathways to provide relief.

*Research Finding:* A strong nurturing maternal culture may be prevalent in PRiH families and communities. These traditional matriarchal roles may not necessarily allow individuality during communal meals. PRiH women with diabetes may feel obligations to provide traditional Puerto Rican foods for their
families. PRiHs with T2DM may feel social pressure to eat traditional foods if offered in a communal setting and prepared by a matriarchal figure.  

*Recommendation:* HCPs may provide additional support to PRiH patients by providing specific tools for PRiHs with T2DM to navigate social pressures around communal meals.

*Research Finding:* Female PRiH adults with T2DM may receive less support with medication adherence and glucose monitoring compared their male counterparts.  

*Recommendation:* HCPs may improve medication adherence and glucose monitoring for PRiH patients with T2DM by determining if they have family or community supports with self-care, and facilitating pathways for additional support when it is lacking.

**Addressing the traditional diet and family gatherings**

*Research Finding:* The traditional PRiH diet and family gatherings are a central and vital component of PRiH culture. Traditional Puerto Rican foods tend to be carbohydrate intensive and conflict with medical and behavioral recommendations for self-care management. This is a cultural conflict.  

*Recommendation:* HCPs may improve diabetic diet adherence by providing consistent, evidence based approaches to directly address and manage this cultural conflict.
Research Finding: Adhering to a diabetic diet may be the most universal cultural challenge for PRiHs with T2DM. Traditional Puerto Rican cuisine is a central component within PRiH culture. The abundance of traditional foods at family gatherings may conflict with diet recommendations. There may be few healthy options in PRiH eating establishments. All of these cultural factors may affect adherence to a diabetic diet.

Recommendation: HCPs may gain insight of their PRiH patients decision around T2DM using standardized methods to inquire about potential barriers to diabetes adherence such as perceptions about cultural conflicts with diabetic diet recommendations.

Recommendation: HCPs may improve PRiH patients’ adherence to the diabetic diet by including specific ways to adhere to a diabetic diet when eating in public restaurants.

Research Finding: The struggles with traditional Puerto Rican cuisine may be contextually different for male and female PRiHs with T2DM. Male may have more difficulty with navigating the diabetic diet at restaurants, whereas, female subjects may have conflicts regarding feeling obligated to prepare traditional foods for their family.

Recommendation: HCPs may gain insight about challenges PRiH patients face regarding adherence to the diabetic diet by inquiring about specific factors that deter adherence.
Recommendation: HCPs may provide additional support for female PRiH patients by acknowledging, providing support for, and providing methods to address perceived obligations prepare traditional PRiH foods for their family.

Research Finding: PRiH adults with T2DM may struggle with not having foods congruent with their diabetic diet available at family gatherings. Subsequently, these individuals may participate in “cheat days”, on which they would disregard their diabetic diet when attending family/community gatherings. Family and community members may not know or understand the emotional stress and conflict their family members with T2DM are faced with in these conflicting situations.

Recommendation: HCPs may improve PRiHs adherence to a diabetic diet by including family and community in the diabetes plan of care and providing resources and information that empower them to provide a therapeutic diet at family gatherings.

Active family involvement in care planning

Research Finding: Despite the integral role and effect of the PRiH family member on diabetes self-care, generally PRiH family members may not be actively included in healthcare appointments and care planning. Passively providing information to these family and community supports may not sufficiently include the family in care planning.
**Recommendation:** HCPs may facilitate family and community involvement in diabetes care planning by actively requesting that family members providing self-care support attend healthcare appointments.

**Research Finding:** HCPs tend to focus a portion of healthcare visits on standard diabetes education. PRiH adults with T2DM may be generally aware of the effect of the carbohydrate rich traditional Puerto Rican cuisine. Other factors aside from low health literacy and knowledge deficits may influence suboptimal dietary adherence.

**Recommendation:** In addition to standard diabetes education, HCPs should evaluate health literacy of their PRiH patients.

**Recommendation:** Additionally, HCPs should formulate methods to inquire about and address other sociocultural or socioeconomic barriers to dietary adherence.

**Dispelling negative attitudes**

**Research Finding:** The high prevalence of T2DM in PRiH communities may contribute to ambivalence about the disease and subsequent sequela. HCPs tend to focus healthcare appointments on their patients’ individual responsibilities and disease management.

**Recommendation:** HCPs may improve patient and community engagement in diabetes self-care management by providing education about diabetes prevention, treatment and management at the community level.
Research Finding: Puerto Rican identified Hispanic adults with T2DM may have a lack of community and family support for, as well as general lack of ambition towards recommended exercise regimens.

Recommendation: HCPs should create standardized methods to determine if PRiHs with T2DM have family and community supports that encourage recommended exercise regimens.

Recommendation: HCPs may improve motivation and adherence to exercise regimens by ensuring PRiH patients with T2DM have adequate family and community supports that encourage exercise regimens.

Addressing emotional tolls

Research Finding: The link between T2DM and depression is well documented in health and science literature. PRiH adults with T2DM may experience depression, sadness, fear and despair after being diagnosed with diabetes. They may experience embarrassed when managing diabetes in public and at family gatherings. Additionally, they may experience low self-esteem and negative feelings associated with obesity and diabetes. Given the known association of depression with diabetes, coupled with social and cultural stressors, PRiH adults with T2DM may be at higher risk for being diagnosed with depression.

Recommendation: HCPs should evaluate PRiHs with T2DM for depression and depressive symptoms on an ongoing basis.
**Research Finding:** PRiH patients with T2DM may experience emotional tolls related to diabetes self-care, social stressors, decreased motivation and concurrent depression. Female PRiHs with T2DM may experience these emotional tolls as well as social isolation related to T2DM self-care.

**Recommendation:** HCPs should use standardized methods to evaluate and treat PRiH adults with T2DM for social stressors, social isolation and concomitant depression.

**Research Finding:** Female PRiH adults with T2DM may be subject to emotional conflicts related to prioritizing their family over their diabetes self-care. These conflicts may involve choosing to prepare a traditional diet for family versus a therapeutic diet for themselves; and difficulty incorporating their diabetic diet with traditional Puerto Rican foods during meal preparation.

**Recommendation:** HCPs may help reduce the emotional burden of diabetes self-care and improve diabetic diet adherence by incorporating methods to determine if these conflicts are present for PRiH women with T2DM, and providing resources to help resolve these conflicts.

**Research Finding:** Family gatherings and traditional foods are a core component of PRiH culture. These gatherings may be a source of emotional distress for PRiHs with T2DM. Some PRiH adults may experience emotional
distress in the form of frustration and embarrassment while managing their diabetes at family gatherings.

*Recommendation:* HCPs may level the playing field and reduce this emotional burden and stress by including the family/community in the diabetes care plan.

*Research Finding:* Some PRiH family members and communities may display a type of communal ambivalence regarding the T2DM, management, and self-care. PRiH adults with T2DM may experience social stress and pressure to partake in traditional meals, despite having adequate knowledge that a high carbohydrate meal is contraindicated in the diabetic diet. This social pressure may come in the form of family and community members encouraging them to eat traditional Puerto Rican foods they should avoid.

*Recommendation:* HCPs may improve dietary adherence for PRiHs with T2DM by determining if they are affected by social pressure to forgo their diabetic diet, providing emotional support, providing resources to help patients cope with these stressors, and including community members and family members in the diabetes care plan.

*Addressing interpersonal relationship strain*

*Research Finding:* Female PRiHs with T2DM may experience emotional distress and conflicts when with preparing food for a non-diabetic spouse.
**Recommendation:** HCPs may reduce emotional toll of diabetes self-care for PRiH women by determining if these social stressors exist, and providing resources to address these concerns.

**Research Finding:** PRiHs with T2DM may experience emotional distress related to interpersonal relationships. Sexual dysfunction may add to the emotional distress of diabetes self-care. Male PRiHs may experience emotional distress related to erectile dysfunction. Female PRiHs may experience emotional distress related to negative body image.

**Recommendation:** HCPs may reduce the emotional tolls of diabetes self-care by determining if sexual dysfunction or negative body perceptions are present for PRiH patients with T2DM, providing resources and or treatment to address these concerns.

**Variable socioeconomic factors**

**Research Finding:** The cost of a “healthy” or diabetic diet may be a source of frustration for PRiHs and their families. PRiH homemakers with T2DM may feel conflicted between providing traditional foods for themselves and their family, versus potentially higher cost foods that are more in line with a diabetic diet.

**Recommendation:** HCPs may provide additional support for PRiH patients with T2DM by determining their socioeconomic status and the effect on decision making and food purchasing.
Research Finding: Generally, PRiHs experience lower levels of education, higher rates of unemployment, higher rates of diabetes, and higher rates of diabetes complications compared to their non-Hispanic white counterparts. However, the PRiH culture and population is complex, and the experiences of those with lower socioeconomic status may be different than those of higher status.

Recommendation: HCPs should inquire as to the socioeconomic status, literacy and health literacy of PRiH patients and their families to gain a more robust clinical picture of the diabetes management plan and self-care.

Inverse Self-Care Effect

In this section, the research findings that describe how T2DM self-care affects Familism dynamics within the PRiH community are described. These sections include social stressors, and effect on female family members. These findings are also discussed throughout chapter five.

Social stressors

The PRiH family may experience financial strain when accommodating a family member who has T2DM. Food items consistent with the diabetic diet may differ from traditional PRiH foods, and may be significantly more expensive. This may place financial strain on the PRiH family as well as interpersonal relationships within the family.
Traditional matriarchal roles may not necessarily allow for individuality during communal meals. Requesting an alternate meal may be insulting towards homemakers and women who prepare meals in traditional roles. This may add an additional stressor for PRiH women charged with preparing foods for diabetic family members.

**Effect on female family members**

Female PRiH family members are a key community resource, often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions. Family members with T2DM may seek out female PRiHs for advice or support. Females in a PRiH families are often tasked with caring for family members with T2DM. If a family member is involved in helping or assisting with diabetes self-care, this family member is most likely female. These family members have a direct effect on their family members’ diabetes self-care. Importantly, the family members' diabetes self-care has an effect on the family member in that they assume some responsibility for helping with self-care. This family member who assists with diabetes self-care, dedicates a certain amount of their time and effort, as well as assumes a variable amount of responsibility for their family members’ self-care. Any female PRiH family member may be involved in caring for a family member with T2DM. These female family may include but are not limited to,

- intimate partners (wives, girlfriends)
- adult children
• ex-intimate partners
• siblings
• grandchildren
• daughter in-laws
• mothers.

Mothers and female family members may be involved in their family members’ self-care by,
• actively or passively checking their glucose levels.
• monitoring for symptoms of high or low glucose,
• checking feet
• checking for vision changes

Trustworthiness and Validity

In this qualitative study, two research questions were asked: in what ways does Familism inhibit or facilitate diabetes self-care for PRiH adults with T2DM, and how can clinicians use Familism to facilitate improved diabetes self-care in Puerto Rican identified Hispanics? These questions were based on three study assumptions: 1. Familism has an effect on T2DM self-care for PRiH adults; 2. PRiH men and women in traditional roles experience the effects of Familism differently; and 3. Healthcare providers do not generally consider Familism as a factor in T2DM self-care.

The data collected for this study included surveys, focus groups, and semi-structured interviews. Surveys, focus groups and interview questions were based on the study assumptions. Survey data was analyzed using simple percentages.
Focus group and semi structured interviews were transcribed, deconstructed and reorganized by question, and analyzed comparatively for themes. Themes were grouped by relevance to each other.

Lincoln and Gubas (1985) Criteria for rigor was used to ensure the findings reflect credibility, transferability, dependability, and confirmability. These sections are described below. The first section, credibility, includes responses from members who ‘somewhat disagreed’ or ‘disagreed’ with some study findings; or ‘agreed’ and added commentary to study findings.

**Credibility**

Credibility was ensured by presenting the study findings to participants prior to any final conclusions were made and findings disseminated. Member and nonmember checking was used to confirm the study findings. Member checking, or the process of confirming the study findings with study subjects, was conducted with n= 5 subjects (2 HCPs, and 1 patient subject, 1 community member subject). Non-member checking, or confirming the study with people who meet study inclusion criteria but were not subjects in the study, was conducted with n= 3 people.

HCP subjects were provided a copy of the study findings electronically. All other member and non-member checking entailed a formal presentation of study findings to members and non-members of the study. Members and non-members were encouraged to use a Likert scale for each study finding to strongly agree, agree, somewhat disagree, disagree or strongly disagree with each study finding.
See Appendix D. Additionally, they were encouraged to give feedback if the disagreed with a study finding. Interestingly all community, patient, and non-member respondents strongly agreed with the findings of the study. Patient and community member subjects expressed gratitude for the opportunity to participate as well as the general aim of the study. None of these subjects offered any written commentary. However, HCP subjects ‘somewhat disagreed’ or ‘disagreed’ with some study findings; or ‘agreed’ and added commentary to study findings. Healthcare provider responses to the study findings are provided below.

*Study finding*: Though T2DM is prevalent within the PRiH community there is widespread attitudes of ambivalence and denial regarding the T2DM diagnosis and seriousness of the disease. These attitudes may make self-care, and specifically, dietary adherence more difficult for PRiH adults with T2DM.

*Member feedback*: One HCP somewhat agreed with this finding, reporting “I would say ambivalence is not widespread, though present at times”.

*Study finding*: For PRiH with lower socioeconomic status, the financial strain of procuring foods consistent with a diabetic diet may inhibit dietary adherence.

*Member feedback*: One HCP somewhat agreed with this finding, reporting “I think the strain is more about changing eating patterns as opposed to a specific financial strain to find DM2-friendly foods”.
Study finding: The struggles with traditional diet are contextually different for male and female PRiHs.

Member feedback: One HCP did not agree with this finding, reporting “this is not something I have noticed in clinical practice”.

Study finding: PRiH women with T2DM in traditional roles may also experience intimate partner relationship strain surrounding accommodating their partner with regards to:
- diet
- social activities
- time management
- negative perceptions.

Member feedback: One HCP did not agree with this finding, reporting “This is not something I have noticed in my practice, though I have not specifically asked about it”.

Study finding: The PRiH community and family may be synonymous in terms of their integral role in managing chronic disease, and more specifically T2DM self-care.

Member feedback: One HCP somewhat agreed with this finding reporting “I think immediate family still has more impact on behavior than larger community.”
**Study finding:** Communal behavioral support may facilitate adherence to the therapeutic diet, recommended exercise regimens, medication adherence, and attending healthcare appointments.

*Member feedback:* One HCP agreed with this study finding but added “ideally, not always true”.

**Study finding:** The collective nature of the PRiH family and community may be a potentially negative inhibitor of diabetes self-care.

*Member feedback.* One HCP agreed with this study finding but added “sometimes”.

**Study finding:** For PRiH with lower socioeconomic status, the financial strain of procuring foods consistent with a diabetic diet may inhibit dietary adherence.

*Member feedback:* One HCP somewhat agreed with this finding, reporting “I think it is financially + social /education”.

**Study finding.** Female PRiHs may receive little or no support from their family regarding:

- encouraging or participating in exercise activities
- medication adherence
- attending their healthcare appointments.
Member feedback: One HCP somewhat disagreed with this finding, reporting "I have found that my patients and families usually encourage them to take medication and attend appointment".

Study finding: Traditional gender role strain, intimate partner relationship strains and the emotional tolls of generally receiving less support may lead to social isolation for PRiH women with T2DM.

Member feedback. One HCP somewhat agreed with this statement, adding "I don’t see it as being particularly isolating".

Study finding: Asking PRiH patients to include their family members in their healthcare appointments may be sufficient method of increasing family member participation in appointments.

Member feedback: One HCP reported they agreed with this finding, but added “provided the patient wants family involvement”.

Study finding: The PRiH family may experience financial strain when accommodating a family member who has T2DM.

Member feedback: One HCP reported they agreed with this finding, but added “offer tools to help HCPs assess this in a sensitive way”.

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Transferability

Transferability was ensured by comparing the study findings to the known body of literature for congruency. Additionally, sample demographics, all methodology including procedures for recruitment, data collection, and data analysis were documented throughout the study. This information will be published for public record and with the intention of replicating this study with similar or different populations.

Dependability

Dependability indicates that the findings are consistent and could be repeated. Dependability was ensured by documenting all study methodology including procedures for recruitment, data collection, and data analysis throughout the study. Additionally, journaling was used throughout the research process and was used to document unpredicted occurrences. This data is summarized and included within the study findings.

Confirmability

Confirmability relates to objectivity of the researcher and ensures the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest. To ensure confirmability, independent researchers (dissertation committee) reviewed the study methodology, data collection procedures, data analysis procedures, and study findings to ensure there was no researcher bias or distortion throughout the study. Additionally, the institutional
review board staff at Baystate Medical Center, served as an independent auditor during phase 1 and 2 of the study.

**Triangulation**

Triangulation is a key component in qualitative inquiry and may be defined as the collection of data from multiple sources for analysis in the same study with each source focused upon the phenomenon of interest (Cowman, 1993). Triangulation increases validity and decreases researcher bias (Cohen & Mamon, 1980). Triangulation for this study included the use of multiple data collection techniques including focus groups with patient subjects; semi-structured interviews (medical providers and community members); participant observation; and field notes. The multiple sources of data strengthened this study methodology and subsequently increased the trustworthiness of the findings.

**Hermeneutic Cycle**

Finally, the hermeneutic cycle was used prior to beginning the research. The hermeneutic cycle necessitates that the researcher identifies personal fore-understandings, beliefs and assumptions, prior to commencement of the study and then throughout the research process (Dale, 1995). One significant fore-understanding was my long standing clinical relationship with the study population. Details of the hermeneutic cycle are discussed in detail in Chapter 3.
**Delimitations**

Delimitations are anticipated constraints in the interpretation of the findings of the dissertation research (Sampson, 2017). Delimitations for this study include a relatively small sample size (which reduces generalizability); un-validated questionnaires; and lack of rigor assigned to analysis of survey data. Additionally, there were no methods included to differentiate between type (physician vs nurse) of HCP experiences. Finally, geriatric subjects were excluded from the study. These delimitations should be considered in context with the data analyzed in this study.

In the next chapter the results are discussed as they apply to the study assumptions and research questions. The findings of this study are compared to the existing body of literature. Additionally, the next chapter includes a theoretical discussion, study challenges, limitations, recommendations and concluding remarks.
CHAPTER V
DISCUSSION

Introduction

In this chapter, the assumptions and research questions are discussed as applicable throughout. Please refer to Diagram 1 in Appendix L as a guide regarding study assumptions, research questions and sub questions discussed throughout this chapter. The findings of this study are discussed in the context of existing literature and compared with previous studies as they relate to Familism, Self-care and Puerto Rican identified Hispanic (PRiH) adults with type 2 diabetes (T2DM). Additionally, this chapter discusses an evaluation of a practical application of Riegel’s et al.’s (2012) theory; Familism factors affecting self-care; and the effect of self-care on Familism dynamics. Next, study challenges; and strengths and limitations of this study are presented, with recommendations to improve subsequent studies. The study impact, implications, recommendations and conclusion are presented at the later part of this chapter.

Background

This study was designed based on three assumptions. The first assumption for this study, that Familism has an effect on T2DM self-care for PRiH adults, was confirmed, and is consistent with the current literature on Familism and Hispanic adults. The second assumption, that HCPs do not generally consider Familism as a factor in T2DM self-care; was confirmed, and is consistent with the current literature on Familism and Hispanic adults. The third
assumption for this study, that PRiH men and women in traditional roles experience the effects of Familism differently; was also confirmed, and is consistent with the current literature on Familism and Hispanic adults.

The primary aim of this study was to illuminate and delineate a specific socio-cultural phenomenon – the effect of Familism on diabetes self-care for Puerto Rican adults with T2DM. A secondary aim was to examine how health care professionals may best include the PRiH family in care planning. Findings from this study support the assumptions from which the study was based; and offer a greater understanding of the role of Familism as it influences to diabetes self-care in the Puerto Rican identified Hispanic population living in the continental U.S. In this chapter, assumptions and research questions are discussed as they relate to the study findings and literature. Finally, the research finding, the effect of diabetes self-care on Familism dynamics, is discussed as applicable throughout this chapter.

Familism

Studies have demonstrated a relationship between social factors and health (Beck, 2007; Penwell and Larkin, 2010). Importantly, studies have suggested that La familia (the family) is an important element in the Hispanic culture (Perez and Cruess 2014). To date, the studies of PRiH adults that investigate diabetes self-care, have not specifically addressed components of Familism or community as a factor in diabetes self-management (Khan et al. 2012; Dharma et al. 2013). Prior to this study, the degree to which each
component of Familism influences self-care behaviors and the differences in Familism related experiences for PRiH men and women had yet to be explored. Relevant studies have investigated the relationship between T2DM, Familism and Hispanic adults, by either focusing on Mexican identified Hispanics Baig et al. (2012); or not identifying the targeted Hispanic subgroup (Ramal et al. 2012, Weiler et al. 2009). Hispanic subgroups are often combined together in health research and this practice likely conceals important differences between Hispanic subgroups (Aponte 2009; Barcelo et al. 2007; Mainous, et al. 2007; Allison et al. 2008). Findings from such studies are ambiguous making it difficult to formulate culturally tailored interventions. Disaggregation of Hispanic subgroups is preferred whenever possible when classifying and studying Hispanic populations. To date, relevant studies either have not specifically explored the impact of Familism on T2DM self-management behaviors for PRiHs (Caban et al. 2006); or have not investigated the influence of community or family on health behaviors for PRiHs (Asgarian et al. 2011), Weitzman et al. 2013).

The findings from this study answer the first research question, “What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?”, and show that Familism does have an effect on diabetes self-care for PRiH adults. Specifically, these findings show that Familism, the effect of family/community members on a persons’ health and health related choices (Beck, 2007; Penwell and Larkin, 2010), has both positive and negative effects on PRiH adults with T2DM. Additionally, findings from this study highlight the dynamic relationships between socioeconomic factors,
sociocultural factors, *Familism* and self-care behaviors for PRiHs. These findings confirm the first assumption for this study, that *Familism* has an effect on T2DM self-care for PRiH adults.

The findings from this study show that the effect of *Familism* is contextually different for male and female PRiHs, which confirms the second assumption for this study, that PRiH men and women in traditional roles experience the effects of *Familism* differently. Finally, the findings from this study suggest that HCPs may be aware of some Familism dynamics affecting T2DM self-care for PRiH adults, however there are no clear guidelines or clinical approaches to manage this. These findings confirm the third study assumption, and were useful in providing recommendations for future studies, clinical practice and education.

**Puerto Rican identified Hispanic Adults and Familism**

The Hispanic family network is a large, interconnected web that extends beyond familial relationships confined to a single household (Perez and Cruess 2014). Some research conceptualizes the Hispanic family as a close and interactive network that consisted of nuclear family and extended kin living within a multigenerational household (Garcia, 1993; Keefe, 1979,1984; Landale and Oropesa, 2007). These family systems may also include esteemed friends, neighbors and members of their religious community through important religious rituals, such as baptism, communion and marriage (Galanti, 2003; Garcia, 1993; Keefe, 1984; Miller, 1975).
Findings from this study show that the PRiH “family” may be defined broadly, and may include an interactive network consisting of a nuclear family as well as extended kin that may or may not live within a multigenerational household/community. These relationships have the potential to both facilitate and inhibit T2DM self-care through relationship dynamics, direct and indirect interactions. In this study, there were consistencies regarding gender and traditional roles as factors in these interactions, which confirmed the second study assumption, that PRiH men and women in traditional roles experience the effects of *Familism* differently. Still, for subjects in this study, family and community support were relatively broad. Findings from this study also show that in PRiH communities and families, self T2DM self-care behaviors and attitudes about T2DM are directly influenced by *Familism*. Importantly, the *Familism* experience for PRiHs may be defined as “a social collective, with close and frequent social interactions, regardless of household size”. These findings also confirm the first and second assumptions of this study, that *Familism* has an effect on T2DM self-care for PRiH adult; and that PRiH men and women in traditional roles experience the effects of *Familism* differently.

**Support Versus Obligations**

*Familism* may be operationalized as constructs. These constructs are composed of multiple sub factors. Some of these sub factors may yield favorable (e.g., perceived support) or disadvantageous (e.g., perceived obligations) outcomes (Knight and Sayegh, 2010; Losada *et al.* 2010). These perceived
supports and obligations, help to answer the first and second research questions; as well as several sub questions.

**Perceived support**

Research suggests that values regarding family cohesion and family support have a positive influence on the self-care behaviors of Hispanic women with diabetes (Fisher *et al.*, 2000; Hsin, La Greca, Valenzuela, Taylor Moine, & Delamater, 2010; Valenzuela *et al.*, 2003). Male and female PRiHs in this study reported receiving social support and direct self-care support from family members. By and large male PRiH subjects in this study reported more net social support than their female counterparts. This does not suggest that female PRiH are "unsupported" by their families, as female subjects in this study did report self-care support from their families. However, when comparing female subjects to their male counterparts, the male subjects were more likely to include their mother and female intimate partners as direct or indirect self-care supports, and females were more likely to report little or no support in certain instances.

These study findings confirm the second study assumption, that PRiH men and women in traditional roles experience the effects of *Familism* differently. These findings also answer sub questions A, showing that PRiH family members may provide support to family members with T2DM; sub question C, showing that family support facilitates diabetes self-care; sub question D, showing that *Familism* may inhibit diabetes self-care for PRiH women as they may have less support than their male counterparts; and sub question E and F, showing how
PRiH women experience *Familism* differently. Finally, these findings answer subquestion G and H, by providing evidence from which HCPs may base clinical decisions and education, to help facilitate the positive effects and prevent negative effects of *Familism*.

**Perceived obligations**

Research suggest that the Hispanic family can function as a source of both support and stress for individuals afforded with the responsibility to preserve this network (Perez and Cruess 2014). Both female and male subjects in this study reported social pressure to consume traditional foods at family gatherings. However, only female subjects described social pressure to forgo self-care to accommodate their family and intimate partners by consuming and preparing traditional foods.

Female PRiH subjects in this study described overwhelming perceived obligations that inhibited or conflicted with their self-care behaviors and attitudes. This perceived obligation may be a social stressor in intimate relationships for PRiH women as they may feel pressure to prepare and consume traditional foods for their mate and family. PRiH women may also prioritize their family/partners needs over their own self-care needs. The collective nature of family gatherings and centrality of traditional foods is a stressor for PRiH women in traditional family roles and they may feel strong social pressure to abandon their diabetic diet and conform to eating/serving traditional foods.
These study findings confirm the first and second study assumptions, that *Familism* has an effect on T2DM self-care for PRiH adults, and PRiH men and women in traditional roles experience the effects of *Familism* differently, respectively. These findings answer sub question B, D, E and F; showing that social pressures to consume traditional foods at family gatherings are negative effects of *Familism*; are inhibitors of diabetes self-care for PRiHs with T2DM; and are felt more acutely by PRiH women. Finally, these findings answer sub question G and H, by providing evidence from which HCPs may base clinical decisions and education, to help facilitate the positive effects and prevent negative effects of *Familism*.

**Discussion on The Theoretical Model**

**Riegel’s (2012) theory**

The theoretical underpinning of this study was based on Riegel, Jaarsma and Stromberg’s (2012) Middle Range Theory of Self-Care of Chronic Illness. Riegel et al.’s (2012) theory is a relatively new theory and the usefulness of this theory for nursing science and practice has yet to be determined as this theory has not been evaluated or empirically tested. Riegel et al. 2012 describes self-care in healthy and ill states can be, but are not always, simultaneous processes. In essence, self-care is not the same for all patients nor is it necessarily consistent over time. Three key concepts for Riegel et al.'s (2012) theory are: self-care maintenance, self-care monitoring, and self-care management. Riegel et al. (2012) offers that these behaviors and activities will not always take place
in the same, linear order and certain steps might be skipped. These concepts were used to explore the first and third assumptions of the study, Familism has an effect on T2DM self-care for PRiH adults, and PRiH men and women in traditional roles experience the effects of Familism differently, respectively. The idea being, Riegel et al.'s (2012) concepts would be used to evaluate specific self-care behaviors.

**Theoretical fit and application**

The assumptions and propositions from Riegel et al.'s (2012) theory were not particularly relevant to this study. Riegel et al.'s (2012) Theory defines eight factors affecting self-care: experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from others, and access to care. For this study, self-care experience was collected via a questionnaire. However, this was not formally compared to the study results as the questionnaire was not validated and information gathered only meant to give context. Intrinsic and extrinsic motivation, confidence, habits, and cognitive abilities were not explored in this study. This is discussed further in the limitations and recommendations sections. PRiHs living in the continental U.S. are citizens by birth and have comparable access to healthcare compared to the general population. In Massachusetts, where the study was conducted, residents have higher access to healthcare and insurance than the national population. For this reason, access to care is was not considered a factor for this study or this study population.
In Riegel et al.’s (2012) theory social support is considered an influence in a person’s ability to perform self-care. This factor, social support, is most relevant to this study. The collective nature of *Familism* in the PRiH community directly or indirectly affects T2DM self-care. Direct effects may include but are not limited to family members performing self-care activities. Indirect effects may include but are not limited to social pressures to indulge in behaviors that contradict the diabetes self-care plan (i.e. non-therapeutic diet).

Additionally, Riegel et al.’s (2012) theory proposes that self-care may be affected by culture, beliefs and values across social domains. This factor was also relevant to this study. Culture beliefs and values indirectly affect self-care decision making for PRiHs with T2DM. Meals and social gatherings are an important component within PRiH culture. These meals are generally carbohydrate intensive, and generally contradict diabetic diet recommendations. There are some wide spread beliefs about T2DM within the PRiH community. These include but are not limited to ambivalence about diagnosis and treatment. PRiH women in traditional roles, may value their family members needs above their own self-care needs. This value of collectivism, may have a direct effect on decision making around self-care behaviors and practices.

Riegel et al.’s (2012) Theory of Self-care and Chronic illness was used as a method to conceptualize the process of self-care for PRiHs with T2DM. This theory provided a synchronous, iterative, overlapping and intertwined process in which the illness is the center. In this theory, self-care maintenance, monitoring
and management are interconnected and in constant motion in order to maintain health and facilitate management of illness.

As a model from which to base this study, the theory was a useful guide in an exploration of diabetes self-care dynamics as they are affected by Familism. The theory provided a structure from which the research questions and interviews could be derived and helped to cement the purpose of the study. The components of self-care (maintenance, monitoring and management) were also used as a general framework to guide the focus groups. Riegel et al.’s (2012) theory was a useful guide for this study. However, their theory is illness-centric and there is limited focus on extra-personal or social forces that affect the self-care process. Familism is, in essence, an interplay of social constructs. Moreover, the eight components of self-care (experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, and access to care) were less applicable to this particular investigation (aside from culture, beliefs, values and support). When examining this theory in a broader application, where the extra-personal and social forces that may affect a patient’s self-care process were the focus, the model fell short.

**Relationship of concepts and constructs**

The constructs explored included diabetes self-care, diabetes self-care maintenance, self-care management and self-care monitoring. These constructs are related as diabetes self-care management, maintenance and monitoring are components of diabetes self-care. The concepts explored were Familism and
diabetes self-care. These concepts are related in that Familism is either an inhibitor or Facilitator of diabetes self-care.

The most notable relationships between concepts and constructs discovered in this study were between sociocultural factors, socioeconomic factors, Familism and diabetes self-care. Research has shown that Familism may have an effect on self-care. Findings from this study suggest that diabetes self-care also has an effect on Familism.

The PRiH family and community may present in various dynamic configurations, with varying levels of support and interaction. As a social concept, Familism is by definition, dynamic and unstable. Regardless of the role of the family member or their level of interaction in supporting self-care, the family member is also affected in that they are participating in self-care activities for their family member.

This can be illustrated operationalizing Riegel et al.’s (2012) self-care maintenance, monitoring and management constructs. For example, self-care maintenance activities are used by patients with a chronic illness to maintain physical and emotional stability. A supporting family member may help a diabetic person adhere to recommended diet, exercise, take medication, and follow up with healthcare professionals. Similarly, self-care monitoring activities involve the process of observing oneself for changes in signs and symptoms. A supporting family member may help a diabetic person monitor glucose levels, check their feet, and check them for vision changes. Finally, self-care management activities include responding to signs and symptoms of disease when they occur. A
supporting family member may help a diabetic person by evaluating them for significant changes in glucose readings, new or changing symptoms, and pain control.

By engaging in and supporting these self-care activities with the diabetic person, the family member may affect self-care. In order for the supporting family member to affect self-care they must invest some amount of time, effort and physical or emotional energy in these self-care activities. The emotional, physical and financial costs to the supporting family member may vary. This is an area that warrants further investigation.

Findings from this study suggest *Familism* within PRiH communities is influenced by sociocultural and socioeconomic factors. These factors have sub factors, which were evident in the study findings. The sociocultural sub factors include traditions, customs, beliefs, attitudes and perceptions. In this study PRiH traditions and customs included a strong collective social fabric; centrality of traditional foods; traditionally carbohydrate intensive foods; high frequency for family/community gatherings; a strong nurturing maternal culture; tendency to prioritize family over self; traditional gender roles; and a propensity for females to be caregivers. Beliefs included the use of traditional or non-medical treatments/remedies and advice. Attitudes and perceptions included negative attitudes towards diabetes and ambivalence towards diabetes.

The socioeconomic sub factors include education, income, and environment. The PRiH population generally has lower education and income levels compared to the general population. This was reflected in the demographic
data collected in this study. Dietary adherence is a central component of diabetes self-care. In this study, the financial strain associated with diabetic diet and meal preparation, as well as social pressures during family gatherings were recurring themes. The influence of these two major factors on Familism may be variable and dynamic. Determining which of these factors and sub factors has greater influence on Familism is an area of study that warrants further investigation. What is evident from this study, is that within PRiH communities, Familism affects diabetes self-care activities and self-care activities, in turn, affect Familism dynamics. Most importantly, within PRiH communities, the sub factors affecting sociocultural and socioeconomic factors have a greater impact on Familism than the diabetes self-care activities of an individual. The implication here is that for PRiHs with diabetes, self-care activities pale in comparison to other, frankly greater, social forces guiding their decision making.

The goal of Familism centered diabetes care should be to redirect the flow of the forces affecting Familism. In this case, Familism may affect socioeconomic and sociocultural forces. Thereby, decreasing, redirecting or halting the negative effects of Familism on diabetes self-care.

For example, operationalizing this conceptual relationship may include using an intervention to improve the attitudes or perception of the family as they relate to diabetes self-care. Redefining the attitudes and perceptions of family members as more positive may lessen the social pressure and solation for PRiHs managing diabetes self-care at family gatherings. This is an area that warrants further investigation.
**Operationalizing Riegel’s 2012 self-care concepts**

Riegel et al.’s (2012) self-care factors (self-care maintenance, self-care monitoring, and self-care management) were used to guide the discussions surrounding the first and second research questions: 1. In what ways does *Familism* inhibit or facilitate diabetes self-care for PRiH adults with T2DM; 2. How can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics? Additionally, the study finding, that diabetes self-care affects *Familism* dynamics, is discussed as applicable.

Additionally, the three assumptions of this study were explored: *Familism* has an effect on T2DM self-care for PRiH adults; healthcare providers do not generally consider *Familism* as a factor in T2DM self-care; and PRiH men and women in traditional roles experience the effects of *Familism* differently.

**Self-care maintenance**

In this section, the findings from this study are discussed as they relate to self-care maintenance and relevant research questions. Research indicates that Hispanic children help their parents with their diabetes care (Mosavel & Thomas, 2009). A supporting family member in a PRiH family may help a diabetic family member adhere to recommended diet, exercise, take medication, and follow up with healthcare professionals.

*Diabetic diet adherence.* Research shows that offspring of Hispanic diabetics help with enabling important dietary behavior (Laroche and colleagues, 2009). In this study, there were some key differences between men and women
as they experienced *Familism* and diabetes self-care. Findings from this study help answer research sub questions A and C, suggesting that the collective culture of PRiH families may be a positive motivator and facilitator to encourage adherence to the recommended diabetic diet.

Findings from this study also show that male and female PRiHs with diabetes receive some variable level of support with adhering to their diabetic diet. However, male PRiHs may have more support from female or maternal figures, while women may receive little or no support. The difference between actual physical or emotional support and perceived support was not evaluated in this study and warrants further investigation. However, these findings appear to confirm the third study assumption that PRiH men and women in traditional roles experience the effects of *Familism* differently; as well as the study finding that diabetes self-care affects *Familism* dynamics. These findings help answer research sub questions C, E, and F; how *Familism* facilitates T2DM self-care, as well as how male and female PRiHs experience *Familism* differently.

**Exercise.** *Familism* may affect self-care agency when it comes to exercising. Research shows that offspring of Hispanic diabetics help with encouraging physical activity (Laroche and colleagues 2009). Research also shows that some Hispanics believe that their motivation to exercise and adhere to therapeutic diet was undermined when family and friends offered them forbidden foods and did not support their efforts to exercise (Wen et al. 2004). These findings help answer research sub questions B and D; showing negative factors that inhibit T2DM self-care for PRiH adults.
Studies also show positive effects of Familism in that Hispanic people were more likely to exercise regularly when supported by their community (Evenson et al. 2003; Dunn, 2008; Mier et al., 2007). In this study, discussion around support or encouragement to exercise was generally a low point of dialogue within focus groups. Findings from this study suggest that if exercise is encouraged or supported within PRiH families, this encouragement or support may come from maternal figures. This confirms the second study assumption, that PRiH men and women in traditional roles experience the effects of Familism differently; as well as contributes to the study finding that T2DM self-care affects Familism dynamics. These findings help to answer research sub questions C, E and F; showing how Familism facilitates T2DM self-care, as well as how female PRiHs experience Familism differently. Interestingly, findings from this study suggest that PRiH culture may not necessarily be a direct factor inhibiting exercise, but rather the overall lack of self-care support and personal inhibitions. This area of discussion should be clarified in future studies.

Medication adherence. Research indicates that the offspring of Hispanic diabetics help with medication reminders (Laroche and Colleagues 2009). Findings from this study suggest that PRiHs with T2DM likely receive some variable support in the form of reminders to take their medications. There may be differences between men and women regarding this level of support. Men may be more likely to receive support from female and maternal figures, while women may receive little or no support regarding medication adherence.
These findings confirm the first and second study assumptions, that Familism has an effect on T2DM self-care for PRiH adults and PRiH men and women in traditional roles experience the effects of Familism differently, respectively. These study findings answer research sub questions A and C; showing positive facilitators of T2DM self-care within Familism dynamics for PRiH adults. Additionally, these findings offer evidence to answer sub question G and H, suggesting that HCPs should consider gender as a potentially positive or negative facilitator of T2DM self-care support within the PRiH Familism dynamic.

Healthcare Appointments. Research shows that the Hispanic family is important in facilitating compliance with appointments (Kruse, Rohland, and Wu, 2002). Research also supports healthcare providers considering the values of the family when managing chronic disease in Hispanic populations, and incorporating family members into treatment (Andres-Hyman et al. 2006; Anez et al., 2005; Ingram et al., 2007; Sheppard et al., 2008). Additionally, research shows that the Hispanic family is important in providing instrumental and informational support (Miville & Constantine, 2006); as well helping with the treatment decision-making process (Maly et al., 2006).

Findings from this study suggests that healthcare professionals (HCPs) working with Hispanic populations are likely aware that it is important to include the PRiH family in office visits when discussing the diabetes plan of care. However, they may have a passive or nonspecific clinical method of including the family in the visit. Similarly, HCPs may be aware of the fact that the head PRiH female care giver plays an integral role in diabetes self-care, however, they may
not have a specific or clinical approach to including these individual in the plan of care. These findings confirm the third study assumption, that HCPs do not generally consider *Familism* as a factor in T2DM self-care; as well as provide evidence for sub questions G and H; suggesting HCPs should formulate active, specific clinical methods of including the PRiH family in care planning.

In PRiH families, support in attending healthcare appointments may be relatively low or nonexistent. If PRiHs with T2DM receive family support in attending healthcare appointments, the supporting family member is most likely female. This supports the study finding that T2DM self-care affects *Familism* dynamics in PRiH communities. Additionally, this finding confirms the second study assumption. Additionally, these findings help answer research sub question G and H, by providing evidence suggesting that HCPs should formulate formal ways of integrating PRiH family members into healthcare appointments, if applicable. However, findings from this study did not discern if male or female PRiHs receive more support with attending healthcare appointments. This is an area that warrants further investigation and should be considered in future studies.

**Self-care management**

In this section, the findings from this study are discussed as they relate to self-care management. A supporting PRiH family member may help a diabetic family member by monitor glucose levels, check their feet, and checking them for vision changes.
Monitor glucose levels. Findings from this study suggest female family members are most likely involved in helping monitor the blood glucose levels of a diabetic family member. Additionally, male and female PRiHs may experience different kinds of support from their family when it comes to monitoring glucose levels, with men receiving active support in the form of female family members monitoring their blood glucose. However, female PRiH may receive less direct or active support in monitoring glucose levels.

These study findings confirm the first and second study assumptions, that *Familism* has an effect on T2DM self-care for PRiH adults and PRiH men and women in traditional roles experience the effects of *Familism* differently, respectively. These findings also illustrate the evidence from this study showing how T2DM self-care affects *Familism* dynamics. Additionally, these findings answer research sub question G and H; suggesting that HCPs may expect male and female PRiHs to receive active versus passive support with monitoring glucose levels, respectively.

Checking feet. Findings from this study suggest that HCPs may be skeptical of the PRiH family’s involvement in checking their diabetic family members’ feet. However, findings from this study suggest that female family members may be more involved in checking the feet of a diabetic family member. These findings confirm the third study assumption, that healthcare providers do not generally consider *Familism* as a factor in T2DM self-care; as well as the study finding that diabetes self-care affects *Familism* dynamics. Additionally, these findings help answer research sub question A; showing the positive
facilitators of *Familism*, as well as how female PRiHs family members may be affected by their family members T2DM self-care. Considering contrary reports from PRiH subjects and HCP subjects in this study, this is an area that warrants further clarification and should be investigated in future studies.

*Check for vision changes.* Findings from this study suggest that PRiH family members may or may not check their diabetic family member for vision changes. However, if a family member is performing this kind of monitoring, the family member is most likely a female. These findings reflect the study finding that diabetes self-care may affect *Familism* dynamics; as well as help answer research sub question A, showing that monitoring for vision changes may be a positive facilitator of self-care within the *Familism* dynamic.

**Self-care monitoring**

In this section, the findings from this study are discussed as they relate to self-care monitoring. A supporting family member may help a diabetic person by evaluating them for significant changes in glucose readings, new or changing symptoms, and pain control.

*Changes in glucose readings.* Findings from this study suggest that PRiH family members are generally involved in monitoring diabetic family members for very high or very low glucose readings; and the supporting family member is most likely female. These finding answers research questions A and C; showing the positive facilitators of *Familism*, as well as the research finding that self-care affects *Familism* dynamics. Additionally, these findings provide evidence for
questions G and H; suggesting that HCPs should consider include glucose monitoring by family members as a potential positive facilitator of T2DM self-care.

*New / changing symptoms.* Similarly, this study suggests that PRiH family members are generally involved in monitoring diabetic family members for new or changing diabetes related symptoms; and the supporting family member is most likely female. These findings, regarding monitoring glucose readings and changing symptoms, confirm first study assumption that *Familism* has an effect on T2DM self-care for PRiH adults, as well as illustrate the study finding that diabetes self-care affects *Familism* dynamics. These finding answers research questions A, and C, showing positive facilitators of T2DM self-care; as well as provide evidence supporting the research finding that self-care affects *Familism* dynamics. Additionally, these findings provide evidence for sub questions G and H, suggesting HCPs should consider include family members monitoring for new/changing diabetes symptoms a potential positive facilitator of T2DM self-care

*Pain control.* Findings from this study suggest that HCPs may overestimate the PRiH family involvement in monitoring diabetic family members for pain. Monitoring for pain may not be a priority for PRiH family members supporting a diabetic person. Future studies should consider additional investigation and clarification of the PRiH family involvement in monitoring diabetic family members for pain.
Discussion on Factors Affecting Self-Care

In this section, answers to the research questions are provided. Answers to research questions 1 and 2, as well as sub questions A-H, are framed in terms of factors including positive facilitators and negative inhibitors. Additionally, these research questions are discussed in terms of variable factors and limited factors. Finally, the section concludes with a discussion of the effect of diabetes self-care on *Familism* dynamics. Please refer to Diagram 1 in Appendix L as a guide regarding study assumptions, research questions and sub questions.

**Positive facilitators**

*Traditional male role*

Research shows that gender roles may be a factor in family dynamics and health decision-making (Carbone et al. 2010). Findings from this study strongly suggest that male PRiHs with T2DM are likely supported by a female family and community members. This support may include maternal figures, children, siblings, spouses, and ex-spouses. Additionally, this support may be indirect in terms of reminders, or direct in terms of actively performing self-care activities. These findings answer research question 1, and sub questions C; showing the traditional male role may be a positive facilitator of T2DM within the *Familism* dynamic. In essence, being male with T2DM within the PRiH *Familism* dynamic, likely results in more family support. Additionally, these findings provide evidence for questions G and H, suggesting HCPs should consider male gender as a positive factor affecting diabetes self-care support within the *Familism* dynamic.
Finally, this evidence supports the research finding that T2DM self-care has an effect on *Familism* in the PRiH community, with female family members being more likely to provide support with T2DM self-care activities.

**Negative inhibitors**

*Sociocultural stressors*

Research shows that, for Hispanic with diabetes, mealtimes are a source of stress as family gatherings centered on traditionally foods (e.g., rice, bean, pasteles etc.) that were typically harmful and family members tended to overlook the individual needs of a person adhering to a therapeutic diet (Adams, 2003).

Finding from this study also suggests that there is a relationship between stressors associated with diabetes self-care and sociocultural stressors (specifically surrounding meals), decreased motivation, and depression. These findings answer research questions B and D; showing that sociocultural stress related to mealtimes are negative self-care inhibitors of *Familism*. These findings also provide evidence for questions G and H, suggesting HCPs should consider mealtimes as negative inhibitors of T2DM self-care within the *Familism* dynamic.

For PRiH with lower socioeconomic status, the financial strain of procuring foods consistent with a diabetic diet may inhibit dietary adherence. This finding also provides evidence for sub questions B and D, showing socioeconomic strain is a negative inhibitor of self-care within the *Familism* dynamic. This finding also provides evidence for sub questions G and H; suggesting that HCPs should consider low socioeconomic status a negative inhibitor of T2DM self-care.
However, the relationship between income and decision making around food preparation was not expounded upon in this study. Future studies should consider investigating the relationship between income and decision making around food preparation for PRiHs with T2DM.

**Traditional diet**

*Familism* may affect self-care agency when it comes to diabetes self-care. The traditional PRiH diet is a central and vital component of PRiH culture. This diet, in essence, is carbohydrate intensive and generally conflicts with the recommended diabetic diet.

Research suggest that the negative effect of *Familism* for some Hispanic diabetics involves the advice from health care providers' being viewed as “conflicting with their traditional diets and forcing them to give up preferred foods or ways of preparing food” (Orzech *et al.* 2012). Findings from this study show that adhering to a recommended diabetic diet is one of the greatest challenges for PRiHs managing T2DM. Importantly, findings from this study show that family support may be absent or contradictory to medical and behavioral recommendations. These findings answer research question 1, and sub questions B and D; showing that the traditional PRiH diet is a powerful and negative T2DM self-care inhibitor within the *Familism* dynamic. Additionally, these findings provide evidence for questions G and H; suggesting HCPs should consider the traditional PRiH diet a negative inhibitor of T2DM self-care and formulate strategies to address this.
**Cultural conflicts for women**

The struggles with traditional diet are contextually different for PRiH men and women. Research indicates for PRiH women, performing self-care routines may also be construed as a violation of the central tenets of *Familism* where familial needs are a priority (Lipton, Losey, Giachello, Mendez, and Girotti, 1998; Oomen et al., 1999; Pineda Olvera et al., 2007). Research also show that PRiH women may feel the need to please their family (Perez and Cruess 2014), as well as prioritize the needs of their family over their own self-care needs (Oomen et al. 1999), and that these conflicting obligations include the need to prepare and consume meals that were appealing to their family Adams (2003). Findings from this study support the current research, with PRiH women reporting that they tend to prioritize their family’s needs over their self-care needs. Additionally, female PRiHs reported unique challenges and conflicts regarding feeling obligated to prepare traditional foods for their family. Specifically, PRiH women reported they experienced conflicts when managing different diets within their homes; difficulty incorporating the diabetic diet with traditional foods; and feeling conflicted when other family members offer foods they should not eat. Finally, findings from this study show that PRiH women may experience stress in intimate partner relationships directly related to preparing food for a non-diabetic spouse. These findings answer research question 1, and sub questions B, D and E; showing intrapersonal conflicts, difficulty prioritizing self over others, and difficulty navigating diabetic diet and traditional meal preparation are negative T2DM self-care inhibitors for PRiH women within the *Familism* dynamic.
Additionally, these findings provide evidence for questions G and H; suggesting that HCPs should consider female gender as a negative inhibitor of T2DM self-care for PRiH women in traditional roles, and should formulate methods to address this when applicable.

**Maladaptive behaviors**

Research shows that Hispanic women may feel that preparing a separate healthier meal was alienating and disrespectful (Adams, 2003). Findings from this study suggest that traditional gender role strain, intimate partner relationship strains and the emotional tolls of generally receiving less support may lead to social isolation for PRiH women with T2DM. Additionally, research shows that some Hispanic participants may experience their friends and family members eating foods in front of them that were restricted from their therapeutic diet and encouraged them to cheat on their diets (Orzech *et al.* 2012). Findings from this study show that the collective social environment within PRiH communities may be largely unsupportive of an individual managing T2DM; and to circumvent social isolation, female PRiHs with T2DM may engage in “cheat days”, when attending family/community gatherings. These findings answer research question 1, and sub questions B, D, and E; showing negative self-care inhibitors of *Familism*, and how female PRiHs are affected by *Familism* differently. Additionally, these findings provide evidence for questions G and H, suggesting HCPs and researchers should include intimate partner relationship strain,
emotional tolls, general lack of community support, and social isolation as potential factors affecting T2DM self-care for PRiH women.

**Negative attitudes**

Though T2DM is prevalent within the PRiH community there are widespread attitudes of ambivalence and denial regarding the T2DM diagnosis and seriousness of the disease. These attitudes may make self-care, and specifically, dietary adherence more difficult for PRiH adults with T2DM. Importantly, PRiHs with T2DM may experience negative feelings like emotional discomfort, social isolation, frustration, and embarrassment when attempting to manage their diabetic diet at family gatherings. Moreover, while PRiH family members may generally be aware that their family member is attempting to self-manage T2DM, family and community members may not be aware of the emotional burden and depressive symptoms they may be experiencing as a result of low social support. As a result, PRiH families may not make significant effort to accommodate a recommended diabetic diet during family and community gatherings. This setting of emotional – informational disconnect may be the underlying reason why PRiHs with diabetes report feeling unsupported. Despite the collective social culture, family members may not necessarily be aware of the distress that is caused or felt around meal times. These findings answer research question 1, sub questions B, D, E and F; showing negative self-care inhibitors of *Familism*, and how male and female PRiHs are affected by *Familism* differently. Additionally, these findings provide evidence for study sub
questions G and H; suggesting HCPs and researchers should consider emotional strain related to family gatherings and T2DM management, as factors affecting T2DM self-care. Future studies should consider investigating and clarifying emotional distress caused or felt around meal times for PRiH adults with T2DM.

**Depressive symptoms**

The lifetime prevalence rates of depression amongst individuals with T2DM is nearly twice that of a person without diabetes at 18 vs. 10 % respectively (Ali *et al*. 2006); and anxiety is higher in individuals with T2DM compared with those without the disease at 20 vs. 11% percent respectively (Li *et al*. 2008). Depression and anxiety rates or severity were not evaluated in this study. However, depression was mentioned several times throughout the focus group discussions. The sociocultural stress of managing a diabetic diet within a culture centered on frequent family gatherings and eating foods that contradict dietary recommendations, was a frequently mentioned stressor mentioned in this study. Emotional stress related to the financial strain of adhering to a diabetic diet was also frequently mentioned. There is a direct relationship between these sociocultural and socioeconomic stressors and emotional well-being of PRiH adults with T2DM. The degree to which these stressors affect and individual and their decision-making warrants further investigation. Additionally, the different effects of the *Familism* social collective on the mental health of PRiH men versus women requires additional clarification, and should be investigated in future studies. These findings answer research question 1, and sub question B;
showing a negative effect of Familism on self-care. Additionally, these findings provide evidence used to answer sub questions G and H, suggesting HCPs should include emotional distress and social stressors as factors affecting T2dm self-care.

**Fatalism**

Fatalism is likely widespread amongst PRiH individuals with T2DM and may be a factor in health perceptions of PRiH individuals with T2DM (Caban and Walker 2006; Smolowitz and Zaldivar 1994; Quatromoni et al. 1994). Research shows that PRiH individuals perceive T2DM as a chronic illness that resulted in complications over time that could not be avoided (Quatromoni et al. 1994; Smolowitz and Zaldivar, 1994). This study did not evaluate the effect of Familism on Fatalistic attitudes directly. However, denial, ambivalence, and negative attitudes were commonly mentioned. These findings help answer and give context to findings related to research question 1; showing that negative attitudes have a negative impact on T2DM self-care. However, the relationship between Familism and fatalism should be investigated in future studies.

**Socioeconomic forces**

Many PRiHs live in urban communities comprised of interconnected family systems and are subject to the environmental and psychosocial stressors of urban living (Mattei, et al. 2010). Fifty-three percent of all PRiHs live in the northeastern states, New York, Pennsylvania, New Hampshire, Massachusetts,
New York, Connecticut, New Jersey and Rhode Island (Census 2010). Future studies may control for urban versus rural environment to clarify if there is a relationship between environment and diabetes self-care behavior.

Nationally, Hispanics experience a disproportionate burden of poverty and poor health outcomes including T2DM (Pe´rez-Escamilla 2010). PRiH individuals are more affected by poverty and are generally less educated compared to non-Hispanic whites (Census, 2010). In this study, the sample of urban dwelling PRiHs reported lower employment rates, and lower education levels compared to the general population. Future studies should control for education and income to determine if SES has an effect on diabetes self-care behaviors for PRiH adults.

Findings from this study suggest that HCPs may clinically approach this health disparity under the pretense that health literacy a significant factor affecting self-care. However, findings from this study contradict those opinions, and suggest that PRiHs with diabetes may be aware of the effect of their traditional foods on their diabetes care and related outcomes. Additionally, findings from this study suggest that knowledge of the negative effect of these foods, may not in its self, be enough of a deterrent for consuming traditional foods. Research shows that Hispanics are likely to engage in faulty eating behaviors because of concerns over financially burdening their family (Horowitz, Tuzzio, Rojas, Monteith, & Sisk, 2004). The current research supports the notion that financial burden is an inhibitor of diabetic diet adherence. This adds to the idea that there are stronger sociocultural forces at play, and these forces may override knowledge in decision making and self-care behaviors.
Research shows that the positive or negative effect on therapeutic diet are related to variables, including the family’s socio-economic status, financial burden, and knowledge of healthy eating (Perez and Cruess 2014). Therefore, some PRiH communities and families with higher socioeconomic status (SES) may be affected differently by some financial factors affecting self-care for the low-income subjects in this study. The financial cost of adhering to a diabetic diet, may be different for families with higher SES. However, in this study, financial burden and cost was a frequently mentioned factor affecting diabetic diet adherence. These findings help answer research question 1, and sub questions B and D; showing that socioeconomic forces (SES, employment status education level etc.) may be negative elements of Familism and inhibit T2DM self-care. Finally, future studies may control for income and further delineate the relationship between financial strain and dietary adherence.

Variable Factors

Social collective as a positive facilitator

Research shows that Familism may demonstrate health benefits in regard to diabetes self-care that are related to the support received from their close-knit family relations (Perez and Cruess 2014). Research shows that PRiHs are more likely to socialize with other Puerto Ricans; preferred to talk to friends/family about health before they would go to the doctor or the hospital (Long, et al. 2012). Research also shows that facilitators of diabetes self-management in Hispanic communities include family support and support of medical practitioners.
(Carbone et al. 2007). Findings from this study also suggest that the collective nature of the PRiH family and community may be a potentially positive facilitator of diabetes self-care. Research shows that PRiHs are more likely to socialize with other Puerto Ricans; preferred to talk to friends/family about health before they would go to the doctor or the hospital (Long, et al. 2012). In this study, the positive aspects of Familism within the PRiH community appears to center around a strong collective nature with an expansive support network that may include 1\textsuperscript{st}, 2\textsuperscript{nd}, 3\textsuperscript{rd} generation relatives, spouses, ex-spouses, non-familial persons, and people who do not work in healthcare.

Research also shows that the Hispanic family infrastructure may facilitate the adoption of dietary habits amongst family members (Page, 2004). Findings from this study also suggest that the collective community culture may potentially facilitate communal behavioral changes such as adherence to the therapeutic diet, recommended exercise regimens, medication adherence, and attending healthcare appointments. Importantly, findings from this study suggest that PRiH families are generally involved to some degree in helping their family members with T2DM self-care and this assistance makes diabetes self-care more manageable and less burdensome. These study findings answer research question 1, and sub questions A, and C; showing that the social collective nature of PRiH communities may be a positive facilitator of diabetes self-care activities. Additionally, these findings provide evidence used to answer sub questions G and H; suggesting HCPs should consider the PRiH family/community as a potential facilitator of T2DM self-care.
**Social collective as a negative inhibitor**

Research shows that some collective values within Hispanic culture may inhibit diabetes self-care (Carbone et al. 2007). Additionally, research shows that some collective values within Hispanic communities may impede self-care behavior when individual needs conflict with family needs (Perez and Cruess 2014). Findings from this study also suggest that the collective nature of the PRiH family and community is potentially an inhibitor of diabetes self-care. These collective values may include but are not limited to frequent social gatherings, during which, the traditional Puerto Rican cuisine is centered. Research also shows that there is potential for traditional gender roles to constrain patients’ ability to make healthful lifestyle changes (Carbone et al. 2007). Findings from this study also suggest that the strong relationship between traditional female gender roles and traditional Puerto Rican foods has a negative effect on diabetic self-care behaviors and decision making. These findings help answer research question 1, and sub questions B and D; showing that the social collective nature within PRiH communities may be a negative inhibitor to T2DM self-care activities. These findings also provide evidence used to answer sub questions G and H; suggesting HCPs should consider the social collective nature of PRiH communities as a potential negative inhibitor of T2DM self-care activities.

**Traditional female roles as positive facilitators**

Findings from this study strongly suggest that female PRiH family members are a key community resource, often in matriarchal roles, usually the
most trusted for health advice, and most likely to discuss health decisions. Findings from this study also suggests that female PRiH family members, specifically those in matriarchal roles, tend to be viewed as a reliable source of support for health information, care, and support. Additionally, female family members are the more likely to be providers of diabetes self-care support. Finally, this study suggests that female PRiH family members, specifically those in matriarchal roles, tend to be viewed as a reliable source of support for health information, care, and support. These findings answer research question 1; showing that traditional female roles have an effect on T2DM self-care, and contributes to the study finding that T2DM self-care has an effect on Familism dynamics in the PRiH community. Additionally, these findings also provide evidence used to answer sub questions G and H; suggesting HCPs should consider the traditional female role as a potential positive facilitator of T2DM self-care.

**Traditional female roles as negative inhibitors**

*Research shows that* traditional gender role expectations, and caregiver burdens were found to be deterrents for participating in care (*Gonzalez 1989*). Research shows that Hispanic women who endorse traditional role expectations may experience higher levels of family caregiver stress associated with perceived family responsibility in addition to the typical stressors surrounding (chronic disease) treatment (*Perez and Cruess 2014*). Findings from this study suggest that female PRiHs diabetics in traditional roles may feel frustration with
being dependent on their family for support. Female PRiH adults with T2DM may experience frustrations regarding concerns that their illness may cause emotional distress for family members. They may experience difficulty with prioritizing self-care due to family demands, and conflicting obligations regarding T2DM self-management activities and daily living. Additionally, for PRiH women, disease management generally being a low priority at family gatherings. Findings from this study are consistent with current research, which shows that under financial duress, some Hispanic women purchase foods that their husbands prefer, which are often harmful to their health or not consistent with their recommended therapeutic diet (Thornton et al. 2006). These findings answer research question 1, and sub questions B, D and E; showing that some of the social demands on PRiH women in traditional roles affect them in a distinct way within their family, and may be negative inhibitors of T2DM self-care. These findings also provide evidence used to answer sub questions G and H; suggesting HCPs should include the social demands on PRiH women in traditional roles as factors affecting T2DM self-care.

Exclusion of the family from self-care activities

Healthcare providers working with Hispanic populations will benefit from understanding the role of Familism in chronic disease management. Research supports the contention that healthcare providers should consider the values of the family when managing chronic disease in Hispanic populations, and incorporate family members into treatment (Andres-Hyman, Ortiz, Anez, Paris, &
Research has also shown that family is important in providing instrumental and informational support (Miville & Constantine, 2006), helping with the treatment decision-making process (Maly et al., 2006) and facilitating compliance with appointments (Kruse, Rohland, and Wu, 2002). Findings from this study also suggest that the PRiH family plays an integral role and has a great effect of diabetes self-care. However, while healthcare professional subjects in this study agreed that involving the family in care planning was important, they did not have any uniform approach to include family members. Additionally, findings from this study suggest that this approach to including family in diabetes self-care is most likely passive and likely unintentional. This study also suggests that, despite their vital role and influence, PRiH family members are likely not formally included in the self-care plan for PRiHs with diabetes.

Research shows that Familism dynamics can also be a dilemma for providers who hold vastly different and often opposing worldviews, such as a desire to focus on the individual as opposed to the system (Perez and Cruess 2014). Research shows that HCPs tend to emphasize giving instructions and information rather than counseling patients on realistic goals and progressive lifestyle changes (Carbone et al. 2007). Findings from this study also suggest that HCPs tend to focus healthcare visits on the individual; specifically addressing standard diabetes education (diet, exercise, medications). Findings from this study also suggest that knowledge gaps may not necessarily be driving the diabetes disparity affecting the PRiH community. Given the profound effect of
sociocultural and socioeconomic forces on self-care behaviors, it is at best ‘hopeful’, to expect an individual existing within a social collective to make the sometimes-drastic behavioral changes needed to self-manage T2DM. This study suggest that HCPs may be aware of these social forces, however they do not necessarily address them directly, or factor them into the plan of care. Finally, this study suggest HCPs lack training or education needed to address the effects of Familism on Hispanic patients in their practice. These findings answer research question 2, suggesting that HCPs should consider the integral role of the PRiH family in their patients T2DM self-care; should have formal, uniformed and active approaches to including the family in care; include strategies to minimize sociocultural/socioeconomic forces inhibiting T2DM self-care; and be formally educated on how to address the effects of Familism on T2DM self-care.

Non-medical remedies and advice

Research shows that PRiHs are more likely to socialize with other Puerto Ricans; preferred to talk to friends/family about health before they would go to the doctor or the hospital (Long, et al. 2012). Other research shows that PRiH individuals tend to prefer standard or alternative therapies recommended from a healthcare provider (nurse or physician) rather than traditional or folk remedies (Quatromoni et al. 1994; Smolowitz and Zaldivar 1994). Findings from this study suggest that PRiH individuals may receive traditional or folk health remedies from family and community members. This discrepancy warrants further clarification. Additionally, there were no findings from this study to suggest that traditional or
folk remedies were commonly offered to treat T2DM within the PRiH community or family. This should also be investigated and clarified in future studies.

**Limited Factors**

**Language**

Limited English proficiency is an independent predictor for poor glycemic control among insured U.S. dwelling Hispanic individuals with diabetes, an association not observed when care is provided by language-concordant healthcare providers (Fernandez et al., 2011). The PRiH subgroup tends to have the highest proportion of native English speakers among Hispanic subgroups. Inclusion criteria for this study required that subjects be able to read and speak English. English proficiency was not formally measured or evaluated. Therefore, while English proficiency is considered a predictor for poor glycemic control, it is not included in the analysis or discussion. English proficiency of the study sample is discussed later in the Limitations section of this chapter.

**Healthcare access**

Puerto Rican identified Hispanics are U.S. citizens by birth. As a result, this population has comparable rates of insurance and healthcare access to the general population. Healthcare access is a limited or negligible factor affecting self-care and or the diabetes disparity affecting PRiHs.

**Diabetes Self-Care Effect on Family Members**

This was an unexpected finding and was not related to any of the study assumptions or research questions. This finding suggests that an individuals’
diabetes self-care behaviors will affect *Familism* dynamics within a PRiH family. PRiH women in traditional roles may have concerns that altering their traditional diet will have a negative impact on their family. The actual effect of modifying the diet for a PRiH family was not investigated in this study. However, the perceived effect versus actual effect of making these changes should be investigated and clarified in future studies.

PRiH women in traditional roles may avoid making changes to their families’ traditional meals in an attempt to avoid financially burdening the family. This study did not investigate if adhering to a diabetic diet actually more expensive than eating or preparing traditional Puerto Rican meals. The perceived effect versus actual effect of augmenting traditional Puerto Rican meals in favor of a diabetic diet should be investigated and clarified in future studies.

Female PRiH family members are a key community resource within PRiH families. They are often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions. Compared to their male counterparts, females in a PRiH families are most often tasked with caring for family members with T2DM. Family members may share a varying amount of responsibility and have a positive direct (i.e. checking glucose, administering medications, preparing meals) or indirect (i.e. reminding to attend appointments etc.) effect on their family members’ diabetes self-care. These supportive family members may include but are not limited to intimate partners (wives, girlfriends), adult children, ex-intimate partners, siblings, grandchildren, daughter in-laws, and mothers.
Finally, the collective social environment of the PRiH family is such that family gatherings are often centered around, often, traditional Puerto Rican foods. An individual who wishes to change the traditional meal to be more in line with a diabetic, they will do so with a net effect on other family members. Food preparation is an expected duty for female PRiHs in matriarchal roles. If the matriarch augments a traditional meal, this seemingly small decision may affect her spouse, children, grandchildren etc. Again, the perceived effect versus actual effect on family members from modifying traditional Puerto Rican meals in favor of a diabetic diet should be investigated and clarified in future studies.

**Study Challenges**

**Theoretical application challenges**

Riegel et al.’s (2012) defines self-care maintenance as those behaviors used by patients with a chronic illness to maintain physical and emotional stability; self-care monitoring as the process of observing oneself for changes in signs and symptoms; and self-care management as the response to signs and symptoms when they occur. When these concepts were applied to diabetes self-care and Familism, it was determined that the best use of this theory was to use the concepts to guide inquiry into the specific associated behaviors of the key concepts as follows: family role in diabetes self-care maintenance; family role in diabetes self-care management; family role in diabetes self-care monitoring.
Specifically, differentiating between the following questions in focus groups proved difficult both for myself as a researcher as well as for the subjects. (See Appendix C for complete focus group moderator guide)

- What is the family’s role in diabetes management regarding checking glucose?
- What is the family’s role in diabetes management regarding self-evaluation for high and low symptoms?
- What is the family’s role in diabetes monitoring for significant changes in glucose readings?
- What is the family’s role in diabetes monitoring for new symptoms or a change in symptoms?

As an interviewer, this line of questioning proved to be very frustrating, as I felt I was burdening the group members with questions that were so similar that they could not differentiate between them (Journal Entry 1/3/17). In retrospect, I had difficulty differentiating them myself, subsequently, I failed to ask questions in the same way each time/group and perhaps missed some important data. To compensate, I also may have asked the question in a way that was too complex for the members. When trying to simplify and condense the questions, I did not stick to the script as well as I would have preferred.

While self-care management, maintenance and monitoring are distinguishable clinically and theoretically, when interviewing subjects, there is considerable overlap in these concepts (Journal Entry 1/2/17). Differentiating these concepts is difficult to convey in a focus group; to lay people; and likely
even more so to people for whom English is not their primary language. As a researcher, asking these questions seemed redundant, so much so, that I inadvertently apologized for the seeming redundancy (Journal Entry 8/15/17).

Medical providers, who anecdotally, were the highest educated of all of the subjects in the study, often requested to offer answers such as “same answer as previous question”, when asked about monitoring, maintenance, and management.

For researchers using Riegel et al.’s (2012) theory for a qualitative study, consolidating these questions during data collection, and deconstructing them during data analysis may be more efficient for the researcher and less confusing for subjects. Riegel et al.’s (2012) theory was helpful in guiding the study questions and providing a framework from which to inquire. However, in this study, the line of questions should have been amended to be more palatable for the researcher and digestible for the subjects. From a practical standpoint, subjects often answered similarly to all of these lines of questions. Perhaps self-care maintenance, management, and motioning are so similar that differentiating them is difficult for the researcher and the subjects. (Journal Entry 5/11/27)

During the focus groups, the aforementioned line of questioning often stalled out, leaving nowhere to go in terms of pursuing deeper or more specific questions. As a result, during data analysis, some of the same answers were used to answer different questions as that is how the subjects responded. These categories of questions produced a generally low yield of data, and less depth to
some of the other data surrounding self-care maintenance, monitoring, and management (Journal Entry 5/11/27).

Data saturation

The original study proposal included 6 focus groups (2 mix gender groups, 2 all female groups, 2 all male groups). However, after conducting 4 focus groups, several strong themes emerged, however no new themes or discoveries at the conclusion of the 4 the group. After consultation with the qualitative methods expert on my committee, regarding collecting data from two additional focus groups, versus amending the study design, it was determined that the two additional focus groups would not necessarily add to the richness of the study data (Journal Entry 11/7/16). However, with only n=17 patient subjects in the study at the conclusion of focus group #4, there were not enough data points, and thus it would be difficult to draw conclusions from the data. The decision was made to use conduct an additional five individual interviews with n=5 community members. The preliminary themes discovered in the focus groups were used to guide these interview questions, and expound upon newly discovered themes.

The inclusion/exclusion criteria for community member subjects was identical to those used for patient subjects. This amended study design strengthened the study by adding a data set from a different vantage point. This new vantage point, community member subject experiences, also allowed true triangulation of the data on the phenomena of interest. Additionally, the recruitment challenges and losses to attrition were minimized by not requiring subjects to return to the research site to conduct the research meeting.
**Interview question challenges**

Some questions were very similar and as the interviewer, I often felt as if I was burdening the focus group and medical provider subjects with questions that were so similar they could not differentiate between them (Journal Entry 1/3/17). In retrospect, I had difficulty differentiating the questions myself. Subsequently, I failed to ask questions in the same way each time/group. In an attempt to compensate for feeling as if I had asked the research question in a way that was too complex for the subjects, I attempted to simplify and condense some of the questions (Journal Entry 1/3/17). My own novice showed as I sometimes stumbled through questions instead of reading them from the script. Additionally, clustering several questions also may have decreased the quality of the data by decreasing specific responses to questions. When clustering questions, subjects tended to respond to some questions and not to others (Journal Entry 5/11/17).

Despite these novice oversights, I do not believe occasionally clustering a line of questions or a slight adlib of 3-4 research questions had any significant effect on the outcomes or themes generated in this study. However, for researchers conducting qualitative studies and using interview guides, it would be prudent to consistently ask the research questions in the same way every time. Importantly, validating questionnaires prior to conducting a qualitative study may prevent some of this confusion.

**Data analysis challenges**

The focus group moderator guide (Appendix C) was helpful in guiding the study questions and providing a framework from which to base the inquiry for this
study. However, when analyzing the transcripts, there was a considerable amount of overlap in describing the tasks involved with self-care maintenance, monitoring, and management (Journal Entry 8/15/16). For example, one questions asked about the family role in self-care monitoring for symptoms of high or low blood glucose. This question is very similar to a line of questions about the family role in self-care management and self-evaluation for symptoms of high or low blood glucose levels (Journal Entry 5/11/17). As a result, this line of questioning had a very low yield of data given the questions were very similar (Journal Entry 1/3/17). However, the difficulty operationalizing these lines of questions was not purely a poor theoretical fit. The theoretical constructs and concepts outlined by Riegel et al. (2012) only described the functions and tasks of self-care maintenance, management and monitoring. I assigned these concepts and constructs to categories and added the somewhat redundant sub questions according to the description of each concept. It wasn’t until the study was operationalized, that the redundancy of some of the research questions became evident.

Making distinctions between these concepts proved to be a difficult concept to convey to lay people in focus groups as well as experienced clinicians. Self-care maintenance, management, and monitoring may be so clinically similar that differentiating them is difficult for the researchers and subjects. Responses from all subjects suggested that the questions were redundant. Future studies may be improved by asking these questions in a different way, which may help clarify this line of questions. Importantly,
procedures to validate research questions prior to conducting a qualitative study may prevent some of this redundancy.

**Subject screening challenges**

The inclusion criteria limited the age of subjects to 21-65. The rationale for this age limit was that the focus of the study was on the experiences of middle age PRiH adults, and truly geriatric subjects may have very different or very specific needs by comparison. While the population of patients at the first research site (Outpatient Community Health Center) had relatively high rates of T2DM, most patient subjects were screened out as their age was > 70 years old.

Additionally, the population of patients at the first research site were mostly PRiH. However, many who met inclusion criteria were screened out as they required Spanish interpreters. All of the patient subjects and community member subjects recruited into the study were English speakers. However, English may have been their secondary language. This could have been a barrier as some patients may have more English proficiency than others and therefore be better able to communicate with the researchers. The proficiency of language was not formally screened, tested, or evaluated; and this may have limited some of the participants as some were more proficient than others. Similarly, community member subjects were English speakers. However, for some, English may have been their secondary language as well. This informal screening for English proficiency presented similar challenges to the focus groups as mentioned above, and may have been a communication barrier during community member interviews. The threshold for being an English speaker was
relatively low as subjects simply answered ‘yes’ or ‘no’ as to whether or not they could read, speak and understand English. Therefore, several patients were included in the study had low English proficiency (Journal Entry 1/2/17). This was evidenced by the quality of answers from some subjects during focus groups and community interviews. It is plausible that the quality of the data may be greatly improved by replicating this study in Spanish, or providing interpreters for those subjects with lower English proficiency.

While the inclusion criteria for patient subjects and community health members was essentially the same, the screening process was different and some challenges and limitations arose as a result. In preparation for recruiting patient subjects into the study a chart review was performed. As the PI, I had access to the patients records and screened by reviewing the following: confirm diagnosis of T2DM as documented on the problem/diagnosis list (diagnosed > 1 year); review demographic forms for self-identified ethnicity; review demographic form to confirm English spoken and read; confirm that the patient did not use interpreter services; and verify age (See Appendix G). During phase 1 of data collection the chart review process provided objective data that could be reviewed prior to recruiting the patient subject, and thus provided somewhat of a stop gap from inadvertently recruiting and including patient subjects that did not meet inclusion criteria. However, while community member subjects were held to the same inclusion/exclusion criteria, objective verification via their health record was not available. As a result, two subjects whom on initial screening identified themselves as being “diabetic”, later during the research interview, described
themselves as pre-diabetic (Journal Entry 4/7/17). Their data was included in the study for two reasons. Firstly, the interview was focused on behavioral self-management and community/family dynamics. If these two subjects were pre-diabetic, their behavioral management would have been the same as, similar to, or perhaps slightly less intensive than a person who carried the diagnoses of T2DM. Therefore, their information was quite relevant and applicable. Secondly, I was able to confirm that they did in fact take medications for diabetes, and therefore were more likely diabetic. The answers these two subjects provided was similar to the answers provided by other subjects. Additionally, the line of questions asked to the community member cohort was not specifically intended to drill down on T2DM self-monitoring, maintenance and management, but rather to affirm social factors and themes not fully fleshed out during the focus groups. Thus, I do not believe this oversight affected the quality of the data. The lesson here is that the inclusion criteria and recruitment process for phase 3 should have been amended to accommodate the inability to objectively screen community member subjects (Journal Entry 4/7/17). Regardless, this methodology oversight is notable and one that should be considered in future studies with similar designs. Especially, if the methodology is amended during the course of the study.

**Recruitment challenges**

Initially the protocol involved mailing recruitment letters to the patient subjects. However, an important modification to the recruitment procedure was made in how the recruitment letter was distributed to subjects. (Journal Entry
Fortunately, the protocol was written in such a way that allowed this modification. This modification involved hand delivering the recruitment letter to the subjects prior to or immediately after their clinic visit, answering any questions they may have, and moving directly into the informed consent process, so long as they were comfortable and wanted to be involved in the study. This active recruiting strategy proved to be not only helpful, but produced high yield of patient subjects agreeing to be in the study.

**Losses to attrition**

Some patient subjects that met inclusion criteria and agreed to participate in the study did not show for scheduled research visits (focus group). Of the 21 patient subjects who consented to be in the study, 3 did not return follow up phone calls, and 6 agreed to attend a scheduled research visit but did not come to the scheduled focus group meeting. The ‘no show rate’, or likelihood that patients would miss their schedule appointment, for the Outpatient clinic where the study was conducted was ~20%. Meaning, 20% of the patients schedule for a visit, would not come to the schedule appointment and would not call to reschedule or cancel the appointment. The ‘no show’ rate for patient subjects in this study was 33% and overall losses to attrition were ~50%. See Diagram 3 in Appendix L. To compensate for this high ‘no-show rate’, 5-7 patient subjects were scheduled to attend a focus group. In nearly all cases, only 3 patient subjects attended. In more than one instance, only two patient subjects showed for a focus group. Fortunately, patient subjects were recruited into the focus groups immediately prior to starting the group. (Journal Entry 9/22/16; 9/29/16;
It is important to note that patient subjects in this relatively impoverished community were offered a monetary incentive that was comparable to similar studies conducted on similar populations and in similar communities. So, while the method of screening, recruiting and consenting patient subjects had a relatively high yield, the rate of return was relatively low.

**Study site challenges**

Prior to conducting this study, I had a longstanding tenure as a clinician at Baystate Medical Center where I primarily served a population of PRiH adults. The outpatient clinic where I practiced and long relationship with the institution proved favorable as I planned, and proceeded to execute this study. This preexisting relationship allowed me great access to the study site, institution administrators, and importantly, the population I was interested in studying. However, after completing phase 1 and phase 2 of data collection, my employment with Baystate Medical Center was interrupted (Journal Entry 1/20/17). As a result, I was no longer allowed to serve as the PI on the approved study or have access to patients’ health records; and as a result, had to close the study and stop recruiting at Baystate Medical Center sites. Fortunately, the study design included constant comparison data analysis, and as such, the data I captured was stored and analyzed by the time my clinician relationship with the research site concluded.

While there were no direct losses of data as a result of these event, there were indirect loses as I no longer had access to the patient subjects’ records and had not harvested their clinical data as they entered the study. As a result,
clinical data from patient subjects was not included in this study. Despite the
aforementioned challenges, which were not insurmountable, gaining access to
both research sites was not wholly arduous. Future researchers should consider
collecting clinical data as early in the data collection phase as possible; and
prepare a contingency plan for continuing the study in preparation for
interruptions between the researcher and the research site.

**Unaccounted for data**

Throughout the course of conducting this study there were several missed
opportunities to gather demographic information including clinical data from
patient subjects and non-normative gender presentations. The original research
proposal included collecting clinical data (i.e. HbA1c readings, blood pressure
readings, diagnosis lists) from patient subject’s records. Harvesting this data was
planned post data collection from focus groups. This information was not
collected. The erroneous assumption on my part, was that the patient subjects’
medical records were permanent records and thus, this data could be collected
at any time. Unfortunately, I separated from the research site as an employee
prior to collecting this clinical data from the patient subjects’ health record. This
information should have been collected after the patient subject completed the
research visit (focus group). Considering the high likelihood that the subjects may
not show for their schedule research visit, I would not suggest collecting this
information prior to the completion of the research visit. However, collecting this
data as soon as the subject has completed a research visit is highly advisable.
Finally, this study did not inquire about, or provide space for subjects to discuss,
Researchers conducting studies with similar methodology should consider collecting all clinical data early in the research process. Additionally, in the future similar studies should consider investigating the relationship between physical/emotional disability and self-care behaviors.

**Transgender subject**

This study was designed to investigate the influence of PRiH culture on T2DM self-care and specifically clarify gender specific cultural factors that influence T2DM self-care. A transgender (male to female) patient subject was screened in to the recruitment pool; ultimately recruited into the study; and contributed to a focus group as one of the female patient subjects (Journal Entry 9/22/19). This patient subject posed several challenges and uncovered several areas within the study design that should be considered if this study was to be replicated.

As the PI screening and recruiting patients, I found myself feeling very conflicted after reviewing the subjects' health record and screening the transgender patient into the recruitment pool. Some immediate thoughts/questions I asked myself included: 1.) does this person fit into this study; 2.) do I have a valid reason for excluding this person from the study; 3.) is it unethical to exclude this person because of my own bias or inexperience; 4.) what focus group should this person be assigned to.

A transgender health clinical specialist was consulted regarding the above concerns. Ultimately, the inclusion or exclusion of this transgender subject
became both a methodological and an ethical dilemma. Several considerations were discussed prior to this decision being made.

One consideration was that the subject had been recruited, was eager to participate, and had already consented to be in the study. In retrospect, the first problem arose in chart review as my focus was primarily on reviewing the chart for inclusion/exclusion criteria, and did not review the other problems in the health record in great depth. In future studies with similar methodology or if this study is replicated, it would be prudent to consider these ethical and methodological challenges before recruiting the patient into the study.

This transgender subject also prompted me to review the general methodological approach and some of the tools used to conduct the study. In general, this study was written with a very heteronormative perspective of gender in that there was no particular allowance or accommodation for gender fluidity or nontraditional gender roles in the LGBTQ community. The research questions were focused on traditional family roles and dynamics for PRiH individuals and seemingly inquire about a binary social dynamic or experience. For example, the focus group moderator guide questions asked about traditional family roles and relationships, without consideration for individuals who may have had more than one gender experience or perhaps did not have a lived experience that fit a traditional gender role.

Secondly, the research team and transgender specialist described the following concerns:
• Inability to allow for full exploration of transgender persons' experience as it pertained to the research topic
• Researcher was not skilled enough to navigate conversation the of transgender identity; study subject; and research questions.
• Exploration of transgender experience may derail focus group topic
• Potential for other subjects reacting negatively to transgender individual and or potentially affecting group dynamics negatively.

Thirdly, the research design and methods did not account for inquiry regarding what age the transgender subject transitioned their gender, and what relevant experiences (if any) were affected by this transition. Finally, the question arose as to whether or not inclusion the transgender subject in the all-female group would affect group dynamics. Of note, the transgender subject had well developed secondary sex characteristics. Ultimately, the decision was made to include the transgender subject in the research study and they were assigned to a mix gender focus group with two male subjects. Some factors that affected the decision to include the subject included generally low representation of transgender people in research (The GenIUSS Group, 2014); potential harm done by “uninviting” the subject; consensus that the mix gender focus group would be the best fit for a transgender person given the circumstances.

This transgender subject did provide some interesting data. The answers to focus group questions provided by the transgender subject did not mention any particular experiences related to her transgender experience during the group. However, the answers the transgender subject provided did suggest that
her experiences were not consistent with other female subjects’ experiences, but they were relatively consistent with the reported experiences other male subjects. The inclusion of this transgender subject in the focus group did not appear to have any negative effect on the focus group dynamics. It is not clear if this subject would have presented with additional, transgender related insights, had they been in the company of transgender peers, or an all-female group. The topics of underrepresentation of transgender individuals in population studies; and the need for study designs that accommodate non-binary gender expressions should be explored further.

**Budget**

The cost for this study was ~$1950.00. The budget was drastically reduced as the transcription costs were significantly lower than expected. This budget included food vouchers for participants, NVivo software, transcription service, and a research assistant. Sources of funding included Sigma Theta Tau, Beta Zeda Chapter via University of Massachusetts Amherst College of Nursing ($1000.00); a dissertation grant via the University of Massachusetts Amherst Graduate School ($1000.00); and the Hluchyj Fellowship ($25,000.00).

Patient subjects and community member subjects received visa like gift cards for completing the research visit ($20.00 each). Interview and focus group data was captured using an audio recording device ($100.00). The University of Massachusetts Amherst Translation Center transcription service was used to transcribe audio recordings (~$1000.00). An independent research assistant
(RA) conducted the participant observation for each focus group ($20.00/hour x 4 hours of data collection + 12 hours for administrative duties = $300). The RA was initially budgeted for 20 hours (6 hours of focus groups + 12 hours of administrative time to compile notes). However, when the study method was amended from 6 focus groups to 4 focus groups, the cost of the RA service was reduced in turn. NVivo software was used to facilitate exploration of the data for themes (Software $230.00 [student software price + renewal]).

**Strengths, Limitations, Generalizability and Bias**

**Study Strengths**

Strengths of this study include the qualitative method of inquiry which allow for investigation of a sociocultural phenomenon. Qualitative data produce massive amounts of data and may be overwhelming from an analytical perspective. Data from this study was analyzed using the constant comparison method. His Grounded Theory approach allowed for amendments to the study protocol during data collection and essentially follow the trail of data as themes emerged.

A strength of this study was the use of Lincoln and Guba’s (1985) validity constructs of credibility, transferability, dependability, and conformability to achieve content validity. Member checking is also a methodological strength of this study. Member checking also provided the community a way to participate in building strategies to improve their own health and wellness.
Formal literacy levels were not tested or evaluated in this study. However, a strength of this study was the collection of level of education from subjects (patients and community members). This information gives context to some of the research findings. Many subjects reported lower education and employment levels, as well as difficulty affording foods suggested for their diabetic diet.

Similar studies (Carbone et al. 2010) collected data from HCPs regarding self-management instructional strategies; perceived patient barriers and facilitators to adopting self-management strategies; experiences supporting patients’ self-management strategies; beliefs and attitudes regarding patients’ abilities to manage their diabetes. In this study explored some of these topics were explored as well as the perceived cultural barriers; strategies to overcome these barriers; best resources for overcoming cultural barriers; as well as techniques that have worked to overcome cultural challenges. Building on existing knowledge such as this, is a strength of this study.

Finally, similar studies (Carbone et al. 2010) used a sample of subjects that were predominantly PRiH. However, not all of the subjects in these studies were PRiHs. A strength of this study methodology is the sampling specifically targeted young to middle age PRiHs.

**Study Limitations**

**Researcher limitations**

Several of the limitations in this study are related to the study PI being a non-Spanish speaker and not allowing for Spanish speaking data to be included in the study. In this study, survey questions regarding primary language showed
to be confusing for this sample bilingual subjects. Moreover, nearly all patient and community member subjects were bilingual. This study was limited in that primarily Spanish speaking subjects were not included and this could have affected the breadth, depth and quality of the data.

Another limitation of this study was that some meaning may have been lost in translation when participants inadvertently used Spanish during focus groups. Contextual and language barriers may have been present as I, the PI and primary contact with all study subjects, did not speak a fluent Spanish. Inclusion criteria for this study required the subjects read and speak English. Initially, the study design and methodology included certified Spanish interpreters being present during focus groups. However, the feasibility of this design was questioned, and it was ultimately removed, in light of budget constraints amongst other factors. Similar studies like Carbone et al. (2010) conducted focus groups with assistance from facilitators who were fluent in English and Spanish. Language proficiency can be a barrier to healthcare for some Hispanic populations. However, PRiHs have some of the highest rates of English speakers amongst Hispanic subgroups. Survey questions regarding primary language showed to be confusing for this sample bilingual subjects. The transcripts and audio recordings suggest that not all subjects were primary English speakers, with some subjects speaking broken but understandable English. This study was limited in that language proficiency was not formally evaluated. When conducting future studies, researchers should include Spanish speaking component and decrease the likelihood of the data literally getting “lost in translation”. Finally,
research shows that PRiHs prefer to consult with family members about health problems prior to consulting with a healthcare provider (Long, Sowell, Bairan, Holtz and Fogarty 2012). However, the relationship between language proficiency and prioritization of family perspectives over health care providers was not explored in this study.

**Setting limitations**

Serving as the PI for this study as well as an employee at the study site proved beneficial. However, when my employee relationship with the study site change, my access to subject records was rescinded. This change of status in the midst of the study was the reason important objective and clinical data was not included in the study. Additionally, the second research site was not a clinical setting, and thus, no objective clinical information was collected. While correlating this clinical data with reported behavioral data may have strengthened the study, I do not believe lacking this data changes the study outcomes.

**Sample limitations**

The sample size for this study was small (n= 25). This small sample, limits generalizability of the study findings. However, this is a common limitation of qualitative methodology. The sample of participants in this study was similar to studies using the similar methodology and investigating similar problems or populations.
Findings from this study suggest that the population of PRiHs from which this sample was collected may have higher rates of T2DM than the national average for PRiH adults (reported 15-20% vs. 10.1% national average); greater concentration of Hispanic adults than the general population (reported 40-90% vs. 14.8% of national population); and higher percentage of PRiH patients than the general population (40-70% vs. 1.5% of U.S. population). The sample of subjects for this study are representative of the general PRiH population in the region where the study was conducted. However, the stratified purposive sampling techniques for this study, and narrow inclusion criteria, decrease the generalizability of the research findings to all PRiHs. Therefore, all of the findings from this study should be further investigated and clarified.

**Methodology limitations**

Several gaps in the literature were not explored in this study. These gaps may add context to the research findings and may have strengthened this study. The study design included methodology that was focused on understanding the influence of Familism on diabetes self-care. Some studies have shown that PRiHs with T2DM use religiosity and spirituality as coping mechanisms (Gonzalez 1989; Caban and Walker 2006). The extent to which these religious/spiritual beliefs affected self-care was not explored in this study. To date, there are no published studies evaluating or contrasting religious or spiritual differences between community dwelling PRiH men and women. Generally, coping mechanisms were not explored in this study. Without an understanding of
how the study subjects cope with the pressures of *Familism*, some context may be lost. Thus, the lack of discussion on coping mechanisms is a limitation of this study. Knowledge gaps regarding diabetes causation may be common in PRiH communities (*Carbone et al. 2007*). There was a recurring theme from HCPs in reference to low health literacy of the study population. However, the topic of knowledge gaps and health literacy were not explored in this study.

**Theoretical limitations**

Riegel et al.’s (2012) theory is illness-centric with limited focus on extra-personal or social forces that affect the self-care process. Additionally, Riegel et al.’s (2012) eight components of self-care were less applicable to this particular investigation. When using this theory in a broader application, where the extra-personal and social forces that may affect a patient’s self-care process were the focus, the model was not a perfect fit for this study. Thus, this study may not be true empirical test of Riegel et al.’s (2012) Theory.

**Generalizability and Bias**

**Generalizability**

The small sample of this study, limits generalizability of the study findings. Additionally, some subjects were excluded (geriatrics, pediatrics, people with Type 1 diabetes) as they may have different needs or experiences compared to the adult PRiH population. Findings from this study may not be generalizable to
the entire PRiH population, and may only apply to young - middle age PRiH adults with T2DM.

Finally, though construct validity was used to ensure trustworthiness of the study findings, this does not ensure that the findings will be generalizable to all PRiHs.

**Bias**

As a practicing clinician within the institution where the study was conducted, I entered the research setting with a certain degree of reporter bias. Subjects were given the opportunity to review and approve study findings prior to publication or dissemination of the results. Still, the study design, my preconceptions, and forethoughts, were influenced by my clinical experience with the study population.

Given my long tenure as a clinician at the research site, there was potential for moderator acceptance bias, where participants who were aware of my clinical role may alter their answers to gain my approval. Subjects with whom I had clinical contact were not included in the study. Despite these precautions, I was a well-known clinical figure in the clinical setting, and some subjects may have been aware of my clinical role.
Discussion on Study Impact

Impact on Researcher

The most notable self-critique throughout the research process was inconsistency in the interviewing process. These inconsistencies were primarily related to either not asking questions in the same way in each research meeting, or not asking a question in a line of questions where responses were low/confusing for subjects. While it is unlikely these inconsistencies dramatically affected the data or research findings, they were apparent enough to draw concern.

Some lessons learned include notable tendency to communicate verbosely in writing and to paraphrase or simplify speech during research related communication. This created a problem as some questions were read to subjects, and in an attempt to paraphrase, caused some inconsistency in the ways in which the questions were asked.

Other lessons learned include the gaining real time experience regarding the value of validating research questions/questionnaires. Some research questions, while seemingly clear when forming them, were confusing for subjects. Other questions, while seemingly relevant, provoked discomfort as a researcher asking the questions. For example, the question “is there anything about being Puerto Rican that makes it difficult to manage diabetes”, seems like an appropriate question. However, at times, a subject would change their facial expression or frown, and an additional the rationale for the question would need to be given. Thus, there was, a possible tone of bigotry or accusation to some of
the research questions. As a person of color, the reaction from some subjects as well as discomfort as the PI, was unexpected.

To some extent, there was difficulty with objectivity and learning to best keep a helpful distance as a researcher. When interviewing patient and community member subjects there was relative comfort in redirecting and guiding the conversation. However, when interviewing HCP’s, there was a tendency to allow them to drift off topic, sometimes becoming tangential.

Personally, and professionally, there may be a tendency to speak, think, and remember in generalities or larger concepts. As a rule, this does produce somewhat less detailed oriented experiences. Throughout the course of conducting this study, the importance of becoming a more detail oriented researcher became very apparent. From conception to finalization, this study evolved and changed in many ways. The many changes that occurred throughout the study were documented through journaling. This process to be invaluable; so much so, that it was almost prudent to incorporate it into personal life as well.

Over the course of this study, there were personal and professional challenges. These challenges included but were not limited to family and financial strain. Valuable clinical skills were essentially stalled while focusing on completing this study. The separation from clinical employment, which also served as research site 1, proved to be especially challenging, as the PI status previously afforded was revoked. This caused an abrupt halt in study recruitment,
and resuming the study at a separate location. This was not wholly bad and actually strengthened the research methodology.

Additionally, conducting this study eventually led to stopping any clinical or didactic teaching appointments. Despite these challenges, this study was completed and the lessons learned solidified the fortitude within to rise to personal and professional challenges.

Finally, the greatest motivation throughout this study came from the subjects, who offered ongoing encouragement. In nearly every encounter with study subjects, they expressed constant gratitude for this work, on what they described as a very important problem within their community. Several female subjects described joy and happiness that ‘someone’ was taking time to work on a problem that, in their eyes, had previously been ignored.

**Impact for Clinicians**

Findings from this qualitative study are not generalizable to the general PRiH population. However, established research in conjunction with the findings from this study strongly support the importance of the family in diabetes self-care activities for PRiH adults. Clinicians may use the findings from this study as a guide for developing strategies for including the PRiH family in their patients’ diabetes self-care. Moreover, clinicians should be aware that powerful communal and social forces influence their PRiH patient’s diabetes self-care behaviors. Finally, additional research is needed before the findings from this study may be used to directly impact clinical practice.
Implications of Study Findings

Implications for research

Hispanic culture is rich and diverse, with many beliefs, customs and traditions; some of which are overlapping between subgroups. However, research has also shown that Hispanic subgroups have varying degrees of differences between them. These differences may affect access to care, attitudes, perceptions, traditions, customs etc. Researchers investigating Hispanic subpopulations should define and target their population sample.

Healthcare is often focused on the health and wellbeing of individuals. However, for individuals managing chronic disease, non-physiologic forces can affect disease pathology. Findings from this study indicate that the sociocultural and socioeconomic forces within the PRiH population heavily impact diabetes self-care. Researchers investigating the diabetes disparity affecting PRiH adults should strongly consider including, and or controlling for these factors in future studies.

Researchers conducting similar studies or using similar methodology should consider reasonable accommodation, deliberate exclusion, or deliberate inclusion for special populations. In this study geriatric, pediatric and people with T1DM were excluded, as these individuals may face different challenges than PRiH adults with T2DM. Additionally, some PRiH sub-communities, such as LGBTQ may face unique challenges. Researchers should approach inclusion or exclusion of these communities within studies ethically and judiciously, as the
challenges and experiences for these groups may differ from the general population.

**Implications for practice**

Type 2 Diabetes self-care requires ongoing behavioral management in order to maintain optimal health and prevent disease pathology. Findings from this study indicate the significance of the social collective within the PRiH community. Importantly, the potentially positive or negative effects of these community forces on diabetes self-care behaviors highlighted in this study may be addressed in clinical settings if applicable.

PRiH family members are likely involved in assisting with their family members self-care activities to some degree. It would behoove clinicians to develop strategies to identify, empower and formally include PRiH family members. This study suggest that clinicians should seek to gain an understanding of the sociocultural and socioeconomic forces affecting diabetes self-care for PRiH patients. This understanding is the gateway to providing interventions and addressing the diabetes disparity affecting PRiHs with T2DM. Additionally, this understanding may allow clinicians to make realistic goals.

The degree of support received and effect of sociocultural and socioeconomic forces weight differently on men and women PRiHs. Clinicians who understand these different experiences of PRiH men and women in traditional roles may be empowered to support these patients as needed. Findings from this study imply that for PRiHs with T2DM, a holistic community
approach to behavioral change may be more effective than focusing treatment on the individual. Clinicians should form strategies to determine the level of support present, support deficits and social pressures affecting their patients; as well as strategies to include family/community members as needed.

**Implications for policy**

Findings from this study are timely as the United States government is currently debating the direction of future healthcare policy. Generally, we have seen the healthcare industry shift focus from individual care to population health. This study suggests that in order to affect positive behavioral change for PRiH adults, the family/community must be the focus. Policy makers should take note of the results of this study as they construct initiatives to improve population health. Additionally, institutional policy makers may benefit from this study. Institutions serving PRiH communities may improve target disease outcomes by focusing their local policy on education and empowering families/communities as well as individuals.

**Implications for education**

In this study, one physician described his lack of education regarding addressing *Familism* dynamics. Additionally, several subjects described a general lack of interest from their HCPs regarding their family. Findings from this study indicate the importance of the PRiH family in affecting self-care behaviors.
Educators should empower budding clinicians with this knowledge and prepare them for the realities of caring for these populations.

**Recommendations**

**Research Recommendations**

*Familism* dynamics as well as the individual, should be the focus of diabetes self-care for PRiHs. To do this, the goals of treatment should focus on the individual and their family. This idea requires additional conceptualization and empirical testing, before it may be applied to practice.

Researchers studying the *Familism* phenomena should consider including this concept, and empirical testing in future studies. Importantly, the small sample size, stratified purposive sampling techniques for this study, and narrow inclusion criteria, decrease the generalizability of the research findings to all PRiHs. Future studies should aim to replicate this study, clarify, and confirm or reject the study findings.

PRiHs with T2DM may use religiosity and spirituality as coping mechanisms (*Gonzalez 1989; Caban and Walker 2006*). There are no published studies evaluating or contrasting religious or spiritual differences between community dwelling PRiH men and women. Future studies should investigate and contrast the coping mechanisms used by PRiH men and women use to manage the T2DM management.

Knowledge gaps regarding diabetes causation may be common in PRiH communities (*Carbone et al. 2007*). Findings from this study show that HCPs
consider low health literacy a factor in diabetes self-care for PRiHs. However, this was not evident from the reports from PRiH subjects in this study. Future studies should investigate the relationship between knowledge gaps, health literacy and diabetes self-care in the PRiH community.

PRiH individuals may receive traditional or folk health remedies from family and community members. However, in this study there were no findings suggesting that traditional or folk remedies were commonly offered to treat T2DM within the PRiH community or family. Future studies should explore the use of traditional or folk remedies used to treat T2DM in the PRiH community.

This study did not discern if male or female PRiHs receive more support with attending healthcare appointments. Future studies should clarify as to whether or not this lack of support with attending healthcare appointments is perceived, lack of emotional support or lack of active support (i.e. attending appointments with a family member). Additionally, findings from this study show conflicting reports from HCPs and patient subjects regarding family involvement in checking their diabetic family members feet. HCPs did not believe family members checked feet and patient subjects reported their family members did check their feet. Researchers studying Familism and self-care behaviors in PRiH adults are encouraged to clarify these findings.

Findings from this study show conflicting reports from HCPs and patient subjects regarding family involvement regarding monitoring for pain; with HCPs reporting that families monitored family members for pain, and patient subjects
Researchers studying *Familism* and self-care behaviors in PRiH adults are encouraged to clarify these findings.

Male PRiHs may have more support from female or maternal figures, while women may receive little or no support. Researchers investigating the effect of *Familism* on diabetes self-care should consider investigating and clarifying the difference between, the presence or absence, of actual physical or emotional support and perceived support for PRiH men versus women. Findings from this study suggest that PRiH “culture” may not necessarily be a direct factor inhibiting exercise, but rather the overall lack of self-care support and personal inhibitions. Researchers investigating the effect of *Familism* on diabetes self-care should consider studying Factors inhibiting diabetes self-care for PRiHs, should consider investigating the relationship between exercise motivation and PRiH culture.

Despite the collective social culture, family members may not necessarily be aware of the distress that is caused or felt around meal times. Findings from this study suggest that there is an emotional – informational disconnect that drives PRiHs with diabetes feelings unsupported by their family. Additional research is needed to determine if this emotional-informational disconnect is perceived or an actual deficit in knowledge.

Findings from this study show that there is a direct relationship between sociocultural, socioeconomic stressors and emotional well-being of PRiH adults with T2DM. Additional research is needed to determine the degree to which these stressors affect and individual and their decision making; as well as
different effects of the *Familism* on the mental health of PRiH men versus women. Additionally, fatalism is common amongst PRiH individuals with T2DM and may be a factor in health perceptions of PRiH individuals with T2DM. Additional research is needed to delineate the relationship between *Familism* and fatalism for PRiHs with T2DM.

In this study, the sample of urban dwelling PRiH reported low employment rates, and lower education levels compared to the general population. Future studies on this phenomenon should control for education, income, as well as urban versus rural environments, to determine if SES and environmental stressors effect diabetes self-care behaviors. Specifically, researchers should seek to delineate the relationship between financial strain and dietary adherence.

PRiH men and women experience *Familism* dynamics differently. PRiH women with T2DM who are in traditional roles may have concerns that altering their traditional diet will have a negative impact on their family. Future studies should investigate the perceived versus actual (social, cultural, financial etc.) effect of modifying the diet of a PRiH family.

Many Hispanic people are bilingual. To avoid loss of data and increase the breadth and depth of the study, future studies investigating the phenomena of *Familism* and its effect on diabetes self-care for PRiHs should include accommodation for primary Spanish speaking individuals. PRiHs have some of the highest rates of English speakers amongst Hispanic subgroups. Still, language proficiency can be a barrier to healthcare for some Hispanic populations. Additionally, future studies should investigate the relationship
between language proficiency and prioritization of family perspectives over health care professionals in the PRiH population.

**Practice Recommendations**

In this section, answers to the second research question are provided. Answers to the second research question, “how can clinicians use *Familism* to facilitate improved diabetes self-care in Puerto Rican identified Hispanics”, are framed and generated by the factors affecting self-care. These factors include positive facilitators and negative inhibitors; as variable and limited factors; as well as the study finding that diabetes self-care affects familyism dynamics.

Findings from this study should be empirically validated. However, some findings are clinically applicable and warrant consideration for inclusion in practice. Two of the most important findings from this study are the importance of Puerto Rican family/community gathering and the centrality of traditional foods at these gatherings. These factors are potentially positive facilitators or negative inhibitors of diabetes self-care in these communities. The most significant recommendation from this study, is that HCPs and researchers should prioritize including relevant family members in the care planning of PRiH patients with T2DM.

Healthcare professionals may facilitate the positive effects of *Familism* by engaging with the PRiH social collective directly. This may include investigating who their PRiH patients’ family supports are. Importantly, clinicians should directly and purposefully empower and include supporting family members into the diabetes plan of care of their patients. This may provide a direct pathway to
affect behavioral change (i.e. diet, exercise), medical management (i.e. medication adherence) and self-care practices (i.e. monitoring, management, maintenance). Family supports should be identified by HCPs, and their roles should be clearly defined, and they should be included in the healthcare visits. PRiH family members are often involved in the diabetes self-care of their family members. HCPs may facilitate inclusions of these supporting family members in health care appointments by seeking approval from the patient and requesting the supporting member attend healthcare visits. The frequency of family involvement in healthcare appointments may vary from person to person and should be determined by the clinician, patient and family member. During healthcare appointments, clinicians should employ empathy for the socioeconomic and sociocultural burden of T2DM self within the PRiH family. Importantly, PRiH patients and families may prefer to receive a more holistic approach to diabetes management as opposed to disease specific informational style visits.

Healthcare professionals may prevent the negative effects of *Familism* on T2DM self-care for PRiHs by addressing the sociocultural stressors associated with self-care. Clinicians should include the sociocultural stressors as barriers to diabetes self-care adherence for PRiHs. These sociocultural stressors may include obstructive behaviors from family members, specifically at communal meals. Through dialogue with patients, HCPs should seek to identify, educated and include influential family members in diabetes care planning. HCPs should become familiar with, show empathy for, and provide pathways to navigate social
responsibilities that may complete with diabetes self-care. HCPs should identify
patients lacking emotional, active or passive diabetes self-care family support; as
well as provide support and resources as indicated.

Socioeconomic forces may affect diabetes self-care behaviors for PRiHs. HCPs should determine if food cost is a barrier to diabetic diet adherence for PRiH patients, and facilitate pathways to provide relief. These actions may reduce sociocultural stress, empower patients and their family members, and subsequently improve diabetes self-care adherence.

Healthcare professionals should address the cultural conflicts PRiHs experiences when managing diabetes at communal gatherings. Communal meals are an ongoing source of sociocultural stress for PRiHs managing T2DM. HCPs should provide additional support to PRiH patients by providing specific tools that help them navigate social pressures around communal meals. Additionally, HCPs should use standardized methods to inquire about potential barriers to diabetes adherence such as perceptions about cultural conflicts with diabetic diet recommendations.

To improved diabetic diet adherence, HCPs should provide consistent, specific, evidence-based approaches to directly address and manage the cultural conflicts of participating in communal meals and managing a diabetic diet. Similarly, HCPs should provide specific methods of adhering a diabetic diet when their patients are eating in public restaurants. Additionally, PRiH women may struggle with perceived obligations that contradict with diabetes self-care. HCPs should provide additional support for female PRiH patients by acknowledging,
providing support for, and providing methods to address perceived obligations prepare traditional PRiH foods for their family. Finally, HCPs should empower and encourage PRiH family members to provide a therapeutic diet at family gatherings by including family and community in the diabetes plan of care, and providing resources and information.

PRiH family members are often involved in self-care activities for PRiHs with T2DM. Healthcare professionals should actively involve the PRiH family and community in diabetes care planning for their patients. Additionally, HCPs should standardize methods of inquiring about and determining family involvement in diabetes self-care.

HCPs should create standardized methods to determine if PRiHs with T2DM have family and community supports that encourage recommended exercise regimens. Additionally, HCPs should ensure PRiH patients with T2DM have adequate family and community supports that encourage exercise regimens. Thereby improving motivation and adherence to exercise regimen.

The sociocultural strains of diabetes self-care may be great for PRiHs. Given the centrality of carbohydrate intensive traditional Puerto Rican foods and frequent family/community gatherings, this strain is associated with social isolation. HCPs should determine Rip diabetic patients are affected by social pressure to forgo their diabetic diet. If so, the HCP should provide emotional support, coping resources, and including community members and family members in the diabetes care plan. Ultimately, this may improve diabetes diet adherence. Additionally, HCPs should evaluate PRiHs with T2DM for depression
and depressive symptoms on an ongoing basis. Additionally, HCPs should use standardized methods to evaluate and treat PRiH adults with T2DM for social stressors, social isolation and concomitant depression. HCPs may help reduce the emotional burden of diabetes self-care and improve diabetic diet adherence by providing resources to help resolve these self-care related stressors.

Puerto Rican identified Hispanics may experience relationship interpersonal relationship strain related to diabetes self-care. These strains may negatively affect diabetes self-care. HCPs should determine if these social stressors and provide resources to address these concerns. Additionally, HCPs should determine if associated sexual dysfunction or negative body perceptions are present for PRiH patients with T2DM, and provide providing resources and or treatment to address these concerns.

Negative attitudes about diabetes self-care are common in PRiH communities. Healthcare professionals should actively work to dispel negative attitudes about diabetes in the PRiH community. HCPs should provide education about diabetes prevention, treatment and management at the community level, thereby improving patient and community engagement.

Finally, socioeconomic forces such as income and education may have a negative impact on diabetes self-care for PRiHs. HCPs should determine the socioeconomic status, literacy and health literacy of their PRiH patients, as well as the subsequent effect on diabetes self-care activities (specifically food purchasing). This information should be used to provide support and resources to address these concerns.
Study Conclusions

The research assumptions for this study were that Familism had a negative effect on T2DM self-care for PRiHs; Familism was an inhibitor of diabetes self-care for PRiHs; PRiH men and women in traditional roles experience the effects of Familism differently; and Healthcare providers did not generally consider Familism as a factor in T2DM self-care. In this section, the research questions 1 and 2 are answered according to the research findings.

This study helped answer the first research question “What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?” Findings from this study show that Familism has a profound effect on diabetes self-care for PRiH adults. Additionally, Findings from this study are consistent with the original study assumptions, that Familism has a negative effect on T2DM self-care for PRiHs. Familism, also has some potential positive affects as well. Potential positive effects include a strong collective nature within the potentially expansive family and community. This social collective, if engaged in health positive behaviors, has the potential to influence diabetes self-care behaviors. Additionally, this communal nature is likely the reason why PRiHs with T2DM often have some level of support with diabetes self-care activities. For PRiHs receiving familial assistance with diabetes self-care, they likely feel relief from social isolation, and the burden of the diabetes activities is lightened. Despite the potential of a positive effect of Familism, the negative effects found in this study were more evident. These negative effects,
are centered around frequency of family/community gatherings and the carbohydrate intensive traditional PRiH meals. Struggles with adhering to a diabetic diet, which directly contradicts traditional Puerto Rican cuisine, was by far one the most apparent finding from this study.

Other ways in which Familism affects diabetes self-care include emotional distress and negative feelings about diabetes self-care. Negative effects of Familism included emotional distress related to social isolation, frustration, and embarrassment. These emotions are intensified at the frequent family gatherings where foods that should be avoided are plentiful and often encouraged. Type 2 Diabetes is prevalent in PRiH communities, however, there are widespread attitudes of ambivalence and denial about the disease. Family members may be aware that their family member is managing T2DM, however, they may not be aware of the emotional distressed they are battling. Finally, the pressure to provide meals that will appease the greatest number of family members versus a “special diabetic diet” is likely an intense stressor and challenge for PRiHs with lower SES.

Findings from this study also show that Familism is a powerful negative inhibitor of self-care for PRiHs. The centrality of traditional food within PRiH culture, coupled with the abundance of these traditional foods during family gatherings, and lack of diabetic friendly options in PRiH eating establishments may impede PRiH adults from adhering to a diabetic diet. Additionally, the strong nurturing matriarchal culture may inhibit diet adherence if these central figures are not supportive of healthier diets. Some family and community members may,
in the spirit of the communal gathering which is centered around meals, encourage nonadherence to the recommended diet.

One assumption for this study was that Familism was an inhibitor of T2DM self-care for PRiHs. In this study, Familism was found to be both a positive facilitator and a negative inhibitor of diabetes self-care. Female PRiHs, especially those in matriarchal roles, tend to be heavily relied on for health information, care and support. Specifically, these individuals may facilitate a diabetic family members’ dietary adherence, exercise regimens, medication adherence and attending healthcare appointments. Female family members are likely key facilitators of diabetes self-care and HCPs should seek methods of empowering these individuals.

Findings from this study support the original study assumption that PRiH men and women in traditional roles experience the effects of Familism differently. There are several ways in which Familism affects men and women in the same way. However, there are some distinct differences between PRiH men and women in these experiences.

Women in traditional roles are a key community resource, often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions. They are often burdened with concerns about the effect of their diabetes self-care on their families. When faced with perceived conflicting obligations, PRiH women tend to prioritize their family and spouses needs over their own. For example, the collective social environment may be largely unsupportive of individuals managing T2DM. PRiHs with T2DM, specifically
women, may engage in “cheat days”, on which they would disregard their diabetic diet when attending family/community gatherings. These conflicts are usually centered around managing a non-diabetic versus their recommended diabetic diet; and weight heavily on PRiH women. However, for PRiH men, diabetic diet adherence is centered around the abundance of carbohydrate centered meals at family gatherings. They may also struggle with dietary adherence due to a plethora of traditional eating establishments within their community.

Diabetes self-care may negatively affect intimate partner relationships for PRiH women and women. For PRiH men, this is likely related to sexual dysfunction. However, for women are likely burdened with perceived conflicting obligations centered around diet, social activities, and time management. Negative self-perceptions are also likely common and include negative body image, and concomitant depressive symptoms.

PRiH women with T2DM may feel less emotional support from their family compared to their male counterparts. This perceived lack of support likely contributes to depressive symptoms associated with decreased motivation, social isolation, sadness, despair, low self-esteem, negative feelings associated with obesity, and denial about their T2DM diagnosis. By comparison, male PRiHs may receive more family support from female family members including but not limited to adult children, spouses, parents, siblings, and ex-partners.

PRiHs women with T2DM likely receive active diabetes self-care support from female family members. This support may include monitoring for symptoms
of high or low glucose, and possibly monitoring for vision changes. They may receive little or no diabetes self-care support with exercising, medication adherence or attending healthcare appointments. On the other hand, PRiH men are more likely to receive maternal support in the form of assistance with medication adherence, and healthcare appointments; as well as support from female family members (spouses, children) which may include actively or passively checking/monitoring glucose levels.

Findings from this study are somewhat consistent with the original study assumption that HCPs generally do not consider Familism as a factor in T2DM self-care for PRiHs. Findings from this study show that HCPs know that the PRiH family plays an integral role and has a great effect of diabetes self-care. However, they likely do not factor socioeconomic and sociocultural forces affecting diabetes self-care for PRiHs. Additionally, HCPs do not have a uniform approach to, and likely overestimate the degree to which they, involve the family include PRiH family members in their patients’ diabetes care planning. The strategies to include family members are at best informal, passive and unintentional. Importantly, this study suggests there is an overall lack clinical training or education regarding managing and addressing effects of Familism on Hispanic populations with T2DM.

An unexpected finding from this study was the effect of diabetes self-care on Familism in the PRiH community. The PRiH family member must navigate potential socioeconomic forces in order to accommodate a family member managing T2DM. Specifically, purchasing foods to accommodate an individual
goes against the principles of *Familism*, which is based on a social collective. These perceived financial burdens may negatively affect intimate partner relationships, though this effect is not clear. Traditional matriarchal roles within PRiH families may not allow for individuality during family gatherings. Requesting alternate or special meals at family gatherings may position an individual PRiH family member as a perceived or actual disrupter to *Familism* dynamics.

Female PRiH family members are a key community resource, often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions. Importantly, PRiH women are often tasked with caring and assisting family members with T2DM. A PRiH family member affects their family dynamics as family members invest time, effort and resources to support them. These supporting family members are likely women and may include intimate partners (wives, girlfriends), adult children, ex-intimate partners, siblings, grandchildren, daughter in-laws, and mothers. These supporting family members may take a varying level of responsibility in assisting with self-care by actively or passively checking glucose levels, monitoring for symptoms of high or low glucose, checking feet and checking for vision changes.

Findings from this study provide greater understanding of the effect of *Familism* dynamics on diabetes self-care for PRiH adults. Hispanic adults with uncontrolled diabetes, has been well studied in nursing and other disciplines with much of the emphasis focused on individuals of Mexican ancestry. PRiHs adults with T2DM, are the second largest Hispanic subgroup and experience similar
and in some cases worse diabetes outcomes compared to the more studied Hispanics of Mexican ancestry.

The findings from this study are significant for nursing and healthcare. Nursing is a science concerned with promoting and maintaining health in individuals and communities. The diabetes PRiH diabetes disparity affects individuals as well as communities and presents systemic burden on the US healthcare system. The overt and subtle socioeconomic and sociocultural forces of *Familism* influence the day-to-day decisions that impact diabetes self-care in the PRiH community; and likely contribute to this disparity.

Findings from this study gives nurses and healthcare professionals a better understanding of these social forces/factors and help them identify and use culturally tailored strategies to improve self-care in these communities. This greater understanding of the effect of *Familism* on diabetes self-care within the PRiH is imperative for implementing culturally tailored primary and secondary prevention addressing the diabetes disparity.

In conclusion, the most significant findings from this study are that *Familism* dynamics have a direct, and mostly negative affect on diabetes self-care for PRiHs; male and female PRiHs experience the dynamics of *Familism* differently; and T2DM self-care has an effect on *Familism* dynamics. Findings from this study strongly suggest that in order to improve diabetes self-care for PRiHs, clinical and research efforts should focus on investigating and addressing the strong sociocultural and socioeconomic forces of *Familism*. 
APPENDIX A

IRB APPROVAL DOCUMENTS AND AGREEMENTS

Baystate Medical Center IRB Approval letter

Baystate Medical Center
Institutional Review Board

DATE: June 28, 2016

TO: Jali Johnson, MS
FROM: Baystate Health IRB #2

STUDY TITLE: [647152-4] Family and Community Challenges in Self Care for Puerto Rican Hispanic adults With Type Two Diabetes

IRB REFERENCE #: BH-16-064
SUBMISSION TYPE: Response/Follow-Up

ACTION: APPROVED
APPROVAL DATE: June 23, 2016
EXPIRATION DATE: June 23, 2017
REVIEW TYPE: Expedited Review
PROJECT RISK LEVEL: Minimal Risk

Thank you for your submission of Response/Follow-Up materials for this research study. The Baystate Health IRB #2 has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

The following items were included in this submission:

- Amendment/Modification - PI Modification Response 2 (UPDATED: 06/15/2016)
- Consent Form - Consent Form Providers (UPDATED: 06/15/2016)

Please remember that informed consent is a process beginning with a description of the study and verification of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and the research participant. Federal regulations require that each participant receive a copy of the signed consent form unless this requirement has been waived by the IRB.

Proposed changes to the research must be submitted to the IRB for review and approval prior to implementation, unless such a change is necessary to avoid immediate harm to subjects.

Any Unanticipated Problems Involving Risks to Subjects or Others, Deviations from the approved research, Non-Compliance, and Complaints must be reported to the IRB in accordance with Baystate HRPP policies and procedures. If this study includes ongoing oversight by a Data Safety Monitoring Board (DSMB) or other such committee, reports generated by the DSMB or oversight committee must be submitted to the IRB.

Continuations must be submitted 60 days prior to the expiration date noted above. The federal regulations provide for no grace period. Failure to obtain approval for continuation of your study prior to the expiration date will require discontinuation of all research activities for this study, including enrollment of new subjects.

The consent document(s) will be forwarded to Interpreter and Translation Services Department for translation. Please allow for a six week turn around time. Once the translated documents have been
University of Massachusetts Amherst IRB Approval letter

Certification of Human Subjects Approval

Date: March 7, 2017
To: Jill Johnson, Nursing
Other Investigator: Cynthia Jacob, Nursing
From: Lynnette Lotz, Secretary, Chair, UMASS IRB

Protocol Title: Family and Community Challenges in Self Care for Puerto Rican Hispanic adults With Type Two Diabetes
Protocol ID: 2017 3700
Review Type: EXPEDITED - NEW
Paragraph H2: 6.7
Approved Date: 03/02/2017
Expiration Date: 03/02/2018

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance #00003909. Approval is granted with the understanding that investigator(s) are responsible for:

Modifications - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

Consent forms - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if unfunded.

Adverse Event Reporting - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

Continuing Review - Studies that received Full Board or Expedited approval must be reviewed three weeks prior to expiration, or six weeks for Full Board. Renewal Reports are submitted through e-protocol.

Completion Reports - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

Consent form (when applicable) will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.
Baystate Health

BUSINESS ASSOCIATE AGREEMENT

This Business Associate Agreement ("Agreement"), effective June 1, 2015 ("Agreement Effective Date"), is entered into by and between UMASS Translation Center, with a place of business at 19 Herter Hall, University of Massachusetts, Amherst, MA ("Business Associate") and Baystate Health, Inc., for itself and on behalf of all its affiliated covered entities, including those that are part of Baystate’s organized health care arrangement and including those identified in Baystate Health’s Notice of Privacy Practices (each individually and collectively, “Baystate”), with a place of business at 759 Chestnut Street, Springfield, MA 01119 (each a “Party” and collectively the “Parties”).

WHEREAS, each Party desires and is committed to complying with all relevant federal and state law with respect to the confidentiality, privacy and security of Protected Health Information, including, but not limited to, the federal Health Insurance Portability and Accountability Act, Subtitle D of Title XIII (Health Information Technology for Economic and Clinical Health Act) of the American Recovery and Reinvestment Act of 2009 and, together with their accompanying regulations, as each may be amended from time to time (collectively the “HIPAA Rules”);

WHEREAS, the purpose of this Agreement is to comply with the requirements of the HIPAA Rules, including, but not limited to, the Business Associate requirements at 45 C.F.R. § 164.504(e) and § 164.314;

WHEREAS, Business Associate performs, or assists in the performance of, certain functions, activities or services involving the use or disclosure of Protected Health Information for or on behalf of Baystate (the “Services”), as business associates are defined under the HIPAA Rules, including in 45 C.F.R. § 160.103;

WHEREAS, each Party desires and is committed to complying with all relevant state law and regulations regarding the security of Personal Information, including, but not limited to the requirements in the Massachusetts Data Security Regulations, 201 C.M.R. 17.00 ("Data Security Regulations"); and

WHEREAS, pursuant to the HIPAA Rules, all business associates of Baystate must agree in writing to certain mandatory provisions regarding the use and disclosure of Protected Health Information.

NOW THEREFORE, in consideration of the promises and mutual covenants contained herein, the Parties agree to the following:

1. DEFINITIONS. Unless otherwise defined herein, all terms used herein shall have the meaning ascribed to them under the HIPAA Rules, including the following:

1.1 Breach. Breach is the unauthorized acquisition, access, use or disclosure of PHI which compromises the security or privacy of such information.
APPENDIX B

RESEARCH CONSENT FORMS

Medical Provider Research Consent Form

Baystate Health

RESEARCH CONSENT FORM
Title of Project: Family and Community Challenges in Self Care for Puerto Rican Hispanics With Type Two Diabetes
Study Sponsor: The Hluchyj Fellowship & The University of Massachusetts, Amherst, Graduate School
Principal Investigator: Jalil Johnson, NP

Study Participant:

WHY ARE YOU BEING ASKED TO TAKE PART IN THIS RESEARCH?
We are talking to you about this research study because you provide care to Puerto Rican identified Hispanic adults with type 2 diabetes. Whether or not you take part in this study is up to you. If you choose not to participate in the study it will not affect your employment or standing within Baystate Medical Center. This form gives you important information. Please read it carefully and ask questions before you make a decision. You may want to talk about this research study with your colleagues or other health care providers. Please take your time. You should not sign this form until all of your questions are answered.

WHY IS THIS RESEARCH STUDY BEING DONE?
The purpose of this research study is to evaluate some of the challenges Puerto Rican families face regarding management of type 2 diabetes.

HOW IS THIS RESEARCH STUDY BEING FUNDED?
This research study is being funded by a grant from The University of Massachusetts Amherst Graduate School. Jalil Johnson NP, the study’s Principal Investigator (the person conducting the study), is not being paid by the grant to conduct this study.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
Thirty to forty (30-40) patients and five (5) medical providers will be recruited from Western Massachusetts and will take part in this research study. The study requires a minimum of thirty patients to complete the study. We expect that some patients may not be able to complete the study and have recruited more patients than is required to complete the study.

HOW LONG WILL YOU BE IN THIS STUDY?
Your participation in this research study is expected to last for 1 hour. The PI will interview you during the research visit. Additionally, you will be asked to complete questionnaires.
A 1-2-hour presentation of the research findings is also available for you to participate; however, this is optional and not required to participate in the study. The follow up presentation is optional for you to attend.

**CAN I STOP TAKING PART IN THIS STUDY?**

Taking part in this study is voluntary. You may choose not to take part or to leave the study at any time. Your decision will not affect your relationship with Baystate Medical Center and will not result in any penalty. Tell the principle investigator if you are thinking about stopping or have decided to stop. There will not be any consequences if you decide not to participate in this research or if you decide not to complete the research study.

If you decide to withdraw from this study, the information (i.e., data from questionnaires) that you provided while participating in the study will be kept with the rest of the study data. This information will be used in analyses of the study data.

The principle investigator may take you out of the study:
- If new information becomes available
- If the study is stopped by the sponsor

**WHAT WILL HAPPEN IN THIS STUDY?**

If you volunteer to participate in this study, the researcher will ask you to do the following:

**Research Visit**
- You will meet with the principle investigator, in a private office at Baystate Medical Center’s outpatient clinic at 140 High St.(basement level-C), Springfield, MA 01199.
- At this visit, you will be asked to (1) sign an informed consent form (this form) after all your questions have been answered; and (2) complete a short questionnaire.
- The PI will interview you for approximately 45-60 minutes.

**Participation in the study**
- The study will involve participating in a 1:1 interview with the principle investigator.
- The interview will last for approximately 1 hour.
- During the interview, the principle investigator will ask questions about how you manage patients with diabetes and how their family affects that management.
- The interview will be audio recorded.
- You will not be required to give any information that may identify you during the interview.

**Follow-up Research Visit** (after the entire study has been completed)
- You will meet with the Principle Investigator and other people who participated in the study for approximately 60 minutes, where the principle investigator will give a formal presentation of the study findings.
• This presentation will be held in a conference room at a yet to be determined location at Baystate Medical Center.
• You will be asked to complete some questionnaires that ask about your experience managing your diabetes and about the presentation of the study findings.
• Attending this presentation is optional.

Sharing Data/Information
• Your personal information will NOT be shared in any publications related to this study.
• Your personal information will NOT be shared with any of the other study participants.

**Future Research:**
In addition to this research, we would like to ask your permission to contact you and to use your comments made during interview discussions for research projects in the future. Information about this is explained in a section towards the end of this document.

**WHAT RISKS OR PROBLEMS COULD YOU HAVE BY BEING IN THIS STUDY?**
You may experience risks and discomforts as a result of being in this study. As with any research study, there could be risks that are not known at this time.

**Risks of Survey Questions:**
• The research questionnaires include some questions that may seem sensitive or personal. You are free to skip any question for any reason.
• The interview questions may include some questions that may seem sensitive or personal. You are free to skip any question for any reason.

**WE WILL DO THE FOLLOWING TO DECREASE THE RISKS OF THIS STUDY:**
• Loss of confidentiality is a potential risk for participating in this study. We will take steps to protect the confidentiality of your research information. These steps are described in more detail later in this form.
• You may skip any question on the survey that makes you feel uncomfortable.
• You may skip any question during the interview that make you feel uncomfortable.

**WILL YOU BENEFIT FROM BEING IN THIS STUDY?**
You may or may not benefit from being in this study. What we learn from this research may help people with type 2 diabetes in the future.

**WHAT OPTIONS OTHER THAN THIS STUDY ARE AVAILABLE TO YOU?**
• If you do not want to be in this study, there is no penalty to you and your employment status at Baystate Medical Center will not change.
• If you do not participate in this study you may still be eligible to participate in other studies.
THERE ARE NO COST TO YOU BEING IN THIS STUDY.
Research-related services are not the responsibility of you or your insurance provider. The procedures or items that are considered research-related in this study include the following:

- Research-related visits with the principle investigator to complete consent form and questionnaires
- Research-related phone calls with the Primary Investigator.
- Conference rooms
- Recording devices
- Food Voucher
- Research personnel
- Meal provided during focus group
- Other research related costs

WILL YOU RECEIVE ANY PAYMENTS OR GIFTS FOR PARTICIPATING?
- Medical providers will not be compensated for participating in this study.

HOW WILL YOUR PRIVACY AND INFORMATION ABOUT YOU BE PROTECTED?
The interview you participate in will be audio recorded. The audiotapes will be stored electronically on a password protected audio recorder and listened to by the principle investigator to make sure that the interviews are being conducted as planned. The original audio recording will be deleted on the recording device immediately after being transcribed and uploaded to the secure computer. The electronic recording file will be deleted (within three months) after the file review is completed and transcribed (conversations will be typed and stored on a protected Baystate computer). The transcripts from the interview you participate in will be coded and not include your personal information.

We will protect your privacy as a participant in this research study and the confidentiality of your research information. We will keep the information gathered about you during this study in restricted areas at Baystate Medical Center. Your study file will be stored in a password protected hard and accessed through the Internal Medicine office at 140 High Street, Springfield, MA. We may be required by law to report some information to a state agency for public health or safety reasons.

Research information that is sent outside of Baystate Medical Center will not have your name on it. If we publish information from this research study or use it for teaching, your name will not be used. All in-person research-related activities (i.e., questionnaires and interview) will take place in a research office at Baystate Medical Center Conference Room. The research visit will be private and confidential. You will meet individually with the principle investigator. All information that you discuss during this session will be confidential, as described in the first paragraph of this privacy section.
INFORMATION ABOUT THE PRIVACY OF PROTECTED HEALTH INFORMATION

Baystate Health has rules in place to protect information about you. Federal and state laws also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it. Generally, only people on the research team will know that you are in the research study and will see your information. However, there are a few exceptions that are listed later in this section of the consent form.

The people working on the study will collect information about you. They may collect information including your name, address, date of birth, and other details. The research team will need to see your information. Sometimes other people at Baystate may see or give out your information. These include people who review the research studies, their staff, administrative personnel, or other Baystate staff.

The fact that you are taking part in this study and information from procedures (such as lab tests) that are done for the research may become part of your medical record.

If we publish information from this research study or use it for teaching, your name will not be used.

People outside of Baystate may need to see your information for this study. Examples include government groups (such as the Food and Drug Administration), organizations that accredit hospitals and research programs, study monitors, other hospitals in the study, and companies that sponsor the study.

We cannot do this study without your permission to use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside of Baystate who receive your information may not be covered by this promise. We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee this.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by contacting the Principal Investigator of this study. The Principal Investigator can be reached at: Jalil Johnson, NP. 140 High Street, C-level, Springfield, MA 01199. 413-794-2038

If you send a letter, please be sure to include the study name and your contact information.

If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

You can ask to see your research records but sometimes that can only happen after the research is completed. If you would like to see your research records please discuss this with your study doctor or a member of the research team.
WHO DO YOU CONTACT IF YOU HAVE STUDY QUESTIONS OR CONCERNS?
If you have any questions about this study, please contact: Jalil Johnson, NP at 413-794-2038, 140 High Street, C-level, Springfield, MA 01199. If you experience a complication or injury that you believe may be related to this study, please contact the PI using the above information. After hours, please call the PI at 508-331-4544. If you would like to discuss your rights as a research participant, or wish to speak with someone not directly involved in the study, please contact the Baystate Institutional Review Board (IRB) at (413) 794-4356.

STATEMENT OF VOLUNTARY CONSENT
I have read this form or have had it read to me. I have been told what to expect if I take part in this study, including possible risks and possible benefits. I have had a chance to ask questions and have had them answered to my satisfaction. I have been told that the people listed in this form will answer any questions the I have in the future. By signing below, I am volunteering to being this research study and authorize my information for the research.

Participant’s Name (Print): __________________________________________
Signature: __________________________________ Date: ____________

STUDY REPRESENTATIVE STATEMENT
I have explained the purpose of the research, the study procedure, the possible risks and discomforts, the possible benefits, and have answered all questions to the best of my ability.

Study Representative’s Name (Print): _________________________________
Signature: __________________________ Date:________________________
Time Consent Obtained: _________
You will receive a copy of this form after it has been signed and dated
STATEMENT OF VOLUNTARY CONSENT
I have read this form or have had it read to me. I have been told what to expect if I take part in this study, including possible risks and possible benefits. I have had a chance to ask questions and have had them answered to my satisfaction. I have been told that the people listed in this form will answer any questions that I have in the future. By signing below, I am volunteering to be in this research study and authorizing the use of my information for the research.

Participant's Name (Print): ____________________________
Signature: ____________________________ Date: ____________

STUDY REPRESENTATIVE STATEMENT
I have explained the purpose of the research, the study procedures, the possible risks and discomforts, the possible benefits, and have answered all questions to the best of my ability.
Study Representative's Name (Print): ____________________________
Signature: ____________________________
Date: ____________ Time Consent Obtained: ____________

You will receive a copy of this form after it has been signed and dated
Community Member Consent Form

RESEARCH CONSENT FORM

Title of Project:  Family and Community Challenges in Self Care for Puerto Rican Hispanics With Type Two Diabetes

Study Sponsor:  The University of Massachusetts Amherst Graduate School

Principal Investigator:  Jalil A. Johnson, MS, ANP-BC, PhD Candidate at University of Massachusetts College of Nursing

Faculty Sponsor:  Cynthia S. Jacelon, PhD, RN, FAAN, Professor at University of Massachusetts College of Nursing

Study Participant:

WHY ARE YOU BEING ASKED TO TAKE PART IN THIS RESEARCH?
We are talking to you about this research study because you have type 2 diabetes. This form gives you important information. Please read it carefully and ask questions before you make a decision. Ask your principle investigator to explain any words or information in this form that you do not understand. You may want to talk about this study with your family, your friends, and your other health care providers. Please take your time. You should not sign this form until all of your questions are answered.

Taking part in this study is your choice. No matter what decision you make, and even if your decision changes, there will be no penalty to you. You will not lose medical care, any legal rights, or any benefits that you are otherwise entitled to. The researcher or team will tell you about new information or changes in the study that may affect your willingness to continue in the study.

WHY IS THIS RESEARCH STUDY BEING DONE?
The purpose of this research study is to evaluate some of the challenges Puerto Rican families face regarding management of type 2 diabetes.

HOW IS THIS RESEARCH STUDY BEING FUNDED?
This research study is being funded by a grant from The University of Massachusetts Amherst Graduate School. Jalil A. Johnson NP, the study’s Principal Investigator (the person conducting the study), is not being paid by the grant to conduct this study.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
Twenty-five to thirty (25-30) people with type 2 diabetes and five (5) medical providers people will be recruited from Western Massachusetts and will take part in this research study. The study requires a minimum of twenty-five people to complete the study. We expect that some people may not be able to complete the study and may recruit more patients than is required to complete the study.

HOW LONG WILL YOU BE IN THIS STUDY?
Your participation in this research study is expected to last 20-30 minutes. Twenty to thirty minutes will be spent attending an individual interview. Additionally, a 1 hour presentation of the research findings is also available for you to participate, however this is optional and not required to participate in the
study. You will be required to be present the Holyoke Senior Center once to complete the informed consent and to participate in the interview. The follow up presentation is optional for you to attend.

**CAN I STOP TAKING PART IN THIS STUDY?**
Taking part in this study is voluntary. You may choose not to take part or to leave the study at any time. Your decision will not affect your relationship with your doctor, medical providers or with the Holyoke Senior Center, nor will it result in any penalty or loss of benefits to which you are otherwise entitled. Tell the principle investigator if you are thinking about stopping or have decided to stop. There will not be any consequences if you decide not to participate in this research or if you decide not to complete the research study.
If you decide to withdraw from this study, the information (i.e., data from questionnaires) that you provided while participating in the study will not be included in the study.

The principle investigator may take you out of the study:
- If your health changes and the study is no longer in your best interest
- If new information becomes available
- If you do not follow the study rules

**WHAT WILL HAPPEN IN THIS STUDY?**
If you volunteer to participate in this study, the researcher will ask you to do the following:

**Research Visit**
- You will meet with the principle investigator for approximately 20-30 minutes in a private room at Holyoke Senior Center, 291 Pine St, Holyoke, MA 01040.
- At this visit, you will be asked to (1) sign an informed consent form (this form) after all your questions have been answered; (2) complete a short questionnaire; and (3) participate in an interview, which will be recorded.

**Telephone Calls**
- The principle investigator may contact you once the study has concluded and invite you to attend a presentation of the study results.

**Participation in the study**
- You will be asked to complete surveys. These surveys will include questions about your gender, age, race/ethnicity, primary language, secondary language, marital status, employment, and education level, and family structure.
- The study will involve participating in an interview with the principle investigator.
- You will be asked to participate in one interview.
- The interview will last for approximately 20-30 minutes but no more than 30 minutes.
- During the interview, the principle investigator will ask questions about diabetes management and how your family affects that management.
• The interview will be audio-recorded in order to accurately capture what is said. If you participate in the study, you may request that the recording be paused at any time. You may choose how much or how little you want to speak during the interview. You may also choose to leave the interview at any time.

• If you agree to participate in this study you must also agree to allowing the researcher to record your interview.

• If you do not want your interview to be recorded, we will not be able to include you in this study.

• You will not be required to give any information that may identify you during the interview.

Sharing Data/Information

• Your personal information will NOT be shared in any publications related to this study.

• Your personal information will NOT be shared with any of the other study participants.

Future Research:

In addition to this research, we would like to ask your permission to contact you and to use your comments made during the interview discussions for research projects in the future. Information about this is explained in a section towards the end of this document.

WHAT RISKS OR PROBLEMS COULD YOU HAVE BY BEING IN THIS STUDY?
You may experience risks and discomforts as a result of being in this study. As with any research study, there could be risks that are not known at this time.

Risks of Survey Questions:

• The research questionnaires include some questions that may seem sensitive or personal. You are free to skip any question for any reason.

• The interview questions may include some questions that may seem sensitive or personal. You are free to skip any question for any reason.

WE WILL DO THE FOLLOWING TO DECREASE THE RISKS OF THIS STUDY:

• Loss of confidentiality is a potential risk for participating in this study. We will take steps to protect the confidentiality of your research information. These steps are described in more detail later in this form.

• You may skip any question on the survey that makes you feel uncomfortable.

• You may skip any question during the interview that makes you feel uncomfortable.

WILL YOU BENEFIT FROM BEING IN THIS STUDY?
You may or may not benefit from being in this study. What we learn from this research may help people with type 2 diabetes in the future.
WHAT OPTIONS OTHER THAN THIS STUDY ARE AVAILABLE TO YOU?

• If you do not want to be in this study, there is no penalty to you and your membership at Holyoke Senior Center will not change.

• If you do not participate in this study you may still be eligible to participate in other studies.

WILL YOU RECEIVE ANY PAYMENTS OR GIFTS FOR PARTICIPATING?

• You will receive $20 in the form of a debit like card for completing the interview. You will receive payment in the form of a debit like card, given to you after you complete the interview with the researcher.

• If you withdraw from the study before you have completed the interview, you will not be eligible to receive the $20 debit card.

• If the University of Massachusetts Amherst pays you more than $600 in a calendar year (or if you are a foreign citizen who is not here as a permanent resident), we must report the payment to the IRS (Internal Revenue Service) and send you a 1099 form.

HOW WILL YOUR PRIVACY AND INFORMATION ABOUT YOU BE PROTECTED?

The interview you participate in will be audio recorded. The audiotapes will be stored electronically on a password protected audio recorder and listened to by the principle investigator to make sure that the meetings are being conducted as planned. The original audio recording will be deleted on the recording device immediately after being transcribed uploaded to the secure computer. The electronic recording file will be deleted (within three months) after the file review is completed and transcribed (conversations will be typed and stored on a protected computer). The transcripts from the interview you attend will be coded and NOT include any of your personal information.

We will protect your privacy as a participant in this research study and the confidentiality of your research information. We will keep the information gathered about you during this study in restricted areas at the University of Massachusetts Amherst College of Nursing. A study file that does not contain any of your personal information will be stored in a secure area in the University of Massachusetts College of Nursing. Medical information created by this research study will not become part of your medical record.

Date:_________, I__________ agree to be audio-taped for the purposes of the study.

Date:_________, I______________ do not agree to be audio-taped for the purposes of the study.

INFORMATION ABOUT THE PRIVACY OF YOUR DATA

The University of Massachusetts Amherst has rules in place to protect information about you. Federal and state laws also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it.

The following procedures will be used to protect the confidentiality of your study records. Most of the information collected from you will not include any of your
personal information. This information will include audio recordings of your interview and surveys. Any of your personal information will be removed from these records.

Some information collected from you may include your personal information. This includes contact information such as phone numbers, addresses and family contact. We need this information to contact you in the future and invite you to the follow up presentation of the research findings. This information will not be used for any other purposes and will not be shared.

The researchers will keep all study records with your personal information, including any codes to your data, in a secure location. These records will be locked in a file cabinet in the University of Massachusetts College of Nursing. Only the researcher will have access to these records.

All other research records will be labeled with a code. A master key that links names and codes will be maintained in a separate and secure location in the University of Massachusetts College of Nursing. The master key and audiotapes will be destroyed three years after the close of the study. No electronic files will be used to store information that could be used to identify you.

Any computer hosting research files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations. None of your personal information will be shared with any other person(s) or agencies. Generally, only people on the research team will know that you are in the research study and will see your information. However, there are a few exceptions that are listed later in this section of the consent form.

If we publish information from this research study or use it for teaching, your name will not be used.

We cannot do this study without your permission to use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee this.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by contacting any of the following:

The Principal Investigator of this study can be reached at:

Jalil A. Johnson, MS, BSN, ANP-BC
651 N Pleasant St, Amherst, MA 01003
Jalii@nursing.umass.edu
(508) 331-4544 [cell phone]
The faculty Sponsor for this study can be reached at:

Cynthia Jacelon, PhD, RN, FAAN  
651 N Pleasant St, Amherst, MA 01003  
jacelon@nursing.umass.edu  
413-545-9576

The University of Massachusetts Amherst Human Research Protection Office can be reached at:

humansubjects@ora.umass.edu  
413-545-3428

If you send a letter, please be sure to include the study name and your contact information.
If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. You can ask to see your research records but sometimes that can only happen after the research is completed. If you would like to see your research records, please discuss this with a member of the research team.

WHAT IF I AM INJURED?
The University of Massachusetts Amherst does not have a program for compensating subjects for injury or complications related to human subject’s research, but the study personnel will assist you in getting treatment.

WHO DO YOU CONTACT IF YOU HAVE STUDY QUESTIONS OR CONCERNS?
If you have any questions about this study, please contact: Jalil A. Johnson, NP at 651 N Pleasant St, Amherst, MA 01003, (508) 331-4544 After hours, please call the PI at 508-331-4544. If you would like to discuss your rights as a research participant, or wish to speak with someone not directly involved in the study, please contact the University of Massachusetts Amherst Human Research Protection Office at humansubjects@ora.umass.edu or 413-545-3428

STATEMENT OF VOLUNTARY CONSENT
I have read this form or have had it read to me. I have been told what to expect if I take part in this study, including possible risks and possible benefits. I have had a chance to ask questions and have had them answered to my satisfaction. I have been told that the people listed in this form will answer any questions that I have in the future. By signing below, I am volunteering to be in this research study and authorizing the use of my information for the research.

Participant's Name (Print): ____________________________
Signature: ____________________________ Date: _____
STUDY REPRESENTATIVE STATEMENT
I have explained the purpose of the research, the study procedures, the possible risks and discomforts, the possible benefits, and have answered all questions to the best of my ability.

Study Representative's Name (Print): ____________________________
Signature: ____________________________
Date: ___________ Time Consent Obtained: _______

You will receive a copy of this form after it has been signed and dated

Research in the Future

STATEMENT OF CONSENT:
I understand that I am being asked permission to be contacted in the future for research and to allow the use of my information for research in the future. I understand that agreeing to these activities is completely voluntary and that I can say no or withdraw my permission at any time without any negative impact on me. I've indicated my choices below.

I give my permission for researchers within University of Massachusetts Amherst to contact me about this research project. I understand that my contact information and basic information about me will be shared.

YES ________ NO ________
(initials) (initials)

I give my permission for the de-identified information gathered about me for this research to be stored and used for future research projects. Information that is provided to researchers will not have my name or other information that directly identifies me on it.

YES ________ NO ________
(initials) (initials)

Please sign and date here:

Signature: ________________________________________ Date: _______
Focus Group Consent Form.

RESEARCH CONSENT FORM
Title of Project: Family and Community Challenges in Self Care for Puerto Rican Hispanics With Type Two Diabetes
Study Sponsor: The Hluchyj Fellowship & The University of Massachusetts Amherst Graduate School
Principal Investigator: Jalil Johnson, NP
Study Participant: 

WHY ARE YOU BEING ASKED TO TAKE PART IN THIS RESEARCH?
We are talking to you about this research study because you have type 2 diabetes. This form gives you important information. Please read it carefully and ask questions before you make a decision. Ask your study doctor or the study team to explain any words or information in this form that you do not understand. You may want to talk about this study with your family, your friends, and your other health care providers. Please take your time. You should not sign this form until all of your questions are answered.

Taking part in this study is your choice. No matter what decision you make, and even if your decision changes, there will be no penalty to you. You will not lose medical care, any legal rights, or any benefits that you are otherwise entitled to. The study doctor or team will tell you about new information or changes in the study that may affect your willingness to continue in the study.

WHY IS THIS RESEARCH STUDY BEING DONE?
The purpose of this research study is to evaluate some of the challenges Puerto Rican families face regarding management of type 2 diabetes.

HOW IS THIS RESEARCH STUDY BEING FUNDED?
This research study is being funded by a grant from The University of Massachusetts Amherst Graduate School. Jalil Johnson NP, the study’s Principal Investigator (the person conducting the study), is not being paid by the grant to conduct this study.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
Thirty to forty (30-40) patients and five (5) medical providers people will be recruited from Western Massachusetts and will take part in this research study. The study requires a minimum of thirty patients to complete the study. We expect that some patients may not be able to complete the study and have recruited more patients than is required to complete the study.

HOW LONG WILL YOU BE IN THIS STUDY?
Your participation in this research study is expected to last for 3-4 hours. Two hours will be spent attending a focus group. Additionally, you will spend 30 minutes to 1 hour completing the informed consent and completing surveys prior to the focus group. A 1-2 hour presentation of the research findings is also available for you to participate; however, this is optional and not required to participate in the study. You will be required to visit the High Street Health Center.
Clinic once to complete the informed consent and once to participate in the focus group. The follow up presentation is optional for you to attend.

**CAN I STOP TAKING PART IN THIS STUDY?**
Taking part in this study is voluntary. You may choose not to take part or to leave the study at any time. Your decision will not affect your relationship with your doctor or with Baystate Medical Center and will not result in any penalty or loss of benefits to which you are otherwise entitled. You can stop taking part in this study at any time. Tell the principle investigator if you are thinking about stopping or have decided to stop.

If you decide to withdraw from this study, the information (i.e., data from questionnaires) that you provided while participating in the study will be kept with the rest of the study data. This information will be used in analyses of the study data.

The principle investigator may take you out of the study:
- If your health changes and the study is no longer in your best interest
- If new information becomes available
- If you do not follow the study rules

**WHAT WILL HAPPEN IN THIS STUDY?**
If you volunteer to participate in this study, the researcher will ask you to do the following:

**Baseline Research Visit**
- You will meet with the principle investigator, in a private location approximately for 30 minutes in a private office at Baystate Medical Center’s outpatient clinic at 140 High St. (basement level-C), Springfield, MA 01199.
- At this visit, you will be asked to (1) sign an informed consent form (this form) after all your questions have been answered; and (2) complete a short questionnaire.

**Telephone Calls**
- Within a week of the baseline research visit, you will receive a call from the principle investigator to answer any questions that you have regarding the study.
- The principle investigator may contact you every other week to update you on the exact date and time of the focus group you will be asked to attend.

**Participation in the study**
- The study will involve collecting some information from your medical record. This may include your medical problems, medications, current diabetes treatment plan, vital signs, and blood tests (HbA1c, blood sugar, cholesterol levels).
- You will be asked to complete surveys. These surveys will include questions about your gender, age, race/ethnicity, primary language, secondary language, marital status, employment, and education level, and family structure.
- The study will involve participating in a focus group with other people.
- You will be asked to participate in one of six focus groups.
- Focus groups may have 3-5 members.
• Focus groups will last for approximately one to one and a half hours but no more than 2 hours.
• During the focus groups the principle investigator will ask questions about diabetes management and how your family affects that management.
• The focus group will be audio-recorded in order to accurately capture what is said. If you participate in the study, you may request that the recording be paused at any time. You may choose how much or how little you want to speak during the group. You may also choose to leave the focus group at any time.
• You will not be required to give any information that may identify you during the focus group.
• Food (lunch or dinner) and beverages will be provided during the focus groups.

Sharing Data/Information
• Your personal information will NOT be shared in any publications related to this study.
• Your personal information will NOT be shared with any of the other study participants.

Future Research:
In addition to this research, we would like to ask your permission to contact you and to use your comments made during focus group discussions for research projects in the future. Information about this is explained in a section towards the end of this document.

WHAT RISKS OR PROBLEMS COULD YOU HAVE BY BEING IN THIS STUDY?
You may experience risks and discomforts as a result of being in this study. As with any research study, there could be risks that are not known at this time.

Risks of Survey Questions:
• The research questionnaires include some questions that may seem sensitive or personal. You are free to skip any question for any reason.
• The focus group questions may include some questions that may seem sensitive or personal. You are free to skip any question for any reason.

WE WILL DO THE FOLLOWING TO DECREASE THE RISKS OF THIS STUDY:
• Loss of confidentiality is a potential risk for participating in this study. We will take steps to protect the confidentiality of your research information. These steps are described in more detail later in this form.
• You may skip any question on the survey that makes you feel uncomfortable.
• You may skip any question during the focus group that makes you feel uncomfortable.

WILL YOU BENEFIT FROM BEING IN THIS STUDY?
You may or may not benefit from being in this study. What we learn from this research may help people with type 2 diabetes in the future.

WHAT OPTIONS OTHER THAN THIS STUDY ARE AVAILABLE TO YOU?
• If you do not want to be in this study, there is no penalty to you and your care you receive at Baystate Medical Center will not change.
• If you do not participate in this study you may still be eligible to participate in other studies.

WILL BEING IN THE STUDY COST YOU ANYTHING?
Usual medical care costs include those services that are considered medically necessary to manage your condition. The costs of usual medical care will be the responsibility of you or your insurance and may include deductibles and co-payments. Some insurance companies will not pay for usual medical care if you are participating in a research study. The research team will not provide clinical and medical services during the research study. These services will continue to be the responsibility of your primary care provider.

Research-related services are not the responsibility of you or your insurance provider. The procedures or items that are considered research-related in this study include the following:

• Research-related visits with the principle investigator to complete consent form and questionnaires
• Research-related phone calls with the Primary Investigator.
• Conference rooms
• Recording devices
• Food Voucher
• Research personnel
• Meal provided during focus group
• Other research related costs

WILL YOU RECEIVE ANY PAYMENTS OR GIFTS FOR PARTICIPATING?
• Baystate will keep a record of any money you are paid, your name, address, and social security number. If Baystate Medical Center pays you more than $600 in a calendar year (or if you are a foreign citizen who is not here as a permanent resident), we must report the payment to the IRS (Internal Revenue Service) and send you a 1099 form.
• You will receive $20 for completing focus group. You will receive payment in the form of a debit like card, mailed to your home address.
• If you withdraw from the study before you have completed the focus group, you will not be eligible to receive the $20 compensation.

HOW WILL YOUR PRIVACY AND INFORMATION ABOUT YOU BE PROTECTED?
The focus groups you participate in will be audio recorded. The audiotapes will be stored electronically on a password protected audio recorder and listened to by the principle investigator to make sure that the meetings are being conducted as planned. The original audio recording will be deleted on the recording device immediately after being transcribed uploaded to the secure computer. The electronic recording file will be deleted (within three months) after the file review is completed and transcribed (conversations will be typed and stored on a protected Baystate computer). The transcripts from the focus groups you attend will be coded and not include your personal information.
We will protect your privacy as a participant in this research study and the confidentiality of your research information. We will keep the information gathered about you during this study in restricted areas at Baystate Medical Center. Your study file will be stored in a secure area in the Internal Medicine office at 140 High Street, Springfield, MA. Medical information created by this research study will not become part of your medical record.

Date:_________, I______________ agree to be audio-taped for the purposes of the study.
Date:_________, I______________ do not agree to be audio-taped for the purposes of the study.

INFORMATION ABOUT THE PRIVACY OF PROTECTED HEALTH INFORMATION

Baystate Health has rules in place to protect information about you. Federal and state laws also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it. Generally, only people on the research team will know that you are in the research study and will see your information. However, there are a few exceptions that are listed later in this section of the consent form.

The people working on the study will collect information about you. This includes things learned from the procedures described in this consent form and may include information from your medical record if needed for the study. They may collect other information including your name, address, date of birth, and other details.

Under HIPAA, authorizations for the use/disclosure of psychotherapy notes cannot be combined with any other authorization. If this study requires the use and/or disclosure of psychotherapy notes, include the following line and have the individual sign the “Authorization to Use or Disclose Psychotherapy Notes for Research” (available on workplace and in IRBNet) in addition to this document: “To do this research, we need to access and use the notes taken about your psychotherapy sessions. We will ask you to sign a separate form for this.”

If the study requires use or disclosure of Social Security Numbers or medical information that could be considered sensitive, such as genetic testing results, information about testing for HIV and/or the diagnosis/treatment of HIV or AIDS, or treatment records for mental health issues, substance abuse, or sexually transmitted diseases, specifically disclose the data to be used and shared and the purpose. For example: “For this study we will need to gather your Social Security Number and share it with the study sponsor so that the sponsor may…” (or) “Because we are giving you an investigational drug, it is important that we have an accurate record of your medical history and any illnesses or conditions that you have while you are on the study. This includes diagnoses and information on mental health, infectious diseases, substance abuse, and any other condition or symptom that you have experienced. We need to share this information with the sponsor. When we send the information outside of Baystate it will be labeled with a code instead of your name.”
The research team will need to see your information. Sometimes other people at Baystate may see or give out your information. These include people who review the research studies, their staff, administrative personnel, or other Baystate staff. The fact that you are taking part in this study and information from procedures (such as lab tests) that are done for the research may become part of your medical record.

If we publish information from this research study or use it for teaching, your name will not be used.

People outside of Baystate may need to see your information for this study. Examples include government groups (such as the Food and Drug Administration), organizations that accredit hospitals and research programs, study monitors, other hospitals in the study, and companies that sponsor the study.

We cannot do this study without your permission to use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside of Baystate who receive your information may not be covered by this promise. We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee this.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by contacting the Principal Investigator of this study. The Principal Investigator can be reached at:

Jalil Johnson, NP
140 High Street, C-level, Springfield, MA 01199
413-794-2038

If you send a letter, please be sure to include the study name and your contact information.

If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

You can ask to see your research records but sometimes that can only happen after the research is completed. If you would like to see your research records please discuss this with your study doctor or a member of the research team.

WHO DO YOU CONTACT IF YOU HAVE STUDY QUESTIONS OR CONCERNS?

If you have any questions about this study, please contact: Jalil Johnson, NP 413-794-2038, 140 High Street, C-level, Springfield, MA 01199. If you experience a complication or injury that you believe may be related to this study, please contact the PI using the above information. After hours, please call the PI at 508-331-4544. For example: “If you have any questions about this study, please call: 413-794-2038 to contact Jalil Johnson, NP. If you would like to discuss your rights as a research participant, or wish to speak with someone not directly
involved in the study, please contact the Baystate Institutional Review Board (IRB) at (413) 794-4356.

STATEMENT OF VOLUNTARY CONSENT
I have read this form or have had it read to me. I have been told what to expect if I take part in this study, including possible risks and possible benefits. I have had a chance to ask questions and have had them answered to my satisfaction. I have been told that the people listed in this form will answer any questions that I have in the future. By signing below, I am volunteering to be in this research study and authorizing the use of my information for the research.

Participant's Name (Print): ________________________________
Signature: ____________________________________ Date: __________

STUDY REPRESENTATIVE STATEMENT
I have explained the purpose of the research, the study procedures, the possible risks and discomforts, the possible benefits, and have answered all questions to the best of my ability.
Study Representative's Name (Print): ________________________________
Signature: ____________________________________ Date: __________
Time Consent Obtained: __________

You will receive a copy of this form after it has been signed and dated

(Consent Rider for Future Research Including Banking of Information & Specimens)

Research in the Future
Consider including the Future Research Rider for all of your research projects, this rider can be stripped down to simply address willingness for future contact for research, or can be used maximally to address future uses of information and specimens. Addressing these issues up front is recommended given the number of requests that the IRB sees for secondary uses of research data or specimens. As with any other research, agreement to future contact and use of information and specimens for other research projects should be on a voluntary basis and enough information must be provided for individuals to make an informed choice. This is particularly important when the primary research offers a potential benefit, such as treatment, that might compel the potential subject to agree to something that they otherwise would not.
HIPAA reinforces this ethical principle by explicitly stating that authorization for “unconditioned” activities, for which there is no associated treatment, benefit or other effect on the individual subject associated with participation, cannot be required.

Suggested text (the text that follows includes examples of text and permissions that may or may not apply to your situation, please review your final draft very
carefully to ensure that it is accurate. Pay special attention to descriptions of how information/specimens may be used, reporting back of incidental findings, and the use of coding and other mechanisms that will be taken to minimize risks.):

**Describe the reasons you are asking for the subjects to allow future contact and/or the storage of their data and samples for future research, for example:**

Researchers are always trying to learn more about cancer, diabetes, heart disease and other health problems. We are always looking for volunteers for research. Much research is also able to be done using leftover samples, such as blood, and information that has been gathered for another purpose. Through these studies, researchers hope to find new ways to detect, treat, and maybe prevent or cure health problems. Sometimes these studies may be about how genes affect health and disease, or how genes affect response to treatment. Some may lead to new products, such as drugs or tests for diseases.

**Summarize what you will be asking permission for, for example:**

We are asking you to let us contact you in the future to tell you about other research studies and ask if you might like to participate. We are also asking you for your permission to store any samples left over when this research is complete, and for your permission to gather and store information about you, for use in research projects in the future.

**Inform subjects that their participation is voluntary, that they can withdraw permission at any time, and that they won’t be penalized if they choose not to participate or to withdraw, for example:**

Whether or not you give us permission for these things is completely up to you. If you say no, or decide that you want to take back your permission in the future, this is okay. Your decision will not affect your medical care or hurt your relationship with your health care providers; you will not lose any benefits that you are otherwise entitled to. Your choice will not impact your ability to participate in the main study.

**Explain how to withdraw permission and any limitations of this (such as if data and samples have been stripped of identifiers), for example:**

If you change your mind, contact (insert name of PI and/or research office) to let us know. You can call us at (insert phone number) or if you wish, you may write to us at (insert address). We may need to call you back to clarify if you want to withdraw some or all permissions, so please leave us your phone number. Sometimes information and samples are provided to a researcher without a code or any other way to link them back to you, if this happens we will not be able to locate your information or samples to stop it from being used. When researchers use your information or samples for research in the future, it is possible that information from the research could end up stored in another scientific database.

**Summarize risks and the steps that will be taken to minimize risks, for example:**

There is a risk that someone could get access to the information we have stored about you. There are laws about unauthorized access to and use of personal
information, but they may not give you full protection. If your sample is used for genetic research, because your genetic information is unique to you, it is possible that someone could trace the information back to you. We believe the chance that someone will access your information without permission or trace information back to you is small, but we cannot promise that it won’t happen. Your privacy is very important to us and we will make every effort to protect it. Here are just a few of the steps we will take:

- Your sample and information will be labeled with a code instead of your name or other information that directly identifies you. We will keep the list that links the code number to your name separate from your sample and information. This list will be kept in a secure location at Baystate and will only be shared with those who have a valid reason to see it, such as people who oversee research to make sure that it is done safely.
- Unless you give us permission, researchers who study your samples and information will not be told who you are. Any information or samples provided to researchers will be labeled with the code.
- We will not give information that identifies you to anyone without your permission, except if it is required by law. Information that is shared outside of Baystate may no longer be protected by the federal privacy law called ‘HIPAA’. But it will be protected as described in this form and may be covered by other privacy laws.

Describe whether or not the additional research will provide the individual subject with any benefit and whether or not they will receive any information from the research. Describe any plans to provide incidental findings, for example:

You will not benefit directly from allowing the use of your information and samples for additional research. Researchers hope the research they do will help other people in the future. The results from such research will not be added to your medical records, nor will you or your study doctor know the results. Occasionally, researchers will find something out that could be important to your health. If this happens, we will try to get in touch with you to let you know and to help you understand what it means.

Disclose any anticipated costs or payments associated with the research, for example:

There will be no costs to you or your insurer for any of the tests done for the research projects. You will not be paid for agreeing to the storage and use of your information and samples. There are no plans to pay you for any information or products that result from research using your information and samples.

Provide the different options that the subject can opt in or out of. An active opt-in must be required for an authorization to be considered valid under HIPAA.

STATEMENT OF CONSENT:

I understand that I am being asked permission to be contacted in the future for research and to allow the use of my information and leftover samples for research in the future. I understand that agreeing to these activities is completely
voluntary and that I can say no or withdraw my permission at any time without any negative impact on me. I've indicated my choices below.

I give my permission for researchers within Baystate to contact me about future research projects. I understand that my contact information and basic information about me will be shared so that this can happen.

YES ________  NO ________
(initials)   (initials)

I give my permission for researchers outside of Baystate to contact me about future research projects. I understand that my contact information and basic information about me will be shared so that this can happen.

YES ________  NO ________
(initials)   (initials)

I give my permission for the information gathered about me for this research to be stored and used for future research projects. Information that is provided to researchers will not have my name or other information that directly identifies me on it.

YES ________  NO ________
(initials)   (initials)

I give my permission for researchers or staff to gather additional information from my medical record for future research projects. I understand that this means that the researchers or staff will have to have access to information that directly identifies me.

YES ________  NO ________
(initials)   (initials)

I give my permission for any of my samples that are left over from the main research study to be stored and used for future research. I understand that my samples will be either stripped of all information that could be used to identify me or that my name will be replaced by a code.

YES ________  NO ________
(initials)   (initials)

My permission for the use of my samples includes genetic research.

YES ________  NO ________
(initials)   (initials)

My permission for my information or samples to be used for research is restricted to research about:

YES ________  NO ________
(initials)   (initials)

My permission for my information or samples to be used for research does not include permission for research about:

YES ________  NO ________
(initials)   (initials)
Community Member Interview Guide

Individual Interview Guide: COMMUNITY MEMBERS
Puerto Rican Families and Type 2 diabetes

Instructions to facilitators are in italics.

General Introduction:
The intent of this portion of the agenda is to welcome participants and make them as comfortable as possible by explaining the interview and letting them know what to expect from the experience. Facilitators can also set ground rules for confidentiality, and explain how data will be dealt with (stored, transcribed, and analyzed).

These remarks include thoughts about the following (SEE BELOW FOR EXACT STATEMENTS):

1) Ground Rules:
   a) Respect all opinions.
   b) Contributions are voluntary: Please feel free to express opinions and share your ideas.
   c) Confidentiality: No information will be shared that in any way might identify you.

2) Purpose of the interview:
   a) To better understand your experience with managing diabetes.
   b) To better understand how your role your family
   c) To better understand how your family affects your diabetes care
   d) To better understand how managing diabetes affects your family
   e) To better understand how doctors can help families support people with diabetes

3) Audiotapes:
   a) The tapes are kept private and safe.
   b) When the tapes are transcribed, participants will be identified by a code.
   c) Anonymous quotations may go into reports or publications.

Format of interview

Overall Design
1. Introduction/Welcome (5 minutes)
2. Health care provider and family involvement in diabetes care. (3 minutes)
3. **Family involvement in your diabetes care?** (3 minutes)
4. **Male vs. Female family member involvement in diabetes management?** (3 minutes)
5. **Traditional Foods?** (3 minutes)
6. **Medical providers involving family in diabetes care?** (3 minutes)
7. **Overall, is there anything else we should have asked you?** (2 minutes)
8. **Questionnaires and Compensation.** (5 minutes)

**Interview Guide**

1. **Introduction/Welcome** (5 minutes)
   
   “Thank you for participating in this interview. My name is Jalil Johnson and I am PhD Candidate at The University of Massachusetts, Amherst College of Nursing. We appreciate your willingness to take time to participate in this interview. I want you to know that your opinion and perspective is important. There are no right or wrong answers. I only ask that you be as open and honest with us as possible. You were selected for this group because you are Puerto Rican and have diabetes. We are hoping to better understand you manage your diabetes with your family to help us design a helpful program for Puerto Rican men and women with diabetes.

   “My role is to be your guide by asking questions and keeping us on time, but this is really YOUR time to talk. You will notice that we are taping this group in order to accurately report all ideas. You do not need to use your first name. Your name will NOT be associated with anything you say. Also, the tapes will be kept private and safe. When the tapes are transcribed, participants will be identified by a code. At this point please turn off your cell phones if you have not done so already. Are there any questions before we get started?”

2. **Health care provider and family involvement in diabetes care.** (3 minutes)
   
   a. Do your medical providers and nurses include your family in your diabetes care plan?
      
      i. Yes.
      
      1. How do they include them?
      
      ii. No.
      
      1. Why do you think this is not done?

3. **Family involvement in your diabetes care?** (5 minutes)
   
   a. Are your family members involved in your diabetes care?
      
      i. Yes.
      
      1. How are they involved?


ii. No.
1. Why are they not involved?

4. **Male vs. Female family member involvement in diabetes management?** (3 minutes)
a. Do you receive more diabetes care support from male or female family members?
   i. Male
   1. Why do you believe this is true?
   ii. Female
   1. Why do you believe this is true?

5. **Traditional Foods?** (3 minutes)
a. Traditional foods may make it difficult to manage diabetes. Does your family/community support your diabetic diet?
   i. Yes.
   1. How do they support?
   2. Does this make managing your diabetes more manageable?
      a. Yes
      i. How so?
      b. No
      i. How so?
   3. Why do you think they are supportive?

   ii. No.
   1. Why don’t they support?
   2. Does this make managing your diabetes more difficult?
      a. Yes
      i. How so?
      b. No
      i. How so?

6. **Medical providers involving family in diabetes care?** (3 minutes)
a. Should medical providers and nurses include your family in your diabetes management?
   i. Yes.
   1. Do you think this would be helpful?
   2. How should they involve them?
   ii. No.
   1. Why should they not involve them?
7. Overall, is there anything else we should have asked you? (2 minutes)

8. Questionnaire and Compensation. (5 minutes)

Total Time: (~25-30 minutes)

Thank you for your time. I have enjoyed my time with you and learned a lot that will greatly help us. BEFORE YOU LEAVE, I also have a small token of our appreciation for you, in this debit like card. I will contact you when the study is complete.

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**Final Presentation Guide**

**Presentation Guideline**

*Puerto Rican Families and Type 2 diabetes*

*Instructions to facilitators are in italics.*

**General Introduction:**

The intent of this portion of the agenda is to welcome participants and make them as comfortable as possible by explaining the presentation and letting them know what to expect from the experience. Facilitators can also set ground rules for discussion.

**Format of Presentation of Findings**

Help yourselves to some healthy snacks

I. Welcome and Introduction (5 minutes)

II. Background & significance of the project (5 minutes)

III. The research Methodology (5 Minutes)

IV. Findings from the research (20 minutes)

V. Conclusions from the research (5 minutes)

VI. Discussion (10 minutes)

VII. Questionnaire (5 minutes)

Total 55 minutes (above times are estimates)
Welcome & Introduction (~ 5 MIN)
“Thank you for participating in this presentation. My name is Jalil Johnson and I am PhD student at The University of Massachusetts, Amherst College of Nursing. I appreciate your willingness to take time to participate in this study. Each of your opinions and perspectives were of great value to this project. Today we will discuss the findings from the research, which will include focus group themes, these from individual interviews, medical provider interview themes, and group observations. There will also be a presentation of a new project that has been designed based on your input. You will have an opportunity to give feedback and your opinion on this intervention during an open group discussion. “It is important to ‘be a good group member.’ This means that participants should be non-judgmental and not critical of others. Please speak when you have something to say, even if it is a different opinion than others might have. You are allowed to disagree and be sure not to interrupt other members. In order to maintain confidentiality, please do not discuss what you hear in this group with people outside this group in any way that might identify the people you met here. Finally, there is a lot of information that we would like to cover today, so there may be times that I need to stop you and move on to a new topic. Are there any questions before we get started?”
Actual topics to be discussed are pending the research and will be added once data has been collected and analyzed.

Background and Significance (~ 5 MIN)
**U.S. Hispanic community**
Represent > 50 million people, 14.8% of the U.S. population
Projected to increase to almost 25% by the year 2050.

**The Hispanic Diabetes Disparity**
Type 2 Diabetes Mellitus is the 7th leading cause of death in the US.
Compared to Non-Hispanic whites, Hispanic Americans with T2DM have higher rates of:
- Mortality related to uncontrolled diabetes
- Diabetic nephropathy
- Lower limb amputations
- And hospitalization for ketoacidosis
- Treatment and medication Non-adherence.

**Puerto Rican identified Hispanics and T2DM**
- Puerto Rican identified Hispanics: 9.6% of U.S. Hispanic population
- Experience considerable health disparities including:
  - T2DM
  - Cognitive disability
  - Obesity
  - Depressive symptomatology
  - Hypertension
  - Age-adjusted T2DM prevalence:
    - Puerto Rican identified Hispanic (10.1%)
    - Non-Hispanic whites (5.9%).
The research Methodology (5 minutes)
Findings from the research (20 minutes)
Conclusions from the research (5 minutes)
Discussion (10 minutes)
Questionnaire (5 minutes)
APPENDIX D
DEMOGRAPHIC FORMS AND QUESTIONNAIRES

Medical Provider Demographics

Please answer all of the following questions.

1. What is your clinical role?
   □ Physician
   □ Nurse Practitioner
   □ Physician Assistant
   □ Nurse Educator
   □ Registered Nurse

2. What is your clinical specialty?
   □ Internal Medicine
   □ Primary Care
   □ Family Medicine
   □ Diabetes Educator
   □ Other__________

3. How many years have you been practicing in your clinical role?
   □ 1-3 years
   □ 3-5 years
   □ 5-7 years
   □ 7-10 years
   □ Greater than 10 years

4. Approximately how many of your patients have diagnosed type 2 diabetes?
   □ 1-5%
   □ 5-10%
   □ 10-15%
5. What percentage of your patients are Hispanic/Latino?
☐ Less than 5%
☐ 5-10%
☐ 10-20%
☐ 20-30%
☐ 30-40%
☐ 40-50%
☐ 50-60%
☐ 60-70%
☐ 70-80%
☐ 80-90%
☐ 90-100%

6. How many of your Hispanic/Latino patients identify as Puerto Rican?
☐ Less than 5%
☐ 5-10%
☐ 10-20%
☐ 20-30%
☐ 30-40%
☐ 40-50%
☐ 50-60%
☐ 60-70%
☐ 70-80%
☐ 80-90%
☐ 90-100%

7. What is your primary language?
☐ English
☐ Spanish
☐ Italian
☐ French
☐ Creole
☐ Other language_________

8. Do you speak a second language?
☐ English
☐ Spanish
☐ Italian
☐ French
☐ Creole
☐ Other language_________

Patient & Community Member Demographic Form

Please answer all of the following questions.

1. What are your phone numbers?
   Home (____) _____- _____
   Work (____) _____- _____
   Cell (____) _____- _____

2. Other Contact information of friends or relatives
   (person who would help us reach you if your contact info changes)

   CONTACT 1
   Name ________________________________________________
   Address ________________________________________________
   Phone Number __________________________________________
   Relationship to you ______________________________________

   CONTACT 2
   Name ________________________________________________
3. What is your mailing address?

<table>
<thead>
<tr>
<th>Street</th>
<th>City</th>
<th>State</th>
<th>Zip Code</th>
</tr>
</thead>
</table>

4. When were you diagnosed with type 2 diabetes?

   mm / dd / yy

5. What is your race? (please check one box)
   - Black / African American
   - White / Caucasian
   - Asian
   - Native Hawaiian / Pacific Islander
   - American Indian / Alaskan Native

6. What is your ethnicity? (please check one box)
   - Hispanic / Latino
   - Not Hispanic / Latino
   - Unknown

7. What ethnic group do you identify with?
   - Puerto Rican
   - Dominican
☐ Cuban
☐ Mexican
☐ Guatemalan
☐ Other___________(fill in)

8. What is your current marital status?
☐ Never Married
☐ Married / Living with partner
☐ Separated
☐ Divorced
☐ Widowed

9. What is your current work status?
☐ Working full-time → please list your current occupation: ________________
☐ Working part-time → please list your current occupation: ________________
☐ Unemployed
☐ Medical disability, unable to work
☐ Student
☐ Retired → please list your past occupation: ___________________________

10. What is the highest level of education you have completed?
☐ Less than 9th grade
☐ 9th-12th grade, no diploma
☐ High school graduate (includes equivalency or GED)
☐ Some college, no degree
☐ Associate degree
☐ Bachelor degree
☐ Graduate or professional degree (master degree, doctorate degree, law degree, etc.)

11. What is the primary language you speak at home?
12. Do you speak a second language?
☐ English
☐ Spanish
☐ Italian
☐ French
☐ Creole
☐ Other language________

13. How long have you had diabetes?
☐ 1-5 years
☐ 5-10 years
☐ 10-15 years
☐ 15-20 years
☐ 20-25 years
☐ more than 25 years

Patients and Community Members Behavioral Data Form

Patient & Community Member Subjects- Behavioral Data

1. How many days of the week do perform cardiovascular exercise (walking, biking etc.) for more than 30 minutes each day?
☐ 7 out of 7 days of the week
☐ 6 out of 7 days of the week
☐ 5 out of 7 days of the week
☐ 4 out of 7 days of the week
☐ 3 out of 7 days of the week
☐ 2 out of 7 days of the week
☐ 1 out of 7 days of the week
☐ I do not exercise

2. How many days of the week do you only eat the foods that are recommended by your doctor/nurse/dietician?
☐ 7 out of 7 days of the week
☐ 6 out of 7 days of the week
☐ 5 out of 7 days of the week
☐ 4 out of 7 days of the week
☐ 3 out of 7 days of the week
☐ 2 out of 7 days of the week
☐ 1 out of 7 days of the week
☐ I do not eat the recommended diet

3. How many days of the week do you take ALL of your diabetes medications?
☐ 7 out of 7 days of the week
☐ 6 out of 7 days of the week
☐ 5 out of 7 days of the week
☐ 4 out of 7 days of the week
☐ 3 out of 7 days of the week
☐ 2 out of 7 days of the week
☐ 1 out of 7 days of the week
☐ I do not take my prescribed medications
☐ I am not prescribed medications for diabetes

4. How often do you take your other medications (not prescribed for diabetes)?
☐ 7 out of 7 days of the week
☐ 6 out of 7 days of the week
☐ 5 out of 7 days of the week
☐ 4 out of 7 days of the week
☐ 3 out of 7 days of the week
☐ 2 out of 7 days of the week
☐ 1 out of 7 days of the week
☐ I do not take my prescribed medications
☐ I am not prescribed any other medications

5. How well controlled is your diabetes?
☐ Well controlled (fasting glucose readings <130)
☐ Fair control but could be better (fasting glucose readings 130-150)
☐ Uncontrolled (fasting glucose readings 150-200)
☐ Poor control (fasting glucose readings greater than 200)
☐ I do not know what my blood glucose readings are
☐ I do not check my glucose readings

6. Who do you consider to be your family support? (check all that apply)
☐ Parents
☐ Siblings
☐ Children
☐ Grandchildren
☐ Cousins
☐ Friends
☐ Extended family
☐ Inlaws
☐ Neighbors
☐ Church members
☐ Personal care assistants (PCA)
☐ I do not have any family support
7. Who helps you most with managing your diabetes?

- Parents
- Siblings
- Children
- Grandchildren
- Cousins
- Friends
- Extended family
- Inlaws
- Neighbors
- Church members
- Doctors
- Nurses
- Personal care assistants (PCA)
- I do not have any support

Follow up Presentation Questionnaire

Please answer all of the following questions.

1. What is your relationship to this study?

- Medical Provider – I was interviewed for this study.
- High Street Health Center – I was interviewed for this study
- Community Member – I was interviewed for this study.
- Community Member – I was **NOT** interviewed for this study
- Medical Provider – I was **NOT** interviewed for this study.
- Nurse – I was **NOT** interviewed for this study.

2. What is your current role in diabetes self management?

- Patient with type 2 diabetes
- Family member of a patient with type 2 diabetes
☐ Researcher
☐ Physician
☐ Nurse Practitioner
☐ Physician Assistant
☐ Nurse Educator
☐ Registered Nurse
☐ Other____________

3. What are your overall impressions of the research findings?
☐ The results are similar to my experiences with managing type 2 diabetes.
☐ The results are NOT similar to my experiences with managing type 2 diabetes.

4. What part of the research findings did you MOST identify with? (please write below)

5. What part of the research findings did you most disagree with? (please write below)

6. In your opinion is there anything you remember from your meeting with the researcher that is missing from the research findings? (write below)
7. Is there anything we should add to the research findings? (please write below)

8. Is there anything we should remove from the research findings? (please write below)

**Member Checking Questionnaire**

In this study there were two research questions and several subquestions. Healthcare providers, patients, and community members were interviewed and their responses were used to provide answers to these questions (and sub questions). The answers were summarized and the most relevant themes were used to answer the research questions.

Please use the box below to give feedback on each research result. Use an “X” to mark the box that best corresponds with your response. If you disagree or somewhat disagree with one of the findings, please leave a comment describing
why you disagree. Please keep in mind that all of the information below is in reference to Puerto Rican identified Hispanic adults with Type 2 diabetes, their families and healthcare providers. Some research results may have additional background information from the study to give context.

**Key Terms**

**Familism:** an aspect of Hispanic cultural dynamics in terms of its role, which emphasizes close, frequent, and meaningful social interactions.

*Sub factors include:*

- favorable influences (e.g., perceived support)
- disadvantageous influences (e.g., perceived obligations).

**Diabetes Self-Care/Management:** the cornerstone of diabetes control and is heavily dependent on behavior modification.

*This Includes:*

- Adherence to a low carbohydrate diet
- Regular exercise
- Monitoring of blood glucose
- Monitoring for diabetes symptoms
- Medication adherence
- Attending scheduled healthcare appointments.

**HCP:** Healthcare provider (Physician, Nurse, Physician Assistant, Diabetes Educator)

**PRIH:** Puerto Rican identified Hispanic

**T2DM:** Type 2 Diabetes

**Research Question 1:** “What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes”

**Sub-question A:** What are the positive effects of familism on diabetes self-care for PRIH adults?

1. **Research Finding:** The collective nature of the PRIH family and community may be a potentially positive motivator of diabetes self-care.

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2. **Research Finding:** The positive aspects of familism within the PRIH community appears to center around a strong collective nature.

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3. **Research Finding:** This support network is potentially expansive, and may include 1st, 2nd, 3rd generation relatives, spouses, ex-spouses, non-familial persons, and people who do not work in healthcare.

| Question 1. Sub-question A. Number 3. | Check One |
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4. **Research Finding:** The PRiH community and family may be synonymous in terms of their integral role in managing chronic disease, and more specifically T2DM self-care.

| Question 1. Sub-question A. Number 4. | Check One |
| I AGREE with this result | |
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| I SOMEWHAT disagree with this result. (Please Comment) | |
| I DO NOT agree with this result. (Please Comment) | |
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5. **Research Finding:** PRiH families are generally involved to some degree in helping their family members with T2DM self-care.

| Question 1. Sub-question A. Number 5. | Check One |
| I AGREE with this result | |
| I SOMEWHAT agree with this result. (Please Comment) | |
| I SOMEWHAT disagree with this result. (Please Comment) | |
| I DO NOT agree with this result. (Please Comment) | |
6. **Research Finding:** Community members whose families help with self-care find their diabetes management activities more manageable and less burdensome.

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**Sub-question B:** In what ways does *familyism facilitate* diabetes self-care for PRiH adults?

7. **Research Finding:** This collective community nature may potentially facilitate communal behavioral changes.

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8. **Research Finding:** This communal behavioral support may facilitate adherence to the therapeutic diet, recommended exercise regimens, medication adherence, and attending healthcare appointments.

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9. **Research Finding:** Female PRiH family members, specifically those in matriarchal roles, tend to be viewed as a reliable source of support for health information, care, and support.
Sub-question C: In what ways does Familism inhibit diabetes self-care for PRiH adults?

10. Research Finding: The centrality of traditional food within PRiH culture, coupled with the abundance of these traditional foods during family gatherings, and lack of diabetic friendly options in PRiH eating establishments may impede PRiH adults from adhering to a diabetic diet.

11. Research Finding: The strong nurturing matriarchal culture may inhibit diet adherence if these central figures are not supportive of healthier diets.

12. Research Finding: Some family and community members may, in the spirit of the communal gathering which is centered around meals, encourage nonadherence to the recommended diet.
Sub-question D: What are the negative effects of *Familism* on diabetes self-care for PRiH adults?

**Research Finding:** The collective nature of the PRiH family and community may be a potentially negative inhibitor of diabetes self-care.

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14. **Research Finding:** The traditional PRiH diet is a central and vital component of PRiH culture. This diet is, in essence, carbohydrate intensive and generally conflicts with the recommended diabetic diet.

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15. **Research Finding:** Adhering to a recommended diabetic diet is one of the greatest challenges for PRiH managing T2DM.

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16. **Research Finding:** Family support may be absent or contradictory to medical and behavioral recommendations.

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17. **Research Finding:** Though T2DM is prevalent within the PRiH community there is widespread attitudes of ambivalence and denial regarding the T2DM diagnosis and seriousness of the disease. These attitudes may make self-care, and specifically, dietary adherence more difficult for PRiH adults with T2DM.

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18. **Research Finding:** PRiHs with T2DM may experience negative feelings like emotional discomfort, social isolation, frustration, and embarrassment when attempting to manage their diabetic diet at family gatherings.

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19. **Research Finding:** PRiH family members may generally be aware that their family member is attempting to manage their diabetes, family and community members may not be aware of the emotional burden and depressive symptoms they may be experiencing from managing T2DM.

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20. **Research Finding:** PRiH families may not make significant effort to accommodate a recommended diabetic diet during family and community gatherings.

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21. **Research Finding:** There is a relationship between stressors associated with diabetes self-care and sociocultural stressors (specifically surrounding meals), decreased motivation, and depression.

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22. **Research Finding:** For PRiH with lower socioeconomic status, the financial strain of procuring foods consistent with a diabetic diet may inhibit diabetic diet adherence.

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Sub-question E: How are PRiH women with T2DM in traditional family roles affected by Familism?

Traditional Family Role
23. Research Finding: Female PRiH family members are a key community resource, often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions.

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24. Research Finding: Female PRiH diabetics may feel frustration with being dependent on their family for support when their traditional role expectations may involve them in caretaker roles.

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25. Research Finding: Female PRiH adults with T2DM may experience frustrations regarding:
- concerns that their illness may cause emotional distress for family members
- concerns about their ability to make necessary lifestyle changes
- concerns about preventing their children from developing diabetes
- difficulty with prioritizing self-care due to family demands
- disease management generally being a low priority at family gatherings
- conflicting obligations regarding T2DM self-management activities and daily living
- difficulty with their family sometimes encouraging non-therapeutic diet.

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**Traditional Diet.**

26. *Research Finding:* Adult PRiH women in traditional roles tend to prioritize their family’s needs over their own.

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27. *Research Finding:* The struggles with traditional diet are contextually different for male and female PRiHs.

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28. *Research Finding:* Managing the diabetic diet presents unique challenges for PRiH women as they may experience conflicts with feeling obligated to prepare traditional foods for their family.

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29. *Research Finding:* Specifically regarding conflicts surrounding preparing traditional foods versus a diabetic diet, PRiH women with T2DM may struggle with:
a. feeling conflicted when other family members offer foods they should not eat
b. difficulty managing different diets within their homes
c. feeling conflicted when preparing foods for a non-diabetic spouse
d. difficulty incorporating recommended diet with traditional PRiH foods

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**Intimate Partner Relationships**

30. *Research Finding:* Type 2 Diabetes management may affect PRiH women in their intimate relationships and sexual function. These women may also experience:

- a. negative self-perceptions
- b. negative body image related to obesity.
- c. concomitant depressive symptoms related to these negative perceptions.

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31. *Research Finding:* PRiH women with T2DM in traditional roles may also experience intimate partner relationship strain surrounding accommodating their partner with regards to:

- a. diet
- b. social activities
- c. time management
- d. negative perceptions.

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Emotional Tolls.

32. Research Finding: Despite their family’s awareness of their diabetes diagnosis, females PRiHs may not receive emotional support from their family. Female PRiHs with T2DM likely experience some degree of:

a. depression
b. decreased motivation
c. social isolation
d. sadness
e. fear and despair
f. low self esteem
g. negative feelings associated with obesity and diabetes
h. denial about their T2DM diagnosis.

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33. Research Finding: Female PRiHs who do receive support from their family members likely receive this support from female family members. This support may include:

a. monitoring for symptoms of high or low glucose
b. monitoring for vision changes.

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34. Research Finding: Female PRiHs may receive little or no support from their family regarding:

a. encouraging or participating in exercise activities
b. medication adherence
c. attending their healthcare appointments.
Cheat Days.

35. **Research Finding**: Traditional gender role strain, intimate partner relationship strains and the emotional tolls of generally receiving less support may lead to social isolation for PRiH women with T2DM.

36. **Research Finding**: The communal nature of the PRiH family is largely centered around gatherings, meals and traditional foods.

37. **Research Finding**: The collective social environment may be largely unsupportive of an individual managing T2DM. To circumvent social isolation, female PRiHs with T2DM may engage in “cheat days”, on which they would disregard their diabetic diet when attending family/community gatherings.
Sub-question F: How are PRiH men with T2DM in traditional family roles affected by Familism?

Female and Maternal Support

38. Research Finding: PRiH men with T2DM may not recognize that their traditional status and role as a man affects their diabetes management. Compared to female PRiHs with T2DM, males may receive more family support from:
   a. adult children
   b. Spouses
   c. Parents
   d. Siblings
   e. Partners
   f. ex-partners

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39. Research Finding: Patriarchal roles may insulate male PRiHs from some of the stressors of self-managing diabetes.

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40. Research Finding: Male PRiHs may be generally supported by female family members and maternal figures.

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   I AGREE with this result
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**Research Finding** 41. Male PRiHs may receive maternal support in helping them with:
   a. medication adherence.
   b. healthcare appointments.

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**Research Finding** 42. Male PRiHs may also receive support from female partners or female adult children with:
   a. actively or passively checking their glucose levels
   b. monitoring for high or low glucose.

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**Traditional Diet**

**Research Finding** 43. Male PRiHs who struggle with adhering to a diabetic diet may have a tendency to struggle with adhering to their diet at PRiH restaurants and eating establishments.

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44. Research Finding: They may experience frustration at family gatherings when there are no food options available to accommodate their diabetic diet.

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Intimate Partner Relationships
45. Research Finding: PRiH men managing T2DM may struggle in their intimate relationships due to sexual dysfunction, specifically erectile dysfunction.

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Research Question 2: How can healthcare providers use Familism to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?

Sub-question G: How can healthcare providers facilitate the positive effects of Familism on T2DM self-care?

Facilitating Care via the Social Collective.
Research Finding: The PRiH family and community may be synonymous and are highly influential in the lives of PRiH adults with T2DM. The collective nature of these social relationships may be used to facilitate positive behavioral change (i.e. diet, exercise etc.).

1. Recommendation: Incorporating family and community members into the plan of care may provide a direct pathway to affect behavioral change (i.e. diet, exercise), medical management (i.e. medication adherence) and self-care practices (i.e. monitoring, management, maintenance).

   Question 2. Sub-question G. Number 1.  
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**Research Finding:** Non-healthcare professionals may be a source of health advice in PRIH families and communities.

2. **Recommendation:** Knowing who these “non-healthcare” supports community are and empowering them with accurate evidence based health information may positively affect behavioral changes (i.e. diet, exercise), medical management (i.e. medication adherence) and self-care practices (i.e. monitoring, management, maintenance).

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**Research Finding:** PRiH family members and communities may offer traditional and home remedies as treatments for medical problems to their family members.

3. **Recommendation:** Knowing and clarifying what these traditional treatments and home remedies are, and if they are being used as primary, secondary therapies or adjunctive therapy, may help improve standard self-care practices (i.e. diet, exercise), medical management (i.e. medication adherence) and overall treatment plan adherence.

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**Facilitating Care via Family Supports**

*Research Finding:* The PRIH family and community offers support for their family members with T2DM. This support may come from 1st, 2nd, 3rd degree relatives. This support most likely comes from female family members that may include spouses, ex-spouses, mothers, sisters, children, grandchildren and other community members.
4. **Recommendation:** Family and community member supports must be identified, and their roles or functions must be defined in order to include them in the care planning. HCPs may have an opportunity to empower these family members to help their patients with diabetes self-care behaviors.

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**Research Finding:** Female PRiH family and community members are often a trusted resource for medical and health advice.

5. **Recommendation:** These individuals may have a direct effect on self-care behaviors. Empowering these individuals may promote behavioral change.

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**Research Finding:** HCPs should know that male PRiH patients with T2DM very likely have a female family or community member who supports their diabetes self-care, and that their female patients may or may not have the same level of support.

6. **Recommendation:** This knowledge should prompt HCPs to inquire as to whom these support persons are, and what their roles are in that support.

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**Research Finding:** Male PRiHs with T2DM may be more likely to receive active support in self-care (i.e. checking glucose levels, checking their feet) from female family members than their female counterparts.

7. **Recommendation:** Identifying these family supports, empowering them with the details of the care plan, and including them in healthcare visits may improve self-care activities.

### Question 2. Sub-question G. Number 7.

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**Facilitating Medication Adherence**

**Research Finding:** PRiH may receive family and community support with medication adherence. This support is variable. However, male PRiH adults with T2DM may be more likely to receive support than their female counterparts. The support for male PRiHs likely comes from female family and community members.

8. **Recommendation:** HCPs may improve self-care and medication adherence by determining who these support persons are and empowering those individuals in this function.

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**Facilitating Glucose Monitoring**

**Research Finding:** Though variable, many PRiHs with T2DM have family that support them by actively (physically checking glucose) or passively (inquiring about glucose levels) checking glucose levels.

9. **Recommendation:** HCPs may empower these family and community members to facilitate more accurate monitoring of blood glucose levels.

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10. Recommendation: HCPs may improve their patients’ clinical picture and self-care practices by identifying who these supporting family and community members are, including them in healthcare visits, and understanding how involved they are in monitoring blood glucose levels.

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Facilitating Communal Healthcare Appointments

Research Finding: PRiH patients may prefer for their family or community member supports to be involved in their healthcare appointments.

11. Recommendation: As PRiH patients to include their family members in their healthcare appointments may be sufficient method of increasing family member participation in appointments.

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Research Finding: PRiH family members who provide diabetes self-care support may receive these requests positively. The preference for family involvement in healthcare appointments may vary between individual patients.

12. Recommendation: Determining the PRiHs patients’ preference for and frequency of involvement from their family and community members in their care may provide a pathway to conversations about social and self-care support.

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13. **Recommendation:** Involving a family or community member who is instrumental in a patients’ diabetes self-care and may strengthen that individuals’ self-care practices, empower the supporting family member, and ultimately improve measurable outcomes.

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14. **Recommendation:** Expressing empathy for the many stressors of diabetes self-care management may foster and improve relationships between clinicians, patients and their families.

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15. **Recommendation:** Considering the encompassing nature of diabetes self-care, PRiH patients and families may prefer to receive a more holistic approach to diabetes management as opposed to disease specific informational style visits.

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**Sub-question H:** How can healthcare providers prevent negative effects of *Familism* on T2DM self-care?

**Addressing Sociocultural Stressors.**

*Research Finding:* PRiH patients with T2DM may be under emotional, financial and social stressors that compete with the behavioral recommendations and medical management (i.e. diet, time management etc.).

**16. Recommendation:** Female PRiH patients in traditional family roles may be subject to more of these stressors and have subsequent emotional burden than their male counterparts. Understanding and addressing these stressors may help with adherence to behavioral recommendations, self-care and interventions used in medical management.

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*Research Finding:* Social and cultural stressors may have a negative effect on diabetes self-care. Some family and community members in PRiH communities may have ambivalent attitudes about diabetes self-care, and may encourage non-adherence to the diabetic diet. For PRiH adults with diabetes, sociocultural stressors coupled with family or community members who obstruct diabetes self-care, may make adhering to the diabetic diet more difficult.

**17. Recommendation:** HCPs may improve diabetic diet adherence by determining if their PRiH patients experience obstructive behaviors from their family and community members, and facilitating education to those individuals or providing additional supports for the patients affected.

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*Research Finding:* Female PRiH patients with T2DM in traditional gender roles may be charged with caring for other family members. These duties may compete with T2DM self-care and behavioral recommendations.
18. **Recommendation**: Gaining knowledge of this potentially competing social responsibility may facilitate communications and interventions to remove barriers to self-care and behavioral recommendations.

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**Research Finding**: PRiH adults may have lower education levels, employment levels and income compared to the general population. Foods included in the recommended diabetic diet may be more expensive than the traditional Puerto Rican diet. This financial burden may affect adherence to a diabetic diet.

19. **Recommendation**: HCPs may improve diet adherence by determining if food cost is a barrier to diabetic diet for PRiH patients, and facilitating pathways to provide relief.

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**Research Finding**: A strong nurturing maternal culture may be prevalent in PRiH families and communities. These traditional matriarchal roles may not necessarily allow individuality during communal meals. PRiH women with diabetes may feel obligations to provide traditional Puerto Rican foods for their families. PRiHs with T2DM may feel social pressure to eat traditional foods if offered in a communal setting and prepared by a matriarchal figure.

20. **Recommendation**: HCPs may provide additional support to PRiH patients by providing specific tools for PRiHs with T2DM to navigate social pressures around communal meals.

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**Research Finding:** Female PRiH adults with T2DM may receive less support with medication adherence and glucose monitoring compared to their male counterparts.

**21. Recommendation:** HCPs may improve medication adherence and glucose monitoring for PRiH patients with T2DM by determining if they have family or community supports with self-care, and facilitating pathways for additional support when it is lacking.

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**Addressing the Traditional Diet and Family Gatherings.**

**Research Finding:** The traditional PRiH diet and family gatherings are a central and vital component of PRiH culture. Traditional Puerto Rican foods tend to be carbohydrate intensive and conflict with medical and behavioral recommendations for self-care management. This is a cultural conflict.

**22. Recommendation:** HCPs may improve diabetic diet adherence by providing consistent, evidence-based approaches to directly address and manage this cultural conflict.

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**Research Finding:** Adhering to a diabetic diet may be the most universal cultural challenge for PRiHs with T2DM. Traditional Puerto Rican cuisine is a central component within PRiH culture. The abundance of traditional foods at family gatherings may conflict with diet recommendations. There may be few healthy options in PRiH eating establishments. All of these cultural factors may affect adherence to a diabetic diet.

**23. Recommendation:** HCPs may gain insight of their PRiH patients’ decision around T2DM using standardized methods to inquire about potential barriers to diabetes.
adherence such as perceptions about cultural conflicts with diabetic diet recommendations.

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**24. Recommendation:** HCPs may improve PRiH patients’ adherence to the diabetic diet by including specific ways to adhere to a diabetic diet when eating in public restaurants.

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**Research Finding:** The struggles with traditional Puerto Rican cuisine may be contextually different for male and female PRiHs with T2DM. Male may have more difficulty with navigating the diabetic diet at restaurants, whereas, female subjects may have conflicts regarding feeling obligated to prepare traditional foods for their family.

**25. Recommendation:** HCPs may gain insight about challenges PRiH patients face regarding adherence to the diabetic diet by inquiring about specific factors that deter adherence.

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**26. Recommendation:** HCPs may provide additional support for female PRiH patients by acknowledging, providing support for, and providing methods to address perceived obligations prepare traditional PRiH foods for their family.


Research Finding: PRiH adults with T2DM may struggle with not having foods congruent with their diabetic diet available at family gatherings. Subsequently, these individuals may participate in “cheat days”, on which they would disregard their diabetic diet when attending family/community gatherings. Family and community members may not know or understand the emotional stress and conflict their family members with T2DM are faced with in these conflicting situations.

27. Recommendation: HCPs may improve PRiHs adherence to a diabetic diet by including family and community in the diabetes plan of care and providing resources and information that empower them to provide a therapeutic diet at family gatherings.

Active Family Involvement in Care Planning.
Research Finding: Despite the integral role and effect of the PRiH family member on diabetes self-care, generally PRiH family members may not be actively included in healthcare appointments and care planning. Passively providing information to these family and community supports may not sufficiently include the family in care planning.

28. Recommendation: HCPs may facilitate family and community involvement in diabetes care planning by actively requesting that family members providing self-care support attend healthcare appointments.
**Comment:**

**Research Finding:** HCPs tend to focus a portion of healthcare visits on standard diabetes education. PRIH adults with T2DM may be generally aware of the effect of the carbohydrate rich traditional Puerto Rican cuisine. Other factors aside from low health literacy and knowledge deficits may influence suboptimal dietary adherence.

**29. Recommendation:** In addition to standard diabetes education, HCPs should evaluate health literacy of their PRIH patients.

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**30. Recommendation:** Additionally, HCPs should formulate methods to inquire about and address other sociocultural or socioeconomic barriers to dietary adherence.

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**Dispelling Negative Attitudes**

**Research Finding:** The high prevalence of T2DM in PRIH communities may contribute to ambivalence about the disease and subsequent sequela. HCPs tend to focus healthcare appointments on their patients’ individual responsibilities and disease management.

**31. Recommendation:** HCPs may improve patient and community engagement in diabetes self-care management by providing education about diabetes prevention, treatment and management at the community level.

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Research Finding: Puerto Rican identified Hispanic adults with T2DM may have a lack of community and family support for, as well as general lack of ambition towards recommended exercise regimens.

32. Recommendation: HCPs should create standardized methods to determine if PRiHs with T2DM have family and community supports that encourage recommended exercise regimens.

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33. Recommendation: HCPs may improve motivation and adherence to exercise regimens by ensuring PRiH patients with T2DM have adequate family and community supports that encourage exercise regimens.

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Addressing Emotional Tolls

Research Finding: The link between T2DM and depression is well documented in health and science literature. PRiH adults with T2DM may experience depression, sadness, fear and despair after being diagnosed with diabetes. They may experience embarrassed when managing diabetes in public and at family gatherings. Additionally, they may experience low self-esteem and negative feelings associated with obesity and diabetes. Given the known association of depression with diabetes, coupled with social and cultural stressors, PRiH adults with T2DM may be at higher risk for being diagnosed with depression.

34. Recommendation: HCPs should evaluate PRiHs with T2DM for depression and depressive symptoms on an ongoing basis.

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Research Finding: PRiH patients with T2DM may experience emotional tolls related to diabetes self-care, social stressors, decreased motivation and concurrent depression. Female PRiHs with T2DM may experience these emotional tolls as well as social isolation related to T2DM self-care.

35. Recommendation: HCPs should use standardized methods to evaluate and treat PRiH adults with T2DM for social stressors, social isolation and concomitant depression.

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Research Finding: Female PRiH adults with T2DM may be subject to emotional conflicts related to prioritizing their family over their diabetes self-care. These conflicts may involve choosing to prepare a traditional diet for family versus a therapeutic diet for themselves; and difficulty incorporating their diabetic diet with traditional Puerto Rican foods during meal preparation.

36. Recommendation: HCPs may help reduce the emotional burden of diabetes self-care and improve diabetic diet adherence by incorporating methods to determine if these conflicts are present for PRiH women with T2DM, and providing resources to help resolve these conflicts.

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Research Finding: Family gatherings and traditional foods are a core component of PRIH culture. These gatherings may be a source of emotional distress for PRIHs with T2DM. Some PRIH adults may experience emotional distress in the form of frustration and embarrassment while managing their diabetes at family gatherings.

37. Recommendation: HCPs may reduce this emotional burden and stress by including the family/community in the diabetes care plan.

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Research Finding: Some PRIH family members and communities may display a type of communal ambivalence regarding the T2DM, management, and self-care. PRIH adults with T2DM may experience social stress and pressure to partake in traditional meals, despite having adequate knowledge that a high carbohydrate meal is contraindicated in the diabetic diet. This social pressure may come in the form of family and community members encouraging them to eat traditional Puerto Rican foods they should avoid.

38. Recommendation: HCPs may improve dietary adherence for PRIHs with T2DM by determining if they are affected by social pressure to forgo their diabetic diet, providing emotional support, providing resources to help patients cope with these stressors, and including community members and family members in the diabetes care plan.

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Addressing Interpersonal Relationship Strain.

Research Finding: Female PRIHs with T2DM may experience emotional distress and conflicts when with preparing food for a non-diabetic spouse.

39. Recommendation: HCPs may reduce emotional toll of diabetes self-care for PRIH women by determining if these social stressors exist, and providing resources to address these concerns.

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Research Finding: PRiHs with T2DM may experience emotional distress related to interpersonal relationships. Sexual dysfunction may add to the emotional distress of diabetes self-care. Male PRiHs may experience emotional distress related to erectile dysfunction. Female PRiHs may experience emotional distress related to negative body.

**Recommendation:** HCPs may reduce the emotional tolls of diabetes self-care by determining if sexual dysfunction or negative body perceptions are present for PRiH patients with T2DM, providing resources and or treatment to address these concerns.

Variable Socioeconomic Factors

**Research Finding:** The cost of a “healthy” or diabetic diet may be a source of frustration for PRiHs and their families. PRiH homemakers with T2DM may feel conflicted between providing traditional foods for themselves and their family, versus potentially higher cost foods that are more in line with a diabetic diet.

**Recommendation:** HCPs may provide additional support for PRiH patients with T2DM by determining their socioeconomic status and the effect on decision making and food purchasing.
**Research Finding:** Generally, PRiHs experience lower levels of education, higher rates of unemployment, higher rates of diabetes, and higher rates of diabetes complications compared to their non-Hispanic white counterparts. However, the PRiH culture and population is complex, and the experiences of those with lower socioeconomic status may be different than those of higher status.

**42. Recommendation:** HCPs should inquire as to the socioeconomic status, literacy and health literacy of PRiH patients and their families to gain a more robust clinical picture of the diabetes management plan and self-care.

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**Additional Research Findings:** The effect of T2DM on *Familism* in the PRiH community.

**Social Stressors**

**43.** The PRiH family may experience financial strain when accommodating a family member who has T2DM.

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**44.** Food items consistent with the diabetic diet may differ from traditional PRiH foods, and may be significantly more expensive for the family unit.

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45. This may place financial strain on the PRiH family as well as interpersonal relationships within the family.

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46. Traditional matriarchal roles may not necessarily allow for individuality during communal meals.

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47. Requesting an alternate meal may be insulting towards homemakers and women who prepare meals in traditional roles.

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48. This may add an additional stressor for PRiH women charged with preparing foods for diabetic family members.

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Effect on Female Family Members
49. Female PRiH family members are a key community resource, often in matriarchal roles, usually the most trusted for health advice, and most likely to discuss health decisions.

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50. Family members with T2DM may seek out female PRiHs for advice or support.

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51. Females in a PRiH families are often tasked with caring for family members with T2DM.

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52. If a family member is involved in helping or assisting with diabetes self-care, this family member is most likely female.
53. Family members have a direct effect on their family members' diabetes self-care. Importantly, the family members' diabetes self-care has an effect on the family member in that they assume some responsibility for helping with self-care.

54. This family member who assists with diabetes self-care, dedicates a certain amount of their time and effort, as well as assumes a variable amount of responsibility for their family members' self-care.

55. Any female PRiH family member may be involved in caring for a family member with T2DM. These female family may include but are not limited to,
   a. intimate partners (wives, girlfriends)
   b. adult children
   c. ex-intimate partners
   d. siblings
   e. grandchildren
   f. daughter in-laws
   g. mothers.
56. Mothers and female family members may be involved in their family members’ self-care by
   a. actively or passively checking their glucose levels.
   b. monitoring for symptoms of high or low glucose,
   c. checking feet
   d. checking for vision changes

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APPENDIX E

RECRUITMENT LETTERS

Patient Subject Recruitment Letter

Baystate Health

Date

Dear Patient Name,

I am writing to let you know about a research study that I am conducting at Baystate Medical Center to improve the care of Puerto Rican adults with type 2 diabetes. The purpose of this study is to understand patients with type 2 diabetes and their families. This program involves attending a focus group and discussing type 2 diabetes. If you decide to participate in this research study, you would be expected to attend a focus group and have an option to attend a presentation of the research at the end of the study.

You may or may not benefit from being in this study. What I learn from this research may help Puerto Rican people with type 2 diabetes in the future. I encourage you to consider participating in this research study. The ultimate goal of the study is to help our patients and medical providers better control type 2 diabetes. However, you are under no obligation, and if you prefer not to participate, nothing will change in terms of your current healthcare.

If the study staff does not hear from you in the next two weeks, we will assume you are interested in participating in the study, and someone will contact you to provide more detailed information about the study and answer any questions that you may have. If you are not interested, please let us know at ___-___-___ to avoid further calls or letters. If you would like to learn more about the study before deciding, please call Jalil Johnson, NP, Researcher, for more information at ___-___-____.

Thank you for your consideration.

Sincerely,

Jalil Johnson, BSN, ANP-BC
PhD Candidate & Principal Investigator
Baystate Medical Center
Community Member Recruitment Letter

Date 5/22/2017

Dear Community Member,

You are invited to be in a research study. The researcher is from University of Massachusetts College of Nursing. This study will help to medical providers understand how to care for Puerto Rican adults with type 2 diabetes. This study involves going to an interview and discussing type 2 diabetes. The interview involves one meeting with the researcher for about 10-20 minutes. There will also be a presentation of the research at the end of the study but this meeting is optional. The researcher will meet you at a place that is convenient for you.

You may or may not benefit from being in this study. What we learn from this research may help Puerto Rican people with type 2 diabetes in the future. We encourage you to consider allowing the researcher to interview you. The goal of this study is to help our people understand how to control type 2 diabetes. You do not have to be involved in this study.

You may be allowed to be in this study if you answer yes to these questions:

Yes____ I am a man.
Yes____ I am Puerto Rican OR my ancestors were Puerto Rican
Yes____ I have had Type 2 Diabetes for more than 1 year
Yes____ I am under the age of 66 years’ old
Yes____ I am able to read and speak English
Yes____ I live in a home or apartment.

If you DO NOT want to be involved in this study, you do not have to do anything further.
If you DO want to be involved in this study, simply let the researcher know. He can be contacted with the information below.

Jalil Johnson
508-331-4544
Jalil@Nursing.Umass.edu

Thank you for your consideration.

Sincerely,
Jalil Johnson, MS, BSN, ANP-BC
PhD Candidate
University of Massachusetts | College of Nursing
Date

Dear Medical Provider,

I am writing to let you know about a research study that is being conducted at Baystate Medical Center outpatient clinics. The aim of this study is to better understand the relationship between family dynamics and type 2 diabetes self-management for Puerto Rican identified Hispanic patients. Ideally, the data collected from this study will be used to create culturally tailored type 2 diabetes interventions for Puerto Rican adults. If you decide to participate in this research study, your involvement will consist of a simple interview and is expected to last for approximately one hour. If you choose to participate the researcher will meet with you at a time that is convenient for you.

You may or may not benefit from being in this study. However, what we learn from this research may help Puerto Rican adults with type 2 diabetes in the future. I encourage you to consider participating in this research study, as it will improve our understanding of how patients and their families experience diabetes self-care. However, you are under no obligation to participate.

If you are interested in participating in this study, please contact the principle investigator directly via any of the following contact information:

Email: ___.____@________.com
Cell Phone: ___-___-____
Work Phone: ___-___-____

Thank you for your consideration.

Sincerely,

____ ________, MD
Medical Director
Baystate Medical Center
APPENDIX F

TELEPHONE SCRIPTS

Telephone Script 1.

I. INTRODUCTION

1. Introduce yourself
   o My name is Jalil Johnson researcher from the University of Massachusetts Amherst. (U. Mass Amherst)

2. Introduce study/basics
   o Calling to follow-up on letter you received about the research study.
   o Researchers at the University of Massachusetts Amherst and medical providers at Baystate Medical Practices are conducting this study.
   o The study is funded by public and private grants
   o Purpose of study is to evaluate how some of the challenges Puerto Rican families face regarding management of type 2 diabetes.
   o Participation involves attending one focus group:
     • Initially meeting with the researcher to learn about the study and sign consent forms
     • This study will involve attending a single focus group.
     • The focus group will be with other Puerto Rican adults who have diabetes.
     • The focus group is expected to last 1 to 1 ½ hours, but no more than 2 hours.
     • After the study has been completed, the researcher will present the findings to all of the study participants. Attending this presentation is optional.
   o Additional contact may involve:
     • Telephone calls from the Researcher (after first visit) to answer questions, provide information and schedule the focus group meeting.
     • Incentives: $20 for completing the focus group (in form debit like card)
     • Whether or not you take part in this study is up to you. If you choose not to participate in the study it will not affect the quality of medical care you will receive.

II. ASSESS INTEREST

1. Does this sound interesting to you?
   o Yes → Go to screening question 1 below
   o No → Thank you for your initial interest and time.
   o Please call me at ____-____-_____ if you change your mind and would like to participate.

III. SCREENING QUESTIONS

1. Do you have any plans to move away from the area in the next few (3) months?
   o YES (Not eligible, stop here)
2. Are you comfortable speaking, reading, and writing English?
   o NO (Not eligible, stop here)

3. Do you live independently in a private home (i.e., not living in nursing home or assisted living facility)?
   o NO (Not eligible, stop here)
4. Are you currently participating in another research study?
   o YES (Not eligible, stop here)

IV. DISCUSS/SCHEDULE BASELINE RESEARCH VISIT
1. Provide Information about the baseline research visit:
   o During this visit, you will meet with me for approximately 1 hour in a private office at ______ OR at a location that is convenient for you.
   o Sign an informed consent form after all your questions have been answered,
2. Schedule appointment to conduct baseline research visit.

3. If you have any questions or need to reschedule the first research appointment, you may call me at ____-____-____.

Telephone Script 2

1. Introduce yourself
   o Jalil Johnson researcher from the University of Massachusetts Amherst.
   o I am Calling to follow-up on the study Family and Community Challenges in Self Care for Puerto Rican Hispanic adults With Type Two Diabetes
   o Are you still interested in participating in the study?
     • Yes → Go to section 2.
     • No.
       ▪ Is there a reason why you do not want to participate?______________________________________
       ▪ Thank you for your initial interest and time.
       ▪ Please call me at ____-____-____ if you change your mind and would like to participate.

2. Your Focus group is scheduled for --/--/2016 at --:-- AM/PM
   o Do you think you will be able to attend this focus group?
     • Yes.
     ▪ Thank you. I will be in touch with you by phone. Is this the best phone number to reach you?
     • No. Thank you.
     ▪ Is there a more convenient date and time for you to attend a focus group?
     ▪ Date______Time.
**APPENDIX G**

**SCREENING AND RECRUITMENT TOOLS**

*Screening, Recruitment & Tracking Form*

<table>
<thead>
<tr>
<th>Appointment Time</th>
<th>First Name</th>
<th>Medical Provider Name</th>
<th>Age</th>
<th>DM Dx</th>
<th>PRiH</th>
<th>English Speaking</th>
<th>Include Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>09:20</td>
<td>Joe</td>
<td>Dr. Stevens</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>Y</td>
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**Enrollment Log**

<table>
<thead>
<tr>
<th>Principal Investigator:</th>
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<tbody>
<tr>
<td>IRBNet # / Study Title:</td>
<td></td>
</tr>
<tr>
<td>IRB-Approved Target Enrollment:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ID</th>
<th>Criteria Met</th>
<th>Consent Date</th>
<th>Version &amp; Date</th>
<th>Copy to subject</th>
<th>PI Initials &amp; Date</th>
<th>Gender &amp; Ethnicity</th>
<th>Terminated/Withdrew &amp; Reason. Date</th>
<th>Lost to Follow-Up</th>
<th>Completed Research</th>
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<td>Y</td>
<td>xx/xx/xxxx</td>
<td>Versión 2.0, March</td>
<td>☒</td>
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<td>FG 01</td>
<td></td>
<td>xx/xx/xxxx</td>
<td>Version 3.0 April 1, XXXX</td>
<td>Hispanic</td>
<td>F Black / Hispanic</td>
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APPENDIX H

RESEARCH ASSISTANT TRAINING

<table>
<thead>
<tr>
<th>Category</th>
<th>Includes</th>
<th>Observer should Note:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appearance</td>
<td>Clothing, age, gender, physical appearance</td>
<td>Anything that might indicate membership in groups or in sub-populations of interest to the study, such as profession, social status, socioeconomic class, religion, or ethnicity</td>
</tr>
<tr>
<td>Verbal behavior and interactions</td>
<td>Who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice</td>
<td>Gender, age, ethnicity, and profession of speakers; dynamics of interaction</td>
</tr>
<tr>
<td>Physical behavior and gestures</td>
<td>What people do, who does what, who interacts with whom, who is not interacting</td>
<td>How people use their bodies and voices to communicate different emotions; what individuals’ behaviors indicate about their feelings toward one another, their social rank, or their profession</td>
</tr>
<tr>
<td>Personal space</td>
<td>How close people stand to one another</td>
<td>What individuals’ preferences concerning personal space suggest about their relationships</td>
</tr>
<tr>
<td>Human trafficking</td>
<td>People who enter, leave, and spend time at the observation site</td>
<td>Where people enter and exit; how long they stay; who they are (ethnicity, age, gender); whether they are alone or accompanied; number of people</td>
</tr>
<tr>
<td>People who stand out</td>
<td>Identification of people who receive a lot of attention from others</td>
<td>The characteristics of these individuals; what differentiates them from others; whether people consult them or they approach other people; whether they seem to be strangers or well known by others present</td>
</tr>
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</table>
APPENDIX I

RESEARCH TRAINING DOCUMENTS

CITI Training Jalil Johnson

<table>
<thead>
<tr>
<th>REQUIRED MODULES</th>
<th>DATE COMPLETED</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoiding Group Harms - U.S. Research Perspectives</td>
<td>10/07/12</td>
<td>3/3 (100%)</td>
</tr>
<tr>
<td>Avoiding Group Harms - International Research Perspectives</td>
<td>10/07/12</td>
<td>3/3 (100%)</td>
</tr>
<tr>
<td>Belmont Report and CITI Course Introduction</td>
<td>10/07/12</td>
<td>3/3 (100%)</td>
</tr>
<tr>
<td>Students in Research</td>
<td>10/07/12</td>
<td>10/10 (100%)</td>
</tr>
<tr>
<td>History and Ethical Principles</td>
<td>10/07/12</td>
<td>6/6 (100%)</td>
</tr>
<tr>
<td>Basic Institutional Review Board (IRB) Regulations and Review Process</td>
<td>10/07/12</td>
<td>5/5 (100%)</td>
</tr>
<tr>
<td>Informed Consent</td>
<td>10/08/12</td>
<td>4/4 (100%)</td>
</tr>
<tr>
<td>Social and Behavioral Research (SBR) for Biomedical Researchers</td>
<td>10/08/12</td>
<td>4/4 (100%)</td>
</tr>
<tr>
<td>Records-Based Research</td>
<td>10/08/12</td>
<td>2/2 (100%)</td>
</tr>
<tr>
<td>Genetic Research in Human Populations</td>
<td>10/08/12</td>
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</tr>
<tr>
<td>Research With Protected Populations - Vulnerable Subjects: An Overview</td>
<td>10/08/12</td>
<td>4/4 (100%)</td>
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<tr>
<td>Vulnerable Subjects - Research Involving Prisoners</td>
<td>08/04/13</td>
<td>4/4 (100%)</td>
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<tr>
<td>Internet Research - SIDE</td>
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<td>5/5 (100%)</td>
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<tr>
<td>FOA-Regulated Research</td>
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<td>5/5 (100%)</td>
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<td>5/5 (100%)</td>
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<tr>
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<td>08/04/13</td>
<td>4/4 (100%)</td>
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<tr>
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<td>08/04/13</td>
<td>No Quiz</td>
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<td>Stem Cell Research Oversight (Part I)</td>
<td>08/04/13</td>
<td>2/5 (40%)</td>
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For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.
CITI Training Jessica Caron

- **Report ID:** 18778404
- **Completion Date:** 02/29/2016
- **Expiration Date:** 02/28/2019
- **Minimum Passing:** 80
- **Reported Score:** 96

### REQUIRED AND ELECTIVE MODULES ONLY

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<td>Belmont Report and CITI Course Introduction (ID: 1127)</td>
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<td>Students in Research (ID: 1321)</td>
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<td>History and Ethics of Human Subjects Research (ID: 496)</td>
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<td>Informed Consent (ID: 3)</td>
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<tr>
<td>Vulnerable Subjects - Research Involving Prisoners (ID: 8)</td>
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<td>4/4 (100%)</td>
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<tr>
<td>Vulnerable Subjects - Research Involving Children (ID: 9)</td>
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<tr>
<td>Stem Cell Research Oversight (Part I) (ID: 13882)</td>
<td>02/29/16</td>
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ram.org
## APPENDIX J

### BUDGET

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<tr>
<th>Item</th>
<th>Estimated cost</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food vouchers for participants</td>
<td>$400.00 ($20.00 voucher x 40 participants)</td>
<td>Determined by Researcher</td>
</tr>
<tr>
<td>NVivo Software License Renewal</td>
<td>$140.00 (student discount) $90.00 (student discount)</td>
<td><a href="http://www.qsrinternational.com/Products/NVivo/Mac/Education/New/NVivoforMacStuLic12Mon">http://www.qsrinternational.com/Products/NVivo/Mac/Education/New/NVivoforMacStuLic12Mon</a></td>
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<td>Transcription</td>
<td>$1100.00 (approximate costs paid for service)</td>
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<td>Audio Recorder</td>
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<td>Total study costs</td>
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### APPENDIX K

**LITERATURE REVIEW MATRIX**

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<tr>
<th>Author(s)</th>
<th>Sample</th>
<th>Purpose</th>
<th>Methodology</th>
<th>Relevant Findings</th>
<th>Limitations</th>
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</thead>
<tbody>
<tr>
<td>Caban et al. (2008)</td>
<td>Sample: 37 Puerto Rican identified Hispanics with type 2 diabetes.</td>
<td>Purpose: explore psychosocial issues that affect diabetes self-management for Hispanic men and women of primarily Caribbean ancestry.</td>
<td>Methodology: Descriptive, qualitative study using focus group design.</td>
<td>Findings: Diabetes had an effect on: 1) sexual health problems, 2) perceptions about the link between depression and diabetes, 3) intergenerational issues and their impact on participants' beliefs about diabetes and perceptions of discrimination, 4) discontinuity in health care. Socio-ecological models of health may be useful to increase understanding of patients' experiences with diabetes and informing the development of psychosocial and educational interventions that consider individuals and</td>
<td>Limitations: Homogeneous sample decreases generalizability of study findings to other Hispanic subgroups.</td>
</tr>
</tbody>
</table>
Familism was not specifically investigated or addressed.

**Gonzalez (1989)**

**Sample:**
12 Puerto Rican identified Hispanics with type 2 diabetes.

**Purpose:**
1) To explore cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida
2) To examine Puerto Ricans' perceptions about their health-care providers.

**Methodology:**
Descriptive, qualitative study using semi-structured interviews.

**Findings:**
Emergent themes included: 1) Expectation of significant others 2) Family interdependence, 3) Caregiver burden. Familism was a consideration in health-care seeking behaviors. Traditional gender role expectations deterred some participants from seeking care even when care was needed. Religiosity and spirituality played a role in coping with the chronic disease. Participants preferred Western medicine for diabetes treatment and preferred ethnically concordant providers.

**Limitations:**
Homogeneous sample decreases generalizability of study findings to other Hispanic subgroups. The cultural heritage of the investigator and the data collection being carried out by a single investigator could potentially reflect a restricted view about the phenomenon of interest.
<table>
<thead>
<tr>
<th>Source</th>
<th>Sample</th>
<th>Purpose</th>
<th>Methodology</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asgari an (2011)</td>
<td>40 adult Latinos with Type II diabetes. Dominican and Puerto Rican backgrounds</td>
<td>to examine factors that may play a role, specifically for Latinos, in the practice of health behaviors related to self-management of Type 2 diabetes.</td>
<td>Descriptive, correlational study using HbA1c and questionnaires that included demographic information, assessment of insight, self-efficacy and acculturation.</td>
<td>There were significant positive correlations between HbA1c and three individual insight questions; one individual self-efficacy question; and acculturation. Various problematic beliefs including: 1) confusion about the heritability of diabetes and 2) use of subjective feelings as indicators of blood sugar level. Familism was not specifically investigated or addressed.</td>
<td>There was no delineation between the findings of the Hispanic subgroups, which limits cultural specificity of the findings.</td>
</tr>
<tr>
<td>Carbone et al. (2010)</td>
<td>36 Puerto Rican identified Hispanics</td>
<td>to inform tailoring of diabetes self-management programs</td>
<td>Descriptive qualitative study using focus groups with</td>
<td>Two key facilitators of diabetes self-management emerged: family support and religious faith. Additionally, there was a</td>
<td>Limitations associated with qualitative design. There was limited data</td>
</tr>
</tbody>
</table>
nics and one Colu-15 medi-15 medical practition-15 ers. for Latino, particularl 15 y Puerto Rican, patients practition-15 ers (assessed perception-15 s of patients’ knowledge, attitudes, and behaviors) and patients (assessed knowledge, beliefs, practices, barriers, and facilitators). noted potential for traditional gender roles to constrain patients’ ability to make healthful lifestyle changes. There was a disconnect in practitioners’ approach to guiding diabetes self-management which emphasized giving instructions and information rather than counseling patients on realistic goals and progressive lifestyle changes. There-468 collected on the samples literacy, health literacy level, and learning preference.

| Long et al. (2012) | Sample: 24 participants took part in one of the four focus groups. (Mexican[6], Latino) | Purpose: to explore similarities and differences in beliefs and attitudes related to health and healthcare practices across four focus groups. | Methodology: Descriptive qualitative study using questionnaires and four focus groups. | Findings: Focus group themes included: 1) views of Health, 2) Access to care, 3) acculturation, and 4) worrying/stress or anxiety. Puerto Ricans felt diabetes was inevitable; acknowledged the advantage of citizenship and use of collected on the samples literacy, health literacy level, and learning preferences. | Limitations: Limitations associated with qualitative focus group design; less female representation in some focus groups; convenience sampling limiting generalizability. |
Dharna et al. (2013)

**Sample:** 20 low-income families with children aged <18 years. Parents were foreign born: (65% from the Dominican Republic, and 35% from Colombia, Puerto Rico, and Mexico). 

**Purpose:**
1) to understand grocery shopping practices among 20 Spanish-speaking, low-income Latino families.
2) to analyze food selection practices in order to determine the effect of nutrition education.

**Methodology:** Descriptive qualitative, Ethnographic study using semi-structured interviews, participant observations, home visits, and quantitative nutritional analyses of grocery store receipts of food purchased by participants. 

**Findings:** Purchases included malt beverages; cold cereals high in sugar; sugary drinks; fruit drinks; instant ramen noodles; and salami, and other less healthy foods. Participants often were surprised to learn about the low nutritional value of many foods they had purchased, and many asked for recommendations they could use to make appropriate changes within their budget. 

**Limitations:** Results were not distinguished between Hispanic subgroup which limits cultural sensitivity to specific subgroups. All of the participants eating behaviors were not accounted for; provided transportation is a potentially confounding factor. 

*Familism is demonstrated as a factor in diabetes self-care.*

English language; preferred Spanish speaking providers; used various herbal remedies; preferred to consult with family/friends or pharmacist; described social isolation.
on changes in shopping practices to later develop educational tools to promote selection of healthier food options.

Familism was not specifically investigated or addressed.

**Orzech et al. (2012)**

**Sample:** Survey of 297 participants (Whites, Blacks, Vietnamese, and Latinos) and a subsample of 71 participants completing focus groups.

**Purpose:** To explore differences in self-reported adherence to diet and exercise plans and self-reported daily diet and exercise practices across four ethnic groups: Whites, Blacks, Vietnamese, and Latinos.

**Method:** Mixed methods study using qualitative survey data and qualitative ethnographic design (focus groups, interviews, chronic disease diaries, home visits).

**Findings:** Latino and Black participants described health care providers’ advice conflicting with their traditional diets, with Latino focus group participants experiencing this loss most acutely. Black and Latino participants complained that friends and family members did not consider their therapeutic diets. Latino and Black participants preferred to exercise in supportive communities of

**Limitations:** Qualitative and quantitative data was not analyzed for all participants in the study. Qualitative data was distinguished by diagnosis (i.e., diabetes vs Hypertension). Grouping participants by diagnosis produced limited data analysis of quantitative
| Weitzman et al. (2013) | Sample: 29 immigrants to the U.S. from Latin America and the Caribbean (Puerto Rico: 42%; Dominican Republic: 24%; South America: 21%; and Central America: 12%) | Purpose: to examine how attitudes and practices related to bodily aesthetic ideals and self-care might inform the engagement of Latinas with type 2 diabetes (T2DM). | Methodology: Descriptive qualitative study using focus group design. | Findings: Four themes emerged: 1) preference for a larger than average body size, perceptions of attractiveness were more closely linked to grooming than body size; 2) diabetic complications, especially foot pain, as a major obstacle to exercise; 3) fatalistic attitudes regarding the inevitability of diabetes and reversal of its complications; 4) social burdens, isolation, and financial stressors as contributing to disease exacerbation. Familism was not specifically data. | Limitations: Sampling bias. Magazine photos were not graded according to BMI of women depicted, and were more of a discussion prompt rather than an individual assessment tool. Findings were not shared with participants, which limits trustworthiness. |
Khan et al. (2012)  

**Sample:** 34 individuals diagnosed with type 2 diabetes. 14 refugees (from Somalia, Sudan, Burma, or Cuba), 8 Puerto Ricans, 6 non-Hispanic Caucasians, 6 African Americans, and 2 Native Americans.

**Purpose:** to explore the subjects’ experiences living with diabetes and their understanding of the illness.

**Method:** Descriptive, qualitative design using semi-structured interviews.

**Findings:** Three broad themes emerged across ethnic groups: 1) the diagnosis of diabetes was unexpected; 2) emotional responses to diabetes were similar to Kubler-Ross’s stages of grief; 3) understanding of diabetes focused on symptoms and diet. Additionally, emotions were expressed that were associated with the stages of grief: denial, anger, bargaining, depression, and acceptance. Familism was not specifically investigated or addressed.

**Limitations:** Linguistic data may have lacked accuracy, as the study did not allow for professional translators.
<table>
<thead>
<tr>
<th><strong>Hu et al. (2012)</strong></th>
<th><strong>Sample:</strong> 43 Hispanics (Mexican immigrants) with type 2 diabetes and their family members/significant others.</th>
<th><strong>Purpose:</strong> to explore the meaning of insulin among a sample of Hispanic immigrants with type 2 diabetes and their family members/significant others.</th>
<th><strong>Methodology:</strong> Qualitative, descriptive study using focus group design. Participants with diabetes and family members were asked to describe their perceptions of insulin.</th>
<th><strong>Findings:</strong> Three themes emerged: 1) negative perceptions of insulin therapy; 2) perceived barriers to insulin therapy; 3) Positive experiences with insulin emerged from qualitative data. There was a general lack of understanding of the T2DM disease process and the progressive nature of diabetes. Familism was not specifically investigated or addressed.</th>
<th><strong>Limitation:</strong> Convenience sampling and homogenous sample limiting generalizability to other Hispanic subgroups.</th>
</tr>
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<tbody>
<tr>
<td><strong>Sawyer et al. (2013)</strong></td>
<td><strong>Sample:</strong> 9 Hispanic (Mexican American) women and their families.</td>
<td><strong>Purpose:</strong> to explore nutritional behaviors and attitudes among Latino women with type 2 diabetes.</td>
<td><strong>Method:</strong> Qualitative, descriptive study using semi-structured interviews in subjects' homes.</td>
<td><strong>Findings:</strong> Acquisition of nutritional knowledge and behavioral capability were positively associated with observational learning, formal nutritional education, and culturally competent meal planners. In the home environment, husbands had the greatest</td>
<td><strong>Limitation:</strong> Convenience sampling and homogenous sample limiting generalizability to other Hispanic subgroups.</td>
</tr>
</tbody>
</table>
influence on Latina women’s attitudes and perceived choices. The social environment, including support and reinforcement, is critical for Latinas’ nutritional success. Observational learning is critical for Latinas’ behavioral capability. Familism was not specifically investigated or addressed.

Meyer et al. (2013)

Sample: 94 Mexican American, mother-child dyads

Purpose: to identify and better understand (1) household and neighborhood environmental physical activity resources/supports, perceived barriers to engaging in physical activity

Methodology: Mixed-methods, descriptive study using face-to-face interviews conducted in Spanish and questionnaires. Descriptive statistics were calculated and differences between

Findings: The most frequently reported barriers to physical activity included were unleashed dogs in the street, heat, bad weather, traffic, no streetlights, and no place like a park to exercise. Locations to perform Physical activity included schools, home, and parks. Physical activity for children

Limitations: Conveniences sampling and homogeneous sample limiting generalizability to other Hispanic subgroups. Descriptive statistical analysis of study measures did not allow for testing for validity and
activity, and physical activity offerings, locations, and transportation characteristics for Mexican-origin children. Included use of equipment, running, playing, and sports. Findings suggest that there are physical activity environmental resources, barriers, and opportunities for Mexican American children on the U.S. Mexico border, however, knowledge of these resources is limited. Familism was not specifically investigated or addressed.

| Hughes et al. (2012) | Sample: 16 adults newly diagnosed with type 2 diabetes (Hispanic subgroup not descr | Purpose: to determine the issues and perceptions of persons newly diagnosed with type 2 diabetes. | Methodology: Primarily qualitative descriptive study using individual interviews and an added questionnaire which including demographics and lifestyle questions. | Findings: Nine word categories emerged: 1) need to (self-management), 2) concerns, 3) “I’m sick”, 4) emotional distress, 5) loss, 6) the no’s (limitations), 7) Fears and complications, 8) Have to (medical management), and 9) coping. The clusters and concepts | Limitations: The Hispanic subgroup was not described explicitly. Convenience sampling and homogeneous sample limiting generalizability to other Hispanic subgroups. |
Subjects collected from San Angel, Texas were asked to write words or phrases that came to mind when thinking about living with diabetes.

Suggest that those educating newly diagnosed people with diabetes should consider a holistic representation of the issues and perceptions. Familism was not specifically investigated or addressed.

| Baig et al. (2012) | Sample: 37 Mexican adults (All participants were Latino, and 60% were born in Mexico) adults who had diabetes or had a family member who had diabetes | Purpose: To assess Latino adults’ preferences for peer-based diabetes self-management interventions and the acceptability of the church setting for these interventions. | Methodology: Descriptive qualitative study using focus group design. | Findings: Many participants believed the group-based and telephone-based one-to-one peer support programs could provide opportunities to share diabetes knowledge. The majority of the group stated the group education model would offer more opportunity for social interaction and access to people with a range of diabetes experience. | Limitations: Convenience sampling and homogenous sample (Mexican American) limiting generalizability to other Hispanic subgroups. Participants tended to have higher level of education, income, and health insurance than national averages for Latinos. |
Participants noted many concerns regarding the one-to-one intervention, mostly involving the impersonal nature of telephone calls and the inability to form a trusting bond with the telephone partner. Participants also stated the church would be a familiar and trusted setting for peer-based diabetes interventions. Church-based Latinos with diabetes and their family members were interested in peer-based diabetes self-management interventions; however, they preferred group based to telephone-based one-to-one peer programs. Familism was not specifically addressed, however the role of
<table>
<thead>
<tr>
<th><strong>Ramal et al. (2012)</strong></th>
<th><strong>Sample:</strong> 27 Hispanic participants from South West U.S.</th>
<th><strong>Purpose:</strong> To identify factors that influence diabetes self-management in Hispanics.</th>
<th><strong>Methodology:</strong> Descriptive qualitative study using focus groups.</th>
<th><strong>Findings:</strong> Four major themes emerged as enhancing or limiting factors to diabetes self-management: 1) access to resources; 2) Struggle with diet; 3) Self-efficacy; and 4) social support. The family’s role as a determinant of diabetes self-management emerged as the underlying subtheme to all four themes.</th>
<th><strong>Limitations:</strong> Unidentified Hispanic subgroups in the sample limit cultural specificity of the study findings. Convenience sampling and homogeneous sample limiting generalizability to other Hispanic subgroups.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aponte et al. (2010)</strong></td>
<td><strong>Sample:</strong> 40 Hispanic (self-identified as Dominican) with type 2 diabetes.</td>
<td><strong>Purpose:</strong> To gather and analyze qualitative data to provide a framework for future studies to develop strategies and interventions that are culturally-</td>
<td><strong>Methodology:</strong> Descriptive, qualitative study using focus group design with questionnaires.</td>
<td><strong>Findings:</strong> Participants had knowledge gaps in the following areas: 1) diabetes prevention; 2) reasons and ways one develops diabetes; 3) an understanding of the physiological short and long-term impact of not maintaining healthier</td>
<td><strong>Limitations:</strong> Convenience sampling and homogeneous sample limiting generalizability to other Hispanic subgroups.</td>
</tr>
</tbody>
</table>
lifestyles and what this means. Additionally, fear was noted as a barrier to seeking care. Participants recommended community based education techniques. Community outreach activities in Dominican communities are needed to provide diabetes awareness on the importance for seeking early and prompt health care services. In addition, awareness is greatly needed on the long-term effects of not receiving diabetes care in a timely fashion. Familism was not specifically investigated or addressed.

| Heuer and Lausch (2006) | Sample: 12 Hispanic (migr) | Purpose: addresses the perceptions of Hispanic | Methodology: Descriptive, qualitative (phenome) | Findings: Six themes emerged: 1) usualness of diabetes; 2) causes of | Limitations: Convenience sampling and |
Weiler and Crist (2009) Sample: 10 Hispanic (Mexican identified) participants Purpose: to explore the sociocultural influence and social context in Type 2 diabetes. Method: Descriptive, qualitative study using grounded theory techniques and in-contextual study using a focus group design. Findings: Four major themes emerged: 1) family cohesion; 2) social stigma of disease; 3) social expectations/perceptions of “illness,”; 4) Fear of long-term complications related to diabetes. Limitations: Convenience sampling and homogenous sample limiting generalizability to other Hispanic subgroups.
Participant lived with type 2 diabetes among migrant Latino adults. Depth semi-structured interviews. Disease knowledge and understanding was influenced by the social context. The family traditions, central to the Mexican culture, had both positive and negative consequences on diabetes self-management. Both positive and negative impacts of Familism on diabetes self-management were described. Ability to other Hispanic subgroups.
APPENDIX L

GRAPHS AND DIAGRAMS

Diagram 1. Study Assumptions and Research Questions

**Study Assumption 1.** Familism has an effect on T2DM self-care for PRiH adults.

**Study Assumption 2.** PRiH men and women in traditional roles experience the effects of Familism differently.

**Research Question 1:** What is the effect of Familism on self-management of type II diabetes for Puerto Rican identified Adults with Type 2 Diabetes?

**Sub-Questions.**

A. What are the **positive** effects of familism on diabetes self-care for PRiH adults?

B. What are the **negative** effects of Familism on diabetes self-care for PRiH adults?

C. In what ways does Familism facilitate diabetes self-care for PRiH adults?

D. In what ways does Familism inhibit diabetes self-care for PRiH adults?

E. How are PRiH women with T2DM in traditional family roles affected by Familism?

F. How are PRiH men with T2DM in traditional family roles affected by Familism?

-----------------------------------------------------------------------------------------------------------------------------

**Assumption 3.** HCPs do not generally consider Familism as a factor in T2DM self-care.

**Research Question 2:** How can clinicians use Familism to facilitate improved diabetes self-care in Puerto Rican identified Hispanics?

**Sub-Questions.**

G. How can health care providers facilitate the **positive** effects of Familism on T2DM self-care?

H. How do health care providers prevent the **negative** effects of Familism on T2DM self-care?
Diagram 2. Recruitment and Sample

<table>
<thead>
<tr>
<th>RECRUITMENT PHASE</th>
<th>ONE</th>
<th>TWO</th>
<th>THREE</th>
<th>RESULTS VALIDATION</th>
<th>STUDY TOTALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUBJECT TYPE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care</td>
<td>12</td>
<td>30</td>
<td>15</td>
<td>5</td>
<td>62</td>
</tr>
<tr>
<td>Providers</td>
<td></td>
<td></td>
<td>Members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Subjects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individuals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CONSENTED</td>
<td>5</td>
<td>21</td>
<td>5</td>
<td>3</td>
<td>34</td>
</tr>
<tr>
<td>PARTICIPATED</td>
<td>5</td>
<td>12</td>
<td>5</td>
<td>3</td>
<td>25</td>
</tr>
<tr>
<td>TOTALS</td>
<td>n=5</td>
<td>n=12</td>
<td>n=5</td>
<td>n=3</td>
<td>N=25</td>
</tr>
<tr>
<td>Health care</td>
<td>Health care Provider Subjects</td>
<td>Patient Subjects</td>
<td>Community Member Subjects</td>
<td>Non-member Subjects</td>
<td>Total Subjects</td>
</tr>
</tbody>
</table>
Diagram 3. Losses to Attrition

**Losses to Attrition**

- 31 Patient Subjects Recruited
- 21 Consented
- 6 No Show to Research Appointment
- 3 Did Not Return Follow Up Call

$n=12$ Participants.
Diagram 4. Substruction

Substruction: Operationalization of Riegel's Self-Care of Chronic Illness Theory & Diabetes Self-Care

**Theoretical System**

- **DM Self-Care**
  - Component(s)
  - Affected by
  - Familism
    - Familism explored through lived experiences
    - Inhibitor vs. Facilitator
    - How does Familism affect Diabetes Self-Care?
  - DM Self-Care M.M is experienced
  - Perceptual Models: Familism, DM Self-Care, & Self-Care M.M

**Operational System**

- **Descriptive Data**
  - Themes
    - Deductive Analysis
  - Familism is an exclusive Inhibitor vs. Facilitator of Diabetes Self-Care M.M.

DM = Type 2 Diabetes
M.M.M = Management, Maintenance, Monitoring

Diagram 5. Riegel's Self-care Maintenance, Monitoring, Management
Graph 1. Marital Status

Graph 2. Employment Status
Graph 3. Highest Level of Education

Graph 4. Duration of Diabetes Diagnosis
Graph 5. Days of Exercise Per Week

Graph 6. Adherence to Recommended Diet
Graph 7. Adherence to Diabetes Medications

Graph 8. Adherence to Non-Diabetic Medications
Graph 9. Blood Glucose Control

Graph 10. Family Support
Graph 11. Diabetes Management Support

Aggregate Male Female

- No Answer
- Siblings
- Grandchildren
- Friends
- Inlaws
- Church Members
- Nurses
- No Family Support

- Parents
- Children
- Cousins
- Extended Family
- Neighbors
- Doctors
- PCA
- Spouse
BIBLIOGRAPHY


   [http://www.niddk.nih.gov/Pages/default.aspx](http://www.niddk.nih.gov/Pages/default.aspx)


