

Self-management Practices and Perspectives of Spanish-speaking
Older Dominican Adults with Type 2 Diabetes

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Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Public Health
under the Executive Committee
of the Mailman School of Public Health

COLUMBIA UNIVERSITY

2020

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Abstract

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Type 2 diabetes is the fifth-leading cause of death among Latinos in the United States. Diabetes is a commonly occurring health condition in older adults, leading to complications that can severely impact quality of life and hasten death. The burden of diabetes is considerable in the older adult population; almost four-fifths of adults with diabetes are 60 and older. Dying from diabetes can be reduced or delayed with effective management of the illness. Older minority adults are more likely to have higher rates of adult-onset diabetes than non-Hispanic Whites, yet few studies have examined the diabetes self-management practices of this group.

These issues are particularly important to investigate among older Dominican adults in Washington Heights/Inwood, New York City, because this group has unique cultural beliefs and practices, is rapidly increasing in population, and has a variety of unmet health-related needs. This study will explore specific barriers encountered (cultural and structural) and the extent to which external factors are associated with self-management practices among older Dominican community residents living in mainland US with Type 2 diabetes.

After 20 years of health disparities research and intervention older adults continue to have problems accessing health care due to structural and socio-cultural barriers.

This investigation will utilize in-depth interviews to examine the cultural and structural barriers to health care and self-management practices existing in this group. Thirty Dominicans 55 years and older were recruited through a community-based senior resource center from the mainland US. This study will illustrate how cultural and structural (societal) factors inform decisions about self-management practices. Incorporating and understanding factors contributing to health disparities in the Dominican community is invaluable for researchers and health practitioners committed to facilitating diabetes self-management of older adults of Dominican origin.

Programs and services that promote healthy self-management practices of older Latino adults need to include a focus on the unique cultural beliefs and behaviors of the individual as well as the broader situational context that impacts their diabetes self-management. Such information is invaluable for researchers and health practitioners interested in diabetes self-management practices of older minority adults.

Keywords: Type 2 diabetes, Dominicans, Spanish-speaking, older adults with Type 2 diabetes.

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List of Charts, Graphs, Illustrations

Table 1: *Constructs Underlying the In-depth Interview*

Topics/Constructs	Description
(1) Perception of illness	Knowledge of diabetes remains important to diabetes management (Beeney, Dunn, & Welch, 1984). General practitioners who work with patients with Type 2 diabetes claim that communication is hindered by low literacy, lack of proficiency in English, and an excessive respect for physicians (Lipton et al., 1998).
(2) Self-management practices of patients with Type 2 diabetes	Self-management practices are complex and lifestyle-restricting. Routines include diet control, exercise, home glucose testing, and adherence to complex medication regimens, as well as comprehensive care which includes dental, foot, and vision care (ADA, 2011).
(3) Barriers to current self-management practices and when dealing with health providers	Limited research of the patient-provider interactions related to diabetes suggests that the level of patient participation in such interactions is related to self-care. This interaction serves as another important source of information and support for diabetics. Such interactions also affect improvements in glycemic control and patient functioning (Greenfield et al., 1988).
(4) Resources and strengths assisting their management of the illness	Studies indicate that family members caring for older adults with diabetes perform a wide range of diabetes-related care tasks, including glucose testing, medication administration and management, monitoring care recipients' adherence to diet, and skin and wound care. Studies that have examined the relationship between family support and levels of self-care or glycemic control have included few members of the older Latino population (Fisher et al., 2000; Gleeson-Kreig, Bernal, & Woolley, 2002). Most studies on family support and Hispanic adults with diabetes involve young adults between the ages of 19 and 55 (Wen et al., 2004).
(5) Cultural practices for managing their illness	Cultural perceptions can influence how illness is perceived and interpreted, and can also influence the ways in which patients view and manage the disease (Landrine & Klonoff, 1992). Culture-based beliefs may also interfere with compliance to medical treatment recommendations. Some Hispanic Americans consider insulin a last resort and view its use as an indication that they are going to lose their eyesight imminently (Zaldívar & Smolowitz, 1994).
(6) Health services	Elderly Dominicans may or may not have access to health or dental care services to assist them in managing their illness and improve their health status (Wallace & Villa, 2003). This study will explore participants' access and use of health services, and determine if respondents include these as part of their self-management regimens for their illness.

Table 2: *Health Conditions Reported by Study Participants*

Health Conditions	Percentage
High Blood Pressure	66%
Cholesterol	36%
Heart Disease	13%
Depression	10%
Glaucoma	10%
Arthritis	6%
HIV Positive	3%
Acid Reflux	3%
Hernia	3%
Pelvic Cystic Fibrosis (Left Kidney)	3%
Memory loss	3%
Hearing Problems	3%
Gastrointestinal Problems	3%

Table 3: *Socio-Demographic Characteristics of Participants (N=30)*










Characteristics	N
Age (55-84)	\bar{x} 67
Gender	
Male	18
Female	12
Primary Language Preference	
English	1
Spanish	29
Race/Ethnicity	
Hispanic Latino/Latina	28
Dominican (self-identified)	2
Education	
Elementary	13
High School	15
Less than four years of college	2
College/University	0
Graduate School	0
Place of Residence	
Home	1
Apartment	29
Nursing Home	0
Community Residence	0
Other	0
Who lives with you?	
Alone	8
Grandchildren	1
Spouse	11
Family members	9
Children	1
Other	0
Employment Status	
Full-time employed	0
Part-time employed	2
Seeking employment	0
Stay-at-home older adult	0
Retired	28
Health Insurance	
Only Medicaid	5
Only Medicare	9
Both Medicare and Medicaid	9
Medicare and Private	2
Private Insurance	1
Health Maintenance Organization (HMO)	1

Other N/A	3
Health Status	
Regular	9
Good	13
Poor	3
Fair	4
Not that good	1
Length of Time in the US	
Less than 5 years	0
Between 5 and 10 years	0
More than 10 years	30
Length of Time with Type 2 Diabetes	
Recent Diagnosis (one year or less)	2
Less than 5 years	8
Between 5 and 10 years	7
More than 10 years	13

Table 4: *The Acculturation Scale*

Questions in Acculturation Scale (N=30)	Percentage	Response
Language Use and Ethnic Loyalty		
1. In general, what language(s) do you read and speak?	60%	“Only Spanish”
2. What was the language(s) you used as a child?	93%	“Only Spanish”
3. What language(s) do you usually speak at home?	86%	“Only Spanish”
4. In which language(s) do you usually think?	63%	“Only Spanish”
5. In general, what language(s) do you speak with your friends?	86%	“Only Spanish”
Media		
6. In what language(s) are the TV programs you usually watch?	43%	“Only Spanish”
7. In what language(s) are the radio programs you usually listen to?	77%	“Only Spanish”
8. In general, in what language(s) are the movies, TV and radio programs you prefer to watch and listen to?	37%	“Only Spanish”
Ethnic Social Relations		
9. Your close friends are:	56%	“All Latinos/Hispanics”
10. You prefer going to social gatherings at which the people are:	43%	“All Latinos/Hispanics”
11. The persons you visit or who visit you are:	53%	“All Latinos/Hispanics”
12. If you could choose your children’s friends, you would want them to be:	43%	“More Latinos than Americans”

Table 5: Examples and Illustrations of Home/Folk Remedies for Type 2 Diabetes

<i>Nombre</i>	Name	Prepared	Image
1. <i>Jengibre</i>	Ginger	Tea	
2. <i>Melaza</i>	Molasses	Tea	
3. <i>Sábila y Piña</i>	Aloe vera and Pineapple	Juice	
4. <i>Avena</i>	Oats	Juice	
5. <i>Dieta de Leon</i>	Herb	Tea	
6. <i>Malegueta</i>	Chile	Tea	
7. <i>Malanga</i>	Root	Tea	
8. <i>Noni</i>	Fruit	Juice	
9. <i>Palo de Brasil</i>	Brazilwood	Tea	







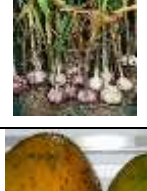


<i>10. Chayote/Tayota</i>	Squash	Juice	
<i>11. Té negro</i>	Black tea	Tea	
<i>12. Sepa de Jericó</i>	Root	Tea	
<i>13. Chinola</i>	Fruit	Tea	
<i>14. Clavo Dulce</i>	Cloves	Tea	
<i>15. Café con Limon</i>	Coffee with Lemon	Coffee	
<i>16. Perejil</i>	Parsley	Tea	
<i>17. Ajo</i>	Garlic	Tea	
<i>18. Naranja Agria</i>	Bitter Orange	Tea	

Table 6: *Overview of Older Dominican Adults Explanatory Model of Type 2 Diabetes*

Cause	Symptom	Treatment	Social Context
Diet *	Fatigue *	Medications *	Family support *
Emotional *	Weakness *	Home remedies *	Relationship with provider
Hereditary *	Sweat	Non-prescription medication	Support from community resources
Culture	Shakes		

* Factors most reported by study participants (Diaz-Román, 2012).

Research Questions:

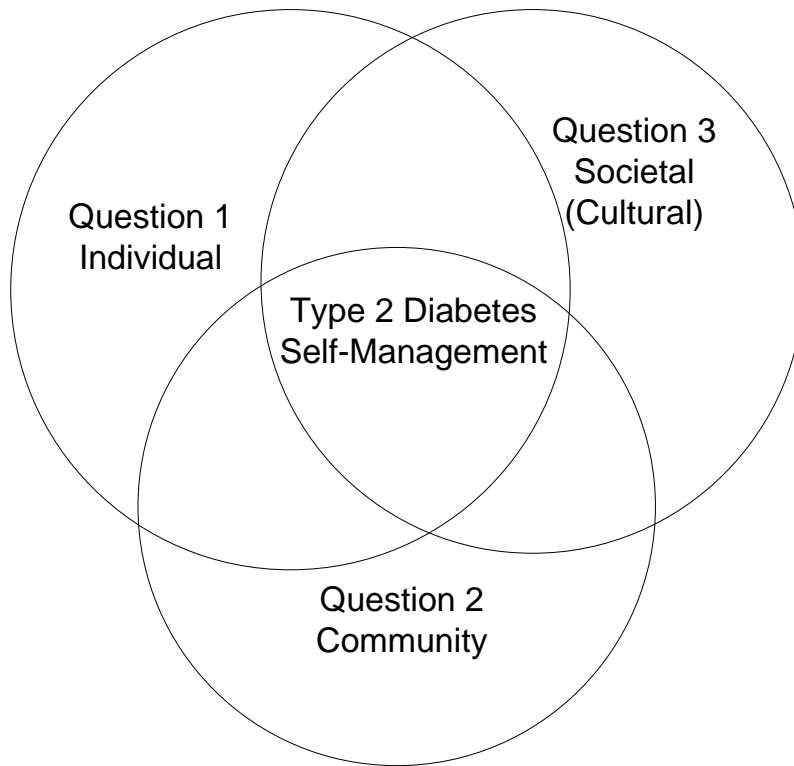


Figure 1. Diagram Illustrating the Research Questions

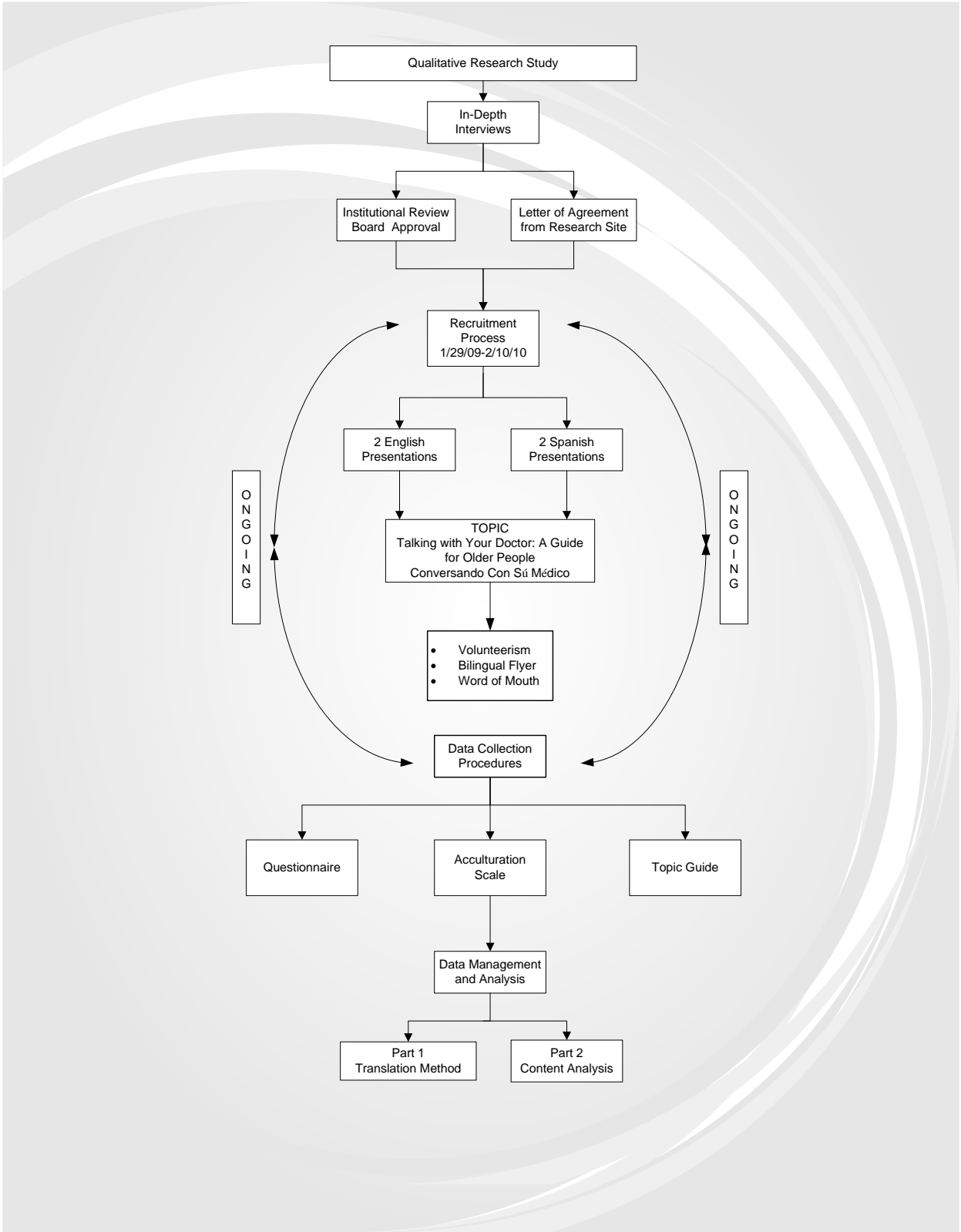


Figure 2. Design and Implementation Model of the Study

Acknowledgments

Many people in my life made this doctoral program a reality for me. I begin by thanking my sponsor, Dr. Victoria H. Raveis, for her guidance, support, and confidence during this process. Life happens when you complete a doctoral program, and my experience was no exception. My sponsor understood all the challenges that come with marriage, parenthood, and a move to California in 2010, but most importantly she never gave up on me. This is the type of support doctoral students need to successfully complete a dissertation. For these reasons and many more, I am forever grateful to Dr. Raveis, my sponsor and mentor.

I am also grateful to Dr. Ngina Lythcott who introduced me to Columbia's Mailman School of Public Health and to the endless research opportunities in the field of public health. Thank you also to Dean Linda P. Fried, Dean Marlyn Delva, Lillian Morales, and Farah Burnett in the Office of Student Affairs for your support and guidance during this process.

I thank Dr. Carol Kunzel for serving as a Co-Chair and mentor on my committee. Your support and guidance began the day we began to work together at Columbia's College of Dental Medicine in the Section of Social and Behavioral Science in 2001.

Many thanks to Dr. Giuseppe Costantino, who began to work with me during the dissertation stage and instantly became a key member of my dissertation committee. I appreciate the time you took to Skype with me after the big move to California. Your presence, despite the distance, motivated and inspired me to work hard to the finish line.

My gratitude also extends to Drs. Helen-Maria Lekas and Keville Frederickson, for their commitment as committee members to my doctoral studies and research endeavors.

This dissertation would not have been possible without my parents, Luis H. Diaz and Martha Y. Diaz. Your vision and aspiration for a better life gave me the opportunity to reach my

dreams and goals in the United States. Thank you for your support and encouragement during my doctoral studies.

Special thank you to my siblings, Melissa Diaz-Lee, Pamela Diaz-Nevsky, and Gregory Diaz, and to my friends and colleagues in New York: Dr. Elaine Walsh and Paula Wicklow of Hunter College City University of New York, as well as Charlotte Mejia, Janine Ting-Jansen, Jenny Alcaide, and Alex Mendez. Likewise, I am sending a special thank-you to the participants in my study, and especially to Judy Nunez, Ariselda Jones, and Carol Ban of the Isabella Senior Resources Center for your support and guidance during the implementation of this study. I also thank my friends Tiphani Burrell-Piggott and Carmelita Reyes Samuel for your long-distance love and support during this process.

I have not forgotten the words of encouragement and prayers from my aunts: Lucero Diaz, Blanca Garcia, and Luz Dalia Diaz. I send a special thank-you to my mother-in-law, Maria Socorro Román, who provided love and support during the entire process, and to the Román family in Medford, New Jersey.

Last but not least, my dissertation could not be completed without the love and support of my family. I send a special thank-you to Ricardo Román, my husband, for his support during this process, and to Marcus A. Román, our son, for his unconditional love and sweet words of encouragement every day.

I am especially thankful for the opportunity to complete my doctoral studies with the support from The Allan Rosenfield Scholars Fund and the National Institutes of Health's Initiative for Maximizing Student Diversity. Thank you for supporting my doctoral studies.

Dedication

My dissertation is dedicated to Edilma Lopez-Diaz, my grandmother; to Luis H. Diaz, my dad; and to Marcus A. Román, my son and inspiration.

Introduction

In the United States today, it is likely that everyone either has diabetes or knows someone who has been medically diagnosed with diabetes. Diabetes remains a public health challenge and a growing epidemic worldwide (American Diabetes Association [ADA], 2006). Diabetes ranks as the seventh-leading cause of death in the United States (US), based on 2007 death certificates, and is a major cause of heart disease and stroke (Centers for Disease Control and Prevention [CDC], 2011). Although diabetes is likely to be underreported as a cause of death, an estimated 35-40% of death certificates show that the person had diabetes, and about 10-15% report diabetes as the cause of death (CDC, 2011). In addition, the risk of mortality among people with diabetes is about twice that of people of similar age but without diabetes. Furthermore, diabetes is a costly disease. In 2007, estimated direct and indirect costs of diabetes totaled \$174 billion, and medical expenses for people with diabetes are more than two times higher than for people without diabetes (CDC, 2011). A diagnosis of diabetes can lead to serious complications and premature death, but people with diabetes can take steps to control the disease and lower the risk of complications (The National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2007).

In addition to high mortality rates and soaring medical expenses, diabetes causes serious health complications throughout the body. Diabetes is the leading cause of kidney failure, non-traumatic lower-limb amputations, and blindness among adults in the US (CDC, 2011). Diabetes continues to command our attention for several reasons. In 2010, 10.9 million (26.9%) of US residents 65 years and older had diabetes. Furthermore, an estimated 215,000 people age 20 or younger had diabetes (Type 1 or Type 2) in the US in 2010 (CDC, 2011).

Among people age 20 or older, 1.9 million were recently diagnosed with diabetes in the US (CDC, 2011).

An estimated 25.8 million Americans (8.3% of the population) have diabetes, of which 18.8 million cases have been diagnosed and 7.0 million cases remain undiagnosed (CDC, 2011). According to the CDC, diabetes has been characterized by high levels of blood glucose resulting from defects in insulin production, insulin action, or both (CDC, 2011). People with diabetes have several treatment options, but there is no known cure. In most cases, diabetes in general is poorly controlled, and regimens to manage the disease effectively are complex and require drastic lifestyle changes. Lack of exercise, poor diet, and poor prescription adherence are all potential risk factors for diabetes, but these factors are greatly influenced by patients' understanding of the disease itself, the benefits and risks of treatments, as well as patients' beliefs about their particular diabetic condition (Mensing, Boucher & Cypress, 2006).

In terms of race and ethnicity, diabetes continues to be a major public health crisis, disproportionately affecting older minority populations, particularly Hispanics/Latinos. National survey data (2007-2009) for people age 20 and older report that 7.1% of non-Hispanic whites, 8.4% of Asian Americans, 11.8% of Hispanics, and 12.6% of non-Hispanic blacks had diagnosed diabetes (CDC, 2011). Further, among Hispanics, the highest rates were for Mexicans (13.3%), Puerto Ricans (13.8%), and Cubans and Central and South Americans (7.65%) (CDC, 2011).

There are two types of diabetes: Type 1 and Type 2. Type 1, formally known as insulin-dependent diabetes mellitus (IDDM) or juvenile diabetes, accounts for 5-10 % of all diagnosed cases (CDC, 2011). Type 1 is caused by a deficiency in the pancreatic secretion of insulin, and occurs mostly in children or young adults (CDC, 2011). Approximately one in every 400 to 600 children and adolescents has Type 1 diabetes. Moreover, approximately two million adolescents

age 12-19 have pre-diabetes (CDC, 2011). Risk factors for Type 1 diabetes may include autoimmune, genetic, and environmental (CDC, 2011). Children who are not treated early tend to grow into adults with diabetes. Symptoms of Type 1 diabetes may include increased thirst and urination, constant hunger, weight loss, blurred vision, and extreme fatigue, usually developing over a short period of time (ADA, 2011). Among adults with diagnosed diabetes (Type 1 or Type 2), 16% take insulin only, 12% take insulin and oral medication, 57% take oral medication only, and 15% take neither insulin nor oral medication (CDC, 2011). Individuals with Type 1 diabetes are insulin-dependent and must have insulin delivered by injection or pump (CDC, 2011). Treating Type 1 diabetes involves a multi-faceted approach which can vary for each individual and change over time.

Type 2 diabetes, formally known as non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset, accounts for 90-95% of all diagnosed cases of diabetes, and in recent years is being diagnosed more frequently among minority groups, including Hispanic/Latino Americans (CDC, 2011). Type 2 diabetes occurs when the body does not make enough insulin or cannot effectively use the insulin it makes (NIDDK, 2007). Symptoms of Type 2 diabetes include feeling tired or ill, unusual thirst, frequent urination especially at night, weight loss, blurred vision, frequent infection, and slow-healing of wounds. Type 2 diabetes may develop gradually and may not be as noticeable as Type 1 diabetes (ADA, 2008). Individuals with Type 2 diabetes can monitor their blood glucose levels by following a healthy diet, exercise program, losing excess weight, and taking medications (CDC, 2011). Type 2 diabetes is also associated with older age, obesity, family history of diabetes, history of gestational diabetes, impaired glucose metabolism, lack of physical activity, and race/ethnicity (CDC, 2011). Specifically, African Americans, Hispanic/Latino Americans, American Indians, and some Asian Americans, Native

Hawaiians, or other Pacific Islanders are particularly at risk for Type 2 diabetes and its complications (CDC, 2011). Type 2 diabetes is being diagnosed more frequently among children and adolescents, especially among American Indians, African Americans, Hispanic/Latino Americans, and Asians/Pacific Islanders (CDC, 2011).

Diabetes and Other Co-morbidities

Having diabetes can seriously impact the way people live with and manage other co-morbidities. In the classic Framingham study, Kannel and McGee (1979) reported that people diagnosed with diabetes have an increased risk of cardiovascular morbidity and mortality. Further, individuals with diabetes have an increased risk of congestive heart failure (Kannel & McGee, 1979). In addition to cardiovascular disease, having diabetes also increases the risk of having a stroke. The risk for stroke is two to four times higher among people with diabetes (CDC, 2011). For adults age 20 or older with self-reported diabetes, 67% had blood pressure greater than or equal to 140/90 millimeters of mercury or used prescription medication for hypertension (CDC, 2011). Further, among adults age 20-74, diabetic retinopathy causes 12,000 to 24,000 new cases of blindness each year (CDC, 2011). In 2008, diabetes was also the leading cause of kidney failure, accounting for 44% of new cases. That same year, 48,374 people with diabetes began treatment for end-stage kidney disease (CDC, 2011). Individuals in the US and Puerto Rico with end-stage kidney disease due to diabetes were living on chronic dialysis or with a kidney transplant (CDC, 2011).

Diabetes also affects the central nervous system, causing approximately 60-70% of mild to severe forms of damage (CDC, 2011). This results in impaired sensation or pain in the feet or hands, slowed digestion of food in the stomach, carpal tunnel syndrome, and other complications (CDC, 2011). An estimated 30% of people 40 years or older with diabetes have impaired

sensation in the feet. More than 60% of non-traumatic lower-limb amputations occur in people with diabetes (CDC, 2011). According to CDC (2011), about 65,700,000 non-traumatic lower-limb amputations were performed in people with diabetes in 2006.

Finally, periodontal (gum) disease has been often linked to the control of diabetes (ADA, 2008; Borrell, Kunzel, Lamster & Lalla, 2007). Almost one-third of people with diabetes have severe periodontal disease with loss of attachment of the gums to the teeth measuring five millimeters or more (CDC, 2011). However, an individual with Type 2 diabetes may or may not always have access to a dentist or use dental services to manage their condition, especially if they lack dental insurance. Yet research studies demonstrated that dental care has been associated with identifying and screening for undiagnosed diabetes (Lalla, Kunzel, Burkett, Cheng & Lamster, 2011; Ship, 2003).

Chapter 1: Diabetes Self-management

Self-management activities related to Type 2 diabetes are complex, lifestyle-restricting, and require that many issues beyond glycemic control need to be addressed (ADA, 2006). Treatment of older adult with diabetes must take into consideration not only the feasibility of recommended medical regimens, but also conditions of cognitive and physical impairment, falls, and other age-related conditions (Chau, Shumaker & Plodkowski, 2003; Rosenstock, 2001). Understanding self-management practices for older Latino adults with Type 2 diabetes, in particular, requires a heightened awareness of cultural norms, sensitivity to health beliefs and practices, and recognition that each group is different although some characteristics are shared. For older adults with Type 2 diabetes, self-management requires careful consideration of the effects that age and changes in health status can have on effective therapeutic intervention (Wallace & Villa, 2003). Reducing the risk of diabetes-related complications for the older Latino population may require ongoing medical monitoring and consideration, and involvement of family members in diabetes self-management activities. Lipton, Losey, Giachello, Mendez and Girotti (1998) reported that family needs were considered most important to Latino patients in treatment and adherence to treatment regimen.

In 2007, the American Association of Diabetes Educators (AADE) declared the need to respect “lay perspectives” and “health beliefs” about diabetes across ethnic groups in order to comprehend the context in which the individual is managing their illness. In addition, the AADE recommended a less conventional approach to diabetes management when treating culturally diverse populations, and a full understanding of how culture, belief, and practices of the individual can influence all levels of effective disease management and practices (AADE, 2007). Without careful consideration and heightened awareness of all factors which can influence self-

management practices, the more challenging it will be to assist individuals from a group that is disproportionately affected by the illness.

In the case of the Hispanic/Latino community, *la Familia*, the family as well as the extended family, is central to a person's identity and can influence how individuals manage chronic health illnesses (Sotomayor & Garcia, 1999; Wen, Shepherd, & Parchman, 2004). The roles of *La Familia* and other cultural beliefs and practices are often overlooked in diabetes care for Hispanic women (Oomen, Owen, & Suggs, 1999). But as Burgos-Ocasio (1996) emphasizes, "All family members are recognized for their contribution to the well-being of the entire family." A study on the effectiveness of family interventions for people with diabetes also suggests that family can play a significant role in managing diabetes for children, adolescents, and adults, particularly when disability exists (Armour, Norris, Jack, Zhang, & Fisher, 2005; Fisher et al., 2000). This is because family members are affected emotionally, cognitively, and behaviorally, and can play a major role in influencing health behaviors and practices (Armour et al., 2005; Fisher et al., 2000; Patterson, 2002).

Because diabetes self-management can be restrictive, complex, and require lifestyle changes, adherence and compliance can be extremely challenging for an older adult of Latino background who speaks only Spanish, for example.

1.1 Factors influencing effective self-management of Type 2 diabetes.

The older adult Hispanic/Latino community in the US shares a common language of Spanish, but each group in the community may represent a different Spanish dialect. Each group also has distinct experiences and values which makes them unique. They come from diverse cultural backgrounds, and their experiences as native and foreign-born older adults vary as well. Furthermore, their assimilation and acculturation process varies, and no groups have the same

exact experience. For these reasons, it is pertinent to understand the general facts about the community as a whole and be informed of the differences that exist within each group.

Several common factors have been associated with the older adult Hispanic/Latino populations in the US. Older Latino adults living in the US have less education (60% have less than a ninth-grade education) compared to their counterparts (Wallace & Villa, 2003). In addition, low levels of education and high prevalence of low literacy and illiteracy present a significant challenge for an older adult trying to understand an illness and adhere to appropriate care practices (Rosal et al., 2005). With little education background and low literacy skills, the older Latino adult may have to rely on forms of support, including family, but this experience may not always be a positive one.

Family members are important for older Latino adults and can be associated with how an older adult manages their diabetes. Fisher et al. (2000) explained that family characteristics can also present negative outcomes when it comes to disease management. Fisher and colleagues have argued that “family characteristics” have demonstrated consistently negative relationships with chronic disease as a result of “low family cohesion,” “high family conflict,” “too rigid or too permeable generation boundaries,” “low levels of family organization,” “hostile family,” “lack of clear communication,” and “low spouse involvement.”

In addition to the level of education and family relationships, other factors can easily influence one’s ability to effectively carry out self-management practices. These factors can also include knowledge and understanding of an illness and how it is managed. Mann, Ponienan, Leventhal, and Halm (2009) explored this topic among low-income minorities with diabetes. Results from this study show that despite length of time with illness and ongoing care for the diabetes, participants preserved beliefs regarding disease and medication that were inconsistent

with a chronic disease model of diabetes (Mann et al., 2009). These findings shed light on why disease management compliance may be more challenging for disproportionately under-represented minority groups. Furthermore, participants in this study also revealed several misconceptions about the illness, such as going to the doctor will cure diabetes, and an unclear understanding of their A1C count (Mann et al., 2009). The A1C test measures a patient's average blood glucose control for the past two to three months (ADA, 2011).

Another frequent misconception when it comes to diabetes is related to the interpretation of glucose levels. In this study (Mann et al., 2009), participants disclosed different interpretations of their glucose levels, demonstrating a lack of understanding and comprehension of what the levels represent and how they should be interpreted.

To date, research on self-management practices of older adults of Dominican origin with Type 2 diabetes has been limited and has focused primarily on Mexican Americans, with few studies exploring Puerto Rican/Caribbean populations of Latinos residing in the northeastern part of the US (Rosal et al., 2005; Tucker, Bermudez, & Castaneda, 2000; von Goeler, Rosal, Ockene, Scavron, & De Torrijos, 2003). As such, few studies have examined the self-management practices of older Dominican adults living in the United States, and even fewer have explored traditional beliefs and practices used by Dominicans in Washington Heights/Inwood to manage their Type 2 diabetes. Most studies on older adults of Hispanic/Latino background have focused on the three major groups: Mexicans, Cubans, and Puerto Ricans (Paulino, 1998). For these reasons, these issues merit investigation and further understanding of Dominican older adults who have unique cultural beliefs and practices, and whose numbers are rapidly increasing in the United States (Dockterman, 2011; Paulino, 1998).

1.2 Factors Contributing to the Growth of Diabetes in the US

Changes in diagnostic criteria. During the past two decades, there have been three important changes in the diagnostic criteria for diabetes. First, in 1997, the ADA's International Expert Committee of the American Diabetes Association made recommendations to lower the diagnostic criteria for diabetes from 140 mg/dl to 126-139 mg/dl when measured by a Fasting Plasma Glucose (FPG) test (Gregg et al., 2002). Lowering the threshold allowed for detection and diagnosis of diabetes in the early stages of the disease. In addition, the Expert Committee recommended new criteria for glucose at high levels, in the range of 110-125 mg/dl (impaired fasting glucose) when measured by an FPG, and the range of 140-199 mg/dl (Impaired Glucose Tolerance) when measured by an Oral Glucose Tolerance test. This illustrates how newly established or impaired glucose levels can progress easily and help to identify early stages of diabetes.

Then, in 2002, the US Department of Health and Human Services (USDHHS) and the ADA announced the adoption of the term "pre-diabetes" to describe ranges of impaired glucose levels and more clearly underline the severity of the condition (USDHHS, 2002). According to A1C levels, 35% of US adults age 20 and older had pre-diabetes (50% of those age 65 or older). In 2003, the International Expert Committee of the American Diabetes Association decreased the diagnosis criteria of pre-diabetes (Impaired Fasting Glucose) from 110 mg/dl to 100 mg/dl when using an FPG test. This resulted in diagnosing pre-diabetes when levels fell between 100-125 mg/dl. The establishment of a lower threshold for diabetes resulted in the identification of millions of additional people at increased risk for developing the disease (National Alliance for Hispanic Health [NAHH], 2010). Consequently, under the new criteria the number of adults with pre-diabetes doubled from 20 to 41 million (NAHH, 2010).

Growth and aging of the population. The anticipated growth of the older adult population in the US is another important factor when thinking about why the prevalence of diabetes continues to rise. Currently, the older adult population is increasing dramatically, from only 3 million in 1900 to 39 million in 2008 (Federal Interagency Forum on Aging-Related Statistics [FIFARS], 2010). By 2030, the older adult population will be “twice as large as their counterparts” in comparison to 2000, and potentially increase from 35 million to 72 million and represent nearly 20% of the total US population (FIFARS, 2010). Currently, the older adult population in the United States is growing rapidly and is more diverse than ever before. Baby boomers (born between 1946 and 1964) began turning 65 in 2011, and will hasten this growth dramatically. This segment of the population is better educated than their predecessors and more racially diverse (FIFARS, 2010).

Another factor to ponder is the increase in the older minority population. In 2008, non-Hispanic whites accounted for 80 percent of the US older population, followed by African Americans (blacks, 9%), Asians (3%), and Hispanics (7%) (FIFARS, 2010). By 2050, the demographic profile of the US will have changed drastically. The older adult population will be 59% non-Hispanic white, 20% Hispanic, 12% black, and 9% Asian (FIFARS, 2010). The increase in population among older adults of Hispanic/Latino background will require attention to health care issues of older Americans, especially Hispanics/Latinos, and this will become a burgeoning concern to both medical and mental health professionals (Costantino, Malgady, & Primavera, 2009).

1.3 Racial and Ethnic Profile of the Older Adult Population

As projected, all racial and ethnic groups are expected to increase, but the largest rise will occur among the Hispanic/Latino population. Currently, the Hispanic population accounts for

50.5 million, or 16.3% of the US population (Ennis, Rios-Vargas, & Albert, 2011). According to the 2010 Census and an analysis conducted by the Pew Hispanic Center, the number of Hispanics counted was 1 million more than expected (Passel & Cohn, 2011). These data illustrate a 43% increase from the 2000 Census, where Hispanics represented 35.5 million of the US population. Between 2000 and 2010, the Hispanic population also represented the largest growth in terms of population for the country (Passel & Cohn, 2011). Further, the Hispanic youth population constitutes 23% of the nation's youth under 18 and is growing at a much faster rate than their counterparts, according to these new data (Ennis et al., 2011).

Further, the Hispanic/Latino older adult population is projected to grow the fastest, from an estimated 3 million in 2008 to 17.5 million in 2050 (FIFARS, 2010). That new older Hispanic/Latino population will most likely experience a higher degree of chronic medical and mental health problems than their older cohorts, suggesting that for Hispanics/Latinos, the biological aging process starts at an earlier age (Costantino et al., 2006). These projections will also require further study and flexibility when thinking about how to develop public health policies and programs in the future, especially for Hispanics with diabetes.

A variety of factors, as described above, contribute to the rapid increase of diabetes in the United States (McBean, Li, Gilbertson, & Collins, 2004). And these factors also propel us to think about how they will influence future public health research with the aging population in the US.

Chapter 2: Diabetes and Hispanics/Latinos

As the Hispanic/Latino population continues to increase in the United States, diabetes rates are rising too. Current figures show that 11.8% of Hispanics/Latinos 20 years and older were diagnosed with diabetes (ADA, 2011; CDC, 2011). Among Hispanic/Latino sub-groups, rates for diagnosed diabetes were 7.6% for Cubans, 13.3% for Mexican Americans, and 13.8% for Puerto Ricans (CDC, 2011). Mexican Americans, the largest Hispanic/Latino subgroup, are almost twice as likely as non-Hispanic whites to be diagnosed with diabetes by a physician. Further, they have higher rates of end-stage renal disease caused by diabetes, and they are 50% more likely to die from diabetes than non-Hispanic whites. Finally, Mexican Americans are 1.9 times more likely than non-Hispanic white adults to have been diagnosed with diabetes by a physician. In 2006, Hispanics were 1.7 times as likely to start treatment for end-stage renal disease related to diabetes, compared to non-Hispanic white men (CDC, 2010)

Diabetes rates among the largest racial and ethnic groups are readily available and accessible on a national level; however, information for every Hispanic group in every county/city in the US is difficult to obtain. Focusing on the top ten states with the largest Hispanic population can assist in obtaining updated diagnosed diabetes rates (NAHH, 2010).

According to 2010 census data, the largest Hispanic population (4.7 million) resides in Los Angeles County (Passel & Cohn, 2011). Further, the ten states with the largest Hispanic populations are, in descending order: California, Texas, Florida, New York, Illinois, Arizona, New Jersey, Colorado, New Mexico, and Georgia (Passel & Cohn, 2011). CDC data from a 2008 Behavioral Risk Factor Surveillance Survey (BRFSS) demonstrated that the prevalence rate of diagnosed diabetes was greater for Hispanics than non-Hispanic whites in seven out of ten states: Arizona, California, Colorado, Georgia, New Jersey, New Mexico and Texas (NAHH,

2010). A similar study by the CDC focusing on six US geographic locations with high Hispanic population from 1998-2002 suggested that diabetes disproportionately affects Hispanics, depending on where they reside, and this can influence how diabetics manages their lives (CDC, 2004; NAHH, 2010).

In a highly cited study published in 2003 in the *Journal of the American Medical Association*, Venkat Narayan and colleagues reported that the lifetime risk for developing diabetes is higher for Hispanic women than for non-Hispanic women, and is also higher for Hispanic men compared to non-Hispanic men. Further, the study stated that Hispanic women born in 2000 have a 52.5% risk of developing diabetes in a lifetime compared to non-Hispanic white women (31.2%). Finally, Hispanic males also have a higher risk (45.4%) of being diagnosed with diabetes in their lifetime, compared to non-Hispanic white men (Venkat Narayan, Boyle, Thompson, Sorensen, & Williamson, 2003).

In 2006, diabetes was the fifth major cause of death for Hispanics, while it was the seventh-leading cause of death for non-Hispanic whites (NAHH, 2010). Furthermore, Hispanics are 1.6 times more likely to die from diabetes as non-Hispanic whites, making this chronic illness much more complex and deadly for all Hispanic groups (NAHH, 2010).

Current and future rates of diagnosed diabetes among Hispanics in the US depict a grim and unstable health outlook in years to come, and more information is needed on subgroups within the Hispanic population because they are rapidly growing in the United States. Researchers Smith and Barnett (2005) and Aponte (2009) have studied Mexican Americans separately and discovered variations in diabetes and in diabetes risk factors, demonstrating a need to disaggregate diabetes data by specific Hispanic subgroups. Smith and Barnett's research

(2005) demonstrates diabetes-related mortality differences among Mexican Americans, Puerto Ricans, and Cuban Americans 35 years and older between 1996 and 1997.

So why are Hispanics/Latinos disproportionately more susceptible to diabetes? What are the risk factors and why are they more likely than their counterparts to develop Type 2 diabetes in their lifetime?

2.1 Diabetes Risk Factors for Hispanics

Although there is no known cure, Type 2 diabetes can be prevented, but several risk factors make some groups more susceptible than others. Race/ethnicity, for example, is one of the known and recognized risk factors for Type 2 diabetes which makes members of the Hispanic population more susceptible to chronic illness. Other known risk factors for Type 2 diabetes include: age, obesity, family history of diabetes, history of gestational diabetes (CDC, 2011). In addition, poor diet, low levels of physical activities, high cholesterol levels, and high blood pressure have also been highlighted as risk factors for Type 2 diabetes (NAHH, 2010).

Obesity, a complex risk factor directly associated with diabetes, is medically described as having a Body Mass Index of 30 or more and is known to significantly increase the probability of acquiring diabetes and/or worsen its associated diabetes (NAHH, 2010). During the past few decades, the rates of obesity have risen drastically in the United States. In the case of Hispanics/Latinos, the rate of obesity in those aged 18 and over increased from 16.8% in 1995 to 26.5% in 2005 (NAHH, 2010). Several factors have been identified as increasing obesity rates among youth in the US: Improper diet (at home and school), a sedentary lifestyle (lack of exercise /physical activity), and lack of quality health care to monitor the condition and its complications appropriately and accurately (Peart, Velasco Mondragon, Rohm-Young, Bronner, & Hossain, 2011). In 2007, the USDHHS reported that Hispanics/Latinos were less likely to eat

five or more servings of fruits and vegetables per day than non-Hispanic whites in eight of ten states with the largest Hispanic populations, and less likely than non-Hispanic whites and blacks in six of these states (USDHHS, 2007). A combination of genetic, environmental, and lifestyle factors increases the Hispanic population's risk of Type 2 diabetes, but effective self-management practices (culturally specific for the community) can increase a person's ability to live a healthy and positive lifestyle.

2.2 Dominicans in the US.

Dominicans have been settling to the United States since the 19th century. One of the most famous early settlers was Mercedes Sagredo, a songwriter who arrived in a steamship in 1929 and who joined about 350 other Dominicans living in New York City (Hoffnung-Garskof, 2008). When Ms. Sagredo published her famous song "Del burro al subway" in 1962, approximately 15,000 Dominicans were in New York City, including those who had arrived in the time of Trujillo's death (Hoffnung-Garskof, 2008). In "A Tale of Two Cities: Santo Domingo and New York after 1950," Professor Hoffnung-Garskof (2008) explains that the large-scale migration from the Dominican Republic began after dictator Rafael Trujillo died in 1961. The large wave of migration was heavily influenced by several factors, including, but not limited to 1) the direct intervention of the United States in Dominican affairs during the transition to democracy, 2) the invasion of Santo Domingo in 1965, and 3) the support for the authoritarian regime of Joaquin Balaguer from 1966 to 1978 (Hoffnung-Garskof, 2008).

According to Dockterman (2011), (79%) of Dominicans reside in the Northeast and 50% of those live in New York. Moreover, most immigrants from the Dominican Republic arrived in the US in 1990 or later, and nearly half (47%) are US citizens (Dockterman, 2011).

In 2006, US census data showed the large concentration of Dominicans ever in the states: New Jersey (167,689), Florida (136,891), Massachusetts (83,700), Pennsylvania (36,091), Rhode Island (30,876), and Connecticut (17,213). These data represent states with 10,000 or more Dominican Americans. In 2006, the Dominican population numbered at 1,217,225 (NAHH, 2010). It is important to illustrate where Dominicans have settled, as well as their numbers in the US and their demographic profile.

According to the 2010 Census, 308.7 million people reside in the United States, of which 50.5 million (16%) are of Hispanic/Latino origin (Ennis et al., 2011). Dominicans, members of the Hispanic/Latino community, comprise 1.4 million (2.8%) and continue to represent the fifth-largest Hispanic/Latino group in the country (Dockterman, 2011; Ennis et al., 2011). During the 1980s Dominican immigrants comprised one of the fastest growing and largest immigrant groups to settle in New York City (Caro-López & Limonic, 2010; Cordero-Guzmán & Grosfoguel, 2000). In 2000, Dominicans accounted for 3% of the total Hispanic population in the US, but data from the 2010 Census revealed that the Dominican population grew by 85%, almost doubling from 765,000 in 2000 to 1.4 million in 2010 (Ennis et al, 2011). In addition, approximately six out of ten Dominicans (57.3%) are foreign-born, compared with 38.1% of Hispanics and 12.5% of the US population overall.

In terms of age, Dominicans are younger than the US population and older than Hispanics overall. The median age of Dominicans is 29 compared to 36, the median age of the US population, and 27 for Hispanics. The ability to communicate is essential, especially for foreign-born individuals. With respect to language, a majority (53%) of Dominicans speak English proficiently, and almost 47% of Dominicans age 5 and older report speaking English less than very well (Dockterman, 2011).

When it comes to education, 15% of Dominicans 25 and older have obtained a bachelor's degree, in contrast to 13% of Hispanics (Dockterman, 2011). Meanwhile, 8.3% of Dominicans 65 years and older have obtained a bachelor's degree compared to 9% of the overall Hispanic population 65 years and older (Eaton et al., 2008).

In studies on Spanish-speaking older adults with diabetes, several researchers found that the high prevalence of low literacy rates among Hispanic groups presents a challenge to the appropriate understanding of diabetes management (Rosal et al., 2005; Therrien & Ramirez, 2001). When it comes to education, it is important to understand that national estimates for the US do not always reflect the education experiences of all foreign-born older adults. For these reasons, it is pertinent to process this information in terms of when and where Dominicans have settled in the US in order to understand and know this community better.

Many older adults in Dominican households are influential as grandparents, primary caregivers, and even decision makers. Burnette (1997) describes an older adult who is involved in the family as a "source of support, conflict, and/or burden, or both." And these identities/roles can be influenced by how much involvement the older adult has in the family. In this capacity, an older adult may have multiple responsibilities in the family that extend outside their role as grandparents and caregivers. Paulino (1998), for example, describes the older Dominican adult as a member of the family who is most likely helping to raise grandchildren, maintaining a household (while adult children work), taking care of other family members including a spouse or their family members, and even making decisions for the family. Burnette's 2009 research demonstrates that 1.4 million Latino (8%) lived with their grandchildren, and 32% of older adults serve primarily as caregivers (Burnette, 2009).

Data collection for people of Dominican origin continues to be a challenge, but improvements have been made. Historically, people of Dominican origin have either been excluded from large data samples or lumped into the large Hispanic category, which includes Mexicans, Cubans, and Puerto Ricans, but this limits their ability to be counted separately or be included in nationwide statistical reporting. The anticipated growth of the Dominican population in the United States will change and influence the way researchers gather information for members of this community.

Since 1970, the Census has collected data for the Hispanic population, but many changes have occurred since then to improve the quality of data for this population. The 2010 Census had three important changes for the Hispanic origin question. The most pertinent change for the Dominican community was the inclusion of Dominicans in the example of six groups listed for the Hispanic population (Ennis et al., 2011). This important change and community recognition helped to improve the quality of data collection for the Hispanic population as well.

Although Dominicans continue to represent a large number of foreign-born residents, many Dominicans are born in the United States. According to the Pew Hispanic Center, 47% of Dominicans are US-born citizens (Dockterman, 2011). Data-gathering continues to be a challenge, especially among recent immigrants, but the Pew Research Center offers an interesting perspective on foreign-born Dominicans.

According to the Pew Research Center, foreign-born Latinos are “more positive and knowledgeable” about the 2010 US Census, compared to US-born Hispanics (Lopez & Taylor, 2010). In addition, foreign-born Latinos respond more favorably because they know and believe that completing census-related forms will help the community and provide additional resources to the state. Through effective community outreach efforts, foreign-born Latinos have been

informed that Census information remains confidential and that questions about their legal status will not be asked (Lopez & Taylor, 2010).

The previous discussion provides a broad overview of the Dominican population on a national scale. Now the goal is to narrow the scope to New York City, where Dominicans continue to increase and where participants of this study reside.

2.3 Washington Heights/Inwood

Since the large-scale migration pattern began, Dominicans have settled mostly on the east coast, especially in several neighborhoods in New York City (NYC), including Washington Heights/Inwood (WHI) in Northern Manhattan, Corona, and now Queens. Settlement in Corona and Queens began in the 1960s, and most settlers came from the Cibao region of the Dominican Republic. Dominicans also lived and worked in middle-class neighborhoods in The Lower East Side, The West Bronx, and Southern Brooklyn (Hoffnung-Garskof, 2008).

WHI is a culturally vibrant and constantly evolving neighborhood, viewed by many as “Little Santo Domingo” or “Dominican World.” Famous for their popular Dominican restaurants, hair salons, and cultural preservation, this is the neighborhood where people feel a connection because of the energy and culture that is exerted and preserved by its people. WHI has had such an impact on people who grew up there or know of the neighborhood that in the past decade a Broadway show called “In the Heights” emerged from the neighborhood’s rich and vibrant reputation.

In 2006, the New York City Department of Health and Mental Hygiene released Community Health Profiles describing the health of 42 NYC communities. This report provides an overview of health statistics for the WHI community and its people and illustrates changes in health pattern for residents (Olson, Van Wye, Kerker, Thorpe, & Frieden, 2006).

Overall, WHI residents have a slightly higher concentration of youth compared to Manhattan and NYC residents. WHI residents are relatively young. For example, youth between the ages of 0-17 years make up 26% in WHI, compared to 17% in Manhattan and 24% in NYC. Adults 65 years and older are slightly lower, at 10%, in WHI compared to 12% in Manhattan and 12% for NYC (Olson et al., 2006).

In terms of education attainment, WHI residents over the age of 25 have completed fewer years of education than those in NYC overall. For WHI residents, 24% have an 8th-grade education, 21% have some high school but no diploma, 19% have a high school diploma, 18% have some college education but no degree, and 18% have a college degree (Olson et al., 2006). Historically, WHI was comprised of mostly white residents, but large migration patterns since 1990s changed the demographic composition of the neighborhood, which is now represented mostly by Hispanic/Latino (Olson et al., 2006). Approximately 51% of WHI residents are born outside of the US, compared to 29% of Manhattan residents and 36% of NYC residents respectively (Olson et al, 2006).

The overall health status for WHI (District 12) residents is rather grim compared to Manhattan and NYC residents. At a glance, the profile reports the following facts about the WHI community (Olson et al., 2006).

- WHI residents are less likely to have a regular health care provider than those in NYC overall
- Foreign-born men are less likely to have a doctor
- One out of five WHI residents is obese, and half of adults are not physically active

When it comes to diabetes (the focus of this study), WHI adults are more likely to have diabetes than Manhattan adults. Type 2 diabetes accounts for an estimated 95% of cases and is

strongly associated with obesity (Olson et al., 2006). Furthermore, 11% of WHI adults have diabetes compared to 7% in Manhattan. Since the publication of Community Health Profiles in 2006, the New York City Department of Health and Mental Hygiene (NYCDHMH) released Community Survey Data (CSD), a telephone survey which seeks updated data on several health topics, including diabetes. CSD reported that 10.4% of WHI residents have been told they have diabetes.

Since 1998, Drs. Hernández and Torres-Saillant have emphasized the need to increase research studies focusing on the health status of Dominicans (Hernández & Torres-Saillant, 1996). In addition, studies focusing on the health behavior and practices of members of the Latino/Hispanic community should focus on individual groups rather than the community at large to obtain a better understanding of the specific health care needs of the target population. Dominican health has improved since 1998, but more work is needed. As a relatively new and fast-growing immigrant group, Dominicans also suffer disproportionately from the stress and turmoil associated with migration to a new country, and this obviously impacts their health (Paulino, 1998).

2.4 Conceptual Framework of the Present Study

This study has been guided by two social theories on aging: The Subculture of Aging Theory (SAT) and the Age Stratification Theory (AST). In addition, this study integrates the theoretical work focusing on acculturation and assimilation. SAT postulates that older people maintain their self-concepts and social identities through their membership in a subculture (Rose, 1965). According to SAT, older adults do not behave in accordance to broader social norms and should not be evaluated as such. Instead, older adults should be evaluated in terms of their peers' behaviors and expectations (Hooyman & Asuman Kiyak, 2005). Because of their shared

interests, background, and commonalities, older adults interact with each other more than they would with other group members. However, this limited group interaction can result in group isolation and self-segregation, which can often occur in retirement communities or “involuntary” segregated settings (Hooyman & Asuman Kiyak, 2005).

The development of an “aging subculture” relies on how older adults react to aging and how they interact with members of the same group, but it does not incorporate socio-cultural factors which can influence the older adult’s aging process experience. The SAT helps to explain how older Latino adults interact with one another and how they are influenced by their social environment, while the AST helps to understand how older Latinos function in the categories in which they have been stratified (Hooyman & Asuman Kiyak, 2005).

AST articulates that older adults are categorized in societal framework in terms of socioeconomic class, gender, and race, and every society divides people into categories or strata according to age: “young,” “middle-aged,” and “old.” Lynott and Lynott (1996) explain further that older adults cannot be judged on the basis of their “engagement or disengagement” or the make-up of their group, but rather the context in which “the system of age stratification” influences how a person’s experiences affect their aging process. These ideas can be directly applied to older Dominican adults as well.

In addition to SAT and AST theories, this study is guided by research on assimilation which helps to describe the varied pathways and experiences for the participants in this study. This idea of having multiple pathways of assimilation can be associated with the different experiences conveyed by participants in this study. Several researchers have proposed that the path toward assimilation has evolved and is less linear than originally understood (Rumbaut & Portes, 2001; Zhou, 1997).

Researchers Golash-Boza and Darity (2008) posit that

“While some immigrants will embark on the traditional path of assimilation toward the Anglo-Saxon core, others will retain some of their traditional values and practices through selective acculturation, and still others will experience downward assimilation and identity with the experiences of non-whites in the US.”

The notion that the assimilation process is anything but linear can assist all health care professionals increase their understanding of the complex, multi-faceted experiences encountered by older, foreign-born Dominican adults in the United States.

2.5 Gaps in the Diabetes Literature

The literature on the self-management practices of older adults with Type 2 diabetes, particularly Dominicans, is limited and overlooks the importance of learning and exploring communities individually, instead of the ethnic group they represent. It is not enough or acceptable to simply categorize everyone into one box or section on a survey. There are cultural and behavioral distinction between groups which should be recognized and incorporated by all health professionals and policymakers in practice and in research. These factors are important in understanding health outcomes for all health care professionals.

This study addressed the limited information available on the self-management practices of older Dominican adults with Type 2 diabetes. Self-management practices, perspectives, and approaches have not been explored to the fullest among Dominicans. Results of this study will facilitate the design of self-care activities for community-based affiliate and health care professionals caring for this population. This is especially critical in view of the excessive projected prevalence of obesity and diabetes in the United States (Shai et al., 2006) and the anticipated growth of the Hispanic population in the United States by 2050 (US Census Bureau,

2000). More studies are needed to further our understanding of the trends and prevalence of diabetes in all Latino subgroups. Exploring the cultural practices and barriers to diabetes self-management is essential to improving the delivery of health care services to the target population.

Chapter 3: Method

Specific Aims

The specific aims of this study were to: 1) Explore the self-management practices (including folk/home remedies) and barriers to diabetes self-management among older Dominican community residents (55+, hereafter referred to as older Dominicans) living in the US mainland with Type 2 diabetes; 2) Describe the role of cultural factors in diabetes self-management among older Dominicans with Type 2 diabetes; 3) Examine the relationship between cultural-societal factors and diabetes self-management practices among older Dominicans.

Research Questions

This study addresses three research questions (see Figure 1):

1. What are the individual self-management practices and barriers of older Dominicans with Type 2 diabetes?
2. What community-level resources in WHI are assisting older Dominicans in managing their diabetes?
3. What role does the Dominican culture and society play in the effective management of diabetes for older Dominicans?

Summary Points.

Most research studies on self-management practices and behaviors of persons with Type 2 diabetes have focused primarily on Mexican Americans (Luchsinger, 2001). Mexican Americans represent only a sub-set of the larger Hispanic population, and most published articles on Mexicans with diabetes are studies from geographical areas like San Antonio, Texas, the San Luis Valley, Colorado, and Albuquerque, New Mexico (Tucker et al., 2000). Relying on data

from one Latino subgroup—for example, Mexicans from one geographic region—increases the potential of subject biases and makes it difficult to generalize findings to other geographical areas like New York and elsewhere in the US because of distinct cultural and regional differences.

While it is necessary to learn about the impact of Type 2 diabetes on Mexicans, it is also important to learn about the distinct cultural and behavioral characteristics that represent other Hispanic subgroups, not always as well represented (Luchsinger, 2001). Dominicans are one of the largest and fastest growing Latino groups in the US, and further information about their health status and how it relates to their diabetes management is necessary for all health care professionals who assess, treat, and interact with members of this group.

This chapter demonstrates the need to explore further our understanding of the self-management practices of older Dominican adults with Type 2 diabetes in the United States. In addition, this chapter demonstrates how few studies have focused on the self-management practices of this group, the barriers they may face, and the factors that may influence the way they manage their illness as they age. Little is known about older Dominican adults' use of home remedies (*remedios caseros*) to manage their illness, and this chapter demonstrates the need to explore how older Dominican adults are impacted by their chronic condition.

This section provides an overview of the study design using qualitative, in-depth, methodological approaches. The first part describes the settings and procedures, and illustrates the study sample. The second part describes the multi-faceted recruitment process using bilingual (English and Spanish) study instruments. The final part describes the data management process with the inclusion of translation and transcription elements for Spanish-speaking in-

depth interviews. This section concludes with a description of the study challenges and lessons learned during the development and implementation of this study.

3.1 Research Study

The purpose of this study is to obtain exploratory, descriptive information that fills these critical gaps in the knowledge base and provides insights for clinical management of Type 2 diabetes in older Dominican adults. To accomplish the objectives, the study used a methodology that is appropriate to the exploratory nature of the investigation. The principal investigator conducted an in-depth investigation to gain insights and generate new information regarding the topics selected within the study population.

The principal investigator relied primarily on qualitative data-gathering (in-depth interviews and audio recording) and data analytic techniques (coding and content analysis) to obtain in-depth information about self-management practices and potential use of folk remedies. Qualitative research strategies are most effective when trying to understand a phenomenon that is limited or not well understood (Rubin & Rubin, 2005). Using qualitative interviews, researchers can take into account cultural, social, and political processes (Rubin & Rubin, 2005). Employing semi-structured (also called focused) questions (Merton, Fiske, & Kendall, 1990) will enhance the understanding of the self-management practices of elderly Dominicans with Type 2 diabetes. Figure 2 illustrates the design and implementation model for this study design.

Study Setting.

Participants were recruited from the Isabella Senior Resource Center (the Center), located at 4026 Broadway at 169th Street in the Washington Heights/Inwood (WHI) neighborhood in New York City. The Center is a central meeting place for seniors in the WHI neighborhood, where they obtain information about medical issues, benefits, safety, nutrition, long-term care, or

any other issue concerning older adults and their families. The principal investigator obtained the letter of agreement for the study from the Center Director, specifying the Center's willingness to assist in the recruitment process of study participants (see Appendix A).

3.2 Study Procedures

Eligible respondents were asked to participate in an in-depth, face-to-face, semi-structured interview by the principal investigator. Individuals were recruited from January 28, 2009 to February 10, 2010, using a multi-level recruitment process with the approval of Columbia University Medical Center's Institutional Review Board (IRB) (see Appendix B). Written and informed consent was obtained from the participants in English and Spanish (see Appendix C and Appendix D). The principal investigator, who is bilingual, conducted all the interviews in Spanish. For each participant, the principal investigator explained the purpose of the study, answered questions or concerns from participants, and read all study instruments and materials. Moreover, the principal investigator ensured confidentiality and trust throughout the entire interview. Interviews were audio-taped for later transcription. Respondents received a \$10 gift certificate to Bravo Supermarket for their participation in the study. The gift certificate incentive was approved by Columbia University Medical Center's IRB and the Center's Director.

Data collection procedures.

Data collection was done at a time and location convenient to each study participant. Thirty in-depth interviews were conducted in Spanish over a one-year period (January 28, 2009–February 10, 2010), and digitally audio-taped for later transcription and narrative analysis. The interviews lasted 60-90 minutes and were conducted by the principal investigator, a native Spanish speaker of Hispanic/Latino origin with experience working with the sample population.

In-depth Interviews.

The primary data-gathering technique in this study was in-depth, face-to-face, semi-structured (also called focused) interviews (Merton, et al., 1990; Rubin & Rubin, 2005). Throughout each interview, the principal investigator encouraged the participants to talk freely, spontaneously, and in-depth about topics being studied, while she remained flexible and patient. Twenty-nine interviews were conducted at the Center. The thirtieth interview was conducted at the participant's home.

The principal investigator facilitated the flow of information about the issues under investigation primarily through interviewing techniques including neutral probes and unstructured questions, and by focusing on general topics or issues of interest, probing only to encourage elaboration or clarification to learn more detail. This process enabled each participant's story to emerge spontaneously, in context, with minimum input or influence from the interviewer (Seidman, 1998). During the interview, the principal investigator listened attentively to the study participant in order to keep the interview moving forward (Seidman, 1998). According to Geertz (1973), the depth, detail, and richness sought in the interviews, also called thick description, are rooted in the interviewee's firsthand experiences and from the material that researchers gather and synthesize (Rubin & Rubin, 2005).

The advantage of this data collection is its unique ability to elicit the participant's own frame of reference for the phenomena under study (Rubin & Rubin, 2005). The use of in-depth, face-to-face, semi-structured interviews allowed the principal investigator to build rapport and establish trust, important factors to consider when working with special populations (Fowler, 2002). Further, this approach gives the researcher and the respondent the opportunity to employ other cultural values including *respecto* and *simpátia* (respect and sympathy). Chong (2002)

reports that Latinos need to perceive respect in their relationships, and a lack of this perception may be interpreted as an absence of respect. It is the researcher's responsibility to express *simpátia* when working with the Latino patient; that is, to demonstrate people-oriented skills by developing a harmonious relationship that expresses a warm and caring attitude (Chong, 2002). Without careful consideration of these cultural attributes, the researcher may risk losing the interest and support of the community.

Study participants.

The study sample comprised Dominicans adults (age 55+) with Type 2 diabetes living in northern Manhattan. Individuals were eligible for the study if: 1) they were 55 years old or older; 2) self-identified as Dominican (either born in the Dominican Republic (DR), or their parents were born or raised in DR, or one parent was born in DR; 3) have been diagnosed with Type 2 diabetes, or 4) have been living with Type 2 diabetes. Study participants were included in the study once the principal investigator screened participants, confirmed their eligibility, and obtained consent from participants to participate in the study.

Self-presentation.

The idea of "self-presentation" as described in Hirsch (2003) is important to consider in any research setting, regardless of your self-identity and cultural background as a researcher. Self-presentation allowed the principal investigator to learn from the study participant in their environment (comfort zone). The principal investigator's identity as a Colombian-American Latina who spoke Spanish fluently did not necessarily create a clear path and access to the members of this community. In order to establish trust and rapport with potential participants, the principal investigator immersed herself in the culture and dynamics of the Center and interacted directly with the members and Center staff. The principal investigator transformed

herself through the culture of the Center. This transformation was necessary because the principal investigator was the outsider trying to be a part of something that was culturally different. This point is relevant because the principal investigator's doctoral study was no exception to the rule.

For these reasons, the principal investigator established a professional relationship of considerable mutual respect with the community. This relationship began as a result of a photovoice project in Dr. Joyce Moon-Howard's Community-Participatory Research Class at Columbia's Mailman School of Public Health's Department of Sociomedical Sciences. For this project, the principal investigator worked closely with the Center's Director and volunteer members, the gatekeepers of the Center and community, who are Dominican, speak Spanish, and live in WHI.

After taking part in Dr. Moon-Howard's course, the principal investigator maintained her relationship with the Center's Director and member volunteers over a four-year period. This relationship was nurtured by visiting the Center periodically and updating the staff of the progress made in the program. The professional relationship with the Center, staff and its members facilitated the study's recruitment process during the implementation of the study.

To formalize the process of implementing the study at the Center, the principal investigator completed the following tasks: 1) obtained an affiliation agreement from the Director which demonstrated the Center's commitment to participating and collaborating in the recruitment process; 2) met with and shared the proposed study with Isabella's Research Director, and 3) participated in a training session for staff and volunteers of Isabella, Inc.

3.3 Recruitment Process

The multi-pronged recruitment process was implemented through public health lectures, public announcements, and ongoing volunteer efforts by the principal investigator. The principal investigator conducted four public health lectures (two in English and two in Spanish) titled *“Improving Communication with Your Provider: Why It Is Important to Your Health/Mejorando la Comunicación con Su Doctor: Porque Es Importante para Su Salud.”* These presentations stem from two educational publications from the National Institute of Health and the National Institute on Aging titled *“Talking with Your Doctor: A Guide for Older People”* and *“Conversando con Su Médico.”* The principal investigator ordered fifty copies which were delivered directly to the Center for the presentations and for the Center’s reference library. Both publications were downloaded for free in both English and Spanish through this link: <http://www.nia.nih.gov/HealthInformation/Publications>.

Public announcements were made by the principal investigator, staff, and volunteer members throughout the entire recruitment process. For example, upon completing the workshops, the principal investigator announced the study (see Appendix E, in English, and Appendix F, in Spanish), and used the English and Spanish flyer (see Appendix G and Appendix H) to recruit participants. Participants either volunteered for the study and/or nominated other potential participants. Throughout the study, the principal investigator used “snowball,” “word of mouth” and “chain” sampling techniques to recruit potential respondents (Patton, 1997). In addition, the principal investigator worked closely with key staff and volunteers at the Center to inform other members of the study and to make referrals. The principal investigator also posted the study flyers throughout the Center and used the study flyers during the entire recruitment process.

Establishing trust and rapport throughout the study was another important level in the recruitment process, and essential for the members at the Center. The principal investigator needed to be known and trusted by the community, and this goal was accomplished through her volunteer activities and personal interaction with volunteers, members and prospective participants over a four-year period. Volunteer opportunities provided a venue and purpose for public health lectures on issues of interest to the community. The principal investigator used these lectures and activities as an opportunity to inform the community about the study.

Confidentiality of Study Data.

In this study, the safety and protection of confidential information and procedures, including the participants' and the Center's, existed at all levels to ensure adequate privacy and early identification of harm. Each participant was assigned an identification number. All study materials were stored by identification number only. All study materials (consent forms, questionnaires, and the acculturation scale) were viewed and handled only by the principal investigator throughout the study. All electronic computer files were password-protected and accessible only to the principal investigator. The present study and all necessary instruments and materials were submitted to the Columbia University Medical Center's IRB.

Potential Benefits and Risks

A potential benefit for participants in this study was the opportunity to discuss and share their experience with Type 2 diabetes and other co-morbidities. There were no foreseeable risks to participating in this research study. Participants who had clinical questions about diabetes and their self-management practices were referred to the community resources available at the Center or in the community.

3.4 Study Instruments and Materials

The following instruments and materials were used in the study: 1) Questionnaire designed to gather socio-demographic information from the respondents in English and Spanish (see Appendix I, in English, and Appendix J, in Spanish); 2) Acculturation Scale intended to measure the level of acculturation or adaptation of the new culture (see Appendix K, five pages, in both English and Spanish); and 3) Topic Guide developed to obtain in-depth information and rich data regarding the self-management practices of older Dominican adults with diabetes (see Appendix L, in English, and Appendix M, in Spanish). Study instruments developed by the principal investigator incorporated the Dominican dialect.

Questionnaire.

The purpose of this questionnaire was to obtain socio-demographic information focusing on the variables listed below. This questionnaire was guided by questions commonly seen in Census 2010, the American Community Survey, and the Hispanic Health and Nutrition Examination.

- age
- gender
- ethnicity
- primary language
- level of education
- type of residence
- whom they reside with
- employment status
- type of medical insurance

- length of time in the US
- other co-morbidities
- length of time with diabetes

Acculturation scale.

This study used *The Short Acculturation Scale* (Marín, Sabogal, Marín, Otero-Sabogal, & Pérez-Stable, 1987) to learn more information about participants' adaptation to their new country's culture. *The Short Acculturation Scale*, which focuses on "Language Use," "Media," and "Ethnic Social Relations," contains twelve questions and is available in English and Spanish. The scale underwent appropriate translation protocol in accordance to the double or back translation procedure (Marín et al., 1987) and was pretested in English and Spanish. In addition, the developers went a step further by having the Spanish version reviewed by Spanish-speakers of different nationalities in order to eliminate "parochial wording" (Marín et al., 1987). According to Marín and Marín (1991), the scale also has good psychometric characteristics, has correlated highly with usual validity criteria such as respondents' generation ($r=.69$), length of residence in the United States for foreign-born respondents ($r=.76$), and age at arrival in the United States ($r=.72$).

The scale's feasibility, psychometric characteristics, length, and its usage for all Hispanic/Latino groups, especially foreign-born, made it an appropriate instrument to incorporate in the principal investigator's study. Acculturation levels in general are useful in helping principal investigators learn more about the participants, including, but not limited to mental health status, levels of social support, levels of social deviance, alcohol and substance abuse, political and social attitudes, and other health behaviors, including smoking, and preventive screening practices and behaviors (Marin & Marin, 1991). This instrument works

well with older Latino adults, is user-friendly and easy to comprehend. In this study, the scale was administered to all participants by the principal investigator in Spanish.

Interview Guide

An interview (topic) guide (see Appendices L and M) was used to reflect the principal investigator's interest in the self-management practices of older Dominican adults living with Type 2 diabetes. In addition, the guide served as a conceptual road map from the interviewer's point of reference to guide the interview and define the relevant range of topics and issues.

Patton (1995) states that the interview guide provides topics or subject areas which the interviewer will explore and probe. The principal investigator used the interview/topic guide to build a conversation within a particular subject style most comfortable for the principal investigator. Upon completing the first interviews, the principal investigator listened to all of the audiotapes prior to conducting more interviews, to determine if the interview guide needed to be revised/expanded upon to incorporate areas that emerged in those first interviews.

The topic guide focused on the following areas: 1) perception of Type 2 diabetes; 2) orientations toward self-management practices of their chronic illness; 3) barriers to current self-management practices when dealing with their health providers; 4) resources and strengths assisting their management of the illness; 5) cultural practices for managing their illness, and 6) access to and use of health services, if any, to manage their illness. Table 1 outlines the construct areas which guided the research study. The principal investigator also obtained information about how they were diagnosed, symptoms experienced, routine care, and health screening.

3.5 Data Management, Translation, and Transcription (Part 1) and Content Analysis (Part 2)

Quantitative Analysis

Frequencies were conducted on the socio-demographic characteristics and the acculturation information. The principal investigator created an electronic version of the data gathered for all the instruments and related study material.

Qualitative Methods

In terms of data management, the principal investigator organized and prepared the data for analysis (Seidman, 1998; Creswell, 2003). In addition, the principal investigator ensured that back-up copies of the electronic transcript files were created and stored in a separate, secure location from the original files.

Part 1 – Translation and Transcription of the In-depth Interviews

Step 1. The principal investigator, who is bilingual in English and Spanish, conducted all the interviews in Spanish. Then the principal investigator translated and transcribed the audiotapes of the Spanish interviews into an English text file, which resulted in Set A.

Step 2. Over an eight-month period the principal investigator listened to all thirty interviews multiple times to capture the richness and detail of the data for the translation. The principal investigator worked in a quiet setting and environment which enabled her to focus and concentrate on the data more carefully and attentively. The process of re-reading required tremendous amounts of focus and discipline. The coding process (Part 2) did not begin until Step 3 was accomplished.

Step 3. Once the principal investigator completed Step 2 for all thirty interviews, a bilingual independent consultant, translator B, was hired and compensated per interview.

Translator B, working independently, followed the same translation steps as the principal investigator, which resulted in Set B. Translator B listened to the original, digitally recorded Spanish interviews and translated them from Spanish to English. Following each second translation to English, translators A and B worked together to verify that both typed English translations matched. The purpose of this task was to examine if Set A and Set B were equivalent in grammatical structure and meaning. Inconsistencies between transcripts for Set A and Set B were resolved through mutual discussion. After the principal investigator established that each dyad of translation for Set A and Set B was equivalent and conveyed the same meanings and ideas (inter-translator reliability), then the coding process began.

Part 2 – Content Analysis of the In-depth Interviews and Validity of the Translation

Method

After establishing that each dyad of translation A and B was conceptually equivalent, as described above—that is, had the same grammatical structure, meanings and expressed ideas—the principal investigator applied new methodology that blended content analysis and coding. This new procedure also validated the method used in translating the interviews. These content analyses and coding procedures were developed by Costantino and Diaz-Román (2011) for this dissertation. The methodology is an adaptation of the content analysis applied to stories given by youngsters in response to the TEMAS (Tell-Me-A-Story) Multicultural Test (Costantino, Malgady, & Rogler, 1988).

The principal investigator analyzed each pair of narrative accounts for Sets A and B in English for all thirty interviews, selecting a phrase from each set which clearly represented one of the six constructs. If the phrase was present in both story A and story B, a score of 1 (100%

agreement) was entered in the excel chart; if the phrase was not present in both sets of stories, a score of 0 (0%) was also entered for the thirty interviews.

These procedures had a dual function. First, it allowed quantifying by percentages the content of the narratives, and second, it showed the degree of agreement between translators A and B, i.e., the equivalence of their translations of the interviews.

Upon completing the task of verifying the accuracy of the translation for Set A and Set B, the principal investigator began the development of a coding sheet for Set A. The development of the coding sheet involved several steps. First, the principal investigator re-read all the quotes in the interviews for Set A. This process allowed the principal investigator to identify themes and issues, and to produce a broad list of codes. Then the principal investigator used a more focused approach during a second read of the data to identify variations in each quote (Miles & Huberman, 1994). Once this lengthy process was completed, the principal investigator applied sub-codes to the data. The sub-codes represented more detailed categories as reflected by the data. To assess (inter-rater reliability), a second coder, working independently re-coded the interviews. Upon completion of this independent code assignment to the transcripts, any discrepancies regarding the coding were resolved by a discussion between the coders.

Once the transcripts were coded, the principal investigator closely examined the data once again and began to organize the data into categories related to the specific aims of the study. The process of organizing and clustering the data was used by the principal investigator as a way to prepare for the conclusion stage of the data analysis.

Study Challenges and Lessons Learned

Translation of documents. When conducting research with the Hispanic/Latino population, several key methodological cross-language steps must be included in order to

accurately and comprehensively complete the translation process. All of the in-depth interviews were conducted in Spanish, but the principal investigator also spoke English from time to time at the Center (research site), depending on the setting and types of conversations with members, staff and the Director. Ongoing communication with members and staff at the Center was essential during all stages of the study.

Although the majority of participants spoke Spanish, participants would on occasion speak English and use words in English during conversations to describe a specific medicine or feeling. When the direct translation of a word from Spanish to English did not exist, the principal investigator kept the original word in Spanish to preserve the word's originality and true cultural meaning. There will always be words in Spanish which cannot be directly translated to English, and vice versa. Once again, all thirty of the in-depth interviews were conducted in Spanish, but memos and ongoing field notes were written in English and in Spanish, mainly to preserve the cultural significance and meaning of specific words and phrases.

In addition to conducting the interviews in Spanish, the principal investigator translated all research documents and protocols from English to Spanish and obtained IRB approval. At the time, the IRB's consent form was not available in Spanish. This required the principal investigator to take time to translate the English consent form to Spanish. All the above steps were arduous and time-consuming, but absolutely necessary in understanding the linguistic cultural elements of the community and the Center. This process enabled the principal investigator to build trust and rapport with Spanish-speaking participants and enhance a professional partnership with staff, members, and volunteers.

Marín and Marín (1991) classify native language skills as similar to the "coordinate bilingual," one who learns the languages at different times and preferably in two different

cultures. A “coordinate bilingual,” according to Marín and Marín (1991), is better able to articulate the cultural meaning of the words instead of deriving the meaning directly from the text, and this description applied to the principal investigator. Although the principal investigator met the qualification of a translator placed by Marín and Marín (1991), the experience in the field was completely different for the principal investigator.

The translation experience served as a valuable lesson for future research studies. All components and elements of a study design should be carefully translated from English to Spanish (in the appropriate dialect, in the specific Spanish of the target country), down to the last detail, especially when conducting a study with a predominately Spanish-speaking population. The principal investigator knew that the study would require an oral and written understanding of the language. Without these skills, it would be extremely challenging to work with the study sample. When designing a research study with older Dominican adults, it is important to design and think in both English and Spanish.

Study setting. Implementing a qualitative research study at the Center was more challenging than anticipated. After establishing trust and rapport, the principal investigator discovered rich and unique cultural experiences, completely different from her Colombian culture, which emerged throughout the study. It is important to share this experience because it provides a description of the cultural and social behaviors of the research setting. The Center was more than just a place to gather data; it was a learning center, a safe haven for the members, and a meeting place where members gathered and socialized. Strong ties within a network of older adults and members existed at the Center.

Work space. In an ideal research setting, the principal investigator would have his/her own Center where participants could privately meet with the investigator to take part in the

study, but in the real world this was not the case. The Center's staff did what they could to make the principal investigator a part of the Center and environment by sharing their space, but space was limited for everyone and it was impossible to conduct interviews in complete privacy. The principal investigator used the Director's office for interviews once or twice, but this was rare and only possible depending on the day and the Director's schedule. The principal investigator overcame the workspace issue by being flexible, patient, and by working in areas where privacy for participants could be obtained.

Translation. All thirty interviews were conducted in Spanish and all the documents were translated from English to Spanish. The translation work carefully incorporated the Dominican dialect with the assistance of native Dominicans from the community. This process was necessary and yet challenging because when Dominicans speak Spanish it is faster and more difficult to understand, even for a native Spanish speaker like the principal investigator. Because all languages continue to evolve, it was necessary to learn the appropriate way of saying things, and most important to obtain help from Dominicans to assure accuracy and comprehension.

The principal investigator's Spanish originated from Colombia, where individuals speak Spanish completely different from Dominican Spanish. For this reason, the interviews were transcribed, read and re-read in Spanish several times, and the words used by the Dominicans were kept the same way to maintain and preserve their cultural meaning and representation. The principal investigator searched for someone of Dominican background to help with the transcription, but it was challenging. Translators A and B learned Spanish the same way, but were not of Dominican background.

Relationships with participants. Because of limited resources and time, the principal investigator was not able to maintain and nurture relationships with the study participants. The

interviews were conducted one time only, without follow-up. During this time, the principal investigator obtained as much information as possible from the participants while balancing inevitable time constraints. Limited time with study participants hindered the principal investigator's ability to explore in greater depth some of the topics presented and to follow up with information they wanted to share but could not during the interviews. This experience served as a lesson for future studies and will be considered carefully in future study design opportunities.

Summary

This chapter demonstrates the various key components of a qualitative research study using in-depth interviews with Spanish-speaking older Dominican adults with Type 2 diabetes. The chapter demonstrates the complexity and rewards of a one-year, multi-faceted recruitment process with the development and design of bilingual study instruments. Finally, this chapter demonstrates the data management process with translation and transcription approaches which should be incorporated and applied specifically when conducting qualitative interviews with Spanish-speaking study participants.

Chapter 4: Results

Part I reports on the demographic characteristics and acculturation responses of thirty study participants from the Isabella Senior Resource Center, who reside in Washington Heights/Inwood (WHI). Part II discusses the findings from the qualitative in-depth interviews as they relate to the specific aims of the study.

4.1 Part I

Demographic characteristics.

Respondents ranged in age from 56 to 84 years, with a mean of 67 years. The study participants consisted of 18 males (60%) and 12 females (40%). All of the participants in this study were born in the Dominican Republic and all reported living in the US for at least 10 years. Most participants (96%) declared Spanish as their primary language, and all preferred the interviews to be conducted in Spanish. When it comes to education, 93% reported primary and secondary education. In the Dominican Republic, primary education (*primaria*) encompasses elementary and middle school education, while *secundaria* represents high school. When it comes to housing, the vast majority (96%) of participants lived in apartments in WHI and 3% lived in a house. Although the majority of participants reside in apartments, 73% declared that they live with family members (spouse, adult child, grandchildren) while 26% reported that they live alone.

The vast majority of participants (N=28, 93%) were retired, and only 7% (N=2) indicated working part-time. The greatest challenge in terms of employment was finding a job or not being able to work because of a disability, and this was particularly difficult to accept among the older adult males in the study. Most of the male adults wanted to work because they wanted to feel good about themselves and to continue to take care of their families as they had done most

of their lives. The shared desire among male participants to seek employment, even if they were physically or mentally disabled, substantiates why it is harder for men to cope with the stress of being unemployed (Mandal & Roe, 2008).

When it comes to health insurance, the majority of participants (90%) had some form of health insurance, but 10% did not have any health insurance at all. Hector, the youngest male participant, stated that not having any health insurance has had a tremendous impact on his health. Hector stated without reservation that all you need is “money” to have better health in the United States. Hector did not have health insurance and did not qualify for Medicaid because of his pension plan from his previous employment.

With respect to health status, 43% of participants declared their health status as good while 30% stated that their health was regular. Participants used different ways to describe their health status. Most participants used the responses featured in the questionnaire, but some participants came up with their own words to describe their health status. For example, instead of using the word *bien* (good), seven participants used the word *regular* (regular) to describe their health. The word *regular* is spelled exactly the same way in English and Spanish, but pronounced completely differently: *regúlar* in Spanish and *régular* in English. Additionally, instead of using the word *pobre* (poor), some participants used the word *mal* (bad). See Appendix J to view the questionnaire in Spanish, or below for an example of the way the question was written with the English translation.

10. *En general, como describiria su estado de salud actualmente?*

In general, how would you describe your health status, at the present?

1. *Muy Bien* (very good)
2. *Bien* (good)
3. *Justo* (fair)
4. *Pobre* (poor)

In addition to the questions listed above, the principal investigator obtained a list of the co-morbidities that can complicate and influence diabetics' self-management practices. See Table 2 for additional health conditions disclosed by participants in the study.

One of the male participants, who reported heart disease as a health condition, suffered a massive heart attack a couple of weeks after the interview. At the time of the heart attack, this participant was participating in an eight-week intensive diabetes-wellness program conducted at the Isabella Senior Resource Center. During the in-depth interview, the participant disclosed that physical activity was not a part of his diabetes self-management practices.

Another interesting finding was the report of arthritis. Also, the length of time living with diabetes varied. A substantial portion of the sample (43%) had been living with diabetes for more than 10 years, while 26% had diabetes for less than five years. While 23% of participants had diabetes between five and 10 years, only 6% have been diagnosed recently (one year or less). Table 3 provides an overview of the socio-demographic characteristics of the study participants.

Acculturation responses. The acculturation levels for the study participants are presented in Table 4.

Findings for the Acculturation Scale. Note: Percentages in excess of .5 have been rounded up to the nearest whole number.

Language. Questions 1-5 focused on language acquisition. Slightly more than half of the sample (60%) reported "Only Spanish," while 37% reported "Spanish better than English," and 3% reported that he spoke "Both Equally."

According to 93% of the respondents, the language spoken as a child was "Only Spanish"; however, 7% stated "More Spanish than English." In addition, 87% declared "Only

Spanish” spoken at home (10 females and 16 males), but 10% reported “More Spanish than English” and 3% stated “Both Equally” in terms of language spoken at home.

With respect to which language you “think” with, 63% selected “Only Spanish,” while 30% claim to think “More in Spanish than English,” and only 7% declared “Both Equally.” Even when it comes to speaking to their friends, 87% of participants prefer “Only Spanish”; meanwhile, 13% claim to use “Both Equally.”

Media. Questions 6-8 focused on the language used with different forms of media outlets. When it comes to watching television, 43% stated “Only Spanish” and 33% watch television “More in Spanish than English.” This information may be associated with a participant’s comfort level with English or interest in learning English because they watch television in English. Only 7% admitted to watching television more in “English than in Spanish” and 17% declared that they watched television “Both Equally” in English and Spanish.

Listening to the radio is completely different from watching television. It is much easier to understand what people are saying during a conversation in person than to comprehend the conversation on the radio. Interestingly, participants reported that they prefer to listen to the radio in Spanish. When it comes to listening to programs on the radio, 77% preferred “Only Spanish.” Of the remainder, 13% listened to radio “More Spanish than English” and 3% listened to “Both Equally,” while 3% listened to the radio only in English. One male indicated that he did not listen to the radio at all. The following question, focusing on “preference,” illustrates a different way of thinking, especially when participants have a choice.

When given a preference, participants expressed more flexibility with respect to hearing or seeing movies, TV and radio programs. In this category, 37% (2 females and 9 males) prefer to watch and listen to “Only Spanish” while 30% (6 females and 3 males) prefer “More Spanish

than English,” and 7% indicated “More English than Spanish.” The word *preferere* (prefer) allowed a few more participants (26%) to disclose that they preferred to hear and watch movies in both languages equally. The two participants who declared that they preferred “More English than Spanish” did not indicate whether or not they do actually hear or watch movies in English only.

Ethnic social relations. The last section of the acculturation scale (Questions 9-12) focused on the type of friends, social events/gatherings that participants prefer for their children. With respect to close friends, 57% disclosed that their friends consisted of “All Latinos/Hispanics,” while 40% reported that their friends were “More Latinos than Americans.” Only 3% shared that her friends consisted of “About half and half.”

With respect to social gatherings or parties, 43% opted for “All Latinos/Hispanics” while 33% revealed that they prefer to socially interact with “More Latinos than Americans.” And 53% of the participants reported that the people they visit or the individuals who visit them are “All Latinos/Hispanics,” while 37% reported “More Latinos than Americans,” with 10% reporting “About half and half.”

The results for the question focusing on the preference of their children’s friends depicted a different outlook. For example, 10% selected “All Latinos/Hispanics,” while 43.5% reported “More Latinos than Americans,” and 43.5% selected “About half and half,” while 3% reported Not Applicable.

According to the acculturation responses for this study, participants continue to speak predominately Spanish, prefer to use Spanish-speaking media networks, and engage and socialize with Spanish-speaking social networks. The acculturation process for this particular study group is not as high as expected, although they have reported living in the United States for

more than 10 years. Clearly, length of time living in the United States is not necessarily directly associated with high levels of acculturation for these study participants, but there are other factors which can influence the acculturation process of an older immigrant adult in the United States.

All of the study participants consider Spanish their primary language, yet they manage to live and work in a country/city where the predominant language spoken is English. This is probably due to several factors, including the residential area, which in this case is WHI, a highly concentrated neighborhood represented mostly by members of the Dominican community, within New York City, a uniquely diverse melting pot comprised of so many different languages and ethnicities in one concentrated area.

Because of the language barrier, it is understandable that participants in this study would prefer to watch and hear media networks in Spanish. Although some participants admit to watching some television in English, it is still difficult for non-native speakers in this study to fully understand information conveyed in English.

One can infer from this study that if study participants are watching television or listening to the radio in English, they are demonstrating signs of gradually acculturating into their new environment even though length of time varies per individual. In addition, some participants prefer to have their children interact and socialize with non-Latinos in the community. This preference demonstrates that members of this generation are taking another step toward acculturating for the future generations, but not so much for participants in the study. This could be mostly because of the notion among immigrants to the US that future generations have to do much better than the first or older generations. It also stems from the conviction among parents

that their child should be better off than they are, although other economic and social factors in the current job market also influence these outcomes.

Although most of my participants have been in this country for more than 20 years, they have not demonstrated through this acculturation scale high levels of acculturation. In the case of the study participants, acculturation will probably be much higher for their children and future generations. Table 4 illustrates the responses provided by participants for the acculturation scale.

4.2 Part II

Aims of this study

Specific aim 1. The first aim of this study is to explore the self-management practices, including folk/remedies and barriers to diabetes self-management.

The results of this study demonstrate that self-management practices for Type 2 diabetes vary and are represented by commonly known factors, including: 1) diet modifications; 2) glucose monitoring; 3) medication adherence; 4) exercise, and 5) diabetes classes. Findings from this study illustrate that male and female participants have mixed self-management practices that assist them in managing their diabetes. Results also demonstrate that participants are interested in “learning” how to manage their diabetes through their participation in classes and diabetes-related workshops.

Diet. A change in diet can be a complex and life-changing experience for many people, especially for individuals who prepare traditional and cultural meals. Diabetes management can be rigid and lifestyle-restricting for an individual living with Type 2 diabetes, as described by many respondents during their interviews. Antonia provided a unique perspective when she described how much food she is able to eat during the process of preparing her meals.

“Regularly, I prepare meals normally, but what happens is that if you are used to eating three cups of rice, then you need to be eating 1.5 cups instead. If you have a cup of beans you can eat ½ a cup instead. If you eat a *china* (orange), an orange has 15 calories, an apple has 15 calories, so you cannot eat at the same time. When you are eating breakfast, you cannot eat more than 60 carbohydrates. So, if you eat toast, it has 30 carbohydrates. You can eat all the meat you want, if it is not greasy. You can eat all the salad you want ... the rest of the carbohydrates you accompany with an apple to complete the carbohydrates, if you want to complete it.”

This participant demonstrated a tremendous amount of restriction and dedication to her daily food intake and dietary regimen; however, this participant also took two courses on diabetes management in the community. This level of detail, when it comes to diet, is not represented in all the interviews.

Fernanda explained, “The only thing I stopped doing was eating candy. I used to make a lot of candy from home in Santo Domingo, not the type of candy you buy at the store. It’s called *Dulce de Toronja*, (candied grapefruit peel), but it is made out of orange.”

This quote illustrates an important dietary change implemented by the participant, and introduces for the first time a candy unique to members of the Dominican community.

Roberto stated, “I try not to eat grease and not eat with a lot of salt. I eat the foods that are healthy for diabetes or cholesterol. I cannot have special food because I do not have money to buy it, but instead I purchased low-fat milk. I have not eaten it yet, but I purchased low-fat cheese. I eat wheat bread. I do not eat white bread. I try to find a way not to increase the diabetes, but instead I try to control the diabetes.”

This statement reflects the concrete changes this participant made with his diet and introduces the idea of “controlling your diabetes” for the first time in the study.

Medications. Participants in this study understood the importance of taking their medication to manage their diabetes. The following quote illustrates different perspectives on medication intake for diabetes management.

Maria stressed, “No, I just use my pills. There are many things you can use. They have told me a lot of things but I have forgotten them. Some people have told me to just use medication to remove diabetes. But sometimes I get scared not to take my pills.”

This quote demonstrates how a participant uses only medication to manage her diabetes, but is also aware of the “other things” you can use to manage diabetes. In this quote, the participant shares something more profound: The misconception in the community that taking medication will “remove” diabetes.

Leila declared, “For breakfast, I eat *pan tostado* (toasted bread), *café con leche* (coffee with milk) but decaffeinated (American), a vitamin and my pill for the diabetes, and a little aspirin because I suffer from high blood pressure. I have an appointment on the 28th of June with my doctor, and every time she says everything is normal, I wonder what she will say next time.”

This quote provides an example of a participant’s breakfast experience. The principal investigator included the Spanish words to provide an accurate representation of how these words are used in Dominican dialect. More importantly, this quote demonstrates how this participant is curious, as well as concerned, about what her doctor will say during the next medical interview.

Esteban stated, “I take medication, but I do not remember the name. They are expensive. I have to buy 200 because I have to take two a day, one in the morning and one in the evening. There is one that I take that is expensive, that is for *temblor* (chills), nausea, and *temblor en el cuerpo* (body tremors), and I have to take two. Last night, something bad happened to me. I had this terrible pain in my spinal cord, and I wanted to throw up.”

This quote illustrates several complex issues going on at the same time with respect to medication intake. First, the participant cannot recall the name of the medication he is taking for his diabetes. This could be a sign of early dementia for this older adult. Second, the medications are expensive and the participant appears frustrated with the task of taking two pills per day. Moreover, the participant is paying for another expensive pill for his chills. In his own words, the participant demonstrates a combination of factors an older adult can experience when taking medication.

Exercise. Exercise varied for each respondent. Physical activity was a challenging task for many participants for a variety of reasons, including the “weather,” “pain,” “lack of social support,” and lack of “resources” to join a gym. Participants were aware of the importance of physical activity, but did not necessarily incorporate it in their diabetes regimen. The following quotes illustrate their varied responses.

Roberto described his exercise regimen as, “Walking in the neighborhood. I walk from 158-190 (32 blocks). I walk alone in the morning. I have no schedule. It depends; I walk and take the bus, too. This morning I took the bus.”

This quote is an example of an older adult’s experience with exercises in a New York neighborhood, and a description of the transportation options available in the city.

Lupe noted, “Yes, I do it daily for 30 minutes. On Telemundo, there is a segment called *¡Rumbale!* from 5-7 a.m., and I do the same things the women do.”

This participant described her experience with the support of Telemundo, the second-largest American television network for Spanish-speaking audiences. This quote provides yet another example of how an older Dominican uses the media (television) to incorporate exercise into their diabetes management regimen.

Eva emphasized, “And exercise. I work hard here. I was washing down the walls. I cannot sit down and cannot lie down either.”

This quote represents a female respondent’s view on exercise through her housework. Although the participant reports that she exercises, housework is the only way she describes her physical activity.

Ximena had a positive outlook when it comes to exercise. She reported, “I walk a lot. I love to walk. I do not like to take the bus. My friend says to me, ‘Your body does not hurt?’ I say, ‘It does not hurt.’ When it hurts, I will say something.”

This quote exemplifies a participant’s determination to exercise despite the excuses, peer pressure, and comments made by her friend. The participant’s positive attitude demonstrates an older adult’s ability to incorporate physical activity into her self-management practices, despite negative influences from older adults. This attitude is not common among all participants.

In addition to exercise, findings from this study suggest that respondents are learning more about diabetes and self-management practices through workshops and classes offered in the community. In the following section, respondents provide examples of the types of classes offered in the community to assist them in the management of diabetes. These findings

demonstrate participants' willingness to learn more about how to effectively manage their illness through existing resources available in the community.

Diabetes management classes. Participants identified diabetes workshops and courses offered in the neighborhood. Respondents mentioned self-management seminars, diabetes and nutrition classes offered at the Naomi Berrie Diabetes Center (NBDC) at Columbia University Medical Center, the Associates in Internal Medicine (AIM) clinic located at Columbia-Presbyterian Medical Center, and the eight-week Diabetes Wellness workshop offered through the Isabella Senior Resource Center.

Antonia noted, "The doctors [at the AIM Clinic] just say to you... 'Look, take this medication and take these classes.' And I did something more by attending the Center [NBDC] because my friend's son gets treatment there and that is how I learned about it. In the hospital, they take their time and they teach you. They take their time with videos. I did not learn, I learned it there...but they taught me. In one day they taught me. When they put the injection in the stomach... They teach you how you can end up... I associated it with other things. If I tell you, this is what impressed me the most in the class."

This is an example of a participant who goes above and beyond to learn about her illness. Not only did she attend one class, but two classes: one at the AIM clinic, and the other at the Naomi Berrie Diabetes Center (NBDC). The approach used at the Center had a lasting impact on the way this participant manages her diabetes. This participant probably took these extreme efforts because she was the only one who reported that her husband passed away due to diabetes-related complications.

Monica also noted her positive experience with the diabetes management classes offered at NBDC. She described, “Yes, I am taking diabetes classes to be informed because there are things I do not know. For example, how to read *la lectura de le etiqueta* (nutrition labels). I did not know how to read them and now I am learning how to read the labels in the foods you eat.”

This quote describes the practical skills taught in one of the diabetes classes. This participant’s positive attitude and willingness to learn assists her with her diabetes management.

The next participant quoted participated in the eight-week Diabetes Wellness workshop at the Resource Center, and during the course of the study, after the initial interview, suffered a massive heart attack.

“I think they [the classes] work. They just started last week.” He added, “The problem with this interview is that since I do not feel anything I have nothing to add to the interview.”

Taking classes for diabetes management does not work for everyone. It is important to include that quote because it demonstrates different views between members of the same community. The quote also epitomizes an unhealthy attitude and perception toward a complex and multi-faceted illness.

Home remedies. Findings in this study revealed the existence and use of home remedies (*remedios caseros*), for diabetes management among Dominican older adults. Home remedies were represented in the form of herbs, teas, and juices prepared by participants in their homes. Home remedies were not used or endorsed by all participants; however, participants who used home remedies for their condition described their experience below. Table 5 illustrates the home remedies described by study participants for Type 2 diabetes.

Roberto noted, “Sometimes I drink *Té Jengibre* (ginger tea), but this is the wintertime, so you will be warm. Then, I take care of myself by covering myself and exercising and eating a lot of salad such as broccoli, celery and things like that. A lot of salad, this is good. In the *campo* (farm), a lot of mango, we eat a lot of fruit.”

This was the first participant interviewed in this study and the first to introduce an example of a home remedy used specifically for his diabetes management. This quote was included to demonstrate the presence of home remedies to manage diabetes in the Dominican community.

Marcos reported, “I am taking medicine, and apart from medication there are people who say that cucumber juice helps, too. In this moment, I am also taking a juice that contains *piña y sábila* (pineapple and aloe vera) and *avena* (oats) every morning, and at night when I am getting ready for bed I drink another cup.”

This quote exhibits natural juice ingredients used with medication for diabetes management and the number of times the participant drinks his juice as part of his diabetes regimen.

Ximena: “I take medication and drink a tea for the diabetes—*diabetes san*—and a little pill capsule that they sell. If you go to the store where they have natural products you will find.... two bottles: One is \$9.99 (comes in a bottle) and the other is \$21.00. Ask for Jose and his wife. Do not worry, I will bring you a bottle for you to make a note of it.”

Not only is this participant drinking tea to manage her diabetes, but she is also taking a pill that is available for diabetes at a local *bodega* (local mini-supermarket). This is an example of how accessible non-prescribed treatment options are to older and vulnerable adults.

Fernanda stated, “I would make juices with celery, cucumber, and carrot, and one day my doctor said, ‘Carrot has a lot of sugar.’ For me, it does not feel like diabetes has changed my life because all my life I have taken care of what I eat. Inclusively, in Santo Domingo, I would not use salt for my blood pressure. I can make you rice and vegetables together, what we call *Moro*. I do not put any grease. I cook everything without salt and grease.”

Although the home remedy described in this interview is made of natural products, the doctor informed this participant that it contained high amounts of sugar. This participant may have thought or was probably informed of the remedy’s potential benefits for diabetes, but discovered from her provider that this remedy was not good for her. This is another example of misinformation circulating in the community, and the misperceptions about what is good or not for diabetes self-management.

4.3 Barriers to Diabetes Self-Management (Results)

In addition to discussing the self-management practices of older Dominicans with Type 2 diabetes, another important goal of this research study was to identify barriers to self-management practices. In this study, a barrier is a factor or a series of factors that make it challenging (impede upon) an individual’s ability to manage their condition. Most of the respondents described one or more barriers when it came to managing their diabetes. The following quotes illustrate barriers to self-management practices for Type 2 diabetes as described by participants in the study.

Perception of Illness. One respondent’s initial barrier was lack of knowledge.

“Not knowing the danger of diabetes, I did not know the danger in the disease until I got to this point. Everything controlled was good, but I would do everything with excess, a

lot of excess. Now I control myself. I learned to control myself. There is a saying...If you want life, you have to take care of yourself. It is like those folks that eat sweets, knowing they have diabetes.” (Alejandro)

One of the most life-threatening factors involved in the management of diabetes is not knowing its complexities and dangers. This is a prime example of how being misinformed or not fully understanding the complexity of an illness can also be a barrier to self-management practices. Although this example is not explicitly stated as a barrier, the principal investigator recognized immediately how an individual’s false perception of an illness or lack of knowledge can be a huge barrier for disease management.

“What I mean is that if you treat diabetes well...you are OK, but if you treat it bad, it can be worse. I think there are two types of diabetes. There is one that is related to your nerves. For example, sometimes my wife says something to me I get irritated, and I feel when my sugars go up. Then when I relax I have to apologize to her because I say things that she does not like. I think my diabetes is *emocional* (emotional) because I do a lot of things in my life that I am not supposed to do.” (Moses)

This quote demonstrates a common perception expressed among many participants that diabetes is *emocional* or triggered by *mala sangre* (bad blood). It is important to recognize that older Dominican adults can perceive diabetes as more than just *azucar en la sangre* (sugar in the blood), and these ideologies can influence disease management as well.

“I think that exercise is good for cholesterol because of the grease, it kills the grease, but for diabetes, no. That is what I think.” (Tito)

The notion that exercise is good for one chronic condition but not another is alarming. It was important to include this quote in order to demonstrate the need for more diabetes education with respect to physical activity and exercise.

Diet. Yolanda misses the food she's eaten most of her life.

“It [diabetes] is difficult especially because of the food. We are used to eating strong food [like] *chicharrón* (fried pork rinds). All parts of the pork and all those things are dangerous. It is difficult to restrain yourself even though you grew up with the food.”
(Yolanda)

This quote provides an example of the food that Dominicans are accustomed to eating and the challenges faced by participants when they change their diet and give up their traditional meals.

“It has changed so much because I cannot eat what I want to eat. Cannot eat fried pork rinds and red meat anymore. I have to take care of myself.” (Romero)

“Well, the most difficult thing has been that you cannot eat... for example, a pizza, fried chicken. You cannot gain a lot of weight.” (Juan Pablo)

These participants experience frustration with not being able to eat what they want to eat, and this is understandable. Not only are Dominicans changing what they are accustomed to eating in their native country, but also what they eat in the United States.

Below are additional barriers presented during the interview, including “language” and “disease complexity.” Here are two interesting perspectives worth mentioning.

Language. Hector stressed, “Language barriers are a big problem...some people never learn English. It is not enough to have an interpreter.” This participant recognizes the limitations of interpreter services in the health care system and expresses his own frustration with

members of the community who never learn English; however, this is not true in all cases. There are those who try but who do not succeed in learning a language proficiently and continue to encounter barriers due to their heavy Spanish accents.

Diabetes complexity. Eva emphasized, “The most difficult thing is when it [diabetes] goes up this way and when it goes down really fast. Yes, because when it goes up I have to eat. When it [diabetes] goes down I take natural juice and add more sugar to it or I eat a pineapple.”

This situation depicts a participant’s direct encounter with her illness. This participant is completely aware that diabetes is unpredictable, and its continuous fluctuation is obviously frustrating. Although complex barriers exist for most participants, some reported no barriers at all. The following participants with Type 2 diabetes experienced no barriers with their self-management practices.

Esteban declared, “No, not a barrier. As long as you have it controlled, you can live many years with diabetes. You can live with diabetes while you have other issues like heart disease.”

It is important to recognize and accept how a participant perceives his or her health status, but it is equally important to recognize that barriers to diabetes self-management practices may not always be obvious to an individual living with the condition and other co-morbidities. In other words, the symptoms can be directly related to diabetes but the individual refuses to recognize and accept any ties to diabetes.

Also noted by Leila, “Mine is controlled because I control my diabetes. My diabetes does not control me. I take care of my husband. If I do not take care of myself, then the only option for him is to go to a home.”

This quote clearly depicts a complex and dual care-giving situation for the participant, who is managing her diabetes and also taking caring of her spouse. From a public health perspective, many complex and external barriers can exist for an older adult who is taking care of an ailing spouse, but in the case of this participant those barriers do not exist.

Fernanda noted, “I do not let diabetes control my life. I sometimes call my friend who I had not spoken to in a long time and she sounds like she is dying from cholesterol, and do you think that I am going to let diabetes and my other condition take over my life?”

This is yet another example of how participants explain their experience with diabetes without perceived barriers. This participant perceives no barriers because she does not let diabetes control her life and has a positive outlook on life.

From a research perspective, unreported barriers in this study do not imply that barriers to effective diabetes management do not exist. It simply means that barriers were not reported by these individuals.

Cost. Another common and highly reported barrier discussed by participants is the cost and expense involved in managing diabetes, especially when it comes to medications. It is necessary to incorporate the statements surrounding this important topic as portrayed by participants in this study. Hector expressed his frustration with the high cost of his medications, one of the many expenses involved in the self-management of Type 2 diabetes.

Hector stated, “They [Hispanics] go to those GNC stores. Not just Dominicans; all Hispanics go there, especially if they do not have health insurance. It is difficult unless they have a good health insurance, money, or Medicaid. So for them [Hispanics], they use alternative medicine. With all respect, this is how.”

Esteban reported, “I take medications, but I do not remember the name. They are expensive. I have to buy 200 because I have to take two a day, one in the morning and one in the evening. There is one that I take that is expensive that is for *temblor* (chills), nausea, and *temblor en el cuerpo* (body tremors), and I have to take two. Last night, something bad happened to me. I had this terrible pain in my spinal cord and I wanted to throw up.”

These perspectives introduce a familiar and commonly reported issue among older adults with respect to their diabetes management. The need to purchase expensive medications for diabetes management is a common frustration and barrier for many older adults, especially those on a fixed and limited budget. The high cost of medications for Type 2 diabetes does not include other economic factors involved in the adequate care of this chronic illness. Other factors worth discussing under the topic of cost include the cost of eating healthy and being able to access and purchase fruits and vegetables in the neighborhood in which you reside.

Specific Aim 2

The second aim of this study is to describe the role of cultural factors in diabetes self-management practices among older Dominican adults. Based on the results of this study, “culture” is associated with how participants in this study manage their Type 2 diabetes. Participants described their unique experiences in New York, but also reflected upon their close ties to the Dominican Republic. This unique experience was more evident among participants who continue to travel back and forth to the Dominican Republic. The following section describes the role of cultural factors in diabetes self-management for study participants.

Family. In this study, participants reported primarily how their spouse/partner relationship influences their self-management practices for diabetes. Most respondents discussed

positive experiences with their spouse/partner, but this was not so for all the participants. Below are examples of positive and negative experiences with family members with respect to diabetes self-management practices.

Alejandro declared, “The system is my wife. She suffers more with my illness than me. With her, I learned to manage my diabetes. Without her, I would not know what would become of me. She is the one... I have a home attendant who is supposed to cook for me. But I do not let the home attendant cook for me. Nor does she [wife] accept either. I eat what she [my wife] prepares for me.”

This is a classic example of how a family member plays an integral and positive role in managing diabetes. This family member is instrumental and influential on a variety of levels, but obviously this one person cannot do it alone. An older Dominican adult with diabetes can also benefit from the support of a home attendant, if necessary.

Angelica pointed out, “Look, he was always making sure that my sugars would not go up. And he lasted one month in the hospital going every day, and he would say to me, ‘Do not get sick because we cannot afford for both of us to get sick.’ He went in for his operation, for heart surgery, and never left the operating room. I say he is the reason why I do not have high sugars, Thank God. I did not cry, not one tear, because I was full of *coraje* (courage), and I say he was the one who helped me.”

It is essential to include this quote to demonstrate how the strength of one spouse provided the will and determination to live for the other. It is not uncommon to see two or more family members living with diabetes in one Hispanic/Latino household. When the husband passed away, the surviving spouse was full of courage (*coraje*). This quote demonstrates the need for increased mental health intervention for older Dominican adults with diabetes.

Roberto exclaimed, “She is the one who prepares my meals, but I am the one who takes care of myself.”

This is an example of how an individual receives support from his wife (with the meals she prepares) but ultimately the diabetes care lies on the individual. This is essential to note, for it demonstrates the distinction and difference in cultural patterns within the Dominican community.

In this discussion, it is also important to note that not all Dominican families have support when it comes to effective disease management.

Esteban clarified, “No, my wife does not have diabetes. She does not help me. I take care of myself and prepare my meals for myself. I eat a little bit. I have to control the grease.”

This quote represents the lack of family support in this Dominican household. One cannot assume that all Dominican families provide a supportive environment for effective diabetes self-management. Since the wife does not have diabetes, the participant reports that she does not help him. This is the negative side of social support.

Romero declared, “My doctor sent my wife a letter indicating that she could not use this *condimento* (condiment) in my food. Ssshh, she is here with me. Without this, it [diabetes] is controlled. If she uses it again, it is not controlled. Yesterday, my sugar was at 256.”

Two issues are clearly represented in this quote. First, the provider reached out to the wife to change the condiments used in his client’s meals. Second, the participant is somewhat fearful of his wife (even during the interview), indicating that she is a huge barrier to his self-management practices and that he probably does not have the courage to stand up to her. This is

another example of how family can influence and have a big impact on self-management practices in a negative way.

Travel to Santo Domingo

All participants in this study have worked and lived in the United States for many years (10 years and more) and revealed strong cultural ties between New York and Santo Domingo. Participants in this study travel to and from Santo Domingo periodically for vacation and to visit family. The length of time for travel varies and depends on the individual and their economic and personal circumstances. The ongoing connection between New York and Santo Domingo can be associated with the changes in “routine” self-management practices. The following examples illustrate some of the experiences encountered by participants in the study.

Juan Pablo noted, “Oh, there is where I loosen the rules. Well, they do *chicharrón* (fried pork rinds) and they make you eat there and you lose the rhythm that you have here, and when you check the sugar — boom, it is around 160, 170, 200. From the moment you arrive [in Santo Domingo], you have people waiting on you. You lose the routine. When they go over there [Santo Domingo], they [visitors from New York] go house to house.”

This quote is an excellent example of the cultural experience of an older Dominican adult when he/she visits Santo Domingo. Notice how the participant is fully aware of how his routine changes when he travels while he explains the process in which it occurs. It is essential to discuss this topic because this particular cohort [age group] travels to and from Santo Domingo several times a year, and this cultural practice has several positive and negative implications for their disease management regimens.

Maria stated, “For lunch in Santo Domingo, you must have rice *habichuelas* (rice and beans) and meat. Meat should be meat, pork or chicken. Or they make rice with beans

together, also known as *Moro*, very heavy. At night, they make another heavy meal, but not everyone does it, especially if they are sick.”

In addition, Maria emphasized, “That is why I say there are a lot of people with diabetes because the diet has a lot of flour so those that live here have the same customs when they come here. Yes, over here they have the same customs. When I came here, I wanted to vary my meal.”

These quotes illustrate in great detail a traditional meal in Santo Domingo. The participant highlights the key components and discusses the process that occurs in the evening with another heavy meal. For an older Dominican adult with Type 2 diabetes, especially one who travels frequently to Santo Domingo, this cultural practice can be extremely dangerous. It is critical to recognize and accept this reality, and incorporate it into diabetes education discussions and practices with all health professionals.

Most participants identified and agreed with the conviction that the Dominican culture influences their self-management practices, but not all participants would blame their culture as the reason for poor self-management practices.

Tomas argued, “Yes, [the Dominican culture] helps because when you take care of yourself, I do not associate it with the country where you are from or live... You need to try to take care of yourself and do the best you can.”

This is a great example of someone who takes ownership over his actions/behaviors and does not believe that a country or culture is to blame for poor self-management practices. This quote exemplifies the need to accept two different perspectives when it comes to an individual’s background and culture.

Specific Aim 3

The third aim of this study is to examine the relationship between cultural-social structural factors and diabetes self-management practices among older Dominican adults. Throughout this study, participants described their self-management practices (i.e., diet, medication, glucose monitoring, and exercise) and cultural factors (family relationships and ties to the Dominican Republic) associated with their Type 2 diabetes. This study also explored the relationship between cultural and structural factors and diabetes self-management practices.

An example of how cultural and structural factors are associated in self-management practices can be seen in Monica's case narrative. During the interview, Monica described her long and difficult journey to the doctor's office to address a serious and complicated vision problem, which resulted in her being partially blind in the right eye for one year. Because of the persistence and support of her family (sister) and her psychiatrist, Monica overcame her fear of doctors and needles in order to save her vision before her condition became permanent.

For this participant, the positive relationship and ongoing efforts between cultural and societal factors played a major role in saving her vision, but it is important to note that this was a complex, arduous, and lengthy process. This unique and classic example demonstrates how poor diabetes self-management practices (over a 20-year period) can adversely affect other parts of the body. This section demonstrates the complexities, including mental and emotional, connected to the self-management practices of diabetes for this particular older Dominican adult.

Problem 1: More than 20 years earlier.

“When I was 20, they [family members] did the same thing because all my teeth were ruined, and at the time they wanted to take out all my teeth and I did not want to go to the dentist. The dentist wanted to take out all my teeth and how was I supposed to go to my

appointments? I did not want to go without teeth. I said I was too young to go out without my teeth. If I go to the dentist I have to take out all my teeth. This is how I ended up at the hospital and ended up blind, and then they sent me immediately to the eye doctor and they told me I had cataracts. I had gone to the eye doctor before and he had already told me that I needed to be operated on the right eye and then on the left eye, and that I only had six months to get it done.” (Monica)

This older adult describes how challenging it can be to overcome her fear of visiting a health care provider. This is important to consider when it comes to effective disease management for Dominican older adults with mental illness as well. In the unique case of this participant, the fear of going to a doctor stems from her early adult years. This level of historical and medical background is essential for all her health care professionals, including her dentist and psychiatrist. The problem for this participant was not unique to her dentist, but also to all other health professionals, and this piece of information is absolutely necessary when considering treatment and intervention options for an older adult with diabetes.

Problem 2: Visiting the Doctor. Then, Monica described how she found out she had diabetes.

“Because I would not go to the doctor. I thought I had diabetes, but did not go for 20 years for fear of doctors and fear of needles. Because I feared doctors, I would not go to the doctor. The police came and said, ‘If you do not go we will take you by force,’ and I told the police that I should not be taken because I was not a delinquent. So it was my sister and Dr. Futenburg, my psychiatrist, the ones who arranged for the ambulance to take me.”

This is a unique and classic example of how cultural and societal factors (if both are present) can work together to influence the management practices of diabetes for an older adult with other co-morbidities, including mental illness. Two key factors (family and health care provider) played a major role in planning and implementing a strategy which involved another key factor (police), and it worked for this participant. However, it is important to stress that this approach may not work for all older adults in the same situation. More importantly, this strategy was carefully directed by key professionals and used with extreme caution with the involvement and careful planning of all key players, including the police, in order to help the participant save her vision and possibly her life.

Culture: Family. “I would tell my sister, ‘Do not worry, I can stay blind,’ and my sister would say, ‘Let’s go so you can get operated on, even if you are mad at me for the rest of my life,’ and because of this I have my eyesight. I have thanked her several times, because of her I was able to see again.” (Monica)

It is imperative to break apart the key factors in this successful narrative in order to better understand the challenges encountered by all key players involved. In the case of this participant, it is clear that the sister played a major role and most likely orchestrated and planned it carefully with other key members of the team.

The family member probably had the most influence because of her close and positive relationship, but this does not imply that the sister had the easiest task. The participant had no problem with saying no to her sister initially, but ultimately was grateful for her sister’s persistent intervention and ongoing efforts. Trust among key family members can influence a successful diabetes treatment intervention option for complex individuals with poor diabetes management practices.

Social structure (institution): Prison.

“I did not want to go to prison. They were going to handcuff me. Since the doctor sent them I have to go, obligated. The hospital sent an ambulance so I went with them. This was the motivation. If I did not go, they would have handcuffed me.” (Monica)

The likelihood of this older adult’s being arrested for not complying with her diabetes regimen was highly unlikely, but the fear instilled in the participant’s mind about the possibility of being arrested was the strongest motivator for compliance. Again, this tactic was carefully used and mapped out by the family because of the challenges presented by the participant. Once again, this was a last and extreme resort strategy used by family members and the participant’s psychiatrist to save her vision and life.

Hospital.

“Yes, but the diabetes came first. I was blind for a year first. They operated on my eyes first because of my blindness. Once at the hospital they assigned a home attendant immediately. After the operation I was there 15 days and since the police took me to the hospital they would do everything for me. They assigned a nurse who would help me bathe, eat, and take care of myself again.” (Monica)

This unique and complex narrative exemplifies the relationship between cultural and structural factors and self-management practices for a complex and difficult-to-reach study participant. Although the participant knew she had diabetes, this factor alone did not influence her to receive medical care. It took the participant’s will to save her vision and most importantly, the direct involvement of family, health professionals, and even the police, to persuade her to accept the medical attention she needed. Once the immediate and most pertinent

health problem received medical attention, then the participant was able to move forward, toward learning the appropriate and adequate steps for medical care.

Examples of Other Cultural and Societal Factors

Participants in this study have demonstrated how cultural and structural factors are associated with disease management practices. Findings from this study illustrate how cultural and structural factors are present in effective disease management.

Relationship with the Provider. Most participants in this study had a positive relationship with their provider. A positive relationship involved not only successful treatment and intervention, but also trust and being able to communicate effectively with the provider. The notion of having a good relationship with a provider was emphasized by the participant who is HIV positive.

Fernanda explained, “Since I have my doctor and I have a worse medical condition. You know, my doctor has been taking care of me for twelve years and she had been taking care of me all my life and my entire health.”

This participant has a strong and healthy relationship with her provider for more than ten years. Because of her HIV positive status, this participant stresses the importance of having a caring and trusting provider. Unlike many patients, this participant is extremely fortunate to have this type of relationship with her provider for such a long period of time. And these key elements, in this particular patient-provider relationship, allow for successful disease management for her diabetes.

Angelica noted, “She [doctor] calls me at home and she went to my house one day. It is very good, very good.”

This is the only participant who mentioned that her doctor went to her house one day. This rare but historical practice among health care providers is a great example of why this participant described her experience in such a positive way.

Leila declared, “My doctor? She is wonderful and I have a good relationship with her. She adores me and says that she wishes all patients were like me. I guess I get along with a lot of people. She is white [Caucasian] but I do not like to see anyone but her. She talks to me since my problem is mostly emotional and she is normal.”

It is interesting and equally important to hear a participant for the first time describe her experience with her provider in relation to the provider’s race. The principal investigator did not ask the race or ethnicity of the health care provider, but the participant felt compelled to share this information with the principal investigator. Once again, this doctor exhibits other key elements for a positive patient-provider relationship. In the case of this participant, compassion and empathy are important components of her medical visit.

Moses explained what it means to be a good doctor. “A good doctor is someone who is not a *practicante* (resident). They always put you with a *practicante* (resident), and by the end of the year they are not there anymore.”

This is a common and frustrating complaint among most of the participants in this study, especially if they are assigned a *practicante* (resident in training). Unfortunately, the participant does not understand that this is common medical practice, especially in a teaching hospital, but the take-home message is simple. Older Dominican adults know and are aware of the type of provider they receive, and it is important to communicate this information directly with the patient first during the medical interview. It is understandable that a patient may feel frustration during his medical visits if every six months he/she encounters a different resident in training.

This is an example of how the system can also negatively influence the successful outcomes of diabetes management.

Communication with Provider. Participants in this study shared the perception that communication with your provider is essential for effective self-management diabetes. Fernanda also pointed out, “She [doctor] loves me and does not want anyone to know about my condition. She is protective. She does not like interpreters because of my medical privacy issue. When she needs to talk to me and we do not understand each other, my doctor calls my daughter.”

This is an example of how privacy and confidentiality are more valuable to the patient than using the services of the interpreter during the medical interview. It is important to respect the wishes of the older adult, even if it means excluding the resources available at the hospital.

Roman pointed out, “He knows what the problem is but he does not know how to express it. I had a problem that occurred to me, but the problem was that he did not speak Spanish, but his secretary did. The secretary told me that I should limit my answers to questions asked by the doctor, and I just said to the secretary, ‘Look, excuse me, I am the patient and I am going to tell the doctor what was happening to me.’ I would answer the question, but as the patient I had a right to tell him my symptoms. She had some nerve doing this.”

This is a case where the interpreter services are lacking during the medical interview and the doctor’s secretary is used as an untrained medical interpreter. Not only does she lack training and cultural competency in this area, but also respect for this older Dominican adult. This is an example of how structural factors can complicate an individual’s ability to effectively manage their diabetes.

Miguel provided this perspective, “I seek out people who speak Spanish, like the majority of people in this office, and that is how I defend myself. I understand a little bit but I cannot say that I understand everything that is said to me.”

It is important to show an example where no interpreter services exist in a medical setting. This quote highlights an older adult’s perspective and experience as he tries to navigate the health care system with limited bilingual skills.

The following section provides additional examples of structural factors associated with diabetes disease management. Cultural factors are represented through the experiences encountered by Dominican older adults.

Lack of Health Insurance. Moses noted, “So yesterday, I had an appointment with Medical Presbyterian, but they did not want to check me because I do not have insurance for the doctor, but I explained to them that I need medicine because I do not have medicine, but they told me they could not do anything because I had to see the doctor so I went to administration and all they said was, ‘I am sorry. I am sorry.’”

This quote exemplifies the experience of an older Dominican adult trying to purchase medication without health insurance. The experience encountered at the administration office exemplifies the need to improve health care services for older Dominican adults. This is a classic circumstance in which the lack of health insurance impeded the participant’s ability to obtain the medication needed to effectively manage his illness. It is also apparent that the administrative staff at the hospital was unable to provide public insurance options for the participant.

Oscar declared, “Back then, I felt bad and I did not have Medicaid, and based on a recommendation from a friend I was able to get Medicaid and transfer to Medicaid

Center. When I met with the doctor at 204th street, I did not have insurance. So when I went to the doctor, it was an emergency visit and this is when they gave me Medicaid.”

This participant felt the need to describe the process of applying for Medicaid and his experience when he did not have medical coverage during a medical visit. This is another example of the people who are eligible for public health insurance but who are not aware of their eligibility until they have an emergency visit to the doctor.

Moses noted, “The person I spoke to at administration spoke Spanish, but the only thing she could say was that she felt bad because I had no health insurance and that I needed insurance so the doctor could check me. I applied for Medicaid. I did it two months ago, and they told me the application was incomplete and incorrect. Now I am reapplying but I had to pay again to see the doctor. I would have to pay if I wanted to see the doctor. I would have to pay to see the doctor. I could not pay because I have no job. When the Medicaid papers arrive to return to the office, I could see a doctor.”

It is important to include this quote to demonstrate the challenging Medicaid application process for older adults. There could be a variety of reasons why the application was incomplete or incorrect, but this process (application rejection) now creates economic hardship for an older adult on limited income, especially if he/she has to pay out-of-pocket for his/her medical visits.

Moses continued, “It has been three years since my last appointment. When you call they tell you the doctor is not available and if you go in person they tell you [the same thing]. They do not call you if they cancel the appointment either. Last month, I went as a walk-in, and they said that they remember that I did not go to the appointment.”

This quote expresses yet another level of frustration for an older Dominican adult as they encounter the health care system. Instead of saying that the receptionist was helpful, the

participant reports how he was treated at the front desk during a medical appointment because he did not go to his previous medical appointment.

In addition to reporting the results of this study as they relate to the specific aims, it is central to discuss findings that also influence when one is conducting research studies and when one is treating older Dominican adults with Type 2 diabetes. The following section will focus on two pertinent findings: 1) the A1C glucose blood test, and 2) mental health issues, which also influence effective and successful management of a chronic condition.

4.4 A1C Test

In several interviews throughout the study, participants demonstrated a lack of knowledge or clear understanding of the A1C test, a test that measures your average blood glucose control for the previous two to three months (ADA, 2011). Many participants were informed and capable of describing their own glucose monitoring process at home (with their finger and machine) but many could not clearly explain the A1C test, what it represents, or how often this test should be administered during the year. Only one participant could correctly define the A1C test and its purpose, and this was the participant who took classes at both the AIM clinic and at Naomi Berrie Diabetes Center through Columbia University Medical Center. Not surprisingly, most participants called the A1C test *el examen de azucar/sangre* (the sugar/blood test), and perhaps this was due to their ambiguity with the technical and medical term more commonly used by health care and diabetes education experts. Another participant called it something else.

Miguel explained, “I do not know, there are a variety of exams she used. An exam for diabetes.”

This is a common way of describing the blood work done at the hospital or medical office. This is also an example of a participant who is not fully informed by the provider or lab

technician of what type of tests are being administered when blood is drawn. This is not always the fault of the individual with diabetes.

Antonia noted, “I know you had to take the blood from the finger, but that only determines the level for the day. But for the last three months or the next three months is determined by the A1C.”

This is the only participant who clearly and correctly defined the A1C test and its purpose. This quote demonstrates an older Dominican adult’s ability to learn and actively engage in the learning process for effective self-management of diabetes.

Ricardo stated, “No, I do not know my A1C count.” He added, “If my blood is clear it is not good either. If it is thicker it is better.”

This participant was not embarrassed to admit that he did not know his A1C count, which was common among many participants, but even more alarming was his analysis and interpretation of his own blood. Perhaps the participant understood or was informed that the thickness or clarity of the blood determined how much sugar one has in the body. This quote clearly supports the notion that more education is needed in the area of glucose monitoring and the A1C test.

4.5 Mental Health

Findings from this study also identified mental health issues associated with effective diabetes management, and this area is worthy of discussion as well. Although this study did not focus primarily on mental health issues, study participants shared this information.

Ximena explains, “Yes, depression makes me cry a lot. And you know what makes me afraid? I close the door and leave the keys in the house. The neighbors help me. They have helped me several times.”

This participant knew without a proper medical diagnosis that diabetes makes her sad. She is also describing early signs of dementia, but she is fortunate to have neighbors who can help her. What makes this situation more difficult is her poor relationship with her family members. She complained about a niece who treats her badly in her own home. This older adult could be experiencing elder abuse along with her other co-morbidities and symptoms of depression. These factors could easily exacerbate her depression.

Marcos declared, “Look, in confidence, this is trauma that obligates you to do something you are not supposed to do. Because you get desperate and you ask yourself, ‘Why live?’ So let’s begin to discuss the problem with the couple. My wife is young, she is only 49 years old.”

This quote is extraordinary because the participant (male) felt comfortable to disclose an extremely sensitive topic few older adults (especially males) care to discuss. For men, sexual dysfunction can be detrimental physically, emotionally, and mentally, especially when they have a younger spouse/partner. This quote illustrates an important co-morbidity rarely discussed, but important to consider when treating mental health issues in older adults with Type 2 diabetes.

Summary

These findings demonstrate the variety of self-management practices and perspectives of the older Dominican adults with Type 2 diabetes. They also illustrate the complex linguistic and economic barriers encountered by older Dominican adults and when family can be associated with how an older adult successfully manages their chronic condition. The unique case study presented in this study demonstrates the need to approach future diabetes care and interventions on an individual basis. Finally, these findings highlight both the traditional cultural (family) and

non-traditional (societal) factors which can be considered when working with a complex and non-compliant older Dominican adult with Type 2 diabetes.

This section reported the culturally unique self-management practices of older Dominican adults with Type 2 diabetes using in-depth interviews in Spanish. The first part provided a demographic overview of the study participants as well as their acculturation levels in the United States. The second part provided a closer look at the unique self-management practices specific to older Dominican adults with Type 2 diabetes. These results demonstrate that cultural and structural factors can be associated with behaviors and perspectives of the older Dominican adult with Type 2 diabetes.

Chapter 5: Discussion

This section discusses and interprets the study findings for the self-management practices of older Dominican adults with Type 2 diabetes. It is organized by the Specific Aims of the study, and introduces a new explanatory model for Type 2 diabetes specific to older Dominican adults, which resulted from the development and implementation of this study design. The study's limitations, implications, as well as recommendations (next steps) for future study with older Dominican adults, will also be discussed.

5.1 Specific Aim 1:

Explore the self-management practices (including folk/home remedies) and barriers to diabetes self-management among older Dominican community residents (55+, hereafter referred to as older Dominicans) living in the US mainland with Type 2 diabetes.

Findings from this study demonstrate that older Dominican adults have an overall basic and general understanding of the self-management practices needed for effective diabetes self-care. Throughout the interviews study participants described self-management practices similar to those outlined in the American Diabetes Association's 2011 Standards of Medical Care in Diabetes. However, findings from this study also revealed that older Dominican adults could benefit from obtaining further guidance and support in order to effectively manage their Type 2 diabetes. In addition, this study discovered that participants would benefit from additional information about Type 2 diabetes. Some participants had limited understanding of their condition which adequately impeded their ability to manage their diabetes and to be able to distinguish the differences between having a Type 1 and Type 2 diabetes diagnosis.

Most participants throughout the study reported diet, medication adherence, exercise, and diabetes classes as part of their self-management practices. However, data from this study also

revealed that many study participants do not perceive or include physical activity as part of their self-management practices for their Type 2 diabetes. A few study participants did not see how exercise could be good for diabetes management. This finding is consistent with a study by Nagelkerk, Reick and Meengs (2006) who found that exercise was not a priority for elderly participants in the study. This finding demonstrates that one area which needs to be emphasized is the importance of exercise for effective diabetes self-management.

Home Remedies

Findings from this study support the assumption that most study participants are aware of existing *remedios caseros* (home remedies) and use *remedios caseros* to assist them in managing their Type 2 diabetes. Home remedies described in this study are unique to members of the Dominican community and most often shared through word of mouth in a variety of settings, including the waiting area in medical offices. The use of home remedies is influenced by cultural and behavioral practices which stem from the Dominican Republic. Most study participants reported the use of plants, herbs, and roots which can be easily accessed in local neighborhood bodegas (small mom-and-pop grocery stores) and mainstream grocery stores in the community.

In addition to preparing home remedies at home, participants described the accessibility of non-prescribed medication through private local business merchants who claim to have medication, especially for diabetes. These businesses were reported by several participants as another venue where one can obtain medication for diabetes in the neighborhood. As this study demonstrates, older Dominican adults have unique ways of managing their chronic illness, and findings from this study identified the existence and use of *remedios caseros*, especially for diabetes management.

Data from this study demonstrates that older Dominican adults are familiar with and oftentimes use home remedies to manage their diabetes. Currently, there are few studies which focus specifically on how older Dominican adults use home remedies to manage Type 2 diabetes. However, a recent study by Vandebroek et al. (2010) found that Dominicans do, in fact, use home remedies to manage a variety of chronic illnesses, including diabetes. The use of home remedies to treat or manage diabetes is culturally acceptable for Dominicans, and data from this study demonstrates the continued existence of the practice in the United States. This awareness and acceptance of these cultural practices by health care professionals can help to explain a common cultural belief and practice in the community. This study extends the literature by discussing how older Dominican adults use home remedies to manage their Type 2 diabetes.

Findings in this study suggest that an in-depth explanation of the extent to which older Dominican adults use home remedies to manage their diabetes and how age, gender and acculturation factors influence the decision to use or not to use home remedies when managing a chronic illness is merited. In 1996, Markides and Black reported that factors such as assimilation, language, and socioeconomic status can influence the use of home/folk remedies in chronic disease management. The findings from this study are consistent with their work.

More research is needed to explore non-conventional practices and potential use of home remedies for diabetes management among older Dominican adults. Studies focusing on this topic often cite or include research studies of Mexican and Cuban populations (de Alba Garcia, Roche, & Lopez, 2007; Mikhail, Wali, & Ziment, 2004; Poss, Jezewski, & Stuart, 2003; Vandebroek et al., 2010). However, as the present study demonstrates, there exist culturally

specific practices and beliefs supporting the importance of increasing the availability and quality of studies in which older Dominican adults comprise the sample.

5.2 Barriers to Diabetes Self-Management (Discussion)

Participants in this study described several barriers which can influence effective self-management, including: 1) perception of illness (not knowing or fully understanding diabetes as an illness); 2) diet; cultural practices; 3) language; and 4) diabetes complexity. Few studies have examined barriers specific to older Dominican adults which can also be associated with poor self-management practices. Findings in this study suggest the need to further explore barriers to self-management practices specific to older Dominican adults. Results reported in this study are consistent with the finding from several research studies, which demonstrate how effective diabetes management can be complex, life-style restricting, and more challenging for older adults, given the co-morbid medical issues and the generally lower functional status of the older adult patient (ADA, 2011; Chau et al., 2001; Hainer, 2006; Tucker et al., 2000).

While a number of studies have focused on the barriers specific to older Hispanic adults with diabetes (CDC, 2011; Coronado, Thompson, Tejada & Godina, 2004; Harris, Eastman, Cowie, Flegal, & Eberhardt, 1999; Hatcher & Whittemore, 2007; Tucker et al., 2000; Rosal et al., 2005; von Goeler et al., 2003), few studies include or examine barriers unique to older Dominican adults. Findings in this study demonstrate the importance of exploring barriers which may be associated with self-management practices for older Dominican adults.

Perception of illness. Findings in this study revealed that perceptions of Type 2 diabetes for participants vary, and certain misconceptions of diabetes continue to exist in the community. A common and highly reported barrier identified in this study was a participant's inability to fully understand the danger and complexity of diabetes. This finding is consistent with studies

which explore how the lack of information or knowledge of disease management (integrating self-management behaviors with daily routines) can serve as a barrier to effective diabetes self-care (Bernal, 1986; von Goeler et al., 2003). Findings in this study revealed misconceptions about diabetes and medication usage among study participants with Type 2 diabetes. This finding is similar to another research which found that regardless of length of time and treatment of an illness, a patient will hold beliefs about disease and medication practices that are inconsistent with a chronic disease model of diabetes (Mann et al., 2009).

Another central feature in this study is the proclaimed causes for diabetes from the perspective of the older Dominican adult. Older Dominican adults in this study reported their Type 2 diabetes as an “emotional” disease and attributed their illness to *mala sangre* (bad blood) or *coraje* (anger) and this too is consistent with other studies focusing on Mexican-Americans which indicate emotional stress and trauma as reported factors for diabetes (Coronado et al., 2004, Jezewski & Poss, 2002).

Findings from this study are consistent with earlier research which examined emotional and lifestyle factors associated with the development of diabetes for Hispanics in New York City (Zaldivar & Smolowitz, (1994) as cited in Caban & Walker, 2006). Data from an investigation on Mexican-Americans in El Paso Texas (Coronado et al., 2004; Jezewski & Poss, 2002) also reported a myriad of reasons Mexican Americans claim to be the cause of diabetes. In the El Paso, Texas study for instance, respondents reported *susto* (scare or fright), unhealthy lifestyle, and hereditary factors as the primary causes of diabetes, and viewed *susto* as a condition that preceded the diagnosis, and a scare or strong emotion (happiness or anger) occurred prior to diagnosis of diabetes (Jezewski & Poss, 2002).

Regional and geographic difference exists between Mexicans in the US, and findings from a study on Mexicans from Yakima County, Washington are similar to the present investigation. Participants in the Washington study also attributed *susto* to the onset of their diabetes, in addition to environmental and genetic factors. Similar to the Mexicans in El Paso, Texas, extreme emotional states such as *coraje* (anger), *tristeza* (sadness), and *gusto* (joy) were also associated with on the onset of diabetes (Coronado et al., 2004). Although both studies focused on Mexican-Americans from different regions, neither included other Hispanic/Latino subpopulations, both pertain to only Mexican-Americans from two different regions.

5.3 The Role of the Older Dominican Adult in the Family

Findings from this study illustrate the various roles older Dominican adults can have in a Dominican family household. These findings are consistent with Paulino's study (1998) which depicts older Dominican adults as 'survivors' because they are resilient and are capable of overcoming so many barriers. Paulino's study describes older adults in the context of "*contra viento y marea*" (against all odds) because they have been able to cope with adverse situations (Paulino, 1998). Paulino (1998) demonstrates that serving as a family caregiver is the primary role of an older Dominican adult in many households.

In this study, many participants reported that taking care of a family member or a loved one (spouse or grandchildren) is a primary role in their life. This finding is consistent with studies which have examined the role of the Latino grandparents as caregivers (Burnette, 1999, 2009). Many participants in this study described their role as family caregivers as "difficult and exhausting." This finding was expressed mostly by female participants who described housework as part of their role as caregivers in their home. This finding is consistent with several studies on caregiving which describe family caregivers as individuals who experience

stress, and more depression and physical problems than their peers (Raveis, Karus, & Pretter, 1999; Raveis, Karus & Siegel, 1998 as cited in Raveis, Gardner, Berkman & Harootyan., 2009).

Interestingly, Burnette (1999) associates the experience of being a caregiver with “role overload.” The notion of “role overload” and the strain of being a caregiver can also be associated with the way an older adult manages their Type 2 diabetes. In addition, the “lack of sufficient resources” to fulfill role expectations can be the most common and severe type of role strain experienced by caregivers (Burnette, 1999). A lack of sufficient resources could help to explain why many older Dominican adults in this study carried out the role of family caregivers while also maintaining a household.

Finally, in this study, several older Dominican adults describe their family caregiving experience as “difficult and exhausting.” This demonstrates that activities related to this role may, in fact, impact an older Dominican adult’s ability to manage their chronic conditions as well. These findings are reflective and consistent with the family caregiving research which has studied the long-term impact associated with caring for family members with chronic conditions (Greenburg et al., 2004; Li & Fries, 2005; Raveis, 1999; Raveis et al., 2009). This study substantiates the need to further explore the long-term impact on older Dominicans when they serve as primary family caregivers while managing and caring for their own chronic condition and related disabilities.

Diet. Findings from this study identified diet as the most complex and highly reported barrier for effective diabetes self-management. This finding is consistent with many studies reporting diet as a major barrier to effective diabetes self-care (Nagelkerk, 2006). Some generalizations can be made from the findings. Study participants reported two types of challenges when it comes to modifying their diet for effective diabetes management. First,

participants need to modify their diet that is highly influenced by their Dominican culture. Secondly, participants need to change the way they are accustomed to eating in the United States as well. This dual life-restricting diet modification task can be daunting and overwhelming for older adults. More research is needed to explore barriers an older Dominican with diabetes may encounter when he/she modifies a diet that is highly influenced by two dominant cultures.

This study finding concurred with Whittemore (2000) who reported several strategies that can be used to facilitate lifestyle change for effective diabetes management. An individual's ability to comply with dietary changes is affected by barriers as well as an individual's lifestyle and confidence in their ability to implement a self-management plan (Whittemore, 2007). In the case of the older Dominican adult, it is necessary to consider barriers as well as the lifestyle of the individual which clearly can impede adherence due to invisible barriers that may be presented from a particular community.

The revelation that diet is a barrier and a challenging element to diabetes care is consistent with other well-known studies (Glasgow, 1984, Nagelkerk et al., 2006) which describe diet as a barrier to diabetes management. In addition to describing diet as a barrier, participants in this study expressed frustration with not being able to eat the foods they were accustomed to eating their entire lives. In this study, participants attached to "comfort food" and this can be difficult and can be associated with sadness or frustration, as expressed among participants. This finding is consistent with a study which discusses the notion of mourning the loss of a patient's usual lifestyles (Nagelkerk et al., 2006). However, there are few studies, if any, which can describe how changes in diet can influence the way older Dominican adults manage their illness.

According to Nagelkerk et al. (2006), many patients struggled with reframing their eating habits because it requires routine mealtimes and changing foods, resulting in a loss of

spontaneous eating, which participants in this study also described and expressed throughout the interviews.

In this study, participants disclosed that dietary restrictions continue to be an ongoing challenge when it comes to diabetes management. Interestingly, for some study participants, it is much easier to give up food in the United States for the sake of improving their diabetes, but they could not always give up food which made them feel good. Certain foods from their culture were associated with comforting the individual with diabetes. This idea is important for health professionals and diabetes educators to keep in mind when developing interventions, especially for older immigrant adults whose diet consists of foods from two important cultures. Interventions of diabetes education plans should incorporate bi-cultural interventions specific to the individual. This finding helped to reshape the way certain foods assist or do not assist with the management of diabetes and how culture continues to play a role in how a Dominican older adult with diabetes manages their chronic condition.

Language. In this study many participants had Spanish-speaking providers, but this was not the case for all respondents. Findings from this study indicate that language barrier is a problem for some participants during a medical interview, especially when a provider did not speak English or when a substitute interpreter, such as the doctor's secretary, became an impromptu untrained medical interpreter. Language barriers were especially challenging when participants inquired about medications or prescriptions. As reported by participants, an individual's inability to understand and read his/her medical prescription is detrimental and can have legal and liability implications as well for all health professionals.

Findings from this study are consistent with studies which indicate that language can be a common barrier to accessing medical and social services among older Hispanic/Latino adults

with limited English proficiency (Mutchfer & Brallier, 1999; Ponce, Hays & Cunningham, 2006). This finding is consistent with a study which found that Latinos who speak primarily in Spanish are less satisfied with their health care than those who speak English (Wallace & Villa, 2003; Weech-Maldonado, Morales, Spritzer, Elliott, & Hays, 2001). A benefit to preserving the Spanish language would be the preservation of ethnic identity and culture. But there are also limitations to speaking only Spanish in the United States, a country in which English continues to be the predominant language. An older Hispanic/Latino adult who speaks only Spanish can become “linguistically isolated,” and this was expressed by many older Dominican adults who never learned to read or write in English.

The notion of being linguistically isolated can be a common phenomenon for an older adult in the United States who does not speak English (Talamantes, et al., 2011). As demonstrated in this study, language barriers can be associated with an older Hispanic/Latino adult’s inability to adequately and effectively manage their diabetes. Paulino (1998) supports this finding by explaining the consequence of a language barrier for an older adult. Paulino (1998) states, “Lack of appropriate integration of valuable culturally specific information places the immigrant family at risk of being misdiagnosed and inappropriate served.” This conviction is true for all older adults of Hispanic/Latino background and has not changed much since Paulino’s study was published in 1998.

This study’s finding demonstrates that effective diabetes management can be influenced by many factors (Flores, Abreu, Oliver, & Kastner, 1998; Jacobs, Karavolos, Rathouz, Ferris, & Powell., 2005; Ponce et al., 2006; Timmins, 2002; Woloshin, Schwartz, Katz, & Welch, 1997). In addition, it is worth mentioning that most studies focusing on the impact of language barriers (linguistic disparities) have focused on children and adults in their child-rearing years (Zhou,

1997). Little attention, if any, has been given to the impact of language on the ability to communicate with older adults, who Ponce et al. (2006) describes as individuals who may be especially vulnerable to adverse health outcomes resulting from language problems in health care access. More research is needed when it comes to understanding how language can be a barrier to older Dominican adults with diabetes.

5.4 Diabetes Complexity

In this study, participants reported and expressed various barriers which influence the way older Latino adults manage their Type 2 diabetes. For participants in this study, the complexity of an illness can be expressed in various forms. Several factors make diabetes a complex and severe illness. This finding is consistent with other research studies which have examined the severity of the illness. Hatcher and Whitemore (2007) explain how Hispanics reported diabetes as a very serious, life-threatening illness, and they lived in fear of the consequences of diabetes. Feelings of anxiety and fear were clearly present among participants in this study and expressed in a variety of ways. For example, a male participant in my study reported frustration with sexual dysfunction as a consequence to his diabetes diagnosis. As a result of his diabetes diagnosis the older adult also expressed anxiety related to his sexual insecurities which can also serve, in turn, as a barrier for effective self-care. This finding is consistent with a study in the literature which presented sexual dysfunction as a lifestyle barrier for both women and men with Type 2 diabetes (de Alba Garcia et al., 2007).

Cost. Another important finding reported by study participants is the cost of expensive medications for diabetes. Participants in this study reported that sometimes they do not have money to purchase medications, and that medication for diabetes is expensive, especially for older adults on fixed incomes. Cost of medication can be a burden for participants, especially for

those who frequently travel to and from the Dominican Republic. Participants in this study reported that when they travel to the Dominican Republic, regardless of length of time, they travel with an ample supply of medication for their entire trip for the reasons described above.

The finding is consistent with a study which indicates that medication for diabetes is expensive and scarce in the Dominican Republic (Barceló, Aedo, Rajpathak, & Robles, 2003). The finding that cost is a barrier to diabetes management is also substantiated by Chesla, Skaff, Bartz, Mullan, & Fisher (2000) and Konrad (2010) who report that cost continues to be a barrier to self-management practices, and this includes the expense of healthy foods, medications, and glucose strips. This study demonstrates that for older Dominican adults living on a fixed income, Type 2 diabetes is a costly chronic illness with many out-of-pocket expenses not necessarily covered by health insurance. Another study found that the lack of resources serves as a common barrier to effective disease management (Schoenberg & Drungle, 2001). And finally, Kuo et al. (2003) reported cost as a known and recognized barrier for effective diabetes management for older Mexican adults as well.

5.5 Explanatory Model for Older Dominicans with Type 2 Diabetes

Findings in this study provide a basis for the development and design of an explanatory model for Type 2 Diabetes specifically for the Dominican community. Table 6 illustrates the perceived causes, symptoms, treatment options, and social context of the disease from the unique perspective of the older Dominican adult.

The development and design of an Explanatory Model of Illness for Dominicans with Type 2 diabetes stems from two pre-existing exploratory models as seen in the literature: Kleinman's (1980) Explanatory Model for Illness, and Jezewski and Poss' (2007) Explanatory

Model for Mexican Americans. The development of these models substantiates the need to develop future models for all members of the Latino community.

Summary

The discussion and interpretation of the study findings in this section provides a clear and concrete example of the self-management practices and perspectives unique to older Dominican adults with Type 2 diabetes. This section highlights self-management practices and reveals certain misconceptions older Dominican adults may have about exercise (physical activity) and diabetes management. In addition, this section demonstrates that most older Dominican adults have a general knowledge base and understanding of existing folk/home remedies for diabetes and may be using (more often than reported in this study) home remedies to manage their diabetes. Furthermore, this section demonstrates that older Dominican adults have access to ingredients in their own neighborhood to help them prepare folk/home remedies for their diabetes management.

This section illustrates the self-management practices and perspectives of older Dominican adults with Type 2 diabetes which include diet modification, adherence to medication, exercise (for most but not all study participants), use of folk/home remedies, and diabetes management classes. Many older Dominican adults in this study also described the many barriers (non-monetary and monetary) which can impact adequate and effective diabetes management, and emphasized the greatest barrier they encounter is the high cost of medication for managing their diabetes.

Specific Aim 2:

Describe the role of cultural factors in diabetes self-management practices among older Dominican adults.

Family

Results from this study demonstrate that in the Dominican culture, the family has a strong presence and can be associated with how an older adult manages their diabetes. Several studies have recognized the family (*la familia*) as influential in providing support or serving as a barrier to effective diabetes management (Edelstein & Linn, 1985; Fisher et al., 2000; Mier, Medina, & Ory, 2007; Vincent, Clark, Zimmer & Sanchez, 2006). Many research studies have focused on the role of family and Type 1 diabetes, primarily with children and adolescents, but few studies have explored the impact on the family for adults with Type 2 diabetes (Edelstein & Linn, 1985; Fisher et al., 2000). In the case of the study participants, many received support from family members with respect to their disease management. However, the present investigation found that family has an impact on effective disease management for older Dominican adults with Type 2 diabetes, and results support the need for more research in the families' role in Type 2 diabetes management.

The majority of participants in this study depict the family in a positive way when it comes to their self-management practices. Most participants identified the spouse or adult child as the family member who supported their management of diabetes. These findings are consistent with several studies which describe how the family members manage his or her Type 2 diabetes (Fisher et al., 2000; Mier et al, 2007; Nagelkerk et al, 2006; Oster et al., 2006; Vincent et al., 2006; Wen et al., 2004). Support for diabetes management was described in a variety of ways, but most of the emphasis was on the way in which spouses prepare meals at home. This

finding shows a need for further research in the area of cooking and preparing home-cooked meals for family members in Dominican households. This area of research is limited but worthy of further exploration and understanding.

Data from this study also revealed that family members can impact diabetes management. This finding is consistent with another research investigation which focuses on the role family members have on diabetes management (Vincent et al., 2006), but that study focused on Mexican-Americans older adults and did not provide a perspective for older Dominican adults.

The present analysis revealed new areas of research meriting additional study for older Dominican adults who experience negative or no support from family members for their diabetes self-management. The challenges encountered by these participants suggest an association between poor self-management practices and a family's inability to understand and support a healthy diet, including healthy eating and healthy cooking. As illustrated by the case of the male participant who clearly was intimidated by his wife who would not listen to the request from the provider. This is supported by research conducted by Lipton et al. (1998) and Vincent et al. (2006).

This was alarming from a research perspective and demonstrates the need to further examine the impact that family members, especially significant others, have on diabetes management in Dominican households.

Overall, this study documents the need to increase awareness among family members as well as providers about the challenge's older Dominican adults encounter with respect to family members and their self-management practices. Research in this area can focus on how health care professionals need to be aware of non-compliance as a family and intervene on that level. Further, future research studies can explore the diabetes management for the individual with

diabetes when the barrier is a family member. We can also explore steps an individual can take to overcome the barriers presented by unsupportive family members. Many studies have investigated the role of the family and its impact on effective diabetes management (Glasgow & Toobert, 1998; Tamez & Vavalis, 1989; Shafer, McCaul, & Glasgow, 1996 as cited in Wen, Shepher, & Parchman, 2004), but few studies have explored the challenges encountered by Hispanic/Latino families, and even fewer studies have included or focused on the older Hispanic population (Fisher et al., 2000; Gleeson-Kreig et al., 2002).

Travel to Santo Domingo

An interesting finding in this study exposed some negative issues related to an older Dominican adult's experience when traveling back and forth to Santo Domingo. Many participants in this study reported changes with their self-management practices when they travel to the Dominican Republic. The challenges related to adhering to their diet, and this is important to mention for a variety of reasons. First, participants in this study have extremely close ties to their native country. Secondly, participants in this study reported frequent travel (several times during the year) to and from Santo Domingo for a variety of reasons. Travel to Santo Domingo is a cultural factor that can be associated with how an older adult manages his/her diabetes. This study revealed the need to further explore the impact of frequent travel to the Dominican Republic on self-management for older Dominican adults with Type 2 diabetes. Findings from this study suggest that strong ties to the Dominican Republic will continue to influence the way in which older Dominican adults manage and think about their illness, even when they reside in the United States.

Regardless of length of time, many study participants expressed a strong connection to their native Dominican culture and their life in New York City. For older adults in this study,

culture plays a major role when traveling to the Dominican Republic to visit family and friends, and this too can impact how the older adult manages their diabetes. Several participants in this study discussed *desprecio* (cultural rejection), a cultural phenomenon understood only by the Dominicans or someone who one has the opportunity to live in the country. Data from this study revealed that when older Dominican adults travel to the Dominican Republic, something happens which participants describe as “losing control over what you eat and how you manage your diabetes.”

This finding supports the assumption that traveling to and from Santo Domingo can lead to the temporary suspension of self-management practice for some older Dominican adults with diabetes. This study demonstrates the need to study the impact of frequent travel between New York City and the Dominican Republic on the traveler’s diabetes management. This information can assist all health care professionals who oftentimes may question the continued absence of an older adult during a period of time or is faced with the challenge of starting all over again when treating an older adult of Dominican background. The findings in the present study do not address what occurs when an older Dominican adult returns to New York City after spending time in the Dominican Republic. However, this information can be helpful not only for the older Dominican adult, but also to all health care professionals who provide treatment options once the older Dominican adult returns to the medical exam room.

Summary

The section highlights how cultural factors (family, and travel to Santo Domingo) can impact diabetes management in a positive and/or negative way. Family members, as described by study participants, can have both a positive and negative impact on how an older Dominican adult manages their diabetes. As discussed in this section, many studies have examined the role

family members have on diabetes management, but this segment also explains how a spouse or adult child in a Dominican household can also influence the way an older Dominican adult manages his/her diet.

Another important cultural factor to consider in relation to effective self-management is the frequent travel of older Dominican adults to the Dominican Republic. The greatest challenge to this cultural factor is the impact that frequent international travel and length of time abroad can have on diabetes management among older Dominican adults, not only while in the Dominican Republic, but after they return from their trip abroad.

As this section demonstrates, older Dominican adults with Type 2 diabetes have unique cultural factors which influence diabetes management: 1) family, and 2) travel to Santo Domingo. The recognition of unique cultural practices and beliefs for older Dominican adults resulted in the development and design of an explanatory model for Dominicans with chronic illness. The development and design of an explanatory model unique to older Dominican adults with diabetes helps to illustrate perceived causes, symptoms, treatment options, and the social context of the disease from the perspective of the older Dominican adult.

Specific Aim 3:

Examine the relationship between cultural-structural and diabetes self-management practices among older Dominican adults

Case Study

Findings in this study suggest the need to examine how cultural and structural factors can be associated with how an older Dominican adult manages their Type 2 diabetes. The complex case of an older Dominican adult female who used cultural and structural factors to address her

complex vision problem while managing her chronic condition highlights the role these factors can have on effective diabetes self-care.

Relationship with Family Members. In the case of this study participant, cultural factors involved the family (sister), and structural factors involved the presence of the participant's physician (psychiatrist) and the police (New York City Police Department). Both cultural and structural factors worked closely with the family to help the older adult female save her vision. Findings from this study are consistent with Wallace and Villa's 2003 study which discusses cultural and structural equity issues for older Latino adults. The authors describe a number of structural or organizational issues that should also be considered when treating an older Latino adult. These structural and organizational factors include: 1) the institutional organization of care; 2) continuity of care, and 3) societal discrimination and policies that shape older Latinos' comfort and trust in the medical system.

Patient-Provider Relationship. A critical finding in this study focuses on the patient-provider relationship and how it can be associated with effective self-management practices for diabetes. In this study, the patient-provider relationship was reported by study participants as influential and essential for their disease management. According to study participants, the patient-provider relationship is "important" and "necessary" for effective diabetes self-management practices. For most of the older Dominican adults, the patient-provider relationship can be associated with the way an older Dominican adult manages their illness. This study finding is consistent with research focusing on the patient-provider relationship and diabetes management (Lipton, Losey, Giachello, Mendez & Girotti, 2007).

This finding also has implications for another general assumption worthy of future study. From this finding one can assume that how patients perceive their provider can also be

associated with how they manage their chronic illness. Older Dominican adults tend to view their providers with utmost respect and regard. However, this perception can sometimes impede the level of verbal interaction with the provider during the medical interview. This finding is supported by Lipton et al., (2007) who report that providers are aware of the “excessive” amount of respect the Latino patient has for the provider which the research indicates can often interfere with the communication between patient and provider. This finding is consistent with the Wallace and Villa (2003) study which highlights the importance of the provider-patient relationship to continuity of care and quality of care for Hispanics patients. This finding indicates the need to explore further the impact of the patient-provider relationship on older Dominican adults.

Communication with Provider. Findings from this study also suggest that effective communication with the provider is an important element of self-management practices for older Dominican adults with diabetes. For older Dominican adults, effective communication entails more than speaking Spanish. Effective communication incorporates the participation of a trained medical interpreter (not a family member) during the medical assessment, as well as the publication and accessibility of diabetes and culturally appropriate health literacy material targeted at older adults in the community.

This finding is supported by Lipton and colleagues (1998) who report that the availability and accessibility of health material in clinical settings, medical exam rooms, and senior centers is essential for effective diabetes management. These findings are also consistent with findings by Wallace and Villa (2003) which report that when focusing on language or other cultural barriers, it is critical to include the “availability and accessibility of those services” (Lipton et al., 1998; Wallace & Villa, 2003). More research is needed to explore how improving communication

between the provider and patient can enhance self-management practices of older adults with diabetes, and how enhancing the development and availability of culturally appropriate health education material targeting the older Latino/Dominican adults can do the same.

Lack of Health Insurance. Another central finding in this study was the issue of health insurance on diabetes management. The health insurance issue was most critical mostly for participants who did not have health insurance. The greatest challenge for participants who did not have health insurance was the high cost of diabetes medication and the high cost of managing their diabetes, especially if they do not have health insurance. These findings are consistent with Wallace and Villa's 2003 study which found that "medical care financing" is an equity issue for older adults. More research is needed to help explain why older Latino adults are more likely not to have health insurance and why uninsured estimates for the 65+ population continue to rise in the United States.

Mental Health. This study also illustrates the need for further research in the area of mental health illness and its impact on effective diabetes management for older Dominican adults. Findings from this study suggest the need to explore the presence of mental health issues with older Dominican adults with diabetes. Many study participants were able to describe how they felt with diabetes, but they did not necessarily include screening for depression as part of their self-management practices. Because diabetes management is complex and multi-faceted, it can also be daunting and overwhelming for an older adult. This finding helps to explain why older adults encounter more challenges when they described their hardships with diabetes and how they attempt to manage their illness. This study finding is supported by Tucker et al. (2000), who demonstrate that "diabetes management requires education and surveillance of risk factors that may apply differently to different ethnic groups."

Findings in this study raised several questions worthy of follow-up. When clinicians deliver messages about self-management practices to older Dominican adults, what are providers saying, and what is the adults' take-home message? Most importantly, how are clinicians delivering and communicating information about effective self-management practices during medical interviews? Are clinicians treating the older Dominican adult with an individualized plan, or as part of a larger Hispanic/Latino group?

Many participants in this study, including male participants, raised the issue of being "sad" because of their diabetes. In the case of many study participants, sadness was not necessarily associated or identified with depression. Instead, participants focused on employment or unemployment factors, relationships with family members, as well as sexuality issues with their spouse/partner. These findings are supported by Mandal and Roe (2008) who discuss job loss, retirement, and mental health issues in older adults, and by de Alba Garcia et al. (2007) who write about sexual dysfunction or loss of sexual desire in older adults. The other feelings of helplessness and frustration as reported by study participants have been supported by Nagelkerk et al. (2006). Economic hardships and stress due to emotional or family-related problems are mentioned by Wen et al. (2004), and Fisher et al. (2000). However, few studies have focused on how symptoms of sadness or depression influence the way in which older Dominican adults with diabetes manage their illness.

More research is needed to explore how symptoms of sadness or depression influence the way older Dominican adults manage their illness. This study described many factors which can trigger symptoms of depression, but literature on this topic as it relates to older Dominican adults is scarce. This discussion illustrates the need to further explore this area because depression is medically recognized as a co-morbidity of diabetes. Little is known about the stigmas that exist

in the Latino community with respect to mental health issues and how these stereotypes can impact effective diabetes management. In addition, this finding demonstrates the need to incorporate and increase awareness among mental health and public health professionals with respect to depression or symptoms of sadness and a diabetes diagnosis, especially for older Dominican adults.

Summary

This section provided a unique perspective on the life of an older Dominican female adult with complex vision and diabetes-related health issues. The most important position in this section is the example of the development and design of a diabetes care plan which incorporates cultural and structural factors most appropriate for the older adult with Type 2 diabetes. The recognition and inclusion of cultural and structural (societal) factors was successful, appropriate, and necessary in the case of this individual.

In addition, this section described other factors which could also influence self-management practices for older Dominican adults, and these include communication with the provider, lack of health insurance, and mental health issues. The recognition of mental health issues in this section demonstrates the need to screen older Dominican adults with Type 2 diabetes for depression or related mental health issues. This is most appropriate when developing and designing a diabetes care plan for older Dominican adults.

The research questions in this study have been answered through the Spanish in-depth qualitative interviews. The study obtained information about the self-management practices and barriers of older Dominican adult individuals with Type 2 diabetes. Secondly, this study gathered and verified information about the awareness and potential use of folk/home remedies for the management of Type 2 diabetes. In addition, the research study gathered information

about the community-level resources in Washington Heights/Inwood that are assisting older Dominicans in managing their diabetes. Finally, this study investigated and gathered cultural and structural (societal) factors which play a role in the effective management of diabetes for older adults.

Limitations. This study was conducted in a multi-cultural, community-based, senior resource center where there is a representation of other Hispanic/Latino groups, but the focus of the study was older Dominican adults with Type 2 diabetes. Twenty-nine participants in the study were recruited from the Isabella Senior Resource Center; only one participant was recruited as a non-member of the Center. The finding may not reflect the experiences of older Dominicans with Type 2 who do not engage in community-based activities or access community resources for seniors. The principal investigator had limited space to conduct the interviews. Working with limited space limited the principal investigator's ability to optimize privacy for study participants, and this may have impacted the information that was disclosed during the interview. Future research is needed to explore the self-management practices of isolated, hard-to-reach, older Dominicans with Type 2 diabetes.

Implications. Based on the study findings, older Dominican adults are able to explain and effectively carry out many important self-management practices for their Type 2 diabetes.

In addition, study participants demonstrated the many cultural and structural factors which can be associated with their self-management practices. However, older Dominican adults in this study also demonstrated an important fact when it comes to adequate and effective diabetes management. All participants in this study would benefit greatly from additional support and guidance for how to effectively improve the way they manage their Type 2 diabetes.

Most study participants would benefit from learning more about their condition through their participation in diabetes education seminars and involvement of supportive family members.

The purpose of these seminars would be to inform participants how to improve the way they manage their illness. The most beneficial class for many participants in this study would be cooking classes specific for diabetes management. The increased involvement and participation from family members could also help many older Dominican adults improve their outlook on overcoming many of the challenges and obstacles presented by diabetes management.

The implication of this study for research is the further development and refinement of the Dominican-focused explanatory model for Type 2 diabetes presented in this dissertation. The focus of this model is to provide health and diabetes experts more information about members of the Dominican community. This could facilitate the interaction between the individual with diabetes and the provider. Many health professionals can also benefit from knowing the specific cultural behaviors and perspectives of members of the Dominican community.

5.6 Recommendations

Next Steps. More research is needed in the area of self-management practices for Type 2 diabetes among older Dominican adults. This recommendation is based on the unique cultural and behavioral perspectives reported throughout this study. When working with older Dominican adults, it is important to understand the cultural and structural factors that may be associated with their diabetes management. Older Dominican adults maintain (regardless of length of time in the US) unique cultural perceptions and beliefs about their Type 2 diabetes. These unique characteristics should be recognized and accepted by community members and all

health care and research professionals when treating an older Dominican adult with Type 2 diabetes in a clinical setting.

The most effective way to recruit older Dominican adults to research studies is to work toward establishing rapport and trust with members of the community. The presence of a researcher in the community allows for participation and engagement in cultural activities and volunteer opportunities at the research site. The process of recruiting older Dominican adults in research studies requires a level of understanding and sensitivity to cultural and structural issues. In addition, it is necessary for the researcher to be present and accessible at the research setting. Regardless of race and ethnicity, it is necessary for the researcher to follow and become a part of the culture of the research setting, and work toward building rapport and trust with community members, staff, and gatekeepers. This process is necessary for the successful recruitment and retention of older Dominican adults throughout the duration of the research study.

Older Dominican adults with Type 2 diabetes can benefit from obtaining additional and tailored information about diabetes management education programs in the community to enhance the way they effectively manage their illness. This task will help to achieve the following goals: 1) increase knowledge about their chronic condition; 2) enhance the way they manage their condition, and 3) empower older adults to take ownership of their chronic condition with increased confidence and support.

The Naomi Berrie Diabetes Center (NBDC), located in Washington Heights/Inwood, is a clinical and research program nationally recognized and accredited by the American Diabetes Association. The NBDC's diabetes education program was successfully used by one female study participant for her Type 2 diabetes self-management. The Center's clinical and diabetes education services are available and accessible to members of the community with a provider's

referral, health insurance, and an appropriate diabetes intervention plan. However, because of the demand for specialized diabetes intervention programs in New York City, the goal for all individuals who participate in the intervention program is to ultimately manage their diabetes on their own once the intervention has been completed.

During a conversation/interview with Ms. Patricia Garnica, RN, MSN, ANP-BC, CDE, an Inpatient Nurse Practitioner and Certified Diabetes Educator of the NBDC on February 16, 2012, the principal investigator confirmed the availability of culturally appropriate diabetes education workshops in the community for individuals of Dominican background, the Latinos most represented at the NBDC's diabetes education workshops. With the exception of one female participant, the rest of the study's respondents did not mention the NBDC as a place to assist them with their diabetes management; however, all participants would benefit from participating in NBDC's comprehensive diabetes intervention program, which includes three workshops most appropriate for participants in this study.

The diabetes education classes include: 1) Exercise and Diabetes; 2) Grandparents and Caregivers Workshop, and 3) Workshop for Spouses: Type 3 Diabetes. In addition to the diabetes education workshops, participants in this study benefit greatly from diabetes education classes which focus on diet and are tailored to Spanish cuisine.

According to my discussion with Ms. Garnica, the NBDC has a cultural understanding and awareness of the Dominican culture which is very much a part of their diabetes education program. In fact, many of the workshops are designed and implemented with the Dominican individual in mind. And the diabetes education staff members at the NBDC are also aware of how cultural factors may be associated with a lack of effective diabetes management when a Dominican travels to the Dominican Republic.

When a Dominican patient with Type 2 diabetes travels to the Dominican Republic and does not follow their diabetes regimen, most of the time they end up in the emergency room. And this is where the expression “from the DR to the ER” comes from. An adult with Type 2 diabetes who does not carefully manage their diabetes in the Dominican Republic will usually end up in the Emergency Room in the US because their diabetes management is completely out of control upon their return from the Dominican Republic.

This reality may be the case for many individuals, but the principal investigator does not support the notion that all Dominicans who travel to and from the Dominican Republic should be labeled in this manner. There should be an awareness of cultural factors, but intervention efforts should be considered on an individual basis.

Self-management and educational public health interventions should be accessible, and culturally and linguistically appropriate for the target audience. It is not enough to provide accurate information in English and Spanish. It is essential to produce appropriate linguistic health messages using the dialect and literacy level for the target community. In order to achieve this goal, it is necessary to include and work closely with people of Dominican background who can provide the insight and cultural perspective to make this program successful. It is not appropriate to design and implement a research study for the Dominican community without incorporating the appropriate culturally and linguistic terminology that is used in the culture, and translation services provided on the Internet do not always meet these academic and cultural needs.

For future intervention efforts, it is necessary to develop and design diabetes self-management education material that addresses mental health issues as well. Because depression is a medically recognized co-morbidity for diabetes, more research is needed to explore the

impact that symptoms of sadness (depression) can have on older Dominican adults with diabetes. Data from this study identified mental health issues as a concern for older Dominican adults and should be addressed when working with this population.

Although the study explored resources available in the community, after completing the data collection, analysis, and gathered information about the formal care received by participants, the principal investigator did not specifically ask about the Naomi Barrie Diabetes Center's programs. Given the availability of culturally appropriate programs at the NBDC, future research is needed to assess why more, if not all, participants in this study were not being served by these programs. In an era of scarce resources for health care, attention needs to be focused to ensure that those most in need are able to access all available services.

Conclusion

In conclusion, it is evident that there is a great need to increase studies on the self-management practices of Type 2 diabetes for older Dominican adults. Studies on this research topic should include and increase the representation of Dominicans as well as other sub-groups within the Latino community. The current literature does not provide enough information about the overall health status of the Dominican community. Second, many research studies on the topic of self-management practices for Type 2 diabetes for the Hispanic/Latino communities have focused primarily on Mexican Americans, the largest Hispanic/Latino community, but more research is needed to explore other groups within the Latino/Hispanic community.

More information is also needed to explore similarities and differences between groups within the Latino community, as well to further understand different patterns of health behavior with respect to diabetes. This conclusion is supported by a comprehensive literature review conducted by Caban and Walker (2006) which posits that more information is needed on Hispanics living on the East Coast because most studies have centered around the Latinos residing primarily in the western or southern part of the United States.

This study demonstrates the need to increase and broaden our understanding of the health status of the older Dominican adult population. It also extends the literature by focusing on the unique, cultural characteristics and self-management practices of older adults with Type 2 diabetes.

References

- American Association of Diabetes Educators (2007). AADE position statement: Cultural sensitivity and diabetes education: Recommendations for diabetes educators. *The Diabetes Educator*, 33(1), 41-44.
- American Diabetes Association. (2011). *Diabetes basics: Symptoms*. Retrieved on June 1, 2011 from <http://www.diabetes.org/diabetes-basics/symptoms/>
- American Diabetes Association. (2011). Standards of medical care in diabetes: 2011. *Diabetes Care*, 34(S-1), S11-61.
- American Diabetes Association. (2011). *Diabetes basics: Type 2*. Retrieved on June 8, 2011 from <http://www.diabetes.org/diabetes-basics/symptoms/>
- Aponte, J. (2009). Diabetes risk factors in Mexican Americans with diabetes. *Medsurg Nursing*, 18(5), 265-271.
- Armour, T. A., Norris, S. L., Jack, L., Jr., Zhang, X., & Fisher, L. (2005). The effectiveness of family interventions in people with diabetes mellitus: A systematic review. *Diabetic Medicine*, 22(10), 1295-1305.
- Barceló, A., Aedo, C., Rajpathak, S., & Robles, S. (2003). The cost of diabetes in Latin America and the Caribbean. *Bulletin of the World Health Organization*, 81(1), 19-27.
- Beeney, L. J., Dunn, S. M., & Welch, G. W. (1984). Measurement of diabetes knowledge: The development of the Diabetes Knowledge Scales. In C. Bradley (Ed.), *Handbook of Psychology and Diabetes*. New York: Psychology Press.
- Bernal, H. (1986). Self-management of diabetes in a Puerto Rican population. *Public Health Nursing*, 3(1), 38-47.
- Borrell, L. N., Kunzel, C., Lamster, I., & Lalla, E. (2007). Diabetes in the dental office: Using

- NHANES III to estimate the probability of undiagnosed disease. *Journal of Periodontal Research*, 42(6), 559-565.
- Burgos-Ocasio, H. (1996). In M. C. Julia (Ed.), *Multicultural Awareness in the Health Care Professions*. Boston: Allyn & Bacon, 111-130.
- Burnette, D. (1997). Grandmother caregivers in inner-city Latino families: A descriptive profile and informal social supports. *Journal of Multicultural Social Work*, 5(3-4), 121-137.
- Burnette, D (1999). Social relationships of Latino grandparent caregivers: A role theory perspective. *The Gerontologist*, 39(1), 49-58.
- Burnette, D. (2009). Grandparent caregiving in Caribbean Latino families: Correlates of children's departure from care. *Journal of Intergenerational Relationships*, 7(2), 331-343. DOI:10.1080/15350770902851262
- Caban, A., & Walker, E. A., (2006). A systematic review of research on culturally relevant issues for Hispanics with diabetes. *The Diabetes Educator*, 32(4), 584-595.
- Caro-López, H., & Limonic, L. (2010). Dominicans in New York City, 1990-2008. Retrieved from Center for Latin American, Caribbean & Latino Studies website <http://web.gc.cuny.edu/lastudies/latinodataprojectreports/Dominicans%20in%20New%20York%20City%201990-2008.pdf>
- Centers for Disease Control and Prevention. (2004). Prevalence of diabetes among Hispanics: Selected areas, 1998-2002. *Morbidity and Mortality Weekly Report*, 53(40), 941-944.
- Centers for Disease Control and Prevention. (2011). National diabetes fact sheet, 2011: National estimates and general information on diabetes and pre-diabetes in the United States, 2011. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention.

- Chau, D. L., Shumaker, N., & Plodkowski, R. A. (2003). Complications of Type 2 diabetes in the elderly. *Geriatric Times*, 4(2).
- Chesla, C. A., Skaff, M. M., Bartz, R. J., Mullan, J. T., & Fisher, L. (2000). Differences in personal models among Latinos and European Americans: Implications for clinical care. *Diabetes Care*, 23(12), 1780-1785.
- Chong, N. (2002). *The Latino Patient: A Cultural Guide for Health Care Providers*. Yarmouth, ME: Intercultural.
- Cordero-Guzmán, H., & Grosfoguel, R. (2000). The demographic and socio-economic characteristics of post-1965 immigrants to New York City: A comparative analysis by national origin. *International Migration*, 38(4), 41-77. DOI:10.1111/1468-2435.00120
- Coronado, G., Thompson, B., Tejada, S., & Godina, R. (2004). Attitudes and beliefs among Mexican Americans about Type 2 diabetes. *Journal of Health Care for the Poor and Underserved*, 15(4), 576-588.
- Costantino, G., & Diaz-Román, Y. (2011). Development of content analyses and coding procedures for in-depth qualitative interview with Spanish-speaking population. Self-management Practice and Perspectives of Spanish-speaking Older Dominican Adults with Type 2 Diabetes (Unpublished doctoral dissertation). Columbia University, New York: New York.
- Costantino, G., Persez, M., Rodriguez, A., Camille, J., Borges, M., Malgady, R., ... Costantino, E. (2006, August). Depression and diabetes in two age cohorts of Latino patients. Poster presentation at the 114th American Psychological Association Convention, New Orleans, Louisiana.

- Costantino, G., Malgady, R. G., & Rogler, L. H. (1988). *TEMAS (Tell-me-a-story) test manual*. Los Angeles, CA: Western Psychological Services.
- Costantino, G., Malgady, R. G., & Primavera, L. H. (2009). Congruence between culturally competent treatment and cultural needs of older Latinos. *Journal of Consulting and Clinical Psychology, 77*(5), 941-949.
- Creswell, J. W. (2003). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. Thousand Oaks: Sage.
- de Alba Garcia, J. G., Roche, A. L. S., & Lopez I., (2007). Diabetes is my companion: Lifestyle and self-management among good and poor control Mexican diabetic patients. *Social Science & Medicine, 64*(11), 2223–2235.
- Dockterman, D. (2011). *Hispanics of Dominican Origin in the United States, 2009*. Washington, DC: Pew Hispanic Center.
- Eaton, D. K., Kann, L., Kinchen, S., Shanklin, S., Ross, J., Hawkins, J., ... Wechsler, H. (2008). Youth risk behavior surveillance: United States, 2007. *Morbidity and Mortality Weekly Report, 57*(SS-4), 1-131.
- Edelstein, J., & Linn, M. W. (1985). The influence of the family on control of diabetes. *Social Science & Medicine, 21*(5), 541-544.
- Ennis, S. R., Ríos-Vargas, M., & Albert, N. G. (2011). *The Hispanic Population: 2010 Census Briefs*. Washington, D.C.: US Census Bureau.
- Federal Interagency Forum on Aging-Related Statistics. (2008). *Older Americans 2008: Key indicators of well-being*. Washington, DC: US Government Printing Office.
- Federal Interagency Forum on Aging-Related Statistics. (2010). *Older Americans 2010: Key indicators of well-being*. Washington, DC: US Government Printing Office.

- Fisher, L., Chesla, C. A., Skaff, M. M., Gilliss, C., Mullan, J. T., Bartz, R. J., Lutz, C. P. (2000). The family and disease management in Hispanic and European-American patients with Type 2 diabetes. *Diabetes Care*, 23(3), 267-271.
- Flores, G., Abreu, M., Oliver, M. A., & Kastner, B. (1998). Access barriers to health care for Latino children. *Archives of Pediatrics and Adolescent Medicine*, 152(11), 1119-1125.
- Fowler, F. J., Jr. (2002). Methods of Data Collection. In *Survey Research Methods*, Vol. 1. Thousand Oaks, CA: Sage.
- Geertz, C. (1973). Thick description: Toward an interpretive theory of culture. In *The Interpretation of Cultures: Selected Essays*. New York: Basic Books, 3-30.
- Glasgow, R. E. (1994). A practical model of diabetes management and education. *Diabetes Care*, 18(1), 117-126.
- Glasgow, R.E., Toobert, DJ, Riddle M, Donnelly, J., Mitchell, DL,.....Calder, D. Diabetes-specific social learning variable and self-care behaviors among persons with type 2 diabetes. *Health Psychology*(8), 285-303.
- Gleeson-Kreig, J., Bernal, H., & Woolley, S. (2002). The role of social support in the self-management of diabetes mellitus among a Hispanic population. *Public Health Nursing*, 19(3), 215-222.
- Golash-Boza, T., & Darity Jr, W. (2008). Latino racial choices: The effects of skin colour and discrimination on Latinos' and Latinas' racial self-identifications. *Ethnic and Racial Studies*, 31(5), 899-934. DOI:10.1080/01419870701568858
<http://dx.doi.org/10.1080/01419870701568858>
- Greenburg, J. S., Seltzer, M. M., Krauss, M. W., Chou, R. J., & Hong, J. (2004). The effect of

- quality of the relationship between mothers and adults with schizophrenia, autism, or down syndrome on maternal well-being: The mediating role of optimism. *American Journal of Orthopsychiatry*, 74(1), 14-25.
- Greenfield, S., Kaplan, S. H., Ware, J. E., Jr., Yano, E. M., & Frank, H. J. (1988). Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *Journal of General Internal Medicine*, 3(5), 448-457.
- Gregg, E. W., Mangione, C. M., Cauley, J. A., Thompson, T. J., Schwartz, A. V., Ensrud, K. E., & Nevitt, M. C. (2002). Diabetes and incidence of functional disability in older women. *Diabetes Care*, 25(1), 61-67.
- Hainer, T. A. (2006). Managing older adults with diabetes. *Journal of the American Academy of Nurse Practitioners*, 18(7), 309-317.
- Harris, M. I., Eastman, R. C., Cowie, C. C., Flegal, K. M., & Eberhardt, M. S. (1999). Racial and ethnic differences in glycemic control of adults with Type 2 diabetes. *Diabetes Care*, 22(3), 403-408.
- Hatcher, E., & Whittemore, R. (2007). Hispanic adults' beliefs about Type 2 diabetes: Clinical implications. *Journal of the American Academy of Nurse Practitioners*, 19(10), 536-545.
- Hernández, R., & Torres-Saillant, S. (1996). Dominicans in New York: Men, women, and prospects. In G. Haslip-Viera and S. L. Baver (Eds.). *Latinos in New York: Communities in Transition*. Notre Dame, Indiana: University of Notre Dame Press, 30-51.
- Hirsch, J. S. (2003). *A Courtship after Marriage: Sexuality and Love in Mexican Transnational Families*. Berkeley, CA: University of California Press.
- Hoffnung-Garskof, J. (2008). *A Tale of Two Cities. Santo Domingo and New York after 1950*. Princeton: Princeton University Press, 1-13.

- Hooyman, N., & Asuman Kiyak, H. (2005). Social theories of aging. Adapted from N. Hooyman and H. Asuman Kiyak. *Social Gerontology: A Multidisciplinary Perspective*. Boston: Allyn & Bacon, 287-293.
- Jacobs, E. A., Karavolos, K., Rathouz, P. J., Ferris, T. G., & Powell, L. H. (2005). Limited English proficiency and breast and cervical cancer screening in a multiethnic population. *American Journal of Public Health, 95*(8), 1410-1416.
- Jezewski, M. A., & Poss, J. (2002). Mexican Americans' explanatory model of Type 2 diabetes. *Western Journal of Nursing Research, 24*(8), 840-858.
- Kannel, W. B., & McGee, D. L. (1979). Diabetes and cardiovascular disease: The Framingham study. *Journal of the American Medical Association, 241*, 2035-2038.
- Kleinman, A. (1980). *Patients and healers in the context of culture* Berkeley, CA: University of California Press.
- Konrad, W. (2010, Nov. 12). Protecting yourself from the cost of Type 2 diabetes. *The New York Times, 86*. Retrieved from <http://www.nytimes.com>
- Kuo, Y. F., Raji, M. A., Markides, K. S., Ray, L. A., Espino, D. V., & Goodwin., J. S. (2003). Inconsistent use of diabetes medications, diabetes complications, and mortality in older Mexican Americans over a 7-year period. *Diabetes Care, 26*(11), 3054-3060.
- Lalla, E., Kunzel, C., Burkett, S., Cheng, B., & Lamster, I. B. (2011). Identification of unrecognized diabetes and pre-diabetes in a dental setting. *Journal of Dental Research*
DOI:10.1177/0022034511407069
- Landrine, H., & Klonoff, E. A. (1992). Culture and health-related schemas: A review and proposal for multidisciplinary integration. *Health Psychology, 11*(4), 267-276.

- Li, L. W., & Fries, B. E. (2005). Elder disability as an explanation for racial differences in informal home care. *Gerontologist, 45*(2), 206-215. Abstract retrieved from <http://www.ncbi.nlm.nih.gov/pubmed>
- Lipton, R. B., Losey, L. M., Giachello, A., Mendez, J., & Girotti, M. H. (2007). Attitudes and issues in treating Latino patients with Type 2 diabetes: Views of healthcare providers. *Diabetes Education, 24*(1), 67-71.
- Lopez, M. H., & Taylor, P. (2010). *Latinos and the 2010 Census: The Foreign Born Are More Positive*. Washington, D.C.: Pew Hispanic Center.
- Luchsinger, J. A. (2001). Diabetes. In M. Aguirre-Molina, C. W. Molina, and R. E. Zambrana (Eds.), *Health Issues in the Latino Community*. San Francisco: Josey-Bass, 277-300.
- Lynott, R. J., & Lynott, P. P. (1996). Tracing the course of theoretical development in the sociology of aging. *The Gerontologist, 36*(6), 749-760.
- Mandal, B., & Roe, B. (2008). Job loss, retirement, and the mental health of older Americans. *The Journal of Mental Health Policy and Economics, 11*(4), 167-176.
- Mann, D. M., Ponieman, D., Leventhal, H., & Halm, E. A. (2009). Misconceptions about diabetes and its management among low-income minorities with diabetes. *Diabetes Care, 32*(4), 591-593.
- Marín, G., & Marín, B. V. (1991). *Research with Hispanic Populations*. Newbury Park, CA: Sage.
- Marín, G., Sabogal, F., Marín, B. V., Otero-Sabogal, R., & Pérez-Stable, E. J. (1987). Development of a short acculturation scale for Hispanics. *Hispanic Journal of Behavioral Sciences, 9*, 183-205.

- Markides, K. S., & Black, S.A. (1996). Race, ethnicity, and aging: The impact of inequality. In R. H. Binstock & L. K. George (Eds.), *Handbook of Aging and the Social Sciences*, Burlington, MA: Academic Press, 153-170.
- McBean, A. M., Li, S., Gilbertson, D. T., & Collins, A. J. (2004). Differences in diabetes prevalence, incidence, and mortality among the elderly of four racial/ethnic groups: Whites, blacks, Hispanics, and Asians. *Diabetes Care* 27(10), 2317-2324.
- Mensing, C., Boucher, J., & Cypress, M. (2006). National standards for diabetes self-management education. *Diabetes Care* 29, 578-585.
- Merton, R. K., Fiske, M., & Kendall, P. L. (1990). *The Focused Interview: A Manual of Problems and Procedures*. New York: Free Press.
- Mier, N., Medina, A. A., & Ory, M. G. (2007). Mexican Americans with Type 2 diabetes: Perspectives on definitions, motivators, and programs of physical activity. *Preventing Chronic Disease*, 4(2), A24.
- Mikhail, N., Wali, S., & Ziment, I. (2004). Use of alternative medicine among Hispanics. *The Journal of Alternative and Complementary Medicine*, 10(5), 851-859.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks: Sage.
- Mutchfer, J. E., & Brallier, S. (1999). English language proficiency among older Hispanics in the United States. *The Gerontologist*, 39(3), 310-319.
- Nagelkerk, J., Reick, K., & Meengs, L. (2006). Perceived barriers and effective strategies to diabetes self-management. *Journal of Advanced Nursing*, 54(2), 151-158.

- National Alliance for Hispanic Health. (2010). *The State of Diabetes among Hispanics*. Retrieved from National Alliance for Health website:
<http://www.hispanichealth.org/assets/pdf/StateofDiabetes2010.pdf>
- National Center for Health Statistics. (2005). *Health, United States, 2005: With Chartbook on Trends in the Health of Americans*. Retrieved August 6, 2010 from
<http://www.cdc.gov/nchs/data/hus/hus05.pdf>.
- National Institute of Diabetes and Digestive and Kidney Diseases (2007). *Diabetes Prevention Program*. Publication No. 09-5099. Washington, D.C.: National Diabetes Information Clearinghouse.
- Olson E. C., Van Wye, G., Kerker, B., Thorpe, L., & Frieden, T. R. (2006). Take Care Inwood and Washington Heights. *NYC Community Health Profiles, 19(42)*, 1-16.
- Oomen, J. S., Owen, L. J., & Suggs, L. S. (1999). Culture counts: Why current treatment models fail Hispanic women with Type 2 diabetes. *The Diabetes Educator, 25(2)*, 220-225.
- Oster N. V., Welch, V., Schild, L., Gazmararian, J. A., Rask, K., & Spettell, C. (2006). Differences in self-management behaviors and use of preventive services among diabetes management enrollees by race and ethnicity. *Disease Management, 9(3)*, 167-175.
- Passel, J., & Cohn, D. (2011). How many Hispanics? Comparing census counts and census estimates. Retrieved April 11, 2011 from the Pew Hispanic Center website:
<http://pewhispanic.org/reports/report.php?ReportID=139>
- Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology, 58(3)*, 233-246.
- Patton, M. Q. (1995). *Qualitative Evaluation and Research Methods*. Thousand Oaks, CA: Sage, 277-283.

- Paulino, A. (1998). Dominican immigrant elders: Social service needs, utilization patterns, and challenges. In M. Delgado (Ed). *Latino Elders and the 21st Century: Issues and Challenges for Culturally Competent Research and Practice*. New York: Haworth Press. 61-74.
- Peart, T., Velasco Mondragon, H. E., Rohm-Young, D., Bronner, Y., & Hossain, M. B. (2011). Weight status in US youth: The role of activity, diet, and sedentary behaviors. *American Journal of Health Behavior, 35*(6), 756-764.
- Ponce, N. A., Hays, R. D., & Cunningham, W. E. (2006). Linguistic disparities in health care access and health status among older adults. *Journal of General Internal Medicine, 21*(7), 786-791.
- Poss, J., & Jezewski, M. A. (2002). The role and meaning of susto in Mexican Americans' explanatory model of Type 2 diabetes. *Medical Anthropology Quarterly, 16*(3), 360-377.
- Poss, J. E., Jezewski, M. A., & Stuart, A. G. (2003). Home remedies for Type 2 diabetes used by Mexican Americans in El Paso, Texas. *Clinical Nursing Research, 12*(4), 304-323.
DOI:10.1177/1054773803256872
- Raveis, V. H. (1999). Facilitating older spouses' adjustment to widowhood: A preventive intervention program. *Social Work in Health Care, 29*(4), 12-32.
- Raveis, V.H., Karus, D., & Pretter, S. (1999). Factors associated with anxiety in adult daughter caregivers to a parent recently diagnosed with cancer. *Journal of Psychosocial Oncology, 17*(3/4), 1-26.
- Raveis, V. H., Gardner, D. S., Berkman, B., & Harootyan, L. (2010). Linking the NIH strategic plan to the research agenda for social workers in health and aging. *Journal of Gerontological Social Work, 53*(1), 77-93.

- Raveis, V. H., Karus, D. G., & Siegel, K. (1998). Correlates of depressive symptomatology among adult daughter caregivers to a parent with cancer. *Cancer*, 83(8), 1652-1663.
- Rosal, M. C., Olendzki, B., Reed, G. W., Gumieniak, O., Scavron, J., & Ockene, I. (2005). Diabetes self-management among low-income Spanish-speaking patients: A pilot study. *Annals of Behavioral Medicine* 29(3), 225-235.
- Rose, A. M. (1965). A current theoretical issue in social gerontology. In A. M. Rose and W. A. Peterson (Eds.), *Older People and Their Social World: The Sub-Culture of the Aging*. Philadelphia: F. A. Davis.
- Rosenstock, J. (2001). Management of Type 2 diabetes mellitus in the elderly: Special considerations. *Drugs & Aging* 18(1), 31-44.
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative Interviewing: The Art of Hearing Data*. Thousand Oaks, CA: Sage.
- Rumbaut, R., & Portes, A. (2001). *Ethnicities: Children of Immigrants in America*. Berkeley, CA: University of California Press.
- Schafer, L.C., McGaul, KD & Glasgow RE. (1996). Supportive and non-supportive family behaviors: relationship to adherence and metabolic control in persons with type 1 diabetes. *Diabetes Care* (9), 179-185
- Schoenberg, N. E, & Drungle, S. C. (2001). Barriers to non-insulin-dependent diabetes mellitus (NIDDM) self-care practices among older women. *Journal of Aging and Health*.13(4), 443-466.
- Seidman, I. (1998). *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. New York: Teachers College Press.

- Shai, I., Jiang, R., Manson, J. E., Stampfer, M. J., Willett, W. C., Colditz, G. A., & Hu, F. B. (2006). Ethnicity, obesity, and risk of Type 2 diabetes in women: A 20-year follow-up study. *Diabetes Care* 29(7), 1585-1590.
- Ship, J. A. (2003). Diabetes and oral health: An overview. *Journal of the American Dental Association*, 134 Special, 4s-10s.
- Smith, C. A. S., & Barnett, E. (2005). Diabetes-related mortality among Mexican Americans, Puerto Ricans, and Cuban Americans in the United States. *Pan American Journal of Public Health*, 18(6), 381-387.
- Sotomayor, M., & Garcia, A. (1999). *La Familia: Traditions and Realities*. Washington, D.C.: National Hispanic Council on Aging.
- Tamez, EG., & Vacalis, TD. (1989). Health beliefs, the significant others and compliance with therapeutic regimens among adult Mexican American diabetics. *Health Education*(20), 24-31.
- Talamantes, M., Lindeman, R., & Mouton, C. (n.d.). *Ethnogeriatric curriculum module: Health and health care of Hispanic/Latino American elders*. Stanford University. Retrieved November 7, 2011 from <http://www.stanford.edu/group/ethnoger/hispaniclatino.html>
- Therrien, M., & Ramirez, R. R. (2001). The Hispanic population in the United States, March 2000. *Current Population Reports*. Washington, DC: US Census Bureau.
- Timmins, C. L. (2002). The impact of language barriers on the health care of Latinos in the United States: A review of the literature and guidelines for practice. *Journal of Midwifery Women's Health*, 47(2), 80-96.

- Tucker, K. L., Bermudez, O. I., & Castaneda, C. (2000). Type 2 diabetes is prevalent and poorly controlled among Hispanic elders of Caribbean origin. *American Journal of Public Health, 90*(8), 1288-1293.
- US Department of Health and Human Services. (2002). HHS, ADA warn Americans of 'pre-diabetes,' encourage people to take healthy steps to reduce risks. Web accessed August 19, 2010. http://dev2.dhh.state.la.us/LaMHA/weekly_articles.htm#Pre-diabetes.
- US Department of Health and Human Services. (2007). Office on Women's Health. Quick Health Data Online. Percent Total Exercise, Age Adjusted by State. Retrieved on August 27, 2010. <http://www.healthstatus2020.com/owh/>
- Vandebroek I., Balick M. J., Ososki, A., Kronenberg, F., Yukes, J., Wade, C., ... Castillo, D. (2010). The importance of botellas and other plant mixtures in Dominican traditional medicine. *Journal of Ethnopharmacology, 128*(1), 20-41.
- Venkat Narayan, K. M., Boyle, J. P., Thompson, T. J., Sorensen, S. W., & Williamson, D. F. (2003). Lifetime risk for diabetes mellitus in the US. *The Journal of the American Medical Association, 290*(14), 1884-1890.
- Vincent, D., Clark, L., Zimmer, L. M., & Sanchez, J. (2006). Using focus groups to develop a culturally competent diabetes self-management program for Mexican Americans. *The Diabetes Educator, 32*(1), 89-97.
- von Goeler, D. S., Rosal, M. C., Ockene, J. K., Scavron, J., & De Torrijos, F. (2003). Self-management of Type 2 diabetes: A survey of low-income urban Puerto Ricans. *The Diabetes Educator, 29*(4), 663-672.
- Wallace, S. P., & Villa, M. V. (2003). Equitable health systems: Cultural and structural issues for Latino elders. *American Journal of Law & Medicine, 29*(2-3), 247-267.

- Weech-Maldonado, R., Morales, L. S., Spritzer, K., Elliott, M., & Hays, R. D. (2001). Racial and ethnic differences in parents' assessments of pediatric care in Medicaid managed care. *Health Service Research, 36*(3), 575-594.
- Wen, L. K., Shepherd, M. D., & Parchman, M. L. (2004). Family support, diet, and exercise among older Mexican Americans with Type 2 diabetes. *The Diabetes Educator, 30*(6), 980-993.
- Whittemore, R. (2000). Strategies to facilitate lifestyle change associated with diabetes mellitus. *Journal of Nursing Scholarship, Third Quarter, 225-232.*
- Whittemore, R. (2007). Culturally competent interventions for Hispanic adults with Type 2 diabetes: A systematic review. *Journal of Transcultural Nursing, 18*(2), 157-166.
- Woloshin S., Schwartz, L., Katz, S., & Welch, H. G. (1997). Is language a barrier to the use of preventive services? *Journal of General Internal Medicine, 12*(8), 472-477.
- Zaldívar, A., & Smolowitz, J. (1994). Perceptions of the importance placed on religion and folk medicine by non-Mexican American Hispanic adults with diabetes. *The Diabetes Educator, 20*(4), 303-306.
- Zhou, M. (1997). Growing up American: The challenges confronting immigrant children and children of immigrants. *Annual Review of Sociology, 23*, 63-95.

Appendix A

isabella

August 13, 2008

Victoria H. Raveis, Ph.D
Associate Professor of Clinical Sociomedical Sciences
Mailman School of Public Health
Department of Sociomedical Sciences
100 Haven Avenue, Suite 6A
New York, NY 10032

Dear Dr. Raveis:

I am pleased to write to you on behalf of Ms. Yessica M. Diaz, MPH,MSW in support of her dissertation research study "Type 2 Diabetes Self-management Practices: Behaviors and Perspectives of Elderly Dominicans." This study has obtained approval to be conducted at the Isabella Senior Resource Center (Isabella), located at 4026 Broadway, New York, NY, for educational purposes only, in fulfillment of her doctoral research studies requirements.

Ms. Diaz has established a professional relationship of considerable mutual respect with the community inspired by her commitment to Latino health issues through her research work and interests in Washington Heights/Inwood area. This relationship grew stronger as a result of a Community-Based Participatory research photovoice project conducted during the researcher's doctoral coursework. In this project, Yessica worked closely with Ms. Judy Nuñez, the Center's Director and volunteer elderly Dominicans, who spoke primarily Spanish and lived in Washington Heights/ Inwood, to further our understanding of social and environmental factors that impact the health outcomes of this elderly community.

Since taking the course, the researcher has maintained her relationship with Ms. Nuñez and volunteers. For this study, Isabella will help in the recruitment and will make space available for the data collection. In this capacity, Ms. Diaz is a volunteer, not an employee of Isabella, and receives no monetary compensation for the project. Either party may terminate participation in the project at any time.

We believe this dissertation topic, which focuses on the self-management practices of elderly Dominicans with Type 2 Diabetes, will make a significant contribution to Isabella community and the aging and health profession. For these reasons, we look forward to learning the results of her findings and wish her success in the completion of the program.

Sincerely,



Robert Corcoran
Vice President of Clinical Support

cc: Judy Nuñez, MPA, Director Senior Resource Center

5-5 Audubon Avenue, New York, New York 10040 - 212-342-9200 - www.isabella.org

Appendix B

Review Correspondence Protocol Number: IRB-AAAD4271 Protocol Current Status: Approved

Notification 11/22/2011
Date:
From: IRB Office
To: Researcher
Subject: RASCAL IRB Protocol IRB-AAAD4271 (Protocol)
Protocol (Approved)
Text: Grant#: 5U01PS00070004

On September 26, 2011, the renewal for the above-mentioned study was reviewed and approved by expedited review, category #7, by the Chair of Columbia University Medical Center Institutional Review Board IRB #1.

It is noted that study enrollment is permanently closed, subjects have completed all research related procedures, long-term follow-up has been completed, and the remaining research activities are limited to data analysis.

As this study is closed to enrollment, at the time of the next submission for this protocol (modification or renewal) please archive/detach ALL obsolete/older versions of documents not in use, including consent forms.

Note: Please submit IRB approvals from Children's Hospital of Los Angeles and Children's Hospital of Philadelphia.

Any proposed changes in the protocol must be immediately submitted to the IRB for review and approval prior to implementation, unless such a change is necessary to avoid immediate harm to the participants. Additionally, any unanticipated problems that involve risks to subjects must be reported to the IRB in accordance with the CUMC Unanticipated Problems: Reporting to the IRB of Unanticipated Problems Involving Risks policy, dated January 24, 2008. All submissions for modifications and unanticipated problems must be submitted through RASCAL.

Renewal applications should be submitted 60 days before the expiration date of this study through RASCAL. Failure to obtain renewal of your study prior to the expiration date will require discontinuance of all research activities for this study, including enrollment of new subjects. You must inform the IRB in writing when your study has been completed.

If you have any questions regarding this approval, please call Challace Pahlevan at (212) 342-0035.

Columbia University appreciates your commitment towards the ethical conduct of human research.

Appendix C (page 1 of 4)

Columbia University Medical Center Consent Form

Attached to Protocol: IRB-AAAD4271

Principal Investigator: Victoria Raveis (vhr1)

IRB Protocol Title: Type 2 Diabetes Self-management Practices:
Behaviors and Perspectives of Elderly Dominicans

Consent Number: CF-AAAJ3529

Participation Duration: 90 minutes

Anticipated Number of Subjects: 60

Contact

Contact	Title	Contact Type	Numbers
Yessica Diaz	Doctoral Candidate	Co-Investigator	Telephone: 917 701-4695
Victoria Raveis	Assoc Prof Of Clinical	Principal Investigator	Telephone: 212-304-5563

Research Purpose

The purpose of this study is to understand the practices and barriers elderly Dominicans face living with and managing their Type 2 diabetes.

Information on Research

Introduction

The purpose of this form is to give you information to help you decide if you want to take part in a research study. This consent form includes information about:

- why the study is being done;
- the things that you will be asked to do if you are in the study;
- any known risks involved;
- any potential benefit; and
- options, other than taking part in this study, that you have.

The Co-Investigator will discuss the study with you. If at any time you have questions about the study, please ask a member of the study team. Take all the time you need to decide whether you want to take part in this research study.

Procedures

If you decide to participate in this study we are asking you to participate in a research meeting with the Co-Investigator. This research meeting will be scheduled at your convenience. It will be held in a

Medical Center Institutional Review Board: 312-305-5883
Consent Form #: CF-AAAJ3529 Copied From: CF-AAAG6540
Printed On: 03/05/2012 at 16:45 page 1 of 4

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private room at the Isabella Resource Center, at your home, or any other meeting space you may prefer.

At this meeting you will be asked to answer a questionnaire that will take about 30 minutes to complete. The questionnaire will contain questions about your health and Type 2 diabetes. We will also ask you some background questions about yourself. You can choose not to answer any question. In the second part of the research meeting, we will ask you to tell us in greater detail about your experiences living with and managing Type 2 diabetes. This portion of the research meeting will take about one hour and with your permission (please indicate by checkmark below), we will tape record it so that it can be typed up and analyzed by the research team. The tape recording will be stored in a locked file cabinet accessible only to the research team. These tapes will only be identified by a unique case I.D. The tapes will be kept for two years following completion of the study, and then destroyed.

- Yes, I agree to the tape recording
 No, I do not agree to the tape recording

Taking part in this study will last approximately one and one-half hours.

Risks

To the best of our knowledge, taking part in this study will not hurt you.

Benefits

You will not receive personal (direct) benefit from taking part in this research study. However, the information collected from this research may help others in the future.

Alternative Procedures

You may choose not to take part in this research study

Confidentiality

Any information obtained during this study and identified with you will remain confidential. Your name or other personally identifying information will not be used in any reports or publications from the study. Your comments will be identified by a unique code number and kept in locked files accessible only to the research team.

WHAT ABOUT CONFIDENTIALITY?

Confidentiality Protection

Any information collected during this study that can identify you by name will be kept confidential. We will do everything we can to keep your data secure, however, complete confidentiality cannot be promised. Despite all of our efforts, unanticipated problems, such as a stolen computer may occur, although it is highly unlikely.



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The research file that links your name to the code number will be kept in a locked file cabinet and only the investigators and study staff will have access to the file.

The following individuals and/or agencies will be able to look at and copy your research records:

- The investigators, who may be evaluating the study
- Authorities from Columbia University and New York Presbyterian Hospital, including the Institutional Review Board ('IRB')

Additional Costs

There are no costs to you for taking part in this study.

Compensation

You will receive a 10 dollar supermarket gift certificate to compensate you for your time.

Voluntary Participation

Participation in this study is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may also discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

Additional Information

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions or concerns about the study, you may contact Yessica Diaz, Co-Investigator at 917-701-4695. You may also contact the Principal Investigator, Dr. Victoria Raveis, at 212-304-5563.

If you have any questions about your rights as a research subject, you should contact the Columbia University Institutional Review Board by phone at (212) 305-5883 or by email at askirb@columbia.edu.

More information about taking part in a research study can be found on the Columbia University IRB website at: <http://www.cumc.columbia.edu/dept/irb>.

STATEMENT OF CONSENT - PARTICIPANT'S STATEMENT

I have read the above purpose of the study, and understand my role in taking part in the research. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later, about the research, I can ask the investigators listed above. I understand that I may refuse to participate or withdraw from participation at any time without any rights to which I am entitled. The investigator may withdraw me at her professional discretion. If I have questions about my rights as a research participant, I can call the Institutional Review Board office at (212) 305-5883. I certify that I am 18 years of age or older and freely give my consent to participate in this study. I will receive a

Medical Center Institutional Review Board: 212-305-5883
Consent Form #: CF-AAAG3529 Copied From: CF-AAAG6542
Printed On: 03/05/2013 at 16:45 page 3 of 4

Inactive

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copy of this document for my records.

Signature

Study Participant

Print Name _____ Signature _____ Date _____

Person Obtaining Consent

Print Name _____ Signature _____ Date _____

Inactive

Appendix D (page 1 of 4)

Columbia University Medical Center Forma de Consentimiento

Protocolo : IRB-AAAD4271

Investigadora Principal: Victoria H. Raveis (vhr1)

IRB Título de Protocolo: Manejar Las Practicas de Diabetes Tipo 2:
Comportamiento y Perspectivas de Personas Dominicanas Adultas

Numero de Consentimiento: CF-AAAD8281

Duración de Participación: 90 Minutos

Numero de Participantes: 60

Contacto

<u>Contacto</u>	<u>Título</u>	<u>Tipo de Contacto</u>	<u>Numero</u>
Yessica M. Diaz	Candidata de Doctorado	Co-Investigadora	917 701-4695

Victoria H. Raveis	Profesora Asociada De Clínica	Investigadora Principal	212 304-5563
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Propósito de Investigación

El propósito de este estudio es entender las practicas y barreras de los Dominicanos de edad que se encuentran viviendo y manejando su diabetes.

Información de la Investigación

Introducción

- porque están haciendo este estudio
- las cosas que le preguntaremos al hacer esta entrevista
- cual que riesgo envuelto
- beneficio potencial y
- opciones, que usted tiene en este estudio

La Co-Investigadora discutirá este estudio con usted. Si en cualquier momento tiene pregunta sobre el estudio, favor dirigirse a cualquier miembro del equipo de

Institutional Review Board (CUMCIRB)	
IRB #	AAAD4271 Approval Date 08/12/08
IRB #	CF-AAAD8281 Expiration Date 12/31/09
Columbia University Medical Center	

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publicaciones. Sus comentarios serán identificados por un número único y guardado en un gabinete cerrado accesible solamente por el equipo de investigación.

Y QUE PASA CON LA CONFIANZA?

Protección de la Confianza

Cualquier información recopilada durante este estudio puede ser identificado por su nombre y puede ser mantenida confidencialmente. Vamos hacer todo lo posible para que sus datos estén seguros, sin embargo no podemos prometerle confianza completa. Aunque todos nuestros esfuerzos no anticipados, como robo de la computadora, pueden ocurrir pero es un riesgo mínimo.

El archivo de investigación que conecta su nombre con el número será guardado en un gabinete que solamente la investigadora y el equipo de estudio tendrá acceso.

Los siguientes individuos o agencias que pueden mirar y copiar su documento.

- Los investigadores, que pueden estar evaluando este estudio
- Autoridades de Columbia Universidad y el Hospital Presbiteriano de Nueva York, incluyendo el Institutional Review Board (IRB)

Costos Adicionales

No hay gastos para usted por participar en este estudio.

Compensación

Usted recibirá por participar en este estudio un certificado de \$10 para en el supermercado.

Participación Voluntaria

Participación en este estudio es voluntaria. No querer participar o participar no lo involucrará en penalidades o pérdidas de beneficios que usted tiene derecho a recibir.

Información Adicional

A QUIEN SE LLAMA SI TENGO PREGUNTAS O PROBLEMAS?

Si usted tiene preguntas o problemas sobre el estudio, se puede comunicar con Yessica Diaz, Co-Investigador al (917) 701-4695. Puede también comunicarse con la investigadora principal, la Dr. Victoria Raveis, al (212) 305-5883.

Institutional Review Board (IRB)	
IRB #	Approval Date
IRB #	Approval Date
IRB #	Approval Date

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Si usted tiene información sobre sus derechos usted puede comunicarse con Columbia Universidad Review Board al siguiente teléfono (212) 305-5883 o E-mail a askirb@columbia.edu.

Más información sobre este estudio puede ser encontrada en la Universidad de Columbia <http://www.cumc.columbia.edu/dept/irb>.

Declaración de Consentimiento - Declaración de Participantes

Yo he leído el propósito de este estudio y entiendo mi papel en esta investigación. Yo voluntariamente participe en esta investigación. Yo tengo la oportunidad de hacer preguntas y si tengo preguntas más tarde, acerca la investigación, voy a contactar a la investigadora. Yo entiendo que yo puedo rehusar a participar o salir de la participación en cualquier momento sin derechos que me merezco. La investigadora puede sacar del estudio con su autorización Profesional. Si tengo preguntas sobre mis derechos como participante, puedo llamar al Institutional Review Board oficina al (212) 305-5883. Yo certifico que tengo más de 18 años y doy consentimiento en este estudio. Voy a recibir una copia para mis records.

Firma

Participante en el Estudio:

Nombre _____ Firma _____ Fecha: _____

Persona Obteniendo Consentimiento

Nombre _____ Firma _____ Fecha: _____



Appendix E

Bilingual text of the announcement for Type 2 Diabetes Study

Thank you for your time and interest in this important workshop. If there are no further questions at this time, I would like to introduce you to a new study that I am conducting focusing on the self-management practices of Type 2 diabetes. As you probably know already, Type 2 diabetes is the fifth leading cause of death among Latinos in the United States. Diabetes is a commonly occurring health condition in older adults, leading to complications that can severely impact the quality of your life. In this study, I am interested in exploring how older Dominicans manage their illness through in-depth interviews. If you are interested in learning more about the study and would like to participate, please speak to me directly and I would be happy to answer your questions.

Appendix F

Texto de el Anuncio para el Estudio de Diabetes 2

Gracias por su tiempo y interés en este taller importante. Si no hay mas preguntas en este tiempo, me gustaría presentarles a un nuevo estudio que estoy haciendo fijandome en las practicas de Diabetes 2. Como probablemente ya saben, la Diabetes 2 es la 5 causa de mortalidad en los Latinos /Hispanos en los Estados Unidos. Diabetes es muy común, ocurre en personas mayores y resulta en complications que pueden gravemente puede impactar la calidad de su vida. En este estudio, estoy interesada en explorar como personas mayores manejan su enfermedades utilizando entrevistas en detalle. Si usted esta interesada/o en aprender mas sobre este estudio y le gustaria participar, por favor hable con migo directamente y con mucho gusto le respondo sus preguntas.

Appendix G

Do you have Type 2 Diabetes?

We are seeking Dominican men and women, 55 years of age and older, with Type 2 Diabetes to participate in a one-hour research interview.



We want to know how people with Type 2 diabetes are living with the disease, how they take care of themselves and what they are doing to manage their diabetes.

For more information, please contact:

Yessica M. Diaz, MPH, MSW

(917) 701-4695 or

ymd2001@columbia.edu

IRB Approval- Approved: _____

Expires: _____

Appendix H

¿Tiene Usted Diabetes Tipo 2?

Estamos buscando hombres y mujeres Dominicanos, de 55 años o mas, con diabetes para participar en una entrevista por una hora.



Queremos saber como personas con diabetes viven con la enfermedad, se cuidan y que hacen para controlarla.

Para mas información, por favor llame a:
Yessica M. Diaz, MPH, MSW
(917) 701-4695 or
ydm2001@columbia.edu

Appendix I (page 1 of 3)

Type 2 Diabetes Self-Management Practices: Behaviors and Perspectives of Elderly Dominicans Questionnaire

Today's Date: _____/_____/_____
MM DD YYYY

Participant # _____

Hello, my name is Yessica Diaz and I am conducting this interview for my doctoral dissertation study. For this part of the interview, I am interested in learning more about your background. This section will only take 20-30 minutes of your time. Most importantly, all your answers will be confidential.

1. Age: _____
2. Gender: Male Female
3. How do you identify yourself in terms of race or ethnicity?
 1. Hispanic or Latino/Latina
 2. Black or African American
 3. Asian, Hawaiian or other Pacific Islander
 4. White
 5. Other
4. What is your primary language?
 1. Spanish
 2. English
 3. Other _____

Appendix I (page 2 of 3)

5. What is the highest level of education that you have completed?
 1. Elementary school
 2. High school or GED
 3. Less than 4 years of college
 4. College (Bachelor's degree)
 5. Post-graduate (Master's degree or higher)

6. Which of the following best describes where you live?
 1. Private Home
 2. Apartment
 3. Nursing home or hospice
 4. Retirement or senior residence community: apartment
 5. Retirement or senior residence community: house
 6. Other

7. Which of the following describes whom you live with?
 1. By myself
 2. With my grandchild/grandchildren
 3. With my spouse or partner
 4. With other relatives
 5. With my child/children
 6. Other (please specify) _____

8. Which of the following best describes your current main daily activities and/or responsibilities?
 1. Working full-time
 2. Working part-time
 3. Unemployed or laid off
 4. Looking for work
 5. Keeping house or raising children full-time
 6. Retired

9. What type of medical insurance do you currently have?
 1. Medicare
 2. Medicaid
 2. Private
 3. HMO/Managed Care
 4. No insurance
 5. Other (please specify) _____

Appendix I (page 3 of 3)

10. In general, how would you describe your current health?

1. Very good
2. Good
3. Fair
4. Poor

11. How long have you lived in the United States?

1. Less than 5 years
2. Between 5 and 10 years
3. More than 10 years

12. In addition to Type 2 Diabetes, please describe each health problem you now have:

1. High blood pressure
2. Heart disease
3. Asthma
4. Other _____
5. Not applicable: No major health problems

13. How long have you been living with Type 2 Diabetes?

1. Recently diagnosed (1 year or less)
2. Less than 5 years
3. Between 5 and 10 years
4. More than 10 years

Thank you very much for your time and thoughtfulness. Your help is very important and your participation is very much appreciated.

Appendix J (page 1 of 3)

Y. Diaz 2/11/2009/

Manejar Las Practicas de Diabetes Tipo 2 Comportamiento y Perspectivas de Personas Dominicanas Adultas

Fecha de Hoy: ____/____/____
MM DD Año

Participante # _____

Hola, mi nombre es Yessica Diaz y yo estoy conduciendo esta entrevista para mi estudio de doctorado. En esta parte de la entrevista, Yo estoy interesada en aprender más sobre su historia. Esta sección durara 20-30 minutos de su tiempo. Importante, todas sus respuestas serán confidenciales.

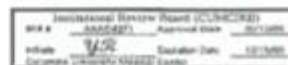
1. Edad: _____
2. Sexo: Hombre Mujer
3. ¿Como usted se identifica en términos de raza o país de origen?
 1. Hispano o Latino/Latina
 2. Africano-Americano
 3. Asiático, Hawaiano u otro Isla del Pacifico
 4. Blanco
 5. Otro
4. ¿Cuál es su idioma primario?
 1. Español
 2. Inglés
 3. Otro _____
5. ¿Cuál es su educación máxima?
 1. Primaria
 2. Secundaria
 3. Menos de 4 años de colegio
 4. Universidad
 5. Post-grado (Profesional)



Appendix J (page 2 of 3)

Y. Diaz 2/11/2009/

6. ¿Cuál es la manera que usted describe donde usted vive?
1. Casa
 2. Apartamento
 3. Asilo
 4. Residencia Comunitaria
 5. Otra
7. ¿Cuales de los siguientes viven con usted?
1. Sola/o
 2. Con nietos
 3. Con esposa o pareja
 4. Con otros familiares
 5. Con hijos
 6. Otros (favor especifique) _____
8. ¿Cuales de los siguientes describe su rutina y responsabilidad diaria?
1. Trabaja tiempo completo
 2. Trabaja Medio tiempo
 3. Sin trabajo o perdió el trabajo
 4. Buscando Trabajo
 5. Manteniendo la casa
 6. Retirada/o
9. ¿Que tipo de seguro médico usted tiene actualmente?
1. Medicare
 2. Medicaid
 3. Seguro Privado
 3. HMO/Managed Care
 4. No tengo seguro
 5. Otro (favor especifique) _____
10. ¿En general, como describiría su estado de salud actualmente?
1. Muy bien
 2. Bien
 3. Justo
 4. Pobre
11. ¿Por cuanto tiempo usted ha vivido en los Estados Unidos?
1. Menos de 5
 2. Entre 5 & 10 Años
 3. Más de 10 Años



Appendix J (page 3 of 3)

Y. Diaz 2/11/2009

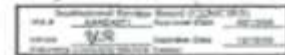
12. A parte de Diabetes, por favor indique que otro problema de salud tiene?

1. Presión alta
2. Enfermedad del corazón
3. Asma
4. Otro _____
5. No aplicable: No problemas de salud mayor

13. ¿Por cuanto tiempo ha vivido con Diabetes Tipo 2?

1. Diagnostico Reciente (un año o menos)
2. Menos de cinco años
3. Entre cinco y 10 años
4. Más de 10 años

Muchas gracias por su tiempo y cooperación. Toda su ayuda es importante y su participación es agradecida.



Appendix K (page 1 of 5)

Appendix A Wording of Items in Acculturation Scale

A. English					
* 1. In general, what language(s) do you read and speak?					
1	2	3	4	5	
Only Spanish	Spanish better than English	Both Equally	English better than Spanish	Only English	
* 2. What was the language(s) you used as a child?					
1	2	3	4	5	
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English	
* 3. What language(s) do you usually speak at home?					
1	2	3	4	5	
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English	
* 4. In which language(s) do you usually think?					
1	2	3	4	5	
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English	
* 5. What language(s) do you usually speak with your friends?					
1	2	3	4	5	
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English	

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Marin, Sabogal, Marin, Otero-Sabogal and Perez-Stable

Appendix A (continued) Wording of Items in Acculturation Scale

6. In what language(s) are the T.V. programs you usually watch?				
1	2	3	4	5
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English
7. In what language(s) are the radio program you usually listen to?				
1	2	3	4	5
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English
8. In general, in what language(s) are the movies, T.V. and radio programs you <i>prefer</i> to watch and listen to?				
1	2	3	4	5
Only Spanish	More Spanish than English	Both Equally	More English than Spanish	Only English
9. Your close friends are:				
1	2	3	4	5
All Latinos/Hispanics	More Latinos than Americans	About Half & Half	More Americans than Latinos	All Americans
10. You prefer going to social gatherings/parties at which the people are:				
1	2	3	4	5
All Latinos/Hispanics	More Latinos than Americans	About Half & Half	More Americans than Latinos	All Americans

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Appendix K (page 3 of 5)

SHORT ACCULTURATION SCALE

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Appendix A (continued) Wording of Items in Acculturation Scale

11. The persons you visit or who visit you are:

1	2	3	4	5
All Latinos/ Hispanics	More Latinos than Americans	About Half & Half	More Americans than Latinos	All Americans

12. If you could choose your children's friends, you would want them to be:

1	2	3	4	5
All Latinos/ Hispanics	More Latinos than Americans	About Half & Half	More Americans than Latinos	All Americans

Spanish

* 1. Por lo general, qué idioma(s) lee y habla usted?

1	2	3	4	5
Solo Español	Español mejor que Inglés	Ambos por igual	Inglés mejor que Español	Solo Inglés

* 2. Cuál fue el idioma(s) que habló cuando era niño(a)?

1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés

* 3. Por lo general, en qué idioma(s) habla en su casa?

1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés

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Marin, Sabogal, Marin, Otero-Sabogal and Perez-Stable

Appendix A (continued) Wording of Items in Acculturation Scale

* 4. Por lo general, en qué idioma(s) piensa?				
1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés
* 5. Por lo general en qué idioma(s) habla con sus amigos(as)?				
1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés
6. Por lo general, en qué idioma(s) son los programas de televisión que usted ve?				
1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés
7. Por lo general, en qué idioma(s) son los programas de radio que usted escucha?				
1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés
8. Por lo general, en qué idioma(s) <i>prefiere</i> oír y ver películas, y programas de radio y televisión?				
1	2	3	4	5
Solo Español	Más Español que Inglés	Ambos por igual	Más Inglés que Español	Solo Inglés

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Appendix K (page 5 of 5)

Appendix A (continued)
Wording of Items in Acculturation Scale

9. Sus amigos y amigas más cercanos son:				
1	2	3	4	5
Solo Latinos	Más Latinos que Americanos	Casi mitad y mitad	Más Americanos que Latinos	Solo Americanos

10. Usted prefiere ir a reuniones sociales/fiestas en las cuales las personas son:				
1	2	3	4	5
Solo Latinas	Más Latinas que Americanas	Casi mitad y mitad	Más Americanas que Latinas	Solo Americanas

11. Las personas que usted visita o que le visitan son:				
1	2	3	4	5
Solo Latinas	Más Latinas que Americanas	Casi mitad y mitad	Más Americanas que Latinas	Solo Americanas

12. Si usted pudiera escoger los amigos(as) de sus hijos(as), quisiera que ellos(as) fueran:				
1	2	3	4	5
Solo Latinos	Más Latinos que Americanos	Casi mitad y mitad	Más Americanos que Latinos	Solo Americanos

Note: An asterisk indicates items making up the first factor (short scale)

Appendix L

Topic Guide for Type 2 Diabetes Study

Can you tell me what you do to manage your Type 2 diabetes?

PROBE: How about the food you eat? Meals? Snacks? Exercise? Other things you do? Any traditional/old country practices? Medicines you take?

What are the practices you use to assist you in managing your Type 2 diabetes?
Please tell me about them.

How did you learn that you had Type 2 diabetes?

Tell me what it is like for you living with diabetes. What do you find problematic? *PROBE*: Issues you face? Examples of specific problems. Family issues? ...

Describe what barriers you face when you try to manage your Type 2 diabetes?
Please explain.

What do you think causes diabetes? Do you think lifestyle is a factor? Why/why not?

Do you use home remedies to manage your diabetes? *PROBE*: What do you do?
Anything else?

Does culture play a role in managing your Type 2 diabetes? Do you use home remedies in managing your illness?

How did you learn that you had Type 2 diabetes? Was it a medical diagnosis?

What has worked well for you in managing your illness? Please elaborate.

What would help you in managing your illness better? Please explain why.

What cultural factors would you say help you manage your diabetes better?

What cultural factors in your life do not help you with managing your diabetes? Why?

What are some structural barriers, if any, that you encountered?

Communication issues with provider? Lack of bilingual services?

How did you overcome these barrier(s)?

How has diabetes changed your life?

What recommendations would you make to others who have diabetes?

Is there anything else you would like to add? Thank you for your time.

Appendix M

Y. Diaz 2/11/09

Gua del Estudio de Diabetes Tipo 2

Puede decirme qué hacer para manejar su diabetes tipo 2?

Investigue: ¿cómo está el alimento que come? Comidas? Los Aperitivos? Ejercicios y otras cosas que hacer?

¿Cuáles son las prácticas que usa para ayudarle a manejar su diabetes tipo 2? Por favor, cuénteme sobre ellas.

¿Cómo se enteró que usted tenía diabetes tipo 2?

Cuéntame como es vivir con diabetes. ¿Qué es lo que encuentra problemático?

Investigue: Cosas que usted enfrenta? Ejemplos problemas específicos. Las cosas familiares? ...

¿Describe qué barreras usted enfrenta cuando usted trata de manejar su diabetes Tipo 2? Por favor Explique.

¿Qué piensa usted que causa la diabetes? ¿Piensa usted que estilo de vida es un factor? ¿Por qué/por qué no?

¿Utiliza usted en casa remedios para manejar su diabetes?
Investigue: ¿Qué hace usted? ¿Otras cosas que hace?

¿Qué papel Juega la cultura para manejar su diabetes? ¿Utiliza usted en casa remedios para manejar su enfermedad?

¿Cómo aprendió usted que tenía diabetes? ¿Fue un diagnóstico médico?

¿Qué le ha funcionado para controlar su enfermedad? Elabore por favor.

¿Qué le ayudaría a manejar su enfermedad mejor? Explique por favor por qué.

¿Qué factores de su cultural le ayuda a maneja mejor su diabetes?

¿Qué factores de su cultural no le ayuda a maneja su diabetes? ¿Por qué?

¿Cuáles son las barreras estructurales que usted enfrenta? Por favor Explique.

-La comunicación pública con profesionales? ¿La falta de servicios bilingües?

¿Cómo superó usted esta barrera (s)?

¿Cómo ha cambiado diabetes su vida?

¿Qué recomendaciones haría usted a otros que tienen diabetes? ¿Hay otras cosa que quiera agregar?

International Review Board (IRB)
IRB # 1450771 Approved Date 05/12/08
IRB # 1450771 Expires Date 12/31/09
Committee Chairperson/Principal Investigator