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Health-care Seeking Behaviors Of Puerto Ricans With Diabetes Mellitus Who Live In South Florida: An Exploratory Study

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HEALTH-CARE SEEKING BEHAVIORS OF PUERTO RICANS WITH DIABETES
MELLITUS WHO LIVE IN SOUTH FLORIDA: AN EXPLORATORY STUDY

by

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ABSTRACT

Latinos are the fastest growing minority population in the United States (U.S.) and have the worst access to health care of any ethnic group. The chronic disease of diabetes is twice as common in adult Latinos as in non-Latino whites, and the risk of death related to diabetes is twofold. Reasons for this disparity have yet to be clearly identified. This study had two purposes: 1) to explore cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida; and 2) to examine Puerto Ricans' perceptions about their health-care providers. The cultural phenomena of interest were familism, religiosity, spirituality, use of ethnomedicine, and perception of ethnic concordance of health-care provider. Numerous studies have examined these phenomena with other Latino groups, but none have specifically focused on Puerto Ricans. An overarching goal of the study was to contribute to the knowledge base on a particular health disparity—diabetes.

Using a narrative inquiry approach, a purposive sample of self-identified Puerto Ricans with diabetes (N = 12) were recruited from six sites in a South Florida city. Data were obtained using a pencil-and-paper demographic instrument, the Short Acculturation Scale to determine language preference of Spanish or English, and a personal interview using a semi-structured, ten-item interview guide. Subjects gave written informed consent for participation, and all data were coded to ensure confidentiality. The personal interviews were tape recorded and transcribed verbatim. Interviews completed in Spanish were translated to English and transcribed. Using content analyses techniques, transcribed narratives were analyzed for content and thematic emergence.

The findings revealed that familism was an important consideration in health-care seeking behaviors. Traditional gender role expectations, coupled with caregiver burdens, deterred some participants from seeking care even when care was needed. Religiosity and spirituality did not influence decision-making but did have a role in coping with the chronic disease. While participants were aware of culturally based ethnomedicine, they preferred Western medicine for the treatment of their diabetes. They also had a preference for a health-care provider who was ethnically concordant. Serendipitous findings that emerged in the analyses included the casual attitude of several participants about their diabetic status and reports of depressive-like symptoms among most of the women. Health-care providers need to take into consideration the cultural and linguistic preferences of Puerto Ricans to develop an appropriate and effective treatment plan. Discrepancies between the health-care providers and the clients' systems must be reconciled to improve adherence to evidence-based treatment.

This dissertation is dedicated to my husband Juan, who has always given me unconditional love and support—he allowed me to do whatever it took to get the job done. And it is dedicated to my sons Taylor Jon and Alex, who inspired me along the way—never allowing me to forget what was truly most important. And finally to my parents Angel and Della Negron who supported me both financially and emotionally through this overwhelming endeavor.

“si se puede”

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CHAPTER I: INTRODUCTION

Latinos are the fastest growing minority population in the United States (U.S.) and have the worst access to health care of any ethnic group. In a national study, Documet and Sharma (2004) found that 37% of Latinos (N = 206) had no health insurance and 26% had not seen a health-care provider in more than a year. More specifically, the chronic disease of diabetes was twice as common in adult Latinos as in non-Latino whites (Documet & Sharma). Reasons for this disparity have yet to be clearly identified. Of the Latino population, Puerto Ricans are the second largest subpopulation. Recent Census estimates indicate that 3.7 million Puerto Ricans live in the continental United States (U.S. Census Bureau, 2006).

In recent years, there has been an extensive debate regarding use of the term *Latino* versus the term *Hispanic*. Marin and VanOss-Marin (1991) defined *Hispanics* as individuals who live in the U.S. but were born in a Spanish-speaking country. The National Rural Minority Health Resource Book (Bushy, 2002) recognized that the term *Hispanic* does not define the ethnic and cultural identities that characterize a diverse population; therefore, the term *Latino* has come into use. Often, the term *Hispanic* is interchanged with *Latino*, but neither term accurately describes this culturally and ethnically diverse population; people of all races make up the Latino population. Latinos, in general, are connected by a common language, Spanish, which is often the national language of countries that Spain colonized hundreds of years ago. These countries include Puerto Rico, Cuba, Dominican Republic, Mexico, and countries in Central and South

America. Although citizens from these countries speak a similar language, each of these nations has a unique ethnic and cultural identity (Spector, 2004).

The classification of *Hispanic* refers to language, while the classification of *Latino* infers ethnicity. In this dissertation, the term *Latino* is used in reference to the population as a whole. The term *Puerto Ricans* is used in reference to a particular ethnic Latino subgroup. Within the review of literature, however, the terminology used by respective authors is retained.

Although this study focuses on Puerto Ricans who live in South Florida, it is important to note that most Puerto Ricans who live in the U.S. maintain very close connections with relatives and friends who live on the island of Puerto Rico. Individuals and families often travel from the U.S. to Puerto Rico and communicate regularly via telephone and correspondence. This phenomenon has been referred to as *circulatory migration* (Christenson, 2001).

Family *interconnectedness* is further facilitated by the U.S. designation of the island of Puerto Rico as a U.S. Commonwealth, which makes Puerto Ricans U.S. citizens. The imposition of few travel restrictions for U.S. citizens, coupled with the close proximity of Puerto Rico to Florida, expedites traveling by Puerto Ricans between the two locations.

The histocultural background of Puerto Rico is examined more thoroughly in the literature review within Chapter II. In reference to place of residence, in this dissertation, Puerto Ricans living in the U.S. are described as living on the U.S. mainland; those who live in Puerto Rico are described as living on “the Island.”

There is wide diversity among demographics of Puerto Ricans as a group. While some are upwardly mobile and well educated, others have not fared as well. Associated with minority status, Puerto Ricans experience a range of psychosocial stressors and financial hardship, especially those who are not proficient in the English language. Puerto Ricans living in the U.S.

have a poverty rate of at least 26%, and their health status is often poor (U.S. Census Bureau, 2006). Based on the 1997-2001 National Health Interview Survey, Zsembik and Fennell (2004) found, among Puerto Ricans age 25 and older (N = 2268), disparities in several health indicators, including tobacco and alcohol usage, participation in regular physical activity, and the prevalence of obesity. They found that Puerto Ricans with poorer health status tended to have lower income and acculturation levels than the general U.S. population.

Ho et al. (2006) compared the health of Puerto Ricans living in New York City with those living on the island of Puerto Rico and with non-Hispanic whites living in the U.S. (N = 11,150). Using data obtained from two randomly sampled surveys, the Behavioral Risk Factor Surveillance System (BRFSS, 1999) and the New York City Survey (1999-2000), a secondary data analysis was undertaken. Variables in the analysis included age, gender, education, employment, annual household income, and self-reported risk factors, including body mass index (BMI), smoking status, cholesterol level, and diabetes. Ho et al found that Puerto Ricans living in New York had a higher rate of diabetes (age-adjusted; gender-adjusted) than did Puerto Ricans who lived in Puerto Rico. Comparing Puerto Ricans living in Puerto Rico with non-Latino whites living in the U.S., health indicators were classified into two categories: 1) lifestyle parameters that included obesity, diabetes, and smoking; and 2) access to health-care parameters that included frequency of routine check-ups and diabetes follow-up care. Puerto Ricans living in New York had a higher prevalence of smoking and poorer health status than did Puerto Ricans living on the Island. Young and middle-aged Puerto Rican adults had the poorest health indicators of the three groups, and the largest disparities were among those 18 to 44 years of age (Ho et al, 2006).

Ho et al. (2006) further noted that Puerto Ricans both in the U.S. and on the Island had increased rates of obesity and diabetes compared to non-Hispanic whites in the U.S. These findings suggest that living in the U.S. may be, in part, responsible for the social stressors that some young Puerto Ricans experience, stressors associated with limited employment opportunities, sedentary lifestyles, and poor decision-making skills that can negatively impact overall health status. The findings illuminate a need for additional nursing studies that examine Puerto Ricans' health-care seeking behaviors and how these behaviors contribute to health disparities within this population.

Purpose

The study had two purposes: 1) to explore cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida; and 2) to examine Puerto Ricans' perceptions about their health-care providers. The cultural phenomena of interest were familism, religiosity, spirituality, use of ethnomedicine, and perception of ethnic concordance of health-care provider. Acculturation was assessed as a proxy for language preference. Numerous studies have examined these phenomena with other cultural and ethnic groups, but none have specifically focused on Puerto Ricans (Campesino & Schwartz, 2006; Holland & Courtney, 1998; Mainous, et. al., 2006; Sabogal, Marin, & Otero-Sabogal, 1987). For the 3.4 million Puerto Ricans who live in the U. S., an increased understanding of cultural preferences and health-care seeking behaviors is warranted.

An overarching goal of the study was to contribute to the knowledge base on a particular health disparity—diabetes. Specifically in respect to Puerto Ricans, *Healthy People 2010* reports, Latinos living in the U.S. are almost twice as likely to die from diabetes as are non-Latino whites (U.S. Department of Health and Human Services, 2000). The findings from this study may assist

in developing culturally appropriate interventions that enable health-care providers, in general and nurses, in particular, to negotiate an appropriate care plan, promote adherence to recommended therapeutic regimens, and ultimately improve health outcomes among Puerto Ricans.

Significance

The prevalence of diabetes increases with age and is found to be higher among certain ethnic minority groups such as Latinos and African Americans. By 2020, it is estimated that 2.9% of the Latino population in the U.S. will be diagnosed with Type II diabetes, which is a 107% increase from 2002 (American Diabetes Association, 2003). As for the projected costs of diabetes and sequela, more than \$132 billion was spent on diabetes-related medical expenditures and lost productivity in the United States alone during 2002 (ADA, 2003).

This dissertation was timely, considering the poor health outcomes identified in the large Puerto Rican population compared to other Latino subgroups as emphasized in *Healthy People 2010* (USDHHS, 2000). The findings could also provide insights about “the Hispanic health paradox,” which continues to confound researchers (Abraido-Lanza, Chao, & Florez, 2005). The Hispanic health paradox refers to Latinos’ initial expectations, upon arriving in the U.S., that they will experience improved living conditions with better health-care access, leading, in turn, to an improved health status. Unfortunately, that outcome is not the case for many Puerto Ricans. There is a critical period when immigrants relocated in the U.S. experience better health status than counterparts who have been here for some time. Researchers have identified a U-shaped health status pattern for many immigrants who enter the U.S. Typically, immigrants arrive in the U.S. in fairly good health; but, after residing in the U.S. for a period of time, their health status deteriorates. Eventually, after achieving increased education and improved socioeconomic status,

along with acculturation into mainstream U.S. society, positive improvements in health occur (Abraido-Lanza, Chao, & Florez; Studnicki et al., 2005; Lara, Gamboa, Iya Kahramanian, Morales, & Bautista, 2005).

The following terms and definitions are used in this dissertation:

- *Familismo* is a Spanish term referring to a preference for emotional support provided within and by the extended family, often characterized by positive familial interactions.
- *Religiosity* refers to membership of a religious denomination and/or engaging in proscribed rituals and behaviors such as attending church.
- *Spirituality* refers to self-transcendence and is associated with a belief in a higher power/being. It is a quality that goes beyond religious affiliation (Ameling & Povilonis, 2001).
- *Ethnomedicine* refers to the indigenous health-care beliefs and practices of an ethnic group or culture that includes the use of herbs, elixirs, organics, and traditional folk medicine and self-care remedies. It is termed *remedios caseras* in Spanish.
- *Ethnic concordance* refers to similarities between the health-care provider and the client, including language and cultural preference.
- *Acculturation* refers to the process whereby an individual of a minority culture relinquishes pieces of cultural identity, characteristics, and behaviors and assumes those of the dominant culture. For this study, level of acculturation is viewed as an attribute of the participants and was determined by use of a Short Acculturation Scale (SAS) (Marin, Sabogal, Van-Oss-Marin, Otero-Sabogal & Perez-Stable, 1987).

In summary, this chapter presented an overview of the phenomena of interest and highlighted their significance to nurses, in particular, and health-care providers in general. The next chapter includes a review of the literature, to be followed by the Methodology in Chapter III, Data Analysis in Chapter IV, and the Discussion and Conclusions in Chapter V.

CHAPTER II: REVIEW OF LITERATURE

This chapter presents background information on the historical and cultural origins of Puerto Ricans, diabetes, and the cultural phenomena of familism, spirituality, religiosity, use of ethnomedicine, and ethnic concordance, as these factors impact health status and health-care behaviors. Also examined herein are the underpinnings of narrative inquiry—the approach used to collect and analyze data from participants in this study.

Histocultural Background

Historically, Puerto Ricans are a melding of three distinct ethnic groups: the Taino Indians who were the indigenous people of the island of Puerto Rico, the Spaniards who arrived during the period of colonization after 1492, and the Africans who arrived later as a result of the slave trade. These three distinct ethnic groups are ultimately the origin of current mainstream Puerto Rican culture (Higgins, 2000).

Despite sharing similarities with other Latino groups, Puerto Ricans also have unique characteristics. One of the most significant differences is the result of the sociopolitical history of Puerto Rico. Puerto Ricans have been U.S. citizens since March 1917, following the signing of the Jones Act that gave Puerto Rico commonwealth status (Ayala & Bergard, 2002). Although Puerto Ricans are U.S. citizens, the Commonwealth of Puerto Rico is a self-governing, unincorporated organized territory of the U.S. An elected Resident Commissioner serves in the U.S. House of Representatives but does not have voting privileges. Puerto Ricans share most rights and obligations of U.S. citizens; however, they are exempt from federal taxes, cannot vote

in national elections, are subject to military requirements, and contribute financially to Social Security (Rivera, 2007). U.S. citizenship also entitles Puerto Ricans to governmental assistance programs—food stamps, Medicaid, and Medicare. Even with these entitlements, Puerto Ricans experience a variety of barriers to accessing health-care services (Smith & Barnett, 2005).

As U.S. citizens, Puerto Ricans are not subject to the same laws that impede Latinos from other countries from immigrating to the U.S. During the 1950s and 1960s, there was an exodus of Puerto Ricans leaving the Island for the mainland U.S. in search of better economic opportunities. In fact, the Puerto Rican government encouraged a massive exodus of poor agricultural workers to relocate to the U.S. east coast, mainly New York City, to find employment. With low-wage earners, who were a burden on the national economy, gone, the Puerto Rican government could more easily foster industrialization on the Island. Subsequently, Puerto Rico moved from an agrarian economy to an industrialized economy with assistance from U.S. corporations (Rivera, 2007).

From a legal perspective, Puerto Ricans do not fit the definition of immigrants because they are already citizens of the U.S. Nevertheless, the reasons Puerto Ricans come to the U.S. are similar to those of immigrants from other countries. Christenson (2001) described demographic patterns of those who left Puerto Rico and relocated in the U.S. from 1980 through the 1990s. At the time, predominantly Puerto Rican males under the age of 40 relocated. This exodus of productive members of Puerto Rican society had an immediate negative economic and social impact on the Island, and the long-term ramifications are yet to be identified.

Even with the freedom to travel between the Island and the U.S. mainland, Puerto Ricans encounter similar conditions when relocating, much like other immigrants in the U.S. Economically, Puerto Ricans rank among the poorest of all ethnic groups, contributing to their

poor health outcomes. In 2000, the poverty rate of Puerto Ricans was 26%, which was higher than the poverty rate of African-Americans and other Latino subgroups (Enchautegui, 2007).

Although English is one of the two official languages in Puerto Rico, the majority of Puerto Ricans prefer to speak and read Spanish, and many have limited proficiency in English. Consequently, Puerto Ricans who have relocated have difficulty assimilating into the social, cultural, and economic environment of mainstream U.S. society (Enchautegui, 2007).

Another factor sometimes attributed to poorer health outcomes is *migration selectivity* of Puerto Ricans—in reference to certain individuals who choose to relocate to the U.S. (Enchautegui, 2007). Currently, Puerto Ricans with lower educational achievement, particularly women, leave Puerto Rico for the U.S. mainland. The impetus for relocating stems from potential employment opportunities; hence, Puerto Ricans of low socioeconomic status stand to gain the most from relocating. Since Puerto Ricans have a lower level of education and corresponding employment options, it is not surprising that their health status is lower compared to the U.S. population, in general, and to other Latinos, in particular (Ho et al., 2006; Smith & Barnett, 2005; Weinick, Jacobs, Stone, Ortega, & Burstin, 2004).

Hispanic Health Paradox

The Hispanic health paradox continues to confound researchers. Interest in this previously little-known phenomenon has increased during the last decade (Abraido-Lanza, Chao, & Florez, 2005). Essentially, the Hispanic health paradox refers to the expectation that when relocating to the U.S., an immigrant has greater economic opportunity and a more affluent lifestyle, which, in turn, leads to improved health status. However, this outcome has not been achieved. At some point after arriving in the U.S., the health status of immigrants actually deteriorates (Abraido-Lanza, Chao, & Florez). Latinos, in general, have a typically lower

socioeconomic profile, less education, and are less likely to have health insurance than non-white Latinos, but they also have a lower all-cause mortality rate and higher life expectancy than non-Latino whites. These facts form the basis for the situation referred to as the Hispanic health paradox.

Using secondary data from the 1991 National Health Interview Survey, it was found that Latinos were less likely to smoke and drink alcohol. However, these same Latinos were more likely to have a higher BMI than their non-Latino white counterparts and less likely to engage in physical exercise (Abraido-Lanza, Chao, & Florez, 2005; Studnicki et al., 2005).

Over time, acculturation into mainstream U.S. society is purported to have a positive effect on health status (Lara, et al, 2005). While these findings may be true for other Latino minority groups, such as Cubans, Dominicans, and Mexicans, positive effects have not been noted as frequently in Puerto Ricans. To illustrate this point, Fitzgerald et al. (2006) examined the associations of socioeconomic status and acculturation with obesity and lifestyle among low-income Puerto Rican women. Using 1998-1999 cross-sectional study data, conducted by interviews of a convenience sample (N = 200), findings indicated a positive association between obesity and acculturation among the Puerto Rican women interviewed. Cigarette smoking and alcohol intake was more prevalent among Puerto Rican participants as compared to Mexican-Americans and other Hispanic groups (Fitzgerald et al.). The participants' preferred language (English or Spanish) was used to measure level of acculturation into mainstream U.S. society. Education and car ownership were used as indicators of socioeconomic status (Fitzgerald et al.).

In 2005, Studnicki et al. conducted a study that compared health data and vital statistics of the Hispanic population living in Orange County, Florida, the majority of whom had relocated from Puerto Rico (51.4%). Various data sources were analyzed including causes of death,

hospital discharges, vital statistics, and other indicators. The indicators were organized into six groups: sociodemographic characteristics, maternal-child health, health status, sentinel events, infectious disease, and social health. Findings suggested that Puerto Ricans residing in Orange County, Florida, experienced poorer health outcomes relative to other Latino subgroups such as Cubans, Mexicans, and Central and South Americans. Additionally, the study found that after adjusting for socioeconomic status, education, and acculturation, mainland Puerto Ricans were less healthy than their Island counterparts. Health indicators, including chronic disease, cancer mortality, and sexually transmitted diseases, including Acquired Immune Deficiency Syndrome (AIDS), were analyzed. Among Latinos living in Orange County, there were higher rates of chronic liver disease, chronic obstructive pulmonary disease (COPD), pneumonia, diabetes, stroke, influenza, AIDS, and motor-vehicle crashes. However, Orange County Latinos did better in comparison to non-Hispanics, having lower age-adjusted rates of death from major causes such as heart disease, cancer, and stroke (Studnicki et al.).

Borell, Dallo, and White (2006) analyzed data from the National Health Interview Survey (1997-2001) and found that among Latinos, educational achievement and the prevalence of diabetes were inversely related ($p < .001$). In other words, individuals with a bachelor's degree were two times less likely than those with only a high-school diploma to develop diabetes. It is not known if findings are applicable to subsets of Latinos, such as Puerto Ricans.

From the literature review, health disparities among Puerto Ricans have been identified, most notably among those with diabetes. Although Puerto Ricans have access to government-funded U.S. entitlement programs (Medicaid, Medicare, and Social Security benefits), health disparities continue to persist, indicating that there is a need to examine other factors that may impact this Latino subgroup's health status.

Diabetes Mellitus: A Health Disparity

Diabetes mellitus is a disease process associated with insulin production. Typically, a diabetic has a deficiency or complete lack of insulin production, resulting in elevated glucose levels. There are two distinct classifications of diabetes mellitus: Type I results from pancreatic β -cell destruction, resulting in absolute deficiency of insulin. Type II diabetes mellitus results from a progressive insulin secretory defect. Type II diabetes is frequently not diagnosed until complications, such as visual disturbances and evidence of poor wound healing, are observed. According to the American Diabetes Association (ADA) (2007), one-third of the general population may be undiagnosed. Additionally, the ADA attributes the increased incidence of Type II diabetes among adults and adolescents in recent years to poor dietary habits and sedentary lifestyles.

According to the CDC (2005), the prevalence (per 1,000 standard population) of diabetes among Latinos since 1998 has increased from 61/1000 to 73/1000. According to the *Midcourse Review* (CDC, 2007) of *Healthy People 2010*, the objectives for the Latino population are early diabetes diagnosis, dilated eye examinations, fewer amputations, and reductions in cardiovascular deaths. To date, the *Healthy People 2010* objectives have been met 50% of the time or less. Diabetics with the best outcomes are females, non-Hispanics, and Caucasians who are college-educated (USDHHS, 2000).

Uncontrolled glucose levels in diabetic individuals result in cellular changes at both the macrovascular and microvascular levels. Diabetics are at risk for stroke, coronary artery disease, renal insufficiency, blindness, and poor wound healing. Treatments aim to maintain a normal glucose level, and interventions consist of diet modification, increased exercise, and pharmacotherapeutics that decrease circulating glucose levels.

In general, the review of literature suggests that Cubans and Mexicans gain health advantages by living in the U.S. However, findings differ for Puerto Ricans living in the U.S. Puerto Ricans experience even poorer health than their Island counterparts as evidenced by higher levels of co-morbidities with diabetes and coronary heart disease (Zsembik & Fennel, 2004).

Health-Care Seeking Behaviors

An individual's decision to seek care for a health problem is complex. Forming generalizations about a subgroup as a whole can be risky and difficult because wide variations exist in health-care seeking behaviors. Findings from the literature indicate that cultural beliefs and preferences can influence health-care seeking practices within a given ethnic community. Although the precise definition of culture is debated, there is consensus that culture is multifaceted and that cultural norms and rituals are transferred from one generation to another. Some of the obvious cultural characteristics of a particular ethnic group are associated with attire, rituals in major life events, and self-care practices such as the use of herbs and teas to manage blood glucose levels in diabetics (Poss, Jezewski & Stuart, 2003; Spector, 2004).

An example of a less obvious cultural characteristic among many Latinos is *filial piety* (Hsueh-Fen & Travis, 2005), and some researchers speculate this attribute influences individuals' health care decision-making. Filial piety refers to a child's long-term indebtedness to his or her parents. Inherent in filial piety is reciprocal responsibility of children to parents in return for the sacrifices they made in their behalf. It infers that children have an obligation to provide material and emotional support to the parents and, in some cases, even to extended family members such as grandparents, a certain aunt or uncle, and one's baptismal godmother or godfather (Hsueh-Fen & Travis). Although no word in the Spanish language exactly expresses

the notion of *filial piety*, Marin posited that among Puerto Ricans, the concept is akin to *familism*, a phenomenon of particular interest in this study. Familism assumes that the eldest daughter in a family will assume responsibility of caring for her ill and aging parents (Marin & VanOss-Marin, 1991; Ramos, 2004). This is but one example of a particular cultural role expectation among Puerto Ricans. The next section focuses on the cultural phenomena of interest in this study: familism, religiosity, spirituality, use of ethnomedicine, and ethnic concordance with health care providers.

Phenomena of Interest

This literature review explores phenomena relevant to health-care seeking behaviors and the impact, if any, that these phenomena—familism, religiosity, spirituality, and use of ethnomedicine—have on the Puerto Rican Latino subgroup. Additionally, articles focusing on acculturation were reviewed. For the initial literature search, the key terms *Hispanic*, *Latino*, *Puerto Rican*, and *diabetes mellitus* were entered into PubMed, and the Cumulative Index of Nursing and Allied Health Literature (CINAHL). Only research articles published from 2000-2007 were reviewed. A subsequent search used the following key terms: *familism*, *religion*, *spirituality*, *ethnomedicine*, *folk medicine*, and *acculturation*. These articles were cross-referenced with the initial search, and four articles that pertained to Puerto Ricans as a subgroup were reviewed. Articles that described the particular phenomena of interest within the Latino population were reviewed. Of these, four were meta-analyses and provided an overview of the phenomena of interest for this study. The low number of empirically based studies speaks to the need for more research about Puerto Rican health-care seeking behaviors.

As recently as 2006, Caban and Walker completed a meta-analysis of culturally relevant literature among Hispanic subgroups in the U.S. and found that more than half of the 33 articles

reviewed focused on Mexican Americans. The review of literature revealed the paucity of information on Puerto Ricans in the studies conducted during the past five years.

Familism

Familism is a cultural phenomenon adhered to by some Latinos, including Puerto Ricans and Mexicans (Romero, Robinson, Haydel, Mendoza & Killen, 2004; Sabogal et al., 1987). Romero et al. described familism as the “collectivistic nature of the Latino culture” and a desire to seek and share information with the family structure (p. 34). Familism can serve as the basis for an emotional support group, from which members gain help and assistance for day-to-day activities. Often, familism is characterized as a positive familial interaction, something one can rely on to successfully complete daily activities, to include health-care seeking behaviors (Romero et al.).

Latinos often seek information and advice on health-care issues from senior family members before seeking the advice of a professional health-care provider. In Latino culture, an individual’s medical condition and treatment are considered a family matter; therefore, important decisions regarding an individual’s health care are made as a family. Warda (2000) found that familism was defined by Mexican Americans as “specific instances when individuals expect their family members to be available to and supportive of them in times of need” (p. 215). The early works of Sabogal et al. (1987) identified familism as a core characteristic of Latino groups, but one that appeared to fade with increased acculturation. Familism among Latinos was more evident than among non-Latino whites.

Chesla, Skaff, Mullan, Gilliss, and Kanter (2003) suggested that the family unit influences an individual’s chronic disease management. However, other research within Latino populations does not support the purported positive relationship (Ramos, 2004).

In a longitudinal study with Latino ($n = 74$) and European Americans (EA) ($n = 113$) based in California, Chesla et al. (2003) examined the manner in which family structure, worldviews, and emotion management impacted disease management over the course of one year. Patients who met inclusion criteria were identified using billing and clinical databases from 11 health-care facilities. The initial assessment consisted of a face-to-face interview and questionnaire. Follow-up one year later included a mailed questionnaire and a home assessment. Findings suggested that participants' ratings of high coherence (positive influences) among Latinos actually predicted calorie overconsumption ($p < .05$) and poorer diabetes glucose management ($p < .01$) when compared to EA. In this study, family cohesiveness and interdependence negatively impacted a member's ability to manage diabetes. The desire to have amicable encounters and to maintain harmony within the family unit often comes at the cost of doing what is medically appropriate for an individual. When a family member's medical needs challenge family traditions, the caregiver may sacrifice the patient's needs for what is considered the good of the family as a whole. While caregivers perceived caregiving as rewarding, most admitted to increased stressors and limited coping strategies (Ramos, 2004). Moreover, Latino households with a family member who was diagnosed with diabetes manifested a more conflicted emotional climate than other Latino households (Chesla et al).

Despite perceived importance, familism can be overshadowed by acculturation. Cortes (1995) found that among Puerto Ricans, higher education was inversely related to familism. In other words, with increased education and socioeconomic status comes a distancing from the family. In fact, the Multicultural Model of Acculturation suggests that cultural structures, such as familism, rarely last beyond the third generation. These findings have been linked to increased education of the younger generations and their increased exposure to English language and

media (Berry, Kim, Power, Young, & Bujaki, 1989; Cortes, 1995). Despite the acclaimed positive connotation of familism on health-care seeking behaviors, high familial cohesiveness has been associated with negative changes in disease management. For example, a person with diabetes may be unwilling to voice concerns about a family-prepared meal in order to avoid confrontation or hurt feelings (Chesla et al., 2003). This finding necessitates further investigation of the relationship between familism and acculturation since the connection impacts both socioeconomic status and health-care choices (Pabon, 1998).

In a study of cardiovascular disease with Latinos in South Florida, psychosocial and cultural factors (including familism and fatalism) were examined to determine whether or not these were related to the cardiac quality of life. Dimensions of quality of life included global, physical, emotional, and social functioning. Hispanic cardiac patients ($N = 120$) participated in a cross-sectional survey administered between the years of 1999 and 2000. Among the female participants ($n = 35$), familism was cited as an important source of social support. Furthermore, the female participants felt an obligation to include family members in decision-making relative to their coronary heart disease. However, they also reported having less social support than men ($t [118] = 2.19, p < .05$). Incidentally higher levels of acculturation were associated with lower levels of familism. Furthermore, approximately 27% of the participants reported having some fatalistic view toward future events and believed such events were out of one's control (Urizar & Sears, 2006).

Weisman, Rosales, Kymalainen, and Armesto (2005) examined ethnicity, family cohesion, religiosity, and general emotional distress among patients with schizophrenia and their relatives. Participants completed the Brief Psychiatric Rating Scale, the Depression Anxiety Scale, and the Family Environment Scale. Findings from this study suggested that schizophrenic

patients (N = 56) with a strong sense of familism had better overall physical health as well as improved emotional health. Weisman et al. hypothesized that familism and strong religious values were associated with less overall psychological anxiety. In the study findings, familism had an overall positive impact among the study participants, which suggested that relative to psychiatric conditions a strong sense of familism may be beneficial when caring for affected family members.

In an ethnographic study among Mexican-American men (N = 36), Sobralske (2006) found that before seeking professional care, Mexican men typically spoke first to their wives or significant others regarding health-care matters. Sobralske's study further suggested that since women are usually the primary caretakers in the family, they are typically responsible for deciding when to access professional care, be it making an appointment with a health-care provider or seeking a recommendation from an extended family member for an over-the-counter medication.

In Ramos' (2004) qualitative study of caregiver stress among Puerto Ricans (N = 68), participants in focus groups were asked six broad, open-ended questions about caregiver stress, appraisal of any stressors, and coping mechanisms. Participants were Spanish-speaking caregivers for the frail elderly in and around the Tri-County area of New York City. The Latino population was predominantly Puerto Rican. Care was provided by family members in the home setting. Caregiver participants were primarily women of low socioeconomic status and acculturation level. The main sources of stress identified by participants included continuously reminding the ill individual to take his or her medications, keeping doctor's appointments, and eating nutritious meals. In addition, several respondents suggested a sense of fatalism, expressed as, "It was meant to be" or "What will be, will be." The Ramos study underscored the

importance of familism in the decision-making dynamics among Puerto Ricans; despite the stress perceived by caregivers, the sense of responsibility to care for their parents remained. In the literature, the positive influence of familism on self-care behaviors is stressed; however, in some instances, familism can be a deterrent in seeking and adhering to appropriate health care (Chesla et al., 2003; Ramos).

Religiosity and Spirituality

In addition to familism, the cultural preferences associated with religiosity and spirituality may impact the health care choices of Latinos. In the literature, the term *religiosity* often is interchanged with the term *spirituality*; however, the two terms are different in nature. Spirituality is an overarching phenomenon that is unique to each individual, dependent on a person's culture, life experiences, and beliefs. Religiosity has been associated with the state of "doing." In other words, religiosity is expression of an individual's spirituality (Potter & Perry, 2005, p.545). Musgrave, Allen, and Allen (2002) define spirituality as a "connectedness with self" or as a "relationship with a supreme being." Koenig (2004) differentiates "spirituality as more individualistic and self determined, whereas religion typically involves connections to a community with shared beliefs and rituals" (p. 1194). Koenig concedes that because of the overlap in meaning of *religiosity* and *spirituality*, the two terms are often interchanged.

More specifically, religiosity has been defined as a personal and institutional system of beliefs, related to but not synonymous with spirituality (Chiu, Emblem, VanHofwegen, Sawatzky & Meyerhoff, 2004). Religiosity focuses on behaviors such as frequency of church attendance, prayer, reading of scripture, and religious rituals such as baptism and receiving communion (Arredondo, Elder, Ayala, Campbell, & Baquero, 2005; Musgrave et al., 2002).

While spirituality goes beyond religious affiliation, it has been referred to as a sustaining power and a desire to achieve inner harmony (Ameling & Povilonis, 2001).

Frequency of church attendance has been associated with better health compared to those who do not attend church. Arredondo et al., (2005) evaluated the relationship between frequency of church attendance, self-rated health and health behaviors, and the influence of acculturation on church attendance and health behaviors. The sample consisted of a subset of participants involved in a previous study entitled, “*Secretos de la Buena Vida*” (“Secrets of a Good Life”). Participants (N = 211) were approached after completion of the primary study and asked to participate in a 10-minute interview. Using semi-structured interviews in Spanish, psychosocial, demographic and health behaviors were assessed. The independent variable was church attendance. The dependent variables included self-rated health, fat and fiber intake, physical activity, demographic variables, and acculturation. Using multiple regression, associations were examined among the independent variable and the dependent variables. When compared to non-church goers, frequent church goers reported their health as excellent ($p = <.05$). The most substantial relationship was between church attendance and acculturation ($p = <.02$). Those who reported greater attendance at church were more acculturated. Additionally, church attendance was associated with higher self-rated health ($p <.05$), fiber intake ($p <.10$), and fat intake. Findings from this study are important because they bring to light the potential role a faith-based community may have in promoting healthy lifestyles in a given population.

Spirituality, is a rather ambiguous phenomenon, and definitions are nebulous as previously mentioned. Campesino & Schwartz (2006), developed the Latino Spiritual Perspective Scale (LSPS) to explore spirituality among Latinas (N = 92). Findings suggested that Latinas were highly spiritual, based on the definition set forth by the study, and that they also

displayed a high degree of religiosity by engaging in personal prayer outside of church ($r = 0.53$, $p = .000$). In this instance, religiosity was defined as the expression of one's spirituality in terms of behaviors and practices grounded in a particular religion (Campesino & Schwartz, p. 70). The findings from this study reaffirm the duality of spirituality and religiosity, but distinct differences between the two remain. Koenig (2002, 2004) identified populations in whom religiosity is particularly relevant, including the elderly, ethnic minorities, and women.

Hahn (2003) conducted a qualitative study with three distinct groups of 17 minority women: Hispanic ($n = 5$), Vietnamese ($n = 5$), and African American ($n = 7$). The intent of the study was to explore ways of offering culturally appropriate health programs in specific faith communities. Participants attended elder centers in and around an inner city region of Texas. Using semi-structured interviews, participants were asked four questions about their perceptions of health and importance of life. Findings from the study suggested that religious commitment among older women of various ethnic backgrounds was positively associated with improved health outcomes and illness prevention. Despite the differing ethnic backgrounds of the women in the study, Hahn found similarities relative to their beliefs of religiosity and spirituality. Since these similarities were associated with perceived religious commitment, the researcher suggested the use of faith communities for health promotion and outreach health-related activities (2003).

According to Stolley and Koenig (1997), approximately 75% to 90% of Latinos identified themselves as Roman Catholic, although there has been an increasing trend toward Evangelical Pentecostalism (Campesino & Schwartz, 2006). As recently as 2007, the Pew Forum (2007) surveyed Latinos ($N = 4,600$) and found that 68% of the Latinos surveyed identified themselves as Catholic and Spanish as their primary language; two-thirds reported being immigrants. The majority of Latinos (68%) reported religion as a very important part of their

daily life, with at least 69% praying daily and 44% attending church at least weekly. Among the Puerto Ricans surveyed, 49% reported being Catholic, and 27% reported being Evangelical. Most Catholics surveyed (74%) believed in divine intervention and miracles being in the realm of possibility. The doctrine of the Catholic Church influences the health-care seeking behaviors of most Latinos. Abraido-Lanza, Vasquez, and Echeverria (2004) found that among 200 Latino patients with chronic illness, such as rheumatoid arthritis, prayer was an active form of seeking help. In particular, women in this study asked God to assist them in their time of need. Participants were found to use religion as an active, action-oriented coping mechanism, and religious coping was associated with greater psychological well-being (Abraido-Lanza, Vasquez, and Echeverria). For Latinos as a group, Catholicism has been associated with better self-reported physical and psychological outlooks (Koenig, 2004).

Shared congregational activities enable many Latinos to have meaningful and positive experiences through ceremonies such as baptism, quinceañera (a celebration at age 15, marking the transition from childhood to womanhood), and marriage. Indeed, a faith-based community commonly becomes a source of information and guidance about health and health-related concerns for Latinos.

Another dimension of religiosity, and perhaps spiritualism, is fatalism (*fatalismo*), which alludes to an external locus of control over life and life events. Latinos often hold a view of life and death as being predetermined by a higher being or a higher power. This culturally based value of fatalism is contrary to that of mainstream U.S. society, which values individualism and personal responsibility (Etnyre, Rauschhuber, Gilliland, Cook, Mahon, Allwein, et al., 2006, Urizar & Sears, 2006).

Anez, Paris, Bedregal, Davidson, and Grilo (2005) suggested that Latinos view life as not fully under the individual's control; rather, life events are perceived as fate, luck, or a decision by a higher power. In turn, fatalism is intricately related to an individual's level of religiosity, expressed as "*si dios quiere*" (God's will) or "*el destino*" (destiny) (Anez et al.). Barron, Hunter, Mayo, and Willoughby (2004) found that Mexicans, hold the belief that the cause of an illness is either natural or unnatural. For them, natural illness is caused by God's will, while unnatural illness results from evildoing or not being in God's good grace. In either case, the outcome is always dependent on God's will, and little can be done by the individual to change the situation. Consequently, Latinos often bargain and make promises of a religious nature when ill (Spector, 2004). Cultural values associated with religiosity, spiritualism, and fatalism may lead to low incentive for an individual to assume responsibility for altering his or her health outcomes. Furthermore, an individual may delay seeking medical attention for acute life-threatening illnesses and chronic conditions such as cancer and diabetes.

Although the majority of Puerto Ricans are Catholic and/or Christian, some believe in Santeria, *espiritismo*, and *curanderismo* (Musgrave et al., 2002). Santeria is an Afro-Cuban religious tradition that combines Catholicism with African tribal beliefs and practices. Santero (practitioners of Santeria) believe in magic and the medicinal properties of flowers and herbs. Musgrave et al. note that *espiritismo* is a belief in communication with spirits to intercede in life events. *Curanderismo* is a system of folk healing involving supernatural illnesses and faith in the natural. Little is known regarding the degree to which these spiritual and folk beliefs impact health-care seeking behaviors among Puerto Ricans. What is known is that among other Latino subgroups, such as Dominicans and Mexican Americans, the melding of *espiritismo* and

curanderismo with Western medicine is an acceptable practice (Hunt, Arar, & Akana, 2000; Reiff et al., 2003; Roy, Torrez, & Dale, 2004).

Use of Ethnomedicine (Remedios Caseras)

Ethnomedicine is also a component of a cultural group's health-care practice. Research on Puerto Ricans' use of ethnomedicine is sparse. Of the six studies that were reviewed on the use of ethnomedicine by Latinos, none focused exclusively on Puerto Ricans.

In a related study with Mexican-Americans, Poss, Jesewski, and Stuart (2003) conducted interviews with diabetics in El Paso, Texas. Using open-ended questions, researchers asked participants about preferred treatments to manage their diabetes mellitus. The findings suggested that the use of herbal remedies in addition to Western medicines (insulin and oral hypoglycemic medications) for diabetes treatment was common practice. Participants indicated that if their health-care providers knew they used ethnomedicine or *remedios caseras*, they would be admonished (Poss et al.). These findings reinforce the suspected wariness by patients to share their ethnic beliefs and cultural healing traditions with health-care providers.

In another study with Mexican-American patients, Hunt et al. (2000) found that among participants (N = 43), only 9% admitted to using alternative remedies, mostly in the form of herbal teas and roots. More than 60% of the participants reported using mainstream Western medicine and rarely using alternatives. These findings confound what was previously believed about Latinos' use of ethnomedicine and warrant further research.

Roy et al. (2004) noted that the majority of Latinos used alternative medicine to enhance or complement traditional therapies, suggesting a symbiosis rather than a competition between Western medicine and alternative ethnomedicine. Roy et al. concluded that the decision to use complementary *remedios caseras* was not made out of necessity or lack of traditional Western

resources; instead, using *remedios caseras* and self-care remedies fit within the cultural context of the group.

Examining current use of ethnomedicine by Latinos, Ortiz and Clauson (2006) reported that 75% of Latino adults who live in South Florida had used at least one herbal remedy within the preceding 12 months; chamomile (58%) and aloe vera (45.3%) were most frequently cited.

The term *curandero*, or *curandera* in the feminine, refers to an indigenous Latino healer. As with indigenous healers in general, a *curandero* has both a physical healing and a religious orientation. The interventions of the *curandero* integrate religious elements that reinforce cultural beliefs about a particular condition. For instance, *curanderismo* includes both a biological event along with a social-interpersonal matrix (Lopez, 2005). *Curanderismo* is more common among Central Americans and Mexicans, persisting among Mexicans despite their exposure to scientifically based Western medicine (Lopez). Additionally, the melding of folk healing with traditional Catholic rituals is widely accepted by many Latinos of all ethnic backgrounds (Spector, 2004).

Puerto Rican and Cuban subgroups commonly practice Santeria, which adheres to a belief in the intercession by saints who have supernatural powers and intercede on the person's behalf. Santeria also includes the use of rituals along with a belief in magic. Santeria has origins in African culture and was brought to America by enslaved Nigerians, who arrived in Puerto Rico and Cuba approximately 400 years ago (Spector, 2004).

In summary, there is a paucity of research on use of ethnomedicine or *remedios caseras* among Puerto Ricans living in the mainland U.S. Further investigation on the place of ethnomedicine among Puerto Ricans is warranted to better understand the health-care seeking behaviors of this cultural subgroup, in particular those having a diagnosis of diabetes.

Acculturation

Acculturation is a process in which individuals and groups engage as they adapt to, or borrow traits from, another culture. Barron et al. (2004) describe the process of becoming acculturated as stressful, so that it can hinder one's ability to understand and put information into perspective. Abraido-Lanza, Chao, and Florez (2005) defined acculturation as a process by which immigrants adopt the attitudes, values, customs, and beliefs of the new culture. Beck, Froman, and Bernal (2005) defined acculturation as a process of cultural adaptation that happens when groups of persons from different cultures are in continuous contact with each other. Finally, Lara et al. (2005) defined acculturation as the relationship between selected outcomes and behavioral outcomes relative to a particular society.

Overall, acculturation is understood as the process by which a minority culture cedes characteristics and pieces of its identity in favor of the dominant culture. Until recently, U.S. policy makers and some religious leaders considered acculturation to be a critical process by which minority groups unlearned their culturally-based behaviors and assumed mainstream American ways (Lara et al., 2005). Cultural adaptation takes place on the part of the individual or group. While not all acculturation behaviors are viewed favorably, they may be necessary for a person of another culture to survive within the dominant culture.

According to Hsueh-Fen and Travis (2005), acculturation has emerged as an important variable in understanding Latino behavior. Recent studies by Abraido-Lanza, Chao, and Florez (2005) ($N = 3154$), and Fitzgerald et al. (2006) ($N = 200$) ($p \leq .000$, $p < .0.05$) respectively reported that less acculturated individual Latinos actually experience better health. Variables in these separate studies included smoking status, alcohol use, exercise, food consumption, and body mass index (BMI). These studies' findings suggested that the healthy behaviors of the less

acculturated conveyed a protection against the high-risk behaviors that included smoking, drinking alcohol, poor dietary practices, and sedentary lifestyles. In the Fitzgerald et al. study, the less acculturated Latinas experienced fewer health problems and risk factors and were also less likely to smoke and engage in risky behaviors than their more acculturated counterparts. In other words, the more traditional health promoting behaviors declined with increased acculturation. The findings from these studies form the basis for an acculturation health-care paradox, or the Hispanic health paradox, and are associated with the inverse relationship between socioeconomic status and poor health. This paradox is the result of high poverty rates, poor or little education, and lack of insurance among Latinos as compared to non-Latino counterparts (Abraido-Lanza, Chao, & Florez). Again, these findings cannot be generalized to all Latino subgroups without further investigation. Even so, among the Puerto Rican sample studied by Fitzgerald et al., alcohol intake and cigarette smoking were directly related to increased level of acculturation.

Abraido-Lanza, Chao, and Gates (2005) studied the relationship between acculturation and cancer screening among Latinas (N = 1370). Using secondary data from the National Interview Survey (1997-2001), multiple regression variables were identified: cancer screening tests, acculturation, and sociodemographics. Acculturation was measured by length of time residing in the U.S. The findings suggested that a higher level of education was not associated with a greater likelihood of having received a recent Pap smear. However, higher levels of acculturation predicted a greater likelihood of engaging in cancer breast screening (odds ratio = 2.15), which suggests that breast cancer screening had greater value among those individuals with increased education and acculturation levels (Abraido-Lanza, Chao, & Gates).

In a study focusing on postpartum depression and acculturation, Beck et al. (2005) found that Puerto Rican women residing in the mainland had higher levels of acculturation as compared to Mexican-American women. Data were collected from mothers (N = 377) using the Postpartum Depression Screening Scale and the Short Acculturation Scale (SAS). Using hierarchical regression, the correlation among ethnicity, depressive symptomatology, and acculturation were examined. Among the Puerto Rican women, increased level of acculturation did not predict depression; however, an increased level of acculturation predicted Caesarean delivery and single parenthood. These findings are particularly important because they allude to the relationship between acculturation and mainstream thinking relative to health-care and medical procedures. Likewise, the findings may be interpreted as negatives in light of society's view on single parenthood, suggesting a move from traditional two-parent households.

The process of acculturation is stressful, not clearly understood, and may result in the adoption of positive along with negative socially driven habits and mores (Abraido-Lanza, Chao, & Gates, 2005; Fitzgerald et al., 2006). The impact these phenomena have on health-care seeking behaviors is not known. There is a critical gap in the literature regarding Puerto Ricans' health-care seeking behaviors. Lack of consensus on Latino subgroups' characteristics and confusion about the phenomena addressed herein require further investigation. An argument can be made that in order to understand the experience of Puerto Ricans with diabetes, there needs to be a more holistic understanding relative to these phenomena.

Narrative Inquiry

Narrative inquiry, sometimes referred to as *narrative analysis*, was the methodology used in this study, and this section discusses the philosophical and theoretical underpinnings. The early work of Riessman (1993) contributed substantially to the understanding of narrative

analysis, and although this pivotal work is somewhat dated, the writings are considered the seminal foundation and theoretical context of narrative analysis. Riessman continues to be viewed as the foremost authority on approaches to narrative analysis (Gale, Mitchell, Garand, & Wesner, 2003; McQueen & Zimmerman, 2006; Paley & Eva, 2005). As a type of qualitative methodology, narrative inquiry requires that the researcher attend to individual stories, in particular, those of the less powerful or the marginalized members of societies such as ethnic minorities (Lagerwey, Phillips, & Fuller, 2003). In use among the social sciences since the 1970s, narrative inquiry has been used to explore numerous phenomena (Arrington, 2005; Baillie, Lovato, Johnson, & Kalaw, 2005; Bradway, 2005; Drew & Hewitt, 2006; Lagerwey et al.).

In the literature, narrative inquiry is sometimes referred to as *illness narratives*, *life stories*, and *narration*, thus contributing to the confusion surrounding the definition of *narrative*. Gale et al. (2003) defined *narrative* as a way of exploring and interpreting. Paley and Eva (2005) distinguish between *story* and *narrative*, arguing that failure to recognize the precise difference can result in misconceptions and imprecise methods. The term *narrative* has also come under scrutiny because of the rather ambiguous nature that generally includes accounts of past or fictional events in rough chronological order. In the broadest sense, *narrative* can be whatever one person relates to another (Paley & Eva). Regardless of the term used, the underlying assumption is that the respondent reconstructs reality in his or her own words while giving meaning to his or her life (Bailey, 1996).

Overcash (2003) observed that a narrative consists of “a person telling their story [which] becomes part of the research decision making process in that they can decide how the story is told, what is included and how lengthy the interview” (p. 181). Narratives provide

researchers with opportunities to tap into the individual experience (McCance, McKenna, & Boore, 2001). Thus, narratives provide *meaning*, not necessarily *truth*.

Analysis of narratives has become a popular research method, suggesting that researchers focus not only on what is said but also on how events are constructed. Themes emerging from narratives can, for example, aid the researcher in understanding the means by which a person lives with chronic disease or undergoes medical treatment (Overcash, 2003). Narratives aid not only the researcher, but sometimes aid the respondent as well. Overcash points out narrative's therapeutic value: "Narrative interview can be helpful to the patient by allowing the person to tell an often emotional, stressful account to someone who is an impartial listener, such as nurse researcher" (p. 17).

The narrative is affected by the listener—in this case, the researcher. Communication between the listener and the participant is the means used to obtain data, especially interviews between the two (Overcash, 2003). The listener guides the process with open-ended questions. In turn, the respondent is influenced by the listener's questions, comments, and facial expressions. In other words, the listener (researcher) inadvertently influences the narrative and must be aware of this fact to ensure that measures are taken to objectively analyze and interpret the data. In most instances of narrative research, data are audio recorded and then transcribed for future reference. Despite the debate of philosophical differences between *stories* and *narratives*, for this study, the interviews were composed of general discourse resulting from open-ended question-and-answer format; narrative units or elements are embedded in the respondents' answers.

Maintaining rigor is an issue in narrative analysis. To ensure credibility and trustworthiness of the data, Tuckett (2005) describes a nine-step process to address trustworthiness in qualitative narrative analysis:

1. Taking field notes and journaling
2. Using an audio recorder
3. Auditing transcripts
4. Purposeful sampling
5. Negative case
6. Member checking
7. Triangulation
8. Thick description
9. Peer review

Additional steps to enhance trustworthiness include the use of key informants from the community to help ensure the reliability of translated narratives. These strategies were incorporated into this study in an effort to assure trustworthiness of the data (Table 1, Chapter III). For studies in which participants prefer to read and speak another language, a translator may be needed for developing appropriate written materials, and an interpreter is necessary for the spoken word. Translators and interpreters should be ethnically and culturally representative of the population among whom the method will be employed and fluent in both the source and the target language (Waltz, Strickland, & Lenz, 2005). Researchers should employ as many of these strategies as feasible to assure methodological rigor and trustworthiness. As Riessman (1993) eloquently states, “In the final analysis, the work is ours; we have to take responsibility for its truth” (p. 67).

A variety of approaches to analyze the oral narratives are described in the literature (McCance et al., 2001; Tuckett, 2005). Most methods use an analytic inductive approach to increase reliability of findings by categorizing the data, based on agreed-upon definitions,

relevant literature, and the researcher's values and experiences (Arrington, 2005). The literature also examines limitations of narrative inquiry as a qualitative methodology. An often listed concern is that of power relative to the generalizability of the findings, as Riessman (1993) points out, "whose voice is represented in the final product" (p. 61). Additionally, the investigator must be ever vigilant during the analysis process so that the elements extracted from the narratives do not echo his or her personal values or previous research as opposed to the respondent's perspective. This view is in direct opposition to Arrington's (2005) position that an investigator's actual experience and personal values are important during the analysis process. It is the opinion of this investigator that actual life experience improves rapport and allows for enhanced communication and empathy with the respondents.

Finally, the decision to use narrative inquiry for a research study is dependent on the phenomenon of interest which directs the questions being asked. According to Duffy (2007), no single story can ever be fully captured using narrative inquiry. Therefore, the qualitative researcher must limit the scope of the question to what is most important and relevant for the respondent to best answer the question; in turn, the qualitative researcher must also recognize that by doing so, the researcher acts as an agent of change to respondents.

This chapter presented a review of the literature focusing on the historical and cultural background of Puerto Ricans, diabetes mellitus as a health disparity within that population, and cultural phenomena associated with their health-care seeking behaviors, specifically familism, spirituality, religiosity, use of ethnomedicine, and acculturation. The chapter concluded with an examination of narrative inquiry method. Chapter III describes the methodology used to achieve the purposes of this study, which were to explore the phenomena of familism, religiosity,

spirituality, and use of ethnomedicine in the health-care seeking behaviors of Puerto Ricans with diabetes who live in South Florida.

CHAPTER III: METHODOLOGY

This chapter describes the methodology used to achieve the purposes of this study, specifically: to explore cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida and to examine Puerto Ricans' perceptions about their health-care providers. Included are sample inclusion criteria, participant recruitment strategies, protection of human subjects, the study setting and details about the researcher. Additionally, this chapter describes the study setting and provides details about the researcher. A comprehensive review is provided relative to the instruments used to implement this study.

Design

This study was conducted using exploratory descriptive methods. Narrative inquiry, based in the foundational work of Reissman (1993), provided the framework for the methodology designed to research the narratives, or stories, of individuals who are often marginalized members of society. In light of this approach, certain safeguards must be included to ensure rigor (Tuckett, 2005), that is, to ensure credibility and trustworthiness of the data collected by a researcher who remains cognizant of his or her role in the qualitative study process.

Sample Inclusion Criteria

A purposive sample was recruited among Puerto Ricans with a diagnosis of diabetes who live in the Tampa, Florida area. Inclusion criteria for this study included: participants 18 years of age or older, self-identified as Puerto Rican with a medical diagnosis of diabetes mellitus, not in

an active disease state, defined as not being hospitalized for any condition within the last six months, and able read and speak English or Spanish.

Participant Recruitment

To recruit a purposive sample, an information flyer (Appendices A and B) about the study was posted in six sites in the Tampa Bay area, including the University of South Florida Medical Clinics, the University of South Florida College of Nursing, a Puerto Rican primary-care physician's office, the Community Outreach Center, Healthy Start office, and a Latino bakery. The flyer invited self-identified Puerto Ricans with diagnoses of diabetes mellitus to contact the investigator if they were willing and able to participate in the study. The process was somewhat modified for those recruited from the physician's office. That is, when an individual expressed an interest in participating in the study, an office manager notified the investigator and provided contact information for the potential participant. After an initial telephone conversation with prospective participants, the investigator met with each interested volunteer to explain the study's purpose and the expectations of those who participated. After this preliminary meeting, if a volunteer expressed interest in participating in the study, an appointment for an interview was scheduled by the investigator at a mutually agreeable time and location. Five of the first six participants were recruited from the physician's office ($n = 5$) and the local Community Health Center ($n = 1$). Using snowball sampling techniques, each of the five individuals referred the investigator to other potential volunteers who met the inclusion criteria for the study. Sampling for the study continued, case by case, until data saturation was achieved ($N = 12$). Data were collected from January 11, 2007 through April, 2, 2007. After interviewing the twelfth participant, the investigator noted saturation of data related to the targeted foci of the study. At

this point, no additional participants were recruited, and the data collection phase of the study was terminated.

Measures for the Protection of Human Participants

Approval for the study was obtained from the Institutional Review Boards (IRBs) at the University of Central Florida and the University of South Florida. Written informed consent was obtained in their preferred language (Spanish or English) from research participants prior to any data collection; additional permission was obtained to audio tape the interview (Appendices C and D).

No anticipated risks were associated with this study. Prior to participation, participants were asked to read and sign an informed consent. All participants were given the opportunity to discontinue the study; none chose this option. Participants were assured by this investigator of the confidential nature of their responses and that their responses would in no way impact their current or future health care. Overall, respondent burden was minimal.

During the study, audiotapes from the interview sessions were kept in a secure, locked box at the University of South Florida. The key for this box was kept at the home of the investigator. Audiotapes were destroyed after the interviews were transcribed. Transcripts were maintained on a password protected computer at the University of South Florida, to which only the investigator had access.

Data were de-identified on the demographic instrument, the Short Acculturation Scale (SAS), the audiotape, and transcribed interviews. The process entailed removing the identifying cover page of the demographic instrument and the SAS and assigning each participant a number code that was used for the instruments and audio taped and transcribed interviews.

Setting

This study took place in locations mutually agreed upon by the participants and the investigator in the Tampa Bay region of South Florida. Of the twelve interviews ($N = 12$), five ($n = 5$) occurred in a private room in the physician's office, another five ($n = 5$) took place in participants' homes, one ($n = 1$) occurred in the participant's place of employment, and another one ($n = 1$) in a private setting in the local public library.

In order to provide additional insight regarding the setting for this study, the following information is provided: the population of the Tampa Bay region is 81% white, 11% black, and 12% Latino. Puerto Ricans constitute 28% of the Latinos in the Tampa Bay region (Tampa Bay Demographics, 2005). The median household income for the Tampa Bay population in general is \$44,000. Of those over the age of 25, 84% completed a minimum of a high-school education.

The Investigator

With narrative inquiry procedures, the investigator is considered a critical instrument in the data collection process. This study was undertaken and completed by a Puerto Rican nurse, who is also a doctoral student, who has lived in both the U.S. mainland and Puerto Rico. Additionally, the investigator is a nurse practitioner who has functioned in an advanced practice role within the community. The investigator is fluent in speaking, reading, and writing both English and Spanish.

To facilitate the flow of the interview, participants were free to speak in their preferred language, that is, English, Spanish, or both. Having a similar ethnic background to the participants, this investigator quickly developed rapport with them as demonstrated by the ease with which conversation flowed and the familiarity accorded to the investigator by the participants. While ethnic similarity can be advantageous, this investigator was cognizant of the

potential for bias in collecting and analyzing data from other Puerto Ricans. To address this risk, the investigator took measures to refrain from making assumptions through journaling, bracketing, and field notes. These strategies allowed the investigator to distance self from each of the respondents and also to develop self-other awareness.

Data Collection Instruments

To obtain data that achieved the purposes of this study, three tools were used with the participants. A demographic instrument, developed by the investigator, was used to collect information from each participant, herein referred to as attributes—the term used with narrative inquiry methods (Richards & Morse, 2007). The Short Acculturation Scale (SAS) provided additional attribute data that helped to determine a participant's language preference, either Spanish or English. Finally, a ten-item interview guide, also developed by the investigator, was used to focus the discourse between the participant and the investigator (Appendix F). Each of these instruments is described in greater detail in subsequent paragraphs.

Demographic Instrument

Demographic data were collected using a form developed in both English and Spanish. The instrument contained items including age, place of birth, length of time in the mainland U.S., income, occupational status, and religious affiliation. To gain insight into the participant's diabetic condition and to ensure that the sample was representative, information was also sought regarding length of time in years the individual had been diagnosed with diabetes, the frequency of health-care visits, any hospitalizations within the last six months, and glycosylated hemoglobin level (HgbA1C). (Appendix E: Demographic Information Form.)

Short Acculturation Scale (SAS)

The SAS was administered to all participants (Appendix F). This tool provided information regarding the participant's language preference for the interview. The original Acculturation Scale consisted of 12 items and was developed by Marin, Sabogal, VanOss-Marin, Otero-Sabogal, and Perez-Stable (1987). This instrument examined three factors to indicate an individual's level of acculturation into mainstream U.S. society: language use, preferred media source, and ethnic social relations.

Upon further testing of the original instrument, Marin et al. found that of three factors, language was the most sensitive indicator of acculturation (Cronbach's alpha of .90). That finding prompted development of a shorter, four-item tool by the researchers, namely the Short Acculturation Scale (SAS). In subsequent studies, Marin et al. found the four-item SAS correlated highly with a person's length of residence in the U.S. ($r = .76, p < .01$), respondent's generation ($r = .69, p < .001$), and age of arrival to the United States ($r = .72, p < .001$).

Internal consistency on the SAS for Latino groups has been established. In examining acculturation level among another Latino groups, specifically Central American women, the SAS demonstrated acceptable internal reliability (.81) as measured by Cronbach's alpha (Wallen, Feldman, & Anliker, 2002). In another study on the acculturation level of postpartum Latina women who were depressed, Beck et al. (2005) found the SAS had a reliability coefficient alpha that ranged between .90 and .94 for Puerto Rican and Mexican women. The overall coefficient for Latina women was .95.

The four-item SAS instrument is a five-point Likert scale ranging from one (respondent speaks and reads Spanish 100% of the time) to five (respondent speaks and reads English 100% of the time). Respondents' ratings for the four items are added together, yielding a total score

ranging from 4 to 20. In other words, the higher the score, the more acculturated that individual is determined to be based on ability to speak and read English.

An advantage of the SAS is that it is easy to administer, with minimal respondent burden, taking no more than five minutes to complete. An individual's total SAS score is a number on a continuum (from 4 to 20) based on language preference and a demographic indicator on the level of acculturation. The SAS is available in both English and Spanish (Marin et al., 1987; Marin & VanOss-Marin, 1991).

Consistent with the literature, a SAS score of 20 in this study was considered complete acculturation. Participants having a SAS score of at least 12 indicated some preference for the English language and were considered somewhat acculturated. The midpoint (3) on the Likert scale of the SAS across the four items is "both equally." This self rating suggests that a respondent reads and speaks both Spanish and English. Participants having a SAS score that was less than 12 had a preference for Spanish; thus, they were considered less acculturated into mainstream U.S. society.

Justification for use of the SAS in this study was based on the premise that language preference is an important demographic attribute and could be an indicator of the individual's level of health literacy. At a minimum, participants with low SAS scores prefer to read and speak in Spanish and have limited English language skills. In order to learn about the individual's health-care seeking behaviors and perceptions of health care providers, it was important to interview the person in his or her preferred language.

Interview Guide

Based on the review of the literature and the investigator's personal insights about the Puerto Rican culture, coupled with almost two decades of professional nursing experience, a ten-

item interview guide was developed (Appendices G and H). This interview guide was designed to focus the discussion in the interview on the phenomena of interest. The open-ended questions focused on two domains: health-care seeking behaviors and participant's perceptions of health-care providers. To address the purpose of the study, the first five questions in the interview guide explored the cultural phenomena of interest: familism, religiosity, spirituality, and use of ethnomedicine. The next five questions focused on perceptions about health-care providers' ethnic concordance.

To address content validity, the interview questions were reviewed for content relevancy, linguistic appropriateness, and clarity (Waltz, et al., 2005). The investigator sought input on the questions in the preliminary interview guide from three bilingual college-educated professionals from the Latino community in the Tampa Bay area. Additional input on the questions and the interview process was provided by Angeline Bushy, PhD, RN, FAAN, an expert in community health nursing and the investigator's major professor as well as the other members of the investigator's dissertation committee with community health expertise. Finally, the initial interview provided an opportunity for the investigator to substantiate the appropriateness of the questions and refine the interviewing process. During the initial interview if the investigator had to explain the questions in greater detail for clarity, changes were made to the script for enhanced comprehension in subsequent interviews. That participant's comments were then validated by the other participants in subsequent interviews.

Data Collection Procedures

Procedures for this study were based on the recommendations of Tuckett (2005) to collect qualitative data. Steps included taking field notes, journaling, bracketing throughout the interview for auditability of the process, audiotaping, and transcribing the interview. Table 1

summarizes the strategies used. Purposeful sampling procedures were implemented, including seeking out negative cases to ensure representedness for the phenomena of interest. Member checking occurred to validate and enhance information provided in prior interviews. Finally, additional steps were initiated by the investigator to enhance trustworthiness of the data and the discussion, including the use of a key informant from the Puerto Rican community to help ensure the reliability and accuracy of translated narratives.

Prior to starting the interview, this investigator asked each participant to state language preference, English or Spanish. Participants who chose to be interviewed in Spanish were provided with the Spanish interview guide to review. Of the 12 interviews, three were conducted in English, eight were conducted in Spanish, and one was conducted in a combination of Spanish and English. The interviews ranged in duration from 35 to 75 minutes. The investigator was mindful of the participant's interest in the study and the therapeutic nature of narrative inquiry. Hence, some interviews were shorter in duration than others. In one instance, the participant chose not to elaborate even after prompting, resulting in a shorter, 35-minute interview. In another instance, the participant expressed a level of comfort with this researcher and chose to elaborate about her difficulties with managing diabetes; that interview lasted 75 minutes.

Interviews began with a broad, open-ended statement by the investigator such as, "Tell me about your diabetes." The investigator found this approach helped allay a participant's anxiety and prepared the individual for the more pointed, thought-provoking questions that followed. This was evidenced by the participant's more relaxed demeanor as the interview progressed and a more open conversation. Additionally, probe questions were asked by the investigator during the interviews to clarify and further explore specific comments made by a participant. The investigator made additional comments during the audio taped interviews for the

purpose of clarification of content or to identify extraneous sounds, such as environmental noise or a participant's crying.

During the interview process, the investigator took field notes to supplement the interviews. For instance, if the participant made a reference to something not familiar to the investigator, the investigator explored the meaning of the comment with the participant while making a notation to further explore the contextual meaning of that particular comment. These notes later served as references for the investigator when interpreting the context as the transcripts were analyzed for themes.

Toward the end of the interview, participants were asked by the investigator, "Tell me in your own words what you think caused your diabetes." Finally, participants were asked, "Is there anything else you would like to add?" This last question allowed participants to summarize answers, express their thoughts and feelings, and clarify and elaborate on previous statements. When generating narratives using a semi-structured interview, the researcher has the freedom to alter the sequence of questions and to probe for more information depending on participants' responses, to obtain a complete perspective for the phenomena of interest (McCance et al, 2001).

Data Analysis Procedures

For this study, transcripts were analyzed using a variation of *directed content analysis* combined with *inductive analysis*. The decision to use elements from both approaches was based on the twofold purpose of the study, that is: to explore cultural beliefs regarding health-care seeking behaviors of Puerto Ricans with diabetes who live in South Florida and to examine Puerto Ricans' perceptions about their health-care providers. Transcribed narratives of the participants were analyzed using Directed Content Analysis (DCA) as described by Hsieh & Shannon (2005).

All of the tape-recorded interviews conducted in English were transcribed verbatim. Next, the interviews conducted in Spanish were transcribed and translated verbatim into English by the bilingual investigator who is proficient in the Puerto Rican dialect. In three separate instances, a suitable English translation did not exist for a particular Spanish word or phrase. In an effort to preserve its meaning, the word or phrase was not translated, and the Spanish term was retained. In these cases, an informational reference comment was inserted next to the term in the transcription explaining the context in which the word was used. Additionally, a key informant of the Puerto Rican community proficient in both English and Spanish reviewed the translated Spanish-English transcripts to ensure accuracy and address inter-rater reliability of the interviews (Goodkind, 2006; Poss et al., 1996; Stone, Pound, Pacholi, Farooqi, & Khunti, 2005). Additionally, one participant was invited to review the transcript of his interview and comment on completeness and accuracy. This participant agreed that the transcribed document accurately reflected comments during the interview, thus substantiating the accuracy and truthfulness of the qualitative data.

The translation and transcription of the interviews was completed using Microsoft Word[®]. Potential major categories and corresponding subthemes were identified and coded. Coding entailed the investigator reading, rereading, and then reflecting on the narrative of the participants' responses to open-ended, focused questions. After the transcripts were deconstructed into fragments through this process, the narratives were further analyzed using an inductive approach.

Although the coding process is described as linear in nature, in reality it is an inductive, dynamic, and iterative activity. That is, the investigator moves forward, then backward, then forward again, with multiple considerations of the meaning of the narratives. The investigator

returns to the original data as often as necessary to triangulate data among the interviews and ensure trustworthiness.

Other activities undertaken by the investigator for the inductive analysis of the interviews were the following: “Describing” provided an opportunity for the researcher to appreciate the sum total of the experience, or the “gestalt.” After repeated readings of this study’s narrative transcripts, certain themes began to emerge, and lists of the recurring themes were compiled. “Organizing” required the investigator to reduce the data and sort into common themes and categories. The organizing stage requires constant comparison across all transcripts to locate themes that linked the text. This phase is highly intuitive, relying on the investigator to form an organizing framework. “Connecting” is done with the researcher remaining engaged, searching for themes and patterns to emerge from the excerpts. “Corroborating” is the process to assure trustworthiness and concordance of the findings (Crabtree & Miller, 1999).

Select excerpts from the transcripts were written on index cards, with a notation made regarding the theme. Excerpts consisted of words, phrases, and, in some instances, several sentences. For instance, excerpts of participants’ answers to the question “From whom do you seek health care first?” were written on index cards: “wife,” “mother,” or “no one” (Richards & Morse, 2007).

After the transcripts were individually analyzed for themes, general commonalities and similarities were noted. This was a reiterative process on the part of the investigator—reading all of the interviews and cross referencing terms and phrases in other interviews to note patterns in the responses for each phenomenon of interest.

In the final phase of analysis, the general categories were further collapsed, thereby producing the sub-themes and categories. Selected participants’ comments were sought to

characterize each of the themes and subthemes (Crabtree & Miller, 1999; Richards & Morse, 2007).

Demonstration of Trustworthiness

The following measures were taken to ensure trustworthiness in this study: reflexivity, member checking, confirmability of the narratives, and maintenance of integrity. See Table 1 for a complete description of the strategies to ensure trustworthiness.

The first strategy was reflexivity. Reflexivity was maintained throughout the interview process by having this investigator disclose cultural likeness to the participants and by maintaining a personal awareness to prevent selective listening that could influence the findings.

A form of member checking was conducted with one participant to review the transcript for credibility. The member checking reinforced to this investigator the importance of the transcript's accuracy. The interactive nature of the interviews allowed the interviewer to ask questions to ensure that participant perception was clearly understood by the investigator (Horsburgh, 2003).

Decisions regarding the analysis process were detailed, and emergent themes were coded from general to specific and written on index cards for reference. All of the interviews were audio taped and transcribed by the investigator. This process, frequently utilized in qualitative research, allowed for further immersion by the investigator in the data (Poss, 1998; Zapata & Shippee-Rice, 1999).

Lastly, a key informant of the Puerto Rican community, fluent in Spanish and the Puerto Rican dialect, listened to cued snippets of the audio tapes. The informant was asked to present his interpretation of the audio taped interviews. Subsequently, the insights were compared with the written narratives. In all instances, there was concordance on the linguistic nuances between

the key informant and the investigator. This process further ensured validation and confirmability of the narratives. Authenticity was addressed by including verbatim quotes of the narratives from the transcripts to illustrate a participant's particular point of view (Chapter IV).

Integrity was maintained by developing clear consent forms written in both English and Spanish. All participants were assured that they could refuse to answer any questions or withdraw at any given moment. The first interview provided this investigator with the opportunity to refine the way in which the interview guide questions were posed—to better fit linguistic preferences of informants.

Table 1

Measures to Ensure Trustworthiness of Qualitative Data in Study

Study Process	Measures	Description of Strategy
Sample	Purposeful Negative Case	Sample selected based on attributes to provide a representative perspective and thick description on the phenomena of interest; e.g., lengths of time with diagnosis, ages, gender, socio-cultural experiences.
Interview	Interview Guide	To ensure all participants are asked same questions. Expert panel of health professionals reviewed/commented on questions. Adaptations based on feedback from first interview to fit investigator's interview style to participant preferences. Successive interviews built on information obtained from previous ones.
	Journaling, Bracketing, & Field Notes Reflexivity	Notations made by investigator for the purpose of reflexivity and to address potential bias. Self-other differentiation.
	Audio Recording	Ensured accuracy of comments. Reference for voice inflection, nonverbal communication, and contextual information.
	Member Checking	One participant reviewed and commented on accuracy of interview.
Data Analysis	Transcription	All narratives transcribed by the researcher, allowing for further immersion in the data.
	Auditing Transcripts	Transcripts reread/reviewed throughout the analysis process.
	Use of Key Informant	Key informant from the Puerto Rican community reviewed translated, transcribed narratives for concordance of linguistics and translations.
	Coding	Emergent themes in analyzed interviews coded from general to specific.
	Development of Thick Description	Raw excerpts from the narrative used to illustrate particular points.
Linguistic Integrity		Assured/maintained by developing clear consent forms both in English and Spanish.

Summary

This chapter detailed the qualitative methodology used in this study. Discussion included sample inclusion criteria, participant recruitment strategies, and protection of human subjects. Additionally, the chapter included a discussion of the setting of the study and details about the investigator. Finally, a comprehensive review was provided relative to the instruments used in data collection and the strategies used to demonstrate trustworthiness. The next chapter focuses on the data analysis, to be followed in Chapter V with a discussion of the findings.

CHAPTER IV: RESULTS AND FINDINGS OF INQUIRY

This chapter focuses on the analysis of the data and the findings of the inquiry. Presented herein are the attributes of the participants in the form of demographic information, along with themes that emerged from the analysis of the narratives and unexpected findings referred to as “serendipitous findings.”

Attributes of Participants

The study sample consisted of self-identified Puerto Ricans ($N = 12$) who lived in South Florida and had a medical diagnosis of diabetes mellitus (Table 2). Of the twelve participants, four were male and eight were female, ranging in ages from 36 to 79 years. The age range for the males was from 54 to 79 years; for the females, it was 36 to 71 years. Ten participants were born on the island of Puerto Rico, and the two youngest women in the study were born in the mainland U.S. Length of time the participants had resided in the mainland U.S. ranged from a high of 57 years to a low of 3 years, with a mean of 26.3 years. Consistent with the literature, participants reported that they traveled from the U.S. to Puerto Rico on a regular basis to visit with immediate and extended family as well as friends. This phenomenon has been referred to as “circulatory migration” (Christenson, 2001) and infers that ethnic and cultural characteristics of the group persist over time.

As for marital status, seven were married; two were single; two were widowed; and one was divorced. With the exception of one 56-year-old female participant who was widowed, all

participants reported living with another person. Two female participants were single; one lived with her mother and unmarried daughter, and the other lived with her sister and father.

Employment status varied. Three men were retired, and one 54-year-old man was disabled. Of the women, three were disabled, one was unemployed; one was employed as a research assistant, two were retired, and one did not report her employment status.

Years of formal education ranged from some elementary school to some college. All of the males ($n = 4$) reported having at least a high-school education. Among the women who reported their education level ($n = 7$), two reported some elementary school; three had a high school education; and two had some college.

With regard to annual income, two women reported incomes ranging from \$50,000 to \$75,000. Three men and one woman reported incomes ranging from \$25,000 to \$50,000; the remaining participants reported incomes of less than \$25,000.

Participants' Short Acculturation Scale (SAS) scores indicated language preference and acculturation. Individuals with a lower SAS score had a greater preference to speak and read Spanish. Conversely, the higher an individual's score, the more pronounced his or her preference to speak and read in English. Scores on the SAS ranged from 4 ($n = 3$) to 16. Of the twelve participants, six scored 11 or lower on the SAS. Among the men, the SAS scores ranged from 5 to 16, and for women, the range was from 4 to 15.

Participants averaged 10.2 years living with a diagnosis of diabetes, with two participants diagnosed within the last three years and one participant having diabetes for 25 years. Eight participants reported visiting their health-care provider at least monthly. Only seven participants were aware of their HgbA1C percentages.

Participants had a variety of insurance coverage for health care. Two participants reported having coverage in a Medicaid Health Maintenance Organization, and six others reported Supplemental Society Security Income (SSI) and regular Medicaid coverage. One retired male had coverage with Medicare and a supplemental Medicare policy. Two women chose not to report insurance status. One participant reported having no insurance coverage; this female was also the participant who admitted to seeing a provider only as needed. Hence, it is unknown what role health-insurance coverage played in the decision to choose an ethnically and culturally concordant provider.

Table 2

Attributes of Study Participants (N = 12)

Partici- pant	Gender	Age	Marital Status	Religion	Employment Status	Education Level	Years in U.S.	Annual Income	Years with Diabetes	SAS Score	SAS Score Interp.
1	M	78	M	NR	Ret	HS	62	25-50	9	16	High
2	M	79	M	Cath	Ret	HS	55	25-50	2	11	Low
3	F	71	D	Cath	Ret	Elem	19	<25	2.5	4	Low
4	M	54	M	Cath	Dis	HS	26	<25	19	5	Low
5	F	46	S	Cath	Dis	NR	41	<25	11	11	Low
6	F	65	W	Pent	NR	HS	36	<25	15	4	Low
7	M	60	M	JW	Ret	HS	41	25-50	7	5	Low
8	F	36	S	7Day	Dis	SC	36*	<25	2	14	High
9	F	56	W	Pent	Ret	Elem	9	<25	25	4	Low
10	F	57	M	Cath	Dis	HS	54	50-75	3.5	11	Low
11	F	69	M	Cath	UE	HS	29	25-50	25	7	Low
12	F	45	M	NR	Empl	SC	45*	50-75	1	12	High

Gender: M = male; F = female. Marital Status: M = married; D = divorced; S = single; W = widowed. Religion: Cath = Catholic; Pent = Pentecostal; JW = Jehovah's Witness; 7Day = Seventh Day Adventist. Employment Status: Ret = retired; Dis = disabled; UE = unemployed; Empl = employed. Education: Elem = elementary school; HS = high school/GED; SC = some college. Income: <25 = less than \$25,000 annually; 25-50 = \$25,000-50,000 annually; 50-75 = \$50,000-75,000 annually. SAS Score Interp.: >12 = Low; <12=High.

*Note: Born in the U.S. Mainland.

Emergent Themes

This section addresses the findings related to the two purposes of the study: *Purpose 1*—to explore cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida; *Purpose 2*—to examine Puerto Ricans’ perceptions about their health-care providers.

Purpose 1: Phenomena of Interest

To address the first purpose of the study, the phenomena of interest were explored—familism, religiosity, spirituality, and use of ethnomedicine among Puerto Ricans with a medical diagnosis of diabetes mellitus who live in South Florida. The narrative inquiry analyses procedures detailed in Chapter III were used to organize the data from the interviews and interpret the findings. Participants willingly shared experiences and offered personal insights allowing the investigator to gain insights into these phenomena. From the analysis of the interviews, dominant themes emerged. Each phenomenon of interest and its corresponding sub-themes are examined in the remainder of this chapter and summarized in Table 3.

Familism

Within the phenomenon of familism, several themes were identified. These include role expectation of significant others, family interdependence, and caregiver burden.

Role Expectation of Others. Eleven of the twelve Puerto Ricans who participated in the study relied on family for support and guidance. Two participants with SAS scores of less than 5 expressed the expectation that as they age, family members will care for them, as evidenced by the following statements by two different participants:

They are responsible to take care of me.

I do what they tell me. When you are old you have to look for their guidance.

In fact, prior to seeking care from a professional health-care provider, nine of the participants reported consulting a spouse or older child for health-care advice. Even when separated geographically from family, participants stated they could telephone extended family members for health-care input. In many instances, these relatives lived in Puerto Rico or in areas of the U.S. other than the Tampa Bay area (i.e., the study location).

Three participants (two females and one male) with acculturation scores greater than 10 reported that they did not seek family input related to health-care issues. These individuals made arrangements directly with their health-care providers for appointments and prescriptions. One male participant reported speaking first to God, referring to *Papa Dios*. He was not as connected to his immediate family as the other participants. Interestingly, this participant also felt strongly that stepchildren do not count as family; he believed that stepchildren care less than “actual” family members.

Three male participants stated that familism positively affected their well-being and health status; living with a spouse or significant other contributed to better health and overall well-being. Conversely, they believed that living alone or being a bachelor for a prolonged period of time contributed to poor health. One participant stated that his diabetes occurred while he was living alone and unmarried: *I was alone for two years without a wife*. Inherent in this statement was the participant’s belief that having a spouse confers protection from illness and would have protected him from diabetes. An understanding that being a bachelor is unhealthy was obliquely expressed by another participant: *I speak with my wife; I am not alone*.

Family Interdependence. Participants with a SAS score of less than 11 reported relying heavily on immediate family members to accompany them to physician offices to act as

translators. In some instances, family members accompanied them into the consultation with the physician. One participant who lived alone relied on her niece, who was a health-care provider, to assist her with translations when *she sought medical care*.

Caregiver Burden. For eight participants, family connectedness was a source of emotional and physical support; however, that was not the case for all participants. Among three of the female participants, the phenomenon of familism negatively affected their health-care seeking behaviors. These women stated they were often so busy addressing the concerns of their family members and others that their own health-care needs became secondary. These women characterized matriarchal households that focused on seeing to the needs of other family members. Women verbalized their inability to care adequately for themselves because they were responsible for the well-being of their families. One participant reported caring exclusively for her husband, a stroke victim, for more than ten years until his death. During that time, she never stopped to consider her diabetes and glucose levels: I dedicated myself to caring for him and did not care for myself.

Similarly, a female participant with poorly controlled diabetes based on self-report of elevated blood glucose levels stated that her mother, with whom she lived, also had diabetes. Despite having diabetes herself, the participant felt obligated to care first for her mother: *I lost my mom more than a year ago. She had diabetes, and she also had a lot of other problems.* Another female participant stated that she was overwhelmed by her diagnosis of diabetes. For three years prior to the study, she sought additional nutritional counseling and specialized care but still was not able to appropriately manage her diabetes. She believed it was probably better that she developed diabetes rather than her husband, who was a borderline diabetic, because it would have been more difficult to care for him. Yet, she was so busy being a wife and a mother

that she had very little time to care for herself. She had the following to say: *In my family, you are so used to doing for everybody else* She added, *I do not want him [her husband] getting sick. I am trying to care for him.*

Another female participant was frustrated by her family's lack of understanding of her diabetes. She reported that her mother, with whom she did not reside, frequently made cookies and did not understand why she would not eat them when she visited. Nor did her mother understand why she refused to eat all the food on her plate. In fact, this participant found herself apologizing to her mother for her behavior.

All of the female participants expressed grave concern regarding the overall health of their children and grandchildren, especially the prospects of their offspring developing diabetes. They reported feeling disempowered and expressed frustration at being unable to help prevent their family members from developing this disabling disease. Lack of resources and knowledge about the condition were given as reasons for being unable to communicate this concern effectively. During the interviews, five of the mothers in the study admitted that their children were overweight with poor nutritional habits. Two participants stated, *I am sure they have it [diabetes] already.*

Familism and Acculturation. The first possible relationship explored was between familism and acculturation. From the interviews, familism was noted to fade as acculturation increases. However, increased level of acculturation did not diminish one's perceived obligation to care for parents, especially on the part of the women in the study. In three instances, familism was found to be counterproductive in the management of diabetes, such as in the instance of the female respondent who was responsible for the care of her ailing father and recently deceased mother.

The analyses further suggested that among the participants with SAS scores of 12 or higher, familism faded and was not associated with health-care seeking behaviors. In fact, for three of the participants, seeking family advice was not a consideration; these participants reported handling matters on their own. When asked whom they consulted first when they were not feeling well, they made the following statements:

I do not consult anybody. I go to the doctor whenever I need to.

If it is something that needs to be taken care, I immediately call my primary care provider.

I have not been to a primary care physician in a while. When I do not feel well, it is either a migraine or diabetes. I will go to either a neurologist or to Dr. [physician name] for my diabetes.

One participant with a SAS score of 14 expressed a high degree of familism relative to filial piety and was responsible for the care of her chronically ill parents. There was an expectation that she would care for aging family members. Even though she willingly assumed this role, her comments indicated resentment:

Our house was stressful while my mom was alive. She had schizophrenia, bipolar disease. She was very, very . . . she had to be in control of everybody. It was very difficult in the house, ummmh, so maybe stress was an inducer. A lot of other factors, just the fact not being able to do what I needed to do just compounded all of the depression.

Well, they did tell me to take diabetes classes at a community hospital. I didn't just for the simple fact I was still dealing with my mom. . . . I had to be there.

After this participant's mother died, she assumed total responsibility for her father's care. Again, the expectations associated with familism were a deterrent to her diabetes management and meeting her personal health-care needs.

Religiosity and Spirituality.

Within the phenomenon of religiosity and spirituality, two themes emerged. These themes were identified as connecting with a higher power and reliance on a faith community.

Although religion generally is considered important among Latinos, attending church was not expressed as important among participants in this study, nor was church attendance required to be considered religious or spiritual. With the exception of two participants, all expressed religious affiliations: Catholic (n = 6), Pentecostal (n = 2), Seventh Day Adventist (n = 1), and Jehovah's Witness (n = 1). However, only three of the twelve participants reported currently attending religious services. The following themes emerged to reflect dimensions of religiosity and spirituality.

Connecting with a Higher Power. All but one participant professed asking for spiritual guidance when faced with adversity. Three participants reported to praying to Him when things go bad or praying to my saint. One participant stated: I ask Him to help me, to get through or whatever He wants from me. I will accept whatever. This comment has a fatalistic undertone. Overall, participants expressed asking for help and connecting with a higher power; at the same time, however, they conceded that their health may be in God's hands and out of their control. The following excerpts provided additional insight into a participant's sense of fatalism: *I cannot control my destiny and ... it is in God's hands.* One participant believed that she was alive only because God willed it: *I thank God every day to be alive for another day.* Interestingly, this participant had poorly controlled diabetes, more so than the others who participated in the study. Indeed, she reported taking no initiative to improve her diabetic outcome as defined by her adherence to a prescribed diabetic diet. Frequently, her glucose levels were 500 mg/dl or higher. She managed her elevated glucose levels with insulin according to how she felt on any given day and not based on the prescribed recommended dosage.

Religiosity and spirituality played a role with regard to diabetes. One participant offered this insight: *You ask Him to watch over you, to help you get through the day. Yes, yes, that goes without saying.*

Reliance on a Faith Community. Beyond the traditional sense of familism reported by participants, one participant, a Jehovah's Witness, stated that he relied on his brothers. These individuals are members of his congregation with whom he associates on a regular basis. In contrast, two other participants reported attending church or belonging to a faith congregation, but they did not regularly attend services and did not demonstrate a reliance on a religious community.

Religiosity, Spirituality, and Acculturation. Although ten participants reported a religious affiliation, only three attended a faith congregation (Mass, assembly) with any regularity. These three individuals are described in greater depth. One participant with a SAS score of 7 reported being a Jehovah Witness. He regularly attended an assembly and relied on his *brothers* to help him during times of illness. A female participant with a SAS score of 14 reported being a Seventh Day Adventist and maintained a diet in accordance with the principles of her church. It was unclear how those dietary restrictions impacted her diabetes. An older female with a SAS score of 6 stated that she relied on a son to take her to church when he was able to do so.

Regardless of level of acculturation, religiosity and spirituality were important to all participants. Eleven participants reported that when they were ill, they prayed and asked for the intercession of a higher power or higher being. Although the majority of participants did not actively participate in organized religion, they reported high levels of spirituality as evidenced by replies when asked "What spiritual guidance do you seek?" This question typically required

clarification, rephrasing the question to, for instance, “When you are ill, do you pray to someone or something to make you feel better?” Illustrative participant responses are as follows:

I talk to Him, I talk to God.

When you are ill, you look more for God and ask for His blessing. Especially when you are ill, you need to have faith. El señor es mas que cuida a uno [God is the one who cares the most for one].

Yeah, you do ask for guidance. You ask for Him to watch over you, to help you get through the day. Yes, yes, that goes without saying.

Yes, when I lay down at night, the first [thing] I do is thank God for letting me see another day, but I am not Catholic in the sense that I go to church all the time.

I have a saint I pray to.

When I have a serious problem, like once my Hgb [A1C] was real bad, I started praying to God to get better.

Only one participant reported speaking to God *first* when he felt ill: *I speak with Him.*

Use of Ethnomedicine (Remedios Caseras)

Although the phenomenon of ethnomedicine has been reported to be popular among Latinos in general, it was not of great importance to participants in this study (Hunt et al., 2000; Lopez, 2005; Ortiz & Clauson, 2006). Even the participants with the lowest SAS scores denied relying on ethnomedicine and admitted to having only a casual interest in ethnomedicine. Only two participants admitted to using any alternative remedies. The following three themes on use of ethnomedicine emerged from participants’ narratives: subtle interest, suspicion, and adherence to family healing traditions.

Subtle Interest. From the interviews, two participants actually used ethnomedicine or remedios caseras while a total of four indicated they were somewhat interested in using ethnomedicine. One participant reported preparing a tea from a specific plant known to reduce blood sugar but conceded that this was not done on a regular basis. Another participant admitted

preparing a tea but was unsure of the actual name of the plant; the remedy had been recommended by a friend. The participant stated that the remedy actually helped reduce blood sugar and shared this information with the health-care provider. The plant from which the participants made the tea was known as the “insulin plant” or “planta de insulina.” References to this plant were made by five participants as an option they had heard about from friends and family members but that they did not use. One participant reported that the plant grew in her backyard but conceded being too lazy to make the tea. Another participant admitted to using fresh grapefruits on occasion—but with no regularity—to control his blood pressure. It is interesting to note that while he showed an interest in ethnomedicine and used grapefruits to lower his blood pressure, his son was a physician and his primary health-care provider. This suggests an understanding on the part of his provider (son) to respect his father’s use of alternative remedies.

Suspicion. One participant expressed distrust of any ethnomedicine: I do not use anything. I am scared of being poisoned. This particular response could indicate there may be underlying distrust regarding the risk and/or benefits to use of ethnomedicine that may require further investigation. Likewise another participant had this to say when asked about ethnomedicine usage: There are a lot of things, but I do not have confidence in them.

Adherence to Family Healing Traditions. When asked about use of ethnomedicine, one participant with a SAS score of 15, stated: That is my family—that is not me. This excerpt suggests that she regards her parents as less acculturated than she is, and that her parents consider use of ethnomedicine a viable option for health-care remedies.

Another participant admitted to using Vicks VapoRub Ointment™ as a remedy for diabetes. Among Puerto Ricans, Vicks VapoRub has become almost iconic as an alternative for

other commonly used self-care products, including aspirin, acetaminophen, decongestants, and pain relievers, to name but a few.

Lastly, the analysis explored the potential relationship between use of ethnomedicine and acculturation. However, use of ethnomedicine was not associated with SAS scores. While all of the participants admitted to having heard about a particular remedy for diabetes from others, the participants expressed only a casual interest in ethnomedicine and, overall, preferred Western medicine for the management of their diabetes.

Table 3

Phenomena of Interest and Corresponding Themes

Phenomena	Themes	Excerpts
Familism	Role Expectation of Others	<p><i>They are responsible for me.</i></p> <p><i>I do what they tell me. I need guidance.</i></p> <p><i>I speak with my wife. I am not alone.</i></p> <p><i>I dedicated myself to caring for him and did not care for myself.</i></p> <p><i>I lost my mom a year ago. She had diabetes—she also had a lot of other problems.</i></p>
	Family Interdependence	<p><i>I have a wife—I am not alone.</i></p> <p><i>I was alone for two years without a wife.</i></p> <p><i>I do what they tell me. When you are old you have to look for their guidance.</i></p>
	Caregiver Burden	<p><i>...in my family you are so used to doing for everybody else...</i></p> <p><i>I do not want him getting sick [her husband]. I am trying to care for him.</i></p> <p><i>My husband had a stroke—I dedicated myself to caring for him.</i></p>
Religiosity and Spirituality	Connecting with a Higher Power	<p><i>I ask Him to help me, to get through, or whatever He wants from me, I will accept whatever.</i></p> <p><i>I thank God every day to be alive for another day.</i></p> <p><i>I cannot control my destiny and that it is in God's hands.</i></p> <p><i>You ask Him to watch over you, to help you get through the day, yes, yes, that goes without saying.</i></p>
	Reliance on a Faith Community	<p><i>I rely on my brothers [church brethren].</i></p> <p><i>My son-in-law takes me to church. I go when my legs work.</i></p> <p><i>I am a Seventh Day Adventist.</i></p>
Ethnomedicine	Subtle Interest	<p><i>...too lazy...</i></p> <p><i>I used to use yerba buena. Now I follow what the doctor tells me.</i></p> <p><i>A friend told me about a plant that lowered his sugar.</i></p> <p><i>I did not like the taste of it...tea or some bark from a tree—you boil it and drink it.</i></p> <p><i>Someone told me about the “hoja de gandule.”</i></p> <p><i>A lot of people use them but not me.</i></p> <p><i>My family does things, and I say okay...but when I get home I do not use them.</i></p>
	Suspicion	<p><i>I do not use anything; I am scared of being poisoned.</i></p> <p><i>There are a lot of things, but I do not have confidence in them.</i></p>
	Adherence to Family Healing Traditions	<p><i>That is my family—that is not me.</i></p> <p><i>My mother uses yerba buena for the stomach and such but never for diabetes.</i></p> <p><i>I use grapefruits for my blood pressure.</i></p> <p><i>We were raised with Vick's VapoRub in my house ...Vick's for this and Vick's for that.</i></p>

Purpose 2: Puerto Ricans' Perceptions about Their Health Care Providers

The second purpose of this study was to explore Puerto Ricans' perceptions about their health-care providers. The concept of ethnic concordance arose from the analysis of the interviews. Concordance was defined by participants as "like" health-care providers. In this context, a "like provider" was defined as a Puerto Rican health professional who could speak both English and Spanish. A consistent theme that emerged from the narratives was the importance attached to having a like provider, one who understands the culture of Puerto Rican clients (Table 4).

Likeness Counts

Nine participants reported that their health-care provider spoke Spanish with them during routine health-care visits. Not only was the provider Latino but Puerto Rican as well. When asked whether their health-care provider understood the Puerto Rican culture, they expressed such beliefs as *He understands me*, and *He knows best*. One participant with a SAS score of 16 reported that he sought care from a non-Latino provider, and stated, *I don't know whether he understands our culture*. Overall, participants expressed satisfaction with the care provided to them by their physician or health-care provider including the one who saw a non-Latino physician.

Even though the question about providers referred to primary-care providers, participants offered insight about consulting physicians for associated co-morbidities, such as cardiac, vision, pulmonary, and dermatological disorders. The consulting physicians tended to be non-Latino and non-Spanish speaking. The following two themes were identified from comments related to the ethnicity of the health-care provider: ethnic discordance and trust issues.

Ethnic Discordance

Three participants received care from a health-care provider who was not of Puerto Rican or Latino origin. One participant admitted to seeing the provider only as needed and, thus, could not discuss perception of satisfaction. The remaining eight participants had a primary-care provider who was ethnically concordant. Based on the narratives, Puerto Rican health-care providers routinely referred participants to other specialists, in particular cardiologists or ophthalmologists. To queries about satisfaction with the health care received from the consulting physicians, participants reported:

My daughter translates for me.

I tell him things and I wonder if he understands me.

I have doubts.

He told me nothing about my condition.

One of the participants whose primary-care provider was ethnically discordant (non-Latino) stated, *He got the job done ... if he can keep sugar at the right level, he gives good care.* While this participant reported being actively involved in his health care, he still expected the physician to *keep me in good health*. While this individual was satisfied overall with the health care he received from his provider, when asked if the physician understood his culture, he had this to say:

He never sits down to discuss how I am feeling or [if] I am doing okay. He does not ask me how I feel. He uses the stethoscope, but that's about it. I follow the regimen he imposes on me.

This participant noted that his physician effectively managed blood glucose levels, a biological function. Yet, he expressed dissatisfaction because the health-care provider did not ask him how he was feeling or doing. Clearly, this participant registered negative feelings about the lack of

attention to his personal and psychosocial needs associated with the lack of expected social discourse.

Another participant who received care from an ethnically discordant provider expressed feeling rushed—not being given time to express her feelings and issues of concern. One must ask how common this sentiment is among Puerto Ricans in general. Overall, data from the narratives suggested that participants expected more personalized attention in the form of *plática* (greetings and small talk) and *simpatía* (things going smoothly). Essentially, Puerto Ricans appreciate small talk and rapport building prior to dealing with the more pressing issues. Failure to make small talk, *la plática*, is considered rude. *Plática* is an imperative component of Latino culture, an expression of good will during clinical (and other types of) encounters, serving as a vehicle for developing rapport or *simpatía*, the perception of things going smoothly (Marin & VanOss-Marin, 1991).

Trust Issues

Five of the participants had the same Puerto Rican physician, and all expressed an overwhelming trust in the health-care provider. In fact, participants reported that when their relatives from Puerto Rico came to the U.S., they personally accompanied them to this particular physician for a “*tune-up*.” One of these participants stated that during the holidays, his family comes to Florida *hecho leñas*, loosely translated, “falling apart.” This participant also expressed the belief that *my mother would be alive today if Dr. R cared for her*. Again, it was not unusual for respondents to report that their relatives sought medical care in the U.S. by this physician but lived in Puerto Rico. These findings are consistent with the circulatory migration pattern identified within this population (Christenson, 2001).

Although none of the participants commented negatively on the care provided by their non-Latino, non-Spanish-speaking consulting physicians, there were some unspoken concerns about trusting those health care providers. Struggling with morbid obesity, one participant stated, *the doctor does have to take into consideration, Americans eat differently from Latinos. . . . I think the doctor has to inform the Latinos that there are different ways to eat fried stuff, not fried!* This female participant was frustrated that her attending non-Latino physician did not understand her culture enough to make suitable dietary recommendations that she could incorporate into her traditional diet.

Familiarity with their primary health-care providers was identified as important. As one participant stated, *I give him a look; then I give him a kiss and a hug. That is the kind of bond we have, but he understands. . . . I am Latina, and it is going to be hard for me.* This individual felt that because her health-care provider was Puerto Rican, he could relate to her difficulties with managing her diet and not be hard on her.

The nine participants with SAS scores of less than 12 all received health care from Spanish-speaking providers. For these participants, choosing a provider who spoke their language was important. This was confirmed by a female participant who felt she could better express herself to her physician when she spoke in Spanish. The decision to seek care from a like provider may be influenced by the ability to express oneself more effectively in one's native language.

Language, in and of itself, however, was not as important as ethnic concordance. The following comments regarding health-care providers emphasize the importance of concordance:

I think if they speak your same language, I feel more comfortable to say anything to them and they will understand.

On the contrary, they come from Puerto Rico . . . bring them to [the doctor's name] and he puts them together. I feel if he was taking care of my mother, she would be alive today.

Oh, yes, definitely you have the "aquel" to speak with him and he will understand, because if you have an interpreter, I can tell him this hurts and he tells the doctor nothing hurts.

Inherent in the first excerpt is the notion that participants may be reticent to express all of their concerns about their health out of fear of embarrassment. The second excerpt relays the feeling of overwhelming trust in his health-care provider to care for his entire family when they come from Puerto Rico. In the third excerpt, not only does the participant state a Spanish-speaking provider would understand her, there is also a sense of distrust that an interpreter may not represent her concerns accurately.

The following excerpt from one participant illuminated the sentiment of a participant regarding her health-care provider and ethnic concordance. When asked if her health-care provider understood her culture, she commented:

Yes, he does, he really does. He says, "You are Latina and these are your eating habits, but they need to change for your well-being, for your health, and for your family." . . . I am okay with that. I give him a look; then I give him a kiss and a hug. That is the kind of bond we have, but he is understanding that I am Latina, and it is going to be hard for me for my eating habits to change.

Overt in this excerpt is the participant's level of comfort with a health-care provider who understands a woman of Latina origins and who realizes that the changes she needs to make in her diet to manage her diabetes will be difficult.

Participants with SAS scores of 14 or higher had English-speaking health-care providers. Although these participants reported satisfaction with the level of medical care provided, when asked whether ethnic concordance was important to them, they stated the following:

I believe I cannot say yes or no, but I do not know whether he understands my culture.

The doctor does have to take into consideration Americans eat differently from Latinos.

They eat a lot of fried stuff. I think the doctor has to inform the Latinos, “Hey, there are different ways to eat fried stuff, not fried!”

Among these three participants, the decision to seek care from a non-Latino provider may have been linked to the ability to speak English with relative ease and the greater level of acculturation. However, their comments suggest cultural rather than linguistic concerns about ethnic concordance.

Table 4

Emergent Themes

Emergent Themes	Excerpts
Likeness Counts	<i>He understands me.</i> <i>He knows best.</i>
Cultural Discord	<i>[The doctor] told me nothing about my condition.</i> <i>My daughter translates for me.</i> <i>I tell him things and I wonder if he understands me.</i> <i>I have doubts.</i> <i>He does not ask me how I feel. He uses the stethoscope, but that’s about it. I follow the regimen he imposes on me.</i>
Trust in “Like” Provider	<i>My mother would be alive today if Dr.R. cared for her.</i> <i>I give him a look, then I give him a kiss and a hug, that is the kind of bond we have. He understands I am Latina, and it is going to be hard for me.</i>

Serendipitous Findings

In the analysis of the narratives, two serendipitous themes emerged. The first theme, “*It’s no big deal*” was elicited from one interview and refers to a perceived casualness about the diagnosis of diabetes. The second theme reflects presence of depressive-like symptoms. Of the

eight female participants in the study, six reported experiencing such symptoms. Selected descriptions that support and illuminate these two additional themes are presented below (Table 5).

Perception of Severity: “It’s No Big Deal”

One of the themes that emerged from the interviews was the sentiment that having a diagnosis of diabetes was not significant in the participant’s life, i.e., *It’s no big deal*. The participants’ seemingly casual attitude toward the diagnosis was alarming to this investigator. One participant reported that his *diabetes was not too bad. The doctor appears sicker than me*. Another participant reported with an undertone of fatalism, *I am not doing too bad, we have to die from something*.

The following excerpts were from one 35-year-old woman: *It’s not so bad you can’t control with diet. . . . Diabetes is not a hassle at all. . . . I know it is physically hurting me, but it is not visible to me because it does not hurt*. This participant was morbidly obese and admitted to not taking prescribed medication. In addition, she did not see a need to monitor her glucose levels with any frequency because; *it [glucose level] is always low*. She admitted those levels were obtained from testing before meals, preferring not to monitor glucose levels after meals. There was a disconnect between the actual seriousness of the disease progression and her perception that *diabetes is not a hassle*. She described having developed a non-healing ulcer on her leg. Yet, when further queried about this complication, the participant was unable to articulate the relationship between elevated blood glucose levels and poorly healing wounds. Happily, she noted her physician finally started to leave her alone about her losing some body weight. Consequently, she continued to eat out regularly and offered a variety of excuses for not

exercising. During the interview she further explained: *To be honest, [I know] when I go out I should order water instead of Dr. Pepper. I know I shouldn't go to the pizza place.*

Another participant commented that *diabetes has not affected my life at all.* This participant was an older woman with a 25-year history of diabetes. She was legally blind as a result of the disease and could no longer leave her home. She related that while her physician prescribed a specific dosage of insulin, she would frequently alter the dose based on how she felt on any given day. She admitted that she had never maintained any specific diet and was quite confident that she never would. As a result of her poor self-care, her glucose levels averaged in the 300 to 500mg/dl range. She casually referred to this elevated glucose as when the *machine* [glucose meter] was saying, *Hi!* [high]. Not even when her glucose levels were extremely high did she feel any urgency to administer medication to reduce the level. This participant reported that her physician had recently informed her that her renal function was deteriorating, yet she felt the situation was not a cause for concern. She expressed pride that she had never been admitted to the hospital for diabetes-related complications, but she had been admitted for visual problems. This comment was further evidence of the incongruent perceptions by four participants relative to the severity of the disease.

Another participant made comments that reinforced the casual attitude toward diabetes exhibited by participants in general: *I always ignore it and I do not lose sleep over it.* This participant reported she had no time for herself because she was also caring for her husband who was severely ill; consequently her own needs were not a priority. She rarely took her prescribed oral medication and never monitored her glucose levels. This participant had not seen a health care provider in a *very long time* and relied on a family member, who was a nurse practitioner, to provide her medication.

Depressive-Like Symptoms

An unexpected finding was allusion to depressive-like symptoms from six of the eight interviews with women. Depression was not a co-morbidity under study. Because of this early finding, the investigator continued to explore the depressive-like symptoms with the participants in subsequent interviews. It is not known if diabetes was directly responsible for the participants' depressive-like symptoms or whether another unidentified factor was responsible. These women were concerned about being depressed and the impact the symptoms had on their ability to care for themselves and their family members. In two of the narratives, the term "depression" was mentioned as many as four and five times, respectively, as being a major concern in their lives. The following are excerpts from the narratives:

Just the fact of not being able to do what I had to do compounded the depression.

I am asking the Lord to help me get over my depression.

I actually cried about it; I had to change my ways.

I was very depressed and alone. . . .

I suffer from depression, it is bad.

I always have depression, but I control it; I have been able to manage it.

But you do become depressed. You think about your grandchildren, you think about your kids . . . you think about your husband. What if something happens to me?

Table 5

Serendipitous Themes from Interview Analysis

Themes	Excerpts
Perception of Severity: It's No Big Deal	<p><i>I am not too bad. The doctor appears sicker than me.</i></p> <p><i>I am not doing too bad, we have to die from something.</i></p> <p><i>It's not so bad you can't control with diet.</i></p> <p><i>Diabetes is not a hassle at all.</i></p> <p><i>I know it is physically hurting me but it is not visible to me because it does not hurt</i></p> <p><i>Diabetes has not affected my life at all.</i></p> <p><i>I always ignore it.</i></p> <p><i>I do not lose sleep over it.</i></p>
Depressive-Like Symptoms	<p><i>Just the fact of not being able to do what I wanted to do has compounded the depression.</i></p> <p><i>I am asking the Lord to help me get over my depression.</i></p> <p><i>I actually cried about it. I had to change my ways.</i></p> <p><i>I was very depressed and alone.</i></p> <p><i>I suffer from depression—it is bad.</i></p> <p><i>I always have depression but I control it. I have been able to manage it.</i></p> <p><i>But you do become depressed. You think about your grandchildren, you think about your kids, you think about your husband— what if something happens to me?</i></p>

CHAPTER V: DISCUSSION

This chapter consists of a discussion of the findings of this exploratory study using narrative inquiry. Explanations of cultural beliefs regarding health-care seeking behaviors in Puerto Ricans with diabetes who live in South Florida are described. Puerto Ricans' perceptions about their health-care providers are also examined. Limitations of the study along with recommendations are included.

Phenomena of Interest

Familism

Three themes emerged from the narrative analysis related to the phenomenon of familism. Familism, among participants in this study, was evidenced by a strong emphasis on unity of the extended family regardless of geographic distance or where they lived, be it in the mainland U.S. or in Puerto Rico. Familism was both a negative and a positive mediator in the participants' health-care seeking behaviors. Three themes emerged in the narratives: role expectations, family interdependence, and caregiver burden. Andrulis (2003) observed where familism is present, decision-making occurs at the family level rather than the individual level. The implications of this statement are that health-care providers should involve family members when planning care for clients regarding their role expectations.

Findings from the Wen, Parchman, and Shepherd (2004) study suggest that Puerto Ricans commonly consult family members before consulting a health-care provider. However, this practice could result in treatment delays for the person who is ill. The findings in this study

reaffirm that Puerto Ricans diagnosed with diabetes often seek input from family members before making any decisions regarding their own diabetes-improvement strategies, lifestyle modifications, and dietary changes. For this reason, health-care providers should schedule regular follow-up appointments and encourage a client to bring family members along to discuss the disease process and regime changes. Engagement in the treatment plan by family members can promote client adherence. Strategies related to family dynamics can be useful to address non adherence behaviors associated with diet and self-care among Latinos with Type II diabetes; in other words, the greater the perceived support, the greater the self-reported adherence with the diabetes regime (Wen et al.).

Role Expectation

Differentiated gender role expectations are a component of familism among traditional Puerto Rican households. For example, women are expected to be the primary caretakers for children and aging parents, and men rely on their spouses or significant others for health-related information. Specifically, women in this study reiterated the need to care for their families, especially when a member was ill. In the case where a woman had a chronic illness such as diabetes, her needs often remained unmet in favor of attending to the needs of other family members. Interestingly, because of these unstated gender role expectations, one male in this study felt strongly that he developed diabetes as a result of being a bachelor. When asked what caused his diabetes, he remarked, *For me it was lack of nutrition because that occurred when I was living in New York City, and I was drinking Yes, I was alone for two years after my first wife, I was doing “desareglo” [disruptive lifestyle].*

Family Interdependence

The importance of family interdependence, defined as the reliance on family members to assist and contribute to the well-being of the family as a whole, was evident in this study (Warda, 2000). Culturally mandated consultations among extended family members contributed to delays in seeking care. It was not unusual for participants to describe how they first discussed health-related matters with extended family members and then built consensus among family members regarding individual treatment. Others described deferring to other family members to make important decisions for them: *I do what they tell me, when you are old you have to look for their guidance.*

If an individual seeks health-care advice from an outside source, family members may feel inadequate, resulting in misconceptions and disagreement. Conversely, if elder family members or patriarchs become ill enough to require care, the children and/or spouse will assume caregiver responsibilities. This role reversal may result in additional emotional conflict if aging parents perceive their role as caregiver has been usurped (Sharma & Kerl, 2002). Behaviors, such as seeking professional care without first consulting members of the family, are perceived as disrespectful. Finally, it is important to understand the social status and hierarchy among the family unit. Assuming that females are typically the caregivers may prove incorrect if, in fact, a male assumes that role in a family.

Participants in this study referred to family interdependence as wife-husband, daughter-father, and mother-child dyads. The caregiver role was perceived as positive in nature. However, in some instances, the expectation of caregiver produced additional pressure and stress, particularly for one female participant who had been responsible for her recently deceased mother's care and then assumed the role of caregiver for her elderly father. The latter

responsibility was cited as key to her inability to control glucose levels and lose weight, contributing to caregiver burden.

Caregiver Burden

Because of important findings regarding familism, a discussion of the caregiver role is warranted. Caregiving has been defined as a dynamic process, one that occurs within a cultural context laden with meanings, symbols, and rituals (Karner & Hall, 2002). The role of caregiver was evident, particularly among the female participants in this study. One admitted that she did not have time to care for herself because she was responsible for the care of her husband. She reported caring for him until his death at their home. Another female participant commented that as the caregiver for her family, she was *glad* that she, not the other members of her family, had diabetes. She also was concerned with her inability to juggle all of the demands of her family with her new diagnosis.

Until recently, only the role of women as caregivers has been documented (Lu & Wykle, 2007; Neary & Mahoney, 2005). Hence, societal expectations of Latino women as caregivers have resulted in the reorientation of social services and community resources with female caregivers in mind. It should be noted that this situation has created difficulties among male caregivers who attempt to access services and who are typically assisted by female caseworkers, thus suggesting a need for more male representation among social-service providers. Since the role of caregiver is typically oriented toward females, daughters often marry and become caregivers in their own homes. Conversely, males may assume the caregiver role out of a sense of duty and responsibility, with little practical preparation. Such situations may result in even greater stress for male caregivers (Delgado & Tennstedt, 1997). Additionally, a male's beliefs and behaviors reflect how he perceives himself in society; illness is seen as a weakness and/or a

threat to his manhood (Sobral, 2006). Among the participants in this study, the caregivers were females.

While caregivers may have the best of intentions relative to the care of a family member, the nature of the relationship may prevent caregivers from perceiving subtle cues that indicate the worsening of an individual's condition. Conversely, one could argue that time spent immersed caring for a family member may provide opportunities to better understand the disease process; this understanding, in turn, can be communicated to the health-care provider.

To summarize, familism was noted to be pervasive among Puerto Ricans in their day-to-day activities, and it impacted their health-care seeking behaviors. Health-care providers need to be cognizant that among many Puerto Ricans, being the caregiver for a family member is a priority. Along with the burden of caring for a family member who is ill, the caregiver may also be responsible for a spouse, children, and household. When Puerto Rican caregivers have a chronic illness, such as diabetes, their personal health needs often remain unmet. Caregivers need empowerment strategies that not only affirm their family role but also afford them the ability to seek personal care without feeling guilty or neglectful of their duties toward others (Ramos, 2004)

Religiosity and Spirituality

Organized religion and church attendance did not emerge as a major theme in the lives of this sample. However, all of the participants reported asking God to intercede on their behalf when they were ill. This finding suggests that spirituality could be a coping strategy among participants for dealing with chronic illness, such as diabetes. Spirituality is often associated with a belief in fatalism, i.e., that life events are out of the control of the individual person and in the hands of a higher power. While the findings from this study are limited with regard to aspects of

religiosity and spirituality, nurses and health-care providers should explore their clients' beliefs about fatalism. Individuals who hold a fatalistic attitude might express that they are helpless to manage their diabetes. Or, they may require other interventions, such as ministerial support or consultation with an indigenous healer, to help them adhere to prescribed medication and care regimens. In this study, one participant stated, *I started praying, me "encomendia a dios" [I entrusted God] to get better.* Another thus related her belief that God controls one's fate: *When I lay down at night, the first thing I do is thank God for letting me see another day, but I am not Catholic in the sense that I go to church.* The latter statement also clearly depicts the difference between spirituality and religiosity voiced by the participants.

Use of Ethnomedicine

Contrary to popular opinion, *remedios caseras* was not used with regular frequency by participants in this study. Or, if these interventions were used, participants chose not to share the information with this investigator. Participants indicated a subtle interest in using alternative medicines but reported a preference for Western medicine to manage their diabetes. Interestingly, all of the participants reported that individuals in their social networks used ethnomedicine regularly. More than half of the participants mentioned hearing from relatives and friends about plants or teas that could be used for diabetes management, but they expressed minimal interest in personally using ethnomedicine. This finding was surprising given the low acculturation scores of some participants. Given the low scores, this investigator expected a greater number of participants to report use of ethnomedicine to control blood glucose. This finding reinforces the concept that broad generalizations about Latinos as a whole may not be accurate for specific Latino populations, in this case, Puerto Ricans. Despite the subtle interest in

use of ethnomedicine expressed by the study participants, health-care providers must still explore this possibility with clients to prevent possible adverse medication interactions.

Acculturation

According to the literature reviews, the SAS score reflects language preference and can be used as an indicator of participants' level of acculturation. However, in this study, a participant's SAS score was not an identified factor in the cultural phenomena of interest—familism, religiosity, spirituality, and use of ethnomedicine.

Language preference of the participants was an important consideration when choosing a health-care provider. Those with a SAS score of 12 or higher had a greater proficiency in reading and speaking English and were more likely to choose an English-speaking provider. They reported being comfortable expressing their medical needs to their English-speaking providers and expressed overall satisfaction with the medical care they received. However, these participants also voiced disappointment in the ability of the provider to meet their cultural needs as evidenced by the following excerpts:

He always cuts me off.

I feel as if I am being rushed.

He never sits down to discuss how I am feeling.

These excerpts point to a need on the part of the provider to develop rapport and demonstrate interest and enthusiasm for the client, as an indication of caring and concern. Even among those with higher SAS scores, the need for ethnic concordance remained constant among the participants in this study.

For the 2 participants with SAS scores above 14, reliance on family or familism seemed to fade. When ill, the individuals felt a lesser need for guidance and assistance from family

members than those with lower scores. Instead, these individuals were comfortable seeking assistance directly from their health-care providers. This situation may be directly related to their ability to speak English.

Even among the Puerto Rican females with the highest SAS score, filial piety remained a constant across generations, as evidenced by their caring for parents and other family members. Although adult daughters are expected to care for aging parents, such care may no longer be viewed as positive or rewarding, but rather as a duty and a family expectation. In this sample, findings suggested that female participants assumed the caregiver role at the expense of their personal health and well-being. These findings are different from those of Ramos (2004), who suggested that although caregiving can result in financial burdens and, in some instances, a sense of intrusion, it “serves as [a] protective factor against stress” (p. 481). In this study, however, increased family cohesiveness often resulted in participants’ inability to express concerns or to take care of their health relative to dietary modification and lifestyle changes.

Likeness Counts

Participants reported strong feelings that having a like provider was important. A like health-care provider was defined as another Puerto Rican or Latino who spoke Spanish. Nine of the participants in this study obtained primary care from an ethnically concordant Latino health-care provider. Among the study participants, the sentiment was that seeing a culturally concordant provider would ensure that their concerns would be addressed and that he or she would understand common cultural nuances. Referral to a consulting physician (e.g., cardiologist, ophthalmologist, pulmonary specialist) was not an uncommon part of receiving care. In these instances, the consulting physicians were not usually of Latino origin and did not speak Spanish. As a consequence, participants voiced several concerns. Trust-related issues,

language barriers, and a general lack of understanding of an individual's culture resonated among the participants. One study participant related that when visiting the consulting physician's office, she typically relied on a staff person in the office to interpret for her, but she also commented that this individual had not accurately communicated her concerns.

Incongruent encounters between health-care providers and patients have been negatively related to adherence, satisfaction, subsequent use of health-care facilities, treatment responses, and the reporting of adverse conditions (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Lange & Piette, 2006). Nine participants, who reported having a Latino health-care provider for routine care and diabetes management, expressed the importance of a trusting relationship. In fact, one participant was so confident in the care provided by the Puerto Rican physician that he reported taking family members visiting from Puerto Rico to this physician for a "*tune-up*." This participant also stated that his mother would still be alive if she had been cared for by this particular physician.

Trust

While participants in the study expressed satisfaction and overall trust in their "like" health-care providers, there is no evidence to suggest that they had better outcomes (such as improved glucose control or fewer complications) compared to those who were cared for by "non-like" health-care providers. The study findings suggest, anecdotally, that participants believed their like health-care providers understood them and their experiences managing their diabetes.

Difference in level of education and income, as well as race and ethnicity, between a health-care provider and a client can inhibit establishing trust. Likewise, the greater the social distance between provider and patient, the less likely a mutually satisfactory patient-physician

relationship can be sustained (Schnittker, 2004). Although the participants in this study described experiencing social distance in education and income compared to their Puerto Rican provider, the importance of these factors seemed less evident because of the shared language and culture.

Ethnic Concordance

Racism was not a phenomenon of interest in this study; however, nine participants sought care from an ethnically concordant (Latino) provider. These findings suggest that seeing a physician of the same ethnicity may be associated with enhanced caregiver-patient relationships. Seven participants who preferred and saw a Puerto Rican physician tended to rate their care as “excellent” compared to those who preferred, but did not receive, care from a physician of similar background. These findings are similar to those reported in the literature. Evidence suggests that race and ethnic concordance are associated with patient satisfaction, adherence, length of visit, decision-making, and utilization of services (Clark, Sleath, & Rubin, 2004; Cooper et al., 2003; LaVeist, Nuru-Jeter, & Jones, 2003). Ethnic-concordant visits were perceived as more satisfactory, and patients felt empowered to participate in decision-making relative to their care. Equally important, communicating in the patient’s language during a medical visit was a strong predictor of provider-patient concordance (Clark et al.). Patients with language-discordant health-care providers may be unaware of changes to their current medications or treatments because of language barriers. Additionally, there may be confusion regarding dosages and indications.

To summarize, participants in this study preferred receiving care from a like provider. The literature suggests that health-care provider-client race and ethnic concordance yields higher levels of client satisfaction, better adherence to treatments such as medication compliance, and increased trust between client and health-care provider (Clark et al., 2004; Cooper et al., 2003;

Schnittker, 2004). However, receiving care from a like provider is not always possible given the lack of Puerto Rican health professionals in the country; consequently, there is a need to recruit and retain minorities to the health profession, in particular those of Puerto Rican origin.

In addition, health-care providers must be aware of their perceptions and behaviors when caring for people from ethnic backgrounds different from their own. Lack of awareness may lead to biases about an individual's access to services and his or her willingness to adhere to the treatment recommendations (Andrulis, 2003). For example, Schnittker (2004) found that Latinos were the least trusting of several cultural groups when faced with culturally-discordant health care providers. Because of this lack of trust, and without conscious efforts by health-care providers to counteract it, Latino families may actually undermine the providers' recommendations for an ill family member.

Building trust requires an initial investment of time, effort, and awareness on the part of the provider. Most importantly, the treatment outcomes of a client often depend on the manner in which this initial investment is made. For instance, when caring for Puerto Ricans, health-care providers need to be sensitive of proscribed social distance and the granted position of authority given to them (Andrulis, 2003; Schnittker, 2004). Health-care providers may need to adapt existing procedures and protocols typically used for obtaining information from their clients in favor of rapport building early on (Andrulis; Clark et al., 2004).

Serendipitous Findings

Depressive-Like Symptoms

While depression was not a co-morbidity of interest in this study, six of eight women alluded to experiencing depressive-like symptoms. In many instances, the actual word *depression* or some variation was used by the participants; however, their personal definitions of

depression were not explored. In one interview, the participant cited depression five times; in a second interview, another participant cited depression four times. One participant reported developing depression as a result of a family situation, and five of the other eight cited depression as a problem that developed after being diagnosed with diabetes. In addition, anxiety and stress were cited as occurring as a result of the diagnosis of diabetes.

The most recently diagnosed participant reported feeling depressed during the aftermath of her diagnosis. She verbalized a fear of losing control: *I do not want diabetes to take over my life, I don't*. She was emphatic that diabetes was not going to control her and that she would take the necessary steps toward living a healthy life.

There is evidence to suggest an association between chronic illnesses such as diabetes mellitus, and depression. The interaction of diabetes and depression has resulted in an increased incidence of negative health outcomes, such as physiologic microvascular and macrovascular changes (Black, Markides, & Ray, 2003). Untreated or undiagnosed depression can minimize a person's sense of self-efficacy, making diabetes management difficult (Sacco et al. 2005). Lastly, it has been found that low-income, minority women with Type II diabetes experience an increase in depression and anxiety disorders (Thomas, Jones, Scarinci, & Brantley, 2003). It is not clear if the pathophysiology of diabetes precipitates depression, or if depression impacts glucose levels and the subsequent development of diabetes. The pathways by which depression impacts diabetes are psychobehavioral and pathophysiological. Depressive-like symptoms may contribute to apathy or decreased motivation to maintain protective behaviors, such as exercising and maintaining a diet, which can prevent worsening of symptoms. Additionally, biological changes may result in hormonal abnormalities, which may increase individual susceptibility to diabetes (Black et al.; Carnethon et al., 2007; Sacco et al.).

Whether or not diagnosed officially with depression, six of the eight women participants described depressive-like symptoms. The study was limited in that it did not screen participants for depression, nor did the data illuminate when depressive symptoms first occurred. Although it is important to know whether a participant's depressive-like symptoms began prior to diabetes diagnosis or after, such knowledge would be inconclusive since depression often remains undiagnosed for long periods.

These findings suggest that health-care providers should routinely screen clients for depressive disorders, as this could be a factor in health outcomes such as improved glucose levels (Black et al., 2003). Depression has also been linked to obesity, which can further exacerbate diabetic complications. In what can be considered a vicious cycle, depression can lead to limited exercise and increased caloric intake, which contributes to poor management of the diabetes. Additionally, the inability to maintain optimal glucose levels may result in a diminished sense of self-efficacy and worsening depression (Sacco et al., 2005). Conversely, implementation of an exercise regimen serves a dual purpose: exercise improves the glycemic index and lessens and/or prevents the onset of diabetes. As with most chronic conditions, a person with the diagnosis of diabetes may benefit from additional emotional support, encouragement, and motivation (Vickers, Nies, Patten, Dierkhising, & Smith, 2006).

Perception of Disease Severity: “It’s No Big Deal”

Concordance between the perceptions of the seriousness of the condition between the health-care provider and the patient may be an important modifier in patient compliance (Kleinman, 1988). A lack of concordance between the health-care provider and client relative to perception of disease severity (i.e., diabetes) was noted in this study. A casual, almost apathetic,

attitude toward the disease process was noted among most participants. Comments varied from the philosophic to obvious denial:

Not too bad.

Not so bad that you can't control with diet.

Doctor appears sicker than me.

I don't lose sleep over it.

I am doing good. ...We have to die from something.

Not a hassle at all.

I know it is physically hurting me, but it is not visible to me because it doesn't hurt.

Diabetes has not affected my life at all.

Most alarming was the observation that one female participant, who stated her diabetes was not a *hassle*, was morbidly obese and had additional co-morbidities, such as sleep apnea. She refused to do daily self-monitoring of her glucose or take her prescribed oral medication. Another participant, who said, *It has not affected my life at all* developed blindness as a result of her diabetes and can no longer leave her home unaccompanied. Yet another participant, who stated, *I don't lose sleep over it* admitted that she *never* monitored her glucose and took her medications in the evening *only* when she was feeling parched and/or thirsty because these symptoms indicated her glucose was elevated.

The casualness expressed by the participants speaks volumes when examining the failed attempts to improve outcomes among this segment of the population. As one participant stated, *I ignore it*. These findings are similar to those in a study of Hispanic migrant workers by Heuer and Lausch (2006). In that study, diabetes among the Mexican-American migrant workers was so common, it was referred to as the “*usualness of diabetes*.”

The degree to which individuals take their diabetes seriously has been the focus of several studies (Lange & Piette, 2006; Weller et al., 1999). Dimension of seriousness refers to a person's beliefs regarding the influence of diabetes on life expectancy, health-related quality of life, and daily functioning. Prior exposure to diabetes, with other family members who have diabetes or personal experience with diabetes, can influence a person's beliefs regarding the seriousness of the disease. Therefore, diabetics with complications and severe symptoms are more likely to take their conditions seriously. Persons with a diagnosis of diabetes typically use symptoms as an assessment of their personal health and diabetes severity (Lange & Piette, 2005). Hence, health-care providers should be aware that diabetics must first be educated to understand what constitutes serious symptoms, for instance, elevated blood glucose levels or poor wound healing.

In one case, a participant typically reported glucose levels of 500 mg/dl, yet denied she was ill. These findings are similar to those of Heuer and Lausch (2006), who suggested that because diabetes was so prevalent among the particular study population, participants manifested little concern if they were diagnosed with diabetes. Perhaps the Puerto Ricans in this study behaved similarly because they have become desensitized to the diagnosis of diabetes. The immediacy and intensity often felt with such a diagnosis may be attenuated by the escalating incidence of diabetes among this Latino subgroup.

Differences in perceptions about a diagnosis or disease process have considerable implications. According to Daniulaityte (2004), an individual's knowledge about diabetes is evaluated and compared to the "correct" and/or mainstream beliefs about diabetes. Customarily, health-care providers compare an individual's perception to the current biomedical model. Research has found that patients typically modify their understanding of the disease to fit their

personal needs. In 1988, Kleinman suggested that an understanding of an individual's belief is an effective way to obtain knowledge relative to perception of disease. There is considerable research to suggest that patients have differing perspectives in terms of severity of disease and expectations regarding their illness (Cohen et al., 1994; McEwen, 2005; McSweeney, Allan, & Mayo, 1997; Warda, 2000).

Finally, the casual attitude toward diabetes shown by study participants suggests the need for heightened awareness in disease management. Nine of the participants manifested no cause for concern or sense of urgency. In fact, they perceived diabetes as a mere *hassle*, something that can be managed with minimal effort. This casual attitude may be partially responsible for the increased incidence of diabetes among Puerto Ricans (Ho et al., 2006). Among the respondents was a sense that because diabetes is so common among Puerto Ricans, the disease is inevitable. The sentiment expressed in the interviews was not *if* . . . but *when I get diabetes, why be concerned; there is little I can do*. In addition, one participant remarked, *You can't see it*; this comment suggests that the lack of visible symptoms of diabetes makes denial likely. This comment also points to the need for aggressive diabetes awareness and educational programs targeting this subgroup, including the young Puerto Rican population, with an emphasis on prevention and effective management of this serious chronic health problem.

Recent findings suggest that Puerto Ricans diagnosed early through routine screening, may not appreciate the severity of the disease or the potential threat to their overall health (Thoolen, DeRidder, Bensing, Gorter, & Rutten, 2006). Puerto Ricans may be less likely to adjust their lifestyles early without in-depth education regarding the need for changes. If Puerto Ricans considered factors such as symptoms, complications, and glucose control in rating the seriousness of their disease, they would have enhanced awareness; however, in the interviews

discussed herein, that was not the case (Lange & Piette, 2006). Participants in this study cited symptoms such as thirst, poor wound healing, and visual disturbances as cues to high glucose levels. To a health-care provider, such symptoms signal a worsening of their conditions. But to the participants, such symptoms were not that serious, not a cause for concern. Furthermore, research has suggested that less acculturated, Spanish-speaking Puerto Ricans believe in fate, rather than in their own health-care behavior. In other words, cultural beliefs affect decisions to seek health-care for chronic illnesses, such as diabetes (Hosler & Melnik, 2005). This study did not focus on Puerto Ricans' belief in fate as a phenomenon; therefore, the degree to which this phenomenon is responsible for the casual attitude with which the participants discussed their diabetes remains to be seen.

Hosler and Melnik (2005) discovered similar attitudes among the Puerto Ricans living in New York City. The findings of a random-digit-dialing survey designed to reach a representative sample of Puerto Ricans (N = 606) suggested they were less likely to know desirable glucose levels or to use a blood glucose monitor with any regularity. Weller et al. (1999) attributed poor self-management to the general tendency not to take the diagnosis of diabetes seriously until late in the course of the disease when there was an exacerbation of serious complications.

Considerable evidence from the literature supports the findings from this study relative to incongruent perceptions between the client and the health-care provider. Failure to explore personal health-care beliefs can result in miscommunication and false expectations. Misperceptions on the part of the client have resulted in delays in care and poor adherence to prescribed medication and health-care recommendations. Among various other ethnic groups, incongruent perceptions may exist relative to the management and causes of a particular disease,

such as diabetes mellitus (Beck et al., 2005, McCabe and Priebe, 2004, McEwen, 2005, Ugarriza, 2002).

To summarize, participants in this study underestimated the severity of their diagnosis and long-term consequences. Ethnic discordance between the client and the health-care provider often translates into poor disease management (Lange & Piette, 2006). When discordance exists regarding the serious nature of the disease, the health-care provider and the individual need to reconcile differing perspectives; this is an important determinant to adherence. Furthermore, efforts made by health-care providers to understand another's perspective may be interpreted by the client as empathetic behavior, which can result in increased patient satisfaction (Weller et al., 1999). It is important for health-care providers to assist clients to modify inaccurate personal beliefs about their diagnosis—without alienating them. Lastly, if screening is used for diabetes detection to identify at-risk Puerto Ricans, health-care providers need to be aware that Puerto Ricans may minimize their diagnosis until symptoms and sequela become severe. Health-care providers must be educated to understand not only the patient's perspective, but also the likely collective perspective of the client's family. The convergence of these perspectives will aid in development of better individual health-care outcomes.

Language Barriers

Among the participants in this study who preferred to speak Spanish, finding a provider who also spoke Spanish was an important consideration. These participants stated that they were fortunate in being able to receive primary care and diabetes management from a Latino physician who was fluent in Spanish. Other study participants expressed a level of comfort with English that allowed them to see an English-speaking provider. The SAS (Marin & Van Oss-Marin, 1991) provided not only a gross indication of acculturation level but also an indication of health

literacy. Overall participant acculturation scores were low; the low score was predictive of language preference. A score between four and eight identified participants who preferred to speak and communicate with friends in Spanish rather than in English, and to read and listen to Spanish media (newspapers, television, and radio). Although most of the participants received care from a culturally and linguistically concordant provider, this situation does not alleviate concerns regarding health literacy. Many health-care providers, Spanish and English-speaking alike, may not have the resources to make available educational materials that fit the cultural and linguistic preferences of their clients.

Among the general U.S. population, Spanish-speaking adults tend to be older, less educated, and unemployed; they lack medical insurance and report poorer overall health. Furthermore, the inability to speak English has been shown to adversely affect glycemic control in Latinos with diabetes (Lasater, Davidson, Steiner, & Mehler, 2001). When Spanish-speaking patients were treated by Spanish-speaking providers, they had better recall of recommendations, missed fewer appointments, asked more questions, and reported better health status (Lasater et al.).

Participants who reported using an office interpreter during their physician visits admitted mistrust of the interpreter. They ended their visits feeling apprehensive that their concerns were not validated or addressed by the health-care provider. Similar findings have been documented by Barr and Wanat (2005) who explored the perceptions of low-income, ethnic minority patients. Using focus groups, the researchers found that among Latino study participants, language discordance was perceived as the biggest barrier to accessing health-care services. Latino participants with limited English proficiency also perceived intolerance toward them by physicians and staff. Inability to communicate occurs not only with language

discordance, but also as a result of cultural differences, misunderstandings, and differences in literacy levels (Andrulis, 2003). Health-care providers who do not enlist the assistance of trained interpreters risk a variety of miscommunications related to medications, instructions, and follow-up (Andrulis).

Although language can be a barrier to effective communication, the ability to speak the same language is only one part of communication. As Mullins, Blatt, Gbarayor, Yang, and Bauquet (2005) point out, diverse ethnic groups may have various inclinations for sharing health information, asking questions, and sharing concerns. The ability to share information and ask questions is vital in the communication process between health care providers and their patients.

Inadequate health literacy has been implicated in increased hospitalizations, medication errors, poor compliance, inability to manage chronic diseases such as diabetes, and premature death (Mullins et al., 2005; Safeer & Keenan, 2005). Persons with diabetes and low health literacy have poorer glycemic control and greater incidence of ophthalmic complications (Safeer & Keenan). Low health literacy among persons with diabetes poses a major barrier to both the health-care provider and the affected individual with regard to education and self-management. Despite low health literacy levels exhibited by many ethnic minorities, diabetes education can improve self-management and glycemic control. The challenge lies in providing culturally and linguistically appropriate educational materials.

While a health literacy screening tool was not used in this study, the health-care provider might consider using one of several screening tools to determine clients' health literacy abilities. Two screening tools currently available to assess health literacy are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy of Adults (TOFHLA). According to Safeer and Keenan (2005), approximately one-half of adults are

unable to understand printed health-care materials, and approximately 90 million adults have fair to poor literacy.

Studies (Lurie & Dubowitz, 2007; Mullins et al., 2005) suggest that limited English proficiency and low health literacy contribute to limited use of provider services. Ethnic minorities who also are insured are less likely to enter the health-care system and establish a regular health-care provider when faced with cultural and linguistic barriers.

According to the Office of Minority Health (OMH) in the U.S. Department of Health and Human Services, all persons entering the health-care system, regardless of race or ethnicity, are entitled to culturally and linguistically appropriate health care. *The National Standards for Culturally and Linguistically Appropriate Services in Health Care* (CLAS) (OMH, 2001) is a required guideline for federally funded health-care providers. The first four standards of CLAS refer to linguistic access: all patients must receive culturally and linguistically appropriate care; health-care providers must have diverse staff; staff must receive cultural and linguistic training to care for diverse populations; and bilingual or interpreter services must be available (Barr & Wanat, 2005). By addressing language barriers and literacy levels, issues of access also are addressed.

Another barrier associated with access is receiving quality care. Participants in this study reported some type of insurance or public assistance. Although race and ethnicity should not be a factor in gaining access to health care, research has found that among specific minority groups with insurance, there was still a notable difference in utilization of health-care services (Andrulis, 2003; Lurie & Dubowitz, 2007; Mullins et al., 2005). These findings have consequences beyond the client-health-care provider relationship. For example, clients who receive care from culturally concordant providers may be more likely to receive referrals to

specialists. Additionally, ethnic minorities without health insurance may rely on the emergency department for routine care or delay seeking care until more serious health issues arise (Andrulis).

Health Promotion and Illness Prevention

Targeted educational programs are needed to help Puerto Ricans better understand the severe consequences of diabetes and to reinforce the importance of adherence to recommended medical management regimens. Traditional diabetic educational programs may have limited value among socially disadvantaged populations. In other words, educational programs need to be tailored to fit the cultural preferences of a client (Glazier, Bajcar, Kennie, & Wilson, 2006). When English is the client's second language, both spoken and written instruction should be in the preferred language. The health-care provider should allow ample opportunity for the client and family members to ask questions and seek clarification. Although follow-up care seems costly in an era of managed care, even a 1% drop in the HgbA1c of a diabetic patient has been associated with a 10% reduction in diabetes complications, resulting in an overall cost saving (Glazier et al.). Lastly, media educational campaigns in diverse languages should focus on prevention and control of diabetes. Among Latinos, prevention is not readily appreciated, so the emphasis must be placed on the cost of benefit as well as lifestyle modifications that can prevent the onset of a particular condition.

Community Outreach

To improve their access to care, targeted efforts must be undertaken to enroll eligible Puerto Ricans in Medicaid and Medicare programs. Insurance coverage may partially eliminate the health-care disparity; however, it does not guarantee access to care, which is a significant disparity among Latinos (Lurie & Dubowitz, 2007). Improving access to care and promoting

better health outcomes mandates recruiting and educating Puerto Ricans to serve as lay diabetes education specialists in their communities (Hosler & Melnik, 2005).

Considering the prevalence of diabetes among Puerto Ricans, one becomes concerned that so little research has been conducted to identify strategies to improve their outcomes. Health-care providers educated in the biomedical model may not realize the significance and cultural meaning that Puerto Ricans ascribe to the diagnosis of diabetes and the meaning of this condition in their day-to-day lives. Moreover, health-care providers may not recognize that certain culturally based phenomena, such as familism, perception of disease severity, provider concordance, and depression, may serve as barriers to care and may be partially responsible for the poor health outcomes in this population. There is a need to eliminate the disparate views on these phenomena held by health-care providers and Puerto Ricans with diabetes.

Limitations

This exploratory descriptive study has several limitations inherent in the methodology that was used. First, the findings have limited generalizability since the sample of twelve was purposeful and representative of Puerto Ricans with diabetes mellitus who live in South Florida. The cultural heritage of the investigator and the data collection being carried out by a single investigator could potentially reflect a restricted view about the phenomena of interest. Finally, there may be an inherent bias associated with purposeful recruitment efforts in one particular geographical area and from the clinic of one Puerto Rican physician. If the study were implemented in another setting, or with other providers, the findings might be different as well.

Recommendations

To help health professionals respond effectively to the cultural preferences of the Puerto Rican clients with a diagnosis of diabetes, the following recommendations are offered for health-care providers, nurse educators, policy makers, and researchers:

For Health-Care Providers

- Allow time in the initial meeting to establish rapport with the client and the family
- Determine the preferred level of family involvement in decision-making
- Involve key family members in the discussions about recommended treatment protocols
- Explore the meaning and impact of diabetes to the client and his or her family members
- Assess for level of social support and potential mental health symptoms as a part of routine follow-up care
- Ascertain the client's level of health literacy

- Learn about the cultural preferences of clients
- Recognize and manage biases and attitudes
- Make available ethnic-concordant caregivers who can effectively and accurately interpret conversations and translate written materials
- Design care plans for clients that include health promotion and illness preventive measures such as eye and foot examinations
- Commit to developing a diverse health professional work force, in particular, among the nursing profession

For Nurse Educators

- Empower clients and families through education to make better health-related decisions
- Design and implement individualized diabetes educational materials and programs that fit individual needs and preferences (e.g., cultural phrases, a range of graphics).
- Provide underrepresented minorities in the health-care fields with the resources to better educate their target populations
- Utilize key community informants to assist in designing, implementing, and evaluating educational programs
- Incorporate cultural and linguistic competence into nursing curricula to raise awareness about the impact of culture and language on health-care delivery
- Design systems to enhance communication among multiple providers to ensure consistency of care

For Legislative and Community Policy Makers

- Support federal, state, local, and community level initiatives such as
 - National Council of La Raza; Institute of Hispanic Health
 - Community Health Care Initiatives that provide community members' affordable health insurance.
- Increase funding to schools of nursing to provide stipends for students preparing to become Advanced Practice Nurses with the stipulation they meet the needs of the underserved populations
- Make health care accessible to underserved populations; e.g., enroll qualifying individuals into Medicaid, Medicare and other publicly funded entitlement programs such as State Children's Health Insurance Plan (SCHIP)
- Enforce the implementation of the Culturally and Linguistically Appropriate Services (CLAS) standards by developing a comprehensive mechanism to provide oversight and assistance to local providers who provide care in ethnic minority locations
- Support initiatives that address health disparities, in particular, the growing incidence and prevalence of diabetes among Latinos as discussed in Healthy People 2010

For Nursing Research

There are numerous opportunities for nurse researchers generated from the findings of this study. Nursing research is needed:

- To better understand the personal explanatory models of diabetes among this cultural group
- To understand the association between acculturation and decision-making relative to health-care seeking behaviors

- To understand diabetes and self-care decision-making processes among Puerto Ricans
- To identify the mediators and moderators that contribute to perception of disease severity
- To identify culturally appropriate strategies to motivate individuals to become more involved in their personal diabetes management
- To explore ways to reduce literacy-related disparities
- To examine the possible relationship between depression and glycemic control
- To examine the use of the Short Acculturation Scale (SAS) as a predictor of health literacy
- Finally, to examine the cultural phenomena of interest in this study with other Latino groups or Puerto Ricans living in other regions of the U.S.

In conclusion, there is much to be gained through the use of narrative inquiry, which can greatly contribute to current nursing research and health care. The participants in this study, namely Puerto Ricans with diabetes who live in South Florida, allowed the investigator a glimpse into their reality. Although the themes that emerged are revealing, more in-depth research is needed to fully understand the perspectives and motivations of this subgroup of Latinos.

APPENDIX A: FLIER ENGLISH

Care Seeking Behaviors of Puerto Ricans with Diabetes Mellitus in South Florida



Are you Puerto Rican, do you have diabetes? if so, would you like to participate in a study that looks at the “Care Seeking Behaviors of Puerto Ricans with Diabetes”.

If you are over the age of 18 years old, with no recent hospitalizations (less than 6 months), can read English you can participate. The study requires an **audiotaped interview (entrevista)** and **(2) brief Paper & Pencil forms**.

All responses will be confidential. Interviews will last approximately 1-2 hours. Interviews will be held in a convenient location. There is **NO risk, to your care or follow up**.

If you are interested please contact LAURA GONZALEZ at (813) 974-8770. This study is being conducted as a dissertation requirement at the University of Central Florida, for more information you may contact Angeline Bushy PhD, FAAN at abushy@mail.ucf.edu or 386-506-4032

APPENDIX B: FLIER SPANISH

Care Seeking Behaviors of Puerto Ricans with Diabetes Mellitus in South Florida



Si usted es Puertorriqueño, y tienes diabetes puedes calificar en un estudio sobre los manierismos de los Puertorriqueños con diabetes.

Si usted está sobre la edad de 18 años, sin las hospitalizaciones recientes (menos de 6 meses), y puede leer inglés usted puede participar. El estudio requiere una entrevista grabada en audio y (2) breve formas del papel y del lápiz. Todas las respuestas serán confidenciales. Las entrevistas durarán aproximadamente 1-2 horas. Serán sostenidos en una localización conveniente. No hay riesgo, a usted cuida o carta recordativa. Si usted está interesado por favor entre en contacto con a **Laura Gonzalez en (813) 974-8770. Este estudio se realiza como un requisito de disertación en la Universidad de Florida Central, para más información usted puede contactar Angeline PhD, FAAN en abushy@mail.ucf.edu o el 386-506-4032.**

APPENDIX C: USF CONSENT FORMS



Informed Consent to Participate in Research

Information to Consider Before Taking Part in this Research Study

Researchers at the University of South Florida (USF) and the University of Central Florida (UCF) study many topics. To do this, we need the help of people who agree to take part in a research study. This form tells you about this research study. We are asking you to take part in a research study that is called:

Care Seeking Behaviors of Puerto Ricans Who Live in South Florida with Diabetes Mellitus

The person who is in charge of this research study is **Laura Gonzalez MS, ARNP**. The research will be done at **University of South Florida Medical Clinics and the Lifelink Transplant Institute**.

Purpose of the study

You have been asked to participate in this study, as you are Puerto Rican and have been diagnosed with Diabetes Mellitus. The purpose of this study is to understand the decisions Puerto Ricans make when caring for themselves, and to understand how Puerto Ricans feel about their doctors.

Study Procedures

If you take part in this study, you will be asked to participate in an audiotaped interview. The interview consists of 10 questions; it may last from 1-2 hours. In addition there will be 1 paper & pencil form with 14 general questions and 1 paper & pencil questionnaire with 4 questions. The audiotape interview will be held at a mutual place of convenience. We hope to enroll 14-18 participants in this study.

Alternatives

You can choose not to participate in this research study.

Benefits

We don't know if you will get any benefits by taking part in this study.

Risk or Discomfort

- There are no known risks to those who take part in this study.
- You may become tired from answering the questions.

Compensation

We will **not** pay you for the time you volunteer while being in this study.

Confidentiality

- Your records will be PRIVATE & confidential. All audiotapes will be kept confidential, immediately after they are transcribed they will be destroyed. The written transcripts will be maintained for three years. The transcripts and information will be kept in a separate locked box which only the researcher has access to. Your personal information **will not be shared with** anyone else. During the written report all personal identifiers will be removed.

However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.) These include:
 - the University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.

We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part **in this study if you want to volunteer**. You should not feel that there is any pressure to take part in the study, to please the researcher. You are free to participate in this research or stop at any time. You will not be in trouble if you decide to stop. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

Questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, call Laura Gonzalez at 813-974-8770 or email lgonzal2@hsc.usf.edu

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-9343.

If you experience an adverse event or unanticipated problem call Laura Gonzalez at 813-974-8770.

If you have questions about your rights as a person taking part in this research study you may contact the Florida Department of Health Institutional Review Board (DOH IRB) at (866) 433-2775 (toll free in Florida) or 850-245-4585.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.

- What procedures/interventions/investigational drugs or devices will be used.
- What the potential benefits might be.
- What the known risks might be.

I also certify that he or she is older than 18 years of age, and does not have any problems that could make it hard to understand what it means to take part in this research. This person speaks the language that was used to explain this research.

This person reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her.

This person does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give informed consent.

This person is not taking drugs that may cloud their judgment or make it hard to understand what is being explained and can, therefore, give informed consent.

Signature of Person Obtaining Informed Consent

Date

Printed Name of Person Obtaining Informed Consent



Consentimiento informado a participar en un estudio de la investigación
Información para considerar antes de participar en este estudio de la investigación

Investigadores en la Universidad de la Florida del Sur (USF) y la Universidad del Central de la Florida (UCF) estudian muchos asuntos. Para hacer esto, necesitamos la ayuda de la gente que acuerda participar en un estudio de la investigación. Esta forma le dice sobre este estudio de la investigación.

Estamos pidiendo que usted participara en un estudio de la investigación que se llame:

“Health care Seeking Behaviors of Puerto Ricans who Live in South Florida with Diabetes Mellitus” (Identificar cuales son los impactos sobre los decisiones del Puertorriqueno con diabetes con respeto al salud)”

La persona que está a cargo de este estudio de investigación es Laura González.

El estudio estará implementado en la **Universidad de la Florida del Sur, y el Instituto de Lifelink.**

Propósito de la investigación:

Le han pedido participar en este estudio, pues usted es Puertorriqueno y se ha diagnosticado con la diabetes mellitus. El propósito de este estudio es entender las decisiones que hacen los puertorriqueños cuando cuidan sí mismos, y entender la relación dentro los Puertorriqueños y sus médicos.

Que le pedirán hacer en el estudio:

Si usted participa en este estudio, le pedirán participar en una entrevista gravada. La entrevista consiste en 10 preguntas; puede durar a partir de 1-2 horas. Además habrá 1 forma del papel y del lápiz con 14 preguntas generales y 1 cuestionario del papel y del lápiz con 4 preguntas. La entrevista será llevada a cabo en un lugar conveniente. Esperamos alistar dentro de 14-18 participantes en este estudio.

Alternativas

Su participación en este estudio es voluntaria.

Beneficios/ Compensación

No sabemos si usted consigue cualesquiera ventajas participando en este estudio

Riesgos

- No hay riesgos anticipados asociados con el estudio.
- Usted se podrá fatigar
- No hay renumeración o ventaja directa a ud. para la participación.

Confidencialidad

- Sus expedientes será PRIVADO y confidencial. Todas las cintas magnéticas para audio serán mantenidas confidenciales, inmediatamente después que son transcrito ellas serán destruida. Las transcripciones escritas serán mantenidas por tres años. Las transcripciones y la información serán mantenidas una caja bloqueada separada a la cual solamente el investigador tenga acceso. Su información personal no será compartida con cualquier otra persona. Durante el informe escrito todos los identificadores personales serán quitados.

Sin embargo, cierta gente puede necesitar ver sus expedientes del estudio. Por ley, cualquier persona que mira sus expedientes debe mantenerlos totalmente confidenciales. La única gente se permitirá que ver estos expedientes es:

- La Investigadora principal
- Cierta gente del gobierno y de la universidad que necesita saber más sobre el estudio. Por ejemplo, los individuos que proporcionan descuido en este estudio pueden necesitar mirar sus expedientes. Esto se hace para asegurarse de que estamos haciendo el estudio de la manera derecha. También necesitan asegurar de que estemos protegiendo las sus derechas y su seguridad.
- Éstos incluyen: La Universidad de la Florida del Sur *Investigational Review Board* (IRB) y los empleados del departamento del IRB. Otros individuos que trabajan para USF que proporcionen otras clases de descuido pueden también necesitar mirar sus expedientes.

Podemos publicar lo que aprendemos de este estudio. No dejaremos cualquier persona saber su nombre. No publicaremos cualquier cosa que dejaría a gente saber quién eres. Mantendremos su confidencialismo.

Participación Voluntaria:

Su participación en esta investigación es voluntaria. No hay pena por no participar. Ud. tiene la derecha de retirarse de la investigación en cualquier momento sin pena.

Quien a entrar en contacto si ud. tiene preguntas sobre el estudio:

Si tienes preguntas sobre el estudio llame Laura González al 813-974-8770 o email lgonzal2@hsc.usf.edu

Si tienes preguntas por lo general sobre sus derechos en este estudio, o quejas come ser humano llame al *División of Research Integrity and Compliance of the University of South Florida* al (813) 974-9343.

Si usted experimenta un acontecimiento adverso o un problema llame a Laura González al 813-974-8770.

Si ud. tiene preguntas sobre sus derechos come participante en este estudio por favor comuníquese con el Florida Department of Health Institutional Review Board (DOH IRB) al (866) 433-2775 (toll free in Florida) or 850-245-4585.

Forma Informada del Consentimiento

Está hasta usted para decidir si usted desea participar en este estudio. Si usted desea participar, satisfacer la muestra la forma, si las declaraciones siguientes son verdades.

Doy libremente mi consentimiento para participar en este estudio. Entiendo que firmando esta forma estoy acordando participar en la investigación. He recibido una copia de esta forma para tomar con mí.

Firma de la persona que participa en estudio

Fecha

Deletrea el nombre de la persona que participa en este estudio

Declaración de la persona que obtiene consentimiento informado:

He explicado cuidadosamente a la persona que participaba en el estudio qué él o ella puede esperar. Certifico por este medio eso cuando esta persona firma esta forma, al mejor de mi conocimiento, él o ella entiende:

- De lo que se toma el estudio
- Qué procedimientos serán utilizados
- Qué las ventajas potenciales pudieron ser.
- Qué los riesgos sabidos pudieron ser.

También certifico que él o ella es tiene mas de 18 años de edad. No tiene ningún problema que podrían hacerla difícil entender lo que significa participar en esta investigación. Esta persona habla la lengua que fue utilizada para explicar esta investigación.

Esta persona lee bastante bien para entender esta forma o, si no, esta persona puede oír y entender cuando la forma se lee a él o a ella.

Esta persona no tiene un problema medico o psicológico que comprometería la comprensión para entender difícilmente qué se está explicando y puede, por lo tanto, dar consentimiento informado.

Esta persona no está tomando las drogas que pueden nublarse su juicio o hacerlo duro entender qué se está explicando y puede, por lo tanto, dar consentimiento informado.

Firma de la persona obteniendo la forma del consentimiento

Fecha

Deletrea de la persona obteniendo la forma del consentimiento

APPENDIX D: UCF CONSENT FORMS

Informed Consent

Please read this consent document carefully before you decide to participate in this study.

You must be 18 years of age or older to participate.

Informed Consent Form

Project title: CARE SEEKING BEHAVIORS OF
PUERTO RICANS WITH DIABETES MELLITUS WHO LIVE IN SOUTH FLORIDA

Purpose of the research study: This study will specifically try to identify what impacts Puerto Ricans with diabetes mellitus decisions' regarding their health care. The study will look at **FAMILISMO, RELIGION, MEDICINA CASERA/CURANDERISMO**. In addition, this study will explore the phenomena of acculturation relative to care seeking behaviors. The research questions emerged from the literature review and the PI personal experience.

What you will be asked to do in the study: You will be interviewed and audiotaped. In addition, you will be asked to complete (2) paper pencil questionnaires. One has 4 questions, and the second has 14 questions.

Time required: One (1) hour- two (2) hours

Risks: There are **No** anticipated risks associated with this study. After subjects consent to participate, they will complete two pencil and paper forms, the demographic form and the Short Acculturation Scale (SAS). The data collection process will involve **audiotaping of semi-structured interviews**. If participants become fatigued during the interview, they have the option to discontinue the interview or return to complete at a later date. Participants' anxiety may increase if they perceive the interview questions as personal and intrusive. Participants will be assured by the Co-PI of the confidential nature of their responses. Attempts will also be made to reassure participants that their responses will in no way impact their current or future health care. Overall, respondent burden is minimal.

Benefits/Compensation: **There is no compensation** or other direct benefit to you for participation.

Confidentiality: **Your identity will be kept confidential.** Your information will be assigned a code number. All audiotapes will be transcribed immediately after transcription the audiotapes will be destroyed. All transcripts will be kept in a locked cabinet at the University of South Florida, where only the Co-PI will have the key.

Voluntary participation: Your participation in this study is voluntary. **There is no penalty for not participating.** You have the right to withdraw from the study at any time without penalty.

Whom to contact if you have questions about the study: Laura Gonzalez, Doctoral Student, College of Nursing, College of Health and Public Affairs, (813) 974-8770 Dr. Angeline Bushy PhD, FAAN, Faculty Supervisor, Professor and Bert Fish Chair, Daytona Beach (386) 506-4032

Whom to contact about your rights in the study: Information regarding your rights as a

research volunteer may be obtained from:

IRB Coordinator

Institutional Review Board (IRB)

University of Central Florida (UCF)

12201 Research Parkway, Suite 501

Orlando, Florida 32826-3246

Telephone: (407) 823-2901

☐ I have read the procedure described above.

☐ I voluntarily agree to participate in the procedure.

☐ I am at least 18 years of age or older.

_____/_____
Participant Date

_____/_____
Principal Investigator Date

Forma informada del consentimiento

**Por favor lee este documento con cuidado antes de decidir participar en la investigación.
Tienes que tener por lo menos más de 18 años de edad para participar.**

Informed Consent Form (Forma informada del consentimiento)

Título de propósito: Identificar cuales son los impactos sobre los decisiones de Puertorriqueno con diabetes con respeto a su salud.

Propósito de la investigación: El estudio mirara **FAMILISMO, RELIGION, MEDICINA CASERA/CURANDERISMO**. Además este estudio explorara el concepto de la aculturación. Las preguntas de la investigación emergieron de la revisión de la literatura y de la experiencia del investigador primaria.

Que le pedirán hacer en el estudio: Ud. será entrevistado con audio, además le pedirán terminar (2) cuestionarios de papel y lápiz. Uno contiene 4 preguntas, y el segundo tiene 14 preguntas.

El tiempo requirió: Se demora dentro de 1-2 horas máximo

Riesgos: No hay riesgos anticipados asociados con el estudio. Después que lo sujetos consienten participar, terminaran dos formas del lápiz y papel, la forma demográfica y la escala corta de la aculturación (SAS). El proceso de colección de datos implicara en audiotape de entrevistas **semi-estructuradas**. Si los participantes se fatigan durante la entrevista tienen la opción de terminar la entrevista o continuar en una fecha mas ultima. La ansiedad de los participantes puede aumentar si perciben las preguntas de la entrevista como personales o intrusas. La investigadora de la naturaleza confidencial de sus respuestas asegurara a los participantes. Intentos serán hechas para tranquilizar participantes que sus respuestas no tenga ningún impacto de la manera de su salud este en riesgo. En total la carga del responder es mínima **Benefits/Compensación: No hay remuneración o ventaja directa a ud. para la participación.**

Confidencialidad: Su identidad será mantenida confidencial. Su información será asignada un número de código. Todas las cintas magnéticas de audio serán transcritas inmediatamente después de las entrevista. Las cintas de audio serán destruido. Todas las transcripciones serán mantenidas en un gabinete bloqueado en la Universidad de la Florida del Sur, donde solamente la investigadora tendrá la llave.

Participación Voluntaria: Su participación en esta investigación es voluntaria. No hay pena por no participar. Ud. tiene la derecha de retirarse de la investigación en cualquier momento sin pena.

Quien a entrar en contacto con si ud. tiene preguntas sobre el estudio: Laura Gonzalez, Doctoral Student, College of Nursing, College of Health and Public Affairs, (813) 974-8770 Dr. Angeline Bushy PhD, FAAN, Faculty Supervisor, Professor and Bert Fish Chair, Daytona Beach (386) 506-4032

Quien a entrar a contacto sobre sus derechos del estudio: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF). For information about participants' rights please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 O por teléfono al (407) 823-2901.

- ☐ Leí el procedimiento descrito
- ☐ Estoy de acuerdo voluntariamente participaré.
- ☐ Tengo por los menos 18 años de edad.

_____ / _____

Participante

Fecha

_____ Estoy de acuerdo, y consiento ser grabada vía audio

Participante

Fecha

Principle Investigator

Date

APPENDIX E: DEMOGRAPHIC INFORMATION FORM

Care Seeking Behaviors of Puerto Ricans with Diabetes

Who Live in South Florida

DEMOGRAPHIC INFORMATION

Directions: please choose the answer that best describes you. If you have questions please direct them to the investigator.

1. Age: _____

2. Marital Status: ☐ single ☐ married ☐ divorced
☐ widowed

3. Living Arrangements: ☐ Alone ☐ With Someone

4. Employment: ☐ Employed
☐ Unemployed
☐ Disabled
☐ Retired

5. Education
☐ Elementary school only ☐ High school/GED ☐ Some college
☐ Bachelor's degree ☐ Post graduate degree

6. Annual Household Income: ☐ under \$25,000
☐ \$25,001-\$50,000
☐ \$50,001-\$75,000
☐ >75,001

7. Were you born in Puerto Rico? ☐ yes ☐ no

8. If so, when did you come to the United States (years) _____

9. How long have you had diabetes mellitus? (years) _____

10. How often do you see your health care provider? ☐ weekly ☐ monthly ☐ yearly
☐ as needed

11. Do you know your HgbA1C? _____

12. Have you been hospitalized within the last six months because of your diabetes? ☐ yes ☐ no

13. Does your health care provider speak Spanish? ☐ yes ☐ no

14. Do you have health insurance? ☐ yes ☐ no, If yes what type _____

15. Do you have a religious affiliation ☐ yes ☐ no, if so please identify _____

If I have any further questions, do I have your permission to contact you at the numbers above?

☐ yes ☐ no

☐ Home ☐ Cell ☐ Work

APPENDIX F: SHORT ACCULTURATION SCALE (SAS)

Care Seeking Behaviors of Puerto Ricans with Diabetes Who Live in South Florida

Short Acculturation Scale (SAS)

Directions: Please choose the answer that best describes you. If you have any questions direct them to the investigator

1. In general, what language do you read and speak?
 1. Only Spanish
 2. Spanish better than English
 3. Both equally
 4. English better than Spanish
 5. Only English

2. What language do you usually speak at home?
 1. Only Spanish
 2. Spanish better than English
 3. Both equally
 4. English better than Spanish
 5. Only English

3. In which language do you usually talk?
 1. Only Spanish
 2. Spanish better than English
 3. Both equally
 4. English better than Spanish
 5. Only English

4. In which language do you usually speak with your friends?
 1. Only Spanish
 2. Spanish better than English
 3. Both equally
 4. English better than Spanish
 5. Only English

Marin, G., Sabogal, F., Van-Oss-Marin, B., Otero-Sabogal, R., Perez-Stable, E. (1987). Development of a SAS for Hispanics. *Hispanic Journal of Behavioral Sciences*. 9(2) 183-205.

APPENDIX G: INTERVIEW GUIDE ENGLISH

Care Seeking Behaviors of Puerto Ricans with Diabetes Mellitus Who Live in South Florida

Interview Guide

Purpose 1: Explore cultural beliefs regarding care seeking by Puerto Ricans with diabetes.

Care seeking

1. When you are ill, describe from whom do you *first* seek health care?
2. Describe the role your *family* plays in assisting you to make health care decisions?
3. Tell me about the type of *spiritual guidance* you seek when you are ill and/or not feeling well?
4. Tell me about *ethnomedicine* and caring for yourself, how do you discuss this topic with your health care provider?
5. Tell me what caused your diabetes?

Purpose 2: To examine patients' perceptions regarding their caregivers' beliefs about Puerto Ricans.

Expectations of provider

1. Tell me about treatment decisions you have made regarding your health care?
2. How does your health care provider make you feel involved in your care?
3. How satisfied or dissatisfied are you with the care you receive from your health care provider?
4. How does your health care provider demonstrate to you that he or she understands your culture?
5. How does your health care provider encourage you to share your concerns?

APPENDIX H: INTERVIEW GUIDE SPANISH

Health care Seeking Behaviors of Puerto Rican with Diabetes Mellitus Who Live in
South Florida: Versión en Español

Purpose 1: El buscar de cuidado

1. ¿Cuándo usted es enfermo, describe de quién solicita su cuidado de salud inicialmente?
2. ¿Describa el papel que juega la familia en asistirle para tomar decisiones sobre su salud?
3. ¿Dígame sobre el tipo de dirección espiritual que usted busca cuando usted es enfermo y/o no se sienten bien?
4. ¿Dígame sobre remedios caseros que ud. ha usado para su diabetes, cómo usted discute este asunto con su médico o proveedor (a) de salud?
5. ¿Dígame qué causó su diabetes?

Purpose 2: Expectativas del médico o proveedor (a) del salud

1. ¿Dígame sobre decisiones del tratamiento médico que usted ha tomado con respecto a su salud?
2. ¿Cómo su médico o proveedor(a) de salud le hace sentir implicada en su cuidado?
3. ¿Cómo satisfecho o descontentado es usted con el cuidado que usted recibe de su médico o proveedor(a) de salud?
4. ¿Cómo su médico o proveedor(a) de salud demuestra a usted que él o ella entiende su cultura?
5. ¿Cómo su médico o proveedor(a) de salud solicite sus preocupaciones?

APPENDIX I: UCF IRB APPROVAL LETTER



Office of Research & Commercialization

January 9, 2007

Laura Gonzalez
14816 Farnham Way
Tampa, FL 33624

Dear Ms. Gonzalez:

With reference to your protocol #06-4008 entitled, "Care Seeking Behaviors of Puerto Ricans with Diabetes Mellitus Living in South Florid," I am enclosing for your records the approved, expedited document of the UCFIRB Form you had submitted to our office. **This study was approved on 1/09/2007. The expiration date for this study will be 1/08/2008.** Should there be a need to extend this study, a Continuing Review form must be submitted to the IRB Office for review by the Chairman or full IRB at least one month prior to the expiration date. This is the responsibility of the investigator.

Please be advised that this approval is given for one year. Should there be any addendums or administrative changes to the already approved protocol, they must also be submitted to the Board through use of the Addendum/Modification Request form. Changes should not be initiated until written IRB approval is received. Adverse events should be reported to the IRB as they occur.

Should you have any questions, please do not hesitate to call me at 407-823-2901.

Please accept our best wishes for the success of your endeavors.

Cordially,

A handwritten signature in cursive script that reads "Joanne Muratori".

Joanne Muratori
UCF IRB Coordinator
(FWA00000351 Exp. 5/13/07, IRB00001138)

Copies: IRB File
Angeline Bushy, Ph.D.

JM:jm

APPENDIX J: USF IRB APPROVAL LETTER



January 11, 2007

Laura Gonzalez, MS, ARNP
College of Nursing
MDC 22

RE: **Expedited Approval** for Initial Review

IRB#: 105335

Title: *Care Seeking Behaviors of Puerto Ricans with Diabetes Mellitus Living in South Florida*

Study Approval Period: January 10, 2007 to January 9, 2008

Dear Ms. Gonzalez:

On January 10, 2007, Institutional Review Board (IRB) reviewed and **APPROVED** the above protocol **for the period indicated above**. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number 6 and 7. Your informed consents & advertisements in, English & Spanish, were also approved along with the (English) questionnaire.

Please note, if applicable, the **enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form**. Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities in the conduction of human participant research. Please read this guide carefully. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

OFFICE OF RESEARCH • DIVISION OF RESEARCH INTEGRITY & COMPLIANCE
INSTITUTIONAL REVIEW BOARDS, FWA No. 00001669
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

APPENDIX K: IRB COURSE COMPLETION CERTIFICATE



Completion Certificate

This is to certify that

laura gonzalez

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 09/09/2004.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health
<http://www.nih.gov>

APPENDIX L: CURRICULUM VITA

Laura González MS, ARNP, Doctoral Candidate

Home:

14816 Farnham Way
Tampa Florida 33624
(813) 961-2562
(813)601-8588

Office:

University of South Florida
College of Nursing
12901 Bruce B.Downs Blvd.
HSC, Box 36
Tampa, Florida 33612

AREAS OF RESPONSIBILITY

2007-2008

Undergraduate Council Committee Appointment
Director of Virtual Simulation and Clinical Excellence
Co-Coordinator of Medical Surgical Nursing Curriculum
Chair of Student Affairs Committee

2006

Director of Virtual Simulation and Clinical Excellence
Coordinator of Medical-Surgical Program

2005

Coordinator of Medical-Surgical Program CON
Tampa General Clinical Team Faculty Instructor
ARC Stream /PACES Liaison
PCIS Liaison
Simulation Grant
Online Pathophysiology 3125
Student Affairs Committee

2004

Nur 4838 Leadership and Management in Professional Nursing
Medical-Surgical Nursing Clinical Faculty
Tampa General Clinical Team

EDUCATIONAL PREPARATION

<u>Institution</u>	<u>Degree/ Major</u>	<u>Year</u>
University of Central Florida College of Nursing	Ph.D.	2008 (in progress)
University of South Florida	M.S.N.	1996

College of Nursing	Adult Health ARNP	
Hunter College Bellevue School of Nursing N.Y., N.Y.	B.S.N.	1989

HONORS & AWARDS

Spirit of Nursing Award		2006 Summer
NCEMNA Mentee Award		2006 March
Deans Award for Faculty Excellence Ted & Marty Couch Award		2005 May
Phi Kappa Phi University of Central Florida Chapter		2005 May
Leadership in Nursing Award Summer 2003 Convocation		2003 July
Sigma Theta Tau		1989

POSTER PRESENTATIONS

National Association Hispanic Nurses Decision making Preferences of Latinos with Diabetes Scottsdale, Arizona		2006 July
National Association Hispanic Nurses Locus of Authority: Hispanics with Diabetes Mellitus Orlando, Florida		2005 July
Southern Nursing Research Society Human Agency in Nursing Louisville, Kentucky		2005 Feb.
Southern Nursing Research Society Puerto Ricans with Diabetes Mellitus: A Health care Disparity		2004 Feb.

PRESENTATIONS

Diabetes in the Older Population USF/AHEC Joint presentation		2005 Apr.
AACN Critical Care Lecture Series		

Renal Pathology	2000 Oct.
AACN Critical Care Lecture Series	
Renal Pathology	
Endocrine Pathology	
Triage	
Management of the Overdose	2001 May
AACN Critical Care Lecture Series	
Renal Pathology	
Endocrine Pathology	2001 Oct.
AACN Critical Lecture Series	
Renal Pathology	
Endocrine Pathology	2002 May
Management of Acute MI	
Sponsored by Genentech	2002 May
AACN Critical Care Lecture Series	2002 Oct.
Triage Course for UCH ED	2003 Aug.

RESEARCH GRANTS

Immersive Virtual Reality in Critical Care Education for Nursing Students

Start date: July 2005	\$15,000
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PROFESSIONAL EXPERIENCE

<u>Position and Title</u>	<u>Employer</u>	<u>Dates</u>
Director of Virtual Simulation And Clinical Excellence	University of South Florida	2006-current
Coordinator	University of South Florida	2004-current
MS Program Instructor	University of South Florida	2003-current
Visiting Instructor	University of South Florida	2002-2003

Nurse Manager Emergency Department Clinical Nurse Specialist Emergency Department	University Community Hospital	2001-2002
	University Community Hospital	1999-2001
ARNP	Lakeside Occupational Medical Center	1997-1999
ARNP	Lifelink Transplant Services	1996-1997
Staff Nurse/ Relief Charge Nurse	St. Joseph's Hospital	1989-1995
Paramedic Instructor	Hillsborough Community College	1994-1995
Nurse Educator	St. Joseph's Hospital	1994-1996
Staff Nurse	University Community Hospital Carrollwood Campus	1990-1995

LICENSURE & CERTIFICATION

Florida- ARNP active

BLS provider

ACLS provider

Member of NCSBN NCLEX Examination Board

PROFESSIONAL MEMBERSHIPS & ACTIVITIES

NCEMNA	2006-current
National Association for Hispanic Nurses	2003-current
Southern Nursing Research Society	2003-current
Patient Identification Task Force	
Chair Person	2001-2002
Presented findings to JCAHO	September 2002
Emergency Nurses Association	1990-current
Sigma Theta Tau	1989-current

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