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# An Exploration of the Culture Care Experiences of Puerto Rican Families with a Child with Special Health Care Needs as Perceived by the Family Caregiver

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AN EXPLORATION OF THE CULTURE CARE EXPERIENCES OF PUERTO RICAN  
FAMILIES WITH A CHILD WITH SPECIAL HEALTH CARE NEEDS AS PERCEIVED BY  
THE FAMILY CAREGIVER

A Dissertation

Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirement for  
the degree of Doctor of Philosophy

By

Karen S. Rousseau

December 2015

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Karen S. Rousseau

2015

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Approved November 3, 2015

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## ABSTRACT

# AN EXPLORATION OF THE CULTURE CARE EXPERIENCES OF PUERTO RICAN FAMILIES WITH A CHILD WITH SPECIAL HEALTH CARE NEEDS AS PERCEIVED BY THE FAMILY CAREGIVER

By

Karen S. Rousseau

December 2015

Dissertation supervised by Dr. Richard Zoucha

Advances in medical care have resulted in rising numbers of children living with chronic illness. Nurses care for families with special needs during all aspects of their care from the office visit, the inpatient stay, and in the home. Therefore, nurses need to be highly skilled and sensitive to the families' cultural needs in order to assist with coping and the daily challenges they face. This study explored the culture care experiences of Puerto Rican families with a child with special health care needs as perceived by the family caregiver. This family member is the individual who has the greatest amount of interaction with the health care system and is most intimately involved in the care of the special health care needs child. Interviews with the family caregiver, using a self-developed semi-structured interview guide explored the culture care experiences of the family caregiver. The Culture Care Diversity and Universality Theory guided

the study and Leininger's four phases of data collection and analysis was implemented. A sample of 16 general and 8 key informants were interviewed and data was organized and managed using NVIVO 10.0 software. The findings included the identification of 14 categories, and 5 patterns from which emerged the themes of: 1) The family caregiver describes the of burden of care, 2) the family caregiver perceives caring behaviors as attentiveness and respect, and 3) the family caregiver's feelings of responsibility for the child creates fear and uncertainty in their ability to meet the child's needs. The themes indicate that nurses must ensure the development of a trusting, respectful therapeutic relationship with the caregiver and the child in order to promote confidence in the caregiver as well as decrease stress and anxiety levels.

## DEDICATION

First, this study is dedicated to all those families who have a child with special care needs and in particular the informants of this study. It was amazing how willing they were to give voice to the level of anxiety and stress they experience related to supporting and nurturing their child and their family. Hopefully some of the insight gained through this study will help to ease their burden to some extent.

I also dedicate this study to my husband Jean, and my daughters Deanna and Dominique. Their support and understanding throughout my journey has not been without sacrifice on their part. They are central to my focus and my vision for our future and I hope they know how much their love and support means to me every day. I learned from my father, Gary Somers, how important it is to set goals and to continue to work towards them and I hope my girls have learned this lesson from me as well.

## ACKNOWLEDGEMENT

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## CHAPTER 1

### INTRODUCTION AND BACKGROUND

#### 1.1 Introduction

The Data Resource Center for Child and Adolescent Health reported that 19.8% or 14.6 million children have special health care needs (SHCN) (2011). The prevalence of children with special health care needs in Massachusetts is reported to be 18.3% or 261,475 (Child and Adolescent Health Measurement Initiative 2012). Further, The Center for Community Based Services (2013) reported that 14.4% of children with English speaking Hispanic ethnicity have some type of special health care needs. The profession of nursing is committed to including cultural considerations in the care of people. This is documented in a number of statements by a variety of nursing organizations including the American Nurses Association (ANA, 1991), the National League of Nurses (NLN, 1979), and the American Academy of Nurses (AACN, 1995; Meleis *et al.*, 1995). Therefore, it is crucial that nurses gain a full understanding of the culture care needs of Puerto Rican families with a child with special health care needs.

Nurses must provide culturally congruent care in order to promote optimal levels of health. The domain of inquiry for this proposed ethnonursing study was the culture care experiences of Puerto Rican families with a child with special health care needs from the perspective of the family caregiver. The Culture Care Diversity and Universality Theory and the ethnonursing method was used to guide this ethnonursing to explore the emic (insider's) views. Discovery of the culture care experiences of Puerto Rican families through the eyes of the family caregiver lead to insight into the provision of culturally congruent nursing care for this group.

The findings from this study were intended to promote nurses' understanding of the culture care needs of Puerto Rican families with children with special health care needs.

## 1.2 Background and Rationale for Study

There are approximately 14.6 million children suffering from at least one chronic health condition and who have special health care needs (Data Resource Center for Child, and Adolescent Health, 2012). The Child and Adolescent Health Measurement Initiative (CAMHI) (2011) described the conditions associated with Children with Special Health Care Needs (CSHCN) to include breathing problems such as asthma (46.5%); ; attention-deficit and attention-deficit/hyperactivity disorder (32.2%); depression, anxiety, or emotional problems (42.9%); and migraine or frequent headaches (29%). As stated previously, there was an estimated 19.8% of children ages zero to seventeen had a special health care need. The results of this survey showed an increase of 5.8% from the previous data collection in 2010 (CAHMI 2012).

Children with special health care needs are reported to represent an important underserved population (AHRQ, 2003; Federal Interagency Forum on Child and Family Statistics, 2007; Van Dyck *et al.*, 2004). Approximately 14.4% of Hispanic children living in English speaking households, and 8.2% of Hispanic children living in non-English speaking household, experienced some type of special health care need (National Center for Community-Based Services, 2013). Families of Hispanic children with special health care needs (SCHN) are 24.8% more likely than non-Hispanic white children (20.7%) to report they have one or more unmet need for healthcare services (Bronheim, Soto & Bruno, 2015). Many children with disabling conditions face discrimination in obtaining services due to the lack of availability, lack

of trust by the family, as well as lack of cultural sensitivity and understanding by health care professionals (Pachter, Bernstein, Szalcha, & Garcia, 2010; Pachter & Coll, 2009; Eddey & Robey, 2005; Robinson & Rathbone, 1999). The National Health Care Disparity Report demonstrated that racial, ethnic, and socioeconomic disparities are national problems that affect health care of children with all medical conditions (AHRQ, 2010). Concern over these disparities resulted in initiatives by various organizations including the American Academy of Pediatrics' (AAP, 2011), and the U.S. Health Resources Services and Administration (HRSA, n.d.). The initiatives were and still are aimed at promoting access to care for families of special health care needs children, including families of diverse ethnic and racial backgrounds. Specifically, the American Academy of Pediatrics promotes the Medical Home Initiative, a national program focusing on the provision of family-centered care through developing a trusting partnership with families, respecting their diversity (American Academy of Pediatrics, 2011). Thus, it is crucial that nurses work to minimize health disparities and barriers to care for groups such as Puerto Rican families with children with special health care needs.

Learning to live with a chronic illness is one of the greatest challenges a family can face (Rehm, 2000). Fear worry and concern over the ability to adequately care for a child with special care needs is part of the family's daily routine and sets the family apart from the mainstream families with *normal healthy* children. As the number of children with special health care needs as well as the complexity of their health care increases, it becomes imperative that nursing continue to explore the culture care experiences of their families. The family caregiver is identified as a key source of information related to the provision of day to day care for the child with special health care needs. Additionally, the family caregiver is most often the family

member who assumes responsibility for the care of the child and is anticipated to have the greatest level of interaction with the health care system. Nursing must continue to build on the body of knowledge related to family responses to health and illness (Feetham & Deatrck, 2002). This should begin with a clear understanding of the culture care needs of families with a child with special health care needs from the perspective of the family caregiver. Flores (1998) in a review of the literature found multiple sources of barriers to care for Latino children. Since that time the United States population demographics have continued to change to reflect a growing population of Latinos, totaling 50.5 million or 16% of the total population (U.S. Census, 2010). The census data shows an increase of 36% increase in the population of Puerto Ricans, rising to 4.6 million, with approximately 31% of the population as uninsured. The prevalence of special health care needs among Latino children varies substantially, depending on whether English or Spanish is the primary language spoken at home. Overall, the prevalence of Hispanic children is 11%; the majority of this percentage varies based on language. Approximately 14.4% of Hispanic children from English speaking families, which is similar to the rates in Caucasian families, while 8.2% of Spanish speaking families have children with SCHN (HRSA 2010). Discovery of the Puerto Rican family cultural needs is critical to planning culturally congruent care for this vulnerable population.

### 1.3 Domain of Inquiry

The domain of inquiry for this ethnonursing study was the culture care experiences of Puerto Rican families with a child with special health care needs, as viewed by the family caregiver. The family caregiver is the self-identified adult member of the family who assumes primary care responsibilities for the child. The self-identified family caregiver is intimately

involved in the day to day care and health care decision making related to the child with special care needs; thus the family caregiver is central to uncovering the phenomena related to the domain of inquiry. Nurses must learn more about how to identify and be sensitive to Puerto Rican families' culture care needs in order to help them cope and improve the health outcomes for their vulnerable children. Discovery of culture care experiences of Puerto Rican families with children with special needs through the eyes of the family caregiver can lead to an understanding how to provide culturally congruent nursing care to this population.

#### 1.4 Purpose

The purpose of this study was to apply the Culture Care Diversity and Universality Theory (CCT) in exploring the culture care experiences of Puerto Rican families with a child with special care needs from the perspective of the family caregiver. Discovery of the culture care experiences of Puerto Rican families with a child with special health care needs as perceived by the family caregiver will provide nursing insight into culturally congruent care. The overall goal of this study was to provide nursing insight using the CCT in order to hopefully decrease health disparities in this vulnerable population.

#### 1.5 Research Questions

The research questions identified for this study were: 1) What are the culture care experiences of Puerto Rican families with a child with special health care needs, as described by the primary family caregiver? 2) What is culturally congruent nursing care within the action and decision modes of CCT, as perceived by the Puerto Rican family caregiver for a child with special health care needs from the insider's (emic) view? These questions seek to address the



action and decision modes of the Culture Care Diversity and Universality Theory as defined by Leininger and McFarland (2002).

#### 1.6 Significance to nursing

The National Survey of Children with Special Health Care Needs (2010) reported that 19.8% children below the age of 18 have special care needs in the United States. The data further identified that 14.4% of children with an English speaking Hispanic ethnicity have some type of special health care needs (Center for Community-Based Services, 2013). There is currently limited knowledge about culture care needs for Puerto Rican families with a child with special health care needs. However, the targeted population was identified as a vulnerable population, at risk for health care disparities. Increased understanding of how Puerto Rican families' access care and the barriers they experience would help to minimize the risk for disparity in care. Nurses must understand how the family caregiver perceives the care their child and family receives, and how this impacts their view of health and the health care system. Although there is literature on the importance of cultural competency in the provision of nursing care, there is little research on how nursing care is viewed by different cultural and ethnic groups with a child with special health care needs, nor has there been an assessment of whether care is considered culturally congruent by the family care provider. Discovery of the culture care experiences of Puerto Rican families with a child with special health care needs as perceived by the family caregiver provides nursing insight into culturally congruent care and may reduce health disparities for this vulnerable population.

## 1.7 Theoretical Framework of the Culture Care Diversity and Universality Theory

The theory of Culture Care Diversity and Universality (CCT) provided the framework for the study and the ethnonursing method was applied as a qualitative nursing research method as a way to study the targeted nursing phenomena. Leininger (2006) developed the ethnonursing research method to help nurses systematically document and gain greater understanding and meaning of people's life experiences related to human care, health and wellbeing. Ethnonursing is a qualitative nursing research method focused on naturalistic, open discoveries, and largely inductive modes to document, describe, explain, and interpret informants' worldview, meanings, symbols, and life experiences as they bear upon actual or potential nursing phenomena (Leininger, 1997a). Thus, ethnonursing research is a people-centered methodology that is rooted in data that support informants' credible emic or insiders' knowledge and lifeways, and yet remains attentive to the etic or outsiders' understanding of factors that could influence data collection and interpretations (Leininger, 1995b, 1996, 1997a, 2001).

### 1.7. a Sunrise Enabler

Leininger developed the *Sunrise Model Enabler* (Appendix A) as a research guide for researchers in identifying culture care phenomena from a holistic perspective (Leininger & McFarland, 2002). The method requires interviews with informants, during which the researcher explores the dimensions in the model including technological, educational, religious and philosophical, economic, political & legal, kinship and social factors, as well as cultural values beliefs and lifeways, within the context of the domain of inquiry (DOI). The Sunrise Enabler assists the researcher in systematically and rigorously discover culture care

meanings, beliefs and practices of informants within their rural environmental context. The family care provider of Puerto Rican families with children with special care needs was the targeted informants and their responses were explored in order to discover insight into culture care with this group.

#### 1.7. b Decision Modes

Leininger envisioned three major modalities or decision modes to guide nursing care decisions and actions: *(a) cultural care preservations and/or maintenance, (b) cultural care accommodation and/or negotiation, and (c) cultural care repatterning or restructuring* (Leininger, 2001, p. 42). The first mode, culture care preservation and/or maintenance refers to those assistive, supportive, facilitative or enabling professional actions and decisions that help people to *retain or maintain meaningful care values and lifeways to recover from illness, or deal with handicaps or dying*. The second mode, culture care accommodation and/or negotiation refers to those assistive, supportive, facilitative, or enabling creative professional actions and decisions that help people *adapt to or negotiate with others for meaningful, beneficial, and congruent health outcomes*. Finally, the third mode, culture care repatterning or restructuring, referred to the assistive, supportive, facilitative, or enabling professional actions and decisions that help clients to *reorder, change, or modify their lifeway for new, different and beneficial health care outcomes* (Leininger & McFarland, 2002). As a result of the application of the modes, the nurse is grounded in culture care knowledge plans for the DOI and is able to make decisions with clients with respect to the care data obtained from informants' interview responses.

### 1.7.c Phases of Ethnonursing Research Data Analysis

The ethnonursing research method is intended for data collection and analysis in relation to the CCT. The process is to begin with the identification of the domain of inquiry and then follows a distinct process as defined in Appendix B. The phases of ethnonursing data analysis provide a systematic data analysis in which data from key and general informants is coded and classified for final analysis and identification of themes. The phases include (1) collecting, describing and documenting raw data; (2) identification and categorization of descriptors and components; (3) pattern and contextual analysis; and (4) major themes, research findings, theoretical formulations and recommendations (Leininger & McFarland, chpt 3, 2002). Overall the first two phases of data analysis include data with code indicators. The researcher identifies recurrent patterns and themes in the third and fourth phases. It is in the fourth phase that the research has to reflect on the findings and synthesize them into care themes.

### 1.7.d Enablers

Leininger developed several enablers to assist in teasing out data related to culture care, health and nursing and include (1) Sunrise Model Enabler (Appendix A); (2) Leininger's Stranger to Trusted Friend (Appendix C); and (2) Leininger's Acculturation Enabler (Appendix D). The researcher uses some or all of the enablers to assist in identifying informant ideas and facts related to the domain of inquiry (Leininger & McFarland, chpt 3, 2002).

## 1.8 Orientation Definitions

The following definitions were used in this ethnonursing study to provide a focus for the discovery of meanings and practices of culture care for Puerto Rican families with children with special health care needs:

1. Care: Those assistive, supportive, and enabling experiences or ideas towards Puerto Rican families with children with special care needs who have evident or anticipated needs to ameliorate or improve a human condition or lifeway (Leininger, 2006, p. 12). It is the essence and central dominant, distinct, and unifying focus of nursing (Leininger, 2006, p. 18).
2. Culture: The learned, shared, and transmitted values, beliefs, norms, and lifeways of a Puerto Rican families with children with special care needs that guides thinking, decisions, and actions in patterns ways (Leininger, 2006, p. 13).
3. Culturally congruent care: Culturally based care, knowledge acts and decisions used in sensitive knowledgeable ways to appropriately and meaningfully fit the cultural values, beliefs, and lifeways of Puerto Rican families with children with special care needs for their health and well-being (Leininger, 2006, p. 15).
4. Culture Care: Phenomena when linked together have the ability to explain health and illness and leads to the discovery of outcomes for Puerto Rican families with children with special care needs within the Culture Care Diversity and Universality Theory (p. 13).
5. Emic: Puerto Rican families with children with special care needs, or insider's cultural knowledge and view of specific phenomena (Leininger, 2006, p. 14).
6. Etic: The outsider's or stranger's views and often health professional views and institutional knowledge of phenomena (Leininger, 2006, p. 14).
7. Child with special health care needs: A child under the age of 18 children who has or is at increased risk for a chronic physical, developmental, behavioral, or

emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson, 1998).

8. Family caregiver: The adult member of the Puerto Rican family who is considered to be the primary care provider for the child by the family (Nehring, 2007).

## 1.9 Assumptions

There are eleven assumptions defined by Leininger and McFarland (2002, chpt 2) to guide nurses in the discovery of phenomena in the application of the Culture Care Theory. The following assumptions, adapted from Leininger (2006) guided this researcher in discover of phenomena for this study:

1. Care is the essence and the central dominant distinct and unifying focus of nursing.
2. Culture care expressions, meaning, patterns, processes and structural forms among Puerto Rican families with chronically ill children are diverse but share some commonalities.
3. Culture care values, beliefs and practices of Puerto Rican families with chronically ill children are influenced by and embedded in the worldview, social structure factures and the ethno-historical environmental contexts.
4. The culture of Puerto Rican families with chronically ill children has generic (emic) and professional (etic) care to be discovered and used for culturally congruent care practices.
5. Culturally congruent care occurs when the Puerto Rican cultural values beliefs, expressions, and patterns are explicitly known and used appropriately, sensitively, and meaningfully with people of diverse or similar cultures.

6. Informants will be truthful in their responses during all interactions with the researcher (p. 20).

#### 1.10 Summary

Families with children with special health care needs are considered a vulnerable population and face health care disparities, however there is limited knowledge related to their unique needs. This study sought to discover the culture care needs for Puerto Rican families of children with special health care needs and in an effort to reveal significant findings that would be used to educate nurses and other health care providers about the provision of culturally congruent care. Additionally, this study adds to the body of transcultural nursing care knowledge and practice with Puerto Rican families with a child with special health care needs. The findings from this study should aid nurses in planning culturally congruent care for a vulnerable population.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### 2.1 The Puerto Rican Family living on Mainland United States

Puerto Rico has been a United States territory since 1898 with its people being United States citizens as of 1917. Originating as a poor agrarian community, Puerto Rico then entered into a phase of industrialization. This resulted in the establishment of a three class urban society. Puerto Rico experienced its first great wave of migration to the mainland US in between 1940-1960 with the search for employment as the primary motive for emigration (Flores 2010). High levels of unemployment in the 1970s resulted in a migration of 1.5 million Puerto Ricans to the U. S. mainland in search of employment (Acosta-Belen, 1986).

Currently, persons of Hispanic or Latino ethnicity comprise approximately 16% of the U.S. mainland population (U.S. Census, 2010). Between 2000 and 2010, the Hispanic population grew by 43%, rising from 35.3 million in 2000 to 50.5 million in 2010. Further, the Massachusetts Census Data (2013) identifies 10.5% of the population as Hispanic or Latino ethnicity. Of note however, 22.5% of the population in the targeted area of Hampden County, Massachusetts self identifies as Hispanic or Latino for census purposes (U.S. Census, 2013).

Additional analysis of U. S. Census data reveals some significant trends within the Hispanic/Latino community including that they are twice as likely as European Americans Caucasians to be unemployed, further below the poverty level. There is a higher birth rate among the Latino population, causing the overall population age range to be younger than the average, with 25% being 18 years of age or younger (U.S. Census, 2009).



### 2.1.a Puerto Rican Ethnohistory

Puerto Rico is an island between the Caribbean Sea and the North Atlantic, located approximately 1000 miles southeast of Miami (Puerto Rico 2010). Originally called Boriken, Puerto Rico was inhabited by the native peoples known as Taino until the Spaniards discovered the island during the second voyage of Columbus in 1493. The culture and lifeways of Puerto Rican families are influenced by three distinct ethnic constituents; Taino, Spanish, and African (Ambert & Figler, 1992). The Taino were the agrarian pre-Columbian Indian people of Puerto Rico. The Spanish first visited Puerto Rico in 1493 on Columbus' second journey to America. This group provided the lasting influence of the Spanish language for the people of the island. African slaves were brought to the Caribbean in 1513 and their culture was incorporated into the worldview of Puerto Ricans over time. The economy of Puerto Rico focused on agriculture for hundreds of years beginning with small farming villages and building towards large agricultural operations producing coffee and sugar. In 1898, the United States invaded Puerto Rico, during the Spanish American War (Brief History of Puerto Rico, 2000). The Foraker Act of 1901 declared the island of Puerto Rico as an un-incorporated territory or possession of the United States (Puerto Rico 2010). The status of the Puerto Rican citizens was clarified in the Jones Act of 1917 which identified the inhabitants of the island as United State citizens, although Puerto Rico remained an un-incorporated territory (Carrion, 1983). Over time, large corporations gained control of small farms and began to produce large amounts of coffee and sugar. All the while, the majority of the people of Puerto Rico lived in poor socio-economic conditions and were ignored by the United States. Operation Bootstrap, following World War II was intended to support economic development on the island (Abohadar, 1993). Industry began to grow quickly and the

per capita income rose dramatically over the next several years. Puerto Rico became the Commonwealth of Puerto Rico and adopted its own Constitution flag and seal. (Brief History of Puerto Rico, 2000). Next, Puerto Rico underwent a social and economic transformation between the ensuing years leading up to the 1970s. Increases in the population growth, and a decline in the sugar industry resulted in rising unemployment and a large migration of Puerto Ricans to the United States (Abohadar, 1993).

Many of the Puerto Ricans who migrated to the mainland United States came in search of employment, education, and a better quality of life (Juarbe, 1998). The largest numbers of Puerto Rican immigrants live in New York City, but other states with large populations of Puerto Ricans include Connecticut, Florida, Illinois, and New York. In general the migrants settle in areas where they can preserve their cultural, social, and familial wealth as well as increase their opportunities for employment and social support (Juarbe, 1998). According to the 1990 U.S. Census on Population and Housing, 2.7 million Puerto Ricans reside in the U.S., of which approximately one half are second and third generation, having been born on the mainland (Puerto Rico, 2010).

#### 2.1.b Language

English and Spanish are both the official languages of Puerto Rico; however Spanish is the dominant language in Puerto Rico (Puerto Rico, 2010). The Migration Policy Institute notes that there are 2.8 million Puerto Ricans who are not proficient in English (2011). Additionally, there are 25.4 million people living on the U.S. mainland who are not proficient in English, with the Spanish speaking population comprising 60% of this number. It is noted that Puerto Ricans are known for their friendliness and warmth during communication. Hand gestures and

movements are often used in daily conversation. Puerto Ricans tend to interrupt each other frequently, sometimes even finish the other's thought and are not upset when this occurs (Puerto Rico 2010). In contrast to many other North Americans, Puerto Ricans will stand fairly close to one another in social settings and moving away from a counterpart may be considered offensive or insulting.

Puerto Rican communication patterns are described as more indirect and non-confrontational involving more touch and are focused on establishing a relationship (Kim, Shin & Cai, 1998; Nine-Curt, 1994). Marin and Marin (1991) report that there may be a fear of disagreeing with those in power, or with those confronting them. This may be related to the cultural value of respect (*respect*), which is the need to maintain respect in social interactions with those in powerful positions (Marin & Marin).

#### 2.1.c Puerto Rican Family Values

Puerto Ricans value the family unit, and *familismo* is central to the Puerto Rican family identity (Berrios, 2003). The concept of familismo implies that the needs of the family are placed before the needs of the individual. Galanti (2003) describes *familismo* as loyalty, reciprocity and solidarity within the immediate and extended family and that there is a real interdependence and cooperation between members of families that is crucial to the family process. Juarbe, (1998) described *La familia* as the nucleus of the community and society and defined the family unit as either nuclear or extended. In general, members of the Puerto Rican family consist of parents, grandparents, great-grandparents, children, aunts, uncles, cousins, and godparents. Frequently there are also close bonds existing between among neighbors and friends. During times of illness and death, family, friends, and neighbors, will help to take care

of the sick or assist in funeral arrangements. Children are the center of the family and are very much desired and cherished (Berrios, 2003). Extended family members are expected to help care for the children, and provide support and are referred to as *compadres* (Rogler & Cloney, 1984).

Gil and Vazquez (1996) describe *machismo* as the male responsibility for the welfare and honor of the family. The wife is expected to carry out the decisions of her spouse. This cultural value or attitude changes somewhat on mainland United States, due to high rates of unemployment (Garcia-Preto, 1996). Galanti (2003) also described male-female relationships between sexes as varying a lot with age, education and amount of time in the US. *Machismo* is a term that is commonly associated with the Puerto Rican culture and it has both positive and negative connotations.

*Personalismo* refers to a style of communication that facilitates the development and maintenance of warm and friendly exchanges and an overall preference for relationships with individuals rather than with institutions (Santiago-Rivera, Arredondo, & Gallardo-Cooper, 2002). This concept of *personalismo* is a type of formal friendliness that defines personal relationships (Warda, 2000). In other words, Puerto Ricans seek a sense of genuine concern and caring in their interactions with others, including health care providers.

Another key cultural value held by Puerto Ricans is *confianza* (Bracera, 1998). This term refers to a sense of trust and intimacy within interpersonal relationships which takes time to build and strengthen through positive interactions. A lack of *confianza* has been linked in the literature to problems accessing health care resources (Reyes-Blanes, Corea, & Bailey, 1999; Harry, 1992).

#### 2.1.d Puerto Rican Views of Health

Hispanic-Americans commonly perceive health as a gift from God regardless of whether they take part in the folk system of healing (Puerto Rico, 2010). Health can be a reward for good behavior, and illness can sometimes be a punishment for wrongdoing. Other potential causes for illness distinctive to Hispanic culture include imbalances between hot and cold, supernatural triggers, and envy.

Folk medicine has a long-standing place in Hispanic-American culture, and is especially common among first-generation Hispanics. Healing through the folk system is practiced in the home by family members or by *curanderos* or *santeros* (Aponte, 2009). *Curanderos* are naturalist healers who use herbs and plants to heal illness. *Santeros*, on the other hand, use the power of the saints to heal, aid, and counsel individuals (Mikhail, Wali, & Zement, 2004). Puerto Rican folk healers are called *espiritistas* (spiritualists) and use prayer, candles, oils, and scents in addition to folk medicine as a form of alternative medicine (Rivera, 2005). In general, the family is usually consulted first in the Latino family and home remedies are the first line of defense for illness. However, holistic healers are also used throughout Latino culture, without regard to socioeconomic status, and are sought for social, physical and psychological purposes. The healers do not advertise their services but are well known through informal communication in the Latino community network. Not all Latinos use the folk system, but health care providers should be aware that patients who seem to have delayed seeking healthcare have most likely counted on curing their illness using the folk process. The folk system is usually used alongside institutionalized medicine and is more likely to be used exclusively in cases of psychiatric disorders, which are often perceived as a doing by evil spirits and forces (Aponte, 2009).

Struthers and Nichols (2004) conducted a systematic review of 26 research articles on complementary and alternative medical practices (CAM) in ethnic groups. Most of the studies reviewed used surveys and self-report of Asians, African American, Mexican Dominican and Puerto Rican groups. Struthers and Nichols (2004) concluded that CAM use occurs as part of cultural behavior. Nahm et al (2003) sought to determine the use of CAM in older interviewed 525 older adults between the ages of 65 and 95 regarding their CAM use. They found that CAM users tended to have lived in the U.S. less than five years and were less educated. Nahm et al (2003) further reported that this was most significant among the Hispanic/Latino participants who often reported use of dietary supplements, home remedies, and *curanderos* as CAM practices. Additionally, while 58% of the Hispanic population reported as CAM users, they were seeing a physician for the same problem. However, only 37.6% disclosed CAM use to physicians. The participants described fear of disapproval as part of the reason for omitting this information. MacKenzie et al (2003), using the National Comparative Health Survey of the Commonwealth, found that Latinos highly used both home remedies as well herbal medicine. However, this study was limited by the age of the data set and lack of review of several important factors related to culture including spirituality and use of folk remedies.

Conversely, Roy, Torrez, and Dale (2004) surveyed children's guardians regarding the use of home remedies for children. These authors found that of the three ethnic groups surveyed, Latinas were the least likely to say that they would treat their child with home remedies. It should be noted that the Latinas of this study were from the Dallas, Texas area and were primarily Mexican American. The home remedies used included teas, rubdowns with Vicks Vapor rub, tepid baths, chicken soup and favorite foods. When asked whom they consulted

initially for health information, most responded “my mother.” Respondents also indicated that when the child was sick, they stayed home from work to care for the child (Roy, Torrez, & Dale).

Overall, nurses need to be aware that Latinos of all subgroups often take folk medicines (Collins et al. 2001,). This author described the findings of the Commonwealth Fund 2001 Health Care Quality survey which identified 18% of Latino respondents reported use of herbal remedies. These findings were echoed in research conducted by Mikhail et al (1994), Howell et al (2006), and in a review of the literature by Hanaan (2015).

## 2.2 Puerto Rican Health Disparities

The Institute of Medicine (2004) reported four areas that specifically contribute to health disparities experienced by Latinos in general: inadequate health coverage; a language barrier; a lack of minority physicians; and healthcare provider bias. The Center for Disease Control (2012) has reported that Latinos make up the largest group in the US without any health insurance, 31.6% of this population being uninsured compared to 15% of the general population. Further, 8% of uninsured Hispanic-Americans are from working families due to the low rates of employer-based coverage (CDC 2010). Additionally, under the Affordable Care Act, Hispanics remained the most likely to be uninsured in 2014 under the Affordable Care Act (CDC, 2014). These results are emphasized by 54.4% of working Hispanic-Americans receiving employer-based health insurance as compared to 73.3% of Caucasians. Additionally, approximately 65% of Hispanic families receive an annual income less than the Federal poverty rate, further intensifying the challenge to obtain affordable healthcare (National Center for Children in Poverty, 2013).

The number of Latino families ability to obtain health insurance in of Latino children identified as 16.3% or one in six children (U.S. Census, 2011). In comparison, 6.9% of white children, 10.5% of black children, and 8.9% of Asian-Pacific Islander children in the US were reported as uninsured. According to Takanishi (2004), the primary reason for poor Latino children maintaining high non-insured rates despite State Children's Health Insurance Program (SCHIP) (spell out first time used) is the unsuccessful efforts to enroll the Hispanic community in the program. A Kaiser Commission (2001) report identified the need for Spanish medical translators as well as increased recruitment and training of Latinos in order to better connect the community to the health care system.

A report from the Institute of Medicine on Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (2002) demonstrated that racial and ethnic health disparities are a major problem in the U.S. health care system. Even when controlled for factors such as access to care disparities exist due to perpetuation of healthcare provider bias and patient beliefs about racism. Chen et al (2005) found that one third of Latinos surveyed in a study looking at racism and preferences for physician race preferred their physician was of their same race. The participants felt that racial beliefs may impact the quality of interaction between physician and patient. In other words, these Latino patients believe healthcare providers' perceptions or assumptions about them based on their racial or ethnic background alters the provision of care. The IOM (spell out first time used)report (2002) also indicated increased refusal rates in minority patients and suggests that this may related to mistrust of care providers or previous negative experiences.



Tucker et al (2010) conducted a 10 year longitudinal study of health disparities in Puerto Rican adults in Boston Massachusetts. The researchers commented that Latino subgroups are frequently combined with other groups in health research and may blur important differences. The results of their study show that Puerto Ricans in Massachusetts experience significant health disparities exceeding those of other Latino subgroups including Mexican Americans. The reasons for these reported disparities are not clear and require further investigation and research.

Overall the IOM report (2002) recommended that efforts to reduce disparities should include strategies to increase understanding of cultural differences as well as increase racial and ethnic representation within the healthcare professions. Mendoza and Fuentes-Afflick (1999) emphasized the importance of research to gain understanding of the social and cultural histories of families in order to use their strengths effectively in planning care.

#### 2.2.a Children with Special Health Care Needs

By definition, “children with special health-care needs (SHCN) are infants, children, and youth from birth to age 18 who have disabling conditions or chronic illnesses that interfere significantly with normal functioning and development and that require significant adaptations for daily functioning, prolonged or periodic hospitalizations, and special services in educational settings” (German, Marine, Nolan, Taylor, Johnson, & Mangos, 1994, p. 57). Chronically ill children and their families have a variety of medical, developmental, social, emotional, and environmental needs

requiring comprehensive case management and long term monitoring. Therefore, chronically ill children are also considered children with special care needs.

### 2.2.b Chronically Ill Children as a Health Care Disparity

The term health disparity is widely used in health care literature and it is frequently associated with racial, gender and cultural differences. However, it is also important to consider how the term is defined in relation to families with chronically ill children. Healthy People 2020 (2005) defined health care disparity as differences that occur in gender, race, ethnicity, education, income, or disability, living in rural localities or sexual orientation. Further, Healthy People 2020 has established the elimination of health care disparities as one of its two overarching goals. The Department of Health and Human Services defines health disparity as a population specific difference in the presence of disease, health outcomes, or access to care (Carter-Pokras, & Baquet, 2002). While disparity is most often discussed in terms of racial or ethnic differences, disparities have also been measured according to illness or disability (Pearcy, & Keppel, 2002). Thus, families of chronically ill children are identified as meeting the descriptors of a health disparity. These families are described as isolated, frequently of low socio-economic status, and often of a minority group. They must navigate the health care system, seeking help and support and may experience obstacles in accessing care. The care provided, as a professional standard, should be culturally sensitive and congruent to their individual needs.

Children with SHCN represent a significant portion of the pediatric population (CAMHI, 2012, Deal, Shiono, & Behrman, 1998; Newacheck, McManus, Fox, Huang, Halfon, 2000; Parrino & Thacker, 1994). Many of these children require complex health care services as well

as education related to the treatment process. Although there has been limited numbers of studies exploring children's experiences living with a chronic illness (Taylor, Gibson, & 2008) the literature demonstrates that families of CSHCN have encountered fragmentation, gaps, and duplication in care (HRSA, 2010, Huang, Kogan, Yu, & Strickland, 2005). Nolan, Orland, & Liptak, (2007) reported that families of CSHCN need to efficiently and successfully access complex health care systems and the services they offer, however they report finding these services often poorly coordinated. In fact their research found that families rank care coordination services the highest priority, next to parent involvement in decisions and communication between providers and families.

#### 2.2.c Puerto Rican Children with Special Health Care Needs

Historically, the medical community has had very little data on the prevalence of chronic and disabling conditions among Latino children (Mendoza & Fuentes-Afflick, 1999). HRSA data from the Survey on Children and Special Health Care needs (2010) identified children with lower family incomes as more likely to have some type of functional difficulty. Overall, 78% of the parents with children with special health care needs reported their child having difficulty with at least one bodily function and 41.4% reported emotional or behavioral difficulties. Of that population 59% of the Hispanic parents reported difficulty with at least one bodily function and 36% with emotional or behavioral difficulties. Further, the report identified that 13.9% of all U. S. children, or 10.2 million, have at least one chronic condition causing a functional limitation (HRSA, 2006). Additionally, 21.8% of all U.S. households have at least one child with special health care needs. The report also identified that although approximately 15% of the non-

Hispanic White children are identified as having special health needs; this statistic drops to 8% of Latino children. However, the National Survey of Children with Special Health Care needs reported that this number is 14%, and rises to 16.7% for English speaking Latino families (HRSA 2008). While this rate is greater than the national rates of special health care needs for the non-Hispanic White children, the rise in the rate of special health care needs is also reflected in the national data.

Gannotti et al (2004) conducted a study of 84 Latino and Euro-American families of children with disabilities. The researchers found that all the families had different perceived unmet needs and expectations even though there were similarities among their children. Latino families had the perception that it was the role of providers to institute change in their treatment plan. This often became hindered with insurance and service provider variation in coverage or plans. However the families did not directly confront the service providers and instead would no longer ask for help. Based on the study findings Gannotti et al (2004) found that the Latino cultural values of respect and familismo play a role in creating barriers to communication and use of the health care system.

### 2.3 Nursing implications for planning care for children with special health care needs

Nurses should establish a strong, trusting relationship with the family of a chronically ill child (Futureofchildren.org, 2011). This relationship provides the foundation for future interactions throughout the course of the child's treatment and promotes family health and well-being. Kirk (1992) and Zoucha (1998), in qualitative studies examining chronically ill patients' perceptions of nursing care, discovered

confidence was to be the essence which tied together all the informants' experiences with good nursing care. Confidence is gained through respectful and culturally sensitive interaction with the client and the family (Kirk).

The literature describes parents of chronically ill children as desiring for guidance and active support to be clear about their role, about what is expected of them, and what they can do to help their child (Coyne 1995, Melnyk 2000, Yin & Twinn 2001). Rose and Garwick (2003) found that affirming encounters between health care providers and families can reduce or eliminate barriers to health services for American Indian families with children diagnosed with childhood asthma. A metasynthesis by Coffey (2006), reviewed research on families of children with chronic illness and identified a sense of anxiety and concern over the ability to meet the needs of the child with a chronic illness, as well as the social isolation felt by the families during this experience.

Family health and the actions of nursing staff have been shown to correlate with each other (Hinds, Clarke-Steffen, Quargnetti, Kreissman, Kazak, Meyer W, Mulhern, Pratt, & Wilimas, 1996). Helseth (2002) reported that support and guidance from the nurse was helpful for parents of children with colic attacks, while Taanila, Järvelin, and Kokkonen (1998) found that the more advice parents had received from nursing staff and the more useful that advice, the better they managed with their sick child at home. In the case of families with chronically ill children, the literature supports the parental desire for guidance and active support to be clear about their role, about what is expected of them, and what they can do to help their child (Coyne 1995, Melnyk 2000, Yin & Twinn 2001). In a study by Hopia, Tomlinson, Paavilainen, and Astedt (2005), interviews were conducted with 29 families who had a child with a chronic illness

which were receiving or had received treatment on the pediatric wards of two Finnish hospitals. The researchers identified five domains in the promotion of family health: (1) reinforcing parenthood, (2) looking after the child's welfare, (3) sharing the emotional burden, (4) supporting everyday coping and (5) creating a confidential care relationship. The importance of cultural competence in the caregiver is inherent in the development of each of these domains. Parental perceptions may affect the management of the illness (Kieckhefer & Ratcliffe, 2000; Van Sickle, & Wright, 2001; Rose & Garwick 2003). The research clearly indicates that supporting families by recognizing their strengths and fears can minimize the disruption and burden caused by chronic pediatric illness. Cultural competence in the nurse is inherent in providing this necessary support to families.

#### 2.4 Cultural competence defined

Culture is a learned worldview or paradigm shared by a population or group and transmitted socially that influences values, beliefs, customs, and behaviors and is reflected in the language, dress, food, materials, and social institutions of a group (Andrews & Boyle, 1999; Leininger, 1999, 1995; Purnell & Paulanka, 1998). Culture is inseparable from the person; thus, consideration of culture is an essential component of care (Burchum, 2002). Campinha-Bacote describes cultural competence is a process in which the healthcare professional continually strives to achieve the ability and availability to effectively work within the cultural context of a client (Campinha-Bacote, 2002). This model of cultural competence views cultural awareness, cultural knowledge, cultural skill, cultural encounters and cultural desire as the five constructs of cultural competence. The ability of the nurse to deliver appropriate care to culturally diverse clients requires commitment to the process of becoming culturally competent.

Leininger (cited in Leininger, & McFarland, 2002) describes cultural competence and cultural congruence as the ultimate goal for transcultural nursing. The term cultural congruence grew from Leininger's Theory of Culture Care Diversity and Universality and is defined as the use of sensitive, creative, and meaningful care practices to fit with the general values, beliefs, and lifeways of clients for beneficial and satisfying health care, or to help them with difficult life situations, disabilities or death (Leininger, in Leininger, & McFarland, 2002, p. 12.). Thus, culturally congruent care should be an integral aspect of the therapeutic relationship between the family and the nurse.

The profession of nursing's commitment to cultural competence in care is well documented in a number of statements by a variety of nursing organizations. The National League for Nursing has required that cultural content be included in nursing curricula since 1977, and accreditation criteria reflect this requirement (Poss, 1999). The American Academy of Nursing and the American Association of Colleges of Nursing have published vision statements and recommendations for the inclusion of cultural content in nursing and other health care provider educational programs (Caffrey 2005). The American Academy of Nurses (AAN) Expert Panel on Culturally Competent Nursing Care (1992) defined culturally competent care as "sensitive to issues related to culture, race, gender, and sexual orientation" (p. 278). The American Nurses Association's Position Statement on Cultural Diversity in Nursing Practice (1997) emphasized the need for all nurses to understand the role that culture plays on the definition of health and illness and its impact on health care delivery. Clearly, it is a professional expectation that nurses seek knowledge and skills related to the diverse cultural needs of clients.

#### 2.4.a Nursing Perceptions of Cultural Competence

There have been multiple studies conducted to review the impact of cultural competence training and its impact on the cultural knowledge of healthcare providers (Jeffreys & Smodlaka, 1999; Napholz, 1999; St. Clair & McKenry, 1999, Majumdar, Browne, Roberts, & Carpie, 2004; Jones, Cason, & Bond, 2004; and Nokes, Nickitas, Keida, & Neville, 2005). A systematic review of health care provider educational interventions by Beach et al. (2005) demonstrated strong support for cultural competence training in improving attitudes and skills of health professionals. Coffman, Shellman, and Bernal (2004) conducted an integrative review of the American nurse's perceived cultural self-efficacy and found that coursework and educational experiences can increase nurses' self-efficacy in delivery of culturally competent care. At the same time, the results also indicated that the nurses in general did not feel confident in the delivery of culturally competent care. Starr and Wallace (2009) conducted a study of public health nurses in Boston Massachusetts and found that the nurses had culturally competent knowledge and attitudes but were unable to fully and consistently apply these in practice. The literature surrounding cultural competency in nursing is primarily focused on assessing health care providers' perceptions of quality (Torsvik & Hellund, 2008; McKenna et. al., 2006; Coffman, Shellman, & Berman 2006; Cortis, 2004). Notably, the effect of cultural competence training and education on patient outcomes has been minimally addressed in the literature.

#### 2.4.b Cultural competency and patient outcomes

Several studies evaluating patient outcomes were reviewed and all reported favorable effects on patient satisfaction (Mazor, Hampers, & Chande, 2002; Way, Stone, Scwager, Wagoner, Bassman, 2002; Wade, & Berstein, 1991). None of these studies targeted nurses; however, one targeting physicians, a second targeting mental health counselors and another



targeting a mixed group of providers. In another study, Majumdar, Roberts, Browne, and Carpie (2004) connected cultural competence to an increase in patient satisfaction; however, the results had limitations related to the cultural diversity of the sample. Increases in patient satisfaction would imply a positive patient outcome; however, there needs to be further exploration of this relationship. Cheney and Cheromcha (2011) describe culturally competent health care as an approach to health care that offers all participants equal access and opportunity to receive quality care with respect for the cultural context of each individual. They developed an approach to prenatal care incorporating cultural competence and connected this to enhancing patient access to care. However this was not evaluated qualitatively or quantitatively from the viewpoint of the patients.

Culturally competent care will be better received by the client and will result in increased client satisfaction (Leininger 1999, 1995). There is strong support within the profession of nursing as well as in the literature related to the importance of the provision of culturally competent health care (Jones, Bond, & Cason, 1998, Napholz, 1999, Leininger, 2006). Willis (1999) stated that “Cultural competence is required if nursing intervention is to be effective” (p. 45). Thus it would appear that the implications for providing care that is culturally competent are that it is therapeutic, beneficial, safe, and satisfying to clients but the phenomenon has yet to be explored in this direction.

For many years, the literature has clearly supported the need to provide culturally competent care (Campinha-Bacote 1995; Leininger 1999; & Meleis 1996). This has been defined as the nurse’s ability to recognize respect and intervene in culturally congruent manner with the values and beliefs of the client. However, there is little research regarding the cultural values and

beliefs of Puerto Rican families, and in particular related to families with children with special health care needs.

## 2.5 Summary of Literature

There is strong evidence in the literature related to the health care beliefs and values of Puerto Rican. However, this knowledge is limited with regards to Puerto Ricans on the mainland in the United States and is even less available with regards to families with children of special health care needs. There is a need for increased understanding of the needs of families of children with special health care needs in relation to cultural beliefs. A review of the literature demonstrated a gap in the knowledge related to culture care needs of a child with special health care needs and their families. Puerto Rican families with a child with special health care needs were identified as a vulnerable population with unique cultural needs. The primary purpose of this study was to describe culture care experiences of the Puerto Rican family with a child with special health care needs through the eyes of the family caregiver.

## CHAPTER 3

### METHODOLOGY

Leininger's Culture Care Diversity and Universality Theory (CCT) was used as a guide throughout the study. Leininger developed the qualitative ethnonursing research method to fit with the CCT, focusing on naturalistic, open discoveries, and largely inductive modes to document, describe, explain, and interpret informants' worldview, meanings, symbols, and life experiences as they bear upon actual or potential nursing phenomena (Leininger & McFarland, chpt 3, 2002). Ethnonursing is described by Leininger as a rigorous, systematic, and in-depth qualitative methodology for studying culture and care with a goal of promoting culturally congruent care. The method enables the discovery of both the etic and emic data and is guided by the Culture Care Diversity and Universality Theory (CCT). The implementation of this method and CCT facilitated rich data collection related to how family care providers of chronically ill children describe their culture and cultural needs.

#### 3.1 Mini-study

The researcher conducted a mini-study that sought to understand the Puerto Rican families with chronically ill children perceptions of culture care through the eyes of the family caregiver. In addition this mini study was intended to refine research questions, methodology and semi-structured interview guide for use in the maxi-study. There were six general informants who participated in the mini-study with beginning identification of themes including lack of control, constant worry, and the need for family support. Two key informants were identified from the initial mini-study. The maxi-study and the semi-structured interview guide was revised based on its previous use. Some initial categories of care and non-care represented key aspects of

the orientational definitions for CCT (McFarland in Leininger and McFarland, chpt 3, 2002).

These categories were evidenced by: care with a strong sense of family support; and non-care as fear related to view of providers, and difficulty understanding access to health care services.

Family care givers expressed frustration with school expectations for their child related to the health conditions as well. Additionally the mini-study helped the researcher to establishing a relationship with a research access site for Puerto Rican families with chronically ill children which was used during the study.

### 3.2 The completed study

The study was designed as a large scale ethnonursing study with a goal of approximately 12 to 15 key informants, and 24 to 30 general informants (Leininger, 2006). The informants were interviewed over a period of approximately twelve months until saturation occurred. Key themes related to the domain of inquiry were sought to provide a deeper understanding of the culture care needs of Puerto Rican families with a child with special health care needs.

### 3.3 Setting and Environmental Context

The setting was two pediatric ambulatory care clinics in Western Massachusetts. The clinics had a large population of children with special health care needs and were seen on a frequent basis as part of their routine care. One clinic was part of a large acute care center with a children's hospital, as part of its subsidiaries. Connection and access to the clinic was established through a relationship with a licensed social worker who oversaw the Medical Home Initiative for the clinic, and the Massachusetts Department of Public Health. Eleven percent of the total households in Springfield Massachusetts are of the Hispanic ethnicity (Springfield Community Profile, 2005). Further, the researcher's contacts within the pediatric clinic report there were a

number of Puerto Rican families that are part of this overall population. The other clinic was a free standing ambulatory care center with a large pediatric population. The researcher had a relationship with the director of nursing for the clinic that will facilitate access to the population.

### 3.3 Sample

The population for this study was the family caregivers of a child with special health care needs in Puerto Rican families. There was a large population of children with chronic illnesses that seek ongoing care in the targeted clinics, and both have a growing membership in the Medical Home Initiative. There was a large Puerto Rican population in the community and a very busy pediatric clinic that is part of the medical center. A family with a child with special health care needs was defined for the purpose of this study as two or more Puerto Rican individuals, living together who depend on one another for emotional and physical support, in which one of the members is a child of less than 18 years of age and is diagnosed with a chronic illness. The target informant was defined as the self-identified adult primary care provider and family member for the child with special health care needs. A child with special health care needs was defined as a child under the age of 18 years old, with a single condition that shapes both the child's life and others' responses to him or her, and how the family interacts with society. A voluntary convenience purposive sample of self-identified Puerto Rican family caregivers for the child with special health care needs was recruited through the Medical Home Initiative of Holyoke and Springfield Massachusetts, supported by a two pediatric ambulatory care clinics.

It was documented in the literature that the incidence of English speaking Hispanic families having a child with special health care needs reflects that of the overall population

(Federal Interagency Forum on Child and Family Statistics, 2005; United States Department of Health and Human Services, 2006). Therefore informants who were English speaking and self-identify as Puerto Rican were recruited through contact with the researcher during a family visit to the clinic. Informants were invited to participate in the study through referrals at the identified facilities. Health care providers at the clinics distributed flyers to families who may be candidates for the study. Contact information for the researcher was included on the flyer so that if family care provider is willing, could make an initial phone contact with the researcher to arrange for a convenient meeting time and place.

Informed consent was obtained, as well as permission for the researcher to visit the family home or comfortable/private place of their choosing for an interview. The snowball technique, which takes advantage of social networks among a population, was used to seek additional referrals from initial informants.. Participants were offered a token gift in the form of a \$10 gift card to Walmart for their time spent in each interview.

The sample included both general and key informants. General informants are defined by Leininger (2002, chpt 3) as those individuals who are studied for representation of the wider community. Leininger (2002, chpt 3) further describes key informants as those who are studied more in-depth with the goal of discovering a deeper understanding of the culture. A sample of 10 to 12 self-identified family caregivers were targeted as general informants. An additional 8 to 10 family caregivers were targeted as key informants following initial interviews. The key informants were interviewed up to three to five times over a six month period for a more in-depth information and greater understanding (Leininger & McFarland, 2002). General informants identified were interviewed, with a target of 10 to 12. Key informants were identified

through the initial interview process with a goal of 8 to 10. Interviews and data collection for all informants continued until saturation occurred. Interviews with the Puerto Rican family caregiver of a child with special health care needs were focused on how the primary family care provider perceives the provision of nursing care in relation to the culture care needs of the family. Inclusion criteria used to obtain the sample of families as general informants included:

1. The family caregiver is the adult member of the family who self-identifies as the primary care provider for the child, and is eighteen years of age or older.
2. A family with two or more individuals, living together, who depend on one another for emotional and physical support.
3. A family who self-identifies as from the Puerto Rican ethnicity.
4. Families with a child birth to age 18 years old who has special health care needs.
5. Families in which the family caregiver is able to speak and understand English.

Additional criteria for families included as key informants:

1. The family caregiver articulates information about the provision of care for their child
2. The family caregiver is willing to participate in added interviews in order to gain a greater depth of information

### 3.4 Enablers

As part of the ethnonursing research method, the Phases of Ethnonursing Research (Appendix B) was used to guide the research process during this study (Leininger & McFarland, 2002). Leininger's (2002) *Sunrise Enabler* (Appendix A) was used as a guide throughout the study to explore the culture care experiences of Puerto Rican families with a child with special health care needs from the perspective of the family caregiver. The *Stranger to Trusted Friend*

*Enabler* (Appendix C), was used from the beginning until the end of the research, and guided the researcher through self-disclosure and self-reflection while working with informants (Leininger & McFarland, 2006). The *Acculturation Enabler* (Appendix D), was used to determine the extent to which informants are oriented to their culture or origin (2006). The self-developed semi-structured interview guide based was organized into ten section based on the elements of the *Sunrise Enabler* as they pertain specifically to the target population was used to guide the interview (Appendix E). The questions were open-ended in order to learn as much as possible about the family as described by the informant. The sections of the interview guide included environment, kinship, religion and spirituality, economics, political or legal factors, as well as caring and curing patterns. The last section invited the informant to share other important information and date related to the domain of interest. This allowed the informant to provide any other information not already shared and may open new avenues for exploration with the researcher.

### 3.5 Ethical Considerations and Informed Consent Procedure

IRB approval was obtained from Duquesne University prior to initiation of the study. A consent form was given to all informants that included information about the details of the study, risks and benefits of participation, right to withdraw, and assurance of confidentiality (Appendix F). The informants were provided a verbal explanation of the study as well as confidentiality. Participants were offered a token of a \$10 gift card to Wal-Mart for their time for each interview. Permission for audio taping was also addressed as part of the informed consent process. The informants' willingness to participate was discussed as well as the right to withdraw at any time. The informants were encouraged to ask any questions and to clarify any concerns prior to



signing the consent form. All documentation resulting from data collection and analysis was stored in a locked cabinet in the office of the researcher and will be destroyed five years after the completion. All electronic documents were maintained under a secure password and will also be destroyed five years after study completion. There are no known risks to the study and benefits were reviewed prior to obtaining informed consent (Appendix F). The researcher also signed and dated the consent form in the presence of the informant, and a copy was offered to the informant. Copies of all original informed consent forms were maintained in a locked drawer separate from all other information regarding the study in the researcher's office. The original consent forms will be destroyed five years after completion of the study

Confidentiality and anonymity of the informants is maintained by randomly assigning a number code to each of the key and general informants. A coding system using pseudo-names is used to represent family caregivers and the master is stored in a locked drawer in the researcher's office. The list will be destroyed five years after study completion. The use of a HIPAA certified transcriptionist was planned for assistance with the data, and a confidentiality form will be completed by this individual (Appendix G). The audio-tapes, field notes, journal entries, and typed entries have also been placed in a locked drawer in the researcher's office and will be destroyed five years after completion of the study. Only the researcher, transcriptionist, and the dissertation chairperson had access to these records.

### 3.7 Data Collection

Data collection was conducted through interviews with the family caregiver of the child by the primary investigator in the family's home or place of their choosing. A goal of a total of 36 to 45 Puerto Rican families was targeted in order to achieve the overall goal for both key and

general informants. The family caregiver interviews were conducted at a time when the informants agreed it was convenient. Only family caregivers who are able to speak and understand English were to be considered part of the sample for the study. General informants and the research met once for approximately 30 to 60 minutes. Twelve to fifteen key informants were to be identified following the initial interview, based on the researcher's observations of their level of knowledge about the domain of inquiry and their interest in participating in the study. The key informants were asked for an additional follow-up interview, which may be conducted by phone. The amount of time spent with the key informant was determined by the level of depth of data obtained related to the domain of inquiry. The interview process used included asking open-ended questions following a semi-structured interview guide. The overall goal of the data collection was to understand, explore and discover data related to the domain of interest. A concurrent analysis of the data was conducted as the interviews progress. Validation and confirmation of data interpretations using Leininger's (2006) criteria for evaluation of ethn nursing studies was sought with each of the key informants in the ensuing meetings. Data was recorded through the use of field notes documented by the investigator, as well as audiotapes of the semi-structured interviews.

### 3.8 Data Analysis

Leininger's four-phase method of analysis was used to analyze the data (Leininger & McFarland, 2002). The analysis proceeded from the first data collection and did not end until saturation was achieved. Raw data was collected and documented using field journals and recorded audiotaped interviews during the first phase. Interview data was transcribed and entered verbatim into the computer using NVIVO 10.0, a qualitative data management software

program. A concurrent data collection and analysis was conducted as the interviews progressed in order to begin to identify categories, patterns and inherent themes in the data. Data continued to be collected until the researcher was able to begin to identify recurrent patterning, confirmability of results among key informants, as well as credibility of results and data saturation. In the second phase, descriptors and categories were identified and studied within context. Next, in the third phase, recurrent patterns were identified from the categories. Finally, in the fourth phase, themes were abstracted from the patterns and theoretical formulations related to the Culture Care Diversity and Universality Theory (Leininger & McFarland, 2002, chpt 3).

### 3.9 Substantiation of the research

The ethnonursing research methodology is intended to discover the care practices and a culture's worldview. Establishing trustworthiness of the findings is key to the credibility of the study (Lincoln & Guba, 1985). Leininger (2006) developed six criteria for evaluating the qualitative research: credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability.

Credibility is the truth accuracy and believability of findings and is established mutual agreement between the researcher and the informant about their experiences and knowledge of the phenomena. These truths, beliefs and values are largely from emic findings and are substantiated through the researcher's observations of situations and events (Leininger 2006).

Confirmability means to "repeated direct and documented evidence largely from observed and primary informant source data and with repeated explanations or interpretative data from informants about phenomena" (Leininger 2006, p. 77). The research will restate ideas with

informants and reflect on what is seen and heard as interviews and observation are conducted in order to promote confirmability.

Meaning-in-context refers to "data that have become understandable with relevant referents or meanings to the informant" (Leininger, 2006, p. 77). The researcher must seek to understand the significance of symbols, events, and communication within the context in which they occur. Once the research begins to interpret the significance of these symbols and events, validation of this interpretation will be sought from the key informants.

Another criterion used is recurrent patterning in which repeated instances, sequences of events, experience and lifeways will be observed for recurrent patterns. The researcher observed patterns of behavior over the length of the study in order to address this criterion.

The researcher conducted an exhaustive exploration of the phenomena to ensure saturation and that there is no further data or insights that might be forthcoming. The researcher monitored for redundancies in the data as the study evolves as well as duplication of ideas, expressions, descriptions and observations. The researcher reviewed emerging themes with key informants for confirmation and validation.

The researcher sought transferability through the study, meaning the findings of the study can be transferred to another similar context or situation. The goal was to discover meanings that can be considered general similarities under similar environment, contexts or circumstances (Leininger, 2006). Thus, the researcher looked for validation from key informants related to culture care for families with children with special health care needs.

### 3.10 Summary

This study sought to discover the culture care experiences of Puerto Rican caregivers with children with special health care needs. The study also attempted to identify actions that would be culturally congruent health care for this focus population. The targeted informants were identified as having the ability to reveal the values, beliefs, and lifeways of the population within the domain of inquiry. The findings from this study add to the discipline and practice of transcultural nursing care for Puerto Rican families with children and special health care needs. The discipline of nursing relates to the knowledge base of nurses in regards to this vulnerable population. The nursing practice aspects relate to the action and decision modes of CCT and support the goal of the study for nurses to be competent and sensitive in their care for Puerto Rican families with children with special care needs. Ultimately the knowledge gained from this study may lead to decreasing health disparities in a vulnerable population as well as add to the body of knowledge related to the Culture Care Diversity and Universality Theory.

## CHAPTER 4

### INTRODUCTION

The chapter presents the findings from this study generated through interviews with the participants in their natural setting. The domain of inquiry for this study was the culture care experiences of Puerto Rican families with a child with special health care needs from the perspective of the family caregiver. The research questions for study were: 1) What are the culture care experiences of Puerto Rican families with a child with special health care needs, as described by the family caregiver? 2) What is culturally congruent nursing care, as perceived the Puerto Rican family caregiver for a child with special health care needs from the insider's (emic) view? The intent was to discover findings that would be used to educate nurses and other health care providers about the provision of culturally congruent care to explore the culture care of Puerto Rican families with a child with special care needs from the perspective of the family caregiver.

#### 4.1 The Community

The target population was located within the community of Western Massachusetts. Western Massachusetts is an area located within the Commonwealth of Massachusetts, which is part of the United States region of New England. Western Massachusetts' population is concentrated in the cities and suburbs along the Connecticut River in an urban axis surrounding Springfield that is contiguous with greater Hartford, Connecticut. The cities of Springfield and Holyoke are identified as two of the larger communities within the region, both of which are located in Hampden County. Both cities are urban and have a past history related to manufacturing. The cities have struggled to regain their economic vibrancy in recent years.

Hampden county census data indicates a population of 463,542, which is approximately 8% of the Massachusetts population. Additionally 22.6% of this total self-reports as Hispanic or Latino. The Massachusetts HRSA data from the Survey on Children and Special Health Care needs (2010) identifies 22% of the children in Massachusetts have special health care needs, and of this total 18.2% are Hispanic or Latino children.

HRSA data from the Survey on Children and Special Health Care needs (2010) identified children with lower family incomes as more likely to have some type of functional difficulty. Overall, 45.6% of the parents reported their child having difficulty with at least one bodily function and 42% reported emotional or behavioral difficulties. Of that population 72.8% of the Hispanic parents reported difficulty with at least one bodily function and 63.3% with emotional or behavioral difficulties. Further, the report identified that 15.1% of all U. S. children, or 11.2 million, have at least one chronic condition causing a functional limitation (HRSA, 2010). Additionally, 23% of all U.S. households have at least one child with special health care needs.

The review of literature indicates that the incidence of English speaking Hispanic families having a child with special health care needs reflects that of the overall population (Federal Interagency Forum on Child and Family Statistics, 2005; United States Department of Health and Human Services, 2010). Therefore, informants, who are English speaking, and self-identify as Puerto Rican, were recruited through contact with the researcher during a family visit to the clinic. Informants were also invited to participate in the study through referrals at the identified facilities. Health care providers at the clinics distributed flyers to families who may be candidates for the study. Contact information for the researcher was included on the flyer so that

willing family care providers could make an initial phone contact to arrange for a convenient meeting time and place with the researcher.

#### 4.2 Informants

A total of eight key informants and 16 general informants, for a total of 24, were interviewed based on Leininger's (2001, 2006) ethn nursing guidelines. Saturation of data was reached after 22 interviews; however additional interviews were conducted to assure this. Saturation of the data occurred when the researcher continued to hear the same categories and patterns in the data. Data were analyzed concurrently with data collection and transcribed verbatim from audiotaped interviews that were conducted over a period of 12 months, until saturation was achieved. All of the informants were the mother of the child with special health care needs, with ages ranging between 20 and 33. The following is a summary of the demographic data related to the participants:

Maternal Age Range	Level of Education	Religion
20 – 33	10 high school	12 Catholic
	6 associate degree	4 Pentecostal
	5 some college	6 Christian
		4 Undeclared

All the informants were born on the U. S. mainland. Eleven of the informants reported being married, and seven had an on-going relationship with the child's father. The remaining six informants reported they no longer had a connection with the child's father, and relied solely on



family support. The following is a table depicting the types of illnesses and age range of the children:

Illness Type	Number of Children	Age Range
Bipolar disorder	1	13
Asthma	9	4 - 14
Diabetes	8	8 - 12
Epilepsy	4	6 - 12
Chron's disease	2	10 - 13

Additionally all informants met the following inclusion criteria:

1. A family caregiver who was an adult member of the family of who self-identified as the primary care provider for the child, and is eighteen years of age or older.
2. A family with two or more individuals, living together, who depend on one another for emotional and physical support.
3. A family who self-identified as from the Puerto Rican ethnicity.
4. Families with a child with special health care needs between the ages of birth to 18 years old.
5. Families in which the family caregiver is able to speak and understand English.

#### 4.3 Setting

The target population for this study was the family caregiver of a child with special health care needs in Puerto Rican families. The setting that provided access to this population was two pediatric ambulatory care clinics in Western Massachusetts, both of which have a large population of children with special health care needs. The Springfield clinic is part of a large acute care center. The Holyoke clinic is a free standing ambulatory care center with a large

pediatric population. U.S. Census data (2010) indicates that 48.4% of the population of Holyoke is of Hispanic or Latino ethnicity.

There is a large population of children with chronic illnesses that seek ongoing care in the Springfield and Holyoke clinics, and have a growing membership in the Medical Home Initiative. A voluntary convenience sample of self-identified Puerto Rican family caregivers for the child with special health care needs was recruited during visits to the clinic by the researcher. Following obtaining informed consent, interviews were conducted at a convenient time and place for the informant, with most occurring in the informants' home.

#### 4.4 Data Analysis

Data was organized and managed using NVIVO 10.0 software in order to connect the data based on Leininger's theory and four phases of ethnonursing analysis for qualitative data. Interviews with the Puerto Rican family caregiver of a child with special health care needs and focused on exploring their culture care experiences with the health care system and with nursing in particular. Leininger's (2002) *Sunrise Enabler* (Appendix A ) was used as a guide throughout the study to explore the influences of culture on care. The *Stranger to Trusted Friend Enabler* (Appendix C ), was used throughout the research in order to guide the researcher through self-disclosure and self-reflection while working with informants (Leininger & McFarland, 2006). Additionally, the *Acculturation Enabler* (Appendix D), assisted in determining the extent to which informants are oriented to their culture or origin (2006). A researcher-developed semi-structured interview guide, organized into ten sections based on the elements of the *Sunrise Enabler Model* as they pertain specifically to the target population guided interviews was used for this study. (Appendix A). The findings reflect the emic perspectives of the family care

providers as well as the interpreted etic perspective of the researcher. The findings of this study are presented according to how the data was analyzed: (a) categories of data, (b) patterns, and finally (c) themes. Based on Leininger's (2001, 2006) ethnonursing guidelines, a total of eight key informants and 16 general informants were interviewed until saturation of data was reached. Data were transcribed verbatim from audiotaped interviews that were conducted over a period of 12 months, until saturation of the data was achieved. Informant inclusion criteria consisted of

1. A family caregiver who was an adult member of the family of who self- identifies as the primary care provider for the child, and is eighteen years of age or older.
2. A family with two or more individuals, living together, who depend on one another for emotional and physical support.
3. A family who self-identifies as from the Puerto Rican ethnicity.
4. Families with a child with special healthcare needs between the ages of birth to 18 years old.
5. Families in which the family caregiver is able to speak and understand English.

As part of the first phase of analysis, the transcriptions of the interviews were imported into NVIVO 10. Then the researcher analyzed the data in relation to the domain of inquiry and study questions. After the initial interview, some informants were invited for a second or third interview due to the richness and depth of the interview, and became key informants of the study. Over the course of the interviews with the key informants, the domain of inquiry was further explored and the researcher was able to confirm or negate the findings from the emic perspective. Data were then coded and classified related to the domain of inquiry and study questions as part of the second phase of analysis (Leininger, 2001). The data were examined

within the emic and etic context and the following categories were identified: a) family, b) health, c) caring, d) non-caring, e) meeting care needs, f) responsibility g) isolation and social barriers, h) supportive communication i) culture and traditions, j) knowing, k) struggle of life, l) feeling different m) self-blame, and n) coping and emotions. Data was then analyzed for patterns related to the domain of inquiry for the third phase of data analysis and were identified as the following: 1) the family as an important source of support, 2) caring is listening, remembering, and respect, 3) non-caring is not being interested, attentive and not actively listening, 4) concern over knowing and understanding how to maintain child's health and 5) feeling isolated, alone or different due to a child with special health care needs. The themes of a) the family caregiver describes the burden of care, b) the family caregiver describes caring behaviors are attentiveness and respect and c) the family caregiver feelings of responsibility for the child creates fear and uncertainty were identified in the fourth phase of data analysis, using evaluation and synthesis of categories and patterns.

#### 4.5 Presentation of Categories

The fourteen categories were identified in concert with the Leininger's culture care theory as depicted in the Sunrise Enabler and included: a) family, b) health, c) caring, d) non-caring, e) meeting care needs, f) responsibility g) isolation and social barriers, h) supportive communication i) culture and traditions, j) knowing, k) struggle of life, l) feeling different m) self-blame, and n) coping and emotions. A complete description of the categories supported by data from the interviews and the researcher's observations from a field journal are presented to provide a contextual perspective to the culture care perceptions of Puerto Rican family caregivers of children with special care needs.

#### 4.5.a Family

Puerto Ricans highly value the family and its unity and this take priority in their worldview. This was supported by many of the participants who described family as coming first, and is a major source of strength and support for the members. This was evident in many of the participant's comments including: "family is everything, and especially my kids. I do not know what I would do without my family. I just wish all of my family was here." Many participants described their families as including parents, children, grandparents, aunts and uncles. One participant defined her family stating: "It is just us, my mother, my son and my sister here in the house but we also have my aunts and uncles nearby and they come to help whenever we need them. We are together all of the time." Another example is of this sense of family includes is "Well, my family that lives in this home includes my husband and my two children, but the rest of my family around here includes my mother, my sister, my aunts, my uncles, my cousins, and then there are my grandparents, um and a bunch more family members that are in Puerto Rico." These comments supports how families are defined to include extended families for Puerto Rican families are described in the literature. Further, one participant clarifies "Family is more than just my kids and my mother, it is a big group of aunts and uncles, and friends and neighbors who all help each other and care for each other. You know they will all be there for you if you need them and so you have to be there for them in the same way."

At times it is difficult for the caregivers to choose between their families and work obligations. This is a struggle because of the importance of family and being there for one another. One informant talked about how challenging it can be to meet the needs of family in relation to work: "It is hard when my kids are sick and I am supposed to work. I have to make

money to support the kids, but I am the one that should be there to take care of the kids when they are sick. It is a hard choice. Having family around helps in that situation ...because I feel ok about my mother being with them for the most part. I do not know what I would do without with my family to support me.”

#### 4.5.b Health

The category of health was very strong in the data analysis, particularly since the caregivers primary focus was on their child’s health issues. Health was described as a goal and a priority by many of the participants and was a source of constant concern for many others. One participant described how her child’s health was always on her mind: “Health is everything and I worry about what will happen to my son. I know he has health problems and I worry about how this will affect him through his life. Right now he sometimes can’t do things the other kids do and I want him to be normal...to be healthy.” Another informant talked about how her view of health may be different: “I look at health as good days or bad days...a good day is when my daughter is feeling good, her blood sugar is ok and she is happy...a bad day is when she is sick and then I worry about her sugar, and what is happening to her...Other families don’t know how lucky they are not to have this kind of worry”

A number of participants described their child’s health as their responsibility. Participants described their role as care provider to include nurturing and making sure health behaviors are maintained so as to ensure a good state of health in their child. An example is “I have to understand how to take care of her because if I do not do what I am supposed to do she will get sick. It is a lot of pressure but her health is everything.”

Many seemed to link health to spirituality and God saying “I pray all the time to God to watch over us and especially my son so that he will stay healthy. I know his asthma will never go away but maybe God will help to keep him feeling good. It is so scary when he is sick and when he can’t breathe sometimes all I can do is pray.” One informant expressed some anger towards God stating “I don’t understand what we did to have this happen to our son. To watch him suffer during a seizure makes me wonder why God would let this happen. But I try to pray and ask for God’s help for us so that we can be safe and healthy anyway...maybe he will listen.” Another participant emphasized this sense of looking to God for help and intervention for health saying “I go to Church every week and I pray...I pray every day so that my family will be healthy and we will have a normal life”

The previous statement also links the sense of health to a sense of normalcy or how this is limited by having a child with health issues. This is exemplified by one participant stating “Other families don’t have to watch what they eat, when they eat and worry about their kids all the time in the same way. We have to make sure that we are doing all of the things to help my daughter stay as healthy as possible and it means we can’t always do what we want. People don’t know how lucky they are to have kids that are normal...that aren’t sick all the time”. Caregivers repeatedly described the desire for their child to be normal, or in other words, to not have a diagnosed chronic illness. However they also expressed an understanding that they needed to focus on maintaining a level of health or wellness. One participant described this as “Well I know that she will have good days and bad days and that we have to watch and be careful so that her diabetes is in good control. If we do what we are supposed to do...eat good...watch her sugar...get exercise...she should stay pretty healthy and not have any problems.”

#### 4.5.c Caring

The way a professional projects a sense of caring was described as very important to the participants and a sign that they were supported and respected. One participant described it as “when they are really listening to you, and not trying to just fill out forms” Another stated “it is when they remember me and about my son...then I know they really care and are interested. Others don’t really look at you, just the computer and click away answering questions. There is one nurse who always stops and talks to me on the way out of a visit...she asks me if I have questions...and she tells me to call her if I need anything...I know she really means it when she says it too.”

Patience, respect and good listening skills were apparent attributes related to caring in participant statements. This was repeated by many participants as well as allowing time to talk and maintaining eye contact. One participant described a caring nurse as “someone who treats you with respect, doesn’t rush you and treat you like a number...someone who listens and lets you take your time to think...that is how I know they respect me and really want to hear what I need to say.”

Some participants noted differences in caring behaviors between acute care and outpatient facilities. One participant described her visit to the emergency department saying “It was so scary and everyone was rushing around. I knew my son was really sick, his eyes were closed and he was just shaking. I know now it was a seizure but then I was just thinking he was going to die. I was afraid the doctors and nurses thought it was my fault...they were so rushed and I was afraid to talk. I know now they were trying to help but I just remember how scared I was and like they did not care at all about me.” She goes on to describe her relationship with the



clinic nurse saying “She is so good to me...she knows that I need extra time to think about my questions and so she even calls me after I go home. This is good because when they change his medicine I like to make sure I do the right thing. I know I can always double check with her and she will not judge me.”

Additionally, caring nurses were seen as people who can teach and inform “the diabetic nurse is the one that taught me how to give insulin, then she worked with my daughter to learn to watch how she feels and to know when her sugar goes low. She is so good with my daughter and my daughter really likes her so she tries to listen and do what she says. I do not think I could have managed without that nurse helping us when she was first diagnosed with diabetes. It was all so much and I felt like if I did not do everything right we would end up in the hospital again.”

The importance of eye to eye contact and limitation of barriers such as computerized documentation was reflected in comments by many participants. One participant reflected this by saying “You can tell when they really care because they do not just stand far away and look at their computer. They come close to your bed, and face you and even smile...they don’t have a paper to fill out or a computer to type on...they ask questions and they really listen to what you have to say.” Another participant said “You can tell when someone cares because they really listen to my daughter answer them after they ask how she is....and then they ask me how I am...that shows respect and that they understand and care about me too.”

#### 4.5.d Non-caring

Participants often referred to those who were not caring as rushed, and impatient or not appearing to have been listening. One participant explained “You can tell when they are just trying to be ...well...professional...they are doing their job but I don’t think they really care

about me or my daughter. They ask questions and just write down the answers. They don't really look and listen to you and they don't remember you the next time you come" Another participant described feeling angry because "sometimes I feel like they are judging me and think I do not take care of my little girl." This sense of non-caring was further described as staff appearing rushed, as though they did not want to stop to attend to their needs. "The nurses are always in a hurry...they just want you to say everything is good..."

#### 4.5.e Pressure of Care Needs

Many participants described a need for support as key to being able to manage the pressures of providing care to a child with special care needs. The need for family, both immediate and extended family was repeated by many participants in order to meet the needs of managing the family care needs. The support that the participants described reflected their definition of family to some extent. For example one participant states: "I do not know what I would do without my mother. I thank God that I live with her and I can rely on her to help me with the kids. She comes to all the doctor visits and this helps me to stay calm. It helps to have her there to listen with me so we can both think about what they tell us and so that we can ask questions. My son's father is not around so I do not think I could do this without her. I worry she will get sick and not be able to help...and I would not be able to take care of her"

The need to be able to share some of the burden of care was echoed by many participants and family was often the source of this type of support. Many described the need to have someone available to help with doctor visits or with sick day child care due to work obligations of the primary care provider. Some families described this supporting each other by sharing the need to provide childcare for sick days. "My husband and I have to take turns staying home with

our son when his asthma is bad. We don't want other family watching him when he is really having trouble because you have to watch him so careful. That is too much to ask for others and so we have to help each other.”

The stress of trying to meet daily care needs of a child with special health care needs was also equated with someone to listen and provide advice. This was described as important for coping with the stress of providing care and trying to meet all of the caregiver obligations and responsibilities. This is reflected in the following: “It helps to be able to talk to my husband about our daughters problems. I usually have to take her to doctor visits but then he calls to see how things went and we talk about her treatment and what the doctor said. It makes me feel like I am not alone so much.”

#### 4.5.f Responsibility

A frequent thread that was noted was the sense of responsibility that the care provider felt in making sure her child maintained a high level of health. Participants describe the need to try to guide and nurture their child and to keep them safe and healthy. This is considered an obligation that is expected with the role and complicated when the child has health issues. One participant described this stating: “I feel like I have to always be on duty, watching for signs of a problem...I know I need to catch her before she gets really sick so that worry is always there that something could be wrong. I also worry that I am not doing the right thing. It is very stressful to have to be thinking about what could happen all the time.”

This sense of responsibility and obligation is evident in discussions with many participants including this statement: “It is my responsibility to make sure he follows the doctor's instructions and that he takes his medicine. I also have to make sure the school knows what to do

if he has a problem. I even have to make sure that my mother and the rest of my family know what to do if he has a seizure. I feel like I need to be there all the time so that he will be safe.” This sense of responsibility was echoed by many participants as they described how they felt they had to be in control and be very knowledgeable. One participant described when her child was first diagnosed with seizures “At the beginning it was very scary because all I could think about was what he looked like when he had that first bad seizure. He was just shaking and turning blue. The ambulance came and we went to the hospital. Everyone rushed around and I felt like I did not know what was happening. It was scary and I felt like I should know what to do....Later on they taught me about how to watch for a seizure and how to make sure he takes his medicine. At first it was so much to learn and I felt like I had so much to worry about. I had to be able to do this for my son.”

The participants also described a sense of responsibility related to teaching their children to be healthy. One participant talked about how this could create conflict within the family at times: “I try to make sure they eat healthy and I teach about this...it can be expensive to buy all the right foods but it is important that I make sure they eat right. Especially since my daughter has diabetes. I need to make sure everyone says healthy and eats right and this will help her stay healthy and help her keep her sugars ok. My mother does not always understand this and gives them foods that are not healthy. I try to teach her not to give them candy and sweets all the time.”

#### 4.5.g Isolation and Social barriers

There were social barriers described by many participants related their child’s health and well-being. Families described how important it is to make sure their child is well cared for, however the impact of this level of responsibility and concern for the child was described as

creating some degree of isolation and loneliness, even in the presence of strong family support. Their child's health care needs would at times limit interactions or social activities with family and friends for both the caregiver and the child. Caregivers described how they felt different from other families because of their need to attend to their child's special health care needs. "Sometimes it makes me mad because I have to worry all the time about what could happen if my son gets sick or has trouble at school. Other mothers do not have this worry all the time. People try to help and ask me how I am, but I feel like I am different and feel alone."

Additionally, some participants described situations in which there was family conflict due to their child's health and concern over exposure to health risks when around other family members. One participant described how her father refused to stop smoking in his home when she visited with her son despite being educated that this was a problem for his asthma. "I have tried to tell him over and over but he says that my son will grow out of it...and that it is his house so he can smoke if he wants. I have had to stop going over because it is bad for my son's lungs. I ask my parents to come over to my house now but I do not know what will happen when the holidays come." Another participant described a similar situation with an uncle, but in this case "my father talked to his brother and told him he must not smoke in the house when the family is together. My father is his older brother and he does what he tells him to do."

Another described how family support and the advice that is often given at times created conflict "Everyone wants to help and to give advice about my son...they do not understand why he has to take medicine for his seizures because they have not seen him have one. They think that the medicine is bad for him to take all the time and try to tell me what to do. It is so hard...I know

they mean well but I feel like I can't talk to everyone about it because they will try to give more advice.”

Concern over limitations to the child's socialization with friends and being labeled as different due to health was frequently described. One participant described how she is concerned for her child's socialization stating: “My son loves soccer and playing sports but his asthma and allergies really make it hard for him to be on a team. I worry that he will have an asthma attack on the field and not be able to breath. What if the coach does not notice...He worries the other kids will make fun of him if he has to sit down because he can't breathe. It is hard to watch your child struggle.”

#### 4.5.h Supportive communication

The need to be able to discuss fears and concerns was described by most participants. This was further defined by the importance of clear and supportive communication by health care providers. This was often described in association with caring behaviors in health professionals as well. Participants consistently described the significance of care providers who explained things simply and allowed time for them to reflect on what was communicated. One participant described this as: “Sometimes they tell you something and you know it is important but all you can think about is what it means for your child. I try to listen but I am thinking about how she will have to go for this test or this procedure and if it will hurt her....Sometimes the doctor or nurse will stop and ask if I understand and I say yes, but really I am just overwhelmed...they don't seem to notice” Another talked about communication with health professionals and the need for support: “I go to a lot of the appointments alone and this is hard

because then I am the only one listening...what if I don't remember it right. I like it when my husband comes...and sometimes I will ask my sister to come he is working...that helps”

The need for time to reflect in order to ask questions was described by many. Some described how a follow-up phone call was very helpful and allowed for better understanding of information “I like the way the nurse at the clinical always comes to me after I talk to the doctor and ask what he said. Then she asks if I have questions and I feel like I can talk to her and let her know if I am not sure about something. She gives me a hug when I am stress...that is really nice. Sometimes she will call me the next day if we have to do something new with her medication to see if I ok and understand what to do. This really helps me understand ....she is easy to talk to...”

#### 4.5.i Culture and Traditions

All participants described themselves as Puerto Rican, but only 5 had been born on the island, the rest have always lived in the United States. Ten of the families had at some time visited their families in Puerto Rico and many did communicate with extended family living on the island. All described a sense of pride related to culture and heritage and described this as being very important to their family. “My father has the Puerto Rican flag hanging on the wall. Both he and my mother go back every year to visit family. I have only been once...I wish I could go with the kids but it is too expensive. I want them to know about where we come from. My father tells them stories about growing up in Puerto Rico and I love that.”

Many families talked about family participation in community events as a way of connecting to Puerto Rican culture and traditions. One participant described a festival that is held each year: “We go to the Puerto Rican festival every year in the summer. It is such a good time

and the kids can see people dancing and playing dominos. It feels like we are in Puerto Rico and it is a good time for families to visit with each other.” Another participant described a cultural tradition: “There is a special parade every year on Good Friday. The men and women from our Church re-enact the crucifixion. I think it is important for our culture and our faith that we keep this tradition. I make sure to bring the kids so they understand what happened.”

Family traditions varied but always reflected the importance of family and togetherness around holiday celebrations. “We get together at Easter and Christmas at my aunt’s house because she has a big house. We have a big meal; we eat pork, and rice and so much good food. I feel bad now because a lot of the food my daughter cannot eat because her sugar will go up. I end up bringing other food for her, and I eat it with her so she will not feel so different. I don’t want to not go because it is important for her to be around family.”

Conversely, most participants stated they did not feel they had any special needs related to culture and family traditions related to the care of their child. They described how health providers will often ask if they have any cultural needs or considerations but that the main concern was to be able to have family support. One example of this is: “I don’t think I have any special cultural considerations because I do not really follow all of the old customs. I know my grandmother would want me to see a folk healer but I always go right to the doctor when she (daughter) gets sick. The only thing I would say is that I wish they would let more family visit. The last time my daughter was in the hospital we could only have 2 people in with her. If my mother wanted to come in my husband had to leave. Family is so important it makes it hard when you have to choose.”

#### 4.5.j Knowing



The idea that they must know and understand a lot of information was described by the majority of participants. While this was seen as important it was also referred to as creating stress connected to this as a responsibility. Knowing what to do when their child had complications was described as a concern repeated in interviews across the participants. This was reflected in their description of their responsibility for care: “There is so much I have to know...I am not a doctor or a nurse...but now I have to know about how to different kinds of food and watch what my daughter eats. I had to learn how to give her shots and what to do if her sugar is too low or too high. There is so much I have to know...sometimes it feels like too much.” One participant described the pressure she felt to know how to respond: “You go to the hospital and they ask you a lot of questions and I just want to scream sometimes that I don’t know! It is so frustrating because I am scared for my child.” Another participant whose son has sickle cell anemia verbalized the learning process: “I have started taking a notebook with me...one nurse suggested this would help. Then I can write down questions that I need answered and I write notes about what the doctor says. It helps me to be able to understand and I think the doctor realizes I am trying to do a good job. I am afraid because sometimes I think they do not think I can take good care of my son because of his disease. There is so much I have to watch for, I am afraid I will forget something important. If I do forget, then he could have a crisis.”

Additionally the importance of family understanding the treatment and understanding it was described: “It is hard because I try to teach my family that she cannot eat sweets and cannot miss meals because it will make her sugar go up or down and that makes her sick. They do not see her as sick because she seems the same. So they try to treat her like they did before. I know I need to get them to understand but it is a struggle.”

#### 4.5.k Feeling Different

A pattern related to the caregiver feeling as though their family was different from others was reflected in a number of different ways through the interviews. Participants talked about how they desired for their child to have friends and to not feel isolated because of their illness. There was concern over how the child was treated at school and whether they had friends. Some talked about how difficult it was when their child was visibly sick at a social event. One participant described how her child had a seizure at a basketball game: “He had the ball and was dribbling down the court and then he fell down and had a seizure...I felt so bad...everyone was watching...later he cried.”

A desire for normalcy was expressed in a number of ways including statements such as “I just wish my son did not have this...that we could be like other families.” Another participant described “I know he wishes he did not have asthma, that he could be like the other kids...it makes me feel so bad.” This struggle to be seen as normal was also expressed in discussion related to the child and their school day. Participants described how sometimes their child would avoid going to the nurse or letting people know they were not feeling well because then the other kids would be aware. This was especially noted by parents of children in the early teen years. One participant described “she is a teenager...she hates to have to eat special food and go to the nurse to get checked because the kids ask questions and look at her...I wish I could make it go away for her.”

#### 4.5.l The Struggle of Life

Most participants talked about how difficult life could be with a child with special needs. This pattern related to the difficulties experienced in providing and accessing care as well as

trying to balance family life responsibilities with work and other life stressors was very clear in most of the interviews. The phrase “It is hard” was repeated over and over again as part of responses to a wide range of questions. Participants talked about how “It is hard to watch her diet” or “It is hard to be sure he gets enough rest.” They also described the pressure they felt working when their child was ill and how difficult it could be to seek medical care with other life stressors.

Caregivers described how they feel pulled by social and work obligations and meeting their child’s health needs. The family had to change routines on many occasions because the child was not feeling well and this included missing time with family. The participants also described how their fear and concern for their child was always present and made life stressful, with one participant saying “It is hard because the worry is always there.” Another talked about how “it is a hard thing for my family.” This level of stress was further described in comments such as “It is so hard to watch her try to breath”...”It is so hard to see him have a hard time playing with the other kids because he does not feel good.” The participants repeated expressed their fear and worry and this is supported by the statement “The hardest thing is you have to be on guard all the time.”

#### 4.5.m Self-blame

A sense of guilt and self-blame related to health complications was expressed by a number of participants. They reflected that they were worried that they had made mistakes in monitoring their child’s health status and this led to complications. One participant described a visit with a physician “I felt like the doctor thought it is my faulty my daughter’s blood sugar

was so high...like I was doing something wrong. I felt so bad ....like I had been a bad mother because I let this happen...but I thought I was doing the right thing.”

This sense of self-blame was further expressed by some when they talked about how they felt judged by the health care providers. “I feel like the doctor thinks I do not do what I am supposed to do...he does not understand she is a kid and sometimes I can’t be with her.” A number of participants described how “it hurts me to see her sick...I wish I could fix it.” Others talked about how hard it was to get help and how “I do my best to get him help but when he is having a seizure there is nothing I can do.” Another participant talked about how she felt guilty when she had to leave her child with a family member, stating “I feel like I should be the one with him but I have to go to work so I can afford his medicine.”

#### 4.5.n Coping and Emotions

All participants described the emotional issues they face related to providing care for a child with special health care needs. This was reflected in many ways including referring to fear, stress, anxiety and worry when discussing their child’s health and their family. This is exemplified in the following: “It is always there, the constant worry...will the phone ring and the school will say he had a seizure and I have to come get him...what if he fell with his seizure and hit his head again...they are talking about having him wear a helmet...will he ever be normal? I get so tired of having to worry all the time...you don’t know ....no one knows what it is like to have that worry all the time.” Another participant elaborated on this degree of worry saying: “Every day I hold my breath when she is at school. I know she does not like to go see the nurse about her sugar and to get a snack. She is almost a teenager, what if she does not follow her diet and then her sugar goes to high. She could end up in the hospital...they say that she can wreck

her kidneys. I am always worried...I know people in my family who ended up on dialysis and they died...God help me that is not what I want for her. I worry about this all the time”

Fear was also clearly expressed by many participants: “I am so afraid that something bad will happen to any of my kids but especially her (daughter). What if she has such a bad asthma attack that she cannot breath and no one is with her....she could die. I feel like I cannot ever let her be alone but I have to work and I have other kids. It is so scary when she has a bad attack and we have to go to the hospital. I feel like I have no control and I can’t help her.”

#### 4.5.o Summary of Categories

The emic and etic descriptors of beliefs and experiences from key and general informants were presented in the above section and similarities and differences were compared and contrasted. Fourteen categories emerged through this review and patterns with the meaning in context were synthesized as part of the third phase of data analysis (Leininger 2001).

#### 4.6 Presentation of Patterns

The following five patterns were analyzed in phase three of data analysis:

1. Pattern of family as important and source of support
2. Pattern of caring as listening, remembering, and respect
3. Pattern of non-caring as not being interested, attentive and not actively listening
4. Pattern of concern over knowing and understanding how to maintain children health
5. Pattern of feeling isolated, alone or different due to a child with special health care needs.

##### 4.6.a Pattern 1: The family is important as a source of support

This pattern was identified in the following categories: a) family, e) meeting care needs, g) isolation and social barriers, and i) culture and tradition. Family was repeatedly described as central to everyday life and to the worldview of the participants. Participants described their family as both their nuclear family and extended family members and that it was important for all of the members to be together. This was described in the following: “We are together every weekend. We go to Church and then to my mother or my aunt’s house to visit. The kids all play and the adults talk...it is nice to be together and it makes us all happy.” Another participant stressed the importance of family and being together: “When we are together, I feel like I am not so alone, that I have help and that other people are watching out for us. I do not know what we would do without my family.”

Acute care was described as often limiting access of family and especially extended family. This was described as creating stress for the care provider and concern over the child’s reaction to not have a particular family member available. This was described by one participant as “I need my family with me when my daughter is sick...I do not understand why they all can’t come to visit us at the hospital. I feel more scared and stressed when I can’t have my mother and my sisters with me. I know they have rules but my family is who I say it is.” Another participant talked about how family members were told to leave: “My mother and my aunts were told to leave because there were too many people in the room. I do not understand why it was too many. They would move so the nurses could come close to my daughter. I felt safe with my family there. I felt so alone after the nurse made them leave. It made me feel like she did not care how I felt.”

Family is central to traditions and maintaining a connection with culture for the participants. This is represented in the following: “We always celebrate Christmas together, we go to my aunt’s house on Christmas Eve and then to Mass at midnight. It is hard for the kids because it so late but they are so excited so they stay awake. We come back the next day for dinner and more celebration...it is like this for every holiday...it can be hard when my son is sick because it is so crowded and he gets over excited but it is important for us all to be together. It would feel very wrong if we were not together”

Additionally, the need to pass on family traditions and culture to children was described by a number of participants: “I was born here, but my mother was born in Puerto Rico...I like to have her tell the kids what it was like living in Puerto Rico. I want to try to make sure the kids know about their culture and I hope they keep with our family traditions...it is what makes us who we are.”

Family as a support to the provision of care was repeatedly described by the participants. The stress of being a caregiver was somewhat relieved by the presence of family. Additionally, family members could give respite from the demands of being a caregiver, especially in times when the child was sick: “Thank goodness for my mother...I do not know what I would do without her. I have to work to support us but she is home. That helps when my son or even one of the other kids get sick because I do not have to stay home all the time. I would lose my job and then where would we be. And if she can’t help I have my sister, and my aunt’s. You have to have family to help...I don’t think I would be able to manage without them.”

Family could also be a source of stress and conflict related to health care and information in some cases. Several participants described feeling stressed by extra advice and guidance from

family members who did not understand the child's illness. It created more stress because they had to refuse to follow advice or try to explain why the suggestion might be an issue. All participants relied on medical intervention and did not practice folk medicine and this was often the focus of the conflict. One participant described this: "My aunt wants me to use herbs to treat my daughter's asthma. She thinks she just keeps getting colds and needs to eat more healthy, take the herbs and get fresh air. I try to explain that she has allergies and even the cold air can make it hard for her to breathe...but she thinks the doctors just want to hand out medicine and make money. I can't make her understand and it gets really frustrating sometimes."

#### 4.6.b Pattern 2: Caring is listening, remembering and respect

This pattern emerged in categories b) health, c) caring, d) non-caring and h) supportive communication, and j) knowing, in which participants expressed the value of patience and active listening by health care providers. Participants discussed the importance of communication that conveyed an authentic interest, beyond completing tasks. Many participants described how they could tell when a nurse was caring by how they listened and allowed them time to respond. For example: "I can tell the nurse at the clinic really cares about me and my son. She asks him how is doing and remembers what grade he is in...then she asks about me too. I am not the patient but she makes me feel like she cares about me. That makes me feel good. She always comes back after the doctor talks to me and asks me if I have questions too. That helps because sometimes I can't think fast enough...it is like she knows I need time to think."

#### 4.6.c Pattern 3: Non-caring not being attentive, actively listening

Similar to pattern 2, the pattern of non-caring is not being attentive and actively listening was identified in categories b) health, c) caring, d) non-caring, h) supportive communication and



k) struggle of life. Participants reflected on what was considered non-caring attitudes in professional health care providers. While they denied needing special attention to their cultural needs they did describe a non-caring attitude when access to family support was limited. This was further described in approaches to communication in which a provider had increased physical distance, focused on obtaining information and documentation of responses. It was common for participants to describe the importance of being recognized as the parent and deserving respect was also described by many. The tendency of health providers to focus on the medical needs and to inform rather than ask the parent about care resulted in caregivers feeling ignored and not respected. One participant states “When we have to go to the emergency room, everyone rushes around and they just tell me to follow them. Sometimes they tell me what is happening but other times they just do things to take care of my son. I know that they have to help him, especially if he is seizing but it seems like I do not matter... I am not making the decisions. In a way I know I can’t because it is an emergency but I like I don’t have any control. It is so stressful.”

This sense of insignificance seemed to be described most often in acute care facilities and in particular in emergency visits. A number of participants described the differences in approach by the clinic nurses and the level of familiarity that is conveyed in their interactions. Participant described the lack of depth to interactions in acute care as professionalism, and that the nurse who interacted with warmth and active listening as caring: “The nurse at the clinic is always nice... she remembers us, she looks at me in the eyes... that does not happen when we go to the hospital. They usually look at their computer or look at my son because they are doing something to him. I am his mother; they should look at me when they talk to me. They just act

professional and do their job. The nurse at the clinic even calls me the day after we visit to see if I have questions or need anything...she really cares”

Participants also describe perceived non-caring nurses and doctors as focused on using the computer and providing minimal eye contact. This is supported by one participant who referred to this behavior as being professional: “Sometimes you can tell they are just doing their job. They are professional and ask questions and just write down the answers or type in the computer. They don’t really look at you or listen to you. You can tell they are just doing a job and don’t really care.” Another participant expanded “They just ask questions like when was the last time you checked her sugar, are you following the diet at home. And they seem to judge when the test comes back and shows that her sugars go up sometimes. They don’t understand...she is a kid, and I am not with her all the time. She has to live and she wants to act like the other kids. They just tell me how sick she could get and try to make me feel guilty.”

A number of participants described non-caring as nurses and doctors who seem rushed or pressed for time. For example: “The last time we were at the ER because of his breathing they would ask me questions, and type the answers and look at their watch, like I was taking too long...but we were there for help right?” Another described how nurses would increase physical space “The nurses at the hospital would stand in the door and ask me if I needed anything. It seemed like they wanted me to say no so they could leave right away. They should come in the room if they really want to know how I am doing.” Communication style was further described as non-caring in the following: “I speak English and understand it because I was raised here but my mother, who always comes with me, does not. She does not understand and the nurses get

impatient when I try to stop them so I can explain to her. It is like all they care about is that I understand...but they talk so fast and I need time to think”

#### 4.6.d Pattern 4: Concern over knowing and understanding how to maintain child’s health

A pattern related to concern over knowing and understanding how to maintain the child’s health was apparent in categories: b) health, e) meeting care needs, f) responsibility, g) isolation and social barriers, j) knowing, k) struggle of life, and m) self-blame. Participants repeatedly described a sense of responsibility and their emotional reaction related to needing to meet this responsibility. This resulted in stress and what was referred to as constant worry by many participants. One participant described the pressure felt related to this responsibility: “I mean I feel like if I do not do everything just right she could get really sick again and end up in the hospital. The first time she got sick she was in the hospital and they said she had diabetes. I did not even really know what that is...I just thought ok she can( I know this is a quote but check it out, I think that this should be can’t not can) eat candy. There was so much I had to know and they kept telling me I had to control her sugar so that her body would not be damaged. Now I worry that if I don’t do a good enough job she will be really sick all her life. It is a lot to handle.” Pressure to know and to be on guard was reflected in many comments including: “I feel like I have to watch him all the time...what if he has another seizure and I am not there...will anyone know what to do? He could die if I am not there to help him...I feel like I have to be on guard all the time.”

The emotional aspect of this level of responsibility was expressed in the coping and emotions category in a number of statements and the statements “I worry” was repeated over and

over by most participants. One participant described “I am so afraid and I wake up at night worried something is wrong...I rush to his room just to make sure he is ok. I get so tired but I know I have to watch him ...It is my job to protect him.”

Stress and anxiety was also expressed and did create some concern for personal health in the participants as well. This is represented in the following: “I am so worried and stressed about my daughter and her health, plus going to school and work I worry that I will get sick...then what will happen to all of us? If I get sick what happens to my daughter...who will take care of her like I do?”

#### 4.6.e Pattern 5: Feeling isolated, alone or different due to a child with special health care needs.

The pattern of feeling isolated, alone or different due to a child with special health care needs evolved through categories a) family, b) health, e) meeting care needs , f) responsibility, g) isolation and social barriers, k) struggle of life l) feeling different, and n) coping and emotions. Participants described how their sense of responsibility for their child meant they had to be vigilant and at times avoid contact with family or limit the child’s activity. This made it hard for the participant as well as created concern for the impact on the child. For example” My son loves soccer but sometimes he can’t run because of his asthma. He does not want to stop and tell the coach he needs his inhaler so he pushes himself. Then I feel like I have to make him stop. It makes him embarrassed. I feel bad but he has to learn to take care of himself...maybe he will have to stop playing.”

These barriers were also encountered with family when other family members would not comply with requests for avoiding health risks such as smoking. One participant complained

about how many family members resisted stopping smoking when they were together because it affected her daughter. “I got so mad that I walked out at Christmas last year. Everyone was having a good time but a lot of them smoke and it was hot in there too. My daughter was starting feel like she could not breathe. I tried to tell my mother but she said they were family and she could not ask them to stop. So I got mad and left...I talked to my parents the next week and they said they would make sure that people do not smoke in the house. It has not happened again but we will see what happens at Christmas...that is when everyone gets together.”

Many participants described a desire for their child to be normal, and for that normalcy to be for their family. They discussed how the changes in behavior to maintain health made them feel different and how they wanted to be free of this level of concern. One participant talked about wanting her child to be normal saying “I just feel bad because she can't do whatever she wants, eat whatever she wants because she has diabetes. I wish she could be better and be normal...so she could live a normal life and we did not have to worry about her all the time.”

#### 4.6.f Summary of Patterns

The five patterns that were identified from the fourteen categories have been explicated and substantiated with evidence from the data. The fourth phase of data analysis is the discovery and presentation of themes which follows in the next section.

#### 4.7 Presentation of Themes

In the phase of analysis for ethnonursing methodology the data is further analyzed and synthesized to identify themes in the findings. Three themes emerged through reflection and analysis from the categories and patterns: 1). the family caregiver describes the burden of care, 2). the family caregiver describes Caring behaviors as attentiveness and respect and 3). the

family caregiver's feelings of Responsibility for the child creates fear and uncertainty. The themes are (bring the connected to the research questions up here with the beginning of this sentence. connected to the research questions and address the culture care experiences and needs of Puerto Rican families with a child with special health care needs from the emic view. The themes will be further explained and evaluated in chapter 5 in relation to the domain of inquiry and the research questions.

#### 4.8 Summary

Puerto Rican family care providers with children with special health care needs were interviewed regarding their culture care perceptions. This chapter presents the findings of phase two, and phase three of data analysis including the identification of fourteen categories and five patterns. The categories which are presented include: a) family, b) health, c) caring, d) non-caring, e) meeting care needs, f) responsibility g) isolation and social barriers, h) supportive communication i) culture and traditions j) knowing, k) struggle of life, l) feeling different, m) self-blame, and n) coping and emotions. The following five patterns were discovered from the analysis of data including 1) Pattern of family as important and source of support, 2) Pattern of caring as listening, remembering, and respect, 3) Pattern of non-caring as not being interested, attentive and not actively listening, 4) Pattern of concern over knowing and understanding how to maintain child's health, and 5). Pattern of feeling isolated, alone or different due to a child with special health care needs. Data analysis proceeded to synthesize findings and to discover three themes: 1) burden of care, 2) caring behaviors are attentiveness and respect and 3) responsibility creates fear and uncertainty, which will be further described in chapter five.

## CHAPTER 5

### DISCUSSION OF THE FINDINGS

Analysis of data during the fourth phase focuses on the researcher's synthesis and interpretation of findings from the first three phases to identify major themes from an emic perspective of the domain of inquiry. This study sought to address the research questions: 1) What are the culture care experiences of Puerto Rican families with a child with special health care needs, as described by the family caregiver? 2) What is culturally congruent nursing care, as perceived the Puerto Rican family caregiver for a child with special health care needs from the insider's (emic) view? The domain of inquiry for this study was the culture care experiences of Puerto Rican families with a child with special health care needs from the perspective of the family caregiver. The intent of the researcher was to discover findings that would be used to educate nurses and other health care providers about the provision of culturally congruent care to explore the culture care of Puerto Rican families with a child with special care needs from the perspective of the family caregiver. There were three themes identified through the fourth phase of data analysis as follows: 1) The family caregiver describes the of burden of care, 2) the family caregiver perceives caring behaviors as attentiveness and respect, and 3) the family caregiver's feelings of responsibility for the child creates fear and uncertainty about their ability to meet their child's needs. These themes will now be presented in depth and a discussion of the implications of study findings follows.

#### 5.1 Theme One: The Family Caregiver Describes the Burden of Care

The theme: *family caregivers describe the burden of care* emerged from the synthesis of categories and the patterns of 1) family is an important source of support, 4) concern over

knowing and understanding how to maintain child's health and 5) feeling isolated, alone or different due to a child with special health care needs. These patterns were connected to the following categories: a) family, b) health c) caring, d) non-caring, h) supportive communication, j) knowing and k) struggle of life. Analysis of the categories and patterns clearly indicated a sense of stress and being overwhelmed with the responsibilities of meeting the care needs of the child as well as the needs of the family, which has been identified as the burden of care.

The family caregivers were noted to repeatedly describe the sense of responsibility that was felt in making sure the child maintained a high level of health. Participants described their expectation that they must nurture their child and to keep them safe and healthy. This was appeared to be considered an obligation or expectation associated with their role as caregiver that was very complicated when the child has health issues. Further, many of participants expressed feeling isolated, alone or different due to a child with special health care needs. This level of stress was frequently referred to as constant worry by many participants and further expanded upon by comments about a desire for a "normal family." This theme of care being a burden was noted when participants described their need to be watchful and on guard for health complications at all times. A number of participants described the need to be always prepared for a problem related to their child as well a degree of sadness because their child was seen as different when their health issues were apparent to other children in their peer group. One participant described it as "I always have to be on guard and ready. We have to pack a bag with his medicine every time we go out of the house. I can't just leave him at the park to play...I have to stay and watch to be sure he is alright." Additionally family care providers expressed guilt or self-blame over their ability to navigate the care needs of their child, with many describing a



concern that their lack of skill in care would result in health complications. This evoked additional fear and expressions of worry and concern over their ability to successfully meet the needs of their child and family. An example is when a participant described her interaction with the doctor “I always feel like he does not think I can do a good job in watching her and I feel bad when her sugar is too high...I don’t always know what to do.”

Puerto Ricans highly value the family and its unity, and this takes priority in their worldview. This was supported by many of the participants who described family as coming first, and is a major source of strength and support for the members. Many participants talked about how “I do not know what I would do without my mother...she is always there to help me...” However, the participants also described how this connection to family could be difficult when confronted by their child’s health issues. Some participants described issues where their decisions were questioned or requests to make accommodations for their child were not necessarily supported within the family. This created barriers for them and potentially limited their access to a strong source of family and cultural support.

## 5.2 Theme Two: Family Caregivers Perceive Caring Behaviors as Attentiveness and Respect

The second theme: *family caregivers perceive caring behaviors as attentiveness and respect* emerged from the pattern of caring as listening, remember, and respect, and the pattern of non-caring is not being interested, attentive and not actively listening. The identification of these patterns grew from a number of categories including b) health, c) caring, d)non-caring, h) supportive communications, j) knowing and k) struggle of life. Data analysis within these categories and patterns identified that family caregiver’s desire authentic interest in their interactions with health care providers. This authenticity extended beyond the skill and

efficiency in which care was delivered and that sincerity and an interest in them as individuals and families was a very important component to their care. This became clear as many participants described how they could tell when a nurse was caring by how they listened and allowed them time to respond. A participant explained “One nurse who always stops and talks to me on the way out of a visit...she asks me if I have questions...and she tells me to call her if I need anything...I know she really means it.” Patience with communication and interactions and a personalized approach including using eye contact and use of personal space were repeatedly described as caring.

The theme: *family caregivers perceive caring behaviors as attentiveness and respect* is further reinforced when families referred to what they believed to be non-caring behaviors. Participants frequently described interactions physicians and nurses who stood at a distance, facing a computer and asking a series of questions and appearing “rushed”. This was described as being “professional” by one participant, meaning that they were doing their job, but they did not really care about her or her child, just the task at hand. This behavior seemed to lead to the perception that the family care giver was seen as inadequate and this resulted in the health care visit. This type of interaction was frequently described related to health interactions in acute care facilities, and in particular related to emergency care room visits. Many participants described a more personalized connection with the nurse at the clinic where they normally received care. Caring behaviors that were described in these instances included the nurse remembering details from a previous visit such as a child’s grade level or personal interest.

The sense of fear related to making a mistake in providing care, as well a concern over being judged by health care providers was often discussed during data collection. Participants

expressed concern that a lot of information is provided at care interactions and that they are fearful of missing or forgetting key information. For example, “I have to understand how to take care of her because if I do not do what I am supposed to do she will get sick. It is a lot of pressure but her health is everything.” At times communications are found to be fast paced and they did not have enough time to think through the impact of the information that was provided. This is explicated in the following: “Sometimes the doctor or nurse will stop and ask if I understand and I say yes, but really I am just overwhelmed...they don’t seem to notice.” Instances in which a nurse returned to follow up related to instructions from the physician and even phone calls another day to inquire about understanding and care management in the home were described as very helpful and perceived as caring and supportive.

### 5.3 Theme Three: Family Caregiver’s Feelings of Responsibility for the Child Creates Fear and Uncertainty About Their Ability to Meet Their Child’s Needs

The third theme: *the family caregiver’s feelings of responsibility for the child creates fear and uncertainty to meet their child’s needs* arose from the pattern of concern over knowing and understanding how to maintain the child’s health and the pattern of feeling isolated, alone or different due to a child with a special care need. The level of stress, fear, worry, and concern that is felt on a daily basis was described throughout many of the categories including: a) family, b) health, e) meeting care needs, f) responsibility, g) isolation and social barriers, j) knowing, k) struggle of life, l) feeling different, m) self-blame, and n) coping and emotions. The perception of personal responsibility for the child’s health as well as the well-being of the whole family have a constant presence in the mind of the family care provider and often became a source of fear and worry.

The difficulties faced in providing a stable living environment for a child with special health care needs as expressed in a wide range of ways by the participants. Many clearly described their fear that they would not be able to meet their child's needs or make a mistake that would result in a complication. One participant described her fears saying "I mean I feel like if I do not do everything just right she could get really sick again and end up in the hospital."

Participants also described how they would feel overwhelmed in trying to balance their child's needs with work and other family responsibilities. This feeling of being overwhelmed is supported by the following: I am so afraid and I wake up at night worried something is wrong...I rush to his room just to make sure he is ok. I get so tired but I know I have to watch him ...It is my job to protect him." The Puerto Rican family caregivers described their family was a strong source of support but at the same time when other family members questioned the care needs of their child it created uncertainty. This could also create conflict within the family and an additional fear related to being able to maintain their cultural identity and connection. One participant described how the extended family celebrated holidays, "I feel bad now because a lot of the food my daughter cannot eat because her sugar will go up. I end up bringing other food for her, and I eat it with her so she will not feel so different." The importance of maintaining their family bond and connection to their Puerto Rican heritage was described by most of the participants. This would often then move to a concern because their child was unable to participate or experience family traditions because of illness and added to their feelings of isolation.

Communications with health care providers was described at times as another source of stress and created additional feelings of inadequacy or uncertainty. Participants described feeling

overwhelmed with information at hospital and physician visits. They further expressed a feeling that they would be seen as poor care providers if their child developed complications. Their insecurity over care management resulted in what was expressed as fear in seeking care. This was most evident in descriptions of care interactions in which a complication had occurred and they had sought help from a less familiar care provider such as through an emergency room visit. Conversely a sense of degree of self-confidence was expressed when describing health care interactions with a well-known health care provider, who was available to answer questions at a later point of contact. For example: “It was scary and I felt like I should know what to do....Later on they taught me about how to watch for a seizure and how to make sure he takes his medicine.”

#### 5.4 Themes Pictorially Displayed



The themes identified through data analysis are pictorially presented above, and clearly indicate the level of stress and anxiety that is felt by the Puerto Rican family caregiver as they try to maintain a normal family life. This is important information and provides a greater depth to the level of understanding about the perception of care received by the Puerto Rican family caregiver. The concentric circles that flow top to bottom represent how the caring attitudes of nurses' and other health care providers' impacts sense of the burden of care. Family caregivers describe high levels of fear and worry over their care responsibilities as depicted by the center circle which flows into the sense that providing care to the child is a constant concern and struggle. All of the anxiety and fear is great influenced by the level of trust and respect that is perceived in interactions with the nurse and other health care providers. Thus, the displaying of caring attitudes of respect and attentiveness impacts levels of fear that is created by the care responsibilities as well as the perceived burden in the provision of care.

#### 5.5 Discussion of the findings related to the literature

The three themes identified in this study can inform the health care provider in forming and culturally congruent therapeutic relationship. The literature supports that many children with disabling conditions face discrimination in obtaining services due to the lack of availability, lack of trust by the family, as well as lack of cultural sensitivity and understanding by health care professionals (Schmitt, Postmes, Branscombe & Garcia, 2014; Francis, 2012; Pachter, Bernstein, Szalcha, & Garcia, 2010; Pachter & Coll, 2009; Edey & Robey, 2005; Robinson & Rathbone, 1999). Further, the National Healthcare Quality and Disparities Report (2014) and CAMHI (2012) demonstrate that racial, ethnic, and socioeconomic disparities are national

problems that affect health care of children with all medical conditions. In the past, the literature frequently focused on the nurses' perception of the provision of culturally competent care. The themes found in this study provide some feedback to the nurses and other health care providers as to how their care is perceived by the recipient.

Leininger's Culture Care Diversity and Universality Theory supports that culturally competent care will be better received by the client and will result in increased client satisfaction (1999, 1995). There is strong support within the profession of nursing as well as in the literature related to the importance of the provision of culturally competent health care (Jones, Bond, & Cason, 1998, Napholz, 1999, Leininger, 2006). Willis (1999) stated that "Cultural competence is required if nursing intervention is to be effective" (p. 45). Further, Leininger (1999) defines cultural congruence as care that is meaningful and fits with cultural beliefs and lifeway (p.9). Thus it would appear that the implications of providing care that is culturally competent and congruent is therapeutic, beneficial, safe, and satisfying to clients but this phenomenon has only minimally been explored in this direction. This was clearly indicated in the data analysis with the population and supported by the emerging themes. Cultural congruence for Puerto Rican families with a child with special care needs would include a focus on developing a trusting relationship, which begins with active listening, remembering personal details, displaying respect, and allowing time for thoughtful communication.

These findings relate to the findings of Coffey, Cloutier Meadow-Oliver, & Terrazos (2012) in a study of Puerto Rican families' experiences of asthma and the emergency room visit emphasize the importance of the therapeutic relationship in the families seeking appropriate care. Kerfeld, Hoffman, Ciol, & Kartin (2010) analyzed data from the National Survey of Children

with Special health Care Needs to better understand if delayed or forgone care was associated with the parent's perception of the health care providers; cultural competency. Perception of cultural competency was defined by the researchers as questions related to time spent with child, respect for family values, listening to the family, sense of partnership, and information provided. The review of the data indicated that perceptions of cultural competency did impact reporting and seeking care. Although many of the parents reported their children received the services they needed, a large number continued to report delayed/forgone care and dissatisfaction with care due to the perception of the provider's cultural competency. Thus, this relates to the theme that family care provider perceived caring as attentiveness and respect, which was clear throughout data collection and when this level of respect was present family caregivers reported feeling more confident in their ability to provide care to their child.

The concept of cultural congruence was examined by Constantino, Malgady, and Primavera (2009) related to the delivery of mental health services to older Latinos. The participants of this study were first-generation Hispanic/Latino immigrants, with 58% coming from Puerto Rico. The researchers studied whether cultural congruence predicted treatment outcomes and found that there was a moderate effect on the reduction of anxiety and a stronger effect on depression symptoms in older Latinos. Thus these findings, while related to an older population, indicate the importance of culturally sensitive and supportive interactions with clients in order to promote positive patient outcomes. This was also identified by Higgins (2000) in a study about Puerto Rican infant feeding practices. The researcher found that one of the strongest values in the Puerto Rican culture was love of family and family togetherness and described how family members were there to care for one another. The findings of this study



identified that health care providers should reinforce this value by initiating family-centered care and that family members should be treated with respect, warmth, and cordiality to establish a trusting relationship with the care provide

Jeglinsky, Autti-Ramo, and Carlber (2011) used The Measure of Process of Care 20 questionnaire to evaluate parents' experience of the family centered services (FCS) approach in care. A total of 53 families with a child with cerebral palsy and 29 providers were interviewed and in general positively rated FCS, however, one weakness noted by parents was consideration of the whole family in providing services. Additionally, the parents rated the perception of treating people respectfully and interpersonal sensitivity as very important. Parents also identified the need for general information but the importance of timing in relaying information. These findings were supported by Dickens, Matthews, and Thompson (2010) and Pickering and Busse (2010) in their studies in which the need for interpersonal sensitivity with the parents and timing were important in providing information as part of the rehabilitation process. The need for sensitivity in providing information supports the identification of the theme the professional caring is attentiveness and respect, as well as the theme of burden of care. Parents can be easily overwhelmed when receiving information and providing respectful and supportive communication as well as time to adjust to the information is important in the therapeutic interaction.

McHattan and Correa (2005) studied the perspectives of stigma and discrimination of Mexican and Puerto Rican mothers of children with disabilities. The researchers used the data from the Latino Family Study Project and transcripts were analyzed in an attempt to answer two research questions: 1). what are the reported perceived experiences of discrimination of Latina

mothers with a disabled child and 2). How do Latina single mothers of young children with disabilities respond to experiences of perceived discrimination? Data analysis indicated that the majority of participants perceived discrimination in their interactions related to their child. The response to this experience was to avoid interaction with others. This perception of discrimination arose from interactions with strangers and professionals. These findings were echoed in a study by Adams (2003), looking at Latinas with a diagnosis of diabetes. The participants described how social interactions with family and friends tended to focus on the disease of diabetes and they felt as though they were under a magnifying glass. These feelings of being different and a sense of isolation were all evident in the current population of Puerto Rican family care givers with a child with special care needs in the theme of burden of care.

Schmitt, Branscombe, Postemes, and Garcia (2014) in a meta-analysis, examined the relationship between perceived discrimination and psychological well-being. They conducted an analysis of correlational studies that revealed a negative relationship between perceptions of discrimination and well-being. They further examined the concept of discrimination across a variety of intergroup contexts, across a range of well-being measures, and for both personal and group discrimination and again it was negatively linked to perceptions of future well-being. The effect size for their findings were larger for children in comparison with adults. These findings related to those found by Lee and Ahn (2013), in another meta-analysis on African Americans in which the effect of perceived racism on psychological distress was larger for children than for adults. Francis (2012) examined the stigma experienced by middle-class parents with children with physical, psychological or behavioral problems. Parents expressed experiencing courtesy stigma and stigma related to being a bad parent. Courtesy stigma was defined as stigma that is

experienced by being associated with someone with a stigma, such as a child with a chronic illness. This is described in the literature especially hard for the parents whose child had no visible disability but experience behavioral or psychological issues (Schmitt, Branscombe, Postemes, & Garcia, 2014).

The results of these studies seem to relate to the themes of caring is respect and attentiveness and burden of care (Schmitt et al, 2014; Lee & Ahn, 2013; Francis, 2012; and McHatten & Corea, 2005). Puerto Rican family care givers often reported feeling alone, and that the responsibility of providing care to their child creates fear and uncertainty about their ability to provide care. Many of the family caregivers described feeling guilty if their child had issues with their health and sensed blame from care providers.

The themes that emerged through the analysis of the interviews with Puerto Rican family caregivers are connected to the literature that parents perceptions of family centered care with much of the findings supporting the need for communication, information, and relationships with health care providers (Siebes, Ketalaar, Gorter, Alsem & Jongmen, 2012; Foster, Whitehead, & Maybee, 2010). Zivaiani, and Darlington, et.al. (2014) examined the experiences of Australian families with complex needs with Early Intervention services. Family support and positive relationships were described as highly important to the participants. Additionally, the parents described the importance of responsiveness to the child and the families' needs, in other words family centered care. The need for informal support networks was as well as great support from family, friends and the community was also identified by this population. Foster, Whitehead and Maybee (2010) conducted a review of the literature expanding the perceptions of family

centered care (FCC) in developed and developing countries. Four themes emerged from the literature including communication, healthcare professional and parent relationships, caring for parents and available resources. The results of this review is related to Jolley and Shields (2009) who found that parents want and expect to be involved in the physical, psychologic, and emotional care of their hospitalized child. However, the review by Foster, Whitehead, and Maybee (2010) found that this level of communication and involvement was not consistently applied across the studies reviewed. Puerto Rican family caregivers reported feeling alone, and stressed over their ability to provide care. They expressed the importance of family support and in some instances described conflict within the family due to the child's SCHN. Including the family in care, such as what is described in the Family Centered Care literature would promote understanding and support.

Parents of chronically ill children have been identified as desiring for guidance and active support to be clear about their role, about what is expected of them, and what they can do to help their child (Siebes, Ketalaar, Gorter, Alsem & Jongmen, 2012; Coyne 1995, Melnyk 2000, Yin & Twinn 2001). Siebes, Ketalaar, et al (2012) conducted literature review on the needs of families with children with a disability. The results of the review emphasized the variety of needs experienced by the families and ranging from information about diagnosis and treatment to child-rearing. The authors summarized that each family has its own unique set of needs and that this should be recognized as part of family centered service provision. Bronheim, Soto and Anthony (2015) examined the used of Family-to-Family Centers as a way to address disparities in access to information for Hispanic families with children with SHCN. Results of this study

indicate that Hispanic families are most likely to seek information when experiencing concern and uncertainty about their children with SHC, such as a new diagnosis, a change in the child's status or a barrier to the child receiving needed services. The families noted that they preferred having one-to-one contact with an individual rather than receiving information from the internet or other electronic media. While web-based information was seen as helpful to answer general questions, this did not meet their needs when they were confused about the information they required to make decisions. Additionally, for Spanish-speaking families and those with low incomes noted limited access to and difficulties navigating the internet due to limited English proficiency. Gannotti, Kaplan et. al. (2004) noted that a central theme in the concept of the role of the healthcare provider for Euro-American and Latino families with children with SHCN was the expectation of competency in dealing with the child's condition as well as the child. This competency was defined as communication and making appropriate referrals. However, differences in communication styles and culturally defined social interactions between Latino and Euro-American parents of children with SHCN. The Latino parents relied on the healthcare providers to assist in conflict resolution with other providers related to care. The researchers concluded that Latino cultural values play a role in creating these cultural differences and created barriers for communication with healthcare providers. The findings of these studies relate to the Puerto Rican family caregivers need for clear supportive communication that allowed for time to think and absorb information so as to allow for questions.

This concept of needing time to absorb information was apparent in the discussions with the informants who described feeling more respected and supported when they were allowed time to think and ask questions. This was related to the description of caring behaviors and this

discussion relates to similar findings by Neary and Mahoney (2006), who looked at Hispanic families providing care to adult family member with dementia. In this study, all of the caregivers also described how the realization about the significance of needed to emerge one step at a time. They stressed that knowledge about the course of dementia and predictions about outcomes cannot be assimilated in the beginning and that they needed time to absorb it. This further supports the suggestion that nurses and other providers assess family caregiver's knowledge and offer information related to their readiness and level of understanding.

Hinojosa, Knapp, et al (2012) examined the impact of caregiving for children with life-threatening illnesses in White, African American and Latino families using the Impact on Families scale (IOF). The Latino families had higher scores on the IOF indicating that the stress and burden for latino families is greater than for white and African American families. The Latino family caregivers were more likely to state that no one understood the burden of care they carry. A metasynthesis by Coffey (2006), reviewed research on families of children with chronic illness and identified a sense of anxiety and concern over the ability to meet the needs of the child with a chronic illness, as well as the social isolation felt by the families during this experience. The results of this literature support the theme identification in the current study in that Puerto Rican family caregivers perceive a burden of care and that the responsibility for care creates fear and uncertainty in the ability to meet the child's needs, while family caregivers perceived caring as attentiveness and respect in interactions with health care providers.

Much of the past literature has focused on the health care providers perceptions of cultural competency in care. There is strong data to support there is a growing population of Puerto Rican families with children with special care needs and additionally literature

that indicates that there is a lack of satisfaction in the provision of culturally competent care by health care providers (Coffey, Cloutier Meadow-Oliver, & Terrazos 2012; Kerfeld, Hoffman, Ciol, & Kartin 2010; & McHattan & Correa, 2005). Hinojosa, Knapp et al (2012) identified that much of the caregiver literature treat Latinos as a cohesive group and that further work is needed on the sub-groups within this population. Further Kerfeld, Hoffman, Ciol & Kartin (2010) found that this dissatisfaction impacted seeking care by the parents of Latino children with asthma. The discovery of the themes from this study should inform nurses in providing care to Puerto Rican families with children with special care needs and to reduce barriers in seeking care.

#### 5.6 Discussion of Culturally Congruent Care

Care must be congruent to the cultural values and beliefs of the individual, family or group. According to Leininger (2006) nursing actions are guided through three components in order to provide culturally congruent care: cultural care preservation and/or maintenance, culture care accommodation and/or negotiation, and cultural repatterning and/or restructuring. The following is a discussion of these components.

##### 5.6.a Culture Care Preservation and/or Maintenance

The mode of culture care preservation and/or maintenance was described by Leininger (2006) as those assistive, supporting, facilitative, or enabling professional actions and decisions that help cultures to retain, preserve, or maintain beneficial care beliefs and values or to face handicaps or death. Nurses need to understand the importance of spending time and establishing relationship with both the Puerto Rican family caregiver and child, rather than just providing attending to the presenting problem of the child with health care needs. Just taking the time to

say hello, make eye contact, within what would be seen as social space with the family caregiver will assist in building trust and demonstrates the nurse cares about them and respects them as a person. The connection between this type of open, warm and friendly approach is key to the perception of a caring interaction with the Puerto Rican family caregiver and cannot be stressed enough. This relationship development is further enhanced with other family members who may accompany the family caregiver and the child with special health care needs are also greeted and acknowledged. Family connectivity and support is very important in the Puerto Rican family and the family caregiver derives a high level of comfort by have extended members present during times of stress. This should be taken into consideration in relation to family visiting policies in acute care situations. Additionally, the need for extra family support should be recognized within visits in physician offices or clinics, with the families being included in discussions with permission from the family caregiver.

#### 5.6.b Culture Care Accommodation and/or Negotiation

Culture care accommodation and/or negotiation and is “those assistive, accommodating, facilitative, or enabling creative provider care actions or decisions that help cultures adapt to or negotiate with others for culturally congruent, safe, and effective care for their health and well-being or to deal with illness or dying” (Leininger & McFarland, 2002, p. 84). Nurses and other health care providers need to incorporate for the presence of Puerto Rican family members, particularly during times of illness or stress. It is very important to Puerto Rican family caregivers to have family members such as adult siblings or grandparents present during illness. The valuing of family is a Puerto Rican cultural pattern and accommodations for added family presence provides an added sense of trust as well as comfort to all family members. This may



need to extend not to just immediate family but also extended family members to meet Puerto Rican values and beliefs.

A second accommodation is to adjust instructional methods to assist in comprehension of large volumes of information regarding illness, symptoms, and care management. Presenting in an attentive, respectful way and displaying active listening skills are very important to the trusting therapeutic relationship with a Puerto Rican family caregiver. Allowing for added time to ask questions and providing reinforcement of information, as well as sharing information with other family members helps to instill confidence and relieve stress and anxiety in the family caregiver.

Another way to accommodate culturally congruent care with Puerto Rican families with children with special health care needs is to develop a collaborative relationship between the school and the health care team. Ensuring clear communication with school nurses and families will aid in maintaining the health and well-being of the child. Supportive communication between care providers across the continuum, with consistent messaging will aid in family caregiver understanding as well as confidence and expertise in their role in maintaining the child's well-being. Additionally, nurses in schools should identify strategies to minimize the impact of appearing different due to illness that may be experienced by the child. Nurses and educators should monitor for isolation of the child due to health concerns and educate peer groups related to acceptance of differences among peers.

#### 5.6.c Culture Care Repatterning and/or Restructuring

Culture care repatterning and/or restructuring, the third mode, is “those assistive, supportive, facilitative, or enabling professional actions and mutual decisions that would help

people to reorder, change, modify, or restructure their lifeways and institutions for better (or beneficial) health care patterns, practices, or outcome” (Leininger & McFarland, 2002, p. 84). Puerto Rican families with children with special health care needs face many challenges to everyday life. Nurses and other health care providers need to assist in finding ways for the family to manage the demands of the providing care to a child with special health care needs while still maintaining family life within the Puerto Rican cultural values and beliefs. Ways to incorporate health behaviors needed by the child into normal daily life should be identified. An example would be in assist in identifying ways to include things like dietary restrictions into the Puerto Rican diet so that separate food does not have to be prepared for the child. This would minimize the sense of feeling different and isolation as well as potential social barriers.

Identifying ways to provide support and minimize the impact of stress and isolation are very important to the Puerto Rican family caregiver. Connecting the family to other families facing similar health issues would provide support as well as the perception that they are not alone. This would be especially helpful if the support was from other Puerto Rican families, so that like cultural and family values can be shared and discussed. Accommodations such as this can be promoted through primary care agencies by organizing family events and would promote family connectivity with the Puerto Rican community. An example of this would be connect with a parish or community agency to provide a health fair and include health information about children with special care needs, and resources available.

Puerto Rican family caregivers experience high levels of stress and anxiety related to their level of confidence in providing care for their child. They have reported feeling “judged” by health care providers. Therefore it is crucial that nurses and health care providers provide warm,

compassionate, and respectful communication at all times with the family. As stated previously, this will help to establish trust between the family caregiver as well as a sense of confidence resulting in decreased levels of anxiety and proficiency in maintaining health care behaviors with their child. This level of connection in communication is supported by a personalized approach including using preferred names as a form of address and including the family caregiver in the discussion of plan of care.

### 5.7 Nursing Implications for Theory Development

The application of the ethnonursing method enabled the discovery of both the etic and emic data and as guided by the CCT (Leininger & McFarland, 2002). The goal of this study was to reveal findings that would be used to educate nurses and other health care providers about the provision of culturally congruent care of the cultural care values of Puerto Rican family caregivers with children with special health care needs. The implementation of this methodology facilitated rich descriptive data collection related to of culture care needs for Puerto Rican families of children with special health care needs as described by the family caregiver. The Sunrise Enabler (Leininger & McFarland 2002) provided a framework for the development of a semi-structure interview which was used in this study.

This study adds to the body of transcultural nursing knowledge by providing knowledge regarding culture care experiences for Puerto Rican families with children with special health care needs, as perceived by the family caregiver. The findings from this study confirm the Culture Care Diversity and Universality Theory in that meanings and experiences of care can become understandable when viewed within a cultural context. In reviewing the assumptions of

CCT, it was identified that six of the eleven assumptions could be adapted to guide the researcher in the data analysis:

1. Care is the essence and the central dominant distinct and unifying focus of nursing.
2. Culture care expressions, meaning, patterns, processes and structural forms among Puerto Rican families with chronically ill children are diverse but share some commonalities.
3. Culture care values, beliefs and practices of Puerto Rican families with chronically ill children are influenced by and embedded in the worldview, social structure factors and the ethno-historical environmental contexts.
4. The culture of Puerto Rican families with chronically ill children has generic (emic) and professional (etic) care to be discovered and used for culturally congruent care practices.
5. Culturally congruent care occurs when the Puerto Rican cultural values beliefs, expressions, and patterns are explicitly known and used appropriately, sensitively, and meaningfully with people of diverse or similar cultures.
6. Informants will be truthful in their responses during all interactions with the researcher (Leininger, 2006, p. 20).

The rich descriptions culture care experiences of Puerto Rican families with a child with special care needs gained through this study contribute to culturally congruent care practices. These descriptions included commonalities within the patterns and themes related to how care is perceived by the care provider within their worldview. These commonalities were identified through the themes and can be used to support that culturally based care is promoted through the

establishment of a trusting, culturally congruent therapeutic relationship which begins with patience and respect in initial interactions.

While each family is unique and individual, the review of data reveals some commonalities in the culture care values, beliefs and practices from the worldview of the family care provider. The informants provided a depth of description related to how they perceive the care that is provided to them and their families in relation to their child with special care needs. The themes that emerged in relation to their world view help to inform nurses as to how their interactions are perceived and whether they are effective in meeting each families' unique needs. Commonalities among the informants included the theme of the burden of care, the sense the care was conveyed through listening and attentiveness and that their sense of responsibility for the care of their child create fear, anxiety and uncertainty about their ability to meet this challenge.

#### 5.8 Implications for Nursing Education and Practice

Children with special health care needs are reported to represent an important underserved population (AHRQ, 2003; Federal Interagency Forum on Child and Family Statistics, 2007; Van Dyck *et al.*, 2004). In 2005, approximately 13% of Hispanic children living in the United States, an identified underserved population, experienced some type of special health care need (United States Department of Health and Human Services, 2006). The literature indicates that children living with disabling conditions face discrimination in obtaining services due to the lack of availability, lack of trust by the family, as well as lack of cultural sensitivity and understanding by health care professionals (Pachter, Bernstein, Szalcha, & Garcia, 2010; Pachter & Coll, 2009; Edey & Robey, 2005; Robinson & Rathbone, 1999). Additionally, the

National Health Care Disparity Report demonstrates that racial, ethnic, and socioeconomic disparities are national problems that affect health care of children with all medical conditions (AHRQ, 2010). Thus, the findings in this study have implications for nursing education and practice related to minimizing health disparities and barriers to care for groups such as Puerto Rican families with children with special health care needs. The importance of family within Puerto Rican culture is not new in the literature so the discovery of the importance of family support in care experiences for Puerto Rican families with children with special health care needs supported this literature. However the level of stress and anxiety that the family caregiver experienced and the increased need for family presence and support further developed the knowledge base regarding this group. Discovering the perceived role expectation and the sense of responsibility and isolation of the care giver was insightful in relation to the need for support from a wide range of family members as well as from health care providers. The complexity in providing care and maintaining daily family life for the Puerto Rican family caregiver requires nurses pay attention to more than the physical needs of the child. Nurses must ensure the development of a trusting, respectful therapeutic relationship with the caregiver and the child in order to promote confidence in the caregiver as well as decrease stress and anxiety levels. Nurses and other health care providers must be educated on seeing the patient and family as one unit, or as Leininger describes, on the interconnectedness as integral to families (Leininger, 2006). Stress and anxiety can occur in one member such as the family caregiver that can result in negative health outcomes on others within the family.

Participants described non-caring as not listening attentively, appearing rushed, not maintaining eye contact or establishing a personal presence with the child and family caregiver.

There were frequent comments about nurses and other health professionals appearing “rushed” or “just looking at the computer”. This is powerful information to be relayed to nurses, nursing students and all health professionals related to verbal and non-verbal components of communication. This information should be used to inform educators as well as providers on ways to promote positive, supportive communication and the establishment of a trusting relationship with families from all cultures and in particular the Puerto Rican culture.

As part of promoting this level of culturally congruent care, nursing curricula should incorporate comparative culture care knowledge. Undergraduate curriculum should include transcultural nursing courses and practicums that provide learning experiences for developing cultural awareness and sensitivity. Additionally graduate curriculum must include transcultural nursing theories, clinical application of those theories, and the introduction to transcultural nursing research through a formal research project using Leininger’s theory or that of another theorist in order to ensure culturally congruent care across the health care continuum.

#### 5.9 Implications for Nursing Research

Family caregiver fear, worry and concern over the ability to adequately care for a child with special care needs is part of the family’s daily routine and sets the family apart from the mainstream families. As the number of children with special health care needs as well as the complexity of their health care increases, it becomes imperative that nursing continue to explore the culture care experiences of their families. The family caregiver has been identified as a key source of information related to the provision of day to day care for the child with special health care needs. Additionally, the family caregiver is most often the family member who assumes responsibility for the care of the child and is anticipated to have the greatest level of interaction

with the health care system. Nursing must continue to build on the on the body of knowledge related to family responses to health and illness (Feetham & Deatrck, 2002). This should begin with a clear understanding of the culture care needs of families with a child with special health care needs from the perspective of the family caregiver. Flores (1998) in a review of the literature found multiple sources of barriers to care for Latino children. Since that time the United States population demographics have continued to change to reflect a growing population of Latinos. Additionally, the National Survey of Children with Special Health Care Needs (2010) reports that 16% of the household in the United States include a child with special care needs in the United States. Findings from this study support the need for additional funding for support and health care initiatives directed towards families with children with special health care needs, and in particular Puerto Rican families.

#### 5.10 Recommendations for future research

In general, while there is literature on the cultural values and beliefs of the Puerto Rican family, there has been little research looking at the culture care perceptions of families. Further study is needed to determine if nursing interventions are meeting the culture care needs of this population. Recommendations for future research would include:

1. Replication of the study with a similar population, however with predominantly Spanish speaking participants
2. Replication of the study with other cultural or ethnic groups such as African or Asian American families in hopes to find commonalities across findings
3. Replication of the study with Puerto Rican families who have adult members with special health care needs.



### 5.10 Limitations

The researcher's inability to speak Spanish was a major limitation in this study in that only English speaking Puerto Rican family caregivers were interviewed. This may have resulted in a group of participants who were more acculturated to the cultural norms of the community. The level of acculturation was not assessed and this might have been important information to evaluate. Future research should include including Spanish speaking caregivers and the use of an interpreter as this may provide an added richness to the data that was collected?

The children that were part of the families all had chronic illnesses; however all were able to attend school and while they had some physical limitations these limitations were not severe. Future research should focus on Puerto Rican families with more severe or limiting health conditions in order to gain a greater depth of understanding of the worldview of Puerto Rican families with children with special care needs.

### 5.11 Summary

Learning to live with a chronic illness is challenging and this is even more complex when it is a child with special health care needs. There is a growing number of Puerto Rican families in the United States that have a child with special health care needs and this is very demanding and stress for the family caregiver. This study sought to discover the Puerto Rican family cultural needs because they are critical to planning culturally congruent care for this vulnerable population. Nursing implications for practice and education included promoting a trusting relationship between the nurse and the family caregiver that includes respectful, attentive listening as well as patience and support of understanding and comprehension of complex health care information. Family support is very important and accommodations should be made to

include additional family members in the plan of care. Policy and administration must focus on the development of funding and initiatives that will provide added support for these families as they attempt to maintain their child's well-being and development. A table with the chronic illness, the number of kids with each diagnosis and their age if available would be nice.

#### 5.12 Conclusion

This study examined the culture care experiences of Puerto Rican families with a child with special health care needs from the perspective of the family caregiver. Data collection and analysis sought to identify what are the culture care experiences of Puerto Rican families with a child with special health care needs as well as what is perceived as culturally congruent care by the Puerto Rican family caregiver. The intent was to discover findings that would be used to educate nurses and other health care providers about the provision of culturally congruent care to explore the culture care of Puerto Rican families with a child with special care needs from the perspective of the family caregiver. Leininger's Culture Care Diversity and Universality Theory and the ethnonursing method were used to conduct the study. In addition to answering the research questions, categories, patterns and themes were discovered and discussed regarding culturally congruent care experiences for Puerto Rican families with a child with special health care needs. Themes that were identified included: burden of care, caring is listening attentively and respect and responsibility creates fear and uncertainty in the ability to meet the child's needs. Nursing implications for practice, and education were presented and limitations were identified. Future areas for research were recommended including replication with other ethnic, minority or cultural groups.

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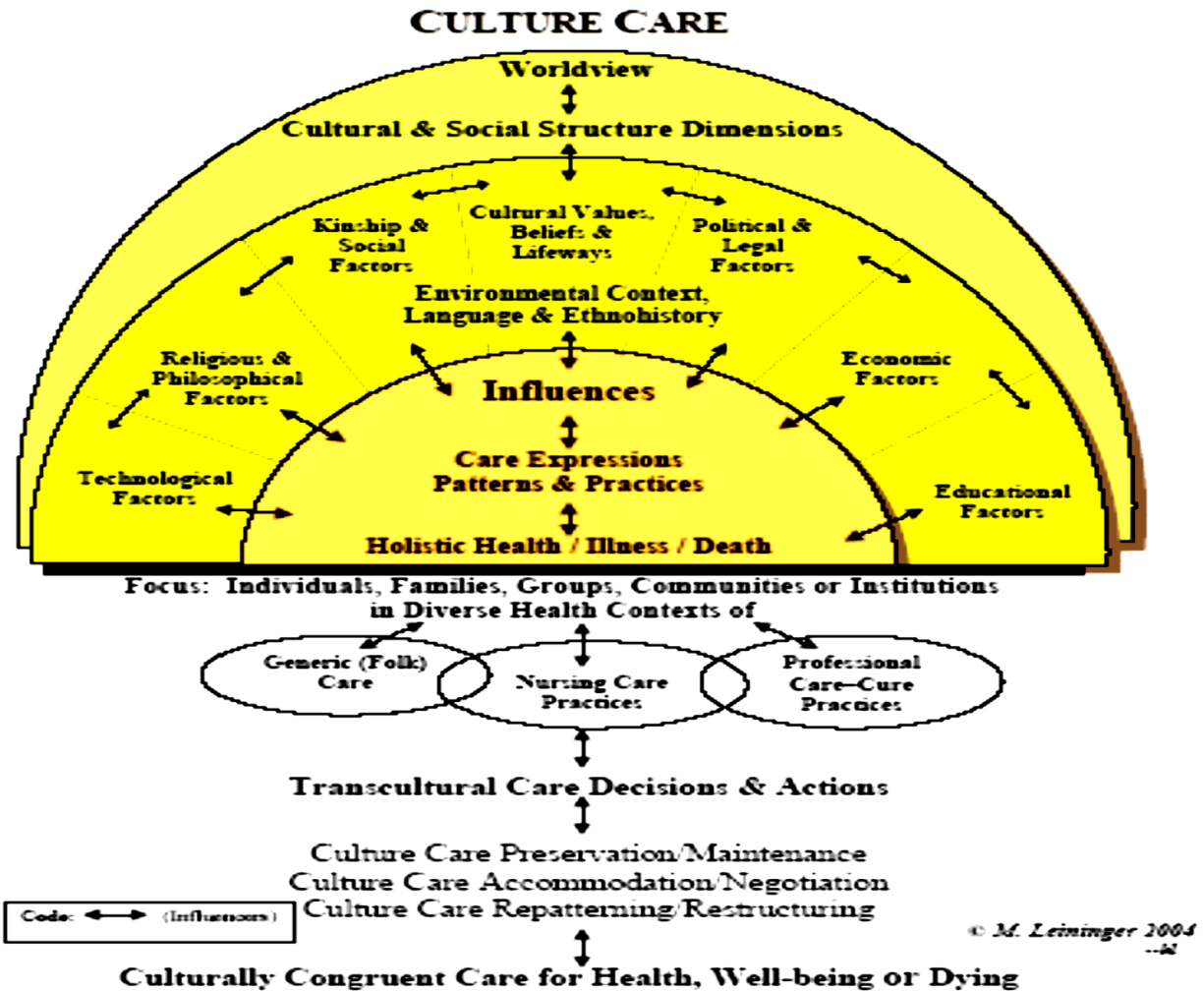
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APPENDIX A

Leininger's Sunrise Enabler to Discover Culture Care



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## APPENDIX B

### Leininger's Phases of Ethnonursing Research

1. Identify the general intent or purpose(s) of your study with focus on the domain(s) of inquiry phenomenon under study, area of inquiry, or research questions being addressed.
2. Identify the potential significance of the study to advance nursing knowledge and practices.
3. Review available literature on the domain or phenomenon being studied.
4. Conceptualize a research plan from beginning to the end with the following general phases or sequence factors in mind.
  - a) Consider the research site, community, and people to study the phenomena.
  - b) Deal with the informed consent expectations
  - c) Explore and gradually gain entry (with essential permissions) to the community, hospital, or country wherever the study is being done.
  - d) Anticipate potential barriers and facilitators related to: gatekeeper's expectations, language, political leaders, location, and other factors.
  - e) Select and appropriately use the ethnonursing enabling tools with the research process, e.g. Leininger's Stranger-Friend Guide and Observation-Participation-Reflection Guide and others. The researcher may also develop enabling tools or guides for their study.
  - f) Chose key and general informants.
  - g) Maintain trusting and favorable relationships with the people conferring with ethnonursing research expert(s) to prevent unfavorable developments.
  - h) Collect and confirm data with observations, interviews, participant experiences, and other data. (This is a continuous process from the beginning to the end and requires the use of qualitative research criteria to confirm findings and credibility factors).
  - i) Maintain continuous data processing on computers and with field journals reflecting active analysis and reflections, and with discussions with research mentor(s). Computer processing with Leininger/Templin/Thompsons's software is a helpful means to handle large amounts of qualitative data.
  - j) Frequently present and reconfirm findings with the people studied to check credibility and confirmability of findings.
  - k) Make plans to leave the field site, community, and informants in advance
5. Do final analysis and writing of the research findings soon after completing the study.
6. Prepare published findings in appropriate journals.
7. Help implement the findings with nurses interested in findings.
8. Plan future studies related to this domain or other new ones.

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From: Leininger, M., & McFarland, M. R. (2006). *Culture Care Diversity & Universality: A Worldwide Theory of Nursing* (2<sup>nd</sup> ed.). New York: National League for Nursing Press. Retrieved from <http://www.madeleine-leininger.com>. Made available under a CC BY 4.0 license.

**APPENDIX C**  
**STRANGER TO TRUSTED FRIEND ENABLER**

The purpose of this Enabler is to facilitate the researcher (or it can be used by a clinician) to move from mainly a distrusted stranger to a trusted friend in order to obtain authentic, credible, and dependable data (or establish favorable relationships as a clinician). The user assesses oneself by reflecting on the indicators while moving from stranger to trusted friend. These are dynamic indicators from cultures.

<b>Indicators of Stranger (Largely etic or outsider's view)</b>	<b>Dates Noted</b>	<b>Indicators of a Trusted Friend (Largely emic or insider's view)</b>	<b>Dates Noted</b>
1. Active to protect self and others. They are <i>gatekeepers</i> and guard against outside intrusions. Suspicious and questioning		1. Less active to protect self. More trusting of researchers (their <i>gatekeeping is down or less</i> ). Less suspicious and less questioning of researcher.	
2. Actively watch and attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.		2. Less watching the researcher's words and actions. More signs of trusting and accepting a new friend.	
3. Skeptical about the researchers motives and work. May question how findings will be used by the researcher or stranger.		3. Less questioning of the researcher's motives, work and behavior. Signs of working with and helping the researcher as a friend.	
4. Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values, and beliefs. Dislikes probing by the researcher or stranger.		4. Willing to share cultural secrets and private world information and experiences. Offers most local views, values, and interpretations spontaneously or without probes.	
5. Uncomfortable to become a friend or to confide in stranger. May come late, be absent, and withdraw at times from researcher.		5. Signs of being comfortable and enjoying friends and a sharing relationship. Gives presence, on time, and gives evidence of being a <i>genuine friend</i> .	
6. Tends to offer inaccurate data. Modifies <i>truths</i> to protect self, family, community, and cultural lifeways. <i>Emic</i> values, beliefs and practices are not shared spontaneously		6. Wants research <i>truths</i> to be accurate regarding beliefs, people, values, and lifeways. Explains and interprets <i>emic</i> ideas so researcher has accurate data	

From: Leininger, M., & McFarland, M. R. (2006). *Culture Care Diversity & Universality: A Worldwide Theory of Nursing* (2<sup>nd</sup> ed.). New York: National League for Nursing. Retrieved from <http://www.madeleine-leininger.com>. Made available under a CC BY 4.0 license.



**APPENDIX D  
ACCULTURATION ENABLER**

**Name of Assessor** \_\_\_\_\_ **Date:** \_\_\_\_\_  
**Informants or Code Number:** \_\_\_\_\_ **Sex:** \_\_\_\_\_ **Age:** \_\_\_\_\_  
**Place or Context of Assessment:** \_\_\_\_\_

***Directions:***

This enabler provides general qualitative profile or assessment of traditional or nontraditional orientation of informants of their patterned lifeways. Health care influencers are assessed with respect to worldview, language, cultural values, kinship, religion, politics, technology, education, environment, and related areas. This profile is primarily focused on *emic* (local) information to assess and guide health personnel in working with individuals and groups. The *etic* (or more universal view) also may be evident. In Part I, the user observes records and rates behavior on the scale below from 1 to 5 with respect to traditional or non-traditionally oriented lifeways. Numbers are plotted on the summary Part II to obtain a qualitative profile to guide decisions and actions. The user's brief notations each criterion should be used to support ratings and reliable profile. This enabler was not designed for quantitative measurements, but rather as a qualitative enabler to explicate data from informants.

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**PART I. Rating of criteria to Assess Traditional and Nontraditional Patterned Cultural Lifeways or Orientations**

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<b>Rating Indicators</b>	Mainly Traditional 1	Moderate 2	Average 3	Moderate 4	Mainly Nontraditional 5	<b>Rater Value No.</b>
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1. Language, Communication & Gestures (Native or Nonnative)  
Notations: \_\_\_\_\_  
\_\_\_\_\_
2. General Environmental Living Context (Symbols, material & nonmaterial signs).  
Specify: \_\_\_\_\_  
\_\_\_\_\_
3. Wearing apparel & Physical Appearance. Notations: \_\_\_\_\_  
\_\_\_\_\_
4. Technology Being Used in Living Environment. Notations: \_\_\_\_\_  
\_\_\_\_\_

<b>Rating Indicators</b>	Mainly Traditional 1	Moderate 2	Average 3	Moderate 4	Mainly Nontraditional 5	<b>Rater Value No.</b>
5.	World View (How person looks out upon the world). Notations: _____ _____					
6.	Family Lifeways (Values, beliefs and norms). Notations: _____ _____					
7.	General Social Interactions and Kinship Ties. Notations: _____ _____					
8.	Patterned Daily Activities. Notations: _____ _____					
9.	Religious (or Spiritual) Beliefs and Values. Notations: _____ _____					
10.	Economic Factors (Rough cost of living estimates and income). Notations: _____ _____					
11.	Educational Values or Belief Factors. Notations: _____ _____					
12.	Political or Legal Influencers. Notations: _____ _____					
13.	Food Uses and Nutritional Values, Beliefs, & Taboos. Specify: _____ _____					
14.	<i>Folk</i> (Generic or Indigenous) <i>Health Care (-Cure)</i> Values, Beliefs & Practices. Specify: _____ _____					
15.	<i>Professional Health Care (-Cure)</i> Values, Beliefs & Practices. Specify: _____ _____					
16.	Care Concepts or Patterns that guide actions, i.e. concern for, support, presence, etc.: _____ _____					

<b>Rating Indicators</b>	Mainly Traditional 1	Moderate 2	Average 3	Moderate 4	Mainly Nontraditional 5	<b>Rater Value No.</b>
--------------------------	-------------------------	---------------	--------------	---------------	----------------------------	------------------------

17. Caring Patterns or Expressions: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

18. View of Ways to: a) Prevent Illnesses: \_\_\_\_\_  
 b) Preserve or maintain wellness or health: \_\_\_\_\_  
 c.). Care for self or others: \_\_\_\_\_

19. Other Indicators to support more traditional or nontraditional lifeways: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Part II. Acculturation Profile from Assessment Factors**

*Directions:* Plot an X with the value numbers rated on this profile to discover the orientation or acculturation gradient of the informant. The clustering of numbers will give information or traditional or nontraditional patterns with respect to the criteria assessed

<b>Criteria</b>	1 Mainly Traditional	2 Moderate	3 Average	4 Moderate	5 Mainly Non Traditional
1. Language & Communication Modes					
2. Physical Environment					
3. Physical Apparel & Appearance					
4. Technology					
5. World View					
6. Family Lifeways					
7. Social Interaction & Kinship					
8. Daily Lifeways					
9. Religious Orientation					
10. Economic Factors					
11. Educational Factors					
12. Political & Legal Factors					
13. Food Uses					
14. Fold (Generic) Care-Cure					
15. Professional Care-Cure Expressions					

<b>Criteria</b>	<b>1</b> Mainly Traditional	<b>2</b> Moderate	<b>3</b> Average	<b>4</b> Moderate	<b>5</b> Mainly Non Traditional
16. Caring Patterns					
17. Curing Patterns					
18. Prevention/ Maintenance Factors					
19. Other indicators					

Note: The assessor may total numbers to get a summary orientation profile. Use of these ratings with written notations provide a holistic qualitative profile.

From: Leininger, M., & McFarland, M. R. (2006). *Culture Care Diversity & Universality: A Worldwide Theory of Nursing* (2<sup>nd</sup> ed.). New York: National League for Nursing Press.  
 Leininger's Acculturation Health Care Assessment Enabler for Cultural Patterns in Traditional and Nontraditional Lifeways originally published in the *Journal of Transcultural Nursing*, 1991.

**APPENDIX E**

**KEY AND GENERAL INFORMANTS OPEN INQUIRY GUIDE**

<b>Demographics</b>	
Codename:	Interview Date:
Age:	Location of interview
Years of education	Best method of contact
Gender:	Age of child
Religious Affiliation:	Gender of Child
Languages spoken	Diagnosis of Child
<b>Open Ended Questions</b>	
Environment	<p>Can you tell me where you were born?</p> <p>Is where you live now different from where you grew up?</p> <p>How?</p>
Kinship/Social Support	<p>Can you describe your family?</p> <p>What is it like to provide care for your child?</p> <p>How does your family make health care decisions?</p> <p>What is it like when your child is sick or needs care?</p> <p>Do you have friends or families that help you when your child is sick?</p>
Cultural/Family Lifeways	<p>What do you think of as your race?</p> <p>How do you describe your usual day and night at home? Does this change when your child needs extra care?</p> <p>How does being Puerto Rican affect how you are as a parent for your</p>

	<p>child?</p> <p>Can you tell me a story about a tradition or a celebration that you have had in your family?</p> <p>Do you feel that your family is different from other families?</p> <p>Can you describe how your cultural needs are included in your care?</p>
Religious/Spiritual	<p>Do you consider yourself a member of a church? Which one? What does that mean to you and your family?</p> <p>Can you tell me about your faith?</p> <p>Does your faith affect your family's health and well-being?</p> <p>Are there any religious traditions you follow to stay healthy.</p> <p>Are there any religious traditions you follow when your child is ill?</p>
Economic Factors	<p>What is getting healthcare like for your family?</p> <p>How do you pay for healthcare for your family? Are there extra expenses that come up in providing care for your child?</p> <p>Do you believe getting healthcare for your family here different than if you lived elsewhere?</p> <p>What is it like when you need to bring your child for health care at the clinic?</p> <p>What is it like when your child needs to go to the hospital?</p> <p>Are you worried about getting the right health care for your child?</p>
Political/Legal Factors	<p>Tell me is there anything about politics or health care policies that affect you and your family's life?</p>

	<p>How does the political system address health care needs for your family?</p> <p>What are some political issues for families with children with special health care needs?</p> <p>How does the political system in the area you live affect the health and well-being of your family?</p>
Education Factors	<p>What do you think about education in your area? Are you satisfied with it?</p> <p>Can describe what it is like for your child to go to school?</p> <p>How do you work with the school personnel to meet your child's needs?</p> <p>How does the educational system in your city affect your child?</p>
Family Health and Well-Being	<p>Can you describe what a healthy family is to you?</p> <p>What do the words well-being mean to you?</p> <p>How do you describe your child's health?</p> <p>What does the word "illness" mean to you?</p> <p>Do you think your child's special health care needs affect your family?</p> <p>How do you see your family when you compare it to other families?</p> <p>Can you describe what you do to help you stay well? What do you do to help your child stay well?</p> <p>What do you do when you become ill? What do you when your child is ill?</p> <p>Tell me about who you ask to help you when your child is ill.</p>



	<p>Who do you look for support when there is someone sick in your family?</p> <p>Is there anything different that you do to stay healthy here than what might be done in Puerto Rico?</p>
Caring Patterns	<p>Can you describe what a caring person is like?</p> <p>What is a caring nurse like?</p> <p>What is a non-caring nurse like?</p> <p>What does it feel like for you to care for your child with special health care needs?</p> <p>What do nurses do to show they care?</p> <p>Is there something that nurses at the clinic (hospital) can do to better meet your family's <i>health</i> care needs?</p>
Curing Patterns	<p>Can you describe what it is like when your child needs attention from a health care provider?</p> <p>Can you describe what it is like when nurses give care to your child?</p> <p>What makes it hard for you to seek health care for your child?</p> <p>What makes it easier for you to seek care for your child?</p> <p>Tell about some ways nurses could help your child stay healthy.</p> <p>Are there some ways nurses could help you when your child is ill?</p>
Domain of Inquiry	<p>Is there anything you would like to share about being from your culture and having a child with special care needs?</p>



**APPENDIX F**

**INTENT TO PARTICIPATE IN A RESEARCH STUDY**

**DUQUESNE UNIVERSITY**

**600 FORBES AVENUE ♦ PITTSBURGH, PA 15282**

**CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

**TITLE:** An Exploration of the Culture Care Experiences of Puerto Rican Families  
with a Child with Special Health Care Needs as Perceived by the Family  
Caregiver

**INVESTIGATOR:** Karen S. Rousseau, RN, MS  
1000 State St.  
Springfield MA 01019

**ADVISOR:** Rick Zoucha, PhD, APRN-BC, CTN  
School of Nursing, Duquesne University  
526 Fisher Hall  
Pittsburgh, PA 15282

**SOURCE OF SUPPORT:** None

**PURPOSE:** You are being asked to assist in a research study that will  
explore the culture care experiences of Puerto Rican  
families with a child with special health care needs are like.

The purpose of the study is to better understand the health values, beliefs and experiences of families such as yours. You may be asked to allow me to interview you from one to three times. The interviews may last from one to two hours and will be audiotaped and transcribed word for word. These are the only things that will be asked of you.

**RISKS AND BENEFITS:**

There are no risks involved in your participation in this study. If you feel uncomfortable or wish to end the interview at any time, you are free to say STOP. You may choose when you would like to take a break during the interview. There is no known direct benefit to you for participating in this study. However, the information you share about being a Puerto Rican family with a child with special health care needs will help nurses learn how to provide the best care possible to families like yours.

**COMPENSATION:**

Participation in this project will require no monetary cost to you, and will have no effect on the care provided to you or your child. You will be offered a token \$10 gift card to Walmart in return for your participation in any interview.

**CONFIDENTIALITY:**

Your name will never appear on any survey or research instruments. A summary of your de-identified quotes may be used, but no name will ever be attached so that confidentiality will be maintained at all times. You will never be identified in the data analysis. All written materials and consent forms will be stored in a locked file in the researcher's office. All information relating to this study will be destroyed five years after completion of the study.

**RIGHT TO WITHDRAW:**

You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time.

**SUMMARY OF RESULTS:**

A summary of the results of this research will be supplied to you, at no cost, upon request.

**VOLUNTARY CONSENT:**

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project. I understand that should I have any further questions about my participation in this study, I may call:

Karen Rousseau, principle investigator,  
PhD student Duquesne University

Dr. Rick Zoucha, of the School of Nursing, Duquesne University, Dissertation Chair  
526 Fisher Hall Pittsburgh, PA 15282 (412)396-6545

Dr. Joe Kush, Chair of the Duquesne University  
Institutional Review Board  
424 Rangos Hall, Pittsburgh PA (412)396-6326.

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Participant's Signature

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Date

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Researcher's Signature

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Date

**APPENDIX G**

**TRANSCRIPTIONIST CONFIDENTIALITY STATEMENT**

Confidentiality Statement

I, \_\_\_\_\_, understand that I may have access to personal information provided by persons involved as part of the study “Culture Care Experiences of Puerto Rican Families with a Child with Special Health Care Needs as Perceived by the Family Caregiver”. As a transcriber participating in the study I recognize I have an obligation to protect the confidentiality of the information acquired during the data collection and conduct of the study. I also recognize that I may disclose information acquired only with the consent of the individual(s) what is (are) the source of the information, and/or whom the information concerns, and of the nurse researcher.

My signature indicates my acknowledgement and acceptance of the obligation and restrictions on disclosure set forth above. I also realize that failure on my part to fulfill this obligation can lead to appropriate legal action.

\_\_\_\_\_  
Transcriptionist Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date