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**The Experience of Elderly Immigrants of Mexican Origin with Life-  
Limiting Illness: A Critical Ethnography**

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**The Experience of Elderly Immigrants of Mexican Origin with Life-  
Limiting Illness: A Critical Ethnography**

**by**

**Sandra Scott Lee, BSN, MSN, CNE**

**Dissertation**

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## **Dedication**

This dissertation is dedicated to the study participants, who generously shared their stories with me. They are, of course, unnamed due to research confidentiality guidelines, but I am ever so grateful to them for allowing me into their lives, families, homes, and communities.

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# **The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A Critical Ethnography**

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A record 33.7 million Hispanics of Mexican origin resided in the United States (U.S.) in 2010, comprising 10.7% of the total population and 63% of all Hispanics (U.S. Census Bureau, 2011a). Individuals of Hispanic or Latino origin made up 7.1% of the U.S. population of elders, aged 65 years and older (U.S. Census Bureau, 2011b). There is a disparity in access and use of health services among immigrant elders (Lowman et al., 2008; Lum & Vanderaa, 2010). The purpose of this qualitative study was to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the U.S. The study, a critical ethnography, was philosophically informed by Jürgen Habermas's critical social theory and guided by Urie Bronfenbrenner's ecological model. Thirteen first and second generation immigrants of Mexican origin were interviewed who were aged 65 years or older and diagnosed with heart disease, cancer, stroke, chronic respiratory disease, or diabetes. The semi-structured, audio-taped interviews were analyzed using Carspeken's five stages of critical qualitative research. Low and high level coding techniques identified the three large categories of *REACTING* to the diagnosis, *RESPONDING* to the illness, and *RELATING* to health care providers.

Findings suggest more research is needed to improve health care delivery to the population. In particular, the immediate emotional needs when diagnosed, appropriate assistance while learning to self-manage, and the paramount role of physicians and nurses in the elders' health care decisions merit further inquiry.



## TABLE OF CONTENTS

List of Tables .....	xii
List of Figures .....	xiii
List of Abbreviations .....	xiv
Chapter 1: Introduction .....	15
Introduction.....	15
Background.....	15
Problem.....	16
Purpose, Aim, and Research Question.....	18
Philosophical Framework .....	20
Overview of Research Design and Methods.....	21
Sample.....	22
Data Collection .....	22
Data Analysis .....	23
Rigor .....	24
Expected Contributions of the Findings and Future Implications .....	24
Plan of Remaining Chapters .....	25
Chapter 2: Literature Review .....	26
Demographic Changes .....	26
The Immigration Experience .....	27
Disparities in Care.....	28
Hispanic Cultural Norms .....	30
Health Care Cultural Norms .....	31

Care for Immigrants in Advanced Disease Stages.....	31
Conclusion of Literature Review and Gaps .....	34
Rationale for the Study .....	35
Chapter 3: Research Design.....	37
Philosophical/Theoretical Framework .....	37
Habermas’s Critical Social Theory .....	37
Bronfenbrenner’s Ecological Model.....	39
Identification of Assumptions.....	40
Methodological Techniques.....	41
Setting .....	41
Site 1 .....	42
Site 2 .....	43
Site 3 .....	43
Site 4 .....	44
Site 5 .....	45
Site 6 .....	45
Site 7 .....	45
Sample.....	46
Inclusion/Exclusion Criteria .....	47
Recruitment of Participants.....	47
Definition of Terms.....	49
Data Collection and Analysis.....	52
Provisions for Rigor.....	58

Potential Limitation .....	60
Ethical Considerations and Protection of Human Subjects .....	60
Protection of Human Subjects .....	62
Chapter 4: Findings.....	64
Introduction.....	64
Sample Characteristics.....	64
Interpretation of the Data.....	66
<i>REACTING</i> to the Diagnosis .....	67
<i>RESPONDING</i> to the Illness .....	71
Self-management .....	71
Self-advocacy.....	72
Interaction with the Community .....	73
<i>RELATING</i> to the Health Care Providers .....	74
Communication with Physicians.....	75
Communication with Nurses.....	78
Rigor with Data Analysis.....	80
Chapter 5: Discussion .....	81
Introduction.....	81
Interpretation of Findings in Relation to the Philosophical Framework.....	81
Interpretation of Findings in Relationship to the Ecological Model.....	84
Individual .....	84
Family .....	85
Community .....	86

Policy .....	87
Study Implications .....	88
Strengths of Study.....	89
Limitations of Study .....	91
Conclusion .....	93
Appendix A: IRB Approval .....	94
Appendix B: Recruitment Flyer.....	101
Appendix C: Research Consent Form.....	102
Appendix D: Participant Demographic Questionnaire .....	105
Appendix E: Interview Guide .....	107
References.....	109
Vita .....	127

## **List of Tables**

Table 3.1. Data Analysis Progression .....	57
Table 4.1. Demographic characteristics of the participants .....	65
Table 4.2. Eligible diagnoses of the participants .....	65

## List of Figures

Figure 3.1. Organizing Framework Based on Bronfenbrenner’s Social Ecological Model .....	41
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## **List of Abbreviations**

AHRQ	Agency for Healthcare Research and Quality
AOA	Administration on Aging
CDC	Centers for Disease Control and Prevention
DHHS	Department of Health and Human Services
IV	Intravenous
U.S.	United States
UTMB	University of Texas Medical Branch

# **Chapter 1: Introduction**

## **INTRODUCTION**

Chapter one provides an overview of the study. The philosophical framework that informs and organizes the study is described. The purpose of the study, significance, and research design are explained. Chapter one concludes with a brief overview of the remaining chapters.

## **BACKGROUND**

Nursing and the United States (U.S.) health care delivery system face a growing number of Hispanics in need of health care, specifically immigrants of Mexican origin. Hispanics, who in 2012 comprised 16.3% of the total U.S. population, accounted for over one-half of the nation's growth mainly due to increased immigration (Gonzalez-Barrera & Lopez, 2013; U.S. Census Bureau, 2010, 2011a). Within this immigrant group, demographic data has suggested a substantially large and unique elderly sub-group population. In 2011, individuals of Hispanic or Latino origin made up 7.1% of the U.S. population of elders aged 65 years and older, and this proportion grew to 8% in 2014 (AOA, 2015; U.S. Census Bureau, 2011b).

Elderly immigrants of Mexican origin likely are impacted by what is now known as a range of unmet health care needs of Hispanics in the U.S. Language, cultural barriers, and lack of access to both health insurance and preventive care shape Hispanic health care and contribute to health disparities (Office of Minority Health, 2013). The Centers for Disease Control and Prevention (CDC) has identified the leading causes of illness and death among Hispanics to be heart disease, cancer, stroke, diabetes and chronic respiratory disease (CDC, 2013). Minority groups underutilize palliative and hospice care, which



would be appropriate during advanced disease progression (Finestone & Inderwies, 2008). Moreover, there is an overall disparity of health services for immigrant elders (Lowman et al., 2008; Lum & Vanderaa, 2010). Specific data on immigrant elders of Mexican origin and end-of-life care have not been collected, but studies show that Hispanics have limited access and utilization of services during advanced disease stages (Park et al., 2012; Walshe et al., 2009).

## **PROBLEM**

There is a paucity of research directed at understanding and improving care of immigrants with life-limiting illnesses (Smith et al., 2009). The majority of literature studies addressing care of elderly immigrants describes demographic patterns and service utilization but neglects contextual factors such as elders' perceived experience, environment, sociopolitical status, and culture. Moreover, there is confusion about the terminology used to define Hispanic, Latino, and Mexican in many studies of immigrants; even the U.S. Census Bureau uses terms interchangeably, making it difficult to distinguish the specific groups under study and any resulting implications (Gonzalez-Barrera & Lopez, 2013; Humes et al., 2011; Passel & Taylor, 2010). The U.S. Census Bureau uses both of the terms Hispanic and Latino because in 1976 legislation was passed that mandated collection of information about U.S. residents of Mexican, Cuban, Puerto Rican, Central and South American, and other Spanish-speaking countries of origin (Talamantes & Sanchez-Reilly, 2010; Taylor et al., 2012). The legislation was due to lobbying by Mexican-American activists and Hispanic organizations to differentiate Mexican, Cuban, and Puerto Rican immigrants from whites (Vargas & Bishop, 2015). Subsequently, in 1997, the term Latino was added. In contrast, the term Hispanic generally refers to persons

of Spanish descent who share common cultural characteristics, regardless of race. Within the U.S., Hispanics include Mexicans, Mexican-Americans, Puerto Ricans, Cubans, Dominicans, Central and South Americans (Marín & Marín, 1991; Massey & Pren, 2012; Pylypa, 2001; Taylor et al., 2012).

Although limited studies have explored the health care needs of elderly immigrants of Mexican origin, Mexican immigrants account for the largest immigrant group in the U.S. As of 2014, 28% of the total immigrant population is of Mexican origin, with 8% of Mexican immigrants being age 65 years and older (Zong & Batalova, 2016). Furthermore, studies to-date do not make recommendations for nursing practice. The reason may be that practice recommendations are de-emphasized in publication criteria, with requirements instead focusing on background, design, methods, and results. The investigator accessed several nursing research textbooks and found that sections on making nursing recommendations were minimal or absent. Thus nursing research in general may not focus on the making of practice recommendations.

Understanding elder immigrants' experience with life-limiting illness is important to nursing because of the likelihood of providing care for those individuals. Nurses are on the front line of patient care in a health care system affected by political, social, and economic forces while being emotionally charged with the issue of immigration. This qualitative, critically-oriented study of the life-limiting illness experiences of elderly Mexican immigrants to the U.S. provides understanding about elderly immigrants of Mexican origin and their health care needs. This understanding is possible because critical approaches emphasize participants' expertise and consider assumptions that underlie the problem, language used to describe experiences, and the historical situation that has led to

oppressive systems (Polit & Beck, 2014). The view of knowledge in critical research is also subjective, dependent, and mediated on values (Polit & Beck, 2014). This critically-oriented study to describe life-limiting illness experiences of elderly Mexican immigrants to the U.S. takes into account elders' knowledge of their situations and experiences. The ethnographic quest of the study is to describe the cultural health beliefs and practices of elderly immigrants of Mexican origin with life-limiting illness.

#### **PURPOSE, AIM, AND RESEARCH QUESTION**

The purpose of this study was to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the U.S. The study aimed to answer the following research question: What are the perceptions of elderly immigrants of Mexican origin with life-limiting illness about their experiences with the U.S. health care system?

I would like to share the background of the dissertation topic selection. I go by Sandy, and I am a Registered Nurse in Texas, my home state. I set out with a passion to understand the experiences that immigrants with long term illness have with their health care experiences in the United States. My interest in the immigrant experience began when I was an undergraduate nursing student from 1985 to 1989 at Baylor University. Because I had some experience in high school with a typing course and medical transcription at an after-school job, I took a student position as a transcriber for the Baylor University Institute for Oral History. I was assigned to the Religion and Culture Project "A Series of Interviews Conducted with Persons who Participated in Church-Sponsored Aid to Central American Refugees" (Baylor University, 1995). The project was directed by Jacklyn Lee Jeffrey, PhD, an anthropologist who became a good friend. More information about the project can

be found in the Institute's archives in which my maiden name, Sandra Scott, is listed as a transcriber. The project was an account of what was commonly known as the "Sanctuary Movement." My role was to accurately transcribe the tapes of interviews with people who participated in church-sponsored aid to Central American refugees from the civil wars of the 1980s in Guatemala and El Salvador. Those who rendered assistance were in violation of U.S. law, since the U.S. government did not consider Central Americans to be legitimate refugees and prohibited them from entering the U.S.

There were 47 hours of interviews conducted between 1985 and 1990, a portion of which I transcribed along with 16 other transcribers and 8 editors. During my time as a transcriber and the many hours I spent listening to tapes in the basement of the Tidwell Building on the Baylor University campus, I gained a lifetime's education. As someone who hailed from an extremely homogenous, conservative small-Texas community, my world was opened to the plight of immigrants, or in this case political refugees, and the complicated and controversial interconnections with United States foreign policy, Regan-era politics, national security interests, international human rights, laws, ethics, and the importance of giving voice to the vulnerable. Consequently, I gained a love for qualitative research, interest in the immigration story, and immigration's relationship to the greater society and health outcomes. I will always be grateful for that opportunity and those days, and to my BSN alma mater for the opportunities I had to question and grow as an emerging young adult and novice nursing student. I also appreciate Dr. Jeffrey, who met with me in the early days of dissertation proposal development to listen to my ideas and offer friendly advice about working with the Mexican-origin population. Twenty years later, as a Registered Nurse who had focused her career, practice, and education in geriatrics, I began

my doctoral journey at University of Texas Medical Branch. Encouraged by faculty to explore literature of interest and find the gaps therein, I wondered about the state of health care for elders and remembered the influx of immigrants I had heard about and transcribed two decades before, although this time I was concerned about elders. A search of the literature revealed increased immigration and a growing population of elderly immigrants with health disparities, although little was known about their experiences with health care from their perspective.

I spent three weeks in summer 2011 in Lancaster, England at the International Observatory on End of Life Care (IOELC) at Lancaster University, where I was a student in the summer research intensive. I listened and learned from researchers who were doing qualitative work with Chinese immigrants and African-Caribbean migrants and was able to focus my study proposal. I am deeply grateful to the faculty at the IOELC, especially Drs. Kathryn Froggatt, Sheila Payne, Donna Wilson, and Jonathan Koffman, who inspired me by their own research to move forward with my study. I believe that the views and perspectives of elderly immigrants of Mexican-origin are very important because I have cared for them in many acute and community settings. These immigrants' views are not considered in program or policy initiatives, so the study opens a window of opportunity to understand experiences from their perspectives and in their own words.

## **PHILOSOPHICAL FRAMEWORK**

Critical theory comprised the study's philosophical foundation and the ecological model served as the organizing framework for the study. Critical theory interprets meaning and truth within the context of history and an understanding of societal structures: power; justice; and ways in which social institutions and constructs such as economy, race, class,

religion, gender, and education interact to construct a social system (Campbell & Bunting, 1991; Kincheloe & McLaren, 2000). Studies using critical theory raise awareness of social problems and power relations so that perspectives of marginalized people are understood and disseminated to affect social and political change (Polit & Beck, 2014; Weaver & Olson, 2006). The study was informed specifically by Habermas's critical social theory (Roderick, 1986). The organizing framework was Bronfenbrenner's ecological model, which aims to understand multiple levels of influences on health behavior (Sallis et al., 2008).

## **OVERVIEW OF RESEARCH DESIGN AND METHODS**

The research employed a critical ethnography design to answer the research question (Carspecken, 1996). Critical ethnography blends critical theory and ethnographic techniques and challenges the researcher to call into question the social and cultural conditioning of human behavior along with prevailing political structures (Kincheloe & McLaren, 2000). Critical ethnography field methods focus on communicative experiences as well as cultural typifications (Kincheloe & McLaren, 2000). Therefore, the selected approach demanded attention to two interrelated dimensions: (a) Elderly immigrants, who commonly face disparities of health access, utilization, and outcomes due to social, political, and historical inequalities and (b) the immigration experience, including its structural inequalities, which deeply and profoundly shapes experiences of those facing life-limiting illness. The literature strongly supported the former and alluded to the latter. The subjective experience of being an elderly immigrant of Mexican origin in the U.S. with life-limiting illness had not been explored previously. Critical ethnography provided a strong methodological approach for this study. Immigration is a condition with legal and

sociopolitical implications as well as a cultural phenomenon that affects health; its incorporation into the research design may add to understanding of the health care experience of elderly immigrants of Mexican origin who have life-limiting illness.

### **Sample**

The study was approved by the University of Texas Medical Branch Institutional Review Board (IRB), protocol 13-0427. Participants were recruited at churches, community centers, and clinics, places where IRB-approved flyers were posted. Sites were selected that primarily service the Hispanic community. Recruitment also occurred by word-of-mouth. Individuals interested in the study contacted the investigator directly using the cell phone information provided on the flyers. Written, informed consent was provided by each participant who met eligibility requirements. An opportunity to answer questions was given before beginning each interview. A purposive, non-random sample of 13 participants was recruited, enrolled, and interviewed. Eligible participants were self-identified as first or second generation immigrants of Mexican origin; aged 65 years or older; with a diagnosis of heart disease, diabetes, cancer, respiratory disease, or previous stroke; and English speaking.

### **Data Collection**

Participants were interviewed face-to-face by the investigator in a private area of their choosing and convenience. Interview protocol followed a semi-structured technique using leading questions and then probes (Georgiou et al., 1996). The researcher also asked demographic questions of participants and recorded the responses on an investigator-developed demographic form. Interviews were digitally recorded. Field notes and

interview jottings were made on A5 dot paper notebooks using a LiveScribe Pulse 4GB smart pen and uploaded to a computer for transcription. To ensure accuracy of transcription and avoid loss of interview data, a backup recording was made with a Sony ICD-PX312D digital voice recorder. The guiding question for elderly immigrants was “Tell me about your health.” Probe questions included “Can you give me an example?” and “Can you tell me more about that?” Initial observations from field notes and brief summaries of interviews were shared with participants at interview completion as part of a member check to achieve validity per Carspecken’s recommendation in Stage Three (Carspecken, 1996). Field notes and journal entries were stored securely in a locked cabinet in the researcher’s office. All interview data were de-identified and stored electronically with encryption and password protection. Data collection procedures are described in detail in chapter three.

### **Data Analysis**

The analysis was guided by Carspecken’s model for critical qualitative research, which has been widely applied to ethnographic studies and draws from a Habermasian perspective (Smyth & Holmes, 2005). Qualitative data collection and analysis occur simultaneously, which aligns with ethnographic methods (Spradley, 1979). Data collection and analysis was guided by Carspecken’s five stages of critical qualitative research: (a) building a primary record; (b) preliminary reconstructive analysis; (c) dialogical data generation; (d) discovering system relations; and (e) using system relations to explain findings (Carspecken, 1996; Hardcastle et al., 2006; Smyth & Holmes, 2005). These stages are described in detail in chapter three.



## **Rigor**

As outlined by Carspecken (1996) and consistent with his approach to critical ethnography, the study applied multiple requirements for validity claims. The processes of data triangulation, peer-debriefing, member checks, audit trail, and non-leading interview techniques to establish validity claims are discussed in detail in chapter three.

## **EXPECTED CONTRIBUTIONS OF THE FINDINGS AND FUTURE IMPLICATIONS**

A qualitative, critically-oriented study of the life-limiting illness experiences of elderly immigrants to the U.S. may offer increased understanding about elderly immigrants of Mexican origin and their health care needs to ultimately achieve social and policy change. The research is important to nursing because of the likelihood that many U.S. nurses will care for elderly immigrants in a variety of different care settings. Nurses are on the front line of patient care in a health care system affected by a political, social, and economic environment that is often emotionally charged with the issue of immigration controversies. Thus, studies that give voice to the stories of elderly immigrant participants who are experiencing life limiting illnesses may guide recommendations that will improve the health of elderly immigrants of Mexican origin. Critically-oriented studies describe the historical, cultural, and social contexts of participants and can reveal hidden power imbalances (Boutain, 1999; Mill et al., 2001). Realities of disparities in health care, which have been well supported by the literature, confront everyday nursing practice. The project contribution is significant because it is the first step in a research continuum expected to inform nursing practice, nursing education, and public policy through its consideration of the multiple influences of community, social, and political factors on delivery of end-of-life care of elderly immigrants of Mexican origin from a critically-oriented perspective.

## **PLAN OF REMAINING CHAPTERS**

This chapter presented an overview of the problem, the background and significance, the guiding framework, and the research question. A brief overview of the study design, methods, limitations, and assumptions was also presented. A review of pertinent literature about immigrants of Mexican origin with life-limiting illness is examined in chapter two. Chapter three details the research methods. The data analysis is presented in chapter four. Chapter five summarizes the findings, compares findings with the current literature, describes strengths and limitations of the study, and considers implications and recommendations.

## **Chapter 2: Literature Review**

The purpose of this chapter is to present a review and critique of published research studies and papers that represent and summarize the current state of knowledge about the experience that elderly immigrants of Mexican origin have with illness and health care. The review suggests gaps in research of the health care experiences of elderly immigrants of Mexican origin with illnesses that are leading causes of death in the U.S. Hispanic population, as well as the appropriate nursing implications for the population. The literature reviewed supports a qualitative, critically-oriented study of the life-limiting illness experiences of elderly immigrants to the U.S. for greater understanding of elderly immigrants of Mexican origin and their health care needs.

### **DEMOGRAPHIC CHANGES**

Demographic changes have necessitated that attention be given to the aging U.S. immigrant population. In 2009, one in eight of the 307 million people in the US was foreign-born (Grieco & Trevelyan, 2010). The American Community Survey data estimated that the total U.S. foreign born population increased by 11.1% from 2000 to 2009 (U.S. Census Bureau, 2009). Hispanics have accounted for over one-half of the nation's growth since 2000, with a growth rate four times that of the total population (Passel et al., 2011; U.S. Census Bureau, 2011a). Hispanics comprised 16.3% of the total U.S. population in 2012, with growth mainly due to increased immigration (Gonzalez-Barrera & Lopez, 2013; U.S. Census Bureau, 2010). The size of the Mexican origin population has risen dramatically since the 2000 census; a record 33.7 million Hispanics of Mexican origin currently reside in the U.S. (Gonzalez-Barrera & Lopez, 2013). In 2011, people of Mexican

origin in the U.S. comprised 10.76% of the total population (U.S. Census Bureau, 2011a). Individuals of Hispanic or Latino origin make up 7.1% of the U.S. population of elders aged 65 years and older (U.S. Census Bureau, 2011b). Second generation immigrants are defined as those born in the U.S. to at least one immigrant parent (Pew Research Center, 2013). In 2012, 20 million second generation immigrants resided in the U.S., and Hispanics comprised 35% of the second generation population (Pew Research Center, 2013). Texas demographic data on elders have been collected and grouped by Hispanics or Latinos of any race, regardless of country of birth. In 2010, Hispanics or Latinos comprised 37.6% of the Texas population (U.S. Census Bureau, 2011a). More recent data suggest that of Texans aged 65 and older, 20% are Hispanic (Hoque et al., 2012; Talamantes & Sanchez-Reilly, 2010). Actual numbers may be higher, as the population is historically undercounted (Alemán, 2000; Yeo, 2010).

## **THE IMMIGRATION EXPERIENCE**

Literature suggests that the immigration experience affects health outcomes. Immigration can be a stressful life event involving financial, medical, psychosocial, and role implications (Gorospe, 2006; Lum & Vanderaa, 2010; Mui & Kang, 2006). Older, foreign-born elders may experience different socioeconomic factors than their native counterparts; these factors also may lead to health disparities. Older, foreign-born elders have been characterized as being more likely to live with family, to be less educated, to live in poverty, and to participate in federal and state assistance programs (Angel et al., 2010; He, 2002). A survey of nationally representative population samples from Mexico and the U.S. revealed substantially higher prevalence of arthritis, cancer, diabetes, heart attack, and stroke among elderly Mexican Americans residing in the U.S. than among

elderly who reside in Mexico (Hazzouri et al., 2011; Patel et al., 2006), suggesting a correlation between immigration and chronic illness.

The immigration experience also may impact the health of second generation immigrants. Second generation Mexican immigrants have greater chronic illness risk than first generation immigrants to the U.S. For example, diabetes risk increases among second generation immigrants as does cardiovascular risk (Afable-Munsuz et al., 2013; CDC, 2015; Morales et al., 2011). Hispanics born in the U.S. have higher heart disease and cancer rates than foreign-born Hispanics (CDC, 2015). Two factors may contribute to increased health risk in second generation immigrants: greater retention of cultural practices from first generation parents and greater likelihood of low socio-economic status, which may limit social mobility (Acevedo-Garcia et al., 2010). The published qualitative studies that have included both first and second generation immigrants point to a social context that influences the declining health of second generation immigrants through a lack of identity support, social relationships, and discrimination practices (Viruell-Fuentes, 2007; Viruell-Fuentes & Schulz, 2009). Given these indicators, inclusion of second generation immigrants in studies that explore health care experiences in the U.S. was warranted.

## **DISPARITIES IN CARE**

A health disparity is a difference in health outcomes, the difference of which is closely related to a social or economic characteristic such as race or ethnicity; gender; socioeconomic status; or mental, physical, or cognitive disability (DHHS, 2008). Hispanics have numerous health disparities: 50% higher death rate from diabetes than whites, 24% more poorly controlled blood pressure than whites, 23% more obesity than whites, and 28% less colorectal screening than whites (CDC, 2015). The disparities in Hispanic health

may be related to education, poverty, and language barriers (CDC, 2015). Surveys have shown consistent disparities in health care services in the U.S. among the older immigrant population with advanced life-limiting illness. The probability of dying in a hospital is greater among immigrant Hispanics and Asians, and may be associated with lack of a relationship with a physician with whom to explore care alternatives or cultural differences in end-of-life preferences, difficulty in engaging the family, or language barriers (Carrion et al., 2011; Gaudio et al., 2012; Gelfand et al., 2001; Johnson et al., 2005; Kelley et al., 2011; Lackan et al., 2009).

Non-U.S. citizens, even those lawfully residing in the U.S., often are not eligible for federal health and welfare benefits when illness worsens (Gorospe, 2006). Benefit coverages for immigrants varies among states, suggesting potential inconsistencies in access to care (Campbell et al., 2010; Straube, 2009; Yee, 1991). States may determine Medicaid benefits within broad federal guidelines. For example, Texas did not expand Medicaid coverage under the Affordable Care Act to include eligibility based on income alone (Medicaid.gov, 2016). Texas also did not provide Medicaid coverage during the first five years of an immigrant's residence (except for children), even if the individual was lawfully present in the U.S. (Medicaid.gov, 2015). Even among those who are Medicare eligible, Hispanics have less utilization of end-of-life care than Whites (Adams et al., 2007; Carrion et al., 2011; Gordon, 1995).

The reasons for these discrepancies are not completely understood but may relate to cultural and family preference, language barriers, more sudden death, lack of referrals to end-of-life care, or misunderstanding about the benefit of end-of-life care. Another reason may be lack of health care coverage. Federal legislation prohibits non-citizens from

receiving federally-funded Medicaid for their first 5 years living in the U.S. (Nam, 2011; Massey & Pren, 2012). Therefore, elders who immigrate to be near family when they are ill are unlikely to have access to publically-funded care for five years. Elders who are undocumented are not covered by the Medicare benefit, nor are they eligible for insurance through the Affordable Care Act (Jaramillo & Hui, 2016).

## **HISPANIC CULTURAL NORMS**

Research literature on Hispanic cultural values has described concepts such as *simpatía* (kindness, dignity, and respect to others), *personalismo* (learning to trust by sharing personal information), *respeto* (acknowledgement of elder authority), and *familismo* (involvement in family culture) (Alemán, 2000; Marín & Marín, 1991). Such cultural norms may impact health. The Hispanic culture has been characterized by loyalty to family and closest friends, called *familismo*. Decisions, made in consultations with the family, are centered on pleasing the family. Extended families require time to discuss important medical decisions. The collectivist culture means that Hispanics often look to one another for advice (Alemán, 2000; CDC, 2012). *Respeto* refers to the cultural practice that individuals defer to someone with greater power or authority; this power is bestowed based upon gender, age, social position or title, and economic status. Because of *respeto*, Hispanics may often be hesitant to question doctors' recommendations (Carteret, 2011). *Fatalismo* is the cultural norm that accepts uncertainty, or that people can do very little to change their fate or health outcome (Carteret, 2011). This belief manifests itself when Hispanics prefer not to know their diagnosis, and if the diagnosis is chronic, they are more likely to consider it to be a death sentence (Carteret, 2011).

## **HEALTH CARE CULTURAL NORMS**

The U.S. health care system is a time and task oriented system. For example, some large clinic systems will cancel appointments if the patient is more than 20 minutes late. The Hispanic culture values relationships over tasks. If physicians are hurried and inattentive, a Hispanic patient may be dissatisfied with care (Carteret, 2011). The Hispanic cultural norm of time is a relaxed approach, focused on the present (Rivera & Rogers-Adkinson, 1997).

The norms of the U.S. health care system have exhibited discriminatory practices as well. Hispanics have recorded the highest uninsured rate of any ethnic group in the U.S., with 34.8% of foreign-born Mexicans living without health insurance (CDC, 2012). The lack of economic access to health care, culturally sensitive care, and policies that restrict Medicaid eligibility are all examples of institutional racism in U.S. health care (Randall, 2002). Many elderly immigrants have experienced life-long discrimination such as poverty and segregation. Thus, policy has threatened health benefits. For example, unlawful residents have not been eligible for health insurance coverage under the Affordable Care Act. Further, many immigrants who had never applied for citizenship lost their health care benefits under the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Talamantes & Sanchez-Reilly, 2010; Yeo, 2016).

## **CARE FOR IMMIGRANTS IN ADVANCED DISEASE STAGES**

Few studies have explicitly considered care for elderly immigrants who were in the advanced stages of life-threatening illnesses. The first identified published report on immigrants and end-of-life care was a descriptive, case-control study of hospice admissions, immigrant status, age, and site of cancer among referrals to St. Mary's Hospice



in Birmingham, England (Rees, 1986). The study found that immigrants overall were more likely to receive hospice care than patients born in Britain; yet within the immigrant group, Pakistani and Afro-Caribbean were less likely to receive hospice care than their European counterparts (Rees, 1986). Rees (1986) showed that at the earliest surveillance of immigrant hospice utilization, there was disparity for certain minorities within the overall immigrant population in Great Britain.

Yee (1991) used case studies and historical reports to identify barriers to health care for elderly immigrants in the U.S. A lack of understanding of culture, health-seeking behavior and beliefs, and service utilization by providers were found to be the primary barriers to service access for immigrant elders. Yee's (1991) work did not specifically address immigrant elders' country of origin but gave insight into the kinds of barriers that elderly immigrants faced when needing health care and potentially end-of-life care.

In the time since the Rees (1986) and Yee (1991) studies, the majority of literature addressing care of elderly immigrants has described quantitative demographic patterns and service utilization. Contextual factors best approached by qualitative inquiry such as lived experience, environment, sociopolitical status, and culture have been neglected. Although qualitative studies have not addressed elderly immigrants residing in the U.S., some studies have considered chronic or terminal illness experiences with adult immigrants aged 18 and over.

Kreling et al. (2007) conducted in-depth interviews with Latino and White non-Latino bereaved family caregivers to contrast experiences when choosing health care and how cultural factors affected their experience. Analysis of transcripts showed that few Latinos had prior knowledge or use of hospice services. The most salient theme was what

investigators described as the “secrecy dilemma,” which consisted of self-reported denial, preferences for minimal information from providers, and maintaining secrecy about prognosis. Latino caregivers were troubled by openness about dying and attempts by providers to talk to patients about death and prognosis. Kreling et al. (2007) suggested there was a cultural preference for indirect communication as well as traditional family-driven decision-making. Study participants were caregivers whose family members were already enrolled in hospice care, so the study did not capture the perspectives of Latinos who were not in hospice care. The participants were not specifically of Mexican origin, and the study sample was not specific to the elderly.

Smith et al. (2009) explored the perspectives of a physician, a social worker, a medical student, and a chaplain who cared for a young Central-American undocumented immigrant who died from leukemia in the U.S. The providers posited that there were significant communication issues due to language barriers, and that the patient’s limited health literacy contributed to misunderstanding of prognosis. Interestingly, health providers reported spiritual and religious misassumptions that the Latino family was Catholic when in fact the patient and partner were evangelical Christians. The authors concluded that aspects of the Latino culture had a profound influence on the end-of-life experience of the patient and her partner and recommended strategies to improve communication and be more culturally sensitive when caring for Latinos who are dying (Smith et al., 2009). A greater understanding of the culture and better communication skills would have likely resulted in greater quality of care during the death.

## **CONCLUSION OF LITERATURE REVIEW AND GAPS**

This review of the literature indicated an overall disparity of care in culturally-informed and accessible care for advanced illness for the growing immigrant demographic. There was a need to understand contextual factors and experiences of elderly immigrants of Mexican origin, and to include both first and second generation immigrants. To date, experiences with the U.S. health care system from the perspective of elderly immigrants of Mexican origin with life-limiting illness have not been adequately explored. Although some studies have focused on end-of-life care or chronic illness among immigrants and may have included some elders in their samples, none explicitly focused on elderly immigrants who had life-limiting chronic illnesses and their experiences with the health care system. The current study focused specifically on the health care experiences of elderly first and second generation immigrants of Mexican origin U.S. with illnesses that were the leading causes of death in the Hispanic population.

The review of literature indicated a gap in knowledge for the content area and weak methodologies. One weakness in most studies was a lack of philosophical foundation. If the philosophical foundation was identified, the methods and analyses often did not reflect the philosophy or general qualitative tenets. Member checks to validate findings with study participants were often absent, yet conclusions were made about the accuracy of participant cultural beliefs and values. Researchers often used qualitative approaches to answer questions clearly framed from an empirical paradigm. Most studies did not clearly reflect trustworthiness criteria, and findings weakly supported or did not reflect presented data.

Another significant literature gap was that in all but one of the qualitative studies reviewed, implications for nursing were not recommended. Anderson (1991) noted the lack

of nursing presence in her interviews with immigrant Chinese women and questioned nursing's invisibility in areas such as diabetic education and meeting patients' emotional needs, all of which are clearly within the nursing practice domain. Taxis et al. (2008) used interviews and transcription analysis to explore how perspectives of elderly immigrant participants of Mexican origin influenced their health care decisions. Although the researchers used their findings to make recommendations for nursing, no clear philosophical foundation or methodology was identified. The sample included Mexican American adults aged 21 years and older, with no specific criteria to include an immigrant or elderly population. Other studies reviewed did not mention nursing, including those conducted by nurse researchers.

#### **RATIONALE FOR THE STUDY**

A qualitative, critically-oriented study of the life-limiting illness experiences of first and second generation elderly immigrants to the U.S. should enhance understanding about elderly immigrants of Mexican origin and their health care needs and provide a starting point for policy recommendation and social change. The research was important to nursing because of the likelihood that many nurses in the U.S. care for elderly immigrants in a variety of care settings. Nurses are on the front line of patient care in a health care system influenced by politics, society, and economics, one that is often emotionally charged with controversies surrounding immigration. Thus, studies that give voice to the stories of elderly immigrant participants experiencing life-limiting illnesses may guide recommendations for improving the health of elderly immigrants of Mexican origin. Critically-oriented studies can describe the historical, cultural, and social contexts of participants and reveal hidden power imbalances (Boutain, 1999; Mill et al., 2001).

Realities of disparities in health care, well supported by the literature, confront every day nursing practice. The project contribution was significant because it could act as the first step in a research continuum expected to inform nursing practice, nursing research, and public policy by considering the multiple influences of communal, social, and political factors on delivery of end-of-life care of elderly immigrants of Mexican origin from a critically-oriented perspective.

## **Chapter 3: Research Design**

The research design is a critical ethnography. This chapter reviews the philosophical underpinnings, methodology of data collection and analysis, provisions for rigor, definition of terms, assumptions, sampling, and data collection. Data management strategies, procedures, and reliability and validity also are discussed.

### **PHILOSOPHICAL/THEORETICAL FRAMEWORK**

This study was philosophically informed by Jürgen Habermas's critical social theory and guided by Urie Bronfenbrenner's ecological model.

#### **Habermas's Critical Social Theory**

Habermas's critical social theory (Roderick, 1986) served as the philosophical underpinning of this study. Habermas approached knowledge by synthesizing the relationship between the empirical/analytical and historical/hermeneutic traditions into a "universal knowledge that will liberate individuals and communities from the power of distorted communication by creating knowledge which furthers autonomy and responsibility" (Welch, 1999, p. 356). Habermas considered modern society to be a division between a system world and a life world. The system world is regulated by money and power, but the life world is where one lived and communicated (Scheel et al., 2008). The system world is shaped by the political economy and state and exists separately from relationships and mutual understanding that comprises the human element, or the life world (Froggatt et al., 2011). Language, culture, and tradition makes up the life world and provides a framework for common understandings (Welch, 1999).

In order for a study to take its true critical, and thus emancipatory, focus, the participants (both subjects and researchers) aim for a communicative interchange that

rejects prejudiced opinion, acknowledges uninhibited self-representation, and claims universal understanding (Habermas, 1999). Dialogue is an interaction with participants that raises consciousness of both researcher and participants; this dialogue becomes a discourse to draw attention to the needs of certain groups. The dialogue between researcher and participant may reveal power structures, hidden meanings, and ultimately result in a plan for action and change at social and policy levels (Welch, 1999). The researcher serves as a transformative agent, advocate, and activist to promote understanding and change (Polit & Beck, 2014). This study achieved communicative interchange by directly involving the investigator in the interview process to seek understanding of how the experiences of life-limiting illness unfolded for the participants.

The study was guided by three major tenets of Habermas's work: (a) knowledge, mediated by social and historical power relations, is value-laden and only known in relation to human consciousness and experience; (b) all social order entails some kind of domination or power, so a critical orientation analyzes the society and culture to transform the status quo; and (c) language is central to knowledge creation and formation of meaning (Browne, 2000). Researchers search for meaning as expressed through verbal and nonverbal communication (Spradley, 1979). Because the critical researcher does not have claim to exact truth but recognizes multiple truths, the researcher can represent truth from the perspective of participants and thus recommend change: this is the overall intent of critical research (Vandenberg & Hall, 2011). While Habermas's ideas provide a framework, the ecological model helps to explain elements of health behavior at multiple levels of influence and outcomes.

## **Bronfenbrenner's Ecological Model**

The systems approach considers multiple levels of influence on health behaviors and outcomes—influences that are interrelated and influenced by environmental constraints (Best, 2011; O'Donnell, 2011). Although many have contributed to the development of ecological model ideas, Bronfenbrenner is frequently credited for its development (Kok et al., 2008). Bronfenbrenner's ecological theory suggests that levels of interaction influence human development and span cultural, social, economic, and political spheres (Ceci, 2006). The social ecological model has been applied to a wide range of health topics and is typically organized into nested sets of interacting levels or dimensions, which are components of individual activities, roles, relationships, or systems that influence health (AHRQ, 2013; CDC, 2015; Dahlberg & Krug, 2002). The idea is that the various dimensions allow for multiple influences among individuals; family members; school and work settings; and the larger social structures of community, economics, culture, and politics (Ceci, 2006; Kok et al., 2008; Sallis et al., 2008)

The social ecological model contains four levels of influence: (a) micro, the immediate environment in which an individual is operating, such as among family members, in a group or neighborhood; (b) meso, the interaction of the microsystems, such as the relationship of family and neighbors, or the impact of a faith community on a neighborhood and their indirect impact on an individual; (c) exo, parts of an environment in which an individual is not directly involved but which impact people, such as the loss of a job; and (d) macro, the larger cultural, social, and political and economic context (Crosby et al., 2011). This study considers individual, family, community, state, and national



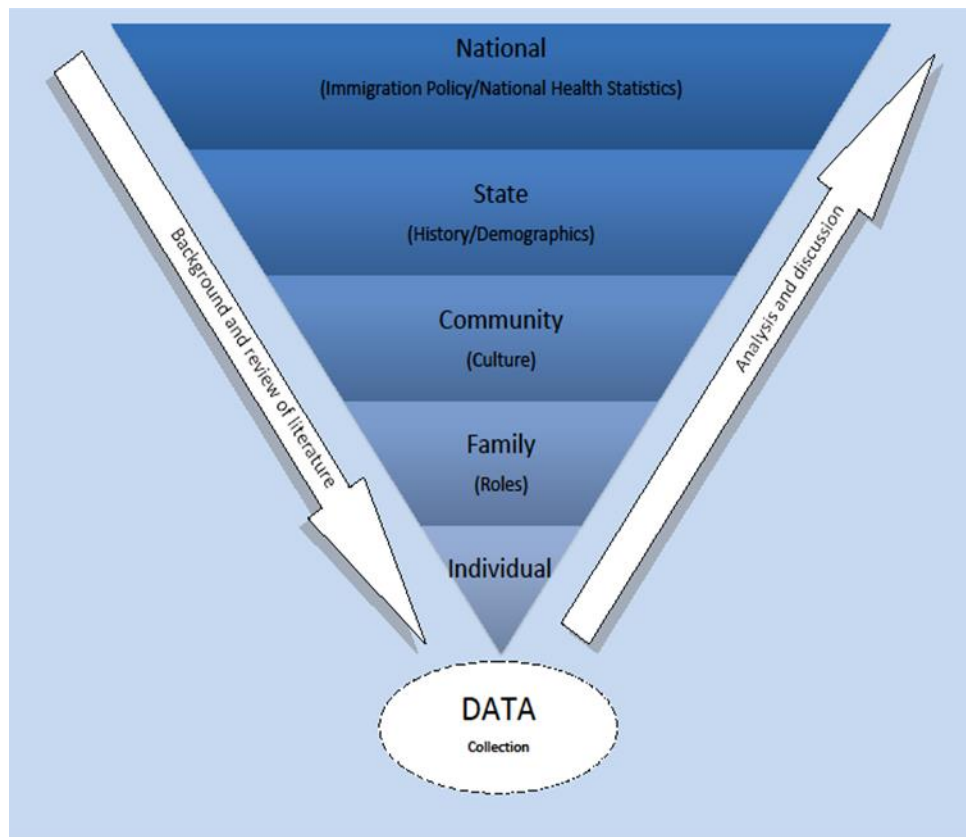
dimensions to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the U.S. (Figure 3.1).

The ecological model was particularly well suited to explore how elderly immigrants of Mexican origin perceived their life-limiting illness experience in relation to their immigration experience. The model guided the study and analysis for a comprehensive understanding at multiple levels of influence: individual needs, family context, culture and community influences, and policy constraints. Additionally, the model may be used to recommend multiple interventions for complex health situation and target possible barriers to effective use of resources and health care (Grzywacz & Fuqua, 2000).

#### **IDENTIFICATION OF ASSUMPTIONS**

The selected approach demands attention to two interrelated dimensions and assumptions: (a) elderly immigrants, who commonly face disparities of health access, utilization, and outcomes influenced by social, political, and historical inequalities and (b) the immigration experience, including its structural inequalities, which deeply and profoundly shapes experiences of those facing life-limiting illness. The literature strongly supported the former and hinted at the latter. The subjective experience of being an elderly immigrant of Mexican origin in the U.S. with life-limiting illness had not been previously explored. The topic warranted inquiry because nurses care for elderly immigrants in a variety of different care settings. Nurses are agents of social and political change through their advocacy activities, and the opportunity to care for vulnerable groups demands public awareness for their needs.

Figure 3.1. Organizing Framework Based on Bronfenbrenner's Social Ecological Model



### **METHODOLOGICAL TECHNIQUES**

Critical ethnography provided a strong methodological approach for this study. Immigration can be considered a topic with legal and sociopolitical implications, as well as a cultural phenomenon that affects people's health. Analyzing immigration in context with health policy may help improve the health care experience of elderly immigrants of Mexican origin who have life-limiting illness.

### **Setting**

A major characteristic of qualitative research is that data collection occurs in natural settings where interviews are comfortable for the participants while ensuring confidentiality and privacy (Creswell, 2007; Munhall, 2007). Twelve interviews took place

in private homes. Five participants opted to be interviewed at the home of friends or family members. One participant was interviewed at a clinic.

### *SITE 1*

Interviews one through four took place in two homes in the same neighborhood of a coastal port city dominated by the petrochemical industry. The neighborhood was lower middle class, with clean well kept small houses with sidings, and built approximately in the 1950's. The first three interviews were conducted in a married couple's home located on a large lot and surrounded by a chain link fence. The investigator was received into the couple's home through the front door by the husband, who held open the door. The investigator entered the home into a living room with family photographs dotting the walls.

The husband (Participant 1), his sister (Participant 2), and a friend (Participant 3) were interviewed at the couple's kitchen table. The wife, who was not eligible for the study, offered water to the investigator and each participant before the interviews started. The investigator entered and exited the home through the front door, but the sister and friend entered and exited the home through the back kitchen door.

Interview four with Participant 4 occurred in the same neighborhood a few streets away. The inside of the house was dark with low lighting, and the occupants were a husband and wife. The wife (Participant 4) answered the door and welcomed the investigator into the living room. The living room had numerous family photographs on the walls. The interview took place in the living room, with the investigator sitting on a chair and the participant on the couch. A side table with a well-worn Bible on the surface was between the participant and investigator. The participant's husband, who had Alzheimer's disease, was across the room but within sight. He sat on a straight chair at a

small table. His severe dementia was evident. He did not verbalize or make eye contact but occupied himself during the interview by playing the keys of a small toy piano.

### ***SITE 2***

The fifth interview took place in Galveston, Texas, a coastal city, at a home in a lower middle class neighborhood. The street was without activity during the morning of the interview. The home was on pilings, with a large, wide wooden stairwell leading up to the porch and front door. The driveway leading up to the home was concrete and uneven. The yard was trimmed and sparse. The participant (Participant 5) greeted the investigator on the porch when she arrived. The interview was conducted at the kitchen table. The living room was similar to the other living rooms in that the walls were covered with family photographs. One wall had a cabinet with many religious objects on display.

### ***SITE 3***

The interview with Participant 6 was conducted in Galveston, Texas, at a social outreach organization for low- or no-income residents called St. Vincent's House. The St. Vincent's property and ministry was owned and operated by the Episcopal Diocese of Texas and included space for after school and community events. The investigator spent a day observing at the clinic. It was a yellow building that had been painted with colorful religious symbols such as crosses, doves, and hearts and displaying positive words such as "Joy!" and "Welcome Bienvenidos" in large lettering. The brightly painted hallways were quite cheerful and led to an area with a large waiting room.

The staff at the clinic was extremely friendly; they made numerous offers to help the investigator, open doors if needed, and post flyers about the study. The clinic medical

and nursing staff were both employees and volunteers of University of Texas Medical Branch; patients at the clinic received care based on a sliding scale, according to income and family size. The clinic rooms were adjacent to the waiting room and on either side of a long hallway. Between the hallway and a large conference room was a charting and consultation area. The large conference room was bordered by windows on one side and by offices for the nurse practitioners on the other side. Each clinic room had a desk and an exam table. The walls of the clinic rooms and bathrooms had health information posters.

#### ***SITE 4***

Interviews seven through ten were at the same home in a neighborhood south of San Antonio, Texas, a large central Texas city. The neighborhood had evident Hispanic influence: signage in Spanish, newspapers in Spanish, and businesses advertising “Se Habla Español” (Spanish is spoken here). The houses and area businesses were painted in bright colors. Lawns and grassy areas were neatly trimmed and well maintained, and owners had placed colorful yard ornaments throughout their lawns. The investigator parked in front of the home, and the husband, Participant 7, met the investigator at her car. He helped the investigator bring the gift bags of fruit into the home and held the door. The modest home had a neatly trimmed front yard, and interviews were conducted at the kitchen table. The wife (Participant 10) told the investigator, “Make our kitchen table your office for the day.” The walls had family photographs. The wife offered water to the investigator and participants. Four interviews were conducted at this location, with Participants 7 through 10, each at the kitchen table, with the participant and investigator seated across from one another.

### ***SITE 5***

Interview 11, with Participant 11, was conducted at a home in a middle class neighborhood on the north side of San Antonio, Texas. The interview took place at a small table. After the interview, the participant's fiancé joined the investigator and participant and showed a photo album full of pictures of their family, including a new grandchild.

### ***SITE 6***

Interview 12, with Participant 12, took place at a senior living apartment complex in San Antonio, Texas. The modest apartment building had a large parking lot and was located off a busy boulevard. The investigator went to the front entrance and noted that the assistant was Spanish-speaking only. All signage was in Spanish, and there were metal stands with local, complimentary Spanish newspapers. The apartment, located on an upper floor, had a balcony with many houseplants displayed on plant stands. The apartment complex was busy with what appeared to be the residents talking, visiting, or coming and going into their neighbors' apartments. The apartment where Participant 12 lived was small, containing a seating area with adjoining space for a small table, a kitchen, and one bedroom. The interview took place at the kitchen table.

### ***SITE 7***

Interview 13, with Participant 13, occurred in a middle-class neighborhood in San Antonio, Texas. The neighborhood had broad, winding streets and brick homes. The home had a long sidewalk leading up to the front door, and a large shade tree in the front with very little grass. The participant, a Benedictine monk, met the investigator at the front door and escorted her to a formal dining area in the back of the home, adjacent to a large, open

kitchen. The home was quite different from the others with sparse furnishings, very little color, and a more modern interior. The floors were laminate, and the furniture large, such as a large dining table with big chairs. The dining area was adjacent to a large, spacious kitchen, again unlike the other homes of previous interviewees.

## **Sample**

A purposive sample of 13 elderly first or second generation immigrants of Mexican origin with life-limiting illness who spoke English was recruited. The elderly immigrants of Mexican origin with life-limiting illness were foreign-born individuals or second generation immigrants, aged 65 years and older, residing in the U.S. with a life-limiting illness, and self-described as of Mexican origin. The study used purposive sampling, often used in qualitative research to select individuals and study sites that can specifically inform the investigator about the research problem (Creswell, 2007). The anticipated sample size was a total of up to 15 participants who were interviewed until data saturation was reached. Cheek (2011) recommends the approach of letting the literature guide the proposed sample size for qualitative studies. Therefore, the rationale for the sample size was drawn from two of the research projects found in the literature: Im et al. (2007), who studied the pain experience among Hispanics with cancer, and Kreling et al. (2010), who conducted in-depth interviews with Latino and White non-Latino bereaved family caregivers to contrast experiences with choosing health care and how cultural factors affected their experience. Each study interviewed 15 participants. According to Hammersley and Atkinson (1983), ethnographers must consider resources and time to interview a group of participants more than once. Typically, ethnographers apply a method called judgmental sampling (Fetterman, 2010) and rely on researcher discretion to select

the most appropriate participants based on the research question, those who have knowledge of the phenomenon under study, and those who are willing to share (Lambert et al., 2011). Recruitment of participants was discontinued once data saturation was reached. Marshall (1996) indicated that data saturation occurs when new themes, explanations, or categories cease to emerge from the data.

### **Inclusion/Exclusion Criteria**

Inclusion criteria for study participants were (a) either foreign-born (first generation immigrant born outside of the U.S. to parents neither of whom was a U.S. citizen), aged 65 years or older, and self-identification of Mexican origin; or second generation (born in the U.S. with at least one immigrant parent), aged 65 years or older, and self-identification of Mexican origin (Pew Research Center, 2013); (b) diagnosis of a life-limiting illness (e.g., heart disease, cancer, stroke, chronic respiratory disease, diabetes); (c) cognitive ability to participate in an interview; and d) English-speaking by self-report and evident ability to converse with the researcher. Exclusionary criteria were (a) inability to share their experiences or carry on a cognitively congruent conversation; (b) non-English speaking; (c) third or higher generation immigrant, meaning that individual and parents were born in the US; (d) under 65 years of age; or (e) free of a life-limiting illness. There were no exclusionary criteria based on co-morbidities, enrollment in formal hospice services, race, ethnic origin, gender, or age at immigration.

### **Recruitment of Participants**

Institutional Review Board approval from the University of Texas Medical Branch-Galveston (UTMB) was obtained prior to recruitment (Appendix A). Participants were



recruited from agencies in southeast Texas that served Hispanic populations and a large number of immigrants. A flyer describing the study and including the researcher's contact information was posted in community center areas (Appendix B). The site directors referred and introduced potential participants to the researcher as a doctoral student who was conducting a research study. In one instance, a church leader referred a married couple, who then recruited a family member and friend for the study. In another instance, a member of a high school alumni association who was not eligible for the study but knew of several interested people contacted her friends in the alumni association and informed them of the study. Participants 7 through 13 were all connected in some way to the high school alumni association, either by their own membership or that of a family member. Interested individuals contacted the researcher by cell phone or, when referrals were received, the investigator called potential study participants. Individual, confidential conversations occurred with elders interested in study participation. During these conversations the investigator described the study and assessed participants for eligibility.. The researcher explained that participation in the study was voluntary, that participants could withdraw from the study at any time, and that nonparticipation or withdrawal from the study would not affect the provision of agency services. Participants were given the opportunity to ask questions. Once eligibility was established, informed consent was obtained to include permission to audiotape interviews. The consent form was read to participants before asking them to sign the consent (Appendix C). A copy of the consent form, the investigator's phone number, and contact information of the dissertation supervisor were provided to participants. Times were arranged for interviews at private locations that were mutually agreeable to participants and researcher. Participants also were recruited by

snowball sampling and word of mouth. Study participants received a small gift bag with an assortment of fruit, a granola bar, a bottle of water for participating in the study, a \$25 gift card to a local supermarket, and a copy of the free, publically available Senior Resource Guide specific to the region where the participant lived; all of these incentives were approved by the UTMB IRB. The bag of fruit was given to support the cultural norms of *simpatía*, treating a host with courtesy, and *respeto*, recognizing that the researcher was a guest in the homes of her hosts and hostesses.

Definition of “first” and “second” generation immigrant became problematic during word-of-mouth recruitment. The investigator used The Pew Research Center (2013) definition of second generation immigrant, i.e., those born in the U.S., Puerto Rico, or other U.S. territories with at least one first-generation immigrant parent. However, the participants were quick to point out that their community defined first generation as the first generation that was born in the U.S.

## **DEFINITION OF TERMS**

- Elderly: This study uses the term “elderly” to refer to individuals aged 65 years and older. In the U.S., 65 years of age is when a person can begin to receive Medicare benefits (Centers for Medicare and Medicaid Services, 2012). Most developed countries have defined the ages of 65 years or older as being part of the elderly population (World Health Organization, 2013).
- Mexican origin: The U.S. Census Bureau has defined “Mexican” and “Mexican origin” interchangeably. The term is used based on self-identification of Mexican origin or descent, not necessarily place of birth or nationality (Ennis et al., 2011). Therefore, a person who was foreign-born (born outside the U.S.) but identified

ethnically with Mexican origin was considered for the study. Second generation immigrants, born in the U.S. to at least one foreign-born parent, who identified ethnically with Mexican origin, were considered for the study.

- Foreign-born, first generation immigrants: The U.S. Census Bureau has defined “foreign-born” as anyone living in the U.S. who is not a U.S. citizen at birth (U.S. Census Bureau, n.d.). More specifically, the Pew Research Center (2013) has referred to “foreign-born” as first generation immigrants, individuals born outside of the U.S., Puerto Rico, or other US territories to parents neither of whom was a US citizen. Furthermore, foreign-born residents are classified by citizenship. Non-citizens may be lawful permanent residents (immigrants) who have permission to live and work in the U.S., temporary migrants (such as foreign students) who are granted permission to be in the U.S. for a specific purpose and limited time, humanitarian migrants (such as refugees or asylees) granted permission to live in the U.S. due to persecution in the country of origin, and people unauthorized to be in the U.S. (The National Center for Children in Poverty, 2005; U.S. Census Bureau, n.d.). Undocumented immigrants may include those who entered the country illegally, or those who entered legally but stayed past the terms or conditions of their visa (Gonzalez-Barrera & Lopez, 2013; The National Center for Children in Poverty, 2005). The definition of “foreign-born” by the U.S. Census Bureau guided the sample selection of first-generation immigrants for this study. Participants in the study who self-reported being born outside the U.S met the foreign-born criterion. Participants were not asked about their legal status.

Citizenship or legal status to reside in the U.S., or lack thereof, was not a condition to participate in the study.

- Second-generation immigrants: The Pew Research Center (2013) has defined second generation immigrants as those born in the U.S., Puerto Rico, or other U.S. territories with at least one first-generation immigrant parent. The definition of “second-generation,” as indicated by The Pew Research Center, guided the sample selection of second-generation immigrants for this study. Participants who self-reported as having at least one parent born outside of the U.S. met the second-generation criterion.
- Life-limiting illness: Life-limiting illness was defined for this study as one or more of the following leading causes of death in the U.S. as identified by the Centers for Disease Control and Prevention (2013): diseases of the heart, all cancers, stroke, chronic respiratory disease, and diabetes.
- Cognitive ability to participate: All participants had cognitive ability to participate in the interview. Cognitive ability was assessed when explaining the study and assessing eligibility criteria. Cognitive ability was determined by behavior and choice of words appropriate to the situation, attentiveness, and concentration while conversing with the researcher (Braes et al., 2012; Milisen et al., 2006).

## **DATA COLLECTION AND ANALYSIS**

Qualitative data collection and analysis occur simultaneously—a characteristic particularly true of ethnography (Spradley, 1979). Data collection and analysis were guided by Carspecken's five stages of critical qualitative research (Carspecken, 1996; Hardcastle et al., 2006; Smyth & Holmes, 2005). Carspecken's data analysis stages were:

1. Building the primary record (Stage One): Initial intensive observations of the surrounding environment, activities, and schedules at the agencies was made and thick descriptions recorded in the field notes. Memos were recorded to merge thoughts and possible low level description of the observations.
2. Preliminary reconstructive analysis (Stage Two): The subjective and normative realms were explored. The cultural context began to emerge in this stage, as observations of roles and possible power relations were reflected upon. Coding and categorization of data began at this stage by reading the records and generating codes and data portions that eventually were used to describe patterns (Georgiou et al., 1996). The field notes were reviewed to identify emerging patterns (Smyth & Holmes, 2005). The investigator closely followed Carspecken's methodology (1996) for coding interview data. Low-level coding, which is very close to the primary record and objective observations and involves very little abstraction, was conducted (Carspecken, 1996). Low-level coding includes direct observations and interview excerpts, especially speech acts of repeated use. Following the low-level coding, high-level coding was applied. High-level coding has a higher level of abstraction and is based on the initial low-level codes (Carspecken, 1996). Coding methods as described by Carspecken (1996) were followed closely and allowed the

investigator to stay immersed in the data.. The final organization into large categories was completed after the data collection, as per Carspecken's method (1996). Table 3.1 (below) provides an example of how the data analysis progressed.

3. Dialogical data generation (Stage Three): Interview protocols followed a semi-structured technique with leading questions and probes (Georgiou et al., 1996). An investigator-designed demographic data form (Appendix D) and semi-structured interview guide (Appendix E), both IRB-approved, were used to collect information from the participants and to facilitate the interviews. The guide had open-ended questions that closely followed Spradley's (1979) guidelines. The researcher asked each participant demographic questions and recorded the responses on the form. Participants were invited to meet in a private area of their choosing and convenience. Interviews were conducted in participants' homes, and in one instance, a clinic setting. Participant observation was made during the interviews in accordance with Spradley's (1980) definition of passive participation. Passive participation means that a researcher is present at the scene but does not participate to a great extent with the participants. Passive participation can move to more involvement, such as interviews, to support the observations (Spadley, 1980). Interviews were digitally recorded. Field notes and interview jottings were made on an A5 dot paper notebook with a LiveScribe Pulse 4GB smart pen and uploaded to a computer for transcription. To ensure accuracy of transcription and avoid loss of interview data, a backup recording was made with a Sony ICD-PX312D digital voice recorder, which was also uploaded to a computer. The broad question to open the interview time was "Tell me about yourself," then "Tell me about your health."

Probe questions included “Can you give me an example?” and “Can you tell me more about that?” Initial observations from field notes and brief summaries of interviews were shared with the participants at the end of the interviews as part of member check to achieve validity, per Carspecken’s (1996) recommendation for Stage Three. Nonverbal cues, such as gestures and facial expressions, were noted in the field notes and included on the transcripts. The researcher maintained a personal journal to record and monitor personal assumptions, beliefs, and pre-conceived ideas that may have informed research process. Field notes and journal entries were secure in a locked cabinet in the researcher’s office. All computerized data were stored electronically with encryption and password protection to protect patient confidentiality. The investigator, who had previous experience in medical, oral history, and qualitative interview transcription, transcribed each of the interviews verbatim and listened to them multiple times during the transcription and analysis process. Each transcribed interview was read and compared to the recording to ensure accuracy. When there were background noise or garbled words, the recording was slowed during transcription and repeated, or the alternate form of the recording was accessed to double-check the words or phrases.

4. Discovering System Relations (Stage Four): Data were linked to broader sociopolitical aspects through objective analytical style and identification of low and high level categories (Carspecken, 1996), and guided by the practical techniques outlined by Ryan and Bernard (2003): note repetitions; co-occurrences and similarities in wording; and descriptions of culture. Kincheloe and McLaren (2000) asserted that research informed by critical theory must include the act of

interpretation. Analysis in this critically-oriented study created a portrait that linked elders' experience in health care with the broader social and political structures that shape the immigrant health experience. During Stage Four, the researcher typically links findings to another cultural site or similar institution or with other resources that give insight into the phenomena (Georgiou et al., 1996). The focus in Stage Four is to look for relationships between specific social sites, sites related to the study site (Carspecken, 1996). This research study interviewed participants from multiple regions in Texas, and the data were consistent among sites. The goal, according to Carspecken (1996), is to notice cultural products that seem to impact the subjects of the study. The researcher consulted published literature during Stage Four to compare and contrast the findings with those results (Carspecken, 1996; Smyth & Holmes, 2005). These comparisons were made to discover possible relationships between the site of the study and other sites in society through existing publications. Data were compared between study sites for system integration; field notes, observations, and interview transcripts were analyzed and compared to construct meaning (Smyth & Holmes, 2005; Vandenberg & Hall, 2011).

5. Using System Relations to Explain Findings (Stage Five): Findings were explained in relation to micro/macro theory (Carspecken, 1996), which was the application of the ecological model in this study. A macrosociological theory, such as the ecological theory, traces cultural themes to economic and political conditions and facilitates understanding of the research findings. From a critical theory viewpoint, the outcome is a description and interpretation of the participants' experiences with the health care system, in relation to the larger social world; individual and family



values; cultural patterns; political and economic conditions; and history factors (Georgiou et al., 1996). The ecological model as conceptualized by the investigator was applied in Stage Five to describe and explain findings in relation to individual values; family roles; cultural, demographic, and historical patterns; and immigration policy and political conditions at the national level.

The final large categories and their sub-categories were as follows:

Large Category: *REACTING* to the Diagnosis, with sub-categories Feelings, and Family Experiences.

Large Category: *RESPONDING* to the Illness, with sub-categories Self-management, Self-advocacy, and Community Interaction.

Large Category: *RELATING* to the Health Care Providers, with a sub-category of Experiences with Physicians and Nurses.

Table 3.1. Data Analysis Progression

Raw data	Low-level Code	High-level Code	Sub Category Example	Large Category
P. Well, you know, I had heard about diabetes, and that it kills you, you know, that if you let it go unattended, you're gonna keel over any day, you know, so if you take yourself, care of yourself, it's gonna affect a lot of organs and such. So I was kinda scared of it. P13, L278-279	Learning about the Diagnosis	Devastation	Feelings	<i>REACTING</i> to the Diagnosis
I. So it sounds like there were a lot of things you couldn't do during that time. P. Oh yes, oh yes. I couldn't do it. There was nothing I...I take my medicine every day, need it or not need it. And, uh, I've been feeling pretty good. P5, L94-96	Following Medical Instructions	Experience of Illness	Self-Management	<i>RESPONDING</i> to the Illness
I. Ok. So you're willing to do exactly what the doctors and nurses tell you to do, P. Yes. I. Right. P. That is, that is because I know they want the best, the better for me. And I trust in them. I. Okay. So trust is important. P. Oh yes, oh yes. The day that I don't feel or I don't receive what I need, or something wrong for me, my confidence is gone. Trusting is the word. I. Yes. P. If you don't trust, it have to be hard for you to do the things they said, because if you trust in them, you know it's good for you. It's the best. P4, L292-316	Trust	Involvement of the Health Care Providers	Physicians and Nurses	<i>RELATING</i> to the Health Provider

## **PROVISIONS FOR RIGOR**

The study applied multiple requirements for validity claims as outlined in Carspecken (1996) and which were consistent with his approach to critical ethnography. Carspecken's requirements for rigor were:

1. Use of multiple instruments to recording data: Data were tape recorded by both a LiveScribe pen and a Sony digital recorder while simultaneously creating field notes. The LiveScribe technology allowed for field notes to be electronically synchronized with audiotaped interviews. Use of multiple recordings supports veracity that what actually was said or took place indeed occurred. Written notes were electronically synchronized with the recorded words to compare observations with responses to the interview questions. Polkinghorne (2005) suggested that interviewing multiple participants also served as a form of triangulation, as the researcher can recognize and locate meaning across different accounts.
2. Use of peer-debriefing to check for biases or leading: A peer debriefer should read field notes and transcripts to check for subjectivity, use of high inference vocabulary, or leading interview techniques. The researcher's dissertation advisor served as a peer debriefer very early in the process, i.e., after the first data were generated and throughout the remaining data collection and analysis. The dissertation advisor reviewed transcript analysis and provide feedback on the interpretation. Transcripts were reviewed independently by the investigator and her advisor, then together as a team. The dissertation advisor was experienced in qualitative methodology. Each interview was reviewed at least

twice by the team, and the investigator reviewed them multiple times to code and identify common categories. The investigator consulted primarily with the dissertation advisor and received input when needed from committee members, particularly in regard to interpretation and explanation of the data. The committee members represented depth and breadth of methodology and clinical interest in the target population.

3. Use of member checks: Member checks were conducted at the end of each interview with each participant according to Carspecken's Stages Two and Three. At the end of each interview, the researcher shared a summary of the interview and any initial categories or consistencies noted. Participants were asked to comment on the summary and provide clarity or validation.
4. Use of an audit trail. Specific sections of the interviews were compared to the reconstructed categories to check for consistency. Interview data were also transcribed and compared for consistency.
5. Use of non-leading interview techniques: The interviews were conducted with non-leading interview questions such as "Tell me about yourself" and "Tell me about your health." The interview guide was carefully reviewed and tested in practice interviews before the proposal was submitted to the IRB. The interview guide was reviewed by the researcher's dissertation advisor and by one of the study site directors for leading questions or bias prior to submission to the IRB, which supported the validity of the interview guide. The power dynamic in this study was extremely sensitive, with a highly educated medical professional interviewing a vulnerable minority group. Great care was taken to avoid what

Carspecken (1996) described as “consent to the articulations of the researcher” (p. 142). If participants deferred to the researcher while minimizing their own experiences and ideas, the situation would be a serious threat to validity and knowledge claim. At a higher philosophical level, Habermas’s goal is to achieve the ideal speech situation, i.e., an agreement on question of truth or norms (Roderick, 1986). Carspecken (1996) interpreted such an agreement as equal power relations between researchers and research subjects, with an outcome of gaining the insider’s perspective insofar as possible. Thoughtful and sensitive grand tour questions generated needed rich data and supported active listening (Carspecken, 1996: Madison, 2012).

#### **POTENTIAL LIMITATION**

A potential limitation in this study was the requirement for participants to speak English. English language abilities suggest that immigrants can negotiate the host society, and thus the health care system, with more ease than those who do not speak English (Gong et al., 2003). Language acquisition suggests higher acculturation level (Marín & Marín, 1991). Being able to speak English could have meant that the participants in the study were more acculturated to the U.S. Therefore, expression of cultural barriers in the interviews or difficulties that immigrants may have encountered in the health care system may have been minimized or absent with more highly acculturated participants.

#### **ETHICAL CONSIDERATIONS AND PROTECTION OF HUMAN SUBJECTS**

Immigrants fear being reported to immigration authorities, so researchers must establish trust when conducting research studies in immigrant communities (Baumann et

al., 2011; Marín & Marín, 1991). The research question and eligibility criteria did not inquire about legal status for residence in the U.S., and the researcher had no legal obligation or authorization to report immigration status. Moreover, no questions on the demographic form or interview guide addressed immigration status. Limits to confidentiality were included on the consent form and verbally explained to the participants during the consent process: (a) suspected elder abuse and (b) report of intent to harm self or others. The researcher had legal obligation to report suspected abuse of elders to Texas Adult Protective Services. Participant reports of intent to harm self or others would have been reported to the supervisory chairperson, and the participant would have been referred to an appropriate person or agency. If a referral for intent to harm were made, the researcher would have asked participant agreement for the referral (Gibson et al., 2012; Pearson et al., 2001). With or without participant agreement, intent to harm self or others would have been reported since the therapeutic imperative is higher priority than the research imperative (Munhall, 2007). As little information as possible was divulged to achieve the safety need of the participant but to maintain confidentiality of information relevant to the study (Madison, 2012; Munhall, 2007). No participants reported intent to self-harm or harm others during the study interviews.

Ferrell et al. (2010) described ethical challenges that may present themselves during research. It is important to be sensitive to the nature of the research, any emotions that surface, and participant fatigue. Participants were offered the opportunity to stop interviews and continue at another time or to stop the process completely. All participants were informed that participation was voluntary and that they could withdraw from the study at

any time without affecting their services received at the agency. No participants requested to stop or pause the interviews.

### **Protection of Human Subjects**

All study procedures complied with the standards of the Institutional Review Board at UTMB for safeguarding the rights and welfare of the study participants. Institutional Review Board approval from UTMB was obtained prior to recruitment and maintained throughout the study. After determining eligibility, the study was described and participants were given the opportunity to ask questions, which were then answered before the participant signed the informed consent. Participants determined the time and type of information shared in the interview. Informed consent was obtained from each participant in a face-to-face dialogue prior to the observation and interview. Confidentiality was protected by conducting interviews in a private area, assigning a research identification number to each demographic sheet, and removing any identifying information on the transcripts.

Limits to confidentiality were the discovery of elder abuse or intent to harm self or others, which was explained to each participant at the time of consent. This study posed no known risk to participants, other than possible experience of sadness while sharing their experiences. If participants stated that they became fatigued or did not feel well during an interview, an opportunity to stop the interview or continue at another time would have been offered; however, this circumstance did not arise. Participant names and contact information were kept confidential, placed in a separate file from the transcripts, and stored in a locked cabinet in the researcher's office protected by security code. Data were digitally stored on a hard drive that was encrypted; the backup copies of data were stored on the

student's UTMB iSpace account, which was password-protected. Transcriptions contained no personally identifiable information. Only the investigator and the research supervisor had access to transcripts. Field notes were stored in a locked cabinet in the researcher's office that was protected by security code. All interview data and field notes will be maintained for three years after data analysis completion, and then destroyed. The findings are presented and explained in detail in chapter four.



## **Chapter 4: Findings**

### **INTRODUCTION**

Chapter four presents the findings, or what Carspecken (1996) referred to as meaning reconstruction, of this critical ethnography for describing and explaining the experiences of elderly immigrants of Mexican-origin with life-limiting illness. Chapter four begins with a description of the demographic data and participant characteristics, followed by presentation of the data and examples. Table 4.1 lists the demographic characteristics of the participants.

### **SAMPLE CHARACTERISTICS**

The 13 participants ranged from age 65 to 86 years. There were seven females and six males. Educational level ranged from completing fourth grade to some graduate school. Six participants completed grades fourth through sixth, one participant completed eighth grade; and three participants had completed high school. In terms of higher education, two participants completed community college degrees, and one had completed a bachelor degree with some graduate level course work. There were five first-generation participants and eight second-generation (born in the U.S.). Interestingly, of the eight second generation participants, two of them grew up in Mexico but had immigrated back to the U.S. Six participants resided in Texas coastal communities, while seven lived in the central Texas area. Of the first generation participants, the time spent living in the U.S. ranged from 38 to 58 years. All five of the eligible disease states were represented in the study. Four participants had heart disease, three had had strokes, one had cancer, four had lung disease, and eight had diabetes. Table 4.2 shows the diagnoses among the participants.

Table 4.1. Demographic characteristics of the participants

Variable	N	Years	Mean
Age in Years	13	65-86	74
Gender			
Female	7		
Male	6		
Highest Grade Completed			
4 <sup>th</sup> – 6 <sup>th</sup> grade	6		
8 <sup>th</sup> grade	1		
High School	3*		
Junior College	2		
Bachelor Degree	1**		
Immigration			
1 <sup>st</sup>	5		
2 <sup>nd</sup>	8***		
Time in U.S. (1 <sup>st</sup> generation)		38-58	50.4
Insurance			
Medicare Plan	12		
Non-insured	1		
Location of Residence			
Texas Coastal Community	6		
Central Texas City	7		

\* One participant completed the GED.

\*\* One participant had taken some graduate level courses.

\*\*\* Two were born in U.S. but grew up in Mexico, then came back to the U.S.

Table 4.2. Eligible diagnoses of the participants

Diagnosis	N (%)
Heart Disease	4 (30.7%)
Stroke	3 (23%)
Cancer	1 (7%)
Lung Disease	4 (30%)
Diabetes	8 (61.5%)*

\*One participant had Type 1 diabetes.

One of the eight people with diabetes had Type I diabetes, with all others having been diagnosed in later adulthood. Eight participants (61.5%) had co-morbidities. Strength of the sample included range of age, gender variance, first and second immigration status, time in U.S., and location. The varied geographical sites met Carspecken's criteria of Stage

Four: Discovering Systems Relations (Carspecken, 1996). During Stage Four of data analysis, the investigator considered the site of interest and compared it to other sites.

Carspecken noted that some ethnographies were interview studies only (1996); this study's data were predominantly interviews. Observations made while in the interview settings supported the interview interpretations. Although Carspecken recommended that data be compared to other social sites—e.g., communities, cultures, and media—that level of comparison would not have been logistical in this “interview only” study. Therefore, the geographical sites were considered site comparisons for the purpose of the study.

This ethnography was not conducted according to traditional repeated observations such as living in a community or spending hours at a time observing families or groups. The notion of extended observations inside participant homes would have been awkward at best, not to mention logistically difficult for a dissertation project. This study generated data through fieldwork, incorporating semi-structured interviews, passive observations of the settings, researcher notes, and additional reviews of the interview transcripts.

## **INTERPRETATION OF THE DATA**

The study findings revealed common large categories across interviews. Low and high level coding techniques identified three large categories of *REACTING* to the diagnosis, *RESPONDING* to the illness, and *RELATING* to health care providers. Several low level categories were identified within *REACTING*, *RESPONDING*, and *RELATING*.

The following sections present the findings according to the three high level categories of *REACTING* to the diagnosis, *RESPONDING* to the illness, and *RELATING* to health care providers. Pseudonyms are used to protect participant confidentiality. Excerpts from the data have been provided verbatim to support the categories. The sources

of the excerpts have been provided within parenthesis. The capital letter “P” was followed by a number, 1-13, indicating the participant who made the statement(s). A capital letter “L” identified the line number where the quote was located in the transcript. A capital letter “I” identified comments or questions by the investigator.

### ***REACTING to the Diagnosis***

The category *REACTING* to the diagnosis emerged from the data as participants described what it was like when they learned that they had one of the diagnoses and then how they felt as they adjusted to the news. *REACTING* also included previous observations and experiences with family members who had the same diagnosis, and how that shaped the participants’ own reaction. The lower level categories of (a) feelings and (b) family experiences organized into the high level code of *REACTING* to the diagnosis.

*REACTING* to the diagnosis encompassed feelings, the depth of emotions that individuals experienced when diagnosed with diabetes, stroke, heart disease, lung disease, or cancer. Participants who had diabetes were particularly descriptive about the feelings of devastation, fear, and uncertainty. The following excerpts are exemplars.

Mr. Gonzalez was a 65-year-old second generation immigrant who made a living by doing home repairs, such as painting, small construction jobs, and cabinet installations. He received care at a clinic for non-and low-resource persons and recently was diagnosed with emphysema.

P. And when she told me about my diagnosis here, it kind of I, I gotta do something, ‘cause I don’t wanna be sick. I guess I gotta, I gotta keep on doing something to make it get better, cause it, it kept on bothering me, you know that, every time I see some guys who got that problem I would say, I hope they don’t have to do that to

me. Cause that would, that would really bring me down, 'cause I couldn't go to work. And, then there was, so right now anything that I can do so they won't have to give me any kind of surgery whatever, I'll do it. And I don't, I don't, I don't think I would go through with that (P6, L57-563).

Mrs. Sanchez, a second generation immigrant in her 80s with diabetes, lived with her son, who had a stroke and required full time care. She explained how the diagnosis was hard for her, as her husband had already passed away. She did not have anyone to talk to when she was diagnosed and ended up missing substantial time from her job in the cafeteria at a local elementary school:

I. I heard you say that when you were diagnosed it hit you kind of hard.

P. Uh-huh, and really, and I got sick, and I remember 'cause I take three weeks from work, and it really hit me. But it, it's that I thought that I was gonna take insulin, and I, and I don't like, no, uh-huh (P8, L211-214).

Mr. Perez was a first generation immigrant. His family moved to the U.S. when he was five years old. He had diabetes, had lost a leg to amputation, and was on hemodialysis.

P. He was a good doctor. He was an Army doctor I think. Like this, when all these people get, you go in there and you see all these poor people with their legs cut off, or their foot cut off, or their toes, but I figured it out now that I'm older, it took a long time to sink in. It's the people with diabetes.

I. That's right.

P. And I say, to them, I used to say geez how can this guy be cutting people's legs and toes...

I. That's it.

P. ...and oh my god, and then, well now I got diabetes, so I gotta watch myself, you know (P7, L738-745).

*REACTING* to the diagnosis encompassed family experiences and was based largely upon participants' personal experiences with family members who had the illness. Several participants described how they had watched or lived through the negative health experiences of close family members, and how they feared that for themselves. Based on experiences they had observed with family members, participants were afraid they would face the same kinds of health outcomes.

Mrs. Gomez, a first generation immigrant, lived with her husband who had Alzheimer's disease. She had an older sister whose legs turned black and needed amputation after the sister fell at home. The participant also described how "it's hard for me to take it, you know, because it could happen to me" (P4, L95-96).

I. Tell me about when you first learned of your diagnosis?

P. I cried and cried and cried. Because, ah, it runs in the family. My grandfather, my father, my oldest sister, and one more, and me, all got diabetes...And that makes me think, but it's something that you, you, you got it in you blood, you know, and, and uh, like a heritage, something, I don't know what you call that, but you have it in you blood, uh, I don't know what, how you call it, like a heritage, but it's not easy yourselves to see you run in you blood, you know...Yeah, genetics, and uh, we don't like it. I cry and cry and cry. I said, "Oh my God." To me it was like the world came upon me, you know, because I know, and I knew the risks of diabetes. It's not easy to have it. It's not easy to live to see what the diabetes do to you. Because the experiences I have with my grandfather and my father, and my oldest sister.

One day at night time, she woke up to go to the bathroom, and she fell. And she stayed like that there all night. And then next day when they found her, her legs were, ah, black. And ah, over here was when she, because of diabetes, she had diabetes. And ah, [pause] one moment they told that I had, that they had to cut this, her legs, because of that. And, that is, ah, it's hard for me to take it, you know, because it could happen to me [starts to cry]. That's ah, that's my experiences (P4, L76-97).

Mrs. Sanchez also explained how diabetes was in her family:

P. Well, most the doctor only said was well now you have to take, this, uh, he gave me a paper and what I was supposed to eat, and this and that, and, and then he said as long as your, you take your medication the way you're supposed to, you'll be all right. So that's what I did, you know.

I. Do you think the doctor picked up on how upset you were? Or did the upset part come later?

P. No, the upset came later, after I got home, after I got home that's when it really hit me. I said, oh, and then I was by myself. I was by myself. There was nobody there with, and then my son the one that lives with me, well he wasn't home. He was working. So when I got home, was, there was nobody for me to say, well I went there and he told me this and that, and my other son, well he was working too. And he was living far from, now he bought the house next door to me, so he's there, you know. But, he has diabetes too. He's got diabetes too, so I said well I guess it runs in the family. Oh, and... (P8, L239-250).

*REACTING* to the diagnosis meant the profound feelings, the extreme and overwhelming emotions that individuals experienced when diagnosed with diabetes, stroke, heart disease, lung disease, or cancer.

### ***RESPONDING to the Illness***

*RESPONDING* to the illness related to the adjustments and life changes participants made for the new diagnosis. *RESPONDING* included lower level categories of (a) actions to self-manage the disease; (b) efforts at self-advocacy; and (c) interaction with the community in order to help other people.

### ***SELF-MANAGEMENT***

Participants discussed commitment and efforts to comply with physicians' instructions and what they called "the rules" to manage their conditions. Mr. Garcia, an 81 year-old first generation immigrant, was retired from a job driving a truck at a warehouse. He identified the importance of following the instructions to manage diabetes: "Follow the rules, the doctor's rules" [diabetes] (P1, L231). Following the "doctor's rules" included a degree of independent decision-making and self-adjustment, particularly with medication.

Mrs. Rodriquez, a first generation immigrant who was 82 years old at the time of the interview, felt like she took too much medicine. Therefore, she monitored her blood pressure and took medication when she felt like she needed it:

P: Well, I know it [medication] helps me, because sometimes I say, "It's too much medicine. I don't want to take the afternoon medicine." Then the next day, I take my blood pressure every day, twice, in the morning and the night. And I know when



I don't take it in the afternoon, in the morning, it's high...So, I say, well I need it then (P2, L170-175).

Mrs. Sanchez negotiated with her physician to take all of her medications at the same time, so she would not have to take them at multiple times throughout the day.

P. Yes, and I asked, I asked the doctor, I said, can I take them all together? I said, I don't want take one at 11, the other one at 1, and then the other one at 2, and I said 'no, no, no' and I said 'is that all right that I take them all together all the time?' He said 'that's all right.' So that's what I do (P8, L303-312).

#### ***SELF-ADVOCACY***

Inherent in participants' self-management plans were their efforts to advocate for themselves. When participants felt like the communication from health care providers was poor or dissatisfactory, participants decided to find another provider; some even requested they be discharged from the hospital. More than one participant insisted on being moved out of the hospital due to poor nursing care and poor responsiveness to their expressed needs. Mrs. Gomez, a first generation immigrant with diabetes, changed medical practices so that she could have a physician who spoke Spanish: "I choose him, and you know what, it was his, he speaks Spanish" (P4, L199-201). Mr. Flores, a second generation immigrant with diabetes and chronic renal failure, advocated for himself to be transferred to a different nursing center in the hospital where he felt more supported: "The way the nurse seemed to, on that floor, treated the patients, was totally different than the way they did upstairs" (P11, L438-457). Mrs. Ramirez, an 85 year-old second generation immigrant, lived in an assisted living apartment complex and had diabetes and asthma. She suffered a stroke when she

was in her 40s and had small children. She was unable to work yet was denied social security benefits. She went directly to her local county commissioner for assistance:

P: So I came and talked to him [the county commissioner], and he sent his secretary. I came all the way downtown. In those times, I didn't have a car. I went on the bus. So I came and talked to him [the county commissioner] and he sent his secretary with me, in his car, to the social security [office]. And they told [asked] me, 'Who was the person I was talking with?' So they called the person, and then they called me, I think the manager or something from social security. They told him, 'You're not right.' They, they gave me the service and everything. And see in that time, I have no problems, after that (P12, L341-351).

#### ***INTERACTION WITH THE COMMUNITY***

Participants described unique ways of reaching out to the community to share their own experiences and to help others with the same diagnosis, including suggestions for how they could be optimally supported. Mr. Flores, a second generation immigrant with diabetes and chronic renal failure, explained patients' support needs for the clinical staff and administration at his local dialysis clinic.

We need to have some kind of education at the clinics, because once the people leave the clinic, they're not gonna, they're not gonna get on, on [the public transportation system], or go to a class or something like that, you need to have it while they're here. And, you, you need to also educate their family, not just the patients. Because a lot of times the mother or the dad, living home with their parents, I mean their daughters or sons, and if they don't know what meals to cook and what not to cook, uh, you know it, they're in for a, for a lot of trouble. So it,

it's not just education, educating the families that are at home. Because the first support they have should be at home, you know (P11, L553-574).

Mr. Garcia, an 81 year-old first generation immigrant, detailed how he waited at the clinic for follow-up appointments, and how the other patients in the clinic would talk among themselves. They would ask one another questions, and give each other advice:

P. Yes. Sometimes I talk to different people at the clinic when they check with the doctor, they have bunches of questions, the people. You know? Everybody want to talk the difference, the difference. I tell them I don't care what you say, I tell you what happen. The doctor told me what happen...So I have the people advice, the difference, sometimes, I know, sometimes I ask them about the doctor, "So why have you coming?" (P1, L268-270)

*RESPONDING* to the illness related to the adjustments and life changes participants made for the new diagnosis, meaning the actions to self-manage the disease, to self-advocate, and to interact with the community

### ***RELATING to the Health Care Providers***

*RELATING* to Health Care Providers encompassed the range of both positive and negative communications and experiences that participants had with their health care providers, which in turn affected participants' understanding of their condition and their experiences with health care. *RELATING* to the Health Care Providers had lower level categories of (a) communication with doctors and (b) communication with nurses. Participants were particularly sensitive to perceived lack of communication from their providers. This lack of attention and communication did not support their cultural norms, *simpatía* or *personalismo*, nor did the hurriedness align with their time orientation.

## **Communication with Physicians**

Mrs. Rivera, a 65-year-old second generation immigrant, was a colon cancer survivor. She described her doctors with admiration:

P. I have a lot of respect for all my doctors, and I have to feel like they really are interested in what's gonna happen to me. If I feel that, that, that I'm, that I'm just an in and out, you know, then, I don't feel like they're gonna know what the real problem could be, you know, with me. So, so then usually, and I haven't had too many that I had to change like that, but I did change a cardiologist. I, I just didn't, it was my husband's cardiologist. And I didn't like the way he treated him, and I didn't like the way he treated me. It was like hurry up, you know, I've got other patients waiting (P9, L369-375).

Mrs. Rivera had been in the hospital all weekend with a cardiac arrhythmia and abnormal laboratory values. The hospital health care team attempted to reach her physician, who did not return calls. On Monday morning, the physician office staff called Mr. Rivera and told him that his wife was "supposed to come to the office first before you get admitted to emergency or . . . any emergency or hospital or wherever" (P9, L200-202). Mrs. Rivera described her husband's response:

P: And [Mr. Rivera] said, my wife almost died over the weekend, and all you care about is who, you know, decides, yeah who decides whether it's an emergency or not. And it's an emergency. And he [Mr. Rivera] said you know what, nevermind. We're just not gonna come back to Dr. [name of MD]. So then he [Mr. Rivera] came back and told me what he had done. And we told the emergency doctor, and he [the emergency doctor] said ok (P9, L203-207).

Nonetheless, participants also had positive experiences with their physicians, and readily described the respect and trust they had for them. The explanations were specifically in relation to the time that physicians took to explain their medical conditions or instructions to the participants. By meeting participants' cultural expectations, the time spent made them feel respected, increasing their understanding of their disease and what was needed to successfully manage their condition. The increased time providers spent with participants also motivated them to follow the medical advice and instructions. Mrs. Rodriguez, a first generation immigrant who had a stroke, expressed confidence in her physician, and described how she knew she had received good attention from her physician:

I: I understand. Well yeah, okay. So tell me about the best experience you ever had when you went to the doctor or clinical or hospital, like a really good experience.

P: Maybe when they had good attention to me when I had a stroke.

I: How did you know that they had good attention? What was it that made you feel the good attention?

P: Well, I feel good. I know that the doctor knew what was wrong with me at this time (P2, L194-199).

Mrs. Gomez, a first generation immigrant, preferred a Spanish-speaking physician and explained how it helped her to understand instructions of her diagnosis, treatment, and medications.

P: Yes, I like it because he explains everything, [unable to understand] everything easier. I can speak English too, but sometimes I see that, that uh, for some people

it's hard to understand English. Cause I don't like speaking too good. But I make me understand, kind of, I think (P4, L203-206).

Mrs. Gomez continued to describe how the communication facilitated the feeling that "I know they [the physicians] want the best, the better for me," which made her trust in them [the physicians]. Because of the trust, she was willing to follow medical instructions to manage her disease (P4, L301-310).

Mrs. Hernandez was a first generation immigrant who lived in a coastal area house with pilings. Her husband had died, and she lived alone. She had asthma, and has also had some recent trouble with eye infections and a broken wrist. Therefore, she had many medical appointments and detailed how important it was for the doctor to take time to explain instructions. She felt that a good doctor, one who took time to explain the diagnosis and instructions, had her best interest at heart. The explanations and attentiveness facilitated her trust in her physician:

I. So, when you say they, the doctor explains everything, it's the doctor who explains?

P. Yes.

I. And does that happen when you go, and you're in the exam room? And before you go home? The doctor stops and explains, or...?

P. Oh yes, yes.

I. Okay. And with the explanation, what makes that good? How does that...

P. Because they tell you what to do. And they tell, they tell you what is good for you, what is good for you, explain to you, real clear (P5, L175-183).

Mrs. Gomez, a first generation immigrant, described how physicians who were Spanish-speaking made “everything easier” and how the explanations in Spanish “make me understand” the instructions (P4, L203-206).

Mr. Torres, a 68-year-old second generation immigrant, had diabetes. He was diagnosed as a young adult and had nine medical encounters in the past 12 months. He described one primary doctor who he especially liked because “He’d always have me last [on the schedule] because he would go over all my blood work. And, and tell me this, and look at this, and let’s compare it to the month before...he’d explain it to me” (P13, L383-386). The explanations and comparisons helped Mr. Torres to see that he was making progress.

### **Communication with Nurses**

Participants had varied and unpredictable experiences with nurses. Some described nurses in positive ways: “But the hospitals and the doctors and nurses [in Puerto Rico] are nowhere as dedicated to their patients as they are here” (P9, L637), or as Mrs. Gomez, a first generation immigrant, described, they were “angels” (P4, L355). Most participants described negative experiences with nurses. One example was Mrs. Ramirez who seemed ambivalent to the nurse’s presence and that the little nurses did was a waste of time:

P. Well, I have a nurse who comes here to the house, you know. But they just, take the vital, things you know, the sugar or heart or lungs or whatever, you know. That’s all they do, you know...No, no. These two comes, sometimes they will, you’re wasting your time, but...if you just come for that, you know, you’re wasting your time, to me you know? Some other patients, maybe they need the things that they’re

looking for, that I don't have you know. But anyway, I really appreciate what they're doing, their time (P12, L214-226).

Mrs. Rodriguez, a first generation immigrant who had a stroke, was very frustrated when she was in the hospital for an infection and tried to get help for an infiltrated intravenous (IV) line. She wanted her bed sheets changed but had to change them herself. She went into detail about how the lack of attention to basic hygiene made her feel like less of a human, and that there was a lack of respect for her personhood and dignity:

P: They [the nurses] put in an IV. And they put it back, the IV. And my hand was swelling. And I call the nurse, and told her come. Don't come, don't come. Finally one coming. I said, please, I need the nurse. My nurse was pass, one boy, when she pass on me and don't come. And I know the nurse, it was not my nurse. I said, "Please give me something." This [unable to understand] awful. My finger don't hurt. But this hurts. [laughs].

I: That doesn't seem right, does it?

P: It hurt. They took it off. They called somebody. [unable to understand] The sheets too, when I was there, the sheets smelled bad, like rot meat. The sheets. And I tell her, these sheets stink. She said, "Oh no." I want to change the sheets. "We'll change the sheets all today." [unable to understand] and we change the sheets today. And then when I did, I turned it over.

I: Okay, but they don't call back?

P: [Shakes head] (P2, I1, L 229-240).

*RELATING* to Health Care Providers meant the communications and experiences that participants had with their health care providers, specifically their doctors and nurses,



which in turn affected participants' understanding of their condition and their experiences with health care.

### **Rigor with Data Analysis**

Provisions for rigor for data analysis were applied: Use of multiple ways of recording to record the data, use of peer debriefing to check for biases, use of member checks during at and the end of each interview, use of an audit trail, and use of non-leading interview techniques. Notes were maintained about data decisions during the analytical process, and these decisions were reviewed weekly with the dissertation supervisor. The interviews were reviewed for consistency of subject narrative throughout. No subject narrative inconsistencies were noted.

Chapter four presented the findings of the data analysis. Low and high level coding techniques identified high level categories of *REACTING* to the diagnosis, *RESPONDING* to the illness, and *RELATING* to health care providers. *REACTING* to the diagnosis included how participants felt when they received a diagnosis, their descriptions of family members who had the same diagnoses, and how those descriptions shaped their own reactions. *RESPONDING* to the illness involved the life adjustments that participants made: actions to self-manage the disease, efforts at self-advocacy, and interaction with the community to help (not for help, but to help). *RELATING* to health care providers encompassed the range of communications and experiences that participants had with their health care providers, specifically doctors and nurses. Chapter five will relate findings to the philosophical underpinning and ecological framework, review study strengths and limitations, and suggest recommendations for nursing practice, education, and research.

## **Chapter 5: Discussion**

### **INTRODUCTION**

The purpose of this study was to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the U.S. This critical ethnography of elderly immigrants of Mexican origin described how participants described their experiences with illness by *REACTING* to the diagnosis, *RESPONDING* to the illness, and *RELATING* to health care providers. This chapter will discuss the findings in relation to the philosophical underpinning, ecological framework, and current literature; review study strengths and limitations; and suggest recommendations for nursing and future research.

### **INTERPRETATION OF FINDINGS IN RELATION TO THE PHILOSOPHICAL FRAMEWORK**

Habermas's critical theory, and specifically the communicative action concept, guided the philosophical underpinning of this study. In everyday speech individuals make truth claims, or self-narratives, of their life world (Bohman, & Rehg, 2014). Understanding of speech acts and truth claims is especially important for nursing because communication with patients is critical to high quality care, patient safety, and patient satisfaction (Vasconcellos-Silva et al., 2007).

This dissertation study explored the experiences that elderly immigrants of Mexican origin had with life-limiting illness, and the results describe how some participants were dissatisfied with communication with their health care providers. Participants were more satisfied when health care providers took time to explain their diagnoses or treatment plan and answer questions, which supported cultural norms of

*simpatía*, *personalismo*, and *respeto*. The Hispanic cultural norm of time centers on a relaxed approach, one that is focused on the present (Rivera & Rogers-Adkinson, 1997). The hurriedness of the health care providers did not align with participants' time orientation. Some of the participants left the medical practice and found another physician in an attempt to feel more supported, obtain more personal information, and to feel respected and dignified.

The study also demonstrates how much participants value the role of their physicians in their disease management process. The literature supports that Mexican-American patients have confidence in the power of physicians to affect their health outcomes and the extent to which medical advice influences their health (Eggenberger et al., 2006). On the other hand, some participants expressed extreme dissatisfaction with their nurses' communication styles. Nurses did not respond to participant requests when hospitalized, appeared to be socializing at the nurses' stations when participants had needs, and did not call participants back when participants attempted to contact physicians.

Vasconcellos-Silva et al. (2007) described health care organizations as linguistic communities because of the number of speech acts that occur through everyday interactions. Speech acts communicate meaning and personal identity and serve as the "medium" for Habermas's lifeworld, those "unregulated spheres" of social life such as family, culture, and political life (Finlayson, 2005, p 51). The "full communicative model" that Vasconcellos-Silva et al. (2007, p. 1534) described is based on the Habermasian concept of communicative action. The situations in which health care professionals and patients agree to coordinate action plans should occur after an ideal speech act, one in which deep listening and shared understanding and meaning was achieved. Perhaps today's

medical environment, with its highly structured system of electronic medical record keeping and computerized documentation, distracts health care providers from patients, which may in turn sacrifice high quality care and safety due to the lack of a shared speech act. In this group of elderly Mexican immigrants with long term health conditions, the concepts of characteristics of good and bad providers were based upon the quality of communication with their patients. The decision to leave medical practices and go to different providers could in fact disrupt continuity and consistency of care in tandem with use of technology.

The literature on Hispanic cultural values describes concepts such as *simpatía* (dignity and respect to others), *personalismo* (learning to trust by sharing personal information), and *respeto* (acknowledgement of elder authority) (Aléman, 2000; Marín & Marín, 1991). Participants changed physicians, left medical practices, complained to those in authority, or self-advocated when they felt that their values were not upheld by health care providers. Disregard of because when providers act without regarding the values, care may be interrupted or rejected.

One way to accommodate such cultural needs may be to have a minimum timeframe before computers are accessed for care, or to take time to make introductions outside of the examination room. Listening to patients, looking at patients, explaining instructions, spending time with patients, and attentiveness are characteristics of care highly valued by the participants but often not received during their health care encounters. Such actions, when applied, helped participants to feel supported and respected. *RELATING* to the health care providers, as revealed in this study, was a critical finding to

understanding the implications of relationships with providers and the cultural context and expectations that impact patients.

#### **INTERPRETATION OF FINDINGS IN RELATIONSHIP TO THE ECOLOGICAL MODEL**

This study considers individual, family, community, state, and national dimensions to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the U.S. The ecological model serves to guide study data collection at the individual level and to understand levels of influence on the elders' perspectives. The ecological model elucidates that circumstances beyond the individual control are powerful contributors to health behaviors and outcomes.

##### **Individual**

Data were collected at the individual interview level. According to Carspecken (2012), individuals make identity claims, stories about themselves, and detail life histories that present in the forms of self-narratives. The ecological model was applied at the individual level by providing participants opportunities to tell their stories, which explored and to explained "the range of possible ways to be a person in a culture" (Carspecken, 2012, p. 55). It is important to recognize that individual self-management of medication practices are genuine rather than examples of non-compliance or non-adherence (Pylypa, 2001). In the best ways that they could, participants were following rules, taking their medications, and self-advocating, as in the example of Mrs. Rodriguez, who self-monitored her blood pressure and took medication when she felt like she needed it.

## Family

The importance of family and relations with family were minimally described in the interviews, which was surprising given the importance of family support and involvement in Mexican culture, or *familialism* (Alemán, 2000; Marín & Marín, 1991). Perhaps the researcher could have inquired more explicitly about family by asking a questions such as “Tell me about your family.” However, participants in the study framed family in terms of how they contracted diabetes, since it ran in their families. Perhaps additional research is needed to explore in greater depth how individuals consider their families to be forbearers and contributors to their disease burden. There may be ways that preventive measures can be applied while considering family as a unit or system, such as in the case of one participant whose doctor met with the entire family to discuss her colon cancer and their individual risks. The doctor was then able to persuade the entire family to come to the clinic for colonoscopies:

P. So anyway, the doctor had anyone come in who was blood-related to the hospital room after I was recuperating, and he said, “Anybody who is related to [name of participant] by blood has to have a colonoscopy. You have to get checked very early, because she’s too young to have colon cancer, so this means that it is genetic. And so you could end up having cancer and not knowing it, like she did.” And, uh, and so then everybody got checked. And my baby sister, who’s eleven years younger than me, guess what? She had five polyps, at the very time. So, if she would’ve done what I did, she might have ended up like I did too. Yeah...Yes, and we didn’t even ask for it or anything, he just did it on his own. He said, on this day, I’m gonna be here at this time. Get everybody here, into your

room, on that day. And they were all sitting everywhere, on the floor, on pillows, on the bed, everywhere (P9, L396-407).

The story provides a model for how health care providers may encourage individuals to complete health screenings. The story is also an example of upholding *familialism*, and is thus representative of cultural values. Literature suggests that Mexican-American families rely on the extended family and receive support from extended family during health care crises (Eggenberger et al., 2006).

### **Community**

Participants described how their lives integrated with the community and made special mention of their own personal contributions. Alemán (2000) recommends that agencies need to develop programs and outreach efforts that encourage utilization of these community-based services because Mexican elders are traditionally reluctant to use them. However, this study was different in that all participants in the study either were using or had used some form of community-based service such as volunteering in programs for older adults, or church outreaches. An explanation for this difference may be that the study group overall had education and English-speaking abilities needed to navigate and learn about community services. The study group of bilingual participants spent much of their lives in the U.S., even the first generation immigrants, and had varied levels of education. All but one participant was enrolled in Medicare. The attributes of the study group may account for the use of community-based services, as well as their overall access to health care.

A study by Pylypa (2001) indicated similar outcomes such that nurses should pay attention to community services and seek out opportunities to strengthen them with

meaningful education or support programs, especially during the vulnerable timeframe following a diagnosis. Participants did not have anyone to speak to about their concerns, feelings, or needs in the timeframe immediately following their diagnosis. Nurses have opportunity for input and presence through follow up home visits, services and interventions. Participants recommended supplemental education for themselves, especially in the areas of practical nutrition—not just what to eat or what not to eat, but also how to accommodate dietary restrictions to cultural traditions. Education and support groups could provide a much needed service from the perspectives of the participants.

## **Policy**

Massey and Pren (2012) make an evidence-based argument that Latinos are the “new underclass” and that U.S. policy has increasingly alienated and exploited the Mexican, South American, and Central American people. Moreover, recent political rhetoric has framed immigration as a grave threat to the nation. What is the appropriate nursing response? Nurses are very well positioned to inform, influence, and support health policy (McCracken, 2010). Nursing has a moral duty to advocate for patients and populations. Political involvement gives nurses opportunities to address health policies that impact access, cost, and quality of care (Hall-Long, 2010). When research is conducted with sensitivity, appropriateness, robust methodology, and rigor, nurses can and should communicate results that convey the voices of vulnerable groups. These perspectives may educate legislative leadership, whether local, state, or national, on elders’ truths as told by their personal experiences and stories. Policy recommendations at a lower level, such as organizational policy, can be implemented immediately following the medical diagnosis



with emotional and practical support such as cooking classes and group support at times convenient to patients.

## **STUDY IMPLICATIONS**

In 2012 Hispanics comprised 16.3% of the total U.S. population, and growth in this population is mainly due to increased immigration (Gonzalez-Barrera & Lopez, 2013; U.S. Census Bureau, 2010). By 2050, Hispanics will make up 29% of the U.S. population, and one in five persons aged 65 years and older will be an immigrant of Hispanic or other origin (Colby & Ortman, 2015; Passel & Cohn, 2008). Therefore, the next generation of older adults will likely be 20% Hispanic, the largest minority population aged 65 years and older (Villa et al., 2012). Villa et al. (2012) found that the health inequities and risks of the Mexican-origin, accumulated over a lifetime, are likely to persist into the elder years. Chronic conditions such as diabetes, obesity, hypertension, and heart disease are not the only clinical conditions that will be seen; aging Mexican immigrants also have other health concerns such as persistent musculoskeletal injury (Weigel et al., 2013). Nurses must be culturally prepared to care for this population, a readiness which will include strong clinical competency and an understanding of the unique needs of Mexican-origin elders. Research methodologies, such as those used in this project, may also serve to guide nurses in linguistic situations and agreement on identity claims that must occur in order to care for, and serve as the voice of, such a highly vulnerable population.

The study results suggest that although nursing academic programs have content for cultural competency, nurses are still not applying culturally sensitive and alert care. The study validates the need for more practice and immersion opportunities for nurses to learn how to approach patient care situations from a culturally oriented perspective.

Study recommendations for nursing education include civic engagement, service learning, immersion experiences, practicums in collaborative care, ongoing continuing education, and training in medical Spanish. The expanding demographic of Hispanic and, in particular, Mexican-origin immigrants means that research efforts must include and fairly represent the population that may benefit from research outcomes. Using an ecological model that considers related contextual factors, such as family, community, and policy influences, can strengthen health research in Hispanic groups (Lopez-Class et al., 2011). Areas of research that warrant further inquiry are (a) Spanish-speaking only immigrants; (b) immigrants who do not use community services as described by their own perceptions and experiences; (c) immigrants of other ethnicities and nationalities; (d) family input, especially how experience with family members who have the disease shape the individuals' and family's reaction to diagnoses and response to the illness; (e) interventions such as increased support following the diagnosis and practical navigation such as cooking classes.

The qualitative research process is, in and of itself, a way of supporting culturally competent care. Listening to the rich stories of elderly immigrants of Mexican origin with life limiting illness and seeking to understand their health behavior and experiences helps nurses who conduct and read the research become more culturally focused and alert. et al. (2006) suggest that although basic knowledge related to a specific culture is important, exploration of contextual understanding facilitates the development of culturally aware care.

## **STRENGTHS OF STUDY**

The study has several strengths. It is the first known study in the extant literature to address the topic of the experience of elderly immigrants of Mexican-origin with life-limiting illness. The growing U.S. population of aging immigrants of Mexican origin is unwavering, yet little is known of their needs, from their own perspectives, when facing life-limiting illnesses. People who are experiencing life-limiting illnesses are extremely vulnerable, and great care must be taken to ensure that they are able to access compassionate and effective end-of-life health care services. The general idea of critical research is to “putting together things that are usually held apart” (Carspecken, 2016, p. 65). This research study is the first that opens a window of understanding into how the population reacts, responds, and relates to life-limiting illness. This study also attempts to give voice to their lifeworld perspectives. Because the study is the first of its kind, it contributes to the field of nursing and health care knowledge. In particular, the study provides recommendations for the supportive care that individuals should receive following a diagnosis such as diabetes, and the critical position that health care providers hold in shaping patients’ responses to their illness.

The study has a connected philosophical and methodological framework, which had been considered a limitation in the reviewed literature. In the reviewed literature, a weakness in most studies was a lack of philosophical foundation in the published format. If the philosophical foundation was identified, the methods and analyses often did not reflect the philosophy or general qualitative tenets. By applying Habermas’s philosophy of reaching mutual understanding of the participants’ lifeworld through shared communication, using that philosophy to guide methodological perspective and approach,

and considering the data through the ecological lens, this study accomplished the goal of conducting a qualitative study on a strong philosophical and conceptual foundation.

The study is well grounded in the domain of nursing and thus has important implications for nursing practice. Understanding participants' needs for support and education following what they perceive to be a major life altering illness is important to nursing because nurses are in critical positions to educate, support, and be present.

The fact that the investigator was not Spanish-speaking could have been a benefit. The investigator, as one who is not enculturated (not aware of or unfamiliar with the tacit aspects of culture), was able to see, or at least question, as an outsider. Taken-for-granted knowledge can be difficult if present when conducting ethnography, but that was not the case in this study (Goodwin et al., 2003).

#### **LIMITATIONS OF STUDY**

A limitation typical of a qualitative study is the small sample size, and this study was no different. The purposive selection of 13 participants limited generalizability and also transferability of findings to other countries or cultural groups. Another limitation of this study was difficulty recruiting participants who met all of the eligibility criteria, in particular the need to conduct the interview in English. Many potential participants met all of the criteria except for the need to speak English, or the requirement to be a first generation immigrant. Once the IRB approved expansion of sampling to include second generation immigrants, recruitment became easier.

All 13 participants spoke Spanish as their first language. Because qualitative research aims to make truth claims of subjective experiences, language and the interpretation thereof is essential. The two-way language process not only expresses

meaning, but constructs meaning (van Nes et al., 2010). For reconstructive analysis to occur, and thus the representation of meaning, the qualitative researcher must interpret and represent both foreground and background of the linguistic expression. Van Nes et al. (2010) explain that “giving words to experiences is a complicated process as the meaning of experiences is often not completely accessible for subjects and difficult to express in language” (p. 314). This seemed particularly true of many interviews, as the participants often struggled to find the English word they wanted, and used a Spanish word instead, or in some cases, apologized for their English.

Although every participant was interviewed and responded to questions in English, the transcription of the interviews was very difficult given the Spanish accent and occasional mixture in some of interviews of both English and Spanish. The investigator’s beginner knowledge of Spanish, along with a robust Spanish dictionary, were valuable to gain understanding of the meaning of isolated Spanish words. Some phrases of transcripts were too difficult to understand so those parts were bracketed as [unable to understand]. On occasion, the doctoral supervisor assisted with translation of isolated words or phrases. However, great caution was taken since translation of concepts by culturally bound words may affect understanding and interpretation of meaning (Smith et al., 2008; van Nes et al., 2010).

Participants described “doctors” and “nurses” throughout their interviews, but the investigator could not validate credentials or educational levels of the health care providers. There is possibility that the providers who diagnosed and treated could be physician assistants or nurse practitioners. Nurses, as described by the participants, could be

registered nurses with either a baccalaureate or associate's degree, licensed vocational nurses, or unlicensed personnel such as medical technicians or patient care attendants.

## CONCLUSION

The purpose of this qualitative study was to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the U.S. This critical ethnography, philosophically informed by Jürgen Habermas's critical social theory (1984, 1999) and guided by Bronfenbrenner's ecological model, answered the research question "What are the perceptions of elderly immigrants of Mexican origin with life-limiting illness about their experiences with the health care system in the United States?" Low and high level coding techniques identified high level categories of *REACTING* to the diagnosis, *RESPONDING* to the illness, and *RELATIONSHIPS* with health care providers. Although the sample size limits generalizability, findings suggest more research is needed to improve health care delivery to this population. In particular, the immediate emotional needs when diagnosed, appropriate assistance while learning to self-manage, and the paramount role of physicians and nurses in the elders' health care decisions merit further inquiry.

## Appendix A: IRB Approval



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Institutional Review Board  
301 University Blvd.  
Galveston, TX 77550-0155  
409.266.9475

31-Aug-2015

### MEMORANDUM

TO: Sandra McNeely, MSN, RN, CNE/Yolanda Davila, PhD, RN  
Grad School Biomedical Science

FROM:   
Janak Patel, MD  
Institutional Review Board, Chairman

RE: Contingent Study Approval

IRB #: IRB # 13-0427

TITLE: The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A Critical Ethnography

Your research study requiring the use of human participants received review by the UTMB Institutional Review Board (IRB) under an expedited review process on 28-Aug-2015.

The IRB found your research project to be approvable, contingent upon your satisfactory response to the following stipulations:

#### OTHER CHANGES:

1. Please be reminded that the on-line training for the protection of research participants is an institutional requirement and needs to be renewed every two years. Yolanda Davila's on-line training for the protection of research participants has expired. They will need to log on at [www.citiprogram.org](http://www.citiprogram.org) to renew their certification.

2. Please be reminded that anyone participating in research at the University must meet the annual Conflict of Interest requirements. The COI Office does not have a record of COI training/disclosure for Sandra McNeely. Please have the individual listed complete their COI training/disclosure as required. Upon completion, the COI office will review the disclosure forms submitted at which time the COI Office will email a memorandum to you confirming all COI requirements have been met. Please upload the COI signed memorandum when responding to this stipulation. For collaborators not employed by UTMB, or for all other COI related issues/questions, please contact Angela Ellis at (409) 747-8795 or Helen MacKay at (409) 266-9435. has not completed COI.

Please do not revise the originally reviewed study documents to include changes other than those

requested by the IRB and outlined above.

In order for your response to be reviewed, please submit your response via InfoEd by selecting the blue [respond](#) link within the submission package. Select the appropriate response type from the drop-down menu. Select the "edit" button next to the document needing revision (documents appear in the light blue fields at the top).

**Important note:** Your response to these stipulations is time-critical, since authorization to enroll subjects currently expires on **11-Sep-2015**. After this date, please be advised that new subjects may not be enrolled in this study during the period of lapsed approval. In addition, no research-related interventions may be performed on currently enrolled subjects, unless necessary to avoid an immediate apparent hazard to the subject, and no federal funds awarded for the research may be spent on study-related expenses.

If you have any questions, please do not hesitate to contact the IRB office at 409-266-9475.



06-May-2015

**MEMORANDUM**

TO: Sandra McNeely, MSN, RN, CNE/Yolanda Davila, PhD, RN  
Grad School Biomedical Science



FROM: Dwight Wolf, MD  
Institutional Review Board, Chairman

RE: Amendment/Miscellaneous Request Approval

IRB #: IRB # 13-0427

TITLE: The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A  
Critical Ethnography

DOCUMENTS: Research Protocol  
Research Consent Form  
Recruitment Flyer

The **Miscellaneous Response** request to the above referenced study has been reviewed via an expedited review procedure on **06-May-2015** and approved by the UTMB Institutional Review Board (IRB) in accordance with 45 CFR 46.110(a)-(b)(2).

The approval period for this modified research protocol begins on **06-May-2015** and lasts until **11-Sep-2015**.

If you have any questions related to this approval letter or about IRB policies and procedures, please telephone the IRB Office at 409-266-9475.

**Description of Changes/Submission**

A modification to expand the subject sample pool to include both first and second generation elderly immigrants of Mexican origin was approved. The research protocol, research consent form and recruitment flyer have all been updated to reflect this modification.

11-Sep-2014

**MEMORANDUM**

TO: Sandra McNeely, MSN, RN, CNE/Yolanda Davila, PhD, RN  
Grad School Biomedical Science



FROM: Dwight Wolf, MD  
Institutional Review Board, Chairman

RE: Final Approval of Continuing Review

IRB #: IRB # 13-0427

TITLE: The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A Critical Ethnography

The UTMB Institutional Review Board (IRB) reviewed the above-referenced research protocol via an expedited review procedure on **11-Sep-2014** in accordance with 45 CFR 46.110(a)-(b)(1). Having met all applicable requirements, the research protocol is approved for continuation for a period of 12 months. The approval period for this research protocol begins on **11-Sep-2014** and lasts until **11-Sep-2015**.

The research protocol cannot continue beyond the approval period without continuing review and approval by the IRB. In order to avoid a lapse in IRB approval, the Principal Investigator must apply for continuing review of the protocol and related documents before the expiration date. A reminder will be sent to you approximately 90 days prior to the expiration date.

If you have any questions related to this approval letter or about IRB policies and procedures, please telephone the IRB Office at 409-266-9475.

#### General Instructions

To maintain IRB approval in good standing, please observe the following requirements:

1. All subjects must sign the consent form before undergoing any research study procedures, including screening procedures. A photocopy of the signed consent form(s) should be given to each participant. The copy of the consent form(s) bearing original signature(s) should be kept with other records of this research for at least six years past the completion of the research study. The IRB considers a subject to be enrolled once s/he signs a Consent Form.
2. Obtain prior IRB approval for any modifications including addition of new recruiting materials, changes in research personnel or site location, sponsor amendments or other changes to the protocol or associated documents. Only those changes that are necessary to avoid an immediate apparent hazard to a subject may be implemented without prior IRB approval.
3. Report all adverse events, protocol violations, DSMB reports, external reports and study closures promptly to the IRB.
4. Make study records available for inspection. All research-related records and documentation may be inspected by the IRB for the purpose of ensuring compliance with UTMB policies and procedures and federal regulations governing the protection of human subjects. The IRB has authority to suspend or terminate its approval if applicable requirements are not strictly adhered to by all research study personnel.
5. When enrolling subjects who do not speak or read English, a bilingual translator must be available to facilitate communications between research personnel and a subject.



19-Nov-2013

**MEMORANDUM**

TO: Sandra McNeely, MSN, RN, CNE/Yolanda Davila, PhD, RN  
Grad School Biomedical Science

*Andrea M King*

FROM: Janak Patel, MD  
Vice-Chairman, IRB #2  
Institutional Review Board 0158

SUBJECT: Expedited Review, Human Subjects

Project Director: Sandra McNeely, MSN, RN, CNE/Yolanda Davila, PhD, RN, IRB #13-0427

Project Title: The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A Critical Ethnography

Under the Institutional Review Board's policies and procedures for reviewing protocols by an expedited review process, your project referenced above was approved on November 14, 2013. I am, therefore, pleased to inform you that you may proceed with this project immediately.

This project will require annual review by the IRB and will expire on November 14, 2014. Research that has not received approval for continuation by this date may not continue past midnight of the expiration date.

Project Directors of approved projects are responsible for reporting to the Institutional Review Board any unanticipated problems involving risks to subjects or others (includes adverse events) observed during the conduct of the project as well as any severe or serious side effects whether anticipated or unanticipated. If the adverse events were unanticipated or death has occurred, the adverse event must be reported to the IRB within 24 hours.

Should your project require modification which alters the risk to the subject or the method of obtaining informed consent (if applicable), the project must be reevaluated by the Institutional Review Board before the modification is initiated. Modifications to procedures or the project to remove an immediate hazard to subjects may be made prior to IRB review.

If applicable to the study, completed subject consents should be maintained in the designated location for at least three years after the termination of the project. In order to be in compliance with the requirements of the regulations, a copy of the completed consent document must be provided to the subject and for

more than minimal risk studies, a "Notice of Research Participation" form must be filed in each subjects' medical record.

Attached is the research consent form with the date of the IRB approval. Please use this form with the IRB approval date and make additional copies as they are needed. In accordance with amendments to 21 CFR Parts 50, 312 and 812 effective 12/5/96, consent forms must be dated when consent is obtained.

JP/ak

Document Uploaded

# Appendix B: Recruitment Flyer

## Your help is needed!

Are you:

1. Age sixty-five or older?
2. Of Mexican origin?
3. Born or at least have one one parent born in a country other than the United States?
4. Someone who has heart disease, cancer, stroke, lung disease or diabetes?

You may be eligible to be in a research study to help healthcare providers learn about your experience with health care in the United States. There will be 1-2 interviews in English with the researcher, lasting up to 60 minutes.

You will receive a small bag of healthy snacks, a copy of a senior resource guide, and a \$25 gift card for your time.



Please contact Sandra McNeely  
Doctoral student at University of Texas Medical Branch  
301 University Blvd. Galveston, TX 77555-1029  
(713) 899-3275 or [ssmcneel@utmb.edu](mailto:ssmcneel@utmb.edu)

Thank you!

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## **Appendix C: Research Consent Form**

### **RESEARCH CONSENT FORM**

You are being asked to participate in the research project entitled, The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A Critical Ethnography, under the direction of Sandra S. McNeely, MSN, RN, CNE, a Nursing PhD student at the University of Texas Medical Branch in Galveston, who is under the research supervision of Yolanda R. Davila, PhD, RN.

### **PURPOSE OF THE STUDY**

The purpose of this study is to help health care providers better understand your experience of facing illness when you are living in the U.S. You are being asked to participate in this research project because you have immigrated to the U.S., or at least one of your parents has immigrated to the U.S., and you are experiencing heart disease, cancer, stroke, lung disease, or diabetes.

### **PROCEDURES RELATED ONLY TO THE RESEARCH**

You will be asked to complete a questionnaire about yourself and to participate in a recorded interview. The interview will include a demographic questionnaire which includes a request for your zip code. Each interview will last up to 60 minutes at a time at a private location and time you choose that is mutually agreeable to both you and Ms. McNeely. You will be asked to describe the experience of illness from your perspective. Ms. McNeely will take notes during the interview, and the interview will be audio-recorded. Ms. McNeely may ask to meet with you for one to two more times, up to 60 minutes per time, for your input into the study findings.

### **RISKS OF PARTICIPATION**

The potential risks from participation in the study are possible feelings of sadness while sharing experiences.

### **NUMBER OF SUBJECTS PARTICIPATING AND THE DURATION OF YOUR PARTICIPATION**

The anticipated number of subjects involved in the study will be up to 15 subjects. The length of time for your participation is a two-week time period for a 30 – 60 minute interview and then possibly one or two follow up interviews for up to 60 minutes. You may be selected for a follow-up interview based on your knowledge, willingness, and insights. A time will be arranged for the follow up interview at a private location that is mutually agreeable to you and the researcher. All interviews will be audio-recorded.

### **BENEFITS TO THE SUBJECT**

There is no benefit to participation for the subjects.

### **SOCIETAL BENEFITS**

Your individual perspectives will help nurses and other health care providers support first and second generation immigrant elders facing life-limiting illness in the U.S..

### **WITHDRAWAL FROM THE STUDY**

You have the right to withdraw from the research project at any time with no consequences from your decision to withdraw. Provision of services received from the agency will not be affected by withdrawal from the study.

### **REIMBURSEMENT FOR EXPENSES**

You will receive a small gift bag of healthy snacks, a hard copy of the local area Senior Resource Guide (which is publicly available), and a \$25.00 gift card for your time and inconvenience.

### **USE AND DISCLOSURE OF YOUR HEALTH INFORMATION**

Study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPAA) provides safeguards for privacy, security, and authorized access of your records. These regulations require UTMB to obtain an authorization from you for the use and disclosure of your health information. By signing this consent form, you are authorizing the use and disclosure of your health information related to the research study. Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of the University of Texas Medical Branch (UTMB).

Confidentiality is limited if elder abuse is suspected or if you state intent to harm yourself or others. If you are in immediate danger of harming yourself or others, the researcher will tell you who is being contacted and seek your agreement, although the contact will be made whether or not you give consent. For records disclosed outside of UTMB, you will be assigned a unique code number. The key to the code will be kept in a locked file in Sandra McNeely's office.

### **ADDITIONAL INFORMATION**

1. If you have any questions, concerns or complaints before, during or after the research study contact **Sandra McNeely at (713) 899-3275 or Dr. Yolanda Davila, the supervisory chairperson, at (409) 772-8237.**
2. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without penalty or loss of benefits and without jeopardizing your medical care at UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If there are significant new findings or we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.
3. If you have any complaints, concerns, input or questions regarding your rights as a subject participating in this research study or you would like more information, you may contact the **Institutional Review Board Office, at (409) 266-9475.**

The purpose of this research study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying **Sandra McNeely at (713) 899-3275.** You will be given a copy of the consent form you have signed.



Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with UTMB.

---

Signature of Subject

---

Date

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject

---

Date

---

Signature of Person Obtaining Consent

## Appendix D: Participant Demographic Questionnaire

Organization\_\_\_\_\_ Start Time\_\_\_\_\_ End Time\_\_\_\_\_

Researcher assigned ID# \_\_\_\_\_ Date of interview \_\_\_\_\_ Zip Code of

Residence\_\_\_\_\_

Date of Birth\_\_\_\_\_ Gender: \_\_\_\_\_Male \_\_\_\_\_Female

Highest grade completed in school: \_\_\_\_\_

Country(s) where education received:

\_\_\_\_\_

Marital Status:      Married      Single      Divorced      Separated

Widowed

Who do you live with? \_\_\_\_\_ # of people in  
home\_\_\_\_\_

How long have you lived in the U.S. in years? \_\_\_\_\_

Country of Birth      Mexico      U.S.      Other\_\_\_\_\_

If 2<sup>nd</sup> generation, which parent born outside US? Mother      Father      Both      which  
country(ies)

What is your religion?

\_\_\_\_\_

Language Spoken      English      Spanish      Both

Language Read      English      Spanish      Both      None

Which of these medical conditions have you been diagnosed with?

Heart condition      Stroke      Lung disease      Cancer      Diabetes

How do you pay for health care?

---

When was the last time you received health care at a hospital or clinic?

---

How many times have you received health care at a hospital or clinic within the last 12 months?

## **Appendix E: Interview Guide**

### **Initial Interview Guide Questions:**

1. How would you describe your experience with having [heart disease, cancer, stroke, lung disease, diabetes]?
2. Tell me about when you first learned of your diagnosis.
3. What has it been like for you to receive health care services?
4. Tell me about a time that you went to the doctor, hospital, or clinic.
5. Tell me about the best experience you had at a medical visit. What made it good?  
What would have made it better? What were your thoughts & feelings during the visit?
6. Tell me about a medical visit that was not a good experience. What happened?  
What would have made it better? What were your thoughts feelings during the visit?
7. Tell me what it is like for you to have an illness like [heart disease, cancer, stroke, lung disease, diabetes].
8. How has living in the U.S. influenced your health?
9. What else would you like to share with me that I did not ask?

### **Probe questions:**

1. Can you give me an example?
2. Can you talk a little bit more about that?
3. I want to make sure I understand. Can you tell me more about that?
4. What happened? Then what did you do? How did that matter?
5. How did you feel about that?

6. How did that work for you?

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## **Vita**

Sandra Scott Lee was born in Atlanta, Georgia on November 4, 1966 to John and Jeanette Scott. Sandra graduated from Greenville Christian School where she was the valedictorian. Sandra obtained her Bachelor of Science in Nursing from Baylor University in Waco, Texas in 1989. Upon completing her degree, Sandra moved to Houston, Texas and began her career The Methodist Hospital Houston as a staff nurse. Sandra entered the Master of Science in Nursing (MSN) program at University of Texas Health Science Center-Houston, where she was a Good Samaritan Scholar. She completed the MSN in 1993 with focus in gerontological nursing and education.

In 2007, Sandra was admitted to the PhD in Nursing program at University of Texas Medical Branch. While in the doctoral program, Sandra received numerous honors including the The Marie and Albert Aulds Scholarship, the Mr. Harry Moore Scholarship, the John P. McGovern Award, the Alpha Delta Chapter of Sigma Theta Tau International, the Hattie Mae Jackson Scholarship, the Arthur V. Simmang Academic Scholarships Award, the NLN Foundation for Nursing Education-Salute to Nursing Scholars' Award, the Edgar and Grace Gnitzinger Scholarship Fund for Geriatric Nursing, the David and Janet Niesel Scholarship, the Florence Thelma Hall Distinguished Professorship in Nursing Award, the Promise of Nursing for Houston/Galveston Regional Faculty Fellowship, and the Lois E. Nickerson, RN Endowed Scholarship. Sandra is a member of Sigma Theta Tau International, the nursing honor society.

Sandra resides in Houston, Texas and is an Assistant Clinical Professor of Nursing at University of Houston School of Nursing. She has three adult children and is married to Dr. Gordon K. Lee.