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Rosemarie R. Garza

# The Dissertation Committee for Rosemarie R. Garza certifies that this is the approved version of the following dissertation:

# Weighing Consequences: An Ethnographic Study of Mexican-American Women with Coronary Heart Disease

**Committee:** 

Elnora (Nonie) Mendias, RN, PhD Chair

Carolyn Phillips, RN, PhD

Yolanda R. Davila, RN, PhD

Judith Drew, RN, PhD

Jean McSweeney, RN, PhD FAHA, FAAN

Dean, Graduate School

## Weighing Consequences: An Ethnographic Study of Mexican-American Women with Coronary Heart Disease

by

Rosemarie R. Garza, RN, M.Ed, MSN

### Dissertation

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### Dedication

To those women affected by heart disease, who so willingly and without hesitation shared their stories, experiences, and time. This dissertation study honors all of you.

And to my husband, Dr. R. Steve Garza, who believed in me. Your love, patience, and support in every way have been my total inspiration.

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### Weighing Consequences: An Ethnographic Study of Mexican-American Women with Coronary Heart Disease

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Coronary Heart Disease (CHD) is a major cause of death in U.S. Hispanics. One third of U.S. Hispanic women have CHD, but research is lacking about the effects of culture on their health outcomes. The purpose of this ethnography was to elicit cultural beliefs, illness interpretations, explanatory models, and self-care practices of Mexican-American women with CHD. Kleinman's Cultural Healthcare Systems model and the construct of lay EMs served as the sensitizing framework.

The sample included 11 English-speaking adult Mexican-American women with self-reported CHD. Using convenience and snowball sampling, participants were recruited from clinics in rural southwestern U.S. Participants were interviewed one to three times using a semi-structured interview guide. Participant observation included home visits and observations at doctors' appointments and other public settings.

The researcher used the constant comparative method to analyze data. Three important criteria (credibility, fittingness, and auditability), developed by Lincoln and

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Guba (1985) and modified by Beck (1993), ensured scientific rigor. Three themes, each with sub-themes, were identified.

The first theme, *Knowing about heart disease*, describes what women believed caused their CHD. There were three sub-themes: It runs in my family, It was my lifestyle, and It's my bad heart. The second theme, *It changes your whole life*, described women's perceptions about how CHD had affected their lives. There were four sub-themes: Bodily changes, Emotional changes, Financial changes, and Role changes. The third theme, *Living with heart disease*, described how women had adjusted to life with CHD. The three sub-themes included Listening to my body, Listening to my doctor, and Relying on my faith.

Study participants incorporated CHD as an enduring reality with persisting effects. Adjustment to CHD was difficult, and participants felt consoled and supported by their faith and by the love and care received from others. Participants modified their lifestyles but struggled to maintain their identities. Although aware of the benefits of healthier behaviors, participants weighed behavioral consequences and made choices congruent with their values.

Findings may improve Mexican-American women's CHD outcomes by providing information needed to deliver individually tailored and culturally-sensitive health care and interventions.

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### List of Abbreviations

AHA	American Heart Association
ССМ	Constant Comparative Method
CDC	Centers for Disease Control
CHD	Coronary Heart Disease
CHS	Cultural Healthcare System
CVD	Cardiovascular Disease
EM	Explanatory Model
GSBS	Graduate School of Biomedical Science
IOM	Institute of Medicine
IRB	Institutional Review Board
L	Line
L MI	Line Myocardial Infarction
MI	Myocardial Infarction
MI NCHS	Myocardial Infarction National Center for Health Statistics
MI NCHS NHLBI	Myocardial Infarction National Center for Health Statistics National Heart, Lung, and Blood Institute
MI NCHS NHLBI NIH	Myocardial Infarction National Center for Health Statistics National Heart, Lung, and Blood Institute National Institutes of Health
MI NCHS NHLBI NIH P	Myocardial Infarction National Center for Health Statistics National Heart, Lung, and Blood Institute National Institutes of Health Participant
MI NCHS NHLBI NIH P RQ	Myocardial Infarction National Center for Health Statistics National Heart, Lung, and Blood Institute National Institutes of Health Participant Research Question

#### **CHAPTER ONE: INTRODUCTION**

#### INTRODUCTION

Chapter One presents the study problem, purpose, and research questions. In addition, the sensitizing framework, Kleinman's (1980) Cultural Healthcare Systems and the construct of explanatory models (EMs), is described. Chapter One establishes the study significance and the justification for the study design. Finally, the chapter provides an overview of the design and plan for the remaining chapters.

#### **STUDY PROBLEM**

More than half (50.8 percent) of individuals in the U.S. population are female, and almost 25 million (6.4 percent) of these females are Hispanic. Hispanics represent roughly 52 million U.S. residents (U.S. Census Bureau, 2013). Hispanics comprise the largest U.S. minority (U.S. Census Bureau, 2011), and by 2050 they are projected to comprise 30.2 percent of the U.S. population (U.S. Census Bureau, 2008). Mexicans ranked as the largest Hispanic subgroup, most recently estimated to comprise 63 percent of Hispanics (United States Department of Health and Human Services [USDHHS], Office of Minority Health, 2012).

Heart disease is a major cause of disability in the U.S., and coronary heart disease (CHD) is considered to be the most common form (Centers for Disease Control and Prevention [CDC], 2010). Coronary heart disease (CHD) is the leading cause of death in U.S. women, accounting for 52 percent of women's deaths and over \$368.4 billion in medical costs per year (CDC, 2010). CHD is the second leading cause of death among U.S. Hispanic females, exceeded only by cancer (CDC, 2013). Research that addresses health promotion and health care delivery for Hispanic women is essential because 1) Hispanics are the fastest growing population segment in the U.S. (U.S. Census Bureau, 2011), and 2) epidemiological data have suggested that one-third of Hispanic women have some form of cardiovascular disease (CVD).

Previous research aimed at identification of CVD risk factors and prevention has suggested that women who are older, have lower socioeconomic status, have less formal

education, and belong to an ethnic minority are more at risk for CVD than the general population (McSweeney et al., 2004). Yet few research studies on CVD and CHD risk factors among Mexican-American women have examined the cultural issues related to health and illness, such as individuals' subjective perspectives, illness meanings and interpretations, self-care practices, and other influences affecting prevention behaviors and health practices (Helman, 2000; Kleinman, 1986; McSweeney et al., 2004).

Better understanding of the cultural beliefs influencing Mexican-American women's CHD experiences may assist healthcare systems and professionals to more effectively reduce CHD incidence, improve health outcomes, decrease CHD morbidity and mortality, and minimize healthcare system burden. Failure of health care providers to respond effectively to needs of minority communities may have severe consequences resulting in poor health outcomes (Mullins et al., 2010).

#### STUDY PURPOSE AND RESEARCH QUESTIONS

The purpose of this ethnographic study was to elicit cultural beliefs, illness interpretations, explanatory models, and self-care practices of Mexican-American women with CHD. The study research questions were as follows:

Research question (RQ) 1.1: How do Mexican-American women with CHD describe and explain their experiences with CHD?

RQ 2.1: What are the self-care practices of Mexican-American women with CHD? RQ 2.2: How do Mexican-American women with CHD describe their self-care practices related to CHD?

#### **OVERVIEW OF THE SENSITIZING FRAMEWORK**

Cultural knowledge and beliefs influence meanings that individuals assign to their illness experience as well as their self-care practices (Helman, 2000). Cultural beliefs affect individuals' decisions about desired treatments for illness and affect the outcomes expected from treatment (Kleinman, 1986). Kleinman's (1980) Cultural Healthcare Systems model and the construct of explanatory models (EMs) guided the current study's context, questions, and methods. Kleinman defines explanatory models (EMs) as cognitive schemes developed by individuals, using cultural beliefs and popular knowledge, to personalize and explain their experiences with health and illness. Over time, some of the knowledge changes when it is subjected to new data, but Helman asserts (2000) that dominant cultural beliefs largely prevail. The EMs of primary concern in this study were those constructed and used by Mexican-American women with CHD to interpret the meanings of their illness experience, to understand their illness, and to influence their self-care practices.

Kleinman's (1980) Cultural Healthcare Systems model uses three sectors popular, folk, and professional—to explain unique, shared, and interactive knowledge people use to construct EMs of health and illness experiences. According to Kleinman, the popular sector involves initial recognition of illness by the individual, who in turn attributes a degree of significance based on previous and vicarious experiences. The folk sector, an important part of all healthcare models, includes culture-specific healers, remedies, and expected treatment outcomes based on cultural etiologies shared by groups. *Curanderos* and other lay healers who may use herbs, potions, or teas to treat illnesses are examples of the phenomena in the folk sector. The professional sector includes physicians, nurses, dentists, and other professionals who historically have developed EMs based in established and sanctioned knowledge of Western medicine.

Kleinman (1980) developed the concept of EMs to understand individuals' beliefs about the etiology, course, and treatment of illness. EMs of health and illness experiences are formulated by individual members of a given sector. EMs may be influenced by culture, perceptions of past experiences, and social environment (Hoke et al., 2006) or may be personalized and different from one's family or ethnic group (Kleinman, 1980). Each sector has unique sets of knowledge and beliefs from which EMs are constructed (Kleinman, 1980). Differing views between health professionals and lay persons may result in conflicting expectations of treatment, outcomes, and evaluations (Cohen et al., 1994), which may lead to non-adherence, dissatisfaction, inappropriate treatment, and poor care (Chandler et al., 2012). To reduce conflict between sectors and increase effective care, Kleinman (1980) suggested that healthcare providers understand and use sectoral EMs to improve and promote patient communications, decrease barriers to accessing healthcare, and enable development of treatment plans with relevance and

meaning to individual patients. EMs have been used to explore relationships, health beliefs, behaviors, illness experience of heart failure and myocardial infarction, and pathways to health through self-care practices (Arslanian-Engoren, 2007; Clark, 2003; Hoke et al., 2006; Russell et al., 1998; Sanchez, 2007). In addition, EMs have been used to study persons with diabetes, cancer, depression, and hypertension (Arcury et al., 2004; Rose et al., 2000). Kleinman's (1980) model is explained in greater detail in Chapter Two.

#### **STUDY SIGNIFICANCE**

Previous research about Mexican-American women has examined CHD prevention and disease symptoms, warning symptoms, lifestyle, and behavioral changes after heart illness (Cooper-Dehoff et al., 2007; McSweeney & Coon, 2004; McSweeney et al., 2003, 2010). Low income and education have been identified as important barriers to healthcare access (Rojas-Guyler et al., 2008). U.S. Hispanic women who lack access to preventive health and health education have higher rates of health problems than non-Hispanic white women (Mullins et al., 2005; Rojas-Guyler et al., 2008). Despite national aims to improve population health, important health disparities persist in racial and ethnic groups and in women (IOM, 2010). Studies addressing significant health issues in Mexican-American women are needed to meet goals for population health advances.

Cultural factors may affect Mexican-American women's health and healthseeking behaviors. For example, Mexican-American women often are expected to uphold traditional cultural and gender roles (de la Torre & Estrada, 2001; George, 1998). The prioritization of family considerations over individual or community needs is a strong universal value in Hispanics, who typically form a strong interdependence with nuclear and extended family members (Kemp, 2005). Mexican-American women value their roles as mothers and family care-givers, which in turn causes them to place family needs and responsibilities above their own needs and to seek and adhere to adult male family members' opinions—including opinions regarding healthcare (Galarraga, 2007; Mendias et al., 2001). Although cultural influences have increased Hispanic women's primary use of Western medical interventions, many traditional Mexican-American women seek help from *curanderos* (lay folk healers) rather than, or as a supplement to, Western medical providers (Spector, 2005; Stevenson et al., 2004). Mexican-American women are more likely to report that CVD is unavoidable (Christian et al., 2007). However, a dearth of research exists regarding the effects of cultural views upon health and health-seeking behaviors in Mexican-American women with CHD.

Self-care is a concept that refers to an individual's abilities and practices that focus on that person's well-being. Self-care is culturally influenced and critical to health promotion and maintenance (Richard & Shea, 2011). Barriers to self-care include insufficient knowledge, economic constraints, and inadequate social support (Bayliss et al., 2003). Self-care management has been correlated with improved health behaviors and outcomes in persons with CHD (Burnette et al., 2004), but Mexican-American ethnicity has been related to lower confidence to self-manage CHD (Blustein et al., 2008). Understanding cultural beliefs and barriers of Mexican-American women with CHD that might deter self-care could have far-reaching implications for CHD prevention, health outcomes, and treatment, yet few such studies have been done.

Gaining a perspective about how the cultural beliefs of Mexican-American women with CHD affect their health and self-care practices requires listening to those with the illness (Eggenberger et al., 2006). Nevertheless, few studies have examined EMs held by Mexican-American women with CHD (Deaton & Namasivayam, 2004; Evans, 2010).

The current study is aimed at providing healthcare professionals with a greater understanding of the cultural beliefs, interpretations, and self-care practices that influence Mexican-American women's ability to combat or control CHD. Exploring clients' EMs may lead to development of culturally appropriate treatment plans and improve health outcomes by increasing health professionals' understanding of linkages between patient beliefs and behaviors and enhancement of strategies for achieving positive health behaviors (Lechuga, 2011; McSweeney, 1993; McSweeney et al., 1997).

#### Justification for the Study Design

The researcher used an ethnographic design to answer the research questions. Ethnography examines persons or groups connected by culture, observes behaviors, and provides voice to persons through abundant descriptions and verbatim quotations that

describe an experience in a culturally germane context (Fetterman, 2010; Spradley, 1980). The ethnographer collects data using an *emic*, or insider, perspective and describes and interprets data from an *etic*, or external, scientific viewpoint (Fetterman, 2010). Ethnographic approaches answer questions about culture and behavior (Atkinson & Hammersley, 2007; Bogdan & Biklen, 1998). Ethnography was an appropriate design for this study because it allowed the researcher to explore values, beliefs, behaviors, understandings, and self-care practices of adult Mexican-American women with CHD (Creswell, 2007; Munhall, 2011).

The researcher in the current study used a non-random sampling of adult Mexican-American women with self-reported CHD who met study criteria, were readily available, and were willing to participate. As the study progressed, snowball sampling was employed when a study participant wished to recommend other participants for the study (Polit & Beck, 2010). Although the researcher had anticipated enrolling a sample of up to 15 Mexican-American participants, data saturation or informational redundancy was recognized after analyzing data from 11 women who met eligibility criteria and gave written informed consent.

Data were collected through in-depth interviews of participants in their homes, observations of participants at doctors' appointments or other community activities, observations in public community settings, and through informal conversations with community members. Each participant was interviewed one to three times.

Wolcott (2008) noted that ethnographic researchers long have identified patterns and themes that appear to describe groups' universal languages and behaviors. Ethnographers code data, discover patterns, and interpret those patterns while considering the cultural context (Fetterman, 2010). The constant comparative methods, acknowledged in ethnography as a key strategy to analyze the narrative data (Atkinson & Hammersley, 2007; Goetz & LeCompte, 1981; LeCompte & Schensul, 1999a, 1999b), is similar in process and outcomes to methods of data analysis presented by grounded theorists (Glaser & Strauss, 1967; Strauss & Corbin, 1990) and other qualitative researchers (Lincoln & Guba, 1985). The researcher elected to use the constant comparative method of data analysis to organize the massive amount of data common to ethnographic research (Corbin & Strauss, 2008; Glaser & Strauss, 1967). The constant comparative method

(CCM) uses repeated review and comparison of data incidents to identify data similarities and differences.

#### SCIENTIFIC RIGOR OR TRUSTWORTHINESS

Lincoln and Guba (1985) established standards for rigor, or trustworthiness, of qualitative research that correspond to quantitative research standards for validity and reliability. These criteria, as modified by Beck (1993), were used to establish the trustworthiness of this study: *credibility*, *fittingness*, and *auditability*. An evaluation of how this study met these criteria is described in Chapter Three.

#### LIMITATIONS

The researcher is not Mexican-American and did not speak Spanish; thus, some access limitations to potential participants may have existed, and the narrative richness may have been diminished in participants whose first language was Spanish. Limiting the participation to those who spoke English also may have influenced the findings because language can be an indicator of acculturation (Phinney & Flores, 2002). The researcher minimized the potential of limited access by participant recruitment in settings such as family practice and cardiology clinics, churches, and local community centers. No obvious problem with access or with language was identified, and participants appeared eager to participate in the study; however, it is possible that study findings may not be applicable to Mexican-American women who primarily or only speak Spanish.

Because the researcher is well known in the community and perhaps known to study participants, participants may have been reluctant to speak freely or may have desired to present themselves in a positive light. Although participants were assured of confidentiality, encouraged to speak openly, and appeared to speak fluently and without hesitation, it is not possible to assess with full assurance whether participants were influenced by the researcher. All interview narratives and journal notes were reviewed with the researcher's supervising professor to determine potential bias; none was noted, although areas for clarification were identified and addressed with participants to ensure the researcher's understanding.

#### SUMMARY

Chapter One presented the study problem, purpose, and research questions. The chapter delineated the sensitizing framework—Kleinman's Cultural Healthcare Systems. Study significance and the justification for the study design were provided. Finally, the chapter provided an overview of the design and plan for the remaining chapters.

Chapter Two provides a review of relevant literature. Chapter Three presents the research design and methodology. Chapter Four presents the demographic description of the sample and findings of this study. Chapter Five provides a summary of the major findings; compares findings to the extant literature; discusses study limitations, strengths, weaknesses, and implications; and makes recommendations for future research.

#### **CHAPTER TWO: REVIEW OF LITERATURE**

#### **INTRODUCTION**

Chapter Two presents a review of literature relevant to the present ethnographic study of the cultural beliefs, illness interpretation, explanatory models, and self-care practices of Mexican-American women with coronary heart disease (CHD). The chapter describes Kleinman's (1980) Cultural Healthcare Systems model and the construct of explanatory models (EMs), which comprised the sensitizing framework used in this study. Chapter Two summarizes relevant extant literature related to 1) heart disease in women and Hispanics; 2) health disparities and access to care; 3) CVD Risks in women and Mexican-American women; 4) culture and Mexican-American women; and 5) self-care and heart disease. Finally, the Chapter identifies gaps in knowledge, justification for the study, and a plan for the succeeding chapters.

#### SENSITIZING FRAMEWORK

Some qualitative studies may use theories or sensitizing frameworks to provide a perspective of the phenomenon of interest to the researcher and serve as a theoretical foundation (Corbin & Strauss, 2008; Fetterman, 2010; Polit & Beck, 2010). Kleinman's (1980) Cultural Healthcare Systems (CHS) model and the construct of explanatory models (EMs) guided this ethnographic study. Kleinman's model has been deemed appropriate for studies that examine how cultural beliefs affect health and illness behaviors.

In Kleinman's (1980) CHS model describes three individual yet over-lapping and interconnected sectors of health care: the popular, the folk, and the professional. Each sector has a unique set of knowledge and beliefs that individuals in the given sectors employ to explain health and illness experiences. Kleinman (1980) developed the concept of EMs to describe individuals' beliefs about illness causes, progression, and treatment. EMs denote people's logical explanations for illness episodes based upon learned and collective cultural knowledge and beliefs (Drew, 2008; Helman, 2000). Kleinman (1980)

developed eight questions to ask in practice and research settings to elicit individuals' EMs. They are:

- 1. What do you think has caused your problem?
- 2. Why do you think it started when it did?
- 3. What do you think your problem does inside your body?
- 4. How severe is your problem? Will it have a short or long course?
- 5. What kind of treatment do you think you should receive?
- 6. What are the most important results you hope to receive from this treatment?
- 7. What are the chief problems your illness has caused you?
- 8. What do you fear most about your illness/treatment? (p. 106)

EMs are dynamic and subject to change (Kleinman, 1988). Both previous experiences and social environments may affect EMs (Hoke et al., 2006). EMs may be personalized and influenced by culture, ethnicity, perceptions of past experiences, and social environment, and, therefore, may vary from one's family or ethnic group (Hoke et al., 2006; Kleinman, 1980).

Individuals use EMs to make decisions about which health care sector to utilize, whom to ask for advice or treatment, choices for self-care, adherence to treatment recommendations, selection of alternate treatments, evaluation of care effectiveness, and satisfaction with care received (Kleinman, 1980). When patients feel their personal values and beliefs are heard, understood, and integrated into their care, they tend to be more likely to participate in treatment planning and to comply with directives (Askim-Lovseth & Aldana, 2010; Cleveland & Horner, 2012; Juckett, 2013; Lechuga, 2011). It is crucial that health care professionals recognize and respect cultural influences on health and illness behaviors.

Kleinman's (1980) first sector, the popular sector, is the lay or non-professional social domain where people first define and acknowledge illness, and where health care activities begin. The popular sector includes a set of beliefs about health maintenance, such as healthy ways to eat, sleep, work, pray, or use of charms and amulets (Kleinman, 1980). Across cultures, people generally select self-care approaches and treatment options during and after consulting from family members as their first therapeutic action

(Kleinman, 1980). Health care provided by family or neighbors typically defines care experiences and women have been shown to be the main providers of such care (Evans et al., 2007; Helman, 2000).

Kleinman (1980) says the second, or folk, sector is an important part of healthcare for many cultures. The folk sector includes non-professional healers, who may be secular lay healers or sacred, such as clergy or spiritual healers (Kleinman, 1980) In Mexican-American culture, the folk sector includes *parteras* (lay midwives), *curanderos*, and other lay healers who may use massage, herbs, potions, or teas to treat illnesses or provide other therapies (Helman, 2000).

The third sector of Kleinman's (1980) model is the professional sector, which includes recognized health professionals, such as physicians, nurses, dentists, midwives, and others, as well as health practitioners belonging to the "professional indigenous medical systems" (p. 87). In the Mexican-American culture, *curanderismo*, or folk healing, although included most appropriately in Kleinman's folk sector, could also be included in the professional sector, especially if folk healers are the first persons from whom women seek advice or consultation upon experiencing a symptom or illness (Helman, 2000).

Each sector has unique sets of knowledge and beliefs from which EMs are constructed (Kleinman, 1980). The language used by members of the professional sector is different from that of the popular or folk sectors, and members of the professional sector have their own technical vocabulary (Helman, 2000). Kleinman (1980) suggested that EMs of different sectors can be in conflict, such as in the recognition of illness and role behaviors between patient and health care professionals. Health care professionals' judgments about patients are influenced by two cultural views, each with their own characteristics: one view is based upon their own cultural background, and the other view is rooted in the culture of medicine (Andrulis, 2003). Differing views between health professionals and lay persons may result in conflicting assumptions about treatments and results, which in turn may lead to non-adherence, discontent, unsuitable treatment, and poor care (Cohen et al., 1994; Moore et al., 2010). Kleinman (1980) believed healthcare providers who understand and use EMs in theory and in practice can improve and promote patient communications and enable development of treatment plans with

relevance and meaning to individual patients, culminating in good outcomes. Improving healthcare professionals' knowledge about sectoral EMs and those of individual patients may enhance treatment quality, patient adherence, and patient involvement in illness care (Andrulis, 2003).

Several studies about the EMs held by Mexican-American men and women with chronic illness have provided significant findings and recommendations. Jezewski and Poss (2002) used grounded theory to examine the EMs of Mexican-American women and men regarding diabetes. Study findings indicated that participants used both folk and professional sectors to explain and to treat their diabetes. The researchers noted that participants integrated knowledge from their diabetic classes into participants' traditional beliefs and practices, interpreting class instruction in such a way as to allow participants to continue their cultural behaviors, although more cautiously.

McEwen (2005) used a critical ethnographic approach to explore EMs of 14 male and female Mexican immigrants about their latent tuberculosis. Findings indicated that study participants felt conflicted about latent tuberculosis treatment because Mexican popular and professional sector advice differed from counsel provided by the U.S. professional sector. McEwen (2005) suggested that differences in U.S. and Mexican health care professionals' explanations led to participants' distrust of both groups. McEwen (2005) proposed that differences in U.S. and Mexican health care professionals' explanations led to distrust of both groups.

Hoke et al. (2006) conducted a descriptive qualitative study of 15 overweight Mexican-American women to examine their EMs about eating habits and weight. Study findings indicated the need to clarify meanings of certain words or phrases, such as "healthy eating" or "overweight," because women's EMs affected how they interpreted and followed medical advice. However, no studies of the EMs of Mexican-American women with CHD were discovered.

#### **REVIEW OF THE LITERATURE**

A literature review for publications from 1980-2013 was conducted using electronic and manual search methods; restrictions included primary research conducted in the United States (U.S.) and studies reported in peer-reviewed journals written in English. CINAHL, Medline OVID, EBSCO, Web of Science, and PubMed were queried using a series of keyword searches: explanatory models (EMs), cultural beliefs, illness interpretation of Mexican-American women, self-care practices, heart disease, coronary heart disease (CHD), and Mexican-American women. Because of the large volume of publications identified in the initial search, the review was limited to studies published within the last 13 years and to seminal studies since 1980. The final review was based on abstracts deemed most congruent with study purpose. Reviewed literature also included publications by authors with expertise related to the study, as well studies cited in reviewed articles. The literature review was organized into five major areas, which are delineated below.

#### Heart Disease in Women and Hispanics

For a number of years, the U.S. has emphasized national health goals aimed to improve health and eliminate health disparities. *Healthy People 2020* has four general goals:

Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death; Achieve health equity, eliminate disparities, and improve the health of all groups; Create social and physical environments that promote good health for all; Promote quality of life, healthy development, and healthy behaviors across all life stages (USDHHS Healthy People 2020, 2012, p. 1).

Heart disease disproportionately affects women and minority groups (NCHS, 2010; World Health Organization [WHO], 2007). Females represent 50.8 percent of the U.S. population, of whom almost 25 million (6.4 %) are Hispanic. Hispanics, the largest minority group in the U.S., represent approximately 52 million U.S. residents (U.S. Census Bureau, 2013). By the year 2050, Hispanics are projected to comprise 30.2 percent of the U.S. population (U.S. Census Bureau, 2008). Hispanics of Mexican origin are estimated to comprise 63 percent of Hispanics (USDHHS, Office of Minority Health, 2012).

Heart disease, also termed cardiovascular disease (CVD), includes constrictions or blockages of blood vessels that can result in chest pain (angina), heart attacks (myocardial infarctions), or strokes (National Institutes of Health [NIH], 2012). Coronary heart disease (CHD) refers to the narrowing of the coronary arteries (NIH, 2012). CHD accounted for one of every six deaths in the U.S. (AHA, 2010), and CVD has been the major contributor to both morbidity and mortality of U.S. women and ethnic minority populations (CDC, 2010; WHO, 2007). As life expectancies lengthen and nations grow more industrialized, CVD rates are anticipated to climb (Yusuf et al., 2001).

CHD is the foremost cause of death of U.S. women, accounting for 52 percent of women's deaths and over \$368.4 billion in medical costs per year (CDC, 2010). CHD is the second leading cause of death among U.S. Hispanic females, exceeded only by cancer (CDC, 2013). Given that the Hispanic population, and especially Mexican-Americans, is the fastest growing population segment in the U.S., research guiding health care delivery for Hispanic women is essential to maintaining a healthy populace (U.S. Census Bureau, 2009). Thus, more studies that explore prevention and treatment of heart disease in women, and especially Hispanic women, are warranted (Mosca et al., 2011; Sherrod, 2011).

#### Health Disparities and Access to Care

The report *Unequal Treatment Confronting Racial and Ethnic Disparities in Healthcare* confirmed persistent disparities in health and health services utilization of U.S. racial and ethnic populations (IOM, 2002). Health disparities have been correlated with inadequate access to quality healthcare and preventative health services (Hargraves, 2004). Lack of insurance, poor language skills, economic constraints, lack of citizenship, lack of minority physicians, and cultural insensitivity of healthcare providers have been identified as key barriers to healthcare access (Dey & Lucas, 2006; Kemp, 2001; Mullins et al., 2010; Pippins et al., 2007; Read et al., 2005; Rojas-Guyler et al., 2008). Mexican-Americans are the highest subgroup of uninsured in the U.S. (U.S. Census Bureau, 2011).

Hispanics have identified language barriers as a major obstacle to healthcare access (Padilla & Villabos, 2007; Pippins et al., 2007; Rojas-Guyler et al., 2008). Language is essential to patient-provider communications to increase understanding and interactivity, especially between patients and physicians (Sudore et al., 2009). Hispanic women in the U.S with low income and education achievement have been more likely to report barriers to healthcare access (Rojas-Guyler et al., 2008). Additionally, U.S. Hispanic women have been more likely to lack access to health education and preventive health care, resulting in higher rates of health problems than in non-Hispanic white women (Mullins et al., 2005; Rojas-Guyler et al., 2008).

Significant health disparities persist in racial and ethnic groups and in women (IOM, 2010). Racial and ethnic minority women have been underrepresented in health research, which has created important gaps in understanding how minority women are affected by illnesses such as CHD; this knowledge gap, in turn, has made minority women an important priority for health research (Adler, 2010; Getz & Faden, 2008). Hispanics represented only 7.6 percent of research participants in National Institutes of Health (NIH) sponsored clinical trials, with even fewer Hispanic women participating in such research (Finn et al, 2009). Members of ethnic minorities may be unwilling to participate in research because they fear being harmed or they mistrust the healthcare system (Ding et al., 2007; Smith et al., 2009). Research that includes vulnerable populations, such as Hispanic women, may inform efforts to reduce health disparities related to health care access, gender, and cultural influences on health.

Despite national aims to improve population health, important health disparities persist in underrepresented racial and ethnic groups and in women (IOM, 2010). Women with CVD encountered issues related to their diagnosis, healthcare management, and outcomes (McSweeney et al., 2011). Studies addressing significant health issues in Mexican-American women are needed to meet goals for population health advances.

#### **CVD** Risks in Women and Mexican-American Women

Some studies have indicated that women consider heart disease to be a "man's disease" (National Heart Lung and Blood Institute [NHLBI], 2012). Arslanian-Engoren's (2007) study examined perceptions of heart disease risk in 30 Hispanic, Black, and White women. All participants believed that men were of greater risk if obese, stressed, or a smoker, but also believed themselves to be at risk due to being overweight, having family history of heart disease, and having a poor diet (Arslanian-Engoren, 2007). While 84

percent of women in the NHLBI (2012) study reported having at least one heart disease risk factor, only 31 percent deemed themselves as at risk for heart disease. Additionally, Lefler et al.'s (2013) descriptive qualitative study of the perceptions of African-American and White older women about cardiac risks indicated that participants inaccurately viewed their risk as low; minority women were less likely than White women to report themselves as at risk for CHD.

Across ethnicities, women have been more likely than men to delay care-seeking for heart disease due to perceptions of low heart disease risk, lack of knowledge and recognition of symptoms of heart disease, and desire to self-treat (MacInnes, 2006; McSweeney et al., 2005, 2010; Rosenfeld, 2006; Thorne et al., 2003). Women over 45 years old were more likely to describe shortness of breath as a symptom of acute Myocardial Infarction (MI) (McSweeney et al., 2005). McSweeney et al. (2010) examined prodromal and acute symptoms of MI in Hispanic, Black, and White women: women, regardless of race, reported unusual fatigue as the most frequent prodromal symptom and shortness of breath as the most frequent acute symptom.

Sjöström-Strand and Fridlund (2008) conducted a qualitative study of 19 Swedish women who had experienced an MI to determine their symptoms and their reasons for delay in seeking medical care. The researchers revealed five causes for delays in seeking care: 1) trying to convince themselves symptoms were not serious and would resolve; 2) trying to resolve the symptoms themselves; 3) minimizing symptoms; 4) prioritizing family responsibilities; and 5) consulting with family and friends before seeking medical care. Similarly, Sherrod's (2011) descriptive qualitative study of the most commonly occurring prodromal and acute symptom reported by 56 Hispanic women found that women delayed care seeking for several reasons: they felt that their symptoms were not acute enough to seek medical care, they first consulted a trusted family member, they lacked confidence in their doctor, they lacked adequate resources (e.g., transportation, insurance), and they prioritized family needs.

Hispanic women's CVD risks increase with older age, lower socioeconomic status, lower levels of formal education, lack of insurance, and limited access to health services (Benjamin et al., 2005; McSweeney et al., 2005; Mensa et al., 2005; Mullins et al., 2010). Mexican-American women are less likely to be tested for and less likely to

know their cholesterol levels than white counterparts (Ford et al., 2010). Hispanic women were more apt to report that there is nothing they can do to keep themselves from developing CVD than white women (Christian et al., 2007).

Poorer outcomes for women with CHD have been linked to women's lack of knowledge of heart symptoms and failure to address symptoms (Rosenfeld et al., 2005; Sherrod, 2011), as well as to health care professionals' failure to recognize women's heart symptoms (Cheek et al., 2008). Women with lower education are less likely to be assessed for CVD risk factors (Merkin et al., 2009).

Mexican-American women may require greater efforts to raise their perceptions of their cardiac risks and to increase their knowledge about CHD symptoms (Cooper-Dehoff et al., 2007; Sherrod, 2011). Studies that examine EMs of Mexican-American women with CHD may provide insight to the development of culturally relevant interventions (Riegel et al., 2006; Sherrod, 2011).

#### **Culture and Mexican-American Women**

Culture is in continuous flux and consists of learned, shared sets of values and beliefs of a particular group that guide thoughts, decisions, and behaviors (Helman, 2000; Leininger, 2002). Helman (2000) described culture as inherited and passed down from generation to generation as symbols and rituals. Kleinman (2004) suggested that

Culture influences the experience of symptoms, idioms used to report them, decisions about the treatment, doctor-patient communications, like the likelihood of outcomes such as suicide, and the practices of professionals (p. 951).

In short, cultural beliefs influence the way people view their health status and health perceptions (Andrulis, 2003; Helman, 2000). Few studies, however, have explored how cultural characteristics affect the health of Mexican-Americans with CHD.

Mexican-American women often are expected to uphold traditional cultural and gender roles (de la Torre & Estrada, 2001; Evans et al., 2007; George, 1998; Mendias et al., 2001). Within the Mexican-American culture, there are a number of commonly accepted cultural values that may affect the Mexican-American women's health and behaviors. Among these shared values are *familismo*, *personalismo*, and *fatalismo* 

(Askim-Lovseth & Aldana, 2010; Espinosa de Los Monteros & Gallo, 2012; Juarez et al., 1998; Santiago-Rivera et al., 2002).

*Familismo* is a powerful commitment to family that places family matters above personal or community needs; it exists as a powerful and universal value among Hispanics, who characteristically form intense, interdependent relationships with family members (Juarez et al., 1998; Toro-Morn, 2013). According to Lugo Steidel and Contreras (2003), *familismo* has four components: 1) familial support; 2) interconnectedness; 2) familial honor; and 4) subjugation of self for family. Familial support reflects the perception that members of families are required always to provide financial and emotional assistance to each other. Interconnectedness measures the perspective that family members are required to have physical and emotional connection. Familial honor indicates the understanding that family members must uphold family image. Subjugation of self for family addresses the perspective that individuals must put the family first.

Davila et al. (2011) conducted focus groups of 50 primarily Hispanic speaking male and female adults with Hepatitis-C infection. *Familismo* emerged as the major theme; familial devotion, responsibility, and duty were the fundamental standards for health decisions and behaviors (Davila et al., 2011). Other studies have confirmed that Mexican-American women value their roles as mothers and care-givers, frequently putting their family needs above their own (Mendias et al., 2001). Placing family needs over personal needs has been identified as a barrier to diagnosis and proper treatment of Mexican-American women with heart disease (Sherrod, 2011). Some researchers have linked the Hispanic cultural construct *marianismo*—prioritization of familial responsibilities, self-sacrifice, respect for motherhood, and devotion to the Blessed Virgin Mary—with Hispanic women's tendency to disregard the women's own health concerns and self-care (D'Alonzo, 2012).

*Familismo* also includes the obligations of the younger generations to care for their elders (Lugo Steidel & Contreras, 2003; Ruiz & Ransford, 2012). However, some studies have questioned whether the cultural value of *familismo* is changing. Ruiz and Ransford (2012) used focus groups to explore perceptions of *familismo* in 25 male and female Latinos 55 years or older and residing in Los Angeles. The researchers' goals

were to discover the participants' definition of family, whom they depended on, and how *familismo* affected their health behavior. The researchers noted several interesting findings. First, participants' definitions of family extended beyond the traditional immediate family and often incorporated neighbors and friends. Second, participants described protecting their busy adult children and encouraging them to concentrate on their own family and work. Conversely, participants described their adult children as being involved in their lives and especially involved in their health care for major illness. Lastly, women participants were more likely to self-treat than men because they have larger social networks. In addition, adult children tended to have traditional gender roles in regard to health care, with female children more likely to provide emotional support and male children providing transportation. Ruiz and Ransford (2012) concluded that the participants were suffering physically and emotionally as a result of sparing their children.

*Personalismo* is defined as the ability to be personal and genuinely kind to others and the desire to be treated in the same way (Santiago-Rivera et al., 2002). *Personalismo* includes showing mutual respect (Ortiz, 2009; Villar-Loubet et al., 2011) and interest in others and having others demonstrate interest in return (Rayle et al., 2006). When the value of *personalismo* is applied to health care, it indicates that patients know their health care professional cares about them (Flores, 2000). *Personalismo* may be physically expressed in the form of a hug or handshake (Cleveland & Horner, 2012; Ortiz, 2009).

*Personalismo* in health communications with Hispanics and the need for friendly and welcoming environments in care facilities for Hispanics has been strongly recommended (Evans et al., 2007; Juckett, 2013). Several adverse effects can occur when Mexican-American women do not perceive the presence of *personalismo* in their health care settings. Mexican-American women value personal interactions with health care professionals, and studies have indicated that Mexican-American women will change providers if they feel disrespected (Cleveland & Horner, 2012; Sanchez, 2007). A phenomenological study conducted by Chandler et al. (2012) examined the experiences of 26 uninsured Mexican immigrant women seeking health care in California. The researchers found that many of the women felt unimportant or dismissed by health care

personnel, which led to perceptions of suffering and lack of adequate healthcare provision.

*Fatalismo* is a belief that predestination or external forces instigate events and nothing can change fate (Abraído-Lanza et al., 2007; Espinosa de Los Monteros & Gallo, 2012). *Fatalismo*, or fatalism, has been associated with a pessimistic view and a passive coping style, leading to poor health outcomes in Mexican-Americans and African-Americans (Abraído-Lanza et al., 2007). Urizar and Sears (2006) examined Hispanic participants with CHD and reported that patients held fatalistic views about future events and believed that having CHD was out of their control; participants' fatalistic beliefs were linked with severe medical problems and depression and lower quality of life, which may negatively affect patients' recovery from CHD. Fatalistic beliefs also have been suggested as an impediment to cardio-metabolic health (Espinosa de Los Monteros & Gallo, 2012).

Abraído-Lanza et al. (2007) reviewed major findings in the literature from studies about *fatalismo* and cancer screening of Latinos. Abraído-Lanza et al. (2007) concluded that the concept of *fatalismo* is poorly defined and its measurement instruments lack construct validity. These problems may contribute to the contradictions found in the literature about *fatalismo*. Abraído-Lanza et al. (2007) recommended a comprehensive review of *fatalismo* and related concepts, construction of valid and reliable measures of *fatalismo*, and rigorous examination of other factors that may affect how *fatalismo* is understood and interpreted.

Culture affects Mexican-American women's health-seeking behaviors. Mexican-American women frequently are expected to seek and adhere to adult male family members' opinions, including those about healthcare (Galarraga, 2007). Because women are the primary healers on the family level, Mexican-American women usually seek advice from female family members or trusted female neighbors (Spector, 2005). Although assimilation of Hispanic women has led some to use Western medical interventions before using traditional healers, many traditional Mexican-American women seek help from *curanderos* (lay folk healers), instead of, or in addition to, Western healthcare providers (Spector, 2005; Stevenson et al., 2004).

Research has suggested that the health of Mexican-American women is strongly influenced by their culture (Hoke et al., 2006; McEwen, 2005; Sherrod, 2011). However, few studies have examined how cultural values and practices affect health and health behaviors of Mexican-American women with CHD (Sherrod, 2011). Knowledge of patients' cultural beliefs, values, and viewpoints may facilitate provision of effective health care (Leininger, 2002; McEwen, 2005; Rogers, 2010; Sherrod, 2011). Understanding how cultural beliefs affect health and health behaviors may aid in development of culturally appropriate interventions to improve the health of Mexican-American women with CHD, eliminate barriers to their health care delivery, and decrease morbidity and mortality.

#### Self-care and Heart Disease

Self-care consists of deliberately performed actions by individuals or communities to achieve, maintain, or promote maximum health, and self-care is guided by individuals' self-efficacy, knowledge, and values (Lipson & Steiger, 1996; Orem, 1995). Self-care is culturally influenced and directs health promotion and maintenance, including activities required to manage acute and chronic health conditions (Richard & Shea, 2011).

In the popular sector where illness is first identified and health care is initiated, self-care is the first healthcare mode used by most individuals and its initiation depends on personal cultural associations (Kleinman, 1980). Barriers to self-care for chronically ill patients include lack of knowledge, financial constraints, and need for social and emotional support (Bayliss et al., 2003). Benefits of self-care include lower rates of complications, decreased healthcare costs, improved sense of control, enhanced coping, deepened sense of meaning, greater well-being, and increased quality of life (Leenerts et al., 2000; Schnell-Hoehn et al., 2009; Sidani, 2011; Song, 2010).

Self-care is an important strategy for Mexican-Americans, especially women (Burnette et al., 2004). Using Kleinman's (1980) framework, Sanchez (2007) described self-care as the major lay or popular sector health care activity employed by Mexican-American women to stay well or recover after chronic illness. Burnett et al. (2004) studied functional abilities as an indicator of self-care in persons with and without CHD

and suggested that CHD management relied more on self-care than professional care. A study of Hispanics with chronic disease, including heart disease, noted that a communitybased health promotion intervention program led to improved health behavior, greater self-efficacy, and lower emergency room use (Lorig et al., 2003). Some ethnic minority patients have been reported to have lower confidence in their ability to self-manage CHD, especially those who had lower income levels and who were non-English-speaking (Blustein et al., 2008). Nonetheless, support and encouragement for self-care in heart patients may increase patients' confidence in their abilities to make lifestyle changes (Schnell-Hoehn et al., 2009). Understanding cultural beliefs and barriers of Mexican-American women with CHD that facilitate or hinder self-care may have far-reaching implications for CHD prevention, health outcomes, and treatment; yet few such studies have been performed.

#### **IDENTIFICATION OF GAPS AND RATIONALE FOR THE STUDY**

CHD is the most significant cause of death in Hispanic women. Mexican-American women are at risk for heart disease due to lack of knowledge (Christian et al, 2007; Lefler et al., 2013), health care access barriers (Askim-Lovseth & Aldana, 2010; DuBard & Gizlice, 2008), and cultural influences (Ai et al., 2012; Askim-Lovseth & Aldana, 2010; DuBard & Gizlice, 2008). Previous research about Mexican-American women has examined CHD prevention and disease symptoms, warning symptoms, lifestyle, and behavioral changes after acute myocardial infarction (Cooper-Dehoff et al., 2007; McSweeney & Coon, 2004; McSweeney et al., 2003, 2010). Moreover, researchers have suggested that Mexican-American women should be encouraged to improve their heart health (Riegel et al., 2006; Sherrod, 2011). However, few studies have examined cultural effects on health and health behaviors of Mexican-American women with CHD. Identifying the cultural beliefs of Mexican-American women with CHD may aid in the development of more culturally appropriate prevention intervention. The current study explored cultural beliefs, interpretations, and self-care practices in Mexican-American women with CHD. Findings may provide information needed for culturally-sensitive healthcare and for development of culturally-sensitive interventions to reduce CHD morbidity and mortality.

# SUMMARY

This chapter presented a literature review relevant to the ethnographic study of cultural beliefs, illness interpretation, explanatory models, and self-care practices of Mexican-American women with coronary heart disease (CHD). Kleinman's (1980) Cultural Healthcare Systems model and the construct of EMs were presented as the sensitizing framework. Chapter Two summarized relevant extant literature related to: 1) Heart disease in women and Hispanics; 2) Health disparities and access to care; 3) CVD risks in women and Mexican-American women; 4) Culture and Mexican-American women; and 5) Self-care and heart disease. Chapter Two described knowledge gaps, study justification, and a plan for the remaining chapters. Chapter Three presents the research design and methodology. Chapter Four presents the demographic description of the sample and findings of this study. Chapter Five summarizes conclusions and recommendations.

# **CHAPTER THREE: METHODS**

#### INTRODUCTION

Chapter Three describes the design and methodology used in the ethnographic study of cultural beliefs, illness interpretation, explanatory models, and self-care practices of Mexican-American women with coronary heart disease (CHD). The chapter presents Fetterman's (2010) ethnographic approach. The chapter briefly explains Kleinman's (1980) Cultural Healthcare Systems model and the construct of lay explanatory models (EMs), which served as the sensitizing framework for this study. The chapter also describes study methods and procedures, which include informed consent, data collection and management, data analysis, criteria and techniques for ensuring study rigor, and human subject protection.

Fetterman's (2010) ethnographic approach guided the study design. Fetterman's approach requires identification and definition of the problem, selection of an appropriate framework or theory, determination of data collection process in the field, data analysis, and ethnographic narration. The application of Fetterman's approach to this study is described in detail below.

# PURPOSE AND RESEARCH QUESTIONS

The purpose of this ethnographic study was to elicit the cultural beliefs, illness interpretations, explanatory models, and self-care practices of Mexican-American women with CHD using Kleinman's (1980) framework as a guide and Fetterman's (2010) methods as the approach. The study answered the following research questions: <u>Research question (RQ) 1.1</u>: How do Mexican-American women with CHD describe and explain their experiences with CHD?

<u>RQ 2.1</u>: What are the self-care practices of Mexican-American women with CHD? <u>RQ 2.2</u>: How do Mexican-American women with CHD describe their self-care practices related to CHD?

#### SENSITIZING FRAMEWORK

Kleinman's (1980) Cultural Healthcare Systems model and the construct of lay explanatory models (EMs) guided this study. Kleinman (1980) described three overlapping and interconnected sectors of health care: the popular (lay or non-professional), the folk (non-professional), and the professional (recognized health professionals). The explanatory models (EMs) concept was developed by Kleinman to explain individuals' beliefs about the causes, course, and treatment of illness. EMs describe individuals' explanations for illness based on learned or shared cultural knowledge and beliefs (Drew, 2008; Helman, 2000).

#### **DESIGN AND METHODOLOGY**

The researcher used an ethnographic design to answer the research questions. Ethnography is a method of studying and learning about persons or groups of people commonly linked by knowledge, belief systems, perceptions, meanings, practices, and heritage (Fetterman, 2010; Sandelowski, 2000; Spradley, 1980) and also refers to the final written report of the study (Agar, 1986; Creswell, 2007). Sociologists, humanists, nurses, and other healthcare researchers have used an ethnographic approach to answer cultural and behavioral questions (Atkinson & Hammersley, 2007; Bogdan & Biklen, 1998).

According to Fetterman (2010), ethnographers adopt a "cultural lens" (p.1) to interpret observed behaviors, and gather data from an *emic* (insider's) perspective and interpret those data from an *etic* (outside social scientist's) perspective. This process ensures that explanations of observations appear valid to participants, as well as others outside the culture (Fetterman, 2010).

Ethnography was the appropriate design for this study because the research questions aimed to explore values, beliefs, behaviors, understandings, and self-care practices of members of a specific cultural group—adult Mexican-American women with CHD. Moreover, the ethnographic approach is consistent with the investigator's philosophic worldview. The ethnographic approach gave the Mexican-American women

who participated in this study the opportunity to voice their experiences using their own words (Fetterman, 2010).

## Setting

The study took place in a rural community in the southwestern U.S. The population of the area is 37 percent Hispanic, of whom 34 percent are of Mexican descent (U.S. Census Bureau, 2010). The setting included participants' homes and community locations.

The researcher has been a long-term resident of the small community in Southwest Texas where the study took place. The researcher also has significant professional and personal long-term familiarity with Mexican-American culture. The researcher's nursing expertise in cardiovascular nursing and clinical practice have given her considerable experience in the healthcare needs of Mexican-American women with heart disease. These experiences underpinned the researcher's interest in the study and contributed to the researcher's current understanding of her population of interest.

#### **Sampling Strategy and Sample**

A non-random sample of women who met study criteria was readily available (Polit & Beck, 2010) and willing to participate. As the study progressed, snowball sampling was employed when a study participant wished to recommend other participants for the study (Polit & Beck, 2010). The researcher used sampling methods that maximized variability in selected participant characteristics, such as age, marital status, place of birth, years living in U.S., education levels attained, employment status, type of work, estimated annual income, number of persons living at home, health insurance coverage, location of healthcare providers, and health self-assessment.

Two principles guided sampling in this study. First, qualitative researchers often use data saturation as an indicator of sample adequacy. Data saturation is achieved when interviews cease to provide new information or themes (Lincoln & Guba, 1985; Roper & Shapira, 2000). Second, the number of informants required for an ethnographic research study is dependent on the quality of the information provided to the researcher; Spradley

(1979) noted that ethnographies may use as few as one participant. Thus, data quality determines sample size in ethnographic research.

The researcher anticipated that up to 15 Mexican-American participants would be enrolled in the study, with the caveat that the actual number of women to be interviewed would be determined as the study moved forward. Data saturation was recognized after nine participants had been enrolled, and two additional women were interviewed to confirm that data saturation had been achieved.

## **Inclusion and Exclusion Criteria**

Study inclusion criteria included persons who 1) were female, 2) were of Mexican-American descent (self-identified), 3) were 21 years of age or older, 4) had a minimum one year self-reported diagnosis of CHD, 5) were able to speak, read, and write English, 6) were willing to share experiences in face-to-face interviews, 7) were willing to have interviews tape recorded, and 8) were community-dwelling at the time of interview. The study exclusion criteria included Mexican-American women who 1) did not self-report CHD, 2) were younger than 21 years of age, 3) were unable to speak, read, and write in English, 4) were unwilling to be interviewed face-to-face, 5) were pregnant, and 6) were not community-dwelling at the time of interview. The time criterion was selected because health paradigms, illness realities, and EMs are best explained by those informants who have lived the experience of illness (Blumhagen, 1982; Eisenberg, 1980; Kleinman, 1980). Additionally, there was a need to study women's cardiac experiences over time after their diagnosis (O'Keefe-McCarthy, 2008).

Only Mexican-American women who self-reported having CHD were selected for study participation. Adult women were targeted because of their possible familial responsibilities for their own children or for other family members. Because the ethnographer was the instrument used to collect and interpret data, it was essential for the researcher to be familiar with informants' language and cultural meanings of informants' words (Spradley, 1979). Thus, the study was limited to English-speaking participants because the researcher did not speak Spanish.

## Recruitment

Participants were recruited using Institutional Review Board (IRB) approved flyers (Appendix A) posted in private family practices, cardiology clinic waiting areas, and community locations (e.g., churches, community centers). The recruitment flyer and announcement summarized the study purpose and provided the researcher's contact information to initiate participation in the study.

#### Instruments

The study used two instruments to collect interview data. The first was a researcher-developed pen and paper demographic form (Appendix B), which was completed by the researcher at the time of the interview. The second was a researcher-developed semi-structured interview guide (Appendix C).

The researcher-developed demographic information instrument (Appendix B) had 13 items that were designed to collect relevant socio-demographic and health data, such as participant age, marital status (married, divorced, or single), country of birth, years living in the U.S., years of education completed (less than high school, high school or GED, some college, or college graduate), employment status (yes or no; if yes, full-time or part-time), type of work, estimated annual income (\$10,000-\$20,000, \$20,001-\$30,000, \$30,001-\$40,000, \$40,001-\$60,000, or more than \$60,000), number of persons living in the home (children under 21 years in the home or persons other than spouse or children in the home), health insurance status (yes or no), healthcare provider location (clinic, doctor's office, or other), and a 1-item self-rating of health (poor, fair, good, or excellent). Data were used to describe study participant diversity and to guide sampling.

The semi-structured interview (Appendix C) was developed by the researcher based on the literature review, Kleinman's sensitizing framework, self-reflection, and comments from dissertation committee members. In addition, words and phrasing for the interview guide were modified using suggestions gathered in informal conversations with Mexican-American women who lived in the study site community and possessed similar socio-demographic characteristics as anticipated study participants. The interview guide used a survey or "grand tour" question designed to elicit comprehensive representation of

participants' experiences and perceptions without imposing the researcher's viewpoint (Fetterman, 2010; Spradley & McCurdy, 1989). The grand tour question was, "Tell me in your own words about any problems you have with your heart." Subsequent questions were guided by participants' responses to the grand tour question (Spradley, 1979). For example, to clarify or augment responses, the researcher could have asked, "Tell me what your heart problem does to your body," or "What do you call your heart problem?" Examples of other possible probes are provided in Appendix C.

The researcher also maintained field notes (Fetterman, 2010) to record descriptions of observations. Field notes augmented interview transcriptions, documented the methodological process, and reflected the researcher's thoughts and perceptions as the research progressed.

# **DATA COLLECTION**

Important characteristics of ethnography include cultural immersion, prolonged engagement, and participant observation (Fetterman, 2010). A key component of ethnographic fieldwork is the researcher's presence, which enables the researcher to observe, ask discerning questions, and note observations (Fetterman, 2010). Participant observation requires the researcher to take part in the community while maintaining professional objectivity (Fetterman, 2010).

The researcher lived, worked, and practiced professionally in the community in which the Mexican-American women study participants resided. Indeed, living in the community provided a great deal of insider knowledge, which served as a foundation for the ethnographic study (Fetterman, 2010). The researcher collected ethnographic data through use of in-depth interviews with participants in their homes and other settings, accompaniment of several participants to doctors' appointments or other community activities, and observation of community members in public settings and community events. The researcher documented community observations in her field notes.

The researcher confirmed study eligibility, explained the study purpose and aims, answered questions, and assured potential participants that every effort would be made to protect their privacy and confidentiality before conducting interviews with interested participants. The researcher obtained signed informed consent (Appendix D) during the

first face-to-face meeting. Once the consent form was signed, the researcher collected bio-demographic data and interview data.

Interviews were conducted in quiet, comfortable areas that provided privacy and freedom from interruption and were acceptable to both participant and researcher. Interviews were audio recorded through use of a primary and back-up recording device. Initial interviews ranged from 60 to more than 120 minutes, with an average of about 90 minutes. Although the researcher had anticipated shorter interviews to avoid fatigue, participants were eager to tell their stories and often prolonged the interviews. Each participant was interviewed one to three times. Eleven women were interviewed once, three women were interviewed twice, and three women were interviewed three times. Each participant was offered a \$20 Wal-Mart gift card as a token of appreciation following completion of each interview.

The second and third interviews served as opportunities to seek clarification or additional data, to verify data with informants, and for member checking (Lincoln & Guba, 1985). Member checks helped to establish credibility of the findings (Lincoln & Guba) and involved debriefings and discussion of preliminary findings of de-identified (no names or other identifying) data with participants (Polit & Beck, 2010). The debriefings allowed for verification of findings, confirmation of congruency with participants' perceptions, and discussion of emergent themes. One participant died so was unavailable for a follow-up interview. (Another participant has since died, but was able to complete follow-up interviews.)

After each interview the researcher listened to the audio recording and made notations in field notes. A professional transcriptionist, fluent in both English and Spanish, transcribed the interviews. Because English-speaking participants occasionally used Spanish words or phrases, the bilingual transcriptionist was very valuable. Every line of each page of each transcript was sequentially numbered, and wide margins were used to permit researcher notations post-transcription. The researcher checked the transcribed documents against audio-recorded interviews and hand-written notes to ensure accuracy, and subsequently corrected any transcription errors where indicated.

## DATA MANAGEMENT

Qualitative interview techniques often produce large amounts of narrative data, and storage and retrieval of data require careful management. The researcher used a password-protected personal computer and Microsoft Word software application to record and manage the storage and allow retrieval of all participant data. Additional methods used to maintain participant privacy included coded materials, de-identification of interviews and study instruments, storage of study materials in a locked drawer in the researcher's office, and aggregated data reports only. Each participant was assigned a code that could not be linked to the informant. Interview transcripts were stored on a password-protected hard drive and back-up USB drive. All study materials were labeled via alphanumeric code to ensure confidentiality; no names or other identifying data were used. Data access was limited to the researcher and her supervising professor. Only deidentified data was shared with others. All study materials with raw data will be destroyed upon study completion.

#### **DATA ANALYSIS**

Ethnographic data analysis is a progressive, iterative process that begins with problem formulation and concludes with completion of the ethnographic report (Fetterman, 2010). The ethnographic process facilitates a researcher's ability to organize the data and comprehend that which was learned through taped interviews, observations, and field notes (Roper & Shapira, 2000). Ethnographers construct a conceptual framework depicting study participants (Fetterman, 2010). Ethnographers use various techniques to interpret data, including triangulation, synthesis, evaluation, and "a large dose of common sense" (Fetterman, 2010, p. 94). Triangulation includes comparison of collected data using various methods and from differing perspectives to test data quality, enhance one's understanding of cultural group members, and develop a broader outlook. Ethnographers compare, contrast, and sort large quantities of data into usable categories and patterns (Fetterman, 2010).

The researcher used two data analysis approaches in this study: 1) descriptive statistical methods (e.g., frequencies, percentages, means) were used to characterize the

participants, and 2) the constant comparative method (CCM) was used to analyze the narrative data, which organized and integrated the data into emerging themes and concepts (Glaser & Strauss, 1967). The CCM has been used in ethnography to analyze narrative data (Atkinson & Hammersley, 2007; Goetz & LeCompte, 1981; LeCompte & Schensul, 1999a, 1999b) and is commonly used in grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Initially, the researcher analyzed audio recordings of the interviews while simultaneously reading transcripts line-by-line (Strauss & Corbin, 1990) to ensure transcript accuracy and notate non-verbal intonations and pauses. Frequent and repeated line-by-line reading of transcripts and journal entries assisted in identification of significant words or phrases and developed an overarching impression of the content (Fetterman, 2010).

The researcher identified incidents that included important words or phrases (Glaser & Strauss, 1967). Each incident was excerpted using a method that indicated the data source by enclosing within parentheses a capital letter "P," followed by a number to indicate the participant, a capital letter "L," followed by the number of the line or lines where the excerpt could be found in the transcript. In the excerpt below, for example, "P2 L48-L61" indicates the quote comes from the second participant's interview and lines 48-61 of that interview transcript. An example of significant excerpts or phrases from an interview with a participant is below:

That's one thing that I don't want anybody to have it, because you could feel something real funny. Like a numbness and tingling. Like a numbness and tingling in all my body. And then, when I had the heart attack. I had two. The big nes, and it start in my right, from my right side. From my leg first, then it came all up here to my arm . . . over the jaw (P2 L48-L61).

Through intensive ongoing reflection, the researcher developed a comprehensive description of significant incidents and organized those events into as many categories as possible (Glaser & Strauss, 1967). Categories were developed by grouping significant incidents into higher-level concepts, and working definitions were developed for each category (Strauss & Corbin, 1990). Next, the researcher searched for other examples of this category in the data and compared them with other incidents in the category or other categories (Glaser & Strauss, 1967). Table 3.1 (p. 34) provides an illustration of how

excerpts from several participants' transcripts were first organized as the categories *Symptoms, Effects, Family History*, and *Diagnosis*. Significant or recurrent words are underlined.

The researcher initially analyzed and coded phrases and statements from the first three participants. Once preliminary coding had been completed for them, the researcher analyzed and coded the remainder of transcripts in sets of two or three, until the preliminary coding was completed for all participants. After each set of data was coded, the categories were reviewed and modified and other categories were added as indicated. Additionally, the researcher began to differentiate sub-categories within the preliminary categories. The process also included developing sub-category definitions for ease in sorting and searching for examples in transcripts. At each step, the researcher validated the coding with her supervising professor.

Table 3.2 (p. 35) provides examples of two sub-categories, *Physical* and *Emotional*, within the *Symptoms* category. Sub-category definitions are provided within parentheses. Exemplars of transcript excerpts are provided, and significant words or phrases are underlined.

As data analysis continued, the researcher refined preliminary category and subcategory codes into higher-level codes. Using the constant comparison method, category labels were clustered, collapsed, and grouped into higher order themes and sub-themes, which were validated by referring to transcripts and comparisons within and across categories (Glaser & Strauss, 1967). Ultimately, three themes and accompanying subthemes were identified. Table 3.3 (p. 36) provides an example of the theme *Knowing about heart disease* with its three sub-themes. Definitions of terms are provided within parentheses. Examples of supporting incidents are also provided.

Participants in this study described how they understood heart disease and its causes (*Knowing about heart disease*), the effects of heart disease on their lives (*It changes your whole life*), and how they have adapted to their heart disease (*Living with heart disease*) (Table 3.4, p. 37). The final themes and sub-themes are presented and described in Chapter Four.

 Table 3.1 Examples of Early Coding Categories

Categories	Excerpts from Transcripts
Symptoms	<ul> <li>That's one thing that I don't want anybody to have it because you <u>could</u> feel something real funny. Like a <u>numbness and tingling</u>. Like a <u>numbness and tingling in all my</u> body. And then when I had the heart attack. I had two. The big ones and <u>it start in my right, from my right</u> side. From my leg first then it came all up here to my arm over the jaw (P2 L48-L61).</li> <li>I was working and I would get tired cause when I would put the clothes is the matrix of the matrix.</li> </ul>
	in the machine, I <u>would get tired and then suddenly I just was very tired</u> (P7 L8-L10) was <u>getting weaker and weaker</u> (P7 L14) So the doctor said I need an open heart surgery, that it was that bad (P7 L14- L16).
Effects	<u>I have learned that you have to take care of yourself</u> . More than you used to. And, there are a lot of things you cannot do. Like picking up heavy things. You know, like me I was used to pick up the baskets full of clothes. <u>I cannot do it anymore</u> . And, a lot of things. <u>I cannot work outside</u> you know, clean the yard, or all that (P2 L187-L192).
	<ul> <li>Right now because of the little pains that I feel or the fear that I have.</li> <li><u>it's, it's limiting still the things that I want to do (P8 L891-L893)</u>.</li> <li>Well sometimes <u>I get tired</u>, you know. I mean, I don't, I can't do things that I used to do before (P7 L209-L210).</li> </ul>
Family History	My <u>father had it</u> . He <u>died of a heart attack</u> . And I had <u>another brother that also died of a heart attack</u> . He was about 30-something years old and he died (P9 L60-L62). I don't know. I don't know. See, because I think some, some, <u>some</u>
	<ul> <li>people would tell me that I'd inherited it because my dad had open heart surgery. My mom died of a stroke (P7 L149-L151).</li> <li>I know one of my brothers He had like a heart attack because he had high blood pressure too. It runs on my family it is inherited (P7 L173-L181).</li> </ul>
Diagnosis	My heart problem is the aortic mechanical valve that I had and it came about because of my dental work that was done was not done properly in Mexico and so it went into my bloodstream and it caused my aortic valv to disintegrate and so I had to have the mechanical valve replaced (P3 L6-L11).

Category	Sub-Category	Excerpts from Transcript
Symptoms	Physical (symptoms related to the body)	But all this time it was <u>pain</u> . I can't explain; it was like <u>pain from below my wais</u> t (P5 L27 L28) two weeks before that, I started having <u>pain and tightness in</u> <u>my chest</u> . The tightness was very not strong but there was tightness and I would get <u>so fatigued</u> just totally <u>energy sapped</u> . I couldn't, you know, I had to <u>really walk very slowly</u> or <u>sit real quietly</u> until it went away (P5 L32 L35).
	Emotional (symptom related to emotions or psychological feelings)	[When she begins to feel pain] <u>I get scared. I get very</u> scared (P2 L8-L10).

Table 3.2 Examples of Sub-Categories within Category, Symptom

Theme: Knowing about heart a	lisease (What women believe caused their heart illness)
Sub-theme	Examples of Supporting Data from Transcripts
1. "It runs in my family"	My daddy was I think he was a little older than me, I
(how women describe their	think he was 51 or 52 when he had his first heart attack,
perceptions of familial or	and then he had a stroke. And then, well he had a
genetic etiological causes of	part of his body was paralyzed. And he lasted I mean
their heart disease)	with the last heart attack, he lasted 5 years more, which
	last year he passed away (P6 L60- L65) 'Cause my
	grandmother, my dad's mom, had it, then my dad, then
	me, and then one of my brothers. Well, two, it's me and
	my brother that has this disease, but mine is worse (P6
	L195 L197).
	I was born with it; it is connected with my father's heart
	problem. There's a disease on my father's side and
	it's a bad one because two of my brothers had died (P1
	L38-L41).
2. "It was my lifestyle" (how	I really think it was my bad lifestyle that I had. Not what
women describe their habits	I did, but how I ate, and not exercising, you know, and
or behaviors as the etiological	maybe stress, you know (P8 L879-L881).
causes of their heart disease)	
	Working very hard and not taking care of myself. Stress
	with the family, you know. Stress most of the time, I
	think it is (P10 L138-L140).
3. "It's my bad heart" (how	I'm sick from my heart (P7 L348).
women describe the	And they did the stress test and they found that I needed
physiological causes of their	to have a valve stent put in there 'cause of my arteries
heart disease)	. He put, had a valve stent put in there Two of them

 Table 3.3 Example of Theme "Knowing about heart disease" with Three Sub-themes

Theme	Sub-Theme
	1. "It runs in my family"
Knowing about heart disease	2. "It was my lifestyle"
	3. "It's my bad heart"
	1. Bodily changes
	a. Symptoms
	i. Past
	ii. Current
It changes your whole life	b. Functional change
	2. Emotional changes
	a. Depression
	b. Fear
	c. Denial
	d. Self-blame
	3. Financial changes
	4. Role change
	1. Listening to my body
Living with heart disease	2. Listening to my doctor
Living with heart disease	3. Relying on my faith

## Table 3.4 Overview of Study Themes and Sub-themes

# Scientific Rigor or Trustworthiness

Quantitative researchers utilize methods to ensure reliability and validity of the study (Burns & Grove, 2005). Similarly, qualitative researchers, with the same intent but through the use of different methods, test for trustworthiness or trust value in a study to ensure scientific rigor (Lincoln & Guba, 1985). This study used three criteria to assure the rigor of the study identified by Lincoln and Guba (1985) and modified by Beck (1993). These criteria include *credibility*, *fittingness*, and *auditability*.

Credibility is a term that relates to "how vivid and faithful the description of the phenomenon is" (Beck, 1993, p. 264; Polit & Beck, 2010). Credibility is demonstrated

when participants and others who have experienced the phenomenon accept the description as authentic (Beck, 1993; Polit & Beck, 2010). Credibility is an indicator of the reliability of the study findings (Lincoln & Guba, 1985; Polit & Beck, 2010). The researcher ensured credibility through in-depth and accurate description of the phenomena, using participant narratives and researcher observations. The researcher ensured credibility through member checks (Lincoln & Guba, 1985; Polit & Beck, 2010), verifying findings and interpretations of data with the participants. The researcher validated the final thematic analysis with three participants, who confirmed its validity.

Triangulation also was used to achieve credibility. Triangulation includes comparison of data collected using various methods and differing perceptions to check data quality, to achieve better understanding of the members of the cultural group, and to develop a broader perspective (Fetterman, 2010). In this study, triangulation was achieved through the use of interviews and observations.

Fittingness is similar to the quantitative term, external validity, which indicates the degree to which study findings can be generalized or transferred to other groups (Lincoln & Guba, 1985; Polit & Beck, 2010). Fittingness is similar to transferability (Lincoln & Guba, 1985) and generalizability (Polit & Beck, 2010). The researcher provided ample descriptions of the sample and the data for other researchers to determine whether data were applicable to others populations (Beck, 1993; Polit & Beck, 2010).

Auditability is defined as "when another researcher can clearly follow the 'decision trail' used by the investigator in the study" (Beck, 1993, p. 264). Auditability is synonymous with dependability (Lincoln & Guba, 1985) and indicates consistency of the research study over time and various conditions (Beck, 1993; Lincoln & Guba, 1985). The researcher provided a systematic audit trail of methods for participant recruitment, data collection, and data analysis. Moreover, detailed field notes and transcripts of audiorecorded interviews were maintained.

#### **Human Subject Protection**

Prior to beginning the study, it was approved by the Institutional Review Board of The University of Texas Medical Branch. The study posed minimal risk of fatigue or loss of confidentiality. No participant appeared affected by study participation or withdrew.

Multiple efforts ensured confidentiality, including conduct of interviews in private locations acceptable to participants and the researcher, use of alpha-numeric coding for all study materials, and storage of consent forms and codebooks with names and numbers of study participants in a locked file cabinet drawer inside the investigator's home office.

Men and children were not included because the study focused on the perceptions of adult women 21 years of age or older. Only Mexican-American women who met study criteria were included because the study elicited and explored the beliefs, interpretations, EMs, and self-care practices of Mexican-American women with coronary heart disease. The participants were limited to English speaking because the researcher speaks primarily English, and Spradley (1979) recommended that the ethnographic researcher be familiar with the participants' language and the cultural inferences of the words they use.

Chapter Three described the ethnographic design and methodology. Fetterman's (2010) ethnographic approach and use in the study were delineated. Kleinman's (1980) Cultural Healthcare Systems model and the lay explanatory models (EMs) construct used as the sensitizing framework were explained. Study methods and procedures were also described, including informed consent; data collection, management, and analysis; trustworthiness criteria; and strategies and human subject protection.

# PLAN OF REMAINING CHAPTERS

Chapter Four will present the demographic description of the sample and findings of this study. Chapter Five will provide a summary of the study, discussion of the findings and implications, recommendations for future research, and conclusions.

# **CHAPTER FOUR: RESULTS**

#### **INTRODUCTION**

Chapter Four presents the findings of this ethnographic study of the cultural beliefs, illness interpretation, explanatory models, and self-care practices of Mexican-American women with CHD. Demographic characteristics of participants are presented, and study findings are categorized as themes and sub-themes, accompanied by supporting data, and organized by the Research Questions (RQs):

<u>RQ 1.1</u>: How do Mexican-American women with CHD describe and explain their experiences with CHD?

<u>RQ 2.1</u>: What are the self-care practices of Mexican-American women with CHD? <u>RQ 2.2</u>: How do Mexican-American women with CHD describe influences on their selfcare practices related to CHD?

## **DESCRIPTION OF PARTICIPANTS**

Eleven Mexican-American women met eligibility criteria and provided written informed consent to participate in the study. Five participants were recruited from doctors' offices, two participants were recruited through flyers posted in community centers, two participants were recruited through flyers placed at local churches, and two participants were referred by other study subjects. A description of participants' demographics is provided in Table 4.1.

Variable	n	%
Education		
Less than High School	4	36.4
High School Diploma	2	18.2
Some college	2	18.2
College Degree	3	27.3
Marital Status		
Single	1	9.1
Married	7	63.6
Divorced	2	18.2
Widowed	1	9.1
Estimated Household Income		
\$0-\$20,000	9	81.8
\$40,001-\$60,000	1	9.1
>\$60,000	1	9.1
Employment		
Full-time	3	27.3
Part-time	4	36.4
Not employed	4	36.4
Health Insurance		
Yes	10	90.9
No	1	9.1
Self-reported health		
Good	4	36.4
Fair	7	63.6
Age		
Range / Mean	48-77	63
Years in U.S.		
Range / Mean	43-76	61

 Table 4.1 Demographics of the Study Participants

All of the women who participated in the study were middle-aged or older, ranging from 48 to 77 years (mean = 63). Seven participants (63.6%) were married, and four (27.3%) were single, widowed, or divorced. Older women (defined as older than the mean age) were more likely to be married than younger women. The majority of participants were low-income, with nine women (81.8%) reporting an annual household income of less than \$20,000. Only one participant (9.1%) reported an annual income greater than \$60,000. The women had lived in the U.S. for several decades, ranging from 43-76 years (mean = 61).

Participants' education levels ranged from less than high school to a master's degree. Four participants (36.4%) had less than a high school degree, two (18.2%) had graduated from high school, two (18.2%) had some college, and three (27.3%) had an associate degree or higher.

Seven participants (63.6%) were employed; of these, three (27.3%) worked fulltime and four (36.4%) worked part-time. One woman was employed in business, two individuals were in education, three individuals were employed in health care, and two individuals were employed as service workers. Four participants (36.4%) were not employed. Older women were less likely to be employed, although two of the older women were still working full-time or part-time.

Most participants reported feeling at least moderately healthy: seven participants (63.6%) reported their health as fair and four participants (36.4%) reported their health as good; no participants described their health as excellent or poor. The majority of participants (90.1%) had some type of health insurance. All participants reported receiving care at a clinic or doctor's office, regardless of health insurance status. No participants reported receiving health care from an indigenous healer.

None of the participants lived alone. Four participants (36.4%) reported 1-3 children younger than 21 years of age living in their home. Four participants (36.4%) reported someone other than their spouse or children under 21 years of age living in their home. Participants with children living in their homes tended to be somewhat younger than those without children living at home.

## **INTERPRETATION OF STUDY DATA**

The researcher utilized the constant comparative method to organize and integrate the study data into emerging themes and concepts (Glaser & Strauss, 1967). Three themes were identified: 1) *Knowing about heart disease*, 2) *It changes your whole life*, and 3) *Living with heart disease*. All three themes addressed the first research question. The theme, *Living with heart disease*, specifically addressed the two-part second research question. Table 4.2 presents the three themes and their sub-themes, and is organized by research question addressed.

Each theme and sub-theme is described and discussed below. Narrative excerpts are provided to illustrate themes and sub-themes. The source of each excerpt appears in parentheses: the capital letter, "P," is followed by a number indicating the participant, and the capital letter, "L," is followed by a number indicating the line or lines of the excerpt in the transcript. For example, the notation "(P9 L60-L62)" indicates the ninth participant's interview and lines 60-62 of that interview transcript.

## KNOWING ABOUT HEART DISEASE

The first theme, *Knowing about heart disease*, described phenomena the participants believed to be causes of their heart illnesses. This theme had three sub-themes: It runs in my family, It was my lifestyle, and It's my bad heart.

#### **It Runs in My Family**

The first sub-theme, It runs in my family, indicated the way in which women described their perceptions of familial or genetic causes of their heart disease. Six participants believed heart disease ran in their families. One participant said, "My father had it. He died of a heart attack. And I had another brother that also died of heart attack" (P9 L60-L62). Another individual said, "Some people would tell me that I'd inherited it because my dad had open heart surgery. My mom died of a stroke. . . . [One brother] had like a heart attack because he had high blood pressure" (P7 L149-L181). Another subject commented:

Research question	Theme	Sub-theme
	Knowing about heart disease	<ol> <li>It runs in my family</li> <li>It was my lifestyle</li> <li>It's my bad heart</li> </ol>
1.1: How do Mexican- American women with CHD describe and explain their experiences with CHD?	It changes your whole life	<ol> <li>Bodily changes         <ol> <li>Symptoms</li> <li>Past</li> <li>Current</li> <li>Functional change</li> </ol> </li> <li>Emotional changes         <ol> <li>Depression</li> <li>Fear</li> <li>Denial</li> <li>Self-blame</li> </ol> </li> <li>Financial changes</li> <li>Role change</li> </ol>
	Living with heart disease	<ol> <li>Listening to my body</li> <li>Listening to my doctor</li> <li>Relying on my faith</li> </ol>
<ul> <li>2.1: What are the self-care practices of Mexican-American women with CHD?</li> <li>2.2: How do Mexican-American women with CHD describe their self-care practices for CHD?</li> </ul>	Living with heart disease	<ol> <li>Listening to my body</li> <li>Listening to my doctor</li> <li>Relying on my faith</li> </ol>

	Table 4.2 Overview of Study	Themes and Sub-themes	s Organized by Research Que	stion
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I have a brother that has an open heart surgery when he was about 31-32 years old . . . . Then I have another brother, ah, he have an open heart surgery . . . Ah, and then I have another brother here . . . and he had open heart surgery just recently. . . . My dad died from a heart attack. So I guess it's all in the family (P10 L40-L60).

Several women believed their illnesses were family-related due to prior conversations with their doctors. One woman said, "So, he [the doctor] explained to me everything. He said, 'You're very young . . . . it runs in the history in your family" (P6 L158-L160). Another participant commented that her doctors have said they "don't want to take any chances, knowing my family history of heart problems" (P10 L40-L41).

Many of the participants were at risk for heart disease, in part due to their own family histories. These individuals had family members with heart disease and had experienced loss of family members due to heart disease. Participants were aware of links between family history and their own potential for heart disease because of experiences with family members and interactions with their physicians.

#### It Was My Lifestyle

The second sub-theme, It was my lifestyle, reflected participants' beliefs that their behaviors and stressors were causes of their heart disease. One participant said, "I really think [it] was my bad lifestyle that I had. Not what I did, but how I ate, and not exercising, you know, and maybe stress, you know" (P8 L879-L881).

Eight participants commented that their behavior had contributed to their development of CHD. Some individuals blamed overeating and dietary choices. One person said, "I think our culture and the way we ate and the way we comforted ourselves, continue with me. My degrees didn't cure that. I think our culture and the way we ate we comforted ourselves, continue with me" (P8 L688-L692). A second individual said, "I try to eat good but ah, I like sweets. Sweets are one of my things, you know" (P10 L71-L75). Another woman commented, "I mean, you're never on a diet" (P3 L6).

Another person posited that, "... how it came about is the overeating, the eating foods that you're not really supposed to eat.... Like all that greasy stuff that we eat that we're not supposed to eat" (P9 L38-144). This individual opined that her obesity and inactivity were the cause of her heart illness: "I think it was [being] overweight, and I

didn't do anything about it. I also didn't work or anything. All I did was just stay at home" (P9 L81-L84). She also blamed herself for not responding to indicators that she was at higher risk for CHD: "I have very, very high cholesterol, I think, and I didn't, back then, do anything" (P9 L127).

Another participant also blamed herself for ignoring problems that increased her risk for heart disease: "[I] never took care of [my] ...blood pressure. My cholesterol, which I never took pills, nothing" (P6 L161-L163). Yet another woman described disregarding her doctor's advice:

I'm going to tell you the truth, I didn't take care of myself real good, and the way I'm supposed to. Because, I mean, they [doctors] tell you how you can eat. How you don't eat too much salt. You don't eat this you don't eat that. You don't drink this, you don't drink that. And sometimes I did, you know, the opposite side (P11 L194-L199).

Six women attributed their illness to their difficult or stressful lives, with one person saying, "I think it was because I worked so much, from five o'clock in the morning when I get up until one or two o'clock in the morning" (P2 L25-L26). Another participant said, "I think that the pain that I was in, and trying to keep a smiley face, and work, and take care of everybody, I must have been in a lot of stress. I think the stress did it . . ." (P8 L881-L883). A third woman added, "I had a rough life . . . and I believe that has to do a lot" (P1 L60-L61). A fourth individual commented: "I go through a lot, you know, during my husband passing away. . . . I haven't been taking care of myself the way I'm supposed to" (P10 L63-L66). Another woman added:

At one time, you know it was bad, bad problem in the family, and then I had my heart, you know, and I went to the doctor and tell him that I feel my heart; it was real, real tired. . . . I said, "My heart is tired, doctor," and I start crying. And the doctor said, "Your heart is tired?" Then he checked and said, "Yes, your heart is real, real tired, you know, because of your problem, a lot of stress, you know" (P11 L63-L71).

The same person continued by saying, "I drink because, like I tell you, sometimes I feel, like, stressful, and it makes me relax. . . . You know, when I have a big problem, I start smoking. I know it's not right" (P11 L296-L307).

Participants described lifestyles that increased their risks for heart disease. Like many other Mexican-American women in the study community, the majority of the participants were overweight. Food was an important part of their social life and frequently offered to visitors. Many women commonly ate high-fat, high-calorie foods such as tortillas, *barbacoa* (typically, slow cooked barbecue of the head of cattle), *refritos* (mashed pinto beans typically cooked with lard), and *pan dulce* (Mexican pastries). Some women described a lack of knowledge about risk factors prior to their heart disease. Other individuals revealed knowledge of their risks for heart disease but admitted making few preventive behavioral changes to prior to their CHD diagnosis. Some women acknowledged feeling guilty about disregarding advice about their health. At times it appeared that subjects' stressful lives exacerbated their unhealthy behaviors.

## It's My Bad Heart

The third sub-theme, It's my bad heart, indicated the way in which participants described the physiological causes of their heart condition. One participant did not ascribe a physiological cause. Another individual simply said, "I'm sick in my heart" (P7 L348). Nine others were more specific about their heart disease. Four participants described blocked arteries. One person admitted:

So uh, that's when I found out that I had blocked arteries. . . . I didn't know that the problems that I have had while I was working were associated with that. And so, that's when I learned about my heart disease . . . and I've had it almost a year now, got treated, and had stent implants (P5 L9-L12).

A second one commented:

Three specialists talked to me 'cause they wanted to do another stent. But the one that I have is, uh, it's the main vein, my artery from the heart is the main one that is 100% blocked. And it's thinner than a hair, and they said that if they could . . . do another stent, that I wouldn't make it, 'cause I would die on the table (P6 L4-L16).

All women had self-reported having CHD. However, when asked to talk about their heart disease, four participants described problems with a heart valve. One woman remarked, I went to see my doctor again, and they tell me that I need a heart surgery. And they [doctor] said something about open my valve, my mitral valve, need to open a little bit . . . I have the other surgery because my valve was leaking (P11 L26-L30, L38-L41).

The third sub-theme, It's my bad heart, reflected most participants' understanding of the nature of their heart disease, regardless of age or education level. They recognized the severity of their heart diagnosis and the risks involved in the surgical procedures they had undergone. The self-identification of CHD did not preclude participants' indicating other heart conditions, which may suggest they might have more than one heart condition or that they lacked understanding of their CHD diagnosis.

The theme, *Knowing about heart disease*, revealed participants' understanding of the risks for heart disease due to family history, lifestyle, and physiological factors, frequently attributing their heart disease to all of these factors. Prior to CHD diagnosis, the participants had not practiced preventive behaviors, perhaps in part due to their emotionally or physically stressful lives. Diagnosis of their heart illness led to comprehension of the severity of their heart disease as well as the need for health behavior change.

#### **IT CHANGES YOUR WHOLE LIFE**

The second theme, *It changes your whole life*, described the women's perceptions of how CHD has affected their lives. This theme had four sub-themes: Bodily changes, Emotional changes, Financial changes, and Role changes.

## **Bodily Changes**

The sub-theme, Bodily changes, described how participants perceive the physical effects of their heart illness. This sub-theme had two parts: 1) symptoms, past or current, and 2) functional changes. Past symptoms were those evident prior to CHD diagnosis or heart surgery. Current symptoms were those that persisted after the diagnosis of heart disease or heart surgery. Functional changes indicated how women perceived alteration of their physical activity or ability due to CHD.

## **PAST SYMPTOMS**

Nine participants experienced heart-related symptoms prior to CHD diagnosis. The most commonly expressed symptoms were fatigue, numbness, and chest tightness or pain. One participant stated, "The most complaint, you know, that I say, is tiredness, you know. Very tired. I couldn't breathe, you know" (P11 L26-L27). Another woman said, "What it does to my body is, I get numb" (P2 L45). A third reported: "You feel nauseated or you feel stomach pain and tightness, tightness, like if somebody is squeezing, tightness, just tightness. No, it's not really pain. It's just tightness and weakness. It's just like completely no energy" (P5 L355-L358). Another participant described her symptoms as follows:

You get chest pains, shortness of breath. . . . It's just something that hits you that you don't know what it's coming from, until you realize that it's your heart. . . . Like the way that I felt that day when I had the heart attack, it was just sweating, and it was nausea that I was feeling, but when I feel that pressure in my chest that would run to my back, my arm would get numb, I couldn't feel my arms. . . . It feels, you know, it feels like something really heavy is in your chest that you can't breathe, because that heavy, heaviest thing that is on top of your chest (P6 L219-L228, L230-L233).

#### **CURRENT SYMPTOMS**

Seven participants reported they were currently experiencing symptoms related to their heart illness. The most common symptoms were fatigue and pain. One participant described her symptoms as: "I feel tired; it gets me tired" (P4 L117). Another person said:

Sometimes I feel like, I get like, very tired. Very, very tired and I really don't feel like doing anything. All I want is for everybody to leave me alone. And all I want to do sometimes is lay down and sleep 'cause I'm very, very tired (P9 L88-L91).

One participant expressed, "Now I feel the little pains that, if I had 'em before, I wasn't paying attention to them. But after my surgery, I'm very aware of them. You

know, constantly aware of it" (P8 L 1086-L1088). Another said, "It'll start hurting" (P2 L8).

Despite surgical interventions, the majority of the participants reported continued serious heart symptoms, notably fatigue and pain. Reporting continued symptoms may have been partly because individuals were more aware of their heart symptoms and what those symptoms could mean, such as an impending heart attack. Participants also may have been more attentive to bodily cues. Although the researcher did not observe serious symptoms, three participants reported mild shortness of breath or chest pain during participant observations; such indications did not alarm participants because they used a short rest to mitigate the physiological symptoms.

## **Functional Changes**

Seven participants reported alterations in their physical activity or ability, or functional changes, since their cardiac diagnosis. As one person verbalized:

There are a lot of things you cannot do. Like picking up heavy things. You know, like me, I was used to pick up the baskets full of clothes. I cannot do it anymore. And, a lot of things. I cannot work outside . . . you know, clean the yard, or all that (P2 L188-L192).

Another participant said:

I used to work many hours. I used to move a lot. . . . Now, I have to just slow down because, I mean, I do a lot of things. I want to rush, and it's just like, you have to just slow down because . . . . You just can't stress your heart, 'cause your heart is already damaged. . . . You can't work it as you used to (P6 L276-L283).

A third woman added:

I'm still so tied down. . . . I mean, I can't even put on my shoes by myself. You know, I can, if I just get all the instruments that I have to put 'em on. But, if I want to put on a support hose, I can't, you know, do that with my little things that I have (P8 L152, L222-L225).

Some women reported that symptoms had restricted their work and social life. One said, "I was working and active, and after my heart disease, I couldn't be that active. I wasn't that social" (P1 L65-L66). Another commented:

When I'm feeling like I'm wanting to go somewhere, I can't do it, or I can't climb things, I can't, you know, go to a lot of places, cause I know, I don't know if I'll be able to walk in there. How many stairs do they have (P8 L187 L191)?

All of the women reported open-heart surgical intervention, and all voluntarily showed their mid-sternal scars. The majority of the participants reported current activity restrictions related to their heart disease diagnosis. Most of the women felt limited in their ability to do things at home or at work and restricted in their sense of independence and social life. Observations supported that three or more women no longer drove themselves, instead relying on other family members to drive for them.

# **Emotional Changes**

The second sub-theme of the theme, *It changes your whole life*, was Emotional changes. This sub-theme described women's affective responses after the diagnosis of their heart illness. Nine women described emotional changes such as depression, fear, denial, and self-blame.

Seven participants described depression. One participant said, "You get depressed first, because you're not the same" (P6 L274). Another individual explained, "Sadness *tambien* [also]. I feel so sad, I don't know I just feel sad, like crying" (P11 L182-L189).

Six participants described being afraid, worried, or concerned. One participant said, "I get scared. I get very scared" (P2 L8-L10). Another woman commented, "But it's very scary . . . I mean, your heart is your heart. There's only one. You cannot live without it" (P5 L430-L431). A third person expressed the following sentiment:

So every little pain, I say, "Oh, my God." I'm afraid to go to sleep 'cause I have heart pain, and I say, "Oh, I don't want to die asleep. I want to die awake." But having to deal with that fear that I didn't have before, even though I probably was sicker then, I just didn't have that fear (P8 L163-L168).

Other participants feared the effect of their heart disease upon their families:

Sometimes I feel like, what it would be like if I didn't have this, and what is going to happen to me in the future if I don't take care of it? Because, if anything happened to me, there will be nobody there to take care of my mom. My main concern is my mom (P9 L151-L155).

One woman expressed disbelief or denial that she is ill: [Sometimes I think] that I don't have anything that's wrong with my heart. That's the way I feel. But, of course, that's just me. . . . I try to ignore what they [the doctors] tell me, because I feel that there is nothing wrong with me. Sometimes I think that they're just making it up (P9 L269-L271, L274-L276).

Two women blamed themselves for their heart disease. One said, "And I'm the only one to blame, I have no one to blame, it's myself" (P5 L431-L432). Another individual said, "I'm mad at myself, I'm eating the wrong things. Because this is affecting it [the heart]. Then it hits me that, 'All you did, is bad for this [heart], you know, this is the one that's gonna kill you'" (P8 L1125-L1130).

Life with heart disease had caused the women to suffer emotionally. Almost every woman cried when discussing her CHD. Participants felt uncertain about their own future and the future of their families, and longed to return to their lives prior to CHD diagnosis.

## **Financial changes**

The third sub-theme, Financial changes, described the way in which heart disease had affected women economically. Three women described financial hardships related to having heart disease, with one saying, "It changes your whole life, how you live. You don't have that much income. You don't have that insurance that you used to have . . . . I had no insurance so I was considered indigent" (P3 L68-L70, L115). The same woman also described how being an indigent single mother affected her healthcare:

The hardest thing for my heart problem, when I found out that I had it, was finances . . . not having insurance, having a [child] in school and being a single parent. . . . Going to the doctors when I can. If I don't have the money, then I don't (P3 L18-L21).

One participant had retired but had to go back to work because of the impact of heart disease on her financial status.

I have all these doctor bills. And I have to pay them, you know. When I work, and I [do] . . . almost every day, 'cause I can't say no. I mean, I'm retired. I get my pay, my . . . retirement check, but I still have so many bills to pay. . . . I think that [having bills to pay] adds to my stress level. And I have to work (P5 L558-L562, L568).

Another woman described having to find a less expensive health care provider even though she had private insurance: "They [clinic personnel] check my high blood pressure, they give me my meds. That's why I go to the clinic, because it's cheaper, you know? My medicines . . . are cheaper." (P7 L248 L250)

Few participants mentioned financial changes after the diagnosis of their heart disease. For some, heart disease meant moving from a higher socio-economic status class with private insurance to a lower income bracket with no private insurance or government-sponsored insurance—they could not maintain their customary lifestyles without working. Concerns about medical care, laboratory, and prescriptions costs affected other women's health care decisions. Most participants had reported annual incomes at or below the poverty level and had lived in modest, older homes for many years. Because of their low baseline income levels, the financial status of these women may not have changed dramatically in spite of increased medical expenses due to their heart disease. Alternatively, the participants may have felt uncomfortable discussing private financial concerns with the researcher.

## **Role Change**

The fourth sub-theme, Role change, conveyed the way in which heart disease affected participants' role identities. Six women in the study described role changes as a result of their heart disease diagnosis. Two participants had to relinquish their care-giver roles. One woman said, "I used to take care of everybody, you know. Now I can't do that" (P8 L227). Another said, "I was no longer a caregiver, and I felt helpless. I felt useless, like if I couldn't do nothing" (P3 L123). She added:

I took care of my father, I took care of my mother-in-law then, and my husband, my son, and other people. Whoever I could help, I used to help. You know. My aunt, I would go help her too. So that affected me, because I was the caregiver, and now I could not be the caregiver (P3 L99-L104, L107-L108).

Other women described their family beginning to take care of the participant. One said:

They're [family] after me every minute. To take care of myself, and do this, and don't do that. I said, "Okay." So they want me to stay in bed, and I said, "Uh uh, I'm not staying in bed." So they got mad at me (P2 L92-L94).

Another reported:

Yeah, my children keep telling me, "Mom, slow down. Remember you have stents, and I don't want to be in the hospital window watching you, that you having the stents put on again." Well, they're my children, they love me . . . . She [my daughter] keeps calling me, "Mom, what are you eating? I know you're eating something. Stop eating that. Or just, just have a bite, okay? You can eat it but have a bite (P10 L233-L240).

Losing the role of caregiver caused some participants to feel useless or helpless, introduced uncertainty about the future, and altered family relationships. Family members' roles changed due to participants' CHD, especially the role of daughters; although appreciative of their families' intentions, participants found adaptation to these changes to be difficult.

The theme, *It changes your whole life*, revealed serious and permanent changes to participants' lives resulting from CHD. Despite ongoing physical and emotional symptoms, participants self-assessed their health to be fair or good. For some participants, heart disease diminished their socio-economic status and affected their health care and employment decisions. The transition from caregiver to care recipient was described as being difficult. All participants reported that family members assisted in their home healthcare, shuttled them to doctor appointments, and loved them. Community observations confirmed that family members were concerned about and involved with participants.

#### LIVING WITH HEART DISEASE

The third theme, *Living with heart disease*, described the ways in which women adjusted to life with heart disease. The three sub-themes included Listening to my body, Listening to my doctor, and Relying on my faith.

# Listening to My Body

The first sub-theme, Listening to my body, included the ways in which women described their understanding of the need to care for their bodies due to CHD and actions taken to accomplish this care. They described the importance of the heart, lifestyle changes, and body cues that signaled the need to adjust their behavior.

Some women described the importance of the heart. One woman said, "Your heart is very, very special. A special little thing, a machine that you have, 'cause this heart runs all your body. Once this heart stops, everything is gone" (P6 L551-L555). A second commented, ". . . the heart is it. I mean, you don't get a second chance. . . . You know, this is serious" (P5 L425 L426). Another participant stated:

If you don't take care of that body, nobody is gonna take care of it. . . . It's just like a plant. If you don't water that plant... It dies. That's the way my heart [is], if you don't take care of your heart or whatever you're having in your body (P6 L485-L486, L489-L493).

Eight women described lifestyle behavior changes they had made to improve their heart health. Some described nutrition and exercise techniques they used to care for their hearts. One woman said, "It's taken me up to this, recently, [to understand that] . . . if I take care of myself, if I eat the right foods . . . that I'll be okay" (P5 L427-L429). Another person said, "You have to take care of . . . what you have inside of your body, 'cause we eat anything" (P6 L471). A third interviewee reported, "I also need to get my cholesterol down 'cause . . . that's an enemy for my heart right now" (P8 L895-L896). Another woman commented, "If you control your diet, and you walk and change the way you're living, I think, you know it will help a lot" (P10 L133-L135).

Some women believed that stress management was an additional method to care for their hearts. One person stated, "It's gonna be okay, if I live my life the way it is

supposed to be. Don't get so stressful, you know" (P11 L58-L61). Another commented, "You cope with them [problems] and be happy. Don't be afraid. That's what I do" (P10 L309).

Participants suggested that others should take better care of their hearts than they did. One woman said, "I tell sick women that we all need to make changes. . . . Make the changes that you have to do when you're young, because when you're old, like me, it's hard to change" (P5 L622-L628). A second advised her daughters: "Take care of themselves better than I did... In the way of eating, exercise, don't smoke, don't drink" (P10 L350-L354). A third woman advised, "Eat salads and take care of yourself, like I tell you . . . No drinking, no smoking, that I did, you know" (P11 L446-L450).

Another participant advised other women about how to cook for their families while maintaining their own healthy diets:

Well, if you cook for the Mexican-American families, you have tortillas, you have beans, you have cholesterol foods. But that's if you're cooking for them, you're going to end up eating that. You have to learn to refrain from that. You have to learn to cook different foods. Or, cook for them and then cook for yourself differently in order for your health to be better (P3 L164-L170, L175-L177).

Nine participants described learned body cues that alerted them to adjust their behaviors and activities. One participant described a signal for knowing when her Coumadin level needed adjustment:

It's just learning how to tell when my levels are high or low and that I go by. If I'm not able to move when I wake up in the morning, I have my bone or joints are very stiff and rigid, then I know that my Coumadin or clotting levels are probably high, and usually that's when I go to the doctor to try to see if they're high, and they usually are, and they adjust my Coumadin, and then I do well. And if they're very low, my vision gets blurry on the right side, like water, and then I know it's too low . . . But that's how I take care of it by learning the symptoms that I get with my body at the time that I feel that its high or low (P3 L34-L44).

Four participants described monitoring heart rate, fatigue, and chest pain and their response to those symptoms. One individual reported her response to a rapid heart rate: "When a fast rate comes, I just sit down, and boom, boom, boom, with my chest, and it's

gone. You know, it only lasts like...maybe less than a minute or so. It's not very long" (P10 L115-L117). Another woman described her response to fatigue: "You gotta rest. You . . . have to take your time in doing things, to rest in between. You know, kind of prioritize your chores. You know, you no longer can do everything that you used to before" (P3 L183-L184). Two participants revealed their responses to chest pain. One woman adjusted her work schedule according to her chest pain: "You just have to change your plans . . . you can't work if you don't feel right at that time" (P3 L147). Another said she rested:

I found out that if I would lay down just for 10 to 15 minutes, that's all I needed . . . rest for 20 or 15 minutes, and I would get up and do the rest of the work (P1 L66-L69).

Some participants mentioned experiencing body cues they ignored. One woman said:

I have to keep going . . . always have something to do. . . . Sometimes I do feel tired or whatever and I do take a rest or take a nap, but, basically, I don't. I'm always on the go (P9 L294-L298).

Another study participant revealed:

I'm always doing something, and then I get tired, and just don't pay attention to it. I just keep on going and going, and then I try to sit down, and that's when I feel shaky.... But other than that, I just keep going. If I'm doing something, I'm gonna finish that, and I don't care how (P4 L85-L90).

One participant described participating in an activity while knowing she would over-exert herself:

I go to the dance, because I'm still alive. . . . I'm not dead. I'm telling the truth, I'm young. But, *le dije* [I'm telling you], next day it's going to be hard for me, you know. If I go to a dance, I can't get up in the morning. You know I have to wait, lay down for longer than the other people, you know. You know, just to rest, rest, and rest and then I feel with energy again. I feel good (P11 L378-L384).

Women participants understood that the heart was essential to life, and believed people need to take care of their health beginning at a young age. Participants acknowledged that they could have engaged in better self-care. Because they learned healthy behaviors after developing heart disease, they desired to educate others (and especially youths) about heart disease prevention. Participants' recognition of and adjustment to body cues enabled them to live with their illness. They were able to continue many of their activities at scaled-back levels. Most individuals had adapted to their physical limitations and learned to prioritize desired activities. Although the women were aware of their physical limitations, some chose to continue certain strenuous activities because of the relative importance of such activities in relation to any potential health consequences. Researcher observations supported continued social participation and overall personal fulfillment despite diagnosis of CHD.

#### Listening to My Doctor

The second sub-theme, Listening to my doctor, demonstrated the extent to which doctors' advice influenced women's self-care. All participants described responding to their doctors' advice.

Most participants reported adherence to doctors' advised medication regimens. One woman said, "You need to take your medicines, you know. I think that's the main thing" (P3 L187-L188). Another commented that, "I take, you know, the prescribed medication that I have to" (P8 L1036). Two individuals specifically mentioned strict adherence to daily medication regimens. One participant said, "Take your pills the first thing. Don't skip some" (P6 L266-L269). Another person said, "Try to take my medication a daily basis. Try not to skip any. Make sure that I do take my medicines" (P9 L169-L172).

Several women reported greater compliance with doctors' advice due to CHD. One participant commented, "I learned that I have to do what he [doctor] tells me. They used to tell me, 'The doctor says this. . . . and doctor says that.' 'Too bad.' But now I do it'' (P2 L 226-L230). A second described her doctor saying, "'You don't like medicine, but sometimes you have to take medicine.' 'Okay, doctor, I'm gonna do it. . .''' (P10 L195-L197). This woman also paid more attention to her doctor's advice about her cholesterol: "Take care of that [cholesterol] for my [participant's] sake and for the

doctor's sake, because he keeps saying, 'You been saying that for years. . . . Okay, so you better do it.' 'I'll do it''' (P10 L101-L104).

Three participants described how they had changed their nutritional intake to adhere to the advice of doctors. One woman said, "I don't eat things that are fatty. 'Cause that's what the doctor told me, just to be on a diet" (P7 L308-L310). Another participant described her doctor as having told her, "You know, like what you should eat" (P8 L1013).

Several women described doctors' advice on exercise. One woman said, "The doctor said it would be good for me to take at least 30 minutes for myself and take a walk. He says for me to walk briskly, you know, if I can" (P9 L216-L218). Another one reported, "The doctor said to me . . . you have to walk 20 minutes in the morning or . . . in the evening (P11 L321-L322). A third commented that her doctor had said, "You could take care of yourself with exercise, the way we talked about it" (P10 L372).

Participants also described being advised to control blood pressure and quit smoking. One person described her doctor as saying, "You need to keep your blood pressure down" (P8 L1016). A second woman said that her doctor had advised "not smoking" (P10 L376).

One participant was motivated by her doctor's description of possible consequences of medication regimen noncompliance: "He said, if I don't take care of myself, what's gonna end up happening, I could have a heart attack or I could have a stroke" (P9 L120-L122). Another person recounted her doctor's guidance during cardiac rehabilitation: "So I took it slowly until the doctor said, 'In six to seven months you can start doing. . .' this and doing that. So, it went. Years passed, and I went [doing more activity] through that\_first step'" (P6 L421-L423). This same woman also felt emotionally supported and motivated by her physicians:

They say, "You need to keep strong. You need to keep on going the way you are." They give me [strength]. . . The last time I went to see him was in January. He said, "Oh, no, you look great! You look great! You don't look like you have [heart disease]" (P6 L361-L368).

Family obligations occasionally were prioritized over medical regimen adherence. One participant explained: My husband got sick that day and I was in the hospital [with him] all day long . . . I had an appointment with the doctor over here . . . . I missed all those appointments. . . . My husband got sick on the first, and I was there in the hospital all this time. . . . I haven't called them back or anything. I'm gonna try to call them back. It's important (P4 L230-L245).

There were no known folk healers in the community, and no participant reported having visited a folk healer for any reason. Only one person admitted use of a folk medicine—*yerba buena*, an herbal tea. Although participants made no mention of soliciting advice from neighbors and friends, some were observed discussing their heart disease in public settings and exchanging advice and recommendations with other heart disease patients.

All participants reported trust in their doctors, and most reported regular visits to their doctors. Perhaps because of women's awareness of their illnesses' severity, they were more willing to listen to and follow doctors' advice. On occasion individuals' family responsibilities took priority over their self-care. Although participants reported using only professional health care sectors, some were observed soliciting advice from the informal health care sector.

#### **Relying on My Faith**

The third sub-theme, Relying on my faith, included ways in which women's beliefs in God have influenced their adjustments after heart disease. All women expressed the importance of their faith. Expressions of faith were clustered as *prayers for assistance*, *prayers of thanksgiving*, and *understanding that God is in charge*.

Four women mentioned having prayed for God's assistance. One person said, "But you know you . . . talk to God and tell him to help you and all that stuff . . . that helps . . . a lot" (P11 L102-L103). Three participants used prayer as a remedy for chest pain. One participant stated, "*Bueno* [Good]... when pain happens, I just start praying, that's all. Nothing else. Just pray and pray and asking God to help . . . for the pain to go away, and He helps me. It goes away" (P2 L239-L242). Another woman said that when she had pain, "I start praying and praying and praying" (P8 L1076). A third participant said that when she felt chest pain, she made the "Sign of the Cross" on her chest with Vicks, "And I ask, please, God help me" (P10 L276). Another woman described praying for healing: "No matter what religion you are, you pray to Him, and He will heal you in different ways" (P10 L385-L386). One participant described telling her surgeon she had asked assistance from God to guide her surgeon's hand: "I'm just asking Him to give you the strength . . . or whatever you need, and give your hands so you could move and you could do the right thing on me" (P4 L123-L132).

Ten women described offering prayers of thanksgiving to God. Several of the participants thanked God for their lives. One participant said, "When I talk to God and I say, 'Look, thank you, God, because I'm alive. I can breathe.' I feel my heart; it's like if he cleaned me from the inside" (P6 L325-L331). Another person said, "My God, He healed me, and I'm gonna be here until He wants me. . . . God is so good with me, and I have to be . . . grateful . . . because He has me here" (P6 L329-L334). A third stated, "Thank God for each day that you're here. . . . That's what I do" (P10 L302-L309).

The women also thanked God for providing strength and faith to continue living. One person commented, "I always give thanks to Him 'cause he gives me that power, I mean, to keep on going" (P6 L392-L393). Another woman stated, "If I didn't have the faith to keep me going, I don't know what I would do. . . . I would just sit in a chair and say, 'Go ahead and take me now'" (P8 L814-L818). A third noted, "You have to cope with it the best you can...but with the help of God, I have gone through it. . . . Thank God" (P1 L29-L35).

Participants were also grateful to God for their health, despite the presence of heart disease: "I have to just turn around and give God thanks that I'm still in better shape than a lot of other people" (P8 L283-L284). Another individual commented, "[People] see me, and they see my sisters, and they say, 'They look more sick than you do!' And, I'm the one that. . . [has] been through a lot of things, 'cause I've been through open heart surgery" (P6 L410-L417).

Women reported prayers of thanksgiving for their families and friends. One person said, "Thank God for your children. They're around you when you need 'em" (P10 L302). Another individual revealed: "I know I have a big circle of family and friends, and I have to thank God for all these blessings" (P8 L815-L816). A third

interviewee was grateful for friends who had prayed for her health: "But, thanks to God that a lot of people were praying for me. . . . They all prayed for me" (P7 L131-L133).

All women conveyed a belief that God was in charge of their lives. Participants expressed trust in whatever God had in store for them. One participant said, "I'm just gonna leave it in God's hands. He's the one that's gonna take care of me . . . (P7 L348-L351). She added, "I tell my husband, God is the one that gives us the strength to accept things" (P7 L472). A second person commented, "I said, 'Okay, God, whatever . . . you want to do from here, I'm in Your hands" (P10 L211). A third individual said, "I talked to my God and I said, 'Okay, here I am, I'm all yours, God, take me. If you want me, take me. If you want to leave me, leave me" (P6 L529-L530).

Despite their strong faith, some women admitted to being overwhelmed. One person noted, "Sometimes you make yourself sick. 'Cause you say, 'Oh, what about if I have a heart attack tomorrow?' . . . It's just making your body sick" (P7 L385-L387). Another woman said, "Any little pain or whatever, and that fear sinks in. And then I'll pray some more and ask God forgiveness that I'm feeling this fear" (P8 L761). The same woman added:

It's my heart, and that's the one that I fear. And then I'll talk myself into or out of it, and say, 'Well, you know nobody knows who can die tomorrow from a heart attack or whatever or deer hitting your car or whatever.' So I have to think and psych myself out of it. And I think I do a pretty good job, but then I get tired or whatever and/or get the headache, and I start feeling the pain, and it's just like, I just crumble again, and I have to go to church or whatever to try to build myself up again (P8 L800-L810).

All participants attended services and community social events at church. Many had religious symbols visibly displayed in their homes—statues or pictures of the saints or Our Lady of Guadalupe, pictures of several Popes, crucifixes, religious candles, rosaries, and holy water fonts—and women frequently placed silk or fresh flowers in front of their statues. Individuals commented on their observance of religious holy days and special rituals, such as abstinence from meat on Fridays during Lent.

God was an important part of participants' daily lives. Faith brought participants peace, helped them cope, and gave women hope for a better life regardless of their heart

disease outcome. Faith helped women continue living with their heart disease, despite any hardships. Prayers of thanksgiving included gratitude for their lives, their blessings, and their family and friends who provided physical and emotional support.

The third theme, *Living with heart disease*, described three major strategies used by the women to adapt to life after heart disease diagnosis. They learned to listen to their bodies and developed new ways to continue living as normally as possible, despite the seriousness of their illness and their continuing symptoms. Although participants sought advice from family and friends, they were more motivated to change their behaviors in accordance with their doctors' advice. A faith in God helped them continue with their lives and afforded peace of mind.

#### SUMMARY OF THE FINDINGS

This study explored cultural beliefs, illness interpretations, explanatory models, and self-care practices of Mexican-American women with CHD. Chapter Four presented the demographic description of the sample and study findings. The research findings revealed three themes: *Knowing about heart disease, It changes your whole life,* and *Living with heart disease.* 

The first theme, *Knowing about heart disease*, reflected the participants recognition of their risks for heart disease due to family history, lifestyle, or heart abnormalities. They realized that behavior change would mitigate exacerbation of heart disease. Participants understood the causes of their heart disease and the health behaviors they needed to change.

The second theme, *It changes your whole life*, participants discussed the serious, ongoing effects of heart disease on multiple areas of the participants' lives. These areas included their physical and emotional health, activities, socio-economic status, and family roles. Participants described the multitude of changes that heart disease had caused them.

The third theme, *Living with heart disease*, revealed the participants' strategies to survive CHD. The women recognized that their lives must necessarily change, and that support from family and friends, doctors, and their faith assisted in any adjustments made. Nonetheless, participants made some decisions based on prioritized values even

when their bodily cues or doctors' advice suggested acting otherwise. Participants learned ways to accept the outcomes of heart disease on their lives.

Researcher observations supplemented the interviews, with some commonalities emerging. For example, family was not mentioned prominently in many participant interviews, yet family members were frequently present during interviews, at doctors' appointments, at social functions, and providing assistance during daily life. Another observation was participants' continued attendance and enjoyment of traditional and often elaborate Mexican-American social events, such as quinceañeras (a celebration of the 15<sup>th</sup> birthday) and weddings, which typically include rich food and music. A third observation was the strong Hispanic influence in the community. For example, religious services often are held in Spanish, Spanish was often spoken, and Spanish words or phrases often are sprinkled in English conversations; grocery stores carry *manteca* (lard) and other traditional Mexican foods, bakeries offer pan dulce (pastries), and restaurants serve menudo (a traditional Mexican soup) and barbacoa (a traditional Mexican barbecue). The community has a hospital and several clinics that practice Western medicine, including one that specifically serves low-income Hispanics. No folk healers are known to practice in the community, and no folk pharmacies or herbalists are known to exist in the community.

CHD profoundly affected the Mexican-American women in the study. Participants' stories related a transition from life before the illness to life after diagnosis. During this transition, participants made sense of their heart disease, acknowledged the painful and permanent changes that heart disease brought to their lives, and have made choices about how to adjust their lives in a way that continued to honor their values. Their transition was supported by family, friends, doctors, and faith.

#### PLAN OF THE REMAINING CHAPTERS

Chapter Five will present study discussion and conclusions. Study findings will be compared to relevant literature. The chapter will discuss implications, limitations, strengths and suggestions for future research.

### **CHAPTER FIVE: DISCUSSION AND CONCLUSIONS**

#### INTRODUCTION

Chapter Five includes overviews of the study problem, methods, and findings. The study findings are compared to results from relevant literature. The chapter also discusses study implications, limitations, strengths, and suggestions for future research.

Coronary Heart Disease (CHD) is the leading cause of death in the U.S., accounting for 52 percent of deaths in women and costing over \$368.4 billion per year in medical expenses (CDC, 2010). Racial and ethnic minority women have been underrepresented in health research, which has created gaps in understanding of how minority women are affected by illnesses such as CHD (Adler, 2010; Getz & Faden, 2008; IOM, 2010). The Mexican-American population is the largest U.S. minority (U.S. Census Bureau, 2011). However, little is known about psychosocial and cultural factors influencing Mexican- American women's understanding of and caring for themselves during illnesses. To provide culturally competent care, it is important for health care professionals to understand Mexican-American women's explanatory models (EMs) of CHD. Findings from this study may help develop culturally competent interventions to reduce CHD incidence, mitigate resulting CHD mortality, and increase quality of life among Mexican-American women with CHD.

The purpose of this ethnographic study was to elicit cultural beliefs, illness interpretations, explanatory models, and self-care practices of Mexican-American women with CHD using Kleinman's (1980) ethnographic framework. Research questions were: <u>Research question (RQ) 1.1</u>: How do Mexican-American women with CHD describe and explain their experiences with CHD?

<u>RQ 2.1</u>: What are the self-care practices of Mexican-American women with CHD? <u>RQ 2.2</u>: How do Mexican-American women with CHD describe their self-care practices for CHD?

Kleinman's (1980) Cultural Healthcare Systems model and the construct of lay explanatory models (EMs) served as a sensitizing framework for this study. Kleinman (1980) developed the concept of EMs to understand individuals' beliefs about etiology, course, and treatment of illness. EMs of health and illness experiences are formulated by individuals and may be influenced by culture, perceptions of past experiences, and social environments; they may be specific to cultural groups or personalized and different from one's family or ethnic group (Hoke et al., 2006). Each sector has a unique set of knowledge and beliefs from which EMs are constructed (Kleinman, 1980).

The researcher used a qualitative ethnographic design to answer the aforementioned research questions. Ethnographers explore, describe, and interpret patterns of values, behaviors, beliefs and languages shared by a cultural group (Agar, 1986; Creswell, 2007; Harris, 1968). Ethnography gives voice to people within their own local context, usually through a reliance on extensive verbatim quotations that provide the ethnographer with a thick description of the event (Fetterman, 2010).

A purposive sample of 11 adult community dwelling, English-speaking Mexican-American women with self-reported CHD was recruited from community settings and physicians' offices in a rural community in the southwestern U.S. Data collection included in-depth interviews and participant observations. The researcher used a constant comparative method to analyze data (Glaser & Strauss, 1967). Three criteria were used to ensure scientific rigor: credibility, fittingness, and auditability; these criteria had been developed by Lincoln and Guba (1985) and modified by Beck (1993).

#### **INTERPRETATION OF THE FINDINGS**

Participants in the study revealed how CHD had affected their lives and how they had learned to understand and live with heart disease. Three themes were identified: 1) *Knowing about heart disease;* 2) *It changes your whole life;* and 3) *Living with heart disease.* Each theme had several sub-themes, which are explained below.

All three themes addressed the first research question: How do Mexican-American women with CHD describe and explain their experiences with CHD? The third theme, *Living with heart disease*, specifically addressed the two-part second research question: 1) What are the self-care practices of Mexican-American women with CHD?, and 2) How do Mexican-American women with CHD describe their self-care practices for CHD? The first theme, *Knowing about heart disease*, reflected the ways in which participants had made sense of their heart disease. The women knew that their heart disease was serious and believed it unlikely they would be granted a "second chance" (P5 L426). The three sub-themes revealed what participants believed were the causes of, or risk factors for, their own heart disease: It runs in my family, It was my lifestyle, and It's my bad heart. Participants understood that behavior changes were necessary for improved health.

The second theme, *It changes your whole life*, described the permanent changes in participants' lives caused by their heart disease. The changes were described as difficult, painful, even frightening. The four sub-themes—Bodily changes, Emotional changes, Financial changes, and Role changes—indicated the breadth of change imposed by heart disease. The physical changes appeared to drive the other changes, as participants realized they could no longer function as they had before their heart disease onset. Individuals understood they were "not the same" (P6 L274) and that they "cannot do it [i.e., function the same] anymore" (P2 L188).

The third theme, *Living with heart disease*, revealed the ways in which participants learned to make the best of their lives with heart disease. The three subthemes, Listening to my body, Listening to my doctor, and Relying on my faith, described strategies developed by participants to manage their heart disease and "keep on going" (P6 L415) with their lives after CHD. Participants attributed the strength received from God as facilitating adjustment to the changes caused by their heart disease. They also expressed gratitude for the physical, emotional, and spiritual support from family and friends. Participants learned to better heed health advice and chose to be more adherent to their treatment regimens: "Listen to what the doctors tell you. They know what they say" (P5 L633). Although participants took treatment recommendations under advisement, their final decisions were based on values and priorities.

CHD diagnosis forced Mexican-American women in the study to incorporate their illness into their lives as an enduring reality with persistent effects. Participants' adjustment to the effects of CHD was not easy; participants felt comforted and strengthened by their faith in God and by the love and care received from others. Even though participants underwent lifestyle modifications for CHD to live healthier lives,

they also struggled to remain the women they were prior to their CHD diagnosis. Thus, participants weighed the consequences of their behaviors and made choices congruent with their values.

#### **COMPARISON OF THE FINDINGS TO THE FRAMEWORK**

The use of Kleinman's (1980) three health care sectors was confirmed by the study. The women in the study described primarily relying on the professional sector for their healthcare, specifically their doctors. Participants may have emphasized the use of the professional sector because Western medicine is dominant in the community and doctors are the primary providers of professional care (Kleinman, 1980).

Study participants consistently described self-care, or their practices that focus on their well-being, which exists as a major component of the popular sector across cultures (Kleinman, 1980). To a lesser degree individuals described a reliance on family and friends for health advice. Nevertheless, observations revealed that participants shared their experiences and exchanged *consejos* (advice or counseling) about their heart disease, treatments, self-care, and test results in a variety of community settings. This finding is consistent with Kleinman's (1980) assertion that people who have received professional treatment typically revert to the popular sector to assess the care provided and to determine how to proceed.

Kleinman (1980) noted that the folk sector may include both secular and sacred aspects. With the exception of one participant who described drinking *yerba buena* (herbal tea), participants denied using folk healers or folk medicine. This trend may be related to the lack of folk healers or folk medicines in the community despite close proximity to Mexico. However, participants frequently mentioned blessings and prayers from their clergy, which is consistent with the sacred aspect of Kleinman's folk sector. The lack of indigenous healers in the community was confirmed and may explain why participants did not mention them. Alternatively, the participants may have been reluctant to discuss with the researcher the use of other health care sectors. Another explanation could be that the many years the participants had lived in the U.S. and used Western medicine could have altered their choice of treatment and providers.

Kleinman (1980) used EMs to describe cultural beliefs. An EM is a belief system used to describe or explain an illness and its causes (Kleinman, 1980; Lechuga, 2011). External influences (e.g., culture) affect how people conceptualize and experience illness (Lechuga, 2011). This study focused on EMs used by Mexican-American women with CHD to interpret meanings of their illness experience, to understand their illnesses, and describe their self-care practices. Kleinman's (1980) eight questions (see Chapter Two) guided the following description of study participants' EMs of CHD.

Participants self-identified as having CHD and described it as a serious illness. Most participants enumerated causal factors of their CHD such as biological, genetic, lifestyle, and cultural influences on lifestyle, such as overeating and the type of food they ate. Some participants also associated CHD with their difficult lives, e.g., family stress, working long hours. Participants indicated that a lack of proper self-care was an important cause of their heart disease—for example, smoking, a lack of treatment of their high cholesterol or high blood pressure, and a lack of exercise. Interestingly, participants' descriptions of their causes of CHD reflected many of the risk factors identified by the American Heart Association (2013). Interviews did not indicate beliefs that CHD was related to supernatural causes.

Participants acknowledged that CHD had affected their bodies and caused major problems in multiple areas of their lives. What participants feared most about their CHD was pain, death, an inability to care for others, and their children's inheritance of CHD. Participants indicated that a faith in God was their biggest comfort.

In response to the effects of CHD, participants moved among the popular, folk, and professional sectors. They relied primarily on their doctors, but they were also dependent on family and friends. While the women did not attribute CHD as being caused by God, they did attribute their healing and the guidance of their physicians' hands to God. Although EMs of different sectors can be a source of conflict between patients and health care professionals (Kleinman, 1980), participants conveyed trust in their physicians and their physicians' treatment regimens. Trust in one's physician did not necessarily result in strict adherence to advice given; rather, patients weighed any doctors' advice against personal values and priorities.

#### COMPARISON OF THE FINDINGS TO THE EXTANT LITERATURE

EMs are dynamic and thus change (Kleinman, 1988). People make decisions about use of health care sector for advice or treatment, self-care choices, adherence, alternate treatment, evaluation of care, and satisfaction with care based on their EMs (Kleinman, 1980). Patients tend to participate in and adhere to treatment planning when there is a sense of being heard and understood (Kleinman, 1980). Although other studies have examined the EMs of Hispanics with chronic illness, no research investigating the EMs of Mexican-American women with CHD was found at the time of this study. Findings from several pertinent studies from the literature are discussed and compared with study findings below.

Some studies have reported that Mexican-Americans attribute their illness to supernatural causes and use traditional herbs and healers in their treatment regimens (Jezewski & Poss, 2002; Kleinman, 1980; Lechuga, 2011). Participants in this study had factual explanations of the cause of their CHD and denied use of folk medicine. This difference may be due in part to diverse population sets—there may be cultural variations in EMs within a population due to exposures with multiple experiential and social factors (Kleinman, 1980; Lechuga, 2011). For example, participants in the study by Jezewski and Poss (2002) spoke mostly Spanish, were born primarily in Mexico, and lived in *colonias*; in contrast, current study participants spoke English, were born primarily in the U.S., and had long term residency and relationships in the community. Thus, while the participants in the Jezewski and Poss (2002) study also described biomedical knowledge from exposure to their diabetic classes, all but one attributed their diabetes to *susto* (fright); no such references to folk disease causation were mentioned in the current study.

Research has indicated a potential for conflict for those individuals with chronic illness who hold EMs derived from their culture of birth but who are receiving healthcare in the U.S. (Kleinman, 1980; McEwen, 2005). Moreover, people who view their illness contextually may have difficulty solely following a biomedical plan of care (Lechuga, 2011). For example, McEwen (2005) found that Mexican immigrants with latent tuberculosis had to choose between differing illness and treatment approaches held by Mexican and U S. professional and popular sectors. The researcher suggested that

participants adjusted their EMs to be congruent with those of U.S. health professionals either because 1) participants believed that U.S. health sector advice carried greater weight, or 2) the power imbalance between patients and U.S. healthcare providers. In the current study, participants did not reveal conflicting views of illness or treatment between their Mexican-American culture and the U.S. health care system providers. In fact, participants indicated primarily relying on and trusting the professional sector for their CHD advice and treatment, even if participants chose not to adhere to that professional advice. Participants also depended on the popular sector, including family and friends, and sacred member of the folk sector (clergy), for advice and support. Overall, members of the popular and folk sectors lived in the same community where participants resided, and were supportive of physicians' plans of care. However, participants' healthcare choices were weighed against participants' cultural values and roles, such as family needs and participants' responsibilities. This concept of weighing advice is similar to the theme "Weighing the Risk" (Lefler et al., 2013, p.112) that was identified in a study of cardiac risk perception in African-American and White older women-those women reported their perceptions of risks as being affected by several factors, including other priorities.

Hoke et al.'s (2006) descriptive qualitative study of overweight Mexican-American women revealed that women's patterns of eating were influenced by their Mexican cultural upbringing, even while acknowledging that such eating behavior was unhealthy. Hoke et al. (2006) reported that women's lives revolved around family and work, and food was a central component of family and social activities. Although participants in the Hoke et al. study understood the value of better nutritional patterns, the benefits of any lifestyle changes were mitigated by participants' perceptions of a lack of resources and support.

Participants in the current study acknowledged that their lifestyles, including nutritional choices, were influenced by culture. Moreover, their lives were centered on family and friends, cultural values and roles, and faith beliefs. The women recognized the value of healthier lifestyles, but decisions for improved self-care were made based on personal values and priorities. Although the women suggested the existence of constraints on financial resources, participants felt supported by family, friends, health professionals, and faith.

Mexican-American women may feel obliged to adhere to conventional cultural and gender roles (D'Alonzo, 2012; de la Torre & Estrada, 2001; Evans et al., 2007; George, 1998; Mendias et al., 2001). Thus, current study findings also were compared to three commonly accepted cultural values that can affect participants' health and behaviors. These cultural values include *familismo*, *personalismo*, and *fatalismo* (Espinosa de Los Monteros & Gallo, 2012; Juarez et al., 1998; Ortiz, 2009; Santiago-Rivera et al., 2002; Toro-Morn, 2013).

Lugo Steidel and Contreras (2003) identified four components to *familismo*: 1) familial support, 2) interconnectedness, 2) familial honor, 4) subjugation of self and for family. A mixed method study by Davila et al. (2011) of perceptions of 50 primarily Spanish speaking men and women with Hepatitis C indicated that *familismo*, feelings of devotion, responsibility, and duty to family, were the central foundation for participants' health decisions and behaviors. Mexican-American women have been reported to prioritize their roles as mothers and caregivers, commonly placing family needs first (Mendias et al., 2001). Researchers have reported the Hispanic cultural construct, *marianismo*, influences Hispanic women to disregard their personal health concerns and self-care (D'Alonzo, 2012). Ranking family above individual needs has been regarded as an obstacle to heart disease diagnosis and treatment in Mexican-American women (Sherrod, 2011).

The current study confirms that Mexican-American women participants put their family first. Some women worried about who will care for the women's parents. All participants with husbands continued to care for their husbands (i.e., cooking, washing clothes, housecleaning) even when women's CHD symptoms worsened as a result. Participants also attempted to not disturb their children, practiced self-care to the fullest extent, and sometimes expressed guilt for needing their child's physical help.

*Familismo* includes the younger generation's obligation to care for family elders, although some researchers have suggested the value is changing (Lugo Steidel & Contreras, 2003; Ruiz & Ransford, 2012). Ruiz and Ransford's (2012) exploratory study of perceptions of *familismo* in 25 older male and female Latinos in Los Angeles revealed a changing and expanded definition of family, a lack of obligation of busy adult children to parental needs, a reinforcement that children prioritize their own family and work over

that of older parents, and engagement of adult children primarily in times of major parental illness. Ruiz and Ransford (2012) suggested that older parents' desire to not trouble children caused parental physical and emotional suffering.

Similarly, while some participants in the current study revealed a desire not to bother their children, participants indicated that their families were always available when needed. Participants' families (including their adult children) were very involved in both women's health care and women's daily lives. Consistent with Ruiz and Ransford's (2012) findings, gender differences in support activities existed, with adult daughters assuming more responsibilities for women's personal care, doctor communications, and health advice. However, husbands and male children would assume some of these responsibilities if needed. Moreover, women received emotional support from their faith community and neighbors that augmented the assistance provided by their families.

A perceived lack of *personalismo* in Hispanics affects their access, interactions, communications, care quality, and satisfaction with health care providers and settings (Askim-Lovseth & Aldana, 2010; Chandler et al., 2012; Cleveland & Horner, 2012; Sanchez, 2007). Mexican-American women have been reported to change health care providers if provider is perceived as lacking *personalismo* (Cleveland & Horner, 2012; Sanchez, 2007). Women in the current study reported feeling connected to their health care provider, described good communication, and expressed satisfaction with their care. This may be because the physicians in the community employed bi-cultural, bilingual (English-Spanish) office staff and many of the providers spoke Spanish, which has been associated frequently with care satisfaction (Askim-Lovseth & Aldana, 2010; DuBard & Gizlice, 2008). Moreover, the perception of feeling connected described by the women in the current study is similar to the concept of being "recognized" (Chandler et al., 2012, p. E28), which was deemed a profound need by Mexican immigrant women seeking healthcare. Women in the current study and their health care providers and staff live in the same community; see each other in church; shop at the same stores; eat at the same restaurants; and send their children to the same schools. Everyone attends many of the same social and community functions. Although distinctions (e.g., status, education, professional role, economic, cultural) remain between providers and patients, they know each other and are deeply interconnected members of the same community.

*Fatalismo* is the belief that events are predestined or externally controlled and has been associated with poor health outcomes in Mexican-Americans (Espinosa de Los Monteros & Gallo, 2012; Reynolds, 2004). Fatalistic beliefs have been linked to lower quality of life, poorer physical health and greater depression (Espinosa de Los Monteros & Gallo, 2012; Urizar & Sears, 2006).

Participants in the current study did not reflect this belief. Rather, they attributed CHD to risk factors commonly linked to CHD and described health behaviors recommended by their doctors to control their CHD. On the other hand, the participants viewed God as a healer and as being in charge of their lives. Participants' belief in God helped them cope with the physical and emotional distress of CHD and increased their ability to enjoy life. Lefler et al. (2013) linked trust in God and belief in luck with feelings of decreased personal responsibility for participants' self-health. In contrast, all current study participants indicated that a trust in God helped them cope with their CHD. Participants knew the importance of taking care of their health and adhering to medical advice.

#### **UNEXPECTED FINDINGS**

One unexpected finding was participants' awareness of the seriousness of their illness and of their symptoms. This study contrasted with findings in a study of Hong Kong Chinese male and female participants by Chan et al. (2010) who reported that even post-MI participants had a tendency to underestimate the gravity of CHD and any associated suffering. Moore et al. (2010) noted that seven post-MI white women in their study viewed being asymptomatic or not feeling unwell as indications of their lives returning to normalcy. Lefler et al. (2013) also reported that asymptomatic African-American and Caucasian older women without heart disease perceived little risk of heart disease or a need to alter risk behaviors. In contrast, at least seven women in the current study manifested persistent cardiac-related symptoms, which reinforced perceptions of heart disease as life-threatening. Similarly, Crane and McSweeney (2003) reported that 93 percent of older post-MI women manifested physical symptoms. The majority of participants in their study reported making some lifestyle changes, providing further evidence that on-going persistent physical symptoms raise women's awareness of CHD

and may motivate them to change their behaviors. Also congruent with the current study, Crane and McSweeney (2003) observed that women's decisions to change behaviors were dependent on multiple factors, such as spiritual support and support from family and friends.

Another unexpected finding was that, despite ongoing physical and emotional symptoms, participants in the current study assessed their health as fair (63.6%) to good (36.4%). This finding is in contrast to the data reported in a national survey of health in minority communities, which found that Hispanic women were more likely to report fair or poor health (31.3%), compared to a national sample of all women (15.3%) (Liao et al., 2011).

Women in the current study felt fortunate to have continued support—both physical and emotional—from physicians, family and friends, and faith. Participants' perceptions of physician support contrasted with reports from other studies, which have indicated that women with chronic illness, especially heart disease, have felt unsupported by their physicians (Chandler et al., 2012; Moore et al., 2010). However, study findings are congruent with other studies that describe women's dependence on physicians' support, especially in relation to health promotion or illness prevention (Chan et al., 2010; Lefler et al., 2013). The importance of family support for older women with heart disease has been well documented (Crane & McSweeney, 2003; Lefler et al., 2013)

A third unexpected finding in the current study was the lack of mention of family involvement in participants' healthcare. Because observations supported extensive family involvement in all aspects of participants' lives, one explanation is that family support and presence is so pervasive in their culture that the women did not even think to mention it, i.e., the *emic* perspective (Kleinman, 1980; Spradley, 1979). Moreover, participants in the current study, even while acknowledging family support, also expressed the desire not to burden their families. This latter finding reflects the results of Ruiz and Ransford (2012), who have suggested that some older parents' desire not to bother their children is more important to parents than their own well-being, even when a lack of support has resulted in parental physical and emotional suffering.

#### **IMPLICATIONS FOR NURSING**

Findings from this study have implications for nursing practice, education, and research. For nursing practice, the findings about the degree of women's physical and emotional suffering as a result of CHD should alert nurses and other healthcare professionals to the care needs of women with CHD both at discharge and post-discharge. Exploration of pain levels or other symptoms experienced by women with CHD can help health professionals to develop appropriate individual therapeutic interventions for symptom prevention and self-management. Depending on patient symptomatology, nurses and other healthcare providers and families, which in turn can lead to adjustments in plans of care and to better adherence. Nurses and other healthcare professionals may encourage women to attend community support group meetings and motivate women to explore existing rehabilitation or support resources within the community. In situations of limited community resources, nurses and other healthcare professionals can advocate for development of needed resources.

A second finding with practice implications is the importance of healthcare professionals' awareness of participants' cultural values and corresponding EMs for illness. For example, participants in the current study often made choices about health behaviors based on assessments of behavior consequences weighed against personal and cultural values. Elicitation of women's input about realistic behavior changes and barriers to behavior change may result in mutual and targeted treatment planning for improved treatment adherence, care satisfaction, and health outcomes.

Study findings have implications for nursing education, supporting a need to teach cultural competencies that facilitate enhanced understanding of culture and any cross-culture differences. Teaching cultural competence from an inclusive perspective could promote improved patient-provider relationship skills and facilitate realistic, individualized, and effective treatment planning.

Study findings have implications for nursing research, supporting the value of qualitative studies that explore women's diverse perspectives about a variety of illnesses and the depth to which these conditions affect their lives. Further studies would be

particularly helpful related to understudied women and their illnesses. Study findings also confirm the need to examine women's EMs for illness because of the dynamic nature of culture. Further, study findings reinforce the need to examine how traditional cultural values have changed and the impact of those changes on health.

#### LIMITATIONS OF THE STUDY

Because the researcher is not Mexican-American and does not speak Spanish, the study group was limited to English-speaking women. The study findings may not reflect the experiences of Mexican-American women who do not speak English. However, the majority of Mexican-American women in the study community do speak English, so participants were considered to be fairly representative of the wider community composition where the study took place. The researcher solicited support from community physicians and recruited via various settings, which maximized access to the study population. No obvious problem with access was identified, and participants appeared eager to participate in the research study.

Sampling bias could have existed in any potential participants not legally in the U.S., due to fear of being reported to Immigration and Naturalization Services. Initially, the researcher addressed this concern through assurances of confidentiality, although study participants reported living in the community for many years and did not express any concerns of this nature. Moreover, while it was possible that potential participants were undocumented and chose not to participate in the study, the researcher was unaware of any undocumented women with CHD in the small community where the study took place.

Because the researcher was well known in the community and perhaps to study participants, participants may have been reluctant to speak freely or wanted to present themselves in a positive light. Additionally, participants may have chosen to participate because they knew the researcher. The researcher assured participants of interview confidentiality to encourage participants to speak openly. While it is possible that some women chose not to participate, participants appeared quite eager to converse openly. Multiple methods were used to ensure the researcher's objectivity, as noted in the discussion of the study trustworthiness procedures.

#### STRENGTHS OF THE STUDY

A study strength was its ethnographic approach, which facilitated exploration of cultural values, beliefs, behaviors, illness interpretations, and self-care practices of adult Mexican-American women with CHD in the study community. Use of participant observation and interviews provided needed insight into the illness experiences of an understudied group of women and suggested strategies to improve health outcomes.

#### SUGGESTIONS FOR FUTURE RESEARCH

Future research may include studies of comparable Mexican-American women with CHD to determine the existence of parallel findings. Other studies that utilize interviews with diverse Mexican-American women with CHD could help to determine the ways in which immigration status, number of years living in the U.S., community size, co-morbidities, length of CHD illness, acculturation, and other variables affect women's EMs of illness and their cultural values, especially as they relate to health behaviors. A third suggestion for future research is to conduct intervention studies, i.e., allow Spanish-speaking community health workers to follow community dwelling Mexican-American women with CHD or other chronic diseases to determine intervention effects on women's adherence to treatment plans.

#### CONCLUSION

Chapter Five presented an overview of the study problem, method, and findings. The study findings were compared to relevant literature, and the chapter discussed study implications, limitations, strengths, and suggestions for future research.

Heart disease remains a major cause of mortality in Mexican-American women. Critical health disparities persist in racial and ethnic groups and in women (IOM, 2010), and studies that examine important health issues for Mexican-American women are needed to advance population health. Overall, limited information exists about the effects of CHD on Mexican-American women after their discharge to their communities. There is a lack of information about the longer-term effects of CHD upon Mexican-American women and their families and communities. There is also a lack of study about Mexican-

American women's EMs of CHD, especially in light of how contemporary culture may be affecting traditional values, such as *familismo*. This study explored the cultural beliefs, EMs, and self-care practices of a group of Mexican-American women with CHD living in a small community in southwestern U.S. Findings from the study may help improve Mexican-American women's CHD outcomes by providing critical information for culturally-sensitive health care and for development of culturally appropriate interventions.

## **APPENDIX A: STUDY FLIER**

# LOCAL RESEARCH STUDY

## IF THE LIST BELOW CHARACTERIZES YOU, PARTICIPATE IN A RESEARCH STUDY:

Female of Mexican-American Descent

ages 21 and over

with a diagnosis of Coronary Heart Disease
and able to speak, read and write in English

NO TREATMENT, INTERVIEW ONLY

Study Conducted By Rosemarie Garza, M.Ed, MSN, RN, UTMB Doctoral Nursing Program Student

> Study Overseen By Dr. Elnora Mendias, RN, PhD & Approved By UTMB Institutional Review Board



#### ANNOUNCING A RESEARCH STUDY

Are you a Mexican American woman with coronary heart disease? Do you speak English, and are you over the age of 21? I am conducting a research study that may help health professionals understand better how to care for women like you. You could take part in a research study to explore the cultural beliefs of Mexican-American women with coronary heart disease as well as how they understand their illness and take care of themselves. I am Rosemarie Garza, M.Ed, MSN, RN, a student in the Doctoral Nursing Program at the University of Texas Medical Branch (UTMB) Graduate School of Biomedical Sciences (GSBS) in Galveston, Texas Dr. Elnora (Nonie) Mendias, RN, PhD, Associate Professor at the School of Nursing will be my dissertation committee chair for this project.

All information about participants is confidential, and the UTMB Institutional Review Board has approved this study. There are no treatments, only conversation as you are interviewed.

If you want to know more about the study, please e-mail Rose Garza at r.garza@umhtx.org. If you would rather leave a telephone message, please call (830) 278-2062, or (830) 278-6251, Extension 1428, and leave a message. Your call will be returned as soon as possible.

Thank you.



OFFICE OF RESEARCH SUBJECT PROTECTIONS Indibutional Review Board

#### 06-Feb-2012

#### MEMORANDUM

TO: Elnora Mendias, PhD,RN,F/Rosemarie Garza, M.Ed, MSN School of Nursing PhD Program 1029

andrea Mtrag

FROM: Richard Rupp, MD Director Institutional Review Board 0158

SUBJECT: IRB #12-029 - Final Approval of Expedited Protocol.

An Ethnographic Study: Beliefs, Interpretations and Self-Care Practices of Mexican-American Women with Coronary Heart Disease

Having met the requirements set forth by the Institutional Review Board by an expedited review process on January 25, 2012, your research project is now approved, effective February 6, 2012.

This project will require annual review and will expire on January 25, 2012. Research that has not received approval for continuation by this date may not continue past midnight of the expiration date.

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.

RR/ak

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OFFICE OF RESEARCH SUBJECT PROTECTIONS Institutional Review Board

25-Feb-2013

#### **MEMORANDUM**

TO: Elnora Mendias, PhD,RN/Rosemarie Garza, M.Ed, MSN School of Nursing PhD Program 1029

Hart Junger, CH

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

SUBJECT: IRB #12-029 - Final Approval of Continuing Review. <u>An Ethnographic Study: Beliefs, Interpretations and Self -Care Practices of Mexican-</u> <u>American Women with Coronary Heart Disease</u>

Having met the stipulations set forth by the IRB by an expedited review process on <u>February 7, 2013</u> your research protocol is approved for continuation. The approval of this protocol is effective <u>February 25, 2013</u> and will expire on <u>February 7, 2014</u>. Research that has not received approval for continuation by this date may not continue past midnight of the expiration date.

<u>Comments</u>: It is the understanding of the IRB that enrollment has ended on this project, therefore, written informed consent is no longer needed. If however, you intend to begin enrolling subjects again or need to re-consent subjects already enrolled, the latest version of the consent form will have to be resubmitted for IRB review and approval.

JP/hs

## **APPENDIX B: BIO-DEMOGRAPHIC DATA**

## Note: This form will be completed by the researcher at the first interview.

## **Bio-demographic Data**

ID Code\_\_\_\_\_

- 1. Age in years: \_\_\_\_\_
- 2. Marital Status:
- 3. Where were you born?
- 4. Years living in United States: \_\_\_\_\_
- 5. Education (circle all that apply):
  - a. Less than High School
    - b. High School graduation or GED
    - c. Some College
    - d. College graduate
- 6. Are you employed?
  - a. Yes
  - b. No
- 7. If yes, are you employed
  - a. Full-time?
  - b. Part-time? (number of hours employed)
- 8. What type of work? \_\_\_\_\_
- 9. Estimated household income per year:
  - a. \$10-\$20,000
  - b. \$21-\$30,000
  - c. \$31-\$40,000
  - d. \$41-\$60,000
  - e. more than \$60,000

10. Number of persons living in the home \_\_\_\_\_

Number of children under 21 in the home

Number of persons other than spouse or children in the home \_\_\_\_\_

11. Do you currently have health insurance?

- a. Yes
- b. No
- 12. Where do you get your healthcare?
  - a. Clinic
  - b. Doctor's office
  - c. Other
- 13. How would you rate your health?
  - a. Poor
  - b. Fair
  - c. Good
  - d. Excellent

## **APPENDIX C: INTERVIEW QUESTIONS**

Adapted from Kleinman (1980)

Introduction by the interviewer: As I explained, I am going to be talking with you about your heart disease. Please feel free to tell me anything you would like.

## Grand tour question:

1. Tell me in your own words about any problems you have with your heart.

## The following are examples of Mini-tour questions that may be asked, to clarify or augment responses to the Grand Tour Question:

- 1. What do you call your heart problem?
- 2. How do you think it came about?
- 3. Why do you think your heart problem started when it did?
- 4. Tell me what your heart problem does to your body.
- 5. How severe is your heart problem?
- 6. Who takes care of your heart problem?
- 7. How did you feel when you found out you have a heart problem?
- 8. What concerns do you have about having a heart problem?
- 9. Tell me how you take care of your heart problem.
- 10. Who gives you advice about your heart problem?
- 11. Tell me about any home remedies you use to treat your heart problem.
- 12. Tell me how your daily life is different now than before you were diagnosed with heart problems.
- 13. Tell me about how you have adjusted.
- 14. Tell me what you think you have learned from having heart problems.
- 15. What would you tell other women about heart problems?
- 16. What else about your heart problem would you like to tell me?

## **APPENDIX D: RESEARCH CONSENT FORM**

You are being asked to participate as a research subject in the project entitled, "An Ethnographic Study: Beliefs, Interpretations and Self-Care Practices of Mexican-American Women with Coronary Heart Disease" under the direction of Ms. Rosemarie Garza, M.Ed., MSN, RN, who is a student in the Doctoral Nursing Program at UTMB Graduate School of Biomedical Sciences (GSBS). Dr. Elnora (Nonie) Mendias, RN, PhD, Associate Professor at the School of Nursing and full member of the GSBS faculty will be the dissertation committee chair of this research project. There is no sponsor for this study. Ms. Garza is not receiving funding in any form from any source to conduct this research project.

## PURPOSE OF THE STUDY

The purpose of this study is to explore how Mexican-American women with coronary heart disease view, understand, and take care of their illness. You are being asked to participate because you are a Mexican-American woman who has been told at least one year ago by your physician or other healthcare provider that you have been diagnosed with coronary heart disease.

### PROCEDURES RELATED ONLY TO THIS RESEARCH

This is an interview study. There are no interventions or experiments. During this study, Ms. Garza will interview you at least once, but not more than three times, about your experiences with coronary heart disease. The interviews will be conducted at a time and place that is convenient for you. Each interview will last no more than one and one-half hours. The study will continue over about a 12-month period. The interviews will be audio-taped and transcribed to ensure the accuracy of your answers. To protect your identity, the audiotapes and transcripts will be coded. Your name will never appear on any study documents or recordings. Both the tapes and interview transcripts will be kept in a locked file cabinet in the researcher's office.

Following the completion of the first interview, Ms. Garza will contact you to set up any additional interviews if needed. Follow-up interviews may be done to clarify information or ask additional information.

In addition to answering the interview questions, you will be asked to answer several questions about your age, marital status, country of birth, years living in the U.S, years of education completed, employment status, occupation, estimated annual income, number of persons living in the home, health insurance status, and how would you rate your health. This questionnaire will also be coded so that no identifying information can be

associated with you. If, for any reason, you are unable to continue your participation in any of the interviews, they will be stopped without any penalty to you.

## **RISKS OF PARTICIPATION**

The potential risks from participation in this study are few. You may become fatigued during the interview. There will be no procedures or treatments associated with this research study, only conversation during the interview. Ms. Garza will take all possible steps to assure your confidentiality by coding study data and removing your name and other identifiers from study materials. However, there remains a minimal risk of the loss of confidentiality.

## NUMBER OF SUBJECTS PARTICIPATING AND DURATION OF PARTICIPATION

The anticipated number of subjects involved in the study will be no more than 15 Mexican-American women with coronary heart disease and who meet study criteria. The study will take no longer than 12 months, and you will be asked to participate no more than three interview sessions.

## BENEFITS TO THE SUBJECT

There are no direct benefits to you for your participation in this research study. By answering the researcher's interview questions, you may gain some insight into your experiences living with your coronary heart disease.

### OTHER CHOICES (ALTERNATIVE TREATMENT)

There are no treatments in this study. You will meet with the investigator only to discuss the interview questions and answers you wish to provide. The alternative to participating in this study is to choose not to participate. Participation in this study is voluntary and not required.

### **REIMBURSEMENT FOR EXPENSES**

There will be no reimbursement of expenses for your participation in this study. After each interview is completed, you will receive a \$20.00 Wal-Mart gift card as a token of appreciation for your participation.

### COMPENSATION FOR RESEARCH RELATED INJURY

There are no treatments or substances given to you as part of this study's procedures. This is a study that only involves being interviewed by the researcher. The likelihood of you sustaining any type of physical injury because of your participation is extremely rare. However, if you are physically injured in any way because of your participation in this study, UTMB will provide you with the appropriate medical treatment not covered by your own insurance or healthcare program at no cost to you to the fullest extent permitted by Texas law. You will be responsible for paying any costs related to illnesses and medical events not associated with being in this study. There are no plans to provide other forms of compensation. However, you are not waiving any of your legal rights by participating in this study.

## COSTS OF PARTICIPATION

There will be no cost to you for your participation in this study.

## REASONS FOR THE STUDY INVESTIGATOR TO STOP YOUR PARTICIPATION

You may be dropped from the study by the study investigator if the study is discontinued. If this is the case, Ms. Garza will contact you and explain the situation.

## PROCEDURES FOR WITHDRAWAL

If at any time you wish to stop your participation in this study, simply contact Ms. Garza at the numbers provided at the end of this consent form. Upon learning of your request, your participation will be ended.

## USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

Even though in this interview study no health information is accessed, collected, or used, you must know that all 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 (HIPPA) provides safeguards for privacy, security, and authorized access to your records. These regulations require UTMB to obtain authorization from you if it or anyone employed their attempts to use and disclose your health information. By signing this consent form, you are agreeing to participate in this study. You are not authorizing the use and disclosure of your health information related to this 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 this study's records. However, you do need to know that study records will be coded without your name and be kept confidential as required by law. You will not be identified by name in study records. A code number will be assigned to you and only Ms. Garza will know that number. The key to the code will be kept in a locked file in Ms. Garza's office.

There are no sponsors for this research. Ms. Garza is acting alone, but under the supervision of her dissertation committee chair faculty, Dr. Mendias, to complete her requirements for a doctoral degree. The study data, meaning the contents of your

interview(s), will not be linked to you as an individual. Instead, the data you provide will be put together with data from all other participants and reported that way. You may see or receive a copy of any research reports of findings from this study at its conclusion. Please request those from Ms. Garza.

If you sign this form, you are giving Ms. Garza permission to collect, use and share the information you provide during the interviews. Your health information is not part of this study and you will not be asked about it nor will it be assessed. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. Whether or not you agree to participate in the research project or give us permission to collect, use or share your interview information will not affect the care you will be given at this southwest private family practice or cardiology clinic.

Your interview information, without your name on it, may be reviewed by Dr. Mendias and other committee members for purpose of assisting Ms. Garza to understand the data. If for any reason you want to stop your participation in this study, you can at any time. However, you need to inform Ms. Garza at the contact numbers listed in this consent form. You need to say that you have changed your mind and do not wish to continue participating in this study. At that time and thereafter, Ms. Garza may not collect any additional interview information from you. However, she may use the information that she has already collected. It is important to learn everyone's experiences, not just those of persons who complete the research study. The results of this study may be published in scientific journals and presented as posters without identifying you by name.

## ADDITIONAL INFORMATION

1. If you have any questions before, during or after the study, or if you need to report a research related injury, you should immediately contact Ms. Rosemarie Garza, M.Ed., MSN, RN, at (830) 278-6251 ext. 1428 or, after normal office hours, at (830) 278-2062 or, Dr. Elnora (Nonie) Mendias at (409) 772-8258.

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 the southwest private family practice and cardiology clinics. 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 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 Ms. Rosemarie Garza, M.Ed., MSN, RN, at (830) 278-6251 ext. 1428 or, after normal office hours, at (830) 278-2062 or, Dr. Elnora (Nonie) Mendias at (409) 772-8258. 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

Signature of Authorized Representative

Date

Description of Representative's Authority to Act for Subject (*if applicable*)

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject and/or his/her authorized representatives.

Date

Signature of Person Obtaining Consent

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## VITA

Rose Garza is originally from the Philippines and grew up in a family who emphasized education. Her father, Dr. Virgilio Rivera, was a dentist, and her mother, Marcela, was a school teacher. Rose was educated in Manila. She attended the University of Santo Tomas where she graduated with her Bachelors of Science in Nursing in March of 1976, and after working for two years at the Philippine Heart Center for Asia, she moved to Texas. She met her husband, Steve, while working as an intensive care unit (ICU) nurse at Mission Hospital in Mission, Texas. They were married in 1981 and moved to Galveston where her husband attended medical school at University of Texas Medical Branch at Galveston.

During her husband's school and Family Practice residency years, Rose worked as an ICU nurse at University of Texas Medical Branch John Sealy Hospital and at Memorial Hospital in Corpus Christi, as a thoracic surgery nurse. Her daughter Kimberly Rose was born on the island in Galveston, and daughter Lindsay Marie was born in Corpus Christi. Rose and her family moved to Uvalde, Texas, in 1988 to begin her husband's private practice, and Rose has worked at Uvalde Memorial Hospital since their relocation. She has worn different hats at the hospital, ranging from ICU staff nurse to RN instructor, education director, ICU/Cath lab director, and Evidence-Based Practice nurse specialist.

Rose obtained her first Master's degree in Education at Sul Ross State University in December of 1996. While serving as clinical instructor in the LVN to RN Career Mobility Program of the San Antonio College of Nursing, she earned a Master's degree in Nursing in 2005 from Incarnate Word University in San Antonio, Texas. She was inducted into the Sigma Theta Tau International Honor Society of Nursing and also into the University of Incarnate Word Nursing Honor Society. She began her PhD studies at The University of Texas Medical Branch at Galveston in 2006 while still performing her duties as ICU/Cath Lab director in Uvalde. She has been awarded with the Lois Nickerson Scholarship and the Thelma Hall Doctoral Scholarship while at UTMB. Rose has participated in medical missions in Mexico with her husband. Activities in her community include: church groups, the American Cancer Society, the American Heart Association, and numerous civic groups. She also serves on the Advisory Board of the LVN and RN programs in Uvalde, Texas.

Rose and her husband Steve continue to live in Uvalde, Texas.