

MEXICAN AMERICAN PARENTS' PERCEPTIONS OF  
CULTURAL INFLUENCES ON GRIEVING THE DEATH OF THEIR CHILD

by

Audrey Russell-Kibble

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## DEDICATION

To my sweet Arielle...

...that memories of her continue to inspire

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## ABSTRACT

In this Practice Inquiry, Mexican American parents' perceptions of cultural influences on grieving the death of their child were described. Findings were used to inform a continuing education module for nurses involved in the care of Mexican American parents who have experienced the death of their child. This line of inquiry is important as the needs of grieving Mexican American parents are not always recognized by those providing care.

Ethnographic methodology was used to explore the narratives of three Mexican American fathers and three Mexican American mothers who had experienced the death of their child. A purposive sample was recruited from a faith based community health center in Tucson, AZ. In depth interviews were conducted primarily in the participants' homes by the researcher. All interviews were conducted in Spanish language. Data sources included participant interviews, participant observation, field notes and measures for demographic data and acculturation (ARSMA-II).

The overarching cultural theme that represents the participants' perspectives is *El Dolor de los Padres*: Pain in the Parent. The three major themes that support the overarching cultural theme include: (a) Enduring Great Pain, (b) Voices of Mexican American Parents, and (c) Cultural Death Traditions. The fourth major theme, Going Forward: For the Provider specifically addresses data gathered to educate nurses for supporting Mexican American parents grieving the death of a child. The findings of the study are interpreted within the context of the Mexican cultural concepts of *familismo*,

*machismo, marianismo, fatalismo, spiritualidad, respeto, confianza* and *personalismo* and the concept of vulnerability.

The study's significance for the practice of nursing is upheld in the findings that are specific to understanding and preventing disparities in the care of Mexican American parents who have experienced the death of a child. Increasing nursing knowledge of the cultural context of grieving, especially *spiritualidad* and continuing memories, offering culturally competent nursing interventions at this time of deep emotional pain are elucidated in this Practice Inquiry.

## CHAPTER ONE — INTRODUCTION

The grief of parents facing the death of a child has been described by Knapp (1986) as *beyond endurance*, and these words illustrate the impact of this life event upon a family. The immense difficulties faced by a family in the tragic circumstance of the death of a child are barely understandable. However the difficulties facing a Mexican American family in this circumstance of loss where immigration status, language, and cultural barriers exist is almost inconceivable. Mexican American parents' perceptions of cultural influences on grieving the death of their child were described in this study. In this chapter, the background, statement of the problem, purpose of the study, the specific research questions, and the significance to nursing are described. The cultural concepts of *familismo*, *spiritualidad*, *respeto*, *personalismo*, and *fatalismo* which have been linked to health care practices (de la Torre & Estrada, 2001) are also described. An explanation of the concept of vulnerability as applied to this study of Mexican American parents' perceptions of cultural influences on grieving the death of their child is provided as the conceptual framework that was used to inform the interview questions, participant observations and interpretation of the data. Additionally, three conceptual articles on the cultural perspectives of bereavement in the Mexican American population are summarized.

### Background

Approximately 150,000 infants, children, adolescents and young adults will die in the United States of America this year (The Compassionate Friends [TCF], 2010). The death of a child is experienced by approximately 1 in 5 persons who live in the United

States, if looking at deaths of children at any age and inclusion of spontaneous abortion in the statistic (TCF, 2010). These numbers include members of the Mexican American community. The Mexican American parents' perception of cultural influences on grieving the death of their child was the focus of this exploratory study.

### **The Population**

The Mexican American population is a subgroup of the Hispanic/Latino people living in the United States. Hispanics are the fastest growing minority in the United States, now standing at 16.3% of the total population (United States [U. S.] Census Bureau, 2010), with 64.5% of the total Hispanic population emigrating from Mexico (U.S. Census Bureau, 2005-2009). The Mexican American people may be recognized as a vulnerable population due to their immigrant status, level of acculturation, and/or English language fluency, and as such, have the potential to be susceptible to harm or neglect of their needs (Aday, 2001; de Chesnay, 2008).

The historical colonization of Mexico by European and Anglo-American powers has a continuing effect on the Mexican people (Campesino & Schwartz, 2006; Estrada, 2009). Centuries of outside control and domination of the Mexican American people based on race, ethnicity, social class, language, and immigration status has led to oppression (Campesino & Schwartz). Socioeconomic and health disparities are a reflection of the long-term consequences of oppression of the Mexican American people (Campesino & Schwartz; Estrada).

### Cultural Concepts

Culture refers to the behaviors, beliefs, and practices of a group of people that have been learned and continue to be shared (Zoucha, 2008). The cultural concepts of *familismo*, *spiritualidad*, *respeto*, *personalismo*, and *fatalismo* have been linked to Mexican American health care practices (de la Torre & Estrada, 2001). The influence of culture on the grieving practices of Mexican American families after the death of a child has been examined (Doran & Hansen, 2006) and will be discussed in Chapter Two. Other authors (Clements et al., 2003; Munet-Vilaro, 1998; Oltjenbruns, 1998) support the need for further studies of the influence of culture on the bereavement and grieving practices of the Mexican American people.

Knowledge of core cultural concepts is needed to provide respectful and trusted care to Mexican American parents at the time of bereavement after the death of a child. The cultural concepts of *familismo* (familism), *fatalismo* (fatalism), *respeto* (respect), *confianza* (confidence), *personalismo* (personal relationship), and *spiritualidad* (spirituality) originate from traditional values that are rooted in Aztec, and Spanish/Roman Catholic influences (de la Torre & Estrada, 2001). These cultural concepts impact the health and psychological care of the Mexican American family and how they go about obtaining, or why they may refrain from, seeking help for family distress (de la Torre & Estrada; Zack Ishikawa, Carmedil, & Falmange, 2010).

*Familismo* is the cultural belief that places the needs of the family above those of the individual (de la Torre & Estrada, 2001). The decisions a family makes at the time of the death of a child will be most influenced by the needs of the family as a whole.



Acculturation does not change the importance of this concept to the Mexican American family (Doran & Hansen, 2006). It has been noted that those who are influenced by a high level of *familismo* are not as likely to seek care outside of the family (Zack Ishikawa et al., 2010).

The concept of *fatalismo* (fatalism) is particularly pertinent to the Mexican American people who have a strong belief in destiny and things being the way they are supposed to be. The concept of *fatalismo* among the Mexican American people removes the ability to control their environment or nature. Therefore, *fatalismo* may limit a questioning of the cause of a Mexican American child's death. The belief that everything is in the hands of G-d contributes to the resiliency and acceptance of the death of the child in Mexican American families.

The cultural concepts of *respeto*, *confianza*, and *personalismo* underpin Mexican Americans' expectation of a personal relationship with their nurse or other health care provider that demonstrates respect and engenders confidence. A nurse or other health care provider who knows the rules of respect in the culture will create confidence that cannot otherwise be obtained. Some of these rules include acknowledgement of the status of individuals in the family (Zack Ishikawa et al., 2010). It is imperative to greet the father of the family first, with an outstretched hand and to state one's name at the same time, and to express pleasure in meeting him. The same is extended to the rest of the family in turn, mother and children. If grandparents are present, the grandfather or patriarch of the family would be greeted first. Courteous listening confers *dignidad* (dignity), *respeto* (respect), *confianza* (confidence), and *personalismo* (sense of a

personal relationship). Physical touch is required and part of the communication of respect. Upon being told of the death of a child by the bereaved, it is respectful, and expected, that the provider of care will reach out and touch them. It is disrespectful not to do so (Clements et al., 2003). *Confianza* will also be generated by a nurse or other health care provider sharing a bit about their personal beliefs about death and bereavement (Munet-Vilaro, 1998).

The cultural concept of *spiritualidad* (spirituality) is deeply rooted in cultural concepts that are aligned with religiosity and traditionalism. The central supposition, with regards to the practice of spirituality, is the cultural/historical origin of religiosity in the Mexican American community that is rooted in Aztec culture and the Spanish influence of Roman Catholicism (de la Torre & Estrada, 2001; Doran & Hansen, 2006; Estrada, 2009; Munet-Vilaro, 1998). In pre-Hispanic cultures, life and death were perceived as opposite but complementary parts of a life cycle (Munet-Vilaro). The belief that death exists as an extension of life is reflected today in the value placed upon a continuing bond with the child who has died (Doran & Hansen; Munet-Vilaro). The cultural concept of *spiritualidad*, together with a continuing relationship with the deceased may have the most potential to contribute to a diminution of grief in Mexican American parents who have experienced the death of a child. Spirituality and religiosity are cultural concepts impacting the social relationship of Mexican American families within the community. Social support is derived from religiosity and positive interactions within the social network of the community of the Roman Catholic Church (Clements et al., 2003).

### Statement of the Problem

The influence of culture on the grief of Mexican American parents who have experienced the death of a child is important for health care professionals to understand in order to provide culturally sensitive care to this population (Clements et al., 2003; Burk, Weiser & Keegan, 1995; Zoucha, 2008). The problem of health care professionals who are uninformed of the cultural influences on grief is significant because of the number of families, one in five, who suffer the death of a child (TCF, 2010) and the rapidly expanding Mexican American population (U.S. Census Bureau, 2010; Falcon, Aguirre-Molina, & Molina, 2001). Of greatest concern is the need for providing culturally competent care (AAN, 2010) to Mexican American parents who have experienced the death of a child. Cultural competence “implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented” by Mexican American parents who have experienced the death of a child (AAN, 2010, p. 24). The meaning and significance of the cultural concepts of family (*familismo*) which is a strong developmental resource, fatalism (*fatalismo*), respect (*respeto*), a sense of personal relationship (*personalismo*), and their spiritual beliefs (*spiritualidad*), are fundamental to understanding the context in which the grief of Mexican American parents is expressed (Clements et al.; Burk et al.).

The concepts of *spiritualidad* and *familismo* strongly influence beliefs and practices related to grieving in the Mexican American culture. Beliefs about death are anchored in pre-historic Mexican culture that emphasizes maintaining a continued bond between the living and the dead (Munet-Vilaro, 1998). In this context grief is seen as an

emotional as well as a physical process (Oltjenbruns, 1998). *Spiritualidad* affects health, longevity, the sense of well-being during illness, recovery from trauma, and bereavement (Campesino & Schwartz, 2006). A state of bereavement and situational depression is understandable in parents grieving the death of a child. However, in the Mexican American culture there is a belief of a continued connection between physical and spiritual realms (Lawson, 1990). Experiencing the presence of the deceased is embedded in the Mexican cultural way of life (Shapiro, 1995). The concept of *personalismo* characterizes the warmth and closeness of relationships, both personal and in connection with a spiritual belief system (Campesino & Schwartz; de la Torre & Estrada, 2001). *Personalismo* is at the core of the concept of *spiritualidad*. Cultural influences on grief may alleviate a lot of the distress involved in the bereavement of Mexican American families who have experienced the death of a child (Clements et al., 2003; Doran & Hansen, 2006; Fierro, 1980; Munet-Vilaro; Oltjenbruns). It is important to recognize specific cultural concepts in the spiritual belief system of the Mexican American population and the relevance of knowledge of those concepts in the provision of culturally competent care (AAN, 2010) following the death of a child. Mexican American parents who have experienced the death of a child are likely to be a part of the population of Latino men, Latinos of lower socioeconomic status, and immigrant Latinos that have been noted to especially refrain from seeking mental health services (Zack Ishikawa et al., 2010) that have the potential to be supportive during the time of bereavement.

The juxtaposition of Mexican cultural influences on grief with the prevailing practice model that recommends detachment from the deceased (Bowlby, 1980),

demonstrates a cultural incongruence of world views that inform clinical practice. A number of factors, including cultural values (Clements et al., 2003; Doran & Hansen, 2006; Munet-Vilaro, 1998; Oltjenbruns, 1998), have been suggested as important influences on the bereavement of Mexican American parents grieving the death of a child.

### **Statement of Purpose of the Study**

The purpose of this study was twofold: (1) to describe Mexican American parents' perceptions of cultural influences on grieving the death of their child; and (2) to use the findings to inform a continuing education module for nurses involved in the care of Mexican American parents who have experienced the death of a child.

### **Research Questions**

The research questions that guided this study were:

- 1) What are Mexican American parents' perceptions of cultural influences on grieving the death of their child?
- 2) What in the cultural experience of parents' grieving can guide nurses to deliver culturally sensitive care to Mexican American parents who have experienced the death of a child?

### **Significance of the Study to Nursing**

This study is significant to nursing because knowledge of the grieving practices of Mexican American parents who have experienced the death of a child will inform nurses of the cultural influences on grieving and the development of culturally competent (AAN, 2001) interventions. This study was born out of a clinical observation of the lack of

knowledge in nurses and other health care providers, who were caring for Mexican American parents grieving the death of a child and, of the relevance of culturally sensitive interventions for this vulnerable population.

There is an immediate need for nurses and other health care providers to be knowledgeable about the cultural influences on grief, if they are to provide culturally sensitive care. Nurses and other health care providers that are not knowledgeable about cultural influences on grief may be perceived by their Mexican American patients as disrespectful (Clements et al., 2003; Lawson, 1990; Munet-Vilaro, 1998). In addition, Mexican American patients have reported a lack of confidence in their providers who don't demonstrate cultural sensitivity in their practice (Munet-Vilaro; Zack Ishikawa, 2010). A potential solution is educating nurses and other health care providers about the cultural concepts that underpin bereavement in Mexican American parents who have experienced the death of a child. This study was conducted with the intention of researching and then providing information to inform a continuing education module specifically for nursing, with knowledge of the need to disseminate this awareness also to the fields of medicine, social work, and other health care professions.

Knowledge of the cultural concepts of *familismo*, *fatalismo*, *respeto*, *personalismo*, and *spiritualidad* is essential to providing culturally sensitive nursing care to Mexican American parents who have experienced and are grieving the death of a child (Clements et al., 2003; Lawson, 1990; Munet-Vilaro, 1998). Nurses who are knowledgeable about *familismo* will assess family member's reliance on each other when caring for grieving Mexican American families. Nurses knowledgeable of the cultural

concept of *fatalismo* will have a cultural context for interpreting a family member's behavior when that individual does not overtly express grief after a death from cancer (Munet-Vilaro). Knowledge of the cultural concepts of *respeto* and *personalismo* will inform nurses who care for Mexican American families in the use of formal language, courteous behavior, politeness, and appropriateness of physical touch (Clements et al.). Knowledge of *spiritualidad*, the cultural concept of death as an extension of life, and a continuing bond with the deceased child is imperative to engender confidence and real compassion in the care of bereaved Mexican American parents (Munet-Vilaro).

### **Impact of Bereavement on Health**

The health outcomes associated with bereavement are outlined in a systematic review of studies conducted in the United States and Europe (Stroebe, Schut & Stroebe, 2007). The review summarized risk factors that were identified as increasing vulnerability for mental and physical health. One finding was that while many people adjust to the death of a loved one after a period of time, for others their health and mortality are affected. For example, bereaved family members may exhibit an array of health issues from headaches, dizziness, and chest pain to increased rates of disability, increases in use of medical services, and increased drug abuse (Stroebe et al.).

### **Conceptual Framework: The Concept of Vulnerability**

Vulnerability is a valuable concept in the social science research of populations deemed to be susceptible to harm or neglect (Aday, 2001; de Chesnay, 2008; Delor & Hubert, 2000; Spiers, 2000). Vulnerable populations have been defined as “at risk of poor physical, psychological, or social health” (Aday, 2001, p. 2). The concept of vulnerability

is applicable to the current study because Mexican American parents grieving the death of a child are susceptible to the spiritual, emotional and/or physical consequences of bereavement. This study was built upon preliminary reviews of the literature conducted by the researcher on the concept of vulnerability in the context of Mexican American families grieving the death of a child (Russell-Kibble, 2009a, 2009c, 2009d).

Assessment of vulnerability is important at the individual as well as community level. This view point is explored in the review of the concepts of health status, relative risk, and resource availability (Aday, 2001). The variable definitions of health, as well as health status, require applicability to the individual and the community (Aday). Relative risk can be accounted for by the “differential vulnerability hypothesis” that proposes variability in effects of negative life events on individuals (Aday, 2001, p. 4). The availability of resources for a population affects both the individual and the community (Aday). Predictors of risk are seen in determinants of social status as well as in measures of social capital and human capital (Aday).

Individual vulnerability differs from that of a vulnerable population (de Chesnay, 2008). Spiers (2000) proposes the perspective of vulnerability be viewed from the externally imposed rules of society and from individual experience. This suggestion specifically notes the importance of knowing which factors create risk while recognizing health as a lived experience (Spiers). Difficulties have arisen regarding application of the concept of vulnerability to real populations (Delor & Hubert, 2000). Delor and Hubert specifically discuss the need to look at the social context in which vulnerability presents itself. Purdy (2004) suggests the essence of vulnerability as one of being “open” to



circumstances that may help or hinder, and similarly, Michaels and Moffett (2008) explain the concept of vulnerability using the words “openness” and fluctuation.

Although there are a number of assumptions that have been suggested as important to the concept of vulnerability, susceptibility appears as a common thread (Aday, 2001; de Chesnay; Delor & Hubert; Purdy; Spiers). Recognition of the vulnerability of a community versus the specific propensity of an individual to be at risk or resilient is generally acknowledged (Aday; de Chesnay; Delor & Hubert; Spiers).

### **Susceptibility**

Susceptibility is defined as “the capability of being affected” (Barnhart & Barnhart, 1990, p. 2112). The immigrant status (Aday, 2001) and level of acculturation (Carter-Pokras & Zambrana, 2001) of Mexican American parents who have experienced the death of a child are indicators of potential susceptibility to stressors. Other potential indicators of susceptibility to stressors for this vulnerable population include socioeconomic status and the amount of family support available. Relative risk is identified with regards to psychological trauma, which in turn affects the health and health status of the Mexican American parents experiencing bereavement after the death of a child.

### **Spiritual Vulnerability**

Spiritual vulnerability in Mexican American immigrants is supported in the literature (Campesino & Schwartz, 2006). Cultural concepts, linked historically to spiritual vulnerability, include *personalismo* (personal relationship), *fatalismo* (fatalism), and *familismo* (familism). The blending, of cultural concepts from Aztec and Roman

Catholic influences, contributes to the spiritual belief of life and death as complementary components in the circle of life (de la Torre & Estrada, 2001; Doran & Hansen, 2006; Estrada, 2009; Munet-Vilaro, 1998). This belief is further reflected in a desire for continuing bonds with the deceased child (Doran & Hansen; Munet-Vilaro; Shapiro, 1995). *Personalismo* implies a personal relationship with G-d, reflected in an acceptance of the consequences of life because of a natural spiritual interdependence (Campesino & Schwartz). This consequence is also dictated by *fatalismo*, the belief that things happen the way they were meant to happen: G-d's will (Lawson, 1990). Spirituality is influenced by *familismo*. Experiences of faith are embedded in family relationships (Campesino & Schwartz). Interference in the ability of Mexican American parents to access cultural components of their faith for grieving the death of their child has the potential to create spiritual suffering.

### **Emotional Vulnerability**

Emotional vulnerability is closely aligned with mental distress and disorders seen during times of stress, such as panic, anxiety, or consequences of bereavement, such as loneliness and insomnia (Stroebe, Schut & Stroebe, 2007). Grief is defined as an emotional response to bereavement (Stroebe et al.). Depression is understandable in times of bereavement. The expression of grief by crying openly is considered an appropriate emotional response in Mexican American individuals, and even fainting is not unusual for the women (Clements et al., 2003). Oltjenbruns (1998) reported a greater intensity of grief among Mexican Americans upon learning of a sudden death, but noted a muted reaction to an expected death, such as in a diagnosis of cancer. This paradox can place

bereaved Mexican American parents at risk of being inappropriately diagnosed as evidencing complicated grief (Oltjenbruns). The belief that a diagnosis of cancer is a death sentence specifically elicits anticipatory grief since the tendency is to initiate the grieving process at diagnosis (Munet-Vilaro, 1998). Mexican American parents grieving the death of a child will most likely turn to their nuclear and/or extended family for emotional support in the tradition of *familismo* (Clements et al.).

### **Physical Vulnerability**

The concept of a vulnerable population or individual to physical disarray conveys the notion of the importance of one's temporal life. There is an increased risk of mortality associated with bereavement (Stroebe et al., 2007). Additionally, a long list of physical symptoms is associated with bereavement, including: headaches, dizziness, indigestion, chest pain, and hypertension (Stroebe et al.). Bereavement is also a predictor of heart attack and cancer (Stroebe et al.). Grief can be associated with symptoms that affect work or activities of daily living, such as difficulty concentrating (Stroebe et al.). The Mexican American notions of health are based on a belief in the validity of both folk medicine and evidence based medical practice (Lawson, 1990). Oltjenbruns (1998) found a high level of somatization among Mexican Americans experiencing bereavement and describes grief as both an emotional and physical process. This interconnectedness may be significant.

### **Implications of Linguistic and Narrative Exploration**

Language is crucial to an understanding of the expression of grief in a culture (Lawson, 1990; Russell-Kibble, 2009a, 2009b). One of the clues to the emotional

vulnerability of the Mexican American parents grieving the death of a child may lie in the linguistic analysis of words they use to describe and express grief. In addition to words that correlate with those found in the English language that describe grief, some Spanish words have meanings which literally translate into words not seen in the English language of grief, except perhaps from a distance: One of the words for grief in Spanish, *la pena*, can be literally translated to mean shame or embarrassment or to imply a penalty (Castillo & Bond, 1987; Marr, 2001). In English we often say, “What a shame.” It is in this same sense that the word *la pena* is used in Spanish, but it is also used to denote grief, sadness and worry. The people say, *me callo un gran pena*, a great grief has befallen me. The thought that parents would connect grief with shame and penalty raises concerns of susceptibility and unintentional self labeling in the Spanish language of grief. Aday (2001) emphasizes the importance of the recognition of a state of vulnerability and the problems inherent in labeling a population.

### **Interconnectedness of Vulnerabilities**

The Mexican American parent grieving the death of a child may experience interconnectedness or blurring of the spiritual, emotional and physical consequences of bereavement (Russell-Kibble, 2009a) (Figure 1). The Mexican American cultural mandate to offer an embrace or touch the arm of one who is grieving demonstrates respect for the bereaved (Clements et al., 2003) and fits within the context of physical vulnerability, but it is also tied to the realm of spiritual vulnerability, given its importance in the culture, and if ignored demonstrates disrespect. The current bereavement model that espouses the expectation of detachment from the deceased is at odds with the

Mexican American cultural concept of spirituality (Shapiro, 1995) and has the potential to create emotional turmoil and suffering.

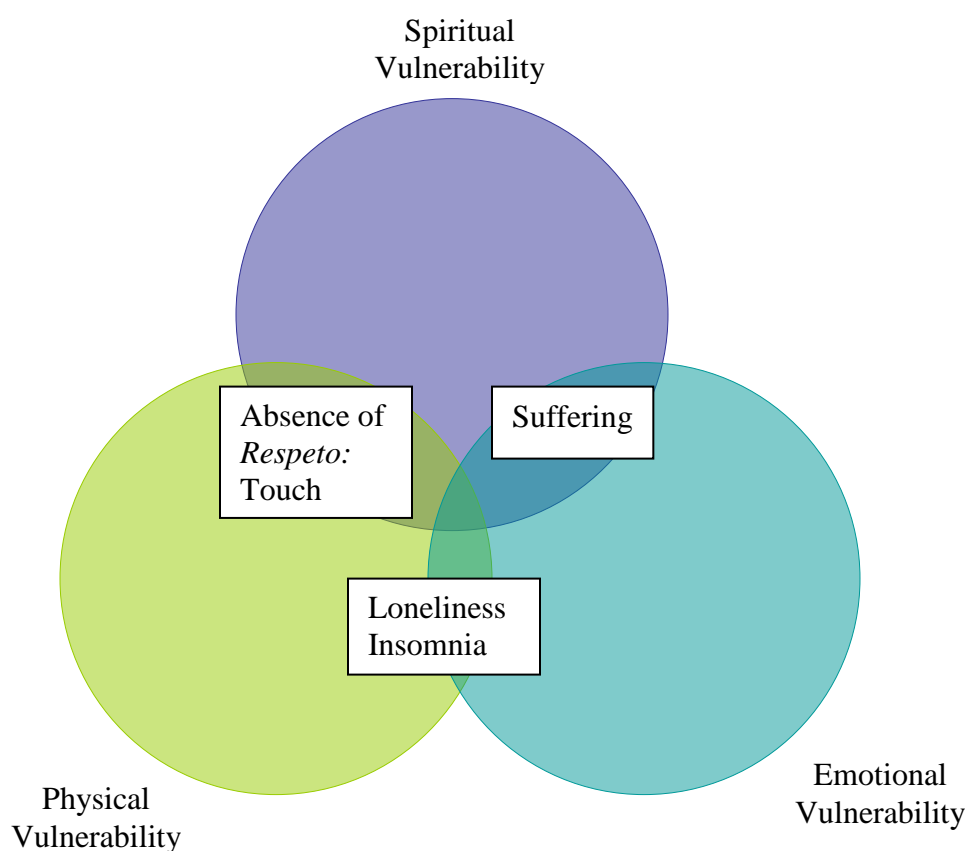


FIGURE 1. Conceptual Schema of the Interconnectedness of Vulnerabilities (Russell-Kibble, 2009a)

### **Literature Relating to Cultural Perspectives of Bereavement**

Three conceptual articles on the cultural perspectives of bereavement in the Mexican American population are summarized.

Clements et al. (2003) discuss the role of culture in the experience of grief and mourning in a conceptual article describing the grieving process for Latinos, African Americans, Native Americans, as well as the rituals of Judaism and Hinduism. The

authors assert the assessment of a response to grief needs to be performed with sensitivity for one's cultural heritage. Nurses can learn to demonstrate respect for families who are honoring deceased loved ones. Consideration of the customs surrounding death and grieving were explained for several ethnicities, including the Latino culture. The level of acculturation of the family is one factor identified in the article as determining in which rituals the family will participate.

The Mexican cultural concept of *respeto* (respect) is important to the grieving Latino family, with the hierarchy of status in the family "ordered from oldest to youngest and from men to women" (Clements et al., 2003, p. 21). Addressing the families formally demonstrates respect. One of the most salient points made in this article is that "human touch demonstrates respect" to the family that is grieving and is vital to include when a health care provider is offering support (Clements et al., p. 21).

Grief is expressed openly by the women in the family (Clements et al., 2003, p. 21). Men are expected to maintain the cultural role of *machismo* that implies their role in responsibility to protect the family (de la Torre & Estrada, 2001, p. 130). This may also make it more difficult for the men to cry or emote (Aros, Buckingham, & Rodriguez, 1999, p. 87). Other culturally bound traditions are rooted in religiosity and spirituality, and grounded in the practice of Catholicism. A connection with the deceased is demonstrative of the belief in continuity between life and death and is practiced through prayer and visitations to the grave. The immediate family is the major source of support for grieving parents, followed by the extended family, friends, and the church (Clements et al., p. 21).

Lawson's (1990) conceptual article offers synopses of cultural characteristics as they relate to death and dying of children in three populations, one of which is the Mexican American community. This conceptual article offers an assessment of the cultural influences on how the members of families grieve, to include: (a) the meaning of a death, which is especially important when the deceased is a child, (b) customs surrounding death, (c) patterns and roles in a family, and (d) expectations of health professionals during this time of death and bereavement.

Lawson defines Mexican Americans as a people who migrated from Mexico and their descendants, with most having learned Spanish as their first language. Family life focuses on the children as an essential part of the family; therefore the death of a child represents a loss of expectations for the future. The structure of the family is identified as patriarchal, with the father being the decision maker and the mother the director of the affairs of the home. Religion, specifically Roman Catholicism, guides the practices that are required such as the praying of the rosary. Belief in both folk medicine and modern medicine enables the family to seek care from both when their equilibrium is disrupted by emotional turmoil, such as during a time of grieving after the experience of the death of a child. Barriers to trust in the medical health care system may be difficult when immigration status, language translation, and literacy obstruct the care that is sought by Mexican American parents who have experienced the death of a child.

Shapiro (1995) offers an integrative theory of family development model that suggests that while Latino families may be from different cultures, their approach to death and grief, in a socio cultural context, can enhance the outcomes of family

bereavement. Shapiro is a psychologist at the University of Massachusetts at Boston, and has written extensively on *grief as a family process*, and has written a book by that title. The tenets of the model include: (a) focusing upon the family as a developmental resource, (b) appreciating the spirituality and psychological continuity between the bereaved and their deceased loved one, and (c) a recognition of continuing bonds and relationship with the deceased. The goal of this bereavement model is an optimal shared understanding for the family, in the past, as well as the present and future.

A prevailing bereavement model in which the goal is detachment is problematic for the Latino family who commonly experiences the presence of the deceased. Recognition of an intergenerational family life cycle in a cultural and historical context is an effective means of comprehending the process through which a Latino family proceeds as it grieves the death of a family member. The social development model recognizes the limitations placed upon Latino families. These systematic limitations and risks include poverty, community violence, deficient urban schools, limited access to health care and mental health care, as well as racism. Conflicts arise as members of the family acculturate at different rates, especially between the generations. A family developmental model emphasizing the social and cultural context of an individual's life looks at the enhancement seen in retaining cultural diversity without minimizing the injustices which are often a burden to their stability within their adopted community.

Recognition of the remarkable strength of the Latino family for coping with bereavement issues in spite of social stress, and inadequate social resources is noted. The death of a family member reveals the cultural arrangements of a society and people. The



Latino people are a diverse culture, but share broadly diverse assumptions about the importance of family, spirituality, and the importance of continuing bonds with a deceased family member.

### **Summary**

Chapter One provided the background for the study of Mexican American parents' perceptions of cultural influences on grieving the death of a child. The statement of the problem, purpose of the study, research questions and the significance of the study to nursing, were presented. The cultural concepts of *familismo*, *spiritualidad*, *respeto*, *personalismo*, and *fatalismo* which have been linked to health care practices (de la Torre & Estrada, 2001) were discussed with regards to the purpose of the study and its significance to nursing. Chapter One also presented a description of the concept of vulnerability and its relevance to the study. Three conceptual articles were summarized that describe cultural influences on grief in the Mexican American population (Clements et al., 2003; Lawson, 1990), including Shapiro's (1995) article about the cultural context of grief in Latino families.

## **CHAPTER TWO — REVIEW OF THE LITERATURE**

Chapter Two consists of a review of the literature on Mexican American parents' perceptions of cultural influences on grieving the death of a child. Three articles specific to the topic are summarized.

### **Search of the Literature**

A focused literature search on Mexican American parents' perceptions of cultural influences on grieving the death of a child was approached by first performing a search at the Arizona Health Science Library (AHSL). Evidence Based Medicine (EBM) was used for the search, which reveals the clinical EBM search engines where General EBM Search was selected. Selected terms of "Mexican American" and "grief" produced eight articles in the Pub Med search engine. One of these eight articles, written within the last five years and specific to the topic of this study, was written by Doran and Hansen (2006). Two additional articles were published in 1998 and contribute to the background of the topic of interest. These were written by Munet-Vilaro (1998) and Oltjenbruns (1998). The Oltjenbruns (1998) article is also found in a search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), using the same words, "Mexican American" and "grief." The Oltjenbruns (1998) article was one of three articles found in the CINAHL search, but the only one that is specific to the topic. The Doran and Hansen (2006), Munet-Vilaro (1998) and Oltjenbruns (1998) articles are summarized below.

### **Review of the Literature**

Doran and Hansen (2006) conducted an ethnographic, collective case study of Mexican American families grieving the death of a child. The Doran and Hansen (2006)

study bears a close alignment with the current study with regards to population of interest and topic. The research questions were clear and substantiated. The primary purpose of Doran and Hansen's study was to provide descriptive information about the process of grief in Mexican American families after the death of a child. The secondary focus was to explore the ways families sustain a bond with the deceased child (Doran & Hansen, 2006). The gaps in the literature were identified by the authors as little being known about the individual and family experience of grief for Mexican Americans (Oltjenbruns, 1998) and the identification of one master's thesis, written in 1992, that focused on the bereavement experience of Mexican American mothers after the death of a child. A purposeful sampling was used. Inclusion criteria were: (a) the deceased child to be under the age of 14 at the time of death, (b) the death of the child occurred at least two years prior to the study, which allowed time for the family grief process to mature, (c) Catholic religion, (d) the deceased was not an only child, and (e) where the cause of death was not suicide. Interviews were completed with three Mexican American families who were grieving the death of their child. The mothers were interviewed, as well as members of the family such as children and grandparents. The researchers asked each family to also designate ancillary contacts to interview. This resulted in interviews with a priest, a school principal and a teacher. The interviews were accomplished individually and in groups totaling 13 participants, representing nine family members including bereaved siblings over the age of six and four ancillary contacts. The participant interview consisted of 33 semi-structured questions that were based on what was known about Mexican American grief from a search of the literature as well as information gathered

from a qualitative study of European American families after the death of a family member. Since the interview questions worked well with the first family interviewed, no modifications were made to the participant interview guide, and that family was included in the study. The children's interviews included the evaluation of drawings of their family and deceased sibling.

A qualitative data management software system, the Qualitative Solutions and Research Non-numerical Unstructured Data-Indexing, Searching, and Theorizing (QSR-NUD\*IST, 1997, Version 4) was used to manage transcripts and records. Data analysis generated themes, regarding the grief of Mexican American families after the death of a child. The themes were extracted by the first author and audited by the second author and five psychologists. The grant team included one individual of Mexican American descent and another individual who demonstrated fluency in the Spanish language. Written transcripts were provided to the participants for their confirmation of the results.

The findings revealed the importance of maintaining a bond with the deceased child through various means: These are listed as: (a) dreams, (b) storytelling, (c) keepsakes, (d) a sense of the presence of the deceased child, (e) faith based connections, (f) proximity connections, (g) ongoing rituals, and (h) pictorial remembrances. Cultural influences on the grief of the Mexican American families after the death of a child are evident in the concept of *familismo* (familism) being described and applied to the participants. The authors found that the Mexican American community was important to families grieving the death of their child.

Oltjenbruns (1998) accomplished a quantitative study comparing college students' responses using the Grief Experience Inventory (GEI). The responses of Mexican American college students were compared to those of Anglo American college students. Inclusion criteria were having experienced the death of an individual who was considered close to them, and within the two years prior to the study. The primary purpose of the study was to explore the personal response to grief within the context of culture. A secondary purpose was to ascertain whether there was a difference noted between ethnicity and gender with regards to bereavement. To provide information for grief counselors and others in the health care community regarding the variability of grief response was a further aim. The author noted little attention has been given to the importance of culture and ethnicity when studying the response to grief. The author further reported a significant difference in the displays of grief in Mexican Americans who are grieving a sudden death as opposed to those who are grieving an expected death.

The investigator sent letters of explanation of the study to a random sample of 630 Anglo American students at a Midwestern state university and to the 519 Hispanic students of that same school. The invitation specifically asked for students to meet the study criteria of: (a) self identify as Anglo or Mexican American, (b) experienced the death of someone close within the previous two years, and (3) 17 to 27 years of age. The study sample included Mexican American (N=39) and Anglo American (N=61) college students. The groups had a mean age of 19.8 years of age. The majority of both groups were represented by women: Mexican American (79.5%) versus Anglo American

(67.2%). Measures included a demographic data sheet, an acculturation scale, and the GEI.

Comparisons of the groups' scores on the GEI were analyzed using a multivariate analysis of variance (MANOVA). The results revealed significant increases in the Loss of Control and Somatization scales for Mexican American college students grieving the loss of someone close to them. The Mexican American students reported that they were more likely to cry in public and to somaticize their reactions to stress. The differences in the GEI in consideration of gender were not specific to the Mexican American population but rather to the women participants in general. The conclusion emphasized the importance for counselors to have knowledge of the differences in "norms, expectations, values, communication styles, and behavioral patterns that distinguish various ethnic or cultural groups" (Oltjenbruns, 1998, p. 152). A complicated grief reaction may be amplified if proper support and understanding of the experience is not recognized. The author suggests the need for further studies with regards to the manifestations of grief in ethnic minorities by providers of both physical and mental health.

### **Critical Synthesis of the Research Articles**

The qualitative research article by Doran and Hansen (2006) and the quantitative research accomplished by Oltjenbruns (1998) both focused on exploring the grief of the Mexican American population within the context of their culture after the loss of someone close to them. Doran and Hansen specifically focused on the process of grief in Mexican American families after the death of a child. They also sought information regarding the way that families sustain a bond with the deceased after the death of a

child. Oltjenbruns (1998) looked at the differences between ethnicity and gender as the secondary purpose of the study.

Doran and Hansen (2006) and Oltjenbruns (1998) called for further research to be done, both qualitative and quantitative, to expand upon their initial findings involving insight into cultural influences on bereavement in the Mexican American population. Doran and Hansen (2006) called for employing a more heterogeneous sampling than they employed, since they mainly interviewed mothers. Oltjenbruns (1998) specifically called for qualitative studies to be done regarding grief responses with specific attention to within group differences.

The Doran and Hansen (2006) and Oltjenbruns (1998) articles specifically support the importance of the study this researcher has accomplished. One specific purpose of this study, to guide nurses and other health care providers in providing culturally sensitive care to Mexican American parents after the death of a child, is supported by the call for further research.

### **Review of a Descriptive Article**

Munet-Vilaro (1998) describes the grieving and death rituals of Island Puerto Ricans and Mexican immigrants in a conceptual article. This descriptive article included a review of the literature and was informed by the clinical experience of the author. A key point made by the author is that Latino culture originates from such diverse locales as Mexico, Central and South America, as well as the Caribbean. In pre-Hispanic culture, life and death were recognized as parts of a continuing life cycle. Mexican culture still allows for a belief in death as an extension of life. This belief is reflected in the value

placed upon a continuing bond between those still living and those who have died. Death is an expected life event. The interrelatedness of life and death also extends to issues affecting health care but Mexican American patients do not often share those views with health care practitioners. A prevailing shared belief among Mexican Americans is that cancer is a death sentence. Although this is seen as a fatalistic point of view, the belief influences an early initiation of grieving, leading to anticipatory grief that mediates the intensity of grief and recovery after the death of a loved one.

Rituals incorporating the belief in death as an extension of life include: *El Dia de los Muertos* (Day of the Dead) celebration and the *Novena* (nine days of mourning after a death). Details of these rituals are described in the article.

Munet-Vilaro (1998) proposes an assessment of the appropriateness of the responses to death that are seen in Latino patients as important in terms of knowledge of four key cultural guidelines: (a) Latinos originate from many different countries with unique cultural backgrounds, therefore, it is important to be cautious in generalizing knowledge of a culture of grieving, (b) extended family members, if available, can be valuable sources of information when cultural competence is sought, (c) the provider of health care who can share personal beliefs about grieving and death in an informal, nonjudgmental way, will engender trust from a bereaved family, and (d) if not fluent in the Spanish language, the use of a trained translator is recommended so that accuracy of information can be assured.



### **Summary**

Chapter Two presented a review of the literature summarizing what is currently published on Mexican American's perceptions of cultural influences on grieving the death of someone close to them.

### **CHAPTER THREE — METHODOLOGY**

Chapter Three describes the ethnographic methodology that was used in a study of Mexican American parents' perceptions of cultural influences on grieving the death of their child. The protection of human subjects, inclusion criteria, recruitment, data collection and procedures for analysis will be discussed. The criteria for trustworthiness in a qualitative study are detailed and the researcher's assumptions are stated.

#### **Ethnography**

Qualitative methodology typically utilizes the collection of subjective data from persons, groups or cultures in ways that are grounded in compassion and caring, for the precise purpose of understanding (Munhall, 2007, p. xv). The question being asked is what determines the methodology for study with vulnerable populations and not whether there is an advantage of one method over another (de Chesnay, Murphy, Harrison, & Taulii, 2008). Ethnography is a method of describing and interpreting a culture of interest (Hammersley & Atkinson, 2007; Wolf, 2007). The selection of ethnographic methodology was appropriate to discover and describe Mexican American parents' perceptions of cultural influences on grieving the death of their child. The use of ethnographic methodology was appropriate to the question that was posed because the question was one in a quest of discovery, description, and interpretation. The "thick description" (Geertz, 1973, p. 6) of cultural influences sufficient to pose recognition of an experience by members of a culture is one of the hallmarks of ethnographic methodology (Lincoln & Guba, 1985).

Ethnographic methodology is comprised of a systemic but naturalistic, qualitative inquiry that provides a means of exploring and understanding the emic, or insider's view of a culture (Hammersley & Atkinson, 2007; Schwandt, 2007). The trademark of cultural anthropology, ethnography, has been adopted by many who conduct nursing research from a qualitative perspective (Hammersley & Atkinson; Prasad, 2005; Spradley, 1979). The features of ethnographic study include: (a) accounts of actions and everyday events in peoples' lives rather than a condition created by a researcher, (b) data that are collected from a variety of sources including documents, interviews, informal conversation, and participant observation, (c) informal and unstructured data collection methods, (d) an in-depth study of a few participants, and (e) ongoing analysis (an iterative approach) that consists of interpreting "the meanings, functions, and consequences" of the actions of the population of study (Hammersley & Atkinson, 2007, p. 3).

The emic view of a phenomenon of interest brings meaning and explanation of that culture to others who can use the information. Key practices in the ethnographic tradition include: prolonged contact in the field, avoiding cultural blindness, using a multiplicity of cultural voices, and writing persuasively, while recognizing institutional constraints on one's writing (Prasad, 2005). For nursing, ethnography is a credible and caring methodology for understanding the influence of culture on a phenomenon of interest.

The researcher used an ethnographic study to explore and describe Mexican American parents' perceptions of cultural influences on grieving the death of their child. The study is described in this chapter.

## **Procedure for Protection of Human Subjects**

### **Protection of Rights**

Protection of the rights of Mexican American parents who have experienced the death of their child was assured by obtaining Institutional Review Board (IRB) approval and following the mandates of the guidelines set forth by that process. Some of the specific issues encountered in this study included awareness of cultural sensitivity and language translation. Mindfulness and thoughtfulness were paramount with regards to the need to demonstrate respect to this population. Consideration must be given to the values, terminology and attitudes of the persons of interest (Murdaugh, Russell, & Sowell, 2000) and the researcher adhered to this.

IRB approval with a plan for cultural consideration for the Mexican American parents who have experienced the death of their child was obtained from The University of Arizona. As far as was possible, all known cultural factors were explained and potential problems accounted for. The IRB has a process for follow-up with any unanticipated problems, and in fact requires report should those occur. Potential language barriers encountered in the conduct of the study, and translation of interview transcripts were addressed. The researcher, who conducted participant interviews, is fluent in Spanish, having grown up on the Arizona-Sonora, Mexico border and also having been raised in a home with one Mexican American parent. The use of a bilingual transcriptionist to translate interview transcripts into English from Spanish was the first step in the use of Brislin's translation/back-translation model for cross-cultural research (Jones, Lee, Philips, Zhang, & Jaceldo, 2001). The second step in the translation process

was accomplished by a second expert blindly translating the document back from the translated version into the original text. Finally, comparisons were made for errors of translation and translation quality, until cultural equivalence and functional equivalence were achieved (Brislin, 1970; Jones et al.).

### **Informed Consent**

The potential for disparities in obtaining informed consent from research participants of vulnerable populations must be anticipated, minimized and accounted for. The process of obtaining informed consent from Mexican American parents who had experienced the death of their child was completed mindfully, taking into consideration the potential for barriers related to culture, language, and/or literacy. Potential participants who acknowledged illiteracy or difficulty reading required additional explanation of the study. Therefore, the consent and the demographic data form were read to those who verbalized difficulty reading. A copy of the consent form was given to each participant. Because the researcher is a Family Nurse Practitioner at the Clinic in which the participants were recruited, to minimize potential for coercion, participants were recruited from other providers and not from the patient population established with the researcher.

The researcher was the only person consenting potential participants. The informed consent was available in both English and Spanish (Appendix A). The researcher clearly articulated that the parents could withdraw from the study at any time with no consequences to their care at St. Elizabeth's Health Center (St. E's). The

researcher verbally assured the potential participants that their care at St. E's would in no way be affected by agreeing or dissenting to be a part of the study.

### **Criteria for Participant Selection**

Mexican origin parents grieving the death of their child were invited to be a part of this ethnographic study. The inclusion criteria were: (a) Mexican origin parents, 18 years of age and older, who had experienced the death of a child; (b) that occurred when the child was an infant through 25 years of age; (c) the child was living in the parent's home at the time of the death; (d) the child's death was at least two years prior to the study; (e) the parent receives health care at St. Elizabeth's Health Center in Tucson, AZ. No upper limit was placed on the time since the death because there is support in the literature to demonstrate that the grief of losing a child continues many years after the event (Lauterbach, 2007).

The inclusion of young adults and older teens that have died in the study is supported by Wright (1994), who notes that parents suffer the greatest bereavement in the death of a child who is in their late teen years. An evolutionary psychological view of the physical and cultural influences on people reveals the enormity of parental grief during the child's adolescent and early adulthood is attributed to: (a) the child is at maximum potential for their life's possibilities; (b) their personalities are well developed; and (c) their future is able to be discerned in a concrete way (Wright, 1994, pp. 174-176). The Pew Hispanic Center (2009) and Purnell (2005, p. 293) note the strength of traditional family values with regards to children living at home until they marry. The Pew Hispanic Center sampled more than 3,200 Latinos between 16 and 25 years of age from August 5,

2009 and September 16, 2009 for their report (Pew Hispanic Center, 2009). The statement, “It is better for children to live in their parents’ home until they get married” was most likely to demonstrate agreement by young Latinos who predominantly speak Spanish (Pew Hispanic Center, 2009, pp. 60-61). That recent study’s upper age limit of 25 was used for this study, in which Mexican American parents’ perceptions of cultural influences on grieving the death of a child was described.

### **Research Site**

A site authorization letter from St. E’s (Appendix B) was obtained to verify permission to recruit eligible patients into the study. St. E’s is located north of downtown Tucson and the Santa Rosa Clinic is located in one of the adjacent *barrios* (neighborhoods). Both clinics are accessible to many of the Mexican American families in Tucson. St. E’s is a not-for-profit, faith based community health center managed under the auspices of Catholic Community Services of Southern Arizona (St. E’s, 2005-2010). Spanish language proficiency is required of the provider staff. The majority (80- 90%) of the patients who receive care at St. E’s speak only Spanish. Because of the close proximity to the United States-Mexico border, most of the patients attending the clinic are from Mexico. The clinic treats the medically underserved and a sliding fee scale is available for those that are uninsured. Data were collected at a location selected by the participants. Offering to conduct interviews either at St. E’s or at the home of the participant gave the participants an element of power. The advantage of the home as a venue was the opportunity to view the home altars and other symbols associated with the deceased and the grieving process (Doran & Hansen, 2006). The home was a place where

the participant was in control of the environment and meeting there saved them the time and expense of a trip to the clinic. The all but one of the interviews were conducted in the participants' homes, and that, second interview was conducted at St. E's in the researcher's office. The use of more than one site as a source for data collection contributed to the overall *credibility* of the study (Lincoln & Guba, 1985).

### **Recruitment of Participants**

Ethnographic methodology relies on purposeful sampling (Lincoln & Guba, 1985). Purposeful sampling is most useful when particular cases in a population are needed to accomplish the intended purpose of a study (Lincoln & Guba). The population of focus for this study was Mexican American parents who had experienced the death of their child 25 years of age or younger, more than two years prior to the time of the study. The researcher works at St. E's where approximately 80% of the patients are of Hispanic/Latino descent (St. E's, 2005-2010). The primary method of recruitment was by referral from the provider staff. Currently there are two Family Practice physicians, three Family Practice nurse practitioners and one Gynecology/Women's Health nurse practitioner employed at the clinic. Other available provider staff includes two Obstetric/Gynecology Attendings, who also supervise Residents at the clinic and other physicians who volunteer. One of the common ways of discovering the death of a child in a family is encountered when performing a general health history. The history regarding a woman's pregnancies, births, and live children often reveals experiences of spontaneous abortions or the loss of one of her children at a later time. These types of encounters offered an opportune time for the providers to briefly explain the study and invite the



parents to express an interest in participation. Men will occasionally reveal their distress over the death of a child or young adult to a provider of health care, and they were also informed of the study.

The potential participant's health care provider at St. E's used the Participant Recruitment Script (Appendix C) that was available in English and Spanish, to explain the study to potential participants. If the potential participant was interested in learning more about the study they wrote their name and telephone number on the Participant Recruitment Script form (Appendix C). The potential participant's provider gave the Participant Recruitment Script form to the researcher. The researcher contacted the parent, arranged a meeting time and place, explained the study, and answered all questions. Only when the researcher was confident that the potential participant understood their role in the study was the Informed Consent Form (Appendix A) signed by the participant and the researcher. The first interview was scheduled at this time. Ultimately, six parents were recruited into the study.

### **Data Collection Procedures**

The planning for data collection and recording modes is discussed in detail by Lincoln and Guba (1985). The main techniques available to the researcher included "interview(s), observations, unobtrusive measures, record analysis, and nonverbal cues" (Lincoln & Guba, 1985, p. 240). Demographic data were collected with the Demographic Questionnaire (Appendix D). Cognitive referents of acculturation are an important part of the assessment of behavior (Cuellar, Arnold & Gonzalez, 1995a; Cuellar, Arnold & Maldonado, 1995b). Therefore, acculturation was assessed using the Acculturation

Rating Scale for Mexican Americans-II (ARSMA-II) (Appendix E). The role cultural factors play in the experience of Mexican American people seeking physical and mental health services is important to note with regards to an understanding of the cultural differences within that population (Cuellar et al., 1995a, 1995b).

### **Participant Observation**

Participant observation requires the researcher to engage in activities in the exploration of a social situation as well as conduct and document observations of that same situation (Spradley, 1980; Davis, Powell Gallardo & Lachlan, 2010, pp. 350-353). The recording of notes, during or immediately after participant observations, results in a field note journal of an expanded account of the cultural influences on the phenomenon and population of interest (Spradley, 1980; Davis et al., pp. 350-353).

The researcher kept a field note journal for the purpose of recording all observations and the ongoing analysis of data as they were collected. Field notes identify the dates and times, the settings and participants, and the activities that were being observed (Hammersley & Atkinson, 2007). Analysis of the details in the field notes assisted with the interpretation of the meaning of events (Hammersley & Atkinson).

### **Interviews**

The ethnographic interviews provided the researcher an opportunity to explore a culture from the emic perspective. It is through the participant's voice that the researcher elucidated a clear cultural description of the phenomenon (Spradley, 1979). The real and/or potential effects of the researcher's background on the study were accounted for and assumptions clearly articulated and documented in a journaling process before the

study was conducted (Hammersley & Atkinson, 2007). An interview guide was used for this study (Appendix F). The questions in the interview guide addressed the parents' memories of the traditions that were used to honor their child at the time of death as well as current traditions, and their memories of their first experience with a health care provider after the death of the child.

The tape recorded interviews for this study were conducted in the language the participants preferred to converse in, either English or Spanish. Two 60-90 minute interviews were conducted with each participant. The second interview was scheduled two to three weeks after the first interview was completed. That schedule allowed time for the participant to develop a relationship (*personalismo*) with, and confidence (*confianza*) in the researcher, after respect (*respeto*) was demonstrated (Clements et al., 2003; Spradley, 1979).

### **Interview Considerations: Grieving Parents**

Ethical concerns in conducting qualitative research are noteworthy when studying Mexican American parents' perceptions of cultural influences on grieving the death of their child. This is especially true when recruiting and interviewing a vulnerable population. Rosenblatt (1995) states that there is a lot more to being ethical than complying with constraints imposed by an IRB. Three of the ethical challenges identified by Rosenblatt are discussed in relation to the vulnerability of Mexican American parents who have experienced the death of a child and in regards to the plan of study for description of parent's perceptions of cultural influences on their bereavement: (a) recruiting people to be interviewed, (b) causing pain, and (c) informed consent.

Recruitment can take the form of coercion when family members pressure others to participate in a qualitative study (Rosenblatt). The concept of *familismo* has potential for impacting recruitment of other family members who may be unwillingly included because of the nature of that cultural value. Rosenblatt discusses the attitude of IRB reviewers who are uncomfortable with a study that “causes people to feel emotional pain” (Rosenblatt, 1995, p. 144). The experience is more complicated and profound than a simple question of causation of pain, because it is recognized that in talking, participants often gain insight in sharing their story with someone who demonstrates a genuine interest in their life (Rosenblatt). That attitude acknowledges that there may be times when family members say destructive things to each other and it is at those times that the researcher may feel that bringing up hurtful topics may be the wrong thing to do (Rosenblatt).

Recognition of the immense pain surrounding bereavement in the death of a child places parents and families in a vulnerable situation. There may be times that the interview process elicits tears, stemming from the raw memories of the death of a child of Mexican American heritage, but in that realization, and with advance knowledge of skills such as offering to stop, or skip a question, or checking with the participant, the complicated issues surrounding the causation of pain can be anticipated and minimized. The importance of being an ethical researcher, who was willing to stop an interview, was acknowledged. Sometimes there is an opportunity to check with participants about their painful experiences at follow-up interviews, and during member checking in review of transcripts and data. There are times that unanticipated reactions may occur during an

interview. Rosenblatt suggests a “processual consent” procedure to repeatedly give participants the opportunity to stop or avoid particularly painful questions (Rosenblatt, 1995, p. 148). An example of a processual consent that this researcher used in interviews with Mexican American families grieving the death of a child is: “I don’t know if it is acceptable to ask this question or not... .” It was with the intention of honoring the cultural values of *personalismo* and *respeto* that the interviews were conducted.

### **Measure of Acculturation**

The ARSMA-II (Appendix E) was used to measure the acculturation of the six participants. The 30-item Likert type scale primarily measures language, ethnic identity, and ethnic interaction (Cuellar et al., 1995a, b). The scale measures orientation toward the Mexican culture and the Anglo culture independently using two subscales: 1) a Mexican Orientation Subscale (MOS) and 2) an Anglo Orientation Subscale (AOS). Scoring of the ARSMA-II is accomplished by comparing the means of the two subscales and subtracting the MOS from the AOS. The scores represent a level of acculturation (Appendix E). A score of less than -1.33 places a participant at Level I, from a possible Level I to Level V, meaning that participant is “very Mexican oriented” (Cuellar et al., 1995b, p. 285).

### **Photography**

The ethnographic record can include photography as a means of documenting an observation (Spradley, 1980). Spradley (1980) describes the ethnographic record as “build(ing) a bridge between observation and analysis” (Spradley, 1980, p. 33). With preceding specific participant consent for photographs, the researcher used photography

to document cultural symbols of grief in Mexican American parents after the death of a child: altars in the participant parents' homes, cemetery decorations on the graves of the children of Mexican American families, and other public displays of the way the families honor their child who has died. One of these public displays is seen in the memorials decalced onto the backs of car or truck windows, "*En memoria de...*" (In memory of...). Photographs of the participants themselves were not a part of the ethnographic record. Explicit photographs containing the faces of the children who had died were obscured electronically to prevent identification of the child and the child's family. Other community displays honoring the death of a child of Mexican descent include *El Dia de los Muertos* (Day of the Dead) murals, public venues where candles are burned, and altars that are on public display. Examples of these were photographed by the researcher. These symbols reflect the cultural concept of *spiritualidad* and the continued connection to the dead. The photographs are not published in this document but will be used in future presentation of this Practice Inquiry.

### **The Process of Analysis**

Geertz (1973) states that analysis is the sorting of elements of significance from the data that are gathered with regards to interpretation and importance to the culture of study. Analysis is not a separate stage in ethnography but rather a process of mindfully recognizing data that emerge during the study (Hammersley & Atkinson, 2007). The iterative process of data analysis provides a "thick description" (Geertz, 1973, pp. 9-10) of the cultural context.

## **Data Analysis**

Data analysis began during data collection. Data were analyzed by reviewing and processing the field notes after each interview and/or participant observation to interpret the phenomena within the cultural context (Spradley, 1979). Interviews, conducted in Spanish, were transcribed in Spanish, translated into English, and then back-translated into Spanish by a second Spanish-speaking translator. The researcher and translators met to discuss and reconcile the accuracy of the cultural and functional equivalence of the English translation (Brislin, 1970; Jones et al., 2001). Description of Mexican American participants' perceptions of cultural influences on their grieving the death of their child emerged through the process of iterative data analysis. Because "data are materials to think with" (Hammersley & Atkinson, 2007, p. 158), it is important to make sense of the data and formulate descriptions as the data are being collected. The process of analysis was not just to manage and manipulate the data, but rather the data were used to shed light on the Mexican American parents' perceptions of cultural influences on grieving the death of their child (Hammersley & Atkinson).

Every line of each interview transcript was numbered and analyzed separately in the search for "tacit or explicit elements that were recurrent in a number of domains" (Spradley, 1979, pp. 186-187). The data bits were then clustered into categories with similar units of meaning (DeSantis & Ugarriza, 2000). Each of the clusters of data were analyzed separately and then compared to find emerging patterns, themes and thematic linkages (DeSantis & Ugarriza). Documentations from the field note journal were included in the interview notes and contributed to the emerging themes. The next step

was combining data bits with recurring patterns and carefully extracting themes into conceptual categories for further analysis (DeSantis & Ugarriza). The categories were reviewed for emerging major themes that captured the essence and meaning of the study (DeSantis & Ugarriza). The overarching cultural theme was abstracted from the major themes.

Hammersley and Atkinson (2007) are quick to point out that there are many ways to go about the process of analysis. However, knowing one's data, generating hypotheses, looking for patterns in the data, and taking care not to turn a blind eye to outliers in the data will produce a more accurate and exhaustive picture of the phenomenon within a cultural context. There can be a systematic process of sifting and comparing, but one still has to guard against assumptions and stereotypes that are not accurate representations of the culture of interest (Hammersley & Atkinson).

### **Evaluation and Scientific Rigor in Qualitative Studies**

The establishment of *trustworthiness* in qualitative methodology lends scientific rigor to a study. The criteria established to accomplish *trustworthiness* are *credibility*, *transferability*, *dependability*, and *confirmability* (Lincoln & Guba, 1985). *Reflexivity* serves as the means for critically examining the process, and determining the value of the study (Lincoln & Guba).

#### **Credibility**

##### **Activities in the Field**

The accurate documentation of field notes was required for the recording of noteworthy detail, and for the effort of mindfulness to the details of personal thoughts



and feelings (Hammersley & Atkinson, 2007). Selectivity of field notes, the difficulty in capturing both breadth of focus and detail, and an awareness of how the focus could change during a study were challenges for the researcher (Hammersley & Atkinson). The dedication of an ethnographer to the time it takes to complete a study and the recognition of the art and science of accomplishing a narrative that offers insight and understanding of a culture of interest requires discipline (Hammersley & Atkinson; Wolf, 2007).

***Prolonged engagement.*** The recognition of the gaps in culturally sensitive care for Mexican American parents whose child had died was born out in repeated and continual observations by the researcher in the clinical setting. Prolonged engagement with Mexican American parents who have experienced the death of a child helped formulate a description of the parents' perceptions of cultural influences on grieving the death of their child. The researcher has been working with the Mexican American community as a Family Nurse Practitioner for 13 years.

***Persistent observation.*** "The technique of *persistent observation* adds the dimension of *salience*" to the details of the experience a researcher is immersed in (Lincoln & Guba, 1985, p. 304). There were elements of the occurrence of cultural events that could only be gleaned by spending time with those who had experienced the event themselves, and keeping a careful record of observations.

***Triangulation.*** The use of varying "sources, methods, investigators and theories" is the hallmark of *triangulation* (Lincoln & Guba, 1985, p. 305). The inclusion of enough parent participants to be able to formulate a description of their life experience was the purpose of this ethnographic study. Additional data sources that contributed to a thick

description of the phenomenon within the cultural context include participant observations, field notes, and photographs. Triangulation of a measure of acculturation (ARSMa-II) and the multiple sources of data were used to describe the cognitive referents of acculturation in the study population.

### **Peer Debriefing**

*Peer debriefing* is a technique used establish credibility in qualitative research (Lincoln & Guba, 1985). In the procedure of peer debriefing, the researcher used a trusted and knowledgeable colleague to discuss the study. The researcher met regularly with the Practice Inquiry Chair to review, discuss and analyze the data as they were gathered. The Practice Inquiry Chair is familiar with the Mexican American culture, having worked with and conducted research with Mexican American families for 20 years in the United States-Mexico border region. The Practice Inquiry Chair is very familiar with Mexican American cultural norms and rules and how they influence health care beliefs and practices, lending credibility of that choice as a true peer.

### **Negative Case Analysis**

Qualitative research often reveals cases that refute the developing analysis of the data. This is recognized as a negative case (Schwandt, 2007). Any developing understanding that needed revision in hindsight was based upon the information gleaned from a negative case (Lincoln & Guba, 1985). The outlier required the reconstruction of the assumptions that were being generated (Lincoln & Guba). The knowledge of the presence of negative case analysis added *credibility* to the study and was a key component of this *naturalistic inquiry* (Schwandt).

### **Referential Adequacy**

The data generated in a qualitative study are precious and all are regarded with importance. It is with this importance in mind that the purposeful inclination to save some portion of the raw data in archives for later recall and comparison provides studies with a rare opportunity to establish *credibility* (Lincoln & Guba, 1985). The researcher had planned to save one such interview to strengthen the credibility of the study, but all data in this time-limited study were used at the time they were generated. Participants were recruited into the study until saturation of data was achieved.

### **Member Checks**

Member checking is the review of both the ongoing analysis, but most importantly the ultimate draft of the study to test for factual and interpretive accuracy and to establish *credibility* (Lincoln & Guba, 1985, pp. 373-374). Member checking is the most crucial technique for establishing *credibility* (Lincoln & Guba). The data, categories revealed in the analysis, the interpretations by the researcher and the proposed conclusions were reviewed and agreed upon by four of the participants in the study to establish *credibility* (Lincoln & Guba).

### **Transferability**

Transferability is the assertion that findings can be transferable from one case to another if the researcher has provided sufficient detail about the circumstances of the situation for others in that situation to recognize it as their own (Schwandt, 2007, pp. 126-128). The generalizability of a finding or a description of one case to another may be unrealizable (Lincoln & Guba, 1985). Researchers and practitioners determine the

transferability of previous research findings to their own settings. The researcher bears the responsibility of producing a *thick description* that may be recognizable to the majority of participants (Schwandt).

Geertz (1973) says *ethnography* provides a *thick description* of a culture. A rich description of the situation being studied is imperative. More than that, it is not simply the amassing of details, but rather the thickly described cultural event that is interpreted from “recording the circumstances, meanings, intentions, strategies, motivations, and so on that characterize a particular episode” (Schwandt, 2007, p. 296).

### **Dependability**

Dependability is the demonstration of reliability in qualitative study (Lincoln & Guba, 1985, p. 299). Dependability is the development of the progression of the research investigation and the responsibility of the researcher to ensure the logical, traceable, and documented process of the conduct of the study (Lincoln & Guba, 1985; Schwant, 2007). The *dependability audit* and the audit trail focus on the assurance that the process of the study and the researcher’s responsibility for it is certain (Lincoln & Guba).

### **Confirmability**

Confirmability is the establishment of the data and the interpretations of the inquiry as fact and not mere figments of the imagination of a researcher (Lincoln & Guba, 1985; Schwant, 2007). The *confirmability audit* calls for the ability to link assertions, findings, and interpretations with the data in ways that distinguish those as meaningful to the study question (Lincoln & Guba). The field note journal and raw transcripts helped to establish the confirmability of this study.

## **Reflexivity**

Reflexivity is the continual self critique of bias, assumptions, and ideology that is mandated to assure credibility in an ethnographic study (Lincoln & Guba, 1985; Powers & Knapp, 2006; Wolf). Rigor is the documentation of adequacy of trustworthiness in ethnographic study (Hammersley & Atkinson, 2007; Wolf, 2007). Rigor and credibility are accomplished by reading and reflecting on the substance of the data and the results of data analysis (Hammersley & Atkinson; Wolf). Reflexivity must be implemented and documented to identify any personal involvement a researcher has in a study (Hammersley & Atkinson; Powers & Knapp; Wolf). The *reflexive journal* or field note journal was used to document the researcher's personal notes and served as a means for critically inspecting the entire study process (Lincoln & Guba).

## **Assumptions**

The process of *reflexivity* requires that the researcher engage in reflexive thought to reveal any assumptions that need to be recognized as a potential influence on the study. Assumptions that this researcher holds are:

1. The researcher has repeatedly observed, during the past 13 years, evidence of culturally insensitive care provided by nurses and other health care providers to Mexican American parents who have experienced the death of a child.
2. A contributing factor to the culturally insensitive care of Mexican American parents who have experienced the death of a child is a knowledge gap among nurses and other health care providers.

3. An educational module that describes and addresses the cultural values and needs of this population would result in the nurses and other health care providers offering culturally sensitive care to Mexican American parents who have experienced the death of a child.

### **Summary**

Chapter Three presented the methodology that was used in this study of Mexican American parents' perceptions of cultural influences on grieving the death of their child. The protection of human subjects, selection criteria, recruitment, data collection and procedures for analysis were discussed. The accomplishment of trustworthiness in a qualitative study was detailed, and the researcher's assumptions were stated.

## **CHAPTER FOUR — PARTICIPANT INTRODUCTION**

Chapter Four introduces the individuals who participated in this ethnographic study to describe Mexican American parents' perceptions of cultural influences on grieving the death of their child. The demographics of the sample (N=6) are presented.

### **Introduction of the Participants**

The Mexican American parents grieving the death of their child, who participated in this study, received their health care from the faith based community health center, St. E's, in Tucson, Arizona. They were recruited by the provider staff at the clinic and interviewed by the researcher. All six of the first interviews were conducted at the participant's homes. One of the second interviews occurred at the clinic, in the private office of the researcher. All interviews were conducted in Spanish language, audio-taped, transcribed, and translated, then back-translated into Spanish by a third party to assure accuracy of the translation (Jones et al., 2001). Five participants were interviewed twice by the researcher, and one participant was interviewed once. All participants lived within 10 miles of St. E's. The six participants in the study were each assigned a pseudonym to protect their confidentiality.

### **Ximena and Xacob**

Ximena was the first participant interviewed and it was not until late in the study that the researcher separately interviewed her husband, Xacob. They had three children. Their son, Xavier was 20 years of age when he died in a motor vehicle accident. He was still alive when he was taken to the hospital and the doctors worked on him. The parents provided an anecdote about the doctor who cared for their son. They recalled that the

doctor was touched by the young man's death and later spoke at his church about their son's death. Ximena and Xacob heard about this event later. They have an appreciation for the pain that the death of a child can also cause to a physician. Eleven months after Xavier died the family suffered a second tragedy with their 19 year old daughter. Xochil also died in a motor vehicle accident, but she died suddenly and was not taken to the hospital. The family is Catholic and has a strong affiliation with their church. Their youngest daughter Xuxa is now 16. They have a simple altar in the home that they decorate with cards and candles depending upon the season and the event, and they visit the cemetery for birthdays and holidays such as Christmas and *El Dia de los Muertos* (Day of the Dead).

### **Valeria**

Valeria's youngest son, Victor was born with cerebral palsy (CP) and had a very difficult time his whole life. Valeria was told that he would not live for too many years. Victor had a feeding tube and a tracheotomy when he was small. She was always expecting him to die from complications of his long illness, such as from pneumonia, but he died from other complications. Victor lived for 13 years and Valeria cared for him at home except for times when he was hospitalized for complications such as pneumonia. Her whole life revolved around Victor's care. All of that has changed since the child died 8 years ago. She has grandchildren from her other grown children that she sees and helps care for on occasion. She has several altars in her home, one of which is quite elaborate. She visits the cemetery for his birthday and for *El Dia de los Muertos*.



**Tomas**

Tomas' family was living in Mexico when his small daughter died of pneumonia at the age of 2. He felt that he wanted to protect his family, and that it was not safe for them to stay in Mexico where bad things could happen to his children, and so he moved his family to Tucson and established them here when the other children were small. The family was thriving. One evening his 19 year old son insisted on running to a local store for an errand just as the family was sitting down to dinner. Their son was shot in a drive-by shooting and later died at the hospital. Tomas again felt helpless to protect his family. The way he tells it, he ran away to the hills and to the streets eventually drinking and doing drugs and losing, for a time, his family. He is now clean and attending a Christian church where a minister has befriended him. His family is now in contact with him, and they celebrate *El Dia de los Muertos* together at the cemetery where his son is buried. He is the only participant who does not have an altar at his home, but he carries a picture of his son in his wallet, and says that his ex-wife has an altar with pictures of both of the children who have died.

**Samuel**

Samuel brought his two sons to live in the United States when they were small and he was divorced from his wife. He wanted them to have the opportunities of the culture here. His sons maintained a relationship with their mother and as they became teenagers they would drive to Mexico to visit her and their friends. It was on one of those visits to Mexico that the boys were in a motor vehicle accident that killed his son, Sergio, and injured his son Saul. He had to leave Sergio's body in Mexico, and attend to Saul

who was flown to a hospital in the United States for care. Later, he made arrangements for cremation of his son and after another year he placed the ashes in the ocean off the coast of Mexico. He carries some of his son's ashes in a leather pouch that he wears on a thong around his neck, "so that he can feel him close." Samuel lives very simply but has an elaborate altar for his son with things that are meaningful to him with regards to the life they lived, for instance he always has a star on it with light, because he believes that his son went up. He visits the site of the accident where his son died every year on the same date, at the same time. Samuel says that sometimes he thinks his son will return to that place on that date, at that same time.

### **Reyna**

Reyna's son was the oldest child of those included in the study. Roberto died at age 23. He was diagnosed with cancer in his vertebrae and died after 13 months of treatment with radiation and chemotherapy. As a single man Roberto still lived with his mother at the time he was taken ill. He was in the Border Patrol and also attending The University of Arizona. In the end he accepted hospice care and the room where his care was provided has become Reyna's bedroom. At the hour of his death, his mariachi friends came to the home and serenaded him until the end. These same friends later played at his memorial service. Roberto expressed a wish to be cremated because he wanted to feel free and he wanted to have his illness completely destroyed. Reyna has an elaborate altar in her bedroom with a bench facing the altar. She celebrates the anniversary of his death and *El Dia de los Muertos* by attending mass at the cemetery.

She also visits the hospitals on the anniversary date to take something to the nurses in his memory; especially the nurses who donated a tree to honor her son.

### **Demographics**

Participant responses to a demographic questionnaire (Appendix D) and the Acculturation Rating Scale for Mexican Americans-II (ARSMA-II) (Cuellar et al., 1995a, 1995b) (Appendix E) were aggregated into a data set using SPSS 16.0 (2007) for descriptive statistical analysis.

### **Demographics of the Parents**

Six Mexican origin parents were included in the study. Three of the parents who were interviewed for the study were men and three were women. The participants' ages ranged from 43 to 64 years, and the mean of their ages was 54.8 years. Three of the participants are currently married and three reported their marital status as divorced. The Catholic faith was reported to be the religious affiliation of five of the participants. One participant stated that he is a Christian (Table 1).

TABLE 1. *Demographics: Parents*

Name	Age	Gender	Marital Status	Religion	Country of Origin
Ximena	43	F	M	Catholic	Mexico
Xacob	50	M	M	Catholic	Mexico
Valeria	60	F	M	Catholic	Mexico
Tomas	58	M	D	Christian	Mexico
Samuel	54	M	D	Catholic	Mexico
Reyna	64	F	D	Catholic	Mexico

### ***La Familia***

The family is identified as important to the Mexican American community and two questions in the demographic questionnaire were posed as questions requiring qualitative answers. These two questions were designed to discover what the concept of “*familia*” meant to the participants. The responses to “Who is living in the home?” brought three basic responses, with two parents reporting that they live alone, one reporting that she lives with her spouse only and three reporting that they live with their spouse and a surviving child. An additional qualitative question that was posed as, “Whom do you consider to be a part of your family?” brought a wide array of responses. Ximena stated that her family consisted of those who are of her blood, but also includes her friends. Xacob also included his friend in his family. Valeria considered her family to be her husband, her children, and her grandchildren. Tomas stated that his children were his family. Samuel stated that “all the world” is his family. Reyna says her family includes her brother.

### **Living versus Children Who Have Died**

None of the participants are childless at this time. Three of the participants have one living child who is still living in the home. One participant has two living children, one has three living children and the final participant has five grown and living children. Three of the participants have suffered the death of one child and three of the participants have experienced the death of two children.

### Demographics Regarding the Child's Death

Specific questions were asked on the demographic questionnaire with regards to the child's death, circumstances of the death, demographics about the child and circumstances of the child's funeral (Table 2).

TABLE 2. *Demographics: Deceased Children*

Name of Parent	Number of Child Deaths	Years Since Death of Child		Sudden vs. Illness		Age at Death		Cremation vs. Burial	
		Child 1	Child 2	Child 1	Child 2	Child 1	Child 2	Child 1	Child 2
Ximena	2	5.5	4.5	Sudden	Sudden	20	19	Cremation	Cremation
Xacob	2	5.5	4.5	Sudden	Sudden	20	19	Cremation	Cremation
Valeria	1	8	X	Illness	X	13	X	Burial	X
Tomas	2	33	16	Sudden	Sudden	2	19	Burial	Burial
Samuel	1	9.5	X	Sudden	X	19	X	Cremation	X
Reyna	1	4	X	Illness	X	23	X	Cremation	X

Half of the parents participating in this study had experienced the death of two children. The years intervening since the deaths ranged from 4 to 33 years. This met and exceeded the criteria for participation in the study, that the child's death was more than two years prior to the study. The mean of years since the death of the first child who died was 10.9 years and the mean of years since the death of a second child for any of the participants who suffered the death of another child was 8.3 years. The mean of years since the death of all children was 10.0 years. Two of the parents cared for children who died after a long illness, one from cancer and one a child who died from complications of CP. Of the children who died suddenly, five died in motor vehicle accidents, one was killed in a drive-by shooting, and one died suddenly from complications of pneumonia.

### **The Children**

The six participants reported on the deaths of a total of nine children for this study. The children ranged from 2 to 23 years of age. Four of the children were 19 years of age at their time of death. Interestingly, all three of the children reported by their parents as being the second child to die in their family were 19 years of age. The mean age of the children who were the first child to die in the family was 16.1 years and the exact mean of the ages of the second children to die in their family was 19 years of age. The mean of the ages of all children who died was 17.1 years. All of the children were living at their parent's home at the time of their deaths.

The children who died were either born in the United States or in Mexico. Of the nine children who had died, seven were born in Mexico and two were born in the United States. Of the six children who were the first to die in their family, four or 66% were born in Mexico and two or 33% were born in the United States. Of the three children who were the second child to die in their family, all were born in Mexico. Of the total of nine children, seven, or 77% were born in Mexico. The two children who died after a long illness as opposed to a sudden death are the same two children who were born in the United States. Valeria and Reyna are the participants who cared for their children through illness until their deaths.

### **The Funeral**

The children who died were either buried or cremated, with six of the nine children's parents electing to cremate them. Of the three children who were buried, one was placed in Mexico and two are buried in cemeteries in the United States. Of the six

children whose remains were cremated, only one was placed in Mexico: the rest have been kept in the United States. Samuel took his son's cremains to the ocean from a beach in Mexico.

### **Cultural Influences**

Two of the questions on the demographic questionnaire specifically addressed events and cultural practices that have been previously identified in the Mexican American culture of grieving: altars in the home and participation in *El Dia de los Muertos*. All six of the participants reported taking part in the events of *El Dia de los Muertos* on an annual basis.

The altar in the home is another cultural practice that is prevalent in Mexican American homes when one is grieving the death of a family member. The researcher was privileged to see the altars that are kept by the participants and to photograph them. Only one participant, Tomas, does not have an altar in his home, but he stated that there is an altar at the home of his children's mother.

### **Demographics Regarding Acculturation of the Parents**

All of the participants are first generation Mexican Americans; they were born in Mexico and have immigrated to the United States and live and work here. The six participants completed the ARSMA-II in the Spanish language version. All six of the participant's ARSMA-II scores were represented at Level I (Appendix E). They ranged from -1.5 to -2.2, with a mean score of -2.0 indicating the parents are "very Mexican oriented" (Cuellar et al., 1995b, p. 285) (Table 3).

TABLE 3. *Acculturation: Parents*

Name of Parent	ARSMA-II Score	Education: Years Completed	Language: Spoken in Home	Language: Read in Home	Years in U.S.	Annual Visits to Mexico
Ximena	-2.1	16	Spanish	Spanish	10	2
Xacob	-1.8	14	Spanish	Spanish	11	0
Valeria	-1.5	9	Spanish	Spanish	33	8
Tomas	-1.8	12	Spanish	Spanish	30	0.17
Samuel	-1.5	14	English	English	22	1
Reyna	-2.2	12	Spanish	Spanish	38	10
			English	English		

### **Education and Language**

All of the participants were educated in Mexico. Three participants reported 14 or more years of formal education, two reported 12 years, and one attended school for nine years. Spanish was the primary language spoken and read in the home for all participants, and Spanish was also the language of their choice for the interview. Four of the participants stated that only Spanish is spoken in the home and two stated that both English and Spanish are spoken at home. Only Spanish is read in three of the homes of the participants, and three reported that both English and Spanish are read in their homes.

### **Time in the United States and Visits to Mexico**

Acculturation was assessed by asking questions about the time the participants had spent in the United States and the frequency of their visitation to Mexico. The participants had been living in the United States from between 10 to 38 years, with a mean of 24 years. The frequency of visitation to Mexico, on an annual basis, was reported by the participants as between no returns to Mexico at all to one participant who



visits about 10 times a year. One participant reported going to Mexico about five times in the last 30 years. The mean number of visitations to Mexico was 3.5 visits per year.

### **Summary**

A total of six Mexican American parents who have experienced the death of a child provided the sample for this ethnographic study. They included three mothers and three fathers. Of the six parents, three had lost two children, for a total of nine deaths. The children ranged from age 2 to 23 years and all lived with their parents at the time of their death. Most died from sudden traumatic death or sudden illness, although one young man died of cancer and one young child died from complications of cerebral palsy. Results of the ARSMA-II indicated that all of the participants demonstrated a Mexican orientation in contrast to an Anglo orientation to their lives.

## CHAPTER FIVE — FINDINGS

Chapter Five presents the findings of the data analysis from interviews and participant observations with Mexican American parents who have experienced the death of their child. The interviews were conducted in Spanish, translated into English and back-translated into Spanish to assure accuracy of the data (Jones et al., 2001). The practice of reviewing and processing the interview transcripts, the fieldwork journal notes as well as meeting with a peer for debriefing contributed to the *credibility* of the study (Lincoln & Guba, 1985). This chapter responds to the research questions that guided this study: 1) What are Mexican American parents' perceptions of cultural influences on grieving the death of their child, and 2) what in the cultural experience of parents' grieving can guide nurses in providing culturally sensitive care to Mexican American parents who have experienced the death of a child?

### **Overarching Cultural Theme: *El Dolor de los Padres***

The overarching cultural theme *El Dolor de los Padres* (*Pain in the Parent*) speaks to the heart of this study (Figure 2). The Spanish word that describes pain, ache, sorrow, or grief is *dolor* (Castillo, 1987, p. 110). A recurrent theme was the parents' description of the pain they were suffering from the death of their child.

Three major themes support the overarching cultural theme *El Dolor de los Padres*. The major themes are: (a) Enduring Great Pain, (b) Voices of Mexican American Parents, and (c) Cultural Death Traditions. The last major theme, Going Forward: For the Provider, specifically addressed data gathered from the participants to assist nurses in supporting Mexican American parents grieving the death of a child.

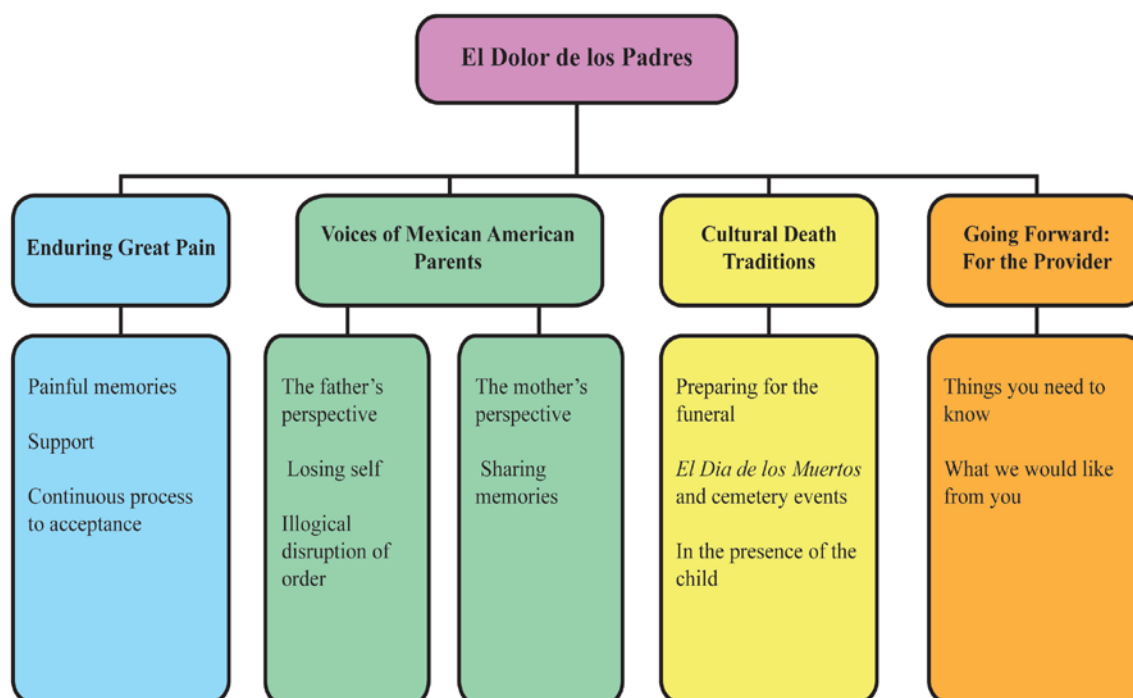


FIGURE 2. Conceptual Schema of Cultural Theme: *El Dolor de los Padres* (Pain in the Parent)

### Major Theme: Enduring Great Pain

Ximena first talked about "... my family and I have *endured this great pain* that we have... ." The conceptual categories from which this major theme was derived include: (a) *Painful Memories and Constant Sorrow*, (b) *Support*, and (c) *Continuous Process to Acceptance*. The death of a child is understandably painful to any parent who has suffered this tragedy, but the categories here are derived from the grief of the loss of children from a specific population: Mexican American parents. Their pain and their grief are affected by their culture and possibly their level of acculturation.

### Conceptual Category: Painful Memories and Constant Sorrow

*Painful Memories and Constant Sorrow* is the first conceptual category that contributes to the major theme of "Enduring Great Pain." The parents talked repeatedly

of how difficult the painful memories are to endure and how, “The pain that we suffer does not go away.” This same participant, Ximena later repeated, “... that pain in the parent, the pain that we suffer, all the parents that lose children, does not go away.”

Xacob stated: “I have that pain and anguish as if it happened yesterday, especially, now, at Christmastime, and when their anniversaries come by, same, same, but I can’t cry as a lot of people do.”

And Tomas said, “...there are memories you can’t erase.” He specifically talked about the difficulties encountered when attending the funerals of others: “...very ugly; it seems I am living those moments again, it’s awful.”

The constant sorrow and pain is recognized by the participants as solely theirs. Tomas stated, “It was a pain that no one could take away.” This man also admitted to having so much distress that, “...many times I wished to die.” He says he “...used to feel as if my house was on top of me and was crushing me down.”

Disbelief contributed to the pain of the loss, and Valeria said, “I never thought that I would be a person losing a child, that my son would die before me.” Valeria also stated, “...when he died, it was as if I did not believe...I didn’t believe that my son had died.” And Tomas said he did not want to believe it either.

The dying process took its toll on the two parents caring for children with an extended illness. The sorrow of caring for someone with an extended illness and the pain of cancer was described by Reyna as she suffered watching her son experience pain from an aggressive cancer in his spine. She cared for him through the young man’s fight for healing through chemotherapy, radiation, rehabilitation, and then through the cancer

recurrence and his death at home in hospice care. Valeria also cared for her son through many long years of illness. In his prolonged illness she was unable to prepare for his death. Valeria said, “I couldn’t think: What am I going to do when he is no longer here? So, I remained without doing anything.” In her prolonged time of care giving during her son’s illness, Valeria reported, “...there is no normal life outside of this.” When she remembered the care giving routines after his death, she was “...missing things about the way we lived...,” it had become so ingrained in her life after 13 years of care.

Tomas asserts that there is a cultural difference in the grief of Mexican American parents who have experienced the death of their child, “Mexicans’ feelings are closer to pain, stronger...a Hispanic feels the pain of losing a child, of a loved one, more than an Anglo.” And, “...the pain, the whole world feels it. Even the Americans feel it, but they are a little more distant.” Tomas believes those of his culture have deeper feelings and suffer more pain after the death of their child.

### **Conceptual Category: Support**

As a way of enduring their pain, the parents recognized, accepted, and sought the support of others. The support came foremost from *la familia* (the family), but also from others. The recognition of support from friends, doctors, nurses, and social workers was mentioned by several participants: “...thanks to the love, the support, and the solidarity of my family, and friends, people of the community, of the church where we go.”

*La familia* was most often mentioned as a source of support and some explained, “Family is the greatest support that we have in Mexican families”, and “...in our Mexican culture we are very close, very united.”

Friends were cited as a source of support.

“...there can be cases where the family gives support, but the greatest support can come from friends. Here it was the family and also the great support of friends. When one experiences pain that is so strong, these people are present.”

Friends of the child also provided support to the parents, both in contributions to the funeral and also by way of traditionally honoring a person, as in the case of Reyna's son Roberto, whose mariachi friends serenaded him both as he died and at his funeral.

Other types of support included turning to religion for help, as well as citing help from memories that were shared by others. Parents received the moral support of family and friends, as well as financial support. Courage, love, solidarity and advice were other types of support that the parents acknowledged.

Reyna's health care provider and the nurses she visits that used to care for her son help her by offering words that are supportive. She visits the hospitals on the anniversary date of her son's death to take something to the nurses in his memory, especially the nurses at one of the hospitals who donated a tree to the family to honor her son. That tree in the yard given by the nurses is much cherished, constantly decorated and is visited by the nurses who also bring items to decorate it:

“Everything they say is supportive for me: to know he is not here, to tell me that he is not suffering any more, to tell me that time will help also; no, we will never forget him but the soul's wounds are healing little by little. The pain- I think the pain of losing a loved one is always great, but my experience, I think there is no greater pain even if you lose other loved ones. I think the pain of losing a child doesn't have any comparison. It is a wound nailed in the heart of a mother forever, 'til I go to reunite with him.”

### **Conceptual Category: Continuous Process to Acceptance**

The conceptual category: *A Continuous Process to Acceptance* supports the major theme: Enduring Great Pain. The identification of the continuous process of moving forward through the grief of Mexican American parents after the death of their child was noted.

Keeping faith is one way that the participants deal with their pain. Samuel said, “I have the Bible...but my pain is my pain.”

The participants talked about accepting that which could not be different as they moved forward in their lives. “I am accepting lots of things that I should accept,” Valeria said. The tincture of time seems to affect the grief and pain for the Mexican American parents after the death of their child and contributes to their acceptance and understanding. Tomas couches it in terms of making peace with his pain, “...I think that there are things we have to accept.”

For the parents who had lost a child after a long illness the time they had for acceptance of the death of their child was lengthened. Valeria said, “G-d gave me a lot of time to think about how to prepare for when my son would be gone.” Valeria cried a lot before her son died because of his suffering throughout his life, but when he died, she did not cry. And yet, the impact and realization of the finality of the death of the child was not fully realized for a time by her, “...not until it was a few days later and I was missing him.”

Some parents were able to look back to the time when they remembered they were still innocent of this loss and its associated pain, with insight: “We didn’t know of the pain of a mother losing her child; we didn’t understand it yet.”

### **Major Theme: Voices of Mexican American Parents**

The voices of the Mexican American fathers and mothers resonated with dissimilar categories of concerns. The unique perspective of the Mexican American father was recognized early in the study interviews and so a third participant who could confirm or refute the data that were being gathered from the other fathers was sought. Xacob, the husband of Ximena, was recruited to be a participant late in the study. With the addition of Xacob the number of fathers participating in the study grew to three, which equaled the number of mothers participating. The major theme “Voices of Mexican American Parents” was subdivided into parallel conceptual categories to represent the voices of the fathers and the mothers (Figure 2). The conceptual categories that support the theme representing the voice of the Mexican American father include: (a) *The Father’s Perspective*, (b) *Losing Self*, and (c) *Illogical Disruption of Order*. The conceptual categories that support the theme representing the voice of the Mexican American mother include: (a) *The Mother’s Perspective*, and (b) *Sharing Memories*.

#### **Conceptual Category: The Father’s Perspective**

Unique to the Mexican American father was the expressed need to be alone with their grief and pain. Tomas said, “I left. I left to go far away, to a mountain.” And another father described his need to be alone, “I would turn off the phone, leave my car there and



leave without saying anything. One or two days, they didn't know where I was: alone, thinking, thinking, and thinking."

Samuel explained the reasons that he sought solitude:

"Leave me alone and if I can't be alone here I leave. I used to go to the fields, to the hills, because I liked to do that, and I would find peace and distraction there, because the places where I would go were very beautiful and I would think and relax by myself there, hmm?"

The fathers do not like being asked rhetorical questions nor do they like questions they believe have obvious answers. Samuel disdainfully mocked the efforts to communicate with him, "They would say: What is wrong? Are you dumb? What is wrong? You feel bad? Of course, I feel bad...They say, I understand. You can't understand. Perhaps you will comprehend, but you don't understand anything."

Xacob provided some of his own assessment, comparing his experiences to that of Ximena. "I do not believe my experience was different than that of my wife. It was the same, very hard, very difficult. I think that I acted differently than she did. She (his wife) fell into a depression and I didn't."

Xacob also said, "Something was telling me that I had to be strong for her, for my daughter." And, "I felt I had to be stronger than they were, because if I would crumble, I didn't know what would happen with everything." That same commitment to protect the family and care for his loved ones that had driven Tomas to bring his family to the United States after the death of his 2 year old daughter so long ago was also evidenced in the words of other men who were looking out for their families the best that they could.

Xacob stated:

“I had things to do, things that I had to do. I was trying to be busy, preparing what I had to prepare. And yes, it affected me a lot, my suffering. But I was not able to cry, I couldn’t cry.”

On supporting his wife and daughter, Xacob offered, “Ximena would go into her room and didn’t want to come out, and I was always there to see what she needed.” “I tried to see only ahead and to see that my wife and daughter were okay.”

Xacob expressed dismay because many friends and family would come to him and ask him how his wife was doing, while either ignoring or not recognizing that the pain he felt was the same as hers.

“What I do think is that sometimes people, when something like this happens, they get close to the mom, and they think that the dad is not feeling the same, and that is not true. The father feels the same. Lots of people think the mom feels more than the dad, but I feel it is the same. As in my case, when someone gets close and says, ‘I am very sorry’ they think it is a great pain for the dad, but that the mom feels it more, and no, if someone wants to help somebody they have to think that they feel the same, not that the mom felt it more than I did. Women always think that they would feel it more than me.”

### **Conceptual Category: Losing Self**

The fathers explained they went through a period of time of losing their self to grief. Sometimes this took the form of depression, such as not being able to function very well, but sometimes this also meant turning to alcohol and drugs. Tomas described, how from the time of the death of his son, which was the second of his children to die, “...my torment started then.” He turned to alcohol and drugs, and was “...throwing everything away.” He was the only participant who reported that they had behaved in this manner, but Xacob and Samuel had witnessed other fathers who had experienced the death of a

child fall into depression and not want to work and turn to drinking alcohol to assuage their pain and it is also reported that sometimes men will leave the family at these times. That was not something they wanted to do.

Samuel's rants in his head took him to places he had never been. Samuel had a hard time with people asking if he was all right. He had no patience for those who offered a pretty word either.

"You don't want to eat, don't want to drink, even if they talk to you, it bothers you because it is a thing from inside that you are cussing. Maybe you don't say, 'G-d, why did you take him? You are unfair! You don't love me because you took my son.' You might not say it, but you think it, and your head is turning, turning, turning, and a person comes and asks you, 'How do you feel?' No, it is logical that a person is not well. Maybe in time- Time, as time passes, you have to go to work, life goes on."

The loss of self seemed to take a toll on some fathers, with others bearing the pain more graciously. Since Tomas is now clean from his time of using alcohol and drugs he has a particularly graphic description of what happened:

"I would be full of pain. There are times that I choke if I think of certain memories. The feelings used to choke me, but now I can bear it. I know how to chew it and digest it. Before I used to chew it but didn't know how digest it. I would swallow it almost whole and that was what was choking me."

### **Conceptual Category: Illogical Disruption of Order**

Understandably, each of the fathers voiced concern about the unfairness of the denial of life to their child and how the normal, logical progression of the order of the generations had now been disrupted. This *Illogical Disruption of Order* is the title of the next conceptual category describing the grief of the Mexican American father and

supporting the major theme: “Voices of Mexican American Parents.” Samuel expressed his disbelief at how illogical the course of events evolved:

“...but a son, not that, not my son, I never thought of that. I knew my mom would die, that she was going to die. She was very old. My dad, or my brothers, but my son, I never thought of it.” And, “You don’t want to be at home, why? I go in the house, I would see him walking, I would see him cooking, I would see him opening the refrigerator, why? Because he used to live with me. I would see his backpack. I would see his clothes, everything, everything and to change in one day to the next your thoughts, because your mind is still with same things... .”

For those parents who experienced the death of a second child the illogical disruption of the order in their lives was even more acutely described. Tomas relates:

“We never thought this would repeat, because as we say: to see our old people die, the grandparents, the parents, is logical. We have an idea that the time has come for them to rest because they are at a certain age, you understand? It hurts, yes, even if it is an old person but it is easier to assimilate the pain. It is a lot more difficult to see one’s own child die, when as parents we expect that our children will bury us, and not us to bury them. That is painful.”

And Xacob echoes the sentiments that Tomas stated.

“They left from the house and I didn’t move, and I didn’t see them again. I couldn’t understand why that happened. I didn’t want it to happen that way, but because it was that way, without having an opportunity to say goodbye. Maybe if they were sick: I would have understood more, but no, young kids, completely healthy, that they were, and they say, ‘We’ll see you later’ and they didn’t come back alive, because life is not like that. I do not understand that.”

### **Conceptual Category: The Mother’s Perspective**

The cultural category, *The Mother’s Perspective* supports the major theme, Voices of Mexican American Parents. In contrast, to the fathers, the Mexican American mothers sought the company and support of others. The mothers in the study liked their family and friends to call and find out how they were doing. Even if their family could

not visit, such as in the case of family members being in Mexico and unable to come to the United States at this time, phone calls were much appreciated and noted by the mothers. Ximena said:

“It helps a lot that you have someone by your side that is asking you, ‘How are you? How do you feel?’ My family, as well as my husband’s family would call us and ask us, ‘How are you? What are you doing?’, and give us advice and courage.”

Ximena also expressed how externalizing and talking about her grief might help other parents come out of their grief, and she likes to talk about it with others, especially at the cemetery. Valeria had a social worker that would visit her and allow her to talk and she liked that availability to communicate. Valeria said that she will always remember those who took time to come to the home to spend time with her and see how she was doing after Victorcito’s death.

Maintaining the atmosphere of the home fell to the mother. This was especially hard for Ximena, whose youngest child was 10 years of age, at the time the two older children in the family died. The mothers took note when family members who had not been in their lives for awhile came around. Valeria stated that her brothers, “...were here more at that time than any other.”

Reyna believes that mothers suffer more than others, “It was especially painful for me, I that was his mother.” Demonstrating dedication to the long years of caring for her son, Valeria stated, “...I consecrated myself to him.”

### **Conceptual Category: Sharing Memories**

*Sharing Memories* is the title of the next conceptual category describing the grief of the Mexican American mother and supporting the major theme: “Voices of Mexican

American Parents.” The mothers talked about their sharing of memories with the family and others. Those discussions with the family and the sharing of past memories are particularly helpful to the mothers. The purpose of the process is to find a way to endure and heal the great pain according to Ximena.

“Sometimes we laugh, sometimes we cry. It is a process, it is a continuous process, and I think that to free yourself and to talk about the children who have died is a way to release yourself. It is something that heals the inside.”

Reyna talked about sharing memories of her son with her son’s friends. She has found comfort in attending a support group at a Catholic Church that is specifically for parents who have experienced the death of a child. She talks of the sharing and celebrating of the life of the child who has died that occurs at the group meetings, and it sustains her.

### **Major Theme: Cultural Death Traditions**

The third Major Theme: Cultural Death Traditions is supported by three conceptual categories: (a) *Preparing for the Funeral*; (b) *“El Dia de los Muertos” and Cemetery Events*; and (c) *In the Presence of the Child*. Multiple sources of data were used to support this major theme. That is, data were gathered from interviews, participant observations, and from a focused literature review (Clements et al., 2003; Lawson, 1990; Munet-Vilaro, 1998). This major theme is best illustrated by the words of Tomas “... *We were made to mourn.*”

### **Conceptual Category: Preparing for the Funeral**

The six participants in the study prepared nine funerals. Interestingly, six of the nine children who died were cremated rather than buried. Of the three children who were

buried, one includes the youngest child in the study, Tomas' daughter. This child, who at two years of age suffered a short illness and died of pneumonia, was laid to rest in Mexico. Her older brother was killed in a drive by shooting many years later and was buried in a cemetery in Tucson. Victor the child of Valeria who died from complications of cerebral palsy (CP) at the age of 13 was also buried in a cemetery in Tucson. The six remaining children were cremated, with four having their ashes placed in a columbarium at a local cemetery, one having his ashes spread at a riverbank, and another's ashes were taken to the ocean off of a beach in Mexico and placed there.

The children were all honored at funerals or memorial services and a Catholic mass was celebrated for them at the time of their death. Samuel's ex-wife had the mass for their son in Mexico where she lives. The funeral and mass for Tomas' 2 year old also took place in Mexico. The remainder of the services took place in the United States. Some of the participants also talked about the ritual of praying the rosary, both in the days leading up to the funeral and afterwards. The *Novenario*, or nine days of prayers and rosaries often occurs in the homes of the bereaved, but sometimes it will occur in the home of a friend or close relative. It is traditional to have a monthly mass for the child who has died for a year, and thereafter on the anniversary date of their death a yearly mass is paid for. When the researcher asked one of the participants what it cost to have a mass said for your child, she said it was relatively inexpensive and that \$10 would usually cover it.

Music at the funerals was mentioned several times with mariachi music being preferred. One participant stated, "...the Mexican celebrates pain." His example of this

was the music that is played to honor the dead. He said that from the time his son died that there were friends of the family and friends of his son hanging around the house and in their cars and blaring music from “boom-boxes” to honor his son. The mariachi group members who were friends of Roberto, Reyna’s son, who had serenaded him as he lay dying, also played music at his memorial service.

It was a somewhat surprising finding to discover that two-thirds of the children who were represented in the study had been cremated. There was not a great effort to discover the reason for that, but some of the parents volunteered their reasons. The body of Reyna’s son was cremated because Roberto wanted to feel free and stated a desire to have his illness completely destroyed. Reyna complied with his wishes. Funeral preparations included a mass with Border Patrol officials receiving the coffin in a special ceremony, because of his work with them. A second memorial service was held when the ashes were spread on a riverbank where a plaque was placed on a tree to mark the spot. At that service the mourners were also encouraged to write a message and place it on a balloon that was released for him. Reyna has kept a few of the ashes which she has on the altar in her home.

Samuel left his deceased son’s body in Mexico while he attended to his other son who had been injured. He returned to Mexico to make arrangements for the body of his son to be cremated. Later he returned to Mexico again and he says they gave him his son in a small box. Samuel carries some ashes in a small pouch on a thong around his neck, “I do not separate from him.” At the one year anniversary of the death of his son, Samuel took the cremains to the sea to place his son’s ashes there, because his son liked to go to



the ocean. Only Samuel, his other son, and his son's mother went to take the cremains to the sea. Samuel admits that this was a non-traditional thing to do.

**Conceptual Category: *El Dia de los Muertos* and Cemetery Events**

The second conceptual category: “*El Dia de los Muertos*” and *Cemetery Events* supports the major theme: Cultural Death Traditions. Some of the actions that the parents perform when participating in these events include: Talking to the child, remembering the child, and praying for them. A yearly mass in the name of the child is usually initiated at the Catholic Church where the parents attend. The mass is often ordered for the anniversary date of the child's death and sometimes on their birthdates. The parents visit the cemeteries with regularity if the child's remains are there, especially when the death is new, but also on major holidays such as Christmas and Easter, as well as *El Dia de los Muertos*. Valeria recalled, “...when he first died, I used to go every day, almost every day.” And Ximena elucidated:

“...celebrations of *El Dia de los Muertos*, as well as December, Christmas, many people go to the cemeteries. There are a lot of people that take music to their loved one: they take music and sing songs that they liked when they were alive. They do this. Some take the mariachis, others take guitars, etc., depending on what they used to like and at Christmastime, a lot of people of our culture go to the cemeteries to honor the loss of their loved ones.”

“*El Dia de los Muertos* is celebrated by attending mass on both November 1st for the Day of All Saints and also on November 2nd, the day exclusively reserved for honoring the souls of the dead,” according to Reyna.

Sharing experiences with others who are also visiting the cemetery to spend time near their loved ones was cited by two participants as important to them. Tomas

mentioned sharing the experience with others at the cemetery visiting their children who have died. Valeria said she had the experience of sharing stories with other families who were grieving and visiting the cemetery.

### **Participant Observation**

Ethnography encourages participant observation (Spradley, 1980). The researcher is encouraged to engage in activities within a culture during their exploration of social situations (Spradley, 1980). The researcher is required to submit documentation of the observations of that participation (Spradley, 1980). The time line of this study allowed for participant observation of two cultural events that were identified by many of the participants as times that they specifically visited the cemetery and the graves of their children. *El Dia de los Muertos* occurs on November 2, and the researcher spent time in the cemeteries on both November 1, identified as All Saints Day and November 2 to witness the events occurring in two cemeteries. Christmastime was also identified as a day that the parents visited the children in the cemetery. Both of the events were recorded by photography as well as in notes in the researcher's personal field note journal. The two cemeteries that were selected for the participant observations are frequented by Mexican American families in Tucson, Arizona.

***Location of the participant observations.*** The Diocese of Tucson maintains Holy Hope Cemetery, a little north of downtown Tucson. Holy Hope Cemetery has a Children's Cemetery where many tiny graves stand in rows, and other medium and full sized graves hold the bodies of young children and teenagers. A great marble statue of Jesus Christ holding his hands out to children is at one end of the Children's Cemetery.

The graves in the Children's Cemetery are colorfully decorated in the seasons of the year. Balloons and toys and candy are on the graves.

South Lawn Cemetery and *Funeraria del Angel South Lawn*, a funeral home on its premises, are located south of downtown Tucson, a little further south, even, from the city of South Tucson, where a lot of the old *barrios* (neighborhoods) have been settled by Mexican American families. The actual name of the funeral home demonstrates the population to which both the funeral home and the cemetery cater, although there are no restrictions with regards to religion or ethnicity. Indeed, there is a Muslim area within this cemetery where the graves are mounded above the ground. The graves at this cemetery are also colorfully decorated, and partially seasonal, but they also have many other colors on them. It is still possible to pick out the graves of the children that are decorated with balloons, and angels.

*El Dia de los Muertos*. The religious and spiritual celebration of *El Dia de los Muertos* is observed by many Mexican Americans, who gather in the cemeteries to pray for and remember those who have died (Brandes, 1998). The cemeteries offer mass to those who come to honor the dead. On November 1, 2010 and on November 2, 2010 the researcher spent time in both cemeteries observing and recording the events of those days. On November 1 the sounds of the graveyard workers at Holy Hope Cemetery: mowing, trimming, and a tractor digging, were relentless. People were walking slowly through the red, orange, and yellow swathed space. Marigolds dominated as the flower of choice for the season. Visitors to the Children's Cemetery section were sitting and

tending to graves with large plastic containers of decorations. Still others sat in small groups evidently praying or chatting quietly in the coolness of a shady area.

The Halloween season was evident with children's graves decorated with ghosts, Casper, pumpkins, and signs that read, "Happy Halloween" and "Beware." There were scarecrows, corn stalks, leaves, cat-o-nine tails, balloons, butterflies, and birds. Flowers were everywhere. Food was also plentiful: *Starbuck's* coffee, *Eege's* iced drinks, and candy. The graves were also decorated by cutouts being carved into the grass. Candles, saints, virgins, and crosses were in abundance. Sugar skulls and *pan de muerto*, a round loaf with colorful sugar and pieces of the dough baked onto the top that look like bones, were also in place at some graves. One man tended a grave and then sat in his blue folding canvas chair. A more elderly man arrived with artificial flowers and arranged them hurriedly on a grave and left. Another man in shorts and sunglasses walked back and forth quite a while reading the headstones before putting his hands in his pockets and walking away. A one-armed man struggled with the flowers he was placing on a grave. Then an old man and his daughter arrived and, while she tended to the grave, he sat on one of the marble benches that have been placed in memory of someone, and played Glenn Miller on a kazoo while rapping a colorful *maraca* onto his metal cane. A sign read: All Souls Day Mass: November 2 at 8:30 a.m.

The South Lawn Cemetery on South Park Avenue, the second cemetery was very quiet during mid-morning. There were a few cars coming and going. The signs stated that *El Dia de los Muertos* event would occur at 4 p.m. in the Garden of the Angel. There was

a small plot with children's graves that had tiny headstones, but only a few were decorated.

Both cemeteries held masses out-of-doors, under canopies. The mass at Holy Hope Cemetery began with a procession including the bishop and members of the Knights of Columbus in full regalia. Children costumed as angels, with large feathery wings, were a part of the procession. The crowd was somber and conservatively dressed, with some in their scrubs and ready for work. Many had rosaries in their hands. Musicians played guitar music at one point. The bishop made his way through the crowd of about 200 at the end of the mass and seemed to touch everyone and say a word to them. After the mass, people fanned out in small groups, tending graves, chatting, and laughing, crying, standing, kneeling, sitting in folded chairs, few cars moved.

At 2 p.m. the cars were coming and going furiously from South Lawn Cemetery. Delivery trucks, party items, the *Popsicle* man, golf carts zoomed around carrying people eating roasted corn. There were people everywhere setting up tables, tents, and altars. Here the colors varied: orange and yellow, purple and green and blue and red. The families of those who had died were setting up elaborate altars for the contest that was to take place later that night.

Music was everywhere for hours before the mass that was scheduled to start at 4 p.m. Musicians played to a truck that blared recorded music, while they played guitars, a bass violin, a tuba and snare drums. The hammering of stakes into the tent posts was heard between the many musicians and mariachi bands. A lone player of a squeeze box accordion-like instrument paid no heed to others and carried on with his own tune.

A priest in purple robes, with one man and one woman acting as attendants in civilian clothes appeared in front of the statue of the angel where the canopies provided shade for a crowd of about 100, but many others stayed out of the canopy. Mass was offered in Spanish, and at the end, the priest sprinkled “holy water” on everyone, and his assistants passed out red carnations, bookmarks with the recipe for *pan de muerto*, and wooden beaded rosaries to the crowd. The families then went to the gravesites and started to eat from coolers or from takeout containers; pizza was a favorite. Some sat in folded chairs others on blankets. Children were running, people were talking, bands played all around and from the din a solitary woman’s voice could be heard chanting and singing. The researcher followed the voice to the area where she sat, and many others had begun to gather around her to listen, so compelling was her song. The timbre and tone of the song left tears on the faces of all who had gathered to take note.

The altars were photographed. The most traditional altars were placed on the graves covered with a sheet, and sugar skulls, *pan de muerto*, marigolds, sunflowers, photos, and flags. Candles were lit on the graves of those who were being remembered, and as the evening grew dark more and more graves were outlined in candlelight.

*Christmas in the cemetery.* The participants in the study mentioned that Christmas was another day that they visited the cemetery to be with their child for a time, and the researcher visited both cemeteries on Christmas morning. The Children’s Cemetery at Holy Hope had numerous full sized Christmas trees that were fully decorated and placed on the graves. Some of the Christmas trees were little, but many were full sized trees. The small groups of people were visiting the red and green

decorated expanse, sitting in lawn chairs, eating boxes of cookies and drinking beer and tequila. Poinsettias were placed on almost every grave. There were still the ever-present balloons, but also snow globes, snowflakes, wreaths, lights, angels, stars, manger scenes, candy canes and toys. There were toys everywhere, dolls, trucks and stuffed animals. At South Lawn Cemetery there was a greater variation in the colors that were decorating the graves, a lot of red and green were still evident, but blue, and white and purple were also used. The full sized Christmas trees were there also, with elaborate displays. Visitors to the cemetery were chatting over the din of boom boxes, and others were driving slowly through the cemetery with their car radio music turned up. One lone drummer snared a tune in the distance.

### **Conceptual Category: In the Presence of the Child**

The final conceptual category: *In the Presence of the Child* supports the major theme, Cultural Death Traditions. This category encompasses both the cultural mandate to keep the memory alive, which was repeated by every participant, but also gives a venue for honoring the cultural death tradition to keep an altar in the home. The category speaks to persistence of the memory the child and the parents feeling of being *In the Presence of the Child*: "...always remember and talk about them with memories."

The participants state that they are always remembering and that it is very difficult to forget for any time at all. They make efforts to honor the memory by spending time at the cemetery or in the case of Samuel, going to the place where his son died.

"I have only an altar, but I go every year on the anniversary of the date, to the same place, at the same time, in the same road they crossed because I always told them when they were very young if they were lost, to come

back. Then for me it is as if he is lost, and he will come back. He will come back.”

Regarding visiting the site of his son’s death each year, “I always come away very calm.”

Wearing the clothes of the child who has died gives peace to some of the parents.

More than one parent reported wearing their child’s clothes, and one parent states that her daughter also likes to wear some of the clothing that her sister left. Samuel’s statement is illustrative:

“There are many times I wear my son’s shirt, the shirt he wore in a photograph of us. I put it on to go see him, and the same shirt I wear it the day I go to visit where he died.”

None of the parents deny the children who have died when asked about their family. One family includes the names of their children who have died on greeting cards they send and draws a small cross by those names. Samuel says, “When someone asks, ‘How many sons do you have?’ I say two, because I have two sons. One is here on earth and the other is in heaven. Maybe he is traveling.”

Awareness of the child’s presence is described both universally and specifically. Samuel’s son’s ashes are in the sea, but he has this to say, “...no one is going to take away your son. Your son will always be with you. He is going to be there. You know that your son is where you are because he is all over the universe.” And Xacob describes it similarly but with a bit of reserve:

“Sometimes things happen that made me think they are here with me, a certain movement, a certain noise: I think they are here, but not as I would like to feel. I hear other people say, ‘I always have felt my kid’s presence’. It is not like that with me, I would like it to be, but is not.”



A home altar is in the bedroom that Reyna occupies, where her son died. A bench for sitting is at the foot of the bed and directly across from the altar. This is the bench where the researcher was invited to sit for the interview. Reyna said, “Come, let’s go be in here in front of him. Let’s go be with my son.” And she elucidated more about the meaning of the altar and her awareness of the presence of her child.

“When I go somewhere, I always bring him something, so that he will know that I always, wherever I am, I am thinking of him, and I bring him a small rock, little things and I also have to say that he has manifested somehow, that he is always with me. On some occasions, I didn’t believe in this, but on some occasions I have said, ‘My son: If you are where I am, show me something that indicates you are with me’. I have found close to the sea, in the sand, I have found a shell in the shape of a heart and I know that he put it there for me, because I have found many shells and only one has the shape of a heart and it is him, and sometimes I have found in some places where I am, I talk with him and he always leaves some little thing that I know it *signifies he is with me*.”

On visiting the cemetery for the event of *El Dia de los Muertos*, and talking to the child and remembering him, one father stated, “It was very nice to be with him, very nice.” The visits to the cemetery to take certain items to the child who has died are done with the intention of honoring the child and to be in their presence:

“These are things that we like to do and we do them with all our hearts and it makes us feel that they are present with us. For me, physically they are gone but spiritually they are always here; I always will feel them here. I am not going to ignore these dates. We never will let them go by. We’ll do it as if they were here.”

The home altar remains the focal point of the parent’s place to be “*In the Presence of the Child*.” The researcher had the opportunity to see the altars of five of the participants and photograph them. Some of the things that were on all of the altars included photographs of the child who had died and candles or another source of light.

Pictures of other family members who had also died were sometimes included as well as pictures of the immediate living family. The Bible was on some altars, and during specific holidays, such as *El Dia de los Muertos*, other cultural icons were seen, such as the *pan de muerto*, sugar skulls, and skeletons. Food and candy that was previously enjoyed by the child who had died were placed on the altar. *Starbuck's* coffee is a favorite. Model cars, shoes, sandals and other clothing that the child wore might be placed there, and the aforementioned cards for the children's birthdays and other holidays are seen.

### **Major Theme: Going Forward: For the Provider**

The Major Theme: Going Forward: For the Provider, is supported by the conceptual categories of: (a) *Things You Need to Know*, and (b) *What We Would Like From You*. This theme was included because the participants were specifically asked questions addressing the subject of what they thought a provider of health care could do to support the Mexican American parent grieving the death of their child (Appendix F). The purpose was to discover what is supportive and what they have found not supportive when they share their stories with nurses and other health care providers. The cultural categories address information that was specifically elicited and will help nurses and other health care providers better understand and offer support for the needs of Mexican American parents who have experienced the death of a child.

### **Conceptual Category: Things You Need to Know**

Nurses and other health care providers need to know that support should be continuous. Nurses and other health care providers need to have awareness that the pain

suffered from the loss of a child does not go away, “The days go by and the months go by and you forget to continue that moral support, solidarity, of feelings towards these persons, like you recognize it but do not continue it.”

“My provider was drugs,” Tomas stated. It is important for nurses and other health care providers to have awareness of this issue. It is one of the things that was reported by both Tomas who admitted that the way he dealt with the death of his son was to run away and drink alcohol and use drugs, as well as witnessed by some of the other participants, specifically of other Mexican American parents grieving the death of their child.

Social support was provided for some participants as private and group counseling, with varying degrees of success. Attending support groups made Tomas feel worse and made him suffer more, but Reyna has found a support group for those who have lost a child that is specifically for parents who are of the Catholic faith and she says that it is very helpful in her process of grieving. In private counseling with his wife and youngest daughter after the death of the second child, Xacob remembered: “He told me that I looked angry, bothered, and when he told me, I realized he was right. I was angry, I was bothered.” He says he did not do much with that information, just took note and dealt with the feelings the best he could. They attended weekly sessions for a few months, and then stopped.

Xacob has strong feelings about providers as well as other people who treat grieving fathers differently than grieving mothers. Xacob stated his feelings on the

matter, specifically asking providers of care to understand this discrepancy that he noted in the care of fathers who have experienced the death of their child.

“...a health care provider that wants to help someone has to think fathers feel the same, the same pain. I have seen cases in other fathers that have lost children and they are in a bad way, they go down deep.”

### **Cultural Category: What We Would Like From You**

Some participants wanted to hear words of support and understanding, such as, “It must be very hard for you and your family.” Reflecting on the pain, offering support, solidarity and saying, “I am sorry” was felt to be needed, and mentioned specifically by the mothers who were interviewed. These responses were seen as the provider giving a kind response.

Participants suggested that the provider of care offer psychological support as available. The participants want us to help parents understand that other parents are also going through this experience and that they are not alone.

Some of the fathers specifically voiced problems with the words they might hear from providers of care. The tone of voice matters a lot:

“What is necessary is a friendly voice, because a word, even if it is pretty, it doesn’t take the pain away, it doesn’t satisfy you when they say, ‘I am sorry’.”

Other fathers voiced skepticism about the level of understanding a provider of care might have. Samuel said it several times: “I think that they can’t do anything, but only the one that has lost a child is the one that knows.” And he also stated:

“Only another person that has gone through the same thing is going to know what it is like and I think that for me, there are no words; there are no words. I think there is silence. Maybe I am there but without saying anything- the person might feel better.”

Xacob never thought that he needed anyone to tell him what to think, or feel with regards to the death of his children. “We have tried to move forward, to be positive, and I have never thought of someone to tell me something to do about it.”

When presented with a Mexican American parent who is grieving the death of a child responding to parents with a hug or a touch is culturally appropriate and demonstrates respect in the Mexican American culture. “A hug makes you feel that someone is with you, that they are supporting you”

Still, Xacob holds out hope for the future of those providing care to the Mexican American parents after the death of a child: “...yes, I would like it if a health care provider were treating someone, if he would understand it more.”

### ***El Dolor de los Padres: An Anecdote***

The participants’ interviews demonstrated an awareness of the effect of the death of their child on others, including the doctors and health care professionals involved in their care at the time of death. The parents spoke of an awareness of a temporal aspect to life. They spoke of knowing how the immediate decision making and care of their child affected not only themselves, but also the doctors. The parents were aware that between life and death, there was pain, distress, and suffering in those providing care at not being able to save a life. This anecdote is included to illustrate that awareness by the participants of feelings in the provider.

“I saw pain in the doctors’ faces, distress, like they were suffering, like it was so painful that they were not able to save a life. That is what I saw in their faces and it was good. I appreciated their fast intervention. They did everything possible to save my son’s life.”

“And later we had an anecdote because one of the doctors that attended my son’s surgery was a friend of a family member on my husband’s side, his niece. They belong to the Mormon religion and that doctor was at the Sunday service talking about an experience he had lived through. When he was talking about the experience he had lived through my niece said, ‘They are talking about my cousin’. Then when they finished their time in church, she got close to him and asked him, ‘Excuse me, I was listening to you and you were talking about my cousin’. He asked, ‘Who is your cousin?’ And she said, ‘My cousin died two weeks ago in an accident. He was taken to Holy X Hospital and died.’ She started to talk about it and the doctor said, ‘Yes, I was talking about your cousin’. And his testimony was that it was very difficult for him when cases would come in where people were so young, and seeing that young man between life and death. When he was in surgery with him, he thought that it was his son; that when they were operating on Xavier. He felt as if he was operating on his own son and that Xavier was an angel for him at that moment, because he saw lots of things around him and he saw how he would direct strength to see his family in a different way, his sons, and it was a twist of fate because we never thought a doctor would talk about what my son made him feel in those moments. It was something beautiful.”

### Summary

Chapter Five presented the findings of the analysis of the data from participant interviews, and demographic questionnaires. The participant observations and field notes that were recorded during *El Dia de los Muertos* and at Christmastime, in the cemeteries, contributed to the richness of the description of the content of the study within its context, regarding the Mexican American parents’ perceptions of cultural influences on their grieving the death of their children. The overarching cultural theme, *El Dolor de los Padres*, was derived from the major themes that were founded on data formulated into conceptual categories. *El Dolor de los Padres* illustrates the depth of the pain that the Mexican American parents who have experienced the death of a child have and how their unique culture contributes to their experience.

## **CHAPTER SIX — DISCUSSION**

Chapter Six presents a discussion and reflection on the findings that were generated in response to the research questions. This ethnographic study focused on providing a description of Mexican American parents' perceptions of cultural influences on their grief. There were two research questions that guided this study: 1) What are Mexican American parents' perceptions of cultural influences on grieving the death of their child, and 2) what in the cultural experience of parents' grieving can guide nurses in providing culturally sensitive care to Mexican American parents who have experienced the death of a child? The Mexican cultural influences on grief are discussed and interpreted within the conceptual framework of vulnerability. Study limitations, reflexivity, the significance to and implications for the practice of nursing are presented. The discussion of the significance for nursing practice presents information to respond to the second research question and informs a continuing education module to guide nurses' interventions during encounters with this potentially vulnerable population. Finally, recommendations for future research and an epilogue of the researcher's experience are offered.

Several findings that represent the participants' perspectives helped to inform a description of the Mexican cultural influences on grieving parents. For example, public education in Mexico is free up to the ninth grade (USDOE, 2003). To continue one's education after this time requires a major financial commitment for the family. The participants in this study, as compared to other studies conducted with Mexican American populations in this United States-Mexico border region (McEwen, Pasvogel,

Gallegos, & Barrera, 2010; McEwen, Baird, Pasvogel, & Gallegos, 2007) and national statistics of Hispanics in the United States (Pew Hispanic Center, 2008) had a high level of formal education. Five of the six participants had at least a high school education and three of the participants had post high school education (Table 3). Most foreign-born Hispanics living in the United States have less than a high school education (Pew Hispanic Center, 2008).

Acculturation is a second finding that illustrates the cultural influences on these grieving parents. The “very Mexican oriented” level of acculturation (Cuellar et al., 1995b, p. 285) was an unexpected finding when juxtaposed with the number of years in which they had lived in the United States (10 to 38 years with a mean of 24 years). One might expect that the level of acculturation might have shifted from “very Mexican oriented” to a “Mexican-oriented to approximately balanced bicultural” level of acculturation (Cuellar et al., 1995b, p. 285). Dissimilarly, the Mexican American college population studied by Oltjenbruns (1998) was described as “Very assimilated, Anglicized” (p. 146). Participants’ level of acculturation remaining “very Mexican oriented” speaks to the preference of immigrants to locate in an area in the receiving country where their cultural values and norms are integrated and sustained in the normal daily rhythm of their community and daily life (Falcon et al., 2001). The influence of acculturation on parental grieving was demonstrated by participants in Mexican cultural rituals. For example, the participants have altars in their homes and take part in culturally specific rituals for the death such as *El Dia de los Muertos*. The researcher’s description



and interpretation of the participants' perceptions of cultural influences on grieving the death of their child will be elucidated in the discussion of the findings.

### **Mexican Cultural Influences on Grieving Parents**

The overarching cultural theme: *El Dolor de los Padres* is an expression of the participants' grief and pain in their experience with the death of their child. The expression of *dolor* was repeated numerous times during participants' interviews. Clarification and validation of the researcher's interpretation of the word *dolor* was sought by consultation with the translators and participants. Participants explained that *dolor* was the pain that they continue to suffer long after the death of their child that was being expressed. The word *dolor* also means grief (Castillo & Bond, 1987, p. 110). Clarification and validation of the researcher's interpretation of the word *de*, in this context was also sought, because, *de* is usually interpreted as "of" (Castillo & Bond, p. 98), but after checking with the translators and with some of the participants, it was made clear that it is the pain "in" the parent that is being described. Therefore the interpretation of the meaning of the overarching cultural theme, *El Dolor de los Padres*, is stated as *The Pain in the Parent*. The major themes supporting the overarching cultural theme were identified as, (a) *Enduring Great Pain*, (b) *Voices of Mexican American Parents*, (c) *Cultural Death Traditions*, and (d) *Going Forward: For the Provider*. The final major theme, *Going Forward: For the Provider* was used to inform a continuing education module for nursing.

*El Dolor de los Padres* explains the pain and grief that is suffered by Mexican American parents who have experienced the death of their child. The impact of this pain

on the parents is partially explained by the ages of the children who died (Table 2).

Wright (1994, pp. 174-176), an evolutionary psychologist, states that parents of children who die in their late teens suffer the greatest bereavement, because: (a) the child is at his maximum potential for his life's possibilities, (b) their child's personality is well developed, and (c) the child's future being discernable with a great deal of certainty.

Having that potential cut short for the Mexican American parents grieving the death of their child was evidenced in the trauma and in the painful memories that the parents expressed. Seven of the nine children were in their teens or early twenties when they died. Following this train of thought as presented by Wright, the parents knew these young people well and knew their potential. Two of the parents suffered the death of two children in this category, which one would anticipate might make their loss even more painful and traumatic. Additionally, Oltjenbruns (1998) reported a greater intensity of grief among Mexican Americans upon learning of a sudden, traumatic death, of which six of the seven children in their teens or early twenties suffered. Reyna, the mother of the young man who died of cancer in his early twenties, knew of her son's impending death. She was prepared when his friends came to play mariachi music as he lay dying. The time for preparation and acceptance to a degree helped her with her grief, and buffered the acute traumatic pain that was experienced by the other parents experiencing sudden death of their teenagers and young adults. Reyna's anticipatory grief diffused some of the intensity of her grief and is reported by Munet-Vilaro (1998) as predictable.

The *illogical disruption of the order of things* was expressed by the fathers in the study. It was hard for them to understand and accept that their child had died when that

child was healthy and strong and full of life. The cultural death traditions are one mechanism that the parents used to help negotiate their pain. The pain in the Mexican American parent after the death of their child was also reported to be more acutely felt by parents of Mexican origin as compared to Anglo parents. One participant specifically stated that those of his culture had deeper feelings and suffered more pain than an Anglo would in this situation.

### ***Familismo***

The findings in the study support Clements et al. (2003, p. 21) assertion and recognition of the immediate and extended family as the major source of support for grieving Mexican American families and has been recognized and reported in other studies (Callister, 2006, p. 229; Munet-Vilaro, 1998, p. 1763; Younoszai, 1993, p. 76). The cultural concept of *familismo* explains a lot of the support that the grieving parents received. Although friends and others, such as acquaintances from their churches also offered support, the greatest support was from family.

It is common for extended family members to reunite at the time of a death in the Mexican American family (Younoszai, 1993, p. 76). The extended family was available and around the participants at this time more than at any other time, and was noticed by the parents in this study. The Mexican American parents grieving the death of their child know that they can count on *la familia*, for support by way of monetary gifts, presence and to understand the depth of their pain.

### ***Machismo***

*The father's perspective* describes the unique experience of the Mexican American fathers interviewed in this study. A focused literature search of studies reporting the grief of Mexican American fathers who had experienced the death of a child revealed only one study that reported on the grief of Mexican American men. Esqueda-Arteaga (2006) used self report questionnaires to collect data on the relationship between acculturation, gender and grief with regards to experiences of grief among Mexican American adults. She reported gender not to be significantly associated with higher levels of grief, but that that unlike predicted men overall, Mexican American men reported higher levels of grief following the loss of a loved one. No studies were found in the literature that specifically described the impact of the death of a child on the Mexican American father, including Doran and Hansen's (2006) article on the grief of Mexican American Families after the death of a child. Doran and Hansen recruited nine family members, of which three generations were interviewed, including grandparents, mothers and siblings of the child who had died, but no fathers were interviewed.

*The father's perspective* illustrates the influence of the cultural value of *machismo*. *Machismo* is personified by the man who takes seriously his responsibility for the welfare of his family and the protection of his wife and children and their honor (de la Torre & Estrada, 2001). There are socially sanctioned behaviors that are expected, relative to *machismo* (Aros et al., 1999). The expectation that men do not cry is one of those socially sanctioned behaviors (Aros et al.). Two of the fathers went back to work immediately, thinking that their role was to continue to care for the family and to keep

the home protected. Getting back to work and keeping the home stable was seen as the task of the Mexican American men with the exception of Tomas who engaged in drugs and alcohol use as a way of dealing with the pain suffered after the death of a child. Both Samuel and Xacob had witnessed other Mexican American men turn to drugs and alcohol after the death of a child. Tomas's choice of turning to drugs and alcohol came after the second death of a child in his family. The influence of the Mexican cultural value of *machismo* was demonstrated when he moved his family out of Mexico after the death of his 2 year old daughter to pneumonia. Tomas sought to keep the rest of his children and family safe and protected. With the death of his son, he was, no doubt, overwhelmed by the inability to provide that protection.

The Mexican American fathers in this study found it difficult to cry in the presence of others. Samuel said, "I think, we think we should help, and be alone to cry, without people knowing about it, because our tradition is: Men don't cry, but you feel it, you feel it." He was voicing the importance of the father being available to help, support the family, and furthermore the importance of suppressing the need to cry until one is alone. Xacob did not believe that it was *machismo* that kept him from crying. He specifically stated that he did not believe in *machismo* because he is an educated man, and implied that his level of education had moved him beyond the cultural influence of *machismo* and yet that cultural value could be ingrained deeper than is acknowledged at this time. Further exploration of the cultural value would be required to tease out the intersecting influences of machismo and grieving. His "very Mexican oriented" level of acculturation (Cuellar et al., 1995b, p. 285) is evidence that it is possible that he is

affected by the cultural influence of *machismo* despite his education or overt awareness of that influence. At this point, Xacob's response represents a negative case in comparison to the responses of the other men. A negative case lends credibility to the study (Hammersley & Atkinson, 2007; Lincoln & Guba, 1985). Purnell (2005, p. 298) specifically states that Mexican American men often approach death stoically and that a lack of an open display of emotion in no way indicates a lack of caring on the part of the mourner.

### ***Marianismo***

*The mother's perspective* describes the experience of the Mexican American mothers interviewed in this study and illustrates the influence of the cultural value of *marianismo*. The cultural concept of *marianismo* is based on the figure of the Virgin Mary in the Catholic Religion, with the expectation that women suffer, and place the needs of her children and husband above her own, as one who oversees the family home (de la Torre & Estrada, 2001, pp. 107-108, 130). Valeria demonstrated *marianismo* in her statement of 'consecrating' herself to her son during his lifelong need for constant care.

Reyna expressed that her grief was significant specifically because she was the mother of a young man who died. Xacob voiced concern about those who believe that the grief of the mother is greater than the grief of the father, but from Reyna's point of view, there could be a basis for that concern, especially within the Mexican American community.

### *Spiritualidad*

The major theme, *Cultural Death Traditions* is steeped in the spirituality (*spiritualidad*) that the Mexican American parent calls upon to honor their child at their death. This honoring of the deceased was observed and reported during the rituals of the funeral and afterwards, especially with the cultural ritual of the creation and maintenance of an altar in remembrance of the child, even as the years pass. The most traditional Mexican American families are Catholic, and their belief system with regards to death is influenced by their Aztec roots, where death is considered a part of life (Munet-Vilaro, 1998; Purnell, 2005, Younoszai, 1993). Five of the six participants stated that they were of the Catholic faith, and one participant stated that he was of the Christian faith.

The funeral, for most traditional Catholic families, will occur as soon after the death as possible, with a prompt burial desired (Younoszai, 1993, p. 76). Although cremation is not encouraged by the Catholic Church (Purnell, 2005, p. 298; Younoszai, p. 76), six of the nine children were cremated. Cremation is less expensive than burial and economics may have been a motivating factor in their decision. However those data were not collected. Socio-economic status is implied in the status of the participants' recruitment from St. Elizabeth's Health Center. The clinic provides a sliding fee for health care services with the intention of serving the uninsured and underserved population (St. E's, 2005-2010). Reyna's son specifically asked to be cremated so that he could feel free and have his cancer completely destroyed. That wish was honored by his family. Reyna keeps a little of her son's ashes in a container on an altar in her home and Samuel carries some of his son's ashes in a pouch on a thong around his neck to keep him

close, and not be separated from him. Some of the parents specifically stated that they knew it was a non-traditional thing to do, to have their child cremated.

*Novenarios*, the nine days of mourning after the death are significant for practicing the ritual of rosaries. Rosaries are said in front of the home altars to honor the child who has died. Participation in the *novena* is related to higher levels of immersion in Mexican culture and lower levels of acculturation (Esqueda-Arteaga, 2006). Some of the participants took part in this ritual. The “very Mexican oriented” acculturation of all of the participants in the study as evidenced by their ARSMA-II scores (Cuellar et al., 1995b, p. 285) makes their participation in the *novenas* evidence of the importance of this cultural influence to their bereavement an expected finding.

The conceptual category, “*El Dia de los Muertos*” and *Cemetery Events* represents the significance of the cultural value of *spiritualidad*. All of the participants stated that they participate in the event of *El Dia de los Muertos*. Participation in the event of *El Dia de los Muertos* has been related to higher levels of immersion in Mexican culture (Esqueda-Arteaga, 2006). *El Dia de los Muertos* provides a cultural event for honoring the child who has died and is “an important part of the cultural matrix” (Fierro, 1980, p. 401). Christmas and other major holidays are commonly celebrated at the cemetery. Birthdays and the anniversary of the child’s death are other major days of visitation. Many of the participants visited the cemetery frequently when the child first died and then, as time passed, the visits became less frequent. Doran and Hansen’s (2006) overarching cultural theme, *Maintaining a Bond With the Deceased*, is echoed by this



study's conceptual category, *In the Presence of the Child*, and explains the spiritual connection that is sought by the grieving parents

The meaning of ritual in the context of the Mexican American parents grieving the death of their child was best exemplified by the conceptual category *In the Presence of the Child*. Participants' stories repeatedly expressed their desire to be close to the child, talk to the child, pray for them, and keep the memory of their child alive. That closeness is accomplished at the cemetery during cultural events and in an ongoing basis at the home altars that honor the child who has died. Only one participant stated that he did not have an altar in the home. However, his former wife has one in her home for their children who died. This participant spoke about spending time in the cemetery with his son. Just as this category was emerging, the final participant invited the researcher into her bedroom to sit at her son's altar and be in his presence. The finding of Mexican American people experiencing a perception of their loved one in their midst is reported in the literature (Kalish & Reynolds, 1973, p. 219-220; Shapiro, 1995).

The spiritual belief system of the Mexican American parent who has experienced the death of their child is deeply rooted in spirituality, religiosity, and tradition. The historical origins of the spirituality are grounded in the Aztec belief system where life and death are seen as opposite but complementary parts of the life cycle (Munet-Vilaro, 1998). Spirituality in combination with Roman Catholic religiosity (de la Torre & Estrada, 2001; Doran & Hanson, 2006; Estrada, 2009) contributes to the continuing honoring of the spiritual presence and bond between the Mexican American parent and the child who has died. *In the presence of the child* represents the intersecting influences

of spirituality, religiosity, and grief among Mexican American parents who have experienced the death of their child. The relationship of Mexican cultural influences on the grief of Mexican American parents who have experienced the death of their child is great. A description of the grief of Mexican American fathers after the death of their child is noted as a salient finding, and was not found to be previously reported in the literature.

### **Relationship of Findings to Concept of Vulnerability**

The concept of vulnerability provided a framework for interpreting the results of this study. The Mexican American parents who have experienced the death of their child were identified as susceptible to the spiritual, emotional and/or physical consequences of their bereavement. The susceptibility of the parents to the effects of grief was evidenced in the physical, emotional, and spiritual suffering they expressed.

Mexican American parents who experienced the death of their child demonstrated spiritual vulnerability, especially for those experiencing the death of an adolescent or young adult (Wright, 1994). This somber and grim experience has the capacity to engender questioning of the core spiritual beliefs (de la Torre & Estrada, 2001; Doran & Hansen, 2006; Estrada, 2009; Munet-Vilaro, 1998) of the Mexican American parent who has experienced the death of their child. Samuel specifically remembers questioning G-d. And Reyna also expressed that she had voiced questions even though her faith in G-d had not wavered. The questioning of faith places the Mexican American parent who has experienced the death of their child at risk of distress and spiritually vulnerable.

The emotional vulnerability of the Mexican American parent who has experienced the death of their child was most illustrated by the conceptual category:

*Losing self.* The fathers running away to grieve and one father turning to drugs and alcohol are illustrative of the emotional vulnerability they exhibited in the experience of their grief. One father talked about his wife's going into her room and not wanting to come out, and his caring for her until she was able to face the world again. Situational depression is an important symptom and an understandable consequence of bereavement (Stroebe et al., 2007). It is an important symptom to note and observe for complicated grief and worsening depression that would require psychological or medical intervention.

Physical symptoms related to grief may include headache, dizziness, indigestion, chest pain, and hypertension among others (Stroebe et al., 2007). Although none of these specific symptoms were mentioned by the participants in this study they are included here as findings from the literature that a nurse or other health care provider could be presented with in their clinical practice. One possible explanation for the participants in this study not reporting a physical symptom is the length of time since the death of their child. The rationale for the inclusion criteria, two years since the death of the child, was selected to give the participants' time since the first reactions to their grief, and to allow time for the process of grief to unfold and to allow for reflection on their experience. This is the same criterion that was used in the Doran and Hansen study (2006, p. 202). The tincture of time may have erased some of the memory of the physical symptoms related to grief in the Mexican American parents participating in the present study.

### **Interconnectedness of Vulnerabilities**

The interconnectedness of vulnerabilities is recognized in the bereavement of the Mexican American parent who has experienced the death of their child (Figure 1). The

current bereavement model with an expectation of detachment from the deceased (Bowlby, 1980) is juxtaposed with the Mexican cultural concept of *spiritualidad* (Shapiro, 1995), and if neither honored nor recognized, a potential for emotional suffering is created. The overarching cultural theme of the present study *El Dolor de los Padres*, echoes the notation by Doran and Hansen (2006) of no one in their study mentioning “moving on” (p. 206), or other terms associated with the breaking ties model of grief (Bowlby). This is supported by the participants’ request that the nurses and other health care providers know that the grief of Mexican American parents who have experienced the death of a child does not go away. And within a cultural context events that honor the child and keep them in their presence are critical to the way they go about living their everyday life. Nurses and other health care providers could unintentionally inflict harm and suffering in both a spiritual sense and an emotional sense by not being knowledgeable of or recognizing the cultural values that contribute to keeping the child in the presence of their parent. Physical symptoms may also be the first presenting problem seen by nurses that could be linked to the emotional vulnerability a Mexican American parent who has experienced the death of a child is experiencing. Close physical proximity in the Mexican American culture is another way of demonstrating *respeto*. For example, the provider might touch the bereaved and acknowledge the importance of the continued memories. These behaviors were noted as important by some of the participants and illustrate the connection with the potential for vulnerability between the physical and spiritual realms of being. These findings are discussed further under the topic *Significance for Nursing Practice*, later in this chapter.

### **Strengths and Limitations of the Study**

A strength of this study was the inclusion of fathers and mothers. This is the only study that was found that describes the grief experienced by Mexican American fathers whose child has died. Esqueda-Arteaga (2006) explored the relationship between acculturation, gender, and experiences of grief among Mexican American adults, and some of the members of the study could have experienced the death of a child, but the grief experienced by the father was not specifically reported.

Another strength of this study is the homogeneity of the study participants, who shared the same level of acculturation despite differing lengths of time they had lived in the United States. The interviews were all conducted in Spanish, the first language of the participants, by the researcher who is fluent in Spanish. Most interviews took place at the homes of the participants, by their choice, giving the researcher an opportunity to view the altars and artifacts in the homes that are maintained by most of the participants. The ability to converse with the participants in Spanish and to be in their homes contributed to the credibility of the study. The meticulous transcription, translation, and back translation of the documents by CITI certified research assistants support strength of the study. The ethnographic record is relatively complete with regard to the specific population that was studied. Saturation of data is evidence of referential adequacy and credibility (Lincoln & Guba, 1985).

Time constraints were the main limiting factor in determining which family members to include in the present study. With less constraint on time, the study could be expanded to include the extended family.

An unexpected finding in the study was the discovery of the uniqueness of the grief of the Mexican American father. A second unexpected finding that was incongruent with the social norms of the Catholic Church was the cremation of six of the nine children who had died.

### **Reflexivity and Trustworthiness**

Reflexivity was achieved through the researcher's continuous self critique of bias, assumptions and ideology (Lincoln & Guba, 1985; Powers & Knapp, 2006; Wolf, 2007) by keeping a field note journal and recording personal thoughts and feelings after interviews and during participant observations (Lincoln & Guba; Spradley, 1979). Reflexivity is integral to an ethnographic study. Reflexivity was demonstrated when Samuel, the only participant who had not been told that the researcher had also experienced the death of a child, was stating, along with raised eyebrows, that the researcher could not possibly understand what it was like to suffer the death of a child; only those who had that experience could understand. Although the researcher had a child who died, this was not revealed to the participant until after the final interview. The process of reflexivity was accomplished through journaling- maintaining the role of researcher, the boundaries required by participant and researcher during the conduct of the study. Samuel offered an *abrazo*. He may have been relieved to know the researcher was not just a curious person, that it was a study of the heart. An assumption held by the researcher is that Mexican American parents who have experienced the death of their child receive culturally insensitive care by nurses and other health care providers. This may be due to a knowledge gap in which case bridging that gap by disseminating a

continuing education module about the findings in this study may lead to culturally sensitive care that demonstrates *respeto*, *personalismo*, and *confianza*.

Trustworthiness is demonstrated by establishing credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Rigor and credibility in this study of Mexican American parents' perceptions of cultural influences on grieving the death of their child were accomplished by reading and re-reading the interview transcripts and reflecting on the data before committing it to a conceptual category (Hammersley & Atkinson, 2007; Lincoln & Guba, 1985). A field note journal was used to document the researcher's personal thoughts and observations during the entire study, supporting credibility (Lincoln & Guba). The credibility was further heightened by the performance of participant observations as well as prolonged engagement, with the researcher working with the Mexican American community as a Family Nurse Practitioner for 13 years. The use of participant observation, interviews, field notes, and photography, as well as multiple sources of data to evaluate the acculturation of the participants, strengthens the credibility of the study. The ARSMA-II (Appendix E) and the demographic questionnaire (Appendix D) were used to describe the cognitive referents of acculturation in the study participants. Peer debriefing was accomplished by regular meetings with the Practice Inquiry Chair, who is familiar with the Mexican American culture, cultural norms, values and rules, and how they influence health care beliefs and practices. All interview transcripts were reviewed with the Practice Inquiry Chair, supporting credibility through peer debriefing (Lincoln & Guba). Member checking was accomplished by the researcher

inquiring of the meaning of significant words and concepts with members, also establishing credibility (Lincoln & Guba).

Transferability was accomplished by the *thick description* available in the reporting of the findings in Chapter Five, especially the transcripts of the participant observations that are included as data. Dependability is assured by the researcher documenting all data and interviews being organized with pseudonyms, and running line numbers in the transcripts that were translated and back translated for accuracy (Jones et al., 2007). Confirmability was established with the data linking to the study questions in a meaningful way, as established by the raw interview transcripts, and field note journal (Lincoln & Guba, 1985).

### **Significance to Nursing Practice**

The focus of this study is in alignment with the Institute of Medicine's (IOM) (2001) mandate to provide patient-centered, individualized care that includes compassion, and responsiveness to the needs and values of the patient (p. 48, 69-70) and the set of standards for cultural competence in nursing practice, recently released by the American Academy of Nursing's Expert Panel on Global Nursing and Health (AAN, 2010). The significance of this study to the practice of nursing was addressed specifically by the second research question that guided this study: What in the cultural experience of parents' grieving can guide nurses to deliver culturally sensitive care to Mexican American parents who have experienced the death of a child? The interview questions in the present study specifically sought a description of Mexican American parents' perceptions of cultural influences on grieving the death of their child and further



addressed the participants' thoughts on what they found both helpful and not helpful when remembering encounters with nurses and other health care providers at the time of the death of their child (Appendix F). The major theme: *Going Forward: For the Provider* gave voice to the participants' experiences with the health care system after the death of their child. Two cultural categories were identified within this theme: *Things You Need to Know* and *What We Would Like From You*.

The cultural category: *Things You Need to Know*, specifically asks providers of care to know that the support that the Mexican American parent who has experienced the death of a child needs is continuous because of the continuing memories, the mandate not to forget the child, the continuing bond that the parent will maintain with their deceased child and to know that, although time may erase the acute pain, the parents continue to suffer. Finding a way to alert nurses to the status of the patient with regards to their grief and loss is imperative. In the chart a notation can be made on the medical record. International Classification of Diseases, 9<sup>th</sup> Revision (ICD-9) (Hart, Stegman & Ford, Eds., 2009) codes that can be used for this purpose include: 309.0 Grief Reaction or 309.0 Mourning. Bereavement that is uncomplicated can be coded as V62.82. It can sometimes be helpful to include in an additional information space the name and age of the child and the cause of death.

Nurses need to look further when presented with Mexican American patients who are using alcohol to excess or have become involved in the abuse of street or prescription drugs. Inquiring about emotional traumas that the patient may be experiencing and seeking to understand root causes for the patient to be committing harmful behaviors is

important but will not occur until *confianza* has been established. The awareness of the use of alcohol and drugs to assuage the pain of grief in Mexican American fathers experiencing the death of a child is important for nurses to be aware of as clinicians who care for this population. Asking about possible loss of a loved one when a nurse is presented with a Mexican American man who is using alcohol or drugs is important to discover the precipitating factors involved in their choices.

The cultural category *What We Would Like From You* demonstrates the importance of knowing what to say, how to say it, and to whom. The Mexican American mothers participating in the present study voiced a need to hear words of support and understanding. They want the nurse who is providing care to reflect on the pain, and offer solidarity. An offering of: “*Lo siento*”, “I am sorry”, may be heard as a nurse giving a kind reply, but the fathers specifically voiced the need for those providing support to withhold shallow words, and that they were more discerning of the tone of voice, and did not want to hear, “*Lo siento*” unless it was offered with heartfelt sincerity. It is proposed that if nurses come to know that they are caring for a Mexican American father who has experienced the death of a child that they first stop and think of what they want to say and how they are going to say it. Stating that they know that the words are hollow in comparison to the grief that the Mexican American parent is experiencing, and yet offering one’s most heartfelt response will at least demonstrate supportive care that is being offered in an attempt to comprehend some of the parents’ pain. It is important for nurses to make an effort to let the fathers know that their grief is equally as acknowledged as the mother’s grief.

The practice of nursing includes the awareness of more than the physical ailments that patients present with, and knowledge of how to approach a vulnerable population when offering care is the most important underlying significance of this study. The findings are specific to understanding and eliminating disparities in the care of Mexican American parents who have experienced the death of a child. The basic tenets are transferable with regards to the expectation of culturally competent care (AAN, 2010). What is most important is for nurses to remain cognizant of the Mexican American parent who has experienced the death of a child, within their culture, while withholding judgments and assumptions about cultural stereotypes (Zack Ishikawa et al., 2010).

Munet-Vilaro (1998) offers guidelines to understand and assess the responses of the Latino population to bereavement. The present study was conducted with participants of Mexican American descent, but Munet-Vilaro points out that the Latino population comes from many countries, each with an individual culture, and an effort needs to be made to understand the different cultures before attempting to give culturally sensitive care in times of bereavement. Munet-Vilaro also recommends consulting with extended family members for information about the values of the family and death traditions. Healthcare providers are encouraged to share a bit of their personal beliefs about grieving in a nonjudgmental way to engender confidence (*confianza*). Finally, the author recommends that those communicating with the population who are not fluent in the Spanish language use a trained translator so that accuracy of information can be assured. Munet-Vilaro's suggested guidelines offer an opportunity to provide culturally sensitive

care during the times of grief for a Mexican American parent who has experienced the death of a child.

Discovering which Mexican American parents have suffered the death of a child is the first challenge that a nurse faces in the attempt to provide support. One of the ways to discover the number of deaths of children that a mother has actually suffered is by asking her about her pregnancy and birth history. By finding out how many pregnancies, births, miscarriages and live children she has, a simple calculation can tell a health care provider whether there is a discrepancy and one seeking to know, can ask about it. Two of the women in the study had suffered the death of one child and one woman had experienced the death of two children. Mexican American fathers who have experienced the death of a child may or may not share the information about the occurrence of a death of a child with nurses as easily. Therefore it is important for nurses to have a higher awareness of that possibility. Depression, sadness, drug or alcohol abuse, multiple or specific body system complaints that are not correlated with a specific cause are clues to inquire of a Mexican American man of a possible grief over loss.

### ***Respeto, Confianza, and Personalismo***

The cultural concepts of *respeto*, *confianza*, and *personalismo* are more than words that imply a nurse should be polite. These cultural concepts are rules of behavior and engagement that are specific to the Mexican culture and if violated will not cause irreparable harm, but rather most likely effect disrespect and disconnection where there could be a relationship leading to meaningful care (Clements et al., 2003).

The fathers in the study all reported a time in which they had to distance themselves from the people who were offering them support. They did not get a lot of comfort from the words of others, in contrast, to the mothers in the study that specifically sought and derived support from the words of others. This was especially true, for the fathers, if the words sounded hollow to them, were rote phrases, and without sincerity, but rather the polite thing to say. In getting away and spending time alone, a sense of peace was achieved by some of the fathers. Specifically, all of the Mexican American fathers did not want to hear words of support or questions that were rhetorical. The fathers could discern one's intent by the tone of voice. The ability for those of Latino heritage to note the quality of warmth in providers of health care has been previously identified (Zack Ishikawa et al., 2010, p. 1567). Nurses need to have awareness that the sincerity of the tone of their voice may be able to be detected when offering condolences or care, especially to the Mexican American father who has experienced the death of a child. It may be that asking what is appropriate to say or offer would be the best reply, if one is unsure of the sincerity of their response. That would at least show interest and caring, and hopefully engender *confianza* and *personalismo*.

The Mexican American fathers noted a discrepancy between the attentions that the Mexican American mothers, who were also grieving the death of a child, received as compared to the attention they were offered. The fathers noted that the support was often offered to the mother rather than the father, which they guessed may have been in part because the mother had "carried the baby inside." The fathers wanted others to know that the pain they suffered was the same as the pain that the mothers demonstrated. It is

important for nurses and other health care providers to be aware that the grief suffered by Mexican American parents whose child has died is the same in the father and the mother despite the mother being more demonstrative in her expressions of bereavement.

The participants want nurses to know that the pain of losing a child does not go away with time and that the support they offer should be continuous. A strategy to prompt continued support by the nurse might be accomplished by including information about the death of the child on the problem list and notes in the medical record. This could be a reminder to prompt the nurse to acknowledge the child's death and "check in" with the parent about their grieving process. This strategy will also promote *confianza* and *personalismo*.

Referrals to counseling or psychological support need to be respectfully and sensitively explored and discussed with the Mexican American parent who has experienced the death of a child (Zack Ishikawa et al., 2010). A nurse referring a Mexican American parent who is grieving the death of a child to counseling has the capacity to influence the outcomes of that utilization process by their manner in addressing the offer of counseling or psychological support (Zack Ishikawa et al.). Counseling may or may not be right for the parents at any given time, but the recommendation is to assess the parent's receptivity to this source of support. It may be more helpful for the Mexican American mother who is grieving the death of her child, because of her propensity to want to talk and hear words of encouragement, in contrast, to the Mexican American father who has more skepticism of "pretty words." Nonetheless, a heartfelt and well intentioned offering will be seen as caring, and

compatible with the cultural values of *respeto*, *confianza* and *personalismo*. This is juxtaposed with a pat answer and blanket statement which may be heard with suspicion of shallowness and would be culturally insensitive. A nurse who sensitively acknowledges complementary coping strategies such as continuing involvement in the church demonstrates support, understanding of the culture and *respeto*. (Zack Ishikawa et al.).

An *abrazo* or a hug or simply touching the Mexican American parent that is bereaved demonstrates *respeto* (Clements et al., 2003, p. 21) and should at least be offered by the nurse because to withhold that expression may demonstrate disrespect. The recognition of the rules of offering respect to the bereaved will be noted by the patient if it is extended thereby engendering *confianza* and *personalismo*.

Recommendations for responding to Mexican American parents who are grieving the death of a child that were generated by study participants were used to develop a continuing education module for nurses (Appendix G). The continuing education module provides guidelines for culturally sensitive interventions with Mexican American parents who have experienced the death of a child. The goal of the module is to inform nurses involved in the care of Mexican American parents who have experienced the death of a child about Mexican cultural values and beliefs that underpin their grieving, which could adversely affect their health. Potentially, the increased nursing knowledge, cultural competence, and culturally sensitive interventions could decrease the vulnerabilities associated with the death of a child.

### **Implications for Future Research**

Future research with the Mexican American population who has experienced the death of a child can be strengthened by the inclusion of the experience of the extended family. Likewise, a study to extend and further explore the specific grief of the Mexican American father who has experienced the death of a child will further inform and add depth to our knowledge for delivering culturally competent nursing care.

### **Summary**

Chapter Six provided a discussion of the findings of the study with regards to Mexican American parents' perceptions of cultural influences on grieving the death of their child and the relationship of the findings to the concept of vulnerability. The strengths and limitations of the study, a discussion on reflexivity and trustworthiness, the significance to nursing practice, and implications for future research were also presented. A continuing education module was developed with the objectives of asking the nurse to: (a) list Mexican cultural influences that may affect the care of parents grieving the death of a child, (b) identify what may be seen as unique about the grief of Mexican American fathers, and (c) describe two cultural values that Mexican American parents who are grieving the death of a child would like integrated into the care they receive from nurses, in order to acquaint themselves with the information provided in this valuable study.



### **Epilogue: The Researcher's Experience**

*"With a strong death tradition,  
a strong tradition for life is possible..."*

Quote: Patrisia Gonzales, Ph.D., Professor of American Indian Studies  
The University of Arizona

Lecture: The University of Arizona, Mexican American Studies:

"Sana, sana. Don't worry my grandma rubbed an egg on me:  
Traditional medicine and self determinism"

October 29, 2009

The participants in this study of Mexican American parents' perceptions of cultural influences on grieving the death of their child illuminated the importance of *spiritualidad*, continuing memories, and the importance of offering culturally sensitive care at this time of deep emotional pain. This study illustrates the willingness of people to share their stories that represent the pinnacle of pain, not easily assuaged. The participants also represent the resilience of human spirit, and the importance of knowing ones roots and culture so well, that even when choices are made that are not in alignment with the culture, they are done in the spirit of beauty and honor, and with *dignidad*. Now informed by the emic perspective of the stories of these six participants, the researcher is challenged to move forward to carry on with the opportunity to continue to encourage other nurses and other health care providers to heighten their awareness of the pain that is suffered by Mexican American parents who have experienced the death of a child and do what they can to demonstrate *respeto*, *confianza*, *personalismo*, and care.

APPENDIX A: INFORMED CONSENT DOCUMENTS

INFORMED CONSENT (ENGLISH)

INFORMED CONSENT (SPANISH)

THE UNIVERSITY OF ARIZONA HUMAN SUBJECTS PROTECTION PROGRAM  
INFORMED CONSENT FORM

*For IRB Office Use Only:*

APPROVED BY UNIVERSITY OF AZ IRB  
THIS STAMP MUST APPEAR ON ALL  
DOCUMENTS USED TO CONSENT SUBJECTS.  
DATE: 06/29/10 EXPIRATION: 06/28/11

Project Title: ON GRIEVING THE DEATH OF A CHILD:  
AN ETHNOGRAPHY OF THE CULTURAL INFLUENCES ON GRIEF  
IN MEXICAN AMERICAN PARENTS

**You are being invited to take part in a research study being conducted by The University of Arizona. You are being asked to read this form so that you know about this research study. The information in this form is provided to help you decide whether or not to take part. If you decide to take part in the study, you will be asked to sign this consent form. If you decide you do not want to participate, that is okay. There will be no penalty to you and you will not lose any benefit which you would normally have.**

**WHY IS THIS STUDY BEING DONE?**

This study is being done to: (1) to explore the cultural influences on the grief of Mexican American parents who have experienced the death of a child and, (2) to use the findings to develop a continuing education model for nurses and other health care practitioners involved in providing care to Mexican American parents grieving the death of a child.

**WHY AM I BEING ASKED TO BE IN THIS STUDY?**

You are being asked to be in this study because you are:

- (a) Mexican origin parents, 18 years of age and older, who have experienced the death of a child,
- (b) that occurred when your child was an infant through 25 years of age,
- (c) your child was living in your home at the time of the death,
- (d) your child's death was at least 2 years prior to this study,
- (e) you receive your health care from St. Elizabeth's Health Center in Tucson, AZ.

**HOW MANY PEOPLE WILL BE ASKED TO BE IN THIS STUDY?**

EIGHT PARENTS (participants) will be enrolled in this study locally. Overall, EIGHT PARENTS will be enrolled at ONE study center. Only parents are being asked to participate.

**WHAT ARE THE ALTERNATIVES TO BEING IN THIS STUDY?**

The alternative is not to participate.

**WHAT WILL YOU BE ASKED TO DO IN THIS STUDY?**

Your participation in this study will last up to THREE WEEKS and includes TWO SIXTY TO NINETY MINUTE audio taped interviews.

The first visit will last about NINETY TO ONE HUNDRED AND TWENTY MINUTES. During this visit YOU WILL COMPLETE TWO QUESTIONNAIRES AND YOU WILL BE INTERVIEWED. The questions you will be asked on the questionnaires will tell the researcher about yourself and your family. The questions are about personal information such as age, gender, and the date of your child's death. Other questions will ask about the extent to which you are affiliated with the Mexican culture.

Version Date:

Page 1 of 3

Subject's Initials \_\_\_\_\_

If you consent, photographs may be taken of a home altar. If a photograph is taken of the altar containing a picture of your child, the face will be blurred so that your identification and that of your child will be protected.

Approximately TWO to THREE WEEKS later a SECOND INTERVIEW will take place, to give you the opportunity to say more about the topic, after you have had a chance to think about it.

#### **WILL VIDEO OR AUDIO RECORDINGS BE MADE OF ME DURING THE STUDY?**

##### ***Required recordings:***

The researcher will make an audio recording of each interview. The audio recordings will be transcribed and translated by a bilingual member of the research team. Any personal identifying information will not be transcribed, the audio recordings will be de-identified. The audio recording will be destroyed by the researcher after the study is completed.

##### ***Optional recordings:***

The researcher may take photographs of altars or other cultural symbols honoring the death of your child. This will occur only if you give your specific permission to do so. The photographs may be used in a presentation of this study at The University of Arizona, College of Nursing, at the end of this study. The photographs will not be published. Initial your decision below.

\_\_\_\_\_ I give my permission for photographs to be taken of altars or other cultural symbols honoring the death of my child during my participation in this research study.

\_\_\_\_\_ I do not give my permission for photographs to be taken of altars or other cultural symbols honoring the death of my child during my participation in this research study.

#### **ARE THERE ANY RISKS TO ME?**

The things that you will be doing have no more risks than you would come across in everyday life. Questions that you will be asked may cause sadness as a result of your memories of the event of the death of your child. You do not have to answer anything you do not want to. The interview may be terminated by you at any time.

#### **ARE THERE ANY BENEFITS TO ME?**

There is no direct benefit to you by being in this study. What the researchers find out from this study may help other Mexican American parents who are grieving the death of their child.

#### **WILL THERE BE ANY COSTS TO ME?**

Aside from your time, there are no costs for taking part in the study.

#### **WILL I BE PAID TO BE IN THIS STUDY?**

You will not be paid for being in this study.

#### **WILL INFORMATION FROM THIS STUDY BE KEPT CONFIDENTIAL?**

Information about you will be stored in a locked file cabinet; computer files protected with a password. This signed consent form will be filed in The University of Arizona, College of

Nursing, Office of Nursing Research.

Information about you will be kept confidential to the extent permitted or required by law. People who have access to your information include the Principal Investigator and research study personnel. Representatives of regulatory agencies such as the Office of Human Research Protections (OHRP) and entities such as The University of Arizona Human Subjects Protection Program may access your records to make sure the study is being run correctly and that information is collected properly. If there are any reports about this study, your name will not be in them.

#### **WHOM CAN I CONTACT FOR MORE INFORMATION?**

You can call the Principal Investigator to tell him/her about a concern or complaint about this research study. The Principal Investigator Audrey [Amparo] Russell-Kibble, FNP-C can be called at (520) 405-4097. You may also contact the Principal Investigator's advisor, Marylyn Morris McEwen, PhD, PHCNS-BC at (520) 626-6926.

For questions about your rights as a research subject; or if you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office.

- Local phone number: (520) 626-6721
- Website (this can be anonymous: <http://orcr.vpr.arizona.edu/irb/contact>)

#### **MAY I CHANGE MY MIND ABOUT PARTICIPATING?**

You have the choice whether or not to be in this research study. You may decide to not begin or to stop the study at any time. If you choose not to be in this study, there will be no effect on your care. You can stop being in this study at any time with no effect on your care.

#### **STATEMENT OF CONSENT**

**The procedures, risks, and benefits of this study have been told to me and I agree to be in this study and sign this form. My questions have been answered. I may ask more questions whenever I want. I do not give up any legal rights by signing this form. A copy of this signed consent form will be given to me.**

\_\_\_\_\_  
Subject's Signature

\_\_\_\_\_  
Date

#### **INVESTIGATOR'S AFFIDAVIT:**

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who signed this consent form was informed of the nature, demands, benefits, and risks involved in his/her participation.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

Version Date: 6/23/10

Page 3 of 3

Subject's Initials \_\_\_\_\_

THE UNIVERSITY OF ARIZONA HUMAN SUBJECTS PROTECTION PROGRAM  
INFORMED CONSENT FORM

*For IRB Office Use Only:*

APPROBADO POR EL IRB DE LA UNIVERSIDAD DE ARIZONA. ESTE SELLO DEBE APARECER EN TODOS LOS DOCUMENTOS USADOS PARA OBTENER EL CONSENTIMIENTO DE LOS PACIENTES.  
FECHA: 07/15/10 VENCIMIENTO: 06/28/11

Project Title: ON GRIEVING THE DEATH OF A CHILD:  
AN ETHNOGRAPHY OF THE CULTURAL INFLUENCES ON GRIEF  
IN MEXICAN AMERICAN PARENTS

FORMA DE CONSENTIMIENTO

Titulo del Proyecto: LA AFLICCION POR LA MUERTE DE UN HIJO:  
UNA ETNOGRAFIA DE INFLUENCIAS CULTURALES EN TIEMPO  
DE PESAR EN PADRES MEXICO AMERICANOS

**Usted ha sido invitado a tomar parte de un estudio de investigacion conducido por la Universidad de Arizona. Usted ha sido leer esta forma para darle informacion sobre este estudio. La informacion en esta forma es proveida para ayudarlo a decidir si quiere o no tomar parte. Si decide tomar parte en el estudio se le pedira que firme esta Forma de Consentimiento. Si decide que no desea participar no hay problema. No habra penalidad para usted y no perdera ningun beneficio que usted tiene normalmente.**

**PORQUE SE ESTA CONDUCIENDO ESTE ESTUDIO?**

Este estudio se esta haciendo: (1) para explorar las influencias culturales en el dolor que los padres Mexico Americanos ha tenido con la experiencia de la muerte de un hijo y, (2) para usar los resultados en desarrollar una educacion continua como modelo para enfermeras y otros practicantes del cuidado de salud en padres Mexico Americanos pasando en afliccion por el dolor de perder un hijo.

**PORQUE SE ME PIDE QUE PARTICIPE EN EL ESTUDIO?**

Se le ha pedido que participe en el estudio porque usted:

- a) Es padre de origen Mexicano, mayor de 18 anos de edad, que ha tenido la experiencia de la muerte de un hijo,
- b) la muerte de su hijo ocurrio entre el nacimiento y la edad de 25 anos,
- c) su hijo vivia con usted cuando murio,
- d) la muerte de su hijo sucedio por lo menos dos anos antes de este estudio,
- e) usted recibe servicios de salud en St. Elizabeth's Health Center en Tucson, AZ.

**CUANTAS PERSONAS TOMARAN PARTE DE ESTE ESTUDIO?**

OCHO PADRES (participantes) seran registrados en este estudio localmente. En total OCHO PADRES seran registrados en un estudio. Solo padres seran invitados a participar.

**CUALES SON LAS ALTERNATIVAS PARA ESTE ESTUDIO?**

La alternativa es no participar en el estudio.

**QUE SE LE PEDIRA HACER EN ESTE ESTUDIO?**

Su participacion en este estudio puede durar hasta TRES SEMANAS incluyedo DOS entrevistas grabadas de SESENTA A NOVENTA MINUTOS.

La primera visita durara de NOVENTA A CIENTO VEINTE MINUTOS. Durante esta visita

USTED LLENARA DOS CUESTIONARIOS Y SERA ENTREVISTADA. Las preguntas que se le haran en los cuestionarios le daran informacion al investigador de usted y su familia. Las preguntas seran personales, tales como su edad, su genero, y la fecha que su hijo murio. Otras preguntas seran acerca de que tan afiliado esta con la cultura Mexicana. Con su consentimiento y si tiene un altar, fotos se tomaran. Si en el altar hay una foto de su hijo, la cara aparecera borrosa para proteger la identificacion de su hijo. En aproximadamente DOS a TRES SEMANAS mas tarde una SEGUNDA ENTREVISTA sera conducida para darle la oportunidad de hablar mas acerca del tema, despues de haberlo pensado mas.

#### SE HARAN VIDEOS O GRABACIONES DE MI DURANTE EL ESTUDIO?

##### *Grabaciones Requeridas:*

El investigador grabara cada entrevista. Las grabaciones seran transcritas y traducidas por un miembro del equipo que sea bilingue. Cualquier informacion personal que lo pueda identificar no sera transcrita, las grabaciones no seran identificadas. Las grabaciones seran destruidas por el investigador despues que el estudio este completo.

##### *Grabaciones Opcionales:*

El investigador puede tomar fotos de altares o de otros simbolos culturales que honren la muerte de su hijo. Esto ocurrira solo si usted da permiso especifico para hacerlo. Las fotos se pueden usar en la presentacion del estudio en la Universidad de Arizona Colegio de Enfermeria, al final de este estudio. Las fotos no seran publicadas. Poner su inicial al lado de su decision abajo.

\_\_\_\_\_ Durante mi participacion en este estudio, doy permiso para tomo de fotos de altares o otros simbolos culturales en honor de la muerte de mi hijo.

\_\_\_\_\_ Durante mi participacion en este estudio, no doy permiso para tomo de fotos de altares u otros simbolos culturales en honor por la muerte de mi hijo.

#### HAY ALGUN RIESGO PARA MI?

En lo que usted hara no habra mas riesgo del que hay en lo que hace diariamente. Algunas preguntas que se le haran le pueden causar tristeza como resultado de sus recuerdos en la muerte de su hijo. No tiene que contestar nada que usted no desee. La entrevista puede ser terminada por usted a cualquier hora.

#### HABRA ALGUN BENEFICIO PARA MI?

No habra ningun beneficio directo para usted por participar en este estudio. Lo que los investigadores aprendan en este estudio puede ayudar a otros padres Mexicano Americanos que estan en afliccion por la muerte de su hijo.

#### ME COSTARA ALGO PARTICIPAR?

Aparte de su tiempo, no habra costo alguno por participar en el estudio.

#### ME PAGARAN POR PARTICIPAR EN EL ESTUDIO?

No se le pagara por participar en este estudio.



**LA INFORMACION DE ESTE ESTUDIO SERA CONFIDENCIAL?**

La informacion acerca de usted sera puesta en un gabinete cerrado con seguro; los archivos en computadora seran protegidos con contrasena. Esta forma de consentimiento sera archivado en La Universidad de Arizona Colegio de Enfermeria en la Oficina de Investigaciones en Enfermeria.

Informacion acerca de usted sera confidencial al extremo que permita la ley. Las personas que tienen acceso a su informacion, incluye el personal y el Principal Investigador en el estudio. Representantes de agencias regulatorias tales como la Oficina De Protecciones en Investigaciones Humanas (OHRP) y entidades tales como el Programa de La Universidad de Arizona En Proteccion de Sujetos Humanos pueden acceder sus archivos para estar seguros que el estudio ha sido conducido correctamente y que la informacion ha sido apropiadamente colectada. Si hay algun reporte acerca de este estudio, su nombre no estara en tal reporte.

**CON QUIEN ME PUEDO COMUNICAR PARA MAS INFORMACION?**

Puede llamar al Principal Investigador para comunicar cualquier queja o preocupacion acerca de este estudio. Se puede llamar al Principal Investigador, Audrey (Amparo) Russell-Kibble, FNP-C, al (520) 405-4097. Tambien puede llamar al consejero del Principal Investigador, Marylyn Morris McEwen, PhD, PHCNS-BC al (520) 626-6926.

Si tiene preguntas acerca de los derechos al sujeto de investigacion; o si tiene preguntas, quejas o preocupaciones acerca del estudio y no se puede comunicar con el Principal Investigador o quiere hablar con alguien mas, puede llamar a La Oficina de la Universidad de Arizona Programa de Proteccion a Sujetos Humanos.

- o Numero local: (520) 626-6721
- o Website (esto puede ser anonimo): <http://orcr.vpr.arizona.edu/irb/contact>

**PUEDO CAMBIAR DE OPINION ACERCA DE PARTICIPAR?**

Puede escoger si desea estar o no en este estudio. Puede decidir no empezar el estudio o cancelar su participacion. No habra ningun cambio en su cuidado de salud. Puede cancelar su participacion cuando quiera sin que esto le afecte en su cuidado de salud.

**DECLARACION DE CONSENTIMIENTO**

Los procedimientos, riesgos, y beneficios de este estudio me han sido explicados y estoy de acuerdo en participar en este estudio y de firmar esta forma. Mis preguntas han sido contestadas. Puedo hacer mas preguntas en cualquier hora. Al firmar esta forma no renuncio a mis derechos legales. Una copia de esta forma firmada se me entregara.

\_\_\_\_\_  
Firma del Sujeto

\_\_\_\_\_  
Fecha

**DECLARACION DEL INVESTIGADOR:**

He explicado cuidadosamente al sujeto la naturaleza de este estudio. Por la presente certifico que el sujeto que firmo esta forma ha sido informado de la naturaleza, demandas, beneficios, y riesgos envoltos en su participacion.

\_\_\_\_\_  
Firma del Investigador

\_\_\_\_\_  
Fecha

Version Date: 7/12/10

Page 3 of 3

Subject's Initials \_\_\_\_\_



APPENDIX B: SITE AUTHORIZATION LETTER

ST. ELIZABETH'S HEALTH CENTER — TUCSON, AZ



*Each Person Matters*

## St. Elizabeth's Health Center

140 W. Speedway Blvd., Suite 100  
Tucson, AZ 85705-7698  
(520) 628-7871  
Fax (520) 205-8461

June 22, 2010

Audrey Russell-Kibble  
2709 E Windsor  
Tucson, AZ 85716

Dear Audrey,

I have reviewed your request to use St. Elizabeth's Health Center as a research site for your project titled "On Grieving the Death of a Child: An Ethnography of the Cultural Influences on Grief in Mexican American Parents". I am happy to support the research and provide the site for your study. I understand 5 – 8 families that receive their care at St. Elizabeth's will be recruited to participate in the study and that the time period will be determined based on approval from the IRB.

The following objectives related to the research have been communicated to me and I approve them in their entirety:

- The research will include the recruitment of participants by the health care providers of St. Elizabeth's, who will identify Mexican American parents that have experienced the death of a child or young adult more than 2 years prior to present time. The health care providers will refer patients to the principal investigator (PI) and collect contact information from the recruits using a recruitment script that will be available in exam rooms. The script will include the project information – title, purpose and contact information for the PI.
- The PI will speak with potential participants to provide clarification about the study, answer questions and consent those individuals who express an interest in participating in the study. Contact and consenting for the study will be conducted by the PI only. All contact and interactions will be confidential and the referring providers will have no knowledge of their patient's participation or lack of participation. The names of study participants will be known only to the PI and the primary transcriptionist. The audio-taped interviews may take place at the clinic or at the participant's homes.

St. Elizabeth's Health Center is looking forward to working with you and in learning more about this important subject matter.  
Sincerely,

Dana G Pepper, RN MPA  
Executive Director  
St. Elizabeth's Health Center

*An agency of Catholic Community Services of Southern Arizona, Inc.*  
[www.ccs-soaz.org](http://www.ccs-soaz.org)

Primary Health Care Services  
Well Woman  
Prenatal Care  
Ophthalmology

Laboratory Services  
X-Ray Services  
Emergency Medication Fund  
Dental Services

Health Education and Outreach  
Optical Dispensary  
Mobile Podiatry  
Diabetes Care Management

## APPENDIX C: PARTICIPANT RECRUITMENT SCRIPTS

PARTICIPANT RECRUITMENT SCRIPT (ENGLISH)

PARTICIPANT RECRUITMENT SCRIPT (SPANISH)

The University of Arizona College of Nursing  
On Grieving the Death of a Child:  
An Ethnography of the Cultural Influences on Grief in Mexican American Parents

PARTICIPANT RECRUITMENT SCRIPT

- You are invited to participate in a study of how culture influences those grieving the death of a child.
- You may be eligible to participate because you are a Mexican American parent who has suffered the death of a child up to the age of 25.
- The purpose of the study is to learn from Mexican American parents how health care providers can give better care to Mexican American parents following the death of their child.
- The study involves two 60-90 minute interviews with the researcher at a place convenient to you.
- If you participate, your care at St. Elizabeth's Health Center will not be affected in any way.
- If you choose not to participate, your care at St. Elizabeth's Health Center will not be affected in any way.
- Information you provide in the interviews is confidential and will not be shared with your health care providers at St. Elizabeth's Health Center.
- If you are interested in learning more about this study please write your name and phone number below and Audrey (Amparo) Russell-Kibble, FNP-C will contact you.

---

Name

---

Phone number

THANK YOU FOR YOUR INTEREST IN THIS STUDY ABOUT THE CULTURAL  
INFLUENCES ON YOUR GRIEVING THE DEATH OF A CHILD.

The University of Arizona College of Nursing  
La Universidad de Arizona Colegio de Enfermeria

LA AFLICCION POR LA MUERTE DE UN HIJO:  
UNA ETNOGRAFIA DE INFLUENCIAS CULTURALES EN TIEMPO DE PESAR  
EN PADRES MEXICO AMERICANOS

MANUSCRITO PARA EL RECLUTAMIENTO DEL PARTICIPANTE

- Estan invitados a participar en un estudio en la influencia cultural en personas afligidas por la muerte de un nino.
- Podrian ser elegibles para participar si son padres Mexico Americanos que han sufrido la muerte de un hijo hasta la edad de 25 anos.
- El proposito de este estudio es aprender de los padres Mexico Americanos de como los proveedores de salud pueden dar mejor servicio a padres Mexico Americanos despues de sufrir la muerte de su hijo.
- Este estudio consiste en dos entrevistas de 60-90 minutos de duracion con el entrevistador en un lugar que sea conveniente para usted.
- Si usted participar en este estudio, su cuidado de salud en la clinica Santa Elizabeth no sera afectado en ninguna forma.
- Si usted desea no participar, su cuidado de salud en la clinica Santa Elizabeth no sera afectado en ninguna forma.
- La information que usted provea in las entrevistas es confidencial y no sera compartida con los medicos de Santa Elizabeth.
- Si esta interesado en mas informacion acerca de este estudio, por favor escriba su nombre y numero de telefono en las lineas de abajo y Audrey (Amparo) Russell-Kibble, FNP-C se comunicara con ustedes.

---

Nombre

---

Numero de telefono

MUCHAS GRACIAS POR SU INTERES EN ESTE ESTUDIO ACERCA DE  
INFLUENCIAS CULTURALES EN SU PESAR EN LA MUERTE DE UN HIJO.

APPENDIX D: DEMOGRAPHIC DATA INSTRUMENTS  
SUBJECT'S DEMOGRAPHIC QUESTIONNAIRE (ENGLISH)  
SUBJECT'S DEMOGRAPHIC QUESTIONNAIRE (SPANISH)

The University of Arizona College of Nursing

ON GRIEVING THE DEATH OF A CHILD:  
AN ETHNOGRAPHY OF THE CULTURAL INFLUENCES ON GRIEF IN  
MEXICAN AMERICAN PARENTS

DEMOGRAPHIC QUESTIONNAIRE

The purpose of this questionnaire is to tell me about yourself and your family. It will take about 20 minutes. The questions will be read to you in the language you want. By answering the questions you are agreeing to let me use the information in the study.

1. How many years ago did you experience the death of your child (children)?  
\_\_\_\_\_
2. What was the date of the death? \_\_\_\_\_
3. Was it a sudden death or a death after a long illness? \_\_\_\_\_
4. How old was your child at the time of death? \_\_\_\_\_
5. Was the child living in your home at the time of death? \_\_\_\_\_
6. How old are you? \_\_\_\_\_
7. Gender: Female \_\_\_\_\_ Male \_\_\_\_\_
8. Marital status: Married \_\_\_\_\_ Divorced \_\_\_\_\_ Separated \_\_\_\_\_ Single \_\_\_\_\_  
Living with a partner \_\_\_\_\_ Widowed \_\_\_\_\_
9. Females: How many pregnancies and births did you have? \_\_\_\_\_
10. How many living children do you have? \_\_\_\_\_ How many children have died?  
\_\_\_\_\_
11. Who lives with you in your home?  
\_\_\_\_\_  
\_\_\_\_\_
12. Whom do you consider to be a part of your family? \_\_\_\_\_
13. What is your religion? \_\_\_\_\_
14. How many years of education did you complete? \_\_\_\_\_
15. What language(s) are spoken in your home? \_\_\_\_\_
16. What language(s) do you read? \_\_\_\_\_
17. In what country were you born? \_\_\_\_\_
18. About your child who died: where was this child born?  
\_\_\_\_\_
19. How long have you lived in the US? \_\_\_\_\_
20. If you were not born in the US, how often do you return to the country where you were born? \_\_\_\_\_
21. Was the child buried or cremated? \_\_\_\_\_
22. Is the child buried in the US or in Mexico? \_\_\_\_\_
23. If cremated, where are the cremains? \_\_\_\_\_
24. Do you keep an altar in your home? \_\_\_\_\_
25. Do you participate in the events of *El Dia de los Muertos*? \_\_\_\_\_

The University of Arizona College of Nursing  
La Universidad de Arizona Colegio de Enfermería

LA AFLICCION POR LA MUERTE DE UN HIJO:  
UNA ETNOGRAFIA DE INFLUENCIAS CULTURALES EN TIEMPO DE PESAR  
EN PADRES MEXICO AMERICANOS

CUESTIONARIO DEMOGRAFICO

El proposito de este cuestionario es de proveer informacion acerca de usted y su familia. Tomara aproximadamente 20 minutos. Las preguntas se le haran verbalmente y en su language de preferencia. Si el cuestionario se completa, el consentimiento para usar la infomacion sera concedido.

1. Cuantos anos hace que murio su hijo (hijos)? \_\_\_\_\_
2. Que fue el dato que se murio? \_\_\_\_\_
3. Fue una muerte repentina o por causa de larga enfermedad? \_\_\_\_\_
4. Que edad tenia su hijo cuando murio? \_\_\_\_\_
5. Vivía su hijo en casa cuando murio? \_\_\_\_\_
6. Cuantos anos tiene usted? \_\_\_\_\_
7. Genero: Femenino \_\_\_\_\_ Masculino \_\_\_\_\_
8. Estado Civil: Casado \_\_\_\_\_ Divorciado \_\_\_\_\_ Separado \_\_\_\_\_ Soltero \_\_\_\_\_  
Union libre \_\_\_\_\_ Viudo(a) \_\_\_\_\_
9. Mujeres: Cuantos embarazos ha tenido y a cuantos dio a luz? \_\_\_\_\_
10. Cuantos hijos tiene que viven? \_\_\_\_\_ Cuantos han muerto? \_\_\_\_\_
11. Quien vive con usted? \_\_\_\_\_  
\_\_\_\_\_
12. A quien considera parte de su familia? \_\_\_\_\_
13. Cual es su religion? \_\_\_\_\_
14. Cuantos anos de educacion completo? \_\_\_\_\_
15. Que idioma(s) se habla en casa? \_\_\_\_\_
16. En que idioma(s) lea usted? \_\_\_\_\_
17. En cual pais nacio usted? \_\_\_\_\_
18. De su hijo que se murio: en cual pais nacio su hijo? \_\_\_\_\_
19. Por cuanto tiempo ha vivido en los Estados Unidos? \_\_\_\_\_
20. Si no nacio en Estados Unidos, con cuanta frecuencia visita el pais donde nacio? \_\_\_\_\_  
\_\_\_\_\_
21. Fue su hijo sepultado o incinerado? \_\_\_\_\_
22. Se sepulto al nino en Estados Unidos o Mexico? \_\_\_\_\_
23. Si fue incinerado, donde estan las cenizas? \_\_\_\_\_
24. Conserva un altar en su casa? \_\_\_\_\_
25. Participa en los eventos de *El Dia de los Muertos*? \_\_\_\_\_



APPENDIX E:  
ACCULTURATION RATING SCALE FOR MEXICAN AMERICANS-II (ARSMA-II)

**On Grieving the Death of a Child:  
An Ethnography of the Cultural Influences on Grief in Mexican American  
Parents  
Acculturation Rating Scale for Mexican Americans-II (ARSMA-II)**

<i>English Version</i>	<i>Versión en Español</i>
What is your religious preference?	¿Cual es su religión predilecta?
(a) Last grade you completed in school: <b>(Circle your choice)</b>	(a) ¿Hasta que grado fué a la escuela? <b>(Indique con un círculo la respuesta)</b>
1. Elementary 0-6	1. Primaria-6
2. 7-8	2. Secundaria 7-8
3. 9-12	3. Preparatoria 9-12
4. 1-2 years of college	4. Universidad o Colegio 1-2 años
5. 2 years of college or more	5. Universidad o Colegio 3-4 años
6. College graduate and higher	6. Graduado, o grado mas alto de Colegio o Universidad.
(b) In what country?_____	(b) ¿En que país?_____
<b>(Circle the generation that best applies to you. Circle only one.)</b>	<b>(Indique con un círculo el número de la generación que considere adecuada para usted. Dé solamente una respuesta.)</b>
1. 1 <sup>st</sup> generation = You were born in Mexico or other country.	1. 1 <sup>st</sup> generación = Usted nació en México o otro país (no en los Estados Unidos (USA)).
2. 2 <sup>nd</sup> generation = You were born in USA; either parent born in Mexico or other country	2. 2 <sup>nd</sup> generación = Usted nació en los Estados Unidos Americanos (USA), sus padres nacieron en México o en otro país.
3. 3 <sup>rd</sup> generation = You were born in USA, both parents born in USA and all grandparents born in Mexico or other country.	3. 3 <sup>rd</sup> generación = Usted nació en los Estados Unidos Americanos (USA), sus padres tambien nacieron en los Estados Unidos (USA) y sus abuelos nacieron en México o en otro país.
4. 4 <sup>th</sup> generation = You and your parents born in USA and at least one grandparent born in Mexico or other country with reminder born in the USA.	4. 4 <sup>th</sup> generación = Usted nació en los Estados Unidos Americanos (USA), sus padres nacieron en los Estados Unidos Americanos (USA) y por lo menos uno de sus abuelos nació en México o algún otro país.
5. 5 <sup>th</sup> generation = You and your parents born in the USA and all grandparents born in the USA.	5. 5 <sup>th</sup> generación = Usted y sus padres y todos sus abuelos nacieron en los Estados Unidos (USA).

## ARSMA-II: SCALE 1

(Circle a number between 1-5 next to each ítem that best applies.)

(Marque con un círculo el numero entre 1 y 5 a la respuesta que sea más adecuada para usted.)

	1	2	3	4	5		1	2	3	4	5
	Not at All	Very little or not very often	Moderately	Much or very often	Extremely often or almost always		Nada	Un poquito o a veces	Moderado	Mucho o muy frecuente	Muchísimo o casi todo el tiempo
1. I speak Spanish	1	2	3	4	5	1. Yo hablo Español	1	2	3	4	5
2. I speak English	1	2	3	4	5	2. Yo hablo Inglés	1	2	3	4	5
3. I enjoy speaking Spanish	1	2	3	4	5	3. Me gusta hablar en Español	1	2	3	4	5
4. I associate with Anglos	1	2	3	4	5	4. Me asocio con Anglos	1	2	3	4	5
5. I associate with Mexicans and/or Mexican Americans	1	2	3	4	5	5. Yo me asocio con Mexicanos y/o mexicano- americanos	1	2	3	4	5
6. I enjoy listening to Spanish language music	1	2	3	4	5	6. Me gusta la música Mexicana (música en idioma Español)	1	2	3	4	5
7. I enjoy listening to English language music	1	2	3	4	5	7. Me gusta la música de idioma Inglés	1	2	3	4	5
8. I enjoy Spanish language TV	1	2	3	4	5	8. Me gusta ver programas en la televisión que sean en Español	1	2	3	4	5
9. I enjoy English language TV	1	2	3	4	5	9. Me gusta ver programas en la televisión que sean en Inglés	1	2	3	4	5
10. I enjoy English language movies	1	2	3	4	5	10. Me gusta ver películas en Inglés	1	2	3	4	5
11. I enjoy Spanish language movies	1	2	3	4	5	11. Me gusta ver películas en Español	1	2	3	4	5
12. I enjoy reading (e.g. books in Spanish)	1	2	3	4	5	12. Me gusta leer (e.g. libros en Español)	1	2	3	4	5
13. I enjoy reading (e.g. books in English)	1	2	3	4	5	13. Me gusta leer (e.g. libros en Inglés)	1	2	3	4	5
14. I write (e.g. letters in Spanish)	1	2	3	4	5	14. Escribo (e.g. cartas en Español)	1	2	3	4	5
15. I write (e.g. letters in English)	1	2	3	4	5	15. Escribo (eg. cartas en Inglés)	1	2	3	4	5
16. My thinking is done in the English Language	1	2	3	4	5	16. Mis pensamientos ocurren en el idioma Inglés	1	2	3	4	5
17. My thinking is done in the Spanish language	1	2	3	4	5	17. Mis pensamientos ocurren en el idioma Español	1	2	3	4	5
18. My contact with Mexico has been	1	2	3	4	5	18. Mi contacto con México ha sido	1	2	3	4	5
19. My contact with the USA has been	1	2	3	4	5	19. Mi contacto con los Estados Unidos Americanos ha sido	1	2	3	4	5
20. My father identifies or identified himself as "Mexicano"	1	2	3	4	5	20. Mi padre se identifica (o se identificaba como Mexicano)	1	2	3	4	5
21. My mother identifies or identified herself as "Mexicana"	1	2	3	4	5	21. Mi madre se identifica (o se identificaba como Mexicana)	1	2	3	4	5
22. My friends, while I was growing up, were of Mexican origin	1	2	3	4	5	22. Mis amigos(as) de mí niñez eran de origen Mexicano	1	2	3	4	5

23. My friends, while I was growing up, were of Anglo origin	1	2	3	4	5	23. Mis amigos(as) de mi niñez eran de origen Anglo Americano	1	2	3	4	5
24. My family cooks Mexican foods	1	2	3	4	5	24. Mi familia cocina comidas mexicanas	1	2	3	4	5
25. My friends now are of Anglo origin	1	2	3	4	5	25. Mis amigos recientes son Anglo Americanos	1	2	3	4	5
26. My friends now are of Mexican origin	1	2	3	4	5	26. Mis amigos recientes son Mexicanos	1	2	3	4	5
27. I like to identify myself as an Anglo American	1	2	3	4	5	27. Me gusta identificarme como Anglo Americano	1	2	3	4	5
28. I like to identify myself as a Mexican American	1	2	3	4	5	28. Me gusta identificarme como México-Americano	1	2	3	4	5
29. I like to identify myself as a Mexican	1	2	3	4	5	29. Me gusta identificarme como Mexicano	1	2	3	4	5
30. I like to identify myself as an American	1	2	3	4	5	30. Me gusta identificarme como un(a) Americano(a)	1	2	3	4	5

**ARSMA-II authored by Cuéllar et al., 1995**

### ARSMA-II: SCORING

Procedure for arriving at the ARSMA-II Acculturation Score for the 30 item scale:

MOS Scale: Add items (1, 3, 5, 6, 8, 11, 12, 14, 17, 18, 20, 21, 22, 24, 26, 28, & 29), obtain the sum and divide by 17. This is the Mean of the MOS scale.

AOS Scale: Add items (2, 4, 7, 9, 10, 13, 15, 16, 19, 23, 25, 27, & 30), obtain the sum and divide by 13. This is the Mean of the AOS scale.

The Acculturation Score is the mean of the AOS minus the mean of the MOS.  
The Acculturation Level is determined by that score.

### ARSMA-II: CUTTING SCORES FOR DETERMINING ACCULTURATION LEVEL

Acculturation Levels	Description	ARSMA-II Acculturation Score
Level I	Very Mexican oriented	$< -1.33$
Level II	Mexican oriented to approximately balanced bicultural	$\geq -1.33$ and $\leq -.07$
Level III	Slightly Anglo oriented bicultural	$> -.07$ and $< 1.19$
Level IV	Strongly Anglo oriented	$\geq 1.19$ and $< 2.45$
Level V	Very assimilated; Anglicized	$> 2.45$

(Cuellar et al., 1995b, p. 285).

APPENDIX F: INTERVIEW GUIDES

INTERVIEW GUIDE (ENGLISH)

INTERVIEW GUIDE (SPANISH)

The University of Arizona College of Nursing

ON GRIEVING THE DEATH OF A CHILD:  
AN ETHNOGRAPHY OF THE CULTURAL INFLUENCES ON GRIEF IN  
MEXICAN AMERICAN PARENTS

Grand Tour Questions

I began this study because I have sometimes seen misunderstandings occur between providers of health care and those grieving the death of a child.

I am interested in learning how your family expresses their grief over the death of your child.

- (a) Tell me about how the death happened.
- (b) What were your thoughts when you first learned about the death?
- (c) How did your family prepare for the funeral of your child?
- (d) Is your child buried in the US or in Mexico?
- (e) What were some of the traditions that your family used to honor your child at that time?
- (f) At this time, what traditions does your family use to honor your child?

Do you have an altar in your home?

- (a) What do you keep on the altar?
- (b) What things do you change out on occasion?

Does your family participate in the events of *El Dia de los Muertos*?

- (a) What special things do you do for that event?
- (b) Do you participate on November 1 or 2?
- (c) What time of day do you conduct your participation?

Tell me about your first experience with a health care provider after the death of your child?

- (a) Did you let the provider know that you were grieving the death of your child?
- (b) What did you wish the provider had said or done that would have helped you in your grief?
- (c) What do you say about the experience of the death of your child to new providers?
- (d) I would like to help other providers to be more sensitive and supportive of parents whose child has died. What are two supportive actions a provider might use when a parent shares that their child has died?
- (e) What are two supportive words a provider might use when a parent shares that their child has died?



The University of Arizona College of Nursing  
La Universidad de Arizona Colegio de Enfermería

LA AFLICCION POR LA MUERTE DE UN HIJO:  
UNA ETNOGRAFIA DE INFLUENCIAS CULTURALES EN TIEMPO DE PESAR  
EN PADRES MEXICO AMERICANOS

Preguntas Importantes

Este estudio resulto porque yo he visto mal entendidos entre los proveedores de cuidado de salud y personas sufriendo por la muerte de un hijo.

Estoy interesada en conocer de que manera su familia expresa el dolor sobre la muerte de su hijo (hija).

- (a) Cuénteme cuales fueron las circunstancias acerca de la muerte.
- (b) Cuales fueron sus pensamientos cuando le informaron de la muerte?
- (c) Como se preparo la familia para el funeral de su hijo?
- (d) Esta su hijo sepultado en Los Estados Unidos o en Mexico?
- (e) Cuales son algunas de las tradiciones que su familia honraba a su hijo en ese tiempo?
- (f) En este tiempo, cuales son algunas de las tradiciones que su familia honraba a su hijo?

Tiene un altar un su casa?

- (a) Que tiene en el altar?
- (b) Que cosas cambia o quita en ocasiones?

Participa su familia en eventos de *El Dia de los Muertos*?

- (a) Cuales cosas especiales hacen en este evento?
- (b) Participa en Noviembre 1 o 2?
- (c) Que hora del dia hacen su participacion?

Puede contarme de su primera experiencia con el proveedor de salud despues de la muerte de su hijo?

- (a) Le informo al proveedor de salud que estaba sufriendo por la muerte de su hijo?
- (b) Hay algo que desea que el proveedor le hubiera dicho o hecho que le podria haber ayudado en su pesar?
- (c) Comparte la experiencia por la muerte de su hijo con los proveedores nuevos?
- (d) Estoy interesada en ayudar a otros proveedores a ser mas sensitivos y ofrecer mas apoyo a los padres que han perdido su hijo. En su opinion cuales son dos cosas importantes que un proveedor puede hacer cuando un padre les diga que su hijo ha muerto?
- (e) En su opinion cuales son dos palabras importantes que un proveedor puede hacer cuando un padre les diga que su hijo ha muerto?

APPENDIX G:  
CONTINUING EDUCATION MODULE DOCUMENTS

## Continuing Education (CE) Module for Nursing

### Mexican American Parents' Perceptions of Cultural Influences on Grieving the Death of Their Child

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#### Abstract

**Purpose:** To describe Mexican American parents' perceptions of cultural influences on grieving the death of their child and to promote the provision of culturally competent care to this potentially vulnerable population.

**Methods:** Ethnographic methodology was used to explore the narratives of a purposive sample (N=6) of Mexican American parents who have experienced the death of their child. Data sources include participant interviews, participant observation, field notes and measures for demographic data and acculturation (ARSMA-II).

**Findings:** The overarching cultural theme, *El Dolor de los Padres*: Pain in the Parent, is supported by four major themes identified from the data: (a) Enduring Great Pain, (b) Voices of Mexican American Parents, (c) Cultural Death Traditions, and (d) Going Forward: For the Provider. The study findings are interpreted within the context of Mexican cultural concepts and the concept of vulnerability.

**Implications for Practice:** Study findings are specific to understanding and preventing disparities in the nursing care of Mexican American parents who have experienced the death of a child. Strategies for improving the cultural sensitivity of nurses to Mexican cultural concepts, and how these cultural concepts may be used to offer culturally competent care are discussed.

[Words 191/250]

**Keywords:** Mexican American, grief, death of a child, qualitative research

#### Objectives

At the conclusion of this activity, the participant will be able to:

- List Mexican cultural influences that may affect the care of parents grieving the death of a child.
- Identify what may be seen as unique about the grief of Mexican American fathers.
- Describe two cultural values that Mexican American parents who are grieving the death of a child would like integrated into the care they receive from nurses.

[Background] In clinical settings, nurses encounter grieving parents from diverse populations. There is an immediate need for nurses to be knowledgeable about the cultural influences on grief, if they are to demonstrate cultural competence in their

nursing practice (AAN, 2010). Cultural competence “implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented” (AAN, p. 24) by Mexican American parents who have experienced the death of a child. The recognition of gaps in culturally sensitive care to Mexican American parents who have experienced the death of a child was born out of repeated observations by the researcher in the clinical setting. There is a gap in the literature and nursing standards that guide culturally sensitive interventions in the care of Mexican American parents who have experienced the death of a child (IOM, 2001). Mexican American parents’ perceptions of cultural influences on grieving the death of their child are described in this module. The goal of the module is to inform nurses involved in the care of Mexican American parents who have experienced the death of a child about Mexican cultural values and beliefs that underpin their grieving and could potentially adversely affect their health. The long term goal is that the knowledge gained from this module will contribute to nurses demonstrating cultural competence (AAN, 2010) in their nursing practice and care of this potentially vulnerable population.

[Statement of the Problem] The influence of culture on the grief of Mexican American parents who have experienced the death of a child is important for informing nurses’ ability to provide culturally sensitive care to this population (Burk, Weiser & Keegan, 1995; Clements et al., 2003; Zoucha, 2008). A potential disconnection exists when nurses are uninformed about cultural influences on grief in Mexican American parents who have experienced the death of a child. Knowledge of the cultural influences on grief is critical because one in five adults suffers the death of a child each year (The Compassionate

Friends (TCF, 2010) and the Mexican American population is among the fastest growing minority in the United States (United States Census Bureau, 2010). The meaning and significance of the Mexican cultural concepts of family (*familismo*) as the a strongest resource for support, fatalism (*fatalismo*), respect (*respeto*), and the importance of a sense of personal relationship (*personalismo*) with health care providers as well as with their spiritual belief system (*spiritualidad*), are crucial to understanding the context in which the grief of Mexican American parents is expressed (Clements et al.; Burk et al.).

Beliefs about death are anchored in pre-historic Mexican culture that emphasizes an importance in maintaining a continued bond between the living and the dead (Munet-Vilaro, 1998). In this historical context grief is seen as an emotional as well as a physical process (Oltjenbruns, 1998). Health, longevity, the sense of well-being during illness, recovery from trauma, and bereavement are affected by *spiritualidad* (Campesino & Schwartz, 2006). The concept of *personalismo* characterizes the warmth and closeness of relationships, in connection with a spiritual belief system as well as in personal relationships (Campesino & Schwartz; de la Torre & Estrada, 2001). *Personalismo* is at the core of the concept of *spiritualidad*. Cultural influences on the grief of Mexican American parents who have experienced the death of a child have the potential to alleviate a lot of the distress involved in their bereavement (Clements et al., 2003; Doran & Hansen, 2006; Munet-Vilaro; Oltjenbruns). Recognizing specific cultural traditions that honor the spiritual belief system of the Mexican American population, such as *El Dia de los Muertos* (Day of the Dead) and *Novenarios* (nine days of ritualistic prayers and rosaries after a death) and the importance of those rituals to the Mexican American

parents who have experienced the death of a child has the potential to influence care that will be seen as familiar, personal, respectful, and congruent within the culture of the grieving parents. The juxtaposition of Mexican cultural influences on grief with the prevailing bereavement model that recommends detachment from the deceased (Bowlby, 1980) poses an incongruence of world views that can adversely affect the care the parents receive.

Vulnerability is a valuable concept in the social science research of populations deemed to be susceptible to harm or neglect (Aday, 2001; de Chesnay, 2008; Delor & Hubert, 2000; Spiers, 2000). Vulnerable populations have been defined as being “at risk of poor physical, psychological, or social health” (Aday, p. 2). This concept is applicable to Mexican American parents grieving the death of a child because they are susceptible to the spiritual, emotional and/or physical consequences of bereavement. Mexican American parents grieving the death of a child may experience a blurring of the spiritual, emotional and physical consequences of bereavement (Russell-Kibble, 2009).

[Systematic and Critical Review of the Evidence] The qualitative ethnographic study by Doran and Hansen (2006) and the quantitative research study accomplished by Oltjenbruns (1998) focused on exploring the grief of the Mexican American population within the context of their culture after the loss of someone close to them. Doran and Hansen specifically focused on the process of grief in Mexican American families after the death of a child. They sought information regarding the way families sustain a bond with the deceased after the death of a child. Although multiple generations were interviewed, no Mexican American fathers were included in their study (Doran &

Hansen). Oltjenbruns explored the personal response to grief within the context of culture by comparing the differences between ethnicity and gender as the secondary purpose of the study. That quantitative study examined the responses of Mexican American college students as compared to Anglo American college students using the Grief Experience Inventory (Oltjenbruns). Oltjenbruns reported Mexican American students as more likely to cry in public and somaticize their reactions to grief, than the Anglo American students. Differences in their findings in consideration of gender were not specific to the Mexican American population but rather to the women participants in general.

[Implications for Clinical Practice] The current study's significance for the practice of nursing is upheld in the findings that are specific to understanding and eliminating disparities in the care of Mexican American parents who have experienced the death of their child. Improving nurses' cultural knowledge of *spiritualidad*, continuing memories, and the importance of offering culturally sensitive care at this time of deep emotional pain is illuminated by the study that guided this continuing education module.

[Clinical Question] The research questions that guided this study were twofold: (1) What are Mexican American parents' perceptions of cultural influences on grieving the death of their child, and (2) what in the cultural experience of parents' grieving can guide nurses to deliver culturally sensitive care to Mexican American parents who have experienced the death of a child?



## **Method**

Ethnographic methodology was used to describe (Hammersley & Atkinson, 2007; Wolf, 2007) Mexican American parents' perceptions of cultural influences on grieving the death of their child. The study also explored the experiences that Mexican American parents who had experienced the death of a child had with providers of health care.

[Sample] Parents of Mexican origin, who were grieving the death of their child, were recruited to participate in this study. Criteria for inclusion were that the participants: (a) be 18 years of age and older, (b) had experienced the death of a child when the child was an infant through 25 years of age, (c) child was living in the parent's home at the time of the death, and (d) child's death was at least 2 years prior to the study. The rationale for the period of time since the child's death was to allow time for the grief to be less acute. Traditional Mexican family values dictate that children live with their parents until they marry (Pew Hispanic Center, 2009; Purnell, 2005, p. 293). Therefore, the age range of potential participants' children was expected to be into early adulthood. Purposive sampling was used to recruit participants from a faith based community health center in Tucson, AZ. Three Mexican American fathers and three Mexican American mothers who had experienced the death of a child were recruited. Three of the parents had suffered the deaths of two children.

[Data Collection] In depth ethnographic interviews were conducted primarily in the participants' homes, in Spanish language by the first author. Data sources included audio-taped participant interviews, participant observation, field notes and measures for

demographic data, and acculturation using the ARSMA-II (Cuellar, Arnold & Gonzalez, 1995a; Cuellar, Arnold & Maldonado, 1995b).

[Translation] Interviews were transcribed in Spanish and translated into English by a bilingual Spanish-English translator/transcriptionist. The interview data were then back-translated into Spanish, from the translated English version, by a second bilingual translator. The researcher and translators reviewed the transcripts, to reconcile the accuracy of the cultural equivalence of the English translation (Jones, Lee, Philips, Zhang, & Jaceldo, 2001).

[Data Management and Analysis] Data analysis began by reviewing the field notes after an interview and/or participant observation to search for evidence of cultural context (Spradley, 1979). The description of participants' perceptions of cultural influences on their grieving the death of a child emerged through an iterative process of data collection and data analysis.

## **Findings**

An overarching cultural theme, *El Dolor de los Padres (Pain in the Parent)* was a dominant description in the interview data. The parents' descriptions of the pain they were suffering after the death of their child were clustered into categories with similar units of meaning from which major themes emerged to support the overarching cultural theme. These major themes included: (a) Enduring Great Pain, (b) Voices of Mexican American Parents, (c) Cultural Death Traditions, and (d) Going Forward: For the Provider. The last theme specifically addressed data gathered from participants regarding their experiences with providers of health care.

### *Enduring Great Pain*

The parents spoke repeatedly of how the pain they suffered did not go away with time. One participant stated that those of his culture had deeper feelings and suffered more pain after the death of a child than their Anglo counterparts. Support for their grief and pain came mainly from the close and extended *familia*. Friends of the child and the family, religious associations, as well as nurses and social workers were mentioned as sources of support. A continual process to accept the death of the child was mentioned by the participants, as well as various means to accomplish that acceptance. Continuing to talk to the family, the sharing of memories and maintaining faith were ways that the parents dealt with their pain.

### *The Perspective of Mexican American Fathers versus Mexican American Mothers*

The emergence of the voice of Mexican American fathers was an unexpected finding, and possibly the greatest strength of this study. Unique to the Mexican American father was the expressed need to be alone with their grief and pain. In contrast, the Mexican American mothers sought the company and support of others. Men are expected to maintain the cultural role of *machismo* that implies their role to protect the family (de la Torre & Estrada, 2001, p. 130). *Machismo* may also make it more difficult for the men to cry or emote (Aros, Buckingham, & Rodriguez, 1999, p. 87). The fathers expressed that their experience was not different than that of the mothers, but rather they responded differently. The fathers expressed dismay at the illogical disruption of the order of things and the unfairness of the denial of life to their child. All of the fathers had suffered the

traumatic, sudden deaths of their children. The mothers specifically sought others with whom to share memories of their child, mainly family and close friends.

### *Cultural Death Traditions*

The six participants in the study prepared nine funerals. Six of the nine children who died were cremated rather than buried, which is an interesting finding given that the Catholic Church does not encourage cremation (Purnell, 2005, p. 298; Younoszai, 1993, p. 76). Although specific data on the reason cremation was chosen was not collected, economics may have been a motivating factor. Catholic masses, funerals/memorial services and *Novenarios*, or nine days of prayers and rosaries were utilized. Many participants reported music being a part of ceremonies and visitations. The parents visited the cemeteries with regularity, and in the case of one of the participants, visitation was made annually to the site of the accidental death. All of the participants continue to take part in the cultural event of *El Dia de los Muertos*. Christmas, Easter, and other holidays, as well as birth and death dates are times of regular visitation to the cemetery.

The belief that death exists as an extension of life is reflected in the value placed upon maintaining a continuing bond with the deceased child (Doran & Hansen, 2006; Munet-Vilaro, 1998). This belief is reflected in the parents seeking to be *In the Presence of the Child*. The parents kept altars to honor the children, and feel their presence there. One father carries some of his son's ashes in a pouch on a thong around his neck, and "do[es] not separate from him." Remembering the child, feeling their child's presence in their midst, talking to the child, and maintaining the altars are all done with the intention of honoring the child who died.

[Significance to Nursing Practice] The practice of nursing includes the assessment and response to more than a patient's presentation of a physical ailment. A significant finding from this study is the discovery of new knowledge that can be used to inform culturally competent care for this vulnerable population. The findings are specific to eliminating disparities in the care of Mexican American parents who have experienced the death of a child. The findings are transferable with regards to being in alignment with standards of practice for culturally competent care (AAN, 2010). Nurses are encouraged to "remain cognizant" of Mexican American parents who have experienced the death of a child, and withhold judgments and assumptions about cultural stereotypes (Zack Ishikawa, Cardemil, & Falmange, 2010, p. 1569).

*Going Forward: For the Provider*

The fourth major theme: *Going Forward: For the Provider* illuminates some of what nurses need to know to care for Mexican American parents who have experienced the death of a child. Information for this major theme was gathered to discover what Mexican American parents' had found supportive and what they had not found supportive when sharing their stories with health care providers. The cultural category: *Things You Need to Know*, asks nurses to know that the pain of losing a child does not go away with time and that the support they offer should be continuous. A strategy to prompt continued support by nurses might be accomplished by including information about the death of the child on the problem list in the medical record. This could be a reminder to prompt nurses to acknowledge the child's death and "check in" with the parent about their grieving process. This strategy will also promote *confianza* and *personalismo*. International

Classification of Diseases, 9<sup>th</sup> Revision (ICD-9) (Hart, Stegman & Ford, Eds., 2009) codes that can be used for this purpose include 309.0 Grief Reaction or 309.0 Mourning and uncomplicated bereavement can be coded as V62.82.

The cultural concepts of *respeto*, *confianza*, and *personalismo* underpin Mexican Americans' expectation of a personal relationship with their nurse. These cultural concepts also demonstrate respect and engender confidence. A nurse who knows the rules of respect in the culture will create confidence that cannot otherwise be obtained. For example, when demonstrating the cultural concept of *respeto* the nurse would acknowledge the status of individual family members (Zack Ishikawa et al., 2010) by greeting the father of the family first and introducing yourself at the same time, and verbally expressing pleasure in meeting him. The same introduction is then extended to the rest of the family. Courteous listening confers *dignidad* (dignity), *respeto* (respect), *confianza* (confidence), and *personalismo* (sense of a personal relationship). When presented with Mexican American patients who are abusing alcohol or drugs, nurses need to inquire about possible emotional traumas that may be underpinning substance abuse. However, the patient may not report this type of personal information until *confianza* has been established.

The cultural category: *What We Would Like From You* demonstrates the importance of knowing what to say, how to say it, and to whom. The Mexican American mothers participating in the present study voiced a need to hear words of support. They want the nurses to reflect on the pain, and offer solidarity. An offering of: "*Lo siento*", "I am sorry", may be heard as giving a kind reply, but the fathers specifically voiced a need

for the nurses to withhold shallow words and do not want to hear, “*Lo siento*” unless it is voiced with sincerity. It is important for nurses to make an effort to let the fathers know that their grief is equally as acknowledged as the mother’s grief. Physical touch is required and part of the communication of respect. Upon being told of the death of a child by the bereaved, it is respectful, and expected, that the nurse will reach out and touch them. It is disrespectful not to do so (Clements et al., 2003). A touch on the arm or putting one’s arm around their shoulder, or even offering an *abrazo* (a hug) demonstrates a culturally correct response. Knowing that this is expected within the culture and demonstrating it will engender *respeto*, *confianza*, and *personalismo*. Referrals to counseling or psychological support need to be respectfully and sensitively explored and discussed with the Mexican American parent who has experienced the death of a child (Zack Ishikawa et al., 2010). A nurse referring a Mexican American parent who is grieving the death of a child to counseling has the capacity to influence the outcomes of that utilization process by their manner in addressing the offer of support (Zack Ishikawa et al.). The recommendation is to assess the parent’s receptivity to this source of support. It may be more helpful for the Mexican American mother who is grieving the death of her child, because of their propensity to want to talk and hear words of encouragement, in contrast, to the Mexican American father who has more skepticism for words of support. Nonetheless, a heartfelt and well intentioned offering will be seen as caring, and compatible with the cultural values of *respeto*, *confianza* and *personalismo*. Acknowledging complementary coping strategies such as continuing involvement in the

church demonstrates support, understanding of the culture and *respeto*. (Zack Ishikawa et al.).

An assessment of Latino patients' responses to death may be guided by four key cultural guidelines (Munet-Vilaro, 1998): (a) Latinos originate from different countries with unique cultural backgrounds, therefore, it is important to be cautious in generalizing knowledge of a culture of grieving, (b) extended family members can be valuable sources of information when cultural competence is sought, (c) the provider of health care who shares personal beliefs about grieving and death in an informal, nonjudgmental, way will engender trust from a bereaved family, and (d) if not fluent in the Spanish language, the use of a trained translator is recommended so that accuracy of information can be assured.

## **Discussion**

Findings of the analysis of the data from interviews, and participant observations, contributed to the description of the content of the study within its context, regarding the Mexican American parents' perceptions of cultural influences on their grieving the death of their children. The overarching cultural theme, *El Dolor de los Padres*, was abstracted up to from the data that represents the voice of all the participants. *El Dolor de los Padres* illustrates the depth of the pain that the Mexican American parents who have experienced the death of a child have and how their unique culture contributes to their experience.

[Strengths and Limitations] A strength of this study was the inclusion of fathers and mothers. This is the only study that was found to describe the grief experienced by Mexican American fathers whose child has died. Esqueda-Arteaga (2006) explored the



relationship between acculturation, gender, and experiences of grief among Mexican American adults, but the grief experienced by the father was not reported. Another strength of this study is the homogeneity of the study participants, who shared the same level of acculturation despite differing lengths of time they had lived in the U.S. The interviews were all conducted in Spanish, the first language of the participants. Most interviews took place at participants' homes giving the researcher an opportunity to view the altars and artifacts that are maintained by most of the participants. The ability to converse with the participants in Spanish and to be in their homes contributed to the *credibility* of this study (Lincoln & Guba, 1985). The meticulous transcription, translation, and back translation of the documents support strength and *dependability* of the study (Lincoln & Guba). The ethnographic record is relatively complete with regard to the specific population that was studied. Saturation of data is evidence of that completion.

Time constraints were the main limiting factor in determining which family members to include in the present study. Future studies could be expanded to include the extended family.

An unexpected finding was the discovery of the previously untold story of the grief of the Mexican American father. This finding calls for the development of culturally congruent interventions for grieving Mexican American fathers that may be different than those interventions for grieving Mexican American mothers. A second unexpected finding that was incongruent with the social norms of the Catholic Church was the

cremation of six of the nine children who had died. Further research is required to interpret this finding within a cultural context.

### **Summary**

Although there is not a universal form to grief (Doran & Hansen, 2006) the spiritual, emotional and physical manifestations of bereavement are experienced within a cultural context. The vulnerability of the Mexican American parent to the consequences of bereavement can be minimized by nurses having an awareness of those cultural influences and demonstrating *respeto*, *confianza*, *personalismo*, and care.

[Word count: 3664/4000]

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[Reference count: 34/ 50]

**Continuing Education (CE) Credit**

Title: **Mexican American Parents' Perceptions of Cultural Influences on Grieving the Death of Their Child**

CE Code: Valid until:

**Circle the best answer for each question. Required minimum passing score is 70%**

[Questions]

- 1. Physical touch is a required part of cultural expression of respect in the Mexican American community, and upon being told of the death of a child it is expected that the nurse will reach out and touch them.**
  - a. T
  - b. F
- 2. The grief of Mexican American fathers is expressed:**
  - a. The same as the mothers but they respond differently
  - b. Unique in their response of avoiding social encounters
  - c. All of the above
- 3. Mexican American parents who are grieving the death of their child are affected by the cultural influence of:**
  - a. *Spiritualidad*
  - b. *Familismo*
  - c. *Personalismo*
  - d. All of the above
- 4. Mexican American parents who have experienced the death of a child want nurses to know:**
  - a. The pain of losing a child does not go away with time
  - b. The support that is offered should be continuous
  - c. A nurse who is knowledgeable about their cultural values and beliefs will engender confidence
  - d. All of the above

5. It is important to reflect on the pain of the Mexican American parent who has experienced the death of a child and offer words only if they can be offered sincerely to engender *respeto*, *confianza*, and *personalismo*.
- a. T
  - b. F
6. Grief counseling is an intervention that should be provided in the plan of care to every Mexican American parent who has experienced the death of a child.
- a. T
  - b. F
7. Courteous listening confers *dignidad*, *respeto*, *confianza*, and *personalismo* to the relationship between a nurse and the Mexican American parent who has experienced the death of a child.
- a. T
  - b. F

[Key to Answers]

- 1. a.
- 2. c.
- 3. d.
- 4. d.
- 5. a.
- 6. a.
- 7. a.

### Evaluation of the CE Activity

**Purpose and Target Audience:** This CE learning activity is designed to augment the knowledge, skills and attitudes of nurses and assist in their understanding of Mexican American parents' perceptions of cultural influences on grieving the death of their child.

- 1. Listed below are the educational activity objectives. Please rate the extent to which you are now able to meet each of the objectives or your level of agreement with the statements (with 1 as the lowest or "no"; and 5 as the highest or "yes" ranking):**

	Low			High	
a. List Mexican cultural influences that affect the care of parents grieving the death of their child	1	2	3	4	5
b. Identify what may be seen as unique about the grief of Mexican American fathers	1	2	3	4	5
c. Describe two cultural values that Mexican American parents who are grieving the death of their child would like integrated into the care they receive from nurses	1	2	3	4	5
<b>2.</b> The teaching method was appropriate and effective for the content presented	1	2	3	4	5
<b>3.</b> The information presented was accurate, current and at an appropriate level	1	2	3	4	5
<b>4.</b> This activity met my personal professional expectations	1	2	3	4	5
<b>5.</b> This content was relevant to my practice as a nurse	1	2	3	4	5
<b>6.</b> This content will cause me to change my practice as a nurse	1	2	3	4	5
<b>7.</b> I believe I will face barriers in my practice to implementing this information	1	2	3	4	5
<b>8.</b> Overall I would rate this activity	1	2	3	4	5
<b>9.</b> Minutes required reading this article and completing the test _____					

To receive CE credits, read the article, answer each question and mail the test answers and evaluation along with your processing fee. CE is provided without charge to subscribers who take the activity online. Make sure to fill out both sides of this application.

*Please Print Clearly*

Name: \_\_\_\_\_ Date activity completed: \_\_\_\_\_

Address for mailing certificate: \_\_\_\_\_

Phone number: \_\_\_\_\_ Email: \_\_\_\_\_

**COMMENTS:**



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