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LOYOLA UNIVERSITY CHICAGO

¿DÉJALO DESCANSAR?

A QUALITATIVE STUDY EXPLORING
THE PARENTAL BEREAVEMENT EXPERIENCE
OF MEXICAN MIGRANT MOTHERS

A DISSERTATION SUBMITTED
TO THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIAL WORK

BY

ILLEANA A. GOMEZ

CHICAGO, IL

AUGUST 2013

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What kept me going was to think about my two daughters, Amanda and Melissa. I wanted them to know that it is important to pursue dreams and that they can “shine” in life.

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The most important things are the hardest things to say. They are the things you get ashamed of, because words diminish them. Words shrink things that seemed limitless when they were in your head to no more than living size when they're brought out. But it's more than that, isn't it? The most important things lie too close to wherever your secret heart is buried, like landmarks to a treasure your enemies would love to steal away. And you may make revelations that cost you dearly only to have people look at you in a funny way, not understanding what you've said at all, or why you thought it was so important that you almost cried while you were saying it. That's the worst, I think. When the secret stays locked within not for want of a teller but for want of an understanding ear.

from "The Body,"
in *Different Seasons*, Stephen King

To the mothers ... I have done my best to listen and understand.

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ABSTRACT

“Déjalo descansar, no le llores” – “Let them rest, don’t cry for them” is an expression Mexican mothers often hear after the death of a child. While accepted as a culturally polite means of expressing condolence, the phrase nonetheless can have a detrimental effect on the parental bereavement experience of these mothers. Through the use of focus groups, 22 Mexican migrant mothers were interviewed to better understand the role that imperatives such as “Déjalo descansar” and other prescribed beliefs, rituals, and customs play in their bereavement experience. From the five focus groups conducted in this qualitative study, participants reported that the expression, “Déjalo descansar, no le llores” and other such culturally normative expressions served to stifle the expression of their grief. In addition to cultural factors unique to this group, the issue of their residency status impacted their grief experience, as these mothers faced difficult decisions regarding the disposition of their children’s remains and the absence of emotional support due to being separated from extended family members in Mexico. Other findings from this study include the importance of maintaining a connection with the deceased child through the use of personal, religious, and cultural activities, the significant role that religion played in serving as a source of support, and the benefit participants reported in talking with others about their bereavement experience. This research study contributes to the literature on grief and bereavement, in the context of parental bereavement and as specifically related to the intrapersonal bereavement experience of Mexican migrant mothers.

CHAPTER ONE

INTRODUCTION

Many believe that the death of a child is the most difficult loss a person can face. This may be due to the fact that, in some societies, this particular kind of death is viewed as rare and unnatural, and the belief may be that children are not supposed to die before their parents. This kind of a death can also bring about special grieving problems since children are often viewed as extensions of their parents, especially as it pertains to the loss of future dreams and hopes, and even to the sense of a legacy. "Research has shown that grief following sudden or preventable death or suicide, and parental grief, is likely to be prolonged, with mourners reporting high distress, disorganization, and active grieving for many years following the loss" (Romanoff & Terenzio, 1998, p.705).

A child's death can often strain marital relationships, which may lead to separation or divorce in some cases (Schwab, 1998). Another difficult challenge faced by bereaved families pertains to the need to restructure the family system and the roles within it. Re-establishing a sense of life's meaning, as well as the task of re-investing in other children and the necessary activities of life, can be especially difficult or even unimaginable for the bereaved parents. Schwab (1997, as cited in Safonte-Strumolo & Balaguer Dunn, 2000) states that,

Parental mourning over the loss of a child has been found to be profound and protracted and to have significant impact on family functioning. Parents often become so distressed that they are unable to fulfill basic parenting roles and functions. Their preoccupation with the loss may result in destabilization of the

family structure and a loss of support for other family members, especially children. (p.335)

For example, Rosen (1985) found that surviving siblings also confront barriers in fully expressing their grief in the aftermath of a sibling death, for various reasons including feeling that they must hide their feelings or refrain from talking about their sibling, for fear of upsetting their parents, as well as developmental factors which sometimes influence children's understanding of death.

Sanders (1980) also compared the intensity of adult bereavement across types of bereavement suffered, and found that the bereaved participants who had experienced the death a child, "revealed more intense grief reactions of somatic types, greater depression, as well as anger and guilt with accompanying feelings of despair, than did those bereaved who had experienced the death of either a spouse or parent" (p. 309).

Thus, it is important to help bereaved parents find a way to express their pain and sorrow, in their own words or through their own cultural rituals and ceremonies. Yet, the variations in mourning and grief process are vast, both within and across societies and cultures (Shapiro, 1995).

"Déjalo Descansar, no le llores"

"Déjalo Descansar, no le llores"¹... don't even talk to me about that saying... I am sick of hearing that from everyone around me!" (Personal communication, bereaved Mexican mother, Luz del Corazon Program, October 21, 2010). For grieving Mexican

¹ "Déjalo Descansar, no le llores" is intended to broadly mean "let them rest, don't cry for them."

migrant² mothers this phrase often serves to silence their voices, in regards to their grief experience. While this phrase is likely related to religious imperatives that direct individuals to accept God's will regarding the death of a loved one, this same phrase is sometimes used and perceived as a discouragement to Mexican migrant mothers who are attempting to overtly grieve and discuss their deceased children.

This study seeks to explore the role that imperatives such as “Déjalo descansar, no le llores” play in the lived parental bereavement experience of Mexican migrant mothers. More importantly, it seeks to enhance our knowledge and understanding of how Mexican migrant mothers experience and negotiate their grief reactions within a personal, socio-cultural and religious context, which may include culturally-prescribed beliefs, rituals, or customs, that may be perceived as helpful or hindering during the bereavement experience.

Mexican migrant mothers must often attempt to express and cope with their grief simultaneously within two cultures, Western³ culture and their own Mexican culture. These women may receive messages from their culture of origin in terms of what is considered to be appropriate grief responses and coping reactions. For example, in facilitating Spanish-speaking parental bereavement support groups, I have often heard Mexican bereaved mothers convey their desperate desire and need to maintain emotional and spiritual connection with their children, which may seem incongruent to the advice

² For the purposes of this study, the term “Mexican migrant” refers to an individual born in Mexico, who is self-identified as being of Mexican heritage or descent, and who has emigrated from Mexico to the United States.

³ For the purposes of this study, the term “Western” refers to dominant, Euro-American culture (Non-Latin American).

they receive from extended family and friends to “Déjalo Descansar, no le llores.” This phrase is likely socio-cultural and religious in origin, and is often used in conveying condolences or support to bereaved individuals who demonstrate overt grief and pain over the death of a loved one. Unfortunately, when this phrase is invoked it may often serve the purpose of discouraging further discussion or emotional expression regarding the deceased child and it serves to inhibit the full expression of their grief. It is important to note that, it is common for bereaved parents to report experiencing health and other problems when they are not able to freely express their grief (Kamm & Vandenberg, 2001).

Many of the underlying assumptions in Western culture, related to death and the bereavement experience, do not always fit with the experiences of other culturally diverse grieving families. There may be significant differences from culture to culture, in regards to what is considered acceptable levels of emotional expression of grief, both private and public, as well as the manner and the length of time assumed normal for mourning (McGoldrick, et al., 2004).

Thus, in Western culture there is often the expectation that after a specified, socially appropriate amount of time, bereaved individuals should return to their normal level of functioning.

American culture has been strongly influenced by the dominant British model of minimizing all expression and rituals for dealing with death. Through legislation, custom, and public health and work regulations, considerable social control is exercised over the process of death. Funeral rituals were taken over and commercialized by the funeral industry, although families are now increasingly taking back control. The allowable leave time for bereavement in the workplace (usually 1 to 3 days) is not adequate for the mourning rituals and customs of many cultural groups. Also, intense emotional displays or outbursts may be more

restricted, as a tacit expectation in American funeral and burial settings. (McGoldrick, et al., 2004, p.121,)

In this way, bereaved Mexican mothers often receive messages from either or both cultures; that outward or prolonged expression is not acceptable beyond what is prescribed in each culture and in the varying socio-cultural situations. In sum, Mexican mothers face many barriers to the full expression of their grief, which could result in additional emotional distress. This may be due, in part, to the lack of emotional support and responsiveness by extended family, community, or mental health professionals, and the lack of avenues in which bereaved Mexican migrant mothers are able to talk about or process their grief experiences. If these bereaved mothers do seek help, many social workers, medical personnel, and other professionals often lack the specialized knowledge to offer the culturally responsive grief support services that may be needed.

Significance of the Study

During the last several years, in my role as a bereavement support group facilitator, I have had the opportunity to observe the grief process of Mexican migrant mothers. Many of them have been able to express and share their intense loss reactions, as well as identify various family or social issues, as well as religious and cultural beliefs and expectations that have helped and hurt them.

At times, these mothers identified some culturally-prescribed beliefs, expectations and behaviors related to the death of their child, which they perceived as incongruent with what they knew or felt in their hearts they needed to do for themselves, in terms of adaptive coping.

While there is consensus in the literature that grief is a highly individualized

process, we also know that how someone grieves is often dictated by socialization and membership in a cultural group. Cowles (1996) asserts that while grief is an individualized, intrapersonal process, mourning, which is the outward expression of this grief, is mediated and influenced by cultural and societal norms. Irish (1993, as cited in Cowles, 1996) also proposes that, “it is essential to have an understanding not only of culturally defined mourning rituals, traditions, and behavioral expressions of grief, but also of how each individual, within him or herself, experiences grief” (p.288).

Therefore, I believe it is important to engage in an inductive exploration regarding the mothers’ intrapersonal experience of grief, first and foremost, and then to explore what their culturally-prescribed traditions, rituals, or behaviors mean to these Mexican bereaved mothers and what part, if any, they play in the women’s overall grief experience. Finally, it will be important to examine how the bereaved mothers are able to negotiate their intrapersonal bereavement experiences within the broader socio-cultural and religious contexts.

Finally, this study will contribute to the literature on grief and bereavement, in terms of expanding our understanding of the parental bereavement experience, as specifically related to the intrapersonal bereavement experience of Mexican migrant mothers.

Purpose of the Study

This specific research would attempt to explore and better understand the parental bereavement experience of Mexican migrant mothers. My research question is: “What is the lived bereavement experience of Mexican migrant mothers?” In addition, my research

would seek to enhance our knowledge and understanding of the ways in which Mexican migrant mothers negotiate culturally prescribed mourning beliefs and behaviors, and the meaning they make from this experience.

Shapiro (1995) suggests that since some grief responses exhibited by Latino individuals do not always fit the prevailing bereavement models, which may emphasize detachment as the goal of grief, pathological labels may often be assigned to these grieving individuals. Shapiro (1995) also proposes that, “the grief experiences of culturally diverse families can help us explore the limitations of current mental health models of grief and their failure to address the full complexity and duration of bereavement for most families” (p.161). For example, some behaviors that Mexican families display as part of their normal grief process, such as setting up candle and food “shrines” in the home for their deceased loved ones, may sometimes be viewed as abnormal or pathological by Western, non-Latino medical and human service professionals (Younaszai, 1993).

Therefore, it is an ethical imperative that professionals working with Mexican bereaved parents seek to better understand the parents’ subjective experiences, in order to provide the culturally responsive and supportive help. The intent is that this information will be useful to social work professionals and others working with bereaved Mexican families and that it will promote quality and culturally responsive interventions in the area of parental bereavement support services.

As outlined in the NASW Code of Ethics (2008), social workers have an ethical responsibility to seek to understand individuals and their behavior in a socio-cultural

context and to provide culturally sensitive and competent services. In addition, they

should promote policies and practices that demonstrate respect for difference, support the expansion of cultural knowledge and resources, advocate for programs and institutions that demonstrate cultural competence, and promote policies that safeguard the rights of and confirm equity and social justice for all people. (NASW, 2008, Section 6.04c)

Therefore, not only will this exploratory study seek to understand the lived bereavement and coping experiences of Mexican migrant mothers, but it will also examine the ways in which these mothers are able to negotiate culturally prescribed mourning beliefs and behaviors within this experience. The ultimate aim of this research is to improve bereavement support service delivery to Mexican bereaved parents and possibly other Latino families.

Theoretical Framework and Assumptions

It is important to acknowledge the potential pitfalls identified by Zucker (2005), in terms of relying too heavily on theories and models, in relation to the grief experience. Zucker (2005) begins by suggesting that relying too heavily on specific grief theories or models might inadvertently devalue each person's uniqueness, especially when the model or theory focuses primarily on "universal" tasks (e.g. Kubler-Ross' stages). He adds that many grief theories or models often pathologize grief, and do not allow for a more fluid perspective in terms of what is considered normal grief versus complicated or traumatic grief. Zucker (2005) also warns that, with many longstanding grief theories, the focus is often on some kind of "recovery," instead of what he refers to as "discovery." That is, he suggests that there really is no "recovery" for bereaved individuals, but rather that bereaved individuals enter into a

process that involves an ongoing discovery in terms of who they are now and who they will become, in the aftermath of their child's death.

Therefore, it is the purpose of this research to utilize a socio-cultural phenomenological theoretical framework which will more thoroughly and more appropriately reflect the research philosophy that allows for an open, flexible exploration of the bereavement experience of Mexican mothers. Werz (2005) proposes that phenomenology runs parallel with a constructivism-interpretive paradigm, which seeks to gain empathic understanding of how people perceive and interpret their everyday experiences.

The central theme of phenomenology is the lived world. Werz (2005) suggests, "The life-world manifests itself as a structural whole that is socially shared and yet apprehended by individuals through their own perspectives" (p.175). This kind of research is typically very descriptive, and according to Werz (2005), "the most outstanding quality of data sought by the phenomenological researcher is concreteness, that the descriptions reflect the details of lived situations rather than hypotheses or opinions about, explanations of, interpretations of, inferences, or generalizations regarding the phenomenon" (p.171). He adds that, "there is no external frame of reference or prior theories imposed onto the process, and the focus is on the meaning of the situation purely as it is given in the participant's experience" (Werz, 2005, p.172). Thus, the main focus or emphasis of phenomenological research is to view the client's problems from his or her own perspective.

Phenomenological theory proposes that human beings cannot exist in a world

without meaning. Therefore, individuals live within a socially constructed reality.

One means by which we can understand another's socially constructed reality is via a narrative approach. Polkinghorne (1988) suggests that, "at the individual level, people have a narrative of their own lives which enables them to construe who they are and where they are headed. At the cultural level, narratives serve to give cohesion to shared beliefs and transmit values" (p.14).

Furthermore, the mothers' narratives represent the mothers' realities in their own terms, what they have thought about, and what is important to them. The words and organizing ideas mothers use in talking about loss and grief shape their grief and create it. Their narratives define their needs, become the medium for defining paths to take and not take, and are the tools available for problem solving. Narratives are not rare or abnormal attributes of verbal production but are predominantly and central in people's lives; left on their own to talk about their lives, people generate narratives (Polkinghorne, 1988, as cited in Rosenblatt 2000, p.6).

Subsequently, there are those life experiences that are interpreted or perceived as normal, expected, and meaningful within a person's life. This constructed reality and its related life experiences provide individuals with guidance and meaning. However, this socially constructed reality is always at risk of being threatened or collapsed. Wheeler (2001) proposes that a crisis, such as the death of a child, constitutes this kind of a collapse or fracture to the "meaning" and sense of order in the parent's life. In fact, previous research has suggested that parents, in fact, report experiencing a severe crisis in meaning, after the death of their child.

My assumption is that the death of a child can be a very painful and difficult event, and that it needs to be explored through the subjective experience and voice of the bereaved mother. I also recognize that each mother's lived experience can be vastly different depending on many factors, including the nature of the child's death. Mothers confront the death of their child within different contexts: catastrophic and sudden, or as a chronic or progressive illness. Regardless of the varying circumstances, parents may ultimately perceive the death of their child as either unexpected or anticipated, and even anticipated but nonetheless defied.

One can assume that parental coping reactions and responses will be extremely subjective. Therefore, another assumption is that all human beings have different phenomenal experiences, and that each person will construct different meanings and realities, at different stages, out of these experiences. Therefore, to look at the phenomenon of bereavement in Mexican mothers directly through the "hearts and minds" of the mothers, in lieu of any prior theoretical assumptions, seems like a more humanistic and respectful approach, given the traumatic nature of this loss. It is hoped that participating Mexican mothers will perceive this study as a reflection that their feelings and experiences are important and that the information they provide will be used to help other Mexican families who must confront the death of a familial child.

Other Study Assumptions

There are two other assumptions related to this study in addition to those identified above. These assumptions have emerged as a result of my own experiential

contact with bereaved Mexican mothers, as well as from the anecdotal, personal communications they have shared within the context of the bereavement support groups.

The first assumption is that the concept or belief of “Déjalo descansar, no le llores” has some relevance in the parental bereavement experience of Mexican migrant mothers. That is, while it is my understanding that this term or advice given to bereaved Mexican migrant mothers is intended to be supportive to the mothers, and is likely grounded in religious and socio-cultural beliefs about a deceased person’s spiritual journey, it can nonetheless become a barrier to the full or externalized expression of these mothers’ grief. The second assumption- and ultimately my hope- is that these Mexican mothers will have a desire to discuss this experience with others, and may even find this experience of sharing, to be positive or beneficial. Mexican mothers may be more available and willing to participate in this study, based on their attendance in the Luz del Corazon support groups. Generally, Mexican mothers tend to assume the primary role of caregiver to the children in the nuclear family. Therefore, this initial exploratory study will focus on parental bereavement within the context of a mother/child relationship.

This, however, does not make the Mexican fathers’ bereavement experience any less relevant or of interest. In fact, Doka and Martin (2010) suggest that there are different kinds of griever which include “instrumental” griever, who are more problem-solving, and thought, task oriented, as well as the “feeling-focused” griever, which are able to more consciously experience and express their feelings of grief and sorrow. In my professional experience, it has been observed that many of the bereaved Mexican and

other Latino fathers present as “instrumental” grievors, while the bereaved Mexican and other Latino mothers appear to be more able to consciously experience and express their thoughts and feelings. Exploring the differences between bereaved Mexican fathers and mothers would certainly warrant future, supplemental research that could expand on the information gathered from this study. However, at this time, the paternal experience is beyond the boundaries of this study.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

Currently there is minimal research available specifically related to the grief experience of Mexican parents. More importantly, there is minimal social work research that has been conducted, as reflected by the limited number of articles in social work journals or abstracts, during the literature search.

Instead, most of the significant research has been developed and published by the nursing, medical, psychiatry, and other mental health professional fields. This literature review is primarily focused at broader theoretical frameworks and models related to loss and grief.

Davies' (2004) literature review traced how theoretical perspectives of parental grief have changed in the last century. The literature is focused on Anglo-American cultural perspective and starts with Freud's analytic tradition that emphasizes breaking bonds with the deceased, or "letting go." This approach is the basis of traditional models of the grief process and tasks of grief.

Moreover, there continues to be a gap in the research, primarily related to socio-cultural and ethnic factors that may be present, in relation to shaping the bereavement experience, and many professionals working in the bereavement supportive services agree that there needs to be a shift in the long-standing grief paradigm, which maintains a

Western and North American cultural perspective that emphasizes the severing of all ties to the deceased, “detaching” or “letting go” of the deceased after specified time periods, and which views the grief process as a fundamentally individual and private process. (Shapiro, 1995, p.160)

However, contemporary research is beginning to propose a paradigm shift, which embraces a different theoretical perspective, that of continuing bonds, as well as sociological perspectives on grief (Silverman, 2002). This paradigm shift also includes meaning making or meaning reconstruction in the grieving process, and some emerging research that explores cross-cultural expressions of bereavement and emphasizes the importance of socio-cultural narratives and other cultural factors in shaping the bereavement experience. Issues related to religion and spirituality is a sub-area that has also been researched regarding parental bereavement.

Some researchers, such as those cited in this literature review, also mention that they emphasize an interview structure for their research that encourages the emergence of the “female or feminist voice,” in lieu of a “male interview paradigm.” Yet, this female “voice” has been primarily represented by Western, Anglo females, and not those women from other ethnic and racial groups (Braun & Berg, 1994). This also supports the specific focus of this study on Mexican mothers.

Nonetheless, this general research in the areas of death studies, and research stemming from palliative nursing and medical fields, has been helpful in offering general insight and greater understanding of the parental bereavement experience, as well as offering some practice suggestions, which can be helpful and applicable even in varying

cultural and ethnic contexts. However, it must be prefaced that in addition to describing what the studies tell us about parental grief, the glaring limitation that the following studies on parental grief all have in common, is that they did not include representative samples of distinct Mexican or other Latino populations and heritage.

A Paradigm Shift in Understanding Bereavement

It is important to understand how prevailing theoretical grief models have shaped our beliefs and understanding of grief and mourning.

Beginning with Freud's 1917 influential "Mourning and Melancholia" the mental health field described normal compared to pathological grief, as characterized by the individual's capacity to disconnect or detach from the relationship with the deceased person, so as to make way for new, need-satisfying relationships (Freud, 1957, cited in Shapiro, 1995).

That is, Freud discouraged prolonged mourning and encouraged detachment as the pathway to healthy mourning. Specifically, he argued that mourning comes to a decisive end when the subject severs its emotional attachment to the lost one and reinvests the free libido in a new object (Clewell, 2004). During this same time, the field of human development was focusing on how people achieved separation and individuation. As a result, this prevailing theoretical stance led to what can be considered a deficit or maladaptive model of grief (Silverman, 2002).

It is interesting to note that Freud later revised his mourning theory in writings concerned with the Great War and in *The Ego and the Id*, where he eloquently described the enduring bonds of love, admitting that the total mourning process could never really

be completed. His reinterpretation suggested that no final severance of attachments could ever take place without dissolving the ego. This reinterpretation was also significant, in the sense that it also came after his own parental bereavement experience, in relation to the death of his daughter (Clewell, 2004).

However, it is Freud's 1917 "Melancholia and Mourning" bereavement theory and legacy that has continued to be most influential, in a large part, because it mirrors several underlying value assumptions in modern Western culture. One of these assumptions includes the belief that death severs all ties to the deceased. Moreover, clinical theories, which narrowly and prescriptively define grief reactions, as well as grief models that are task-focused, have been remarkably persistent in spite of research with normal populations, which contradict them (Shapiro, 1995).

Doran and Downing Hansen (2006) emphasize that in the past 15 years, the longstanding grief model, which focuses on breaking ties with the deceased, has been abandoned, and in its place the continuing bonds model has been forwarded. The continuing bonds model emphasizes connection and continuity by viewing the sustained bond with the deceased as a healthy and adaptive way to cope with the loss.

From the continuing bonds perspective, Silverman (2002) suggests that a more common reaction or motivation, during the grief experience, is the mourner's need and desire to "hold on" to the deceased loved one. The relationship with the deceased is also described as changing with time. That is, as individuals go on with their life, they continue to honor their loved ones by continuing to recognize the connections to them, and that they also recognize that the connections and relationship to the deceased loved

one can change and grow in different ways, as the bereaved individual goes through life and also changes.

Foster et al. (2011) also identified that there are various ways in which bereaved parents experienced continuing bonds with their children, including purposeful and non-purposeful reminders. They described “purposeful reminders” as actions on the part of the parents, which were purposeful, voluntary and conscious. They also described “non-purposeful reminders” as reminders experienced by parents, which were involuntary, non-conscious, and often occurred unexpectedly. It is important to note, however, that the research done on the continuing bonds model, especially as it relates to a child, has been very limited and focused on European American families (Doran and Downing Hansen, 2006).

Recently, other contemporary theoretical models have emerged related to bereavement, which include meaning-making and meaning reconstruction, narrative theory, and models that also explore grief in religious, familial and socio-developmental contexts. These contemporary models support and align with the continuing bonds perspective.

Parental Bereavement and Meaning-Making and Reconstruction

Braun and Berg (1994) suggest that the death of a child is such a unique and unexpected phenomenon, that this kind of bereavement is not simply resolved according to the established stage-wise grief process. Braun and Berg (1994) explored the ways in which bereaved parents develop an understanding of their experience and how it relates to reconstructing or incorporating a new reality after the death. The theory that emerged

included three phases in the process of meaning reconstruction: discontinuity, disorientation, and adjustment. The ability to restore meaning after the death of a child was clearly linked to the prior existence of a meaning structure that could account for and explain or reconcile the child's death. The findings of the study suggest that the process of meaning reconstruction is a unique and significant aspect of the parental grieving experience.

Similarly, Neimeyer (2001) presents human beings as meaning-makers and offers a constructivist framework for understanding the significance of loss and what we might do to accommodate it more adequately in our lives. He challenges the traditional assumptions we have made about grief and the so-called course of its resolution. Neimeyer (2001) suggests that in regards to grief, there is no single road or clearly marked stages, and no defined tasks to negotiate. He proposes, instead, that there are different cognitive, emotional, behavioral, and existential pathways or trajectories that grieving people follow as they negotiate the new terrain of loss in their lives. Furthermore, Neimeyer (2001) emphasizes that meaning reconstruction is an extremely important factor that significantly impacts the parental bereavement experience. He proposes that there are three significant processes involved in post-loss meaning reconstruction. The first is "sense-making" which involves an attempt on the part of the parent to wrap some kind of meaning around the event of the death. This can be related to aspects such as the specific and concrete explanations for the child's death, or even exploring and answering fundamental existential questions. The second aspect involves "benefit finding," which has to do with identifying any possible silver lining in light of

the loss or some life lessons to be gained from their painful experience. That is, the parents attempt to identify some greater good that can be realized in the midst of the pain of having had their child die. Examples can include a strengthened or closer relationship with God, or enhanced family unity or marriage as a result of the experience. The third aspect or process of meaning reconstruction involves “identity reconstruction” that involves the radical reordering of a parent’s sense of self. Specifically, it involves the emergence of a post-loss identity, which can either be progressive in nature (closer to an ideal self) or regressive (farther from the ideal self).

Wheeler (2001) also suggests that reconstructing meaning is a central process of grieving for parents. That is, that acceptance of the death of a child involves finding a way to make meaning of it. This was a descriptive, qualitative study, which involved 176 parents, who answered questions about the experience of their child’s death and the meaning of their lives since the death. For most of the parents, the death precipitated a severe crisis of meaning, and a search for meaning that not only involved cognitive mastery, but also a renewed purpose.

Narrative theory also provides a means by which grief is understood. The perspective taken is that Mexican mothers are the experts on their own experience and constructed realities, as well as the ways in which other individuals and situations have hindered or helped them in coming to these realities. As such, it is through the sharing of their stories that parents are able to derive some meaning making and healing in regards to their grief.

Rynearson (2001) has embraced a narrative approach for working with bereaved

individuals. He introduces the concept of a “restorative narrative,” specifically related to bereaved individuals who have experienced a traumatic loss of a loved one. Thus, he uses the concepts of narrative theory to facilitate a restorative process, which involves having the clinician and the bereaved client engage in retelling the stories together. The goal is not to change the client’s stories, but rather the goal is to help redefine or reinterpret the meanings attached to them, when the original interpretations and meanings are keeping the individual obsessed or possessed by the trauma, in unhealthy or destructive ways. In a narrative context, the client’s narrative is viewed as being rooted or grounded in real, personal events, and conscious thoughts are viewed as significant.

Family and Social Contexts of Parental Grief

Gilbert (1996) asserts that family provides a social context in which an individualized grief response is experienced. Gilbert (1996) also suggests that while families can support one another through the grief process, they can also add to family members’ stress if they experience grief differently. Her recommendations for bereaved families include facilitating “open and honest communication”; she adds that “sharing certain aspects of the loss is helpful, and this may consist of such activities as family members spending time together or working together to achieve certain goals” (Gilbert, 1996, p. 279).

Shapiro (1995) also examines the grief experience in a family and cultural context and proposes that the death of a family member initiates a crisis within the family and it creates the challenge of rebuilding a new family identity, both in managing family roles and responsibilities, as well as in managing intense shared emotions. That is, the death of

a family member disrupts the work of the family, and forces the family to reorganize the ways in which it fulfills family work roles and in how the members process their emotions. The social developmental theory of grief also proposes that family members will also have to redefine their relationship with the deceased family member and that “grief is resolved through the creation of a living, growing relationship with the dead family member that recognizes the new, psychological, or spiritual rather than physical dimensions of the relationship” (Shapiro, 1995, p.163).

It is important to be aware that when a close family member dies, “the bereaved family members face a destabilizing discontinuity, and in response, will turn to their own idiosyncratic rituals as a means of establishing some sense of stability, social support, and continuity with cultural and family traditions” (Shapiro, 1995, p.170).

Parental Bereavement, Religion, and Spirituality

There is increasing recognition in the health care literature that attention to spiritual and religious matters can have a positive influence on the experience of dying and bereavement and several early studies examining general populations of bereaved parents found religious coping to be positively related to adjustment. (Vandenberg, & Chibnall, 2005). Gerhild et al. (2007) provide the following definition of *Religiosity* as:

the expression of faith or belief in a higher power through rituals or practices of a particular religion or denomination. *Spirituality*, however, is a more abstract and elusive term. Preliminary definitions indicate that spirituality is broader than religion and relates to the universal quest to make sense out of existence, a characteristic of human beings. The Oxford English Dictionary defines spirituality as ‘a vital life principle which integrates other aspects of the person and is an essential ingredient in inter-personal relationships and bonding.

Meert, Thurston, and Briller (2005) explored the spiritual needs of parents at the

time of their child's death in the pediatric intensive care unit and during bereavement, and found that the main spiritual need described by parents was that of maintaining connection with their child. In this study, the parents reported that connections with their deceased children was maintained through storytelling, keepsakes and mementos, memorials, and altruistic acts such as organ donation, volunteer work, charitable fund raising, support group development, and adoption. Other spiritual needs identified by the parents included the need for truth; compassion; prayer, ritual, and sacred texts; connection with others; bereavement support; gratitude; meaning and purpose; trust; anger and blame; and dignity.

Sormanti and August (1997) also explored the connection between parental bereavement and spiritual connections to the deceased child, and concluded that, "with very few exceptions, the parents who experienced continued connection to their dead child derived psychological benefits from this spiritual connection" (p.468). Furthermore, the majority of the respondents felt their religious and cultural background had influenced their beliefs and reactions to the death.

However, in examining religion and meaning change after bereavement, Wortmann and Park (2009) suggest that, the experience of loss can also lead to shifts in fundamental beliefs or goals, with resolution often accompanied by increased or changed faith, but sometimes by loss of faith. That is, sometimes individuals may be unable to reconcile the circumstances of the loss with their belief in God or trust in church, and they must reject their prior beliefs. Others may temporarily struggle but develop a new understanding of God or how religion or spirituality matters in their lives and transforms

their struggle into comfort.

Helping Bereaved Families

Castle & Phillips (2003) emphasize the positive effects of talking and sharing with others, for the support and validation it offers, and as a way to reduce the bereaved person's sense of isolation. Therefore, it is common for bereaved parents to rely on the emotional support of friends and extended family members to assist them in the immediate aftermath of the death of a child (Silverman, 2002). Unfortunately, as time goes on, bereaved parents often find that their immediate family and friends are unable to meet their ongoing need for support. In these instances, bereaved parents can make use of a variety of bereavement support services to help them cope with the death of their child. However, one common source of bereavement support available is in the form of self-help, peer support groups, such as The Compassionate Friends.

Established in England in 1969, The Compassionate Friends (TCF) was organized for parents grieving the death of a child (The Compassionate Friends [TCF], 2010). Services provided through TCF groups (known as chapters) include informational materials and monthly meetings for TCF members. Chapters of TCF have been available in the U. S. since 1972; currently over 600 TCF chapters exist in the U. S. (TCF, 2010). Braun and Berg (1994) found that groups like The Compassionate Friends were helpful and provided support to bereaved parents, due to their structure which emphasizes sharing your experience and own meaning as it relates to the child's death, and refrains from offering advice or explanations regarding a child's death.

Similar to their English-speaking counterparts in the Heartlight Bereavement

Program at Lurie Children's Hospital of Chicago, the grieving Luz del Corazon families have become members of "the club no one wants to join" (Schuurman, 2004, Para 1). In spite of the fact that Chicago has one of the fastest growing Latino populations, Luz del Corazon is one of the few programs offering Spanish-Speaking support groups in the Chicago land area, to those families that find themselves in need of help to process and cope with this extremely tragic event.

Although the Luz del Corazon bereavement groups are offered at Casa Central Agency, which is located on the west side of the city, in the Humboldt Park area, the families who attend have varied ethnic backgrounds, which include Mexican, Puerto-Rican, Cuban, Nicaraguan, Guatemalan, Peruvian, and El Salvadoran. Although many of the parents that attend the groups are immigrants, there are also those that are already 2nd or 3rd generation, and yet still prefer Spanish-speaking services. However, the majority of the Spanish-speaking families who have attended the Luz del Corazon program have historically been of Mexican descent.

Typically the families who have utilized Luz del Corazon support services tend to have several children and come from a lower socio-economic status. These families also typically have a low level of acculturation, as evidenced by their limited fluency in English and their limited contact with mainstream social service organizations (N. Torres, Luz del Corazon program, Lurie Children's Hospital of Chicago, personal communication, March 2, 2010). The level of need experienced by these families has at times been overwhelming. While the range of human emotions that constitutes grief will be quite similar across cultures and ethnic groups, the manifestations may take on unique

dimensions within a culturally specific group.

The Latino community represented within the Luz del Corazon groups has presented with multiple losses. Additionally, financial need has often been quite prominent. Many families have discussed being socially isolated. Many do not have relatives living in the Chicago area from whom they could rely on for emotional support. Multiple family members are welcomed in the support groups, including extended family members and Compadres (godparents), and this accommodation has been made because there is no other place to send them for support. In addition to providing Spanish-Speaking staff and services, the program also provides transportation assistance, before-meeting meals, the expanded definition and inclusion of family members, referral and linkage assistance to other community services, in-home visitation to the families when requested, an enhanced psycho-educational component in the support groups, and additional programming that celebrates significant cultural holidays such as Dia de los Niños (Day of the Children) and Dia de los Muertos (Day of the Dead). In addition, the program provides specialized grief support services to the surviving children in the families. These are the various ways in which Luz del Corazon has culturally tailored its model, to better service the Latino families. In addition, Leon & Dziegielewski (1999) found that group services are particularly effective and helpful to Hispanic immigrant women given their communal structure and nature, and especially when psycho-educational components are incorporated.

Luz del Corazon program is now entering the 12th year, and continues to be one of the very few support groups in Chicago offering services in Spanish for bereaved

families. One of the main reasons for the program's success and longevity is that it has adapted its programming, staffing, and interventions in ways that acknowledge the families' socio-cultural needs (N. Torres, Luz del Corazon program, Lurie Children's Hospital of Chicago, personal communication, March 2, 2010). In sum, it is important to note that in regard to parental bereavement

the value of self-help and support groups has long been established (Silverman, 1981, 1986) and they can provide opportunities for education and ventilation, places to bond with supportive others, suggestions for adapting, and hope that one can survive the loss as others have done for seem to be doing.

Other benefits include improvement in self-esteem in the very nature of mutual support reinforces a sense of normality of the grief experience as well as furthering self-reliance (Doka and Martin, 2010, p. 196).

The Role of Culture in the Grief Process

While bereavement is a universal phenomenon, the cultural attitudes toward and the expression of grief vary considerably throughout the world. There exists a diverse range of behavior by which individuals, families, and communities express grief (Doran & Downing Hansen, 2006).

One's culture plays an important role in defining and shaping how grief is expressed through mourning rituals particular to that culture. Mourning rituals are shaped by how a particular culture understands death. Even so, it is important to remember that there is considerable variability within cultural groups in mourning rituals. Differences are present even in our dominant Euro-American culture. So cultural variations in mourning practices may be determined by ethnicity, religion, tradition, circumstances, or choice.

There may be significant differences from culture to culture, in regards to what is considered acceptable levels of emotional expression of grief, both private and public, as well as the manner and the length of time assumed to be normal for mourning (McGoldrick et al., 2004). In general, rituals, mourning rituals in particular, provide a structure for containing our distress and emotional chaos of grief. In addition, mourning rituals help facilitate the construction of and shared meaning for the loss; oftentimes individuals will resume “long abandoned cultural or ethnic practices, likely in an attempt to make sense of the world when death occurs” (Eisenbruch, 1984b, as cited in Doran and Downing Hansen, 2006). In essence, mourning rituals help re-establish stability in a family and community that was upset through a death.

Culture plays a critical role in the ways in which survivors understand death and think about the deceased, as well as how relationships are rebuilt within families and community following a death (Shapiro, 1995). The bereaved person’s grief experience is shaped by his/her culture and the cultural practices that prescribe acceptable mourning behavior following a death.

Clements (2003) proposes that, “all cultures have developed methods for adaptive coping, grief, and mourning. Subsequently, a lack of sensitivity to these practices by health care professionals may interfere with the necessary grieving process” (p.20). In the context of culture and its intersection with grief, it is also extremely important to understand and acknowledge culturally driven rituals, as a powerful means for containing and facilitating individuals’ grief.

Rosenblatt (2000) emphasizes the importance of rituals, imbued with cultural

meanings, in facilitating the grief process for parents. The rituals themselves provide a means by which the parents can stay connected to their deceased child and are “central to redefining the parent-child connection” (Rosenblatt, 2000, p. 63).

Therefore it is imperative that those assisting bereaved parents are knowledgeable of the mourning rituals particular to the population with whom they are working so as to best support these parents through their bereavement.

Bereavement and Mexican Families

In examining bereavement and Mexican culture, Silva (2003) provides a broad definition of Mexican culture as “a blend of the Indian-Mesoamerican and Spanish-European cultures, in which rituals of death, dying, and religion brought together a mosaic of practices” (p.104). It is also important to note that information related to mourning in the Mexican culture, reflects general themes about mourning within the Mexican community, and that there is variation within this ethnic group, so that it may not apply to every Mexican family. “Even within the same community, people approach death in contextually specific ways” (Brandes, 2003, p.135).

While death is often considered by some to be a prevalent motif in Mexican culture, “little is presently known about the individual and family experience of grief for Mexican Americans” (Oltjenbruns, 1998, as cited in Doran and Downing-Hansen, 2006, p.200). Only a few studies have been conducted to compare grief reactions between Mexican Americans and European Americans. Moreover, the literature on the Mexican American grief experience is scant, and encompasses bereavement based on a myriad of relationships--death of a grandparent, parent, spouse, friend, sibling, and child (Doran

and Downing Hansen, 2006).

Kalish and Reynolds (1976) conducted a landmark survey, that surveyed 114 Catholic, predominantly recent immigrant Mexican Americans regarding their thoughts and behaviors about death, dying and grief. Results from that study indicated that associated feelings of grief following a death was experienced intensely by the participants; religious symbols and rituals played an important role in their bereavement; and that large supportive Mexican American family networks provided comfort and practical aid while grieving.

Doran and Downing Hansen (2006) conducted an exploratory study using an ethnographic qualitative approach, with the primary purpose of exploring the unique bereavement experiences of Mexican-American families after the death of a child. The secondary focus of the study was to explore the ways in which Mexican-American families sustain their bond with their deceased child. Maintaining a bond with the deceased child emerged as a clear and prevalent theme in the study, and the eight primary means through which participants maintained their bond included: dreams, storytelling pertaining to the deceased child, keepsakes, feeling an enduring sense of presence of the deceased child, faith-based connections, proximity connections, ongoing rituals, and pictorial remembrances. Of these eight means through which connections were maintained, proximity, ongoing rituals, and pictorial remembrances were found to be particularly significant for the study participants (Doran and Downing Hansen, 2006).

In regards to maintaining proximity connection with their children, the first generation of Mexican American families, in particular, described the dilemma of having

to decide where to bury their children, whether in the United States or Mexico. Ongoing rituals were also identified as a significant means for maintaining a connection with the deceased children, with some of the rituals being regular visitation at the cemetery, special masses for the children (i.e., death and birth anniversary masses), the annual Day of the Dead celebration and personal rituals based on the family's own unique traditions. Interestingly, while some of the Mexican participants perceived the Day of the Dead celebration as comforting, other participants reported that they did not publicly observe this traditional Mexican remembrance of the dead, reflecting that, "I don't like it at all ... going to the cemetery. It's just too hard because I relive it all" (Doran & Downing Hansen, 2006, p. 208).

In addition, pictorial remembrances were identified as a useful means for maintaining a connection with their deceased children, especially in terms of the prominent location of the photos on the home altars which all of the families reported having. These home altars, which tend to be permanently displayed in the homes, usually contain meaningful photos, mementos, and religious artifacts. One parent commented on the function of the home altar, by saying, "So Timothy is always close to us" (Doran & Downing Hansen, 2006, p.208).

Clements (2003) suggests that the importance of religion and spirituality to Mexicans is central to understanding the role that culture plays in mediating the grief experience for this group. In particular, Catholicism, the dominant mainstream religion for Mexicans, provides a means by which death and the afterlife is understood. Vasquez (1993) proposes that most

Hispanics are Roman Catholic and their Catholic beliefs are sometimes mingled with indigenous traditions. For Christian Hispanics there is no finality in death. Dying is seen not as an end but as a beginning, as passing from one state to another. For those of Catholic background, death brings a passage to heaven if their actions have warranted that and if their sins have been forgiven, or if they have received the last rites. Yet the meaning of death is different for different groups. (p.204)

In particular, Mexican families tend to believe in the spiritual and psychological continuity between the living and the dead. This relationship between the living and the dead is considered sacred, and is often expressed through prayers, visits to the grave, and other rituals dedicated to the dead. Mexicans also believe in the interdependence between life and death, and view life and death not as opposite, but as two complementary parts that form the complete cycle of life. Thus, death is viewed as an extension of life (Munet-Vilaro, 1998).

As such, Mexicans also view death as an unavoidable event, often referred to as “fatalismo” (fatalism). Mexicans value living life to the fullest, living in the present, and being at peace with the inevitability of death. These are values that have helped Mexicans cope with life in their countries of origin, where poverty, lack of access to medical resources, war, and oppression have made them very familiar with death (McGoldrick et al., 2004). Younoszai (1993, cited in Lobar, Youngblut, & Brooten, 2006) also asserts that

Mexicans have more understanding and acceptance of death, because their country is primarily rural, poor, religious, and very young on average. Death is portrayed in Mexican statues, art, literature, and history, and Mexican children are socialized early to accept death, giving Mexicans a cultural familiarity with death. (p.44)

It is important to note that familiarity with death does not diminish the intense

grief that Mexicans may feel following a death. However, it is the very familiarity itself that may be most helpful in their acceptance of the death: “When we are more familiar with something, we are more accepting of it” (Younoszai, 1993, p.70).

However, deaths that occur at an untimely stage of the life cycle, as with the sudden death of an infant or child, are often difficult for Mexicans to accept (McGoldrick et al., 2004). Thus, culturally driven rituals and traditions are powerful means for containing and facilitating individuals’ grief, and can be particularly helpful to bereaved Mexican families experiencing the death of a loved one.

One ritual in Mexican culture of particular relevance for bereaved parents is the “Misa de Angelitos” (Little Angels mass). Having its origin in Spanish Catholicism, this ritual of “little angels” is still widely embraced by many Mexicans today. Marino (1997) explains that,

According to the Catholic dogma, children die without mortal sin, and go directly to Heaven where they become angels, without having to pass through Purgatory. Consequently, the death of a little angel, in spite of the pain it inflicts on parents, is a happy event. This ancient ritual arrived in this side of the Atlantic as part of the Spanish culture, and rooted perfectly in Mexico through the Pre-Hispanic celebration defined as the “Miccaihuiltontli”, which is a diminutive noun, and means the festivity of dead children and is a celebration for deceased innocent children. (p.37)

In “Misa de Angelitos,” the deceased child is traditionally dressed in white, such as to reflect an angel (a symbol of pureness) and decorative flowers or palm leaves are placed inside and around the coffin (to denote virginity). The ritual may also include special prayers, the singing of Marian praises, music, dances, sweets and drinks, and special games (Marino, 1997). The “Misa de Angelitos” ritual reinforces the concept of continuity of life and death. This is reflected by Mexican bereaved parents who report an

awareness of a constant, benevolent presence in their lives that they identify as being that of their deceased “angelitos” (Luz del Corazon support group participant, personal communication, December 2010). The sense that their deceased children continue to be near them is a prevalent theme that arises for Mexican parents participating in bereavement support groups (N. Torres, Luz del Corazon program, Lurie Children’s Hospital, personal communication, January 2011).

Some of the other values and traditions that are important in Mexican culture, and during the bereavement experience, include the concepts of familismo and its role in the funeral process, the nine-day Novena, and Dia del Los Muertos. These values and traditions are described below.

“Familismo” is a strong value in the Mexican culture, and stems from a collectivist perspective that the family’s needs outweigh the interests or needs of an individual family member. In this case, family is understood broadly to include the nuclear family, as well as extended family members, godparents, and close friends and neighbors (Flores & Carey, 2000). As such “death is very much a family event for Mexicans and it pulls together geographically separated family members both physically and psychologically, as no other event can” (Silva, 2003, p.110).

The funeral brings together the family, often from diverse locations, as family members make special efforts to attend in order to represent their branch of family relatedness to the deceased. Attendance at funerals is important to Mexican families, and the family of the deceased hopes for a large or well-attended funeral not only to demonstrate how much the person was revered, but also to show how strong the family is

in the face of death. Therefore, one can imagine the difficulties that arise for family members unable to return to their country of origin for a funeral. The wake or “velorio” also provides an opportunity for the collective sharing of grief and mourning of the dead. It is also an opportunity for reminiscing and expressing grief over other losses of people, relationships, possessions, and their homeland (Silva, 2003).

The Novena, a post-death ritual based on the teachings of the Catholic religion, involves nine days of mourning following the burial. A rosary, or prayer is said each of the nine days on behalf of the deceased person, by friends and relatives at the home of the deceased. Refreshments are served after each rosary, and conversations regarding the deceased are encouraged. This Novena is believed to help the soul find its way to heaven with all sins forgiven. People usually dress in black, white, or purple, and candles are lighted. The house of the deceased is also usually kept closed during the day to allow family members time to mourn in private (Munet-Vilaro, 1998).

Munet-Vilaro (1998) and Brandes (1997) describe the “Dia de Los Muertos” (Day of the Dead) as a unique Mexican holiday and celebration held annually on November 1st and November 2nd, which is a Mexican adaptation of the pan-Roman Catholic celebration of All Saints and All Souls Day. This Mexican celebration has its roots in both pre-Hispanic Mexican and Catholic rituals, and serves to honor deceased loved ones. Some Mexican communities have one day for honoring deceased children (Dia de los Niños, Day of the Children) and another day for honoring deceased adults. Other Mexican communities combine these into one day. In this celebration, families welcome back into their homes the spirit of their deceased loved ones. Families attend mass and visit the

cemetery where flowers and other mementos are placed on the grave. Family home altars are dressed with white cloth, candles, sweet bread (pan de los muertos, or bread of the dead), sugar-skull candy, photos of the deceased, and the favorite food dishes of the deceased loved one. These various items are referred to as the “ofrenda” or offering. The food is later shared with friends and family members, when it is believed that the souls have left to continue their journey. The home altars and decorations are removed two days after the celebration. However, some Mexican families maintain the home altars permanently in their home, in honor of their deceased family member. Children are also encouraged to participate in the Day of the Dead activities, and often receive a sugar skull candy with their name written on its forehead. The candy is eaten, teaching the children not to fear death, but to show respect to the dead so they can be reunited at a later time with their loved ones.

Therefore, given the strong sense of family and longstanding traditions that exist in Mexican culture related to the death experience and bereavement, one can imagine the difficulties that arise for family members unable to return to their country of origin or gather together due to distance for a funeral or the post-burial mourning rituals.

Migration and Bereavement

There is the assumption that the migration experience for some of the Mexican mothers may play a role in how the mothers experience their grief, and that the migration factor may impact their meaning-making process. For example, many of the bereaved Mexican families in the Luz del Corazon group have conveyed their shock and disbelief that their children died while under the care of American medical institutions or as a

result of community violence. Thus, many of the parents had maintained a strong assumption or belief that their children would have healthier and safer lives once the family migrated to the U.S. Furthermore, many Mexican families expressed their feelings of confusion, guilt, and social isolation, as they confronted the death of their child while living in the United States.

In their recent study of Mexican families in pediatric palliative care, Contro, Davies, Larson, and Sourkes (2010) explored the experiences of Mexican American family members who immigrated to the United States and then experienced the death of a child while in the United States. Participants described difficulties they encountered crossing the border, leaving the culture of their homeland, and then caring for a seriously ill child who later died. Four themes characterizing the participants' experience were identified: a backdrop of poverty, the absence of traditional community support, the challenge of caring for siblings, and the comfort parents found in maintaining connections with their deceased child through rituals derived from their home country. These findings echo those from an earlier study in which Spanish-speaking parents of children with life-limiting illnesses encountered many of the same difficulties as English-speaking parents, except their problems were exacerbated by poverty, language barriers, and issues of discrimination (Contro, Larson, Scofield, Sourkes, & Cohen, 2002).

At the time of their child's illness and death, almost all of the families were living on incomes below or close to the poverty level. For families who had long hospital stays and had to travel long distances to the hospital, this experience negatively impacted their already fragile economic situation. Families also noted high cost of funerals and related

cemetery expenses, as compared to in Mexico, became an additional source of stress for them during their bereavement. However, despite their economic hardships, the families reported that they felt they were better off financially than they would have been in Mexico.

Participants also placed a high value in terms of the human connection and support they received in Mexico that alleviated feelings of being alone at particularly difficult times in their lives. Many participants reported missing the support they received in Mexico from their priest, extended family members, and their community in general.

As one parent remarked,

When someone is sick there [in Mexico], the first thing we do is to take them to a priest. People go visit us and the patient. If they can't see the patient, they visit the parents, the relatives. And it's a big support... The pain you feel as parents nobody is going to take away, but it makes the load a little lighter when a lot of people are behind you telling you, "Hang in there. I went through something similar." But not here (in the United States), because the two of us are alone. (Contro et al., 2010, p. 191)

As a result, participants reported that the lack of community support in the U.S. made them feel socially isolated and added stress to an already challenging situation. Because of the emphasis that many Mexicans place on family support, the death of a child may also be particularly painful and difficult to integrate when their extended family and friends remain in the country of origin, and are unable to mourn alongside the parents.

Study participants also indicated that rituals from their country of origin provided a useful means by which to remain connected to their deceased child. As Contro et al. (2010) state,

Adults and children observed rituals from their home country to honor and maintain an ongoing connection with their deceased child. Frequent visits to the cemetery and keeping the burial site clean and adorned with flowers were important family activities. These rituals may act as a bridge from the home country to life in the United States and aid in the bereavement process. (p.198)

Thus, participants made use of familiar rituals to serve as representations of the comfort and support they would have found in their home country.

Anin-Boateng's 2009 study supports the importance of rituals for migrant families experiencing grief. Her qualitative and phenomenological study of 20 Ghanaian migrants living in the United Kingdom found that when confronted with death, the study participants relied heavily on familiar cultural bereavement rituals to assist them in coping with their grief. While distance from their home country was certainly a mediating factor in their grief, the study participants sought ways to replicate the sources of support familiar to them from Ghana. Overall, the study results seem to suggest that Ghanaians living in the U. K. are able to obtain or re-create the necessary support that is helpful to them at the time a death occurs. As Anin-Boateng (2009) says, "in the event of death these distances were overcome" (p. 158). All of the aforementioned studies, then, highlight the critical importance of familiar mourning rituals in helping overcome the difficulty that distance poses for migrant families.

Other Barriers to the Expression of Grief

Social stigma may also be a barrier to these mothers utilizing informal (i.e., family, friends) and formal (i.e., counseling and grief support services) sources of support especially after a prolonged period of grieving time.

Link and Phelan (2001) emphasize that the concept of stigma has been

criticized as being too vaguely defined and individually focused. In response to these criticisms, Link and Phelan (2001) constructed a revised conceptualization of this term and define it as “the co-occurrence of its components-labeling, stereotyping, separation, status loss, and discrimination” (p.363).

For the Mexican mothers who participate in the Luz del Corazon groups, there is a reported sense of self-consciousness in regards to discussing their involvement with the group with extended family and friends, because the mothers state that they have already been dismissed or criticized by extended family members or friends, for their prolonged mourning experience.

While it is well known that there are cultural differences in terms of how grief is expressed, at the same time we also know that many Mexican and other Latino families may not get the help they need due to lingering disparities in mental health services. The most comprehensive consideration of ethnic and cultural disparities in mental health was introduced at the annual convention of the American Psychological Association Convention in 2001, when the Surgeon General released “Mental Health: Culture, Race, and Ethnicity.” The U.S. Department of Health and Human Services Executive Summary suggests that there exist several disparities affecting mental health care of racial and ethnic minorities compared with whites. Among these, the summary indicates that minorities have less access to mental health services and that there is a lack of adequate and sufficient services available to them. Moreover, when they were able to access mental health services, they were often of a poorer quality. The summary also indicated that the lack of culturally responsive or competent clinical environments deters many

minorities from seeking help (U. S. Department of Health and Human Services, 2001).

Finally, Latinos' level of acculturation, socioeconomic class, family and gender roles often affect both their adherence to traditional cultural values and their help-seeking behaviors, so that some Latino families may be less likely to seek mental health or bereavement support services. Language barriers, generational factors, socio-cultural and ethnic factors, immigration issues, as well as religious and philosophical beliefs are all factors that may disconnect Latino families from their social support community and can impede their sense of safety, trust and ability to seek or access mental health support services (Flores & Carey, 2000). For example, Zack Tshikawa, Cardemil, & Falmagne (2010) have noted that some Hispanic mothers may refrain from help-seeking due to specific socio-cultural beliefs or factors. Specifically, they note one possible reason, which is that

Marianismo could shape help-seeking behavior by calling for women to respond to their family's suffering before they tended to their own. Although participants themselves did not use the term, it is possible that a phenomenon resembling marianismo might impede the help-seeking and help-receiving processes for both men and women in the following way: If one felt unjustified asking for help because of the desire to appear strong, and the fear of overburdening family members, the options for receiving help would drop off considerably. (p.1564)

Anecdotally, many of the Mexican mothers who currently participate in the Luz del Corazon program, have also commented that their biggest fear when they initially joined the support groups was that they didn't fully understand how support groups functioned, or what the expectations were in this kind of process. As a result, many reported being very intimidated and confused. However, it is also important to note that,

Minorities may face cultural, social, or economic barriers to seeking help from

health services providers, or they may already be getting the support they need from their own families or ethnic communities. It is difficult to draw conclusions since there has been little research into service utilization by bereaved families from different ethnic and cultural backgrounds. (Shaefer, 2003, p.3)

Literature Review Summary

In sum, review of the literature suggests that there are some significant themes and certain experiences associated with the parental bereavement experience. It must be reiterated, however, that this literature review is a reflection of an absence of Mexican or Latino parents' input or "voice" within the research community as it relates to the experiences of bereaved parents. It continues to be uncertain whether the aforementioned experiences or central themes identified in the bereavement literature are applicable to the lived experience of bereaved Mexican parents. Therefore, exploration of the lived bereavement experience of Mexican migrant mothers can certainly strengthen understanding of the bereavement process from a cross-cultural perspective, in order to provide more culturally responsive services.

CHAPTER THREE

METHODS

This research attempted to explore and better understand the parental bereavement experience of Mexican migrant mothers. In addition, this research sought to enhance knowledge and understanding of the ways in which Mexican migrant mothers negotiate their intrapersonal bereavement experiences within the broader socio-cultural and religious contexts, including prescribed mourning beliefs and behaviors. The specific research question for this study is: “What is the lived bereavement experience of Mexican migrant mothers?”

The research design was exploratory in nature, and utilized qualitative research methods and grounded theory analysis, which was well suited for the research objective of exploring the parental bereavement experience of Mexican migrant mothers. Grinnell and Unrau (2005) suggest that a qualitative research approach “aims to answer research questions that provide you with a more comprehensive understanding of a social problem from an intensive study of a few people” (p.85). Furthermore, Anastas (1999) proposes, “while the purposes of flexible method studies may vary considerably, the emphasis is usually on the discovery of new phenomena or on the redefinition of phenomena in a way that remains close to the experience of the research participants themselves” (p.57).

In terms of research design, qualitative research provides more humanistic, natural, and interactive methods for obtaining information and it is emergent rather than

tightly prefigured (Marshall & Rossman, 2006). This design, which utilizes flexible methods, provides rich, comprehensive descriptions in relation to the parental bereavement experience of Mexican migrant mothers. This method also fits with an inductive model of logic. That is, reasoning and theories are derived from the data. One advantage of this method is that it allows for taking in new information and incorporating it into the study design. However, it is acknowledged that this method (qualitative data from focus groups) can also be time consuming because the qualitative method can generate volumes of data, which can often be difficult to manage.

For the purpose of this study, bereavement is understood to be the experience of losing a loved one by death. Consistent with this image, we respond to loss with grief, which is understood to be a dynamic, pervasive and highly individualized process (Cowles, 1996). Often the words “grief” and “bereavement” are used synonymously throughout bereavement literature, and are also used interchangeably for the purpose of this study, including terms such as “bereavement experience” or “grief experience”. Furthermore, it is understood that the experiences of grief and bereavement often involve intense physical and psychological distress. Mourning is understood as the outward expression of the bereaved person’s grief, which is mediated by cultural and societal norms, and is used synonymously with the term “outward expression of grief” in this study. In addition, rituals are understood as

any activity-sacred or secular, public or private, formal or informal, traditional or newly created, scripted or improvised, communal or solitary, prescribed or self-designed, repeated or one-time only- that includes the symbolic expression of a combination of emotions, thoughts, or spiritual beliefs of the participant(s) and that has special meaning for the participant(s). (Castle & Phillips, 2003, p.43)

“Mexican migrant mother” is defined in this study as a female parent of Mexican descent or heritage, as self-identified, born in Mexico and who has immigrated to the United States, and then experienced the death of a familial child¹, which occurred while the family lived in the U.S.

Although this is an exploratory, qualitative research design, the researcher sought to maintain descriptive and interpretive validity (i.e., how well the experience of parental bereavement as reflected by the respondents was described and interpreted), by utilizing peer debriefing and support, which provided the researcher with additional feedback and varying perspectives regarding the data analysis and interpretations. This was important in terms of addressing any issues of researcher biases that may also exist. Consistent auditing and process journaling was also an integral part of the process, in order to document what the researcher did to control for biases and preconceptions. Grinnell and Unrau (2005) suggest that, “the researcher should develop an audit trail in the form of documentation and a running account of the process throughout the study” (p.441). The use of the computer software program, NVivo, also supported enhanced reliability in terms of providing a consistent method for managing the data that is obtained.

Population and Sample

This study is specifically exploring parental bereavement in Mexican migrant mothers. The target group was Mexican migrant mothers who had the shared experience of parental bereavement, as the result of the death of a child in the family. Specifically, the respondents recruited for this study were selected for their common similarities or

¹ “Familial child” for the purposes of this study, is defined as a son or daughter, of any age, biological or fostered/adopted, within a family.

characteristics, which included 1) that they self-identified as “Mexican” or “Mexican American” and were born in Mexico; 2) they resided in the Metropolitan Chicago area; and 3) they were mothers who had experienced the death of a familial child of varying age ranges. This purposive sample was used because, as bereaved Mexican migrant mothers, the women had expert knowledge and experience related to the phenomenon of parental bereavement, and specifically in the socio-cultural context of being Mexican migrant mothers.

Recruitment

Institutional Review Board (IRB) approval was obtained in June 2011, accordingly, as it relates to all aspects of confidentiality protection and protocols. Recruitment for participants began in September 2011, with the initial distribution of recruitment flyers to specific community partners and via a Lurie Children’s hospital mailing to Luz del Corazon families during the fall of 2011.

Luz del Corazon bereavement program, at Lurie Children’s Hospital, maintains a client database, which was made available to the researcher for the purpose of recruiting participants for the study. This database maintained information on Spanish-speaking and Latino bereaved families that had been referred by community partners, social service agencies and other hospitals, or whose children had received medical treatment at Lurie Children’s Hospital, but later died. Luz del Corazon is currently one of the few Spanish-speaking parental bereavement support programs in the Metropolitan Chicago area. Specifically, utilizing the current Luz del Corazon families’ database, which at the time

maintained information on 266 Spanish-speaking and Latino families², research recruitment flyers were mailed to these families identified in the database, as part of a routine outreach mailing done by the Luz del Corazon program. This mailing occurred during the month of October 2011 and with the approval and support from the Luz del Corazon program. The research flyer specifically targeted self-identified Mexican mothers (with definition of this term provided on the flyer) and the flyer identified the study as an independent research study being conducted by a doctoral student at Loyola University Chicago, School of Social Work. A copy of the recruitment flyer is provided in (Appendix A).

During October of 2011, and intermittently thereafter, recruitment flyers were also posted at the Luz del Corazon meeting site at Casa Central Agency on the West Side of Chicago. Information about the study and copies of the research recruitment fliers were also sent to various bereavement-focused community partners and Latino-focused social service agencies, via email and hard copy distribution, by the researcher.

Recruitment of participants was a time intensive and challenging process. It is assumed that this was primarily due to the sensitive nature of the research topic and due to the fact that this targeted population is difficult to identify, outside of specific sources. The previous or current relationships that potential study participants had with other community-based professionals, who acted as liaisons for the researcher, significantly helped during the recruitment process.

In addition, and due to the difficulty in identifying and recruiting participants for

² Of the 266 families included in this database, approximately 20 families were actively participating in the Luz del Corazon groups at the time.

the study, snowball sampling was also used to recruit participants. At the conclusion of focus groups, the researcher asked participants to help identify other mothers who might be eligible and interested in participating in the focus groups.

Screening

The recruitment flyer provided contact information for the researcher. Twenty-seven women contacted the researcher to participate in the study and were screened for eligibility. The researcher reviewed eligibility information and also discussed the purpose and nature of the study. Questions were asked of potential participants in order to confirm eligibility to participate in the study.

Based on the eligibility criteria, 5 women were deemed ineligible for the study due to the following reasons: 3 women self-identified as being of Puerto Rican heritage, 1 women self-identified as being of Cuban heritage, and 1 women self-identified as being of Mexican background or heritage but reported that she had been born in the United States and had lived in the U.S. her entire life. Therefore, a total of 22 mothers were deemed eligible to participate in the study.

For those deemed eligible, the researcher explained that participation in the study involved a time investment of at least two hours. The researcher also explained the voluntary nature of the study, as well as the emotional distress that it could cause some participants. The researcher also obtained contact information from the participant, including phone number and address. The researcher informed the participants that some documentation would be mailed to them, prior to the scheduled date of the focus group, which they were asked to review the documentation thoroughly and to provide their

signatures, unless they had any questions or concerns.

Documentation was subsequently mailed to each participant, usually within 1-2 days after the initial screening and it included a cover letter, the “Consent to Participate in Audio Taping” form, and a “Demographic Information” form. The cover letter provided the date and location of the focus group interview, as well as a reminder asking the participants to review and complete all of the enclosed documentation and to bring it with them on the night of their focus group interview. The “Consent to participate in audio-taping” and “Demographic information” forms were provided in both Spanish and English. The “Consent to Participate in Audio-taping” form is provided in (Appendix B). The “Demographic Information” form is provided in (Appendix C).

In order to ensure optimal attendance at the various focus groups, the researcher also initiated reminder phone calls to each participant 1-2 days prior to each of the scheduled focus group interviews.

Data Collection

Focus groups were used as the means of gathering data for this study. Marshall and Rossman (2006) also suggest that this method is socially oriented and can be more comfortable than one-to-one interviews. It can also promote greater reflection, as people listen to others’ opinions and understandings to form their own. Furthermore, “the cost of focus groups is relatively low, they provide quick results, and they can increase the sample size of qualitative studies by permitting more people to be interviewed at one time” (Marshall & Rossman, 2006, pp.114-115).

Focus groups also are culturally congruent with the collectivist, socially oriented

characteristics of many Mexican families. Focus groups also parallel the Luz del Corazon support group modality with which these Mexican mothers seem comfortable. One disadvantage of focus groups concerns the power dynamics that could emerge resulting in less control over the process by the researcher. However, the researcher had solid experience with group facilitation and was comfortable dealing with small group dynamics.

Focus groups were conducted at a community agency, Casa Central Social Services Agency, located in the Chicago metropolitan area, and at other community-based agencies that serve Latino families. The focus group interviews lasted 90 minutes and were conducted in the language preferred by the participants, which was Spanish. The researcher and another licensed clinical social worker conducted two of the interviews, and the researcher conducted three interviews independently.

During the focus group interviews the researcher asked a series of open-ended guiding questions using a semi-structured format. The guiding questions pertained to various aspects of the lived bereavement experience of the participants. The complete list of interview items is provided in (Appendix D).

For purposes of confidentiality, only first names of the participants were used. At the beginning of every focus group interview, participants were asked to introduce themselves using first names only. The researcher and co-facilitator addressed participants by first name only as well. Other group members were asked to do the same. When two participants had the same first name, middle names or other distinguishing information was applied.

The interviews were tape-recorded in their entirety, for purposes of accurate transcribing and subsequent coding and categorizing. The specific procedures that were utilized in the transcription and translation of the data are explicitly and comprehensively described in the data management section, which follows.

Data Management

Transcription

The audiotape-recorded data from the focus groups was provided to a qualified transcriber with experience in the process of transcription of Spanish audiotapes and who was fluent in the Spanish language. Only first names were included in the transcriptions. Transcripts also included any nuances that could be heard on the tapes, such as sighs, repetitions, pauses, laughing, weeping, and emphases, or other non-lexical information to describe any emotion attached to responses. The transcriber who had signed a confidentiality agreement prior to beginning the transcription work, then returned the transcriptions to the researcher electronically.

The audiotapes were provided to the transcriber as the various focus group interviews were conducted between November 2011 and August 2012. All transcription work was completed in September 2012.

Translation

In this particular study, one of the challenges involved the collection of data, in the Spanish language. This involved some cultural similes and sub-cultural idiosyncratic terminology, which required translation into English in easily understood terms. As Marshall and Rossman (2006) point out, “the focus on generating accurate and

meaningful data through translation processes is paramount” (p.111). Therefore, various steps were taken to insure the accurate translation of the Spanish language transcripts.

Spanish language transcripts from three focus groups were translated into English by the same individual who completed transcription of these audiotapes, given she was already familiar with the content and she also had adequate experience in Spanish to English translation. Spanish language transcripts from the two last focus groups were translated into English by the researcher. The researcher is fully bilingual in both languages.

The transcribed data was reviewed for accuracy by the researcher and some minor adjustments were made as needed. Specifically, each Spanish-language transcript was reviewed via side-to-side comparison with its designated Spanish audiotape. Some slight revisions were done in order to supplement some content that was inaudible to the transcriber but that was recognizable to the researcher, as a result of her direct participation in the interviews. In addition, the researcher incorporated additional, subtle nuances that could be heard on the tapes that were not included in the initial transcriptions. Next, the researcher reviewed each English-language transcript via side-by-side comparison with its designated Spanish-language transcript, in order to confirm that the English and Spanish content aligned and that the final English translations accurately reflected the words and comments made by the mothers throughout all of the interviews.

The researcher referred to the Revised 2nd Edition Oxford Spanish dictionary and engaged in ongoing consultation with fluent Spanish-speaking Mexican peers in order to

address any sub-cultural idiosyncratic terminology that was identified, and to determine accurate definitions and intent for some words used. The researcher then determined that the English language translations were accurate and aligned to the fullest extent possible.

During the period of time the researcher needed to listen to the tapes, the tapes and transcribed materials were kept in a locked file cabinet at the researcher's professional office. In addition, electronic versions of the transcriptions and tapes were stored in a password-protected personal computer. Once the transcribed data had been reviewed, the audiotapes were destroyed.

Furthermore, only first names of the participants will be included in any future presentations, reports or articles related to this research. When individuals are mentioned, it will be done in a way that disguises their identity.

Data Analysis

Grounded theory analysis is well suited for qualitative inquiry in the phenomenon that was explored since it supports and fits appropriately within the constructivism and phenomenological paradigms. This is an emergent process, in which both methodology and theory develop gradually as data and interpretations accumulate. That is, in grounded theory methodology it is assumed that theory is concealed in the data for the researcher to discover. The process is driven by the data in such a way that the final shape of the theory is likely to provide a good fit to the situation.

Fassinger (2005) provides an extremely informative and comprehensive description of this method of data analysis:

Grounded theory holds as its core tenet the construction of theory out of lived experiences of participants, and as such, it integrates theory and practice in

ways that few other approaches can boast, constituting a methodological exemplar of the scientist-practitioner model. (p. 165)

Data analysis, via a grounded-theory method, involved the transcribing of the interviews, and a subsequent process which involved thoughtful and ongoing coding, categorizing and sub-categorizing, in terms of common, significant themes and key concepts. In addition, the researcher interpreted and analyzed these concepts within context as they emerged. This process of data analysis also incorporated memo writing and auditing aspects to help track and record the decision-making and analysis process. The use of a qualitative software program, NVivo 9, was utilized to support the analysis, and for the purposes of enhanced efficiency in the management and coding and analysis of the data.

Data analysis followed the traditional steps of the grounded-theory method which involved the process of constant comparison. The constant comparison method is one of the key components of the grounded-theory approach. This method developed by sociologists Glaser and Strauss involves a cyclical process of induction, deduction, and verification to code the data. The method of constant comparison included a two-level process of coding in which meaning units were first identified, and then further organized and categorized by carefully examining the similarities and differences among meaning units (Grinnell and Unrau, 2005).

Strengths and Limitations of the Study Design

The main strength of this qualitative, flexible methods study is that it emphasizes the “discovery of new phenomena... in a way that remains close to the experience of the research participants themselves” (Anastas, 1999, p. 57). The use of focus groups as a

means of data collection allows for the phenomena to be obtained “in context in terms that are as ‘experience-near’ as possible” (Anastas, 1999, p. 57). The strength of this type of methodology is that you will obtain rich, “thick” data that more fully explores the research question than a quantitative study would.

Another significant strength of this study is that it explores new phenomena and follows what has been very limited research in this particular area of study. Findings will contribute to the bereavement literature and will provide a cross-cultural perspective of the parental bereavement experience. The researcher’s fluency in Spanish as well as her prior experience and knowledge in the area of parental bereavement also helped to strengthen the study, in that it afforded participants the opportunity to communicate their experiences in their primary and preferred language and the interview process occurred with cultural sensitivity and competence demonstrated by the researcher.

One limitation of this study concerned the potential for researcher bias. Using an audit trail, in which the researcher carefully documents details of the research study (Anastas, 1999), journaling, and the use of peer review and consultation will help to address the potential researcher bias.

The use of focus groups could also be an issue of concern should the researcher lack experience in facilitating groups and in managing the small group dynamics that emerge. As mentioned earlier, however, the researcher had solid experience in facilitating of support groups and was comfortable dealing with group dynamics.

It is also important to note that due to the nature of this study, the findings cannot be generalized to the broader population of bereaved mothers or parents.

Finally, is it possible that when it comes to the personal experiences of grief, there will be some feelings or thoughts that participants are not comfortable or willing to share with others. As a result, it should be acknowledged that it is likely that some perspectives are not captured in this study.

Role of the Researcher

Because the researcher is immersed in the research field for this qualitative study (Anastas, 1999), it is important that the researcher take steps to control for researcher bias. This is especially important during the data collection as well as during the data analysis components of the study. Keeping a log or journal that details decisions made throughout the research process can help control for potential bias (Anastas, 1999).

The researcher sought to maintain descriptive and interpretive validity (i.e., how well researcher described and interpreted the experience of parental bereavement as reflected by the respondents), by ensuring that each interview was recorded and later transcribed verbatim, and that the notes compiled during the interview were an accurate reflection of the information being provided by the participants. This was supplemented by post-interview debriefing with the co-facilitator when possible, to discuss general observations and process issues. This helped to control any researcher biases and preconceptions. Focus group summaries, a reflective journal, and memos (within the NVivo software program) were maintained which included general observations, comments, tentative interpretations and emerging thoughts and ideas, which collectively documented the unfolding analysis process.

Peer debriefing and support was also utilized which provided the researcher with

additional feedback and varying perspectives regarding the data analysis and interpretations. Strategies such as peer review helped to reduce the biggest threat to the internal validity of the study, “observer effects” (Anastas, 1999, p. 72) or “researcher bias” (Johnson, 1999, p. 160).

Using these various methods was important in this study, since the researcher was familiar with some of the participants and their bereavement experience narratives. Therefore, transparency and reflexivity on the part of the researcher was essential to the trustworthiness and credibility of the study’s results.

To reiterate, steps were taken to insure that research bias was carefully monitored and assessed through regular journaling, co-facilitator post-group processing, the use of peer review and consultation, the use of the NVivo 9 computer software to ensure a consistent method for data management, and the use of verbatim quotes to reflect participants’ thoughts, feelings, and experiences.

Ethical Considerations

The primary ethical considerations for this study involve protection of confidentiality and anonymity for participants and informed consent of participants. Studies of this nature are subject to review and approval by The Loyola University Chicago Institutional Review Board (IRB); consequently, a thorough description of all processes and instruments utilized in this research study, including the interview guide, recruitment flier, and consent forms were submitted for IRB review and approval.

The researcher was also aware that the sensitive and painful topic of this study could trigger strong emotional reactions in the respondents. In terms of ethical

considerations, bereaved mothers who had experienced the death of a child within the last six months (at the time of the interviews) were not eligible to participate in the study.

However, there was no outside time limit established, in terms of years since the death of their child in order to be eligible to participate in the study. It was also anticipated that some of the study participants would have prior experience with group participation through their attendance at the Luz del Corazon program, and so there would be familiarity with sharing in a group setting.

The voluntary aspect of this study was consistently emphasized, as well as the sensitive nature of the phenomenon being explored. Voluntary participation in this study presumed a desire by the participants to further discuss their experiences as bereaved mothers, although it was understood that their participation could evoke painful memories. Special attention was given, during the recruitment phase, to ensure that participants were made aware of the sensitive nature of the research study, and mention was made of the possible emotional distress that it could cause participants, via review of the consent form.

While we know that grief is not a linear process, bereavement professionals providing grief support services do tend to agree that in the initial days, weeks, and months after the death of their child parents often experience intense loss reactions. Some parents may knowingly utilize self-initiated cognitive distortions, not to be confused with denial. It keeps the grieving individual's functioning intact. However, initial and intense loss reactions can be so pervasive during the first few months that probing at such a vulnerable point could exacerbate the grief experience. While that is still a possibility at

any time, interviewing after a longer healing time allows parents a better opportunity or space to self-identify their comfort. (K. James, Heartlight Program, Lurie Children's Hospital of Chicago, personal communication, April 29, 2010). Furthermore, in this researcher's experience as a bereavement support group facilitator, it has been observed that mothers seem to be the best judge regarding if and when they are ready to share their feelings and grief narratives.

Furthermore, at the beginning of each focus group, a list of bereavement support services (in both English and Spanish) was provided to all participants by the researcher. In addition, special care and attention was given during the actual interviewing to allow the participants opportunities to take breaks or to excuse themselves if the discussion became uncomfortable or they felt distressed.

It was also assumed that there was a possibility that as a consequence of sharing their feelings and thoughts regarding their bereavement experience, there might be some positive and supportive effect for the participants, although that was not the intention of the interviews. It should be noted that the researcher did not provide any direct support or advice during the course of the interviews.

CHAPTER FOUR

RESULTS

This chapter will describe characteristics of the five focus groups and its participants. I will present the results obtained in regard to the purpose of the study, reporting the way in which the data was organized in codes and themes using the software package NVivo 9. Further elaboration on the collected data will be provided, quoting some relevant comments made by the participants in the focus groups from which the data was collected.

Focus Groups and Participant Characteristics

Twenty-two Mexican migrant mothers participated in five focus groups. Five focus groups were conducted between November 2011 and August 2012. One focus group was conducted in November 2011, and included 4 participants. One focus group was conducted in February 2012 and included seven participants. Two focus groups were conducted in April 2012 and included six participants (four participants and two participants). The final focus group was conducted in August 2012 and included five participants.

The target population was Mexican migrant mothers who had the shared experience of parental bereavement, as the result of the death of a child in the family. Specifically, the respondents recruited for this study were selected for their common similarities or characteristics, which included 1) that they self-identified as “Mexican” or

“Mexican American” and were born in Mexico; 2) they resided in the Metropolitan Chicago area; and 3) they were mothers who had experienced the death of a familial child of any age; and 4) the death of the child had occurred six months or more prior to the interview.

Demographic Information for the Participants

Demographic information was collected from participants via the Demographic Information Form and results revealed that the majority of these mothers were largely Catholic, married, lived in low income households, primarily Spanish-speaking, and had limited formal education.

Specifically, 16 participants were married, 17 participants were of low or modest income households (based on \$29,999 or less annual household salary), and 17 participants had completed high school or a lower level of education. Almost all of the participants (twenty) reported affiliation with the Catholic religion. The number of years that participants had resided in the United States ranged from 5 years to 36 years. The ages of the participants ranged from 24-years-old to 59-years-old. At the time of the interviews, the number of years since the death of their child ranged from one year to just under 11 years since the death of their child. The ages of the children at the time of death ranged from a few days old to 32 years of age. In addition, one death was reported as a late stage miscarriage.

Based on responses, slightly more than one half of the children (twelve) died as a result of medical issues and other children died from causes such as homicides, car accidents, a household accident and a suicide. More detailed demographic information about participants is listed in Table 1.

Table 1. Participant Demographic Information

Name	Age	Years in U.S.	Marital Status	# of Surviving Children	Age of Child	Cause of Death	Gender	Biological/ Adopted/ Foster Child	# of Years Since Death	Religion	Educational Level	Annual Income Range
#1 Mother	46	17	Married	3	16	Car Accident	Daughter	Biological	5 yrs / 5 mos	Catholic	Voc / Tech	40-49,999
#2 Mother	29	6	Married	4	15 Days	Medical complication	Daughter	Biological	3 yrs / 7 mos	Catholic	Elementary	0-10,000
#3 Mother	55	15	Divorced	1	25	Homicide (drug related)	Son	Biological	1 yr/7 mos	Catholic	Elementary	10-19,999
#4 Mother	40	26	Single	5	21	Homicide (gang related)	Son	Biological	1 yr/2 mos	Catholic	Secondary	10-19,999
#5 Mother	49	22	Civil Union	1	21	Car Accident	Daughter	Biological	1 yr/2 mos	Catholic	Voc/3 yrs College	20-29,999
#6 Mother	46	23	Married	2	11 Mos	Acute illness	Daughter	Biological	5 yrs/4 mos	Catholic	Sec / GED	10-19,999
#7 Mother	44	22	Civil Union	2	10	Acute illness	Son	Biological	10 yrs/2 mos	Catholic	Sec / GED	20-29,999
#8 Mother	26	8	Married	4	6 Mos	Medical/never left Hosp.	Son	Biological	2 yrs/6 mos	Catholic	No Schooling	10-19,999
#9 Mother	44	19	Married	2	20	Leukemia	Daughter	Biological	1 yr/7 mos	Catholic	Sec / GED	10-19,999
#10 Mother	48	21	Married	3	16	Homicide (gang related)	Son	Biological	10 yrs/6 mos	Adventist	Elementary	20-29,999
#11 Mother	59	36	Separated	1	32	Heart Attack	Son	Biological	6 yrs/4 mos	Catholic	Sec / GED	0-10,000
#12 Mother	41	24	Married	4	7	Homicide (shooting)	Daughter	Biological	8 yrs/8 mos	Catholic	GED / Sec (H.S.)	30-39,999
#13 Mother	32	8	Married	3	few days	Medical Complications	Daughter	Biological	1 yr/11 mos	Catholic	GED / Sec	0-10,000
#14 Mother	24	5	Civil Union	0	Miscarriage	Medical/unknown	Daughter	Biological	2 yrs/10 mos	Catholic	Voc/Tech	10-19,999
#15 Mother	38	7	Married	2	34 weeks	Medical (twins)	Daughter	Biological	3 yrs/4 mos	Catholic	GED/HS/Sec	10-19,999
#16 Mother	35	15	Married	3	11 Mos	Chronic illness	Son	Biological	1 yr/3 mos	Catholic	GED / HS	20-29,999
#17 Mother	54	34	Married	2	14	Car Accident	Son	Biological	9 yrs/10 mos	Catholic	Elementary	30-39,999
#18 Mother	34	11	Married	4	4	Accident (household)	Son	Biological	4 yrs	Catholic	Voc /Tech	0-10,000
#19 Mother	34	22	Married	3	7 weeks	Medical (twins)	Son	Biological	4 yrs	Catholic	Elementary	10-19,999
#20 Mother	40	35	Married	2	9	Acute illness	Son	Biological	2 yrs/6 mos	Protestant	Univ / College	50-75,000
#21 Mother	52	28	Married	2	24	Suicide	Son	Biological	1 yr/10 mos	Catholic	Sec / GED	30-39,999
#22 Mother	36	18	Married	4	16	Homicide (gang related)	Son	Biological	1 yr/4 mos	Catholic	Elementary	20-29,999

Averages: 41.18

2.59

average time = 4 yrs

All the focus groups were conducted at community-based agencies. Three groups were conducted at a community agency, Casa Central agency on the west side of Chicago. One focus group was conducted at Little Company of Mary Hospital located in Evergreen Park. One focus group was conducted at Enlace social service agency, located in the Pilsen neighborhood on the west side of Chicago. The decision to conduct two focus groups at sites other than Casa Central was based on difficulties with transportation and distance and in an effort to offer convenient locations for the participants. Colleagues from these two agencies offered their space to the researcher.

Two focus groups were co-conducted by the researcher and a Spanish-speaking Licensed Clinical Social Worker and the researcher conducted three groups independently. The researcher and co-facilitator, Noe Torres, are both fluent in Spanish and have provided Spanish-speaking services to Latino clients for over 20 years. In addition, both the researcher and co-facilitator have professional experience working in the area of parental grief support to Latino families. The co-facilitator signed a confidentiality agreement prior to conducting the focus groups, to ensure appropriate confidentiality throughout the study. Prior to conducting the focus group interviews, the researcher and Mr. Torres met to review process, roles and responsibilities, the interview guide, and to clarify other logistical issues.

Focus Group Interviews

In compliance with IRB regulations the researcher insured that participants were treated with sensitivity and ethical care throughout the entire interview process. Participants were oriented to the environment and they were reminded of their rights to

stop their participation at any time. Researcher collected all signed consent forms from each participant and they were also provided with a copy of their signed consent forms. It should be noted that none of the participants reported any difficulty reading or comprehending the consent form.

Prior to the start of each focus group interview all participants were compensated with a \$25.00 Visa gift certificate by the researcher. This amount was deemed reasonable and appropriate in order to acknowledge their time investment, or to support any transportation or childcare arrangements that were made. In addition, all participants received a bereavement support resource list, provided in both Spanish and English, prior to the start of the interview.

Each interview lasted 90-minutes and all the interviews were tape-recorded in their entirety for purposes of accurate transcribing and subsequent coding and categorizing. All of the focus group interviews were conducted in Spanish as preferred by all of the participants in the study.

For purposes of confidentiality only first names of the participants were used. At the beginning of every interview participants were asked to introduce themselves using first names only. This was recorded and used as a reference point for subsequent transcription. The researcher and co-facilitator addressed participants by first name only as well. Other group members were asked to do the same. If two participants had the same first name, middle names or slight variations were used.

A semi-structured interview format using an interview tool with 11 open-ended questions was used to guide the discussion and gather the data (Appendix E). The same

guiding questions were used for all the interviews with an additional question introduced in the last three interviews. (This will be further explained in the Q9 Tree Node section of results). Probing questions, such as “Can you explain that a little more? How old is she? Do they live here in the U.S. or in Mexico? So did that help you?” were used only to clarify or confirm comments made by the participants. During the interviews the researcher also took additional notes related to general observations.

At the conclusion of each focus group interview, participants were thanked for their involvement in the study and acknowledged for their willingness to share their personal experiences.

General Observations

The participants demonstrated mutual rapport and were all actively engaged in the group process. Issues related to self-disclosure or social influence were not identified by the researcher or reported by any of the group participants as having a negative impact on the process. Some questions seemed to trigger emotions at times but this did not appear to limit any of the participants’ ability to share or communicate. Collectively the emotional state was grounded and none of the participants excused themselves due to distress or other reasons. The researcher and co-facilitator worked well together and both interchangeably posed the interview questions, while the researcher also monitored equipment, took observational notes and monitored individual and group emotional states. In focus group interviews conducted solely by the researcher it was also possible to manage these various tasks independently.

In fact, at the end of each interview many of the participants stated that they felt

comfortable and that their participation in the focus group had been a positive experience. Several of the participants reached out to one another for social conversation at the conclusion of the interviews as well. A few mothers specifically thanked the researcher for the “opportunity to talk and share their feelings and thoughts”. On three occasions, the researcher observed some participants exchanging phone numbers.

Organizing and Coding the Data

Once the focus groups concluded, the researcher conducted an extensive review of the data, including re-listening to the focus group audiotapes, rereading her field notes, and relooking at all of the available data. This data includes journal entries and field notes the researcher made throughout the data collection stage of the study. In addition, as previously mentioned, the researcher translated the transcripts into English, further enhancing the iterative and progressive focus of interacting with the data. After all of the interview tapes had been appropriately transcribed and subsequently translated into English, the reviewed, transcribed data was imported into the computer-assisted qualitative data analysis software package NVivo 9. NVivo assists researchers in organizing and analyzing non-numerical (qualitative) data, and thus is appropriate to use for this study. The software enables researchers to organize, classify, sort and arrange data as well as examine relationships in the data. In this manner, NVivo software provided a systematic way in which to organize and manage the data analysis process. A password-protected personal computer was used to store the electronic files within the NVivo software package.

The constant comparison method (Grinnell & Unrau, 2005; Marshall & Rossman, 2006) was utilized throughout the data analysis process.

Each of the five focus group transcripts was imported into NVivo becoming five sources, as referred to in NVivo. Data from each source was then sorted and organized into 11 coding categories (referred to as “parent or tree nodes” in NVivo) according to the interview schedule used for the focus groups, resulting in 11 coding categories¹. Participant responses were organized and categorized (as “child” or “sub” nodes, as referred to in NVivo) under the appropriate tree node in the open coding step of data analysis, as is consistent with the constant comparison method. Thus, every participant response was compared with others for similarities and differences. Onwuegbuzie, Dickinson, Leech, & Zoran (2009) also suggest that “focus group data can be analyzed via constant comparison analysis, especially when there are multiple focus groups within the same study, which allows the focus group researcher to assess saturation in general and across-group saturation in particular” (p.6).

This coding process was followed for each of the 11 interview items. Two hundred ninety-four sub-nodes resulted from the first-level (open) coding process. At this level the researcher is focused at attaching a descriptor, or code, to each unit of meaning which can be one word, one sentence, or several sentences and phrases representing more extensive thoughts, memories or experiences.

¹ Ten questions were posed in focus groups 1 and 2, and 11 questions were posed in focus groups 3 -5. As noted earlier, this adjustment will be clarified in more detail in the Q9 Tree Node section of the results.

The constant comparison method was also used during the second-level coding; this step is referred to in NVivo as “merging nodes” and “shaping the node system.” Sixty-seven sub-nodes under the original 11 tree nodes resulted from the second-level coding process.

Two colleagues, one of them a Ph.D. and the other a Ph.D. candidate, were then asked to review the researcher’s coding. Their way of organizing the data was compared with the one used by the researcher. Based on this comparison and with the colleagues’ feedback, some revisions were made and an agreement was reached. A total of sixty-seven nodes within the eleven “trees” emerged from the data. The trees and the nodes organized into each, including the number of sources—meaning the number of focus groups in which responses to the specific questions occurred—and the number of references—meaning the total number of citations related to the topic (otherwise referred to as frequency)-are listed in Tables 2-12.

The following results are organized according to the 11 interview items previously discussed.

This opening question was intentionally broad and asked the following:

Q1 Node Tree: “Can you tell us if this experience has changed you as a person, and if so, how?”

Five nodes were organized under this tree and reflected the ways in which the participants felt they had changed as a result of their child’s death: They had become angry or had feelings of anger toward family, friends, God, or others in general (coded as “angry”), the changes the participants experienced were viewed as positive or for the better, and included not only personal changes but changes that occurred in their families

or in other family members (coded as “changed for the better or positive impact”), the changes the participants experienced were viewed as negative or for the worse, and included not only personal changes but changes that occurred in their families or in other family members (coded as “changed for the worse or negative impact”), and two additional nodes which described personal experiences that did not fall clearly within any of the aforementioned node categories. These included: feeling that God or their faith had helped in the grief experience (coded as “God, church, and prayer helped”) and a feeling or resolve to “keep going, and move forward” in spite of the profound pain and sense of loss (coded as “resolve to keep going, move forward”). Frequencies for this coding tree are provided in Table 2.

Table 2. Tree Node for Question 1

Can you tell us if this experience has changed you as a person, and if so, how?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Angry	2	3
Changed for the better or positive impact	3	8
Changed for the worse or negative impact	4	31
God, church and prayer helped	3	3
Resolve to keep going, move forward	2	6

In regard to this question, many of the responses (31 references, 4 sources) represented the ways in which participants felt that their lives had been negatively impacted or changed for the worse by the death of their child. Responses reflected the mothers’ views that there had been negative impact or changes for the worse in regard to

their personal feelings, values, beliefs, view of life, to their immediate families, as well as to their relationships with extended family and friends.

Mothers described the various ways in which their experiences had significantly challenged their beliefs about life and their view of the world. One mother commented:

For me personally, my life changed completely. It was something that... as a mother, you never think that it can happen to you. It totally changed my life. It was something so painful and it is still. It's something that I don't wish on anyone... because this shouldn't happen... we should not be burying our children. Our children should be burying us. It's too painful. I carry this pain inside of me... I know I should go on with my life because I have my children who need me... but honestly... I can't overcome this.

Mothers discussed the negative impact on their immediate families and the various changes that occurred in how family members' related to and interacted with one another.

One mother described how the death impacted her children:

After the death of my son, my life has changed a lot. My son was assassinated. So life before and then life after, is very difficult and very different. It is very difficult to see your other small children with so much anger and hate towards the people who did it. Hearing them say that they want revenge, and to hear a child 6, 7 years old saying, "When I grow up I am going to kill them."

Mothers also discussed the negative impact on their social relationships and they stated that extended family and friends had withdrawn or distanced themselves from them. One mother described her experience:

People also change with you. All of our friends have distanced themselves, and it's as though they act like my husband has some kind of illness that is contagious, and that they are going to catch it... because they all stay away from us. We moved because, as I've said, they killed my son and my husband was fearful because he was also shot-but survived. So yes, my life has changed a lot, very much. First, because of my children and secondly, because of our friends who completely disappeared.

Mothers also described how their experience had negatively impacted their personal feelings and emotional states, and their sense of self. Feelings described included: sadness, unhappiness, disbelief or shock, as well as despair. For example:

There are moments when you feel fatalistic. A moment came when I didn't want to live anymore... I wanted to be with her. For me, it was very sad and it still is... and I believe that regardless of what happens... I will never overcome this... or replace, or forget.

In contrast, some responses (8 references, 3 sources) expressed the positive changes or impact that the mothers felt they had experienced in the aftermath of their child's death including increased understanding and sensitivity with others, greater spirituality, and a desire to help others. One mother stated:

Yes, it has changed me... a lot. I have learned a lot. Now I'm willing to help and to pray for anyone who I see suffering, and to talk to them... even if they hang up on me. If I get the opportunity to come to their door... I get down on my knees, and I hold their hands... and I tell them that I'm with them... and I tell them not to worry, because life is short... So I'm willing to offer all of my profound love to anyone who is grieving whoever they are. I'm there to give them all of my love, and to talk with them... of what I've learned on this journey of pain.

In addition, some responses (6 references, 2 sources) reflected the mothers' sense of resolve or their view that they must "keep going" and "move forward". One mother commented:

You keep going because you have to keep going. You have other children, and there's no other way. And I think that if you just had a way to... you can't find that motivation to keep yourself going. But it's a fight with yourself... you feel guilty. You feel guilty when you do things to keep going or move forward, with your other children. So here we are and we try to take it day by day, and to keep going.

Additionally, there were a few responses (3 references, 3 sources) which expressed the mothers' view that they had gained a sense of support from God, their

church, and through prayer. A few responses (3 references, 2 sources) also reflected feelings of anger that some mothers felt towards family members, friends, God, or others in general.

In sum, many of the responses described the mothers' views that the death of their children had negatively impacted their personal feelings, beliefs, view of the world, and that it had also negatively impacted their immediate families and their relationships with extended family and friends.

In discussing how the experience negatively impacted them, participants talked about their feelings of pain and emphasized the uniqueness and profundity of the pain. Mothers described their grief experience as an "emptiness or void" that had been permanently left in their lives. Other descriptions included feeling as though "there is no escape" or as "something I cannot bear or overcome". Participants described the pain as "the worst pain" and "something I would not wish on anyone". The spectrum of feelings described included sadness, anger, resentment, disbelief or shock, as well as despair. In addition, participants commented that their views of life had changed and they described their struggle to understand and accept their loss, as well as their view of life as being fragile and unpredictable.

Mothers described the negative impact within their immediate families, including the impact on their children; the mothers also described the changes they observed in themselves in terms of how they interacted with their husbands and children. For example, the mothers talked about their fearfulness and overprotective parenting in regards to the safety of their other children.

Participants also described the negative impact or changes they felt had occurred in their relationships with extended family and friends, and the distancing or lack of support they felt from extended family and friends around them.

However, some responses reflected the mothers' views that there had been positive changes experienced in their lives including the desire to become better person, the desire to help others, having become more understanding and sensitive to others' pain, and feeling that their religious faith was stronger and they were closer to God.

Some responses also reflected the mothers' resolve to keep going and move forward for the sake of their other children. In addition, a few responses expressed the sense of support and strength felt from God, the church, and prayer. Last, a few responses expressed anger felt towards family, friends, God, or others in general.

This second question was also broad and similar in some ways to the opening question:

Q2 Node Tree: "Has this experience altered your perspective of the world or life? If so, how?"

Eight nodes were organized under this tree and reflected the ways in which the participants felt that their perspective or view of life or the world had been altered: their perspective changed for the better or they maintained a positive view of life or the world (coded as "changed for the better or positive view"), their perspective changed for the worse or they maintained a negative view of life or the world (coded as "changed for the worse or negative view"), they experienced an altered view of the parent and child relationship (coded as "changed view of parent/child relationship"), and five additional nodes which described personal experiences that did not fall clearly within any of the

aforementioned node categories. These included: feeling that counseling had not helped them or their family in the grief experience (coded as “counseling did not help”), feeling that the occurrence of dreams of the deceased child had helped in accepting the loss and bringing some peace in the grief experience (coded as “dreams of daughter helped”), feeling that priests and faith in God helped them in the grief experience (coded as “priests, God helped”), that their feelings of anger had changed to forgiveness (coded as “moved from anger to forgiveness”), and a resolve to “keep going, and move forward” in spite of their profound pain and sense of loss (coded as “resolve to keep going, move forward”). Frequencies for this coding tree are provided in Table 3.

Table 3. Tree Node for Question 2

Has this experience altered your perspective of the world or life? If so, how?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Changed for the better or positive view	3	4
Changed for the worse or negative view	4	12
Changed view of parent/child relationship	2	2
Counseling did not help	1	1
Dreams of daughter helped	1	1
Priests, God helped	1	1
Moved from anger to forgiveness	1	1
Resolve to keep going, move forward	1	1

In regard to this question, many of the responses (12 references, 4 sources) described negative views or changes in regard to the mothers’ perspectives of the world or life. Responses also reflected the participants’ struggle to understand and to accept their loss. Mothers commented on their view of life, as saw it as fragile or unpredictable.

One mother commented:

I think that when something like this happens, like it happened to us... you realize how fragile life is. You never think that it can all end in a second. It makes you think more about the reality of living in the moment. You never know when you will be gone. So I think it's better to keep that in our minds. Because that's what has happened to us... we never thought that it was going to happen to us... that we would lose someone... your child... who you've put your hopes in... who gave you so much happiness... some sorrow, as well, of course.

Another mother said:

I lost my baby a year ago. And you think that it will never happen to you. You hear stories, but you tell yourself that it could never happen to you. But life has surprises... and I don't know how I'm still standing, I can't imagine how that is. I still think it's a dream. His absence. He came into my life and left so quickly. But everything happens for a reason.

The feeling of "surviving" and "learning to live with the pain and void" were also mentioned by the mothers. One mother stated:

Yes, I do believe, absolutely, that it does change your life totally, as well as your perspective on life. Our world is totally different from that moment on, after that bitter experience. But I wouldn't say resignation... no. But rather, you learn to live with the pain. I think that's it... right? You learn to live with... that void... that pain.

In addition, responses reflected the mothers' view that their loss was so unique and associated with such profound and unbearable pain, that family and friends could not understand what they were experiencing. Some mothers described it as "the pain with no name". One mother commented:

Because that's how the phrase goes "If you lose your parents you are an orphan... If you lose your husband then you are a widow... but what name do you get when you lose a child?" There is no name.

Another mother stated:

In my opinion, personally, I feel that it changed my life. I lost a baby... she was a

newborn. But for me it has been a lot of pain. And many people do not understand why. They say, “Don’t cry, she wasn’t aware... she was just a baby... and at least the good thing is that you didn’t get attached to her”. It’s those kind of things that make it hurt more. And it isn’t like that, as she said, you learn to live with this pain.

Mothers described their emotional states and feelings in the context of their life or worldviews. The range of feelings described included sadness, regret, anger, despair, sense of injustice, and even a desire to die in order to be with their child.

As an example:

There were days when I was “scratching at the walls”. That is, I felt that I wanted to die when people told me “Don’t worry; you’ll be with your daughter again someday”. And I thought, “Well, if I’m going to be with her, then let it be today. I don’t want to wait any longer.

Some responses described the mothers’ views that there had been a negative impact on their other children. One mother commented:

So it was very difficult because she would say that she always wanted to die and that there was no reason to keep living and it really affected her. It affected her at school and in her classes; she didn’t want to interact with any classmates. She became very quiet and withdrawn and she was not like that before. They would call me from school to ask me if something was wrong with my daughter and I had to tell them that “yes”, there was something going on and I explained what had happened to us.

However, some responses (4 references, 3 sources) reflected the positive impact or changes that the mothers felt they had experienced in regard to their perspective of the world or life, including the desire to help others and to be a better person, an acceptance of the loss, and desire to find new meaning or purpose in life. One mother stated:

Yes, life changed for me. I see it differently. In certain ways, it has made me a better person. Now I see other families and their situations... those who are going through the same thing... and to try to help them. Because we’ve gone through it and we understand the pain. So if I have an opportunity to help someone who is in this same situation...it helps me... to help them.

In addition, two responses (2 references, 2 sources) reflected that there had been a change in how the mothers viewed parent and child relationships. One of the mothers stated:

So it has changed my life completely. For one thing, it changed my perspective about students and adolescents. Before I believed that you had to push them and pressure them and always be “on top of them”. But now I know that it isn’t necessary. For example, many times we are on top of pressuring our children, and sometimes we don’t need to... they know what they want... where they are going in life. That was one of the things I came to realize. That is, when they already have a vocation, or have something in their minds to do... all we should do is guide them... we don’t need to be pushing them. One realizes that.

In sum, many of the participant responses reflected that there were negative changes or impact in regard to the mothers’ views of life or the world. Participants talked about their realization or view of life as “fragile” and “unpredictable.” Participants discussed their struggle to understand their loss and the need to find some meaning to their child’s death.

As with Question 1, participants talked about the uniqueness of their parental loss and the profound, unbearable pain associated with it. They described it as “the pain with no name” or “no name for this pain” in reference to the fact that there is no name for the role they have assumed as mothers whose child has died. Mothers also felt that those who had not experienced this type of loss could not understand their experience.

Mothers described feeling as though they were solely “surviving” and that they were “learning to live with the pain”. Other feelings described included sadness, anger, a sense of injustice, as well as despair.

However, some responses reflected positive impact or changes in regard to the

mothers' perspectives of life and the world including an acceptance of the loss and resolve to find new meaning in life, and an enhanced sense of altruism. Two mothers also described their changed views in regard to parent and child relationships.

Last, various responses were also provided in regard to other personal thoughts, feelings, and experiences which included views that counseling had not been helpful, that dreams of the deceased child had been helpful, that priests and faith in God had been helpful, that feelings of anger had changed to forgiveness, and that there was a resolve or belief that one should "keep going, and move forward" (See Table 3 for details.).

The third question posed the following:

Q3 Node Tree: "Has your child's death affected your relationships with family or friends? If so, how?"

Six nodes were organized under this tree and reflected the ways in which the participants felt that their child's death had affected their relationships with family or friends: the participants felt that there was a negative impact on family or social interactions or relationships and this included any negative impact on either immediate or extended family relationships (coded as "negative impact on family and social relationships"), the participants felt that there was a positive impact on family or social interactions or relationships, and this included any positive impact on either immediate or extended family relationships (coded as "positive impact on family or social relationships"), the participants felt that there was a negative impact on their other children, including emotional, academic, and behavioral problems (coded as "negative impact on children"), the participants felt that there was a negative impact on their marital or partner relationships in various ways (coded as "negative impact on marital or

partner relationship”), and two additional nodes which described personal experiences that did not fall clearly within any of the aforementioned node categories. These included: it impacted the decision to have a subsequent child (coded as “impacted decision to have a subsequent child”), and a resolve to “keep going, and move forward” in spite of the profound pain and loss (coded as “resolve to keep going, move forward, be strong”). Frequencies for this coding tree are provided in Table 4.

Table 4. Tree Node for Question 3

Has your child’s death affected your relationships with family or friends? If so, how?			
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References	
Impacted decision to have a subsequent child	1	1	
Negative impact on family and social relationships	5	31	
Negative impact on marital or partner relationships	2	5	
Negative impact on children	4	10	
Positive impact on family and social relationships	3	7	
Resolve to keep going, move forward, be strong	1	3	

In regard to this question, many responses (31 references, 5 sources) pertained to the mothers’ view that there had been negative impact on their family and social relationships. Participants commented that they had experienced a lack of support or understanding from extended family or friends around them or that support was offered in ways that were not perceived as helpful or meaningful for the mothers.

As an example:

All of my family is in Mexico. His family never helped us at all. Not with financial help... and primarily not with emotional support. Because financial help doesn't matter, but it's the support that we needed at that time.

Another mother commented:

The only family here is solely my husband's family, which consists of his brother and cousins. But I don't have any family here, just one brother and one sister, but during that time my sister wasn't here, just my brother. But not him, to the contrary. He would constantly say to me, "Why are you always visiting the cemetery so much? And I would respond "It is my life, leave me in peace and stop bothering me. I am doing what pleases me and makes me feel better." But yes, you change a lot with your family.

One mother also described the harm that was caused to her children by extended family at a time she needed support:

No, he has all his family here, and I have no one... no one. I have two more children and they traumatized them. They would lock them in the bathroom and they would hit them. My children spent a year with a psychologist. Because my son was 3 years old, and the other one was 1 year old and 2 months... and he couldn't be in the dark because he would start screaming and would get scared. If anyone said anything to him, he would start crying. In fact, even now if he hears that someone has died or if his sister is sick... he says that he doesn't want his sister to die like the other baby. Since I am alone here... all of his family members get involved and cause a lot of trouble between my husband and me. Actually, I have thought about going back to Mexico because it's too much... living with a family that offers you no support... nothing.

Participants commented that as a result of the lack of support and understanding they experienced from extended family and friends their situations were made more difficult and painful.

Participants talked about the fact that many family and friends no longer remembered their children or that they no longer remembered important dates, such as their child's birthday or anniversary of death, and they felt that this negatively impacted those relationships with others. Mothers commented that they believed "life had

continued on” for those around them. As one mother said:

Sometimes there are birthdays or anniversaries, and not even a call to say, “How are you feeling?” or “How are you?”... or something. So I really do think that it does affect relationships a lot.

Similarly:

Then, when you have their anniversaries or anything else, when you would like them to be there with you to remember your child, they are not... during that time you need them. When it first happens, everyone, the whole world, is there with you. But as time passes no one remembers what happened or your deceased child anymore.

The inability to express grief openly, around extended family and friends was described by mothers. Participants commented that family members and friends sometimes became “scared”, uncomfortable or upset when the mothers attempted to talk about their children, or to express their outward grief. As one mother described:

I think when my daughter’s accident happened it did affect relationships. Because sometimes you want to talk to friends or family, but you might start to cry a lot... and people say, “No”. So the ones that haven’t felt this kind of pain, they distance themselves from you. They get scared. They get scared that you are going to talk about all that pain or they are going to feel bad because of the pain we are feeling. I don’t know... you do begin to isolate yourself like the other lady said. And people don’t want to hear about your moments of pain.

Negative impact on family and social relationships was also attributed to hurtful comments made or platitudes offered by extended family and friends, which the mothers felt made their pain worse and often caused them to withdraw from others. Some participants also talked about their difficulty or inability to participate in family gatherings and social events:

I try to go out for my other daughters, but I feel bad. I feel uncomfortable to see another baby, or to have to attend baby showers... or to see the birth of my nieces and nephews. Currently, I have a nephew, the son of one of my brothers. He was born in December and I haven’t gone to see him for the same reason. Because I

know I'll feel bad seeing him, or seeing other babies... and even attending children's birthday parties. Why? Because I remember my daughter, and she was my youngest... and so she was my baby.

As with responses provided in Questions #1 and #2, several responses (10 references, 4 sources) described the negative impact that the mothers felt the death had on their other children. Mothers described the various ways in which their children had been impacted including becoming withdrawn, angry, depressed, "clingy", desiring retaliation or revenge, and being unwilling to talk about their feelings or the loss of their sibling. Participants stated that this made their situations more difficult and that it negatively impacted their relationships with their children at times. One mother commented:

I have two other daughters. At that time the oldest was 6 years old and the youngest was 1 ½ year old. The oldest saw the entire accident. My daughter was left practically traumatized... but I didn't speak English... I don't speak English... but with the little I knew, I called 911. My daughter could speak English and when the paramedics arrived and everyone else... she could understand perfectly what was happening. And because of that ... she isn't the same anymore. My daughter changed the day my son died. And to this day, I can't deal with her. It's sad because it's as though I lost two children on that same day... my son and my oldest daughter... She is traumatized. In fact, she hides under her bed... she hides inside the dryer to cry...and talks to her brother.

Another mother described her experience:

In regard to my relationship with my other children, it has also changed a great deal. They have become more silent and they live locked up. They don't want to talk to anyone. I have tried to keep going, but it hurts too much. At the same time, it worries me that they haven't been able to overcome this. I don't think any of us has overcome this, but it's even less in their case. They don't want any kind of help. They don't want counseling from anyone.

In addition, some responses (5 references, 2 sources) described the different ways in which the death of their children had impacted the mothers' marriages including initial plans to separate, conflict and blaming, feeling of anger or resentment towards one

another, and lack of marital intimacy. For example:

It did affect my marriage a little. When my baby died, he was six months old... he lived six months in the hospital. He was receiving milk from a tube... and they were going to discharge him when he was two months old, because he was doing well. One nurse got there and moved all the tubes, and the milk spread throughout his body, and that wasn't good. They told us to sign a paper, which said that the baby was with artificial life support...and it said to disconnect him. My husband signed the paperwork saying to disconnect him, and I told him that it was his fault, that he had killed him. And he said no, because the nurses, the counselors and social workers had explained to us that they couldn't do anything more for the baby. But I spent a year, and even to this day, I still tell him that it is his fault that the baby is dead.

However, some responses (7 references, 3 sources) reflected mothers' views that there was a positive impact on family and social relationships. Mothers stated that they had received adequate support from their immediate and extended family, as well as from friends and some commented that their families had become closer and more unified. One mother stated:

Thank God, my partner... my children... we have a lot. We talk a lot and we always try to be unified. Communication is the most important thing...and support. And really, thank God I have my mother with me, and she supports me. I have my brothers and sisters... along with my husband... I have my sister-in-laws and my father-in-law. They are always with us during every anniversary... my son's birthday...they are always there supporting us. I wish I could say that all of my family is the same way, but they are not.

As with responses provided in Questions #1 and #2, a few responses (3 references, 1 source) expressed the mothers' resolve or belief that they should be strong, keep going and move forward:

So sometimes we need to continue like that and just keep going, moving forward...and to forget or let go of some of those feelings. If we go backward instead of forward, we will never heal. So sometimes I think it is better to look forward and not to look back so much. I believe that our children would want that... they would want to see that we are being strong.

Last, one response (1 reference, 1 source) described how the death of the child had impacted one mother's decision to have another child:

I got pregnant with my youngest boy in the hope that God was going to return my son to me. But when I delivered him at the hospital he was totally different. My other deceased son was very light... and this youngest son is very dark. My other son had no hair... and this one was really hairy ... and it was all disheveled. I felt something. And this same thing that I felt, my husband also felt. I never rejected him, because he is my son and I love him... and I adore him with all my heart. But I had that hope that God was going to give me my son back, and that he would be the same. But now I understand why God sent him to me, being so different... my son, M-. My other son was named M-, and I also named this one M-. He made this one so different so that I wouldn't be thinking that he was the same... perhaps because I would have suffered more.

In sum, in response to this question, many responses reflected the various ways in which the mothers felt that there had been some negative impact on their family and social relationships. Participants attributed it to the lack of support or understanding they experienced from those around them. For some, it was due to the fact that support from extended family and friends was not offered or offered in ways that were not perceived as helpful or meaningful. Participants commented that the lack of support or understanding experienced and their view that others no longer remembered their children, served to make their situations more difficult and painful, and to negatively impact those relationships. Mothers also talked about how their intense feelings and outward expression of grief made family members and friends uncomfortable, and they felt that this exacerbated their sense of isolation.

As with Questions #1 and #2, participants also talked about the impact that the death had on their other children. Mothers talked about the emotional and behavioral changes they observed in their children, including withdrawal, anger, depression,

“trauma,” clinginess, the desire for retaliation or revenge, or an unwillingness to talk or express their feelings. Some mothers also stated that these problems negatively impacted their relationships with their children, as their children had difficulty accepting help from them.

At the same time, however, some responses expressed the participants’ views that the death of their child had impacted their relationships with family and friends in positive ways. Mothers stated that they had received adequate support from their immediate and extended family, as well as from their friends, and that their families had become closer and more unified.

And as with Questions #1 and #2, a few responses also expressed a resolve or belief that the mothers needed to be strong, keep going, and move forward.

The fourth question posed the following:

Q4 Tree Node: “Can you talk about confronting this experience being a Mexican mother living in the United States?”

The researcher provided clarification pertaining to this question. After the first focus group interview, the researcher and co-facilitator (in their post-group debriefing) agreed that this question seemed to have triggered some confusion or slight discomfort in the participants. It was felt that the participants’ reaction to this question was likely due to their interpretation of the question. Some of the responses given, such as “the pain is the same anywhere” seemed to reflect that some of the mothers understood the intent of the question to be specifically related to their grief experience, rather than referring to any external circumstances or issues surrounding their grief experience, as was the intent of the question.

Therefore the researcher included this clarification in all of the subsequent focus group interviews. As part of the clarification the researcher used words like “situation” or “things” to reflect external circumstances as simply as possible. Clarification was posed in the following manner by the researcher:

For example... I don't mean the pain itself, I understand the pain is the same anywhere ...but was there anything about living here, in the United States, rather than in Mexico, at the time of your child's death, that made your situation better in any way, or that made your situation more difficult in any way?

Five nodes were organized under this tree and reflected what the participants felt were the factors associated with confronting this experience as a Mexican mother living in the United States: the participants felt that they had a positive experience in the United States associated with their grief experience, they felt gratitude towards the United States, or they felt an enhanced connection to the United States in the aftermath of their child's death, and for some it impacted their decision to remain in the United States (coded as “Gratitude or positive experience, or connection with United States”), the participants felt disappointment with the United States or felt that their experience had been more difficult as a result of living in the United States had made it more difficult (coded as “Disappointment or more difficult being in United States”), the participants felt that their immigrant or residency status in the United States had impacted their decision-making regarding their child's remains (coded as “impacted decision-making regarding child's remains”), the participants felt that in terms of their internal grief experience it would have been the same anywhere (coded as “felt that pain is the same anywhere”), as well as one additional node which described a personal experience that did not fall clearly within any of the other aforementioned node categories: the participants held a negative view of

Mexico for various reasons (coded as “negative view of Mexico”). Frequencies for this coding tree are provided in Table 5.

Table 5. Tree Node for Question 4

Can you talk about confronting this experience being a Mexican mother living in the United States?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Disappointment or more difficult being in United States	5	9
Felt that pain is the same anywhere	3	4
Gratitude or positive experience, connection with United States	5	10
Impacted decision making regarding child's remains	4	13
Negative view of Mexico	2	2

In regard to this question, many responses (13 references, 4 sources) pertained to the mothers' residency status in the United States and how it had impacted their decision-making in regard to their child's remains. Issues identified by participants included whether to bury or cremate their children, and where to place their children's remains (in the United States or in Mexico). Participants described feelings associated with the initial decision making, including confusion, doubt, and anxiety.

Based on information gathered in the interviews, a majority of the children were buried in the United States (14), some were buried in Mexico (3), some were cremated (4), and the disposition of one child's remains remained unknown.

Mothers talked about their fear or confusion in not knowing what they would do if they were ever forcibly sent back to Mexico or if they someday returned voluntarily.

Others commented that their decisions to bury their children in the United States now

posed concerns regarding any future plans to return to Mexico. One mother commented:

Well, I think that more than anything, as a Mexican mother, which I am... I would have been, well... that is... I am here now, right... in the United States? But I buried my daughter here. However, if in the future I return to Mexico, I would rather take her back with me to my country, where I am from... because I don't want to leave her behind in United States.

Some participants also stated that their ultimate decision to bury their children in the United States had been based on their desire to remain close to their children. Some commented that the ability to visit the cemetery regularly was comforting and helpful in their grief experience. One mother commented:

But I did make the decision to bury her here...to bury her here for the same reason. I said, "If I take her over there, I won't be able to go see her when I feel lonely...or when I feel sad... or when I feel desperate". And that's what I do when I feel lonely or sad... I go to the cemetery. And there, I am with her. So for me that was a good decision. I don't know if later on I will regret it...I don't know what will happen but I feel like I made the right decision, the decision to bury her here. As I've said, I feel relieved... I go and sit with her... I talk...lots of things...I return to see her...I don't know.

Participants who buried their children in Mexico described their inability to visit their children regularly and commented that these circumstances made their experience more difficult or painful. One mother shared her experience:

In fact, I buried my son in Mexico. I took him there... because here... I practically went crazy... I didn't know where my children were... until they started giving me medication. Because I was lost... I was just lost. Later, when I was calmer, I made the decision to take my son there, to Mexico... because, well, we always thought that we would be returning. But it has been four years and we still haven't been able to leave. But... well... waiting... the waiting is hard, because I can't even go visit him once in a while...because of financial issues... and a lot of things... but I have faith in God that I will be able to go there, where my son is. As of now, I have been able to go every year. But you wish you could go more often... but sometimes it is difficult.

Participants who cremated their children commented that their decisions to cremate were also primarily due to uncertainty regarding whether their families would remain in the United States or return to Mexico.

Several responses (9 references, 5 sources) also expressed the mothers' views that there were factors or circumstances associated with living in the United States, which made the mothers' experience more difficult or resulted in disappointment. The factors or circumstances described by participants included experiencing the absence of significant extended family members (who resided in Mexico) to offer support, the view that there was lack of justice in the United States, the view that gangs were unique to the United States and had contributed to their child's death, and regret regarding the decision to emigrate to the United States, which emerged in the aftermath of their child's death.

Participants commented that they would have felt more comforted and less alone if they had extended family with them in the United States, and that this absence of family support made their experience more difficult and painful.

For example:

I agree... I think the pain is the same wherever we are. Obviously, it might have comforted us a little bit more if we had more family with us... because in my case, I'm alone. I live here with my husband's family, but on my side, I don't have anyone. So perhaps that would have been some comfort to me... but the pain is the same...but yes, it could have made a difference... because not having them... at that moment, I felt more alone.

Another mother shared her experience:

I think that in terms of the death, it doesn't matter where it was... but here if... well, I feel that if we had been in Mexico maybe the same thing could have happened, but I also wonder why we even came here, and why he had to die... I always ask myself that. I ask myself "why did I come to the United States, to just have a son die? Because I don't have any family here, especially since all my

family is in Mexico. And here, I have just one brother, who is a half-brother. And so I felt very alone. I don't know why I had to come here. So if it had to happen, I would have preferred it happen in Mexico. But oh well... that didn't happen... so what can I do, right? But yes, in terms of the "where" I would have preferred that it happen in Mexico, and not here.

Another mother stated:

I think that if I had been in Mexico... especially since I had wanted to send my son to Mexico a couple of times, but he didn't want to go... and because the gangs were bothering him here... and there ... where I am from, there isn't any of that... no gangs... I think that if my son had gone to Mexico... or I had been living in Mexico... he wouldn't have been killed.

One mother described her view that there was a lack of justice demonstrated in regard to her son's death:

So it was a very painful fight during four years, very painful. I used to believe that the laws in Mexico were dishonest, but now I feel that it is the same here. They lost all the evidence, and then they said that she was within the legal limit in her blood level... which was a lie. All of that happened to me, to us... and she was only sentenced to one year in jail.

At the same time, several responses (10 references, 5 sources) reflected views that there were factors or circumstances associated with living in the United States, which made the mothers' experience more positive or resulted in gratitude. Factors or circumstances described by participants included the support that mothers felt they had received from family and friends who were in close proximity, and their positive experiences in regard to various services received such as quality medical care, financial assistance, access to support groups and counseling, and other services provided to their children.

For example:

Well, I feel that in terms of the pain, regardless of the location, it was going to be the same. But in terms of the moral support we received here, I can't say that it

wasn't there. We had a lot of moral support from the community, from a lot of people, from the authorities, police. With all of that, we didn't feel we were alone. There was a lot of support, and so I think that here the support was not bad. I think that if it had happened in Mexico, the situation would have been much different. Unfortunately, in our country, the financial support would have been more difficult to get. Also, it depends on the situation and how things happen. In our situation, the State helped us. I don't know about Mexico, and what would have been the financial support there.

Another mother described her gratitude:

Before I used to say, "Yes, let's go back to Mexico to live". But after what happened to me... what happened to us... I see things differently. Here, I am totally grateful to the hospital. Because in my case, the twins I had were only 29 weeks old when they born. They were premature and very sick. I think that if I had been in Mexico, in the same situation, neither of them would have survived. The truth is that science and everything is more advanced here. I would say that my twins were a miracle... my little miracles of life. And my little one, O-, who survived... they made him "brand new". I don't know, in Mexico, I see similar cases and the babies don't survive. I think that there's a lot of help here... a lot. Everything is totally advanced. After what happened to me... well, I never thought that it would happen...but it did unfortunately. But regardless, I am totally grateful to the hospital. Because my other baby, they made him better... and he is fine. He has a few problems, but he is fine. And the help is there for you. Knowing where to look for it, you are able to get the help. In contrast, in Mexico I see it as more difficult... totally difficult. Here, you have help from all sides. And even more when it's a child... they get even more help. But we do too. There are programs that help you... programs like Corazon for parents like us. And it's just looking for the help. Like that woman said, I'm also "from here". To go back to Mexico... no... because my heart is here... my life ... and I will stay here.

One mother described her solidified connection to the United States as a result of her son's death:

Before my son's death I used to view life differently. I used to think that someday I would leave to Mexico. Not anymore. Because it's not about where we are born, but rather, where we make our life. And with such a big loss, like the loss of a child, your life changes completely. I used to tell my family that lives over there... that someday I would go back. But now I tell them that I will never leave here, never. For me, my children are what I love most in my life... so by leaving I would be abandoning him. Because like the other woman had said... I am the only one that goes to visit his grave. Because I went through pain to have him, and I have felt the pain in losing him... no one else has. I will never leave here...

my plans are now to stay and be here. My plans are to be in the same cemetery... to buy a plot... because that's what we have to do. You know that tomorrow you may die ... and when? We don't know when. But there is no doubt that it will happen someday. I used to say that I wouldn't buy a plot in a cemetery... no. But now my life has changed... 100% ... and now I am from here. My family is over there... but now I belong here.

In addition, two responses (2 references, 2 sources) expressed the mothers' view that Mexico was a dangerous place and their belief that there was a lack of justice in Mexico when crimes occurred. Last, some responses (4 references, 3 sources) reflected the mothers' view that their experience of pain would have been the same regardless of where their children's deaths had occurred.

In sum, in regard to confronting this experience as Mexican mothers living in the United States, many of the responses were associated with the mothers' immigrant or residency status and how it impacted their decisions regarding their child's remains. The issues described had to do with whether to bury or cremate their children, as well as which country to place their children's remains. Participants stated that this particular decision making made their grief experience more difficult and painful due to fear or confusion in not knowing what they would do if they were ever forcibly sent back to Mexico or if they voluntarily returned to Mexico.

Several responses reflected the mothers' views that there were factors or circumstances associated with living in the United States, which made their experience more difficult or caused them to feel disappointment in the United States. Factors or circumstances included experiencing the absence of extended family members (residing in Mexico) to offer support or comfort, the view that there was lack of justice in the United States, the view that gangs were unique to the United States and associated with

their child's death, and a general regret in having emigrated to the United States, felt in the aftermath of their child's death.

At the same time, several responses reflected the mothers' views that there were factors or circumstances associated with living in the United States, which made their experience more positive or caused them to feel grateful. Factors and circumstances described, included having adequate family and social support in the United States, and having received other kinds of support such quality medical care, financial assistance, access to support groups and counseling, and other social services that were received for their children.

Last, additional responses included some negative views of Mexico and mothers' beliefs that the pain experienced would have been the same regardless of where the death occurred.

The fifth question posed the following:

Q5 Tree Node: "When you hear the phrase "Déjalo descansar, no le llores" (Let them rest, do not cry for them), what do you think or feel?"

Eight nodes were organized under this tree and reflected what the participants thought or felt when they heard the phrase "Déjalo Descansar, no le llores" (Let them rest, do not cry for them): hearing the phrase made them angry or upset, (coded as "hearing phrase made them angry or upset"), the participants talked about their need or desire to cry and they felt that crying helped or comforted them in different ways, during their grief experience (coded as "the need or desire to cry"), the participants viewed this phrase as a prescription to forget or not talk about their child and they felt it limited or

stifled their expression of grief (coded as “phrase viewed as prescription to forget or not talk about child”), the participants viewed the phrase as a common cultural term of condolence and felt that it was well-intended but naïvely offered as support or comfort by others (coded as “view of phrase as cultural or well-intended”), the participants viewed the phrase as ignorant or rude (coded as “viewed as ignorant or rude phrase”), the phrase resonated and was accepted as serving a helpful function in the grief experience (coded as “phrase resonated and accepted”), as well as two additional nodes which described personal experiences that did not fall clearly within any of the aforementioned node categories: donating the child’s belongings helped in the grief experience (coded as “donating belongings helped”), feelings of anger changed to acceptance and forgiveness (coded as “moving from anger to acceptance and forgiveness”). Frequencies for this coding tree are provided in Table 6.

Table 6. Tree Node for Question 5

When you hear the phrase “Déjalo Descansar, no le llores” what do you think or feel?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Donating belongings helped	1	1
Hearing phrase made them angry or upset	5	28
Moving from anger to acceptance and forgiveness	1	1
Phrase resonated and accepted	1	1
Phrase viewed as prescription to forget or not talk about child	4	10
The need or desire to cry	5	18
View of phrase as cultural or well intended	5	7
Viewed as ignorant or rude phrase	3	6

In regard to this question, almost all participant responses reflected negative

reactions or feelings, including shock, resentment, anger, pain, sadness, and distress in regard to the phrase “Déjalo descansar, no le llores”. Specifically, a majority of the responses (28 references, 5 sources) reflected that the phrase caused the mothers to become angry or upset. For example:

When I would hear that phrase, I would get very angry... very angry. I felt like I hated the people that would attempt to say that to me. I felt such anger... they don't know the pain that you are going through. Sometimes a hug would have been better, than to use that phrase. I felt so much anger when they said it to me. In fact, my mother said it to me. At the time, my mother told me that I should stop crying because I had other two daughters, and that God had left me two daughters. So, in anger, I told her that I wasn't o.k. with her saying that... because I also had another daughter besides them.

Another mother stated:

At least for me, when I was at my daughter's funeral and people approached me and said: “Don't cry for her, she is resting in peace now”... it has a great impact on you. That hurt me more, than if someone had... I don't know... hit me. I felt... I don't know... it's so shocking... for me, it was quite a bad feeling that they would say to me, “Let her rest... and... don't cry for her anymore.

Several responses (6 references, 3 sources) also reflected mothers' views that the phrase was “ignorant” and “rude”. Several responses (10 references, 4 sources) also described the mothers' view of this phrase as advice or others' prescriptions to forget or not talk about their children. One mother commented:

Until this day I do not agree with that idea of “let them rest”... because every day of my life I will be thinking of my daughter. I don't think that would bother her at all... quite the contrary... So for me that phrase “let her rest” is like distancing myself from her... and moving on. Frankly, I have heard the same thing, and lot of people do tell you that because it is simply so easy for them to say something like that to you. Because they don't understand that we don't want them to leave us. They will always be with us... just like we will always be with them... until the last day of our lives. They will continue being our children, and not anyone or anything is going to prevent that. So I don't agree with that phrase, “let them rest... don't cry for them”. I cried and cried all the time... all the time... because it is one way to have her feel my love. I wish I wouldn't cry but it's one way to let

out my great pain.

Mothers commented that this phrase often served to stifle or limit the full expression of their grief. Some described their need to cry privately, in order to avoid upsetting family members. One mother commented:

I have let it out. But sometimes my husband also has the idea that.... All he says is... He says, "We have to keep going and move forward".... "We have to keep going and move forward"... and I hear him, and say "you sound like a broken record". So the only thing I can do, so he doesn't see me... I don't know if it is a coincidence.... is that, whenever I go to the bathroom, that's when I feel like crying. And I say to myself "at least he can't see me"... so that he doesn't start saying to me, "don't cry"... don't cry". But then, every time I go in to take a bath, while I am taking a bath... all the memories come to me. And I begin to cry... and cry... and I let it all out in the bathroom for about ½ an hour. And so what I do so that he doesn't know that I've been crying, is that I stay locked up in my bedroom for a long time. And then when I feel a little more tranquil, then I come back down. I say to myself "After all that he doesn't even know I was crying". He thinks that everything is fine... and it's not true. But I have to make him believe that I am doing everything he thinks. But I feel... I know I don't... because he and I think differently.

At the same time, several responses (7 references, 5 sources) expressed the mothers' understanding of this phrase, as a common term used in the Mexican culture by friends and family when offering condolences. For example:

Yes, I feel the same, as the rest of you. It's an ignorant phrase... but unfortunately it exists and even more in our culture. Those people, they do it because they want to make us feel better...but they say it to us in ignorance.

One response (1 reference, 1 source) reflected a mother's view that this phrase had influenced and resonated, in regard to her own desire or need to stop crying. This mother described her experience:

Now, I have been able to overcome this a little more. Because at the beginning it was very unpleasant when they would say, "just let him rest". Because in my case, the truth is that I was always crying and crying. For me, days were very difficult. I couldn't go one day without crying. And that lasted for a long time.

Until one day I was talking to my sister and she said “Don’t be crying, let him rest. Otherwise your crying is not going to let him rest.” And I had two dreams, where he kept being thrown out of his burial site ... he kept being taken out. So I said to my sister; “Can you believe that I have been having dreams of my son, and that in one they keep taking him out of his tomb and leaving him out in the open, and in another dream they kept moving his burial site around... and my sister told me “You need to stop crying, because he isn’t able to rest in peace”.

For me, those dreams were a relief. Because my sister had kept saying “he can’t be at peace. So you can’t be crying, you need to stop crying because he is not going to be able to rest in peace, so he is going to keep being in your dreams”. And so it’s almost as though that gave me some peace, and so I was able to calm down. So, little by little, I began trying to stop the crying... because it was hard to do. And so from there, it calmed me a little bit, because my sister was still telling me to let him rest.

In regard to this question, there were also many responses (18 references, 5 sources) directly related to the mothers’ view of crying as something necessary and natural. The mothers commented that crying was what helped them the most to feel better and that it offered comfort and relief in their grief experience. Some stated that crying represented something innate and inevitable; some commented that it was their way to express the severity of the pain and the significance of their loss; others felt that it was one way to express their love for their child. One mother commented:

Yes, when they say, “Let them rest” it’s because people, albeit ignorantly say, “If you cry you are not letting them rest in peace”. And I don’t think that... I believe that it’s better to cry, to cry about everything you are feeling... and to cry and pray for them. Crying is the only thing that is going to help you get it out, that’s what I think.

Two additional responses were also provided in regard to other personal thoughts, feelings, or experiences, and included a view (1 reference, 1 source) that donating their child’s belongings was helpful and a view (1 reference, 1 source) that feelings of anger (towards those responsible for the child’s death) had moved towards forgiveness.

In sum, the majority of responses pertained to the negative reactions or feelings

that the phrase “Déjalo Descansar, no le llores” caused the mothers, when heard. The range of negative feelings or reactions that the phrase triggered were described as shock, resentment, anger, pain, sadness, confusion, and distress. Several participants described the phrase as “ignorant” and “rude”.

Participants stated that this phrase was sometimes used to stop them from crying “too much” or that it was used to limit their outwardly expression of grief. They also commented that this phrase was evoked especially at times when others seemed uncomfortable or distressed by their crying. Mothers also felt that this phrase represented advice or encouragement to forget or distance themselves from their children.

At the same time, mothers viewed the phrase as a sincere, but unwelcomed, attempt on the part of others to console them. Mothers described this phrase as a common condolence used in the Mexican culture, and some commented that it was a term they often heard in their own families by parents and other relatives while growing up.

Only one mother stated that, although the phrase initially triggered negative feelings in her, that it eventually resonated in light of her own desire to cease crying.

This question also prompted many responses in regard to the mothers’ crying and they described various reasons why they felt that they needed or wanted to cry. Mothers talked about various ways in which crying helped them in their grief experience. Some stated that they felt crying was a natural or inevitable reaction to the loss they had experienced, others commented that it expressed and released the pain being felt, and others commented that it also expressed the love and yearning that they felt for their children. Participants also stated that crying offered the most comfort and relief in their

grief experience.

The sixth question posed the following:

Q6 Tree Node: “Were there any religious or cultural traditions, rituals, or expressions that helped you?”

Four nodes were organized under this tree and reflected the religious or cultural traditions, rituals, or expressions that participants felt had helped them: the participants maintained altars for their child, containing child’s photo(s), symbolic memorabilia, candles, flowers, and other items which were viewed as cultural or religious (coded as “Altars”), the participants felt that attending mass and holding special Masses, Novenas, Rosaries, prayer, reading of biblical scripture, attending church retreats, and other similar activities were all helpful (coded as “Religious traditions, activities”), participants felt that some cultural celebrations, and the Day of the Dead in particular, were helpful (coded as “Cultural traditions, activities”), and an additional node for activities that participants felt were helpful, but that did not fall clearly within any of the aforementioned node categories (coded as “other things that helped”). These activities included attending a support group, reading, crying, personal family events, a hospital sponsored memorial service, and a special ritual that had been conducted at the hospital. Frequencies for this coding tree are provided in Table 7.

Table 7. Tree Node for Question 6

Were there any religious or cultural traditions, rituals, or expressions that helped you?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Altars	3	4
Cultural traditions, activities	3	3
Other things that helped	3	5
Religious traditions, activities	5	17

In regard to this question, many of the responses (17 references, 5 sources) indicated that the mothers engaged in various religious traditions, rituals or activities, which they described as helpful in their grief experience. Some of the religious traditions, rituals or activities described included attending regular and special masses, participating in Novenas (9-day Rosary) and rosaries, reading biblical scripture, attending special church retreats, reciting special prayers (e.g. La Magnifica, mentioned by some mothers), and “regular prayer “ to God and their saints.

Participants described traditional Catholic rituals, such as masses and rosaries, which they found comforting and also felt served to honor and remember their children. Mothers also talked about the comfort they found in praying. As an example:

Every time that I go to mass I entrust her to God... every time.

Another mother stated:

In the same way, I think that you have to take refuge in God’s word, and that this spiritual comfort helps. I have also prayed and I always keep in mind the “La Magnifica” prayer. For me, this is one of the prayers that comfort me a lot. We do that prayer on our own, by ourselves... me and my husband and our kids.

Another mother described praying to her deceased son, which she viewed as

helpful:

Another thing... I don't know if it's wrong... but sometimes when I have a problem or especially when my daughters get sick... I pray to him. I say: "My son, you're so close to God... intercede on our behalf... so that... this or that, whatever it is. A lot of people tell me it is wrong. But I see him as an angel, as though he can intercede for us. I always have him in my thoughts... and I view him as a saint... I don't know... I always ask him... and when I ask with all my heart... and it's not just that I'm saying it... but those things do come true... it helps me because I feel that he is with me.

Another participant described a spiritual retreat she attended and how it helped her regarding her anger and search for understanding:

Later, I went on a spiritual retreat from my Catholic church and it helped me very much. It helped me find myself. It helped me to get out all the anger. Because when you go through a loss like this, you feel a lot of anger towards God... and others...towards yourself. The need to know why things happened this way... and so it helped me a lot to go on this spiritual retreat... it was for three days.

In addition, some responses (4 references, 3 sources) described the altars that participants maintained in their homes. Mothers commented that their altars were a source of comfort and support and that they also served to help remember and honor their children. One mother described the altar she maintained for her son:

Yes, as of now, I still have an altar... and I just wanted to share the fact that I change it according to every season. Easter, Valentine's Day, all of them. My grandchildren and I... we decorate his altar for every holiday or season... at Christmas we put a little Christmas tree... ornaments... all on top of the altar... and as always, the little candles. . . right?

At the same time, a few responses (3 references, 3 sources) identified the Day of the Dead, Day of the Children ("Día de los Muertos" and "Día de los Niños") in particular, as a special cultural tradition (or celebration), which mothers found helpful and comforting. For example:

I think this is a ritual that helps people a great deal. And it is not only during the 1st and 2nd of November... but rather, that you dedicate the entire month to their memories. During the entire month of November, you pray for their souls and their eternal rest... all of our beloved brothers and sisters. And I think that as Mexicans, this is a very good traditional ritual.

Additional responses (5 references, 3 sources) described other activities, rituals, and traditions, which were viewed as helpful by participants. These included personal family traditions, memorial services or ceremonies, support groups, reading, and the use of a special ritual performed on a mother's baby to improve his physical condition. For example:

Now, on Sunday, they are doing the ceremony at the hospital, and we have always attended every year... as well as my nephews, and my sister... they also go. My kids say "Ma, its April... have they sent the invitation yet?" and I say, "Yes, I already have it"... and now that they are older and they work, they say "so I can ask for the day off"... on that day... it's the 22nd... Yes, it comforts us and helps us to keep going, to carry on.

In sum, many of the responses described the various religious traditions, rituals or activities that the mothers engaged in, which they viewed as helpful in their grief experience. Some of the religious traditions, rituals or activities described included attending regular and special masses, participating in Novenas (9-day Rosary) and rosaries, reading biblical scripture, attending special church retreats, reciting special prayers (e.g. La Magnifica, mentioned by some mothers), and "regular prayer " to God and their saints.

Mothers also described the altars that they maintained in their homes. Mothers commented that their altars were a source of comfort and support and that they served to help remember and honor their children.

Last, a few responses identified the Day of the Dead, Day of the Children (“Dia de los Muertos” and “Dia de los Niños”) as a cultural tradition (or celebration), which the mothers viewed as helpful and comforting.

The seventh question posed the following:

Q7 Tree Node: “Were there any religious or cultural traditions, rituals, or expressions that did not help or made it more difficult?”

Three nodes were organized under this tree and reflected the religious or cultural traditions, rituals, or expressions that participants felt did not help or that made it more difficult: three participants felt that biblical scripture and common religious or cultural expressions, which were offered as condolences, did not help and sometimes made it more difficult (coded as “religious or cultural expressions, scripture”), and two additional nodes for other things that participants felt made it more difficult: one mother felt that seeing photos of her child made it more difficult (coded as “photos of child”), and one mother felt that commemorating her child’s birthday, death anniversary, or other significant dates via formal memorials, gatherings, or special events, made it more painful and sad (coded as “memorials or remembrance activities”). Frequencies for this coding tree are provided in Table 8.

Table 8. Tree Node for Question 7

Were there any religious or cultural traditions, rituals, or expressions that did not help or made it more difficult?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Memorials or remembrance activities	1	1
Photos of child	1	1
Religious or cultural expressions, scripture	2	4

In regard to this question, there were only a few responses provided throughout the five focus groups. However, a few responses (4 references, 2 sources) expressed the mothers' views that there were some religious and cultural expressions used by others, which they felt made their situations more difficult or triggered negative reactions. Examples included the phrase “Déjalo Descansar, no le llores” and other comments such as “your child is in a better place” or “God needed an Angel”. For example:

Yes, I have one phrase that comes immediately to mind since I actually heard someone say it again recently. But at the time, initially, when I heard it... I was in such pain... even though I knew that it was something they we are all culturally, accustomed to saying... but the phrase is ‘Let him rest, don’t cry for him’.

Another mother said:

There are some... and I used to say them too... but now that this happened to me... The truth is that there are phrases that pierce my ears when I hear them. Like the one, ‘God needed an angel’. And I say to myself ‘wow!’ That sounds so silly to me now... because He has thousands of angels. Also, ‘these are tests from God’. I can’t believe that...as I’ve said, God is love. He wouldn’t play with people like that... to take their child, to see what you will do... I do not believe God would do that.... I can’t conceive that.

One response (1 reference, 1 source) reflected a mother’s experience regarding her child’s photos, which she stated was too difficult and painful for her. One response

(1 reference, 1 source) also had to do with a mother's experience with memorial activities or events. This mother commented:

I don't do a cake, because I ask myself "what for?" he's not here anymore. Since he has been gone, life has been very simple. I don't do a lot of those things, because for me it is more painful and sad. That is why I don't do anything like that. As I've said, it is nice to remember him. But once I was told that I should do things like that to remember him... but it doesn't make me feel better. So I've just become accustomed to having it this way... for that reason, I hardly do any memorials. His birthday, and his graduation date, I always remember those, but nothing else.

In sum, in response to this question, some responses expressed mothers' views that there were some religious and cultural expressions used as condolences, which made their experiences more difficult and triggered negative reactions. Two additional comments were regarding the difficulty and pain experienced when viewing photos of the deceased child and in having commemorations through special events and family or social gatherings.

The eighth question posed the following:

Q8 Tree Node: "Was there anything else that helped you, or anything else that did not help or made it more difficult?"

Two primary nodes were organized under this tree, to reflect things that did not help or made it more difficult (coded as "did not help or made it more difficult") and things that helped (coded as "helped"). Under these two nodes, additional sub-nodes were organized accordingly to represent what the participants viewed as helpful and unhelpful (including things that also made it more difficult) in their grief experience.

Eight sub-nodes were organized under the "*helped*" parent node, which identified a range of factors and experiences that participants felt helped them, including all of the

following: (1) talking to others and participation in support groups (coded as “talking to others and support groups”), (2) activities that honored, remembered, or helped participants to feel connected to their children (coded as “honoring, remembering and connection to child”), (3) maintaining their faith, God, and support from the church and their priests (coded as “God and church, faith”), (4) support from family, friends or community (coded as “support from family, friends or community”), (5) having subsequent children (coded as “having subsequent child helped”), (6) working and keeping busy (coded as “working, keeping busy”), (7) music and reading (coded as “music and reading”), and (8) therapy for their grieving children (coded as “therapy for children helped”).

Seven sub-nodes were organized under the *“did not help or made it more difficult”* parent node, which identified a range of factors and experiences that participants felt did not help or made it more difficult, including all of the following: (1) feelings of anger (coded as “feelings of anger”), (2) felt counseling did not help or was unavailable (coded as “counseling did not help or unavailable”), (3) the decision making regarding child’s remains (coded as “decision making regarding child’s remains”), (4) the absence of family support (coded as “absence of family support), (5) the view that others no longer remembered their children (coded as “no one remembers”), (6) reminders of their child via their belongings (coded as “children’s belongings”), and (7) the negative impact experienced by their other children (coded as “negative impact on the other children”).

Frequencies for this coding tree are provided in Table 9.

Table 9. Tree Node for Question 8

Was there anything else that helped you, or anything else that did not help or made it more difficult?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Did not help or made it more difficult:		
Absence of family support	1	1
No one remembers	1	1
Counseling did not help or unavailable	3	5
Decision making regarding child's remains	2	3
Feelings of anger	2	2
Children's belongings	1	2
Negative impact on the other children	2	3
Helped:		
God and church, faith	4	8
Having subsequent child helped	2	2
Honoring, remembering, and connection to child	5	15
Music and reading	2	4
Support from family, friends or community	3	4
Talking to others and support groups	4	19
Therapy for children helped	1	1
Working, keeping busy	1	1

In regard to this question, many of the responses (19 references, 4 sources) expressed participants' views that talking to others was helpful in their grief experience.

Participants stated that any opportunity to talk was viewed as helpful and some commented that they talked with a immediate family members, some friends, their priests, hospital workers, other bereaved parents, and even with their deceased children.

Various comments included:

Talking with my family, talking with the priests... To me, that was what helped me the most.

For me personally, (name omitted) helped me a lot. Even up to a year after my daughter died, they kept calling me, and calling me... and he was the one that helped me a lot emotionally. He would talk to me every week, and he would spend a lot of time talking with me... He helped me a lot.

Even though people might say I'm crazy... but I don't think so...no. I talk to him a lot.

Participants also viewed their experiences with support groups as helpful and they commented that these groups provided an opportunity to talk with other bereaved parents who could understand their experience in ways that others could not:

At the hospital, we also had some good friends, and they have been there through it all, and they haven't left our side. They are more than friends to us. Thanks to them, because they kept insisting that we come to the support group. For me, honestly, this program was something that I really needed. Because I was in a deep depression... so it was something that I was looking for. I had tried to look for help, for the depression... but I didn't want anything just individually for me. I wanted something like a group... of people... just like that... parents who had experienced the same thing as I had. So when they talked to us about it... for me, honestly, everything has changed a lot, and positively. So thanks to these programs... because they really do help a lot.

Many responses (15 references, 5 sources) also included descriptions of the various activities that mothers engaged in, which they viewed as helpful, comforting, and serving to help remember, honor, and feel more connected to their children. Activities described were maintaining altars in their homes, engaging in altruistic activities or events in honor of their children, having dreams of their children, visiting the cemetery, visiting places associated with their children, and viewing their children's photos, videos, and belongings.

As with Question #6, participants talked about the altars they maintained in their

homes and they commented that the altars were very comforting in their grief experience.

As an example:

For me, well, I have a table with his pictures, a candle, and little angels... and up until now I still have that... except not the candle. But a person used to tell me to remove it all, because perhaps, that was what was making me feel worse. It was like saying that I should forget him. But that is something that shouldn't be up to them... it should be up to you.... because you are the one going through this experience. And you don't need to pay attention to what other people say, like "Don't cry anymore... don't do this or that". No.... you are going to do what you want or what you feel. I had it there for about six years, I think... but then it was always, "The house is going to catch on fire... and this and that...". But it made me feel good... I liked it. But now instead of a candle, I have a little lamp, and his picture is in a display case. It is surrounded with saints and little angels. And that picture of him is there day and night...and it's not about what other people say... you do what you think makes you feel good.

Participants also described altruistic activities in honor of their children. One mother stated:

My daughter was very gifted as an artist. She used to draw... she had a lot of drawings... of everything. So when I was gathering her things, I found a lot of oil paintings and things that she had painted by hand. So I made a gallery and I am going to take it even further. My husband and I plan to create a foundation in her honor to help students. She had so many problems in getting loans or scholarships... but she was committed to becoming a doctor. So that is what I want to do now. It's something that helps us... We have the gallery, and some people have visited it... our friends, people she worked with... Truthfully, this has helped us tremendously because it was one of our dreams... There was a man, an artist, who helped us decorate it... He said that he hoped someone would, perhaps, someday love him that much, after he died, that they would build a gallery in his honor, in the same way we had done for our daughter. I felt very good.

Another mother commented:

So it has helped...to be able to talk and to do positive things in his honor. I still have a vision to continue doing more things. So because of his diabetes, along with the JD Group, which is the Children's Diabetes Group, we have done the walk-a-thon. We participated this past year, and it was difficult... because you think to yourself, why couldn't my son have done this while he was alive?

Participants described their dreams about their children, and they stated that the dreams helped them to feel more connected to their children and provided comfort. One mother stated:

I don't know... I would say that I am very spiritual... because I would dream about my daughter a lot. I dreamt a lot about her. And I think that she brought me a lot of comfort because she used to tell me, "Mami, you need to go on, there is nothing wrong with me, I'm fine" and I would dream of her and I could almost see her.... "I'm fine mami, you keep going... go on" and I believe it is what helped me the most.

As noted earlier, participants described other activities such as visiting places associated with their children, visiting their children at the cemeteries, and looking at their children's pictures, videos, and belongings, and they stated that these were all personal activities that they viewed as helpful and provided comfort in their grief experiences.

Several responses (8 references, 4 sources) expressed participants' views that religious faith and their belief in God was helpful in their grief experiences. Participants described getting closer to God, praying and talking to God, praying to the Virgin of Guadalupe and other saints, talking with their priests, attending church and mass, and reading biblical scriptures as activities that were all helpful. One mother stated:

For me, personally, church has helped me a lot... going to mass. Before, we didn't go very frequently. This is something fundamental for us. It helps us greatly to talk with the priest, and to go to mass... also, when I go to church, I talk a lot to the Virgin.

In addition, two responses (2 references, 2 sources) reflected mothers' views that having subsequent children after the death of their child had helped them in their grief experiences. One mother said:

And well, now my newborn daughter has been like a salvation for us. She is like a new hope... I think it was God's plan to give her to me... because I had two sons. So this is also different... all new to us... and she is the only granddaughter. It's been something new for the entire family... I think it's been like a therapy... because she keeps us so busy... constantly... and it's always something new.

In addition, a few responses (4 references, 2 sources) reflected mothers' views that other activities such as reading and listening to music were helpful in their grief experiences. Other responses (4 references, 3 sources) also reflected views that the support mothers received from friends and family and their communities had been helpful in their experiences. One response (1 reference, 1 source) expressed a mother's view that working and keeping busy had been helpful to her. Two examples:

I have read a lot of books about children who have died and gone to Heaven. That has helped me a lot. Because in the beginning, it was like I didn't know how to see things.

And also what is helping to heal my pain is that I didn't work before... but a year ago I started working. Because at work, it is a way to keep my mind busy. I was very depressed before. I was just at home, only thinking about my daughter. So now I keep myself busy. Of course, she is still in my heart... I am not going to forget her. I am always remembering her... but by working and going out... because before I would lock myself up at home and I didn't want to see or talk to anyone... by going out and talking with friends, or co-workers, you go out and do things... things at home, you're rushing here, there... to school ... to work... and that helps you.

Last, one response (1 reference, 1 source) also reflected a mother's view that the therapy provided to her grieving children had been helpful. She commented:

Some programs that helped us, primarily with our children, was therapy for them... emotional therapy and participating in some activities, where they met other children that had gone through similar situations. So that helped them to know they weren't the only ones.

However, there were also things that participants viewed as unhelpful or that

made their experiences more difficult. Several responses (5 references, 3 sources)

described the mothers' participation in individual or family counseling, and their view

that these counseling experiences were not helpful. One mother stated:

So yes, it was very difficult, so difficult that I tried different ways to help her, and so we all went to a counselor at (name omitted). They have a program. But my family felt that the counseling didn't help. She would say "mom, don't take us there anymore, we are wasting our time... I have homework to do... we have school so don't take us. We don't like what they do there. And the activities they make us do don't help us." So we didn't go anymore. I also felt, on my part, that the counseling wasn't helping. Especially when the counselor, after everything that I told her, decided to send me to a psychiatrist. She said that I needed medication because of the way I was expressing myself. So at that point, even my husband was honest with her and said "You know what; I don't think that even the best psychiatrist in the world is going to cure us of this pain. I think that the only one who can help us to overcome this is God. So I am sorry, I'm not saying that the work of psychiatrists isn't any good, but in our case, we're sorry, but that's how we feel. So we stopped going to counseling.

As with previous questions, some responses (3 references, 2 sources) pertained to mothers' experiences in having to decide about the placement of their child's remains, and mothers commented that this made their experiences more difficult and painful. One participant stated:

Yes, my husband wanted to send my daughter's body to Mexico but I did not want that. I also cremated her. I also have her in my home. Well for me, it's not the nicest thing... but it is the best solace, having her with me. Because if I had buried her or they would have sent her to Mexico... perhaps my pain would have been worse. If I had her far away from me... to not have been able to visit her... or to have to visit her at the cemetery... or to not have been able to get to the cemetery when I needed to... then perhaps the situation would have been worse. Given the situation I found myself in... this has been something better ... to have her with me.

Another mother said:

For me, there was no time to decide. I don't know how it happened. I think I was in shock. But I never even thought of taking him to Mexico with me... or that my

husband's plans have always been to want us to return to Mexico. He has told me to send him to Mexico. And yes, it's true that I was the one that brought my husband here. But I just don't know... I did think about it... and what am I going to do over there all alone? All of the family is here now.

As with previous questions, some responses (3 references, 2 sources) described the impact that the death caused on their other children and commented that this also made their experiences more difficult. One mother said:

The fact that my son wasn't able to say goodbye to his brother... has been something very difficult as well. Because it was all so sudden... and at the time, I don't think I understood that. But as he gets older, he has been able to express that pain. Seeing that his brother isn't with him, when he is playing alone... that has been the most difficult. One day he shared that he wasn't able to say good-bye to him, and he was crying. He said that he would have wanted that, but for us... he was so little... well, not that little... he was seven years old. But at the time you don't think. And we didn't want him to get traumatized... especially when we saw how he would get, seeing all the machines.

In response to this question, a few responses (2 references, 2 sources) expressed feelings of anger that mothers were experiencing. Mothers commented that they felt their anger sometimes made their situations worse, because it impacted family interactions and relationships. As an example:

In fact, today I was talking with my husband and we were watching TV. There was a news story about a mother that had abandoned her baby. It was so easy for him to say, "Fathers love their children, more than the mothers" so I said, "How dare you say that?" and he said: "Yes, because a father would never abandon their child, so why does a mother do that?" So I told him, "You don't know what you are talking about". It made me so angry.

A few responses (2 references, 1 source) reflected the pain and difficulty some mothers experienced when they handled or came across their children's belonging. As an example:

For me, taking down his crib was traumatic... it was for all of us in the house. I

decided to remove it because I know that it is just an empty crib. Now I will donate it to someone. And his hair... looking through his things and finding his hair... that impacts you... but for me, the most difficult thing was taking down his crib.

Last, one response (1 reference, 1 source) reflected a mother's view that an absence of family support due to distance (relatives in Mexico) had made her experience more difficult. One other response (1 reference, 1 source) reflected a mother's view that family and friends no longer remembered her child, and she commented that this made her experience more difficult. She said:

And it is more difficult to know that no one asks you about her... like "what would you have wanted for your baby?"

In sum, many of the responses expressed participants' views that talking to others about their experiences was most helpful in their grief experience and mothers also viewed bereavement support groups as very helpful in this regard. Participants also viewed engaging in activities that helped them to remember and honor their children as very helpful. Examples included altruistic activities (such as public awareness events and scholarships), maintaining home altars for their children, dreaming of their children which the mothers said were reassuring and made them feel more connected to their child, visiting the cemetery, visiting places associated with their children, and viewing their children's photos, videos, and belongings.

Participants also stated that the support they felt from God, their religious faith, and from their church was helpful in their grief experience. Participants described getting closer to God, praying and talking to God, praying to the Virgin of Guadalupe and other saints, talking with their priests, attending church and mass, and reading biblical

scriptures as activities that were all helpful.

Other activities described as helpful included working and keeping busy, reading and listening to music, having received support from family, friends and their community, therapy provided to their children, and having subsequent children.

Many of the responses also expressed the participants' views regarding things they felt did not help or made their experiences more difficult including individual and family counseling, decision making regarding the placement of their children's remains, the negative impact of their child's death on their other children, feelings of anger that impacted family relationships and interactions, an absence of family support due to separation from family members in Mexico, the belief that no one remembered their child, and encountering or handling their children's belongings.

The ninth question posed the following:

Q9 Tree Node: "Do you feel you have been allowed or have allowed yourself to express your grief or feelings in a way that you needed or wanted?"

It should be noted that the researcher introduced this question during the third focus group interview and thereafter. Based on comments made by participants in the previous interviews, the researcher felt it would be helpful to ask this additional question in order to obtain richer and more specific information in this area, in relation to the participants' lived experience.

Three nodes were organized under this tree and represented whether or not participants felt they had been allowed or had allowed themselves to express their grief or feelings in a way that they needed or wanted: participants felt they were able to express

grief (coded as “able to express grief”), participants felt they were not able to fully express grief (coded as “not able to fully express grief”), and one additional node which described a personal experience that did not fall clearly within any of the aforementioned node categories: participants felt that taking medication had helped them manage depression and anxiety which they felt was associated with their grief (coded as “took medication to manage, help with grief”). Frequencies for this coding tree are provided in Table 10.

Table 10. Tree Node for Question 9

Do you feel you have been allowed or have allowed yourself to express your grief or feelings in a way you needed or wanted?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Able to express grief	2	2
Not able to fully express grief	3	8
Took medication to manage, help with grief	2	2

In regard to this question, several responses (8 references, 3 sources) reflected the participants’ views that they had not been able to fully express their grief in ways that they needed or wanted. Mothers commented that their external expressions of grief, which were described as crying, yearning or reminiscing, were limited or stifled by their husbands, children, or others. For example:

I haven’t. I feel that they did not let me feel my grief in the way I wanted, because I have other children. So all my family... and my husband... would tell me that I needed to contain myself because of the children and that if I needed to cry... to do it privately, on the inside. So there were a lot of times that I would hold it in... and I didn’t cry sufficiently. There were a lot of things that I didn’t do, that I would have wanted to, so that I wouldn’t hurt my children.

Another mother stated:

Well for me I feel it has not been easy... that it is a little difficult. For me it is a little difficult, to talk much about him. We hardly talk. I don't know... a counselor told me that it would be good if we talked about it in our family, and with our other children. But I don't talk about it because my children always begin to ... (pause)... For example, if I say "oh, J- was like this or like that" ... it seems like I see him as such a good person, although I know he was bad sometimes too... but I am holding on to his good side... I mean, they are all really good aren't they... even with their flaws? So whenever I try to talk about him... I don't know how to say this... but it's their reaction and what they say. They say "It's always about J- this, or J- that, with you!" It's like they are always saying that I only loved him so much. No, I love them all equally, but it's just that the four children were very different... and are very different. But they don't understand when I try to get them to see that... so for that reason, I hardly talk about him.

Participants also talked about their own need or desire to control their outward expression of grief in order to avoid harming their children and they described their private grieving, to avoid upsetting their children or husbands. For example:

I have let it out. But sometimes my husband also has the idea that.... All he says is... He says, 'We have to keep going'.... 'We have to keep going'... and I hear him, and say 'you sound like a broken record'. So the only thing I can do, so he doesn't see me... I don't know if it is a coincidence.... is that, whenever I go to the bathroom, that's when I feel like crying. And I say to myself 'at least he can't see me'... so that he doesn't start saying to me, 'don't cry'. But then, every time I go in to take a bath, while I am taking a bath... all the memories come to me. And I begin to cry... and cry... and I let it all out in the bathroom for about half an hour. And so what I do so that he doesn't know that I've been crying is that I stay locked up in my bedroom for a long time. And then when I feel a little more tranquil I come back down. I say to myself 'After all that he doesn't even know I was crying'. He thinks that everything is fine... and it's not true. But I have to make him believe that I am doing everything he says or thinks. But I feel... I know I don't... because we think differently.

At the same time, a few responses (2 references, 2 sources) reflected mothers' views that they had been able to express their grief in ways needed or wanted. One mother talked about her experience:

I did. I cried and still cry. And I will keep on crying because of what I feel... and I don't care if people see me crying, or they don't, or if they criticize me... I don't care. This pain is my pain...and I am the one that feels it. So whenever I want... whether I am alone or with someone... I don't care... that is how I feel... and if my husband doesn't like it... he needs to deal with that...I don't care.

In the context of this question, a few responses (2 references, 2 sources) were also provided which pertained to participants' use of medication for anxiety and depression. One mother explained how her external and intense expression of grief had impacted a decision to seek psychiatric support. She commented:

I also suffer from anxiety, but I definitely couldn't do a thing without the medication. Sometimes when I would go to the store... and see or hear something that reminded me of my son... and right there in the middle of Wal-Mart, or wherever I was... I would get crazy, crying and screaming. And the people around me would act like they had to be careful. And I would be driving...so that's why M- took me to the psychologist and the psychiatrist. I would lose my mind thinking of my son... crying and crying...and sometimes I would drive through red lights. Only God knows why I never had an accident. But yes, I was very bad...very, very bad. So it has helped me. My children are very young and I have to take them to the school...feed them...bathe them. And if I don't take my medication, I'm lost...I can't do anything... I'm shaking... I'm bad.

In sum, several responses reflected the participants' views that they had not been able to fully express their grief in ways that they needed or wanted. Mothers commented that their external expressions of grief, including crying, yearning and reminiscing, were limited or stifled by their husbands, children, or others. Some reasons given included their own efforts to limit their crying or reminiscing to avoid upsetting their families or friends, and also due to the expectations expressed from people around them, regarding the need to limit their outward expressions of grief.

At the same time, a few responses reflected mothers' views that they had been able to express their grief in ways they needed or wanted.

Last, a few responses pertained to participants' use of medication for anxiety and depression. Mothers commented that medication helped them to stabilize their emotions and manage their daily responsibilities.

The tenth question posed the following:

Q10 Tree Node: "If you could share one thing about your child's death, or how it has affected you, what would it be?"

Four nodes were organized under this tree and reflected the responses given by the participants in terms of how their child's death had affected them, or one thing they wanted to share about their child's death: participants felt that the death had affected and changed them as a person and parent, which included changes in their personal or emotional feelings, their feelings associated to caring for their children, or a changed sense of self or identity, in general (coded as "has changed me as a person or parent"), participants felt that the death had affected and changed their view of life or the world, which reflected negative, positive or neutral changes (coded as "has changed my view of life or the world"), participants felt that the death had a negative impact on their family and relationships, including negative impact within their immediate families or on their immediate family members (coded as "has had a negative impact on family and relationships"), and participants felt that the death had a positive impact on their family and relationships, including positive impact within their immediate families or on their immediate family members, (coded as "has had a positive impact on family and relationships"). Frequencies for this coding tree are provided in Table 11.

Table 11. Tree Node for Question10

If you could share one thing about your child's death, or how it has affected you, what would it be?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Has changed me as a person and parent	4	8
Has changed my view of life or the world	4	5
Has had negative impact on family and relationships	4	7
Has had positive impact on family and relationships	1	3

In regard to this question, several responses (8 references, 4 sources) reflected participants' views that they had changed personally and as parents. Participants stated that there were changes regarding their personal feelings or emotions. Changes described included having become fearful, unhappy, angry, curt with others, feeling a sense of impotence, and having become less assured or expressive. Mothers also stated that they had changed as parents, and they commented that there were changes in how they parented and cared for their children, including feelings of fearfulness and overprotectiveness as it pertained to their children's safety or well-being. For example:

Now I am terribly afraid that this will happen again. I don't know... I am so fearful... and I wasn't like this before. I'm also unsure of myself now... I became this way, because I wasn't like that before... I used to be able to express myself... I was very happy... but not anymore.

Another mother commented:

I have felt very impotent in regard to my son's death, because of the manner in which he died... because they stabbed him. I found him in the alley, as though he were an animal. That is where they left him. And I have felt a lot of impotence

with the police, because, I don't know... there's a lot of things they can do, but they don't. I have felt a lot of impotence in that way, because they don't help you. They look at it like another one on the list.

One mother said:

I have two daughters and one of them will be sixteen soon. It's the fear of having her get to that age, and then losing her too. It's the fear of having to go through that phase again. I'm more protective now with my daughters. I'm trying to avoid the same mistakes I made with G-. I'm probably too overprotective with them, and sometimes that affects them. Because G- was a good girl and a good person. But I worry that they will go through that same phase... when you're around sixteen or in your teens... I don't know... that's affected me. It makes me feel more afraid... and especially if something like that happens again.

Participants also described a general change in their sense of self and stated they were "no longer the same person" that they were before the death of their child. For example, "I feel, personally, that losing a child changes your life 100%, and you are never the same person again."

Another mother said, "You can't do the same things... you are not the same person that you were before... because you feel like a part of you is gone."

Several responses (7 references, 4 sources) also reflected the participants' views that there had been negative impact on their immediate and extended family relationships. Mothers commented that they felt as though extended family members no longer cared about them and had forgotten their children. One mother stated:

The way it has affected me, is in terms of my family. That is... my brothers, my nephews. And so how it has affected me, is that R-'s death was the closest death to us all. Two years ago my dad died. When R- had died there were a lot of promises made. One brother had said, "Mijo... you'll see... I promise you that I will quit drinking"... things like that, you understand? And I see now that life continues... and that, yes... they forgot about my son. And so sometimes I feel that they don't even care about me, or my pain... But I thought that now, in light of my son's death... and because of the great love that they supposedly had for

him... they were going to make changes in their lives... but no, they are still the same.

One mother described the blame and pressure she felt from family members:

It has affected me in different ways. Because it's difficult to say that even my own family has sometimes pressured me by saying, "Why are you crying so much... when you were an unnatural mother, who didn't want to go bury your son?" They don't realize that I don't have a social security card so I couldn't have returned... because I couldn't go... and even if I had gone, it wasn't going to bring my son back. Also, I had a lot of other good reasons why I couldn't go... So that has really affected me. Because people have asked me why I didn't go there... people who are outside of my family and also my own family members. It hurt a lot, because your own family should understand. It's enough that they have called me an unnatural mother...but then, "Why are you crying...why do you cry... why didn't you go to your son's funeral?" It is another torture for me.

One mother described her own withdrawal and distancing from family:

But I distanced myself from my family...my entire family. I didn't want to see them. I started working, probably too much... to forget what happened. And I can't believe that more than a year passed, and I still believed that I was pregnant. I would take care of my belly and was still taking care of myself in that way. That's why I distanced myself from my entire family because I thought that they were thinking that I was crazy... even though that's not how they viewed it... but at the time, for me, I was sure they thought I was crazy by the way I was acting. That's why it changed my entire life.

One mother talked about her changed role within her family and commented:

It affected me, in the way that it weakened me. Because he was my support and respect... and they have all lost respect for me. My family... I am of no value to them... for any of them. The respect... because I got weak. He gave me strength, he would give me my place and he considered my opinions. It is very painful because I always gave 100%...and they ignore me. They are talking and if I want to say something, they act as if I am not there. They ignore me, even when I am right. ...So... it's the lack of respect... because if my son were still here, I wouldn't be like this, I would have my place... Yes, and that is the most painful part for me.

Participants also noted the changes and impact on their families. For example:

Yes, it does affect you and life is never the same. Life in your family changes

totally. Because as much as you may try to keep living your life normally, it just isn't easy anymore. Because there is always someone who is missing in your family. So it is very difficult. But you have to accept this reality with a lot of pain. And you just have to keep going/moving forward, but it does affect you.

Some responses (5 references, 4 sources) reflected participants' views that their perspectives of life and the world had changed. Mothers commented that they now viewed life as fragile and some said they no longer feared death. One mother stated:

I also see life differently... in certain ways I'm afraid of death and yet I'm not afraid of death. When you haven't been through something like this, you often don't think about it or you think it will never happen to you. When people used to talk about cemeteries, I would say, "don't talk about that" ... and I would never go to one. But now I can go... it can be at night, during the day, any time ... and I'm not afraid. In fact, I've said to my husband and my family, that the day I die... because we bought plots next to him... so I want to be put there with him, except that I want to be cremated... and then they can put my ashes with him. That's another way we're different... you are able to talk more openly about death... because we'll all end up there, it's our destiny.

Participants also described their changed views of life and the world in the context of prior behavior or priorities. One mother commented:

Well, that when you have your children, you need to love them with all your heart. Love your children a lot, love them a lot. Because when you lose a child, it is the worst of the worst that can happen to you. So love them a lot, enjoy their childhood, and everything... just everything. Because when my son was little, since I had brought them here from Mexico when they were very young, well, I would leave them alone a lot. Sometimes when they went out on the street I would never accompany them. I remember at school, when my son graduated from kindergarten, I wasn't able to get there on time. It's like sometimes you come here... ignorant. At least I was... I was ignorant. I don't know about other people... but I just didn't get to his kindergarten graduation. Now I really regret that, because I wasn't there at such a beautiful moment. My son was alone. I got there, but it was after everything had ended. That is why I say to those parents, who still have their children, that they should love them a lot. I wish I could return to that time when my children were little, so I could take advantage of all those things I that wasn't able to do with them.

At the same time, a few responses (3 references, 1 source) described participants'

views that they experienced personal changes that were positive and that there were positive changes that occurred in their families. Mothers described experiencing that their families were stronger and more unified, that family members were more expressive and demonstrative of their love, and that they had become more understanding and supportive towards others.

One mother stated:

In reference to my family, I'm always telling them that I love them. I don't want to regret later that I never said that to them. With my son, we say that everyday... how much we love each other. He hugs me. I hug him. He is very expressive. Also with my husband... now I have learned that it is better to tell him while he's alive... than to regret later that I never told him. I have also tried to help as many other people as I can. This is something that I've learned, on the positive side... which is that we need to help each other, that we need to help others... and that the more you help others.... these are the little steps you take to get up there, to Heaven.

In sum, in regard to this question, several responses expressed participants' views that they had changed personally and as parents. Participants stated that there were changes regarding their personal feelings or emotions. Changes described included having become fearful, unhappy, angry, curt with others, feeling a sense of impotence, and having become less assured or expressive. Mothers also stated that they had changed as parents, and they commented that there were changes in how they parented and cared for their children, including feelings of fearfulness and overprotectiveness as it pertained to their children's safety or well-being.

Several responses also reflected the participants' views that there had been negative impact on their immediate and extended family relationships. Mothers commented that they felt as though extended family members no longer cared about them

and had forgotten their children.

Some responses reflected the participants' views that their perspectives of life and the world had changed. Mothers commented that they now viewed life as fragile and some said they no longer feared death.

At the same time, a few responses expressed the participants' views that they experienced personal changes that were positive and that there were positive changes that occurred in their families. Mothers described experiencing that their families were stronger and more unified, that family members were more expressive and demonstrative of their love, and that they had become more understanding and supportive towards others.

The final question was intentionally broad, in order to capture any final thoughts or feelings that were not previously shared. The question posed the following:

Q11 Tree Node: "Is there anything else that comes to mind?"

Seven nodes were organized under this tree and reflected additional feelings, thoughts, or experiences by the participants. Some participants used this question as an opportunity to reiterate previous thoughts, feelings, or experiences. Responses included: (1) one participant felt that talking to others had helped (coded as "talking to others helped"), (2) one participant felt that there had been negative impact to her immediate family as a result of her child's death (coded as "negative impact on immediate family"), (3) one participant felt that her initial feelings of anger had eventually changed to forgiveness towards the individuals responsible for her child's death (coded as "moving from anger to forgiveness"), and (4) one participant felt gratitude to the United States for

the support made available to her family and immigrants, in general (coded as “gratitude to United States”). Three additional responses, not mentioned by participants earlier included: (1) three participants felt that dreams and premonitions that they had experienced prior to the death of their children were meant to either warn or prepare them (coded as “dreams and premonitions”), (2) one participant felt that her subsequent experience in being called to jury duty had triggered negative reactions and memories related to her son’s death (coded as “jury duty, painful reminder of child’s death”), and (3) one participant described her lingering sadness despite the supportive services that she had received (coded as “Continuing sadness despite support”). Frequencies for this coding tree are provided in Table 12.

Table 12. Tree Node for Question11

Is there anything else that comes to mind?		
Name/Category	# of Sources (focus groups) in which this response was given at least once	Total # of References
Continuing sadness despite support	1	1
Dreams and premonitions	1	3
Gratitude to United States	1	1
Jury duty, painful reminder of child’s death	1	1
Moving from anger to forgiveness	1	1
Negative impact on immediate family	1	1
Talking to others helped	1	1

In regard to this question, various responses were provided which reflected experiences, thoughts, and feelings that had already been mentioned in previous

questions. However, some responses reflected personal experiences, thoughts, and feelings that had not been previously mentioned. For example, some responses (3 references, 1 source) described mothers' experiences with dreams and premonitions, prior to the death of their children, which they felt were meant to warn or prepare them. One mother commented:

The last time, a day before the accident... I fell asleep with him, and we were sleeping and I was dreaming about him. We have a swimming pool, and I was dreaming that I found him drowned at the bottom of the pool. And that I took him out of the pool and that he was dead. I woke up so frightened. I have a Christ image and I jumped up to see Him and I remember saying to Him, "Oh God, thank you... thank you because it was a dream". And sometimes I would see him sleeping... and I would only feel like this with him... but I would hug him and say to him, "Oh my son, what would I do without you". Because I was feeling that... like I felt something... and then he would talk to me about death. One day we were in the bathroom, I was combing his hair and he said: "Mom, I'm going to die... are you going to cry?" And also, I had taken him to the park a few days earlier and we were playing on the swings, and he was saying to me, "Harder mommy, swing me higher, I'm going up into the sky... swing me higher, mommy, all the way up to the sky". All those things have stayed recorded in my heart, and in my life... and in my mind... I carry them day-to-day. I am washing the dishes and I remember his words... when he told me that he was going to die... because he sensed it. And I was also sensing it... because I was dreaming about it.

Another mother stated:

I dreamt the same thing. And at first I became very anxious...worried... very worried. I dreamt it before she got sick...that she was going to die. I don't know why, but she also had a dream. And I don't know why... but I also had a dream that she was going to die.

In addition, one response (1 reference, 1 source) described a mother's experience with jury duty, after the death of her son, which she said had triggered negative reactions and memories. One response (1 reference, 1 source) also described a mother's distress at her continuing sadness, which she described as "feeling down", despite the support she

felt she had received.

Last, some responses reiterated experiences, which included the view that talking to others had been helpful, a view that this experience had negatively impacted her immediate family, having experienced feelings of anger, which changed to forgiveness, and a sense of gratitude that was conveyed towards the United States for support received.

In sum, the responses described experiences, thoughts, and feelings not previously mentioned by participants, as well as others that had been previously mentioned. Some responses (not previously mentioned) described dreams and premonitions mothers had experienced, prior to the death of their children, which they viewed as warnings or signs meant to prepare them. Other responses included an experience with jury duty, which triggered painful memories, and a mother's sense of continuing sadness despite the support she received.

Some responses reiterated participants' experiences, which included the view that talking to others had been helpful, the view that the experience had negatively impacted their immediate family, an experience that feelings of anger had changed to forgiveness, and a sense of gratitude that was conveyed towards the United States for support received. See Table 12 for details.

Summary of Results

Five focus groups were used to gather data from twenty-two Mexican migrant mothers, in order answer the research question, "What is the lived parental bereavement experience of Mexican migrant mothers?" Data from the focus groups was coded using

the constant comparison method utilizing qualitative data analysis software NVivo 9.

Data was organized by the 11-item interview schedule.

Results and themes are summarized as follows, which reflect the data from the sixty-seven node categories:

The loss was viewed as unique, profound, and associated with intense pain; many aspects of the participants' lives were impacted including their feelings, beliefs, values, life priorities, sense of self, and their relationships with others; Loss was confronted with a variety of coping strategies and grief reactions; The grief experience involved a struggle or crisis in meaning; God and religion played an important role in meaning making and as a source of support; There was a need to maintain connection with the deceased child, and this occurred through various means including personal, secular, religious, and cultural rituals and other remembrance activities; The need to cry and to talk with others was viewed as most helpful in the bereavement experience; The phrases "Déjalo descansar, no le llores" and "Seguir adelante" were viewed as limiting the full expression of grief feelings; The desire to maintain close proximity and decisions regarding the disposition of the child's remains, as well as potential support from significant family members (who resided in Mexico), was impacted by the migration experience.

Themes generated from the node categories and the high frequency responses also serve to provide a broader representation and description of how the participants viewed their parental bereavement experience.

In sum, three broad themes emerged and reflect that 1) although the participants' personal grief experiences differed in various ways, the participants also shared some

similarities in their grief experience which involved a crisis in meaning and engaging in post-loss meaning reconstruction, the need to maintain a connection to their child, and their view that religious faith was an important source of support; 2) there were socio-cultural factors and imperatives that shaped and impacted the mothers' grief experiences; and 3) the mothers' migration and residency status impacted their grief experiences.

CHAPTER FIVE

ANALYSIS AND DISCUSSION

Introduction and Overview

The intent of this qualitative study was to examine the research question “what is the lived parental bereavement experience of Mexican migrant mothers”. The study sought to enhance knowledge and understanding of how Mexican migrant mothers experience and negotiate their grief reactions within personal, socio-cultural and religious contexts, which may involve prescribed beliefs, rituals, or customs in the bereavement experience. The role that imperatives such as “Déjalo descansar, no le llores” play in the bereavement experience of Mexican migrant mothers was also explored. This chapter presents the ways in which the study results, based on the literature review, answers the research questions and supports the assumptions of the study.

First, the study findings reflect that there were both similarities and differences in the mothers’ lived bereavement experiences. Differences in their experiences were influenced by various factors, including the nature of the child’s death, the time that had passed since the death, different personal backgrounds, as well as the protective and risk factors that were present in their lives. The mothers confronted the deaths of their children within different contexts (e.g. violent and sudden or progressive illness) and the findings reflected the varied feelings, coping reactions, and grief experience trajectories described by the participants. For example, and at the time of the interviews, some

mothers maintained a sense of resolve to reinvest in life and in relationships with others and they engaged in activities that they said helped them cope. However, some mothers also described intense and prolonged grief feelings, accompanied by a sense of meaninglessness and inability to engage in life activities or in relationships with others.

These findings confirm previous bereavement research (Wheeler, 2001) which also suggests that in the case of parental bereavement the ability to cope and adapt is often affected by many factors such as prior experiences with similar loss, the amount of time since the death, the cause or type of death (e.g. suicide or homicide), as well as personal beliefs or values associated with the death.

However, there were common feelings and coping reactions identified by the mothers, which were reflected in the study findings. Moreover, the findings also indicate that certain aspects of their bereavement experience were similar to the experiences of other bereaved parents. For example, the mothers' intense grief reactions, prolonged mourning, and their view of the loss as unique and devastating, has been noted rather extensively in the parental bereavement literature. The study findings also parallel those reported by many bereavement authors, in regard to common experiences in parental bereavement, including the experience of an existential crisis and search for understanding or meaning in regard to their child's death (Neimeyer, 2001, Wheeler, 2001, Braun and Berg, 1994); the role of religion or spirituality in serving as a significant source of support and meaning making (Wortmann and Park, 2009, Meert, Thurston, and Briller, 2005, Sormanti and August, 1997, Klass, 1995, Gilbert, 1992); and the parents' need to remember and

maintain a continuing connection with their deceased child, as a central theme in the parental bereavement experience (Klass, 1993, Silverman, 2002, Davis, 2004, Doran & Downing Hansen, 2006).

In addition, the findings reveal that many aspects of the participants' lives were significantly impacted including their feelings, beliefs, values and priorities, sense of self, and that their relationships with family and friends were also significantly impacted. These findings align with other parental experiences described by bereavement authors (Shapiro, 1995, Gilbert, 1996) who have examined parents' grief experience in a family and social context.

The findings also indicate that certain family and socio-cultural factors played a role in shaping the Mexican mothers' grief experience, in both positive and negative ways. Specifically, the findings indicate that traditional cultural and religious mourning rituals served to support the mothers in their bereavement experience. The mothers reported that familiar rituals and traditional activities served to comfort and support them and the mothers viewed these traditional customs and activities as ways to remember, honor, and feel connected to their children. However, the mothers also felt that there were some cultural imperatives, which served to stifle the full expression of their grief.

Specifically, the phrase "Seguir adelante" (keep going, move forward) emerged as a cultural imperative, which was both self-directed and imposed by others, which influenced the mothers' bereavement experience. The need or resolve to "keep going and move forward" reflected the mothers' strong commitment to their

children and husbands and their desire to put the needs of their families first, even if it meant setting aside their own personal needs.

“Déjalo descansar, no le llores”, as another socio-cultural and religious imperative, also had significant relevance for the Mexican migrant mothers, and this is a complicating factor that has not been given any attention in earlier bereavement research on Mexican families (Doran and Downing Hansen, 2006, Contro, Davies, Larson & Sourkes, 2010, and Kalish and Reynolds, 1975).

Another prominent theme that emerged from the study findings pertained to the mothers’ strong desire and need to be understood and heard in regard to their bereavement experience. Crying was viewed by a majority of participants, as a natural and inevitable expression of their love for their children and a way to express their profound pain and sense of loss. The mothers also felt that crying was very helpful and comforting in their grief experience. In addition, the opportunity to talk with others about their grief experience was also viewed as most helpful by the participants, in regard to their bereavement experience. However, some socio-cultural factors, including specific platitudes or imperatives previously noted, shaped and impacted the mothers’ personal grief experiences in ways that made it difficult for them to cry; talk with others, or to fully express their grief.

In addition, the findings reveal that the mothers’ migration experience had significant relevance and that it impacted their bereavement experience. Specifically, the mothers stated that as a result of separation from significant extended family members who resided in Mexico, their feelings of pain and loneliness were

exacerbated, making their bereavement experience more difficult.

Last, the mothers' migration experience was also a complicating factor in regard to decisions about the disposition of the children's remains and in having to decide in which country to place their child. This reportedly created an additional source of anxiety or distress for the mothers, and they said that this made their experience more painful and difficult. As another unique issue, it has not been extensively addressed in other previous bereavement research on Mexican families, although the issue of decision making and the desire to maintain close proximity after death has been noted in other studies (Doran & Downing Hansen, 2006, Contro, Davies, Larson, & Sourkes, 2010).

The following represents the themes that emerged from the study findings, including some sub-themes that were associated with particular themes.

Similarities in the Grief Experience

Although grief feelings and reactions varied among the participants, the findings reflect that there were some common feelings identified by the participants. For example, grief feelings associated with the death of their child were experienced intensely by all the participants. The participants described their loss as unique and previously unimaginable, and it was associated with profound pain. For many participants, the expectation was that they would live with the pain forever. The following excerpt from the interviews illustrates this feeling:

So as of now... it's such a great pain. So no one, in all of my life, will be able to fill that void. I haven't been able to overcome this. Right now, I don't think that I will ever be able to overcome this... as much as I want or regardless of what I do.

An “emptiness and void” was a term used by many of the participants in describing their feelings of grief. In fact, many bereaved parents use this metaphor to describe their grief experience, and in regard to the absence of their child. Rosenblatt (2000) found that

Parent narratives often connect feelings to the child’s absence. With child missing from the environment, a metaphor that encompasses both that absence and parent feelings is the metaphor of something missing. The emptiness is in the physical, social, and emotional environment, both present and future. Also, the emptiness is in the self. Many parents talked about feeling empty or about having a hole in themselves. (P.77)

The range of feelings described by participants included profound sadness, confusion, and loneliness, a sense of isolation, anger, shock, anxiety, desperation, and depression. A few mothers also talked about their intermittent suicidal thoughts and felt that they were solely “surviving” at times. One participant described her personal experience:

It is hard to carry this pain. So, what I’m saying is that it’s been three years, and I’ve still not... or rather, I feel that I’ve tried to get ahead or move forward, but no... my life is still the same. And these three days that I spent crying, I was wallowing and asking myself, why did she die? Why did she get sick like that?

These intensified grief reactions described by the participants, are consistent with the findings reported in many bereavement studies (Sanders, 1980, Romanoff & Terenzio, 1998, Rosenblatt, 2000) which have found that bereaved parents experience more intense grief reactions in comparison to other bereaved individuals and that their feelings of grief tend to be prolonged with high levels of distress. The following comment by a participant reflects this experience:

Well, the truth is that the loss of one’s child is the worst thing that can ever happen to you. As a mother, to lose a son in the manner that I lost my son... is an

unbearable pain. It's a... it's something so bad... that won't go away... you can't erase it... the years can pass... I think that as more years pass the more we remember our child... the more we feel it... the loss becomes greater.

The participants also reported that their views of life and the world had been significantly altered and the mothers described a keen awareness of how their lives had changed in the aftermath of their children's deaths. For example:

Yes, my life has changed a lot since the death of my baby. Before that, I remember being happy. I lived a good life with my children. And now I am experiencing what pain really is. Yes, my life has changed a lot. I have tried to survive this, as calmly as possible. But it is not that easy. It is something very difficult. I have seen a lot of changes in myself and in my children too, who suffered and lived through the death of their little sister. It's difficult.

Many mothers also commented that they now viewed life as fragile and unpredictable. Some mothers said they no longer feared death, and that they were more prepared for it. Some mothers felt that their own death represented an opportunity to be reunited with their child someday. These are common reactions and responses that have been observed in other bereaved parents. These reactions represent the existential crisis that many bereaved parents confront as they realize that events that were previously considered "unthinkable", such as the death of their children, are in fact possible (Talbot, 2002).

Meaning Making in the Grief Experience

The search for meaning was a key theme that emerged in the study findings, and was reported by many of the participants. The following excerpt provides an example of one mother's experience:

Yes, you do change... totally. You begin to see life in a different way... and you begin to ask "Why me?" And you try to understand why it happened to you and not someone else. Always asking, "Why...why did this happen to me?" And I do

believe that we become more sensitive to the pain of others and we do try to be more understanding of others, more than anything.

Wheeler (2001) suggests that acceptance of the death of a child involves finding a way to make meaning of it. The findings also reflect that participants engaged in processes and efforts to understand and find some meaning to their experiences. For some, meaning making was associated with religious beliefs, and some mothers commented that they attributed the death of their child to a divine plan by God. One participant commented:

There is something very interesting... and that is that I have never blamed God. I have never asked why... knowing that he was my only son... but absolutely nothing. I believe in God, I love God very much... because I know how much he loves me. And He didn't give me my son... He lent me a son. He made me a mother so I could help unfold what He wanted me to do. God also gave him his mission... and he also accomplished it. I offered him back into His arms at the moment they had given him to me. It's incredible... As of now I still cannot believe it.

Some mothers felt that there was redeeming value or positive outcomes that had resulted from their child's death, including "getting closer to God", becoming more spiritual, becoming a better or more caring person, becoming a more unified family, and feeling that their subsequent children were "gifts from God" sent to help them with their grief. Meaning making was also associated with acts of altruism and engagement in activities that the parents believed honored their children and also benefited other individuals and society. One mother shared her experience:

Yes, I think it has changed me. This experience, of grieving our children's death, is very powerful and it changes us. I think it has made me more spiritual...and maybe even a little more understanding with those who also go through this. So I've decided to begin studying, and I'm currently studying to be a teacher. When my daughter died she was 16 years old, and she also died in a car accident. Some gang members hit her car and she died in that accident. I think that parents

sometimes neglect their children... and that the kids are vulnerable at the time they join gangs. They don't care about hurting others. And I believe that this all starts in childhood. So I think if we can do a little more to help young children, when they are older... with better upbringing... they might be less likely to hurt others... or our children. I think this has made me more spiritual.

However, the findings also reveal that for some mothers, there was an ongoing inability or struggle to make sense of their loss and the mothers reported that as a result they were left with lingering feelings of anger, despair, and other similar feelings.

These findings are consistent with previous bereavement studies (Braun and Berg, 1994; Rosenblatt, 2000, Wheeler, 2001, Talbot, 2002), which emphasize that while there are various trajectories, meaning making is nonetheless a central theme in the parental bereavement experience. Neimeyer (2001) also discusses post-loss meaning making and meaning reconstruction and he identifies some primary processes involved, which include sense making, benefit finding, and identity reconstruction, which may result in either a regressive or progressive post-loss identity. To illustrate, the following excerpt describes one mother's experience:

It affected me regarding my family; because now I am not the same person...I'm not. I wasn't like this before. I became angry with my family. I became curt; abrupt... they tell me that they can't say anything to me because I snap back at them. And I know that it shouldn't be like that but I can't control myself. I wasn't like that before. But it's an anger that I have inside and sometimes I say that I'll change... but then when I'm alone or they say something to me, I can't stop myself from saying something. But it's because of my son's death, because I wasn't like that before.

Finally, the findings reflect that not only did the mothers experience an existential crisis in meaning after the loss of their children, but their responses also indicate that they had or were engaging in various processes of post loss meaning reconstruction. That is, some were still at the point of trying to make sense of their loss; some were trying to

construct a greater good or benefit to be realized-some already had. Some were attempting to reconstruct a post loss sense of identity and view of life and of the world-some already had. It also appears that post loss reconstructions varied and that they were both progressive and regressive in nature. A fewer number of the responses (related to positive personal impact and changes, as well as post loss positive views of life and the world) reflected the experiences of mothers that had likely constructed or acquired post loss identities and meaning, that were progressive in nature.

The Role of Religion in the Bereavement Experience

The findings reflect that most of the participants were affiliated with Catholic religion, and that there was a strong sense of religiosity reported by the mothers. Mothers stated that the support they received from their faith and from God was helpful and significant in their grief experience. The study findings parallel previous research (Munet-Vilaro, 1998, Younoszai, 1993, Silva, 2003, Marino, 1997, and McGoldrick et al., 2004), which has found that Mexican families view religion as a protective factor. Clements (2003) also suggested that the importance of religion and spirituality to Mexicans is central to understanding the role that culture plays in mediating the grief experience for this group. He also emphasizes that Catholicism, the dominant mainstream religion for Mexicans, provides a means by which death and the afterlife is understood. One mother shared her personal experience and belief:

So when I used to drive by that spot, we Catholics say: "God, give him eternal rest". I remember looking at my husband, when we were driving passed there together, and he would be crying. The tears would be there, but he never said anything. And once I asked him, "What are you feeling?"... "Why don't you say anything?" And he said to me: "This is the place where the sky opened up to let our son pass through into Heaven". Oh, my... when he said that to me... well, I

can only tell you how important a phrase or a certain word can be... and after I heard that... it was such a marvelous thing. I never asked him anymore... and I never checked after that to see what he did. But I felt that sense of happiness from him and what he had said... and I just agreed with him. He had said: "Here is where the sky opened up to let Ricky go through". It was beautiful... very beautiful coming from him.

Other excerpts illustrate the role that religion played in a majority of the mothers' bereavement experience:

Because since before, as I've mentioned, I'm Catholic, all I usually did was to go to Sunday mass. But a few months before, I had started to get a lot closer to the church and to God. And so, yes... I think that God was preparing me. To have not been able to feel His presence, His strength... I would not have been able to hang on, or to bear this pain. Without God's presence, or this faith that I have in my heart and that has changed my life... It has shown me that... yes... it is the path we are going to follow.

For me, the most fundamental thing has been the faith that I have... and to talk with God

Moreover, the findings reflect that religious belief in God and in an afterlife provided comfort and the opportunity for meaning making as the mothers were able to envision their children in a safe and happy place. It also provided a way to maintain a spiritual connection to their children and allowed them to embrace the belief that they would someday be reunited with their children:

Because that emptiness and that absence of your child... and in my case, my son.... for me... from day-to-day, I try to fill that with faith, and with hope... hoping that someday soon I will see him again. That someday soon I will be with him again. That's how you live.

Some mothers reported that they envisioned their children as guardian angels in Heaven and maintained hope of being reunited with them some day; others felt that they received dreams from God about their children, which provided comfort and reassurance that their children were happy and well. A few mothers also felt that their subsequent

children were “gifts from God” sent to comfort them in their grief experience.

However, a few mothers described their temporary struggle in regard to their faith, immediately after the death of their child. One mother commented:

Well, I did renounce Him...and said a lot of things to Him. Then I regretted it. But I did ask, “Why me?” and when feelings were emerging in me... I don’t know how to explain it. But sometimes I would look at people... or I would be at a mall and see a mother with her children... they were all happy... and I would feel angry. I don’t know if I was crazy... because now I can see it differently, and I have asked for God’s forgiveness. But yes, I was mad at God and said a lot of things.

In addition, a few mothers also reported there was a loss of faith and they reported anger or blame towards God and talked about their ongoing struggle to maintain their belief or trust in God.

In spite of the different reactions and feelings described, the findings indicate that for most participants, religion and faith played an important role in the mothers’ bereavement experience. Talbot (2002) has suggested that

the unfair and atypical reality that confronts bereaved parents forces them to sort through their personal spiritual beliefs in an attempt to make sense of why bad things happen in our world. To survive, parents must reconcile their loss with their worldview and their belief in God or a power greater than themselves. Parents must be able to place their child somewhere beyond the grave (p.7).

The findings also confirm previous bereavement research (Meert, Thurston, and Briller, 2005, Sormanti and August, 1997, Klass, 1995, Gilbert, 1992), which suggests that religion and spirituality play an important and role in regard to meaning making and in maintaining continuing bonds with the deceased child. The findings also parallel other bereavement research (Wortmann and Park, 2009), which has found that some bereaved parents experience shifts in their fundamental religious beliefs, in the aftermath of a

child's death.

Maintaining a Connection with the Deceased Child

Maintaining a connection with their deceased child, through various means, was important to the participants and it emerged as another important theme in the study findings. These findings have also been noted extensively in other previous bereavement research (Silverman, 2002, Klass, 1993, Davis 2004, Doran & Downing Hansen, 2006, Rosenblatt, 2000, Talbot, 2002), which propose that the need to maintain a continuing bond with the deceased child is a significant aspect in the parental bereavement experience. Furthermore, it serves to support bereaved parents in their coping and meaning making. The need to “remember”, “hold on to”, and “to keep them in my heart forever” were some of the descriptions provided by the participants as it related to their desire to maintain a connection to their children. Other comments made by participants included “I will never let him go” or “I will never forget”.

As one participant explained:

Because it is such a great pain... so great... and you have to understand that you don't want to be separated from that person...as much as you'd like... you cannot separate yourself from them.

Davis (2004) stipulates that a continuing bonds perspective places an emphasis on maintaining an ongoing connection with the deceased child, despite societal expectations that the parents should get on with their lives, and that it is important for parents to talk about their children and the ways in which their children continue to be important and present in their lives. Therefore, special rituals associated with their child, as well as their belongings and personal mementos often serve to comfort the parents and they help the

parents maintain a sense of connection.

One mother talked about her continuing bond with her son despite advice she received from others to “let him rest”:

For me, that phrase doesn't even exist... when they tell me, “Let him rest”, I say to them: Yes, he is resting... I know that he is fine... he is a little angel that is caring for us... he is our guardian angel... he is fine because he is with God... he is a lot better off than all the rest of us who are here”... simply because I cry for him or that I remember him, because he is with me. He lives in me. He is not with me physically... but he will always live in me. He will also live in me, and will be alive in me, like my other children. The difference is that he is not here physically like my other children... he lives with me... he is like a little angel for me.

The findings indicate that these participants also maintained a connection with their deceased children through various remembrance activities including talking to their deceased child, engaging in activities that honored their children, maintaining and looking at mementos and photos of their children, visiting places associated with their children, commemorating their child's birthday or anniversary of death, attending memorial services and ceremonies, praying to their children, maintaining altars, keeping their child's ashes in their homes, and visiting their children at the cemetery:

I go to his grave and clean it, and I always make sure it looks nice. I know that my son is with me, and I say to him playfully “I'm here to clean your room.” So I am able to keep it clean and nice, and that helps me feel calm. When I don't go to clean it... or it is no longer summer and they don't have the flowers there... it makes me feel restless.

In addition, some mothers also reported sensing their child's presence and having dreaming about their children. One mother described her experience:

If I am feeling very sad or depressed, I look at a picture of him. And for me, it's like talking with him. I have dreams about him. When I am sad, I don't know... sometimes things happen to you... and we think that those things don't exist... but sometimes they are like signs.

The activities and experiences described by the participants are consistent with previous bereavement research (Foster et al., 2009, Doran and Downing Hansen, 2006, Klass, 1993, Rosenblatt 2000), which identified similar continuing bond activities and experiences in the parental bereavement experience.

In particular, participants commented about the home altars for their children, which prominently displayed meaningful photos of the child, personal mementos, and religious figurines and similar items. The mothers stated that their home altars were comforting and meaningful in their bereavement experience, and that they helped the mothers to feel that their children were still a presence in their homes. Shapiro (1995) also emphasizes that one of the tasks for a grieving family, and particularly the mothers in this case, is to be able to redefine their relationship with their deceased child. For the participants, these various activities represented a way to symbolically keep their children “alive”. The following excerpt poignantly illustrates this theme:

I still have an altar for her. It has a big picture of her. Before I used to have her pictures put aside. Only my daughters had her pictures. My daughters have her photos, decorating their rooms. But I don't. I made an altar for her. I also have candles on it. I became accustomed to putting Roses on it too. Because for me, she was like a flower... a flower I had hoped would grow... but she wasn't able to keep growing. So then I put flowers on it and when they wilt, I go and buy more... and then I buy some more... and so I have this altar for her. And it makes me feel good. And I'm not interested in what people say... I feel good with this. My daughters come and go, and they say, “Aw, how are you, baby?” because they always used to called her “baby”. They say, “How are you baby?” They come home and the first thing they do is to go see their sister. But, it's like you feel good and comfortable doing this... and so you should continue with whatever tradition you want... and let people say... whatever they want.

The Grief Experience in a Family and Socio-Cultural Context

As previously mentioned, the findings indicate that familial and socio-cultural

factors played a role in shaping the Mexican mothers' grief experience, in both positive and negative ways, including some unique themes that emerged in regard to socio-cultural imperatives which impacted the mothers' bereavement experience.

Impact on Family and Social Relationships

The participants felt that their personal, family, and social lives had been significantly impacted and changed radically. They reported that they had changed as individuals, wives, mothers, and in how they related to others, including extended family and friends. For many, specific changes included the need for some of the mothers to assume new responsibilities and roles within their families; to adapt their parenting role and level of responsiveness in order to meet the needs of their other children; experiencing negative impact on their marriages; and experiencing negative impact on their family and social relationships.

Some participants reported that their relationships with family and friends had been positively impacted, and changes included becoming a more unified family, becoming more loving and stable as a couple, and a willingness or desire to express love and positive feelings for one another more readily within their immediate families.

However, many participants described the sense of loneliness and isolation, which was caused by the different ways in which individual family members were experiencing and expressing their grief. These findings reflect what bereavement authors (Shapiro, 1995, Gilbert, 1996) have previously referred to as the destabilization that often occurs within families after a death.

Gilbert (1996) asserts that family provides a social context in which an

individualized grief response is experienced and that while families can support one another through the grief process, they can also add to family members' stress if they experience grief differently. The following excerpt illustrates one mother's personal experience:

I remember... my family completely fell apart. Sometimes I just wanted to be with them... at our house, together. But they were all in other rooms. If I tried to be with them, they would move to other rooms. Later they told me that they did that, because they didn't want to show their pain... because it would make me feel worse. But what I needed was to know that if we needed to cry, that we could cry together. But we isolated ourselves to hide the pain. I would go to another room, away from my husband. I remember going to the bathroom and grabbing a towel, biting it, and then yelling and shouting so no one could hear me. My husband too... he was... isolated. Totally. My entire family was like that... all of us, everyone.

Participants also felt that their relationships with others were significantly impacted and in various ways. In addition to the difficulties that mothers described in regard to their immediate families, they also reported that they felt a lack of understanding and support from extended family members who were in close proximity, and that this made their experience more difficult.

The following is an excerpt of one mother's experience:

In my case it has affected a lot. Because, really, you realize who is truly there for you... as they say... in both the good times and bad... and who really cares about you and who doesn't. People always talk about "family"... but sometimes it is your family that can say things or do things, that hurts you the most. Instead of offering comfort, they affect you more (make it worse). Sometimes I think to myself that it would be better if they didn't say anything at all, than to say something that hurts you.

Another mother commented:

It does get affected, our relationships, especially when some of their words or comments are hurtful. Maybe they do it with good intentions to comfort us. But it does make you feel worse. And there are certain comments they say, and

especially as a mother they tend to blame you, such as “You didn’t take enough care of yourself, you didn’t do this or that...” and they make us feel even guiltier for what has happened. And that makes you distance yourself. So you start distancing yourself little by little.

Concerns associated with parenting their other children also emerged as an issue for many of the participants. The mothers stated that the negative impact on their other children, including emotional, behavioral, or academic problems, had resulted in additional challenges or difficulties for them. These findings confirm previous bereavement research, which found that some siblings also experience difficulties in fully expressing their grief (Rosen, 1985). Many of the mothers reported that they had attempted to seek support (e.g. community or school-based counseling) for their children, but that in several cases their children were unwilling to participate in services and refused supportive interventions. As a result, the mothers commented that these experiences with their other children made their situation more difficult and painful.

The issue of protective parenting also emerged as a theme throughout the interviews, and many of the mothers stated that the death of their children had caused them to become very fearful and overprotective in their parenting. One mother commented:

It affected me... I am more overprotective with my children, for any reason. I am scared that something will happen to them. I’m afraid that I will go through the same thing. I can’t... I am always... I’m always watching what they are doing... where they are. With the oldest, it’s like, “Don’t go over there... be careful... watch out for yourself... be very careful.” Sometimes I don’t want to let him go out. It’s mainly the fear that we are left with ... because we don’t want to go through this again. Now I am terribly afraid that this will happen again. I don’t know... I am so fearful... and I wasn’t like this before.

Rosenblatt (2000) states that after the death of a child, parents become very aware

of the fragility of life and the vulnerability to death. As a result they are often left feeling extremely overprotective with their other children. The findings also reflect that protective parenting also took on other forms such as attempting to hide their feelings in the presence of their children and putting aside their personal needs aside when required (e.g. continuing to engage in holiday celebrations although the experiences caused them sadness or pain). These findings are also noted in the bereavement literature related to common reactions in bereaved parents (Rosenblatt, 2000).

Traditional Socio-cultural and Religious Rituals

In addition to the remembrance activities previously mentioned, the findings also reflect that the mothers utilized traditional socio-cultural and religious rituals and activities as positive sources of support in their grief experience. These findings parallel previous bereavement research (Rando, 1984, Klass, 1993, Romanoff & Terenzio, 1998, Rosenblatt, 2000, Silva, 2003, Doran and Downing Hansen, 2006, and Contro, Davies, Larson & Sourkes, 2010, Anin-Boateng, 2009), which confirms the therapeutic role of traditional religious and cultural grief rituals, as important tools in dealing with loss.

The participants described religious rituals and activities, which they felt provided comfort and support, and served to commemorate their children. These included attending regular mass and coordinating special masses on their children's special anniversaries, holding Novenas (9-day Rosaries) and conducting monthly Rosaries in their homes or at the cemetery, engaging in regular prayer to God and their saints (e.g. La Virgin de Guadalupe), and religious support and conversations with their priests. A few mothers also identified special prayers that provided comfort in their bereavement

experience, such as “La Magnifica”. The following is an excerpt describes one mother’s experience with a traditional religious activity:

During the last five years, ever since my daughter’s death, we also do a mass for her every month. And on the 12th day of each month, which is the day that she died, we also do a Rosary in my house... with my daughters, my husband, my mother and brothers, anyone who wants to attend. Every month we do that. We never forget a month.

Another mother shared the joy she experienced when she visited Mexico annually to engage in a traditional religious ritual, for her son who was buried there:

Yes, yes, since the beginning. Over there, we took music and I really liked it over there. I have been to a lot of burials here... but not over there... over there I really like the Novena, the Rosary of 9 days... and on the last day is the lifting of the cross. We did a mass and they blessed the cross... and we took it to the cemetery to put the wooden cross up. He had his godfather... who was a young man at that time... it was a young man he loved a lot. He helped him a lot. It was very beautiful... because he came and said to me, “I am going to give the cross.” And so there are a lot of beautiful things they do. The mass... after the mass they do a celebration... it is a party because they are celebrating in Heaven... so those of us who are here must be happy. Then I hosted a get-together for all the people who were there, and had music... At home, we did the get-together... for all the people who accompany us at the mass, and that help us. Over there, I have friends that help me... they cook the food... they do everything. And in my mother’s home, which is small, is where we get together... every year.

Some participants also commented that they found comfort in maintaining some of their own socio-cultural customs while living in the United States, such as keeping altars in their homes, and celebrating the Day of the Dead, which has also been cited in earlier research (Brandes, 1997) as an important and symbolic way to honoring the dead in the Mexican culture. One mother shared her view:

Yes, these are very significant dates. And more importantly, now we understand and appreciate them more, when you’ve gone through this kind of pain. I used to view this just traditional, like with Mother’s Day, Day of the child... but I think these are nice dates in which to remember your loved ones... and I don’t know... to be able to remember them. And to also maintain those traditions that we bring

from our culture... I think that is very nice.

Outward Expressions of Grief

Socio-cultural expectations on the part of extended family and friends in regard to the participants' outward expressions of grief, such as crying, talking, and reminiscing about the child, often varied based on each mothers' unique family and social environment. At times, there were some overt socio-cultural imperatives placed on the mothers by others, which influenced their personal understanding in regard to what was acceptable or "normal" in terms of their outward expressions of grief. For example, mothers stated that their family members and friends expected that their demonstrations of grief should subside with the passing of time. One mother commented:

Maybe it's because they haven't experienced something like this or maybe it's because they say that it's been four since I lost my baby. They say, "Let him go, it's been four years... don't cry for him, he's gone, let him go."

There were expectations from family members and friends that the mothers should also limit or stifle their crying when they were around their own children or the children of others. Last, there was the expectation that mothers should refrain from crying or reminiscing about their deceased children at family holidays or social events, which was viewed as socially inappropriate, due to the discomfort it triggered in others.

"Seguir Adelante" as a Socio-cultural Imperative

It is important to acknowledge that the phrase "seguir adelante" ("keep going, move forward" can be viewed as a common term, heard in many other cultures or societies, and that it is often used to emphasize the need for perseverance and fortitude when confronting challenging situations or setbacks in life. In this context, the phrase

would not be considered unique to the Mexican culture. In the context of parental bereavement, this phrase also has unique implications in regard to the grief process.

Rosenblatt (2000) suggests that,

many parents used the metaphor of a journey in their narrative about their grief process. A journey gives a sense of going forward, going through something to someplace else, or going from one place to another. The metaphor of the journey highlights that there is a process of the parent moving from a starting place (for example, devastation, total numbness, or the most intense grieving imaginable) to someplace else. For some parents, the journey metaphor highlights what might be called destinations in the grief process- for example, normality. For other parents, the journey metaphor highlights that grieving is a part of all of life, that whether a person wants to or not, a person must experience loss on the journey of life. (p.111)

As such, this phrase “Seguir adelante” (keep going, move forward) did emerge as a theme for the bereaved mothers. However, the findings suggest that the use of this phrase also had a strong association with the socio-cultural aspects of the mothers’ lives and as such, it influenced their bereavement experiences. For some mothers this view or resolve represented their desire to reinvest in life and in other relationships for the sake and well-being of their children and families. In contrast, some mothers reported that it was the result of the external pressure they felt from their family members and friends who offered advice and expectations that the mothers should “move on” and “move forward”. In addition, some mothers stated that their need or resolve to “Seguir adelante” was motivated by their own concerns that they were harming their children as a result of their prolonged grieving.

As described by the mothers, this phrase also represented an imperative, sometimes self-directed and at other times offered by their family members and friends, which involved the need to move away from their own personal grief, for the sake and

well being of their children and families. The use of this phrase, and its self-sacrificing underpinnings, seems to align with the value of “familismo” which is a cultural value and that the family’s needs should outweigh the individual’s needs (Flores & Carey, 2000).

It also appears to reflect the traditional value of “marianismo” that many Mexican mothers still maintain, and which has been noted often in culturally focused research literature (Silva, 2003, Zack Ishikawa, Cardemil, & Falmagne, 2010). This specific value highlights the importance of the Mexican mother’s role within the family, and emphasizes the mother’s responsibilities in regard to nurturing and caring for her children and husband, and in ensuring their happiness and well-being.

The following excerpts reflect this belief or view:

But you have to keep going and move forward... for your children... because you have to take care of them.

But I have to be strong and keep going because I have other daughters to fight for... and just keep going and move forward.

However, for some of the participants, this resulted in emotional conflict, as they attempted to keep going or move forward but stated that in doing so, they also felt that they were “letting go” or “moving away from” their deceased child.

“Déjalo descansar, no le llores” as a Socio-cultural, Religious Imperative

The findings indicate that the phrase “Déjalo Descansar, no le llores”, as a socio-cultural and religious imperative, also had relevance in the mothers’ bereavement experience. Participants stated that this phrase was common in the Mexican culture, and some mothers mentioned that they had heard the phrase used often by parents, grandparents, and others around them. Mothers also agreed that the phrase had religious underpinnings, and that it had become a common, culturally driven form of condolence.

Nonetheless, findings also indicate that the use of this phrase caused negative reactions and feelings in all the participants:

And if people say to us, “don’t cry for them, because you are not letting them rest or leave... they can’t rest because you are crying”... well...I have to cry for him, because I have to release the pain that I’m feeling for him. It’s a way to show him that I love him... that his loss hurts me... and no, I will never get over this. But I know that...for me... I know that it doesn’t bother him that I am crying for him. On the contrary... crying for my son, is like kissing my son... It’s as though I were kissing him... it’s like that for me.

Participants also felt that the use of this phrase made their grief experience worse, by causing feelings of anger, pain, shock, and resentment, when heard.

Several mothers also described this phrase as “cruel”, “ignorant” and “rude”. One mother shared her personal view of the phrase:

I think this is a cruel phrase... very cruel. It’s ignorance on the part of others. But I think it is cultural. In Mexico, this is the custom. This is the phrase that people usually say. But for those of us who are going through, we hear this phrase and we react to it. It brings out those feelings of anger, and rage... because “How is it possible that they would try to tell you that this is the only way they will get to this beautiful place, Heaven, and be able to rest?” or that by loving them, whether they are your father, or brother, or your mother.... I never imagined that one of my children would leave me... and so I hear that phrase “let him rest” and I think, “Don’t you think I want that?”.... “Don’t you think I want my son to be at rest?” It is very cruel. And I think that this serves to really educate us... to help us be more conscientious...to be more careful of what we say at times. As Alicia said... if they want to make you feel better and to let you know they are there with you, they should just say “Here I am, and here’s a hug”. Or they should tell you “Cry, go ahead and cry... if you need to cry... cry”. By crying, we are not taking away or hindering our children’s...or any loved one’s... glory into Heaven.

Based on many comments made by the mothers, such as the one above, this phrase may also serve to reflect the traditional Catholic beliefs maintained by many Mexicans families, and their understanding of death and the afterlife, as noted in previous research (Clements, 2003, Vasquez, 1993). Specifically, Catholics do not view death as

final, but rather the belief is that the deceased pass from one state to another, and that death can also bring a passage to Heaven under appropriate circumstances, such as the forgiveness of sins (Vasquez, 1993). As noted earlier, Clements (2003) suggested that the importance of religion and spirituality to Mexicans is central to understanding the role that culture plays in mediating the grief experience for this group.

As a result, the use of this phrase, when viewed in a religious context, could be very distressing for bereaved mothers, and create significant internal conflict, if or when they are made to feel or believe that their crying or yearning, will somehow impede their child's glory or passage into Heaven.

In addition, many participants felt that the use of this phrase served to limit the full or externalized expression of their grief and that it was an imperative to forget or distance themselves from their children:

...And what I heard from her, was "well, don't cry anymore, let her go... she is now resting". But at that moment, it shocked me. I said, "I know that you never went through this... you never went through it... you didn't lose a child, mama... we are all alive... but the reality is that this pain is really hard." She told me "you have four other children". I said "but it is not the same, it's not the same because I loved her... and I wanted her here with me". Well, I was still crying on the phone and telling her that I wasn't doing well.... I was telling her "the truth is I'm not well, I am feeling very desperate".... "It's been three years that my daughter died and the grief I am feeling is painful"... "I don't know, I feel the grief is still very difficult". And she asked me "what is this grief?" I said, "You don't understand this, mama, why am I trying to explain? Just let me cry". But she yelled at me, and said, "Don't cry anymore.... I don't want you crying anymore... let her rest... your daughter is fine". And at that moment, I felt a lot of anger, because she said that to me.

As a result, the use of the phrase was also viewed by the mothers as being incongruent with their need to maintain an emotional and spiritual connection with their children, and in regard to their need to express the pain and love they felt for their

children. It is interesting to note that the use of this phrase seems to subtly mimic Freud's early detachment focused grief theory, which emphasized breaking bonds with the deceased in order to allow for new relationships and also discouraged prolonged mourning. As such, this same phrase with its underpinnings, would be considered incongruous in many ways, to the aforementioned bereavement research that has emerged in recent years, which embraces very different theoretical perspectives, including central themes in the parental bereavement experience which would validate the mothers' need to cry and their struggles to let their children "rest" if and when it represented the severing of love and connection to their child.

How the mothers negotiated their personal grief within the context of this cultural and religious imperative, varied. For some, the phrase represented a prescription to distance themselves from their children and to forget them. Other mothers felt that this phrase represented an unreasonable or insensitive imperative since they viewed crying as something innate and inevitable, to express the severity of their pain and the significance of their loss. For others, the phrase represented a rigid or misdirected view of God, heaven, and the afterlife and the mothers stated that in grieving for their children they did not feel or believe that they were compromising their child's "glory" or soul.

Nonetheless, upon hearing this phrase most participants reported that they felt inhibited or stifled in regard to expressing their outwardly grief. Mothers also reported that the use of this phrase "Déjalo descansar, no le llores" exacerbated their sense of isolation, because it often had the effect of silencing them. Some of the ways in which the mothers negotiated their personal grief within the context of this cultural imperative

included making efforts to control or contain their outwardly expressions of grief while in the presence of others; withdrawing from those family members and friends who responded to the mothers' crying by using this phrase; and by grieving privately in order to avoid hearing this phrase from those around them.

A few mothers, however, reported that they were able to overtly reject this phrase and that they were able to grieve in ways that were personally helpful and meaningful to them. For these mothers, the need to express personal feelings in their own way, did take precedence over the cultural imperatives they were confronted with. However, these mothers also talked about their feelings of anger and resentment in regard to the continuing use of this phrase by others around them.

It is also likely that for some of the mothers, their outside experiences and relationships via participation in support groups, counseling, and conversations with others outside of their immediate circle of family and friends, may have served to help them internalize or strengthen their beliefs about the importance of normalcy of crying and talking about their children and their feelings.

In addition, some participants stated that there were other religious or cultural phrases, which were used as condolences that were not helpful in their grief experience. Some of these included "your child is an angel in Heaven now" and "these are tests from God".

These findings reflect that certain socio-cultural or religious imperatives were found to be unhelpful in the mothers' bereavement experience and that for most participants the particular phrase "Déjalo Descansar, no le llores" served to inhibit or

stifle the outwardly expression of their grief. Moreover, the findings highlight how certain cultural mourning prescriptions can pose a challenge to the bereaved mothers' need to grieve in a way that is personally meaningful and helpful.

Crying, Talking to Others, and Finding Support

Another significant theme to emerge from the study findings, had to do with the participants' view that crying, remembering and talking about their child was a helpful source of support in their bereavement experience:

I also think that it's something inevitable. Because it's the one thing we have...the comfort of crying for those we have lost. How can I explain it...? There is nothing more inevitable... no other more natural feeling, than to cry... to express our pain through our tears. Yes, you do feel better. I remember I would be crying and then I would fall asleep. You fall asleep that way, and I think it calms you a lot... to cry.

The mothers stated that opportunities to talk about their grief and about their children offered a great deal of comfort and they reported that it lessened their sense of isolation and that it was most helpful in their bereavement experience. These findings are consistent with previous bereavement research, which highlights the benefits of talking and sharing with others (Castle & Phillips, 2003).

In regard to their need to cry and to talk with others, the participants reported that they had expected to be able to talk and share with their immediate and extended family members and friends. Although the findings indicate that some mothers were able to do this, the findings also reflect that this was not the case for most participants. Most participants stated that many of their family members and friends were not sensitive or supportive to their needs and that they distanced themselves. As a result, many mothers described feelings of anger, sadness, and disappointment associated with these

experiences. Participants also commented that they could not always or fully express their grief, due to negative reactions by family members and friends.

Many mothers commented that in not being able to talk with family members or friends about their grief experiences, they slowly began to withdraw from some of those relationships and often grieved in isolation. An important factor to consider is whether any of the mothers may have felt that their needs were unreasonable or unjustified, causing them to refrain from reaching out beyond their family systems, as suggested in previous research (Zack Tshikawa, Cardemil, & Falmagne, 2010).

Another factor to consider has to do with possible barriers they may have existed in regard to their lack of familiarity, comfort, or ability to access formal counseling or community-based support services, as was the case with one participant, and which has been noted by the U.S. Department of Health and Human Services (2001). Spanish language needs might also have posed an additional barrier.

At times there are also assumptions in regard to the Mexican culture that Mexican families may usually prefer to deal with their personal and family issues privately or via “their priest” as the only other viable option. These assumptions are likely associated with the Mexican concept of “familismo” (Flores and Carey, 2000), which emphasizes a strong sense of support and cooperation among extended family members and their close social relations. However, it is difficult to know the extent in which the behaviors associated with “familismo” were demonstrated by family members and close friends, in regard to the mothers’ experiences. One can only speculate whether the mothers experienced an outpouring of support and assistance immediately after the death of their

child as would be expected, and a few mothers commented that this was their experience. However, it is difficult to distinguish between the support that the mothers may have received immediately after the death of their children and very early in their experience, in comparison to the experiences they described during the interviews, which also represented a wide range of timeframes, since their child's deaths. So it is difficult to fully assess the role that "familismo" may have played in the mothers' experiences. However, the findings reflect the mothers' views and feelings at the time of the interviews, including their interpretations of their past and current experiences. However, the findings do parallel other bereavement research (Rosenblatt 2000, Talbot, 2002), which suggests that bereaved parents often experience a sense of isolation and disconnection from others and that their feelings of grief become a very private and personal experience. Some bereavement authors refer to this experience as something that resembles "a chasm between the bereaved parent and the rest of the world" (Rosenblatt, 2000).

These study findings seem to support the "chasm" that most participants felt had emerged between them and the people around them.

However, the findings also indicate that in spite of encountering difficulties or inability to utilize family and friends as informal social supports, some mothers stated that they found alternative ways to connect with others. Those that sought out alternative help and support stated that they participated in bereavement support groups, individual and family counseling, used psychological or psychiatric services, obtained religious support (e.g. talking with priests, going on spiritual retreats), and used psycho-

educational literature and media. The following is an excerpt to illustrate one mother's experience:

When you try to talk with your family about this topic, they want to cut you off. For example, even when I tell them that it is alright and that we want to talk about what we've gone through...and that it helps us... I want to say that what helped me a lot... is that now I can talk more... I can talk... because it used to be very hard for me. So now I feel that I can talk, and express myself a little bit more... express my feelings.

The findings also reflect that the mothers viewed support groups as particularly helpful in offering an opportunity to share their grief experience in an environment that supported open expression of feelings and thoughts. One participant described her experience:

The group, it has been a great refuge for me, to have found this group. Because there, I am among other people who have gone through this same pain. We are able to talk and be understood. And it's because we have gone through the same thing. This is something that we are not able to do with our own family, sometimes. Sometimes you would like to talk with them, but your family members distance themselves... are the first ones to turn you down. More than anything, this group has helped me to express my feelings and they understand us... talking helps a lot.

For the mothers, support groups offered a comfortable and effective way in which to obtain support outside of their family and social environments, reduce their sense of isolation and to normalize their grief feelings and reactions. These findings also confirm previous research, which found that group services are particularly helpful to Hispanic immigrant women (Leon & Dziegielewski, 1999). It is also interesting to note that in coming together for the purpose of the focus group interviews, the participants found some relief in that they were able to talk with others who had a similar experience.

Mothers who stated that they had engaged in family and individual counseling,

reported both satisfaction and dissatisfaction with these formal support services. Some mothers felt satisfaction with the follow-up counseling support offered through the hospitals their families had been affiliated with. One mother felt that the child-focused grief support services her children received were beneficial. For those mothers that reported dissatisfaction with individual and family counseling services, the reasons given included the view that the services were not helpful and that interactions with a particular clinical provider had been a negative experience. The following excerpt illustrates this mother's experience:

After the funeral, they made appointments for me to see the doctor, and every time we visited the doctor he would tell them, "You have to go to the psychologist... take her... make her go". And so I began with the psychologist. And with the psychologist, they would give me pills... but I declined. At then once I tried to set-up an appointment with a female psychologist. And I remember that she asked me if I had insurance, and then said "No... this isn't covered". Then, she said, "Oh, I have to tell you something ...I'm pregnant" so I said: "So does that mean you can't see me... or how long before you'll be able to see me?" and she said "No, no... I can see you... the issue is that in some situations, given I am pregnant... some people who are going through what you are experiencing, may find it too painful to see this kind of happiness in others". I was completely shocked. Yet I made the appointment. But I thought to myself, "what is the matter with this lady? I mean, I can be suffering through my own pain... but I'm not crazy... "What's wrong with her?" I can tell you, that I went to that appointment, but I never returned again.

Other reasons that were given for dissatisfaction included feeling that psychotropic medication prescribed had made the mother's situation worse, and in the case of another mother it had more to do with her inability to access the necessary services (due to a waiting list).

However, as previously mentioned, language barriers, generational factors, socio-cultural and ethnic factors, immigration issues, as well as religious and philosophical

beliefs are all factors that may disconnect Latino families from their social support community and can impede their sense of safety, trust and ability to seek or access mental health support services (Flores & Carey, 2000). This is particularly important to note given the demographic characteristics of this study population. The majority of these bereaved mothers maintained a strong sense of religious faith and traditional cultural values, which could impact their comfort or willingness to seek secular or professional support services. Moreover, most of the mothers reported an inability to speak English, had limited financial resources, and many reported experiences of isolation and absence of family and social support. All of these various socio-cultural factors, as well as possible immigration status issues for some, could likely result in additional challenges or barriers in accessing bereavement support services or individualized mental health services, for those mothers who may be in need of additional support.

Further study in regard to factors that impact the mothers' help-seeking behavior, and examination pertaining to their experiences with therapeutic and support service providers, would be useful to help determine what interventions they find helpful or unhelpful. However, it is important for clinical service providers working with clients of diverse socio-cultural backgrounds, such as the population in this study, to invest time in providing psycho-education, as needed, in order to help these clients understand all the various aspects and implications of the therapeutic process.

The Grief Experience as Impacted by Migration

Absence of Family Support

In addition, participants reported that they felt an absence of support as a result of

separation from significant loved ones who were living in Mexico. The mothers reported that the lack of their presence and the support they felt their loved ones would have provided, served to exacerbate feelings of loneliness and yearning for their family members- usually their parents and siblings. One mother commented:

Personally, I don't think the pain would have been any less, since the damage was already done. But the difference would have been in having my mother and father during those moments, when I really needed them. My friends had to be with me, by my side, instead of my parents. I feel that I would have felt more supported, but the pain would have still been the same for me. But yes, with my mother and father's love... I feel as though I would have felt more security, safer with... I don't know... I feel that it would have been better if they had been here.

Another mother said:

Because when the baby died, and when they disconnected him from the machine... they gave him to me and he was still alive... and he died in my arms. That is horrible. More than anything, when you don't have any family here.

As a result, the mothers stated that these situations made their bereavement experience more painful and difficult. These findings confirm previous research (Contro, Davies, Larson, & Sourkes, 2010), which noted that the absence of traditional family and community emotional support is a central theme in the bereavement experience of Mexican families.

Decisions Regarding the Disposition of Their Child's Remains

Another significant theme that emerged from the study findings, related to the impact that the mothers' residency status had on decisions regarding the disposition of their children's remains. As a complicating factor it was associated with the mothers' desire to remain in close proximity to their children, but involved decisions that had to be made in regard to where to place their child's remains, whether in Mexico or the United

States. This theme emerged primarily in the context of the mothers' responses to two interview questions: "things that did not help or made it more difficult" and as associated with "confronting this experience as a Mexican mother living in the United States". The following excerpt illustrates the impact of migration and residency status on one mothers' decision-making and in her attempts to maintain close proximity to her child:

For me personally, this has been the most painful experience in my life and it involved vital decisions because of my situation here in this country...as an immigrant. Having to decide what to do with my daughter's body... at the time, I don't know if I made the wrong decision or the right one... but we had to choose the option of cremation and to keep her ashes. Our thoughts are still to someday leave this country and go back to Mexico... and we would have had to leave her here. So now it is better. If we leave someday, we will bring her ashes with us...and she will always be with us. But now I wonder... I don't even know when we will ever leave and if we might actually stay here. And I would have liked to have a little place for her at the cemetery... where I could leave flowers. I sometimes hear the other parents talk about that, and I have her in my home. So I would have wanted a special place, like that, for her too. But I don't know; maybe it was at that moment... with so much pain... and all the decisions you have to make. Maybe it was the wrong decision, or maybe it was right, I don't know how it happened... but she is with me... and well, I don't know.

Several of the participants reported that they had initially planned on returning to Mexico someday and that as a result, their decision to bury their children in the United States was a current source of anxiety or distress:

My son died here in the U.S. And I have often thought to myself, what would I do if I ever returned to Mexico? How would I do that? Or if something else ever happened.... What would happen to my son, who is here? One night I was thinking about all of that. Soon after my son had died, I was really in a depression.... and I would get almost crazy, with anxiety... and I would begin to think about that.... "What will happen to my son?" and at the time, I could never come up with any answers. And up to now, I still don't know what will happen. Because even if we wanted to leave... no... because in our family, we are the only ones who go see him... he only gets visits from us, from my own family.

In addition, some participants commented that they had made a final decision to

remain in the United States, as a result of their decision to bury their child in the United States, albeit they had planned on someday returning to Mexico.

It is important to also note that only one mother commented that she had obtained the necessary information needed in order to make plans to exhume her son's body at a later time, when she returned to Mexico. Based on the findings, however, it remains unclear whether participants were unaware of the option of exhuming or whether they viewed it as an undesirable or unfeasible option-due to the complexity in planning or due to the costs involved. In addition, one can only speculate whether financial constraints impacted the mothers' decisions in regard to disposition of their children's remains. For example, financial constraint was identified as a complicating factor, which impacted the mode of disposition for their children's remains, in a previous study with Mexican parents (Contro, Davies, Larson, & Sourkes, 2010).

Although the demographic information obtained indicates that many of the mothers resided in low-income households, the issue of financial constraints was not identified in any of the focus group interviews.

Instead, some mothers stated that their decision to cremate their children was based on the uncertainty regarding plans to return to Mexico someday and their view that it represented the most manageable way to keep their children close to them. As an example:

I also made the decision to cremate my daughter, for that same reason. We are not from here, and my daughter had been born in Mexico. I have other children who were born here, but she was born over there. So I said to myself "Well, if we go back someday, since we don't know how the laws will change... and they could send us back... how can we leave our daughter here?" And it's the same for me...I have my daughter's ashes in my house.

These findings confirm previous research (Rando, 1984), which addresses the importance of explaining all the various options open to families in regard to their decisions about mode of disposition. Rando (1984) has suggested that this is especially important to do, when cremation is being considered, and if there is any possibility of regret at a later time, experienced by any of the family members.

Participants whose children were buried in Mexico, also shared their feelings of sadness at not being able to visit their children's grave regularly, and for these mothers it was felt that these circumstances made their experience more difficult and painful.

This issue highlights the importance of explaining the various options available to bereaved families, and also the importance of exploring financial concerns that may be driving the families' decision-making, as well as the due diligence needed on the part of social workers and other helping professionals (e.g. medical and palliative care workers, and community-based support service providers) to explore possible sources of financial assistance that might be available for the families, as they confront this painful and overwhelming experience.

Conclusion

Grief experiences are understood to be very individualized and subjective, yet they are also shaped by various socio-cultural and religious factors. As such, the findings confirm that there were obvious differences noted regarding all of the mothers' grief feelings and reactions. However, these mothers also shared similarities in their grief experiences, which involved a view of their loss as an unimaginable and extremely painful experience that affected them profoundly; a struggle and search for meaning; the

desire to maintain a connection with their children; and a view of religious faith as a source of support.

The findings reflect that this population of bereaved parents utilized their religious faith and various activities and rituals, which helped them in their bereavement experience. However, they also confronted several socio-cultural issues, which made their experience more difficult or painful, including the inability or limited ability to talk with their family and friends about their bereavement experience, and confronting socio-cultural and religious imperatives that stifled their outward or full expression of grief. These mothers also faced additional challenges associated with their migration experience, which also impacted their grief experiences.

In sum, while there were appeared to be religious and socio-cultural factors that served to support and shape the mothers' bereavement experiences in positive ways, these mothers also faced several barriers to the full expression of their grief, as a result of religious and culturally prescribed beliefs and expectations that restrict the ways in which they are allowed to publicly express their grief; the lack of emotional support or responsiveness from those around them, including family members and friends; and the lack of or limited avenues in which they are able to talk about or process their grief experiences.

CHAPTER SIX

SUMMARY AND FURTHER STUDY

Summary

There is minimal research available related to the bereavement experience of Mexican parents. The intent of this dissertation research study was to examine the lived parental bereavement experience of Mexican migrant mothers, as they experienced the death of their child in the United States. In addition, the study sought to enhance knowledge and understanding of how Mexican migrant mothers experience and negotiate their grief reactions within a personal, socio-cultural and religious context, which often include prescribed beliefs, rituals, or customs in the bereavement experience. The role that imperatives such as “Déjalo descansar, no le llores” play in the bereavement experience of Mexican migrant mothers was also explored.

This research study contributes to the literature on grief and bereavement, in the context of parental bereavement and as specifically related to the intrapersonal bereavement experience of Mexican migrant mothers. In addition, further study would be useful in order to expand on this initial research.

Further Study

Although this study provides useful information, it was exploratory in nature and further study would make it possible to obtain additional information in regard to the parental bereavement experience of Mexican migrant mothers, as well as their families.

Ideas for further study are described below. Narrowing the scope of the current study through the use of multiple case study methodology could provide richer, more in-depth information about the lived parental bereavement experience of Mexican migrant mothers. The study would seek to recruit Mexican migrant mothers, to participate in one-to-one interviews, and would utilize a Narrative theoretical framework. The data from this proposed study could be compared with the findings from the current study, for both uniqueness and commonality.

It would also be beneficial to conduct a similar, qualitative research study with bereaved Mexican migrant fathers, in order to explore their parental bereavement experience, and to compare results with that of the mothers, from this current study. Mexican bereaved fathers represent a population that has also been underrepresented in the bereavement literature.

Furthermore, based on experiences described by some participants in this study, it would be useful to delve further into their bereavement experience, in the context of their help-seeking behavior and service delivery experiences-including accessing counseling or support services, relating to helping professionals, and exploring their expectations of the counseling process. An exploratory, qualitative methods design would be utilized, similar to this current study, using focus group interviews.

Disseminating The Study's Findings

Study results will be provided in the form of presentations, at annual conferences or symposiums, which focus on the advancement of knowledge and practice in the area of grief and loss. In addition, presentation of the study results will be provided to staff at

Ryan's Place Grief Center, in Elkhart Indiana, on September 27th, 2013. Local consultation and presentations to grief centers, bereavement support programs, as well as to churches, hospitals and hospice programs, will also be offered to assist helping professionals determine ways in which this information can be used to improve their service delivery. A journal article that summarizes the study's findings is planned as well.

Implications for Social Work Education

The intent of this study is that this information will be useful to social work professionals and others working with bereaved Mexican families and that it will promote quality and culturally responsive interventions in the area of parental bereavement support services. Results from this study can be helpful by increasing social workers' competency and skills in the area of grief and mourning, and specifically with this underserved population.

Social workers maintain an ethical responsibility to seek to understand individuals and their behavior in a socio-cultural context and to provide culturally sensitive and competent services.

The findings from this study are related to three competency areas outlined by the 2008 Council on Social Work Education (CSWE) Educational Policy and Accreditation Standards: understanding diversity and difference in social work practice, advancing human rights and social and economic justice, and knowledge of human behavior and the social environment (Council on Social Work Education, 2008).

Furthermore, infusing information about cultural variations in mourning into content for courses such as group work and human behavior and the social environment

would help advance these three competency standards.

Clinical Implications

This study provides information that can be helpful to medical providers, professional and faith-based counselors, social workers, as well as social service agencies and bereavement support programs in order to increase understanding and knowledge associated with service delivery and support to bereaved Mexican mothers.

Specifically, for clinical practitioners, these findings highlight the importance of offering therapeutic support services, which are sensitive and responsive to the families' language and cultural needs. It is critically important to assess and consider the various socio-cultural factors which may be shaping the individuals' or families' grief experiences, including those that can serve as sources of support, as well as any that may be hindering adaptive coping. In this way, practitioners can support and assist parents in identify personal and meaningful ways in which to redefine and maintain a sense of continuing connection with their deceased children. Other effective and supportive service interventions would include those that embrace and utilize a family-centered perspective and that incorporate a psycho-educational component, in order to help family members normalize their grief experiences, and to gain a better understanding in regard to the varying grief feelings and reactions experienced in the aftermath of a loss.

The findings also indicate that self-help peer support groups can serve as encouraging and comfortable environments, in which bereaved parents can connect with others who have had the same experience and obtain mutual support. Groups can also serve to reduce the sense of isolation experienced by many of these families due to the

absence of traditional family and community support.

Previous research highlights the lack of accessibility to Spanish-speaking services experienced by Hispanic minorities and the findings suggest that, as such, bereavement support programs in particular should seek to expand service provision, when possible, in order to adequately meet the needs of Spanish speaking bereaved parents. Increased availability and access to Spanish language support groups and Spanish language grief counseling services could provide safe and encouraging “spaces” which offer bereaved parents opportunities in which to share and process their grief experiences. This is especially important in cases where parents are experiencing a lack of support within their family and social environments, or in cases where the parents feel a sense of isolation due to the absence of support from significant family members (who reside in Mexico).

For those helping professionals (such as medical and hospice social workers, and community-based social service providers) assisting families with burial planning, the findings also highlight the importance of providing comprehensive information to these families regarding the various options available, in light of residency status issues that may exist.

Limitations of the Study

The results of the current study need to be interpreted with an understanding that bereaved mothers who had experienced the death of a child within the last six months (at the time of the interviews) were not eligible to participate in the study. Although this was based on ethical considerations, it is possible that the findings would have been different

in regards to the bereavement experience of mothers whose losses were more recent. In addition, there was no outside time limit established, in terms of years since the death of their child in order to participate in the study. Therefore, the findings represent grief experiences, which ranged from one year to eleven years in duration.

Conclusion

This research study examined the lived parental bereavement experience of twenty-two Mexican migrant mothers, including the ways in which they negotiated culturally prescribed mourning beliefs and behaviors within this experience. An exploratory approach was used involving the collection of qualitative data using focus groups. Grounded-theory analysis was used to generate information related to the phenomenon of parental bereavement, as experienced by bereaved Mexican migrant mothers.

The findings reflect that the mothers who participated in this study viewed their loss as unique, profound, and that it was associated with intense pain. Many aspects of the mothers' lives were impacted differently and in various ways including their feelings, beliefs, values, life priorities, sense of self, and their relationships with others. The mothers also confronted their loss with a variety of coping strategies and grief reactions. However, in regard to similarities, the mothers' grieving experiences involved a struggle and search for meaning, a desire to maintain a continuing bond with their children, and a view of their religious faith as a source of support.

The study findings also reflect what the mothers viewed as helpful in their bereavement experiences, including the opportunities to talk with others about their grief

experience, their religious faith, and engaging in a variety of rituals and activities which served to help the mothers remember, honor, and feel connected to their children.

Findings also reflect what the mothers viewed as unhelpful or which made their bereavement experiences more difficult or painful, including certain cultural imperatives which were associated with expectations regarding the manner and length in which their grief should be expressed, decisions regarding the disposition of their children's remains and the absence of extended family support which were impacted by the mothers' migration experiences and residency status.

Language and immigration issues, religious and cultural issues, limited financial resources, isolation and absence of family or social support, were also identified as socio-cultural factors associated with this population of bereaved mothers. These factors could likely impact some of the mothers' ability to access community services or to receive adequate and culturally competent bereavement support when needed.

Last, the perspective taken in this study is that the mothers were the experts on their own experiences, including the feelings, beliefs, personal thoughts, and stories, which each mother felt was relevant or important to share. Collectively, the mothers wanted others to know that their lives have been impacted and irrevocably changed in ways that only other bereaved parents can understand. They wanted others to know that they will never forget their children or "let them go". They wanted others to know that they are trying to find their own ways of living with their pain and learning how to live without their children. They wanted others to know that they sometimes want or need to tell their stories and talk about their children and all the things that made them special.

They wanted others to know that they are finding their own ways to continue loving, remembering, honoring, and staying connected to their children. What is also unique about these women is that they found their own personal ways to balance or negotiate what some of their cultural or religious beliefs and values told them to do, and what they knew in their hearts they needed to do for themselves.

It is my hope that through the sharing of their experiences the mothers were able to derive some positive benefit in regard to their grief journey.

APPENDIX A

PARTICIPANT RECRUITMENT FLYER

¿Déjalo Descansar? ¿No Lo Llores? The Parental Grief Experience of Mexican Migrant Mothers



A research study being conducted by Illeana A. Gomez, L.C.S.W. for a dissertation under the supervision of Marcia Spira, Ph.D. in the Department of Social Work at Loyola University Chicago.

Are you able to talk about the death of your child?

The goal of this study is to better understand the parental grief experience of Mexican migrant mothers. The aim of this research is to improve grief support services to bereaved Mexican families.

Eligibility:

This study seeks to recruit 25 women who meet the following criteria:

- Mothers who have experienced the death of a familial child while living in the United States;
- Mexican heritage or descent and born in Mexico; and
- Currently residing in the Metropolitan Chicago area.

Due to this sensitive topic, mothers who have experienced the death of a child within the last six months will not be eligible to participate in this study.

Discussion Groups:

If you agree to be in the study, you will be asked to participate in a discussion group. The discussion groups will last 2 hours and will be conducted at Casa Central Agency at 1343 North California.

In the discussion group, you will be asked questions pertaining to the death of your child, including your thoughts and feelings regarding that experience.

Risks/Benefits:

Participation in this study may trigger some strong emotional reactions. Support resources will be made available to all participants.

While there are no direct benefits for your participation, your participation may help to provide more culturally responsive grief support services to bereaved Mexican families.

Confidentiality:

Participants are not required to share any identifying information. Anything said in the discussion group will be kept strictly confidential by the researcher. Only first names will be used.

Participation in this study is voluntary and participants will receive a \$25.00 visa gift card.

Contact Information:

For additional information or to participate in this study, please contact:
Illeana Gomez, at 1 (773) 645-2326.

¿Déjalo Descansar? ¿No Lo Llores?

La experiencia del duelo de madres mexicanas migrantes



Un estudio de investigación llevado a cabo por Illeana A. Gómez, L.C.S.W. para tesis bajo la supervisión de Marcia Spira, Ph.D. del Departamento de Trabajo Social de la Universidad Loyola Chicago.

¿Es capaz de hablar acerca de la muerte de su hijo/a?

El objetivo de este estudio es tener una mejor comprensión sobre la experiencia del duelo de las madres mexicanas migrantes. El propósito de este estudio es mejorar los servicios de apoyo para manejar el duelo de las familias mexicanas afectadas.

Elegibilidad:

Este estudio tiene como objetivo reclutar a 25 mujeres que cumplan con los siguientes criterios:

- Madres que hayan sufrido la pérdida de un hijo/a mientras vivían en los Estados Unidos
- Nacidas o de origen mexicano; y
- Que residan en el Área Metropolitana de Chicago.

Debido a lo delicado del tema, aquellas madres que han sufrido la pérdida de un hijo en los últimos seis meses, no serán elegibles para participar en este estudio.

Grupos de discusión:

Si acepta estar en el estudio, será cuestionada para participar en un grupo de discusión. Los grupos de discusión durarán dos horas y serán llevados a cabo en la agencia Casa Central en 1343 North California.

Durante los grupos de discusión, se le harán algunas preguntas relacionadas con la muerte de su hijo/a, así como de sentimientos y reacciones que ha tenido a partir de esa experiencia.

Riesgos/ Beneficios:

Participar en este estudio puede provocar reacciones emocionales muy fuertes. Recursos de apoyo estarán disponibles para todos los participantes.

Mientras no hay beneficios directos por su participación, su participación puede ayudar a proveer servicios de apoyo más sensibles culturalmente para familias mexicanas afectadas por el duelo.

Confidencialidad:

Los participantes no están obligados a compartir nada de su información personal. Todo lo que se comente en los grupos de discusión será guardado de forma estrictamente confidencial por la investigadora. Solo el primer nombre será usado.

La participación en este estudio es voluntaria y los participantes recibirán una compensación de \$25.00 por su participación en el estudio.

Información de contacto:

Para información adicional o para participar en este estudio, favor de contactar a:
Illeana Gómez, al 1 (773) 645-2326.

APPENDIX B

CONSENT TO PARTICIPATE IN AUDIO TAPING FORM

Loyola University Chicago: Lakeside Campuses
Institutional Review Board for
The Protection of Human Subjects

CONSENT TO PARTICIPATE IN RESEARCH
Audiotaping of focus groups

Date of Approval: 06/06/2011

Approval Expires: 06/06/2012

Project Title: ¿Déjalo Descansar? The Parental Bereavement Experience of Mexican Migrant Mothers

Researcher: Illeana A. Gomez, LCSW

Faculty Sponsor: Marcia Spira, Ph.D.

Introduction:

You are being asked to take part in a research study being conducted by Illeana A. Gomez for a dissertation being directed under the supervision of Marcia Spira, Ph.D. in the Department of Social Work at Loyola University Chicago.

You are being asked to participate in this study because you are a Mexican woman who has experienced the loss of a child. The researchers would like to understand your thoughts and feelings as they relate to the bereavement process.

Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

Purpose:

The goal of this study is to better understand the parental bereavement experience of Mexican migrant mothers, and to use the information learned to make recommendations regarding culturally responsive grief support services to bereaved Mexican families.

The primary research questions to be explored in this study are: (1) What is the lived experience of bereaved Mexican migrant mothers? (2) Were there issues, events or factors associated with the bereavement experience that helped or hindered?

The ultimate aim of this research is to improve grief support services to bereaved Mexican families.

Procedures:

If you agree to be in the study, you will be asked to participate in a focus group. The researcher will be conducting the focus group in a private setting at Casa Central Agency. The focus groups will consist of 7 to 9 members, and should last no longer than 2 hours. You will also be asked to provide some written, non-identifying demographic information prior to the focus group. During the focus group you will be asked some questions pertaining to the death of your child, as well as the feelings or reactions you have experienced since that time.

The focus group will be audiotaped and transcribed. These tapes will be coded so that they have no individual identifying or personal information on them, except for participants' first names. During the period of time the researcher needs to listen to the tapes, they will be safeguarded in a locked filing cabinet in the researcher's professional office.

Your privacy will be protected. In the case of electronic files, they will be stored in password-protected computers. Only the researcher will have access to these electronic files. All tapes will be destroyed after they have been transcribed and coded. Transcribed materials will also be kept in a locked filing cabinet in the researcher's professional office. At the end of the study, all electronic files and transcribed notes will also be destroyed. The researcher will make every effort to protect your confidentiality in any presentations and/or publications that might result from this study.

If you need to leave the focus group for any reason, either briefly or early, you may do so. There are no consequences for deciding to no longer participate in the focus group. You can leave the focus group at any time, and may keep a bereavement resource list and compensation, which will be provided to you at the beginning of the focus group.

Risks/Benefits:

We realize that participation in this study may provoke painful, sad, or emotionally distressing memories and reactions. Your participation in this study is strictly voluntary. Your decision whether or not to participate will not affect your current or future relations with either Casa Central or the Luz del Corazon Program and you can withdraw your participation in the study at any time.

At the beginning of the focus group, participants will be provided with a list of grief and loss support services and the researcher's contact information. You may contact researcher, Illeana A. Gomez, at a later time, for any further assistance, regarding any issues related to your participation in this study or pertaining to bereavement support services.

There are no direct benefits to you as a participant of this study. However, the findings have the potential to improve loss and support services so that they are more culturally appropriate for bereaved Mexican mothers.

Compensation:

If you agree to participate, you will be given a visa gift card worth \$25, at the beginning of the focus group, to compensate you for your time. If you decide to leave the focus group at any time, you may keep the gift card.

Confidentiality:

Participants are not required to share any personal information about themselves. Anything said in the focus group will be kept strictly confidential by the researcher. However, the researcher has no control over what participants say outside of the focus group. Participants should not to repeat what is said during the focus group. In addition, as addressed above, all data will be kept secure in a locked file cabinet or a secured computer under the care of the researcher.

Voluntary participation:

As mentioned earlier, participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free to not answer any question or to withdraw from participation at any time without penalty.

Contact Information and Questions:

If you have any questions about this research project, please ask before you sign this consent.

If you have questions later or want additional information, please feel free to contact Ileana A. Gomez, at (773) 645-2326 or the faculty sponsor Dr. Marcia Spira at (312) 915- 7580.

If you have any questions about your rights as a research participant, you may call Loyola's Office of Research Services at (773) 508-2689.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form

Participant Signature: _____ Date: _____

Participant's Printed Name

Researcher Signature: _____ Date: _____

CONSENTIMIENTO PARA PARTICIPAR EN INVESTIGACION
Grabaciones de audio de Grupos Focales

Título del proyecto: ¿Déjalo Descansar? La experiencia del duelo de madres mexicanas migrantes.
Investigadora: Illeana A. Gomez, LCSW
Patrocinador de la Facultad: Marcia Spira, Ph.D.

Loyola University Chicago: Lakeside Campuses
 Institutional Review Board for
 The Protection of Human Subjects

Date of Approval: 06/06/2011

Approval Expires: 06/06/2012

Introducción:

Usted ha sido invitado a participar en un estudio de investigación llevado a cabo por Illeana A. Gomez para tesis bajo la supervisión y dirigida por Marcia Spira, Ph.D. del Departamento de Trabajo Social de la Universidad Loyola Chicago

Como madre mexicana que ha sufrido la pérdida de un hijo/a, ha sido invitada a participar en este estudio de investigación. Los investigadores quieren estudiar y comprender sus pensamientos y sentimientos durante su proceso de duelo.

Por favor lea cuidadosamente esta forma y pregunte cualquier duda que tenga antes de decidir si participar o no en el estudio.

Propósito:

El objetivo de este estudio es tener una mejor comprensión sobre la experiencia del duelo en madres mexicanas migrantes, y usar esa información aprendida para hacer recomendaciones respecto a servicios de apoyo más sensibles culturalmente para familias mexicanas afectadas por el duelo.

Específicamente, las dos preguntas de investigación que serán exploradas en este estudio son: (1) ¿Cual es la experiencia vivida por las madres mexicanas migrantes en duelo? (2) ¿Hubo cuestiones o factores asociados que ayudaron o un estorbaron la experiencia del duelo?

El objetivo final de esta investigación es mejorar los servicios de apoyo para las familias mexicanas que enfrentan el duelo.

Procedimientos:

Si acepta participar en este estudio, usted será invitado a Participar en un grupo focal. La investigadora estará dirigiendo el grupo focal en la agencia Casa Central. Los grupos focales consistirán de 7 a 9 miembros, y duraran no más de dos horas. Se le pedirá que provea alguna información demográfica por escrito previo al grupo focal. Durante el grupo focal le serán hechas preguntas relacionadas con la muerte de su hijo/a, así como de sentimientos y reacciones que ha tenido a partir de ese momento.

Los grupos focales serán audio grabadas y transcritas. Estas grabaciones serán codificadas de tal forma que no exista información individual o persona en ellas, excepto el primer nombre de las participantes. Durante el periodo de tiempo que el investigador necesite escuchar las grabaciones, estas estarán guardadas de manera segura en un gabinete cerrado en la oficina del investigador.

Su privacidad será protegida. En el caso de los archivos electrónicos, estos serán guardados en computadoras protegidas con contraseña. Sólo la investigadora tendrá acceso a estos archivos electrónicos.

Todas las grabaciones serán destruidas después de haber sido transcritas y codificadas. Los materiales transcritos también estarán guardados en un gabinete cerrado y seguro en la oficina del investigador. Al final del estudio, todos los archivos electrónicos y notas transcritas también serán destruidos.

La investigadora hará cada esfuerzo de proteger su confidencialidad en cualquier presentación y/o las publicaciones que quizás resulten de este estudio.

Si tienes que dejar el grupo focal, por cualquier motivo, ya sea brevemente o temprano, usted puede hacerlo. No hay consecuencias para la decisión de no participar en el grupo focal. Puede dejar el grupo focal en cualquier momento, y puede mantener la lista de recursos de apoyo y su compensación, que se le preverá al inicio del grupo focal.

Riesgos/Beneficios

Sabemos que la participación en este estudio puede provocar reacciones y memorias difíciles, tristes y dolorosas emocionalmente. Su participación en este estudio es estrictamente voluntaria. Su decisión de participar o no, no afectará su presente o futura relación ya sea con Casa Central o el Programa Luz del Corazón, y usted puede retirar su participación en el estudio en cualquier momento.

Se proveerá a los participantes una lista de Recursos de Apoyo relacionados con el duelo y la pérdida al inicio del grupo focal. Usted puede contactar a la investigadora Ileana A. Gomez, mas tarde en cualquier momento, para más información y asistencia relacionada con el dolor emocional o alguna otra preocupación, como resultado de su participación en el estudio.

No hay beneficios directos para usted como participante de este estudio. Sin embargo, los resultados tienen el potencial de mejorar los servicios para las madres mexicanas que se enfrentan al duelo.

Compensación:

Si usted acepta participar, se le dará una tarjeta de regalo Visa con valor de \$25, al inicio del grupo focal, para compensarle por su tiempo. Si usted decide dejar el grupo focal en cualquier momento, usted puede mantener la tarjeta de regalo.

Confidencialidad:

Los participantes no están obligados a compartir nada de su información personal. Todo lo que se comente en los grupos focales será guardado de forma estrictamente confidencial por la investigadora. Sin embargo, la investigadora no tiene control sobre lo que dicen los participantes afuera de los grupos focales. Los participantes no deben repetir lo que se dice en los grupos focales. Además, como se mencionó arriba, toda la información será guardada de manera segura en un archivador cerrado o en una computadora bien asegurada bajo el cuidado de la investigadora.

Participación voluntaria:

Como se mencionó anteriormente, la participación en este estudio es voluntaria. Si usted no quiere ser parte de este estudio, no tiene que participar. Incluso si usted decide participar, tiene la libertad de no responder a cualquier pregunta o retirarse como participante en cualquier momento sin ninguna penalidad.

Información de contacto y preguntas:

Si tiene alguna pregunta sobre este proyecto de investigación, por favor pregunte antes de firmar este consentimiento.

Si posteriormente tiene preguntas o desea información adicional, siéntase libre de contactar a Ileana A. Gómez, al (773) 645-2326 o el Patrocinador de la Facultad, Dr. Marcia Spira al (312) 915- 7580.

Si tiene alguna duda sobre sus derechos como sujeto de investigación, usted puede llamar al Director de Conformidad de la Oficina de Servicios de Investigación de Loyola al (773) 508-2689.

Usted recibirá una copia de esta información para que la guarde en su archivo.

Declaración de consentimiento:

He leído (o alguien me ha leído) la información de la parte de arriba. Me fue dada la oportunidad de hacer preguntas y dichas preguntas fueron contestadas con satisfacción. Acepto participar en esta investigación. Me ha sido otorgada una copia de esta forma.

Firma del participante: _____ Fecha: _____

Nombre del participante

Firma del investigador: _____ Fecha: _____

APPENDIX C

PARTICIPANT DEMOGRAPHIC INFORMATION FORM

Focus Group # _____ Date : _____

First Name Only: **(optional)**

1. My age is _____.
2. How many years in the United States: _____ / _____
years months
3. Marital status:
 - ☐ Never married
 - ☐ Currently married
 - ☐ Divorced
 - ☐ Separated
 - ☐ Widowed
 - ☐ Common law
4. Parental status, currently: _____ # of children.
5. How old was your child when he/she died? _____
What was the cause of the death? _____
Was your child a: girl _____ or boy _____
Was your child: biological _____ or fostered/adopted _____
6. How long ago did you lose your child to death? _____ / _____
years month

What was the cause of the death?

Was your child a: girl _____ or boy _____

Was your child: biological _____ or fostered/adopted _____

7. My religion is:

- ☐ Protestant
 ☐ Muslim
☐ Catholic
 ☐ Buddhist
☐ Jewish
 ☐ Pentecostal
☐ Jehovah Witness
 ☐ None
☐ Other

8. My educational level achieved is:

- ☐ Elementary/grade school
- ☐ High School/GED
- ☐ Vocational or Technical training
- ☐ University/College
- ☐ Post-Graduate Studies

9. Our annual household income is:

- ☐ Less than \$10,000
- ☐ \$10,000-\$19,999
- ☐ \$20,000-29,999
- ☐ \$30,000-\$39,999
- ☐ \$40,000-\$49,999
- ☐ \$50,000-\$75,000
- ☐ \$75,000 or more

Demographic Information Form - Spanish

Título: ¿Déjalo Descansar? La experiencia del pesar entre madres migrantes mexicanas

Grupo focal # _____ Fecha: _____

Nombre (opcional, y sin apellido): _____

Información Demográfica de la Participante-Confidencial

1. **Tengo _____ años.**
2. **Cuantos años en los Estados Unidos: _____ / _____**

años
meses
3. **Estado civil:**

<input type="checkbox"/> Nunca casada <input type="checkbox"/> Casada actualmente <input type="checkbox"/> Divorciada	<input type="checkbox"/> Separada <input type="checkbox"/> Viuda <input type="checkbox"/> Unión libre
---	---
4. **Estado de madre, actualmente: _____ # de hijos/hijas (# de hijos ahora)**
5. **¿Qué edad tenía su hijo/hija cuando murió? _____**
¿Causa de la muerte? _____
¿Era?: niña _____ o niño _____
¿Su hijo/hija era?: biológico(a) _____ o de crianza o adoptivo _____
6. **¿Hace cuánto tiempo perdió a su hijo debido a la muerte? _____ años / _____ meses**
7. **Mi religión es:**

<input type="checkbox"/> Protestante <input type="checkbox"/> Católica <input type="checkbox"/> Judía <input type="checkbox"/> Testigo de Jehová <input type="checkbox"/> Otra: _____	<input type="checkbox"/> Musulmana <input type="checkbox"/> Budista <input type="checkbox"/> Pentecostal <input type="checkbox"/> Ninguna
---	--
8. **Mi nivel de educación es:**
 - ☐ Elemental/primaria
 - ☐ Secundaria/"GED"-equivalente a secundaria
 - ☐ Vocacional o entrenamiento técnico
 - ☐ Universidad
 - ☐ Estudios posgrado
9. **El ingreso anual de nuestro hogar es:**
 - ☐ Menos de \$10,000
 - ☐ \$10,000-\$19,999
 - ☐ \$20,000-29,999
 - ☐ \$30,000-\$39,999
 - ☐ \$40,000-\$49,999
 - ☐ \$50,000-\$75,000
 - ☐ Más de \$75,000

APPENDIX D
FOCUS GROUP INTERVIEW GUIDE

Focus Group Interview Guide

Focus Group Interview Guide- *Revised April 2012*

Thank you all for agreeing to participate in this focus group. This group interview should last about 1 1/2 hours. I'll be asking some questions regarding the death of your child, including some questions about your thoughts, feelings, and reactions to that experience. Remember, if you feel that this discussion becomes too distressing or painful please know that you can excuse yourself at any time to take a break or you can end your participation in the discussion. Before we get started, do you have any questions about the interview process?

Question 1

Can you tell me if this experience has changed you as a person, and if so, how?

Question 2

Has this experience altered your perspective of the world or life? If so, how?

Question 3

Has your child's death affected your relationships with family or friends? If so, how?

Probe: Were there any family members, friends or others that were available to listen to you?

Question 4

Can you talk about confronting this experience being a Mexican mother living in the United States? *Meaning, was there anything about living here in the United States that made your situation better, or more difficult... or was there was no difference at all?*

Question 5

When you hear the phrase "Déjalo Descansar, no le llores" what do you think or feel?

Question 6

Were there any religious or cultural traditions, rituals, expressions that helped you in this experience?

Question 7

Were there any religious or cultural traditions, rituals, expressions that did not help you, or that made it more difficult?

Question 8

Was there anything else that helped you? Or anything else that did not help you or made it more difficult for you?

Question 9- additional question added

Do you feel that you have been allowed or have allowed yourself to express your grief or feelings in a way you needed or wanted?

Question 10

If you could share one thing about your child's death, or how it's affected you, what would it be?

Question 11

Is there anything else that comes to mind, that we haven't talked about?

Conclusion:

I would like to thank you all for sharing your personal feelings, thoughts and experiences with me. My hope is that this information you have provided will improve bereavement support services to other Mexican families.

Focus Groups Interview Guide (Spanish)

Guía de la entrevista- *Revised April 16 2012*

Gracias a todas por participar en este grupo de discusión. Esta entrevista durara cerca de una hora y media.

Hare algunas preguntas con respecto a la muerte de su niño o niña, incluyendo algunas preguntas sobre sus pensamientos, sensaciones, y reacciones a esa experiencia. Recuerde, si usted siente que esta discusión llega a ser demasiado dolorosa sepa por favor que pueden excusarse en cualquier momento para tomar un breve descanso o usted puede terminar su participación totalmente en la discusión. Si antes de comenzar, tienen alguna pregunta sobre el proceso de la entrevista, puede hacerla.

Pregunta 1- ¿Puede usted decirme si esta experiencia la ha cambiado cómo persona? y en que forma o manera?

Pregunta 2- ¿Puede usted decirme si esta experiencia ha alterado su perspectiva u opinión del mundo o de la vida? y cómo?

Pregunta 3- ¿Siente que la muerte de su hijo/a ha afectado sus relaciones con familia y amistades? en que manera?

¿Hubo miembros de su familia o algunos amigos que estuvieran disponibles para escucharla?

Pregunta 4 ¿Puede usted decirme como afronto esta experiencia, siendo una madre mexicana, viviendo en los Estados Unidos? *Por ejemplo, hubo algo que la ayudo por causa de estar viviendo aqui? or algo que hizo mas dificil su situacion estando aqui?*

Pregunta 5: ¿Puede usted hablarme sobre la frase; Dejalo Descansar, no le llores"? ¿Cuándo usted oye esta frase qué piensa o siente?

Pregunta 6: Usted siente que hubo algunas expresiones, rituales o tradiciones religiosas o culturales, que la ayudaron?

Pregunta 7: ¿Usted siente que hubo algunas expresiones, rituales o tradiciones religiosas o culturales que no la ayudaron o que hizo mas dificil su experiencia?

Pregunta 8: ¿Hay otras cosas que usted piensa que la ayudo? ¿Hay otras cosas que usted piensa que no la ayudo o que hizo mas dificil su experiencia?

(inserted) Pregunta 9: ¿Crees que le han permitido apenarse o afligarse en una manera que necesitabas o querias? o si usted misma se dejo?

Pregunta 10: ¿Si usted pudiera compartir una cosa sobre la muerte de su hijo/hija, o cómo le ha afectado, cuál sería?

Pregunta 11 (pregunta de la conclusión): ¿Hay algo mas que viene a su mente que no se hablo?

Conclusión: Quiero agradecerle a todas por compartir sus experiencias personales conmigo. Es mi esperanza que la información que usted ha proporcionado servira para mejorar los servicios de asistencia sobre la pérdida para otras familias mexicanas.

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VITA

Illeana A. Gomez was born and raised in Chicago, Illinois. She is a licensed clinical social worker with over 25 years of experience in working with children, youth, and families. Before attending Loyola University Chicago, she attended the University of Illinois at Chicago, where she graduated with a Baccalaureate Degree in Social Work in 1987. She also completed her graduate studies at the University of Illinois at Chicago, where she received a Master's Degree in Social Work in 1988.

Illeana began her career as a medical social worker at Lurie Children's Hospital of Chicago (formerly known as Children's Memorial Hospital) and there she served families in the areas of oncology, neurology, and immunology. Later, she joined Casa Central Agency, one of the largest Hispanic social service agencies in metropolitan Chicago. At Casa Central Agency, Illeana served as the Director of Foster Care from 1992 to 2004. In 2004, she was promoted to Deputy Director of the Older Adult and Community Programs and today she continues to serve as the agency's Deputy Director of Family and Community Programs.

Illeana has extensive experience in the areas of clinical assessment and intervention, child welfare, and trauma and loss. She has also facilitated parental bereavement support groups, on behalf of the Luz del Corazon Program at Lurie Children's Hospital of Chicago since 2001. Illeana has served as an adjunct professor at North Park University and St. Augustine College and she is a member of the National Association of Social Workers.