Title

Suffering in Solitude: Early Pregnancy Loss Experience for Latina Women and their Family Members

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Abstract

Suffering in Solitude: Early Pregnancy Loss Experience for Latina Women and their Family Members

For many women and their families, the news of a pregnancy is a time of joyous celebration. However, not all pregnancies end with the birth of a healthy baby. Some pregnancies end suddenly and unexpectedly and often leave women struggling to make sense of the loss. Society often celebrates pregnancy and birth yet ignores the silence that follows pregnancy loss, which results in an emotional burden for both the women and their family members. Most studies note that 15 to 25 percent of women will experience a pregnancy loss (the loss of a fetus or infant through miscarriage, ectopic pregnancy, or stillbirth) at some point in their childbearing years. However, few studies examine the experience of pregnancy loss from the perspective of Latina women and even fewer from other members of the immediate family. This qualitative grounded theory study explored the experience of pregnancy loss for Latina women and their family members and how they integrated the loss into the life of their family. Women and their family members provided first person accounts of their experience with pregnancy loss from miscarriage or ectopic pregnancy all of which occurred before 13 weeks gestation. Interviews, field notes, memos were the primary sources of data. Participants included mothers (n=7), fathers (n=3), mothers and mothers-in-law of the women (n=5), and one mother's sister from nine families. Participants ranged in age from 32 to 57 years. All participants lived in the Central Valley of CA at both the time of the interview and at the time of the loss. Interviews occurred six months to nine years following the loss. Suffering in solitude distinguished the central aspect of the participants' experience that began with the realization that the pregnancy was in jeopardy. Their suffering continued over time following the loss of their baby. Support from friends and family inversely diminished over time, contributing to the women's suffering. Negative encounters with HCPs furthered their anguish. Aspects of Latino culture (pressure to bear children, family communication patterns of keeping things private, and the need to protect one another from emotional distress) also contributed to suffering in solitude. Living in silence was the eventual outcome for both women and their family members.

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Chapter One: Introduction

A Birth Healing Blessing

Blessed sister, beautiful one
with broken wings.
Your journey is a difficult one
that no mother should have to endure.
Your path is steep, rocky and slippery
and your tender heart is in need of gentle healing.

Breathe deeply and know that you are loved.
You are not alone,
though at times, you will feel like a
desolate island of grief
untouchable
distant.
Close your eyes.
Seek the wisdom of women who have walked this well-worn path before you,
before,
and before,
and before you yourself were born.
These beautiful ones
with eyes like yours
have shared your pain, and
weathered the storms of loss.

You are not alone (breathe in)
You will go on (breathe out)
Your wings will mend (breathe in)
You are loved (breathe out)

~ Mary Burgess

Author, *Mending Invisible Wings*, a healing journal for mothers following the loss of their baby through late-term miscarriage, stillbirth, or neonatal death. (reprinted with permission)

Background and Significance

With the knowledge of pregnancy, women and their families enter into a transitional phase of preparation, making ready for the new baby to become a part of their nuclear and extended family, as well as their social network of friends. Pregnancy can be a social event, often when friends or family members are pregnant at the same time. Pregnancy can foster the development of a new and often deeper relationship between partners. However, when pregnancy loss occurs, the losses can compound and affect multiple people on multiple levels. Mother's Day celebrations, planned play dates with friends, having a grandmother baby-sit for a date night: all these normal and expected parenting plans dissolve. Pregnancy loss is not only grounded in grief, but in the specific and unique life and history of the family.

Pregnancy loss is defined as the loss of a fetus or infant through miscarriage, ectopic pregnancy, or stillbirth. Fifteen to twenty five percent of women will experience a pregnancy loss at some point in their childbearing years (Conway & Russell, 2000; DiMarco, Renker, Medas, Bertosa, & Goranitis, 2002; Smith, 1988; Swanson, 1999). Grief is defined as the normal process of reacting to a loss, often including painful and intense emotions. Although often mistakenly seen as interchangeable words, bereavement refers to the state of loss, whereas grief is the reaction to loss. Bereavement is a normal event occurring in most people's lives at some point and can cause significant suffering, often associated with consequences to the health and well-being of bereaved persons (Stroebe, Hansson, Stroebe, & Schut, 2001). However, the bereavement that results from pregnancy loss is unexpected and not considered a normal part of childbearing years. Minority families are just as likely, if not more, to experience a pregnancy loss at some point in their childbearing years (Schott & Henley, 2007; Van, 2001; Van & Meleis, 2003).

Latinos are one of the fastest growing populations not only in California (CA), but in the United States (U.S.) as well (Galanti, 2003). According to the U.S. Census Bureau (2011), of the 36.3 million people who live in CA, 13.1 million are Latino (36%). Minority women, including Latinas, are more likely to have late entry or no prenatal care, higher perinatal mortality rates, higher teenage birth rates, come from poorer families, and have poorer health status and less primary care (Healy, et al, 2006; Muhuri, MacDorman, & Ezzati-Rice, 2004; Solorio, Yu, Brown, Becerra, & Gelberg, 2004). The social and personal construct of motherhood is central for Latina women. In most contemporary Latino societies, motherhood is conceptualized as a gendered division of labor, ideal femininity, symbolized by the Virgin Mary, whose primary responsibility is to raise children (Guendelman, Malin, Herr-Harthorn, & Vargas, 2001). These values and beliefs are important elements in pregnancy loss since Latina women receive the majority of their support from their family (Whitaker et al., 2010).

The goal of this chapter is to provide a framework for this dissertation. The introduction includes a biography of the researcher to situate the research, the research questions and their transition during data collection and analysis, a brief overview of the method and rationale to support its choice, a discussion about theoretical underpinnings, and an opening discussion about the key findings. This chapter concludes with an introduction to the remaining chapters.

Researcher Biography

In 1985, several months after the birth of my first and only biological child, a very close friend experienced a pregnancy loss at 20 weeks gestation. Although I had recently graduated from nursing school, I had not yet begun working as a nurse and had little experience to offer sound counsel. All I could do was to provide a shoulder to cry on, which I frequently did. However, despite my inexperience, it was clear to me that the care she received at the hospital during her loss had a profoundly negative effect on her over the next several years. As she narrated the experience to me over and over again, reliving it in painful detail, one consistent theme was evident: insensitive healthcare providers had profoundly underestimated the impact of her loss.

Her story began with what many women who experience pregnancy loss describe as the realization that something was wrong. She began spotting and cramping and phoned her physician with concerns. She recalled that his response was dismissive and offered no reassurance, advice, or assistance. When the pain became unbearable and the spotting continued, she decided to go to the Emergency Room at the hospital where she planned to eventually deliver. She was told abruptly by an ER physician she had never met, that she was losing the baby and was subsequently admitted to the labor and delivery unit. In her story, she recalls that there was no preparation for what was to come, no advice from the nurses, and no emotional support. In fact, there was very little contact from the nurses at all, whom she believed were avoiding her. The birth occurred within a couple hours after her arrival to the labor and delivery unit. Just seconds after the birth, she was asked if she wanted an autopsy but in the midst of her physical and emotion pain, she refused. Not once did anyone offer to allow her to see or hold the newborn. It was whisked out of the room immediately and she has no idea to this day if the baby was born alive or not. Within an hour she was transferred out of labor and delivery to the surgical floor where she spent the night. The following morning she was discharged without a single recognition of her loss. No reading materials were offered, nor were any mementos such a photograph, blanket, or footprint given. No information about what to expect in the grieving process was provided. She recalls that the staff acted as if it had never happened.

In the months and years to come, my friend was tormented by what she described as insensitivity on the part of the nurses and physicians she encountered in that less than 24-hour experience. She felt strongly that she should have been given some preparation of what was to come before the birth. Decisions about autopsy or wanting to see the baby should have been offered more than once, both before and after the birth. She felt the total lack of mementos was a direct denial of her child's life, which was profoundly painful. For a very long time (almost 2 years), each and every time I saw her, she recalled elements of the loss and felt the need to criticize the healthcare providers for their failures to care. Almost 2 years later, she delivered a healthy baby girl and in the months that followed, I began to notice a significant decline in the frequency of discussions about her loss, and although she did not talk about it as often, the pain was just as vivid many years later.

In less than a year from the time of her loss, I became a labor and delivery nurse at the same hospital where she delivered. During my orientation, I soon realized that there was very little offered to parents who experienced a pregnancy loss in the obstetrical unit. In fact, I subsequently learned that there was nothing offered. But soon thereafter, I became aware of and then attended a grief and loss counseling and coordinator training program for labor and delivery units. This four-day seminar emphasized the need for healthcare providers to recognize the impact of pregnancy loss and to provide both sensitive care and mementos. Over the next 10 years, I initiated and then coordinated grief and loss programs at every hospital where I worked (3 in total). The program included providing training to nurses in each department. The training seminar I attended was called *Resolve Through Sharing*, then a national organization dedicated to training healthcare professionals and providing resources for parents who experienced pregnancy loss. Now called RTS, the international organization is well known for its perinatal bereavement education including perinatal palliative care (Bereavement Services, 2012). For the past 26 years as a labor and delivery nurse, I have cared for countless women and their family members as they begin their journey of bereavement from pregnancy loss.

Looking back, I now realize that what both my friend and I experienced during those early years was the beginning of a societal paradigm shift for pregnancy loss care standards. RTS began training professionals in 1981 (Bereavement Services, 2012) and I first attended in 1987. Not everyone was in favor of the new standards. One of the nurses I worked with shortly after the program was initiated was adamantly opposed to the new standard of care. She was older and had personally experienced several miscarriages in the early 1950's. Based on her own experience, she felt that offering to see and hold a dead newborn was the worst thing we could do, despite the growing research that supported the desire of many parents for the chance to be with their child. She was offended that we would take photographs or provide other mementos such as foot prints or locks of hair. Her perception was that these would only become constant reminders of the loss and would inflict much more pain than having no mementos. However, practice over the past two to three decades has changed to include more compassionate care, including recognition of the impact of the loss and the provision of tangible mementos.

Having a specific standard of care for women during pregnancy loss provides nurses with a framework to support their care during this emotionally challenging experience. However, as I became more experienced and comfortable caring for women and their families during pregnancy loss, I began to see more details of each family experience and beyond the general standard of care. Grief is a unique experience and each and every family travels through the experience in a different way. I also began to see the influence that cultural values and beliefs had on the pregnancy loss experience. One of the pivotal moments for me was what I call *the hiding grandmother*.

I was caring for a couple where the partners came from different cultural backgrounds. The young woman was Hispanic and the young man was African American. They were being induced for a 34-week fetal demise. Shortly after the birth, the father's family members were all in the room. The baby had been born dead within the previous hour. The grandparents were there, as were several other extended family members, including the siblings of the young father. All family members held the baby, cried, laughed, and talked about distinctive features the baby had, like her father's nose and the mother's eyes. It was two hours of family shared grief mixed with shared joy. It was a time of recognizing the positive aspects of a new baby all the while experiencing the profound loss of all their hopes and dreams.

A couple hours later the young woman's family arrived. Although several extended family members came to the hospital, only her mother stayed in the room for more than a few moments. At one point, I had taken the baby from the room for weighing, bathing, and some photography. The woman called and asked to see the baby again, and I brought the baby to the room and placed her in her arms. About a half hour later, I was called into the room again and found the woman's mother (grandmother of the baby) standing behind the privacy curtain with the baby in her arms. I went to the woman and asked what she needed and she indicated that she wanted to hold her baby again. I guided the grandmother back to her daughter and helped her place the baby into her arms. An hour or so later I came back into the room and again found the grandmother with the baby hiding behind the curtain. I quietly asked the grandmother why she was hiding behind the curtain. She said she was there because every time I gave her daughter the baby, her daughter cried. The grandmother's desire to protect her daughter from that emotional pain is something that I discovered in this research as a central element in the experience of pregnancy loss for Latina women and their family members. Although I was unable to articulate that finding at the time, because of that contrast between the two different cultures, I could see that there are differences between cultural groups in the experience of pregnancy loss. This experience, in addition to my years of working with families during pregnancy loss, led me to consider a broad research question: What are the cultural differences in pregnancy loss for women and their family members? In order to eventually answer that research question, a detailed exploration of the experience of one cultural group needed to be undertaken. From the hiding grandmother experience and the number of Latina women in my community, the research question became specific to the experience of pregnancy loss for Latina women and their family members.

Research Questions

One of the long-term goals for my program of research is the development of culturally relevant care for Latina families, which represent the largest minority group in the Central Valley of California. Developing a culturally relevant standard of care is challenging when intervention studies that use control groups are not ethically achievable with pregnancy loss experiences. However, it is possible to explore the experiences of Latina women and their family members during and after pregnancy loss and gain valuable insight without an experimental study. Since the purpose of this study is to describe the experience of loss, identify cultural values and beliefs, and to examine the perception of care received, qualitative research is best suited to meet these aims. To begin this exploration, the following research questions were considered:

1) Describe the experience of grief and bereavement for Latino women and their family members following pregnancy loss:

    a) How are individual family members affected by the loss?
    b) What is the process that these family members use to integrate the loss into the life of their family?

2) Identify what roles cultural values and beliefs play in the grief experience after pregnancy loss within Latino families:
    a) How do Latino family members and families express their values and beliefs surrounding pregnancy loss?
3) Examine how hospital based care was perceived for Latino women and their families during hospitalization:
    a) How do Latino family members incorporate aspects of care (support, comments, information) into their loss experience?

Theoretical Framework

Symbolic Interactionism (SI) provided the conceptual base upon which Glaser and Strauss developed grounded theory (Annells, 1997; Crooks, 2001; Jeon, 2004; McCann & Clark, 2003; Streubert-Speziale & Carpenter, 2003). The term *Symbolic Interactionism* (SI) was coined by Blumer in 1969, and built upon the works of American philosopher George Mead and the German sociologist Max Weber in the 1930's. SI is a distinct approach to the study of human group life and human conduct (Blumer, 1969). It rests on the following three premises: 1) human beings act toward things on the basis of the meanings that the things have for them, 2) that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows, and 3) that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he/she encounters (Blumer, 1969).

The first premise, that human beings act toward things based on the meanings they attach to them, is central to understanding pregnancy loss. What it means to be pregnant and what meanings the baby holds for the future, are questions that have yet to be answered for Latina family members. Assumptions made about how someone might react to a pregnancy loss come from an individual's perspective, rather than being derived from the empirical world. Despite studies that have put forward various conceptualizations about pregnancy loss, none of them reveal a single truth, should such a thing exist. SI is based on the idea that the meanings that things have for human beings are central in their own right, and cannot be ignored. Understanding the premises of SI was important for these research aims because they attempt to examine the meanings behind the experience of loss, how the loss is integrated into the life of the family, including the actions and behaviors that arise from the meaning the loss holds for family members, and the role of cultural values and beliefs on that experience.

SI includes five central aspects: 1) social interaction, 2) thinking, 3) definition, 4) the present, and 5) the active human being (Blumer, 1969). Individuals interact, societies are made up of interacting individuals, people are constantly undergoing change from these interactions, and society thus changes (Charon, 2004). Interaction is an ongoing activity. SI describes the actor (human) as a being that interacts, thinks, defines, applies his or her past, and makes decisions in the present based on factors in the immediate situation. Charon emphasizes the importance of perspective, and how different perspectives can lead to different truths. No one research project provides any one single truth, but research provides a greater understanding of an event and of the participants' perspectives.

Symbolic Interactionism is useful when examining the values and beliefs of cultural groups. Since "meaning" is one of SI's major elements in understanding human behavior, revealing the often hidden meanings of cultural values and beliefs is congruent with the SI perspective. SI can also be valuable when investigating family issues. It is through social interaction that people learn meanings and symbols, and families often provide significant social interaction for their members, thereby constructing and revealing those meanings through example and ongoing negotiation. Using the SI perspective, grounded theory provides a means of studying human behavior and interaction, creating a new perspective and understanding of those behaviors (Sheldon, 1998).

Design

Researchers are often intrigued with the complexity of social interactions and the meanings of those interactions as described by participants (Marshall and Rossman, 1999). Since the purpose of this study was to describe the experience of loss, identify cultural values and beliefs, and to examine the perception of care received, qualitative research was best suited to meet these aims. Although well-developed measurement tools exist within the research area of pregnancy loss, a quantitative approach was eliminated for two main reasons: 1) existing psychometric tools in pregnancy loss focus on the grief response (active grief, difficulty coping, and despair) following loss and do not include information about cultural values and beliefs, and 2) no literature could be found that examined the grief experience of either Latinos or family members following pregnancy loss. A quantitative design was also rejected since the research aim was not to investigate cause and effect relationships, nor was it attempting to test any existing theories. Qualitative research provides the opportunity to explore understudied people and situations. It also provides the opportunity to study everyday life situations in their natural setting. The choice of grounded theory was driven by the research questions. Since grounded theory aims to develop substantive or formal theory as a means to explain social processes (Jeon, 2004), understanding the processes by which Latino families integrate their loss experience was deemed to be best understood by using grounded theory.

Ethical Considerations

Codes of ethics for conducting research have been developed "...to ensure that participants will not be harmed" (Kylma, Vehvilainen-Julkunen, & Lahdevirta, 1999, p. 225). Ethical concepts include what is good, right, moral, just, proper, virtuous, and lawful (Kylma, et al., 1999; Rosenblatt, 1995). In light of the population studied (Latino/Latina bereaved parents and family), care was taken to reflect on all these ethical considerations of research, including vulnerability. Most often, vulnerability is typically emphasized only in children, marginalized populations, or the elderly (James & Platzer, 1999). However, bereaved parents are also vulnerable, since grief reactions and feelings are evident years after the event (Buchi, et al., 2007). Qualitative studies often focus on the inner feelings and thoughts of participants, requiring sensitivity and diplomacy on the part of the investigator. Caution was taken to avoid the tendency to provide therapy and counseling, rather than gather information and collect data (Cook, 1995; Kylma, Vehvilainen-Julkunen, & Lahdevirta 1999; James & Platzer, 1999; Rosenblatt, 1995). In addition to participants being vulnerable as grieving parents, they were also vulnerable as a minority group. Despite the fact that Latinos represent the largest and most rapidly growing minority group (U.S. Census Bureau, 2011), little is known about Latino families and pregnancy loss.

James and Platzer (1999) note that "...risks may be posed by the researcher as a result of ignorance or a lack of understanding of a particular culture or language, and an inability to reflect on the participants' values and beliefs" (p. 74). Since this population belongs to a cultural group other than the principle investigator's cultural background, assistance was sought from a

Latina professional colleague with experience in pregnancy loss, to help uncover meanings that might otherwise be missed. She became the sole research assistant and was actively involved in the data collection, analysis, and approval of the first manuscript. Guidance was also sought from an informal advisory board of Latina professionals (one registered nurse, one certified nurse's aide who was a physician in Mexico, and one Latino Catholic Priest) who provided insight into some of the cultural norms of the participants and a better understanding of the cultural context, including childbearing expectations and family communication patterns.

Ethics are more than a set of principles or rules, but rather refer to actions that exist in the way of doing and practicing research (Davies & Dodd, 2002). Ethical considerations were applied throughout the research process. Approval was obtained from the UCSF Committee on Human Research and was maintained until data collection and analysis were complete. Participants were given both written and verbal informed consent in their language of preference (Appendix A).

Efforts were made to recognize the emotional impact of participants recalling and discussing their pregnancy loss. Participants were reminded that they could stop the interview at any point in time or could refuse to answer any questions. Although some family members refused to participate in the research study, none of the participants refused to answer questions once they agreed to join. Community resources such as counseling services and support groups were available but none of the participants expressed a need to desire to be referred. However, all of the mothers, two of the fathers, and one of the mother's mother expressed a profound gratitude for the opportunity to talk about their loss at the conclusion of the interview.

To ensure anonymity, pseudonyms replaced any identifying information in the transcripts, including participants' names and those of the healthcare providers they identified.

All transcripts, memos, and analytic content were password protected on the computer of the primary investigator and were kept in a secure location. Selected de-identified data were shared with the research assistant and the faculty advisor.

Data Collection

Participants were recruited from flyers in OB/GYN physician offices and then through snowball sampling (Appendix B). Women who had experienced pregnancy loss were typically the primary contact, with family members being recruited subsequently. Participants were self-identified as Latino/Latina and experienced a pregnancy loss in the past 10 years. Interviews took place in their home or in the office of their healthcare provider (HCP) according to participants' preference. Interviews were audiotaped, transcribed verbatim, and checked for accuracy. Interviews in English (n=13) were conducted by the primary author. The primary author instructed the research assistant (RA), a Master's prepared bilingual bicultural Latina nursing faculty member, about how to conduct the interviews; as well, the RA attended three interviews with the primary author in order to observe how to conduct interviews. The RA then conducted the interviews in Spanish (n=3), with the primary author in attendance at the first two. Conversations between the primary author and the RA held immediately following each joint interview were also audiotaped and transcribed verbatim. Field notes taken by both researchers were also included in the data analysis. Interviews were initially directed by a formal interview guide (Appendix C). However, as the interviews and analysis progressed (and interview experience was gained with participants more clearly focusing their comments), the nature of the questions changed accordingly. The result was that participants' stories naturally unfolded regarding their experience with loss, their interactions with friends and family, and finally, their experience with HCPs.

Data Analysis

Data analysis began when the first interview was complete. Transcripts were read and re-read to fully understand the events being described. Data were analyzed using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to identify similarities and differences across interviews. Using open coding, the researchers began to identify, name, and categorize phenomena, such as *keeping things private* and *feeling the loss profoundly*. Codes were created and then elevated to conceptual levels where themes began to emerge. For example, the code *keeping things private* became merged with several other codes related to communication patterns noted among participants. After open and axial coding, selective coding began with the core category of *suffering in solitude* and its consequence (or aftermath), *living in silence*. Interviews continued until data saturation occurred and a full description of the process resulted.

ATLAS.ti (2007) was used as a data management tool during the analytical process. The primary researcher read and re-read all transcripts. Initial coding was done by the primary researcher and then discussed in-depth with the secondary researcher and faculty advisor to clarify, confirm, or reject meanings. The faculty advisor read several of the transcripts and was directly involved with the development of the conceptual model during the analytic phase. Member checking occurred informally during data collection and formally after analysis with a discussion of the conceptual model with three of the participants, all of whom agreed it reflected their experience accurately. Throughout the data collection and analysis, several formal and informal conversations also took place with members of the advisory board, the research assistant, and the faculty advisor. Several versions of the conceptual model evolved over time with feedback from those involved with the study.

Key Findings

This was a study of Latina women and their family members who experienced an early pregnancy loss within the 10 years preceding the interviews. The sample consisted of seven mothers, three fathers, five mother's mothers or mothers-in-law, and one mother's sister from nine families. Details of each woman's reproductive history and each family member's family role are summarized in Appendix D. All participants lived in the Central Valley of California, both at the time of the loss and the interview.

Suffering in Solitude emerged as the central theme for the women and their family members. Living in silence was the eventual consequence, where participants felt isolated and alone. Their suffering was influenced by strong cultural expectations for childbearing, family communication patterns of keeping things private, and by their desire to protect one another from emotional distress. Support from friends and family quickly diminished after the loss, which contributed to their suffering. Encounters with HCPs also contributed when insensitive comments were made and no support was offered. The conceptual model depicting the central findings can be seen in Appendix E.

Unexpected findings occurred during data collection and analysis. Grandfather participation proved to be a challenge, in that two initially agreed to participate and then backed out when asked to schedule an interview. However, as the analysis progressed, it became clear that the influence of not talking about sensitive issues was salient for all the participants; a likely explanation for the grandfathers' reluctance to disclose private matters. The findings of how women and family members integrate the loss into their family were also surprising, in that there was no indication of integration. Instead, there was strong evidence that women and their family members suffered alone and continue to live in silence long after the loss. Sadly, it was also clear that encounters with HCPs were a source of dissatisfaction because their comments inflicted additional emotional pain during a time when participants were particularly vulnerable. As a HCP myself, I was profoundly disappointed to realize that “we” had failed to protect these women and their family members.

Organization of Chapters

The rest of the dissertation is organized into four remaining chapters. Findings are presented in Chapters Two, Three, and Four. Chapter Two, entitled “Suffering in Solitude: Pregnancy Loss Experience for Latina Women and their Family Members,” presents overall study findings. This article will be submitted as a manuscript for review to *Death Studies*. Chapter Three, entitled “The Role of Protector: Latino Cultural Values and Beliefs Related to Early Pregnancy Loss,” presents findings pertaining to the cultural influences on pregnancy loss. This chapter focuses on the communication pattern of keeping things private and the way in which participants protected one another from emotional pain. This chapter is being converted to a manuscript for review by *The Transcultural Nursing Journal*. The final findings chapter, “’It Was a Baby to Me’: Latina Women and their Family Member’s Encounters with Healthcare Providers During and After Pregnancy Loss,” addresses participants’ dissatisfaction with the care they received from HCPs. A manuscript resulting from this chapter will be submitted for review to the *Journal of Emergency Nursing*. In the final chapter, findings are summarized and discussed and the implications for nursing practice and for future research are noted.

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Chapter Two: Suffering in Solitude

Suffering in Solitude: Pregnancy Loss Experience for Latina Women and their Family Members

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Abstract

Objective: The purpose of this study was to explore the experience of pregnancy loss for Latina women and their family members and to examine the process they used to integrate the loss into the life of their family.

Design: Qualitative study using a grounded theory approach.

Setting: Participants were self-identified as Latino and all lived in the Central Valley of California at the time of the interviews.

Participants: A total of 16 family members from 9 families shared their stories. Seven mothers, five grandmothers, three fathers, and one aunt discussed their experiences with pregnancy loss. Losses occurred six months to nine years prior to their participation. Losses occurred between 6-12 weeks gestation.

Methods: Interviews were tape recorded and transcribed verbatim. Analysis included open, selective, and theoretical coding, using the constant comparative method. Completion of analysis occurred with data saturation and the emergence of a central process.

Results: Suffering in solitude emerged as the central process, which contributed to a life of silence. This suffering occurred in the context of cultural and family expectations and communication patterns. Support from friends and family decreased soon after the loss, furthering the silence. Negative encounters with healthcare providers also contributed to the suffering.

Conclusion: As healthcare providers (HCPs), nurses need to become more aware of the impact they have on women and their family members who have experienced pregnancy loss. In addition to providing more sensitive care, healthcare providers need to nurture an environment where women and their families can share their stories of loss and not be left to suffer alone.

Suffering in Solitude: The Pregnancy Loss Experience for Latina Women and their Family Members

Background and Significance

For many women and their families, the news of a pregnancy is a time of joyous celebration. However, not all pregnancies end with the birth of a healthy baby. Some pregnancies end suddenly and often leave women struggling to make sense of the loss. Researchers note that society relishes birth, yet "…there is a silent disregard for the grief and despair that pregnancy loss evokes" (St. John, Cooke, & Goopy, 2006, p. 8). Pregnancy loss is a difficult life event (Swanson, Conner, Jolley, Pettinato, & Wang, 2007), which can result in emotional burdens for both men and women (Cumming et al., 2007). Pregnancy loss is defined as the loss of a fetus or infant through miscarriage, ectopic pregnancy, stillbirth, or neonatal death. Most studies note that 15 to 25 percent of women will experience a pregnancy loss at some point in their childbearing years (Conway & Russell, 2000; DiMarco, Renker, Medas, Bertosa, & Goranitis, 2002; Smith, 1988; Swanson, 1999).

Prior to 1970, very little research existed pertaining to the pregnancy grief and loss experience (Hughes & Riches, 2003; Robinson, Baker, & Nackerud, 1999; Toedter, Lasker, & Janssen, 2001). Fortunately, the body of research in this area is more extensive today. Women who have experienced pregnancy loss have significant levels of anxiety, depression, sleep disturbances, stress, and numerous other psychosomatic complaints (Armstrong, 2002; Neugebauer, et al, 1997; Thebert-Wright, 2002; Walker & Davidson, 2001). Further studies examined the relationship between Peritraumatic Dissociation (which occurred in 70% of pregnancy losses) and Post-Traumatic Stress Disorder (PTSD) symptoms following pregnancy loss (Engelhard, Van Den Hout, Kindt, Arntz, & Schouten, 2003; Engelhard, Van Den Hout, &

Vlaeyen, 2003). Other studies noted that pregnancy loss can have a negative impact on prenatal attachment and on the development of the healthy child born subsequently (Armstrong, 2002; Hughes & Riches, 2003; Vila, 2001). Most of the literature reviewed on pregnancy loss focused on Caucasian women. Few studies were found that included the perspective of men (McCreight, 2004; Puddifoot & Johnson, 1999; Samuelsson, Radestad, & Segesten, 2001), and even fewer studies that focused on minority women (Hsu, Tseng, & Kuo, 2002; Van & Meleis, 2003).

Latinos are one of the fastest growing populations in the United States and are defined as people whose family origins include Mexico and the countries of Central and South America, including Puerto Rico and the Dominican Republic, (Galanti, 2003). Accounting for more than 16% of the U.S. population, Latinos numbered 52 million in 2011 (CDC, 2012). In California, the location of this study, Latinos represent nearly 38% of the population (U.S. Census Bureau, 2011). Latinas, like other minority women, have a greater risk for perinatal mortality, high risk births, teenage births, and late entry to or no prenatal care (Muhuri, MacDorman, & Ezzati-Rice, 2004; Healy, et al, 2006). Compared to non-Latina Whites, pregnant Latina adolescents come from poorer families, have poorer health status, and have less primary health care (Solorio, Yu, Brown, Becerra, & Gelberg, 2004). Latina women also have the highest fertility rates, when compared to White, Black, Native American, and Asian/Pacific Islanders (Aliyu et al., 2005; Arias, MacDorman, Strobino, & Guyer, 2003). Mexican American women born in the U.S. have an increased risk for preterm birth and more pregnancy complications than their Mexican-born counterparts (Crump, Lipsky, & Meuller, 1999; Heilemann, Lee, Stinson, Koshar, & Goss, 2000). Minority women are just as likely, if not more, to experience a pregnancy loss at some point in their childbearing years (Schott & Henley, 2007; Van, 2001).

In addition to the lack of literature on minority women and pregnancy loss, there is also a lack of literature on the impact of loss on other family members. Although few studies could be found that examined pregnancy loss from the fathers' perspective, no studies were found that included other family members, such as grandparents or siblings. The literature concerning the impact of pregnancy loss is limited in both scope and depth of knowledge of pregnancy loss in two important areas: 1) impact of loss for minority groups, and 2) the impact of loss on individual family members. Therefore, the purpose of this study was to explore the experience of early pregnancy loss for Latina women and their family members and to examine the process they use to integrate the loss into the life of their family.

Methodology

Symbolic interactionism (SI), which helps to understand human group life and human conduct, served as the theoretical framework for this grounded theory study (Blumer, 1969). SI addresses how people use an interpretive process to handle and modify meanings of situations they encounter. This interpretive process is central to understanding pregnancy loss. What it means to be pregnant and what meanings the pregnancy/baby holds for the future, are questions that have yet to be answered for Latina women and their family members. White, Walker, and Richards (2008) note that SI suggests persons in grief and loss situations define the meaning of their loss through their interactions with others, such as friends and family members. Healthcare providers (HCPs) are also influential when women are constructing meanings around pregnancy and loss. Grounded theory, rooted in SI, was selected to examine the process or processes which characterize how Latina women and their family members experience pregnancy loss.

Sample

In total, 16 Latino participants from 9 families agreed to share their stories of loss. The sample consisted of seven mothers, five mothers of the mothers, three husbands, and one mother's sister. Initial participants were recruited through flyers posted in OB/GYN and Family Practice offices in the Central Valley of California. Office personnel gave study information sheets to women who expressed interest in participating after having seen the flyers. At the conclusion of each interview, study information sheets and contact information were given to participants and they were asked to pass that information on to other friends or family who had also experienced a pregnancy loss. This snowball sampling technique resulted in subsequent participants. Inclusion criteria were self-identification as Latino/Latina and experienced a pregnancy loss within the last 10 years. Demographic information was obtained at the time of interview. Participant ages ranged from 32 to 57 years. Before the interview began, participants received both written and verbal informed consent in their language of preference (English or Spanish). Ethics approval was obtained from the Committee on Human Research from the University of California, San Francisco.

All participants lived in the California Central Valley when interviewed and at the time of their loss. Pregnancy losses included both miscarriages and ectopic pregnancies and all occurred before 13 weeks gestation. Interviews occurred between six months and nine years (average 3.6 years) following the loss. All participants except one had living children or were pregnant again at the time of the interview. See Table 1 for demographic information.

Data Collection

Participants were interviewed by either the primary author or the research assistant in their preferred location, either in their HCP's office or the participant's home. The research assistant (a bilingual bicultural Latina faculty member) received training in conducting interviews and attended several interviews with the primary researcher before conducting any interviews on her own. The primary author conducted all interviews with English-speaking participants (n=13); the research assistant conducted interviews with Spanish-speakers (n=3). Interviews lasted an average of 60 minutes. In order to establish a relationship with the participant before discussing the sensitive area of pregnancy loss, interviews began with the question, “Tell me about when you first found out you were pregnant.” Interviews continued with questions related to the participants’ experience with pregnancy loss, cultural values and beliefs related to their loss, and their interactions before, during, and after the loss with friends, family, and HCPs.

Interview questions were modified throughout the process of data collection to reflect participant comments from previous interviews and ongoing analysis. For example, the initial interview guide did not include questions about family communication patterns; however the first participant discussed ways in which her family did and did not talk about issues, which resulted in the code *keeping things private*. In subsequent interviews, if participants did not bring up the issue of family communication, they were asked what issues were considered private. Interviews were recorded digitally and then transcribed verbatim. The RA then translated Spanish transcripts into English and verified them for accuracy (reviewed with audiotape). Observational notes taken during the interviews and immediately after, as well as discussions between the researchers following the joint interviews, were also transcribed verbatim and were considered as data during the analysis. Data collection ceased when data saturation was achieved and no new codes or categories emerged.

Data Analysis

Data analysis began with the first interview. Transcripts were read and re-read to fully understand the events being described. Data were analyzed using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to identify similarities and differences across interviews. This involved taking each piece of the data and comparing it to other pieces, always asking "What is going on here?" Using open coding, the researchers began to identify, name, and categorize phenomena, such as *keeping things private* and *feeling the loss profoundly*. Codes were created and then elevated to conceptual levels where themes began to emerge. For example, relationships between the code *keeping things private* and several other codes related to communication patterns were noted. Through axial coding, data were examined for context, causal and intervening conditions, and consequences (Strauss & Corbin, 1998). After open and axial coding, selective coding began with the core category of *suffering in solitude* and its consequence (or aftermath), *living in silence*. ATLAS.ti (2007) was used as a data management tool during the analytical process. The primary author read and re-read all transcripts, did the initial coding, then discussed the coding in depth with the RA to clarify, confirm, or reject meanings. The faculty advisor read several of the transcripts and was directly involved with the development of the conceptual model during the analytic phase. Member checking occurred informally during data collection and formally after analysis with a discussion of the conceptual model with three of the participants, all of whom agreed it accurately reflected their experience.

The primary author remained cognizant of her own perceptions of pregnancy loss from her years of working with families in the labor and delivery setting and made efforts to not allow her experience to color the data inaccurately through the process of memo creation and discussions with the research team. An informal advisory board was also consulted during the analysis phase to answer questions about cultural values and beliefs typical of Latino families, since the primary researcher was not Latina herself. The board consisted of one Latino Catholic priest, one Latina certified nursing assistant who had been a physician in Mexico, and one Latina labor and delivery nurse with 28 years of experience working with families during pregnancy loss in the hospital setting. Advice from board members was sought when situations described by the women and/or their family members had social or religious implications and needed further clarification.

Results

Suffering in solitude distinguished the central aspect of the participants' experience that began with the realization that the pregnancy was in jeopardy and continued long past the pregnancy loss. Support from friends and family inversely diminished over time, contributing to their suffering. Negative encounters with HCPs furthered their anguish. The pregnancy losses occurred within the context of their Latino culture. Three cultural dimensions were particularly prominent: the Latino cultural characteristics of *familismo* and *respeto* (defined in a later paragraph) as well as the related expectation of having large families; the Latino family communication pattern of *keeping things private;* and the significance of protection, particularly against emotional distress. Living in silence was the eventual outcome for both women and their family members. A conceptualization of the process of suffering in solitude can be seen in Figure 1 (Appendix E).

Suffering in Solitude

All the women, most of whom were trying to get pregnant at the time, were happy about their pregnancy whether it was planned or not. They were excited and quickly shared their joy with friends and family, despite some warnings from family to wait until further along in the pregnancy. All the women expected that everything would be okay. For some, the first sign of complication, typically bleeding, came at home or at work. For others, the news came as a shocking surprise when they were visiting their physician's office for a regular check-up and learned there was no fetal heartbeat. Realizing their pregnancy was in jeopardy, the women desperately clung to hope, even when faced with concrete news that the pregnancy was ending. One woman frantically searched the Internet for any ray of hope after learning that there was no heartbeat on an ultrasound:

> Maybe it's a mistake. I went and looked on the Internet and of course I saw stories of people that had a miscarriage. But other people said that the doctor was wrong and everything was fine. And so I was holding onto that (participant #6).

This same woman requested two more ultrasounds even after the first diagnosed the demise. She also continued to take several home pregnancy tests " …and they all came back positive. It was just so great to keep looking at that. It just felt so good" (participant #6).

The pregnancy loss was profound, painful, and distressing. One woman referred to the difficulty she had in accepting the reality of the loss:

> You know, I didn't want to accept it at all. It took me at least three to four months, to kind of accept it. Not accept it, because I still don't accept it [nine years later], but life goes on. That's the way I felt. At the time the family wanted to come to see me, I didn't want anybody near me. I wanted to be in my own world (participant #2).

Other women also found the entire experience " hard" and "difficult," and although the acute pain of the loss lingered for months, a residual pain stayed with them for much longer.

For women who had to make an active decision about ending the pregnancy, such as whether to undergo a dilation and curettage (D&C) or surgery for an ectopic pregnancy, their religious convictions compounded their distress. All women discussed their commitment to the Catholic religion and their doctrine against termination of pregnancy, which became a concern for them even when the baby had already died. One woman talked about her physician recommending a D&C as soon as possible since her body had failed to pass the fetus. Her concerns prompted her to seek the advice of her priest, who was against the procedure, despite the fact that the baby was already dead. His recommendation was to wait until her body expelled the fetus. Several days later, when her temperature became elevated and concerns for infection were evident, she finally agreed to the procedure despite her priest's advice. She discussed the fact that this conflicting advice from the physician versus the advice from her priest contributed to her suffering. Although she felt it was the right decision at the time to have the procedure, she expressed guilt afterwards, wishing she had waited.

Two women who had ectopic pregnancies also experienced greater difficulty in agreeing to have surgery, compared to their previous experience with spontaneous miscarriages. Although one of the women did not realize the nature of the surgery until later, both women were conflicted with the need for surgery to save their own lives and knowing the surgery would terminate their pregnancy. Both women noted that having to actively make the decision to agree to end the pregnancy compounded their suffering.

All women found the loss experience to be very difficult, frequently commenting that "it was so hard." When asked what made it hard or how it was hard, they were at a loss for words, indicating that they were overwhelmed by their loss. Guilt also characterized the women's experience. They worried that their actions in some way contributed to the loss: "moving heavy furniture," "working too much", or "being on your feet for hours." The pressure to have children, most often exerted from their mothers and mothers-in-law, contributed to their guilt because of their inability to fulfill the expectation for childbirth. Guilt was also evident in women who perceived the loss as being due to religious or spiritual reasons, such as “God’s will”, “punishment from God”, or a natural event with first pregnancies.

Following their pregnancy loss, the women felt alone and many of them described being depressed. They were unable to get out of bed, go to work, or feed their children:

> I wasn’t taking care of my kids. It was affecting my life. I wasn’t sleeping, I still remember my boy walking around with peanut butter, like a spoon full of peanut butter because I wasn’t feeding my babies (participant #3).

One woman stayed in her room for two months, refusing to answer the phone, not allowing family to visit:

> My brother from Mexico wanted to come and see me and I told him I didn’t want to see him. I wasn’t going to open my doors. Because I was crying and I was depressed. At the time I said no, I don’t want any more babies. That was it. No more babies (participant #2).

Their depression was exacerbated by the loneliness that resulted from their self-imposed isolation and the unintentional yet harmful words from friends, family, and HCPs. Many of the HCP comments that the women felt were hurtful centered on terms that minimized their loss. Language such as ‘fetus’ or ‘embryo’ or ‘tissue’ failed to recognize the impact of the loss, since the women used the word’ baby’ from the moment they found out they were pregnant. Hearing such words, the women could not share their sorrow with the HCP and their suffering was heightened, further compounding their loneliness and depression. Any attempt to initiate conversations with the HCP resulted in further emotional distress. Moreover, in addition to thoughtless comments from HCPs, when women were quickly dismissed by their HCP, they were reluctant to return to ask for support or admit that they were still struggling in the weeks and months after the loss. Several of the women refused to go back to their same provider after the loss. Consequently, the women lived in silence about the loss of their baby and its impact on them. Despite the apparent depression for many of the women, only one woman sought professional help from a counselor and took anti-depressant medication prescribed by her physician.

Family members typically experienced a similar trajectory and also suffered in solitude. However, the women's loss was more intense than for their family members, as the family was ready to move on from the loss sooner than the women. Family members initially rejoiced in the news of the pregnancy and subsequently were greatly saddened by the loss, but for less time than the women. Not all family members were present when the women learned that the pregnancy was in jeopardy, but they all became involved soon thereafter. Family members focused their responses during the interview on the experience of the women rather than on their own personal feelings. They felt that their primary responsibility at the time was to protect the woman and this became their "experience". However, they also suffered in solitude by not having anyone to talk to about the impact of the loss on their own lives in the months and years that followed. One woman talked about "missing her sister" because of not wanting to talk about the loss, which resulting in them rarely communicating. One woman's mother desired to talk with her daughter about the loss but did not initiate conversations thinking that she was protecting her from the suffering. When family members were asked about the effect of the loss on themselves, only one father, whose wife lost a twin pregnancy, was able to articulate how the loss affected him personally:

> When I found out that we lost the babies it is like cutting your air supply. Like reaching in your gut and squeezing your lungs dry. Your heart at the same time is painful

> especially when you are beginning to make some plans. Wow. Just like being hit in the gut and as soon as you start to catch your breath you get hit again. And then it is indescribable (participant #15).

Despite his agony, he had no one with whom to share it and he too suffered in silence.

Childbearing Expectations and Family Communication Patterns

Suffering in solitude occurred within a larger context of cultural and familial expectations for childbearing, often including the expectation they would have a large family. Many participants either had several siblings themselves or came from parents with multiple siblings. Women talked about the pressure to either have children quickly after marriage, to have several children, or to begin trying again soon after a loss:

> In my culture…I have a cousin, he is an engineer and his wife is a teacher. They have been married for 3 years and they just don't want a baby yet. My aunt is hounding them all the time. 'What's going on? Can she have babies? Is there something wrong?' And they just don't want babies yet. So I think it is family [where the expectation comes from]. Because you are just expected to have tons of babies. That's like the ultimate goal, getting married and having babies. You are expected to have a baby. If you are Mexican, and you get married, and by a year, if you're not pregnant, something is wrong. So you are expected to have babies (participant #3).

> Every year there are two or three pregnancies going. Either my cousin or my aunt or somebody is pregnant (participant #13).

Although some of the pressure or expectation came from what the participants described as general cultural norms, pressure was conveyed directly by family members. Mothers and mothers-in-law were the most likely family members to verbally apply these pressures. "She'd [mother-in-law] say '…well, are you guys going to try again? Are you guys going to try? You guys need to try.' And I felt like she was pushing us and pressuring us (participant #1)." Underlying the expectation for childbearing were the cultural influences of familismo and respeto. Familismo is noted to be the most important culture-specific set of beliefs and attitudes about family commonly held by Latinos (Coohey, 2001). Familismo is defined as a desire to maintain strong family ties, a feeling of loyalty to the family, a commitment to family needs over individual needs, and family as the primary provider of emotional support (Guilamo-Ramos, Dittus, Jaccard, Johansson, Bouris, & Acosta, 2007; Halgunseth, Ispa, & Rudy, 2006; Romero, Robinson, Haydel, Mendoza, & Killen, 2004). *Respeto* is the maintenance of interpersonal relationships through respect for self and others and includes respecting the role of each member in the family (Galanti, 2003). For the women who lost a pregnancy in this study, pressure not only came verbally from their family members, but also indirectly from their need to put family first and specifically respect their mothers.

Suffering was also influenced by a strong family communication pattern of *keeping things private*. Although talk about becoming a mother was open and encouraged within the family structure, any talk about pregnancy loss was not. Silence predominated as a communication pattern following pregnancy loss. Family members identified several private issues that were not talked about openly in their families, both growing up and as adults. Private issues included anything related to reproduction, sex or sexuality, or other personal issues such as pregnancy and infertility. For example, participant #1 said "…my mother did not talk to me about that [menstruation]. Very, very private. Very private". Another participant (#4) said "We didn't talk about the birds and the bees, I'll tell you that. That was a no no". Consequently, pregnancy loss was not a topic that was freely discussed after the initial loss. Participants also mentioned other losses in the family that were not talked about, such as the death of a 1-month old niece in one family and a 10- year old niece in another. "…nobody ever talks about my little niece that passed away (participant #3)." One mother whose daughter had a miscarriage discussed how much her daughter did not want to reveal the pregnancy or the loss to her other family members because she was not married at that time and she continued to keep the loss confidential even years later:

> She [her daughter who miscarried] hasn't mentioned it at all. I remember at the time, you know before the miscarriage and even afterwards and everything, she really did not want the rest of the family to know. I don't know that she's ever talked to them about it (participant #5).

The third and final cultural aspect in which suffering occurred was the dimension of protection. All family members talked about protecting the women during and after the loss; most often manifested by protecting them from emotional distress. One mother's mother made general statements about why she believed that friends and family do not talk about early pregnancy loss:

> …in Hispanic culture… you don't want make the mom cry so you don't want to bring up the fact that it definitely was a baby. So people [friends and family] try to make light of it by saying 'oh well you were only two months along'. I think it's just a way to comfort the mom. That's why they say things like that (participant #9).

Although comments arose from a desire to protect, they added to the women's suffering not only because of their insensitive nature, but also because being protected in this way inhibited any opportunities to talk about their loss, which was something all the women felt a need to do.

One husband talked about being strong for his wife not only at the time of the loss but as a continuous support today: “I try to be strong for her just to be there for her so she can lean on me if necessary (participant #15).” That same husband’s wife felt a similar need to protect her husband when she said “I felt like I had to keep it together because my husband was there and he was ready to start crying. More than anything he wanted a third child” (participant #13). Fulfilling a role of protector was evident both in the women and their family members. The most often cited reason for family members not talking about the loss in the weeks, months, and years after the loss was the desire to protect the women from emotional distress. They commented frequently about the need to keep the woman from crying. After sharing the story of her own three losses (one ectopic and two miscarriages), one woman also shared that her sister had lost a baby at one month of age. This woman never talked with her sister about her own loss or her sister’s loss, despite the fact that she too expressed a desire to have opportunities to talk about her loss. She did not want to make her sister cry.

Living in Silence

For the women with recent pregnancy losses, it was not surprising that their pain and suffering was acute and profound. These women shed tears as they recounted their experiences. But even the women with losses as long ago as nine years continued to feel their loss deeply. They all shared moments of joy and pain as they detailed their journey from finding out they were pregnant through to the present day. Their experiences were marked with one common thread: living with the loss in silence and not being able to freely share their suffering with others. As the support from friends and family diminished over time, the suffering in solitude expanded. The silence was furthered when the women experienced added pressure to hide the pregnancy, as was the case in three of the pregnancy losses where the woman was not married.

At the end of each interview, the women expressed profound gratitude for having an opportunity to finally talk openly about their loss.

Discussion

Living in silence characterized the long term experience for the Latina women in this study. It was also the experience, although to a lesser degree, for their family members. Women felt isolated and alone in the weeks and months after their loss when their friends and family did not grieve the loss with the same intensity as they did. Recognizing that their social network was not supportive is not unique to these Latina women. In one study of the silence of grief following fatal traffic accidents (Breen & O'Connor, 2011), participants also reported that social networks were not readily supportive and noted that their friends and family said harmful things in order to protect themselves from painful emotions. As a result, many of the participants found their social networks changed irrevocably following the deaths of their loved ones. They coped by using support groups, or by seeking out others who had experienced similar losses. None of the women or family members in our study attended support groups or sought out help or support from someone with similar losses. In fact, some of the women talked about knowing others with losses yet specifically avoided talking with them in order to protect them from painful emotions. The women themselves participated in the same silencing behavior that they experienced.

In a study about the experience of miscarriage for Israeli women, participants talked about pressure from their partners, friends, and family to quickly bounce back, forget, and move on (Gerber-Epstein, Leichtentritt, & Benyamini, 2009). Similarly, for the Latina women in our study, support faded quickly and they heard hurtful comments from their support network to "get over it". In contrast, several of the Israeli women sought professional support from counselors, where only one of the participants in our study did so.

In an Australian study of women who experienced a perinatal loss, silence was also the central theme (St. John et al., 2006). The silence began "…when they were no longer defined by being pregnant, nor by being a mother…" (p. 10). Their silence continued when their friends and family failed to recognize the loss as real and was furthered when healthcare providers did not validate their experience. For these women, the silence returned with a subsequent pregnancy, when the guilt they felt over being pregnant when others were not, left them isolated. When asked what could have helped them in their loss, all the Australian women would have liked to have had someone to talk to, a finding in our study as well. The Latina women in our study also experienced a profound silence when their pregnancy, a manifestation of motherhood, ended unexpectedly.

For the women in our study and in others, the context in which the loss occurs was directly related to their experience of loss. Callister (1995) notes that in the U.S. after pregnancy loss, there is minimal recognition for parents. For the Latina women in our study, their loss occurred within a societal view that early pregnancy loss should have a minimal, if any, impact and women are expected to quickly bounce back and return to work. Latina women have additional pressure from their cultural expectations to bear children, have a large family, and assume traditional gender roles. Other cultural groups have similar pressures. Gerber-Epstein et al. (2009) note that Israel is a child-centered culture, where birth is proof of femininity and is the central element of a woman's gender identity. St. John et al. (2006) also conclude that Australian society relishes birth, yet disregards the grief experience after pregnancy loss. For the Latina women in our study, these cultural pressures situated them in a place of vulnerability and contributed to their feelings of guilt and isolation.

In a literature review by Lee and Slade (1996), no clear predictors were found for depression and anxiety following perinatal loss. Neither did they find any clear consensus about predictors for grief after loss, such as marital status, having other children, or planned versus unplanned pregnancy. They did, however, describe variables that contribute to the distress of miscarriage, such as grief and bereavement, trauma and the process of miscarriage, and dissatisfaction with care. For the Latina women in this study, the silence they experienced after their loss was furthered due in part to their dissatisfaction with care.

One of the most striking findings in our study was the overall lack of support, both individually and collectively, from a health care perspective. HCPs, including nurses, nurse practitioners, and physicians are uniquely situated to be the first persons to support women and their family members during such a time of crisis. HCPs at all points of access, whether it be in the office, emergency room, or in the labor and delivery setting, must be aware of the long-lasting impact of their words and actions in the months and years following pregnancy loss. The women and their family members wished for simple acts of compassion and care in their encounters with HCPs. When asked specifically what HCPs could have done for them, the women most often said “give compassion.” They wished HCPs would have been sensitive to their experience of loss, acknowledging that the loss was a devastating crisis for them. They also wished for written support materials, such as pamphlets on grief reactions following loss. In addition, since family members often stayed silent out of fear they may say the wrong thing, HCPs could offer family members guidance on how to support someone during and after loss. Pamphlets, such as the one from RTS, a perinatal grief and loss support program (Bereavement Services, 2012) offers friends and family guidance for what to say and not to say after loss.

These simple interventions would lessen the suffering of other women and the families in situations of pregnancy loss.

Future research should include learning about the experiences of additional family members, including both grandfathers and extended family, and in larger numbers. Since the majority of the family member participants in our study focused on *their support* of the women after loss, rather on the experience of loss from their own perspective, future studies could attempt to clarify and differentiate the experiences of family members. To further examine the cultural influence of *keeping things private*, more in-depth study of communication patterns between Latina women with pregnancy loss and their family members would enhance understanding of how communication patterns affect coping after loss. As well, similar studies of pregnancy loss in diverse cultures would help to broaden our understanding of this experience for a broader range of women and their family members.

As HCPs we must value the stories of Latina women and their family members and provide the compassionate and sensitive care they so desire. We must find ways to create nurturing environments so they feel safe and secure in sharing their experience. Family members should also be considered when implementing ways to best care for women experiencing pregnancy loss. Helping all family members cope with their own loss as they support one other should be the priority of HCPs. No one should be left to suffer alone.

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Chapter Three: Role of Protector

The Role of Protector: Latino Cultural Values and Beliefs Related to Early Pregnancy Loss

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Abstract

Purpose: The purpose of this study was to explore cultural values and beliefs that influenced the pregnancy loss experience for Latina women and their family members through an examination of the role of protector.

Design: Qualitative grounded theory.

Method: Participants included sixteen members of nine Latino families living in the Central Valley of California who experienced a pregnancy loss in the last 10 years.

Findings: The role of protector was a key element in the experience of pregnancy loss for Latino women and their family members which included protecting the pregnancy, protecting one another, and protecting their identity as mothers and fathers. Protection strategies were employed by women who had experienced a pregnancy loss and their family members and were most often used to protect one another from emotional distress.

Discussion: Healthcare providers should strive to facilitate protective efforts of Latina women and their family members and to assist them in protecting one another in positive and compassionate ways.

Key words: Pregnancy loss, miscarriage, grief, Latino, family, protection

The Role of Protector: Latino Cultural Values and Beliefs Related to Early Pregnancy Loss

Background and Significance

For most families, the news of a pregnancy brings joy and anticipation for its members. Mothers and fathers are typically eager to share their excitement with both friends and family in their social arena. However, not all pregnancies culminate in the birth of a healthy baby. One out of every five women will suffer a pregnancy loss at some point in their childbearing years (Conway & Russell, 2000; DiMarco, Renker, Medas, Bertosa, & Goranitis, 2002; Smith, 1988; Swanson, 1999). Pregnancy loss is defined as the loss of a pregnancy or baby through miscarriage, ectopic pregnancy, stillbirth, or newborn death before the first 28 days of life. Before the 1970's, very little research focused on the experiences of women suffering pregnancy loss (Hughes & Riches, 2003; Robinson, Baker, & Nackerud, 1999; Toedter, Lasker, & Janssen, 2001). Fortunately, the body of research today is quite extensive. Pregnancy loss or miscarriage results in increased levels of depression, anxiety, and somatization when compared to women who gave birth to a live baby (Janssen, Cuisinier, Hoogduin, & de Graauw, 1996). Pregnancy loss is both physiologically and psychologically stressful, with short and long term effects (Klier, Geller, & Ritsher, 2002; Magee, MacLeod, Tata, & Regan, 2003; Walker & Davidson, 2001).

Despite the growing number of studies in the area of pregnancy loss, the body of research consists of studies whose participants were predominately Caucasian women, leaving healthcare providers who care for minority women and their family members at a loss as to how to provide culturally appropriate care. Although the authors of one review referred to studies that included Latino participants, no published studies were found that examined pregnancy loss from the Latina mother's perspective (Whitaker, Cavanaugh, & Klima, 2010). Moreover, the only studies that examined pregnancy loss from the perspective of other family members, such as grandparents, siblings, or aunts and uncles, were studies reported from the parents on the perspective of other family members (O’Leary, Warland, & Parker, 2011) or were studies of grandparents’ grief following the death of a child (Ponzetti, 1992; White, Walker, & Richards, 2008).

Although a gap exists in the literature on pregnancy loss for Latina women and their family members, literature on general Latino cultural values and beliefs is plentiful. Several values and beliefs are directly related to Latino family structure and function and are influential on the road to recovery after the loss of a pregnancy. Two values and beliefs of particular interest are Familismo and Respeto. Familismo is noted to be the most important culture-specific set of beliefs and attitudes about family commonly held by Latinos (Coohey, 2001). Familismo is defined as a desire to maintain strong family ties, a feeling of loyalty to the family, a commitment to family needs over individual needs, and family as the primary provider of emotional support (Guilamo-Ramos et al., 2007; Halgunseth, Ispa, & Rudy, 2006; Romero, Robinson, Haydel, Mendoza, & Killen, 2004). Respeto is the maintenance of interpersonal relationships through respect for self and others and includes respecting the role of each member in the family (Guilamo-Ramos et al., 2007).

In addition to these Latino values and beliefs, the social and personal construct of motherhood is central for Latina women. In most contemporary Latino societies, motherhood is conceptualized as a gendered division of labor, ideal femininity, symbolized by the Virgin Mary, whose primary responsibility is to raise children (Guendelman, Malin, Herr-Harthorn, & Vargas, 2001). These values and beliefs are important elements in pregnancy loss since Latina women receive the majority of their support from their family (Whitaker et al., 2010).

Latinos are one of the fastest growing populations not only in California (CA), but in the United States (U.S.) as well (Galanti, 2003). According to the U.S. Census Bureau (2011), of the 36.3 million people who live in CA, 13.1 million are Latino (36%). However, these statistics do not likely represent the actual population since many undocumented immigrants are reluctant to declare residency. Minority women, including Latinas, are more likely to have late entry or no prenatal care, higher perinatal mortality rates, higher teenage birth rates, come from poorer families, and have poorer health status and less primary care (Healy, et al, 2006; Muhuri, MacDorman, & Ezzati-Rice, 2004; Solorio, Yu, Brown, Becerra, & Gelberg, 2004). Minority women, including Latinas, are just as likely if not more, to experience a pregnancy loss at some point in their childbearing years (Schott & Henley, 2007; Van, 2001). With the large number of Latino families in CA, and the lack of literature on the Latino experience of pregnancy loss, a clear need exists for research that focuses on the pregnancy loss experience of Latina women. The purpose of this study was to explore the influence of Latino cultural values and beliefs on the experience of pregnancy loss.

Method

Symbolic interactionism (SI), which helps to understand human group life and human conduct (Blumer, 1969), served as the theoretical framework for this grounded theory study. SI addresses how people dealing with life's experiences use an interpretive process to handle and modify meanings. Grounded theory, rooted in SI, was selected to examine how cultural values and beliefs influenced Latina women and their family members experience with pregnancy loss. In this paper, one portion of an overall study is presented. The parent study explored the experience of pregnancy loss for Latina women and their family members and to examine the process used to integrate the loss into the life of their family. In the overall study, *Suffering in*

Solitude emerged as the central process characterizing the pregnancy loss experience for Latina women and their family members (submitted for publication). Suffering occurred in the context of cultural and family expectations for childbearing and communication patterns of keeping things private. Suffering was furthered by negative encounters with healthcare providers. Because the context of Latino cultural values and beliefs was so influential to the experience of loss for these women and their family members, a closer examination of the values and beliefs and their impact was completed and is reported in this paper.

The sample consisted of 16 women and their family members who experienced pregnancy loss in the past 9 years. Participants included mothers (n=7), mothers of the mother (n=5), fathers (n=3), and one mother's sister from nine families. Pregnancy losses included both miscarriages and ectopic pregnancies and all occurred before 13 weeks gestation. Ages of the participants ranged between 32 and 57 years of age. All participants lived in the Central Valley of CA at both the time of the interview and the loss. Interviews occurred between six months and nine years following their loss. Ethical approval was obtained by the Committee on Human Research at the University of California, San Francisco. Written and verbal informed consent was obtained before the interview began in the language of participants' preference (English or Spanish). Participants were encouraged to terminate the interview at any point if it became too difficult to talk about their experience. Contact information for counseling services and for a grief and loss support group were available but no participant wished to contact these services at the time of the interview. Upon completion of the interview, participants were given a small gift of appreciation (a small wooden angel statue) for sharing their stories. Interviews were digitally recorded and transcribed verbatim.

Data analysis began when the first interview was complete. Transcripts were read and re-read to fully understand the events being described. Data were analyzed using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to identify the similarities and differences across interviews. This involved taking each piece of the data and comparing it to other pieces, always asking "What is happening here?" Using open coding, the researchers began to identify, name, and categorize phenomenon, such as *Stayed Within the Family* and *Dealing With Issues Alone*. Codes were created and then elevated to conceptual levels when themes began to emerge. For example, the code K*eeping Things Private* and *Stayed Within the Family* became merged with several other codes related to communication patterns noted among participants. This process of axial coding is the practice of relating codes to one another, through examination of their context, causal and intervening conditions, and consequences (Strauss & Corbin, 1998). ATLAS.ti (2007) was used as a data management tool during the analytical process. The primary researcher read and re-read all transcripts. Initial coding was done by the primary researcher and then discussed in-depth with other members of the research team to clarify, confirm, or reject meanings. Participant member checking occurred informally during data collection and formally after analysis with a discussion of the conceptual model with three of the participants, all of whom agreed it reflected their experience accurately.

Findings

The importance of family, specifically expressed as the *Role of Protector,* was the central cultural value and belief that emerged in this study of Latino women and their family members who had experienced pregnancy loss. The role of protector comprised three components: protecting the pregnancy, protecting one another, and protecting the identity. The role of protector was a code seen early in the data analysis when family members described the support they gave to one another at the time of the loss. It was noted again when family members discussed why they do not talk about the loss with friends or family. As the analysis developed and more interviews took place, more examples appeared in which both the women who suffered the pregnancy loss and her family members were protecting one another from painful emotions. The role of protector was also evident when families talked about what women should and should not do during pregnancy to protect the baby. Finally, protection also played a role in the women's identity as a mother and to a limited degree, the men's identity as a father.

Protecting The Pregnancy

Ways in which women protect their pregnancy were evident in how participants described what was allowed or forbidden during pregnancy. One woman changed jobs from a nurse's aide at a convalescent hospital to a nutritional services worker so she would not be doing heavy lifting. Women protected their pregnancy by taking "extra special care of myself" (mother #2) or "taking it easy, staying on bed rest" (mother #1). Advice passed down from generation to generation on how to take care of themselves during pregnancy was often heeded, such as "… my mom always told us not to bend down, not to go down a set of stairs, and not to carry heavy items" (grandmother #11). Heavy lifting, climbing down stairs, and stretching were ways in which pregnancies could be put into jeopardy. Some examples were implicated in causing injury to the baby and others included a risk for pregnancy loss. For example, stretching was thought to cause the umbilical cord to wrap around the baby's neck and heavy lifting could cause a miscarriage. One mother blamed her pregnancy loss on not yet knowing she was pregnant before spending the weekend moving furniture. However, with her subsequent pregnancy, she followed all the advice from her mother, rested, did no lifting or hard work and still miscarried again and the distress she experienced with the second loss was equal if not more than her first loss.

Also important to participants were particular pieces of advice that were common knowledge among Latina women. In particular, during a solar or lunar eclipse, it was important for the women to provide special protection for their unborn by wearing a red ribbon or red underwear, or attaching a safety pin, a small iconic medal or a key to the pregnant woman's blouse or underwear. Although not all participants shared a belief in the protective capacity of these practices, even those who did not believe, said they would wear them "just in case". Their intention to protect the baby was evident in their adherence to these beliefs. "I will always wear a safety pin for my pregnancies. I will do anything for my kids" (mother #10).

Women avoided specific substances that were known to be harmful to their babies, such as drugs and alcohol. When one woman was in the emergency room, cramping and bleeding on the day of her miscarriage, she refused to take morphine for the pain "just in case" the baby survived. Another mother always took a pregnancy test before drinking any alcohol in case she was pregnant. Avoiding alcohol, smoking, second hand smoke, and caffeine were common practices for pregnant mothers. Others identified the value of avoiding certain foods such as hot chili, lemons, and chocolate as they might also be harmful to the baby.

Protecting the pregnancy was also how both mothers and fathers clung to hope, even when there was little or no hope for the pregnancy's survival. One couple went to see their physician for a routine appointment where he bluntly told them that he did not see a heartbeat on ultrasound and the woman had miscarried. The husband clung to hope and offered words of encouragement to his wife even after hearing they had lost the baby: "So, we went home. And my husband kept saying 'It's okay, it will be fine. Maybe it's a mistake' (mother #6). It took two more weeks, a second opinion, two more ultrasounds to confirm the loss, and signs of infection before this woman agreed to have the recommended dilation and curettage (D&C). Other women also clung to hope even when the doctor told them they had lost the pregnancy. "… you have to play to that little piece of hope… that maybe it's still OK" (mother #8). After a miscarriage diagnosis, two mothers continued to take several home pregnancy tests to verify that they had been pregnant.

Protecting One Another

The second component of protection involved protecting one another, where both women and family members found ways to care for and support one other. Fathers and family members were excited to hear the news of the pregnancy. Fathers continued to protect mothers by offering words of encouragement when the pregnancy was in jeopardy and with their physical presence during the loss. After the loss, fathers protected mothers by sheltering them from friends or family when mothers did not want to see anyone or talk about the loss. However, mothers did not always appreciate several of the fathers' protective actions. Specifically, when fathers did not cry in front of them, did not show any emotion, and did not talk about the loss, the mothers felt isolated and alone. One mother recalled how her husband would not share his feelings in front of her: "I know he was sad. I could see it on him. But he just would not go with it [his feelings] and explain to me how he felt or anything" (mother #2). Another mother felt she "…was there for him and he was not there for me. I never saw him grieve over it, not once" which she eventually named as a contributing factor in the dissolution of their marriage.

Family members protected each other through a conscious refusal to talk about the loss. Both mothers and fathers avoided talking about the loss with each other to protect one another from emotional distress. Their silence was also motivated by a desire to "be strong" for each other. Although feeling a need to be strong was more frequent with the fathers, mothers also felt a similar need to be strong for fathers and other family members. One couple protected one another from emotional distress by not crying in front of each other, knowing that they each very much wanted the pregnancy. “She is very strong and didn’t show me emotions when we got the news about losing the babies but I knew she was hurt” (father #15). One woman, years later, finally asked her husband why he stopped talking about the baby after the loss was confirmed. He revealed that he wanted to be strong for her and he could not accomplish this while showing his own emotional distress:

> But then when he heard I had to go and have the D&C done, he totally changed. He was so strong. He never ever mentioned the baby again. Now he tells me that he stopped talking about the baby because he had to be strong for me. He never mentioned the baby again. Like he just switched. Because I was hearing him cry over all the days before, and then he just stopped. No more crying or nothing (mother #3).

Fathers and family members also felt the need to protect mothers from crying and to “prevent tears” whenever possible. They purposefully avoided talking about the loss out of fear that if they brought it up, the mother would start crying again; they needed to keep the mom from crying. One mother who lost three of her own pregnancies also used silence to protect her sister from crying, even though they shared the experience of having lost a baby: “It’s two factors: One, it’s hard to see your sister cry and not know what to do. The other part is wanting to protect her from something that might be sad for her to experience” (mother #3). One mother who had her own pregnancy loss talked about her sister’s pregnancy loss and her own refusal to bring up the subject when they were together: “I would rather not talk about that [her sister’s miscarriage]. It is not that it is something forbidden to talk about but it makes me upset so I don’t want to talk about it. It makes me cry to remember and it makes her cry as well” (mother #13).

Protection from the emotional distress and tears from pregnancy loss was not the only reason some women and their family members stayed silent. One mother's mother stayed silent out of respect for her daughter's desire to maintain secrecy about the pregnancy. Her daughter, who was in high school at the time of her loss, did not want to reveal the pregnancy or the loss to the rest of her family since she was unmarried. Over the years she maintained her silence with her daughter in order to protect her from emotional pain, but suffered having no one to share the pain of the loss of her first grandchild. One mother kept quiet with her family about two of her pregnancies because she was not married at the time. Although the father of the babies knew, he was the only one and years later she continued to suffer in silence over losing both pregnancies and not being able to share her pain with the rest of her family.

Other family members purposefully stayed silent out of not knowing what to say or a fear of saying the wrong thing. One mother recognized why her family never asked her how she was doing after her pregnancy loss: "They are scared to make it worse. They might say something wrong so they just wait" (mother #10). One family member described it simply: "I really don't know what to say to her" (grandmother #9). Despite the fact that women and family members had numerous reasons for maintaining silence the women wished that they lived in an environment where their loved ones would ask them about their loss and allow them to talk. Every woman at the end of the interview expressed profound gratitude for the opportunity to talk about their loss, often for the first time, as did some of the family members.

Participants also protected one another through acts of service and support. Acts of service included babysitting other children so the mother and father could spend time alone, cooking meals, doing laundry, and providing a means of distraction, such as shopping. Whether family or friends lived close or far from each other, the most frequent way in which family showed support was by phoning or checking in regularly. One mother cherished the calls from her family, even when she felt she was unable to be open to receiving the support:

> They were calling me on a daily basis, you know, calling me, calling me. And that really helped me. Even if I wouldn't play it [the answering machine], I would hear what they were saying. And if I was locked in my room, my husband would play it. Sometimes he would play it over and over so I could hear it. That was helping me. I know somebody cares for me, besides my husband, somebody cares for me (mother #2).

Encouraging words, a shoulder to cry on, helping them get rest, hugs, and family visiting were all ways in which participants protected one another through supportive action. Mothers and mothers-in-law offered words of encouragement. However, some of those words were hurtful. "You need to get over it" and "At least you didn't know it" were comments that the women felt were insensitive.

Protecting Their Identity

The final component of protection involved the participant's identity as a mother, father, or grandmother. Who they were and are today as parents was evident in several ways, including their joy when finding out they were pregnant, belief that life begins at conception, their profound loss when the pregnancy ended, and their explanations of why the loss occurred. When the women learned they were pregnant, they identified themselves as mothers, not mothers-to-be, and made plans for their future family life. They were excited and shared the news with friends and family, even when some family encouraged them to wait until the pregnancy was further along before revealing the news. When complications with the pregnancy became evident, this news presented a threat not only to the life of the baby, but also to the women's identity as a mother. They responded by clinging to hope, even when they were told the baby had died in utero. Women asked for a 2nd and 3rd ultrasound, asked for a second opinion from another provider, continued to take home pregnancy tests, searched the internet for stories that would support their hope, and then delayed any decision by asking for more time. Not only were these actions ways in which mothers and fathers protected their unborn, but were also ways in which they protected their own identity as parents.

Lack of Protection

Women and their family members felt a lack of protection from their healthcare providers (HCP) during and after their loss. Behaviors of HCPs rarely met their expectations and needs as a grieving parent or family member. For many of the women and their family members, their loss was compounded when healthcare providers failed to recognize their belief that life begins at conception and their attachment to the pregnancy, despite the early gestational age. One woman described how the physician told her there was no baby after her loss through ectopic pregnancy which was very difficult for her because to her it was a baby. She felt his statement diminished her loss and failed to recognize her identity as a mother. Another mother struggled with a similar encounter with her HCP: “I don’t know if it was the Catholic in me, or if it was the Mexican in me, but to me, when he told me that it was an embryo, that hurt (begins crying). To me that was a baby” (mother #6).

The loss for these women was significant in that they felt devastated and often depressed in the weeks and months following the loss. Some of them isolated themselves from their support system, by refusing to answer their phone or allow family to come and visit. One mother revealed that her husband came home and found the kids wandering around eating peanut butter from the jar because she had been too depressed to care for them and make their lunch. Other family members also felt the loss profoundly. One father was devastated after he and his wife miscarried twins: "…to lose your babies, it is something else. Like plucking your heart out but then again, have to put it back in to move forward (father #15).

For these mothers and fathers, their identity was further injured when members of their support system made insensitive comments. Although many of the women suffered from the silence that ensued when friends and family did not know what to say, others suffered from hearing comments that diminished their identity as a mother or father. Comments such as "you can get pregnant again" or "just get over yourself" typically came from the women's mothers or mothers-in-law. However, healthcare providers were equally likely to make insensitive comments that dismissed their role as mothers or fathers. "It wasn't a baby anyway" or "It was just a clot" were hurtful comments that demonstrated a failure to recognize the importance of the pregnancy for these parents. Consequently, women and their family members were dissatisfied with the care they received.

In order to protect their identity as mothers and fathers, parents developed explanations for why the loss occurred. Many of their explanations were linked with advice from their own mothers and grandmothers. Although no single explanation emerged as central, several shared similar beliefs. Some women felt that they contributed to the loss in some way, either by their activities (heavy lifting, moving furniture, working long hours), or having an illness. One believed that miscarriages can happen if a woman receives a bad scare during her pregnancy, although this had not happened to her. Religious beliefs also played a role in explaining the loss. Two women felt that pregnancy loss in general could be the result of punishment from God for some sin. Several believed the loss was a part of God's plan, even when they did not understand it. In their words, the loss was "meant to be."

Finally, religion played a central role in the pregnancy loss experience. For several women, religious beliefs or advice from religious leaders complicated their suffering, either when it conflicted with HCP recommendations or when a pregnancy outside of marriage left them feeling isolated. For the women who experienced an ectopic pregnancy, the active decision to terminate the pregnancy conflicted with their beliefs that life begins at conception and abortion is not accepted. For other women whose pregnancy loss occurred outside of marriage, their pain after loss was exacerbated because they felt they could not talk about the pregnancy or the loss with family members. One women hid the pregnancy and the loss from her family because of their disapproval of the relationship since they were not married:

> None of my family members wanted me to see my boyfriend. They were totally against our relationship. So when I went to see him I told my family I went out with some friends. When I found out I was pregnant, I couldn't tell them [her family]. So the whole thing I went through with just my best friend. I had to hide everything from my family, everything. So I went and stayed with her and she helped me through the whole thing. So nobody knows, they don't know about my 2 miscarriages at all (mother #3).

Discussion

Cultural values and beliefs play an essential role in how individuals process important life events. For Latina women and their family members, the cultural context of childbearing expectations, communication patterns of keeping things private, and the need to protect one another from emotional pain, all contributed to their suffering after their pregnancy loss. The importance of family, as expressed through the role of protector, was evident in how family members protected one another from the emotional pain inherent in the loss of a baby.

In the Latino culture, the concept of family is of utmost importance, even more important than self, where self-worth is determined by one's role in the family and by meeting family obligations (Zebracki & Stancin, 2007). For the participants in this study, family obligations included a deep need to protect one another from what was perceived as unnecessary pain. However, despite this strong desire to protect, the fear of saying or doing the wrong thing was often conducive to an environment of solitude and silence, wherein women felt they could not share their pain. In their study on intergenerational support following infant death, White, Walker, and Richards (2008) noted that grandparents were hesitant to initiate discussions about a child's loss, where grandfathers in particular were at a loss as to what to say. In contrast, grandfathers approached to participate in this study refused, citing that they had nothing to offer to the experience or did not know what to say. However, the grandmothers demonstrated contradictory behaviors of support, from offering appreciated acts of service to saying insensitive and tactless comments. Whitaker et al. (2010) noted that most of the support Latinas receive comes from their family. Consequently, when family members want to protect individual members from distress, and in turn when they are the ones to inflict the pain, grieving mothers suffer even more and feel very much alone.

Findings also indicated how the Latino communication pattern of keeping things private related to how women and their family members protected one another. Participants' communication patterns, typical in Latino families, included several topics that are considered taboo. Topics that were not openly talked about included anything related to reproductive issues: menstruation, dating, pregnancy, and sex. Taboo topics also included issues that were considered sensitive and might cause emotional distress, such as miscarriage or death. Other studies confirm this finding. For example, very little research exists on how Latino parents talk to their adolescents about sensitive subjects such as dating and sex (Romo, Lefkowitz, Sigman, & Au, 2002). In their study on Latina disclosure of intimate partner violence, Ahrens, Rios-Mandel, Isas, & Lopez (2010) noted Latino cultural taboos against any discussions involving sexual matters. They also identified the cultural norm of family well-being over personal well-being, which was expressed through the protection of their family members from distress. Latino caregivers of hospice patients felt truth telling about death was harmful and were likely to protect the patient from discussing a terminal diagnosis (Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt, 2010). These researchers also discussed the difficulty they experienced in recruitment for their study because Latino caregivers did not feel comfortable talking about death. The women and family members in our study experienced similar reluctance to talk about their loss out of a need to protect one another from emotional pain.

Related to secrecy and the communication pattern of keeping things private was the hesitancy of Latino men and women to seek professional help for emotional distress. Only one participant sought professional help from her primary care physician and he referred her to a psychologist for counseling. In their study on help seeking and receiving behaviors for emotional distress, Ishikawa, Cardemil, and Falmagne (2010) reported that seeking professional help was influenced by the family’s opinion of disclosing issues to people outside the family. They also discovered that Latinos are less likely to seek formal treatment for emotional distress, including mental health services. As well, families who discouraged help seeking left the distressed family member to suffer alone, a finding similar to the experience of the women in our study.

The importance of family is not the only influence on the loss experience for Latino women and their family members. Societal views provide an overarching context that also influences the way in which family members navigate the world after the loss of their baby.

Although no studies were found that examined the impact of cultural values and beliefs for Latina women after loss, a limited number of studies referred to the societal view as influential. In one Israeli study of women after miscarriage, the researchers were attentive to the women's child-centered culture, where birth is proof of femininity and is the central element of their identity (Gerber-Epstein, Leichtentritt, & Benyamini, 2009). Similar to the women from our study, the Israeli women had a clear cultural expectation for childbearing. These women also experienced a decline in support over time and a society that was not attentive to the personal impact of the loss, as did the women in our study. In Australia, researchers also identified that the general societal discourse on death includes a taboo of discussing grief and loss (Breen & O'Conner, 2010).

Conclusions and Implications for Nursing Practice

Results of this study of Latino women and their family members contribute to the current knowledge base of experiences following pregnancy loss. Overall, Latina women and their family members employed several strategies of protecting one another during and after their loss experience. Participants protected their pregnancies through the avoidance of harmful substances and activities. They protected one another from painful emotions through acts of service and by avoiding any discussions of the loss in an effort to prevent any tears. Unfortunately, their silence also contributed to their suffering because even though the women all expressed a desire to talk about their loss, they felt they had no opportunity to do so within their own support systems. Insensitive comments from friends, family, and HCPs contributed to the suffering of the mothers and fathers, since the comments diminished the impact of the loss and left them without recognition of the identity they sought to protect.

Family members’ communication patterns of keeping things private and protecting one another from emotional distress present a complex dilemma for HCPs. Although the intentions of family members are noble, they result in an environment where women are not encouraged to share their feelings after the pregnancy loss. The challenge for HCPs becomes how they can foster communication that would allow for more sharing of the entire family’s grief over time. One area that participants identified as an area HCPs could improve upon was follow-up. They received very little if any resources after their loss and felt abandoned when there was no continuous care. Office personnel are rarely prepared or have the time to spend with women and their family in order to assess and facilitate communication needs. One possible solution would be follow-up home visits from a public health nurse trained in both assessment and supportive strategies for women and their family members after pregnancy loss. These nurses could help family members learn what to say and not to say, could follow women over time, and could refer them to other resources when needed.

Since the responsibility of the health and wellbeing of the entire family continues to rest upon women (Mendelson, 2003), how pregnancy loss affects women’s sense of identity within the family needs further exploration. Research that includes more family members, including grandfathers and siblings, should also be considered. Healthcare providers need to recognize the strategies Latino women and their family members use to navigate their journey after pregnancy loss, including the role of protector, paying special attention to the negative impact insensitive comments have on their loss experience.

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Chapter Four: “It Was a Baby to Me”

“It Was a Baby to Me”:
Latina Encounters with Healthcare Providers during Pregnancy Loss

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Abstract

Objective: The purpose of this study was to explore Latina women and their family members' encounters with healthcare providers during pregnancy loss.

Design: Qualitative study using a grounded theory approach.

Setting: Participants were self-identified as Latina and all lived in the Central Valley of California at the time of the interviews and at the time of the loss. Ages ranged from 32 to 57 years and included women (n=7) who experienced a pregnancy loss, their husbands (n=3), their own mothers and mothers-in-law (n=5), and one woman's sister. Losses occurred between 6-12 weeks gestation and six months to nine years prior to their participation in the study.

Methods: Interviews were audio recorded and transcribed verbatim. Using a grounded theory approach, data were coded and analyzed using the constant comparative method until the central themes were identified and thematic saturation was achieved.

Results: Participants' stories reflected dissatisfaction with the care they received both during and following their pregnancy loss resulting from the lack of compassion, understanding, and support from health care providers. Rather than alleviating their suffering, negative encounters with healthcare providers contributed to the women's distress. Women believed that sensitive care would have included healthcare providers who chose words carefully and compassionately and would have been present for them in the weeks and months subsequent to their loss.

Conclusion: Showing compassion was a strong recommendation from women and their family members when questioned on how healthcare providers (HCP) could support them during and after pregnancy loss. A kind word, an attitude of concern and respect, and simple physical touch can lessen the tragedy of pregnancy loss.

Keywords: Pregnancy loss, miscarriage, Latina, dissatisfaction with care.

“It Was a Baby to Me”: Latina Encounters with Healthcare Providers during Pregnancy Loss

Introduction

Although rarely anticipated, approximately 15-25% of childbearing women will suffer a pregnancy loss at some point in their childbearing years (Conway & Russell, 2001; DiMarco, Renker, Medas, Bertosa, & Goranitis, 2002; Smith, 1988; Swanson, (1999). Pregnancy losses are typically diagnosed during a routine prenatal appointment or with presentation of abnormal symptoms, such as cramping and bleeding. The setting is usually the healthcare provider’s (HCP) office or the emergency department, which likely includes a provider unknown to them. Regardless of setting, the realization that all might not be right with the baby is usually met with fear and anxiety and will be remembered forever by the woman and her family. Despite the increase in the past 30 years of research on the emotional sequelae of miscarriage, women continue to express dissatisfaction with the care they receive from HCPs during pregnancy loss (Gellar, Psaros, & Kornfield, 2010; Stratton & Lloyd, 2008). HCPs include physicians, nurse practitioners, midwives, physician assistants, and nurses. Insensitive comments such as, “That’s not a baby” in response to a blighted ovum, is but one example of the many insensitive comments and attitudes of HCPs who do not recognize the impact of their words on a woman’s long-term fragile healing journey after pregnancy loss.

The impact of HCP behavior on the miscarriage experience has received little focus in the literature (Stratton & Lloyd, 2008: Tsartsara & Johnson, 2002), despite numerous studies that report long term emotional sequelae following pregnancy loss. Women’s responses to loss include minor impact for some; others may experience anger, guilt, anxiety, and profound long term distress such as depression and post-traumatic stress disorder (Bacidore, Warren, Chaput, & Keough, 2009). Findings from the few studies that directly examined the relationship between patient and provider point to a clear association between satisfaction with care and psychological distress after an early pregnancy loss (Lasker & Toedter, 1994; Paton, Wood, Bor, & Nitsun, 1999). When HCPs are sensitive and attentive, women are more satisfied with their care (Lasker & Toedter, 1994). Yet, the impact of pregnancy loss on women is not recognized by many HCPs (Brier, 1999; Stratton & Lloyd, 2008). Moreover, very few studies have examined encounters with HCPs from the perspective of fathers or other family members. The overall (parent study) purpose was to explore the experience of pregnancy loss for Latina women and their family members and to examine the process they used to integrate the loss into the life of their family; this paper specifically focuses on the encounters of Latina women and their family members with HCPs during and after pregnancy loss.

Method

Symbolic interactionism (SI), is a theoretical approach to understand human group life and human conduct (Blumer, 1967), and served as the framework for this grounded theory study. SI addresses how persons dealing with life's encounters use an interpretive process to handle and modify meanings. Grounded theory, rooted in SI (Jeon, 2004), was selected to examine how Latina women and their family members experience pregnancy loss. In the overall study, *Suffering in Solitude* emerged as the central process characterizing the perinatal loss experience for Latina women and their family members (submitted for publication). Suffering occurred in the context of cultural and family expectations for childbearing and communication patterns of keeping things private. Suffering was furthered by negative encounters with HCPs. Because the HCP encounters were predominately negative, a closer examination of the encounters and their impact was completed and is reported in this paper.

Recruitment and Sample: A purposive sample was recruited in the Central Valley of California through flyers posted at obstetric provider offices and then through snowball sampling. Flyers invited potential participants to share their stories of pregnancy loss, the influence (if any) of Latino cultural values and beliefs, and their encounters with HCPs. After women were recruited from flyers, they shared information about the study with their family members by giving them a study information sheet that told them how to contact the primary investigator. Family members were also recruited through snowball sampling upon completion of the mother's interviews. To be included, participants self-identified as Latino or Latina, personally experienced a pregnancy loss or neonatal death in the past 10 years or were the immediate family member of such a woman, and spoke either English or Spanish. Sampling continued until data saturation was achieved.

The final sample included women and their family members who experienced pregnancy loss in the past 9 years: mothers (n=7), women's husbands (n=3), women's mothers or mothers-in-law (n=5), and one woman's sister. Pregnancy losses included both miscarriages and ectopic pregnancies; all occurred before 13 weeks gestation. Since some of the women had multiple losses, the total number of losses was 14, with nine occurring in office settings and five in the emergency department. Participant ages were between 32 and 57 years. Interviews occurred between 6 months and 9 years following the loss.

Data Collection: Ethical approval was obtained from the Committee on Human Research at the University of California, San Francisco. Participants were given both written and verbal informed consent in their language of preference (English or Spanish) before the interview began. Pseudonyms were used for reporting findings. Semi-structured interviews were conducted in the participant's home or in the office of their primary HCP (not where pregnancy care was received). Interviews lasted an average of 60 minutes, were conducted by the primary researcher (in English) or the research assistant (in Spanish), and were audio-recorded. Interviews began with the request for participants to describe their response to initially finding out they were pregnant. Details of the loss typically followed spontaneously or were prompted with the question “When did you first realize something was not right?” Details about dissatisfaction with care also emerged spontaneously or when they did not, resulted from the request to “Tell me about the care you received either at the hospital or the office”.

The primary author conducted and transcribed all English interviews (n=13). The research assistant (RA), a bilingual, bicultural Latina nursing faculty member, received training from the primary author that included attending three interviews and subsequently conducted the Spanish interviews (n=3) with the first author present for the first one. The RA transcribed the audiotapes verbatim in Spanish and subsequently translated the transcripts into English. Both the primary author and the research assistant then listened to the audiotaped interviews while reading the transcripts for accuracy.

Data Analysis: In the parent study, grounded theory approaches were used to examine the data. Analysis began with the completion of the first interview and continued with each subsequent interview, using the constant comparative method (Charmaz, 2002; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Data were examined for differences and similarities across all interviews. Detailed steps of the analysis are reported elsewhere (submitted for publication). After the analysis was complete in the parent study and the central process of *Suffering in Solitude* was identified, the data were re-examined specifically to explore participants’ discussions of their encounters with HCPs. The primary author read and re-read all transcripts, performed the initial coding, and then returned to the transcripts and code list to re-examine the encounters with HCPs. Questions such as “What is happening here?” and “How was the encounter received?” were among the ways data were examined in order to detail the properties and dimensions of each encounter. Data were also specifically examined for positive and negative encounters, the settings in which they occurred, the reasons care was initially sought, and the impact or aftermath of each encounter. Atlas.ti (2007) was used as a data management tool during the analytical phase of the study. Rigor was achieved through purposive sampling, extensive time with the data, member checking, use of data management software for auditability, data saturation, and a full description of the participants' experience.

Results

Participants recalled their experience with vivid detail, with both smiles when recalling the joys of pregnancy and tears when reliving their pregnancy loss. All but one of the women and all family members described their encounters with HCPs during the loss as negative. Because the women and their family members expected that HCPs would help to alleviate suffering, they were intensely affected by their negative encounters with HCPs, both in office and emergency department settings. Such experiences compounded their distress and dissatisfaction. All had lasting negative consequences for the women and their family members, leaving them feeling isolated and alone. They perceived HCPs lacking in three areas: 1) compassion, 2) recognition of the depth of the loss, and 3) supportive actions. HCP behaviors deepened suffering in that participants interpreted them as indicators that the HCP did not care, did not understand, and did not support them. Both the women and their family members, despite varying lengths of time since the loss, recalled in vivid detail specific HCP comments, often becoming tearful as they remembered these hurtful encounters. Participants had definite ideas and suggestions for HCPs to improve their care of women throughout pregnancy loss.

Lacking Compassion: “You did not care!”

Women recalled numerous examples of insensitive care, typically involving tactless and inconsiderate comments. Those comments were not only painful at the time, but were repeatedly hurtful in the years that followed whenever the women remembered their pregnancy loss, interacted with other pregnant women, had subsequent pregnancies, or received any other health care. Most women reported receiving several negative comments from a variety of HCPs at the time of their loss; some reported only one negative comment, but even that sole comment changed the entire experience of loss. When it was their personal HCP who made insensitive comments, women's trust was shaken and they subsequently changed providers. For other women, the insensitive comments came from encounters with unfamiliar emergency department HCPs; these too were deeply distressing. Comments that contributed to the women's suffering were curt and dismissive in nature, and lacked empathy, such as "*Better luck next time*" - a comment made by an emergency department physician as she left the woman's room.

Only one woman remarked that her obstetrician was sensitive to the fact that she was miscarrying and spent time with her; however, she did not receive the follow up care she felt she needed. All the women acknowledged that HCPs may have offered their comments as gestures of support or with the right intention, but the women's perceived insensitivity of the HCP's comments outweighed any good intentions. The women expected that HCPs would understand the depth of distress that accompanies pregnancy loss and would respond with comforting words. Statements such as "*well, let's try again*" and "*there's always next time*" were particularly upsetting. The emphasis on "*trying again*" minimized the women's need to deal first with the impact of the loss before contemplating the future. Although one woman was partially satisfied with the care she received in the emergency department, none of the other women or family members felt that emergency department personnel had a caring and compassionate attitude; no HCPs said they were sorry for the woman's loss.

Insensitive care was not limited to HCPs' tactless comments, but also included HCP silence. One woman described her ultrasound in the emergency department: "*she [the ultrasound technician] did the ultrasound and she's looking and I'm looking. I'm asking her questions and she was just silent the whole time. I didn't want her to lie to me … I wanted her to be honest, but just the silence was horrible*." Other women supported the idea that HCPs did not always know what to say, so they either made inappropriate comments or said nothing at all. Because HCPs did not know what to say, mothers believed they quickly left the room, leaving the women with no opportunity to ask the many questions they had. Moreover, when the HCPs were abrupt and rushed, spending too little time with them, the women's distress escalated. Particularly in the weeks after the loss, mothers felt abandoned when HCPs failed to make follow-up appointments, to ask about the loss, and to offer an accepting environment where women felt they could return and give voice to their suffering.

When family members were asked to describe the care they received at the office or hospital, they often recalled the same insensitive HCP comments reported by the mothers, even if they were not present when the comments were made or the comments were not directed towards them personally. Not only mothers felt hurt by HCPs' insensitive comments, but family members were as well because their desire to support and protect the mother was thwarted. One woman, for example, retold the events surrounding disclosure of the pregnancy loss to her sister and brother-in-law, describing the HCP as abrupt, uncaring, and with "no bedside manner." Such accounts distressed family members and resulted in their feeling helpless.

Most insensitive encounters were attributed to physicians, either in the medical office or the emergency department. Comparatively few comments were made about nursing personnel but were noted by some. When asked specifically about the nurses in the emergency room, some women did not remember them at all or that they displayed much compassion. One woman described the nurse as *"…doing her job, but not emotionally doing her job.*" Participants perceived nurses as being rushed at times, not taking time to explain procedures, and sometimes excluding family members.

Some women provided excuses for poor HCP behavior, such as the busy pace in the emergency department. "*But they were so busy, you know, it's the emergency room*." One woman, whose physician called her loss "*just a clot,*" justified his comment as medically correct but doing so did not alleviate the woman's distress: "*I think he was just trying to make me feel better*." Another woman referred to gender as an explanation for insensitive care. "*Maybe it's because he was a male. He doesn't know what I'm going through*." None of the women felt the insensitive treatment they received was related to their ethnicity.

Lacking Recognition: "You did not understand!"

The women's dissatisfaction also resulted from their perception that the HCPs they encountered at the time of their loss failed to recognize how important the pregnancy was to them and how attached they were to their baby. All the women were excited to find out they were pregnant and subsequently were distraught when they lost their baby. As they shared their stories of loss, several women emphasized, "*It was a baby to me*" in response to their description of the HCPs' failure to recognize the level of attachment they had developed and the impact of the pregnancy loss. "*Even if to him [the physician] it was just a little bunch of cells, that didn't matter. To me it was a child already and I loved it*." The women felt that if their HCP had listened to them as they expressed their concern, they would have been less likely to make comments that were hurtful, since they would have recognized the impact of the loss.

One woman described how unprepared she was for her loss after having surgery for an ectopic pregnancy. Although the emergency department physician explained the urgent need for surgery to save her life, including the risks and benefits, he failed to talk about the loss of the baby itself. After surgery, she said: "*I remember I asked the doctor, so how is the baby? Is everything ok? And he just told me, there is no baby. And I was like, what do you mean? And he said it wasn't a baby anyway. That's what he told me. And I said yes it was. It was my baby*." The HCP's failure to clarify the actual procedure left this woman imagining things that were even more distressing to her than the truth which she learned years later. "*I pictured how it happened. He [the surgeon] told me they [ectopic pregnancies] grow and feed off the nutrients in your tube, except it ruptured. So I pictured the baby suffering and the baby drowning. So that's why it was so hard. He told me it was just a clot, it wasn't a baby. But it was a baby to me*." Another woman described a similar experience when she went to the emergency department with heavy bleeding. She had passed a large blood clot at home and not knowing what to do with it; she took it with her to the hospital. She began to explain to the nurse about the clot. "*But she [the nurse] said 'Oh, we don't need that. Just throw it away.' And I thought maybe it was...(long pause)…the baby. And I didn't want to get rid of it*".

The woman whose distress was compounded by the ultrasound technician and the abrupt emergency room physician thought perhaps the frequent occurrence of pregnancy loss in the emergency department might contribute to the callous treatment. "*I know they see it daily but I don't care. It doesn't happen to me daily.*" Other comments reflected this perception that the pregnancy loss was a singular, devastating, and unfamiliar experience for the women and their family members, even though it may be a routine event for the HCPs. Women and their family members arrived in the emergency department in a state of crisis, knowing there was something terribly wrong and their pregnancy was in jeopardy. However, instead of receiving acknowledgement of their loss and compassionate care, their distress was compounded when HCPs failure to acknowledge the importance of the loss.

Family members were also distressed by the pregnancy loss. Although some did not articulate what the pregnancy loss meant to them personally, they felt protective of the mother and were also distressed by HCPs' insensitive language. Describing her sister's suffering after her physician discounted her loss with an insensitive comment, one family member said, "*She cried and cried saying 'my baby, my baby'. There was nothing I could say to make her feel better… Nothing I could say or do*." Family members felt hurt when HCPs failed to recognize the importance the pregnancy held for their family.

Lacking action: "You did not support!"

Women and their family members longed for supportive actions from their HCPs. The women hoped that HCPs, particularly their primary physician, would create a place of empathy and understanding where the mothers could feel safe sharing their pain, even if for only a few brief moments. Supportive action was lacking during the immediate event and in the weeks following the loss. Describing the isolation on a surgical floor after an ectopic pregnancy, one woman said, "*They had me up on the surgical floor afterwards, so I never felt like they [HCPs] thought of it as a baby…it wasn't really a loss*." When asked if they received any grief-related resource discussing miscarriage or pregnancy loss, none of the women or their family members recalled receiving any supportive materials. No one received any mementos such as a baby blanket or an ultrasound picture. During the interview in her home, one woman left the room to get a file folder to show the interviewer. It contained 10 home pregnancy tests, all with positive results still visible. She was noticeably proud to show them, as they were her only tangible pieces of evidence of being pregnant. She had continued to take the tests even after the doctor told her she had miscarried and the tests remained positive for several days after the loss. She held the tests in her hands and smiled at the memory of finding out she was pregnant and then shed tears over the reality of the loss. Another woman brought a book to her interview that her husband had given her about pregnancy loss. She clearly treasured this book and held it close to her heart during the entire conversation.

One of the women visited her physician two weeks after her pregnancy loss and asked for more time off from work. Her physician refused and told her to "*Go back to work and forget about it*." She then went to her human resources department and "begged" for more time off, which they gave her. One woman's mother accompanied her to the two-week follow-up visit after having had a dilation and curettage (D&C) for a miscarriage and was shocked that not one word was mentioned about the loss. The only thing that was discussed was birth control. "*There was no discussion about the miscarriage. No discussion about what she might be experiencing, what could be happening, how are you feeling? Nothing. Nothing emotional*." All the women experienced lack of follow-up after the loss. They felt that as soon as the loss was confirmed, they were left to deal with the loss alone. One woman had positive comments about the care she received in the emergency department when the physician told her it was not her fault and encouraged her to follow-up with her primary doctor. Although she appreciated the support, it was short lived since it was her primary physician who told her to go back to work and forget about it, refusing to give her the extra time she needed off work to heal.

Only one woman described her care as supportive and was satisfied with the care she received both in the hospital and in her HCP's office. Although she denied having received any written support materials from any HCP, she did not express any dissatisfaction with this.

Participants' Recommendations for Healthcare Providers:

When asked what HCPs could do differently, the women and their family members offered clear suggestions for HCPs. "*Compassion. That's the number one thing. It didn't seem like they had any compassion. I had the feeling that it wasn't even a loss to them. It was something that happened and they see it all the time. But you know that shouldn't have been the way they treated us*." This woman went on to say how compassionate care would have changed their entire experience: *"… we, my husband and I, would have left there feeling a lot better than we did. We already felt devastated; but on top of that, the way it all went down was just more devastating.*"

The women also asked for more time with the person giving them the bad news. They felt the HCP who delivered the news did not want to be there, rushed from the room as soon as possible, and did not allow enough time for them to ask questions.

All the women recommended HCPs offer written materials on pregnancy loss. For example, they would have appreciated having information about the causes of pregnancy loss and about how men and women might grieve differently. One woman had other small children and suggested materials be given on how to discuss pregnancy loss with them. Some of the women and family members proposed that offering a support group or individual counseling could be helpful, although only two of the women and no family members actually used this type of support.

Family members felt at a loss for what to say and wished for some guidance in this area. They felt helpless as they stood by and watched their loved one suffer. When asked what HCPs did to specifically support family members they all gave the same response: “Nothing.” However, when asked what HCPs should have done, they recommended HCPs offer written materials about what to say and not to say, suggest ways in which they could be more involved, extend visiting hours or allow some exceptions to hospital rules, and acknowledge that they also were grieving the loss of a loved one (a child, a grandchild, or a niece or nephew).

Discussion

Participants’ accounts of encounters with HCPs occurred spontaneously as they recounted their stories of pregnancy loss. These distressing encounters stood at the forefront of their memories and attested to their long-lasting impact. The women’s suffering was compounded because in response to the HCP behaviors, they felt as if their HCP did not care (lack of compassion), did not understand (lack of recognition), and did not support them (lack of action). Most HCP behaviors were at a minimum rude, and at worst, disrespectful. For women and their family members, the moment of learning about the loss changed their lives forever. That moment was recalled repeatedly in vivid detail in the years that followed, and each time triggered the women’s initial trauma of having the news delivered without sensitivity.

The women’s dissatisfaction was not unique to our study. A lack of compassion and sensitivity leading to dissatisfaction with care was also noted in a study conducted in the United Kingdom that examined hospital care after miscarriage (Paton et al., 1999). A literature review of encounters with HCPs indicated that lack of communication was a major factor in women’s dissatisfaction with care and included avoidance, thoughtless comments, cold or neutral attitude, and insensitivity (Gold, 2007). Although the review encompassed a 40-year timespan and included more than 60 studies, miscarriage studies were excluded since they "…are typically managed in an outpatient setting or may not require medical attention at all" (p. 231). However, our findings indicate that women's and their family members' experiences with HCPs in the emergency department and beyond are equally important with early as with later pregnancy losses. In another study in which women were asked about their experience with care at a specialized miscarriage clinic, findings revealed that humanistic care, including sensitivity, recognition of their loss, and not feeling rushed, were the most important factors in their satisfaction (Tsartsara & Johnson, 2002). Providers need to recognize the importance of these factors when caring for women and their family members during and after pregnancy loss.

The women in our study felt that HCPs did not recognize that they had lost a 'baby" and that they loved that child just as much as if it had been born alive at full term. Other researchers reported a similar result in a study of pregnancy loss aftercare in which they noted a clear discrepancy between the HCP and the patient in relation to the importance of the loss, where providers often did not recognize the magnitude of the loss for women (Geller et al., 2010).

The impact of pregnancy loss for family members has not been reported elsewhere. The family members in our study not only experienced their own loss, but also felt the need to fiercely protect their loved one from unnecessary emotional pain. Consequently, when HCPs either made insensitive comments or failed to recognize the magnitude of the loss, family members were twice injured, not only from their own personal loss but also from the pain inflicted upon the mother.

Women and their family members longed for support that included not only tangible written materials but also a place to express and share their pain. When HCPs' comments were insensitive, participants felt alone with nowhere to go. Anger and dissatisfaction from a lack of opportunity to talk about their loss has been experienced by others as well (Brier, 1999). When HCPs were attentive and provided adequate time to talk about their loss, to ask questions, and to express feelings, women were more likely to be more satisfied with their care (Brier, 1999; Gold, 2007). Our participants encountered insensitive encounters in a variety of settings, including phone calls from home, HCP offices, and emergency departments. Although not all HCPs follow patients long term, an attitude of caring and compassion is an important element for satisfaction at every moment of contact whether that be during a first time meeting at 3a.m. in the emergency department or a routine visit in their personal HCP's office.

A possible explanation for HCPs' lack of sensitivity may be their limited training on how to convey difficult news. Literature on breaking bad news indicates a common thread: physicians receive little or no training in this regard (Colletti, Gruppen, Barclay, & Stern, 2001; Guerra, Mirlesse, & Baiao, 2011). A recent commentary on how to deliver bad news, geared toward physicians, outlined several credible suggestions: speak frankly but compassionately, use simple language avoiding scientific descriptions, remain with the patient, and avoid defensiveness (Loaiza & Arroyyave, 2009). However, the same article recommended that practitioners say "I know how hard it is for you. I understand how you feel" (p.67). This advice is in direct contrast to what the women in our study said they needed. Even if a HCP has personally experienced a pregnancy loss, no one can know exactly what another is experiencing and to say so tends to diminish the significance and personal nature of the other's loss. Although several studies offer descriptions of how to manage early pregnancy loss, the focus was on medical versus surgical management and failed to address the psychological impact altogether. Moreover, no evidence was reported in the literature about how to advise "middle persons" such as an ultrasonagrapher, other technicians, or nurses on how to discuss potentially negative findings or other bad news, especially when professional standards or agency guidelines prohibited them from actually conveying such news. All clinical care providers should be taught about the psychological impact of pregnancy loss on women and their families and trained how to optimize their encounters with individuals in this situation (Borrell & Stergiotou, 2013; Colletti et al., 2001; Guerra et al., 2011; Loaiza & Arroyave, 2009). Training about how to interact compassionately should occur during early training and be reinforced during residency or through attendance at specialty conferences, such as those offered by RTS (Resolve through Sharing), an organization committed to educating clinical practitioners on providing sensitive care across the spectrum of pregnancy loss (Bereavement Services, 2012).

For the women in our study, tangible items that either verified or represented their pregnancy were meaningful, particularly when HCPs minimized their loss. For one woman, it was the handful of home pregnancy tests; for another it was the book on loss her husband gave her. For others it was an ultrasound picture. The practice of providing tangible mementoes for early pregnancy loss is a challenge. When pregnancy loss is further along, such as during the second and third trimester, mementoes such as footprints, locks of hair, photographs, and clothing can be offered to women and their family. Some studies have shown that satisfaction with care is greater with later losses, compared with early ones (Geller et al., 2010; Tsartsara & Johnson, 2002). One possible explanation for the discrepancy is the lack of tangible proof of pregnancy or simple mementoes for women experiencing early pregnancy loss. However, possible mementoes include ultrasound pictures, baby blankets, and books or pamphlets that support parents after miscarriage. Other ideas include supporting the women to start a grief journal, plant a memorial garden, or wear a piece of jewelry with special meaning.

Limitations

In recruiting family members for this study, female family members were more willing to participate than males. Of the seven fathers who were approached, only three agreed to share their stories. Two grandfathers initially agreed to participate, but eventually declined because “there was nothing to talk about.” In total, eight grandfathers were asked to participate but all refused. Additionally, siblings were not included because most families had children too young to participate. However, in one family with children old enough to know about the loss and participate, the mother declined their participation. Her rationale was to protect them from any emotional pain, which was consistent with the expressed expectation of family members to protect one another from distress. Despite the limitation in recruitment, the women and family members who did participate articulated not only their own experience but also elements of the experience of others in their families.

Implications for Emergency Nurses

Women experiencing pregnancy loss encounter nurses at many points of care; from the HCP office or clinic, to the emergency department, to the operating room, and beyond. Emergency department nurses are front line HCPs who are often the first contact when patients experience unexpected complications with pregnancy. Emergency department nurses are also uniquely positioned to help model sensitivity for other HCPs, such as physicians or obstetricians in the emergency department. Since many HCPs do not receive adequate training and practice delivering difficult news, they would benefit from seeing what compassionate care looks like. Most physicians learn how to deliver bad news through trial and error or from observing other physicians (Colletti et al., 2001). Sitting with the patient, taking time, holding a hand, and even shedding tears were all ways in which women and their family members felt emergency department nurses could show compassion to families during and after pregnancy loss. All the women who lost their pregnancies in the emergency room could not recall any specific instances of compassionate care provided by the nurses during their brief stay.

In the real world setting of the emergency department, where census changes rapidly and acuity of the patient load for each nurse varies from moment to moment, having the time to sit at the bedside of a patient for an extended period can be challenging. However, being compassionate takes no more time than being insensitive. A kind word, an attitude of concern, and simple physical touch can lessen the tragedy of pregnancy loss. In some emergency departments, other personnel could often be the ones to supplement this supportive care. Patient advocates, social workers, and volunteers can be trained through educational events sponsored by each organization to provide compassionate support after pregnancy loss.

Future studies should focus specifically on satisfaction with care during and after miscarriage, both in the office setting and in the emergency department with women who have been satisfied with their care. Areas of interest could include what made the care outstanding, how did the care affect their overall experience, and how was it healing for their journey of grief. Examining the training emergency physicians and nurses receive in relation to delivering difficult news and how that education could be improved may reveal the specific deficiencies. Studies that include women at all gestational ages and their family members might reveal significant differences in how care is delivered at different stages of pregnancy. For example, some studies have revealed that parents appreciate seeing and holding their stillborn after birth or receiving mementoes such as footprints; yet early pregnancy losses do not have such opportunities. This information might lead to the development of interventions appropriate for differing gestations. In addition, studies that examine the impact of interventions following miscarriage (i.e. ultrasound pictures, mementos, grief and loss written support materials, and community support resources) are needed to determine the most beneficial standard of care to improve the well-being of mothers following pregnancy loss.

Conclusion

Despite the pain women and their family members experienced from the insensitive care they received, they were able to articulate what sensitive care should entail: HCPs who spend time with their patients, choose their words carefully and compassionately, and stand beside them in the weeks and months following the loss. Although emergency nurses do not follow patients after they leave the department, they are responsible for making sure the patients have all the necessary information they need when they are discharged. This responsibility includes providing a place for women to share their responses to the loss of their baby, whether that is having someone hold their hand in silence or simply acknowledging the loss and accepting various expressions of emotion. It also could include offering tangible resources to help women hold the few memories they have of the pregnancy. At the very minimum, nurses have a responsibility to recognize the impact of early pregnancy loss and be compassionately purposeful with the words they use in talking with the women and their family members.

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Chapter Five: Conclusions

Understanding the experience of pregnancy loss for Latina women and their family members was the aim of this dissertation. The study was qualitative in design, using a grounded theory approach to answer the research questions. Although one of the original research questions involved how women and their family members integrate the loss into the family, it became clear early into data collection and analysis that integration was not part of the experience for these participants. Instead, suffering in solitude and living in silence were more reflective of the experience for Latina women and family members.

Suffering in Solitude

For many women and their family members, the news of a pregnancy is a time of celebration and joy. Many families begin planning for the future as soon as the pregnancy is confirmed. Names are chosen and nurseries are painted as families prepare for the new arrival. This was the experience of the women and family members in this study. All were excited to be pregnant and quickly began planning for their family's future. However, not all pregnancies end with the birth of a healthy baby. In all, seven women and nine family members shared their stories of loss, which included 14 losses in total as some women had more than one loss. When pregnancies end suddenly and unexpectedly, women often struggle to make sense of the loss. The women in this study were surrounded by friends and family at the time of the loss, but shortly thereafter their support system faded and they were left to suffer in solitude.

Living in Silence

For the women whose pregnancy losses were recent, it was not surprising that their pain and suffering was acute and profound. These women shed tears during the interviews as they recounted their experiences. But even the women with losses as long ago as nine years continued to feel their loss deeply. They all shared moments of joy and pain as they detailed their journey from finding out they were pregnant through to the present day. Sadly, their experiences were marked with one common thread: living with the loss in silence and not being able to freely share their suffering with others. Researchers note that society relishes birth, yet "…there is a silent disregard for the grief and despair that pregnancy loss evokes" (St. John, Cooke, & Goopy, 2006, p. 8). This silence was evident in the experience of both the women and the family members, as they recounted their journey through loss. In an Australian study of women who experienced a perinatal loss, silence was also a central theme (St. John et al., 2006). The silence began "…when they were no longer defined by being pregnant, nor by being a mother…" (p. 10). Their silence continued when their friends and family failed to recognize the loss as real and was furthered when healthcare providers did not validate their experience. The Latina women in our study shared a similar experience where friends and family failed to recognize the importance of the loss and their support quickly faded. In addition, the encounters with HCPs were abrupt and uncompassionate, which left the women feeling they had nowhere to go.

Cultural Influences

Suffering did not occur from the impact of the loss alone. Although the loss was devastating and painful for the women and their family members, their suffering was compounded by several factors. For Latina women and their family members, the cultural context of childbearing expectations, communication patterns of keeping things private, and the need to protect one another from emotional pain, all contributed to additional suffering.

Childbearing Expectations

For these Latino women, there was pressure to have children and become mothers. This finding was also noted in women having a miscarriage in Israel, where the culture is child centered and birth is proof of femininity (Gerber-Epstein, Leichtentritt, & Benyamini, 2009). Although the researchers noted the cultural influence of childbearing and gender identity, they also noted a societal lack of attentiveness to the personal impact of pregnancy loss, another finding similar for the Latina women. In the Latino culture, the concept of family is of utmost importance, even more important than self, where self-worth is determined by one's role in the family and by meeting family obligations (Zebracki & Stancin, 2007). For the women, pressure to have children, have more children, and in the face of loss, try again quickly, were brought to bear by mothers and mothers-in-law. The "try again quickly" comments only served to further the women's suffering as they left no room for them to grieve the loss of the recent pregnancy.

Keeping Things Private

In their study on Latina disclosure of intimate partner violence, Ahrens, Rios-Mandel, Isas, & Lopez (2010) noted Latino cultural taboos against any discussions involving sexual matters. They also identified the cultural norm of family well-being over personal well-being, which was expressed through the protection of their family members from distress. Participants in this study revealed similar communication patterns that were typical in their families, including several topics that were considered taboo, such as anything related to reproductive issues, including menstruation, dating, pregnancy, and sex. Taboo topics also included issues that were considered sensitive and might cause emotional distress, such as miscarriage or death. Living in an environment where sensitive issues are not discussed furthered the silence the women experienced after their loss. Women and their family members disclosed issues that should "stay within the family", a cultural norm that contributed to their reluctance to share concerns outside the family structure.

Role of Protector

Whitaker, Kavanaugh, & Klima (2010) noted that most of the support Latinas receive comes from their family. The importance of family, as expressed through the role of protector, was evident in these participants, as they protected one another from the emotional pain inherent in the loss of a baby. However, despite this strong desire to protect, the fear of saying or doing the wrong thing often resulted in an environment of solitude and silence, where women felt they could not share their pain. Family members felt that talking about the loss would cause the woman to cry, resulting in emotional distress, which they wanted to avoid at all cost, in order to protect her from anguish. In a study of caregivers of hospice patients, Latino caregivers wished to maintain secrecy about a terminal prognosis, did not want detailed information about death and dying, and were surprised and disturbed by the open communication about death (Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt 2010). Similar to the women in our study, the participants felt truth telling was harmful to the patient and cruel to the family, where their responsibility was to protect the patient and not cause harm to one another

HCP Lack of Compassion, Recognition, and Support

HCP behaviors were also implicated in contributing to the women's suffering. Lack of compassion, recognition of the impact of the loss, and support were behaviors that the women and their family members perceived as insensitive, leading to their dissatisfaction with care. Dissatisfaction was not unique to the women from this study. A lack of compassion and sensitivity leading to dissatisfaction with care was also noted in the United Kingdom in their examination of hospital care after miscarriage (Paton, Wood, Bor, & Nitsun, 1999). As well, in a literature review of encounters with HCPs, lack of communication, including avoidance, thoughtless comments, cold or neutral attitude, and insensitivity, was a major factor involved in dissatisfaction with care.(Gold, 2007). In another study about their experience with care at a specialized miscarriage clinic, women indicated that the most important factor in their satisfaction was humanistic care, including sensitivity, recognition of their loss, and not feeling rushed (Tsartsara, & Johnson, 2002).

Several possible explanations for HCP insensitivity exist. One, is the possibility of a lack of training for physicians, who were the HCPs making the insensitive comments and the ones who disclosed the bad news. One recent commentary on how to deliver bad news, geared toward physicians, outlined several credible suggestions: speak frankly but compassionately, use simple language avoiding scientific descriptions, remain with the patient, and avoid defensiveness (Loaiza & Arroyave, 2009). However, the same article also recommends that practitioners say “I know how hard it is for you. I understand how you feel” (p.67). This advice is in direct contrast to what the women in our study said they need. Even if a HCP has personally experienced a pregnancy loss, no one can know exactly what another’s experience, and to assume so has the effect of diminishing the other’s experience. Another possible explanation for physician insensitivity is the lack of literature directed toward physicians. When miscarriage was used as a search term, most of the studies geared towards physicians were about medical versus surgical management of miscarriage and did not discuss the psychological implications of loss or best practices leading to satisfaction with care.

Physicians were not alone in lacking support and compassion for the women in our study. Albeit fewer in number, participants also referred to insensitivity by nurses. Moreover, despite the goal of nursing to provide comfort to vulnerable patients, no participant mentioned that a nurse had spoken kind words or offered compassion. Lack of training on the impact of early pregnancy losses could be one possible explanation. However, all nurses receive training in their education on how to provide compassionate care in a variety of complex situations. Although they are not often the ones to directly deliver the news of a pregnancy loss, they are the HCPs that often stay at the bedside when the physician leaves, a practice not noted by our women. The pace and acuity of the emergency room and the workload of the nurses could be an explanation for why nurses were “*doing their job but not doing their job*” as our women experienced.

Hearing of the pregnancy loss for the first time occurred in one of two environments for the women in our study: the HCP office or the emergency room. For those who first heard the news in an office setting, their physician may be the only provider with any experience in providing compassionate care. Most physician offices today employ medical assistants rather than nurses, although that is not always evident to the public. It is unclear if the medical assistant training includes compassionate care or how to support women and their family members during and after pregnancy loss. Moreover, in addition to a lack of professional training, a societal view still exists that early pregnancy loss is something quickly forgotten and has no lasting negative consequences.

Implications for Practice

Participants repeatedly expressed a desire for HCPs to provide comfort and compassion in their caregiving encounters, that is, to provide an environment where the women could share their distress over the loss of their baby. A place where a HCP might even momentarily hold their hand in silence, or take a few minutes to let them shed tears or talk about their feelings of grief.

Nurses, nurse practitioners, and physicians are uniquely situated to be the first persons to support women and their family members during this time of crisis. They are also the ones likely to break the news to the women who have miscarried that something terrible has happened. At all points of care for women experiencing pregnancy loss, whether in a medical office or clinic, an emergency room, or in a labor and delivery setting, HCPs must be aware that their words and actions have a significant impact not only in the moment but continue in the months and years following the loss. The women wished for sensitivity on the part of HCPs, shown by their acknowledgment of the pregnancy was more than just an embryo. The women perceived words such as “products of conception,” “embryo”, or “fetus,” as dismissive and they felt the HCPs minimized their loss and ignored the idea that to them it was a baby. The women also desired simple acts of compassion from HCPs, such as taking the time to listen or spending even a few moments with them after delivering bad news.

In addition to desiring that HCPs use sensitive and caring language, women also would have welcomed supportive written materials, such as books or pamphlets that provide information about and guidance for how to manage loss and grief. Although giving such resources is a common intervention in late pregnancy loss (stillbirth and neonatal death), none of the women in this study, who all had early losses, received any such written materials or mementoes. Family members also wished for written materials, especially with guidance on what to say and not to say or how to support a loved one after loss. Pamphlets, such as the one from RTS (formerly known as Resolve Through Sharing), a perinatal grief and loss support program, offers friends and family guidance for what to say and not to say after loss. These simple interventions could lessen the suffering of other women and families who experience early pregnancy loss.

Although the women did not verbally express a desire for tangible mementos, they spontaneously showed the interviewers the few treasured mementoes they had: a book given by a husband, numerous positive pregnancy tests, and an ultrasound picture. Again, there is a discrepancy in the standard of care between early and late pregnancy losses. Most hospitals offer mementoes with late pregnancy loss: typically, photographs, footprints, baby clothes/blanket, or a lock of hair. Even when miscarriage occurs early in the pregnancy and does not provide an opportunity for footprints or photographs, other mementoes could be offered to acknowledge that the women indeed had baby that was lost. Such mementoes could include an ultrasound picture (even when there is no heartbeat), a gender neutral baby blanket, a small stuffed animal, plant or tree seeds that could be planted in memory, or a list of other ways to memorialize a baby lost to miscarriage (such as jewelry, naming, memorial gardens, and/or grief journaling).

Implications for Future Research

Since the responsibility of the health and wellbeing of the entire family continues to rest upon women (Mendelson, 2003), how pregnancy loss affects women's sense of identity within the family needs further investigation; in particular, their identity as mothers. The relationship between the role of protection from emotional pain and the consequence of silence also need more exploration. Research that includes more family members, including women's fathers and children, should also be considered. With the lack of literature on other minority groups and pregnancy loss, future research needs to include minority members as participants. In this study, family members were interviewed individually and asked about their experience and the experience of other family members. Future research should include entire family units using family interview techniques. Individual participants, other than the mothers, focused their loss experience in relation to how it affected the mother, rather than on their own sense of loss. Understanding the experience of loss from a grandmother's or a father's perspective needs further exploration.

This study included women and family members who all experienced early pregnancy losses, which may not have the same "silent disregard" as later losses. Many of the studies with satisfaction with care as a variable, include providing the mother with opportunities to see and hold the baby, and offering mementoes, where in early pregnancy loss there are no such opportunities. Lastly, since the encounters with HCPs were predominately negative in this study, examining encounters with HCPs that were positive would provide greater insight into how and why women were more satisfied with their care.

Limitations

In recruiting family members for this study, female family members were more willing to participate than males. Of the seven fathers who were approached, only three agreed to share their stories. Two grandfathers initially agreed to participate, but eventually declined because "there was nothing to talk about". In total, eight grandfathers were asked to participate but all refused. Additionally, siblings were not included because most families had children too young to participate. However, in one family with children old enough to know about the loss and participate, the mother declined their participation. Her rationale was to protect them from any emotional dismay, which was consistent with the expressed expectation of family members to protect one another from distress. Despite the limitation in recruitment, the women clearly articulated their own experience and family members related their experience of responding to the women.

Since cultural influences of keeping things private was an important finding, there is a concern that the findings here only represent women and family members who were willing to talk about their experience with a stranger, which might be different for those Latinas who have an even greater sense of keeping things private or family members with an even stronger role of protection.

One other possible limitation was that of the exclusion criteria. The loss was no less than 6 months ago and no greater than 10 years ago. Although this broad time range allowed women and their family members to participate from both recent and long standing experiences, it excluded women with more recent losses. In addition, it excluded women and their families that experienced a pregnancy loss in a time where standards of care might have been quite different than they are now.

Overall, this examination of the experience of pregnancy loss for Latina women and their family members gives voice to the women and their family members who so graciously shared their stories of emotional distress and their resulting ongoing silence about the loss. It also illustrates the importance of context, where Latina women feel pressure to move on quickly from their losses and not share their experience of loss within their families. This study also revealed the important role of the HCP whose interactions distressed the mothers not only at the moment the loss was realized, but in the weeks and months afterwards as well. In particular, words chosen in haste and stated insensitively left these Latina women feeling isolated and distressed. Their suffering could have been lessened by simple acts of compassion and caring.

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Appendix A

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Cultural Differences in Perinatal Grief and Loss: A Qualitative Study

This is a research study about Latino families who have experienced the loss of a pregnancy or newborn, through miscarriage, stillbirth, or neonatal death. The study researchers, Marla Marek, MSN and Betty Davies, Ph.D. from the UCSF Department of Family Health Care Nursing will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you have experienced a perinatal loss (miscarriage, stillbirth, neonatal death) and are Latino. Other members of your family will also be asked to participate in the study.

Why is this study being done?

The purpose of this study is to understand the experience of families after perinatal loss, to understand the unique needs of the Latino family, and to learn about the care received during the hospital stay.

How many people will take part in this study?

About 20 people will take part in this study. The study will include parents, grandparents, and siblings age 7 and older, with their permission and parental consent.

What will happen if I take part in this research study?

If you agree, the following procedures will occur:

- You will be interviewed by the researcher in the location of your choice (most likely your home, although other choices will be offered). You will be asked about your pregnancy, your loss, your cultural beliefs, and the care you received in the hospital.
- The researcher will make a tape recording of your conversation. After the interview, someone will type into a computer a transcription of what's on the tape and will remove any mention of names. The tape recording will then be destroyed.

How long will I be in the study?

Participation in the study will take a total of about 60-90 minutes. The first interview will last approximately 60 minutes. A second interview may be requested by either you or the nurse for clarification of topics discussed and would last approximately 30-60 minutes.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher right away if you wish to stop being in the study.

Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest or if the study is stopped.

What risks can I expect from being in the study?

- The researchers understand that pregnancy loss is often hard to talk about. Some of the questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer.
- The interview is time consuming and may be boring, but you can stop at any time

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals learn more about perinatal loss for Latino families and how to better care for them during their hospital stay.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you can still get your care from your institution the way you usually do.

Will information about me be kept private?

We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Organizations that may look at and/or copy your research records for research, quality assurance, and data analysis include:

- UCSF's Committee on Human Research

What are the costs of taking part in this study?

There will be no costs to you or your family as a result of participating in this study.

Will I be paid for taking part in this study?

Although you will not be paid for taking part in this study, a token of appreciation will be given at the end of the interview.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits, and you can still get your care from your institution the way you usually do.

Who can answer my questions about the study?

You can talk to the researcher(s) about any questions or concerns you have about this study. Contact the researcher(s) Marla Marek at (209) 988-6998 or Susan Kools at (415) 476-4040.

If you have any questions, comments, or concerns about taking part in this study, first talk to the researcher (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

You can reach the CHR office at **415-476-1814**, 8 am to 5 pm, Monday through Friday. Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

****

CONSENT

You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

The person being considered for this study is unable to consent for himself/herself because he/she is a minor. By signing below, you are giving your permission for your child to be included in this study.

Date	Parent or Legal Guardian
Date	Participant's Signature for Consent
Date	Person Obtaining Consent

Appendix B

Your Experience

Research study with Latino Women and their Families

Who have experienced miscarriage, stillbirth, or newborn death

Marla Marek, a labor and delivery nurse, and Dr. Betty Davies, a researcher at the University of California, San Francisco, are doing a study about Latino families who have experienced a pregnancy loss or newborn death. They want to ask about your experience with loss, what it is like to be Latino during this time, and to see if the care you received in the office or hospital was helpful or not. They would like to speak with everyone in the family.

Here's what would happen if you decide to participate in the study.

- You would be asked about your pregnancy, the loss of the pregnancy or the baby, how Latino cultural beliefs affected you during this time, about your hospital experience, and about the experience for the whole family. The conversation will be tape recorded, but only the research team will know what you said.
- You will speak with the nurse initially for about 30-60 minutes. A second interview, for about the same amount of time, may be requested to clarify any questions that come up from the first interview.

If you think you might be willing to be in the study you can:

- Call Marla at 209-988-6998 to ask questions about the study process
- Tell your doctor or midwife you would like to participate in the study
- Talk with your family members to see if they would also agree to be interviewed

To be in the study you need to be Latino, have experienced a miscarriage, stillbirth, or newborn death in the past 10 years, and be willing to be interviewed for 30-60 minutes. Information that you provide may help health professionals learn more about perinatal loss for Latino families and how to better care for them during their experience.

Use the numbers below to contact the nurse if you have questions or are interested in participating in this study.

Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998	Marla Marek RN, MSN (209) 988-6998

Appendix C

Mother Interview Guide

I just want to review with you the purposes of this study. We are interested in finding out about the grief experience for families after a pregnancy loss from miscarriage, stillbirth, or infant death. We would also like to know how your cultural values or beliefs influenced your grief experience, especially in relation to the care received while in the hospital.

I want to remind you that you can stop the discussion, you don't have to answer any question, or take a break at anytime during the interview today if you are feeling tired or uncomfortable or for any reason.

1. Tell me about the time when you first found out you were pregnant.
2. Tell me about the time when you first realized something was not right?
3. How did you find out that the baby had died? Or the pregnancy had ended?
4. What kind of feelings did you have in the first weeks after the loss?
5. What did you actually do when you felt …(those feelings)?
6. What kinds of feelings do you have now, compared to then?
7. What was the hardest part about the loss?
8. How do you see the loss affected other members of your family?
9. How did other people react after the loss?
10. What kinds of things were helpful to you after your loss? What didn't help?
11. Tell me what it means to you to be a part of the Latino culture.
12. In the Latino culture, what specific rituals or rules or beliefs are there about pregnancy?
13. Is pregnancy loss something that is talked about in the Latino culture?
14. Are there any beliefs about what might cause a pregnancy loss?
15. Tell me about the care you received in the hospital.
16. What would have made your hospital stay a better experience?
17. What kinds of mementoes did the hospital give you, if any? (like photos or footprints or baby hat)
18. What kinds of mementoes or grief materials were helpful?
19. Where there any mementoes or grief materials that you thought were inappropriate or offensive?
20. If there was something you could have to remember your baby, what would it be?

21. Is there anything else I should know about?
22. Thank you for sharing your experience.

Age G P Years since loss

Family Member Interview Guide

23. Tell me about the time you first found out your (wife, son, daughter, sister, brother) was pregnant.
24. Tell me about the time when you first realized something was not right.
25. How did you find out that the baby had died? Or the pregnancy had ended?
26. How did you react when you first heard the news that the baby had died?
27. What kind of feelings did you have in the first weeks after the loss?
28. What did you actually do when you felt …(those feelings)?
29. What kinds of feelings do you have now, compared to then?
30. What was the hardest part about the loss?
31. How do you see the loss affected other members of your family?
32. What kinds of things were helpful to you after the loss? What didn't help?
33. Tell me what it means to you to be a part of the Latino culture.
34. In the Latino culture, what specific rituals or beliefs are there about pregnancy?
35. Are there any beliefs about what might cause a pregnancy loss?
36. Tell me about the care your family member received in the hospital.
37. Tell me about what it was like to watch your family member go through this experience.
38. How do you feel about the ability of the hospital staff to meet your needs as a…
39. Partner/Father?
40. Grandparent?
41. Sister/Brother?
42. Aunt/Uncle?
43. Where there any grief materials or mementos offered to you specifically? (foot prints, photos)
44. Where there any mementoes or grief materials that you thought were inappropriate or offensive?

45. What would have made the entire experience better for you or your family member?
46. Is there anything else I should know about?
47. Thank you for sharing your experience.

Children Interview Guide

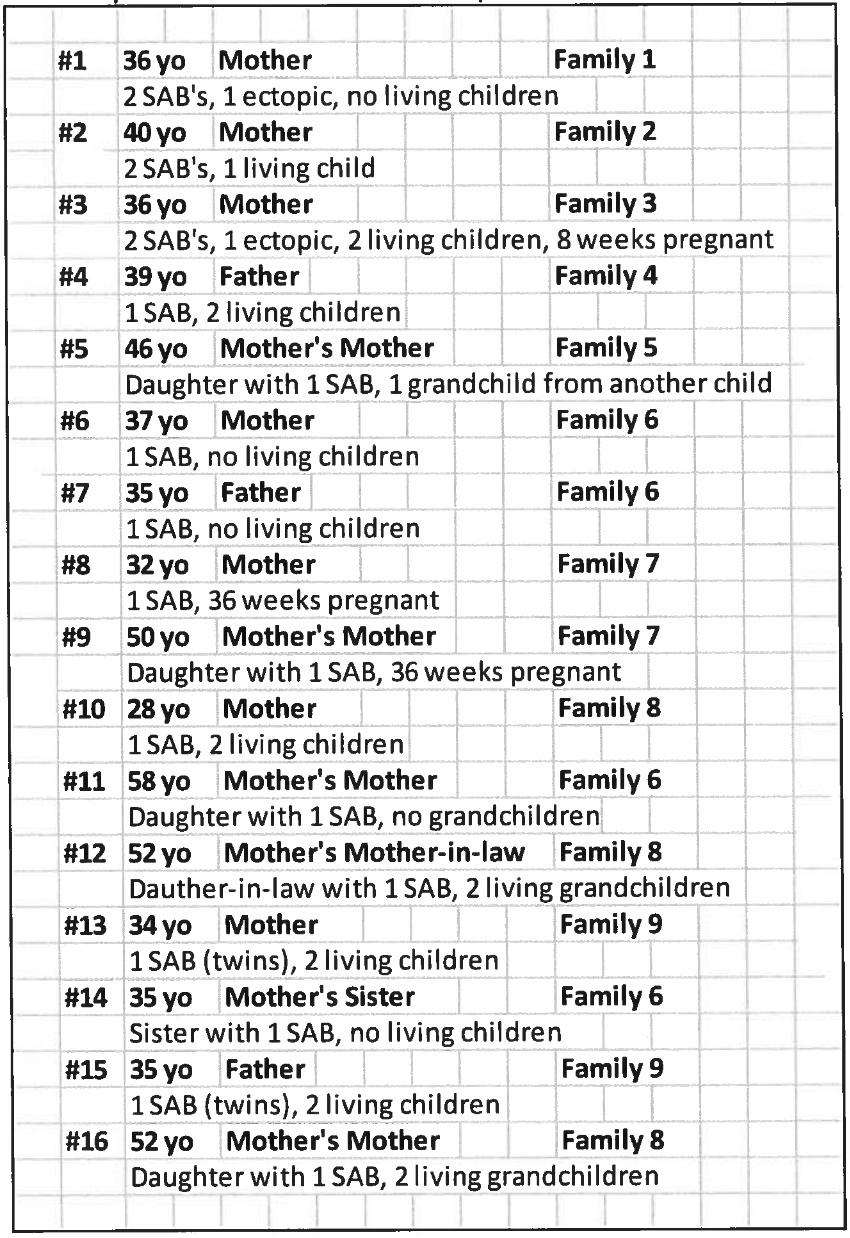
48. Tell me about the time you first found out your mother was pregnant.
49. What kinds of feelings did you have about the pregnancy?
50. Tell me about the time when you found out the baby had died.
51. What kind of feelings did you have right after the baby died?
52. What kinds of feelings do you have now?
53. What was the hardest part about losing the baby?
54. How do you think the loss affected your parents? And your grandparents?
55. What kinds of things were helpful to you after the loss?
56. Tell me what it means to you to be Latino.
57. How has "being Latino" made you look at this situation differently than other people might.
58. What kinds of things happened at the hospital that were helpful to you?
59. Tell me about the things that happened at the hospital that you didn't like.
60. What would have made the entire experience better for you or your parents?
61. Is there anything else you would like to tell me?
62. Thank you for sharing your experience.

Prompts/Probes

Could you tell me a little more about that
In what way do you mean
Could you give me an example of that
How did that make you feel
So what you are saying is…
That must have been very difficult for you

Appendix D

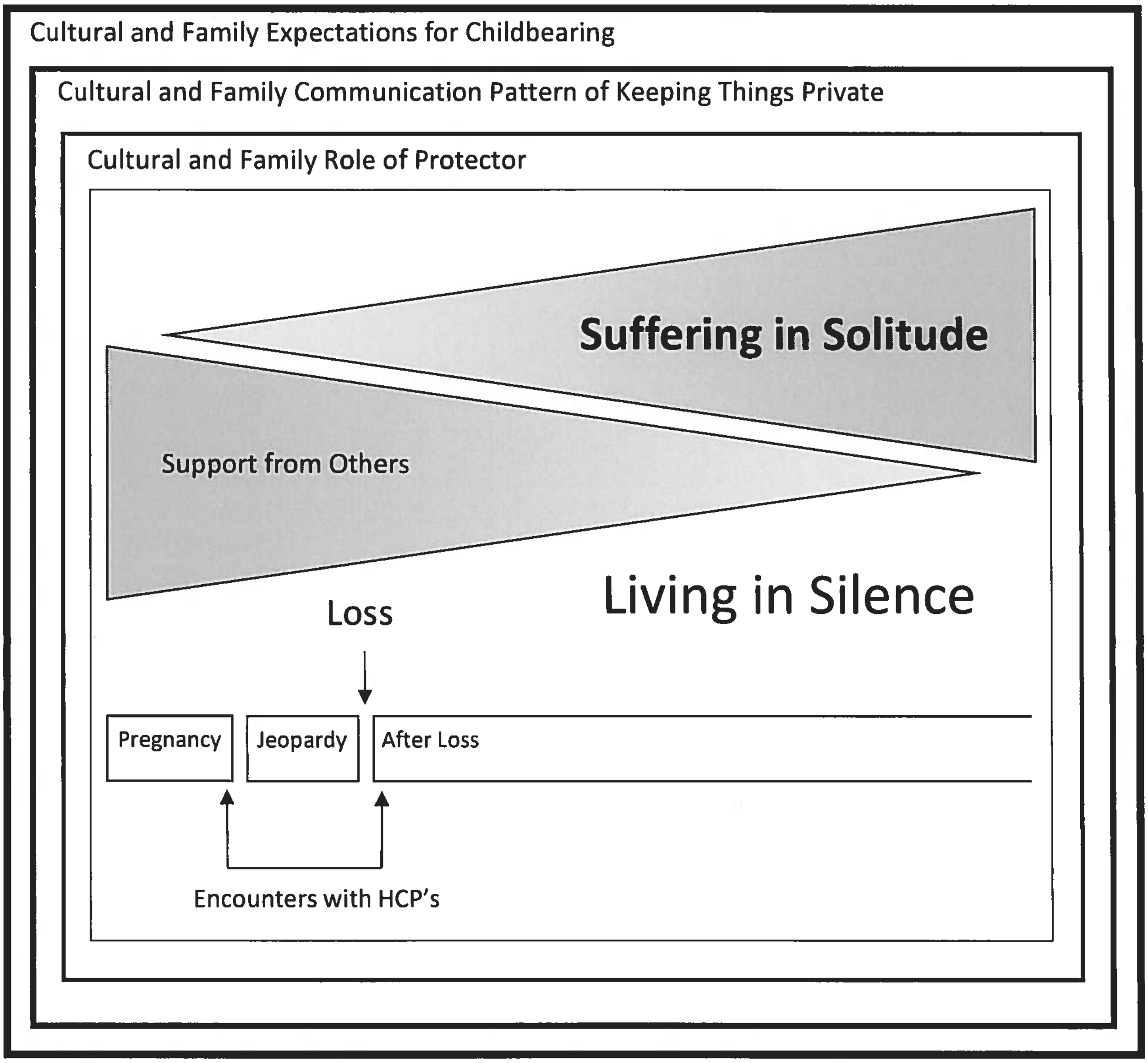
Table 1
Sample Characteristics of Participants



#1	**36 yo**	**Mother**	**Family 1**
	2 SAB's, 1 ectopic, no living children		
#2	**40 yo**	**Mother**	**Family 2**
	2 SAB's, 1 living child		
#3	**36 yo**	**Mother**	**Family 3**
	2 SAB's, 1 ectopic, 2 living children, 8 weeks pregnant		
#4	**39 yo**	**Father**	**Family 4**
	1 SAB, 2 living children		
#5	**46 yo**	**Mother's Mother**	**Family 5**
	Daughter with 1 SAB, 1 grandchild from another child		
#6	**37 yo**	**Mother**	**Family 6**
	1 SAB, no living children		
#7	**35 yo**	**Father**	**Family 6**
	1 SAB, no living children		
#8	**32 yo**	**Mother**	**Family 7**
	1 SAB, 36 weeks pregnant		
#9	**50 yo**	**Mother's Mother**	**Family 7**
	Daughter with 1 SAB, 36 weeks pregnant		
#10	**28 yo**	**Mother**	**Family 8**
	1 SAB, 2 living children		
#11	**58 yo**	**Mother's Mother**	**Family 6**
	Daughter with 1 SAB, no grandchildren		
#12	**52 yo**	**Mother's Mother-in-law**	**Family 8**
	Dauther-in-law with 1 SAB, 2 living grandchildren		
#13	**34 yo**	**Mother**	**Family 9**
	1 SAB (twins), 2 living children		
#14	**35 yo**	**Mother's Sister**	**Family 6**
	Sister with 1 SAB, no living children		
#15	**35 yo**	**Father**	**Family 9**
	1 SAB (twins), 2 living children		
#16	**52 yo**	**Mother's Mother**	**Family 8**
	Daughter with 1 SAB, 2 living grandchildren		

Appendix E

Figure 1: Suffering in Solitude was the central theme in this study. Suffering resulted in the eventual outcome of Living in Silence. Suffering occurred within the context of cultural norms of having a large family, keeping things private, and the family role of protecting one another. Suffering increased over time as support from others diminished. Encounters with healthcare providers (HCPs) typically occurred when the pregnancy was in jeopardy, during the loss, and immediately after.



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9/6/13

Date