Parenting a Lone Twin: When One Twin Dies

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PARENTING A LONE TWIN: WHEN ONE TWIN DIES

Dissertation
by

KELLY L. GRADY

submitted in partial fulfillment of the requirements
for the degree of

Doctor of Philosophy

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abstract

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Parents who simultaneously grieve the loss of one twin and nurture the surviving twin experience a paradox of grief and joy. The acute grief of losing a twin coincides with a critical time in the development of the parental role and relationship with the surviving twin. Very few researchers have addressed the unique parenting situation in which one twin infant dies.

The aim of this qualitative descriptive study was to describe the experience of parents who lose one twin in utero, at birth, or in the neonatal period. The study question was “What is the parenting experience of mothers and fathers who simultaneously face the grief of the loss of one twin while nurturing the surviving twin during infancy?” Nine parents, recruited via a support group, were interviewed. Systematic content analysis, emphasizing in-vivo coding (participant’s own words), was conducted until data saturation was reached.

A comprehensive description of the experience of raising a surviving twin was constructed. Four descriptive themes were identified: (1) Living with ambiguity: the irony of raising a lone twin, belonging and not belonging, and at least there is one; (2) Communicating the family journey: telling or not telling, deciding who needs to know, and how many children; (3) Parenting with wonder and worry: doubt and hyper-vigilance, unanswered questions, and the living twin as a unique person; and (4) Life is different now: loss of innocence, honoring both twins, making and keeping relationships, work-life challenges, and accepting that it doesn’t go away. Issues raised by parents included the ambiguity and irony of losing one twin, no one understands, multiple losses, and living with this loss.
The description of this experience gives insight to the dynamics and burden of this loss. Data from this study can inform pediatric nurses about the issues, concerns, and needs of parents who sustain this kind of loss. Therapeutic interventions based by the tenets of family-centered nursing care can be developed by understanding the long-term effects of grief on parenting.
Acknowledgements

It is difficult to thank and acknowledge the contributions of so many, and humbling, too. Foremost, I wish to thank the parents who graciously allowed me a sacred view of their family stories and also to be a part of honoring their twins. I feel privileged to have been granted this opportunity, and hope to have done so with the grace these families so richly deserve. The honesty and willingness with which the mothers and fathers in this study shared their wisdom and experiences for the sake of others in similar situations and for health care professionals was remarkable.

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Chapter 1
Overview of the Study

Introduction

The experience of parents who simultaneously grieve the loss of one twin and nurture the surviving twin represents a paradox of grief and joy (Bryan, 1995; Sychowski, 1998; Van der Zalm, 1995a). When one twin dies, the loss encompasses complex emotions that may represent cumulative layers of grief for mothers and fathers. Adding to the already multi-dimensional and complex process of parenting the surviving twin, there is the loss of the special relationship and status of twins (Bryan, 1995) and the challenge of meeting the needs of an infant while grieving, both acutely and chronically. The demands of parenting a surviving twin while facing the difficulties associated with losing the other twin represent a unique set of issues faced by those who experience this phenomenon.

Significance of this Perinatal Loss

An increasing number of families are becoming pregnant with twins; unfortunately, these pregnancies are associated with higher risks, morbidity, and mortality for both the mother and infants than singleton pregnancies. In the United States, the twin birth rate increased to 33.2 per 1,000 births in 2009, a number that has continued to rise for a period of over 20 years (Martin, Hamilton, Ventura, Osterman, Kirmeyer, & Wilson, 2010). A twin pregnancy is three to five times more likely to result in a perinatal loss, death in the neonatal period, or disability for either fetus or both than a singleton pregnancy (Bryan & Hallett, 2004). In 2007, the infant mortality rate for twins was nearly five times that of singleton births (Mathews & MacDorman, 2011); multiple births accounted for 3 percent of all live births but 15 percent of all infant deaths in the United States. Importantly, even before birth, the consequences of high-risk pregnancies may
adversely influence maternal attachment (Feldman, Weller, Leckman, Kuint, & Eidelman, 1999), a fact important for optimal infant outcomes (Ard, 2000). The relationship between bereaved parents and their surviving twin may be affected by the conflicting emotions of joy and sorrow and the permanence of the reminder of the loss in the life of the surviving twin.

Very few researchers have addressed the unique parenting situation associated with multiple pregnancies in which one baby dies leaving one or more survivor(s) (Bryan, 1995, 1999). Few researchers have focused specifically on either mothers’ or fathers’ experiences during the first few months of the survivor’s life, when grief is likely to be most intense. Further, fathers’ experiences have been particularly neglected in terms of their parenting processes in general; certainly little attention has been paid to the fathers’ experiences of perinatal loss. Paradoxically, the acute grief of losing a twin during infancy occurs during a critical time for the development of the parental role and relationship with the surviving infant. The early months of the survivor’s life may be complicated not only by the expected grief at the loss of a child, but also by the loss of becoming the parent of twins. Transitioning to the role of parent is critical under the best of circumstances. The influence of the conflicting emotions of grieving for one child while also celebrating the birth of the surviving twin is largely unknown.

The research question I addressed in this study was: “When one twin dies, what is the experience of parenting the lone twin?”

Purpose

The purpose of this qualitative descriptive study was to describe the experience of parenting a surviving twin from the perspective of those mothers and fathers who experienced the loss of one twin in utero (after 20 weeks gestation), during birth, or in the immediate neonatal period (first six weeks of life). Specifically, this research was designed to describe (1) how the
grief involved in the loss of one twin influenced the daily processes of parenting the other twin; (2) how the mothers and fathers who lost a twin coped with the challenges of simultaneously dealing with the resulting grief and yet attach with and nurture the other infant; and (3) how the emotional effects of this challenging experience affected the parents. I designed this research to provide a comprehensive description of this event grounded in the everyday language used by those men and women who were immersed in it. The primary outcome is a qualitative description intended to inform perinatal and family nurses so they can use this information to provide more insightful and sensitive care.

**Significance for Nursing**

When one twin dies, a complicated context of grieving and attachment influences the parenting experience of mothers and fathers at a crucial time in the surviving infant’s development. Because the impact of the loss of one twin on the attachment to the surviving twin is unknown, an examination of parental responses to such a loss and the management of the demands of parenting a surviving twin is needed. It is evident that a number of dimensions are involved in this process, notably, the processes of becoming parents and the stresses and anxieties associated with multiple birth pregnancies are seemingly compounded when an infant dies. Appropriate nursing care, namely, family bereavement interventions, is critical to the health and welfare of both the parents and the surviving infant’s development. This research is congruent with contemporary theories about grief and bereavement. It represents an initial step forward in the development of the nursing science of caring for families dealing simultaneously with perinatal loss and newborn care.

Because technological advances in maternal-fetal medicine resulting in fertility successes have moved forward so significantly and rapidly in recent years, there is a subsequent need for
advances in the science of the nursing care of these families to move forward as well. The care of bereaved mothers and fathers who parent children while managing the emotional challenges of loss and grief is multifaceted.

A changing paradigm for a model of grief emerging in the literature reflects a shift from the modernist approach of grief explicated as a linear sequence of phases to grief portrayed as an ongoing, livable experience (Moules, Simonson, Prins, Angus, & Bell, 2004). Described experiences of grief contradict traditional models of intervention whose creators’ aims were to facilitate processes by which persons symbolically and emotionally let go of individuals who die. The traditionally-described discrepancy, arising when a person does not or cannot let go, can cause feelings of failure and more suffering for bereaved persons (Moules et al., 2004). With such a change in fundamental beliefs about grieving, a re-examination of the meaning of various losses to the individuals who experience them is warranted. Such introspection is qualitative by nature and requires a significant amount of descriptive study in order to develop a more contemporary model.

By conducting this research, I acknowledged and described the experience of an at-risk, and perhaps hidden, group of parents. Health care professionals have been negligent in giving perinatal loss the attention it deserves (Hebert, 1998). In the case of stillbirth or infant death, parents can experience disenfranchised grief if the loss is not validated by others (Capitulo, 2005). The words of the mothers and fathers who experience the loss of a twin are likely to reveal opportunities and provide evidence for future development of nursing interventions designed to support parents through this challenging experience.

Family nurses have the obligation and opportunity to support a positive outcome of the parenting experience for mothers, fathers, and children, particularly when perinatal grief is
involved. Knowledge gained from the description of the phenomenon of parenting a surviving twin will inform the nursing care of these developing families by identifying the challenges they face and will be the foundation for an evidence-based approach to guiding these bereaved parents. The knowledge gained will contribute to contemporary nursing science that supports family growth and creative strategies for families coping with grief and decrease any interference with the normal developmental enactment of parenting and the important process of attachment between infants and parents. Ultimately, all parents who nurture children while experiencing bereavement could benefit from this research.

In Chapter 2, I examine the phenomena of parenting a surviving twin infant, an experience that encompasses a continuum of expectations from being pregnant with twins to the reality of nurturing only one. Parent-infant relationships and early parenting behaviors are grounded in attachment theories. Bereavement theories address the realities of the acute grief suffered by these parents, grief that is known to be experienced differently for mothers than fathers. Chapter 3 details the research design and methodology for data analysis implemented for this study. Research findings are reported in Chapter 4. Lastly, in Chapter 5, I included a summary of the study, as well as conclusions and implications for future research, and application of findings to clinical practice.
Chapter 2
Review of the Literature

This literature review encompasses contextual and situational dimensions involved in the continuum of both mothers’ and fathers’ experiences over time from first expecting twins to nurturing a surviving infant twin. The review is organized into the following sections: (1) the processes of early parenting, including prenatal attachment and early parent-infant relationships and interactions; (2) the experience of expecting twins, including prenatal experience of being pregnant with twins, attachment to twins, high risk pregnancies, expectations of becoming a twin family, and the challenges and risks of giving birth to twins; (3) parental bereavement, including the meaning of perinatal loss, multiple birth as a context for perinatal loss, pregnancies subsequent to perinatal loss, and parenting surviving children over time; and (4) the state of the science of bereavement theory and interventions.

Early Parenting

Several overarching facts are evident in a review of the available research about the experiences of mothers and fathers as parents during the perinatal period. First, there is the clear paucity of research conducted with fathers. Fathers’ parenting experiences have been studied considerably less than those of mothers’. Second, is that literature about parents is often confusing and may even be misleading because what is entitled “parents” in a publication, keyword, or abstract, upon closer examination, is very often research conducted primarily with mothers. Similarly, in a recent integrative review of parenting in nursing research, the authors described the use of the terms ‘parent’ and ‘parenting’ as ambiguous and inconsistent, referring to mothers, fathers, grandmothers, or both mothers and fathers together (Gage, Everett, &
Indeed, some researchers inappropriately generalize findings from research conducted with only mothers to apply equally to fathers and/or other family members.

For this review of literature, I have described the current knowledge of mothering and fathering experiences. Given the clear historical emphasis on mothering, there is an obvious gap in knowledge about fathering processes. In more recent years, there appears to be an increasing effort to address that gap, reflecting perhaps a changing societal acknowledgement of the importance of both parents in the development of their children. Not only is this imbalance being recognized, but there is also an appreciable emphasis describing the fathers’ experiences as well as those of both parents together. More researchers appear to be attending to the shared experiences of mothers and fathers while acknowledging and recognizing the differences between them (Gage et al., 2006).

**Prenatal attachment.** Pregnancy is a time of anticipation and expectation. Pregnancy, for many parents, is thought to be the context for the beginning of attachment between parents and their unborn and expected baby. Historically, like most aspects of parent-infant relationships, researchers studying prenatal attachment have focused mainly on the mother. In this realm, too, fathers are being increasingly acknowledged as important to the overall health of the developing family. Further, reproductive technological advances impact both parents, and the need for an understanding of both parents’ perspectives is evident in research recommendations for needed study.

Maternal-fetal attachment was posited to describe the relationship between a pregnant woman and her fetus (Salisbury, Law, LaGasse, & Lester, 2003). Rubin (1975) in her early work indicated that maternal-fetal attachment is based on cognitive representations of the fetus including imagined scenarios between mother and child, and a mother’s attribution of physical
and emotional characteristics to the fetus. According to classic research on binding-in, immediate mother-infant bonding is a consequence of prenatal experiences that stimulate emotional closeness (Rubin, 1977). Evidence continues to support the theoretical premise first described by Bowlby (1982) that attachment correlates with positive outcomes, such as positive mother-infant interactions and maternal competence (Cannella, 2005).

Prenatal parental-fetal attachment may begin with the positive pregnancy test and attachment has been linked to the increased use of ultrasound that has become the norm of prenatal care in Western civilization. Prenatal attachment is presumed to be a different experience for men and women, as only the mother-to-be is viscerally aware of the baby. Fathers’ prenatal attachment is more abstract due to the lack of a similar physical relationship (Sandelowski & Black, 1994). However, the more frequent ultrasounds enable fathers to view their child early in the pregnancy even before quickening (Garcia, Bricker, Henderson, Martin, Mugford, Nielson, et al., 2002; Sandelowski, 1994). Nevertheless, the effect of early and frequent ultrasounds is not fully understood. Historically, quickening has been understood to be the point at which the fetal life becomes a reality for the mother, and perhaps the father. This reality of the infant’s presence is thought to correlate strongly with maternal-fetal attachment and may also correlate with paternal-fetal attachment as well. For fathers who experience the phenomenon of a visual experience of fetal life on ultrasound, Sandelowski (1994) used the term “technological quickening.” The visual phenomenon of experiencing an unborn child’s life in utero may have a tremendous effect upon both mothers’ and fathers’ ability to attach to their unborn fetus.

Additional technological advances also contribute to the care of childbearing families and parent-infant attachment. Successful fertility treatments are allowing significant numbers of men
and women to conceive who had previously been unable to do so. For many who experience fertility treatment success, a pregnancy carried to term follows a prolonged period of grief and disappointment. In some cases, those disappointments included multiple pregnancy losses in addition to the challenges and strain of decision making and undergoing the actual treatments. Another example of available reproductive science includes earlier detection of a pregnancy with easily assessable home test kits. With the availability of four-dimensional, detailed images of fetuses in utero, chromosome analysis, genetic testing, in utero fetal blood sampling, and fetal surgery, scientific advances are changing women’s experiences of pregnancy (Hedrick, 2005). What remains unclear is the effect of such practices on men’s experiences of pregnancy. The outcome of these technological advances is largely unknown in terms of prenatal attachment. However, many researchers take seriously the possibility that the practice of ultrasound scanning may be a helpful and important means of investigation for a complete explanation of prenatal attachment and parental representations of their unborn child (Ainsworth, Blehar, Waters, & Wall, 1978).

**Parent-infant relationships.** Early parenting experiences are marked by a period of connection, relationship building, and an intense time of dependency between an infant and his or her parents. There is a significant body of literature available about the tasks and processes of early parenting. The processes involved in becoming the parents of an infant, also known as a time of role transition, have been studied widely in social science literature, including several integrative reviews and meta-analyses. In addition, special populations of parents have been studied and their parenting roles dissected. For example, Gage and colleagues (2006) developed a comprehensive list in their integrative review of parenting that includes adolescent parents, single parents, adoptive and foster parents, parents with cancer, parents who have themselves
experienced abuse or are perpetrators of abuse, gay and lesbian parents, divorced parents, first-time parents, multiparous parents and those with multiple birth children. Issues of racial and socio-economic disparity among parents are increasingly evident in the literature (Gage et al., 2006). Researchers have employed various conceptual approaches in the measurement of the experience of parenting including self-efficacy, as well as developmental and family systems theories (Gross & Tucker, 1994; McCarter-Spaulding & Kearney, 2001; Mercer & Ritchie, 1997; Riesch, Coleman, Glowacki, & Konings, 1997; Sawin, Bellin, Roux, Buran, Brie, & Fastenau, 2003).

It is clear that infant development is sensitive to the quality of the interactions between an infant and his or her parents. Becoming a mother, a process previously known as maternal role attainment, includes the acquisition of competence in providing skilled, sensitive care that fosters healthy infant development (Mercer, 1981, 2004; Mercer & Ferketich, 1995). Researchers have provided a broad evidence base in support of the significant impact made by parent-infant attachment on the critically sensitive period of infant development and the attainment of parental identity (Ainsworth, Bell, & Stayton, 1972; Bowlby, 1982; Ferketich & Mercer, 1990; Kennell & Klaus, 1979, 1984). Success in the attachment process has been associated with long lasting and positive results for the parenting mother and child (Cranley, 1981; Karl, Beal, O'Hare, & Rissmiller, 2006). Attentive, warm, and responsive care giving during infancy is believed to result in motivated, competent and emotionally healthy children (Belsky & Fearon, 2002).

Maternal attachment. A number of seminal studies form the foundation for understanding the nature of early mother and infant relationships. The terms bonding or attachment are used to describe the connection between mother and infant. However, there is no clear consensus about the similarities and/or differences between attachment and bonding. In
some seminal work, the focus is on bonding. Bonding is distinctively defined as the emotional connection made by mothers with their newborns (Kennell & Klaus, 1979). Attachment, on the other hand, was described by Kennell and Klaus as the relationship that a mother and her child develop during the first years of life, implying the process extends beyond infancy. Classic attachment theory provides a view of this developing relationship as a relational process between mother and infant (Klagsbrun & Bowlby, 1976), which has been called a reciprocal waltz they dance together (Beeghly, Brazelton, Flannery, Nugent, Barrett, & Tronick, 1995). Cranley (1981) defined maternal-fetal attachment as ‘the extent to which women engage in behaviors that represent an affiliation and interaction with their unborn child’ (p. 181).

Describing the concept of maternal-infant attachment as developmental and reciprocal is evident in Mercer’s program of research focusing on the process of becoming a mother. Mercer (2004) highlighted two critical aspects of maternal-infant attachment: (1) feeling love for and attachment to the child, regardless of problems that may be encountered; and (2) engagement, which includes child-care activities that change as the child grows. Nelson (2003) in a meta-synthesis of qualitative research about the transition to motherhood identified the processes of engagement and growth and transformation as inherent in maternal transition. In addition, synchronicity and reciprocity in the parental-infant dyad are seen as important areas influencing the developmental trajectory of the infant (Fowles & Horowitz, 2006).

**Paternal attachment.** Literature about fathers is scarce despite the fact that fathers are believed to make a unique contribution to the growth of each family member (Pruett, 1998; Montigny & Lacharite, 2005). Compared with the breadth of study about mothers, little is known about the perceptions of men who become fathers, despite the fact that fathers are expected to be participants in pregnancy and labor and delivery. Indeed, involved fatherhood has
become a culturally sanctioned expectation and the norm (Goodman, 2005). New fatherhood is a challenging and significant life change. Men are actively involved in anticipating and preparing for the birth of their children, and play a major role in their upbringing (Badenhorst, Riches, Turton, & Hughes, 2006). However, almost exclusively, the mother-infant dyad has been the primary focus of research on attachment and early relationships, ignoring the father’s contribution during this critical time in family development.

Research conducted with fathers, though limited, provides a description of some of the facets of the early parenting experiences of new fathers with their infants. It is known that the involvement of fathers with their infants after birth is important for continued development of the father's role and for the infant's well being (Parke, 1995). Further, it is through fathers’ continued involvement and interactions with their children that they form their identity as parents and solidify their emotional attachment with their children, a finding that is similar to that about mothers.

Across multiple studies, fathers demonstrate active and intentional movements toward actualizing the paternal role. In the early weeks of new or expanding fatherhood, these activities include balancing the demands of work and home, dealing with stress, managing their time, developing routines, and reprioritizing (St John, Cameron, & McVeigh, 2005). The active process of transitioning to fatherhood over time was described by Jordan (1990) as: (1) grappling with the reality of the pregnancy and child; (2) struggling for recognition as a parent; and (3) plugging away at the role making of involved fatherhood. Similarly, Goodman (2005) in a meta-synthesis of involved fatherhood identified four phases that describe fathers of infants. Those phases are (1) entering with expectations and intentions; (2) confronting reality; (3) creating one’s role of involved father; and (4) reaping rewards.
Many family researchers have recommended that future researchers approach the family as a research unit, specifically, the mother-father-infant triad (Bell, Goulet, St-Cyr Tribble, Paul, Boisclair, & Tronick, 2007; Gage et al., 2006; Gilbert & Smart, 1992). In fact, careful attention to fathers is important because of the significance of both the father-infant relationship and the couple relationship to overall individual and family well-being (Goodman, 2005).

**Stress and parenting infants.** In a meta-analysis of parenting during the first year, Nystrom and Ohrling (2004) accentuated the difficulties inherent in early parenting experiences for both parents. In their analysis of research findings from 1992-2002, these authors described the first year of parenting as “probably the most challenging responsibility faced by a new parent,” (p. 319) resulting in a generalized sense of “living in a new and overwhelming world” (p. 320). Mothers, according to the review, are overwhelmed by the primary responsibility of the child, which causes strain, limited time they have for themselves, and feeling fatigued and drained. Fathers were found to feel strained by the difficulties in living up to the new demands, to be hurt when prevented by the mothers from achieving closeness to the child, and to be the protector and provider for the family.

Being overwhelmed and experiencing stress as a parent are not new concepts in parenting literature. Theorists describe a relationship between parenting and stress that lends itself to several important implications for the process of becoming a parent. For example, Belsky’s (1984) model of parenting determinants and Abidin and Wong’s (1989) model of parenting stress described the complex nature of parenting and the intratwining of psychological, situational and child factors (Secco & Moffatt, 2003). Parenting stress affects the normal processes of bonding, attaching to, and nurturing a baby. The role of parent is an enduring role that requires continual adaptation and coping strategies in order to accommodate the changing
set of more or less stressful variables (Abidin & Wilfong, 1989).

Expecting Twins

The portrayal of twinship in society contributes to the meaning of having twins, and likely affects the transition to parenting. This portrayal often connotes having twins as a special achievement and the identity as a special family (Bryan, 1995). Mothers who are expecting twins are given extra attention, respect, and even admiration, from the medical community, their family, and friends. The confirmation of a twin pregnancy is often a surprise (Hay et al., 1990), requiring adjustment and reorientation.

Twin pregnancy. A frequent comment of authors in the research literature summarizing the prenatal experiences of the women is the uniqueness of having twins. In an interpretative analysis, mothers attributed special meaning and significance to the word twin (Van der Zalm & Bergum, 1999). The phenomenon was described as a positive ‘specialness,’ “because twins are an ‘honor,’ a ‘blessing,’ and a ‘privilege,’ women who are carrying twins receive more attention from others” (p. 110). In another study, this phenomenon was described as a “joyful, excited, and blessed. . . ” experience (Holditch-Davis, Roberts, & Sandelowski, 1999, p. 205).

Other women expressed a negative view of the uniqueness of twins. Van der Zalm and Bergum (1999) provided the following example of the negative connotation expressed by one participant: “Then going to these clinics and everything, I felt like I was this walking time bomb sometimes you know. I think that’s because just going to that clinic I just wasn’t a normal pregnant lady. . . a ticking time bomb waiting to go off. . . because you are not normal you are high risk” (pp. 105-106). One pertinent quote from Collopys’s (2000) research highlights the uniqueness of the situation when the woman conceives higher order multiples that are then reduced to twins: “After all this time . . . you’re having multiples, and then . . . all these extra
tests . . . then to have to do it [the reduction] was just like, like sliding down that hill, you know? one thing after another” (Christine, p. 80).

There is evidence to demonstrate that multiple birth families (those with twins, triplets, or more) face specific challenges related to the fact that their pregnancies are at a much higher risk for both psychological and physiological problems than are singleton pregnancies (Watson-Blasoli, 2001). Although few researchers have addressed men who become fathers of twins, becoming a mother of twins is described as a significantly challenging process, which under the best of circumstances, prenatally and after birth, includes the management of twin infants. A myriad of concerns are highlighted in the literature including the nature of high-risk pregnancies with stress and anxiety, infertility treatments, and the uncertainties of higher morbidity and mortality for both mother and infants (Collopy, 2004; Van der Zalm, 1995b). In addition, there are the physical and emotional challenges of a twin pregnancy and of managing two babies, including maternal-infant attachment, and a higher risk for postpartum depression (Anderson & Anderson, 1987; Beck, 2002; Holditch-Davis et al., 1999). Extant research chronicles the many stressful aspects related to becoming the parents of twins, suggests multiple nursing implications, and underscores the need for further research.

**Attachment to twins.** Relevant issues that contribute to the overall picture of mothering twins are evident in research findings focused on maternal-twin attachment. Prenatal attachment in multifetal pregnancies may differ from that of singleton pregnancies; it is known that mothers pregnant with twins relate to the babies in utero both individually and as a pair (Damato, 2004). Anderson and Anderson (1987) described an emergent theme of maternal justice from their study in the following account of one mother: “I try to make an effort to hold Mary when I feed her, and I also noticed that in the evening Jane settles down earlier than Mary, so at that time Mary
gets more cuddling and more attention. So I don’t know if it quite works out evenly in the end, but she does get more at the end of the day” (p. 97). A similar issue discussed by Holditch-Davis and colleagues (1999) related a parental desire to “be able to personalize with the babies by spending meaningful time with each of them and worried that their interactions might instead be task-oriented” (p. 207).

**High-risk experience.** Being pregnant with twins is an anxiety-laden and stressful experience for both parents. Indeed, prenatal care protocols treat multiple birth pregnancies as high-risk and, as such, the care of these pregnancies includes significantly more prenatal appointments, closer supervision of fetal well-being with multiple ultrasounds, as well as many restrictions placed on the women, such as particular attention to nutrition and weight gain, very careful monitoring of blood pressure and signs of preterm labor, and activity restrictions above and beyond that of lower risk, singleton pregnancies.

**Giving birth to twins.** The high-risk nature of twin pregnancies may influence maternal-infant attachment, which may in turn affect the early mother-infant experiences. The consequences of high-risk pregnancies may adversely influence maternal attachment (Feldman et al., 1999), which is important for optimal infant outcomes (Ard, 2000). Stainton and colleagues (1992) found that some mothers experiencing high-risk pregnancies resisted attaching to their fetuses during their pregnancies because of a fear that one or more of their infants might die. Another researcher asserts that the importance of a lack of prenatal attachment by women during pregnancy could have long-term effects on mothers’ abilities to meet the many needs of her children (Hedrick, 2005).

**Challenges and risks.** Authors of the literature about parenting twins paints a challenging perinatal picture, from conception to infancy, and includes a description of
overwhelming tasks associated with managing the needs of twin infants. Mothers of twins experience high-risk pregnancies and anxiety, which are often preceded by infertility and assisted reproductive technology. In many cases, the process of becoming pregnant is compounded by a myriad of additional concerns, such as possible multifetal reduction, the uncertainties of higher morbidity and mortality for themselves and both babies, and the challenges and expectations of managing the care of two babies, both physically and emotionally.

High-risk twin pregnancies present significant challenges to caregivers and families. These pregnancies are known to have significantly higher morbidity and mortality for both the mothers and infants (Kinzler, Ananth, & Vintzileos, 2000; Smith, Fleming, & White, 2007). Known increased risks include pre-eclampsia, prematurity (five times more likely in twins than in singleton pregnancies), growth restriction and twin-to-twin transfusions resulting in an overall perinatal mortality rate nearly five times greater in twins (Khalil & O’Brien, 2007). Other sources reported that a twin pregnancy is three to five times more likely than a singleton birth to result in a perinatal loss, death in the neonatal period, or disability for either one or both fetuses (Bryan, 2004). Current debate about the safety and optimal labor and delivery strategies of twins is ongoing given that even in cases of twins born after 36 weeks, there is an increased risk of death of the second twin associated with intrapartum anoxia or trauma with a trend towards greater risk among those delivered vaginally versus caesarean section (Smith et al., 2007).

Caring for twins. The post-birth picture of mothering twins is flooded with descriptions of complex issues relating to the attachment process between mothers and their twins. Beck (2002) described mothering twins during the first year of life as “releasing the pause button,” and identified four phases within a basic social psychological problem of “life on hold.” Beck
depicted the first phase as draining power; one participant describes this part of her life as “like being a servant to two very demanding people. It’s draining because you have to nurture two” (p. 600). The second and third phases involve pausing own life and striving to reset, indicative of the overwhelming loss of self, followed by the last phase, which identifies an eventual progression to ‘resuming own life,’ as one mother realized “now I am reaping a lot of the blessings of the twins interacting…in the beginning, I kept saying to my friend, ‘Where is the blessing? I’m waiting for the blessing.’” (p. 605). Similar to Beck’s (2002) discovery of “life on hold,” Van der Zalm’s research described a loss of self in women pregnant with twins (1999).

**Parental Bereavement**

Bereavement is a universal human experience. Grief, the emotional response to bereavement, is known to be a complex, evolving, and multi-dimensional process (Stroebe, Hansson, & Stroebe, 1993) representing a normal, healthy, and universal response to loss (Capitulo, 2005). For parents who lose an infant, grieving is a lifelong process of coping with the death of an infant, integrating that loss, and rebalancing life (Wallerstedt, Lilley, & Baldwin, 2003). Parental grief is an individual and couple process for which few recognized social rituals exist (Gilbert & Smart, 1992), even though bereaved parents have more unresolved grief than any other group of bereaved individuals (Zisook & Lyons, 1988). Grief has also been called dynamic, individualized, and normative (Reed, 2003). Bereaved parents often exhibit symptoms characteristic of complicated grief, and intense grief reactions can last for years (Johnson, Rincon, Gober, Rexin, & Johnson, 1993; Rando, 1986, 1991).

**Perinatal Grief**

**Meaning of perinatal loss.** Parents are recognized as individuals who form strong attachments to their developing babies and who, when they experience a perinatal loss,
frequently report profound and persistent grief reactions (Brownlee & Oikonen, 2004). Perinatal grief is dramatically different than other forms of grieving (Wallerstedt & Higgins, 1994) as multiple distinctions and circumstances exist. Since the 1980s, the significant psychological effect of perinatal death on families, primarily mothers, has been studied extensively (Chambers & Chan, 2000).

Parent-infant interaction is considered to be vital to the normal attachment processes, but equally important for parents is the detachment process that occurs when an infant dies (Thomas & Cordell, 1983). Psychological tasks that parents must manage when a child is sick or premature may be relevant to the loss of a twin, particularly if it is known that one twin is threatened in utero. These tasks have been described as anticipatory grieving and withdrawal from the relationship established in pregnancy, acknowledgement of parental feelings of guilt and failure, and the resumption of the relationship with the surviving infant that had been disrupted (Caplan, Mason, & Kaplan, 2000).

**Mothers’ experiences.** The attachment between a mother and her infant in perinatal death is unique because all aspects of the relationship involve future realizations (Uren & Wastell, 2002). Parenting amid grief and loss has not been well studied although the experience of perinatal loss has been described as an ambivalent transition into motherhood (Lundqvist et al., 2002). Mothers who experience a perinatal loss feel extreme sadness, guilt, suicidal ideation, emptiness, isolation, irritability, and anger (Kavanaugh, 1997). Even those mothers who experience complicated pregnancies are unprepared for their infant’s death and the intensity of the grief (Kavanaugh, 1997).

For mothers, the grieving process for perinatal loss may be significant and traumatic, last for months to years, and extend into subsequent pregnancies (Hutti & Usui, 2004). The effects
of grief on the mental health of mothers who experience perinatal loss is known to increase both anxiety (Armstrong, 2002; Armstrong & Hutti, 1998; Beutel, 1995; Cote-Arsenault, 2003a) and depression (Armstrong, 2002; Armstrong & Hutti, 1998; Nelson, McMahon, Joffe, & Brensinger, 2003; Stirtzinger, Robinson, Stewart, & Ralevski, 1999; Swanson, Pearsall-Jones, & Hay, 2002). Mothers conceptualize grief as an interpretive phenomenon, elicited by a loss, which upsets life purposes and implicates the need to reinstate meaning of the event in the context of their lives (Uren & Wastell, 2002).

**Fathers’ experiences.** Fathers who experience perinatal loss have been studied significantly less than mothers and have been called “the forgotten mourners” (Revak-Lutz & Kellner, 1994). Armstrong (2001) described the intensity of the grief experienced by fathers at the time of fetal death as “greater than had been anticipated” (p. 149). Armstrong further detailed effects of the perception of the reality of the baby and the investment in the pregnancy on perinatal grief. The reaction of fathers to a stillborn child is known to be a major psychological trauma (Samuelsson, Radestad, & Segesten, 2001). The process of becoming a father to a stillborn infant encompasses anticipating the infant, acknowledging the infant’s reality, experiencing empty arms, incorporating the infant into the family, struggling for recognition, accepting the reality of altered fatherhood, and maintaining memories (Worth, 1997).

In a review of the psychological effects of perinatal death on fathers, Badenhorst and colleagues (2006) concluded that fathers experience classic grief responses, but less so than mothers. In their review they presented evidence that fathers do experience grief, shock, anger, emptiness, helplessness, and loneliness after a perinatal loss. There is also a growing sense that the intensity of grief, connected to the prenatal attachment, is increasingly influenced by the use
of ultrasound; like mothers, fathers’ prenatal attachment is influenced by the reality of the life of the developing infant.

The prescribed role of providing support for their partners may influence the experience of fathers’ grief, as fathers may not be expected or allowed to display their emotional distress; this expectation was described by Wagner and colleagues as a belief that fathers need to be the strong ones and must put their grief “on hold” for their spouses (p. 16, 1997). Men’s traditional role as defenders of the family can actually intensify their grief because they are more sensitive to the pain of their spouses and children (Diltz, 2001). Fathers’ experiences of perinatal loss may be influenced by their social role and conflict between couples that are grieving (Badenhorst et al., 2006), which lends further support for the need to study both parents.

**Gender differences.** Mothers and fathers experience pregnancy and prenatal attachment differently; therefore, it is not surprising that there is evidence that responses to grief differ between men and women (Adler & Boxley, 1985; Gilbert, 1989; Gilbert & Smart, 1992; Kamm & Vandenberg, 2001; Schwab, 1996). Researchers focusing on the perinatal loss experience of mothers and fathers often compare depression and anxiety. Generally, fathers are described as experiencing both at lower levels than the mothers (Badenhorst et al., 2006). Other evidence suggests that fathers’ experiences of perinatal loss can be similar to that of mothers’ experiences but are different in terms of intensity or length of grieving.

**Loss of a twin.** The loss of one infant of expected twins encompasses the loss of the dream, hope, and expectations of becoming a special family. It entails the loss of an individual baby, as well as the loss of the special achievement of having twins (Bryan, 1995). The events of life and death, two of life’s greatest transitions, may be overwhelming for any family when
they occur in separate pregnancies; when they occur simultaneously it is both confusing and difficult to put the flood of emotions into perspective (Bryan, 1995; Swanson-Kaufmann, 1988).

Cote-Arsenault (2003a) characterized the birth loss of one twin as the loss of an infant with multiple meanings to a family/couple/mother. Tracy (2000) named it the loss of the “ultimate” sibling. Bryan (1995) and Swanson-Kaufmann (1988) described it as a loss of the specialness of a multiple birth and the identity of a multiple birth family, with special meaning and status in society. For many it is the loss of a normal pregnancy experience and may represent the end of a high risk pregnancy and/or infertility journey. The loss may be just as intense following a planned fetal reduction of a multiple pregnancy (Collopy, 2004). Frequently it is one more in the accumulation of losses related to the pregnancy.

The meaning of the loss of one twin has been explored from the parents’ subjective perspective in only a few studies. In one phenomenological study, Sychowski (1998) used letters and poetry written by parents and published in a support group newsletter to supplement interview data. Themes identified were: (1) the two worlds of life and death; (2) the need to be recognized as parent of twins; (3) the dual emotions of joy and grief; and (4) mothers’ hope that others would understand a surviving twin makes grief more complex, not easier. Although Sychowski’s findings indicated that those mothers were describing feelings of persisting acute grief, they were equally concerned about the effects of the loss on the surviving twin. One case study placed the twin loss experience within the context of attachment and detachment of the mother to each baby (Van der Zalm, 1995a, 1995b). This appraisal of one mother’s experience highlighted the uniqueness of the phenomenon by describing how the detachment from the lost infant complicated the mother’s ability to attach to the surviving one. Van der Zalm suggested
that grief may delay the attachment and interaction with the living baby. Little to no literature exists whose authors explored the experiences of fathers who have lost one twin.

Researchers addressing depression have underscored the at-risk nature of this parenting experience as the perinatal loss of a singleton infant or the loss of a twin during the postpartum period increases the presence of depression. Mothers and fathers who lose a twin have been compared to families who have lost a singleton baby in terms of depression (Wilson, Fenton, Stevens & Soule, 1982). The findings confirmed previous conclusions that symptoms of grief and depression diminish over time but the authors provided a unique description from their data. The presence of a living twin in no way lessened the grieving process. Therefore, an important implication for healthcare professionals is to make a conscious effort to support parents in expressing their feelings of loss when a twin dies, rather than primarily focusing attention on the surviving twin. Rowe and colleagues found postpartum depression lasted longer for multiple birth mothers who lose one or more infants than for mothers with a singleton loss (1984). Further, they reported that raising a so-called replacement baby (which they defined as either a child born after a perinatal loss or a lone twin who survives a twin pregnancy) did not decrease the depressive symptoms reported by mothers. Other investigators have described the impact of depression, including a negative correlation between depression and parenting a surviving twin (Netzer & Arad, 1999), and also between depression and parenting a subsequent child (Theut, Pedersen, Zaslow, Cain, Rabinovich & Morihisa, 1988).

In her meta-analysis, Leonard (2002) stated that “each twin [and higher order multiple] leads an extraordinary life before birth” (p. 248). Further, Leonard reported that the response of a multiple to the death of a co-multiple during pregnancy or after birth may be influenced by the relationship they shared in utero (2002). After birth, the surviving infant may want to be held
more often (Pector, Green, Ehlers, Carr, Larsen & Monaghan, 2002) and expression of this need will affect the behavior and the parenting of that infant. Parents are challenged to nurture the survivor’s development without becoming overly protective in fear of losing the other infant (Woodward, 1988). Findings from several studies indicate that parents with previous perinatal loss have more concerns for their subsequent children and are often overprotective (Cote-Arsenault & Morrison-Beedy, 2001; Theut et al., 1992).

The authors of the extant literature depict this group of parents as being at-risk because the process of becoming the parent of a lone twin is complex. Moreover, because most of the authors have focused on experiences of mothers after the loss of one twin, very little is known about the experience of fathers in the context of perinatal grief. Differences between the grief responses of mothers and father likely influence the way each one parents the surviving infant after a perinatal loss. The literature is void of family studies whose authors explored the parenting dynamic of bereaved mothers and fathers as they work to nurture the surviving children. Further, because gender differences result in an incongruence in the grief experience and affect both the communication and relationship between partners, some researchers believe there is a need to explore couples’ interactional processes after a perinatal loss (Gilbert & Smart, 1992).

Bereavement Theory

**Contemporary theory.** Conventional linear grief theories do not match the realities of parents who experience perinatal loss (Brownlee & Oikonen, 2004). This incongruity motivates practitioners to search for more flexible models to explain the uniqueness of such experiences. Bereavement theories, across multiple disciplines, have been changing to better reflect reality.
No longer are they describing a process through which individuals resolve grief but rather they explain the mounting evidence that individuals learn to live with grief.

The belief that grief is something to be dealt with and resolved is the message of traditional theories that may be held by friends or even helping professionals (Moules et al., 2004). Moules and colleagues (2004) further asserted that a bereaved person’s belief that he or she is not living up to a personal or societal expectation if unable to “get over” grief can lead to suffering in physical, emotional, and spiritual health (p. 100). Researchers need to explicate how people manage grief, as an ongoing circular process (Brownlee & Oikonen, 2004; Eakes, Burke, & Hainsworth, 1998; Moules et al., 2004; Neimeyer, 2001).

**Multidisciplinary perspectives.** Assessment and appraisement of the multidisciplinary literature revealed that a paradigmatic shift to a post-positivist view of grief and bereavement had occurred in nursing, psychology, and social work. The previous allegiance to prescribed grief work entailed a staged process of resolution and letting go of the deceased. Although initially the theory provided an explanation of human response to loss, over time it became evident that the unexplained behaviors and responses outnumbered those explained. One poignant description of this traditional view of bereavement was “a theory in search of data” (Bonnano & Kaltman, 1999, p. 761). Although the evolving theoretical frameworks presented by authors in each discipline have their own unique perspectives, there are theoretical commonalities. The common perspectives are a conception of grief as an interpretive, contextual experience that is ongoing and the universal importance of meaning making as a coping strategy by the bereaved. The idea that grief is an ongoing integration of loss into life is found in the rich description of bereaved parents’ experiences. Moules described this process as “finding a way through suffering and
sorrow to make room for a relationship with grief that is livable, acceptable, creative, and for a life that may even be richer for its presence” (1998, p. 100).

In an integrative perspective of bereavement from a psychological perspective, Bonnano and Kaltman (1999) described four interactive aspects of the grieving process: context, meaning, representation of the lost relationship, and the role of coping and emotional regulation. Such a framework emphasizes the contextual factors of age, gender, income level, type and expectedness of the loss, previous experience with loss or depression, and perceived social support. These psychological perspectives highlight meaning-making and individual differences in grief as a continuum.

Nursing researchers have also illustrated the evolution and shift toward interpretive views of grief. Davies’ (2003) review of multiple studies using different research designs and methods of data collection (including interviews, parent writing, newsletters, and notes from meetings of support groups) resulted in an overall thesis of continuing bonds with the deceased. Other authors have metaphorical language to describe the grief process from the parents’ perspective. For example, grief has been characterized as “an ambivalent transition to motherhood” (Lundqvist, Nilstun, & Dykes, 2002, p. 621), and a graceful, periodic, deliberate walk backwards while keeping a sure foot in living forward (Moules, Angus, & Bell, 2004). Cote-Arsenault described a process by which parents weave remembered babies into the fabric of their families after perinatal loss (2003b).

A portrayal of the social world of bereaved parents where a continuing bond with their deceased child is acknowledged is found in qualitative work from both sociology and social work. The authors echoed the previously described nursing and psychology frameworks of grief as ongoing and contextual connection between parents and their deceased infant. Ethnographic
researchers have supported the claim that bereavement takes place in the social world in which the bereaved parents remain. Parents stated that their deceased children continue to influence their thoughts and feelings (Riches & Dawson, 2000).

Similarly, a social work framework for practice, based on the premise that conventionally held theories of grief fall short of parents’ realities, has been developed. Brownlee and Oikonen (2004) made the case that a narrative model for care would allow for the evolution of the story as part of the grieving process, allowing parents to reflect upon their own experiences in a way that allows the recognition of social context and culture in response to loss.

**Emerging theory.** Chronic sorrow may offer a philosophical fit with a post-positivist view of livable and ongoing grief. Though never tested in a childbearing population, the scope of the nursing middle range theory of Chronic Sorrow has the potential to capture experiences of perinatal loss (G. Eakes, electronic personal communication, November, 2005). The presence of chronic sorrow has been demonstrated in single loss events, like the acute loss when a loved one dies, and in ongoing loss, as the loss of function (Eakes et al., 1998). Emphasized in the preliminary research conducted with the Chronic Sorrow theory is the ongoing disparity between the wished-for presence of the loved one who has died and the reality of the absence of that person created by the loss, an essential characteristic of chronic sorrow. Relationships in the theory of Chronic Sorrow involve trigger events (milestones) that bring about re-grief, which are the circumstances that bring the negative disparity resulting from the loss into focus (Eakes et al., 1998; Teel, 1991). The memories of a lost baby and anniversaries of what would have been developmental milestones of a lost baby have the potential to be lifelong reminders of the loss and may cause such a disparity.
Summary

Thorough study of the extant literature about early parenting and perinatal loss revealed several gaps in the literature, namely, gender differences in grief responses, and the experience of simultaneously grieving one infant while nurturing another infant. Couples who lose one multiple may experience a delay in grief while they attend to their remaining children and may have difficulty attaching to surviving infant(s) (Pector & Smith-Levitin, 2002). Through this study, I gained increased understanding to explain how mothers and fathers grieve while living, and how they maintain a connection with an infant who has died while raising their surviving infant.

Twin births have increased dramatically both nationally and internationally and so have the unique needs of these families. Multiple births present multi-dimensional challenges to families as well as numerous opportunities for nurses to intervene creatively and therapeutically. Perinatal grief has a profound effect on families. Nurses are in a unique position to intervene therapeutically with multiple birth families that experience loss; specifically, when a family loses one of a set of twins. The paradox of the realities of simultaneous birth and death make this group of parents important to study. Although the work of researchers who focus on multiple births has increased since the success of infertility treatments, little has been published describing the perinatal loss of one twin and the simultaneous parenting experience of the survivor. With more twins being conceived and identified early, so comes more twin loss and grief for parents. The nursing care of these patients has subsequently become increasingly important: nurses must begin to address twin loss therapeutically.

While studies about perinatal grief are plentiful, very few researchers have explored the profound loss and parenting experience associated with multiple births in which one baby dies.
leaving one or more survivor(s), despite the fact that many more parents of twins face the tragedy of bereavement than do parents of singletons (Bryan, 1995, 1999). The purpose of this research was to learn from parents who have experienced a twin loss their perceptions of how it affects their parenting role. The research question was: “When one twin dies, what is the experience of parenting the lone twin?”

The purpose of this qualitative descriptive study was to describe the experience of parenting a surviving twin from the perspective of those mothers and fathers who experienced the loss of one twin in utero (after 20 weeks gestation), during birth, or in the immediate neonatal period (first six weeks of life). Specifically, this research was designed to describe (1) how the grief involved in the loss of one twin influenced the daily processes of parenting the other twin; (2) how the mothers and fathers who lost a twin coped with the challenges of simultaneously dealing with the resulting grief and yet attach with and nurture the other infant; and (3) how the emotional effects of this challenging experience affected the parents.

Nurses share life-changing experiences such as suffering and pain with their patients and provide therapeutic interventions that include active listening, comfort, and honoring the meaning of birth and death and the dignity of individuals and families. The simultaneous grieving of the perinatal loss of one twin and transitioning into the parenting of the surviving infant is one such experience. By virtue of their profession, nurses have the opportunity and obligation to assist families with issues inherent in these high-risk pregnancies, including anxiety, stress, potential for loss, and financial, emotional, and physical burdens. Women and men who parent a surviving twin are faced with a difficult reality following what is often a stressful pregnancy. The unique realities of this situation are minimally addressed in the literature. Therefore, this study represents an initial exploration with the most central players in
the phenomenon, the mothers and fathers, with the belief that the parents of twins are a growing group who face prenatal and post-natal challenges inherent in a pregnancy more likely to result in an infant loss, before or at birth.

Research about parenting a lone twin, an experience of joy and grief, is incomplete. Researchers have neglected fathers in particular, both in terms of becoming a parent and in experiencing perinatal grief. Therefore, this research has the potential to contribute to two significant gaps in the literature. Qualitative methods are well suited for this research; descriptive work exploring the experience of living with grief (i.e., parenting a surviving twin) has expanded knowledge and provided a basis for intervention studies. Presently there are no best practice guidelines dedicated to the care of parents who experience perinatal loss and subsequent grief. Considering that the already complex circumstances of twin pregnancies and births become more complicated when perinatal loss occurs, optimal nursing care requires a well-informed and comprehensive understanding of this experience. This understanding can be gained only from the mothers and fathers who share their experiences with researchers who in turn communicate these needs and concerns to providers. My findings will facilitate providers’ understanding of such a loss, enabling them to better assist these parents in coping with the loss while developing their parental roles, and establishing a strong relationship with their surviving infant.

Rapid and significant advances in maternal fetal medicine and fertility successes have assisted many developing families to become pregnant; however, the nursing science needed to care for these families is lagging behind in relation to the perinatal death of one twin and survival of one twin. My intent in undertaking this dissertation research was to provide a basis for the development of much needed family bereavement interventions. Parents who have lost one or
more babies from a multiple pregnancy, and are parenting surviving children, represent a rapidly
growing group of individuals with unique, yet, for the most part, undescribed emotional needs.
Because of the significance of the crucial nurturing relationships between mothers, fathers, and
developing children, parenting and experiencing grief simultaneously affects the well-being and
emotional development of all family members. Grief itself is a complicated experience;
parenting while grieving is a challenge that is significant and essential for nursing researchers to
address.

A comprehensive description of this perinatal loss phenomenon will facilitate meaningful
improvements in the care of these families. This is also the first study in a program of research to
formulate a contemporary theory of family bereavement and coping with loss; parenting a lone
twin may be especially challenging as the survivor is a constant reminder of the lost twin. In
order to provide appropriate support to bereaved parents, interventions are needed that promote
parenting the surviving twin while also supporting healthy grieving for the lost twin. Thus, a
thorough description of this unique parenting experience was needed as the first step in designing
interventions for the optimal support of these developing families.
Chapter 3

Methods

Research Design

Mothers and fathers who have lost one or more infants from a multiple pregnancy, and are parenting the survivors represent a rapidly growing group of individuals with unique, yet, for the most part, undescribed needs. A comprehensive understanding of this perinatal loss experience has the potential to facilitate meaningful interventions for the care of these families. As a perinatal nurse and educator, I wanted to learn more about this experience from the parents who lost one twin and were in the process of raising the surviving twin sibling. Thus in my research I explored the simultaneous experiences of grieving the loss of one twin while nurturing and celebrating the life of the living twin. My research question was: “When one twin dies, what is the experience of parenting the lone twin?”

I used the inductive approach of qualitative description for this study because of the paucity of prior research findings available to answer the research question. In this chapter, I have provided a comprehensive discussion of the research design including the methodology, sample and setting, data collection and analysis, rigor, and human subject concerns.

Qualitative methods are used when the research question is about human experience and/or the perception or perspective of a phenomenon. Inductive approaches facilitate understanding that clearly contributes to Carper’s (1978) empirical, moral, aesthetic, and personal knowledge development; this knowledge influences nursing care in the health and illness of humans (Van der Zalm, 2000). Benner reflected that nursing interventions are more effective when based on dynamic knowledge gained from the experiences and perspectives of our patients (Tanner, Benner, Chesla, & Gordon, 1993). Gadow (1985) stated that knowing a
patient is a central aspect of nursing practice and is essential for patients to feel cared for and about.

Qualitative methods provide rich primary data that legitimizes the authenticity of a patient’s perspective of an event and the purposeful process by which nurses attend to patients and families. It is in the human sharing of events and responses to events that understanding is gained of the meaning of the experience (Moules, 1997; Crabtree & Miller, 1999). Learning about a phenomenon from individuals who know it best because of experience provides nurses with insight and understanding of that experience. The realism lies within the persons who experience an event and understanding comes from their descriptions and explanation of the phenomenon. The relevance of this philosophy to nursing today rests in the significance of this personal relationship that inherently values each individual encountered by a nurse.

The philosophies for qualitative inquiry are significant for the growth of nursing knowledge as the holistic nature of such an approach embodies both the art of nursing (the value of the human experience) and the interactive relationship of the nurse with his or her clients. Nurses learn from their clients who are experiencing the phenomenon and therefore are the experts. Nurses then use this data in purposeful interaction with future clients.

**Qualitative Descriptive Design.** The overall goal of a qualitative descriptive study is a comprehensive description of a phenomenon of interest. This research was grounded philosophically in naturalistic inquiry and social constructivism. In a naturalistic paradigm, there are no preset variables, no manipulation of variables, and no a priori commitment to a theoretical view of the target phenomenon (Lincoln & Guba, 1985). Naturalistic inquiry inherently values the subjective nature of data whereby the participant is the final authority of the experience (Denzin, 1992). According to social constructive thought, the individual produces reality and
constitutes a self through the dialectic between nature and the socially constructed world (Berger & Luckmann, 1966).

In a qualitative descriptive study, the researcher aims to describe large amounts of text by first getting a sense of the whole and then identifying similar meaning units in participants’ responses that describe the phenomenon of interest. The aim is to provide knowledge by illuminating the participants’ perspective of the event or phenomenon. It is different from grounded theory in that it does not seek to develop new theory by focusing on the discovery of the process of experiencing some phenomenon.

Phenomenology was not chosen for this research due to the paucity of research about this parenting process; rather than seeking the essence of the experience, a broader approach was needed first to learn perceptions and experience. In seeking the comprehension of the experience rather than the essence, my goal was to formulate a broad and thorough description of the of the perceptions of the phenomenon of interest as experienced, reflected upon, and shared by participants (Sandelowski, 2000).

As described in Chapter Two, gaps exist in the current literature that dictated the need for further exploration. Authors of the literature who addressed the experience of parenting a lone twin from the parents’ perspective are few. Therefore, in matching question and method it was obvious that an inductive approach was needed to fill in the literature gaps and learn about the phenomenon from the experts, the parents who experienced simultaneous grief and joy as they buried one twin and nurtured the other.

Qualitative description is a methodology that has not been widely discussed in the literature. Qualitative description is a fit when the desired outcome is a thorough description of a phenomenon and the goal is a comprehensive summary of events in the everyday language of
those involved (Sandelowski, 2000). Researchers conducting qualitative descriptive studies stay close to their data and to the surface of words and events. The qualitative descriptive design includes purposive sampling, and subjective data collection, content analysis, and re-presentation techniques. In terms of evolution, Sandelowski wrote that researchers often “claim methods they are really not using and not. . . the method they are using; namely, qualitative description” (p. 334). Qualitative descriptive researchers seek not to reveal truth but to generate insights by describing and increasing understanding of the nature of reality through participants’ perspective with careful and on-going attention to context (Milne & Oberle, 2005). These philosophies are the enabling force that allows entrance into meaningful shared realities that provide insight and understanding of the phenomenon of interest.

At the heart of this research was my belief that the unique experience of parenting in this complex circumstance was and will continue to be crucial to the personal development of both parents and infants. For this study I focused on the depiction of parents’ experience of losing a twin, representing the way in which they saw themselves symbolically in the role of parenting the surviving infant and the way they described and explained the experience in their own words.

**Purpose.** The purpose of this qualitative descriptive study was to describe the experience of parenting a surviving twin from the perspective of those mothers and fathers who experienced the loss of one twin in utero (after 20 weeks gestation), during birth, or in the immediate neonatal period (first six weeks of life). Specifically, this research was designed to describe (1) how the grief involved in the loss of one twin influenced the daily processes of parenting the other twin; (2) how the mothers and fathers who lost a twin coped with the challenges of simultaneously dealing with the resulting grief and yet attach with and nurture the other infant; and (3) how the emotional effects of this challenging experience affected the parents. Through this research I
have provided a comprehensive description of this event grounded in the everyday language as described by those men and women immersed in it. The primary outcome is a fundamental qualitative description intended to inform perinatal and family nurses to use this information to provide more insightful and sensitive care.

Sample

Sampling in qualitative research seeks in-depth descriptive data from experts, those who experienced the phenomenon (Miles & Huberman, 1994; Sandelowski, 2000). I recruited a purposive sample of mothers and fathers who had experienced the loss of one twin for participation. Sampling continued until data saturation was attained, that is, until no new information emerged in the interviews (Patton, 1999). Recognition of data saturation was dependent upon concurrent data analysis.

It was anticipated that a number of participants would have experienced the intrauterine loss of a twin, a situation whereby the relationship between the unborn infant and the mother was likely to be significantly different than that of the father to the unborn infant (Brownlee & Oikonen, 2004). Additionally, authors of the literature from singleton perinatal loss described differences in grief responses between men and women (Adler & Boxley, 1985; Gilbert, 1989, 1992; Kamm & Vandenberg, 2001; Schwab, 1996). Due to these known differences, mothers and fathers who lose a twin warrant attention as a couple and required a design inclusive of both conceptual viewpoints. Because gender differences may cause incongruent grieving and effect the communication and relationship between partners, there is a need for research inclusive of the couple’s processes after a perinatal loss (Gilbert & Smart 1992).

Contact with and previous work with a support group led me to believe that this study would be feasible. For my master’s thesis (Grady, 2002), I completed a narrative analysis of
parent writings as provided in the Center for Loss in Multiple Birth (CLIMB) Organization’s newsletter. CLIMB can be accessed from the world wide web at http://www.climb.org. In that study, I analyzed the stories parents wrote, stories that depicted their experiences following the loss of one twin. In collaboration with the director of CLIMB, Ms. Jean Kollanti, we contacted each parent whose story I used for permission to cite them. Therefore, I had an established relationship with the founder of the organization as this prior experience was mutually positive. All eighteen women granted me permission without any hesitation. At that time, several of these mothers commented that they would be interested in future research, which supported my belief that access to this population would be feasible via the CLIMB support group.

CLIMB is a web-based support group for those who experience loss in multiple birth pregnancies and publishes a quarterly newsletter. It is a 501(c)(3) non-profit organization based in Anchorage, Alaska, serving families and others throughout the United States, Canada and beyond, including Australia, New Zealand and Europe. No demographic information is collected from the membership; however, CLIMB is a support group that welcomes membership of any person who has lost a child(ren) of multiple birth pregnancy. I acknowledge the potential bias of a support group population. The members are a self-selected group who seek and find support through sharing anonymously with others who have experienced a similar perinatal loss.

Inclusion criteria. Criteria for participation in the proposed study included mothers and fathers who (1) were at least 21 years of age; (2) read, spoke, and understood English; (3) lived within 200 miles radius of the researcher; (4) experienced the loss of one twin either in utero (after 20 weeks gestation) or in the immediate neonatal period (less than 6 weeks of age); and (5) were parenting a surviving twin who was at least one year of age and had not completed his or her third year of life.
The criterion that participants be at least 21 years of age was based on evidence that adolescents experience a transition to motherhood that is significantly different from that of adult women due to adolescents’ concurrent maturational and developmental issues, including the process of attachment, which is considered critical for the surviving twin’s development (Ard, 2000). Assessment instruments measuring mother-infant interaction at times of stress demonstrated that increased cognitive ability of adult mothers was related to increased interaction with the infant when compared to adolescent mothers. Very little is known about adolescent fathers. Therefore, I excluded adolescents because of their potential to introduce confounding issues (Sommer, Whitman, Borkowski, Schellenbach, Maxwell, & Keogh, 1994).

Finally, the geographical area of a 200 mile radius from my home included populations of several large and diverse cities as well as suburban and rural areas.

I intended that the sample be drawn from a target population of parents who had experienced the loss of one twin within the past three years, and the surviving twin would be equal to or greater than one year of age. I wanted to balance the time of initial crisis surrounding the birth of the twins and death of one twin with some measure of elapsed time for reflection of the parenting experience with the surviving infant. Though it is likely that some details of the acute loss experience may be forgotten over time, emotionally laden memories are less likely to be forgotten (Collopy, 2000).

Given the incidence of preterm births of twins, it was not practical to exclude parents who experienced an extended hospitalization of the surviving twin. Instead, I asked parents to share their accounts of their surviving twin’s hospital stay as part of the comprehensive description of the experience. Consistent with the philosophical stance of naturalistic inquiry, in which the participants identify the salient aspects of an experience, no theoretical sampling was
planned in terms of specific types of cases of a twin loss (that is, no specific causes of death of the infant or number of previous pregnancies).

**Human Subjects Concerns**

This research involved human subjects. Consent forms were prepared in accordance with the guidelines of Boston College’s Office of Research Protection. Informed consent was obtained from each study participant (Appendix G).

The means whereby human subjects were protected were carefully presented to participants in the consent form. The consent addressed the following: (1) participants’ right to withdraw voluntarily from the study at any time without consequence; (2) the central purpose of the study and the procedures to be used in data collection; (3) the protection of participant confidentiality; (4) a statement about risks and benefits of participation; and (5) a place for each participant to sign and date the consent.

The participants were men and women who were parenting the survivor of a twin pregnancy during which one twin had died. No parent was excluded from participation based on race or ethnicity. CLIMB is a “virtual” support group; there are no regular meetings and the director and webmaster operate the support group from undisclosed sites. The one exception is an occasional conference where, according to the website, members meet every couple of years for several days. As a virtual organization, no demographic data are available; therefore none were collected. However, for the purposes of inductive research, the only important criterion for participation was the experience of being the parent of a lone twin.

Confidentiality was protected by: (1) the removal of all identifying information from all study data substituting a pseudonym; (2) the storage of all data in a secure locked file cabinet under my sole jurisdiction; (3) an explanation that any part of participation could be eliminated
and participants could withdraw from the study at any time; and (4) an explanation that declining to participate would have no effect on any services they might wish to access for themselves or their families at any time in the future.

The names of participants were known only to me and were kept separate from the raw data and stored in a locked file accessible only to me. De-identified data were stored on CD-ROM technology (with back up copies stored on a computer hard drive). Audio recordings of interviews were erased after data analysis was complete. Prior to erasure they were stored in a locked file accessible only to me. All recordings were handled in accordance with the NIH guidelines for storing and destruction of such data.

**Protection from Risks.** Participants were informed that the purpose of the study was to describe the experience of parenting a surviving infant twin. Participants were informed that the interviews were estimated to last approximately one hour. Strategies for minimizing risk and the recognition of self-protective behaviors were employed to protect respondents’ psychological well-being (Kavanaugh & Ayres, 1998). After interviewing mothers who experienced perinatal loss, Kavanaugh (1997) concluded that being guided solely by participants may not be possible if they lack the ability to manage their own distress. Vulnerable participants may send subtle cues not readily apparent or be at risk for over-disclosure. I was alert throughout the process for signs of potential distress and reminded myself that these interviews were inherently indeterminate and dealt with a sensitive topic. No one could predict what might emerge from the conversation as participants shared their experiences. The structure of the interview was flexible and easily adapted to the participants’ need for a break or moving to another section of the interview. I was aware of and accepted the fact that some situations might be too distressing to discuss. Most of
the parents did express sadness, and many did cry during the interview; however, with brief
breaks and with the use of silence, all continued with the interview.

Participants were informed that there were no known risks to participation, however, the
conversation might be distressing and difficult. I indicated that they could take breaks during the
interview and/or that they may end the interview at any time without consequences. As the
researcher, I kept foremost the well-being of participants and used silence and empathy to
convey respect. If, in my judgment, there was any concern about a participant’s well-being, I
was prepared to refer him or her to a counselor for screening via telephone. Such referral was
not necessary with the study participants. I had a psychiatric nurse practitioner mental health
consultant on-call (prearranged specifically for this study) for immediate referral if I deemed
such a referral necessary. If the telephone screen prompted the need for follow-up care, I had
referral information and counselors available.

**Potential Benefits to Subjects.** At the end of each interview and after the audio tape
recorder was turned off, I validated the participant’s experience and emotional state. If desired, I
spent time after the interview for debriefing allowing the parent to share whatever feedback he or
she wanted about this experience. Participants were informed that there were no direct benefits
anticipated for them but that they might gain a sense of personal validation, as well as a sense of
purpose in sharing their experiences of grieving a lost twin while parenting the surviving twin.
Because parents may feel alone in their experience of losing a twin and parenting the surviving
twin, the opportunity to share information about their experiences may be a source of support
and empowerment.

Participants may benefit personally by knowing that their sharing provided valuable
information for nurses and other health care professionals to improve their care of families
experiencing perinatal loss. Based on personal clinical experience and the literature, I anticipated that any distress associated with discussing this experience would be outweighed by the relief felt as they shared their unique parenting experience. Data from this study will inform nurses about the issues, concerns, and needs of parents who sustain this kind of loss. With new understanding, additional studies can be designed to explore with parents what programs and interventions might be created to interrupt the cycle of isolation and confusion associated with perinatal loss. Knowing that the information they shared can help other persons who experience a similar loss can be empowering to participants.

**Recruitment.** I recruited the sample of mothers and fathers who experienced the loss of one twin using two specific strategies for recruitment: (1) advertisement in the Center for Loss in Multiple Birth (CLIMB) support group e-newsletter; and (2) self referrals via snowballing to any persons who became aware of this study from personal relationships with support group members or referrals from personal or professional contacts. In order to use snowball sampling, I asked potential participants to share my email address with any other parents they knew who had this experience. Finally, I requested that professional colleagues and personal acquaintances who knew parents who met the study criteria to share my contact information with them. The catchment area included multiple urban healthcare facilities that have twin birth rates above the national average as well as diverse patient populations. For the years 2005-2007, twins accounted for more than 4 percent of all birth (more than 40 per 1,000) in Massachusetts, Connecticut, and New Jersey (Martin, Hamilton, Sutton, Ventura, Mathews, Kirmeyer, & Osterman, 2010).

For recruitment, I submitted a brief article in which I discussed the study including the data collection plan of an in-depth interview at a location of the participants’ choosing. I
emphasized that the purpose of the interview was to gain insight and understanding about how their experience influenced their parenting experience. I provided my contact information for parents who were interested in getting more information and potentially participating in the research. Ms. Kollantai placed the article in two consecutive quarterly issues of the group’s online newsletter, Spring 2010 and Fall 2010 (Appendix B: CLIMB Advertisement).

Recruitment advertisements were my access to parents for this research. The advertisement was published in the quarterly E-notice of CLIMB’s Newsletter. The E-Notice briefly described the study and provided my contact information if a parent wished to discuss possible participation. The CLIMB support group allows members to express themselves in print and contact one another voluntarily. The group’s membership is based exclusively on the commonality of experiencing the loss of one or more infants of a multiple birth pregnancy. Prior to initiating the study, I received Institutional Review Board approval from Boston College and a letter of agreement was signed by the Director of CLIMB (Appendix A).

After the recruiting advertisement was published, those who responded presented an interesting dilemma. Although several respondents did not meet all of the stated inclusion criteria, a number of parents contacted me anyway and expressed the desire to participate in the study. These parents were convinced they had important insights to share. I thoughtfully and carefully reconsidered the inclusion criteria related to the time limit for participation (that is, elapsed time since the loss of the infant twin), geographic location of participants, and age of the surviving twin. I submitted the modifications, with the following justifications as amendments to the Boston College Institutional Review Board (IRB).

The first inclusion criterion affected was the time period since the loss of the infant twin. In the original design, I assigned a somewhat arbitrary time period of more than one year and no
more than three years since the loss of the twin infant. The criterion that the surviving twin be 1-3 years of age originally was designed to allow time for parents to gain some perspective and routine following the potentially stressful initial weeks of the surviving twin, who may have been seriously ill and/or premature.

I concluded after a re-examination of the literature that there was no best time for research participation following a significant loss. Of the parents who initially contacted me, all eight had experienced the loss of their twin more than 3 years ago (range of 4 – 24 years). Thoughtful reconsideration of this criterion compelled me to believe that in a truly naturalistic approach, the parents should be the ones to determine when they were ready to share their perspectives. Therefore, I requested permission to eliminate this criterion.

The second criterion involved the catchment area. Since more than half of those who contacted me lived beyond a reasonable driving distance for a face-to-face interview, I had to decide whether or not to include them. I sought advice from a number of experienced nurse researchers, notably Dr. Cheryl Beck of the University of Connecticut. She has used email exchanges as a data collection method with parents in multiple studies, including those with postpartum depression, post traumatic stress disorder related to birth experiences, and mothers whose children suffered traumatic birth injuries. Additionally, Beck enthusiastically supported my reconsideration of time lapsed since the loss of a twin as well. In a personal electronic communication with me in June 2010, she described her approach to time parameters for participation this way: “I do not put a limit on the studies I have conducted because what I have found is that if the experience has been so profound to participants, the details stay with them no matter how much time has passed.” Beck shared verbiage she used for consent forms with me. I concluded that electronic communication was a potentially valuable and emerging research tool
and a practical solution to travel limitations for my data collection. It also gave me a more diverse sample by including participants from other geographic locations such as Texas, Wisconsin, New York, and Tennessee as well as New England. Subsequently, I amended the original IRB application to accommodate those parents who lived outside New England and wished to participate. To add an electronic mail exchange as an interview mode, I had to design additional procedures to collect the electronic data as well as modify the informed consent to include this option and specifically discuss handling procedures for the safety and confidentiality of the electronic data (Appendix H). The original inclusion criterion of participant location in New England was not changed but rather I made the inclusion of exceptions on a case-by-case basis.

I interviewed a total of 9 parents for this study either in-person, on the telephone, or via electronic communication (email). Eight were mothers, and the father who participated was interviewed at the same time as his wife, as noted (Table 1). The fathers in the families where the mothers responded to the invitation for participation were specifically invited to participate; one father contacted me via email. I sent the interview questions to him but he did not respond. All participants contacted me via email after reading the study invitation in the newsletters.

**Procedures**

**Informed Consent.** Obtaining consent for participation was a multi-step process. Step 1 was the recruitment invitation with my phone number and email address so parents who were interested in the study could contact me for more information and possible participation. This invitation was published in the CLIMB E-newsletter as previously detailed. Potential participants contacted me via email with interest in hearing more about the study. In Step 2, either over the phone or in an email, I contacted those parents who responded to the invitation. If
the parents had given me a phone number in the email, I called them. If they did not, I responded via email. In either case, I thanked them for their interest and answered their questions about the study. For those parents to whom I spoke on the phone, the conversation included the following script: “I would like to talk to you about my study and discuss any questions you may have about meeting with me. It should take about 5-10 minutes. Would you like to continue?” If they indicated that they did, the follow-up question was “The purpose of this study is to describe the experience of parenting a lone twin, when one twin has died. If you would like to meet with me and discuss your experiences, a complete informed consent process will take place when we get together. May I ask you a few questions?” If the time was convenient and the participant agreed, I completed the Telephone Screening Instrument with them (Appendix C). If the time was not convenient, a mutually convenient time was arranged for the telephone screen. If our communication was by email only, I replied with an email

Table 1. Description of the Sample

<table>
<thead>
<tr>
<th>Parent(s)*</th>
<th>Type of Interview</th>
<th>Home State</th>
<th>Circumstances of loss</th>
<th>Living twin’s age at interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Katie</td>
<td>In-person</td>
<td>ME</td>
<td>late pregnancy loss; twin died at 40 weeks in utero</td>
<td>10</td>
</tr>
<tr>
<td>Lori</td>
<td>In-person</td>
<td>MA</td>
<td>genetic anomaly; twin died shortly after birth</td>
<td>6</td>
</tr>
<tr>
<td>Anne &amp; Mark</td>
<td>In-person</td>
<td>MA</td>
<td>genetic anomaly; twin died shortly after birth</td>
<td>18</td>
</tr>
<tr>
<td>Barbara</td>
<td>Email</td>
<td>WI</td>
<td>unknown; twin died at 31 weeks in utero</td>
<td>14</td>
</tr>
<tr>
<td>Sally</td>
<td>Telephone</td>
<td>NY</td>
<td>born at 25 weeks; twin died 2 days after birth</td>
<td>4</td>
</tr>
<tr>
<td>Claire</td>
<td>Email</td>
<td>TX</td>
<td>born at 25 weeks; twin died 9 days after birth</td>
<td>9</td>
</tr>
<tr>
<td>Debbie</td>
<td>Email</td>
<td>MO</td>
<td>placental complications; twin died 16 days after birth</td>
<td>24</td>
</tr>
<tr>
<td>Karen</td>
<td>Email</td>
<td>CO</td>
<td>unknown; twin died at 32 weeks in utero</td>
<td>13</td>
</tr>
</tbody>
</table>

*Pseudonyms
describing the study and requested that they send all questions to me. In each case, parents who contacted me described where they live and the circumstances of their twin loss. As I was able to determine with the first contact which parents lived outside the New England area, I offered them the opportunity to participate via a phone interview or respond to interview questions via email.

For those parents who lived in New England, we then arranged a convenient time and place for the interview. I followed the same consent and data collection process with the interview I conducted via the telephone for the participant who lived beyond 200 miles from my home as for the face-to-face interviews. Following consent, I arranged a mutually convenient interview time. I audio taped the interviews and the interview questions and procedures I followed a similar format for the electronic interviews except there was no interaction between the participant and me, so it was more like a question and answer response format.

For those who did not live in New England, I either spoke to them on the phone or emailed the electronic process that had been arranged for data collection. Step 3, I elicited written informed consent (Appendix H) in person prior to the commencement of the face-to-face interviews. For those who participated in the interview process electronically, I emailed the consent forms to them for their signature and they returned a signed copy to me in the mail. After I received the signed consent forms, or received notification that they were on the way from the participants themselves, I sent the interview questions.

**Data Collection.** I conducted a minimum of two, and in a few cases, three interviews with participants. The first contact took place either on the telephone or in an email exchange (Interview 1). The second interview took place either face-to-face, on the telephone, or via email exchange. The in-person and telephone interviews (Interview 2) were audio recorded, open-
ended interviews that lasted approximately one hour. These interviews were conducted face-to-face in English in a quiet, private setting of the participant’s choosing. The second interview for email participants was the interaction by which I sent interview questions and they responded by answering those questions. In a few cases, I asked for additional information, along with demographic information, to supplement their original responses (Interview 3). Participants gave informed consent after a multi-staged process in adherence with Protection of Human Subjects Criteria. I asked each participant to provide basic demographic information. Each parent chose a pseudonym, or I assigned one. That pseudonym was the name used to identify the interviewee throughout the research. One mother and father couple participated in the study together; they were interviewed together as was their choice. A gift card of $25.00 was given as remuneration to each participant for time spent and childcare expenses. During the interviews, I was prepared that if the surviving twin or other children were present and there was an interruption, I would pause the audio recorder until the parent was able to resume the interview, which occurred only one time during a telephone interview. When the participant returned from the interruption, I gave a prompt like, “we were just talking about the first time you saw the baby after the delivery. . .” (K. Collopy, personal communication, March 2007). No observations of the parent-child interaction were included as data for this research study. As part of the interview, I included time for get acquainted conversation at the beginning and time for wrap up conversation at the end. Interviews were not scripted and were designed to support the participants explore and share whatever was important to their experience. Most of the in-person and telephone interviews lasted approximately one hour as anticipated, but some continued for up to 120 minutes per parent request. I checked with the parent/parents after 60 minutes of elapsed time and asked if they wanted to conclude or continue and followed their lead.
I began each interviews with the initial query: “What is it like to be the parent of a surviving twin?” Silence and clarifying questions (“Do you mean that…,” “Tell me more…,”) were used as necessary to convey support and ensure understanding (Kvale, 1996). I used an interview guide with proposed questions (Appendix D) as needed after the initial query. The proposed interviews did at times evoke strong emotions from parents and I respected at all times their need to take a break in conversation or end that topic or the interview. After each interview I dictated field notes to record specific details and thoughts about the interview circumstances. I included comments about the environment, observations of behavior and mannerisms, non-verbal expressions, and tone of the interview. These field notes were transcribed and considered with each transcript as contextual data. Finally, I reflected on my own reactions to the interviews by journaling after each interview and discussed my experiences with my committee.

With participants’ permission, I contacted each one of them approximately two weeks after the in-depth interview via telephone or email, if the interview was conducted via email (Interview 3). I sent the parents who had been interviewed in person or on the phone a copy of their interview transcript. During the follow-up phone call or email, I asked the parents if they had any further thoughts, comments, ideas, or concerns to share or if there was anything they wanted to clarify or expand. I noted the comments on their transcript and incorporated them into the data analysis.

**Data Analysis**

I remained true to the philosophic underpinnings of the qualitative descriptive method. A foundation of the naturalistic inquiry paradigm is that the inductive approach is appropriate for learning and describing a phenomenon about which little is known. Therefore, I used no predetermined theory, framework, or time restriction. I carefully examined and set aside my ideas
and experience as a perinatal nurse and the parent of a lone twin. The time lapse since that event has enabled me to create distance and objectivity. I knew that my experience might facilitate understanding or bias in my analysis of the data; thus I always confirmed my thinking, insights, and coding with my dissertation chair. If asked by a participant if I ever experienced a similar event, I was honest.

I analyzed the data using conventional content analysis, which allowed for dynamic analysis of the data as described by Sandelowski (2000) and Hsieh and Shannon (2005). For time efficiency, I employed a professional transcriptionist to provide a verbatim transcription of the data. I de-identified all data using pseudonyms instead of given names. After I received each transcript, I read it while listening to the tape so I could verify accuracy, and added clarifications as necessary. Everyone involved with data transcription and data analysis completed CITI Training for the Protection of Human Subjects (Appendix G), to ensure the protection of the participants’ privacy. Data analysis was concurrent with data collection and continued until data saturation was reached. This decision was determined collaboratively with my dissertation chair.

During the coding process, I checked for gaps or confusing and unclear statements in the descriptions and examples participants shared. When significant gaps or potential misunderstandings were identified, and, with participants’ permission, I contacted them in a follow-up phone conversation and asked specific probing questions to close the gap or clarify their comment to prevent any misunderstanding. During this time of reading I was totally immersed in the data, always alert to what they might be telling me about how these parents perceived their experience and the role it played in their parenting.
I began the coding process by reading and rereading the transcript to get a sense of the data, to learn what the data revealed about the phenomenon, to gain an appreciation for the whole, and to uncover what was important to the participant. I highlighted data that portrayed a comprehensive understanding of the content, which enabled me to remain true and faithful to the participant’s intent (Sandelowski, 2000). I spent a significant amount of time with the first transcript, in particular, to be sure the research question was being answered by the data. As necessary, I modified interview questions during future interviews in order to achieve a better fit between the question and the participant’s understanding and response.

While reading each transcript, I wrote preliminary thoughts in the margins; this was the first step in the creation and definition of first level codes. These initial codes were extracted from the data and were in the participant’s own words, known as in-vivo coding. The initial codes also included phrases and words that were repeated or said with emphasis denoting importance. Other comments highlighted as codes were reflective thoughts about the event as a whole or some particular aspect of the event that carried significance for the participant. These key thoughts and meaning units all functioned as in-vivo codes as they were in the words of the participants. Field notes that I had recorded at the time of the interview provided context for these first level codes and aided in understanding the why and how.

After coding the first transcript and at periodic intervals, I consulted with my dissertation chair for purposes of substantiating my identification of in-vivo codes. Each transcript was considered as a whole; within document first level coding always was completed prior to any comparison or clustering of codes.

Second level coding consisted of looking for similarities and differences, first within the transcript and then across transcripts. Similar in-vivo codes were placed together in a cluster to
capture key thoughts or meaning units. These then were relabeled using a more inclusive term and defined as a category. Categories reflected multiple but related *in-vivo* codes, thus making the number of codes more manageable without reducing the significance of the participants’ experiences. Likewise, I discussed my forming and naming of categories with my dissertation chair. This process helped to organize the data.

Systematic data analysis continued both within documents and across documents (Downe-Wamboldt, 1992; Sandelowski, 2000). To manage the data and provide visual clarity of my thinking, I constructed a matrix of rows for content and columns for major categories and organizing groups (Miles & Huberman, 1994). This matrix portrayed contrasts and commonalities across cases (Table 2). In addition, I reanalyzed earlier data for repeated statements, looking for information that I might have missed as new categories were identified across documents. I remained open to differences among participants, and sought the unique qualities of each parent’s experience, and considered new categories as analysis progressed.

At the third level of coding, I analyzed the categories and noted the emergence of patterns that were evident by combining some of the categories. These ideas about patterns were presented to my dissertation chair for discussion and agreement, an activity that minimized the possibility of researcher bias in coding and assisted me to keep the aim of the study in focus. This activity offered validity to claims that the descriptions accurately flow from and were true to the data.

By analyzing the relationship between and among different categories both within and across documents, I found that I could combine some to create new groups. I labelled and defined the new groups as patterns since each represented a more abstract and holistic
understanding of the phenomenon. Putting them all together, I discovered that these patterns eloquently described the experience of parenting the lone twin.

Table 2. *Example of Matrix: Commonality and Contrast*

<table>
<thead>
<tr>
<th>Content clusters</th>
<th>Quotes</th>
<th>Initial Category: Remembering: having one of two</th>
</tr>
</thead>
<tbody>
<tr>
<td>One but not two</td>
<td>I remember this one woman saying to me &quot;at least you have one,&quot; at the time, I just couldn't believe she said it to me, I thought it was horrendous. Actually, in hindsight, I am thinking at least I do have one. Some people do lose both.</td>
<td>Reflection - &quot;I do have one…&quot;</td>
</tr>
<tr>
<td></td>
<td>I have felt that way quite a bit [no one really understands what it is like to lose one twin]….it may have been easier since I still had a baby to hold.</td>
<td></td>
</tr>
<tr>
<td>Someone is missing</td>
<td>I've taken offense to people who have said ‘well at least you got one’…like our daughter was a consolation prize!</td>
<td>Reflection - &quot;at least you have one…”</td>
</tr>
<tr>
<td></td>
<td>I have heard other parents say after the loss of their single baby that all they wanted was to hold a baby…but I always told them that your arms ache for that baby.</td>
<td></td>
</tr>
<tr>
<td>Table 3. Example of In-vivo Categories and Patterns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>In-vivo</strong> units of significant comments</td>
<td>Categories</td>
<td>Patterns</td>
</tr>
<tr>
<td>What I ended up doing is just really not saying anything unless I thought they needed to know, so obviously teachers knew, and babysitters, because we talk about Jason at our house. My concern was that she would talk about her brother and that they would assume that was an imaginary friend. I wanted to make sure they knew Jason wasn’t “play” or a figment of her imagination. Now the people who are important in my life know, but some people don’t, and then I forget who I told, who I haven’t. Occasionally I even surprise a friend with a piece of information that they didn’t know.</td>
<td>Who needs to know?</td>
<td>Telling and not telling</td>
</tr>
<tr>
<td>When “show and tell” was going on in school, she would many times take a picture of her twin sister or something pertaining to her sister. I would have to talk to the teacher at the beginning of each year to let them know that, yes, she had a sister that died and that it was okay for her to talk about that loss. They were all receptive to my discussions and those early school days went just fine. All her friends also were aware of her loss and when they came to play at the house, that picture was no big deal to the friends also.</td>
<td>Who needs to know?</td>
<td>Telling and not telling</td>
</tr>
<tr>
<td>We had only just started to get to know people in our neighborhood, so some people kind of knew; others knew I was pregnant and huge. They had no idea anything was wrong and then they saw me with a baby and they were appropriately excited because “hey, look, she was pregnant and now she had the baby.” It was really hard to constantly manage that interaction, it just exhausted me. I just did my best, and it almost never worked out comfortably, I don’t think there was any way for it to have worked out comfortably. Especially in the first 8 months...as soon as someone asked, they could see they had stepped into something, and nobody could possibly imagine what it was. If you didn’t say anything, you felt terrible, and if you said anything, you felt terrible.</td>
<td>Consequences of telling</td>
<td></td>
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</tbody>
</table>
It was really hell dealing with the fall-out…we had to do the “undoing” of all the shared happy news that we were expecting twins. The hardest was to our four year old who was really looking forward to two babies. Every time we had to tell someone it was horrible. Amazingly enough, years after they were born, there were still people who asked “How are your twins?” not knowing that Anthony didn’t survive.

When Taryn was younger, she’d reply for me and say, “I have a brother in Heaven” to which most people didn’t know what to say or do. I’ve had to share our story with strangers who would probably rather run in the other direction than to learn our truth. I’ve taken offense to people who have said “well at least you got one” or “now you have your set (meaning a girl and a boy)”…like my surviving twin was a consolation prize? The insensitivity of people, even those close to our family, has been the hardest over the years.

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How many children is really hard because in my heart it’s three, but I just can’t go there with a stranger, so I’ll just say two. It feels dishonest in my heart. There is this woman in my building who is awful – she has twins and she didn’t know that my son was a twin and she moved here after he was born...she would start talking to me about the twins, the twins this, because they are twins they have to have this…for the longest time, I’ve been wanting to say my twin was a twin, but I haven’t. I couldn’t go there because it seems like there is no point to it, I mean, what am I going to say? I still do think about telling her that but I just don’t know how I’d say it.

<table>
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People ask how many kids we have and I will tell them...“I have 4 surviving kids” or something like that. People used to ask me...if my kids were twins or triples...it [answering] gave me a little piece of that...sometimes…I will just say “yes...” I would quite often say "he is, they aren’t" and walk off and that would leave people totally stumped. And you know, but it would give me some sort of sick satisfaction...I’m just validating that I did have twins. I am not going to lie but they ask if I have twins [I answer] “well, yes I do, but it is not any combination of those children.” Sometimes I will say “he is, but they aren’t, his sister passed away.” The look of horror on people’s faces would tell it all but I really didn’t care. It totally depended on my mood and the situation, what I felt like hearing because I knew the responses.

<table>
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</tr>
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</table>
It’s better now, although on the off-day, very painful. It took me quite a long time to figure out a way to answer that question that felt honest…and finally I ended up hitting on “they are not twins with each other” which felt comfortable and answered the direct question without too much information, and I’ve said that a thousand times…One woman was like “what the hell does that mean?” I told her, because she asked. And another woman asked quite nicely and I explained everything to her….and it’s been this constant battle not to just blow these people out of the water because I know I have the power to do it and to just be like “well, here’s how I know”…my first twin pregnancy was a twin pregnancy…here’s what happened at the end…but I don’t…for the most part, that urge has really passed.

<table>
<thead>
<tr>
<th>Answering “How many children?”</th>
<th>Telling and not telling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nick had only a 50/50 chance of survival, and it was so weird to think about that. It’s min-boggling to me. He’s so special. I mean every mother feels this about their child, but there is just something about him, people are really drawn to him. He has this really amazing quality about him. I think part of it might be because he’s such a fighter, or I don’t know, but he has this amazing little personality and it’s right now [that] we can sort of breathe a sigh of relief that he will have a normal life. I remember feeling that Brian had the…attributes…the strength of two people in one. In other words, he is a very talented person, super smart and well-liked…my point is that I felt like Brian got what Michael couldn’t [be]…I mean that is how I felt. I recognize that it’s completely irrational…but that’s how I felt…I think he had the goodness of two people coming through.</td>
<td></td>
</tr>
<tr>
<td>Reverence for the living twin</td>
<td>Parenting with wonder and worry</td>
</tr>
<tr>
<td>I was sort of on autopilot. I didn’t know what else to do but be a Mom to my older son and Brent. I would look at Brent nonstop trying to picture his twin, wondering if he was missing him. He was so content as a baby that it made me feel better that he didn’t seem agitated that he was “alone.”</td>
<td></td>
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<tr>
<td>Did my grief affect my surviving twin?</td>
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</table>
I cried all the time and I wonder if that is what made him more sensitive, I don’t know. I don’t know if he could sense any of that...I mean I cried a lot...he is quick to cry...not a real strong “go out and tackle him” sort of kid...I blame myself... if he could just “suck it up” and “be a boy” more, he would have an easier time with friends...probably every couple of months, he comes into a situation where he is brought to tears and somebody makes fun of him...I really, really worry about him in the middle school years. So I am really pushing him into activities that he is really good at so that he can really build self-esteem because he has a really hard time with that. He has a really hard time feeling good about himself, more so than the other kids.

It was always like “it’s supposed to be 3 of us.” And you know and I did cry a lot, she saw me cry a lot, and I always wondered how that would impact a kid, knowing, but she’s a very, very sensitive kid and my pediatrician tells me that you cannot cause or create a child’s temperament, that you can nudge it, but you can’t, and I wouldn’t choose to believe it anyway. You know I think the other thing that is true is that I used to be very worried about a lot of stuff, kind of “Type A,” and it totally stripped me of that. Now I’m just like I can’t control so I’m not going to worry about that – it’s done, it’s past and she is just who she is, and we love her. I think she’s a very happy kid, so I’m not going to spend that time stressing about it.

Over the years, seeing twins, especially boy-girl twins, seems to pull at my heart. I often find tears in my eyes and wonder and ask “why couldn’t I have both of mine?” when I know that’s not a question that can be answered...With each of her milestones, though, I found myself (and still do) wondering “what would it be like if both of them were doing that?” or “would he be interested in this too?”

We always wonder if they would have been alike or gotten along or looked alike or developed a special language. It’s the “what if’s” that are difficult.

When my surviving twin was little, I would watch her play and think or imagine that I could see my other twin playing right alongside of her.
I documented in my reflective journal all decisions made in the process of the research. This activity served as an explication of my thinking and rationale for decision-making throughout the process (Koch, 2004). In this journal I also tracked methodological developments and decisions, data-related insights, and my own emotions and responses. I reread and pondered my reflections numerous times and, in some cases, they reshaped the way the research progressed. The journal entries including discussion points with peers and experts were woven into the coding process and illustrated how I understood the data. Significant descriptive statements were integrated into a comprehensive retelling of the description of the participants’ perceptions of the experience, with particular emphasis on vivid quotes from participants that captured the identification of *in-vivo* codes, categories, and patterns.

**Rigor**

Rigor was built into this qualitative proposal at all levels. I consulted with my dissertation committee and especially my chair on a regular basis about all aspects of the research design and all of my coding decisions.

Throughout the process I maintained a reflective journal. In it I recorded my own thoughts as well as input from my dissertation committee related to all decisions such as sampling and related amendments, recruitment, and data collection. I reserved a separate section for data analysis including my coding discussions, how I made decisions, and how findings were ascertained (Knafl & Webster, 1988; Sandelowski, 2000). Field notes that supplemented interview text and provided context from nonverbal cues displayed by participants during interviews were recorded in the journal. This journal also served as an audit trail as I documented significant statements made by participants as well as how I organized initial (*in-vivo*) codes into categories and then patterns. In it, I illustrated the creative way the data shaped
the text and recorded both my contributions as the researcher and those of my committee. This journal entry routine provided rigor by providing future readers with the ability to judge the credibility of the final description.

Philosophical agreement between the purpose and methods was held to standards of rigor put forth by Beck (1993), namely, the evaluation of credibility, fittingness, and auditability. It was also my aim that the concepts of trustworthiness, consistency, and the transparency be evident during all phases of this research.

Qualitative research is widely considered a reflexive process. The researcher is part of the world being studied rather than separate from it (Lincoln & Guba, 1985). Reflexivity describes the researcher’s self-reflection upon preconceptions and feelings with the understanding that they represent an influential presence in the analysis of data. For this research, I acknowledged that 12 years prior to beginning the study, I had become the parent of a lone twin, which gave me a high degree of familiarity with the phenomenon. Both I and my dissertation committee took the potential for bias in all phases of the study very seriously, hence the significant methodological support throughout. I have worked through my own grief process to the point at which I was able to appropriately conduct this research. Throughout the course of my PhD program, I intentionally pursued academic exercises that challenged my emotional readiness for this endeavor, including interviewing a mother who had experienced a perinatal loss.

My research question required an inductive design and qualitative descriptive provided the best fit because the researchers seek representation of the data in the participants’ own words to convey their perceptions of the experience. Since there is a paucity of literature and essentially no research on the phenomenon, the place to begin studying the phenomenon is with
the parents’ sharing of their experiences. Therefore, with each encounter I mindfully separated my own circumstances from those of the participant. Because of my ‘a priori’ knowledge of this experience, I intentionly maintained a dedicated, cautious and continuous focus on the participants’ own descriptions. I firmly believed that my clinical and personal experiences were expressly what motivated my commitment to this study and program of research.

Credibility refers to how faithful the description of the phenomenon of concern is to the data (Beck, 1993). Both participants and other researchers who experienced this phenomenon should be able to relate to the description. This study design maximized rigor in data collection and analysis by maintaining a faithful accountability to readers and participants alike. The purpose of the proposed research was to describe the experience of parenting a lone twin from the perspective of those parents who experienced the phenomenon. Therefore, credibility lies within the words of the participants. Subjectivity is essential for an authentic account of participants’ perceptions of their experiences. In-depth interviews encouraged a rapport based on shared understandings and empathy, on gaining the trust of the parents to ensure data rich in meaning. Truthfulness was evident in findings when participants judged them meaningful and confirmed that the findings resonated with them.

The transferability of findings indicates the fittingness of the research. Fittingness means how well the research conclusions fit into a similar but different context (Beck, 1993). Qualitative researchers aim for reliability in data based on consistency, careful research practices, and a reflective stance about subjectivity, but not necessarily generalizability and replication (Davies & Dodd, 2002). Ideally the patterns that emerged are sufficiently holistic to provide direction for future research that eventually suggest interventions or design of a nursing
model or mid-range theory conceptualizing the phenomenon of parenting the lone twin. I plan to build on these findings as I progress in my program of research.

Trustworthiness is the process of data collection whereby the research is auditable and visible to the reader; the goal is to practice good science, rather than being “right” about the phenomenon (Sandelowski, 1993, p. 2). The transparency of the analysis is intended to provide the reader an opportunity to make his or her own judgment about the understanding of the data (Green, 1998). In this way, quality can be measured by a reader’s ability to identify the process by which the researcher explored the data. The focus of this research was the reflection and description these mothers and fathers gave about themselves and their experiences. The community of parents who suffer perinatal loss was served by the research, as it offered the opportunity for multiple parents’ voices to be heard and the phenomenon to be understood from their perspectives. I used quoted text was used to illustrate the most poignant facets conveyed by participants.
Chapter 4

Findings

Description of the Sample

The aim of this qualitative descriptive study was to describe the experience of parenting a surviving twin from the perspective of those mothers and fathers who experience the loss of one twin in utero (after 20 weeks gestation), during birth, or in the immediate neonatal period (first six weeks of life). Specifically, this research was designed to describe (1) how the grief involved in the loss of one twin influenced the daily processes of parenting the other twin; (2) how the mothers and fathers who have lost a twin coped with the challenges of simultaneously dealing with the resulting grief and yet bonded with and nurtured the other baby; and (3) the emotional effects of this challenging experience on the parents.

Study participants were eight mothers and one father who experienced the loss of one twin and subsequently are raising the living twin. The circumstances of the perinatal twin loss varied greatly. Two parents (one of whom was the only father in the study) learned that one twin had a genetic anomaly that was incompatible with extrauterine life, and therefore knew for months that one twin would not survive after delivery. Five mothers experienced preterm labor and delivery resulting in complications arising from prematurity and death of one twin within hours/days of birth. Two of these mothers described a lengthy stay in the NICU for the surviving twin. Two parents discovered that one twin had died in utero of unknown causes. One had this information for a short time (hours/days) before delivery and one for a period of weeks before delivery. Those mothers delivered a live twin and a stillborn twin.

These parents all had other children, either before or after the twin pregnancy. For four families, the twin pregnancy in which one twin died was their first pregnancy; for the others it
was not the first pregnancy. At the time of the interview, the age of the surviving twins ranged from 5 years to 24 years of age. A number of the mothers in the study had given birth to subsequent children within one year of their participation in this study.

Although the invitation for participation in this study was advertised for both mothers and fathers who had experienced the loss of a twin, as in previous research focusing on perinatal loss, only one father agreed to participate in this study.

Three interviews were conducted face-to-face with two mothers and a mother and father dyad living in New England. Four mothers who lived outside the geographic region of New England participated in the study; one of these interviews was conducted on the telephone, the others, via email (Table 4).

**Introduction of the Participants.** Katie’s twin pregnancy was her first. She experienced difficulty getting pregnant and received infertility care. She delivered a stillborn girl and her surviving twin son at term, shortly after discovering her twin daughter had died in utero of unknown causes. Her living twin son was 10 at the time of the interview. After the twins, she then had 4 more pregnancies, one a miscarriage. Katie has 2 sons and 2 daughters.

Lori’s twin pregnancy was her first. At 19 weeks gestation, she discovered that one twin, a son, had a genetic disorder that was incompatible with extrauterine. Lori carried the twins to term and delivered a daughter and son at 38 weeks. As anticipated, her son died within hours of birth. Her living twin daughter was 7 at the time of the interview. Lori had two pregnancies after the twins; she has a second daughter and, at the time of the interview, an infant son.

Anne and Mark’s twin pregnancy was their second pregnancy. They experienced infertility treatment. At 20 weeks during their twin pregnancy, they were told that one of their twin boys had a genetic anomaly incompatible with extrauterine life. Anne delivered her twin
boys at term, and one twin died shortly after birth. At the time of the interview, their living twin son was 18 years of age.

Table 4. Description of Participants

<table>
<thead>
<tr>
<th>Parent(s)*</th>
<th>Twin who died*</th>
<th>Living twin*</th>
<th>Living twin's age (years) at time of interview</th>
<th>Twin pregnancy/other children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Katie</td>
<td>Anna</td>
<td>Aiden</td>
<td>10</td>
<td>Twins - first 3 younger children</td>
</tr>
<tr>
<td>Lori</td>
<td>Jason</td>
<td>Deidre</td>
<td>6</td>
<td>Twins - first 2 younger children</td>
</tr>
<tr>
<td>Anne &amp; Mark</td>
<td>Michael</td>
<td>Brian</td>
<td>18</td>
<td>Twins - second 1 older child</td>
</tr>
<tr>
<td>Barbara</td>
<td>Anthony</td>
<td>Brent</td>
<td>14</td>
<td>Twins - second 1 older, 1 younger child</td>
</tr>
<tr>
<td>Sally</td>
<td>Stacey</td>
<td>Nick</td>
<td>4</td>
<td>Twins - first 1 younger child</td>
</tr>
<tr>
<td>Claire</td>
<td>Ryan</td>
<td>Taryn</td>
<td>9</td>
<td>Twins - first 1 younger child</td>
</tr>
<tr>
<td>Debbie</td>
<td>Amy</td>
<td>Christine</td>
<td>24</td>
<td>Twins - first 4 older children</td>
</tr>
<tr>
<td>Karen</td>
<td>Morgan</td>
<td>Patrick</td>
<td>13</td>
<td>Twins - second 1 older child</td>
</tr>
</tbody>
</table>

*Pseudonyms

Barbara’s twins were her second pregnancy. She delivered a live twin and a stillborn twin, both boys, at 36 weeks. One twin had died in utero of unknown causes, thought to have been a cord accident. At the time of the interview, her living son was 12 years of age. She has an older son and a subsequent child, a daughter.

Sally experienced the preterm delivery of twins with her first pregnancy. She delivered a girl and a boy. Her daughter died shortly after birth from complications related to prematurity; her son subsequently spent 4 ½ months in the NICU. At the time of the interview, he was 4 years old and Sally had recently given birth to a second daughter.
Claire’s twin pregnancy was her first. She delivered her twins, a girl and a boy, at 25 weeks. Her twin son died at 9 days of age in the NICU and her twin daughter had a nearly 3 month stay in the NICU before being discharged home. Claire also has a second son who was born after her twins.

Debbie had four boys at home when she discovered she was pregnant with twin girls. One of her twins died after birth due to complications related to a placental problem and prematurity. Her living twin daughter is now 24 years old.

Karen’s twin pregnancy was her second pregnancy. She learned at 29 weeks that one twin boy had died in utero of unknown cause. She delivered her twin boys at 32 weeks. Her living twin was 13 years old at the time of the study, and her eldest son was 17 years of age.

Result of Data Analysis

From a qualitative content analysis perspective, four patterns became evident and formed the structure and significance of the parents’ on-going experiences of parenting the lone twin (Table 5: Summary of Findings). Each pattern was comprised of categories that added detail and understanding to the pattern. As noted in Chapter Three the data used to construct the categories remained close to the words of the participants and was a synthesis of their reflected experiences.

Living with the ambiguity. Raising a lone twin is inherently incongruous. The dichotomy of this experience was clearly evident and difficult for the parents in this study. These mothers and father experienced both ends of the continuum – life and death, celebration and mourning, a birthday and a funeral – simultaneously. They revealed conflicting emotions of joy and sorrow when they brought one baby home and buried the other, along with the bitterness of not only losing a child but also losing the specialness of being the parents of twins. Over
time, they created and re-created meaning from the experience as they found themselves parenting amidst a sense of going back and forth in their grief, at times unexpectedly.

Table 5. *Summary of Findings*

<table>
<thead>
<tr>
<th>Patterns</th>
<th>Categories</th>
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<tbody>
<tr>
<td>Living with the ambiguity</td>
<td>Irony in raising a lone twin</td>
</tr>
<tr>
<td></td>
<td>Belonging and not belonging</td>
</tr>
<tr>
<td></td>
<td>At least there is one</td>
</tr>
<tr>
<td>Communicating the family journey</td>
<td>Telling and not telling</td>
</tr>
<tr>
<td></td>
<td>Deciding who needs to know</td>
</tr>
<tr>
<td></td>
<td>How many children</td>
</tr>
<tr>
<td>Parenting with wonder and worry</td>
<td>Doubt and hyper-vigilance</td>
</tr>
<tr>
<td></td>
<td>Unanswered questions</td>
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<tr>
<td></td>
<td>Living twin as a unique person</td>
</tr>
<tr>
<td>Life is different now</td>
<td>Loss of innocence</td>
</tr>
<tr>
<td></td>
<td>Honoring both twins</td>
</tr>
<tr>
<td></td>
<td>Making and keeping relationships</td>
</tr>
<tr>
<td></td>
<td>Work-life challenges</td>
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<tr>
<td></td>
<td>Accepting that it doesn’t go away</td>
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</table>

**Irony in raising a lone twin.** The irony of raising a lone twin was expressed repeatedly by the parents in this study. For them, their expectations of giving birth to and raising twins ended all too abruptly, with conflicting sorrow and joy, a contradiction that has outlasted the early grieving period following the death of their infant twin. Lori described her feelings this way:

I literally felt like I was going to split in two... when you have a twin die, it’s incredible; it feels so horrible to be taking any joy from it. I wouldn’t never step back there in a million years, I’d rather go back to junior high again than do that.

Making the irony even more difficult was the fact that the loss of a twin is largely invisible. These mothers had been pregnant, and, after delivery, came home with one baby. In the public view, they were women who had been visibly pregnant and then had a baby in their
arms; anyone unaware that the family had been expecting twins would have no idea that one child had died. However, the parents knew and they were pained by the loss of their child and the opportunity to parent twins, which socially has special status. As Debbie described:

> Being a parent of a twin is still somewhat out of the ordinary. After all, most babies are single births. But with my loss, I knew that I was the mother of twins, yet no one could see that.

Lori echoed this sentiment when she related:

> The thing I loved about that time was that we spent all our time together, the way to you do with your first one. . . we went out in the stroller, for rides, and we’d walk around the neighborhood, we had a coffee shop, so she got a lot of one-on-one attention, it felt very much like me and Deidre in the world, it was great . . . but it was always like “it’s supposed to be 3 of us.”

They had mixed emotions in seeing others’ twins, be they family or strangers in the community as it was difficult to have yet another reminder of their twins and one was missing.

Katie not only had a difficult time when her sister’s twins turned one, but she discussed her longing to have twins and intentionally having her children close in age:

> . . . I did not go to their first birthday party and my family all gave me grief for it . . . I did not want to spoil her day and I knew if I was there that was no way that I was going to hold it together. It is tough because my older three are so close in age . . . that was my motivation to have kids close in age . . . I did wish that I would have another set of twins. I do not know how I would have survived the pregnancy but I do feel like I was gypped out of being a twin mom.
Seeing twins in public evoked strong emotions from Lori. She felt angry: “. . . they look tired, of course, they looked harried. I wanted to run them over with my car, and I’m not kidding…I was so tempted to take them out. They did not look appreciative enough of their twins.”

**Belonging and not belonging.** The invisibility of the loss of one twin contributed to feelings of not belonging. These parents did not belong to a support group of parents who had lost a baby, they did not have the public identity of being parents of twins, and they did not have the typical experience of having a baby; yet, all of these contributed to their profound sense of loss at the same time.

Even in the hospital, immediately after delivery, these parents felt they did not belong, an impression that made the experience all the more difficult and isolating. Since these parents had other children, either before the twin pregnancy or after, they were acutely aware of the differences between the birth experiences. Katie described her hospital experience this way:

> I had a baby. I did not get to experience any of those nice things. I didn’t get to experience that nice dinner they give new parents . . . I got gypped out of all those things for him. But, wait a minute, you know, what about him [living twin]? There was never any of that.

After losing their twin, a number of the families attended pregnancy loss support groups, where they found themselves in awkward and difficult positions when in discussion with other mothers and fathers who had lost an infant. Having a child, but having lost one, was an experience incomprehensible and unknown to the other parents, and, in some cases, even the facilitators of the support groups. The mixed messages were confusing and the experiences painful, as Anne related:
. . . I remember we broke into an argument one day because someone said to me ‘I don’t understand why are you here, you have a baby.’ And then the other people started yelling at her – ‘how can you say that, she lost a baby, that’s why she’s here.’ I felt that I had to defend myself; it never occurred [to me] that I was there for any other reason other than the fact that my son died, he’s a different person than the other one. I was such a problem . . . I thought ‘my God’ the amount of emotion and energy in that group, I almost felt like it was a responsibility to go there for the other people, but it wasn’t really helping me.

Katie had a similar experience when she attended a hospital support group with her living twin:

We went when Aiden was maybe 6 months old, but . . . no one could relate to having one and losing one. As a matter of fact, sometimes they would get annoyed because you would bring a newborn with you to the support group . . . the nurse who knew that I was coming to the group regularly…asked me if I would not bring my baby with me . . . I was really angry, I mean, I understood but, I was still angry because they thought my loss was not really as important, just because I have a surviving baby, I could not leave my baby [home] . . .

**At least there is one.** When the twin loss was known to others, these parents had to contend with well-intentioned comments plus their own contentious feelings. They described how their inner conflicts colored their perspective and response. Barbara expressed her coping with parenting her living twin with a sense of gratitude as she realized both of her twins could have died when she said:
I can’t fathom what it must be like for parents who lose both twins in a first pregnancy. I still got to have the joy being a mom . . . just not the way I thought it was going to be. It was a tough thing to put in perspective, but that’s the way it is.

Dealing with other peoples’ comments about the fact that one twin survived evoked an emotional reaction from Katie, as she commented:

… the common thing people would say to you over and over again, at least you have one and he’s healthy and you have him and you want the smack them in the head. You understand because they don’t know what else to say. You just want to smack them . . . you do not think that I am happy and very thankful that I have him . . . ? But it doesn’t take away from the fact that I don’t have her . . . .

Sally recalled being told ‘at least you have one,’ but relayed her perspective this way: ‘at the time, I just couldn’t believe she said it to me, I thought it was horrendous. Actually, in hindsight, I am thinking at least I do have one. Some people do lose both.’

Debbie answered the comment in yet another way when trying to relay how it felt to have one:

When you have one surviving twin you can hold that baby and yet your arms physically ache for the other twin. I have heard other parents say after the loss of their single baby that all they wanted was to hold a baby. But I always told them that your arms ached for “that” baby.

Lori wondered if mothers of twins might understand:

. . . sometimes Moms with twins do really get it, they know they don’t have a baby and a spare, so they understand that you haven’t been given the “bonus” kid. And they can much more put themselves in the situation, ‘what would it be like if I didn’t have one of
my kids,’ but a lot of people they just don’t understand the kind and types of joys of the whole thing is.

**Communicating the family journey.** Although the circumstances of the death of the twin were different, a number of common threads about communication arose in the parents’ stories. Among these threads was the telling, un-telling, and re-telling of the news of their twins. These parents were intentional about who should know, and how, what, and when to tell their family’s journey of expecting twins, losing one twin, and parenting one twin.

**Telling and not telling.** Telling the journey of the lone twin, whether to a close friend who offered support and comfort, or to a school official in anticipation of comments made by the surviving twin, held tremendous power and represented an ongoing connection to the lost child. At times, the decision to tell or not to tell happened at the beginning of a relationship and was forever a part of that relation.

The deliberate and conscious effort required for managing ongoing relationships and communication took a toll on these parents. Lori described her experience with her neighbors:

We had only just started to get to know people in our neighborhood, so some people kind of knew; others knew I was pregnant and huge. They had no idea anything was wrong and then they saw me with a baby and they were appropriately excited because “hey, look, she was pregnant and now she had the baby.” It was really hard to constantly manage that interaction, it just exhausted me. I just did my best, and it almost never worked out comfortably, I don’t think there was any way for it to have worked out comfortably. Especially in the first 8 months [after losing her twin], as soon as someone asked, they could see they had stepped into something, and nobody could possibly
imagine what it was. If you didn’t say anything, you felt terrible, and if you said anything, you felt terrible.

Decisions about telling, not telling, who to tell, when to tell do not disappear. These decisions reoccurred many times and in varying circumstances, both anticipated and unanticipated. Lori’s family moved when her surviving twin was 3 ½ years old:

Then there was a whole new set of people in my life who did not know. We were way past the time that people think you should be experiencing that kind of emotion and so it’s almost like do you bring it up or do you not bring it up, going through that initial period over again. What I ended up doing is just really not saying anything unless I thought they needed to know, so obviously teachers knew, and babysitters, because we talk about name at our house. My concern was that she would talk about her brother and that they would assume that was an imaginary friend. I wanted to make sure they knew Jason wasn’t “play” or a figment of her imagination. Now the people who are important in my life know, but some people don’t, and then I forget who I told, who I haven’t. Occasionally I even surprise a friend with a piece of information that the they didn’t know. I think because now I don’t usually cry and I don’t usually tell things, just recite the facts of it, they are okay.

Others described how difficult it was to respond when people commented on their living twin in public. In Barbara’s words, “It was tough when people would compliment me on how cute Brent was. Sometimes I wanted to just blurt out ‘he’s a twin!’ because I felt like he was missing out on so much with people assuming he was a singleton.” Katie commented on her experience of discussing her twins when she attended a mothers’ group with Aiden:
They would always open with a question for the Moms; a lot of times it was “what do you remember on the day they were born?” . . . if the regular person running the class saw me coming she would avoid that question. There was one set of newborn twins that never came back again after I spoke. I was honest.

It was clear that talking about the loss to people who knew they had been expecting twins, including the siblings of the child they lost, was a significant emotional challenge. Barbara verbalized the difficulty this way:

It was really hell dealing with the fall-out . . . we had to do the “undoing” of all the shared happy news that we were expecting twins. The hardest was to our four year old who was really looking forward to two babies. Every time we had to tell someone it was horrible. Amazingly enough, years after they were born, there were still people who asked, “How are your twins?” not knowing that Anthony didn’t survive.

**Deciding who needs to know.** Parents protected the family from unwanted attention or overly inquisitive acquaintances by distinguishing who needed to know about their twins and what they needed to know. This intentional process and vigilance in balancing privacy with the need for select people to understand was particularly perceptible outside their immediate and extended families. All too often casual friends did not fully comprehend the significance of the loss and this lack of understanding created tension as told by Katie:

We made the decision to talk openly about it with the kids right off the bat and even though always we have gotten grief along the way, people constantly say that you should be over it by now; now not so much because it is more of a “don’t ask, don’t tell” policy. It is almost like nursing my youngest one until she was 4, you know, “don’t ask, don’t tell.”
Communicating the family narrative was a continuous challenge both within the family circle and outside the family circle. Most of these families chose to speak freely within their family and openly acknowledged their lost twin. However, for many parents the context of the situation dictated who “needed to know” outside the family for the sake of their surviving twin. To manage communication with consistency, they constructed a wide continuum of greater and lesser degrees of that “need to know.” Debbie stated, “Depending on the conversation, I would tell some people that I had twin girls, and at other times, not say anything to that effect.” Other, more significant relationships, such as those with childcare providers, schoolteachers, and playmates, posed a significantly different set of circumstances. Debbie elaborated on “show and tell” at school for her twin:

We always had a picture of our baby sitting next to the bed of our surviving twin. We would kiss the picture goodnight and talk to our daughter about her sister. Being in a family with all boys, she needed to hear that she did have a sister and not just brothers. When “show and tell” was going on in school, she would many times take a picture of her twin sister or something pertaining to her sister. I would have to talk to the teacher at the beginning of each year to let them know that, yes, she had a sister that died and that it was okay for her to talk about that loss. They were all receptive to my discussions and those early school days went just fine. All her friends also were aware of her loss and when they came to play at the house, that picture was no big deal to the friends also.

For Lori, school represented a loss of control over the journey and precipitated an intentional change in her philosophy:

Kindergarten was a huge milestone . . . . Her understanding of the experience, which is different from mine, had to become in our mind what was really important in the family.
Like I could have my personal feelings about it but I didn’t want to burden her with that very adult stuff. She’s proud to be twin, she’s the only twin in the family, and she’s very excited, she loved her brother, which we thought was a great thing, and beautiful. It wasn’t until she was about to enter Kindergarten that I think she was able to articulate that clearly. Most of all, above and beyond, I really need to make sure that the teachers and people that surround her in school, and babysitters and friends, are people who are going to respect that this is a journey and we are not entirely sure where it’s going.

She described further the process of including the deceased twin in communication within the family, and then subsequently how she dealt with the consequences of this behavior:

Talking about this with teachers and school administrators, and then other parents of twins in the class has been a consistent challenge... One of the things I was afraid would happen actually happened – Deidre was sitting across the table from the little girl... and said “hey I’m a twin, too”... and the little girl said “no, no you aren’t a twin, you are lying.” Deidre, bless her heart, said “I am a twin and my brother died.” The girl said, “Well, that makes me feel sad” and they walked away. This is partially why I wanted the Mom to know, because that’s a tough thing for another kid to hear who is a twin, and I wanted her to be prepared if it went home. My daughter came home and told me about it and I just said “its fine to tell people about Jason, and it might be sad, it is a sad thing when a baby dies, but that’s not a reason not to tell people about him.” I also once had a teacher tell me, Deidre was going on 4 - it might help if I started to tell her that other people didn’t want to hear about Jason... I don’t think you can tell a 3 year old that and have them understand, they can’t understand the nuances of that. And, that’s not how we’re rolling with this anyway.
For these parents, there always was a deliberate protectiveness involved when addressing the loss of their twin. Sometimes they felt victimized by insensitive, uncaring, and thoughtless responses from those they told. At these times some parents felt anger and others sensed frustration at peoples’ lack of understanding and unwillingness to learn about the grief journey.

*How many children.* This casual question often used to start a conversation or to get to know someone, was instead interpreted as precipitously difficult by these parents. The question, “how many children do you have?” was most difficult for them to answer. Regardless of how parents chose to answer this question, there was internal turmoil. They knew that they either had to respond to the reactions of others or rationalize being untrue to the identity of their family.

This turmoil seemed to contribute to the ongoing tension of their loss. As parents, they had to relive the pain of losing a child each time they answered the question. Barbara described it this way: “I rarely shared this info with people, unless it was someone I know I would establish a relationship with. I still struggle a bit when people ask me how many kids I have. It’s just so easy to say three . . . but in my heart, I am shouting “FOUR!!”

The negative consequences of telling people about the twin who died compounded the already difficult task of answering the question about the number of children in the family. Claire highlighted her experience in being asked the dreaded question:

> When Taryn was younger, she’d reply for me and say, “I have a brother in Heaven” to which most people didn’t know what to say or do. I’ve had to share our journey with strangers who would probably rather run in the other direction than to learn our truth. I’ve taken offense to people who have said “well at least you got one” or “now you have your set (meaning a girl and a boy)” . . . like my surviving twin was a consolation prize?
The insensitivity of people, even those close to our family, has been the hardest over the years.

The sense of being dishonest when not acknowledging the deceased twin and the subsequent internal turmoil were equally painful for parents. As Sally conveyed,

How many children is really hard because in my heart it’s three, but I just can’t go there with a stranger, so I’ll just say two. It feels dishonest in my heart. There is this woman in my building who is awful – she has twins and she didn’t know that my son was a twin and she moved here after he was born. I would like see her on the elevator and she would start talking to me about the twins, the twins this, because they are twins they have to have this . . . for the longest time, I’ve been wanting to say my twin was a twin, but I haven’t. I couldn’t go there because it seems like there is no point to it, I mean, and what am I going to say? I still do think about telling her that but I just don’t know how I’d say it.

Parents were keenly aware that telling the truth was nebulous and the question “how many children do you have” was a complex one that brought their loss to the fore immediately. If they responded honestly, the questioner was caught off-guard and may or may not recover tactfully. If they did not include the deceased twin, they feel dishonest as if they had betrayed both of the twins. Not only was this a painful question, but sometimes it was made even more awkward when people asked if the surviving twin and another sibling were twins. Katie described her approach to that question this way:

People ask how many kids we have and I will tell them 6 because we had a miscarriage between our 2 youngest and we “count” that . . . we will say “I have 4 surviving kids” or something like that. People used to ask me . . . if my kids were twins . . . it [answering]
gave me a little piece of that . . . it is very hard to tell if they are twins . . . sometimes . . . I will just say “yes.” Are they twins or triplets? I will quite often say he is, they aren’t, and walk off and that would leave people totally stumped. And you know, but it would give me some sort of sick satisfaction. I’m just validating that I did have twins. I am not going to lie . . . [I answer] “well, yes I do, but it is not any combination of those children.” Sometimes I will say “he is, but they aren’t, his sister passed away.” The look of horror on people’s faces would tell it all . . . totally depended on my mood and the situation . . . because I knew the responses.

Lori echoed some of these feelings when she added how complicated and difficult it can be to respond patiently and tactfully to strangers who seem to not want to understand.

The question I get asked most frequently about my girls is, are they twins? They look a lot alike . . . . It’s better now, although on the off-day, very painful. It took me quite a long time to figure out a way to answer that question that felt honest . . . . And finally I ended up hitting on “they are not twins with each other” which felt comfortable and answered the direct question without too much information, and I’ve said that a thousand times . . . . One woman was like “what the hell does that mean?” I told her, because she asked. And another woman asked quite nicely and I explained everything to her . . . and it’s been this constant battle not to just blow these people out of the water because I know I have the power to do it and to just be like “well, here’s how I know” . . . my first twin pregnancy was a twin pregnancy . . . here’s what happened at the end . . . but I don’t . . . for the most part, that urge has really passed.
Parenting with wonder and worry. The mothers and father in this study expressed a wide array of emotions surrounding their experiences in parenting their living twin and their other children after their twin died. Universally, there was worry about the living twin, accompanied by many “what if” questions, some unspoken. Raising a lone twin, after one twin has died, was a context that began with grief and was consistently shadowed by doubt and wonder. Anne described her worrying when she conveyed: ‘First of all I just wore myself out so much by worrying and being anxious . . . I just felt like hyper-vigilant, for years. And I was kind of an older mother to begin with.’

These parents worried how growing up knowing one is a twin but living as a singleton might affect their living twin as well as their other children. Barbara voiced the gamut of these feelings when she said:

It was weird . . . because Brent was so wonderful that he made me happy when I was sad. And I didn’t want my older son to see me sad . . . he was such a bright light for us too because he just ‘LOVED’ being a big brother . . . the fact that I didn’t get to parent twins comes into play and then I also feel sad thinking about Brent not getting to grow up with his twin.

Sally, too, pondered the loss of the twin relationship for her living son:

It was so devastating, and it’s still, 4 years later, still so hard to see twins and everything – it’s bittersweet, because I have this great son, he’s wonderful and he’s amazing, but you know, he had a sister and he doesn’t know really at all about his sister . . . . I do feel that Nick and Stacey had a relationship too and I feel like they did know that there was somebody else in there with them, in some way. But I don’t know . . . I know there is all
this research done about twins – that they know the other twin is gone, a grieving process as a baby. Like something is missing . . . it’s so hard to go there, to think about that. Lori’s expressed her reluctance to write her feelings in her living twin’s baby book when she commented:

There are questions in that baby book I can’t answer, like “How did you feel when your baby was born?” I don’t know what to write there, to write what I really felt? Maybe when she’s an adult that would be a conversation, but you know, I just don’t really know what to put there.

*Doubt and hyper-vigilance.* The challenge of nurturing an infant while grieving was clearly difficult. The mothers in this study expressed their isolation and sense of invisibility as a time of ‘going through the motions,’ that was vastly different from the experience they had anticipated. Katie reflected that she was ‘in a fog for probably the first 5 months…a complete and utter fog…just going through the motions purely because I had a baby…I probably cried every moment I had him. I cried all the time. Anne remembered those early months this way: ‘I still remember I would be breastfeeding and I would be crying…I spent a lot of time sitting in that rocking chair in the living room. And I was just kind of at wits end. I really was.’ Though many of the mothers remembered the active grieving vividly, Barbara put things in perspective when she described her early parenting:

I was sort of on autopilot. I didn’t know what else to do but be a Mom to my older son and to Brent. I would look at Brent nonstop trying to picture his twin, wondering if he was missing him. He was so content as a baby that it made me feel better that he didn’t seem agitated that he was ‘alone.’ I still got to have the joy being a mom . . . just not the way I thought it was going to be. It was a tough thing . . . but that’s the way it is.
Some parents acknowledged the infancy of their living twin was filled with sadness and guilt, they also worried that they changed their living twin because they grieved during the infancy of that child. Lori recounted her doubts this way:

We didn’t know Deidre would survive . . . I can just tell you it’s horrible. And then to come out and sort of have to just function, it’s asking way too much . . . the first 8 months, I had a peculiar sensation of having a bubble around me that only I could see . . . . I was functioning normally, inside the bubble. And, to . . . walk around with Deidre, I felt separately physically from the world, it’s like nothing could pierce the bubble, nothing could get through until I lost that feeling when she was 9 months old and I got pregnant again . . . .

There was guilt as parents wondered if they influenced their twin’s developing personality by crying, as Lori elaborated,

I did cry a lot, she saw me cry a lot, and I always wondered how that would impact a kid . . . she’s a very, very sensitive kid and my pediatrician tells me that you cannot cause or create a child’s temperament . . . it’s done, it’s passed, and Deidre is just who she is, and we love her . . . .

Katie echoed this when she shared the following:

I cried all the time and I wonder if that is what made him more sensitive, I don’t know. I don’t know if he could sense any of that . . . mean I cried a lot . . . I held him nonstop because one it was the only way that he was quiet and I went through the motions. . . . [now that he’s older] he gets picked on because he is quick to cry. . . . I blame myself . . . probably every couple of months, he comes into a situation where he is brought to tears and somebody makes fun of him . . . he has a really hard time feeling good about himself,
more so than the other kids . . . we had to intervene a couple of times . . . if his twin sister had been there would things have been any different? He is super, super sensitive. He is my only kid that will cry at the drop of anything. I don’t know; is this who he would be anyway? . . . I question it all of the time . . . would he be different, would it be that way?

There were other concerns about the development of the living twin. Lori also wondered if her living twin would have been the same person if raised with her twin brother, as she described her daughter this way:

Deidre is a high anxiety kid, she worries a lot . . . the anxiety has seemed to have shifted as she has gotten older, she asks a lot of questions . . . this sounds terrible, but when she was 3 ½, she was very strange in that way . . . we were actually worried for a while. She also went into a phase where she really wanted to be a boy . . . I know that kids [do that] . . . she did say once ‘why was Jason the boy and I was the girl? I think I should have been the boy.’ There is no way to know if she would have been like this, or would have had those thoughts, if she had been a singleton birth or if we hadn’t told her . . . but of course we wondered and I sort of wish that we could see her without sort of gloom . . .

While coming to terms with the reality of parenting a lone twin, these parents were very concerned about the health of their living infant, an uncertainty and tenuousness that undoubtedly contributed to the hyper-vigilance they described. Lori described this uncertainty when she said,

What happened with Deidre after she was born . . . and I still experience this now, I’m much more emotional than I had been, waiting for the other shoe to drop . . . I was just sure that she was going to die. I mean, how did we just manage to get her out of the situation full term, alive, and she did everything early, she walked at eight months. She
talked, and I always thought that was just so I would worry less, instead of doing things on the later side as we may have expected. I worried and worried, and I know people say...’all parents worry that their child will die . . .you know, everybody sneaks in to see if they are still breathing.’ I want to say it’s just different, and how can I know that? How can I know that? No one else was freaking on the same level that I was freaking.

The worry felt by these parents extended to their other children as well. Anne told a journey about her older son, who after she lost her twin, didn’t want to go back to school:

I made arrangements with the teacher for him to go back . . . I promised that later in the week I would bring the baby in . . . when I got there, the school psychologist was there. And, apparently what had happened in the morning was that he had told the teacher that he was not really coming back to school, he was just there today because his baby brother was coming to visit. The psychologist had to convince him that it was [his] job to go to school and he couldn’t stay home and take care of the baby. That is what he thought he was going to do . . . as far as he was concerned he was dropping out of school because he wanted to help take care of the baby. So it was tough because I didn’t expect . . . didn’t know what he was thinking or what was going on there everyday . . . [that day] he put his coat on when I was ready to leave . . . that was the end of school career.

Unanswered questions. The unanswered questions, both spoken and unspoken, have lingered and have significantly contributed to the stress of these parents. For some parents, these questions were more obvious, for example, not knowing the cause of death of their twin.

Claire’s questions were telling when she said, “over the years, seeing twins, especially boy-girl twins, seems to pull at my heart. I often find tears in my eyes and wonder and ask ‘why couldn’t I have both of mine?’ when I know that’s not a question that can be answered.” For others, the
most difficult questions were unspoken. Debbie echoed this sentiment when she pictured the twins together in her mind: “When my surviving twin was little, I would watch her play and think or imagine that I could see my other twin playing right alongside of her.”

“What if” questions surfaced that highlighted the loss of the specialness of having twins and their children being twins. Claire discussed this when she noted, “With each of Taryn’s milestones, though, I found myself (and still do) wondering “what would it be like if both of them were doing that?” or “would Ryan be interested in this too?” Karen expressed her questions this way: “We always wonder if they would have been alike or gotten along or looked alike or developed a special language. It’s the ‘what if”s’ that are difficult.” Sally described it this way: ‘the fact that I didn’t get to parent twins comes into play and then I also feel sad thinking about Nick not getting to grow up with his twin.’ Echoing these feelings, Katie expressed ‘over the year . . . I look at my son quite often and wonder what would it have been like. Sometimes I imagine his sister sitting in the back seat of the car, back there too, two kids, same size.’

**Living twin as a unique person.** While there was worry, paradoxically, the mothers and father in this study described their living twins with reverence. Not only was there a sense of wondering what the twin who died might have been like, but also a sense of awe about their living twin, whom they characterized as special and different. As Mark described:

One of the things I remember feeling . . . and I felt this very strongly, and I want to preface by saying that I am the last thing from a superstitious person even a spiritual person in . . . the conventional sense . . . I remember feeling that Brian had the…attributes . . . the strength of two people in one. In other words, he is a very talented
person, super smart and well-liked . . . my point is that I felt like he got what Michael couldn’t [be] . . . I think he had the goodness of two people coming through.

Sally relayed her feelings about her son, who spent months in the hospital after birth, in this way:

Nick had only a 50/50 chance of survival, and it was so weird to think about that. It’s mind boggling to me. He’s so special. I mean every mother feels this about their child, but there is just something about him, people are really drawn to him. He has this really amazing quality about him. I think part of it might be because he’s such a fighter, or I don’t know, but he has this amazing little personality…

**Life is different now.** Parents voiced the realization that losing a twin has changed them as individuals and parents. In this study, these parents told their family’s journey by beginning with their twin pregnancy and delivery; the loss of one twin was the impetus for a changed perspective about expectations and caused these parents to re-think priorities, relationships, and accept the realities of their situation. The acceptance implied a level of intentionality, which surfaced in this study as ways in which these parents protected themselves, made decisions, and maintained whatever balance they could in their lives.

**Loss of innocence.** The initial shock of discovering that one twin had died was indelibly marked in their memories. They experienced a loss of naiveté when the unexpected happened to their family. The abrupt realities were evident, as Sally illustrated:

I had some trouble getting pregnant and it’s interesting because I never thought, I mean of course you don’t think anything is ever going to happen, it’s an ignorance is bliss sort of thing . . . everything fell apart in one day and in a second . . . everything when I was pregnant was focused on twins . . . I was thinking ‘how am I going to breastfeed, how am
I going to take them out on a walk,’ everything . . . focused around two. And to just have one, it was just really one, and I had to . . . everything was just different . . . .

Anne conveyed her loss of innocence in this manner:

…you might be worried about something . . . and think ‘oh, you know I’m worried about this but those kinds of things never really happen, they always happen to somebody, someone else.’ But then, it happens to you, and then you know that it not only can happen, but it could happen again, you know. And that was very, very difficult, that was a real life changing thing.

Anne’s husband Mark described what happened when they discovered one of their twins would not live after birth:

. . . Clearly what happened shortly after [receiving the news that one twin was not going to survive] . . . my wheels were turning, both our wheels are turning . . . we just realized that we had a lot of things to deal with . . . now this, which is bigger than all of them . . . and so, I remember that winter, it was . . . the first time in my life, when I felt . . . ’wow I am grown up now’ . . . this is not kid stuff anymore. I felt an incredible amount of responsibility, obviously some pressure . . . and I remember kind of like knowing that this was going to be a really difficult winter . . . I have often referred to that as the most difficult time of my life . . . . Now, eighteen years later . . . I think of that year as the year that I grew up.

Parents in this study were articulate about how the experience changed them permanently as parents and individuals. Along with the loss of innocence verbalized by several of these parents, they all have been able to find and create meaning and positive growth for their families. Katie stated that ‘Ten years down the road now I can say to people that it is an
experience that changed me permanently and I have had to go on and learn to live each day as a different person . . . a better person.’ Lori verbalized a similar perspective:

‘. . . I wish it hasn’t colored my whole universe, but I think at some point I came to terms with the fact that my world is different, and there are certain things that just are just going to concern me. Life is totally different, I’m a totally different person . . . a better person . . . it’s like trial by fire, um, it just strips everything away and it makes you see what is most important in your life, I lose track of that occasionally but I always come back. We are just tremendously lucky people, my family and I . . . this is kind of where it’s brought me after 6 years. Ever hear that saying God only gives you what you can handle, right? Um, I would’ve liked one less lesson, but the refrain is that I wish he didn’t trust me so much! It’s how come me? It’s belonging to this club that you never wanted to belong to, and feels uncomfortable at first, but strength and joy of getting through it, and the connection to us . . .

Honoring both twins. The mothers and father in this study spoke in a number of ways about how they honor their twin who died, which has helped them to cope with this loss over time. Though every milestone for the living twin was potentially an opportunity to feel (again) the loss of the twin who died, these parents were focused in the present – with an ever-present awareness of the living twin. Honoring the twin who died was seen as part of this process, just as it was in the stories about family pictures and mothers’ jewelry.

As Lori reiterated:

‘I’m happy for Deidre . . . because I have come to see Jason as being . . . in our lives, he’s brought us a lot. She’s lucky to have someone like that sort of alive with her, but at the same time in some ways she doesn’t get to stand on her own as much, like her birthday,
because he died on her birthday, there’s all of that . . . and we try not to let that to be too obvious. We do a little . . . remembering the day . . . but it’s just so very, very complicated.

She went on further to say ‘there is some beauty in watching your child, surviving twin, connect . . . however that happens. For me it’s been very exciting and very touching to watch Deidre having connections with Jason.’

Although others might not necessarily know that these families had been expecting to raise twins, these parents sought ways to acknowledge their twins in a visible way, especially within their own families. An example of this was shared by Katie when she described having a family picture created that they displayed in their home:

. . . we had professional picture with myself and my husband holding Aiden and . . . had an artist paint a portrait, putting Anna in our picture, in our arms too, so we have a big wall portrait of the two of us holding the two of them . . . it is actually behind [the front door] and you don’t see it when you come in.

Katie also singled out her twin’s birthday as a significant time of intentionally recognizing the twins. As she related:

I wanted to make sure that our kids knew and that is tough every year on their anniversary because it also Aiden’s birthday. So celebrating his birthday and also remembering Anna is different. The first birthday we did, we had both of their names put on the cake. People thought we were weird for it and the Christmas cards we sent out once or twice we put everyone’s name on it.

**Making and keeping relationships.** Losing a twin, and the way others react to the experience, changed these parents’ relationships, including those within and outside the family.
Some of the mothers in the study described how a lack of understanding of this loss has created barriers in their relationships.

Extending perhaps from the protective stance that many of the parents articulated when they discussed parenting their living twin, many also adopted a protective nature in terms of relationships. With regard to friends, Lori decided ‘if you can accept my family, and that my son died then we’ll be friends, but if you can’t, you can’t, then we can’t be friends, I’m not wasting my time there . . ’. Katie also approached situations carefully with a defensive posture as she described:

I am very quick to be opinionated . . . if something you know is not in the best interest of my children, I will be right there and I will stand up and I will shout it loud. It’s not always made for making good scenes and not always made for making friends – I have a few close friends. It has put a wedge between me and my sister who I don’t even actually, this year, haven’t even really spoken to her much, because I flat out told her that my kids come first . . . my attitude towards my children and my family which all stems from having lost Anna . . . sometimes you feel like you are using it as an excuse, like you know there are definitely time if I am really, really pissed off at somebody, I will almost shove it in their face and say, well, you just can’t understand unless you have been there and done that…the part that I find hard because everyone that I know seems to say “well, you just get over it,” and I tell them it is not a matter of getting over it. I don’t think my mother truly gets it, I know my siblings don’t get it.

It was evident that it was painful and difficult when someone close did not understand; at times, these situations seemed for these parents to be forgivable, and yet, not always. Katie described two close family members who misunderstood how she felt, as she stated:
My husband’s family is small, and his father is older. We don’t see him frequently.

After we found out [our daughter had died] but before the twins were delivered, he did say to me ‘you have to focus on the healthy boy now and forget about the girl.’ I know he didn’t mean it, but it was very painful.

She further elaborated,

And . . .to my great surprise, my Mother gave me a Pandora bracelet, and put 3 charms on it, one for each of the children, and she didn’t include one for Anna . . .never would have thought in a million years that she would have done that. She sort of seemed to know in the moment, but I looked and I didn’t understand what they were, so she said, “you know, one for our second daughter, one for Aiden, and one for [the new baby] . . .” But I was thinking I have 4 kids, and . . .obviously in her mind I have 3 . . . I don’t think I can change that, she was very quick to say ‘I’ll get you another one,’ but she didn’t. I have never taken it out of the bag; I’m trying to decide what to do with it . . . I was really surprised because I thought that she understood that.

A number of the parents in this study recognized that the experiences of their spouse were very different from their own. Several of the mothers spoke specifically about the differences they saw in carrying the twins and experiencing the life of the twin that died in a way not possible for the fathers. As Lori reflected,

…Even my husband, he doesn’t really understand what it’s like to carry the pregnancy around…the physical stress of knowing that my body was responsible for carrying, nurturing these two children, one who was to die, a huge responsibility, and he, to his credit, participated in a couple of things at the hospital . . . he said that he knew that this was horrible and he knew I was going through hell and he couldn’t figure out how to
access it, what to do, how to access me, how to help me, and that he felt very helpless because he just couldn’t figure out what to do. Coming through this thing . . . we all do the best we can . . . I’ve never felt angry with him [husband] for not understanding. He did his very best, and he was a real support. I carried Jason and I know that when I drank chocolate milk, he moved a lot. I knew where his head was, right here, and I could tell [husband] those things but it’s not the same. I think that’s true, it doesn’t become real until the baby is born . . . they can’t feel the baby move, and so forth.

Sally also believed this as she conveyed,

I don’t think Dads could ever feel like a mother. Also the baby has relationship and knows the Mom’s smell, and . . . he or she does know the voices, too, but the mother is carrying him or her, and knows them in a way that is so important and essential.

While these mothers reflected about their husband’s perspective, Mark shared this about Anne:

I remember like steeling myself almost, to stay calm, stay focused. Deal with the several different things; go from one to the other . . . and I remember, I said this at the time of the funeral . . . I felt like my wife put a lifetime of motherhood into those five and a half [fetal] months while Michael was alive.

**Work-life challenges.** Another aspect of life that changed for some of these parents was their careers. A few of the mothers experienced a change in priorities and were unwilling to sacrifice the vigilance of parenting the living twin to work in the same capacity they had before the loss. They described choices that were clearly influenced by their experience of losing a twin. As Katie discussed,

I have been unable to finish my grad degree but it is because I want to spent time with my children. I have been unable to go back to work, every time I think about it I start to have
major anxiety over it... my husband is fine with it and luckily he has a job that we can survive. So we bought a really tiny house so we could afford it and not have to stress so much, of course, money is always a stressor but you know, it would be a lot easier if I did get a job but I want to treasure every single moment that I have, even when all of my subsequent children would be up in the night nursing, sick and crying, can’t sleep... I would just sit there and soak it in and so, they are only going to be young once and I will never get these moments back (crying).

Anne related that her career was ‘set adrift’ after losing her twin and explained,

...I...wanted to work, I didn’t want to work, and you know, I’d never had had that trouble before...it wasn’t just anxiety, but just it was a conscious choice, but just I couldn’t figure out how to balance things anymore. Because, you know, once you, um (sigh), once you lose a child, you know that things are just never normal again. You know they are not because you know that it can happen and therefore what it did to me was, it made me, um, absolutely determined to stay home, more. And, and since then, I’ve never taken a job where I’ve actually been committed to working for more than twenty hours a week. My career really got derailed that decade. It really did...I’ve never again, since then, felt as confident with my career...and the time I took off, and the time that I was depressed and the time I spent being hyper-vigilant about everything...I’ve become a slightly different person than I thought I was before....

Accepting that it doesn’t go away. Parents were clear that the loss of a twin is one experience that is re-lived over and over again and isn’t one that people “get over.” Throughout this chapter, there have been examples of how these mothers and father have continued to experience the joys and sorrows of losing a twin and raising the other twin, regardless of how
much time has lapsed since the death of their twin. Several of these parents expressed a desire to help others and indicated that they participated in the study with a hope that others who experience the same loss would know they are not alone. When asked what other parents need to know, the most central message was that the twin is never forgotten and the grieving changes but never goes away.

Debbie stated ‘Probably a day does not go by that I don’t think about her . . . it is not like you are dwelling and crying every day but probably you know, there is always something that makes you think of her and makes you wonder, a fleeting thought . . . . Karen, whose living twin is 24 years old, agreed:

I think parents of loss need to know that it gets better. Not OK. There isn’t a day that goes by that I still don’t think of my baby even after 24 years. But I have found that the pain of the loss is still there but contained.

Claire summed her feelings up this way:

I’ve had friends and even family members have twins who seem to share their experience with me instead of avoid me. On the other hand, I’ve also been told that some people “don’t quite know how to handle me” . . . I’m a mommy who lost a precious child. It’s who I am. It’s part of my life.

Lori conveyed that the grief ‘gets tamped down, but it lasts.’ She went on and added:

I don’t know how to explain to people that it never gets any better. Its like having your soul ripped out, there’s always the presence and people look at my family and think we look happy and to a certain extent [we are] . . . we’ll never really be complete, there will always be this missing piece. That’s what it’s like for me.
Again, these parents were quite eloquent in describing their families and their coping and strength can be appreciated. As Claire emphasized, “we continue living with our precious angel’s memory every moment of our lives . . . they’re never forgotten. We sometimes hurt over others’ insensitivity, but must be strong enough to weather the storms of the questions people ask or their reactions to us.”

Barbara also spoke of strength gained by living through this experience when she stated,

> While losing a twin is a tragedy and I would never wish it on anyone, it is a part of our family’s fabric. We are blessed in so many ways, and my lost twin’s sweet little life has made me a more sensitive and compassionate. Everyone has a story. I try and remember that . . . .

Given that the grief of losing a twin doesn’t go away, two of the mothers voiced a wish that it would be acceptable to discuss their twin that died. In their own way, each described beliefs about death that made things more difficult for them in their own grieving processes.

Katie related her belief that losing a child was not a loss to ‘get over’ when she stated:

> I just wish people would look at death as being so taboo. It is the whole idea of letting go and moving on; I absolutely think that is wrong . . . I just think that you can still have a normal life without letting go and moving on. To me, that just sounds final . . . and there is nothing final to it. It’s not . . . I don’t know if there is such a way of truly moving on and getting over it or whatever the phrase is that people use . . . .

Lori described her feelings about not feeling able to talk about her twin who died:

> Why is it okay to be sitting with a group of women and have someone say ‘Ah, I was thinking of my grandmother, I really loved that woman, she was great, made me chocolate chip cookie . . . I was eating a choc chip cookie, and . . . I really miss her.’ But
I can’t say ‘I saw some twins today, reminded me of my son . . . ’ that’s not okay.

Socially that’s not okay . . . so it’s a huge struggle and I find it challenging to walk that line . . .
Chapter 5

Discussion

The aim of this study was to describe the experience of parenting a surviving twin from the perspective of those mothers and fathers who experienced the loss of one twin in utero (after 20 weeks gestation), during birth, or in the immediate neonatal period (first six weeks of life). These experiences were described at a point in time after the acute loss and initial grieving period when the parents were not only ready, but had a desire to share their experiences. Parents described their loss and parenting experiences within the context of their own families, shared profoundly moving accounts of their lives, and described the impact of the loss of one twin. In this chapter, I will discuss the major findings of the study, and strengths and limitations. In addition, I will explicate implications for nursing practice, theory, education, and propose directions for further research.

Summary of Study

The parents in this study were eloquent and poignant in sharing their stories. All of them were parents of a living twin plus additional children. They described a process that involved the act of simultaneously parenting the surviving twin and other children while grieving the lost twin. Parents began their interviews by detailing the account of their twins, beginning with the twin pregnancy and the circumstances surrounding the death of their twin. It was evident that the telling of the details was important to these parents, regardless of how long ago their twins were born. For several of the families, the twin who died was stillborn; for others, the twin died shortly after birth, leaving each set of parents feeling that the only time they were the mother and father of twins was during their pregnancies. The parents portrayed this experience as life-changing; a process of grieving that has not ended even though it has changed. The phenomenon
of losing one infant of a twin set may be the ultimate example of parents knowing what they do not have – and being reminded of the loss every day. Nurturing and caring for the surviving twin, watching him or her grow and develop, made the experience of living with this grief challenging in many ways, as was expressed eloquently by the participants.

The limited available literature whose authors discussed the experience of losing one twin was focused on the acute grief experience of the perinatal loss. Thus, there was a significant void in the literature relative to the parenting of one twin beginning with the birth and death of the twins and continuing throughout the life of the living twin. Few, if any, studies exist whose investigators sought to understand the parents’ perspective of their challenges, coping strains, and emotional needs as they faced the reality of living after losing one twin, and managing a number of difficulties that have arisen during the development of the living twin. A description of the experience of parenting a living twin and other children, both younger and older, had yet to be explored.

The experience of losing one twin and parenting the living twin is more complicated than merely the perinatal bereavement experience of losing an infant plus raising an infant. The simultaneous nature of these events for parents who raise a lone twin raises questions I sought to explore in this study. While parental grief has been described as incomprehensible and devastating, it is also considered to be personal, unique, and known only to the parents who experience it (Arnold & Gemma, 2008).

In order to access this unique study population, I designed a qualitative descriptive study consisting of in-depth, open-ended interviews with a purposive sample to construct a description of the experience from the parents’ perspectives. In the interviews, the parents spoke openly about their twin loss. They reflected and shared their perspectives about their most difficult
times and their joys. All of these parents had other children, and they were able to describe how different and difficult this experience was in comparison with their other birthing events. They recounted how their expectations, priorities, and relationships changed after losing their twin. They were frank about the realities of raising their children, including their living twins. These parents expressed deep emotions; their interview data provided rich detail from which a description of parenting a lone twin was formed.

It was clear that telling the story of the loss of one twin, which began during their twin pregnancies, was very important to these parents. It was interesting, although contrary to prior thought (Arnold & Gemma, 2008), that these parents seemed eager to share their personal struggles and joys of parenting their living twin. They all hoped that by doing so they could help other parents in a similar situation. The early identification with becoming parents of what they anticipated would be a pair of infants was clearly an integral aspect of their overall development as parents. Unfortunately, this was the only time these parents literally parented twins, as most lost one twin either during pregnancy or shortly after birth. Even those parents who experienced the birth of two live infants did not get to be the parents of twins in a tangible way after delivery. The ambiguity and ongoing nature of living through this parenting experience changed how each of these parents looked at their children, their families, both nuclear and extended, and the world. Further, this very brief identification as the parents of twins, acknowledged only by those persons who were aware they were expecting twins or those they chose to tell, created a largely invisible loss for these parents. The loss of being twin parents was significant.

Interviews with the parents in the study demonstrated that parenting a lone twin was a process with a number of unique characteristics. They acknowledged that their early parenting experiences in particular were clouded by grief, and that their philosophies about parenting and
life changed significantly after their loss. They described themselves as being vigilant, protective, and cautious with every day parenting issues. They were in awe of the person their living twin has become. These parents coped with cruel fate, faced life and death in their children simultaneously, and gained strength and fortitude from the experience. Four patterns with supportive categories deliniating the experience emerged from the study data: (1) living with the ambiguity (irony in raising a lone twin, belonging and not belonging, at least there is one); (2) communicating the family journey (telling and not telling, deciding who needs to know, how many children); (3) parenting with wonder and worry (unanswerable questions, doubt and hyper-vigilance, living twin as a unique person); and (4) life is different now (loss of innocence, honoring both twins, making and keeping relationships, work-life challenges, accepting that it doesn’t go away).

**Strengths and Limitations**

The aim of the study was accomplished. A description of the experience as perceived by these participating parents who had lost one twin, and were parenting the living twin, was constructed. Although no generalizations can be made from the data provided by these study participants, they did represent the intended target population. There were limitations in the sample population, as all of the participants learned of the opportunity to participate in the study by reading the invitation in an online support group newsletter. Therefore, the study sample consisted only of participants who had online access and were reading support group literature.

While there may be limitations in drawing a convenience sample from a support group population, the parents in the sample were those who both wanted and were ready emotionally to share their experience so others could benefit from it. However, during the interviews and when immersed in data analysis, I noted indications that the nature of their grief was so intense at times
that it would not, nor may it ever, be resolved. In addition, there was little time to address it, as the care needs of the living twin were always present and demanding attention. Therefore, participating in this study could have served as a form of therapy for some of the participants. It provided them with the opportunity to talk through their experiences and receive some assurance that they were not alone or inappropriate in their thinking.

During proposal development, I investigated a strategy to include primary care offices, where parents who had lost one twin seek care for their living twin, other children, and themselves. While they expressed interest in assisting with the study, several health care providers from primary care sites in this large metropolitan system of outpatient services responded that because they had no systematic way to identify these parents, they could not assist in recruiting participants.

Finally, the sample included only one father, who was interviewed with his wife. Unfortunately, this was fairly typical of other studies in which researchers have noted that fathers are reluctant to express their grief (Stinson et al., 1992) and especially to do so openly (Buetel, 1995). McCreight (2004) described the lack of attention given to fathers who experience the death of an infant “a grief ignored” (p. 326). From the mothers’ comments, it was clear that while fathers grieved, they were less overt in how they expressed their grief. However, they were an integral part of each family’s coping, as they focused on providing support and maintaining family functioning by tending to the mundane tasks related to finances and maintenance. Nonetheless, new strategies must be employed to explore their experiences of parenting a lone twin, coping with loss while delighting in a new offspring.

Despite these limitations, there were sufficient variations in the sample so while purposive, it was not homogeneous. The study sample includes a varied set of perinatal
circumstances responsible for the death of one twin including expected death related to a congenital anomaly or syndrome incompatible with life, stillborn of unknown etiology, and complications related to prematurity. The wide range of ages of the living twins at the time of the interviews (5-24 years) also contributed to making the variation robust. This range of time that elapsed since the birth of the twins added depth and perspective to the parents’ descriptions of their experiences.

The parents as individuals related similar experiences, emotions, questions, doubts, and resolutions that provided a coherent picture of the experience of parenting a lone twin. They articulated their journey from expecting twins to parenting one twin and reflected on their own growth and perspective gained over time. The experiences they shared and the insights they gained can be used as a guide for nurses to support future parents who experience the phenomenon of simultaneous joy and grief in preparing to parent a lone twin.

There were few difficulties with data collection or analysis. When the study was amended to include several parents via secure electronic mail rather than a live discussion, there was a noticeable decrease in the volume of data collected. Rather than a conversational dialogue with those parents, their reflections consisted of significantly shorter answers to the interview questions. Although I used the same questions as those I asked during in-person interviews, the parents gave short answer responses rather than the stream of conscious memory of events and reflections that characterized an open discussion. In the process of data analysis, it became evident that the data obtained from the four electronic participants essentially provided a member check of the data I collected during the live interviews conducted with four parents in-person. During data immersion, it became abundantly clear that the core experiences were similar; the electronic participants expressed them more succinctly and the in-person participants described
them at great length and exquisite detail.

**Issues Raised by the Parents**

The parents in this study portrayed the experience of parenting a lone twin after the death of the other twin as an invisible loss with multiple layers. The reality of living with the ambiguity of raising a lone twin meant their loss of naivete, which changed their expectations of life. The task of managing the family journey and responding to the questions and reactions of others, of re-evaluating relationships and being intentional in decisions, and of rebalancing family dynamics posed continual challenges. However, these challenges led to growth, strength and a re-prioritization of what was important to them. They also looked for ways to help others understand the reality of this loss. These parents identified the following four issues as critical aspects of the experience and important for future parents to know when confronting the experience of parenting a lone twin.

**The ambiguity and irony of having a lone twin.** It is important to acknowledge that parenting a lone twin is a process infused with ambiguity and irony, a process accentuated by the presence of the living twin who will be an ever-present reminder of the twin who died. Grief is an emotion that draws one toward what is missing and highlights the fact that the world is not what it should be (Parke, 1993). The death of one infant of an expected pair leaves parents with the constant reminder that a member of their family is missing. Grief becomes intertwined with parenting experiences and reality is impeded by the emotional confusion between the living and dead twin (Bryan, 1995). It is important for the parents to be prepared for countless ambiguities and ironies such as answering the question ‘how many children do you have?’

**No one understands.** The invisibility of the loss accentuates the pain. The loss is made more difficult and isolating by the perceived lack of understanding of family members and close
friends who ordinarily provide emotional support. This insensitivity to loss, although likely unintentional, is a significant challenge. Particularly distressing are the comments ‘at least you have one’ and ‘isn’t it time to get over this?’ There is no rule for deciding whom to tell, what to tell, or when to tell. It is an individual decision that requires significant energy to manage. Additionally, the consequences of telling about the twin who died can be met with various reactions as society’s beliefs about the death of an infant are varied. Parents need to be prepared to feel disenfranchised related to the discomfort of others who are not comfortable hearing about the death of an infant.

**Multiple losses.** There are many losses involved in this experience: the loss of a family member, the loss of the status of being parents of twins; the loss of a twin sibling for the living twin; the loss of expectations of the pregnancy and birth; and the loss of naivete and innocence. The losses contribute to doubt, anxiety, and stress as losing a twin, and raising his or her living twin sibling, is most certainly complicated.

**Living with the loss.** Coping is challenged by going in and out of grief and living with the grief rather than getting over it. Specific events, such as the birthday of the living twin, first steps, first words, or first day of school, might be difficult as each is a reminder of the experience and absence of the twin who died. At other times, the reminders come as a surprise, such as an offhand comment or communication with a stranger. Many of these situations bring about a resurgence of grief that is painful. Although difficult and painful, over time there is acceptance and the realization that the changes are positive.

**Implications**

**Research.** The richness of the data and the openness of the participants as they each reflected on their life confirmed my belief that parents want to share their experiences. Parents
were willing to talk about the meaning and influence the experience of losing an infant continues to exert on their lives (Davies, 2004). Although these parents vigilantly protected their families, they wanted to help others by sharing, especially with other parents who have lost one twin and with healthcare providers who care for families who have lost a twin. Woven into their stories was a loneliness in not being understood and isolation when close family members did not understand. Their loss, usually invisible to the public, was made visible when they shared their wisdom and insights learned from the experience. When following up with one mother after our interview, she shared how positive the interview had been for her in that it enabled her to clean and reorganize the room where her pictures and other memorabilia of her twins were stored. Learning that she was not alone in her reactions encouraged her to address what she had avoided and in the process honor her twin; as a result, she was now able to use that room. This type of personal benefit had been noted recently by other researchers (Hynson, Aroni, Bauld, & Sawyer, 2006), which may help allay concerns about the vulnerability of conducting research with bereaved parents.

Further research is needed to fully explore this experience of parenting a lone twin. Strategies must be explored of creative ways to include parents who may not participate in or seek support group membership to ensure diverse backgrounds. As noted, new strategies must be developed to foster fathers’ participation and/or data collection from both parents.

Grief and all its complexities played a powerful role in the development of parenting behaviors and personal growth. The care demands of the living twin prolonged the parents’ grief work. Complicating matters, their grief was their connection to the twin who died, a phenomenon noted in the literature, most recently by Arnold and Gemma (2008), who asserted that the grief associated with the death of a child is lifelong and “becomes the connection
between parent and child beyond the child’s death” (p. 658). Both of these concepts, the ongoing nature of the grief and lasting connections, were factors made visible by this study. Researchers need to develop assessment strategies to better match interventions with personality and thus provide meaningful assistance in coping with grief over time.

Acceptance and meaning-making have been discussed positively in a number of perinatal grief and loss studies. Davis suggested that the most important part of meaning-making was the individual’s ability to derive meaning that was satisfying to him or her (2000). Neimeyer (1998) connected acceptance and meaning-making by asserting that it may be more useful to find meaning in the individual’s own life rather than in the loved one’s death. The parents in this study seemed to have reached acceptance, albeit, at times reluctantly, where the meaning they attached to the experience largely focused on the family and parenting roles. In spite of past and occasional present difficult conversations, uncomfortable moments, and tears, they affirmed the positive growth and strength within the family as evidenced by the description of the living twin. The living twin was described with reverence and awe, as a special, unique, and sensitive individual. A research question waiting to be asked would be to learn the connection between how parents make meaning out of the experience and how being special affects the child’s personality development.

Given the concerns of the parents in this study, researchers focusing on the living twin have the potential to identify the possible impact the loss of a twin sibling may have on his or her social development. Designing studies to include other family members, for example, grandparents may also be important to understanding the nuances of family support and coping with this perinatal loss.
Practice. The primary outcome was a fundamental qualitative description intended to inform perinatal and family nurses so they might use this information to provide more insightful and sensitive care. Through this study, I have provided a comprehensive description of the parents’ emotions and concerns. I identified a number of salient issues for clinicians to consider in designing strategies to support these parents. While the parents made few direct references to the health care providers who cared for them, they shared a number of indirect remarks illustrating their perceptions that care of these families could have been better. These parents experienced anxiety, sadness, worry, and doubt that made them vulnerable and threatened their ability to maintain a healthy emotional balance for themselves and their families.

My findings indicate that when parenting a lone twin, parents need help in meeting the simultaneous demands of attending to their emotions and grief while nurturing their living twin (and other children). They need honest answers to their questions and a safe place to voice concerns. They need supportive relationships with health care providers who are sensitive to their needs, knowledgeable and able to offer anticipatory guidance and make helpful referrals. This is not a new role for care providers. Jordan and Neimeyer (2003) stated that “compassionate and empathetic caregivers are needed to provide mourners with a healing experience of being understood and supported in their journey of loss” (p. 780). Rosenbaum, Smith, Zollfrank (2011) reported that the death of an infant may complicate, disrupt, or end relationships between parents and lead to decreased quality of life.

My findings underscored some of the differences between mothers and fathers in how they responded to the perinatal death, and revealed that these differences made a difficult parenting situation even more challenging. These findings were similar to those of a considerable number of researchers in literature who identified differences in grief between men
and women, as discussed in Chapter Two. The parents in this study were intact couples; it was obvious from their comments that they recognized a difference in their perspectives as wives and husbands. Nurses need to be alert for couples who may need additional assistance in understanding each others’ perspectives and in finding ways to support each other. Sometimes a professional grief and/or marital counselor can best provide this assistance.

There were no direct interview questions about parents’ experiences with nurses and only one participant acknowledged any nursing presence. One mother who knew one of her twins would die from a congenital condition incompatible with life was involved with a palliative care team that included nurses. She described the team as being integrally involved in planning for procedures at the hospital. After the birth, however, there was an obvious gap in following up with the family and addressing their grief and other needs. Clearly this is an area for nurses to explore and provide creative, therapeutic interventions.

One opportunity for nursing practice improvements for these parents may be in adopting a care/case management role in their care. These families should be targeted for focused and long-term follow-up. Parents value emotional support and need grief education (Gold, 2007). Potentially, models currently under development in the nursing case/care management role, stemming from medical home models, may offer a strategy for maintaining close contact with these families, offering anticipatory guidance, education, support, and referrals as needed, over time. One question that requires an answer before implementing the role is should one provider or a multidisciplinary team consisting of representatives from primary care, obstetrics, and pediatrics be the most appropriate vehicle for this type of service?

Regardless of the provider, my findings suggest that the care of these families must be customized. Parents need to be able to ask the unspoken and unanswered questions about both
twins and share their victories and difficulties, which requires nurses to be active listeners in the
dialogue and to learn from the parents before offering support. An ongoing and relationship-
based connection is required for the assessment of the parents’ needs as these change over time,
given that parental bereavement is a process.

As noted above, parents need anticipatory guidance in order to cope with the ambiguities
involved in the loss of a twin while simultaneously parenting the living twin. They may benefit
from knowing that there are resources, including virtual support groups, which may help them to
understand they are not alone. They need to know that it is a normal aspect of grieving to find
birthdays and other milestones difficult, to discover some events trigger a resurgence of sadness,
and to unexpectedly be overwhelmed by another’s reaction to perinatal death. These parents
need to be encouraged to honor and hold onto their connection to the twin who died, even though
it may be in conflict with others’ expectations that parents should get over their child’s death
(Davies, 2004).

There is certainly not a one-size-fits-all approach. The development, testing, and
application of best practice guidelines could help provide a basis for optimal care of the parents
who experience this perinatal loss. Traditional pregnancy loss or infant loss support groups may
not be appropriate for the parents who lose one twin and are simultaneously parenting the other
twin. Customized care planning, based on a trusting relationship with these parents, and founded
on specialized knowledge about perinatal bereavement, is needed. Given the tremendous growth
in knowledge about the complex experiences and difficulties of parents who experience all kinds
of perinatal losses, particularly multiple birth losses, it may be time for the care of these families
to be a focused specialty in nursing practice and education.
**Education.** My findings emphasize the need for nursing curricula to include the communication skills required for relationship building. In addition, knowledge and understanding of the various family theories and frameworks is a necessary component of nursing education. In order to support the development of parents and families, nurses must be able to assess family dynamics, family function, and family members’ coping strategies. To be effective, nurses must then use the assessment data to communicate effectively with members of a family, provide anticipatory guidance, education, and connect them with appropriate resources.

Ideally, childbearing and family nursing courses would also include content about parental bereavement and grief, at both the undergraduate and graduate levels. The body of science about the specialized needs of multiple birth families is growing. Ideally, a nursing course focused on those needs, including coping, healing, and meaning-making from the complexities, risks, and losses involved in parents’ multiple birth experiences would be available, particularly in graduate programs in women’s health, pediatrics, and midwifery.

**Theory.** As noted in the conclusion, this unique parenting experience is one surrounded by complex layers of loss. There is no one theory or model that explains the phenomenon of parenting a lone twin. Like the experience itself, it is not simply grieving one infant and raising the other infant; rather it is a complicated process of living with the loss of a twin and simultaneously nurturing the other twin; of battling sadness and feeling guilty to be happy; of self blame compensated by over protection; of honoring a memory quietly or being out-spoken. The contradictions that define reality as the parent of a lone twin are endless.

Models whose creators seek to describe processes by which individuals move through linear stages of grief, and eventually and optimally resolve it, are changing. Literature documents what researchers have been describing as a changing paradigm of grief. This new
paradigm involves the concept of living with loss, a factor identified in this study. Moules (2004) described this process as “making room for grief: walking backwards and living forward,” which aptly describes the parents in this study (p. 99).

This study could serve as a foundation for further development of, or a contribution to, an expanding body of knowledge that human beings learn to live with grief and that grief can be a growth-producing experience. A new understanding of the phenomenon of grief will help caregivers to identify positive strategies that can be used to cope with the ongoing processes of dealing with a loss and going on with life. Parenting with, and amidst grief, as described by the parents in this study who experienced the loss of a twin and raised the living twin, could provide the template for such a process whereby individuals simultaneously face loss and yet grow and go forward.
References


Kavanaugh, K., & Ayres, L. (1998). "Not as bad as it could have been": Assessing and mitigating harm during research interviews on sensitive topics. *Research in Nursing & Health, 21*(1), 91-97.


Swanson-Kaufman, K. (1988). There should have been two, nursing care of parents experiencing the perinatal death of a twin. *Journal of Perinatal and Neonatal Nursing, 2*, 78-86.


Appendix A: Letter of Support from CLIMB

February 27, 2010

Kelly Grady, RNC, PhD(c)
91 Harvey Lake Rd.
Northwood NH 03261

Dear Ms. Grady,

I have previously reviewed your research proposal related to parenting of a survivor of the perinatal death of a twin, and your recruiting strategy for soliciting participation from CLIMB members. When you begin recruitment, I will approve a brief notice (on reverse, as drafted by you) of the study with your e-mail address for interested parents of a survivor of loss in multiple birth to contact you for more information about your research and potential participation. This notice will be included in our monthly e-mail bulletin to members for the number of months you request. A copy of this letter may be included in your proposal for the purpose of demonstrating such permission for access to this population of bereaved parents.

Sincerely,

Jean Kollontai
Founder, Director CLIMB

By and for parents throughout the United States, Canada and beyond who have experienced the death of one or more, both or all their children during a twin, triplet or higher multiple pregnancy, at birth, or in infancy or childhood, and surviving others

Chef Jean Kollontai, P.O. Box 9377, Anchorage AK 99529
907/272-5343 (604) 274-7005, info@kitchen
clinical@psawalk.org
CLIMB E-NOICE

Losing one twin and raising the other is an experience largely unknown to health care professionals. I am a labor and delivery nurse and I am conducting a study of mothers' and fathers' experiences; I would like to talk with mothers and fathers in New England (Maine, New Hampshire, Massachusetts, Connecticut, or Vermont) who have faced the challenge of nurturing an infant while grieving the death of his or her twin. I will be speaking with parents who have experienced the loss of one twin either during pregnancy (after 20 weeks gestation), at birth, or in the first six weeks of life. If you would like to receive more information about the study, please email me at analyk@acme.com with your phone number and convenient time for me to call you about the possibility of participating in my study.
Appendix B: Advertisement of the Study (Climb E-Notice)

Losing one twin and raising the other is an experience largely unknown to health care professionals. I am a labor and delivery nurse and I am conducting a study of mothers’ and fathers’ experiences; I would like to talk with mothers and fathers in New England (Maine, New Hampshire, Massachusetts, Connecticut, or Vermont) who have faced the challenge of nurturing an infant while grieving the loss of his or her twin. I will be speaking with parents who have experienced the loss of one twin either during pregnancy (after 20 weeks gestation), at birth, or in the first six weeks of life. If you would like to receive more information about the study, please email me at gradykf@bc.edu with a phone number and convenient time for me to call you about the possibility of participating in my study.

Sincerely,

Kelly Grady
Appendix C: Screening Instrument

“Thank you for your interest in my study. I’m happy to explain my study in more detail and answer any of your questions. First, I’d like to ask you a few questions to determine if you meet the criteria for the study.”

“The purpose of this study is to describe mothers’ and fathers’ experiences of parenting a lone twin when one twin has died. If you choose to participate, a complete informed consent process will take place at the first meeting. Here are my questions:”

1. “Have you experienced the loss of a twin during pregnancy (after 20 weeks gestation), at birth, or in the first six weeks of that infant’s life?”

2. “How old is your surviving twin?”

3. “Do you speak and read English?”

4. “Are you at least 21 years of age?”


6. “Have you ever met or spoken with me before?”

If he/she does not meet the criteria: “I am very grateful for your interest, but I am afraid that (STATE REASON, such as “because you just delivered two weeks ago”) you are not eligible to participate in the study. I do appreciate your call and wish you (and your family – if appropriate) the best.”

If he/she does meet the criteria: “You are eligible to participate in the study. May I ask you a few more questions?” Continue with the following questions:

“What is your name?”

“City and State:”

“Telephone Number: Is this a home or work number?”

“If you are not in, may I leave a message for you at this number? If it is necessary for me to leave you a message, I will state my name and phone number only.”
“Would you be willing and able to be interviewed for about an hour with an email or phone call follow-up?”

“These interviews should take place someplace quiet, private, and convenient for you. Some parents prefer to meet at their homes. Where would you prefer to be interviewed (home, office, different site)?”

“What days and times would be most convenient for you to meet with me?”

SET DATE FOR MEETING: ________________________________

SITE FOR MEETING: ________________________________

“I would like to give you a phone call a few days before our first meeting to confirm the time and place. What is the best number for me reach you at that time?”

“As I mentioned at the beginning, there will be a formal, informed consent process where we discuss the study and your rights as a participant in detail in person before we begin our discussion. Do you have any questions for me now?”

“(Name), I am delighted that you are interested in participating in this study. I will see you on _____ at ________. I will call you at _________________ a few days before we meet to confirm the time and place. In the meantime, if you need to reach me, you can call me collect at (603) 496-0407 or by e-mail at: gradykf@bc.edu. Thank you so much for calling. Goodbye.”
Appendix D: Interview Guide

1. Tell me about your twin pregnancy – can you tell me what happened to your twins?

2. “Tell me what it was like to be the parent of __________ during his/her first year of life.”

3. “Tell what it is like to nurture a baby while experiencing the loss of one.”

4. “What kinds of challenges did you face in dealing with the loss of one twin and raising his or her brother or sister?”

5. “Often parents comment, ‘No one really understands what it is like to lose one twin.’ Have you ever felt that way? Tell me what that was like. What do you think parents like you need to know?”

6. At the conclusion of the interview: “Is there anything else you want me to know about your experience?”

7. “With your permission, I’d like to call in 2-3 weeks in case there is anything you’d like to clarify that we’ve talked about. Would that be okay with you?”
Appendix E: Letter to Mental Health Consultant

February 15, 2010

Joanne Wojcik PhD, APRN, BC
Associate Director
Commonwealth Research Center
Instructor of Psychiatry Harvard Medical School
The Massachusetts Mental Health Center Public Psychiatry Division of the
Beth Israel Deaconess Medical Center Department of Psychiatry
CRC at MMHC
180 Morton St
Jamaica Plain, MA 02130

Dear Dr. Wojcik,

Thank you so much for agreeing to assist me with my dissertation research. As we discussed, due to the nature of the conversations that I will be having with my participants, the possibility exists that a participant may become distressed. If, in my judgment, there is any concern about his or her well-being, I would like to refer her to you for a screening via telephone. This would be for the purposes of assessment and making a proper referral for follow-up care if you think he or she is in need of professional assistance. I appreciate your interest in my research and your willingness to assist in this endeavor.

Sincerely,

Kelly Giaday PhD(F), RN
Appendix F: Letter of Support from Mental Health Consultant

Joanne D. Wojcik, PhD, APRN, BC
21 Fifield St
Watertown, MA 02472

February 23, 2010

Kelly Grady, PhD(c), RNC
Boston College School of Nursing
Chestnut Hill, MA

Dear Kelly,

As per our conversation, as an advanced practice psychiatric nurse clinical specialist, I would be happy to serve as a consultant on your study. I understand that I may be asked to speak with participants in the event you are concerned about a high level of distress that may occur during your conversation with them. My role will be to provide a brief clinical assessment regarding their level of distress, depression or any thoughts of self harm. If necessary, I will help them devise a plan for follow-up care such as calling their PCP or a current or past therapist or psychiatrist. Of course, if appropriate, a referral to a local emergency department could also be made.

I am assuming that with the participant’s permission, you would contact me and give me her contact information. My voice mail is 617 626-9411, if you need to reach me immediately; you may call my cell 617 962-3698 or page me at 617 546-0144.

I look forward to hearing about the progress of your research.

Sincerely,

Joanne Wojcik, PhD, APRN, BC
Appendix G: CITI Certificate

CITI Collaborative Institutional Training Initiative

Human Research Curriculum Completion Report
Printed on 3/18/2010

Learner: Kelly Grady (username: gradykf@bc.edu)
Institution: Boston College
Contact Information: Phone: 603-226-1185
Social/Behavioral Research Course:

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For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator
CITI Collaborative Institutional Training Initiative

Human Research Curriculum Completion Report
Printed on 3/18/2010

Learner: Kelly Grady (username: gradykf@bc.edu)
Institution: Boston College
Contact Information: Phone: 603-228-1185
Email: gradykf@bc.edu

Students enrolled in NU 820:

Stage 1. NU 820 Passed on 02/06/10 (Ref # 4084067)

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For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.

Paul Braunswegler Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator
Appendix H: Informed Consent

Boston College Consent Form

Boston College Connell School of Nursing
Informed Consent for Participation as a Subject in
“Parenting a Lone Twin: When One Twin Dies”
Investigator: Kelly Grady, RN
Type of consent: Adult Consent Form
Date Created: 03/22/10

Introduction
- You are being asked to be in a research study about being the mother or father of a surviving twin baby.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:
- The purpose of this study is to describe the experience, thoughts, and emotions of mothers and fathers who have experienced the loss of a twin and, at the same time, have nurtured the surviving twin infant. The findings of this study will be used to assist health care professionals who care for parents who unfortunately experience this kind of loss.
- Participants in this study are from Maine, New Hampshire, Massachusetts, Rhode Island, Vermont, and Connecticut. The total number of participants is expected to be approximately 10.

Description of the Study Procedures:
- If you agree to be in this study, we ask you participate in the following: at least one phone conversation or email exchange and one in-person interview. The first conversation, either on the telephone or via email, will last for approximately five to ten minutes. The purpose of this conversation is to answer your questions and to find out if you meet the criteria to participate in the study. If you do meet the criteria and choose to participate, Ms. Grady will schedule an in-person interview with you to take place within two weeks. The in-person interview will last approximately one hour and will take place in your home or another private, comfortable setting of your choice. The purpose of this interview is to discuss your experience in parenting a lone twin. Interviews will be recorded. With your permission, Ms. Grady will call you on the telephone approximately 2 weeks after the in-person interview to ask if there is anything else you would like to share.

Subject’s Initials_______
Risks/Discomforts of Being in the Study:
There are no reasonable foreseeable risks to participating in this study. There may be unknown risks. There is the possibility that discussing these topics may be uncomfortable, or may cause you to experience difficult emotions. You may choose not to answer any questions that make you feel uncomfortable and you may withdraw from the study at any time.

Benefits of Being in the Study:
• The purpose of the study is to describe the experience of nurturing a surviving twin baby while grieving the loss of his or her twin.
• There are no expected benefits, but we hope to gather information that will help us to understand how health care professionals can help parents who lose a twin.

Payments:
• You will receive $25.00 to offset childcare expenses you may incur as a result of meeting with Ms. Grady, which you will receive after your in-person interview.

Costs:
• There is no cost to you to participate in this research study.

Confidentiality:
• The records of this study will be kept private. In any sort of report we may publish, we will not include any information that will make it possible to identify you. Research records will be kept in a locked file. This informed consent document, with your name on it, will be stored in a locked cabinet at Ms.Grady’s office, where no one but she will have access to it. The informed consent documents will be destroyed by shredding three years after the results of the study are published.
• All electronic information will be coded and secured using a password protected file.
• The audio recordings will be transcribed by a trained professional, and any information that might identify you to others will be removed during the transcription process. Once Ms. Grady checks the electronic transcripts with the audio recordings, the recorded interviews will be erased. All electronic information will be coded and secured using a password protected file. The transcripts will be kept by Ms. Grady for use in future research and might be shared with other researchers.
• Access to the records will be limited to the researcher; however, please note that regulatory agencies, and the Institutional Review Board and internal Boston College auditors may review the research records.
• No one at any organization through which you may have heard about this study will know whether or not you are a member of this study group. Information that you provide will not be shared with any individual or organization.

Subject’s Initials_______
Voluntary Participation/Withdrawal:
- Your participation is voluntary. If you choose not to participate, it will not affect your current or future relationship with Boston College.
- You are free to withdraw at any time, for whatever reason.
- There is no penalty or loss of benefits for not taking part or for stopping your participation.

Contacts and Questions:
- The researcher conducting this study is Kelly Grady, RN, PhD(c).
- For questions or more information concerning this research you may contact her at (603)496-0407 or by email (gradykf@bc.edu) or her Dissertation Chair: Assistant Professor Sandra Mott at (617)552-4278 or by email (mott@bc.edu). If you feel any distress as a result of participating in the study, you can contact any of the above individuals, as well as Joann Wojcik, PhD(c), APRN, BC, who is acting as a mental health consultant to the study at (617)626-9411.
- If you have any questions about your rights as a research subject, you may contact: Director, Office for Human Research Participant Protection, Boston College at (617) 552-4778, or irb@bc.edu

Copy of Consent Form:
- You will be given a copy of this form to keep for your records and future reference.

Statement of Consent:
I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this study. I have received (or will receive) a copy of this form.

Signatures/Dates

Study Participant (Print Name):___________________________________________
Participant or Legal Representative Signature: ______________________________
Date ________________________________________________________________