PARENT PERSPECTIVES OF NEONATAL INTENSIVE CARE AT THE END-OF-LIFE AND SUBSEQUENT BEREAVEMENT AND COPING EXPERIENCES AFTER INFANT DEATH

by

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A DISSERTATION

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ABSTRACT

Introduction: Little is known about parent experiences with end-of-life and palliative care consultation in the neonatal intensive care unit (NICU). The purpose of this study was to: (a) describe parent experiences related to their infant’s NICU hospitalization, end-of-life care, and palliative care consultation, and (b) parents’ bereavement and coping experiences after infant death.

Methods: A descriptive qualitative approach was used to explore and describe parent experiences during their infant’s hospitalization in the NICU and bereavement and coping experiences after infant death. Ten parents (seven mothers and three fathers) of infants who had previously died in the NICU were recruited using convenience sampling methods until data saturation was met. Background information was obtained from a demographic questionnaire. Interview data were analyzed using qualitative content analysis.
Results: In-person semi-structured interviews revealed two major themes with five categories. “Life and Death in the NICU Environment” was the first major theme with the following categories: (a) the ups and downs of parenting in the NICU, (b) decision-making challenges in the NICU, and (c) parent support. “Life after Loss” was the second major theme that emerged from the interviews with the following categories: (a) living with loss and (b) coping with grief over time.

Conclusions: “Being a parent” was extremely important for these participants regardless of the infant’s prognosis. Nurses played a critical role in facilitating parenting in the NICU. Parents encountered various challenges in the NICU and reported several sources of support that helped them through the hospitalization. Although barriers to initiating palliative care consultation were present, palliative care was a helpful source of support for parents in the NICU. Living with infant loss was a catastrophic and life-changing event for these parents. Coping with infant death proved to be a complex process that evolved over time. Parents oscillated between focusing on the loss and living in a world without their infant. The results from this study suggest there are areas for improvement in the provision of end-of-life and palliative care in the NICU that may be addressed by further research efforts and changes in practice and policy.

Keywords: NICU palliative care, NICU end-of-life care, infant death, parent bereavement, parent grief
DEDICATION

This dissertation is dedicated to parents who have suffered from the pain of losing a child. The parents in this study trusted me to share their stories, and for that I am honored.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>iii</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>v</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>vi</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>xii</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xiii</td>
</tr>
<tr>
<td>LIST OF ABBREVIATIONS</td>
<td>xiv</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>1</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>4</td>
</tr>
<tr>
<td>Specific Aims and Research Questions</td>
<td>4</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>5</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>7</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>9</td>
</tr>
<tr>
<td>Summary</td>
<td>11</td>
</tr>
<tr>
<td>REVIEW OF LITERATURE</td>
<td>12</td>
</tr>
<tr>
<td>Parent Bereavement Related to Infant Loss</td>
<td>12</td>
</tr>
<tr>
<td>Antecedents to parental Bereavement</td>
<td>13</td>
</tr>
<tr>
<td>Anticipatory Grief</td>
<td>13</td>
</tr>
<tr>
<td>Perinatal Palliative Care</td>
<td>13</td>
</tr>
<tr>
<td>Risk Factors for Complicated Grief in Parents of Infants and Children</td>
<td>16</td>
</tr>
<tr>
<td>Parents Needs During Hospitalization</td>
<td>18</td>
</tr>
<tr>
<td>Consequences Related to Parent Bereavement</td>
<td>21</td>
</tr>
<tr>
<td>Parent Coping and Adaptation to Infant Death</td>
<td>24</td>
</tr>
<tr>
<td>Social Support Related to Coping with Grief and Loss</td>
<td>27</td>
</tr>
<tr>
<td>Spirituality</td>
<td>29</td>
</tr>
<tr>
<td>Palliative Care and End-of-Life</td>
<td>30</td>
</tr>
</tbody>
</table>
Themes.................................................................................................................................63

Theme 1 - Life and Death in the NICU Environment ..........................................................63
    The Ups and Downs of Parenting in the NICU .........................................................64
    Decision-Making Challenges in the NICU .................................................................72
    Parent Support in the NICU .......................................................................................79

Theme 2 - Life after Loss...................................................................................................86
    Living with Loss .............................................................................................................87
    Coping with Grief over Time ......................................................................................93

Parents’ Comments about Interview Participation .......................................................105

DISCUSSION, CONCLUSIONS, IMPLICATIONS
AND RECOMMENDATIONS .................................................................................................108

Discussion ..........................................................................................................................108
    Life and Death in the NICU Environment .................................................................108
        The Ups and Downs of Parenting in the NICU .....................................................108
        Decision-Making Challenges in the NICU ............................................................112
        Parent Support in the NICU ..................................................................................115
    Life after Loss ..............................................................................................................120
        Living with Loss .......................................................................................................120
        Coping with Grief over Time .................................................................................125

Conclusions ......................................................................................................................134
    Implications for Nursing Research ............................................................................135
    Implications for Nursing Education ...........................................................................137
    Implications for Nursing Practice and Policy ..........................................................138

Limitations ..........................................................................................................................139

Strengths ............................................................................................................................141

Future Recommendations ...............................................................................................141

LIST OF REFERENCES .....................................................................................................143

APPENDICES

A Copyright Permission for the Use of the Dual Process Model of Coping with
Bereavement ....................................................................................................................156

B University of Alabama at Birmingham
    Institutional Review Board Approval ........................................................................158

C Demographic Questionnaire .......................................................................................160

D Interview Script and Questions ....................................................................................16

xi
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Tables</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parent Reasons for Not Participating in the Study ($n = 11$)</td>
</tr>
<tr>
<td>2</td>
<td>Parent Demographics ($N = 10$)</td>
</tr>
<tr>
<td>Figure</td>
<td>Page</td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
</tr>
<tr>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

The Dual Process Model of Coping with Bereavement

xiii
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AACN</td>
<td>American Association of Colleges of Nursing</td>
</tr>
<tr>
<td>COPE</td>
<td>Creating Opportunities for Parent Empowerment Program</td>
</tr>
<tr>
<td>CPR</td>
<td>cardiopulmonary resuscitation</td>
</tr>
<tr>
<td>DPM</td>
<td>Dual Process Model</td>
</tr>
<tr>
<td>DNR</td>
<td>Do Not Resuscitate</td>
</tr>
<tr>
<td>EOL</td>
<td>end-of-life</td>
</tr>
<tr>
<td>HCP</td>
<td>healthcare provider</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
</tr>
<tr>
<td>NICU</td>
<td>neonatal intensive care unit</td>
</tr>
<tr>
<td>PC</td>
<td>palliative care</td>
</tr>
<tr>
<td>PI</td>
<td>principal investigator</td>
</tr>
<tr>
<td>PICU</td>
<td>pediatric intensive care unit</td>
</tr>
<tr>
<td>PTSD</td>
<td>Post-Traumatic Stress Disorder</td>
</tr>
<tr>
<td>UAB</td>
<td>University of Alabama at Birmingham</td>
</tr>
<tr>
<td>USCB</td>
<td>United States Census Bureau</td>
</tr>
</tbody>
</table>
CHAPTER 1
INTRODUCTION

The death of an infant in the neonatal intensive care unit (NICU) is a profound and unexpected loss for parents that result in long-term psychological consequences (Klass, 1997). Advanced healthcare technology has extended the lives of many infants thereby creating ethical dilemmas that consequently necessitate dignified, compassionate care for infants in the NICU and their parents (Field & Behrman, 2003). Although palliative care (PC) is recommended by the American Academy of Pediatrics and the Institute of Medicine for infants with life-limiting or life-threatening illness, barriers remain in the integration of PC in NICU settings (American Academy of Pediatrics [AAP], 2000; Catlin, 2011, 2003; Field & Behrman, 2003; Kain, 2006). Further, there is a paucity of research focused on the parental experience with neonatal intensive care at the end-of-life (EOL), pediatric PC consultation in the NICU, and the bereavement and coping experiences of parents who have received EOL and PC consultation in the NICU.

Statement of the Problem

In 2010, 24,572 infant deaths occurred in the United States. Congenital anomalies, low birth weight, and Sudden Infant Death Syndrome accounted for 46% of total infant deaths in 2010 and 35.2% infant deaths were preterm-related. The overall infant mortality rate was decreased to 6.14 deaths per 1,000 live births in 2010 from a rate of 6.39 in 2009. Non-Hispanic black mothers retain the highest proportion of infant
mortality at the rate of 11.46 per 1,000 infant deaths in 2010 compared to those infants of Cuban descent (infant mortality rate 3.79 per 1,000 live births) (Mathews & MacDorman, 2013).

While neonatal mortality has decreased over time, rates of morbidity associated with very preterm birth have increased and include long-term sequela of prematurity such as respiratory problems, learning difficulties, cerebral palsy, behavioral problems, vision impairment, hearing loss, and mental retardation (Costeloe et al., 2012; Institute of Medicine [IOM], 2006). Furthermore, increased medical technology has improved the longevity of high-risk infants with a terminal diagnosis (AAP, 2007). Although PC and EOL care provided at the beginning of life may seem paradoxical, this type of specialized care is essential to address the trend of increasing preterm-related infant morbidity. Ideally, perinatal PC consultation should be provided antenatally for fetuses with a life-limiting illness and their parents, and should involve communication between the obstetrician and neonatology medical teams before the infant is born irrespective of the decision to terminate the pregnancy or continue with neonatal intensive care (AAP, 2007). The American Academy of Pediatrics (2000) and Institute of Medicine (2003) recommend integrating PC at the time of diagnosis to improve care for both children who succumb to illness, those who survive, and to provide quality family-centered care.

Although the integration of curative and PC is recommended as a standard of care in seriously ill adults, and is associated with higher quality of life, access to PC is disproportionately limited for infants and their parents who also need these essential services (Catlin & Carter, 2002; Davies et al., 2008; Eden & Callister, 2010; Rushton, Spencer, & Johanson, 2004). The Center to Advance Palliative Care reported that the
United States improved from a ‘C’ rating for percentage of hospitals with a palliative care program in 2008, to a ‘B’ rating in 2011 (Center to Advance Palliative Care [CAPC], 2011). However, disparities exist within states and geographic locations (CAPC, 2011). That is, Alabama and Mississippi were rated as a ‘D’ and ‘F’, respectively, for PC access, and there were fewer PC services available to those individuals living in rural areas as compared to those living in urban locations (CAPC, 2011). The State of Alabama was given a ‘D’ rating because only 28% of the hospitals in the state offer palliative care services (CAPC, 2011). In terms of pediatric PC, Children’s of Alabama is the only children’s hospital in the State of Alabama that offers formal PC consultation for infants and their parents in the NICU (Children’s of Alabama, 2011). Without quality PC and EOL care for infants with life-limiting and/ or life-threatening illness, there may be undue suffering in both infants in the NICU and their parents.

Interdisciplinary PC provided to infants in the NICU in the context of EOL care may improve anticipatory grieving and provides support for parents throughout the entire NICU hospitalization (Rini & Loriz, 2007). However, initiating PC in NICU settings is severely limited due to the complex nature of the ethical challenges parents and healthcare professionals encounter, problems in determining futility, and the uncertainty of medical prognosis for infants (Catlin & Carter, 2002; Meier, Isaacs, & Hughes, 2010; Rushton, 2005). Further, there is a lack of education among parents and healthcare providers regarding the use of PC for infants and children (Armentrout & Cates, 2011; Nicholl & Price, 2012; Pector, 2004). Thus, PC is commonly misconceived as EOL or hospice care; conversely, PC is not mutually exclusive of EOL care and may be combined with curative treatment efforts (Himelstein, 2006).
Pediatric PC is defined by the World Health Organization (2011) as “the active total care of the child’s body, mind, and spirit”, and also involves giving support to the family; whereas, EOL care is conceptualized by the Institute of Medicine (2003) as the “management of the end-stage of a medical condition.” Although PC throughout the NICU hospitalization and at the EOL is essential for providing quality care to infants and their parents in the NICU in the presence of life-threatening or life-limiting illness, there is a critical shortage of research exploring the parental experience of neonatal intensive care at the end-of-life, PC consultation in the NICU and the subsequent coping experiences of these parents who experienced NICU end-of-life care and PC consultation in the NICU (Moro, Kavanaugh, Okuno-Jones, & VanKleef, 2006).

Purpose of the Study

Therefore, the purpose of this study was to describe parent experiences related to their infant’s NICU hospitalization, end-of-life care, and palliative care consultation and to describe parents’ bereavement and coping experiences after infant death.

Specific Aims

The specific aims of this qualitative study were:

1. To describe parent experiences related to their infant’s hospitalization in the NICU, end-of-life care, and palliative care consultation.

2. To explore bereavement and coping experiences in parents who experienced infant death in the NICU.
Research Questions

1. How do bereaved parents describe their experiences related to their infant’s NICU hospitalization, end-of-life care, and palliative care consultation?

2. How do parents who experienced infant death in the NICU describe their bereavement and coping experiences?

Theoretical Framework

The Dual Process Model (DPM) of coping with bereavement developed by Stroebe and Schut (1999) will be used as a guide to understand individual differences in coping with bereavement, and manifestations associated with bereavement outcomes and adaptation. Many underlying constructs within the DPM are defined using Cognitive Stress Theory (Lazarus & Folkman, 1984). More specifically, stressors are considered the impetus for coping, appraisal processes attach meaning to perceived threat, and coping processes involves strategies to manage perceived stressor (Lazarus & Folkman, 1984). The DPM purports additional constructs such as oscillation, loss-orientation stressors, and restoration-orientation stressors. Loss-orientation stressors involve appraising and processing the loss itself; whereas, restoration-stressors involve secondary stressors related to bereavement such as living with the loss of the infant in a changed world without the deceased child (Stroebe & Schut, 1999; Stroebe & Schut, 2010).
Individuals oscillate between loss-oriented and restoration-oriented stressors in a dynamic process confronting and avoiding the loss (see Figure 1) (Stroebe & Schut, 1999). Coping is conceptualized as a flexible, regulatory process where the individual must oscillate between loss and restorative stressors to successfully adapt to loss and negate poor outcomes of bereavement such as poor mental and physical health. The dynamic nature of oscillation renders parents able to successfully adapt to loss, pursue respite in grieving, and distinguishes the DPM from previous models of bereavement and adaptation. The underlying premise that individuals oscillate between various coping strategies over time will provide a framework for understanding how bereaved parents adapt to life after the death of their infant (Stroebe & Schut, 1999; Stroebe & Schut, 2010).
Definition of Terms

For the purposes of this research, the following terms were defined:

*Adaptation* is an outcome of coping and involves successfully integrating the loss of the infant into the parents’ changed world without the presence of social or occupational impairment (Larazus & Folkman, 1984).

*Anticipatory grief* is a process of anticipating bereavement and grief before it occurs (Schulz, Boerner, & Herber, 2008).

*Bereavement* is the condition of enduring the loss of a loved one (Stroebe, Schut, & Stroebe, 2008).

*Complicated grief* is a deviation from cultural grief norms, is clinically significant and involves a level of social, occupational, or other level of impairment (Stroebe, Schut, & Stroebe, 2008).

*Coping* is a process to manage psychological stress (Lazarus & Folkman, 1984).

*End-of-Life care* is the management of the end-stage of a medical condition and may include palliative and hospice care (Field & Behrman, 2003).

*Family-centered care* is operationalized as an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers (Institute for Family Centered Care, 2009).

*Grief* is the emotional reaction to bereavement and loss of a loved one, and grieving is a process that involves restructuring meaning around a changed reality of the deceased infant and a modified family structure (Armentrout, 2009; Klass, 1997; Stroebe, Hansson, Schut, & Stroebe, 2008).
**Hospice** is a program of care for the dying. As of March 2010, Section 2302 (Concurrent Care for Children Requirement) within the Affordable Care Act now allows children covered by Medicaid or Children’s Health Insurance Program to receive curative and hospice care simultaneously (National Hospice and Palliative Care Organization [NHPCO], 2010).

**Life-limiting illness** involves no realistic hope of cure and life-limiting conditions are those that are incurable and will end in a premature death (NHPCO, 2010).

**Life-threatening illness** is (a) an illness that has substantial probability of death in childhood, although treatment may succeed in curing the condition or substantially prolonging life, and (b) illnesses that are perceived as having a potentially fatal outcome (Field & Behrman, 2003).

**Loss** refers to the death of a loved and may be experienced across the lifespan (Stroebe, Schut, & Stroebe, 2008).

**Palliative care consultation** involves the pediatric provider initiated interest in receiving palliative consultation services. The pediatric palliative care team at Children’s of Alabama hospital is a consultation service and works with the primary medical team to address physical, social, emotional, and spiritual suffering (Children’s of Alabama, 2012).

**Parent** is defined as a biological mother, father, or a legal guardian that had custody of the infant during the NICU hospitalization (i.e., adoptive or foster parent, or family member that had legal custody).

**Perinatal loss** is defined a miscarriage, stillbirth, or neonatal death up to 28 days of life (Armstrong, 2002).
Pediatric palliative care was defined by the World Health Organization (2011) as “the active total care of the child’s body, mind, and spirit”, and also involves giving support to the family. Individualized patient care, support for the family, an interdisciplinary approach, and effective communication comprise the core of palliative care.

Perinatal palliative care should be provided to parents of a fetus a life-limiting diagnosis regardless of decision to continue or terminate pregnancy and involves providing compassionate care for the family and support during the decision-making process (Munson & Leuthner, 2007).

Religion will be generally defined as a belief shared by a group of people and involves a personal or institutional system of attitudes, beliefs, and practices (Doka, 2011).

Social Support is context-specific and involves reciprocal verbal and non-verbal communication. Social support involves advocating processes through means of emotional and instrumental support (Finfgeld-Connett, 2005).

Shared decision-making is a decision-making process that involves collaboration between physicians and parents, and emphasizes the importance of parent values (Boss, Hutton, Sulpar, West, & Donohue, 2008).

Spirituality involves an existential world of meaning (Doka, 2011).

Significance of the Study

Despite the importance of integrating curative and PC at time of diagnosis for infants with life-limiting and/ or life-threatening illness, barriers exist in PC provision within the NICU setting. Parents remain the focus of ethical decision-making; however,
there is a paucity of research on parental perceptions of PC, and why these services may be underused or avoided in the NICU until EOL care is initiated and death is imminent (Catlin, 2011). One study conducted by researchers at a Wisconsin children’s hospital that offers pediatric PC consultation in the NICU found that the median length of time from initiation of PC to infant death was 5.5 days (Leuthner & Pierucci, 2001). Of the 898 total NICU admissions and 51 infant deaths included in the medical record review, only 12 infants and families received PC before death although services were accessible to all infants (Leuthner & Pierucci, 2001).

Furthermore, NICU palliative care protocols have been developed by Catlin and Carter (2002), and interdisciplinary interventions to educate healthcare professionals about pediatric PC and reduce professional suffering related to caring for infants and children near the EOL have been implemented by Rushton and colleagues (2006); however, the transition from curative to PC is complex in the NICU. Advanced technology lends itself to more sophisticated diagnoses and prognoses; however, it is important to note that parental agreement remains the determinant for the initiation of PC, and in some cases EOL care, rather than the infant’s physiologic state and prognosis (Catlin, 2011). Further, there is a critical shortage of research focused on parental experiences with pediatric PC consultation in the NICU, and the bereavement and coping experiences of parents who have been exposed to PC consultation. Thus, describing parents’ bereavement and coping experiences with the death of their infant and describing these parents’ experiences with EOL care and pediatric PC consultation during their infant’s hospitalization in the NICU is critical to understand why these services that increase quality of life and diminish suffering are avoided. This research is valuable for
infants, parents, and healthcare providers in the NICU because these findings contribute to an improved understanding of the complexities associated with the provision of PC and EOL care in NICU settings and how bereaved parents cope with grief after infant death.

Summary

There is a dearth of research on parent experiences with EOL care in the NICU, pediatric PC consultation in the NICU, and the bereavement and coping experiences of parents who have been exposed to PC consultation and EOL care in the NICU. This study addressed gaps in knowledge through the exploration of parental experiences with end-of-life and palliative care consultation in the NICU and subsequent bereavement and coping experiences after infant death. Although limitations exist in this qualitative study, this research was necessary to further the scientific development of PC and EOL care provision in the NICU and inform healthcare professionals how to improve the quality of care for this unique population of infants and their parents. This study provided a significant contribution to nursing research by thoroughly examining parental experiences with consultations received from a formal Pediatric Palliative Care Program in the NICU setting, neonatal EOL care, and parent bereavement and coping experiences after infant death in the NICU.
CHAPTER 2
REVIEW OF LITERATURE

Literature germane to PC and EOL care in the NICU was included from various disciplines including nursing, medicine, psychology, and social work. Because there is a severe paucity of literature specifically related to parents’ experiences with PC consultation in the NICU and these parents’ bereavement experiences related to infants, additional literature related to parents of children with life-limiting and/or life-threatening illness will be included. Parent bereavement after infant loss, parent coping and adaptation, and decision-making preferences of parents were included in the following literature review.

Parental Bereavement Related to Infant Loss

Infant and child death is a tragic and unexpected loss for parents, resulting in a higher frequency of intense grief than in any other group of bereaved individuals (Kamm & Vandenber, 2001). Grief is defined as the emotional reaction to bereavement and loss of a loved one, and grieving is a process that involves restructuring meaning around a changed reality of the deceased infant and a modified family structure (Armentrout, 2009; Klass, 1997; Stroebe, Hansson, Schut, & Stroebe, 2008). Children embody parental hopes, dreams, and future purpose, as well as a reflection of parent and caregiver identity (Wheeler, 2001). Grieving is an unfolding process that may begin as early as
fetal diagnosis and recognizing the loss of the “perfect baby” (Cote-Arsenault & Denney-Koelsch, 2011). Because parents may develop long-standing grief symptoms, understanding the antecedents and consequences of infant death is essential to identify parental bereavement needs.

Antecedents to Parental Bereavement

Anticipatory Grief

Anticipatory grief occurs before an expected loss and is understood to affect bereavement; however, the underlying processes remain equivocally understood (Schulz, Boerner, Herber, 2008). More specifically, it is unknown if the predictable nature of prognosis prior to death or the cognitive processes related to impending death render anticipatory grief helpful in the grief process (Schulz et al., 2008). Although parent bereavement outcomes and the quality of care may be greatly affected by the introduction of PC consultation antenatally and in the NICU, there is a dearth of information related to parents in the NICU and how the initiation of PC may affect anticipatory and long-term grief.

Perinatal Palliative Care

The American Academy of Pediatrics (2007) recommends the initiation of palliative care services before birth with fetuses with life-limiting illness to improve the transition from obstetric care to the neonatology medical team and improve the quality of care for the infant and their family. Perinatal PC is a specialty service that provides supportive care to fetuses with a life-limiting diagnosis and to their families who may be
planning for the birth and the death of their infant simultaneously (Wool, 2013). Mothers and fathers are often unprepared for a life-limiting fetal diagnosis and may begin to grieve multiple losses when faced with tragic circumstances such as infant death (Wool, 2013). More specifically, parents may grieve the loss of a healthy pregnancy, healthy baby, and the future role as a parent (Cote-Arsenault & Denney-Koelsch, 2011). In addition, parents may encounter social isolation and social challenges due to friends and family not recognizing and validating the pregnancy or unborn child (Cote-Arsenault & Denney-Koelsch, 2011; Wool, 2013). Furthermore, concurrent life stressors may encumber anticipatory grief. For example, low-income African American parents reported difficulty preparing for the grief associated with the death of their newborn infant due to economic hardship and loss of family members during their pregnancy (Kavanaugh & Hershberger, 2005).

Anticipatory grief is prevalent in parents who are informed that their unborn child may not survive and may cope by turning to faith communities and searching for meaning in their pregnancy and unborn child, preparing for the worst outcomes, and maintaining hope (Bennett, Dutcher, & Snyders, 2011; Wool, 2013). In a systematic review of perinatal PC, Wool (2013) purported that 32% of the studies (n = 20 studies) reported the parental desire to preserve hope regardless of prognosis and diagnosis. Managing hardships throughout pregnancy and the stress of an impending NICU hospitalization is challenging and parents of pre-term infants have also expressed the importance of maintaining hope (Boss, Hutton, Sulpar, West, & Donohue, 2008). Kavanaugh (2005) and Boss and colleagues (2008) purported the importance of hope for parents confronting infant death in the context of a “medical miracle” related to advanced
medical technology; however, it is unclear if parent hopes were limited to infant survival alone. Parent hopes may adapt to the fetal life-limiting diagnosis and evolve from a healthy pregnancy and infant to maximizing the time with their infant who may only live for a short time after birth (Wool, 2013). Feudtner (2005) contends that parents may have hopes beyond survival for their children during EOL care, such as enhancing comfort, diminishing suffering, and hopes for family preferences such as place of death.

Palliative care provides consultation to parents regarding goals of care and advanced care planning, anticipating death and grief, and preferences near the EOL (Field & Behrman, 2003). Therefore, perinatal PC is an appropriate intervention for parents experiencing anticipatory grief either before the termination of a pregnancy or before the birth of a critically ill infant (Balaguer, Martin-Ancel, Ortigoza-Escobar, Escribano, & Argemi, 2012; Munson & Leuthner, 2007). Providing PC consultation before the birth of the infant with life-limiting illness may increase the amount of time parents can spend with their infant immediately after birth by preparing for a potentially chaotic delivery (Wool, 2013). Parents have reported beneficial outcomes from the introduction of PC consultation antenatally such as reducing fragmentation of healthcare. For example, repeating information from the genetics medical team, to the obstetrics team, to the neonatal intensive care team is challenging and unnecessary and can be minimized if a PC team is involved through each stage of treatment. A PC team may arrange a tour through the NICU, and although parents reported this as a difficult experience, the preparation was helpful to parents after the birth of their infant (Miguel-Verges et al., 2009). In a case study conducted by Ramer-Chrastek, and Thygeson (2005), perinatal PC was helpful to the family included in their case study by providing support to siblings and
including child-life specialists, and including pastoral care to address spiritual suffering. The family in the case study emphasized the healing properties of perinatal PC during bereavement (Ramer-Chrastek & Thygeson, 2005).

Although research efforts have contributed qualitative, exploratory research studies on perinatal PC, limitations exist in the lack of prospective longitudinal studies examining the beneficial outcomes of initiating perinatal PC before an NICU hospitalization. Gaps in the existing literature include a dearth of empirical data examining culturally sensitive interventions, and legal implications in the healthcare setting for providing perinatal PC care (Wool, 2013). Further, the studies that were included in the literature review focused on decision-making and how the PC team supports the parents through challenging decisions (Balaguer et al., 2012). Although supporting parents with decision-making is a critical component of perinatal PC, the parental experience of other interventions remains unknown and must be explored in order to tailor individualized interventions for parents facing the birth of a fetus with a life-limiting illness. Because many parents report hope as an important process within anticipatory grieving, the concept of hope should be further explored in order to address parent needs before and after birth, and potentially improve grief and bereavement outcomes.

**Risk Factors for Complicated Grief in Parents of Infants and Children**

Risk factors for complicated grief symptoms in parents of hospitalized infants and children include being the biological mother or female guardian, single parent, lower education, and traumatic nature of death (Meert et al., 2010; Wijngaards-De Meij et al.,
Complicated grief involves intrusive thoughts of the deceased, clinically significant symptoms, and a level of social or occupational impairment (Stroebe et al., 2008). Complicated grief is germane to parents of infants in the NICU because complicated grief symptoms at six months post-death have been found to be associated with poor mental and physical health, and reduced quality of life in parents of infants and children hospitalized in the pediatric intensive care unit (PICU) (Meert et al., 2010). Moreover, bereaved parents have higher mortality rates and psychiatric hospitalizations when compared with parents who have not experienced the death of a child (Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003). Youngblut, Brooten, Cantwell, Del Moral, and Totapally (2013) studied health and functioning in parents (176 mothers and 73 fathers) 13-months after infant or child death in the NICU or PICU. Twenty-nine percent of the parents reported stress related hospitalizations, numerous newly diagnosed chronic health conditions, clinical depression (35% of mothers and 24% of fathers), and clinical Post-Traumatic Stress Disorder (PTSD) (35% of mothers and 30% of fathers). One mother attempted suicide six months after her child’s death (Youngblut, Brooten, Cantwell, Del Moral, & Totapally, 2013). Youngblut and Brooten (2009) also reported that more Hispanic and Black mothers, compared to White mothers, reported moderate to severe depression at six months after infant or child death and more PTSD at every time point in their study.

Grief symptoms fluctuate and change over time. That is, parent scores from the Inventory of Complicated Grief were considered high (score > 25) at 18-20 months post-death, and were inversely related to time in parents of children younger than 30 years of age (Dyregrov, Nordanger, & Dyregrov, 2003; Keesee, Currier, & Neimeyer, 2008;
Wijngaards-De Meij et al., 2005). Depending on the nature of death (i.e., chronic and prolonged suffering or acute traumatic death) parents reported various magnitudes of grief symptoms (Dyregrov et al., 2003). For example, some parents who watched a child suffer over a long period of time, reported feelings of relief when death ended their child’s suffering (Wheeler, 2001). However, these findings include bereaved parents of children ranging in age from neonates to adult, and it remains unknown whether parents of infants in the NICU have similar grief symptoms and consequent health risks because of the unique considerations for this population, such as limited lifespan and time spent together.

**Parent Needs during Hospitalization**

Parents of infants and children in the PICU have reported individualized needs during their child’s hospitalization including environmental and communication preferences (Meert, Briller, Schim, Thurston, & Kabel, 2009; Pector, 2004). Bereavement needs of parents begin during NICU hospitalization (Meert et al., 2009). Privacy is priority for parents as they anticipate the death of their child, in addition to the need for reverence and sacredness in the child’s hospital room (Meert et al., 2009). Interruptions from nearby healthcare professionals such as laughter or knocking on the door unnecessarily, may cause family members to feel uncomfortable, and in some cases feel rushed to leave the room if death has occurred (Meert et al., 2009). Allowing parents and other family members ample time with the infant or child surrounding the death experience is a priority as parents begin to make sense of their loss (Meert et al., 2009).
Parents of infants and children in the PICU have also reported the need to maintain their identity as parents by providing, protecting, and maintaining authority for their hospitalized children (Meert et al., 2009). It is known that facilitating parental role is helpful to parents and should be continued in EOL care (Meert et al., 2009). The Creating Opportunities for Parent Empowerment Program (COPE) is an evidence-based intervention that has been applied to parents in the NICU and fosters parent role development (Melnyk, Crean, Feinstein & Fairbanks, 2008). The COPE intervention engages parents in developmentally sensitive parenting role behaviors (Melnyk et al., 2008). Melnyk and colleagues (2008) found that The Index of Parental Behavior in the NICU (measures quality of parenting in the NICU) scores were higher after the COPE intervention supporting the importance of parent role development by NICU nurses. Turner, Winefield, and Chur-Hansen (2013) explored emotional and support experiences in parents who had an infant hospitalized in the NICU and found that nurses helped to engage develop the parent role during the NICU hospitalization.

Furthermore, parents of infants in the NICU reported the need for nurses to take care of parents during the infant hospitalization by protecting their image as a good parent (Brosig, Pierucci, Kupst, & Leuthner, 2007; Caemaex et al., 2011). For example, nurses who suggested parents leave the bedside to enjoy a meal and rest were very important to parents who needed “permission” to leave the bedside without feeling like a bad parent (Brosig et al., 2007). Maintaining the role of caregiver and parent has been evidenced by the need for parents to be present with their dying child regardless of lifesaving procedures at the bedside (Tinsley et al., 2008). Tinsley and colleagues (2008) conducted interviewed parents in the PICU who witnessed cardiopulmonary resuscitation
(CPR) on their child and found that parents reported feeling scared during cardiopulmonary resuscitation, but that being present brought comfort to their child and would help them accept their child’s death. Similarly, Hinds and colleagues (2009) explored the meaning of a “good parent” in parents of children with incurable cancer, and found common themes of “being there for my child” and “advocating for my child.” Facilitating the role of parenting may comfort parents and facilitate long-term grieving. However, long-term grief symptoms and health outcomes subsequent to facilitating parent role in the NICU palliative and EOL care remains unknown (Moro et al., 2006).

A multidisciplinary team is necessary to meet parent needs surrounding infant death including facilitating parent role; however, Meert and colleagues (2009) found that parents in the PICU reported that the constant introduction of healthcare professionals from various disciplines as an “unwelcome challenge” and sought support only from those they trusted to provide sincere sympathy. Further, feelings of abandonment were reported from parents of infants with complex chronic conditions related to fragmentation of care during their hospitalization (Tan, Docherty, Barfield, & Brandon, 2012). Therefore, multidisciplinary teamwork and continuous communication may not be therapeutic for parents if communication is fragmented and ineffective.

Pector (2004) examined preferred communication near the time of death in bereaved parents of multiple infants (e.g., twins, triplets, quadruplets) in the NICU through the use of narrative emails and found that parents preferred straight-forward, parsimonious death notification; whereas, parents developed aversion to medical phrases such as “expired” and to explanations such as “this was meant to be.” Contact after death in the NICU and PICU was appreciated from familiar hospital staff, as well as the
opportunity to meet with physicians in a post-death bereavement conference, and discuss autopsy reports and the events leading up to their child’s death (Brosig et al., 2007; Meert et al., 2009; Meert et al., 2007; Raingruber & Milstein, 2007). Further, in a study of parents of children hospitalized in the NICU and PICU, parents considered sensitive and caring health care providers as those who cried and prayed with the parents, called parents after the hospitalization, provided parents with a memory box for their infant, and attended the child’s funeral (Brooten et al., 2012). Thus, it is important for communication to be sincere, sensitive, non-judgmental, and this may continue after hospitalization.

Consequences Related to Parent Bereavement

Parental bereavement, or the condition of enduring the loss of a loved one, is unique regarding infant death because the amount of time parents have spent with their infant may be limited, leaving few memories for parents to maintain a connection to the infant after death (Grout & Romanoff, 2000). Moreover, many infants are not discharged from the NICU before death and PC and EOL care may play an important role in creating memories for infant family members (Catlin & Carter, 2002). After infant and child death, memories serve to maintain the connection with the deceased by recognizing the loss and the longing for the missing family member (Grout & Romanoff, 2000). Memories allow parents to memorialize their infant or child through ritualistic behaviors, altruistic acts, and sharing stories about their child (Brosig et al., 2007; Grout & Romanoff, 2000; Meert, Thurston, & Briller, 2005; Meert, Thurston, & Thomas, 2001; Tan et al., 2012). Altruism may be evidenced by organ donation where parents believe
this altruistic act further maintains the connection to their deceased child (Bellali & Papadatou, 2006). However, Bellali and Papadatou (2006) reported similar grief processes from their qualitative study comparing parents who consented to organ donation and those who chose not to donate their child’s organs or tissues. Some parents who did select to donate their child’s organs reported relief from grief because of the continued bond with their child through another living child; however, other parents reported lack of clarity from the transplant team and were unprepared for the donation process which left the parents with traumatic memories of the PICU (Bellali & Papadatou, 2006). Bereaved parents have also volunteered in pediatric palliative care education through the Initiative for Pediatric Palliative Care (Adams, Green, Towe, & Huett, 2013). Parents reported a sense of purpose and it was determined that more benefits than burdens were experienced by parents volunteering in pediatric PC education (Adams et al., 2013).

The untimely death of a child often shatters meaning and purpose in life for bereaved parents (Wheeler, 2001). Spiritual suffering is often encountered by parents as they try to make sense of the loss and address existential questions such as “Why my baby?” or “Why would God allow my baby to suffer?” (Bellali & Papadatou, 2006; Kavanaugh & Hershberger, 2005; Raingruber & Milstein, 2007; Rosenbaum, Smith, & Zollfrank, 2011). In addition to spiritual suffering, grief symptoms are frequently experienced by bereaved parents and include emotional reactions such as anxiety, depression, anger, hopelessness, loneliness, and a sense of emptiness; as well as somatic complaints, including sleep loss, decreased energy, and social difficulties (Dyregrov & Dyregrov, 1999; Laakso & Paunonen-Ilmonen, 2001). Physical reactions to grief have
been reported by bereaved parents as “a feeling of actual pain, like a real broken heart” (Wheeler, 2001).

Symptoms of grief may contribute to marital discord in bereaved parents (Kamm & Vandenberg, 2001). Vance, Boyle, Janman, and Thearle (2002) matched non-bereaved parents with parents whose infant suffered from Sudden Infant Death Syndrome and perinatal death and found that bereaved parents reported increased marital dissatisfaction when compared to non-bereaved parents at 2-, 8-, 15-, and 30- months post-death. Further, feelings of blame and guilt may lead to marital dissatisfaction where there is suspected or known congenital or genetic cause of death (Littlefield & Silverman, 1991). Littlefield and Silverman (1991) found that in the presence of genetic-related death, fathers tended to accept and receive responsibility. In contrast, mothers reported more dissatisfaction with their spouses’ behaviors, the perception of their spouse’s marital satisfaction, and placed more emphasis on the genetic attribution of death. However, it is unknown what additional factors contribute to marital dissatisfaction such as number of living children, the ability of parents to successfully procreate after their loss, as well as major life events, in parents who received PC consultation in the NICU. Further, it is unknown whether support from PC consultation in the NICU may affect the hospital experience through the creation of memories, and facilitate parents in making sense of infant loss throughout bereavement.

In summary, parents who experience infant death in the NICU may be at-risk for intense grief symptoms and increased morbidity and mortality. Anticipatory grief may affect long-term grief outcomes; however, it is unknown how PC consultation and EOL care communication may affect grief outcomes. Parents who suffer from infant death are
unique because many infants are not discharged from the NICU before death and there may be limited time to create memories that serve to maintain the connection to the infant after loss. Because parents may suffer with intense grief symptoms from the sequela of infant death, identifying risk factors for complicated grief in parents of infants with life-limiting and/or life-threatening illness is essential to providing quality family-centered care in the NICU. Each parent has individualized needs and preferences during and after infant hospitalization and must be accommodated in order to facilitate parental bereavement. This study explored bereavement experiences of parents in the NICU who have received EOL care, and/or PC consultation during their infant’s hospitalization.

Parental Coping and Adaptation to Infant Death

Coping has been conceptualized by Lazarus and Folkman (1984) as a process to manage psychological stress. Cognitive appraisal of a stressor occurs in three stages: Primary, secondary, and reappraisal. Cognitive reappraisal involves the perception and categorization of a perceived stressor, perception of solutions to manage the stressful situation, and re-evaluating the stressful situation by integrating newly acquired knowledge from the environment (Rew, 2005). Successful adaptation to a balanced state is the terminal goal during coping processes (Kuhns, 2002). Adaptation is an outcome of coping and involves successful social functioning and somatic outcomes after a stressor, such as infant death (Lazarus & Folkman, 1984).

Coping and grieving processes are interrelated throughout bereavement. Parents use coping strategies to manage grief, including making sense of the loss, focusing on existential questions, and managing social isolation (Brosig et al., 2007). Therefore, how
grief symptoms are cognitively managed is related to successful adaptation and integration of the loss in a meaningful and comforting way. Six months after premature infant death, Glaser and colleagues (2007) found that parents were able to cognitively reappraise their loss and reported comforting thoughts knowing their preterm infant was no longer suffering and in a safe place. Some parents believed that the infant could still be connected to their family as a guardian angel. In addition, some parents were relieved to avoid the burden of rearing a disabled child (Glaser, Bucher, Moergeli, Fauchere, & Buechi, 2007).

Neimeyer (2000) contends that another critical aspect of successful adaptation is meaning reconstruction, which involves sense-making and benefit-finding. The importance of meaning reconstruction in bereaved parents was further underscored when Ronen and colleagues (2009) explored continuing bonds in bereaved parents of children 18 years or younger. Continuing bonds involve parents adjusting to the loss while sustaining a level of connection to the deceased. Parents without complicated grief reported more positivity and ability to make sense of the loss by successfully sustaining continuing bonds with their deceased child (Ronen et al., 2009). Although a small sample of bereaved parents ($n = 6$), data were strengthened by triangulating with quantitative complicated grief symptoms, structured interviews on continuing bonds, and projected drawings that were interpreted by a certified art therapist (Ronen et al., 2009). Projected drawings also supported the differences in parents with complicated grief, as these parents developed drawings indicative of maladaptive coping (i.e., black, brown, and purple colors), while parents in the non-complicated group developed drawings that included many colors and positive symbolism (Ronen et al., 2009).
The degree of adaptation to infant and child death changes over time. At six months post-preterm infant loss \( (n = 10 \text{ mothers}; n = 9 \text{ fathers}) \), parents reported 48% of cognitive processes involving guilt and failure, and 52% of cognition involving peace because their child was no longer suffering (Glaser et al., 2007). Whereas, at 3.5 to 6.5 years post-death, parents reported 63% positive cognitive processes involving emotional integration of the loss and the ability to feel as if the child was still in their family without sadness and sorrow (Glaser et al., 2007). Cognitive appraisal continued to render comfort and purpose for the infant’s life; however, the question of “why my baby?” continued in one third of the parents at 3.5 to 6.5 years post infant death (Glaser et al., 2007).

Although grief symptoms have been studied in parents of deceased infants and children, the long-term changes in cognitions and emotions related to coping with grief and bereavement remain unknown in parents of infants in the NICU who received PC consultation during hospitalization and within the context of EOL care, and how PC may affect adaptation.

Similar to grief, coping is a highly individualized process unfolding over time. Bereaved parents commonly report that being able to talk about the loss of their child and feeling understood by others facilitated their coping with the loss of their child (Braun & Berg, 1994; Brosig et al., 2007; Meert et al., 2009). It is important to note that parents have reported therapeutic benefits from research participation in bereavement studies associated with the desire to help other bereaved parents and as an outlet to express pain and share thoughts (Kavanaugh & Hershberger, 2005; Ronen et al., 2009). In addition to cognitive processes, a myriad of coping strategies have been reported by parents of
infants in the NICU, including social support and relying on religious and/or spiritual faith (Brosig et al., 2007; Hughes, McCollum, Sheftel, & Sanchez, 1994).

**Social Support Related to Coping with Grief and Loss**

Many parents report social support as a major coping resource as they grieve the loss of their child (Kavanaugh, Trier, & Korzec, 2004; Sutan, Amin, Ariffin, Teng, & Rusli, 2010). Social support is context-specific and involves reciprocal verbal and non-verbal communication (Finfgeld-Connett, 2005). Social support involves advocating processes through means of emotional and instrumental support (Finfgeld-Connett, 2007). Instrumental support, such as a trusted friend staying with the dying child and providing parents respite, is reported to be highly valuable to parents (Meert et al., 2009). Although parents who have experienced infant death often seek social support from members of the community, many parents continue to report feelings of social isolation, or a lack of social support (Cote-Arsenault & Freiji, 2004; Kavanaugh & Hershberger, 2005; Kavanaugh et al., 2004). Mothers have reported the instinct to withdraw from society as a result of hurtful comments from friends and family (Glaser et al., 2007). Further, tension as evidenced by dissonant coping needs between spousal partners may affect successful adaptation, especially in women. For example, it is common for mothers to desire talking through the loss more than fathers (Wijngaards-De Meij et al., 2008).

Parents may also experience disenfranchised grief and feel abandoned by their community and/or family because of the perceived dismissal or avoidance of their loss and hurtful communication (Brosig et al., 2007; Doka, 2008; Kavanaugh, 1997; Meert et
al., 2009; Stroebe et al., 2008). The very young and old are often excluded from grief recognition because of the perceived inability to process grief (Doka, 2008). Brosig and colleagues (2007) and Youngblut and Brooten (2013) purported the importance of sibling involvement with EOL care in the NICU; however, parents reported limited time allowed for sibling involvement in the hospital setting. Thus, the consequences of disenfranchised grief remain understudied for other members in the family such as grandparents and siblings of infants in the NICU and how family-centered PC and EOL care interventions may affect these family members.

Consequent to parents’ social worlds not recognizing or avoiding infant loss, Meert and colleagues (2009) discovered that parents drifted apart from friends who did not recognize their loss and avoided talking about their child. In contrast, parents gravitated towards supporters who recognized the life of their deceased child and other parents who had also suffered infant loss (White, Walker, & Richards, 2008). Turner and colleagues (2013) found that other NICU families were a source of support through hospitalization and friendships were maintained after the NICU hospitalization. Turner and colleagues (2013) interviewed parents whose infants survived; however, the parents’ infants were also critically ill in the NICU and found comfort in talking with those who understood what they were going through. Bereavement support groups are available to parents of deceased infants as a coping resource. However, Brosig and colleagues (2007) found that support groups with parents of infants and children of all ages could result in the comparison of grief and parents of infants were made to feel their loss was less traumatic than those who knew their children for a longer period of time. Additional avenues of seeking social support were identified through religious or spiritual
affiliations (Brosig et al., 2007; Kavanaugh & Hershberger, 2005; Kavanaugh et al., 2004). In a pilot case study conducted by the PI with a bereaved mother of an infant who died in the NICU, religious and spiritual coping resources served as a means of seeking instrumental and emotional social support through the church congregation, and were crucial to coping with infant death (Currie-Routh, 2010).

**Spirituality**

Spirituality involves an existential world of meaning, whereas religion may be generally defined as a belief shared by a group of people (Doka, 2011). The concept of an afterlife is thought to be comforting for bereaved parents especially if they have watched their child suffer prior to death (Rosenbaum et al., 2011). In a study of parents who received community PC services for their children, Knapp and colleagues (2011) found that non-White parents reported the use of spirituality as a coping strategy more frequently than White parents. Similarly, Kavanaugh (2005) found that African American parents who suffered from perinatal loss relied heavily on spirituality as a coping resource. Spirituality provides an avenue for making sense of the loss during a time of chaos helping integrate the deceased infant into the parents’ lives in a meaningful and positive way (Catlin et al., 2001). However, it is essential that spiritual needs are addressed on an individual basis. For example, Meert and colleagues (2009) found that a Jewish family was read the “Lord’s Prayer” at the time of death, and this spiritual care was identified as hurtful and distressing for the parents. Feudtner, Haney, and Dimmers (2003) examined the perspective of chaplains employed in children’s hospitals and reported 60% - 80% of parents receiving chaplain services had difficulty coping with
their child’s painful symptoms and questioned why their child was suffering, indicating
the need for spiritual care near the EOL. Budgetary constraints associated with in-patient
spiritual care, conceptual vagueness, and the lack of scientific rigor in the measurement
of spirituality have led to a paucity of information on spirituality in the context of coping
with infant death (Feudtner et al., 2003; Field & Behrman, 2003). However, supporting
all aspects of coping, including social support resources, family support, and spiritual
needs, is essential in the provision of quality palliative and end-of-life care for infants and
their parents.

In summary, infant death is a tragic loss that requires various coping strategies to
manage intense grief symptoms. Parents utilize a variety of coping strategies such as
finding benefits and meaning through cognitive reappraisal, social support and
spirituality. Because many infants are not discharged from the NICU before death,
bereaved parents of infants face unique challenges with limited time for creating
memories that serve to maintain the connection with their deceased infant. In addition,
many parents suffer from disenfranchised grief in the community. This study explored
coping experiences of parents who have received EOL care and/ or PC consultation in the
NICU prior to their infant’s death.

Palliative Care and End-of-Life Care Decision-Making with Parents of Infants

Ethical considerations in decision-making related to palliative and EOL care have
lagged in comparison with the medical and technological advances within the NICU, thus
engendering long-standing complexities in the integration of palliative care (Purdy, 2006;
Purdy & Wadhwani, 2006). A fervently debated issue in neonatal intensive care is
ethical decision-making regarding the use of highly technical medical intervention to extend the life of critically ill infants resulting in poor quality of life (Purdy, 2006; Purdy & Wadhwani, 2006). Despite the importance of implementing PC interventions at the time of diagnosis for infants with life-threatening and/or life-limiting illness, barriers including uncertainty associated with the infant’s prognosis and quality of life further complicate these difficult decisions for parents (Meert et al., 2009; Rushton, 2005; Rushton, Williams, & Sabatier, 2002; Solomon et al., 2005; Wright, Prasun, & Hilgenberg, 2011).

**Barriers to Palliative Care in NICU**

Despite the importance of implementing PC consultation at the time of diagnosis for infants with life-limiting and/or life-threatening illness, barriers exist in the provision of palliative care services and EOL care in the NICU. Specific barriers to providing PC include: uncertainty associated with determining the infant’s prognosis, environmental limitations such as lack of privacy and comfort for parents at the bedside in the NICU, and lack of education regarding integrating palliative care with curative care among nurses, physicians, and the family (Rushton, 2005; Rushton et al., 2006; Rushton et al., 2002; Solomon et al., 2005; Wright et al., 2011). Further, many healthcare professionals report moral distress in providing care to infants and children near the EOL because of the perceived discomfort that infants and children experience with continued complex medical intervention (Rushton et al., 2006). Although NICU end-of-life and PC protocols have been developed by Catlin and Carter (2002), and interdisciplinary interventions to educate healthcare professionals about pediatric PC have been implemented by Rushton and
colleagues (2006), the transition from curative to palliative care is complex and complicated in the NICU. Nurses and physicians in the NICU are able to identify physiologic factors and futile prognoses due to advanced technology; however, parental agreement remains the determinant for the initiation of palliative care rather than the infant’s physiologic state and prognosis (Catlin, 2011).

Although parents remain the focus of ethical decision-making in the NICU, there is a paucity of research on parental perceptions of PC, and why these services may be underused or avoided in the NICU (Catlin, 2011). Researchers at a Wisconsin children’s hospital that offers PC consultation in the NICU found that the median length of time from initiation of PC consultation to infant death was 5.5 days (Leuthner & Pierucci, 2001). Moreover, of the 898 total NICU admissions and 51 infant deaths, only 12 infants and families received PC even though services were available (Leuthner & Pierucci, 2001). Although all infants and families had access to PC in the NICU, only 13% of families with infant deaths in the NICU received PC (Pierucci, Kirby, & Leuthner, 2001). This study (Leuthner & Pierucci, 2001; Pierucci et al., 2001) provides valuable data describing the underuse of PC in the NICU; however, the use of a retrospective chart review approach limits the understanding of parental experiences and the underlying reasons why available PC was underused or avoided until infant death was imminent (Leuthner & Pierucci, 2001; Moro et al., 2006; Pierucci et al., 2001). Because parents are the surrogate decision-makers for their infants in the NICU, it is imperative to explore parental experiences with PC consultation in the NICU and the parent perspectives of decision-making in the NICU to gain a deeper understanding and determine why PC maybe delayed or avoided until impending infant death.
Parent Decision-Making related to Palliative Care

The American Academy of Pediatrics recommends a shared decision-making process related to PC involving collaboration between physicians and parents, and emphasizes the importance of parent values (Boss et al., 2008). In contrast to the belief that parents are the most appropriate surrogate for infants and children who lack self-determination, some countries employ a paternalistic approach to decision-making in the NICU. Paternalistic decision-making may still involve parents in the discussion of decisions made for their infant; however, the final decision that involves life or death will be determined by the medical team (Brinchmann, Forde, & Nortvedt, 2002). Rationale for this approach involves a perspective that parents are too emotional to make rational decisions and lack professional experience to make decisions that reflect beneficence (Caeymaex et al., 2011; Orfali, 2004; Paris, Graham, Schreiber, & Goodwin, 2006).

Irrespective of the decision-making process, communication preferences and factors that influence decision-making related to PC and EOL care are similar across parents of various cultural backgrounds.

Communication Preferences

Central to all parents facing infant and child death is communication from healthcare providers that is compassionate, sensitive, kind, sincere, non-judgmental, and sympathetic (Brinchmann, et al., 2002; Brooten et al., 2012; Brosig et al., 2007; Caeymaex et al., 2011; Meert et al., 2009; Pector, 2004). Parents of infants hospitalized in the NICU preferred straight-forward information that was presented in a positive way due to parental beliefs of medical miracles and the importance of maintaining hope in the
decision-making process (Boss et al., 2008; Pector, 2004). Although parents have reported supportive communication from physicians who empathetically stated “If it were my child, I would take him off the respirator,” it may not be ethical to guide parents based upon by personal values (Pector, 2004). Parents of infants and children in the NICU and the PICU reported the importance of health care providers sharing information that was understandable to parents in order for the parents to fully participate in the decision-making process for their child (Brooten et al., 2012).

Communication between parents and healthcare professionals could be potentially damaging in the decision-making process. For example, the following communication from a nurse to a patient who received fertility treatment imbues judgment: “Babies are a blessing. How can you do that when you worked so hard to get your babies?” (Pector, 2004, p. 7). Pector (2004) found that 13 out of 71 parents experienced judgment when either maintaining or withholding life support for their infants in the NICU. Brooten and colleagues (2012) found that some parents of infants and children in the NICU and PICU were not informed of their child’s critical medical state and the possibility of a DNR order until the child was in a code situation. For example, a mother was at her child’s bedside when the code began and did not have an opportunity to discuss medical decisions with her husband resulting in a frantic and pressured decision to withdraw care (Brooten et al., 2012). It is known that living with life and death decisions is difficult enough when parents feel supported by the healthcare team (Boss et al., 2008; Caeymaex et al., 2011; Cote-Arsenault & Denney-Koelsch, 2011; Pector, 2004). Therefore, placing the burden of guilt on parents for making an incorrect decision is unacceptable and unprofessional, as well as not adequately informing parents of their infant’s prognosis.
and treatment options before a critical decision must be made. (Caeymaex et al., 2011). In addition, there may be specific cultural considerations to consider when examining ethical decision-making in PC (Brooten et al., 2012; Bullock, 2011; Davies, Contro, Larson & Widger, 2010; Lobar, Youngblut, & Brooten, 2007).

*Racial and Ethnic Differences*

Bullock (2011) examined differences between White and Black older adults making EOL and PC decisions and found that White individuals preferred autonomous decision-making and a positive perspective of PC and hospice care. In contrast, Black individuals preferred collective decision-making with family members and a distrust of the medical team leading to a negative view of PC and hospice (Bullock, 2011). Furthermore, Black individuals associated advanced directives with hastening death and believed that advanced directives may lead to a premature death (Bullock, 2011).

Although older adults were included in this study, implications for culturally sensitive PC are present for supporting all parents in the EOL and PC decision-making process for their child.

Specific to NICU and pediatric intensive care settings, Brooten and colleagues (2012) found racial differences in what parents did not find helpful from healthcare providers near the EOL. White and Hispanic parents reported insensitive and non-supportive staff as the most unhelpful characteristics; whereas Black parents reported conflict between providers and parents as the least helpful (Brooten et al., 2012). Davies and colleagues (2010) explored the PC experiences of Mexican and Chinese American parents of children. Less optimal patterns of communication, including no information or
basic information regarding prognosis and updates of child health status resulted in parent frustration, anger, and sadness in bereaved parents (Davies et al., 2010). In addition to communication from physicians, nurses, social workers, and chaplains, some parents require the use of an interpreter in the decision-making process related to PC. Although a fatal prognosis may be challenging to communicate, the interpreter must communicate information that remains free from subjectivity and emotion. Lack of accurate interpretation could result in the perpetuation of cultural barriers and make the already tragic experience worse for these vulnerable parents. Known differences between racial backgrounds, cultures, and communication preferences undergird the importance of providing culturally sensitive PC and EOL care to address the individual needs of parents in the NICU.

*Factors that Influence Parent Decision-Making*

Although parents make decisions regarding their infant’s healthcare, the information received from healthcare professionals must be accurate, honest, and objective in order to support parents in determining what is best for their child (Brosig et al, 2007). The infant’s quality of life, degree of pain, suffering, likelihood of survival, and the physician’s recommendations have been identified by parents as influential aspects in the decision-making process (Sharman, Meert, & Sarnaik, 2005). Parents have reported feelings of personal suffering related to the physical appearance of their child and feel the need to protect and advocate for their infant throughout the decision-making process (Sharman et al., 2005). However, if accurate and honest information is conveyed, parents may not incorporate this information in their healthcare decision-
Values associated with maintaining hope were of particular importance in the healthcare decision-making process to newborn infant parents, and these parents were found to mistrust physicians who did not express hope and compassion for their child (Boss et al., 2008). Friends and family encouraged parents of premature infants with life-threatening congenital anomalies to place the baby in God’s hands, pray for a miracle, and transfer to a hospital that was capable of miracles (Boss et al., 2008). Feudtner and colleagues (2010) found that hopeful patterns of thinking were related to decision-making in parents of children who received pediatric PC consultation. Specifically, increased hope at baseline was significantly related to a subsequent limitation of intervention, or limiting medical interventions to promote comfort, quality of life, and dignity for their child. Positive affect and hope were also positively correlated in parents who received pediatric PC consultation services (Feudtner et al., 2010). Feudtner and colleagues (2010) suggest that parents with increased hope may be more likely to accept a broader range of medical and nursing goals of care.

Affect states are another dimension of parent emotion and cognition that may influence decision-making. Madrigal and colleagues (2012) assessed parents in the PICU and their decision-making preferences and found that increased levels of self-reported positive affect were associated with an increased preference of shared decision-making. Thus, further examination of affective states and hope as internal guidance should be examined in parents of infants in the NICU so that health care professionals can better support parents when facing difficult decisions at the infant’s EOL. Further study is
necessary to understand how individual factors such as family support systems and available resources affect the parents’ perception of their ability to care for an infant with life-limiting and/or life-threatening illness, and the associated decisions for PC and EOL care for their infant.

*Differences between Parents and Healthcare Providers*

Barriers to the integration or the transition to PC may include anxiety and feelings of guilt in parents who feel as if they are “giving up” on their child (Knapp & Thompson, 2012). Perceptions of the purpose and benefits of PC may differ between parents and healthcare professionals, further creating difficulty in understanding how parents make decisions for their child at the EOL (Rushton, 2004). Boldt, Yusuf, and Himelstein (2006) delved into parents’ and health care professionals’ perception of the term palliative care and a palliative care program description in a descriptive survey study. Parents were provided with the terms “palliative” versus “supportive care” and asked how likely they were to use this service in the future. Parents responded more positively to “supportive care” when compared to healthcare professionals; however, after a non-threatening program description was provided, parents were equally positive about the terms “palliative care” versus “supportive care”. Thus, implications for PC in the NICU include further examination of barriers associated with the term palliative care and the need to educate parents about PC and include a non-threatening program description when introducing PC (Boldt et al., 2006).

Tomlinson and colleagues (2011) compared the preference of supportive care versus chemotherapy in parents of children with incurable cancer and healthcare
professionals who care specifically for cancer patients. Although parents of children with cancer may have different needs during the decision-making process compared with parents of infants in the NICU, it is possible that there are similarities and congruencies in how decisions are made to transition to PC. Results indicated that parents desired more aggressive treatment and chemotherapy compared with healthcare professionals (Tomlinson et al., 2011). Further, parents reported hope as an important factor in decision-making about treatment for their children and would hypothetically select aggressive treatment even if quality of life was comprised. Whereas, healthcare professionals regarded supportive care as more desirable when compared to parents. It is possible that the knowledge and experience of healthcare providers in caring for patients at the EOL may have an effect on these differences. Understanding differences between healthcare providers and parent perspectives of decision-making in the context of EOL and palliative care is essential to addressing the individual needs of parents and supporting this vulnerable population during distressing and traumatic decisions about their child’s life (Tomlinson et al., 2011).

**Outcomes of Decision-Making Related to Grief and Adaptation**

There is a paucity of research on how EOL decision-making affects long-term grief and adaptation to loss. However, one study by Caeymaex and colleagues (2012) aimed to explore the perceived role in neonatal intensive care EOL decision-making and grief response in a sample of French parents. Although paternalism predominantly guided EOL decision-making in the NICU, shared decision-making is increasingly advocated to support parents facing EOL decisions for their infant. Parent grief reactions
were assessed using the Texas Revised Inventory of Grief two years post-infant death and resulted in significantly lower grief scores for those parents who participated in shared decision-making during their infants’ hospitalization. Parents who felt as if their infant suffered at the EOL reported significantly higher grief scores (Caeymaex et al., 2012). In a qualitative study by Caeymaex and colleagues (2011), parents reported the difficulty of facing life and death decisions that resulted in only negative outcomes. Some parents explained that it was selfish for them to prolong care and cause discomfort to their infant, and it was selfish for them to make the decision to withdraw support to avoid caring for a disabled child. However, parents did report feelings of relief that their infant was no longer suffering three years after infant death (Caeymaex et al., 2011).

Implications for practice include the involvement of parents in the decision-making process for EOL and PC and the integration of shared decision-making in historically paternalistic cultures. Further research should involve parents with infants hospitalized in United States neonatal intensive care units and how PC consultation affects the decision-making process and the subsequent grief and adaptation to infant loss in the NICU.

In summary, ethical decisions related to PC and EOL care in the NICU are complex because of the advances in technology. Despite recommendations from the American Academy of Pediatrics to initiate PC consultation services at the time of diagnosis for infants with life-limiting and/ or life-threatening illness, barriers exist in the provision of PC to infants and their families in the NICU. Parent communication preferences, infant state, and additional factors such as parent hope and affect influence the decision-making process; however, it is unknown if these factors are interrelated and
affect parents in the NICU when making decisions. Further, acknowledging the differences between healthcare providers and parents in the decision-making process is essential to support parents in difficult decisions for their infant in the NICU. This study addressed the paucity of research on parents who received EOL and/or PC consultation and how these parents reflect on the decisions made for their infant during an NICU hospitalization.

Summary

Infant and child death is a tragic and unexpected loss for parents, resulting in a higher frequency of intense grief than in any other group of bereaved individuals, as well as an increased risk for morbidity and mortality. However, bereaved parents who receive EOL care and/or PC consultation during an NICU hospitalization and subsequently experience infant death remain poorly understood and understudied. Despite the importance of implementing PC consultation at the time of diagnosis for infants with life-limiting and/or life-threatening illness, barriers exist in the provision of palliative care in the NICU. The parental perspective of receiving pediatric PC consultation in the NICU and why PC services are underused or avoided until death is imminent remains unknown. Parents have individual needs and communication preferences during NICU hospitalization. Supporting parents in the decision-making process and maintaining hope is essential to help parents live with their decisions after infant death. Parents have reported various methods of coping with the grief associated with infant loss, such as obtaining religious and social support, as well as seeking spiritual involvement to facilitate their making sense of the loss of their infant.
CHAPTER 3

METHODOLOGY

Research Design

A descriptive qualitative approach was used to: (1) explore and describe parent experiences related to their infant’s NICU hospitalization, end-of-life care, and palliative care consultation; and (2) to describe parents’ bereavement and coping experiences after the death of their infant. Qualitative descriptive research aims to present an inclusive summary of the phenomena in question (Burns & Grove, 2009; Polit & Beck, 2012; Sandelowski, 2000, 2010). Thus, the use of this type of method was appropriate to address the aims of the proposed study. Further, Sandelowski, argues for the use of qualitative description when there is an appropriate match with posed research questions (Sandelowski, 2000).

The goal of this study was exploratory and was guided by naturalistic inquiry; thus, it was imperative to allow the participants to openly describe their experiences with minimal influence by the investigator (Polit & Beck, 2012). Naturalistic inquiry is based on the need to describe experiences in everyday language as they would naturally occur in nature. Further, research designs that are based on naturalistic inquiry typically do not include pre-selected variables or the manipulation of variables.
Setting

The setting for the proposed study was Children’s of Alabama hospital, a private not-for-profit teaching hospital where infants were hospitalized in a Level-IIIC NICU. Children’s of Alabama is a regional children’s hospital that is recognized as the third largest pediatric medical facility in the United States housing 332 beds and 48 NICU bassinets (Children’s of Alabama, 2012). Children’s of Alabama hospital is the only freestanding acute care hospital in the State of Alabama dedicated to serving children (Children’s of Alabama, 2011). Birmingham, Alabama is located in Jefferson County, a metropolitan county with 660,009 residents and the following demographics: Caucasian 54.7%, African American 42.3%, Hispanic or Latin 4%, Asian 1.5%, and American Indian and Alaskan natives 0.4% (United States Census Bureau [USCB], 2013b). The reported per capita income in Jefferson County is $26,962 (USCB, 2013b). Children’s of Alabama serves the southeast region of the U.S. and the predominantly rural population of Alabama with the following demographics: 4,822,023 total citizens of which 70% are Caucasian, 26.5% are African American, and 4.1% are Hispanic/Latino (USCB, 2013a). In 2011, the median household income was $42,934 with 17.6% of the residents living below the national poverty level (USCB, 2013a).

Participant Recruitment

Research participants (N= 10) were recruited six months from December 2013 to May 2014. Prior to making contact with participants, all recruitment materials were approved by the Institutional Review Board (IRB) at the University of Alabama at
Birmingham (UAB) (Appendix B). Children’s of Alabama protocol for research was followed and the appropriate department was notified of the research and was provided verification of the UAB IRB approval before recruiting any participants. Parents of infants who have expired in the NICU receive a bereavement packet 15-months post-death from Children’s of Alabama hospital. The bereavement packets are not mailed on major religious holidays nor on Mother’s Day/ Father’s Day because of the potential to cause distress related to intense grieving by parents on these holidays. Similarly, recruitment materials were mailed in a separate packet at least 15-months post-infant death excluding major grief-related holidays to avoid causing unnecessary distress. The following materials were mailed at least 15-months post-infant death or NICU discharge to potential parent participants: (a) an introductory letter co-signed by the attending physician of the Pediatric Palliative Care Program and the Treating Neonatologist from the NICU at Children’s of Alabama, (b) a form indicating participant interest and preferred contact information with pre-paid postage for return, (c) principal investigator (PI) contact information, (d) the informed consent document, (e) Health Insurance Portability and Accountability Act authorization form, (f) and the demographic questionnaire. Because Children’s of Alabama hospital reported a low response rate of 5%, a follow-up phone call using an IRB approved script was made to each potential participant by the PI two weeks after the initial recruitment letters are mailed (S. Day, PhD, RN, personal communication, May 9, 2013).

Parents were contacted by the hospital regardless of their interest in study participation; therefore, these recruitment strategies should not have placed undue distress on parents who may or may not have been interested in participation. Parents
were recruited for this study through the Hands of Hope bereavement program in the neonatal intensive care unit at Children’s of Alabama. Some parents selected “no” to receiving any additional/ follow-up materials from the NICU at time of discharge or infant death. These parents who selected “no” were not contacted in any way for research recruitment. One mother called the PI to complain about being previously contacted by the NICU bereavement program at Children’s of Alabama. However, the PI contacted this parent by mistake because she did not select “no” to the bereavement communication after hospitalization. The PI apologized for causing any additional and undue distress and explained how her information was obtained. The PI also explained that she would contact the bereavement program in the NICU at Children’s of Alabama and remove her name from any communication/ follow-up materials. At the end of the conversation, this parent expressed gratitude for the apology, explanation of study procedures, and actions to remove her name from the bereavement program communication list.

A total of 181 packets of information were mailed to potential participants. However, only 78 potential participants could be reached due to invalid addresses and phone numbers. It should be noted that the PI started recruiting those parents who experienced death closer to the February 2009 cut-off date before those more recent deaths. Therefore, this could have influenced the inability to contact many of the potential participants. Of the 78 parents, the PI was able to establish contact either by phone or returned inquiry forms, 10 participants agreed to participate. Another 10 participants discussed the study with the PI and were possibly interested but did not re-contact PI to schedule an interview, and 11 parents responded with “no”. The majority of
Parents did not want to participate because of events in their life. The below table illustrates the parents’ reasons for not wanting to participate.

Table 1 Parent Reasons for Not Participating in the Study (n = 11)

<table>
<thead>
<tr>
<th>Number of Respondents</th>
<th>Reason for Not Participating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not English speaking</td>
</tr>
<tr>
<td>1</td>
<td>Unsure of which child was hospitalized in the NICU at Children’s of Alabama</td>
</tr>
<tr>
<td>1</td>
<td>Pregnant/ avoiding additional stress</td>
</tr>
<tr>
<td>2</td>
<td>Scheduling difficulties</td>
</tr>
<tr>
<td>2</td>
<td>Currently have an infant hospitalized in the NICU at Children’s of Alabama</td>
</tr>
<tr>
<td>4</td>
<td>No desire to participate because of the research topic</td>
</tr>
</tbody>
</table>

Sample

Purposive convenience sampling was used to obtain a sample of parent participants (N = 10) who met the inclusion criteria. Parent participants were recruited until data saturation was achieved in the semi-structured interviews (Polit & Beck, 2012). Maximum variation sampling was used to purposefully select information-rich cases that represented a diverse sample (Sandelowski, 1995). Specifically, fathers were targeted to represent both paternal and maternal experiences.

Participants were recruited from parents who received end-of-life care and/ or palliative care consultation after February 1, 2009 while their infant was hospitalized at Children’s of Alabama. Parents who experienced infant death at least 15-months prior to
the enrollment date were eligible. Because the Pediatric Palliative Care Program was initiated at Children’s of Alabama hospital in February 2009, parent participants whose infants were hospitalized from 2009-2012 were recruited in an attempt to maximize the number of parents who were exposed to PC consultation in the NICU. However, the number of PC consultations at the Children’s of Alabama hospital NICU have consistently decreased each year (2010= 35 consults, 2011= 18 consults, 2012= 11 consults) due to Pediatric Palliative Care Program personnel change and barriers related to palliative care among healthcare professionals in the NICU (Sam Perna, MD, personal communication, May 9, 2013).

In 2010, 23.5% of 172 total hospital palliative care consultations occurred in the NICU at Children’s of Alabama, with 53.5% Caucasian, 37.8% African American, and 8.7% Hispanic/ Latino (Faught, 2011). The pediatric PC team reported 43.5% of total hospital consultations to infants (birth to one year of age) in 2010 (Faught, 2011). In addition to the available sample through the Pediatric Palliative Care consultations in the NICU, there are 60-70 deaths/ year in the NICU at Children’s of Alabama and potentially 120-140 parents who received end-of-life care each year. The sample for this study included 10 parent participants (seven mothers and three fathers). The sample size was determined by the richness of the data, when redundancy was noted in the data, and when data saturation was determined. This sample size is comparable to similar exploratory studies in the literature ranging from six to nineteen (Brinchmann, Forde, & Nortvedt, 2002; Brosig, Pierucci, Kupst, & Leuthner, 2007; Rainbruger & Milstein, 2007; Ronen, Packman, Field, Davies, Kramer, & Long, 2009).
Hospitalized infants who received EOL care and those who received additional PC consultation received similar neonatal intensive care throughout the hospitalization. Palliative care consultation was an additional layer of support for the infant, infant’s parents, and for the NICU medical team. Therefore, there were no major treatment differences throughout the NICU hospitalization that affected data analysis. In addition, some infants and their parents chose to receive EOL care in another setting such as a private family room within the hospital. Although there may be differences in the environmental setting at the EOL, this exploratory study examined the needs of these parents near the infant’s EOL and the experiences of these parents after infant death.

Inclusion Criteria

A parent was defined as a biological mother or father or a legal guardian who had custody of the infant during the NICU hospitalization (i.e., adoptive or foster parent, or family member who had legal custody). The sample included bereaved parents who were: (a) over the age of 19 at time of enrollment, (b) fluent in English (must read, speak, and understand English), (c) had an infant hospitalized in the NICU at Children’s of Alabama before infant death, (d) at least 15 months post-infant death, and (e) infant death occurred on or after February 1, 2009 (Pediatric Palliative Care Program initiation date). The maximum time since infant death was based on the February 1, 2009 initiation of the Pediatric Palliative Care Program at Children’s of Alabama hospital. Both parents from a spousal dyad were invited to participate and were interviewed separately.
Exclusion Criteria

Exclusion criteria included: (a) parents who are under the age of 19, (b) parents who have experienced infant death less than 15 months from the study enrollment date (Note – According to Children’s of Alabama NICU Bereavement Services policy to minimize parental stress, parents who have experienced infant death less than 15 months from the study enrollment date must be excluded) (J. Faught, FNP, personal communication, May 1, 2010), (c) parents who experience infant death before February 1, 2009, and (d) parents who are not fluent in English because the PI only speaks English. It is essential that the PI understand and speak the same language as the participants to ensure proper informed consent and understanding of verbal and non-verbal communication during the interviews.

Human Subjects and Ethical Considerations

Potential Risks

Participants

There was no physical risk with the proposed research study. However, there was a psychological risk because there was a potential for parents to experience psychological distress when discussing and reporting experiences regarding the loss of their infant. Infant death was considered a sensitive topic because the participants shared deeply personal experiences (Kavanaugh & Ayres, 1998). Bereaved parents may be at risk for symptoms similar to post traumatic stress disorder, as the NICU experience itself is considered to be a traumatic stressor (Peebles-Kleiger, 2000).
Researcher

There was a potential physical risk for the PI because data were collected in unknown environments within participant homes and communities. However, the PI did not experience any physical risks during the data collection process. In addition, the sensitive topic of infant death is emotionally-laden and could have placed the PI at risk for compassion stress during the data collection and data analysis procedures (Rager, 2005). Compassion stress is defined as the manageable demand that is associated with feelings of compassion or sympathy and should be addressed in order to prevent the researcher from experiencing compassion fatigue (Pickett, Brennan, Greenberg, Licht, & Worrell, 1994). Compassion fatigue should involve an intervention for the researcher and involves feelings of helplessness, isolation, and confusion, and is also known as secondary Post Traumatic Stress Syndrome (Pickett et al., 1994).

Protection against Risks

Participants

Several procedures were designed in the data collection and data analysis procedures to protect the participants from potential psychological distress and breach of confidentiality. Strategies to reduce psychological distress in interviews covering sensitive topics included a flexible interview format to allow for breaks after emotional discussion and continuously assessing for signs of emotional distress, such as crying, throughout the entire interview process, and debriefing the participant after the interview is complete (Kavanaugh & Ayres, 1998). Several of the participants did cry and become teary during the interviews and were asked by the PI to take a break if needed. Although
many of the parents did appear teary and emotional, they expressed similar feelings of gratitude for the opportunity to talk about their infant even if it was difficult for them.

At the end of the interview, the participants were given an opportunity to reflect on the interview and how they felt about participating in the interview. All of the participants discussed similar feedback in response to the question “What was it like for you to participate in this study today?” Parents explained that the interview process was positive and less difficult than they anticipated.

In the case of emotional or psychological distress, additional resources were available to each participant, if necessary. Dr. Sam Perna is the attending physician of the Palliative Care Program at Children’s of Alabama and has training in child and family psychotherapy. Dr. Perna was available for participant support as he is also a member of the PI’s PhD dissertation committee. In addition, Dr. Perna will facilitate participant access to the Amelia Center, a grief and bereavement service provided at no cost by Children’s of Alabama hospital. Although these resources were available to all parent participants, none of the research participants appeared to be in emotional distress after the interview. The participants were given information to contact the Amelia Center after the interview was completed.

The participant’s home or meeting place in the participant’s community was structured to provide privacy, a comfortable environment, and was stocked with tissues and water for each participant. Confidentiality was maintained throughout the transcription and interpretation process to protect the privacy of the participant by the use of pseudonyms, encrypted data storage device (iron key), and hard copies of transcriptions were kept in a locked filing cabinet owned by the PI (Burns & Grove,
Each participant was given a pseudonym to interpret the data and the correlating names were stored on the encrypted hard drive (Burns & Grove, 2009). The hard copies of the transcribed interviews and demographic questionnaire forms will be shredded or placed in an approved UAB IRB recycling receptacle after this research protocol is complete. Electronic copies of information will be erased and deleted before the UAB IRB approval expires. Data obtained from the demographic questionnaire was coded to match a pseudonym given to the interview transcription to prevent any risk of inappropriate disclosure of information.

*Researcher*

To address the potentially harmful emotional distress associated with collecting data on sensitive topics such as infant death, the PI engaged in debriefing sessions with the Dissertation Co-Chair, Dr. Christian, after the completion of every third interview. Debriefing sessions provided the opportunity for the PI to discuss the interviews and address feelings of emotional distress and isolation (Pickett et al., 1994). Throughout the data collection and data analysis processes, the PI engaged in stress-reducing activities to reduce the emotional burden associated with this sensitive research. It was essential for the PI to address any emotional distress in order to reduce personal bias that may have affected the trustworthiness of the findings (Rager, 2005).
Human Subjects Procedures

Protection of human participants and IRB approval rests upon the awareness of autonomy, beneficence, and justice as evidenced by integration of these principles into the methodology, interview techniques, and data interpretation of this study (Orb, Eisenhauer, & Wynaden, 2000). Informed consent addresses the participants’ autonomy by providing adequate information regarding the terms of participation and the right to withdraw at any time throughout the study free from penalty (Orb et al., 2000). The informed consent document clearly articulated the following: a statement that the study involves research, an explanation of the study purpose, the expected duration of the participant’s participation, a description of the procedures, a description of potential risks or discomfort, a description of potential benefits for the participant, a statement describing confidentiality, PI contact information, contact information for participants to inquire about a research-related injury or participant rights, information on incentives, and a statement that participation is voluntary (Office for Human Research Protections, 1998).

Potential Benefits of Research Participation

Therapeutic benefits of participating in qualitative research have been reported from parents suffering from perinatal and infant loss, such as emotional relief, a unique opportunity to talk, an opportunity to help others, gaining a better understanding of their own experience, and discovering that somebody else cares about them (Kavanaugh & Hershberger, 2005). Many bereaved parents purport the need for friends to listen to their experiences and allow for them to express their feelings; however, many times there are
barriers in receiving such social support (Kavanaugh & Hershberger, 2005; Kavanaugh, Trier, & Korzec, 2004; Raingruber & Milstein, 2007).

Instruments

Demographic Questionnaire

Parent demographic characteristics including age, gender, relationship to infant, race/ethnicity, educational level, religious affiliation, marital status, household income, number of living children and pregnancies since infant loss, type of infant delivery (multiple vs. single birth), live births since infant loss, and major life events since infant loss were obtained in a 30-item demographic information questionnaire. Infant characteristics such as date of birth, race/ethnicity, diagnosis, name of hospital where infant was born, length of hospitalization at Children’s of Alabama hospital, if applicable, reason for initiating palliative care in the NICU, and the cause, date, and location of infant death were obtained in-person (Appendix C).

Semi-Structured Interview

Semi-structured interviews and field note observations were used to describe parent experiences related to their infant’s NICU hospitalization, EOL care, PC consultation, and parents’ bereavement and coping experiences after the death of their infant (Appendix D). All interviews were conducted by the PI at least 15-months after the death of the infant per Children’s of Alabama hospital policy to minimize parental distress (J. Faught, FNP, personal communication, May 1, 2010). Fourteen interview questions and 12 probes were included in the semi-structured interview for all
participants and an additional five questions and four probes were included for those parents who received PC consultation. The PI asked these questions in a non-judgmental manner and free from guidance or leading in concert with the naturalistic inquiry paradigm. Interviews were conducted with mothers and fathers separately in order to gather data that are free from spousal or partner influence (Rosenblatt, 1995). Based on similar studies, the interviews were estimated to be approximately 1.5–2 hours long (Brooten et al., 2012; Kavanaugh & Hershberger, 2005; Raingruber & Milstein, 2007). The participants determined the length of the interview in order to share their entire experience. These interviews ranged from 24 minutes to 136 minutes with a mean length of 69.3 minutes.

In addition to the data collected by the interview questions, detailed field notes were documented and transcribed after the interview including sights and sounds. A digital recorder was used to record the entire interview verbatim and each interview was saved to a password protected encrypted hard drive. The audio recordings were transcribed verbatim by the PI and verified for accuracy to ensure the trustworthiness of the data (Munhall, 2007). While it is important to transcribe unaltered data, the researcher removed self-identifying information to prevent a breach in confidentiality. Upon completion of the interview, participants received a $25 Visa gift card, a personalized thank you card, and an infant keepsake box for the participant’s personal mementos.
Data Collection Procedures

Parents were given the option to meet in a mutually convenient location or in their home for the interview. The majority \((n=6)\) of the interviews took place in the participants’ homes and two interviews took place in a private area of a restaurant at a location and time selected by the participant. The remaining two participants were married and selected a private office at the wife’s place of employment for the interview location. An attempt to ensure as much privacy as possible was made for the interviews that took place in restaurants by selecting seats in the corner of the room. The PI verified that no one else could hear the participants during the interview and the participants were asked if they felt private enough before starting any research procedure. Because it is imperative that the participant feel comfortable in order to share their experiences openly, the PI engaged in non-research related conversation in an effort to help both the researcher and the participant feel more comfortable. For example, one parent was wearing her work uniform that prompted a discussion about her day at work. Another parent had a pet dog that jumped up next to the PI on the couch and this started a conversation about a mutual love for dogs.

Before starting any research procedures, the PI explained the informed consent document and invited questions from the parent participants, as well as reiterated that the participant had the right to withdraw from the study at any time free from penalty to avoid coercion. Power differential and uncertainty of the interview process have been documented as triggers for psychological distress and were minimized through providing an informative and comprehensive informed consent process (Kavanaugh & Ayres, 1998). Once informed consent was signed, parent and infant demographic information
was then obtained with a demographic questionnaire. Several of the participants verbally clarified some of their responses to the questions on the questionnaire before completing. Parent experiences related to their infant’s NICU hospitalization, end-of-life care, palliative care consultation, and parents’ bereavement and coping experiences after the death of their infant were explored using semi-structured interviews.

The majority of parents did not require probing throughout the interview and the questions flowed naturally. Some of the parents discussed the subsequent interview questions during the first question “Tell me about your baby” for up to one hour. One parent did require extensive probing on most of the interview questions. Most of the parents did become teary at some point during the interview, especially during questions surrounding the time of infant death. Upon completion of the interviews, an incentive of a $25 Visa gift card, personalized thank you note, and infant keepsake box were given to the parent participants. Field notes were documented during the interview, and immediately following the interview in order to capture the sights, sounds, smells, and any other observations that would enrich the interview transcripts.

Data Analysis

Qualitative content analysis was used to analyze the qualitative descriptive data (Krippendorff, 2004; Miles & Huberman, 1994). The PI transcribed each interview and field notes verbatim, including all expletives, behaviors and actions, such as laughter or crying, immediately after completion of each interview in an effort to be immersed in the data. Data were simultaneously collected and analyzed to allow the PI to accommodate new insights and emerging data patterns (Burns & Grove, 2009). The trustworthiness of
the data hinges upon the accuracy of the transcribed content; therefore, the audio-recorded interviews were verified against the transcription to assess for accuracy as soon as possible after interview was complete.

Participants were interviewed until data saturation was noted (Polit & Beck, 2012). No new information was revealed after ten interviews and data saturation was met when redundancy was heard throughout the interviews. Data saturation was determined with a sample size of $N=10$ because of the rich and in-depth interviews and redundancy of common themes throughout each interview (Sandelowski, 1995).

**Data Analysis Procedure**

Data were analyzed by coding each line of the interview transcripts using qualitative content analysis. Codes emerged from the data that represented common themes or ideas central to the experience of parenting a critically-ill infant in the NICU and living with the loss of an infant. The coding process involved capturing common threads of information in an iterative process while staying true to the data. Codes were refined with Dissertation Co-Chair, Dr. Christian, and similar codes were clustered together. Categories were made up of similar codes and categories were grouped together to represent common themes in these data (Miles & Huberman, 1994).

Data are not categorized based on similar words alone, rather, the meaning behind the participants’ experience (Miles & Huberman, 1994). For example, a parent may describe experiences with seeking support from a family or friends, and although the word ‘coping’ may not be evident in their statement, the information could be still
categorized the ‘coping’ category. A component of Krippendorff’s cognitive operations in classifying information guided the process of categorizing data (Krippendorff, 2004).

Krippendorff (2004) contends that units of information are categorically distinct if they are grouped together by having something in common. Therefore, the coder placed units of data that are similar in the same category. Labels of categories were not determined a priori, rather, categories were identified from the data. Descriptive codes represent general concepts that are true to the existing data (Miles & Huberman, 1994). Thus, the end product of data analysis were comprehensive descriptive summaries that accurately reflected the meaning participants attributed to their experiences with EOL and/or PC in the NICU, and subsequent bereavement and coping experiences after infant death (Polit & Beck, 2012; Sandelowski, 2000, 2010).

**Strategies to Ensure Rigor and Trustworthiness of Qualitative Findings**

Standards of trustworthiness in qualitative research are not as cut-and-dry as quantitative criteria, but rather involve criteria proposed by Lincoln and Guba (i.e., credibility, dependability, confirmability, and transferability) (Denzin & Lincoln, 2011; Lincoln & Guba, 1985; Polit & Beck, 2012). Credibility is an overarching goal in qualitative research and refers to the believability and confidence in findings. Member-checking involves confirming the interpreted findings with the participants and is a viable technique for ensuring credibility (Polit & Beck, 2012). All of the participants were contacted for the member-check process; however, some of the parents no longer had working telephone numbers and three participants contacted the PI and completed the member-check process. The study findings were explained to the participants over the
phone and there were no discrepancies noted between the participants’ feedback and the study findings. Dependability is similar to reliability in that study findings may not be considered credible if it is not dependable, and establishing an audit trail of field notes, transcribed interviews, and detailed notes of data analysis is one strategy for ensuring dependability and was incorporated into this research study (Munhall, 2007).

Confirmability involves minimizing research bias and ensuring that the data are accurately reflected in the findings. Reflexivity strategies such as self-reflection were necessary throughout the study to determine researcher biases that may affect the accuracy and confirmability of the study findings. The PI engaged in journaling frequently throughout the data collection and data analysis processes in order to bracket biases that may have affected the trustworthiness of the data. In addition, Dr. Becky Christian, assisted the PI through the data analysis process and confirming the interpretations from the interview transcripts. The PI and Dr. Christian achieved 100% agreement for analytic codes and categories. Transferability refers to including thorough description of data so that findings may be applicable in other settings. Including a thorough description of interview questions, probes, and the interview script is imperative for the findings to be applicable in other settings (Polit & Beck, 2012).
CHAPTER 4

RESULTS

Parent and Infant Background Characteristics

A total of seven mothers and three fathers were recruited for research participation, all of whom were the biological parents to the deceased infant and the majority (n = 6) reported Christianity as their religious affiliation. Nine of the parents lived over an hour away from Children’s hospital throughout their infant’s hospitalization and four parents reported staying at the Ronald McDonald house. Six parents received palliative care consultation while their infant was hospitalized in the NICU. While ten parents participated, two married couples were recruited and interviewed separately; therefore, 10 parents of eight infants participated in this study. The infant dates of death ranged from 2/18/2009 to 9/25/2011 and the lifespan ranged from 1 day to 234 days with a mean age of 97 days. All of the infants died in the NICU at Children’s of Alabama hospital except for one infant who was moved to a private room on another unit at Children’s of Alabama for withdrawal of care. For the majority of infants (n = 6), cause of death was due to congenital anomalies, while prematurity complications accounted for the remaining two infant deaths. At the time of the parent interviews, the average time since infant death (as of August 2014) was 50 months or approximately 4 years.
Parent Demographics

Seven mothers and three fathers participated in this study and the fathers (age range 29 – 43 years; mean age 35 years) were slightly older than the mothers (age range 24 – 41 years; mean age 30 years). The majority of participants were Caucasian (n = 7), married (n = 6), and educated with at least a two-year college degree (n = 7). It is notable that half of the participants reported an annual household income of less than $10,000. See Table 2 for further parent demographic information.

Table 2

*Parent Demographics (N= 10)*

<table>
<thead>
<tr>
<th></th>
<th>Frequencies (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/ Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>African American</td>
<td>3 (30%)</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>High School of GED Equivalent</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Some College</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Two Year College Graduate</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>1 (10%)</td>
</tr>
<tr>
<td><strong>Annual Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>Less than $10,000</td>
<td>5 (50%)</td>
</tr>
<tr>
<td>$20,000 - $40,000</td>
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<td>$40,000 - $60,000</td>
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<tr>
<td>$60,000 - $80,000</td>
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<tr>
<td>$80,000 – $100,000</td>
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</tr>
<tr>
<td>$100,000 - $250,000</td>
<td>1 (10%)</td>
</tr>
<tr>
<td><strong>Current Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single/ Never Married</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Married</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Separated/ Divorced</td>
<td>2 (20%)</td>
</tr>
<tr>
<td><strong>Marital Status at Time of Infant Loss</strong></td>
<td></td>
</tr>
<tr>
<td>Single/ Never Married</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Married</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Separated/ Divorced</td>
<td>1 (10%)</td>
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</tbody>
</table>
Themes

Parent interviews revealed rich data that were analyzed using content analysis methods (Krippendorf, 2004) and resulted in two major themes: ‘Life and Death in the NICU Environment’ and ‘Life after Loss’. Pseudonyms will be used for parents to maintain their anonymity and confidentiality in quotations to illustrate themes. This chapter will focus on the findings from the following research questions: 1) How do bereaved parents describe their experiences related to their infant’s NICU hospitalization, end-of-life, and palliative care consultation? 2) How do parents who experienced infant death in the NICU or following an NICU hospitalization describe their bereavement and coping experiences? Parents’ experiences related to research participation will be reported after the two major themes.

Theme 1 – Life and Death in the NICU Environment

Parenting a critically ill infant in the NICU presented unique challenges for parents in this study. Parents struggled with wanting to do the “normal” things that most parents would have the opportunity to do with their infant such as holding, comforting, and feeding. With these hospitalized infants, parenting was not always easy due to the infant’s critical state and the chaotic NICU environment. At the time of the participants’ hospitalization, Children’s of Alabama NICU was an open-bay unit with only two private rooms. All of the participants talked about how important their parenting experiences were not only while their child was alive, but also surrounding the time of infant death. This theme included the following three categories: (a) The ups and downs of parenting in the NICU, (b) decision-making challenges in the NICU, and (c) parent support.
A. The Ups and Downs of Parenting in the NICU

All participants described the ups and downs of parenting in the NICU. The good times were marked by parents having the opportunity to “be a parent” and make the most of the limited time they had with their infant by creating special memories together. The more difficult experiences were related to barriers to parenting in the NICU such as conflicts between parents and healthcare providers, hardships associated with traveling to the NICU, financial burdens, parents “not being heard by the nurses”, the critical state of the infant, and dealing with the maternal cesarean section aftermath.

Being a parent in the NICU. It was important for participants to have the opportunity to “be a parent” in the NICU regardless of how much the parents could participate in the infant’s care. For example, Lisa discussed how she could be a parent to her son, who was receiving respiratory and cardiac support through Extracorporeal Membrane Oxygenation (ECMO) therapy:

My experiences were just to be there for him to hold his hand, to be there if he were to open his eyes or were to come through or, um, but for the most part I just sat there and watched him and held his hand.

Sarah discussed the importance of doing anything that was “mom-like” and spending as much time as possible with the infant:

She (nurse) let me do anything I could possibly do that was mom-like you know. Anything that was non-nurse she let me handle. That was so exciting to me cause, all, all I could do was touch her hand through there but they let me, um, stay in there as long as I wanted to.

Time spent together between parent and infant was precious and it was important to make the most of the limited time together. Nurses played a critical role in facilitating parent bonding in the stressful NICU environment. Children’s of Alabama NICU is one
of the few hospitals that provide ECMO to the most critically ill patients. Because ECMO patients are unstable and depend on intravenous access to critical medications, it can be challenging to involve parents in the care and move the infant into the parents’ arms. For example, Sally described her parenting experiences with her infant who was on ECMO:

> Probably the most helpful thing for me was the nurses teaching me how I could bond with him. You know, he wasn’t a typical baby that you could pick up and hold and love on. How to start learning how to soothe him and how to be a comfort to him without agitating him. Um, once he came off ECMO they respected my wishes to be able to hold him and spend that time with him even though he was still hooked up to multiple lines and still on the ventilator and those kinds of things. Um, just making sure we could make the most of the time that we had was probably most helpful.

Even for an infant who was not in a critical state such as ECMO, there were unique considerations to parenting. Megan described trying to feel involved in the care of her child who had a tracheostomy and would be categorized as a chronic NICU patient:

> And helping me to learn how to change his diapers and stuff because it was really hard with all of the wires and stuff like that, letting me take his temperature, trying to make me feel involved in taking care of him what I would have normally been doing if he had been at home. And that helped a lot to get through it to be able to know that I’m able to provide some care.

All of the parents discussed their experiences around the time of death. These experiences ranged from a planned withdrawal of care in a private hospital room to being absent for the death because of NICU policy or living a great distance from the NICU. For example, Joseph appeared to be holding back tears when asked “Tell me about your experiences in the hospital near the end of William’s life” and requested that this question and the decision-making questions be asked at a later time in the interview. At that time he started drinking the first of three beers. Before the PI could offer a break, the
participant stated that he wished to continue with the interview “because it was
important,” but that he needed some time before he could address the more difficult
questions. Joseph discussed his experiences with their infant in a planned withdrawal of
care below:

Probably handled that better than anything. I mean they just left us in a room
with our son that had gone away. Um, they said after he’s gone you guys can
bath him, change his clothes, I thought that was so, I was just surprised. You
think someone’s going to come in and try and get him. But yeah, that was an
awful part, I mean holding your baby. I mean holding your baby that is not alive
anymore. That’s tough [teary]. Still tough.

Some of the parents were absent for their infant’s death. For example, Brandon
was unable to be present for the death of his child because several months before he had
raised his voice in the NICU and experienced an altercation with a nurse and was then
escorted out of the NICU by security. From that point on, he could no longer visit the
infant in the NICU without a security officer present. This father was standing outside
the NICU while he knew they were coding his child and only his wife was allowed inside
because there was not a security guard available at that time. Michelle missed the death
of her infant because she and her husband could not find parking and the security officer
at the front entrance of the hospital would not let them leave their car unattended.
Michelle described just missing the death, below:

When we got there, they told us on the day that we were trying to get there before
he passed away and um, I remember the guy in the parking lot or what not. He
wouldn’t let us in, they told us to go up to the front and go up, but he wouldn’t let
us do that, and it costs us very very valuable minutes. I mean like, he was still
warm, it was just like you knew that you had just missed it (infant’s death).

Another mother, Julia, described being unprepared for what to expect after her
infant had died. She was still hospitalized at the birthing hospital in Montgomery when
her infant died at Children’s of Alabama in Birmingham approximately 80 miles away. Even though Julia was still recovering from the delivery and surgery, she made the decision to drive over one hour to Children’s of Alabama in Birmingham to hold her deceased infant with hopes of having some closure. Although Julia wanted to be there to hold her infant, it proved to be too much for her when she realized that her daughter was no longer alive in her arms:

I was there and nobody was telling me that she would probably get cold soon. Because they actually had kept her under the light until I got there, to keep her warm. And when I got her, she was still warm, so you know I’m thinking I’m like my child is alive why did they tell me, you know, that she’s dead. And after that, when I hold her for a little while, like a minute or two, she got really heavy to me she. And she was real cold, that’s what brought me back to life because I’m still looking at the fact that my child is still not dead….And when I snapped out of it, you know, it was a disaster for me. And I could not hold her, I told them, I can’t do it.

**Barriers to parenting in the NICU.** All parents described some kind of barrier to being a parent to their infant in the NICU, including conflicts between parents and healthcare providers (HCPs), hardships associated with traveling to the NICU, financial burdens, parents “not being heard” by the nurses, the critical health state of the infant, and dealing with the maternal cesarean section aftermath.

Conflicts ranged from the style and frequency of communication between parents and HCPs to conflicting stories among members of the health care team. Parents did not always expect good news regarding their infant’s prognosis; however, they did want to hear this bad news in a hopeful and considerate way. As Joseph stated, “it would make me mad when I would get a physician that was just candid and frank and the prognosis is bleak and this is it and you know. That was real unsettling.”
Sometimes there were differences in how often parents wanted to hear a poor prognosis and how frequently the physicians wanted to discuss the plan of care. For example, Megan often disagreed with the physicians’ medical opinions because as she described the situation, the neonatology team reportedly stated that “it was not worth it to keep him in a state like this.” Megan then stated, “I think that’s great that they tell you that, but I don’t feel like at every meeting it should be brought up. I think that I left a lot of those meetings crying.” Megan continued to explain why she felt like she could not withdraw treatment from her infant:

So I didn’t feel like at the time I could just stop (treatment for her infant), that knowing that he was okay as long as he had all that and he wasn’t on life support or anything. He was just getting medicine and stuff. But it was brought up almost every meeting. And it’s really hard to keep having to hear it, it’s not like I forgot.

Although nurses were generally regarded as helpful and supportive in the NICU, nurse-parent communication was also a source of distress for some parents. For example, Sarah spent eight days with her daughter and she reported feeling very close to her. She wanted to bathe and dress her infant even after death. However, Sarah believed that the nurse infringed on her role as the infant’s mother:

When they asked me if I wanted to bathe her or if I wanted to assist in bathing her and dressing her, um, she was a young nurse. It was a Black girl I don’t remember her name. Sweet as she can be, but you could tell she was still new at everything cause she immediately started bathing her. And then, she had already picked out a dress for her. And all the stuff, and it was blue, ok? My child was a girl. I’m sorry [teary] I know that sounds silly [laughing/crying]. At first I said, I just stopped her, Stop it! Do not touch my child. I said “I want to bathe her. I want to dress her. I want to clean her up”.

Many of the parents discussed conflicting stories from doctor-to-doctor, or nurse-to-nurse. For example, Jim and Sally experienced a breakdown in communication over
the weekend when a new physician was covering for their usual HCP team and he wanted to change the plan of care. Another mother, Lisa, received devastating news that her son would not survive through the night. After receiving this news, she left the Ronald McDonald house to visit her son and upon arrival was told contrarily different news that the infant was stable and that she needed to leave because the visiting hours were coming to an end. Lisa described her conflict:

I’d went up, they’d call me at like 11 o’clock at night and I went up there to check on him cause I didn’t, they said he wasn’t gonna make it through the night. So I went up there and I wanted to be by his side just in case. Didn’t want him to be alone. So, I went up there, and she basically said you need to get out of here. Um, we have this, he’s gonna make it, the doctors came and told me that. He’d make it through the night and you need to go home and get some sleep, and stop. She was just very rude. She really didn’t care about my needs or my wants and I just don’t remember her name now, but I just wished that she was better off at the time that I, that I was dealing with that. I was just told my son was not going to make it through the night and here she is kicking me out of the NICU.

Children’s of Alabama NICU provides care to infants who are from the state of Alabama and the region. However, many parents experienced the burdens associated with traveling long distances to visit their child in the NICU and from being isolated from the comfort of family and friends. Often, the time spent together with the infant was restricted because of the parents’ need to travel long distances from home to visit the infant in the hospital. For example, Joseph described his challenges below:

It was pretty routine. We went often, you know. We’d stay the hour they would let you stay or however long and then we would leave and go eat and come back. That was kind of, that was something we didn’t like. We didn’t, it seems like we were coming from so far that maybe they should’ve been a little more accommodating. I know everybody’s got a story but you know, we were driving up three hours and we don’t have that long?

In contrast, Michelle was the only participant who lived in the area close to the hospital although she also described the physical challenges of traveling to visit her son
in the NICU shortly after delivery as, “But as far as actually traveling, this was in 2011 the road was very bumpy on the way to Children’s, so I was in a lot of pain driving.”

Not only was the burden of traveling to and from the NICU challenging, but also paying for hospitalization–related costs and continuing to pay for life outside the NICU was a common challenge for these parents. As Joseph stated, “Bills, still the same amount of bills,” referring to life expenses that continued outside of the NICU. Brandon explained how difficult it was to pay for lodging expenses during the hospitalization. Brandon stated, “You still had to pay something. It was based off of what you made and everything, but sometimes we couldn’t even afford to pay it. We had to wait a couple of weeks to try and get caught up.” Although the Ronald McDonald costs were minimal at approximately $5.00 per night, these parents struggled to pay the fees. For example, Megan, who was married to Brandon, described how the financial burdens have impacted their life long-term after the hospitalization:

Since Matt passed away, when we come home, we didn’t have nowhere to live. ‘Cause we gave up jobs and everything to go up there and be with him. So we ended up staying with family for a while to get back up on our feet. It took a lot, it took about a year for us to get back up on our feet.

In addition to the expenses incurred while their infant was alive, many parents discussed the difficulties associated with expenses related to the healthcare bills after infant death. For example, Michelle explained how difficult it was to receive the phone calls from bill collectors, not only because of financial strain, but because it was an unwelcome reminder of her infant’s death:

And so you know and that was really hard to deal with and people call and, because we didn’t have it (referring to money for payment) and it was just like, well we’re calling, well how’s Cameron doing? Well, by the way he’s passed away and I don’t have $2,000 to give you for extra ambulatory when they moved him from Hospital A to the NICU (at Children’s of Alabama hospital).
Funeral costs were also identified as burdensome. Michelle explained how burial expenses were somewhat unexpected because there were no financial resources available such as life insurance policies. Julia underestimated the actual cost of the funeral and stated, “Because a thousand dollars is a lot on the funeral. And I did not expect a child’s funeral to cost that much money. But I paid $3,000 for the funeral.”

Another major barrier to being a parent in the NICU was “not being heard by the nurses.” For example, Megan described repeatedly telling the nurses that her son was having seizures. Her older child suffered from seizures as an infant and she was aware of how the seizures presented in infants and young children. After multiple attempts at seeking the nurses’ attention, she waited until the nurses were congregated together and asked the group to assess her son. Electroencephalography subsequently revealed over 100 seizures per day. Her husband, Brandon, expressed similar sentiments:

And he was having over 100 and something seizures a day, and that’s another thing they need to, when a parent sits there and tries to tell the nurses that they think their kids are having seizures, not to let it go. And finally, a month goes by and they finally realized that he is having seizures. Nurses need to pay better attention to the parents instead of just [shaking his head].

Similarly, Anna was confused about why the nurses did not respond to her expressed concerns about her infant’s drastic change in appearance. Her infant progressed to septic shock quickly and without warning. When the nurses were questioned about the severe and rapidly progressive swelling (approximately 10 lbs. gained over two days), the nurses dismissed the mother’s concerns. The infant died shortly after the onset of edema from complications of septicemia. Anna described her experiences:

That’s when I asked her about the swollen, he was very swollen then when I went. His face was pushed to the side, like he was just, he was big. And she (nurse) would just like he’s growing and I’m like two days, it’s like 10 pounds, I didn’t get that. He went from being that small [pointed to a picture on the wall] and I
got the last pictures of him, his face was huge, and she just saying that he’d been eating. So, I, I didn’t get that at all.

Because all of the parents in this study had infants who were in a critical condition requiring intensive care, this resulted in barriers to “normal” newborn parenting. For example, Lisa described her infant’s appearance, “Um, the first day I was real groggy and what not. So I got to see him the next day, he was hooked up to all kinds of tubes, it was just really bad looking.” Another mother, Julia, described one of the only times she was able to hold her child but the infant could not tolerate stimulation: “I didn’t get a chance to hold her before. You know, well after I had her, they did let me hold her for a little while, but I couldn’t hold her for long because her oxygen level dropped.”

Most of the mothers in this study described how the recovering from their cesarean section procedure diminished time and the ability to parent their newborn infant. For example, Julia had very little time with her child because the infant was taken to Children’s of Alabama without her consent or acknowledgement. One of the only times Julia held her infant was limited because she was very groggy from the pain medication:

They did give me a chance to go to the NICU at the hospital, you know to see her and so I did get that chance, so, you know, to hold her hand and stuff like that and take pictures, but I was so drugged up I was going to sleep and I was like y’all could have waited to give me this medicine!

B. Decision-Making Challenges in the NICU

Decision-making was a complex process that was mostly guided by the best interest of the infant, the infant’s appearance and cues, and parents hoping to have more time together. In addition, direct and honest information from nurses and physicians, as
well as personal advice were also identified as helpful to parents. Parents made difficult and sometimes life-and-death decisions for their infants while facing judgment and differing opinions from friends and family. Some parents reported feeling left out of the decision-making process. Living with decisions was an oscillating process between feeling at peace with decisions and wrestling with the “what-ifs?”

_Challenges in decision-making._ The decision-making process was often complicated by undue judgment by friends and family or being left out of the decision-making process. Parents struggled with making the best decisions for their infant while facing judgment by friends and family. For example, Julia drove over an hour to Children’s of Alabama to hold her daughter, who had already died. Because it was only one day after delivery, her family thought this would be too difficult for her. As Julia described her experiences:

> And you know, I needed that to get a peace of mind because I had actually, you know, my family tried to get me to make decisions to not go and see her and, you know, I just told them I don’t think that I will not be able to live with myself, you know, because I only got one chance to see her one and that’s when she was born.

One father, Joseph, also discussed how difficult it was making difficult decisions when family placed blame on the parent for the infant’s negative outcome:

> I mean, anything in your life outside of the situation that’s not going good. Family giving you a hard time, putting blame on you. That might be an issue. I think a lot of times in these situations you got a family member that puts the blame on you. You know, you either shouldn’t of had the baby or shouldn’t of been with that person. You know, you don’t need any of that. You need to focus on the positives, not the negatives.
Another mother, Megan, described making decisions for her infant and how her family could not understand how difficult it was for her. She described how trying it was for her to make life and death decisions:

Like, I think they want to, but I think a lot of people want to tell you it would be better just to let him go. But it’s hard to make that decision. I think it’s different when it’s something that come from you. When it’s a child that come from you, you are too close to it to really see. Like I see what they are saying and I understand it, but I’m not connecting with it.

While some parents felt very much engaged in the decision-making process, several parents felt left out. For example, while still hospitalized in the birthing hospital, Julia received a phone call from the NICU at Children’s of Alabama notifying her that there was nothing else the physicians could do for her infant and they needed permission to withdraw care. Making decisions is a central role of a parent of an infant in the NICU, yet this mother was not afforded the opportunity to advocate for her infant, as she described:

I was in my right mind and I really didn’t want my child to suffer anymore and for me I wouldn’t have let them took her to Birmingham (infant was transferred to another city without parental consent). I would’ve let her spend her last hours or days with me….And I felt my parental rights was taken from me because, I knew what the situation was and I was prepared for it. Um, and I would have rather, you know, my child to die with me then to die without me….So I do feel you know, I’m still angry about that today because I shouldn’t have had my parental rights taken from me even though it was fine for her, but I should have been able to make those decisions on my own. So you know I felt like the hospital made the decision for me and I didn’t like that. So to answer that, I’m still upset about, you know, that issue about decisions that they made ‘cause I really didn’t have any to make.
Life and death decisions. A common thread throughout the parents’ decision-making experience was making life and death decisions for the hospitalized infant and living with their decisions. Two parents made the decision to plan for a withdrawal of care. Most parents did make the final decision to stop active resuscitation, or an active code, for their infant. For example, Megan discussed being present at the code while the nurses provided CPR to the infant and how she came to this decision:

The nurses helped me understand because they were doing CPR sometimes it would blip that he was coming back and he wasn’t. It’s a glitch from the computers when they’re doing CPR. That was hard. And so I just told them to stop and let him go.

Some of the parents that decided to withdraw care during an active code discussed how they were incapable of making the decision to plan a withdrawal of care stating, “I couldn’t do that to my child.” Brandon and Megan described not being able to make the decision to withdraw care from their infant:

(Megan) And it’s like, the day he passed away, I prayed the night before, I’m not real religious, but I’ve been in church all my life. I prayed about it and I was like I can’t make this decision, I just can’t. Next day I didn’t have to. It happened on it’s own. And I was relieved.

(Brandon) I just knew that I couldn’t bring myself to do it [make decision to withdraw care], and I just, I wouldn’t. I wanted to give him every fighting chance. I mean, I just told myself I couldn’t do it to my son, to one of my kids.

What guided decision-making. Parents identified numerous factors that influenced and affected their decisions. The perceived best interest of their infant was the most common influence on decisions. Other factors included cues from the infant and hoping for more time together. In addition, upfront and honest information was crucial to helping parents make informed decisions. Two of the parents reported that personal
advice from nurses and physicians was influential when making decisions. All of the parents who were afforded the opportunity to be engaged in the decision-making process described making decisions based on the best interest of their child. For example, Lisa described “letting her baby go” to avoid suffering:

We either, he was now bleeding internally. So we had to either, A, let him be brain dead and all that kind of stuff, bleeding internally until he finally went, or we were to pull the plug on him and go peacefully. So that’s what we did. We let him go peacefully.

Another mother, Megan, depended on her infant’s cues. She felt as if she could tell when he wanted to fight for his life and when he was ready to go, based on his interactions with her:

And then, maybe some of the other decisions were just based off how I felt about Matt and how I felt about how well he would do with something. Like, you know, I was asking why I didn’t, why did I think he would pull through when the doctors were telling me he wouldn’t, and I said well when you look at him and you see how he looks at you and I can’t explain it, you know when a baby’s sick and when they are giving, you know when someone is giving up….So he would make that sound, and I’d go look at him and he’d stop and I’d walk away and he’d make it again. So, it was something he had learned on his own to get attention. So to me that felt like, well he wants to be here.

Often times, parents made decisions that resulted in more time together regardless of the infant’s condition or prognosis. For example, Sally described her requests to the surgery team for maintaining ECMO treatment after the recommended time frame had elapsed:

We’re watching him, and I just remember leaving every time the surgeons wanted to take him off (of ECMO), he is alive right now, let’s please just give him more time, or let’s just do this. So I’m thinking any decisions that we made were advocating for him and his life.

The majority of parents discussed the importance of upfront and honest information sharing from nurses and physicians so that parents could make informed decisions. One father, Jim, discussed how helpful the healthcare team was:
Everyone was pretty much upfront and honest with what was going on and you could tell they really wanted to help and they were doing everything they could, you know, to try and help us and give us as much information as they had and try to put it in a form that we could understand.

Family presence was also considered supportive. Lisa described how helpful it was for the father of the infant and the infant’s paternal grandmother to be present when making difficult decisions to “back her up,”

Having his (infant’s paternal grandmother) mom there, him (infant father), just somebody being the extra word for me, like, I was not sure what I was going to do, what I was going to say, and they were like this is tough, I’ll help you through it.

Furthermore, nurses and physicians offered two parents personal advice when making critical decisions. Joseph discussed the last days of treatment with the neonatologist who described the severity of pain the infant was experiencing and explained that he had recently lost his mother and he discussed how he made decisions for her. Sally became close friends with a nurse who shared her personal opinions:

I mean, I remember one of the nurses, you know, talking hypothetically. So I knew the DNR (Do Not Resuscitate) talk was probably coming at some point because she was talking about, if it was her children, you know, she would probably, she would have a difficult time taking them off the ventilator, but could probably make that decision to be a DNR.

Another mother, Megan, discussed how her past experiences facing impossible odds affected her decision-making related to her infant. Because another child had survived a poor prognosis at birth, Megan developed distrust towards the physicians’ medical opinions:

I’ve already got a child I made it through impossible odds. I was told she’d never lived to see her first birthday. She’s nine years old this year and they told me she’d never live and she did. So with me it was kind of hard to be told your kid’s not going to make it….but the doctors were wrong before. How do I know you’re
right this time? If I had listened to y’all before maybe I would’ve let something happen to my daughter and, you know, that’d be on my conscience.

Living with decisions. All parents except for Anna and Julia described the experience of living day-to-day with the decisions they made during the infant’s hospitalization. While many parents described being at peace with decisions and making the best decisions given the information they had available, the same parents described wrestling with decisions and wondering what the outcomes would have been if they made different decisions. For example, Jim and Sally were married and they both described the most “ideal hospital experience” compared to the other parents in the study. There was an immense sense of trust between the parents and the healthcare team. Sally described how being part of the decision-making process has helped her with the coping process:

I think the open and honest format of communication at Children’s NICU really helped us. Feeling like we were an integral part of this team in the decision-making process for his care that we actually got to be parents there. It wasn’t somebody else calling all the shots helped, you know, helped us to be okay. We did what we could, we tried everything, you know, we needed to try really kind of, I mean, helped us in the coping process.

Paradoxically, parents commonly “wrestled with decisions” while simultaneously feeling “at peace”. From one sentence to the next, parents would state they were at peace with decisions, but wondered “what if?” Sally described how her career in palliative and hospice care changed her perspective on the decisions surrounding her infant’s death:

Obviously, working in palliative care and hospice now I can recognize a lot more of the signs that Timothy had and while I knew we did everything we could for him with the information we had, knowing the outcome that, um, his death was not a peaceful transition. It was not a calm serene environment. Jim was not there, I mean, there’s, you know, you just wonder, Or I just wonder if it, um, well it could’ve been different. We could’ve planned it differently, we could’ve done things differently.
Another father, Joseph, decided to withdraw care and he reported feeling angry and living with regret over his decisions:

If I really think about it [pause], I may be a little more angry about it now. And you asked that question about it, earlier on if I would do anything about it different in retrospect. I might not have agreed to let him go. It’s just now I don’t have him, before had I had him at least a little bit. So if I could go back in time I wouldn’t have made the deal. Even if it was the right thing to do. You know sometimes a person gets pushed so hard they don’t care about the right thing.

C. Parent Support

All parents described receiving some type of support during the NICU hospitalization from a variety of sources, such as nursing support, religion and prayer, other NICU families, helpful and unhelpful family support, as well as from palliative care as an additional layer of support in the NICU.

Nurse support in the NICU. All parents reported nurses as a lifeline of communication while the parents were present in the NICU and through their phone communications when they were outside of the NICU. Nurses supported parents through open communication, being a comforting presence, preparing for the infant’s death, caring for the whole family, and providing consistent communication.

For example, open communication with good or bad news was important to Joseph:

I think it helps to have consistent communication between the hospital and the patient and to the patient’s family. Even if it’s not good news, like I said earlier, just to have the communication it feels like somebody cares, keeps you from doing something crazy.
Informative nurses were seen as helpful with updating parents on what was going on with the infant while parents were at the bedside. Lisa described her experiences:

Um, some of the nurses were very helpful in telling me how to react with my son, um, what they were doing, you know, every hour he had to have this medicine, every hour he had to have that medicine. They were very informative.

Communication was essential to parents feeling involved in the care of their infant because nine of the ten parents lived at least an hour away from the NICU. In addition, three parents reported nurses as a comforting presence when visiting their child. For example, Sally described her friendship with the nurses: “And then just the friendship and the camaraderie that came with being with the nurses 16 and 18 and 20 hours a day for weeks on end was a comfort.”

Nurses played a central role in preparing parents for the death of their infant by helping to create memories and educating parents on what to expect. For example, Sally described preparing to remove her infant son from ECMO:

We’re getting ready to come off ECMO, so we had a Timothy day. We did footprints. We, I think Amanda painted his toenails – that was her specialty. Um, we had just all the different nurses that I had, you know, then but that’s for almost two months. We just kind of had a party that day.

Not only did nurses care for the infant, but they cared for the family members as well. It was important for nurses to recognize the needs of the parents and other family members at the bedside. Another mother, Megan, discussed how the nurses helped you to take care of yourself:

They were really helpful and then they don’t let you forget to take care of yourself, Like Miss Megan, it might be time for you to go home, you’re nodding off over here [laughing]. You know you can come back as soon as you wake up we’ll still be here. So, they make sure I wasn’t like passing out, and make sure did you go eat yet, ‘cause we tend to forget those things and when we’re sitting there [laughing].
Consistent communication and consistent nurse assignments were also considered to be helpful. One father, Jim, described how appreciative he was of their “main” nurses:

I would have to really give a big thank you to the nurses that we had several that were, uh, three to, four, to five, somewhere in there that were kind of assigned to him that we had on a daily basis.

On the contrary, it is important to note that not all parents were given the opportunity to have consistent nurses. The parents who did not receive consistent nurse assignments made a point to discuss this. Parents suggested that consistent nurse assignments would increase the quality of care their infant would receive because the nurse would be more familiar with the infant’s personality and medical circumstances. Moreover, some parents felt a more consistent nursing staff would minimize parent-nurse conflicts.

Religion and prayer as a source of support. Religion and prayer were considered supportive whether it was on an individual basis, with a church pastor, or with the hospital chaplain. Julia described her session with the hospital Chaplain after her infant had died in the NICU:

So, after that, they um, we had like a little, like session before they brought the baby in, and they talked to me, you know, they brought in a Chaplain, and they prayed, and they told me everything that happened before I got there, you know, what all work that they did to her while she was there.

While most of the parents (n= 7) described the supportive nature of religious faith and prayer during the trying times of the NICU hospitalization, one mother (Michelle) was unable to bring her pastors to the hospital to pray for her child in the NICU. Because Michelle was the worship leader at a Non-Denominational Charismatic Christian church, it was distressing to her that she was not allowed to bring her pastors to the NICU:
I do remember that with that said, we are from a Non denomination Charismatic church. Well, our pastors couldn’t come and that was really disturbing because we believe in like the full gospel, like laying on of hands, and it was disturbing, very, very disturbing that they couldn’t come.

**NICU families as support.** Several parents explained how other families in the NICU were a great source of support for them because they understood what they were going through. These families provided supportive friendship that many times extended beyond the hospitalization. One father, Brandon, discussed his relationship with other NICU families:

Just getting to know several families down there, just getting to know some of the parents and everything. You see cause there was one family down there, their daughter had sort of some things like Matt did. With the bilateral cleft lip and palate and stuff, and we was talking to them all the time about how Matt and everything about surgery and everything. That was, we just talked about our kids and stuff like that and everything. We got real close to some of them down there. We just, it was helpful to have people to talk to you while you were down there and everything and not just be thinking about your kids all the time, and not worrying that something’s going to happen.

**Family and friends.** The majority of parents described family and friends as a supportive presence in the NICU and with life outside the NICU. Jim described “placing people around you, knowing they are going to be that support that you need” as a way of seeking support. Given the chaotic NICU environment with alarms sounding off and the constantly changing state of the infant, caring for critically ill infants in the NICU was stressful on a day-to-day basis. Additionally, life outside of the NICU continued with daily hassles and life stressors.
For example, Megan described how critical her family support was:

My mom took care of my daughter. Between my mom and my mamaw, they took care of my daughter Stacey because she was young and everything. She lived with them and went to school. They made sure she got to school, brought her up to see her brother.

Because life in the NICU could be stressful and isolating, friends and family provided healthy distractions from solely focusing on the infant. Sally was grateful for her friends:

I had a friend who would try to come at least once a week, or every other week, and literally drag me out of the hospital because there was a, between, at shift change in afternoon there was a three-hour time and afternoon in the NICU was closed. So she would literally drag me out of the hospital and take me just somewhere away from the hospital.

Ineffective Family Support. The majority of parents described some type of ineffective family support, such as an absent spouse or lack of helpful family involvement. Spouses were absent during the NICU hospitalization because some of the fathers went back to work to maintain insurance health benefits and financial revenue. The father of Lisa’s child was not available to support her in the NICU as she stated: “John, he was, he was the dad, we were dating at the time. Um, one of the experiences that was not good was the fact that he had left me. He (father of infant) couldn’t deal with the stress.” Although Joseph’s spouse was physically present throughout the hospitalization, she could not provide any emotional support as he described, “Emma was awful for me, she was awful. She was not there for me at all.”

One of the most extreme examples of ineffective family support occurred as a result of NICU policies enforced by the nursing staff. Megan was alone in the NICU for the majority of the last three months of her infant son’s life because of an altercation between her husband, Brandon, and the nursing staff in the NICU that prevented him
from being present in the NICU. After this incident, he was only allowed in the NICU for 30 minutes at a time when a security office was available to escort him. Brandon’s absence was particularly difficult for Megan because he was forced to wait outside the NICU for her during visiting hours. Thus, Brandon could have had much more time with his son than he was allowed. This policy was not altered when the infant coded Megan was at her child’s bedside alone while the Brandon stood outside the NICU doors although they let him in the NICU after the infant had died. For example, Megan described her experiences below:

Um, I think the only bad experience was not really being able to have Brandon with me. I feel like maybe since, it was so bad [crying] and they (medical team) knew how bad it was that maybe they should have let up (lifted the policy on banning father from NICU). He got to walk in but it was after it had done happened. He missed it (referring to missing infant death).

In addition to absent spouses, absent parents (infant grandparents) was also unhelpful. Megan described how her father never met her son because of his poor prognosis and it was unlikely the infant would survive outside of the hospital,

I was really upset, my dad felt like since Matt was in a situation he was in that he couldn’t live through getting attached to him and losing him. So he (infant’s grandfather) never met him. And that was hard [teary].

Not only was the absence of spouses and family difficult for parents, two of the parents reported family involvement that was harmful. Brandon and Megan collected donations in their community to help pay for their Ronald McDonald expenses and their family stole the money out of collection jars before the parents could use it. Brandon described his family as unhelpful, “We had took up money for Matt while we stayed at the hospital and family members take it before you get to get it and everything.”
Palliative care – An added layer of support. Six of the ten parents received PC consultation during their child’s NICU hospitalization. Four parents were unaware of what PC was before their child’s hospitalization. One parent was familiar with PC, but associated it with hospice, and another parent was aware of the implications for PC beyond hospice and for management of symptoms associated with chronic illness.

Although all parents who received PC would recommend this service to other parents, none of the PC consultations were parent initiated – all were nurse or physician initiated. Palliative care was negatively associated with “giving up” and losing hope of aggressive, curative treatment. For example, Sally explained her feelings about starting palliative care:

I was not receptive to the palliative care consult once I came in because I heard of palliative care and I thought hospice and, you know, we’re still fighting…. So when I heard palliative care, I heard hospice, I knew we were teetering on the edge of life. Instead of looking at the positives that it could do, I was just looking at, you know, I’m not ready to transition to that. We’re still fighting, I still want aggressive care. I want these things.

Although most parents were initially resistant to PC consultation in the NICU, after these services were provided, all of the parents explained how beneficial they were as an added layer of support. Megan described using PC as a “sounding board” because she felt safe asking questions in privacy:

Really understanding, didn’t judge…always made sure we had privacy so we didn’t have to worry about other people hearing my thoughts on things unless I wanted them to hear them [laughing]. Sort of like a sounding board to sound off what I wanted to, like, I had stuff I wanted to tell the doctors and I’d sound it off on them first and ask them, you know, is this coming off wrong because this is what I’m trying to say and they’d help me with it.

Husband and wife, Jim and Sally, explained that they were unaware of PC involvement in their son’s case and that they worked “behind the scenes” to foster memories and respect
the parents’ wishes for the time together with their child. Sally elaborated on her experiences:

So they, the nurses, were able to tell that my wishes and, you know, wanting to hold him wanting to do as many typical things as I could with him…being able to spend as much time with him as I said. And the palliative care team worked to make that happen behind the scenes since I was not willing to let them do it in front of me.

Jim felt as if there was another advocate for their child by including PC:

Um. I think they were actually coming around before we got those results. And they were just kind of following the case and making sure, you know, they were making sure the patient was being taken care of. They were an advocate for the patient, you know when you have someone that, whether it be an infant or an adult it’s good to have someone kind of overviewing looking at the case, making sure i’s are being dotted and t’s are being crossed.

Similarly, Joseph appreciated the additional communication from the PC team:

I liked it. Like I said I like, I loved being informed. I love someone taking the time to call me or you know talk to me about it. Loved it. It gave me comfort because regardless of the bleak prognosis, um, it was usually, unless it was fatal, Unless they’re calling you to tell you that this is it, other than that the prognosis.

Theme 2 – Life after Loss

The loss of their infant was a profound tragedy in all of these participants’ lives. Some of the parents did become emotional at different points during the interview, but they refused the opportunity to stop and take a break because they enjoyed talking about their infant even if they became emotional. Living with the loss of an infant was an immense challenge for parents and grief was described as a process that evolved over time. While many of the parents were able to function and continue with their daily lives, they described grief as “always being there”. Some of the challenges parents discussed were physical and mental health changes, spiritual suffering, and feeling the deceased
infant’s presence. Parents also reported feeling as if infant death was a unique type of
grief that could not be compared to other losses. All parents described the challenges of
coping with grief as a process that continually evolved over time.

A. Living with Loss

Bereavement and grief over time. It was clear that there were long standing
ramifications related to the death of their infant for all of these families. For example,
Joseph explained how grief still affected his family at the time of study participation,
“But yeah, the death, the leaving of William. It had ramifications that I still feel today
and my family. Still, over three years later. Almost three years.” Throughout her
interview, Sarah discussed how grief changed and was processed over time:

Each year’s been different. The first year was still kind of in shock. You know, I
was just trying to at that time, I really still wanted to be with her dad and by the
end of that year I was done with him. By, what would have been her first
birthday, I didn’t know what to feel. By the time her second birthday rolled
around, I was a mess. It was like the shock had worn off and I would have
moments, I still have them, every once in a while, but then they were frequent.

Infant death was a life changing tragedy for these parents and the grief associated with
their infant intensified near challenging grief days like the birthdays, anniversaries, and
holidays. As Lisa stated, “he’s always there, but he’s not on my mind all the time, so that
helps.” While parents revealed how the pain from grieving the loss of their child never
went away completely, the painful emotions associated with loss were more tolerable
over time. Sarah discussed how the pain never goes away:

So, I’ve had to do a lot of adjusting, um, lots of anger and, you know, I just break
down sometimes, but I feel like I’m, each year it gets a little bit better. Um, the
pain never goes away. But, it eases, it’s, you know.

Two of the mothers discussed physical health changes such as becoming
overweight. Michelle discussed how her weight gain affected her ability to be physically
active: “but I just couldn’t do anything. I think I was so big, I remember I couldn’t get off the floor.”

Mental health changes ranged from being moody on hard grief days to suicide attempts. Lisa described her mental health changes after the death of her child:

I was in and out of the hospital for depression and suicide attempts, but after, I got on some good medications, doctors put me on. Some Abilify and they put me on something for OCD called Prozac because I ended up getting OCD after he was born. Um, so, I’m on my medication every day. Um, I take it faithfully so that nothing does happen emotionally.

Additionally, Lisa reported feeling out of control and worthless after the death of her infant:

There were times when I would be so upset that I would feel, I wouldn’t feel in control of my life or my, my actions. That scared me. I would get so upset and I would just be crying and, I really wanted just to die. I mean, it was just like, why am I here? I can’t, I couldn’t do anything right. I don’t give birth to healthy babies.

Some of these mental health changes precluded parents from functioning in their day-to-day lives. Michelle could not return to work for over a year after her infant died because she did not feel mentally “sharp enough”. Brandon described consistent intrusive thoughts about his deceased infant that affected his ability to focus on anything in life besides his child: “I had to be put on medicine because [sniffle] I think about him all the time and it’s hard to control your thoughts with what you’re doing when you got your mind on your little boy that’s passed away.” Megan described how difficult it has been for her husband, Brandon, who lost his job and now receives disability support because of severe depression and long-standing grief symptoms that affect his functionality,
My husband’s on disability now and that’s (referring to being banned from the NICU) part of it. He’s in counseling and he’s severely depressed. [crying] He can’t deal with the fact that we lost Matt and he wasn’t there for him. He feels like he let him down. And um, it’s caused a lot of trouble between us because I was there and he wasn’t. And he feels like he can’t be a good father to our kids because he wasn’t there for him and it’s, he’s on a lot of anti-depressants and stuff.

At over four years after the loss of her infant, Julia was still unable to sleep at night due to reported paranoia, and this resulted in the inability to keep a job and forced her relocate to government-funded housing. She lived alone and had minimal interaction with the outside world. Julia described how she was unable to leave her home and her change in job status below:

Employment wise, you know, I did, I couldn’t function as much as I wanted because I wasn’t sleeping. So my first job, that was a job that I was working before I went on maternity leave. I um, I didn’t keep that job because I wasn’t able to function. And it was in office administration job where you needed to be alert daily. So that job I did, I lost that job….I don’t even come out the house. I barely go outside. I’m actually in my house all day, all day and all night unless I have to go to the doctor or my mom, you know, she’ll come and get me just so I won’t be here.

Parents encountered spiritual suffering when trying to make sense of the loss asking, “Why God? Why me?” Michelle was a devout Charismatic Christian and did not understand why she had lost her infant because “she had done everything right spiritually.” Sarah fostered anger towards other mothers who had children and did not take care of them properly and she asked herself, “I don’t know why, I lost my child, or why I was chosen to be her mom. But, I was. So, that’s the one thing that I still question is like why me? Because that’s hard to deal with.” Parents also questioned their faith when coping with grief. Lisa described her spiritual suffering:
To where two years ago right after the death, it was more or less, why? Why did you take him? Very angry at God. I lost my religion, stopped going to church for a while. I ended up getting into church though, but, at the time, at now, the time it’s a lot easier to deal with it. Um, but I felt like I lost God completely, I felt like he wasn’t on my side, he wasn’t there for me.

Two of the parents discussed feeling the infant’s presence after the death. Julia was bothered by the persistent infant presence:

But I’m paranoid, I hear things, you know. And I don’t think that, you know, I think that is normal especially until they get to the point where, you know, I just completely out of it but, you know, but. I’m in my, you know, my right mind daily. It’s just sometimes at night, it’s like I hear her crying. And you know, that bothers me.

Brandon also described feeling the presence of his deceased infant at the gravesite:

It’s like the night that we buried him, I stayed out there the whole night and we always had a little TY beanie baby cat in the crib with him, and the night that we buried him, I was sitting out there, and all of a sudden this little cat came up and jumped in the back of the trunk. And I said well, Matt knows I’m here.

*Life changes after loss.* Almost all (*n* = 9) of the parents did experience major life changes after the loss of their infant, ranging from the birth of children to a change in career. Eight of the parents had another child after the loss of their infant and described how other children bring meaning and purpose to their lives and how it created more of a reason to live.

Jim and Sally both changed careers because of their hospitalization experiences and living with the loss of their child. Jim described how his experiences in the NICU led him to become a nurse:

Well, in 2010, I quit a full-time job, went back to school and got a degree in nursing….So I would say my experiences at Children’s Hospital, and the people we are involved with, kind of led me back to nursing.
Sally described how her loss led her to a career in hospice social work:

So after that, I went back to work (after infant death) and I still enjoyed my work, but there was not the same level of satisfaction and there was a lot of things that, bothered me more after having a child than I had noticed prior to having Timothy….So, it um, didn’t feel like a match that anymore. I stayed on the year making sure it wasn’t just the grief, it wasn’t just my experience, it wasn’t something I just needed to work through. Um, and then the hospice door opened. And it felt like a very good fit.

While these changes in careers have led to rewarding life paths, some parents have lost their jobs after the infant died. It should be noted that Jim and Sally reported an ideal NICU experience with an excellent support network during the hospitalization and after infant death. However, many other parents in this study recounted bad memories from the NICU that made the grieving process more difficult.

Life perspective and personal growth after loss. The majority of parents reported personal growth after the loss of their infant. Anna described her growth, “I think I matured a little bit. Became more stronger. Um, always have loved kids, so it made me love them even more.” Two of the parents explained how they became closer to God and grew spiritually after the loss of their infant. Michelle described how she spent her time grieving, “I wrote songs and spent a lot of time in prayer and meditation, and as a result I just grew, I grew a lot spiritually.”

Some of the same parents who reported personal growth also reported feelings of fear for future pregnancies because of the trauma of losing a child so early in life and unexpectedly. Julia described conflicted feelings about her fear for future childbearing:

And it’s been four years for me and at this point I’m not looking to have any children. And it’s mostly because I’m afraid. And not just because I don’t think that you know I’ll be a good parent, or not financially stable, or whatever. It’s
just I don’t know how I would accept being pregnant again. And it’s a mental thing, you know. It’s emotional to but it’s mostly mental, just thinking of what could happen and what couldn’t happen.

Parents (n= 4) who had children after the death of their infant described changing their perspectives on parenting with other children and future children. Parents reported changing safety practices and appreciating the time and milestones they spend with the children. For example, Michelle described changes in her precautions during her second pregnancy:

I will say with the second baby, I was very very cautious you know, [laughing], I made sure that all the water was filtered and you know, we probably went overboard with it, but I will say that it did have a reflection, like everything was like very very clean. But you know you are just over protective, and as a result he is very spoiled.

Two of the parents described the challenges associated with introducing themselves to new people after the loss of their infant. For example, Sarah described a common encounter that results in distress:

And, that has been a big deal for me to say, people say do you have any children? ‘Cause you dread that question…somebody meets you for the first time. Oh do you have kids? Well, I did, but she passed away 5 years ago, Oh I’m sorry and then it’s just like this whole thing you have to go no, it’s ok, it’s ok, that’s my angel and, go through that whole spiel…there have been times that I’ve said no because I didn’t want to have to deal with it.

Parents described grieving the loss of their infant as a unique type of loss that could not be compared to other losses, especially miscarriage. Sarah described how she considered herself to be in a unique category of loss:

You know, people who miscarry, um, I don’t consider myself in that same category. You know, they might, but I don’t because, I mean, she was, I was 29½ weeks, she was kicking, she loved Christmas, you know. I got to hold her. She opened her eyes all, you know all of those things that they don’t experience. I did, so, even though she was only here eight days, you know I’ve had that
comment, well, I’ve had my child and my child passed away at 6 years old. Mine passed away at 8 days, I can’t experience that because I wasn’t there for the past 6 years of their life, but this is what my experience was. So I don’t know, I’ve met a lot of different types of people and there, people lump us all into one category and I’m like no, [laugh], it’s not the same, it’s not the same at all.

Joseph also described his loss as unique:

   It was probably different than losing your, you know, your 16-year-old kid, um, but it’s also different then losing, you know, a baby in the womb. You know. I, this is a baby that we held and fed and kissed. It was tough. It was tough.

B. Coping with Grief Over Time

   Barriers to coping with loss. All parents described some type of barrier to coping with the loss of their infant, including: dealing with multiple losses, well-intended, but hurtful communication from friends and family, nosy people, encountering spousal and family grief differences, avoiding professional counseling, family members who are unable to understand, unhelpful chaplains, loss-focused behaviors, and unanswered questions about the life and death of their infant.

   Over half of the parents experienced multiple losses during the pregnancy and when grieving the loss of their infant. For example, Megan miscarried after the loss of her infant son in the NICU. In addition to more recent losses, Julia discussed the challenges of visiting her infant’s gravesite because her father is buried near the infant’s grave:

   I won’t even go now. Like for her birthday, I didn’t even go. And the first two years I was there, you know, every two or three weeks, I would go change flowers, do you know, and stuff like that. And it was even more emotional for me to go there because my daughter is buried at the feet of my daddy’s grave. So, I’m there for the both of them, so it’s real emotional for me.
Managing multiple losses was not limited to the death of a loved one. Three parents reported the end of a significant relationship as a painful loss. Sarah stated throughout her interview how difficult it was to be alone during her pregnancy, NICU hospitalization, and living with her grief. Throughout her interview she stated “that was the one thing that would have made me feel complete” referring to the longing for the infant’s father to be a presence in her life.

Six of the parents described some type of support and communication that was meant to be helpful although it ended up being hurtful and damaging to the parents. While this was considered a barrier, parents seemed to understand that sometimes people do not know what to say in these sensitive situations and they do the best they can. Jim described communication that was hurtful:

Well yeah, you got people, what really, and it still irritates me to this day when people say “I know how you feel” because they don’t. Um. Every case is different. You know, I don’t. I’ve lost a child, but I can in no way tell someone he was losing a child or is lost a child how you feel, because I don’t. So that’s a big, not just with children and anything, that’s a phrase I’m not a big fan of [laughing]. Because nobody knows really and truly what anyone is thinking or how they’re feeling. You know, you can offer support, but, don’t use the phrase “I know how you’re feeling.”

Sarah explained how she became angry with individuals who did not know how to communicate with her in a sensitive way and in an effort to “move on,” she reported distancing herself from these hurtful people:

There were some people I had to distance myself from just because, [laugh] most people don’t know what to say. They feel at a loss for words and then there’s those that think they know what to say and half the time they don’t and those were the people I had to distance myself from, because was just like, yea, I ended up getting angry with them. I need to move on so I just stayed away from those people. And you find out really fast who those people are.
Along the same lines of unhelpful support, parents described intrusive people as hurtful when coping, especially when parents could not discern between true concern for their family or wanting to gain information to gossip. Brandon explained how nosy people were unhelpful when grieving, “People that just keep, going on asking questions, and people putting their nose where it don’t belong.”

Half of the parents reported grieving differently from their spouses and their families. Julia found it difficult to talk about her infant after she died because her mother and sisters would become very emotional and “break down.” Moreover, Julia’s family assumed she was grieving at the same time they were, but she reported she did not grieve the loss of her child until years after. Deciding to participate in the interview triggered a self-awareness that she needed to confront her loss and cope with her grief. Joseph described some major grief differences between his spouse and himself at their son’s funeral:

She didn’t care even at the funeral. Nothing. I’m sitting at the casket, I’ve got my head buried in the casket just crying and nobody’s coming around me, nobody’s letting, my guys weren’t going to let anybody come and mess with me, you know. And I remember getting up and standing up and turning around and seeing her through the crowd laughing at a joke. I’m not saying, I mean I know it hurt her, but just that kind of different way of grieving and handling it. You know for her, she needed to not think about it. For me, I just I couldn’t help it.

Michelle also described how her spouse’s way of grieving differed from her own and that he was incapable of giving the support she needed:

My husband didn’t heal the way, or men sometimes aren’t vocal, so that was a little strange. I think I expected more from him, but where I kind of wanted to talk about everything, he was just like, I don’t wanna. I think he took it as more of a failure more than ohhhhh, the baby’s in heaven, like no. So, I feel like that maybe, I won’t say it was a hindrance, but I think I was expecting more support from him, but I think he was incapable of giving that support.
Parents also reported the difficulties of watching other family members grieve, including siblings of the deceased infant. Megan explained how difficult it was to watch her child grieve the loss of her infant brother:

And um, had to deal with my daughter, um, not you know she understood he was gone, but it’s been hard for her. She don’t understand why, um, how it happened, and why he’s gone. And she was worried that God was going to take her next. And that was really hard for me to hear [crying].

Only one parent received professional counseling and this was ordered as part of his obtaining disability support for grief and depression related to the infant death.

However, three parents reported the need to speak to a counselor to help effectively cope with grief, and regretted not seeking professional support. Michelle was a devout Charismatic Christian and was employed full-time as the worship leader at her church. She explained her need for professional counseling:

I would tell anyone you can pray all day, you still have the brain that is in your natural body here and you need some keys or someone to sit there and talk to you and explain to you. The pamphlet was great, they send cards afterwards, but I needed psychiatric counseling….So yea, there needs to be some like clinical, because I couldn’t imagine if someone didn’t have a strong faith or some type of like community network, like I was on the dark side, it was not, it was a life time movie probably will be one! [laughing].

While hospital Chaplains were considered a source of support to some during the hospitalization, chaplains were not considered helpful with the support of the infant death if there was no connection with the parent. Sarah explained this dilemma:

They sent the chaplain in there who I was not very nice to. I didn’t want anybody but Father Michael. I, I was trying, I didn’t feel like, I know he was doing his job, but I did not, because I was not used to him. I didn’t feel a connection to him at all so it was like he was trying to comfort me and I was like who the hell are you? I don’t even know your name? I’m not listening to anything you are telling me, you could try and comfort me all you want to but I don’t like you. That’s, that was my
immediate thought was that you don’t even know my name and you are trying to make me feel better?

While family support was crucial to parents when coping with this loss, there was a limit to how much family could understand and therefore knowingly comfort the bereaved parent. Julia described how her mother and grandmother tried to comfort her:

And it was getting very emotional being there with her because, you know, she would try really, you know, she would think that what she was doing is helping me. But she really can’t comfort me because she has never been put in that situation. And you know a lot of my family members they’re not able to comfort me, they don’t know what to say. Simply because they still have all their children. And you know, my grandmamma, She can’t even help me because she still has all her children. You know they lost, you know, a family member too. But it’s different when it’s your child.

It was inevitable that during the coping process parents underwent some type of loss-focused behavior; however, if these behaviors occurred “all the time” then it interfered with their coping ability. Anna explained how these loss-focused behaviors were detrimental to her, “Probably would be looking at the picture book (baby book) all the time. Not helpful at all.” Furthermore, Sally discussed how “grieving can be quite exhausting” when focusing on loss-focused behaviors. Sarah explained how she limited how frequently she looked through her infant’s memory box:

I still have her memory box, um, I made a decision to only get her things out maybe twice a year. Cause it’s real emotional for me. Not so much to the point where I’m sad, it’s just it takes a lot out of me.

Two of the parents explained that they still do not understand what really happened and what caused their infant’s death. The death certificate listed the medical cause of death as heart failure. However, the contributing factors related to the infant’s ongoing medical conditions were not included or discussed. Thus, parents reported misunderstandings related to what they had been told in the hospital and what was listed
as the cause of death on the death certificate. Anna was confused because the death
certificate presented new information that was not previously discussed. Julia was
similarly confused regarding the details of her daughter’s death:

Because I still, you know, I still don’t really know the full details on, you know,
everything that happened because she had a heart attack and they did not tell me
that. The only way I knew that was from the death certificate.

Further, Julia was left with many questions related to the care her infant received
in the hospital, such as the unclear impetus to move her infant to another hospital without
her permission. Julia alluded to a hospital “cover-up” due to the unanswered questions
about her infant’s death:

I have been calling and calling the hospitals and they put me on hold. I’ll, they’ll
call get my number to call me back and I haven’t heard from them. And you know
that kind that it makes me angry because I’m living at the fact that is there
something that you’re trying to hide, you know, somebody hasn’t talked to me yet.
And, you know, it’s a lot to think about the way that everything happened, how
they just took her without my consent, you know, I’m really feeling like they’re
trying to hide something.

One father explicitly stated how his negative experiences and marred memories in
the NICU made the coping process more difficult for him. When asked the interview
question, “How have your experiences in the NICU helped you help to cope or made it
more difficult to cope?” Brandon responded, “Made it worse, because that’s where I’ve
got threw out of when that nurse did what she did. And it made it harder on me because I
couldn’t, I wasn’t able to see my son.”
Helpful strategies for coping with loss. The nature of coping with grief changed over time as the parents’ grief changed. Progress with coping advanced uniquely for each parent. Michelle discussed how her coping changed over time:

I didn’t really talk to people a lot and I will say that the main strides that I made were like further, like nine, initially you are kind of like in shock and you don’t really start, well I didn’t really start to deal with it until like eight or nine months later.

Similarly, Sally recalled her timeline of coping:

Coping was not a strong suit of mine other than just getting through each day without biting someone’s head off. Um, and that went on for a few months and then, I just kind of realized I can be miserable or I can be thankful for the time we had with Timothy and I can put a smile on my face and I can enjoy the life that we have here and wait to see him….I think the day to day behaviors and the anger and frustration of the situation has changed by choosing to have a different outlook.

The majority (n= 7) of parents explained how remembering the infant through traditions was helpful when coping with the loss. Remembering the infant typically involved traditions that were supported by friends and family. Anna talked about how her family remembered what would have been her infant’s first birthday “Family made t-shirts they never forgot him. For his first birthday everyone, everyone wore the t-shirts and, they still talks about it.”

Sarah discussed how important it was for her friends participate in remembering her infant’s birthday:

I throw a birthday party for her every year and I have, um, my girlfriends who are like my sisters, they come with me and there’s only, I have a number of girlfriends, but there’s only two that will, I mean like they bring gifts and we’ve just made it a tradition to go eat Mexican. And now one of them is letting their daughter be a part of it, we release balloons and everything. It’s really nice that I’ve got people that, you know, they know, they Facebook, they wish her happy birthday, and all that kind of stuff.
The majority \((n=8)\) of parents explained how keeping physical reminders of the infant was helpful to them. Infant keepsakes from the hospital were treasured and stored carefully. Sarah explained how important some of her infant’s belongings were to her:

I still have her dress it’s hanging in my closet. I won’t, they (funeral home) laundered the dress for me but they left her bonnet and it still has some of her hair in it. And that’s why they didn’t do it, they said “we did not do this” and they said, we wanted to ask you first. And I said thank you, cause I won’t touch it. It’s hanging up. Um, you know I’ve got her feet prints, I’ve got her hand prints I’ve got all that kind of stuff.

Physical memories created by the parents were also important. Megan purchased a replicated doll of her son because she feared forgetting her child’s appearance over the years. She and her husband also collected animals that reminded them of her son, “But I’ve got a Siamese cat that I’ve gotten since he passed away to help me deal with that because his favorite TY beanie baby was the Siamese cat.”

Joseph and his family remembered his infant on family vacations and in their day-to-day lives:

He even goes with us on all of our trips. He’s, we have got this teddy bear, we talked about it, that has their little shirt with Children’s Hospital one of the nurses wrote William on it right when they gave it to him, that’s William. I mean that’s him, I mean that’s physically him. He goes everywhere with us. Um, he’s on my made bed right now. On my made bed between two pillows. So he’s talked about in the house all the time.

All parents described that having a good support system as a critical element in coping with infant death. Elements of family support surfaced throughout the interviews and were evident throughout the coping process. Joseph discussed how important his family support was to him, “Yeah I just I had a great family support group. I mean everybody was calm everybody around me I couldn’t imagine not having.” However, half of the parents reported feeling isolated at times throughout while coping with grief
despite adequate family support stating things like their tendency was to shut people out, or not wanting to open up about their grief. Sarah discussed how she helpful her great support system was; however, she still felt alone at times, “Sometimes I feel like I’m alone but I’m really not. Oh, I know all I gotta do is make a phone call.” Sally explained how her tendency was to self-isolate in the presence of a strong support system: “I think having a strong support network even though my tendency was to kind of push away and just be alone.”

When reflecting on what was helpful with coping, parents often discussed a support system of family and friends that were sensitive to hard grief days and the needs of the parents around those somber times. Lisa explained how her support system supported her through the hard days:

I had a good support system that I still have. Uh, that have been trying to help me out when the times (referring to anniversary birth/death) comes near, they ask if I am OK. Do I need anything, could I be, you know, could they help me in any way.

Parents discussed how helpful the bereavement follow-up care was to them. Sally described how her supportive relationship with the NICU nurses extended beyond her hospitalization:

The friendship from the nurses, um, and, you know, the check-ins after he died and the contacts from them helped during our coping process….The cards that we got from the NICU after-the-fact. When those would come in there would be nice to notes written from the nurses and people who would cared for him those kinds of things were helpful.

Timing in receiving photographs saved to a CD from the Children’s hospital was also important as stated by Joseph:

They waited because it was almost like perfect timing. They waited, I mean you’re still grieving, it still hurts but, um, you know, but you find the occasional
good memory or just getting back to your life and then you get these pictures. I thought it was perfect timing actually. It was a long time. You might could check into it and see how long. It was a long time before we got that CD in the mail just out of the blue.

Jim discussed how important it was to see the nurses that took care of his son in the NICU at the funeral service:

We had several nurses that came to his service. Which was big. I mean that’s a big, to me that was a pretty big deal….So that made a big impact to see how much people really do care. How much they cared about your child, how much they cared about you. And that made the whole experience a lot easier. A lot easier.

The majority (n= 7) of parents described some type of financial support, which was perceived as helpful in the coping process. Financial support ranged from meals provided to the family, money for shopping, or funds for the funeral service. Megan’s son died at Thanksgiving and she was focused on spending all of her time her son whose health had deteriorated. Thus, she missed the opportunity to place their older child’s name on their church “Angel Tree” so that she could receive a Christmas gift. Megan was very emotional during this point in the interview when she expressed her gratitude to the church members who knew what her family was going through and provided Christmas gifts to not only to her daughter, but to herself and her husband. Megan was also thankful for the financial support for the funeral costs:

I know Children’s has the pastoral care. They paid for Matt’s funeral. And we had a church that paid for his tombstone. And people you don’t know that you never met, churches you’ve never been to, they, it was printed up in the newspaper that Matt passed away by the funeral home and we had people show up that we’ve never seen before.

Over half of the parents (n= 6) discussed how important it was to talk through the life of their infant and their grief after infant loss with those who “know the road” and
those who were non-judgmental. Jim explained how helpful it was to talk through his experiences with others who understood what he had been through:

I think just talking, talking to others that have lost children, talking to others who still have children and that went through NICU experiences. That’s pretty much it on that regard. You know, like I said, there was a couple of families we’re still in contact with, you know. We still talk to them to this day, so that’s very helpful because they know. Even though their children are still alive, they know the road so it’s very helpful to talk to those individuals.

Six of the parents discussed strategies for making sense of the their infant’s life in the NICU and making sense of their loss. Julia has vehemently attempted to obtain the health records to understand what happened in the last day of her infant’s life. Sally discussed her strategy of making sense of her infant’s life after he died:

The information, all the questions that I had asked while he was sick and learning about his medications and his condition, the different things they were doing, you know, talking about that with people in the medical field afterwards, and realizing how sick he truly was, um, was just another level of learning about him.

Michelle spent her time studying grief materials and studying heaven in an attempt to understand her son’s death from a spiritual perspective:

I studied a lot on, just heaven, and the studying from different people’s accounts even though it’s not necessarily in the Bible, they all kept saying the same thing. So, something must be, you know, certain details, these people are not making this up and then, the characteristics, are like the same so, that gave me a lot of peace, so anything, I did a lot of studying on heaven. And that probably helped, just knowing that he’s in a better place and you will see him later and so I guess spiritually, you know, that was just what helped me.

Altruism was important to these parents because they could remember and bring meaning to their infant’s life by helping others. Michelle discussed how coping with her loss was a challenge that she wanted to help others with: “Just kind of feel like that was kind of a badge that I kind of earned (coping with her infant’s death) and it was time to go back and help someone else, and, so that’s another way of coping.” Sarah was
employed as a personal trainer and volunteered every year at an elementary school in her community around the time of her daughter’s death:

So it’s, these kids know why I am there and there is no place I would rather be than with 800 kids teaching them fitness and healthy lifestyle than there [teary] if I can’t, that’s my birthday celebration for her and I honestly don’t think people realize how much that means to me to let me go in and do that. I teach eight PE classes on that day, and I’m exhausted [laugh] by the end of the day. But to see those kids faces and to know that they, when they see me walk through the door or when they walk in the PE room or the gym, they all come and hug me and it means the world.

Jim explained how his experiences with his son in the NICU led him to helping other families through his new career as a nurse:

But now some of the impact that I received from nurses and medical staff, I have a chance to make on patients and families. So that’s really been a big, um, now I can offer the same kind of support in the hospital that I received, so that’s been a big help, that’s been a big help.

Religious faith and prayer played a major role in helping parents cope with the death. Michelle explained how she “dwelled heavily on my faith” and “wrote songs and spent a lot of time in prayer and meditation” when coping with grief. Joseph explained how important it was to have a religious foundation:

The Lord. The Lord. That’s it. I mean I don’t even want to tell you where I would be or what I would have done in my life. I mean, so you know, if you don’t have some kind of religious foundation.

The majority of parents (n= 8) described some type of loss-avoidance behavior, such as staying busy, as a helpful strategy in coping with the loss and transitioning to life without their infant child. Sally stayed focused on completing tasks following the infant death, “Completely redid our kitchen and den, and kind of overhauled a few areas in the house and I guess just tried to stay busy in some way, and then started back to work.” Sarah focused on creative outlets to stay busy, “Um, I’m, I kept myself surrounded with a
lot of people and, um, kept myself busy. I started painting and you can see this here, um, I did this painting right here [pointing to painting].”

Three parents described an increase in risky behaviors and habits that helped them cope with the loss. Lisa recognized these as the “bad” parts of coping, “Eating, smoking, they were the bad parts that helped me get through it.” Sarah discussed how she started drinking more after the loss of her infant: “That went on for about a year and a half. Where I was drinking more than I should, I guess the past three years is when it, it’s continued to dwindle down.”

Parent’s Comments About Interview Participation

After the interview questions related to the research questions were completed, all of the participants were asked to honestly answer what it was like to participate in the interview. All of the participants described various benefits and helpful feedback for future research efforts. Sarah described research participation as part of her process of coping with grief:

One of the reasons why I wanted to talk to you was to do, because it is coming up on February (infant’s birthday) and it’s something I felt like [teary] as far as my process, something I felt like I needed to do.

Anna was very quiet during her interview and was the only participant who required extensive probing. While she was not emotional during the interview, the PI was concerned that she was quiet because she having difficulty participating in the interview. However, Anna described her interview participation as “Actually, good [smiling]. I think I needed to talk about it.” Similarly, Lisa described her interview experience as unique.
It was OK, at first I thought it was going to be hard, but it didn’t seem that hard. It seemed more, every day talk, every day, wasn’t afraid to talk about it, wasn’t sad to talk about it. Um, but it was just like an everyday just talking to a friend.

In contrast to Anna and Lisa who were not emotional in their interviews, Megan was teary and cried intermittently throughout her interview and the PI asked her several times if she needed a break. She responded throughout her interview with responses like, “I know this sounds strange, but I enjoy crying because I remember. I like talking about it, it might not look that way, but I do. I enjoy talking about him.” Similarly, Sally described a unique opportunity to talk about her infant, “some reflection back to that time, time to talk about Timothy and his life.”

Julia discussed the positive outcomes of interview participation. She explained how this study helped her and how she had not talked through any of her coping and grief experiences until participating in this study:

I really want to say though that this study really helped me. And it really helped me see clear on what I need to do, you know, as a parent coping with this issue….I never told my mom, I never told any of my family members. I never told my pastor. The only person that knows me, you, and God. But it was, you know, this was an eye-opener for me.

Moreover, Julia described some of the cathartic benefits of research participation:

So for me, you know, this (research participation) has affected me in a good way so, you know, I could be able to do more to help me. And you never know how I may sleep tonight. I just made because this is something that has been on my mind that I didn’t know was on my mind. So for me this was, this was something I really needed and I’m just thankful that, you know, and I think maybe God know I needed this. So this was, this was real good for me.

Another positive outcome was the opportunity to help other parents suffering from the grief of losing their infant.
Parents explained that interview participation was an avenue to help other parents:

Hopefully, I can be of some help, you know, to someone down the road and some help to you in your course of study and that’s the main thing we are looking at when we decided to participate. Maybe in some way this is going to help a family down the road. That’s one thing why it’s important us.

It is important to note that Michelle did not report any negative experiences from interview participation; however, if this interview was conducted at an earlier point in time it would have been distressing, “it was fine, like I said, I was kind of to a closure point, um, so, but if you had, If I’d done this like two years ago it would have not have been good.”
CHAPTER 5
DISCUSSION, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

This chapter presents a discussion of the findings from this study in addition to study conclusions, implications for research, education, and practice, limitations and strengths of this study, and future recommendations.

Discussion

The purpose of this study was to: (1) to describe parent experiences related to their infant’s NICU hospitalization, end-of-life care, and palliative care consultation; and (2) to describe parents’ bereavement and coping experiences after infant death. Qualitative content analysis was used to analyze the interviews from ten parents that resulted in descriptive comprehensive summaries of the parents’ experiences during the NICU hospitalization and their lives after the death of their infant. Two major themes emerged from the content analysis: (1) Life and death in the NICU environment; and (2) Life after loss.

Life and Death in the NICU Environment

The Ups and Downs of Parenting in the NICU

“Being a parent” in the NICU was extremely important to these participants regardless of how much they could be involved in the care of their infant. Parenting in
the NICU was full of ups and downs such as traveling far distances to be with their infant, staying abreast with their infant’s constantly changing life-threatening condition, and facing various conflicts between parents and their infant’s healthcare providers. Regardless of the strife endured, parents treasured the time they had with their infants. Similarly, Hinds and colleagues (2009) explored the meaning of a “being a good parent” with parents of children with incurable cancer and found common themes of “being there for my child.” As Hinds and colleagues (2009) reported, parents of infants in the NICU wanted to remain at the bedside of their child irrespective of difficult circumstances. Parent stressors within the NICU are documented in the literature with respect to changes in the infant’s appearance and behaviors, as well as alterations in parental role (Miles et al., 1991; Miles et al., 1993). Nurses in the NICU are positioned to play a role in reducing parent “worry” about their infant’s medical state and facilitating parental role development by teaching parents how to care for infants hospitalized in the NICU (Docherty et al., 2002; Miles et al., 2011). Consistent with findings in the literature, (Holditch-Davis, 2005; Turner et al., 2013), NICU nurses in this study played a critical role in facilitating parenting in the NICU by teaching the parents how to interact with their critically ill infant and remaining a source of support throughout the NICU hospitalization. Further supporting the importance of parental role development, the Creating Opportunities for Parent Empowerment (COPE) Program offers evidence-based practice guidelines for facilitating the parent role in the NICU (Melnyk et al., 2008). Nurses in this study helped parents make the most of the time together by creating memories and taking the time to do special activities that gave more meaning to the infant’s life. Catlin and Carter (2002) developed neonatal palliative care guidelines and
suggested that nurses and physicians encourage parents to be a family as much as possible and assist them to carry out their individual wishes.

Parents in this study discussed infant end-of-life experiences that ranged from planned withdrawal of care, to unsuccessful resuscitation efforts, to being absent for the death. Regardless of the circumstances leading up to the death, parents discussed how important it was to maintain the role of the parent after their infant died. For example, having adequate time to hold their child in private was important to parents. Consistent with the literature, maintaining the role of caregiver and parent has been evidenced by the need for parents to be present with their dying child regardless of lifesaving procedures at the bedside (Tinsley et al., 2008). Tinsley and colleagues (2008) found that parents of children hospitalized in the PICU reported their being present during CPR brought comfort and additionally would help parents accept their child’s death. Allowing parents and other family members ample time with the infant or child surrounding the death experience is a priority as parents begin to make sense of their loss (Catlin & Carter, 2002; Meert et al., 2009).

All parents faced some type of barrier to parenting during their infant’s hospitalization. The majority of conflicts between parents and healthcare providers centered on fragmented communication, a mismatch of preferred communication style, and parents’ concerns about not being heard. Parents wanted straightforward and honest communication; however, they did not want information to be presented bleakly and without hope. Similarly, Boss and colleagues (2008) and Pector (2004) discovered that parents of infants hospitalized in the NICU preferred straight-forward information that was presented in a positive way due to the importance of maintaining hope in the
decision-making process and the possibility of “medical miracles” (Boss et al., 2008; Pector, 2004). Moreover, these parents were found to mistrust physicians who did not express hope and compassion for their child (Boss et al., 2008).

Other barriers to parenting such as fragmentation of care were described by parent as conflicting stories between healthcare providers. Similarly, Tan, Docherty, Barfield, and Brandon (2012) found fragmentation during the hospitalization of infants with complex chronic conditions. Participants reported situations where the nurse did not listen to their concerns and this inaction imbued feelings of exasperation and animosity.

Financial burdens were a significant challenge to parents in this study. Most of the parents lived over an hour away from the NICU where their infant was hospitalized and half of the parents reported a household income of less than $10,000. Many parents had to relocate from their homes to Birmingham for the duration of their infant’s hospitalization in the NICU leaving behind a stable income for one parent, or in some cases both. Four parents reported staying at the Ronald McDonald House for the duration of the hospitalization. Moreover, parents explained how life expenses outside of the NICU remained the same while their financial income decreased, and healthcare costs increased. While most of the families were affected by these financial burdens, the families who had the lowest financial resources seemed to be disproportionately affected. For example, one family in this study became homeless after diminished financial resources resulting from their infant’s hospitalization. Fox, Cacciatore, and Lacasse (2014) examined the financial burdens of bereaved parents six months after child death and found the economic burden related to grief was great. More specifically, Fox and colleagues (2014) found that parents’ inability to work resulted in the bulk of the
economic burden associated with grief. Some of the parents in this study were unable to return to employment for an extended period of time or lost their jobs after their infant died. At the time of the interview averaging four years since infant death, some of the parents were still unable to work. While funeral costs associated with perinatal death cost the least compared to other types of funeral arrangements, the economic burdens were still notable for bereaved parents (Fox et al., 2014).

*Decision-Making Challenges in the NICU*

Parents described decision-making as a complex process that was mostly guided by the best interest of the infant, the infant’s appearance and cues, and parents hoping to have more time together. While parents in this study described personal advice from nurses and physicians as helpful, and this finding was supported by the literature (Pector, 2004), it is not evidence-based practice to guide parents based upon personal values. Similar to the study findings, the infant’s quality of life, degree of pain, suffering, likelihood of survival, and the physician’s recommendations have been identified by parents in the PICU as influential aspects in the decision-making process (Sharman, Meert, & Sarnaik, 2005). Parents in this study explained how important it was for nurses and physicians to avoid presenting the infant’s prognosis bleakly; rather, parents preferred information be presented in the most hopeful way possible. Similarly, Kavanaugh (2005) and Boss and colleagues (2008) purported the importance of hope for parents confronting infant death while hoping for a “medical miracle” because of the perceived advanced medical technology. Nurses in this study were seen as a “lifeline” of communication and parents heavily depended on nurses and physicians to share honest
and understandable information so that parents could participate in the decision-making process. Similarly, in another study, parents of infants and children in the NICU and the PICU reported the importance of health care providers sharing information that was understandable to parents in order for the parents to fully participate in the decision-making process for their child (Brooten et al., 2012). The information received from healthcare professionals must be accurate, honest, and objective in order to support parents in determining what is best for their child (Brosig et al, 2007).

Parents in this study made difficult and sometimes life-and-death decisions for their infants while facing judgment from friends and family. While parents in this study encountered judgment and differing opinions from their friends and family, Pector (2004) found that parents experienced judgment from nurses and physicians when deciding to maintain or withhold life support for their infants in the NICU. Some parents in this study were left out of the decision-making process and this resulted in embitterment. Relatedly, Brooten and colleagues (2012) found that some parents of infants and children in the NICU and PICU were not informed of their child’s critical condition and the possibility of DNR order until the child was in a resuscitation (code) situation. However, it was not helpful for parents to be left out of critical life and death decisions during these parents’ time of crisis (Brooten et al., 2012).

Making decisions for infants in the NICU was complicated by facing life-and-death decisions that parents had to live with after their loss. Some parents described being unable to make the final decision for their infant and could not opt for a planned withdrawal of care even when aggressive care was futile. Many of these parents who wanted aggressive care until their infant coded were present at the code and contributed
to the decision to stop the code. One mother prayed that God would take her son when he was ready because she could not make that decision. Boss and colleagues (2008) similarly found that parents employed religious values and spiritual guidance when making decisions for their child.

Similar to the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999) where bereaved individuals cope by oscillating between focusing on the loss and living in a changed world without their infant, living with decisions for parents in this study was an oscillating process between feeling “at peace” with decisions and wrestling with the “what-ifs?” Parents would state they were “at peace” with their decisions given the information they had at the time, and then question what could have unfolded differently in the next sentence. One father was told his son was suffering and that he had diminished brain function and, thus, he decided to withdraw care based on the physician’s recommendations. This father explained how he regretted the decision to withdraw care, stating “even if it was the right thing to do,” he would make a different decision if he had another opportunity. These findings are somewhat inconsistent with the literature. Glaser and colleagues (2007) found that parents were relieved about not having to care for a disabled child and that their premature infant was no longer suffering. Caeymaex and colleagues (2011) found that parents struggled with making life and death decisions for their infants in the NICU, but were also relieved that their hospitalized infant was no longer suffering and that the infant would not struggle as a handicapped person. In contrast, parents in this study discussed how they would have liked more time with infant regardless of their medical state. However, feelings of relief related to the end of the infant’s suffering was only mentioned by one parent and did not emerge as a
major theme. Implications for practice include efforts to validate parents’ decisions so that parents do not struggle with end-of-life decisions made for their infant. For example, Meert and colleagues (2007) found that physician and parent meetings after their child’s death in the PICU were helpful for parents to resolve questions about their child’s life leading up to his/her death, autopsy findings, and identifying bereavement support resources.

*Parent Support*

All parents in this study described some type of support received during their NICU hospitalization. Nurses were identified as a key source of support and a “lifeline” of communication for their infant’s care in the NICU. Participants valued open communication regarding their infant’s care. Nurses were a comforting presence offering kind and sensitive words of consolation. Consistent with findings in the literature, parents facing infant and child death appreciated communication from healthcare providers that was compassionate, sensitive, kind, sincere, non-judgmental, and sympathetic (Brinchmann et al., 2002; Brooten et al., 2012; Brosig et al., 2007; Caeymaex et al., 2011; Meert et al., 2009; Pector, 2004). Parents reported that nurses supported them by making the most of their time together and preparing them for the infant death. For example, parents in this study explained how nurses respected their wishes such as holding their critically ill infant and involving parents in the care of the infant. However, there were notable differences in the consistency of nursing care parents received. Parents of infants who received specialized treatments such as ECMO or dialysis received consistent nursing assignments because there were a limited number of nurses on each shift who could take care of those patients. These parents described
how helpful it was to have the same nurses consistently. Catlin and Carter (2002) identified consistent staff for each infant in the NICU as part of an optimal environment for neonatal death and necessary for providing quality palliative care. In contrast, other parents explained the frustration associated with having a different nurse every time they visited their infant.

Treatment appeared to be inconsistent from family to family. Moreover, Mefford and Alligood (2011) examined nurse staffing patterns in the NICU and found that consistency of nursing caregivers served as a mediator of infant length of stay, mechanical ventilation, supplemental oxygen, and parenteral nutrition. Therefore, primary nursing, or consistent nurse caregivers, may significantly improve the quality of care and health outcomes for infants in the NICU and their families (Mefford & Alligood, 2011). Implications for practice include the integration of primary nursing in NICU nurse staffing to support consistent caregiving.

Another important role of the nurse was supporting the entire family. In this study, nurses reassured parents they would be updated on the care of their infant and were encouraged to take breaks away from the NICU to ensure adequate rest and self-care. Similarly, Brosig and colleagues (2007) found that parents of infants in the NICU favored nurses who protected the parents’ image and gave the parents “permission” to leave the bedside and take care of themselves. Meert and colleagues (2009) found that trustworthy healthcare providers were critical to parents being able to leave their child in the PICU without worry and take time away from the hospital to care for themselves.

Another major source of support during the NICU hospitalization that was consistent with the literature was the importance of religion and prayer. Parents
explained how helpful it was to receive support from their religious community through visitations in the NICU and in prayer. Similarly, parents reported their faith in God was their basis for hope and a source of encouragement during the ups and downs of their infant’s hospitalization (Boss et al., 2008; Knapp et al., 2011; Meert et al., 2005).

Four parents stayed at the Ronald McDonald house with other parents of hospitalized children and sought support through other NICU families. These families were supportive because they provided camaraderie during stressful times and reportedly eased the constant worry parents experienced because they could empathize with each other openly and without judgment. These friendships strengthened during the hospitalization and many times remained intact after the infant death. Family and friends became a network of support that helped parents with the ongoing needs of life outside the NICU and provided healthy distractions away from the NICU. The majority of parents described “placing people around you” in hard times when they needed support. Turner and colleagues (2013) also found that other NICU families were a source of support through hospitalization and friendships were maintained after the NICU hospitalization. While Turner and colleagues (2013) interviewed parents whose infants survived, their infants were also critically ill in the NICU and similarly found comfort in talking with those who understood what they were going through because they had similar experiences.

In contrast, the majority of parents in this study experienced some type of ineffective family support at some point during the NICU hospitalization. Regardless of marital status and how well spouses could support each other, logistics presented challenges when spouses (mainly husbands) were required to leave the NICU and return
to employment to maintain health insurance and financial revenue for the family. Thus, many mothers reported an absent spouse through much of the hospitalization. Other spouses were absent by choice or because of NICU policy. Kavanaugh (2005) explored the experiences of perinatal loss among low-income African American mothers and similarly found that many of the mothers reported absent fathers throughout the NICU hospitalization and thus, a lack of support. Lack of family presence and harmful family involvement were also reported from some of the parents in this study. One mother became very emotional while describing how difficult it was for her when her father refused the opportunity to visit her because of the infant’s poor prognosis for survival. Similarly, Cote-Arsenault and Denney-Koelsch (2011) found that some of the parents who received a lethal fetal diagnosis reported a disconnect from family and friends because of a perceived lack of understanding of what they were facing due to the avoidance of the impending or actual perinatal loss. An implication for nursing practice could be for nurses to normalize the experience for parents explaining that what they are experiencing happens to many other parents and they are not alone with facing these challenges.

Palliative care as an added layer of support. Six of the ten parents in this study received PC consultation in the NICU and the majority of parents were unaware of what PC was before receiving these services. The NICU physicians and nurses initiated all of the PC consultations. In contrast, Catlin (2011) reported that parental agreement remains the determinant for the initiation of PC rather than the infant’s physiologic state and prognosis. Parents in this study associated PC with “giving up” on their infant and relinquishing hope for aggressive and curative treatment. Similarly, Knapp and
Thompson (2012) found barriers to the integration or the transition to PC may include anxiety and feelings of guilt in parents of children with chronic illnesses who feel as if they are “giving up” on their child (Knapp & Thompson, 2012).

While parents described the negative connotations associated with PC and resistance to initiating these PC consultation services, all of the parents who received PC services explained how helpful PC was to them as an added layer of support and that they would recommend these services to NICU families. Parents described how the PC team supported them in a myriad of ways such as being a “sounding board” regarding questions for the neonatology team, providing non-judgmental support for parents when making decisions for their infants, when trying to make the most of their time together, and surrounding the time of their infant’s death. Brosig and colleagues (2007) also found the palliative care team to be supportive to parents of infants in the NICU and PICU. Eight of the 19 parents in Brosig and colleagues’ (2007) exploratory study received some type of PC consultation or hospice care for their infant in the NICU or PICU; however, there were no significant differences in Revised Grief Experience Inventory scores between parents that did and did not receive PC services. Other measures of health and functioning were not explored, as well as the experiences that led to initiating palliative care.

Therefore, to better understand why and how PC services were initiated and why these services remain underused when they can be integrated with aggressive care and were accessible to all parents in the NICU, further research efforts are necessary to determine the benefits of PC consultation related to coping, grief outcomes, health, and functioning in bereaved parents of infants in the NICU. Furthermore, Boldt and
colleagues (2006) provided parents and HCPs with the terms “palliative” versus “supportive care” and asked how likely they were to use this service in the future. Parents responded more positively to the term “supportive care” when compared to healthcare professionals; however, after a non-threatening program description was provided, parents were equally positive about the terms “palliative care” versus “supportive care”. Thus, implications for research include further examination of barriers associated with the term “palliative care” and the need to educate parents using a non-threatening program description (Boldt et al., 2006).

Life after Loss

It was evident throughout each of the interviews in this study that infant death was a catastrophic loss for each of these parents and feelings of loss continued over time. Even for those parents who appeared to function well in life, grieving their infant was something that was held close to their hearts on a day-to-day basis. The findings from this study support the Dual Process Model (DPM) of Coping with Bereavement and will be discussed throughout the remaining discussion (Stroebe & Schut 1999).

Living with loss. Living with grief and loss was a process that resulted in long-standing ramifications such as physical and mental health changes and spiritual suffering. Regardless of how long the infant survived (infant lifespan ranged from one day to 234 days; mean age 97 days), infant death was a profound tragedy that marked the beginning of a life-changing grieving process that endured over time.

Cote-Arsenault and Denney-Koelsch (2011) explored the context in which parents experienced a lethal fetal diagnosis and later suffered from perinatal loss. These parents
also described their grief as an unfolding process (Cote-Arsenault & Denney-Koelsch, 2011). Scores from the Inventory of Complicated Grief were inversely related to time in parents of children younger than 30 years of age; thus over time, levels of grief were decreased, further supporting the findings that suggest grief evolves as a process over time (Dyregrov, Nordanger, & Dyregrov, 2003; Keesee, Currier, & Neimeyer, 2008; Wijngaards-De Meij et al., 2005).

While parents in this study described the pain of grief being worse on hard grief days such as the infant’s birthday and then easing over time, their grief never completely subsided and was always present in some way. These findings are similar to those found by Ronen and colleagues (2009) where parents held continuing bonds to their deceased children adjusting to the loss while sustaining a level of connection to the deceased. According to the DPM (Stroebe & Schut, 1999) changes in coping with grief are expected for the duration of bereavement and will gradually focus less on loss-orientation stressors that focus on the loss itself, then shift to restoration-orientation stressors that focus on secondary stressors related to consequences of bereavement, such as struggling to reorient oneself to a changed world without the deceased infant (Stroebe & Schut, 1999; 2010). Individuals must oscillate between these two types of stressors in order to adapt successfully to loss (Stroebe & Schut, 1999; 2010).

In particular, the more significant findings from this study were the physical and mental health changes parents experienced when grieving the loss of their infant. Mental health changes ranged from being moody around harder grief days to multiple hospitalizations resulting from suicide attempts. Severe depression requiring long-term medication regimens and physical changes such as weight gain and sleep pattern
alterations affected the functionality of these parents on a daily basis. These study findings were supported by the literature. Bereaved parents have higher mortality rates and psychiatric hospitalizations when compared with parents who have not experienced the death of a child (Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003). Specifically related to parents after child death in the NICU or PICU, Youngblut and colleagues (2013) studied health and functioning in parents 13-months after infant or child death and found that parents reported stress related hospitalizations, numerous newly diagnosed chronic health conditions, clinical depression, and clinical PTSD.

Grief symptoms of bereaved parents reported in the literature include emotional reactions such as anxiety, depression, anger, hopelessness, loneliness, and a sense of emptiness; as well as somatic complaints, including sleep loss, decreased energy, and social difficulties (Dyregrov & Dyregrov, 1999; Laakso & Paunonen-Illonen, 2001). Many of the grief symptoms parents reported in this study were consistent with those reported by other bereaved parents in the literature. However, some of these parents reported grief symptoms that were more intrusive and affected the ability to function in their daily lives. While none of the parents were clinically assessed and screened, complicated grief involved intrusive thoughts of the deceased, clinically significant symptoms, and a level of social or occupational impairment (Stroebe, Hansson, Schut, & Stroebe, 2008). Thus, it is possible that some of these parents were experiencing complicated grief following the loss of their infant. Complicated grief is germane to parents of infants in the NICU because complicated grief symptoms at six months post-death have been found to be associated with poor mental and physical health, and
reduced quality of life in parents of infants and children hospitalized in the PICU (Meert et al., 2010). Conversely, parents without complicated grief reported more positivity and ability to make sense of the loss by successfully sustaining continuing bonds with their deceased child (Ronen et al., 2009). An implication for practice may include a process for screening parents at-risk for complicated grief during bereavement. Complicated grief should be assessed during the NICU hospitalization and during bereavement follow-up at six months after infant death to determine those individuals who may experience severe consequences from grief such as depression, anxiety, and the inability to function day-to-day.

The DPM purports that with extreme adherence to focus on one type of stressor and a lack of oscillation between loss-orientation and restoration-orientation stressors will result in maladaptation (Stroebe & Schut, 1999). This could potentially explain why some parents in this study appeared to cope and adapt better or worse to loss of their infant. For example, one mother did not address her loss or discuss her grief until study participation and she could not function well in her day-to-day life. Another father appeared to only focus on loss-orientation stressors as evidenced by visiting the grave every day for four years after infant death and the inability to work because of intrusive thoughts about his deceased infant. Moreover, these two parents discussed mainly negative hospital memories and only focused on loss-orientation stressors. These parents did not appear to be adapting successfully because of their inability to function in their day-to-day lives and their inability to integrate their deceased infant into their lives in positive and meaningful way. In contrast, other parents in this study who reported personal growth and the ability to function in their daily lives while integrating their loss
in a meaningful and positive way evidenced the oscillating process between loss-orientation and restoration-orientation stressors. Negative consequences of bereavement such as mental health changes and dysfunction in day-to-day lives may be explained by maladaptation and the adherence to only one type of stressor when coping with bereavement. Thus, findings from this study support the usefulness of the DPM in explaining grief and coping processes. Further research is necessary to better understand how prequel events to infant death affect coping with bereavement and how coping may be facilitated in bereaved parents of infants.

Parents in this study often encountered spiritual suffering as they tried to better understand the life and death of their infant. Parents asked, “Why God?” “Why me?” and similar findings were present in the literature. Similarly, spiritual suffering was often experienced by parents as they tried to make sense of the loss and address existential questions such as “Why my baby?” or “Why would God allow my baby to suffer?” (Bellali & Papadatou, 2006; Glaser et al., 2007; Kavanaugh & Hershberger, 2005; Raingruber & Milstein, 2007; Rosenbaum, Smith, & Zollfrank, 2011).

While these parents experienced trying and debilitating effects of grief, paradoxically, many of the parents reported personal and spiritual growth when living with loss. Two of the parents in this study completely changed careers after the loss of their infant and found a more gratifying life path as a nurse and hospice social worker. Other life changes involved being more cautious with future pregnancies and cherishing even the difficult times with their other children. Some parents were reluctant to become pregnant after the death of their infant because of fear for what could happen in future pregnancies. Similarly, Kavanaugh and Hershberger (2005) found that some parents who
experienced perinatal loss avoided future pregnancies because of fear for another perinatal loss.

Perinatal loss is currently defined as miscarriage, stillbirth, or neonatal death up to 28 days of life (Armstrong, 2002). However, parents in this study explained how infant death was a unique type of loss and could not be compared with other types of losses such as miscarriage or the loss of an older child. In a recent study evaluating the reliability and validity of the Perinatal Grief Intensity Scale, Hutti, Armstrong, and Myers (2013) found that mothers in the neonatal group experienced more intense grief compared to those mothers who experienced miscarriage or stillbirth. While this study does not provide conclusive evidence that neonatal death should not be operationalized similarly to miscarriage and stillbirths, the findings from this study suggest that there is a need to further investigate the appropriateness of grouping miscarriage, stillbirths, and neonatal deaths in the same category when measuring grief outcomes.

*Coping with grief over time.* All parents described some type of barrier to coping with the loss of their infant including: dealing with multiple losses, well-intended but hurtful communication from friends and family, nosy people, encountering spousal and family grief differences, avoiding professional counseling, family members who are unable to empathize, unhelpful and unfamiliar chaplains, loss-focused behaviors, and unanswered questions about the life and death of their infant.

The majority of parents experienced some type of communication that was well-intended but hurtful. Parents did recognize that infant death was a difficult subject to broach and that their friends and family earnestly attempted to be sympathetic when
discussing their loss. However, there were times that parents felt as if people could have selected their words more carefully and were not sensitive to their loss. These participants also saw “nosy” individuals as hurtful because parents struggled with differentiating between sincere concern and those who wanted to gain information for “gossip” purposes. These findings were consistent with studies that found parents experienced disenfranchised grief and felt abandoned by their community because of the perceived dismissal of their loss and hurtful communication (Brosig et al., 2007; Doka, 2008; Kavanaugh, 1997; Meert et al., 2009; Stroebe et al., 2008).

Parents encountered grief differences between spouses and family members that made coping more difficult. At times, these discrepancies resulted in the inability for family members or spouses to provide support to each other. For example, in this study Michelle explained how her spouse did not want to talk about the loss because he took their infant death as a “personal failure”. Similarly, Wijngaards-DeMeji and colleagues (2008) found that it was more common for mothers to desire talking through the loss than fathers. Vance, Boyle, Janman, and Thearle (2002) matched non-bereaved parents with parents whose infant suffered from Sudden Infant Death Syndrome and perinatal death; they found that bereaved parents reported increased marital dissatisfaction when compared to non-bereaved parents at 2-, 8-, 15-, and 30- months post-death. Contrarily, this study only revealed one marital separation after infant death that was only partially related to the infant death. While differences in coping with grief were noted, marital dissatisfaction did not emerge as a major theme from these parents. Moreover, as Michelle discussed her spousal differences in coping, but she later stated that dealing with the loss of their baby “made the bond very strong” between her and her husband.
Watching family members grieve also complicated the coping process. Parents reported the difficulties of watching their other children, spouses, and their parents grieve the loss of their child. Parents described how difficult it was for family members to provide support when they “didn’t get it” and couldn’t understand what they had been through with their infant loss. For example, Julia had a very difficult time seeking support from her mother because every time she attempted to discuss her deceased infant, her mother would become emotional and was not able to talk about it. Megan struggled to explain the loss to her young child who had a hard time understanding why her little brother never made it home from the hospital or why God would take him away.

Youngblut and Brooten (2013) purported the importance of sibling involvement with EOL care in the NICU; however, parents in this study reported limited time allowed for sibling involvement in the hospital setting.

Dealing with multiple losses also added to the complexity of coping with grief. Other losses were identified such as the deaths of loved ones, miscarriages, and the loss of significant relationships. Comparably, Kavanaugh and Hershberger (2005) found that low-income African American parents reported difficulty preparing for the grief associated with the death of their newborn infant due to the loss of family members during their pregnancy (Kavanaugh & Hershberger, 2005).

Other barriers to coping with loss were the use of burdensome loss-focused behaviors and not seeking professional counseling. Parents in this study described the underutilization of professional counseling services encumbered coping with grief and if they could make different decisions in the aftermath of losing their child, they would have sought out professional mental health counseling services. Kavanaugh (2005)
similarly found that many mothers expressed a need for counseling services; however, only one mother reported the use of counseling services when coping with perinatal loss. Parents in this study described the need for professional grief counseling. Most parents in this study lived over an hour away from Children’s of Alabama hospital. Currently, there are only in-person counseling services provided at the Children’s of Alabama Amelia Center (free service to parents through Children’s of Alabama) and parents may have been unable to access these services because of difficult traveling logistics.

An unbalanced focus of attention on the deceased infant was not reported as helpful in coping with the loss and was exhausting for the parents further supporting the Dual Process Model (DPM) of Coping with Bereavement (Stroebe & Schut, 1999). Within this model, parents must successfully oscillate between loss-orientation and restoration-orientation stressors rather than focusing on one stressor alone (Stroebe & Schut, 1999). An example of a loss-focused activity that was not helpful if performed in excess was repeatedly looking through the infant’s photo album. Additional research is needed with the DPM in this specific population of bereaved parents to better understand how these loss-oriented stressors impact coping.

In terms of the NICU hospitalization, unanswered questions regarding their infant’s life and death led parents in this study to question the care their child received. This uncertainty surrounding the cause of death resulted in anguish because parents felt as if information received from the nurses and physicians was not truthful or had been withheld from them. Davies and colleagues (2010) similarly found that less optimal patterns of communication, including no information or basic information regarding
prognosis and updates of child health status resulted in frustration, anger, and sadness in bereaved parents.

While some parents described hospital chaplains as a source of support during their NICU hospitalization, if there was no connection between the chaplain and the parent, the chaplains’ attempts at comforting the parents after the loss of their infants were seen as unwanted and ineffective. Correspondingly, Meert and colleagues (2009) found that parents in the PICU reported that the constant introduction of healthcare professionals from various disciplines as an “unwelcome challenge” and sought support only from those whom they trusted to provide sincere sympathy.

The nature of coping with grief changed over time and progressed uniquely for each parent. The findings from this study support the DPM where coping with grief was conceptualized as a process that involved vacillating between confronting the loss-oriented stressors and focusing on restoration-oriented stressors (Stroebe & Schut, 1999). When asked what helped parents cope, they described confronting and avoiding the loss in an attempt to adapt to life without their infant. Parents integrated their child into their lives by remembering the infant through traditions that were supported by family and friends and keeping physical reminders of the infant. It was clear to the PI how important these physical reminders were to these parents because after three of the interviews, parents asked to show the PI their infant’s keepsakes from the hospital and other beloved physical memories. Altruistic acts were loss-focused behaviors that allowed the parents to remember their infant while helping others. For example, one mother participated in a charity walk every year in the name of her infant. These findings were parallel to what has been reported in the literature. After infant and child death, memories served to
maintain the connection with the deceased by recognizing the loss and the longing for the missing family member. Memories allowed parents to memorialize their infant or child through ritualistic behaviors, altruistic acts, and sharing stories about their child (Bellali & Papadatou, 2006; Brosig et al., 2007; Grout & Romanoff, 2000; Meert, Thurston, & Briller, 2005; Meert, Thurston, & Thomas, 2001; Tan et al., 2012). A recently published qualitative study examined bereaved caregiver experiences as a volunteer in pediatric palliative care education through the Initiative for Pediatric Palliative Care (Adams et al., 2013). Parents reported benefits such as a sense of purpose associated with helping with palliative care education. Implications for further practice include providing bereavement education to parents in NICU and volunteering to support other bereaved parents. Further research is required to determine the risks and benefits experienced by parents.

Other loss-focused coping behaviors such as talking it through with those who have experienced infant loss and “know the road”, making sense of their infant’s life and death, and religious faith and prayer were also helpful to parents in this study. The majority of parents discussed how important it was to talk through their loss with those who could understand and not place undue judgment on them. These findings were consistent with the literature. Parents have commonly reported that being able to talk about their loss and feeling understood by others facilitated their coping with the death of their child (Braun & Berg, 1994; Brosig et al., 2007; Meert et al., 2009). Moreover, parents gravitated towards supporters who recognized the life of their deceased child and other parents who had also suffered infant loss (White, Walker, & Richards, 2008).
Other parental behaviors that focused on the loss were making sense of their infant’s life and addressing existential questions surrounding their infant’s death. Religious faith and prayer was cited as a helpful coping mechanism in these parents; however, prayer did not always have to be reciprocal to be considered helpful. For example, Julia did not discuss her loss with her pastor, but did accept his prayers for her. Parallel to the literature, religious or spiritual affiliations were reported as helpful by bereaved parents (Brosig et al., 2007; Kavanaugh & Hershberger, 2005; Kavanaugh et al., 2004). There were no racial differences in this sample when it came to the use of religious faith or prayer. This finding contrasts with Knapp and colleagues (2011) who found that non-White parents reported the use of spirituality as a coping strategy more frequently than White parents in a sample of parents who received community PC services for their children. Additionally, Kavanaugh (2005) found that African American parents who suffered from perinatal loss relied heavily on spirituality as a coping resource. More research is needed to determine cultural differences in coping with grief after infant loss so that nurses can address the needs of parents in a culturally-sensitive way.

Restoration-oriented grief behaviors, or those behaviors that focused on living in a world without their deceased child, such as staying busy and an increase in risk habits, were also reported as helpful to these parents. “Staying busy” referred to parents’ attempts at distracting themselves from their painful grief symptoms in an attempt to adapt to life without their child. In addition, other secondary restoration-orientation stressors were attending to new life changes and denial or purposeful avoidance from grief. The majority of parents in this study engaged in a process of oscillation between
loss-orientation and restoration-orientation behaviors that support the DPM (Stroebe & Schut, 1999). More specifically, oscillation occurred between loss-oriented appraisal processes such as: making sense of the life and death of the infant, interpreting events surrounding infant death, pondering over the “what-if’s” of their decision-making, and asking questions like “Why God? Why me?”; and restoration-orientation appraisal processes included: attending to new life changes or purposeful denial and distraction from grief by “staying busy.”

Parents reported various means of support while they coped with grief. Support systems included immediate and extended family, friends, and community members who reached out to the parents, and church communities. However, some of these parents felt isolated despite the presence of support. These findings may be partially explained by parents who engaged in reclusive, self-protective behaviors to avoid hurtful communication from those who did not understand what they are going through. Concurring with the findings in the literature, parents who experienced infant death often sought social support from members of the community, though many parents continue to report feelings of social isolation, or a lack of social support (Cote-Arsenault & Freiij, 2004; Kavanaugh & Hershberger, 2005; Kavanaugh et al., 2004).

The majority of these parents discussed some type of financial support they received from either family, donations through a church, or hospital/pastoral services. Financial support after infant death ranged from delivered meals after the death to assistance with funeral expenses.

Bereavement follow-up care was also seen as very helpful to parents, especially when nurses attended the infant’s funeral. In addition, communication from the
bereavement program was seen as supportive and thoughtful. Parents valued the cards that were sent in the mail after infant death and the pictures that were taken around the time of the infant’s death. Similarly in the literature, contact after death in the NICU and PICU was appreciated from familiar hospital staff (Brosig et al., 2007; Meert et al., 2009). Further, in a study of parents of children hospitalized in the NICU and PICU, parents considered sensitive and caring health care providers as those who cried and prayed with the parents, called parents after the hospitalization, provided parents with a memory box for their infant, and attended the child’s funeral (Brooten et al., 2012).
Conclusions

The findings from this study exposed the importance of exploring parents’ experiences during their infant’s care near the end-of-life in the NICU and these parents’ bereavement coping experiences after infant death. “Being a parent” was extremely important for these participants regardless of the infant’s prognosis. NICU nurses played a critical role in facilitating parenting by teaching the parents how to interact with their critically ill infant and remaining a source of support throughout the NICU hospitalization. Participants reported barriers to parenting such as conflicts between healthcare providers, challenging logistics of traveling to visit their infant, financial burdens associated with the life and death of their infant, mothers managing the aftermath of a cesarean birth procedure, and the critical medical state of the infant. Adding to the strife parents endured in the NICU was the lack of family support because of an absent spouse or harmful family involvement. Conversely, parents also described various means of helpful support from nurses, chaplains, family and friends, as well as support through personal faith and prayer. Parents valued this support as they faced difficult, and sometimes life-and-death decisions for their infants. Living with these decisions proved to be an oscillating process between being “at peace” with decisions and wondering if they had made the best decisions for their child, similar to the process depicted in the DPM conceptual model.

Living with the loss of an infant was a catastrophic and life-changing event for these parents. Parents continued to cope with the loss; however, the painful grief symptoms never completely subsided, they only diminished over time. While some parents reported gratifying life changes and some parents reported the inability to
function in their day-to-day lives, the majority of the parents described major life changes after the death of their infant. Coping with the loss of their infant proved to be a complex process that also evolved over time where parents oscillated between focusing on the loss and focusing on living in a world without their infant.

Implications

Implications for Nursing Research

The findings from this study address the shortage of research on the EOL care provided to infants and their families surrounding infant death in the NICU, palliative care consultation experiences in the NICU, as well as bereavement and coping experiences after infant death. Parents described research participation as a positive and cathartic experience. This qualitative exploratory study points to the need for further research in the following areas:

- While this study does not provide conclusive evidence that infant death in the NICU should not be operationalized similarly to miscarriage and stillbirths, the findings from this study suggest that there is need to further investigate the differences between grief experiences among parents who experience miscarriage, stillbirths, and neonatal deaths, as well as the appropriateness of categorizing them together when measuring grief outcomes.
- Longitudinal studies are necessary to better understand how the type of care received in the NICU (i.e., end-of-life and/ or palliative care) affects coping, grief outcomes, health and functioning in bereaved parents so that changes in practice
and policy may be developed to improve the care parents and infants receive in the NICU.

- Barriers to initiating palliative care from the perspective of parents and healthcare providers require further investigation due to the misconceptions that palliative care may not be combined with curative and aggressive care.

- Financial burdens affected the majority of parents in this study. Long-term financial burdens associated with NICU hospitalization and infant death necessitate further study to determine the most effective way to target those parents at-risk of financial devastation after infant death and provide resources.

- Because the risk for increased morbidity and mortality is concerning in bereaved parents, and many parents in this study reported mental health issues affecting day-to-day functions, better understanding of parental mental health issues, and identification of risk factors for parents with infants in the NICU may be used to predict complicated grief.

- Parents described the need for professional grief counseling in this study. Most parents in this study lived over an hour away from Children’s of Alabama hospital. Currently, there are only in-person counseling services provided at the Amelia Center (free service to parents through Children’s of Alabama) and parents may be unable to access these services because of difficult traveling logistics. Further research is needed to determine what type of interventions would be helpful to parents of deceased infants in the community and at what time intervals these interventions would be most helpful.
• While it is unknown, bereaved parents of infants may be eager to volunteer in palliative care educational opportunities or community grief outreach with other parents who have suffered from infant loss. Because many of the parents discussed how important it was to talk with someone who could be empathetic to their needs, these may be valid interventions, but would require careful investigation of the risks and benefits for these vulnerable parents.

• The effectiveness of a follow-up meeting between the healthcare providers and parents after infant death may help to validate the decisions parents made in the NICU and clarify any questions related to the life and death of their infant.

• The Dual Process Model of Coping with Bereavement was supported by findings from this study and should be studied further in neonatal, infant, and pediatric deaths to better understand how parents cope with the grief associated with infant or child death.

Implications for Nursing Education

Results from this study suggest that nurses in the NICU play a critical role shaping memories that parents live with when grieving the loss of their infant. Therefore, it is necessary to educate nurses on providing compassionate and non-judgmental care to parents in the NICU who are facing infant death to better serve these infants and their parents. The Initiative for Pediatric Palliative Care, Robert Wood Johnson Foundation and the Institute of Medicine determined that healthcare professionals are not adequately trained for providing quality palliative care to neonates and infants (IOM, 2003; Meier, Isaacs, & Hughes, 2010; Solomon et al., 2002). The American Association of Colleges
of Nursing (AACN) has supported a national project educating nurses all over the country through the End-of-Life Education Consortium beginning in 2000 (AACN, 2010).

**Implications for Nursing Practice and Policy**

Findings from this study suggest there is much that can be done to improve the end-of-life and palliative care provided to parents of infants in the NICU. These results are important to nursing practice because the experiences of these parents can inform nurses on the difficulties parents faced during the NICU hospitalization, after losing their infant, and how these bereavement experiences continued over time. These findings may lead nurses to be more sympathetic to parents in the NICU given the known challenges these parents experienced. Implications from this study for nursing practice are:

- Nurses may help parents to normalize the experience of “feeling alone” due to an absent spouse because this is a common experience for parents in the NICU.
- Relationships among NICU parents and families should be fostered within the NICU by promoting activities together and healthy distractions away from the NICU.
- Primary nursing staffing models should be employed in the NICU to ensure consistent nursing care is provided to infants and their parents.
- Parents should be engaged as much as possible in the care of their infant in the NICU regardless of prognosis.
- A systematic method of determining appropriate palliative care referrals in the NICU may break through some of the barriers associated with both parents’ and
healthcare professionals’ resistance to palliative care initiation even when medically appropriate. Catlin and Carter (2002) suggest diagnoses common in the NICU that should automatically receive a palliative care consultation.

- Marketing “palliative care” using a different term such as “supportive care” may address some of the barriers associated with initiating these PC services due to the parents’ fear of discontinuing aggressive and curative treatments and the loss of hope.
- A process for screening parents at-risk for complicated grief during bereavement should be assessed during the NICU hospitalization and during bereavement follow-up at six months after infant death to determine those individuals who may experience severe consequences from grief such as depression, anxiety, and the inability to function day-to-day.
- Infant grief support in the community is limited, and although parents can access free grief support through the Amelia Center at Children’s of Alabama hospital in Birmingham, AL, difficult traveling logistics may prevent parents from benefitting from these services. Thus, distance grief support may be necessary for these parents for many years.

Limitations

During the interviews, parents recalled events that occurred in a past NICU hospitalization and their experiences following their child’s death (average time since infant death was four years). While these experiences were traumatic and not easily forgotten, it is possible that parents could have recalled some of their experiences
inaccurately or responded with socially desirable answers. Because the end product of data analysis was to provide comprehensive descriptive summaries that accurately reflected the meaning participants attributed to their experiences, the researcher must trust that the participants were being truthful in their responses (Polit & Beck, 2012; Sandelowski, 2000, 2010).

Parents described their grief and coping experiences as an evolving process. However, the use of a qualitative design study with one data collection point limits the understanding of coping with bereavement over time. Future studies would benefit from a prospective, longitudinal design to better understand how coping with grief evolves in parents who have lost an infant.

It is possible that some of the parents who sought the opportunity to participate in this research study needed a chance to talk about their loss because they were not adapting successfully to life after the death of their infant. Thus, these findings may reveal another perspective from parents who did not have an adequate support network with whom the parents could talk about the life and death of their infant as well as their life since infant death.

In terms of selecting a representative sample, more mothers \( (n=7) \) were recruited than fathers \( (n=3) \) and future studies should target an increased representation of fathers to better understand paternal experiences related to life before and after infant death in the NICU. While a diverse sample was recruited in terms of household income and education, non-English speaking parents were excluded and parents were recruited from a single hospital institution. More Caucasian parents \( (n=7) \) were recruited than minority parents \( (n=3) \); thus, future studies should target ethnically diverse parents to account for
cultural variations in NICU care and coping with grief. In addition, recruiting parents from multiple institutions where neonatal EOL and pediatric PC consultation is provided may strengthen findings.

Strengths

The PI made every attempt to make the parent participant feel comfortable and openly share their stories. The interviews yielded rich findings that addressed a gap in the literature on parent experiences with neonatal EOL and palliative care consultation and bereavement and coping experiences after infant death in the NICU. In contrast with many previous studies, parents from diverse income backgrounds were recruited in this study. Also, in previous studies many parent dyads have been interviewed together; however in this study, each parent was interviewed separately to understand their individual experiences without spousal influence.

Future Recommendations

The results of this study suggest there are areas for improvement in the provision of end-of-life and palliative care in the NICU that may be addressed by further research and changes in practice and policy. Parents described research participation as a positive and cathartic experience and this population should continue to be recruited in future research efforts. Future recommendations for research include: (a) Investigating barriers to initiating palliative care from the perspective of parents and healthcare providers because of the misconceptions that palliative care may not be combined with curative and aggressive care, (b) Longitudinal studies to better understand how the type of care
received in the NICU (i.e., end-of-life and/or palliative care) affects coping, grief outcomes, health, and functioning in bereaved parents, and (c) Further research is needed to determine what type of grief support interventions would be helpful to bereaved parents of infants in the community and at what time intervals these interventions would be most helpful.
List of References


doi: 10.1542/peds.2006-3180


doi: 10.1080/07481180600923257


Faught, J. (2011). Palliative Care Program at Children's Hospital of Alabama. from National Palliative Care Registry.


APPENDIX A

COPYRIGHT PERMISSION FOR THE USE OF
THE DUAL PROCESS MODEL OF COPING WITH BEREAVEMENT
Dear Erin,

Thank you for your kind words about our work, we are very pleased that you find it useful. Of course you may use the model, and since we hold the copyright for the figure, there is no problem if you wish to reproduce it. All the very best for your research and dissertation. Henk Schut and Margaret Stroebe

Sent from my iPad On 6 okt. 2014, at 17:16, "Erin R Currie" <ecurrie@uab.edu> wrote:

Hello Dr. Stroebe and Dr. Schut,

I am a PhD student at the University of Alabama at Birmingham in the USA and my dissertation research is a qualitative study focused on parent perspectives of neonatal intensive care at the end-of-life and bereavement and coping experiences after infant death.

I have thoroughly enjoyed reading your work related to bereavement and coping and I am writing to ask your permission to use your Dual Process Model of Coping with Bereavement in my Dissertation as well as my Defense presentation. Specifically, I would like to include the image of your model in my work.

Best regards,

Erin R. Currie, MSN, RN

University of Alabama at Birmingham School of Nursing PhD Candidate 850.698.4128

ecurrie@uab.edu
APPENDIX B

UNIVERSITY OF ALABAMA AT BIRMINGHAM
INSTITUTIONAL REVIEW BOARD APPROVAL
UAB’s Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on January 24, 2017. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: ROUTH, ERIN M
Co-Investigator(s): 
Protocol Number: X130912012
Protocol Title: Parent Perspectives of Neonatal Intensive Care at the End of Life and Subsequent Bereavement and Coping Experience after Infant Death

The IRB reviewed and approved the above named project on 11.22.15. The review was conducted in accordance with UAB’s Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.
IRB Approval Date: 11.22.13
Date IRB Approval Issued: 11.22.13
IRB Approval No Longer Valid On: 11.22.14

Marilyn Doss, M.A.
Vice Chair of the Institutional Review Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.
APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE
participant pseudonym __________

demographic questionnaire

date: _________

1. parent age: _________

2. parent gender: _________ female _________ male

3. relationship to infant
__________ biological parent
__________ legal guardian of infant
__________ if legal guardian please list your specific relationship (i.e.,
grandparent, aunt, uncle, foster parent etc.)

4. race/ethnicity:
__________ african american/ black
__________ asian
__________ caucasian
__________ hispanic
__________ other: please list _________

5. education level
__________ high school or equivalent (ged)
__________ some college
__________ two year college graduate
__________ bachelor’s degree
__________ master’s degree
__________ doctoral degree

6. religious affiliation
________________________________________

7. current marital/relationship status
__________ married
__________ separated
__________ divorced
__________ single/ never married
__________ living with someone (cohabitating)
8. MARITAL STATUS AT TIME OF INFANT LOSS:

- Married
- Separated
- Divorced
- Single/ never married
- Living with someone (Cohabitating)

9. CURRENT ANNUAL HOUSEHOLD INCOME

- Less than $10,000
- $10,001 - $20,000
- $20,001 - $40,000
- $40,001 - $60,000
- $60,001 - $80,000
- $80,001 - $100,000
- $100,001 - $250,000
- Greater than $250,000

10. CURRENT TOTAL NUMBER OF INDIVIDUALS LIVING IN HOUSEHOLD

11. NUMBER OF LIVING CHILDREN

The remaining questions are directly related to the death of your infant.

12. NUMBER OF PREGNANCIES SINCE INFANT LOSS

13. NUMBER OF LIVE BIRTHS SINCE INFANT LOSS

14. LIST ANY MAJOR LIFE EVENTS THAT HAVE OCCURRED SINCE YOUR INFANT LOSS

15. INFANT DATE OF BIRTH

16. HOSPITAL WHERE INFANT WAS BORN
17. TYPE OF INFANT BIRTH

__________ Single Birth
__________ Multiple Birth (twins, triplets, etc.)

18. TYPE OF INFANT DELIVERY

__________ Vaginal birth
__________ Cesarean birth (C-section/ surgery)

19. INFANT GENDER __________ Female __________ Male

20. INFANT RACE

__________ African American/ Black
__________ Asian
__________ Caucasian
__________ Hispanic
__________ Other: Please list __________

21. LENGTH OF HOSPITALIZATION AT CHILDREN’S OF ALABAMA HOSPITAL__________________________________

22. TRAVEL TIME FROM RESIDENCE TO CHILDREN’S OF ALABAMA HOSPITAL DURING YOUR INFANT’S HOSPITALIZATION IN THE NICU

__________ Less than 10 minutes
__________ 10-30 minutes
__________ 31-60 minutes
__________ 61-90 minutes
__________ 91-120 minutes
__________ Greater than 120 minutes

23. DID YOU STAY AT THE RONALD MCDONALD HOUSE DURING YOUR INFANT’S HOSPITALIZATION?

__________ Yes
__________ No

24. DID YOU RECEIVE PALLIATIVE CARE CONSULTATION BEFORE YOUR BABY WAS BORN?

__________ YES
__________ NO
25. DID YOU RECEIVE PALLIATIVE CARE CONSULTATION AT CHILDREN'S OF ALABAMA?

_________ YES
_________ NO

26. IF YES TO #25, WHY DID YOU START TO INCLUDE PALLIATIVE CARE IN THE NICU?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

27. LOCATION OF INFANT DEATH (i.e. hospital- NICU, hospital- private room, hospital- family room, hospice, home)

____________________________________________________________________
____________________________________________________________________

28. DATE OF INFANT DEATH___________________

29. CAUSE OF INFANT DEATH___________________

30. DID YOU USE A GRIEF SUPPORT GROUP AFTER YOUR LOSS?

________ Yes
________ No
APPENDIX D

INTERVIEW SCRIPT AND QUESTIONS
Interview Script

I want to thank you for your interest in this study and for allowing me to spend this time with you today. I will be recording your interview today with an electronic voice recorder. I will be asking you questions about your experiences with the NICU hospitalization and care at the end-of-life during your baby’s hospitalization. I will also ask you about your life since the loss of your baby.

The interview is tape recorded so that I do not miss anything that you tell me about your experiences. Please know that the tape recordings are confidential and will not be shared with anyone.

I understand these are sensitive questions and I recognize that you may need a break or be unable to finish the interview due to emotional distress related to talking about your baby. Please let me know if you need to stop the interview at any time. Do you have any questions before we begin?

I would like to start the interview when you are ready.

Interview Questions

Aim 1

NICU End-of-Life care

1. Please tell me about your baby.
   a. If a specific probe is needed to help the participant start the interview, I will ask:
      I would like to understand what your baby’s life was like. Please introduce me to “infant’s name” and what his/her life was like?

2. Tell me about your experiences with (infant’s name) hospitalization leading up to the end of (infant’s name) life?
   a. Tell me about some of the things that were helpful for you as a parent in the NICU?
   b. Tell me about things you experienced that were not helpful to you as a parent in the NICU?
   c. What other experiences with your family or friends were helpful to you during the hospitalization?
   d. What other experiences with your family or friends were not helpful during the NICU hospitalization?

3. Tell me about your experiences in the hospital or with home care near the end of (infant’s name) life?
   a. What, if any, hospital experiences helped you cope with your loss?
4. Tell me about the decisions you had to make near the end of (infant’s name) life?
   a. Thinking back, what was helpful for you when you were making decisions for (infant’s name)?
   b. Was there anything that made these decisions for (infant’s name) more difficult?
   c. When you think back about these decisions, how do you feel about them?
   a. How, if at all, have your feelings about these decisions changed over time?

---

**Palliative Care Consultation**

*If parents were exposed to palliative care consultation the following questions will be asked:*

Now I would like to ask you some questions about your experiences with the palliative care team during (infant’s name) hospitalization.

5. Did you know what palliative care was before you received consultation from the palliative care team in the NICU?
   a. Please explain what palliative care meant to you.

6. How did you decide to use palliative care while in the NICU?
   a. How did you feel about beginning palliative care for (infant’s name)?

7. Tell me about your experiences with the palliative care team in the NICU?

8. How did your treatment in the NICU change after the palliative care team began to work with you and your baby?
   a. Were the differences in the way nurses and doctors treated you? Please explain.
   b. Were the changes in the way other parents in the NICU treated you after you started palliative care? Please explain.

9. Would you tell other parents to use the palliative care team? Please explain why you would or would not recommend palliative care for other parents in the NICU.

---

**Aim 2**

**Bereavement and coping experiences**

Now I would like to ask you some questions about your life since the loss of (infant name).

1. Tell me about your life since the loss of (infant’s name)?
2. Tell me about the things you did to cope with your grief after losing (infant’s name)?
   a. How have they changed from the time you lost (infant’s name) to now?

3. Tell me about any support that you received in coping with the loss.
a. How did you receive support from your community? For example: Family, friends, support groups, religious activities etc.?

4. Tell me what was helpful in coping with your loss?
5. Tell me what was not helpful to you in coping with your loss?
6. How have your experiences in the NICU helped you cope with the loss and/or made it more difficult for you to cope with the loss?
7. What are some things in your life that helped you get through the loss of (infant’s name)?
8. How have you changed since your loss?
9. How has your perspective on life changed since your loss?
10. Based on your experience, what would you tell other parents to help them cope with the loss of their infant?

Interview closure

11. Is there anything else you would like to add?
12. What was it like for you to participate in this interview today?

Probes
Interview probes will be used to gain richer data and more detailed explanations from the participants regarding their experiences.

1. Please tell me more.
2. Go on if you can.
3. Could you please tell me more about your experience?