

Parental Loss and Grief in the Neonatal Intensive Care Unit:
A Systematic Review of Qualitative Evidence

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Abstract

Premature and ill infants are admitted to neonatal intensive care units (NICU) for specialized medical and nursing care. Infants admitted to NICUs require the use of life sustaining technology and care from a multidisciplinary health care team. While in hospital, an infant's prognosis and expected outcomes can dramatically change. Depending on the circumstances of their infant's health, parents may choose to withdraw life sustaining treatment, or alternatively, face a future reality with the potential of long-term impact related to their infant's diagnosis. Parents with an infant in the NICU experience many different types of losses which can generate a grief response. The purpose of this thesis is to explore parental loss and grief in the NICU. A systematic review of qualitative evidence modelled on the Joanna Briggs Institute method (2014) was completed. This approach included a systematic and rigorous approach to the searching, critical appraisal, and aggregation procedures. Four databases (CINAHL, Medline, PsycINFO, Nursing and Allied Health) were systematically searched using pre-identified search criteria. Two reviewers were involved in the search and screening, and three additional reviewers were used to identify included articles. This search process resulted in five studies being included in the review. Five themes were identified from the original research studies: support, not knowing what to expect, hospital practices, communication, and coming through grief. The results of this systematic review of qualitative evidence demonstrate that loss and grief have been described by parents in the NICU, both in the presence and absence of neonatal death.

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Chapter 1: Introduction

1.1 Background

Neonatal intensive care units (NICUs) provide specialized care to critically ill neonates and their families (Marchuk, 2016). While neonates are defined as infants under 28 days old (Mosby, 2009), prematurity often constitutes a reason for admission to the NICU. Infants born prematurely at less than 33 weeks, for example, comprise 27% of the admissions to Canadian NICUs (Canadian Neonatal Network [CNN], 2016). Infants born this early have profound immaturity of their organ systems and often require the use of life supporting technologies (e.g. mechanical ventilation and gavage feedings) (Kenner & Lott, 2014). Infants are also admitted to the NICU for reasons other than prematurity including low birth weight, infection, congenital defects, and difficulties transitioning to the extrauterine environment (American Nurses Association [ANA] & National Association of Neonatal Nurses [NANN], 2013).

The admission of an infant to a NICU is often sudden and unexpected. Kenner and Lott (2014) note that many of these infants require the use of complex technology and comprehensive neonatal care. In 2015 alone, 14,815 infants were admitted to 32 Canadian NICUs and 376 infants died (CNN, 2016). As Hurlimann (2005) described, we “are now able to save many imperiled infants who, in previous times, would not or could not have been resuscitated because of a presumed lack of viability or merely because of the absence of effective technical means” (p. 2).

Medical and technological breakthroughs have impacted the specialized needs of these infants over time (ANA & NANN, 2013). In 2001, for example, a Canadian study examined morbidity and mortality in a large cohort of extremely preterm infants (infants born at less than 25 weeks gestation) (Chan et al. 2001). Chan and colleagues (2001) found that for infants born

at 22 weeks gestation, the rate of survival was 14%, and by 25 weeks it had increased dramatically to 76%. Findings from this study also indicated that infants who were born at 22 weeks suffered multiple illnesses while in hospital, such as chronic lung disease, retinopathy of prematurity, severe intraventricular hemorrhage, and patent ductus arteriosus (Chan et al., 2001). These comorbidities presented health challenges to the infant and family both while they were in hospital, as well as when they were discharged home. Recently the Canadian Paediatric Society position statement on counselling and management for anticipated extremely preterm birth stated that between 2010 and 2015 the survival of infants born at less than 23 weeks gestation increased slightly to 18%, with the survival at 25 weeks gestation increasing to 79% (Lemyre, Moore, & the Canadian Paediatric Society Fetus and Newborn Committee, 2017). Despite a slight increase in the survival rate over time, extreme prematurity continues to have an influence on an infant's long term outcomes. Extremely premature infants are at a higher risk of developing moderate to severe neurodevelopment disability (e.g., cerebral palsy, cognitive and motor impairment, as well as visual and hearing deficits) (Lemyre, Moore, & Canadian Paediatric Society Fetus and Newborn Committee, 2017).

In the NICU, neonatal nurses work within the context of an interdisciplinary health care team comprised of, but not limited to, physicians, respiratory therapists, social workers, dietitians, and pharmacists. Neonatal nurses, who have the most prominent bedside presence, strive to provide care that is both comprehensive and individualized in order to meet the unique needs of each infant and their family (ANA & NANN, 2013). This nursing care involves continuous assessment, developmentally supportive care, and a family centred approach (ANA & NANN, 2013). Developmental care encompasses care delivery that is tailored to the unique needs of the infant and involves decreasing environmental stimuli, such as noise and light, in

efforts to enhance neurodevelopment (Premji, 2014). Developmental care involves therapeutic positioning (e.g. positioning infants with their hands close to their face, and their body in a midline position), which aims to promote normal musculoskeletal development (Bradley & Ritter, 2014). Family centred care recognizes the family as an integral part of effective care delivery and aims to create a partnership between families and the health care team (Canadian Nurses Association [CNA], 2017). In the NICU, nurses spend a significant amount of time teaching and supporting families in addition to providing care to medically complex infants.

Many parents of infants admitted to a NICU face the challenges of having an infant who is critically ill, who could die, or who might face lifelong medical complications (Hall et al., 2015a). Parents are actively involved in the decision making process regarding their infant's care, including decisions related to withdrawal of treatment. Parents of infants admitted to the NICU experience a plethora of emotional, psychological, and situational stressors, placing them at a "significantly higher risk for numerous psychological problems compared with parents of healthy term infants" (Hall et al., 2015a, p. 24). Parents can also experience complex feelings such as depression, anxiety, stress, loss of control, as well as grief (Obeidat, Bond, & Callister, 2009). These feelings can be overwhelming and affect parents' coping abilities, both while their infants are in the NICU, as well as after discharge. NICU nurses often develop close relationships with families because of their continual presence at the bedside.

In the NICU, emotional and psychological support is provided to parents grieving the death of their infant. However, parents with an infant struggling to survive also experience losses that are outside of the context of death and dying (Woodroffe, 2006). In a study by Baum, Weidberg, Osher and Kohelet (2012), for example, a sense of loss was described by mothers after the birth of their premature infant. As one mother described "I felt pained that I couldn't

have my baby in the room. You want to be with your child, and you can't, because she's in an incubator....I don't know how to explain it. You feel that something is missing" (Baum et al., 2012, p. 600). A literature review by Obeidat et al. (2009) also found that a NICU hospitalization caused role strain, distress, and emotional pain for parents. Parents can experience different types of losses while in the NICU, such as the loss of control of their parental role after a preterm birth (Spinelli et al., 2016), resulting in a mix of emotional experiences while their infant is in the unit. It is, therefore, vitally important that nurses support parents across the health and illness trajectories of neonates. Loss is the antecedent to grief and there is a need for research regarding grief responses in association with various types of losses experienced (Cowles & Rodgers, 1991). In order to provide holistic care to the infant and their family, the complexity of loss and grief as it is experienced by parents within NICU requires exploration.

In summary, it is imperative that neonatal nurses are able to recognize loss and grief experiences of families and assist them to cope with the challenges associated with a NICU admission. This thesis will explore loss and grief as described by parents in the NICU. Through this exploration and elaboration of parents' experiences we can gain valuable insight into the impact that a NICU admission has had on them. Understanding these experiences is vital in designing unique, holistic, and specialized care for these parents.

1. 2 Personal Experiences of Loss and Grief in the NICU

As a registered nurse in the NICU, I have cared for many families who have enriched my nursing career over the years. I have seen, and personally experienced, the celebration of new life at birth, as well as the joy that can be experienced when an infant is discharged home. Caring for these infants and families and watching them grow and develop is awe inspiring.

Families often spend many months in our units, and as a result, members of the health care team often develop strong bonds with many families. These experiences have provided me with the satisfaction and pride to continue to nurse in the NICU *even* on the most difficult days.

Sadly, I have also observed the profound despair a family experiences when their infant is admitted to our unit only to be told that there is nothing more that can be done for their baby. I have journeyed with families through their personal moments of loss and grief, and held their hand when the worst of news is delivered. For example, as neonatal nurses, we participate in family meetings where physicians disclose to parents the results of a head ultrasound revealing devastating consequences for their infant. Depending on the circumstances of their infant's health, parents may choose to withdraw life sustaining treatment, or alternatively, face a future reality with the potential of long term impact related to their infant's diagnosis. Regardless of the decision the family makes, our role as health care providers and as neonatal nurses, is to support them throughout this experience.

In my personal experiences, two families in particular have caused me to reflect on the care I provide and look for ways to improve. The first family, whose son was born at 24 weeks gestation, demonstrated the astounding impact of neonatal care. This boy progressed well throughout his hospitalization and is a testament to the amazing care provided in our NICU. Through continued contact with his family, they have shown me that even upon survival, the impact of a NICU hospitalization is long lasting, and the experiences they had in our unit continue to affect many aspects of their lives, long after their infant was discharged home. This continued effect on their lives is related to both the long term medical implications of caring for an infant born prematurely, as well as the psychological impact of a prolonged hospitalization.

The second family is one which troubles me, even years after their infant died. This family faced a devastating prognosis, and despite initiation of multiple interventions there was little we could do to delay their infant's inevitable death. This family was shocked and devastated and despite multiple attempts at establishing a therapeutic relationship with them, they withdrew from our efforts to support them. The nurses held this infant as she died, and I longed to be able to provide more to assist this family. I had hoped that even as medical interventions failed, our attempts at emotional support would be useful. This family demonstrated to me that as nurses we need to ensure we not only provide the highest standard of medical and nursing care to our patients, but also consider how we can best support families, especially after a difficult outcome.

1.3 Loss

Loss is "the instance of losing or having lost something" (Robinson & McKenna, 1998, p. 780). Further, loss is a natural part of our human existence and can be experienced at various points throughout life (Rando, 1984). Loss may occur due to changes in roles, expectations, body image and function as well as loss due to the death of a significant other (such as a family member or friend) (Payne, Horn, & Relf, 1999). Each loss will have an impact on an individual and the grief reaction that follows can differ based on an individual's personality, as well as their other experiences (e.g. if a similar situation has been experienced in the past it may be slightly easier to cope with) (Rando, 1984).

Rando (1984) identified two types of losses, physical and symbolic. A physical loss can be experienced after the death of an individual. A symbolic loss can involve life experiences and situations such as divorce or preterm birth (Rando, 1984). In comparison to physical losses, symbolic losses may not be as easily identified or understood (Rando, 1984). Both types of

losses can be experienced in the NICU. Physical loss can be experienced by parents after the death of their infant. Examples of symbolic losses in the NICU that have been described in the literature include: the loss of a term pregnancy and normal labor and delivery experience (Affonso, Bosque, Wahlberg, & Brady, 1993; Flacking, Ewald, Hedberg Nyqvist, & Starrin, 2006), loss of parental role (Holditch-Davis & Miles, 2000, Spinelli et al., 2016), and loss of control (e.g. over the pregnancy and subsequent events when an infant is admitted to a NICU) (Affonso et al., 1993; Obeidat et al., 2009).

The role of neonatal nurses can involve working with families to identify and acknowledge the types of losses they may be experiencing, even if the loss is not due to a death. This involves helping them through the grieving process, as well as assessing whether further assistance is needed. Individual mothers and fathers in the NICU may grieve differently with the losses they experience and having some knowledge of these types of reactions can better prepare nurses to provide this type of care. If parents do not identify and acknowledge the types of losses they are experiencing, this could have devastating consequences for parenting (Woodroffe, 2006).

Parents' experiences of loss in the NICU can also be influenced by an infant's illness, prognosis, as well as the potential long term impact(s) of their illness and/or hospitalization. The types of feelings that can be associated with, as well as evoked by a loss include anger, helplessness, guilt, resentment, fear, isolation, frustration, panic, confusion, devastation, exhaustion, and worry (Woodroffe, 2006). Unfortunately, for many families, the admission of their infant to a NICU is both sudden and unexpected, and as such, it is possible that families may be ill prepared for what might occur.

1.4 Grief

Grief is a dynamic, pervasive, and individualized process in response to a loss (Cowles & Rodgers, 1991). Many different types of losses generate a grief response; these responses can be influenced by a person's gender, family, religion, and culture (Dyer, 2005). Dyer (2005) elaborates further by describing grief as a response to loss that "includes psychological, behavioral, and physical reactions combined with cognitive, emotional, behavioral, social, spiritual and somatic elements" (p. 39). Grief is a natural and expected reaction to a loss (Rando, 1984). The nature, intensity and length of the grieving process can be influenced by a number of factors such as the relationship with the deceased, the cause of death, or the perception of the loss itself (Rando, 1984).

Cowles and Rodgers (1991) state that grief can potentially influence every aspect of an individual's existence. For example, physical reactions to grief can include alterations in heart rate and blood pressure, crying, and gastrointestinal disturbances (Cowles & Rodgers, 1991). The emotional response can evoke feelings of loneliness, helplessness, fear, anxiety, panic, and shock (Dyer, 2005). Further, social responses can involve avoiding others, withdrawal, and a lack of interest in activities of daily life (Dyer, 2005). Dyer (2005) also reports that intense grief related emotions and reactions are common in the early days following a loss and can involve numbness, disorganization, and depression. While over time, there is usually a gradual decline in distress and symptoms (Dyer, 2005), the length of time that an individual grieves is unique. The terms grief and bereavement are often used interchangeably, however, bereavement is the objective state of having lost someone or something, and is the term used to describe having suffered a loss due to the death of an individual (Dyer, 2005). Individuals can experience grief due to many different types of losses, not just because of the death of an individual (Thompson,

2012). Thompson (2012) describes grief as a set of processes that vary between individuals, but that can also vary based on social groups, culture, and gender.

In an attempt to explain grieving, various approaches have developed over time. A number of researchers have investigated the concepts surrounding grief (Bowlby, 1980; Lindemann, 1994; Parkes 1976, Worden, 1991). Many grief theories and frameworks have common themes or stages (Buglass, 2010). One common stage model is that of Kubler-Ross (1969) which involves five stages that individuals experience in response to a loss, which include denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969). A limitation of this model, however, is that it suggests that grief follows a set pattern (Buglass, 2010), which may not reflect the experiences of all individuals. Hindmarch (2009) describes how conventional grief theories may be inadequate when it comes to the death of a child in part because past research has been concentrated on the death of a spouse or partner.

The unique grief experience of losing a child may not be comparable to other types of losses that an individual can experience. Grieving the loss of a child can involve a loss of hope for the future, as well as the loss of an individual who is an extension of the parents (Freeman, 2005). Parents that lose their infant in the NICU may face a challenging situation, because as Freeman (2005) suggests, the death of one's child can be considered one of the most difficult circumstances an individual can experience. The families of infants who die in the NICU will have unique needs and it is important that neonatal nurses adequately identify potential types of losses (beyond death and dying), as well as assess and manage grief in families in the NICU. As a result, neonatal nurses need to consider the unique nature of grief, even when an infant survives. Grief can occur as parents cope with the loss of control over their parenting role, as well as the loss of a normal pregnancy and delivery experience (Dyer, 2005).

1.5 Helping Families with Loss and Grief

Thompson (2012) describes how there is a need for a good understanding of loss and grief if we are to assist individuals in health care settings. In a concept analysis on loss Robinson and McKenna (1998) describe how grief can be understood as the consequence to a loss, and thus, from this perspective, loss and grief are related concepts. Importantly, neonatal nurses require an understanding of loss and grief, in order to assess the types of losses parents may experience and to identify the ensuing grief response.

Although nurses are often present during situations involving loss and grief, they do not always have the knowledge, skills, and confidence to provide optimal care (Buglass, 2010). Robinson and McKenna (1998) note that loss is an individual and subjective experience and so it is important that nurses be familiar with potential sources of loss in the NICU. Further, it can also be difficult to identify grief because the assessment of it cannot be based on outward symptoms alone (Cowles & Rogers, 1991). Therefore, it is imperative that nurses be knowledgeable regarding the complexity of loss and grief, and thereby able to tailor care and supportive resources to the individualized experiences within which neonates and their parents are situated.

It is vital that nurses be both aware of and prepared for, loss and grief reactions that may be observed in both the presence *and* absence of death (Walsh-Burke, 2006). Nurses can assist in parental transitions through the grief process by offering information and support and by working with them to find effective coping strategies (Dyer, 2005). Neonatal nurses are positioned to use their knowledge and skills to assist families throughout their journey of loss and grief. This thesis will provide insight into the loss and grief experiences of parents with infants in the NICU as described in extant literature. Recognizing a link between loss and grief,

combining both concepts in a systematic review of qualitative evidence will enhance our understanding of the experiences of parents in the NICU.

1.6 Research Question

The research question for this project was: *how are loss and grief experienced by parents in the NICU?* The aim of this thesis was to explore and describe existing literature on parental experiences of loss and grief in the NICU. This approach involved examining published qualitative studies exploring loss and grief from the perspective of the parents.

1.7 Thesis Structure

A systematic review of qualitative evidence was used to explore loss and grief within the context of parental experiences in the NICU. In this Chapter, my personal motives for the research question were presented, as well as an overview of neonatal care including the role that nurses play in supporting parents who experience loss and grief in the NICU. Additionally, literature related to loss and grief was described and linked both to the NICU context and the phenomenon of interest – parents' experiences of loss and grief.

Chapters two through four will outline the systematic review in depth. In Chapter two, I will describe the methodology used for the review and the results are presented in Chapter three. In Chapter four, I provide a discussion of the findings, the implications for nursing practice, research, and education, and the limitations of the systematic review.

Chapter 2: Methods

In this chapter, I describe the methodology used for this systematic review of qualitative evidence. This includes a description of review methods and the rationale behind the chosen approach. Additionally, I explain the steps taken in this review, the design of the search strategy, the methods used for critical appraisal, and the aggregation procedures, in an effort to demonstrate rigour and methodological transparency (Hannes & Macaitis, 2012). The results of this review will be presented in Chapter Three.

2.1 Qualitative Research

Qualitative research consists of “a set of interpretive, material practices that make the world visible” (Denzin & Lincoln, 2018, p. 10). Qualitative approaches to research can be used to explore human phenomena, and strives to understand the viewpoints of the participants (Streubert & Rinaldi Carpenter, 2011). Qualitative research allows for the exploration of the perspectives of people living with a particular experience and readily acknowledges the many subjective experiences that exist (Streubert & Rinaldi Carpenter, 2011).

Further, qualitative research can be used to study a variety of topics within health care including experiences of health and illness. Qualitative studies are increasingly being used to inform evidence-based health care, give voice to the patient in health care decision making, to assist in understanding how individuals perceive health, and to make decisions regarding health care usage (Joanna Briggs Institute (JBI), 2014). For research questions regarding the ‘experience’ of health care services, the findings of qualitative studies can be the best source of information (Popay & Mallinson, 2010). Qualitative data collection methods include, but are not limited to, interviews, focus groups and field observations (JBI, 2014). These data collection

methods allow for rich descriptions of participants' experiences and can assist both researchers and health care providers alike in understanding the topic under review in greater detail.

The parental experience of loss and grief in the NICU has been explored using qualitative approaches. The benefit of using such approaches to explore the phenomenon is that it allows for an in-depth exploration and understanding of parental experiences as described by the parents themselves. Streubert and Rinaldi Carpenter (2011) suggest that nurse researchers are now being tasked with moving beyond reporting of individual findings to aggregating and synthesizing multiple studies. In aggregating the results of multiple qualitative studies about a particular phenomenon (in this instance parental experiences of loss and grief in the NICU), a more reliable evidence base can be produced (Popay & Mallinson, 2010).

2.2 Review Methods

The expansion of evidence-based practice across health care has led to the development of various types of review methodologies (Grant & Booth, 2009). In nursing research, for example, topics such as the nursing role in stroke rehabilitation (Clarke, 2013), new graduate nurses experiences of patient death (Zheng, Lee, & Bloomer, 2016), resiliency in nursing and midwifery students (McGowan & Murray, 2016) and the experience of chronic pain across conditions (Crowe et al., 2017) have all been studied using review methodologies. Webb and Roe (2007) note that multiple review methodologies are used for both qualitative and quantitative data, and that these methodologies continue to evolve over time. It is important then to first consider the nature of the research question and the type of literature that may inform a review, prior to choosing the most appropriate review methodology.

The primary purpose of a review of existing knowledge “is to gain an in-depth understanding of a phenomenon by building on the work of others” (Broome, 2000, p. 231).

Through the integration of related knowledge generated from separate research studies, a more comprehensive understanding of a phenomenon may occur (Kirkevold, 1997). Kirkevold (1997) suggests that systematic reviews can contribute to the expansion of nursing science, improve practice, as well as create a more unified knowledge base for clinical nurses. It is important that nurse researchers present a comprehensive, critically evaluated understanding of a problem, in order for nursing research to be accessible to clinical nurses (Kirkevold, 1997).

A systematic review seeks to identify, critically appraise, and analyze data from previous studies, and may also incorporate statistical analysis methods to analyze results (Grimshaw, 2011). A variety of research questions can be examined using this approach, in particular questions regarding the efficacy and effectiveness of health care interventions (Grimshaw, 2011), however, there are many types of research questions that do not fit this synthesis approach. As a result, in recent years, there has been an expansion of the different types of review methodologies used in health care (Grimshaw, 2011). Some methodologies capture diverse bodies of literature and include approaches such as scoping reviews or basic literature reviews (Grant & Booth, 2009). These approaches aim to identify the nature and extent of current research and may be used to examine the need for future work (Grimshaw, 2011). A scoping review, for example, can be completed as a preliminary assessment of the size and scope of current literature, and can identify the need for a full systematic review (Arksey & O'Malley, 2005). Scoping reviews can also summarize research findings, as well as identify gaps in current literature (Arksey & O'Malley, 2005). A limitation of both scoping reviews and traditional literature reviews is that they do not necessitate the same rigour and quality appraisal as traditional systematic review methodologies. While they are quicker and less resource intensive

as a result, the findings of scoping and literature reviews should not underpin policy or practice changes because of their methodological limitations (Grant & Booth, 2009).

Other methodologies such as a mixed methods review and systematic reviews of qualitative evidence are more precise in their approaches. A mixed methods review aims to capture both qualitative and quantitative literature and can be used to provide a more holistic answer to a clinical question (Grant & Booth, 2009). A benefit of such an approach, is that the combination of both qualitative and quantitative literature has the potential to allow a broader understanding of a phenomenon through triangulation of different forms of knowledge on the topic, as well as a more complete picture of research completed in a specific area (Grant & Booth, 2009). A challenge associated with this methodology, however, is the difficulties that can be encountered when completing both the quality appraisal and data synthesis, using qualitative and quantitative data (Grant & Booth, 2009). For instance, challenges may be encountered when trying to identify a quality appraisal tool that can be used for both qualitative and quantitative data. Finally, systematic reviews of qualitative evidence are specialized and precise approaches which are used to aggregate qualitative research and involves similar steps as a systematic review. The advantage of a systematic review of qualitative evidence is that it aims to bring together data from individual qualitative studies (Tong, Flemming, McInnes, Oliver, & Craig, 2012) which can lead to theory development, an overarching understanding of the phenomenon studied, or a broader generalization of the concepts under review (Grant & Booth, 2009).

2.3 Systematic Reviews of Qualitative Evidence

Various qualitative review methodologies (e.g., meta-ethnography, meta-synthesis, meta-study, grounded theory synthesis, critical interpretive synthesis, meta-aggregation) have been used to aggregate and synthesize the findings of qualitative literature. The benefit of these

approaches is that the results can provide a range and depth of meanings, experiences, and perspectives as described by the participants themselves (Tong et al., 2012). These methodologies have the ability to broaden the transferability and clinical applicability of qualitative studies, however, can be challenging due to the contextual nature of qualitative findings (Whittemore, 2005). Qualitative literature is often grounded in the participants experiences, is context dependant, and the findings can be influenced by the researcher's experience and viewpoint (Streubert & Rinaldi Carpenter, 2011). These characteristics can add complexity when trying to summarize and aggregate the findings from multiple qualitative studies.

A systematic review of qualitative evidence modelled on the JBI (2014) method for qualitative reviews has been used in this thesis to explore parental loss and grief in the NICU. As described in Chapter 1, for many parents, having a child in the NICU can evoke feelings of stress, strain, depression, and despair, as well as a vacillation between hope and hopelessness (Obeidat et al., 2009). Qualitative literature was purposely selected for this review to ensure the findings of the review emerge from the experiences of parents themselves. The findings revealed through the integration of multiple studies exploring loss and grief in the NICU will increase nurses understanding of parental experiences of these phenomena.

2.3.1 Joanna Briggs Institute qualitative reviews. The JBI is a research and development organization that aims to promote and enhance the synthesis, transfer, and utilization of evidence in health care (JBI, 2014). The JBI proposes an approach to qualitative reviews that includes a comprehensive search, independent critical appraisal, and data extraction using a standardized template (JBI, 2014). JBI qualitative reviews can include studies with a range of methodologies including but not limited to ethnography, phenomenology, qualitative

inquiry, action research, discourse analysis, and grounded theory (JBI, 2014). The JBI approach to qualitative reviews has clear, concrete steps that allow the researcher to move systematically through the review process. JBI (2014) also recognizes that there is no hierarchy of evidence among qualitative studies, therefore the units of analysis used for the review are the themes or concepts as identified by the researcher.

The JBI (2014) approach was chosen because data analysis is completed using a meta-aggregative approach which aims to preserve original study findings and does not seek to re-interpret these findings during the data analysis stage. The goal of data analysis using this approach is to produce findings (themes or categories) based on similarities between studies, with these findings supported by primary study data (Lockwood & Pearson, 2013). These findings, presented as lines of action, can facilitate the development of practice recommendations that are grounded in the direct connection between primary study findings (Lockwood & Pearson, 2013). For this current research, the strength of this approach was that it allowed for a summary of findings regarding loss and grief in the NICU. The concept of lines of action also facilitated the development of recommendations for clinical practice (see Chapter 4).

2.3.2 Reporting the synthesis of qualitative research. In recent years there has been an increasing number of systematic reviews of qualitative literature being completed and the types of qualitative review methodologies used vary (Tong et al., 2012). In an effort to promote consistency and transparency, Tong and colleagues (2012) proposed a guideline entitled: Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ). The aim of the ENTREQ guideline is to reinforce the use of an explicit methodology and to assist in identifying the key steps involved (Tong et al., 2012). The guideline consists of five domains: introduction, methods and methodology, literature search and selection, critical appraisal, and

synthesis of findings (Tong et al., 2012). For each domain the ENTREQ guideline outlines the appropriate steps that should be followed, which aid in improving the quality and reporting of qualitative synthesis methods (Tong et al., 2012). The ENTREQ statements are presented in Appendix A.

2.4 Philosophical Assumptions Underpinning Meta-Aggregation

It has been increasingly acknowledged that the richness of qualitative research can provide credible, complementary data to address practice and policy related questions in health care (Hannes & Lockwood, 2011). This can be further enhanced with the use of qualitative review methodologies that are completed to combine various studies, with the intention of contributing a broader, more complex understanding of a phenomenon. The JBI methodology that was used to guide this current systematic review differs in its underlying philosophical assumptions when compared to other qualitative review methods (Hannes & Lockwood, 2011). Barnett-Page and Thomas (2009) describe various qualitative review methodologies, and the epistemological assumptions underlying each approach, which include methodologies underpinned by constructivist/interpretivist approaches. These approaches include meta-narrative synthesis, critical interpretive synthesis, and meta-study, which are all completed from a constructivist approach (Barnett-Page & Thomas, 2009). In these methodologies the authors gain an in-depth understanding of the phenomena being studied by further interpreting the findings from individual studies (Barnett-Page & Thomas, 2009). Reviews grounded in constructivism differ from the JBI methodology wherein the reviewer does not seek to re-interpret the findings from the included studies.

Hannes and Lockwood (2011) described how the philosophy of pragmatism has influenced the development of the JBI approach to qualitative reviews. Pragmatism, which was

initially described by Peirce (1878) lost its initial popularity in the 1930's and 1940's but has recently seen a resurgence (Mounce, 2000). Peirce, as cited by Doane and Varcoe (2005), explained that the significance of a thought or concept was the result it produced and describe pragmatism as a process, rather than a result. A pragmatic perspective involves placing theory to work within every day practice experiences in order to engage in continual inquiry (Doane & Varcoe, 2005). Hannes and Lockwood (2011) further described the foundation of pragmatism as being how the value of an idea or proposition can be found in the practical consequences of accepting it. Completing research from a pragmatic perspective involves a process that is grounded in immediacy, experience, and expertise rather than “from a unified, fixed perspective” (Doane & Varcoe, 2005, p. 83). It involves recognizing the link between theory and practice, and encourages inquiry that is rooted in practice (Doane & Varcoe, 2005).

The data analysis within a JBI qualitative review can be completed using a pragmatic lens or approach (Hannes & Lockwood, 2011). Data aggregation is completed by extracting findings from the included studies, however, this does not include re-interpreting these findings, as was previously mentioned. Meta-aggregation includes extracting the themes in a way that maintains “representativeness with the primary literature available” (Hannes & Lockwood, 2011, p. 1634). This allows the results of the meta-aggregation to be rooted in the findings of the original studies, and the creation of categories reflective of the authors' knowledge and understanding of the included studies (Hannes & Lockwood, 2011). This approach to data analysis aims to create practice recommendations that can subsequently be used and implemented in practice. Further, meta-aggregation is the preferred methodology for creating lines of action and these recommendations can be used to guide practitioners and policy makers (JBI, 2014).

2.5 Research Question

The research question that guided this review was: *how are loss and grief experienced by parents in the NICU?* Parents were chosen as the focus of this review because their first hand experiences, rather than interpretations of parents' experiences as provided by health care professionals (HCP), best illuminate the complexity of loss and grief in the NICU. The design for this research study was a systematic review of qualitative evidence modelled on the JBI methodology for qualitative systematic reviews.

2.6 Inclusion/Exclusion Criteria

To effectively examine how loss and grief is experienced by parents in the NICU, a pre-planned and peer-reviewed search was designed, in consultation with a health science librarian, to identify all pertinent studies (Tong et al., 2012). The search was designed using the following acronym; population, phenomena of interest, context (PICO) (JBI, 2014). The population of interest for this search was parents and the phenomenon was the experiences of loss and grief. The context was parents that had an infant admitted to the NICU.

The inclusion criteria (See Table 1) for this qualitative evidence review included full text articles where the aim of the study and/or research question was to explore parental loss and/or grief in a NICU. As previously described loss and grief are related concepts and therefore both concepts were explored in this review. Articles were included if the study sample was mothers, fathers, both parents, single parents, or adoptive parents that had an infant admitted to a neonatal unit regardless of length of time they were admitted. Included articles were empirical research using a qualitative methodology. Mixed methods studies were also included if the qualitative component met inclusion criteria.

Table 1 Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Literature type	Full text articles	Theses and Dissertations Conference abstracts Book reviews Grey literature
Study Design	Qualitative Mixed Methods	Quantitative Literature Reviews
Population	Mothers, fathers, both parents, single parents, and adoptive parents Mixed samples where parent quotes were identifiable	Health Care Professionals
Context	NICU	Pediatric Intensive Care Unit Neonatal deaths that occurred outside of the NICU Stillbirth or Pregnancy loss
Phenomenon of Interest	Research studies which sought to explore loss and/or grief*	Studies with a different purpose or phenomena of interest.

*Note: Loss and/or grief were included as they are related concepts

Upon completion of the search strategy, decisions were made regarding included and excluded articles. Initially it was felt that all articles that found loss and/or grief as a finding should be included. However, this became challenging because of the types of studies that were retrieved during the search process. There were articles, for example, that were screened wherein loss and/or grief were mentioned as a finding, yet their research question was unrelated to loss and/or grief. For instance, a mixed methods study by Rossman, Greene, and Meier (2015) explored the impact of the mother's birth experience, the stress of her infant's hospitalization, as well as what factors affected the development of the maternal role. They found that mothers reported a *loss* of the dream after delivering a preterm infant, and almost half the participants experienced the *loss* of the last trimester of pregnancy (Rossman et al., 2015). A second qualitative study by Swanson et al. (2012) explored the impact of preterm birth to understand mothers' experiences of infant feeding behaviors. They found that mothers reported a *loss* of

reality, in particular after a traumatic or sudden delivery (Swanson et al., 2012). This finding is difficult to interpret, however, given the focus on infant feeding in the study. The interviews that were completed with mothers focused both on their experiences as well as feeding behaviors. These articles prompted multiple discussions with all members of the thesis committee. A decision was made to include only those articles where the authors had explicitly stated that the aim of their study was to examine loss and/or grief. Therefore, articles were excluded where loss and/or grief experiences were reported only in the findings.

Exclusion criteria (See Table 1) included theses and dissertations, conference abstracts, and book reviews. Theses and dissertations were excluded because it was determined that institutional practices vary regarding the peer review of student work. Articles that discussed neonatal palliative care or treatment withdrawal in the NICU, but that did not explore loss and grief as an aim of the study were excluded. Articles that examined loss and grief in parents in the PICU were also excluded, as well as families that experienced a stillbirth or pregnancy loss. Articles were excluded if they explored loss and grief in a neonatal unit from the perspective of HCPs, however, they were considered for inclusion if there was a mixed sample and parents' experiences were readily identifiable, and supporting quotes were from the parents themselves. Literature reviews were excluded but their reference lists were examined to determine if any further studies warranted inclusion.

2.7 Search Strategy

For this review, four electronic databases, CINAHL, Medline, PsycINFO and Nursing and Allied Health, were accessed using pre-identified search terms (Appendix B, C, D, E). These databases were chosen because they broadly capture nursing literature, as well as literature published by other health care disciplines. The search strategy encompassed only electronic

databases because my aim was to include peer-reviewed and published evidence on the topic to enhance trustworthiness of the findings. While grey literature is often included in systematic review studies, it is difficult to judge the credibility of the data obtained through these sources. No specific date ranges were used. All searches were limited to results published in English.

Search terms for the context of care included neonatal intensive care units, neonatal intensive care nursing, neonatal nursing, NICU, hospital nurseries, nursery, and neonatal unit, department, or care. These search terms were included because neonatal care can be provided in NICUs but also in special care and newborn nurseries. The term nursery was used during the search process because neonatal care can be provided to less acutely ill infants in special care nurseries. These search terms were used to allow for a broad retrieval of literature relevant to this context of care.

Search terms used to capture parents included parents, mothers, fathers, single parent family, adoption, and adoptive families. Though the phenomena of interest in this review were loss and grief, the most appropriate MeSH heading was bereavement because it broadly identified literature pertaining to both loss and grief. Keywords searched included: loss, grief, grieving, and bereavement in efforts to further capture parents' experiences of loss and/or grief.

To identify qualitative data in this search both related MeSH terms as well as multiple keywords were used. The MeSH terms qualitative studies, qualitative research, and interviews were used to capture qualitative literature indexed under those terms. Multiple keywords were also used, including: interview, focus group, qualitative, experience, narrative, ethnography, grounded theory, phenomenology, participatory action, and case study. This approach allowed for retrieval of all types of qualitative studies.

2.7.1 Study screening. Using the search terms, references were retrieved and study screening began. Duplicates were removed and the remaining articles were screened using a three stage approach. The first stage of title/abstract screening was completed by two reviewers (ER, BV) using an online program called Covidence. Covidence is a screening and data extraction tool that allows multiple reviewers to simultaneously screen articles for reviews (<https://www.covidence.org>). The use of this program facilitated the process by allowing for an organized and systematic process for screening articles that also tracked and recorded screening decisions. The benefit of using this program was that it allowed for two individuals to track their screening decisions, and also required that a rationale be provided when an article was excluded. This also allowed for discrepancies to be discussed and subsequently resolved. During this stage all title and abstracts were read and reviewed for relevance to the research question.

The second stage of screening included screening the full text of the remaining articles. During this stage two reviewers (ER, BV) read all full text articles to screen for relevance to the research question. Three additional reviewers (AV, FFB, WP) then assisted with a second round of full text review. This assisted in identifying studies where the aim and/or research question explored loss and/or grief. After the second stage of screening, the reference lists of included articles were examined. This involved looking for articles that explored the parental experience of loss and/or grief in the NICU. Results of this screening process are described in detail in Chapter 3 – Results.

2.8 Methodological Quality

Quality appraisal can be used in a qualitative review to assist the reader to make judgements regarding the credibility, dependability, transferability, and confirmability of the included studies (Tong et al., 2012). Appraisal can also be used to inform the development of

future research studies on the topic of interest, particularly if a methodology has been used well in a recent study (Tong et al., 2012). Quality appraisal of each included study was completed by ER and BV using the Critical Appraisal Skills Programme (CASP) tool (CASP, 2013), as well as the JBI critical appraisal checklist (JBI, 2016). Each reviewer completed the quality appraisal tools independently, then the results were combined in a Word document. Discrepancies in the critical appraisals were then resolved through discussion. During this meeting the criteria assessed using both tools were revisited and a consensus was reached.

The CASP tool includes 10 questions used to address the principles and assumptions supporting qualitative research (Tong et al., 2012). The questions involve evaluating study design and methodology, and answering ‘yes’, ‘no’, or ‘can’t tell’ to the accompanying questions (CASP, 2013). The JBI critical appraisal checklist is a 10-item tool “designed to assess the methodological quality of a study and to determine the extent to which a study has addressed the possibility of bias in its design, conduct, and analysis” (JBI, 2016, p. 2). It involves answering ‘yes’, ‘no’ or ‘unclear’ to the accompanying questions (JBI, 2016). Both tools have been used in multiple other qualitative reviews and it has become more common practice to include quality appraisal in the completion of a systematic review of qualitative literature (Hannes & Macaitis, 2012).

Use of the CASP tool allowed for appraisal of the components that should be included in a qualitative report, however, this tool has limited ability to address the underlying theoretical or interpretive validity of the methodology used (Hannes & Lockwood, 2011) including whether or not the methods used are consistent with the chosen approach. The use of the JBI tool allowed for an increased ability to assess the quality of the methodology for each included study and the use of both tools facilitated a more detailed appraisal process. It was determined by the thesis

committee that by using the JBI tool with the CASP tool, it facilitated an in-depth appraisal of the included studies and assessment of congruency between the research methodology and the methods used in each study. In this review no articles were excluded from this review based on quality appraisal. This decision was influenced by the limited published studies on the topic under review in addition to the lack of a standardized approach to quality appraisal in qualitative reviews (Tong et al., 2012). This allowed the reviewers to identify potential areas of weakness in the study designs but did not impact the extraction of findings from each study.

2.9 Data Collection

In this review all findings were independently extracted by ER and BV using a standardized template. This template was created in a Word document by ER to capture all necessary information in the included studies. The following information was extracted from each study: bibliographic details (title, author, journal, year and setting), study design, aim/objective, sample strategy/population, data collection and analysis, findings or themes, and supporting quotes. During extraction of the findings in each study, all accompanying quotes or illustrations were extracted. The first step involved extracting all findings from included papers with an accompanying quote or illustration. A finding was considered a verbatim statement of the author's interpretation of the results of the data (JBI, 2014). This involved extracting themes, as well as subthemes and categories as interpreted by the study's author(s). Regardless of the level of finding (i.e. theme, subtheme, or category), they were considered an individual finding. For the purpose of this review, findings describing loss and grief were not extracted separately. The aim of the included studies was to explore loss and/or grief, and during extraction it was felt that both loss and grief should be extracted as they were described and explored in the included articles. Therefore, during data extraction loss and grief were not viewed as separate concepts.

As noted above, the data extraction was completed independently by ER and BV; discrepancies were resolved through discussion. Complete data extraction tables are presented in Appendix F.

2.10 Aggregation of Data from Included Studies

Data analysis was done using the meta-aggregation approach, which involves categorizing and re-categorizing data to create aggregated findings (JBI, 2014). For each finding, a level of credibility was assigned as unequivocal, credible, or unsupported (JBI, 2014). Findings were considered unequivocal when they were supported by a parental quote that clearly demonstrated the described finding, and credible if the parental quote lacked clear association with the finding (JBI, 2014). Findings were labelled unsupported if there was no parental quote provided (JBI, 2014). Of note, findings that had illustrative quotes that were provided by HCPs were not labelled as unsupported but rather, were not included in the aggregation (see below).

A summary statement was then created for each finding, which included a brief description of the finding. These summary statements were created by ER after repeated reading of the finding and its associated quotes. Summary statements were also reviewed by BV. Subsequently, ER and BV met to complete the data analysis which involved looking for similarities between findings (using the summary statements) and creating themes to capture these similarities (JBI, 2014). This involved reading each individual finding, and summary statement, and aggregating them together based on commonalities. The latter was completed through repeated reading of the summary statement, as well as referral back to original study if clarification was needed. Within each identified theme, the individual findings were subsequently re-read and grouped into sub-themes by ER and BV. Again, this was completed by looking for similarities in wording as well as in the parental quotes that were associated with the finding. The identified themes and sub-themes were then reviewed again, and at this point they

were considered aggregated findings. Overarching descriptions of each theme and subtheme were also created. This process permitted the preservation of individual study findings, but also allowed for the meta-aggregation of parental experiences within the NICU. The results of the review are presented in Chapter 3.

2.11 Summary

In this chapter, I presented an overview of the aggregation methods and highlighted the particular approach used in this study: a systematic review of qualitative evidence modelled on the JBI approach. Finally, I presented the procedures undertaken during this review, including steps used to identify pertinent literature, extract and aggregate data, and assess the quality of the included studies.

Chapter 3: Results

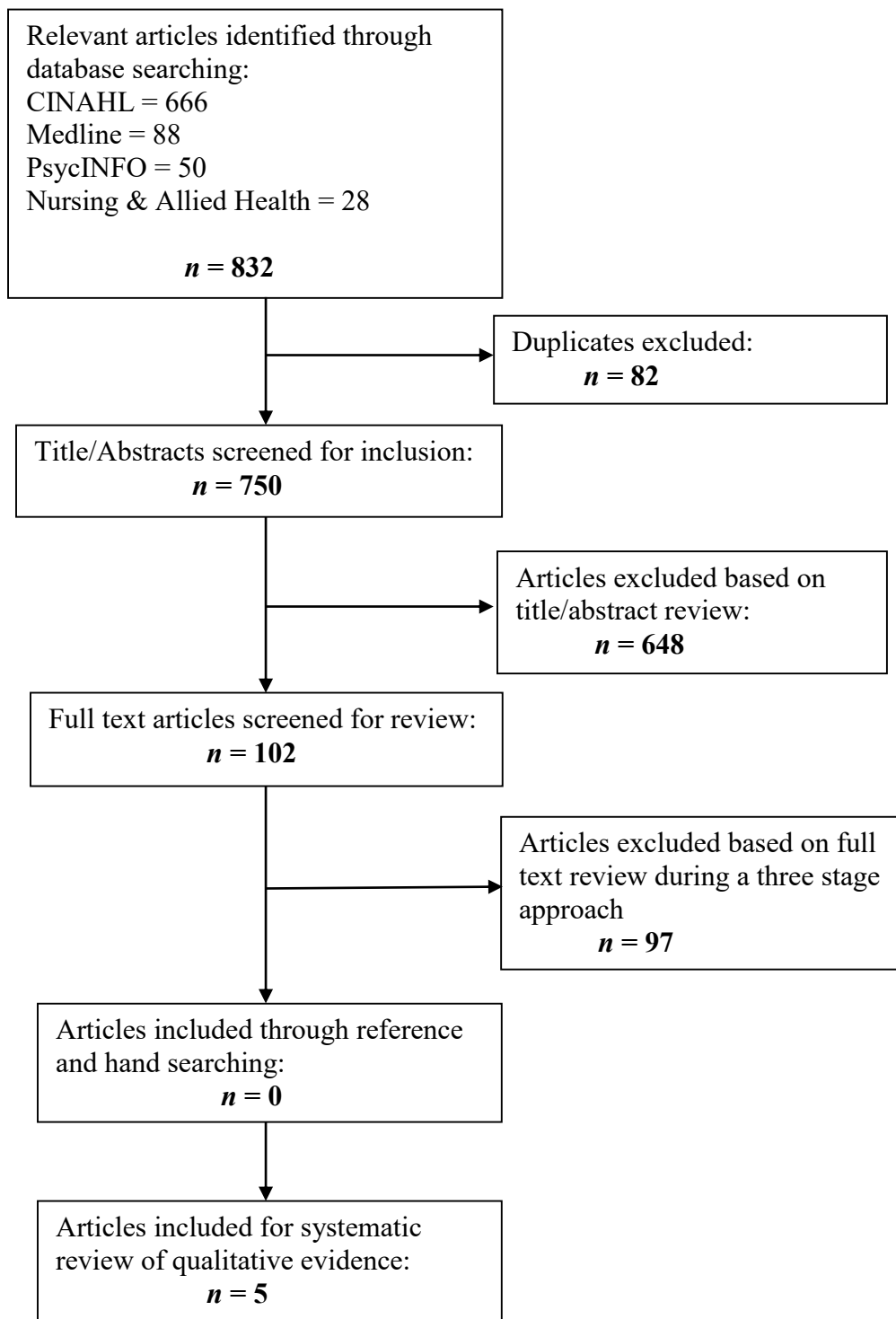
The findings from a systematic review of qualitative evidence can be used to develop new insights into a phenomenon by going beyond simply summarizing included studies (Tong et al., 2012). Results from a qualitative review can inform practice and policy, identify research gaps, as well as provide evidence for the development of health interventions (Tong et al., 2012). A systematic review of qualitative evidence modelled on the JBI (2014) approach to qualitative reviews was used to explore and describe parental loss and grief in the NICU. This chapter presents the results from this systematic review and includes a description of the search results, the results of the quality appraisal, the characteristics of the included studies, a description of the extracted data, as well as a meta-aggregation of the data.

3.1 Search Results

The results of searching four databases, CINAHL, Medline, PsycINFO and Nursing and Allied Health, yielded 832 references (Figure 1). Duplicates were removed, leaving 750 articles to be screened. Title/abstract screening was completed by ER and BV; 648 articles were excluded using Covidence. The majority of the articles were excluded due to the population, study design, setting, and/or methodology that was used. Following this stage, the first of three rounds of full text review was completed by ER and BV. During this stage, 77 additional articles were excluded. The rationales for exclusion during this stage included: a) one article ($n = 1$) with unclear methodology; b) two articles ($n = 2$) that were not from the parent's perspective; c) two articles ($n = 2$) that contained no identifiable parental quotes; d) five articles ($n = 5$) that did not mention loss and/or grief; e) seven articles ($n = 7$) where the context of care was not a neonatal unit f) 14 articles ($n = 14$) were not primary research; g) 18 articles ($n = 18$) where the

population of interest was not parents; and h) 28 articles ($n = 28$) that did not use a qualitative research design.

Figure 1 Search Results



During the second round of full text screening, 25 articles ($n = 25$) remained. During this stage, three additional reviewers assisted with discussion regarding included/excluded articles (FFB, AV, WP). Nine articles ($n = 9$) were excluded during this screening stage. Four articles ($n = 4$) were excluded because there were no parental quotes or findings regarding loss and/or grief. Five articles ($n = 5$) were excluded because they were a mixed sample of parents where not all families had their infant cared for in a NICU and it was not discernable from the parental quotes where they had been cared for. The remaining 16 articles ($n = 16$) were subsequently screened a third time. During this stage of screening, articles were included if the aim and/or research question was to explore loss and/or grief in a neonatal setting. This led to the exclusion of 11 articles ($n = 11$), therefore five articles ($n = 5$) were ultimately included for analysis (Armentrout, 2009; Geetanjli, Vatsu, Paul, Mehta, & Srinivas, 2012; Golish & Powell, 2003; Hasanpour, Sadeghi, & Heidarzadeh, 2016; Richards, Graham, Embleton, Campbell, & Rankin, 2015). The reference lists of these five articles were hand searched and no further studies were identified from this approach.

3.2 Quality Appraisal

Quality appraisal was completed using both the CASP tool as well as the JBI critical appraisal checklist for qualitative research. The results of the quality appraisal using the CASP tool and JBI checklist are presented in Tables 2 and 3 respectively. Using the CASP tool I found that overall the included articles fulfilled the majority of the criteria evaluated. The CASP tool results ranged from seven to nine out of the ten (7-9/10) criteria examined. The average score of the five articles was eight out of ten (8/10). One area that was consistently unaddressed by each article was exploration of the relationship between the researcher and the participants ($n = 5$).

The article by Golish and Powell (2003) also lacked clarity regarding both the recruitment strategy, as well as the consent process used.

Results from the JBI checklist demonstrated which articles were methodologically sound, as well as which articles had identifiable gaps in the description of their methodology. The range of scores was three to ten out of a possible ten (3-10/10). The average score of the five articles was seven (7/10). The study by Armentrout (2009) fulfilled only three of the ten (3/10) criteria examined. This score resulted from a lack of clarity in the explanation of their methodology. Four authors ($n = 4$) also failed to explore the relationship between the researcher and participants. This was consistent with the findings from the CASP tool. The article by Richards et al. (2015) was the only article that fulfilled all the criteria (10/10) examined when using the JBI tool.

Table 2 CASP Quality Appraisal Tool

CASP Quality Appraisal Tool	Armentrout (2009)	Geetanjli et al. (2012)	Golish & Powell (2003)	Hasanpour et al. (2016)	Richards et al. (2015)
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Can't Tell	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes
Has the relationship between the researcher and participants been adequately considered?	No	No	No	No	No
Have ethical issues been taken into consideration?	Yes	Yes	Can't tell	Yes	Yes
Was the data analysis sufficiently rigorous?	Can't tell	Yes	Yes	Yes	Yes
Is there a clear statement of the findings?	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	Yes is valuable	Yes is valuable	Yes is valuable	Yes is valuable	Yes is valuable
Totals:	Yes - 8/10 No - 1/10 Can't tell -1/10	Yes - 9/10 No -1/10	Yes - 7/10 No - 1/10 Can't tell – 2/10	Yes 9/10 No 1/10	Yes 9/10 No 1/10

Table 3 JBI Critical Appraisal Checklist for Qualitative Research

JBI Critical Appraisal Checklist	Armentrout (2009)	Geetanjli et al. (2012)	Golish & Powell (2003)	Hasanpour et al. (2016)	Richards et al. (2015)
Is there congruity between the stated philosophical perspective and the research methodology?	Unclear	Yes	Unclear	Yes	Yes
Is there congruity between the research methodology and the research question or objectives?	Unclear	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the methods used to collect data?	Unclear	Yes	Unclear	Yes	Yes
Is there congruity between the research methodology and the representation and analysis of the data?	Unclear	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the interpretation of the results?	Unclear	Yes	Yes	Yes	Yes
Is there a statement locating the researcher culturally or theoretically?	No	No	No	Yes	Yes
Is the influence of the researcher and the research, and vice-versa addressed?	No	No	No	No	Yes
Are participants and their voices adequately represented?	Yes	Yes	Yes	Yes	Yes
Is the research ethical according to current criteria or for recent studies, and is there evidence of ethical approval by an appropriate body?	Yes	Yes	Unclear	Yes	Yes
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Yes	Yes	Yes	Yes
Totals:	Yes – 3/10 Unclear - 5/10 No - 2/10	Yes - 8/10 No - 2/10	Yes - 5/10 Unclear - 3/10 No - 2/10	Yes - 9/10 No -1/10	Yes - 10/10

3.3 Study Characteristics

There were five qualitative studies that sought to explore loss and/or grief in the NICU from the parents' perspectives included in this systematic review of qualitative evidence. A summary of these articles is presented in Table 4. The studies were conducted in four countries, which included experiences of parents from India ($n = 1$), Iran ($n = 1$), the United Kingdom ($n = 1$), and the United States ($n = 2$). The dates of publication ranged from 2003-2016.

Three articles included in this review sought to explore loss and/or grief after an infant's death (Armentrout, 2009, Hasanpour et al., 2016, Richards et al., 2015). Richards et al. (2015) sought to explore mothers' grief experiences after the loss of a twin. Hasanpour et al. (2016) studied parental needs both before and after an infant's death. Armentrout (2009) explored end-of-life decision making in the NICU, specifically the experiences identified by parents as factors in their decision making, as well as the barriers and facilitators that parents faced in their grieving process. The remaining two articles explored loss and/or grief in parents that had an infant in the NICU (Geetanjli et al. 2012, Golish & Powell, 2003). Geetanjli et al. (2012) explored parental loss and grief related to their infant being admitted to a neonatal unit. Golish and Powell (2003) sought to answer two primary research questions: 1) what dialectical tensions do parents of a premature infant experience as they grieve the loss of a full-term pregnancy; and, 2) what communicative strategies do these parents use?

Two studies incorporated open-ended questions within the context of face-to-face interviews in order to elicit either the story of their loss (Richards et al., 2015) or parental needs both before and after their infant's death (Hasanpour et al., 2016). Armentrout (2009) also gathered data during interviews with the use of open ended questions. Geetanjli et al. (2012) interviewed parents using a General Health Questionnaire which also included four broad

questions (which were not reported) to explore parents' experience of loss and grief after their infant was admitted to a neonatal unit. Golish and Powell (2003) used a questionnaire that was designed to elicit parents' reactions to the early birth of their child, how this impacted them, as well as how parents communicated challenges that resulted from the crisis. The questionnaire was sent to families whose infant had been cared for in a neonatal unit and it consisted of both demographic and open-ended questions (from which verbatim statements were reported), and participants were instructed to give as much detail as possible to assist in helping others to visualize and understand their experiences (Golish & Powell, 2003).

The sample sizes across the included studies ranged from 14-48 participants, with the largest sample size ($n = 48$) in the study by Golish and Powell (2003). In the five studies, a total of 134 ($n = 134$) parents participated with 117 ($n = 117$) being mothers and 17 ($n = 17$) fathers. The marital status of the parents was only reported in the study by Golish and Powell (2003). All five studies used purposeful sampling. Geetanjli et al. (2012) interviewed parents while their infant was still in the NICU, however, the remainder of the studies collected data from parents after their NICU experience. There was variation between the studies in the length of time that had passed since the parents NICU experience. For example, Golish and Powell (2003) administered the questionnaire to parents of premature infants between five weeks to 16 years after the birth of their infant. The remaining studies interviewed parents between six months and 12 years after their infant's hospitalization.

Table 4 Summary of Included Articles

Author	Title	Study Aim	Year	Sample	Data Collection Method
Armentrout	Living with grief following removal of infant life support: Parent Perspectives	To explore how parents whose infant died in the NICU made life support decisions, the role they had in the decision-making process, and how their infant's death influenced their lives.	2009	15 parents – 4 couples and seven mothers	Interviews
Geetanjli, Manju, Paul, Mehta, & Srinivas	Loss and grief response and perceived needs of parents with the experience of having their newborn at neonatal care units	To explore loss, grief, and the perceived needs of parents whose infant is admitted to a neonatal unit	2012	16 parents – both mothers and fathers	Interviews
Golish & Powell	'Ambiguous loss': Managing the dialectics of grief associated with premature birth	To explore the dialectical tensions of parents grieving the loss of a full term pregnancy, and the communication strategies used to manage these tensions.	2003	48 parents -45 mothers and 3 fathers	Open-ended questionnaire
Hasanpour, Sadeghi, & Heidaarzadeh	Parental needs in infants' end-of-life and bereavement in NICU: A qualitative study	To explore parents needs both during and after their infants end-of-life, and the bereavement stages they experience.	2016	24 participants – including mothers (9), fathers (2), grandparents (3), nurses (3) and doctors (1)	Interviews
Richards, Graham, Embleton, Campbell, & Rankin	Mothers' perspectives on the perinatal loss of a co-twin: a qualitative study	To explore mothers experiences of losing a twin pregnancy, and subsequently having an infant in the NICU.	2015	14 mothers	Interviews

3.4 Extracted Findings

A total of 50 findings were extracted from the five studies (Table 5). The levels of credibility of all findings were examined, and all 50 findings were designated unequivocal because they were each accompanied by at minimum one illustrative quote that was reflective of the individual finding (JBI, 2014). The level of credibility of each finding was determined by both ER and BV, and there were no discrepancies between reviewers. The article by Hasanpour et al. (2016) had five findings that were not included in the final analysis because these findings only had supporting quotes from HCPs. It was felt that since there were no parental quotes supporting these findings they should not be included in the aggregation. A total of 45 findings were included for the final analysis.

Table 5 Extracted Findings

Findings/Themes (As labeled by the original author)	Illustrative Codes YES/NO	Armentrout (2009)	Geetanjali et al. (2012)	Golish & Powell (2003)	Hasanpour et al. (2016)	Richards et al. (2015)
Making the decision to withdraw life support	Yes	UE				
Things they would have changed	Yes	UE				
Health care providers	Yes	UE				
Initial shock	Yes	UE				
Differences in grief between mothers and fathers	Yes	UE				
Family and friends	Yes	UE				
Feelings of isolation	Yes	UE				
Remembering activities	Yes	UE				
Moving forward	Yes	UE				
Altered perspectives of life	Yes	UE				
Spiritual/religious perspectives	Yes	UE				
Grief reaction of parents in response to loss	Yes		UE			
Coping -Helpful factors	Yes		UE			
Coping -Not so helpful/hindering factors)			UE			
Friendly visiting policy	Yes		UE			
Need for information and communication	Yes		UE			
Expectations of parents	Yes		UE			
Joy/grief contradiction	Yes			UE		

UE = Unequivocal, C = Credible, U = Unsupported

Findings/Themes	Illustrative Quotes YES/NO	Armentrout (2009)	Geetanjli et al. (2012)	Golish & Powell (2003)	Hasanpour et al. (2016)	Richards et al. (2015)
Denial and disbelief	Yes			UE		
Anxiety	Yes			UE		
Sadness	Yes			UE		
Anger and Jealousy	Yes			UE		
Guilt and self-blame	Yes			UE		
Grief management	Yes			UE		
Gathering information about technology and preemies	Yes			UE		
Educating family members about prematurity	Yes			UE		
Family members providing reassurance and support	Yes			UE		
Communicating a sense of teamwork with one's spouse	Yes			UE		
Emphasizing the present	Yes			UE		
A need for the presence of a spouse by mother's side	Yes				UE	
A need for the bereaved mother's bed not being by the side of a mother having an infant	Yes				UE	
A need for health care personnel treating infant's mother properly	Yes				UE	
A need for maintained contact between the treatment team and the bereaved family	Yes				UE	

UE = Unequivocal, C = Credible, U = Unsupported

Findings/Themes	Illustrative Quotes YES/NO	Armentrout (2009)	Geetanjli et al. (2012)	Golish & Powell (2003)	Hasanpour et al. (2016)	Richards et al. (2015)
Family's need for receiving information on how to treat a bereaved mother					UE*	
Family's need for counselling and training after infant's death	Yes				UE	
The need for preparing the family for delivering the bad news of infant death					UE*	
Difficulty of delivering the news of infant's death					UE*	
Avoiding mother's sudden knowledge of infant's death					UE*	
Family and fathers role in delivering the bad news of their infant's death					UE*	
Family's need to get informed about the bad news of their infant's death	Yes				UE	
Feeling special	Yes					UE
Acknowledging bereavement and twin-ship	Yes					UE
Trauma and grief on hold	Yes					UE
Emotion work	Yes					UE
Continuity of information	Yes					UE
Continuity of staffing and trust	Yes					UE
Location of care and lack of control	Yes					UE
Impact of trauma upon actions	Yes					UE
Impact of trauma upon perceptions	Yes					UE
How mothers take control	Yes					UE

UE = Unequivocal, C = Credible, U = Unsupported

* Finding which contained illustrative quotes from health care professionals only

3.5 Meta-Aggregation of the Findings

Data analysis in this review was completed using the JBI (2014) meta-aggregative approach and the meta-aggregation was completed by ER and BV. A summary document of the aggregated findings was created, and subsequently reviewed by both ER and BV. Table 6 presents a summary of the findings from the meta-aggregation and their source. Aggregation of the findings produced five main themes: support, not knowing what to expect, hospital practices, communication, and coming through grief. The themes of support, communication and coming through grief each had two subthemes. A detailed description of the themes found in this review, as well as the findings and summary statements associated with each theme can be found in Appendix G.

Table 6 Summary of Meta-Aggregation

	Armentrout (2009)	Geetanjli et al. (2012)	Golish & Powell (2003)	Hasanpour et al. (2015)	Richards et al. (2016)
Theme 1: Support					
Subtheme 1.1: Support offered by family and friends	+		+	+	
Subtheme 1.2: Support offered by HCPs	+			+	+
Theme 2: Not knowing what to expect			+		+
Theme 3: Hospital Practices		+		+	+
Theme 4: Communication					
Subtheme 4.1: The role of HCPs		+		+	+
Subtheme 4.2: The role of the parents, family, and friends			+		+
Theme 5: Coming through grief					
Subtheme 5.1: The immediate period following the loss	+	+			+
Subtheme 5.2: The long term response – moving on	+		+		+

+ = theme found in study

3.5.1 Theme one: support. The theme of support includes twelve findings from four different studies, and has two subthemes: 1) support offered by family and friends; and 2) support offered by HCPs. This theme includes the description of positive experiences wherein parents felt supported, but also highlights areas in which parents felt unsupported.

3.5.1.1 Support offered by family and friends. In three articles (Armentrout, 2009; Golish & Powell, 2003; Hasanpour et al., 2016) family and friends played a key role in parental experiences in the NICU, particularly with respect to providing them with support. Emotional

support from family and friends included listening and consoling, while tangible support was provided by assistance with daily needs. Parents reported feeling supported when their families and friends offered them assistance in a way that was respectful, compatible with their needs, and sensitive to the multitude of feelings they were experiencing. A parent described: “my parents were calling me asking me how he was. If we got a bad report (they were) asking if the baby was going to be okay, or what long-term problems he would be having from this” (Golish & Powell, 2003, p. 327). Support offered by family and friends was also inclusive of small actions (Golish & Powell, 2003). As one parent described: “if we wanted to cry, they were there for that, if we wanted to just throw an anger fit, they were there for that” (Armentrout, 2009, p. 260). Overall, parents described the impact of the support they received from family and friends, both in the presence or absence of neonatal death.

In contrast, parents also described negative experiences that caused them difficulties or were perceived as hurtful when limited support was available. Some parents described feeling unsupported when the nature of their situations distanced their experiences from those of other parents. One parent stated he: “could not understand why she was so quiet and her cry was so weak. He did not seem to grasp how sick she was...my brother and his wife were completely confused. They did not understand the severity of the situation” (Golish & Powell, 2003, p. 327). When the parents were unable to relate to others, whether it be family members, friends, or peers with neonates, they felt isolated. Additionally, parents described how they believed that their family members and friends were unable to understand the magnitude of the emotions they experienced. In some cases, parents were hurt by insensitive comments spoken about their child. One parent described how he was frequently told: “Oh, you’ll get through this, you’ll have another baby” (Armentrout, 2009, p. 260).

Additionally, parents felt that the magnitude of their feelings was not always acknowledged by family members and friends (Armentrout, 2009). Parents in the study by Golish and Powell (2003) described challenges when family members did not understand the severity of illness associated with a NICU admission. In situations where the infant survived their NICU stay but had developmental delay, parents described how unsupportive comments regarding their child's delayed development were hurtful (Golish & Powell, 2003). These parents felt it was necessary to remind family and friends of the importance of not comparing their infant with another infant not born prematurely (Golish & Powell, 2003). For example, a parent stated: "I also insisted that none of my family use the word 'normal' as it suggested that Adam was abnormal" (Golish & Powell, 2003, p. 326).

3.5.1.2 Support offered by HCPs. Parents described the support offered by HCPs in three studies (Armentrout, 2009; Hasanpour et al., 2016; Richards et al., 2015). Support and empathy offered by HCPs was important, and parents appreciated actions taken by HCPs to acknowledge their infant. One parent had reflected on how he appreciated when HCPs were: "calling in on their days off to see how he was doing" and "requesting to be assigned to him" (Armentrout, 2009, p. 257). Parents also requested a specialized approach that was tailored to the needs of parents whose infant died (Hasanpour, 2016). When treatment was withdrawn, parents in the study by Armentrout (2009) felt it was an important opportunity to hold and spend time with their infant, and appreciated efforts by HCPs to facilitate this experience (for example taking pictures together as a family, hair cutting, and molds of the infant's feet). Similarly, mothers appreciated HCPs that offered emotional support and that the establishment of relationships with care providers was important (Richards et al., 2015). One parent stated: "She [nurse] was really nice, we got a lot of support off her...she was more on our wave length,

someone you can sort of feel comfortable talking with” (Richards et al., 2015, p.5). Midwives and nurses in particular played a key role, as they often had daily contact with mothers which also facilitated continuity of care and parents’ perceptions of support being provided (Richards et al., 2015). As one parent in the study by Richards et al. (2015) described: “the nurses are very good, they’d sit and listen to you talk until the cows came home which was brilliant” (p. 5) and “I just loved her [nurse]...she took me under her wing as soon as I got in that hospital...you know and she just, I felt like I didn’t want to let her go home that night, I just wanted her to stay with us” (p. 6).

The support and empathy offered by HCPs after the death of an infant was greatly appreciated. Small actions such as HCPs crying demonstrated to parents that their infant was “more than just a patient” (Armentrout, 2009, p. 257). A show of emotion from nurses, or an expression of affection for the surviving twin also helped parents cope in the study by Richards et al. (2015). In contrast, a lack of support both before and after an infant’s death was described by parents. Parents wanted HCPs to know that the “grief lasts longer than they will ever imagine...that it effects families on a deeper level than they will ever imagine” and that maintaining contact with families after they were discharged home would be helpful (Armentrout, 2009, p. 257). One mother stated: “I expected them to treat me properly and answer my questions properly and do not mislead me” (Hasanpour et al., 2016, p. 4). In the studies included in this review parents desired support after being discharged home: “I try to adapt and cope but it is very difficult. It takes a lot of time to get prepared and try to resume my normal life” (Hasanpour et al., 2016, p. 4). One parent also described: “the medical professionals who have become your support system and your family while your child is

alive...all of a sudden they are gone...I think it's important to have some kind of support system or information...otherwise it's like stepping into this huge abyss" (Armentrout, 2009, p. 257).

3.5.2 Theme two: not knowing what to expect. The second theme, not knowing what to expect, involved the actions and emotions caused by the admission of a child into the NICU. This theme included six findings from two different studies (Golish & Powell, 2003; Richards et al., 2015). For parents whose infants were cared for in the NICU, the experience was identified as both unexpected and unfamiliar, and the health status of their infant could change frequently throughout their hospitalization. The parents in the study by Golish and Powell (2003), for example, described how they were shocked, saddened, and angered that their child was suffering from a serious medical condition, and could die. The authors described how through reading the narratives that parents wrote about their experience, it became clear that parents were attempting to manage a family crisis which had resulted from the ambiguous loss of having an infant in the NICU. This theme was also described in the article by Richards et al. (2015) who studied mothers' experience after the loss of a twin. These parents described how having an infant admitted to the NICU caused them to feel a loss of control because they were no longer the primary care giver due to the type of care their infant needed (Richards et al., 2015). Mothers felt that the trauma of the death of one of their twins as well as the hospitalization of their sibling, resulted in feelings of passivity and helplessness (Richards et al., 2015). A parent described: "because your baby's in an incubator, what's your natural thing to do? You can't just pick your baby up and cuddle her, you can't just do what you want to do with your baby..." (Richards et al., 2015, p. 9). Feelings of lack of control encouraged mothers to seek opportunities to regain control (Richards et al., 2015). One mother described, how she pumped breast milk for her son because she "couldn't do anything else" (Richards et al., 2015, p.9).

The parents also described a mix of emotions including joy, grief, denial, disbelief, guilt, self-blame, anxiety, and sadness (Golish & Powell, 2003). Parents described being torn between grieving the loss of a normal birth and celebrating a new life (Golish & Powell, 2003). Parents were excited about the birth of their baby, however, this was muted due to not knowing what would happen regarding their baby's health (Golish & Powell, 2003). As one parent reflected: "...I couldn't understand why I felt such grief and didn't feel that I had the right to grieve as my son is alive and doing relatively well" (Golish & Powell, 2003, p. 320). Parents also described simultaneous feelings of joy and grief (Richards et al., 2015). Mothers described having to put their "emotions on hold" while caring for their surviving twin as they felt they needed to be strong for their infant (Richards et al., 2015, p.4). Mothers described how focusing on their surviving infant helped them to "stay strong during the initial stages of their loss" (Richards et al., 2015, p. 4).

Some mothers expressed guilt. They felt they had somehow contributed to their infant's preterm birth (Golish & Powell, 2003). One parent reflected: "I had nightmares for a long time. While the rational me knew this was not "my fault," my subconscious kept searching for reasons..." (Golish & Powell, 2003, p. 324). This was more common if a mother had given birth to more than one premature infant. Parents also described feeling torn between spending time with their preemie, and the needs of their partners and other children (Golish & Powell, 2003). One mother described: "it was so difficult having a younger child at home and feeling so torn between your baby in the NICU and your child at home" (Golish & Powell, 2003, p. 324).

3.5.3 Theme three: hospital practices. The third theme, hospital practices, included five individual findings from three studies (Geetanji et al., 2012; Hasanpour et al., 2016;

Richards et al., 2015). Parents described how hospital practices including location and care as well as the NICU environment affected their experience of loss and grief.

Location of care was one hospital practice that had the potential to negatively impact the experience of parents, in particular new mothers. The location of care for the mother, for instance the postpartum unit, and resulting impact it had on parents, was described (Hasanpour et al., 2016; Richards et al., 2015). Mothers reported how difficult it was for them to be near mothers who had healthy babies. One parent stated: “I’d just lost me baby and the other baby was in special care and I’m surrounded by babies when I didn’t have either of mine really...I just wanted to be on me own...” (Richards et al., 2015, p. 7). This experience negatively impacted parents and it was suggested they be cared for in a separate room. One mother described: “when I was hospitalized after delivery, all mothers who were hospitalized there had their infant by their side, but mine was not with me. It was horrible” (Hasanpour et al., 2016, p. 4). In both studies, parents emphasized the importance of location of care of the mother, and how the presence of other healthy newborns intensified their feelings of loss and grief.

A second hospital practice that influenced the loss and grief experiences of parents was the presence of the spouse in proximity to both the mother and infant. Parents described how fathers had limited contact with mothers after delivery (Hasanpour et al., 2016). The mothers in this study described how the absence of their spouse impacted the support they were able to receive from them. As one mother described: “I was feeling terrible and I needed him. One sometimes needs someone to talk to, for support and sympathy” (Hasanpour et al., 2016, p. 4). Mothers also described the challenges of being transferred to another facility: “as soon as you get shifted [to another hospital], it’s like you fall into this hole. No one can help you because they don’t know [who should be helping] so I had to find it all out for myself” (Richards et al., 2015,

p. 8). Proximity to their infant with regards to visiting policies was also described by the parents in the study by Geetanjli and colleagues (2012). Parents desired a more open visiting policy, in particular when parents were fearful something was wrong with their child (Geetanjli et al., 2012). Parents desired to provide care to their infant such as holding them or changing their diaper, which was possible if there was an open visiting policy (Geetanjli et al., 2012).

3.5.4 Theme four: communication. This finding described the crucial role communication played in parent's experiences, and involved nine findings from four different studies (Geetanjli et al., 2012; Golish & Powell, 2003; Hasanpour et al., 2016; Richards et al., 2015). There were two subthemes: 1) the role of HCPs and 2) the role of the parents, family, and friends.

3.5.4.1 The role of HCPs. Parents described the importance of suitable and timely communication with the health care team in three studies (Geetanjli et al., 2012; Hasanpour, 2016; Richards et al., 2015). This involved the need for accurate information regarding their infant from both physicians and nurses. As one father described: "Doctors should call the father or mother at least once in a day and should tell that your baby has done this, she is well, this was the deficiency that was seen" (Geetanjli et al., 2012, p. 115). The appropriate transfer of information between team members was also desired: "What I found really annoying was that I had to keep repeating my story to the nurses who were looking after [twin]. I had never met them before" (Richards et al., 2015, p. 6). Parents felt that it was important that they were informed of all aspects of their infant's progress and that they were aware of all changes, with a particular emphasis placed on the need to know if their infant's health had deteriorated. When communicating bad news, parents desired information in a timely and sensitive manner: "If there

is any problem with infant or mother herself, it should be told to them clearly and without any ambiguities so mothers have everything in their mind” (Hasanpour et al., 2016, p. 5).

When parents perceived a lack of communication, they experienced negative emotions, such as stress and dissatisfaction. As one parent stated: “the sisters have all the information about babies. In the absence of the doctors we have to wait for them, if they are inside, even then they make us wait...When we ask from the sister they do not tell us and direct us to ask from the doctors” (Geetanjli et al., 2012, p. 115). When communication errors occurred, either through written or verbal communication, parents experienced increased distress: “One of the nurses that was least conscientious towards other people’s feelings kept calling him [surviving twin] by his brother’s name afterwards” (Richards et al., 2015, p. 4). Overall, parents described communication as both a helping and hindering factor, and this influenced the degree to which parents felt informed and involved in their infant’s care: “The nurses inside nursery instead of teaching how to hold baby and feed they scold by saying you don’t even know how to feed” (Geetanjli et al., 2012, p. 115).

3.5.4.2 *The role of the parents, family and friends.* Communication also intersected with the roles of parents, family and friends. Parents felt traumatized after the death of their infant and also felt that immediately after the death of their infant they were unable to digest information:

I just got railroaded into going for a cremation with nothing...and it’s just...I just think, I think that, I was given the options, you can have a burial. It was just kind of ‘this is what people do’ and you, when you’re just in a bit of daze, I just think you go along with what people say and now I just think.....that’s my biggest regret (Richards et al., 2015, p. 8).

In one study parents described feeling angered when people (e.g., family and friends) made comparisons between their preterm infant and other full term infants: “Normally I avoid conflict, but when comments were made about him [son] not walking or talking, I stood my ground. I firmly reminded the family members that he was a preemie” (Golish & Powell, 2003, p. 326). Parents found it challenging to communicate the differences that could be seen with a preterm infant. They were also challenged in communicating their needs immediately following a loss.

Communications between parents (i.e. between spouses) also impacted their experiences of grief and loss (Golish & Powell, 2003). Mothers, for example, were often angered by their husbands’ lack of emotions, and this was interpreted as a lack of concern for their infant (Golish & Powell, 2003). One parent stated: “I am a worrier, my husband is not, so I feel a lot of the strain...” (Golish & Powell, 2003, p.324). Parents described the need to be open and honest about their feelings with each other, as well as coming to the realization that husbands and wives can grieve differently (Golish & Powell, 2003). One mother described how over time her “communication skills got much better because we had to be able to communicate our feelings to each other if our relationship was to survive this excruciating ordeal” (Golish & Powell, 2003, p. 327). Through effective communication, discussing these differences, and working together, parents were able to find strength in their relationship, in order to deal with the challenging circumstances.

Of note, gathering information and using technology was also an important way families managed the feelings associated with their infant’s hospitalization and positively influenced their ability to communicate their needs (Golish & Powell, 2003). This involved using the Internet, books, and medical staff to learn more about prematurity, as well as the use of technology such as email to keep family members informed (Golish & Powell, 2003). Parents also reached out to

other parents with premature infants, through support groups and online chatrooms. One mother described the benefit of a support group: “We bring the boys and share our experiences and tips on how we ‘coped’. I think that has helped tremendously, knowing that I may be helping someone else who is walking down that scary road I’d already travelled” (Golish & Powell, 2003, p. 326).

3.5.5 Theme five: coming through grief. This theme presents parents’ experiences of grief, and the resulting impact these feelings had on their lives in both the immediate timeframe as well as more long term. It included 13 findings from four different studies (Armentrout, 2009; Geetanjali et al., 2012; Golish & Powell, 2003; Richards et al., 2015). It had two subthemes: 1) the immediate period following the loss, and 2) the long term response – ‘moving on’.

3.5.5.1 *The immediate period following the loss.* Mothers described long periods of time after their loss where they had difficulty engaging in activities of daily life (Armentrout, 2009). For example, one mother described how challenging it was to care for her other child in the initial days after her infant’s death: I “would get up in the morning...I would be...normal...after about 2 weeks, 3 weeks...act normally...take the little one to school, stay in the car for a while...come back home and get into bed for the next 6 hours...and cry, and do whatever I need to do” (Armentrout, 2009, p. 257). The physical reactions to having a baby in the NICU experienced by both mothers and fathers included difficulty sleeping, the loss of appetite, as well as an overall sense of poor health (Geetanjali et al., 2012). One parent described: “I feel very weak because of my health. I have gone very weak. I feel a lot of pain in my head, eyes and body. For the last three to four days I have been feeling pain in my chest” (Geetanjali et al., 2012, p. 114). Parents suggested that it was important to allow for these initial emotions and understand that there was no set timeline for their grief (Armentrout, 2009).

Parents also described things they would have changed about the immediate period following their infant's death such as parenting acts not performed. Parents wished they had spent more time with their deceased infant, taking pictures and cherishing every minute (Armentrout, 2009). When asked what suggestions they would provide to other families in similar circumstances they described the importance of spending as much time as possible with their infant before and after their death, and encouraging siblings and other family members to spend time with the infant (Armentrout, 2009). One mother in particular described: "I think later it would have helped with our grief to have had more family involvement in the hospital experience" (Armentrout, 2009, p. 256).

Mothers who had lost a twin in the NICU also described a rollercoaster of emotions while in the hospital with the surviving twin (Richards et al., 2015). Mothers spoke of having to place their grief "on hold" due to the unique situation of losing an infant while having the surviving twin in the NICU (Richards et al., 2015, p. 4). Mothers suggested that the death of their twin impacted their perception of health risk in relation to the surviving twin (Richards et al., 2015). A mother described: "they did try to put our minds at rest but I think that was just the way we were feeling...it didn't matter what anybody said really" (Richards et al., 2015, p. 8).

3.5.5.2 The long term response – 'moving on'. The long term response of the loss and grief experienced by parents included altered spiritual and religious perspectives (Armentrout, 2009), grief management (Golish & Powell, 2003), and altered perspectives of life (Armentrout, 2009). Parents described the multiple ways the death of their infant had impacted their life adding that they would never be the same, and that part of their grief may never fade away (Armentrout, 2009). One parent described: "life will never be the same....you'll forever be changed....but you do have to go on with your life" (Armentrout, 2009, p. 261). Parents also felt

that although one can never fully heal from such an experience, they could learn to manage it (Golish & Powell, 2003). A parent reflected:

The circumstances surrounding our son's premature birth and the aftermath have become woven into the framework of our lives. While we don't allow this to control our lives, it most certainly has become a part of our lives that must be dealt with. (Golish & Powell, 2003, p. 325)

Similarly, another parent reflected: "move on...Life will never be the same...You'll forever be changed...but you do have to go on with your life...You have to find a new normal for you" (Armentrout, 2009, p. 261). All of the participants in the Armentrout (2009) study spoke of a shift in life priorities as they started to recover from their intense grief and loss (Armentrout, 2009). Many parents, for example, spoke of re-evaluating areas of their life, as well as remembering how important it was not to take family and friends for granted (Armentrout, 2009). Other parents dealt with their grief by emphasizing the present, and trying to live in the moment to cope with both the joy and grief they experienced after the birth of their preterm infant (Golish & Powell, 2003). This involved focusing on their child in the present state, while also recognizing the loss they had endured (Golish & Powell, 2003).

Parents described how differences existed in the grief response between mothers and fathers (Armentrout, 2009). Long term grief was experienced differently, and couples felt that it was important that they support each other throughout the grief process despite the differences in how they demonstrated this grief (Armentrout, 2009). Although some families had been made aware of this difference, not all families were cognizant that each spouse may cope differently: "I came to realize pretty quickly that his grief was just different from mine....he wasn't crying on the outside....like I was 24/7" (Armentrout, 2009, p. 259). Despite each couple grieving

differently, parents described how living through this difficult ordeal had brought them closer, and also made their relationship stronger: “We grieved...while our son was alive, we really clung to each other...for the immediate aftermath” (Armentrout, 2009, p. 259). There was also a long term impact experienced by parents as a result of losing one child of twins: “and [surviving twin’s birthday party] it’s a week after; it’s the Sunday after her birthday not at the weekend of her birthday because I couldn’t...I couldn’t em I just can’t, I just find her birthday a really difficult day” (Richards et al., 2015, p. 4).

3.6 Summary

The use of a meta-aggregative approach allowed for the preservation of individual study findings but also facilitated a comprehensive exploration of parental loss and grief in the NICU as it was described in the included literature. The five themes described in this chapter contribute to a better understanding of how parents experience loss and grief both in the presence of neonatal death as well as while dealing with a surviving child in the NICU. In the following chapter, I will present the discussion and implications of the findings.

Chapter 4: Discussion

The completion of a systematic review of qualitative evidence modelled on the JBI (2014) approach to qualitative reviews allowed for the meta-aggregation of findings from five studies examining parental loss and grief in the NICU. The findings reveal patterns within the experiences of parental loss and grief within the context of the NICU based on existing research. In this chapter, I discuss loss in the NICU, the themes identified in this review, and explore the implications for practice, research, and education. The strengths and limitations of the review will also be described, followed by the conclusion.

4.1 Discussion

4.1.1 Loss in the NICU. The parents in this review described both physical and symbolic losses. Parents in three studies described the experience of losing an infant (Armentrout, 2009; Hasanpour et al., 2016; Richards et al., 2015) and in one study this occurred after the removal of life-sustaining treatment (Armentrout, 2009). In one study the infant that died was a co-twin therefore the mothers in this study were grieving the loss of their infant, as well as the symbolic loss of having twins (as only one twin survived) (Richards et al., 2015). Another symbolic loss that was described was the loss of a full term pregnancy. The parents in the study by Golish and Powell (2003) described the ambiguous loss they experienced when their infant was born premature. Parents in the study by Geetanjli and colleagues (2012) also described the loss, and subsequent grief response, of having an infant admitted to a neonatal unit. It is crucial therefore that neonatal nurses are aware of the different types of losses that parents may experience and how to help them with the grief that follows.

4.1.2 Support. The parents in the included studies elaborated on the support that was provided by family and friends, as well as HCPs. Emotional and tangible support was described

as being highly beneficial to parents, helping them to cope with the challenges associated with their experience. The availability of support systems is an important factor that influences parental reactions to an infant's hospitalization (Kenner & Lott, 2014). Neonatal nurses should always strive to develop an individualized plan of care for each family (CNA, 2017), and this can involve ensuring that the appropriate types of support are available.

4.1.2.1 Peer Support. Parents in this review described many different ways that support was provided to them. For example, parents described their desire to speak to others who had gone through similar experiences. Peer-to-peer support is when support is provided by volunteer parents, who have had similar experiences, and have often received specialized training (Hall, Ryan, Beatty & Grubbs, 2015b). These programs can be offered in the hospital or community (Hall et al., 2015b). Peer-to-peer support within the NICU context, is important and can result in multiple benefits, such as the opportunity for parents to learn about shared experiences, as well as the feeling of safety and comfort fostered among parents (Hall et al., 2015b). Peer-to-peer support can provide psychosocial and emotional support to parents (Hall et al., 2015b).

Ardal, Sulman, and Fuller-Thomson (2011) examined mothers' assessment of a peer support program in the NICU, and found that parent buddies assisted mothers to mobilize their strengths. A component of this particular program was that mothers were paired with other mothers who were linguistically and culturally similar. This pairing approach allowed for normalizing shared experiences and informational support and the mothers in this study described how beneficial the buddy program was, and how it helped them cope (Ardal et al., 2011). Thomson-Salo, Kuschel, Kamlin and Cuzzilla (2017) described their successful implementation of a weekly support group for fathers. This peer support group was facilitated by two neonatologists and a psychologist, and in their groups the fathers described "their sharing

and mutual support as having a powerful therapeutic effect” (Thomson-Salo et al., 2017, p. 296). Despite different experiences, as well as backgrounds, the fathers were able to connect and share their stories easily (Thomson-Salo et al., 2017). It can be suggested that peer-to-peer support could be beneficial for both families that have infants in the NICU, as well as for those whose infant has died. Unfortunately, not all parents receive peer-to-peer support, and the reasons for this are unclear. Based on my practice, I believe many nurses, as well as parents, are unfamiliar with existing services. Ensuring that neonatal nurses are knowledgeable about peer-to-peer support services available to the parents in their care will increase the likelihood that parents benefit from this important source of support.

4.1.2.2 Nurses as supporters. Parents in the studies included in this review elaborated on the support that was provided by HCPs and how this impacted their experiences. Parents also described the challenges they encountered when a lack of support was provided. In the NICU, nurses can offer support and assistance to families throughout an infant’s hospitalization. For example, nurses play an important role in educating extended family and friends regarding an infant’s health condition, and also by helping to ensure family members feel welcome in the NICU. It is important that nurses in particular facilitate and maintain a collaborative partnership (due to their constant close proximity to parents) and provide support to both mothers and fathers (McGrath, 2014). Nurses can achieve this partnership through developing close relationships with parents. Lack of continuity of care that results from many different nurses caring for an infant during their hospitalization, or high nurse to patient ratios, make it difficult for HCPs, namely nurses, to support parents (Aagaard & Hall, 2008). A meta-synthesis of mothers’ experiences in the NICU found that continuity of care, can affect a mother’s perception of her infant’s safety, as well as her own emotional well-being (Aagaard & Hall, 2008). The mothers in

a qualitative study by Spinelli and colleagues (2016) also describe the challenge of having lack of continuity of nurses caring for their infants. One mother described “everyday, I find a different nurse, and everyone has a personal theory. One says you can hold him before meals, another says you can hold him after meals” (Spinelli et al., 2016, p. 196).

A quantitative study conducted by Mefford and Alligood (2011) evaluated nursing staffing patterns and infant outcomes in a NICU. They found that nursing staffing patterns in the NICU that provided greater levels of continuity of care could help minimize complications as well as the need for additional resources (Mefford & Alligood, 2011). For example, the use of primary nurses that followed an infant throughout their hospital stay, were predictive of shorter length of hospital stay, and shorter duration of mechanical ventilation, oxygen therapy, and parental nutrition (Mefford & Alligood, 2011). Although primary nursing, or other forms of relationship based, family-focused care have been advocated in past literature, there are limited studies examining a primary nursing model in the NICU (Mefford & Alligood, 2011). Based on research from other areas, it is likely that infants and families in the NICU will benefit from having consistent nurses responsible for their care. More work is needed to explore the use of a primary nursing model within the NICU context.

4.1.2.3 When support is lacking. Parents in the included studies described how hurtful it was when HCPs used terminology that was insensitive to their experiences of loss, and how a lack of support from HCPs affected them. A systematic review by Gold (2007) outlined areas of dissatisfaction that included a lack of emotional support, insensitivity in comments made to parents, as well as situations where their deceased infant was treated carelessly. Overall parents expressed dissatisfaction with care when HCPs were unaware of their loss, or when they were perceived as avoiding families (Gold, 2007). In a mixed methods study Pector (2004) examined

the perceptions of multiple-birth parents and found that parents described negative experiences with hospital staff after the loss of an infant. Inappropriate comments such as “this was meant to be”, “it happened for a reason”, and “you have a surviving child” were described by parents (Pector, 2004, p. 9). Nurses need to be aware of how comments can influence families they care for. When providing support to families, nurses need to communicate in a sensitive and compassionate manner.

4.1.2.4 Follow-up support. In the studies included in this review, parents elaborated on the importance of follow-up care. An essential component of care both after a NICU hospitalization, as well as a neonatal death, is the offer of assistance after their loss. Nurses in the NICU are involved in discharge planning, which includes the identification and optimization of community resources (ANA & NANN, 2013). An appropriate plan for discharge includes “building upon the partnership formed between the family and the health care team” (ANA & NANN, 2013, p.11). Follow-up support should target two areas; medical management and emotional coping (Williams, Munson, Zupancic, & Kirplani, 2008). Medical management can include working with HCPs to identify the cause of death if unknown, as well as assisting with maternal postpartum health concerns (Williams et al., 2008). Emotional support can involve addressing the impact the loss has had on families, and assistance with helping the family return to normalcy (Williams et al., 2008). Follow-up support could include post-discharge phone calls, as well as appointments with HCPs. Nurses should also be mindful of the location of follow-up care, as it can be difficult for families to return to the unit where their infant was cared for, or had died (Richards et al., 2015). For example, the parents in a study by Cortezzo, Sanders, Brownell, and Moss (2015) described the importance of follow-up after an infant death, and suggested a follow-up phone call as one method of how this support could be provided.

A qualitative study by Whittingham, Boyd, Sanders and Colditz (2014) explored parental preferences for support in the NICU. Parents described feeling uncertain about what type of developmental expectations they should have for their child since they were born preterm (Whittingham et al., 2014). Parents explained how their initial time in the NICU gave them a heightened awareness of medical and developmental issues particularly if they were concerned that their infant might have long term developmental disorders or medical illnesses (Whittingham et al., 2014). These findings suggest that parents whose infant has survived may also face challenges once their infant is discharged home. These parents may need different types of support that target some of the challenges they may encounter over time

4.1.3 Not knowing what to expect. The parents in the included studies describe a multitude of feelings associated with a NICU admission in particular being unfamiliar with what they could do as a parent as well as not knowing what could happen to their infant. There were particular challenges associated with the inability to hold or care for their infant. Obeidat and colleagues (2009) completed a systematic review of parents' experiences in the NICU and reported that parents in the included studies felt alienated when their infant was admitted to the NICU, and felt anxious and insecure as they desired to have closeness and proximity to their infant. They found that parents in the NICU are faced with a stressful and overwhelming situation and do not know what to expect (Obeidat et al., 2009). Obeidat and colleagues (2009) also demonstrated that mothers who did not see or touch their infant often felt distressed and that parents can experience grief and concern if they feel their infant may not survive.

Using a qualitative study design, Hall (2005) explored parents' experiences of having a critically ill infant. Findings reported suggested that parents felt that their experience was "alien to what they knew", which caused them feelings of shock, fear, and worry (Hall, 2005, p. 181).

The authors in this qualitative study described a theme of “what is going on?” wherein parents wanted to fully understand what was going on with their infants, however, at times felt left out from the care that was provided (Hall, 2005, p.182). The authors in a qualitative study examining fathers’ experiences in the NICU also reported that fathers described fear about risks involved in their infants’ treatment, as well as fear their infant would not survive (Lindberg, Axelsson, & Ohrling, 2007). Fathers wanted to be in control of the situation, and wanted to know what was happening (Lindberg et al., 2007). Obeidat and colleagues (2009) suggest that parents require attention from nurses such as; a caring approach, consistent information, education, follow-up, and a close proximity to support their fragile infant. These interventions can be provided by nurses and will assist families to manage the feelings associated with an infant’s hospitalization. These actions will also help families anticipate potential complications, and feel more prepared for situations as they arise.

Mothers have described how difficult it is to ask nurses whether they could participate in their infant’s care, in particular when this decision seems to be arbitrarily made by the health care team (Spinelli et al., 2016). For mothers this can cause the “perception of not having the right or opportunity to make choices” for their infant (Spinelli et al., 2016, p.196). Parents need to be involved as much as they are comfortable with their infant’s care. This could involve family presence at daily rounds, continuous updates from nurses, and a care schedule tailored to meet the needs of the infant and parents. Nurses must strive to ensure families feel like an integral component of the infant’s care.

4.1.4 Hospital practices – what can be done? A qualitative study that explored mother’s experiences in a neonatal unit found that women reported a loss of autonomy when their infant was admitted, as there were often rules and procedures that controlled contact with

their infant (Swanson et al., 2012). Mothers reported feeling frustrated especially if they were unable to hold and feed their infant when desired (Swanson et al., 2012). Infants in the NICU may have umbilical intravenous lines, and the presence of an endotracheal tube, which may limit parent's ability to hold or care for them. Further, McGrath (2014) identified potential barriers to parents caring for their infant such as nurses asking families to leave during shift report, an infant's schedule that is determined based on unit and nursing needs, and an attitude that parents are only seen as adjunct to their infant's care.

The location of care for the mother can impact parents' experiences in the NICU. In current practice infants are often cared for in NICUs that are separated from where their mother is receiving care. Therefore, mothers are often cared for by a nurse in the post-partum unit, but would also have frequent contact with the nurses in the NICU. In 2011, the Provincial Council for Maternal Child Health (PCMCH) published guidelines on the mother-baby dyad and how this can be optimized in practice (PCMCH, 2011). They described that despite strong evidence for supporting a mother-baby care delivery model that endorses limited separation, there are still variations in practice (PCMCH, 2011). This includes what type of infant care can be provided in a post-partum unit, and what types of babies may need to be admitted to special care nurseries, or NICUs, for infant care (PCMCH, 2011). They recommend trying to provide as much care as possible while the infant stays with its mother, and limit separation (PCMCH, 2011). This type of care could provide parents with the opportunity to stay with their infant while also ensuring the mother receives the necessary care for her needs. Although potentially challenging with more acutely ill infants, it can be suggested that this type of care could be expanded for infants that require more complex medical interventions.

The NICU environment and the resulting impact it had on parents was described in the included studies in this qualitative review. There was the desire to have private spaces for parents and practices that were conducive to having parents visit for long periods of time. Current recommendations for NICU design recommend private rooms as the optimal standard of care (White, Smith, & Shepley, 2013). Although it is unclear in the included studies what type of NICU design existed, consideration should be given to the impact room design and unit configuration may have on parents. In a systematic review examining the impact of the design of neonatal intensive care units on neonates, staff, and families, it was found that private room design is beneficial for parents, and can improve patient care and parent satisfaction (Shahheidari & Homer, 2012). This includes increased privacy (for example, while pumping breast milk), reduced noise (due to fewer infants in a room together), increased parental contact, and increased opportunities for parents to provide care (Shahheidari & Homer, 2012). Parents in open bay wards felt a lack of privacy to express their emotions while private rooms could aid in providing a space for parents to bond and care for their infant in a more intimate setting (Shahheidari & Homer, 2012). For units that currently do not have private rooms, attention should be given to unit practices that may increase privacy for parents, as well as encourage parental contact.

Organizational factors such as a lack of collaboration with other units, and a lack of staffing continuity can also negatively impact communication (Wigert, Dellenmark Blom, & Bry, 2013). Nurses must strive to work collaboratively with all members of the health care team, and try to ensure consistency in the information presented to parents. This can include a detailed handover during transitions between different HCPs (for example using a standardized report tool), as well as consistent teaching processes for HCPs to follow to help ensure accurate information is provided.

4.1.5 The need for communication. Parents in the studies included in this review elaborated on the role communication had on their experiences, and described how crucial it was that communication be offered in a timely manner, with consideration of how the information was presented. Parents also wanted details regarding their infant's health status. A qualitative study by Wigert, Dellenmark Blom, and Bry (2014) explored the role of communication with parents and HCPs in the NICU and found that communication with HCPs was essential to parents' management of their experience. Parents felt that they were given attention when staff made themselves available and showed compassion (Wigert et al., 2014). This can be demonstrated by nurses through multiple attempts at interaction, which could involve asking how they are managing, and whether further assistance is needed. Aagaard and Hall (2008) also described how the mother-nurse relationship could be further enhanced through chatting or informal discussions at the bedside, as it was an informal way to relay information between nurses and parents. This allowed nurses to share knowledge and expertise with parents rather than informing them, and helped parents feel active and involved in the care of their infant (Aagaard & Hall, 2008). Nurses often interact frequently with parents at the bedside. Communication can be facilitated by nurses having the opportunity in their shift to sit and spend time with parents. Overall attentive conversations with staff can create a trusting relationship, and give parents the ability to orient themselves during such an unfamiliar experience (Wigert et al., 2014).

It is an identified competency of neonatal nurses that they communicate effectively and professionally with both families and other HCPs (CNA, 2017). This includes using written and verbal methods and is particularly important when working with families in the NICU. Parents in a mixed methods study by Wigert et al. (2013) felt that nurses' readiness and openness in

answering questions made them feel informed, however, a lack of professionalism, and the use of medical jargon negatively impacted communication. It is important that nurses understand the resulting impact communication can have for parents, and strive to ensure that communication is always offered in a manner that is sensitive to parents' needs. This also involves ensuring that information provided to parents is well understood.

It is also important that nurses assist parents in the NICU by encouraging both mothers and fathers to discuss the resulting impact of their infants' hospitalization, as well as by encouraging open communication between both parents. A lack of communication may contribute to feelings of isolation, as well as resentment between partners (McGrath, 2014). It is particularly important that nurses educate parents about the different ways they may react to their infant's hospitalization and how they might grieve. Nurses need to reinforce that these feelings are not unusual, and it is important to share these feelings with each other (McGrath, 2014). Fathers have reported that they valued sharing and talking with their partner about the challenges they have encountered in the NICU (Lindberg et al., 2007). This was important when trying to manage the situation (Lindberg et al., 2007). Mothers in a qualitative study by Swanson et al. (2012) also described the importance of gaining reassurance or support from their partner.

4.1.6 Helping parents to continue on. Parents in this review elaborated on the difficulties they encountered after the death of their infant. The death of an infant can be devastating, and parents can experience depression, post-traumatic stress disorder (PTSD), and chronic health conditions both immediately after the death of an infant, as well as many months after (Hawthorne, Youngblut, & Brooten, 2016; Youngblut, Brooten, Cantwell, Del Moral & Totapally, 2013). Buchi and colleagues (2007) studied grief in parents using the Munich Grief Scale and they demonstrated that two to six years after the death of a premature infant, parents

still suffered from their bereavement. The grief process after the death of an infant can be lifelong and parents may also move through the grief process differently (Kenner, 2014). It is important that nurses educate families that grief is an individualized process (Kenner, 2014), and that it may take many months for parents to cope with the loss they have experienced. Nurses should also speak to parents about the potential long term impact of loss and grief, and encourage parents to seek assistance if needed.

Similar to the parents in the reviewed studies, Brosig, Pierucci, Kupst and Leuthner (2007) found that parents emphasized the importance of having something tangible to remember their infants after they died, such as photographs or clothing the infant wore. As one parent described “looking back we have not only our memories but some of the things...those things are very important” (Brosig et al., 2007, p. 514). The parents in a qualitative study by Cortezzo and colleagues (2015) and in a mixed methods study by Shelkowitz, Vessela, O’Reilly, Tucker and Lechner (2015) also described the importance of memory making. This included a memory box filled with items their infant wore or used, as well as handprints, footprints, locks of hair, and photos (Shelkowitz et al., 2015). The benefits of memory making include creating opportunities for bonding and providing positive experiences that parents may remember (De Lisle-Porter & Podruchny, 2009). Memory making can also assist the family to begin the grieving process (De Lisle-Porter & Podruchny, 2009). These activities can be facilitated by nurses as they are often present with parents before and after an infant’s death. Nurses can also encourage parents to spend time with their infant, and help to ensure they spend as much time together as they would like.

Parents whose infant survived after the NICU hospitalization also described the long term impact of their infant’s hospitalization. Parents in the study by Whittingham et al. (2014)

described feelings of isolation after their infant was discharged home. In many instances this isolation was purposeful in order to prevent the spread of infection to the infant. They also described how it was important that their grief be recognized while in hospital, in order for them to focus on parenting after their infant was discharged home (Whittingham et al., 2014). In 2015, Gondwe and Holditch-Davis completed a systematic review on posttraumatic stress symptoms in mothers of preterm infants. They found that mothers who had an infant born prematurely displayed a high incidence of posttraumatic stress symptoms which included re-experiencing, avoidance, and hyper-arousal about the traumatic experience they endured (Gondwe & Holditch-Davis, 2015). They also found that after their preterm infant was born mothers used a variety of coping mechanisms such as discussing their experience with other mothers of preterm infants, seeking out information and spending more time with their infant (Gondwe & Holditch-Davis, 2015). Regardless of whether a neonatal death has occurred, parents experience many emotions in the period following their infant's hospitalization. It is crucial that nurses understand the long-term impact of a NICU hospitalization so they can provide interventions to assist parents.

4.2 Implications for Nursing Practice, Research, and Education

4.2.1 Nursing practice. With respect to nursing practice, nurses should assess for, acknowledge, and aid in assisting parents grieving both symbolic and physical losses. Findings of this qualitative review also suggest that many of the recommendations made by parents to help them through their loss and subsequent grief are components of family-centered care (FCC). The themes of support, hospital practices, and communication all involve aspects of FCC. In North America, FCC is envisioned in adult, pediatric, and neonatal ICUs and guidelines have been established to ensure this type of care is provided (Davidson et al. 2017). FCC is an

approach to care delivery that is “respectful and responsive to individual families’ needs and values” (Davidson et al., 2017, p. 105). These guidelines describe the importance of family presence, including during interdisciplinary rounds as well as resuscitation efforts (Davidson et al., 2017). It also involves offering opportunities for parents to be involved in their infant’s care, as well as family education programs and peer-to-peer support (Davidson et al., 2017). In the NICU, implementing FCC involves multiple strategies such as encouraging parents to provide care to their infant, providing support and resources to parents that can assist with the impact of having an infant in the NICU, and educating parents about prematurity (McGrath, 2014).

Results of this synthesis illustrated the importance of clear and frequent communication for parents. FCC ensures families receive accurate and timely information regarding their infant (ANA & NANN, 2013). Communication should occur on a frequent basis with the health care team, and can include interdisciplinary family conferences, as well as HCPs’ use of communication techniques such as active listening, expressions of empathy, and supportive statements (Davidson et al., 2017). It can also involve training for nurses to enhance their ability to communicate effectively with parents (Davidson et al., 2017). Harrison (2010) described that despite FCC being the philosophy of pediatric care for many years, there are still gaps in how this care is provided. In the included studies, limited description of the clinical context of the individual NICUs does not allow for a determination of whether or not FCC was actively practiced within these units. Implementing FCC in a critical care environment with premature and ill infants can be challenging (Coughlin, 2014), given the vulnerable health status of all infants and the medical equipment required. It can be suggested that although FCC has been a philosophical underpinning of care in many NICUs, there remains room for improvement, in

particular in North America. The delivery of FCC that is both sensitive and unique to each family can greatly impact parents' experiences of loss and grief.

Additionally, a strength of the JBI (2014) methodology for qualitative reviews is that specific recommendations are created, designated as lines of actions. The following is a summary of the recommendations that can be implemented in clinical practice (Table 7). These recommendations can be used by neonatal nurses to guide their care.

Table 7 Summary of Practice Recommendations

Theme	Practice Recommendation
Support	Nursing care should be provided in a manner that enables emotional, tangible, and informational support to be offered from nurses. This can include helping parents to recognize the loss and subsequent grief they may be experiencing.
Not knowing what to expect	Care in the NICU should involve the assessment and management of the psychological impact of a NICU hospitalization on parents. Nursing care should promote FCC where parents play a vital role in the management of their infant.
Hospital Practices	Hospital care should be provided to parents in a way that is both sensitive and compassionate to their unique needs. This can include optimizing care while limiting separation, and a neonatal unit that provides privacy and designated space for parents.
Communication	Communication with parents should be provided in a timely and thorough manner. This communication should be provided in a way that is understood by parents. Communication amongst parents, as well as family and friends, should be promoted by nursing staff.
Coming through Grief	Nursing care should be provided in a manner that assists parents with the shock and grief immediately following either the loss of a full-term pregnancy or the loss of their infant. This also involves enhancing support and care after families are discharged home.

4.2.2 Nursing research. The findings of this review highlight the limited number of qualitative studies examining parental loss and grief in the NICU. There were only five studies that met inclusion criteria, despite a rigorous search process. Further, we found only three qualitative studies examining loss and grief after a neonatal death specifically and two studies exploring loss and grief while the neonate is in the NICU. To better understand these similar,

but separate experiences, more qualitative research is warranted. There were also no Canadian studies that met inclusion criteria. Future studies should aim to examine loss and grief in the context of a Canadian NICU, given the potential variations in practice that may exist between different neonatal units, in particular in different countries.

When examining the distribution of mothers' and fathers' in the included samples only 17 fathers were included out of the 134 parents studied. The studies in this review focused primarily on the experiences of mothers, and one study in particular included only mothers in their sample. Future research should ensure a mixed sample of mothers and fathers, or alternatively study both mothers and fathers' experiences separately, to ensure adequate representation of both individual views. Authors such as Arockiasamy, Holsti, and Albersheim (2008) and Lindberg et al. (2007) have studied fathers' experience in the NICU, however, further research should be completed to examine the experiences of loss and grief in fathers.

The types of losses explored in the studies in this review included loss of the experience of delivering a full term infant, and the loss of an infant after birth. Woodroffe (2006) describes multiple types of losses that can occur in the NICU, which can also include the loss of the normal labour and delivery experience, loss of control, loss of confidence as a mother, as well as the loss of immediate parenting acts (Woodroffe, 2006). Further work on the concept of loss, in particular, in the NICU would assist in understanding what types of losses parents experience and how the experiences of these losses may extend beyond the NICU environment. This could include a concept analysis, as well as qualitative studies examining loss specifically in the NICU.

4.2.3 Nursing education. The findings of this review, as well as broader literature related to loss and grief should be shared with clinical nurses. This can be provided through many different ways such as undergraduate nursing education, as well as more targeted

approaches such as webinars, in-services, and educational presentations as nurses become more specialized in their area of practice. It is the expectation of nurses entering into the profession that they demonstrate knowledge of nursing theory, social sciences, and humanities which can include loss and grief (College of Nurses of Ontario [CNO], 2014). In addition, the Canadian Association of Schools of Nursing [CASN] (2011) have developed competencies for palliative and end-of-life care. These competencies include knowledge of common manifestations of grief, factors that affect grieving, and family needs related to loss, grief, and bereavement (CASN, 2011).

A qualitative study by Yam, Rossiter and Cheung (2001) that examined nurses' experience of caring for dying infants in the NICU found that nurses reported having inadequate knowledge and expertise to comfort grieving parents. One nurse described "when I saw parents cry, I didn't know how to comfort them. I didn't know what to say" (Yam et al., 2001, p. 655). Although this study examined the experience of providing care to infants that are dying, nurses may also feel uncomfortable supporting parents experiencing other types of losses. During orientation to the NICU, literature related to loss and grief should be covered to ensure nurses not only have knowledge regarding these concepts, but also begin to develop the skills to support parents. This type of education could also be followed by support from managers or educators in the unit as questions and difficulties arise. Novice nurses in particular may need additional education in order to develop these skills. It is especially important that nurse educators encourage nurses to reflect on their practice, and look for ways to assist nurses to improve their care (CNO, 2009). This may involve debriefing after difficult situations as well as providing ongoing support to assist nurses to understand the types of loss and grief they may encounter.

A finding of this review is that parents greatly valued support offered by HCPs, however, nurses must feel comfortable providing this type of support to parents, in particular during situations that involve loss and grief. Despite a strong focus on the clinical care of complex infants in the NICU, neonatal nurses should be open to understanding the psychological impact that this type of care has on parents. This involves understanding the challenges associated with a NICU admission, such as navigating how difficult the NICU can be for parents. Nurses need education on how to support parents, as well as a knowledge of loss and grief to better assist parents in the NICU. This education should occur in a supportive and engaging manner, recognizing that nurses may have differing levels of comfort in providing this type of support.

4.3 Strengths and Limitations of the Thesis

The strength of this review was that it was conducted in a manner that followed a rigorous process modelled on the JBI (2014) approach. The search process was created with assistance from two librarians and the use of four databases allowed for a broad retrieval of studies. Conducting a rigorous search that is both reproducible and comprehensive is an important step in qualitative review methodology (Tong et al., 2012). The search screening was completed by two individuals (ER and BV), with three additional reviewers assisting with the final screening decisions (FFB, AV, WP). The assistance from multiple reviewers enabled a more comprehensive screening procedure. Critical appraisal and data extraction was also completed by two individuals, which helped ensure a more rigorous process. The use of both the CASP and JBI quality appraisal tool addressed potential limitations from the use of one tool alone, and allowed a more extensive appraisal of each study.

Findings from this review authentically represented data from the primary studies and were used to create practice recommendations (lines of action) (JBI, 2014). The practice recommendations proposed in this chapter are applicable to nurses working in neonatal settings, and a strength of this review is that the dependability of these findings are grounded in each study's findings, and not in the interpretive ability of the review's author (Lockwood & Pearson, 2013).

It is possible that the use of other review methodologies that include quantitative studies, as well as grey literature, could have helped to further increase the understanding of loss and grief in the NICU. It was felt that the focus of this review should be on the parental experiences as described by the parents themselves, however, studies that have examined loss and grief using other methodologies could have contributed to the findings of this review.

The studies included in this review examined parents' experiences at time points varying from between five weeks to 16 years. It is important when designing future studies, to consider the length of time that has passed since the parents' experiences. Over time, the distress and symptoms associated with loss and grief, may change (Dyer, 2005), and this can impact how parents describe their experiences. Therefore, the length of time since their infant's NICU hospitalization could have impacted how families described their experiences.

The purpose of this review was to study parental loss and grief together, however, challenges were encountered during both the design and screening process. Some of these challenges arose due to the complexity of studying two separate yet related concepts. Initially after the research question was chosen, we worked with two librarians to design a comprehensive search. It was difficult, however, to conduct a search that captured studies that encompassed both concepts, and this was partly due to the terminology used in each database. One example is

the search strategy for the Medline database where the MeSH heading bereavement was used as well as multiple keywords such as loss, grief, grieving, and bereavement. The term bereavement is related to loss pertaining to the death of an individual. It was essential that the search capture more broadly the experience of loss and grief, not only in those situations involving death. However, not all databases had an appropriate MeSH heading. Also upon review of the search strategy it was identified that when searching the CINAHL database the term bereavement was used as a MeSH heading, but this was not exploded when completing the search. Using this approach would have captured articles indexed under bereavement, but not those indexed under grief. This may have potentially limited search results. This error prompted discussion and it was felt that the use of multiple keywords when searching both the title and abstract would have assisted in capturing relevant articles.

Another potential limitation is that articles that described loss and grief as a finding were not included due to the nature of their research question. Articles were only included if the study aim was to explore loss and/or grief. This could have potentially impacted the findings of this review. It is also possible that studying loss and grief together could have impacted the findings. The extraction of both loss and grief combined may have inadvertently limited the understanding of each concept separately. It was determined that given how closely related the concepts are the design of the review was appropriate, however, exploration and understanding of each concept separately would likely enhance our knowledge about the concepts under review.

4.4 Conclusion

A systematic review of qualitative evidence using a meta-aggregative approach (JBI, 2014) was used in this thesis to explore loss and grief experienced by parents in the NICU. This approach included a systematic and rigorous approach to the searching, critical appraisal, and

aggregation procedures. Four databases were systematically searched using pre-identified search criteria. Two individuals were involved in search screening, and three additional reviewers were used to identify included articles. This search process resulted in five studies being included. Quality appraisal was completed to examine the methodological quality of the included studies however no articles were excluded based on the results of this appraisal.

Data aggregation was completed modeling the JBI (2014) approach. During data aggregation, individual study findings were reread and grouped together by similarities. They were then categorized into broader, overarching themes. This represented the meta-aggregation of multiple study findings. This approach also ensured the results of the review resonated from the findings of each individual study. Meta-aggregation in this review resulted in five themes which were: support, not knowing what to expect, hospital practices, communication, and coming through grief. The resulting themes were used to provide recommendations for neonatal nurses working in the NICU.

As a nurse educator in the NICU, the findings of this review as well as the steps involved in this thesis, have greatly impacted my work. In my role I am constantly involved in ensuring the most current and up to date practice is implemented into our neonatal unit. In the NICU this entails working closely with nurses to ensure their practice needs are met. It also involves constantly assessing the current state of knowledge regarding various practice issues, as well as building this knowledge into current policies, procedures, and practice. It is crucial as a nurse educator that I have the ability to evaluate and critique research studies, then subsequently evaluate how they can be used in clinical practice.

The findings of this review highlight the importance of the neonatal nurse's role in providing not only comprehensive care to the infant, but also the importance of caring for the

family as a whole. FCC is a strong focus in the NICU, however, it is crucial that nurses have the knowledge and skills to be able to assess and manage the impact of a NICU hospitalization.

Nurses need to have time throughout their shift to provide FCC, and hospital administrative staff need to support and promote this type of care. Nurses should be aware of loss and grief in particular, as these feelings can both impact a family while in the NICU, as well as after they are discharged home. Regardless of whether a neonatal death has occurred, parents in the included studies have described experiences of loss and grief. It is imperative that neonatal nurses are aware of the types of feelings parents may have while in a NICU.

It is my hope that this review has summarized the state of knowledge regarding loss and grief, and has made the findings from multiple studies more accessible to neonatal nurses. I plan to disseminate these findings through a presentation to colleagues, as well as at a neonatal conference and through publication. This may also involve engaging in future research to examine more closely the experience of loss and grief in the NICU. Overall the completion of this review has also greatly enhanced my understanding of these concepts, and has raised questions about the type of care we provide in the NICU. For example, I hope to see more comprehensive follow-up after a neonatal death, as well as protocols implemented to ensure all families have the necessary opportunities to create memories before and after their infant dies.

In summary, it is crucial that neonatal nurses understand the key role they have in helping parents manage the loss and grief associated with a NICU hospitalization. While in hospital these parents have unique needs. Parents who have lost an infant in the NICU also describe profound feelings of loss and grief. Nurses must have the expertise and knowledge to support parents in both situations. It is through offering education, support, and assistance that neonatal nurses will greatly impact parents' experiences while in the NICU.

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Appendix A

Enhancing the Transparency in Reporting the Synthesis of Qualitative Research: ENTREQ

Statement

Item	Guide and descriptions
Aim	State the research question the synthesis addresses.
Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology.
Approach to searching	Indicate whether the search was pre-planned or iterative.
Inclusion criteria	Specify the inclusion/exclusion criteria.
Data sources	Describe the information sources used and when the searches were conducted; provide rationale for using the data sources.
Electronic search strategy	Describe the literature search.
Study screening methods	Describe the process of study screening and sifting.
Study characteristics	Present the characteristics of the included studies.
Study selection results	Identify the number of studies screened and provide reasons for study exclusion.
Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings.
Appraisal items	State the tools, frameworks, and criteria used to appraise the studies or selected findings.
Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was reached.
Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give rationale.
Data extraction	Indicate which sections of the primary studies were analyzed and how were the data extracted from the primary studies?
Software	State the computer software used, if any.
Number of reviewers	Identify who was involved in coding and analysis.
Coding	Describe the process for coding of data.
Study comparison	Describe how comparisons were made within and across studies.
Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.
Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or author's interpretations.
Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies.

Appendix B

Search Terms: CINAHL

Search Step	Query	Results
S1	(MH “Intensive Care Units, Neonatal”) OR (MH “Intensive Care, Neonatal”) OR (MH “Neonatal Intensive Care Nursing”)	11,178
S2	(MH “Nurseries, Hospital”)	251
S3	TI (nursery or NICU or (neonatal N2 unit? or department or care)) OR AB (nursery or NICU or (neonatal N2 unit? or department or care))	468,181
S4	S1 OR S2 OR S3	472,814
S5	(MH “Parents+”)	48,375
S6	TI (parent* or mother* or father* or adoptive famil*) OR AB (parent* or mother* or father* or adoptive famil*)	91,641
S7	S5 OR S6	110,976
S8	(MH “Bereavement”)	4,900
S9	TI (grie* or loss or bereavement) OR AB (grie* or loss or bereavement)	63,169
S10	S8 OR S9	65, 245
S11	(MH “Qualitative Studies+”)	81,687
S12	TI (interview* or focus group* or qualitative or experience* or narrative* or ethnograph* or grounded theor* or phenomenolog* or participatory action* or case stud*) OR AB (interview* or focus group* or qualitative or experience* or narrative* or ethnograph* or grounded theor* or phenomenolog* or participatory action* or case stud*)	307,632
S13	S11 or S12	329,919
S14	S4 AND S7 AND S10 AND S13	718
S15	S4 AND S7 AND S10 AND S13 limit to English	666

Appendix C

Search Terms: Medline

Search Step	Query	Results
1	Intensive Care, Neonatal/	4857
2	Nurseries, Hospital/	1542
3	((neonatal adj2 (unit* or department or care)) or nursery or NICU).ab.ti	29,131
4	1 or 2 or 3	32,272
5	exp parents/or single-parent family/	89,591
6	Adoption	4543
7	(parent* or mother* or father* or adoptive famil*)ab.ti.	498083
8	5 or 6 or 7	522,345
9	exp bereavement/	11,737
10	(grie* or loss or bereavement).ab.ti	735,515
11	9 or 10	740,549
12	exp qualitative research/	31,530
13	(interview* or focus group* or qualitative or experience* or narrative* or ethnograph* or grounded theor* or phenomenolog* or participatory action* or case stud*).ab.ti.	1,243,726
14	12 or 13	1,246,614
15	4 and 8 and 11 and 14	100
16	Limit 15 to English language	88

Appendix D

Search Terms: PsycINFO

Search Step	Query	Results
1	neonatal intensive care/	1330
2	((neonatal adj2 (unit* or department* or care)) or nursery or NICU.ab.ti	6297
3	1 or 2	6643
4	exp parents/	80,889
5	(parent* or mother* or father* or adoptive famil*)ab.ti	305,818
6	4 or 5	311,233
7	exp BEREAVEMENT/	12,961
8	(grie* or loss or bereavement).ab.ti	104,901
9	7 or 8	106,650
10	exp qualitative research/or interviews/	14,641
11	(interview* or focus group* or qualitative or experience* or narrative* or ethnograph* or grounded theor* or phenomenolog* or participatory action* or case stud*)ab.ti	837,371
12	10 or 11	837,978
13	3 and 6 and 9 and 12	55
14	Limit 13 to English language	50

Appendix E

Search Terms: Nursing and Allied Health

Search Step	Query	Results
1	Mesh.Exact (“Intensive Care, Neonatal” OR “Neonatal Nursing” OR “Intensive Care Units, Neonatal”)	1,710
2	ti(neonatal NEAR2 (unit* or department or care) or nursery or NICU) OR ab(neonatal NEAR2 (unit* or department or care) or nursery or NICU	3,901
3	Mesh.Exact (“Intensive Care, Neonatal” OR “Neonatal Nursing” OR “Intensive Care Units, Neonatal”) OR ti(neonatal NEAR2 (unit* OR department OR care) OR nursery OR NICU) OR ab(neonatal NEAR2 (unit* OR department OR care) OR nursery OR NICU	5,045
4	Mesh.Exact(“Parents”)	4,368
5	ti(parent* or mother* or father* or adoptive famil*) OR ab(parent* or mother* or father* or adoptive famil*)	123,023
6	Mesh.Exact(“Parents”) OR ti(parent* OR mother* OR father* OR adoptive famil*) OR ab(parent* OR mother* OR father* OR adoptive famil*)	123,796
7	Mesh.Exact(“Bereavement”)	537
8	ti(grie*loss or grieving or bereavement) OR ab(grie* or loss or grieving or bereavement)	146,240
9	Mesh.Exact(“Bereavement”) OR ti(grie*loss OR grieving OR bereavement) OR ab(grie* OR loss OR grieving OR bereavement)	3,198
10	mesh.Exact(“Qualitative Research”)	3,198
11	ti(interview* or focus group* or qualitative or experience* or narrative* or ethnograph* or grounded theor* or phenomenology* or participatory action* or case stud*) OR ab(interview* or focus group* or qualitative or experience* or narrative* or ethnograph* or grounded theor* or phenomenology* or participatory action* or case stud*)	442,161
12	mesh.Exact(“Qualitative Research”) OR ti(interview* OR focus group* OR qualitative OR experience* OR narrative* OR ethnograph* OR grounded theor* OR phenomenology* OR participatory action* OR case stud*) OR ab(interview* OR focus group* OR qualitative or experience* OR narrative* OR ethnograph* OR grounded theor* OR phenomenology* OR participatory action* OR case stud*))	442,549
13	3 AND 6 AND 9 AND 12	28
14	Limit 13 to English language	28

Appendix F Data Extraction Tables

Title: Living with grief following removal of infant life support: Parents' perspectives

Author: Armentrout, D.

Year: 2009

Country: USA

Journal: Critical Care Nursing Clinics of North America, 21.

Research type Aim/Objective	Sample Strategy/Population	Data Collection	Data Analysis
-Grounded theory -This article expands on the concepts identified by parents as factors in their decision making (to withdraw care) and on the facilitators and barriers that parents faced, and continue to face in their grieving process.	- Participants were recruited from a large support group for parents who experienced the neonatal death of a child -15 parents (4 couples, and seven mothers), 13 were white -Participants had made the decision to withdraw treatment	-Interviews (face to face or by phone) -All participants were asked "Tell me about your son/daughter?" - Subsequent questions were asked regarding families feelings before, and after their infant's death.	Unclear

Finding Themes/ Supporting Quotes

1) Making the decision: This included a description of family's experience of how the decision was made and that many felt that this was the right decision for their infant)

“the decision was pretty clear cut. He wasn't going to get better,”

“There wasn't a big decision...There wasn't any need to go on...He was just suffering, and we didn't want him to suffer”

Parents perceived their infant to be *“slowly dying, so if we did not remove life support, he would die on his own”*

Others felt that the infant *“was just artificially kept alive, and I don't think we was really there”*

The decision was described as *“heartbreaking” “a nightmare of a situation...just horror...just a very painful thing”*

Deciding to remove their infant from life support was expressed as *“the hardest decision we've ever had to make”* but, considering *“the magnitude of what the baby was going through,”* also *“the most loving”* decision the parent could make for the child.

Parents perceived that they *“did the best we could under the circumstances” “If there had been hope...a chance for cure...a full recovery or even a somewhat normal life existence, though difficult, that would be different but in our hearts we knew there was nothing more and it was the best decision”*

“I would do everything....well, we felt like we did.....we exhausted all that we could, and this was what was best for her.”

For some it was their only opportunity to hold and talk to their infant *“like a normal baby without all the tubes and wires”*

Her daughter *“would have left the world with all the tubes, and that's just not something that I wanted...I would have had to live with that for a long time, too. I think this was better”* She got to hear her dad sing, she got to...she knew we were holding her so...yeah. I think we made the best decision. I have doubts, like I said, about if she would have fought for another day... but I don't have the regrets. It's hard to imagine what your life would have be like if you would have made another decision. There would have been a lot of images I would have had to live with...It would have been a different was for her to go. It wouldn't have been holding her.... It would have been sitting there...looking at her...on the bed”

“They asked me if I wanted to, like, pull the tubes out completely—that would require another surgery—or just clamp them off and cut them. And I was afraid that with another surgery he would already be dead when I would get to hold him, so we just clamped them. We stayed there for a little while, and we carried him back to that room. .We were alone then.”

“Holding her when she died...that's not a memory I want to have to have but...my feeling is if your child has to die, what better place than in mom's arms...so...I try and make that a good memory, but it's a very sad good”

2) Things they would have changed:

Believing that *“there was nothing that anybody could do to make it better...your baby's going to die”*

Parents did not feel guilty about choices made, however they did have regrets surrounding three different areas:

Parenting acts not performed: *“I didn't look at her hair, you know, to see how much hair she had, I didn't take the time to look at her body and just study every little bit of her.” “Personally my only regret was that I didn't bathe him that day and that I didn't dress him.in the outfit that I wanted to see him in.”*

Finding Themes/Supporting Quotes

Taking pictures and creating other memories:

“We took a lot of pictures...but I don’t think you ever have enough”

‘The nurses did a little foot plaster of her feet, and then they cut it out of the shape of a heart, a little bow on it...and I’ll tell you what... that was awesome having that was just...one of the most special things.’

“And the baptism...why didn’t we do it sooner...why did we wait for somebody on call to show up with a bottle of sterile water and a cotton ball...why didn’t we do it right away?”

Having friends and family see and know their infant: *“I think later it would have helped with our grief to have had more family involvement in the hospital experience” “I would have invited more people to see her before.... we took her off life support ... because to me the more people that would have seen her ... they would have realized our loss more.” “ The only thing we might have done...some of our closest friends...it would have been nice to have them there as well...none of our friends got to see or meet him while he was alive”*

What advice did they have for other couples: *“clipping his hair, his fingerprints, his footprints...have pictures with him...we never had a family portrait with him. “You have to cherish every minute with them” “Take that time with their baby...to hold their hand and to really love them and care about them. I think it’s important to allow yourself to be a mother before you let go...of the baby...to be a parent to some degree...to change their diaper...feed ‘em if you can...play with their toes and fingers and nose and...just be a mother to ‘em...be a parent to ‘em...before you turn it off, because that...is something that you will cherish for the rest of your life”*

An area of uncertain regret was whether parents should involve other living children at the time of the infant’s death: *“Might have had my kids there more than I did...and I even recently I considered...should I have had my older children with us when we took he off life support?...I don’t know the answer...but I’ve considered thinking I wonder if we should have said do you want to be with us...should we have included them more...would it have made it easier for them...I don’t know”*

“that the day that we went to remove her from life support . that morning we explained to the kids what her situation was, and that we didn’t know for sure if she would be coming back, and we would be taking pictures...We had already been taking pictures, but what I did was I got a tape recorder, and I had all the kids record...introduce themselves on the tape recorder, and we, we played that for her at the hospital...but the social worker was encouraging us to let the kids come, but....it was so painful...We didn’t want them to feel what we were feeling,...but, like I said, now I know they were feeling pain...that is one thing I wish I could have changed.”

3) Health Care Providers:

Most of the study participants’ experiences with health care professionals were of a positive nature. *“the nursing staff, the doctors...they really know what they’re doing...not only medically, but dealing with us personally...that helped a lot.” “one of the nurses wrote down that she liked to be swaddled...and that she didn’t like it when her diapers were wet...It was like a piece of information ...that gave me something about her character.” “Calling in on their days off to see how he was doing...requesting to be assigned to him”*

Finding Themes/Supporting Quotes

Study participants also valued health care professionals' support and empathy for the horrific situation the participants faced. It was *“such a great blessing...that there was no hindrance in the terms of any kind of an attitude or anything with the nurse or the attending doctor that made us feel uncomfortable or gave us any additional grief.”* Several parents expressed appreciation for the tears shed by health care providers for their infant, because *“it meant so much to know that others were sad”* for their infant, *“that he was more than just another patient.”*

When asked how health care professionals could have helped more during this extremely emotional period, parents responded *“to encourage them to be parents...during that time...help them to collect memories...pictures as a family...hair cuttings...plaster feet...blankets...sound kind of unimportant...but mean so much.”*

It was later in their grieving that parents occasionally commented that health care professionals *“dropped the ball.”* *“the medical professionals who have become your support system and your family while your child was alive ...all of a sudden they're gone...I think it's important to have some kind of support system or information...otherwise it's like stepping into this huge abyss.”* *“would want them to know that it lasts...the grief lasts longer than they will ever imagine . that it affects families on a deeper level than they will ever imagine...that what happens in the NICU...that families carry that with them forever.”*

4) Shock:

Mothers repeatedly commented that, despite performing normal activities, they were essentially dysfunctional for lengthy periods of time. One mother stated I *“would get up in the morning...I would be...normal...after about 2 weeks, 3 weeks...act normally...take the little one to school, stay in the car for a while...come back home and get into bed for the next 6 hours.and cry, and do whatever I needed to do...and I'd say, “OK gotta go get her, so I guess I'd better shower.” You know, get up, take a shower, get dressed, go pick her up...then it was little baby steps. I would go home, and I wouldn't get into bed, I would sit on the sofa. I have a very leafy backyard, and I would sit on the sofa and stare...just stare. I was incredulous for a very long time. I was just in shock for a very long time. The milestone of a year was really bad. And it is still bad. I mean I'm functioning. I put on make-up. I get dressed. I go out. I look normal...but it lasts for a long time...the bad thing.”* Another mother felt her son *“was the only thing I felt I had to get up for in the morning...but I guess I feel like I lost about a year of my son's time. He turned 3 shortly after my daughter died, and it wasn't...until he was a little after 4 that I turned around in the kitchen and saw this little boy . and said ‘Who are you?’...I wasn't all there for about a year...and this little boy, even though he was the one who got me through it...I really didn't know who he was.”* *“time, more time...I was nonfunctional for the first year. . For the first couple of months I could hardly leave the house...It was like leaving the house was like a sensory overload. I had so much energy going into coping I couldn't do anything else...Parenting my surviving child took every ounce of energy that I had...The first year was just awful...The second year was not a lot better, but I was pregnant again,...and so I had that to focus on...it was probably 3 years before I could really...I really felt I had turned a milestone.”*

The fathers in the sample commented that *“although we're hurting every day, we get up and continue on.”* Undertaking household projects and returning to work was described by fathers in the study as their “grief work.” One father's description *“your mind is always on it ...regardless of*

Finding Themes/Supporting Quotes

how busy you are....There are always reminders...no matter where you turn....You just have to realize...that you're not doing yourself any justice or your child any justice...You'll be doing them a bigger disservice by not attempting to get on with your life...not being able to do the everyday tasks that everybody else has to do...You have to get up...You have to...get back in the grind....You have to go back to work...You can't just...life.can't stop...Life just doesn't stand still...It has to keep going.in order for people to survive and in order for memories to carry on...You have to...keep functioning."

In asking what advice they would give to other couples grieving in a similar situation, study participants uniformly commented that there *"wasn't a set formula"* and that people had to *"allow themselves to feel sad...to feel bad."* That, unfortunately, one should *"try not to avoid the pain...The more you try to put it behind you or rise above it or whatever...you just can't...you're just gonna have to go through that agony. .There's just no way out of it."* As one mother explained *"people kind of give you a year to be absent minded and kind of ditzy, but after that you should be OK. And that's just not the case...That hasn't been my experience."*

Parents interviewed all suggested *"not to expect too much of yourself for a long time"* and *"not to let anybody push you into doing or going or being or acting how they think you should be...You deal with it with what works for you."* *"If that's just a little for you, well, then, it's a little for you...But if you're really wanting to grieve a lot, and everyone's telling you it's sufficient, you just need to listen to your own heart."*

5) Differences in Grief between mothers and fathers:

Some parents had been informed that differences in grieving would occur between couples that had lost an infant, others were not provided this information. One mother stated that being provided this information *"helped save our marriage"* because her husband *"wasn't on the same page with me, and it almost seemed like a betrayal."*

Couples commented that it was important for them *"to stick together...with your spouse...and make decisions together and communicate together and...and no matter what it takes...you've lost enough with losing a baby,...and you don't need to lose your marriage, so...just stick together and talk and communicate."* *"We grieved...while our son was alive, we really clung to each other...for the immediate aftermath. I can't think back and not feel his arms around me...I mean, he was terribly supportive, and...then, I would say after about 5 or 6 months, the only thing we had in common was that we had lost the same child....Everything was different."* Mothers found themselves *"needing to talk,"* to *"just to sit and cry,"* to *"research the Internet,"* to *"visit the cemetery every day,"* to *"send flowers,"* whereas

fathers *"alphabetized the garage, changed all the doorknobs in the house,"* *"did something physical, hit balls at batting cages."* One father said that *"I did a lot of crying around the time he died and up until the point he died, even, but ...basically, from the funeral on,...as much as it hurt that just didn't happen for me so.it was hard for me to understand sometimes why she was...and it was hard for me to figure out OK what am I suppose to do...but...I don't think I ever resented the fact that we've grieved differently. . I think I've become more understanding,"* to which his wife responded, *"I came to realize pretty quickly that his grief was just different from mine...He wasn't crying on the outside...like I was 24/7, which I didn't understand how he could not be...but he definitely was on the inside....I think we pretty quickly figured out that we were just responding in different ways."* For them it was a matter of *"just respecting each other's differences."*

Finding Themes/Supporting Quotes

One mother commented that although her *husband “definitely went through his grieving a lot more quickly than I did, he never made me feel like I wasn’t allowed to grieve, and anytime I wanted to talk about it, he pretty much would stop what he was doing and give me his full attention...allow me to talk.”* Another mother commented that she would ask her husband *“to talk...You know, I said, ‘Tell me what this is like...you have to share with me,’ but it’s never been his thing....Then every once in awhile he ...1 year he surprised me, and he had written a poem...and 1 year he bought a star...you know, the star registry,...and last year he shows up, it was a surprise, he had taken our son’s footprints...and he had a tattoo put on his upper arm of his footprints.so you know I know that it’s still there for him...but he just, he doesn’t talk about it very much.”* For another mother it was necessary *“to give each other space...It’s a long, hard process, but...if you stick together...everything will be worth it in the end.”*

6) Family & Friends:

Many parents had very supportive families and friends, but others found themselves facing further hurt when people close to them did not recognize their loss. Parents commented that *“the reality that there was a child and a life that came and went seemed to have been lost on a lot of people”* and that *“not treating her as if she was a person that was here...is hurtful.”* As one parent responded back to family members who viewed another family member’s stillbirth at 4 months as more of a “real loss” than the death of his 25-week daughter at 3 days of age, *“No, we had our hopes and dreams shattered right before our eyes. Once you hold a child, regardless of their size, there’s a lot of things going through your mind. You’re thinking about for their future and all the fun times you’re going to share as a family and all that.”* His wife added, *“She was here. She...held your hand. My dad took his ring and slipped it up her arm. She was a person that was here.”*

Another parent expressed that *“people just think, ‘Oh, the baby died.’...Well, you know they didn’t see her, it doesn’t mean so much.”*

Parents interviewed felt that friends and family *“wanted to be helpful and supportive, but people didn’t know what to say.”* As one mother stated, *“I think the things they were saying were supposed to be right and helpful...but they didn’t feel right and helpful.”* One mother was told *“But you have three other beautiful children’ and I say ‘But I had four.’”* One father was frequently told *“Oh, you’ll get through this, you’ll have another baby’. I mean, this is such an experience...that the last thing you want to think about is having kids.”* One mother, on being told that she can always have another baby, tearfully responded *“But it wouldn’t be that baby.”* Parents frequently were told *“At least you didn’t have her long enough to miss her,”* that the baby *“is in a better place,”* that it *“was part of God’s plan,”* or *“at least you didn’t bring her home,”* remarks they described as *“hurtful.”* One parent suggested that people *“felt like they needed to say something positive, and they felt like I needed to put a positive spin on something that doesn’t have one.”*

What parents identified as being helpful from friends and family *“was just ”being there...for us...that is what we needed....If we wanted to cry, they were there for that...If we wanted to just throw an anger fit, they were there for that.”* Having friends and family that *“didn’t overwhelm us... they just let us tell them what we needed, and they would respond. . They would basically just let us know they were just there for us, that they cared . was a lot more important and effective in helping us deal with our grief.”* One father commented that *“communicating your feelings to somebody that you trust was probably the thing that gets me through almost on a daily basis.”*

Finding themes/Supporting Quotes

7) Feelings of Isolation:

Having the support of family and friends for the horrific decision they had to make *“was important not...just our recovery...coming through grief... but knowing they supported our decision and supported us...made the process easier than...it would have been otherwise.”* Several of the study participants, however, revealed that they have *“never really told outside friends or distant families that we actually took him off the ventilator... I didn’t think it was anyone’s business...except our families.”* One mother discovered not finding anything *“about having to make the decision to take your child off life support....I think it’s probably something that people don’t want to talk about.”* Even participation in a parent loss support group was difficult *“This is not something that you normally hear...people who have had similar experiences taking them off life support.”* Although none of the parents expressed regret over their decision to remove life support, parents felt that they would like the opportunity to *“kind of compare...issues...and feelings,” and “to talk to somebody who has been through it and has survived.”* A mother of four older children and a surviving twin sibling to a daughter born with lethal congenital defects echoed this sentiment as she poignantly commented she does *“not have the opportunity to talk with parents that have had babies on life support and had to remove them. . And I just kind of wanted to know what other parents think”*

8) Remembering Activities:

Most mothers put together a memory box or scrapbook containing the few *“tangible things I have of her...which I share with her siblings, family... just everyone.”* Every day one mother wears *“an angel of some sort...and that’s what it’s for...that’s how I remember her.”* Another mother wears *“the little necklace that has your children’s charms on it,...and I wear five of them.”* Special Christmas ornaments are *“bought every year and hung with the other kids’ ornaments...and they know those are his.”* One father frequently stops by the cemetery where his son is buried: *“I talk out loud...about my day...what’s going on...Talking to him now...because he’s not here...that’s what helps...I guess keeps me grounded.”* One mother involves herself in various causes *“because of her...like the Heart Walk...and for her 1-year birthday I ran a blood drive...just anything I think of that...I would have done only because she was here...and I needed to help.”* One mother whose infant was cremated *“planted a garden in the front yard...bought a special fountain for next to her stone...made her seem more permanent.”*

9) Moving Forward:

With the passage of time parents realized that they had to *“move on...Life will never be the same...You’ll be forever changed...but you do have to go on with your life...You have to find a new normal for you.”* A mother of a premature son stated *“all of a sudden I realized it’s okay that I don’t cry every day...I still cry, but I think you have to realize that there’s still joy in life...Yes, we lost a son, but life is still...the sun still comes up, and there are still good things in the world, and there are still things to look forward to.”* Even though they have moved forward, there is still a void that never goes away. One mother commented, *“There’s just a hole that will never get filled up...not with another baby,...not with anything....I mean, there’s just no filling that hole. It’s just always there. . Sometimes its closer to the*

Finding Themes/Supporting Quotes

surface, and other times it's not, but it never goes away. . It just never goes away." One mother compared her loss of 12 years earlier to *"people who lose limbs...there's never a day they don't wish their arm or leg was there, but they learn to function in spite of its absence, and I think losing a child is very much like that . when there's always an awareness that someone is not there that should be there, but...you learn to function in spite of it."* Another mother views *"losing a baby like back pain...you injured your back, it's never going to be the same...and you get used to...there are certain things you can and can't do with your injury,...and it's always there,...but it's lightened up a lot,...but it's never going to go away...It's the same thing with my grief...It's there...I can just deal with it now,...and I know there are just some things I can't do,...and there's some things I can do....You know,...but it's an injury, so to speak, that's just always going to be there...and you just...have to accept that it's always going to be there...and you, you work around it...I think most people think grief is something that's going to go away...and I don't, I don't agree.... Maybe there are certain griefs that do, but not grief over losing a child. . It doesn't go away. . You learn how to handle it, that's all...That's not an easy thing to learn how to do."*

Essential to study participants' ability to move forward was their belief that their infant was still *"very much a part of our family, even though she's not here."* This belief was verified by one mother who proclaimed, *"She is not left out because she's dead, and I think because of that we go forward, and we're OK."* Another mother explained, *"She's here, but I guess in a different way. We've just incorporated her into our lives in a different way than the other kids...That's been important to us."* One mother commented, *"We have her pictures up with everybody else's.... Everybody else gets a new picture every year for school, except hers is the same...But that's just the way it is....Every now and then I come across...well, I don't come across—we only have about 2 dozen photos of her to begin with...I'll think, 'Maybe that one we can turn and crop, and do this, and do that and make it a new one,' and that's really exciting when I manage how to do that."*

All parents described maintaining an awareness of the deceased infant for both older and subsequent siblings. One mother commented, *"He's our son, he always will be...Our daughter points to his picture...She knows that's her brother, and she will always know that that's her brother, and he may not be here with us physically, but he's always going to be a part of our lives."* Another mother, *"always had photos of him up. . His footprints are framed and also hanging up. . I have a hope chest with his belongings from the hospital and stuff from the pregnancy, the blankie, and... his urn, and those kinds of things that I've shared with them. . I went ahead and put together a baby book for him, and I've shared that with them."* A mother who commented, *"On his birthday we go to the beach. Of course, when they were little, my other children didn't understand the significance, but as they grew older and were able to...they now know that that's where his ashes are scattered"* provided another example of including siblings.

10) Altered Perspectives of Life:

All study participants talked about a shift in life priorities as they emerged from their intense grief and loss. *"It kind of re-focuses you...There are some things in life that really matter, and there are other things that just don't."* As one mother explained, *"Things that used to seem like a big deal just aren't a big deal. My perspective has changed a little bit. I hope I'm more compassionate...to other people."* Their experiences

Finding Themes/Supporting Quotes

were described as an *“eye opener...you look at everything a little differently...You can’t judge people...You never know what they’ve gone through.”* Parents described a *“loss of innocence”* and a *“sense of powerlessness”* over events in their lives at the same time they *“gained an appreciation of life more...how fragile it is, and that it can go so easily...You need to treasure it and take every moment.”*

When asked what advice they would have for other parents facing the loss of their infant, the most participants responded not to *“take things for granted...just realize that there’s no guarantees of anything...nothing at all,”* that people are *“not immune from all the things you read.”* Not taking family and friends for granted became more important. *“It makes you want to pick up the phone and just call and talk...Let them know your feelings for them...you never know from 1 day to the next.”*

Parents also spoke of becoming stronger and better people for having lived through this terrible ordeal.

One father felt that *“it’s obviously helped us to be more sensitive to people who have experienced the same thing...I think it has helped us...well, I think we’re stronger people...You don’t go through something like this and survive it...including our marriage...we’ve, we’ve figured out that we’ve been to the depths of hell, and we’ve survived...not only as individuals but as a couple, and I know a lot of times that doesn’t happen.”* One mother felt that she *“can’t be worse because that’s a very shameful legacy to leave my child...a mom that’s worse because of her.”* Despite seeing themselves evolving into better people, all would *“give it all up happily...to be selfish.to have him back.”* As one mother concluded, *“It was rough, but we got through it, and we’re better people for it...but I would rather have my daughter.”*

11) Spiritual/Religious Perspectives:

Faith was a significant component for study participants as they went on with their daily lives. Some parents always were able to draw comfort from their faith: *“That strong relationship I have with Him... I know carried me through that time,” “Through the whole thing, I really felt very strongly that God just really gave me a strength I never knew I had...you know that when they’re with the Lord, there is nothing better.”*

Others expressed anger at God while still embracing faith: *“I am very angry at God, but I still attend church, I still talk to my priest...I don’t think I have anything else to hang onto but my faith.” “I mean, I certainly went through a period where I was pretty mad...you know ‘Why me? Why us?...and I’m not ever going to have an answer to that,...but I guess the realization that He lost a son too...more than anything helped me to realize that He truly understands...all that we were going through.”* Still others abandoned the God of their childhood for belief in a higher being that is not all-powerful: *“I had a hard time making sense of how this omniscient, omnipotent being could allow such horrible things to happen...I was never able to reconcile my belief in God and what He does with the reality of life....I think what I have now is a collection of what works for me, and I believe in a higher being, but I don’t think he is all powerful because...children wouldn’t die.”*

For many study participants it was the belief that their child was *“in heaven, and we’ll all be together one day”* that *“helps get me through.”* It was this *“belief in an afterlife that makes it easier. I think if families don’t have that,...that would be more difficult. I mean, if you really believe you die, and you go in the ground, and that’s the end of you, that would be kind of scary and depressing.”*

Finding Themes/Supporting Quotes

Parents expressed a need for *“something good to come out of something so bad.”* A father of an extremely premature infant described, *“We tried to use this in a positive way in our lives, and...every night, as we get ready to go to sleep, we always have a prayer time together, and one of our prayers from the very beginning has always been, ‘God, please use his life and allow us to be a part of it,’ and that’s still our prayer. We want good to come out of what we had to go through...and we want to be able to be a blessing to others....to help others to walk through this thing.”*

A mother felt that her daughter *“also showed me a deeper compassion for those that are born with handicaps and disabilities, and what I have found myself doing after she passed away was just going out and trying to encourage other women who have lost children...A year after she died I started a ministry in my church for parents who have lost children...So that’s one area, a huge area, where she really has changed my life...And all this is a result of what she has meant and what she has done...done for me.”* Another mother came to the realization *“that faith could keep growing, and I could keep learning more and more and more about faith and everything about God and everything how it affects our life and what we do, and I have to say, it’s intensified...that knowledge, that love, that foundation,...and I guess perspective on life, that that is what matters most.. that is my...main goal....to teach that to my children....to show that to my children...to example that to my children,...because I just feel...one is Delivered...to heaven.”*

Title: Loss and grief response and perceived needs of parents with the experience of having their newborn at neonatal care units

Author: Geetanjli, Manju, V.K., Manju & Srinivas

Year: 2012

Country: India

Journal: International Journal of Nursing Education, 4(2)

Research type Aim/Objective	Sample Strategy/Population	Data Collection	Data Analysis
-Qualitative -The purpose of this study was to determine the loss and grief responses and perceived needs of parents (of infants in a neonatal unit) so appropriate nursing care could be provided.	-Purposively selected sample of 8 parent pairs (mothers and fathers) of newborns admitted to neonatal units for more than 48 hrs. -Parents were included if they could speak and understand Hindi, English and Punjabi -Out of all deliveries, 4 were preterm, 4 were term	-Subject data sheet, in-depth interview tool (with four broad questions) and general health questionnaire	-12 steps which were developed by using Van Manen's approach. -Categories, subthemes and themes were developed. -A conceptual framework was then developed.

Finding Themes/ Supporting Quotes

1) Grief reaction of parents in response to the loss:

This included both a psychological reaction which included emotional, behavioral, and cognitive aspects, as well as a physical reaction which included loss of appetite, difficulty sleeping, and other physical problems.

Psychological reactions like fear, tension, sadness, repeated questioning and anxiety were commonly related to the survival and infection of baby. NICU parents had feelings of fear related to medical equipment and condition. Mothers had a strong desire to see and touch their baby especially if mom was not able to go to the NICU for the first 3-5 days after delivery.

“The mother of the other baby....I should not use the word ‘dirty’, but I did not like her. There was a fear that she may spread infection to my baby”

“Whenever I used to go to the nursery, I try to control myself even then tears use to drop down. I used to feel as if I will lose her too”

“I feel very weak because of my health. I have gone very weak. I feel a lot of pain in my head, eyes, and body. For the last three to four days. I have been feeling pain in my chest. Now I don’t know whether it is because of breasts or due to some other reason”

“I don’t know whether I feel it because I get very emotional or I think too much about the baby. I feel that pain has started in my chest, and pain is felt on touching the chest”

2) Coping –Helpful factors:

Helpful factors – Parents reported that they feel good, satisfied, relaxed and consoled after seeing/touching the baby. Mothers showed a desire to care for the baby on their own. Parents reported that they feel satisfied/hopeful after conversations with doctors, and some reported requiring assurance from hospital staff.

“Now when I go there, I change the nappy, clean them, and massage them with oil, and make them wear cap, socks and I feel happy. They open eyes, smile, sleep and I feel very happy looking at them. I don’t feel like coming back from there”

“After seeing I felt that they are my babies and got relaxed”

3) Coping- Not so helpful/hindering factors:

Parents reported being dissatisfied, sad, unhappy, and distressed if not allowed to see their baby or if there was a lack of information and preparation about the nursery and keeping the baby there. Parents reported that the environment of the nursery was very strange and fearful when they went to see the baby the first time.

“We did know anything about nursery. We thought baby will stay inside for 2-3 days and then will come out. We knew nothing...”

“I felt envious looking at other babies who were coming home after recovery...”

“Not it is out of our control, now I am losing my patience after seeing baby in no of needles how one can relax and can smile they just keep say keep smiling be happy and don’t tell anything properly. Why pneumonia occurred, baby was alright yesterday and they were saying to take her out but now why she is put on the ventilator again”

Finding Themes/ Supporting Quotes

4) Perceived Needs -Friendly visiting policy:

Parents desired to have some change in visiting policy, to have transparency/glass to see the baby, and to allow to visit in case of emergency.

“It is better if a glass or crystal is fixed to see the baby so that the staff can show the baby by lifting the curtain and let us know the condition of the baby. Because if the parents will see their baby without going inside, there will be no danger to him and they will also be satisfied”

5) Perceived Needs- Need for information:

Families desired complete and correct information from doctors and nurses. From the nurses this included needs of the baby, feed taken/not taken, lactation counselling, activities of baby, reason for putting baby on ventilator, and chances of recovery. From doctors this included providing information without asking as set time, in proper place, and in detail by senior physician. The content of information covered by physicians were condition of baby, improvement/deterioration, problems of baby, and plan of treatment.

“Doctors should call the father or mother at least once in a day and should tell that your baby has done this, she is well, this was the deficiency seen or this good thing is seen in her”

“The sisters have all information about babies. In the absence of doctors we have to wait for them, if they are inside, even if they make us wait....When we ask from the sister they do not tell us and direct us to ask the doctors”

6) Perceived Needs - Expectation of parents:

This included physical and comfort facilities for parents (waiting room, sitting arrangement, canteen facility, admission of mother of baby, need for comfort/privacy of admitted mother). Parents also wanted health care professionals to consider the convenience of parents. Parents wanted everybody to strictly follow rules and regulations of the unit.

“The nurses inside nursery instead of teaching how to hold baby and feed they scold by saying you don’t even know how to feed, how you will take care of baby. I have become mother for the first time they should teach”

“Doctors should understand the emotions of the parents and guardians, should pay attention towards the permission to allow them to visit and should fix the time earlier by understanding their problems”

Title: Ambiguous loss: managing the dialects of grief associated with preterm birth

Author: Golish & Powell

Year: 2003

Country: USA

Journal: Journal of Social & Personal Relationships, 20(3)

Research type Aim/Objective	Sample Strategy/Population	Data Collection	Data Analysis
-Qualitative -Research Qestion #1= What dialectical tensions do the parents of a premature child experience as they grieve the loss of a full term pregnancy? -Research Question # 2= What communicative styles do the parents of a premature child use to manage these dialectical tensions?	-Study announcement was posted on two preemie list servs asking for volunteers -48 participants (45 were female, 3 male)	-Open ended questionnaire emailed to participants then returned. -Included demographic questions, then participants were asked to describe their reactions to their child's preterm birth, and the circumstances surrounding the birth. -Other questions included how the parents communicated challenges that resulted from the crisis	-A qualitative/ Interpretive approach was used to identify themes that captured the essence of the participants experiences -Involved reading all transcripts (thinking about overarching themes), reread transcripts paying more attention to emergent themes (used constant comparison method), -Both researchers then shared ideas about themes and created an outline of the categories -Final stages was then the researchers further refined the categorization scheme by applying it to the data.

Finding Themes/Supporting Quotes

1) Joy-grief contradiction:

Parents were excited about the prospect of becoming parents, but were limited in their ability to experience this joy because of uncertainty of their baby's health.

One mother stated that holding her baby for the first time *'was a dangerous kindness, what with her wires and mine we seemed like spaghetti. My husband was not there and there were no photos but that moment, holding her for the first time, I knew I loved her'*

"I recall when our preacher's wife had their baby . . . and I went to see her. I told her I was there for her. I also told her that I could not imagine what she was going through and did not want to imagine. Eleven days later, I was in her shoes. She walked into my room right after our delivery and we locked eyes and just stared and then cried. I looked at her and said, 'Now I know.' It is something that no one can understand and say they understand unless they have walked the path and ridden that ride of the NICU"

Parents described the 'ride' of the NICU as one filled with uncertainty and fear about the health and future of one's child

Parents did not know how to feel grief or if they should even be permitted to grieve because they were supposed to be experiencing the joy of their newborn baby

"My healing process has only recently begun . . . I couldn't understand why I felt such grief and didn't feel that I had the right to grieve as my son is alive and doing relatively well".

This tension was complicated by extended family members confusion over the same feelings:

"Family members were supportive" Nancy explained, 'but did not treat me like a "real" new mom. While I did receive flowers etc., and many people visited, I felt it was because of illness and not because of joy at a new life. I just wanted to be treated like any other new mom"

One participant said *"her parents felt a little lost. They weren't sure if they should be excited or hold back in case things took a turn for the worst"*

2) Denial and disbelief:

Families were shocked they were going into premature labour.

"When I first arrived to the hospital,' one parent explained, 'I only heard that I was in labor prematurely. I was so frightened; I couldn't explain my terror. I felt like a deer caught in headlights"

"My husband and I joked and laughed all the way to the hospital. We didn't even pack a bag, thinking we'd be home later that evening. When two nurses and an OB examined me internally and said these babies were coming now, I burst into tears and just could not believe it"

Regardless of how much they prepared themselves physical and mentally, parents still experienced a sense of shock and denial.

"I remember the doctor coming in to check in on me and saying that I was fully dilated and ready to deliver. My response was 'I have not taken the birthing class yet. I was still in disbelief that this was all happening"

Finding themes/Supporting Quotes

One couple received a tour of the unit, yet was in denial. *“The patient care coordinator showed us babies that were around the same size as ours was . . . I look back and think, ‘How dumb was I?’ I just kept looking at these tiny little babies with the tubes in them thinking, ‘Gosh, this must be awful. I feel so bad for these parents,’ not even considering that the reason I was there was because they knew our child was going to be a preemie. I was in complete denial”*

These feelings resulted from the contradiction of wanting to acknowledge the fact that they were new parents, but denying the birthing experience because they could not truly experience a full pregnancy.

“Although my OB warned me that she may be premature, I never really thought that it would be that early. . . . There was no holding the baby afterwards, no breastfeeding (only pumping), no Apgar scores, no happy welcome home”

Some women were also highly medicated at the time of birth *“It took me three days to realize that I had given birth”*

3) Anxiety:

Parents felt anxiety about the birth and health of their child

“I will never forget the helplessness I felt when I was told I had to have an emergency c-section,” stated one mother. ‘Nothing compares to how it feels when you can’t touch your baby for days and don’t hear them cry for weeks”

“I felt scared . . . and wanted to keep her from coming for another 7 or 8 weeks. . . . I was afraid I didn’t get a good enough look at her and what if she didn’t make it?”

This emotion involved the certainty-uncertainty contradiction magnified by the technology and look of the preemies in the NICU:

“The first baby I saw was a baby that was swollen and had staples down the whole front of his chest and stomach, the second baby was hooked up to some blood machine and all I could think was ‘my God.’ All I kept hearing was buzzers and beeps, I kept looking around to try and figure out where it was all coming from. I was wheeled to this plastic box and inside was my tiny little baby that was hooked up to all these monitors and IVs. Her monitors kept going off and each time I felt like I was going to throw up”

Family members nonverbal and verbal communication escalated anxiety: *“I don’t think any of them thought they would/could live”*

This uncertainty also affected bonding: *“I was looking at Katie and I was trying to have it register that she was MY baby; she was the one that was inside me for seven months. She was taken away so quick after I gave birth, I was trying to bond with her but it was hard when she was in a plastic box”*

4) Sadness:

The sight of their newborn baby’s unstable condition created a strong sense of loss because their hopes and expectations for a typical pregnancy were shattered *“When I first laid eyes on him I was so heartbroken,” Elizabeth explained, ‘He was ventilated and was trying to cry but no noise came out of his mouth. I was devastated. That night all I could do was cry”*

Finding Themes/Supporting Quotes

‘I feel sad that I did not get to hold her and feel her after she was born. I feel sad that I did not get to experience a full pregnancy; I did not get to feel all the kicks and punches. I did not get to go to any childbirth classes. I don’t even remember having her because I was so drugged. . . . when I found out I was pregnant I was waiting for all these things and it just did not go as I planned!’

5) Anger & Jealousy:

This anger was often targeted at mothers who had full term pregnancies

“I still get jealous when I see women almost to term, I have watched The Baby Show on the Learning Channel and I get jealous and usually cry when their babies are born because I know that excitement when they place the baby on your stomach and of course my preemie and I didn’t get that”

“The difficulty of explaining that (adjusted age) more to friends than family is often tiring, especially when you have someone who is a comparer of their child versus yours”

Another participant described her anger toward her father-in-law’s reaction of seeing her daughter for the first time. *“He took one look at our daughter and asked what was wrong with her. He then said that people were going to make fun of her because of her eyes and the way she looked”*

These emotions also caused a theme of openness and closedness between couples, or potential difference in how they each reacted

“I am a worrier, my husband is not, so I feel a lot of the strain felt after Benji’s birth was due to my expecting Allen would be as worried and concerned about things as I was. He of course wasn’t, having the attitude that everything was going to be fine. I wanted him to worry with me, and yet I needed the strength and confidence he was showing”

6) Guilt & Self Blame:

Some mothers felt that they had caused their child to be born early.

“I had nightmares for a long time. While the rational me knew that this was not “my fault,” my subconscious kept searching for reasons. I had to have done SOMETHING to cause an abruption”

Mothers also felt guilty for spending so much time with their preemie at the expense of their other children:

“It was so difficult having a younger child at home and feeling so torn between your baby in the NICU and your child at home,’ she indicated. ‘They each have your heart and are tugging at it constantly”

7) Grief Management:

Participants felt that one can never fully heal from such an experience, but can only learn to manage it.

Finding Themes/Supporting Quotes

“The circumstances surrounding our son’s premature birth and the aftermath have become woven into the framework of our lives. While we don’t allow this to control our lives, it most certainly has become a part of our lives that must be dealt with”

Some families felt uncertainty around the decision to have another child:

“The thought of having another child is terrifying and do not want to live through it again. We have been very fortunate with our daughter thus far and I am afraid to try again for fear that we will not be as lucky next time if I don’t go full term”

“It grew increasingly more difficult in the sense that our family would say, “He’s better now” or . . . “He’s over the prematurity.” I don’t think you ever get over it”

8) Communication Praxes:

Gathering Information about Preemies: Gathering as much information as possible helped reduce parent’s uncertainty and shock.

“The hospital prepared me so well, with a trip to the O.R. in case I was rushed there in an emergency, I would not be so shocked. I was given a tour of the NICU and shown babies born at much earlier gestation, so I was aware of how much they could do for my baby”

“An NICU can be a place where a parent feels as though they are not the caregiver. This staff made sure I never ever felt that way. Even when I could not hold him I was shown how to touch him, including reflexology in order to stimulate him. I was shown his chart every day. I was always informed, I never ever, ever felt that I was not the one completely and entirely in charge of his life”

Support groups also helped parents connect to other parents that had similar experiences:

“We bring the boys and share our experiences and tips on how we ‘coped’. I think that has helped me tremendously, knowing that I may be helping someone else who is walking down that scary road I’d already travelled”

9) Educating family members about prematurity:

Educating family members about prematurity helped deal with some of the tensions they experienced.

“Unfortunately so many people know so little about preemies that they were a little too upbeat about everything for my taste . . . I just didn’t feel like many family members understood enough about prematurity to really digest our situation”

“Normally I avoid conflict but when comments were made about him (son) not walking or talking, I stood my ground. I firmly reminded the family members that he was a preemie and to expect “normal”. I also insisted that none of my family use the word “normal” as it suggested that Adam was abnormal”

10) Family members providing reassurance and support:

“My parents were calling me asking me how he was. If we got a bad report, [they were] asking if the baby was going to be okay, or what long-term problems he would be having from this. Asking if we needed them to come out and help with our other son or maybe stay at the

Finding Themes/ Supporting Quotes

hospital with the baby. Crying when we would have to go back to the hospital. Crying when we would get good news”

“I was aggravated by my father’s reaction.... (He) could not understand why she was so quiet and her cry was so weak. He did not seem to grasp how sick she was...My brother and his wife were completely confused. They did not understand the severity of the situation. My sister was supportive, just listened and observed”

11) Communicating a sense of teamwork with one’s spouse:

One woman noted *“communication skills got much better because we had to be able to communicate our feelings to each other if our relationship was to survive”*

“We were so involved in the care of our son that it really caused us to see that we are truly a good pair and that we’re good parents and that our relationship can survive anything”

One father indicated *“Because we process things differently there were some strains but they were easily ironed out as long as we talked about them. Also, early on we realized how each other dealt with the various things that would happen and we respected each other that way”*

12) Emphasizing the Present:

Parents often tried to emphasize the present and live in the moment.

“He [husband] looks at our children and sees them as they currently are – healthy and normal. His perspective has enabled me to begin the healing process, and to let go of these feelings of bitterness and guilt, and to take each day as it comes. My husband has taught me to look at the bright side of things, rather than on the dark past or the ‘what-ifs.’ The healing has begun”

“For my family, it has faded, distant memory, but for me, I can see it, hear it, feel it, and still taste the salt of my tears on Jeremy as if it was yesterday. . . . Writing about my babies is always painful, and I have been choking back tears as I write. But I would like to say that Emma is doing wonderfully well. She is a bright, bouncy, happy little three-year-old girl who lights up my life”

Title: Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study

Author: Hasanpour, Sadeghi, & Heidarzadeh

Year: 2016

Country: Iran

Journal: Journal of Education and Health Promotion, 5

Research type Aim/Objective	Sample Strategy/Population	Data Collection	Data Analysis
-Qualitative -This study was conducted to explore family's needs at the end-of-life and bereavement stages so that their needs are deeply understood, and proper support is provided for reducing their grief and enabling them to cope. -To provide an Iranian perspective on the above topics	-24 participants (including mother, father, grandmother, nurse and doctor) who met inclusion criteria -Purposeful sampling -Inclusion criteria for family members was having experienced at least one infant death in the last 6 months in the NICU -9 mothers and 2 fathers participated	-Semi-structured interviews -Interview started with "Can you tell me about your needs, when you knew your newborn was in end-of-life and near death?"	-Content analysis -Included selecting a unit of analysis, then obtaining condensed meaning unit as a code, then similar codes were merged into subcategories, then subcategories into broader categories, then classifying categories into themes.

Finding Themes/ Supporting Quotes

1) Family's support needs before the infant's death – A need for the presence of the spouse by the mother's side:

Family's mentioned that it was necessary that the spouse be present by the hospitalized mother's side.

"My husband was not by my side from the moment of delivery. He was not by my side for the first 1½ days. I was feeling terrible, and I needed him. One sometimes needs someone to talk to, for support and sympathy, for encouragement. However, he was not there."

"... When they were taking me to the delivery room, I was so stressed- out. I would have felt less stressed if my husband were by my side. It would have been so different if they had let him come up to the delivery room door. It would be very nice if they make it possible to have husband's support from the very first moment."

2) Family's support needs before the infant's - A need for the bereaved mother's bed not being by the side of a mother having an infant:

Mothers wanted to be hospitalized in a separate room, not by the side of other mothers whose infant was by their side.

"The first problem I had was that when I was hospitalized after delivery, all mothers who were hospitalized there had their infant by their side, but mine was not with me. It was horrible. I was hospitalized in a ward where all other mothers had their infant with them, breastfed them, and I was exactly in the same room. In my opinion, it would be better to have such mothers hospitalized in another room. It was so annoying to me and affected me negatively."

3) Family's support needs before the infant's - A need for the health care personnel treating infant's mother properly:

Mothers wanted doctors and nurses to treat them differently, to not ask questions unwittingly on infants as it would lead to mother's annoyance.

"I expected them to treat me properly and answer my questions"

"Nurses' attitude toward mothers who do not have their infant by their side should be different than that toward mothers who have their infant by their side. They must mind their words. They should talk differently. They should mind what they should say and should not say. It has happened to me several times when I did not know about my infant's condition, and they asked where my infant was. I used to reply that I did not know about my infant as it is in the incubator."

4) Family support needs after the infant's death – A need for maintained contact between the treatment team and the bereaved family:

Nurses mentioned that they do not keep in touch with bereaved families after discharge, while families stated they go through events that required the treatment teams support

"I am not in touch with them anymore. It is so busy here, and it would be really good if someone follows up bereaved parents for mental and spiritual support"

Finding Themes/ Supporting Quotes

“... Many get depressed, after all, these issues. They face many problems. I came to terms with myself, but I am not sure I can avoid depression after my infant’s death. I try to adapt and cope, but it is very difficult. It takes a lot of time to get prepared and resume my normal life.”

4) Family’s support need after the infant’s death - Family’s need for receiving information on how to treat a bereaved mother:

Families needed guidance and information on how to treat their bereaved mother.

“Please tell me now what I should do. What should I do with her mood? What her husband should do? I am at my wits’ end. I need your help. Please tell me what I should do”

5) Family’s support need after the infant’s death- Need for counseling and training after infant’s death:

Families required counseling and training on the physical and mental problems after delivery.

“... Counseling on doctors I can refer to for avoiding reoccurrence of this issue. I wish hospitals could introduce some doctors who are experts at this ...”

6) Management of the bad news of infant’s death by treatment team – The need for preparing the family for delivering the bad news of infant’s death:

Treatment team members believed that infant’s family should be prepared for the news of infant’s death from the moment the infant is hospitalized

“I was taking care of an infant who was delivered after 10-12 years of infertility. It weighed around 600-700g and we really tried for this infant. The infant was placed on mother’s breast by continuous positive airway pressure for Kangaroo Mother Care. However, the infant died. The parents were really attached to the infant. It was a shock to me as we had not prepared the family for the news as it was progressing well, and the infant was feeling well those days”

7) Management of the bad news of infants death by treatment team - Difficulty of delivering the news of infant’s death:

Most nurses mentioned a need for an experienced person for delivering the bad news of infant’s death to families.

“I suggest that there should be one person to talk to the families on infant’s condition and death. Not all nurses do have the information and experience. For instance, only the head nurses can talk to them. I mean they do not accept anyone else’s words. It would be better if the words come from an experienced person”

8) Management of the bad news of infants death by treatment team - Avoiding mother’s sudden knowledge of infant’s death:

Finding Themes/ Supporting Quotes

All nurses agreed on the idea that mother's sudden encounter with her infant's death should be avoided.

"They had told her that she could breastfeed her infant from the day after. However, the infant had gone through some bleeding the night before and, therefore, had passed away. It was really difficult. The mother did not believe it all. She just fell on the ground"

"I saw a mother with two bags of milk in her hands. She was looking for her infant. She went to the NICU and could not find her infant there. All of us were embarrassed. They told her that her infant was in NICU. She could not find her infant there as well. The head nurse called her then and told her that her infant had passed away"

"An infant got ill. All team members joined to resuscitate her. Despite all efforts, the infant passed away. The mother was walking in the corridor and was thinking that her infant was simply ill like before. After the infant had passed away, the nurse wrapped its body. The mother, while unaware of her infant's death, entered the ward and went toward her infant, but suddenly faced the corpse of her infant. She then just fainted and fell on the ground"

9) Management of the bad news of infant's death by family - Family and fathers role in the delivering bad news of infant's death to its mother:

Most nurses preferred to let the father know of infant's death so he could gradually deliver the news to mother. However fathers find it difficult to deliver such news and ask for treatment team's assistance in this regard.

"As we never deliver the new of infant's death directly to the mother, I never do that; we try to deliver the bad news to infant's father. Or we do not deliver it to the mother during the night. The mother may not know that the infant is not well, but we never tell her that the baby may die that night. If the infant dies, we never let the mother know, unless the father is so sympathetic"

"We usually deliver the bad news to the father and set the scene through the father so that they father supports the mother and deliver the news gradually as mothers are less patient"

"As mothers are more sensitive, and as mothers are more attached than fathers to their infant, then we prefer to deliver the bad news to fathers"

10) Management of the bad news of infant's death by - Family's need to get informed about the bad news of their infant's death:

Families requested to get informed about infant's death so they can make proper decisions on the way to tell the mother

"I just prefer doctors to tell mothers all the things, to tell the truth"

"At the hospital, the first request is that doctors talk to the mother, nurses talk to the mother and tell the mother everything. They should not make decisions on behalf of mothers. If there is any problem with infant or mother herself, it should be told to them clearly and without any ambiguities so the mothers have everything in her mind."

Title: Mothers perspectives on the perinatal loss of a co-twin: a qualitative study

Author: Richards, Graham, Embleton, Campbell & Rankin

Year: 2015

Country: UK

Journal: BMC Pregnancy & Childbirth, 15

Research type Aim/Objective	Sample Strategy/Population	Data Collection	Data Analysis
-Qualitative -The aim of this study was to gain in-depth understanding of the experiences of mothers who have had a loss from a twin pregnancy.	-14 mothers with a twin pregnancy from which the loss of a twin had occurred during pregnancy or in the neonatal period (recruited from one hospital). -5 mothers lost their baby during pregnancy, and 9 in the neonatal period -Within the sample the loss of a twin was experienced between six months and two years prior to the interview -Fathers could attend the interviews if they wanted, in 2 cases the baby's grandmother was present.	-Semi-structured interviews designed to elicit mothers' interpretations of their loss and the health care received related to the loss. -Mothers were encouraged to tell the 'story of their loss' -Interviews were recorded and transcribed.	-A thematic approach was used, but it was also influenced by the constant comparison method -Transcripts were read, alongside listening, and initial codes were identified. Further interviews were then conducted and transcribed. – -Coding was revisited by three individuals. This involved a collective analysis of key themes. Coding then continued using a process of constant comparison.

Finding Themes/ Supporting Quote

1) Status as special -Feeling special:

Mothers spoke of feeling special when they discovered that they were expecting twins:

“I was excited...I felt, how can I put it...I felt special. I felt special to be carrying two babies, you know, I really wanted my two babies who, I seen two babies on that scan, I wanted two babies”

The unexpected loss of a baby was a devastating blow which left mothers grieving for the loss of their special status. All the mothers felt strongly that one baby cannot replace another:

“What I got a lot of ... the doctor at the time really quite upset me... she often said to me, ‘At least you’ve still got one’, and that was one of the worst things that anyone could possibly say. ‘You’ve still got [surviving twin] though’ and I know I’m really grateful I still have[surviving twin] but that’s like saying to someone that has a child of four and six and the six year old one dies, ‘well you’ve still got the other one, so that’s ok’. And it was really quite upsetting. I knew that she didn’t mean it in any nasty way”

For many mothers watching the surviving sibling grow up actually exacerbated their grief as milestones were reached:

“And [surviving twin’s birthday party] it’s a week after, it’s the Sunday after her birthday not at the weekend of her birthday because I couldn’t ...I couldn’t em I just can’t, I just find her birthday a really difficult day”

2) Status as special - Acknowledging bereavement and twin-ship:

Mothers appreciated HCP’s who endeavored to keep the special twin identity alive:

“One of the nurses that was least conscientious towards other people’s feelings kept calling him [surviving twin] by his brother’s name afterwards”

“They [health professionals] always wrote on the board... like in [NICU] they’d always write the name and then ‘twin 1’ or ‘twin 2’ underneath and they said, they asked us if we wanted that to be done or not done you know, so they were thinking about how[we felt]... I think what you didn’t want was, you know, as soon as [deceased twin] had died was everyone just treating [surviving twin] as if he was a singleton, because he wasn’t”

3) Status as special - Coping with trauma and grief on hold:

Mothers who had suffered the loss of a twin experienced a rollercoaster of emotions – both joy and grief.

“I think I totally switched off looking back now, from the moment I got back to the hospital, I think I just went into autopilot...yes, this is not happening, because there were no tears or anything was there? Nothing at all for days”

A grief reaction often emerged weeks, months or even years later:

“We saw her [deceased twin] for some time after losing her and then our focus to help us get through, it was wanting to be out of hospital...and went up to [other hospital] to be with [surviving twin]. That was giving us some strength...being there for him”.

Finding Themes/ Supporting Quotes

"It was about six months...we went for bereavement counselling...I was suddenly feeling so bad...really angry"

4) Trust -Emotion work:

Recognition of, and evaluation of, emotion work was an issue universally raised by all participants

"One of the senior nurses... he just came over to me and said 'we know what you've been through...if you ever want to talk about it or you want any, you know what I mean, we are here, we will not ram it down your throat, but we are here"

"She [nurse]was really nice, we got a lot of support off her...she was more on our wave length, someone you can sort of feel comfortable talking with"

"The nurses were very supportive...the doctors I don't think so much, but only because they do ward rounds and they have to assess what is in front of them there and then and they are doing such an important thing aren't they really, that's kind of not relevant to them. I think the nurses are very good, they'd sit and listen to you talk until the cows came home which is brilliant"

"I had issues with one of the doctors..because he was like 'oh, she's not going to make it, oh she's, do you understand has a blood clot,' I knew he was doing his job, but I just don't think that the way they get across bad news to parents is the best"

HCP's who were perceived as 'just doing their job' did not seem to recognize the needs of mothers:

"It's just they (nurses) they can be seen to be like 'it's just a job' you know. Some of them on Special Care Baby Unit was just like that and just like, 'it's just their job' you know. They come in and they do their job and go"

The perception of emotional responsiveness had an impact on parents experiences when away from the hospital:

"Especially on a night shift, I found that was when they [nurses] just didn't, just didn't seem to care. They were like...they just go in for a social and I used to come home nervous"

5) Trust -Continuity of Information:

A key area was the efficient transfer of both verbal and written information

"Yeah and all the things that if I'd gone to a parenting class that they would have taught me there ... I had nothing and it's like I don't even know how to dress her and they [nurses] were brilliant, they showed me how to dress her, they showed me how to bath her, they showed me how to do nappies"

"What I found really annoying was that I had to keep repeating my story to the nurses who were looking after [twin]. I had never met them before. Now in a handover, that is really very important that they know that [survivor] was a twin and I'm very delicate...it would have been in my notes"

"It was maybe a week or something after we were discharged we got a discharge letter about [deceased twin] who was referred to repeatedly as twin 2... Yeah I mean he had a name and the letter itself it was written by somebody who to our knowledge had never even laid eyes on [deceased twin] or us, and some of the information in it wasn't even right about him erm you know, it like mixed up things"

Finding Themes/Supporting Quotes

about him. So I think that our big thing, [we were] really angry about it, that's a very simple thing to sort out, if the baby's got a name, that's who he was but by that stage he wasn't twin 2 anymore. At the time we just read the letter and thought, 'I can't believe they've managed to deal with the situation so well and then summarize it so badly'

6) Trust - Continuity of staffing and trust:

Mothers built trusting relationships with staff members they had frequent contact with

"I just loved her [nurse]...she took me under her wing as soon as I got in that hospital...you know and she just , I felt like I didn't want to let her go home that night, I just wanted her to stay with us...she's just lovely and I trusted her implicitly"

"What I found quite hard, but this is totally understandable, is that obviously it was a different nurse looking after her [surviving twin] every day. When it was nurses that you got to know, you found it a bit easier because they knew what had happened but it felt like a lot of days it was a new nurse"

A dedicated midwife for families of twins was very helpful:

"I think if we hadn't had [dedicated midwife] it would have been much, much more difficult. Yeah, you know she was absolutely amazing all the way through and we did see her like I said, every two weeks... so we saw her quite a lot"

7) Control and empowerment - Location of care and lack of control:

The location of care recurred in mother's accounts. Mothers talked about their experiences in relation to different locations within the hospital.

"[Consultant] gave us a steroid injection and said he wasn't quite sure what was going on but he kept us in [private room] for observation overnight, but by which time, by the time I was admitted, it was like midnight so there was nobody about. I think there was one midwife...I've never felt so lonely and so petrified in all me life, it was horrible, because you just don't know what's going on"

Those who didn't stay in a private room expressed their distress at their baby being placed next to those that had health twins.

"I'd just lost me baby and the other baby was in special care and I'm surrounded by babies when I didn't have either of mine really...I just wanted to be on me own...it was just terrible"

'I think they were very caring and supportive but I think the only way you'd probably want a distinction made [from singleton] would be kind of kept away from people who have twins. It sounds awful but that can't really happen in a hospital'.

Mothers who had a twin transferred to another hospital felt that they were not supported in terms of practical help and financial matters.

"As soon as you get shifted [to another hospital], it's like you fall into this little hole. No one can help you because they don't know [who should be helping]so I had to find it all out for myself...they keep calling me 'out of area' and that's what I was and as soon as you are out of area, you slip through the net"

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Mothers also suggested that they declined the opportunity for follow-up appointments as they were held near where they lost their baby
“That was hard mind, going back to fetal medicine...to the fetal medicine waiting room. Very hard, especially when you are sitting there and someone else gets bad news because you are sitting there thinking ‘that was me not so long ago’...maybe somewhere else in the hospital would have been better”

8) Control and Empowerment - Impact of trauma upon actions:

Mothers described being traumatized after the loss of their baby which impacted their actions and perceptions while in hospital

‘The night I had her [deceased baby], I was kind of put in a room on me own and no one checked on us all night, I was kind of left which..., I didn’t ask for her to be brought in...I was on my own for about twelve hours’. [Midwife] left her [deceased baby] on the ward so I could see her...in hindsight she should have been with me, yeah she was in a different...I don’t know whether they have like a chiller room...I wasn’t really sure. I mean I know she was somewhere on the ward and I knew I could get her if I wanted but I didn’t and now when I think about it, I don’t know why I didn’t”

“I just got rail, not railroaded but swept along with what they generally do, I just got railroaded into going for a cremation with nothing...and it’s just...I just think, I think that, I was given the options, you can have a burial. It was just kind of ‘this is what people do’ and you, when you’re just in a bit of a daze, I just think you go along with what people say and now I just think,...that’s my biggest regret, I’ve got nothing”

Mothers who experienced a loss in utero were sometimes given the option of making decisions before the birth of the deceased:

“(Planning in advance) was very helpful because I didn’t know at the time but as they said you know when everything kicks off do you really want to be making decisions and meeting new faces? Yeah so I met (bereavement officer) so eventually, when everything did happen, I knew her and the lady who organized the funeral arrangements...I signed all of the forms and everything before it all happened. So everything was sort of in place and it meant I didn’t have to worry about anything which I think is very good for the hospital to think that far ahead you know to give you that option”

9) Control and Empowerment- Impact of trauma upon perceptions:

While HCP’s gave them clear and timely information, they recounted feeling anxious or in denial about their surviving baby’s health risks:

“I think they probably thought we were a bit stupid (laughs) because twenty-eight weeks is nothing, they deliver loads of babies at that but to us...we didn’t know if we were going to bring her home...they did try and put our minds at rest but I think that was just the way we were feeling [after their bereavement], it didn’t matter what anybody said really”

“They kept telling us it could happen with [poorly twin]...he could pass away, but I was ignoring them. I didn’t see it like that, I shut down, I ignored them. I looked for the positives, ‘he’s here... and even if he dies that is something we will deal with when we come to it. He’s lived for 24 hours, he has got a chance’. I mean I know at this point the senior nurse said obviously he’s having seizures and was

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having this that and the other but I chose to ignore that saying ‘well look, he is breathing’

10) Control and Empowerment - How mothers take control:

Lack of control was a common theme in the interviews. Mothers felt a lack of ownership of their surviving baby in the critical care environment.

“Because when your baby’s in an incubator, what’s your natural thing to do? You can’t just pick your baby up and cuddle her, you can’t just do what you want to do with your baby so you do get a little bit detached and then you, and then you feel guilty because you don’t have that attachment. I don’t think it occurs to the nurses that you don’t feel like your baby is yours”

“But then you think, we can’t complain because then you will be known as the complaining parents and he’s still got loads of treatments to do, so we never complained”

Mothers revealed ways in which they attempted to regain control.

“I used a breast pump and sure enough there was some (milk) there and I thought, that was the one thing I could do for him, I couldn’t do anything else, I was completely helpless...I think that’s the thing that actually kept him alive”

Other ways in which mothers gained control; passing on information about their baby to nursing staff, reading medical entries in infant care notes, watching nursing staff carry out procedures, and swapping advice and information with other parents.

“We were there every single day a lot of the time, we were telling the nurses what had happened the previous day...albeit they do a very good job. It’s our[baby] we were saying ‘look, his stomas on that side, he doesn’t like laying on that side you know”

Appendix G Summary of Meta-Aggregation of Individual Findings

Theme 1: Support

Subtheme 1.1: Support offered by family and friends		
Author	Finding	Summary Statement
Armentrout (2009)	Feelings of Isolation	Families felt isolated due to the unique nature of their situation (ie. having to remove life support).
Armentrout (2009)	Family & Friends	Parents felt that their loss was not always acknowledged by family and friends. Comments to parents were often interpreted as hurtful. Unconditional support was helpful to parents.
Golish & Powell (2003)	Educating family members about prematurity	Family members offered support (hospital visits, cards, help with other children etc.) which helped families cope. Support was offered through communicating a sense of concern for the health of the baby, while remaining optimistic.
Golish & Powell (2003)	Family members providing reassurance and support	Educating other family members about premature babies helped them deal with the emotions they felt. This included information about corrected age and appropriate development.
Hasanpour et al. (2016)	A need for the presence of spouse by mother's side	It is necessary that the mother's spouse be present by the hospitalized mother's side or be able to visit in order to offer support.
Subtheme 1.2: Support offered by health care professionals		
Armentrout (2009)	Making the decision	Parents spoke of the realization that despite hope and prayer their infant was not going to survive. The decision to remove life support was described as one of the hardest things to do. Removing life support facilitated time with their baby without all the wires and tubes, in particular for families to hold their baby while they died.
Armentrout (2009)	Health care providers	Families spoke of positive experiences with healthcare providers, and appreciated actions that acknowledged their child's life. Support and empathy were important to the families. Families would also like HCP's to understand how difficult the loss is, and offer support especially after the infant's death.

Hasanpour et al. (2016)	Family's need for counseling and training	Families required counseling and training on the physical and mental problems after delivery, follow-up for future pregnancies and counseling with a clergyman or religious person.
Hasanpour et al. (2016)	A need for maintained contact between the treatment team and the bereaved family	Families desired maintained contact with the treatment team to facilitate support.
Hasanpour et al. (2016)	A need for the health care personnel treating infant's mother properly	Mothers needed doctors and nurses to understand the condition of their infant and treat them differently, with special attention paid to their individual circumstances.
Richards et al. (2015)	Continuity of staffing and trust	Mother's described building trusting relationships with certain members of the health care team. The dedicated midwife specialist was very helpful to families.
Richards et al. (2015)	Emotion work	Recognition, and evaluation of, emotion work was an issue universally raised by all participants in their accounts of interactions with HCP's, in particular nursing staff. Midwives and nursing staff played a key role as they were in daily contact with the families.

Theme 2: Not knowing what to expect

Author	Finding	Summary Statement
Golish & Powell (2003)	Sadness	The uncertainty parents felt caused sadness and depressive feelings. This continued on even after their child's condition stabilized.
Golish & Powell (2003)	Anxiety	Mothers wanted to keep their baby from being born early but were unable to control their circumstances. This also included thoughts of certainty and uncertainty. The uncertainty surrounding their infant's prognosis as well as the presence of medical equipment prevented initial bonding.
Golish & Powell (2003)	Guilt and self-blame	Some mothers felt guilt over potentially cause their baby to be born premature. Mothers also felt guilty over spending so much time with their preemie at the expense of their other children or husband.
Golish & Powell (2003)	The joy-grief contradiction	Parents experienced the loss of a normal birth however felt joy at the celebration of new life. Parents felt cautious joy, as their child's health was uncertain. Parents weren't sure how to grieve because their baby was still alive.
Golish & Powell (2003)	Denial and disbelief	Many families were in shock and denial when they were in preterm labour, even if they had some time to mentally prepare. This was also affected by the way in which they delivered, and the type of care their baby required after birth.
Richards et al. (2015)	How mothers take control	Mothers felt that the trauma of their loss rendered them somewhat passive and helpless. They also lacked ownership of their surviving baby in a critical care environment.

Theme 3: Hospital Practices

Author	Finding	Summary Statement
Geetanjli et al. (2012)	Helping factors	Helpful factors came from spending time with their infant, and being able to provide some care to them.
Geetanjli et al. (2012)	Friendly visiting policy	Parents felt that they needed access to their baby to be able to know they were okay.
Geetanjli et al. (2012)	Expectations of the parents	Expectation of the parents included the need for facilities for parents, and consistent following of unit practices.
Hasanpour et al. (2016)	A need for the bereaved mother's bed not being by the side of a mother having an infant	Hospitalized mothers who had an infant that was in the NICU, or that had died, wanted to be cared for an area not beside other mothers with their infants as they found it difficult.
Richards et al. (2015)	Location of care and lack of control	When mothers were admitted they requested having a private room when possible. Those that didn't stay in a private room expressed their distress at being placed next to those that had healthy twins. It was suggested that follow-up appointments possible be held elsewhere.

Theme 4: Communication

Subtheme 4.1: The role of HCPs		
Author	Finding	Summary statement
Geetanjli et al. (2012)	Need for information and communication	Families wanted timely and accurate information regarding their infant both from the nurses and doctors.
Geetanjli et al. (2012)	Not so helpful/hindering factors	Families reported feeling stressed/dissatisfied if they were unable to see their baby, or felt there was a lack of information.
Hasanpour et al. (2016)	Family's need to get informed about the bad news of their infant's death	Families requested to get informed about the infant's death so they can make proper decisions on the way to deliver news to the mother.
Richards et al. (2015)	Continuity of information	Mothers valued the efficient transfer of both written and verbal information. This included teaching provided to the family that they may not have received prior to their infant's birth, but also the transfer of information between HCP's regarding their infant (and deceased twin).
Richards et al. (2015)	Acknowledging bereavement and twin-ship	Mothers appreciated HCP's that endeavored to keep the special twin identity of the surviving baby alive while in the NICU. When errors were made these instances were memorable for the families.
Subtheme 4.2: The role of the parents, family, and friends		
Golish & Powell (2003)	Anger and jealousy	Anger was demonstrated toward mothers that experienced a full term pregnancy, as well as when comparisons were made between a preemie and full term infant. These feelings also affected a couple's closeness and communication. Couples often demonstrated different ways of coping.
Golish & Powell (2003)	Gathering information and technology and preemies	Parents tried to gather information about preemies from the internet, books and medical staff which helped with coping. They also used technology to share information about their baby with family.
Golish & Powell (2003)	Communicating a sense of teamwork with one's spouse	Open communication with spouses helped coping. It was also helpful for families to realize that their spouse may react differently.
Richards et al. (2015)	Impact of trauma upon actions	Mothers described feeling traumatized after the loss of their baby which impacted upon their actions and perceptions while in hospital. The trauma

		of their loss impeded their ability to digest information and advice, and ask for what they really wanted.
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Theme 5: Coming through grief

Subtheme 5.1: The immediate period following the loss		
Author	Finding	Summary Statement
Armentrout (2009)	Things they would have changed	Parents in this study described regrets such as not performing parenting acts, taking pictures and creating memories, and having friends and family know their infant. An area of uncertainty was how to involve other siblings both before and after death.
Armentrout (2009)	Initial shock	Mothers commented how they had trouble functioning for long periods after their infant's death. Fathers commented that although they were hurting they had to get up and continue on. Parents felt that there was no set timeline for grief and that they each dealt with it in different ways, and over different periods of time.
Geetanjli et al. (2012)	Grief reaction of parents in response to loss	This included both a psychological and physical grief reaction. Psychological grief responses included emotional, behavioral and cognitive effects. Physical reaction included loss of appetite, difficult sleeping, as well as others.
Richards et al. (2015)	Impact of trauma upon perceptions	Mothers suggested that their bereavement impacted their perceptions of risk in relation to the surviving twin.
Richards et al. (2015)	Trauma and grief on hold	Mothers who had suffered the loss of a twin experienced a rollercoaster of emotions whilst in hospital with the surviving baby and beyond. Mothers spoke of the need to keep their emotions on hold, however this caused a strong grief reaction even years after their babies were discharged.
Subtheme 5.2: The long term response – moving on		
Armentrout (2009)	Spiritual/religious perspectives	Faith was a component in many families coping, however also challenged some individuals' beliefs.
Armentrout (2009)	Differences in grief between mothers and fathers	Grief was experienced differently between mothers and fathers, and it was important that they recognized this, and supported each other in the grieving process.
Armentrout (2009)	Moving forward	Over time families had to move on, however their life would never be the same, and part of the grief may never go away. Parents maintained an awareness of their deceased infant in particular for other siblings.

Armentrout (2009)	Altered perspectives of life	Families discussed a shift in priorities after the loss. Families described how important it was not to take friends and family for granted.
Armentrout (2009)	Remembering activities	This included small actions parents completed to help remember and honor their infant.
Golish & Powell (2003)	Emphasizing the present	Families tried to emphasize the present and live in the moment. Focusing on the positive and embracing the present helped parents manage their loss.
Golish & Powell (2003)	Grief management	Families felt they could not heal from the experience but could learn to manage it. Uncertainty carried over into thoughts about future children. Families also felt frustrated when others felt they should be at a level of acceptance but they weren't.
Richards et al. (2015)	Feeling special	Mothers spoke of feeling special when they discovered they were expecting twins. The unexpected loss of a baby was a devastating blow that left mothers grieving the loss of their special status, alongside the death of their baby. Watching the surviving sibling grow up exacerbated grief as milestones were reached