

**Understanding and Supporting Parental Bereavement in the Neonatal Intensive Care Unit**

by

Jenna Lakhani

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

Medical Sciences - Paediatrics

University of Alberta

© Jenna Lakhani, 2023

## **Abstract**

Death is no stranger to the neonatal intensive care unit (NICU). Extreme prematurity, congenital abnormalities, and other complexities that may occur surrounding pregnancy and delivery can turn what was hoped to be a very exciting moment in a family's life into one of despair and grief. There are many infants that not only do not survive, but also have a medicalized death necessitating complex medical decision-making, weighing quality of life versus duration. Parental bereavement after the death of an infant in the NICU is a multifaceted and nuanced experience. Support from healthcare practitioners can have a significant impact on bereavement experiences in the short- and long-term, and identifying ways in which healthcare practitioners can support parents through this journey can ultimately help optimize their grief and bereavement.

This thesis contains two main sections. The first section is a systematic review synthesizing empirical research with a goal to identify considerations that ought to guide our caregiving practices as healthcare practitioners to support parental bereavement. Data for this review was collected from studies identified in three databases (MEDLINE, Embase, CINAHL) and the search was limited to English-language studies describing parental bereavement in the NICU population from January 1990 to November 2021. Of 581 studies initially identified, 47 studies of varying geographic locations were included. Various themes surrounding healthcare support in parental bereavement were identified including ensuring the opportunity for parents to spend time caring for their child, understanding their perception of infant suffering, recognizing the impact of communication experiences with healthcare practitioners, and offering access to alternative means of support, all of which have been described as suboptimal. Parents generally want the opportunity to say goodbye to their infant in a private and safe space, be supported through their decision-making and be offered bereavement follow-up after loss. The systematic review identifies methods

of support in parental bereavement based on first-hand parental experiences and routine implementation of these strategies may be beneficial in supporting parents through their bereavement after the loss of a child in the NICU.

The second part of this thesis is a narrative inquiry study with an opportunity to learn from the stories of parents who chose palliative care for their child in a local NICU program. From a narrative ethics perspective, their stories speak to normative aspects of parenting, decision-making, and receiving medical care that affect their moral sense-making of their NICU experience as well as their longer term living with the loss of their child. Their stories expressed the importance of having meaningful time with their children, maintaining direct and frequent communication, managing uncertainty, and emphasizing compassion as methods of providing support to parents as they navigate their bereavement after losing an infant in the NICU.

Through understanding bereaved parents' experiences, both from the existing literature and based on first-hand experiences described through a local narrative inquiry study, how parents are supported through their bereavement clearly has a substantial and long-lasting impact. As healthcare practitioners, our role in providing support through communication, end-of-life care and bereavement support is essential to providing holistic care to critically ill infants and their families. Understanding how these practices can be improved will allow us to optimize the care we, as healthcare practitioners, can provide in the future.

## **Preface**

This thesis is an original work by Jenna Lakhani. The research project, of which the thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Parental stories of bereavement following the death of a child in the NICU”, No. Pro00117084, February 28, 2022.

Chapter 2 of this thesis has been published as: Lakhani J, Mack C, Kunyk D, van Manen M. Considerations for practice in supporting parental bereavement in the neonatal intensive care unit – a systematic review. *Journal of Palliative Medicine*, February 2023 ([DOI: 10.1177/08258597231158328](https://doi.org/10.1177/08258597231158328)). I was responsible for the systematic review and manuscript composition. Dr. Michael van Manen was the supervisory author and was involved with concept formation and manuscript composition. Drs. Cheryl Mack and Diane Kunyk assisted with edits of the manuscript. Janice Kung, a librarian at the University of Alberta, assisted in the development of the search strategy for the review.

Chapter 3 of this thesis has been submitted for publication to *Qualitative Health Research* as: Exploring and supporting parents’ stories of loss in the NICU: a narrative study. I was responsible for ethics approval, participant recruitment and consent, conducting the interviews and manuscript composition. Dr. Michael van Manen was the supervisory author involved in protocol formation and amendment as well as manuscript composition. Drs Cheryl Mack and Diane Kunyk assisted with edits of the manuscript in its final stages.

## **Dedication**

This thesis is dedicated to my parents, Nazlin and Alnoor Lakhani, for giving me invaluable educational opportunities and instilling in me the confidence to follow my dream of pursuing a career in Neonatal-Perinatal Medicine, and to my sister, Jahan Lakhani, for teaching me the value of hard work and dedication which has allowed me to embark on this academic journey.

## **Acknowledgements**

First and foremost, I would like to thank the parent participants who agreed to take part in the narrative inquiry study. The dedication of their time and sharing of their experiences was an incredible asset to the project.

I thank my supervisor, Dr. Michael van Manen, for his unwavering support and guidance in completing this thesis. I would also like to thank the members of my MSc committee, Dr. Cheryl Mack and Dr. Diane Kunyk, for their continuous encouragement.

I would like to acknowledge the Clinical Investigator Program (CIP) for their support in the pursuit of this research. I would also like to thank the Neonatal Program at the University of Alberta for encouraging my engagement in this work.

## TABLE OF CONTENTS

<b>List of Tables .....</b>	<b>xi</b>
<b>List of Figures.....</b>	<b>xii</b>
<b>List of Appendices .....</b>	<b>xiii</b>
<b>I. Chapter 1: Introduction .....</b>	<b>1</b>
1.1 Background: Bereavement in the context of the NICU .....	1
1.2 Research Questions .....	2
1.3 Relevance of research questions to clinical practice.....	2
<b>II. Chapter 2: Considerations for practice in supporting parental bereavement in the neonatal intensive care unit – a systematic review .....</b>	<b>4</b>
2.1 Introduction.....	4
2.2 Methods.....	5
2.2.1 Search Strategy.....	5
2.2.2 Selection of Studies .....	5
2.2.3 Data Analysis .....	6
2.3 Results.....	7
2.3.1 Parents may experience a manifold of different emotions anticipating and following the death of their child .....	7
2.3.2 Parents may experience a cascade of different losses shaping their bereavement and healthcare practitioners can affect this burden of loss .....	8
2.3.3 Parents live with their perspectives of the suffering their child experienced and their communication experiences with healthcare practitioners .....	9

2.3.4	Parents may benefit from a variety of different supports in the NICU in anticipation of bereavement .....	11
2.3.5	Parents live with their decisions in bereavement — with time, they may question, re-evaluate, or come to terms with the decisions they made .....	12
2.3.6	Parental bereavement may benefit from support beyond the NICU .....	13
2.3.7	Understandings are needed for unique NICU bereavement experiences .....	14
2.4	Discussion .....	15
2.4.1	Key concepts of supporting parental bereavement in the NICU .....	15
2.4.2	Gaps in the literature .....	16
2.4.3	Unresolved tensions in the literature .....	17
2.4.4	Limitations of research .....	17
2.4.5	Opportunities for future research, medical education & practice change ....	18
2.5	Conclusion .....	19
2.6	Tables .....	20
2.6.1	Table 1: Included Articles Describing Support of Parental Bereavement in the NICU .....	20
2.6.2	Table 2: Mixed Methods Appraisal Tool (MMAT) .....	27
2.6.3	Table 3: Primary and Secondary Themes .....	28
2.7	Figures .....	29
2.6.1	Figure 1: Article Selection Flow Diagram .....	29
<b>III.</b>	<b>Chapter 3: Exploring and supporting parents’ stories of loss in the NICU: a narrative study .....</b>	<b>30</b>
3.1	Introduction .....	30



3.2 Methods.....	32
3.2.1 Narrative ethics .....	33
3.2.2 Recruitment .....	33
3.2.3 Data collection.....	34
3.2.4 Analysis and interpretation.....	35
3.2.5 Ethical considerations .....	35
3.2.6 Participants .....	36
3.3 Findings.....	37
3.3.1 Parents recounted stories of the time they had with their children . . . ..	38
3.3.2 Parents shared stories of the healthcare practitioners doing what they could and should do for their children . . . ..	40
3.3.3 Parents told stories of living with uncertainty, ambiguity, and indecision . . . .....	43
3.3.4 Parents shared stories that expressed values of caring . . . ..	44
3.3.5 Parents talked about what their child’s life was like . . . ..	46
3.3.6 Parents shared stories of living with loss . . . ..	47
3.4 Discussion.....	50
<b>IV. Chapter 4: Conclusion and Future Directions .....</b>	<b>54</b>
4.1 Common and divergent themes from systematic review and narrative study .....	54
4.2 Considerations for practice .....	55
4.3 Strengths and limitations.....	56

4.4 Recommendations for future research .....	57
4.5 Considerations for education .....	57
<b>References</b> .....	59
<b>Appendices</b> .....	67
Appendix 1: Search Strategy Outline .....	67
Appendix 2: Participant Letter of Information .....	68
Appendix 2: Consent Form.....	70

## **List of Tables**

Table 1: Included Articles Describing Support of Parental Bereavement in the NICU

Table 2: Mixed Methods Appraisal Tool (MMAT)

Table 3: Primary and Secondary Themes

## List of Figures or Illustrations

Figure 1: Article Selection Flow Diagram

## **List of Appendices**

Appendix 1: Search Strategy Outline

Appendix 2: Participant Letter of Information

Appendix 3: Participant Consent Form

## **I. Chapter 1: Introduction**

### **1.1 Background: Bereavement in the context of the NICU**

Death in the neonatal intensive care unit (NICU) is a common, yet difficult occurrence. With a patient population that consists of extreme prematurity, complex congenital anomalies, and other life-limiting illnesses, some babies admitted to the NICU do not survive despite maximum medical interventions.<sup>1-4</sup> Most of these deaths occur after a decision to withdraw life-sustaining medical interventions – a decision that is not taken lightly and one that often requires lengthy and difficult conversations between healthcare practitioners and patient families.<sup>2-3</sup>

Involving parents in caring for critically ill infants is essential and can be enhanced through family-integrated care. This approach includes not only providing care to the infant, but also supporting parents to directly deliver care to their children.<sup>5</sup> The importance of building rapport, providing clinical updates, maintaining communication, and supporting parents through goals of care decisions by following a family-centered approach is invaluable. Goals of care discussions surrounding end-of-life and understanding how to optimize the bereavement support healthcare practitioners can provide is an ongoing challenge. The optimal methods of delivering information in an unbiased manner and outlining the potential choices and associated outcomes remains imprecise.<sup>6</sup> The perspectives of parents who have chosen palliative care are relatively absent from the neonatal intensive care literature. As such, understanding how to assist parents to reach goals of care and support their bereavement is incomplete. And yet, understanding parental perspectives is paramount to the training of healthcare practitioners for their reflective practice.

## **1.2 Research Questions**

Undoubtedly, the intricacies of navigating bereavement care in the NICU pose ongoing challenges for healthcare practitioners. This project aims to more clearly understand the difficulties associated with providing holistic and family-centred care in the NICU, particularly in cases that result in the loss of an infant. The goal is for such understanding to be applied to develop the training of healthcare practitioners to optimize the provision of bereavement support. This thesis has two major parts:

- (1) A systematic review of empirical NICU studies relating to parental bereavement. The research questions is: what considerations ought to guide caregiving practices of practitioners to optimize bereavement care for parents who lose a baby in the NICU?
- (2) A narrative inquiry study with parents who have experienced the loss of a child in a local NICU. The research question is: how may we understand NICU parents' stories of goals of care decision-making and related experiences as supporting their bereavement? Goals of care include decisions about specific treatments, the intensity of care, and planning for future care needs. Bereavement describes parents' sense-making and living with the loss of their baby.

## **1.3 Relevance of research questions to clinical practice**

There are various difficulties healthcare practitioners face when engaging in conversations surrounding goals of care including discussing the prognostic ambiguity and unpredictable outcomes, varying sociocultural beliefs, and differing individual goals and wishes. Additionally, providing support through end-of-life care and following the death of a child is inherently a

difficult experience for those working in the NICU; however, supporting parental bereavement is an essential aspect of holistic neonatal care.

The heavy burden of infant loss and the impact of healthcare provider support has been well-described. Providing care in the NICU often involves supporting parental bereavement and assisting families through periods of uncertainty, decision-making, grief, and loss. Understanding the intrinsic challenges of providing neonatal bereavement care, learning the valued aspects of bereavement support explained first-hand through experiences of bereaved parents and reviewing the literature on bereavement practices can allow healthcare practitioners working in the NICU to optimize the care provided in these difficult circumstances.



## **II. Chapter 2: Considerations for practice in supporting parental bereavement in the neonatal intensive care unit – a systematic review**

### **2.1 Introduction**

Death is no stranger to the Neonatal Intensive Care Unit (NICU). Because of extreme prematurity, congenital anomalies, or other complex medical issues, some babies cannot survive despite medical interventions. Others are anticipated to have persistent health problems that severely impact their quality of life. Most NICU deaths result from withdrawing or withholding medical interventions.<sup>1-4</sup>

End-of-life decision-making and subsequent neonatal death can create significant emotional turmoil for parents as they navigate their loss and associated bereavement.<sup>7</sup> These parents need to live with the ethical decisions they make, recognizing that the decisions themselves have moral weight. The occasion of the birth of a child, which typically brings excitement and happiness, can instead be filled with grief, despair, and guilt.<sup>8</sup> Recognizing the importance of, and supporting parents through, this loss is a challenging task for those working in the NICU. Healthcare practitioners need to have insights into parents' experiences to ensure not only that they support decisions that forefront the interests of NICU infants, but also support the parents' subsequent bereavement. It is important to understand what considerations ought to guide the caregiving practices of practitioners. Through consistent and compassionate bereavement care, practitioners will ultimately be able to enhance experiences for families as they navigate the complexities of infant loss.<sup>7,9,10</sup>

There have been no systematic reviews in the past decade exploring parental bereavement support in the NICU; however, there have been several related empirical qualitative studies. These

studies provide understandings, reflections, and considerations regarding how healthcare practitioners can support families after a neonatal loss.

This review aimed to synthesize the findings of empirical NICU studies relating to parental bereavement and elaborate on considerations that healthcare practitioners can use to guide their caregiving practices and bereavement support.

## **2.2 Methods**

### *2.2.1 Search strategy*

The search strategy for this review was developed with the assistance of a medical research librarian. A search of three electronic databases (MEDLINE, Embase and CINAHL) was performed using a combination of keywords specific to the population (baby, neonate, newborn), the experience pertaining to loss (bereavement, death, dying, grief), and the type of care (palliative, terminal, end-of-life, comfort care). See Appendix 1 for details of the search terms and strategy used.

### *2.2.2 Selection of studies*

This review included peer-reviewed articles published from January 1990 to November 2021. This date range was chosen to explore contemporary experiences surrounding parental bereavement in the NICU. After excluding duplicates and non-English studies, articles were eligible if based on the primary analysis of empirical data (such as interviews, surveys, and questionnaires). Systematic reviews, editorials, opinion pieces, conference abstracts, and articles published before 1990 were excluded. Grey literature was not reviewed; however, references from included studies were reviewed to ensure no key literature was missed.

After abstract screening by two independent reviewers (JL/MvM), studies that involved general pediatric populations, combined pediatric and neonatal populations, or stillbirths and fetal death were excluded unless there was specific mention of independently analyzed NICU-related results. After screening full texts of the remaining results, 47 articles were included. Figure 1 illustrates the study selection process.

### *2.2.3 Data analysis*

Each study was reviewed by two independent reviewers (JL/MvM). Descriptive data on the studies included first author, year of publication, location of study, journal of publication, research design (as described by the author), study purpose, and representative findings. The studies themselves were subjected to a qualitative description analysis, as described by Sandelowski, which seeks to summarize and present information in a coherent manner.<sup>11</sup> For this study, the aim was to articulate themes that respond directly to the question: For parents experiencing the death of a child in a NICU, what considerations ought to guide the caregiving practices of healthcare practitioners to support parental bereavement? In this way, the analysis was oriented specifically to the clinical practices of physicians, nurses, and others working in the NICU. The Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of included studies.<sup>12</sup> An overall quality score was generated based on the percentage of quality criteria met, ranging from 0 to 100% such that the higher the percentage, the higher the study quality. Two reviewers (JL/MvM) independently assessed the quality of the studies and consensus was reached through discussion for any discrepancies.

## 2.3 Results

A total of 581 studies were identified using the described search strategy. MEDLINE provided 282 studies, Embase provided 102 studies and CINAHL provided 197 studies.

Forty-seven studies (n=47) were included in this review after assessing relevance. Geographic diversity was identified with the majority of studies being from the United States (N=22) and others originating from the United Kingdom (N=7), Australia (N=5), Canada (N=3), Jordan (N=2), Netherlands (N=2), Switzerland (N=1), France (N=1), Norway (N=1), Ireland (N=1), Israel (N=1) and China (N=1). Demographic information was variably presented in the reviewed papers and the majority did not specify details on participant demographics. However, eighteen of the studies reported a participant population that largely included Caucasian mothers who were married at the time of infant death and with some level of higher education. Table 1 describes each included study in detail.

Seven thematic considerations with relevant subthemes were derived from the analysis of included studies (see Table 2).

### *2.3.1 Parents may experience a manifold of different emotions anticipating and following the death of their child*

Shared between the included studies is the consideration that parents vary in how they identify and resolve their emotional reactions to the loss of their baby. Grief was described as a predominant constellation of emotions experienced by parents in coping with the acute loss of their baby. From a psychological perspective, grief may be specified as those emotions associated with loss (compared to mourning as those actions resulting from grief).<sup>13</sup> Encircling grief is uncertainty, disappointment, shame, guilt, suffering, and helplessness.<sup>14-18</sup> During an infant's end-of-life,

parents often need to balance attachment to their infant with the impending separation.<sup>18</sup> Following, grief may be described as a social phenomenon that is resolved through interactions with various support systems.<sup>19</sup> Severity of grief can be linked to the baby being acknowledged as a separate entity and the duration of postnatal bonding time.<sup>20-22</sup> Finally, grief may be conceptualized as evolving through stages: denial, anger, bargaining, depression, and acceptance.<sup>23</sup> With a neonatal loss, parents may experience these stages partially or fully, in a variety of sequences, and acceptance may never fully transpire.

Bereavement, like grief, is highly individual, yet also a recognizable human experience, as parents live with the loss of their child over time.<sup>13-16</sup> Living with loss is a sense-making experience as parents come to terms with what their child's life was like, their presence for their child as parents, and other value-judgements.<sup>16</sup> Healthcare practitioners may anticipate, recognize, and respond to parental grief to support evolving and delayed emotional reactions that accompany bereavement.<sup>13,15</sup> Focusing on attaching positive meaning to the life lost and maintaining hope – that suffering has ended or that the infant's life had purpose – can support parental bereavement.<sup>13,15,23</sup> However, this consideration cannot be generalized because parents' wishes, values and other moral beliefs may vary.<sup>14,15</sup> Generalizations can lead to a disconnect between healthcare practitioners and parents by influencing opinions on what the perceived right action may be in a difficult scenario.<sup>24</sup>

### *2.3.2 Parents may experience a cascade of different losses shaping their bereavement and healthcare practitioners can affect this burden of loss*

The reviewed studies reflect the broader NICU literature describing the complexity of losses parents may experience when their child requires hospitalization in a NICU: physical

separation in the first days of life, parental role interruptions, and so forth.<sup>4,15,25-27</sup> Parental bereavement unfolds against the backdrop of parents' NICU experiences, which can include loss experiences before, and in addition to, the death of their child.<sup>11,12,24</sup> Activities of healthcare practitioners that support parental involvement may potentially alleviate some of what is lost in these situations.<sup>4,14,15,27,28</sup> From the void of loss, healthcare practitioners can support meaningful moments and memory-making, which is highly valued as part of bereavement.<sup>14-16,24,27,29,30-35</sup> Parents seemingly appreciate any opportunity to be involved in their infant's care including bathing, dressing, diapering and taking on other parental responsibilities.<sup>4,14,15,27,35</sup> Photographs and other media provide parents with tangible objects to relieve their worry of their baby's memory fading over time.<sup>36</sup> It also allows them to share memories and experiences with others who may not have been present for this difficult journey.<sup>14,29,34</sup> Other objects include hand/foot molds, clothing, identification bands, or blankets.<sup>34</sup> Photographs taken after death can depict loss and provide meaning to the experience as one of the most common forms of memory-making at neonatal end-of-life.<sup>36</sup> Individualizing the extent of bereavement care is essential as some parents may not be comfortable with these opportunities and can feel pressure if nurses elude to any associated regrets that may arise in the future.<sup>24,32,34,35</sup>

### *2.3.3 Parents live with their perspectives of the suffering their child experienced and their communication experiences with healthcare practitioners*

Families carry with them what happened in the NICU.<sup>4,15</sup> In several studies, associations between the perception of infant suffering and the degree of parental grief, adjustment difficulty, and post-traumatic stress symptoms were clearly illustrated.<sup>17,26,37-39</sup> Parents perceive suffering through their infants' symptoms and based on information received from healthcare

practitioners.<sup>4,17,26</sup> Distressing symptoms include skin breakdown, respiratory distress, pain, agitation, lethargy, feeding difficulties, and edema.<sup>4,17,39-41</sup> A common finding illustrated that parents more often perceived suffering in their baby compared to healthcare practitioners.<sup>30,39</sup>

How healthcare practitioners communicate with parents is highly consequential: the language used needs to be sensitive yet appropriate to the situation.<sup>14,16,25,41,42</sup> Statements that presume understanding such as “I know how you feel” can be distressing.<sup>16,25,42,43</sup> Though parents often want to be told medical information in a sensitive, yet straightforward manner, ambiguity may be the reality regarding the timing of death and other less predictable events.<sup>41-44</sup> A lingering prolonged death may undermine parents’ confidence in their decisions.<sup>41</sup> Multiple studies portray the difficulties that arise for parents at the last moments of a baby’s life in the NICU. Ensuring privacy, comfort, and security are generally valued.<sup>14,19,28,31,36</sup> Healthcare practitioners can support families by being deliberate yet flexible in end-of-life care practices.<sup>16,36,43</sup> Some parents may not be comfortable being present for the final moments of their child’s life. In these cases, parents may still find comfort in speaking to their baby before death, holding their baby while still warm, or entrusting the care of their child to a friend or healthcare provider.<sup>27,36,43</sup> For others, holding their child is deeply meaningful.<sup>15,27,31</sup> Removing monitoring and medical devices may support a family to focus on their baby.<sup>15,27,31</sup> Managing end-of-life symptoms can help parents achieve a “good death” for their child.<sup>39</sup> Practitioners should be aware that the suffering perceived by parents can contribute not only to their end-of-life decision-making, but also to how they ultimately live with their decisions in bereavement.<sup>17</sup>

#### *2.3.4 Parents may benefit from a variety of different supports in the NICU in anticipation of bereavement*

Several studies explored the support parents value when navigating the emotional complexities of neonatal end-of-life. The benefits of spiritual care, including prayer, rituals, clergy, and belief in the transcendent quality of the parent-infant relationship are well established; however, healthcare practitioners may feel uncomfortable broaching such subjects.<sup>13,15,23,32-34,44</sup> Education in spiritual and religious concepts can help diminish the disconnect between parental values and provider discomfort.<sup>23</sup> In comparison, palliative care consultation can offer expertise in psychosocial support, symptom management, and coordination of care.<sup>26</sup> Neonatal practitioners find benefit in palliative care team members' ability to learn about each family's individualized priorities, circumstances, and wishes.<sup>30</sup> Palliative care involvement is associated with an increase in the number of family meetings, the identification of more symptoms, and creating symptom management plans.<sup>40</sup>

Developing bereavement expertise among a subset of NICU team members can support the provision of palliative care.<sup>32,42</sup> Parents often look to nurses for support as the time spent at the bedside helps build trust and effective communication.<sup>4,9,15,20,35</sup> Tailored education with a focus on communication, coping strategies, and enhanced exposure may help practitioners develop skills in enabling quality of care and supporting grief, navigating anxiety, and overcoming inexperience in end-of-life scenarios.<sup>13,14,25,28,42,45,46</sup> Workshop initiatives have been piloted including the TEARDROP program (Teaching, Excellent, pArent, peRinatal, Death-related inteRactions, tO, Practitioners), which uses a SCORPIO (Structured, Clinical, Objective, Referenced, Problem-oriented, Integrated and Organized) approach to teach practitioners bereavement care strategies.<sup>45</sup>



*2.3.5 Parents live with their decisions in bereavement — with time, they may question, re-evaluate, or come to terms with the decisions they made*

In bereavement, parents live with their decisions from the NICU.<sup>4,15</sup> As such, it is important to consider how parents are supported in their decision-making. Studies describe various models of decision-making including shared decision-making (parents and practitioners approach a decision together), medical/paternalistic decision-making (a decision made exclusively by healthcare practitioners), and informed parental/autonomous decision-making (parents make a decision after a provider explains the medical information).<sup>37,43</sup> Shared decision-making is generally recognized as the most appropriate approach as it benefits from healthcare practitioners' medical expertise and family members' values and beliefs.<sup>37</sup> These conversations provide opportunities to clarify understanding, align clinical care with care goals, and express compassion to families.<sup>9,10,43,47</sup> Parents should have the opportunity to express their preferences for their role in decision-making.<sup>37</sup> Continuity of care and relationships, veracity in communication, expressions of empathy, expertise and use of evidence, and clear documentation have all been identified as beneficial.<sup>4,9,10,25,26,39,43,46</sup> Parents who experience shared decision-making seem to have less grief than those who experience medical or parental decision-making.<sup>37</sup>

Included studies also highlighted how parents not only live with their decisions regarding goals of care and medical interventions, but also those decisions impacting how present they were for their child engaging in parenting actions, memory-making, and involving others in the lives of their child.<sup>4,15,16,27,34,47</sup> There are also those decisions specific to end-of-life that parents live with in their bereavement. For example, whether to pursue an autopsy can be a challenging decision. Often the infant's cause of death is known; however, errors in diagnoses may be found in post-mortem evaluations.<sup>48</sup> Parents may find benefit in an autopsy's ability to assess obstetrical and

genetic risks for future pregnancies.<sup>48</sup> Information may also be found that validates end-of-life decisions. These benefits are not always encountered as practitioners may be hesitant to offer an autopsy.<sup>48</sup>

### *2.3.6 Parental bereavement may benefit from support beyond the NICU*

It is well recognized that parents whose children died in the NICU have increased risks for physical health concerns, including hospitalizations and higher mortality.<sup>16,19</sup> Bereaved parents also experience higher rates of clinical depression, anxiety, and post-traumatic stress.<sup>38,49</sup> Screening for pre-existing mental health concerns and developing support strategies before an anticipated death can be beneficial.<sup>26</sup>

To support mental health, professional counselling, support groups, peer counselling, and community physicians have all been described as potentially helpful to support acceptance and adaptation to loss.<sup>16,33,40,50</sup> For some families, spiritual or religious supports are significant; however, finding adequate support can be challenging.<sup>15,16,27,49</sup> Additionally, there is a timeliness to the extent, interval, and duration of support.<sup>51</sup> Parents may experience an abrupt loss of support following the death of their child as they lose the support of the NICU.<sup>30</sup> Initiation of timely supportive care to where parents are in their grieving beyond the NICU is needed.<sup>18,30</sup>

Most parents will attend a follow-up appointment with the healthcare team if offered.<sup>52</sup> It would seem that these follow-ups should be scheduled six to eight weeks after the death and in a location outside of the NICU.<sup>52</sup> These follow-up visits can help provide answers to parents' questions and reassurance about end-of-life decision-making.<sup>52</sup> Other options for bereavement follow-up involve familiar staff individualizing follow-up contact over time, sending a card on the first anniversary of the infant's death, and telephone calls by the involved neonatologist.<sup>32</sup> Parents

described benefit from being copied on the written summary from the NICU.<sup>51</sup> Neonatologists should ensure that these summaries maintain sensitivity, use the baby's chosen name if available, and simplify terms to ease parental understanding.<sup>51</sup> Deficiencies in bereavement support include medical follow-up, autopsy discussion, sibling grief management, marital concerns, and expectations surrounding return to normalcy.<sup>48,49</sup>

### *2.3.7 Understandings are needed for unique NICU bereavement experiences*

Bereavement following the loss of one infant from a multiple gestation pregnancy is a unique phenomenon that may be encountered in the NICU. Losses may occur before or following birth leading to varied bereavement experiences.<sup>15,44,53,54</sup> At times, NICU healthcare practitioners may fail to acknowledge pregnancy loss as the focus is diverted to the surviving infant receiving care.<sup>15</sup> It is essential to document and communicate pregnancy loss to NICU team members to acknowledge this grief potential.<sup>53</sup> It can be challenging for parents to balance grieving the deceased while maintaining attachment to the living.<sup>53</sup> Grief may be compounded by a failure to acknowledge the loss and/or by associated challenges of the surviving sibling.<sup>15,21,54</sup> Some families will request aggressive treatment for the surviving child despite poor prognosis, while others are willing to stop when treatment is considered futile.<sup>43</sup> The complexities of loss and survival of siblings may be challenging for families to navigate, recognizing mothers and fathers may vary in their bereavement.<sup>44</sup>

Another unique phenomenon surrounding neonatal loss involves lactation. Studies reflect a movement to advocate for a holistic approach to supporting mothers with lactation through their bereavement.<sup>55</sup> Pumping milk has been an outlet for grief and milk donations have been associated with acceptance and healing.<sup>42,53</sup> Mothers may experience several emotions when pumping after

neonatal death including sadness, emptiness, anxiety and relief.<sup>53</sup> They may find strength in believing that donating milk will help sustain their child's legacy, maintain their parental identity, and keep the memory of their infant alive through helping others.<sup>33,55</sup>

Bereavement experiences can continue into future pregnancies.<sup>13</sup> The decision to have another child after a neonatal loss may be very difficult.<sup>22,49</sup> However, it would seem most parents have additional children following their loss and this is associated with fewer symptoms of prolonged grief and posttraumatic stress.<sup>13,22</sup> It is suggested that healthcare practitioners should not discourage or provide recommendations for the timing of future pregnancies.<sup>22</sup> Instead, they should approach such discussions non-judgementally with compassion and sensitivity.

## **2.4 Discussion**

### *2.4.1 Key concepts of supporting parental bereavement in the NICU*

Through conducting this review, several themes exploring parental bereavement after the death of an infant in the NICU were identified based on primary data gathered from direct communication with bereaved parents. Although the burden of neonatal death and the impact of provider support is well-established in the literature, this review revealed that the ability of parents to spend time caring for their child, their perception of infant suffering, their communication experiences with healthcare practitioners, and the access to alternative means of support is often suboptimal. These themes can be a starting point in enhancing the support healthcare practitioners deliver to parents experiencing the loss of an infant and their subsequent bereavement. Based on the reviewed studies, implementing additional methods of support including access to spiritual and palliative care, shared decision-making, lactation support, and ensuring ongoing bereavement support may have significant benefits. Although general themes have been identified, it is

important to appreciate that bereavement care both during and after an infant's death should be individualized. Different values, cultural backgrounds and family circumstances can contribute to different wishes and coping mechanisms for a family during their bereavement. Recognizing these nuances, healthcare practitioners need to customize their approaches to ensure optimal outcomes.

#### *2.4.2 Gaps in the literature*

There is an abundance of literature surrounding bereavement care after pregnancy loss, stillbirth, and perinatal death, including the death of a fetus between the 22<sup>nd</sup> full week gestation (or 500g estimated weight) and 7 days after birth.<sup>56</sup> While some of this literature appeared to include parental perspectives of those whose child died in the NICU, issues unique to perinatal bereavement for such families were left unarticulated. There is a clear need for literature which focuses exclusively, or at least forefronts some of the perspectives of parents whose child received medical interventions and admission to a NICU. The notion of perinatal death includes experiences that may resemble yet also differ from those occurring in the NICU.

Given that the studies reviewed reported specific demographic information on participants being Caucasian, educated, English-speaking and married, uncertainty remains in the influence of familial and cultural diversity in contributing to parental bereavement after a neonatal loss. Broader populations including those who are geographically distanced, recent immigrants, or less educated may have different values in bereavement practices, satisfaction, access to care and involvement in decision-making. An attempt to close this research gap by diversifying inclusion in related research studies could impactfully contribute to the current literature.

### *2.4.3 Unresolved tensions in the literature*

Although several conclusions can be formed through similarities found in the reviewed articles, some discrepancies remain. Cultural differences when providing bereavement care is a complex area to navigate. In some cultures, burial and body preparation as well as seeing the body after death is not considered appropriate; however, mothers often find it difficult not to have this opportunity and the literature strongly supports inviting parents to participate.<sup>13</sup> Additionally, in similar cultures, the delivery of news about prognosis and goals of care are often relayed through family members and not the mother directly – which is contradictory to what is considered beneficial to parents as described in most papers.<sup>13</sup> Mothers often find lactation difficult when their neonate is critically ill and despite several papers focusing on pumping and donating milk as an emotional release, some mothers find the pressure to pump and produce milk adds to their burden of stress.<sup>14</sup> Despite education surrounding communication in goals of care and end-of-life being described as rare and suboptimal, one paper explores how practitioners feel confident in end-of-life care.<sup>16</sup> Majority of other papers describe practitioners' desire for further education and training in this area of neonatology.<sup>17,30</sup> Moreover, despite the abundance of literature describing the benefit of pediatric palliative care consultations in the NICU, one paper illustrated palliative care as being nonsignificant when reporting parental satisfaction.<sup>40</sup> These specific controversies remain unresolved but are crucial to consider when establishing bereavement practices and further emphasize the importance of individualizing care based on each family's beliefs and values.

### *2.4.4 Limitations of research*

The majority of included studies were small-scale studies identifying themes and conclusions based on local trends. A narrative approach was chosen for this review to capture the

diversity of research methods employed. The analysis also included the use of the MMAT demonstrating the findings of the study as credible, meaningful, and relevant to neonatal practice. Given the small-scale studies and results from predominantly developed English-speaking countries, caution should be exercised regarding generalizations. However, appreciating that several studies identified similar conclusions, despite the results of each being subjective and individualized, the commonality of these opinions strengthens the review's findings.

#### *2.4.5 Opportunities for future research, medical education & practice change*

Future research into parental bereavement for those who have lost an infant in the NICU should include exploring the contribution of culture on optimal bereavement support. The geographic diversity of studies in this review alludes to the individualization of care for each family, but also for each culture – and investigating these nuances may be beneficial in further tailoring neonatal bereavement care.

Other areas for research involve expanding on education initiatives in equipping healthcare practitioners with communication and support skills to assist families in their bereavement as well as ensure they are getting the support they need, especially if there is a history of pre-existing mental health concerns. Additionally, understanding the influence of autopsy on grief, closure, and future pregnancies could indicate the importance of offering post-mortem examination in both confirming diagnoses as well as providing closure. Obtaining longitudinal follow-up data would also be a useful contribution to the literature as understanding how bereavement experiences impact families long-term can help prioritize areas for improvement.

## **2.5 Conclusion**

This review is the first of its kind in the past decade to explore current perspectives on parental bereavement and what considerations ought to guide the caregiving practices of healthcare practitioners. Various methods of support have been identified based on first-hand parental experiences and routine implementation of these strategies may be beneficial in supporting parental bereavement. Future studies exploring the success of implementing these recommendations from parents' experiences can help determine the usefulness of these strategies and provide the next steps to further enhance parental bereavement support in the NICU.



## 2.6 Tables

2.6.1 Table 1: Included Articles Describing Support of Parental Bereavement in the NICU

Author (Year), Country	Design	Population (N)	Study Purpose	Representative Findings	MMAT Score
Abdel Razeq & Al-Gamal <sup>13</sup> (2018) <i>Jordan</i>	Phenomenology, thematic analysis: Interviews	12 parents	To understand bereavement and its associated meanings as lived and experienced by bereaved NICU mothers	<ul style="list-style-type: none"> <li>- 3 main themes: (1) Longing and grieving, as natural emotional response to the loss; (2) Adaptive work of coping, as the mother internalized meanings to cope with the loss; and, (3) Moving forward but with a scar, as the mothers moved on with their lives while they carried the unforgettable memories of their newborn's death</li> <li>- Bereavement support services as essential services</li> <li>- practitioners can support through understanding parents' spiritual values and coping mechanisms</li> </ul>	100%
Abdel Razeq & Al-Gamal <sup>19</sup> (2021) <i>Jordan</i>	Phenomenology, thematic analysis: Interviews	12 parents	To understand the lived experiences of mothers surrounding the time of being informed of neonatal death in the NICU	<ul style="list-style-type: none"> <li>- 3 main themes: (1) Minimize the hurt, which described how mothers intuited overprotection by their family; (2) The striking reality of death, which captured mothers' distressing experiences while realizing the loss of their neonate; and, (3) Farwell my baby, which accentuated mothers' needs and experiences while neonates' bodies were honored and prepared for burial per the cultural norms in Jordan</li> <li>- Opportunities for parental involvement in care practices at the end-of-life</li> <li>- Need for specialized bereavement support at time of death</li> </ul>	100%
Abraham & Hendriks <sup>14</sup> (2017) <i>Switzerland</i>	Ethnography, content analysis: Interviews	20 parents	To illustrate the parental perspectives of those who lost an extremely premature infant in the hours/days after birth in the NICU, and how healthcare practitioners can facilitate bonding between parent and child during this time	<ul style="list-style-type: none"> <li>- 2 main themes: (1) After the baby' transfer to the NICU, a phase of uncertainty; and, (2) The end-of-life phase, when death is certain</li> <li>- Parental role may evolve from time of birth to time of death, from distant parenting to embodied parenting</li> <li>- Importance of parents being able to take on roles in providing care and parenting role</li> <li>- Ensuring privacy and opportunities to hold at end-of-life</li> <li>- Offering memory-making including photography is valued</li> </ul>	100%
Akard et al. <sup>58</sup> (2018) <i>USA</i>	Qualitative description, content analysis: Focus groups	6 parents	To explore bereaved parents' perceptions of legacy-making interventions after infant death	<ul style="list-style-type: none"> <li>- 4 main themes: (1) Parents' willingness to participate in legacy intervention; (2) Suggestions for feasible interventions; (3) Suggestions for acceptable interventions; and, (4) Parents' perceived benefits of legacy-making</li> <li>- Parents support use of legacy-making interventions, finding them to be feasible, acceptable, and beneficial</li> <li>- Bonding can continue after loss and can be shared with extended family members</li> <li>- Barriers include timing of approach, sensitivity to uncertain prognosis and logistical barriers</li> </ul>	100%
Alexander <sup>36</sup> (2001) <i>USA</i>	Qualitative case series, narrative: Interviews	4 parents	To understand the benefit of perinatal bereavement photography	<ul style="list-style-type: none"> <li>- Bereavement photography should be included in loss policies and procedures</li> <li>- Photography should be personalized</li> <li>- Photographs can assist in grief</li> <li>- Sharing photographs with other children to help with sense-making and understanding</li> </ul>	80%
Armentrout <sup>47</sup> (2007) <i>USA</i>	Grounded theory: interviews	15 parents	To describe parents' experiences about life support decisions, infant death, and lives thereafter  To report basic social processes parents revealed as vital to sustaining infant's memory	<ul style="list-style-type: none"> <li>- 3 main themes: (1) Facing the decision - no real choice, time with the baby; (2) Life goes on – listen to your heart, an abiding loss, not left out; (3) Lives forever changed – new perspective, preparing to meet again</li> <li>- End-of-life decision making complex, often require prognostic information from healthcare practitioners to contextualize situation</li> <li>- Parents value choosing how to spend time with infant after difficult decisions – seemingly where regrets were found on parental reflection</li> </ul>	100%

				<ul style="list-style-type: none"> <li>- Concept of “shadow grief” - lessens with time but never forgotten</li> <li>- Important for families to maintain infant’s place as part of family long after death</li> </ul>	
Armentrout <sup>15</sup> (2009) <i>USA</i>	Grounded theory: Interviews	15 parents	To explore concepts identified by parents as factors in decision-making and on facilitators and barriers encountered in grieving process	<ul style="list-style-type: none"> <li>- Varied experiences of end-of-life decision making around in the NICU</li> <li>- Individualizing and personalizing care to each infant and family is appropriate</li> <li>- Parents may vary in their experiences of loss and bereavement</li> <li>- Cultural and social values may be expressed in coping strategies</li> <li>- Parents may appreciate encouragement to parent their child during NICU stay and end-of-life</li> <li>- Parental grief and loss become incorporated into parents ongoing lives and living with loss</li> </ul>	100%
Armentrout & Cates <sup>25</sup> (2011) <i>USA</i>	Qualitative description: Interviews	14 parents	To explore parental perceptions of experience of being informed of infant’s inevitable death	<ul style="list-style-type: none"> <li>- Lack of education in palliative care poses stress to NICU practitioners</li> <li>- Transparency of practitioners in decision-making highly valued</li> <li>- ABCDE approach: Advanced preparation, Building therapeutic environment, Communicating well, Dealing with patient and family reactions, and Encouraging and validating emotions</li> <li>- Simulations of difficult conversations may increase comfort levels of practitioners</li> </ul>	20%
Baughcum et al. <sup>35</sup> (2017) <i>USA</i>	Qualitative content analysis: Interviews	45 parents	To examine parent perspectives of infant’s end-of-life experience 3 months – 5 years after infant death	<ul style="list-style-type: none"> <li>- Themes: (1) Parents as partners in care; (2) Communication with health-care team; (3) Relationship with staff; (4) Bereavement support</li> <li>- Bereavement resources highlighted by parents as influential</li> <li>- Highlight of importance in relationship of trust between parents and healthcare practitioners, staff members compassion, and parental involvement in infant bonding</li> <li>- Areas for improvement included importance of participation in care and having space to do so optimally,</li> <li>- Fathers often had higher satisfaction of care compared to mothers</li> </ul>	100%
Baughcum et al. <sup>26</sup> (2020) <i>USA</i>	Mixed methods: Questionnaires, interviews	69 parents	To examine parent perceptions of infant end-of-life experiences (e.g., symptom burden and suffering) and satisfaction of care in the NICU	<ul style="list-style-type: none"> <li>- Perceptions of infant suffering relate to lower satisfaction with care in the NICU</li> <li>- Satisfaction with care relate to parents’ partnership in care, communication, relationships with staff, and bereavement support</li> <li>- Families have various needs that are variably met: keepsakes, acknowledgement of loss, ability to say goodbye, treating infant with dignity, involvement in infant care, availability of neonatologist, mitigation of suffering, contact with team after death (follow-up)</li> <li>- Practitioners should consider: palliative care basics, palliative care team, screening for mental health concerns, discuss coping strategies</li> </ul>	100%
Blood & Cacciatore <sup>29</sup> (2014) <i>USA</i>	Modified grounded theory, mixed methods: Questionnaires	181 parents	To examine the meaning, usefulness, and social context of bereavement photography in the eyes of NICU parents	<ul style="list-style-type: none"> <li>- Photography can foster sense of ongoing connection and help other family members (e.g., siblings) with understanding and coping</li> <li>- Photography practices should be individualized as some families and some cultures may not find them acceptable</li> </ul>	60%
Bourque et al. <sup>50</sup> (2020) <i>Canada</i>	Mixed methods, convergent analysis: Field notes, questionnaires	8 parents 16 healthcare practitioners	To describe the ongoing involvement and bereaved parents’ perspectives in different activities in the NICU and practitioners who work with them	<ul style="list-style-type: none"> <li>- Identified benefit of using resource parents (those who have previously experienced NICU hospitalization of infant) to improve care and experience for current parents</li> <li>- Themes identified: family perspectives, helping bereaved parents, improving system, giving back, promoting empowerment, targeting improvement in relationship with practitioners</li> <li>- Mutual beneficial relationship – gain control of experience, help with coping and healthcare practitioners get parental viewpoints directly</li> </ul>	80%
Caeymaex et al. <sup>37</sup> (2013) <i>France</i>	Mixed methods: Interviews	78 parents	To investigate parents’ perceptions on type of involvement in end-of-life decision-making and effect on long-term grief	<ul style="list-style-type: none"> <li>- Perceived suffering of infant associated with higher grief scores</li> <li>- Shared decision-making resulted in lower grief scores relative to medical or informed parental decision-making</li> <li>- Involvement in decision-making based on parental wishes</li> </ul>	100%

Calhoun <sup>20</sup> (1994) <i>USA</i>	Descriptive survey: Questionnaires	23 parents	To confirm appropriateness of nursing interventions that are commonly accepted as beneficial to parents during neonatal end-of-life	<ul style="list-style-type: none"> <li>- Nursing interventions very impactful in parents' experience at end-of-life</li> <li>- Parents valued interventions that dealt with acknowledgement of baby</li> <li>- Strategies employing educational/information/written material, general emotional support/communication, and general emotional support/interventions were valued</li> <li>- Parents may vary in how they grieve</li> </ul>	60%
Clark et al. <sup>38</sup> (2021) <i>USA</i>	Qualitative cross-sectional survey: Questionnaires	67 parents	To explore associations between perceptions of infant suffering in NICU and parental adjustment after death	<ul style="list-style-type: none"> <li>- Parents perceptions of infant symptoms and suffering were linked with levels of grief</li> <li>- Symptom management may support parental coping</li> <li>- Parents may vary in how they grieve</li> </ul>	100%
Clarke & Booth <sup>51</sup> (2011) <i>United Kingdom</i>	Descriptive survey: Questionnaires	13 parents 53 healthcare practitioners	To evaluate the opinions of bereaved parents on being provided written summary of infant's care and death in NICU	<ul style="list-style-type: none"> <li>- Most bereaved parents welcomed a copy of the detailed medical summary that provides a complete record of the clinical course, brief life, and terminal events in the NICU</li> <li>- Post-mortem and bereavement follow-up visits may be helpful for parents</li> </ul>	60%
Cortezzo et al. <sup>30</sup> (2015) <i>USA</i>	Descriptive cross-sectional survey: Questionnaires	7 parents 104 healthcare practitioners	To determine perceptions of end-of-life care practices in NICU from neonatologists, practitioners, nurses, and parents and identify areas for improvement and involvement of palliative care team	<ul style="list-style-type: none"> <li>- Most neonatologists and advanced practitioners comfortable with EOL care but think there would be benefit in having designated palliative care team</li> <li>- Parents stressed the importance of memory-making and follow-up/bereavement support</li> <li>- Palliative care team to spend time with the families enabling a true understanding of how significant the situation is and understanding their wishes/backgrounds would be beneficial</li> <li>- Value of consistency among practitioners, symptom management, early and clear communication, bereavement support, staff debriefing</li> </ul>	60%
Cuisinier et al. <sup>53</sup> (1996) <i>The Netherlands</i>	Qualitative description comparison study: Questionnaires	142 parents	To investigate differences between parental grief following death of neonatal twin in comparison to singleton	<ul style="list-style-type: none"> <li>- Bereaved twin parents did not differ in grief reactions from bereaved singleton parents in short or long term</li> <li>- Differences in grief experience as twin parents have to balance grieving loss of twin relative attachment to twin still living</li> <li>- Suggestions that parents make memories of twins separate and together</li> <li>- Important to document that live infant was product of twin pregnancy when dealing with parents and to examine potential consequences</li> </ul>	60%
Currie et al. <sup>16</sup> (2019) <i>USA</i>	Qualitative description: Interviews	10 parents	To explore parents' bereavement coping experiences after experiencing infant death in the NICU where palliative care was provided	<ul style="list-style-type: none"> <li>- 2 main themes: (1) living with loss, as bereavement and grief over time, mental health challenges, spiritual suffering, personal growth after loss, and life changes after loss; and, (2) coping with grief over time as barriers to coping with loss and helpful strategies for coping with loss</li> <li>- Infant death was a tragic and life-changing loss for parents with feelings of loss evolving over time</li> <li>- Varied grief symptoms may be experienced</li> <li>- Parents navigate different barriers to coping with varied supports</li> </ul>	100%
Currie et al. <sup>4</sup> (2016) <i>USA</i>	Qualitative description, content analysis: Interviews	10 parents	To investigate how bereaved parents describe their experience related to NICU hospitalization, end-of-life care, and palliative care consultation	<ul style="list-style-type: none"> <li>- Primary theme: life and death in the NICU environment with categories of ups and downs of parenting in the NICU, decision making challenges in the NICU, and parent support</li> <li>- Parents appreciate the chance "to be a parent" regardless of how much they could be involved in the care of their infant, regardless of the strife endured, and regardless of how much time they ultimately had</li> <li>- Palliative care consultation often associated with some hesitancy but retrospectively appreciated as extra support</li> <li>- Standardized protocols involving palliative care consult may be of benefit</li> </ul>	100%
Fortney et al. <sup>17</sup> (2020) <i>USA</i>	Qualitative description:	46 parents	To examine bereaved parents' perceptions of infant suffering in the NICU	<ul style="list-style-type: none"> <li>- 4 main themes: (1) the presence/absence of suffering; (2) indicators of suffering; (3) temporal components of suffering (trajectory); and, (4) influence of perceived suffering on parents, infants, and decision-making</li> </ul>	100%

	Interviews, questionnaires			<ul style="list-style-type: none"> <li>- Perceptions of suffering are informed by infant observations and information received from healthcare team members</li> <li>- Suffering perceptions influence parental decision-making</li> </ul>	
Gilmour et al. <sup>40</sup> (2017) <i>Australia</i>	Retrospective cohort study: Chart review	46 infant charts	To characterise end-of-life care provided in a tertiary centre through assessing performance with known key components of palliative care	<ul style="list-style-type: none"> <li>- Indicators of quality palliative care varied with some activities routine such as family meetings, social worker involvement, and memory-making opportunities while others were infrequent antenatal resuscitation planning, discussion of preferred location of death, and access to bereavement care</li> <li>- Respiratory symptoms, neurological symptoms, and pain were most commonly identified distressing symptoms</li> <li>- Neonatal staff have significant scope to improve end-of-life care by providing psychosocial, emotional, and spiritual supports</li> </ul>	60%
Harrigan et al. <sup>21</sup> (1993) <i>USA</i>	Longitudinal study: Questionnaires	27 parents	To describe grief experiences of multi-gestation pregnancies after loss, to compare differences between mothers and fathers, to analyze psychometric Perinatal Grief Scale for use in this population, and to develop foundation to study risk for pathological grief	<ul style="list-style-type: none"> <li>- Grief scales as instruments reliable in population but sensitivity reduced</li> <li>- Coping strategy effectiveness dependent on time since infant death and length of infant's life</li> <li>- Longitudinal follow-up essential as grief is often prolonged when loss of one twin and surviving twin remains</li> <li>- Practitioners can help validate or refute relationships suggested in grief model and normalize development of perinatal grief</li> </ul>	60%
Keim et al. <sup>22</sup> (2017) <i>USA</i>	Qualitative description, content analysis: Interviews	69 parents	To examine relationship between parent perceptions of infant suffering, parental distress, and the decision to have more children after infant death	<ul style="list-style-type: none"> <li>- 4 main themes: (1) Impact of infant death; (2) Facilitators and barriers; (3) Timing and trajectories of decisions; and, (4) Not wanting to replace the deceased child</li> <li>- Mothers who had subsequent children following a loss had lower post-traumatic stress symptoms and fewer symptoms of prolonged grief</li> <li>- More positive NICU experiences was associated with willingness to have other children</li> <li>- Practitioners should not discourage parents having other children and be cognisant of the advice they give</li> </ul>	100%
Kochen et al. <sup>42</sup> (2021) <i>The Netherlands</i>	Qualitative exploratory study: Interviews	22 healthcare practitioners	To understand pre-loss care and challenges practitioners face in providing end-of-life care	<ul style="list-style-type: none"> <li>- 3 main themes: (1) Sustaining hope versus realistic prospects; (2) Obtaining emotional closeness versus emotional distance; and, (3) Exploring emotions versus containing emotions</li> <li>- Practitioners weigh strategies based on their perceptions of parental needs, the situation, and their own competencies</li> <li>- Uncertainties as to whether the pre-loss care they provided constituted optimal care may exist</li> <li>- Working as a team is beneficial to learn from one another, prevent burnout and diversify care</li> </ul>	80%
Kymre & Bondas. <sup>31</sup> (2013) <i>Norway</i>	Phenomenology: Interviews	18 healthcare practitioners	To describe how nurses enact skin-to-skin care at the end-of-life	<ul style="list-style-type: none"> <li>- Strong belief in the urgency of skin-to-skin care in providing mutual proximity and comfort for dying preterm newborns and their parents</li> <li>- Skin-to-skin care seen as the preferred caring practice at end-of-life by nurses</li> <li>- Often more comfortable with less tubes/wires both for parents and for baby</li> </ul>	100%
Leitao et al. <sup>45</sup> (2021) <i>Ireland</i>	Pilot workshop: Questionnaires	95 healthcare practitioners	To develop and implement a multidisciplinary perinatal bereavement care training to develop compassionate culture for bereaved parents	<ul style="list-style-type: none"> <li>- TEARDROP program = Teaching, Excellent, pArent, peRinatal, Deaths-related, inteRactions tO Professionals</li> <li>- Participants were satisfied with the workshop rating level of information and quality of teaching high</li> </ul>	60%
Levick et al. <sup>32</sup> (2017) <i>USA</i>	Qualitative description: Questionnaires	36 families 11 healthcare practitioners	To describe an approach to delivering bereavement services to NICU families as well as education and support to NICU staff	<ul style="list-style-type: none"> <li>- Bereaved parents and caregivers find meaning and purpose in the act of creating keepsake memories at the time of an infant's death</li> <li>- Individualized follow-up contacts by staff familiar with bereaved parents supports mutual healing</li> <li>- Families vary in their desired involvement in bereavement activities</li> </ul>	60%

Lizotte et al. <sup>46</sup> (2020) <i>Canada</i>	Simulation session: Observation, scoring checklist	6 parents 13 healthcare practitioners 2 standardized actors	To identify core behaviours associated with good communication during and after unsuccessful resuscitation	<ul style="list-style-type: none"> <li>- Participants judged as good communicators more likely to introduce themselves, use the infant's name, acknowledge parental presence, prepare the parents, stop resuscitation without asking parents, clearly mention death, provide or enable proximity, sit down, decrease guilt, permit silence, and have knowledge about procedures after death</li> <li>- Many simple behaviors, identified by parents and practitioners, are associated with good clinician-parent communication</li> </ul>	80%
McHaffie <sup>9</sup> (2001) <i>United Kingdom</i>	Qualitative description: Interviews	108 parents	To explore the perceptions of responsibility, burden and helpfulness or participation of parents in care withdrawal decisions	<ul style="list-style-type: none"> <li>- Nurses play a key role in providing emotional support for families during the process of treatment withdrawal</li> <li>- Key elements include expressing compassion, demonstrating expertise and evidence, and consistency and honesty in information sharing</li> <li>- Parents valued nursing and staff attendance at funeral</li> </ul>	100%
McHaffie et al. <sup>48</sup> (2001) <i>United Kingdom</i>	Qualitative description: Interviews	108 parents	To determine parental views on autopsy after treatment withdrawal	<ul style="list-style-type: none"> <li>- Autopsy may be helpful even if cause of death known or expected as may provide additional information</li> <li>- Main reasons for declining autopsy were concerns about disfigurement, a wish to have the child left in peace, and a feeling that an autopsy was unnecessary</li> <li>- Parents did not appear to express regret about their autopsy decisions</li> <li>- Commonest cause for not receiving autopsy was not being asked</li> <li>- Consent and disclosure recommended to be done by neonatologist or trusted team member</li> </ul>	100%
McHaffie et al. <sup>52</sup> (2001) <i>United Kingdom</i>	Qualitative description: Interviews	108 parents	To explore parents' experiences of bereavement care after withdrawal of care in an NICU	<ul style="list-style-type: none"> <li>- Appointments should be scheduled soon after death, certainly within 2 months of the death regardless of whether or not autopsy results are available; with the attending neonatologist; and, in a setting away from the hospital</li> <li>- Parents value efforts to find out how they are coping, honest information given sensitively; and, reassure where possible</li> </ul>	100%
McHaffie et al. <sup>41</sup> (2001) <i>United Kingdom</i>	Qualitative description: Interviews	108 parents	To explore parents' experiences with treatment withdrawal of their baby and the dying process	<ul style="list-style-type: none"> <li>- Parents often had regrets on lacking information to support decision making and the length of time it took to make decisions to withdraw medical interventions</li> <li>- Length of the dying process could undermine parents confidence in their decisions or otherwise contribute to their distress</li> <li>- Medical predictions of time to death often were inaccurate</li> <li>- Better to give uncertain answer vs. committing to a time frame of death after withdrawal</li> </ul>	100%
Oreg <sup>33</sup> (2020) <i>Israel</i>	Phenomenology: Testimonials, interviews	88 parents	To discover ritual structures and embodied processes that occur during milk donation after loss	<ul style="list-style-type: none"> <li>- 2 main themes: (1) Extracting milk and continuing bonds with the lost baby; and, (2) The transformation in meaning through the milk extraction process</li> <li>- Bereaved mother may experience ambiguity in loss as the combination of physical absence and psychology presence of their baby</li> <li>- Producing (through the process of lactating), extracting (through repeated pumping), and donating milk may be understood as a grief ritual, allowing mothers to maintain and reconstruct bonds with their babies</li> <li>- Milk seen symbolic gift from deceased infant and donating it to other babies could be way of their own infant living on in others</li> </ul>	100%
Pector <sup>43</sup> (2004) <i>USA</i>	Mixed methods survey, grounded theory: Questionnaires	71 parents	To assess the experiences of bereaved parents of multiples with resuscitation and life-support discussions, process of dying, and conversations with healthcare practitioners about death	<ul style="list-style-type: none"> <li>- Parents of multiples exhibit diverse and at times divergent opinions regarding resuscitation, coping styles, and approach decisions from varied perspectives</li> <li>- Careful, clear, and summaries of conversations supported parental decision-making</li> <li>- Language used to express empathy or support decision making is meaningful</li> <li>- Time with the deceased was valued</li> <li>- Death notification is a sensitive task</li> </ul>	40%

Rosenbaum et al. <sup>49</sup> (2015) <i>USA</i>	Randomized controlled trial, mixed effects model: Questionnaires	73 parents	To evaluate the impact of viewing bereavement support DVD on parental grief compared with standard bereavement care	<ul style="list-style-type: none"> <li>- Limited numbers of parents watched the DVD</li> <li>- Analyses based on intention-to-treat did not demonstrate significant differences</li> <li>- Analyses of viewer compared to nonviewers showed differences in anxiety</li> </ul>	40%
Rosenbaum et al. <sup>23</sup> (2011) <i>USA</i>	Case descriptions: Narratives	not specified	To increase awareness of spiritual and existential distress and to provide strategies to cope at end-of-life	<ul style="list-style-type: none"> <li>- Families may rely on their faith and spirituality to assist them through end-of-life journey</li> <li>- Incorporating spiritual support can support parental bereavement</li> <li>- Spiritual support benefits from certified chaplain, clinician trained in spiritual care, or other individual with such expertise</li> <li>- Health care practitioners may become more acquainted with the meanings of spiritual and religious concepts that emerge for patients and families in their clinical practice</li> </ul>	20%
Shultz et al. <sup>39</sup> (2017) <i>USA</i>	Mixed methods: Questionnaires	67 parents	To compare reported/documentated symptoms at end-of-life and associations with parent perceptions of infant suffering	<ul style="list-style-type: none"> <li>- Parents report symptoms of respiratory distress, agitation, pain, and lethargy most commonly</li> <li>- Parental perceptions of infant suffering were correlated with total number of symptoms</li> <li>- Managing end-of-life symptoms is part of establishing “good death”</li> <li>- Discrepancies may exist between parents and medical team regarding perceptions of pain and other symptoms</li> </ul>	60%
Skene <sup>24</sup> (1999) <i>USA?</i>	Qualitative description: Interviews	9 parents	To evaluate existing research and contribution to current bereavement practices and illustrate individual nature of bereavement experiences by hearing individualized stories	<ul style="list-style-type: none"> <li>- 10 main themes: (1) Relationship with the baby; (2) Staff; (3) Conflict over baby’s treatment; (4) Information; (5) Discontinuation of treatment; (6) Time in NICU following the baby’s death; (7) Holding and bathing the baby; (8) Support at home; (9) Partners; and, (10) Photographs and reminders</li> <li>- Individualization of care is needed for varied bereavement experiences</li> </ul>	100%
Swanson et al. <sup>44</sup> (2009) <i>Australia</i>	Mixed methods study: Questionnaires, interviews	104 parents	To compare coping among couples who experience the death of a twin and who have a surviving twin or higher order multiple	<ul style="list-style-type: none"> <li>- Gendered differences in reports of grief and depression</li> <li>- Parental spiritual beliefs may increase after loss, with some parents turning to spiritual support</li> <li>- Parents value support from partners, talking (especially with each other), family and friends offering acknowledgement/understanding, spiritual and religious beliefs, surviving twin and other children</li> </ul>	80%
Swanson et al. <sup>54</sup> (2002) <i>Australia</i>	Mixed methods study: Questionnaires, interviews, focus groups	66 parents	To explore the nature of bereavement in losing one or more infants in a multiple pregnancy, how mothers cope and how they can be better supported	<ul style="list-style-type: none"> <li>- Mothers show higher levels of active grief than difficulty coping, and more difficulty coping than despair</li> <li>- Spiritual beliefs may increase after loss, with some parents turning to spiritual support</li> <li>- Helpful themes: surviving children, acknowledgement from family and friends, support from father of twins, spiritual/religious beliefs</li> <li>- Unhelpful themes: Unacknowledged grief, insensitive comments, social workers’ interaction and attempt to give advice on how to grieve, seeing live twin pairs, lack of support from twin father, being blamed</li> </ul>	80%
Thornton et al. <sup>27</sup> (2021) <i>Australia</i>	Grounded theory: Interviews	18 parents	To explore the significance and impact of memory-making on parents’ experience at end-of-life	<ul style="list-style-type: none"> <li>- Core category of “Affirmed parenthood” was underpinned by: (1) Creating evidence; (2) Needing guidance; and, (3) Being a parent</li> <li>- Parents value being supported to have contact, engage with, and provide care for their baby in end-of-life care as critical elements of memory-making and being a parent in a situation where many “normal” parenting activities were not possible</li> </ul>	100%
Thornton et al. <sup>34</sup> (2020) <i>Australia</i>	Grounded theory: Interviews	18 parents	To explore the significance and impact of memory-making on parents’ experience of loss following neonatal loss	<ul style="list-style-type: none"> <li>- “Creating evidence” was a key theme of memory-making involving taking photographs, creating mementos, as well as involving friends and family during their baby’s time in the NICU</li> </ul>	100%

				<ul style="list-style-type: none"> <li>- Memory-making may affirm the life of the baby and the role of the parents to ultimately support parental bereavement</li> <li>- Creating evidence does not just take the form of tangible artefacts but also social interactions and other memories</li> </ul>	
Welborn <sup>55</sup> (2012) <i>USA</i>	Phenomenology: Interviews	21 parents	To explore the lived experience of milk donation in bereaved mothers	<ul style="list-style-type: none"> <li>- 4 main themes: (1) Identifying as a mother, grieving the loss of motherhood; (2) Meanings associated with the experience of pumping milk; (3) Finding meaning in and integrating the experience of perinatal loss; and, (4) The importance of addressing lactation with bereaved mothers</li> <li>- Bereaved mothers benefit from support and education regarding lactation following loss</li> <li>- Pumping milk was a way of grieving loss, donating milk was a way of accepting and healing from loss</li> <li>- Advocacy for more holistic approach to lactation including physiological and emotional aspects, and supporting bereaved mothers in lactating needs</li> </ul>	100%
Williams et al. <sup>18</sup> (2009) <i>Canada</i>	Qualitative description: Interviews, questionnaires	11 parents	To develop and pretest a questionnaire on withdrawing life-sustaining interventions in NICU based on bereaved parents' experiences	<ul style="list-style-type: none"> <li>- 6 domains: (1) Communication; (2) Quality of care; (3) Quality of life; (4) Shared decision-making; (5) Withdrawal of life-sustaining treatment process; and, (6) Bereavement care</li> <li>- Withdrawal of life-sustaining treatment process needs were identified as most likely met while those related to quality of care and bereavement care were not consistently met</li> </ul>	100%
Wool et al. <sup>10</sup> (2018) <i>USA</i>	Descriptive survey: Questionnaires	405 parents	To assess parental satisfaction with care received in context of a life-limiting fetal diagnosis and subsequent birth	<ul style="list-style-type: none"> <li>- Parents value being supported by their healthcare team and describe components of care</li> <li>- Predictors of parent satisfaction include: provision of compassionate care, physicians taking time to talk to parents, and help with emotional coping</li> <li>- Parents value clinicians listening to them, incorporating their perspectives in decision-making, and supporting choices (continuing pregnancy with life-limiting condition)</li> <li>- Bereavement support available to help parents cope which is highly valued – includes navigating anticipatory grief after infant is born</li> </ul>	60%
Yam et al. <sup>28</sup> (2001) <i>China</i>	Qualitative description, content analysis: Interviews	10 healthcare practitioners	To explore experiences of neonatal nurses caring for dying infants, their perceptions on palliative care and factors influencing care	<ul style="list-style-type: none"> <li>- 8 categories: (1) Disbelieving; (2) Ambivalence and helplessness; (3) Protecting emotional self; (4) Providing optimal physical care to infant; (5) Providing emotional support to family; (6) Expressing empathy; (7) Lack of knowledge and counseling skills; and, (8) Conflicting values in care</li> <li>- Need for professional development in palliative care nursing education</li> <li>- Implementation of bereavement support team may support practice improvements</li> <li>- Small changes can make a big difference: flexible visiting hours, multipurpose rooms for family members, private room for family privacy and religious activities</li> </ul>	100%

2.6.2 Table 2: Mixed Methods Appraisal Tool (MMAT)

	<b>Paper</b>	<b>1.1</b>	<b>1.2</b>	<b>1.3</b>	<b>1.4</b>	<b>1.5</b>	<b>Total Score</b>
1	Abdel Razeq et al 2018	Y	Y	Y	Y	Y	100%
2	Abdel Razeq et al 2021	Y	Y	Y	Y	Y	100%
3	Abraham et al 2017	Y	Y	Y	Y	Y	100%
4	Akard et al 2018	Y	Y	Y	Y	Y	100%
5	Alexander 2001	Y	-	Y	Y	Y	80%
6	Armentrout et al 2007	Y	Y	Y	Y	Y	100%
7	Armentrout et al 2009	Y	Y	Y	Y	Y	100%
8	Armentrout et al 2011	-	-	Y	-	-	20%
9	Baughcum et al 2017	Y	Y	Y	Y	Y	100%
10	Baughcum et al 2020	Y	Y	Y	Y	Y	100%
11	Blood et al 2014	Y	-	Y	-	Y	60%
12	Bourque et al 2020	Y	Y	Y	Y	-	80%
13	Caeymaex et al 2013	Y	Y	Y	Y	Y	100%
14	Calhoun 1994	Y	-	Y	-	Y	60%
15	Clark et al 2021	Y	Y	Y	Y	Y	100%
16	Clarke et al 2011	Y	-	Y	-	Y	60%
17	Cortezzo et al 2015	Y	-	Y	-	Y	60%
18	Cuisinier et al 1996	Y	Y	Y	-	-	60%
19	Currie et al 2019	Y	Y	Y	Y	Y	100%
20	Currie et al 2016	Y	Y	Y	Y	Y	100%
21	Fortney et al 2020	Y	Y	Y	Y	Y	100%
22	Gilmour et al 2017	Y	Y	Y	-	-	60%
23	Harrigan et al 1993	Y	-	Y	-	Y	60%
24	Keim et al 2017	Y	Y	Y	Y	Y	100%
25	Kochen et al 2021	Y	-	Y	Y	Y	80%
26	Kymre et al 2013	Y	Y	Y	Y	Y	100%
27	Leitao et al 2021	Y	-	Y	-	Y	60%
28	Levick et al 2017	Y	-	Y	-	Y	60%
29	Lizotte et al 2020	Y	Y	Y	Y	-	80%
30	McHaffie 2001	Y	Y	Y	Y	Y	100%
31	McHaffie et al 2001	Y	Y	Y	Y	Y	100%
32	McHaffie et al 2001	Y	Y	Y	Y	Y	100%
33	McHaffie et al 2001	Y	Y	Y	Y	Y	100%
34	Oreg 2020	Y	Y	Y	Y	Y	100%
35	Pector 2004	Y	-	-	-	Y	40%
36	Rosenbaum et al 2015	Y	Y	-	N	N	40%
37	Rosenbaum et al 2011	-	-	Y	-	-	20%
38	Shultz et al 2017	-	-	Y	Y	Y	60%
39	Skene 1999	Y	Y	Y	Y	Y	100%
40	Swanson et al 2009	Y	-	Y	Y	Y	80%
41	Swanson et al 2002	Y	Y	Y	Y	-	80%
42	Thornton et al 2021	Y	Y	Y	Y	Y	100%
43	Thornton et al 2020	Y	Y	Y	Y	Y	100%
44	Welborn 2012	Y	Y	Y	Y	Y	100%
45	Williams et al 2009	Y	Y	Y	Y	Y	100%
46	Wool et al 2018	Y	-	Y	-	Y	60%
47	Yam et al 2001	Y	Y	Y	Y	Y	100%

1.1. Is the qualitative approach appropriate to answer the research question?

1.2. Are the qualitative data collection methods adequate to address the research question?

1.3. Are the findings adequately derived from the data?

1.4. Is the interpretation of results sufficiently substantiated by data?

1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

Y = yes  
- = no

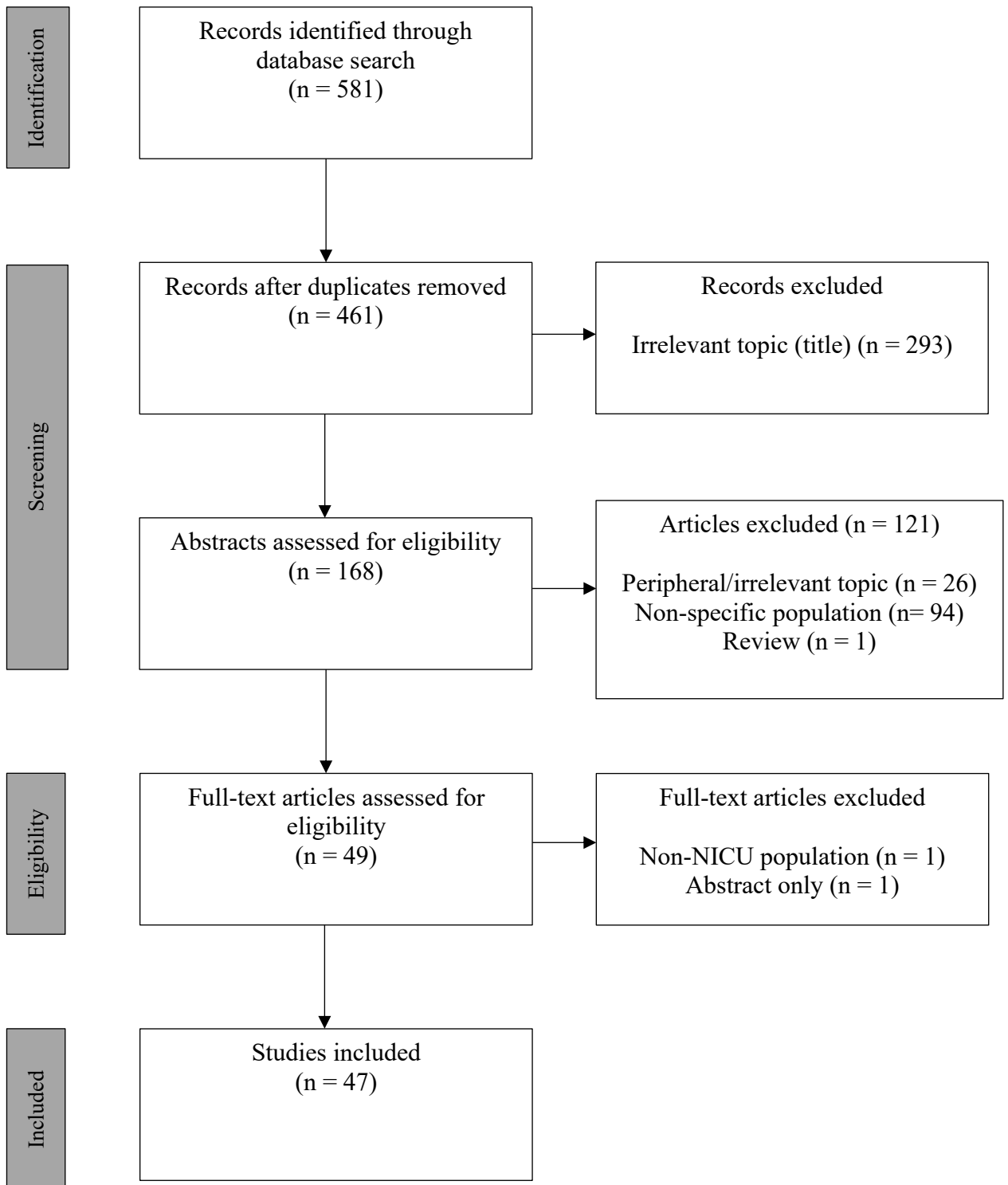


2.6.3 Table 3: Primary and Secondary Themes

<p><b><i>Parents may experience a manifold of different emotions anticipating and following the death of their child</i></b></p> <ol style="list-style-type: none"> <li>1. Grief as an emotion and as a constellation of emotions</li> <li>2. Evolution of grief and bereavement</li> <li>3. Individualizing bereavement care</li> </ol>
<p><b><i>Parents may live with a cascade of different losses, including the loss of their child, shaping their bereavement</i></b></p> <ol style="list-style-type: none"> <li>4. Complexity of loss and losses</li> <li>5. Parental presence and involvement in care</li> <li>6. Meaning and memory-making</li> </ol>
<p><b><i>Parents live with their perspective of the care their child and they received through their NICU journey</i></b></p> <ol style="list-style-type: none"> <li>7. Perceptions of pain and suffering</li> <li>8. Supportive communication</li> <li>9. Care at the end-of-life</li> </ol>
<p><b><i>Parents may benefit from a variety of different supports in anticipation of bereavement</i></b></p> <ol style="list-style-type: none"> <li>10. Spiritual/religious support</li> <li>11. Pediatric Palliative care and bereavement services</li> <li>12. NICU team support</li> </ol>
<p><b><i>Parents live with their decisions in bereavement; with time, they may question, re-evaluate, or come-to-terms with the decisions they made decision-making</i></b></p> <ol style="list-style-type: none"> <li>13. Individualizing involvement in shared decision-making</li> <li>14. Autopsy</li> </ol>
<p><b><i>Parental bereavement benefits from support beyond the NICU</i></b></p> <ol style="list-style-type: none"> <li>15. Physical and mental health outcomes</li> <li>16. Bereavement follow-up</li> <li>17. Future pregnancies/children</li> </ol>
<p><b><i>Understandings are needed for unique NICU bereavement experiences</i></b></p> <ol style="list-style-type: none"> <li>18. Loss of single twin</li> <li>19. Breastmilk production after loss</li> </ol>

## 2.7 Figures

2.7.1 Figure 1: Article Selection Flow Diagram



### **III. Chapter 3: Exploring and supporting parents' stories of loss in the NICU: a narrative study**

#### **3.1 Introduction**

With the high acuity seen in neonatal intensive care units (NICUs), death is an inevitable phenomenon. Most of these deaths occur following a decision to withhold or withdraw life-sustaining medical interventions, which differs from the general pediatric population where death more often occurs despite escalating intensive care.<sup>2,3</sup> With advancements in healthcare technologies, the survival of extremely premature infants or those with significant medical and/or surgical issues is improving; therefore, quality-of-life considerations are moving to the forefront.<sup>4</sup> These complexities create significant challenges in decision-making as the burden of hospitalization or permanent medical issues may be perceived as less favorable relative to intensive care's anticipated benefits.<sup>3</sup>

Using a shared decision-making model is the gold-standard for approaching medical intervention, end-of-life, and other consequential discussions.<sup>59</sup> There are, however, various difficulties that healthcare practitioners face when engaging in conversations surrounding goals of care such as diagnostic uncertainty, prognostic ambiguity, and differing sociocultural beliefs of parents and practitioners.<sup>60</sup> The most appropriate manner to deliver information in an unbiased manner with well-defined choices based on possible outcomes remains unclear.<sup>6</sup>

People seem to think about the value of preterm infants lives differently compared to those born at term, independent of predicted survival and developmental outcomes.<sup>61</sup> For instance, preterm infants are more likely to receive in-hospital cardiopulmonary resuscitation shortly before death compared to mature infants, despite having a higher-associated mortality, and psychosocial

factors within the healthcare team may contribute to this finding.<sup>62</sup> These nuances in care perspectives and practices can add to the complexities of end-of-life decision-making in the NICU.<sup>62</sup> Although national guidelines exist for decision-making, physicians are often unaware of how to implement them into practice, and personal opinions may differ.<sup>59</sup>

The perspectives of parents who ultimately chose palliative goals of care are relatively absent from the NICU literature. Supporting parental bereavement is an essential aspect of holistic NICU care, yet understanding how to assist parents to reach their goals and support their bereavement is incomplete. The heavy burden of infant loss and the impact of healthcare provider support has been well-described, whether it be through shared decision-making approaches, memory-making strategies, or intricate communication techniques.<sup>14-16</sup> In a recent systematic review exploring strategies for healthcare practitioners to support parental bereavement, the ability of parents to spend time caring for their child, their perception of infant suffering, their communication experiences with healthcare providers, and their access to alternative means of support such as palliative and spiritual care appeared to be suboptimal.<sup>63</sup> In the included literature, parents described inconsistently being supported to hold their child, to participate in their daily care as parents, and to share their thoughts and ideas with the healthcare team. These omissions may lead to additional felt losses compounding their grief and bereavement.

Involving parents in each aspect of caring for a critically ill infant is essential and can be enhanced through family-integrated care. This collaborative model integrates families as partners in the NICU healthcare team to effectively provide a structure that supports the implementation of family-centered care.<sup>64</sup> Family-centered care in the NICU incorporates mutual respect and shared decision-making between the healthcare team and families, ensures quality psychosocial supports, promotes resource allocation focused on family wellbeing, as well as encourages families to

directly deliver care to their infants, which can contribute to improved parent and infant outcomes related to bereavement.<sup>5</sup>

Attached to the loss or impending loss of a child is a plethora of emotions: grief, helplessness, guilt, and sadness. Parents, particularly mothers, may feel that when the focus is primarily on their child's medical management, there is no space for them to express these feelings and this can impact their developing sense of parenthood.<sup>65</sup> The importance of building rapport, providing clinical updates, maintaining communication, and supporting parents through decisions following a family-centered and shared decision-making approach is invaluable and can be considered best practice in the NICU.<sup>5,37</sup> However, goals of care discussions surrounding end-of-life and understanding how to best to support bereavement may be challenging for parents and healthcare professionals. Consequently, there is a need for research that gives voice to parental perspectives to inform the reflective practice of healthcare practitioners.

The purpose of this study was to elicit and represent NICU parents' stories of goals of care decision-making and experiences that support their bereavement. Goals of care include decisions about specific treatments, the intensity of care, and planning for future care needs. Bereavement describes parents' sense-making and living with the loss of their baby.

### **3.2 Methods**

This explorative study employed a narrative research design.<sup>66,67</sup> Narrative inquiry understands stories as meaningful representations of people's lives.<sup>68</sup> In the telling and retelling of stories, people make sense of their past in the present. Stories are paradoxically both our own and shared as they reflect both our own sense-making as well as draw on the sense-making of others. To share a narrative means to articulate truths, find meaning in common experiences, and

transform one's identity in a social context.<sup>69</sup> The reflection taking place through narrative inquiry creates a story that can be filled with meaning, allowing the creation of self-identity while examining the underlying social and cultural contexts.<sup>69</sup>

### *3.2.1 Narrative ethics*

At the core of narrative inquiry is an understanding of ethics whereby moral truths are founded and expressed in narratives.<sup>70,71</sup> A narrative is not simply a story encompassing characters and events, but rather a means of sense-making of human life, and specifically, moral life. We can understand moral sense-making by attending to how a narrator is situated within a story; a story's beginning, plot, and ending; the relationships between characters of a story; and, how a story is shared over time in the telling and retelling of a story.<sup>72,73</sup> We seem able to accept those moral situations which we can talk about as 'good' stories, not in the sense of entertaining stories, but rather moral stories that we can recount without a sense of regret, despair, or wrongdoing. For this study, the stories of NICU parents were recognized to express normative aspects of NICU care that affect their living with the loss of their child. Following, aspects of care that speak to supporting bereavement are those which can be remembered, shared, or otherwise told; in comparison, those aspects of care that challenge bereavement are those which are recounted with sorrow, distress, or cannot be spoken of.

### *3.2.2 Recruitment*

Bereaved parents, who experienced a loss in the last five years, were approached by an intermediary through the Aid for Symptoms and Serious Illness Support Team (ASSIST) Program. Exclusion criteria included a loss in the preceding six months or identified psychosocial distress.

If consent to contact was obtained, a member of the research team contacted the potential participant by telephone or e-mail (based on the participant's preference) to provide details of the study, review the study information, and obtain consent for participation as appropriate. None of the members of the research team had ongoing clinical involvement or responsibilities to the families.

### *3.2.3 Data collection*

Interviews were scheduled virtually (based on the participant's preference) to elicit the stories of parents who had lived the experience of losing a child in the NICU, recognizing that the parents' present telling of their stories reflected their bereavement. In situations where both parents agreed to participate, we offered the opportunity to conduct interviews separately or together. While the interviews were oriented to participants' stories, there were no specific initial or probing questions. Typically, the conversation started by asking participants: "Why don't you tell me about the experience you and [your baby] had in the NICU." The purpose of using an unstructured method was to ensure parents had the autonomy to share stories that were impactful to them regarding their experience with their child in the NICU. Participants were invited to share any or all aspects of the journey they had in the NICU as well as details on the pregnancy and post-NICU bereavement care. The interviews should be considered dialogic in the sense that the interviewer engaged in discussion with participants around their stories to elicit details and clarify understandings.<sup>72,73</sup> The interviewer had no previous clinical contact with the families, specifically in their clinical care during their time in the NICU. Interviews were conducted from June to October 2022. Discussions were audio-recorded and transcribed verbatim with identifying features

removed. Participants were also informed and provided consent for medical charts for their infants to be reviewed to contextualize demographic and clinical details after the interviews took place.

#### *3.2.4 Analysis and interpretation*

Participants' stories were read to explore normative aspects of their storied experiences that supported their bereavement. The stories that the parents recounted were read both holistically in the sense of the story of their child and family's life, and piecemeal as composed of fragmented stories, happenings, and anecdotes that stood out in their family's journey. Qualitative data analysis software was not utilized. A typology of stories was used to thematize the interview material, reflecting the methodological commitments of dialogical narrative analysis.<sup>72,73</sup> The analysis of the raw interview material, including the articulation of thematic aspects and selection of key quotations, was completed by Author #1 and Author #4. All listed authors contributed to the development of the narrative text. In the writing of the findings, we aimed to amplify and connect the themes from the participants' stories. We included short, anonymized quotes with the use of pseudonyms to support the reader's contextual understanding yet also preserve participants' anonymity. The quotations can be read to provide supportive evidence for the validity of themes and to help convey contextual meanings of the findings of the study to the reader. From a positionality perspective, the authors have clinical backgrounds in medicine, nursing, and ethics.

#### *3.2.5 Ethical considerations*

This study was reviewed by [the Authors' institutional] Research and Ethics Board. Before conducting interviews, participants provided consent for the study investigators to contact them



regarding participation. They were made aware that the study was to uphold confidentiality and that no identifying information would be disclosed. All participants signed an informed consent document prior to the interview after receiving verbal and written information about the study. Participants were also informed that they could stop the interview at any time or refuse to answer any questions. When each interview ended, the interviewer attempted to understand the state of mind and emotional wellbeing of each parent. Additionally, parents were advised they could contact the interviewer or study team if they had more information to share, needed psychosocial support, or if they wanted to meet again for any reason. Given the sensitive nature of the conversations and the experience these parents have had losing a baby in the NICU, there could be a degree of distress felt by the participants in the telling of their stories. By providing the option to have multiple meetings rather than a single very long meeting, the interview was paced to the participants' comfort. More so, this approach supported the participants to speak to their experiences in more comfortable pieces rather than an exhaustive whole.

### *3.2.6 Participants*

Seven parents, five mothers and two fathers, of five different infants who passed away in a Northern Alberta Canadian NICU program, participated in the study. Specifically, three mothers were interviewed on their own; while two mother/father dyads were interviewed as a couple based on their requests. This number of participants supported a depthful engagement in their storied experiences. Like others, we would argue that saturation has differing relevance across traditions of qualitative inquiry.<sup>74</sup> Specifically, for narrative inquiry, saturation has limited relevance as experiences themselves are considered rich with a manifold of lived meanings that are variably disclosed through narrative descriptions. In other words, narrative studies cannot achieve

saturation because there is always more meaning at the heart of experiences that in the telling and retelling of stories could yet be disclosed.

To provide additional context, participating parents had all experienced the loss of a child in the NICU within the preceding five years. They varied in their identified race and religion. Two families included parents that were newcomers to Canada. The duration of admission of the participants' infants in the NICU ranged from three hours to four months. In three of the cases, there was an antenatal diagnosis of a significant life-limiting condition, whereas in the other two cases, diagnoses were made or confirmed after birth. Several syndromic diagnoses were made including, but not limited to, conditions of aneuploidy. Most of the infants underwent surgical interventions with the aims of prolonging their lives. A minority of families had a plan for comfort care in place before their children's birth. All the infants passed away following a decision to withhold or withdraw life-sustaining medical interventions, such as mechanical ventilation. This demographic information is provided in narrative form to preserve the anonymity of the participants.

### **3.3 Findings**

Parents recounted stories and perspectives related to experiences with the NICU from before birth, to time in the NICU, to time after the death of their child. Narratives from parents contained many similar elements including having experienced an antenatal consultation, the use of medical interventions by the NICU team, and the loss of a child in the NICU setting. Variability, however, existed in the nature of each infant's conditions, the number of subspecialists involved in decision-making, the need for transfer to different NICUs, the duration of admission, the chronological age of their child at the time of death, and ultimately, the wishes of each family as

they redirected care to comfort and palliation. From the parents' experiences, we offer the following typology, recognizing that these normative aspects of care should not be read as thematically isolated, but rather as converging on one another.

### *3.3.1 Parents recounted stories of the time they had with their children . . .*

“At that time, we only wanted to hold her . . . to have that time.”

Parents' stories spoke to how their bereavement was supported by memories of being with their children. With relative ease, parents affectionately recounted watching over their children, holding their children, feeding their children, reading to their children, and other moments of being present for them in the NICU. Even in the context of illness, various critical care technologies, multiple healthcare practitioners, and so forth, parents' stories of togetherness were celebrated as sources of meaning. Together is from Old English *togaedere*, “so as to be present in one place, in a group, in a body.”

“We sat the chair right beside the window, so we could hold him, and they brought in his bed. They had taken out his catheter, and then we went to the room, and I could just hold him. It was around 10 pm. And it was . . . it was a beautiful day. A beautiful day outside. There were no clouds in the sky. And the sun was setting, and we were just sitting there, the three of us.”

Stories included moments facilitated, affected, or otherwise mediated by unit technologies, healthcare provider practices, and other happenings in the NICU.

“They had a camera setup so even when we were at home, we could see him. So that was a really amazing thing. I think I had that camera open the entire time that we were at home.”

“And the nurse in the evening shift. She came in. And she said, ‘Can we give him a bath?’ So, we gave him a sponge bath. And after that, I just said to her like, ‘Can I just hold him? Because I had never held him freely attached from tubes or anything.’ So we just held him, and walked around the room. And we were in there for probably about a half hour just holding him, and then put him back down on the bed.”

Parents’ living with the loss of their children was storied by having had time together: time not just in the quantitative sense of a particular amount of time, but rather time in the relational sense of having had the time to be with their child as their child’s parent, to come to know them, and for their child to know their family. In this way, parents’ stories of bereavement reflected their ability to ‘be there’ to enact their felt need to care for their child in their child’s time of need; and, their stories spoke to how the loss of their child left them with the memories they had of their time together, as they experienced their role of being a parent, as an enduring and continuing bond.

“God let me hold my baby for fourteen days . . . I can still hold him, and he can hold my hand. I see him smile at me and his daddy, and he holds our hand, like this is my mama, you know what I mean? And when he, every day I [didn’t] leave my son from the moment he [was] born until his time he passed away . . . he knows his mama always be there for him, yeah, that's it.”

In comparison, those moments of separation and disrupted togetherness were recounted with disease, discomfort, and distress. For example, parents reflected on having their baby experience an ambulance trip without having a parent present and those moments of leaving their baby in the hospital when they were discharged home from postpartum:

“So the first time he ever went outside, the first time he was ever in a vehicle, no parent was with him, and it's really hard for me to remember because he was by himself, and I don't like that.”

“It was hard definitely for when I was discharged from the hospital to leave him there and not come home with a baby in my arms.”

Regardless of whether the full diagnoses and extent of illnesses were known prior to delivery or not, parents' stories expressed the depth and varied emotions parents experienced when their child was taken to the NICU or away from them so soon after delivery. The etymology of bereavement is founded from the Old English *bereafian*, “to deprive of, take away by violence, seize, rob.” Following, stories of separation may be understood to have anticipated bereavement. In other words, at a time when parents were still fostering connections to their children, separation anticipated their longer term living with loss as bereavement.

### *3.3.2 Parents shared stories of the healthcare practitioners doing what they could and should do for their children . . .*

Each parent wanted to know that the practitioners were doing what they could do and all that was going on with their child, to ensure that everything was being done and that nothing was

being hidden. In this way, parents' stories expressed the impact that healthcare practitioners had on their child's NICU journey prior to their loss, and the effects these relationships had on their bereavement. Generally, parents fondly recounted the conversations they had with members of the healthcare team and the relationships that were built over their time in the NICU. Although there were distinctions, nuances, and other individual aspects of valued communication, all parents shared stories appreciated timely and honest communication supporting confidence and trust in the healthcare team.

“The communication piece [with hospital staff], I would say through it all, was definitely above and beyond than what we would ever expect.”

“And whatever questions I had they gave me the answers. And they made me feel that they were taking care of him the best that they could.”

Tailoring care to each family's beliefs of what was in their child's interests based on their individual, family, and cultural background was something that parents described as invaluable. However, their stories also reflected how consideration needed to be given to varied understandings of their beliefs that may or may not align with healthcare practitioners' interpretations of them:

“I [had] a proper Muslim doctor tell me to take off oxygen from my son, because it doesn't help him . . . [that] he will not survive. But in my beliefs, doctors come to save people, they don't try to give up [on] the patient's life . . . but this doctor, [a] proper Muslim doctor tells me, even [he] tells me, he wants to bring my Imam.”

Practitioners doing what they should do is related to notions of confidence and trust. While the etymologies of confidence and trust intersect, distinctions can be made. Confidence is based on evidential skills, knowledge, and qualifications. In comparison, trust has a normative quality, which may or may not be based in perceptions of skillfulness, reflecting how we feel towards the moral character of another. Following, not only did parents positively recount doctors, nurses, and other healthcare practitioners' expertise, but also that they appropriately acted in the interests of their child. More so, parents felt like they were part of the medical team, and that their opinions were acknowledged and valued. Parents' stories recognized that they knew their child in a different, and arguably better, way than the healthcare team – allowing parents to feel they could and should contribute to the care of their children. Moments, whereby parents were less engaged in both extraordinary and everyday moments of care, were recounted as missed opportunities, at times with regret and sorrow.

“I think I had only held him on one occasion before he passed away . . . Or they let us and gave us the opportunity to help like change his diaper, even though he had a colostomy bag and catheter anyways . . . We did have those options, but I wish it would have been more, offered to us again and again.”

Although the medical interventions undertaken in support of a child's condition were not always successful, parents' stories highlighted how having done all that could and should be done supported parents' living with their end-of-life decisions. In addition, the storied accounts of the medical team's exhaustive efforts, not to change the outcome or alter the prognosis for their child, but to ensure each infant was comfortable and supported were valued.

### 3.3.3 Parents told stories of living with uncertainty, ambiguity, and indecision. . .

Uncertainty is an inherent challenge of prognostication in the NICU, and parents' stories reflected this difficulty when receiving information about their children's diagnoses and prognoses and facing subsequent decision-making. Nothing in medicine is ever one hundred percent certain, and this not only troubles the healthcare team as they attempt to support parents' decision-making on how to proceed, but it can also cause a significant mental burden for families as they attempt to make decisions that will impact the fate of their child's life.

“It would have been [nice] to know the prognosis like way in advance and know what we're looking at. Because it was like, it was frustrating and it was hard like emotionally and physically, everything, just not knowing what's going on. Right? And people want to reach out, they want to ask, we just didn't know anything, right?”

Parents recounted with sensitivity and, at times, difficulty, stories of receiving unexpected news that contributed to further ambiguity of their child's condition. The etymology of ambiguity is from Old French *ambiguite*, encompassing aspects of doubt, indecision, and hesitation. An ambiguous situation is open to varied interpretations in its equivocality. While uncertainty was resolved in time for some of the parents, for others, bereavement encompassed living with unresolved ambiguity. This was difficult and burdensome for families.

“I remember like when they brought him back and then we're like, oh his lungs looked irregular like, he knew like something else was not good . . . there's something else that's going on . . . to us he looked like perfect . . . And then the condition that he was diagnosed with is super rare.”



Stories of uncommon, undifferentiated, or unknown diagnoses wore on families as they lacked an ending. And yet, even in the face of uncertainty and ambiguity, some parents reflected on specific events or even just a moment when they realized that it was time to change the course of their infant's care and accept palliation as an appropriate next step.

“They actually said to us that he is not strong enough to have that surgery. And when we heard that we said, we just thought, okay, well, the decision that we can make for him is to let him be in peace as compared to continuing to suffer in the hospital like he is.”

Parents reflected on the difficulty in making this decision; most did not seem to regret their choice, but some continued to question, in recounting their stories, what would have happened if they had one or two different choices along their journey.

“I think there's always going to be that what if question of, what if we decided to not put them in comfort care? Obviously, he would still be here living with [his] syndrome. But like, how sick would he be? Would he be okay? Would he need specific medication? What would have his potential life expectancy be?”

### *3.3.4 Parents shared stories that expressed values of caring . . .*

Parents' stories spoke of the difficult and emotional moments they experienced in the NICU. These onerous moments were at times alleviated by, or at least eased by, the caring actions of the healthcare team. Specific bedside nurses stood out as key characters in the parents' stories who were supportive in both day-to-day care and those exceptional events in their children's lives. Virtues of honesty, compassion, trust, resourcefulness, and patience were recognized in the skillful manner that these healthcare practitioners worked with them.

“Nadine was definitely a rock that day. Whatever we needed she was there.”

“Stephanie literally thought of everything that we didn’t. She had all his stuff packed, like she helped organize, she helped just get everybody just be there and fill in everything that we needed. They moved a couch for us at one point.”

Parents’ stories emphasized how the close relationships that were built over time in the NICU created an outlet of support within the medical team. Being able to release the mental and emotional burden to someone you trust is something that was storied as highly valuable to parents. Familiar personnel that understood not only their child’s medical history, but also their family’s circumstances, their wishes for their child, and their coping abilities were fondly described by several parents through their stories. For example, one family spoke highly of the primary care team that they chose for the infant and the role this had in supporting them through the difficult moments in their child’s course:

“[The neonatologist] understood it was important to us to have him actually physically talk, instead of getting it third party . . . so he made times on weekends to meet us up at the [hospital] or calls at night . . . and that made everything better.”

Of all the encounters parents reflected on through their stories, receiving direct, open, and honest updates expressed through care about their children’s clinical status and prognosis often helped parents cope with the news they were receiving and eased the mental burden of decision-making. Parents’ stories spoke to the value of candid and timely conversations that necessitated a caring relationship of trust.

“Hearing that as a parent, it’s very, very hard. But we also put our complete trust into the doctors and the nurses and the people who are caring for him to do the best that they can do.”

### *3.3.5 Parents talked about what their child’s life was like . . .*

Regardless of the number of days, hours, or minutes spent with their child, parents described the significance of their child’s life and the experiences their children were afforded before their death. While the time had with their children was highly valued, parents’ stories expressed the tension between affording time together and potentially prolonging pain, suffering, or discomfort.

“I would go to touch his head, and he would kind of like, I don't know what the word is, but make a face that that wasn't comfortable for him. It was painful.”

“. . . as we got like further along and I remember like towards the end he was so swollen and just looked like sick and uncomfortable.”

“. . . is that like humane? . . . [to] sedate him so much? So he doesn't pull out his tube, and then tie him – like have him restrained.”

The events leading up to the redirection of care towards palliation, withdrawal of life-sustaining medical interventions, and the resulting final moments of their children’s lives were often recounted in great detail, illustrating the impact these events have had on parents over time. Perceptions of suffering often lead to a change of heart and shifting treatment goals towards comfort care.

“And then, so Jeff and I came home and talked. We spent all day Thursday up there going through everything. And then we came home again and decided that . . . ‘We can’t see him suffer anymore.’”

“They had asked us if we wanted to wait . . . but Aliyah was just, at that point, suffering, and you could see it.”

Parents’ stories illustrated the difficulty in deciding to redirect the care of their infant as one of the toughest decisions they have had to make in their lives; however, seeing their child at peace after their final moments validated these decisions and provided them with comfort.

“Yeah. And I think the one thing that helped us – well I guess not helped us, but kind of just reassured [us] was time, was that he didn’t last long without the breathing tube.”

“I think like, she wasn't kind of like gasping for air . . . so she looked at peace.”

### *3.3.6 Parents shared stories of living with loss . . .*

Often healthcare practitioners do not have a chance, or fail to think about, the moments just after a baby passes away in the NICU; however, through parents’ stories, it is clear that these times are some of the most challenging for parents as they come to the realization that they will be leaving the hospital without their baby. The time spent in the NICU working towards comforting and supporting their child is no longer part of their daily life – their world as they know it will be entirely different from that point forward.

“After she had passed away, I didn’t know what was next. I have no idea like what happens now. And she was given to me. She stayed with us in the room. Like she was kind of like put in kind of like a cold crib. And then like, I was like, my husband was saying like ‘I’m arranging for burial.’ And I was like what do we do? Do we just go out? Do we just – I don’t know.”

It is more than knowing the next steps of identifying a funeral home, planning a service, and so forth. Families’ stories expressed the lasting impressions they were left with of their children and the care they received.

“There’s one thing that I regret. And that’s when I was leaving, I just took one more glance into the room. And it’s a very weird being and seeing situation, where for the past three weeks, your son is in a room and he’s got these tubes, he’s got these monitors, he’s got everything and everyone that’s looking after him. There’s always somebody in the room watching him. And then when you leave, he’s the only one in the room. There are no monitors on, he’s sleeping in his bed, and that’s all you see. And that’s one memory that I wish I didn’t have to experience. It’s really painful to think back to.”

Parents’ stories shared the various emotions that arise when living with loss over the coming days, weeks, months, and years including sadness, emptiness, guilt, grief, regret, uncertainty, and, in some cases, acceptance. Parents describe these emotions as connected, interspersed, and ongoing.

“And like, but I think I knew that deep down but it's still I still like will go back and forth and be like, you know what, I wish I could have . . . And that's just how I am in my daily life.”

Finding appropriate support, from both personal contacts and health practitioners, was described through parents' stories as being appreciated and helpful in not necessarily overcoming their loss, but learning to live with it. Through follow-up with the hospital team, having a chance to ask questions and seeking support from a bereavement counsellor long-term, parents' stories spoke of the ability to process grief and learn to live with it individually as well as within the context of their relationships with one another.

“[The bereavement counsellor] helps a lot with like the milestones. So, like when we reached [his] first birthday, the anniversary of his passing, and like going through the holidays and that . . . ”

“What was really better for us was bereavement counseling that was offered to us through the [hospital]. Because she helped us understand the way that each other was grieving.”

Regardless of the duration of their children's lives, parents' stories spoke to how their bereavement, both in the short and long-term, has been supported by tangible memories they could keep, display, or share with loved ones. With positivity and happiness, parents' stories expressed their love for their children while describing or presenting these mementos as a chance to share their quality time with their infants through long-lasting physical objects. These objects and the memories they sparked were recounted as continuously cherished by families.

“They brought us a little memory box, with his prints in it, the card with his name on it, his wristbands, he had a comb, his nose apparatus, breathing things, just like the personal things that they could put into the box for him . . . it was hard, definitely. But they personalized it . . . and that was really special.”

### **3.4 Discussion**

This study sought to explore NICU parents’ stories of goals of care decision-making and experiences that helped support their bereavement. Through interviewing a diverse group of parents who have gone through such an experience in a Northern Alberta Canadian NICU, we were able to identify areas of ‘value’ (moral sense-making). We learned how their stories reflected on the importance of having meaningful time with their children, maintaining direct and frequent communication with the healthcare team, acknowledging uncertainty, and emphasizing the positive impact of compassion as helpful to navigate their bereavement. The storied experiences described by parents provide unique insights for healthcare practitioners in supporting bereavement in the NICU as individualizing support is an essential component to family-centered care.

The stories told by bereaved parents and the unique experiences they had in the NICU parallel the values and recommendations of bereavement care seen in the neonatal literature, thus unveiling similar strengths and weaknesses in neonatal bereavement care.<sup>63</sup> For example, parents’ stories emphasized the importance of participating in their child’s care, whether it be changing diapers or assisting with feeds, as well as the opportunities they had to hold their infant and create an emotional connection. This correlates with several studies where early involvement in care and taking on the parenting role is an essential method of support for parents of critically ill

children.<sup>4,14,15,34,35</sup> Recognizing that early physical bonding experiences can have formative impacts on parents as they navigate the uncertainty of their infant's prognosis, healthcare practitioners should attempt to support early experiences such as skin-to-skin, hand holds, and other physical contact whenever safe and appropriate to do so to limit early physical separation and the associated burdens. Similarly, the appreciation parents felt for photographs and tangible mementos to maintain their child's legacy is one that has been well-described.<sup>30-33,36</sup> Parents' stories alluded to how the care they received in the NICU contributed to sense-making in the time following the death of their infants, and some explicitly described the importance of tangible items in assisting that healing process. Being able to make sense of the experienced loss can help parents navigate grief and move towards acceptance.<sup>75</sup>

Bereavement is a long-term process that involves optimizing communication, promoting shared decision-making, and individualizing care to help parents grieve, find closure, and move toward acceptance after loss.<sup>16,30,33,51</sup> The stories told by parents did elicit some unexpected discrepancies in methods of support that have been previously identified in the literature. For example, while the benefits of cultural relatability and alignment have long been well-described;<sup>13,15,23</sup> it is important to consider individual understandings and interpretations of cultured values and beliefs, which may not have such a positive impact. Although a religious or cultural similarity may exist between a family and members of the healthcare team, priorities and values regarding patient care may not be aligned and this can cause additional stress and turmoil for parents. These discrepancies help emphasize the importance of individualizing bereavement care to each family and their sociocultural circumstances.

Though individualizing care is an essential component to providing effective bereavement care, parents' stories wholly illustrated the impact healthcare providers had on their bereavement



in the short and long-term. There are several supportive measures, as seen in the literature, that healthcare practitioners *should* provide that help support families – frequent communication with the healthcare team, encouraging parents to participate in daily rounds, involving ancillary services, and supporting parents to spend quality time with their infants.<sup>5,16,30,33,51</sup> This study illustrated additional ways healthcare practitioners *could* enhance family-centered care and provide parents with other realms of support in their bereavement. Some techniques gathered through parent stories contribute new understandings to the existing literature on neonatal bereavement support and these include offering additional points of contact to discuss medical updates and decisions, appointing a primary care team to take the lead in their child’s care, and providing guidance on steps to take in the immediate moments after death. These added supportive measures, not as prominently seen in the existing literature but seen as highly valued as recounted through parents’ stories noticeably illustrate the variety of ways healthcare practitioners can contribute to not only the care of a critically ill child, but also assist in the support of their families as they navigate their grief and bereavement during, and after their loss. These themes found through parents’ stories can ultimately be used to further develop healthcare providers’ reflective practice and training techniques for healthcare professionals to help optimize bereavement support and communication in the NICU.

Limitations of this study relate to the number and diversity of parents interviewed from a single institution. All the participants had a partner to share these experiences with. Some stories recounted the comfort and support that their significant other provided both during the critical decision-making period as well as during their bereavement. Future work should consider the experiences of single parents, parents affected by poverty, siblings and extended family, Indigenous families, and other groups that have traditionally not been engaged in empirical

qualitative NICU research studies. The small number of participants from a single geographical area may limit the generalizability of the gathered stories; however, the ability to obtain in-depth reflections from the participants elicited important insights and unique contributions to the current literature.

From exploring bereaved parents' stories, we are offered understanding into aspects of NICU care that may support their bereavement. Supporting parents to have meaningful time together with their children, orienting care towards what we can do for a child, acknowledging and dealing with uncertainty as able, focusing on values of caring, and fore-fronting what a child's life is like may ultimately support parent's living with the loss of their infant. At the same time, we may recognize bereavement as "an ever-open wound".<sup>76</sup> Care for these families does not end with discharge from the NICU. Instead, they have ongoing needs that may benefit from coping strategies and work towards acceptance as opposed to dissolving the emotions surrounding grief and loss.

## **IV. Chapter 4: Conclusion and Future Directions**

### **4.1 Common and divergent themes from systematic review and narrative study**

Existing neonatal literature on supporting parental bereavement, seen through the systematic review, gives insight into the variety of ways in which healthcare practitioners can attempt to ease the immense burden parents face when losing a child in the NICU. This review clearly and consistently describes some of the effective methods including supporting parents to spend time caring for their child, understanding their perception of infant suffering, and optimizing their communication experiences with healthcare practitioners with frequent and direct contact. This, in addition to offering ancillary supports including palliative and spiritual care and longer-term bereavement support, can help optimize the care families receive during such a challenging time in their lives.

Narrative inquiry provides unique perspectives and has the potential to provide essential insight and additional information from the existing literature. Eliciting parents' stories has helped develop further understanding on what strategies in end-of-life and bereavement care are valued by parents including specific planning focused on a child's final moments and using a primary care team to optimize the individualization of care and strengthen communication.

The perspectives described through parents' stories paralleled the reviewed literature and contradictions were few and far between. There was higher cultural variability seen through parents' stories allowing the contribution of diverse perspectives of religious and faith backgrounds compared to that seen in the existing literature. This diversity provided additional insight on how care was perceived in the context of familial sociocultural beliefs and the impact it can have on family-integrated care, shared decision-making, and psychosocial support.

The depth of information gathered from the telling of stories provides invaluable insight, not only into the events surrounding each child's end-of-life as recounted by parents, but also illustrates the impact of time and reflection on processing grief – a feature that is not as easily illustrated on review of the existing literature. In this way, the narrative inquiry study ultimately enriches understanding of the findings of the systematic review with respect to meaning and meaningfulness with respect to loss and bereavement.

#### **4.2 Considerations for practice**

Death is a not an infrequent occurrence in the NICU, yet the difficulties that exist in supporting families through the associated decision-making, uncertainty, and bereavement continue to be a challenge for healthcare practitioners. Through conducting the systematic review identifying what considerations ought to guide the caregiving practices of healthcare practitioners as well as leading interviews with parents who have had their own firsthand experiences with loss, several methods have been described as valuable in enhancing bereavement support. These findings have the potential to change how we, as healthcare practitioners, support families as they navigate bereavement after infant loss. Prioritizing family-centred care through constant communication, shared decision-making and understanding parents' individual values and wishes is highly recommended.

Understanding the commonly identified aspects of care valued by parents is an essential step in to optimizing and developing strategies to providing the most effective bereavement care to these patients and families. Although specific themes have been identified through the systematic review and the narrative inquiry study, arguably the most important approach is to

individualize bereavement care to each family through learning their hopes, goals, wishes and beliefs.

### **4.3 Strengths and limitations**

Identifying common themes and value areas of end-of-life care and bereavement support through the several articles seen in the systematic review of the recent neonatal literature provides solid guidance for the future bereavement care that can be delivered by healthcare practitioners in the NICU. These identified methods of support are strengthened by the paralleled descriptions of parents' stories seen in the narrative inquiry study. The ability to obtain first-hand experiences provides invaluable understanding as these stories provide descriptions of nuanced and personal experiences, illustrating the importance of individualizing care that parallels the general themes seen through the reviewed literature.

Limitations to this research includes the subjectivity that can arise through conducting qualitative research. The use of small sample sizes, seen in the existing literature as well as the number of participants in the narrative inquiry study can limit the generalizability of the findings. Research in neonatal bereavement care is a specialized area that has an inherent tendency to focus on a specific demographic - predominantly well-educated, married, Caucasian Canadian families - as seen in both the articles selected for the systematic review as well as through some participants of the narrative inquiry study. The glimpse of diversity seen through the parent interviews briefly introduced the impact of geographic and cultural differences, a consideration that can significantly contribute to optimizing and individualizing bereavement care and guide future research endeavours.

#### **4.4 Recommendations for future research**

Future research investigating differing perspectives that exist because of sociocultural diversity is one of great importance. Specifically, beginning to understand the diverse values and beliefs that may guide care of various Indigenous populations is an area that may bring new insight and strategy into neonatal bereavement care, particularly in Canada. Additionally, investigating the differences in care priorities based on marital status, geographic background and educational variability could have great implications as this diversity is not well described in the current literature. The added insight of pursuing future research in these areas can have great implications on contributing to optimal family-centred care through prioritizing individual family values, cultural beliefs, and psychosocial circumstances.

#### **4.5 Considerations for education**

The insights into providing high-quality bereavement care to families in the NICU can help establish tools that can be utilized in, not only assisting healthcare practitioners supporting families through the loss of an infant, but also to incorporate the aspects of providing this care into training programs for healthcare practitioners. With a future research focus on individualizing care, understanding the role of sociocultural diversity on bereavement care needs, as well as understanding the comfort levels, barriers, and hesitations of healthcare practitioners in providing neonatal bereavement care, there will be immense potential in establishing support for future practice through consistent training and guideline implementation, while simultaneously promoting individualized family-integrated care. Ideally, using current and future research initiatives to create a set of tools to guide bereavement support would give practitioners a higher

level of comfort, experience, and assistance in navigating the nuances and difficulties of providing neonatal bereavement care in the NICU.

## References

1. Eshete A, Abiy S. When Do Newborns Die? Timing and Cause-Specific Neonatal Death in Neonatal Intensive Care Unit at Referral Hospital in Gedeo Zone: A Prospective Cohort Study. *Int J Pediatr*. 2020; 8707652. Published 2020 Feb 15. [doi:10.1155/2020/8707652](https://doi.org/10.1155/2020/8707652)
2. Richards CA, Starks H, O'Connor MR, Bourget E, Hays RM, Doorenbos AZ. Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care. *Am J Hosp Palliat Care*. 2018;35(4):669-676. [doi:10.1177/1049909117734843](https://doi.org/10.1177/1049909117734843)
3. Verhagen AA, Janvier A, Leuthner SR, et al. Categorizing neonatal deaths: a cross-cultural study in the United States, Canada, and The Netherlands. *J Pediatr*. 2010;156(1):33-37. [doi:10.1016/j.jpeds.2009.07.019](https://doi.org/10.1016/j.jpeds.2009.07.019)
4. Currie ER, Christian BJ, Hinds PS, et al. Parent Perspectives of Neonatal Intensive Care at the End-of-Life. *J Pediatr Nurs*. 2016;31(5):478-489. [doi:10.1016/j.pedn.2016.03.023](https://doi.org/10.1016/j.pedn.2016.03.023)
5. Sigurdson K, Profit J, Dhurjati R, et al. Former NICU Families Describe Gaps in Family-Centered Care. *Qual Health Res*. 2020;30(12):1861-1875. [doi: 10.1177/1049732320932897](https://doi.org/10.1177/1049732320932897)
6. Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Semin Perinatol*. 2014;38(1):38-46. [doi: 10.1053/j.semperi.2013.07.007](https://doi.org/10.1053/j.semperi.2013.07.007)
7. Wool C, Catlin A. Perinatal bereavement and palliative care offered throughout the healthcare system. *Ann Palliat Med*. 2019;8(Suppl 1):S22-S29. [doi:10.21037/apm.2018.11.03](https://doi.org/10.21037/apm.2018.11.03)
8. Thornton R, Nicholson P, Harms L. Scoping Review of Memory Making in Bereavement Care for Parents After the Death of a Newborn. *J Obstet Gynecol Neonatal Nurs*. 2019;48(3):351-360. [doi:10.1016/j.jogn.2019.02.001](https://doi.org/10.1016/j.jogn.2019.02.001)
9. McHaffie HE. Withdrawing treatment from infants: key elements in the support of families. *J Neonatal Nurs*. 2001;7(3):85-89
10. Wool C, Kain VJ, Mendes J, Carter BS. Quality predictors of parental satisfaction after birth of infants with life-limiting conditions. *Acta Paediatr*. 2018;107(2):276-282. [doi:10.1111/apa.13980](https://doi.org/10.1111/apa.13980)



11. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health*. 2010;33(1):77-84. [doi:10.1002/nur.20362](https://doi.org/10.1002/nur.20362)
12. Hong QN, Gonzalez-Reyes A, Pluye P. Improving the usefulness of a tool for appraising the quality of qualitative, quantitative and mixed methods studies, the Mixed Methods Appraisal Tool (MMAT). *J Eval Clin Pract*. 2018;24(3):459-467. [doi:10.1111/jep.12884](https://doi.org/10.1111/jep.12884)
13. Abdel Razeq NM, Al-Gamal E. Maternal Bereavement: Mothers' Lived Experience of Losing a Newborn Infant in Jordan. *J Hosp Palliat Nurs*. 2018;20(2):137-145. [doi:10.1097/NJH.0000000000000417](https://doi.org/10.1097/NJH.0000000000000417)
14. Abraham A, Hendriks MJ. "You Can Only Give Warmth to Your Baby When It's Too Late": Parents' Bonding With Their Extremely Preterm and Dying Child. *Qual Health Res*. 2017;27(14):2100-2115. [doi:10.1177/1049732317721476](https://doi.org/10.1177/1049732317721476)
15. Armentrout D. Living with grief following removal of infant life support: parents' perspectives. *Crit Care Nurs Clin North Am*. 2009;21(2):253-265. [doi:10.1016/j.ccell.2009.01.003](https://doi.org/10.1016/j.ccell.2009.01.003)
16. Currie ER, Christian BJ, Hinds PS, et al. Life after loss: Parent bereavement and coping experiences after infant death in the neonatal intensive care unit. *Death Stud*. 2019;43(5):333-342. [doi:10.1080/07481187.2018.1474285](https://doi.org/10.1080/07481187.2018.1474285)
17. Fortney CA, Baughcum AE, Moscato EL, Winning AM, Keim MC, Gerhardt CA. Bereaved Parents' Perceptions of Infant Suffering in the NICU. *J Pain Symptom Manage*. 2020;59(5):1001-1008. [doi:10.1016/j.jpainsymman.2019.12.007](https://doi.org/10.1016/j.jpainsymman.2019.12.007)
18. Williams C, Cairnie J, Fines V, et al. Construction of a parent-derived questionnaire to measure end-of-life care after withdrawal of life-sustaining treatment in the neonatal intensive care unit. *Pediatrics*. 2009;123(1):e87-e95. [doi:10.1542/peds.2007-2950](https://doi.org/10.1542/peds.2007-2950)
19. Abdel Razeq NM, Al-Gamal E. Informing mothers of neonatal death and the need for family-centered bereavement care: A phenomenological qualitative study. *J Spec Pediatr Nurs*. 2021;26(2):e12328. [doi:10.1111/jspn.12328](https://doi.org/10.1111/jspn.12328)
20. Calhoun LK. Parents' perceptions of nursing support following neonatal loss. *J Perinat Neonatal Nurs*. 1994;8(2):57-66. [doi:10.1097/00005237-199409000-00010](https://doi.org/10.1097/00005237-199409000-00010)
21. Harrigan R, Naber MM, Jensen KA, Tse A, Perez D. Perinatal grief: response to the loss of an infant. *Neonatal Netw*. 1993;12(5):25-31.

22. Keim MC, Fortney CA, Shultz EL, Winning A, Gerhardt CA, Baughcum A. Parent Distress and the Decision to Have Another Child After an Infant's Death in the NICU. *J Obstet Gynecol Neonatal Nurs*. 2017;46(3):446-455. [doi:10.1016/j.jogn.2017.01.009](https://doi.org/10.1016/j.jogn.2017.01.009)
23. Rosenbaum JL, Smith JR, Zollfrank R. Neonatal end-of-life spiritual support care. *J Perinat Neonatal Nurs*. 2011;25(1):61-71. [doi:10.1097/JPN.0b013e318209e1d2](https://doi.org/10.1097/JPN.0b013e318209e1d2)
24. Skene C. Individualised bereavement care. *Paediatr Nurs*. 1998;10(10):13-16.
25. Armentrout D, Cates LA. Informing parents about the actual or impending death of their infant in a newborn intensive care unit. *J Perinat Neonatal Nurs*. 2011;25(3):261-267. [doi:10.1097/JPN.0b013e3182259943](https://doi.org/10.1097/JPN.0b013e3182259943)
26. Baughcum AE, Fortney CA, Winning AM, Dunnells ZDO, Humphrey LM, Gerhardt CA. Healthcare Satisfaction and Unmet Needs Among Bereaved Parents in the NICU. *Adv Neonatal Care*. 2020;20(2):118-126. [doi:10.1097/ANC.0000000000000677](https://doi.org/10.1097/ANC.0000000000000677)
27. Thornton R, Nicholson P, Harms L. Being a Parent: Findings from a Grounded Theory of Memory-Making in Neonatal End-of-Life Care. *J Pediatr Nurs*. 2021;61:51-58. [doi:10.1016/j.pedn.2021.03.013](https://doi.org/10.1016/j.pedn.2021.03.013)
28. Yam BM, Rossiter JC, Cheung KY. Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong. *J Clin Nurs*. 2001;10(5):651-659. [doi:10.1046/j.1365-2702.2001.00532.x](https://doi.org/10.1046/j.1365-2702.2001.00532.x)
29. Blood C, Cacciatore J. Parental grief and memento mori photography: narrative, meaning, culture, and context. *Death Stud*. 2014;38(1-5):224-233. [doi:10.1080/07481187.2013.788584](https://doi.org/10.1080/07481187.2013.788584)
30. Cortezzo DE, Sanders MR, Brownell EA, Moss K. End-of-life care in the neonatal intensive care unit: experiences of staff and parents. *Am J Perinatol*. 2015;32(8):713-724. [doi:10.1055/s-0034-1395475](https://doi.org/10.1055/s-0034-1395475)
31. Kymre IG, Bondas T. Skin-to-skin care for dying preterm newborns and their parents--a phenomenological study from the perspective of NICU nurses. *Scand J Caring Sci*. 2013;27(3):669-676. [doi:10.1111/j.1471-6712.2012.01076.x](https://doi.org/10.1111/j.1471-6712.2012.01076.x)

32. Levick J, Fannon J, Bodemann J, Munch S. NICU Bereavement Care and Follow-up Support for Families and Staff. *Adv Neonatal Care*. 2017;17(6):451-460. [doi:10.1097/ANC.0000000000000435](https://doi.org/10.1097/ANC.0000000000000435)
33. Oreg A. The grief ritual of extracting and donating human milk after perinatal loss. *Soc Sci Med*. 2020;265:113312. [doi:10.1016/j.socscimed.2020.113312](https://doi.org/10.1016/j.socscimed.2020.113312)
34. Thornton R, Nicholson P, Harms L. Creating Evidence: Findings from a Grounded Theory of Memory-Making in Neonatal Bereavement Care in Australia. *J Pediatr Nurs*. 2020;53:29-35. [doi:10.1016/j.pedn.2020.04.006](https://doi.org/10.1016/j.pedn.2020.04.006)
35. Baughcum AE, Fortney CA, Winning AM, et al. Perspectives from bereaved parents on improving end of life care in the NICU. *Clin Pract Pediatr Psychol*. 2017;5(4):392-40
36. Alexander KV. "The one thing you can never take away". *MCN Am J Matern Child Nurs*. 2001;26(3):123-127. [doi:10.1097/00005721-200105000-00004](https://doi.org/10.1097/00005721-200105000-00004)
37. Caeymaex L, Jousset C, Vasilescu C, et al. Perceived role in end-of-life decision making in the NICU affects long-term parental grief response. *Arch Dis Child Fetal Neonatal Ed*. 2013;98(1):F26-F31. [doi:10.1136/archdischild-2011-301548](https://doi.org/10.1136/archdischild-2011-301548)
38. Clark OE, Fortney CA, Dunnells ZDO, Gerhardt CA, Baughcum AE. Parent Perceptions of Infant Symptoms and Suffering and Associations With Distress Among Bereaved Parents in the NICU. *J Pain Symptom Manage*. 2021;62(3):e20-e27. [doi:10.1016/j.jpainsymman.2021.02.015](https://doi.org/10.1016/j.jpainsymman.2021.02.015)
39. Shultz EL, Switala M, Winning AM, et al. Multiple Perspectives of Symptoms and Suffering at End of Life in the NICU. *Adv Neonatal Care*. 2017;17(3):175-183. [doi:10.1097/ANC.0000000000000385](https://doi.org/10.1097/ANC.0000000000000385)
40. Gilmour D, Davies MW, Herbert AR. Adequacy of palliative care in a single tertiary neonatal unit. *J Paediatr Child Health*. 2017;53(2):136-144. [doi:10.1111/jpc.13353](https://doi.org/10.1111/jpc.13353)
41. McHaffie HE, Lyon AJ, Fowlie PW. Lingering death after treatment withdrawal in the neonatal intensive care unit. *Arch Dis Child Fetal Neonatal Ed*. 2001;85(1):F8-F12. [doi:10.1136/fn.85.1.f8](https://doi.org/10.1136/fn.85.1.f8)

42. Kochen EM, Teunissen SCCM, Boelen PA, et al. Challenges in Preloss Care to Parents Facing Their Child's End-of-Life: A Qualitative Study From the Clinicians Perspective. *Acad Pediatr*. 2022;22(6):910-917. [doi:10.1016/j.acap.2021.08.015](https://doi.org/10.1016/j.acap.2021.08.015)
43. Pector EA. Views of bereaved multiple-birth parents on life support decisions, the dying process, and discussions surrounding death. *J Perinatol*. 2004;24(1):4-10. [doi:10.1038/sj.jp.7211001](https://doi.org/10.1038/sj.jp.7211001)
44. Swanson PB, Kane RT, Pearsall-Jones JG, Swanson CF, Croft ML. How couples cope with the death of a twin or higher order multiple. *Twin Res Hum Genet*. 2009;12(4):392-402. [doi:10.1375/twin.12.4.392](https://doi.org/10.1375/twin.12.4.392)
45. Leitao S, Helps A, Cotter R, O'Donoghue K. Development and evaluation of TEARDROP - a perinatal bereavement care training programme for healthcare practitioners. *Midwifery*. 2021;98:102978. [doi:10.1016/j.midw.2021.102978](https://doi.org/10.1016/j.midw.2021.102978)
46. Lizotte MH, Barrington KJ, Sultan S, et al. Techniques to Communicate Better With Parents During End-of-Life Scenarios in Neonatology. *Pediatrics*. 2020;145(2):e20191925. [doi:10.1542/peds.2019-1925](https://doi.org/10.1542/peds.2019-1925)
47. Armentrout D. Holding a place: parents' lives following removal of infant life support. *Newborn Infant Nurs Rev* 2007;7(1):e3-8.
48. McHaffie HE, Fowlie PW, Hume R, Laing IA, Lloyd DJ, Lyon AJ. Consent to autopsy for neonates. *Arch Dis Child Fetal Neonatal Ed*. 2001;85(1):F4-F7. [doi:10.1136/fn.85.1.f4](https://doi.org/10.1136/fn.85.1.f4)
49. Rosenbaum JL, Smith JR, Yan Y, Abram N, Jeffe DB. Impact of a Neonatal-Bereavement-Support DVD on Parental Grief: A Randomized Controlled Trial. *Death Stud*. 2015;39(1-5):191-200. [doi:10.1080/07481187.2014.946628](https://doi.org/10.1080/07481187.2014.946628)
50. Bourque CJ, Dahan S, Mantha G, Reichherzer M, Janvier A. My child's legacy: a mixed methods study of bereaved parents and practitioners' opinions about collaboration with NICU teams in quality improvement initiatives. *BMJ Open*. 2020;10(9):e034817. Published 2020 Sep 6. [doi:10.1136/bmjopen-2019-034817](https://doi.org/10.1136/bmjopen-2019-034817)
51. Clarke P, Booth D. Copying medical summaries on deceased infants to bereaved parents. *Acta Paediatr*. 2011;100(9):1262-1266. [doi:10.1111/j.1651-2227.2011.02276.x](https://doi.org/10.1111/j.1651-2227.2011.02276.x)

52. McHaffie HE, Laing IA, Lloyd DJ. Follow up care of bereaved parents after treatment withdrawal from newborns. *Arch Dis Child Fetal Neonatal Ed.* 2001;84(2):F125-F128. [doi:10.1136/fn.84.2.f125](https://doi.org/10.1136/fn.84.2.f125)
53. Cuisinier M, de Kleine M, Kollée L, Bethlehem G, de Graauw C. Grief following the loss of a newborn twin compared to a singleton. *Acta Paediatr.* 1996;85(3):339-343. [doi:10.1111/j.1651-2227.1996.tb14028.x](https://doi.org/10.1111/j.1651-2227.1996.tb14028.x)
54. Swanson PB, Pearsall-Jones JG, Hay DA. How mothers cope with the death of a twin or higher multiple. *Twin Res.* 2002;5(3):156-164.
55. Welborn JM. The experience of expressing and donating breast milk following a perinatal loss. *J Hum Lact.* 2012;28(4):506-510. [doi:10.1177/0890334412455459](https://doi.org/10.1177/0890334412455459)
56. Fernández-Sola C, Camacho-Ávila M, Hernández-Padilla JM, et al. Impact of Perinatal Death on the Social and Family Context of the Parents. *Int J Environ Res Public Health.* 2020;17(10):3421. Published 2020 May 14. [doi:10.3390/ijerph17103421](https://doi.org/10.3390/ijerph17103421)
57. Newborn Health: *Newborn health in the Western Pacific.* <https://www.who.int/westernpacific/health-topics/newborn-health>. (Last accessed May 3, 2022).
58. Akard TF, Duffy M, Hord A, et al. Bereaved mothers' and fathers' perceptions of a legacy intervention for parents of infants in the NICU. *J Neonatal Perinatal Med.* 2018;11(1):21-28. [doi:10.3233/NPM-181732](https://doi.org/10.3233/NPM-181732)
59. Shaw C, Stokoe E, Gallagher K, Aladangady N, Marlow N. Parental involvement in neonatal critical care decision-making. *Sociol Health Illn.* 2016;38(8):1217-1242. [doi:10.1111/1467-9566.12455](https://doi.org/10.1111/1467-9566.12455)
60. Dombrecht L, Piette V, Deliëns L, et al. Barriers to and Facilitators of End-of-Life Decision Making by Neonatologists and Neonatal Nurses in Neonates: A Qualitative Study. *J Pain Symptom Manage.* 2020;59(3):599-608.e2. [doi: 10.1016/j.jpainsymman.2019.10.007](https://doi.org/10.1016/j.jpainsymman.2019.10.007)
61. Janvier A, Lantos J, Deschênes M, Couture E, Nadeau S, Barrington KJ. Caregivers attitudes for very premature infants: what if they knew?. *Acta Paediatr.* 2008;97(3):276-279. [doi:10.1111/j.1651-2227.2008.00663.x](https://doi.org/10.1111/j.1651-2227.2008.00663.x)

62. Fry JT, Matoba N, Datta A, et al. Center, Gestational Age, and Race Impact End-of-Life Care Practices at Regional Neonatal Intensive Care Units. *J Pediatr*. 2020;217:86-91.e1. [doi: 10.1016/j.jpeds.2019.10.039](https://doi.org/10.1016/j.jpeds.2019.10.039)
63. Lakhani J, Mack C, Kunyk D, Kung J, van Manen M. Considerations for Practice in Supporting Parental Bereavement in the Neonatal Intensive Care Unit-a Systematic Review [published online ahead of print, 2023 Feb 27]. *J Palliat Care*. 2023;8258597231158328. [doi:10.1177/08258597231158328](https://doi.org/10.1177/08258597231158328)
64. Waddington C, van Veenendaal NR, O'Brien K, Patel N; International Steering Committee for Family Integrated Care. Family integrated care: Supporting parents as primary caregivers in the neonatal intensive care unit. *Pediatr Investig*. 2021;5(2):148-154. [doi:10.1002/ped4.12277](https://doi.org/10.1002/ped4.12277)
65. Baum N, Weidberg Z, Osher Y, Kohelet D. No longer pregnant, not yet a mother: giving birth prematurely to a very-low-birth-weight baby. *Qual Health Res*. 2012;22(5):595-606. [doi: 10.1177/1049732311422899](https://doi.org/10.1177/1049732311422899)
66. Clandinin DJ. Narrative inquiry: a methodology for studying lived experience. *Res. Stud. Music Educ*. 2006; 21(1): 44-54. [doi: 10.1177/1321103X060270010301](https://doi.org/10.1177/1321103X060270010301)
67. Frank AW. The wounded storyteller: Body, illness, and ethics. *The University of Chicago Press*. 1995.
68. Frank AW. Health stories as connectors and subjectifiers. *Health (London)*. 2006;10(4):421-440. [doi: 10.1177/1363459306067312](https://doi.org/10.1177/1363459306067312)
69. Weiss CR, Johnson-Koenke R. Narrative Inquiry as a Caring and Relational Research Approach: Adopting an Evolving Paradigm. *Qual Health Res*. 2023;33(5):388-399. [doi:10.1177/10497323231158619](https://doi.org/10.1177/10497323231158619)
70. Frank AW. Truth Telling, Companionship, and Witness: An Agenda for Narrative Ethics. *Hastings Cent Rep*. 2016;46(3):17-21. [doi: 10.1002/hast.591](https://doi.org/10.1002/hast.591)
71. Murray TH. What do we mean by "narrative ethics". *Med Humanit Rev*. 1997;11(2):44-57.
72. Frank AW. What is dialogical research, and why should we do it?. *Qual Health Res*. 2005;15(7):964-974. [doi: 10.1177/1049732305279078](https://doi.org/10.1177/1049732305279078)

73. Frank, AW. Practicing dialogical narrative analysis. In J. A. Holstein, J. F. Gubrium (Eds.). *Varieties of Narrative Analysis*. 2012; 33-52. Los Angeles, California: SAGE. [doi: 10.4135/9781506335117](https://doi.org/10.4135/9781506335117)
74. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893-1907. [doi:10.1007/s11135-017-0574-8](https://doi.org/10.1007/s11135-017-0574-8)
75. Keesee NJ, Currier JM, Neimeyer RA. Predictors of grief following the death of one's child: the contribution of finding meaning. *J Clin Psychol*. 2008;64(10):1145-1163. [doi:10.1002/jclp.20502](https://doi.org/10.1002/jclp.20502)
76. Sartre JP. Merleau-Ponty *vivant*. In J. Stewart (Ed.), *The debate between Sartre and Merleau-Ponty*. 1998; 565–625. Evanston: Northwestern University Press.

## Appendices

### Appendix 1: Search Strategy Outline

#### 1. MEDLINE/OVID:

- a. Exp infant, premature/ OR exp infant, newborn/ OR neonat\* OR perinat\* OR baby OR exp premature birth/ OR babies OR exp infant, diseases/ OR newborn\* OR exp intensive care, neonatal/ OR NICU or exp intensive care units, neonatal AND
- b. (Bereave\* OR grief OR grieving OR loss) adj3 (Parent\* OR caregiver\* OR mother\* OR father\*) AND
- c. Exp palliative care/ OR palliative OR exp palliative medicine/ OR comfort care OR exp patient comfort/ OR terminal\* OR exp terminal care/ OR "end of life" OR exp death/

\*1990-current, English language, excluding comments, editorials, reviews or systematic reviews  
= **282 results**

#### 2. EMBASE:

- a. Exp neonatal intensive care unit/ OR exp prematurity/ OR neonat\* OR perinat\* OR exp newborn/ OR baby or exp baby/ OR babies OR exp newborn period/ OR newborn OR exp newborn death/ OR exp newborn/ OR exp newborn mortality/ OR newborn intensive care or NICU AND
- b. (Bereave\* OR grief OR grieving OR loss) adj3 (Parent\* OR caregiver\* OR mother\* OR father\*) AND
- c. Palliative OR exp terminal care/ OR exp patient comfort/ OR comfort care OR terminal\* OR "end of life"

\*1990-current, English language, excluding editorials, reviews or systematic reviews  
= **102 results**

#### 3. CINAHL

- a. (MH "Intensive Care Units, Neonatal") OR (MH "Neonatal Intensive Care Nursing") OR (MH "Intensive Care, Neonatal+") OR (MH "Infant, Newborn, Diseases+") OR (MH "Perinatal Death") OR (MH "Infant, Newborn+") OR (MH "Infant, High Risk") OR (MH "Infant Mortality") OR "neonat\*" OR "perinat\*" OR (MH "Infant, Newborn, Diseases+") OR "baby" OR (MH "Infant, Premature") OR (MH "Infant, Postmature") OR (MH "Infant, Premature, Diseases+") OR (MH "Infant Death+") OR "babies" OR "newborn\*" OR "NICU" AND
- b. (Bereave\* OR grief OR grieving OR loss) N3 (Parent\* OR caregiver\* OR mother\* OR father\*) AND
- c. (MH "Palliative Medicine") OR (MH "Palliative Care") OR (MH "Terminal Care+") OR "palliative" OR (MH "Comfort Care (Saba CCC)") OR "comfort care" OR "terminal\*" OR "'end of life'"

\*English language, peer reviewed journal, 1990-present, abstract available  
= **197 results**



## *Appendix 2: Participant Letter of Information*

### **Letter of Information**

#### **End-of-life decision making in the neonatal intensive care unit (NICU): understanding parental stories of goals of care decisions to support parental bereavement.**

*Study Investigators:* Dr. Michael van Manen & Dr. Jenna Lakhani

Dear \_\_\_\_\_,

#### **Introduction**

You are being invited to participate in a research study. The aim is to understand the experiences of parents who have had a child pass away in the NICU. We appreciate that for many parents that these experiences are very challenging to live through and talk about. We hope that through hearing about your experiences from your perspective that we will be better able to support future parents living through their child's death in the NICU.

#### **What are the objectives of the study?**

The specific objective of this study is to explore parents' stories surrounding goals of care and end-of-life discussions in the NICU. We want to hear what it was like from those who have lived through this experience. We hope that through hearing these personal experiences, we can find ways to better help support parents through bereavement and other challenges they face as they go through these difficult times.

#### **Who can participate?**

All parents or primary caregivers that have experienced the loss of an infant in the NICU at one of the Edmonton-zone hospitals (Royal Alexandra Hospital, University of Alberta Hospital, Misericordia Hospital, Grey Nuns Hospital, and/or Sturgeon Community Hospital) in the past 5 years are eligible to participate. This excludes those who have undergone this difficult time in the last 6 months.

#### **What is involved in the study?**

This study will involve participating in a one-on-one interview with the study investigators either via telephone, videoconferencing, or in-person (pandemic restrictions permitting). It is up to you with regards to how you would like to participate. We hope to conduct 2 to 3 interviews with you that will each last approximately 1 to 2 hours.

#### **Potential benefits**

This study offers an opportunity for us to gain a sense of parents' experiences when discussing goals of care, including both positive and negative aspects. This will contribute to informing us how we are able to optimize these difficult encounters to support bereavement efforts for families and work towards implementing a guideline and education strategy.

## Potential risks

We appreciate that discussing the difficult time of having a very sick infant in the NICU can be a challenge and difficult emotions may arise during the interview process. You may refuse to answer any questions, take a break, or postpone the interview to a later date whenever you choose. The recording device can be paused at any point if a break is requested. If you need additional support, resources can be made available through the Stollery Bereavement Program, and we will do our best to help in any way we can.

While we will do our best to make sure any information you share is private and secure, it is important to acknowledge that no videoconferencing tool is entirely secure. There is a risk that your information may be intercepted or disclosed to third parties when using videoconferencing. To help keep your information secure, we will use a password-protected video-conference link and use a University of Alberta Zoom account.

## Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any question during the interview, or withdraw from the study at any time. The result of the study can be provided to you at your request when the study is finished.

## Confidentiality

All information will be kept private, except in the unlikely case when professional codes of ethics or the law require reporting. If you agree to participate, the conversation will be transcribed (transformed into written text). All names and other identifiers will be removed. Parts of the responses may be used in future discussions with parents and health care practitioners to develop resources to support families and health care practitioners in navigating these difficult conversations. Responses may also be used in public discussion, presentation, or publication.

The information gathered for this study will be stored in a locked filing cabinet for a minimum of 5 years. The data may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically. During research studies it is important that the data we get is accurate. For this reason, your health data, including your name, may be looked at by people from the University of Alberta or the health research ethics board.

## Contact Information

You may contact Dr. Jenna Lakhani by email at [jenna.lakhani@albertahealthservices.ca](mailto:jenna.lakhani@albertahealthservices.ca) or Dr. Michael van Manen at [michael.vanmanen@albertahealthservices.ca](mailto:michael.vanmanen@albertahealthservices.ca) at any time if you have any questions or concerns about the study.

If you have concerns about any part of this study, you may contact the University of Alberta Research Ethics Office at 780-492-2615. This office has no affiliation with study investigators.

*Appendix 3: Participant Consent Form*

**Consent Form**

**PROJECT TITLE:** End-of-life decision making in the neonatal intensive care unit (NICU): understanding parental stories of goals of care decisions to support parental bereavement.

**RESEARCHERS:** Dr. Jenna Lakhani [jenna.lakhani@albertahealthservices.ca](mailto:jenna.lakhani@albertahealthservices.ca)  
Dr. Michael van Manen. [michael.vanmanen@albertahealthservices.ca](mailto:michael.vanmanen@albertahealthservices.ca)

Department of Paediatrics, Faculty of Medicine & Dentistry

	YES	NO
Do you understand that you have been asked to participate in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Letter of Information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of anonymity and confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that the interview data you provide for this study may be analyzed in future studies?	<input type="checkbox"/>	<input type="checkbox"/>
Would you like a report of the research findings sent to you when the study is completed? If yes, e-mail address:	<input type="checkbox"/>	<input type="checkbox"/>

This study was explained to me by: \_\_\_\_\_

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to his/her child participation.

\_\_\_\_\_  
Signature of Researcher or Designee

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date