

2021

## Exploring Factors that Contribute to Bereaved Parents' Perceptions of Neonatal Palliative Care: A Systematic Literature Review

Marie Hamel  
*University of Central Florida*

Find similar works at: <https://stars.library.ucf.edu/honorsthesis>  
University of Central Florida Libraries <http://library.ucf.edu>

This Open Access is brought to you for free and open access by the UCF Theses and Dissertations at STARS. It has been accepted for inclusion in Honors Undergraduate Theses by an authorized administrator of STARS. For more information, please contact [STARS@ucf.edu](mailto:STARS@ucf.edu).

---

### Recommended Citation

Hamel, Marie, "Exploring Factors that Contribute to Bereaved Parents' Perceptions of Neonatal Palliative Care: A Systematic Literature Review" (2021). *Honors Undergraduate Theses*. 1100.  
<https://stars.library.ucf.edu/honorsthesis/1100>

EXPLORING FACTORS THAT CONTRIBUTE TO BEREAVED  
PARENTS' PERCEPTIONS OF NEONATAL PALLIATIVE CARE: A  
SYSTEMATIC LITERATURE REVIEW

by

MARIE NICOLE HAMEL

A thesis submitted in partial fulfillment of the requirements  
for the Honors Interdisciplinary Thesis Program in Social Work  
in the College of Sciences  
and in the Burnett Honors College  
at the University of Central Florida  
Orlando, Florida

Summer Term  
2021

Major Professor: Susanny J. Beltran

## ABSTRACT

Neonatal palliative care (NPC) is an emerging subset of care in United States (US) neonatal intensive care units (NICUs) that provides relief for both infants and families at the end of life for infants with terminal diagnoses. Families play a large role in the decision-making process for their infant, but their experiences with and perceptions of the support and care provided to them via NPC is unclear. This literature review summarizes the state of knowledge on parents' perspectives of NPC while focusing on the specific factors that influence their experiences and satisfaction with NPC. This literature review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Findings of the literature review broadly include the importance of consistent communication with providers, parental involvement in the care process, and the minimization of infant suffering. Providers must focus on these important quality indicators to ensure they provide the best care possible to the patients and families that they serve. Further research must be done to investigate parent satisfaction and needs in relation to NPC more deeply and to develop interventions and protocols that better incorporate these needs.

## ACKNOWLEDGEMENTS

I would like to thank my thesis mentor Dr. Beltran for all of her support throughout the last two years working with her, as well as my committee members Dr. Martinez and Dr. Francies. I would also like to thank the 2021 Summer Undergraduate Research Fellowship (SURF) program at UCF for their support in my research career and assistance with this project.

## TABLE OF CONTENTS

LIST OF FIGURES.....	V
LIST OF TABLES .....	VI
INTRODUCTION.....	1
BACKGROUND .....	4
METHODOLOGY.....	6
RESULTS.....	9
PERCEPTIONS OF INTERACTIONS WITH PROVIDERS.....	10
<i>Communication with Providers</i> .....	11
<i>Involvement in Decision Making</i> .....	13
<i>Continuity of Care and Relationships with Providers</i> .....	14
PERCEPTIONS OF INTERACTIONS SURROUNDING THE INFANT.....	15
<i>Maintaining the Parental Role</i> .....	15
<i>Having Quality Time with the Infant</i> .....	16
<i>Parents Perceptions of Infant Symptoms and Suffering</i> .....	17
PARENT INTERACTIONS WITH CARE AND SUPPORT FOR THEMSELVES.....	19
<i>Support during the Parents' Stay in the NICU</i> .....	19
<i>Bereavement Support</i> .....	20
DISCUSSION.....	22
CONCLUSION.....	26
APPENDIX: DATA EXTRACTION TABLE.....	27
REFERENCES .....	32

## LIST OF FIGURES

Figure 1: Prisma Flowchart of Article Selection Process .....	7
---	---

## LIST OF TABLES

Table 1: Data Extraction Table Describing Key Components of Each Article .....	28
--	----

## INTRODUCTION

According to the Center for Disease Control (CDC), 21,467 infants died in the US in 2018.<sup>1</sup> For many of these infants, the services provided under the neonatal palliative care (NPC) model may have been beneficial to relieving infant and family suffering and providing a peaceful dying process. NPC is a unique interdisciplinary approach to end-of-life care for neonates facing challenging medical diagnoses that may result in death.<sup>2</sup> Due to advances in prenatal screening technologies, some parents may be made aware of the benefit of NPC services prior to the birth of a terminally-ill infant.<sup>2</sup> This provides parents with the time to process and understand the role of NPC in providing a peaceful dying process. In contrast, some parents may not have any time to process the need for NPC before the sudden deterioration of their infant's medical condition. This requires efficient and sensitive counseling and preparation of the parents so that they can make the best decisions for their family during this time.

In both of the cases above, NPC involves preparing both the infant and their parents for the end-of-life. For the care of the infant, this may include comfort care such as administration of pain medication and withdrawal of invasive or potentially painful treatment. For the parents, this may include education about the infant's prognosis and involvement of parents in decision making as well as caring for the infant. If the deterioration of their infant was not anticipated, it is important to give parents time to process the imminent death of their infant.<sup>2</sup> Memory making strategies, such as photographs, foot prints, and other mementos, are strategies incorporated within NPC to support the family throughout their grieving process.<sup>3</sup>

Undoubtedly, the death of an infant is a difficult time for all individuals involved in their care. This is a time of extreme distress for parents. One of the main goals stated by parents during this time is to experience and enjoy parenthood and to not have regrets regarding how they spent their time with their infant before death.<sup>2</sup> Parents experience high levels of stress during their infant's illness and death. This likely comes from the alteration of their parental roles as they care for their infant in the NICU. This leads to elevated rates of acute stress disorder (ASD) in parents. One study measuring the stress levels of parents utilizing NPC services found that over one-third of the parent participants met the clinical diagnostic criteria for ASD while in the NICU.<sup>4</sup> ASD encompasses symptoms like anxiety, dissociation, general functional impairment as well as frequent overstimulation. The psychological impact of losing an infant is life-long, however, and the grieving process extends well beyond the time spent in the NICU.

The grieving process for parents who have lost an infant is complex and long-lasting. Their grieving process is especially unique because they often do not have a long period of time to spend with their infant to create memories. This complicates the grief process and can lead to negative long-term impacts. If parents do not properly process their emotions and feelings surrounding the loss of their infant, they are at higher risk for adverse health and psychological effects.<sup>5</sup> Bereaved parents who have suffered the loss of an infant are more likely to be psychiatrically hospitalized, experience PTSD, and be diagnosed with clinical depression compared to parents who have not suffered the loss of an infant. They also suffer from somatic symptom such as insomnia, decreased energy and interest in social activities, as well as an increase in chronic disease diagnoses.<sup>5</sup> Providers play a vital role in facilitating an adaptive grieving process and providing long-term support to these families, due to the numerous long-

term impacts that bereaved parents may face once they leave the NICU. During this time of heightened emotions and increased need for psychological support, it is important to understand parents' perceptions of what provider practices are actually helpful in supporting them.

## BACKGROUND

Literature investigating provider experiences delivering NPC indicates that providers employ a variety of tactics to promote infant comfort and facilitate the parent grief process through the end of life such as memory making, involvement in decision making, and bereavement support after the infant's death.<sup>3</sup> Providing culturally and spiritually sensitive care is at the center of care decisions so that parents' wishes and goals are aligned with the care plan for their infant.<sup>2</sup> This focus on supporting and including the parents in the provision of NPC is in accordance with the movement of the US healthcare system towards a patient-centered care (PCC) model that emphasizes collaboration between the patient and provider so that the patient is an active participant in their care experience.<sup>6</sup> Yet, there lacks overall consensus on the specific factors of NPC that parents need in order to be satisfied with the care provided. Incorporating the factors of NPC that most contribute to the wellbeing of the parents will help providers to better serve these families.

Health care providers are also significantly impacted by the death of an infant under their care. Health care providers play an intimate role in the care of the infant and their family during the death process and develop an attachment and sense of personal responsibility for the family. This creates unique psychological distress after the death of an infant, including feelings of professional inadequacy since they were not able to save the infant.<sup>3</sup> Providers commonly reported feeling shock, denial, and sadness after the death of the infant.<sup>7</sup> One important way to prevent the feelings of professional inadequacy and sadness felt by providers is to enable them to provide the best care possible. This can be done by evaluating and summarizing the needs of

parents so that providers know how to best care for their families during the death of the infant and know that they did the best that they could for their patient.

Evaluating patient care experiences and satisfaction can help hospitals assess care plans, improve care quality, develop quality indicators of patient satisfaction, and reduce costs.<sup>8</sup>

Informed by the PCC model, understanding the parent's perspective of what constitutes quality care is key to the improvement of NPC in US hospitals. One of the few quantitative studies that have examined parent satisfaction with NPC found that parents reported increased satisfaction with care when utilizing NPC services.<sup>4</sup> However, the study did not explore the specific factors of NPC that contributed to their satisfaction. Understanding the factors that can be used to increase parent satisfaction with NPC is vital to the evidence-based improvement of NPC following the PCC model.

Families play an important role in the decision making and care process for their infant during NPC, and understanding and incorporating their needs and opinions is vital to providing excellent NPC. This study specifically aimed to address this need by summarizing the literature present on parents' experiences with and perceptions of the factors that encompass NPC with the hopes of identifying important needs and concerns of parents. This included both facilitators of and barriers to positive NPC experiences for parents as well as future research suggestions and practice implications based on the findings of the literature review.

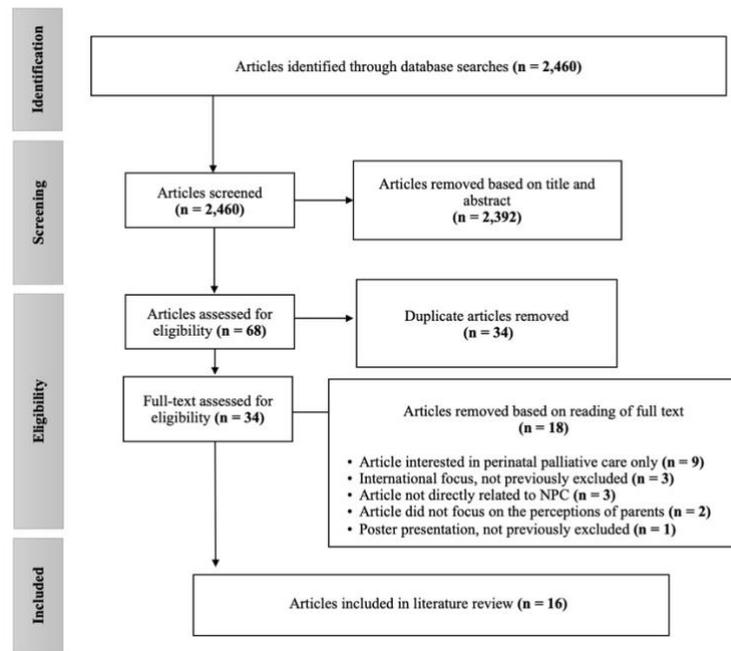
The specific research question for this study was: What are parent experiences with NPC and their perceptions of the factors that contribute to good quality NPC?

## METHODOLOGY

A systematic literature review of parents' experiences with NPC was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Peer-reviewed articles were included that were published between January 1st of 2010 and June 12th of 2021. The databases that were included for this search are EBSCOhost (encompassing Academic Search Premier, CINAHL Plus with Full Text, ERIC, MEDLINE, PsycInfo), PubMed, and Web of Science. Varying combinations of the terms *families, parents, experiences, perceptions, neonat\**, *end-of-life, pall\* care* were used to search for relevant articles. Asterisks were used to allow for iterations of the search terms to be included in the results. Boolean operations were used to specify searches to ensure relevant articles were included. For each database, the following search terms were utilized: *Neonat\* OR perinat\* OR newborn OR infant AND end of life care OR palliative care AND parent\* OR family OR families OR mother\* OR father\* OR caregiver AND experiences OR perceptions OR needs*. Articles were included if they met all of the following criteria: (1) the article must be peer-reviewed and published in a scholarly journal (theses and dissertations were excluded), (2) the article must focus on parents' experiences with and perceptions of the factors of NPC, and (3) the article must only focus on the experiences of parents within the United States. If articles included experiences of both parents and health care providers, the article was included if the parents' experiences could be separated from those of the providers for the purposes of this study.

A total of 2,460 articles were identified through the initial database searches. Upon review of the titles and abstracts of these articles, 68 articles were selected as relevant to the research question. From these 68 articles, 34 duplicates were removed, resulting in 34 articles

that were then screened based on full-text readings. 18 articles were removed after reading the full text, which resulted in a final sample of 16 (N=16) articles for the literature review. The 18 articles that were removed after reading of the full text were disqualified for a variety of reasons. Of the removed articles, nine were excluded because they focused on perinatal palliative care, which provides comfort care to families prior to the birth of the infant. An additional three articles were found to not be related to NPC in general, and two articles were not focused on the perceptions of parents. The remaining articles were either not published in the US or did not meet the initial search criteria. This process is illustrated in Figure 1.



**Figure 1: Prisma Flowchart of Article Selection Process**

The final sample of 16 articles were then analyzed using a theoretical thematic analysis. Per the theoretical thematic analysis framework, only data relating to the central research

question of factors that influence parents' perceptions of NPC were included in the findings of the literature review. Furthermore, a semantic themes approach was employed in which the literature review aimed to describe the presented data and not analyze the underlying reasons for these findings. The findings from the literature were then grouped into categories based on the way in which they were related to the parents' perceptions of NPC.

## RESULTS

The final sample of 16 articles was examined for similar themes via the theoretical thematic analysis approach described above. Eight of the studies included in the final sample were parent surveys with open-ended questions. The validated survey tools utilized in these surveys varied, including the Bereaved Parent Satisfaction and Unmet Needs Questionnaire, Neonatal Unit Parental Stressor Scale, and Depression Anxiety Stress Index-21 to name a few. Seven studies utilized qualitative interviews with parents in order to collect data. Many of these interviews were semi-structured in order to thoroughly cover the main areas of research interest in relation to parents' perceptions of the NPC they received. These interviews were conducted in person, on the phone, or in focus groups. The remaining two articles utilized a mixed-methods approach in their studies.

Via manual coding of themes presented in the articles, several overarching ways in which these themes relate to parents' perceptions of NPC were identified. These overarching categories include 1) perceptions of interactions with providers, 2) perceptions of interactions pertaining to their infant, and 3) perceptions of care directed towards themselves as parents. Perceptions of interactions with providers encompasses the following three themes: the relationship with their care team, involvement in decision making for their infant, as well as the providers adherence to the decided upon care plan.<sup>9-11</sup> A common finding throughout the articles was the importance of consistent and compassionate communication in facilitating a positive experience for parents.<sup>9,12,13</sup> Perceptions of care pertaining to the infant includes the following three themes: involving parents in the care of their infant, allowing alone time for the parent and infant to bond, as well as parents' perceptions of their infants' symptoms and whether or not they were

suffering. Two articles focused specifically on the perception of infant symptoms and suffering through the eyes of the parents.<sup>14,15</sup> Lastly, perceptions of care directed towards themselves as parents includes the following two themes: emotional support inside the NICU as well as bereavement care following infant death. One article also focused specifically on parents' willingness to participate in a legacy-leaving intervention.<sup>16</sup> Articles mostly mirrored each other in findings related to parents' wishes and general trends in their NPC needs.

The articles in this study were published across a variety of journals including those related to neonatology, nursing, palliative care, and pain management. Journals in which more than one article in the review was published include the *National Association of Neonatal Nurses*, *Advances in Neonatal Care*, and the *Journal of Perinatal and Neonatal Nursing*. Table 1 (found in appendix 1) provides additional information on the study design, setting, and main findings from each article.

### Perceptions of Interactions with Providers

Many of the articles explored parents' perceptions of interactions with their health care providers. Through analysis of these articles, three main themes related to the factors that influence parents' perceptions of NPC were uncovered: 1) communication between parents and providers, 2) parent involvement in the decision-making process and 3) continuity of care among staff.

## Communication with Providers

Communication between parents and providers is important for managing care of the infant and to ensure that the parents are informed of their infant's condition and can thus make appropriate care decisions. Frequently in the studies, parents emphasized the importance of honest and transparent communication with providers.<sup>9-11,13,17</sup> Parents held value in being able to understand the reality of their infants' medical condition so that they could have realistic expectations surrounding their infants' end of life.<sup>11</sup> A qualitative, descriptive study by Tan et al found that parents who were informed of the possibility of death for their infant reported less distress during the infants' death and afterwards.<sup>13</sup> This highlights the importance of realistic expectations which are formed via transparent communication and education from providers. A study by Baughcum et al, found that most of their participants, including 70% of mothers and 94% of fathers, felt that they were well informed and consistently updated by their providers.<sup>11</sup>

Transparent communication also facilitates the building of trusting relationships between parents and providers, which plays an important role in decreasing anxiety in parents around their infants' deterioration.<sup>10</sup> In a study by Baughcum et al, multiple parents noted that they did not know what to expect at the end of their infants' life and would have appreciated education on this prior to the infants' death.<sup>11</sup> One way that quality communication was achieved was through confidential family meetings that included the care team and parents of the infant.<sup>10</sup> In NICUs that utilize an open-room design, it can be especially difficult to have confidential conversations, but parents noted confidential communication as very important to maintaining their privacy during this difficult time.<sup>10</sup>

Another important aspect of communication for parents is maintaining hope. Regardless of the infants' medical condition, parents reported wanting to remain hopeful throughout their time in the NICU.<sup>9</sup> This also highlights the importance of sensitive and thoughtful communication on behalf of the care team. In a series of semi-structured interviews by Moro et al, one parent described a disheartening interaction with a provider who offered their condolences to the mother once they entered the delivery room, however the baby was still alive. This was saddening for the mother, who still had hope that her infant might live, and this interaction created a negative memory for her.<sup>18</sup> Compassionate care from providers was key to maintaining a trusting relationship and supporting parent satisfaction.<sup>12</sup>

Parents also explicitly stated the important role of nurses in communicating with the care team. Nurses usually spend a significant amount of time with the families and develop strong relationships.<sup>9</sup> Nurses are a primary method of contact for parents in the NICU, and when parents are not able to be physically present in the NICU, nurses provide updates to them via phone calls.<sup>9</sup> Parents found this to be important so that while they were away, they could still be updated on their infants' condition. A source of conflict in NICUs reported by parents was not feeling like they were being heard by the nurses.<sup>9</sup> Parents spend a lot of time at the bedside with their infant, and they may notice changes in their infant before health care providers can. It produces feelings of anxiety and stress for parents when their observations are not taken seriously by providers.<sup>9</sup> Compassionate and receptive communication is overall an important facilitator of quality NPC provision.

## Involvement in Decision Making

Decision making during the end of life for an infant is a result of collaboration between the care team and the parents. For many parents, this is a very difficult time for them as they want to oversee their infants' care, but they lack the medical expertise and experience of a health care provider. Regardless of these difficulties, parents reported wanting to play an active and informed role in the decision-making process.<sup>9</sup> Many parents viewed decision making as an important aspect of maintaining their identity as a parent.<sup>11</sup> It is natural that parents have a hard time deciding the right thing to do for their family, but parents found that having transparent and comprehensive education from providers assisted them in being able to make these tough decisions.<sup>9</sup> In a survey of 67 bereaved parents by Baughcum et al, parents rated providers explanation of their infants' prognosis as well as assistance in the decision-making process as needs that were not well met by their care team.<sup>17</sup>

The outlooks of parents can evolve when it comes to decision making. In a study by Moro et al, all mothers who participated in the study cited wanting to exhaust all possible medical treatments after the infant was born.<sup>18</sup> When life support was necessary for their infants, these mothers identified the infant's pain and suffering as well as their own hope that the infant will recover as important factors in making the decision whether to remove care. The impact of infant symptoms and suffering plays an important role in parents' decision-making processes and will be discussed later. Overall, parents who were an active participant in the decision-making process and considered all possible medical interventions experienced fewer feelings of distress

after the death of the infant.<sup>13</sup> This highlights the importance of parents' role in informed decision making alongside the care team as contributing to their perceptions of good quality care.

### Continuity of Care and Relationships with Providers

Parents across studies have reported that building trusting, long-term relationships are important to their overall satisfaction with NPC.<sup>11,12</sup> Factors that influence the building of these relationships include physical availability of staff, communication, trust, as well as compassionate and genuine interactions.<sup>11,18</sup> Parents found nurses to be generally more available than physicians, which in turn, facilitated the building of strong relationships with the nurses.<sup>17</sup> The familiarity with the same set of nurses instills trust within parents and confidence in the nurses that are caring for their infant.<sup>10</sup> Parents also noted that having consistent physician assignments improved the adherence to a consistent care plan and allowed for smoother transitions between providers.<sup>10</sup>

On the other hand, having inconsistent health care provider assignments created conflict and stress in parents across several studies.<sup>9-11,13,18</sup> Parents reported that having to keep track of conversations with multiple different health care providers was emotionally draining. Parents also had difficulty learning and responding to the varying communication styles of health care providers.<sup>10</sup> One parent suggested the possibility of having one primary contact point between the family and care team to reduce this strain.<sup>11</sup> Changing the providers taking care of their infant also created feelings of abandonment in parents during this incredibly difficult time for them.<sup>13</sup> With the introduction of new providers with varying ideas as to how best to care for the infant,

parents start to lose trust in the credibility of the providers.<sup>13,18</sup> Parents had a hard time trusting providers that they didn't know to take care of their infant which can increase conflict. This conflict was exacerbated when parents felt that the providers were not sensitive to their needs.<sup>9</sup> Overall, having a consistent care team promotes parent satisfaction through building a trusting relationship with a consistent care plan.

### Perceptions of Interactions Surrounding the Infant

Parents' ability to interact with their infant and feel like a parent are central to the needs of parents during NPC.<sup>9</sup> These interactions are multifaceted and can include the direct care of the infant as well as spending the little time they have to just get to know each other and feel like a family. Because parents are often at the bedside for more time than the health care providers, noticing their infant's symptoms and condition is also a large part of their experience. Factors related to parent-infant interactions that contribute to good quality NPC include: 1) maintaining the role of a parent, 2) having quality time with the infant, and 3) understanding and perceiving the symptoms and potential suffering of their infant.

### Maintaining the Parental Role

Parents across studies found it to be important that they were viewed in a parental role and were able to perform typical parenting duties for their infant throughout their life and after their death.<sup>9</sup> Parents who were at their infants' bedside for all or most of the time found that this allowed them to maintain their identity as a parent and be involved in caring for their infant.<sup>11</sup>

Parents reported having regrets about not participating in care after the death of their infant.<sup>11</sup>

There were discrepancies between studies as far as how well parents' needs were met in terms of being involved in care. In a cross-sectional survey by Shelkowitz et al, 79% of the mothers surveyed felt that the number of ways that were presented for them to be involved in the care of their infant was adequate.<sup>19</sup> However, in a qualitative interview-based study by Baughcum et al, parents reported that their participation in the care of their infant was not a well met need, and that they were frustrated with providers that did not facilitate their involvement in care.<sup>11,17</sup>

For parents, involvement in care looks different based on the clinical state of the infant. Depending on the stability of the infant, bonding between the parent and infant can be facilitated through changing diapers, feeding their infant, and bathing. If the mother wishes, breast feeding can be attempted via nonnutritive suck under the supervision of a provider or speech pathologist.<sup>20</sup> Parents reported that these activities helped to bond with the infant and allow them to feel like they were providing for their child like a parent.<sup>20</sup>

### Having Quality Time with the Infant

Apart from being able to participate in traditional parenting activities, allowing the family to spend uninterrupted quality time together was of extreme importance for many parents.<sup>13</sup> This quality time can be hard to come by in the NICU due to the fragility of the infant who may need frequent medical attention as well as the potential open room design of the NICU.<sup>10</sup> However, parents greatly appreciated having time in a private space with their infant.<sup>11</sup> This also includes being able to allow other visitors such as siblings, grandparents, and other family and friends to

see the infant before their death.<sup>11</sup> Parents reported being unsure of how to handle introducing their infant to their other children and would have appreciated resources to navigate these interactions.<sup>11</sup> Lastly, giving parents and their infant alone time allows for the parents to properly say goodbye to their infant which helps to support an adaptive grieving process.<sup>17</sup> Although quality time with their infant may be short-lived and difficult to obtain, it is of vital importance to parents.

Parents also reported that having the infant treated with dignity by providers was a need that was well met.<sup>17</sup> Treating the infant with respect and dignity helps the family to be able to bond as they would with a healthy infant and facilitates quality NPC.<sup>17</sup> One of the ways that this can be facilitated is through memory making strategies to preserve memories of the infant during their short life. Parents identified this as a need that was well met in a study by Baughcum et al.<sup>17</sup> Examples of memory making activities include taking photos, hand and foot prints, and other mementos for the parents to keep.<sup>17</sup> By keeping the dignity of the infant and the precious time that they have in this world at the forefront of providers minds, quality NPC can be provided to parents by allowing them to spend time and create memories with their infant.

### Parents Perceptions of Infant Symptoms and Suffering

Parents' perceptions of infant symptoms and suffering are linked to their satisfaction with the care their infant was provided.<sup>17</sup> Minimizing infant suffering has been shown to reduce guilt and distress in parents as they grieve.<sup>13</sup> On the other hand, increased perception of infant suffering was found to be associated with increased levels of post-traumatic stress symptoms and

prolonged grief.<sup>21</sup> Despite this, a study by Baughcum et al, found that parents did not feel their need to reduce infant suffering was well met.<sup>17</sup> In a 2019 study by Fortney et al, 57% of mothers and 31% of fathers strongly believed that their infant had suffered.<sup>14</sup> In another study by Cortezzo et al, a discrepancy was found between one-third of parents who believed their infant was in pain during the end of life, versus the vast majority of providers who did not believe this.<sup>22</sup> Although the quality of care may differ between institutions, the findings from these studies cannot be ignored. In order to provide the best care possible, it is important to understand how parents perceive symptoms and signs of suffering in their infant.

In a prospective mixed-methods survey of 35 bereaved parents by Parravicini et al, the majority of participants described that making sure their infant was not thirsty, hungry, cold, or in pain was important for them to feel like their infant was not suffering.<sup>23</sup> Some of the symptoms that infants may present with at the end of life can be distressing for parents, specifically physical symptoms such as skin color change or swelling, trouble breathing and gasping, unpleasant noises, and agitation.<sup>14,17</sup> In a study by Shultz, respiratory distress was indicated as the worst symptom that parents observed.<sup>15</sup> Multiple studies found that both the number of perceived symptoms as well as the number of medical interventions increased parents' perception that their infant was suffering.<sup>14,15</sup> In the same study by Shultz, 96% of participants reported that they believed their infant suffered moderately in the last week of their life.<sup>15</sup> Understanding the complex nature of parent perceptions of infant suffering is key to providing quality NPC and facilitating an adaptive grieving process for parents.

## Parent Interactions with Care and Support for Themselves

While caring for the infant is a major component of NPC, it is also important to consider the individual needs of the parents, who are going through a very emotional and foreign experience. These parents still have lives outside of the NICU that need their attention such as children, jobs, and all the expenses that come with being in the hospital.<sup>9</sup> Balancing all of this is a common challenge for parents in the NICU. On top of this, parents are also struggling psychologically with the idea of NPC and the perception of “giving up” on their infant, which contributes to their distress.<sup>9</sup> Two themes were extracted from articles pertaining to caring for parents in the NICU: 1) support during their stay in the NICU, and 2) bereavement support during the grieving process.

### Support during the Parents’ Stay in the NICU

Adjusting to the environment of the NICU and processing the news that their infant may not live creates feelings of anxiety, helplessness, and loss of control over the situation.<sup>10</sup> Parents commonly reported feeling guilty and taking responsibility for their infants’ condition as well as feeling like they were abandoning their infant when they were unable to be in the NICU.<sup>10</sup> Parents expressed that the emotional support provided by NICU staff was very helpful in coping with these emotions.<sup>10</sup> In a study by Cortezzo et al, nearly three-fourths of participants felt they received adequate emotional support from staff.<sup>22</sup>

Common supports for parents within the NICU included religious leaders such as chaplains as well as social workers, both of which were considered supportive for parents.<sup>10,17</sup> In

a 2019 study by Baughcum et al, mothers with increased contact with a social worker reported that their needs were very well met.<sup>17</sup> Outside of the NICU staff, parents also found comfort in communicating with parents of other infants in the NICU.<sup>13</sup> By communicating with other parents, both in-person and through social media, parents felt that they were more prepared for the death of their infant and had more realistic expectations.<sup>13,18</sup>

### Bereavement Support

Bereavement support is an important component of NPC that supports families through their grieving process once they have left the NICU. Most of the parents in the studies were provided with bereavement support, but the amount of support and how it was administered differed based on the institution. In the study by Cortezzo et al, 85.7% of parents stated that they were offered information about bereavement support as well as 71.4% of parents stated receiving follow-up contact from their providers.<sup>22</sup> However, about half of these parents wanted more follow-up contact and support from their providers.<sup>22</sup> The 2020 study by Baughcum et al found that parents' needs for follow-up contact with providers was not well met; however, another study by Levick et al found that two-thirds of their participants felt they had the right amount of follow-up contact.<sup>17,24</sup> Overall, consensus from these studies on what bereavement support tactics and what frequency of contact was ideal was not achieved.

A few studies also mentioned the importance for parents of leaving a legacy for their infant in the grieving process. By telling the story of their infant and helping other parents in similar positions to them, parents were able to find positive meaning in their grieving process.<sup>13</sup>

One study by Akard et al interviewed bereaved parents on their interest in participating in a digital legacy-leaving program.<sup>16</sup> This program would allow the parents to tell the story of their infant while supporting other parents in the NICU. All parents involved in the study said they would have been interested in participating in a program like this after their infant died. Parents also noted that they would have been unprepared to create a legacy project on their own without the help of the NICU.<sup>16</sup> Overall, parents found bereavement and follow-up services as well as the opportunity for legacy-leaving to be factors that contributed positively to their satisfaction.

## DISCUSSION

This literature review aimed to highlight factors that influence parent perceptions of NPC. While there has been an increase in the number of studies on this topic in the last few years, there is still research that needs to be conducted to more fully understand the needs of parents and the efficacy of existing NPC protocols. By uncovering the factors that shape parents' experiences with NPC, several recommendations for practice implications and future studies can be drawn.

One area of the literature in which parents stated that their needs were not consistently met is being involved in the care of their infant. Some parents felt that they were presented with sufficient opportunities to provide care for their infant, but some parents were frustrated that they were not invited by some providers to participate in care activities.<sup>17,19</sup> Parents wanting to be involved in the care of their child is mirrored throughout pediatric care literature and has many benefits for both the parent and child.<sup>25</sup> To ensure that parents are given sufficient opportunities to care for their infant, researchers have developed and piloted family-centered care protocols in US NICUs which have been endorsed by the American Academy of Pediatrics.<sup>26</sup> In Sweden, families take on major roles in the care of their infant in the NICU, and this practice has been shown to provide many benefits for both the parents and the infant.<sup>26</sup> By incorporating parents into the care process for their infant, providers can ensure that parents feel supported in their role as caregivers.

Another area in which parents were not always satisfied with care was consistent communication with providers. Due to frequent changing of care provider assignments, parents

often would have to contact and explain their needs to a variety of providers during their stay in the NICU which contributed to emotional distress and fatigue.<sup>11</sup> This need is also one well documented in literature surrounding parents with hospitalized children and continues to be an area for improvement in the US.<sup>27</sup> Providers and institutions must find ways to remedy this, whether through more consistent provider assignments to each infant or through regular family meetings with the entire care team. Best practices for family meetings in the NICU have been explored.<sup>30</sup> In order to hold effective family meetings, providers should prepare parents before the meeting, address their needs and concerns with the group early on in the meeting, and use visual aids to assist the parents in understanding their infant's condition. These steps can help to include the parent as an active participant in the care of their infant and minimize miscommunication between providers.<sup>28</sup>

In the literature, there was a discrepancy between how much parents thought their infant suffered versus how much health care providers thought the infant suffered.<sup>22</sup> This pattern is found in other articles examining parent versus provider perceptions of pain and suffering in children, in which physicians rate the pain of their patients significantly lower than the parents rate their child's pain.<sup>29</sup> In order to resolve this issue, parents should be educated on the actual meaning behind the symptoms that their infant is exhibiting and if that means that they are in pain or not. To this date, there are very few pieces of literature or interventions that address this; therefore, more research should be done to explore this issue.

Multiple parents cited the importance of online resources and communities for education and support purposes.<sup>13,18</sup> In an increasingly digital age, providers can support parents by guiding them towards useful organizations and sites to support themselves during their time in the NICU

and throughout their grief process. There are many online support groups and hot lines such as NICU Helping Hands, Mothers Enduring Neonatal Loss (M.E.N.D), and the Tiny Miracles Foundation. Parents also cited wanting resources and guidance on how to introduce their other children to the dying infant. Groups such as the Infant Loss Resources organization have put out guides in order to support families in facilitating conversations around the death of their new sibling.<sup>30</sup>

Bereavement support was the final topic in which parents were not always satisfied with the care provided by institutions.<sup>17,22</sup> Due to the complex nature of each family and their experience in the NICU, a “one size fits all” approach is not appropriate when it comes to bereavement support and follow-up contact. This finding is consistent with broader research exploring the bereavement needs of parents of children of all ages with terminal-illnesses such as cancer.<sup>31</sup> Hospitals should assist the parents in arranging funeral services and should offer resources for grief support and counseling at the time of discharge.<sup>32</sup> After the parents have left the NICU, a sympathy card and/or phone call are current standards in many hospitals.<sup>32</sup> Apart from this, there are not many interventions or studies that have worked to understand the effectiveness of bereavement and follow-up support provided by hospitals. A push to provide personalized bereavement support is necessary to increase parent satisfaction with NPC.

In addition to addressing the issues outlined above, further research should be done to further investigate the NPC needs of parents. This should include understanding the different needs of parents based on factors like religion, cultural background, and socioeconomic status. Parents or single mothers with low external support from family and friends may need more support from social services within the NICU. The idea of palliative care is something that is not

understood or accepted in multiple cultures, so culturally-sensitive education for parents on the idea of comfort care should be implemented. There should also be an increase in the number of interventions assessed for their efficacy in relation to these areas of concern so that providers may have evidence-based guidance on what practices are actually supportive for parents.

There are several weaknesses of the body of literature surrounding parents' perceptions of NPC that must be addressed. Firstly, only 16 articles were identified that matched the selection criteria for the literature review. This indicates that somewhat of a smaller pool of knowledge exists on this topic which limits the educational value that providers may pull from research on this topic. As more articles are published in the future years, since this is an emerging subset of neonatal research, another literature review should be done. Of the articles that were included in the review, seven of them relied on qualitative interviews only. Of the eight articles that did use surveys, only a handful utilized validated survey tools. This limits the reliability and confidence in the findings from these studies. In the future, the development of validated survey tools for this topic as well as pursuing more quantitative data will serve to increase the state of knowledge on this subject.

There are a few weaknesses of this literature review that must be addressed. There is a possibility that in searching through the results from the databases, relevant articles may have been overlooked. This could have been due to the use of improper search terms that did not accurately describe the available data, or due to human error while reading through the results from each database. Overall, this literature review was conducted in a systematic manner using PRISMA guidelines, so there can be relative confidence in the results of this study.

## CONCLUSION

The goal of this literature review was to summarize parents' perceptions of NPC with a focus on identifying the specific factors that contribute to their perceptions and satisfaction with care. Through analysis of the 16 articles included in the literature review, factors of NPC were broken down into those related to interactions with providers, interactions with the infant, and interactions with oneself. Among the literature related to interactions with providers, important factors that shape parents' perceptions of NPC include building relationships and trust with staff through consistent staff assignments and compassionate conversations. Having honest and open communication with providers in a private, confidential setting was found to promote quality NPC. Educating and informing parents on their infants' condition allowed parents to feel more comfortable participating in the decision-making process.

Factors that shaped parents' perceptions of NPC related to the care of their infant included their ability to maintain their role as a parent through care giving, bonding, and memory making activities. Additionally, parents' perceptions of infant symptoms and suffering played a large role in their perceptions of and overall satisfaction with the care they were provided. Parents also had NPC needs related to taking care of themselves emotionally. Factors that shaped their experience with NPC related to themselves included religious support, emotional support from social workers, staff, and other parents, as well as online resources. Bereavement support and follow-up contact from staff was also indicated as important to parents in facilitating their grieving process. Overall, these factors need to be considered by providers to deliver the best NPC possible to support these parents and their infants.

## APPENDIX: DATA EXTRACTION TABLE

**Table 1: Data Extraction Table Describing Key Components of Each Article**

<b>Authors (year)</b>	<b>Study Design</b>	<b>Sample and Setting</b>	<b>Key Findings</b>
Baughcum, Fortney, Winning (2017)	-qualitative interviews with parents to assess their satisfaction with NPC	-29 mothers and 16 fathers whose infant had died in a large, level 4 NICU in the Midwest	-interviews uncovered four primary themes among parent responses: parents as partners in care, communication, relationships with staff, and bereavement support -parents indicated being involved in care both while the infant was alive and post-mortem -parents appreciated alone time to bond with the infant and allowing siblings to also be involved
Currie, Christian, Hinds (2016)	-descriptive qualitative study related to parent's experiences with NPC and end-of-life in the NICU -in depth, face-to-face interviews	-10 bereaved parents who had lost a child in the NICU at least 15 months before the interviews -level 3 NICU in the Southeast United States	-parents reported wanting to be involved in the care for their infant and the decision-making process -parental emotional support was identified as important through interactions with staff -parents were initially reluctant to accept NPC
Cortezzo, Saunders et al (2015)	-descriptive exploratory cross-sectional study -administered surveys that included Likert scale and free response questions	-28 parents who had recently lost an infant at Connecticut Children's Medical Center -health care providers were also surveyed	-parents reported feeling that their infant was in pain -parents indicated wanting more extensive bereavement/follow up support and memory making
Tan et al (2012)	-a longitudinal, qualitative, descriptive study of parents bereavement process after their infants death	-72 interviews from 14 parents who had lost their infant in a Southeast medical center	-parents identified several important factors in quality bereavement care: having realistic expectations, continuous care, memory making, social support, and being able to support other parents in their situation
Baughcum, Fortney (2020)	-survey included the Bereaved Parent Satisfaction and Unmet Needs Questionnaire, Pediatric Quality of Life Inventory (PedsQL)	-67 bereaved parents whose infant had died more than three months before the interview from a Midwestern level 4 NICU	-parents identified the following areas for improvement: provider availability and communication, participation in care, and infant suffering -parents identified the following areas as needs that were well met: memory

	Healthcare Satisfaction Module 4.0, and -results analyzed by statistical analyses		making, quality time with infant, and upholding the dignity of the infant -parents who perceived that their infant was suffering reported lower satisfaction with NPC -parents were most distressed by negative physical changes in their infant
Clark et al. (2021)	-retrospective, cross-sectional study -survey utilized the Impact of Events Scale-Revised and Prolonged Grief-13 scales	-same participant population as the Baughcum 2020 article, additional publication	-mothers perceptions of symptom burden as well as the number of medical interventions performed in the last week of life contributed to increased post-traumatic stress symptoms (PTSS) and prolonged grief (PG) - fathers perceptions of infant suffering were correlated with increased PTSS and PG -mothers and fathers may have different factors that contribute to their grief process
Parravicini et al (2018)	-prospective mixed-method survey of parents perceptions of infant comfort during NPC	-35 parents whose infant died under the care of a standardized NPC team at Columbia University Medical Center	-parents scored the ability to experience kangaroo care and feedings the lowest of the comfort care items -parents considered comfort to be more than pain relief, citing bonding as a major factor -parents identified caring, support, healing and transcendence as major descriptors of quality NPC
Falck et al (2016)	-qualitative, descriptive study of both mothers and providers using semi-structured interviews -investigating their perceptions of NCP	-six mothers, five nurses, and one physician were interviewed -mothers had lost an infant in the level 4 NICU, their responses are separate from those of the providers	-5 themes emerged from the data: communication, privacy, continuity of care, maternal knowledge seeking, and emotional turmoil -the NICU in this study had an open room design, causing privacy to be of main concern to mothers -maternal knowledge seeking refers to mothers wanting to learn more about their infants conditions, medical equipment, and the roles of each provider
Callahan et al (2019)	-prospective cohort study to determine the impact of NPC on parent stress/anxiety levels -the Neonatal Unit Parental Stressor Scale and Depression Anxiety Stress Index-21 were used	-77 parents whose neonate had died due to congenital heart disease and undergone NPC	-parents of infants with congenital heart disease often learn of their infants diagnosis prenatally, causing more time for stress and anxiety to build -the intervention focused on bonding, feeding, memories, emotional/psychological support from a multidisciplinary care team

	-intervention group received the BACI intervention, created by the researchers		-the intervention decreased overall stress in the intervention group versus the control group, specifically of stress surrounding the appearance of the neonate as well as social/outside life hassles
Fortney et al (2019)	-qualitative telephone interviews exploring parents perceptions of infant suffering at end of life	-46 parents whose infant had died in a level 4 midwestern NICU and received NPC	-themes from the data include: the presence of suffering, indicators of suffering, timeline of suffering, and impact of perceived suffering on parents - 57% of mothers compared to 31% of fathers believed their infant had suffered -common signs parents reported of suffering included difficulties breathing and feeding, swelling, and lethargy. -33% of mothers noted an increase in suffering at EOL
Shultz et al (2017)	-retrospective comparison of electronic medical records reports of symptoms versus parent narratives of symptoms -surveys of parents to explore their experiences with NPC as it relates to infant suffering	-67 parents of infants who had died and undergone NPC, part of a larger review -electronic medical records were also referenced for the infants of the parents in the study	-according to mothers, the worst symptom reported was the infant's overall appearance and swelling. -mothers listed on average 6.63 symptoms, while fathers listed 5.67 symptoms -there were no significant differences in the number of symptoms reported by parents and the electronic medical records
Wool et al (2017)	-online survey of quality indicators of NPC through the Quality Indicators and Parental Satisfaction of Perinatal Palliative Care Instrument -part of a larger study titled 'The Voices of Parents'	-405 parents who had experienced the loss of an infant and undergone NPC, national sample	-statistically significant quality indicators include compassionate care, ample time to talk with physicians, and emotional support -if parents were satisfied with care, they were twice as likely to endorse the above indicators
Levick 2017	-qualitative surveys administered via mail 1 year after the death of the infant	-36 parents of infants who died in a level 4 NICU in West Michigan	-34 of the 36 parents indicated that they were treated with kindness, understanding, and quality care -negative aspects of these parents' care experiences include no laundry service for the parents who are at the bedside all day as well as too graphic photos produced during memory making practices -positive experiences of these parents' care included memory making such as photos and hand/footprints as well as follow-up contact from HCPs

Shelkowitz (2015)	-cross-sectional survey study of bereaved mothers to determine perceptions of NPC care options for their child	-28 mothers whose infant had died between one and five years from the survey date in the NICU or delivery room	-79% of mothers felt that the number of options for infant care (ex. bathing, keep sakes, spiritual care) were adequate -least utilized care options included lighting and music wishes during birth
Moro (2011)	-four semi-structured interviews throughout the process of birth and death of the infant -informed by the Ottawa Decision Support Framework	-five cases were chosen from a larger study to analyze the interviews of parents and staff of these infants who died in their NICU	-mothers indicated wanting to exhaust all treatment/life-saving options for their infant -pain and suffering of the infant as well as hope for survival largely impacted care decisions -decision making includes more than just the nuclear family -rapport with and consistent staff was denoted as important by mothers -communication with staff can be a source of frustration and distress for mothers -mothers also used online resources that influenced their decision making and overall mentality
Akard 2018	-focus group with semi-structured interviews with bereaved parents -examined parent perceptions of a digital storytelling legacy intervention	-six bereaved parents participated in the focus groups 3 to 12 months after the death of the infant	-major themes collected from the interviews include the willingness to participate in legacy interventions, interventions that parents believe would be beneficial, and the perceived benefits of legacy interventions -all six parents indicated being willing to participate in a legacy intervention -parents were unprepared to initiate their own memory-making during the death of their infant

## REFERENCES

1. Infant health statistics. CDC/National Center for Health Statistics website. Updated March 2, 2021. Accessed July 25, 2021. <https://www.cdc.gov/nchs/fastats/infant-health.htm>
2. Parravicini E. Neonatal palliative care. *Curr Opin Pediatr*. 2017;29(2):135-140. doi:10.1097/MOP.0000000000000464
3. Beltran S, Hamel MN. Caring for Dying Infants: A Systematic Review of Healthcare Providers' Perspectives of Neonatal Palliative Care. *Am J Hosp Palliat Care*. 2020. doi: doi.org/10.1177/1049909120965949
4. Petteys AR, Goebel JR, Wallace JD, Singh-Carlson S. Palliative care in neonatal intensive care, effects on parent stress and satisfaction: a feasibility study. *Am J Hosp Palliat Care*. 2015;32(8):869-875. doi:10.1177/1049909114551014
5. 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
6. Epstein RM, Street RL Jr. The values and value of patient-centered care. *Ann Fam Med*. 2011;9(2):100-103. doi:10.1370/afm.1239
7. Kain VJ. An exploration of the grief experiences of neonatal nurses: A focus group study. *J Neonat Nurs*. 2013;19(2):80–8. doi: 10.1016/j.jnn.2012.04.001
8. Al-Abri R, Al-Balushi A. Patient satisfaction survey as a tool towards quality improvement. *Oman Med J*. 2014;29(1):3-7. doi:10.5001/omj.2014.02

9. 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
10. Falck AJ, Moorthy S, Hussey-Gardner B. Perceptions of Palliative Care in the NICU. *Adv Neonatal Care*. 2016;16(3):191-200. doi:10.1097/ANC.0000000000000301
11. Baughcum AE, Fortney CA, Winning AM, Shultz EL, Keim MC, Humphrey LM, Schlegel AB, Gerhardt CA. Perspectives from bereaved parents on improving end of life care in the NICU. *Clinical Practice in Pediatric Psychology*. 2017; 5(4): 392–403. doi: 10.1037/cpp0000221
12. 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
13. Tan JS, Docherty SL, Barfield R, Brandon DH. Addressing parental bereavement support needs at the end of life for infants with complex chronic conditions. *J Palliat Med*. 2012;15(5):579-584. doi:10.1089/jpm.2011.0357
14. Fortney CA, Baughcum AE, Moscato EL, Winning AM, Keim MC, Gerhardt CA. Bereaved Parents' Perceptions of Infant Suffering in the NICU. *J Pain Symptom Manag*. 2019. doi: 10.1016/j.jpainsymman.2019.12.007
15. 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

16. 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
17. 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
18. Moro TT, Kavanaugh K, Savage TA, Reyes MR, Kimura RE, Bhat R. Parent decision making for life support for extremely premature infants: from the prenatal through end-of-life period. *J Perinat Neonatal Nurs.* 2011;25(1):52-60. doi:10.1097/JPN.0b013e31820377e5
19. Shelkowitz E, Vessella SL, O'Reilly P, Tucker R, Lechner BE. Counseling for personal care options at neonatal end of life: a quantitative and qualitative parent survey. *BMC Palliat Care.* 2015;14:70. Published 2015 Dec 2. doi:10.1186/s12904-015-0063-6
20. Callahan K, Steinwurtzel R, Brumarie L, Schechter S, Parravicini E. Early palliative care reduces stress in parents of neonates with congenital heart disease: validation of the "Baby, Attachment, Comfort Interventions". *J Perinatol.* 2019;39(12):1640-1647. doi:10.1038/s41372-019-0490-y
21. Clark OE, Fortney CA, Dunnells ZDO, Gerhardt CA. Parent Perceptions of Infant Symptoms and Suffering and Associations with Distress Among Bereaved Parents in the NICU. *J Pain Symptom Manage.* 2021; 000:1-8. doi: 10.1016/j.jpainsymman.2021.02.015
22. 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

23. Parravicini E, Daho' M, Foe G, Steinwurtzel R, Byrne M. Parental assessment of comfort in newborns affected by life-limiting conditions treated by a standardized neonatal comfort care program. *J Perinatol*. 2018;38(2):142-147. doi:10.1038/jp.2017.160
24. 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
25. Melo EM, Ferreira PL, Lima RA, Mello DF. The involvement of parents in the healthcare provided to hospitalized children. *Rev Lat Am Enfermagem*. 2014;22(3):432-439.  
doi:10.1590/0104-1169.3308.2434
26. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. *J Perinatol*. 2015;35 Suppl 1(Suppl 1):S5-S8. doi:10.1038/jp.2015.142
27. Heller KS, Solomon MZ; Initiative for Pediatric Palliative Care (IPPC) Investigator Team. Continuity of care and caring: what matters to parents of children with life-threatening conditions. *J Pediatr Nurs*. 2005;20(5):335-346. doi:10.1016/j.pedn.2005.03.005
28. Drago M, Lorenz JM, Hammond J, Hardart GE, Morris MC. How to hold an effective NICU family meeting: capturing parent perspectives to build a more robust framework [published online ahead of print, 2021 Apr 21]. *J Perinatol*. 2021;1-8. doi:10.1038/s41372-021-01051-4
29. Brudvik C, Moutte SD, Baste V, Morken T. A comparison of pain assessment by physicians, parents and children in an outpatient setting. *Emerg Med J*. 2017;34(3):138-144.  
doi:10.1136/emermed-2016-205825

30. Helping Children Cope with the Sudden and Unexpected Death of an Infant. Infant Loss Resources website. Accessed July 26, 2021. [http://infantlossresources.org/?page\\_id=916](http://infantlossresources.org/?page_id=916)
31. Giorgali S. Bereaved parents' needs regarding hospital based bereavement care after the death of a child to cancer [published online ahead of print, 2020 Sep 24]. *Death Stud.* 2020;1-9. doi:10.1080/07481187.2020.1824202
32. Kenner C, Press J, Ryan D. Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach. *J Perinatol.* 2015;35 Suppl 1(Suppl 1):S19-S23. doi:10.1038/jp.2015.145