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REVIEW

Scoping Review of Memory Making in Bereavement Care for Parents After the Death of a Newborn

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ABSTRACT

Objective: To summarize and synthesize extant literature on memory making in bereavement care for parents who experience the death of a newborn and to identify opportunities for future research.

Data Sources: We conducted a systematic search of four health-related databases (MEDLINE Complete, CINAHL Complete, Embase, and PsychINFO) for original research in January 2019. We then conducted a manual search of the reference lists of all included articles and a citation search via Scopus.

Study Selection: Selection criteria initially included all original research articles available in English that related to parents' perceptions of perinatal or neonatal palliative care or bereavement care for parents after the death of a newborn. These criteria were refined as we developed familiarity with the available literature. Our initial screening of article titles and abstracts yielded 287 articles for full-text review. After full-text analysis, we included all 25 qualitative or mixed method research articles that met selection criteria.

Data Extraction: We used a spreadsheet modeled on the Joanna Briggs Institute Review Guidelines (2015) for data extraction.

Data Synthesis: Available research was focused primarily on parents' perceptions of care during and after the death of their newborns. Memory making interventions emerged as significant elements of the experiences of bereaved parent. Several researchers examined parents' perceptions of specific memory making interventions, such as bereavement photography. Contact with the newborn, opportunities for caregiving, bereavement photography, and the collection or creation of mementos emerged as important elements of memory making. Parents also identified a need for guidance about each of these key strategies for memory making.

Conclusion: We identified few studies focused entirely on memory making as an intervention in the context of bereavement care for parents. However, memory making emerged as a recurring theme throughout qualitative and mixed method studies on parents' perceptions of perinatal or neonatal end-of-life care. Further research is required to provide evidence to guide memory making interventions for bereaved parents who experience the death of a newborn.

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For most families, the birth of a child is a time of anticipation, excitement, and joy. However, for some families, the joy of birth is followed all too quickly with the devastation of loss. Indeed, in 2017 alone, an estimated 2.5 million infants died worldwide during the neonatal period (United Nations International Children's Emergency Fund, 2018). With the death of a newborn, parents are placed at risk of complicated and often prolonged grief (Cacciatore, 2013; Kersting & Wagner, 2012). The provision of appropriate psychosocial care is vital to promote optimal outcomes for bereaved parents who experience the death of a newborn (Koopmans, Wilson, Cacciatore, & Flenady, 2013; McGuinness, Coughlan, & Power, 2013).

As part of a strategy for psychosocial bereavement care, memory-making practices have become commonplace in neonatal units (Gibson, Finney, & Boilanger, 2011; Robertson, Aldridge, & Curley, 2011). In addition, numerous perinatal and neonatal palliative care guidelines include recommendations for promoting bonding between newborns and parents and encouraging parents to engage in caregiving with their newborns before or after death (Australian College of Neonatal Nurses, 2010; British Association of

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Perinatal Medicine, 2010; Department of Health and Human Services Victoria, 2017; Perinatal Society of Australia and New Zealand, 2009). It is posited that these interactions provide significant memories for parents, help confirm the significance of the newborn's life and death, and help create a sense of identity for the stillborn or newborn infant (Flenady et al., 2014; Rådestad et al., 2009).

The collection or creation of mementos, such as photographs, personal items, clothing, or footprints, also has become common in practice and is recommended throughout perinatal and neonatal palliative care guidelines (Australian College of Neonatal Nurses, 2010; British Association of Perinatal Medicine, 2010; Department of Health and Human Services Victoria, 2017; Perinatal Society of Australia and New Zealand, 2009). Findings of several studies indicated that the provision of mementos is an important aspect of care for bereaved parents (Baughcum et al., 2017; Cacciatore & Flint, 2012; McGuinness, 2015; Shelkowitz, Vessella, O'Reilly, Tucker, & Lechner, 2015). As described by Branchett and Stretton (2012), for parents who experience the death of a newborn, "memories became fundamental, as parents could take only these with them, not the baby they were expecting" (p. 41).

Despite the identification of memory making as an important component of bereavement care for parents after perinatal or neonatal death, few researchers have explored memory making as an aspect of bereavement care in detail. The aim of this scoping review was to summarize and synthesize evidence about parents' perceptions of memory making interventions in bereavement care after the death of a newborn and to highlight opportunities for further research.

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Design

Scoping reviews provide a mechanism to clarify concepts, synthesize evidence, and provide focus for future research (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010). In particular, scoping reviews provide a way to synthesize evidence when significant complexity or heterogeneity in the literature precludes full, systematic reviews (Khalil et al., 2016). Additionally, scoping reviews allow for greater flexibility of inclusion criteria than systematic reviews, which results in a broader view of the available evidence (Joanna Briggs Institute [JBI], 2015). Currently, evidence on memory making related to the death of a newborn is scattered throughout nursing, psychology, and social work literature, and there is considerable heterogeneity in the methodology and quality of the available studies.

Arksey and O'Malley (2005) provided a useful framework with which to undertake scoping reviews. They proposed a five-stage process that starts with framing a research question and identifying potentially relevant research through a systematic literature search. The selection of studies is then undertaken. However, unlike a systematic review, which has fixed inclusion and exclusion criteria, a scoping review is iterative in nature, and inclusion and exclusion criteria are adapted as reviewers become increasingly familiar with the literature (Arksey & O'Malley, 2005). Once studies have been selected for review, Arksey and O'Malley (2005) recommended the use of a data charting form to promote consistent extraction of data. Finally, narrative analysis is used to synthesize extracted data (Arksey & O'Malley, 2005). It should be noted that formal evaluation of the quality of the included studies is not typically performed in a scoping review; rather, scoping reviews provide a broad picture of all of the available literature, regardless of quality (Arksey & O'Malley, 2005; JBI, 2015).

The following research question underpinned this review: what is known about parents' perceptions of memory making in bereavement care after the death of a newborn? Given the potential ambiguity of the concept of memory making, we decided to include any intervention or experience that encouraged contact or interaction between parent and newborn and any intervention that resulted in the creation or collection of mementos. Arksey and O'Malley (2005) recommended "a wide approach in order to generate breadth of coverage" (p. 23) be maintained. Therefore, the concept of memory making was deliberately left broad to allow for the identification and review of as many relevant articles as possible.

Search Strategy

We searched four electronic databases in January 2019: MEDLINE Complete, CINAHL Complete, PsychINFO, and Embase. A liaison librarian with expertise in health-related systematic reviews assisted in refining the search strategy. Search terms were tested to identify those that would yield relevant articles. The final search terms included combinations of the following: newborn, neonat*, infan*, perinatal, early infant; palliative, end-of-life, dying, bereave*, terminal care; memento, photo*, ritual*, memor*, material culture; and mother*, father*, parent*.

This search produced 6,851 citations, which we screened for duplicates. A total of 1,681 duplicates were removed, which left 5,170 articles for screening by title and abstract. To supplement this systematic search, we searched the reference lists of the included articles. Finally, we conducted a search in Scopus for each of the included articles. We reviewed new articles that cited the included articles for potential relevance. This process yielded 10 additional articles for screening.

We used an iterative approach to study selection. The initial search was designed to uncover the breadth of literature that may be relevant to the research question. As our familiarity with the literature increased, criteria for selection were developed to enable a focus on parents' experiences and perceptions. To be included in this scoping review, studies were required to meet four inclusion criteria:

1. Included parents of neonates as research participants.
2. Included one or more memory making intervention as the focus of investigation or as a finding.
3. Contained original data from the perspective of bereaved parents; opinion pieces, news items, editorials, and review articles were excluded.
4. Available in English.

We conducted screening in two stages. First, the first author (R.T.) reviewed all citations by title and abstract. We excluded 4,893 citations at this stage, most commonly because study interventions or study populations were outside the scope of the review. Full-text review was conducted of 287 studies. The first author performed most of the full-text screening and sought consensus from coauthors (L.H. and P.N.) if there was ambiguity around the relevance of the study to the scoping review or when decisions to amend inclusion criteria were made.

In the included studies, parents needed active guidance and practical support to engage in memory making with their newborns.

For example, we decided to exclude quantitative studies during full-text screening. On reading these studies, it became apparent that the data were too heterogeneous to permit meaningful synthesis and were not primarily focused on parents' perceptions of memory making. We also made the decision to exclude studies that were more than 30 years old during full-text evaluation because they did not reflect current practice or social norms surrounding perinatal death.

Full-text screening resulted in the exclusion of a further 249 articles; 13 articles were excluded because of quantitative methodology or age. Twenty-five articles were included in this review. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart was used to track the inclusion and exclusion decisions throughout the course of the study selection (see Figure 1).

Data Abstraction and Synthesis

We entered data from each of the included studies into a custom spreadsheet that allowed for consistent documentation of the characteristics and key findings of each study. We developed the data charting form based on the JBI (2015) manual for scoping reviews, which draws together the work of Arksey and O'Malley (2005) and Levac et al. (2010). As per the manual, we extracted the following data from each study: author(s), year of publication, country of origin, study population and sample size (if applicable), methodology/methods, study focus or intervention, and key findings. For the purposes of this review, only findings relevant to parents' perceptions of memory making interventions were documented; most of the studies included multiple aspects of bereavement care. We provide a summary of the extracted data in Supplemental Table S1.

A narrative analysis of the qualitative content of each of the included studies was undertaken. Use of the narrative analysis provided a way to synthesize the findings from a range of study types into meaningful implications for practice and provided context about the type of studies to assist in decision making (Arksey & O'Malley, 2005). Results of this narrative analysis showed five themes that recurred throughout the literature: *Contact With the Newborn*, *Opportunities for Caregiving*, *Bereavement Photography*, *Collection and Creation of Mementos*, and *Guidance in Memory Making.*

Results

Study Characteristics

Of the 25 studies included in our review, most ($n = 20$) were qualitative and used a range of approaches, including qualitative description and thematic analysis, phenomenology, and grounded theory. Five were mixed methods studies. The quantitative components of these mixed methods studies were heterogeneous and were not focused on parents' perceptions of memory making. Given this heterogeneity and the overall purpose of this review, we decided to exclude quantitative data; however, relevant qualitative data from the five mixed methods studies were incorporated.

Most of the studies eligible for inclusion in this review were conducted in the United States ($n = 19$). Only one study originated from each of the following countries: Canada, Iran, Ireland, Sweden, Switzerland, and the United Kingdom. Of the studies included in this review, only one was published before 2000; seven studies were published between 2000 and 2010. Most studies ($n = 17$) were more recent and were published between 2011 and 2019.

Sample sizes within the included studies varied widely from four participants in one case series to 181 participants in a survey-based mixed method study. Most studies included mothers and fathers ($n = 18$). However, all but 2 of these 18 studies had a disproportionately high number of participants who were mothers, which meant that the views of fathers were typically underrepresented. Of the 25 included studies, 13 provided details about the cultural and religious characteristics of their samples. In

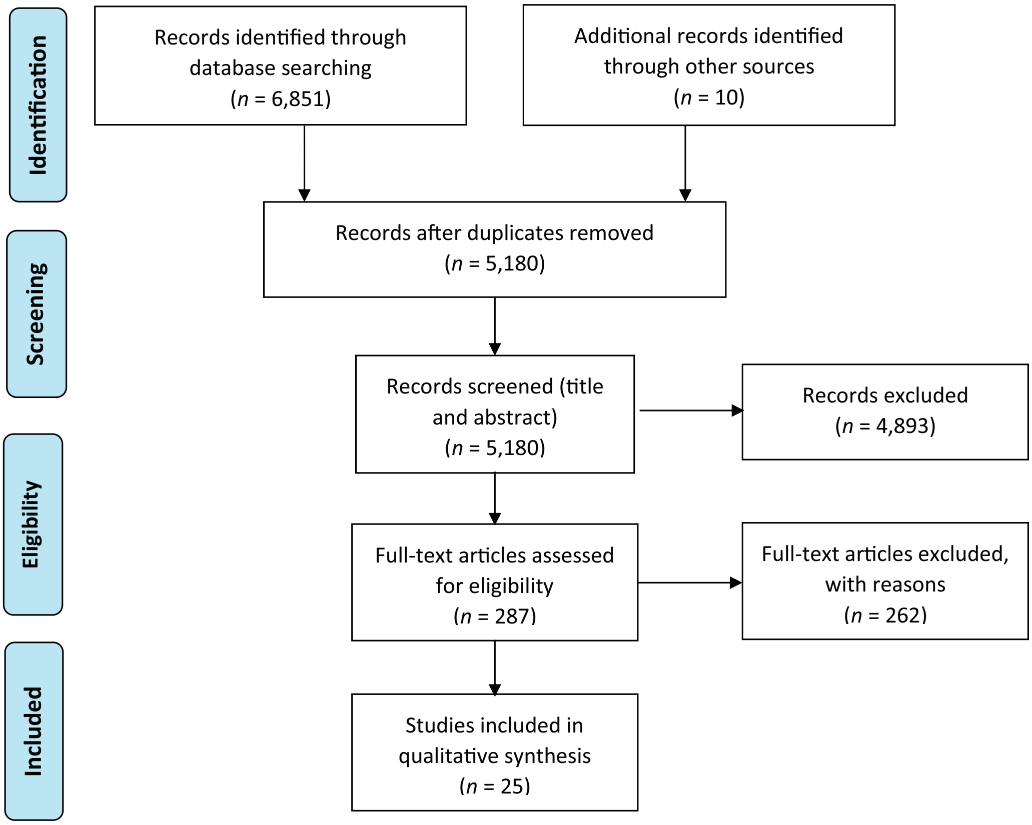

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart: memory making in bereavement care for parents after the death of a newborn.

11 of these studies, individuals who identified as White and of Christian faith were most heavily represented; two studies were specifically focused on African American parents experiencing perinatal loss.

Contact With the Newborn

Most parents across studies considered the opportunity to see, touch, and hold the newborn during end-of-life care to be valuable (Abraham & Hendriks, 2017; Baughcum et al., 2017; Lemmer, Boyd, & Forrest, 1991; Limbo & Lathrop, 2014; McGuinness, 2015; Sadeghi, Hasanpour, & Heidarzadeh, 2016). Abraham and Hendriks (2017) described parents' "profound need to fulfil this parental role and to give some warmth and support to their dying baby" (p. 2107). Similarly, McGuinness (2015) explained that spending time with the newborn, holding the newborn, and providing "comfort, warmth, love and time" (p. 63) was central to the experience of mothering for bereaved mothers in her study. Physical contact with newborns while they were alive enabled parents to form important bonds and to create memories that were helpful after their newborns had died.

Holding the newborn as he or she died was helpful for some parents but was also emotionally difficult (Kavanaugh & Hershberger, 2005; Lemmer et al., 1991; Lundqvist, Nilstun, & Dykes, 2002; Pector, 2004). Kavanaugh and Hershberger (2005) reported that all but one of the mothers of live-born infants in their study held their newborns as they died and that for many of them, this represented their first opportunities to hold their newborns. Conversely, in their phenomenological study, Lundqvist et al. (2002) found that mothers whose newborns died experienced ambivalence about being present during the death; most valued the experience but needed the support and reassurance of staff.

Finally, several researchers explored parents' perceptions of time spent with their newborns after death. In their study of 20 bereaved parents, Abraham and Hendriks (2017) reported that "all parents felt the need to spend some time with their deceased baby even though this varied from a few hours to a week" (p. 2107). Indeed, parents' failure to spend time with their newborns or to contribute to their newborns' care after death was associated with regrets in two studies (Baughcum et al., 2017; Cacciatore & Flint, 2012).

Opportunities for Caregiving

In addition to being present, participating in bedside care was identified as a helpful practice by parents in several studies (Abraham & Hendriks, 2017; Armentrout, 2009; Baughcum et al., 2017; Brosig, Pierucci, Kupst, & Leuthner, 2007; Currie et al., 2016; Lemmer et al., 1991). In a descriptive study by Currie et al. (2016), parenting in the NICU emerged as a primary concern for parents:

> It was important for participants to have the opportunity to "be a parent" in the NICU regardless of how much the parents could participate in the infant's care. One of the mothers described her time parenting in the NICU, "She (nurse) let me do anything I could possibly do that was mom-like. . . . That was so exciting." (p. 481)

Similarly, Baughcum et al. (2017) conducted surveys and interviews with bereaved parents about their perspectives of end-of-life care in the NICU. Although some of their study was focused on participation in decision making, memory making also emerged as a significant theme. Parents expressed a "strong preference" for being involved in their newborns' bedside care. These authors reported that parents experienced frustration when staff did not welcome their participation in care and felt regret when their involvement in care was limited.

Lathrop and VandeVusse (2011) conducted a narrative analysis of mothers' stories about perinatal hospice. They also found that caregiving emerged consistently throughout the narratives. Caregiving was described as central to the concept of motherhood in these women's narratives, indicating that beyond supporting the development of important memories, providing care for their newborns may help individuals develop their identities as parents.

Bereavement Photography

Several researchers explored parents' experiences of bereavement photography in-depth (Alexander, 2001; Blood & Cacciatore, 2014a; Blood & Cacciatore, 2014b; Martel & Ives-Baine, 2014). For example, Blood and Cacciatore (2014a) conducted a mixed methods survey of bereaved parents to identify recommendations for best practice from the perspective of parents. Their findings indicated that most parents who received photographs were supportive of bereavement photography as an intervention, and most parents who did not receive photographs of their newborns wished they had. Although bereavement photographs were largely appreciated by parents, this was not universal. For example, Alexander (2001) cautioned that bereavement interventions such as photography need to be tailored in response to parents' needs and values.

Parents described a range of barriers to bereavement photography, including their own state of shock, and practical obstacles, such as a lack of available photography equipment (Blood & Cacciatore, 2014a). Consent was also identified as a concern; however, parents wanted health providers to offer education and encouragement to ensure that photographs were taken, even if the suggestion was initially met with some reservation (Blood & Cacciatore, 2014a).

In studies on parents' perceptions of neonatal end-of-life care, bereavement photography also emerged as an important intervention (Baughcum, 2017; Cacciatore & Flint, 2012; Lemmer et al., 1991; McGuinness, 2015; Shelkowitz et al., 2015). Researchers who studied child deaths across different age groups emphasized that parents who experienced perinatal loss were more likely to place value on bereavement photography than parents who experienced the loss of an older child (Cacciatore & Flint, 2012).

The quality and content of photographs were identified as important to parents (Alexander, 2001; Blood & Cacciatore, 2014a). For example, parents favored images that captured moments or activities associated with parenting. This included images of the newborn without medical equipment, tubing, and wires and those in which the newborn was posed as for normal photographs (Branchett & Stretton, 2012; Kavanaugh & Hershberger, 2005; Martel & Ives-Baine, 2014). Parents of multiples also expressed a desire for photographs of their newborns together (Pector, 2004).

Several researchers explored the significance that photographs hold for parents. In helping confirm the newborn's existence, perinatal bereavement photography may also legitimize the parents' loss (Alexander, 2001; Blood & Cacciatore, 2014b). Such images may also provide the basis for a continuing relationship between parents and child (Martel & Ives-Baine, 2014) or provide a mechanism for others to meet or get to know about the newborn (Limbo & Lathrop, 2014). Finally, photographs are important cues for memory to help parents process their losses (Alexander, 2001; Blood and Cacciatore, 2014b).

Collection and Creation of Mementos

In most studies, researchers described the collection or creation of mementos as meaningful from the perspective of bereaved parents (Akard et al., 2018; Armentrout, 2009; Baughcum et al., 2017; Cacciatore & Flint, 2012; Côté-Arsenault, 2003; Kavanaugh & Hershberger, 2005; Lundqvist et al., 2002; McGuinness, 2015; Shelkowitz et al., 2015). Commonly collected mementos included hand- or footprints or molds (Baughcum et al., 2017; Cacciatore & Flint, 2012; Côté-Arsenault, 2003; Fenstermacher & Hupcey, 2019; Levick, Fannon, Bodemann, Munch, & Ahern, 2017; Shelkowitz et al., 2015), items of clothing or blankets that had been in contact with the newborn (Brosig et al., 2007; Fenstermacher & Hupcey, 2019; Kavanaugh & Hershberger, 2005; McGuinness, 2015), and locks of hair (Cacciatore & Flint, 2012; Côté-Arsenault, 2003; Shelkowitz et al., 2015). Memory boxes, which typically contained an assortment of mementos, were also generally well received (Branchett & Stretton, 2012; Fenstermacher & Hupcey, 2019; Shelkowitz et al., 2015) but were less commonly described in the literature.

Brosig et al. (2007) studied the experiences of parents who lost infants from birth to 12 months of age and reported the following:

> Parents emphasized the importance of being able to bring things of the child home from the hospital, such as photographs, plaster casts of the child's hands and feet, or clothing that the child wore in the hospital. This was important especially since the parents were coming home without a baby. (p. 514)

Similarly, Côté-Arsenault (2003) studied the experiences of mothers who were pregnant after perinatal loss, including an unidentified number of mothers who experienced the death of a newborn. She explained the following:

> Despite the absence of the actual babies, families found ways to reflect their physical

> presence. They did this through concrete objects clearly and directly connected with the babies, something to touch, to see, or to hang on to in contrast to symbols with personal meanings that many would not recognize. (p. 29)

Objects such as handprints, photographs, or personal items associated with the newborn were found to help these mothers in “weaving of lost babies into the family fabric” (Côté-Arsenault, 2003, p. 33).

Guidance in Memory Making

The fifth theme that was evident across many of the included studies was parents’ need to be supported and guided through the process of memory making (Akard et al., 2018; Armentrout, 2009; Blood & Cacciatore, 2014b; Branchett & Stretton, 2012; Cortezzo, Sanders, Brownell, & Moss, 2014; Levick et al., 2017; Martel & Ives-Baine, 2014; Shelkowitz et al., 2015). For example, Shelkowitz et al. (2015) conveyed the importance of guidance for parents “given that this was a very difficult time and they were not prepared with the knowledge of what reasonable options are and what would be helpful to them in their long-term grieving process” (p. 7). Similarly, Akard et al. (2018) reported that parents felt emotionally unprepared to create mementos with their newborn in the NICU and were grateful to staff who actively supported them to engage in memory making. Abraham and Hendriks (2017) explained that parents in their study needed guidance simply to enter and move around in the NICU space, including guidance about how to approach, touch, and handle their newborns.

The need for guidance was especially strong related to bereavement photography; parents’ profound shock and grief affected their capacity to make decisions about photographing their dead or dying newborns (Blood & Cacciatore, 2014b; Martel & Ives-Baine, 2014). Parents across studies expressed the need for guidance with regard to all aspects of memory making, including spending time with their newborns, having physical contact, and collecting or creating mementos.

Discussion

Overall, the results of our scoping review provide evidence that parents valued the opportunity to spend time with their newborns while they were still alive and were grateful for the option of being present during their newborns’ deaths. Spending time with the newborn postmortem was experienced as challenging but was important to many families, whereas failure to spend time with the newborn after death was a source of regret for some families. Most researchers found that holding and touching their newborns, especially while the newborns were alive, was an important experience for most parents. However, the unique needs and preferences of each family must be respected. It is critical to avoid pressuring parents to engage in memory making activities that are inappropriate for them on personal, cultural, or spiritual grounds.

Opportunities to bond with their newborns and to create tangible mementos were important aspects of bereavement care for parents.

These studies also affirm that parents should be supported where possible to engage with their newborns throughout their stays in NICUs because time spent holding or caring for their newborns was regarded as important to parents after the newborns’ deaths. The importance of maintaining a parenting role throughout end-of-life care has been identified in several studies outside of the NICU context. For example, McGraw et al. (2012) found that parents who experienced the death of a child in pediatric intensive care units “sought meaningful ways to express and assert their parenthood” (p. e350) and that this was in part achieved when parents were able to remain close to their children and to contribute to their physical care.

The findings of the studies included in this review also showed that bereaved parents appreciated photographs and other tangible mementos of their newborns’ brief lives. Limbo and Kobler (2010) described the role of bereavement photography in supporting parents after perinatal loss. The authors argued that photographs act not only to confirm the newborn’s existence and to document his or her features but also to honor the relationship between the newborn and the family. Perhaps one of the most compelling features of the literature surrounding memory making as a bereavement intervention was the emergence of parents’ need for guidance. Although there is a growing body of research on parents’ decision making in other elements of neonatal end-of-life care, the need for guidance related to memory-making activities is less well understood.

The findings of our review indicate that parents needed active guidance and practical support to engage in memory making with their newborns.

Gaps in the Literature and Directions for Future Research

Authors of most studies included in this review failed to provide data about the cultural and religious background of their participants or used samples that included disproportionately high numbers of participants who identified as White and Christian. Across studies, we found limited focus on the influence of culture or spirituality on parents' preferences for perinatal end-of-life and bereavement care. It is crucial that future researchers assess the appropriateness and acceptability of the full range of memory making activities for spiritually and culturally diverse populations.

We found that many researchers explored perinatal loss; however, it was difficult or impossible to distinguish data collected from parents who experienced stillbirth from data collected from parents who experienced the death of a newborn. Although there are likely to be commonalities in the needs of bereaved parents regardless of whether the death occurred before, during, or after birth, it is problematic to assume that the needs of parents in different contexts are identical. For several studies, it was difficult to ascertain the number of participants or the settings from which the participants were drawn, so it was also more difficult to determine the fit of these studies with different clinical environments or populations or to make a formal assessment of research quality.

Finally, few researchers focused specifically on memory-making practices, and most who did focused on a single intervention (e.g., bereavement photography). Further detailed exploration into memory-making practices is required to develop a more nuanced understanding of how these practices affect parents' experiences of loss. Results from such studies would enable more robust clinical recommendations and would contribute to the evidence base that underpins bereavement care for parents in the context of newborn loss.

Limitations

One limitation of our review is the exclusion of articles in languages other than English. We acknowledge that this may have resulted in pertinent studies being excluded and is likely to have affected the range of cultures represented in the included studies. The heterogeneous nature of the quantitative data in this field also precluded a meaningful meta-analysis, which may have provided useful insight into parents' experiences of memory making.

In keeping with the objectives of a scoping review, the included studies were not formally assessed for methodological quality. Although this allowed for inclusion of a broad range of studies, caution should be exercised when considering the incorporation of the described interventions into clinical practice. Further research is required to evaluate the effectiveness and potential risks of memory making interventions for parents in the context of neonatal end-of-life care.

Recommendations for Practice

Based on the evidence from our review, we recommend the following:

- Offer parents opportunities to spend time with their dying newborns and support them to engage in caregiving activities to the extent that they are capable and comfortable.
- Offer parents a range of mementos, including but not limited to photographs, items of clothing worn by their newborns, and other items used in their newborns' care. When parents are reluctant to accept these items for personal or cultural reasons, staff should offer to collect these items and store them for the parents should they want them later.
- Although respect for personal, cultural, and religious needs is paramount, nurses and midwives should normalize memory-making practices and actively guide parents to engage in those memory making activities that are personally and culturally appropriate.

Conclusion

Through our scoping review, we identified a small but significant body of evidence surrounding memory making for parents after the death of a newborn. Evidence to support memory making often emerged incidentally in investigations of parents' experiences of palliative and bereavement care for their newborns. Opportunities to bond with their newborns and to create tangible mementos were described as important aspects of bereavement care by parents across studies.

We also found that parents who were distressed and overwhelmed at the loss of their newborns appreciated being guided through options for memory making. Further research into parents' experiences of memory making is required to provide a more robust evidence base to guide practice.

Supplementary Material

Note: To access the supplementary material that accompanies this article, visit the online version of the *Journal of Obstetric, Gynecologic, & Neonatal Nursing* at http://jognn.org and at https://doi.org/10.1016/j.jogn.2019.02.001.

REFERENCES

Abraham, A., & Hendriks, M. J. (2017). "You can only give warmth to your baby when it's too late": Parents' bonding with their extremely preterm and dying child. *Qualitative Health Research, 27*(14), 2100–2115. https://doi.org/10.1177/1049732317721476

Akard, T. F., Duffy, M., Hord, A., Randall, A., Sanders, A., Adelstein, K., & Anani, U. E. (2018). Bereaved mothers' and fathers' perceptions of a legacy intervention for parents of infants in the NICU. *Journal of Neonatal-Perinatal Medicine, 11*(1), 21–28. https://doi.org/10.3233/NPM-181732

Alexander, K. V. (2001). "The one thing you can never take away." *American Journal of Maternal Child Nursing, 26*(3), 123–127.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology: Theory and Practice, 8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Armentrout, D. (2009). Living with grief following removal of infant life support: Parents' perspectives. *Critical Care Nursing Clinics of North America, 21*(2), 253–265. https://doi.org/10.1016/j.ccell.2009.01.003

Australian College of Neonatal Nurses. (2010). *Palliative care in the neonatal nursery: Guidelines for neonatal nurses in Australia.* Retrieved from http://www.acnn.org.au/resources-and-research/clinical-guidelines/G3-Palliative-care-in-the-neonatal-nursery.pdf

Baughcum, A. E., Fortney, C. A., Winning, A. M., Shultz, E. L., Keim, M. C., Humphrey, L. M., … Gerhardt, C. A. (2017). Perspectives from bereaved parents on improving end of life care in the NICU. *Clinical Practice in Pediatric Psychology, 5*(4), 392–403. https://doi.org/10.1037/cpp0000221

Blood, C., & Cacciatore, J. (2014a). Best practice in bereavement photography after perinatal death: Qualitative analysis with 104 parents. *BMC Psychology, 2*(1), 15. https://doi.org/10.1186/2050-7283-2-15

Blood, C., & Cacciatore, J. (2014b). Parental grief and memento mori photography: Narrative, meaning, culture, and context. *Death Studies, 38*(4), 224–233. https://doi.org/10.1080/07481187.2013.788584

Branchett, K., & Stretton, J. (2012). Neonatal palliative and end of life care: What parents want from professionals. *Journal of Neonatal Nursing, 18*(2), 40–44. https://doi.org/10.1016/j.jnn.2012.01.009

British Association of Perinatal Medicine. (2010). *Palliative care (supportive and end of life care) a framework for clinical practice in perinatal medicine (2010).* Retrieved from https://www.bapm.org/resources/palliative-care-supportive-and-end-life-care-framework-clinical-practice-perinatal

Brosig, C. L., Pierucci, R. L., Kupst, M. J., & Leuthner, S. R. (2007). Infant end-of-life care: The parents' perspective. *Journal of Perinatology, 27*(8), 510–516. https://doi.org/10.1038/sj.jp.7211755

Cacciatore, J. (2013). Psychological effects of stillbirth. *Seminars in Fetal & Neonatal Medicine, 18*(2), 76–82. https://doi.org/10.1016/j.siny.2012.09.001

Cacciatore, J., & Flint, M. (2012). Mediating grief: Postmortem ritualization after child death. *Journal of Loss and Trauma, 17*(2), 158–172. https://doi.org/10.1080/15325024.2011.595299

Cortezzo, D. E., Sanders, M. R., Brownell, E. A., & Moss, K. (2014). End-of-life care in the neonatal intensive care unit: Experiences of staff and parents. *American Journal of Perinatology, 32*(8), 713–723. https://doi.org/10.1055/s-0034-1395475

Côté-Arsenault, D. (2003). Weaving babies lost in pregnancy into the fabric of the family. *Journal of Family Nursing, 9*(1), 23–37. https://doi.org/10.1177/1074840702239489

Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., & Meneses, K. (2016). Parent perspectives of neonatal intensive care at the end-of-life. *Journal of Pediatric Nursing, 31*(5), 478–489. https://doi.org/10.1016/j.pedn.2016.03.023

Department of Health and Human Services Victoria. (2017). *Palliative (end-of-life) neonatal care.* Retrieved from https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/procedures/palliative-care

Fenstermacher, K. H., & Hupcey, J. E. (2019). Support for young urban black women after perinatal loss. *American Journal of Maternal/Child Nursing, 44*(1), 13–19.

Flenady, V., Boyle, F., Koopmans, L., Wilson, T., Stones, W., & Cacciatore, J. (2014). Meeting the needs of parents after a stillbirth or neonatal death. *British Journal of Obstetrics and Gynaecology, 121*, 137–140. https://doi.org/10.1111/1471-0528.13009

Gibson, J., Finney, S., & Boilanger, M. (2011). Developing a bereavement program in the newborn intensive care unit. *Journal of Perinatal & Neonatal Nursing, 25*(4), 331–341. https://doi.org/10.1097/JPN.0b013e3182307ffe

Joanna Briggs Institute. (2015). *The Joanna Briggs Institute reviewers' manual 2015: Methodology for JBI scoping reviews.* Retrieved from http://joannabriggs.org/assets/docs/sumari/Reviewers-Manual_Methodology-for-JBI-Scoping-Reviews_2015_v2.pdf

Kavanaugh, K., & Hershberger, P. (2005). Perinatal loss in low-income African American parents. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 34*(5), 595–605. https://doi.org/10.1038/jid.2014.371

Kersting, A., & Wagner, B. (2012). Complicated grief after perinatal loss. *Dialogues in Clinical Neuroscience, 14*(2), 187–194. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3384447

Khalil, H., Peters, M., Godfrey, C. M., Mcinerney, P., Soares, C. B., & Parker, D. (2016). An evidence-based approach to scoping reviews. *Worldviews on Evidence-Based Nursing, 13*(2), 118–123. https://doi.org/10.1111/wvn.12144

Koopmans, L., Wilson, T., Cacciatore, J., & Flenady, V. (2013). Support for mothers, fathers and families after perinatal death. *Cochrane Database of Systematic Reviews, 2013*(6), CD000452. https://doi.org/10.1002/14651858.CD000452.pub3

Lathrop, A., & VandeVusse, L. (2011). Affirming motherhood: Validation and invalidation in women's perinatal hospice narratives. *Birth, 38*(3), 256–265. https://doi.org/10.1111/j.1523-536X.2011.00478.x

Lemmer, S. C. M., Boyd, P., & Forrest, D. (1991). Parental perceptions of caring following perinatal bereavement. *Western Journal of Nursing Research, 13*(4), 475–493. https://doi.org/10.1177/019394599101300404

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science, 5*(1), 1–9. https://doi.org/10.1186/1748-5908-5-69

Levick, J., Fannon, J., Bodemann, J., Munch, S., & Ahern, K. (2017). NICU bereavement care and follow-up support for families and staff. *Advances in Neonatal Care, 17*(6), 451–460. http://doi.org/10.1097/ANC.0000000000000435

Limbo, R., & Kobler, K. (2010). The tie that binds: Relationships in perinatal bereavement. *American Journal of Maternal Child Nursing, 35*(6), 316–321. https://doi.org/10.1097/NMC.0b013e3181f0eef8

Limbo, R., & Lathrop, A. (2014). Caregiving in mothers' narratives of perinatal hospice. *Illness, Crisis & Loss, 22*(1), 43–65. https://doi.org/10.2190/IL.22.1.e

Lundqvist, A., Nilstun, T., & Dykes, A.-K. (2002). Both empowered and powerless: Mothers' experiences of professional care when their newborn dies. *Birth, 29*(3), 192–199. https://doi.org/10.1046/j.1523-536X.2002.00187.x

Martel, S. L., & Ives-Baine, L. (2014). "Most prized possessions": Photography as living relationships within the end-of-life care of newborns. *Illness, Crisis & Loss, 22*(4), 311–332. https://doi.org/10.2190/IL.22.4.d

McGraw, S. A., Truog, R. D., Solomon, M. Z., Cohen-Bearak, A., Sellers, D. E., & Meyer, E. C. (2012). "I was able to still be her mom": Parenting at end of life in the pediatric intensive care unit. *Pediatric Critical Care Medicine, 13*(6), e350–e356. https://doi.org/10.1097/PCC.0b013e31825b5607

McGuinness, D. (2015). A shortened experience of motherhood. *World of Irish Nursing & Midwifery, 23*(9), 63–65.

McGuinness, D., Coughlan, B., & Power, S. (2013). Empty arms: Supporting bereaved mothers during the immediate postnatal period. *British Journal of Midwifery, 22*(4), 246–252. https://doi.org/10.12968/bjom.2014.22.4.246

Pector, E. A. (2004). Views of bereaved multiple-birth parents on life support decisions, the dying process, and discussions surrounding death. *Journal of Perinatology, 24*(1), 4–10. https://doi.org/10.1038/sj.jp.7211001

Perinatal Society of Australia and New Zealand. (2009). *Clinical practice guideline for perinatal mortality.* Retrieved from https://sanda.psanz.com.au/assets/Uploads/Section-3-Version-2012.pdf

Rådestad, I., Surkan, P. J., Steineck, G., Cnattingius, S., Onelöv, E., & Dickman, P. W. (2009). Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery, 25*(4), 422–429. https://doi.org/10.1016/j.midw.2007.03.005

Robertson, M. J. P., Aldridge, A., & Curley, A. E. (2011). Provision of bereavement care in neonatal units in the United Kingdom. *Pediatric Critical Care Medicine, 12*(3), e111–e115. https://doi.org/10.1097/PCC.0b013e3181e911e3

Sadeghi, N., Hasanpour, M., & Heidarzadeh, M. (2016). Information and communication needs of parents in infant end-of-life: A qualitative study. *Iranian Red Crescent Medical Journal, 18*(6), e25665. https://doi.org/10.5812/ircmj.25665

Shelkowitz, E., Vessella, S. L., O'Reilly, P., Tucker, R., & Lechner, B. E. (2015). Counseling for personal care options at neonatal end of life: A quantitative and qualitative parent survey Psychosocial. *BMC Palliative Care, 14*(1), 1–11. https://doi.org/10.1186/s12904-015-0063-6

United Nations International Children's Emergency Fund. (2018). *Neonatal mortality.* Retrieved from https://data.unicef.org/topic/child-survival/neonatal-mortality