



Creating Evidence: Findings from a Grounded Theory of Memory-Making in Neonatal Bereavement Care in Australia

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ARTICLE INFO

Article history:

Received 22 January 2020

Revised 6 April 2020

Accepted 6 April 2020

Keywords:

Bereavement
Infant, newborn
Memory-making
Parent
Photography

ABSTRACT

Purpose: Perinatal and neonatal palliative care guidelines recommend the provision of photographs and other mementos as an element of care for parents bereaved by neonatal loss. However, little is known about parents' perceptions of such bereavement interventions. This study explored the significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of loss following neonatal loss.

Design and methods: We conducted semi-structured interviews with 18 bereaved parents. A grounded theory approach informed by Corbin and Strauss was used to underpin data sampling, data collection and data analysis. A constant comparative approach was used to engage in open, axial and selective coding to distil parents' stories into categories supporting a core concept.

Results: "Creating evidence" emerged as a key theme in the grounded theory of memory-making in bereavement care for parents following neonatal loss. Creating evidence involved taking photographs, creating mementos, as well as involving friends and family during the baby's time in the Neonatal Unit.

Conclusions: Creating evidence affirmed the life of the baby and the role of the parents. Creating evidence was a significant element of memory-making that had a positive impact on parents' experience of bereavement.

Practice implications: Parents should be supported to create evidence of their baby's life, through taking photos, creating mementos, and involving others in their baby's care. Such interventions provide affirmation of the baby's life and of the individual's role as a parent.

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Introduction

Background

The loss of an infant in the perinatal period places parents at increased risk of a range of adverse psychological outcomes. These may include complicated or prolonged grief responses (Kersting & Wagner, 2012; Koopmans, Wilson, Cacciatore, & Flenady, 2013; McSpedden, Mullan, Sharpe, Breen, & Lobb, 2017), depressive symptoms and anxiety (Heazell et al., 2016) and trauma-related outcomes such as Post-Traumatic Stress (Chung & Reed, 2017; Murphy, Shevlin, & Elklit, 2014). These clinically significant and prolonged grief and trauma responses highlight the importance of appropriate bereavement care in the context of perinatal loss.

While grief and trauma may result from any form of loss, the death of an infant before or soon after birth presents unique challenges. For

example, the loss of an infant may threaten the identity of the individual as a parent (Crawley, Lomax, & Ayers, 2013; Lathrop & Van De Vusse, 2011). Parents who have experienced the death of their baby may experience disenfranchised grief due to a lack of social recognition of their infant as a 'real' and loved individual and their loss as legitimate (Cacciatore, 2013; Heazell et al., 2016)

Perinatal palliative care and bereavement guidelines recommend supporting parents to make memories with their babies. This can include collecting items that might hold significance for parents, such as items of clothing, hospital identification bands, or blankets and soft toys belonging to the infant (Australian College of Neonatal Nurses, 2010; British Association of Perinatal Medicine, 2010; National Association of Neonatal Nurses, 2015; Perinatal Society of Australia and New Zealand, 2019). These guidelines also recommend that clinicians offer to assist in taking photographs of the baby and family, and to create other mementos such as handprints or footprints.

While such practices have become common over the past 20 years, evidence for memory-making as a perinatal bereavement intervention remains limited. A scoping review by Thornton, Nicholson, and Harms (2019) revealed that while the collection or creation of mementos

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arose frequently as a finding within qualitative studies of parents' experiences of perinatal bereavement care, fewer studies examined specific memory-making interventions in detail.

Those studies that have explored bereavement photography have identified that parents are typically grateful for photographs provided by hospital staff, while parents who were not offered photographs frequently expressed regret following their loss (Alexander, 2001; Blood & Cacciatore, 2014a; Cacciatore & Flint, 2012). The collection or creation of mementos has also been identified in some studies as an important element of care for parents experiencing perinatal loss (Baughcum et al., 2017; Cacciatore & Flint, 2012; McGuinness, 2015; Shelkowitz, Vessella, O'Reilly, Tucker, & Lechner, 2015). While this literature provides some insight into the significance of photographs and mementos for bereaved parents, limited evidence exists to guide practice. The purpose of this study was to explore the significance of memory-making activities for parents experiencing the death of a neonate, and the impact that these activities have on parents' experience of bereavement.

Methods

Design and methods

This study was conducted using the grounded theory approach described by Corbin and Strauss (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 2015). Grounded theory has been identified as being particularly useful where limited knowledge exists (Engward, 2013; Schreiber, 2001), and where generation of theory would be valuable (Merriam & Tisdell, 2015). Although there is an increasing body of research exploring perinatal bereavement, little is known about bereavement interventions in the context of neonatal death. A grounded theory approach was selected to address this gap in the literature and enable the development of a substantive theory that could be used to guide practice. These findings represent one of three key categories to emerge from a larger grounded theory study that explored bereaved parents' experiences of memory-making during their baby's end-of-life care in the Neonatal Unit (NNU).

Setting and participants

To be eligible to participate parents needed to have experienced the death of their infant in a neonatal unit in Australia, and to be able to communicate in English without an interpreter. The decision was made not to exclude parents on the basis of time elapsed since the loss, as limited evidence exists for such restrictions. Bereaved parents were informed of the study via community-based not for profit perinatal bereavement services (for example, SANDS and Red Nose). Each organisation posted news items either in their regular newsletters or via open Facebook groups, enabling parents to contact the researchers to express interest in participating.

Eighteen bereaved parents were selected to participate in the study using theoretical sampling. This type of sampling is defined as "the process of data collection for generating theory, whereby the analyst jointly collects, codes and analyses his data, and decides what data to collect next and where to find them, in order to develop his theory as it emerges" (Glaser & Strauss, 1967, p.205). This cyclical approach to data collection and analysis enabled the researchers to make sampling decisions based on the emerging theory. The initial informants recruited into the study were individuals with rich experience of the phenomena of interest. Both the first and second participant had undertaken volunteer roles providing support to other bereaved parents, in addition to having experienced the loss of their own baby in the neonatal unit setting. Analysis of these initial interviews yielded a number of important concepts, which were used to guide future sampling decisions, both around the selection of participants, and around the sampling of incidents within the data. For instance, early participants experienced the loss of their baby within the first 24 h of life, and described this as impacting on their opportunities

for memory-making while the baby was alive. As this appeared to have a significant impact on parents' experiences, the researcher then sought to interview parents whose babies had survived for longer in the neonatal unit. Analysis of these subsequent interviews revealed that parents who had spent longer in the neonatal unit with their baby were typically offered more opportunities for memory-making. This cyclical approach to analysis and sampling was also used to explore other key features of parents' experiences, such as gender and engagement with professional bereavement photography services. Sampling continued until no new categories or subcategories were emerging from subsequent interviews, and until the categories and subcategories were well developed in terms of their properties and dimensions, adding to the theoretical rigour of the emerging grounded theory.

The following table (Table 1) summarises the characteristics of the sample. More mothers (13) than fathers (5) participated in the study, and most babies were born prematurely with only four infants born at term. The majority of babies lived between one and seven days; however, one baby died within 2 h of birth while another survived 13 weeks. Average time elapsed since the loss was six years (range 6 months to 17 years).

Data collection

Fourteen parents were interviewed individually, while two couples elected to be interviewed together. Data were collected using extended digitally-recorded semi-structured interviews. Parents were offered a choice of in-person, telephone or Skype interviews, with interviews lasting between 53 and 117 min. In keeping with the tenets of grounded theory, an initial interview guide was developed with several broad, open-ended questions. Each interview commenced with the question "Tell me a bit about (baby's name)" to encourage parents to recall the circumstances of the birth, care and death of their infant. The interview guide was updated after each interview, enabling exploration of emergent categories and subcategories.

During the interviews, field notes were kept to record the setting, as well as non-verbal and para-verbal cues, from participants. Immediately following each interview, the primary author listened to the recorded interview in full, and then listened a second time, transcribing the interview verbatim. Following transcription, the recording was reviewed and inconsistencies between the recording and the transcript were corrected.

Ethical considerations

Prior to commencing data collection, ethics approval was obtained from the University of Melbourne Behavioural and Social Sciences Human Ethics Sub-Committee. Due to the emotive nature of the topic, minimising the distress of participants was a key concern. Strategies included standard provisions for the protection of privacy and ensuring informed consent, as well as a specific distress protocol and the provision of support for parents throughout the research process. The elements of the distress protocol were informed by the work of (Draucker, Martsof, & Poole, 2009) and included the use of an interviewer specifically trained to support individuals experiencing psychological distress, as well as constant observation of the emotional state of the participant throughout their interview. In addition, participants were reminded of their right to pause or cease the interview both at the beginning and during the interview if they became tearful, and were provided with the contact details for perinatal bereavement services. Finally participants were encouraged to debrief at the end of the interview and were offered a follow-up phone call the next day.

Data analysis

Data analysis using Corbin and Strauss' approach to grounded theory requires three levels of coding: open, axial and selective, which are used in an iterative and recursive manner (Chen & Boore, 2009). Transitioning

Table 1
Demographic data.

Interview Number	Parent number	Mother, Father or both	Year of birth	Gestation of baby at birth	Age of baby at death
1	1	Mother	2007	24 weeks (twins)	Both at 1 day
2	2	Mother	2009	26 weeks	1 day
3	3	Mother	2010	32 weeks	2 h
4	4	Mother	2015	29 weeks	4 days
5	5	Mother	2010	Term	16 days
6	6	Mother	2015	28 weeks	6 days
7	7	Mother	2003	28 weeks (twins)	1 baby at 6 days
8	8	Father	2016	Term	7 days
9	9	Father	2010	26 weeks	3 days
10	10	Mother	2016	Term	4 days
11	11	Father			
12	12	Mother	2006	27 weeks	18 h
13	13	Mother	2004	Term	5 days
14	14	Mother	1999	24 weeks	15 days
15	15	Mother	2009	31 weeks (twins)	1 baby at 13 days
16	16	Father			
17	17	Father	2014	Term	13 weeks
18	18	Mother	2015	24 weeks	7 days

between levels of coding allows concepts and categories to be drawn from the data while becoming increasingly abstracted from that data, enabling theory generation. NVivo 11 (QRS International) was used to code interviews at each level of analysis and to facilitate constant comparison throughout data analysis.

Open coding has been described as a process of “fracturing the data” (Strauss & Corbin, 1990, p.13) into its smallest components. In the current study, this was achieved through line-by-line coding, with each line or phrase from the transcript being given one or more conceptual labels or codes. During axial coding, “categories are related to their subcategories, and these relationships are tested against the data” (Strauss & Corbin, 1990, p.13). This process enables the researcher to consolidate open codes into conceptually dense categories that are well-defined in relation to dimensions and properties. Table 2 provides a summary of the codes generated through open and axial coding to enable the development of the category “creating evidence” and its subcategories “having photographs”, “creating and collecting mementos”, and “involving others”.

Enhancing rigour

The primary means of defending rigour in grounded theory research is to ensure that the grounded theory method is carefully followed. Corbin and Strauss (2008) explain that elements of the grounded theory approach, including prolonged engagement, microanalysis of the data, and constant comparative analysis, help to ensure the credibility of the resulting theory. In addition to these inherent elements of the grounded theory method, additional approaches such as “cross-checking emerging concepts against participants’ meanings, asking experts if the theory ‘fit’ their experiences, and recording detailed memos outlining all analytical and sampling decisions” can be used to enhance rigour (Cooney, 2011, p.17). In this study, the use of an evolving interview guide enabled researchers to check emerging concepts

with new participants, while extensive memos were recorded regarding all sampling and theoretical decisions.

A decision was made not to engage in traditional member-checking based on the work of (Cooney, 2011) and (Cutcliffe, 2005), who argue that grounded theory studies that aim to generate abstract explanations rather than descriptions of the lived experience of individuals are best evaluated for credibility and fit by experts within the field. The provisional findings of this study were presented at an international conference, enabling researchers to obtain feedback from clinical experts around the fit of the emerging theory with their own experiences in practice. This feedback indicated that expert clinicians saw the emerging theory of “affirmed parenthood” as credible and relevant to their own areas of practice.

Results

This study resulted in the development of a grounded theory titled “Affirmed Parenthood” (Fig. 1). The core category affirmed parenthood was supported by three key categories; “Being a parent”, “Being guided” and “Creating Evidence”. “Being a parent” included spending time with the baby before and after death, holding or touching the baby, and providing physical care. “Being guided” represented parents’ need to be supported and encouraged throughout the process of memory-making. Finally, “Creating evidence” captured parents’ efforts to collect or create tangible evidence of their baby’s life through photographs and other mementos, and by involving others with their baby to ensure that people outside the immediate family would have memories of their child. Where all three key themes were addressed in bereavement care, parents experienced affirmation of the significance of their baby’s life, affirmation of the significance of their loss, and affirmation of their role as a parent. This article provides a detailed overview of the category “creating evidence” as a central element of memory-making in the context of neonatal loss and a key component of the grounded theory “Affirmed Parenthood”.

Table 2
Overview of category development: “creating evidence”.

Open coding	Subcategory development	Category development
Candid photos “Normal baby photos” Stark photos Clinical photos Having “lots” of photos Not having photos	Content of photographs	Having photographs
Having a “proper” camera iPhone photos Polaroid photos Wanting photos Importance of photos Not wanting photos Disliking photos Parents taking photos Staff taking photos Heartfelt (professional photographers)	Quantity of photographs Quality of photographs	
Displaying Photographs Handprints Footprints Imprints Clothing Toys and Blankets Cot-cards and ID bands Locks of hair Cards, journals and poems Memory-boxes/books Displaying mementos Sharing mementos Putting things away Keeping things safe Not looking at mementos Creating jewellery Creating artwork Importance of Mementos Proof of life Making them “real” Inviting others in Having people visit Having family present Rituals Baptism Blessing	Valuing photographs Reluctance to have photographs Creating photographs Types of mementos Displaying mementos Storing mementos Creating new mementos Valuing mementos	Creating & collecting mementos
	Others “meeting” the baby Involving others through ritual	Involving others

Creating evidence

“Creating Evidence” emerged as significant psychosocial process underpinning memory-making in parents' stories. Each parent described artefacts and experiences that helped create evidence of their child's brief life. Parents engaged in creating evidence through having photographs, collecting and creating mementos, and through involving others.

Having photographs

Each parent described having photographs of their baby. Most parents had taken their own photos, while the majority also had photographs taken by others. For parents who experienced their loss more than a decade ago these were generally taken by family members or nursing staff, while parents who had experienced more recent losses also described photographs taken by a not-for-profit bereavement photography service.

Parents who felt they had a sufficient number of photographs of their baby were generally positive about this aspect of their experience. For instance, one father was asked what was most helpful in supporting him to remember his baby, and he replied:

P11: they made sure that you had lots of photos.

Conversely, another father reflected:

P16: That's something I particularly regret as well. The fact that we don't have a huge amount of photos, or a huge number of photos of (baby) when he was alive in the hospital. We've got a few, but certainly you can never have enough.

Having a collection of photos was a helpful intervention for these parents, while a paucity of photographs was a source of regret for others.

While the quantity of photographs was important, the content was also significant to parents. For example, photos that were natural rather than being staged were generally preferred:

P10: you can feel the natural love in the photos. It wasn't forced...

P4: they are normal baby photos, but they are taken in a really discrete manner. They're not posed.

P17: It wasn't a staged photo-shoot. It was more about just capturing us as a family.

Interestingly, several parents also commented that candid photos were important even when these captured the grief and pain that parents were experiencing:

P8: the most powerful photo that we've got is one where my wife is holding (baby). And you can just see the heartbreak on her face. At the time I felt bad taking that photo. But I'm very glad we did, because as I said, it kind of reminds you that it did really happen. The pain was real. And her existence was real.

Photographs were not only evidence of the baby's existence but also evidence of the real and significant grief experienced by bereaved parents.

Parents also valued photos that were not overly stark or confronting. One mother explains:

P12: the photos I have are horrific. They are not something that I can put up.

Photos that were sensitively taken and that appeared to be of a living infant were generally preferred by parents. Not only were these images less distressing, but parents also felt they could share or display such photos more readily.

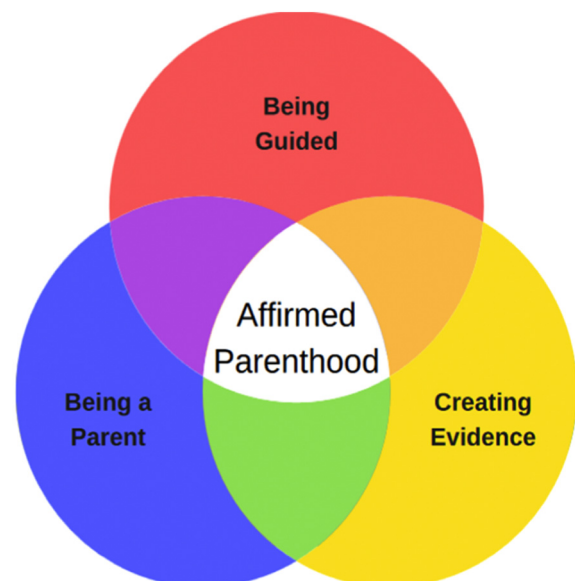


Fig. 1. Grounded theory of “affirmed parenthood”.

The majority of parents described being grateful for the photos they had of their baby's time in NNU, whether these were taken by professional photographers, healthcare workers or by the parents themselves. For instance, one mother explained:

P18: ...you don't bring a baby home from hospital, so it's like only a couple of people really met him ...But he does exist for me still. And I think that's the part where the photos really do help. Sharing something that happened to you or in your family with other people that didn't meet him. I really do think it's really important.

When describing the significance of photographs, another mother explained:

P2: And I mean, for me, I can go back and look at that. And see that my baby did exist. I have proof that he lived.

These sentiments capture the role that photographs play, as both evidence of the baby's life and evidence of parenthood, especially in situations where only a few people 'met' the baby during their brief life.

Collecting and creating mementos

In addition to photographs, each parent had items that served as a memento of their baby. These mementos included footprints or handprints, hospital ID bands, or locks of hair, in addition to the baby's belongings, such as clothing, toys or blankets.

Ink-based footprints and handprints were identified by parents as important mementos. While any memento was potentially meaningful for parents, these prints served as evidence of the baby's physicality and size:

P4: it's just really nice to just remember how big he actually was, not just in photos.

Handprints or footprints were routinely collected by nursing staff and provided to parents, however some parents also participated in creating these items.

Several parents also received clay or plaster imprints of their baby's hands or feet. These held particular meaning for parents:

P8: they are the thing that I touch on a day to day basis the most. And they are definitely the most physical reminder...you can feel the little crevices in her footprints and the like.

Similarly, when discussing plaster imprints provided by the hospital, one parent reflected:

P16: something that's tactile, that you can touch and feel is really cool.

This tactile element of imprints provided additional meaning compared with traditional ink-based hand and footprints.

Most of the parents had kept at least one item of clothing worn by their baby, and these items were valued by parents. As with imprints, the sensory and tactile nature of fabric lent the baby's clothing special significance.

P13: I think that was helpful. Just to have something that she's worn, that you can touch and hold.

P4: we kept the clothes that they did have him in. And that's really important. I've sealed them up in a bag, just because to us, they even smell like him. So that's something that's really, really important. You know, the knitted outfit. Just knowing that he wore it.

Parents also kept blankets that their baby had been wrapped in, especially when these had been used to keep the baby warm during cuddles outside the incubator. Items that had been in contact with the baby

were regarded as important mementos by parents, acting as tangible evidence of their baby's existence.

In addition to prints and items of clothing, several parents treasured the name-card from their baby's cot.

P15: they laminated the name plate for him. And all these things we've now got in a memory box. Yeah, it was just fantastic.

In particular, these cards helped to confirm the baby's identity as an individual. For example, one father explained:

P8: Her having a nametag on her crib was very important. She's a person, she's got a name.

Mementos such as cot-cards helped to generate a social identity for the baby and as such were regarded as significant.

As with photographs, mementos acted as powerful evidence of the baby's existence and of the participants' role as a parent. For example, when asked how having mementos had impacted on her loss, one mother explained:

P4: it sounds really morbid, but we can put it in peoples face, and we can show them that you know, he had hands and feet. And you know, by having his things in the house, and having all those bits and pieces that we collected, it does validate the fact that he was alive. And the fact that he did exist.

Having photographs and mementos reassured parents that their experience was valid, and that their baby was a real person worthy of remembering and of mourning.

Involving others

Photographs and mementos acted as important evidence of the baby's brief life and as evidence of the participants' role as parents. Interestingly, this evidence was also generated by involving others during the baby's time in NNU. Involving others included inviting them to visit the baby before or after their death and engaging with others in rituals.

The majority of parents were able to invite others to "meet" the baby, and this was often described as valuable by parents:

P6: we were lucky he met most of the important family members.

Interestingly, for several parents the idea of having others visit was not a priority while their baby was in NNU, however after their loss, these parents were grateful they had involved others in this way:

Interviewer: Was it important to you that other people got to meet him?

P15: at the time, no. Afterwards yes. At the time we were just basically coping. Afterwards that was really amazing that they all got to meet him. I would have wished that we had invited more people.

Conversely, parents who were not able to involve others in this way expressed regret:

P13: And I think probably that's one of our regrets, and it was the circumstance we were in, but I know lots of people who have gotten everyone in to meet the baby, whether it's after the baby has died or before...for a long time we did struggle with the fact that she wasn't really real for anyone else. And she really wasn't. She was born and then she was dead and not many people saw her.

Where parents were able to involve others through "meeting" the baby, these experiences provided further affirmation of the baby's existence and of the participants' parenthood. Where such opportunities were missed, however, there was a sense of the baby only being "real" for the parents.

Finally, six parents used rituals such as blessings or baptisms to involve others. For the majority of these parents, the involvement of others gave special meaning to these rituals. For example, one parent described involving their extended family in their son's baptism in the NNU:

P13: I just thought it was important. And it is important. And our families were involved, so I guess that was another memory making thing.

For another parent, baptism provided a meaningful way to engage with staff who had cared for his son over a period of weeks:

P17: we had four nurses as his god-parents. So there were four nurses that were very attached to him, and they put their hands up and said they would be honoured to do it. So we had a full baptism in his room as well. So that meant a lot to me, because I am a little bit religious.

While the spiritual element of such rituals was important to these parents, the opportunity to involve others in their baby's life was also meaningful.

For parents involving others through inviting them to meet the baby, or engaging in rituals, were important ways to create evidence of the baby's life outside of the immediate family. For example, one father describes leaving the hospital with his wife while their daughter was in NNU:

P8: there was no pram, no baby with us, and she said "the whole pregnancy could have been a dream". If it weren't for having those people that we know had visited her, to validate that she did exist, it would have been a lot harder to convince ourselves that it had actually happened.

Creating evidence through collecting mementos, taking photographs and involving others provided parents with crucially important affirmation of the baby's essential reality, and of the participants' status as parents.

Discussion

As discussed previously, there is considerable evidence that parents appreciate photographs of their baby, and that these photographs have a significant impact on parents' experience of grief. As with the participants in the current study however, research demonstrates that the content of such photos is important to parents. For example research indicates that photographs taken while the baby was alive are more acceptable to parents (Harvey, Snowdon, & Elbourne, 2008). In our study, multiple parents also commented on the value of photographs that were natural and not "staged", especially where these captured interaction between the baby and family.

The quality of the photos also emerged as significant to parents. Photos taken by a not-for-profit bereavement photography service (such as Heartfelt in Australia) were viewed as being beautiful and sensitively done, while the quality of photos taken by hospital staff was described as variable. While the quality of photographs should be taken into account, studies indicate that perinatally bereaved parents "overwhelmingly support postmortem bereavement photography when conducted sensitively, even if imperfectly executed" (Blood & Cacciatore, 2014a, p.1). Therefore, photographs of the baby should be taken and offered to families, even if these images are not 'perfect'.

Parents in this study described photographs as providing important evidence that their baby did exist as a "real" person. In turn, this affirmed their role as parents and legitimized their loss. Similar findings have been reported in a number of studies exploring perinatal bereavement photography (Alexander, 2001; Blood & Cacciatore, 2014b; Layne, 2000; Riches & Dawson, 1998) For example, a modified grounded

theory study with 181 bereaved parents and found that photographs were vital in "helping parents identify their child as real and share that reality with others, in opposition to the stated or implicit invalidation of either the child's existence or the legitimacy of their grief" (Blood & Cacciatore, 2014b, p.228). For these parents, photographs are far more than keepsakes. Rather, photographs are critical evidence that their baby did exist, that they are in fact parents, and that their grief is real.

Similarly, the use of mementos to provide affirmation or validation of perinatal loss has been recognised in the literature. For example, Lundqvist, Nilstun, and Dykes (2003) explain that mementos may help to "validate the parents' sense of loss, help them relive the experience and attach meaning to the loss" (p.197). Similarly, a study of mothers in a perinatal hospice setting revealed the importance of tangible mementos, as proof that the pregnancy and the baby were real (Lathrop & VandeVusse, 2011). The authors explain that "Tangible mementoes were another way that mothers sought to affirm their babies' reality" (p. 260). The current study contributes to the evidence surrounding photographs and other mementos as a means of recognising and honouring the life of the baby, and recognising the loss of the parents as being real and important.

Parents in our study described a range of mementos that held particular significance for them. In particular, mementos that were unique to the infant and that were tactile in nature, such as a tiny hat worn by the infant, a soft blanket that was used to wrap them, or a clay footprint that preserves the lines and creases of the baby's foot were described by parents as especially significant. Such mementos provided important evidence that the baby was "real" and acted to affirm participants' roles as parents. A similar need for affirmation was identified by Cacciatore (2010) who reported that for women experiencing stillbirth, "there are few tangible artefacts to remind her of the baby, and she may desperately cling to anything that recognises and validates her sense of motherhood" (p.142).

Perhaps most interesting within the category "creating evidence" was the emergence of evidence not just in the form of tangible artefacts but also in the form of social interactions. In particular, parents who had invited others in to the NNU to "meet" their baby were positive about this aspect of their experience. Perinatal bereavement guidelines are increasingly acknowledging the importance of involving others in end-of-life and bereavement care. For instance, the Canadian Pediatric Society perinatal loss guideline states that supporting friends and extended family to visit the baby "can validate the infant's existence and death, thereby acknowledging the parents' loss and their need for grieving" (Canadian Pediatric Society, 2001, p.472). Opportunities to have others "meet" the baby, whether in person, or through photographs and artefacts, provide important evidence of the baby's existence, which in turn affirms the life of the baby, the role of the parents, and the significance of the loss endured.

Clinical implications

Creating evidence was a critical psychosocial process underpinning memory-making for parents experiencing the loss of an infant. Parents need to be supported to create evidence as a means of affirming the life of the infant and their personal identity as parents. Evidence, which can be shared with others, also acts to provide social affirmation of the infant's death as a legitimate loss that is worthy of being mourned. Specific interventions, such as the creation of tactile mementos including clay imprints, or the collection of tactile items such as blankets or clothing, are currently under-emphasised in perinatal bereavement guidelines and should be prioritised in clinical practice. Such items have unique significance for parents as proof that their baby did exist and was a "real" person in ways that less tactile items may not. Similarly, parents appreciated most images of their infant, but were especially grateful for images that captured their infant's unique personality without being staged or stark. Such images are not only important to parents, but can also be shared with others, allowing

parents to fully step into their identity as parents. Finally, parents should be supported to involve others in the life and death of their baby as a means of creating evidence of the infant's existence outside of the immediate family. Neonatal unit and hospital policies need to support families in involving others during their baby's stay in the unit, both during life and after death. Creating evidence provides affirmation of the value of the baby's life and the individual's role as a parent, with important implications for parents' experience of bereavement.

Conclusions

The grounded theory of "Affirmed Parenthood" was underpinned by three categories: being a parent, being guided, and creating evidence. 'Creating evidence' was achieved by parents through bereavement photography, through the collection or creation of mementos, and through involving others during and after the NNU stay. This evidence helped to affirm the baby's existence, to affirm the role of the parents, and to affirm the grief that parents experienced. These findings are well aligned with the current literature surrounding perinatal bereavement care, and support the use of memory-making interventions in neonatal end of life care. This research contributes to understandings of the significance and impact of memory-making activities for parents experiencing the loss of an infant in the neonatal unit.

CRedit authorship contribution statement

Rebecca Thornton: Conceptualization, Methodology, Data curation, Formal analysis, Investigation, Writing - original draft, Visualization. **Patricia Nicholson:** Conceptualization, Methodology, Writing - review & editing, Supervision. **Louise Harms:** Conceptualization, Methodology, Writing - review & editing, Supervision, Project administration.

Declaration of competing interest

None.

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