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Being a Parent: Findings from a Grounded Theory of Memory-Making in Neonatal End-of-Life Care

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ABSTRACT

Purpose: Neonatal palliative care guidelines increasingly recommend that parents be encouraged to provide care for their dying baby and to spend time with the before and after death. However, little is currently known about how parents perceive such memory-making interventions. This study explored the significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of neonatal end-of-life care.
Design and methods: We conducted extended interviews with 18 parents who had experienced neonatal loss. Corbin and Strauss' grounded theory method was used throughout sampling, data collection and data analysis. A constant comparative approach was utilised throughout each stage of the data collection/data analysis process, resulting in the development of a grounded theory titled “Affirmed Parenthood”.
Results: The core category of “Affirmed parenthood” was underpinned by three primary categories: ‘Creating Evidence’, ‘Needing Guidance’ and ‘Being a parent’. Opportunities to parent the baby by having contact with them, engaging with them, and providing care were central to parent's experiences of memory-making in the context of neonatal bereavement.
Conclusions: ‘Being a Parent’ provided important affirmation of the baby's identity and importance, and affirmed the role of the parents. ‘Being a Parent’ was a critical element of memory-making and had a significant impact on parents' experience of loss.
Practice implications: Parents should be supported to have unrestricted contact with their baby, to engage with them, and to provide care throughout the baby's brief life and after their baby's death.

Introduction

Worldwide, over 2.4 million infants died in the first month of life in 2019 (UNICEF, 2020). The death of an infant before or soon after birth has been identified as a unique and complex form of bereavement that may have a profound and enduring impact on parents (Kersting & Wagner, 2012; Koopmans et al., 2013; McSpedden et al., 2017). Indeed, the death of an infant before or soon after birth presents several unique challenges. For example, parents whose baby has died may experience disenfranchised grief, defined as “grief that is not, or cannot be, openly acknowledged, publicly mourned or socially supported” (Doka, 1999, p. 37). Cacciatore (2010) argues that even today, perinatal loss is “generally minimized and negated and is often treated as a non-event” (p. 137). This lack of acknowledgement denies bereaved parents access to traditional sources of support, and the rituals that give shape and meaning to socially recognised loss. For this reason, the delivery of appropriate bereavement care is vitally important for this potentially vulnerable group.

Those who have experienced perinatal loss may also question the legitimacy of their own roles as parents (Crawley et al., 2013; Lathrop & Vandevusse, 2011; Malacrida, 1997; Robinson et al., 1999). For instance, Cacciatore et al. (2008) argued that for parents experiencing stillbirth, “their status as ‘parents’ becomes complicated because there are no tangible signs of parenthood to affirm their roles” (p. 443). Similarly, Crawley et al. (2013) described the role confusion experienced by mothers following perinatal loss; the woman is at once a mother, having had a baby, and not a mother, being unable to physically hold or nurture her child.

Given these unique challenges, perinatal bereavement guidelines increasingly recommend bereavement interventions that recognise the significance of the loss of the infant as a person, while validating the role of bereaved parents. These interventions include memory-making interventions, such as supporting parents to spend time with their infant, and to see, touch and hold them both before and after death

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(Australian College of Neonatal Nurses [ACNN], 2010; British Association of Perinatal Medicine [BAPM], 2010; National Association of Neonatal Nurses [NANN], 2015; National Institute for Health Care Excellence [NICE], 2016; Perinatal Society of Australia and New Zealand, [PSANZ], 2019). Memory-making interventions may also include encouraging parents to participate in typical parenting activities such as changing nappies, bathing their infant and dressing them (ACNN, 2010; BAPM, 2010; NANN, 2015; PSANZ, 2019). Of note, while these activities are recommended, most guidelines provide limited evidence to support these interventions. A 2013 Cochrane review identified that "the true benefits of currently existing interventions aimed at providing support for mothers, fathers and families experiencing perinatal death is unclear" (Koopmans et al., 2013, p. 2). More recently, a scoping review by Thornton et al. (2019) revealed little high-quality evidence examining the significance and impact of memory-making interventions from the perspective of bereaved parents.

The purpose of this study was to generate a substantive theory of memory-making in neonatal end-of-life care. We used the grounded theory approach described by Corbin and Strauss (2008); Strauss and Corbin (2015), resulting in the development of the grounded theory "Affirmed Parenthood" (see Fig. 1). The core category of affirmed parenthood was underpinned by three key psychosocial processes; creating evidence, being guided, and being a parent. "Creating Evidence" reflected parents' need to collect and create mementos and images that acted as proof of their baby's existence and of their own role as parents (Thornton et al., 2020). "Being Guided" captured parents' need to be supported and encouraged through the process of memory-making, even when they were hesitant or afraid. Finally, "Being a Parent" was a critical psychosocial process in which individuals saw, touched, held and cared for their infant as a means of becoming a parent to that child. In this paper we present the key theme "being a parent" which emerged as central to parents' experiences of memory-making in the neonatal unit.

Methods

Grounded theory is a qualitative research method developed "for the purpose of constructing theory grounded in the data" (Strauss & Corbin, 2015, p. 4). As the aim of this research project was to develop theory to guide memory-making in neonatal end-of-life care, a grounded theory approach was identified as appropriate. Grounded theory has also been identified as a particularly useful approach to research when limited knowledge exists around a topic (Engward, 2013). Although there is a growing body of research surrounding perinatal bereavement, limited evidence exists to guide bereavement care in the neonatal unit. This dearth of existing evidence reinforced our decision to use a grounded theory approach.

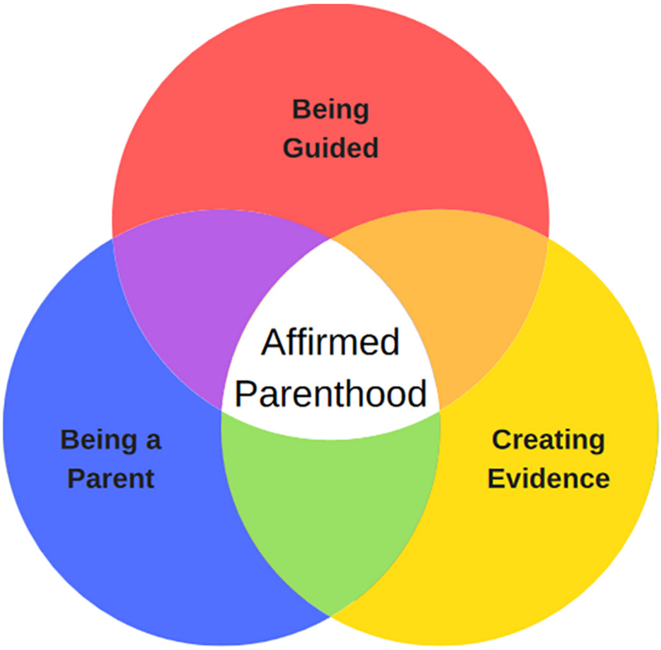

Fig. 1. Grounded theory of affirmed parenthood.

Ethics

Approval from the University of Melbourne Behavioural and Social Sciences Human Ethics Sub-Committee was obtained prior to commencing this study. Given the sensitive nature of this research, protection of participants from potential harm was of vital concern. A detailed distress protocol was designed based on the work of Draucker et al. (2009), in addition to standard ethical considerations such as informed consent and protection of privacy. This protocol included using interviewers with expertise in working with bereaved individuals, and remining attentive to participants' emotional states throughout the interview. Participants were also reminded that they could pause or stop the interview before the interview began and again during the interview if demonstrating signs of distress. Particpants were provided with contact details for national perinatal bereavement services, and were also offered a follow-up phone call the day after the interview.

Sampling and participants

Sampling in this study was initially purposive and then theoretical. Glaser and Strauss (1967) defined theoretical sampling as a process in which "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 process of data collection and analysis allowed researchers to sample on the basis of the developing theory, promoting the development of robust categories and subcategories that were well defined in relation to their properties and dimensions. In this study, early participants were selected on the basis of rich personal experience of newborn loss; the first three participants had not only experienced their own loss but were also volunteering in not-for-profit organisations for bereaved parents. These participants also experienced the loss of their infant in the first 24 h of life, and identified that this brief time with their baby impacted on their experience of memory-making. Theoretical sampling was subsequently used to select parents whose babies had survived longer, enabling comparison of participants' experiences. Theoretical sampling was also used to explore other emerging themes such as the significance of gender in parents' response to memory-making interventions, and the use of professional bereavement photography services to capture images of the baby either during life or following their death.

Study details were provided to parents via community-based not for profit perinatal bereavement services (for example, SANDS and Red Nose). These organisations posted news items in their social media pages, as well as in regular newsletters. This approach resulted in contact from a total of 28 bereaved parents. Of these, eight were not eligible to participate having experience a stillbirth or death outside of the neonatal unit, while two others failed to provide information regarding their availability for interview. Eighteen bereaved parents participated in the current study, including 13 mothers and five fathers. The majority of babies were born prematurely and most lived between one and seven days (range 2 h to 13 weeks). Given limited evidence to justify exclusion of recently bereaved individuals, the decision was made to support the self-determination of bereaved parents who wished to participate, regardless of the time elapsed since their loss. The average time between the death of their infant and parents' participation was 6 years (range 6 months to 17 years). See Table 1 for details regarding the final sample.

Table 1
Participant demographics.

Interview	Parent	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	Father			
11	12	Mother	2006	27 weeks	18 h
12	13	Mother	2004	Term	5 days
13	14	Mother	1999	24 weeks	15 days
14	15	Mother	2009	31 weeks (twins)	1 baby at 13 days
	16	Father			
15	17	Father	2014	Term	13 weeks
16	18	Mother	2015	24 weeks	7 days

Table 2
Overview of category development: Being a parent.

Open Coding	Subcategory Development	Category Development
Being with the baby Visiting	Spending time with the baby	Contact
Limited contact Being separated	Restricted contact	
Having access Unlimited contact “Cure to Care”	Facilitated contact	
Touching the baby Holding the baby Having cuddles	Touching and holding	
Examining the baby Watching the baby	Studying the baby	Engaging
Talking to the baby Reading to the baby Singing to the baby	Talking, reading and singing	
Bathing the baby Changing the baby Dressing the baby Choosing clothing	Providing care	Caregiving

Of note, the needs and concerns expressed by parents were consistent regardless of the time elapsed since their loss, and parents who had experienced loss many years ago still had vivid recollections of their experiences around memory-making during and after their infant's death.

Data collection

The bereaved parents in this study participated in in-depth interviews of 53 to 117 min duration. Parents were initially offered individual interviews, however two couples requested to be interviewed as a pair to provide each other with support. Parents were offered the option of telephone, Skype or face-to-face interviews, and each interview commenced with the prompt “tell me a bit about (baby's name)” to encourage parents to share salient aspects of their baby's birth, care and death. An interview guide was developed and was updated after each interview. Prompts that were added to the interview guide included questions about emerging concepts and tentative categories. For example, when specific parenting activities such as caregiving and contact emerged as significant in early interviews, prompts were added to ensure these topic was explored in subsequent interviews.

During each interview, field notes were used to document the physical setting and the physical and para-verbal cues displayed by participants. These field notes were used to facilitate recall and capture nuance in the parents' responses that might be lost in an audio recording alone. Immediately after each interview, the primary researcher listened to the recorded interview in its entirety and then listened a second time to transcribe the interview verbatim. The interview was then listened to a third time to check the transcript for accuracy.

Enhancing rigour

As described by Strauss and Corbin (2015) careful application of grounded theory methods enhances the credibility of the resulting theory. Such methods include prolonged engagement in the field and constant comparative analysis throughout the data collection/data analysis cycle. In addition to meticulous application of the grounded theory method, other techniques can be used to enhance rigour, including “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” (Cooney, 2011, p. 17). Rigour can also be enhanced through “theoretical sensitivity” (Strauss & Corbin, 2015). The lead researcher in the current study is an experienced neonatal nurse. This clinical experience was used to differentiate common elements of newborn care from aspects that are unique to bereavement care in this setting. In the current study, detailed memos were kept regarding both insights into the data, and sampling decisions. In addition, the interview guide was updated after each interview so that emerging concepts could be checked with subsequent participants. Finally, the emerging theory was evaluated for “fit” and credibility by experts in the field of perinatal bereavement as recommended by Cooney (2011) and Cutcliffe (2005). Feedback on the emerging theory was sought from experts in neonatal and perinatal palliative care at national and international conferences. This feedback indicated that the grounded theory of “affirmed parenthood” and the category of “being a parent” were credible and relevant to experts in the clinical context.

Data analysis

This study was informed by Strauss and Corbin's (2015) approach to grounded theory. In keeping with their method, three levels of coding were undertaken; open, axial and selective. Strauss and Corbin (1990) describe open coding as “fracturing the data” (p. 13) into its smallest components, with one or more conceptual labels or codes being attached to each line or phrase in the transcript. The process of axial coding then enables open codes to be compared and grouped, creating conceptually dense categories that are well described in terms of their properties and dimensions. During axial coding, “categories are related to their subcategories, and these relationships are tested against the data” (Strauss & Corbin, 1990, p. 13). Coding was undertaken in an iterative manner across these three levels, enabling the emergence of concepts and categories that remained grounded in the data while become increasingly abstract in nature. All three levels of coding were undertaken using NVivo 11 (QRS International), which supported constant comparative analysis. Analysis was undertaken by the lead author in the first instance, with cross-checking undertaken by both co-authors at each level of analysis. Table 2 provides an overview of the codes that emerged during open and axial coding underpinning the category “being a parent” and the subcategories “contact”, “engaging” and “caregiving”.

Results

Contact

Each of the parents in this study identified that contact with their baby was central to their experience of memory-making in neonatal end-of-life care, and fundamental to their experience of "being a parent". Contact included both physical contact, such as touching and holding, as well as simply spending time with the infant.

All of the parents in this study described the time they spent with their baby as critically important to them. In particular, parents treasured opportunities to spend time with their baby while they were alive. For example, one father recalls:

> *P9: So (wife) and I had about an hour and a half, or more, with just him and I. And that was a really precious time, which we didn't realise at the time, but it gave us time to say goodbye.*

Another mother of twins describes the significance that spending time with her babies had for her:

> *P1: I got to feel like they were mine, rather than just something that happened… They were real people. And they even had personalities and um… yeah…. They were real. It was very real thing that I did. And yeah, it made them a real part of our lives, and not just this bad thing that happened in hospital one time.*

Spending time with the baby enabled participants to create a social identity for the infant as a person, and for themselves as parents, while simultaneously providing an opportunity to say goodbye to the infant.

In addition to spending time with the baby during life, each parent also had some form of contact with their baby after the baby had died, and such contact was described as important by most parents. For instance, when asked what she would like staff to know about caring for bereaved parents, one mother explained:

> *P3: I think for staff to know that the time that you give somebody with their baby is so… so important.*

However, the experience of spending time with the baby after death was also difficult at times:

> *P5: So yeah, we got some time in the bed with him (inaudible) but it was really, really hard. I mean I'm glad I had that time. I am sure a lot of other people would stay, but at the time, it was just a few hours.*

Despite this being an intensely emotional experience, none of the parents expressed regret around spending time with their baby after death.

For parents in this study, being given unrestricted, uninterrupted time with their baby was seen as a gesture of caring from staff. For example, one couple reflects:

> *P10: they never rushed us.*

> *P11: that was the nice thing. It wasn't like they were "come on, we've got to go home sometime today" sort of thing. It's like they really showed such a caring nature that I was very impressed by.*

Another mother explains:

> *P15: We knew that the nurses were there, they would make themselves known outside the door but they didn't intrude in any way. But to have that time and also the space. To have the space was really good.*

Time spent with the baby was critical for these parents, and this experience was enhanced when parents were not rushed and were allowed to spend time with their baby without interruption.

In addition to spending time with the baby, all of the parents in this study described the importance of opportunities to touch and hold their baby. For instance, one mother explains:

> *P12: (the nurse) took him out, and I nursed him. Thank god. And I nursed him for… probably about three hours. She adds: Holding him was huge. Huge.*

Another father recalls:

> *P8: We had many cuddles, up on our chests, in our arms. We cuddled heaps. He adds: It was mainly just talking with her, and cuddles. Physical touch was very important.*

As with spending time with the baby, all parents particularly valued opportunities to touch and hold their baby during their brief life. For example, when one mother was asked to describe the aspect of care that had the most significant impact on her experience of loss, she stated:

> *P5: I would say it's mostly just been being able to hold him. Especially before… while he was still alive.*

However, some parents also described this experience as stressful, especially when the baby was unstable:

> *P14: They really really encouraged us to get him out and hold him. And that I value a lot. Because at the time I didn't want to, because it stressed him out so much. But looking back I wish we had have had more experiences holding him and cuddling him. So that was really good.*

Despite the stress and effort involved in holding their critically ill infants, parents regarded holding their child to be a significant element of memory-making. Touching and holding their child while they were alive was an important aspect of "Being a Parent" and helped participants to form memories with their baby that were non-clinical in nature.

All of the parents in this study were present when their baby died, either holding the baby or supporting their partner to do so. While recounting the moment of death was intensely emotional for participants, several also expressed gratitude for being able to hold and comfort their babies in their final moments:

> *P1: I just asked if they could…. If I could hold them while they passed…. And I got to hold them while they passed. And um… yeah, I got to hold them for quite a while. I think if that hadn't have happened, it would have been a massive regret. So, yeah, that was really important. Yeah. I was lucky enough to do that, so that was good.*

Despite their profound grief, participants described being able to hold their child during their final moments as central to their experience of being a parent.

Despite the importance of contact with their baby, parents described a range of barriers, both to physical contact and to spending time with their baby. In particular, several parents described being separated when their baby was transferred to a NICU or to another hospital:

> *P15: We didn't get to see him, he was taken straight away. And then we are approached by the doctors to say that things weren't well. So he got whisked straight to NICU.*

> *P10: I just gave birth to him, they'd just sewed me up, I got five minutes to see him, and he got taken to a different hospital and I was in a ward filled with mothers and babies crying. So when they are in NICU, you are not with them. But you sort of feel…. What just happened? You feel really empty.*

Separation was experienced as distressing by parents, even when it was understood to be necessary. Separation impacted significantly on parents' contact with their baby, and in turn impacted on their experience of being a parent.

The medical instability of some infants also impacted on opportunities for physical contact. Notably, some parents avoided handling their baby out of fear of causing deterioration:

> *P6: It's that feeling of helplessness and hopelessness when you're standing there. You know, every time you touch him, his blood pressure would either drop through his boots, or go through the roof.*

For other mothers, their own physical condition impacted on their contact with their baby. For instance, this mother recalls being too unwell following an emergency C-section to engage with her babies:

> *P1: I only got up there once. And I couldn't actually hold them while they were … because they were so small. And I couldn't actually touch them, because I couldn't actually reach my hand up to get in, because I couldn't get out of the wheelchair.*

Factors such as physical separation following transfer, and the health condition of the mother and baby resulted in restricted contact at times.

Conversely, participants also described factors which facilitated contact with their baby. For example, parents who were able to remain near their infant due to open visiting policies and parent accommodation felt that this enhanced their contact with their baby:

> *P8: Staying in the same building was really good. So we could just pop down the corridor and just visit, for a bedtime story or… you know, we could go 24 h a day.*

> *P4: We could come and go as we pleased. So (husband) his dad was with him pretty much the whole time. And beyond that, we could come and go as we pleased.*

Interestingly, several parents remarked that their contact with their baby was also facilitated by a transition from active treatment to comfort care:

> *P7: once they ceased treatment, he was really just handed to us like a normal baby.*

> *P9: we actually took away all his tubes and stuff and we actually got to hold him for that last couple of hours.*

A shift from curative to comfort care provided parents with opportunities to see, touch and hold their baby without the barriers associated with medical management. This contact was treasured by parents and contributed significantly to their experience of memory-making.

All of the parents in this study emphasised the importance of contact with their baby through spending uninterrupted time together, and through touching and holding their baby. Contact with the baby allowed parents to create memories with their baby, and to step into their role as parents. Contact was facilitated through supportive visiting policies and by keeping parents and babies together, as well as through clear communication of the shift from curative to comfort care.

Engaging

In addition to spending time with their baby, several parents described intently studying their baby's features. For example, one mother recalls:

> *P14: I wanted to see him. I wanted to see his toes and his fingers, because I hadn't really… as much as I had touched him, I hadn't really held him.*

Similarly, another mother describes the importance of studying her sons while giving them a final bath:

> *P1: And I just got to touch them and study their feet and study their faces. And just soak them in, not forgetting one little detail. She adds: That was really amazing. And that was really important. I can still close my eyes and see their faces eight years later. So um, yeah, that was really important.*

For these parents, time spent studying the details of their baby's appearance was valued as an important activity that allowed them to form enduring memories of their children.

Parents in this study also engaged with their babies through talking, reading or singing. For instance, one father explains the significance of having time to talk to his newborn daughter:

> *P8: I had a big list and we chatted about everything. That was… saying all those things that you don't get to say later. He adds: For me, making that list of everything that I would like to say to my daughter and would have done… you know, walk her down the aisle, I can't walk her down the aisle, but I can talk to her about it.*

For this father, talking to his daughter about the life he had envisioned for her provided a meaningful way of engaging with his baby, while also enabling him to step into his role as a father.

Finally, several parents described reading as a way of engaging with their baby in the neonatal unit. For example, one couple remembered a midwife suggesting that they read to their son".

> *P15: She could tell that we just didn't know what to do, and she said, "well, why don't you read to him?" and so that then became our thing. And that is a really important memory…*

> *P16: What we found that was really good was to feel like you were doing something. To feel like you were interacting and doing something with your baby.*

Not only did reading to their son provide this couple with positive memories, but it also provided a way of doing "something" for their baby.

Parents in this study valued opportunities to engage with their babies. Engagement occurred through studying the baby, and also through talking, singing or reading to them. Engagement provided a source of meaningful memories for participants and helped them to step into their role as parents.

Caregiving

Parents in this study described caregiving activities such as changing, bathing and dressing their baby as critical elements of memory making. In particular, bathing was described by the majority of parents as the quintessential caregiving activity that allowed them to feel like parents to their babies. In part, this was valued as a "normal" parenting activity:

> *P17: being able to get him into a bath and have a good wash and have bubbles on him and that, it's just the normal things that you do as parents.*

Similarly, another parent reflects that washing her baby helped her step into her role as a mother:

> *P7: we bathed him, it was just a sponge, but she was really good. She allowed me… you know, she helped me to do all that, but gave me that mothering. Because when your baby's being looked after by others all the time, you don't get much of that chance.*

Opportunities for caregiving not only provided important memories for participants but also supported 'being a parent' in a situation where many 'normal' parenting activities were not possible.

Interestingly, while bathing the baby was important to participants, it was also perceived as stressful when the baby was unstable or when death was considered to be imminent:

> *P4: we were able to bath him, which was good. But we had to wait until they'd removed everything. So we had a lot of… it was just that uncertainty, because obviously once they remove things you just don't know how long they will last. So the hospital, I guess they can't… they just don't know, so they can't really plan for that. But we were quite lucky that we did get to bath him while he was still alive.*

However, when asked which activities helped her form memories with her baby, this mother stated:

> *P4: I'm really, really glad we got to bath him.*

Despite her trepidation, this mother viewed the experience of bathing her baby as invaluable.

Sadly, some parents were not supported to bath their baby, resulting in regret:

> *P15: one of the things that would have been cool, and this is only in retrospect, bathing him… even though he was dead, just bathing him afterwards. Because he still had all the tapes from the sensors and stuff. Especially on his face, from the CPAP machine. So having had the opportunity to bathe him, even though he was dead, afterwards, I think I would have appreciated that.*

> *P12: I wish we had washed her. I mean I don't know if they made the call not to do that because I was in an ICU. I guess I feel like I missed the chance to mother her. (crying)…. I would have liked to have done something like that.*

Such stories highlight how significant experiencing of caregiving are to parents' experience of 'being a parent' and therefore to affirming parenthood through memory-making.

Parents also described the significance of dressing their baby. For example, one mother explains that dressing her baby helped her process his death:

> *P10: I changed him. It was nice to do that, because he… I wasn't able to put clothes on him much while he had all the wires on him. So to be able to do that was nice. But I think it also helped me understand that he was dead, if that makes sense.*

Interestingly, parents also described choosing clothing as an important aspect of memory-making. For some parents, this meant being able to dress their baby in clothing chosen or made especially for them:

> *P7: there were things my mum had made, and I wanted to use those.*

However choice was also valued when parents were dressing their baby in clothing provided for pre-term infants by the hospital:

> *P6: they had a little pack there with a coupled of options to choose from in the 26–28 week size. She adds: The nurse brought out a couple of options for us to choose from, so that was nice. And then I sort of… she was really good, she was great. Because I didn't like the beanie in one of the packs, but I liked the beanie in the other pack, and I didn't like the booties (laughs). And she's like that's alright, we'll just swap them all around.*

Alternatively, being denied a choice of clothing was a source of regret for some parents:

> *P5: I probably would have wanted to dress him in what I wanted. The hospital had their own clothes, but I had my own clothes that I wanted him in. That probably sounds really superficial, but… yeah, when I think of it that way it was pretty important. I mean I know they changed him later for the funeral. But I think even at the time I really wanted him in the clothes that I had.*

For these parents, being given a choice of clothing affirmed the baby's identity as an individual and their own role as the baby's parent.

Finally, the simplest acts of caregiving such as changing nappies, stood out for some parents as important. For example, one mother explained:

> *P15: Certainly, things like changing his nappy and being involved in his cares, they stood out more so than just holding him. You felt so helpless, so actually doing something was definitely a stronger memory. She added: Just changing his first nappy, that was… that is a very vivid memory.*

When asked what aspects of care had helped him feel like a father, one participant explained:

> *P8: nappy change. For sure. Each of us got to do that a couple of times. It got a bit tricky when they had catheters and stuff in, but….*

Another mother explains the significance of simple caregiving in helping her to connect with her baby:

> *P10: So just being able to do those sorts of things, it made that bond with him. That most people would have gotten anyway. Just being able to be closer to him, to touch him and to clean him, and to feel useful. Because most of the time we just sat there, watching him and holding his hands, and we couldn't do anything.*

Being able to provide care helped parents to bond with their baby and form memories, while also allowing them to develop their identities as parents.

Parents in this study described a range of actions and strategies that supported them in "being a parent". Contact with the baby through spending uninterrupted time together and through touching and holding was a significant experience for parents. These types of contact were also a precondition for other elements of being a parent, including engaging and caregiving. Parents identified caregiving as especially important, allowing them to create positive memories with their baby while simultaneously helping them to step into their role as a parent.

Discussion

'Being a parent' emerged as a key concern for parents experiencing the loss of a newborn. Participants described 'being a parent' through having contact with the baby, by engaging with them, and particularly through caregiving. These findings correspond with previous research emphasising the significance of contact between parents and their dying newborns (Abraham & Hendriks, 2017; Baughcum et al., 2017; McGuinness, 2015). For example, Abraham and Hendriks (2017) report that parents "felt a profound need to fulfil this parental role and to give some warmth and support to their dying baby" (p. 2107). This highlights the importance parents place on opportunities to see and hold their newborns in the context of neonatal palliative care.

Despite the importance of contact, parents in this study described multiple barriers to such contact with their baby, including the NICU environment, being separated at birth, and the physical condition of mother and child. Multiple studies have described the NICU environments as a potential barrier to contact between babies and their parents (Abraham & Hendriks, 2017; Currie et al., 2016). Indeed, Gale and Franck (1998) explain that "Parents may feel as if they are strangers; are fearful of touching anything, including the baby; and may also feel incompetent in providing care for their newborn" (p. 64). Not only is the physical environment of the NICU unwelcoming, but parents are fearful of harming their baby by touching or holding them. Restricted contact may reduce opportunities for parenting, and as such have a significant impact on parents' experience of memory-making.

Parents in this study also described engaging through studying the baby, and through talking, singing or reading to them, as a means of parenting the baby. This aligns with findings from the broader perinatal bereavement literature (Abraham & Hendricks, 2017; Baughcum et al., 2017; Cacciatore & Flint, 2012). For instance, Baughcum et al. (2017) reported that when infants were too unstable to be handled, parents engaged with their baby through studying them or talking to them as a way of 'doing something' for their baby. Similarly, parents in the current study described the desire to do *something* for their baby, especially in situations where physical contact was limited.

Finally, participants in this study described the importance of caregiving in developing their own identity as parents, while also honouring the identity of their baby as an individual. Several studies have described caregiving as a critical element of neonatal bereavement care (Abraham & Hendriks, 2017; Baughcum et al., 2017; Brosig et al., 2007; Currie et al., 2016; Lathrop & Vandevusse, 2011; Lemmer et al., 1991). In particular, opportunities to engage in "normal" tasks such as bathing, changing and dressing have been identified as significant for bereaved parents (Meert et al., 2005). While there is a growing body of research emphasising the importance of caregiving experiences for perinatally bereaved parents, fewer studies have explored *why* parents place such significance on this element of memory-making. In the current study, parents explained that providing care for their baby allowed them to *become* parents to their babies. The relationship between caregiving activities and parental identity is supported by Currie et al. (2016) who found that "maintaining the role of the parent was a priority during the infant's life, surrounding EOL (end-of-life) care, and at the time of death." (p. 481).

The significance of opportunities for 'being a parent' was perhaps most evident where these opportunities were denied. In particular, parents in the current study repeatedly expressed the wish that they had engaged in more "normal" caregiving activities with their babies. This finding is consistent with the existing perinatal bereavement literature (Gold et al., 2007; Harvey et al., 2008), and with neonatal palliative care guidelines (ACNN, 2010; BAPM, 2010; PSANZ, 2019). These experiences were central to 'being a parent' and missed experiences were mourned as lost opportunities for memory-making.

One of the unique findings from the current study was the importance that parents placed on selecting clothing for their child. While this finding was not described in the perinatal bereavement research, one bereavement support site captures this concept eloquently with a quote from a bereaved parent: "Midwives shouldn't choose the clothes, parents should, because you want to do something for your baby, and there is very little that you can do as parents." (Red Nose Grief and Loss, 2016). Even seemingly small opportunities for parenting, such as choosing the child's clothing or changing a nappy may be treasured, enabling parents to bond with their baby and to step into their role as a parent.

Limitations

One of the potential limitations of this study was the relative homogeneity of the sample. While specific data were not captured relating to ethnicity or faith, the sample was predominantly Anglo-Saxon/Angelo-Celtic in origin and all participants were English speaking. Although cultural and spiritual needs did not emerge as significant elements of participants' stories, it is important to note that faith and culture may play an important role in parents' needs and preferences in relation to bereavement care, and that these variations may be more evident in a more diverse sample.

The other key limitation of this study is the proportion of the sample who could be described as "help-seeking". Sampling for this study was in part conducted through bereavement support groups. It is possible that parents who engage with support services may not be representative of the broader population and may hold different views regarding memory-making than other bereaved individuals.

Implications for practice

The findings described in this article, in addition to those from the broader grounded theory of "Affirmed Parenthood" emphasise the need to support contact between parents and their newborns in the context of neonatal end-of-life care. Recognising the impact of separation on memory-making, staff across the healthcare organisation have a critical role to play in minimising the duration of separations. Involvement of hospital leadership and administration is crucial in the development of policy and clinical guidelines that support parenting activities in the context of neonatal end-of life care.

At the bedside, staff need to provide emotional support and encouragement so that parents can overcome the fear engendered by the NICU environment to engage with their babies. Perhaps most importantly staff can support parents to provide care for their baby through bathing, dressing and changing, and through choosing the baby's clothing. While parents may experience some anxiety around such activities, all participants in the current study were profoundly grateful to the health professionals who encouraged them to care for their baby, enabling them become parents to their baby.

Conclusion

Being a parent emerged as a central element of memory-making in neonatal end-of-life care from the perspective of bereaved parents. Contact, engaging and caregiving were profoundly important to participants, allowing them to honour the individual identity of their baby and to step into their own role as parents. Health professionals are uniquely placed to support and encourage parents to engage in meaningful memory-making, and in doing so, can help to affirm parenthood for those experiencing the loss of a baby in the neonatal unit.

Declaration of Competing Interest

None.

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