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Mothers, milk and mourning: The meanings of breast milk after loss of an infant

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Abstract

Breast milk is a highly valued substance, immunologically and nutritionally, which also signifies maternal care and love for the infant. This intersection of biological and cultural qualities confers breast milk with complex meanings, which necessarily shape the experience of breastfeeding. Our research, investigating the experience of lactation *after* the loss of an infant, casts a novel light on these meanings. This article analyses the experience of 17 Australian bereaved mothers and 114 health professionals charged with their care. We find that while all the mothers found post-loss lactation emotionally painful, many also found redemptive meaning in their milk-production, as a bond with the lost child, as confirmation of their maternal competence and as a life giving substance that they could donate to other needy infants. These complex meanings and positive connotations were at odds with hospital cultures that regard post-loss lactation as valueless and best dealt with through medical suppression, despite the more complex insights of individual health-care professions.

KEYWORDS
breast milk, donation, infant death, motherhood, tissue donation

INTRODUCTION

Breast milk is a highly valued substance in several different senses. Its immunological qualities and ability to transfer maternal immunity to infants are the focus of increasing quantities of biomedical research (Palmeira & Carneiro-Sampaio, 2016). Its singular nutritional qualities are habitually contrasted with the lesser qualities of infant formula, as part of the 'breast is best' public health campaigns (Bartlett, 2003; Wiant Cummins, 2020). It is the optimal nourishment for premature infants whose immature digestive tracts are prone to necrotising enterocolitis if fed non-human milk (Bellodas Sanchez & Kadrofske, 2019). As a means of maternal care for the infant, it carries an incalculable affective charge: it readily stands for all forms of maternal love, nurture, self-sacrifice and domestic safety, a significance with a long historical genealogy in art and literature as well as in everyday life (Ventura, 2018). Breastfeeding is a synecdoche for good motherhood and women readily adopt a version of this significance when trying to understand their own experience of infant care (Johnson et al., 2009). This intersection of biological and cultural qualities confers breast milk with complex meanings, which necessarily shape the experience of breastfeeding for both mother and child.

Our research, investigating the experience of lactation *after* the loss of an infant, casts a novel light on these meanings. Lactogenesis forms part of the physiology of pregnancy and birth. Breast milk may be produced from as early as 16 weeks' gestation and will become copious after the birth of the placenta (Kennedy et al., 2017; Neville et al., 2001). Women who experience late termination or miscarriage, relinquishment or infant removal after birth, stillbirth or early neonatal death, usually find that their breasts engorge and produce milk (McGuinness et al., 2014). Those who experience the death of an older infant may have well-established lactation that does not cease with the loss of the child.

As our research and the work of many others attest, women in Australia, the United States and other developed nations are often unaware that they may commence or continue to lactate in the absence of an infant (Carroll & Lenne, 2019; McGuinness et al., 2014; Sereshti et al., 2016; Welborn, 2012). This general lack of awareness is compounded by systemic oversights in hospital and health care, which leave bereaved mothers without advice or guidance regarding lactation onset and management (Britz & Henry, 2013; Carroll et al., 2014; Noble-Carr et al., 2021; Redshaw et al., 2014). Lactation after the loss of an infant can hence be a shocking, isolating experience, where the woman's grief for her lost child is inflected through the dense significance of breast milk and the poignancy of lactation without an infant.

In what follows, we set out an analysis of this experience, based on interviews with mothers who have experienced stillbirth and infant death and health professionals charged with their care. Our data give us singular insight into the social significance of breast milk, because they are generated at the intersection of two forms of silence. One is around the death of infants, a general cultural aversion to the acknowledgement of infant loss as a possible result of pregnancy, and the particular kind of grief associated with the loss of a child at the very beginning of its life (Layne, 2003). The other is around lactation itself and its associations with shameful bodily excess: a lack of control and a need to carefully manage the distinction between the sexual breast and the nurturing breast (Bartlett, 2003). The difficulty of containing the lactation process, its unpredictability and stigmatised messiness has resulted in its historical relegation to a privatised domestic realm excluded from the public sphere, although this relegation is now much contested (Hausman, 2003). Lactation after loss is, generally speaking, an intensely privatised experience with few opportunities for public expression or social acknowledgement.

We have written elsewhere about the implications for the organization of health systems and the need for specific kinds of care for this group of women (Noble-Carr et al., 2021). Here, we draw on this occluded experience to explore the *meaning* of breast milk, both in these particular circumstances and more generally. Lactation after loss *inverts* the common significations of breast milk and feeding. Instead of warm associations with new life, new motherhood, nurture and intimacy, it aligns with death, loss, waste and absence. Hence, as an experience, it illuminates both the sanctified and unsanctified meanings of human milk and the social dynamics and relations which underpin them.

METHOD

Our study was funded by an Australian Research Council Discovery Grant and aimed to understand bereaved mothers' experiences of lactation after infant death. We were specifically interested in understanding the meanings that bereaved mothers attribute to lactation, breast milk and breast milk donation and how decisions about lactation and donation may influence their grief and motherhood experiences. Alongside this, and in line with a feminist ethic of care (Code, 2015; Evans et al., 2017), our aim was to apply bereaved mothers' knowledge to inform care delivery in maternity, bereavement and milk banking services. To ensure that our research enhanced practice and took account of contemporary health-care contexts and constraints, we also explored perinatal and lactation health-care providers' perspectives and practices of bereaved lactation care and milk donation.

Participant recruitment

To conduct the study, partnerships were formed with three large tertiary hospitals located in three eastern Australian states and territories. Hospitals were selected because each had a Level 4 or 6 Neonatal Intensive Care Units (NICU) and two of the three hospitals had an onsite Human Milk Bank (HMB). A Stakeholder Advisory Group (SAG) comprising of medical, lactation and infant bereavement specialists and a mother with experience of infant bereavement was established at the commencement of the study.

SAG members at each hospital site invited relevant health professionals from a range of disciplines, including obstetricians, neonatologists, midwives, neonatal nurses, lactation consultants, social and pastoral care workers, HMB staff and specialist perinatal bereavement nurses to participate in focus groups and interviews conducted at each health site. Staff from three additional Australian HMBs were also invited to participate.

SAG members also assisted with the recruitment of bereaved mothers, identifying eligible mothers from hospital infant death records and/or breast milk donor databases of on-site HMBs. Key inclusion criteria specified mothers who had experienced either a stillbirth (foetal death after 20 weeks of gestation), neonatal death (first 28 days of life) or older infant death (1–12 months) in the last 24 months. Upon consultation with stakeholders and perinatal grief scholarship (Cronin, 2020), mothers were excluded if they had experienced the bereavement within the last 3 months. Hospital staff sent out an invitation letter to eligible mothers. Those choosing to opt in to the study directly contacted researchers to request an interview or to provide a written response.

The participation of health professionals and mothers was voluntary and all participants were made aware that their care or employment with associated hospitals would not be

adversely affected if they chose not to participate. All invited participants were able to access free twenty-four-hour anonymous support from specialist infant bereavement counsellors before or after interviews. All participants were provided with written informed consent to take part in the study. Ethics approval for the study was provided by Human Research Ethics Committee (HREC) and/or Research Governance Office of each participating hospital and by the researchers' University HREC. We note that our research data are not shared as we do not have HREC approval to do so.

Data collection

Data collection methods were designed to be sensitive to the needs of participants and consistent with best practice in grief scholarship (Dyregrov, 2004; Stroebe et al., 2003) and research into health-care quality (Pope et al., 2002).

Health professionals

Seventeen profession-specific focus groups with a total of 108 health professionals were conducted across three hospital sites to investigate the perspectives, experiences, practices and practice contexts of hospital-based health professionals who may provide lactation and/or grief care to bereaved mothers following infant death. Additional interviews were conducted with six health professionals, including HMB Staff and Specialist Bereavement Nurses, whose unique roles in the hospital/HMB settings were informative for our study.

Focus groups were chosen as the most appropriate method for health professional data collection as they are an effective way for health professionals to share, question, debate perspectives and practice experiences and to uncover issues yet to be considered by researchers (Jayasekara, 2012; Pope et al., 2002). All focus groups and interviews, each lasting approximately 1 hour, were conducted between February and November 2019. Each focus group was facilitated by one of two researchers (DNC and KC). Each focus group or interview discussed the same topics, including generalist bereavement care and lactation care currently provided, preferred lactation care practices, challenges and barriers to providing care and what is required to enhance care (further details can be found in Noble-Carr et al., 2021).

In total, 114 hospital-based and/or HMB health professionals from three hospitals and three separate HMBs participated in the study. These participants included 29 neonatologists, 20 social workers/pastoral care workers, 19 neonatal nurses, 17 obstetricians, 14 lactation consultants, nine midwives, four human milk bank staff and two specialist bereavement nurses. Eighty-two percent were female and almost half had over 15 years of professional experience.

Bereaved mothers

Interviews with bereaved mothers were conducted by one of two researchers (DNC and KC) in 2019 and 2020 following a staged recruitment process at each study site. Interviews took place between 3.5 and 24 months since the time of infant death, with the average time being 13.7 months. Consistent with best practice in grief research, mothers could choose the time and location of the interview and chose the mode of engagement. Six interviews were conducted

in mothers' homes, six via phone interview (including 1 with an interpreter), four via zoom and one mother opted to provide a written response. Most interviews lasted one and a half hours, covering key topics, including their experiences of pregnancy, the birth, life and death of their baby; lactation experiences before and after the death of their infant; lactation care received and preferred; breast milk donation and living with grief and loss. Interviews were conversational in style, conducted in a manner that allowed the researcher to 'sit alongside' bereaved mothers (Rowling, 1999) to support them to share as much of their experience as they wished. For some mothers this meant sharing photos, clothing and other artefacts with the researcher, an approach that helped to honour the deceased's life within the research encounter (Valentine, 2007).

In total, 17 Australian bereaved mothers of 21 deceased infants (eleven stillborn, eight neonatal and two older infant deaths) participated in the study. Four mothers had twin infants, two of whom had a surviving twin. Seven mothers donated milk following their infant's death. Three donated frozen stores of milk available at the time of death, and four chose to sustain their lactation for two to six months following infant death for the purpose of donation (one mother did this following two separate infant bereavements). One of the donating mothers also shared milk informally with a friend, while another also saved milk to feed her subsequent child.

At the time of their interview, participating mothers ranged in age from 24 to 45 years and all were living with the deceased infants' father. Ten of the mothers had an older child at the time of their infant's death. Almost two-thirds of the mothers held a bachelor's degree or higher and 13 were in paid work at the time of their interview. Three mothers' primary language was not English, with one requiring an interpreter for their interview. Eight mothers stated they had no particular religious affiliation or beliefs, five stated they were Catholics, three were Christians and one mother was a Hindu.

Data analysis

Each interview or focus group with health professionals and mothers was audio recorded and transcribed for analysis. As is common to research on sensitive issues, researchers were careful to ensure that embodied means of communication such as crying, facial expressions, silences and reluctance to talk on particular issues were included in transcripts for analysis (Evans et al., 2017, p. 594). Thematic data analysis, using NVIVO coding software (Jackson & Bazeley, 2019) was separately applied to the health professional and bereaved mother data sets. For each data set, researchers began with a set of deductive themes, based on key questions posed in interviews/focus groups that sought to answer our research questions about mothers' experiences and meanings of lactation after loss and the lactation care they receive and require. Inductive coding was then applied, with each transcript read in full by two researchers before one researcher created a hierarchical coding framework, developing new themes and subthemes based on the emerging data (Braun & Clarke, 2013). A coding document outlining key findings was developed for each data set, with final themes then being confirmed, discarded and re-categorised through discussion between all researchers. Health professional data were further interrogated utilising Willis and colleagues' (2009) and Moen and colleagues' (2010) critical questions for interactional analysis (Moen et al., 2010; Willis et al., 2009). This further analytical step uncovered significant meanings and relationships across themes that had emerged as a result of ideas and topics being discussed, challenged and contested within the focus group setting.

LIMITATIONS OF THE STUDY

This study was conducted within Australia, which has several intersecting factors that shape health service access and provision, and therefore bereaved lactation experiences. Australia is a high-income country with a universal and highly resourced health-care system. Australia has held a prominent international role in developing mother-to-mother breastfeeding support (formally the Nursing Mothers Association of Australia, now known as the Australian Breastfeeding Association) and in professionalising the lactation consultant role (Carroll & Reiger, 2005). Australia, however, lags in its milk banking sector, with very little national coordination or advocacy and with limited bereaved milk donation programmes (Sweeney et al., 2019). Despite these highly resourced cultural contexts, bereaved lactation faces little health service attention in Australia. This suggests that other high-income countries may be good comparators in future work, and further research is also needed in the formal and informal health and lactation support services in lower and middle income health systems. Importantly, our study did not hear the voices of bereaved parents from LGBTQI + individuals or families nor did it incorporate the experiences of lactation and bereavement of First Nations Australians. Given the propensity for marginalised people to face structural discrimination in health care, these areas need to be urgently pursued in further research in Australia to provide inclusive and culturally safe health services for bereaved families.

RESULTS

Milk out of place

For many of the women, the sudden onset or continuing production of breast milk despite the loss of their child was hard and overwhelming. Few mothers felt adequately informed or supported to appropriately manage their lactation. Those whose newborns were initially transferred to NICU were often in receipt of breastfeeding care because of their relationship with the unit and the infant's need for their mothers' milk. Following the demise of their infant, however, the issue of mothers' milk faded from most professionals' concerns, and mothers were often left without necessary guidance and support.

For those who experienced late miscarriage or a stillborn baby or whose infants died soon after birth, lactation was often the last thing on their mind. Among this group, lactation most often occurred once mothers had returned home and were without ready access to the hospital and expert care. In our study, five of the seventeen bereaved mothers were either not alerted *at all* to the possibility that their milk would continue to come in or were advised that this was unlikely to occur. They evinced distress at what seemed an incongruent bodily response to their loss:

> I was like, I feel like I'm getting milk. It was horrible. It was horrible because here you are, (crying) producing, and you don't have a baby. It doesn't make sense, and your brain is like, "She died. Why is this happening?"
>
> (Maria)

> You've given birth to a baby; the baby's not alive, and your body is going, "You had a baby!" Like, it's so confronting...you can actually feel it. You can't hide from it... It felt like I was supposed to have my baby, I was supposed to breastfeed. And nature is

> nature, so your body's going, "You've had a baby" but you ain't (sic) got your baby. So it's like, "thanks for that"...excuse my language, but "You bastard. I hate you."
>
> (Millie)

The improbable (for the women) presence of breast milk, the experience of engorgement and leakage and the sheer physical insistence of breast milk production in the absence of an infant to feed meant that the milk and breast engorgement were often experienced as direct, unmediated expressions of grief:

> It was really heavy, and, yeah. Like, the grief that sits right on your chest...And that's right where your breasts are, too, so it's quite tied together.
>
> (Ashley)

> I was upset for a long time, but if I would kind of burst out in tears crying, they [my breasts] would leak.
>
> (Rosie)

Here, we can see that for Rosie, milk production was coterminous with tears. Both body fluids overflowed simultaneously as expressions of loss and pain, both beyond her control, their insistency driven by the perpetual absence of the much-wanted child. For Ashley, engorgement was often extremely painful, so that the experience of physical and emotional pain was fused into a single point converged on the breasts. In these cases, breast milk production compounds the experience of pointless loss, or worse, a punitive betrayal by their body, whose obtuse lactation is wildly out of keeping with grim reality of foetal or neonatal death. As Amanda puts it:

> "Why is my body doing this to me?" That was my very first reaction. This is not fair. Why?... I really felt upset, thinking, this is not fair. After everything, why do I have to do this now?
>
> (Amanda)

Here, the physiology of the fourth trimester, the postpartum period during which the mother and infant are still physiologically intertwined with each other (Isaacs, 2018) renders the mother's body itself as another site of loss, precisely because it is tied to the absent child.

Milk and remembrance

The inescapable and potent conjuncture of lactation and an absent child was clearly articulated by the two mothers feeding a surviving twin infant. They explained that expressing milk for or breastfeeding their living infant, whilst drawing inescapable attention to the physical absence of their deceased infant, also provided them with time and space for remembrance:

> I really felt [infant's] absence ... in the night-time feedings, because it was dark, it was quiet, it was just me and [living twin], and that's when it's like... it should be the three of us doing this, not just the two of us. It was really when her space that she should have been occupying that it was really noticed. And it still is. So that's continued....It

> doesn't make it harder. Yeah. It just made it really special, actually. Yeah. And sad. It made it really bittersweet.... That's when a lot of the tears would come, too.
>
> (Ashley)

For these mothers, breastfeeding was a form of memory, a material trace of their baby's fleeting existence that brought pain but also some comfort. Mothers without a living infant could also sometimes conceptualise milk leaked or expressed as a significant and positive reminder of their infant, whom they were in no hurry to forget:

> It was the last piece of him living.
>
> (Sarah)

> For me, It's positive because it just makes me remember him, remember that I was pregnant with him.
>
> (Madison)

Their leaking milk constituted a material bond with the lost child, and the bond was precious and to be preserved.

This sentiment also attached to frozen stores of milk, kept at the hospital or at home. For many of these women, whose babies died in the days, weeks or months after birth, the need to nurture the child, however briefly, gave their milk production a sense of high purpose. This was particularly true because milk production was often the only kind of physical relationship they could have with their ailing babies:

> That's the only thing you can do, when your baby's in NICU and you can't hold them, you can't do anything for them, the only thing you can do is nourish them through your breast milk...We couldn't hold him...Pumping was basically the only thing that I could provide for him.
>
> (Sarah)

> All I could for him was pump. I couldn't be a parent to him in any other way.
>
> (Christine)

Milk production, using a breast pump, came to stand for all forms of maternal love and care, bonding and connection with their baby (Hurst et al., 2013). Pumping, a commonly disliked activity described by women generally as mechanical, slow, painful and humiliating (D'Ignazio et al., 2016), became for this group of women a concerted act of love and the primary material means through which they could attend to their child (Rossman et al., 2013). This relationship imbued frozen stores of milk with the same memorial qualities associated with breast feeding a surviving twin, so that frozen stores were extremely meaningful for most of the women who retained them. We will return to this point in the section 'Milk as Valuable' below.

Suppression is best

For those women who did receive guidance from the hospital about their post-discharge lactation, they were advised, almost exclusively, to suppress. For example, following her stillbirth, Karen explained that she was told by the clinical staff charged with her care that:

> It can be quite upsetting for women after having a stillbirth when their milk comes in, that there is a number of things that you can do to try to prevent it happening, to suppress the breast milk. That was kind of how it was all framed.... I went .... 'OK, I need to suppress this, I need to stop this from happening. I'm upset enough as it is. I don't want to do anything to be more upset'.
>
> (Karen)

The health professions in our focus groups noted repeatedly that suppression was the preferred and indeed almost always the only option available or supported by the hospital culture. This understanding of lactation after loss was driven, according to our participants, by two factors. One of these was compassion for the women, the sense that they have already gone through so much pain that they should be spared this dimension if possible. One lactation consultant gives particularly graphic expression to the negative status of post loss milk. She describes milk as an antagonist, a malicious obstacle to healthy grieving and an absolute waste that should be pre-empted through suppression:

> I feel that [for many health professionals] the milk is the enemy, all of a sudden, in going through the bereavement, and I feel that I don't want to see it like that and I want, you know, to actually say to the mother, and sometimes I do, it depends where she's at, "This is normal. Your body is actually working really well, but now that's what we've got to do, because .... the milk is not needed in that context, and so this is what we can do for you to help you suppress it." But, yeah, I do feel that milk is often the enemy in bereavement because we want to shut it all down.
>
> (Lactation Consultant)

Another professional acknowledged that this constellation of malevolent meanings made milk disturbing, not only for the women themselves but also for the hospital staff:

> It's fear of the milk, because milk is a trigger, a threat, an emotionally-charged, natural, physical response, but just a nasty killer of a reminder of the loss...And I think it's scary for staff. I mean, I'll acknowledge that, because that's probably why I want people to know, at least technically, in a calm manner, know how to manage it, how it's normal, and all that, but it's just the kicker, you know? ...your body starts to make milk for a child you haven't got. It's just grief on grief. It's cruel, but it's...I've also known about letting your milk flow, and you can express milk, and for some women that's very healing, ...I wish it could be seen like that.
>
> (Lactation Consultant)

The second driver of the suppression approach identified by our participants was a desire to 'tidy things up' as one health professional puts it:

> There is this innate drive to deal with this situation as quickly as possible... and that drive tends to come from the doctors...I think it's their anxiety to tidy things up and make things better... it's that, "OK you've got a problem, we're going to take over now, and we're going to fix this for you," which is coming from a good place, but it's not always the right thing to do.
>
> (Nurse)

One of the mothers, herself a health professional, noted dryly that the salience of suppression as the only real option stemmed from the discomfort of the health professionals and their desire for a clean managerial approach to lactation and grief:

> I think health professionals kind of want to wrap everything up and tie a nice little bow on it as quickly as they can, and if someone lactates for two months to donate after their birth, I think that they can't just wrap it up and discharge them.
>
> (Samantha)

In the hospital culture and procedures, it appears that milk is understood on a single axis. It is nutrition for the child, and in the absence of the child, it is framed as meaningless and pointless. The quotes above suggest that individual health professionals did not entirely concur with this sense. Indeed, they themselves suggest that most health professionals regard post loss milk as somewhat malevolent, but *they act as if* milk is without meaning. This anxiety and the desire to address and manage post loss lactation as rapidly as possible meant that women were almost exclusively advised to suppress, using dopamine agonists, an approach advocated by specialists (Royal College of Obstetricians & Gynecologists, 2010) or through more gradual non-pharmacological measures—cold compresses, minimal manual expression, anti-inflammatories and so on.

In the hospital, bereaved lactation care was usually provided as a one-off, brief intervention (Noble-Carr et al., 2021). Only nine mothers stated they received breast care advice and information following loss from hospital health professionals, generally limited to mechanical advice concerning physical pain and milk management. Some felt that suppression was offered as an alternative to or avoidance of discussion about the meaning and depth of their lactation-related grief:

> When they brought me the tablet, possibly they could have explained all of my options so I could have known, and then I could make, for me what could be the right call at that time. One of the midwives just brought in the tablet. I would have been happy for any of the midwives to talk to me just so I'd know my options...no-one actually spoke to me about "What would you like to do?"
>
> (Madison)

Hospital culture and grief management

This 'neat' approach to lactation management contrasts strikingly with the empathic, process-oriented psychological support provided by hospital health professionals for bereaved parents, to give them time and space to work through their grief. Nurses and midwives ensured that parents could come to know and continue to care for their child for a period of time after death, facilitated by cold cots in the hospital, palliative care facilities and for one mother at home. Quiet time with the baby following death was appreciated as time to hug, hold and make memories and mementos together:

> We were offered to wash them and clothe them and do all the kinds of things that a normal person would do with their baby. I just didn't really want to interfere with how they were. To me, they were just perfect. I mean, [baby's name] had a bit of infection on his face, and they were like, "Do you want to give his face a wipe?" And

> I just didn't want to touch, or change, anything about him. And then we had lots of people come and bring some clothes in if we wanted to dress them, but I felt weird about that, so we just kind of swaddled them, and left them swaddled all the time.
>
> (Rosie)

> I think we held her for God knows how many hours after she passed away. They just let us...be with her, and hug her, and just love her for that little bit longer.
>
> (Lily)

Hospital staff gave careful attention to the creation of mementos of the child's existence. Part of the particular difficulty of infant death for the parents is the absence of witnesses to the child's existence (Oreg, 2019). Apart from the bereaved parents, and sometimes close family, health professionals were often the only witnesses to the child's life. Hence, they took on a particular importance for the grieving parents:

> She's [midwife] so intertwined with our experience with [deceased infant]...so few people will get to meet my baby, and the fact that, you know, she would be, it felt like she was impacted by it as well, and, as I say, she kind of forms part of [infant's name] story.
>
> (Karen)

Professional photography was organised for all families across sites (with the exception of one mother's first stillbirth loss that had occurred almost a decade ago). Charities such as Bears of Hope and Precious Wings assisted with memory boxes. Health professionals offered to provide locks of hair, fingerprints and footprints, gowns, clothes, wraps and quilts for infants.

So we can see that the grief and emotional pain of mothers and parents was well acknowledged in the hospital, and that an entire infrastructure of grief support and material witness to the lost child came into play to facilitate the grieving process. *However, lactation itself was not acknowledged in this way nor was it explored as potentially meaningful for the parents.* As we noted above, milk was regarded by health professionals as an inappropriate and insistent intruder upon legitimate *psychic* grief, something that interrupted the temporality of proper grief processing.

We would argue that the elaborate attention and care given to the psychological grief of bereaved parenthood in the hospital reverses a historical neglect. During most of the twentieth century, the common practice was to place bereaved mothers in the labour ward surrounded by other women with living infants, to remove dead infants quickly, to dispose of them without a funeral and to discharge women without postpartum support (Thompson, 2012). Hence, the contemporary infrastructure to acknowledge and process grief is a response in part to a prior 'suppression' approach, a clean managerial disposal of both the child and the painful maternal affect associated with its demise.

So we can see that facilitating *psychological* grief is now understood in Australian hospitals as healthy, appropriate care for bereaved mothers and parents. *However, the grief associated with milk production is treated by hospital protocols along the same lines as the historical approach to psychological grief; a matter for (at best) medical management and suppression and at worst complete silence.*

This speaks to something of a lingering mind–body split within the hospital organisation and its care ethos, a tendency to regard the physiological as quite separable from the psychological. It also reflects the comparative newness of lactation consultants, who subscribe to a more

holistic and woman-centred approach, as professionals within the hospital hierarchy (Carroll & Reiger, 2005). Milk production after death is understood by the majority of our health professional group to be distressing, but it is also understood by most to be primarily a physiological matter, an unfortunate and inappropriate aspect of forth trimester embodiment that should if possible be shut down. The possibility that milk production could become a healthy part of grieving and conferred with redemptive meaning is generally not entertained at a systemic level, although individual health professionals in our focus groups acknowledged that this was possible (2021).

We will see that the majority of the women we interviewed did not share these assumptions. Their milk did not lose significance or value nor did it become empty waste. Their milk's significance was dynamic and complex, modifying over time as they moved through different points in the arc of loss. Its intense set of cultural meanings—care, love, nurture, intimacy and maternity—changed and adapted, but they did not lose their intensity.

Milk as valuable

All the mothers regarded breast milk as a valuable substance, as intrinsically nurturing and life giving and as a means of expressing love and care. For the majority of women, some sense of this value persisted after the loss of the child, often despite their sense of distress. Some experienced their continuing lactation as a testimony to the maternal competence of their bodies. This was especially poignant for those participants in our study with long histories of failed fertility treatment and previous loss, and for some of them, lactation indicated their body could in fact adapt to motherhood:

> I think I was just really upset about [lactating]. Probably after a couple of weeks and it all settled, and I guess emotions were starting to even out, I'm probably glad that I did [lactate], in the end, because I thought, OK, at least my body was doing what it was meant to do. ... having to go through IVF to fall pregnant, I wasn't sure... so yeah, I thought I was kind of glad because I thought if we are lucky enough to fall pregnant again, then I hopefully will be able to breastfeed.... It was doing what it was meant to do! Finally,! (slight laugh) So yeah, first reaction was just really, why did this have to happen? Being upset about it. But then, after a while, I was glad that it did.
>
> (Amanda)

Nine women felt strongly that they wanted to avoid or stop their breast milk and where necessary they pursued suppressive approaches. However, for some of these mothers, and for others, some continuation of lactation, either through deliberate maintenance or inadvertently, through the often protracted process of gentle suppression, became a way to maintain a psychic link to the lost child:

> Then it ended, and then you wanted it back! Does that make sense? Because that's part of pregnancy, part of having a baby. So, when it comes in, you go, "Oh, my god, thanks for that, I don't need reminding I've just not had a baby", but when it goes, it's another loss... Like, I lost my baby all over again.
>
> (Millie)

A number of the mothers had stored milk, generated through prenatal expression, pumped during their child's life, produced while they waited for suppression methods to work or deliberately maintained. Because mothers valued their milk, regarded it as a life giving substance or as a signifier of their maternal capacity or relationship with the child, almost all were concerned that it should not be wasted. Fourteen mothers explicitly mentioned they wanted their milk to be used purposefully, and several expressed extreme distress at the idea that it might be discarded, regarded as waste:

> I remember asking, "I've all this colostrum in the freezer, you know?" All this hard work...The idea of going to the freezer and putting it in the bin just seemed horrendous...It was just like this amazing superfood, and I think it just seems to wasteful that it wasn't able to be used somehow.
>
> (Karen)

> I didn't want to bloody well and truly waste it! I didn't want it to be thrown in the bin. I think I would have had feelings about that. It took me a lot of time and effort, when I added it all up over all the days.
>
> (Christine)

Ten women had frozen stores of milk at the time of loss, which to them represented many hours of material and emotional labour, and constituted an invaluable store of nutrition and love that should not under any circumstances be disregarded and unvalued. Mothers who were not presented with any viable option for using milk felt that the value of bereaved mothers' milk was discounted:

> I felt a bit upset in the way that no-one got to use, make use of it. I felt a bit sad that my babies should have been feeding from this ...I don't know how I felt other than a bit sad, you know, that somebody should—well, my babies, firstly, should be using this; secondly, if they're not, somebody else should.
>
> (Rosie)

Milk donation

In addition to keeping their milk and using it over time to feed or bathe their other infants or to share informally, 10 mothers asked a health professional if they could donate milk to an HMB. Generally, this desire was not based on medical advice that such donation was possible, but rather on spontaneous or researched action taken by the mothers:

> I didn't even know there was such a thing as a milk bank before I offered. I didn't even know it was a thing .... I just thought, well, my babies have died. How can I stop another baby dying? And that was the first thing. I've got food for them. And in my head, I didn't even think, OK, it's got to go to a milk bank, it's got to be cleaned, or sterilised, or whatever. I just thought, express, and take it straight down to NICU if you have to! I don't even—I didn't really process it all. I just wanted to help...I

> thought, my life's turned to shit, so maybe I can help somebody else's. And I asked them, can we collect it and donate it to the babies in the NICU or something.
>
> (Rosie)

Other mothers knew of HMBs and donation through personal or professional experiences within NICUs. These mothers were quick to make decisions about wanting to donate their frozen stores of milk that were in the hospital:

> I'd never heard of donor milk or anything before [my infant was in the NICU], so I was just kind of like, "Wow! This is amazing!" I just thought it was so amazing that other women were giving that option to sick little babies. It was just...it was beautiful.... So if I have too much milk, I want to do that, too. I was already feeling that... I wouldn't want this experience to be harder for somebody else. Because it comes too easily to me, that's one way that I can make somebody else's journey less difficult.
>
> (Jessica)

Three of the mothers seeking to donate milk were in the Australian Capital Territory, which lacks a donation facility or programme, and they were told this was not possible.

Four mothers sustained their breast milk expression for the purpose of donation. In contrast to the relative ease of organising the donation of frozen stores of milk (which was facilitated for three study mothers), sustaining lactation for the purpose of donation was a time consuming and laborious task involving detailed compliance with HMB guidelines, effectively constituting a form of 'care work' (Carroll, 2015). It involved pumping every 4 hours, four or five times a day. Mothers, often aided by their partners (Noble-Carr et al., 2022), quickly developed a routine of expressing, washing and sterilising bottles and pump equipment, collecting and labelling milk, storing milk in the freezer and organising collection. The demanding routine, while daunting, also conferred a sense of purpose and structure, a mission to see them through the worst days of early grief:

> I couldn't just collapse down into myself, so I think the expressing the milk and donating the milk was keeping me up. It was my good thing that was going, you can do this. You can keep going. If you're feeling really sad, we'll just focus on this and think about the good that's coming from it...It was my way of picking myself up and going, "You can do this. You can do this".
>
> (Jessica)

Mothers with a professional or personal experience of the NICU had a particularly acute sense of the benefit of donation. They had witnessed the vulnerability of premature infants and the necessity of human milk as the only safe nutrition. They were focussed on their ability to save the lives of other babies and to prevent other unknown mothers from going through the loss they had just experienced themselves:

> I think that was one of the good things about donating...that it would go to the babies that needed it the most. The NICU babies. And it really came down to, I can't do anything for [my baby], but there's a possibility that these other babies might get to go home and (crying)...It was just that ability to be able to help somebody else, even though I couldn't help my own baby.... It's so absolutely unbelievably massive, it's ridiculous...it's still massive...I think, as well, knowing that I was donating that

> milk, and...(sighs) I would never actually meet those babies that get to go home, but knowing that they would get to go home. Knowing that it improved their chances of getting to go home, and getting to have long, healthy lives with their families.
>
> (Samantha)

> It felt really good to be able to donate that much milk and, I mean, babies are only having tiny little increments of that, so I'm thinking, how many babies are getting fed with this stuff? That's crazy! So, I was thinking that's good, I can basically feed the entire ward if necessary!
>
> (Jessica)

Here, we can see that, while their own infants' life had been curtailed, unable to begin, they found compensation in their ability to give the prospect of life to others—babies who could leave NICU, go home and begin a viable life. While their milk had been intended to sustain the single life of their own infant, they could potentially multiply the number of lives the milk could support, giving the hope of long life to many. Their capacity to sustain many lives enhanced their sense of competent motherhood and altruistic care, providing some consolation for their inability to direct these self-understandings through their own infant (Oreg, 2019).

In this sense, the emotional and moral logic of milk donation is almost identical to that of posthumous organ donation—the family of the lost loved one decides to redeem this lost life by giving prolonged life to others (Healy, 2006; Waldby & Mitchell, 2006). One mother gave a particularly interesting interpretation of this logic when speaking of her desire to donate. She had made a significant effort to prolong lactation after her child died and she did this so that her baby's truncated life had a purpose. As devout Catholics, she and her partner believed that each person is born with a mission. Her infant's mission was to save the lives of other babies through donation:

> After [infant] passed away, we knew there was a mission, but we didn't know why or what...I knew I was going to produce milk, so ... we decided that her mission was to donate the milk to other babies, donate her milk to other babies whose mothers couldn't produce or had problems breastfeeding...Now, obviously she had 32 weeks of gestation. I was 32 years of age. And at 32 weeks of gestation, she accomplished so much in her life, really. Donating milk to other children!
>
> (Laura)

Here, the infant herself is understood to be the donor and the mother as a proxy who fulfils the infant's mission on her behalf. This form of reasoning brings milk donation even closer to posthumous organ donation, where the donor must rely on their loved ones to fulfil their intent to donate (Healy, 2006).[1] While this idea was not shared by the other interviewees, it suggests ways that the experience of organ donation and milk donation after loss could inform each other regarding the medical, moral and psychological value of the gift.

CONCLUSION

For women who have endured an early child loss, it is evident that their breast milk cannot be a neutral, physiological fact. Lactation in these circumstances is profoundly entangled with all of the complex, melancholic meanings of the child's perpetual absence: mourning for both the

infant and a longed for maternal identity; the loss of a particular future and family contour; and for some, an encroaching sense of bodily incompetence, compounded by a history of fertility treatment and previous miscarriage and stillbirth. Despite these mournful associations, many of the women we interviewed were able to find a measure of consolatory or redemptive value in their lactation; as a material testimony to their maternal capacity and continuing bond with the child, as a form of remembrance and as a legacy, a gift to bequeath other infants to sustain their fragile lives.

We can see that there is a yawning gulf of incomprehension between the thick significance of lactation for the mothers, and the thin, limited meanings with which it is attributed in Australian hospital culture. Because post-loss lactation has not been critically reassessed within hospital procedure and approached in the same way as the more general phenomenon of early infant loss, the inextricable nature of the two has not been properly recognised. While individual health-care professionals demonstrated intuitive insights about the complexity of meanings for their patients, they were not yet able to make systematic inroads into the procedures that constituted the default assumptions of the hospital administration.

Our research suggests some specific and systemic changes needed in Australian hospitals to better support grieving mothers. At the most practical level, mothers require much more careful and open-ended advice and support about the realities and psychological impact of posthumous lactation and ways to manage it. They require this advice in a timely fashion, not after they begin producing milk but rather when it has become evident that the infant may not be viable. All of the medical disciplines they may encounter—neonatologists, social workers, midwives, nurses and obstetricians—should receive appropriate training regarding the meaningful nature of breast milk for mothers who lactate after loss and fully comprehend the value that these women place on their milk.

At a more systemic level, the thoughtful, empathic care provided in the hospital around infant loss more generally needs to be extended to incorporate the significance of milk and lactation for the mother and her partner. Several of the participants noted their surprise at the contrast between poor or absent lactation care they received and the rich, generous ethos of hospital bereavement care. They stated in different ways that lactation care should become part of this thoughtful, informed bereavement ethos.

Systemic change is also needed to create more accessible and numerous milk banks in Australia, with policies that facilitate and understand bereaved donation as a legitimate and highly meaningful gift. Currently, only a few of the already small number of HMBs in Australia will accept milk from bereaved donors. International models are available. Many not-for-profit HMBs in USA, for example, have dedicated milk donation programmes for bereaved families. These facilities not only enable the logistics of milk donation, they also provide recognition and legitimacy to the donors and their experience. The banks include memorials for bereaved donors, public testimonies and fact sheets for bereaved donors on their websites, and regular heartfelt posts thanking bereaved donors on their social media pages.

Our research also points towards some fundamental questions in the sociology of health and illness. Most salient of these is the under-explored relationship between organ and blood donation and human milk donation. While the first topic has attracted a vast literature, the second is far less considered from a social perspective and rarely are the three kinds of donation considered together. What can milk donation tell us about the nature of the gift relation, and what kind of tissue economy (Waldby & Mitchell, 2006) does it constitute? A second question pertains to the ways in which hospital organisation and disciplinary divisions can perpetuate a mind–body split in clinical thinking, with multiple consequences for patients whose experience

cannot be neatly compartmentalised in this way. We intend to explore these questions in subsequent articles, and we hope that our finding may inform other sociologists considering these matters.

Our research, enabled by the humility and honesty of health-care professionals and the courage of the women who spoke to us despite their grief, can, we hope, provide some way forward for both practical policy and social theory.

AUTHOR CONTRIBUTIONS

Catherine Waldby: Conceptualization (Lead); Funding acquisition (Lead); Supervision (Lead); Writing—original draft (Lead). **Debbie Noble-Carr**: Data curation (Equal); Methodology (Equal); Project administration (Equal); Writing—review & editing (Supporting). **Katherine Carroll**: Conceptualization (Equal); Data curation (Equal); Funding acquisition (Equal); Writing—review & editing (Supporting).

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DATA AVAILABILITY STATEMENT

We note that our research data are not shared, as we do not have HREC approval to do so.

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ENDNOTE

[1] The legal dimensions of organ donation vary from jurisdiction to jurisdiction, but only a few legislatures will pursue organ retrieval without the consent of the family.

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