Australian National University

Lactation After Infant Death: Partners' Experiences

A pilot study funded by the
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Introduction to Study

This pilot study interviewed seven bereaved fathers[1] in the Australia Capital Territory (ACT) and Queensland (QLD) in order to examine the experiences, perspectives, and practices of bereaved fathers toward their partner's lactation after stillbirth and infant death. The need for this study was identified by the research team who, while conducting a larger Australian Research Council funded research project on bereaved mothers' experiences of lactation after stillbirth and infant death,[2] found a large gap in research conducted specifically with fathers.

Despite improvements in neonatal survival, a large proportion of neonatal deaths occur in the neonatal intensive care unit (NICU). In Australia, the majority of mothers with infants in the NICU provide breastmilk to their babies, and therefore most mothers who experience an infant death in the NICU will have early or established lactation [1]. Therefore, the Newborn Intensive Care Foundation was approached in 2019 for funding to redress this gap in knowledge of father's experiences toward lactation in early grief and bereavement. The aim of this study was to produce findings that would inform hospital-based lactation care and human milk banking, and better tailor lactation and bereavement care to the needs of grieving families.

This report is structured as follows. First, it summarises the existing knowledge from the extant literature on fatherhood and infant loss, fatherhood and lactation, and fatherhood and human milk donation (p. 2). Second, it details the research method applied to conduct the pilot study (p. 3). Third, the characteristics of the fathers who participated in the study are provided (pp. 3-4). Fourth, the five key findings developed from our interviews with fathers, complemented by exemplar quotes, are then detailed (pp. 5-10). Fifth, the implications these findings have for how fathers and their families can be better supported with lactation care following infant death are provided (pp. 10-12). Implications specific to the ACT health policy context are included due to the Newborn Intensive Care Foundation's focus on providing support to the NICUs in the ACT. (p.12). The report then concludes by outlining the study limitations, consequent areas requiring further research and how the research team intend to further disseminate important learnings elicited from the pilot study (p.13).

[1] While the title of this study refers to partners' experiences, all partner participants in our study were fathers. Thus, this report will refer to participants as 'fathers'. We will at times use 'partner' where specifically relevant.
[2] see: https://sociology.cass.anu.edu.au/research/projects/lactation-after-infant-death

Background Literature

Much of the literature on infant bereavement is concerned with the experience and impacts of infant death for mothers [2], [3]. When included, researchers have found that while fathers' often experience significant grief after infant loss, they often feel as though they need to present a stoic face and 'be strong as a man' [2]. In turn, although fathers' grief is variable, they are often perceived as 'instrumental grievers', that is, not outwardly expressing their emotions and instead focusing their attention on keeping busy, moving forward and supporting their partner after infant death [3], [4].

Similarly, fathers often find themselves on the periphery of lactation and breastfeeding research, policy and practice that has an emphasis on supporting the mother-infant dyad. Thus, fathers' often feel excluded from lactation practices, which are viewed as being the job of the mother [5]. Despite this, it has been established that fathers have a significant impact on lactation decision making and breastfeeding duration/cessation [6], value being involved in breastfeeding or lactation, and some place importance on bottle-feeding their child, viewing this as an integral part of creating a bond with their child [7]. The importance of fathers' supporting role in provision of breastmilk to infants in NICU environments is also increasingly being acknowledged [8], [9]. When asked, Australian fathers stress the importance of their supporting role to their partner, stating that the provision of breastmilk to preterm babies is critical for their infants' health and their own notions of good parenting [10], [11].

Little is known, however, about how fathers experience their partner's lactation following infant death, and consequently how families are ideally presented with bereaved lactation care. Recent research has established that bereaved mothers often receive limited lactation care from hospital-based health professionals and are rarely presented with support to make informed decisions about how to manage their lactation or existing frozen stores of breastmilk [12], [13], [14], [15]. While suppressing lactation may be the most common practice in bereavement, sustaining lactation, keeping milk as a memento, or donating breastmilk can assist some women to cope with their grief [16], [17]. Despite the benefits of diverse lactation practices, bereaved milk donation remains an elusive option to bereaved mothers in Australia [18], [19] and researchers are yet to uncover fathers' perspectives or experiences of lactation after infant death, and the role that they play in diverse bereaved lactation practices, including breastmilk donation [18], [20].

Research Method and Participant Recruitment

Qualitative interviewing is an in-depth method that seeks to understand – from the perspective of the research participant – the multifaceted and complex lived experiences of a particular phenomenon. In this pilot study, we used qualitative interviews to understand, from the perspective of bereaved fathers, their experiences, views and practices surrounding their bereaved partners' lactation after infant death.

Potential father participants were identified via interviews with bereaved mothers as part of the larger study.[3] At the end of their interview, participating mothers agreed to provide their partner with an invitation pack, including participant information and consent forms. Interested fathers then opted-in to the study by contacting the research team. Purposive sampling was implemented to include fathers who had been involved in one of two types of lactation practices: (1) fathers who had supported mothers to donate breastmilk after infant death to a Human Milk Bank (HMB), and (2) fathers who had not been involved in milk donation after loss.

Following best practice on conducting research with bereaved parents [21], fathers based in the ACT and QLD were offered two modes of engagement with researchers: an hour-long semi-structured interview, or a written survey answering approximately 15 open-ended questions.

Interview questions

Interviews asked fathers about: (i) their partner's pregnancy (including expectations or pre-existing knowledge and attitudes of parenthood and breastfeeding); (ii) anything they would like to share about the life and death of their baby; (iii) observations of their partner's lactation experiences prior to and after their baby's death; (iv) support provided to their partner to suppress, express or donate breastmilk after their infant's death and how this fitted in with grieving the loss of their baby; (v) the lactation options (including breastmilk donation) they think may support bereaved mothers; and (vi) how lactation care and support can be improved.

Participants

Of the 15 bereaved mothers who participated in our study across the ACT and QLD, seven of their partners agreed to be interviewed for this study. This was below the initial target of ten participants, with the COVID-10 pandemic significantly affecting recruitment.

[3] The Canberra Hospital and Royal Brisbane and Women's Hospital were the two study sites for this pilot project

The seven fathers shared their experiences of fathering a total of 20 children, 10 of whom had died as a result of stillbirth or infant death. All interviews with fathers took place within 26 months of their most recent infant bereavement.

Five interviews were conducted with fathers from a range of urban and regional areas across QLD, all of which involved situations of breastmilk donation to a HMB. Two interviews were conducted with fathers in the ACT who had not been involved in milk donation after infant death. Bereaved parents in the ACT are rarely offered breastmilk donation due to no HMB operating within the Territory.

A total of four fathers were interviewed face-to-face, two via Zoom video and one via phone. Two fathers spoke a language other than English as their first language, with one father requiring a translator for the interview. At the time of the interview all fathers were employed on full-time basis, and held post-secondary school qualifications. Further key characteristics of the fathers, including the type of infant deaths they experienced and whether they had been involved in breastmilk donation, are provided in Table 1.

Table 1. Participant Characteristics, Type of Infant Death Experienced & Donation Experience

Participant	Location	Age (yrs)	Type of infant death	Gestation of stillbirth / Age of infant at death	Breastmilk Donation
1	ACT	37	Neonatal	Aged less than one day	Not presented as an option
2	ACT	33	Stillborn	Stillborn at 40 weeks gestation	Not presented as an option
3	QLD	36	Three deaths: - Stillborn - Stillborn - Neonatal	- Stillborn at 26 weeks gestation - Stillborn at 26 weeks gestation - Aged 12 days	Stillbirth 1: Not presented as an option. Stillbirth 2: Donation of milk from partner's sustained expression for approx. 4 months. Neonatal death: Donation of milk from partner's sustained expression for approx. 6 months.
4	QLD	35	Neonatal	Aged 18 days	Unsure if frozen stores of breastmilk in the hospital were donated.
5	QLD	38	Stillborn	Stillborn at 32 weeks gestation	Donation of milk from partner's sustained expression for approx. 2-3 months.
6	QLD	48	Death of twins: - Stillborn - Neonatal	Twin 1: Stillborn at 27 weeks Twin 2: Aged 8 days	Donation of milk from partner's sustained expression for *"months and months and months"* (number of months not specified).
7	QLD	27	Infant death	Aged 5 weeks	Donation of frozen stores of partner's milk from hospital and hospice.

Findings

(1) Fathers assuming the supporting role after infant death and during lactation

Our interviews confirmed that fathers may experience immense sustained grief following the loss of an infant. Despite this, the fathers in our study expressed a need to remain 'stoic' in the face of their immediate grief, by focusing on supporting their partner, caring for their children, returning to work and undertaking the majority of unpaid labour in the home. Some of the fathers explained that this has resulted in a need to address their grief years later. As ACT Father 1 said, he initially turned down counselling as he thought "I'll be fine", but now, two years later, feels he finally needs to talk about his grief in a professional setting:

> "I do need counselling, and I can only recommend it to anyone. I just haven't had the time. I've pushed it back a little bit, because it's not really a topic you'd like to dig up every week, but it's definitely something that's on my list of things to do to get sorted."

Similarly, when discussing lactation, fathers perceived their primary role as being the supporter of their partner. This was true of their experience of lactation with their living infants or after the death of an infant. In particular fathers stated they see lactation as primarily the business of the mother, seeking to provide emotional and logistical support in the process. Fathers stated that where possible, they did enjoy being involved, primarily through bottle feeding. QLD Father 5 for example summarises this relationship to lactation:

> "It's quite nice that I get to play a part, because there's not much a male can do in the first six months to a year. You kind of – you feel like you're useless because it's all Mum and all she wants is Mum, especially when she was breastfeeding, because [partner] would get frustrated, but then she wanted milk so she needed to be with [partner], and then I just had to sort of calm the situation, I guess, and try and get everyone back on a level head, and settle the baby, and sort of talk some sense into [partner] at the same time."

(2) Lactation in the NICU/palliative care environment holds significance for fathers

Fathers who experienced neonatal deaths spent time in their interviews discussing their experience of spending time with their infants within NICU or palliative care settings, whilst also supporting their partners. Fathers spoke about the significant role that lactation practices often play in these environments and they sought to support their partner as much as possible. Some fathers were intimately involved in breast care and lactation practices at this time. As QLD Father 4 describes:

> "I remember [partner] was trying to massage her breasts and squeeze them and get stuff happening, and it seemed to be a lot of work just to get a couple of drips of colostrum out to suck up in a syringe. But, you know, she tried her best. Being small-handed and all that, she had quite a lot of trouble, I suppose, just massaging for half an hour and all that, so I'd help her with that. To massage the breast and get them flowing. Eventually, I think whatever – I must have spent a bit of time there in that week. A few days here, I must have spent four or five days there in a row. I got pretty good at it, at massaging, and getting the flow, because by the time I had to go back to work for a couple of days just before [infant] died, the flow was quite good and constant, and she was getting quite a bit of colostrum (sic) there."

Although fathers primarily sought to support their partner's capacity to undertake feeding responsibilities, they also welcomed opportunities to be directly involved in feeding breastmilk to their child. Fathers often saw feeding as the most tangible thing they could do to help their children, and being involved provided them with a deep intimate connection to their child. As QLD Father 5 said about feeding his child:

> "We did all the feeds. So, she had a line in her nose, and then syringe, so you'd fill it up, and then obviously you'd suction (sic) it so it would go through. And you'd sit there holding bub!...Yeah, it was awesome. Unreal. Like, again, it made you feel like you were actually doing something for your daughter."

QLD Father 2 echoed these sentiments demonstrating how health professionals actively facilitated their involvement to ensure feeding became a shared experience between them, their partner and their infant:

> "I think it [feeding] played a very central and essential role while [infant] was alive for all the reasons I've already said, in terms of us having some element of, or some medium in order to help [infant], and to be part of his growth and care. I think [partner] feels this way, too, but it was really special when we were able to first feed [infant] [partner's] milk…We were brought into that process as well, and the nurses let me squeeze the syringe! Like, feed [infant]. That, to me, was more important than being able to help change his nappy, or change his sheets. Yeah. I think it was…to be honest, I really believe it was the one thing we could do for him."

(3) Father's awareness of, and role in, lactation after infant death

Despite fathers' keen awareness of, and involvement in lactation and provision of breastmilk to their infants, two of the seven fathers stated that prior to our interview they had not considered lactation after infant death. These fathers reported that they were unaware of

their partner lactating after their infant's death and had little memory or awareness of any discussions about lactation with their partner or healthcare professionals after their infant had died. As ACT Father 1 said, for example:

> "I don't have a recollection of there being any issues, or me having to support with the lactation. I think she sort of handled that by herself. She also didn't really talk about it."

Our study however, has found that this was different for fathers whose partners were actively expressing breastmilk after infant loss – either for the purpose of suppression or for donation to a HMB. Perhaps due to the visibility of lactation practices and breastmilk, these fathers indicated a stronger awareness of, and connection to the experience of lactation after infant death. This included greater involvement in lactation care and often an intimate understanding of their partners' lactating body and associated feelings. For example:

> "She would have to wear breast pads all the time. Whenever she was in the shower, the milk would run." (QLD Father 1)

> "I remember being in the hospital still that afternoon, after [infant] passed away, and [partner] was just like, "My boobs are going to explode. What do I do? What do I do?" And the nurse just sort of rolled in a pump and was just like, "Use this pump." I actually do remember this. It was like a really clear moment, just looking at this milk, and it was, like, it was the one thing she could do for [infant] and now she was just like… "What do I do with this? Do I pour it down the sink?" Like…she was like, "I don't know what to do." So yeah, she poured it down the sink, and she was trying to ask these questions. "How do I do this?" and just not being able to get a straight answer from anyone at the hospital. One nurse was like, "Just don't pump. Just suck it up. Wear tight shirts." (QLD Father 2)

Fathers who had partners with established lactation and/or whose partners chose to sustain their lactation by continuing to express for the purpose of donation frequently assumed a strong supporting role in lactation after infant death. As a result this brought fathers to have a closer proximity to lactation practices and breastmilk. This was especially apparent in couples engaged in sustained expression for the purpose of donation. With their partner often focused on the constant demands of regular expressing, father's supported their partners with the ongoing work associated with donation (e.g. organising and cleaning equipment multiple times a day), and the emotional and practical work of taking over other daily household tasks, and 'keeping their family together'. For example:

> "The breast pump and all that needed washing. We had to buy a couple of breast pumps because we left one in Brisbane, and stuff like that, so money was, you know, had to provide that, because [partner] doesn't work. Yeah. Just washing up, you know, bringing the pump to her sometimes, or if she's pumping, make dinner and just support her in that, whatever needed to be done. Probably more the washing up sort of side of it, or bringing things to her when she needed it. Otherwise she was pretty right once she got hooked up to it. Sometimes she had two bottles and needed three, so you had to run and grab another one, or something like that." (QLD Father 4)

> "My focus was on the family and on [partner], and supporting her and being up with her in the night, caring for her and making things easier for her, and making sure that she didn't have that extra labour of having to wash bottles and sterilise the pump, and all this sort of stuff." (QLD Father 1)

As well as practical support, fathers provided high levels of emotional support for their partner whilst they were sustaining expression for the purpose of donation. Through father's support, breastmilk donation after infant loss often became an intimate and shared experience for parents:

> "My support for her [while she was donating the milk] is always to see how she feels, talk to her, talk to each other, make decisions together, and be with her all the time." (QLD Father 3)

(4) Milk donation may assist with father's grief and meaning-making

Despite the demands involved in sustained expression and donation, all fathers indicated strong support for donation after infant death. Fathers primarily expressed support for donation as it helped others. Initially this was framed through the lens of their partner, with fathers focusing thoughts on how donation helped their partner through their grief. As QLD Father 1 stated for example:

> "The act of expressing and donating the milk took the focus away from [partner] and her pain, and put it on something else, so she had a purpose, and another focus, and there was a reason to express because she could donate it to other babies, and she could help all these other babies."

As this quote exemplifies, fathers involved in their partner's donation of breastmilk also indicated support for donation as it helped other families going through similar difficult circumstances. QLD Father 3 reinforced this when he stated:

> "It was an opportunity to live life after someone's death, so basically an opportunity to keep someone alive through someone's death. It was an opportunity to donate the milk to help other people keeping them alive, and basically keeping a memorial to [infant] at the same time."

Fathers reported it was through helping others – their partner and other families – that they found something positive amidst their painful loss experience that then assisted them with their grief after infant death. All participating fathers agreed that breastmilk donation should be available and presented as an option to all families following an experience of infant death.

(5) Fathers need support to become involved in, and continue to support mother's lactation

The fathers in our study were willing to be involved in their partner's lactation in all circumstances; at home with their infants, in the hospital, NICU or palliative care environment, and after infant death. In the NICU and/or palliative care settings this involvement was facilitated by health professionals, who encouraged fathers to feed their infants. Once an infant had died however, lactation transitioned to be viewed as a private matter, with couples receiving little support from health professionals or other parties. Fathers noted that most often, after infant death, they were unaware of, or dissatisfied with the lactation care received by their partner. In retrospect, fathers noted that this lack of information and support was frustrating as they had hoped to support their partner with any and all of their needs following their infant's death. As ACT Father 1 said:

> "And yes, I, as a dad, didn't think about the whole lactation issue…So, as I said earlier, as part of those information sessions that are offered, it's probably important to say, well, to the mum, "There will be lactation," and this and that, but also include the dad, and say what can you do to support your partner in this process? Because it's probably still seen as when a woman lactates, the mother breastfeeds the child, and that's it, and dad has nothing to do with it bar than the occasional bottle. But what happens if the child's no longer there? Then it shouldn't be just the mother's issue."

A lack of health professional support was also reported by fathers involved in milk donation. Fathers reported it was often the parents themselves who asked about and instigated donation processes. Without parents' own prior knowledge, some fathers suggested that donation would not have been presented or supported as an option. In one instance, it was a father who had initiated this conversation with his partner and had sought support from the hospital to explore their options for donation. Once interested in donation, fathers often expressed frustration with how difficult it was to obtain information about donation

processes, and reported receiving limited support from health professionals or Milk Banks. QLD Father 2 for example said that the bureaucracy became too much for him and his partner to donate their frozen stores of milk:

> "I don't think it got donated in the end, because the process and the bureaucracy around it was too much…. I remember being pissed off. I remember, like, what's the point? The hospitals need it, the kids need it, and you've created a system where you just make it near impossible for someone to go through that process in the position that we're in, so what's the point?"

For those who had a longer relationship with Milk Banks, as a result of ongoing donation through sustained expression, frustrations were even more apparent. Milk donation as a result of sustained expression was described by the fathers as being challenging and time consuming, and sometimes placing a strain of the daily life of families. The lack of support families received with donation, appeared to intensify the role of fathers, with fathers having to become active in negotiating with Milk Banks, and supporting their partners with all aspects of the donation process. QLD Father 1 stated:

> "It [expressed milk] was never transported by the milk bank or the hospital or anything. It was always transported by us. Looking forward, that's something that could definitely improve donations from regional areas, if there is some sort of courier that could transport."

Finally, fathers indicated a desire for greater recognition of their partner's donation. QLD Father 1 for example wrote to the local newspaper asking them to write a story about his partner, while QLD Father 5 simply asked for a registration system so they could know who benefited from their partners' milk.

> "If, I guess, the milk bank had registered and told you when it got used, I guess, that would be a nice – sort of like blood donation, I guess."

Implications of Findings

Fathers perceive they have an important and primary role to provide practical and emotional support to their partners in their lactation and following their infant/s' death. This role needs to be acknowledged, respected and supported.

Following infant death, fathers experience significant grief, but often place the needs of their partner and family ahead of their own. As a result, our study confirms fathers may need assistance to balance their need to support others, whilst also receive adequate support themselves [3]. As such, they require sustained access to effective grief and bereavement support services.

Where possible, many fathers welcomed and appreciated being intimately involved in lactation practices and feeding their infants. This appeared to be especially meaningful in the NICU and palliative care settings. Health professionals working in these settings have important roles in facilitating fathers' involvement in lactation and feeding practices.

Fathers appear to have varying, and often limited levels of awareness of their partner's experiences of lactation after infant death. This was especially true of fathers whose partners were not actively expressing breastmilk (for the purpose of suppression or donation to a HMB) after infant loss. Fathers, wanting to support their partner, would welcome being involved in lactation care management discussions, and would like to receive information and assistance to help them to better support their partners.

In comparison, fathers whose partners were expressing breastmilk for the purpose of lactation suppression or milk donation most often had intimate knowledge of their partner's lactation. Moreover, they were providing high levels of support. For mothers sustaining expression for the purpose of donation, fathers were often the primary, and sometimes the only, source of support. These fathers' experiences indicate a lack of information and practical and emotional support from health professionals. Again, our findings indicate that providing clear information on donation processes and ongoing support to bereaved families interested in donation to HMBs is critical. This support should be provided in a way that acknowledges, respects and supports the important role fathers can play.

Fathers indicated strong support for the availability of milk donation as an option for bereaved families after infant death. Fathers reported milk donation provided significant meaning for them and their partner. This extends current understandings that highlight the benefit of milk donation to bereaved mothers' identity and meaning making following infant death [17], [20], [22], [23] by showing that fathers also receive benefit from their partners' altruistic breastmilk donation practices. Breastmilk donation after infant loss also resembles posthumous organ donation, in that the families of deceased children often express the desire to give life to organ recipients, and create some value and meaning from the death [24].

Fathers, who had partners that were not presented with an option to donate breastmilk following infant death expressed a desire to have been given the choice to do so. Our findings indicate support for ensuring bereaved milk donation is accessible and well supported across all cities, and regional centres. As well as increased support, fathers sought increased public awareness and recognition from hospital staff of the act of bereaved donation and their own partners' contribution to saving the lives of vulnerable infants.

Implications of findings specific for the Australian Capital Territory

Our findings on the importance of including father's experiences of, and care about lactation after infant death align with the findings of the 2020 ACT Government's Maternity Services Review [25]. Specifically, recommendations 6, 7, 8 and 30 of the Review argued for the enhanced inclusion of partners into the following aspects of maternal healthcare: referral for postnatal mental health issues; in birth and postnatal stay at hospital, and birth debriefings with a health professional. Our study supports that a family-centred approach to care prior to and after infant death should include partner involvement in lactation practices and support.

In 2019, the ACT Government reported on a study that investigated the feasibility of establishing a HMB in the ACT to "give ACT region women an opportunity to donate" in addition to supplying breast milk to babies [26]. The focus of the report is on the benefits of donor breast milk for various cohorts of infants and their clinical contexts. It also pays attention to the significance of meaning breastmilk donation holds for those in the ACT community. The review acknowledged that a milk bank in the ACT would create a solution for the "strongly expressed desire of the community to donate breast milk" and provide a space for "the sense of community inclusion and support for both potential donors and the parents of PDHM (donor milk) recipients" (p.10). Such attention to the benefits for the donor community is supported by research [17], although unfortunately the report stops short of consulting the research evidence of the social, emotional, and psychological benefits of milk donation for donor families, particularly for bereaved parents.

The ACT Government report into the feasibility of establishing a milk bank in the ACT [26] concluded, "Development of a local Milk Bank is not a cost-effective option for the ACT" (p.27). Therefore, the ACT will continue to source its donor milk for use in The Canberra Hospital from NSW. Of importance, however, recommendation 5 of this report stated: "A number of Canberrans have a desire to donate human milk to a milk bank. The milk bank provider [of donor milk into the ACT] should be informed about their desire to donate. If there is need for human milk collection [from the ACT] by the milk bank, the desire of Canberrans to donate human milk to the milk bank should be facilitated" (p.27). Our findings strengthen the need to implement this recommendation with consideration to the unique circumstances, wishes and needs of bereaved parents. The establishment of evidence-based systems and support services to enable milk donation from bereaved parents in the ACT to the existing milk banks outside of the territory would be welcomed [16], [27], [28].

Pilot Study Limitations

The sample size of seven participants presents some obvious limitations to the scope of experiences, family unit types, types of infant deaths, and stages of lactation experienced by mothers and their partners that we can represent in this report. The emphasis in the findings on milk donation is also brought about by the fact that the majority of fathers opting in to the study were partnered with milk donors. The willingness of these partners to participate in the study may reflect the significance of milk donation held by bereaved fathers, and also what fathers deemed to be "helpful" as to specific contributory practices surrounding their partner's lactation after infant death. Despite the limitations, the data presented significant richness, providing a strong data set for a pilot study.

Further Research

Further research is required to replicate this pilot study at a national level. This would facilitate a larger data set, including greater diversity in regards to type of infant death, access to and practices of donation, in addition incorporating the experiences of Indigenous Australians, those of diverse cultural and linguistic backgrounds, and of LGBTQI+ families. A national study would also be able to examine experiences of support for fathers and partners with lactation across different health policy and practice frameworks.

Planned Dissemination of Pilot Study Findings

Two academic papers reporting on fathers' experiences of lactation after infant death are currently in development and will be submitted for peer review in 2021.

The findings from this pilot study will be incorporated into a larger report which will be provided to all participating study sites in 2022. The report will identify opportunities for enhanced hospital-based lactation care policies and practices and training/education activities for health professionals.

Further resources and papers stemming from the broader study will draw on our findings from bereaved mothers, bereaved fathers, and health professionals – a unique opportunity to match identified needs of mothers and fathers with what health professionals have informed the research team about practice strengths, challenges and contexts.

The researchers have been and will continue to work closely with organisations such as the Human Milk Banks in Australia, Red Nose (including SANDS), Australian Breastfeeding Association, Miracle Babies, Raising Children's Network and Stillbirth Foundation. Each organisation is keen to better understand the role of the fathers' in lactation after loss and ensure relevant information, support and training materials reflect our study's findings.

References

1. Chow, S.S.W. 2013. *Report of the Australian and New Zealand Neonatal Network 2011*. Sydney. ANZNN.
2. Aydin, A. and Kabukcuoğlu, K. 2020. Fathers' experiences of perinatal loss: a sample meta-synthesis study, *Journal of Family Issues*, 1-28.
3. Obst, K., Oxlad., M., Due, C, et al. 2021. Factors contributing to men's grief following pregnancy loss and neonatal death: further development of an emerging model in an Australian sample, *BMC Pregnancy and Childbirth*, *21*(29): 1-16.
4. Obst, K., Due, C., Oxlad, M., et al. 2020. Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model, *BMC Pregnancy and Childbirth, 20*(11): 1-17.
5. Hounsome, L. and Dowling, S. 2018. 'The mum has to live with the decision much more than the dad': a qualitative study of men's perceptions of their influence on breastfeeding decision-making. *International Breastfeeding Journal, 13*(3): 1-10.
6. Ng Wan Leng, R., Shorey, S., Pang Pui Chan, C., et al. 2019. Fathers' involvement in their wives'/partners' breastfeeding: a descriptive correlational study. *Journal of Human Lactation, 35*(4), 801-812.
7. Sihota, H., Oliffe, J., Kelly, M. and McCuaig, F. 2019. Fathers' experiences and perspectives of breastfeeding: a scoping review. *American Journal of Men's Health*, 1-12.
8. Alves, E., Magano, R., Amorim, M., et al. 2016. Factors influencing parent reports of facilitators and barriers to human milk supply in neonatal intensive care units. *Journal of Human Lactation, 32*(4), 695-703.
9. Denoual, H., Dargentas, M., Roudaut, S., et al. 2016. Father's role in supporting breastfeeding of preterm infants in the neonatal intensive care unit: a qualitative study. *BMJ Open, 6*:e010470.
10. Sweet, L. 2008. Expressed breast milk as 'connection' and its influence on the construction of 'motherhood' for mothers of preterm infants: a qualitative study. *International Breastfeeding Journal, 3*(30), 1-12.
11. Sweet, L. and Darbyshire, P. 2009. Fathers and breast feeding very-low-birthweight preterm babies. *Midwifery, 25*, 540-553.
12. Basile, M.L. and Thorsteinsson, E.B. 2015. Parentsʹ evaluation of support in Australian hospitals following stillbirth. *PeerJ, 3*:e1049:1-18.
13. Chen, F-H., Chen, S-L. and Hu, W.Y. 2015. Taiwanese women's experiences of lactation suppression after stillbirth. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 44*(4):510-517.
14. McGuinness, D., Coughlan, B and Butler, M. 2014. An exploration of the experiences of mothers as they suppress lactation following late miscarriage, stillbirth or neonatal death. *Evidence Based Midwifery, 12*(2):65-70.

15. Redshaw, M., Rowe, R. and Henderson, J. 2014. *Listening to parents after stillbirth or the death of their baby after birth*. University of Oxford: National Perinatal Epidemiology Unit.
16. Welborn, J. 2012. *Lactation support for the bereaved mother: A toolkit - information for healthcare providers*. Fort Worth: Human Milk Banking Association of North America.
17. Oreg, A. 2019. Milk donation after losing one's baby: Adopting a donor identity as a means of coping with loss. *Social Science & Medicine, 238*:1-8.
18. Carroll, K., Lenne, B., McEgan K, et al. 2014. Breast milk donation after neonatal death in Australia: A report. *International Breastfeeding Journal, 9(*23):1-9
19. Sweeney, L., Carroll, K., Noble-Carr, D. et al. 2020. Lactation after infant death: an analysis of Australian healthcare agencies' online health information. *Health Sociology Review, 29*(1), 45-61.
20. Oreg, A. 2020. The grief ritual of extracting and donating human milk after perinatal loss. *Social Science & Medicine, 265*, 1-8.
21. Butler, A.E., Hall, H. and Copnell, B. 2018. Bereaved parents' experiences of research participation. *BMC Palliative Care*, 17:122, 1-9.
22. Carroll, K. & Lenne, B. 2019. Suppress and Express: Breastmilk Donation after Neonatal Death, in Charlotte Beyer and Andrea Robertson (Ed.) *Mothers Without Their Children*. Demeter Press. Pp. 229-244.
23. Welborn, J. 2012. The experience of expressing and donating breast milk following a perinatal loss, *Journal of Human Lactation*, 28(4), 506-510.
24. Darlington, A-S., Long-Sutehall, T., Randall, D., et al. 2019. Parents' experiences of requests for organ and tissue donation: the value of asking, *Archives of Disease in Childhood, 104*, 837-843.
25. Rachel Stephen-Smith, MLA Minister for Health. 13 August 2020. *ACT Government Response to the Standing Committee on Health, Ageing and Community Services Report 10: Report on inquiry into maternity services in the ACT*. The Legislative Assembly for the Australian Capital Territory.
26. Health Policy & Strategy Branch, ACT Health Directorate. October 2019. *Feasibility of establishing a milk bank in the ACT.* ACT Health, ACT Government.
27. Carroll, K., Noble-Carr, D., Sweeney, L., et al. 2020. The "lactation after infant death (AID) framework": A guide for online health information provision about lactation after stillbirth and infant death. *Journal of Human Lactation, 36*(3):480-491
28. PATH. 2019. *Strengthening Human Milk Banking: A resource toolkit for establishing and integrating human milk banks – A counselling guide for engaging bereaved mothers*. Seattle. Washington: PATH.