



## Lactation after Infant Death:

Breastmilk suppression, expression and donation in contemporary motherhood and health service delivery

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### Newsletter – March 2020

Welcome to the 6th Edition of the '*Lactation after Infant Death*' Study Newsletter.

The '*Lactation after Infant Death*' study aims to explore both bereaved women's lactation experiences and those of the multidisciplinary health professional team who are engaged in their care with a view to enhancing care delivery in Australia's maternity, bereavement and milk banking services.

In partnership with hospitals in the ACT, Victoria and Queensland, researchers have conducted focus groups with 114 health professionals and are interviewing up to 40 bereaved mothers and 10 of their partners.

The study is being conducted by ANU researchers: Dr. Katherine Carroll, Professor Catherine Waldby & Dr. Debbie Noble-Carr, with funding from the Australian Research Council (ARC) and ANU. Funding from the Newborn Intensive Care Foundation has also allowed us to employ Simon Copland to conduct our sub-study with the partners of bereaved mothers. The project will operate from August 2018 – August 2021.

We encourage you to circulate this newsletter to your colleagues and to sign up to receive future quarterly editions by sending an email to: [lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au)

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#### Events since our last newsletter in December 2019...

The last three months have been challenging for many of us around Australia – with many affected by smoke, fires, hailstorms, floods and now the COVID-19 pandemic. Our thoughts are with those who have been adversely affected by these events and with the amazing emergency services workers/volunteers and health professionals who continue to go above and beyond to assist and support our community.

At times like this, it is more important than ever to stop, reflect and celebrate efforts and achievements. Therefore, on pages 1-3 of this newsletter we are happy to report some **GOOD NEWS STORIES** from the last 3 months of our study. On pages 4-5 we also present some preliminary findings from our data collection with Health Professionals.

- ❖ In January the findings of our review of Australian health organisations' online information about lactation after infant death was published in **Health Sociology Review**. Details of the article and the abstract are below. The full article is available at:

<https://www.tandfonline.com/doi/full/10.1080/14461242.2019.1708206>

*A study funded by an Australian Research Council Discovery Grant*

**Lara Sweeney, Katherine Carroll, Debbie Noble-Carr & Catherine Waldby (2020): Lactation after infant death: an analysis of Australian healthcare agencies' online health information, Health Sociology Review, DOI: 10.1080/14461242.2019.1708206**

#### **ABSTRACT**

Lactation is a potent signifier of maternal love and care commonly associated with early motherhood and infant survival. It is common, however, for bereaved mothers who have recently undergone miscarriage, stillbirth or infant death to produce breastmilk.

Drawing on a critical feminist lens that seeks to understand how maternal subjectivities and lactation norms are constructed through public and reproductive health information, this article tests whether lactation management options after stillbirth and infant death are comprehensively covered in Australia's health organisations' online information.

A qualitative directed content analysis was conducted to critique the information provided on 21 Australian websites. Information extracted from websites was compared to a 'best-practice' Lactation After Infant Death (AID) Framework developed by the research team for the review.

We found a notable absence of comprehensive lactation management information targeted directly to bereaved mothers. Moreover, the most common lactation option presented for women without a living infant was lactation suppression. This dearth of appropriate and comprehensive lactation information curtails maternal subjectivities and diverse lactation practices and further isolates women dealing with the painful contradictions of lactation after loss.

- ❖ The research team has now contacted every organisation included in our online review. We have provided individualised reports and targeted feedback to many organisations that have expressed an interest in improving their online information. If you are interested in working with us to enhance your resources, please contact us at: [lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au)
- ❖ In response to our study findings, the **Australian Breastfeeding Association (ABA)** worked collaboratively with our research team to develop a new online resource on lactation after infant death. We are happy to report that the ABA now have a dedicated resource on lactation after infant death available on their website: <https://www.breastfeeding.asn.au/bfinfo/lactation-after-infant-death>
- ❖ Thank you to the **Australian Perinatal Loss Professionals Network** for recognising our recent work and publicising ABA's new online resource to your members.

- ❖ To further publicise this work, **Miracle Babies** published a blog on their website, ensuring our work can be viewed by those interested in supporting families of premature and sick newborns. The blog can be found at:  
<https://www.miraclebabies.org.au/blog/archive/lactation-after-loss-ensuring-bereaved-mothers-have-the-information-they-need/>
- ❖ We have recently worked with **ACT Health and Calvary Hospital** to help develop lactation after infant death fact sheets and resources for health professionals and families.
- ❖ Katherine and Debbie had been accepted to present at two upcoming conferences to be held in Melbourne, including: the **Academy of Breastfeeding Medicine** Australian and New Zealand Regional Conference & the **International Conference on Grief and Bereavement**. These events have unfortunately been postponed or cancelled due to the COVID-19 pandemic.
- ❖ Many of you may also be interested in another paper recently published by Katherine Carroll (and her colleagues: Kathryn Eden, Rebecca Williamson, Andrea Butler and Julie Smith) in the journal **Breastfeeding Review** titled: 'Designated private breastfeeding spaces in the university sector: An audit of one Australian university'. This paper is available at:

<https://search.informit-org.virtual.anu.edu.au/fullText;dn=869271079488471;res=IELAPA>

### Continuing our data collection (interviews and focus groups)...

#### Mothers

Twelve mothers have now participated in our study – six have had face-to-face interviews, five have had phone interviews and one mother has provided a written response. Due to our purposive sampling methodology, half of these mothers have donated breastmilk after the death of their infant.

In early March, our hospital partners in the ACT and Queensland sent out a further 50 invitation letters to eligible mothers in the ACT and QLD. We hope to begin interviews with some of these mothers and their partners in April. Due to COVID-19 we will only conduct these interviews using Skype, zoom, telephone or written questionnaire. We have decided to suspend further recruitment until the COVID-19 situation improves.

#### Intimate Partners

With our generous funding from the Newborn Intensive Care Foundation we have now interviewed six partners of bereaved mothers. This includes five fathers from Queensland – whose partners had donated milk – and one father from the ACT.

We hope to recruit another four partners from our current recruitment round in the ACT which will complete the data collection for this component of our study.



## Health Professionals

By the end of 2019 we had successfully completed 17 focus groups and five interviews with a total 114 health professionals. Health professionals participating included: Obstetricians, Neonatologists, Neonatal Nurses, Midwives, Lactation Consultants, Social Workers/Pastoral Care Workers and Specialist Bereavement Workers at our partner hospitals in the ACT, Queensland and Victoria and Human Milk Bank staff from three Human Milk Banks in Australia. We have begun analysing the data from these focus groups and interviews. Some of our Preliminary Findings:

- Lactation after infant death is often considered *“too sensitive to discuss”* with bereaved families. Lactation care provided to bereaved mothers appears to differ according to the culture of the organisation and the knowledge, attitudes, experience and comfort level of the individual health professionals providing care to bereaved families.
- Pharmacological agents to assist in suppression of milk, or advice on gentle suppression, were the most common type of lactation care provided to bereaved mothers. Where frozen milk was present, health professionals stated mothers are often asked if they would like to keep the milk or have professionals discard it. Where Human Milk Banks operate onsite donation of frozen stores of breastmilk was *sometimes* presented as an option to bereaved mothers. One of the Human Milk Banks we spoke to does not accept donations of breastmilk from bereaved mothers.
- Very few health professionals had thought about, or had experience in discussing, options beyond suppression. Sustained expression, using milk as a memento, or donating or sharing breastmilk were often unfamiliar and rarely discussed responses to lactation after infant death. Where discussion of these options had taken place, it was usually in response to the mothers’ suggestion. Due to limited training, experience, knowledge or information health professionals stated they had to *“feel”* or *“fumble their way through”* providing this care.
- Health professionals’ stated that providing care to bereaved families is one of the most challenging aspects of their job. However, over time they are able to build their capacity to respond sensitively and comprehensively and to support bereaved families to make many difficult decisions before and after the birth and death of their infant. Many of the skills they have developed in having *“tough conversations”* can be used to structure sensitive and appropriate discussions with women about their lactation care.
- Health professionals believe that, where possible, bereaved women should be presented with comprehensive lactation care, including having an informed choice regarding lactation management and what happens to their milk. They stated this would become possible if:

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- Hospitals have clear policies, pathways and practices to guide the provision of lactation care to bereaved families
- Training and education on lactation after infant death is provided to all health professionals who may interface with bereaved families
- Further evidence is collected and provided to health professionals on bereaved mothers' views and experiences about the significance, meaning and use of breastmilk after infant death
- Written information on lactation after infant death relevant to health professionals and bereaved families is readily available
- Bereaved mothers and their families are able to receive continuity of care during, and after, their hospital stays
- Human Milk Banks are available and appropriately resourced to provide targeted support to bereaved mothers wanting to donate their breastmilk after loss
- There can be an increased number and availability of Lactation Consultants and other health professionals to ensure dedicated time can be spent providing comprehensive bereavement care to families experiencing infant death
- Infant death and lactation are more openly discussed in community and health professional settings.

We aim to help inform, and work towards meeting, many of these factors that were identified by health professionals as being critical to enhancing lactation care for bereaved families.

### **Want more information?**

As always, to stay informed about our project and to locate study publications and resources, visit our project webpage:

<http://sociology.cass.anu.edu.au/lactation-after-infant-death>

To contact the research team, or register to receive this quarterly project newsletter, email:

[lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au)

*Until our next update, in these challenging times, we hope you stay safe and well  
Kindest regards...*



*Dr Katherine Carroll*



*Professor Catherine Waldby*



*Dr Debbie Noble-Carr*



*Simon Copland*