



Lactation after Infant Death:

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

Newsletter – June 2020

Welcome to the 7th Edition of the '*Lactation after Infant Death*' Study Quarterly 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 and interviews 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 the ANU. Additional funding received 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 – December 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

Important happenings in the last three months...

Stakeholder Advisory Group Meeting

In May 2020 we met (via zoom) with our Stakeholder Advisory Group (SAG).

Representatives in the group include key professionals from each of our study sites: Professor Zsuzsoka Kecskes & Mary-Ellen Youseman (The Canberra Hospital), Dr. Gillian Opie & Chelsea Webster (Mercy Hospital for Women, Victoria), Dr. Pieter Koorts & Karen Langford (Royal Brisbane and Women's Hospital), Jocelyn Weis & Jane Wiggill (Red Nose) and Tara Corder (bereaved mother representative).

The SAG meeting provided us with an opportunity to hear from front-line hospital staff regarding how COVID-19 has impacted neonatal care, bereavement care and milk banking, and how our research process may best be adapted to meet the changing demands on hospital staff. We heard how the COVID-19 impacts have been felt differently across units within and across hospitals. We wish to thank each and every health professional for the work they do to provide the best possible care for infants and their families.

A study funded by an Australian Research Council Discovery Grant

As a result of this SAG meeting, we were able to make tentative plans for the resumption of a final round of recruitment with bereaved mothers and their partners. There is still an opportunity for a further 24 mothers and 3 of their partners to participate in our study. We hope that we are able to resume data collection in Spring 2020.

Our next meeting with our Stakeholder Advisory Group in November 2020 will allow us to begin planning for the best way to disseminate our results back to our hospital sites.

Our latest publication - Journal of Human Lactation

We are pleased to announce that in May 2020, our latest research article was published in the *Journal of Human Lactation*. Our article titled: **‘The “Lactation After Infant Death (AID) Framework”: A Guide for Online Health Information Provision About Lactation After Stillbirth and Infant Death’** provides a comprehensive evidenced-based description for each of the 25 information criteria that the Lactation AID Framework designates as necessary to promote effective management of, and informed decision-making about, lactation after infant death in online health information.

The development of the Lactation AID Framework provided a timely opportunity to critically review the growing international research and available best-practice resources within the milk banking, bereavement, and lactation/breastfeeding sectors. Within the article, the Framework’s limitations are discussed, and the article concludes by discussing how health organisations around the world may be able to adapt the Framework to better meet the unique cultural needs of the families they are aiming to inform and support.

The article is freely available and can be downloaded from SAGE Open Access using this link:



<https://journals.sagepub.com/doi/10.1177/0890334420926946>

As a result of this work we continue to work with many Australian health organisations to assist them to review and enhance their online information. The latest organisation to report changes on their website as a result of our review is **Raising Children**. We are happy to report that Raising Children have now added a link to the new Australian Breastfeeding Association (ABA) resource ‘Lactation after infant death’ in the external links section of the following *raisingchildren.net.au* articles:

- [Stillbirth: a guide](#)
- [Neonatal death: a guide](#)
- [Grief after stillbirth or neonatal death](#)

Continuing our data collection

Due to COVID-19 social distancing requirements we are now conducting interviews using zoom, telephone or via a written questionnaire. In March of this year we made the decision to suspend recruitment until the impact of COVID-19 on our hospital partners and the community eases. We hope to resume recruitment in Spring 2020.

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Mothers

Sixteen bereaved mothers from our study sites in QLD, ACT and Victoria have now participated in our study. Due to our deliberate sampling methodology (“purposive sampling”) we have ensured we have heard the experiences of mothers who have chosen to donate milk. Six of the 16 mothers interviewed have donated breastmilk after the death of their infant. The diversity of all mothers’ experiences, particularly in regard to the significance of lactation, the personal meanings applied to breastmilk, and the intended and actual uses of breastmilk after loss continue to inspire us to speak to more mothers.

Intimate Partners

Funding from the Newborn Intensive Care Foundation has allowed us to conduct seven interviews with the partners of bereaved mothers. Five interviews have been conducted with bereaved fathers from QLD. Each of these fathers had supported their partner to donate milk after infant death. Two interviews with bereaved fathers have been completed in the ACT, with three more interview slots remaining for bereaved partners wishing to participate.



All of the interviews so far have been with male partners (fathers) and have drawn attention to the significant roles and responsibilities of fathers following infant death. For some fathers, this has included providing extensive support around lactation decision making after infant death and assisting their partners in a range of ways to manage breast care and to help prepare the collection, storage and donation of breastmilk.

Health Professionals

In our last newsletter we reported some of our preliminary findings from the 17 focus groups and five interviews we had conducted with a total 114 health professionals across all study sites and three Human Milk Banks in Australia. We have now finalised our data analysis and are currently preparing articles and conference presentations that will report on our major findings regarding contemporary lactation care and how care may be enhanced to better support 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



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