



# Lactation after Infant Death:

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

## Newsletter – September 2019

Welcome to the third 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 will be conducting focus groups with up to 150 health professionals and interviews with up to 40 bereaved mothers and 10 of their intimate 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). The project will run from 2018 -2021.

In this issue we provide an update on the study, including a progress report on our data collection with health professionals and mothers. 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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### Our work over the last 3 months:

#### Data Collection – Health Professionals

After completing focus groups with lactation consultants, social workers, neonatal nurses, midwives, obstetricians and neonatologists in the ACT earlier this year, we are now conducting health professional focus groups at the Mercy Hospital for Women in Victoria. Four focus groups have been conducted at this site with seventeen staff including: social workers and pastoral care staff, midwives, neonatal nurses and lactation consultants.

Health professionals have shared many similar experiences and perspectives. Professionals have told us the lactation care bereaved women currently receive can be dependent upon the awareness, knowledge and confidence of individual staff. The majority of staff believe that bereaved mothers should be presented with information about all lactation options to ensure they receive effective lactation care and are supported to make informed decisions about their own breast milk. However, implementing this care can be challenging. Increased training and education of professionals, and the availability of quality written information that

can be provided to mothers and their families are emerging as key priorities to enhance lactation care.

### **Data Collection – Mothers**

The first wave of interviews with ACT mothers have now been completed and the research team is now supporting our partners at Mercy Hospital for Women (in Victoria) and Royal Brisbane and Women's Hospital (in Queensland) to recruit eligible bereaved mothers. So far, the mothers who we have spoken to have reinforced the importance of compassionate, non-judgmental and timely lactation care following infant death. The various meanings and uses of breastmilk have also begun to surface as mothers describe their diverse practices and experiences of lactation after infant death.

### **Improving online information on lactation after infant death:**

Our initial interviews with bereaved mothers and health professionals have confirmed that women will often be discharged from hospital within days of their bereavement, and often before the onset of lactation. Evidence suggests that when they return home many women and their families may turn to online health information to help guide their lactation care or decision making.

In July 2019 at the AMIRCI Conference in Sydney, Ms. Lara Sweeney (ANU sociology student) presented the findings of a review that explored the information currently presented on Australia's health websites on the issue of lactation after infant death. This presentation marked the first public release of the 'Lactation AID' Framework – a Framework developed by our research team to guide the provision of evidenced-based online information regarding lactation care and decision making after infant death. The framework contains 25 criteria, cohered into a set of seven overarching categories, advocating that bereaved mothers and their families be provided with information regarding:

- The acknowledgement of breastmilk and lactation after infant death
- Breast changes commonly associated with milk production
- Advice on alleviation of symptoms such as discomfort, engorgement, leakage and infection
- A description of the full range of suppression options
- A description of sustained expression options
- A description of milk donation options
- Recognition that additional bereavement or lactation support may be necessary

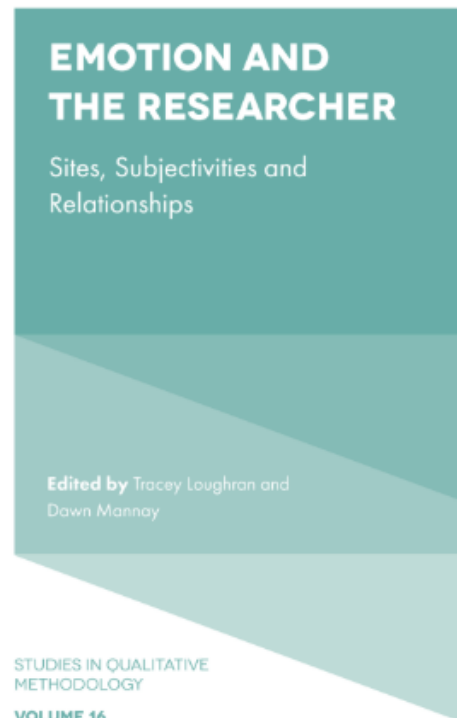
Further publications that outline the development of the 'Lactation AID Framework' and the findings of our online review will be available for public release soon.

The research team is keen to begin collaborating with Australian health organisations to support the development of evidenced-based resources that can provide women with timely, accurate and non-judgmental information to assist in their lactation care and decision making following infant death. If you are interested in working with us, or know someone who would be, please contact us at: [lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au)

## Feature Publications:

Dr. Katherine Carroll was recently awarded a 2019 Emerald Literati Award for Outstanding Author Contribution. Dr. Carroll's book chapter: **Approaching bereavement research with heartfelt positivity** was described by the award panel as being "*one of the most exceptional pieces of work the team has seen throughout 2018*". The chapter can be found in *Studies in Qualitative Methodology, Volume 16*. This volume edited by Tracey Loughran and Dawn Mannay brings together a collection of works that consider the vexed issue of: *Emotion and the Researcher: Sites, Subjectivities and Relationships*.

In recognition of the award, the book chapter is now freely available for 12 months, at the following link:



<https://www.emerald.com/insight/content/doi/10.1108/S1042-319220180000016007/full/pdf?title=approaching-bereavement-research-with-heartfelt-positivity>



We were also very pleased to be advised that the following paper authored by Dr. Katherine Carroll was recently reviewed in a feature article for the Australian Breastfeeding Association (ABA) Professional Member eNewsletter:

**Carroll, K. (2015). Representing ethnographic data through the epistolary form: A correspondence between a breastmilk donor and recipient. *Qualitative Inquiry*, 21(8), 686–695.**

The ABA's Miranda Buck, recommended the paper stating: Dr. Carroll's paper conveys important new knowledge and ideas about milk sharing and donation and demonstrated great expertise in how findings are analysed and discussed.

## Welcome to Simon Copland

We would like to introduce Simon Copland who has recently joined the research team. Simon will be undertaking interviews with 10 partners of bereaved mothers who have opted to participate in our study. Simon is a PhD student in the School of Sociology, ANU, and brings a wealth of knowledge and experience to the team. The addition of Simon to our research team also allows bereaved mothers' partners to choose if they would prefer to be interviewed by a male or female researcher.



The findings from our interviews with bereaved mothers' partners will assist us to fill a significant gap in the literature by exploring how intimate partners perceive and experience lactation, including human milk donation, after infant death.

Invitations have now been sent to the partners of our ACT mothers who had previously participated in an interview. It is expected that Simon will also interview partners of bereaved donors who we aim to recruit in partnership with Royal Brisbane and Women's Hospital.

We are extremely grateful to the Newborn Intensive Care Foundation who have generously supported our study to include partners of bereaved mothers.

To learn more about the work of this foundation please go to: <https://newborn.org.au/>



## 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 December  
stay safe and well.  
Our kindest regards...*



*Dr Katherine Carroll*



*Professor Catherine Waldby*



*Dr Debbie Noble-Carr*

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