



Lactation after Infant Death:

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

Newsletter - December 2018

Welcome to the first edition of the 'Lactation after Infant Death' Project Newsletter.

We are excited to introduce you to this important study and to provide an update on our progress to date. In this issue you will find some initial information about:

- The aims of our study;
- What we will be doing over the course of the project;
- The team of researchers and health professionals who have come together to research this important, but often overlooked, issue; and
- What we have achieved so far.

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

Introducing the study:

Breastfeeding and human milk banking has attracted a lot of research and public health attention over recent years. However, a mother's lactation when no living infant is present in her life is often overlooked. Every year in Australia, almost 3500 women will experience lactation after infant death. Without appropriate support, this can be an unwelcome and distressing experience that can threaten women's physical health and psychosocial wellbeing. However, pilot research reveals for some women, sustaining lactation or donating breastmilk after infant death can also be a positive experience.

To further our knowledge of this important issue, the Australian Research Council (ARC) has provided funding to allow a team of Australian National University (ANU) researchers to conduct a 3-year study. The study aims to explore bereaved women's lactation experiences - including the factors that influence their decision to suppress, express or donate breastmilk - with a view to enhancing care delivery in Australia's maternity, bereavement and milk banking services. To conduct the study researchers will recruit:

- **40 bereaved mothers** (including those who have and have not donated breastmilk after infant death) to participate in interviews or provide a written response to an open-text survey; and
- **100 perinatal health professionals** (including: midwives; lactation consultants, neonatologists, neonatal nurses, obstetricians, bereavement counsellors/social workers and human milk bank staff) to participate in focus groups and interviews around Australia.

Introducing our research team:

This study is being conducted by a group of researchers from Australian National University. The team includes leading international experts in the sociological exploration of human tissue donation who have been at the forefront of research into donor milk banks and women's experiences of breastmilk donation after infant death.



Professor Catherine Waldby is a chief investigator on the study. Catherine is a leading scholar in the field of social studies of biomedicine and the life sciences. Her work on reproductive tissue economies has been particularly influential. Catherine brings extensive knowledge and experience to her role as co-lead on the project, and will contribute to higher level data analysis, results integration and dissemination across all aspects of the study.

Dr Katherine Carroll is a chief investigator on the study. Katherine has conducted several pilot studies with bereaved mothers and health professionals on the topic of lactation and milk donation and has published widely on the topic of human milk banking and donation. Katherine will oversee the project, liaise with clinical research partners, and conduct interviews with mothers and health professionals.



Dr Debbie Noble-Carr is responsible for the day-to-day management of the project, including conducting interviews with mothers and health professionals. Debbie is a social worker who has extensive experience in conducting qualitative research on sensitive issues such as grief and loss, informal carers and the safety and wellbeing of children and their families.

Our key research partners:

This study would not be possible without the support of our key research partners: Canberra Hospital in the ACT, Mercy Hospital for Women in Victoria & Royal Brisbane and Women's Hospital in Queensland.

Key professionals including Professor Zsuzsoka Kecskes & Mary-Ellen Youseman (Canberra Hospital), Dr Gillian Opie (Mercy Hospital for Women), Dr Pieter Koorts & Karen Langford (Royal Brisbane and Women's Hospital) have joined our Stakeholder Advisory Group. This group will help inform study design, assist with ethics applications and recruitment of participants, and ensure appropriate and effective dissemination of our findings.

We are very excited to also welcome Tara Corder (Red Nose) onto our Stakeholder Advisory Group. Tara brings extensive knowledge, skills and experience in working as an Education Services Officer with Red Nose, as well as providing important perspectives and insights based on her lived experience as being a mother bereaved by infant death.

A study funded by an Australian Research Council Discovery Grant

Our work so far:

Project Launch

Although not officially billed as a project launch, three members of our research team recently participated in an important symposium held at ANU. Professor Catherine Waldby, Dr Katherine Carroll and Professor Zsuzsoka Kecskes presented on key aspects of our study at the August 2018, *Conversations Across the Creek* symposium. The presenters highlighted the significance of the study to the scholarly fields of reproductive tissue economies and the sociological analysis of motherhood, whilst also emphasising the need for, and challenges involved in, effective lactation healthcare delivery in maternity, bereavement and milk banking services in Australia.

<http://sociology.cass.anu.edu.au/events/conversations-across-creek-presentation-lactation-after-infant-loss-contemporary-motherhood>

Ethics approval

We are excited to announce that we have recently received ethics approval for the study from our primary Human Research Ethics Committee (ACT Health). Further ethics applications are currently under consideration by ANU and our other key hospital partners.

Our approval from ACT Health HREC allows the research team to proceed with the planned recruitment of bereaved mothers and health professionals in mid-2019. This timeline will allow us to complete data collection by the end of 2019, enabling data analysis and the release findings throughout 2020 and 2021.

An analysis of Australia's on-line health information

In addition to reviewing the relevant scholarly literature on the issue of lactation after loss, the research team is also conducting a Directed Qualitative Content Analysis (DQCA) of the available online health information provided by Australian health organisations in regard to lactation after infant death.

Our Stakeholder Advisory Group assisted us to select 21 Australian websites and Lara Sweeney - our research assistant and ANU Sociology student - has conducted an initial content analysis to determine the quality, scope and nature of information provided for bereaved mothers. Preliminary findings have highlighted the variable, but often limited and prescriptive nature of the available online information. The research team is currently working towards completing this analysis, with the aim of presenting our findings in an academic journal and motherhood conference in mid-2019.

Informing policy and practice

The research team have a strong commitment to ensuring their work can enhance policy and practice in the areas of milk donation and support of bereaved mothers. We are pleased to report that Dr Carroll's pilot work on lactation after loss recently informed a bill presented by MLA Tara Cheyne in the ACT Legislative Assembly to investigate the establishment of a milk bank in the ACT.

<https://www.abc.net.au/news/2018-10-31/breast-feeding-milk-bank-canberra-calls/10447854>

Dr Katherine Carroll has also been busy ensuring that her own work environment, at ANU, is one that values and supports breastfeeding. Last month, Katherine and her colleagues from the *Supporting Breastfeeding at ANU Working Group*, were recently awarded the **Clare Burton Award for Excellence in Equity & Diversity** at the inaugural ANU Vice-Chancellor's Annual Awards. The award recognised the work done by the working group to ensure that ANU provides a supportive and breastfeeding friendly workplace for its staff with young children. Congratulations to Katherine, Andrea Butler, Rebecca Williamson, Julie Smith, Kathryn Eden & Meetu Sharma Saxeena for receiving this award.

Coming up:

We have some important work to do in the coming months to progress important ethical approvals to allow us to conduct the study in each of our three study sites around Australia. While our applications are being considered by Human Research Ethics Committees, we will continue to review the literature and disseminate our findings from our content analysis of 'Australia's online health information available to bereaved mothers'.

Dr Katherine Carroll will also continue to share the findings of her pilot work. In March 2019, Katherine will be presenting:

Lactation Guidance for Bereaved Mothers' after Infant Death by Health

Professionals: at the Perinatal Society of Australia and New Zealand (PSANZ):

Surfing the Waves of Evidence - XXIII Annual Congress on the Gold Coast (Qld).

If you are at the conference please introduce yourself to Katherine.

Want more information?

To stay informed about our project please express your interest in receiving this quarterly project newsletter by emailing: lactationafterloss@anu.edu.au

To listen to an audio recording of Dr Katherine Carroll talking about the project, or to find relevant publications and resources on the study, please access our project webpage:

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

Thank you for your interest in our study.

*We look forward to keeping you informed of our
study progress and findings over the next 3yrs.*

*Until then have a safe and enjoyable
Christmas and New Year.*



Image Source: Mark Manger