



Lactation after Infant Death:

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

Newsletter - March 2019

Welcome to the second 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.

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 and what we have been doing since returning from our Christmas break. 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

Stakeholder Advisory Group:

The membership of our Stakeholder Advisory Group has been finalised and in February we successfully held our first National Stakeholder Advisory Group meeting. We feel very fortunate to have assembled a wonderful group of experts, who collectively represent a wealth of expertise and experience from across the diverse range of professional fields that may encounter and support bereaved mothers with lactation.

Representatives on the group include key professionals from each of our study sites: Professor Zsuzsoka Kecskes & Mary-Ellen Youseman (Canberra Hospital), Dr Gillian Opie, Dr Asiyath Rasheed & Chelsea Webster (Mercy Hospital for Women), Dr Pieter Koorts & Karen Langford (Royal Brisbane and Women's Hospital). Tara Corder (Education Services Officer, Red Nose) and Jocelyn Weis (Bereavement Counsellor, Red Nose) have also joined the group to provide important perspectives and insights in regard to mothers bereaved by infant death.

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 would particularly like to thank Tara and Jocelyn from Red Nose who are currently reviewing and providing valuable feedback on the interview schedules developed to guide our in-depth interviews with bereaved mothers.

Important developments over the last 3 months:

Ethics approval

In addition to receiving ethics approval from our primary Human Research Ethics Committee (ACT Health), our study has now been approved by Mercy Health Human Research Ethics Committee (Victoria) and ANU Human Research Ethics Committee.

These approvals have been critical in allowing us to begin recruitment of bereaved mothers and health professionals at our first study site – ACT Canberra Hospital, and to keep on track with planned recruitment for mid-late 2019 at our other two study sites – Mercy Hospital for Women in Victoria and Royal Brisbane and Women's Hospital in Queensland.

Data Collection

In addition to hearing from 40 bereaved mothers, the study aims to speak to up to 100 health professionals from a diverse range of fields including: Midwives; Lactation Consultants; Neonatologists/Neonatology Fellows; Neonatal Nurses; Obstetricians; Bereavement Counsellors & Social Workers; and Human Milk Bank Staff.

In February we successfully conducted our first health professionals' focus group with nine Obstetricians at The Canberra Hospital. In March, eight Neonatal Nurses also opted-in to participate in a focus group. The focus groups have elicited much discussion about health professionals' current practice with bereaved mothers, especially in regard to the lactation support they provide, and what services and supports they would like to offer women following infant death. A further four groups at The Canberra Hospital will be conducted in the coming months.

Invitation packs have also now been provided to Canberra Hospital, and will soon be sent out to bereaved mothers who in the last 12 months, have experienced either:

- Still birth (fetal death after 20 weeks of gestation); or
- Neonatal death (first 28 days of life); or
- Older infant death (1 – 12 months of age) and were producing breastmilk, or had breastmilk stored in a fridge or freezer, at the time of the infant's death.

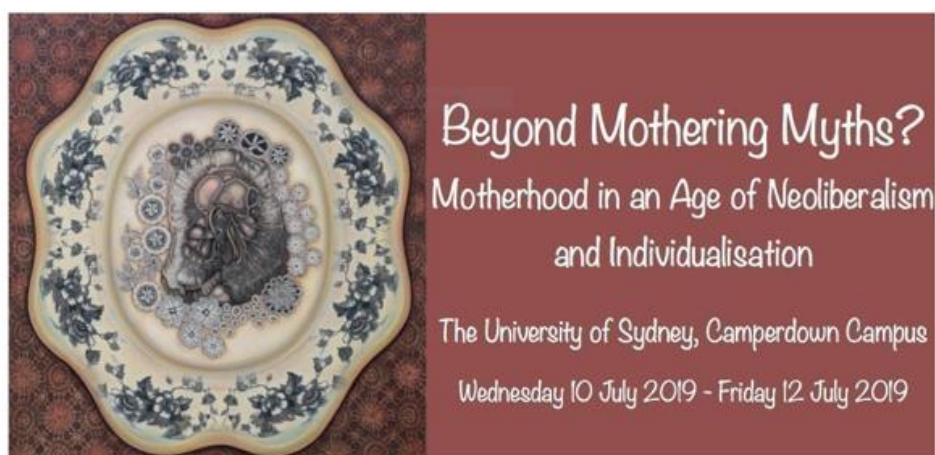
Mothers will only receive an invitation for research participation after a minimum of three months have passed from the date of infant death and are excluded from the study if the infant death was the result of a termination of pregnancy; or prior to death the infant had been removed from their care by Care and Protection authorities; or they experienced postpartum psychosis after the birth of the deceased infant.

Upcoming Publications & Presentations:

An analysis of Australia's on-line health information

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

Lara Sweeney - our research assistant and ANU Sociology student – has reviewed 21 Australian websites and has been accepted to present the results of this content analysis at the upcoming AMIRCI conference in Sydney on 10-12 July 2019. Lara's presentation titled: *'Websites and oversights: Investigating the shortcomings of lactation management information for bereaved mothers on the websites of Australian health care agencies'* highlights the limited and fragmentary nature of the information currently available to bereaved mothers, and references Douglas (2002) work to suggest that bereaved mothers' milk is 'matter out of place' in these online spaces.



Also presenting at AMIRCI Conference...

Dr Debbie Noble-Carr and Dr Katherine Carroll have also been accepted to present at AMIRCI Conference.

Debbie's presentation is titled, *'Researching bereaved mothers' experiences of infant death'*. She will report on the extent and nature of research conducted with women who have experienced infant death and will explore the ethical and methodological challenges involved and outline the approach of the current study underpinned by a feminist ethic of care.

Katherine will report on her pilot work in the USA which led to the current study, in a paper titled *'Health professionals' experiences of providing lactation guidance to bereaved mothers'*. The presentation will highlight the temporal influences of work practices and values about lactation after loss held by health professionals who provide lactation guidance to bereaved mothers.

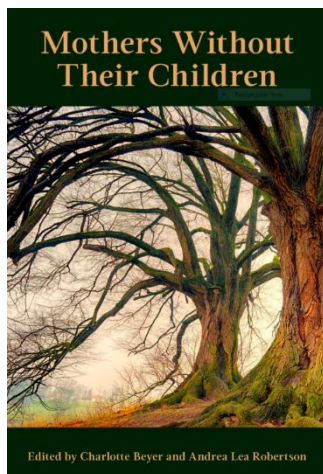
Recent Publications & Presentations:

ANU Reporter



Our study was recently profiled in a feature article titled '*Lactation after Loss*', written by Adam Spence in the Autumn edition of the ANU Reporter, Volume 50, No 1. The article can be accessed here: <https://reporter.anu.edu.au/lactation-after-loss>

The release of Dr Carroll's latest book chapter



Mothers without Their Children, is an edited book (Eds. Carolyn Beyer & Andrea Lea Robertson) that examines mothers lives when their children are not present. Dr. Carroll's chapter (with Dr. Brydan Lenne) is titled '*Suppress and Express: Breast Milk Donation After Neonatal Death*'. The chapter draws on research with bereaved mothers in the USA and Australia. It explores their lactation experiences and lactation and donation decision-making. It highlights the pride, productivity and positivity experienced by the bereaved mothers who donated milk to human milk banks in the USA or Australia after the death of a baby.

The book is available here: <http://demeterpress.org/>

PSANZ Conference

On 19th March, Dr Katherine Carroll presented at *The Perinatal Society of Australia and New Zealand (PSANZ): Surfing the Waves of Evidence – XXIII Annual Congress*.

Katherine's presentation on '*Lactation Guidance for Bereaved Mothers' after Infant Death by Health Professionals*' was well-received by the audience of health practitioners and researchers in attendance. Dr. Gillian Opie from Mercy Hospital was also in attendance.

Want more information?

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

***Until our next
update, stay safe and
well and have a
Happy Easter.***



Dr Katherine Carroll



Professor Catherine Waldby



Dr Debbie Noble-Carr

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