



Lactation after Infant Death:

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

Newsletter – December 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), ANU and the Newborn Intensive Care Foundation. The project will run 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

Our work over the last 3 months:

Stakeholder Advisory Group Meeting – November 2019

In November we held a successful meeting with our Stakeholder Advisory Group consisting of: Neonatologists, Lactation Consultants, Milk Bank Managers, a Bereavement Counsellor and Red Nose Education Officer who has a lived experiences of infant bereavement. At this meeting we confirmed plans for further recruitment of mothers (and their partners) and discussed strategies for effective research dissemination that can contribute to improved lactation care policy and practice.

Data Collection – Health Professionals

We have now completed our data collection with health professionals at each of our study sites. The table (on the next page) provides an overview of the total number of professionals who have participated in either focus groups or interviews with researchers. The knowledge, attitudes and experiences of the professionals who participated in interviews or focus groups was diverse, however, they all agreed that lactation management and care could be enhanced and are keen to learn from mothers about how they can do this. Our next newsletter will feature a summary of our main findings from these interviews and focus groups.

Type of Health Professional	Number of participants				
	The Canberra Hospital (ACT)	Mercy Hospital for Women (VIC)	Royal Brisbane & Women's Hospital (QLD)	Other Human Milk Banks	Total
Obstetricians	9	-	8	n/a	17
Social Workers	11	5	4	n/a	20
Midwives	3	3	3	n/a	9
Neonatal Nurses	8	5	6	n/a	19
Neonatologists	6	6	17	n/a	29
Lactation Consultants	7	4	3	n/a	14
Milk Bank Staff	n/a	1	2	1	4
Other – perinatal bereavement nurses	n/a	n/a	2	n/a	2
TOTAL	44	24	45	1	114

*n/a = not applicable

Data Collection – Mothers

We have now had 14 bereaved mothers across Victoria, ACT and Queensland opt in to participate in our study. Half of these are mothers who had donated breastmilk after the loss of their baby. Further recruitment in the ACT and Queensland has been planned for January.

We have already noticed that there is a huge variance in the significance and meaning that women attribute to their breastmilk and lactation. For some, lactation has been an unwelcome signifier of the reality of their loss. Whilst for others, lactation has reinforced faith in their body that it can perform the required acts of motherhood.

In line with this, women have also shared many different experiences regarding what they have done, or would have liked to have done, with their breastmilk following the death of their baby. Some have wanted to suppress their milk as quickly as possible. Many of the women we have spoken to have chosen to donate milk to help sustain the life of other infants. The act of donating milk has provided important meaning and purpose to these women and their families at a time of overwhelming grief.

Despite the significance of their lactation experience, most women have reported that they received minimal information and support on how to manage their lactation. All of the women have shared their own ideas on how lactation care can be enhanced, including the importance of providing women with enough information and support to enable them to make their own decisions on what they would like to do with their breastmilk.

Data Collection – Intimate Partners



With our generous funding from the Newborn Intensive Care Foundation we are now able to include 10 partners of bereaved mothers in our study. We have conducted our first interview with a bereaved father and will be conducting further interviews in the New Year in the ACT and Queensland. Five of these interviews will be with fathers who supported their partner to donate breastmilk after loss.

Improving online information on lactation after infant death:

Our interviews with bereaved mothers and health professionals have confirmed the need for families and health professionals to have access to quality evidenced-based written information regarding lactation management and care after infant death.

The review we conducted of the information presented by 21 Australian health organisations' websites confirmed it is not easy to locate evidenced-based information relating to lactation management after infant death. Some of our major findings included:

- ❖ No organisation provided a stand-alone document or drop down menu that specifically addressed the experience of lactation after loss (including infant death).
- ❖ Less than half of the websites reviewed acknowledged the presence of breastmilk or lactation after infant death.
- ❖ Lactation suppression was presented as the most prominent, and often the only assumed response to lactation after infant death across the reviewed websites.
- ❖ Very few organisations presented information on options such as: sustaining expression, donating breastmilk or using breastmilk as a memento.

In response to these findings, the research team has been busy reaching out to, and collaborating with, prominent Australian health organisations responsible for providing information and support about lactation, infant bereavement or milk banking.

To date, we have held productive meetings with the Australian Breastfeeding Association, SANDS, Red Nose and Miracle Babies who have all expressed a commitment to enhance their online information and resources regarding lactation after infant death.

Individualised findings and feedback (from our review) have also been provided to many other Australian organisations who are keen to ensure bereaved mothers have access to timely, accurate and non-judgmental information to assist in their lactation care and decision making following infant death.

To further disseminate our findings we have also:

- Presented our online review findings to the Midwifery students at the University of Canberra.
- Completed a paper on the findings of our online review that is expected to be published by Health Sociology Review early in 2020. We will send a link to the article in our next newsletter.
- Submitted a further paper on the development of the evidence-based Lactation After Infant Death (AID) Framework – that outlines the 25 criteria required to present comprehensive information on lactation care and management to bereaved mothers.

The Lactation AID Framework can also be used to guide the development of education and training materials. If you are interested in accessing this Framework, or working with us to enhance your resources, please contact us at: lactationafterloss@anu.edu.au

Acknowledgement of our commitment to healthcare policy and practice:



We are very excited to announce that Dr. Katherine Carroll was recognised at the 2019 Australian Sociological Association (TASA) Conference in Sydney.

Dr Katherine Carroll, a Research Fellow in the ANU School of Sociology received the 2019 Sociology in Action Award, recognising the impact in medical and health service delivery across Australia and the United States of her research involving video-reflexive ethnography (VRE).

The research, in collaboration with health care professionals, uses VRE to assess practitioner methods and patient experiences, to better understand and improve healthcare processes.

Accepting the award at the conference dinner, Dr Carroll recognised the importance of collaboration between researchers, health practitioners and patients in improving healthcare policy or practices.

Katherine is pictured above with Dr Brydan Lenne, a PhD Candidate co-supervised by Dr Carroll, Professor Catherine Waldby and Associate Professor Melinda Cooper at University of Sydney. Dr Brydan Lenne received the 2019 Jean Martin Award for the best PhD thesis in the Social Sciences in Australia (2017-2019). Her thesis used VRE to understand the clinical experiences for autism spectrum disorders.

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

*Until our next
update we wish you a
safe and happy
Christmas and
New Year!
Kindest regards...*



Dr Katherine Carroll



Professor Catherine Waldby



Dr Debbie Noble-Carr