



### Lactation after Infant Death:

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

## Newsletter - June 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.

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: <u>lactationafterloss@anu.edu.au</u>

#### What we have been doing over the last 3 months:

With ethics approval now provided for all study sites – ACT, Victoria and Queensland – we are moving ahead with our data collection processes and practices. Over the life of the study we are hoping to conduct focus groups with up to 100 health professionals and interviews with up to 40 bereaved mothers. Here is an update on our data collection activities:

#### **Data Collection – Health Professionals**

We would like to thank our partners at Canberra Hospital for assisting us to successfully recruit and complete a number of focus groups with health professionals. Special thanks to Zsuzsoka Kecskes, Mary-Ellen Youseman, Audra Hooge, Chris Evans, Fiona Holihan and Nancy Jacobs from the Canberra Hospital for going 'above and beyond' your job roles to organise focus groups.

A total of 44 health professionals from Canberra Hospital have participated in six focus groups, including: 3 Midwives; 7 Lactation Consultants; 6 Neonatologists/Neonatology Fellows; 8 Neonatal Nurses; 9 Obstetricians and 11 Social Workers. We are very thankful to these professionals who took time out of their busy schedules to participate. We were able to hold full and frank discussions that contributed greatly to our understanding of their role, and their needs, in providing lactation care.



We will begin our analysis of this material soon, as we swiftly move onto conducting focus groups at our second study site - the Mercy Hospital in Melbourne, Victoria.

#### **Data Collection – Mothers**

Invitation packs have been sent to eligible mothers who had experienced an infant death at the Canberra Hospital in 2018. Invitations were extended to mothers who had experienced still birth, neonatal and older infant death. To date, five mothers have opted to participate in the study.

As well as finding out about experiences of lactation after infant death, the study provides an important opportunity to further our knowledge about how to conduct research with bereaved mothers in a way that is both ethical and responsive to their needs.

The importance of offering multiple ways of participating in the research has been highlighted already; with two of the five mothers opting to complete a phone interview, one mother opting to complete a written response and another two mothers choosing to conduct interviews face-to-face in their own homes.

It is an immense honor to be able to listen to women as they discuss their pregnancy, birth, loss and lactation experiences. We are extremely grateful to all of the mothers who have generously decided to share their stories with us. We hope to begin data collection with mothers at our other study sites later this year.



#### Amendment to include mothers who have a medical termination

We have sought, and received, an important amendment to our eligibility criteria for bereaved mothers. This change, approved in the last meeting of the ACT Health Human Research Ethics Committee, will enable us to recruit and interview mothers who have experienced a medical termination after 20 weeks gestational age. We are delighted with this news, as the research team believes it is extremely important that every bereaved mother be provided with equal opportunities to participate in research.

#### But, what about the partners?

"But, what about the partners?" is a question Dr Katherine Carroll has often been asked when presenting on the issue of lactation after infant death or breast milk donation.

To help address this issue, we are very pleased to announce our project has recently secured funding from the Newborn Intensive Care Foundation to be able to include a small sample of partners in our data collection. The aim of including partners is to better understand:

Partners' perspectives and experiences of lactation, and possible breastmilk donation, after infant death.



To help us address this question more fully we have recently welcomed a third year ANU sociology student to our research team - Kristina Bergmark. Kristina will be conducting a literature review on intimate partners' perspectives and experiences of lactation after infant death. As this is a novel area of research, Kristina's literature review will most likely focus on bringing together two currently distinct areas of research including: the impact that partners may have on lactation experiences (including donation of breastmilk) and partners' experiences of infant death.

We take this opportunity to welcome Kristina and look forward to the contribution she will be making to our project.

To check out the amazing work of the Newborn Intensive Care Foundation who have generously supported our study to include partners of bereaved mothers please go to: <u>https://newborn.org.au/</u>



#### **Upcoming Presentation:**

On 10th –12th July 2019, The Australian Motherhood Initiative for Research and Community Involvement (AMIRCI) will hold their 9th International Conference on Motherhood in Sydney.

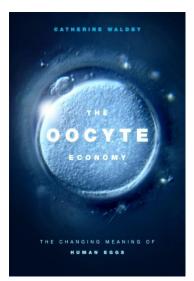
On Wednesday 10<sup>th</sup> July, Lara Sweeney – a third year Sociology student – who has been assisting us to conduct a review of online health information will present: **Websites and oversights:** Investigating the shortcomings of lactation management information for bereaved mothers on the websites of Australian health care agencies. This paper presents the findings from a review of the online health content of 21 Australian health care agencies.

If you are attending the conference, please come to the presentation and introduce yourself to Lara.





#### **Feature Publication:**



We are very excited to announce the publication of Professor Catherine Waldby's latest book –

# The Oocyte Economy: The Changing Meaning of Human Eggs

In recent years increasing numbers of women from wealthy countries have turned to egg donation, egg freezing, and in vitro fertilization to become pregnant, especially later in life. This trend has created new ways of using, exchanging, and understanding oocytes—the reproductive cells specific to women.

In *The Oocyte Economy* Professor Waldby draws on 130 interviews - with scientists, clinicians, and women who have either donated or frozen their oocytes or received those of another woman - to trace how the history of human oocytes' perceived value intersects with the biological and social life of women. Demonstrating how oocytes have come to be understood as discrete and scarce biomedical objects open to valuation, management, and exchange, Waldby examines the global market for oocytes and the power dynamics between recipients and the often younger and poorer donors.

With this exploration of the oocyte economy and its contemporary biopolitical significance, Waldby rethinks the relationship between fertility, gendered experience, and biomedical innovation.

The book is available through Duke University Press: <u>https://www.dukeupress.edu/the-oocyte-economy</u>

#### Want more information?

As always, to stay informed about our project, and to locate study publications and resources visit our project webpage: <u>http://sociology.cass.anu.edu.au/lactation-after-infant-death</u>

To contact the research team or register to receive this quarterly project newsletter email: <u>lactationafterloss@anu.edu.au</u>

Until our next update in September, stay safe and well. Our kindest regards...







Dr. Katherine Carroll

Professor Catherine Waldby

Dr. Debbie Noble-Carr