

'A storehouse of mother's unconditional love and nectar'

**The role of the National Comprehensive Lactation Management Centre in
strengthening feeding of premature infants in New Delhi, India**

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This thesis is submitted in partial fulfilment of the requirements for the degree of
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Outside The National Comprehensive Lactation Management Centre (NCLMC) at Lady Hardinge Medical College, New Delhi, India. Photographer: Oslo University Hospital

Abstract

Introduction: Providing human milk to sick- and premature infants is a lifesaving intervention that alone can reduce neonatal mortality. Studies have shown that donor human milk is the second-best alternative after mother's own milk (MOM). The establishment of human milk banks and lactation centres, give mothers a better chance to establish lactation. Along with this, donor human milk can be provided to the premature infants as 'gap-filler' until the mother is able to produce adequate amount of MOM for their premature infant. The National Health Mission in India has established Lactation Management Centres at secondary and tertiary level public health facilities. These function as human milk banks and lactation counselling centres.

Aim: The aim of this study was to explore the role of the National Comprehensive Lactation Management Centre (NCLMC) in strengthening feeding of premature infants in a tertiary care hospital in New Delhi, India.

Methodology: During a three-month period, data were collected through seventeen in-depth interviews. Eleven of these was with lactation counsellors working in the NCLMC and six with mothers who delivered prematurely and received lactation counselling in the NCLMC. The interviews with the lactation counsellors were conducted over the online platform Zoom, while the interviews with the mothers were collected face-to-face in New Delhi by a research assistant. After translation and transcription, the data were analysed while using systematic text condensation (Malterud, 2012).

Findings: The main findings illuminate mothers' and lactation counsellors' lived experiences related to infant feeding. It demonstrates how practical challenges complicates the process of establishing lactation, and how this combined with separation of mother and infant, caused feelings of failed motherhood. Practical, physical, emotional, and social support from the lactation counsellors was vital, but the findings also show that involving mother-in-law in counselling sessions was essential as their perceptions and presence influenced the mothers' practices. Practicalities related to availability of electric breast pumps around the clock, challenged the mothers' possibilities of providing MOM at all hours of the day. Restrictions due to Covid-19, caused delays in early initiation of lactation and created communication difficulties in counselling sessions. Motivational factors for donating MOM were related to

reciprocal benefits and a religiously based motivation to do good as an act of solidarity towards mothers who did not have MOM.

Discussion: The discussion draws upon concepts in medical anthropology, and existing research to make sense of the findings. The theory of health literacy illuminates how the mothers in the study understand their situation of providing MOM to their premature infant, and how the lactation counsellors approach them according to their level of health literacy. The theory of authoritative knowledge is used to understand how the lactation counsellors impart knowledge to mothers in the counselling sessions.

Conclusion: There is great need for Lactation Management Centres in New Delhi, India to ensure access to MOM and to provide safe use of donor human milk (DHM) to infants admitted to the Neonatal Intensive Care Units. Lactation Support to a mother with a premature infant must go beyond establishing lactation. It should include practical, physical, emotional, and social support to ensure that the individual mother is capable to provide MOM to their infant. Future studies are needed to get a broader understanding of how of the Lactation Management Centres improve the access of human milk for infants, and how these centres can develop ways of reducing distance and increase possibilities for attachment between premature infant and mother during the first critical phase after birth.

Key words: Human milk bank, lactation counselling, mothers' own milk, breastfeeding, infant feeding, infant nutrition, motherhood, premature infants, prematurity

Contents

Chapter 1: Introduction and Background.....	1
Global trends in breastfeeding.....	1
Why is human milk important?	2
Global burden of preterm births	3
Human milk for the preterm infant	3
The role of human milk banks.....	4
The importance of lactation counselling	5
Lactation Management Centres.....	6
Social and cultural context of breastfeeding and lactation counselling	7
Acceptance of milk donation.....	8
The impact of Covid-19	8
Rationale of the study.....	9
Study objectives	9
Chapter 2: Methodology.....	10
Study context.....	10
<i>National Comprehensive Lactation Management Centre (NCLMC)</i>	10
<i>Impact of Covid-19</i>	12
Collaboration partners	13
Study Design	14
Recruitment and training of Research Assistants.....	15
Recruitment of study participants	16
Characteristics of study participants	17
Data collection.....	19
<i>Online in-depth interviews with lactation counsellors</i>	19
<i>Face-to-face in-depth interviews with mothers</i>	20
Ethical and Data Management Approval	21
Ethical Considerations.....	21
Data analysis	22
<i>Transcription and translation</i>	22
<i>Systematic text condensation</i>	23
Reflections on researcher’s position	25
Chapter 3: Theory and Concepts	27
Health literacy	27
Authoritative knowledge	28

Chapter 4: Supporting a mother with a premature infant	30
Threatened motherhood.....	30
Creating a platform where mothers feel seen.....	31
Handling customary expectations	33
‘They do not think colostrum is important milk’	33
Honey is the first thing given to the child.....	35
‘Mother-in-law have their own set-up-rules’	37
Chapter 5: Feeding a premature infant.....	40
Establishing milk production for the premature infant	40
<i>The blessing of the breast pump</i>	40
<i>The pain and frustration of hand expression</i>	42
<i>Breastfeeding promotion</i>	43
<i>Delay in producing mother’s own milk</i>	43
‘Donor human milk is meant as gap-filler’	45
Chapter 6: Donating own mothers ‘milk.....	47
‘It is in our culture to share’	47
Taking advantage of the surplus.....	49
Act of solidarity.....	51
Chapter 7: Discussion and Conclusion	53
Discussion of findings.....	53
<i>Rebuilding motherhood</i>	53
<i>Establishing the link between knowledge and practice</i>	55
<i>The tension between local ideas and evidence-based knowledge</i>	56
<i>Delays in establishing lactation</i>	57
<i>Sharing milk</i>	58
Reflections of methodology	59
Conclusion and Recommendations	61
References.....	63
Appendix A: Written consent form, English.....	67
Appendix B: Written consent form, Hindi	70
Appendix C: Semi-structured in-depth interview guide to Lactation Counsellors.....	73
Appendix D: Semi-structured in-depth interview guide to mothers.....	76
Appendix E: Ethical approval from Institutional Ethics Committee at Lady Hardinge Medical College & Associated hospitals	78
Appendix F: Timeline for data collection	79

Acronyms and Abbreviations

BFHI	Baby Friendly Hospital Initiative
BPNI	Breastfeeding Promotion Network of India
DHM	Donor human milk
KSCH	Kalawati Saran Children's Hospital
LHMC	Lady Hardinge Medical College
MOM	Mothers' own milk
NCLMC	National Comprehensive Lactation Management Centre
NCR	National Capital Region
NICU	Neonatal intensive care unit
WHO	World Health Organization

List of figures

Figure 1: Levels of facility-based Lactation Management Centres in India (Bhasin, Nangia & Goel, 2020), p.6

Figure 2: Daily intake of MOM, Pasteurized DHM, artificial formula in the NICUs at LHMC & KSCH (Nangia, 2021), p. 12

Figure 3: Human milk donations at the NCLMC, April 2019 to August 2020 (Bhasin, Nangia & Goel, 2020), p. 12

Figure 4: Numbers of deliveries at LHMC from April 2019 to August 2020 (Bhasin, Nangia & Goel, 2020), p.13

Figure 5: Overview of the study participants religious status, p.17

List of tables

Table 1: Overview of mothers as study participants for in-depth interviews, p.18

Table 2: Example of systematic text condensation used in the analysis of the data, p. 24

Table 3: Mothers and lactation counsellors experiences: themes and categories, p. 25

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Writing a master thesis in the middle of a pandemic has for sure been challenging. From the very start, I had to change the plans for going on field work. In the thick of it I thought I would never be able to finish ... But here I am! With my very first study on human milk banking!

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Chapter 1: Introduction and Background

“I wasn’t able to produce milk and the nurse told me that I had to expel it as my baby was premature and only this milk could save his life. I used to feel embarrassed since I could only send 4 drops of milk and my baby needed much more.” (Meena, mother, P6)

These words were spoken by Meena, a 28-year-old primipara mother, who delivered prematurely in week 28. While her infant was admitted to the neonatal intensive care unit (NICU) receiving intensive treatment, she was in the maternity ward trying to contribute to her infant’s health by getting her milk production started. Hidden behind success stories of mothers who exclusively breastfeed their infant right after birth, are mothers like Meena who found it difficult to live up the expectations of breastfeeding.

This study explores the experiences of mothers who like Meena struggled to establish lactation and a sense of motherhood after the delivery of a premature infant, and the experiences of lactation counsellors providing support and guidance to these mothers.

Global trends in breastfeeding

It has been estimated that more than 820 000 children could have been saved yearly if all children between 0-23 months were optimally breastfed (Victoria et al., 2016; WHO, 2019a). Breastfeeding is the best nutrition for infants and is globally considered as one of the most important factors for child survival (Gardner & Lawrence, 2016). World Health Organization (2019c) recommends that children initiate breastfeeding within the first hour after birth and are exclusively breastfed for the first 6 months of life. Children who have breastfed for longer periods have lower infectious morbidity and mortality, fewer dental malocclusions, and higher intelligence compared to those who breastfeed for shorter periods or do not breastfeed at all (Victoria et al., 2016).

High-income countries have shorter breastfeeding duration than low- and middle- income countries. However, even in low- and middle-income countries, only 37% of all infants exclusively breastfeed for the recommended 6 months. Supporting mothers to initiate breastfeeding preferably within the first hour after birth is important in high-, middle- and low-income countries alike (Victoria et al., 2016). In India, 42% initiate breastfeeding within the

first hour after birth, 81% initiate breastfeeding within one day after birth, and 55% of all children under six months are exclusively breastfed (IIPS & ICF,2017; Ogbo, 2019; Unicef India, 2019). Data from The National Family Health Survey in India indicates that infants whose delivery was assisted by health personnel or were born at health facilities were more likely to start early breastfeeding than others (IIPS & ICF, 2017).

Although breastfeeding is a natural function, it is not a reflex response. Rather, it is a highly complex interaction and interdependence between mother and infant. To be successful, mother and infant must synchronize their behaviour and physiology (Gardner & Lawrence, 2016). In 1991, WHO and UNICEF launched Baby Friendly Hospital Initiative (BFHI) to ensure that health facilities implement practices that protect, promote and support breastfeeding (Unicef, 2005). Health facilities that are baby-friendly have shown to improve the breastfeeding rates (Gardner & Lawrence, 2016). Breastfeeding Promotion Network of India (BPNI) is India's answer to BFHI. BPNI works in close liaison with the Government of India and is recognized for its technical expertise and their credible standing on the issue of child health and nutrition (BPNI, n.d.).

Why is human milk important?

Human milk has been recognized as the gold standard for infant nutrition for centuries (Gardner & Lawrence, 2016). It is a complete food source, which is safe, clean and contains antibodies which help protect against common childhood diseases (Hilton, 2010; WHO, 2019a). Its nutritional properties are tailored to meet the developmental need for the infant, and plays an important role in providing immunological protection (Hilton, 2010). Along with this, lactating women have a reduced chance of developing ovarian- and breast cancer (Victoria et al., 2016).

The composition of human milk varies with the stage of lactation. Colostrum is produced immediately at delivery and is full of proteins and nutrient dense. It is low in fat, easy to digest, rich in antibodies and plays a crucial role in building the infants' immune system (Gardner & Lawrence, 2016; Medela, 2020). Within five days postpartum, colostrum changes to transitional milk and finally to mature milk by 2 weeks. All stages benefit the baby with the right amount of nutrients (Medela, 2020).

Mothers' own milk (MOM) from a mother who delivered prematurely differs from that of mothers who delivered at term. Preterm MOM is initially higher in fat, protein, amino acids, and sodium, but after few weeks after delivery these levels normalises (Underwood, 2012).

Global burden of preterm births

Globally, 15 million infants are born preterm yearly, which indicates a global preterm birth rate of about 11%. Preterm is defined as infants born alive before 37 weeks of pregnancy (WHO, 2018b). With 1 million preterm infants dying every year, preterm births is the leading cause of death among children under the age of five, followed by pneumonia, birth asphyxia, congenital anomalies, diarrhoea and malaria (Walani, 2020; WHO, 2020b). Preterm deaths account for 18% of all deaths under the age of five, and 35% of all deaths in the neonatal period (<28 days). There are notable variations in preterm birth rates and mortality between and within countries. The incidence is particularly high in low- and middle-income countries, especially in Southeast Asia and sub-Saharan Africa (Walani, 2020). India has the highest under-five year mortality rate with 0.9 million deaths in 2016. Half of these deaths occur during the neonatal period. Factors such as poverty, poor water and sanitation, poor healthcare access and non-exclusive breastfeeding for the recommended first six months of life contributes to the high mortality rate (Ogbo et al., 2019).

Preterm infant have a higher risk of morbidity, infectious diseases, stunting in childhood, and long-term developmental and physical ill health including adult-onset chronic conditions such as cardiovascular disease (Blencowe et al., 2019). The global burden of preterm birth is of paramount significance for achieving the sustainable development goal target 3.2, which aims to end all preventable deaths in children under the age of five by 2030 (Walani, 2020).

Human milk for the preterm infant

Human milk plays a vital role in promoting health of preterm infants (Hilton, 2010). WHO (2019b) recommends that preterm infants should be fed with MOM. Preterm infants have an underdeveloped gastro-intestinal tract, which makes them extra vulnerable. Tolerance to milk feeds is often a time of transition until the gastro-intestinal tract is matured and able to digest and absorb the nutrients found in both human and artificial formula milk. The immaturity of the gut associated with preterm infants causes an increased risk of developing necrotizing enterocolitis. Preterm infants fed with artificial formula milk have five times the risk of

developing necrotizing enterocolitis with a 20% mortality risk compared to term infant (Hilton, 2010).

In preterm infants, immaturity including a weak sucking reflex coupled with mother's underdeveloped breast tissue, makes it difficult to initiate breastfeeding. Mothers of preterm infants commonly face anatomical, physiological, and emotional challenges related to initiation of lactation. The decision to provide MOM requires commitment by the mother herself as well as support and counselling from professional health workers (Hilton, 2010). Evidence shows that interventions such as Kangaroo Mother Care (KMC) are associated with increased milk flow, early initiation and exclusive breastfeeding for low birth weight infants, and therefore should be applied in the process of establishing lactation (Mazumder et al. 2018).

Despite the support and counselling being provided to mothers of preterm infants, sometimes the delay in establishment of MOM is unavoidable. In these cases, the alternatives are either donor human milk (DHM) or artificial formula milk (Hilton, 2010). Evidence shows that compared with artificial formula, DHM is associated with lower incidence of severe gut disorders, necrotizing enterocolitis and infections related to hospital stay after birth. Therefore DHM is considered as the best second alternative after MOM (WHO, 2019b). DHM plays a lifesaving role by helping these infants receive the benefits of early initiation and exclusive feeding of human milk (Child Health Division, 2017).

The role of human milk banks

Safe use of DHM is essential and it should therefore be delivered through human milk banks (WHO, 2011). The establishment of human milk banks has become a widespread global phenomenon. As of now, 60 countries globally have established human milk banks, and only in Europa more than 270 human milk banks exist (European Milk Bank Association, n.d.; Fang et al., 2021). In India, over 50 human milk banks are operational (Bhat & Adhisivam, 2018).

To ensure the safety of donor human milk, a rigorous human milk bank system for screening, pasteurizing, storage and distribution is required (PATH, 2020). Along with this, provision of lactation support to lactating women is a key component for protecting, promoting and supporting breastfeeding (Child Health Division, 2017).

Scaling up and integrating quality human milk banks with other components of newborn care has been challenging for low-and middle-income countries such as India. Starting a human milk bank is relatively easy because it does not require much medical technical equipment. However, sustaining voluntarily milk donations and maintaining the quality of DHM are arduous but essential factors for success (Bhat & Adhisivam, 2018). Along with this, use of MOM and support to establish and maintain lactation and transition to breastfeeding have the highest priority in a human milk bank setup and therefore needs to be focused upon through lactation counselling (Arskaboglu et al., 2013).

The importance of lactation counselling

Lactation counselling is a key intervention to improve lactation and breastfeeding rates (Arskaboglu et al., 2013). The aim of lactation counselling is to empower, support and assist mothers to breastfeed. Lactation counselling is anticipatory, and the counsellors support mothers in achieving their individual goals for breastfeeding, as well as guiding the mothers facing challenges with continuation of breastfeeding (WHO, 2018a).

Mothers of premature infants usually must initiate lactation by expression, either by hand or electric breast pump. Supporting lactation and breastfeeding for these mothers requires collaboration between the staff at the human milk bank, neonatal intensive care unit and the maternity ward, and strategies to support breast milk production and breastfeeding should be in place. According to Lucas & Briere (2016), this includes the following:

- Educate mothers on lactation and provide instructions on pumping technique (hand expression, manual, and/or electric breast pump).
- Initiate lactation within six hours of birth.
- Initiate skin-to-skin contact as soon as possible after birth and promote frequent sessions.
- Pump at least eight times every 24 hours.
- Provide emotional support and acknowledge difference between breast pumping and breastfeeding.
- Initiate direct breastfeeding when the infant is ready and has established sucking. Infant should be put to breast when waking up and on showing signs of hunger.

Lactation Management Centres

The National Health Mission in India has taken the initiative to establish Lactation Management Centres at secondary and tertiary level public health facilities to improve the access to lifesaving human milk for infants (Child Health Division, 2017). There are three different levels of facility-based Lactation Management Centres (figure 1):

- The Lactation Support Units (LSUs) are established in the Sub district hospital/Community Health Centres/Primary Health Centres (delivery points) for the purpose of promoting and providing lactation support to all mothers at the hospital.
- Lactation Management Centres (LMCs) are established in the health facilities for the purpose of providing lactation support to all mothers within the health facility. Along with this the LMCs collect, store, and dispense MOM for consumption for the mother's infant.
- Comprehensive Lactation Management Centres (CLMCs) are centres at health facilities with the purpose of comprehensive lactation support and management of all mothers within the hospital. The CLMCs have facilities for collection, screening, processing, storage and dispensing of DHM for infant without access to MOM. They also offers possibilities for expressing and storage of MOM (Child Health Division, 2017).

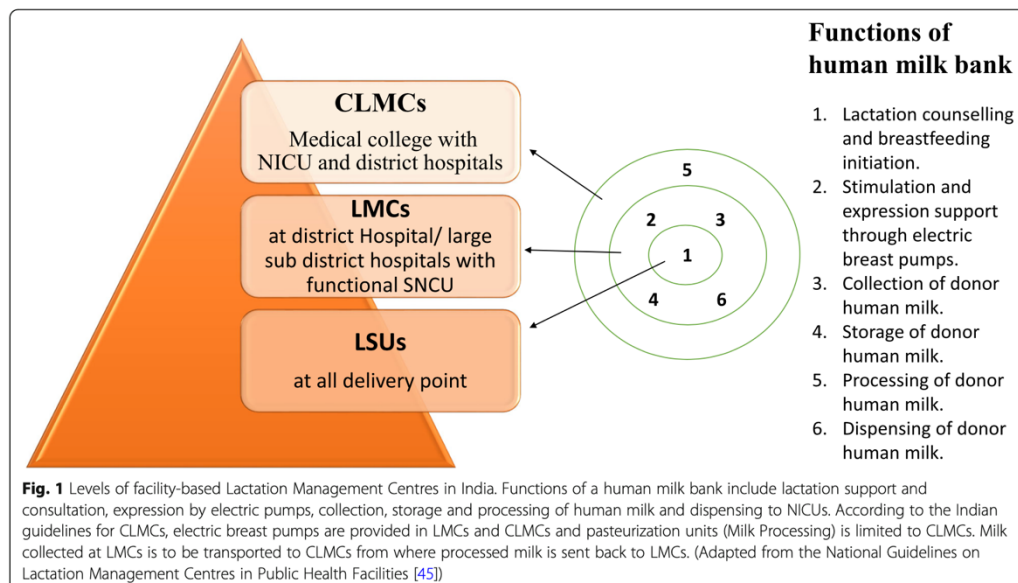


Figure 1: "Levels of facility-based Lactation Management Centres in India" (Bhasin, Nangia, Goel, 2020)

Social and cultural context of breastfeeding and lactation counselling

Reasons for mothers to seek lactation counselling vary with mother's circumstances. Traditionally in Indian culture, elderly female family members have an important role in caring for mothers during the postnatal period and are considered the main source of knowledge and the main supporters of the mother (Melwani et al. 2018). Although women may receive lactation counselling from health personnel, these elderly female family members have an important influence on breastfeeding practices (Laroia & Sharma, 2006).

As birth of a baby is a celebration for family and society, breastfeeding is strongly influenced by cultural and religious ceremonies, especially in Hindu communities. Many mothers discard colostrum, believing that it is harmful to the child (Laroia & Sharma, 2006). Pre-lacteal feeding such as honey, clarified butter (ghee), tea, animal milk, boiled water or ghutti (water mixed with honey and herbs) is instead given to the infant to stimulate meconium. This practice delays the initiation of breastfeeding and reduces the establishment and future success of breastfeeding (Laroia & Sharma, 2006; Mahmood, Srivastava, Shrotriya & Mishra, 2012).

Breastfeeding is one of the oldest practices recommended in the ancient Hindu Scriptures. However, there is increasing concern in recent years about the change of pattern of breastfeeding. A downward trend in breastfeeding has been seen in urban areas, especially among mothers with an improved socioeconomic status who can afford using artificial formula feeding for their infant. Most Indian mothers have some understanding of the superiority of human milk. However, advertisement of artificial formula milk has affected their perceptions. Behaviour change in breastfeeding can be achieved through existing health care systems if trained health workers provide lactation counselling to mothers and their families (Laroia & Sharma, 2006).

According to Wells & Dietsch (2014) disparities in maternal and infant health strongly depend on the person's class, wealth, place of residence and education. Mothers in rural areas access healthcare less than those in urban areas and professional lactation counselling to mothers in rural areas is limited.

Acceptance of milk donation

Acceptability of milk donations is closely related to cultural and religious concepts. In Turkey for example, no human milk banks are available because of ethical problems arising from religious beliefs and attitudes. Islamic prohibitions are seen as the most important factor. Infants who receive human milk from the same woman become milk siblings, and this creates worries regarding their possible marriage in the future, which is considered legally forbidden and/or unlawful among milk siblings according to Islam (Kardioglu, Avciapar, Sahin, 2018).

In Buddhism, Christianity and Hinduism on the other hand, sharing of human milk is not a problem; on the contrary, it is encouraged (Kardioglu et al., 2018). In India, providing donor milk for infants is an old tradition and has been practiced through wet nursing for generations (Laroia & Sharma, 2006).

An Indian study done in Bhopal, India on acceptability of human milk donations among mothers, found that most mothers were willing to donate, but to what extent this attitude would be reflected in practice if the issue arises is not known. The actual practices the authors argue, would be affected by the knowledge, attitude and behaviours of other family members (Melwani et al. 2018).

The impact of Covid-19

The Covid-19 pandemic caused by SARS-CoV-2 virus has created challenges for providing optimal care for mothers and infants. According to Breastfeeding Promotion Network of India (BPNI) (2020), there are concerns related to practicing skin-to-skin contact, rooming-in and breastfeeding by Covid-19 suspected and confirmed mothers.

As for now, there is no evidence of transmission of Covid-19 from mother to infant in-utero or through breastmilk (WHO, 2020a). Salvatore et al. (2020) emphasizes this and says that perinatal transmission of Covid-19 virus is unlikely to occur if correct hygienical precautions are undertaken. Allowing infant to room in with their mothers and direct breastfeeding are therefore safe procedures. UNICEF and WHO encourage suspected or confirmed Covid-19 positive mothers to initiate or continue with breastfeeding (Unicef, 2020; WHO, 2020a). Furthermore, mother and infant should be enabled to remain together to practice skin-to-skin

contact, especially immediately after birth and during establishment of breastfeeding, even if the mothers or their infant are suspected or confirmed Covid-19 positive (WHO, 2020a).

Rationale of the study

Human milk banking is a growing global phenomenon, and the medical and nutritional assets are well documented particularly for premature infants. According to a randomized control trial from Jaipur, India, lactation counselling through a Lactation Management Centre resulted in improved initiation, breastfeeding rates at discharge and follow-up. It concludes that lactation counselling is useful and that every opportunity of counselling should be availed to promote breastfeeding (Choudhary et al., 2017). Lactation counselling is also important in recruitment of milk donors and therefore seen as an important intervention in a human milk bank setup (Bhat & Adhisivam, 2018).

How lactation counselling and milk donations are perceived and experienced by lactation counsellors and mothers who have delivered prematurely is however less known and varies across social and cultural contexts. Hence this study investigates this issue in New Delhi where the prevalence of premature births is high, and the concept of human milk bank is established at selected tertiary level public health facilities.

Study objectives

The aim of this study was to explore the role of the National Comprehensive Lactation Management Centre (NCLMC) in strengthening feeding of premature infants in a tertiary care hospital in New Delhi, India. The specific objectives were:

- To explore the experiences of mothers with premature infants on lactation support and the motivation to donate mothers' own milk.
- To explore the experiences of lactation counsellors on lactation support and on guiding mothers with premature infants on milk donations.

Chapter 2: Methodology

The following chapter includes a description of the study context, as well as collaboration partners, study design, reflections of own position, data collection and data analysis.

Study context

Since the study aimed to explore the role of the National Comprehensive Lactation Management Centre (NCLMC), the study was carried out in New Delhi, India. India is a multi-cultural society with more than 20 principal languages and 225 dialects (Wells & Dietsch, 2014). Hinduism is the most followed religion in India with 79,8% of the inhabitants identifying themselves as Hindu. Furthermore, 14,2 % identifies as Muslim, 2,3% as Christian, and 1,7% as Sikh (Cultural Atlas, n.a.).

The country comprises 28 states and 8 Union territories. Diversity among the inhabitants is the nation's prominent characteristic. Each state and Union territories has a unique history, culture, demography, dress, festival and language (Know India, 2020). New Delhi is an urban district located in Government of the National Capital Territory of Delhi, also called National Capital Region (NCR). It is home to approximately 30 million inhabitants and it is the capital of India (Know India, 2020; World Population Review, 2020).

The study setting was Lady Hardinge Medical College and Kalawati Saran Children hospital (LHMC & KSCH) which is located in New Delhi, and together constitute a teaching institution under Ministry of Health & Family Welfare. LHMC & KSCH is one of the largest children's hospitals in Asia with 80 neonatal beds and 13000-14000 deliveries every year. The National Comprehensive Lactation Management Centre is located at LHMC and is run by the Department of Neonatology (OUH, 2016).

National Comprehensive Lactation Management Centre (NCLMC)

The National Comprehensive Lactation Management Centre (NCLMC) is a milk bank and lactation centre that offers lactation counselling and collect voluntarily donated human milk from mothers admitted to the affiliated hospital. The NCLMC is named in Hindi, 'Vatsalya Maatri Amrit Kosh', meaning 'a storehouse of mother's unconditional love and nectar'. It is the largest human milk bank and lactation centre available under the public sector in North India (Indian Bureaucracy, 2017). NCLMC follows the national guidelines for milk bank and

lactation centres (Child Health Division, 2017), and acts as the teaching, demonstration and training site for other milk banks under the Ministry of Health and Family Welfare, Government of India (Indian Bureaucracy, 2017).

Twelve lactation counsellors work in the NCLMC along with five additional staff. The main task for the lactation counsellors is to counsel mothers in lactation, both in the maternity wards, and in one-to-one counselling session offered in the NCLMC. On average, 180-200 mothers are counselled daily, of these approximately 60 is referred to the NCLMC for support with one-to-one counselling and breast pumping. Those who produce more MOM than their baby requires, may donate the surplus to the NCLMC. The donated milk is given to infants admitted to the neonatal intensive care unit at LHMC & KSCH, who do not have access to MOM. All donated human milk is being pasteurized (Bhasin, 2020). The NCLMC is open from 09:00-17:00 Monday to Saturday and have five available electric breast pumps for mothers to use during opening hours.

The NCLMC follows strict screening, processing, and dispensing guidelines to ensure the safety of DHM. Potential donors provide complete medical and lifestyle histories and must undergo blood tests. Donated human milk is pasteurized to kill any bacteria or viruses. Further, before DHM is dispensed, bacteriological testing is done by an independent lab to ensure safety (Bhasin, 2020).

Till March 2020 around 655 346 litre DHM has been dispensed (Nangia, 2021) and more than 3500 babies have had the benefits of receiving DHM as supplements or as a replacement of own mothers milk (Bhasin, 2020).

There have been significant changes in the daily intake of MOM, DHM and artificial formula in the NICUs at LHMC & KSCH since the opening of the NCLMC in June 2017. In 2016, before the NCLMC was established, 68% of the daily intake consisted of artificial formula, while 32 % of MOM. In 2019, the use of MOM had increased to 74,3% and artificial formula reduced to 20,8%. In addition, use of DHM was implemented as “gap-filler” to premature infant admitted to the NICU until their mothers were able to produce MOM, and consisted of 3,9% of the total intake (Figure 2) (Nangia, 2021).

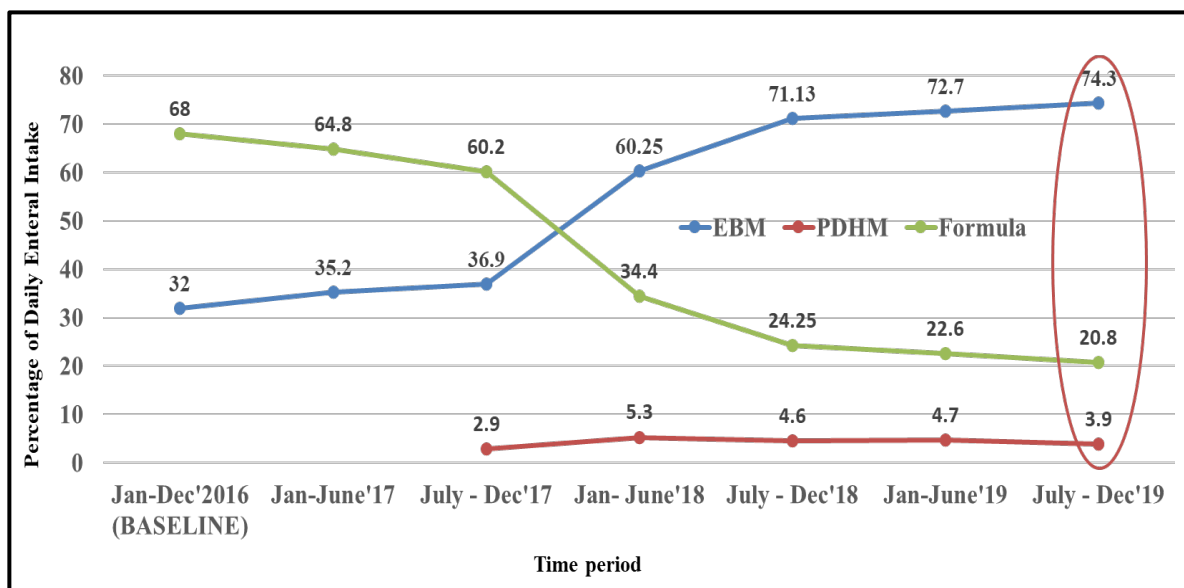


Figure 2: Daily intake of MOM, Pasteurized DHM (PDHM), artificial formula in the NICUs at LHMC & KSCH (Nangia, 2021)

Impact of Covid-19

The Covid-19 pandemic has had significant impact on the operation of the NCLMC. It has hampered the capability to provide sufficient DHM and challenged the lactation counselling sessions due to hygienic precautions. In April 2019, 24 085 litre expressed breast milk was donated to the NCLMC, while in April 2020 only 5 150 litre was donated (Figure 3).

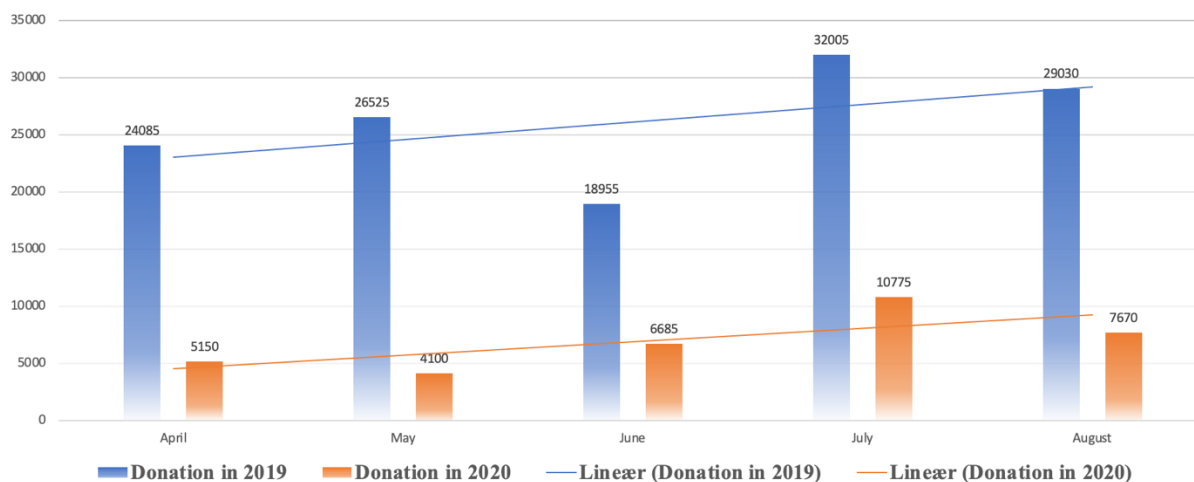


Figure 3: Human milk donations at NCLMC April 2019-August 2020 (Bhasin, Nangia, Goel, 2020)

The same reduction is seen in the amount of lactation counselling sessions. In 2019, the average counselling session per women delivered at LHMC was 8.0, compared to 5.5 in 2020. The reduced average of donation and counselling session can be attributed to the early discharge and home isolation of mothers amid Covid-19. However, LHMC has also experienced reduced

delivery rates at the hospital. In April 2019, 858 women delivered at the hospital compared with 478 in April 2020 during the pandemic (Figure 4). Travel restrictions and the fear of being Covid-19 infected at the hospital may be the cause (Bhasin, Nangia, Goel, 2020).

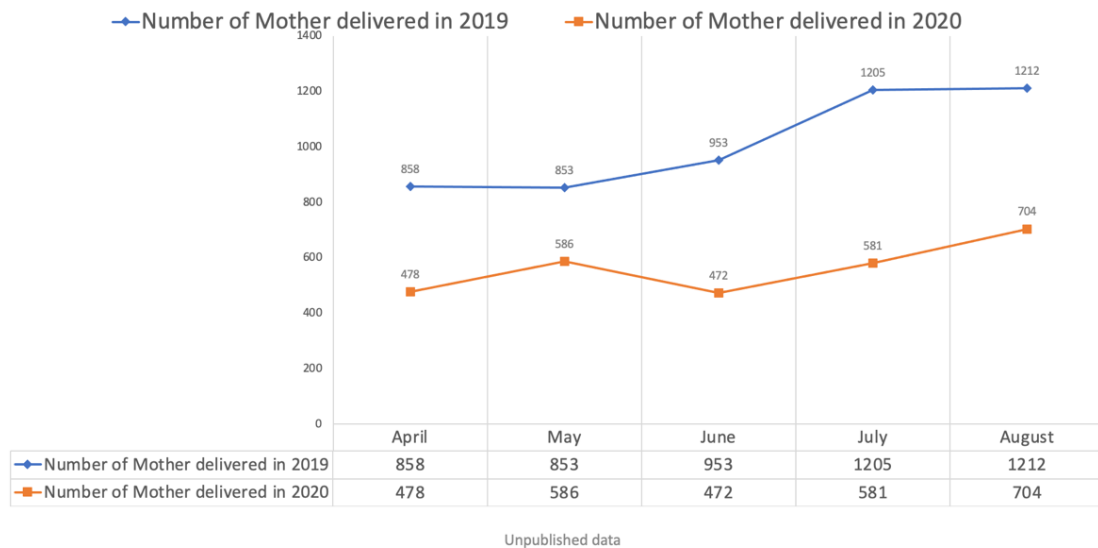


Figure 4: Numbers of deliveries at LHMC from April 2019 to August 2020 (Bhasin, Nangia, Goel, 2020)

Collaboration partners

This study was carried out in collaboration with ‘Oslo-Delhi: Improve Newborn Care Program’, which is a collaboration project between Oslo University Hospital in Oslo, Norway, and Lady Hardinge Medical College & Kalawati Saran Children’s Hospital (LHMC & KSCH) in New Delhi, India. The overall goal of the project is to improve the care of sick and premature infants, in line with evidence-based practice, in New Delhi, India. Furthermore, the project aims to provide Norwegian health personnel with experience in diagnosis and treatment of patients in these areas that exceed the exposures they will get in Norway. A long with this, the project intends to increase multicultural understanding within newborn health care" (OUH, 2020).

The collaboration project started in 2017 and is funded by The Norwegian Agency for Exchange Cooperation (Norec). Norec is an executive body under the Norwegian Ministry of Foreign Affairs and is a competence centre for international exchange that support international organizations that want to exchange personnel to learn and develop (Norec, 2020). The Royal Norwegian Embassy in New Delhi, India support the project by providing “gap funding”

channelled through the bilateral health cooperation Norway India Partnership Initiation (OUH, 2020).

A key component in the collaboration project has been the bilateral exchange program that placed Indian nurses and doctors in Oslo for training, and Norwegian nurses and doctors in New Delhi. However, due to the global Covid-19 pandemic, exchange of health personnel has been difficult to carry out the recent two years. Therefore, a comprehensive online program was started in January 2021 to ensure continuity and sustainability of the project goals.

Simple interventions such as focusing on improving hygiene, involving the parents in the care of the infants, and ensuring that all infants in the NICUs receive human milk have been the main focus areas during the years of collaboration. Statistics from LHMC & KSCH show that the mortality rate at the two neonatal intensive care units have been reduced from 11,03 % in 2016 (before the start of the project) till 5.6% in 2019 (Bhasin, Nangia & Goel, 2020).

Through the collaboration project the National Comprehensive Lactation Management Centre (NCLMC) was established at LHMC in 2017 funded by Oslo University Hospital, Norec and Norway India Partnership Initiative (OUH, 2020).

Study Design

A qualitative approach was used in this study. Qualitative approaches provide strategies for exploring experiences, practices, and phenomena in sociocultural worlds. It have an interest in what people do, and why, in the context of social relationships (Green & Thorogood, 2018), and offer an inductive inquiry suitable to discover ways in which people encounter and understand a phenomena (Moen & Middelthon, 2015). In this study the phenomenon of the feeding of a premature infant.

A major aim of qualitative research is to engage and understand the individual study participants experiences seen from their point of view (Moen & Middelthon, 2015). To do so, qualitative researchers pursue a holistic approach so that all parts are interpreted within the overall context. A basic premise in qualitative research is that the researcher and the study participants influence each other, and that the preconceptions and expectations of the researcher

influence the entire research process and should be discussed openly (Green & Thorogood, 2018).

In this study, in-depth interviews were used as method. What was first planned, was to go on field work to New Delhi to do participant observation and face-to-face in-depth interviews with mothers and lactation counsellors. However, due to the Covid-19 pandemic I was not able to travel, and I therefore had to drop participant observations and concentrate on the information attained through in-depth interviews. An in-depth interview is a special form of conversation that entails interpersonal interaction between active subjects. It aims to joint construction of knowledge through reflection and articulation (Moen & Middelthon, 2015). The in-depth interviews were conducted through the online platform Zoom, and with help from research assistants.

Recruitment and training of Research Assistants

As this study was conducted through 'Oslo-Delhi: Improve newborn care program', research assistants were recruited within the collaboration project. Due to the Covid-19 pandemic and the cancelled field work, I had to find assistants that I trusted to ensure quality of the study. The project coordinator, Maheshwar Bhasin, who is also the manager of NCLMC, acted as one of the research assistants. He has worked in the NCLMC since the opening in 2017 and have great knowledge about human milk banking. He helped planning the interviews, conducted the signed consent forms and helped with technical issues during the online in-depth interviews with the lactation counsellors. He is well known with the Ethics Committee for Human Research (ECHR) at Lady Hardinge Medical College & Kalawati Saran Children's Hospital (LHMC & KSCH) and therefore helped shaping the application form.

Sister Shalini Rawat, who is a staff nurse working in the neonatal intensive care unit at LHMC acted as the second research assistant in this study. Sister Shalini Rawat have been on exchange to Oslo University Hospital for six months through the collaboration project and is familiar with the Norwegian health care structure and culture. She also has great knowledge about breastfeeding, counselling of mothers and care of sick- and premature babies. She conducted the face-to-face interviews with the mothers in Hindi with supervision from me. Before the interviews took place, I presented Sister Shalini Rawat with a thorough overview of the study objectives. I also briefed her about qualitative research, methods of questioning, and the

importance of observations and recording notes about body movements, silences, and long pauses, surrounding area, emotions and so on. She was also trained in how to operate the audio-recorder to ensure that it worked correctly during the interviews.

A professional translator was hired to translate and transcribe the interviews with the mothers from oral Hindi to written English. My co-supervisor, Dr Sushma Nangia oversaw finding the right person and ensured that the transcripts were done in the right manner.

Dr Sushma Nangia, Maheshwar Bhasin and Sister Shalini constituted my local research team. We kept a close dialogue during the whole process of data collection and guided each other along the way.

Recruitment of study participants

A combination of purposeful and convenience sampling strategy was used to identify relevant study participants. There were twelve lactation counsellors working in the NCLMC at the time of recruitment, however only eleven was asked to join the study because one of them were newly posted in the NCLMC and was in training. With help from the research team, the potential study participants were approached and explained the purpose of the study in detail. Since these interviews were planned to be held in English, an eligibility criterion for the study participants was that they could speak English well enough for us to hold conversation on the chosen topic. Another eligibility criterion was that they had to be employed at Lady Hardinge Medical College (LHMC) or Kalawati Saran Children's Hospital (KSCH) and posted in the NCLMC, working as lactation counsellor. The research team mapped this out in the recruitment process. All the eleven lactation counsellors were willing to participate in the study and were recruited for interviews.

Mothers who had received lactation counselling and donated MOM to the NCLMC was also recruited with the help of the research team. Eligibility criterion for the mothers, was that they had to have received lactation counselling in the milk bank as well as have donated MOM at least once. Another eligibility criterion was that they were able to speak Hindi since the interviews were planned to be held in Hindi. Since Sister Shalini Rawat, who conducted the interviews with the mothers, work in the neonatal intensive care unit (NICU) at LHMC. Potential study participants got recruited from this NICU itself. This was due to both time limit

and Covid-19 restrictions such as Sister Shalini Rawat was not able to enter other units. All recruited study participants had therefore their baby admitted to the NICU at LHMC. Before the interviews took place, the study participants were explained about the purpose of the study in detail and that it was voluntary to participate. Six mothers in total were recruited for interviews.

In the recruitment process, the local research team made sure that the selected study participants did not have serious mental or emotional instability. If this were the case, these would have been excluded.

Characteristics of study participants

The study participants were of two types; lactation counsellors working in the NCLMC, and mothers who had received lactation counselling and donated own mothers' milk to the NCLMC. A total of seventeen study participants were recruited for the two components of the study, eleven lactation counsellors and six mothers.

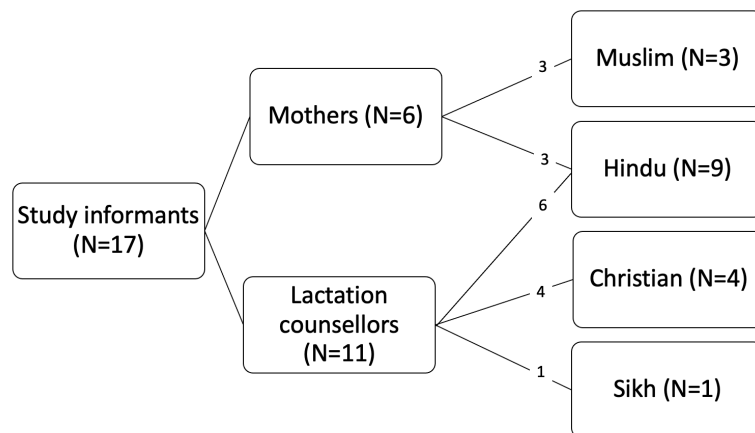


Figure 5: Overview of the study participants religious status

All the lactation counsellors had diploma in nursing and two of them had additionally master's degree, one in medical surgery and the other in psychiatry. In the time before they started working in the NCLMC they all had worked in other departments both medical and surgical, at Lady Hardinge Medical College & Kalawati Saran Children's Hospital (LHMC & KSCH). Most of them had either experience from working in a maternity ward or at a paediatric ward. They varied in age from 29 to 51 years. Three of them were employed at KSCH, while eight was employed at LHMC. Number of years worked at either KSCH or LHMC varied from

2 to 28 years, however, mean duration was 16,5 years. All of them had been posted in the NCLMC for at least one year at the time of the interviews. Five had been posted in the NCLMC since the opening in June 2017. Nine had children and personal experience with lactation and breastfeeding. All were married. Religion varied between the lactation counsellors. Six identified themselves as Hindus, four as Christian and one as Sikh (Figure 5). All of them lived in National Capital Region, however seven of the lactation counsellors originally came from NCR or Haryana which is in North India, three study participants from Kerala in South India and one from Madhya Pradesh in Central India. Further details of each of the lactation counsellor is not added in this thesis to ensure confidentiality.

The mothers varied in age from 19 to 29. Two of them had bachelor’s degree and worked as teachers, while four had high school or higher secondary education level and were housewives at the time of the interviews. Three of them identified themselves as Hindus and three as Muslims (Figure 5). All of them delivered prematurely (before week 37). Four of the mothers were primipara. One of them delivered twins. The remaining two mothers were multipara. All were married and lived and came from NCR, North India. See Table 1 for further details.

Overview of mothers as study participants for in-depth interviews									
#	From where in India	Mother tongue	Religion	Age at interview	Education level	Occupation	Marital status	Number of children	Gestational age of admitted baby (GA)
1	Delhi	Hindi, Urdu	Islam	27	8 th standard	Housewife	Married	3	27+5
2	Delhi	Hindi, Urdu	Islam	23	12 th pass	Housewife	Married	1	30+1
3	Delhi/Bihar	Hindi	Hinduism	19	12 th pass	Beautician, housewife	Married	2 (twins)	36+2
4	Delhi	Hindi	Islam	22	10 th pass	Housewife	Married	1	29+3
5	Delhi	Hindi	Hinduism	29	Master	Teacher	Married	2	33+3
6	Delhi	Hindi	Hinduism	28	BA history	Art teacher	Married	1	28+2

Table 1: Overview of mothers as study participants for in-depth interviews

Data collection

Data collection and other activities including planning, obtaining ethical approval at Lady Hardinge Medical College & Kalawati Saran Children's Hospital (LHMC & KSCH), transcription, and translation of data for the study was conducted from 9th October 2020 – 15th January 2021. See Appendix F for timeline of the data collection.

Semi-structured interview guides (Appendix D & E) were developed before the study began and were used for the in-depth interviews. The interview guide evolved as the interviews went on, based on some of the answers from the study participants. I added some questions after getting a better understanding of the cultural norms, such as how the mother-in-law contributed during the postpartum period. Each interview was of an individual nature. However, the content was mainly around their experiences of being a mother/lactation counsellor in the NCLMC, and on how they faced challenges and responded to them. This was related to both practical and socio-cultural factors.

Online in-depth interviews with lactation counsellors

The interviews with the lactation counsellors took place over Zoom and were held in English by me. In the beginning we faced some challenges with internet connection but after trying several locations and switching on and off the WI-FI, we managed to find a place in the NCLMC that was quiet enough, with good connection to do the interviews. I audio-recorded each interview with consent from the study participants. With help from one of the research assistants, Maheshwar Bhasin, we planned the interviews according to when it was the best timing for the lactation counsellors, usually after their daily rounds to the units. Each interview lasted between 40-60 minutes. To create a confidential atmosphere, I made sure that only the study participant and myself were present during the interviews. Each interview started by me introducing myself and the project, and then we spent a few minutes on small talk about what they like to eat, family and how they are coping with the Covid-19 pandemic. I also asked them about socio-demographic facts such as when they got married, how many children they had and so on. This helped me to establish rapport (REF) with the study participants before I started on the interview guide. I referred to the study participants who were older than me as “Didi”, which means elder sister/women in Hindi and is a sign of respect.

I have met several of the lactation counsellors before because I am involved in the collaboration project (see 'Reflections on researchers' position' for further details). During the interviews I

noticed that those who did not know me referred to me in a more formal way using respectful words such as “Mam”, “Sister” or “Jii”. This is important to notice because this might have affected the outcome of the interviews.

Most of the lactation counsellors were able to communicate in English without any problems. Some of them used Hindi words in between, but since I can understand a little Hindi, I was able to translate it to English in the transcripts. Also, in some interviews where I felt that the language barriers interrupted the flow, I skipped some questions and tried to focus on the topics they were comfortable talking about. I found that some of the study participants were not always elaborating on the answers as much as I had hoped, even when I tried to probe them. I changed the approach slightly with each study participant, depending on the situation. To be able to remember the whole scenario, I took notes about emotions expressed and body language during the interview.

Face-to-face in-depth interviews with mothers

Since most mothers admitted to Lady Hardinge Medical college (LHMC) do not speak fluent English, we decided that Sister Shalini Rawat, one of the research assistants would conduct the interviews with the mothers in Hindi. Along with my supervisors and the research team, we discussed back and forth if I should join in on the interviews over Zoom, but we concluded that it would be best if Sister Shalini Rawat conducted them alone because an observer would potentially be a distracting element, especially if I was to join on Zoom and needed translation.

Before Sister Shalini Rawat conducted the interviews, we went through the interview guide, and I explained to her that creating an informal conversation on the study topic might help the study participant to talk freely on the chosen topic. Sister Shalini Rawat and I cooperated well throughout the interview process. She asked questions and shared how she experienced it. This facilitated an active role for me supervising her and an opportunity to share my thoughts.

The interviews were held at a convenient time and place for the individual study participant. Sister Shalini Rawat made sure that they were alone in the room during the interviews. Each interview lasted between 30-45 minutes. With consent from the study participants, an audio recorder was used so it would be possible to transcribe and translate the interviews verbatim afterwards. Some of the study participants were curious about whom Sister Shalini Rawat conducted the interviews for, and therefore I got video-called so they could say hi and they could see me. This was also a good way for me to get an impression of the interview situation.

Sister Shalini Rawat made notes regarding emotions expressed, and body language during the interview. She also wrote a couple of sentences about how she experienced each interviews in terms of how open the study participants were and their emotional state. This was a very good tool for me when analysing the data.

The audio record from the first interview was shared with my co-supervisor, Dr Sushma Nangia because she was able to understand the interview in Hindi and made sure the interview-process was in accordance with how we wanted it to be conducted. She gave Sister Shalini Rawat constructive feedback and shared her thoughts on the interview with me.

The content in the interviews were mainly focusing on mothers' experience with delivering prematurely and how it was for them to establish lactation with support from the NCLMC and on motivational factors for donating MOM.

Ethical and Data Management Approval

Ethical approval from The Ethics Committee for Human Research (ECHR) at Lady Hardinge Medical College & Kalawati Saran Children's Hospital (LHMC & KSCH) was received on 6th of November 2020. The document is scanned and attached in Appendix E. Ethical approval was also requested from REC west (Regionale komiteer for medisinsk og helsefaglig forskningsetikk), but the study did not require such approval to be carried out.

Approval from the Norwegian Centre for Research Data (NSD) was requested and received on 24th of August 2020 with reference code: 342925. The study has also been registered in RETTE, System for Risk and Compliance at University of Bergen with the same reference code as NSD.

Ethical Considerations

Informed consent was taken from all the study participants. The consent form was written in both English and Hindi. All the study participants were able to read it. The main points in the consent were verbally restated to ensure that the content was understood. The study participants were informed that it was voluntary to participate and that they were free to withdraw without any explanation or consequences. The mothers were also informed that their participation would not have consequences for their infant. Recording the interviews was important to get complete narratives and to validate the translation, especially in the interviews with the mothers that I, the main investigator did not attend. All study participants agreed to get audio recorded. The consent forms are attached in Appendix A & B.

All audio files, consent forms and notes from the interviews were encrypted and was kept safe in a password protected computer file until the end of the project. All data got de-identified to ensure confidentiality. Confidentiality was also ensured when audio files from the interviews with the mothers were given to the person who translated and wrote the transcriptions. Audio files were anonymized, and signed consent forms and notes were sent directly to me. This was closely followed up by my co-supervisor Dr Sushma Nangia.

The ethical principles for medical research involving human subjects stated in 'Declaration of Helsinki' by the World Medical Association were followed by the research team throughout the study (WMA, 2018).

Data analysis

Data analysis for this study has been a continuous process throughout the course of the study. Preliminary analysis was done during the data collection. Based on the responses, I added some questions to the interview guides and changed the interviewing approach to get the best data quality. I also had a close dialogue with Sister Shalini Rawat, who conducted the interviews with the mothers, to ensure that the questions were relevant according to how the mothers responded to them.

Transcription and translation

All the digitally recorded interviews with the lactation counsellors were transcribed by me right after each interview. This gave me an insight into the findings of the interviews early in the process. I included the observation notes I took during the interviews in parenthesis in the transcript, because it would help me to remember my own experience along with the transcript when analysing it. When I transcribed the first interview, I noticed there was some information the study participants shared that I did not catch during the interview-process. I was probably too concentrated on the question I was about to ask and did not fully grasp everything that was said. Listening to the audio record along with transcribing it therefore became an important tool for me in further development of the interviews and later in analysis.

Interviews with the mothers got transcribed and translated from Hindi to English by a hired translator. My co-supervisor Dr Sushma Nangia strictly made agreement with the translator

regarding how we wanted the finished transcripts to be. The finished transcripts were in Microsoft Word format. Sister Shalini Rawat, who conducted the interviews with the mothers, cross checked the transcriptions to ensure that they represented the same content as the actual interviews.

Systematic text condensation

Systematic text condensation by Malterud (2012) was used when analysing the data. The method represents a pragmatic approach, focusing on the experience of the participants as expressed by themselves, rather than exploring possible underlying meaning of what was said. It offers a process of intersubjectivity, reflexivity, and feasibility, while maintaining a responsible level of methodological quality (Malterud, 2012). The analysis procedure consisted of the following steps:

1) Total impression – from chaos to themes:

First, it was important to get an overview of the data. I read the transcript several times to get a general impression of the whole, looking for preliminary themes associated with the objective of the study. This was especially important with the transcripts from the interviews with the mothers, as I did not conduct the interviews myself and was not as familiar with the content as I was with the interviews with the lactation counsellors. As suggested by Malterud (2012), I tried to bracket my preconceptions about infant feeding for premature infants, and tried to encounter the data with an open mind. I identified six preliminary themes as they intuitively emerged during the reading of the interview. As suggested by Malterud (2012), I did a new review of the transcript and decided on three preliminary themes for further analysis. These preliminary themes became the starting point for analysis the data.

2) Identifying and sorting meaning units – from themes to codes:

The second step was about identifying *meaning units*. A meaning unit is a text fragment containing some information about the research question (Malterud, 2012). Once the interviews were reviewed and the meaning units identified, they were sorted into codes. As explained by Malterud (2012), the coding implied decontextualization, where part of the text was removed from the original context for cross-case synthesis with the themes as “road signs”. The coding was done by marking the different meaning units with different colours, according to the type of group they currently belonged to. These meaning units was then copied and sorted in

different piles. I tried the whole time to have the study objectives in my mind when doing the codes. However, during this step, I lost some direction and ended up with a lot of irrelevant material that did not answer my study objectives. According to Malterud (2012), creativity will be beneficial when working inductively. With this in mind, and guidance from my main supervisor. I ended up sorting all the meaning units all over again and reconsidered the codes according to what was relevant for my study objectives.

3) Condensation – from code to meaning:

The third step of analysis, implied systematic abstraction of meaning units within each code groups established in the second step. I reduced my empirical data to a decontextualized selection of meaning units sorted thematic code groups. Each of the code groups were taken for a further abstraction by condensation of content. The condensate represented a unifying text from the content of the meaning units of this subgroup (Malterud, 2012). For each condensate, I added a quote that illustrated the point I wanted to make.

4) Synthesizing – from condensation to descriptions and concepts:

In the fourth step of analysis, the pieces got put back together again and the data was re-contextualized. The three preliminary themes identified in step one, became the main themes for the findings, while the categories became sections (Table 3). I used the condensate to write up an analytical text for each code group, together with quotes that illustrated the findings. By going back to the transcripts and reading through the interviews one more time, I ensured that the analytical text written in my findings contained the essence of what the study participants had said (See example in table 2).

Meaning unit	Condensed text	Code	Category	Theme
“My milk was produced in surplus; it was more than what my baby needed. It was getting wasted. I thought that instead of wasting, it could have been useful for some other baby.” (Woman, P3)	Taking advantage of the milk produced in surplus instead of wasting it	Motivational factors for donations	Taking advantage of the surplus	Donating own mothers’ milk

Table 2: Example of systematic text condensation used in the analysis of data

Themes	Category
Supporting a mother with a premature infant	Threatened motherhood Creating a platform where mothers feel seen Handling customary expectations
Feeding a premature infant	Establishing milk production for the premature infant 'Donor human milk is meant as gap filler'
Donating own mothers' milk	'It's in our culture to share' Taking advantage of the surplus Act of solidarity

Table 3: Mothers and lactation counsellors experiences: Themes & categories

Reflections on researcher's position

In qualitative research it is crucial to identify own pre-existing beliefs, thoughts, and values towards the study topic. According to Malterud (2001), awareness on such biases enables us to guard against our influence in order to produce unbiased and fair account of the study.

I have a bachelor's degree in nursing and have experience from working at different neonatal intensive care units in Norway. I have also participated in the collaboration project between Oslo University Hospital and Lady Hardinge Medical College & Kalawati Saran Children's Hospital (LHMC & KSCH), and I spent a year (in 2017-2018) working as a nurse at the neonatal intensive care units at LHMC & KSCH in New Delhi, India. The NCLMC was established during my time in New Delhi, and I am therefore well acquainted to the practices and routines in the NCLMC. As for now, I am still involved in the project through my position as a project advisor at Department of Global Health at Oslo University Hospital. I am aware of the positive changes that have taken place at LHMC & KSCH during the collaboration project, and how these changes have affected maternal and child health at LHMC & KSCH. There is a possibility that some preconceptions may have been formed during my time as a participant in the project and as an advisor at Department of Global Health, and that they might have affected the study. In order to deal with such preconceptions, transparency is essential (Malterud, 2001) and I have tried to describe my dual role as a project advisor and a researcher. I have been very much aware that tensions between these roles could complicate the study and have made an effort to develop neutral interactions and not display any personal biases.

An advantage of being involved in the collaboration project is that I have to a certain extent an 'insider' perspective due to earlier experiences in the project and in the hospital. This 'insider'

perspective is important for producing an account of a social setting that is faithful to the perspectives of the study participants (Malterud, 2001). However, I am still an 'outsider' in the Indian society and culture. The distance of an outsider, is needed to discover the taken for granted routines, practices, and knowledge of an insider. I was thus at an added advantage to obtain both an insider and an outsider perspective and knowledge while striving to maintain the appropriate detachment (Green & Thorogood, 2018).

Chapter 3: Theory and Concepts

In this study, two theories and concept will be used to understand and discuss the findings. These concepts are described below.

Health literacy

Health literacy is a multidimensional concept which is becoming increasingly important for social, economic and health development (Kickbusch, 2001). WHO (2009) define health literacy as:

“Cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information which promote and maintain good health”.

According to Nutbeam (2006), improving health literacy involves more than transmission of health information, even though this will remain a fundamental task. Helping people to develop confidence to act on the knowledge and the ability to work with and support others will be best achieved through community-based educational outreach and through personal forms of communication (Nutbeam, 2006).

Nutbeam (2006) suggests a model that distinguishes three levels of health literacy. Level 1, *Functional health literacy*, refers to the basic understanding of factual health information. Level 2, *Interactive health literacy*, reflects more advanced cognitive and literacy skills joined with social skills to improve an individuals’ personal capacity for integrative communication. Level 3, *Critical health literacy*, is when the individual critically can analyse and apply health information for the sake of greater control over life events and situations. Through this model health education can be directed through achieving change in the social, economic and environmental determinants of health which may benefit the health of whole populations, along with programs directed at individual lifestyles and health system use (Nutbeam, 2006).

The theory of health literacy will help illuminate how the mothers in this study understand their situation of providing MOM to their premature infant, and how the lactation counsellors approach the mothers according to the mothers’ level of health literacy.

Authoritative knowledge

Jordan (1997) speaks of the concept of authoritative knowledge as,

“The knowledge that participants agree counts in a particular situation, that they see as consequential, on the basis of which they make decisions and provide justification for courses of action. It is the knowledge that within a community is considered legitimate, consequential, official, worthy of discussion, and appropriate for justifying particular actions by people engaged in accomplishing the task at hand”.

The constitution of authoritative knowledge is an ongoing social process that builds power relationships within a community of practice. It comes in such ways that the participants relate to the current order as a natural order as the way things are. Authoritative knowledge does not have to specifically come from people in an authority position. People in an authority position are members of a community or practice, where they will share the local version of authoritative knowledge with other members. It is the local production and display that account for their position. However, in the medical field, authoritative knowledge is legitimized and hierarchy distributed and limited to the authorized staff (Jordan, 1997).

Authoritative knowledge is persuasive because it seems natural, reasonable, and consensually constructed. For the same reasons it can carry with its possibilities for powerful sanctions, ranging from physical coerciveness to exclusions from the social group. However, people not only accept authoritative knowledge, but also are unselfconsciously and actively engaged in its routine production and reproduction. The power of authoritative knowledge is that it counts, not that it is correct (Jordan, 1997).

Jordan (1997) question how we can move from a situation in which authoritative knowledge is hierarchically distributed into a situation in which it is, by consensus, horizontally distributed.

The theory of authoritative knowledge is commonly used to generate and define the field of anthropology of birth (Jordan, 1997), but in this study it will be used to understand how the lactation counsellors impart knowledge to the mothers in the counselling sessions.

Findings chapter 4, 5 and 6

In this section, I will present the findings of this study in three chapters: supporting a mother with a premature infant; feeding a premature infant; and donating own mothers 'milk. The findings are presented with the perspective of how mothers who have delivered prematurely experience infant feeding, including cultural interpretations, and what premises the lactation counsellors put into guiding and supporting the mothers. As presented earlier, there were two groups of study participants. One group represented mothers who had delivered prematurely and had received counselling from the NCLMC and donated MOM, and the second group included lactation counsellors who work in the NCLMC.

The study participants used the terms “baby” and “milk bank” when explaining their experiences. I have however chosen to use the terms “infant” and “NCLMC” in the explanations of the findings. The mothers have been given a fictive name in the description of the findings.

Chapter 4: Supporting a mother with a premature infant

Giving birth too early and getting a premature infant is usually an unexpected and often frightening event. In addition to worries related to the health and survival of the infant, feeding is a huge challenge. Breastfeeding, which should have been a natural process after birth, become interrupted partly because premature infants have a weak sucking reflex and partly because the breast tissue of the woman may be underdeveloped. This chapter aims at exploring how mothers who have delivered prematurely experience becoming a mother to a premature infant with its challenges related to infant feeding, and how the lactation counsellors go about guiding and motivating them to cope with the situation.

Threatened motherhood

For the participating mothers, all the expectations of becoming a mother involved being able to breastfeed. However, due to the premature delivery they all struggled to live up to these expectations. Hence the disappointment of not being able to do so was great. Two of the mothers, multiparous, had experience with breastfeeding their other children. One of them, Bhavna, explained how breastfeeding was tied to motherhood and why it was so important for her. She said:

“How can one be a mother if she can't feed [breastfeed] her own baby? There is a lot of struggles in life, and I want my child to be a fighter, therefore, I have to provide him my milk.” (Bhavna, mother, P5)

She was able to establish lactation and provide MOM to her infant, but heavily felt the separation from the baby that prevented her from breastfeeding:

“When milk is produced it is a great feeling, but the problem in my case was that my son was not with me. I was helpless; even if I wanted [to breastfeed], I could not have done anything since my baby was in Nursery [NICU].” (Bhavna, mother, P5)

The pressure to perform as a mother producing milk for her infant concerned Meena, a primipara mother who compared her achievements with other mothers with premature infants. She felt shameful for not being able to produce enough MOM. She said:

“I wasn’t able to produce milk and the nurse told me that I had to expel it as my baby was premature and only this milk could save his life. I used to feel embarrassed since I could only send 4 drops of milk and my baby needed much more.” (Meena, mother, P6)

All the expectations connected to breastfeeding and motherhood could result in significant stress. Hence receiving practical and emotional support to establish and manage lactation and to cope with the feelings of not being ‘mother enough’ was necessary.

Creating a platform where mothers feel seen

Lactation counselling was offered to the mothers and involved emotional support to make sure that they felt seen. Recognizing their stressful situation of being a mother to a premature infant and showing affection to it was something the lactation counsellors aimed for. One of the lactation counsellors explained how emotional support was important to secure the mothers to start the process of establishing lactation:

“Many of the mothers we meet are in difficult situations (...). When the baby is being taken away from them, they feel very hopeless. So, we must meet them on that, if not they will not want to come to milk bank to do pumping and so.” (Lactation counsellor, P1)

Another lactation counsellor highlighted how emotional support is located at the core of counselling:

“We become good counsellors when we have the confidence to meet the mothers in their vulnerable situation” (Lactation counsellor 5)

The link between stress and lactation challenges was emphasized:

“If the mother is stressed, the amount of milk she is producing will decrease. Easy as that. They need to take rest, have a good sleep, take proper diet and avoid stress. But many times, they are not listening because they are too busy trying to get their lives around. I also try to counsel the husband and the mother-in-law. I am telling them that a stressful mother creates problems for the baby.” (Lactation counsellor, P7)

For Meena the stress she faced got released through daily conversation with the lactation counsellors:

“It was good, and I followed their instructions. Apart from milk production and feeding, they guide us on improvement of over-all health. I have been here for 1,5 months - away from home, and the good thing is that they even help in dealing with mental health issues like depression. We have a lot of fun together. They tell us to chill out and focus on the baby and not to think about anything else. We can share our personal life with them, they want to hear us out, they can gauge that we are depressed by looking at our faces, they even advise us not to take stress as it can impact milk production. It is a wonderful feeling being there since we can speak our heart out. We have good time together and we are comfortable with the nurses.” (Meena, mother, P6)

However, in a time where social distance was practiced and hygienical precautions such as the need to wear personal protective gear due to the ravaging Covid-19 pandemic was mandatory, it was experienced as challenging and created communication problems. The contact between the mothers and lactation counsellors got disrupted and the conversation did not flow as naturally as they had experienced before the pandemic. One of the lactation counsellors explained:

“It is very exhausting to counsel when wearing mask and PP kit [personal protective gear]. It is very hard to hear them [mothers] because they are also wearing mask. Counselling is about connection. How can I get that when it is even hard to hear what they are saying?” (Lactation counsellors, P7)

Another lactation counsellor commented:

“It is frustrating because they cannot hear us. It is like putting a barrier between the patient and me.” (Lactation counsellor, P10)

Despite the challenges that came with the Covid-19 pandemic, the lactation counsellors aimed for creating fruitful conversations with the mothers, where they could ask questions of interest:

“They [mothers] do and should ask questions. I try to answer it the best I can. I think that make them feel seen. That I listen to what they ask. If I was just talking and talking and no one asked question, what is that for use? Then they will not be connected, and the counselling is not of use, because will they understand what I am telling? I am trying to create a conversation where information goes both ways. That is the main job I have as counsellor, creating a platform where mothers feel seen at the same time as I can counsel her to take good choices.” (Lactation counsellor, P9)

Handling customary expectations

Even though being attentive to the mothers’ individual situation and to her suffering was considered vital, disseminating knowledge on lactation, and guiding the mothers on how to establish lactation in the absence of a suckling infant was their main task and overall concern. However, one challenge was that knowledge and practice did not always represent the same. One of the lactation counsellors explained:

“I ask them[mothers]; “do you know the importance of human milk?” Some says “yes”. Then I always ask; “but have you given it to the child?”, because their words are not always what they do and many times, they are saying; “No I have not yet, because sister, I have not eaten anything yet, so how will the milk come?”. (Lactation counsellor, P9)

Mapping out cultural perceptions, and how they influenced the feeding practices was essential for securing MOM for the premature infants.

‘They do not think colostrum is important milk’

Most of the study participants gave complex accounts of how cultural and religious rituals influenced the way of thinking about infant feeding. These perceptions were tied to spiritual protection of the mother and infant and gives an important backdrop for the infant feeding challenges experienced in the hospital. One common perception mentioned by most of the lactation counsellors was that colostrum was in many communities seen as impure and deleterious for the infant, hence, to be discarded. One of the lactation counsellors explained:

“It [colostrum] is very little in amount so mothers feel that is not sufficient for the baby. Secondly, they don’t think it is important milk. In Indian culture earlier it was said that the milk produced the first three days is dirty milk.” (Lactation counsellors, P1)

Another lactation counsellor explained how continuous counselling was essential for the mothers to be able to change the practice of discarding colostrum:

“This [discarding colostrum] is a main misconception which is happening in our community. It won’t change within one or two days, it is a long process. Again, and again counselling. If we counsel one day, the next day they will do the same ritual again, so continuous counselling is a crucial thing here.” (Lactation counsellor, P9)

Even though discarding colostrum might be common in the community setting, none of the participating mothers had discarded the first milk, even if they perceived it insignificant in amount. All of them had heard about the benefits of colostrum at the time of the interview; most of them from the NCLMC. Amina, a primipara who delivered in week 30, had read about colostrum on the internet before delivery, and was aware that it should be given to the infant already one hour after birth. Despite the knowledge, her infant did not receive it:

“I was operated [caesarean section] and I was lying [in bed] for twenty hours. My child was in the Nursery [NICU] and I had told my husband to send the colostrum for my baby, but my baby’s condition was also such that she could not receive it.” (Amina, mother, P2)

When she was asked if she started hand expression to expel colostrum right after birth, she said that she had enough with handling the situation she was in and did not think of doing so. It was the unforeseen situation of delivering prematurely and going through a caesarean section that created a delay in establishing lactation, hence her infant did not receive colostrum as she had planned:

“I did not have a thorough knowledge about it [how to establish lactation without breastfeeding] because I had not experienced all of this personally. Now since I have experienced it myself it is a huge difference”. (Amina, mother, P2)

The mothers undergoing caesarean section did not receive enough follow-up in the time after the surgery. Even though the lactation counsellors went on rounds and had made a system for tracking which mother needed counselling, these mothers could fall out of the priority list:

“Every day we are checking yesterday’s counselling chart to ensure to follow-up those who came for counselling yesterday. Most of mothers do as we say and come to milk bank, but some of them don’t, so we are following them up, and again counselling them about why they should come to milk bank.” (Lactation counsellors, P5)

Amina’s situation emphasizes the importance of having available and present lactation counsellors to guide the mothers delivering prematurely, especially those undergoing caesarean section. Even though they have knowledge on infant feeding, they also need the support and guidance to ensure that the mothers act upon the knowledge they receive regarding best optimal practice on infant feeding.

Honey is the first thing given to the child

Another challenge that the counsellors addressed was the practice of giving pre-lacteal feeds based in the idea that colostrum is impure. It is given before initiating breastfeeding and can according to the study participants consist of honey, ghutti, jagary, water or cow’s milk. One of the lactation counsellors explained the idea behind pre-lacteal feeds:

“After the baby is born, they use to give some honey or ghutti. They think that the ghutti will be very good for the baby, and that the ghutti will protects from cold and makes baby healthy and strong. We are trying to discourage them that it is not good practice, but yes, ghutti is very much practiced in India”. (Lactation counsellor, P3)

In Bhavna’s family, pre-lacteal feed had been practiced in several generations:

“My grandmother had given me pre-lacteal feed; similarly, my husband’s grandmother had also given it to him. My mother-in-law gave it to my elder son. I don’t know the logic behind it, but the custom persists.” (Bhavna, mother, P5)

Some of the study participants pointed out that these cultural practices were mostly prevalent in Hindu communities. However, for Ruhi, a Muslim woman, pre-lacteal feeds were a known practice in her communities as well. She said:

"I belong to a Muslim community and in our community, honey is the first thing we give to the child. We give honey to our babies because Prophet Muhammad gave dry dates to a baby, which are made soft, and the child licks it like honey, and it holds a lot of significance in our religion." (Ruhi, mother, P1)

Even though many of the mothers were used to give pre-lacteal feeds such as honey, they were not allowed to do so as long as their infant were admitted to the NICU. The health personnel in the NICU had the right to decided what to feed the infants, and the mothers had to follow their guidance. Bhavna emphasized this and said:

"The younger one is in the hospital [NICU], so only doctors are giving him milk." (Bhavna, mother, P5)

However, even though pre-lacteal feeds were not allowed in the NICU, the practice of mixed feeding would persist once the infant had returned home. One of the lactation counsellors emphasized this pointing out how complex the encounter between knowledge and practice is, and how challenging it is to handle the tension. She said:

"Honey would never be given in Nursery, but you never know what will happen when baby get discharged. That is why counsel them on this is important, so they don't start bad practices when they get home. But many don't listen." (Lactation counsellor, P3)

The lactation counsellors tended to believe that understanding the importance of MOM was closely connected to the mother's level of education:

"Counselling an educated person is different. You don't need so much time, but if that mother has already made up her mind, she won't listen to anyone or do it. Counselling an illiterate person, all we are saying will be new to them, so it takes time. ... It is like

speaking a new language to them, so again and again we have to go and the same things have to be told.” (Lactation counsellor, P9)

After gaining knowledge about infant feeding and best practice, Tamanna reflected on the practice of pre-lacteal feeding as an uncritical act with too little attention to the infant health. She said:

“In my point of view there should be logic behind whatever we do, and we should be careful about the hygiene for both the baby and the mother because many times people don’t care about hygiene while following those rituals. We are so absorbed in following our customs and traditions that we ignore hygiene.” (Tamanna, mother, P4)

These practices were strongly influenced by relatives, especially mother-in-law.

‘Mother-in-law have their own set-up-rules’

In most of India, mothers-in-law have an important role in guiding their daughter-in-law and making decisions on how to feed the infant. According to some of the study participants, being a daughter-in-law consisted of fulfilling the expectations of the mother-in-law, and whatever she says they have to do. One of the lactation counsellors explained:

“Mothers-in-law have their own set-up rules. Whatever they think, they use to tell their daughter-in-law. “You have to do this and that”. The daughters-in-law must follow their rules. Even though the mothers are willing to follow our advises sometimes they can’t because of their mother-in-law”. (Lactation counsellor, P3)

Another lactation counsellor emphasized this by explaining mother-in-law’s role in cultural practices:

“The ritual of ghutti [prelacteal feed] is started by mother-in-law, and sister-in-law. They believe that if mother-in-law and sister-in-law will come and give, the baby will be fat. They clean the breast with raw milk of animals, like cow’s milk, and then they feed the ghutti in single drops.” (Lactation counsellor, P6)

Bhavna was supported by her mother and mother-in-law throughout the whole process of initiation lactation. Their advice was based on local ideas that tended to contradict the knowledge of the lactation counsellors on important points:

“My mom and mother-in-law told me the steps of the procedure [discarding colostrum and waiting three days before breastfeeding] ... I have still not been able to understand their logic, though I believe they must be having some logic.” (Bhavna, mother, P5)

The lactation counsellors were aware of the influence from the relatives and therefore involving them in the counselling was considered vital:

“We need to counsel them [mothers-in-law] how to counsel the mothers.” (Lactation counsellor, P5)

Even though the relatives had an important role in practicing rituals and customs that was not valued by the lactation counsellors, they also had a supportive role for the mothers:

“They [relatives] have very good impact on them [mothers]. If the mother is not willing to feed the baby, for reasons like she is having pain, she is feeling sleepy or any reason, so the family members help her. The family members ask her that you have to feed the baby like the counsellor is saying. So, family has good impact on the mothers.” (Lactation counsellor, P1)

Another lactation counsellor commented:

“If we find some difficulties when counselling the mothers, we call their families. They listen to their husband and mother-in-law.” (Lactation counsellor, P4)

Amina received great support of her mother-in-law during a time of hardship:

“My mother-in-law helped me a lot. Since I had undergone a surgery [caesarean section], I was not comfortable sitting, so she made me sit and placed a pillow which

could support my back when I had to feed the baby and she even helped in taking the milk out with her hands.” (Amina, mother, P2)

Chapter 5: Feeding a premature infant

Providing MOM to the premature infant can be a demanding process, but it is usually possible and certainly essential for growth and development of the premature infant. Even though breastfeeding might be challenging, the infant can receive expressed MOM. This chapter aims at exploring how mothers who have delivered prematurely experience the process of establishing lactation and how the lactation counsellors facilitate to get the milk production started.

Establishing milk production for the premature infant

A common experience among the mothers was that the process of establishing lactation required patience and effort. Since their infants were too immature to suckle and thus stimulate the breast and the milk production, the mothers needed other methods to get the milk production started, either an electric breast pumps or by hand expression.

The blessing of the breast pump

Meena, a primipara mother who delivered in week 28, explained how establishing lactation was a difficult process. Her baby was moved to the neonatal intensive care unit (NICU) for intensive care right after birth, while she herself was admitted to the maternity ward. She started stimulating her breasts two days after birth by performing hand expression every two hours. However, even with hard work, only a small amount of milk got expressed. She said:

“I tried my best level, but nothing was working [to start the milk production], then I tried hot fomentation as suggested by the doctor in the room. I was also told to massage. Whatever little amount of milk I could produce, 2-3 drops; I used to send it for my child.” (Meena, mother, P6)

Meena had a great desire to produce MOM for her infant and said it was “*really important*” to her. She was advised to register in the NCLMC so she could receive guidance from the lactation counsellors and use the breast pumps available there. The assistance she received from the NCLMC enabled her to feed her infant with MOM as she describes below:

“When the machine [breast pump] was used to take out milk, it was the same feeling as if a baby is taking a feed. What my baby was not able to do, was being done by the machine. The forty minutes that one spends there is not a waste of time; it is utilization of time. Earlier I was not able to produce even 1 ml of milk, but now I am feeding my child 21 ml of milk every day.” (Meena, mother, P6)

Establishing lactation requires diligent work which many mothers are not aware of. There is a general expectation that breastfeeding should come naturally after birth. One of the lactation counsellors said:

“Some are just waiting for the milk to start flowing. It is not working like that. You have to stimulate the breast for it to be started.” (Lactation counsellor 10)

But the lactation counselling process where the counsellor uses her hands to touch and stimulate the breast was commonly experienced as challenging. Amina experienced receiving one-to-one counselling in such an intimate and private manner as strange. She said:

“Since I had undergone a surgery [caesarean section], I was having a lot of difficulties sitting and I wasn’t even comfortable with anyone touching my breast and had the feeling of fear. The nurses educated me about pumping, and even how to use hand expression, so that I didn’t face any difficulty in their absence, but it was a very weird feeling that someone was touching my breast.” (Amina, mother, P2)

The combination of giving birth prematurely and undergoing a caesarean section made it particularly challenging for Amina to get the milk production started. However, the feeling of mastering it was irreplaceable:

“When I saw that my milk was released and my child could be fed, and the fact that it was beneficial in every way, my fear vanished.” (Amina, mother, P2)

Priya pointed out how nerve wracking the situation had been to her:

“When the milk was released with the help of a machine [electric breast pump], I felt that one of my blocked nerves opened because of it. I got a lot of relief from my pain and it helped me to a large extent.” (Priya, mother, P3)

It was not just the practical situation of feeding their infant that was at stake. Succeeding as a mother giving MOM to their child was an expectation that was important for them to live up to.

The pain and frustration of hand expression

Even though the mothers found the electric breast pumps beneficial, the NCLMC was closed during evening and night-time, hence during this time the mothers needed to perform hand expression to maintain the milk production. Bhavna explained how painful hand expression was to her:

“At night I had to do it [hand expression] myself and I didn’t even know how to do it. The breast used to be engorged and it was painful taking it out with my hand. It was not possible to empty the breast.” (Bhavna, mother, P5)

Hand expression was unfavourable not only because the mothers found it uncomfortable. It was difficult and the mothers had to use the right technique to get the milk expressed. However, the premises for the performance were improved with the support from the lactation counsellors. Bhavna explained:

“I used to wonder what to do, how to do it, but as they had guided me that I had to take the milk out every two hours, I started doing it and gradually that breast engorgement had gone and even the milk started coming out in adequate quantity.” (Bhavna, mother, P5)

Yet the need to hand express every two hours was experienced as particularly demanding. Amina said:

Using hands is very time consuming, and with pumping, milk comes out in good quantity and the child gets adequate amount of milk.” (Amina, mother, P2)

For Meena, the limited access to the electric breast pumps at night made her resort to artificial formula feeding:

“I give my milk to my baby from morning to evening, till 7 or 9 PM, but after that I am producing less milk, so I give him formula feed and I see nothing wrong in it.” (Meena, mother, P6)

Breastfeeding promotion

Along with establishing lactation and ensuring that the premature infant receive MOM, there is need to practice breastfeeding. Once the infant could suck and swallow at the same time they should be put to the mothers breast. However, there is no doubt that the focus on establishing and maintaining lactation takes a lot of the mothers attention, and practicing breastfeeding received less attention. During each interview, the lactation counsellors were asked if they manage to promote and facilitate breastfeeding. One of them said:

“Hmm.. Yes. We are telling them “go to milk bank, go to milk bank”, but are they practicing breastfeeding? Hmm.. I am not sure. I have to look into that. I hope the nurses in Nursery [NICU] are focusing on breastfeeding.” (Lactation counsellor, P9)

Even though the counsellors are trained to support and promote breastfeeding, this does not receive a lot of attention in counselling session with the mothers with premature infant and tends to draw in efforts to establish lactation through pumping. Hence, it is primarily the NICU staff that pay attention to breastfeeding.

Delay in producing mother’s own milk

Another challenge for the mothers, was the ravaging Covid-19 pandemic. For infection control purposes, everyone entering the NCLMC needed a negative Covid-19 report. This led to delays in one-to-one-counselling and availability of the breast pumps, which again led to delayed expression of MOM. It was not only that Meena found it too demanding to hand express during evening and night. She also had to wait for several days before she could receive help and use the breast pumps in the NCLMC. These delays resulted in Meena’s infant not receiving MOM as early as it could have. She said:

“I was told to get my covid testing done and if my report was negative, I would get milk bank’s [NCLMC] aid. Eventually, after some days my report was negative, and I got to register in milk bank.” (Meena, mother, P6)

The precautions taken and the delays implied added to the stressful situation in which the mothers already found themselves. One of the lactation counsellors said:

“The pandemic causes many problems for the mothers. They need a negative report to enter milk bank and therefore they are not able to use the pumps [electric breast pumps] right away. This will create a delay in producing the milk, which will hinder the baby to receive mothers’ milk. Mothers are already stressed, and this is just extra for them. I feel sorry for them.” (Lactation counsellor, P11)

However, the precautions taken to prevent transmission of Covid-19 also made the mothers feel safe visiting the NCLMC. As Tamanna said:

“Hygiene was given utmost importance. It seemed that there was no possibility of contracting the disease. We were instructed to wash our hands properly and were not permitted to carry our mobile phones. Before going inside, I had to wash my hands, I was told to clean my breast with soapy cotton, then with normal water and then I had to wash my hands thoroughly. Overall hygiene standards were very high.” (Tamanna, mother, P4)

Other challenges faced by the lactation counsellors was that many mothers feared that the MOM would be contaminated with the Covid-19 infection. This also contributed to delays in the milk production. One of the lactation counsellors explained:

“Some mothers hesitate to give the milk because they are afraid of contaminating the milk. We are separating the covid positive mother and her baby, because we don’t want the babies to be infected. We are going to the covid wards and counsel the covid positive and suspected mothers. We are telling them that their baby still needs the milk and that

covid will not spread through the the milk. The milk will protect the baby and make it stronger to fight the disease.” (Lactation counsellor, P11)

‘Donor human milk is meant as gap-filler’

In additions to delays due to Covid-19, some of the mothers struggled to produce adequate amounts of MOM as required for their infant. Based on how premature the infant was and the mother’s health status, donor human milk was given to the infant as a temporary solution until lactation was established. One of the lactation counsellors explained how donor human milk was intended:

“Donor human milk is meant to be a “gap-filler”, so the mothers are able to get time to get milk herself. It takes longer time and is more challenging for preterm mothers. First, because the body is not ready, and second because they are separated from the baby.” (Lactation counsellor, P5)

Two of the six participating mothers had given donor human milk to their infant. One of them, Meena, worried about the quality of donor human milk. She had heard people sitting in the waiting area outside the NCLMC talking about it. She explained:

“I could hear people sharing their apprehensions about donor milk. They would say that if a woman is suffering from any disease, the disease may get transmitted to the baby. Only a mother should feed her baby. One can’t rely on the quality of donor milk”. (Meena, mother, P6)

Meena decided to make up her own mind of donor human milk and began to observe closely how the lactation counsellor handled milk donations:

“When I went to the milk bank, I was very observant, and I noticed that a woman had visited to donate her milk as she was producing a lot of milk. Before keeping her milk, they took her record for the last year. She was asked if she was suffering from any ailment and if there was blood transfusion at the time of her delivery. She even had to undergo a blood test to verify if the milk given to the baby was safe for them. When they are absolutely sure, then only they send the milk from the milk bank to Nursery. So, the

tension that I had about the quality of donor human milk also vanished.” (Meena, mother, P6)

Being a recipient of donor human milk comes with expectations to the effort the mothers put into establishing lactation. Reasons for this is to ensure that donor human milk will not become a permanent solution or a springboard to artificial formula milk:

“If their child receives donor human milk, we think that they should at least do an effort to get own milk through pumping. We are counselling them, like your child is getting another mother’s milk, it is your responsibility to come to milk bank to make an effort to get own mothers milk. So, even though not a single drop is coming, they have to start and pump, because eventually it will come. But ahh.. it is hard motivating these. They need to be empowered.” (Lactation counsellor, P9)

Not being able establish lactation can be a great defeat for the mothers and therefore paying attention to the mothers needs during the establishment process was seen as vital. Ruhi emphasized this and explained the importance of being able to give MOM to her infant:

“I was elated when my baby was getting my milk. I know how tortured a mother feels if she is not able to produce milk.” (Ruhi, mother, P1)

Chapter 6: Donating own mothers ‘milk

Even though the premature infants do not need large quantities of milk the first weeks of life, their mothers must ensure that they increase MOM along with the infant’s growth. The mothers who manage to establish lactation tend to have milk in surplus in the early phase until the feeding demand of the infant increases. During this time of surplus milk production, mothers are asked if they are willing to donate MOM to the NCLMC. One of the lactation counsellors explained the idea behind donations:

“Mothers can establish good lactation, make sure her baby gets enough milk at the same time as she cares for other babies through donation. It is voluntary and no one should be forced, but we counsel them very smoothly and make them understand. Also, only those with lots of milk will be advised to donate. In the end, if a mother donates, she is helping more babies having better chance to survive.” (Lactation counsellor, P2)

The decision to donate MOM depended on what perceptions the mothers had about milk donations and how the lactation counsellors were able to guide them throughout the time they were present in the NCLMC. This chapter aims at exploring mother’s motivation to donate MOM and how the lactation counsellors go about counselling them on milk donations.

‘It is in our culture to share’

Wet nursing has deep roots in the history of infant feeding in India and according to the study participants, it is still practiced within many communities. Even though it is not recommended at the hospital for hygienical reasons, it was still practiced in the maternity wards between mothers who have delivered to term. One of the lactation counsellors explained a situation she commonly faced:

“Day before yesterday I was at night duty, and I met a mother. The baby was crying and therefore the mother next to her was feeding the baby. When I entered the room and started counselling her, I told her about the risk of wet nursing and why they should come to milk bank. Situations like this happens in every maternity ward.” (Lactation counsellor, P4)

Another lactation counsellor emphasized the same and said that the NCLMC could be beneficial for both the mothers in a wet nursing situation, the one who are giving away milk and the mother to the infant who receives it. She said:

“I get this question; “Sister jii, I have enough milk to feed the other child. Should I?”. We are not supporting that, because one mother can have diseases and bacteria that can affect the baby. We are telling them both to come to milk bank, the mother with less milk to get counselling, and the mother with a lot of milk to donate.” (Lactation counsellor 5)

For Meena, who belonged to a Hindu community, wet nursing was a common practice:

“I have seen it [wet nursing] at my own home. My sister and sister-in-law delivered at the same time and my sister-in-law was not able to produce enough milk, so my sister used to feed both the babies.” (Meena, mother, P6)

The traditions with wet nursing have paved a way for milk donations. One of the lactation counsellors explained:

“It is in our culture to share. We have done it always, but now we should do it in a safe way through donating to the milk bank.” (Lactation counsellor, P8)

However, the issue of milk kinship arises when talking about wet nursing and milk donation:

“Some mothers are not willing to donate because of religious aspects if they feed the baby. If they are giving milk to one child, their child cannot marry this one.” (Lactation counsellor, P3)

This is especially for Muslim mothers, because according to Islamic law, milk siblings, i.e. children who have been breastfed by the same woman, are forbidden to marry each other:

“Muslims don’t go for donation, even though they have a lot of milk.” (Lactation counsellor, P3)

Level of education played a crucial role when it came to this mind set:

“It is mostly among the uneducated Muslims. They say that if we give milk to another baby, the baby will be a sister or brother.” (Lactation counsellor, P9)

Amina, who belonged to a Muslim community, had no apprehensions regarding either receiving DHM or donating MOM. However, she got reactions from her relatives once they had heard that her infant had received DHM and that she had donated MOM:

“They said that milk should not be donated. It is believed in our society that milk should not be donated without husband’s permission. (...) I had donated my milk without my husband’s permission; I felt that I had committed a mistake, so I spoke to him about it, but he didn’t have any problem knowing I had already donated it. He did not hold any grudge against me and was very supportive.” (Amina, mother, P2)

Due to her level of knowledge gained in the NCLMC she was convinced that the benefits with milk donations should transcend cultural ideas:

“When our baby is receiving someone else’s milk, then why can’t we donate it? My child had been in Nursery for five days where it was receiving someone else’s milk. I used the same logic to my mother, and she was also happy that I had done a good deed.” (Amina, mother, P2)

All the participating mothers saw the joy of donated MOM, but the motivation differed and as observed by the lactation counsellors, it was based on the mothers’ given situation.

Taking advantage of the surplus

For Priya, throwing away the surplus milk, which could be beneficial for another infant, was something that made her go for donation. She said:

“My milk was produced in surplus; it was more than what my baby needed. It was getting wasted. I thought that instead of wasting, it could have been useful for some other baby.” (Priya, mother, P3)

Being able to help others while sustaining the amount of MOM was an appealing thought. It was a reciprocal act, where both parts are mutually benefitted. One of the lactation counsellors explained:

“There was this mother with her baby in Nursery. She decided to donate the milk in surplus because her baby could not get all the milk she produced. To sustain the amount, she donated and made sure someone else could have the surplus.” (Lactation counsellor 9)

Another lactation counsellor also emphasized how donation can be of mutual benefit:

“The motivation has to be that she can help other babies at the same time as she helps her own baby.” (Lactation counsellor, P5)

However, not every mother in the NCLMC want to donate the surplus. It could be because of lack of knowledge or simply because they do not feel like it. One of the lactation counsellors explained how she approached these situations:

“Some mothers say they don’t want to donate this milk because they want to have all their milk to their child only. It is a little bit challenging process because we must counsel them again and again. Those who have babies in the NICU, there is no need for all that milk because the baby might only need 10-15 ml per meal. We are again explaining to her that some mothers are not having any milk for their baby and telling her that her valuable drops of milk can help someone else. It will be a blessing for another mother and child, but again, we never force them. It has to come from their own will, but the thing is that milk donation is a very new concept in India and if we don’t counsel them on this, they will not understand why it is important and all.” (Lactation counsellor, P9)

Act of solidarity

A unique thing about the participating mothers was that they all had experienced how hard it was to establish lactation when breastfeeding was not possible. Solidarity with the mothers going through the same challenge became important to some of them. Priya explained:

“I had myself suffered when I wasn’t able to produce adequate milk for my child who was ill; I knew it would have helped in my child’s recovery, and I don’t want others to go through the same turmoil. I am very aware of its [human milk] significance for a baby and especially a premature baby. I felt that some other baby could benefit because of it. I had the notion that it could help in the recovery of some other child.” (Priya, mother, P3)

Some of the lactation counsellors said that the mothers lived experience with being a mother to a premature infant made them understand the importance of donor human milk and how crucial it was to their infants. Showing compassion and donating when they were in surplus was something that came natural to many of the mothers. One of the lactation counsellors explained:

“After getting enough milk for her baby, many of them decide to donate to be able to give same help to other babies as her baby got during the time, she did not have enough milk herself.” (Lactation counsellor, P5)

Being able to help others in need through donation, was satisfying to many of the mothers and something that made them feel good about themselves as human beings and mothers:

“The fact that milk production was more than what we needed, and someone else’s baby could be fed, gave everyone, both me and my family immense satisfaction. Imagine the condition of the baby whose mother is not able to produce milk.” (Priya, mother, P3)

Donation gave the mothers a feeling of fulfilment, like there was a desired achievement:

“Donating milk is a noble act. When I donated milk, it gave me tremendous happiness and satisfaction. I thought about my baby whom I could not breastfeed for five days, and she must have received someone else’s milk. I felt really good after donating my milk. I feel that some poor child or any child for that matter should receive it.” (Amina, mother, P2)

One of the lactation counsellors explained how donating milk could be seen as giving a sacred gift:

“Some mothers are there and say it is a religious thing, that they are giving away [MOM] to some babies that do not have the opportunity to get own milk. Like a sacred gift or something. Gifting someone their own milk is a powerful act for them.” (Lactation counsellor, P3)

Another important motivation factor for donation was the role model of other mothers donating MOM. One of the lactation counsellors had observed this social influence closely:

“They see other mothers also donate and they are talking to each other. One mother came with another mother who also wanted to donate.” (Lactation counsellor 6)

Another one emphasized the same:

“Some mothers come to the milk bank and are saying they want to donate. They explain that someone told them about the milk bank and that she wants to donate.” (Lactation counsellor, P9)

Chapter 7: Discussion and Conclusion

Discussion of findings

The findings in chapter 4,5 & 6, illuminate of mothers' and lactation counsellors' lived experiences related to infant feeding. The main findings demonstrate how practical challenges complicate the process of establishing lactation, and how this, combined with separation of mother and infant, caused feelings of failed motherhood. Practical, physical, emotional, and social support from the lactation counsellors was vital, but the findings also show that counselling mothers alone was not always sufficient considering the central role of mother-in-law and her perceptions on infant feeding. Practicalities related to availability of electric breast pumps around the clock, challenged the possibilities of providing MOM at all hours of the day. Restrictions due to Covid-19, caused delays in early initiation of lactation and created communication difficulties in counselling sessions. Motivational factors for donating MOM were related to reciprocal benefits and the fact of being able to do an act of solidarity to provide DHM for infants who did not have available MOM.

In the following, I will discuss the issue of rebuilding motherhood; establishing the link between knowledge and practice; the tension between local ideas and evidence-based knowledge; and the motivation for sharing milk and finally the need to support, protect and promote breastfeeding within the milk bank. In discussion of these topics, I will draw upon the concept of health literacy and authoritative knowledge in particular.

Rebuilding motherhood

As the narratives of the participants in my study indicates, breastfeeding was seen as a natural function connected to being a mother. Thus, the disappointment of not being able to breastfeed was great. Establishing lactation with the help of an electric breast pump was demanding and time consuming and was experienced as the opposite of the natural and easy process they assumed feeding their infant would be. Hence as Gonzales (2018) reports in her study, the breast pump and the absence of the infant transforms the experience of being a mother to that of being a milk producing machine. From being a subject in a close mother-infant dyad, the mother is reduced to being an object of milk production which fundamentally affects her sense of self-worth. As many of the mothers needed time to get the milk production started, their infant received DHM or artificial formula in the meantime, which exacerbated the mothers'

feeling of failure. In addition to struggling to establish lactation, the mothers had to cope with an unfamiliar situation of becoming a mother to a premature infant, hence another factor that may have threatened their motherhood.

Gonzales (2018) emphasizes that when breastfeeding is framed as natural, it is inherent to the biological design of a woman's body, thus something all mothers should be able to perform. This natural perception of breastfeeding implies that it is instinctive and easy, hence the opposite of what the mothers in the study felt. 'How can I be a mother if I can't breastfeed?', as one of the mothers said, reflects how she felt threatened as a mother and the intimate link between breastfeeding and motherhood. Even though she was able to produce adequate amount of MOM to her infant, it was the fact that she could not breastfeed that caused the feelings of failing. Finlayson, Dixon, Smith, Dykes & Flacking (2014) explain that it is common for mothers with a premature infant to struggle in taking up their anticipated maternal role. It is therefore important that the mothers are counselled to accept that the postpartum period will look different when delivering prematurely, and that establishing the maternal role will take longer. According to Lucas & Briere (2016), the lactation counsellors have a responsibility to help the mothers to acknowledge the difference between breast pumping and breastfeeding, but it also requires commitment by the mother herself as stated by Hilton (2010).

'My fear vanished' and 'my blocked nerves got opened', as remarked by two of the mothers, reflects how emotionally challenging it had been for them to establish lactation, and how relieved they felt once they were able to produce MOM. Brown et al., (2016) emphasize that feeding is an excellent way of involving the mother in the care of the premature infant. The ability to provide MOM to their infant remains the one aspect of care she alone can do for her infant. This unique position provides the mother with motivation in the process of establishing lactation and contributing to the care of the premature infant. The mothers in this study regained their identity as a mother and developed a greater self-efficacy when being able to provide their premature infant with MOM. However, mothers' ability to involve themselves in the care of their infant through providing MOM is reliant on the mothers ability to gain access to, understand and use information (WHO, 2009).

Establishing the link between knowledge and practice

Becoming a mother to a premature infant is itself a complex task that requires 'critical health literacy' to analyse and apply health information (Nutbeam, 2006). How the lactation counsellors guide and support the mothers is key to a successful outcome (Lucas & Briere, 2016), but often the link between knowledge and practice is taken for granted, and practical and emotional support to apply the knowledge practically is inadequate.

Even though many of the mothers faced obstacles from the very start getting the milk production started, all of them were able to provide MOM to their infant. They even produced more than their infant needed, hence all of them donated MOM once or several times to the NCLMC. Nevertheless, one of the mothers in the sample ended up giving artificial formula feed to her infant during night-time because the electric breast pumps were not available, and hand expressing MOM was too cumbersome. The example illustrates the gap between knowledge and practice. This can be seen in light of Paache-Orlow & Wolf (2007) explanations of health literacy consisting of more than just transmission of knowledge, it is linked to the capacity and ability to enact of the knowledge. In the example above, the unavailability of electric breast pumps at night-time worked as an obstacle to apply the knowledge on MOM.

Another factor that may interfere in the link between knowledge and practice, is the communication between counsellor and mother which may be clouded by their unequal position. In the encounter between counsellor and mother, it is the counsellor that posits the authoritative knowledge defined as the knowledge that counts (Jordan 1997). The authoritative position of the counsellor legitimises her knowledge as superior and as unquestionable and places the mother in a subordinate position in the hierarchy prevailing in the hospital. This is particularly pronounced vis-à-vis the uneducated, rural, poor mothers who may have had difficulties interpreting the knowledge transmitted by the lactation counsellors. Such a subordinate position commonly involves powerlessness and lack of ability to ask questions, which in turn lead to less patient activation.

According to WHO (2018a), lactation counselling should be a process of interaction between the counsellor and the mother based in a horizontal relationship. It should not be a 'top-down' intervention of 'telling the mother what to do'. Even though the lactation counsellors in this study aim to 'meet the mothers in their vulnerable situation', it is obvious that their 'main task

and overall concern' is to ensure that MOM is given to the baby. Hence the lactation counsellors need to 'make the mothers understand' the importance of MOM. This distinct way of communicating is clearly hierarchical and is characterized more by instructions than a horizontal way of sharing knowledge. In this context the authoritative knowledge of the counsellors implies that counsellors expect their instructions to be followed. It also implies that the mothers feel committed to follow the instructions. The lactation counsellors represent evidence-based knowledge, which according to Sargent (1997), is scientifically valid and naturally authoritative. In the Indian context, hierarchy is fundamental to social organisation. Indian communities have been hierarchically organized since the very beginning of the caste system. One can then argue that this 'top-down' approach is culturally acceptable and something that is naturally given to the lactation counsellor in a counselling session.

The tension between local ideas and evidence-based knowledge

Infant feeding must be understood in a bio-social framework which acknowledges that in addition to being a biological body function, it is a phenomenon that is socially constructed, where "the cultural body and the corporeal body meld together and appear to be the same" (Blum, 1999, p. 3). It is anchored in social relations of power and hierarchy. In this study, it is the power of mother-in-law that is the most important one at the community level.

The study sample reflects how mothers-in-law influence the mothers' perceptions of infant feeding, and how 'the daughters-in-law have to follow their rules'. Melwani et al., (2018) emphasize the same saying that elderly family members such as mother-in-law is seen as the main supporters of the mother. An important issue in a discussion of health literacy is the expectations from the family and local community and how this social influence affects the possibilities for increased health literacy. To explore this issue, I draw lines to how local ideas such as discarding colostrum and giving honey as pre-lacteal feeds, which is culturally conditioned and something that has been practiced in generations, hence an expectation that the mothers will continue these practices. Even though the mother might feel that these local ideas and practices are not optimal, her mother-in-law might tell her to do so. In a context where young women have limited say over their infant, the pressure to enact these local ideas are hard to resist. In the age hierarchy of the local community, the power to make decisions about the infant rests with the mother-in-law representing yet another obstacle to adhere to the advice from the counsellors. Here the authority of the counsellors competes with the authority

of mother-in-law in ways that produce unpredictable outcomes. Health literacy is important to impart on the mothers, but in the current context, it is not sufficient. High level of health literacy may be undermined in the face of traditions unless an alliance between the lactation counsellors and the older generations is established. Therefore, involving mothers-in-law in the counselling session, as emphasized by the lactation counsellors is essential because it will have an impact on the mother-in-law's health literacy, and therefore on the mothers' ability to put knowledge into practice. As among others, Beauchamp et al. (2015) and Laroia & Sharma (2006), have pointed out, providing education and support to family members is a recognised strategy in health promotion.

Whether there is a clear distinction between local ideas as community based and evidence-based knowledge as hospital based or the degree to which they spill over to each other can be discussed. As part of a local community themselves, lactation counsellors are also infused with these local ideas. The role of mother-in-law is culturally conditioned and therefore also relatable for the lactation counsellors who may themselves experience similar pressure in their private lives, but probably posit a health literacy that makes them better prepared to resist it conversely. Knowledge acquired in hospital also makes its way to the communities and gradually affects ways of doing things.

Delays in establishing lactation

The ravaging Covid-19 pandemic created additional practical challenges. The mothers got delayed in establishing lactation because they needed a negative Covid-19 report to enter the NCLMC. Hence, they were not able to stimulate the breast with the electric breast pump within few hours after birth as recommended for mothers with premature infant by Gardner & Lawrence (2016) and Lucas & Briere (2016). The situation required the mothers to have a greater practical ability to carry out the plan of providing MOM to their infant, which again is connected to the mothers' level of health literacy (Nutbeam, 2006). Receiving support and guidance before they could enter the NCLMC was important and until the mothers could enter the NCLMC for pumping, the lactation counsellors went on rounds in the maternity wards to encourage the mothers to hand express MOM.

The lactation counsellors experienced it challenging to provide sufficient counselling sessions to the mothers because they had to wear personal protective gear, which created

communication problems. The remark that 'it is like putting a barrier between the patient and me' emphasizes how the connection with the mothers was challenged, but also how counselling is about building a relationship with the mothers. Ensuring that mothers made progression in providing MOM to their infant and that they developed 'critical health literacy' (Nutbeam, 2006), was a responsibility that the lactation counsellors felt rested heavily on their shoulders.

Sharing milk

The findings reflect different motivational factors for donating MOM. The mothers themselves had faced challenges in the process of establishing lactation and by donating their surplus milk, they were able to 'give back' and help other mothers going through the same experience in a spirit of reciprocity. By sustaining their own milk production through donations and at the same time helping other mothers to regain their motherhood, gave them increased self-esteem. The mothers felt a 'tremendous happiness and satisfaction' once they had donated despite the fact that most of the mothers had not heard about milk donations in a milk bank beforehand. Their open attitude to donations could be linked to the tradition of wet-nursing which has been practiced in most communities in India for centuries. Wet-nursing is also religiously conditioned and is written about in Ayurvedic texts which are considered important for Hindus (Laroia & Sharma, 2006). Kardioglu et al. (2018), emphasize the same saying that sharing of human milk is encouraged within many religions. It could therefore be in a religious context that donating MOM is perceived as a 'noble act' of giving a 'sacred gift'.

'It is in our culture to share' and 'we have done it always', represent a safe spot for the mothers, something they can relate to, something natural. Adapting the idea of wet-nursing and sharing into the counselling about a safe way of sharing MOM, could make it easier for the mothers and not the least the mothers-in-law to accept donating as well as receiving donated milk.

A general idea held among the lactation counsellors is that Muslim mothers will not donate MOM because of the issue of 'milk kinship'. Indeed some Islamic countries do not accept human milk banks to be established because of the danger of 'milk kinship' among otherwise eligible marriage partners (Kardioglu, Avcialpar, Sahin, 2018). However, this pre-conception may be counterproductive and the issue of the acceptability of milk donation should be discussed individually. The study provides evidence to this as two of the mothers in the sample

belonged to an Islamic community, and both donated MOM to the NCLMC. They were also open to their infant receiving DHM if they were not able to produce adequate amount of MOM. Such preconceptions may underestimate the mothers' ability to acquire knowledge to improve their health literacy. To ensure that the counselling is 'health literacy responsive', it needs to understand the health literacy strengths and limitations of people in the communities that it seeks to serve (Beauchamp et al., 2015). The knowledge of milk kinship should be used by the lactation counsellors to understand what the mothers' starting point is, not as a prejudice which hinders milk donations.

Protecting, promoting, and supporting breastfeeding

Ensuring that the premature infant breastfeed when discharged from the hospital, is a single intervention that can save lives (Victoria et al., 2016; WHO, 2019a). For this to happen, it requires 'hard work' and willpower from the mothers coupled with a well-functional system and structural routines from the NCLMC. It is common and expected that premature infants face more interruptions when it comes to breastfeeding than full term babies due to immaturity of sucking and swallowing techniques. Mothers with premature infants also have an underdeveloped breast tissue (Hilton, 2010). However, even though it might require patience and effort, it is possible.

The study sample does not go into depth on how breastfeeding is followed up and how it is being practiced in the NICU as this might be more of a neonatal nursing task, than allocated to the lactation counsellors. Nevertheless, it emphasizes that the lactation counsellors could be more attentive to the importance of promoting breastfeeding during the counselling sessions rather than solely focusing on milk expression and donation.

Reflections of methodology

The study sample included mothers who had delivered prematurely and had their infant admitted to the NICU and lactation counsellors working in the NCLMC. There may have been a selection bias while tracing the mothers as study participants. Since I could not travel to India and do the data collection myself due to Covid-19, one of the research assistants selected the study participants out from a criteria list given to her by me. She had to choose study participants from the NICU she worked in because she was not allowed to visit the other NICU due to Covid-19 restrictions. Since she worked as a nurse in this NICU, it could imply that

these study participants were more 'connected' to the research assistant and had access to information that affected the answers given.

The participating women who delivered prematurely have been referred to as mothers in this study. This could potentially seem excluding for women who for various reasons no longer can be defined as mothers, but still receive lactation support. However, I have chosen to use the term 'mothers' since that is how the women receiving counselling were referred to and because in this capacity, they received counselling.

Each of the interviews with the mothers and the lactation counsellors was limited to 30-60 minutes. This limited the possibilities to develop a deeper level of rapport (REF) with the study participants and might have affected the quality of data to some extent. In addition, the original plan was to not only collect data through in-depth interviews, but by also performing participant observation. This triangulating effect would have strengthened the transferability of the study findings. However, whatever methods used, no study can provide findings that are universally transferable (Malterud, 2001).

Another important aspect of transferability is that the results of a qualitative study must be understood within the context of the organization and the geographical area that the field-work was carried out (Shenton, 2004). Since I was not doing fieldwork, there may be a chance that I have over-interpreted my data. I have tried to be sensitive to the context of the findings, and my earlier observations and experiences from working at Lady Hardinge Medical College & Kalawati Saran Children's Hospital (LHMC & KSCH) have provided me with insight to what the study context involves.

I have tried my best to not bring any personal biases to the study, but since I am familiar with the collaboration project, the study setting, and some of the study participants, this may have affected my findings to some degree. Since I am an 'outsider' in the encounter with the Indian culture, this might also affect how I interpreted the findings of my study.

The analysis of the study was done using the transcripts and translations. Since the in-depth interviews with the mothers were collected by a research assistant, it made it difficult to fully catch on the verbal-communication even though the research assistant shared notes during the

interviews. The transcript from the interviews was translated from Hindi to English. However, the person transcribing was not present during the interviews, hence some words might have meant something else if circumstances and the body language was considered. The strength however was that my co-supervisor Dr Sushma Nangia and research assistant crosschecked each interview after translation and ensured that they were consistent with the interviews.

Despite these reservations I would argue that the relevance of the major findings extends beyond the study sample to other lactation counselling sessions in the NCLMC, but also to other Lactation Management Centres within the same social and cultural context in India.

Conclusion and Recommendations

This study has explored the role of the National Comprehensive Lactation Management Centre (NCLMC) in New Delhi in strengthening the feeding of premature infants through mother's own milk (MOM) and milk donation. Through the narratives of lactation counsellors and mothers, who at the time of the study received services from the Lactation Management Centre, the study has demonstrated that providing MOM to a premature infant is a complex challenge and a multi-layered experience for the mothers concerned. Lactation counselling to these mothers requires a holistic approach, including practical, physical, emotional, and social support.

At the medical level, it requires early lactation support, preferably before giving birth as well as during the hospital stay and after returning home. Along with this, accessible electric breast pumps and available lactation counselling around the clock is essential. This is to ensure that the mothers can produce adequate amounts of MOM and hopefully can breastfeed their infant once it is mature enough to suckle the breast. The circle of milk donation that the mothers who produced surplus milk engaged in, provides other vulnerable premature infants who are not able to receive MOM, with donor human milk as a second-best alternative after MOM. In this way the premature infants can be ensured human milk instead of artificial formula feeds as gap-filler before their own mother can provide them with MOM. At the community level, more awareness of the best infant feeding practices is required. The premature infants should be provided with MOM exclusively and with close follow-up from health centres after returning home in order to protect, promote and support breastfeeding as well as ensuring the premature adequate nutrition.

At the research level, more studies are needed to get a broader understanding of the function of the Lactation Management Centres established at secondary and tertiary level public health facilities in India. With the ambitious ideal of being '*a storehouse of mother's unconditional love and nectar*', the Lactation Management Centres need to develop ways to reduce distance and increase possibilities for attachment between the premature infant and the mother during the first critical phase after birth. Based on the findings in this study, research on how this could be achieved is warranted.

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Appendix A: Written consent form, English



UNIVERSITY OF BERGEN

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Exploring the role of the National Comprehensive Lactation Management Centre in strengthening infant feeding for newborns in a tertiary care hospital in New Delhi, India

Research investigator: Ingvild Andresen (Centre of International Health, University of Bergen)

Supervisors:

Professor Karen Marie Moland (Centre of International Health, University of Bergen) & Dr. Sushma Nangia (Department of Neonatology, Lady Hardinge Medical College)

You have been asked to participate in this research project because you are either a lactation counsellor working at the National Comprehensive Management Centre (NCLMC) or a woman who have received lactation counselling and donated own mothers' milk to the NCLMC. Your participation in this study is voluntary.

PURPOSE OF THE STUDY AND RESEARCH INTERVENTION

The purpose of the study is to explore the role of the NCLMC in strengthening breastfeeding and use of pasteurized donor human milk for newborns in a tertiary care hospital in New Delhi, India.

This research will involve your participation in an interview that will last for approximately one hour. The interview will be audio recorded and all information will be processed and anonymous. You will be asked questions about your experiences with breastfeeding

counselling and donation/use of pasteurized donor human milk. Information regarding your socio-demographic factors will be collected, such as age, marital status, how many kids you have, education level, profession, ethnicity, address, and religion.

For the participating mothers, a research assistant working at the NCLMC will collect the interviews one-to-one with you in Hindi. For Lactation counsellors, the interviews will be held over an online platform called Zoom. The Research investigator will be the interviewer.

VOLUNTARY PARTICIPATION

Participation in the research study is voluntary. If you wish to take part, you will have to sign the consent declaration. You can withdraw your consent at any time, and ask for your personal data regarding your health to be deleted, unless it have already been analysed or used in scientific publications.

YOUR RIGHTS

As long as you can be identified in the collected data, you have the right to:

- Access the personal data that is being processed about you
- Request that your personal data is deleted
- Request that incorrect personal data about you is corrected/rectified
- Receive a copy of your personal data (data portability), and
- Send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

WHAT WILL HAPPEN TO YOUR PERSONAL DATA?

We will process your personal data based on your consent. Personal data concerning your health will only be used in the purpose of the study. All information will be processed and used without your name or personal identification number. The data will be locked away in an encrypted file in a password-protected computer. Only my supervisors and I will have access to the information you have given. Information about you will remain anonymous during the whole study period and will be deleted after the end of the study.

ETHICAL APPROVAL

Ethical approval for conducting the study has been obtained from the Norwegian Centre for Research Data (NSD). Simultaneously ethical approval has been obtained from the Institutional Ethics Committee at Lady Hardinge Medical College.

Based on an agreement with University of Bergen, NSD has assessed that the processing of personal data in this project is in accordance with data protection legislation.

CONTACT INFORMATION

If you have any questions regarding the study, or want to exercise your rights, contact:
University of Bergen via Ingvild Andresen, Phone: + 47 48104940, email:
andreseningvild@gmail.com

You can also contact the supervisors who is responsible for the data protection:
Professor Karen Marie Moland,
Centre for International Health, University of Bergen
Phone: +47 55 58 99 62, Email: Karen.moland@uib.no

Dr. Sushma Nangia,
Director Professor & Head, Department of Neonatology, Lady Hardinge Medical College &
Kalawati Saran Childrens Hospital
Phone: +91 9810838181, Email: drsnangia@gmail.com

I CONSENT TO PARTICIPATE IN THE RESEARCH STUDY DESCRIBED ABOVE

Participant's Name (in BLOCK LETTERS)

Date & signature Participant

I confirm that I have given information about the research project:

Date & signature research investigator

Appendix B: Written consent form, Hindi



UNIVERSITY OF BERGEN

एक अनुसंधान परियोजना में भाग लेने के लिए सहमति

नई दिल्ली, भारत में एक तृतीयक देखभाल अस्पताल में नवजात शिशुओं के लिए स्तनपान और पाशुपरीकृत दाता मानव दूध के उपयोग को मजबूत बनाने में राष्ट्रीय व्यापक स्तनपान प्रबंधन की केंद्र भूमिका

अनुसंधान अन्वेषक: Ingvild Andresen (अंतर्राष्ट्रीय स्वास्थ्य केंद्र, बेरगेन विश्वविद्यालय)

पर्यवेक्षकों:

प्रोफेसर करेन मैरी मोलंड (इंटरनेशनल हेल्थ का केंद्र, बेरगेन विश्वविद्यालय) और

डॉ सुषमा नांगिया (नियोनेटोलॉजी विभाग, लेडी हार्डिंग मेडिकल कॉलेज)

आपको इस शोध परियोजना में भाग लेने के लिए कहा गया है क्योंकि आप या तो राष्ट्रीय व्यापक प्रबंधन केंद्र (एनसीएलएमसी) में काम करने वाले स्तनपान काउंसलर हैं या एक महिला जिन्होंने स्तनपान परामर्श प्राप्त किया है और एन.सी.एल.एम.सी को अपनी माताओं का दूध दान किया है। इस अध्ययन में आपकी भागीदारी स्वैच्छिक है।

अध्ययन और अनुसंधान हस्तक्षेप का उद्देश्य

इस अध्ययन का उद्देश्य नई दिल्ली, भारत में एक तृतीयक देखभाल अस्पताल में नवजात शिशुओं के लिए स्तनपान और पाशुपरीकृत दाता मानव दूध के उपयोग को मजबूत बनाने में एन.सी.एल.एम.सी की भूमिका का पता लगाना है।

इस शोध में एक साक्षात्कार में आपकी भागीदारी शामिल होगी जो लगभग एक घंटे तक चलेगी। इंटरव्यू ऑडियो रिकॉर्ड किया जाएगा और सारी जानकारी और कार्रवाई गुमनाम होगी। आप स्तनपान परामर्श और दान के साथ अपने अनुभवों के बारे में सवाल पूछा जाएगा / पाशुपरीकृत दाता मानव दूध। आपके सामाजिक-जनसांख्यिकीय कारकों के बारे में जानकारी एकत्र की जाएगी, जैसे उम्र, वैवाहिक स्थिति, आपके पास कितने बच्चे हैं, शिक्षा का स्तर, व्यवसाय, जातीयता, पता और धर्म।

भाग लेने वाली महिलाओं के लिए एनसीएलएमसी में कार्यरत एक शोध सहायक हिंदी में आपके साथ साक्षात्कार एक-एक कर एकत्रित होंगे।

स्तनपान काउंसलर्स के लिए, साक्षात्कार “जूम” नामक एक ऑनलाइन मंच पर आयोजित किया जाएगा। रिसर्च अन्वेषक साक्षात्कारकर्ता होंगे।

स्वैच्छिक भागीदारी

शोध अध्ययन में भागीदारी स्वैच्छिक है। यदि आप भाग लेना चाहते हैं, तो आपको सहमति घोषणा पर हस्ताक्षर करने होंगे। आप किसी भी समय अपनी सहमति वापस ले सकते हैं, और अपने स्वास्थ्य के बारे में आपके व्यक्तिगत डेटा को हटा दिया जा सकता है, जब तक कि इसका विश्लेषण या वैज्ञानिक प्रकाशनों में पहले से ही उपयोग नहीं किया गया हो।

आपके अधिकार

जब तक आप एकर किए गए डेटा में पहचाने जा सकते हैं, तब तक आपको अधिकार है:

- आपके बारे में संसाधित किए जा रहे व्यक्तिगत डेटा देखें
- अनुरोध करें कि आपका व्यक्तिगत डेटा हटा दिया जाये
- अनुरोध करें कि आपके बारे में गलत व्यक्तिगत डेटा को ठीक/सुधारा जाये
- अपने व्यक्तिगत डेटा (डेटा पोर्टेबिलिटी) की एक प्रति प्राप्त करें, और
- अपने व्यक्तिगत डेटा के प्रसंस्करण के बारे में डेटा संरक्षण अधिकारी या नार्वे डेटा संरक्षण प्राधिकरण को शिकायत भेजें

आपके व्यक्तिगत डेटा का क्या होगा?

हम आपकी सहमति के आधार पर आपके व्यक्तिगत डेटा को संसाधित करेंगे। आपके स्वास्थ्य से संबंधित व्यक्तिगत डेटा का उपयोग केवल अध्ययन के उद्देश्य में किया जाएगा। सभी जानकारी पर कार्रवाई की जाएगी और आपके नाम या व्यक्तिगत पहचान संख्या के बिना उपयोग किया जाएगा। डेटा को पासवर्ड-संरक्षित कंप्यूटर में एन्क्रिप्टेड फ़ाइल में बंद कर दिया जाएगा। केवल मेरे पर्यवेक्षकों और मैं आपके द्वारा दी गई जानकारी तक पहुंच प्राप्त करेंगे। आप के बारे में जानकारी पूरे अध्ययन अवधि के दौरान गुमनाम रहेगा और अध्ययन के अंत के बाद हटा दिया जाएगा।

नैतिक अनुमोदन

अध्ययन कराने के लिए नैतिक अनुमोदन नार्वे के अनुसंधान डेटा केंद्र (एनएसडी) से प्राप्त किया गया है। इसके साथ ही लेडी हार्डिंग मेडिकल कॉलेज में इंस्टीट्यूशनल एथिक्स कमेटी से नैतिक मंजूरी ली गई है।

बेरोन विश्वविद्यालय के साथ एक समझौते के आधार पर, एनएसडी ने आकलन किया है कि इस परियोजना में व्यक्तिगत डेटा की प्रसंस्करण डेटा संरक्षण कानून के अनुसार है।

संपर्क जानकारी

यदि आप अध्ययन के बारे में कोई सवाल है, या अपने अधिकारों के आबकारी करना चाहते हैं, संपर्क करें:

Ingvild Andresen,

फोन के माध्यम से बेरगेन विश्वविद्यालय: + ४७ ४८१०४९४०,

ईमेल: andreseningvild@gmail.com

आप उन पर्यवेक्षकों से भी संपर्क कर सकते हैं जो डेटा सुरक्षा के लिए जिम्मेदार हैं:

प्रोफेसर करेन मैरी मोलंड,

सेंटर फॉर इंटरनेशनल हेल्थ, बेरगेन विश्वविद्यालय

फोन: +47 55 58 99 62, ईमेल: Karen.moland@uib.no

डॉ सुषमा नांगिया,

निदेशक प्रोफेसर और विभागाध्यक्ष, नियोनेटोलॉजी विभाग, लेडी हार्डिंग मेडिकल कॉलेज और कलावती सरन चिल्ड्रन अस्पताल

फोन: +91 9810838181, ईमेल: drsnangia@gmail.com र वर्णित अनुसंधान अध्ययन में भाग लेने के लिए सहमति

प्रतिभागी का नाम (ब्लॉक पत्र में)

तिथि और हस्ताक्षर प्रतिभागी

मैं पुष्टि करता हूँ कि मैंने अनुसंधान परियोजना के बारे में जानकारी दी है:

दिनांक और हस्ताक्षर अनुसंधान अन्वेषक

Appendix C: Semi-structured in-depth interview guide to Lactation Counsellors

Interview guide, Lactation Counsellors
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Name:	Contact number:
Date:	Place:
Recorder (yes/no):	Signed consent (yes/no):
Age:	Educational level:
Marital status:	Number of children:
Religion:	Ethnicity:
Number of years worked in the hospital:	Number of years worked in NCLMC:
<p>Organization, practices and routines</p> <ul style="list-style-type: none"> - Can you please explain to me how the milk-bank is working? - Could you maybe tell me about how you experienced the process of establishing the milk-bank? So what has your role been in this? What kind of obstacles or difficulties did you meet? - What impact do you think the NCLMC has on infant health and survival here at the hospital? - Can you please describe to me the routines in the milk-bank? <ul style="list-style-type: none"> o What about now, during the Covid-19 pandemic? Has anything changed? o What about hygiene and infection control during the Covid-19 pandemic? - Where do you counsel the mothers and how do they get admitted to the NCLMC? 	
<p>Lactation and breastfeeding support</p> <ul style="list-style-type: none"> - How do you consider the importance of own mothers milk? How do you think mothers value breastfeeding? How about colostrum? - Can you tell me about a typical counselling session and what advise do you give about breastfeeding and lactation support to mothers? <ul style="list-style-type: none"> o What is your thoughts on exclusive breastfeeding? - Can you remember a counselling situation that you experienced as particularly difficult? What was it that made this situation difficult? Can you elaborate? Do you have other examples? <ul style="list-style-type: none"> o What about the Covid-19 pandemic? Is that affecting the counselling sessions? 	

- In the NICU mothers are expected to express own milk as well as establish breastfeeding their preterm infant. What are your experiences with this?
 - o How do you counsel mothers in this very vulnerable situation and how open and receptive do you experience that they are?
 - o From your experience, what does it take to initiate and establish lactation for a preterm?
- Based on your experiences, are there any cultural barriers?
 - o When it comes to you as a health worker counselling a woman on infant feeding?
 - o How in your experience do mothers react receiving donor milk to their infant? Is it acceptable or is it culturally problematic? Any examples?
 - o Can you please explain what kind of challenges you have faced during counselling?
- How about religious rituals and customs related to feeding the newborn?
 - o Pre-lacteal feeds: sugar, honey, ghee?

Donation

- One would think that it would be difficult to find mothers who wanted to donate their milk, but maybe I am wrong. What are your experiences? How do you go about recruiting them?
 - o What information do you give to mothers in regards to donation (spoken? Written? Both?)
 - o What do you think motivates mothers to donate?
- Based on your experiences, how do mothers feel about being milk donors and how do they feel about receiving milk? Is this an acceptable thing to do?
 - o How is the Covid-19 situation affecting this?
- Have you experienced any cultural barriers regarding donor human milk?
 - o What do you think will be the reactions from the family when mothers decide to donate milk? How about receiving milk?
- Is wet-nursing a practice that you are familiar with?
 - o Does it happen in your community?
 - o What are your thoughts about this practice?
 - o What do you think about the concept of milk siblings? Is this of relevance to donation of milk in the milk bank?

Closure

- Looking forward, what impact do you think the counseling of mothers has for establishing breastfeeding in preterm babies?

- Is there anything else you would like to tell me about lactation counseling and acceptability of DHM that I have not asked about and that you feel is important?
- Do you have any questions for me?

Appendix D: Semi-structured in-depth interview guide to mothers

Interview guide, mothers

Name:	Contact number:
Date:	Place:
Recorder (yes/no):	Signed consent (yes/no):
Translator (yes/no):	Age:
Educational level:	Occupation:
Religion:	Ethnicity:
Marital status:	Number of children:
Number of pregnancies:	Date of admission:
Gestational age and date of birth on baby admitted to hospital:	Ward admitted to (both mother and baby):
-	
<p>Lactation and breastfeeding support</p> <ul style="list-style-type: none"> - You have just given birth. How are you and your baby doing? <ul style="list-style-type: none"> o If preterm baby – when did you start the stimulation of the breast and how did you experience the support that you received in this process? o If full-born baby- can you remember at what time your baby was put to your breast? Who assisted you and how did you experience it? - Now you are admitted to the milk bank and have received counselling. <ul style="list-style-type: none"> o Can you explain to me how you got in contact with the milk bank? o Can you please tell me about the conversation that you have had with the lactation counsellors? How do you / did you feel about it? - People can have different experiences with establishing lactation, how was it for you? <ul style="list-style-type: none"> o Did you face any challenges with establishing lactation? o What about breastfeeding? Have you tried to initiate it? Or how is that for you and your baby? o What are your thoughts and or experiences with exclusive breastfeeding? 	

- Are there any family members that are especially involved in helping and guiding you with lactation and breastfeeding?
 - Can you say a little bit about your experiences or thoughts about this?
 - What are your thoughts about colostrum, the first thick yellowish milk? Would you give it to your baby? Would your relatives approve of it? What is common in your community?
- How about religious rituals and customs related to feeding the newborn?
 - Pre-lacteal feeds: sugar, honey, ghee?

Donation

- Have you ever come across a woman in your community that gives breastmilk to another woman's baby? If so, what did you think about it?
- Here in the hospital, we talk about donor milk. What have you come to know about donor human milk?
 - What information have you got regarding human milk donation? (spoken? written?)
- People can have different reasons for donating milk. Can you try to explain what your reasons were?
- What do you think will be the reactions from your family when/if you donate milk?
- Have you experienced any other reactions from your friends or the society you live in?
- Is wet nursing a practice that you are familiar with?
 - Does it happen in your community?
 - What are your thoughts about this practice?
 - What do you think about the concept of milk siblings? Is this of relevance to donation of milk in the milk bank?

Closure

- All in all, how have you experienced being admitted to the milk bank?
- Is there anything else you would like to tell me about lactation counselling and milk donations that we have not talked about and that you feel is important?
- Do you have any questions for me?

Appendix E: Ethical approval from Institutional Ethics Committee at Lady Hardinge Medical College & Associated hospitals

INSTITUTIONAL ETHICS COMMITTEE LADY HARDINGE MEDICAL COLLEGE & ASSOCIATED HOSPITALS, SHAHID BHAGAT SINGH MARG, NEW DELHI-110001, INDIA.

LHMC/IEC/2020/91

Dated: 06 Nov. 2020

Dr Sushma Nangia,
Department of Neonatology,
Lady Hardinge Medical College & Associated Hospitals,
New Delhi.

Sub: Research project entitled, "The role of the national comprehensive lactation management centre in strengthening infant feeding for newborns in a tertiary care hospital in New Delhi, India."

Dear Dr Nangia,

Institutional Ethics Committee, LHMC & Associated Hospitals, New Delhi in its meeting held on 05 Nov. 2020 via Microsoft Teams, reviewed and discussed your application in respect of the research proposal "The role of the national comprehensive lactation management centre in strengthening infant feeding for newborns in a tertiary care hospital in New Delhi, India."

Following members were present in the IEC meeting held on 05 Nov. 2020


1. Dr. A.K. Dutta	External Member	Chairperson
2. Dr. Harish K. Pemde,	Internal Member	Member Secretary
3. Mr. Munawwar Naseem	External Member	Legal Expert
4. Mr HR Meena	External Member	Lay Person
5. Dr. J.S. Arora	External Member	Social Scientist
6. Mr. Rajeev R. Singh	External Member	Social Scientist
7. Dr. Sudha Chandella	External Member	Clinician
8. Dr. Monika Bahl	External Member	Medical Scientist
9. Dr. Anup Mohta	Internal Member	Clinician
10. Dr. Ekta Debnath,	Internal Member	Basic Medical Scientist
11. Dr.Indranil Banerjee	Internal Member	Basic Medical Scientist
12. Dr. Manish K. Goel	Internal Member	Public Health Expert

The Committee decision is as under:

Decision- Approved.

The study should be conducted in accordance with the provisions of New Drugs and Clinical Trial Rules 2019, GCP regulations and the ICMR Guidelines for Biomedical Research on Human Participants (2017). You are required to inform IEC, LHMC about any serious adverse events or death of study participants and the amendments in Protocol/ study procedure/site/investigator and also about premature termination of study with reasons. You are also required to submit a final study report at the completion of study/termination of the study, and copies of any future publication arising out of the same. The IEC shall be conducting site visit any time before the completion of the study.

Place- New Delhi


(Dr. Harish K. Pemde)
Member Secretary, IEC



डॉ. हरीश कुमार पेम्दे / Dr. Harish K. Pemde
सदस्य सचिव / Member Secretary
मानव अनुसंधान हेतु आचारणीय समिति
Ethics Committee for Human Research
लेडी हार्डिंग मेडिकल कॉलेज एवं सह-अस्पताल
Lady Hardinge Medical College & Associated Hospitals
शाहीद भगत सिंह मार्ग, नई दिल्ली-110001
Shahid Bhagat Singh Marg, New Delhi-110001

Appendix F: Timeline for data collection

When	Activity	Place	Interviewer	Organiser
10-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
12-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
15-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
19-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
23-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
27-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Kristiansand	Ingvild Andresen	Maheshwar Bhasin
29-Oct-2020	Interview Lactation Counsellor	Zoom: New Delhi/Hovden	Ingvild Andresen	Maheshwar Bhasin
03-Nov-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
04-Nov-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
05-Nov-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
06-Nov-2020	Interview Lactation Counsellor	Zoom: New Delhi/Oslo	Ingvild Andresen	Maheshwar Bhasin
06-Nov-2020	Received ethical approval from ECHR November 6 th , 2020, for conducting interviews with the mothers			
07-Nov - 07-Dec-2020	Study break + planning interviews with mothers			
15-Dec-2020	Interview woman	NICU at LHMC, New Delhi	Sister Shalini Rawat	
15-Dec-2020	Interview woman	NICU at LHMC, New Delhi	Sister Shalini Rawat	

16-Dec-2020	Interview woman	NICU at LHMC, New Delhi	Sister Shalini Rawat
18-Dec-2020	Interview woman	NICU at LHMC, New Delhi	Sister Shalini Rawat
19-Dec-2020	Interview woman	NICU at LHMC, New Delhi	Sister Shalini Rawat
20-Dec-2020	Interview woman	NICU at LHMC, New Delhi	Sister Shalini Rawat
2-Dec-2020 to 15-Jan-2021	Transcription and translation of interviews with mothers	New Delhi	Professional translator
15-Jan-2020	Finalizing data collection		