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The long-term use of pasteurised donor human milk for infant feeding: Mother's perspectives

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Dakota Sykes

CHAPTER ONE: INTRODUCTION

1.1 BREAST MILK AND BREASTFEEDING

From the beginning of time, humankind has grown, survived and flourished on the sustenance of human breast milk. The World Health Organisation (WHO) (2024) recommends that infants be exclusively breastfed from birth until six months of age. Beyond this, infants can be provided with safe and nutritious, complementary foods. However, breast milk can continue to supply infants with half (or more) nutritional requirements from 6-12 months old, and one third of their required nutritional needs in their second year of life (WHO, 2024). WHO (2024) continues their recommendation to state that children should be breastfed until 2 years of age or beyond. The importance of providing breast milk according to these recommendations cannot be understated. Breastfeeding is associated with a decreased likelihood of sudden unexplained death in infancy, obesity, diabetes, asthma, and cardiac conditions later in life (WHO, 2024; Agho, 2023). Furthermore, the benefits to breastfeeding are also relevant to mothers, as women who breastfeed show greater protection against diseases such as ovarian and breast cancer (WHO, 2023a). Breastfeeding also releases oxytocin in the brain of the mother which promotes mother-infant bonding, which is crucial in the early days of parenthood (Modak et al., 2023; Abugov et al., 2021).

How mothers[1] supply their milk to their baby can vary. Some mothers will choose to breastfeed directly from the breast, while others may express their milk using a pump and feed with the use of bottles, syringes, spoons or cups. The decision to feed at the breast or with the use of feeding devices can be influenced by multiple factors (Monteith et al., 2024). The decision to breastfeed is influenced by external factors (Monteith et al., 2024; Ballesta-Castillejos et al., 2020). Mothers may choose to express milk to share feeding duties with a partner, the infant may not be latching well at the breast, need 'top-up' feeds, or the mother is needing to return to work and cannot be available at all feed times (Ballesta-Castillejos et al., 2020). Whether the infant is fed directly from the breast or not, the benefit of receiving breast milk remains the same.

The benefits of breast milk are particularly crucial for infants who are born prematurely. Premature infants are categorized as being extremely preterm (less than 28 weeks), very preterm (28-32 weeks), or moderate to late preterm (32-37 weeks) (WHO, 2023c). Infants born in these categories are at a high risk of morbidity in infancy and childhood, plus greater risk for stunted growth and developmental delay (WHO, 2023a). Sadly, approximately 1 million children die every year as a result of complications from preterm birth

[1] To be a woman, mother or identify with she/her pronouns is not defined by specific genitalia or a biological relationship. However, for the purpose of this study and thesis, the terms woman/women, mother, and she/her will be used to identify women who carry and birth children.

(WHO, 2022). Of those who survive, many can be left with long-term complications such as physical disability, hearing and sight impairments (WHO, 2023c). Furthermore, these infants are particularly vulnerable to infections and illnesses due to their low birthweight (LBW) or very low birthweight (very-LBW) status. For these infants, receiving breast milk is crucial because it contains antibodies and other protective elements which help protect against childhood illnesses and severe gut infections (WHO, 2024). Neonates who require hospitalisation in the neonatal intensive care unit (NICU) are more likely to be discharged early, have lower re-hospitalisation rates, and have greater protection against severe retinopathy of prematurity if they are breastfed (Abugov et al., 2021). Of the illnesses that cause morbidity in children, most concerningly is necrotizing enterocolitis (NEC). NEC is a gut illness caused by bacterial infection in the intestinal wall resulting in severe inflammation which escalates to necrosis of the bowel (Ginglen & Butki, 2024). The progression of this illness can lead to a perforation causing intestinal contents to move into the abdominal cavity and result in peritonitis, sepsis and death (Ginglen & Butki, 2024). This infection almost solely affects neonates with 90% of cases occurring in very-LBW premature infants (Safer Care Victoria, 2024). Additionally, NEC has a mortality rate of up to 50% (dependent on severity of illness at time of diagnosis) and of those that do survive, 25% will go on to develop long-term medical requirements (Ginglen & Butki, 2024; Safer Care Victoria, 2024). It is not completely understood as to why this illness occurs, and due to non-specific symptoms, it can be difficult to diagnose early (Safer Care Victoria, 2024). In premature neonates, it is thought that the immaturity of the gut likely plays a role in the development of NEC and therefore, creates a vulnerability to the illness (Ginglen & Butki, 2024). Current evidence suggests formula fed infants are six times more likely to develop NEC than an exclusively breastfed infant (Safer Care Victoria, 2024). These considerations highlight that all infants, but most importantly, premature infants, should be fed breast milk to help protect their current and future health.

Despite recommendations from the World Health Organisation, statistics from the period of 2015-2020 suggest that approximately 44% of children worldwide were exclusively breastfed until the age of six months (WHO, 2023). Brown et al., (2014) state that women who breastfeed report early cessation of breastfeeding due to concerns regarding their milk supply, inconvenience and fatigue. In other cases, mothers may want to start or continue breastfeeding but may not be able to due to illness, low milk supply, previous breast surgery, or contraindication to breastfeeding due to medication use (Whitburn, 2022). Additional barriers can exist for mothers who have birthed prematurely, with Dong et al., (2022) finding that over 50% of mothers with preterm infants were unable to initiate breastfeeding due to delayed onset of lactogenesis II. This stage of lactation is defined as the onset of copious amounts of milk production and generally occurs between 50-73 hours postpartum (Dong et al., 2022). Prematurity presents barriers to breastfeeding due to the baby being hospitalised for a period of time (Abugov et al., 2021). During this hospitalisation period, delayed initiation of breastfeeding may occur due to factors such as separation of mother and infant, medical fragility, maternal distress, lack of privacy and consistent support, and rigid feeding schedules (Abugov et al., 2021). All of these factors contribute to mothers being unable to supply

their own milk to their infant (Abugov et al., 2021). In such cases where mother's own milk is unavailable to an infant, the WHO (2023a) states that donor human milk is the next best alternative.

1.2 HISTORY OF HUMAN MILK DONATION AND SHARING

Donor human milk is milk that is supplied from lactating women for the purpose of being fed to infants who are unable to access or receive adequate supply from their own mother (Peregoy et al., 2022; Whāngai Ora Milk Bank, n.d). Before 1865, alternatives such as infant formula were not yet developed, and infants required human breast milk to have the best chance at survival (Stevens et al., 2009). However, during the 17th and 18th centuries in England, half of children born alive would die by the age of 2 due to being fed directly from an animal such as a goat or donkey, while others were fed a mixture of bread and water (pap) instead of milk (Weinberg, 1993). According to Weinberg (1993) maternal breastfeeding was not hugely popular due to woman feeling as though it soiled their clothes and restricted their ability to enjoy their usual activities. It was soon recognised that the use of raw animal milks and pap often risked infants' lives by causing failure to thrive leading to a premature death (Radbill, 1981 as cited in Stevens et al., 2009; Weinberg, 1993). Developments came slowly when Dr Hugh Smith made recommendations to start boiling animal milks for the first 2 months of an infant's life, but still high mortality rates persisted (Weinberg, 1993). Eventually it was recognised that babies needed to be fed their mother's own milk (MOM) to have the best chance at survival or alternatively, another lactating women's milk would also suffice (Stevens at al, 2019; Weinberg, 1993).

Before the introduction of infant formula, in scenarios of illness, death, separation, an unwillingness to breastfeed, or difficulty with milk supply, women would often utilize the services of a wet nurse (Marinelli, 2020; Stevens at al, 2009; Weinberg, 1993; Baumgartel et al, 2016). In the United States of America, the responsibility of being a wet nurse was one which often landed in the hands of black women in slavery, required to feed the infants of the white families who enslaved them (Marinelli, 2020; West & Knight, 2017). Meanwhile, the wet nurses' own children were fed by other enslaved women or given animal milks despite the known health risks (Marinelli, 2020; West & Knight, 2017). In America in 1865, Justus von Liebig developed the first infant formula (Radbill, 1981 as cited in Stevens et al., 2009), and by 1883, 27 different infant formulas were available for purchase (Fomon, 2001). Stevens et al. (2009) states that by 1900, a shift from utilizing wet nurses to utilizing powdered forms of infant formula took place. Wet nurses developed a bad reputation for supplying opiate medications as sleeping aids to the infants they fed and new beliefs arose that infants could be transmitted illnesses or adverse characteristics through the milk they received from these women (Stevens et al., 2009; Weinberg, 1993; Baumgartel et al, 2016). For these reasons, the concept of using another women's breast milk became socially unacceptable and high-income families began using infant formula as their alternative form of feeding (Stevens et al., 2009). Following the Industrial Revolution, women began working to contribute financially to the household and could not always stay home to feed their infants. In these scenarios, families who could not afford infant formula

were left to utilise the services of peasant women to step into the mother's place to breastfeed on their behalf (Stevens et al., 2009).

Moving forward to current times, women of reproductive age hold a significant role in the labour market and often find alternate care arrangements for their children to be able to return to work (Gammage et al., 2019). However, with the developments of infant formula, bottles, and breast pumps, it is now easier for children to be fed in alternate ways (e.g., formula fed or expressed breast milk in a bottle) and the need for a wet nurse (a women directly breastfeeding another women's baby) has all but disappeared (Stevens et al., 2009). Although the concept of a wet nurse has fallen away, the act of utilising another women's breast milk (in a donated sense) is far from being extinct. As previously discussed, there is a definite need for alternate sources of human milk when a mother is unable to provide adequate supply herself. This is most crucial for infants who are born pre-term, low or very-low birth weight, and require breast milk over infant formula to decrease the risk of conditions such as NEC. The process of obtaining donated milk takes various forms and is perceived differently from culture to culture, with ancient Egyptian depictions highlighting wet nurses as being close in nature to their goddess of fertility, Hathor (Baumgartel at al, 2016). Comparably, in areas of Islamic faith, sharing breast milk with another child creates a milk kinship relationship where the recipient child and the biological child of that women become milk siblings (Long, 2003; Karacan et al., 2024; Akpinar et al., 2022). This creates some tension in Muslim cultures about whether milk sharing is an appropriate practice or not due to the potential of milk siblings marrying in the future (Long, 2003; Karacan et al., 2024; Akpinar et al., 2022). The key feature of these feeding arrangements is that the infant is generally still fed by one women (Thorley, 2008). However, in some areas of Australia, such as within Indigenous cultures, the feeding of an infant has been known to be shared between two or more woman who are well known to each other (Thorley, 2008). This type of feeding arrangement is known as cross-feeding and differs from wet nursing as it is usually a reciprocated arrangement where each of the women have a child that is fed by themselves and others (Thorley, 2008). The practice of cross-feeding is not isolated to remote or rural Indigenous communities of Australia, with reports of these same feeding practices occurring in Brazil. Interestingly, despite Brazil having the largest network of formal milk banks worldwide (Boccolini et al., 2023), women have reported using cross-feeding instead of milk banks. However, the exact motivations for this (in the context of a country with a significant amount of milk banks) remain not fully understood (Boccolini et al., 2023). Comparatively, in Auckland (New Zealand's largest and most populated city) there is no formal human milk bank available for parents to receive pasteurised donor human milk. Therefore, parents who wish to provide breast milk to their child without their own sufficient supply, turn to informal milk sharing relationships, such as ones sought through social media platforms (Harris et al., 2024).

1.3 DONOR HUMAN MILK

In some locations across the world, the main form of obtaining human milk is through peer-to-peer relationships, often formed through the internet and social media platforms (Peregoy et al., 2022). In these

relationships, often one woman (milk donor) has an oversupply of milk (or previously expressed excess milk to donate), and another (milk recipient) has an under supply, and an informal agreement takes place where an exchange of milk is made (Peregoy et al., 2022). These relationships can be arranged as a free exchange of milk or for monetary gain for the donor. Alternatively, like in cross-feeding, there appears to be no financial or social gain for either party, it is simply viewed as a way of life (Thorley, 2008). If the milk is sold, then this is referred to as 'milk selling'. Informal milk sharing or selling relationships can be surrounded by controversy due to the inability to test the milk that is donated/sold to ensure its safety before feeding it to the infant (Palmquist & Doehler, 2016). Furthermore, the women donating milk are not systematically screened for any diseases or medications which could penetrate their milk supply (Palmquist & Doehler, 2016). Despite these risks, in countries such as the United States of America (USA), the selling of breast milk is considered similar to selling any other food source. It is not illegal, but some regulations do exist (Milet, 2020). For example, women can face legal implications if they are found to be knowingly selling compromised milk, such as milk being bulked up with water or cow's milk, or milk expressed by a person with known medical conditions or medications which could impact the infant (Dawson, 2011). However, due to a buyers' inability to use human milk analysers, it is difficult to prove that milk has been tampered with and therefore, hard to prosecute (Dawson, 2011). Comparably, in New Zealand, laws exist which do not permit private sale of breast milk as it is considered human tissue under the Human Tissue Act 2008 (New Zealand Breastfeeding Alliance, 2019). Therefore, for women in New Zealand to receive donated breast milk, they would need to engage in an informal milk sharing relationship (either through a family member, friend or unknown person) or seek help from a milk bank where donors are screened and voluntarily donate their milk for no monetary gain (Harris et al., 2024). Due to the limited number of milk banks in New Zealand, this is not an option for all women. Some women report being offered milk from other parents they know and using this for their baby (Harris et al., 2024). Informal milk sharing holds some risk of inadvertent transfer of pathogens. Therefore, recommendations in New Zealand exist that if women are to use another women's unpasteurised breast milk, they should ask the milk donor to complete baseline screening for HIV, human T cell lymphotropic virus, hepatitis B and C, syphilis and cytomegalovirus (Starship, 2019). For women who live in areas of New Zealand where human milk banks are available, this is the preferred method of using another women's milk. Milk banking is a legal and regulated process for women and families to receive donated breast milk (Tyebally Fang et al., 2021).

1.4 HUMAN MILK BANKING

A human milk bank is a service which recruits and screens acceptable donors, collects donated milk, tests and pasteurises[2] the milk, and distributes it to families with infants that need it for optimal nutrition (Tyebally Fang et al., 2021). Milk obtained in this manner is safe to feed to infants (Whangai Ora Milk Bank,

[2] Pasteurised milk refers to milk which has undergone a process of heating to a specific temperature for a period of time to kill any harmful bacteria or organisms within the milk (South Australia Health, 2024).

n.d.). The first milk bank opened in Vienna, Austria in 1909 and operated alone for 10 years before another opened in Boston, USA in 1919 (Kim & Unger, 2010). Slowly but surely, milk banks opened in more places across the globe until the 1980s (Kim & Unger, 2010). In this decade, human immunodeficiency virus (HIV) received a lot of public attention and the fear of transmission from infected mothers to vulnerable babies was rife (Kim & Unger, 2010; Meeks et al, 2019). This fear led to many milk banks closing globally, and women's alternative feeding options once again became limited (Kim & Unger, 2010). To counteract the risk of HIV transmission through donated breast milk, regulatory bodies were developed (such as Human Milk Bank Association of North America and United Kingdom Association for Milk Banking), and laws to govern the process of milk donor screening and pasteurisation were defined (Monti et al, 2024). Governing bodies like the Human Milk Bank Association of North America (HMBANA) consist of medical professionals such as doctors, nurses, lactation consultants, infection prevention teams and dieticians to oversee the working of milk banks and ensure the risk of transmission of infectious diseases remains low (Kim & Unger, 2010). Through the development of these regulatory processes, human milk banks became an arm of the health system. Faith in the safety of milk banks was restored and the option of using pasteurised donor human milk was available again.

In New Zealand, the first human milk bank, Waitaha Canterbury Human Milk Bank, was established in 2014 at Christchurch Women's Hospital (Te Whatu Ora, 2024a). This milk bank was originally aimed at supporting mothers who desire to breastfeed, and their secondary goal was to provide optimum nutrition to vulnerable babies who were high risk for gastrointestinal infections due to their preterm and LBW/very-LBW status (Meeks et al., 2019). Meeks et al, (2019) state that these aims were set out in this order following an audit of formula use within the hospital's neonatal unit. This audit showed that significant levels of formula were being used predominantly in the late preterm population (34 – 36 weeks gestation). Therefore, this cohort of infants would likely be the greatest users of PDHM. Given the gestation of these infants, it was presumed that on average the supply of milk coming from their own mothers would be established and sufficient by 7-days of life. Therefore, each infant would likely need PDHM for a week before being fully fed by their MOM (Meeks et al., 2019). The Waitaha Canterbury Human Milk Bank recognised that infants born earlier than 32-weeks' gestation would likely require PDHM for a longer period however, the numbers of babies born this early were relatively small (Meeks et al., 2019). However, the number of preterm babies requiring PDHM is likely rising as according to the World Health Organization (2012) the global rates of preterm birth are increasing and have been for some time. This could therefore impact the overall aims of a milk bank and the accessibility to the milk for some families. To increase accessibility across the country, since the development of the first milk bank in New Zealand, a further three have now become operational with Waitaha Canterbury Human Milk Bank facilitating the opening of another with specialised training (Te Whatu Ora, 2024). Additionally, the National Breastfeeding Strategy for New Zealand Aotearoa highlights support for safe provision of donor breast milk as a key outcome area (Te Whatu Ora, 2024b). Within this key outcome area, New Zealand's health system is currently aiming to increase accessibility for families to use pasteurised donor human milk through registered milk banks (Te

Whatu Ora, 2024b). However, this strategy does also recognise and aims to work on strengthening safety protocols for families who use informal milk sharing practices, such as free screening, support systems and guidelines for storage and transportation of breast milk (Te Whatu Ora, 2024b).

1.5 THE CONTEXT OF MILK BANKING IN NEW ZEALAND

Milk banking is a relatively new venture in the New Zealand health system, with the first human milk bank (HMB) opening in 2014 in Canterbury (Lamb et al., 2021). There are now 5 milk banks across the country (Te Whatu Ora, 2024). These milk banks are called and located in:

- Waitaha Canterbury Human Milk Bank – Canterbury
- Pataka Miraka Mothers Milk Bank – Wellington
- Whāngai Ora Milk Bank – Manawatū-Whanganui
- Rotary Community Breast Milk Bank – Canterbury
- Nelson and Wairau Maternity Unit Milk Banks – Tasman/Malborough[3]

These services receive milk from lactating women which is pasteurised for the use of being fed to infants (Whāngai Ora Milk Bank, n.d.). Milk banks are available to parents who are needing to supplement their newborn's feeding requirements and can access the service to receive safe, tested human milk (Whangai Ora Milk Bank, n.d.). However, the availability of this milk varies across locations based on stock levels of milk. The Human Milk Bank in Canterbury opened in 2014; however, it was not until 2017 that this service was able to offer their milk stores to families outside of the NICU that it was supporting (Te Whatu Ora, 2024a). From here, it took another 3 years to extend their services to other hospitals and NICUs, as stock levels allowed (Te Whatu Ora, 2024a). This demonstrates that since 2014, there has been a rise in the amount of women donating breast milk to milk banks in New Zealand. Therefore, allowing a broader spectrum of where these services are utilised. Even so, the amount of milk being donated may not always meet the needs of the community. Therefore, all locations follow the same standard that milk stocks be given to the highest priority infants first, such as neonates in NICU who cannot and do not have any alternative (Australian Government Department of Health and Aged Care, 2022).

Mother's own milk is specifically designed for her infant and the nutritional properties within the milk change depending on the needs of the baby. This process is so specific to the needs of the infant that the milk can be adapted from one feed to another or even from the start of a feed to the end of it (Australian Government Department of Health, 2014). The concern with PDHM is whether it is as beneficial to the infant as their mother's own milk. Research in New Zealand has investigated the properties of pasteurised human milk, and has demonstrated that following the pasteurisation process, human milk continues to hold over 200 components which support infant health and growth (Te Whatu Ora, 2024a). Furthermore, Lamb et al., (2021) states that in the future there is opportunity for human milk banks (HMB) to utilise

[3] Not yet operational.

human milk analysers to gain further nutritional information on the milk that is donated. This could then allow the individualisation of milk prescriptions for infants (Lamb et al., 2021). For example, donated milk that is protein dense could then be prescribed for a neonate in NICU who is experiencing protein deficiency (Lamb et al., 2021). Similarly, mothers whose infants are experiencing poor weight gain or feeding intolerances, could have their milk tested for further nutrient information (Lamb et al., 2021). Breast milk contains differences in composition during daytime and nighttime hours. Breast milk is influenced by a women's circadian rhythm and milk that is produced during the day tends to have higher levels of cortisol, a hormone that helps to keep us awake (Akanalci & Bilici, 2024). Comparatively, breast milk that is produced overnight contains higher levels of melatonin, a hormone that helps us sleep (Akanalci & Bilici, 2024). There is future potential in being able to analyse breast milk so specifically, that melatonin rich milk could be fed to an infant at night to aid in supporting their circadian rhythm. These examples demonstrate the impact PDHM could have on the health and wellbeing of infants and their families.

1.6 MILK BANKING CONTEXT GLOBALLY

AUSTRALIA

Australia currently has 5 operational human milk banks situated in Western Australia, New South Wales, Victoria, and Queensland, and are connected to both public and private hospitals (Australian Government Department of Health, 2014).

EUROPE

Europe has approximately 282 human milk banks operating throughout various countries (European Milk Bank Association, 2021). Some of these are located in the following places:

Table 1: European countries and corresponding amount of operational milk banks

Country	Milk banks
France	36
Italy	39
Sweden	28
United Kingdom	15
Finland	17
Norway	12

Note: Human milk bank estimates as per European Milk Bank Association (2021).

NORTH AMERICA

Approximately 29 not-for-profit milk banks operate across United States and a further 3 in Canada (Human Milk Banking Association of North America, 2024).

BRAZIL

Brazil has 228 human milk banks plus an additional 236 collection stations (Pan American Health Organization, n.d.).

HUMAN MILK BANKS COMPARISON BETWEEN COUNTRIES

Table 2: Human milk banks per 1,000,000 people

Country	Population estimates	Milk banks	Human milk banks per 1,000,000 people
France	67 million	36	0.5
Italy	58 million	39	0.7
Sweden	10 million	28	**2.8**
United Kingdom	67 million	15	0.2
Finland	5 million	17	**3.4**
Norway	5 million	12	**2.4**
Canada	38 million	3	0.08
United States	333 million	29	**0.09**
New Zealand	5 million	5	**1**
Australia	26 million	5	**0.2**
Brazil	215 million	228	1

Note: Population estimates all retrieved from The World Bank (2024).

The above data highlights multiple important concepts. First, that human milk banking appears to be more available in some countries compared to others. By considering the population of a country alongside the amount of milk banks, a 'per 1 million' calculation can be made to enable an easier comparison. Through this calculation, some assumptions could be made that in countries such as Sweden, Finland, and Norway, there is a higher amount of milk banks available per million people because there are high rates of breastfeeding. High levels of breastfeeding promote more women to donate, therefore, the incoming supply is adequate to justify more milk banks (European Milk Bank Association, 2021). Greater levels of donation may be due to decreased social stigma or efficient and targeted public health education programs. Additionally, it could be argued that more milk banks are simply a direct result of having a higher population. Yet comparatively, in the United States the opposite appears to be true, and the large population has not resulted in a significant amount of milk banks. This may be due to the commercialisation of donor milk resulting in a decreased demand and therefore, supply. For example, in the US, milk banks often charge hospitals a processing fee of US$3-5 per 30ml of donated breast milk (equally approximately NZ$100-166 per litre of milk) and oftentimes this fee is passed onto the families directly (Australian Government Department of Health, 2014). The hypothetical demand for more HMBs to

serve the large population may be there, but due to women and families being unable to afford donated milk (due to level of health insurance), the literal demand may be low resulting in a minimal amount of HMBs. Rose et al., (2022) state that safety-net hospitals (healthcare institutions who see patients regardless of their insurance status) and Black and Hispanic women are the least likely to utilize donor human milk (McNeill et al., 2023). This demonstrates that despite North America having non-profit milk banks available in the health system, those most likely to be without health insurance are still facing barriers to using such services (Rose et al., 2022). This highlights an equity issue in terms of who donor milk is available to and used by.

Additionally, *Table 2* highlights an important factor in the global picture of milk banking, that although Australia is close to New Zealand in both a cultural and proximity context, the human milk bank landscape is very different. With New Zealand's population of approximately 5 million people, exists 5 human milk banks (Stats NZ, 2023). Comparatively, Australia holds a population of approximately 27 million and also has 5 milk banks (Australia Bureau of Statistics, 2024). This demonstrates greater milk banking accessibility in a New Zealand context, compared to Australia. However, the cause for this is difficult to ascertain given the similarities between the two countries in regard to the social norms of breastfeeding. It is possible that this difference lies solely in the differences of healthcare systems. Overall, by considering the differences between countries in milk banking, it is possible to view New Zealand's milk banking abilities within a wider context of what is the norm globally.

1.7 POSITIONALITY OF THE RESEARCHER

When I became a mother, I was privileged to have a child born full term (at 40 weeks exactly). He was born without any significant health concerns, and I was also healthy and well. I spent a few days learning how to help him latch and breastfeed. There were times when he wouldn't latch at all, and under my midwife's direction, I syringe fed expressed colostrum to him. However, these minor hiccups soon passed, and he and I both somewhat mastered the art of breastfeeding (in our own way). He was exclusively breastfed for 4 months, where we then moved to formula and eventually solids. Ultimately, when I look back on my early days of motherhood and feeding, I can still feel the overwhelm of wanting to do what is 'right'. There is an unspoken aspect of becoming a new mother, one that was not mentioned to me before I experienced it - that along with the new bundle of joy in your arms, comes a heavy weight on your shoulders. That every decision you make, you will second guess, and every decision you make, will be the wrong one to someone else. Many people, should they be privy to your life and decisions, will question whether you are doing what is 'right'. The decision of how to feed a baby, is not exempt from this, more so, I believe it receives more scrutiny than a lot of the other decisions parents make.

When a child is born, a mother goes through a physical, psychological and social change, a stage referred to as matrescence (Raphael, 1981). Often in medical and social terms, matrescence is not sufficiently recognised in the aftermath of birth, instead the focus is shifted from the mother to the baby. It often becomes more about what the baby needs and less about what the mother needs. This can be particularly

true when it comes to feeding infants. For example, an exclusively breastfed infant continues to need to feed, even when the mother is experiencing breastfeeding complications such as painful, cracked, bleeding nipples or even mastitis (The Royal Women's Hospital, n.d.). Furthermore, a baby may not simply take to a bottle purely because their mother needs to return to work (Maxwell et al., 2020). In the same regard, a premature neonate who is classified as having a low or very low birth weight, has the best chance of thriving and growing, if they have access to breast milk (WHO, 2024). This does not change even if their mother is unable to produce enough breast milk for them.

These examples demonstrate that mother's needs, emotional and physical, are often secondary to that of their infant. This process of stepping into a new role and recognising the shift in the hierarchy of needs can be difficult, physically and emotionally. A mother's choice to choose pasteurised donor human milk (PDHM) to meet the needs of her infant, may be questioned by others (social stigma) or questioned by the mother herself (feelings of uncertainty, ashamedness, inadequacy). Women should be supported through their journey into motherhood. For some women, their journey is reasonably straight forward, like my own. For others, the journey of matrescence is one that is shrouded in decisions which feel difficult but are for the best needs of their baby. For the women who have walked that path, and the ones that will in the future, I hope to explore the experiences of women who use or have used pasteurised donor human milk. Through this, if there are common themes of experiences, this knowledge could inform better supports and better education for future donor and recipient mothers, and the social and medical professionals working with them.

1.8 STUDY JUSTIFICATION

It has been previously discussed that infants have the greatest potential to thrive when provided with their optimal nutrition, breast milk (WHO, 2024). However, when faced with not being able to breastfeed for either personal, medical or environmental reasons, formula tends to be the most popular alternative feeding option that parents turn to. This could be due to accessibility issues, religious or cultural reasons, social stigma, or lack of knowledge and understanding of using PDHM.

In the literature, there has been greater emphasis on researching the viewpoints of milk donor, and much less on the women receiving the milk. Although there is a benefit in understanding how women, nurses, midwives, fathers and milk donors feel about milk donation, it is vital to explore the lived experiences of mothers receiving donated milk for their infants. Within the limited capacity in which mother's lived experiences have been explored, it is often mothers who have used PDHM short-term. Often these studies investigate the experiences of women who have used PDHM for a couple of feeds to a couple of days. As Meeks et al., (2019) explain, auditing of formula use within neonatal units (specifically in Christchurch, New Zealand), has demonstrated that late preterm infants are the greatest users of short-term formula following birth, and this has therefore been translated into this same group being the greatest users of short-term PDHM (following the opening of a local milk bank in this area). This clinical context of milk banking could partly justify why women who use PDHM short-term are more thoroughly represented in the

available literature (Kair & Laherman, 2017; Jackon et al., 2023; Loh et al., 2022; Ahmed et al., 2024; Chaudari & Ayer, 2024; Kimani-Murage et al., 2018; Akpinar et al., 2022; Karacan et al., 2024; Esquerra-Zwiers et al., 2016; Mahlatjie et al., 2022; Magowan et al., 2020; Noble-Carr et al., 2022; Namuddu et al., 2023; Howard, 2012; Obeng et al., 2023). Despite the greatest use of PDHM being in the first 7-days of life, there are many scenarios where women are unable feed their own milk to their infant after this period or need to continually supplement their own milk supply. For these women, there is a lack of exploration into the experiences of mothers who have engaged with breast milk bank services and utilised PDHM long-term. These women should have their experiences, thoughts, beliefs and feelings considered to fill knowledge gaps and highlight areas of improvement for milk banks supporting long-term users.

Women who use PDHM long-term may do so because of an inability or difficulty to breastfeed due to medical reasons such as previous breast surgery, receiving current cancer treatments, or taking other medications which are not proven to be safe for breastfeeding (Stanescu et al., 2019). In other scenarios, women simply cannot produce enough milk for their baby long-term. This study aims to investigate the lived experiences of mothers that have used PDHM on a long-term basis. For the purpose of this study, long-term is defined as equal to or greater than two weeks. Within the included dataset, women used PDHM from three weeks until six months. Through thematic analysis, as outlined by Braun & Clarke (2012), themes will be inductively identified, and it is hoped that these themes will shape the way that support for PDHM is offered within the maternal health space. The use of in-depth semi-structured interviews have been used to explore the physical and emotional journey of mothers who use PDHM to feed their child. To develop a comprehensive understanding of this journey, this research undertakes a narrative enquiry approach. This research has been guided by the following research questions (1) how do women describe using pasteurised donor human milk long-term? (2) how are mothers currently supported to use PDHM in a long-term sense (both from a medical and community standpoint)? (3) how does long-term use of PDHM affect their sense of being a mother? And (4) what more can be offered to women using PDHM long-term to support this part of motherhood?

CHAPTER TWO: LITERATURE REVIEW

2.1 REVIEW OF LITERATURE WHICH EXPLORED PERSPECTIVES OF PASTEURSED DONOR HUMAN MILK

Massey Discover was the chosen search engine for finding relevant literature. It incorporates literature from a wide variety of databases including Medline, PsychINFO, and CINAHL. The final literature search string was *(("donor* milk" OR "milk bank*" OR "donor human milk" OR "donated milk" OR "donated human milk")) AND ((qualitative OR "grounded theory" OR phenomenolog* OR ethnog* OR "case study" OR historical OR "focus group" OR "thematic analysis" OR ethnogr* OR "action research" OR "participatory research" OR "semi-structured interview*" OR narrative OR "lived experience*" OR "subjective*

experience" OR "personal experience*"))* and resulted in 397 hits, of which 205 were duplicates. The remaining 193 articles were screened by title and abstract for their relevance to this literature review.

During this screening process, 22 articles were excluded due to being written in a non-English language and 149 were excluded for being beyond the scope of this research. Of the remaining 22 articles, an additional eight articles were excluded due to being focused on mother's own milk or donor milk that is not pasteurised. This literature search resulted in 14 articles being included in the final review. An additional search was conducted through PubMed using the same search string. This resulted in 85 hits, although many were duplicates of the initial search through Discover. These 85 articles were screened by title and abstract and one additional article was selected to be included in the final review. This resulted in a total of 15 articles of relevant literature.

Multiple research topics are noted within the literature. Experiences have been explored of women who use PDHM, women who donate milk, partner/husbands of women who use or donate milk, and health professionals who care for families who use PDHM (Kair & Laherman, 2017; Jackon et al., 2023; Loh et al., 2022; Ahmed et al., 2024; Chaudari & Ayer, 2024; Kimani-Murage et al., 2018; Akpinar et al., 2022; Karacan et al., 2024; Esquerra-Zwiers et al., 2016; Mahlatjie et al., 2022; Magowan et al., 2020; Noble-Carr et al., 2022; Namuddu et al., 2023; Howard, 2012; Obeng et al., 2023). These perspectives provide beneficial insight and are helpful to see the bigger picture of milk donation in the maternal and child health space. Additionally, this literature can help identify knowledge gaps and potential stigma throughout communities. However, the women who use the milk for their infants are at the centre of this phenomenon and it is essential their stories, feelings and beliefs are sufficiently explored. From the reviewed literature, there is some research into the thoughts of mothers who have used PDHM on a short-term basis (from a couple feeds to a couple of days). However, there appears to be a knowledge gap and limited research into how women who use PDHM long-term perceive their journey.

Below is a review of literature that surrounds PDHM. This includes beliefs of women when deciding whether or not to use PDHM, women who donate breast milk, partners of birthing women, and medical professionals working in child and maternal health environments. The literature on PDHM is complex because one study often investigates the views of some or all of the above people. Additionally, the researchers often ask of the participants to consider not only receiving donor milk, but also donating their milk to someone else.

2.2 WOMEN'S BELIEFS OF ACCEPTING AND DONATING BREAST MILK FOR SHORT-TERM USE

For mothers who have used PDHM, the available literature mostly considers those who have used it short-term. This might be because PDHM is largely considered a short-term 'solution' even when some mothers have a long-term 'problem' of not being able to feed their own milk. However, it could also be because audits of PDHM use in hospitals have shown that most commonly, women use PDHM in the first 7-days of their child's life (Meeks et al., 2019). Short term PDHM use has been investigated across multiple countries

to seek the perspectives of mothers who needed to supplement their breastmilk with formula or PDHM (Kair & Laherman, 2017; Jackon et al., 2023; Loh et al., 2022; Ahmed et al., 2024; Chaudari & Ayer, 2024; Kimani-Murage et al., 2018). Reasons for infants requiring supplemental feeding appear to be similar across studies and are usually due to concerns being cited as premature birth, low milk supply, difficulty latching, cleft lip/palate, hypoglycaemia or high infant weight loss (Kair & Flaherman, 2017; Jackon et al., 2023; Loh et al., 2022). Generally, women face a range of cultural, social and health and safety concerns when deciding to use PDHM and these are explored further below.

FACTORS WHICH AFFECT A WILLINGNESS TO ACCEPT DONATED MILK

Women tended to view PDHM as a short-term solution whereas formula is a long-term plan. This was partially due to the unknown costs of utilizing pasteurised donor breast milk. Particularly within studies conducted in America, the concern of paying for PDHM on an ongoing basis was relevant as within the USA, it is a commercialized product (Kair & Flaherman, 2017). Comparatively, none of the women in the research conducted by Kair & Flaherman (2017) felt concerned about their ability to access and afford infant formula and therefore, felt safe choosing this option. Both studies found some mothers initially had no plans to move to infant formula but were offered free samples of it during their hospital stays and therefore, decided it was a good option of supplementation. The available literature demonstrates that a key factor to accepting donated breast milk short-term is understanding one's own limitations in what a women can provide for her baby (Loh et al., 2022). Loh et al. (2022) found that women describe an innate sense of maternal responsibility to feed their infant and can feel shame and guilt when they are unable to fulfill this. Some research outlines preconceived ideas of PDHM and how this affects a women's willingness to accept it for their baby. Kair & Flaherman (2017) found that women who choose PDHM considered it to be a "healthy" and "natural" alternative to their own breast milk, whereas those who didn't, felt hesitant and saw it as "creepy" and "weird". Similar negative feelings toward PDHM were found in research conducted by Jackon et al. (2023) when one mother likened using donated breast milk to use someone's hairbrush or underwear. While another stated she would sooner give her baby porridge to eat than milk from another women (Jackson et al. 2022). Loh et al. (2022) outlines that a deciding factor of how women move past the initial hesitancy phase and end up choosing PDHM is if they reach a level of acceptance of their own milk supply and have a strong preference for breast milk over formula. Another contributing factor to moving through the stage of hesitancy was women feeling it was the best for their baby (Esquerra-Zwiers et al., 2016; Obeng et al., 2023). Most women across a range of literature who decide to use PDHM, find comfort in their child's ability to still receive human breast milk and its benefits, despite it not being their milk (Loh et al., 2022; Jackon et al., 2023; Kair & Flaherman, 2017). Yet, on occasion women have felt their baby did not tolerate the PDHM, noting their child had excessive milk spills, and therefore this created a negative experience for them (Chaudari & Ayer, 2024).

CULTURAL INFLUENCES ON RECEIVING DONATED MILK

What is noticeable across most studies, is how women perceive PDHM use (both as a recipient and a donor) is impacted by their culture. This is demonstrated in the research by Loh et al., (2022) which

investigated mothers who have used PHDHM in Singapore. Loh et al. (2022) reinforced the generalised experience of hesitancy found in studies conducted by Kair & Laherman (2017) and Jackon et al. (2023). However, Loh et al. (2022) also found that for some participants, this hesitancy stretched further beyond just how they felt and into the rules they abide by under Islamic Law (Loh et al., 2022). Hesitancy to accept donated milk due to Islamic faith has been documented across studies with research by Ahmed et al. (2024) and Karacan et al. (2024) uncovering similar findings. When the research of Ahmed et al. (2024) asked 410 women about their willingness to receive donated milk, 129 (31.5%) stated not wanting to receive PDHM out of fear of the milk being unsafe and culturally and religiously inappropriate. Similarly, a study conducted in Turkey found that women often declined PDHM due to religious reasons also (Karacan et al., 2024). These studies highlight that in Islamic faith it is believed that if an infant receives breast milk from a woman greater than five times, this infant then becomes a 'milk sibling' to that woman's children and it is forbidden for this 'milk child' to marry her biological child (Karacan et al., 2024; Ahmed et al., 2024; Loh et al., 2022; Akpinar et al., 2022; Kimani-Murage et al., 2018; Obeng et al., 2023). Woman of Islamic beliefs feel they cannot accept donated breast milk unless they are given the details of the mother who donated it and can ensure their biological and 'milk' children do not marry (Karacan et al., 2024; Kimani-Murage et al., 2018). Akpinar et al. (2022) found the same belief of milk siblings in a separate Turkey-based study, where 196 (72.3%) women stated they would not seek donated breast milk from a milk bank if the need arose. Interestingly, women agreed they would be willing to donate their milk for another to use. However, specific to this study of Islamic women, there were restrictions on what donation would look like, such as wanting to donate to a known person but not an anonymised milk bank (Akpinar et al., 2022). Conversely, the Muslim women in research conducted by Loh et al. (2022) believed they could be exempt from the issue of milk siblings because the milk they received was from an anonymous donor.

WOMEN'S REASONS FOR DECLINING PDHM

A strong reason women choose to not accept PDHM is beliefs that their child could receive unwanted illness through the donated breast milk (Chaudari & Ayer, 2024). This was particularly true in Kenyan-based research conducted by Kimani-Murage et al. (2018), where some women shared strong opposition to the thought of human milk banking due to fears of HIV transmission. Furthermore, some women express concern about the lifestyle of the donating women with fears around their alcohol and tobacco consumption, or even if they eat meat or not (Chaudari & Ayer, 2024). Most concerning are misbeliefs around donated milk that babies could receive the characteristics of the women who is donating to them (Chaudari & Ayer, 2024). Research by Kimani-Murage et al. (2018) found similar attitudes of women fearing what is passed onto the child but also how it would affect their mother-baby bond. Some women even described a sense of jealousy that somebody else could feed their baby, but they couldn't (Esquerra-Zwiers et al., 2016). While others took the offer of PDHM as a personal attack on their ability to provide their child, citing their anger towards health professionals for even offering it, as if they couldn't do a good enough job themselves (Esquerra-Zwiers et al., 2016). An additional aversion against PDHM has been noted with most mothers lacking education on the pasteurisation process but had some thought that the

milk was being 'cleaned' in preparation for infant feeding (Kimani-Murage et al., 2018; Chaudari & Ayer, 2024). These myths of PDHM and the personal attack that women are feeling show that offering PDHM should be done with thoughtfulness and a willingness to educate.

'IT'S OK FOR SOMEONE ELSE BUT NOT FOR ME'

Within the literature, there is an apparent disconnect between how women feel about receiving milk versus donating it. Most women interviewed in research can agree to the benefits that breast milk can offer infants (Ahmed et al., 2024; Kair & Laherman, 2017; Jackon et al., 2023; Loh et al., 2022). However, participants often report seeing value in the role of PDHM for others but view it as unusual if they were the ones who needed it for their own babies. An example of this is within the research by Akpinar et al. (2022) where women were asked about their thoughts on receiving donated milk compared to donating the milk themselves. Over half of the women interviewed (57.9%) states they would be happy to donate their milk to a milk bank (Akpinar et al., 2022). However, less than a third (27.7%) stated they would agree to receiving milk for their infant. Similarly, Kimani-Murage et al. (2018) found that women were generally happier to donate their milk to a human milk bank than receive it for their own child.

HOW WOMEN FEEL ABOUT DONATING THEIR MILK

Ahmed et al. (2024) found all mothers viewed milk donation for others as a positive way to manage excess milk supply and assist others in need. These findings are replicated in multiple others, whereby women report their willingness to donate their milk to a human milk bank (Kimani-Murage et al., 2018; Chaudari & Ayer, 2024; Jackon et al., 2023; Kair & Laherman, 2017). Mothers stated not wanting to waste milk when it could be donated and wanting to support other mothers and unwell infants (Ahmed et al., 2024; Jackson et al., 2023; Akpinar et al., 2022). Women who donate milk in research conducted by Jackon et al. (2023) cited formula shortages as a driving factor for their willingness to donate excess milk. They felt concerned about babies going hungry from having an unreliable food supply such as formula (Jackon et al., 2023). Regarding milk donation, some had personal beliefs on who they felt should receive the milk. For example, some women thought that if a baby was needing PDHM because of a mother's personal preference to not breastfeed, then they should not get priority over children whose mothers wanted to breastfeed but couldn't (Kimani-Murage et al., 2018).

2.3 HEALTH PROFESSIONAL'S PERSPECTIVES OF PDHM, AND THEIR INFLUENCE ON WOMEN'S DECISION-MAKING

HOW HEALTH PROFESSIONALS VIEW PDHM USE

Health professionals are influential in affecting the decision making of women around infant feeding. Therefore, women could be influenced by health professional's personal beliefs around PDHM. In some literature, nurses and midwives were asked about their perspective of PDHM and how this impacts their work with families. In a South African study, all nurses and midwives interviewed reported that they see

great benefit of PDHM for their patients and support its use in practice (Mahlatjie et al., 2022). They also reported a preference for donated breast milk over formula for infants who cannot access their mother's own milk, as they recognised the importance of it in limiting the risk of NEC (Mahlatjie et al., 2022). Magowan et al. (2020) uncovered similar thoughts and beliefs from the health care workers in Uganda. The nurses interviewed communicated their trust in the process of screening and pasteurisation and report that they are actively counselling mothers about the myths of pasteurised donor human milk and the evidence that reinforces its safety. Mothers in this study felt concerned that PDHM could be putting babies at risk of contracting non-communicable diseases such asthma or sickle cell disease (Magowan et al., 2020). Additional beliefs were raised that African babies would change skin colour if fed milk from a Caucasian women (Magowan et al., 2020). Nurses were able to educate women that these concerns are unfounded and instil trust by reiterating that babies would only receive nutrition from the milk and no genetic components (Magowan et al., 2020). Mothers report feeling greater trust and acceptance of PDHM when nurses are able to explain the screening and pasteurisation process (Magowan et al., 2020; Akpinar et al., 2022). This demonstrates nurses who are well educated on the processes of PDHM and are able to share this education with mothers, likely are impacting women to positively engage with milk banks and PDHM (Magowan et al., 2020; Akpinar et al., 2022; Jackson et al., 2023).

Contrarily, Namuddu et al. (2023) interviewed health professionals in Uganda who work in similar maternity and neonatal environments and found vastly different responses to those mentioned above. Nurses and midwives in this research referred to using another women's milk as "disgusting" (Namuddu et al., 2023). Furthermore, paediatricians also shared concerns about the risk of genetic traits being transferred to the baby by another women's milk (Namuddu et al., 2023), directly contradicting the education that health professionals in the research by Magowan et al. (2020) undertook. Interestingly, this stark contrast of opinion is occurring within the same country of Uganda with one study (Namuddu et al., 2023) taking place in central Uganda and the other (Magowan et al., 2020) in east Uganda. These different opinions could be due to differences in culture, education and societal norms within separate communities. However, how often these health professionals are working with PDHM in their careers could also be a contributing factor. Magowan et al. (2020) conducted research within the context of health professionals not having access to a human milk bank, and instead was done to ascertain willingness to accept PDHM in the hopes of opening one. Comparatively, Namuddu et al. (2023) completed their research multiple years after the opening of Uganda's only milk bank. This milk bank is in the same hospital where Namuddu et al. (2023) interviewed health professionals (Nakibuuka et al., 2024) and therefore, the context of this study is that these health professionals are readily working alongside women who have access to PDHM. Concerningly, between the two studies, it is the healthcare workers who engage with the milk bank that feel negatively toward it.

A common theme in all of the studies that reported negative views of PDHM from health professionals was they felt concerned about who the breast milk came from, what the donor's demographic background is, and whether they had any diseases, particularly HIV (Chaudhari & Aiyer, 2024; Mahlatjie et al., 2022;

Namuddu et al., 2023). Importantly, there were significant concerns voiced about the screening process and safety procedures to make the milk appropriate for infant feeding (Mahlajtie et al., 2022; Namuddu et al., 2023). This uncertainty of safety highlights a broad lack of knowledge of the process of pasteurisation for healthcare workers who are counselling women on PDHM use.

HOW HEALTH PROFESSIONALS AFFECT A WOMEN'S DECISION-MAKING: FOR OR AGAINST PDHM

Within existing literature, women report health professionals as having a significant impact on whether they would accept PDHM or not. In a Turkey-based study, Akpinar et al. (2022) discovered that of the women who indicated they would happily receive PDHM for their infant, 40.5% of these women expressed this was because they trusted the health professionals who were caring for them and their baby. They felt that only something good would be supported by health professionals, and therefore this must be the right option for their child (Akpinar et al., 2022). Jackson et al. (2023) found that women's willingness to receive PDHM was also impacted by health professionals but in a different sense. Compared to Akpinar et al. (2022), the women in the research conducted by Jackson et al. (2023) voiced that the education they received from their nurses and midwives regarding PDHM was critical in influencing their decision to accept it. However, this experience of support appears to be inconsistent with more participants from the same study indicating they received no more education regarding PDHM than those that did (Jackson et al., 2023). Moreover, these 12 participants received an entirely different perspective and didn't just receive a lack of education but were encouraged to use infant formula as an alternative to breastfeeding (Jackson et al., 2023). It is difficult to know if some women were recommended PDHM and others not based on the supply levels of donor milk in the milk bank at the time, as this was not documented in the study. If donor milk supply was low, it may have been the nurses and midwives' jobs to support other parents in commencing formula instead of offering PDHM. Alternatively, it could be that the nurse or midwife working with these women allowed their personal beliefs of PDHM to impact how they provided education. Within research by Namuddu et al. (2023), similar negative perceptions of PDHM are shared between healthcare workers and women. This brings about questions as to whether their opinions were influenced by the health professionals working with them. The influence of health professionals is noted in a study conducted by Chaudhari and Aiyer (2024) in India, where nurses would counsel women on the use of PDHM and share personal beliefs on whether they recommended it or not. They reported telling women that infections can spread through the use of donated breast milk and cow's milk is a better alternative (Chaudhari & Aiyer, 2024). In a case study, Howard (2012) writes about a mother who wished for her child to have breast milk, however due to a cancer diagnosis in pregnancy, there was to be a 4-week postpartum period whereby she would be receiving chemotherapy and not recommended to initiate breastfeeding (Howard, 2012). Living in the United Kingdom (UK), Jane applied for funding to receive PDHM. However, due to birthing at a hospital where the use of donor milk was not heavily practiced or supported, Jane was declined this opportunity (Howard, 2012). This mother was able to move herself and her infant to a hospital which did support and promote PDHM use, and she received the funding to provide PDHM to her newborn (Howard, 2012). This case study demonstrates how the attitudes of health professionals are shaping the

feeding journey of mothers, to the extent that they would not support a mother to provide her preference of nutrition to her infant. Across some studies, health professionals were asked why they had particular beliefs, however they generally could not provide more insight other than they thought donated milk was not a good alternative (Chaudhari & Aiyer, 2024; Namuddu et al., 2023; Mahlatjie et al., 2023).

2.4 PARTNER'S AND HUSBAND'S VIEWS ON DONOR BREAST MILK

HOW PARTNER'S AND HUSBAND'S VIEW PDHM USE AND THEIR INFLUENCE ON WOMEN'S DECISION-MAKING

In some of the research, women identified their partner's and husbands as having a significant influential factor on whether they used PDHM. Some mothers were able to report support from their partner about the use of PDHM and that they believed it was the superior nutritional option (Namuddu et al., 2023). However, others stated their husbands deemed it as disgusting and were not supportive of it as a feeding option out of fear of their child mixing their genetics with strangers (Namuddu et al., 2023). Some fathers that were interviewed even shared fears of the mother becoming neglectful because she isn't breastfeeding (Namuddu et al., 2023). Research conducted in India and eastern Uganda by Chaudari & Ayers (2024) and Magowan et al. (2020) respectively told of women seeking permission from their husbands before they could agree to use PDHM. They spoke of their husband's being the final decision-makers in their family, and only if they agreed to it, would they use it. In a similar sense, Esquerra-Zwiers et al. (2016) noted that several women declined PDHM because of their husband's hesitancy and preference for baby to receive their mother's own milk only. These examples highlight that the role of a partner or husband is significantly influential on a women's decision-making regarding PDHM. Loh et al. (2022) found a husband consented for the hospital to feed PDHM without the mothers knowledge and she reported feeling incredibly unhappy about this. In some of the literature, women even talked about needing to ask their husbands if it would be okay for them to donate their milk before they could freely do this also (Jackson et al., 2023; Magowan et al., 2020). The women in these studies reported that their husband's took some convincing before they saw any positive benefit to donating excess breast milk. Comparatively, Noble-Carr et al. (2022) conducted research into father's experiences of their partners donating their breast milk following the death of their infant. Nobel-Carr et al. (2022) found that all fathers saw significance in lactation and assisting their partner to maintain supply for donation. They felt that breast milk held purpose, and they had a responsibility to assist their partner in maintaining a supply for donation, if their partner wanted to. Fathers often noted that this provided them with structure and purpose when they were otherwise entirely consumed by grief (Noble-Carr et al., 2022). However, some fathers noted that they were not offered the opportunity to learn more about milk donation but wish they had (Noble-Carr et al., 2022). For women living in cultures where it is expected of them to seek approval from their partner or husband before agreeing to PDHM, education for father's should be supported.

2.5 SUMMARY

The available literature regarding PDHM use all contain similar themes regarding the experiences of women, health professionals and husband/partners. Women are guided by the external factors of their culture, social beliefs, partner/husband's, health professionals and PDHM myths when deciding to choose PDHM for their infant. Those that do use it tend to journey through a sense of guilt or shame around their own milk production, hesitancy to use PDHM and then into a feeling of acceptance of how they can still provide breast milk for their infant. None of the abovementioned articles discuss pasteurised donor human milk as a long-term feeding option. Instead, women and health professionals view PDHM as a short-term bridging option to mother's own milk or formula. A gap in the cited literature is that many studies don't specify how long each women used PDHM for and whether their experiences changed dependent on this timeframe. What the research doesn't explicitly investigate is whether these themes are relevant to women who use pasteurised donor human milk for long-term feeding. This study aims to fill the gaps of knowledge on how long-term users of PDHM talk about their experience and what supports they need to better this aspect of new motherhood.

CHAPTER THREE: METHODOLOGY

This study aims to research the experiences of women who use or have used pasteurised donor human milk for a period of 2 weeks or longer. Narrative enquiry methodology has been used to guide how this research explores the lived experiences of these mothers. The findings will be analysed using thematic analysis (Braun & Clarke, 2012). The themes which arise will be used to inform how long-term PDHM usage is approached in by both the maternal users and milk banks.

3.1 THEORETICAL FRAMEWORK

In the late 1980s, researchers within the social sciences began using narrative inquiry as a methodology to investigate and communicate their findings (Delmas & Giles, 2023). Originally this incorporated many different types of data such as photographs, transcripts, field notes and conversations (Clandinin & Connelly, 2000). This was eventually added to, to include storytelling, journal records, letter writing and auto- and biographical writing (Savin-Badin & Niekerk, 2007). Ultimately the aim of narrative inquiry is that stories are collected and used as a means of understanding the human experience (Delma & Giles, 2023).

"Stories help us transform the present and shape the future... So that it will be richer or better than the past" (Dyson & Genishi, 1994).

Dyson & Genishi (1994) argue that everyone has the need for organising the important events of their life into stories and that these stories demonstrate meaningful experience and connection to the life around them. Mertova & Webster (2020) echo this notion by stating that the narrative of human experience is so pivotal that researchers cannot solely focus on observational and statistical data to determine significance of experience. Furthermore, they propose critical event narrative inquiry as a methodology of researching the human experience to fully understand what participants find significant, and not dismiss

what quantitative research otherwise might have (Mertova & Webster, 2020). This way of researching is readily used across a range of disciplines such as philosophy, psychology, education, economics, biology, medicine and environmental studies (Mertova & Webster, 2020). Delma & Giles (2023) state that people tend to lean towards sharing stories and experiences which are central to their journey. However, interpreting these stories can be difficult and recognition of whose story it is must be at the forefront of a researcher's approach when conducting data analysis and finding meaning in a story that is not their own (Delma & Giles, 2023).

Narrative inquiry seeks to capture the 'whole story', where other forms of methodology may dismiss aspects of data that are important to the participant but show no significant value to the researcher (Mertova & Webster, 2020). To gather the whole story, it is necessary to explore issues that are assumed and issues that not directly stated within the participants retelling of events (Pino Gavidia & Adu, 2022). Furthermore, the use of narrative inquiry in analysing data allows researchers to develop the participant's "character" and uncover the complexities of relationships and settings that reside in the story (Mertova & Webster, 2020). Pino Gavidia & Adu (2022) argue the role of the researcher within narrative inquiry is to become a co-participant and work alongside the participant to collect, interpret and find meaning in the stories they tell. This way of researching has been selected for this study because each participant's story, although sharing similarities, has its own significant intricacies. Motherhood is a deeply personal journey, and thus the analysis of each story has been done through a lens of viewing the individual story as a whole, before placing it in the context of the stories around it.

Mertova & Webster's (2020) approach to narrative inquiry is that each story is itself a critical event to the participant but that each of these stories hold within it, critical events that are important in their own right. What makes an event critical to a person is generally the impact it has on their life (Bohl, 1995). Over the course of time, our minds discard and refine memories and details which hold unnecessary detail. But those events which challenge our feelings, thinking, beliefs and comfortability are ones which stay in our minds and shape our future behaviours and understanding (Mertova & Webster, 2020). One of the first researchers to discuss critical events, Strauss (1997) highlights that these critical events only exist in hindsight, and that we cannot be aware of them occurring in real time. For women, the transition from woman-without-child to woman-with-child is a significant, critical life event (Blachnio & Kuryś-Szyncel, 2022). Using a theory of critical events, it is presumed that within the critical event of transitioning to motherhood, many critical macro-events occur, and within these are critical micro-events and so on. One of these events being how a women chooses to or is able to feed her child (Knapp, 2021). By examining this aspect of motherhood through a critical event narrative inquiry approach, it is hoped that women's stories will be understood and translated in a way that does not dismiss the complexities of each step in their stories. Clandinin & Connelly (2000) describe this process of analysis by using tools such as broadening, burrowing, and storying and restorying. This involves identifying the wider context of the participants story, focusing in on specific details of the data and storying or restorying these details in a way which truly highlights the lived experience of the chosen critical event for the individual (Clandinin & Connelly, 2000).

3.2 ETHICS

Ethics approval was sought and approved through Massey University Human Ethics Committee, Ohu Matatika 1 (application OM1 23/23). During the initial contact with participants, they were all offered a participant information handout which specified the purpose of the study and their role in it, should they wish to participate. They were advised of their right to withdraw at any time and their right to review and alter their transcript for a 2-week period after it had been formulated. Participants were provided with consent forms which were required to be signed prior to the interview being conducted. At the beginning of the interview, participants were reminded of their right to not answer a question or withdraw from the interview and/or study at any time. All participants were offered the opportunity to have a support person present during their interview, and an attempt at follow-up contact was made to assess the welfare of the participant following their interview. Confidentiality was prioritised throughout the research process. Participants were advised that all information they provide will be anonymised and during the results section of this thesis, all participants have been provided a pseudonym to protect their identity. Additionally, all participant information and transcripts were saved on a password protected computer. To thank all the women who took part in this study, a voucher was provided to participants as a small token of gratitude for their contribution.

3.3 PARTICIPANT RECRUITMENT

Women have been highlighted as the centre of this story by asking them to share their personal experiences, thoughts and beliefs. Participants were recruited with the help of the milk bank manager at Palmerston North. The milk bank manager identified eligible participants and made initial contact with them via email to identify who would be interested in participating in this research. Once participants got back to the milk bank manager, their details were then forwarded onto the research supervisor, Dr Ying Jin and from here contact was made via email to each participant to gain informed consent and organise an interview time. Additionally, this study analysed secondary data from interview transcripts which were part of a larger study investigating mother's experiences of using pasteurised donor human milk in Palmerston North (ethics no. OM1 23/23). The key criterion for sample selection was that all participants must be aged over 16 years, be proficient in English, and their newborns received pasteurised donor human milk long-term (greater than 2 weeks) during 2022 and 2023. Women excluded from participating would be younger than 16 years old and mothers who received donor milk via private milk sharing practices.

Below is a table summary of included participants:

Participant Pseudonym	Age	Ethnicity	Highest Educational Achievement	Length of time using PDHM
Kaia	30	New Zealand European	Bachelor's Degree	6 months

Jill	42	New Zealand European	University Entrance	6 months
Beck	29	Chinese	Bachelor's Degree	4 weeks
Renee	39	New Zealand European	Diploma – Level 6	3 months
Ann	37	New Zealand European	Graduate Diploma	3 weeks
Farah	34	New Zealand European	Master's Degree	3 weeks

3.4 DATA COLLECTION AND ANALYSIS

The primary data within this research involved interviews which were arranged via email and conducted through Zoom and recorded with consent. These interviews were thirty to sixty minutes in length and were conducted during July 2024. A semi-structured interview approach was used with an interview schedule (see Appendix 1) to guide the discussion with women about their experiences using PDHM. Women were asked about their pregnancy and feeding journey, about their use of PDHM, how they felt about it prior to using it, how they feel about it now, how PDHM use impacted their breastfeeding journey, and what advice they would share with other mother's needing to use PDHM. The secondary dataset was originally collected in a similar way; however, the interview schedule was slightly different (see Appendix 2). The transcripts for the secondary data were obtained through Dr Ying Jin and Dr Linda Murray and included in the analysis phase of this research.

Thematic analysis was used as the method of analysis for this research. Thematic analysis is a common method of analysis in qualitative research and is used to identify patterns and themes between each interview, analyse and report on them. Thematic analysis in this research has been conducted through the following six steps (as outlined by Braun & Clarke, 2006):

FAMILIARISATION WITH THE DATASET

The primary data interviews were listened to as a whole to gain a greater understanding of the participant's perspectives. As the interviews were recorded on Zoom, a transcript was obtained from this software. These transcripts were read through and then compared to the audio recordings to confirm translations and adjustments were made to ensure the transcripts were transcribed verbatim. For the secondary data interviews, these transcripts were already transcribed verbatim (through a professional transcribing agency), so these were read through twice. Due to not having access to the audio recordings of the

secondary data set, reading these transcripts twice allowed for a more sufficient understanding of the women's perspectives before coding.

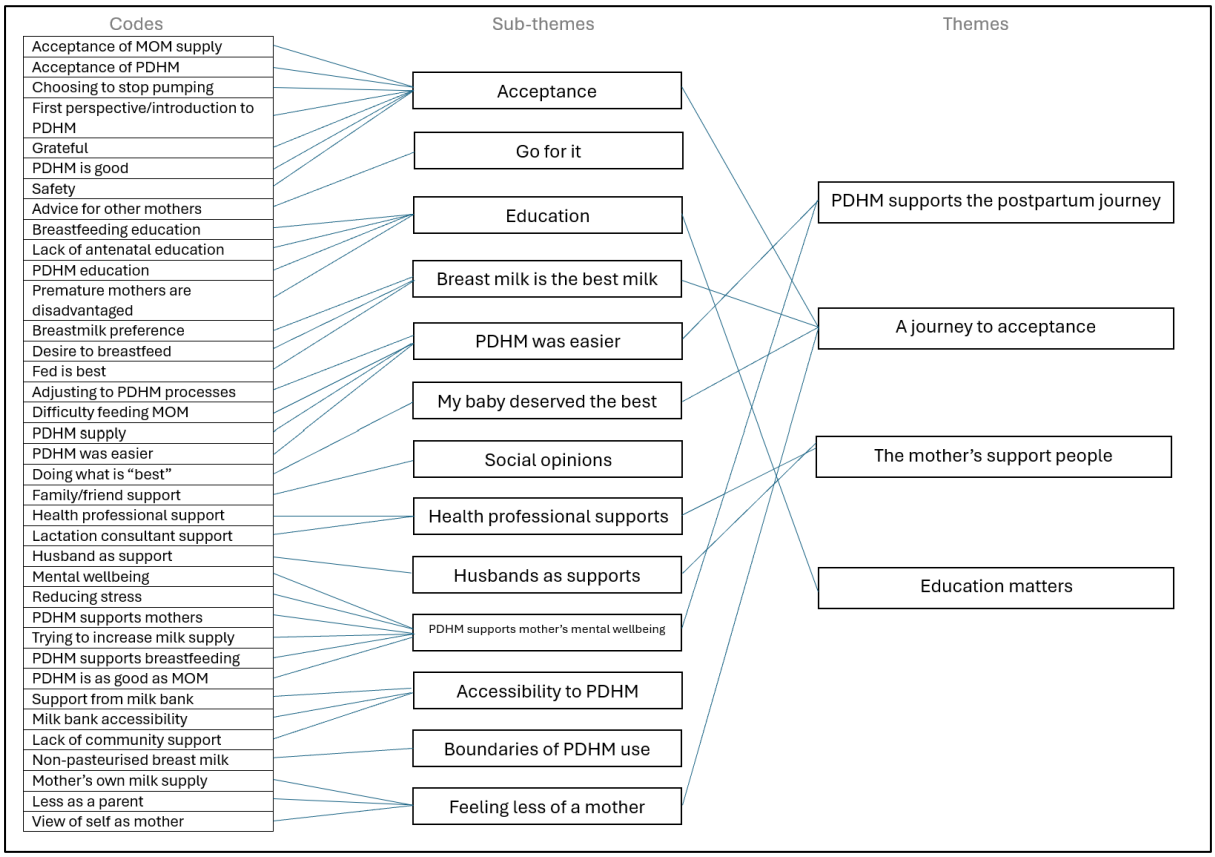
CODING

Developing codes in the research process is essential in building a foundation for thematic analysis to take place (Byrne, 2022). These initial codes are the smallest unit of analysis in the thematic process and at their most basic level, demonstrate commonalities and shared core ideas between datasets (Braun & Clarke, 2006). Byrne (2022) describes the concept of coding as a being flexible and organic which is true to the process which took place in this research. Datasets were read multiple times to highlight core concepts, and this also increased familiarity with the data which aided the analysis further. To generate codes, all transcribed data was uploaded to ATLAS.ti (2024) (qualitative software) and was analysed manually. This qualitative software does include options of artificial intelligence analysis however this was not used in this study. Within this software, coding of the data took place by highlighting areas of text which potentially relate to the research questions. These areas of text were then labelled with simple descriptive codes. From this process, 37 codes were created and are outlined in the below table. A systematic approach was undertaken whereby each interview was reviewed separately and thoroughly to carefully highlight areas of interest. The chosen descriptive codes were used to succinctly label the data whilst being able to clearly communicate the core ideas within it. Once the initial codes were formed, all codes and corresponding data were reviewed to ensure relevance of what was included and any information that lacked relevance to the code and research questions were discarded as necessary.

GENERATING THEMES

Braun & Clarke (2012) state that themes are not already sitting in the data waiting to be found, but rather that the active analysis of the codes and the relationships they share is what uncovers themes. In this study, the generated codes were reviewed to assess for concepts which shared meaning. A reflexive approach was undertaken whereby themes were not predefined prior to coding, instead interpreting what has been found in the data and using these insights to generate themes organically through core commonalities (Byrne, 2022). Codes which demonstrated similarities were assessed for suitability to be merged to create the sub-themes. From this process, the original 37 codes were collapsed to create 13 sub-themes (*Figure 1*). Quotes were reviewed in each sub-theme and those that were related in their core ideas and shared the same overarching narratives were able to be further collapsed into overall themes (*Figure 1*). With recognition that generating too many themes can create an incoherent and flimsy analysis of the dataset, yet too few could not fully demonstrate what was found (Byrne, 2022), 4 overall themes were decided on. Sub-themes which did not fit into the overall analysis were discarded from the final themes (*Figure 1*) (Byrne, 2022).

Figure 1: Process of developing themes



DEVELOPING AND REVIEWING THEMES

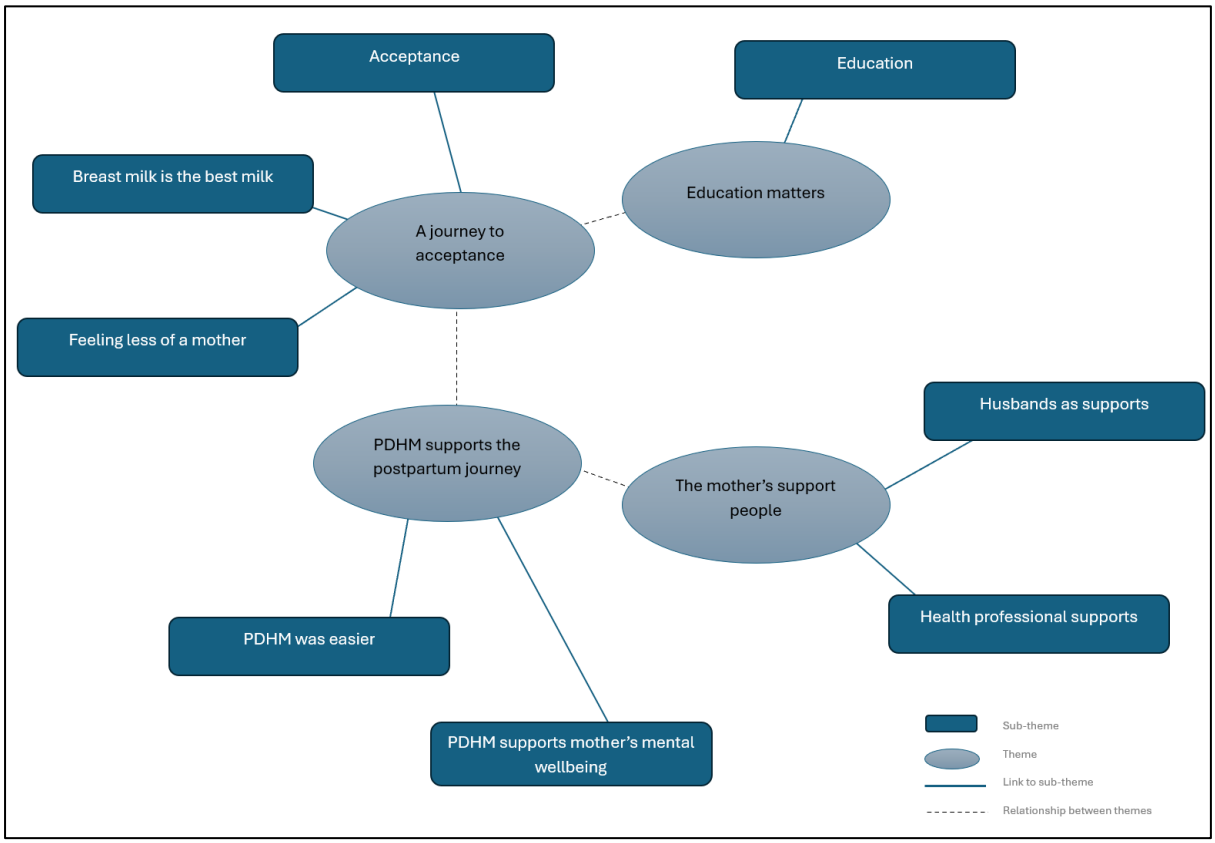
A recursive review is recommended by Braun & Clarke (2012) to determine the suitability of themes. This is done to confirm that chosen themes communicate meaningful interpretations of the data and address the research questions (Byrne, 2022). As proposed by Braun & Clarke (2012), the following questions can be asked and considered when completing this review:

- Is this a theme (or just a code)?
- If it is a theme, what is the quality (does it provide useful information about the data set and the research question)?
- Are there boundaries of the theme (what is included and excluded)?
- Is there meaningful data to support the theme?
- Is the data too diverse (does it lack coherence)?

Braun & Clarke (2012) state that the reviewing phase of themes should be done through two stages, level one and level two. During the first level of review, codes within each theme should be reviewed to determine whether they show a coherent pattern (Braun & Clarke, 2006). If a coherent pattern is determined, then this theme moves onto the level two stage of the review. However, if during level one, the coded data demonstrates an incoherent pattern, it must be determined if it is the theme itself that is the problem or if simply aspects of the included data do not fit within that specific theme (Braun & Clarke,

2006). Data which does not fit can be discarded, reworked into an additional theme, or could remain in the current theme. However, this may need to be redefined to ensure the included data makes sense (Braun & Clarke, 2006). Once the data is reviewed at the code level, moving onto level two of the review is necessary. This stage involves a similar process but requires the researcher to consider the data as a whole and how each theme interacts with the others (Braun & Clarke, 2006). Through the process of level one and level two review, a thematic map can be formed which should accurately represent the data and the interactions between themes (*Figure 2*) (Byrne, 2022). Through this process of reviewing, it is possible to continue to find new codes and therefore new themes, however Braun & Clarke (2006) warn that coding could continue on for an infinite period of time, and researchers should recognise when sufficient representation of the dataset has been reached.

Figure 2: Thematic map



DEFINING AND NAMING THEMES

During this phase, each theme and sub-theme is to be conveyed in a way that accurately reflects both the dataset and the research questions. Patton (1990) states that each theme should provide a consistent account of the data, and these same notions are not able to be expressed by the other themes. However, all themes together should present a coherent narrative that represents the dataset as a whole while informing the research questions (Byrne, 2022). During this phase, it is also necessary to choose which extracts from the data are to be used in the discussion of the findings. Bryne (2022) states that any chosen extracts should provide a compelling report of the arguments made in each theme. Additionally, multiple

extracts should be used to demonstrate multiple expressions and their meaning across the entire dataset. Ultimately, each extract should be thoroughly explored to truly uncover it's meaning in relation to its allocated theme, but also how this answers the overarching research questions (Braun & Clarke, 2012).

PRODUCTION OF REPORT

In the final phase of analysis, themes are written up and discussed in a meaningful and logical manner which builds a comprehensive narrative of the data (Braun & Clarke, 2012). Byrne (2022) describes this final stage as being recursive like the analysis of codes and themes. This means this phase can be ever evolving and adjusted throughout the writing process, as the researcher continues to gain greater understanding of the depth of the topics at hand as they go along (Byrne, 2012).

3.5 RIGOUR

Rigour determines the trustworthiness of the research in both the data collection and analysis (Maher et al, 2018). Ensuring a high level of trustworthiness is pivotal for the findings of the research to have meaningful impact. Lincoln & Guba (1986) describe four main criteria for determining the overall rigour of qualitative research. Below each criteria are described, with how this was met within this study.

Evaluative Criteria	Meaning	How this is met within this research
Credibility	Confidence that the findings represent truth	The interview schedules were reviewed by research supervisors to ensure their relevance to the research questions. Additionally, the interviews were transcribed verbatim to ensure the perspective of the participants were adequately represented.
Transferability	To extend the degree to which the findings can be transferred or are applicable to other contexts	Purposive sampling was used whereby women who are known to have used PDHM were used in this research sample. Additionally, saturation of data has been noted in the recurrence of themes across different interviews.
Dependability	The findings are consistent and could be replicated	The research process has been described in sufficient detail that if another researcher wished to conduct this same research, they could follow the same steps.
Confirmability	The research communicates that the results are based on information gathered and not biases of the researcher	The themes highlighted in this research are shown to reflect the data gathered by referencing quotes from interviews. This reinforces that the results are based on the information gathered from participants and not individual interpretations of the research team.

Additional to meeting the above criteria, this research demonstrates integrity by ensuring all interviews were audio recorded to accurately reflect the participants thoughts, beliefs and experiences. All interview recordings were transcribed verbatim and returned to the participants to review to ensure their views have been captured appropriately. Participants were offered a 2-week period to amend their transcript. Once transcripts were confirmed, all data was thematically analysed through ATLAS.ti (2024) to form appropriate themes.

CHAPTER FOUR: FINDINGS

4.1 CHAPTER INTRODUCTION

The aim of this research was to investigate:

(1) How do women describe using pasteurised donor human milk long-term?
(2) How are mothers currently supported to use PDHM in a long-term sense (both from a medical and community standpoint)?
(3) How does long-term use of PDHM affect their sense of being a mother?
(4) What more can be offered to women using PDHM long-term to support this part of motherhood?

Through thematic analysis, 4 main themes were identified:

1. A journey to acceptance
2. The mother's support people
3. PDHM supports the postpartum journey
4. Education matters

These themes have been laid out in a manner which represents four critical events that women faced along their feeding journeys. These critical events are related to (1) acceptance (2) support (3) PDHM and (4) education. Each of the interviewed women had experiences which correlated to these themes and were able to review them in hindsight as being significant to their wider story of feeding their child. By drawing on analysis theories by Clandinin & Connelly (2000) an emphasis on storying and restorying has been undertaken. This involved identifying the wider context of the mother's story, focusing on specific details of the data and storying and restorying this data in a way which truly highlights the lived experience of the individual. Several of these themes have been collapsed into their sub-themes to convey the findings in a meaningful and logical sequence.

4.2 THEME ONE: A JOURNEY TO ACCEPTANCE

FEELING LIKE LESS OF A MOTHER

Some mothers described their inability to breastfeed as influencing their perception of themselves as a parent. They reported preconceived ideas that women's bodies should automatically know how to make enough milk for a baby. When their own experience challenged this societal norm, the result was that women felt 'less of mother' because their bodies did not live up to this expectation. Kaia expressed this feeling of diminished self-worth and inadequacy when she was unable to fulfill the job of breastfeeding. Additionally, she compared herself to other women who can produce breast milk and conveys a sense of being hurt by their ability to do it for her baby, when she was unable to. Ultimately, she identifies this critical moment as having significant emotional impact in her parenting journey and how she identified as a mother in those early moments of parenthood.

"It definitely made me feel less as a parent. You know, like I wasn't able to provide for my child… It definitely wasn't easy. Knowing that, you know, someone else or some other people were able to feed my child, and I wasn't able to." (Kaia)

Similarly, Jill described feeling like her body didn't do what it was supposed to do. Again, reinforcing that women have a sense that their bodies are expected (by themselves and others) to fulfil certain requirements once a child is birthed. And should this requirement not be fulfilled, that the resulting impact can be on mother's sense of who they are as a mother and how they fit into the role of motherhood.

"I always felt disappointed that I couldn't like, I… I suppose that I couldn't do this thing that's supposed to just be part of the journey. But umm so, it turns out I grow a really good baby. I just can't feed a baby (laughing). And, and yeah, so it did make me quite upset that I couldn't." (Jill)

Jill is able to look back on this part of motherhood through a strengths-based lens by recognising she birthed a child she is proud of. Yet, recognises there was disappointment surrounding her inability to achieve the breastfeeding journey she had thought would come naturally.

Mothers described doing many different things to try inducing or increase their milk supply to be able to feed their baby themselves. Women were driven by beliefs that there body should be able to fulfill the role of feeding their child and also that they would rather supply human milk than offer formula. Although if trying to increase lactation was unsuccessful, this was felt to be disappointing and added another layer of failure to comply to the social norm of what mothers' bodies 'should' do in the postpartum period. Renee describes the effort (both emotionally and physically) she invested into induce lactation.

"I did everything imaginable to try and bring it on… I took domperidone, I took all the lactation supplements, ate the cookies, had the shakes, did all of that, and it didn't really work. I've persisted because I really wanted, I guess, that dream of breastfeeding because it felt like that was part of the mothering experience." (Renee)

This demonstrates the level of commitment that women have to feeding their own milk and reinforces the narrative of breastfeeding as being an innate experience of being a mother. Women are left with feelings of disappointment when even their greatest efforts do not produce their desired result.

"BREAST MILK IS THE BEST MILK"

Following the initial feelings of disappointment in being unable to feed their children their own milk, women described their thoughts of wanting to give their child the next best alternative. That despite their inability to breastfeed, their babies still deserved the best. Women reported a range of thoughts and feelings when first being introduced to PDHM. Kaia reported an initial sense of hesitancy about PDHM because of how she felt about herself as mother and not being able to feed her own milk to her child. But similar to Renee, both these mothers had birthed prematurely, and they appeared to view the use of PDHM as a way of protecting their baby after they had been born so early. Both mothers described their babies in a sense of them being vulnerable and long-term PDHM use gave them the opportunity to care for them and keep them safe.

"It definitely wasn't as easy as a 'yep, let's go do it'... But seeing how little she was... And seeing how sick the formula made her; I knew I had to make the choice to do it." (Kaia)

"I'd always wanted to breastfeed him. It was hard coming to terms with the fact that that couldn't be my milk. But it was a case of that or not giving him the best options. Because he was already very little and already starting on a back footing, I wanted to give him the best of whatever I could. Whether it was my milk or somebody else's, it was important that he got the best that was available." (Renee)

Other mothers tended to talk about their beliefs that breast milk, whether from themselves or someone else, is the best milk their baby could have (if they couldn't have their mother's own milk). However, some women did still describe an initial hesitancy at the concept of somebody else's milk. Ann's thoughts about PDHM were influenced by her husband whose African background meant he had been exposed to milk sharing in his culture. This helped her conclude that for her, PDHM was the more natural option and therefore the better long-term option for her family, compared to formula use.

"It was, like, a good idea because I thought it was strange because someone's else's milk. But then I'm like, but it's actually better than formula because it's more natural. And I've heard of other people that have especially because my husbands from Africa. I've heard of people that if they can't get the milk, they just use someone that's had a baby and then they just drink off the mum." (Ann)

Mothers conveyed a sense of distrust in formula and a strong mindset of not wanting to use it. Some mothers simply felt this was because they had heard breast milk was the best infant feeding option, but other women described a true fear of formula and it's potential for harm.

"It's just my mindset that breast milk is always better than formula milk. So that's why even if I don't have enough milk, don't have enough breast milk, I still choose donor's milk more than formula milk." (Beck)

"I'd always heard that breast is best, and it was always my goal to give him breast milk." (Renee)

"I knew I didn't want her on formula... So, to have to know that she was at least getting donor milk. Well, I say "at least", but it was probably way better than that I could produce (laughing). So, it was probably a superior alternative." (Jill)

All of these mothers refer back to their preconceived idea that providing breast milk to their baby is the best option. This is presumably what they had decided on during their pregnancy journey or even before it, and what they wanted to accomplish as part of their postpartum experience. Although women were initially faced with feelings of inadequacy or failure at their inability to breastfeed or induce lactation, there was a sense that long-term use of PDHM could lessen these feelings by allowing women to remain aligned with their goal of providing breast milk. Farah shared her fear that formula posed too many potential risks and how this fear was a driving factor for her to consider PDHM. She reported feeling as though formula has a history of recalls and supply shortages and for these reasons was not comfortable with choosing this as a feeding option for herself and her baby.

"I've got some reservations against formula, mostly because there are frequent recalls... There's been a few too many shortages in formulas, so I didn't want to become reliant on something that I couldn't guarantee was going to be available." (Farah)

ACCEPTANCE

Following their feelings of being "less than", mothers often reported ending up with a level of acceptance of their own milk supply and what they could or could not produce for their baby. Many of these mothers were able to recognise and reflect on how their attempts at providing their own milk were impacting their physical and mental health. Through this recognition, women were able to gain insight and come to a place of acceptance with where they were in their feeding journey. For Jill, this acceptance was her realising that long-term her baby needed more than what she could offer, and that she needed to regain more of her own health back to be able to adequately support her baby.

"I was like, "I'm never going to be able to feed her enough by myself". And it's just like, physically, it was getting really hard and mentally, it was really hard too. So, we just made the decision to like cut the co-feeding and just go with the donor milk." (Jill)

Some participants described that the potential of having pasteurised donor human milk was what helped them accept that their milk wasn't going to be enough for their child to thrive on. Similar to Jill, they described feeling as though the effort they were putting into trying to increase or maintain their own milk supply was physically and mentally exhausting. Some women felt that this energy could be redirected elsewhere once they knew their baby would still have access to breast milk long-term, even if they stopped trying to feed and pump. In this regard, there appeared to be an underlying narrative that PDHM provided

mothers permission to stop pushing their bodies to the limit and simply stop and begin to enjoy their child more without the stress of their milk supply.

"If I'm only getting such a minimal supply and putting in such a lot of effort to achieve that, then am I really benefiting either of us? At that point, I made the decision to transition off." (Renee)

Although women describe PDHM as being a factor in choosing to stop providing their own milk long-term, they also voiced it as a protective factor for wanting to produce any of their own milk at all. They felt if another women's breast milk wasn't an option for interim feeding, then it would simply be easier to just go to formula anyway and save themselves any physical or mental stress. This therefore means that the option of long-term PDHM is what supported women's breastfeeding journeys at the beginning and also when they chose to bring it to an end.

"I reckon I would have done it for shorter. Because it would have just been easier to make up a bottle. And to kind of be like, well, this isn't... It's not working." (Jill)

SUMMARY

From the transcribed interviews, women described an expectation on themselves and their bodies as they enter into their pregnancy and mothering journey. Mothers tend to hold preconceived ideas on what they should be able to achieve in terms of feeding their child. But if they are unable to meet these societal and personal expectations, the result is a feeling of not being "good enough" or not doing what they are 'supposed' to be able to do. There is a sense of maternal guilt surrounding these perceived failures and how they view themselves as mothers. These feelings of inadequacy directly affect a women's journey through motherhood (both physically and mentally) by driving her attempts at providing her own milk. Some women describe a significant effort of taking supplements, eating specific diets, being medicated and spending hours pumping to produce their own milk and these efforts lasted for weeks to months on end. This continued effort, when not producing results, drives the disappointment of not being able to feed their own baby. Mothers describe being comforted by the option of long-term pasteurised donor human milk and how it offers their baby the same benefits without the uphill battle of pushing their bodies to the limit in a mental and physical capacity. Through the desire to feed their baby breast milk over formula, these mothers reach a point of acceptance where they felt providing pasteurised donor human milk was the best milk their baby could have. Long-term PDHM use appeared to allow women to offer themselves 'permission' to let go of their preconceived ideas of how they thought they would feed their baby, and instead embrace what is.

4.3 THEME TWO: PDHM SUPPORTS THE POSTPARTUM JOURNEY

Women reported feeling like being able to use PDHM was supportive to their postpartum journey in multiple ways. This included supporting their mental wellbeing by reducing stress but also their physical

capability to increase their own milk supply. This theme has been collapsed into two subthemes including 'PDHM was easier' and 'PDHM supports mothers'.

PDHM WAS EASIER

This subtheme describes the way women persevered to provide their own milk to their children. The mothers in this study described difficulty, stress and concern when they were either unable to breastfeed or did not have enough milk to feed their baby. One mother talked about how the prematurity of her baby was a significant factor which contributed to his difficulty in latching and feeding. Furthermore, she described that even once he was bigger and ready to be stepped down from the NICU, there was a lack of support available to her to start breastfeeding at that point. For this mother, the lack of support to initiate breastfeeding meant she felt was left to her own devices to continue producing what milk she could, without anyone's help. With this continued decreased support, Renee's baby was eventually transitioned to being fully fed by PDHM and Renee decided to stop trying to maintain any of her own milk. What is described by Renee, is that feeding her baby PDHM was easier than the effort she was putting into maintaining a minimal supply of her own milk.

"Getting him to latch with him being so young and so little, that was really difficult. We tried all the little tricks that they had. But also, that time when he was right to try breastfeeding was right at the end of our NICU journey before we transitioned to SCBU in Palmy. There was less support, I think, at that point. Also, their LCs were limited supply. They were stretched against... NICU was over full at that point. I think it was a 40-bed unit, and they were maxed out... It was the feeling of like—and then I'm sure it was done with love, but it was like, you're not really one of our high needs' babies anymore, so feeling like they're pushing you out the door to a certain extent... It was once he came home, and part of it was the fact that if I'm only getting such a minimal supply and putting in such a lot of effort to achieve that, then am I really benefitting either of us? At that point, I made the decision to transition off." (Renee)

Furthermore, Renee narrated her experience of hospital staff also feeling that PDHM would be easier for her and her baby. The reason for this was that Renee's milk production was unreliable, and therefore PDHM would be a steadier feeding option and likely easier for staff to access. However, in Renee's circumstance, she had voiced that she felt unsupported to build up a reliable breast milk supply, but then felt the hospital staff used this information as a reason for why she should cease trying to feed her own milk. For Renee, this somewhat compounded her feelings about the lack of support she received. Although PDHM was a secondary feeding option, she felt she should have been supported to continue offering her own milk where possible. Unfortunately for Renee, this aspect of care appeared to be lacking:

"I think there was a push from staff as well to rely more on donor milk and then the transition to a formula because in a way, it was easier because it was more readily available. The supply was more consistent, then a little bit here and there from me that they couldn't really rely on." (Renee)

Similar to Renee's experience, Beck had a difficult time breastfeeding but persevered due to her preference for breast milk for her child. When Beck was given the opportunity to offer her baby PDHM instead, this gave her the ability to let go of the stress of maintaining lactation and instead focus on feeding her baby PDHM, which was ultimately less stressful for her. In this regard, Beck describes a sense of relief to her stress of trying to maintain a milk supply. Furthermore, although Beck tried to breastfeed for the first few months, her story presents as though she used this time to journey through to acceptance and eventually decided it would be easier to give PDHM.

"It was quite a stressful time because he just wouldn't latch properly. So that's why eventually I gave up. Eventually, so I was quite stressful for the first 2-3 months because I always wanted to do breastfeeding. But he doesn't because of his health issues and everything, and for some reason I don't have enough breast milk. So, I was quite stressful with the milk supply. Because I have quite, at that point, I have a strong mindset of breast milk is good for baby." (Beck)

Across all interviews, women reported putting in significant efforts to increase and maintain their own milk supply, and this took both a physical and mental toll on them. Some mothers described 'triple feeding' their infants which involved feeding on the breast, topping up with PDHM and pumping to promote milk production. Others told of their attempts at 'co-feeding', which involved setting up a tube on the breast which allowed their baby to latch to the breast and receive PDHM while also promoting lactation through sucking. After a period of doing this and recognising the impact this was having on their postpartum journey, women described "surrendering" their attempts at providing their own milk and felt that PDHM was easier. Furthermore, some women felt isolated in their attempts to produce their own milk supply. For example, Jill described her experience of co-feeding and how she struggled to do this type of feeding in public because of needing to set everything up for it. She felt it wasn't as easy as being able to just prepare a bottle or feed a baby only from the breast. The level of difficulty in feeding this way and the limits it put on Jill's ability to feed outside of her home, ultimately impacted her choice to move to solely feeding PDHM.

"I found it super awkward to go to these things, because I had, like this whole very intricate setup... So, I had my set up, because I, you had all the bits and pieces that wasn't as what I consider easy as like, you know getting your boob out and sticking your baby on it. It was this whole like things having to balance certain places and then changing them over, and then the... The teat falling off." (Jill)

"It was more exhausting than anything, cause you know I'd get up; I'd feed her... top up and then I'll try and pump. So, I think that's what made me stop, because I was just... I was more exhausted than anything." (Kaia)

PDHM SUPPORTS MOTHERS MENTAL WELLBEING

Further to these mothers explaining that PDHM supported them to reduce the stress of trying to produce their own milk, they felt PDHM supported their mental wellbeing in the postpartum period by allowing them the ability to regain their sense of self.

"...raising a child is quite demanding mentally. It takes a lot out of you, and you need to have that balance of emotional integrity and being able to do some exercise, being able to get more comfortable back in your own skin, get your own pre-pregnancy body back, and all of that stuff... Using donor milk allowed me the ability to then focus on myself as well as focusing on getting that balance." (Renee)

Similar to this notion of Renee feeling as though PDHM supported her ability to support herself, Farah also reports that PDHM supported her ability to practice self-care while her child had an extended stay in the NICU. Farah felt that having the option of PDHM allowed her to be okay with leaving to have time for herself to fulfill basic needs. In contrast, she thinks if her baby could only have her breast milk or formula, she would have found it difficult to leave and not be consistently trying to get milk for her baby.

"...also used it to make sure that I was taking care of myself and had a space out of the hospital... You've got this food here is an option for your baby... go out and get a coffee for yourself and get some fresh air and see some daylight because you really need it... And again, I know you can do it with formula, but if your preference is breast milk, it just makes it a little bit less stressful. Whereas if you're exclusively breastfeeding, which was my aim, and there was no option for breast milk, then I would have been tied a lot more to the chair in the hospital than I was." (Farah)

Additional to the reduced stress that women felt from using PDHM, Kaia describes her inability to breastfeed as a causative factor for feeling a sense of worthlessness in those early days of motherhood. This reiterates the narrative of a mother's sense of self being tied to their ability to provide breastmilk for their child. However, she voiced that using PDHM supported her mental wellbeing and lessened these negative feelings because she was able to see how it helped her baby thrive:

"And it made me not feel, you know, worthy, like I was unable to provide for my child. But as the days and weeks kind of went on, I was, you know, I was just happy to see my child happy and thriving and kind of doing well." (Kaia)

For Jill, she describes that having the option of human milk is what supported her to feel mentally okay about how their feeding journey ended up. For her, she felt her mental health would have been worse, had they not had the option to use PDHM. What Jill describes here is that PDHM directly supported her mental wellbeing in her postpartum journey. Many women talked about wanting their bodies to do what it was "supposed" to do in feeding their baby, and being faced with not being able to offer their baby human milk compounded this feeling of failure. PDHM supported mothers' mental wellbeing by filling the gap of what they wanted to give their babies but couldn't make themselves.

"I think because for me it was important for her to have human milk. If I hadn't had the option, I would have felt worse mentally... But knowing that she could have something, you know, like. That we had access to donor milk. That made me feel better about it." (Jill)

SUMMARY

Women's ongoing struggles to produce milk sufficient for their child's needs created a significant stress for them. This stress was an influencing factor on how women tried to produce milk, and often saw them spending many months pumping, taking additional medications and supplements, plus attempting to feed using various contraptions (like co-feeding set ups) to mimic breastfeeding. All of this activity was undertaken by mothers with the goal of producing their own milk supply and being able to feed their baby directly from the breast. However, when repeated attempts led to minimal desired results, this promoted more stress, and the cycle continued. The availability of PDHM gave women solace, as it allowed them to still provide breastmilk to their babies which aligned with their values and reduce the stress of trying to maintain their own supply.

By using PDHM, women described their increased ability to practice self-care such as leaving the hospital for coffee, natural sunlight and fresh air. Although women recognised this is possible with infant formula also, they reported that if PDHM weren't an option, they would have spent even more time promoting their own milk production, rather than taking time to care for themselves. These continued efforts could support mothers' mental health by giving them a sense of hope and purpose in their postpartum journey. However they could also have detrimental effects if they continue to feel that sense of failure by not meeting their own expectations. By having access to PDHM, women had the ability to stop the cycle of trying to lactate and instead care for themselves. Women reported a direct impact on their mental wellbeing and knowing they were in a better place because of their access to PDHM. Ultimately this was tied into the feeling that PDHM was easier than putting their bodies through the physical and mental strain of trying to breast feed or produce milk that simply was not coming.

4.3 THEME THREE: THE MOTHER'S SUPPORT PEOPLE

HUSBANDS AS SUPPORT

Women described their husbands as both a support person who helped them decide to use PDHM but also as a person who didn't have as much emotional weight in the decision as a mother does. This could be because as fathers, they don't have the ability to feed the baby so therefore, for them it is not as emotionally impacting when the mother's own milk is not a viable option. Conversely, partners sometimes took a step back from this decision because they understand a mothers emotions tied to breastfeeding and want to empower their partner to make a choice that works for them. Mothers reported talking about PDHM use with their husbands, but that their husbands would have been happy with either PDHM or formula. Farah described her husband as having faith in her decision-making capacity, and that he would be happy with whatever she decided provided that their baby was getting fed. Despite the support of her husband, this did create a situation where Farah had sole responsibility of choosing to use PDHM or not. Although Farah does not describe this in a negative light, there was a sense of feeling left to manage this part of motherhood alone whilst in a vulnerable position and needing ample support. Jill describes her partners lack of feeding preference also and says the decision to use PDHM came down to her personal

preference. Furthermore, Jill had known about PDHM before delivering her child and therefore described feeling less of the burden of choice due to her background knowledge.

"I think my husband wouldn't have really been concerned one way or another. I think he was just more concerned that our son was getting fed, but he trusted my decision on preferences for feeding... He's just like, "yeah, breast milk is good for you, then that's good for him", and he's happy with that. It's something I probably looked into a little bit more, so we'd conferred briefly with each other, but that's probably something he's left a little bit more up to my decision." (Farah)

"I don't think my partner cared. But I was quite keen if that, if we had the ability to, that's what I preferred her to have." (Jill)

Although the concept of a father's lack of preference for feeding is logically understandable (considering their biological inability to self-feed), for a mother's wellbeing, having shared decision-making could assist women to not continue to carry the whole weight of how to feed their baby. This echoed narratives of women being viewed as the 'default' parent in heterosexual parenting relationships and being left with the sole burden of decision-making could add to an already stressful situation. If husbands and partners were more involved in this, it could relieve women of some of the mental weight of choosing.

Farah went on to describe how using PDHM supported her and her husband as it allowed him to take on some of the feeding responsibilities and tube feed their child while in NICU. His ability to take on feeding tasks assisted Farah's mental health by relieving this ongoing stress for her. Furthermore, his involvement in feeding their baby would increase his bonding experience also. She recognised this same outcome could essentially be achieved through the use of formula too, however she thought she would be less inclined to accept this as feeding option due to her preference for breast milk. Highlighting that if she didn't have the option of PDHM, then her mental wellbeing would've been impacted due to her feelings of uncertainty around formula.

"Having the donor milk, I think, took a lot of stress off me. It also meant that the nurse... I know the nurses could have fed him formula during the night as well, but my hubby, he could tube feed him. I know that they would have done the same with the formula, but I think just having the breast milk as an option made me feel less stressed. It was just one less thing to be worried about. I think in the back of my mind, I would have worried a little bit more about formula, and I don't think it's pragmatic and I don't know why I just would have." (Farah)

HEALTH PROFESSIONAL SUPPORT

The mothers in this study reported varied experiences of how health professionals supported them throughout their journey. Not only did women have different experiences between them but also within their own stories, their experiences differed greatly from one type of health professional to another. Women often described nurses and midwives as being friendly and accessible and that they provided

knowledge which aided their feeding journey. Nurses and midwives were generally reported as being the most accessible health professional while these women and their babies were in hospital and therefore, they are a key person to be providing support. Although generally this support wasn't described as helping their ability to breastfeed, more so that women spoke of them fondly in terms of how they advocated of their babies to receive PDHM and supported mothers in feeling good about using it. Nurses appeared to be key in supporting women by gently nudged them to practise self-care and take time away from the hospital to rest and reset.

"All the nurses on the NICU were extremely knowledgeable about it. The nurses I came into contact within the maternity ward were also pretty good about it... They explain how much it would help us in that time. I felt like the access to it was really good and it was really... Once we were in maternity, it was well publicised and well discussed." (Farah)

"I had a nurse who she was amazing, absolutely incredible. Was very firm on, after I'd been in the hospital for about five or six days, I was in NICU in the centre of the hospital with no natural lighting and no... It's only recycled air. You start looking like bag-lady very quickly and you're in a high-end stress situation. After about four or five days of this, she's like, "you need to leave this space". I've already got the eMOM [PDHM] out, so you'll just have to go because it's going to go sour if you don't go out because otherwise no one's going to use it." (Farah)

Although women reported feeling adequate support in how they were personally treated from nurses and midwives, there appeared to be a gap in how women were routinely supported to breastfeed. Regarding lactation consultants. Some mothers found them extremely helpful and engaging, whilst others felt as though they were lacking sufficient support. There was an overall notion that lactation consultants were in short supply, and this decreased accessibility directly affected how mothers were supported during attempts of inducing or maintaining their own milk supply. Furthermore, women felt that had there been more options available to them to utilise lactation consultant services, that this would have help them feel supported in a more beneficial way. Instead, women were left with feelings of disappointment in an already discouraging situation.

"There was a couple of times that LC would say, "I'll come around tomorrow, and we'll try again, try putting on the breast". But then they didn't come because then they had to be somewhere else or something else popped up. That was a little bit disappointing, I think." (Renee)

Renee spent time across two hospitals, Palmerston North Hospital and Wellington Hospital, so was able to make a direct comparison of the lactation services available between both hospitals. In her experience, she generally found that the services available at a larger hospital were more supportive of her breastfeeding journey. Whereas she believed she was somewhat cast aside once she returned to the smaller hospital environment. Even though she did engage with lactation consultant services in Palmerston North, there were concerns raised regarding the inconsistent care and the result was she felt

generally uncared for and lacked the level of support she had received elsewhere. In Renee's experience, she looks back over her journey and feels as though she was given the best possible chance to succeed because of being in a larger hospital and therefore, felt this experience positively impacted her overall feeding journey.

"If I didn't start off in Wellington, I think that would really have hindered my breastfeeding experience quite a lot because it took a lot of support in Wellington just to get where I got, which wasn't even to that full-on breastfeeding experience. But I think if I was reliant solely on Palmy and the support that they have here, it just wouldn't have happened at all." (Renee)

"...the LC just stopped turning up one day, that was just it. There was no extra support. It felt like I was just booted a little bit. There wasn't any other information. I did ask about it because we were discharged from Palmy and spent a couple of days in Wellington NICU, which was for the hernia surgery he had. At that point, the LC popped around just to see me, but it was more like a friendly, just catch up from having not seen us for a few months, for a month or so. I mentioned to her about I'd still wanted to try breastfeeding for him. She did say, "oh, well, there's one LC in Palmy that works privately. You might want to catch up with her". But that was all. I was never actually told who that person was, how to access them. There wasn't that support there at all." (Renee)

A universal experience within the cohort was women reported that upon discharge from the hospital, the support from a lactation consultant ceased and women generally were left to manage their ongoing feeding concerns independently. Given women were using PDHM long-term, there was an underlying expectation that they would receive ongoing support once they were home. However, women instead described being left to fend for themselves for the duration of time (up to 6 months) of using PDHM. This outcome was conveyed with a sense of disappointment, that women then had to face the ultimate acceptance that wherever they were at with their feeding journey at discharge, was likely going to be their ongoing experience due to the lack of additional support in the community.

"No, I never heard from the lactation consultant again." (Kaia)

"It's something that they've definitely discussed in the postnatal class is that there is no services or very minimal services in the community. Once you're no longer in the hospital, there's really no options." (Farah)

SUMMARY

Mothers narrated their experiences of support systems as, whilst friendly, lacked a true sense of community and substance. Women were able to clearly identify who key support people were, such as husbands, nurses, midwives and lactation consultants. However, when outlining the support they received, there was either a lack of help or consistency. Husbands and partners were generally described as being the person that women turn to when they are making decisions about whether to use PDHM or

not. However, mothers still being somewhat sole decision-makers as their husbands don't have a preference either way. This could be due to father's lack of education regarding breastfeeding and PDHM. Or it could be due to their lack of investment in feeding practices due to their biological inability to self-feed a child. Women didn't tend to speak of their husbands/partners in a negative light regarding this, however, if they were more involved in the choice, this could lessen women of the burden of being the "default parent".

Women described nurses and midwives as a significant support regarding their ability to maintain self-care practices and use PDHM whilst they were in the hospital. However, they generally experienced lacking support to begin or maintain breastfeeding and continue to use PDHM long-term once they were discharged home. Women did often describe lactation consultant services from a smaller rural hospital as being inadequate (both in the hospital but especially in the community) and perceived the services at a larger hospital as being more beneficial. Women felt this had a direct effect on their ability to provide their own milk to their baby and influenced how they moved through their feeding journey.

4.5 THEME FOUR: EDUCATION MATTERS

Women described varied experiences of how they first came to know about PDHM, and how they were educated about it to make an informed choice. Despite surface level differences between participant stories, universally there was a common theme of lacking antenatal education. Some participants shared that they were aware they would deliver early due to various medical conditions such as premature rupture of membranes or intrauterine growth restriction. The women who had these experiences were delivering their children as early as 27-weeks' gestation. Despite there being existing evidence that early delivery can decrease a women's chances of lactation or even just delay lactation onset, women who knew they would have a premature birth report they were not given knowledge of PDHM in advance. Kaia reports that it wasn't until her 30-week gestation baby was born and was then struggling to thrive on formula, that pasteurised donor human milk was first mentioned to her as an option. What this means for mothers is that when they're in the depths of early postpartum, they are having to make crucial decision for themselves and their baby without having adequate time to be educated and process this information. Instead, they are making decisions in an already stressed state of mind. Kaia even felt that if she had known about the donor milk sooner, her feelings within herself wouldn't have been as impacted, as she could see her daughter struggling with the formula so thought the only other option was to produce her own milk. For this reason, she pushed herself to pump 2-hourly around the clock and this took a toll on her own wellbeing. For Kaia, if she had received proactive education, this critical part of her story could have been very different.

"No, it wasn't until, you know they were obviously… Were aware that her body wasn't coping with the formula and that's when they mentioned about the donor milk… I guess the fact that I wasn't producing anything and this baby kind of needed to be fed, so that was even, you know, it was hard. It definitely wasn't easy, 'cause I was trying my best, but no matter what I was doing, it kind of wasn't… Nothing was

working... I definitely think if I had more support around it, and knew about the donor milk earlier, I wouldn't have tried as hard as I did... Cause I was pumping every 2 hours, you know, I was constantly up, and then I had the worry of this child that was downstairs that was... She was ok but she wasn't ok." (Kaia)

Another mother, Renee, believed she was disadvantaged and did not know about the option of long-term PDHM only because she did not reach the gestational age when antenatal education classes are typically held. She recognised that many mothers of premature babies would likely share in this disadvantage. Furthermore, Renee describes the sudden onslaught of education as being a significant amount of information to take in in a time when she is overwhelmed by the early arrival of her baby. Similarities between Kaia and Renee's stories are that both these women were aware they would deliver early, yet still neither of them was given any prior knowledge of what their feeding journey may look like. Although both these women were provided education before consenting to PDHM, their consent was not given in a time where they were entirely able to calmly process what was going on, when there was ample opportunity prior to birth for this to occur.

"It's probably something that would be the same for a lot of premature birth mothers because I never got to the point of antenatal classes. They were from maybe 32 or 35 weeks old. Because you missed out on that, I never learned anything about what to do with the baby when it comes, and consequently, nothing about donor milk and breastfeeding. It's not like you pick those classes up later on. You just end up missing out completely. I'd imagine a lot of premature birth mothers probably are in the same boat. They don't get the information, and there is just this real gap. It's suddenly thrust upon you when you're in hospital, when you're about to give birth and everything else is a bit of a whirlwind, and then suddenly they talk to you about breastfeeding. If you're not mentally prepared to be popping a baby out at that moment, it's quite a lot to take in." (Renee)

When this experience is compared to the women in this study who did deliver their babies at full term, unfortunately they also report that they did not learn about the option of PDHM in their antenatal classes. This demonstrates that even though Renee feels her lack of education was purely due to delivering prematurely, this is simply not the case. Rather, women who use PDHM are at a disadvantage from the outset by healthcare providers failing to offer adequate breast feeding and donor milk education in the antenatal period.

"Neither of my husband and I can remember the mention of donor milk... That wasn't really something that I learned about until we were in need of it." (Farah)

There was one participant who was told by her health care provider that she may struggle to breastfeed due to the lack of physical change in her breasts during pregnancy. However, this was not then followed up by any education about PDHM or how she may be able to use it long-term. Instead, this mother took it upon herself to research how else she could feed her baby with the hope she wouldn't have to move straight to formula at birth. Through her own investigation, she educated herself on the option of PDHM,

aware she could advocate to have it for her baby and went into her birthing and postpartum experience with the knowledge of what it is and how to access it. For this mother, her determination to feed human milk over infant formula helped her be fully informed and therefore, when it was raised as an option, she didn't feel blindsided and out of her depth.

"So, I had looked into it... And I had... self-referred myself to the milk bank here in Palmerston North... I don't remember talking to the specialist at all. It never came from them. It just came from my own research." (Jill)

When mothers were educated on PDHM, they described inconsistencies in how this information was given. Women often reported the means in which the information was given played an important role. Some described it happening in a rushed manner, and with little recognition of the overload of emotion and information mothers would already be receiving at the time of their child's birth. For Ann, this moment of education was lacking, and she was left to decide without being fully informed. Renee had a similar experience of being overwhelmed with the initial education she was provided but then felt she was given time to process it and have this information reinforced later on. This process of multiple steps of education aided her ability to be adequately informed to consent to PDHM long-term. Unfortunately, not all mothers would receive this reinforced and staggered information, and be left somewhat in the dark, like Ann was.

"So, they just gave a consent form and said, "oh, yeah, we would like to use donor milk for her. And yeah, if you consent, then we'll start giving it to her". And so, I was just like, oh, okay, the information was just given very quickly." (Ann)

"It's suddenly thrust upon you when you're in hospital, when you're about to give birth and everything else is a bit of a whirlwind... it's quite a lot to take in. But what was really good is that that same information was followed up after baby was born." (Renee)

SUMMARY

Mothers in this study spoke of a lack of well thought out education regarding breastfeeding and pasteurised donor human milk. This was true for all women who participated in this research but particularly for women who delivered prematurely. For mothers who are able to anticipate early birth because of medical conditions, there is a unique opportunity to provide them with education and make post-birth feeding decisions in the moments leading up to their birth. However, it appears as though this opportunity is not as adequately utilised as it could be. This leaves prematurely birthing mothers in a place of overwhelm with the early arrival of their baby (who is likely requiring medical intervention), potential breastfeeding difficulties and an entirely new idea of feeding milk donated from other women long-term. By not educating these mothers in the time leading up to their premature birth, they are not being adequately supported or prepared for their postpartum experience.

For mothers who are delivering babies at term, the education regarding infant feeding appears to also lack key information. Mothers reported routine antenatal classes are excluding key feeding information that allows mothers to know about the option of PDHM before they birth. Instead, women who are adequately educated are having to rely on their own initiative to know about alternative feeding options. Not all women were aware that there were other options out there, and therefore may not take the time to do this independent research. Women should not have to rely on themselves to find the answers when healthcare professionals are adequately equipped with this information. However, it is noted that even when healthcare professionals' step into the role of providing education, there were inconsistencies in how this was done. Some women receive sufficient, supportive information which set them up for success of using PDHM long-term. Meanwhile, others were left feeling as though little care was taken to ensure they truly understood everything that was said to them and felt they were left 'in the dark' in for an extended part of their feeding journey.

CHAPTER FIVE: DISCUSSION

5.1 CHAPTER INTRODUCTION

This thesis explored the experiences of women who have used pasteurised donor human milk long-term (equal to or greater than two weeks). All women in this study utilised milk through the Whāngai Ora Milk Bank in Palmerston North, New Zealand. Most current research which investigates women's experiences of using PDHM does so in a short-term sense. Many women who use PDHM do so for only a couple of feeds to a couple of days, which can explain why short-term experiences are the most prominently researched. However, there are mothers who do use PDHM as a long-term feeding option. Therefore, this thesis aims to be one of the first to explore how these women experience long-term PDHM use and how their experiences may differ from what we already know about short-term PDHM use.

The findings of this research suggest that women who use PDHM long-term are faced with complex emotions around how they view themselves as mothers, how their mental wellbeing is impacted by these feelings, and how PDHM supports them in their postpartum journey. The themes in this research have created useful narratives by highlighting four critical events which occur in a women's feeding journey of using PDHM and therefore, show four critical areas where further support should occur. From what women described, it was clear that being educated on PDHM and accepting it as a feeding option was the greatest hurdle for women initially. However, once deciding to use PDHM, having sufficient support while using it and coming to terms with their own milk production is what women struggled with long-term. By generating themes which have adequately outlined this series of events, the findings of this research are able to be utilised in a more meaningful capacity.

Narrative inquiry has the potential to inform funding and policy by increasing how people live and make sense of the world (Pino Gavidia & Adu, 2022). For example, the narratives of this theses could be used to

shape how funding is distributed in roles like lactation consultants. Furthermore, overall policy change could be impacted in how we educate women on feeding options during their pregnancy, to ensure adequate preparedness in the postpartum period. Husbands, partners and health professionals are key in being able to support women through their postpartum journey, but often a lack of staff, time, or education is getting in the way of mothers being as adequately prepared as they could be. Ultimately, greater staffing levels in key roles such as lactation consultants and more intensive antenatal education could be what supports mothers who use PDHM long-term to have a more positive experience.

5.2 IMPACT OF FEEDING DIFFICULTIES ON MOTHER'S SENSE OF SELF AND MENTAL WELLBEING

Women carry an expectation that transitioning into motherhood, they should feel a certain way and be able to fulfil certain actions, such as their bodies producing milk to feed their baby (Wagg et al., 2022). For some mothers this internalised image of what a 'good' mother looks like begins in pregnancy for even before (Seagram & Daniluk, 2008; Wagg et al., 2022). Part of this image is often formed around their desire to breastfeed and therefore associate a positive breastfeeding experience with excelling as a mother (Seagram & Daniluk, 2008; Wagg et al., 2022). This expectation of early motherhood is not purely shaped by personal expectations, but also those of the society around us (Gutierrez, 2022). Breastfeeding is a perceived normalcy in motherhood and societal expectations claim that women should be subscribing to this role to fulfil the job of being a 'good' mum (Frankhouser & Defenbaugh, 2017; Thomson et al., 2015). This belief can live innately in a women and surface in the early motherhood period without her even being truly aware of it (Frankhouser & Defenbaugh, 2017). Constantinou et al. (2021) describes this self-prescribed ideal of a mother as the 'motherhood myth'. In the postpartum period, when a mother is unable to meet these expectations of herself, the result can be a pervasive loss of sense of self, inclusive of self-identity and autonomy (Frankhouser & Defenbaugh, 2017; Constantinou et al., 2021; Wagg et al., 2022). Within this study, this phenomenon was evidenced in the way women spoke about themselves and their ability or not to produce milk. At times describing their inability to breastfeed as leading them to feel unworthy or a failure, a theme seen in other literature regarding breastfeeding (Niela-Vilén et al., 2014). Women also described a sense of jealousy around their baby being able to be fed by another women's milk but not their own. These negative feelings contribute to an overarching feeling of maternal guilt in not being able to fulfil the roles they believed of themselves before motherhood (Frankhouser & Defenbaugh, 2017; Constantinou et al., 2021; Wagg et al., 2022).

Mothers who unknowingly subscribe to the 'motherhood myth' and subsequent feelings of maternal guilt displayed actions of 'intensive mothering' as a way to regain their sense of being a 'good' mother (Frankhouser & Defenbaugh, 2017; Constantinou et al., 2021; Kim & Kerr, 2024). Intensive mothering was first described by Hays (1996, as cited in Constantinou et al., 2021) as an ideology which identifies mothers as being self-sacrificing in their attempts to care for their infant and provide them with the very best resources while being the primary and preferred parent (Kim & Kerr, 2024). In this study, a version of intensive mothering was demonstrated by mothers who focused a significant portion of their energy on

undertaking activities which could help their milk supply such as taking medications and spending countless hours pumping. For these women, the idea of feeding their baby their breast milk was so heavily tied to their sense of motherhood that the resulting negative emotions of not breastfeeding induced a version of intensive mothering. Although women are encouraged to try inducing their own milk supply through these methods, the negative impact is seen if mothers persist with extensive efforts of pumping for months on end with no positive results and this continues to erode their sense of success as a mother (Kam et al., 2024). These same notions were found in a study conducted by Kam et al. (2024) where women with low milk supply felt feelings of grief, anger and regret about how their bodies weren't living up to their expectations and how all their intensive efforts of inducing lactation were unsuccessful. Although for some women in this thesis, repeated efforts at pumping did eventually induce a milk supply that allowed them to breastfeed. For others, they voiced an emotional strain from their efforts failing to lead to their desired breast milk result. The risk for long-term users of PDHM is a mother's high expectations of herself, and the resulting intensive mothering actions can negatively impact her mental health over time (Kim & Kerr, 2024; Kam et al., 2024).

Of the available literature regarding the use of pasteurised donor human milk, there has been very limited exploration of recipient mother's mental health. Similar to this study, Loh et al. (2022) highlights that mothers, particularly those who birthed prematurely, voiced feelings of inadequacy, self-blame and guilt for not being able to produce their own milk supply. Loh et al. (2022) was also able to highlight a similar experience of intensive mothering whereby women felt a pressure and self-expectation to do everything they could to try produce what their baby needed but reported the significant stress this placed on them. Interestingly, outside of PDHM use, similar depictions of intensive mothering are found in Wagg et al. (2022) study that researched perspectives of women who used informal milk sharing as their alternate feeding option. This feeding option differs from PDHM as women were sourcing milk through informal relationships, such as women they met through social media groups. Despite the difference in how they got the milk, Wagg et al. (2022) highlights that women feel an intense impact to their mental health while trying to produce their own milk. Specifically, women stated that for them, it wasn't sustainable to continue this long-term. This theses reinforces these findings by Loh et al. (2022) and Wagg et al. (2022) and highlights that women need ongoing support during their journey of using PDHM to ensure their mental health is not being negatively impacted by their ongoing efforts of pumping and high expectations of themselves. For women who use PDHM short-term, this concern may be short-lived purely because of the limited time they use it for, thus it is not heavily referenced in current literature. However, this notion has been demonstrated as true for women in a study which received non-pasteurised donor human milk; as they felt their mental health was protected by their ability to gain a milk supply and then be able to offer this to their baby (Brown & Shenker, 2022). For other women, such as those who require PDHM long-term, they may be pursuing efforts to feed their own milk for long durations of time, therefore their risk of deteriorating mental health (related to feelings of failure) could be greater without the reprieve of eventually producing milk.

Mothers ultimately described long-term access to PDHM as a significant support through this critical phase of emotions in their feeding journey. For many of the women who talked about their efforts to produce their own milk, they described a point in which they decided it was no longer serving them or their child well to continue trying. They surrendered to the ability to use PDHM instead and felt content with this decision for their family. This notion of being okay with using donated milk instead of mother's own milk is replicated in other research such as Wagg et al. (2022). Women described donor breast milk (from informal sources) as something that "saved" them from the feelings of failure associated with trying to meet an infant's needs unsuccessfully.

For these women, intensive mothering efforts should be monitored closely by a support person who can openly and honestly discuss what is working for the mother. This support person, whether a health professional or partner, should be capable of supporting the mother to continue trying to maintain their milk supply if she wishes, but also support her to know it's okay to stop if needed.

5.3 HOW CAN HUSBANDS AND PARTNERS BETTER SUPPORT MOTHERS THROUGH THEIR FEEDING JOURNEY

Fathers, husbands and partners play a vital role in supporting a mother through the feeding journey, whether she chooses to breastfeed, bottle feed or use alternative feeding options like PDHM (Agrawal et al., 2022). However, partners can at times feel excluded from the mother-infant relationship and feel like their infant-bonding is jeopardized by a baby who is breastfeeding (Sihota et al., 2019). They may feel like their relationship with their partner has been altered and that they don't have a significant share in infant-caring tasks, therefore diminishing their role as a father (Sihota et al., 2019). These things can have a direct effect on how they view themselves as parents and partners. Whilst also having the capacity to directly impact their quality of life and risk of postnatal depression (Sihota et al., 2019). For these reasons, fathers may not share in the same desire as mothers to ensure their baby is breastfed, but instead approach infant feeding in a 'no preference' type of way (Wang et al., 2018). Additionally, due to an overall lack of education regarding breast milk and breastfeeding, fathers generally leave feeding decisions primarily up to the mother (Wang et al., 2018; Hounsome & Dowling, 2018). However, women have reported a higher likelihood of initiating and maintaining breastfeeding when their partner shows a preference for the baby to receive breast milk (Wang et al., 2018; Hounsome & Dowling, 2018). These findings differ slightly in the case of using PDHM, with husbands demonstrating more of a preference when the milk is not coming from the mother. In available literature, how husbands view PDHM tends to be impacted greatly by their culture and at times women described needing to seek permission from their husbands to use it (Chaudari & Ayers, 2024; Magowan et al., 2020). There is a wide range of opinions with some men feeling PDHM is good and acts as a beneficial alternative to mother's own milk. While others viewed it as a disgusting option that they wouldn't want for their own child (Namuddu et al., 2023). In some research, women report declining PDHM based on their husband's opinion, even if it was something they wanted (Esquerra-Zwiers et al., 2016)

Comparably, within this research, women talked about their husbands and partners as having a lack of preference as to whether their babies were fed mothers own milk, PDHM or formula. Generally, husbands were described as only caring that the baby was fed, in one way or another. The interviewed mothers described their husbands in a way that echoed the findings of how men view general breastfeeding choices as found in the research conducted by Wang et al. (2018). These findings tended to sit outside of what has been found about husband's views of PDHM in other literature (Chaudari & Ayers, 2024; Magowan et al., 2020; Esquerra-Zwiers et al., 2016; Namuddu et al., 2023). Women described having most of the decision-making power when choosing to use PDHM. They stated that their husband's had a high level of trust in their insight and decision-making capabilities. This finding fits within a generalised rule that women tend to be the key decider in how a baby is fed (Radzyminkski & Callister, 2016; Hounsome & Dowling, 2018). However, women report this decision is significantly impacted by the people who support her and how she feels her decisions will be perceived by those around her (Radzyminkski & Callister, 2016). This means that the mothers in this study, despite having the decision-making power to choose PDHM, could have been consciously or subconsciously impacted by their husband's perceived preference.

The difficulty in giving this choice completely to the mother, is that they then have to take on the mental load of decision-making (Dean et al., 2021). At a time when they are feeling stressed and potentially unsure of how best to help their baby. For most women in this study, they did not receive adequate education about breastfeeding and PDHM prior to the delivery of their baby, and neither did their husbands. Fathers may choose to leave the choice of infant feeding up to a mother, on the assumption that they know more about it (Wang et al., 2018). When in reality, they likely have the same level of understanding at that moment. Alternatively, these husbands may also be subconsciously subscribing to the idea that women decide how a baby is fed due to it fitting a gender norm (Delgado-Herrera et al., 2024). Ultimately, by leaving mothers with the full decision-making power of using PDHM, fathers may be inadvertently adding to a mother's mental load. 'Mental load' is described as the unseen thinking, scheduling, and planning of a family. It stretches beyond cognitive labour and into emotional labour also, as women are generally making decisions based on feelings of love, care and responsibility for people who depend on her (Dean et al., 2021). The mental load of motherhood can be enduring due to the nature of a decision being tied to the ongoing care of a loved one (Dean et al., 2021). From the findings of this study, it is argued that the choice to use PDHM is not a singular moment in time but an ongoing decision which women were seemingly left to carry themselves. Particularly, because the women in this study used PDHM long-term, this means for some of them, the continued choice to feed their baby PDHM was one they carried for up to six months. Comparably, mothers who use PDHM short-term may feel less decision-making mental strain due to using it for only a few feeds or a few days. Women who use PDHM long-term would be better supported during this time if their husband's received education about it during the antenatal period, alongside them, so they could fully partake in the ongoing joint decision-making process.

5.4 MATERNAL PREPAREDNESS FOR PDHM AND LACKING ANTENATAL EDUCATION: WHAT CAN HEALTH PROFESSIONALS DO BETTER?

Antenatal education is a recognised and encouraged practice of providing education to expecting parents to increase parental preparedness for pregnancy, birth and postpartum (Barimani et al., 2018; Pylypjuk et al., 2022). Furthermore, WHO (2023b) states that women should be specifically educated on the benefits and management of breastfeeding. Given that the World Health Organisation (2023a) recommendation on breastfeeding includes the use of donor milk (should a mother's own milk not be available) then this antenatal feeding education could involve discussing this option with parents also. Despite this, none of the women who took part in this research voiced feeling adequately educated or prepared during pregnancy for the concept of feeding their infant pasteurised donor human milk. Ellsworth et al. (2021) found similar concepts in which women reported they were rarely offered sufficient counselling regarding the use of donated milk. In this research, health professionals may have assumed that for some of these women the potential of using PDHM was unlikely due to the expected delivery of a healthy, term baby. However, for others, they were aware and waiting for the premature delivery of their babies yet still, women were not given opportunity to learn and understand the potential feeding consequences of this in advance.

Women could have been educated about how reduced pregnancy length can cause insufficient breast tissue preparation for milk production and that immature sucking reflexes of premature infants creates difficulty latching (Peng et al., 2024). Alongside this information, women could then be informed that PDHM is an option they should consider for their infant if these difficulties arise. Women who are adequately prepared in this regard are then aware of what could happen and have the knowledge to provide informed consent for PDHM if needed. By missing out on this vital stage of adequately informing women about PDHM, there is a risk of delaying optimal nutrition for the preterm infant whilst education and acceptance of PDHM occurs post birth (Government of Western Australia Child and Adolescent Health Service, 2023). Of the six women who were interviewed, only one reported that she was aware of PDHM prior to delivery. However, this was only because of her own research and initiative to understand alternative feeding options when an obstetrician told her she may have difficulty feeding due to her breast size not changing much through her pregnancy.

As seen in other literature, mothers have voiced concerns regarding PDHM due to lacking knowledge around it. For example, many women hear and believe myths about PDHM such as it having the capacity to pass on genes and personal traits (Namuddu et al., 2023), undermine mother infant bonding (Kair & Flaherman, 2017; Namuddu et al., 2023), and be unclean and potentially infectious (Kair & Flaherman, 2017; Karacan et al., 2024). Some women in these studies went on to refuse the option of PDHM for their infants because of these untrue beliefs (Namuddu et al., 2023; Kair & Flaherman, 2017; Karacan et al., 2024). This demonstrates that women must be empowered with accurate knowledge to be able to make truly informed decisions about the feeding options available to them. Although women in this research did not believe any such myths, the basis is the same in that only with sufficient knowledge; can come a true understanding of what PDHM is and how it helps women and babies. Along with this fully informed consent then comes the trust and reduced stress for parents to use it.

The findings of this study differ slightly to other research in that all women were given enough knowledge of PDHM to feel comfortable consenting for it. However, the education given was timed poorly or inconsistent. Some women reported having conversations with lactation consultants or midwives during their premature labour and others were not told about PDHM until their child had spent time struggling on infant formula. This indicates a lack of consistency around PDHM education of what women are told and when. Some women in this study received ongoing advice and education about breastfeeding and PDHM in the weeks following birth in NICU. While others who were discharged home felt discarded and left to their own devices. In the research conducted by Pylypjuk et al. (2022), a review was done of an antenatal breastfeeding and PDHM education program for women who were considered high risk for newborn admission to NICU post birth. This program demonstrated similar findings of inconsistencies in feeding education for women in the antenatal period. It was found that women who were educated on breastfeeding and the potential use of pasteurised donor human milk throughout their pregnancy showed better postpartum success of initiating and maintaining breastfeeding (Pylypjuk et al., 2022; Phipps Smeltzer, 2016). Furthermore, the authors of this study agree that education regarding the use of donor milk should begin during pregnancy, especially for women who have anticipated premature deliveries (Pylypjuk et al., 2022). Antenatal counselling of women expecting premature birth has the ability to build a strong relationship between women and healthcare provider early on, while allowing parents to consider their own values and goals before reaching the most challenging and stressful time of their journey (Jefferies et al., 2012). Furthermore, by engaging in education early, this builds capacity for shared decision-making between health professionals and families, which can ultimately lead to less stress for parents who may feel that need to make hard decisions alone (Jefferies et al., 2012). Overall, from measuring the success of a maternal preparedness program, the authors found that a standardised approach to antenatal education offered the greatest number of women the chance to succeed in their feeding journey (Pylypjuk et al., 2022). In this research, women ultimately voiced that there was no standardised approach to education in each of their stories, but if there had then they could have felt more supported in their postpartum journeys.

5.5 STRENGTHS AND LIMITATIONS

The purpose of this study has been to understand women's experiences of using pasteurised donor human milk long-term within New Zealand. A strength of this study is that to the best of our knowledge, it is one of the first to exclusively investigate long-term PDHM use. Therefore, the perspectives obtained in this theses are newly uncovered and have the potential to shape how women who utilise PDHM long-term receive care. Additionally, by researching women's own perspectives, this research has been able to place women at the centre of the story and give them a voice to express their narrative.

Within the service area of the Whangai-Ora Milk Bank, long-term use of PDHM is quite a rare clinical event, offered only in special circumstances. Therefore, only a small sample size of women was able to be interviewed, and the experiences of the included participants may not be representative of the nationwide

context of using PDHM long-term. Additionally, all women in this study utilised PDHM from Whangai-Ora Milk Bank and received antenatal care through Palmerston North and Wellington Hospitals. Without the experiences of women who have utilised other hospitals and milk banks around the country, it cannot be ascertained if the perspectives in this study are representative of women using services in other parts of New Zealand.

The majority of women in this research identified as New Zealand European, aside from one mother who identified as Chinese. Within New Zealand, a multicultural population exists of European, Māori, Pacific peoples, Asian and other ethnicities (Stats NZ, 2024). This research did not seek to specifically research any single culture's experiences of using PDHM long-term. However, as seen in relevant literature, the experience of using PDHM differs between cultures. Therefore, research that can adequately explore the voices of women from other ethnic backgrounds could make a significant contribution to how PDHM use is approached by health professionals in various different contexts. Sharing the voice of women from different cultural contexts should be considered in future research.

5.6 RECOMMENDATIONS

Based on the findings of this research, the following recommendations are made to better support women who use PDHM long-term:

1. Women who have delivered prematurely have not felt adequately pre-warned about the potential difficulties of breastfeeding. Women who are deemed high-risk for premature delivery or whose babies are deemed high-risk of admission to the neonatal intensive care unit, should be counselled on the potential of delayed onset of lactation and difficulty latching.
2. Women who delivered prematurely have not been adequately educated on the potential of needing to use PDHM for their baby. Based on an assessment of whether a women is deemed high-risk for premature delivery or NICU admission, women who have an increased likelihood of needing to utilise PDHM should be given opportunity to learn about PDHM during their pregnancy where possible.
3. Education in the above situations should be done in conjunction with a midwife or lactation consultant. Women should be offered the opportunity to leave this education session with information, process it and return for a follow-up session to clarify any questions or concerns. This education should be conducted with women and partners (where possible) between 22-28 weeks gestation. This is to ideally catch most women following their 20-week morphology scan and prior to premature delivery.
4. Education sessions can be offered in group settings or one-on-one with a midwife or lactation consultant.
5. Fathers and partners often leave feeding decision up to the mother, inadvertently placing this burden of decision on her. To ensure fathers and partners are more adequately informed and are better positioned to be supportive to the mother, non-birthing partner-only education should be

given. This could be done in the form of a tailored education pamphlet or a group education session.

6. Women and their partners should be encouraged to have conversations about infant feeding options and PDHM prior to delivery of their baby. In situations where a women is expected to deliver prematurely, health professionals should actively engage in this conversation with the family to help mediate expectations and provide additional information as needed.
7. Women report feeling inadequately supported by lactation consultant services. Funding should be increased for lactation consultant services for women to have appropriate access to a service which supports their feeding journey. Funding should be considered in regard to the following recommendations:
    a. Lactation support services should be developed which allows for either a lactation consultant or midwife to complete follow up phone calls to women utilising PDHM on discharge from the hospital. Mothers should be asked about the physical aspects of breastfeeding and pumping and offered tailored support as needed. Mothers should also be asked about feelings of stress and overwhelm and if they feel that continuing to try breastfeeding, pumping, taking supplements and medications for milk supply is still working for them.
    b. Women should remain on the discharge call list until such time as they stop using PDHM. Frequency of calls can be negotiated between health professionals and mothers at the time of the first phone call. If a women decides to not utilise this additional service, they should still be able to call back at another time in their feeding journey if they change their mind.
    c. Women who use PDHM long-term should be offered opportunity to meet with a lactation consultant face-to-face if they report having ongoing difficulties as they go along their feeding journey.

CHAPTER SIX: CONCLUSION

Breast milk offers the best nutritional start for infants, especially those that are born prematurely. However, for many women, being able to offer their own milk to their child can be a significant challenge that is not always overcome. For women who cannot feed their own milk to their child, donor human milk is the next best alternative. Most of the current literature about women who use pasteurised donor human milk, seeks to understand their perspective of using it short-term. This thesis aimed to build on current research by understanding how long-term users of PDHM perceive their feeding journey. Additionally, it was hoped to understand what more could be offered in the maternal health space to better support these mothers and their families.

Women who have used PDHM long-term have reported a clear relationship between their feeding abilities and how they view themselves as mothers. All mothers spoke of their desire to breastfeed and when they

were unable to, they viewed themselves as having failed at something that they perceived a mother should be able to do. This sense of failure was not felt in a singular moment in time but something that endured within the mother as she continued to try to produce breast milk unsuccessfully over a period of weeks to months. Many women undertook 'intensive mothering' efforts of pumping around the clock, taking medications and eating specific diets in order to obtain their goal of being able to breastfeed. Although women are encouraged to continue trying to stimulate a milk supply while using PDHM, these mothers reported a clear lack of support to achieve this.

Women felt isolated and at risk of continuing efforts past the point of it being physically and mentally beneficial for them. Lactation consultants were described as being in short supply or inconsistent. Meanwhile, women's husbands, although supportive of their journey, lacked a true background knowledge of infant feeding to adequately hold space for the mother. This often manifested in how they deferred responsibility of decision-making onto women under the guise of having no specific preference of how their baby is fed. Both women and their husbands were left to navigate these journeys without significant support or education. Although they ultimately reported a positive experience of using PDHM long-term, changes in funding and policies should be considered to offer to these families a more positive, holistic experience.

Women and their partners should be armed with adequate infant feeding knowledge in the antenatal period. Women can feel blindsided when their postpartum body doesn't meet self-perceived expectations of what a mother 'should' be able to do. If women are told about these potential outcomes before they arise, they will be better set up to make informed decisions, have alternative feeding plans in place and feel less of a sense of failure if they are unable to breastfeed. Meanwhile, husbands and partners should also be educated to be better equipped to join a women in the decisions around infant feeding, therefore reducing her mental load. To fulfill these recommendations, funding should be concentrated on increasing lactation consultant roles and formulating programs which support women during long-term PDHM use. Fundamentally, health professionals should not be afraid to engage in conversations with families early on in the parenting and pregnancy journey, as sufficient parental preparedness will only set families up for success, and not perceived failure.

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APPENDIX

1. Interview questions used in primary data collection

Participant details

Name:

How old are you?

What ethnic background to you most closely identify with?

What is your highest educational achievement?

Prompt: Highschool year 9/10, NCEA level 1, NCEA level 2, NCEA level 3, Diploma, Bachelor's, Postgraduate Diploma, Master's, PhD

How many times have you been pregnant? Gravidity:

Prompt: number of times being pregnant regardless of the outcome

How many children do you/have you had? Parity:

Prompt: number of pregnancies that have resulted in viable births e.g., from 24 weeks onward

Pregnancy and birth

Tell me about your pregnancy:

How far along in your pregnancy were you when you baby was delivered?

Can you tell me about their birth?

How long did you and your baby stay in hospital after they were born?

Feeding your baby

Tell me about your feeding journey and at what point it was offered to you to use PDHM and why?

Had you known in your pregnancy that this could be an option for you?

When did you learn about PDHM and how?

Are you able or were you able to produce any breast milk?

Throughout your feeding journey, how important has it been to you to be able to supply your own milk to your child?

Have you been able to give any of you own milk to your child in addition to PDHM?

If you can lactate, in your opinion, while using PDHM in a longer-term sense, has your ability to supply any of your own milk to your baby been positively supported or negatively impacted in any way?

Were you given additional support to help you supply your own milk to your baby?

Prompt: Referred to a lactation consultant or support from midwives/nurses

What were your initial thoughts and feelings about PDHM when you first learnt about it and the potential of using it?

Who helped you decide to use PDHM and what did they do that assisted you?

Prompt: was it a medical professional explaining the PDHM process or was it a partner, friend or family member providing general support

Did you have any concerns about using PDHM?

Did you use PDHM only while in hospital or did you use it post-discharge also?

How long did you use/have you used PDHM?

When you started using PDHM, did you expect to use it for that length of time?

If you have stopped using PDHM, what feeding option did you move to? If you have not stopped using PDHM, what feeding option do you expect to move to?

- MOM only
- Formula only
- Solids only
- MOM & formula
- MOM & solids
- Formula & solids
- MOM, formula & solids

How do you feel about PDHM now that you have used it?

How do you feel about donor breast milk from other sources – such as a friend/family member or through an informal milk sharing relationship?

In the early days of your feeding journey, did you have any specific feelings about using PDHM and how you viewed yourself as a mother? How about now?

If the circumstances arose to use it again in the future, would you feel comfortable doing so?

Did you share with anyone that you were using PDHM?

If yes, what sort of feedback or opinions regarding PDHM did you receive from these people? (Negative or positive)

Was there anything during your PDHM journey that was challenging for you?

Was the process of receiving the milk and using it, user friendly and sustainable for long-term use?

When you look back over your feeding journey, is there anything that you think would have helped you that you did not receive or were not offered?

What would you say to other women in a position of needing to decide if they will use PDHM?

2. Interview used for secondary data transcripts

Name of the interviewer:

Interview number:

Location of the interview: Zoom/Telephone/Home visit

Date:

1. What is your age? _____

2. Which is the main ethnic group that you identify with most? Please select one_____

    - NZ Māori
    - New Zealand European
    - European
    - Pacific (Pacific NFD (not further defined), Samoan, Cook Island Māori, Tongan, Niuean, Tokelauan, Fijian, Other)
    - Indian
    - Asian (Asian NFD, Southeast Asian, Chinese, other Asian)
    - Other

3. What is your highest qualification? Please select one _____

    - Higher/Postgraduate
    - Bachelor's degree
    - Diploma/Trade cert
    - Sec School/NCEA 1-4
    - No qualification

Firstly, can you tell us about your birthing and feeding journey with this new baby? How did you come across using PDHM? (PDHM – pasteurised donor human milk)

What were your initial thoughts and feelings when you learned that you could receive PDHM for your baby?

Who helped you decide? What factors influenced your decision to use PDHM for your baby? (For example, whether adequate information was available about accessing PDHM and any knowledge or awareness of any health dimensions/implications of its use, information given during pregnancy?).

How did using PDHM affect you or your feeding journey, your emotional well-being, or your overall postpartum experience?

Can you describe any positive outcomes that you experienced from using PDHM for your baby?

Can you describe any challenges from your early feeding journey that included PDHM?

What impact do you feel receiving PDHM had on your wider family?

What were other people's reactions to your use of PDHM?

After the first few weeks after discharge from the hospital, if you were breastfeeding your baby, how did receiving PDHM affect your experience of breastfeeding?

What information did you receive in helping with sustaining your breastfeeding journey? What support did you receive (such as from health professionals, peer support or family)? Who was your primary support from your family?

Would you like to share any advice or suggestions for other mothers in a similar position who may be considering using PDHM?

Is this your first baby? Yes

What was the baby's gestational age at birth? _____

- Extremely preterm (less than 28 weeks)
- Very preterm (28-32 weeks)
- Moderate to late preterm (32-37 weeks)
- Term (37 weeks plus)

How long was your baby in the Neonatal Unit of Palmerston North Hospital? _____ Days.

How long was your baby in the Postnatal unit of Palmerston North Hospital? ____ Days.

What was your baby's main food during the hospital stay? ___ _____

What was your baby's main food at hospital discharge?

How old is your baby now?

What is your baby's main food currently?

- Only PDHM (Pasteurised Donor Human Milk)
- PDHM + MOM (Mothers' own milk)
- PDHM + Formula
- PDHM + MOM + Formula
- MOM + Formula
- Only MOM
- Complementary foods
- Solids

Is there anything else you want to share about your experience using PDHM from the Whāngai Ora Milk Bank?

3. Consent form

MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

A bridge to a better future - Does the use of pasteurised donor human milk support breastfeeding practice and improve maternal wellbeing?

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read and understand the Information Sheet attached. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study within two weeks of receiving my interview transcript.

[ ] I agree to participate in this study under the conditions set out in the Information Sheet.

[ ] I agree to have the interview recorded and transcribed verbatim.

[ ] I agree that I can read the transcripts and make amendments as appropriate. If I do not respond within two weeks of receiving the transcripts, this means I do not wish to make further changes to the transcripts.

[ ] I agree that the edited transcript and extracts from the interview (de-identifiable data) may be used in reports and publications arising from the research.

[ ] I wish to receive the summary of the study results.

Declaration by Participant:

I _____ hereby consent to take part in this study.

Signature: _____ **Date:** _____

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4. Information sheet

MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

A bridge to a better future - Does the use of pasteurised donor human milk support breastfeeding practice and improve maternal wellbeing?

INFORMATION SHEET

Invitation to Participate in this Project.

Dr Ying Jin from the School of Health Sciences, Massey University will lead this project. Co-investigators include Dr Linda Murray from the School of Health Sciences and Associate Professor Lisa Te Morenga, from the Research Centre for Hauora and Health, Massey University. Our collaborators include Jacquie Nutt (Lactation Consultant) - Whāngai Ora Milk Bank Coordinator, and Louise Wedgwood, Lactation Consultant at the Neonatal Unit of Palmerston North Hospital.

Please read this Information Sheet carefully before deciding whether you wish to take part in our study. You are under no obligation to participate in this study. Non-participation will not impact further access to the Whāngai Ora Milk Bank. Feel free to discuss participation with your family, whānau, and friends.

Project Description

Good nutrition for vulnerable infants is important to support their growth and development. Breastmilk provides optimal nutrients for infants. When a mother's own milk is temporarily unavailable, the World Health Organization recommends donor human milk (DHM) as the next best alternative. Since 2019, the Whāngai Ora Milk Bank has been providing DHM locally. The milk bank is a charitable trust, set up to assist mothers, especially those with premature or ill babies, to source safe supplies of human milk when mothers have not established their own breastmilk supply. There is limited information on the experiences of mothers who received pasteurised DHM for their babies. This study aims to explore the impact of using pasteurised DHM on maternal breastfeeding practice and maternal wellbeing after hospital discharge.

Participant Identification and Recruitment

We aim to recruit 50 mothers to complete an interview. All women who completed interview will receive a $40 voucher. An invitation email/text will be sent via the Whāngai Ora Milk Bank Coordinator, containing a full research information sheet and consent form. Selection criteria: all mothers who are aged over 16 years, who are proficient in English, and whose newborns received pasteuriesed DHM (short -term or long-term users) during 2022 and 2023. Exclusion criteria: 1) mothers who are younger than 16 years old; 2) mothers who received donor milk via private milk sharing practices.

Massey University
Te Kunenga ki Pūrehuroa
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand
+64 6 350 5701 | contact@massey.ac.nz | massey.ac.nz

What does the project involve?

Mothers will be asked to take part in an interview of around 30-45 minutes, only your voice will be recorded, it can take place via zoom/telephone/home visit of your choice. There will be an opportunity to read the description of the study and be advised about confidentiality of data collection before participating. The interview transcript will be sent for you to read and make amendments as you wish. If there is no response within two weeks of sending the transcripts, we will assure you are happy with the current transcripts.

Data Management

Participation in the research is confidential. All data collected will be used only for this study. Participants will be identified only by a unique study identification code (not your name). The data will be stored on computers, which are protected by passwords, using only the unique study identification code and will be accessible only to the researchers. The project data will be stored as outlined above for 10 years by Massey University.

Should you wish, a summary of the study results can be sent to you. The findings of this project will be reported back to collaborators at Palmerston North Hospital and Whāngai Ora Milk Bank. This information will be useful for future planning and advocacy for their services. Findings may be published in scientific journals or presented at relevant conferences. This ensures that a wider community, including health professionals, can know and read about the findings. You and your baby will not be identified any of these publications or presentations.

Participant's Rights

You are under no obligation to accept this invitation. If you are taking part in an individual interview, you can ask for the recorder to be turned off at any time during the interview. If you decide to participate, you have the right to:

- *decline to answer any question.*
- *withdraw from the study within two weeks of receiving your interview transcript.*
- *ask any questions about the study at any time during participation.*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher.*
- *be given access to a summary of the project findings when it is concluded.*

Project Contact

Dr Ying Jin, Lecturer, School of Health Sciences, Massey University
Email: y.jin@massey.ac.nz

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 23/23. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz

5. Ethics approval for secondary dataset

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

12/07/2023

Dear: Dr Ying Jin

Re: Ethics Application - OM1 23/23 - A bridge to a better future - Does the use of pasteurised donor human milk support breastfeeding practice and improve maternal wellbeing?

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 1 at their meeting held on **Tuesday, 13 June 2023**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

6. Ethics approval for primary dataset

From: Patsy Broad <P.L.Broad@massey.ac.nz>
Sent: Monday, March 11, 2024 3:12 PM
To: Ying Jin <Y.Jin@massey.ac.nz>; Linda Murray <L.Murray1@massey.ac.nz>
Subject: HEC: Ohu Matatika 1 OM1 23/23 - Amendment One

OM1 23/23 **A bridge to a better future- Does the use of pasteurized donor human milk support breastfeeding practice and improve maternal wellbeing?**
Dr Ying Jin, Dr Linda Murray, & A/Pro Lisa Te Morenga (HE: Ohu Matatika 1 Application OM1 23/23)
Department: School of Health Sciences

Minor Amendment to a previously approved application

Thank you for your email dated 5 March 2024 outlining the change you wish to make to the above application.

The change has been approved and noted, as follows:

- The inclusion of Dakota Sykes (undertaking a Master of Public Health) to the research team, to conduct some of the interviews and analysis under the supervision of Dr Ying Jin and Dr Linda Murray.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee. If over time, more than one request to change the application is received, the Chair may request a new application.

Ngā mihi
Patsy Broad
On behalf of the Chair, Ohu Matatika 1

Patsy Broad *(she/her)* **| Team Leader**
Research Ethics Team

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