DECISION MAKING SURROUNDING HUMAN MILK DONATION: ATTITUDES SOCIAL NORMS AND BARRIERS

by

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Abstract

Although milk from the milk bank is the medically preferred choice when a mother's own milk is not available (Kim, Unger, Canadian Pediatric Society [CPS] & Nutrition and Gastroenterology Committee, 2010), it is frequently in short supply and new donors are always needed (BC Women's Hospital and Health Centre, 2018). There is no published literature on attitudes, subjective norms and barriers surrounding breastfeeding and human milk donation nor how these constructs influence intention to donate within the context of mothers in British Columbia (BC). Seven hundred fifty-four women residing in BC, with a child 24 months old and younger, were recruited for this internet based study examining attitudes, subjective norms and barriers in relation to intention to donate human milk to the BC Women's Provincial Milk Bank. These participants were recruited through multiple methods including: one on one requests to fill out a survey at 16 public health units where posters and advertisements were placed; an invitation in Fraser Health's Best Beginnings e-Newsletter; snowball sampling through online Facebook community groups; and one of the researcher's Twitter accounts. Analysis included ANOVAs, Chi-square analyses and hierarchical logistic regressions. Overall results indicated a positive attitude and subjective norms toward human milk and the Milk Bank. The logistic regression results showed that those who scored themselves as likely to donate to the Milk Bank believed that human milk banking is important; believed other mothers have donated; scored high on the ease of donation scale; had one child; and had previously shared milk. Sub-analysis of mothers who were breastfeeding at the time of the study, revealed similar results. Mothers who indicated human milk banking is important and scored high on the ease of donation scale more often rated themselves as likely to donate. The results of this study allow policy makers and healthcare providers to focus their recruitment efforts on facilitators that would increase intention to donate. Further research on specific barriers to human milk donation is needed.

Lay Summary

The goal of this study was to explore attitudes, perceived social norms, and barriers toward breastmilk donation to the BC Women's Provincial Milk Bank. This was done through an internet survey study of mothers of children 24 months old and younger, living in British Columbia. Results showed that mothers had positive attitudes and felt society had positive attitudes toward human milk and the Milk Bank. Intention to donate breastmilk was higher when women: believed human milk banking was important, believed other mothers had donated, scored high on the ease of donation scale, had one child, and had previously shared milk. Although more research on this topic is needed, this study provides information that can be used by health care workers to work with the community to increase intention of women to donate breastmilk to the Milk Bank.

Preface

This thesis is original, unpublished work by Damaris Grunert. I conducted the literature review, collected the data and wrote the Chapters 1-6. Dr. Suzanne Campbell oversaw the conceptualization and literature review, as well as writing of Chapters 1-3 and 6. Design and analysis of research data was completed in collaboration with Dr. Susan Dahinten, who oversaw and edited the writing of Chapters 4 and 5. Lynne Palmer reviewed and gave feedback, which was incorporated on all 6 chapters.

Ethics Approval for this project and its pilot project were granted via a harmonized review through the Fraser Health Research Ethics Board and the UBC Behavioural Research Ethics Board.

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I would also like to thank the Quintessence Foundation for their grant received through the Wah Wong Lactation Support, which aided in recruitment of participants, and thereby allowed me to complete this project.

And, of course none of this would have been possible without the support of my friends and family. I would like to thank my friends, Rebekah for her encouragement, assistance with grammar and use of her images in presentations stemming from this research. Anne, Dorothea and Cyndi for keeping my spirits up and encouraging me to persevere. I have amazing friends! Finally, I would also like to acknowledge and thank my family, Angela, Horst, Amber and Christoph for their incredible patience and support throughout this process.

Dedication

Dedicated to my family, friends, and all the wonderful momma’s and babies I have had the honour of caring for, through both the best and worst times of their life.

Chapter 1: Introduction

It is universally accepted that human milk is the optimum exclusive food source for infants up until the age of six months and a healthy part of a child's diet up until two years of age and beyond (Kim, Unger, Canadian Paediatric Society [CPS] & Nutrition and Gastroenterology Committee, 2010; Boland, 2005). The Canadian Paediatric Society (CPS) recommends, in order of preference, a mother's own human milk, pasteurized donor milk, followed by human milk substitute (Kim et al., 2010). Although, human milk is both recommended and beneficial, not all mothers are able to exclusively breastfeed their infants at all times.

When mothers are not able to provide the necessary human milk themselves, they are faced with a decision of three alternatives, namely: unscreened shared human milk, pasteurized human donor milk or human milk substitute (commonly known as formula). Unscreened shared human milk, acquired through lactating friends, family members or the Internet, is frequently criticized. It is considered unsafe by many health professionals and the CPS does not recommend sharing unpasteurized human milk (Kim et al., 2010). This leaves mothers in British Columbia (BC) with two recommended choices, pasteurized donor milk from the BC Women's Provincial Milk Bank or human milk substitute. Although milk from a donor bank is the medically preferred choice (Kim et al., 2010), it is frequently in short supply and new donors are continually being sought (BC Women's Hospital and Health Centre, 2018).

Little research has been done on the attitudes, subjective norms and barriers surrounding a mother's intention to donate human milk to the local Milk Bank, or the characteristics of women that are likely to donate to the Provincial Milk Bank. This study focused on mothers with infants 24 months and under, located in BC, Canada, and will help healthcare providers better understand this population and support these mothers in their decision to donate to the Milk Bank.

Background/Significance

The interest in human milk and human milk donation has fluctuated throughout the last century (Jones, 2003). Prior to the 20th century, when mothers were unable to breastfeed their infants, wet-nursing was common. According to Barret (as cited in Jones, 2003), the first human

milk bank opened in 1909 in Vienna. In North America, milk banks started in 1910 as directories for wet nurses providing milk to infants (Jones, 2003). In 1934, after a media appeal to the public, the famous Dionne quintuplets were fed with donated pasteurized human milk first prepared in Toronto's Hospital for Sick Children, then in Montreal. The infants were fed donated human milk for the majority of their first 5 months of life (Infant Feeding Action Coalition Canada, N.D.). This drew the public's attention to the importance of milk donation. Advances in artificially prepared human milk substitutes saw interest in human milk decrease throughout the 1950's and 1960's (Jones, 2003). With support for it growing once again throughout the 1970's and 1980's, resulting in the establishment of 23 milk banks throughout Canada (Sauve, McIntosh, Clyne, & Buchan, 1982 & Bednarek, 1982, as cited in Jones, 2003). With the discovery, spread and fear of HIV and AIDS (Kim et al., 2010; Infant Feeding Joint Working Group, 2014) the majority of these milk banks were eventually closed.

In 1985, with the increased concerns surrounding milk banking, the Human Milk Banking Association of North America (HMBANA) was formed to ensure that standard protocols for the operation of milk banks were available (Jones, 2003; Updegrove, 2013). Despite this, in 1995 the CPS released a statement on human milk banking (CPS, 1995) that criticized human donor milk as insufficient for preterm nutrition and too high risk for term infants in western society. This statement did not differentiate between wet nursing and pasteurized donor milk and used these references interchangeably. Of interest is their recommendation that "the routine use of human donor milk is… not recommended for either preterm or term infants. Furthermore, funds currently being used to support human milk banks could be redistributed to establish lactation clinics" (CPS, 1995, p. 3). Although all other milk banks in Canada closed after these recommendations, the BC Women's Milk Bank, now known as the BC Women's Provincial Milk Bank, remained open.

The CPS' change in position statements toward human milk banking highlights the change in attitudes toward human donor milk throughout time. With increased research surrounding the contents and the benefits of human milk, the CPS currently supports feeding pasteurized donor milk as the primary alternative to a mother's own milk resulting in increased support for milk banking in Canada (Kim et al., 2010). There are currently 3 milk banks located within Canada: the BC Women's Provincial Milk Bank in Vancouver, British Columbia; the

Calgary Mother's Milk Bank in Calgary, Alberta; and the newly opened Roger Hixon Ontario Human Milk Bank in Toronto, Ontario.

Milk banks provide human milk for infants whose mothers are unable to provide their own human milk. There are many benefits to breastfeeding and the provision of human milk to infants. Some of these benefits will be outlined below.

Studies have shown that breastfeeding is associated with a decrease in ear infections, obesity in childhood and adolescence, respiratory and gastrointestinal infections, type 1 and 2 diabetes later in life, (Bowatte et al., 2015; Hörnell, Lagström, Lande, & Thorsdottir, 2013), sudden infant death syndrome, atopic dermatitis in children with a family history of this and asthma in children less than 10 years old with a family history of asthma (Renfrew et al., 2012; Perinatal Services of British Columbia [PSBC], 2012). In addition, breastfeeding has demonstrated beneficial effects on intelligence as measured with IQ (Victora et al., 2016) and breastfeeding for a minimum of 6 months has also been associated with a reduction of acute lymphocytic leukemia and acute myelogenous leukemia (PSBC, 2012, Renfrew et al., 2012). Although it is difficult in many cases to determine if it is the human milk that produces the beneficial effects noted or the act of breastfeeding, these noted benefits associated with providing infant nutrition through breastfeeding need to be considered when examining the use of pasteurized donor milk.

Studies on pasteurized donor milk are limited, but have shown a significant reduction in necrotizing enterocolitis in preterm infants when compared to human milk substitute fed preterm infants (Quigley & McGuire, 2014). Although the research comparing pasteurized donor milk and human milk substitutes is minimal, pasteurized donor milk is recommended by the CPS when mothers' own milk is not available (Kim et al., 2010). Donor milk has been shown to contain many of the "valuable components of human milk after heat treatment as long as the temperature is well controlled" (Tully, Jones & Tully, 2001, p.153).

As a perinatal nurse working within the BC health care system and a member of the Fraser Health Breastfeeding Council, I recognize the emphasis over the last five years on promoting human milk donation within Fraser Health. Posters, newspaper articles, radio promotions and pamphlets inform the public of the existence of the BC Women's Provincial Milk Bank, which is working on increasing its services to the entire province. In an attempt to

decrease barriers for women and increase donations, Fraser Health has opened 17 human milk depot sites where women can drop off their donated human milk, and other health authorities are following their lead. Health authorities of BC are striving toward becoming increasingly "Baby Friendly" by continuously promoting breastfeeding, and the availability of human milk and donor milk for all infants.

Problem Statement

According to the BC Women's Provincial Milk Bank, the need for pasteurized donor milk frequently exceeds the supply available and new donors are always needed (BC Women's Hospital and Health Centre, 2018). There is very little research on the characteristics of human milk bank donors within British Columbia. Examining parents' current attitudes, motivations and barriers toward donating human milk in BC can provide foundational information for health professionals to advocate for the donation of human milk and adjust systems to better support lactating women. This study examined the current attitudes, subjective norms and barriers in relation to intent to donate in women living in BC who have given birth to an infant within the past 24 months. Knowing what increases the intent to donate will allow health care workers and decision makers to better support women to donate their milk to the milk bank, which will in turn result in more available milk for vulnerable infants.

Purpose

The purpose of this thesis was to explore attitudes, subjective norms and barriers of women in British Columbia, with children 24 months and younger, toward donating human milk to the Provincial Milk Bank at BC's Women's Hospital. In addition, this study describes characteristics of women that best predict their intention to donate human milk.

Research Questions

The research question for this study was: what are the attitudes, subjective norms and barriers of women in BC, with children 24 months old and younger, toward donating human milk to the BC Women's Provincial Milk Bank? This was examined through an internet survey with the following sub-questions:

Among women in BC with children 24 months old and under:

1. What are the self-reported attitudes, subjective norms, and barriers of women regarding milk donation and intention to donate human milk?
2. What are the demographic characteristics and other situational factors that are associated with the intention to donate milk?
3. What attitudes, subjective norms, and barriers are associated with the intention to donate milk?
4. What are the set of demographic characteristics, attitudes, subjective norms and barriers that best predict the intention to donate milk?

Although the initial plan for this thesis was to explore motivations of women who had donated to the milk bank, as well as attitudes, subjective norms and barriers, because of privacy regulations at the milk bank, women who donated could not be directly contacted and invited to the study. Thus the method of recruitment for the online survey resulted in only a small number of the study participants actually donating to the Milk Bank and results were used to predict likelihood of donation to the milk bank among a group of mothers in BC with children 24 months and under.

Theoretical Framework

The Theory of Planned Behavior was used to guide this study, specifically in the development of the survey and analysis of results. This theory had previously been used to examine breastfeeding behaviours in vulnerable groups such as teenage mothers (Giles et al., 2007), ethnically diverse populations (Dodgson, Henly, Duckett & Tarrant, 2003; Mutuli & Walingo, 2014), and groups at risk for adverse health outcomes (Wambach et al., 2011; Wambach & Koehn, 2004). It had also been used to explore intention to donate blood (Veldhuizen, Ferguson, de Kort, Donders & Atsma, 2011), motivation for blood donation (Hyde, Knowles & White, 2013), and to predict retention of first time blood donors (Masser, Bednall, White & Terry, 2012). This theory fits well when examining a complex behaviour like human milk donation, and it has provided a good framework for this study examining women's intention to donate human milk. Chapter 2 will outline the tenets of the theory in more detail.

Summary of Chapter

Human milk has been found to be beneficial to the majority of infants, and is the gold standard for feeding most infants (PSBC, 2012; MacDonald, CPS & Infectious Diseases and Immunization Committee, 2006), especially premature infants (Quigley & McGuire, 2014). Regardless of the benefits of breastfeeding and human milk, there is an insufficient supply of donor human milk available to infants who would benefit from it. To better support women donating to the Provincial Milk Bank in BC it is important to increase our understanding of the population of mothers eligible to donate within the province of BC. Given the lack of research on this topic within Canada and globally, this study has helped to provide insight into the intention to donate human milk in relation to characteristics, attitudes, subjective norms and barriers held by women with a child 24 months old and under, in BC.

Chapter 2: Theoretical Framework

The Theory of Planned Behavior informed this study. The theory indicates that behavioural intentions can be predicted by examining "attitudes toward the behaviour, subjective norms with respect to the behaviour, and perceived control over the behaviour" (Ajzen, 1991, p.206). These intentions then interact with perceived behavioural control to directly predict or influence behavioural achievement of the planned action (Ajzen, 1991). Although attitudes, subjective norms and perceived control all contribute to intention, the amount each contributes varies (Ajzen, 1991). Therefore, when trying to encourage behaviours such as milk donation to donor milk banks, it is important to examine attitudes, subjective norms and perceived control toward breastfeeding and human milk donation, as well as actual barriers. This in turn contributes to identifying intention to donate, which, when combined with perceived behavioural control, can attempt to predict the behaviour of a woman donating to the human Milk Bank.

According to Ajzen (1991), attitudes toward the behaviour refers to "the degree which a person has a favourable or unfavourable evaluation or appraisal of the behaviour" (p. 188). In this study, this would refer to the attitudes of women toward human milk and donating human milk to the provincial Milk Bank. Both of these were important to examine and were included in the scale on attitudes, as the values placed on human milk over other alternatives could influence the attitudes toward donating human milk. Attitudes are influenced by surroundings and the context in which the women live and may therefore be different for the women in this study when compared to previous international research. Identifying attitudes of women is one branch of this theory that influences intentions of women in donating human milk, which in turn may impact actual donations to the Milk Bank. According to the Theory of Planned Behavior, a positive attitude toward donation will increase the intention to donate and may result in an increased likelihood of the woman donating to the Milk Bank. Identifying attitudes women in British Columbia hold toward both human milk and the Milk Bank will allow local authorities to concentrate resources on interventions that increase positive attitudes, thereby increasing intention to donate.

Subjective norms with respect to the behaviour "refers to the perceived social pressures to perform or not to perform an action" (Ajzen, 1991, p.188). Social pressures examined within

this study are based on the perceptions women hold in regards to the beliefs of the general public, their friends, and their family. Do most people believe human milk is the best food for babies? Do most people, friends and family members believe it is good to donate to the provincial Milk Bank? Do women believe the provincial Milk Bank is important, or that it is better to donate to the Milk Bank than share with a friend? These are some of the aspects of subjective norms that will be examined in relation to intention to donate.

The third branch of the Theory of Planned Behavior is the branch of perceived behavioural control, which refers to "perception of the ease or difficulty of performing the behavior of interest" (Ajzen, 1991, p.188). Is milk donation seen as feasible to breastfeeding mothers? What are the barriers that are preventing mothers from donating that are seen to interfere with perceived behavioural control? Identifying barriers to donating human milk is the first step in addressing them as a society. In this study behavioural control was broken into two sections, a scale of perception of barriers, referred to as ease of donation, and actual individual specific barriers, which could interfere with the donating process.

It was the hypothesis of this study that higher scores on the attitude and subjective norm and ease of donation scale (lower perceived barriers) would contribute to a stronger intention to donate human milk to the Milk Bank. Conversely, lower scores on the attitude and subjective norms, and ease of donation scale (higher perceived barriers) would result in increased overall barriers which would lead to a decreased intention to donate human milk to the Milk Bank.

According to Ajzen (1991), "the more favourable the attitude and subjective norm with respect to a behavior, and the greater the perceived control, the stronger should be an individual's intention to perform the behavior under consideration" (p.188). By examining parts of all three aspects influencing intention to donate human milk, the aim of this study was to provide information to health care workers that can be used to inform campaigns to further encourage breastfeeding mothers to donate their human milk to the BC Women's Provincial Milk Bank. Figure 1 indicates how the Theory of Planned Behavior informs this research study.

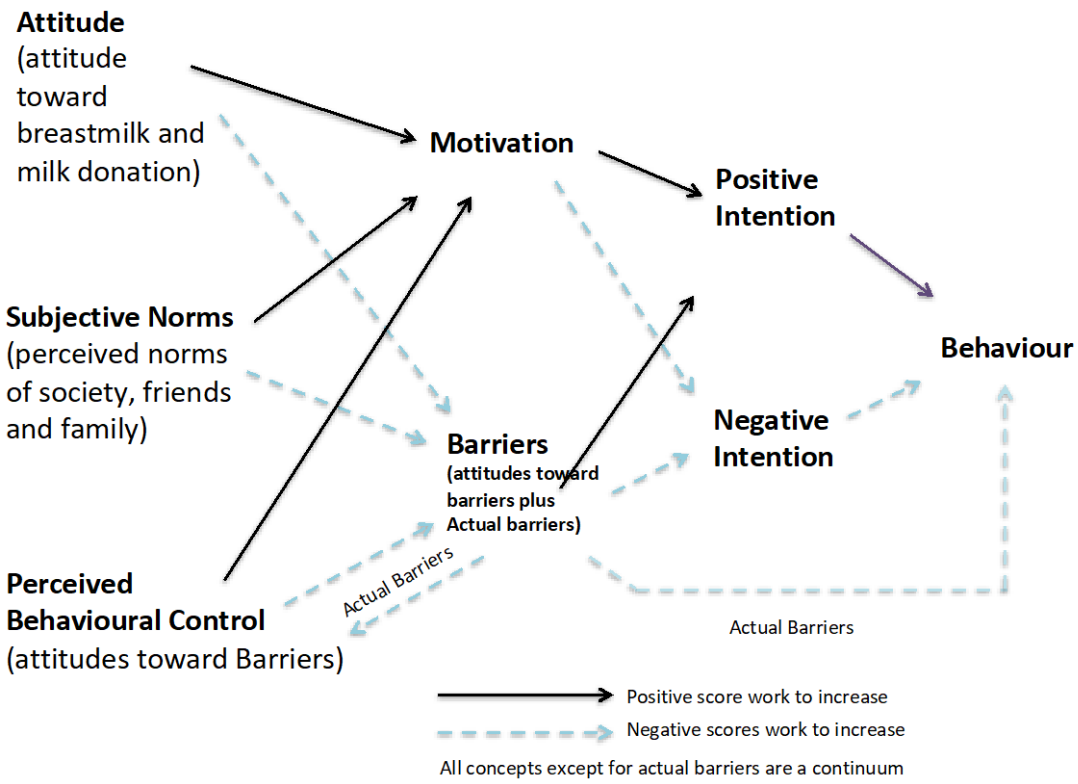

Figure 1. Theory of Planned Behavior in relation to attitude, subjective norms and barriers toward donating breastmilk to the BC Women's Provincial Milk Bank. Figure based on and adapted from Ajzen, I., (2002). Constructing a TpB Questionnaire: Conceptual and methodological considerations. Retrieved on December 7, 2015 from: http://chuang.epage.au.edu.tw/ezfiles/168/1168/attach/20/pta_41176_7688352_57138.pdf

Chapter 3: Literature Review

In order to lay the foundation for this research study, a literature review was conducted and findings from the review are highlighted in this chapter. Pub Med, Psych Info and CINAHL databases were reviewed for applicable studies. Key words searched in CINAHL included: human milk, attitudes, and milk banks; in PubMed: tissue donors/psychology and milk banks; and in Psych Info: milk bank and milk donation. Articles were reviewed based on their titles, abstracts and key words for any information pertaining to attitudes, motivations and barriers toward donating human milk to milk banks. After identifying articles that met the criteria, the abstracts were examined through the web of science to confirm they would provide relevant information for this study. Twelve studies and one literature review were identified that examined current attitudes, motivations and barriers surrounding human milk donation to local milk banks. Three studies that were published in Portuguese were excluded. An article written in Spanish, with an English abstract was retained.

Overall, there have been very few published studies on the attitudes, subjective norms, motivations and barriers toward donating human milk. Indeed, many of the studies commented on the lack of relevant literature on the topic and referenced the same studies. The literature review conducted by Martínez-Sabater, Siles-González, Escrivá-Aparisi & Ballestar-Tarín, (2014) identified seven of the twelve studies located through this literature review. All twelve identified studies were localized and based in specific regions around the world. Studies have been conducted in France, Brazil, Nigeria, Eastern Anatolia in Turkey, Madrid in Spain, Texas in the United States of America and South Australia. No published studies were found that were conducted within British Columbia or elsewhere in Canada. A summary of the findings on existing literature on attitudes, motivations and barriers toward donating human milk to milk banks is included below.

Benefits of Pasteurized Donor Milk for Infants

Numerous researchers have compared breastfeeding to human milk substitute (formula) feeding and have demonstrated health benefits of breastfeeding for both mothers and infants (Ip et al., 2007; Ip, Chung, Raman, Trikalinos, & Lau, 2009). However, there are a limited number

of studies that have evaluated infant outcomes when fed with pasteurized donor milk versus human milk substitutes, and most of these studies did not examine the influence of fortification of donor human milk on infant health.

Infant feeding with pasteurized donor milk compared to human milk substitutes has been found to decrease the incidence of necrotizing enterocolitis (NEC) (Arslanoglu et al., 2013; Quigly & McGuire, 2014). Necrotizing enterocolitis is a serious bowel disease with a fatality rate of up to 50% for infants born below 1000 grams. It occurs in 1 out of 1000 live births and in 5% of all infants born weighing less than 1500 grams (Gardner, Carter, Enzman-Hines & Hernandez, 2016). Although the evidence demonstrates pasteurized donor human milk may decrease the incidence of NEC (Arslanoglu et al., 2013; Quigly & McGuire, 2014), demand for donor milk outweighs supply for British Columbia neonatal care units (BC Women's Hospital and Health Centre, 2018).

In addition to reducing the incidence of NEC, there is evidence that donor breastmilk may benefit preterm infants in a variety of other ways. Donor human milk may protect against bronchopulmonary dysplasia, eczema in infants at high risk for allergies and, when unfortified, it may improve feeding tolerance and reduce cardiovascular risk factors during adolescence (Arslanoglu et al., 2013).

Donor human milk is usually fortified for preterm infants in BC's Neonatal Intensive Care Units (NICUs). Unfortified human milk is currently considered inadequate nutrition for premature infants and may result in slower growth (Quigley & McGuire, 2014) because of the milk's low protein content and the infant's decreased ability to absorb fat (Arslanoglu et al., 2013). Although fortifying donor milk is a common practice in NICUs, further research of the effects of this fortification on the donor milk and infants receiving it is required.

Characteristics of Human Milk Donors

The available studies on human milk donation were conducted in diverse international settings and most studies collected some demographic data about donors. However, factors such as culture, social support, norms of the region and community in which the data is gathered may impact their applicability to the Canadian and, more specifically, British Columbian context.

This section examines what is currently known about women who donate human milk based on existing research.

Age.

There are conflicting research findings on the age of the typical donor. In their profile of milk donors in France, Azema and Callahan (2003) found that milk donors were of average childbearing age. This is consistent with findings from a Brazilian study in which the average age of donors was between the ages of 25 and 33 (Pimenteira Thomaz et al., 2008). Arnold and Borman (1996) concluded from anecdotal evidence that teenage mothers are unlikely to be donors, as they frequently lack time and motivations required to donate human milk. However, Osbaldiston and Mingle (2007) reported an inverse correlation between age of the donor and the amount of milk donated, noting that, the "younger donors donated more milk" (Osbaldiston & Mingle, 2007). This suggests that younger donors are less likely to donate, but when they do donate, they donate more milk than the average aged donor. It is likely that the average age of donors is related to the country and culture in which the donor is embedded. Currently, no information is available regarding the typical age of donors at the BC Women's Provincial Milk Bank nor the effect of age on intention to donate milk.

Relationship status.

Support from significant others is important to women donating human milk. A qualitative study in Australia, conducted prior to the development of a milk bank, found that partner support was the deciding factor in a woman's decision to donate human milk and whether the baby should receive donated human milk (Mackenzie, Javanparast & Newman, 2013). These findings echoed Azema and Callahan (2003), who also found support in donation and breastfeeding may be an important factor in whether a woman donates. The majority of women donors in the Azema and Callahan study were found to be living with either a husband or another person. The support of living with another person may take many forms including that of financial support (Azema & Callahan, 2003). In Spain, the majority of women donating human milk were also found to have a stable partner (Sierra Colomina et al., 2013), and typical donors in Texas were also married (Osbaldiston & Mingle, 2007). Although it was expected that social support, and support of a partner strongly effects a woman's intention to donate human milk, prior to this study this had not been examined within the BC context.

Work status.

In literature, the typical work status of women differed related to social context and social support systems available to them. In the United States, Arnold and Borsma (1996) suggested that women in the workforce often make great donors even though there may be many time constraints (e.g. limited maternity leave). This was different in the study by Azema and Callahan (2003) in which it was found that a majority of French donors did not work outside of the home, and a quarter of those who did work outside of the home were working in social and medical fields (Azema & Callahan, 2003).

When examining these different findings one needs to consider the different social support systems offered to women in the postpartum period as well as legislated maternity leaves. In Canada, at the time of this study, women who were employed receive 17 weeks of pregnancy leave followed by 35 weeks of parental leave. There are multiple limitations around this policy, financial restrictions, and the fact that benefits often do not cover self-employed mothers unless they have chosen to contribute. These benefits differ from those in both France and the United States. It was expected that the typical mother in BC who had high intention to donate would be either on parental leave or maternity leave.

Number of children.

Azema and Callahan (2003) found that most women who were human milk donors had less than 3 children. Pimenteira Thomaz et al. (2008) confirmed this finding. Most women in BC do not have more than three children, therefore it is expected that like previous studies (Azema & Callahan, 2003; Pimenteira Thomaz et al., 2008), most women with high intentions to donate will have 3 or less children. There were no published statistics on whether mothers donating to the BC Women's Provincial Milk Bank are first time mothers or multiparous, nor if mothers with more than one child have a higher intention of donating human milk to the Milk Bank.

Education level.

In a Brazilian study by Pimenteira Thomaz et al. (2008), it was found that the typical women who donated had at least a primary education but that the likelihood of becoming a repeat donor increased with a higher education level. In Spain it was found that the typical donor had a university education (Sierra Colomina et al., 2013) and in Texas the typical donor was well

educated and financially secure (Osbadiston & Mingle, 2007). It was unknown what correlation, if any; education may have on the intention of women to donate human milk in the BC context.

Health and prenatal care.

Pimenteira Thomaz et al. (2008) found that the average donor in their Brazilian study attended more than 7 prenatal visits. In Osbaldiston and Mingle's (2007) study, donors of human milk were found to make healthier food choices than non-donors. Canada has a universal health care system in which all women have access to prenatal care. The majority of women have Internet access and a wide range of information available to them on child bearing and raising. Therefore, this will not be a focus of this study.

Of the characteristics of human milk donors previously reported in the literature age, relationship and work status, number of children and education level were theorized by the author to also impact the intention of BC women to donate to the Milk Bank, by influencing the women's attitude, subjective norms and barriers. This study will provide an understanding of the characteristics that increase intention to donate in BC.

Attitudes of Women toward Donating Milk

Attitudes "[reflect] the individual's global positive or negative evaluations of performing a particular behaviour" (Armitage & Conner, 2001, p.474). When examining attitudes toward human milk banking, inevitably one needs to consider the individual's attitude and the value the individual places on human milk in general, as well as the donation process. The following section will summarize the international literature found on attitudes toward human milk banking.

In the Brazilian study, the majority of mothers (91.7%) reported the experience of donating as positive and 66.7% said they would continue donating (Alencar & Seidl, 2010). Similarly, an American study found that donating human milk was more satisfying than only breastfeeding and 97% said they would donate again if they had an opportunity (Osbaldiston & Mingle, 2007). However, some mothers in the Brazilian study (19.4%) also reported doubts about donating. These doubts included questions about how the milk was processed, infant access to the milk, as well as procedural questions around the pumping and storing of milk. Mothers suggested that discussing human milk donation in the early perinatal period, touring the

human Milk Bank to observe the different steps of pasteurization, and touring the maternity ward to meet the infants receiving the human milk may be of benefit in decreasing their doubts, answering their questions, and increasing the likelihood of them donating (Alencar & Seidl, 2010).

Alencar and Seidl (2010) also questioned women about the supports they received in the process of donating. Ninety-two percent of women reported being satisfied with the personal supports received through "people in their social life" (Alencar & Seidl, 2010, p.386) and 58% reported being satisfied with the support received from the institution to which they were donating (Alencar & Seidl, 2010). These supports from their social life and the Milk Bank included perceived emotional support, as well as assistance with the practical aspects of donation, such as locating containers to express into and assistance expressing human milk (Alencar & Seidl, 2010). These may be different within the BC context.

Women in the South Australian study supported donating human milk if a milk bank were established, as long as donation was simple and not too time consuming (Mackenzie et al., 2013). In the same study, mothers anticipated the attitudes of health professionals to be a barrier toward milk banking. Some women had encountered individual health professionals who were unsupportive of breastfeeding and encouraged human milk substitute use, and therefore suggested these health professionals would be unsupportive of human milk donation. However, they did think that these health professionals would be more supportive of milk from an established milk bank than human milk informally shared (Mackenzie et al., 2013).

Interestingly enough, the perception of health professionals' attitudes toward human milk was contrary to the findings by Lam, Kecskes, and Abdel-Latif (2012). In a study examining attitudes toward milk banking in twenty-five Australian Neonatal Intensive Care units, 78.8% of healthcare providers thought pasteurized donor milk was preferable to human milk substitutes. "The majority of nurse/midwives (90%) and doctors (70%) agreed that donation of breastmilk is important" (p. 835), and 67.5% thought setting up a human milk bank was justifiable (Lam, Kecskes, & Abdel-Latif, 2012). Mothers in the Mackenzie, Javanparast and Newman, (2013) and the Lam et al. (2012) studies both recommend education for professionals to increase their knowledge surrounding milk donation. This, in combination with general education about donor human milk to the public and pregnant mothers during their antenatal visits, was thought to be

important in supporting human milk donation and the distribution process, and may also be of benefit in BC.

When attitudes toward human milk donation were studied in Jos, Nigeria, 680 breastfeeding women were interviewed. Of the 680 women, 38% of women said human milk from a well established milk bank would be acceptable (Ighogboja, Olarewaju, Odumodu & Okuonghae, 1995); the remainder of women cited "religious injunctions (27%), fear of transfer of genetic traits (17%), possible transfer of disease (11%), cultural inhibition (4%), and personal dislike (2%)" (Ighogboja et al., 1995, p. 95) as reasons they would not accept donated human milk. Despite this hesitance to accept donor human milk for their own infants, over 60% of those questioned still indicated that they would donate to another infant in need (Ighogboja et al., 1995). Mothers who were employed and had a secondary or higher education were significantly less likely to state that they would accept donor human milk for their infant, bringing the author to the conclusion that more education on milk banking and donor milk is required (Ighogboja et al., 1995). According to the authors, these results are similar to two studies conducted in 1987 and 1984 that were published in the Nigerian Journal of Paediatrics, but were inaccessible for this literature review.

Similar findings were noted in a study conducted with 350 women in the Anatolia region of Turkey (Gürol, Ozkan & Celebioğlu, 2014). In this study, authors found that 90.6% of women did not know about human milk banking. After hearing an explanation about milk banking, 64.3% thought that they would like to see milk banking in Turkey. However, only 43.1% of women indicated that they would accept milk from the milk bank for their infants, with 36.3 % stating religious objections and 28.9 % indicating that there would be social/ethical problems. As with the study by Ighogboja et al. (1995), a larger percentage (64%) would be willing to donate to infants in need. According to Gürol et al. (2014), Turkey is a Muslim country where religious practices such as milk kinship play an important role within its society.

As indicated within this literature, attitudes appear mainly positive once people become aware of the role of a milk bank within their community. The BC Women's Provincial Milk Bank, in collaboration with local health authorities, has been working on improving awareness through media campaigns. Knowing the general attitude of women in BC toward donating human milk may be of benefit in these campaigns. It is difficult to examine attitudes in isolation

from subjective norms and barriers, which is why the design of this study also considered these in relation to intention to donate.

Subjective Norms Affecting Milk Donation

A subjective norm "refers to the individual's perception of general social pressure to perform…the behaviour" (Armitage & Connor, 2001, p.474). Partners, friends and expectations of society as a whole can place pressure to breastfeed on women. Subjective norms influence and are influenced by the individual's attitude toward a behaviour, as well as the behavioural controls. This adds to motivation and barriers to either increase or decrease intention to donate, which is then thought to influence the behaviour of donating (Figure 1). Therefore, subjective norms are an essential aspect of the intention to donate and were examined in this study. The next section will review the current literature on religion and culture as they relate to milk sharing, reflecting subjective norms that may also influence society's attitude toward donating human milk to a milk bank.

Religion and culture.

Religion and culture strongly influence subjective norms related to human milk donation and sharing. According to Thorley (2014), many Muslims practice milk kinship or Mahram (Gürol et al., 2013). When an infant receives the human milk of a woman who is not the mother, a new familial relationship is created. This infant is now considered a sibling to her own children and may not marry her children (Thorley, 2014).

Religion and culture also impact subjective norms around accepting donor human milk for infants who may require it. For example the process of preparing and pasteurizing human milk is problematic for Orthodox Jews and Muslims. Orthodox Jews may request milk from kosher-keeping mothers (Kassierer, O'Connor, Rutherford, Rolnitzky, & Unger, 2014). In most milk banks, the milk from multiple women is pooled to be pasteurized and donors are unknown to recipients. This can be problematic for mothers as neither dietary habits, (Kassierer et al., 2014) nor the milk siblings will be known (Thorley, 2014). According to Thorley (2014), similar beliefs surrounding milk kinships existed in Europe in the past and currently still exist in the Middle East. Although a variety of religious scholars, both within the orthodox Jewish religion and the Muslim religion, have issued rulings permitting donation and receiving of donor milk

(Kassierer et al., 2014; EL-Khuffash & Unger, 2012) many mothers may not be aware of these rulings, and these beliefs may still affect mothers.

The BC population is highly multicultural, and is becoming increasingly diverse in religious beliefs and cultural backgrounds (Statistics Canada, 2011a). Aside from individual family beliefs these backgrounds and religious beliefs may affect the attitudes women have toward milk donation and warrant further investigation of current attitudes, subjective norms and barriers surrounding milk donation.

Milk Sharing.

Although human milk sharing is not endorsed by Health Canada (Government of Canada, 2010, Infant Feeding Joint Working Group, 2014) or the Canadian Paediatric Society (Kim et al., 2010), the World Health Organization considers wet nursing by a healthy wet-nurse a valid option for feeding an infant when breastfeeding by the infant's mother is not possible or safe, for medically indicated reasons (World Health Organization, 2003). With today's advances in technology, mothers often seek out other lactating mothers over the Internet. This is often done through milk sharing websites or websites on which women sell their own human milk (Wittmann, Ross, Geiger, Jones, & Scott, 2015). This presents potential safety issues due to bacterial contamination, illness transmission and possible drug contamination (Government of Canada, 2010).

Although the women sharing their human milk through these informal channels may be the same group of women who are donating to the milk bank (Rochman, 2011), Gribble (2013) suggests that this group of women may be a different subset that is ineligible to donate to a milk bank or have personal reasons to choose peer to peer donation over official milk banking. Reasons women choose to donate through peer to peer milk banking networks include: lack of opportunity to donate to a milk bank (no local milk bank, did not qualify, milk bank not accepting more donors, was not pre-screened, milk bank did not respond); perception of milk banking as difficult (viewed the process of donating as a barrier, don't know about milk banks, didn't want to ship milk); philosophical objections to milk banking (object to parents having to pay for banked milk, do not like milk to be pasteurized, local milk banks are for profit); and philosophical attraction to peer sharing (prefer to know the recipient, wanted to help mothers and children who could not qualify for banked milk) (Gribble, 2013). Even though this group

represents a subset of mothers, these reasons and attitudes toward human milk donation need to be taken into consideration when examining women's attitudes toward human milk donation.

According to Jones (2003), wet nursing was commonplace prior to the 20th century. Women acting as wet nurses were frequently in need of money and were selling their services (Thorley, 2008). With the advancement of the internet and social media it is now possible for mothers to easily connect to possible buyers of their human milk and earn extra income. Through websites such as onlythebreast.com mothers can advertise their human milk. As indicated by Geraghty et al. (2013), very little is known about the frequency of and risks associated with this practice. Despite the small amount of published research on this group of women, popular media reports as found on onlythebreast.com indicate this practice is primarily motivated by financial gain (The Doctors, N.D.; Only the breast: A community for moms, 2015).

Traditionally hospitals and patients in BC have had a "don't ask, don't tell" relationship in regards to human milk donation (PSBC, 2016). Recently, Perinatal Services of British Columbia (PSBC) has acknowledged that milk sharing commonly occurs amongst mothers and has provided a practice resource guide to assist health care providers in counselling their patients. The guide emphasizes Canadian feeding recommendations, different levels of risk associated with the source of shared milk (close relative/friend vs. internet unknown donor) and the patient's autonomy to make their own decisions once aware of both risk and benefit of milk sharing and human milk substitute (PSBC, 2016). Individual health authorities have followed this lead in creating health authority milk sharing policies, guiding the practice of health care professionals working within their institutions.

The subjective norms surrounding human milk and its use are quite complex and at times controversial, yet many of these factors influence new mothers in their decision-making. Popular culture, images in the media and information found on web sites influence mothers in their decision-making, as well as their thoughts around the use and value of human milk. This study examined parts of this interaction and how subjective norms influence intention to donate.

Barriers: Perceived behavioural controls, and attitude toward barriers

Barriers are not uncommon in life. However, we theorize that attitudes toward those barriers often increases or decreases motivation and thereby influences intention. For the

purposes of this study barriers will be examined in relation to perceived influence on future intention to donate to the Milk Bank. Barriers can negatively affect intention to donate but can often be overcome with a positive attitude and positive subjective norms.

A common barrier to milk donation is milk supply (Alencar & Seidl, 2010). This can be perceived or actual low milk supply. Alencar and Seidl (2010) suggest many situations can influence women's perception of milk supply and can act as barriers toward donating. Milk supply was perceived to be decreased by women when they: had not eaten or drank enough fluids; left the house and thereby got out of their routine; started on contraceptives; had negative emotions; did not have enough time to pump; felt the feeding demands of their own infants had increased; were physically tired; and feeling lazy (Alencar & Seidl, 2010).

Many donating mothers are affected by breastfeeding challenges, which can be seen as barriers (Azema & Callahan, 2003), as many of these struggles are temporary. A third of the donating mothers stated that their main breastfeeding struggle was engorgement (Azema & Callahan, 2003). This was similar to the results from the study conducted by Osbaldiston and Mingle (2007), who reported that donors had difficulties with engorgement (58%), cracked or chapped nipples (33%) and breast infections or mastitis (20%). Yet, despite these problems, the majority of women (89%) reported breastfeeding as excellent or good (Osbaldiston & Mingle, 2007). This could indicate that the attitude of these women toward overcoming these subjective barriers is positive. Rather than giving up and feeding human milk substitutes, women struggled on and even donated milk for other infant's in need. Although both donor and non-donor women faced problems with breastfeeding, donors who were diagnosed with thrush at some point were even found to have donated significantly more milk than women who did not have thrush (Osbaldiston & Mingle, 2007).

Another specific barrier is transportation of the milk. Unlike in the Brazilian studies, where the milk banks often arrange transportation of the human milk, the study by Sierra Colomina et al. (2013) in Spain found that the major barrier for donating women was the transportation of the milk to the milk bank. Setting up a transportation network to ship milk from the women's homes to the milk banks was also suggested by South Australian mothers to increase the ease of donation (Mackenzie et al., 2013). Other suggestions included setting up spaces for pumping, supplying equipment and simplifying long bureaucratic screening processes

as much as possible. These mothers did not feel a need to be paid as donors, but they did suggest that the milk bank should cover any expenses (Mackenzie et al., 2013), indicating that financial considerations and complicated screening processes could act as barriers.

Barriers can be specific to the individual, region and system. There is no published literature on the barriers mothers in BC encounter when considering donating to the Milk Bank. This study examined how some of these barriers influence intention toward milk donation to the Milk Bank.

Motivations

Motivation to donate was considered in relation to attitudes, subjective norms and barriers, all of which can either increase or decrease motivation. Due to the small number of donors within the sample, it was not possible within the confines of this study, to examine the specific motivations of BC donors to the BC Women's Provincial Milk Bank. Motivating factors increase a person's intention to donate while barriers decrease a person's intention to donate. "Intentions are assumed to capture motivational factors that influence a behaviour; they are indications of how hard people are willing to try, of how much effort they are willing to exert, in order to perform the behaviour" (Ajzen, 1991, p.181).

Within current published literature, multiple motivating factors for why women choose to donate human milk have been identified. Some motivating factors speak to the attitudes of women toward human milk and its donation, while other factors are clearly influenced by society's norms and expectations. Arnold and Borman (1996) suggested that mothers are motivated to donate for two primary reasons: "they do not want to waste the milk which they worked hard to express" (p.143) and they want to help an ill child either get better or live. This is mirrored in the Brazilian study by Alencar and Seidl (2009), the Spanish abstract by Sierra Colomina et al. (2013) and Azema and Callahan (2003) who indicated in their study of French donors that their main reasons for donating were that they "had too much milk and preferred to donate rather than dispose of it" (p. 201) and to "help others" (Azema & Callahan, 2003, p. 201).

Other reasons for donation mentioned include: donation is a healthy thing to do (13.6%), donation is natural (2.9%), donated milk was available to my child (1.9%), would hope someone would donate for my child if they were in need (1.9%), know someone who has a baby in need

of donated human milk (1%), and know that the milk bank needs donations (1%) (Azema and Callahan, 2003).

In a Brazilian study by Pimenteira Thomaz et al. (2008), the top reasons found for donating human milk were "recommendation by a health care professional" (n=395, 61.3%), followed by "knew the needs of the babies the banks serve" (n=163, 25.3%), "involved in social activities" (n=56, 8.7%), and "knew an infant who needs/needed donor human milk" (n=47, 7.3%) (p.71). In this study, women who were under the age of 18, were unable to read and write, did not work outside of the home, had four or less prenatal visits, had a premature delivery or were first time donors were more likely to donate based on a health care professional's advice. Women who were more highly educated, had more than seven prenatal visits, or were repeat donors were more likely to state as a reason for donating that they knew the needs of the infants whom the milk bank served (Pimenteira Thomaz, 2008).

Results of both the Brazilian study and the French study indicated a desire to help infants in need through donation to the milk bank. However, unlike the French study, the Brazilian study indicates a strong influence of health care providers in the decision-making process. The motivating influencers within the BC context are yet to be determined.

Another motivation for donating human milk to the milk bank has been found among mothers who have given birth to stillborn infants or infants who have died shortly after birth. Although research on this topic is minimal, Welborn (2012) suggests that some bereaved mothers continue to express milk to identify as a mother and grieve the loss of motherhood, to stay connected to their infants, to relieve physical symptoms of discomfort and to create meaning of the experience of loss by providing their milk to another sick infant (Welborn, 2012). Moore and Catlin (2003) also agree that some women may find meaning by donating human milk to a milk bank to assist other infants in need, which in turn may assist the women in the grieving process (Moore & Catlin, 2003; Woo & Spatz, 2007). Unfortunately, "after the death of an infant, breast milk often is disposed of without consideration of donation because public and health care providers are unaware of human milk banks" (Woo & Spatz, 2007, p.150). The Provincial Milk Bank at BC Women's Hospital accepts any amount of breastmilk from grieving mothers. These motivations may not be the most common reasons for donating human milk but

they do need to be considered when examining characteristics, attitudes, social norms and barriers toward donating human milk.

Costs associated with feeding human milk substitutes instead of donor milk

Human milk is the best food for most babies, especially for preterm and very low birth weight infants, in which the rates of NEC are decreased when fed donor human milk instead of human milk substitutes. Aside from the emotional toll NEC takes on the families and the suffering of the infants, it also takes a toll on the publicly funded health care system.

The cost of the increased medical stay of 22-60 days, resulting from NEC are between $110,484 and $251,570, for those infants treated medically, and between $301,320 and $686,100, for those treated surgically. These costs do not include surgery, physicians' fees or specialized tests (Bisquera, Cooper & Berseth, 2002; Cummings, 2012). In addition to this according to Spencer et al. (2008), short bowel syndrome, a serious complication for infants that have required surgery for NEC can lead to a mean cost per infant of US $1,619, 851 +/- US $1,028,985 over a 5 year period. The costs of feeding an infant donor milk from a milk bank until the age of 32 weeks gestational age, when the risks of NEC decreases, can be as low as $27 to $590, depending on how much of her own milk the mother is able to provide (Carroll & Herrmann, 2013).

In BC, in the 2001-2002 fiscal year, 712 infants weighing less than 1500 grams were born (Kendal, 2002). These infants are at the highest risk of developing NEC. The number of infants born weighing less than 1500 grams has only increased since then. If 5% (36) of these 712 infants develop NEC the cost to the system for just their extended stay is between $3, 977,424-$22,539,600, excluding physicians' fees, special tests, surgery costs, and long-term complications. Had all these infants been fed with donor milk and all avoided NEC, and the extended stay associated with it, the cost would be between $19,224-$420,080, much less than the care of one infant requiring surgery to treat NEC. In light of this, it seems logical to feed these infants donor milk from a milk bank, to promote and invest in milk banks as a society and health care system, and to support donors in any way possible.

Summary

There is evidence that human donor milk is superior to human milk substitutes especially for preterm infants. Characteristics of milk donors as well as attitudes, subjective norms and barriers to milk donation have been described within specific social and cultural contexts. However, there have been no published research studies describing the influences of these constructs on women's intention to donate within BC. When a mother cannot provide her own milk, human donor milk is superior over human milk substitutes and recommended by the Canadian Paediatric Society.

Chapter 4: Methods

The purpose of this study was to describe the attitudes, subjective norms and barriers of women in BC, with children 24 months and younger, toward donating human milk to the BC Women's Provincial Milk Bank.

The research objectives included:

1. To describe self-reported attitudes, subjective norms, and barriers of women regarding milk donation, and intentions to donate breastmilk.
2. To identify demographic characteristics and other situational factors that are associated with the intention to donate milk.
3. To identify attitudes, subjective norms, and barriers that are associated with the intention to donate milk.
4. To identify the set of demographic characteristics, attitudes, subjective norms and barriers that best predict the intention to donate milk.

This chapter describes the methods that were used in this study.

Study Design

This study used an exploratory descriptive, correlational design with cross-sectional data collected through an internet-based survey. Cross-sectional studies are appropriate for describing the prevalence of an experience or for describing relationships among phenomena at a fixed point in time, but cannot be used to infer causation. Very little was known about the attitudes, subjective norms and barriers toward milk donation within the British Columbian context and the characteristics of women likely to donate to the Milk Bank. Survey research can be used to obtain information about "people's activities, beliefs, preferences, and attitudes via direct questioning" (Polit & Beck, 2012, p.744), which can then be used to make generalizations about the population being studied (Alderman & Salem, 2010). Using a survey design in this study also allowed for the collection of demographic data, as well as answers to short open-ended questions directly aimed at the objectives.

The survey was administered over the World Wide Web. As per Statistics Canada (2010) 85.4% of BC residents had access to the Internet in 2009. This percentage steadily increased

from 2005-2009 (Statistics Canada, 2010) and has more than likely continued to increase over the last 9 years. Administering the survey via the internet allowed for access to a geographically dispersed population (Sell, 1997) reaching further than paper or face to face interview methods (Wyatt, 2000). It allowed more data to be collected and for easier recruitment of large numbers of participants (Wyatt, 2000). Internet surveys have a "lower cost, reduce survey administration overhead and collect survey data quickly and efficiently" (Schleyer & Forest, 2000, p.122). Using an established Internet survey provider, Fluid Survey, also allowed for easy transfer of data into statistical programs such as IBM SPSS (version 23) and for faster and more cost efficient analysis (Wyatt, 2000).

Sampling Plan

Sample population.

The target sample of this study was a convenience sample of mothers with children 24 months and younger, who currently reside in BC, at the point of data collection. According to PSBC 43,856 infants were born between April 1st 2012 and March 31st, 2013 (PSBC, 2015a) and 43,155 between April 1st, 2013 and March 31st, 2014 (PSBC, 2015b). Therefore, there are approximately 87,011 mothers with children 24 months and under, within the province of BC.

Sample size requirements are related to the type of analysis being planned. For bivariate correlations of .30 and power of .80, approximately 85 participants are required (Polit & Beck, 2012). For a logistic regression 10-20 cases are recommended per predictor variable (Polit, 2010). With 10 predictors a generous sample size of 200 cases was required. To ensure an adequate number of completed surveys and to account for incomplete surveys, the aim was to collect a minimum of 450 responses, which seemed feasible given the size of the target population (87,011). Although ensuring a generous sample size reduced the likelihood of incurring a Type II error, it was expected that the majority of respondents would be from the Lower Mainland (and Fraser Health Authority, in particular) and, therefore, may not be representative of the provincial population.

Inclusion and exclusion criteria.

Inclusion criteria consisted of mothers residing in BC who had given birth to a child who was 24 months and under at the time of the study, had access to the internet or attended a public health clinic within the Fraser Health Authority while the researcher was present to provide access to the survey via an iPad with an internet connection. Exclusion criteria consisted of mothers whose youngest child was older than 24 months at the time of the study, mothers who lived outside of the province of BC, mothers who were not literate in the English language without translation and mothers who did not have access to the internet when the researcher was not present at a public health clinic within Fraser Health. Mothers whose youngest child had passed away within the past 24 months were included in this study, as donating breastmilk often assists mothers in their grieving process (Moore & Catlin, 2003; Woo & Spatz, 2007; Welborn, 2012).

Recruitment.

Recruitment for this study was done through the use of social media and through direct data collection at public health offices within the Fraser Health Authority. Survey participants self-selected to participate in the survey. With approval from directors at Fraser Health a recruitment notice, with a link to the survey, was sent out via the Fraser Health Best Beginnings e-Newsletter. Although recruitment was initially planned through Fraser Health Media Channels on Facebook and Twitter, as well as the Kelly Mom Facebook page, this was not feasible. The contingency plan was initiated, and link to survey was posted on 10 different community Facebook groups, as well as a committee members Twitter account. Sharing and liking of the link and internet recruitment notice was permitted, opening up recruitment to the snowball sampling process.

Women also had the opportunity to learn of the study through one of 16 public health offices within Fraser Health (Fraser Health Authority, 2011) which are generally accessed by women throughout the early years of their infant's life. In the fiscal year of 2013/2014, there were 16,764 infants born to women residing within Fraser Health (PSBC, 2015b). One can estimate that approximately 14,467 infants under the age of one year are followed up through the public health system in Fraser Health within a year (or 1,206 per month) as, according to PSBC

(2014a), approximately 13.7% of 16,764 deliveries had some care within their pregnancy provided by a midwife (p.36). Unless referred to another primary care provider midwives follow their patients for 6 weeks (College of Midwives of British Columbia, 2015) and these women may not have encountered the public health system in the same manner as women who had the majority of their care provided by physicians.

Mothers access public health maternal-child services for a variety of reasons, including healthy start/baby programs, breastfeeding support, and to have their children immunized. During any of these times mothers may have been exposed to recruitment notices. Recruitment notices consisted of business cards and posters that were printed with a link to the study (Appendix A & B), which led the potential participants to the participant information letter. After viewing the letter of information, participants' informed consent was assumed if they choose to proceed with and submit the survey. Posters were posted at public health offices within Fraser Health. Business cards, that contain a link to the information letter and the online survey, were available through these public health offices distributed through either the researcher, the receptionist at the public health clinic or a public health nurse.

To further increase participation, the researcher spent time at 16 of the public health offices in Fraser Health, providing assistance and access to the survey through an iPad while mothers waited post immunizations. This increased enrolment of mothers who may not have been as comfortable with internet surveys, and gave mothers who may not have access to the internet on their own, the ability to participate.

Internet surveys often have a "response rate of less than 50%" (Polit & Beck, 2012, p.305). A meta-analysis of internet survey response rates conducted by Cook, Heath and Thompson (2000) found the response rate for electronic internet World Wide Web surveys was between 34.6% and 39.6%. When this response rate is considered in light of the approximate 1206 women that are estimated to have had contact with the Fraser Health Public Health system, 417-478 women could have been expected to complete the survey within a month. However, not all 1206 women would have attended public health clinics. Some mothers may have chosen to seek out their physician for vaccinations. Others would fall into a higher risk category requiring a public health visit at the clients' home, in which case exposure to the survey was dependent on the individual public health nurse.

Cook, et al. (2000) also suggests that internet response rates can not be calculated for surveys posted to websites as anyone is able to access these sites and the "population is not defined" (p. 825). One has no control over a survey posted to a community Facebook page, where people, from a variety of walks of life, can share the survey.

Recruitment was further assisted by the option for participants to enter a draw for one of six $50 email gift cards from Amazon as a gratuity for their time. Participants were eligible for the draw even if they started but then chose to not complete the survey. Public Health offices participating in the recruitment of participants were given a gift basket for staff to share as a way of thanking them for their involvement and the extra effort involved in promoting the survey. Thus, the gratuities were intended to encourage recruitment efforts by public health office staff and, in turn, encourage mothers' participation in the survey.

Data Collection

Once the questions were developed, an expert was hired to place the survey in an online format that was user friendly for participants. This on-line survey was pilot tested with seventeen mothers with children 24 months and younger, and their feedback helped to ensure the questions were asked in an appropriate, easy to interpret manner. Data for the pilot study were collected in the form of notes as participants were reviewing the survey, as well as an open-ended question at the end of the survey leaving opportunity for suggestions for improvements. A content analysis for improvements was conducted looking for themes and areas in the survey that needed to be changed or clarified. This pilot process and the feedback collected allowed for adjustments to the survey prior to widespread dissemination.

In the full study, mothers were asked to answer a survey through a UBC Fluid Survey account. The survey was open for 2 months. Data was transferred to the IBM SPSS (version 23) program on the supervisors UBC secured computer. Email addresses and case numbers were not linked. Anonymity was maintained by keeping email addresses collected for the draw for the gratuity in a separate password protected, encrypted file, assigning case numbers. The thesis supervisor randomly selected 6 participants to receive a $50 email gift card as a gratuity. Once these recipients were selected and the gift certificates were emailed to the recipients, the file of email addresses was deleted.

Measures

The on-line questionnaire consisted of a number of scales and additional individual items. Scales on attitudes, subjective norms and barriers were developed by the researcher for use in this study. Items within the scales were developed based on the literature review and clinical experience. Richard Osbaldiston, PhD was contacted for further information on his study of milk donors, and selected barriers identified in his study with co-author Leigh A. Mingle were incorporated. A first draft of the items for the survey was reviewed by the researcher's thesis committee, which includes an International Board Certified Lactation Consultant (IBCLC) and two researchers with expertise in instrument development. After significant revisions to better match the items to the theoretical framework for the study, the items were presented to a group of experts for feedback. Experts were contacted via an email sent by the researcher and included: board members of the British Columbia Baby Friendly Network (BCBFN), nurses involved with the BC human Milk Bank and the Fraser Health Baby Friendly Practice Council. Further revisions were made. The final survey can be found in Appendix C.

A pilot study with 17 participants was conducted to gain feedback and ensure survey feasibility, readability of the questions, and to test the technology involved. The survey link was accessed by 17 mothers through the researcher's iPad at one of three public health units. A targeted convenience sample was used to gain feedback. Feedback from the pilot study was used to improve the data collection process as well as the survey prior to implementation of the final study. Feedback on the survey was gathered through notes made by the participant as they were progressing through the survey, as well as an open ended question at the end of the survey asking the 17 participants to elaborate on their experiences taking the survey and any difficulties encountered. Survey data from the pilot study was not included in the final survey analysis, as the questions in the final version changed based on the feedback given by the mothers in the pilot study.

Attitudes to human milk and human milk donation.

Attitudes to human milk and human milk donation were assessed using a Likert-type response scale ranging from 1 (strongly disagree) to 7 (strongly agree). Items on the survey

included preference of human milk over other feeding choices and attitudes toward donation to the local human Milk Bank. For this study, general attitudes to: breastmilk is best, it is better to donate to the Milk Bank than to share with a friend and the importance of the Milk Bank were examined. Breastmilk is best and it is better to donate to the Milk Bank were measured using a 1-7 scale, while two questions (item 2 and 4) were combined to measure attitude toward the Milk Bank, for a total possible score of 2-14. Higher scores indicating a more positive attitude toward human milk and milk donation.

Subjective norms to human milk and human milk donation.

Subjective norms were measured by asking participants to report their perceptions of others' attitudes toward breastmilk and breastmilk donation to the local Milk Bank, using a 7-point Likert response scale. Items 9 through 17 examined participants' perceptions of attitudes held by the majority of BC residents; items 18 through 25 measured participants' perceptions of their friends' attitudes, and items 26 to 33 measured participants' perceived attitudes of family members. Similar to the approach used to measure participants' own views on the importance of the Milk Bank, two items were combined (others in BC: items-10 and 12; friends: items-19 and 21; family members: items-27 and 29). In addition, there was one question that measured participants' beliefs that many other mothers have donated to the human Milk Bank (item 13). Higher scores for these items indicated a perception of more positive subjective norms toward human milk and human milk donation to the BC Women's Provincial Milk Bank.

Barriers and perceived ease of donating.

The questionnaire had been developed with the intent of measuring barriers using two different approaches. Ease of donation was measured with 5 researcher-developed questions (items 37-41), on a Likert scale of 1-7. Items 38 and 41 were reverse coded, and the 5 scores were summed. This yielded a total possible score of 7 to 35 with higher scores indicating a higher perceived ease of donating despite barriers that may be present.

Items 41-51 were developed to measure specific barriers that may have influenced the women's intention or likelihood to donate milk to the Milk Bank (e.g., lack of knowledge about milk banking, financial issues and specific issues pertaining to the process of donation); these

items were drawn from the literature review and clinical experience. However, despite trialing the questionnaire, during analyses these items were found to be double-barrelled questions that comprised more than one issue (but allowed only one answer) leaving an ambiguity about the response. Therefore, these items were not used in the analyses.

Intent to donate scale.

Intent to donate was assessed with a single item (#36) that asked participants the likelihood that they were going to donate milk to the Milk Bank, using a response scale ranging from 1 (definitely not going to donate) to 7 (definitely going to donate). Although initial plans had been to assess intent to donate using two items (35 and 36), examination of the data suggested that these two items were measuring different constructs. Item 36 was chosen to indicate intent as the wording was found to be the clearest, suggesting it was easiest for participants to understand. This variable was then recoded into 2 new variables that were used in the analysis. The first was a 3-category variable where responses of 1-3 were recoded as not likely to donate, 4 as undecided, and 5-7 as likely to donate. The second was a binary variable, which saw the undecided group eliminated leaving those scoring 1-3 categorized as not likely to donate and those scoring 5-7 as likely to donate.

Analytic strategies

Data were imported into SPSS where it was cleaned by examining the frequencies, and maximum and minimum values for each of the variables. Errors were identified and corrected as much as possible using frequency listings and logic checks. The valid and missing cases were identified and examined. When there was a small amount of missing data, cases were excluded pairwise (in most analyses) to ensure that participants were included in any analysis procedures for which data were available (Pallant, 2010). Incomplete surveys were analyzed to the extent of the information available.

SPSS was used to examine the data for normality, linearity and homoscedasticity to ensure the appropriateness of statistical tests. Potential outliers were examined by looking for z-score values of 3.3 or greater, or -3.3 or less (Palant, 2010); none were found. Alpha was set at .05 for the statistical tests.

Research objective 1.

1. To describe self-reported attitudes, subjective norms, and barriers of women regarding milk donation, and intentions to donate breastmilk.

Descriptive statistics were calculated to describe the self-reported attitudes, subjective norms, barriers and intentions related to breastmilk milk donation. Means and standard deviations were calculated for continuous level variables that were normally distributed. Frequencies were calculated on the categorical level data.

Research objectives 2 and 3.

2. To identify demographic characteristics and other situational factors that are associated with the intention to donate milk.
3. To identify attitudes, subjective norms, and barriers that are associated with the intention to donate milk.

Analysis of variance (ANOVA) was used to examine differences in explanatory variables (i.e., participant characteristics, attitudes, subjective norms, barriers) that were measured as continuous level variables with respect to the three categories of intent to donate (not likely to donate, undecided, likely to donate). Chi-square analyses were conducted to determine relationships between explanatory variables that were measured as categorical variables and the three categories of intent to donate. No cells had a frequency of less than 5; therefore, the Pearson chi-square test with asymptotic significance values was used to identify significant relationships between variables.

Research objective 4.

4. To identify the set of demographic characteristics, attitudes, subjective norms and barriers that best predict the intention to donate milk.

Hierarchical logistic regression analysis was used to identify the demographic characteristics, subjective norms, and barriers that best predict intention of donating. Predictor variables that showed statistically significant relationships with intent to donate in the bivariate tests (i.e.,

ANOVA and chi-square tests) were included in the logistic regression model. Variables were entered in the following order:

- Model 1 included the demographic characteristics of maternal age in years, child age in years, employment status and number of children.
- Model 2 added two variables pertaining to the respondent's attitudes (belief that breastmilk is best, importance of the Milk Bank).
- Model 3 added two subjective norm variables (family members - importance of the Milk Bank, and perceptions that other mothers have donated).
- The final model, Model 4, added two variables representing barriers (ease of donation and having shared milk).

The Omnibus Tests of Model Coefficients and the Hosmer and Lemeshow Tests were examined to obtain an indication of how well the model as a whole predicted intent to donate. Cox & Snell R Squared and Nagelkerke R Squared values were also examined to obtain an indication of the amount of variation in intent to donate that was accounted for by the set of predictors (Pallant, 2010). Finally, B values were examined to determine the direction of the relationship between predictor variables and the outcome, and the Exp (B) was reported as the odds ratio for each predictor.

After conducting the logistic regression analysis on the full sample, the regression was then conducted using a subsample of mothers who reported that they were still breastfeeding (either partially or exclusively), using the same procedure described above. Mothers were selected from the larger sample based on their answer to item 72 and 74. Results for both regressions are reported.

Ethical Considerations

Ethics approval was obtained from the University of British Columbia (UBC) Behavioural Research Ethics Board (BREB) and the Fraser Health Authority for both the pilot study and the full study. An information letter explained the purpose of the survey (see Appendix D & E), its voluntary nature and that participants had a choice to exit the survey at any point in time. Participation in the survey inferred consent. The survey was anonymous. The researcher's contact information was provided to participants should they have any questions

about the survey or to request a copy of the results. A website link and phone number for contacting the UBC BREB with any questions or concerns about the study was also provided in the information letter form. A summary of the research results will be posted for participants on the social media site where the original link for access was posted.

As it was recognized that infant feeding choice is often a sensitive and polarized topic, human milk substitute-feeding mothers were not excluded from participation. At the end of survey, there was an opportunity for participants to express any concerns or identify issues that they felt were not addressed appropriately, in an effort to ensure that participants felt heard and properly understood. Survey information was gathered through the UBC survey tool, Fluid Survey, which was hosted in Canada and complied with the British Columbian Freedom of Information and Protection of Privacy Act (University of British Columbia, N.D). From there, the anonymous data were transferred into Excel and IBM SPSS (version 23) on a password protected encrypted lap top computer and USB stick. Only the researcher and two committee members had access to these data.

Chapter 5: Results

This chapter presents the findings of a study that explored the factors that are associated with likelihood of donating breastmilk to the Provincial Milk Bank. The first section reports the descriptive characteristics of the study participants. This is followed by study results pertaining to each of the four research questions. Descriptive statistics are presented first, followed by bivariate statistics, and multivariate statistics.

Demographic Characteristics of Study Participants

Table 1 displays the demographic characteristics of the final sample of 754 women. The women ranged in age from 19 to 46 years (M = 32, SD = 4.2), and most were in a married or common law relationship (96.6%). The majority of women were educated at a baccalaureate level or higher (61.4%) and were on maternity leave or working as stay at home mothers (60.3%) at the time of the survey. One third of the sample worked in the health care or the social services sector (33.7%). The majority of participants (92.9%) lived in household with incomes above $35,000, which is the cut off for housing assistance (British Columbia Housing, 2018). Slightly more than half lived within the boundaries of the Fraser Health Authority (57.8%), followed by participants living within the Vancouver Island Health Authority (19.5%) and the Interior Health Authority (14.2%). Only 8.2% and 0.5% of the women resided within the boundaries of Vancouver Costal or Northern Health authorities, respectively.

Although, British Columbia is multiculturally diverse, most participants self-identified as Canadian (81.6%). Approximately 10% identified as East Asian, South Asian, or Southeast Asian. The majority of participants reported no religious affiliations (58.5%), and a third self-identified as Christian (33.7%). Each of the categories of Sikh, Buddhist, Jewish, and Muslim comprised less than 2% of the sample.

Half of the participants were first time mothers (50.7%), and their youngest child ranged in age from 1 week to 24 months (M = 10 months, SD = 6.3). Almost 22% of the infants were still exclusively breastfeeding at the time of the study.

Table 1

Demographic Characteristics of Participants (N=755)

	M (SD) Range	Frequency	
		n	%
Age in years	32.0 (4.2) 19 - 46		
Education			
Baccalaureate degree or higher		462	61.4
Less than baccalaureate degree		292	38.6
Employment			
On Mat leave/Stay at home mom		455	60.3
Others		300	39.7
Sector			
Other		427	66.3
Health Care and Social Services		217	33.7
Income			
> $35,000		652	92.9
≤ $35,000		50	7.1
Relationship Status			
Married, Common Law		728	96.6
Widowed, Divorced, Separated		8	1.0
Single		188	2.4
Number of Children			
1 child only		380	50.7
2 children		279	37.2
3 children		65	8.7
4 or more children		25	3.3
Health Authority of residence			
Fraser Health		435	57.8
Vancouver Island		147	19.5
Interior Health		107	14.2
Vancouver Costal		62	8.2
Northern Health		4	0.5
Culture			
Canadian		616	81.6
East Asian		47	6.2
South Asian		20	2.6
European		19	2.5
Latin/South/Central American		17	2.3
Southeast Asian		11	1.5
Aboriginal		7	0.9
African		3	0.4
Other		15	2.0

Table continues on next page

Table 1.
Demographic Characteristics of Participants (N=755) continued

	M (SD) Range	Frequency	
		n	%
Religion			
No Religion Affiliation		444	58.5
Christian		252	33.7
Sikh		12	1.6
Buddhist		9	1.2
Jewish		8	1.1
Muslim		6	0.8
Hindu		4	0.5
Other		14	1.9
Age of youngest child? (months)	10.0 (6.3) 0.25 - 24		
Where did your youngest receive his/her first non-breastmilk meal?			
At home		456	60.8
N/A (still breastfeeding)		164	21.9
In hospital		120	16
Out and about		10	1.3

Research Question 1. What are the self-reported attitudes, subjective norms, and barriers of women regarding milk donation and intention to donate human milk?

As seen in Table 2, the participants' attitudes toward human milk (breastmilk is best) were overwhelmingly positive with a mean of 6.6 (*SD* = 0.9) on a scale of 1 to 7 (strongly disagree to strongly agree). Mothers reported that they believe in the importance of the Milk Bank (*M* = 6.4, *SD* = 0.8), but were more neutral regarding whether it is better to donate to the Milk Bank than to share their milk with a friend (*M* = 4.1, *SD* = 1.6). They were also rather neutral in their beliefs that other women donate to the Milk Bank (*M* = 4.0, *SD* = 1.5), neither agreeing nor disagreeing with the statement.

With respect to subjective norms, participants reported that friends and family also consider breastmilk to be the best food for infants, although they reported slightly lower scores than for their own attitudes toward breastmilk. Perceptions about the beliefs of friends and family regarding the importance of the Milk Bank were also positive, with means of 5.8 (*SD* = 0.9) and 5.3 (*SD* = 1.2) for friends and family respectively. Similar to their own attitudes, participants perceived that friends and family were rather neutral regarding donating milk to the

BC Milk Bank versus sharing milk with a friend (*M* = 4.3, *SD* = 1.4 for friends, and *M* = 4.5, *SD* = 1.4 for family).

Almost half the sample knew a friend (42%) or family member (7%) who had donated to the BC Milk Bank, or babies who had received milk from the provincial Milk Bank (44%), and approximately a quarter of participants had shared their breastmilk with another infant (24%). Despite this, many participants believed that it would be difficult for them to donate, with a mean of 3.8 (*SD* = 1.3) on the 1 to 7 ease of donation scale. When questioned about the likelihood of donating breastmilk, 12.2% of women said they were definitely not going to donate, 15.6% indicated they were highly unlikely to donate, 18.6% were somewhat unlikely to donate, 14.5% were undecided, 22.7% were somewhat likely to donate, 10.3% highly likely to donate and 6.1% were definitely going to donate.

For the purpose of bivariate analysis, responses were grouped into three categories. Women who scored themselves as definitely not going to donate, highly unlikely to donate and somewhat unlikely to donate were combined to create a "not likely to donate" category. Women who indicated they were definitely going to donate, were highly likely to donate and were somewhat likely to donate, were combined into a "likely to donate category", leaving the remainder of women in the third category of "undecided". In the final logistic regression only the two categories of likely to donate and not likely to donate were used.

Table 2
Maternal Perception of Attitudes and Subjective Norms: Self, Family, and Friends.

Question	**Self** *M (SD)*	**Family** *M (SD)*	**Friends** *M (SD)*
Breastmilk is best	6.6 (0.9)	6.2 (0.9)	6.2 (1.1)
Better to donate to Milk Bank than share with a friend	4.1 (1.6)	4.3 (1.4)	4.5 (1.4)
Importance of Milk Bank	6.4 (0.8)	5.8 (0.9)	5.3 (1.2)
Beliefs that other women donate to the Milk Bank	4.0 (1.5)		

Research Question 2. What are the demographic characteristics and other situational factors that are associated with the intention to donate milk?

Table 3 presents the results from bivariate statistical tests that examine the association between demographic characteristics and women's reported likelihood of donating to the Milk Bank. Analysis of variance (ANOVAs) showed that mother's age, F (2, 736) = 4.05, and their youngest child's age F (2, 751) = 3.60, were significantly associated with likelihood to donate. Post-hoc tests indicated that women who reported being likely to donate were younger than mothers in the other two groups. Women in the undecided group had children who were younger than in the groups who were more certain about donating or not donating.

Chi-square tests of independence were performed to examine the relationships between categorical demographic characteristics and likelihood to donate. Results showed that employment χ^2 (2, n = 754) = 9.23, p <.05 and number of children χ^2 (2, n = 748) = 13.40, p <.01, were significantly associated with likelihood to donate. Women with two or more children, and those who were working or a student, tended to be grouped as less likely to donate. Education, sector, income and health authority showed no statistically significant associations with likelihood to donate.

Table 3

Association between Demographic Characteristics and Likelihood to Donate

	Not likely to donate ***N* = 350** *M (SD)*	**Undecided** ***N* = 109** *M (SD)*	**Likely to Donate** ***N* = 295** *M (SD)*	**Statistical test**
Mother's Age (years)	32.4 (4.2)	32.4 (3.7)	31.5 (4.2)	$F = 4.05$*
Youngest Child's Age (months)	10.2 (6.3)	8.5 (6.1)	10.3 (6.4)	$F = 3.60$*
	n (%)	n (%)	n (%)	
Education				
< Baccalaureate Degree	128 (44.1%)	41 (14.1%)	121 (41.7%)	χ^2 (2) = 1.26
≥ Baccalaureate Degree	220 (47.6%)	68 (14.7%)	174 (37.7%)	
Employment				
Leave/Homemaker	201 (44.2%)	80 (17.6%)	174 (38.2%)	χ^2 (2) = 9.23*
Working/Student	149 (49.8%)	29 (9.7%)	121 (40.5%)	
Sector				
Health Care Social Service	107 (49.3%)	29 (13.4%)	81 (37.3%)	χ^2 (2) = 0.76
Other	202 (47.3%)	66 (15.5%)	159 (37.2%)	
Income				
> $35,000	301 (46.2%)	98 (15.0%)	253 (38.8%)	χ^2 (2) = 2.66
≤ $35, 000	20 (40.0%)	5 (10.0%)	25 (50.0%)	
Number of children				
1 only	152 (40.1%)	62 (16.4%)	165 (43.5%)	χ^2 (2) = 13.40 **
2 or more	197 (53.4%)	44 (11.9%)	128 (34.7%)	
Health Authority				
Fraser Health	205 (47.2%)	66 (15.2%)	163 (37.6%)	χ^2 (8) = 2.89
Vancouver Costal	31 (50.0%)	8 (12.9%)	23 (37.1%)	
Interior Health	45 (42.1%)	16 (15.0%)	46 (43.0%)	
Northern Health	2 (50.0%)	0 (0.0%)	2 (50.0%)	
Vancouver Island	67 (45.6%)	19 (12.9%)	61 (41.5%)	

Notes: Statistical tests: ANOVA (*F)* for continuous predictor variables, Chi-squared (χ^2) for categorical predictor variables. * $p < .05$, ** $p < .01$, *** $p < .001$.

Research Question 3. What attitudes, subjective norms, and barriers are associated with intention to donate milk?

Table 4 presents the results from bivariate statistical tests (ANOVAs and chi-square tests) that examined the association between key study variables (attitudes, subjective norms, ease of donation) and women's reported likelihood of donating to the Milk Bank. Statistical differences at the $p < .001$ level were found in the variance of means for attitude: breastmilk is best F (2, 750) = 9.35. Post-hoc comparison using the Tukey HSD test indicated that the mean score for the group not planning to donate (M = 6.5, SD = 1.0) was significantly lower than the likely to donate group (M = 6.7, SD = 0.7). There were no statistically significant differences between the mean scores of the undecided group (M = 6.8, SD = 0.6) and the undecided or likely to donate groups. Statistical differences were found for the attitude of importance of the Milk Bank, F (2, 284) = 10.19, $p < .001$. Using the Tukey HSD test for post hoc comparisons indicated the mean of the group likely to donate (M = 6.6, SD = 0.6) was significantly higher than the undecided group (M = 6.3, SD = 0.9) and the group not planning to donate (M = 6.3, SD = 0.9). There was no statistically significant difference between the means of the undecided and not likely to donate groups.

With regard to subjective norms, there were no statistically significant differences found in participants' perceptions of attitudes held by their friends, and only one difference found for attitudes of family members. Post hoc comparison using the Tukey HSD test indicated that the group not likely to donate perceived that their family members held less positive attitudes about the importance of the Milk Bank than did participants who were undecided or likely to donate, F (2, 749) = 4.50, $p < .05$. Similarly, women who were not likely to donate were less likely to believe that other women had donated to the Milk Bank than women who were undecided or likely to donate, F (2, 746) = 8.04, $p < .001$.

Barriers, as measured through the ease of donation scale, also showed significant differences, F (2, 748) = 99.61, $p < .001$, between the three groups. The likely to donate group reported the highest ease of donation scores (M = 4.4, SD = 1.3), and the not likely to donate group showed the lowest ease of donation scores (M = 3.1 SD = 1.2).

Chi square analyses were conducted with categorical data. No differences were found between groups with respect to knowing friends or family who have donated, or knowing babies

who have received milk from the Milk Bank. However, more women who had shared breastmilk with another baby were in the likely to donate group than in the undecided or not likely to donate groups, χ^2 (2, n = 754) = 27.53, *Cramer's V* = .92.

Table 4

Descriptive Characteristics for Key Variables by Likelihood to Donate (N=754)

	Total Sample *N* = 754	Not Likely to Donate *N* = 350	Undecided *N* = 109	Likely to Donate *N* = 295	Statistical Test
	M (SD)	*M (SD)*	M (SD)	*M (SD)*	
Attitudes					
Breastmilk is best	6.6 (0.9)	6.5 (1.0)	6.7 (0.7)	6.8 (0.6)	*F* = 9.35***
Better to donate to Milk Bank than to share with friend	4.1 (1.6)	4.2 (1.6)	4.1 (1.6)	4.0 (1.6)	*F* = 0.39
Importance of Milk Bank	6.4 (0.8)	6.3 (0.9)	6.3 (0.9)	6.6 (0.6)	*F* = 10.19***
Subjective Norms - Friends					
Breastmilk is best	6.2 (0.9)	6.2 (0.9)	6.2 (1.2)	6.2 (0.9)	*F* =0.27
Better to donate to Milk Bank than to share with friend	4.3 (1.4)	4.3 (1.4)	4.5 (1.3)	4.2 (1.4)	*F* =1.26
Importance of Milk Bank	5.8 (0.9)	5.8 (0.9)	6.0 (0.8)	5.9 (0.9)	*F* =2.37
Subjective Norms – Family Members					
Breastmilk is best	6.2 (1.1)	6.1 (1.2)	6.3 (1.0)	6.2 (1.0)	*F* =2.37
Better to donate to Milk Bank than to share with friend	4.5 (1.4)	4.4 (1.4)	4.7 (1.3)	4.5 (1.5)	*F* =1.74
Importance of Milk Bank	5.3 (1.2)	5.1 (1.2)	5.4 (1.1)	5.4 (1.3)	*F* =4.50*
Subjective Norms					
Beliefs that other women donate to the Milk Bank	4.0 (1.5)	3.75 (1.5)	4.3 (1.5)	4.2 (1.6)	*F* =8.04***
Ease of Donation	3.8 (1.3)	3.1 (1.2)	4.1 (1.1)	4.4 (1.3)	*F*=99.61***

Table continues on next page

Table 4. *Descriptive Characteristics for Key Variables by Likelihood to Donate (N = 754) Continued*

	Total Sample *N* = 755	Not Likely to Donate *n* = 350	Undecided *n* = 109	Likely to Donate *n* = 295	Statistical Test
	n (%)	*n* (%)	*n* (%)	*n* (%)	
Subjective Norms					
Know friends who have donated					
Yes	308 (42%)	136 (44%)	42 (14%)	130 (42%)	χ^2 (2) = 1.96
No	418 (58%)	202 (48%)	61 (15%)	155 (37%)	
Know family members who have donated					
Yes	50 (7%)	27 (54%)	4 (8%)	19 (38%)	χ^2 (2) = 2.06
No	677 (93%)	313 (46%)	99 (15%)	265 (39%)	
Know babies who have received milk from Milk Bank					
Yes	317 (44%)	141 (45%)	40 (13%)	136 (43%)	χ^2 (2) = 2.95
No	408 (56%)	197 (48%)	61 (15%)	150 (37%)	
Have shared breastmilk with another baby					
Yes	183 (24%)	58 (32%)	24 (13%)	101 (55%)	χ^2 (2)= 27.53***
No	571 (76%)	292 (51%)	85 (15%)	194 (34%)	

Notes: Statistical tests: ANOVA (*F)* for continuous predictor variables, Chi-squared (χ^2) for categorical predictor variables
* $p < .05$, ** $p < .01$, *** $p < .001$.

Research Question 4. What are the set of demographic characteristics, attitudes, subjective norms and barriers that best predict the intention to donate milk?

Hierarchical logistic regression analyses were conducted to determine the set of variables that best predicts the likelihood of donating to the Milk Bank among the subsample of women who identified as likely to donate or not likely to donate (i.e., the 109 women who were undecided were excluded from this analysis). Variables were selected for inclusion in the logistic model based on statistical significance in bivariate analyses described above. The logistic regression analyses consisted of four models, with variables entered based on the Theory of Planned Behavior as follows:

Model 1: Demographic characteristics - maternal age in years, child age in months, employment status, number of children

Model 2: Attitudes - breastmilk is best, importance of the Milk Bank

Model 3: Subjective Norms - family members beliefs about importance of the Milk Bank, own beliefs about other mothers have donated

Model 4: Barriers - ease of donation, have shared breastmilk.

Table 5 summarizes the logistic regression results for the four models, conducted with the full sample of 626 participants. The final logistic regression model containing all predictors was statistically significant, χ^2 (10, N = 626) = 194.87, $p < .001$, indicating the model was able to distinguish between mothers who are and are not likely to donate. The Cox and Snell R squared and Nagelkerke R squared statistics (26.7% and 35.7%, respectively) provide an indication of the moderate substantive significance of the model (Field, 2013), though some authors interpret these pseudo R squared statistics as the proportion of the variance in the outcome measure that is explained by the predictor variables (e.g., Pallant, 2010). Overall, the final model correctly classified 71.9% of the participants. More specifically, the final model correctly classified 74.9% of the women not likely to donate and 68.3% of the women likely to donate.

The final model indicates that number of children, beliefs about the importance of the Milk Bank, beliefs about other mothers donating, ease of donation, and prior sharing of breastmilk were significant predictors of a mother's intention to donate milk to the Milk Bank. Women with two or more children were half as likely to report being likely to donate milk as women with only one child (*OR* = .497, 95% *CI* = .335, .736). Women were 1.5 times more

likely to report being likely to donate to the Milk Bank for every point they scored higher on beliefs about the importance of the Milk Bank scale (*OR* = 1.450, 95% *CI* = 1.065, 1.970), and 1.1 times more likely for every point they scored higher on the scale measuring beliefs that other mothers have donated to the Milk Bank (*OR* = 1.149, 95% *CI* 1.013 = 1.304). When examining barriers as evaluated through the ease of donation scale, mothers were 2.3 times more likely to intend to donate for every point they scored higher on the ease of donation scale (*OR* = 2.305, 95% *CI* =1.942, 2.737), and 1.7 times more likely to intend to donate if they had shared milk with another baby (*OR* = 1.673, 95% *CI* =1.067, 2.621).

Maternal age and belief that breastmilk is best were predictive of likelihood to donate in Models 1 through 3, but became non-significant when barriers and having shared milk with another baby were added to the final model. Likelihood to donate was not uniquely predicted by child's age, employment status, or perception of the family members' beliefs about importance of the Milk Bank.

Table 5

Results of Hierarchical Logistic Regression Analyses for Likelihood of Donating Milk to the Human Milk Bank (N = 626)

	Model 1	**Model 2**	**Model 3**	**Model 4**
Likelihood of donating to the Human Milk Bank	*OR* (95% *CI*)	*OR* (95% *CI)*	*OR* (95% *CI*)	*OR* (95% *CI*)
Maternal Age in Years	.960* (.924, .998)	.951* (.914, .990)	.957* (.919, .996)	.972 (.928, 1.017)
Child Age in Months	1.012 (.983, 1.042)	1.008 (.978, 1.038)	1.008 (.978, 1.039)	1.021 (.986, 1.056)
Employment Status	1.125 (.775, 1.635)	1.174 (.800, 1.722)	1.204 (.818, 1.773)	1.450 (.934, 2.252)
Number of Children	.672* (.486, .929)	.683* (.491, .951)	.683* (.487, .957)	.497*** (.335, .736)
Attitude-Belief Breastmilk is Best		1.536** (1.189, 1.984)	1.557** (1.205, 2.011)	1.154 (.889, 1.497)
Attitude-Importance of Milk Bank		1.417* (1.080, 1.859)	1.368* (1.033, 1.813)	1.448* (1.065, 1.970)
Subjective Norm-Family Members Importance of Milk Bank			1.035 (.900, 1.191)	.997 (.852, 1.168)
Subjective Norm-Other Mothers have Donated			1.200** (1.073, 1.341)	1.149* (1.013, 1.304)
Ease of Donation				2.305*** (1.942, 2.737)
Have Shared Breastmilk				1.673* (1.067, 2.621)
Cox & Snell R^2	2.1%	6.3%	8.1%	26.7%
Nagelkerke R^2	2.8%	8.5%	10.8%	35.7%
Correct Classification	56.9%	62.1%	60.9%	71.9%
Unlikely to donate	73.7%	70.8%	69.6%	74.9%
Likely to donate	36.9%	51.9%	50.5%	68.3%

Notes: Employment status: 0=working/student, 1=leave/homemaker, Number of children: 0=one child, 1=two or more children, Shared breastmilk: 0=no, 1=yes, *p<0.05, **p<0.01, ***p<0.001.

The same hierarchical regression analysis was conducted for a subsample of the 201 mothers known to be breastfeeding exclusively or partially, with similar results (see Table 6). The final logistic regression model containing all predictor variables was statistically significant χ^2 (10, N = 201) = 69.44, p <.001. The model as a whole explained between 29.2% (Cox and Snell R squared) and 39.0% (Nagelkerke R squared) of the variance in likely to donate (versus not likely to donate). The model correctly classified 72.1% of the cases (68.8% of the unlikely to donate group, and 75.2% of the likely to donate group).

In this sub-analysis, importance of the Milk Bank and ease of donation were the only significant predictors of likelihood to donate to the Milk Bank. For every point women scored higher on beliefs about the importance of the Milk Bank scale, participants were 1.83 times more likely to indicate they planned to donate milk to the Milk Bank (*OR* = 1.831, 95% *CI* = 1.070, 3.169). Each point that women scored higher on the scale examining barriers (measured through ease of donation) almost tripled their likelihood of indicating that they were likely to donate human milk to the Milk Bank (*OR* = 2.828, 95% *CI* = 1.928, 4.088). As for the full sample, maternal age was predictive of likelihood to donate in Models 1 through 3, but became non-significant when barriers and having shared milk with another baby were added to the final model. The remaining variables did not make a unique statistical contribution to the model in predicting likelihood to donate.

Table 6

Results of Hierarchical Logistic Regression Analyses for Likelihood of Donating Milk to the Human Milk Bank (N = 201)

	Model 1	**Model 2**	**Model 3**	**Model 4**
Likelihood of donating to the Human Milk Bank	*OR* (95% *CI*)	*OR* (95% *CI*)	*OR* (95% *CI*)	*OR* (95% *CI*)
Maternal Age in Years	.921* (.861, .986)	.920* (.858, .986)	.920* (.585, .987)	.930 (.858, 1.009)
Child Age in Months	.995 (.932, 1.062)	.986 (.921, 1.056)	.984 (.918, 1.054)	1.009 (.931, 1.092)
Employment Status	.865 (.439, 1.705)	.886 (.437, 1.798)	.930 (.454, 1.906)	1.512 (.664, 3.439)
Number of Children	.651 (.358, 1.183)	.650 (.351, 1.204)	.651 (.347, 1.221)	.672 (.316, 1.430)
Attitude-Belief Breastmilk is Best		1.479 (.919, 2.380)	1.493 (.904, 2.466)	1.161 (.665, 2.025)
Attitude-Importance of Milk Bank		1.604* (1.008, 2.554)	1.668* (1.034, 2.690)	1.831* (1.070, 3.169)
Subjective Norm-Family Members Importance of Milk Bank			.869 (.671, 1.126)	.855 (.636, 1.151)
Subjective Norm-Other Mothers have Donated			1.205 (.982, 1.480)	1.240 (.984, 1.563)
Ease of Donation				2.828*** (1.928, 4.088)
Shared with other Babies				1.045 (.447, 2.446)
Cox & Snell R^2	4.7%	9.9%	11.5%	29.2%
Nagelkerke R^2	6.3%	13.2%	15.4%	39.0%
Correct Classification	62.2%	60.2%	62.7%	72.1%
Unlikely to donate	55.2%	51.0%	55.2%	68.8%
Likely to donate	68.6%	68.6%	69.5%	75.2%

Notes: Employment status: 0=working/student, 1=leave/homemaker, Number of children: 0=one child, 1=two or more children, Shared breastmilk: 0=no, 1=yes, *p<0.05, **p<0.01, ***p<0.001.

Summary

In summary, among women with children 24 months of age and under, women who have only one child, women who believe the provincial Milk Bank is important and believe that other mothers have donated to the Milk Bank, women who have previously shared milk and score high on the ease of donation scale have a higher likelihood of stating that they will donate to the Milk Bank. However, among women who are still breastfeeding, beliefs about the importance of the Milk Bank and ease of donation are the only variables that predict likelihood to donate over and above the other variables in the model.

Chapter 6: Discussion

The Canadian Paediatric Society recommends breastfeeding exclusively for the first 6 months of an infant's life. If mother's milk is not available during this time the recommended alternative is pasteurized human milk from a milk bank (Kim et al., 2010). Unfortunately, there are more infants requiring human milk than what is available.

This study was an exploratory survey study conducted over two months in the summer of 2017, examining attitudes, subjective norms and barriers toward donating human milk to the provincial Milk Bank, in women with children 24 months old and younger in BC. Prior to this study there was no available published literature on attitudes, subjective norms and barriers within BC toward human milk donation to the Milk Bank. This study provides baseline information on the subject, which can be used to promote breastmilk donation thereby increasing the supply of human milk available from the Milk Bank.

A survey was designed based on clinical knowledge, expert feedback, international literature and the Theory of Planned Behavior. The survey contained 74 multiple choice and short answer questions. After getting feedback from multiple experts and committees specializing in lactation, the survey was trialed with 17 women who gave feedback to the researcher verbally while taking the survey, as well as providing notes on a separate paper. Specific changes were made to the survey based on these recommendations prior to the start of data collection.

Data were collected from 856 women; 755 met the inclusion criteria, and 754 had answered item 36 asking about their likelihood to donate as required for analysis. The first month was spent recruiting in person at public health centers as well as with posters and recruitment cards at those sites. In addition, the Best Beginnings E-newsletter for Fraser Health listed an invitation to the study and after one month, online snowball recruitment was added through social media (Twitter and Facebook). This final approach using social media dramatically increased recruitment, with 19 participants on the first day of online recruitment, 94 on the second, progressively increasing to 293 on day 4. Throughout these days, links were systematically posted on a variety of community Facebook pages. Completion rates were monitored and as interest waned, the link was posted on new community Facebook groups to

increase recruitment. At the completion of the survey 27 participants were recruited through the best beginnings E-newsletter, 11 through the poster and business card advertisements, 532 through Social Media and 183 through in person recruitment by the researcher at Fraser Health Public Health units.

Bivariate analyses were conducted, these included ANOVA's and Chi-square tests of independence, followed by hierarchical logistic regressions. The final hierarchical logistic regression model of the full sample, which explained 68.3% of likelihood to donate, showed that women: with one child; who believe the human Milk Bank is important; who believe other mothers have donated to the Milk Bank; who have previously shared their milk with another baby; and who score high on the ease of donation scale are more likely to intend to donate than those who score lower. A sub-analysis of mothers within the sample known to be breastfeeding was also conducted with similar results, indicating that women who believed in the importance of the Milk Bank and scored high on the ease of donation scale would be more likely to report intention to donate than those who score lower. This chapter will review how the results of this study fit with known literature on the topic, the potential impact of this study on informing nursing practice and policies, and it will suggest future research avenues.

Characteristics

Women with one child.

This study indicates that women with one child were more likely to rate themselves as likely to donate human milk to the Milk Bank than women with more than one child. Prior to this study, there were no published BC statistics on the likelihood of human milk donation related to the number of children. Previous research from France and Brazil (Azema & Callahan, 2004; Pimenteira Thomez et al, 2008), found that most women who donated to a milk bank had less than 3 children. In BC, the majority of households have 1 or 2 children (Statistics Canada, 2013), therefore this is not a surprising outcome. Recognizing that woman with only one child are more inclined toward donating will allow health care providers to specifically target this population when promoting donation to the Milk Bank.

Women who have previously shared their milk with another baby.

Previous research reports varied on whether women who shared human milk were the same group of women who would be likely to donate to a milk bank (Rochman, 2011; Gribble, 2013). Gribble (2013) suggested women might have philosophical objections to milk banking and choose sharing over donating to a milk bank. Yet, within the BC context, participants in this study who previously shared milk were more likely to report a higher intention of donating to the Milk Bank compared to women who had not shared their milk. Perhaps previous milk sharing indicates that these women understand the value of their breastmilk and have already overcome barriers associated with the pumping and storage process, although possibly not to the standard required by the Milk Bank.

Further research is required to determine what exactly drives this group of women toward sharing rather than donating to the Milk Bank in BC. Further analysis of the qualitative data, the responses of the 183 women (24%) who had shared their milk, (in particular item 59a on the survey), may reveal more information about their reason for sharing rather than donating to the Milk Bank. This could inform health care practitioners when working in partnership with these mothers to consider donation to the Milk Bank.

The fact that milk sharing is occurring is evident once again from the results of this study, and the potential risks involved cannot be ignored. Providing information in a family-centred way, including discussion of risk reduction and the role of the Milk Bank in safely providing human milk to infants and families in need, may help to counter any myths or misinformation about human milk banking. As awareness of milk sharing grows within the province, individual health authorities, as well as the provincial overseeing body, PSBC are developing resources for health practitioners to use to assist parents in making informed decisions around this important topic of milk sharing (PSBC 2014b; PSBC, 2016).

Attitudes

According to Ajzen (1991), attitude, as defined within his Theory of Planned Behavior, "the degree which a person has a favourable or unfavourable evaluation or appraisal of the behaviour" (p. 188), has a strong influence on a persons intention to perform a behaviour. Therefore, it was not surprising to find that women in BC who believe the Milk Bank is

important, indicated they are more likely to donate, than women who do not believe the Milk Bank is important.

Recommendations by the CPS promoting breastfeeding and the provision of human milk for human babies (Kim et al., 2010) are reflected in the overwhelmingly positive attitudes of BC mothers toward both breastmilk and in support of human milk banks. International research conducted in South Australia (Mackenzie et al., 2013) examined the attitudes of women toward human milk donation, and found they were unanimously in support of human milk banks assuming minimal barriers in the process of donation. Australian mothers were also noted to have a positive attitude toward human milk, similar to the BC mothers in this study, recognizing it as the best nutrition for infants (Mackenzie et al., 2013). Interestingly, Lam et al. (2012) suggested in their study that health care providers might not be as supportive of human milk or human milk banking. Similar to the results found in Australia (Mackenzie et al., 2013), responses of mothers in this study did not reflect health care providers' lack of support. Despite one third of the participants in this study being employed in the health care and social service sectors, attitudes toward human milk and the Milk Bank were found to be positive.

In this study, attitudes among the women were noted to be different toward the Milk Bank when mothers were asked if they believed it is better to donate to the Provincial Milk Bank instead of sharing with a friend. Although participants reported that they believed the Milk Bank was important, their responses were neutral, on average, when asked to whether it is better to donate milk to the Milk Bank or to share milk with a friend's baby. Approximately a quarter of this sample had previously shared their milk, which is consistent with the results reported by O'Sullivan, Geraghty, Rasmussen (2016) in which many mothers were willing to share their own milk, as long as their supply was adequate for their own infant and they had excess milk to give away. Further research needs to be done into the reasons the attitude toward the Milk Bank changes when mothers are asked to choose between sharing with a friend and donating to the Milk Bank.

Subjective Norms

According to the Theory of Planned Behavior, subjective norms reflect "the individual's perception of general social pressure to perform…the behaviour" (Armitage & Connor, 2001,

p.474). Examining subjective norms revealed mothers believed breastmilk and the Milk Bank were generally regarded positively by both family and friends. Despite this positive perception by mothers, results revealed that women thought their families and friends regarded breastmilk and the Milk Bank less positively than they did. To date there are no published research studies on BC mothers' perceptions of how breastmilk, or the Milk Bank is valued by their local community. Even so, breastfeeding rates continue to climb within Canada, from 85% in 2003 to 89% in 2012. British Columbia has the highest average with 96% of mothers initiating breastfeeding and a rise from 28%-41% in infants exclusively breastfed until 6 months over the same time span (Statistics Canada, 2015a).

The pressure of perceived social norms on mothers was also noted in this study with the statistically significant finding that women rated themselves as highly likely to donate if they believed other mothers had donated to the Milk Bank. This finding was expected based on Ajzen's (1991) Theory of Planned Behavior, indicating the strength subjective norms have over our expressed intentions as humans.

Although currently British Columbia has the highest breastfeeding rates within Canada, this may change with the advancement of the "fed is best" movement (Fed is Best Foundation, 2016) influencing society, and mothers sharing their stories of feeling social pressure to breastfeed, as breastfeeding becomes the social norm within BC society. Pressures to present as the perfect parent have increased with the growth of social media, and the ability of mothers to compare themselves within this venue (Coyne, McDaniel & Stockdale, 2017). In addition, there is dwindling social support, as many households in BC now require two incomes to maintain their standard of living, and extended family increasingly lives outside of the province/country. All of these factors may add to mothers pushing back when hearing breast is best.

Barriers

Barriers, represented by the ease of donation scale, were found to be significantly predictive of a woman's intention to donate to the human Milk Bank. Barriers measured by the ease of donation scale included ease of breastfeeding, expression, and beliefs of adequate milk supply, and ease of donation. Some of these could be seen as actual barriers preventing women from donating, others are beliefs that can be influenced. All the barriers included within the ease

of donation scale are broad and can be broken into more specific barriers, for example, ease of donation-transportation of milk or cost of pumping equipment.

A break down of these more specific barriers was initially included within the study. Questions (items 42 through 52), included statements such as “transporting the breastmilk to the Milk Bank is too difficult”, “the supplies are too expensive to donate breastmilk to the Milk Bank” and “I’m too tired to pump extra breastmilk to donate to the Milk Bank”. Despite feedback and the pilot project, upon conclusion of data collection, it was noted phrasing of the questions did not allow for analysis. In the future, further research targeting specific issues women encounter will need to be conducted. Examining qualitative portions of this research may yet reveal further insight into this important area, and may inform health care providers to assist mothers in overcoming barriers to donation as this is a key in increasing women’s likelihood to donate.

International research demonstrates similar results to this study related to the impact of ease of donation on likelihood to donate. Alencar and Seidl (2010) suggested that perceived low milk supply could impact donations to the Milk Bank and Azema and Callahan (2004) suggest breastfeeding challenges affect human milk donors and could act as barriers toward donation. Osbaldiston and Mingle (2007) reported that despite breastfeeding challenges, many donating mothers still reported breastfeeding as good or excellent. Perhaps it is partially the attitude women have toward these challenges that affect their likelihood to donate. Within this survey mothers rated their own likelihood and the impact that these barriers would have on their likelihood of donating, their perception of these barriers reflecting in the score they assigned themselves. For example, item 37, part of the ease of donation scale, states: “Breastfeeding is easy for me”. This is a subjective statement. Two mothers may encounter the same breastfeeding difficulty, i.e. difficulty latching, and while one may consider the resulting work of breastfeeding excessively difficult or even impossible to overcome, the other may perceive it as a normal aspect of working through the initiation of breastfeeding, a barrier that can be overcome. The latter may therefore rate breastfeeding ease as higher than the first. Other barriers such as not lactating are actual barriers, concrete barriers that may not be overcome despite the amount of effort and work put in by the mother.

Further research is required to address the perceived and actual barriers to donating to the human Milk Bank and to analyse if these mothers are affected mainly by perceived subjective barriers that can be overcome with appropriate health care provider/system support or by actual barriers which may not be overcome, even with the most positive of attitudes and endless effort.

Strength and Limitations of the Study

This study used a variety of different recruitment methods including: posters, Fraser Health's Best Beginnings E-newsletter, in person recruitment and data collection, and social media snowball invitations to participate. The study was, therefore, able to reach over 800 participants and the final sample of 754 women provided a broad representation of mothers across the province, thereby increasing the generalizability of the results. Combining in person and on-line recruitment extended the reach of data collection to include mothers who might not have computer or internet access, although the majority of respondents participated directly online.

The average age of participants (32 years) was comparable to the average age of the childbearing population in BC, which was 31.4 years in the 2015/2016 fiscal year (PSBC, 2017). The large proportion of participants with no religious affiliation and those with Christian beliefs are reflective of the larger population in Canada (Statistics Canada report, 2015b). The underrepresentation of other religious beliefs may be due to more recent immigration status and language barriers associated with this (Pew Research Center, 2013). Although efforts were made to access a representative sample, it is expected that because the survey was shared with nurses as an e-newsletter, and it was posted on social media by the researcher and one of the supervisors, a large percentage of participants were from the health care and social services sectors, which often provide maternity leaves that are supported by the employer, and provide living wages. Efforts to recruit from neutral community social media sites are expected to have minimized this recruitment bias.

Limitations of this study include not capturing input from non-English speaking participants, as this survey study was only available in English. This may have limited the effects of cultural practices and beliefs on attitude, subjective norms and barriers faced by

specific cultures, or religions, and limits the generalizability of results not fully representing all BC mothers of children 24 months old and younger.

Due to the sensitivity of this topic, some participants may have chosen to not start or complete the survey. Women may have felt guilty for not donating breastmilk, being unable to breastfeed their infant or for choosing to feed their infant human milk substitutes despite the known benefits of breastfeeding for both the mother and infant. Although it is unlikely that one could completely eliminate this sensitivity, care was taken to word the questions in a factual, non-judgmental manner and an introduction was provided acknowledging the difficulties in the transition to parenthood, and the many complicated decisions associated with this transition. It was anticipated that by creating a permissive, anonymous environment (Polit & Beck, 2012) women would feel comfortable in initiating and completing the survey. To further address this potential difficulty, the information letter at the beginning of the survey clearly stated that the purpose of the survey was to learn more about what makes it easier and harder to donate. This also allowed participants to feel that they were making a contribution to the health and wellness of mothers and vulnerable infants despite the fact that they may have chosen not to donate their milk to the Milk Bank.

Other limitations specific to data collection with the survey include the lack of a questions specifically identifying feeding status as exclusively breastfeeding, mix-feeding (combination of human milk and human milk substitute), total breastfeeding, or human milk substitute feeding. This was managed by identifying mothers still breastfeeding from other questions (item 72 and 74 of questionnaire) or qualitative data to allow for the sub-analysis of the model with 201 participants who were still breastfeeding at the time of the study. Further clarification would have been of benefit for ease and comparison of the survey analysis and results. Although wording of specific questions was reviewed by expert panels and tested through a pilot study with mothers, during analysis, several of the questions specific to barriers were found to be unclear and were discarded.

Although this study included participants from all over BC, the majority of participants were found to be from Fraser Health Authority and Vancouver Island Health Authority. This could in part be due to the state of emergency and evacuation throughout a large part of the interior of the province due to wildfires at the time of recruitment. Potential participants of

Interior Health and Northern Health may have been busy evacuating, or preparing to accept evacuees, or may have been without power and Wi-Fi access to use the online survey. If this study is repeated care needs to be taken to specifically target these health authorities to ensure equal representation.

Infant nutrition is frequently a very polarizing topic. Using social media for recruitment, it is impossible to determine if one specific online community group, holding strong opinions toward either human milk or milk banking, has biased the results. To manage this bias and minimize the chances of it occurring, efforts were made to recruit through a variety of methods (E-newsletter, in person recruitment, posters and advertisements) in addition to online posting. When posting links online for recruitment, care was taken to post to neutral community groups to minimize any bias present which might influence the results.

Finally, this study also relied on mothers to accurately and honestly self-report on their infants feeding habits and their attitude toward breastfeeding, which may be affected by recall memory, as well as societal pressures to answer in a manner that is within keeping with the values of Canadian society (Polit & Beck, 2012).

Impacts on Nursing/Policy/Research development

The results of this study add to the information of what we know influences women's decision making in regard to milk donation within the BC context, specifically their intention to donate. Results provide a baseline measure of women's attitudes, with children 24 months old and younger, toward human milk donation and their perception of the social norms surrounding them, including attitudes toward human milk and the Milk Bank.

This study suggests that rather than focusing on changing women's attitudes toward human milk, which are for the most part very positive, efforts by health care providers should focus on normalizing milk donation, and highlighting the importance of the Milk Bank. This can be done both on a systems level, for example, by publicly recognizing the women who donate and giving women the opportunity to talk about their gift of donation, and on an individual level, by health care practitioners highlighting the number of women donating to the Milk Bank and the benefits of the Milk Bank to our society.

Considering the extremely quick uptake of the survey through Facebook and Twitter, highlighting women's stories of donating to the Milk Bank through these social media sites may be of benefit and interest to women in BC. Other venues to spread how many women are donating may be in the form of women telling their donation stories which are captured in print for E-newsletters or on video and posted on health authority websites and social media groups. Mother's may share their stories at baby groups within the public health system or in community support groups. Public health units throughout BC could make an effort to tally the number of women donating in addition to monthly updates on the amount of milk donated. It is also of interest to note for future research, posters and business card advertisements saw minimal recruitment compared to social media, and may not be the ideal method for reaching this population.

Next Steps

There currently is very little published research on attitudes, subjective norms and barriers surrounding human milk donation in BC or globally. Analysis of the qualitative data gathered in this study, but not yet analyzed, may add to the understanding of the quantitative results presented in this paper and may provide direction for future research. It will also contextualize the women's stories, providing detail that cannot be captured through numbers alone. Barriers were examined on a broad scale of ease of donation but further exploration of specific barriers women encounter in their efforts to donate to the Milk Bank is required. The individual health authorities can address these to increase supply of milk to the Milk Bank and thereby the babies in need.

Further research is also required to examine when, by whom and how mothers would like to be approached about milk banking. This is especially important for mothers who have already shared their milk with another infant. Surveying those already sharing to determine reasons for sharing versus donating may also be of benefit, as these may be areas that can be addressed by health care practitioners and the health care system to further increase donations and awareness of the Milk Bank. Finally, although some mothers within our survey had donated to the Milk Bank, gaining ethics permission to approach donors to examine their attitudes, subjective norms

and barriers and motivating factors encountered by the women already donating to the Milk Bank can also add to the knowledge on the topic within our specific BC context.

Conclusion

The Canadian Paediatric Society currently recommends infants be exclusively breastfeed for the first 6 months of life (Kim et al., 2010). This is not always possible. When mothers cannot provide their own milk, milk from a milk bank is recommended. In BC there is currently not enough donor milk available for every infant in need of it. This study provides a baseline assessment of mothers' attitudes, subjective norms and barriers surrounding human milk donation. Learning more about what increases the intention of mothers to donate to the BC Women's Provincial Milk Bank will assist health care providers in working with interested and motivated mothers to overcome their perceived and actual barriers to donate, thereby increasing the supply available to infants in need. Creating innovative ways to share the Milk Bank story in BC, especially since it is the oldest continuing Milk Bank in North America, could increase the outreach to mothers who would be ideal to donate.

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&SUB=0&Temporal=2013&THEME=94&VID=0&VNAMEE=Religion%20(108)&VNAMEF=Religion%20(108)

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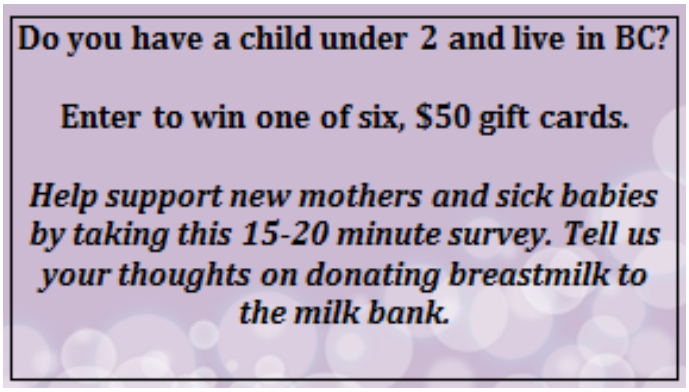
Appendix A - Business Card-Recruitment Notice



Front of business card-recruitment notice

Back of business card-recruitment notice

Appendix B - Poster-Recruitment Notice

Appendix C - Questionnaire -Breastmilk Donation Survey

NOTE: This survey asks your thoughts, as well as your perceptions about the views of your friends and family.

Definitions

Donated Breastmilk: breastmilk from an official Milk Bank

Shared Breastmilk: breastfed by another woman not the mother, expressed breastmilk from another woman

Formula: A commercially prepared breastmilk substitute

SECTION 1: YOUR THOUGHTS

Instructions: Please indicate which response best represents your level of agreement or disagreement with each of the following statements.

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
1. I believe breastmilk is, in most circumstances, the best food for babies.	○	○	○	○	○	○	○
2. I believe it is good to donate breastmilk to the	○	○	○	○	○	○	○

Provincial Milk Bank.							
3. I believe it is better to donate to the Provincial Milk Bank than to share it with a friend's baby.	○	○	○	○	○	○	○
4. I believe the Provincial Milk Bank is important.	○	○	○	○	○	○	○

If available, I would feed my baby:

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
5. Breastmilk rather than formula.	○	○	○	○	○	○	○
6. Breastmilk from a friend rather than formula.	○	○	○	○	○	○	○
7. Breastmilk from a milk bank rather than formula.	○	○	○	○	○	○	○
8. Breastmilk from a milk bank rather than shared breastmilk from a friend.	○	○	○	○	○	○	○

What do you think other people think?

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
9. Most people believe breastmilk is in most circumstances, the best food for babies.	○	○	○	○	○	○	○
10. Most people believe it is good to donate breastmilk to the Provincial Milk Bank.	○	○	○	○	○	○	○
11. Most people believe it is better to donate to the Provincial Milk Bank than to share it with a friend's baby.	○	○	○	○	○	○	○
12. Most people believe the milk bank is important.	○	○	○	○	○	○	○
13. Many mothers have donated to the Provincial Milk Bank.	○	○	○	○	○	○	○

If available, I believe most mothers in BC would feed their baby:

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
14. Breastmilk rather than formula.	○	○	○	○	○	○	○
15. Breastmilk from a friend rather than formula.	○	○	○	○	○	○	○
16. Breastmilk from a milk bank rather than formula.	○	○	○	○	○	○	○
17. Breastmilk from a milk bank rather than shared breastmilk from a friend.	○	○	○	○	○	○	○

Instructions: Please indicate which response best represents your level of agreement or disagreement with each of the following statements.

SECTION 2: MY FRIENDS...

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
18. Believe breastmilk is in most circumstances, the	○	○	○	○	○	○	○

best food for babies.							
19. Believe it is good to donate breastmilk to the Provincial Milk Bank.	○	○	○	○	○	○	○
20. Believe it is better to donate to the Provincial Milk Bank than to share it with a friend's baby.	○	○	○	○	○	○	○
21. Believe the Provincial Milk Bank is important.	○	○	○	○	○	○	○

If available, I believe my friends would feed their baby:

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
22. Breastmilk rather than formula.	○	○	○	○	○	○	○
23. Breastmilk from a friend rather than formula.	○	○	○	○	○	○	○
24. Breastmilk from a milk bank rather than formula.	○	○	○	○	○	○	○
25. Breastmilk from a milk bank rather than	○	○	○	○	○	○	○

shared breastmilk from a friend.

Instructions: Please indicate which response best represents your level of agreement or disagreement with each of the following statements.

SECTION 3: MY FAMILY MEMBERS...

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
26. Believe breastmilk is in most circumstances, the best food for babies.	○	○	○	○	○	○	○
27. Believe it is good to donate breastmilk to the Provincial Milk Bank.	○	○	○	○	○	○	○
28. Believe it is better to donate to the Provincial Milk Bank than to share it with a friend's baby.	○	○	○	○	○	○	○
29. Know why the Provincial Milk Bank is important.	○	○	○	○	○	○	○

If available I believe my family members would feed their baby:

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree
30. Breastmilk rather than formula.	○	○	○	○	○	○	○
31. Breastmilk from a friend rather than formula.	○	○	○	○	○	○	○
32. Breastmilk from a milk bank rather than formula.	○	○	○	○	○	○	○
33. Breastmilk from a milk bank rather than shared breastmilk from a friend.	○	○	○	○	○	○	○

DONATING TO THE MILK BANK

My intention

34. Are you eligible to donate breastmilk to the milk bank?

- ○ Yes
- ○ No
- ○ I do not know if I'm eligible

34a. If no, what is the reason you are not eligible to donate breastmilk to the milk bank?

35. It is my intention to donate breastmilk to the Provincial Milk Bank.

- ○ 1. Strongly Disagree

- ○ 2. Disagree
- ○ 3. Slightly Disagree
- ○ 4. Neither Disagree nor agree
- ○ 5. Slightly Agree
- ○ 6. Agree
- ○ 7. Strongly Agree

36. What is the likelihood that you would donate breastmilk?

- ○ 1. Definitely not going to donate
- ○ 2. Highly unlikely
- ○ 3. Somewhat unlikely
- ○ 4. Undecided
- ○ 5. Somewhat likely
- ○ 6. Highly likely
- ○ 7. Definitely going to donate

Instructions: Please select the response that best represents your level of agreement or disagreement with each of the following statements about breastfeeding and ease of donation.

What directly affects your decision?

	Strongly Disagree	Disagree	Slightly Disagree	Neither Disagree nor Agree	Slightly Agree	Agree	Strongly Agree

37. Breastfeeding is easy for me.	○	○	○	○	○	○	○
38. I did not have enough breastmilk to donate to the milk bank.	○	○	○	○	○	○	○
39. Expressing breastmilk is easy for me.	○	○	○	○	○	○	○
40. Donating to the milk bank would be easy for me.	○	○	○	○	○	○	○
41. There are too many barriers for me to donate breastmilk.	○	○	○	○	○	○	○

Instructions: On a scale of 1 to 7, to what degree have the following factors influenced your intention or likelihood of donating breastmilk to the milk bank?

1= Did NOT affect my decision 7= Affected my decision a lot

	1	2	3	4	5	6	7
42. I did not know about milk banking.	○	○	○	○	○	○	○
43. The screening process is too difficult to complete to determine eligibility to donate.	○	○	○	○	○	○	○
44. I don't have the time to donate breastmilk.	○	○	○	○	○	○	○
45. I'm too tired to pump extra breastmilk to donate to the milk bank.	○	○	○	○	○	○	○

46. Transporting the breastmilk to the milk bank is too difficult.	○	○	○	○	○	○	○
47. Donating breastmilk to the milk bank is difficult due to my religious beliefs.	○	○	○	○	○	○	○
48. The supplies are too expensive to donate breastmilk to the milk bank.	○	○	○	○	○	○	○
49. I'd rather sell my breastmilk than donate it to a milk bank.	○	○	○	○	○	○	○
50. I'd rather donate my milk to a friends or someone I can connect with in the community.	○	○	○	○	○	○	○
51. Donating breastmilk through a milk bank is too impersonal.	○	○	○	○	○	○	○
52. My partner does not support me donating breastmilk to the milk bank.	○	○	○	○	○	○	○

53. Other barriers that prevented you from donating or made donating difficult.

54. I have donated breastmilk to the milk bank.

- ○ Yes
- ○ No

54a. Have you encouraged others to donate?

- ○ Yes
- ○ No

54a.1 How many friends have you encouraged to donate (enter number of people)?

54a.2 How many family members have you encouraged to donate (enter number of people)?

54a.3 How many other people did you encourage to donate (enter number of people)?

54b. What was your motivation to donate?

55. My baby has received donated breastmilk from a milk bank.

- ○ Yes
- ○ No

55a. Have you encouraged others to donate breastmilk to the milk bank?

- ○ Yes
- ○ No

55a.1 How many friends have you encouraged to donate (enter number of people)?

55a.2 How many family members have you encouraged to donate (enter number of people)?

55a.3 How many other people did you encourage to donate (enter number of people)?

56. How many friends do you know that have donated breastmilk to the milk bank (enter number of people)?

57. How many family members do you know that have donated breastmilk to the milk bank (enter number of people)?

58. How many babies do you know who have received breastmilk donated to the milk bank (enter number of babies)?

59. I have shared my breastmilk with another baby.

- ○ Yes
- ○ No

59a. What were the reasons you chose to share your breastmilk, rather than donate it to the milk bank?

Demographics

60. What is your age in years?

61. What is your educational level?

- ○ No formal schooling completed
- ○ Less than grade 9
- ○ Some high school, no diploma
- ○ High school graduate, diploma or the equivalent (for example: GED)
- ○ Some college credit, no degree
- ○ Trade/technical/vocational training
- ○ 2 year college degree
- ○ Bachelor's degree
- ○ Master’s degree
- ○ Professional degree
- ○ Doctoral degree

62. What best describes your employment status?

- ○ Not currently employed
- ○ Employed Part time-for wages
- ○ Employed Part time but on maternity leave

- ○ Employed Full time-for wages
- ○ Employed Full time for wages but on maternity leave
- ○ Self-employed
- ○ A Homemaker
- ○ A Student
- ○ Other, please specify... _____

63. If you are employed, what sector do you work in?

- ○ Retail trade
- ○ Health Care and social assistance
- ○ Manufacturing
- ○ Educational service
- ○ Public administration
- ○ Professional, scientific and technical services
- ○ Construction
- ○ Accommodation and food services
- ○ Transportation and warehousing
- ○ Other Services (except public Administration)
- ○ Finance and insurance
- ○ Wholesale and trade
- ○ Administration and support waste management and remediation services
- ○ Agriculture, forestry, fisheries and hunting
- ○ Information and cultural industries
- ○ Arts, Entertainment and recreation
- ○ Real Estate and rental and leasing
- ○ Mining, quarrying and oil and gas extraction
- ○ Utilities
- ○ Management

- ○ Other, please specify... _____

64. What is your household income before taxes?

- ○ Less than $15,000
- ○ $15,001–$20,000
- ○ $20,001–$25,000
- ○ $25,001–$35,000
- ○ $35,001–$50,000
- ○ $50,001–$75,000
- ○ $75,001-$100,000
- ○ $100,001-$150,000
- ○ $150,000-$200,000
- ○ More than $200, 001
- ○ Prefer not to say

65. What is your relationship status?

- ○ Married
- ○ Widowed
- ○ Divorced
- ○ Separated
- ○ In a domestic partnership with a significant other (common-law)
- ○ Single

66. What culture do you most identify with?

- ○ Canadian
- ○ European
- ○ East European (Ukranian, Hungarian, Polish,etc.)
- ○ East Asian (Chinese, Japanese, Korean, etc.)

- ○ South Asian (Indian, Iranian/Persian, Afghan, etc.)
- ○ Aboriginal/First Nations
- ○ Southeast Asian (Indonesian, Cambodian, Vietnamese, Filipino, etc.)
- ○ Latin/South/Central American
- ○ African
- ○ Other, please specify _____

67. What religious affiliation do you most identify with?

- ○ Catholic
- ○ Protestant
- ○ Christian Orthodox
- ○ Christian not included elsewhere
- ○ Muslim
- ○ Jewish
- ○ Orthodox Jewish
- ○ Buddhist
- ○ Hindu
- ○ Sikh
- ○ Eastern Religions
- ○ No Religious Affiliation
- ○ Other, please specify... _____

68. How many children have you given birth to (enter number of children)?

Please use the following map as a reference for questions 69 and 70.

69. What health authority do you live in?

- ○ Fraser Health (e.g. Burnaby, Surrey, Fraser Valley, etc.)
- ○ Vancouver Coastal (e.g. Vancouver, Richmond, North Shore, etc.)
- ○ Interior Health (e.g. Williams Lake, Penticton, Lilloet, etc.)
- ○ Northern Health (e.g. Quesnel, Prince Rupert, Haida Gwaii, etc.)
- ○ Vancouver Island Health (eg. Campbell River, Gulf Islands, Greater Victoria, etc.)
- ○ Other, please specify (Province/State and Country)..... _____

70. What health authority was your youngest child born in?

- ○ Fraser Health
- ○ Vancouver Costal
- ○ Interior Health
- ○ Northern Health
- ○ Vancouver Island Health
- ○ Provincial Health Service Authority (BC Women's Hospital)
- ○ Other, please specify (Province/State and Country)... _____

71. What is the age of your youngest child today (enter number)?

Weeks ☐

Months ☐

72. At what age did your youngest child receive his/her first non-breastmilk meal?

Days ☐

Weeks ☐

Months ☐

If still breastfeeding, write N/A

73. Where did your youngest child receive his/her first non-breastmilk meal?

- ○ In hospital
- ○ At home
- ○ Out and about
- ○ Not applicable (e.g. still exclusively breastfeeding)

74. Do you have any other things you would like to share with the researcher?

Thank you for participating in this survey.

If you do not want to enter the draw, please click submit.

To enter the draw for one of six, $50 gift certificates please enter your name and email address below. If you are selected your gift certificate will be emailed to you.

Name

Email address

Appendix D - Pilot Study Participant Information Letter

Fraser Health Authority
Fraser Health Suite 400, Central City Tower
13450 – 102nd Avenue
Surrey, BC Canada V3T 0H1

The University of British Columbia
School of Nursing
T201-2211 Wesbrook Mall
Vancouver, BC Canada V6T 2B5

Phone 604 822 7747
Fax 604 822 7423
www.nursing.ubc.ca

Pilot Study Participant Information Letter

Hello,

My name is Damaris Grunert and I am a student in the Masters of Science in Nursing program at The University of British Columbia (UBC). I am working together with my supervisory committee:

Suzanne Campbell, PhD, RN, IBCLC (Lead Investigator-UBC)
UBC School of Nursing,
Telephone #: xxx-xxx-xxxx

Damaris Grunert, BSN, RN (Lead Investigator-Fraser Health Authority)
UBC Student
Telephone #: xxx-xxx-xxxx

Susan Dahinten, PhD, RN, MBA (Committee Member)
UBC School of Nursing UBC
Telephone #: xxx-xxx-xxxx

Lynne Palmer, MSN, RN, (Committee Member)
Fraser Health Authority
Telephone #: xxx-xxx-xxxx Local xxxxxx

Why are we doing this study?

As a mother of a child under the age of two living in British Columbia, Canada, we invite you to take part in this online survey. We are doing this study to improve a survey for a bigger study looking at women's thoughts around feeding their baby and giving their breast milk to the provincial milk bank. This study is part of a bigger study and will help identify problems taking the survey and any questions that are difficult to understand.

What happens if I want to participate?
Starting this survey will show that you have agreed to participate in this survey. Once you start you will be asked to answer an online survey that takes about 20-30 minutes to complete. A note pad will be provided. Please record on this pad any questions that are unclear, that you have a hard time understanding and any other problems or concerns with the survey, or survey process. The answers to your survey questions will not be included in the final study but will help inform the development of the final survey for the bigger study. This survey is confidential; all completed surveys will be kept private and will only be available to my supervisor and supervisory committee. Survey information will be gathered through the UBC survey tool, by Fluid Survey, which is hosted in Canada and complies with the British Columbian freedom of information and protection of privacy act.

Where can I find the results of this study?
The results of the larger research study will be published and available to the public as part of my thesis paper. No information or records that disclose your identity will be published. A summary of the results will be available on request from xxxxxxxxxxxxx.

Is there any way being in this study could be bad for you?
There are no expected risks to taking part in this study. Some of the questions may seem sensitive or personal as feeding choices can be a delicate topic for some mothers. If this is the case for you please note these on your pad of paper. Although the information you provide is highly valued, you do not have to answer any questions, you do not want to answer.

What are the benefits of Participating?
We do not think taking part in this study will help you; however in future, other mothers may benefit form what we learn in this and the larger study.

You will not be paid for your time to take this survey, but as a token of appreciation for your time and effort you will be given a gift certificate to either Chapters, or Best Buy for participating in the survey. You will need to sign an acknowledgement of receipt for this certificate, which will be kept separate from your survey answers and notes.

How will your identity be protected?
As a client of health authorities in BC, your personal information is subject to protections under the BC Freedom of Information and Protection of Privacy Act (FIPPA). To participate in this initiative as a survey respondent, you are being asked to consent to provide the following information for use by Dr. Suzanne Campbell, Dr. Susan Dahinten, Lynne Palmer and Damaris Grunert: Personal views opinions as expressed in the survey. These views and opinions are considered personal information. Access to your information is limited to the survey administrator. The survey administrator will maintain the survey, and provide a report based on the survey results.

Your confidentiality will be respected; the survey is completely anonymous and individual responses cannot be linked back to the participant. You do not need to answer any question you do not want to. Participation is voluntary. Initiating the survey will indicate willingness to

participate in this study and it will be assumed consent has been given. The study is confidential and you may withdraw at any time without penalty.

Research records may be examined in the presence of the research team, Health Canada, and the University of British Columbia / Fraser Health Authority Research Ethics Board (UBC/FHA REB) for the purpose of monitoring the research.

Who can you contact if you have any questions?

If you have any questions or concerns about what we are asking of you, please contact the study leaders or committee members. The names and telephone numbers are listed at the top of this form.

Who can you contact if you have concerns about this study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics toll free at 604-822-8598 or if long distance e-mail: RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

You may also contact those who monitor us Fraser Health REB co-Chairs by calling 604-587-4681. You may discuss these rights with one of the co-chairs of the Fraser Health REB.

Thank you for considering participating in this Survey,
Damaris Grunert

Appendix E - Participant Information Letter

Fraser Health Authority
Fraser Health Suite 400, Central City Tower
13450 – 102nd Avenue
Surrey, BC Canada V3T 0H1

The University of British Columbia
School of Nursing
T201-2211 Wesbrook Mall
Vancouver, BC Canada V6T 2B5

Phone 604 822 7747
Fax 604 822 7423
www.nursing.ubc.ca

Participant Information Letter

Hello,

My name is Damaris Grunert and I am a student in the Masters of Science in Nursing program at The University of British Columbia (UBC). I am working together with my supervisor and committee on a study entitled: Decision Making for Breastmilk Donors: Attitudes, Motivations and Barriers. The members involved in this study are:

Suzanne Campbell, PhD, RN, IBCLC (Lead Investigator-UBC)
UBC School of Nursing,
Telephone #: xxx-xxx-xxxx
Email: xxxxxxxxxxxxx

Damaris Grunert, BSN, RN (Co-Investigator)
UBC Student,
Telephone #: xxx-xxx-xxxx

Susan Dahinten, PhD, RN, MBA (Committee Member)
UBC School of Nursing,
Telephone #: xxx-xxx-xxxx

Lynne Palmer, MSN, RN, (Committee Member)
Fraser Health Authority,
Telephone #: xxx-xxx-xxxx Local xxxxx

Why are we doing this study?
As a mother of a child under the age of two living in British Columbia, Canada, we invite you to take part in this online survey. We are doing this study to learn more about your thoughts around feeding your baby and giving breastmilk to the Provincial Milk Bank. All mothers with a child

under the age of two are invited to participate, no matter how you feed/fed your baby (breastmilk or formula) and whether or not you donate/donated breastmilk.

What happens if I want to participate?

Starting this survey will show that you have agreed to participate in this survey. Once you start you will be asked to answer an online survey that takes about 15 minutes to complete. The survey is confidential; all completed surveys will be kept private and will only be available to myself, my advisor and committee. Survey information will be gathered through the UBC survey tool, by Fluid Survey, which is hosted in Canada and complies with the British Columbian freedom of information and protection of privacy act.

Where can I find the results of this study?

The results of the research study will be available to the public as part of my thesis paper, and may be published. No information or records that disclose your identity will be published. A summary of the results will be available on request from xxxxxxxxxxxxxx

Is there any way being in this study could be bad for me?

There are no expected risks to taking part in this study. Some of the questions may seem sensitive or personal as feeding choices can be a delicate topic for some mothers. Although the information you provide is highly valued, you do not have to answer any questions that you do not want to answer.

What are the benefits of participating?

We do not think taking part in this study will help you; however, in the future, other mothers may benefit from what we learn in this study.

You will not be paid for your time to take this survey but as a token of appreciation for your time and effort you will have a choice to enter a draw for a chance to win one of six gift certificates to Chapters, Best Buy or Amazon. You will be given the choice to enter for the draw by submitting your email address at the beginning of the survey.

How will my identity be protected?

As a client of health authorities in BC, your personal information is subject to protections under the BC Freedom of Information and Protection of Privacy Act (FIPPA). If you chose to participate in this survey, your views and opinions expressed are considered your personal information and access to this information is limited to the survey administrator and Dr. Suzanne Campbell, Dr. Susan Dahinten, Lynne Palmer and Damaris Grunert. The survey administrator will provide a report based on the survey results.

Your confidentiality will be respected; the survey is completely anonymous and individual responses cannot be linked back to you. You do not need to answer any question you do not want to answer. Participation is voluntary and you may withdraw at any time without penalty. Initiating the survey will indicate willingness to participate in this study and it will be assumed

consent has been given. A study number, not your name or other identifying information, will be used with your information and it will be kept on password-protected computers, in password-protected files. If you enter the draw to win a prize, your email address will be kept separate from your survey data and will be deleted as soon as the gift certificates have been distributed.

Research records may be examined in the presence of the research team, Health Canada, and the University of British Columbia / Fraser Health Authority Research Ethics Board (UBC/FHA REB) for the purpose of monitoring the research.

If you have accessed this survey through Facebook or another social media site please be reminded that any comments you post on these sites may be visible to the public. Encouraged you understand your individual privacy settings for use of these sites. If you came directly to this survey by accessing the link on the Poster Advertisement or Business Card Recruitment Notice, you have been taken directly to this survey, bypassing any of the social media sites.

Who can I contact if I have any questions?

If you have any questions or concerns about what we are asking of you, please contact either myself at xxx-xxx-xxxx or my supervisor at xxx-xxx-xxxx or email at xxxxxxxxxxxxxx as noted at the top of this form.

Who can I contact if I have concerns about this study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics toll free at 604-822-8598, or if long distance e-mail: RSIL@ors.ubc.ca or call toll free 1-877-822-8598. You may also contact those who monitor us, the Fraser Health Research Ethics Board (REB) co-chairs, by calling 604-587-4681.

Thank you for considering participating in this survey. By completing the questionnaire, you are consenting to participate in this research.

Sincerely,

Damaris Grunert