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Mothers Voices: The Lived Experience of the Human Milk Banking Association of North America Milk Donor

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Laura Marie Dambra-Candelaria

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Abstract

Objectives: The purpose of this study was to examine the lived experience of the milk donor who donated milk to a hospital-based bank regulated under the policies and procedures set forth by the Human Milk Banking Association of North America (HMBANA). The literature has examined and established the life-saving benefits of donor milk for the vulnerable infant. Currently, there is a shortage of donor milk available for vulnerable and premature infants. Learning more about the experience of donation from the perspective of the donating mother can aid in the future education, recruitment, and retention of donors.

Method: This study utilized a qualitative phenomenological approach to describe the experience of the donor. Donors approved through the Human Milk Banking Association of North America were selected for this study at the Children's Hospital of Philadelphia. Participants were interviewed using a face-to-face semi-structured interview format. Edmund Husserl's philosophical framework and Colaizzi's method of data analysis were utilized. The voices of women who lived the experience of donating their milk illuminated the essence of the phenomenon.

Results: Four themes illuminated the phenomena of donation: A Ripple of Hope and Help, The Dynamic Interplay of Nurturance, Standing on The Shoulders of Others, and Sharing Their Story. The first theme expressed the ripple effect of the positive emotions experienced by each participant. The dynamic interplay of nurturance demonstrates the participants' knowledge that her donation is helping another infant and family, and how that leads to her feeling good while acting as a motivating factor. The third theme, standing on the shoulders of others, illuminates the staff as the central facilitating factor in donation, and helps us understand the elements of that relationship. Lastly, every participant wanted to share their story and teach others about donation because they wanted other women to have the same experience. Donation was described as a positive, valuable, and nurturing experience that motivated donors to continue. This study illuminated the positive emotional experiences associated with milk donation.

Dedication

To Rosetta Marie Dambra. This was your dream for me. Well, we did it! I love and miss you more than words can express. *Amor di madre, amore senza limiti…..*

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Chapter One: Introduction

Introduction and Research Goal

Human milk donation (HMD) is a process by which a breastfeeding woman donates pumped milk to be used for a child other than her own. There are several ways for a woman to donate her milk. Donors may choose to donate informally, through word of mouth, or online. In such cases, donors may or may not be screened, and milk is not pasteurized or tested. Another method of donation includes donation to the Mothers Milk Cooperative (MMC), a cooperation owned and democratically controlled by its members, the people, who use the co-op's services or buy its goods, not by outside investors (Mothers Milk Cooperative [MMC], 2017). According to MMC (2017), those who donate chose their first 100 ounces to cover qualification expenses. Subsequently, donors are paid $1.00 per ounce for milk that meets the quality criteria. Donation to for-profit companies, such as Prolacta Bioscience, is a method in which donor milk is used to make specialized formulations made from human milk for vulnerable infants (Prolacta Bioscience, 2014).

In 1985, the Human Milk Banking Association of North America (HMBANA) was established, with one of the main goals being to develop standards for all North American milk banks (HMBANA, 2016). Prior to donating, a HMBANA donor must undergo a series of medical and laboratory tests, as well as a medical interview to ensure that she is a healthy

candidate. After medical interview and testing is complete, the potential donor is approved for donation to a milk bank. Once received, donor milk is pasteurized and cultured for bacterial growth. Following processing and negative cultures, donor milk can be shipped to hospitals or infants at home who were prescribed donor milk.

Current literature supports that human donor milk is essential for preterm and other vulnerable infants, as it protects them from infection (Ahrabi, Faraghi & Schanler, 2013). In many hospitals across the United States, donor milk has become integrated into practice as a standard of care for vulnerable infants. Yet more needs to be understood regarding this process and the women who come forward to donate this vital and scarce resource.

According to the HMBANA, the roots of donor milk banking date back to 2250 BC, when children were breastfed by friends, relatives, or strangers, a practice referred to as "wet-nursing" (HMBANA, 2016). In 1909, the first human milk bank was established in Vienna, Austria, with the second to follow in the United States in Boston in 1919 (HMBANA, 2016). The use of banked donor milk was first mentioned in medical literature in 1914, when ill children were seen to fare better when fed human donor milk (Miracle, Szucs, Torke & Helft, 2011). According to HMBANA (2016), during the mid-1980s, there was a rapid decline in the number of milk banks in the United States due to concern regarding the human immunodeficiency virus (HIV). The number of milk banks in the United States is now

increasing. The American Academy of Pediatrics (AAP)'s (2012) position statement recommends that if a mother's own milk (MOM) is unavailable or its use is contraindicated, that pasteurized human donor milk (PHDM) appropriately fortified should be used (AAP, 2012). This position statement was updated in 2016 to include education regarding dangers of informal milk sharing and a call for policies to provide high-risk infants access to donor human milk based on documented medical necessity, not financial status (AAP, 2016).

In a systematic review and meta-analysis, Boyd, Quigley and Brockelhurst (2007) discussed the advantages of human milk for the preterm infant over commercial formula which include the presence of active enzymes that enhance maturation of the underdeveloped gut, an earlier tolerance of full enteral feedings, and anti-infective properties which protect against infection (Boyd et al., 2007). According to Edwards and Spatz (2012), PHDM should be used as a supplement to mother's own milk or in place of infant formula for vulnerable infants.

HMBANA reported an urgent need for milk donors due to a shortage in the overall supply of available milk. It has been a challenge for milk banks to increase the volume of donations to meet the ever-increasing need for donor milk (Thomaz, et al., 2008). In 2013, 3.2 million ounces of donor milk were collected and distributed in the United States; however, current national need is at 9 million ounces (HMBANA, 2014). Increasing awareness among healthcare professionals and lactating women may help increase the number of women who

consider using and or donating human milk. There is an understanding of the importance of donor human milk for the vulnerable infant for greatly improving health outcomes; however, what is lacking is an understanding of the experience of the donor, which is my primary research goal for this study. When understood, such information may aid in the creation of educational interventions and recruitment strategies to increase current supply to the level needed to meet infant demand.

Although a substantial body of literature has addressed the physiological benefits of donor milk for the infant, paucity exists regarding the psychosocial benefits for the donating woman. Britton and Britton (2008) discussed two studies in which breastfeeding mothers scored higher on several individual dimensions of self-concept, notably those reflecting self-satisfaction, behavior, moral worth, value as a family member, and physical appearance. In the studies discussed by Britton and Britton, which took place in separate populations in Utah and Arizona, they noted that breastfeeding women had a higher self-concept than those who formula fed. A better understanding of the experience for the mother who opts to donate her milk may lead healthcare providers to interventions to increase self-concept, enhanced breastfeeding, and mothers wishing to donate.

A mother's degree of ego or self-development appears to influence maternal-infant interaction and attachment and is related to feelings of nurturance, empathy, and enjoyment of

children (Britton & Britton, 2008). Other important psychological variables for a breastfeeding woman include self-esteem and self-efficacy, which are concerned with judgments of personal capability and self-worth (Bailey, Clark & Sheperd, 2008). Papinczak and Turner (2000) found that breastfeeding duration was significantly associated with maternal self-esteem as well as breastfeeding self-confidence. Understanding the experience of the mother who donates her milk to a HMBANA milk bank may provide added insight into such concepts, which is my goal in this research study.

Dennis (2003) first proposed the use of a Breastfeeding Self-Efficacy Scale (BSES) to measure maternal confidence, which has been positively associated with breastfeeding duration. Consequences of self-efficacy that lead to the maintenance of the behavior are enjoyment, persistence, and the use of a positive internal dialogue. Breastfeeding self-efficacy is a salient variable in breastfeeding duration, as it predicts whether a mother chooses to breastfeed, how much effort she will expend, whether she will persevere until mastery is achieved, whether she will have self-enhancing or self-defeating thought patterns, and how she will emotionally respond to difficulties (Dennis, 2003).

The concepts of self-esteem, self-concept, and self-efficacy are essential to understanding the essence of the experience of the donating mother. If breastfeeding increases such concepts, this study could help shed light on the donor as we move forward towards developing a greater

understanding of this phenomenon. As post-natal breastfeeding self-efficacy is predictive of duration, there is also a predictive relationship between antenatal breastfeeding self-efficacy scores and breastfeeding outcomes (Bailey et al., 2008). There is a dearth in the literature regarding these concepts in relation to women who donate their milk to another infant, which speaks to the necessity of understanding the experience of the donating mother.

Benefits of Human Milk

Infants who are not breastfed have increased incidence and severity of infections including respiratory tract infections, otitis media, diarrhea, bacterial meningitis and sepsis, increased rates of sudden infant death syndrome and post neonatal death, and increased risk of chronic illness as adults, such as obesity and diabetes (Spatz & Lessen, 2011). Ehrenkranz Dusick, Vohr, Wright, Wrage, Poole (2006) studied neurodevelopmental and growth outcomes in vulnerable infants, and noted an increase in developmental outcomes at 18 months of age in extremely low birth weight (ELBW) infants with a diet in the 80th percentile compared with a diet in the 20th percentile for human milk intake. In addition, in their UK-based study, Isaacs, Fischl, Quinn, Chong, Gadian, and Lucas (2010) reported a significant correlation between the percentage of human milk consumed by the preterm infant and the brain and white matter volume on magnetic resonance imaging performed in a follow up at 13 to 19 years of age, as well as positive correlation in verbal IQ scores during adolescence.

Human milk contains bioactive agents, which contribute to the maturation of gastrointestinal function and protect against inflammation (Ballard & Morrow, 2013). Necrotizing enterocolitis (NEC) is a complex disease process in which the lining of the intestinal wall becomes necrotic and dies. Infants who are formula fed are at an increased risk of developing this condition (Stuebe, 2009). Formula does not contain the immunological and bioactive properties present in human milk, and therefore does not offer the same protection against disease.

Arslanoglu, Ziegler and Moro (2010) discussed clinical benefits of donor human milk for vulnerable infants. Human milk contains oligosaccharides, which are multi-functional bio-molecules that modulate immunity as they exert a prebiotic function, and act as epithelial receptors for specific microbes, preventing their adhesion to the intestinal walls, which provides a protective effect against NEC (Arslanoglu et al., 2010). In 2012, the Centers for Disease Control and Prevention (CDC) published statistics from 2010 regarding the leading causes of infant mortality (CDC, 2012). NEC is the 10th leading cause of infant death in the United States (CDC, 2010). According to The Economic Benefits of Breastfeeding: A Review and Analysis published by the United States Department of Agriculture (USDA), the incidence of NEC in exclusively breastfed low-birth weight (LBW) infants was 1 percent, compared to an incidence of 7 percent in formula-fed LBW infants (Weimer, 2001). According to Weimer, data indicated

that the average length of stay at a hospital for an infant with NEC was 38.9 days, at an average cost of $118,240 (physician's charges not included). This disease places a large financial burden on the U.S health care system, and therefore has become a major public health issue. If we could better understand the experience of the donating mother, we could create and implement strategies to increase supply. One could assume that such intervention could lessen the burden on an already struggling health care system.

Infants who develop NEC face many challenge's including but not limited to: sepsis, intestinal perforation, intestinal stricture, peritonitis, and colostomy or ileostomy placement following surgical removal of the necrotic bowel (Gregory Deforge, Natale, Phillips, & Van Marter, 2011). Infants who survive NEC are at a higher risk for developing long-term complications such as significant growth delay and adverse neurodevelopmental outcomes (Gregory et al., 2011). The long-term costs over the lifetime of a child who survives NEC is a monumental issue in public health, as they may require therapies and special services throughout the course of their lives (Ganapathy, Hay & Kim, 2012). Therefore, increasing the number of infants who receive pasteurized donor human milk (PDHM) could decrease health care costs and improve health outcomes for this vulnerable population (Ahrabi et al., 2013).

Choosing a method of feeding is of critical importance for the vulnerable infant. Human milk supplies the newborn with a multitude of protective elements essential for supplementing

host defense systems (Cilieborg, Boye, & Sanglid, 2012). Human milk contains active enzymes that enhance the maturation of the underdeveloped gut, and has anti-infective properties, which protect the newborn from infection (Boyd et al., 2007). Edwards and Spatz (2012) discussed the immunological components in human milk responsible for protection and maturation of the gastrointestinal tract, which include (alpha)-lactalbumin, epidermal growth factor (EGF), immunoglobulin A, lactoferrin, lysozymes, oligosaccharides, and albumin. Therefore, the immunological properties of human milk supplement the vulnerable infant's immune system and offer protection from NEC.

Specific Aims

The Surgeon General released *The Surgeon General's Call to Action to Support Breastfeeding* with action 12 stating, "Identify and address obstacles to greater availability of safe banked donor milk for fragile infants" (Office of the Surgeon General, 2011, p. 49). In other countries, donor milk banking is considered preventative medicine and is highly regarded, with a wealth of documentation to support promotion, protection, and support of donor milk banking as an integral part of child health and survival (Arnold, 2006). My specific aims in this research study support the strategic objective of the National Institute of Nursing Research (NINR) to promote health and prevent disease by identifying "factors that influence decision-making that results in behavioral changes that promote health and prevent disease" (NINR, 2010, p. 10).

Therefore, outcomes of this study will identify which social and behavioral factors contribute to a woman's decision to repeatedly donate her milk.

Healthcare professionals should be adequately prepared to proficiently educate their patients regarding the benefits associated with PHDM and the opportunity of donation. Spatz (2006) discussed the importance of quality care for the mother-infant dyad during infant illness, requiring vigilant monitoring of the lactation experience and the commitment of healthcare providers to take a family through the process needed to ensure positive outcomes related to the use of human milk for vulnerable infants. The gap must be bridged between the comprehensive research that exists regarding the importance of human milk, and the knowledge that nurses possess (Spatz & Pugh, 2007).

Mothers of vulnerable infants require specialized care and education, as human milk is essential for vulnerable infants. Mothers need and want professional advice regarding lactation for term and preterm infants, so that they can use this information to make the best choice for themselves and their infants (Miracle, Meier, & Bennett, 2004). Pasteurized human donor milk is a suitable alternative for mothers who are unable or unwilling to provide their own milk, and can be regarded as preventative "medicine" for the vulnerable population by reducing the incidence of NEC and optimizing central nervous system development (Arnold, 2006).

For milk banks to thrive and meet current supply and demand, there needs to be an adequate number of women donating their breast milk. In 2007, there were 133 hospitals across North America receiving human donor milk from one of the HMBANA milk banks (Miracle et al., 2011). In addition to using donor milk for vulnerable infants, there is a growing trend for physicians to order PDHM for older infants and toddlers for a variety of health conditions, which is leading to competition for this scarce resource (Miracle et al., 2011).

This study examines the lived experience of the milk donor to further develop an understanding of the psychosocial and emotional ramifications associated with the experience of donating one's milk. Understanding the donor's experience can aid in developing donor recruitment and retention strategies, which could lead to an increase in supply so that more infants will benefit from PDHM. It is imperative for clinicians to gain an understanding of the thoughts, emotions, and experiences of the milk donor so we can move forward towards a national initiative to increase the supply to the level needed for the current clinical environment (Miracle et al., 2011). Examining and understanding the essence of the lived emotional experience of this population will enable nurses to educate and support women in their choice to donate.

Study Approach

Specific aims of this study included expanding the body of knowledge surrounding the lived experience of HMD, as well as generating an understanding of the innate maternal emotions related to initiation of, and continued donation. I utilized qualitative phenomenology to further understand the lived experience of the woman who donates her milk to a HMBANA bank. In doing so, I captured the voices of women who donated milk to describe their thoughts and experiences before, during, and following the donation process. A deficit in the literature exists, as researchers have documented the significance of HDM and its role in infant health and mortality, but have failed to elucidate the thought processes and lived experience of the women who come forward to donate. Such information is vital, as continued efforts to understand the correlates of the maternal thought process, beliefs, and attitudes related to donation can lead us to creating better interventional strategies, increasing the number of women who donate. It also leads to uncovering additional variables and contextual factors necessary to facilitate the donation process for a breastfeeding woman.

The grand tour question for this study was, "What is the lived experience of women who donate their milk to a HMBANA milk bank?" A sub question of this study was, "Is there is a changing dynamic in the perception of one's self during and following milk donation to a HMBANA milk bank?" Donors had the opportunity to share their thoughts, views, and feelings

related to the phenomenon of interest. Women participated in individual interviews, which helped elicit information regarding factors that prompt the initiation and continuance of donation, barriers to the process, and the psychosocial and emotional consequences of the methodology of human milk donation.

Study Significance

Although donor milk banking thrives in other countries, it is still not widely accepted in the United States. In countries where donor milk banking is protected, promoted, and supported as an extension of national breast-feeding policies, milk banking is considered an effective part of health care delivery for infants and children (Arnold, 2006). Not being fed human milk is associated with an increased incidence of infectious morbidity, as well as elevated risks of childhood obesity, Type 1 and Type 2 diabetes, leukemia, necrotizing enterocolitis, and sudden infant death syndrome (Stuebe, 2009).

Health care providers should ensure that breastfeeding and human milk are priority in the Neonatal Intensive Care Unit (NICU), and that families be encouraged to meet their personal goals for providing human milk to their child (Spatz, 2012). The current clinical environment lacks the amount of donor milk in reserve to provide for infants in need, as current need demands 9 million ounces with only 3.2 million ounces collected in 2013 by HMBANA milk banks (K. Updegrove, personal communication, October 14th, 2014). Increasing the number of donors to

HMBANA milk banks is essential for meeting clinical demand. The development of an understanding of the lived experience of the milk donor may aid in bridging the gap between supply and demand.

To meet current national demand for donor milk, there needs to be an increase in the numbers of women who come forward to donate. Education and increased awareness regarding the concept of HMD and the associated maternal experience is a step in the right direction. Published evidence suggests that many nurses and physicians are not well-informed about breastfeeding topics, and that conflicting advice from providers can deter the use of PHDM (Woo & Spatz, 2007). Data regarding the psychosocial and emotional experience the education of donor mothers is lacking. This study is significant, as it adds to the body of knowledge on the maternal psychosocial experience that occurs with human milk donation to a HMBANA milk bank.

The remainder of this document will chronicle the related literature pertaining to human milk donation, and specifically, the lived experience of the donating mother. In addition, I will review literature appropriate to the history, process, costs, and ethical considerations regarding human milk donation. I will present methodological design choices and analysis decisions in Chapter Three. I will also include pertinent information regarding the studys participants. In

Chapter Four, I will present the study's findings as well as an exhaustive description of the phenomenon of donation. Furthermore, in Chapter Four, I will also highlight the essential structure of the maternal donation experience. In Chapter Five I will will focus on the study's conclusions, implications, and recommendations for future research.

Chapter Two: Literature Review

Historical Perspectives

Prior to the 20th century, babies were breastfed by their own mothers. When a mother's own milk was unavailable, the mother would utilize a wet nurse. Use of a wet nurse, "a woman who breastfeeds another's child" (Davis, 1993, p. 2111) was a common practice before the introduction of the feeding bottle and formula. Historically, wet nurses came from the ranks of poor, single mothers, who were employed by wealthy families to breastfeed their babies (Golden, 1996). This led to early commodification of human milk in which wet nurses would receive $25 to $100 a month for their milk (Golden, 1996). Wet nursing began as early as 2000 BC and extended until the 20th century, becoming a well-organized profession with contracts and laws designed to regulate its practice (Stevens, Patrick & Pickler, 2009).

According to Jones (2003), by the early 20th century, it was becoming increasingly difficult to maintain the services of wet nurses, which led physicians to ask lactating women to express extra milk for use in feeding sick and preterm infants. In 1902, one physician noted that human milk going to waste should be utilized, while another wrote that ill children do much better if they are fed wholly or in part on human milk and that donor banked human milk reduced the incidence of infection (Jones, 2003). Such knowledge led to the creation of operational milk banks.

The first donor milk bank on record was founded in Vienna in 1909, with the second opening in Boston, and the third in Germany (Jones, 2003). According to Golden (1996), the Boston milk bank was the first milk bank on record in the United States. In 1908, Dr. Fritz Talbot, a physician from Massachusetts, spent days riding street cars in search of wet nurses to provide milk for a sick infant in his care (Talbot, 1913). Later, Talbot realized he had "traveled many miles and wasted a lot of time" (p. 760) which led him to open the Directory For Wet Nurses in 1910, that further evolved into the first operational donor milk bank (Talbot, 1913). During its first summer operating season, the Boston Floating Hospital, so called because it served its patients on a boat that sailed Boston Harbor, collected four quarts of human milk each day; the following year collected over 200 quarts; and by 1915, it distributed 368.5 quarts during one 80-day period (Golden, 1996).

According to Golden (1996), by 1929, milk banks existed in at least 20 cities, sometimes as a part of a hospital or as independent services led by child welfare organizations. Many early banks compensated donors financially and charged recipient hospitals, with donors receiving an average monthly wage of $28, with the cost to recipients varying from $0.10 to $0.30 per ounce (Jones, 2003). Throughout the developed world, donor milk banking began to grow as pediatrics progressed, and increasing numbers of vulnerable and preterm infants began to thrive.

In the 1980s, the emergence of HIV led to the closing of several milk banks due to fears related to disease transmission (HMBANA, 2014). The 1980s also brought the marketing and refinement of commercially prepared premature and specialty infant formulas (Miracle et al., 2011). In 1985, HMBANA was formed with the purpose of developing standards for milk banks across North America and Canada (HMBANA, 2014). By the 1990s, with additional evidence of safety and increased research on the benefits of human milk, the number of donor milk banks began to rise (HMBANA, 2014).

Benefits of Human Milk for Vulnerable Infants

The benefits of human milk for the vulnerable infant have been well documented in the literature. Mother's milk protects infants from costly and handicapping morbidity, and is readily available and virtually risk free (Rodriguez, Miracle & Meier, 2005). According to the American Academy of Pediatrics (AAP) Policy Statement on Breastfeeding and the Use of Human Milk, infants who are fed human milk have a decreased risk of infectious morbidity, including otitis media, allergic disease, gastroenteritis, necrotizing enterocolitis and pneumonia, as well as decreased risks of childhood obesity, diabetes, leukemia, and sudden infant death syndrome (AAP, 2012).

According to Rodriguez et al. (2005), additional health benefits of a human milk diet include improved visual acuity and higher scores on tests of neurocognitive outcomes. The

oligosaccharides in human milk prevent common respiratory pathogens from attaching to the respiratory epithelium, such as Haemophilus influenzae and Streptococcus pneumoniae, while lipids in human milk appear to have antiviral activity against respiratory syncytial virus (RSV); RSV accounts for a majority of respiratory hospitalizations for vulnerable infants (Stuebe, 2009).

Research by Deoni, Dean, Piryatinsky, O'Muircheartaigh, Waskiewicz, Lehman and Dirks (2013) investigated brain white matter maturation in 133 healthy toddlers, with results pointing to improved developmental growth and increased development in late maturing white matter regions in infants who received a human milk diet. Kotey and Spatz (2013) discussed white matter injury in preterm infants, and explored the importance of human milk in slowing and preventing cerebral white matter injury, a common occurrence in pre-term infants. Isaacs et al. (2010) studied the impact of human milk on IQ, brain size, and white matter development, and found that human milk promotes brain development, particularly white matter growth. These studies demonstrate that infants fed a human milk diet score higher on tests of cognitive function than those who are formula fed, with premature and vulnerable infants deriving the greatest benefit (Anderson, James, Bryan, Johnstone & Remley, 1999). Surgical necrotizing enterocolitis has been shown to be associated with adverse neurodevelopmental outcomes at 18-24 months, which lends to the importance for this population to receive a diet comprised of human milk (Unger Gibbins, Zupancic, & O'Connor, 2014).

Twigger Hodgetts, Filgueira, Hartmann, and Hassiotou (2013) discussed the recent discovery of breast milk stem cells providing new grounds to support the argument that benefits to infants may extend well beyond immunological protection, as it has spurred scientists to investigate their potential functions in the development of the infant's brain and other organs. The involvement of the major constituents of breast milk on brain development, including evidence of increased white matter volume in infants fed human milk versus delayed brain messaging in formula-fed infants, suggests improved functional performance in infants fed a human milk diet (Deoni et al., 2013). Considering the previously mentioned neurocognitive, immunological, and unknown benefits of a human milk diet for the vulnerable infant, it obviates the necessity to examine the essence of the maternal experience to foster increased donation, which may increase the supply of human milk for this vulnerable population.

Human milk contains immunological components including (alpha)-lactalbumin, epidermal growth factor (EGF), immunoglobulin A, lactoferrin, lysozymes, and oligosaccharides, as well as the nutritional components (alpha)-lactalbumin, casein, glucose, lactose, and sodium, and the developmental components docosohexaenoic and arachidonic acid (Edwards & Spatz, 2012). The components in human milk contribute to gastrointestinal maturity and improved feeding tolerance for the low-birth weight and vulnerable infant (Sisk, Lovelady, Gruber, Dillard, & O'Shea, 2008). Human milk also supplies acetylhydrolase that itself has been

shown to block platelet aggravating factor, a major trigger in the uncontrolled inflammation called NEC (Maffei & Schanler, 2016). In a study by Sisk et al. (2008), infants who were fed a higher proportion of human milk reached full enteral feedings before those fed a lower concentration. Infants who received at least 50 ml/kg per day of human milk during hospitalization had fewer episodes of feeding intolerance and required a shorter time to reach full enteral feedings (Sisk et al., 2008).

Necrotizing enterocolitis (NEC) is a leading cause of morbidity in the vulnerable and premature infant. Boyd et al. (2007) reported that donor human milk (DHM) versus formula provides a protective effect against NEC. According to Rodriguez et al. (2005), the multitude of components in human milk protects the infant from NEC by preventing, mediating, and repairing inflammation in the bowel wall, and by preventing the overgrowth of bacteria. In 2007, Heiman and Schanler reported that infants who receive formula instead of human milk are 6.5 times more likely to develop NEC. Kantorowska Wei, Cohen, Lawrence, Gould, and Lee (2016) reported donor milk use was associated with lower rates of NEC in very low birth weight infants, reporting a 2.6 % decrease in NEC rates when DHM was. Furman Taylor, Minich, and Hack (2003) reported that in a sample of 202 extremely low birth weight infants, if their diet consisted of more than 50% mothers own milk (MOM) in the first 14 days, there was an 83% reduction in subsequent development of NEC compared with a diet of less than 50% MOM. In a large

retrospective analysis of 1,272 infants, the likelihood of NEC or death after 14 days was decreased by a factor of 0.83 for each 10% increase in the proportion of their total intake of human milk, suggesting the importance of dose and the predominance of a human milk diet (Meinzen-Derr Poindexter, Wrage, Morrow, Stoll, & Donovan, 2009). Maffei and Schanler (2016) reported that the declining rates of NEC in the vulnerable infant population were most likely a result of the increased utilization of DHM.

Benefits of Pasteurized Donor Human Milk for Vulnerable Infants

There is limited data on the benefits of PDHM versus commercial formula in the vulnerable infant population. In a Cochrane review of nine randomized controlled trials, Quigley and McGuire (2014) reported that in preterm and low birth weight infants, feeding with formula compared with donor human milk resulted in a higher rate of short term growth, but also a higher risk of developing necrotizing enterocolitis. In a randomized clinical trial of 840 infants from 4 neonatal units in Ontario Canada, a reduction in NEC rates in the donor milk group was consistent with findings by Quigley and McGuire, further suggesting donor milk offers additional protection against NEC (O'Connor et al., 2016). In a systematic review and meta-analysis, Boyd et al. (2007) found that donor human milk was associated with a lower risk of NEC as well as fewer episodes of feeding intolerance. Lucas et al. (1984) found a lower risk of mortality at ages 9 months and 18 months in donor milk-fed infants compared to formula-fed

infants. Other researchers found that infants fed donor milk had significantly fewer episodes of mild diarrhea in the first two weeks after birth (Schultz, Soltesz & Mestyan, 1980).

Arslanoglu, Bertino et al. (2010) have observed a reduction in the incidence of sepsis and of bronchopulmonary dysplasia. Data from the Italian Neonatal Network (INN) showed that in NICUs, exclusive breastfeeding at discharge was achieved for nearly 30% of neonates when banked milk was available during hospitalization, and for only 16% when it was not (Bertino et al., 2013). According to Quigley Henderson, Anthony, and McGuire, (2007) additional randomized controlled trials are needed to compare feeding with formula versus nutrient fortified donor human milk in vulnerable infants.

Cultural Perspectives

The World Health Organization, the American Academy of Pediatrics, the Canadian Pediatric Society, and the Israeli Paediatric Association, all recommend exclusive breastfeeding for the first 6 months of life (Kassierer, O'Connor, Rutherford, Rolnitzky, & Unger, 2014). In cases when a vulnerable infant is in need of human milk and mother's own milk is unavailable, PHDM may be a viable option; however, this may pose a challenge in families of certain faiths. Developing knowledge of such beliefs is essential for the nurse to provide culturally competent care in the maternal-child setting.

Ozdemir Ak, Karatas, Ozer, Dogen, and Karadag (2014) studied 401 religious officers in Turkey, and found that 63.3% were in favor of administering PHDM when human milk is unavailable from an infant's mother; however, only 1.7% advocated the use of Western-style human milk banks, as the identities of donors should be known by recipient families. This is related to the concept of milk siblingship, which can be either religious or secular, depending on the culture and setting (Thorley, 2014). According to El-Khuffash and Unger (2012) in Islamic tradition, the introduction of HDM to the infant establishes "milk kinship," thus posing a challenge to people of the Islamic faith. Muslims believe that accepting HDM establishes a kinship between the donor mother and recipient in which children of the donor mother and recipient infant are regarded as siblings and are therefore not allowed to marry one another (El-Khuffash & Unger, 2012). Thorley (2014) discussed this as an element of the consanguinity laws in Islam, religious laws setting prohibitions for Muslims on who can marry whom to prevent incest. In some Muslim nations where hospitals provide donor milk from a single donor (not pooled) to infants, the donor and recipient families can meet to agree that their offspring cannot marry (Ghaly, 2012). The thought of Western-style milk banking in these areas is of concern, as milk is pooled from multiple donors, therefore creating unknown kinships.

In 2004, the European Council for Fatwa and Research (ECFR) issued a decree permitting the use of DHM for infants when provisions for identifying the donor are not in place,

citing this does not establish kinship, as the Quran forbids marriage between those who have "suckled at the breast" of the same woman; therefore milk provided through feeding tube or bottle does not institute kinship (Ghaly, 2012). According to EL-Khuffash and Unger, (2012) no formal process exists to announce the decree, as Muslim families may not be aware of its existence; at the current time, Muslim countries are considering plans for the development of milk banks as a result of its issuance.

Thorley (2014) discussed the concept of milk siblingship throughout history, originating in the eastern Mediterranean and Caucasus with similar beliefs discussed in Greece, Turkey, Poland, France, Iran, and Australia, where there is conviction of the bond created by individuals receiving the same milk. Observant Jews also have specific guidelines regarding wet nursing and milk donation. According to Kassierer et al. (2014) human milk is exempt from dietary laws, and is permitted from women regardless of whether they keep kosher; however, some rabbinical authorities consider it preferable for a milk donor to keep kosher, as it is believed that what people eats affects their soul. The *pikuach nefesh,* or preservation of life, is an overarching law in Judaism; this principal provides for breaking all other Jewish laws if needed for the critically ill in order to preserve life (Kassierer et al., 2014). Therefore, providing DHM from a non-kosher donor would be considered if it were of critical importance for the infant's health.

Observant Jews may request donor milk from a kosher mother; however, donor milk from HMBANA banks is pooled, making such a request unfeasible. According to Kassierer et al. (2014), signed consent for DHM cannot be obtained during *Shabbat*, as writing is prohibited, so verbal consent may be required in an emergent situation. Prior to initiating a discussion on milk donation, healthcare professionals need be aware of such dietary and religious laws to provide culturally competent education and care to promote and sustain donation within the observant Jewish population.

According to Arnold (2006), donor milk banking thrives in other countries such as Brazil, where there has been a concerted effort to incorporate milk banks into health policy, as it is protected and supported as an effective part of their health care system. Brazil has the largest number of milk banks to date, with over 181 donor banks across the country, with a bank located in every state (Thomaz et al., 2008). According to Tully (2002), in the state of Brasilia, fireman collect milk from the homes of donors and deliver it to milk banks, and the national breastfeeding promotion program trains letter carriers around the country to provide breastfeeding advice and information. As of 2010, milk banking systems are available in France, the United Kingdom, Venezuela and the Caribbean, India, Russia, Italy, China, Australia, Kuwait and Africa, as well as several other countries (International Milk Banking Initiative [IMBI], 2010).

IMBI is a group of milk banks and health care providers interested in establishing an international association of non-profit milk banks globally through the development of better communication (IMBI, 2010). The IMBI was founded at the International HMBANA Congress held in Washington DC in 2005, with a mission of promoting ethical and safe accountable human milk banking across the globe, promoting HDM as the optimal choice for a vulnerable infant when mother's own milk is unavailable, facilitating international links between banks, and promoting and supporting ethical research into HDM (IMBI, 2010). There is paucity in the literature regarding human milk donation. Because there are so few milk banks in the United States as opposed to other countries, healthcare professionals are seldom exposed to the phenomenon of milk banking (Woo & Spatz, 2007). This lends to the importance and significance of this study.

Donor Milk Banking Policies and Procedures in the United States

HMBANA is a professional association that provides guidelines for non-profit milk banks across the United States and Canada. The mission of the HMBANA organization is to develop guidelines for donor human milk banking practices, provide a forum for information sharing among professionals, provide information to the medical community, encourage research of the properties of human milk, assure adequate distribution of human milk, and to act as a liaison between member banks and governmental agencies (HMBANA, 2016).

As per HMBANA (2016), the screening process for a donating mother begins with a short telephone interview to determine eligibility. Donating mothers must be in good health, not regularly on most medications (except for prenatal vitamins, human insulin, thyroid replacement hormones, nasal sprays, asthma inhalers, topical treatments, eye drops, and low dose birth control pills), willing to undergo blood testing at the milk bank's expense, and willing to donate a certain number of ounces of milk during their infant's first year of life (HMBANA, 2016). A woman would not be a suitable donor if she uses illegal drugs, smokes, has received a blood transfusion in the last 4 months, has received an organ or tissue transplant in the last 12 months, regularly drinks more than 2 ounces of alcohol per day, or is positive for HIV, human T-lymphotropic virus (HTLV), hepatitis B or C, or syphilis (HMBANA, 2016). Additionally, if a woman's partner were at risk for HIV, if she had been in the United Kingdom for more than 3 months from 1980-1996, or has been in Europe for more than 5 years since 1980, she would not be considered for donation (HMBANA, 2016).

As previously stated, human milk is pasteurized using the Holder method of pasteurization. Once milk is received from a donor, it is poured from milk storage containers into glass flasks and then mixed with milk from 3 to 5 donors to ensure an even distribution of milk components (HMBANA, 2016). Milk is then poured into glass bottles and pasteurized in a heated shaking water bath with samples taken during the process to check for bacterial growth.

Following pasteurization, a sample of milk from each bottle is tested to ensure the treatment was effective. Any milk that is contaminated is discarded (HMBANA, 2016). Milk is then ready for freezing and storage and/or distribution to hospitals or individual recipient infants at home with a prescription for human milk. Storage guidelines from HMBANA recommend that recipient hospitals store and use refrigerated thawed DHM within 24 hours of thawing (HMBANA, 2016). Each bottle of DHM that is shipped out is labeled with an expiration date to ensure quality and safety (HMBANA, 2016).

Safety and Heat Treatment of Pasteurized Donor Human Milk

Heiman and Schanler (2007) discussed challenges with the routine use of donor human milk (DHM), which include the obligatory need for pasteurization as well as the effect of pasteurization on the active components in DHM. HMBANA (2016) recommends that all DHM be pasteurized using the Holder method (heating to 62.5 ° C and maintaining that temperature for 30 minutes) to eliminate viral and bacterial pathogens. Pasteurization does alter some of the active components in human milk (Edwards & Spatz, 2012). According to Ahrabi et al. (2013), although there is a loss of some of the biologically active components in human milk following pasteurization, certain bioactive constituents such as oligosaccharides, long chain polyunsaturated fatty acids, epidermal growth factors, and vitamins A, E and D appear to remain unaltered. These bioactive components are significant, as they prevent infection while enhancing

gastric motility, growth, brain and visual development, and protect the gastrointestinal system of vulnerable infants (Edwards & Spatz, 2012).

Both mother's milk and donor milk can lack sufficient nutrients to meet the high metabolic demands of the vulnerable infant (Corpeleijn, Vermeulen, van Vliet, Kruger, & van Goudoever, 2010). According to Morales and Schanler (2007), the overall nutritional needs of the low birth weight infant are met if a nutrient supplement, or fortifier is added to the milk. Spatz (2012) discussed types of available human milk fortifiers, which include traditional optoins comprised from cow's milk, and Prolact-Plus ®, made from human milk. A significant reduction in the rate of NEC has occurred when feeding very low birth weight infants on an exclusive human milk diet with a fortifier made from human milk (Sullivan et al., 2010).

Prior to fortification, human milk should be analyzed (Spatz, 2012). Nutritional analysis of DHM could be conducted using full spectrum infrared spectroscopy which reads fat, lactose, and protein content of the milk, allowing for specific pooling of milk to ensure adequate calories and protein content, and labeling of milk with this information and to allow for specific fortification (HMBANA, 2014). Individualized fortification of PDHM is suggested using either targeted or adjustable fortification (Spatz, 2012). According to Spatz (2012), targeted fortification requires an institution to have access to a human milk analyzer to determine the

amount of fortifier, while adjustable fortification analyzes the infant's metabolic response through lab analysis of the infant's blood urea nitrogen.

As discussed by Edwards & Spatz (2012), many neonatal intensive care units (NICUs) use bovine-based fortifiers instead of Prolacta due to cost; however, in some cases, insurance companies will cover the cost warranted by cost savings when NEC can be prevented. According to Sullivan et al. (2010), the main barrier to the widespread use of Prolacta is cost, at approximately $5.63 per milliliter. Although the health benefits outweigh the cost, until all NICUs can receive reimbursement for the product, its use will likely remain limited (Spatz, 2012). Considering the apparent health benefits and potential cost savings, all NICUs should implement PDHM programs for their vulnerable infant population (Edwards & Spatz, 2012).

Costs and Ethical Considerations

According to Jones (2003), donations are encouraged through altruistic intentions, as donors are not financially compensated. In the United States, banked donor milk can cost as much as $4.50 per ounce (Woo & Spatz, 2007). The cost of donor milk comes from extensive testing and processing costs (HMBANA, 2016). Donor milk is dispensed based on healthcare provider order and medical need, not ability to pay (HMBANA, 2016). Fees charged by HMBANA member milk banks help defray the cost of donor screening, as well as milk processing, record keeping, donor recruitment, and dispensing of pasteurized milk (HMBANA,

2016). In 2012, HMBANA banks dispensed nearly 2,500,000 ounces of processed milk, an increase of 67% since 2009 (Updegrove, 2013).

According to Sullivan et al. (2010), an exclusive human milk-based diet decreased medical NEC by 50%, and surgical NEC by 90%, which could save an estimated $138,000 to $238,000 per case if infants requiring DHM could achieve an exclusive human milk diet. In another study, Ganapathy et al. (2012) found a reduction in costs of $8167 per infant when they achieved a 100% human milk diet with no bovine fortification. They discussed expenses associated with infants who have survived NEC, with estimated costs reaching as high as $130,000 to $250,000.

In one fiscal year at Children's Hospital of Philadelphia (CHOP), PDHM costs reached $155,693.71, which equals approximately $426 per day, or $47 per patient, while on average the cost of each patient receiving total parenteral nutrition (TPN) was approximately $1436.46 daily (Edwards & Spatz, 2012). Edwards and Spatz reported that if vulnerable infants were to receive exclusive human milk feeds, that the amount of TPN needed would be significantly reduced, thus making economic sense for CHOP to continue to invest in the purchase of PDHM for their infants. CHOP could use the healthcare model to promote and guide program development in institutions around the world.

PDHM can be ordered from the nearest milk bank on hospital purchase order, or via a physician order for a child who is not hospitalized (Tully, 2002). In some instances, when there is a shortage of DHM, milk banks must prioritize recipients. HMBANA has created a tool to aid in prioritizing the allocation of donor milk (HMBANA, 2016). Recipient factors considered are age of infant, projected length of need, medical condition, prognosis, prevention of problems, and research; maternal and time factors are also considered (HMBANA, 2016). From a societal point of view, giving priority to the vulnerable infant will save lives, and reduce the cost of care. From an individual perspective, no child should be denied human milk if it is possible to obtain it (Brent, 2013).

According to Miracle et al. (2011), key ethical considerations include marketing PDHM and infant commercial formulas. HMBANA member milk banks are not the only entities that compete for human milk, with the existence of informal mechanisms of distribution such as Internet sites, mother groups, and Internet blogs (Miracle et al., 2011). The International Breast Milk Project (IBMP) is a nonprofit international milk bank developed for the task of distributing donor milk to developing countries (IBMP, 2017). According to IBMP, 25% of the first 400,000 ounces of human milk donated will be shipped to developing countries, while the other 75% will remain in the United States to be used in making Prolacta's human milk fortifier as per their partnership with Prolacta Bioscience (IBMP, 2017). Prolacta Bioscience also recruits donors to

donate milk to make human milk-based nutritional products (Prolacta Bioscience, 2014). Miracle et al. (2011) discussed additional organizations that compete for human milk, which include those that utilize human milk for research such as life science and pharmaceutical companies, which further leads to scarcity of this resource. With so many companies and Internet sites competing for milk, donors must make an ethical decision as to where they would like their milk to go and what purpose they would like it to serve.

Additional ethical considerations include donor families; there are concerns when a lactating mother donates her milk, as she needs to ensure that her supply is sufficient for her own infant (Brent, 2013). A donor must also be cautious if she took medication, was ill, or drank excess alcohol (Brent, 2013). The ethical concept of informed consent, which requires disclosure and understanding of treatment alternatives, suggests that clinicians should provide information about the current state of knowledge about PDHM as part of the informed consent process for infant feeding decisions, especially in settings in which donor milk is readily available (Miracle et al., 2011). Another area that affects ethical medical decision-making is the issue of conflicts of, interest for physicians and hospitals as they may receive financial incentives for using commercial formulas (Miracle at al., 2011)

Froh and Spatz (2014) discussed the best interest principal as it relates to an ethical case for the provision of human milk in the neonatal setting. This philosophy provides a rationale for

decision-making if a person is unable to make decisions for themselves, as is the case with the vulnerable infant regarding infant feeding decisions (Froh & Spatz, 2014). The effects of decisions made on behalf of the infant reach not only the infant, but those who will assume care for the infant, as it is the responsibility of a surrogate (most often the parent) to follow the best interest principle to the best of his or her ability (Froh & Spatz, 2014).

Several factors contribute to the limited availability of human milk in the United States, including rates and duration of breastfeeding, lack of knowledge about options for donation, increased demand from competing entities to receive donated human milk, increasing orders for inpatient and outpatient recipients, and the exportation of donor milk to other countries (Miracle et al., 2011). Breastfeeding is still not the cultural norm in the United States, which is another obstacle to promoting human milk donation (Woo & Spatz, 2007).

Factors Influencing Maternal Decision Making to Donate Milk

There is limited research on the psychosocial benefits and influencing factors for the lactating woman who decides to donate her milk. Donation depends on a biological environment that promotes milk production, and a social context that includes the donor's age, education, political beliefs, and culture and financial position, all of which can support or interfere with a woman's decisions to donate her milk (Thomaz et al., 2008). In a study of donors in Brazil, de Alencar and Seidl (2009) reported that altruism and excess milk production were the most

frequent reasons for the donation of human milk. According to de Alencar and Seidl an important focus was placed on the support of relatives and health care professionals, which is believed to be a part of the socio-cultural aspect in response to the educational efforts that Brazil has undertaken in recent years in favor of breastfeeding.

Thomaz et al. (2008) examined motives and influencing factors of donating women in a cross sectional survey study in Alagoas, Brazil, and found that donors explained their interest was primarily in response to recommendation from a healthcare professional, and secondly because they were aware of the needs of the infants the banks serve. Donors who were young (<18 years of age), illiterate, and unemployed with a preterm infant were observed to be the most influenced by their provider to become a milk donor (Thomaz et al., 2008). According to Thomaz et al., the only reliable predictors of becoming a regular donor were a higher education, and 4 to 7 pregnancies.

De Alencar and Seidl (2010) examined breast milk donation and social support in Brazil in 36 women, and found that the process of deciding to donate can be influenced by the kind of assistance received, whether it is humanized or not, and the valorization of autonomy, highlighting that adequate communication has a fundamental effect on the process of donation. Another important issue discussed among participants was the method of expressing, in which manual hand expression was still preferred; however, they would consider the use of an electric

or manual pump (de Alencar & Seidl, 2010). Situations such as lack of time and physical exhaustion to express milk are cited categories that deserve further study, becuase manually expressing demands a great deal of time, and may limit the practice of donation (de Alencar & Seidl, 2010).

Gribble (2013) studied perceptions of donor milk banks in 98 milk donors in Australia, and found that most donors preferred not to donate to a milk bank, as they preferred to know the recipient and why they needed the milk; they placed a high value on their milk, and wished to ensure the need was genuine and that the recipient appreciated its worth. Although none of the donor respondents desired payment for their time and effort in donating their milk, there was the sense that information about their recipient's need for their milk constituted a reward for their work, which facilitated the donation process (Gribble, 2013).

In Southern Australia, Mackenzie, Javanparast, and Newman (2013) conducted a qualitative study of 12 women, examining the knowledge and attitudes towards human milk banking, and found that breastfeeding mothers unanimously supported donating their milk to a milk bank provided it was easy and not overly time consuming. According to Mackenzie et al., many participants did not know about milk banks, as there were none in Southern Australia at the time of this study, yet they were in accord with the establishment of a milk bank, as they perceived it to be the best nutrition for babies. Participants indicated that successful milk banking

would require consistent information and support, particularly from health care professionals, friends, and family, and that benefits of human milk banking should be publicized (Mackenzie et al., 2013).

In a similar prospective cross sectional study in Spain, Sierra-Colomina, García-Lara, Escuder-Vieco, Alonso-Díaz, Esteban, and Pallás-Alonso (2014) studied donors (n=391) to determine the relationship between different social and demographic variables of donors and their infants, and found that donors with previous experience with donation donated more milk. According to the investigators, the sooner women began donating and the lower the gestational age of their child, the more milk they donated. By contrast, maternal age, number of previous children, and place of residence did not affect the volume of milk donated (Sierra-Colomina et al., 2014).

Azema and Callahan (2003) studied the attitudes, motivations, demographic information, and personality characteristics of milk donors in 103 women in France at several milk banks. Reasons for donation were largely altruistic, and a general optimistic attitude prevailed among study participants (Azema & Callahan, 2003). Women cited reasons for donating included overabundance of supply, helping others, and the feeling that it is a healthy and natural thing to do. The authors also noted that a large percentage of donors (97%) were married or living with

someone, suggesting that partner support may be significant for the donation of milk (Azema & Callahan, 2003).

Emerging research exploring the essence of human milk donation and the psychosocial experience of donors is an important factor in the acceptance and utilization of human milk banks (Mackenzie et al., 2013). In many countries, donor milk banking has been incorporated into child health policy and regulation, and is promoted and supported (Mackenzie et al., 2013). Although research discussed in the previously mentioned studies suggests both optimistic and altruistic qualities in milk donors, an understanding of the essence of the donor experience may further guide recruitment and aid in the expansion of HMBANA milk banks in the United States and milk banks around the world.

Chapter Three: Methodology

Introduction

I utilized a qualitative, phenomenological approach to better understand the essence of the lived experience of the human milk donor. This type of methodology aids in describing the common meaning for individuals on their lived experience throughout the process of donating milk. Phenomenologists focus on describing what participants have in common as they experience a phenomenon, then reduce those experiences with a phenomenon to a description of a universal essence ["a grasp of the very nature of the thing,"] (van Manen, 1990).

Edmund Husserl, a German philosopher, is credited as being the primary pro-component of phenomenology (Valle, King, & Halling, 1989). A major concept of Husserl's phenomenology is the experience of self-revealing objects, which further implies that phenomena can be scrutinized and subjected to this special kind of investigation (Welch, 1939). The word 'phenomenon' comes from the Greek "*phaenesthai*," to flare up, to show itself, or to appear (Moustakas, 1994). Thus, the motto of phenomenology is: "*Zu den Sachen*" which means both "to the things themselves" and "lets get down to what matters" (van Manen, 1990)

Little is known in this specific area of inquiry about women who come forward to donate their milk; therefore, I implemented a phenomenological qualitative methodology for this study. To ascertain the lived experience of the donor, it was necessary to enter the donors' worlds,

entice their stories, and put a voice to the many different realities of the experience. Phenomenology becomes a method whereby one enters the world of the participant through the means of a respectful dialogue, which serves to uncover and understand the person's thoughts (Aprigliano, 2000). Donors had the opportunity to share their thoughts, views and feelings related to the phenomenon of interest.

The lack of knowledge and understanding regarding the experience of human milk donation helps one to realize the importance of developing an understanding of this phenomenon, which may contribute to changes in practice and policy. Such changes may include promotion through state and federal agencies to facilitate the use of HMBANA donor milk by further integrating donor milk into the public health landscape. Therefore, phenomenology, as a method of understanding and describing an experience, is advantageous to capture the essential elements of the essence of the experience of the milk donor. According to Aprigliano (2000), the outcome of phenomenological inquiry is a report wherein language is used to transmit the essential parts of the phenomena in question.

I employed Husserl's theoretical framework for the foundation for this study. Husserl believed that subjective information should be important to scientists seeking to understand human motivation because human actions are influenced by what people perceive to be real (Lopez & Willis, 2004). As humans go about the business of living without critical reflection on

their experiences, he believed that a scientific approach was needed to bring out the essential components of the lived experiences specific to a group of people (Lopez & Willis, 2004). According to Husserl (1982), science of experience is to be viewed as science of fact. The goals of Husserl are strongly epistemological, as he regarded experience as the fundamental source of knowledge in phenomenology (Racher & Robinson, 2003). Edmund Husserl believed that the aim of phenomenology is the rigorous and unbiased study of things as they appear, in order to arrive at an essential understanding of the human experience and consciousness (Valle et al., 1989).

Phenomenology and Philosophy

Phenomenological philosophy is universal, as it attempts to capture, describe, and understand the experience of being human (Aprigliano, 2000). Husserl named the philosophy "phenomenology", and although it did not dominate, it became a significant movement in 20th century philosophy with the philosophical focus placed on consciousness, human existence, or the very nature of being itself (Giorgi, 2005). According to Husserl (1960) it is the dominant characteristic of philosophy that, rather than surrender itself naively to the philosophical impulse, it will by means of critical reflection and methodological investigation constitute itself as a rigorous science.

According to Husserl (1960), the science of pure possibilities must precede the science of real facts, and give it the guidance of its concrete logic. Therefore, it becomes imperative to understand the phenomenon from those who have experienced it. The shift in the movement of philosophy was aided by Husserl himself when he designated consciousness as the point of departure for phenomenology, reasoning that anything that had to be dealt with in the world had to come through consciousness (Giorgi, 2005). Furthermore, Husserl (1960) discussed phenomenology as a conceived sub-domain of empirical psychology, as a reason containing imminent descriptions of psychical events or "*erlebnisse,*" which remains within the framework of the inner human experience or *"erfahrung."* Therefore, an examination of the human experience of milk donation can aid in the creation of a more concrete logic by understanding the experience that people arrive at this through an exploration of their consciousness.

Husserl's theory of "wholes" and "parts" and the differentiation of those parts into "pieces" and "moments" is very helpful in guiding research methodology in nursing science (Schultz & Cobb-Stevens, 2004). As a frame of reference, the theory serves as a philosophical base from which researchers can explore the nature of that being studied and formulate appropriate research questions (Schultz & Cobb-Stevens, 2004). The philosophical theory of "wholes" and "parts" will aid in the exploration of the phenomena of milk donation, while

reflecting on the human condition and meaning of personhood through an understanding of the lived experience of the donor.

Theoretical Framework

Husserl's phenomenological inquiry provides the theoretical framework for this study. It is through the phenomenological method of inquiry that personal meaning in experiences can be extracted and discussed (Aprigliano, 2000). Husserl introduced the concept of the "life-world" and "lived experience," claiming that the life world is not readily accessible because it constitutes what is taken for granted, or those things that are common sense (Koch, 1995). Engaging study participants in open-ended interviews will allow them to consider and reflect upon the phenomena in question. According to Husserl (1960) the proper task of reflection, however, is to not repeat the original process, but to consider it and explicate what can be found in it.

Husserl's theory of time-consciousness centers on the idea of an extended or living present, which involves not only the momentary now, but extends into the past and the future (Kelly, 2014). Phenomenology offers neither metaphysical speculation about time's relation to motion, nor the psychological character of time's past and future moments, nor transcendental-cognitive presumptions about time as a mind-dependent construct; however, it investigates the essential structures of consciousness that make possible the unified perception of an object that

occurs across successive moments (Kelly, 2014). In its nuanced attempts to provide an account of the form of intentionality presupposed by all experience, Husserl's phenomenology of time-consciousness provides important contributions to philosophical issues such as perception, memory, expectation, imagination, habituation, self-awareness, and self-identity over time (Kelly, 2014). Some of the previously mentioned philosophical issues of time-consciousness may present themselves through exploration of the phenomena in question for this study.

Husserl's theory of intentionality was based on the assumption that our own conscious awareness was one thing of which we could be certain, and that building our knowledge of reality should start with conscious awareness (Koch, 1995). This being in consciousness is a "*being-in of a completely unique kind':* not a being-in-consciousness as a really intrinsic component part, but rather a being-in-it 'ideally' as something intentional, something appearing or being-in-it as its immanent *'objective sense"* (Koch, 1995). This notion of intentionality further explicates why understanding a phenomenon from the donors' perspective is imperative. Husserl set out to understand consciousness in all of its manifestations, and recognized it to be a medium between human beings and the world (Giorgi, 2005). By intentionality, every act of consciousness takes an object that transcends the act meaning that consciousness is, among other things, a principle of openness (Giorgi, 2005). Consciousness actualizes presences; because of it, we are present to the world, others, and ourselves (Giorgi, 2005). According to Husserl (1960),

every consciousness has the essential property, not just of being somehow able to change into continually new modes of consciousness of the same object and that this is concretely accessible to investigation.

According to Husserl (1970), if knowledge will investigate the problems of the correlation between consciousness and being, it can have before its eyes only being as the correlate of consciousness, as something "intended" after the manner of consciousness: as perceived, remembered, expected, represented and evaluated. It is clear, then, that the investigation be directed toward a scientific essential knowledge of consciousness (Husserl, 1970). When the phenomenologist explores everything objective and what can be found in it he does not consider, and describes only straightforwardly but does rather with reflective regard, he uncovers the definite courses of the modes of consciousness and explores changing perspectives (Husserl, 1960). According to Husserl (1970) science must be able to describe and determine phenomena with conceptual rigor. When there is a new experience, a new science must arise (Husserl, 1960). As previously stated, the dearth of nursing science related to the experience of why one donates milk requires, as Husserl demonstrates, understanding it from their "life" world.

To capture the essence of the phenomena of the donation experience, phenomenological inquiry aided in providing a rich description of the experience. Husserl emphasized that the manner in which an object presents itself to the consciousness of the researcher is critical for

determining the strategies that are to be used for studying it (Giorgi, 2005). According to Husserl (1960), one should set aside all previous habits of thought, see through and break down the mental barriers which these habits have set along the horizons of our thinking, and in full intellectual freedom, proceed to lay hold on those genuine philosophical problems still awaiting fresh formulations, which the liberated horizons on each side disclose to the researchers. Understanding the lived experience of donors through phenomenology will lead me to transform interview data into a disciplinary expression with both fidelity and validity.

Participant Sample

The voices of women who had the lived the experience of being a donor to a HMBANA milk bank in the United States illuminated the phenomenon of interest. I recruited a convenient purposive sample of milk donors from Children's Hospital of Philadelphia (CHOP) for participation in this study. Donors met the criteria of being at least 21 years of age and medically cleared by HMBANA to formally donate milk to an approved HMBANA bank. Donors were required to speak, write, and understand the English language, allowing me to adhere to the chosen methodology for this study.

Exclusion criteria included bereaved donors as well as donors who have donated milk informally during the time of the study or any time in the past. Such donors may have a different lived experience, which would require a separate individualized exploration. I maintained control

over the selection sample to ensure participants were appropriate for inclusion in this study. I used purposive sampling as the recruitment method for this research study. The idea of purposive sampling is to purposefully select participants who will best help the researcher answer the research question (Creswell, 2009). In phenomenological inquiry, purposive sampling is commonly used with individuals selected to participate based on their knowledge of the phenomena in question (Creswell, 2009). Purposive sampling for demographics aided me in obtaining the maximum variation in sample.

In a phenomenological study, sample size is determined by the quality of the interviews, and when the point of saturation has been reached. According to Creswell (2009), when the researcher begins to hear the same information repeated from multiple participants, the point of data saturation has been reached. The number of interviews in similar phenomenological studies tends to be between 7 and 15 participants (Creswell, 2009). I continued to interview donors until there was saturation of disclosed information from the interviews.

Recruitment

I accomplished recruitment through distributed flyers at CHOP, and direct referral through the Director of the Lactation as well as nursing and hospital staff. The Director of Lactation contacted me directly through a password-protected email on a secure network to provide contact information for each participant. I contacted each prospective participant via telephone or email to screen for inclusion criteria and set up a mutually agreeable date and time for the interview. I conducted interviews in a private conference room or the patient's private room at CHOP; interviews lasted approximately 30 min to an hour.

Data Management

I used two audio digital recorders to record each interview, and data was immediately stored on two electronic flash drives. Following each interview, I transferred the files to a secure Internet network and a password-protected personal computer. I journaled and took field notes, and included personal information I deemed appropriate for the study. I securely uploaded the field notes to a secure password-protected computer to maintain confidentiality. I identified participants by pseudonym. I only coded data by pseudonym. I kept the master list of the pseudonym's and patient information in a private locked file. I will keep all storage media, hard copies of consent forms, and transcriptions in a private locked file cabinet at Molloy College in Rockville Centre, NY for a period of up to five years.

Data Collection

According to Creswell (2013), the data collection circle includes locating the site/individual, gaining access and establishing rapport, purposefully sampling, collecting and recording data, resolving field issues, and storing data. To investigate the lived experience of the milk donor, the phenomenon of interest must have already occurred, therefore interviews took place following participant's medical approval and milk donation to the milk bank at CHOP.

I interviewed participants using a face-to-face semi-structured open-ended interview format, engaging in probes during the interview. This type of semi-structured interview assisted me in guiding the conversation while allowing the participant to focus on her individual experience. I utilized an interview and observational protocol to enable me to take notes and organize ideas and thoughts (Creswell, 2013). I utilized a private, comfortable room at CHOP for each interview, to maintain each participant's level of comfort and privacy.

According to Wall, Glenn, Mitchinson and Poole (2004) "bracketing" is the researcher's attempt to achieve the state of transcendental subjectivity (neutrality) by putting aside prior understanding or preconceptions about the phenomena under investigation. "Reflexivity" is an important method in qualitative research, as it requires researchers to be willing and able to acknowledge and take into account the many ways in which they can influence their findings (Clancy, 2013). This can be accomplished by using the field notes as a reflective "diary" to write

down the researcher's observations, assumptions and confusions; by seeking critique for the researcher's insights from methodological experts, or others who have personal or professional experience with the phenomena in question, and by maintaining an ongoing sense of caution about the role personal bias plays when making sense of data (Wojnar & Swanson, 2007). I utilized bracketing to mitigate the deleterious effects of preconceptions related to the phenomena in question to enhance the rigor of this research study.

I developed open-ended interview questions based on the current state of the literature pertaining to HMD, and an understanding of the nature of the lived experience in phenomenological qualitative research. I developed questions in order to help guide the interview process, as well as to allow the opportunity to ask situational questions and use probes to elicit additional information when appropriate (Rubin & Rubin, 2012). According to Rubin and Rubin, asking the participants the same questions assures the emergence of similar data, and is a strong indicator for the reliability of data collection. The grand tour question for this study was: "What is the lived experience of women who donate their milk to a HMBANA milk bank" A sub question of this study was: "Is there is a changing dynamic in the perception of one's self during and following milk donation?"

I asked each participant in the study to verbally respond to the following questions. Given the emerging nature of the design of phenomenology, I maintained flexibility within the realm of these questions.

- Tell me about yourself and what brought you to CHOP.
- Describe your motivation behind donating your milk.
- Please explain what being a milk donor means to you.
- Explain how the experience has changed how you view yourself and your body.

I asked additional open-ended questions in response to participants' individual answers. I considered data obtained from the participants free of influence from possible differences in interviewing style or in the difference of personalities from me (Rubin & Rubin, 2012). Therefore, I was the only interviewer for all interviews, which was desired to enhance the reliability of gathered data. I utilized a short demographic questionnaire with study participants to ascertain age, marital status, location of current and past births, past infant feeding practices, and history of donation. (Appendix B).

Analysis

I utilized Colaizzi's (1978) phenomenological method for analysis to guide data analysis. Colaizzi contended that "our experience is not inside us but instead our experience is always of

how we behave towards the world and act towards others" (p. 52). To efficiently capture the lived experience of the participant as it is enacted requires the formulation of a phenomenological description (Aprigliano, 2000). Colaizzi calls this "fidelity to the phenomena" (p. 52). According to Wojnar and Swanson (2007) the end point of phenomenological investigation is to present a theoretical model representing the essential structures of phenomenon under study. Consistent with the Husserlian tradition, if the true structure of the phenomenon is identified, then anyone who has experienced the phenomenon should be able to identify his or her own experience in the proposed description (Wojnar & Swanson, 2007). Colaizzi's (1978) method consists of the following seven steps:

1. Reading and rereading participants' descriptions of the phenomenon to acquire a feeling for their experience and make sense of their account.
2. Extracting significant statements that pertain directly to the phenomenon.
3. Formulating meanings for these significant statements. The formulations must discover and illuminate meanings hidden in the various contexts of the investigated phenomenon.
4. Categorizing the formulated meanings into clusters of themes that are common to all participants; referring these clusters to the original transcriptions for validation and confirming consistency between the researchers emerging conclusions and the

participants original stories; not giving in to the temptation to ignore data which do not fit or prematurely generating a theory which conceptually eliminates the discordance in findings thus far.

5. Integrating the findings into exhaustive description of the phenomena being studied. Employing a self-imposed discipline and structure to bridge the gaps between data collection, intuition and description of concepts. Describing includes coding segments of text for topics, comparing topics for consistent themes, and bridging themes for their conceptual meanings. Based on this description a prototype of a theoretical model about the phenomenon under investigation is formulated.
6. Validating the findings by returning to some participants to ask how it compares with their experiences.
7. Incorporating any changes offered by the participants into the final description of the essence of the phenomenon (Colaizzi, 1978, pp. 48-71).

I repeated this process for each participant. I then focused on the essences of the lived experience of milk donors to allow for their voices to emerge. I professionally and securely transcribed the audio recordings; I listened to them multiple times while comparing them with transcribed data to ensure transcription accuracy. I paid close attention to non-verbal audible sounds such “Um” or “Ah” which can be known as “habitual modes of expression” as these

sounds are of importance to the qualitative researcher (Rubin & Rubin, 2012). I worked with members of the dissertation committee to assist in evaluating the data, and differentiating and identifying codes and themes.

I utilized computer-assisted qualitative data analysis program ATLAS ti. I used this software to aid in systematically managing the analysis of complex phenomena in the data, and to provide additional tools for me to locate, code, and annotate findings to visualize the complex relations between them (ATLAS ti, 2015)

Reliability and Validity

Qualitative validity occurred as I checked for accuracy of research findings by employing certain procedures, while qualitative reliability indicated that my approach remained consistent across different researchers (Creswell, 2009). Gibbs (2007) suggested several reliability procedures, including checking transcribed data for transcription error, and ensuring there is not a drift in the definition or meaning of codes. I adhered to these reliability procedures throughout this study to maintain good qualitative reliability.

Validity is one of the strengths of qualitative research, and is based on determining whether the findings are accurate from the standpoint of the researcher, participant, or readers (Creswell, 2009). I actively incorporated multiple validity strategies to enhance my ability to assess the accuracy of findings. I used several validity strategies, including member checking by

taking the findings back to the participants to determine if they felt themes were accurate, using rich, thick description to convey findings, and bias clarification through journaling and self-reflection.

Lastly, I allowed an external consultant to examine the product of the account, assessing the accuracy (Creswell, 2013). According to Creswell, while assessing the final product, the auditor will examine whether the findings, interpretations, and conclusions are supported by the data. This provided additional validation and a sense of inter-rater reliability to this study.

Ethical Considerations and Protection of Human Subjects

It is the ethical obligation of the researcher to protect study participants and to safeguard their identities as well as their shared experiences. My research study posed no serious ethical issues, and was conducted in accordance with Molloy College and CHOP's Institutional Review Board rules and regulations. I obtained written informed consent from all participants prior to the interview, for both the interview and audio recording.

The informed consent form acknowledges that participant's rights was protected during data collection (Creswell, 2009). According to Sarantakos (2005), elements of this form should include identification of the researcher, sponsoring institutions, purpose of the study, guarantee of confidentiality, assurance the participant can withdraw at any time, as well as the provision of names of contact persons to contact should questions arise. I utilized the CHOP approved

consent form (Appendix A). Each signed informed consent form was kept in a secure, locked file cabinet at Molloy College. I gave participants a copy of the consent form, and assigned each study participant a pseudonym to maintain confidentiality. I discussed any risks to the participants prior to the study. I made a referral for counseling available if any participants exhibited any signs of emotional distress during the study.

I protected study participants' data by locking all documents in a secure location at Molloy College, and password-protecting computer and Internet files. While coding and working using Atlas ti, I saved files multiple times so that data was not compromised in any way.

Personal Beliefs

Because the researcher is the primary tool in a qualitative study (Creswell, 2009) it is essential for the researcher to articulate personal values, assumptions, and biases at the outset of this study. Due to personal experiences as a NICU and maternal-child nurse, I bring certain biases to this study. As a staff nurse in a large New York State level four neonatal intensive care unit, I witnessed the deleterious effects of necrotizing enterocolitis (NEC) with many of the vulnerable infants I cared for. It was around that time that a friend of mine donated her milk to a HMBANA milk bank following the loss of her son. Up until that point I had never heard of milk donation. While assisting her through the donation process, I began to learn more about how her

milk could help other vulnerable infants to survive. I learned about how it could help to protect vulnerable infants from NEC as well as many other medical conditions.

I recalled the numerous times that women would ask me to throw away their excess milk from the hospital when their infants were discharged because they didn't have room at home to store it. As a mother of three exclusively breastfed children and an educated nurse, I remember the internal struggle I had throwing something in the garbage that I knew was extremely valuable and life-saving. I began to research the process of human milk donation, and eventually wrote a research paper on the topic during graduate school. I began to wonder why there is such a lack of awareness among mothers as well as healthcare providers. While I have read numerous studies on the benefits donor milk and the process of milk donation, it is clear to me that the lived experience of donating milk is yet unknown, and awaits discovery.

Although I made every effort through bracketing and debriefing regularly with the dissertation committee, it is possible that data collection and analysis was shaped by my personal beliefs and experiences. Rather than seeking to confirm that this research was free of biases, I recognized the possibility. I used field notes and journaling to identify personal frames of reference, and bracketed such beliefs throughout the entire research process.

According to Hamill and Sinclair (2010), qualities of the bracketing researcher include being self-critical and self-aware (reflective), curious and quizzical to understand the

phenomenon as described by participants, insightful, and open with honesty and transparency. Achieving bracketing can occur through reflective journaling, the development of an audit trail to provide a framework for establishing the trustworthiness of the study, utilizing committee feedback throughout interpretation, and through participant feedback following data analysis (Hamill & Sinclair, 2010). I strictly adhered to these processes and supported by the dissertation committee throughout this study.

Limitations

The sample for this study was a sample of convenience, meaning results may not be generalizable to the larger population. Limitations of generalizability of naturalistic inquiry are that prominent themes and patterns may not be reflective of the general population. Another limitation is time, as data may be reflective of the specific time period in which interviews were performed and may or may not be influenced by current events and recent publications related to breastfeeding or HMD.

Research quality in qualitative research is heavily dependent on the individual skills of the researcher, and more easily influenced by the researcher's personal biases and idiosyncrasies (Anderson, 2010). To limit researcher bias, the researcher is to create an environment of openness regarding the participants and data in an attempt to not hinder the perception of the desired phenomena used bracketing, also known as “epoche”. Edmund Husserl described epoche

as “freedom of suppositions,” and is viewed by many as an ethical imperative (Polit & Beck 2004). I performed epoche and took bracketing notes throughout the process to aid in suspending any prior judgment.

Informal and compensated donors were not included in this study. Informal donors do not go through the same processes as those who donate to a milk bank. Those who donate for financial compensation may have a different lived experience, and thus would require a separate and individualized research study. I also excluded those bereaved following the loss of an infant from this study, as the lived experience of these women warrants a separate exploration of a unique shared experience. The aim of this study was to reach the true essence of the shared lived experience among donors who donate to a non-profit HMBANA milk bank.

The choice method for this study was qualitative phenomenology due to the fact that there is little or no published research in the intended area of inquiry. The voices of those women who have lived the experience of donating their milk illuminate the essence of the phenomenon of interest. I employed Edmund Husserl’s philosophical framework and Colaizzi’s method of data analysis for this study, as both are considered influential contributors to phenomenology as a philosophical and methodological approach. Lastly, the research questions in qualitative research can be considered delimitations, as they defined the boundaries of the study. However, I maintained flexibility with the naturalistic approach of questioning in phenomenology, and asked

open-ended questions in response to the participant's answers as to not limit the collection of vital data related to the phenomena.

Delimitations

A central delimitation of this study was that results are somewhat limited to the geographical area sampled, which is the milk bank of The Children's Hospital of Philadelphia (CHOP) located in Pennsylvania. However, the Center for Fetal Diagnosis and Treatment at CHOP is an international referral center, with over 50% of families coming from over 100 miles away from CHOP, including countries outside of the United States. Donors studied were those formally donating human milk to a non-profit HMBANA milk bank in a hospital setting.

Summary

The purpose of this phenomenological study was to examine the lived experience of the HMBANA milk donor. Following IRB approval and obtaining consent from participants, data collection took place using face-to-face semi-structured interviews at The Children's Hospital of Philadelphia, in the Eastern region of the United States. I employed the philosophy of Husserl's descriptive phenomenology and Colaizzi's method of data analysis for this research study. This research has the potential to illuminate the lived experience of the HMBANA milk donor, which can lead to increased donation through awareness and changes in practice and policy while contributing to the advancement of nursing science.

Chapter Four: Study Results and Analysis

Introduction to Findings

This study illuminates the lived experience of women who donated their milk to a hospital-based milk bank in the Northeastern region of the United States. The participants in this study represented milk donors with neonates hospitalized at the Children's Hospital of Philadelphia (CHOP) neonatal intensive care unit. A phenomenological method of inquiry followed by philosophical analysis allowed patterns and themes to emerge. The emergent realty of twelve milk donors permitted the discovery of the essence of the phenomena. This chapter reveals the experience of human milk donation and the possible meaning in formation of the participants' worldviews. Presentation of codes, significant statements and formulated meanings will be presented in light of each donor's individual words. The chapter will conclude with an exhaustive description of the phenomena.

Study Sample

The recruitment process began as soon as I obtained Institutional Review Board approval from Molloy College and the Children's Hospital of Philadelphia. I achieved recruitment through online and telephone collaboration with the director of lactation and staff at CHOP. Prior to the start of each interview, each participant completed a demographics form (Appendix A). Data collected included address, age, marital status, race, current child's diagnosis, gravidity, and

number and ages of other children at home. Participants were asked if they breastfed previous children at home and the duration, and if they have ever used or donated milk at any time. This information provided further description of the participants, enriching the findings of their experience. I conducted face-to-face semi-structured interviews until data saturation occurred.

The study sample consisted of twelve English-speaking women who were approved milk donors at the CHOP Mothers' Milk Bank (a HMBANA milk bank). Participants ranged in age from 21-39. One reported home residence in Alaska, six donors reported home residence in Pennsylvania, three resided in New Jersey, one resided in New York, and one resided in Maryland. Twelve participants were White and married. No participants were divorced. Infants' diagnoses included three with gastroschisis, two infants with congenital diaphragmatic hernias, two infants with congenital heart malformation, one infant with meconium aspiration, one infant with hydrocephalus, one infant with duodenal atresia, one infant with cranio-facial disorder, and one infant with spina bifida. Six participants had no other children at home, four had one other child at home, and two had two other children at home. Eight participants had never breastfed, one breastfed less than one month, one for 1-2 months, and two breastfed for more than six months. No participants had ever donated milk or used pasteurized donor human milk with children at home. A brief demographic of the participants is included and shown in Table 1. Breastfeeding demographics are shown in Table 2.

Table 1: Demographic Characteristics of Participants

Variable	N (%) Total N= 12
Age	
21-29	6 (50)
30-39	6 (50)
40+	0 (0)
Primary Home Address	
Alaska	1 (8.3)
Pennsylvania	6 (50)
New Jersey	3 (25)
New York	1 (8.3)
Maryland	1 (8.3)
Marital Status	
Single	0 (0)
Married	12 (100)
Divorced	0 (0)
Race	
White	12 (100)
African-American	0 (0)
Hispanic or Latino	0 (0)
Asian/Other	0 (0)
Infant's Diagnosis	
Gastroschisis	3 (25)
Meconium Aspiration	1 (8.3)
Congenital Diaphragmatic Hernia	2 (16.6)
Hydrocephalus	1 (8.3)
Congenital Heart	2 (16.6)
Duodenal Atresia	1 (8.3)
Craniofacial Disorder	1 (8.3)
Spina Bifida	1 (8.3)

Table 2: Breastfeeding Demographics of Participants

Gravidity (Number of Pregnancies)	
1	6 (50)
2	4 (33.3)
3	2 (16.6)
4+	0 (0)
Breastfeeding History (Children at Home)	
Never	8 (66.6)
<1 month	1 (8.3)
1-2 months	1 (8.3)
2-4 months	0 (0)
4-6 months	0 (0)
6 months +	2 (16.6)
Breastfeeding History (Current Birth)	
Breastfeeding only	12(100)
Breastfeeding and formula	0 (0)
Donated Milk (Children at Home)	
Yes	0 (0)
No	12 (100)
Used Pasteurized Donor Milk (Children at Home)	
Yes	0 (0)
No	12 (100)

Data Collection

The lactation director and lactation team at CHOP began to recruit donors for this study during their initial interview to become a donor to the CHOP Mothers Milk Bank. Donors were told that if they produced a surplus of milk, that donation would be an option. Once a potential donor accumulated over ten bins of frozen milk (approximately 1,500 ounces) she was approached and asked if she would like to donate. Once she agreed to donate, participants were

asked if they would like to volunteer to be part of a study about donation. The participants' contact information was given to me. Once the participant's information was received, I contacted her via telephone to coordinate a date and time for meeting. All interviews took place at CHOP and were face-to-face in a location chosen by the participant to provide a comfortable setting. Some participants wanted to remain with their infant; therefore, several interviews took place at the participant's infant's bedside while others took place in a private reserved conference room in the neonatal intensive care unit.

At the beginning of each interview, I explained the study's purpose and nature, and reviewed and secured written consent. I always had copies of IRB approval present. I assured the participant's confidentiality, and requested each one create a pseudonym for herself and her infant. I informed participants that collected information would not be shared with outside individuals. I asked participants if they would like to be contacted following the study's completion for further validation of the study's findings, and all participants agreed. I followed the interview with a guide with related probes for each interview. The length of the interviews ranged from 20 to 50 minutes. All the participants were eager to share their story. I took exhaustive field notes during each interview, and thanked each participant after her interview,.

I recorded interviews using two digital recorders in the event of technical difficulty. I had back-up batteries on hand. I uploaded each interview to a password-protected computer using a

secure system. I sent all interviews to a professional transcription company for contracted confidential transcription. I reviewed each transcript for accuracy. Once transcribed, I uploaded data into *Atlas ti* qualitative management software on the same password-protected computer. All data related to this study including transcripts will be kept for a period of at least three years in a locked file cabinet at the Molloy College Hagan School of Nursing.

Field Notes

I collected descriptive field notes on every participant in the study. I dedicated a separate notebook to this study, which provided me an opportunity to describe the participant in greater detail, along with non-verbal behaviors and expressive emotions. I also described the setting in detail. Using field notes enabled me to reflect on her personal assumptions and biases related to the study.

Description of the Participants

The following descriptions reflect my direct observations of each participant alongside an introduction to her personal journey to provide further insight into her life and personal experience. Each participant and neonate is listed as the participant's self-chosen pseudonyms to protect confidentiality.

Participant 1: Elizabeth. Elizabeth is the 32-year-old mother of infant boy Jackson. Jackson was born at 35 weeks' gestation with duodenal atresia. Jackson underwent surgery at

three hours of life. After a month in the neonatal intensive care unit, he was thriving and anticipating discharge home to his parents. Elizabeth had been pumping milk since Jackson's birth, and had accumulated a supply that far exceeded Jackson's needs.

The interview took place in a small private conference room in the neonatal intensive care unit. Elizabeth had requested to bring her son Jackson to the interview. During the interview, she held Jackson attentively in her arms kissing his forehead and rocking him slowly. Through her dialogue it was apparent how grateful Elizabeth was to be bringing her son home in the upcoming days. She reflected on friendships with other mothers she had met during her time in the neonatal intensive care unit, and explained how many of them have babies that are still very sick. She expressed empathy and concern for the others she had met, with hopes that they too would be headed home soon. At one point during the interview, Elizabeth began to cry, as she reflected on how the experience of donating her milk made her feel *"so good"* inside to know that her milk is helping other babies.

> *I have the understanding that it'll go towards other moms who have sick babies, you know, that need the help. But… yeah, I mean that's… I think that reason… that is what is your driving factor, right? That you're gonna… that milk is in turn gonna go and let*

somebody else… some other baby, you know, become big and heavy and fat and happy.

Elizabeth thanked me for allowing her the opportunity to share her experience. She planned to continue donating her milk for as long as possible.

Participant 2: Stephanie. Stephanie is 32-year-old mother to full term infant boy Atlas. Atlas was born with a severe gastrointestinal malformation. Atlas underwent multiple surgeries and was progressing well. Immediately following delivery, Stephanie began to pump her milk. She had planned to breastfeed after learning of Atlas' diagnosis, and learning how her milk would be the best choice for him. She happily explained how the nurses were impressed that she pumped a full ounce the first time she tried and at one point had over 3,000 ounces of milk saved in the freezer at CHOP. Stephanie also expressed how her family and friends were surprised with her decision to donate as she reflected on her lifestyle and how donating helped her to feel whole.

I will have to say like I was brought up very spoiled and, you know, I didn't learn to appreciate stuff until obviously you get… you grow up and all that stuff. So I think like it surprised like my mom and my friends 'cause they're like, oh, like you're giving back?

And I'm like, yes. Like it makes you feel like a whole person to give finally than to take.

The interview with Stephanie took place in a small private conference room. She was thankful for the opportunity to share her story. Stephanie explained how she had given many of her friends information on how to donate and felt like *"an expert"* after her experience at CHOP. She planned to continue donating for as long as possible.

Participant 3: Maggie. Maggie is a 32-year-old who recently gave birth to her third child, Lorenzo. Lorenzo was born premature at 29 weeks' gestation and was facing many hurdles. Maggie requested her interview take place at Lorenzo's bedside in his private room. During the interview, Maggie expressed how lucky she felt to be producing such a large surplus of milk. The lactation staff approached Maggie to consider donation. She explained that she had heard of donation before, and looked forward to helping other babies. Maggie has since discussed donating her milk with her older children and reported that they viewed milk donation as *"normal"* and *"something that you just do."* Maggie had already donated over 1900 ounces of breast milk and planned to donate more if able.

Participant 4: Lacey. Lacey is the 23-year-old mother of infant boy, Jax. Jax was born with gastroschisis and underwent surgery at several days of life. During the interview, Lacey

repeatedly expressed how proud it made her feel of herself and her body to donate her milk and help other babies.

> *It just makes me feel so proud of myself that I'm able to do this. Definitely I have, um… it's weird 'cause like after kids like you hear most moms… they are like so… like feel weird about their bodies, and like I'm just like kinda proud of my body 'cause I feel like I'm… I'm awesome. (Laughing) Again, like I can produce this milk, and I can also help out other babies. Like how cool is that?*

Lacey's interview took place at the private bedside of baby Jax. Lacey was happy, as Jax was going to be discharged soon. She explained how she enjoyed the experience of donating and thanked me repeatedly for the ability to share her story. Lacey planned to continue donating for as long as she is able.

Participant 5: Sarah. Sarah is a 25-year-old mother to infant boy, Aidan. Sarah requested to be interviewed in Aidan's private room. She sat in a rocker near his crib, often glancing over at him while he slept. Aidan was born prematurely and had undergone multiple surgeries.

Sarah explained how she was looking forward to being able to give Aidan her milk again. He was able to tolerate a small amount of her milk at birth, but then had trouble. Sarah reported

that surgeons were hopeful Aidan should soon be able to tolerate her milk again. Sarah discussed how she had made friends with another mother on the neonatal unit that had already donated her milk. Her friend had shared her story and explained the process to her, which led Sarah to inquire if it was something she could do as well. She reported an overabundance of milk. It was evident that Sarah was proud to be able to help other babies, even though she was unable to feed her own baby.

> *I feel like if someone can't produce enough or whatever the circumstance is of the babies that need it, I feel if I can provide that for them when… if their mother can't——or if they're just at the hospital and they don't have enough milk or whatever, if I can't provide that and help the babies, I think it's just all about the babies. (Chuckling) Babies getting breast milk, I'm all about the breast milk. I'd rather them not get the formula if they don't have to get formula.*

Sarah repeatedly thanked me, stating that she was grateful for the opportunity to share her experience.

Participant 6: Teresa. Teresa is 31-year-old mother to infant girl, Charlotte. Charlotte was born with a congenital disease and faced many obstacles during her time at CHOP. Teresa

was preparing for upcoming discharge after spending almost a year on the unit. Teresa asked that her interview take place in Charlotte's private room. Charlotte was asleep in her crib. Teresa seemed excited to share her experience and the motivation behind her decision.

> *I work in law enforcement… that's my background. And I've just always been a protector of people. That's just my nature, like… what makes me who I am. And when I was here and seeing all these other babies and there was nothing I could do. I don't have a medical background. I couldn't run over to help. I couldn't do anything. And it was one thing that I felt like I could do not only for my daughter, but for other babies as well, and feel like I wasn't sitting in my little spot watching these children suffer and not be able to make an impact at all. That was the main reason.*

Teresa explained how the breastfeeding culture at CHOP made it so easy for her to donate her milk. She expressed much gratitude for the lactation staff and nurses on the unit. Teresa had made several friendships on the unit during her time at CHOP. Several days after making her first donation, one of her friends on the unit explained how her child was doing much better after beginning feedings of donor milk. Although privacy and confidentiality laws prohibit

Teresa from knowing the recipients of her donation, she explained how she felt it might have been her milk and felt a connection to the other family and infant.

> *It's hard here because you don't… because of like all the regulations, I have no idea who gets whose milk, but knowing that one baby and knowing his story and knowing the details of his medical journey and knowing that he couldn't tolerate the formula, and just not only how grateful his mother is for but also seeing medically what impact the donor milk had on his recovery…its somebody that I know I'll be in touch with forever, so now… I mean, you know, he was born with the same diagnosis as my daughter and ten years from now like part of me is him.*

Participant 7: Jessica. Jessica is 29-year-old mother to infant Nolan, born at 26 weeks with hydrocephalus. The interview took place in a small private conference room on the neonatal unit. Jessica happily explained that she had several hundred ounces of her milk in her freezer at home, as well as over 1,050 ounces on the unit at CHOP. At multiple times during the interview, Jessica reported that donating her milk made her feel like a better person. *"Um, it makes me feel like a better person. It makes me wanna donate more for other families in need."*

Jessica explained her goal to continue breastfeeding and donating for one year.

Participant 8: Lauren. Lauren is 22-year-old mother to infant girl, Nicole. Nicole was born with a congenital defect and had multiple surgeries. Lauren asked that she be interviewed in Nicole's private room. Lauren explained that she pumped milk for several months and had recently learned that Nicole would be unable to tolerate her milk. She cried as she explained how it felt to donate her milk as she was experiencing sadness that it wouldn't go to her own child, and happiness at the same time that it would be helping others.

> *It's emotional, that's for sure. It's definitely… like you know it's a good thing, but it like… your… it's kind of selfish, because you want it to go to your baby, but you know it's gonna do something so good… like at first I was like, I don't know if I can do it 'cause I feel like I worked so hard, and I'm still hoping that she'll like be able to take it and… but she's not. So it's definitely emotional to be in this place.*

Lauren shared that she recently had stopped pumping and was happy that her donated milk would be helping other babies survive.

Participant 9: Danielle. Danielle is 22-year-old mom to infant boy, Stormy. Stormy was born with a congenital disorder and required multiple surgeries. The interview took place in a private conference room on the neonatal unit. Danielle explained that she failed trying to

breastfeed her other child at home, and was nervous to try again. Danielle explained how the staff at CHOP motivated and encouraged her and reported that she was grateful to them. She felt empowered throughout her donation experience., *saying,"Like I said, it's just so empowering that you can do it, you know?"*

She reputedly thanked me for the opportunity to participate. Danielle discussed wanting to continue breastfeeding and donating for as long as she can.

Participant 10: Casey. Casey is 32-year-old mom to infant boy, Chase. Chase was born with a congenital heart defect. The interview took place at the bedside in Chase's private room. Casey explained how Chase was unable to tolerate her milk due to a temporary gastrointestinal complication, and that she had decided to donate it. She described how her decision made her feel good inside.

> *You know, just being able to give back. You know, we don't want it to go to waste. It was, you know, something that… I think it was like one of the easiest decisions to make. It was like, absolutely. If I have a chance to donate it, I want to.*

Casey explained that she would recommend milk donation to others, and would like an opportunity to donate again of she has more children. Casey repeatedly thanked me for the opportunity to share her story.

Participant 11: Jessica. Jessica is 33-year-old mother to infant boy, Xander. Xander was born with a congenital syndrome. Jessica requested to be interviewed in Xander's private room. Jessica reported a positive donation experience and felt she was lucky to make so much extra milk to help other babies. Jessica also spoke about her time on the neonatal unit and how she met other mothers who were disappointed because they were not making enough milk.

> *Life in the NICU is a lot different than a special care nursery or… it's different, and so you see babies who are very, very, very sick, and you see the moms come down for the first time, and you see them like… like you almost like see them like praying. Like please let me get a little colostrum just so I can like swab the baby's mouth.*

Jessica explained how the nurses were her greatest supporting factors. She began to tear up as she described how grateful she was for them. *"Cause you can't… you cannot thank the nurses enough. You just can't"*

Jessica was grateful to me for being able to share her donation experience. She reported that she would continue to donate her milk for as long as possible.

Participant 12: Jenny. Jenny is 34-year-old mother to infant girl, Hannah, who was born with spina bifida. I interviewed Jenny in a small private conference room on the neonatal unit.

Jenny reported that she heard about donation from the lactation staff and was proud to donate her milk. She reported the experience as seamless, and expressed gratitude to staff members. She also described how donating milk changed her perspective on using donor milk for her own child.

> *Before I had a kid I think I may have been one of those people that was worried about using someone else's milk, you know? But now that I've done this I can see that it's not really a big deal, the process that you go through to make sure it's completely safe for the baby to use is pretty thorough.*

Jenny explained that she would like to continue donating for as long as she is able. She thanked me for the opportunity to participate.

Data Analysis

I conducted semi-structured face-to-face interviews at the Children's Hospital of Philadelphia, using pre-prepared interview guide, and encouraged participants to talk freely. Each interview lasted from 25 to 50 minutes, and was conducted by me. At the end of each interview, I reminded the participant that I would contact her to discuss the findings and make sure her lived experience was reflected. I determined the level of data saturation, which was based on consensus between me and the doctoral committee. Saturation of data occurred by the

tenth interview, but the last two participants were included to ensure a rich description of the phenomenon, and to observe the importance of inclusion in the study. Interviews began in August of 2015 and ceased in September 2016; data collection took place over a period of 13 months.

Following professional confidential transcription, I listened to each interview multiple times and then read transcripts several times to immerse myself with the data and gain a sense of the whole content. I stepped away from the data and returned multiple times to assess. During this time, I added any thoughts, feelings, or ideas that arose related to my previous work in neonatal intensive care to my notebook for bracketing. By doing so, this helped to explore the phenomenon as experienced by the participants themselves. I then uploaded transcripts to data management software Atlas ti (Version 7.0 ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Atlas ti assisted my ability to analyze data through organization, indexing, and searching.

Initial engagement with the data led to many periods of reflective analysis. I analyzed data using the Colaizzi (1978) method. I extracted and recorded significant statements that pertain to the phenomenon. I organized these statements on separate sheets, and coded them based on the transcript, page, and line number. After extracting significant statements from

transcripts, I discussed findings with my committee chairperson and a psychosocial nurse expert, and reached consensus.

I formulated meanings from significant statements with each underlying meaning coded on one category, as they form the exhaustive description. I developed codes to assist in isolating topics and categories. I utilized the codes consistently throughout analysis of data. Together with committee chairperson, a qualitative methods expert, and psychosocial expert consultant, I condensed the categories and their meanings into four essential themes. I undertook this process to validate the coding schema, derivation of significant statements, and higher level formulated meanings. I integrated the findings of the study into an exhaustive description of the phenomenon. I took the description back to several participants, and asked them to validate if it maintained faithfulness to their story. All participants agreed with the description. All essential themes had a similar depth, and can be differentiated but not separated, as they form the lived experience of the donor. Themes reflected in Table 3 represent mothers' voices, illuminating the lived experience of milk donation.

Table 3: Primary Themes and Thematic Elements

Theme	Thematic Elements
The Ripple of Hope and Help: Giving Back	The desire to give back and help families in need with no expectations in return. A selfless type of giving to others.
The Dynamic Interplay of Nurturance: It Makes Me Feel Good	As the recipient infant is nurtured in a physiological manner, the donor mother is simultaneously nurtured in an emotional manner.
Standing on the Shoulders of Others: They Made it So Easy	An innate gratitude towards staff members who facilitated and celebrated their success alongside them. The strength to persevere through the unknown. Knowing what to expect and having everything they need.
Sharing Their Story: The Light That Shines From Within	The strong desire to share the beauty of their experience with others and shed their light on the phenomena.

Study Findings: Themes

Theme One: A Ripple of Hope and Help: Giving Back.

"Just as ripples spread out when a single pebble is dropped into the water, the actions of individuals can have far-reaching effects." (Dalai Lama, 2013)

The theme "A Ripple of Hope and Help: Giving Back" represents the ripple effect of hope, and how participants embodied the hope that their donation would have a meaningful and

beneficial effect on others. Participants spoke to an experience that began with making a very easy decision to "*give back,"* and how the ripple of hope has no logical end from the infant to the family and on to the future.

Casey spoke about being able to give back through her donation and how easy the decision was to begin the process and give back.

> *The other thing is just being able to help other people. You know, just the feeling of being able to give back. You know, we would never want it (donor milk) to go to waste. It was, you know, something that…I think it was one of the easiest decisions to make. It was like absolutely. If I have a chance to donate it, I want to.*

Stephanie shared that once she learned about being able to donate, that she wanted to facilitate the process. She explained how happy she felt to help others*: "But once you realize that you can begin (donating) you're like oh, cool lets get moving. Like I can really help. This is awesome. I am just happy that it can go to anyone."*

Participants in the study felt an innate need to give back to other infants and families. They understood and appreciated the magnitude their donation would have on the lives of others.

Casey discussed giving back and the way that it made her feel.

It's…you know, just being able to give back, no matter who it is…who it helps. Knowing that there's babies that will benefit from it, really benefit you know, gives you a little bit of joy…and, you know, makes your heart happy. (Laughing)

Lauren spoke about how she felt her donation would help other babies survive. She explained she wasn't looking for recognition, that giving life was her personal reward, as every ripple has no logical end when the gift is life itself.

Most people, when they do nice things for other people and give back, they like to show it off, and knowing that I'm doing it, but I will never like…like I'm never gonna get like any reward for it, but I feel like I am rewarding myself by doing it because I am making another baby get what they wouldn't get in the beginning….a start….like to help another baby survive and have their life.

Elizabeth noted how it saddened her that not every mother was able to produce enough milk and felt every infant and family deserved the same opportunity. All the participants spoke positively about helping others and giving back: *"If you can give back to somebody else something they are lacking, you know, and put them at an even ground with you, I think that's...that's something huge. You know you're helping someone else thrive, which is great."*

Stephanie also discussed other families on the unit, and how even though you don't know which babies you're helping, it's just important to help them, like a silent ripple of caring that has endless possibility.

> *Like even the moms like now…because in the wing I'm in right now, like all the moms…you know, you can tell. Some of them still have that scared look on their face, and all you want to do is be like, I just want to hug you and it will all be ok. I can help her this way and she doesn't even have to know it was mine. It's fun to think about who will get my milk and the (future) possibilities and the situations.*

Sarah discussed how giving back was the motivation for her to continue pumping and donating her milk. Sarah described how her donation would go forward to help many, as her donation created a ripple effect to improve the lives of others. Sarah also expressed gratefulness for the others that had helped them, as she too, was cared for in the NICU.

> *You know, pretty much helping all the other babies is really the big motivation for me to just keep pumping and donating. I wanted to do this, to give back, but I'm lazy, but the helping babies, it just really means a lot to me, 'cause everyone's helped us, you know in*

this situation. If I can do this and make a difference in other lives, I am so happy.

Jessica spoke about the scenario she envisioned in her mind when she thought about who might receive her donation. Jessica expressed hope that the recipients would survive. She expressed sadness for the other families who were struggling in the NICU and her desire to make a difference in their lives.

This sounds sick, but in my mind I picture a small preemie baby, or preemie babies who are like really sick getting my milk, and then they like turn this corner, and they get better. It's sad…I can picture their little faces. I want to help them. It makes me feel like a better person, it makes me wanna keep donating and giving back to other families in need cause at the end of the day, I'm gonna get to leave and go home with my baby. (Crying) And some moms don't. So if it helps them to bring their baby home, that's the best you could pray for.

Jessica went on to explain…

But the donation piece of it, at least I know that I'm giving back a little bit. 'Cause like you can never thank the nurses enough or the

doctors enough for like everything they've done for your baby.

Like you can say thank you—but it's not like enough, and like I feel

like another mom like walking that walk…like… I don't know.

Maybe I could ease their stress just a little bit (by donating).

Yeah, it's like I'm like paying it forward a little bit.

All the participants experienced a desire to help others and give back through their donation. There was an understanding that their donation would help the recipient infant and their family and provide hope for the future. The ripple effect from their donations would go on to touch the lives of many.

Theme Two: The Dynamic Interplay of Nurturance: It Makes Me Feel Good Inside

Participants expressed how donating milk made them feel good inside. As donor milk nurtures its recipient's body physiologically, the donor is also being nurtured in an emotional way, as they too experience nurturance. The participants went into detail about how donating made them feel. Participants described feeling *"proud"* and *"better"* about themselves after donating.

Danielle described how providing for her child and donating her milk made her feel empowered*: "Like I said, it's just empowering that I can do it, you know? It's an empowering feeling that you have the ability to do this for your own children and then others too."*

Lacey was proud of being able to donate her milk and explained how her family was also proud and supportive of her. She laughed and smiled as she explained the positive emotional experience she felt fortunate to have.

> *Oh, I am just so proud of myself. It makes me feel awesome I just feel great doing this. Even my family is super proud of me for doing it. I just think I'm awesome…I'm awesome cause I…I can do it. (Laughing)*

Lacey went on to explain how donating made her feel proud of her body, as she was proud of her body after giving birth. Lacey repeated the phrase "*I'm awesome*" several times during her interview regarding how donating made her feel*: "It's weird cause like after kids you hear most moms…they are like so…like feel tired and weird about their bodies and I'm just kinda proud of my body 'cause I feel like I'm…I'm awesome."*

Stephanie explained how donating made her feel like a better person, and how she has changed and grown as an individual through her donation experience. She also experienced a greater appreciation for the important things in her life.

> *This is something extra that I get to say. This is like at the end of my resume when, you know, you can say you speak Spanish, 'It's like, yes, I donated milk. It's just like crazy how good I feel about*

myself. I'm learning now that there's ways to become better than you used to be. This experience really makes you appreciate everything.

I feel it's changed me.

Elizabeth also discussed how donating made her feel inside.

I mean I think that in the end it just…it makes me feel like a better person. I wanted to do this, it's like on my plate of list of things to do, and you know it's something good and nice...I like how it's making me feel.

Sarah explained how she felt to be a donor.

I mean…I am so proud of myself that I can do this. It's cool that I can make milk and feed other humans…and not just my own. Yeah, and I have a positive outlook on it. It makes me feel like a better person.

Sarah continued…

And there's the thing… I mean, I'm here all the time, like can I go out and like volunteer and stuff and if I can just pump and donate

my milk, then it makes me feel good, you know, just to help people, 'cause some people have helped us through this whole thing.

Casey described how donating to others made her feel good about herself while she was feeling helpless in the NICU environment.

And then not only that, but, you know, just the idea that you're helping the babies. You know, that makes you feel pretty good about yourself, too, that you can do something else, especially if you're in the NICU. There's not much you can do and it feels helpless sometimes. So it's just… you know, you feel good inside that you did it. It wasn't easy, but it was some… it was a nice experience to have.

Casey went on to describe her sense of accomplishment and how it led her to feeling like a better person.

Like I didn't really ever think that I could even do any of this to begin with. You never really know what you can do until you are put into a situation. So I think, you know, you kind of look at yourself a little differently, and you realize, oh, you know, I can do… I can do something like different. You know, something I

wasn't ever prepared to do before, and it all turned out fine and, um… you just feel like a better person.

Danielle shared how reading something online about donating gave her a good feeling inside. She began to think about it through the perspective of the recipient mother and how grateful they were.

I saw something online the other day when I was looking around and it was actually talking about moms who donated milk and how they were… like how the mothers of the babies that received it were so thankful and they don't know what they would do without those people, you know? I think that made me feel better about it and it's like, you know, wow, I didn't realize that it really helped like that. It's a good feeling that you were able to do something to help out somebody who needed it.

It was clear from the participants that donating helped them feel good. They expressed only positive emotions related to their experience. Both recipient infant and donor are nurtured through the donation experience. The donor mother is nurtured emotionally as she experiences good and uplifting positive emotions throughout the experience. Participants' own infants were

hospitalized in the NICU at the time of their interviews. The donation experience brought forward positive feelings and emotions in an otherwise difficult and stressful time.

Theme Three: Standing on the Shoulders of Others: They Made it So Easy

All of the participants expressed how grateful they were for the staff. They discussed how easy the process of donation was, and how the staff facilitated the process and made it simple for them. Participants felt encouraged and supported, and discussed how the staff was influential and motivational throughout their experience.

Jessica spoke about her experience and the support she received in the NICU.

> *I met with lactation and they kind of explained exactly how it should go. Having all that support throughout the hospital made it really, really easy. The nurses in the NICU are so great. You cannot thank the nurses enough. You just can't.*

Jessica also spoke about feeling encouraged and challenged to keep going as she continued pumping and storing her milk in the NICU. Once she had enough milk in the refrigerator, they began freezing her milk.

> *They'll (the nurses)… they'll be like, oh, you're in one bucket. Okay, we're moving you to the freezer, and you're like, yes, I made it to the freezer. Like I don't know why that's so exciting, but it is*

when you see that, so the nurses are like… they're always like, you know, okay, we took one of the buckets out of the refrigerator, put it in the freezer. We're gonna start freezing your milk or… you're like, oh, great.

Sarah too, had a positive experience with the staff, and felt they helped her succeed and were helpful and motivating.

You know, um, a lot of hospital staff, they always mention… like I have like a big supply in the freezers and they're proud of me. You know, they're really proud. Um… a lot of the nurses, they actually recommended it. Um… I spoke with a lot of lactation and they all helped me begin paperwork. Um, the nurses, a lot of them call… would call lactation all the time for me and just answer basic questions I had. They're really awesome. They really kind of pushed me towards that, you know? Um, I had also one nurse that she shared her donating experience and this is when I was first like doing the paperwork and she was just kind of motivating me. You know, so they've been great. Everyone here has been great, very supportive.

Later in the interview, Sarah further illuminated the experience, saying, "*Everyone around me is just really supportive and positive about the whole thing and yeah, I've just had a great experience here with the donation you know?All I have to do is pump and it just happens."*

Elizabeth shared her feelings related to staff and her donation while emphasizing that all members of the team that worked with her were very helpful*: "The nurse was very helpful, and really, I mean all of the lactation people who came to see me were…were quite a few."*

Lacey shared similar feelings as to who helped her the most*: "They've been the biggest help, the lactation team."*

Teresa spoke about how easy the process was made for her, thereby promoting the unfolding of the experience.

> *I was pretty motivated on my own to pump, but I think they made it easier. So I didn't have to…everything was just provided for you. If you had any questions the resources were right there for any questions, it was just really easy.*

Jenny explained how the nurses were most helpful to her.

> *Yeah, the nurses are the most helpful, anything I need from them, to help me get everything is done, and they're on top of it. They*

kinda just made sure I got in touch with the people that I needed.

Yeah, I think the nurses were the most helpful for me.

Casey discussed how she felt the nurses took good care of her and were there to answer her questions and help with anything she needed.

When I was pumping and stuff, they always made sure that you had enough supplies to keep going. Every (nurse)… you know, they were very encouraging. You know, keep doing it. Keep going. Don't get discouraged, you know? You know, setting you up with everything that you need, and then just giving us the information and contacting the right people to be able to donate. So they've been really helpful.

Stephanie spoke about the staff and classes on the unit and how they helped to educate her. She learned little things that she found helpful.

As much as I knew I wanted to pump and… and breastfeed, I knew nothing about it. So having them just educate me on certain things, like even on Fridays at 4:30… every Friday at 4:30 there's a moms that breastfeed meeting, and it's… granted, they may feed you, which is awesome, but they also educate you on the whole

process of breastfeeding. It was really cool that we could all kind of come together and talk about, you know, our situations, and of course they're all different, but it was helpful to just even learn. You know, like I just… just stupid little random things that you didn't know, and I'm like, oh, yeah, that's helpful. Okay.

Lauren shared how the nurses supported her and helped her to keep going, *saying, "They're amazing (the nurses).They're… (Crying). I feel so supported. Like even the lactation consultant, she like… most of them are like, no, don't give up. Keep going. She was like, amazing. She didn't push me."* Lauren continued*: "So that was really nice, and then they were always there. Like the lactation consultant always came by. She talked to me. She was like, oh, you're on the right track, which was amazing, and it really helped me."*

All the participants reported how the staff was helpful and encouraging. They also explained how the staff emotionally supported and motivated them to succeed. They felt comfortable and supported in their environment. While standing on the shoulders of the staff, participants could succeed and have a positive donation experience. The staff provided the necessary foundation for the experience to be easy and enjoyable for the participants and their families. The participants felt supported and secure. They experienced professional and emotional support that was consistent and unwavering.

Theme Four: Sharing Their Story: The Light That Shines From Within

The participants felt a need to share their story with others. They were proud of donating and enjoyed talking about it. Interestingly, all of the participants would recommend milk donation to another woman, and would use donor milk for their own child. Sharing their story would shed light on donation, a topic that participants have realized is unknown to many.

Casey spoke about how she brought light to donation through educating other mothers and giving out information.

> *A lot of people were like surprised that you could even do that (donate milk). They didn't know, so they were, you know, happy that there was something like a milk bank.*
>
> *And other people actually decided that they would like to donate, so I was able to give the information out to other moms, either their kids are out of the breastfeeding stage, or maybe they went back to work and they have so much left, and some other scenarios. So they were willing to take the information and see what they can do. So I think a lot of people were, you know, really pleased that…you know, I brought to light that something that nobody really knew about.*

Jessica's friends wanted to learn more once she began telling them about her experience and hopes that other women would be able to experience donation*: "Um, I told my friends and they think it's awesome and wanted to learn more about it. And you know, sharing this experience we hope will somehow help other women get to have it as well."*

Sarah explained how she tells everybody she knows to donate*, saying, "I tell everybody I know to donate. (Chuckling) I tell them my story."*

Stephanie discussed how she would recommend donation, and how sharing her story may make another mother more willing to try.

> *I definitely recommend it (donation). I feel like showing them or educating them in some way about it definitely would make them feel more willing to do it. Just saying, hey, you should really donate… it really doesn't, I think, mean anything. I feel like you have to give them your story with it or an experience or some kind of knowledge, and —they're a little bit more willing. Um, and… and I do believe that's how I was probably 'got', if you will.*

Maggie also shared similar thoughts*, saying, "I would recommend donation. I would urge people to donate or accept."*

Lacey explained how she would encourage another mother and hopes to help other mothers*, saying, "After donating, I told them (family and friends) the process. Like um, you know, I had to get blood work done for it and fill out paperwork. People wanted to know about it."* Lacey continued:

> *Oh gosh, I'm a huge supporter of it (donation) you know? I just encourage like…I encourage any mom to donate if they're able to. Who knows like what will come in my path. Maybe I can help out a mom with it and encourage her. I can teach others about this now.*

Teresa had similar feelings and explained how she told her friends about donation, and that several have already inquired since learning her story.

> *Like I already have had a few friends that have reached out and asked if they can donate here at CHOP because they have extra and they don't want to… they're like it's so much to work this, it's so great, I don't wanna dump it out but my child doesn't need it anymore. Now they know they can donate it.*
>
> *I would definitely recommend it to other people.*

All of the participants would recommend donation, and expressed joy in sharing their story. They expressed gratitude for their own experience, and a desire to share it with others in their lives.

All four themes represent the participants' dialogue with donation. To summarize, the first theme provides insight into the ripple of hope as participants described the impact their donation would have on others. They all felt a strong need to help other infants and families, and hoped their donation would make a significant difference in the lives of the recipient. The second theme provides insight to the emotional nurturance a donor experiences. Participants expressed how donating made them feel good inside. The third theme represents the influential and motivational role that the nursing and lactation staff had on participants. Theme four demonstrates how donors feel positive about sharing their story and teaching others about donation.

The following section of this chapter will provide an exhaustive description of the phenomena of donation.

Description of the Phenomena of Donation

Mothers' voices become evident through the dynamic interplay of the ripple of hope and standing on the shoulders of others and sharing their story, which lends to the creation of the sphere of nurturance. The need to give back with no expectation in return led to increased

motivation for continuance of the phenomena. The awareness of the ripple of hope fueled their determination to give back and help others.

The supportive and motivational environment provided the strong foundation for women to maximize their voice of hope. The voices of women continually uncovered a sense of positivity as the ripple of hope propelled forward, fueling the dynamic of each donation. This existential environment allows for the unfolding of the sphere of nurturance in which donor and recipient are positively nurtured. The voices of women continually uncovered a sense of positivity as the ripple of hope propelled forward, fueling the dynamic of each donation.

This study illuminates the positive emotional experiences associated with milk donation. At each stage, women proudly shared their stories of hope and desire to give. They were thankful for the experts who supported them during each step. During an already difficult time in their lives, women could experience a sense of hope and positivity and feelings of increased self-esteem. As the recipient infant is nutritionally nurtured, the donor is emotionally nurtured, creating the dynamic interplay of nurturance.

Summary

The twelve participants candidly shared the aspects of their lived experience through their interviews. Their verbatim transcripts provided the raw data for analysis using the Colaizzi method of phenomenological analysis. The context of the participants' experience is clearly

dynamic with all four themes, interrelated and in motion together. Understanding the phenomena of donation provides a new basis of knowledge and awareness of the lived experience. The emergence of the thematic elements discussed in this section deepens the understanding of the lived experience of mothers who donated to a hospital-based milk bank.

This chapter illustrates the experience of the donor and the meaning from the participants' worldview. An overview and summary of the research findings, significance to nursing, as well as recommendations for further research, will be discussed in Chapter Five.

Chapter Five: Discussion

Summary

This chapter includes a discussion of the phenomenon of the lived experience of milk donation in women who donated milk to a hospital-based HMBANA milk bank in the Northeastern region of the United States. This chapter will begin with a summary of the study. I will follow with research questions, links to nursing theory, and integration of study findings with current literature. I will discuss study strengths and limitations, and follow with a discussion of implications for nursing science and practice. I will conclude the chapter with future recommendations for nursing research and personal reflections.

The purpose of this study was to examine the lived experience of the milk donor who donated milk to a hospital-based bank regulated under the policies and procedures set forth by the Human Milk Banking Association of North America (HMBANA). I conducted an extensive review of the nursing literature, including benefits of human donor milk for vulnerable infants, cultural perspectives in milk banking, and past and current donor milk banking policies and procedures in the United States. I expansively researched safety and heat treatment of pasteurized donor human milk (PDHM), costs, and ethical considerations. Lastly, I investigated factors influencing maternal decision making to donate milk. There is a clear understanding of the importance of donor human milk for the vulnerable infant for greatly improving health

outcomes; however, what was lacking was an understanding of the experience of the donor, which was the primary research goal of this study. There are no studies that examine the lived experience of the milk donor to a hospital-based HMBANA milk bank in the United States. This study strengthens the evidence and science related to the phenomenon of milk donation.

I utilized a phenomenological qualitative approach using Husserl's theoretical framework and Colaizzi's seven-step method of data analysis for this study. The lack of knowledge and understanding regarding the experience of human milk donation lent to the importance of developing an understanding of this phenomenon. When there is limited information on a topic, a phenomenological approach is recommended (Creswell, 2009). I chose a qualitative phenomenology method for this study due to the limited research in this area of inquiry. I utilized purposive sampling to generate a sample of twelve participants. In phenomenological inquiry, purposive sampling is commonly used with individuals selected to participate based on their knowledge of the phenomena in question (Creswell, 2009). Purposive sampling allowed me to recruit donors for in-depth face-to-face interviews. The idea of purposive sampling is to purposefully select participants who will best help the researcher answer the research question (Creswell, 2009).

To ascertain the lived experience of the donor, it was necessary to enter the donors' world, learn their stories, and put a voice to the many different realities of their experience.

Donors shared their thoughts, views, and feelings related to the phenomenon of donation to provide insight on their lived experiences. Where there is a new experience, a new science must arise (Husserl, 1960). As previously stated, the dearth of nursing science related to the experience of why one donates milk required, as Husserl asserted, is understanding it from their "life" world. Consistent with the Husserlian tradition, if the true structure of the phenomenon is identified, then anyone who has experienced the phenomenon should be able to identify his or her own experience in the proposed description (Wojnar & Swanson, 2007). Consistent with the Colaizzi method of data analysis, I brought the description to the participants and asked, "Is this your story?" to ensure participants agreed with the study's findings.

This research was based on the lived experience of twelve donors who donated to a HMBANA hospital-based bank in the Northeastern region of the United States. I recruited a convenient purposive sample of milk donors from Children's Hospital of Philadelphia (CHOP) for participation. Donors met the criteria of being at least 21 years of age, English-speaking, and medically cleared by HMBANA to donate. Exclusion criteria included bereaved donors, and donors who have donated milk informally during any time. I conducted in-depth face-to-face interviews and audio-recorded, and professionally and confidentially transcribed each one. I used Atlas ti data management software for management and analysis of data.

Synthesis of Research Questions

The grand tour question for this study was, "What is the lived experience of women who donate their milk to a hospital based HMBANA milk bank?" Sub questions include, "What is the changing dynamic in how one feels about them self following donation?" and "What are the facilitating and motivating factors related to human milk donation (HMD)?".

I asked participants a series of questions using an open-ended interview format. The four themes that emerged from the data were: the ripple of hope and help; the dynamic interplay of nurturance; standing on the shoulders of others; and sharing their story. These themes illuminated the uniquely human phenomenon experienced by each participant.

Grand Tour Question. "What is the lived experience of women who donate their milk to a hospital based HMBANA milk bank?"

I utilized phenomenology to enter the world of the participants through the means of a respectful dialogue. The word "phenomenon" comes from the Greek "*phaenesthai*", to flare up, to show itself, to appear (Moustakas, 1994). Thus, the motto of phenomenology is, "*Zu den Sache*n," which means both "to the things themselves" and "lets get down to what matters" (van Manen, 1990). By entering each participant's life world through face-to-face open dialogue, the most meaningful feelings and emotions of each participant were illuminated.

The lived experience of participants was highly regarded and positive. What mattered most to all participants was giving back and helping others. Participants agreed upon a valuable emotional experience. Each participant was proud to have donated, and enjoyed the experience during and following donation. It was evident that participants were emotionally supported in their environment. They bared witness to the unfolding of the phenomena as they described the essence of the nurturance they experienced. Various participants described their donation as a "gift" and described it as "giving back" to others. They illuminated the significance of the staff as monumental in facilitating and motivating them, making donation achievable.

Participants described feeling accomplished. They felt honored and grateful for the opportunity to help another child with their donation. There was a strong desire to share their experience with family and friends. Several participants discussed their experience on social media, where they offered support and help to other women looking to donate to a milk bank. There was an innate gratitude towards the nursing and lactation staff at CHOP for their support in helping mothers reach their personal breastfeeding goals and facilitating the donation process. The donors felt motivated, supported, and encouraged, which they said helped make the process easier. Their lived experience was self-empowering and self-nurturing. Every participant reported she would donate again in the future, if able, and would recommend donation to other mothers.

Sub Questions.

"What is the changing dynamic in how one feels about themselves following donation?". Phenomenological philosophy is universal, as it attempts to capture, describe, and understand the experience of being human (Aprigliano, 2000). Husserl's theory of "wholes" and "parts" serves as a philosophical base from which researchers can explore the nature of the studied phenomenon (Schultz & Cobb-Stevens, 2004). The philosophical theory of "wholes" and "parts" aided the exploration of the phenomena of donation while reflecting on the human condition and meaning of personhood through an understanding of each participant's personal and unique story.

The participants interviewed for this study were mothers of infants who were hospitalized in the neonatal intensive care at CHOP at the time of their donation and interview. They described having a hospitalized infant as overwhelming and frightening. Participants explained how donating helped them feel good despite the stress they were experiencing with their own child. They described the experience as uplifting and beneficial. Participants described feeling accomplished and proud of their bodies for producing enough milk for their own infant with surplus to donate for others.

Donating made them feel something unique and special. There was a dynamic shift in how they perceived themselves. Capturing this change in perception was critical to

understanding how donating affects the human condition. Donors could experience this changing dynamic during their own child's hospitalization.

"What are the facilitating and motivating factors related to HMD?".

Nursing theory developed through a phenomenological approach, reflecting the reality of nursing practice, which is complex and situational (Dowling, 2007). This study uncovered which facilitating factors made the biggest impact on each participant's personal experience. All participants reported the staff as the greatest facilitating factor throughout their donation experience. They mentioned multiple CHOP staff members by name, and expressed strong gratitude. Describing the staff brought several participants to tears, stating they found it difficult to find the words to explain how much their support meant to them. Participants referred to the staff as motivating, encouraging, helpful, and available at any time. Participants discussed how the provision of supplies such as bottles and labels helped to make things simpler, thus facilitating the process, making it was one less thing they had to worry about. The staff's motivation, education, and assistance facilitated an experience that made donating not only achievable, but also valuable and positive.

When asked to describe motivating factors, participants discussed the concept of "giving back" and how it motivated them to think about the babies that would receive their donation and how it would help them. Participants understood the impact their donation would have on the

recipient baby and their family, and were happy to be helping. The positive feelings associated with "giving back" were a central motivating factor for donors.

Husserl's theory of intentionality assumed that our own conscious awareness was one thing of which we could be certain and that the building of our knowledge of reality should start with conscious awareness (Koch, 1995). This study uncovered the conscious awareness of each participant. The dynamic interplay of nurturance unfolded during each participant's experience, as all they described it in the same manner. It made them feel good to be a donor and help other infants, which led to an increased motivation to continue donating. This study further illuminated the importance of facilitating and motivating factors in donation.

Integrating Findings with Previous Literature

As the literature review revealed, there is limited research exploring the lived experience of women who donate milk to a hospital-based bank in the United States. This study supports the findings of several studies. Findings from this study support those of Thomaz et al. (2008) and de Alencar & Seidl (2010), where an important focus is placed on the support of health care professionals in order for mothers to complete the donation process.

Thomaz et al. (2008) examined motives and influencing factors in donating women in a cross sectional survey study in Alagoas, Brazil, and found donors' interest was primarily in response to a healthcare professional, and secondly because they were aware of the needs of the

infants the banks serve. This study further links healthcare professionals to positive donation experiences as well as infant need serving as a motivational factor.

De Alencar & Seidl (2010) examined milk donation and social support in Brazil in 36 women, and found that the process of deciding to donate can be influenced by the kind of assistance received, which is further supported by this study's findings in all participants. Mackenzie et al. (2013) examined the knowledge and attitudes towards human milk banking in Southern Australia, reporting donor's indication that successful milk banking would require consistent information and support, particularly from health care professionals (Mackenzie et al., 2013).

Both Thomaz et al. (2008) and Gribble (2013) reported that knowledge of recipient need facilitated the donation process. Gribble studied perceptions of donor milk banks in 98 milk donors in Australia, and reported that none of the donors desired payment for their time and effort, that there was the sense that the recipient's need for their milk constitutes a reward for their work, which facilitates the donation process (Gribble, 2013). In a study of 103 donors in France, Azema & Callahan (2003) reported reasons for donation were largely altruistic, with donors optimistic to help others. Similar to studies by Thomaz et al., Gribble, and Azema & Callahan, this study cited the desire to help recipients while experiencing an emotional reward for their donation.

Study Strengths

I accomplished rrustworthiness in this phenomenological study through face-to-face contact with each participant during an in-depth interview. Lincoln and Guba (1985) posited that trustworthiness of a research study is important to evaluating its worth. Trustworthiness involves establishing credibility, transferability, dependability and confirmability. All the interviews took place in CHOP's NICU environment, with several of the recipient's infants present during the interview. By engaging in the field of the participant's current environment, I was able to further illuminate the context of their life world. Participants each generated thick descriptions with rich details of their lived experiences, enhancing transferability of research findings. Active listening and time spent in the environment enhanced rapport with participants, and aided in the development of a trusting relationship.

I use thematic analysis to illuminate the lived experience of the milk donor to a hospital-based HMBANA bank. Themes discerned were member-checked with several participants, a key aspect in confirming creditability of research findings. During the last step of analysis, participants assessed the fairness of research findings in relation to their own lived experience to ascertain truthfulness of findings. Documentation of raw data, reflective journaling, and an audit trail of my decision-making processes augmented dependability and authenticity of research findings.

Study Limitations

Both oral and written language are limited in what can be expressed, understood, and conveyed in the form of research findings. In this study, I attempted to explore the lived experience of the milk donor to a hospital-based HMBANA milk bank, motivating and facilitating factors, and associated emotions through dialogic face-to-face interviews using phenomenology.

Purposive sampling in this phenomenological inquiry allowed me to recruit donors who met inclusion criteria. Participants were recruited from CHOP's neonatal intensive care unit in Northeastern Pennsylvania, so their lived experiences may not be representative of women in other areas of the country. Although CHOP is in Northeastern Pennsylvania, many patients travel to CHOP for specialized care. Six participants resided in Pennsylvania (50%), 3 in New Jersey (25%), 1 in New York (8.3%), 1 in Maryland (8.3%) and 1 in Alaska, (8.3%). All the participants self- identified as White, which may not reflect the experiences in women of another race or in more ethnically diverse regions in the U.S.

The study's site was a level IV NICU in a specialized children's hospital with an on-site milk bank, which may not reflect the experience in other NICU settings without an on-site bank. Additionally, nursing staff in the CHOP NICU all take a two-day intensive course on human milk and breastfeeding and are highly engaged in the provision of evidence-based lactation

interventions, care, and support. This may not be representative of nursing staff and care in other NICUs.

Another limitation is time, as data may be reflective of the specific period in which interviews were performed, and may or may not be influenced by current events and recent publications related to milk donation. Research quality in qualitative research is heavily dependent on the individual skills of the researcher, and more easily influenced by the researcher's personal biases and idiosyncrasies (Anderson, 2010). For this reason, I utilized bracketing and reflective journaling.

Implications of Findings

I undertook this study to evoke the rich meaning of the lived experience of milk donation. Major themes that emerged were: A ripple of hope and help, a dynamic interplay of nurturance, standing on the shoulders of others, and sharing their story. The themes all reflected a positive and valuable experience. The first theme expressed the ripple effect of the positive emotions experienced by each participant. The dynamic interplay of nurturance demonstrates the participants' knowledge that their donation was helping another infant and family, and how that lead to her feeling good while acting as a motivating factor. The third theme, standing on the shoulders of others, illuminates the staff as the central facilitating factor in donation and helps us

understand the elements of that relationship. Lastly, every participant wanted to share her story and teach others about donation because she wanted other women to have the same experience.

The participants in this study had unique and compelling stories to share. They were all committed to sharing the lived experience by describing, in an authentic manner, those experiences and emotions that were memorable for them. Understanding the participants lived experience, from their own vantage points and perspectives, made their lived realities more meaningful to me.

Conclusion

Although this study's sample was small and results are not generalizable given the qualitative methodology used, this study's findings are consistent with the broader body of research related to milk donation. In this study, I examined the lived experience of milk donors to a hospital-based HMBANA milk bank. Through phenomenology, their lived experience provided meaning and contribution to nursing science. Per Husserl (1960), science of experience is to be viewed as science of fact, as where there is a new experience, a new science must arise (Husserl, 1960). Mothers' own voices lent a voice to the lived experience of the milk donor, which has further contributed to nursing science.

This study adds to the growing body of research on milk banking and donation. Based upon the strength and limitations of this study's findings, the following implications for nursing and recommendations for future research are made.

Implications for Nursing Practice

This study illuminates the lived experience of milk donation for this group of mothers. I explored facilitating and motivating factors and associated emotional experiences. All participants named the nursing staff as their greatest facilitating factor during their experience. Recommendations for practice include increasing nursing education practices regarding milk donation, and the role of the professional nurse in supporting and educating potential and current donors. It is imperative that nurses be aware of the integral role they play in donation, and to understand that their role encompasses both educational and emotional support.

Nursing staff provides front-line donation education and support. Health care providers should ensure that breastfeeding and human milk are priority in the Neonatal Intensive Care Unit (NICU), and that families be encouraged to meet their personal goals for providing human milk to their child (Spatz, 2012). As per the literature and findings in this study, nurses need to be knowledgeable regarding the donation process and criteria to donate. They need to be able to

identify potential donors, educate them regarding the process of donation, and provide the necessary equipment to facilitate donation with ongoing support.

The clinical environment at CHOP is unique, where there is a 99% pumping initiation rate (D. Spatz, personal communication, February 6th, 2017). Many patients are transferred to the Special Delivery Unit (SDU) at CHOP during the later stages of pregnancy. This was the case for most participants. Patients at CHOP receive a personalized one-to-one patient consult that focuses on the provision of human milk as a medical intervention which utilizes the 10 Step Model for Human Milk and Breastfeeding (Spatz, 2006).

Prior to the study's initiation, I took a tour of the neonatal unit and the Mother's Milk Bank (MMB), and accompanied the lactation director on a prenatal consult to learn more about the clinical environment. Both parents were asked to be present during the consult, where they were educated regarding the use of human milk for their infant. At the end of the meeting, both parents were knowledgeable regarding the use of human milk as a medical intervention for their infant, how to use and assemble/disassemble their pump, how to maintain and clean their supplies, and how to properly store their milk.

It was during this consultation that the family learned about donor milk, its use on the unit, and the possibility that they may be candidates to use and/or donate. Additionally, the patients' support person was given a role in the process to make things easier for the patient.

During this consult, I witnessed the father to be learning how to disassemble the pump and clean its parts. He was asked to take responsibility for this role at home and agreed. The consult was directed at both parents, providing them education with a detailed plan. The lactation director ended the consult by explaining that staff would be available around the clock for any additional questions and concerns, and gave them her contact information.

Donating milk leads to a positive emotional experience. The interplay of nurturance could be discussed during patient education with potential donors. This may increase their desire to donate. If potential donors understand that donating can help them to feel good and bring forth a positive emotional experience, they may be more likely to donate. It is possible that the results of this study may have the potential to be used to create a tool to assist individuals who may be considering donation. Participants enjoyed sharing their stories with others and teaching them about donation. The creation of social networking sites and/or peer support groups linking HMBANA donors who have completed the donation process with mothers who are considering or just beginning to donate can lead to positive outcomes for new donors through increased education and support.

Implications for Nursing Education

Given the findings of this research, there are several recommendations which academia may consider implementing, in order to increase nurses' knowledge related to donation practices.

Because there are so few milk banks in the United States as opposed to other countries, healthcare professionals are seldom exposed to the phenomenon of milk banking (Woo & Spatz, 2007). It is recommended that education on donor milk banking be a part of nursing school curricula at both the undergraduate and graduate level to increase the level of competency among nurses to identify, educate, and support donors.

Nurses in this study were provided additional on-the-job training in milk donation, a unique element at CHOP that may have contributed to donors' positive experiences. Implementation of on-the-job training programs and continuing education practices in donor milk banking is recommended for nurses who work with pregnant and lactating women, and where donor milk is collected and/or used.

Implications for Health Policy

Although the intent of this qualitative study was not to determine health policy implications, participants' experiences reflected the need for continued support in health policy, as did the reviewed literature. All the participants in this study had access to a breast pump. The CHOP NICU provides a breast pump at every bedside to facilitate the ease of moms pumping. The lactation team at CHOP works to ensure that mothers can easily access a breast pump and supplies, which are necessities for donors at hospital discharge. It is evident that continued and

increased support and reimbursement from insurance companies to institutions and patients for breast pumps and supplies is vital for mothers to be able to donate their milk.

Currently, the Affordable Care Act (ACA) is in danger of repeal under the new administration of President Trump (Beck, 2017). The ACA includes a clause that is specific to breast-feeding and covers lactation support and counseling. These include lactation education, consulting services, equipment and supplies, such as pumps, and infrastructure, such as pump rooms and break time (Beck, 2017). The type of pump a mother receives can be instrumental in her ability to establish and maintain her milk supply so that she can meet her breastfeeding goals. It remains unknown how the current political environment will continue to affect the healthcare of women and infants.

In many countries, donor milk banking has been incorporated into child health policy and regulation, and is promoted and supported (Mackenzie et al., 2013). Per the literature, a continued and increased support from state and federal agencies to integrate donor milk into the public health landscape is essential to increase donation rates in a nation where current national need is not met. Participants in this study donated to a HMBANA bank. Continued legislative and financial support from state and federal agencies is vital for HMBANA to continue operating and increasing the number of banks across the U.S. and Canada.

The current clinical environment limits the use of donor milk due to availability and affordability. In further support of health policy for donor milk, The American Academy of Pediatrics (AAP) has published an update of their 2012 policy statement regarding donor human milk (AAP, 2016). The AAP statement highlights continued support for HMBANA and donor milk practices, supports health care providers in educating the public regarding unsafe practices in milk sharing, and asks for policies to support that infants receive donor milk based on medical necessity, and not ability to pay (AAP, 2016). In addition, health care providers can continue to advocate legislative bodies for enhanced hospital policies that provide availability and affordability of donor milk for vulnerable and premature infants.

Recommendations for Future Research

Phenomenology supports the re-examination of a taken-for-granted experience, and, through examining the qualities of the experience, allows us to describe its essence. Further phenomenological research related to the lived experience of milk donation is warranted, given the limited research available. This study was conducted in the Northeastern region of the United States in a hospital-based HMBANA bank. Suggestions include repeating this study in other regions of the United States, and in community-based milk banks. Additional studies exploring use of the Spatz 10 Steps to promote and protect the use of human milk and breastfeeding for

vulnerable infants and the impact that may have on facilitating milk donation should be explored in other settings.

Although this study did not explore the concepts of self-esteem and self-efficacy, results of this study point towards a possible increase in both concepts among participants. Suggestions for future study include a separate study to further examine and measure each concept in milk donors. The lactation staff was considered the core facilitating factor in donation, therefore, an exploration of the experience of the facilitating provider can provide insight into the counseling experience through their world lens and perspective. This could aid in the way staff is trained, counseled, and supported. This could be accomplished through phenomenological inquiry.

Exploring the lived experience of milk donors in other countries and/or cultures where donor milk banking has been incorporated into child health policy and promoted could aid in the creation of better interventional programs in the United States to recruit donors. We could develop a foundation of a more concrete logic by understanding the experience one arrives at through an exploration of consciousness in donors representing different cultural, geographic and ethnic backgrounds under different healthcare delivery systems.

As a frame of reference, phenomenology serves as a philosophical base from which researchers can explore the nature of that being studied and formulate appropriate research

questions (Schultz & Cobb-Stevens, 2004). The philosophical theory of "wholes" and "parts" could aid in further exploration of the phenomena of milk donation reflecting on the human condition through an understanding of the personal experience in women of other cultures. Findings from these types of studies could enhance and promote milk donation in the United States and abroad.

In the United States, there are women who continue to donate milk through informal means. The new AAP policy statement on donor milk includes support for health care providers in educating the public regarding unsafe milk practices (AAP, 2016). Learning about the lived experience of the donor who donates informally can provide insight and add to the body of knowledge regarding donation. Such knowledge could aid providers in effectively educating women regarding unsafe milk practices.

Although there has been some research on the donation experience for a bereaved mother, it would be important to learn even more about the experience from their perspective. Bereaved mothers were excluded from this study, as I believed their unique emotional experience requires a separate research study.

Personal Reflections

I have come to feel as if this work has chosen me. As a neonatal nurse, I've cared for many infants who were candidates for donor milk, while as a post-partum nurse I've cared for

potential donors. The institution neither used nor accepted donor milk. It was not a part of the institution's culture. Many nurses I worked alongside did not know that milk donation existed.

Over the years, donor milk banking has become more popular with more NICUs utilizing evidence-based practice by providing donor milk when an infant's mothers own milk is unavailable. Before the use of commercial formula, however, it remains underutilized and undervalued in neonatal care. This study validated my lifelong commitment to seek additional ways to support and promote human milk donation and banking through research, science and education.

Each donor that I spoke with left an impression on my heart. I will always remember them. As I reflect on their stories, I admire the participants' willingness to share their experiences and for their strength and perseverance. They were so grateful for their opportunity to give back and help others, and while doing so, had a positive emotional experience that they wanted to share. The nursing profession will be enriched, due to these participants putting a voice to the phenomena of milk donation. I remain eternally grateful for every participant in this study, for sharing their lives with me, and in turn, brightening mine.

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Appendix A

CHOP Approved Consent Form

The Children's Hospital of Philadelphia®
RESEARCH INSTITUTE

INSTITUTIONAL REVIEW BOARD

Date: October 21, 2015

To: Diane Spatz
CC: Elizabeth Froh
From: The Committees for the Protection of Human Subjects (IRB)

Re: IRB 15-012386, **Protocol Title:** The Lived Experience of the Human Milk Donor
Sponsor or Funder: University of Pennsylvania

IRB SUBMISSION: EXEMPTION GRANTED

Dear Dr. Spatz,

The study referenced above was reviewed by the IRB on October 21, 2015. The IRB has determined it is exempt from IRB review per 45 CFR 46.101(b)(2).

Document(s) Reviewed:

- Protocol, dated October 19, 2015
- Consent Form, dated October 13, 2015 (uploaded October 19, 2015)
- Qualitative Interview Guide, uploaded September 29, 2015
- Appendix A - Face Sheet, uploaded September 29, 2015
- Appendix B - Demographics Questions, uploaded October 19, 2015
- Recruitment Flyer, uploaded September 21, 2015
- Molloy College IRB Correspondence, dated May 28, 2015
- Proposal Defense Approval, signed April 23, 2015

If you change protocol design in any way, please submit an amendment to the IRB.

Staff change amendments are not required for exempt studies. It is the Principal Investigator's responsibility to ensure that all study team members have up to date human subjects training, no conflicts of interest, and appropriate credentials for their role in the research.

3535 Market Street, Suite 1200, Philadelphia, PA, 19104
Tel: 215-590-2830
Email: IRBOffice@email.chop.edu
Website: https://irb.research.chop.edu/

If you have any questions, please click on the IRB# (above) and contact the IRB analyst listed in the study work space.

DHHS Federal Wide Assurance Identifier: FWA0000459

IS_020

**** *This memorandum constitutes official CHOP IRB correspondence.* ****

3535 Market Street, Suite 1200, Philadelphia, PA, 19104
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Appendix B: Demographic Questionnaire

Subject ID # _____ Demographic Questions

Please provide your answer in the blank lines.

Age: _____

Marital Status: _____

Race: Circle One: White African-American Hispanic or Latino Asian Other

What is your child's diagnosis? _____

Are you a first time milk donor? _____yes _____no

If you answered no to the above question:
Have you ever been compensated (paid) to donate your milk in the past? _____yes _____no

How many times have you been pregnant? _____

Do you have other children at home? _____yes _____no

If yes, please list the ages of your children_____

Did you breastfeed? _____yes _____no

For each child you breastfed, please write the total duration of breastfeeding (in months) and if you exclusively breastfed or used formula as well

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Have you ever used donor milk in the past with your other children? _____yes _____no

If yes, please explain: _____

Please check which steps you have already completed in order to donate your milk at CHOP.

_____ Initial Screening Done
_____ Long Form Paperwork& Health Provider Form Done
_____ Blood Work Done
_____ Approved to Donate
_____ Have Already Donated Milk

Please share anything else you wish to add _____