

**STATUS OF HUMAN MILK DONATION AND ASSOCIATED KNOWLEDGE,  
ATTITUDES AND PERCEPTIONS OF PRE-NATAL AND POST-NATAL WOMEN AT  
ST. FRANCIS HOSPITAL, NSAMBYA, KAMPALA CITY**

**BY**

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UNIVERSITY**

**OCTOBER, 2024**

**DECLARATION**

I declare that this dissertation is original work and has never been presented for any award in any other institution.

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**APPROVAL**

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Date

.....  
Date

## **DEDICATION**

I dedicate this dissertation to my lovely daughter Kobusinge Theodora Adriel. Never be afraid to chase your dreams. To God be the glory.

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## LIST OF ACRONYMS

ACOG	American College of Obstetricians and Gynaecologists
AIDS	Acquired Immune Deficiency Syndrome
BFHI	Baby Friendly Hospital Initiative
DHM	Donor Human Milk
EFCNI	European Foundation for the Care of Newborn Infants
ELBW	Extremely Low Birth Weight
FDG	Focus Group Discussion
HIV	Human Immunodeficiency Virus
HMB	Human Milk Bank
HTLV	Human T-Lymphotropic Virus Type 1
IRB	Institutional Review Board
IYCF	Infant and Young Child Feeding
KII	Key informant Interview
LTLT	Low Temperature Long Time
MIYCAN	Maternal, Infant, Young Child and Adolescent Nutrition
MOM	Mother's Own Milk
MS	Multiple Sclerosis
NDP	National Development Plan
NGT	Nasogastric Tube
NEC	Necrotizing Enterocolitis
NICU	Neonatal Intensive Care Unit
ROP	Retinopathy of Prematurity
SD	Standard Deviation
SDGs	Sustainable Development Goals

UBOS	Uganda Bureau Of Statistics
UDHS	Uganda Demographic and Health Survey
UNICEF	United Nations Children's Fund
VLBW	Very Low Birth Weight
WHO	World Health Organization

## ABSTRACT

Human milk donation is a growing phenomenon worldwide and Uganda is one of the countries that have embraced the use of donor human milk (DHM) to improve the survival rates of preterm babies. Despite the launching of the first human milk bank (HMB) at St. Francis hospital, Nsambya in November 2021, the HMB was challenged with small number of milk donors as little as six women donating their breast milk per month. Little was also known about whether mothers understand the concept of human milk donation, their attitude towards the practice and the status of human milk donation at the hospital.

The purpose of this study was therefore to establish the status of human milk donation and the associated knowledge, attitudes and perceptions of pre-natal and post-natal women at St. Francis hospital Nsambya, Kampala City. The study adopted a cross-sectional design with both quantitative and qualitative approaches deployed to obtain statistical information and detailed narratives about human breast milk donation. A sample size of 190 (95 pre-natal and 95 post-natal women) was used for quantitative data collection and 8 milk donors and 10 knowledgeable health workers were used for the purpose of qualitative data collection. Statistical analysis was conducted using SPSS 22 to determine descriptive and inferential statistics and data obtained from the focus group discussion and key informant interviews was transcribed, coded and triangulated to obtain thematic information flow patterns on factors that facilitate and constrain human milk donation among mothers.

The study revealed a low uptake of human milk donation at the hospital and that only 20 (10.5%) of the interviewed pre-natal and post-natal women had ever donated their breast milk. Further, only 90 (47.4%) of these women had previous information on human milk donation services. There was a statistically significant relationship established between the women having previous information on human milk donation and them donating their breast milk. ( $p < 0.001$ ).

The mean knowledge score of post-natal women 7.57 (SD=2.36) was higher than that of pre-natal women 6.80 (SD=2.04). In addition, the mean attitude score of post-natal women 44.36 (SD=8.174) was higher than that of pre-natal women 38.82 (SD=2.39). There was a statistically significant relationship between the women's attitude and human milk donation ( $p < 0.001$ ) and women who had primary level of education and below were less likely to donate their breastmilk (OR 0.136; 95% CI: 0.035- 0.528;  $p < 0.05$ ).

Milk donors and key informants perceived human milk donation as a safe and lifesaving practice. Facilitators of human milk donation expressed included: past experiences, having excess breastmilk, and verbal encouragement to donate breast milk whereas barriers expressed included; fear of screening, insufficient breastmilk and lack of incentives.

In conclusion, this study showed that there were few women donating their breast milk and that most women did not have previous information on human milk donation. Human milk donation services at the hospital were associated with the pre-natal and post-natal having previous information on human milk donation services, the number of children they had as well as their attitude. In addition, there was a knowledge gap about the concepts of human milk donation among the pre-natal and post-natal women despite the fact that majority having a good attitude.

Key words: donor human milk, human milk donation and human milk bank

## CHAPTER ONE: INTRODUCTION

### 1.1 Background

Donor Human Milk (DHM) plays an imperative role as a substitute for infant formula if the mother's milk is not available (Yang et al., 2020). It is recommended that DHM is given in a situation where there is lactation insufficiency; when breast milk is inappropriate for example when a mother has a human T-lymphotropic virus type 1 (HTLV-1) infection or when the mother uses medications contraindicated during breastfeeding (Smyk et al., 2021).

Donor human milk is also a good alternative for vulnerable neonates including preterm babies who have an immature gastrointestinal tract and comparatively poor immune function which makes them susceptible to various complications (Tian et al., 2021). Donor human milk may be given to these babies whose mothers are unable to initiate milk expression in the neonatal intensive care unit (NICU) to prevent infectious diseases, enhance feeding tolerance, improve neurocognitive function, and other long-term health benefits due its anti-microbial and anti-inflammatory properties (Jahan et al., 2022). In addition, DHM is cost-effective as it lowers the expenditure for individuals and families by reducing the length of hospital stay (Natal et al., 2018).

Globally, the number of babies preterm is on the raise with an estimated 13.4 million babies born preterm as of 2020 (WHO, 2023). The uppermost rates of preterm birth globally are reported to be in Sub-Saharan Africa and Asia which is at 60% and of which over 80% of these preterm babies die annually due to complications related to preterm birth (Wagura et al., 2018). Uganda ranks 28th worldwide in preterm births, with an estimated 13.6 per 1,000 live births (Ssekandi, 2020) and complications due to prematurity accounting for 31% of deaths of these neonates (Tibaijuka et al., 2021).

In order to curb the mortality rate among preterm babies, various interventions like neonatal resuscitation, kangaroo mother care, use of continuous positive air way pressure, use of surfactant and the use of DHM in preterm babies whose mothers have no breast milk have been put in place to increase their survival rates during hospitalization (Kirabira et al., 2018). The practice of using DHM is however still a growing phenomenon globally with many infants benefiting from DHM due to the fact that its more tolerable, reduces the incidence of infections, less necrotizing

enterocolitis (NEC), and decreased lengths of hospital stay (Ahmed et al., 2024). In 2022, the World Health Organization (WHO) recognized that over 60 countries had established human milk banks (HMBs) globally with relatively small but increasing numbers of human milk banks functioning in low-income and middle-income countries (WHO, 2022). Brazil is widely acknowledged to have the most extensive and perhaps the best-organized system of human milk banking worldwide (Petherick, 2015).

On the contrary, Africa has not yet fully embraced human milk donation probably due to cultural and religious factors (Iloh et al., 2018). Uganda is one of the countries that have embraced human milk donation with the first HMB being launched in St. Francis hospital, Nsambya to provide safe and quality DHM milk to preterm babies (Ahmed et al., 2024). However, the practice of human milk donation in Uganda is challenged by many factors such as the fact that little is known about, the levels of breast milk donation, whether breast feeding mothers understand this concept, and the way they feel about donating their breast milk.

## **1.2 Problem Statement**

Globally, the need for Donor Human Milk (DHM) is on the rise to cater for the increasing case of preterm babies and complicated pregnancy outcomes. The situation is more precarious in babies who lose their mother during childbirth and in some cases mothers with rare infections and those taking medications that are contraindicated in breastfeeding (Smyk et al., 2021). More recently, the demand for DHM among vulnerable infants exceeds the supply (Kaech et al., 2022), implying a growing challenge of preterm birth and or related complications. The incidence of preterm birth is increasing globally. Out of about 140 million babies born annually, an estimated 13.4 million were preterm as of 2020 (WHO, 2023). Moreover, approximately 70% of neonatal deaths, 36% of infant deaths, and 25–50% of cases of neurological impairment in children can be attributed to preterm births (Walani, 2020). Uganda ranks highly among countries with preterm birth challenges. An estimated 13.6 per 1,000 live births are preterm in Uganda (Ssekandi, 2020) and complications due to prematurity accounting for 31% of deaths of these neonates (Tibaijuka et al., 2021), posing a serious challenge to the healthcare system. The absence of the institutional supply of DHM within the public health system further complicates the options available for therapeutic treatment of preterm babies in need of breastmilk. St. Francis Hospital, Nsambya is currently the

only private not for profit facility providing DHM services in the country yet it faces challenges of insufficient DHM to meet the demand for premature infants hospitalized within the hospital.

Therefore, given the high risk of mortality among preterm babies due to inadequate access to DHM, and the increasing need for this service in Uganda's health care system, the purpose of this study was to assess the status of human milk donation and the associated knowledge, attitudes and perceptions of pre-natal and post-natal women at St. Francis hospital Nsambya, Kampala City.

### **1.3 Study objectives**

#### **1.3.1 General objective**

The general objective of this study was to establish the status of human milk donation and the associated knowledge, attitudes and perceptions of pre-natal and post-natal women at St. Francis hospital Nsambya, Kampala City.

#### **1.3.2 Specific objectives**

The specific objectives of this study were to:

- (i) Establish the status of human milk donation and the extent of practice at St. Francis Hospital, Nsambya.
- (ii) Assess the knowledge of pre-natal and post-natal women in regard to human milk donation.
- (iii) Explore the attitudes and perceptions of pre-natal and post-natal women towards human milk donation.
- (iv) Identify the factors that facilitate and constrain human milk donation among mothers.

### **1.4 Research questions and indicators**

Table 1 shows research variables, their specific objectives, research questions and indicators explored while conducting the study.

**Table 1: Linking research variables, specific objectives, research questions and indicators**

<b>Variable</b>	<b>Specific Objective</b>	<b>Research question</b>	<b>Indicators</b>	
<b>Human Milk Donation (Dependant variable)</b>	Assess the level at which human milk donation is being practised at St. Francis Hospital, Nsambya.	How many pre-natal women have previously donated breast milk?	The percentage of pre-natal women that have previously donated breast milk.	
		How many post-natal women have previously donated breast milk?	The percentage of post-natal women that have previously donated breast milk.	
		How many pre-natal women have previous information on human milk donation?	The percentage of pre-natal women that have previous information on human milk donation.	
		How many post-natal women have previous information on human milk donation?	The percentage of post-natal women that have previous information on human milk donation.	
	Identify the factors that facilitate and constrain human milk donation among mothers.		What are the individual, social and systemic facilitators of human milk donation?	Individual, social and systemic facilitators of human milk donation.
			What are the individual, social and systemic barriers to human milk donation?	Individual, social and systemic barriers to human milk donation

Variable	Specific Objective	Research question	Indicators
Knowledge <b>(Independent variable)</b>	Assess the knowledge of pre-natal and post-natal women in regard to human milk donation.	to human milk donation?	
		How many pre-natal women are knowledgeable about human milk donation?	The percentage of pre-natal women knowledgeable about human milk donation.
Attitude <b>(Independent variable)</b>	Explore the attitudes and perceptions of pre-natal and post-natal women towards human milk donation.	How many post-natal women are knowledgeable about human milk donation?	The percentage of post-natal women knowledgeable about human milk donation.
		How many pre-natal women have a good attitude towards human milk donation?	The percentage of pre-natal women with a good attitude towards human milk donation.
		How many post-natal women have a good attitude towards human milk donation?	The percentage of post-natal women with a good attitude towards human milk donation.

### 1.5 Significance of the study

Establishing levels of human milk donation at the facility provided an opportunity to estimate the number of women participating in this life-saving practice. Depending on the numbers estimated, new methods would be devised to educate and engage potential donors about the importance of donating milk, the process involved, and the impact it would have on the vulnerable infants. This

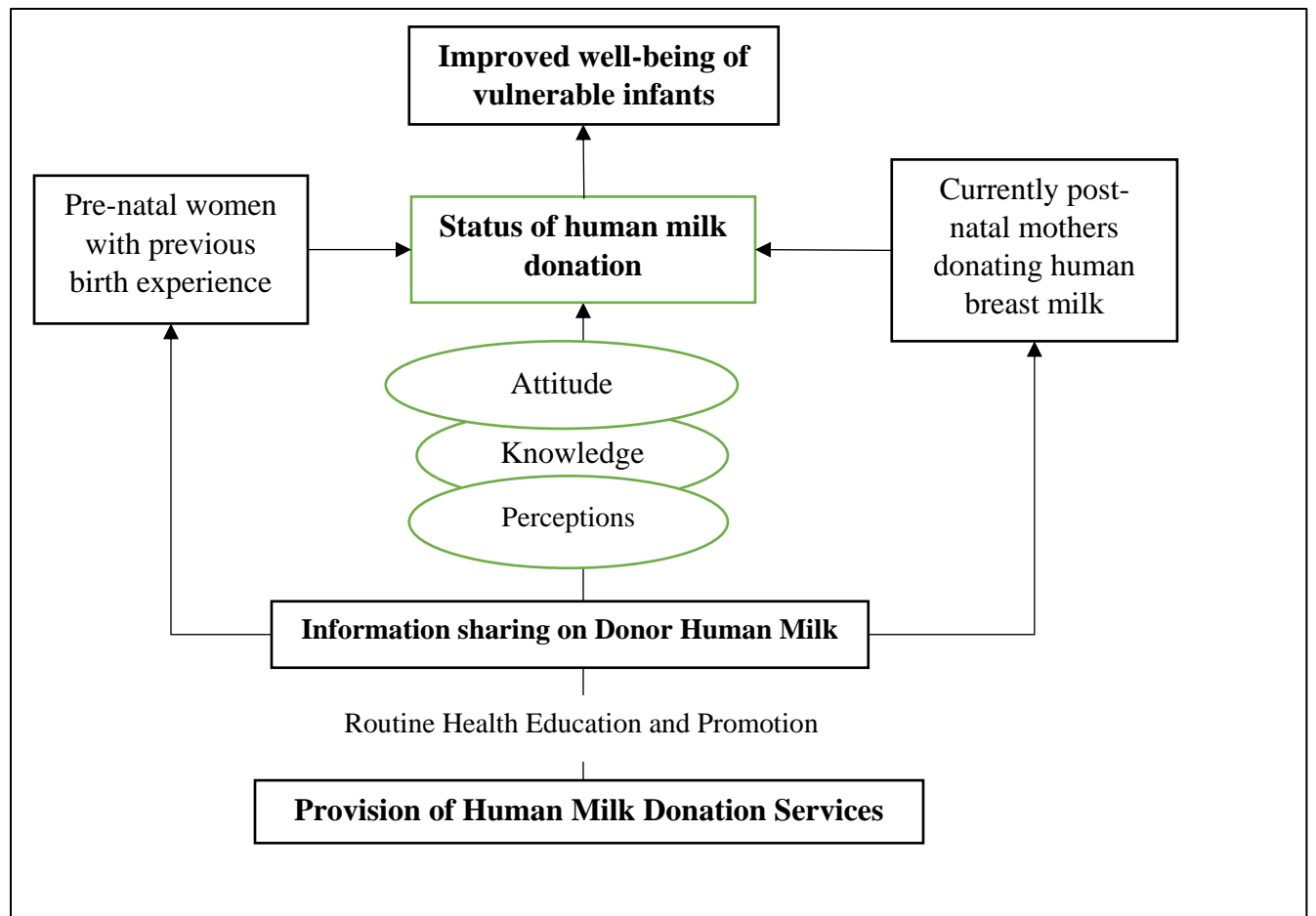
in turn would help on increasing donor participation and promoting a culture of milk donation within the hospital community.

Knowledge on human milk donation plays a very important role in influencing a mother's decision to donate. Thus, assessing the knowledge of pre-natal and post-natal women would evaluate whether these women are conversant about the requirements needed to be a milk donor, importance of DHM and storage and handling of DHM. Knowledge gap among these women would probably lead to low rates of donation as they are not aware of the essence of human milk donation and the criteria needed to be a milk donor.

In addition, establishing the facilitators and barriers of human milk donation would highlight what the facility was doing right and what was lacking in regard to human milk donation. Identifying the loop holes in human milk donation at the facility would be of importance in laying strategies to improve on milk donor rates.

Lastly, given the fact that little research has been conducted in the field of human milk donation in Uganda as it's a new phenomenon. This research study being the first of its kind would add information to the research field for future researchers who would intend to partake in writing research papers on human milk donation in Uganda.

## **1.6 Conceptual framework of human milk donation**



**Figure 1: Conceptual framework of the study**

The human milk bank at St. Francis Hospital, Nsambya provides human milk donation services to mothers which include: recruiting and screening of potential milk donors, hygienic pumping of breast milk from milk donors, heat treatment (pasteurization) of donor human milk (DHM) to kill harmful bacteria and viruses and distribution of DHM to vulnerable infants in need of it. Routine health education talks by health workers on safe practices during pregnancy, the benefits of breast-feeding infants and donating human milk are accorded to women who attend the pre-natal and post-natal clinics at the hospital every morning before seeing the doctor as part of the hospital policy.

Information sharing on human milk donation services at the hospital not only informs the pre-natal and post-natal women on the availability of the human milk bank within the hospital but empowers them with information on milk donor requirements, benefits and the storage and handling of donor

milk. Nevertheless, the decision of these women to donate their breast milk mainly depends on their attitude, knowledge and perceptions on human milk donation services.

Pre-natal and post-natal women perceiving human milk donation as a lifesaving practice can positively impact their attitude towards donating their breast milk. In addition, these women being knowledgeable about the importance of DHM and procedures involved in donation can also attract them to donate.

In conclusion, more women donating their breast milk at the hospital would ensure a continuous flow of DHM to meet the growing need hence improved well-being of vulnerable infants in need of DHM. This is because the use of DHM milk in preterm babies whose mothers do not have sufficient breast milk has been linked to less development of complications like necrotizing enterocolitis (NEC) (Yang et al., 2020).

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Breast milk composition and its benefits**

Breast milk is the ideal food for new-borns and breastfeeding is one of the most effective interventions to ensure child health and survival (Child & Nutrition, 2021). The World Health Organization recommends early initiation of breastfeeding within the first one hour of birth and exclusive breastfeeding for the first six months of life. From six months of age, complementary foods should be introduced in addition to breastfeeding up to two years and beyond (WHO, 2023).

Breast milk comprises of carbohydrates, protein, fat, vitamins, minerals, digestive enzymes and hormones (Lyons et al., 2020). In addition to these nutrients, it also contains immunological properties such as macrophages, stem cells, and numerous bioactive molecules (Martin, Ling, & Blackburn, 2016). These many components in breast milk make it more suitable for infant consumption as compared to other breast milk substitutes (Ahmed et al., 2024).

There are numerous advantages of breastfeeding infants. Unlike infant formula, breast milk changes over time to meet the needs of the growing child and it also has immunological properties that protect babies from illnesses (CDC, 2021). Some other benefits of breast milk include; it is easily digested, it contains all the nutrients needed for healthy growth and development, and it is readily available (Child & Nutrition, 2021).

### **2.2 History of human milk donation**

Human milk donation is a process in which a mother expresses her breast milk after which it is processed by a human milk bank for use by a recipient that is not the mother's baby (Natal et al., 2018). Previously, wet nursing was a common practice where a lactating mother would directly breastfeed an infant whose mother was unable to provide breast milk for them (Haiden & Ziegler, 2017). Unfortunately, with the increasing numbers of various transmissible infections like HIV/AIDS and hepatitis B, wet nursing is phasing out and more people are embracing DHM obtained through HMBs (Fang et al., 2021).

Apparently, human milk donation is not a new practice and it can be traced back to as far as 1909 when the first human milk bank (HMB) opened in Vienna, Austria. This was then followed by the

first American milk bank in Boston in 1910, known as the Boston Wet Nurses Directory, and the third one in Germany in 1919. In 1985, the Human Milk Bank Association of North America (HMBANA) established guidelines to ensure the safety and quality of DHM for neonates in the intensive care unit (ICU) whose mothers had no breast milk (Moro, 2018). Since then, many human milk banks have been established globally to better neonatal health through the provision of safe DHM. In 2020, it was reported that there were over 756 milk banks in 66 countries (Fang et al., 2021). Brazil takes the lead with 214 active milk banks followed by South Africa with 44 milk banks (Altobelli et al., 2020). Uganda has only of recent opened the first human milk bank in November 2021 at St. Francis hospital, Nsambya a hospital known for its competence in the management of preterm babies and it registers about 35 to 40 premature infants each month (Namuddu et al., 2023).

Even though human milk donation is a growing phenomenon, the practice varies greatly between different parts of the world due to a variety of reasons such as limited resources to set up infrastructure and limitations due to religious and cultural beliefs (Doshmangir et al., 2019).

### **2.3 Considerations for human milk donation**

Protecting the health of babies who receive donor human milk from human milk banks is very important. Unfortunately, there is no global coordinating body that has issued minimum quality, safety and ethical standards to inform national policies on DHM thus milk banks adapt to the restrictions, resources and needs of their local area (Fang et al., 2021). Despite the absence of guidance from a global coordinating body, it is standard health procedure that all milk donors undergo screening just like blood donors in order to rule out certain conditions like hepatitis B and C, HIV, syphilis and the human T cell leukemia virus (Haiden & Ziegler, 2017). Medical history is also taken to identify conditions that would prevent a lactating mother from donating such as chronic health condition e.g., multiple sclerosis (MS) or a history of cancer (CHOP, 2022).

### **2.4 Benefits and shortcomings of donor human milk**

Donor human milk is of very grave importance to low birth weight (LBW) infants, including those with very low birth weight (VLBW), who cannot be feed on their mother's milk (Altobelli et al., 2020). This is because unlike other breast milk substances, DHM contains active enzymes that

enhance the maturation of the underdeveloped gut, more tolerable and contains anti-infective properties which protect the new-born from infections (Yang et al., 2020). In addition, it is associated with lower risks of necrotizing enterocolitis, retinopathy of prematurity, and sepsis in preterm infants (Kantorowska et al., 2016) It can also be given to sick infants and should be fortified to ensure optimal nutrient intake and this involves supplementing the milk with specific macronutrients, vitamins, and minerals (Pound et al., 2020).

Despite DHM being more advantageous than other breast milk substitutes for vulnerable babies whose mothers have no breast milk, it can also pose a great risk to babies as it can expose them to infectious diseases, including HIV, to chemical contaminants, such as illegal drugs, and to a limited number of prescription drugs that might be in the human milk, if the donor has not been adequately screened (FDA, 2018).

## **2.5 Human milk bank requirements**

Human milk banks are established to ensure the quality and safety of donor human milk (Gutierrez Dos Santos & Perrin, 2022) and the Centres for Disease Control and Prevention (CDC) describes human milk banking as a service which collects, screens, processes and dispenses by prescription human milk donated by lactating mothers who are not biologically related to the recipient infants (Unger & O'Connor, 2024).

In order to ensure the smooth running of a human milk bank, it should have an area for; acceptance, administration, preparation, and issuance of the breast milk, the refrigerators and freezers, a “dirty” room for cleaning all utensils, storing breast milk and one for mothers to sit and pump breast milk using breast pumps (EFCNI, 2018). In terms of management, human milk banks are managed by a senior midwife, a paediatrician or a senior scientist and nursery nurses handling the milk from donors (HMB, 2015).

Donor human milk requires collection, freezing, storage and pasteurization to ensure its safety before being distributed. Low-temperature long-time (LTLT) pasteurization, also known as the Holder method (HoP), is recommended to be the standard for DHM pasteurization to preserve key components. In this procedure, human milk is incubated for 30 min at 62.5 °C in a water bath or other devices that ensure effective heating (Wesolowska et al., 2019).

## **2.6 Factors that influence human milk donation**

Many factors influence mother's decision to donate or not to donate her breast milk. These factors can be subdivided into facilitators and barriers to human milk donation. Some barriers that have hindered human milk donation include: individual barriers like a mother not having sufficient breast milk and not qualifying for milk donation, systemic barriers like lack of milk banks and access to milk banks and social barriers like culture and religion (Doshmangir et al., 2019). Indeed, religion plays a big role in human milk donation and it has been indicated that mothers in Muslim communities are still hesitant about human milk donation (Karadag et al., 2015).

On the other hand, breastfeeding mothers donate their expressed milk for several reasons such as; commitment for donating, motivation in donating, and support (Rojjanasrirat et al., 2023) as expressed in one study. Another study showed that mothers donated their breast milk because of a general knowledge and recognition that human milk is better than formula milk and a strong belief in health workers (Magowan et al., 2020).

## **2.7 Knowledge on human milk donation**

Many countries have embraced the concept of human milk donation and have even started up many HMBs to cater for the increasing demand for DHM. Various kinds of research have been conducted to understand whether mothers understand this concept and its importance (Naidoo, et al., 2023). One study conducted in China among hospitalized mothers indicated that the answer rate about the knowledge on breast milk donation was not high (29.23%) (Zhang et al., 2020). Another study also conducted to assess the knowledge regarding human milk donation among 100 post-natal mothers in selected hospitals of Pune city in India showed the correct answer rate was also low with only 8(8%) mothers scoring highly (Pareshkumar Naik & Mahadalkar, 2020).

On the contrary, one study conducted in Italy among 3290 women to assess women's knowledge and attitude towards human milk donation showed that 76.57% were knowledgeable about human milk donation (Zobbi et al., 2021). In general, educating women on the benefits of mother's milk as well as donor breast milk and milk banks are an important public health initiative needed to increase acceptance of human milk as the most advantageous form of nutrition in infants (Pal et al., 2019).

## **2.8 Attitudes and perceptions on human milk donation**

The way mothers feel about and perceive the practice of HMD is very imperative. A qualitative study conducted to determine the perceptions of breastfeeding mothers on breast milk donation and the establishment of a human breast milk bank in Hong Kong indicated that participants expressed a positive attitude towards breast milk donation and the establishment of a breast milk bank (Leung & Yau, 2015). Another study conducted in Kenya among 868 mothers showed that majority (80%) of them had a positive attitude towards donating breast milk to a human milk bank (Kimani-Murage et al., 2019).

On the contrary, research conducted among Turkish women to assess their knowledge, attitudes, and behaviours on wet- nursing, milk sharing and HMB indicated mothers were hesitant to donate their milk to human milk banks. This is because of a belief in Muslim communities that accepting DHM creates a “kinship” between the donor’s children and the recipient of DHM and are therefore not allowed to marry each other (Ergin & Uzun, 2018).

Based on available information, there is gap in literature on knowledge and attitude on human milk donation in Uganda and Africa in general given that human milk donation is still a growing practice in Africa. This provided the basis of this investigation to understand the status of human milk donation and how it is influenced by knowledge, attitude and practices in the St. Francis Hospital Nsambya, the only facility providing these services in Uganda.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Study Area**

The study was conducted at St. Francis hospital, Nsambya because it housed the first human milk bank to be established in Uganda. The hospital is a Catholic Mission hospital that was founded in 1903 and it is owned by the Archdiocese of Kampala and managed by the Little Sisters of St. Francis of Assisi (UCMB, 2022). St. Francis hospital, Nsambya is located on Nsambya hill in Makindye division, which is one of the five divisions of Kampala the capital city of Uganda as indicated in Appendix 1.

The hospital has a bed capacity of 361 inpatients and it not only engages in patient care but also offers research and teaching. It also offers specialist services in emergency medicine, surgery, internal medicine, paediatrics and obstetrics and gynaecology (St. Francis Hospital, 2021).

### **3.2 Study design**

The study adopted a cross-sectional and descriptive design because there was a limited time frame and resources to conduct the research study thus multiple follow-ups and contact with study participants was not feasible. A cross-sectional study is defined as a research design in which data is collected from many different individuals at a single point in time (Wang & Cheng, 2020). Both quantitative and qualitative approaches were deployed to obtain statistical information and a wider perspective of the problem.

### **3.3 Study population**

The study was conducted among pre-natal and post-natal women who were attending the pre-natal and post-natal clinics respectively on the gazetted dates for data collection. The study population was heterogeneous in nature because it included both pre-natal and post-natal women. This allowed for a comprehensive understanding of the entire spectrum of experiences related to human milk donation. Pre-natal women provided insights into the attitudes and knowledge surrounding the concept of donation before they have personally experienced the process. On the other hand, post-natal women offered perspectives based on their actual experiences with breastfeeding, milk production, and potential challenges they may have encountered.

### 3.4 Selection of study participants

#### 3.4.1 Stratified simple random sampling of pre-natal and post-natal women

On the days gazetted for data collection at the health facility, women who were attending the pre-natal and post-natal clinics at the hospital were separated into two groups of pre-natal and post-natal women known as strata. The women in each group would then be allocated a number on a piece of paper for identification. The papers were then collected and underwent a raffle after which numbers would be chosen randomly (Eldridge, 2024). The target was to recruit at least 10 women from both the groups a day. Table 2 below shows the date of data collection, total number of attendance and number of women recruited for each group.

**Table 2: Selection of pre-natal and post-natal women**

<b>Date of data collection</b>	<b>Total attendance</b>	<b>Post-natal women selected</b>	<b>Pre-natal women selected</b>
23/Jan/2023	62	10	10
24/Jan/2023	73	7	10
25/Jan/2023	84	10	10
26/Jan/2023	61	9	10
27/Jan/2023	87	10	10
30/Jan/2023	77	10	10
31/Jan/2023	55	10	10
1/Feb/2023	82	10	10
2/Feb/2023	73	10	10
3/Feb/2023	71	9	5
	<b>Total</b>	<b>95</b>	<b>95</b>

#### 3.4.2 Snowball sampling of milk donors

Eight milk donors who had previously donated their breast milk were involved in a focus-group discussion. The women were obtained through the snowball method whereby an identified milk donor recommended other milk donors to the study investigator (Naderifar et al., 2017).

### 3.4.3 Purposive sampling of key informants

Ten knowledgeable health workers and other stakeholders who were actively involved in human milk donation within the hospital premises were selected to participate in the study. These included: 2 experienced nurses from the human milk bank, 1 skilled nutritionist specializing in infant feeding, 2 expert paediatricians with extensive knowledge in breastfeeding, and 5 experienced nurses from the baby unit (nursery) who have worked closely with donor milk recipients (Palinkas et al., 2015).

### 3.5 Sample size calculation

Given lack of information on the prevalence of human milk donation. Preterm births were used as a proxy for sample size estimation since preterm babies predominately rely of donated human milk. As such, the sample size for pre-natal and post-natal women was obtained using the Fisher et al., 1998 formula indicated below:

$$N = \frac{Z^2 pq}{e^2}$$

Where:

- N is the sample size
- $Z^2$  is the abscissa of the normal curve that cuts off an area  $\alpha$  at the tails
- e is the desired level of precision (i.e., the margin of error)
- p is the (estimated) proportion of the population which has the attribute in question, in this case, the number of preterm births is estimated 13.6 per 1,000 live births in Uganda (Ssekandi, 2020).
- q is (1 – p)

$$N = \frac{Z^2 pq}{e^2}$$
$$N = \frac{1.96^2 \times 0.136(1-0.136)}{0.05^2}$$
$$= 180 \text{ women}$$

Adjusting for a potential 5% non-response

$$n = N / (1 - Q)$$

Q- Proportion of expected non-response

$n=180 / (1-0.05) = 190$  women

All 190 women (95 pre-natal and 95 post-natal women) were interviewed as well as the 10 key informants and 8 milk donors.

### **3.6 Inclusion and exclusion criteria**

#### **3.6.1 Inclusion criteria**

Pre-natal and post-natal women included in the study:

- (i) Women of age 18 years and above.
- (ii) Women attending the pre-natal and post-natal clinics within the hospital premises.
- (iii) Women who voluntarily accepted to take part in the research and signed the informed consent.

#### **3.6.2 Exclusion criteria**

Pre-natal and post-natal women excluded from the study:

- (i) Women who had severe medical complications.
- (ii) Women who were diagnosed with postpartum depression or a severe mental health condition; and
- (iii) Women who had lost their babies.

### **3.7 Data collection**

#### **3.7.1 Data collection methods**

##### **(a) Face-to-face interviews**

The main method of data collection was face to face interviews guided by a structured questionnaire. Before administration of the tool, rapport was established with each of the selected participants and consent was sought using an information and consent form (Appendix 2). Identification numbers were allocated to each participant in order to separate the pre-natal women from post-natal mothers as well as to protect their identity.

### **(b) In-depth interviews**

In order to determine factors that facilitate and constrain human milk donation among mothers, in-depth interviews were conducted among ten (10) key informants. Informed consent was obtained prior the interviews and each key informant was also allocated a number from one to ten (1-10) to protect their identity. The questions in the interviews were open ended and the participants were allowed ample time to think questions through before giving a response. In addition, the sessions were recorded and notes taken in order not to miss out on valuable information.

### **(c) Focus Group Discussion**

In addition, one focus group discussion was also held with eight (8) milk donors in order to obtain further information on factors that facilitate and constrain human milk donation among mothers. Each milk donor signed an informed consent and was allocated a number from one to eight (1-8) to protect their identity. The milk donors were briefed about what the discussion would revolve around and the session was also recorded and notes taken. The focus group discussion was conducted in a well-lit and private room to prevent any interruptions.

## **3.7.2 Data collection tools and standardization**

### **(a) Structured questionnaire for pre-natal-and post-natal women**

The main tool for the study was a structured questionnaire (Appendix 3). It was mainly provided with closed ended questions to quantify responses provided by pre-natal and post-natal women. It had three sections (A, B and C) to collect the quantitative data on socio-demographic information, knowledge and attitude assessment respectively.

The questionnaire was pretested on 10 participants (5 pre-natal and 5 post-natal women) which accounted for 5% of the total sample size at the hospital. The data from the pre-test was not included in the final analysis. This procedure was done to ensure that all relevant data needed would be captured and necessary amendments to be made prior data collection. The methodology used to assess knowledge and attitude of pre-natal and post-natal women was adapted from a similar study conducted to assess lactating women's knowledge and attitude about donor human milk in China (Tian et al., 2021).

### **(b) Key informant interview guide**

The key informant interview guide comprised of eight (8) open ended questions to provide an opportunity for detailed description and explanation of issues by the key informants. This enabled limited interruption of information but also accommodated probing of more details using expression such as: “could you explain more” and “what do you think about.”

### **(c) Focus group discussion guide**

The focus group discussion guide comprised of 10 (ten) open ended questions to also enable probing. The questions the milk donors were asked revolved around their human milk donation experience at the hospital, what inspired them to donate and possible barriers around human milk donation.

**Table 3: Data types, collection methods, tools and participants**

<b>Type of data</b>	<b>Method</b>	<b>Data collection tool</b>	<b>Participants</b>
Quantitative	Face-to-face interviews with pre-natal and post-natal women	Structured questionnaire	190
Qualitative	Focus group discussion with milk donors	Focus group discussion guide	8
	Key informant interviews with knowledgeable health workers and other stakeholders	Key informant interview guide	10

## **3.8 Data analysis**

### **3.8.1 Scoring of knowledge on human milk donation**

In this study, 25 questions divided into two subscales were used to score the women’s; knowledge (13 questions) and attitudes (12 questions). The women were asked a series of 13 questions on milk donor requirements, benefits and the storage and handling of donor milk. These questions had three possible answers: “yes,” “no”, and “not sure”. The total score ranged from 0–13 points

with 1 point awarded for every correct answer and 0 points awarded for every wrong and uncertain answer. The cut-off points for total scores on knowledge were: 0-4 points as poor and 5-9 as average and 10-13 as good as detailed in section b of Appendix 3.

### **3.8.2 Scoring of attitude towards human milk donation**

The women were also asked a series 12 questions on the advantages, disadvantages, and use of donor human milk. The questions were answered using a 5- point Likert- type response scale ranging from “strongly agree” at 5 points, “agree” at 4 points, “neither agree or disagree” at 3 points, “disagree” at 2 points and “strongly disagree” at 1 point. Four questions (27, 29, 30 and 34) were scored as “strongly disagree” at 5 points, “disagree” at 4 points, “neither agree or disagree” at 3 points, “agree” at 2 points, “strongly agree” at 1 point. The total scores ranged from 12–60 points. The cut off points for total scores on attitude were: 12-36 as poor attitude and 37-60 as good attitude as indicated in section c of Appendix 3.

### **3.8.3 Statistical analysis**

Statistical analysis was conducted using SPSS 22 to determine descriptive and inferential statistics. Chi-square test was used to determine statistically significant relationships for example it was used to test for socio demographic characteristics associated with human milk donation. Variables with 0.05 as a test level, and ( $p < 0.05$ ) were considered statistically significant. ANOVA test was also used to test for difference in means of the knowledge and attitude scores of the pre-natal and post-natal women. There was a significant difference between means when ( $p < 0.05$ ). Binary logistic regression was also used to predict likely hood of sociodemographic characteristics influencing attitude and knowledge at 95% confidence interval and odds ratio greater than 1 implied there was a greater odds of the event happening.

Dummy variables were created for the variable knowledge in order to determine the association between knowledge and human milk donation. All those with a good knowledge score between (10-13) were considered as knowledgeable about the concepts of human milk donation whereas those with average knowledge scores between (5-9) and poor knowledge scores between (0-4) were considered as not knowledgeable about the concepts of human milk donation. For the purpose of assessing associations between variables, dummy variables were also formed for socio-demographic characteristics.

#### **3.8.4 Triangulation of qualitative information**

Data from the focus group discussion and key informant interviews was transcribed verbatim with the help of a research assistant. The researcher also transcribed and translated the transcripts to ensure validity. The transcripts were reviewed and compared to rule out discrepancies. The transcripts were then analysed using thematic analysis comprising of six stages: familiarization of the data, generation of codes, generation of themes, themes review, defining the themes and writing the report. Selected quotations from milk donors and key informants were used in the presentation of the study results and to maintain confidentiality pseudonyms coded as focus group discussion (FGD), milk donor (MD), key informant interview (KII) and respondent (R) were used. Milk donors were assigned numbers from 1-8 whereas respondents from key informant interviews were assigned numbers from 1-10. Research findings were presented as per order of the specific objectives being investigated in the research study.

#### **3.9 Ethical considerations**

Basing on existing ethical requirements, every participant was provided with a consent form as indicated in Appendix 2 and participation was voluntary. Information obtained from the participants was kept confidential and pseudonyms were used for reporting qualitative data. Approval to conduct the study research was obtained from the Kyambogo University Graduate School as indicated in Appendix 6 and St. Francis Hospital, Nsambya Institutional Review Board (IRB) as indicated in Appendix 7 (SFHN-2022-58). Since the research study was for a master's student and not a randomized clinical trial, UNCST approval was not obtained before conducting the research as per guidance from the St. Francis Hospital, Nsambya IRB. Additional permission to conduct the research was obtained from the administration of St. Francis hospital, Nsambya as indicated in Appendix 8.

## CHAPTER FOUR: FINDINGS

### 4.1 Socio-demographic characteristics of the pre-natal and post-natal women

A total of 190 (95 pre-natal and 95 post-natal) women were interviewed in the study. The socio-demographic characteristic age was categorized as below 35 years and older than 35 years because advanced maternal age starts at 35 years and older (ACOG, 2022) as shown in Table 4.

**Table 4: Characteristics of the pre-natal and post-natal women**

Characteristic	Pre-natal women		Post-natal women	
	Number (n)	Percentage (%)	Number (n)	Percentage (%)
<b>Age</b>				
≥ 35	18	18.9	28	29.5
<35	77	81.1	67	70.5
<b>Highest level of education</b>				
Diploma, Degree and above	72	76	40	42
Certificates	5	5	28	29
Secondary education	17	18	16	17
Primary education	1	1	11	12
<b>Marital status</b>				
Married	92	97	82	86
Single	3	3	13	14
<b>Occupation</b>				
Housewife	20	21	22	23
Employed	36	38	48	51
Self-employed	39	41	25	26
<b>Religious Affiliation</b>				
Christian	78	82	78	82
Muslim	14	15	12	13
Other religions	3	3	3	3
Unaffiliated	0	0	2	2
<b>Number of children</b>				
<3	90	94.7	84	88.4
>3	5	5.3	11	11.6

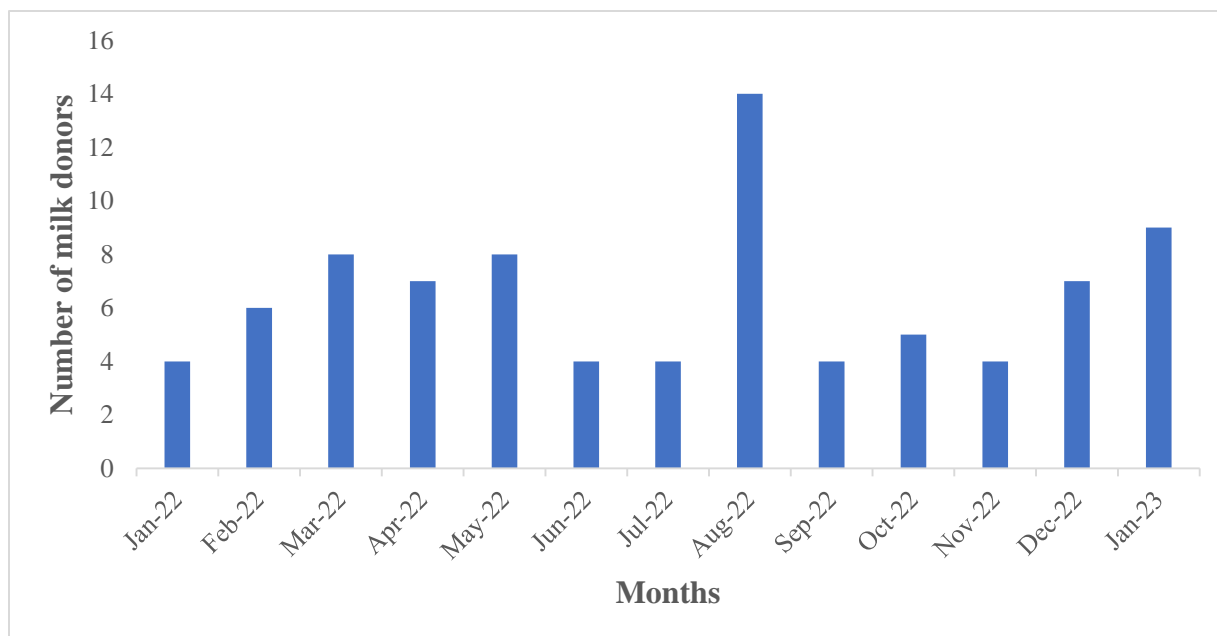
According to Table 4, majority of both pre-natal and post-natal women were aged below 35 years, accounting for 77 (81.1%) and 67 (70.5%) of the total, respectively. Most pre-natal women 72 (76%) had a diploma, degree, or higher education level, while 40 (42%) of the post-natal women had the same level of education. In terms of marital status, the study found that 92 (97%) of the pre-natal women were married, whereas 82 (86%) of the post-natal women were married. Regarding occupation, a higher proportion of pre-natal women were self-employed, with 39 (41%) falling into this category, while a larger percentage of post-natal women were employed, totalling 48 (51%).

Christianity was the dominant religion among both pre-natal and post-natal women, with 78 (82%) identifying as Christians. When considering the number of children, it was observed that 90 (94.7%) of the pre-natal women had less than three children, whereas 84 (88.4%) post-natal women had less than three children. The mode of delivery was only applicable to post-natal women. Out of the women in this group, 59 (31.1%) had given birth normally, while 36 (18.9%) had undergone a caesarean section.

## **4.2 Status of human milk donation**

### **4.2.1 Human milk donation at St. Francis hospital, Nsambya**

Given that not all milk donors were assessed by the study and the need for previous information on the numbers of milk donors in the past months, information on status of donation was from both primary and secondary data to cover the period of the January 2022 to January 2023. From the data collected, it was estimated that an average of six women per month had donated their breastmilk over this duration as shown in Figure 2.



**Figure 2: Level of human milk donation over a period of 1 year**

Source: St. Francis Hospital, Nsambya milk donor register (2023).

#### 4.2.2 Frequency of human milk donation of pre-natal and post-natal women

Majority of the women 170 (89.5%) had never donated their breastmilk. This implied that there was a low rate of human milk donation at the hospital. Among pre-natal women, 91(53.5%) had never donated while among post-natal women 79 (83.2%) had never donated. Of those who had donated 20 (10.5%), 16 (80%) were post-natal women whereas 4 (20%) were pre-natal women who had previous births as shown in Table 5.

**Table 5: Human milk donation among pre-natal and post-natal women**

Category	Has donated		p-value
	Yes n (%)	No n (%)	
Pre-natal	4 (20%)	91(53.5%)	0.005
Post-natal	16 (80%)	79 (46.5%)	
<b>Total</b>	<b>20 (10.5%),</b>	<b>170(89.5%)</b>	

### 4.2.3 Association between human milk donation and different variables

Statistically significant associations with human milk donation were determined using chi-square test. Pre-natal women and post-natal women having previous information on human milk donation services had an association with them donating their breast milk ( $p < 0.001$ ). Also, the attitude of these women had an association with human milk donation ( $p < 0.001$ ). In addition, a statistically significant relationship was determined between the number of children the women had and human milk donation ( $p = 0.049$ ) as shown in Table 6.

**Table 6: Association between human milk donation and different variables**

Variable	Has donated milk		P-value
	Yes n (%)	No n (%)	
<b>Age</b>			
≥ 35	7 (35.0)	39 (22.9)	0.234
<35	13 (65.0)	131 (77.1)	
<b>Level of education</b>			
Primary and below	2 (10)	10 (5.9)	0.474
Above primary	18 (90)	160 (94.1)	
<b>Marital status</b>			
Married	19 (95.0)	155 (91.2)	0.560
Single	1 (5.0)	15 (8.8)	
<b>Occupation</b>			
Housewife	4 (20.0)	38 (22.4)	0.810
Working	16 (80.0)	132 (77.6)	
<b>Number of children</b>			
>3	4 (20.0)	12 (7.1)	0.049*
<3	16 (80)	158 (92.9)	
<b>Access to information</b>			
Yes	19 (21.1)	71 (78.9)	<0.001*
No	1 (1.1)	99 (99.0)	

Variable	Has donated milk		P-value
	Yes n (%)	No n (%)	
<b>Knowledgeable about human milk donation</b>			
Yes	5 (17.2%)	24 (82.8%)	0.44
No	15 (9.3%)	145 (90.7%)	
<b>Attitude</b>			
Poor	3 (9.4%)	29 (90.6%)	<0.001 *
Good	17 (10.8%)	141 (89.2%)	

### 4.3 Access to information on human milk donation

#### 4.3.1 Frequency of pre-natal and post-natal women's access to information

Majority of the women 52.6% (100) had no previous information regarding human milk donation of which 61 (64.2 %) were post-natal women and 29 (30.6%) were pre-natal women as shown in Table 7. There was a statistically significant relationship using chi-square test between the category the women fell in and access to information on human milk donation ( $p < 0.001$ ).

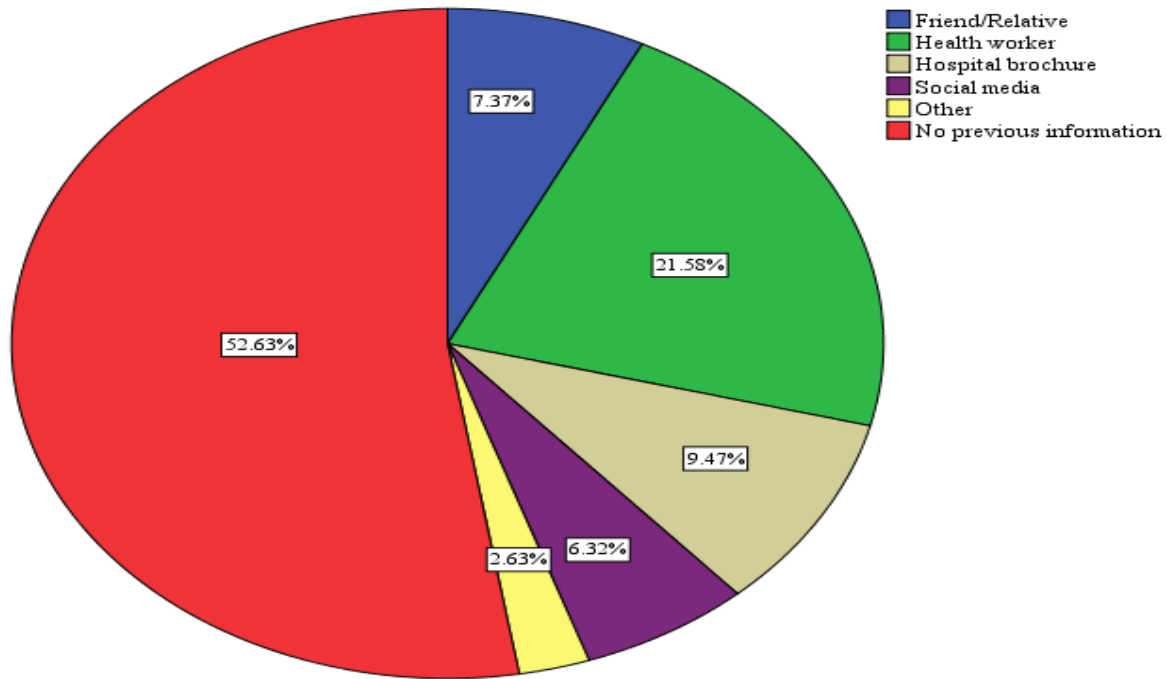
**Table 7: Access to information on human milk donation among pre-natal and post-natal women**

Access to information on human milk donation	Pre-natal n (%)	Post-natal n (%)	p-value
Yes	29 (30.6)	61 (64.2)	
No	66 (69.4)	34 (35.8)	<0.001 *
<b>Total</b>	<b>95 (100)</b>	<b>95 (100)</b>	

#### 4.3.2 Source of previous information on human milk donation

Majority of the women who had previous information got the information from a health worker 41 (21.6%), 18 (9.5%) got the information from the hospital brochures, 14 (7.37%) got the

information from a friend/relative, 12 (6.3%) got the information from social media and 5 (2.6%) got the information from other sources as shown in Figure 3.



**Figure 3: Source of information on human milk donation**

#### **4.4 Knowledge scores on human milk donation**

##### **4.4.1 Mean knowledge scores on human milk donation**

The mean knowledge score of post-natal women 7.57 (SD=2.36) was higher than that of pre-natal women 6.80 (SD=2.04). There was also a significant difference determined in mean knowledge scores between the pre-natal and post-natal women ( $p=0.017$ ) using ANOVA test. In addition, the mean knowledge score of women who had more than three children 8.25 (2.30) was higher than that woman who had less than three children 7.09 (2.21). There was also a significant difference in the mean knowledge scores between women had more than three children and those had less than three children ( $p=0.046$ ) as shown in Table 8.

**Table 8: Mean knowledge scores based on different variables**

<b>Variable</b>	<b>n</b>	<b>Mean (SD)</b>	<b>p-value</b>
<b>Category</b>			
Pre-natal	95	6.80 (2.04)	0.017*
Post-natal	95	7.57 (2.36)	
<b>Age</b>			
≥ 35	46	7.72 (2.36)	0.063
<35	144	7.01 (2.17)	
<b>Level of education</b>			
Primary and below	12	6.42 (2.68)	0.220
Above primary	178	7.24 (2.20)	
<b>Marital status</b>			
Married	174	7.13 (2.21)	0.291
Single	16	7.75 (2.54)	
<b>Occupation</b>			
Housewife	42	6.74 (2.10)	0.143
Working	148	7.31 (2.26)	
<b>Number of children</b>			
>3	16	8.25 (2.30)	0.046*
<3	174	7.09 (2.21)	

#### **4.4.2 Frequency of knowledge scores of the pre-natal and post-natal women**

More post-natal women 19 (20%) scored highly between (10-13) as compared to pre-natal women 10 (11%) whereas more pre-natal women 71 (75%) had an average score between (5-9) than post-natal women 69 (73%). More pre-natal women 14 (15%) scored poorly between (0-4) as compared to post-natal women 7 (7%). In general, most women 140 (74%) had an average score (5-9), followed by good 29 (15%) and poor 21 (11%) as shown in Table 9.

**Table 9: General knowledge scores of pre-natal and post-natal women**

Knowledge score grading	Pre-natal	Post-natal
	n (%)	n (%)
Good (10-13)	10 (10.53)	19 (20)
Average (5-9)	71 (74.74)	69 (72.63)
Poor (0-4)	14 (14.74)	7 (7.34)
<b>Total</b>	<b>95 (100)</b>	<b>95 (100)</b>

#### 4.4.3 Socio-demographic characteristics influencing knowledge

Table 10 shows the frequency of distribution of socio-demographic characteristics of the 190 women based on knowledge as well as socio-demographic characteristics influencing knowledge.

**Table 10: Socio-demographic characteristics influencing knowledge**

Socio-demographic characteristic	Knowledgeable about human milk donation		p-value	OR	95% CI
	Yes n (%)	No n (%)			
<b>Age</b>					
≥35	18 (12.5)	126 (87.5)	0.082	0.441	0.175-1.109
<35	11 (23.9)	35 (76.1)			
<b>Level of education</b>					
Primary and below	1 (8.3)	11 (9.7)	0.490	2.196	0.235-20.472
Above primary	28 (15.7)	150 (84.3)			
<b>Marital status</b>					
Married	25 (14.4)	149 (85.6)	0.346	1.845	0.516-6.593
Single	4 (25)	12 (75)			
<b>Occupation</b>					
Housewife	3 (71)	39 (92.9)	0.102	2.971	0.807-10.944
Working	26 (17.6)	122 (82.4)			

Socio-demographic characteristic	Knowledgeable about human milk donation		p-value	OR	95% CI
	Yes n (%)	No n (%)			
<b>Number of children</b>					
>3	4 (25)	12 (75)	0.547	0.654	0.164-2.602
<3	25 (14.4)	149 (87.5)			

\*P<0.05, OR= Odds ratio at 95% CI, >1=More likely, =1= Equal, <1=Less likely

Basing on women aged 35 years and older, 126 (87.5%) were not knowledgeable about human milk donation. Also, of those who were married 149 (85.6%) were also not knowledgeable about human milk donation. Overall, there was socio-demographic characteristic associated with knowledge.

#### 4.5 Attitude scores on human milk donation

##### 4.5.1 Mean attitude scores on human milk donation

The mean attitude score of post-natal women 44.36 (SD=8.174) was higher than that of pre-natal women 38.82 (SD=2.39). There was also a significant difference determined in mean attitude scores between the pre-natal and post-natal women (p=0.000) using ANOVA test. In addition, the mean attitude score of women who had a level of education above primary 41.90 (SD=6.02) was higher than that of woman who had a primary and below level of education 36.92 (SD=10.32). There was also a significant difference in the mean knowledge scores between women who had attained a level of education above primary and woman who had a primary and below level of education (p=0.011) as shown in Table 11.

**Table 11: Mean attitude scores based on different variables**

<b>Variable</b>	<b>n</b>	<b>Mean (SD)</b>	<b>p-value</b>
<b>Category</b>			
Pre-natal	95	38.82 (2.39)	0.000*
Post-natal	95	44.36 (8.174)	
<b>Age</b>			
≥ 35	46	42.74 (8.18)	0.176
<35	144	41.22 (6.02)	
<b>Level of education</b>			
Primary and below	12	36.92 (10.32)	0.011*
Above primary	178	41.90 (6.02)	
<b>Marital status</b>			
Married	174	41.61 (6.61)	0.862
Single	16	41.31 (6.91)	
<b>Occupation</b>			
Housewife	42	40.90 (6.64)	0.449
Working	148	41.78 (6.62)	
<b>Number of children</b>			
>3	16	44.31 (7.72)	0.085
<3	174	41.34 (6.47)	

#### **4.5.2 Frequency of attitude scores of the pre-natal and post-natal women**

Overall, majority of the women 158 (83%) had a good attitude towards human milk donation accounting for 79 (83%) pre-natal and 79 (83%) post-natal women. 32 (17%) women had a poor attitude towards the practice accounting for 16 (17%) of pre-natal and 16 (17%) of post-natal women.

**Table 12: General attitude scores of pre-natal and post-natal women**

<b>Attitude score grading</b>	<b>Pre-natal n (%)</b>	<b>Post-natal n (%)</b>	<b>p-value</b>
Good (37-60)	79 (83%)	79 (83%)	
Poor (12-36)	16 (17%)	16 (17%)	1.000
<b>Total</b>	<b>95 (100)</b>	<b>95 (100)</b>	

#### **4.5.3 Socio-demographic characteristics influencing attitude**

Table 13 shows the frequency of distribution of socio-demographic characteristics of the 190 women based on attitude as well as socio-demographic characteristics influencing attitude. Of the women aged thirty-five and below, 122 (84.7%) had a good attitude. Majority of married and working women had a good attitude 144 (82.8%) and 121 (81.8%) respectively. Though statistically significant, women who had primary level of education and below were less likely to donate their breastmilk (OR 0.136; 95% CI: 0.035- 0.528;  $p < 0.05$ ) as determined using binary logistic regression.

**Table 13: Socio-demographic characteristics influencing attitude**

Socio-demographic characteristic	Attitude		p-value	OR	95% CI
	Poor n (%)	Good n (%)			
N=190					
<b>Age</b>					
≥35	10 (2.7)	36 (78.3)	0.298	0.612	0.243-1.544
<35	22 (15.3)	122 (84.7)			
<b>Level of education</b>					
Primary and below	6 (50.0)	6 (50.0)	0.004*	0.136	0.035- 0.528
Above primary	26 (14.6)	152 (85.4)			
<b>Marital status</b>					
Married	30 (17.2)	144 (82.8)	0.750	0.770	0.154- 3.856
Single	2 (12.5)	14 (87.5)			
<b>Occupation</b>					
Housewife	5 (11.9)	37 (88.1)	0.132	2.512	0.758-8.324
Working	27 (18.2)	121 (81.8)			
<b>Number of children</b>					
>3	1 (6.3)	15 (93.8)	0.237	3.921	0.408-37.671
<3	31 (16.3)	143 (83.2)			

\*P<0.05, OR= Odds ratio at 95% CI, >1=More likely, =1= Equal, <1=Less likely

## 4.6 Perceptions on human milk donation

### 4.6.1 Lifesaving practice

The use of donor human milk (DHM) in vulnerable infants especially preterm babies whose mothers have insufficient breast milk has been shown to improve their survival rates during hospitalization (Ssekandi, 2020). Most of the key informants expressed that many preterm babies had benefited from DHM during their stay at the hospital to prevent complications like necrotizing enterocolitis (NEC). One key informant stated that:

*“Many babies in the NICU have benefited from donated milk when their mothers are unable to provide for them breast milk” (R7/KII).*

#### **4.6.2 Solves the distress of mothers with insufficient breast milk**

Preterm birth in most cases is associated with many challenges especially feeding challenges. Most preterm babies are born with poor suckling reflexes which makes oral feeding difficult (Grassi et al., 2019). This requires mothers to express their breast milk in order to feed these vulnerable infants using a nasogastric tube (NGT) with assistance from a trained health worker. Mothers who have insufficient breast milk are more prone to undergoing stressful emotions as they cannot meet the needs of these infants. Most of the milk donors expressed that donating helps many mothers with insufficient breast milk. One milk donor expressed:

*“I donated because I know the challenges you can go through when you do not have enough breast milk to feed your baby.”*

#### **4.6.3 Safe practice**

Measures are taken into place to ensure the safety and the quality of donor human milk (DHM). These include procedures like: pasteurization of DHM to kill bacteria and viruses and sterile pumping of breast milk from milk donors in the human milk bank (Haiden & Ziegler, 2017). Most of the key informants expressed that DHM is safe for consumption by intended recipients at the hospital.

*“Safety procedures like screening of mothers and pasteurization of donor human milk in the milk bank ensures milk donated is safe for consumption” (R4/KII).*

#### **4.6.4 Use of donor human milk is cheaper than infant formula**

Preterm babies usually have a longer hospital stay as compared to full term babies (Maier et al., 2018). This requires a cost-effective feeding solution that will not put further financial expenses on the parents on top of the hospital bills. Use of donor human milk (DHM) is thus a good alternative to infant formula as it is free of charge and safe for preterm consumption in mothers who have insufficient breast milk. One key informant expressed:

*“Using infant formula can cause complications in preterm babies and its expensive therefore, it’s better to use donated human milk which is freely given from the milk bank to mothers who have no breast milk”*

#### **4.7 Facilitators influencing human milk donation**

##### **4.7.1 Having excess breast milk**

A mother having surplus breast milk can greatly influence her decision to donate. Most of the participants expressed that mothers who had excess breast milk after giving birth were more likely to donate their breast milk to the human milk bank. One of the milk donors stated:

*“I had a lot of milk and it was giving me too much pain, I was like why can’t I take this milk to those who are in need of it” (MD5/ FGD).*

##### **4.7.2 Support from health workers**

Health workers play a vital role in helping mothers initiate breastfeeding after giving birth within the first one hour. They also help mothers who have delivered preterm babies in expressing breast milk to feed their preterm babies as most preterm births are associated with feeding difficulties (Grassi et al., 2019). Most of the milk donors expressed that the nurses at the human milk bank offered them a warm reception and greatly assisted in pumping their breast milk which attracted them to come back and donate. One of the milk donors expressed:

*“When I reached the human milk bank, the nurses welcomed and helped me in the process of donating breast milk. They cleaned my breasts and pumped the milk using an electrical pump which was not painful” (MD6/FGD).*

##### **4.7.3 Having access to information**

Health workers at St. Francis Hospital, Nsambya offer routine health education on the benefits of breastfeeding infants and donating breast milk to vulnerable infants in need of it. This information is shared in the pre-natal and post-natal clinics as part of the hospital policy. Most of the key informants agreed that sharing information with mothers regarding the process of human milk donation and the benefits of donor human milk (DHM) to vulnerable infants influenced many mothers to come donate their breast milk. One of the key informants expressed:

*“Some mothers pick interest when we inform them that the hospital has a milk bank and that they can donate their breastmilk to help babies in need of it” (R3/ KII).*

#### **4.7.4 Verbal encouragement to donate breast milk**

Mothers are more likely to donate their breast milk when they are encouraged by another milk donor through experience sharing. Most of the milk donors shared that encouraging other mothers to come donate their breastmilk to the human milk bank helped a lot in boosting the rates of milk donors. One of the milk donors expressed:

*“I had just come back from my maternity leave and I was heavily depressed by the milk I had. So, a colleague who is also a mother encouraged me to come and donate breast milk” (MD1/FGD).*

#### **4.7.5 Past experiences**

Mothers who have had preterm babies or who work with preterm babies are more likely to donate their breast milk because they are familiar with the challenges encountered with preterm feeding during hospitalization. Some of the key informants expressed that some people donate their breast milk because they have had an experience with a preterm baby thus, they know how DHM can be of help to mothers who have insufficient breast milk and have preterm babies. One key informant expressed:

*“Even before I gave birth, I was working in the NICU so I would see how those mothers struggled to get breastmilk. So, my prayer was when I give birth and have sufficient breast milk, I will help those babies” (R7/KII).*

#### **4.7.6 Altruism**

Donating one’s breast milk as a way of helping other mothers with insufficient breast milk is a form of altruism. Most of the milk donors expressed that they donated their breast milk as a way of assisting other mothers who were having challenges with insufficient breast milk. One of the milk donors stated that:

*“When I saw the babies in the NICU and some of the mothers who were stressed because they didn’t have breast milk. I said to myself, I have to come and donate breast milk” (MD5/FGD).*

## **4.8 Barriers of human milk donation**

### **4.8.1 Anonymity of the identities of donors**

Mothers with preterm babies and have insufficient breast milk are more likely to receive DHM from an unknown milk donor during their hospital stay. This may cause anxiety among some mothers as they are unsure about the source of the DHM despite standard procedures having been taken to ensure the safety and quality of the DHM. Most of the milk donors shared that some mothers are not comfortable with the idea of receiving DHM from people they do not know. One milk donor expressed:

*“Some mothers are not confident with other people’s milk; they ask themselves is this milk really safe? Is it going to change the genes of my baby, the behaviours or character?” (MD8/FGD).*

Another milk donor added:

*“They are not confident because they do not know the donor’s health status. They assume maybe the donor is sick and the baby will get infected. They are also not sure of the character of the donor, what if the person is a night dancer?” (MD4/FGD).*

### **4.8.2 Fear of screening**

Potential milk donors have to be screened before donating their breast milk to rule out diseases like HIV and hepatitis B and C (Haiden & Ziegler, 2017). This ensures that donor human milk (DHM) does not pose as a health risk to the intended recipients. Some of the participants narrated how some mothers fear undergoing the screening process in which various blood tests are conducted to rule out certain disease conditions. One key informant expressed:

*“Some mothers get discouraged when they learn you have to withdraw blood and run some tests in order for them to donate. They fear being diagnosed with diseases they are not aware of” (R10/KII).*

One milk donor added also expressed:

*“I think some fear the tests. Being pricked again yet they have previously done tests”*  
(MD8/FGD).

#### **4.8.3 Lack of incentives**

Mothers who are given any form of incentive after donating their breast milk are more likely to come back and donate. This is probably because they feel appreciated for taking part in this life saving practice. Some of the milk donors noted that some mothers fail to come to donate because they stay far from the hospital and even when they come to donate there is no form of transport reimbursement accorded to them. One of the milk donors expressed:

*“One challenge is some mothers think they will be given transport refund or refreshments and snacks after donating their breast milk”* (MD2/FGD).

All the milk donors agreed that bringing human milk donation nearer to mothers in the community would boost the donation rates hence increasing the DHM supply. One of the milk donors expressed:

*“Mothers within the hospital easily give but when they go home, they feel burdened to come back and donate. The distance, I wish they would bring the services closer”*  
(MD4/FGD).

#### **4.8.4 Religion**

Religion plays a very big role in influencing one’s decision to donate their breast milk (Rojjanasrirat et al., 2023). Some of the milk donors noted that they believed some religions are not in support of human milk donation and this hinders some mothers from donating their breast milk. One milk donor expressed:

*“I think there are religions which don’t encourage donation of blood. They must be the same which don’t encourage donation of milk. They do not encourage any kind of donation. So, I really think they do not allow the donation of milk”* (MD5/FGD).

#### **4.8.5 Lack of time to donate**

Human milk donation at the hospital requires time to run blood samples in order to rule out specified diseases as well as time for pumping breast milk in the human milk bank with assistance from the nurses. Some of the milk donors expressed that some mothers fail to donate because they fear they will spend the whole day in the hospital yet they have other obligations.

*“Some mothers think they will spend the whole day in the hospital running tests so they end up opting out” (MD3/FGD).*

#### **4.8.6 Lack of information**

Mother’s being knowledgeable about the human milk donation process and the benefits of donor human milk (DHM) can greatly influence their decision to donate. Some of the key informants expressed that mothers not knowing about the human milk bank at the facility and the benefits of DHM hinders many from donating their breast milk. One key informant stated:

*“Some mothers are not even aware that the hospital has a human milk bank and that preterm babies whose mothers have no breastmilk can be given donor milk” (R2/KII).*

## CHAPTER FIVE: DISCUSSION OF THE FINDINGS

### 5.1 The practice of human milk donation

The secondary data obtained from the human milk bank showed that few mothers were donating their breast milk with as little as six mothers donating in a month. These finds are also similar with the primary data obtained which showed that majority of the interviewed women had never donated their breast milk. Few mothers donating their breast milk implied that there would probably be a shortage of donor human milk (DHM) to meet the needs of vulnerable infants at the hospital. The low uptake of human milk donation in this study is similar to a study conducted in Poland among lactating mothers which also found the donation rates were low with only one in ten mothers having donated (Smyk et al., 2021).

Few pre-natal and post-natal women had previous information on human milk donation services at the hospital. In addition, human milk donation was also associated with the pre-natal and post-natal women having access to previous information on human milk donation. This implied that if women were accorded adequate information on human milk donation services, then probably there would be higher rates of human milk donation. A study conducted in China among post-natal mothers also showed that no mother had previous information about human milk donation (Pareshkumar Naik & Mahadalkar, 2020). On the contrary, a study conducted in Turkey among women aged between 15–49 years who had given birth within the last 5 years showed that majority had heard of human milk donation (Ergin & Uzun, 2018). Majority of the women did not have previous information on human milk donation probably because most of the women come late to the pre-natal and post-natal clinics thus miss out on the morning sessions where education talks on breastfeeding, human milk donation and other relevant topics are given by health workers.

Other probable causes of the low status of human milk donation at the hospital probably included: the fact that as of 2022, Uganda and WHO have not yet established guidelines on human milk donation to ensure the quality and safety of DHM supplied to vulnerable infants (WHO, 2022). This may make some mothers sceptical about participating in the practice let alone give DHM to their babies. St. Francis hospital, is also a private hospital so some mothers may perceive it as a hospital for mothers with high income status thus opt to go public hospitals which limits their access to the human milk bank. Lastly, milk donors expressed the lack of incentives especially in

the form of transport re-imbusement discouraged mothers outside the hospital premises from coming to donate their breast milk.

## **5.2 Knowledge on human milk donation**

In general, this study showed that few women were knowledgeable about the concepts of human milk donation probably due to the fact that few women had previous information on this lifesaving practice. Post-natal women were more knowledgeable on human milk donation than pre-natal women which implied that probably health education at the hospital was accorded more to post-natal women. In addition, women who had more than three children were more knowledgeable on human milk donation than those who had less than three children. This implied that women who had more three children were more likely to have information on human milk donation.

The findings on knowledge on human milk donation among pre-natal and post-natal women in this study are similar to a study which was conducted in China among hospitalized mothers in obstetrics department to assess their knowledge on breast milk donation in which the correct answer rate was low with few mothers scoring highly (Huang et al., 2021). Another study also conducted to assess the knowledge regarding human milk donation among post-natal mothers in selected hospitals of Pune city in India showed the correct answer rate was also low with few mothers scoring highly (Pareshkumar Naik & Mahadalkar, 2020).

## **5.3 Attitude towards human milk donation**

Majority of the women assessed had a good attitude towards human milk despite the low donation rates. Post-natal women had a better attitude towards human milk donation services than pre-natal women. This implied that women who had gone through child birth experience were probably more likely to donate their breast milk. In addition, women who had attained level of education above primary had a better attitude than those who had not probably due to the fact that they were educated on of the health benefits of breast milk and donor human milk (DHM) to infants.

The findings of this study are contrary to a study conducted to assess the attitude towards human milk donation among postpartum women in Kings County Hospital, located in Brooklyn, New York. The study showed that majority of the women had a negative attitude towards the use of donor human milk and in fact preferred to use infant formula (Pal et al., 2019). Another study also

showed that the average attitude score on human milk donation for mothers was relatively low indicating the attitude was not positive (Huang et al., 2021).

#### **5.4 Perceptions on human milk donation**

The perceptions explored in this study included: human milk donation being a lifesaving practice, DHM relived the burden of mothers who have no breast milk and have pre-term babies, DHM is more beneficial than infant formula and human milk donation being a safe practice.

A cross-sectional study conducted to assess the knowledge and perceptions on human milk bank among post-natal mothers in India showed that majority of the post-natal mothers agreed that human milk donation can save babies (Jahan et al., 2017). This is similar to what was expressed by the milk donors in this study. Another study conducted in Ghana among women to explore their perspectives on human milk banking also showed that the majority of the women expressed DHM is more beneficial than infant formula (Obeng et al., 2023). In addition, a study conducted in Nigeria among mothers to assess their perception of the use of banked human milk for feeding of the infants showed that mothers also expressed the need to help fellow mothers who had vulnerable babies and had no breast milk in order to relieve their burden (Abhulimhen-Iyoha et al., 2021).

#### **5.5 Facilitators of human milk donation**

Facilitators of human milk donation expressed in this study included: having excess breast milk, past experience in the NICU, support from health workers, verbal encouragement, having access to information, verbal encouragement and altruism. Health workers supporting post-natal women to initiate breastfeeding of newborn babies and in the process of human milk donation is very key. In addition, women having access to information on human milk donation increases their awareness about the practice thus can positively influence their decision to donate. A study conducted among mothers in Brazil to assess factors associated with breast milk donation (Meneses et al., 2017) also had the same findings.

Mothers donating their breast milk to vulnerable babies of mothers who lacked breast milk as a form compassion was also expressed among milk donors in North America who were engaged in a study to assess facilitators of human milk banking (Candelaria et al., 2018). Other facilitators of human milk donation expressed by the milk donors like having excess breast milk and verbal

encouragement are similar to findings found in a study conducted among mothers who delivered at two different hospitals in Turkey to establish their perceptions on human milk donation (Karadag et al., 2015).

The facilitators of human milk donation established in this study imply that human milk donation does not only centre on knowledge and attitude of the women as the main facilitators of human milk donation but also other factors can enhance women to donate their breastmilk

### **5.6 Barriers of human milk donation**

On the other hand, barriers of human milk donation expressed included: fear of screening, lacking of incentives, anonymity of identities of donors, time consuming process, fear of screening, lack of information about milk banking and religion. The milk donors expressed that the fear of screening and human milk donation being a time-consuming process inhibits some mothers from donation. These findings are similar to a study conducted among women who had donated breast milk in the United States in which the same was expressed (Rojjanasrirat et al., 2023). The milk donors also expressed that some mothers are not certain about the safety of donor human milk thus fear giving it to their babies. This concern was also expressed in a similar study conducted among caregivers in Uganda (Magowan et al., 2020). In addition, religion was also another barrier of human milk donation expressed in which some religions are not in favour of human milk donation. This finding is similar to a study which was conducted in Turkey among Moslem women in which majority of the women did not donate their breast milk due to religious concerns (Ergin & Uzun, 2018).

The findings of this study on barriers of human milk donation imply that women can choose not to donate their breastmilk based on individual, systematic and social reasons as mentioned above.

### **5.7 Methodological strengths and limitations**

The methodological strengths of this study included:

- (i) Human milk donation is a growing phenomenon in Uganda and few research has been conducted in this area in Uganda thus this research study was the first of its kind on this research topic.

- (ii) The study used a mixed method approach.
- (iii) Both pre-natal and post-natal women were used to in order to capture their perspectives on the study topic.

On the down side, the methodological limitations of this study included:

- (i) The study mainly concentrated on knowledge, attitude and perceptions as the main factors influencing human milk donation.
- (ii) A small sample size was used to collect qualitative data (8 milk donors and 10 key informants).
- (iii) There were few literatures on human milk donation in Uganda thus most reference material was from other countries.
- (iv) A cross-sectional research design was design was used thus there was no follow up of study participants.

## **CHAPTER SIX: RECOMMENDATIONS AND CONCLUSIONS**

### **6.1 Recommendations**

Based on the main findings and their implications, the following recommendations are proposed to improve HMD in Uganda and future studies in this novel and evolving field:

#### **6.1.1 Recommendations for practice**

- (i) Offering of incentives to milk donors like transport re-imburement, snacks and refreshments, badges or wrist bands to encourage them to come back and donate at the health facility.
- (ii) Human milk donation services should be brought closer to lactating mothers in the community who are not able to access the health facility.
- (iii) Education and awareness creation on the subject of human milk donation through utilization of mass media campaigns, brochures and routine education talks in the communities. In addition, more emphasis should be put on educating pre-natal women on human milk donation services at the hospital.
- (iv) Formation of public-private partnerships for mobilization of funds needed in the establishment of more human milk banks to ensure continuous supply of DHM to vulnerable infants.

#### **6.1.2 Recommendations for policy**

- (i) Formulation of guidelines and policies on human milk donation in Uganda to ensure the quality and safety of donor human milk supplied to vulnerable babies.

#### **6.1.3 Recommendations for research**

- More research needs to be conducted in the area of human milk donation in Uganda particularly on factors affecting mothers' decision to donate and the use of DHM.

### **6.2 Conclusion**

Human milk donation is a complex subject and still a growing phenomenon in Uganda. This study has shown that there is still a low uptake of human milk donation at the hospital with majority of

the pre-natal and post-natal women having never donated their breast milk. The study further showed that women donating their breast milk was associated with them having access to information on human milk donation, their attitude towards the practice and the number of children the pre-natal and post-natal women had. There was a knowledge gap about the concepts of human milk donation with post-natal women being more knowledgeable than pre-natal women.

On the other hand, majority of the pre-natal and post-natal had a good attitude towards the practice with post-natal women having a better attitude than pre-natal women. Human milk donation was perceived as a safe and lifesaving practice. Women were more likely to donate their breastmilk when they had excess breast milk and being supported by health workers whereas women were less likely to donate their breast milk due to lack of incentives and fear of screening.

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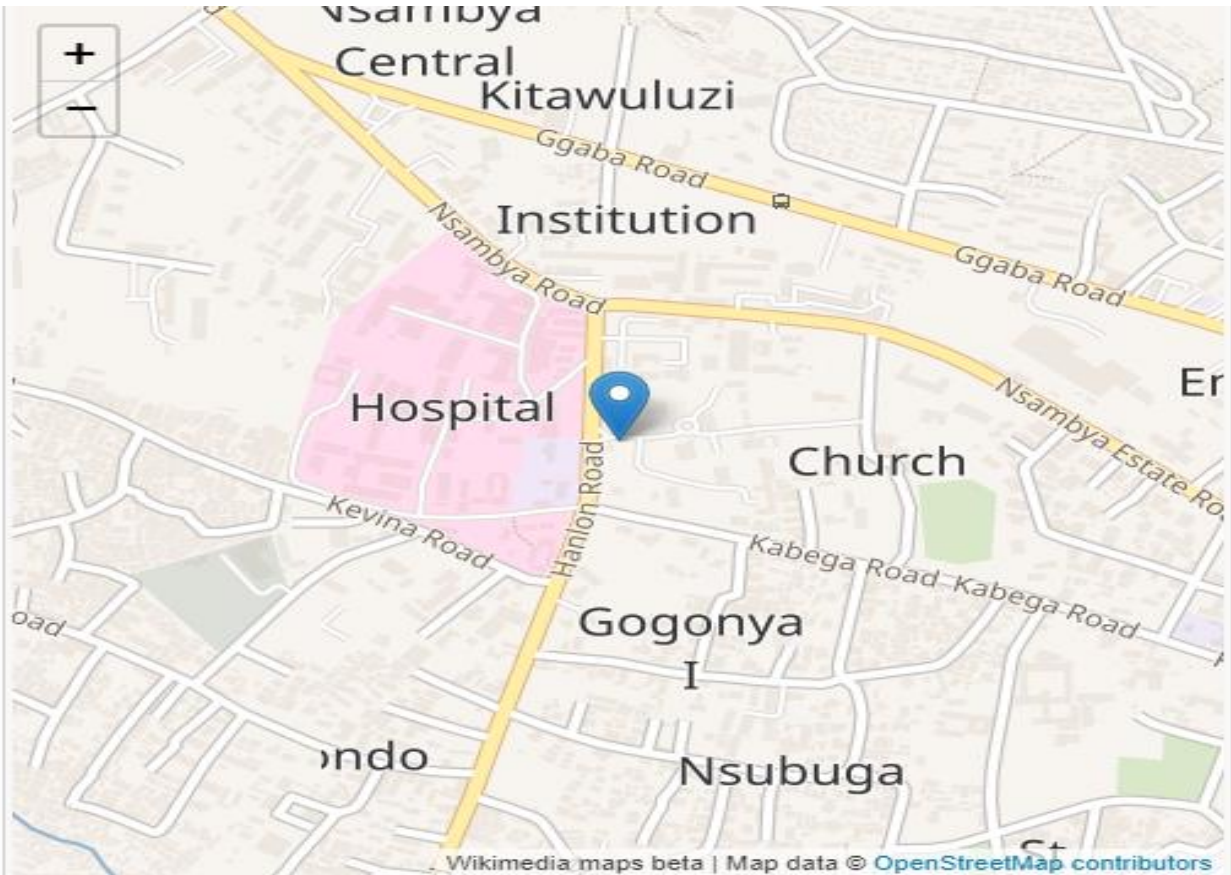
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## APPENDICES

Appendix 1: Map showing location of St. Francis hospital, Nsambya



## **Appendix 2: Information and consent form**

### **Human milk donation and associated knowledge, attitudes and perceptions by postnatal mothers at St. Francis hospital, Nsambya, Kampala city**

#### **Principal Investigator**

Name : Nakasiita Felista  
Department : Kyambogo University  
Address : Kampala, Uganda  
Phone : +256750582656  
Email : [felistakasiita@gmail.com](mailto:felistakasiita@gmail.com)

#### **Introduction**

Hello, I am part of the team from Kyambogo University, Graduate school conducting a study on human milk donation and associated knowledge, attitudes and perceptions by postnatal mothers at St. Francis Hospital, Nsambya, Kampala City.

#### ***What is the purpose of the study?***

Donor human milk has proven to be advantageous for new-born babies whose mothers are not able to provide them with breast milk due to its immunological and nutritional benefits. However, this phenomenon is new in low-income and middle-income countries of which Uganda is inclusive. The purpose of this study is thus to obtain information on the extent of human milk donation and the associated knowledge, attitudes and perceptions of post-natal mothers at St. Francis hospital Nsambya, Kampala City.

#### **What will I be asked to do?**

You will be required to answer a set of questions or participant in a discussion with the aid of a structured questionnaire or semi-structured guide respectively. The duration of the

interviews/discussions may range from 30-60 minutes per session. You are kindly requested to give the most honest responses to the best of your knowledge during the session.

### **What are the risks of this study?**

There are no direct risks linked to the study though your time is required in order to get information necessary for the research study. Participation in this study is voluntary. You may decline to answer any or all questions and you can withdraw consent at any time.

### **What are the benefits of this study?**

We hope that the information obtained from this study may be used to better the rates of human milk donation at the hospital. This in turn aids in improving the survival rates especially for preterm babies whose mothers are unable to provide them with their own milk.

### ***Confidentiality***

For this study, we will only keep your personal information until it is uploaded into data software for interpretation. Your name will not be identified in any publication and your data will not be used for any future research after this study is complete.

### ***Contact Information***

If at any time you have questions concerning this study at present and in the future, the investigator is available to answer any questions and if you think that you have suffered any undesirable effects as the result of participating in this study, you may contact the researcher whose contact information is provided on the first page. If you have questions regarding your rights as a research participant, or if problems arise which you do not feel you can discuss with the Primary Investigator, please contact the study supervisor **Dr. Faith Muyonga** on **+256772485711/+256704493451**

### ***Authorization***

By signing this form, you agree that you have read this consent form and that the study has been explained to you. You also agree that your questions have been answered and that you agree to

take part in this research study. You do not give up any of your legal rights by signing this consent form. You will receive a copy of this consent form.

***Signature***

I have read and I have understood the provided information and have had the chance to ask questions. I acknowledge that my participation in this study is voluntary and that I have the right to withdraw at any time, without giving a reason and without cost. I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

***Witness Statement:***

The participant was unable to read or sign this consent form because of the following reason:

- The participant is illiterate
- The participant is visually impaired
- The participant is physically unable to sign the consent form. Please describe:
- Other (please specify):

\_\_\_\_\_

Name of witness: \_\_\_\_\_ Date of Signature: \_\_\_\_\_

Signature of Witness to Consent Process: \_\_\_\_\_

### Appendix 3: Structured questionnaire

#### Questionnaire for the assessment of socio-demographic data and knowledge and attitude

<b>ID</b>		<b>Date</b>	
<b>Interviewer's name</b>			
<b>Section A: Socio-demographic data (<i>Indicate answer were applicable</i>)</b>			
<b>No.</b>	<b>Question</b>	<b>Response</b>	
<b>1</b>	Age a) 18-25 years old b) 25-34 years old c) 35- 44 years old d) >45 years		
<b>2</b>	Highest level of education  a) Diploma, Degree and above  b) Certificate  c) Secondary  d) Primary  e) None		
<b>3</b>	Marital status  a) Married  b) Single  c) Divorced  d) Widowed		
<b>4</b>	Occupation  a) Housewife b) Employed c) Self-employed		
<b>5</b>	Religious affiliation  a) Christian		

	<ul style="list-style-type: none"> <li>b) Muslim</li> <li>c) Other religion</li> <li>d) Unaffiliated</li> </ul>	
<b>6</b>	<p>Number of children</p> <ul style="list-style-type: none"> <li>a) 1</li> <li>b) 2</li> <li>c) 3</li> <li>d) &gt;3</li> </ul>	
<b>7</b>	<p>Mode of delivery</p> <ul style="list-style-type: none"> <li>a) Vaginal</li> <li>b) Caesarian section</li> </ul>	
<b>8</b>	<p>Have you ever donated breast milk?</p> <ul style="list-style-type: none"> <li>a) Yes</li> <li>b) No</li> </ul>	
<b>9</b>	<p>Do you have previous information on human milk donation?</p> <ul style="list-style-type: none"> <li>a) Yes</li> <li>b) No</li> </ul>	
<b>10</b>	<p>If yes, what was your source of information?</p> <ul style="list-style-type: none"> <li>a) Friend/Relative</li> <li>b) Health worker</li> <li>c) Hospital brochure</li> <li>d) Social media</li> <li>e) Other</li> </ul>	

<b>Section B: Assessment of knowledge on human milk donation</b>			
<b>No.</b>	<b>Question</b>	<b>Correct response</b>	<b>Score awarded</b>
11.	There are more advantages to feeding premature or low-birth- weight infants with donor milk than with formula.	Yes	1
12.	When mothers are unable to breastfeed owing to illness or insufficient milk, donor milk may be used instead.	Yes	1
13.	Donor milk has an expiry date	Yes	1
14.	Can a person with HIV be a breast milk donor?	No	1
15.	Mothers do not need a medical examination before they donate their milk	No	1
16.	Sterilized donor milk is stored frozen and valid for 3 to 6 months.	Yes	1
17.	Milk donors require regular medical examinations to continue donating.	Yes	1
18.	Donor milk can be given to infants without disinfection.	No	1
19.	Donor milk is stored in milk banks.	Yes	1
20.	After pasteurization, the nutrients in milk are all destroyed	No	1
21.	Using donor milk can reduce the incidence of heart diseases in preterm infants	No	1
22.	Everyone can donate their excess milk.	No	1
23.	There are several milk banks in Uganda	No	1
	<b>Total Score</b>		<b>13</b>

<b>Section C: Assessment of attitude towards human milk donation</b>						
<b>No</b>	<b>Question</b>	<b>Correct scoring</b>				
		<b>Strongly Agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
24.	Breast feeding premature babies with donor human milk is more beneficial than formula feeding.	5	4	3	2	1
25.	Donor human milk may carry viruses and spread disease.	5	4	3	2	1
26.	Donor human milk can solve the distress of mothers who cannot breastfeed their children.	5	4	3	2	1
27.	Donor human milk is someone else's milk. Although I cannot breastfeed, I do not want to feed my child with donor human milk.	1	2	3	4	5
28.	Donor human milk can treat new-borns who weigh less than normal at birth	5	4	3	2	1
29.	The nutrients of donor human milk would be destroyed after pasteurization, so it is better to feed infants with formula milk	1	2	3	4	5
30.	The source of donor human milk is unsure, and I do not want to feed my child with donor human milk.	1	2	3	4	5

31.	Donor human milk should be used widely in hospitalized children who cannot be breastfed.	5	4	3	2	1
32.	Health workers play a very important role in human milk donation.	5	4	3	2	1
33.	When I cannot breastfeed, I would like to find donor human milk to feed my child.	5	4	3	2	1
34.	Donor human milk is not fresh. I don't want to feed my child with it.	1	2	3	4	5
35.	When my milk is sufficient, I would actively donate my milk.	5	4	3	2	1

## Appendix 4: Focus group discussion guide

Date.....

Moderator: .....

Venue: .....

### Introduction (for moderator only)

Hello and welcome to our session. Thank you for taking off some time to join us to talk about human milk donation at St. Francis hospital, Nsambya. My name is..... and I will be your moderator for the focus group discussion about your perceptions on human milk donation.

I would like to inform you that there are no wrong answers but rather different points of view. Please feel comfortable sharing your point of view even if it differs from what others have said. Keep in mind that I have interest in both negative and positive comments, and usually the negative comments are the most helpful. You have most likely noticed that I have an audio recorder.

I am audio recording this session because I don't want to miss capturing any of your comments. You may say helpful information in this discussion and I may not be fast enough to write all the information down. We shall use first names only and we won't use any of your names in our reports. You are guaranteed of complete confidentiality. I have placed name cards on the table in front of you on which we shall write down our first names only to help us remember each other's names. Well, let us begin the discussion.

### Questions

1. Please tell me how you found about human milk donation at St. Francis hospital, Nsambya?

**Probe: Find out the source of information and dates are also relevant when information was obtained**

2. What come into your mind when you heard about human milk donation?

**Probe: Capture the thoughts (anxious/excited/inquisitive) of participants**

3. What was your experience of human milk donation?

**Probe: Find out step by step process the milk donor went through. What were the positive and negative experiences?**

4. From your experience, would you recommend another mother to donate her breast milk?

Probe: Which people are they likely to recommend i.e., close friends, sisters and neighbours?

5. In your opinion, what encouraged you to come and donate your breast milk?

**Probe: What was the source of encouragement? Was it a family member, previous experience or health worker?**

6. In your own opinion, what hinders mothers from donating their breast milk?

**Probe: What are the individual, infrastructural and social factors why they do not donate their milk?**

7. In your own opinion, do you think donor human milk is of importance? If so, how is it of importance?

**Probe: How is the donated milk utilized? Who consumes it? What are the benefits of its consumption?**

8. In your opinion, why do some mothers fear donating their breast milk?

**Probe: What are the fears? Hints like being screened/tested for HIV and other diseases), not having enough milk etc**

9. In your opinion, do you think society plays a role in human milk donation?

**Probe: Factors like culture and religion with examples were possible**

10. What do you think can be done by the hospital management to encourage mothers to donate their breast milk?

**Probe: Find out infrastructural, individual and other means of improving the rates of human milk donation**

**Appendix 5: Key informants interview guide**

**ID:** .....

**Date:** .....

**Designation:** .....

**Venue:** .....

**Introduction (for the interviewer)**

Hello and welcome to this session. Thank you for taking off some time to join me to talk about human milk donation at St. Francis hospital, Nsambya. My name is..... and I will be your interviewer.

I would like to inform you that there are no wrong answers therefore please feel free to share your point of view. Keep in mind that I am just as interested in both the negative and positive comments and usually the negative comments are the most helpful. You may have probably noticed that I have carried along an audio recorder.

I am audio recording this session because I don't want to miss capturing any of your comments. You may say helpful information in this interview and I may not be fast enough to write all the information down. I shall use your first name only and I won't use your name in our reports. You are guaranteed complete confidentiality. Well, let us begin the interview.

**Questions**

1. Please tell me about the human milk donation process at the hospital.

**Probe: Ask about the criteria needed to be a milk donor, the tests carried out, milk collection, pasteurization and distribution process**

2. What are the mothers saying about human milk donation?

**Probe: Are they buying into the practice or unsure about it?**

3. On average, how many mothers donate their breast milk in a week?

**Probe: Are the mothers from within the hospital premises or outsiders?**

4. In your opinion, what are the benefits of human milk donation?

**Probe: Benefits to a mother and newborns?**

5. In your opinion, what challenges have you faced in human milk donation?

**Probe: What are the bottlenecks interfaced as an individual, with the milk donors and systematic challenges?**

6. In your own opinion, what hinders mothers from donating their breast milk?

**Probe: What are the individual, infrastructural and social factors why they do not donate their milk?**

7. In your own opinion, what are the reasons mothers give for donating their breast milk?

**Probe: What are the individual, infrastructural and social factors why they donate their milk?**

8. In your opinion, what can be done to improve the rates of human milk donation?

**Probe: What can be done to attract milk donors and improve services in the human milk bank?**