

# **Stakeholder attitudes and acceptability on donating and receiving donated human breast milk**

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**BSc Dietetics**

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for the degree *Magister Scientiae* in Dietetics at the  
Potchefstroom Campus of the North-West University

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## **Preface**

The article format has been selected for this study. The *Magister Scientiae* (MSc) student, Ms Charlene Oosthuizen, conducted the research and wrote the manuscript under the supervision of Dr Namukolo Covic, Dr Welma Lubbe and Dr Robin Dolman, the co-authors of the article. Dr Namukolo Covic acted as supervisor, and Dr Welma Lubbe and Dr Robin Dolman as co-supervisors.

The researcher wrote the manuscript: “Stakeholder attitudes and acceptability on donating and receiving donated human milk,” according to the instructions to authors; it will be submitted to the Journal of Human Lactation.

The references of each chapter are kept separately, as the referencing style of the article differs according to author guidelines.

Permission was obtained from Dr Namukolo Covic, Dr Welma Lubbe and Dr Robin Dolman for the article (manuscript) to be submitted for examination purposes.

As yet, no permission was obtained from the editor of the journal for copyright.

### **DECLARATION FROM STUDENT THAT PLAGIARISM HAS BEEN AVOIDED**

I, Ms Charlene Oosthuizen, ID 870211 0035 089, student number: 20304811, hereby declare that I have read the North-West University’s “Policy on Plagiarism and other forms of Academic Dishonesty and Misconduct” (NWU, 2011).

I did my best to acknowledge all the authors that I have cited and I tried to paraphrase their words to the best of my ability, while still portraying the correct meaning of their words.

I also acknowledge that by reading extensively about the topic, some information may have been internalised in my thinking, but I tried my best to give recognition to the original authors of the ideas.

I declare that this dissertation is my own work, although I respect the professional contribution made by my supervisors and I would like to give due recognition to them.

Ms Charlene Oosthuizen

Date: November 2014

## **Abstract**

### **Key terms**

Human milk bank, mothers, breastfeeding, attitudes, acceptability, donating milk

### **Background**

Benefits of breastfeeding for infants and mothers are well recognized. South Africa has a very low breastfeeding rate. Strategies to improve and promote exclusive breastfeeding rates include implementation of human milk banks (HMB). The North West Province started its first HMB in 2012 and the success and sustainability will depend on numerous factors, including identification of possible barriers to donation or receiving donor human milk. In support of such an intervention, the attitudes of each relevant stakeholders, mothers, community members and health care providers on acceptability of donating and receiving donated breastmilk is therefore important for the success of such an intervention

### **Objectives**

The objective of this dissertation was determining the attitudes on acceptability regarding the donation and receiving of human breast milk for key stakeholders, namely mothers, healthcare workers and the elderly representing grandmothers.

### **Methods**

This study was conducted at a public hospital and nearby clinics in North West province, South Africa using qualitative research methodology of focus group discussions (FGDs) for data collection. Eight focus groups discussed the attitudes, 3 of mothers of 0 to 12 month old infants (n=13), 3 of elderly participants older than 60 years (n=17) and 2 of healthcare professionals, working with infants younger than 1 year (n=11).

### **Results**

Important attitudes on acceptability of receiving and donating human donor milk were identified from the literature and this research project. Stakeholders had safety and cultural concerns regarding donation and receiving of donated human milk. Participants also indicated the need for education that may improve the attitudes. These findings may inform future policy planning and HMB promotion in communities. The identified attitudes reflected barriers to exclusive

breast feeding, donating and receiving breast milk. These included, the need for HIV screening; cultural beliefs relating to transfer of personality traits and bonding and fears of not having enough milk for their own infants; perceived changes in quality of donated milk during pasteurisation and transportation as well as HIV transmission.

## **Conclusion**

The study identified important attitudes that may be possible barriers and fears to accepting or donating human breast milk. Some of the identified attitudes could also limit exclusive breast feeding. Further research is recommended to determine how prevalent the identified attitudes are in this and similar community settings.

# **Opsomming**

## **Sleutelterme**

Menslike melkbank, moeders, borsvoeding, houdings, aanvaarbaarheid, skenking van melk

## **Agtergrond**

Die voordele van borsvoeding vir babas en moeders word wyd erken. Suid-Afrika het 'n baie lae borsvoedingskoers en die strategieë om die eksklusiewe borsvoedingskoers te verbeter sluit die bevordering en ondersteuning van menslike melkbanke as 'n effektiewe wyse waarop borsvoeding bevorder kan word in. Die Noordwes-Provinsie het sy eerste menslike borsmelkbank (BMB) begin. Die sukses en volhoubaarheid van 'n BMB word deur verskeie faktore bepaal, wat die identifikasie van moontlike struikel bloke om skenker melk te skenk of te ontvang, insluit. Die ondersteuning van die relevante gesondheidsorgwerkers, asook die gemeenskap wat die hospitaal bedien is nodig vir die sukses en volhoubaarheid van die melkbank.

## **Doelwitte**

Die doelwitte van die verhandeling was die bepaling van die houdings en aanvaarbaarheid van die skenking en ontvangs van menslike borsmelk van die sleutel belanghebbers, naamlik moeders, gesondheidsorgwerkers en bejaardes.

## **Metodes**

Die studie het plaasgevind in 'n hospitaal en naby liggende klinieke in die Noord-Wes provinsie, Suid Afrika deur gebruik te maak van kwalitatiewe navorsings metodes wat bestaan uit fokus groep besprekings vir data insameling. Agt fokus groep besprekings het die houdings bespreek, 3 van moeders met babas van 0 tot 12 maande (n=13), 3 van bejaardes ouer as 60 jaar (n=17) and 2 van gesondheidsorgwerkers wat werk met babas jonger as 1 jaar (n=11)

## **Resultate**

Gevolgtrekkings oor die houdings en aanvaarbaarheidsfaktore van die ontvangs en skenking van menslike skenkers melk is uit die literatuur en navorsing gemaak. Die sleutel belanghebbers het bekommernisse getoon rakende veiligheids en kultuur sensitiewe onderwerpe en het rapporteer dat met voldoende inligtingsessies die aanvaarbaarheidsfaktore

positief beïnvloed kan word. Hierdie bevindinge mag 'n bydrae lewer in toekomstige beleids beplanning en die bevordering van menslike melkbanke in die gemeenskap. Die studie het moontlike struikelblokke vir eksklusiewe borsvoeding oor 'n langer tydperk geïdentifiseer, wat tot struikelblokke in die skunking van menslike melk tot skenkersbanke kan aanleiding gee, omdat moeders wat nie borsvoed nie ook nie melk kan skenk nie. Hierdie struikelblokke het toetse vir MIV, kulturele oortuigings en vrese vir die aanvaarding van borsmelk van menslike melk banke of die saking daarvan aan BMB ingesluit.

### **Gevolgtrekking**

Die studie het belangrike houdings wat moontlike struikelblokke en vrese kan skep tot die aanvaarding of donasie van menslike borsmelk banke. Sommige van die geïdentifiseerde houdings kan ook eksklusiewe borsvoeding beperk. Verdere navorsing word aanbeveel om te bepaal hoe prevalent die geïdentifiseerde houdings in die en ook soortgelyke gemeenskappe is.

## Acknowledgements

I would like to give thanks to

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## List of abbreviations

AFASS:	Acceptable, feasible, affordable, sustainable and safe
AIDS:	Acquired immunodeficiency syndrome
AOM:	Acute Otitis Media
ARA:	Arachidonic acid
ARV:	Antiretroviral
BMI:	Body Mass Index
DHA:	Docosahexaenoic acid
EBF:	Exclusive Breastfeeding
EFF:	Exclusive formula feeding
ELBW:	Extremely low birth weight
GI:	Gastrointestinal
GIT:	Gastrointestinal tract
HIV:	Human Immunodeficiency Virus
HMB:	Human milk banks
LRTD:	Lower respiratory tract disease
MBF:	Mixed breastfeeding
MDGs:	Millennium development goals
MTCT:	Mother to child transmission
NBF:	Not breastfeeding
NEC:	Necrotising Enterocolitis

NICU:	Neonatal intensive care unit
ParBF:	Partial breastfeeding
PreBF:	Predominant breastfeeding
PHC:	Public health care
RF:	Replacement feeding
SA:	South Africa
VLBW:	Very low birth weight
WHO:	World Health Organisation

# Chapter 1: Introduction and motivation

## 1.1 Introduction and motivation

According to the 2003 Demographic and Health Survey, South Africa (SA) is one of only 12 countries in the world where infant, child and under-five mortality have increased from 1988 to 2003 (South Africa, 2007). In 2011, SA still had the 58th highest under-five mortality rate (UNICEF, 2012). Prior to 2003, when the national antiretroviral (ARV) roll-out in SA was launched (Uebel *et al*, 2010), this phenomenon was possibly due to the human immunodeficiency virus/Acquired immunodeficiency syndrome (HIV/AIDS) epidemic in SA, as HIV/AIDS was identified as the leading cause of premature mortality in all the provinces in the year 2000. In 2011, the situation still looked bleak, as almost two-thirds (64%) of the 6.9 million deaths in children under the age of five years, were caused by infectious diseases and conditions such as pneumonia, diarrhoea, malaria, meningitis, tetanus, HIV and measles. Furthermore, around 40% of all under-five deaths occurred in the neonatal period (within the first 28 days of life), the majority from preterm birth complications and intrapartum-related complications (complications during delivery) (UNICEF, 2012). Preterm infants are especially at risk, as they are born with disadvantages regarding feeding skills, stamina, and a risk for conditions such as hypoglycaemia, hyperbilirubinaemia, and slow weight gain (Walker, 2008; Wright, 2001). Necrotising Enterocolitis (NEC) is a condition in preterm infants where the inflammation and death of intestinal tissue occur and it often occurs in neonatal intensive care units (NICU). Therefore, this is a further contributor to the increase in the mortality rate of premature infants, which is three times higher than in full term infants (Lin & Stoll, 2006; Patel & Shah, 2012; Patole, 2007).

Considering the current situation regarding infant and child mortality as described above, reducing child mortality is one of the most important priorities in SA. Researchers at the consultative breastfeeding conference in 2011 identified that breastfeeding as a child survival strategy is central to this priority. The findings of this conference lead to the Tshwane declaration (South Africa, 2011). Among others, the declaration recommended that SA move to an exclusive breastfeeding (EBF) strategy, by discontinuing the practice of formula milk provision at hospitals and clinics, except when prescribed by an authorised health practitioner. In addition, the declaration also recommended that human milk banks (HMB) should be promoted and supported as an effective approach to promote breastfeeding. In SA, most breastmilk banks' primary focus is to promote infant survival in the NICU by decreasing the incidence of NEC; in this way they also contribute to a decrease in the mortality rate.

Hence, the NorthWest Province opened the first human milk bank (HMB) in June 2012. The North West Department of Health plans to open more HMBs across the province in the future, in an effort to reduce neonatal and post-natal morbidity and mortality for infants who cannot breastfeed.

Despite multiple evidence on the benefits and safety aspects of HMBs, the literature describing the attitudes on acceptability towards such a venture, especially in the South African setting, is scarce. This is a new health intervention and determining its acceptability among the community, may be beneficial to the successful implementation of HMBs in the province. Research has been conducted on the safety and scientific aspects of donor milk, and the motives and experiences of donors and women and families whose infants receive this milk. However, only one study has been conducted in the South African setting. This study was performed in KZN, but cannot be generalised to the NorthWest Province, as there are cultural and other contextual differences between the communities (Coutsoudis *et al.*,2011). No studies have been performed on the NorthWest population.

The success and sustainability of a HMB are determined by numerous factors, including the support of the relevant healthcare workers, as well as the community that the hospital serves (Arnold, 2006). It is therefore vital to determine the attitudes of the community, as well as that of the healthcare workers towards such a venture. Without the support and commitment of all the relevant stakeholders, the sustainability of a HMB is threatened. Understanding the attitudes of doctors, nurses and dieticians that work with mothers towards HMBs, will provide valuable information that can be incorporated into future training programs. By understanding the acceptability and attitudes of the various members of the community that the hospital serves, will enable the Department of Health and healthcare workers to develop appropriate educational material and communication for the community and other stakeholders.

## **1.2 Aims and objectives**

**The purpose of this research project is to:**

- Determine the attitudes on acceptability of the donation and receiving of human breast milk of key stakeholders (mothers, the elderly representing grandmothers and healthcare professionals).

**Specific objective:**

- To conduct separate focus group discussions with the key informant stakeholders (mothers, the elderly and healthcare professionals) to assess the attitudes on acceptability of breast milk donation and the use thereof to better understand possible barriers.

**1.3 Research design and method**

The researchers chose a qualitative, descriptive and exploratory research approach, using focus group discussions (FGDs) for data collection in this study to assist the researchers in gaining an improved understanding and knowledge of the attitudes and acceptability factors for the selected stakeholders on donating and receiving donated human breast milk. The researcher conducted eight FGDs with the help of a trained research assistant in the local language. The informants included three groups: mothers, elderly representatives of grandmothers and healthcare professionals. Additional FGDs were conducted until data saturation was reached in all the groups, in other words, until no new themes emerged from the process in any of the three groups (Creswell *et al.*, 2011). The information generated from this study, will help to provide educational messages to the various stakeholders to facilitate the implementation of more HMBs in the province.

**1.3.1 The key informant participants**

The FGD informants included mothers, with infants between 0 and 12 months; all the healthcare professionals who care for these mothers and their infants; and elderly people, to represent grandmothers. All the participants attended or were working at the selected healthcare facilities in the Kenneth Kaunda district on the day of data collection. Each of these groups has been purposely selected due to the influence that they can have on the choices that mothers may make regarding HMBs. Studies have shown that family involvement and their influence were assumed to be an important factor, and the elderly of a community play a leading role in infant feeding (Laar & Govender, 2011; Thairu *et al.*, 2005).

**1.3.2 Recruitment**

The data collection took place at selected healthcare facilities in the Kenneth Kaunda district, NorthWest Province, South Africa. All facility managers gave permission for the data collection in their facilities. See annexures E, F and G for their written consent. The researcher and research assistant went to the identified healthcare facilities to conduct the FGDs. For the FGDs with the mothers, the research team preferred visits on Thursdays, as this was immunisation day and it was expected that more mothers with infants would be present. Therefore, the

specific catchment population would be reached. The researchers approached the participants whilst waiting in queues at the selected clinics. Special arrangements were made with the clinics and hospital management for mothers who participated in the FGDs to be seen after the FGD without having to queue again. Appointments were made with the healthcare professionals to ensure that their working schedule was not interrupted.

At the time the research was completed, 41 stakeholders participated, 14 in the mother participant category, 17 in the elderly participant category and 11 in the healthcare participant category. Fortunately, this sample size was not a problem, because data saturation was reached with this sample size.

### **1.3.3 Data collection**

The researcher collected the data through focus group discussions that took place at selected healthcare facilities over a period of three months involving four to 10 informants as recommended by Creswell *et al.*, 2011. For this purpose, the researcher extensively trained and tested a research assistant for effective FGD conduction using the focus group discussion guides (see Annexures A and B). The research assistant was fluent in Setswana, Afrikaans and English to ensure that the focus groups discussions could be conducted in the participants' preferred language. All FGDs took place in Setswana.

The researcher used a set of nine to 13 open-ended questions, adapted from Coutsoudis *et al.* (2011), to guide her FGDs with the healthcare professionals, mothers and elderly respectively. Translators translated the FGD guides into Setswana, Afrikaans and English prior to the research assistant training process. The translation ensured that the FGDs were conducted in the language of choice of the discussants. During the translation of FGD guides, the focus was on expressing the correct meaning of the questions and not on the correct usage of language. The English version of the FGD guide used for mothers and elderly participants is attached in Annexure A; the questionnaire for healthcare professionals is attached in Annexure B. The participants were guided and encouraged to share their experiences and interaction was encouraged among members throughout discussions. The end goal was to promote a robust discussion of the involved issues in order to determine the attitudes and perceptions on matters relating to the donation and receiving of human breast milk. The researchers conducted the FGDs in a separate room to ensure anonymity and to encourage the participants to speak freely.

#### 1.3.4 Data capturing and analysis

The data was analysed for themes or participant viewpoints and a few themes emerged as described by Creswell (2009:184). This data analysis was performed using a phenomenological approach, taking into account both the manifest and latent content to determine the emerging themes and subthemes of the types of attitudes and acceptability factors. The following basic method, as explained by Creswell (2009:185-190) was followed as a guideline during the data analysis.

Firstly, the organisation and preparation of the data were done by putting group transcripts together (Creswell, 2009:185). The FGD's were transcribed *verbatim* and then translated. Two independent translators who speak Tswana and English fluently translated the transcripts. These translated transcripts were then compared to the original transcripts to ensure that the meaning after translation stayed intact. No discrepancies were found during the comparison of the independent translations. All transcripts were typed for easier reading. Annexure I contains an example of the translated transcripts.

The researcher then read through all the collected data to obtain a "general sense" of the information and to think about the general meaning of the data (Creswell, 2009:185). She made notes on the transcripts and common thoughts were written down (Creswell, 2009:185).

A comprehensive analysis of the data was performed by using a coding process (Creswell, 2009:186). According to Rossman and Rallis (cited by Creswell, 2009:186), coding is the process in which different sections of the text referring to specific ideas are identified for sorting into categories and emerging themes. During the data analysis, the data was coded by organising the data into text sections before a meaning was attached to the information (Creswell, 2009:186). Portions of the text were arranged into categories; these categories were labelled with a term, often based on the original words used by the participants (Creswell, 2009:186).

According to Tesch (1990; cited by Creswell, 2009:186), there are eight steps in the coding process. The researcher used them as a guideline to code the data.

- (1) The researcher obtained a feeling for the complete data set by first reading through all the data and by writing down thoughts and facts as they emerged (Creswell, 2009:186).
- (2) The researcher selected one transcript, and after going through it, she tried to determine its fundamental meaning and wrote ideas that came to mind on the transcript (Creswell, 2009:186).

- (3) The researcher repeated this process for a number of transcripts and then she made a list of all the topics, grouping similar topics together at the same time. These topics were now fashioned into columns and arranged as main topics and excess topics (Creswell, 2009:186).
- (4) Thereafter, the researcher took this list back to the data where the topics were abbreviated to codes. These codes were written in the sections of the text where they fitted. The researcher used this initial organising system to see if any new themes and codes materialised (Creswell, 2009:186).
- (5) The topics were described in the most expressive words, where after the researcher transformed them into themes. The topics that related to one another were grouped together in order to reduce the total list of themes (Creswell, 2009:186).
- (6) The researcher took a final decision on the term to be used for each theme and she arranged the codes in logical order, although according to Creswell (2009:186), they can be arranged in alphabetical order as well. The data for each theme was gathered in one place and an initial data analysis was performed (Creswell, 2009:186).
- (7) The researcher recorded the existing data when needed (Creswell, 2009:186).
- (8) The coding process produced a description of the themes for analysis (Creswell, 2009:189). The coding process revealed a small number of four main themes. These themes referred to the most important findings and were used to create the headings when the results were reported (Creswell, 2009:189).

After the data analysis, the data was analysed by an independent co-coder to enhance rigour (Annexure M). A protocol for the data analysis of the translated transcripts of the FGDs was developed (Annexure C) and given to the co-coder. The researcher and the co-coder then scheduled a meeting to discuss the results of the qualitative data analysis and to reach consensus regarding the main themes and the subthemes that emerged from the data. The researcher, co-coder and supervisors reached consensus with regard to the final organisation of the themes and sub-themes that were used to report, discuss and interpret the qualitative findings of the study. This final organisation of the themes and sub-themes is provided in Annexure J.

The researcher presented the findings by means of a comprehensive discussion of all the themes and sub-themes that emerged from the focus group interviews (Creswell, 2009:189). The findings were grounded in literature (see Chapter 3: Results and Discussions section).

### 1.3.5 Ethics approval and considerations

According to study protocol, the researcher had to obtain ethical approval from the Faculty of Health Science, Research Ethics Committee of North-West University (NWU-00083-13-S1) (Annexure D).

The researcher obtained approval to conduct the research at the various healthcare facilities from the Policy, planning, research, monitoring and evaluation department of the NorthWest Province (Annexure E). Thereafter, written permission was granted by the Dr. Kenneth Kaunda sub-district and the office of the clinical manager of one of the selected healthcare facilities, see Annexure F and G respectively.

Finally, written informed consent was obtained from each participant individually after providing him/her with information on what the project entailed. The informed consent form that was used is provided in Annexure H.

### 1.4 Research team

The contributions of the researchers listed as authors in the article that were part of this research project are presented in Table 1-1.

**Table 1-1: List of members and their contribution to this research project**

<b>Name</b>	<b>Role in study</b>	<b>Institutional affiliation</b>
C Oosthuizen	<ul style="list-style-type: none"><li>– Responsible for the planning, execution and management of this project</li><li>– Responsible for obtaining informed consent and data collection</li><li>– Data analysis and primary writing of the article</li><li>– Preparation of the dissertation</li></ul>	MSc Student and researcher
N Covic	Guidance on all aspects of the research.	Supervisor for MSc student
R Dolman	Guidance on all aspects of the research	Co-supervisor

W Lubbe	Guidance on research design and other aspects of the research	Assistant supervisor
M. Thomas	Responsible for data collection and translation	Research assistant

## 1.5 Research report structure

This dissertation consists of four chapters that each contains a reference list of works referred to in the text.

### **Chapter 1 : Overview of study**

Chapter 1 provides an overview of the course of this study. This chapter includes a brief introduction to the study, containing the motivation for this study, followed by the aims and objectives. The researcher also explains the research design and research method that were used in this study. The measures to ensure rigour and the ethical considerations are described as well as the research contributions from the study team members. This chapter is written according to the NWU manual for postgraduate studies (Font: Arial, Size: 11, one-and-a-half line spacing).

### **Chapter 2 : Literature review**

Chapter 2 consists of a literature review that will discuss the available evidence and highlight the shortcomings in the literature. This chapter is written according to the NWU manual for postgraduate studies (Font: Arial, size: 11, one-and-a-half line spacing).

### **Chapter 3 : Manuscript**

The third chapter includes the manuscript titled: "Stakeholder attitudes and acceptability on donating and receiving donated human breast milk", prepared for submission to the *Journal of Human Lactation*. The manuscript consists of the following sections: background, methods, results, discussions, conclusion as well as funding and conflict of interest. The researcher followed the instructions for authors, but for the purpose of this dissertation, the researcher did not adhere to the word count in order to describe the research thoroughly. The article will be shortened accordingly before submission for publication. The researcher inserted tables as part of the text in the dissertation for logical discussion and will be sent as requested by the author instructions with submission. The researcher adhered to the text style as specified in the author

instructions (Font: Arial, size: 12, double spacing), hence the format of this chapter differs from the rest of the dissertation. The referencing style is also different, as the author instructions state that references should be numbered consecutively as they appear in the text, using superscript Arabic numerals after punctuation.

## **Chapter 4 : Detailed conclusion on themes and related recommendations**

This chapter provides detailed conclusions on the findings and discusses related recommendations. This chapter is written according to the NWU manual for postgraduate studies (Font: Arial, Size: 11, one-and-a-half line spacing).

### **1.6 Conclusion**

In this chapter, an overview was given by identifying the “gap” in the literature and the well-established research. The researcher also included the motivation for this research, explained the methods through which she conducted this study, as well as the role of the research team. Lastly, the structure of this dissertation was provided.

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## **Chapter 2 Literature review**

### **2.1 Introduction**

Child mortality is a clear concern, as is signified by the emphasis it receives in the Millennium Development Goals (MDG's) and other national policies that address this issue. All World Health Organisation (WHO) guidelines focusing on decreasing infant mortality, state that exclusive breastfeeding (EBF) for the first six months of an infant's life is important for child survival. It has been reported that breastfeeding has improved maternal and infant health outcomes (Butte *et al.*, 2002; Chiricoet *al.*, 2008; Hamosh, 2001; WHO, 2010:)However, evidence shows that South Africa (SA) has a low EBF rate of only 8% (South Africa, 2007).

The benefits of breastfeeding are well documented (UNICEF, 2011). According to scientific evidence from a review (Jones *et al.*, 2003), EBF reduced under-five mortality by 13 percent globally (WHO, 2000). The WHO pooled analysis of multiple studies found that, compared to infants who were exclusively breastfed, infants aged 0-5 months who were not breastfed, had a six-fold and a two-and-a-half-fold increased risk of death from diarrhoea and pneumonia respectively (WHO, 2000). When maternal breast milk is not available, literature suggests that donor breast milk should be given as an alternative source of nutrition; as greater benefits from donated human milk compared to formula milk are evident, especially in the preterm infants (Arslanogluet *al.*, 2010; Bertinoet *al.*, 2009; Boyed *et al.*, 2009; Morales &Schanler, 2007; Wright, 2001). Therefore, donated human milk is a suitable feeding alternative for infants whose mothers are unable or unwilling to breastfeed (Gartner *et al.*, 2005; Geraghty *et al.*, 2010).

For this reason, strategies to improve the EBF rate include that human milk banks (HMBs)be promoted and supported as an effective approach to promote breastfeeding (South Africa, 2011).Numerous available studies explain the safety aspects and the implementation of HMBs, but according to our knowledge little is known about the attitudes and acceptability toward such an initiative. This literature review will present evidence in support of breastfeeding for the first year of life and the role that human milk banks can play in promoting breastfeeding.

### **2.2 The Millennium Development Goals (MDGs) and the Tshwane declaration**

The MDGs are eight international development goals that were formally established following the Millennium Summit of the United Nations in 2000 (WHO, 2008; South Africa, 2011). The purpose of the initiation of the MDGs was to improve the lives of hundreds of millions of people

around the world. As a member state of the United Nations, SA is a signatory to this agreement. The eight MDGs are listed in Table 2-1

**Table 2-1: Millennium development goals**

<b>The eight Millennium Development Goals</b>
1. To eradicate extreme poverty and hunger
2. To achieve universal primary education
3. To promote gender equality and empower women
4. To reduce child mortality
5. To improve maternal health
6. To combat HIV/AIDS, malaria and other diseases
7. To ensure environmental sustainability
8. To develop a global partnership for development

(World Health Organization, 2008)

Goal number four is specifically aimed at reducing the mortality rate of children under five by two thirds between 1990 and 2015 (WHO, 2008; UNICEF, 2012:11). Researchers identified EBF as the most effective intervention in reducing the risk of neonatal infections such as pneumonia and diarrhoea globally; therefore, it has a significant effect on the reduction of mortality (UNICEF, 2012). The infant mortality in SA has declined from an estimated 63.5 per 1000 live births in 2002, to 41.7 per 1000 live births in 2013. However, this decline is still not sufficient to meet the MDG before 2015 (STATSSA, 2013).

Due to high mortality rates and the high priority of reducing child mortality, the Government of SA joined stakeholders at a national breastfeeding consultative meeting in August 2011. During this meeting, the representatives committed to and called on all stakeholders to support and strengthen efforts to promote breastfeeding, as breastfeeding plays a crucial role in child survival, growth and development (UNICEF, 2012). At the consultative breastfeeding conference that formed part of the Tshwane declaration of support for breastfeeding, the delegates identified breastfeeding as a child survival strategy (South Africa, 2011). The declaration recommended that SA moves to EBF as a primary child survival strategy, and that the practice of providing milk formula through hospitals and clinics should discontinue, except

when prescribed by an authorized health practitioner. In addition, the declaration recommended that HMBs be promoted and supported as an effective approach to promote breastfeeding.

### **2.3 Child mortality**

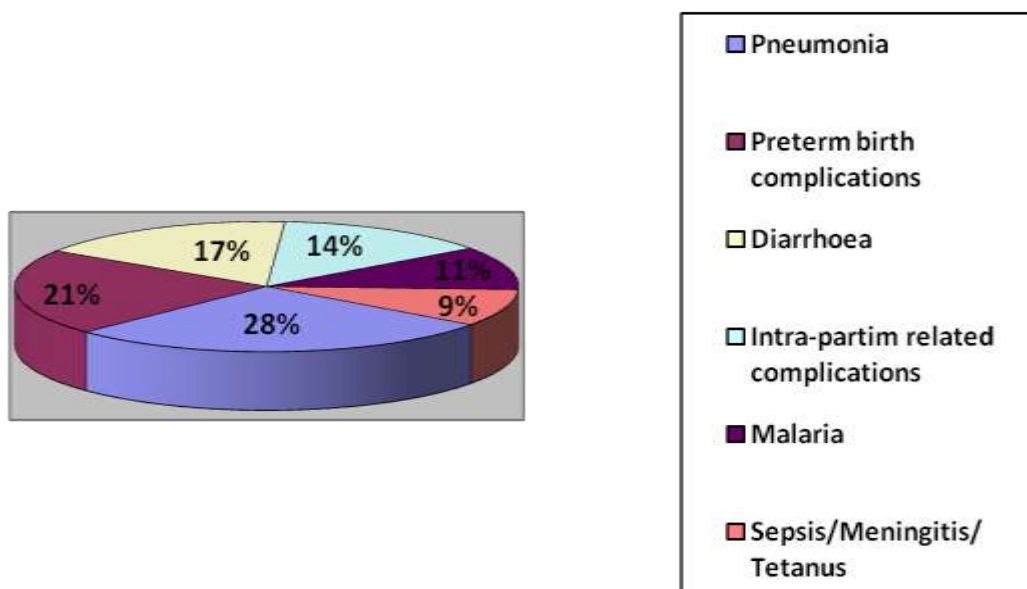
A number of indicators, such as infant and child mortality, number of children who are stunted and antibiotics administered for pneumonia, reflect the overall level of the health of children. When focusing on infant and child mortality, the United Nations Children's Fund (UNICEF) Child survival report 2012, reported that the annual rate of reduction in under-five mortality (3.2%) is insufficient to meet the MDG 4 target in 2015. This report included developed and developing regions (UNICEF, 2012:9).

There was a 41 percent decline in the under-five mortality rate from 1990 to 2011 globally (UNICEF, 2010:9). Five of the nine developing regions, including Eastern Asia, Northern Africa, Latin America and the Caribbean, have contributed to this global reduction by each showing a reduction of more than 50 percent between 1990 and 2011 (UNICEF, 2010:9). Sub-Saharan Africa showed a smaller reduction of 39 percent. Despite the progress in Sub-Saharan Africa, under-five deaths are still concentrated there. Of the 24 countries with an under-five mortality rate of above 100 deaths per 1000 live births in 2011; 23 countries were in Sub-Saharan Africa (UNICEF, 2010:9). In 2011 researchers still ranked South Africa (SA) as having the 58th highest under-five mortality rate, with a rate of 47 deaths per 1000 live births (UNICEF, 2012:12). More recent statistics show a decrease to 41.7 per 1000 live births in 2013 (STATSSA, 2013).

According to the 2012 UNICEF report on levels and trends in child mortality, neonatal mortality (covering deaths in the first month after birth) had increased in every region and in almost all countries despite the decrease in under-five mortality (UNICEF, 2010:12-13). Breastfeeding during this time may play an important role in saving lives, as it is a cost effective intervention to reduce mortality.

As indicated in Figure 2-1, the leading causes of death among children under five worldwide, include pneumonia, preterm birth complications, diarrhoea, intrapartum-related complications, malaria, neonatal sepsis, meningitis and tetanus (UNICEF, 2012:15)

## Leading cause of death in children under 5



**Figure 2-1: Leading causes of child mortality (UNICEF, 2012: 15).**

These causes of mortality are often associated with poor home environments, malnutrition and a lack of access to basic health services. Malnourished children are often weak and more likely to die from illnesses such as pneumonia, diarrhoea, malaria, measles and AIDS (UNICEF, 2012:21). With adequate nutrition and the promotion of optimal breastfeeding practices in early life, these deaths are for the most part preventable (UNICEF, 2012:16-18). Optimal breastfeeding practices include early initiation of breastfeeding; exclusive breastfeeding for six months and continued breastfeeding complimented with suitable food thereafter. Children who are not breastfed, have a 14 times higher risk of dying from all these causes in the first six months of life (UNICEF, 2012:21). Early initiation of breastfeeding and exclusive breastfeeding for the first six months is crucial for child survival and development. Table 2-2 clearly describes the feeding definitions that the researcher is using throughout this paper.

**Table 2-2: WHO feeding definitions**

<b>WHO feeding definitions</b>	
Exclusive breastfeeding	Giving the infant breast milk only and any minerals, vitamins and prescribed medicines if needed, for the first six months
Mixed breastfeeding	Giving the infant breast milk and other fluids and solids. MBF may be further classified into predominant breastfeeding and partial breastfeeding:  Predominant breastfeeding (PredBF) means giving the infant breast milk and non-nutritive liquids.  Partial breastfeeding (ParBF) means feeding breast milk and non-nutritive and nutritive liquids and solids.
Exclusive formula feeding	Giving the infant only commercial infant formula milk for the first six months of life.
Replacement feeding	Refers to the process of feeding a child who is not receiving any breast milk a diet that provides all the nutrients the child needs until the child is fully fed on family foods. During the first six months a suitable breast milk substitute should be used and subsequently complementary foods made from appropriately prepared and nutrient-enriched family foods should be added.

(Goga *et al.*,2012).

#### **2.4 Breastfeeding rate in SA**

As previously stated, South Africa has a very low exclusive breastfeeding rate of only eight percent for infants under six months (South Africa, 2011). Apart from this eight percent, a further 19 percent were not exclusively breastfed as the mothers provided water in addition to breastfeeding. In a National survey done by the Department of Health; the North West Province reported the lowest proportion (only 54%) of infants ever breastfed as is evident from Table 2-3 (South Africa, 2007). To our knowledge, there is currently no new statistics available on the current exclusive breastfeeding rates in SA. This low EBF rate is alarming, as the risks of suboptimum breastfeeding, such as increased morbidity and mortality, have been documented well in several studies (Black *et al.*, 2008; Black *et al.*, 2003; Bahl *et al.*, 2005; Jones *et al.*, 2003).

**Table 2-3: Initiation of breastfeeding in South Africa**

Province	Percentage ever breastfed	Number of children breastfed(n)	Of those ever breastfed, percentage who started breastfeeding:	
			Within one hour of birth (%)	Within one day of birth (%)
Western Cape	87.1	323	69.26	84.97
Eastern Cape	77.4	266	66.78	81.76
Northern Cape	90.1	46	55.12	88.78
Free State	78.8	130	62.32	83.49
KwaZulu Natal	76.7	117	45.57	81.4
North West	54.4	192	62.05	78.64
Gauteng	82.4	588	61.07	78.46
Mpumalanga	87.8	169	52.78	89.06
Limpopo	93.0	288	58.2	86.16

(South Africa, 2007).

The Bellagio Child Survival Study Group identified breastfeeding during the first year as one of the most important strategies for improving child survival (Black *et al.*, 2003; Jones *et al.*, 2003). By promoting, protecting and supporting breastfeeding; child mortality can be reduced and the health and development of young children and their mothers can improve (WHO, 2000). The pattern of feeding, be it EBF, mixed breastfeeding (MBF), exclusive formula feeding (EFF) or replacement feeding (RF), as defined by the WHO (Table 2-2), is a significant predictor of child morbidity and mortality. PredBF, ParBF or not breastfeeding (NBF) is associated with a higher mortality risk in general compared to EBF (Bahl *et al.*, 2005; Goga *et al.*, 2012; WHO, 2000; WHO, 2003). Furthermore, there is an increased risk for diarrhoea and pneumonia morbidity and mortality in all feeding patterns except for EBF during the first 6 months (Black *et al.*, 2008:250). There is also an increased risk for hospitalisation with ParBF and NBF compared to PredBF (Bahl *et al.*, 2005:423). Suboptimum breastfeeding is clearly a large contributor to the disease burden as it causes 12% of under-five deaths, a further three quarters of this deaths is due to non-exclusive breastfeeding in the first 6 months of life. According to research, even the provision of water or tea in low socio-economic circumstances leads to an increased risk of

death as these additions are non-nutrient supplementations for breastmilk (Black *et al.*, 2008:254).

A meta-analysis performed in developing countries by Imdad *et al.*(2011), showed that by promoting breastfeeding strategies that include education, counselling and support for mothers, the rate of EBF can increase with 89% 4-6weeks from the promotion intervention. The EBF rate will show a six-fold increase after six months (Imdad *et al.*, 2011). Furthermore, a study by Horton *et al.*(1996) measured the costs and impact of three breastfeeding promotion programs performed in developing countries. This study found that breastfeeding is one of the most cost effective preventative health interventions for cases such as diarrhoea. Promoting breastfeeding was also more cost-effective than oral rehydration therapy (ORT) and cholera immunisation (Horton *et al.*, 1996). Not only does breastfeeding play a vital role in decreasing mortality, but it also decreases health costs.

## **2.5 Benefits of breastfeeding**

The importance and beneficial effects of breast milk on the growth, development and overall health of infants are widely known. Human milk provides the unique balance of nutrients required to meet the nutritional needs of growing infants (Butte *et al.*, 2002). Breast milk changes its composition to meet changing infant needs, for example from colostrum for a newborn infant, to mature milk for older infants (James & Lessen, 2009:1929).The WHO acknowledges replacement feeding as a possibility as long as milk substitutes are acceptable, feasible, affordable, sustainable and safe (AFASS) (WHO, 2010:1). These conditions are seldom present in low-income countries, for this reason, WHO recommends EBF for the first six months of life (WHO, 2010:1). Scientific evidence has demonstrated the benefits of EBF and continued breastfeeding for all children up to one year, including those who are HIV exposed and HIV positive (WHO, 2010). According to Jones *et al.*(2003), EBF reduced the under-five mortality rate by 13 percent globally (Jones *et al.*, 2003; James & Lessen, 2009:1926). Breastfeeding does not only result in beneficial outcomes for infants, but for breastfeeding mothers as well. These beneficial outcomes include short- and long-term outcomes, such as protection against infection, respiratory disease, otitis media, gastrointestinal tract infections and preterm birth complications. The following divisions briefly discuss the benefits associated with breastfeeding.

### **2.5.1 Infectious Diseases**

One of the most prominent benefits of breastfeeding is its protective effect against infectious diseases. Breast milk protects the infant through secretory antibodies and immune factors,

including milk lipids that serve a role in nutrient provision and health protection (Chiricoet *al.*, 2008; Goldman, 2012; Hamosh, 2001). The lipids in human milk become antiviral, antibacterial and antiprotozoal *in vivo* after digestion in the gastrointestinal tract (GIT). The information available therefore suggests that there are added benefits from feeding infants breast milk (Isaacs, 2005; Isaacs *et al.*, 1990). Breastmilk also contains immunoglobulins with antibody activity against common bacteria, such as *Haemophilus influenzae* and *Streptococcus pneumoniae* (Chiricoet *al.*, 2008; Heinig & Dewey, 1996; Heinig, 2001; Oddy, 2001).

### **2.5.2 Respiratory diseases**

As previously mentioned, respiratory infections, such as pneumonia, is one of the common medical problems leading to mortality among infants and children. Studies indicated that when infants younger than one year were exclusively breastfed for four months or more, a 72% reduction was found in the risk of hospitalisation due to lower respiratory tract diseases (LRTD) (Duijts *et al.*, 2010; Slusser, 2007:3; Ketan & Ketan, 2005:828-829; James & Lessen, 2009:1926). A WHO analysis of studies also found that compared to infants who were exclusively breastfed, infants aged 0-5 months who were not breastfed had a two-and-a-half-fold increased risk of death from pneumonia (WHO, 2000).

### **2.5.3 Otitis Media**

Furthermore, breastfeeding has a protective effect against other common infections, such as acute otitis media (AOM) or infection of the ear during childhood. Otitis media often begins with an upper respiratory tract infection, by causing Eustachian tube dysfunction. The viral infection leads to the development of AOM in the child. The AOM enhances nasopharyngeal colonisation with middle ear pathogens (Slusser, 2007: 27). Breast milk contains components that interfere with the attachment of *Haemophilus influenzae* and *Streptococcus pneumoniae* to nasopharyngeal epithelial cells. Thus, by administering milk with anti-adhesive substances into the nasopharynx of the infant, the extent of colonisation may be reduced and the infant is protected against infection (Chiricoet *al.*, 2008:1802s-1803s; Slusser, 2007: 27).

In a meta-analysis of five cohort studies of good and moderate methodological quality, researchers found that breastfeeding was associated with a 23% reduction in the risk of AOM when compared to EFF. They found that EBF for 3 months or more reduced otitis media with 50 percent (Duijts *et al.*, 2010). As stated, general consensus exists in the available research that breastfeeding protects against many infections, including AOM and upper and lower respiratory tract infections (Abrahams & Labbok, 2011:509; Chiricoet *al.*, 2008:1802s-1803s; Dewey, 1996; Heinig & Heinig, 2001; James & Lessen, 2009:1926; Oddy, 2001).

#### **2.5.4 Gastrointestinal tract infections**

As indicated before, diarrhoea is still a main contributor to under-five mortality in children. Several studies have shown that breastfeeding protects infants against diarrhoea (Duijts *et al.*, 2010; Chiricoet *al.*, 2008:1801s; Morrow *et al.*, 2004:297; James & Lessen, 2009:1926). Research in literature suggests that infants who did not receive breast milk, had a 3.5 to 4.9 times higher risk of developing diarrhoea than infants who were EBF in the first six months of life (Slusser, 2007:37). A WHO pooled analysis of studies found that compared to infants who were EBF, infants aged 0-5 months that were not breastfed, had a six-fold increased risks of death from diarrhoea (WHO, 2000).

Throughout the literature, there is clear evidence that breastfeeding for 6 months (especially EBF) seems to have protective effects against the development of respiratory, gastrointestinal and AOM infections.

#### **2.6 Preterm birth complications**

Complications related to preterm birth (before 37 completed weeks of gestation), account for a great majority of neonatal deaths (UNICEF, 2012:20). Necrotizing enterocolitis is one of the most common gastrointestinal emergencies in newborn infants (Lin & Stoll, 2006; Patel & Shah, 2012; Patole, 2007).

NEC is an inflammatory gastrointestinal (GI) disease process characterized by tissue necrosis and multisystem organ failure; this leads to an acute clinical presentation of feeding intolerance, bloody stools, cardio respiratory compromise and severe haemodynamic instability (Lin & Stoll, 2006; Martin & Walker, 2006; Patel & Shah, 2012; Patole, 2007). NEC globally affects one in between 2,000 and 4,000 births, or between one and five percent of neonatal intensive care unit admissions. The disease occurs in nearly 10% of premature infants, but is rare in full term infants (Hunter *et al.*, 2008; Meizen-Der *et al.*, 2008; Sisk *et al.*, 2007:428). While researchers identified numerous risk factors in a multitude of studies, many are nonspecific, complex and shared by a vast majority of sick preterm infants in the NICU. The most consistent epidemiologic risk factors include: preterm neonates (gestation before 28 weeks), particularly with extremely low birth weight (ELBW); formula feeding, enteral feeding, growth restricted neonate, maternal hypertensive disease of pregnancy, placental abruption, absent or reversed end diastolic flow velocity, use of umbilical catheters, low Apgar scores, packed cell transfusions (Henry & Moss, 2008; Hunter *et al.*, 2008; Kosloske, 1997; Martin & Walker, 2006; Patel & Shah, 2012; Shah & Shah, 2009).

The significant mortality and morbidity rates related to this illness and the increasing numbers of preterm survivors at risk have resulted in the prevention and treatment of NEC becoming an important issue for those involved in neonatal intensive care (Patole, 2007). Research has shown that when infants fed breast milk or donated breast milk are compared to infants fed preterm formula products, affected infants have an improved feeding tolerance and a lower incidence of late onset sepsis and NEC when they are breast fed or receiving donated milk (Arslanglu *et al.*, 2010; James & Lessen, 2009:1926; Lin *et al.*, 2013; Rodriguez *et al.*, 2005; Sullivan *et al.*, 2010:562).

## **2.7 Decreasing NEC**

In most instances, breast milk is the optimal feeding method when available, as it protects against NEC (Arslanglu *et al.*, 2010; Sullivan *et al.*, 2010). Breast milk contains growth hormones that may promote GI adaptation and contains lactase that helps to digest lactose. Depending on the mother's diet, breast milk is usually a good source of docosahexaenoic acid (DHA) and arachidonic acid (ARA). DHA and ARA are long-chain polyunsaturated acids, vital to the structure and functioning of cell membranes. Current research elucidates their contribution to retinal and central nervous system development and immune functioning (Koletzko *et al.*, 2005; Parrish, 2008; Arslanglu *et al.*, 2010). Both human milk and donor breast milk feeding have been associated with significantly reduced incidences of NEC (Bertino *et al.*, 2013; Lin *et al.*, 2013; Schanler *et al.*, 2005; Sisk *et al.*, 2007:431; Sullivan *et al.*, 2010). Although many studies have found similar conclusions, research concerning NEC has been very controversial. Earlier studies have found a significant decrease in NEC when comparing preterm infants who have been fed donor human milk to infants who have received preterm infant formula. On the other hand, more recent trials have found no significant benefits in the donor human milk group (McGuire & Anthony, 2003; Schanler *et al.*, 2005). A possible reason for the inconclusive evidence could be the recent reporting of changeable fluid amounts of human milk that may have an impact on reducing the risk of NEC (Furman *et al.*, 2003; Meizen-Der *et al.*, 2009:59; Morales & Schanler, 2007). There is growing evidence regarding the relationship between the risk of NEC and the amount of human milk received. However, no specific dose has yet been established, although significant lower rates of NEC are seen when >50ml/kg human milk is given to preterm infants (Furman *et al.*, 2003; Meizen-Der *et al.*, 2009:59; Schanler *et al.*, 2005; Schanler *et al.*, 1999; Sisk *et al.*, 2007:431). A recent study indicated that exclusive breast milk fed preterm infants had as much as a 77% reduction in NEC compared to infants fed breast milk supplemented with infant formula products (Sullivan *et al.*, 2010:565).

The evidence therefore supports the notion that EBF protects infants against NEC. Breast milk is more protective for preterm infants, as all protective factors (nutritional, enzymatic, anti-infective, anti-inflammatory and immunomodulatory factors) are more concentrated in breast milk when infants are born early (Goldman, 2007; Schanler, 2001). It is clear that the composition of breast milk compensates for developmental delays in the immunological system of the preterm infant in order for their specialised needs to be met (Goldman, 2012; Heiman & Schanler, 2005). This further highlights the necessity of promoting breastfeeding, since it is clear that every mother's milk is suited to her infant's needs.

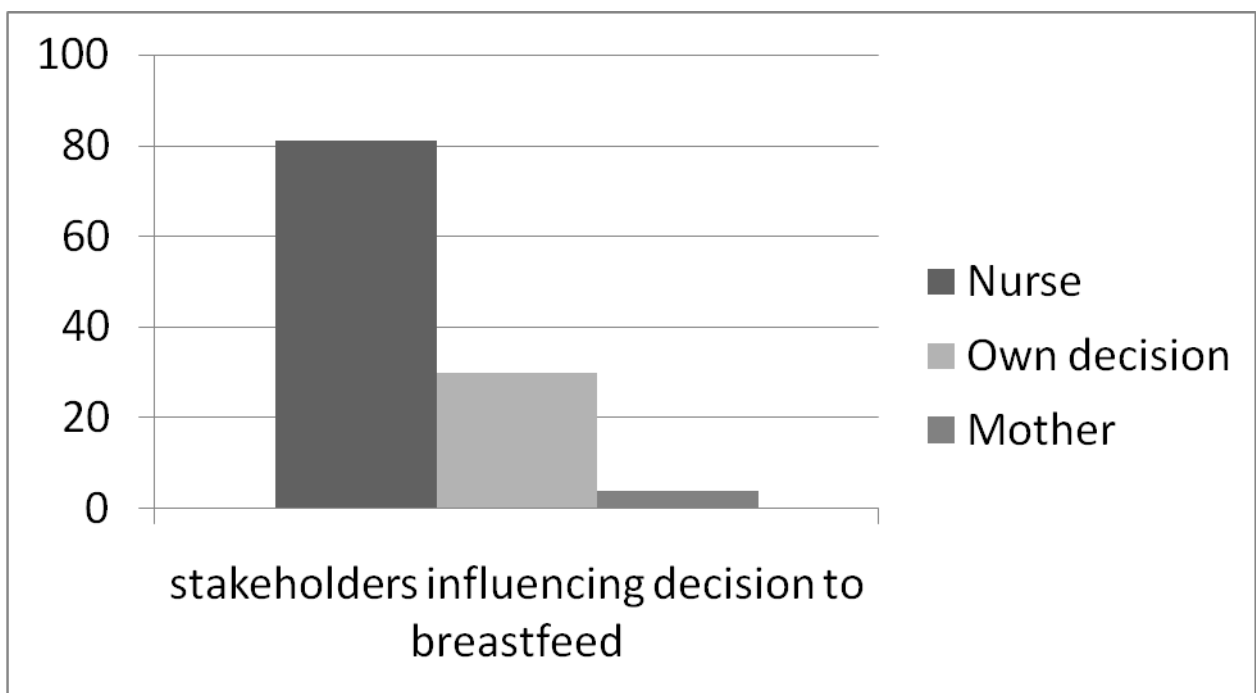
The information presented above provides strong evidence that optimal breastfeeding practices potentially have one of the largest impacts on child mortality and optimal health as a preventative intervention. Healthcare practitioners should therefore promote optimal breastfeeding.

## **2.8 Socio-cultural influences on infant feeding choices**

In a survey done on infant feeding practices, the researchers found that one third of the women involved decided on a feeding practice before they became pregnant (Lupton & Whelan, 1998). On reviewing the literature on studies mostly performed in the United States on the attitudes and beliefs related to the promotion of breastfeeding, researchers found that younger women (<19 years) had a significantly lower rate of breastfeeding than older women (Dennis, 2002; Spear, 2004). A typical profile of a breastfeeding mother is someone who is older, well-educated and married. These traits are not necessarily representative of a young adolescent mother. Nurses often believe that young mothers would not be interested in breastfeeding their infants (Osbaldiston & Mingle, 2007; Ryan *et al.*, 1991; Spear, 2004).

In SA, one of the major topics of discussion of socio-cultural influences concerns the HIV status of mothers and mother to child transmission (MTCT) (Thairu *et al.*, 2005; Tijou Traoré *et al.*, 2009). Current policies state that EBF; when certain conditions are met, such as maternal adherence to antiretroviral (ARV) regimens; may also be effective in reducing MTCT, whilst ensuring optimum nutrition (Thairu *et al.*, 2005; WHO, 2010). In a local study by Thairu *et al.* (2005) on other factors that influence infant feeding decisions, the researchers found that family influence and advice were strong factors. A single study performed in SA reported that younger women (<19 years) tended to base their decision more on what their elders believe to be best for the baby. This was less the tendency with older mothers. Younger mothers are apprehensive to oppose their family's opinion, especially if they are financially and emotionally dependant on them (Thairu *et al.*, 2005). In another study in South Africa, it was found that nurses had a strong influence on the decision of a feeding regime (Sibeko *et al.*, 2005). In fact, the

researchers found that 70% of mothers felt that nurses had influenced them to breastfeed (Sibeko *et al.*, 2005:35). Another study indicated that nurses who are more knowledgeable about breastfeeding, have a more positive attitude about breastfeeding (Spear, 2004). Therefore, in the case of this study, nurses in the area may have been well informed about the benefits of breastfeeding. The mothers also stated that they were more likely to consult medical staff if they had problems regarding lactation (Sibeko *et al.*, 2005:35). The cost of supplying formula milk was also an influencing factor in mothers' decision (Thairu *et al.*, 2005; Sibeko *et al.*, 2005:35).



**Figure 2-2: Stakeholder influencing decision to breastfeed**

(Adapted from Sibeko *et al.*, 2005:35)

When it comes to the donation of breast milk, Thomaz *et al.*(2008) performed a study in Brazil, which has the largest network of human milk banks in the world, on the profiles of mothers who donate their milk. They found that most mothers primarily donated their milk after a health professional recommended it to them and also because they were aware of the needs of the infants the banks served (Thomaz *et al.*, 2008). This research corresponds with the abovementioned (Sibeko *et al.*, 2005) **Error! Reference source not found.** that states that 81% of mothers were influenced by nurses to breastfeed. Current research also indicates that healthcare personnel involvement is necessary to encourage human milk donation (Geraghty *et*

*al.*, 2005; Thomaz *et al.*, 2008). In the only South African study done on the attitudes regarding HMBs, education about donor milk was one of the main points of discussion when mothers were asked in what way the use of donor milk can be more acceptable. Mothers and nurses felt that education about breast milk donation during the antenatal phase, as well as informing extended family members, would help mothers to make a choice to donate their milk (Coutsoudis *et al.*, 2011). However, these findings cannot be generalised to the current setting, as there are vast cultural differences among the different communities in SA.

## **2.9 Donated breast milk versus mother's own milk**

Researchers performed several studies to determine the beneficial effect of using donated human milk from mothers rather than a substitute formula (Bertino *et al.*, 2013; Boyd *et al.*, 2007; Gross *et al.*, 1981; Vieira *et al.*, 2011). One of the concerns leading to these types of studies is that breast milk from mothers with term infants have a lower content of protein and host defence protein than those of a mother of a preterm infant. The composition of breast milk also varies from mother to mother, especially concerning the fat content that differs during lactation (from foremilk to hindmilk), throughout the day and within a single milk expression (Heiman & Schanler, 2006). Therefore, the donor milk might not necessarily support the special requirements or VLBW infants in the way the mothers' own breast milk would (Bertino *et al.*, 2013; Boyd *et al.*, 2007; Gross *et al.*, 1981; Vieira *et al.*, 2011). In a study done by Schanler *et al.* (2005), the researchers found that only 27% of mothers had sufficient breast milk at birth to meet their premature infants' needs; therefore, donor human milk is often considered (Schanler *et al.*, 2005; Sullivan *et al.*, 2010). Although many studies have associated poor growth with children who received donor human milk as will be discussed in the following section, researchers also indicated numerous other lifesaving benefits with the use of this milk (Schanler *et al.*, 2004; Sullivan *et al.*, 2010).

## **2.10 Concerns regarding the use of donated breast milk**

### **2.10.1 Growth**

It has been suggested that human milk may not meet the high nutrient needs of the VLBW infant; even more so in the case of donor milk that is likely to have a lower protein content, as mentioned previously (Arslanoglu *et al.*, 2010; Leaf & Winterson, 2009; Vieira *et al.*, 2011; Quigley *et al.*, 2007). Multiple studies, including a meta-analysis of 16 articles done by Boyd *et al.* (2007) found that during the early postnatal period, formula fed infants in fact had a significant higher rate of weight gain when compared to unfortified donor breast milk fed infants (Arslanoglu *et al.*, 2010; Boyd *et al.*, 2007; Schanler *et al.*, 2004; Sullivan *et al.*, 2010). In the

meta-analysis, the majority (9 out of 13 studies) found that weight gain was faster in the EFF group when compared to the exclusively fed donor milk group. However, one study found that donor milk fed infants grew faster and the remaining three stated that there was no significant difference between the groups (Boyd *et al.*, 2007). More importantly, when measuring the infants' growth again at 9 months, 18 months and 7.5-8 years, the donor milk group and formula fed group were similar when comparing weight, height, skinfold thickness and body mass index (BMI). This indicated that the slower weight gain found in the exclusively fed donor milk group during the early postnatal period, had no long-term effect.

### **2.10.2 Effects of pasteurisation on human milk and alterations in quality of milk**

According to a review, the quality of donor human milk may be affected during the pasteurisation process (Boyd *et al.*, 2007). Inconsistency in the nutrient composition of the donor milk may be attributable to the change in the circumstances of the collection, storage, refrigeration and distribution of the donated breast milk (Heiman & Schanler, 2006). Vieira *et al.* (2011) reported that the pasteurisation process significantly reduces the concentration of fat and protein.

The abovementioned concerns should not be a barrier to the use of donated breast milk, as its benefits, of which there are sufficient evidence, outweighs the concerns.

### **2.11 The history of human milk banks and breast milk donation**

WHO recommends that infants who cannot receive breast milk from their own mothers, should receive the next preferred option, donated breast milk (WHO, 2009).

In the South African setting, breast milk banking existed informally in hospitals around the country prior to 1980 (HMBASA, 2012). Mothers with excess breast milk expressed and donated it for preterm babies whose mothers did not have sufficient milk. However, the mothers were not screened as they are today, and the milk was used without being pasteurised. With the increasing awareness of HIV/AIDS and the fact that the virus can be transmitted through breast milk, these breast milk banks stopped operating. Through the discovery of the Holder method of pasteurisation, the safe operation of breast milk banks became feasible again (Israel-Ballard *et al.*, 2005). Researchers found that pasteurisation destroyed HIV/AIDS and other potentially harmful viruses and bacteria, while retaining the nutrients and most of the immune properties (HMBASA, 2012).

The first milk bank in South Africa was started in 2000 in Durban, Kwa-Zulu Natal (KZN). The need for a breast milk bank stemmed from the high HIV infection rate at that time. This

pandemic resulted in thousands of infants either being abandoned when their mothers discovered they were HIV infected, or being orphaned when their mothers died of HIV/AIDS (HMBASA, 2012). HIV/AIDS was the leading cause of premature mortality in all provinces in 2000, therefore it was a major contributor to child mortality in SA (Bradshaw *et al.*, 2004, Newell *et al.*, 2004; UNICEF 2006).

## **2.12 Human milk banking in South Africa**

The Human Milk Banking Association of South Africa (HMBASA) coordinates human milk banking in South Africa by providing HMBs with practice guidelines based on the best available evidence. The aim of HMBASA is to reduce mortality by providing donated milk to infants where direct breastfeeding is not possible (HMBASA, 2011). The guidelines for the operation of a human milk bank in South Africa are provided in annexure K. This guide includes guidelines on amongst others the screening of donor mothers, the collection, storage and thawing of donated milk and pasteurisation.

## **2.13 The role of human milk banks in increasing breastfeeding rates and thus child survival**

Breast milk banks play an important role in promoting breastfeeding, as researchers reported an increased breastfeeding rate for very low birth weight (VLBW) infants at discharge from hospital in the presence of a human milk bank (HMB) and the use of donated breast milk in NICU (Arslanoglu *et al.*, 2013). BMBs ensure that donated breast milk is available for the preterm and vulnerable infants whose mothers are not able to provide breast milk during the first fourteen days of life (Arslanoglu *et al.*, 2010).

## **2.14 Current situation in South Africa**

Very little data is available on the number of human milk banks in South Africa, or the need for these interventions. The researcher could find no literature on the successes or failures of human milk banks in South Africa. It is clearly a new health concept in South Africa and therefore determining its acceptability among the community may be beneficial for the successful implementation and sustainability of such interventions in the province and country. There is ample research available on the safety and scientific aspects of donor milk, and the motives and experiences of donors and women and their families whose infants receive this milk, however, not in the South African setting. As mentioned, only one study has been done in the South African setting; this study cannot be generalised to the NorthWest Province. No studies have been done on the NorthWest population. By identifying the attitudes towards the donation and receiving of human breast milk among different stakeholders, strategies for

enhancing the acceptability and sustainability of breast milk banking in the province can be strengthened.

## 2.15 Conclusion

This literature review presented background information on human milk banks, provided evidence in support of breastfeeding in the first year of life and indicated the role that human milk banks can play in promoting breastfeeding. The researcher also identified the shortcomings in the literature, namely the little available research on the attitudes and acceptability factors of stakeholders, especially in the South African setting.

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## **Chapter 3 Manuscript prepared for submission to Journal of Human Lactation.**

### **Stakeholder attitudes and acceptability on donating and receiving donated human breast milk**

#### **Authors:**

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### **3.1 Permission to submit this article for examination purposes**

I, the supervisor, hereby declare that the input and the effort of Charlene Oosthuizen in writing this article reflect research done by her on this topic.

I hereby grant permission that she may submit this article for publication for examination in partial fulfilment of the requirements for the degree Magister Scientia Dietetics.

---

Supervisor: Namukolo Covic

Date:

---

Co-supervisor: Robin Dolman

Date:

---

Assistant supervisor: Welma Lubbe

Date:

### **3.2 Declaration by the researcher**

I hereby declare that this research 'Stakeholder attitudes and acceptability on donating and receiving donated human breast milk' is entirely my own work and that all sources have been fully referenced and acknowledged.

---

C.S. Oosthuizen

---

Date:

### **3.3 Declaration by the language editor**

I hereby confirm that I have language edited the article titled 'Stakeholder attitudes and acceptability on donating and receiving donated human breast milk'.

Elma de Kock

22 November 2014

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When including participant photographs, please try to avoid making them recognizable (for example, do not show a face). If a photograph is recognizable, please include a statement in your manuscript indicating that written consent for using the photograph(s) was obtained. If your manuscript is accepted for publication, you will be asked to have the person in the photograph sign an additional *Journal of Human Lactation* photo consent form.

#### **Audio/Video Files**

*JHL* is now accepting audio/video files. The following file types can be handled by our manuscript submission Web site, Sage Track. Audio/Video: asf, avi, flv, mov, mp3, mp4, mpeg, mpg, wav, wma, wmv. For optimal viewing, videos should be 480x360 pixels. If it is a different size/aspect ratio, it will be resized upon upload. There is no limit to the length of the video, although the maximum file size allowed is 1GB. Videos hosted elsewhere (such as YouTube), can be included as links. Once uploaded, the videos will only be viewed in the HTML version of an article.

#### **Tables, Figures and Images**

Each table/figure/image must be uploaded as a separate file, not as part of the main text document. If there are multiple tables/figures/images, please upload each one as a separate file. Number tables/figures/images consecutively as referred to in the text. Provide each table/figure/image with a brief title above the table/figure/image. Place explanatory matter or data incorporated from another source in footnotes. Indicate footnotes with lowercase letters (a, b, c, etc.); do not use symbols. Presentation of the results from logistic regression, Poisson

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regression, or Cox regression should be the exponentiated parameter estimate (ie, the odds ratio, incidence rate ratio, or hazard ratio) and corresponding 95% confidence interval rather than the parameter estimate. The inclusion of *P* values is unnecessary when 95% confidence intervals are presented. As appropriate, identify and specify units. Do not use excess precision in expressing results.

**Tables:** Please double-space tables and provide column headings. Tables should be self-explanatory and should supplement, rather than duplicate, the material in the text. Column headings should be capitalized as titles (all words capitalized except articles and prepositions) and bolded. Row headings should be capitalized as sentences, but not bolded. When a row heading is divided into several subheadings, the subheadings should be indented but not placed in bold, italics, or underlined.

**Figures and Images:** Submit all figures, images, and charts in their original format and in the best reproductive quality. Include a brief and specific title at the top of all figures and images followed by a description (if applicable) at the bottom. Use scale markers and legends as needed. Capitalize figure titles and axis labels as titles (all words capitalized except articles and prepositions). Do not bold axis labels.

Figures and images can be printed in color for a fee (online color reproduction is free). Contact JHL editorial staff for fee schedule.

#### **Funding Source**

At the end of the main text, authors must include disclosure of funding received for the work from organizations such as National Institutes of Health (NIH), private foundations, industry, etc.

#### **References**

Reference all quotations, previous study findings, and facts the reader may question. Personal communications and all other materials not yet accepted for publication may be mentioned only in the body of the manuscript. Number references consecutively as they appear in the text, using superscript arabic numerals after punctuation, *like this*. Follow the *American Medical Association, 10<sup>th</sup> Edition* style for references. Use journal abbreviations as listed in PubMed; if the periodical does not appear in Index Medicus, use a complete title. Include issue numbers for journal references. Citation examples follow:

##### ***Journal***

Kamholz KL, Parker MG, Philipp BL. Implementing change: steps to initiate a human donor milk program in a US level III NICU. *J Hum Lact.* 2012;28(2):128-131.

##### ***Journal Article Published Online ahead of Print***

Van der hoek L, Pyrc K, Jebbink MF, et al. Identification of a new human coronavirus [published online March 21, 2004]. *Nat Med.* doi:10:1038.nm1024.

##### ***Book***

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Jelliffe DB, Jelliffe EFP. *Human Milk in the Modern World: Psychosocial, Nutritional and Economic Significance*. Oxford, UK: Oxford University Press; 1978.

#### Chapter in book

Kennedy KI. Fertility, sexuality and contraception during lactation. In: Riordan J, Auerbach KG, eds. *Breastfeeding and Human Lactation*. Boston, MA: Jones and Bartlett; 1993:429-457.

#### Thesis or dissertation

Heinig MJ. *Relationship of Energy and Protein Intake and Complementary Feeding to Growth Patterns of Breastfed and Formula-fed Infants* [dissertation]. Davis, CA: University of California; 1992.

#### Website

International Society for Infectious Diseases. ProMED-mail website. <http://www.promedmail.org>. Accessed April 29, 2004.

## REQUIREMENTS FOR ARTICLE CATEGORIES

### Quick Check: Manuscript Requirements

Article Type	Word Count	Abstract	Well Established / Newly Expressed	Funding Source	Ethical Approval Statement (include name of Institution)	Title Page
Reviews	4000 words	250, unstructured	No	Yes	No	Yes
Original Research	3500 words	250, structured	Yes	Yes	Yes	Yes
Original Research, Brief Report	1500 words	250, structured	Yes	Yes	Yes	Yes
Student Research	3500 or 1500	250, structured	Yes	Yes	Yes	Yes
Case Reports	1500 words	250, unstructured	No	Yes	No, but consent if photos	Yes
Insights in Practice	1500 words	250, unstructured	No	Usually N/A	No (assuming no study)	Yes
Insights in Policy	2000 words	250, unstructured	No	Usually N/A	No (assuming no study)	Yes
Commentaries/Special Reports	1500 words	None	No	Usually N/A	No	Yes
Inside Track	1200 words	None	No	Usually N/A	No	Yes
Letters to the Editor	500 words	None	No	Usually N/A	No	Yes

#### Reviews

4000-word limit. JHL welcomes reviews on lactation-related topics. The review should reflect a clearly formulated question or objective to identify, select, and appraise relevant research, and to collect and summarize data or information from the studies that are included in the review. Statistical methods may or may not be used to analyze and summarize the results of the included studies. A limitations section is expected. An unstructured abstract limited to 250 words, summarizing review content, is required. Contact the JHL editorial office with questions pertaining to appropriate review topics.

#### Original Research

Original research is welcome on the broad field of lactation. Methods may involve but are not limited to: quantitative or qualitative approaches; basic science; modeling; controlled trials;

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imaging studies; observational studies, and economic evaluations. The formatted manuscript should include the following sections:

**Well Established/Newly Expressed:** Two brief summary paragraphs stating what is already known on this topic (Well Established; 40 words max) and what this study adds (Newly Expressed; 40 words max). Please label each section separately and write clearly in layman's terms.

**Abstract:** A structured abstract (250-word limit) with the following headings: (1) Background, (2) Objective(s), (3) Methods, (4) Results, (5) Conclusion(s).

**Text:** 3500-word limit. Must include the following sections: (1) Background with clearly stated objective(s); (2) Methods; (3) Results; (4) Discussion; (5) Conclusion and (6) Funding and Conflict of Interest.

1. **Background:** should succinctly summarize the literature with regards to the objective(s).
2. **Methods:** must state the study design, and should include setting and dates of study, subject selection criteria, data collection methods, and statistical methods used. Statistical analysis should include the following items, as appropriate: pre-study calculation of sample size; statements adequately describing or referencing all statistical procedures used; confidence intervals given for the main results. **IMPORTANT:** please include a statement regarding which institution(s) granted ethical approval (see Ethical Approval section above).
3. **Results:** should clearly state the final sample size(s), participation and exclusions, and primary analyses that are parallel to the Objectives.
4. **Discussion:** should address the importance of the findings reported in the results section and how they compare to other published reports of a similar nature. A limitations section is expected.
5. **Conclusion:** should briefly summarize conclusions based on the content of the paper.
6. **Funding and Conflict of Interest:** Should comprise a brief summary of all funding sources and any conflict of interest that exists (for example funds or honoraria paid from any source that stands to gain financially from the outcomes described in the study.) This is included in the manuscript to ensure the information is visible to reviewers. When not applicable, the authors should state that no conflict of interest exists.

#### **Original Research: Brief Reports**

1500-word limit excluding Abstract, tables, figures, and references; limit to 1 table and 1 figure. Brief reports on new, interesting findings will meet the same criteria as Original Research but will be reported in shorter format reflecting a less complex study design or original findings not requiring an extended manuscript. A title page, Well Established/Newly Expressed section, and structured abstract (250 words) are required. Manuscripts should be formatted using the same headings as Original Research articles (see above). **IMPORTANT:** please include a statement regarding which institution(s) granted ethical approval (see Ethical Approval section above).

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### **Student Research**

For Original Research and Original Research: Brief Reports by students currently enrolled in a degree-seeking program please follow requirements above. *JHL* seeks to foster an interest in the field and in early career development, by dedicating space to student-led research. Student Research manuscripts will undergo the same blinded, external peer-review process as other manuscripts. It is expected that the student is first-author on the manuscript, and has had a significant contribution to at least two of the following areas: study design and concept, implementation, data collection, statistical analysis and interpretation, drafting of the manuscript. NOTE: On the title page, please include 1-2 sentences describing the student's current situation i.e., the course/program where the student is currently matriculated.

### **Case Reports**

1500-word limit, excluding tables, figures, and references. Include an unstructured abstract (250 words). For the main text, include the following section headings: (1) Background: a brief introduction, including a review of the literature relating to the problem; (2) Case Report: the case presentation, including history of the problem and other pertinent information, clinical approach, and outcome; (3) Discussion: discussion/recommendations regarding future investigations and/or assistance of future clients; and (4) Conclusion. Client confidentiality must be protected in the presentation, and if identifiable photos are used, a statement regarding obtaining written consent must be included (see Photos section above). Tables should be kept to a minimum.

### **Insights in Practice**

1500-word limit, excluding tables, figures, and references. Innovative teaching aids and procedures, charting, and referral forms specific to a lactation workup are appropriate for this article category. We also invite general discussions about running a lactation consultant practice, hospital-based management and service issues, and contemporary insights related to clinical experience. The manuscript should include an unstructured abstract (limit 250 words), a background stating the issue/problem, a presentation of the recommendations, a summary of the information presented, and a conclusion. Include subheadings as necessary.

### **Insights in Policy**

2000-word limit, excluding tables, figures, and references. This article category is designed to feature new steps in policymaking, for example, innovative policies on lactation-related, hospital clinical practice, or steps forward in national or international policymaking, such as development of national guidelines for implementation of the Baby-Friendly Hospital Initiative. We also invite general discussion and contemporary insights on policymaking and ways in which policies can be changed or implemented. The manuscript should include an unstructured abstract (limit 250 words), a background stating the issue/problem, a presentation of the recommendations, a summary of the information presented, and a conclusion. Include subheadings as necessary.

### **Commentaries and Special Reports**

1500-word limit, excluding tables, figures, and references. Perspectives related to timely issues in the field of human lactation are appropriate for this article category. Commentaries and

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Special Reports do not have abstracts. When submitting your manuscript, there is no “Special Report” category in ScholarOne; please select “Commentary.”

#### **Letters to the Editor**

*JHL* readers are encouraged to exchange information or provide input related to a recently published journal article or contributions to a controversy or debate by submitting a letter to the editor. Letters should not exceed 500 words; no abstract is required. Letters commenting on recently published articles should reference the particular article. References should be kept to a minimum. In addition to including a title page (see Title Page section above), please include the following information in the Letter’s main document: authors’ names, academic degrees, affiliation (if you wish to print this), city, state/province, country, and e-mail for correspondence. Letters to the Editor are not sent out for peer review.

#### **Inside Track**

##### **What is an *Inside Track*?**

Each *Inside Track* is a 2-page handout written for breastfeeding mothers. The concept is to provide a resource that IBCLCs and other clinicians working with breastfeeding mothers can share with their clients.

##### **How does *Inside Track* differ from other *JHL* papers?**

All other papers in *JHL*, from Editorials and Commentaries to Original Research and Independent Study Modules, are aimed at lactation professionals (clinicians, researchers, educators, etc.). By contrast, *Inside Track* is for mothers. It is written in a low-literacy style to be readable by most breastfeeding mothers.

##### **How is *Inside Track* similar to other *JHL* papers?**

Like all other articles in *JHL*, *Inside Track* must be based on the latest evidence and research. Information needs to be referenced to a reliable, independent source or research publication (see References below). The fact that *Inside Track* is published in *JHL* lends it credibility that requires it to go beyond the average patient handout and include up-to-date, evidence-based information.

##### **What topics are suitable for *Inside Track*?**

Any topic that is practically applicable to a breastfeeding family. For example, milk supply, expressing and pumping for a premie, toddler nursing, returning to work, etc. It is important that topics are narrow enough in focus to incorporate into a single-page, double-sided handout. It is recommended that authors read past *Inside Tracks* and choose a topic that has not been previously addressed.

##### **Who can publish an *Inside Track* in *JHL*?**

At least 1 of the authors must be an IBCLC, and the lead author must be an ILCA member. If the lead author is not an ILCA member when the *Inside Track* is submitted, he or she must join ILCA prior to its publication. *Inside Track* seeks to promote the IBCLC and to foster new writers among ILCA’s membership.

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**Specifics:**

- Maximum word length: 650 words.
- Writing must be clear and use layman's terms; this would be a reading level of around age 10 (for example in the US – grade 5; approximating the reading level of WIC materials). This is not "talking down" to women but rather ensures accessibility for the widest possible audience, including women with lower literacy skills, women with limited English, and tired, new mothers!
- To achieve this, use short words and sentences, an active voice and conversational style, avoid double negatives, reduce use of words with 3 or more syllables and use bullets.
- *JHL* is an international journal, with readers from all levels of society all over the world. Avoid phrases that portray a narrow frame of cultural reference (such as "5<sup>th</sup> grade" or "here in the US"); avoid making assumptions about socioeconomic status ("use a private office to pump" or "be sure to sign up for WIC"). If you do need to use examples that might not be universal, qualify them ("In the US and some other countries..." or "If you can, ask for a private space to pump...") As for all *JHL* articles, American spellings are used.
- Provide 2 relevant photographs. You will be asked to obtain written permission from the photographer(s) to use the photos. If a photo is recognizable (i.e., if a face is shown), you will also be asked to obtain written permission from the person (or parent of the person) photographed. High-resolution (at least 300 dpi) images are required and .jpg images are preferred. Tiff and .pdf images are also acceptable. Upload images separately from main text and title page files. In the main text file, indicate where you would like to place each photograph and provide captions.
- Include 1 or 2 bulleted lists to break down information into an easy-to-read format.
- Include information about the role of the IBCLC in relation to the topic presented in the *Inside Track*.
- Consider including a list of 1-5 relevant websites to provide mothers with helpful resources.

**References**

There is no need to reference well-known, evidence-based statements, for example, that breastfeeding is healthier than formula feeding, or that the BFHI improves hospital practices for breastfeeding women. Statements or claims that are not common knowledge, however, need to be referenced. So as (random!!) examples, the following would need to be referenced:

- Breastfeeding reduces ovarian cancer
- Premies born in Baby-Friendly hospitals breastfeed longer
- Breastfeeding moms cannot use Drug X
- Most newborns cry at least 2 hours a day

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References should be included for the benefit of the authors and the reviewers. They will not be published in the final *Inside Track*. References should be *primary sources*, that means, a (recent) paper from academic literature, a (recent) book, etc. Websites designed for popular reading are not valid reference sources, but websites by highly credible sources such as the CDC or the WHO are appropriate as references. References do not count in your word limit.

**Title page:**

*Inside Track* submissions require a Title Page. This is the only file that should include the authors' names. The Title Page must be uploaded as a separate file to ensure blind peer-review. The Title Page must include: (a) Complete manuscript title; (b) Authors' full names, academic degrees, and affiliations; (c) Name and address of corresponding author, including fax and telephone numbers, and email address; (d) Address for reprints if different from that of corresponding author; (e) Word counts for the abstract, and for text independent of abstract; (f) keywords which will be used for PubMed reference (always include "breastfeeding" as a keyword).

**Submission and peer review:**

All *Inside Tracks* should be submitted directly to *JHL* via the submission site at <http://mc.manuscriptcentral.com/jhl>. When the site prompts Manuscript Type, select *Inside Track* as the option. Reviewers will be chosen by *JHL* editorial staff, and will be alerted to the fact that this is an *Inside Track*, because the criteria for (readability, applicability, etc.) are different from other papers. Comments to the author will go directly to the author. As with other *JHL* papers, authors should allow a lead-time of approximately 4-6 months between submission and the article going into print. Not all submissions are guaranteed acceptance.

**Before submitting your *Inside Track*:**

- Is at least 1 author an IBCLC and is the lead author a member of ILCA?
- Is the word count 650 words or less?
- Is it written in a low-literacy style and have you included 2 photographs and 1-2 bulleted lists?
- Have you considered including a list of 1-5 helpful websites?
- Is the information based on the latest evidence and research?
- Have you included references to statements that are not common knowledge?
- Have you included information about the role of the IBCLC in relation to the topic presented?
- Have you uploaded separate main text, title page, and photograph files?

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### 3.5 Title page

Complete Manuscript title:

Stakeholder attitudes and acceptability on donating and receiving donated human breast milk.

Authors' full names, academic degrees, and affiliations

- 1) Charlene Sherryl Oosthuizen, Obtained BSc Dietetics degree at the School of physiology nutrition and consumer science, Centre of Excellence for Nutrition, North-West University, Potchefstroom campus.

Currently enrolled for a MSc in Dietetics at the Centre of Excellence for Nutrition North-West University, Potchefstroom campus.

- 2) Welma Lubbe, PhD (Nursing Science); Advance midwifery and neonatal nursing science, diploma in nursing education. Senior Lecturer, School of Nursing Science, North-West University (Potchefstroom Campus),
- 3) Robin Claire Dolman, PhD Dietetics, Centre of Excellence for Nutrition, North-West University, Potchefstroom Campus
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Address for reprints if different from that of corresponding author

Word count for the abstract, and for the text independent of abstract

Keywords which will be used for PubMed reference

“Breastfeeding”; “donated human breast milk”; “breast milk bank”; “attitudes”; “acceptability”

Acknowledgements

This work is based on the research supported by the National Research Foundation. Grant reference number: TTK20110914000027025.

### **3.6 Manuscript for submission to the Journal of Human Lactation**

## **Stakeholder attitudes and acceptability on donating and receiving donated human breast milk.**

Charlene S. Oosthuizen, Welma Lubbe, Robin C. Dolman and Namukolo Covic

### **Well established**

Human breast milk has great benefits for preterm and term infants. When mothers' own milk is not sufficiently available, the next best option is donor breast milk. The safety and nutrient composition of donor milk have been widely researched.

### **Newly Expressed**

Research regarding the attitudes and acceptability of women who donate their milk as well as women whose infants receive donor milk are limited, especially in the South African setting where breast milk banks are still being established. This study therefore determines the attitudes of the key informants of the relevant community stakeholder categories, as well as the health workers towards such a venture.

### **Abstract**

#### **Background:**

The benefits of breastfeeding for infants and mothers as strategies to promote higher exclusive breastfeeding rates include, promotion and support of human milk banks (HMBs). Numerous factors determine the success/sustainability of HMB, including support from relevant healthcare workers and community members that HMBs serve.

**Objectives:**

Attitudes on acceptability of donation and receiving of human breast milk of key stakeholders, mothers, healthcare workers and the elderly (representing grandmothers and hereafter referred to as grandmothers) were determined.

**Methods:**

The study sites were a public hospital and nearby clinics in North West province, South Africa. The investigation involved eight focus group discussions, 3 with mothers of 0 to 12 month old infants (n=13), 3 of grandmothers above 60 years (n=17) and 2 with healthcare professionals, working with infants younger than 1 year (n=11).

**Results:**

Stakeholders expressed concerns on safety and cultural issues. Participants recommended education on HMB procedures to improve the attitudes on acceptability of HMBs. Attitudes were identified which may pose barriers/fears to donating and accepting human milk and exclusive breastfeeding. The barriers included need to undergo HIV testing, cultural beliefs on personality traits transfer and bonding. Fears included not having enough milk, changes to donated milk quality during pasteurisation and transportation processes as well as fear of HIV transmission.

**Conclusion:**

Attitudes were identified that may be important barriers to donating and receiving donated human milk as well as exclusive breastfeeding. A quantitative survey is recommended to determine the prevalence of the attitudes in this and similar community settings.

1.

## **Background**

The importance and beneficial effects of exclusive breastfeeding on the growth, development and overall health of infants are widely known. Numerous studies have reported that breastfeeding has improved maternal and infant health outcomes.<sup>1,2,3,4</sup> Breast milk provides the unique balance of nutrients to meet the nutritional needs of growing infants.<sup>1</sup> The Bellagio Child Survival Study Group<sup>5,6</sup> identified breastfeeding during the first year as one of the most important strategies for improving child survival.<sup>5,6</sup> Moreover, according to a UNICEF (2012) report, exclusive breastfeeding (EBF) is the most effective global intervention in reducing the risk of neonatal infections such as pneumonia and diarrhoea; therefore, it has a significant effect on the reduction of mortality.<sup>7</sup>

In most instances, breast milk is the optimal food for preterm infants when available. Its benefits, such as protecting against infections, providing all the nutrients needed for growth and protecting against necrotizing enterocolitis (NEC), among others, are well known.<sup>8,9</sup> NEC is one of the most common gastrointestinal emergencies in newborn infants.<sup>10,11,12</sup> NEC is an inflammatory gastrointestinal (GI) disease process characterized by tissue necrosis and multisystem organ failure; this leads to an acute clinical presentation of feeding intolerance, bloody stools, cardiorespiratory compromise and severe haemodynamic instability.<sup>10,11,12,13</sup> When maternal breast milk is not available, it is strongly recommended that donated breast milk is the next option, as both the mother's own milk and donor human milk feeding have been associated with significantly reduced incidences of NEC.<sup>9,14,15,16</sup>

Human milk banks have been shown to play an important role in the promotion of breastfeeding. An increased rate of breastfeeding at discharge from the hospital has been observed for very low

birth weight (VLBW) infants in the presence of a human milk bank (HMB) and when donated breast milk is provided in the NICU.<sup>17</sup> Due to the supporting evidence, South Africa declared in the Tshwane declaration of 2011, that HMBs should be promoted and supported as effective approaches to promote breastfeeding. Participants of the National Breastfeeding Consultative meeting adopted the Tshwane declaration in support of breastfeeding. Furthermore, a study from Horton *et al.* (1996),<sup>18</sup> measured the costs and impact of three breastfeeding promotion programs performed in developing countries.<sup>19,20,21</sup> This research indicates that breastfeeding and donor milk banks are also some of the most cost effective preventative health interventions.<sup>18,19,20,21</sup>

Numerous factors determine the success and sustainability of a HMB, including the support of the relevant healthcare workers, as well as the community that the hospital serves. It is therefore vital to determine the attitudes of the community, as well as those of the healthcare workers towards such a venture. Without the support and commitment of all the relevant stakeholders, the sustainability of a HMB is threatened. Understanding the attitudes of doctors, nurses and dietitians that work with mothers towards HMBs, will provide valuable information that can be incorporated into future training programs and policies regarding the start-up of HMBs. Understanding the acceptability and attitudes of various members of the community the hospital serves, will enable the Department of Health and healthcare workers to develop appropriate educational material and messages for the community and other stakeholders.

Little research has been done in the South African setting on the acceptability and attitudes of stakeholders toward such a venture, especially in the NorthWest community, where a HMB has been established. This study therefore aimed to determine the attitude and acceptability factors of stakeholders including mothers, grandmothers and healthcare professionals toward the donation and receiving of donated human breast milk.

## Methods

**Setting and design:** This study was performed in the NorthWest Province, South Africa; as the province opened their first HMB in June 2012. The researchers used an observational study that made use of a qualitative research design of focus group discussions (FGDs) with key informant participant groups, to identify the attitudes and acceptability factors using a phenomenological approach.

**Selection of focus group participants:** Three groups of stakeholders, based on the following criteria, were included for participation: (a) mothers with infants aged 0 to 12 months; (b) elderly people representative of grandmothers in the community (at least 60 years old); and (c) healthcare professionals that care for mothers with infants aged 0 to 12 months regularly, who operate in healthcare facilities. Each of these groups had been purposely selected due to their potential influence on mothers' choices regarding breast milk donation, since research highlighted the involvement and influence of family and the elderly, especially grandmothers, in a community as an important factor in infant feeding choices.<sup>22,23,24</sup>

**Data collection:** The key informants for the FGDs were recruited through two local clinics and one hospital in the Kenneth Kaunda district between April and June 2014. The researchers selected the clinics because one recently received a Mother and Baby Friendly Health Institution (MBFHI) status. This is also one of two clinics in the district currently delivering infants. The other is a very busy clinic (the largest in the sub-district) with a total head count of approximately 529 infants per month (February Department of Health 2013 statistics). The recruitment of key informants through these facilities targeted the catchment population that would sustain the HMB that has been established.

A research assistant facilitated the FGDs for the mothers and the elderly in the local language, Setswana. The research assistant was trained on facilitating FGDs and aspects concerning the

study, including aim, inclusion and exclusion criteria and obtaining consent. In addition, information on HMB procedures was covered to provide the research assistant with an adequate background on issues related to HMBs to be able to guide discussions effectively. The first FGD for each group also served as a practice session to develop rapport with the discussion process. The researcher completed two practice sessions with the research assistant to ensure that she felt comfortable with the procedure. These practice sessions were included in the final data analysis. Thereafter, the researcher contacted the various health facility managers to enquire about specific infant consultation days in order to reach the target population. The research assistant approached participants whilst waiting in cues at selected clinics. Special arrangements were made with the clinic and hospital management for mothers who participated in the FGDs to be seen after the interview without having to queue again. The principal researcher conducted the two FGDs with the healthcare professionals and she made appointments with them to ensure that the FGD did not interfere with their working schedule.

In total, eight FGDs were conducted; 3 with mothers (n=13), 3 with elderly participants (n=17) and 2 with healthcare professionals (n=11) (Table 2). These numbers are adequate according to FGD guidelines. Privacy and anonymity were ensured by conducting the discussions in a separate room and by not using the names of the participants in the discussions. For quotation purposes, each participant received a number during transcription according to the order in which they participated; for example P1, P2 and so forth. The participants cannot be identified according to this numbering system.

The sessions began by providing information on the research project, obtaining informed consent and collecting demographic data from the participants. The FGD guide consisted of 13 open-ended questions for mothers and elderly participants and 9 open-ended questions for healthcare professionals (Table 1). These were adapted from a similar study done in the KwaZulu Natal

Province by Coutsoudis *et al.* (2011).<sup>25</sup> The same questions were used for the mothers and elderly representatives of the grandmothers, but a slightly different guide was used for healthcare professionals to include their attitudes and perceptions regarding the use of a HMB. The researcher encouraged robust discussion during all the FGDs. Data saturation was reached across all FGDs. Henceforth, mothers will be referred to as mother informants, representatives of grandmothers as grandmother informants and healthcare professionals as healthcare informants.

**Table 1: Set of open-ended questions used during Focus Group discussions**

<b>FGD guideline for mothers and grandmother informants</b>
1. Between formula and breast milk, which do you feel is a better choice for feeding infants and young children, why?
2. What do you think the mothers should use to feed their babies?
3. How common do you think breastfeeding is in your community?
4. Has anyone heard of something called ‘wet nursing,’ or the practice of giving a child whose mother cannot breastfeed to another mother to breastfeed the infant/child for her?
5. What do you think about this practice? And have you ever heard of it being practiced before?
6. Has anyone heard of something called ‘breast milk donation? If so: Could you explain what it is?
7. What do you think about this practice of breast milk donation?
8. Do you think most women would be willing to donate their milk?
9. Would you be willing to donate your milk if you were breastfeeding?
10. What might prevent women from wanting to donate their milk?
11. What will traditional healers and community leaders think of breast milk donation?

12. Do you have (or have you heard of) any fears about donating your milk?
13. What do you think will help promote breast milk donation?
<b>FGD guideline for healthcare informants(additional questions)</b>
1. What are your thoughts on the establishment and operation of the HMB at the local hospital?
2. Have you been involved at all with this HMB?
3. Is there anything you would like to see done differently at the HMB?
4. How can we make it easier for you to prescribe/supply donor breast milk?
<b>FGD guideline for healthcare informants (questions left out)</b>
1. Has anyone heard of something called ‘wet nursing,’ or the practice of giving a child whose mother cannot breastfeed to another mother to breastfeed the infant/child for her?
2. What will traditional healers and community leaders think of breast milk donation?

### **Focus group discussions and analysis**

Eight FGDs were conducted involving 41 participants. All participants lived in the catchment area of the hospital where the HMB is situated. Participants were asked to indicate their age according to the following age groups: 15-24yrs, 25-34yrs, 35-44yrs, 45-54yrs, 55-64yrs, 65-74yrs, 75>. None of the recruited participants was excluded during the study.

All FGDs were audio recorded and transcribed *verbatim* in the language of administration (Setswana) and then translated into English by the research assistant; the purpose of the translation was to preserve meaning. This type of translation emphasises intended meaning as opposed to linguistic or grammatical correctness. A second independent research assistant also transcribed and translated the transcripts to ensure validity. Both transcriptions were compared for any discrepancies and none was found. To ensure anonymity, all digital audio recordings

were copied to and stored on a password-protected computer, and permanently deleted from the recording devices.

The transcriptions were analysed and coded by using a qualitative phenomenological approach, taking into account both manifest and latent content to determine themes and sub-themes of the types of attitudes and acceptability factors that emerged. Specific categories of attitudes and acceptability factors were analysed and the researcher did the coding twice, once by hand using a qualitative content analysis and once using the software package Atlas. Ti, version 7.1.8. A co-coder also coded the transcriptions independently to enhance rigour. The researcher and co-coder jointly compared and finalised the themes and labelled them.

During the transcription of the FGDs, participants were labelled either M if part of the mother participant group, G if part of the grandmother participant group, or HC if part of the healthcare participant group. Thereafter came the order in which they spoke during discussions, for example M1, if she spoke first. The number of the group then followed, for example if it was M1:3, she was from the third FGD with mothers.

### **Ethical approval and considerations**

Ethical approval was obtained from the North-West University Health Research Ethics Committee. Ethics number NWU-00083-13-S1. Permission to undertake the study in healthcare facilities was obtained from the following department in the NorthWest Department of Health: Policy, planning research, monitoring and evaluation. Thereafter the Tlokwe sub-district office in the Kenneth Kaunda district was informed in writing. Approval to collect data in specified clinics was also obtained from the district primary health care (PHC) manager at. The managers of the selected healthcare facilities were contacted either telephonically or in person and informed about the permission obtained to collect data, the type of data that will be collected and

the procedures to do so. Regarding the FGDs, written voluntary consent was obtained from every participant after the purpose of the discussion was explained; for the use of their statements and permission to be audio recorded. The researcher assured participants of confidentiality in that no statements would be used in such a way that they could be identified. All consent forms were available in the three local languages representative of the regional dialects to ensure participants had a choice of language they felt comfortable using.

## **Results**

Most mother participants fell in the age group 25-34years, grandmother participants 55-64years and healthcare professionals 25-34years. Three mothers reported to have completed grade twelve and one reported that she completed grade 4, which are respectively the highest and lowest qualification levels among the group of mothers. Thirty five percent of the elderly had undergone some form of education, whilst the rest have not had any form of education. Among all groups, most participants were unemployed except in the healthcare worker group where all the participants were employed (see table 2).

**Table 2. Characteristics of focus group discussion participants**

	<b>Participant categories</b>		
	Mother participants (M)	Grandmother participants (GM)	Healthcare participants (HC)
	<b>Number of FGDs held (number of participants in each respective group)</b>		
	3 (4) (4) (5)	3 (5) (7) (5)	2 (6) (5)
	<b>Total participants in category</b>		
	13	17	11
<b>Age range (yrs.)</b>	<b>Number of participants in age range</b>		
	15-24	6	
	25-34	7	7
	35-44		
	45-54		3
	55-64	16	1
	75-85	1	
	<b>Education level</b>	<b>Number of participants in education level</b>	
No school education		11	
Primary school		4	2
High school		9	4
Tertiary education			11
	<b>Number of participants employed</b>		
	4	1	11

Four main themes were identified from FGD data and are reported below.

### **Perceptions regarding breastfeeding and formula feeding**

Participants regarded breastfeeding superior to formula feeding based on the benefits of breastfeeding. The benefits mentioned by all participant categories, included convenience, since breast milk is readily available and no temperature adjustments or mixing is required, protection against infections, bonding facilitation and affordability. Affordability was an important reason among all representative groups for perceiving breastfeeding as superior. Mother and healthcare participants clearly stated that formula milk is expensive; this cost poses the risk of diluting formula to prolong the use thereof and can lead to the early introduction to solids, as these participants mentioned.

*“Sometimes the milk is not enough you then decide to reduce the scale to save some for the following day.”(M3:3)*

*“They start to give infants food when they are 3 months because there is no money for formula.”*  
(HP5:1)

Mother participants discussed that healthcare staff influenced their choice to breastfeed, because it was encouraged at the local healthcare facilities. Furthermore, nurses discussed stated that they felt the use of formula was the main reason for the occurrence of malnutrition at their facilities, due to the financial implications, as mentioned above. Despite the fact that participants indicated breastfeeding as the superior option, an isolated opinion from the mother participant group and healthcare participant group still felt that they would give formula milk if they could afford it. According to grandmother participants, formula feeding whilst at work during the day and then breastfeeding at night is a common practice.

Mother and grandmother participants perceived breastfeeding as occurring less frequent nowadays and, as one mother stated, it is no longer a common practice amongst especially younger mothers.

*“Usually young mother’s live fast lives. It is not usual to find them breastfeeding. It is only older woman who do it. The young women are after the fun times.” (M2:1)*

Some reasons provided for the decrease in the prevalence of breastfeeding included: it is no longer trendy among peers, peer pressure in favour of formula feeding, it is not practical for mothers who have to return to work, mothers believe they do not have sufficient amounts of breast milk, and the cultural belief that mothers who breastfeed are not allowed to have intercourse whilst breastfeeding. In this regard, there were perceptions that mothers have to make a choice between breastfeeding their children and intercourse with their partners as one mother commented.

*“They have boyfriends so they just want to get back to them, like according to our culture you should mourn in a way of respect for your child when you breastfeed. For about 3 – 4 months without sex so young mothers think 4 months is too much they can’t wait for 4 months so it’s best for them to bottle feed so that they have sex freely.” (M1:1)*

### **Exposure to the concept of wet nursing**

Participants indicated having knowledge of the practice of wet nursing, through direct family experiences or had practiced it themselves as this grandmother remarked:

*“I know it, I have done it myself but in the family. My cousin and I were both breastfeeding when she was not home I would feed her baby my milk as the baby was only fed breast milk.”(G2:1)*

However, a number of participants, especially in the grandmother participant category, reported that they no longer condone this practice in present times due to fear of diseases that may infect

the child. In most cases, diseases referred to the Human immunodeficiency virus (HIV), as mother participants remarked on checking their “*status*”. However, participants indicated that they would be willing to practice wet nursing if they knew the other person involved well, and knew their status; they added that it had to be a family member to ensure that they are comfortable with this practice.

A theme of cultural beliefs that emerged from the discussion on wet nursing, was the fear of the infant bonding with the wet nurse. This fear also came up again during the discussion of the fears regarding the donating and receiving of donor human milk. Participants from all three categories discussed this fear; they are afraid that the infant will bond with the person whose milk he or she receives, or inherit some of her personality traits when receiving her breast milk. It was a clear concern for the participants that a deeper connection may be carried over by the breast milk:

*“You might lose the love from mother to child.”* (M3:2)

*“I breast feed the child or if it is my child give the child to someone to feed the child there is something we call bond when you breast feed. So it means that person will bond with my child.”*

(M3:1)

### **Awareness on human milk banking**

All participants have heard about human milk banking, mostly from the healthcare facilities they attended or worked at. However, not everyone was clear on the processes followed in milk banking. Healthcare participants added that they have worked with it.

### **Attitudes and perceptions regarding donation of breast milk**

When asked how they would feel about donating breast milk, or what difficulties they thought donors may encounter; mother and healthcare participants raised questions such as: would donation affect the availability of breast milk for their own child; would donating breast

milk leave the donor feeling weak or exhausted; would milk donation result in fluctuation of breast size; and the effort of expressing milk for donation as reported by a mother:

*“To express, it’s difficult sitting the whole day expressing.” (M4:5)*

These questions did not arise in the grandmother discussions.

As part of the discussion process, participants asked questions of clarification afterwards on what happened to the milk and how donors were screened. When the researcher offered an explanation on how this is done, participants seemed to be much more open to the idea of breast milk donation. However, one mother was still concerned about the reaction that HIV testing would invoke from potential donors, since she commented:

*“Some people don’t like to go through tests. They ask themselves what if they are ill; those are the fears people have.” (M4:5)*

This was, however, an isolated concern as all groups discussed that proper safety testing would make them feel more at ease about human milk banking.

### **Attitudes and perceptions regarding receiving donated breast milk**

When asked how participants felt about their own infants or grandchildren receiving donated breast milk, they again discussed safety as a main concern, especially regarding HIV transmission. They expressed opinions that screening tests must be implemented to ensure that the donor is healthy, as one mother reported here:

*“If they have checked my milk and that of another woman. They are the same as long as they are clean.” (M4:1)*

A final issue that related to the discussion above was the concern on who the donor mother was. When addressing this issue with the healthcare participants, one felt that it would only be

acceptable if the donor is a relative. There seemed to be sensitivity towards the issue of race among the participant categories, as they felt that it mattered who the donor is and what culture they were from; as is evident from the statement of one mother:

*“We black people have the tendency of saying English is not my language as it is something you never got from your mother. So if a child drinks someone else’s’ breast milk they will be confused.”* (M3:1)

In healthcare participant discussions, participants made suggestions that screening should involve testing heritage and genes to ensure that the culture is compatible. Although participants also felt that if donor breast milk is tested for diseases and safety for use, it would be comforting enough for them.

Healthcare staff raised concerns about practicalities, such as the transport of the donated milk from the donor to the bank, and the logistics, such as keeping the cold chain and how this would affect the donor milk quality, as communicated by one of the doctors:

*“Now it’s transport to the clinics, refrigeration of the milk, you don’t know the quality of the milk when it reaches you.”* (HC5:2)

Table 3 indicates the suggestions to improve the acceptability of human donor breast milk as obtained from the FGs of all stakeholder categories.

**Table 3:** Suggestions made to improve acceptability of human donor breast milk during focus group discussions

<b>SUGGESTIONS TO IMPROVE ACCEPTABILITY OF HUMAN DONOR MILK</b>	
<b>Mothers and representatives of grandmothers</b>	<b>Healthcare professionals</b>
Improve general knowledge on human milk banking for example <ul style="list-style-type: none"> <li>• How it works</li> <li>• Why is it important</li> <li>• Inclusions and exclusions</li> </ul>	Improve general knowledge on human milk banking for example <ul style="list-style-type: none"> <li>• How it works</li> <li>• Why is it important</li> <li>• Inclusions and exclusions</li> </ul>
Advertising through: <ul style="list-style-type: none"> <li>• Television</li> <li>• Radio talks</li> <li>• Pamphlets</li> <li>• Health education talks</li> </ul>	Advertising through: <ul style="list-style-type: none"> <li>• Television</li> <li>• Radio talks</li> <li>• Pamphlets</li> <li>• Health education talks</li> </ul>
	Reward donors
	Test for heritage and genes as well
	Set guidelines to ensure that milk is not misused or abused
	Continuation of recruiting donors
	Increase awareness of Human Milk Banking among doctors and paediatricians
	Follow up monthly with donors
	Information regarding criteria on who may receive donated milk

### **Perceived opinions of community leaders and traditional healers**

When asked about perceptions of community leaders and traditional healers on the donation and receiving of human breast milk, the participants had mixed responses, as some felt that

traditional healers would support the venture if they received proper education, while others felt they would not agree.

## **Discussion**

South Africa has a low breastfeeding rate of only eight percent for infants younger than six months, with the lowest exclusive breastfeeding (EBF) rate being in the NorthWest Province, despite evidence supportive of EBF<sup>26</sup>. A HMB recently opened in this province. This study therefore determined the attitudes on acceptability of the donation and receiving of human breast milk of key stakeholders, namely mothers, healthcare workers and the elderly. The identified attitudes were categorized under four main themes, regarding donating and receiving donated breast milk, exposure to the concept of wet nursing, opinions of community and traditional leaders, breast feeding vs formula feeding. The implications of the attitudes under these themes is discussed.

It was important to determine participants' perceptions regarding breastfeeding versus formula feeding, as these perceptions provide an indication of where education should be started. In the discussions the main participants stated that breastfeeding is superior to formula feeding. The most predominant perceived reasons for breast milk's superiority, was cost benefits or savings, benefits to the infant's health, convenience, strengthening of bonding between mother and child and risks associated with formula feeding. Other studies support these findings.<sup>23,24,27,</sup>

Although mothers theoretically support breastfeeding, on reviewing literature the researchers found that younger women had a significantly lower rate of breastfeeding than older women<sup>24,28,29</sup> as confirmed by the findings of this study. Reports from the elderly and nursing staff stated that the prevalence of breastfeeding mothers has decreased and that few modern mothers in developing countries practice it; this is confirmed by a recent review.<sup>30</sup>

Education about feeding options early on is very important in the health setting, as literature suggests that the mothers decide on their feeding option before pregnancy and during early pregnancy.<sup>27,31</sup> The researchers also perceived this in their study, where mothers indicated that choices on whether to breastfeed or not was influenced by the education received from the local healthcare facilities. Furthermore, mothers who breastfeed were more prone to support HBM and felt that breast milk was the optimum nutrition for infants.<sup>32</sup> During the discussion with the healthcare participants, a few negative perceptions arose, such as concerns about the quality of donor milk after transportation and issues related to where the donor milk came from seeing as they felt the genes and heritage of the donor is important. As education prior to pregnancy and during early pregnancy is mainly the responsibility of healthcare staff, the researchers are of the opinion that not enough attention is paid to the training of healthcare staff on such issues. In the particular community in which this study was performed, the participants were divided on whether traditional healers and community leaders would support this venture or not. Traditional healers and community leaders should also be specifically targeted regarding training on infant feeding related issues, as they are very influential in the wider community and their opinions are highly valued.

Strong cultural beliefs may influence mothers' choices of feeding, such as the belief that intercourse should be prohibited whilst breastfeeding. This tendency was mentioned in two other studies performed in Africa, Tanzania<sup>33</sup> and Cameroon,<sup>34</sup> but to our knowledge it has not yet been reported in literature on the South African context. Such a belief would encourage mothers to cease breastfeeding early, as they feared their partners would become dissatisfied. The given concern may be a barrier to exclusive breastfeeding in the South African context that needs to be explored to determine how prevalent these beliefs are in communities. Participants also raised cultural belief concerns when it came to receiving donated human milk. Participants feared that

certain personality traits could be transferred from the donor to the recipient infant, as stated by these healthcare participants:

*“Some families have heritages, so I would be giving another child my heritage.” (HC3:1)*

*“Let’s say you are a slow learner that baby can also be a slow learner too.”(HC2:1)*

These concerns raise the need for education early in pregnancies in all healthcare facilities, to ensure mothers receive the correct and scientific based facts on infant feeding. Most health education concerning this topic concentrate on mothers, but grandmothers should also be included in education as culture, perception and beliefs are transferred from generation to generation. Furthermore, community leaders and traditional leaders should also be involved as they have a great influence and by educating them, it would help to create a positive culture regarding receiving and the donation of human milk.

The mother and grandmother informants included participants who had experienced or practiced wet nursing or informal sharing of breast milk themselves. Individuals, who experienced wet nursing positively, may be more likely to be positive about human milk donation. Respondents provided mixed responses on whether the participants in the FGs who had previously practiced wet nursing would still consider the practice. There were concerns about safety issues that referred to the risk of HIV transmission in expressed human milk. Only one previous study done in SA reported similar findings on this topic<sup>25</sup>. Fears of HIV transmission are not surprising in the South African context, considering the high HIV prevalence in the population. These results again emphasise the need for education, especially on breastfeeding in the context of HIV and the safety precautions taken in human milk banking operations.

Participants in all three categories of the focus groups had knowledge about human milk banking, although not everyone especially mothers and the elderly was certain on the criteria and

processes involved. This was expected, as the first HMB in the province was opened in the area where the study took place and one of the facilities had already achieved MBFI accreditation during the course of the study. On the donation of human milk, some mothers had concerns that it may affect their health, because of the donation of additional milk. Some also felt that some mothers may be discouraged to donate when advised that HIV screening tests were necessary. In recommendations given by the participants on how to increase the acceptability of donating and receiving donor human milk, participants advised that procedures, benefits and processes should be well broadcasted throughout the community to attract potential donors and recipients. Campaigning on a large scale with additional resources such as pamphlets, radio talks and community meetings, may therefore be a productive manner in reducing scepticism regarding human milk banks in South Africa. A participant commented that education will help to make human breast milk banking more acceptable among stakeholders:

*“But if you understand more I don’t think there will be any problems. If nurses in clinic can explain it well like you have just done people will understand more and know how important it is to donate” (M1:D5).*

## **Limitations**

Limitations of this study include that the perceptions, beliefs and opinions presented by the informants cannot be generalised due to the qualitative nature in which they were observed. However, the information obtained would form a basis upon which to design a structured questionnaire that could be used to determine the prevalence of the observed perceptions, beliefs and opinions to the wider stakeholder categories involved in this study.

## **Conclusion**

The study has shed light on the attitudes that could pose possible barriers and fears to donating and receiving donated human breast milk. These may include fear of the need for HIV testing, cultural beliefs relating to the transfer of personality traits and bonding, fears of not having enough milk for their own babies, fears that the additional milk expression may cause ill health, fears of changes in the quality of donated milk during pasteurisation and transportation and fears of HIV transmission. In addition, some attitudes may pose possible barriers to exclusive breastfeeding, such as the need for cessation of intercourse in order to breastfeed, peer pressure and BF not being fashionable. Given these findings, further research is recommended to determine the prevalence of the identified attitudes in communities served by the HMB. The identified attitudes could form the basis for designing an appropriate structured questionnaire. Additional research is also needed on the opinions and attitudes of community leaders and traditional healers regarding HMB.

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The authors declared no potential conflicts of interests with respect to the research, authorship, and/or publication of this article.

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## **Chapter 4: Detailed Conclusions on themes and related recommendations**

### **4.1 Introduction**

The final chapter consists of detailed conclusions on the findings of the study and related recommendations. The aim of this chapter is to summarise the research with respect to the research aim and objectives. The researcher drew the conclusions from the literature review as well as from the qualitative findings. The conclusions from the qualitative findings are presented according to the key findings from the themes observed in this research. Lastly, the researcher makes recommendations related to these findings.

The main aim or research question of this study was: to determine the attitudes on acceptability of the donation and receiving of human breast milk for key stakeholders (mothers, healthcare workers and the elderly). To reach the aim of the research study, the researcher pursued the following objective:

- Conduct focus group discussions with key informant stakeholders (mothers, elderly and healthcare professionals) on the attitudes on acceptability of breast milk donation and the use thereof to better understand and identify relevant attitudes and acceptability factors.

From the discussion of the conclusions drawn from the research, it became evident that the objective that was set for the study was reached. The researcher could make conclusions from the literature and the empirical results (qualitative findings).

### **4.2 Meeting the aim and objectives**

The abovementioned objective was achieved through the literature review and the qualitative research conducted. The literature review revealed the “gaps” in research on the attitudes and acceptability of human breast milk donation, especially in the South African setting. The researcher identified the following shortcoming in the literature: As human milk banking is still a relatively new venture in South Africa, especially in the NorthWest Province, compared to places where it is well established, such as Brazil, the researcher identified a need to identify the attitudes and acceptability factors that may influence such a venture. Positive attitudes and acceptability can ensure the success and sustainability of HMBs. The qualitative findings produced themes regarding the attitudes and perceptions on breastfeeding versus formula feeding, exposure to the concept of wet nursing, attitudes and beliefs regarding breast milk donation or receiving and opinions of the community leaders and traditional healers. This gave the researcher an in-depth

view of the attitude and acceptability factors. In addition, the research has shed light on possible barriers to accepting or donating human breast milk to and from HMBs. Detailed information on all the attitudes identified is presented in Annexure J.

### **4.3 Conclusions**

#### **4.3.1 Conclusions from the literature**

The researcher examined the literature from the inception of the study to identify the currently known and unknown aspects of the subject. It became clear that little literature is available on HMB, especially in the South African setting. During the writing of the proposal and overview of the study the literature review provided a background for the study (Chapter 1; Introduction and motivation section); it supported the literature review (as presented in chapter 2); and it too grounded some of the qualitative findings and compared them to other published reports of a similar nature (See chapter 3; Discussion section)

The literature review gave a description of the terms and concepts used within the literature and empirical study. The researcher provided a broad overview of MDGs, child mortality, breastfeeding and socio-cultural influences, as well as concepts of human milk banking and its role in child survival. Furthermore, attention was given to the current situation of HMBs in South Africa, as this is a growing initiative. This gave the researcher a better understanding of the abovementioned topics to enable her to view the qualitative findings in context.

#### **4.3.2 Conclusions from the qualitative findings**

The researcher formed conclusions from the empirical research themes, that were generated, as mentioned before (see complete table of themes and sub-themes in Annexure J). The conclusions in this section are based on the key findings of this study which are: the identification of perceived possible barriers regarding donating and receiving donor milk including testing for HIV, cultural beliefs relating to transfer of personality traits and bonding, fears of not having enough milk for their own babies, fears that the additional milk expression may cause ill health, fears of changes in the quality of donated milk during pasteurisation and transportation and fears of HIV transmission. The data analysis of this study was done according to the qualitative processes as described in Chapter 1, section 1.3.4.

The qualitative approach using focus group discussions was the appropriate research design, seeing that the information gathered was in the form of descriptions and words that gave meaning to the attitude and acceptability factors of stakeholders. The researcher was able to obtain first-hand information by using focus group discussion (FGD) guides during the FGDs (Annexure A &

B). The researcher can recommend these methods to future researchers who are aiming to explore the attitudes and acceptability factors of mothers, grandmothers and healthcare professionals.

One of the main findings produced by the research was attitudes that pose possible barriers to exclusive breastfeeding. All stakeholders indicated that mothers ceased to breastfeed when returning to work, as they had the impression that they could not do both. This feeding choice was also regarded as a tradition in the culture. Mother participants also revealed that, according to cultural beliefs, they were not allowed to have intercourse whilst breastfeeding and this caused them to stop breastfeeding, as they were concerned that their partners would become dissatisfied if they avoided intercourse for six months while breastfeeding. The researcher concluded that mothers gave up on breastfeeding even before starting due to this belief, as they felt it was a choice between breastfeeding and a happy relationship. These findings are important, because breastfeeding mothers are potential donors and if there are no breastfeeding mothers to donate, HMBs will not be sustainable.

The other main finding was attitudes that may pose possible barriers to accepting or donating human milk. These included beliefs such as that certain personality traits may be transferred by breast milk, or that by drinking the breast milk itself a bond is formed between the infant and the women whose breast milk he or she is receiving. Representatives of grandmothers felt they wanted to know whom the donor was, specifically referring to their culture and race. What stood out here was that some of these concerns were also raised by the healthcare professional group. Mothers and healthcare participants again raised the same concern. This time they were concerned that by donating, the donor's infant may not have sufficient milk to sustain growth. The fear of ill health from expressing extra breast milk was discussed, but peer participants stated that donation is no different than breastfeeding itself.

Participants also raised concerns about the safety of using donor milk and their uncertainty about the testing procedures. After an explanation from the facilitator, addressing their concerns, participants immediately reacted more accepting and positive towards this venture and even felt that it was their obligation to do their part if it could save an infant's life.

Lastly, healthcare participants were concerned that some nutrients may get lost during the pasteurisation process, thus not completely trusting the pasteurisation process. There is ample research on this particular subject that can be discussed in depth with the healthcare personnel to emphasise the benefits and need for HMB to them.

#### **4.4 Recommendations**

The research recommends that when a new HBM is started, it should be broadly campaigned via television or radio advertisements or even public announcements at church gatherings or community meetings. All the doctors and paediatricians should also be informed, to gain their support on this venture. Campaigning should be focused on infant feeding choices, HMB procedures and guidelines, criteria for donors and recipients, tests performed to ensure safety and the role a HMB plays in child survival.

For healthcare facilities that make use of a HMB, clear guidelines on who qualifies to donate and receive donor milk should be included in policies and all staff should be informed on these. All paperwork, such as consent forms, should be easily available to ensure that use of the HMB is as effortless as possible. There should also be a clear plan in place on how continuous recruitment of donors will occur. This may be a designated person to whom this task is delegated, but it will be more motivating if healthcare facilities can create a post in their structure specifically for this task. Another suggestion from the FGDs was to arrange monthly follow-up visits with donors. This was a valuable suggestion, as it would show support to donors and encourage them in this way to spread a positive and open attitude to other possible donors. By creating an overall accepting and positive attitude towards donating, continued donation is ensured, which is critical to the sustainability of a HMB.

##### **4.4.1 Recommendations for research**

Future research can focus on a larger sample in order to test results. From this research, possible future research can focus on the effect that mother baby friendly initiative accredited facilities have on the attitudes that the community has towards human milk banks. Researchers can also perform further investigations on the attitudes and acceptability factors of traditional healers and community leaders concerning the donation or receiving of milk, specifically as they greatly influence cultural beliefs. The effect traditional medicine may have on breast milk and the production of breast milk, will also help to establish whether its use should be prohibited during donation.

#### **4.5 Closing statement**

In conclusion, the researcher can declare that the aim and objective of the study were reached because the attitudes on acceptability factors of stakeholders were obtained.

## **Annexure A: Focus guideline for mothers and elderly participants**

Adapted from Coutsooudis, I., Petrites, A. & Coutsooudis, A. 2011. Acceptability of donated breast milk in a resource limited South African setting. International Breastfeeding Journal, 6:3.

### **GUIDELINES FOR DISCUSSION IN FOCUS GROUPS DISCUSSIONS**

For elderly representing grandmothers and mothers:

What do you think about breastmilk vs. formula?

How do you think mothers should feed their babies?

How common do you think it is to breastfeed?

Has anyone heard of something called 'wet nursing,' or babies being fed the breastmilk of someone other than their mothers?

(Explanation) In the past, if women didn't have enough breastmilk they would ask other women to temporarily breastfeed their babies for them.

What does everyone think about this practice?

Has anyone heard of something called 'breastmilk donation'?

: (Explanation) Breastmilk donation is a way of giving the benefits of breastmilk to babies whose mothers cannot breastfeed them themselves. We ask breastfeeding women some questions to make sure that they are healthy and free of disease, and then they express and donate their extra milk. This milk is heated to make sure that it is safe, and then it is given to babies who need it.

What do you think about this practice?

If there was a situation where your daughter couldn't breastfeed herself, how would you feel about her accepting donated breastmilk to feed her baby?

What might prevent women from accepting another woman's milk?

Are there any fears about breastmilk?

Does it matter who donated the milk?

Does it matter what race they are?

How do you think sangomas or community leaders will accept this practice?

What could be done to make donated breastmilk more acceptable?

What do you think about the SABR brochures?

Adapted from:

Coutsoudis, I., Petrites, A. &Coutsoudis, A. 2011. Acceptability of donated breast milk in a resource limited South African setting. *International Breastfeeding Journal*, 6:3.

## **Annexure B: Focus group guideline for healthcare professionals**

Adapted from Coutsooudis, I., Petrites, A. & Coutsooudis, A. 2011. Acceptability of donated breast milk in a resource limited South African setting. *International Breastfeeding Journal*, 6:3.

### **GUIDELINES FOR DISCUSSION IN FOCUS GROUPS DISCUSSIONS**

For Healthcare Professionals:

What do you think about breastmilk vs. formula?

How common do you think it is to breastfeed?

Has anyone heard of something called 'breastmilk donation'?

: Breastmilk donation is a way of giving the benefits of breastmilk to babies whose mothers cannot breastfeed them themselves. We ask breastfeeding women some questions to make sure that they are healthy and free of disease, and then they express and donate their extra milk. This milk is heated to make sure that it is safe, and then it is given to babies who need it.

What do you think about this practice?

Do you think it's safe?

Would you use donor milk for your own child?

What are your thoughts on the establishment and operation of the breastmilk bank at Potchefstroom hospital?

Have you been involved at all in the breastmilk bank at Potchefstroom hospital?

Is there anything you would like to see done differently at the Potchefstroom hospital breastmilk bank?

How can we make it easier for you to prescribe/supply the donor breastmilk?

## **Annexure C: Protocol for qualitative data analysis**

### PROTOCOL FOR QUALITATIVE DATA ANALYSIS

Dear co-coder,

Hereby the protocol for the data analysis of the transcriptions of the focus group discussions.

The purpose of this research is to determine the attitudes and acceptability of the donation and receiving of human breast milk of key stakeholders namely mothers, healthcare workers and the elderly.

Specific objectives:

- Conduct focus group discussions with key informant stakeholders on the attitudes and acceptability of breast milk donation and the use thereof to better understand and identify relevant attitudes and acceptability factors.

The interview schedule for the focus group interview is included as “Focus Group Interview”.

According to Rossman & Rallis (cited by Creswell, 2009:186), coding is the process where the text is arranged into sections and then sense is made out of the information. During data analysis, the data can be coded by organising the data into sections of text, before meaning is attached to the information (Creswell, 2009:186). Portions of the text can be arranged into categories and these categories can be labelled with a term, often based on the original words used by the participant (Creswell, 2009:186).

According to Tesch (1990) (cited by Creswell, 2009:186), there are eight steps in the coding process that can be used to code the data:

1. A feeling for the complete data set can be obtained by first reading through all the data and by writing down thoughts and facts as they emerge (Creswell, 2009:186).
2. Select one paper and after going through it, try to determine its fundamental meaning and write ideas that come to mind in the border of the page (Creswell, 2009:186).
3. Do this for a number of papers and then make a list of all the topics, while grouping similar topics together. These topics can now be fashioned into columns and arranged as main topics, exceptional topics and excess topics (Creswell, 2009:186).

4. This list can now be taken back to the data where the topics may be abbreviated as codes, and the codes can be written in the fitting sections of the text. This initial organising system may be used to see if new categories and codes materialise (Creswell, 2009:186).

5. The topics may be described by the most expressive words and then turned into categories. Topics that relate to one another may be grouped together in order to reduce the total list of categories. Lines may be drawn between categories to illustrate relationships (Creswell, 2009:186).

6. A final decision needs to be made regarding the acronym for each category and the codes must be arranged in alphabetical order (Creswell, 2009:186).+

7. The data that fits into each category can be gathered in one place and an initial analysis may be performed (Creswell, 2009:186).

8. The existing data may be recorded as needed (Creswell, 2009:186).

You are also welcome to write your own reflection and interpretation.

Feel free to contact me if needed.

Charlene Oosthuizen

084 605 7793

**Annexure D:Ethical approval letter from NWU**



NORTH-WEST UNIVERSITY  
YUNIBESITHI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT  
POTCHEFSTROOM CAMPUS

Private Bag X6001, Potchefstroom  
South Africa 2520

Tel: 018 299-1111/2222  
Web: <http://www.nwu.ac.za>

To whom it may concern

Faculty of Health Sciences  
Tel: 018 2992092  
Fax: 018 2992088  
Email: [Minrie.Greeff@nwu.ac.za](mailto:Minrie.Greeff@nwu.ac.za)

30 July 2013

Dear Dr. Covic

**Ethics Application: NWU-00083-13-S1 Summary Report**

**"Breast milk bank implementation attitudes and acceptability in the North West Province"**

All ethical concerns were addressed in this application and ethical approval is recommended.

Yours sincerely

Prof. Minrie Greeff  
Ethics Sub-committee Vice Chairperson

Original details: Prof. Minrie Greeff(10187306) C:\Users\13210572\Documents\ETIKI\2013 ETHICS\NWU-00083-13-S1 Summary Report.docm  
30 July 2013

File reference: NWU-00083-13-S1

**Annexure E: Permission from the National Department of Health to  
conduct the research in facilities**

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**Annexure F: Approval to conduct the research from the Tlokwe sub-district**



**health**

Department of  
**Health**  
North West Province  
REPUBLIC OF SOUTH AFRICA

Private Bag 2558  
Pretoria 0001  
2520

Tel: (018) 2070000 x157  
Fax: (018) 201 6600  
E-mail: smchuleca@nw.gov.za  
Enclosed: A/na Monus.co

---

OFFICE OF THE PHC MANAGER: TLOKWE SUB DISTRICT

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07 March 2014

**To : Ms C.S Oosthuizen & Ms M.A Pretorius**  
**From : FROM TLOKWE SUB-DISTRICT DR KENNETH KAUNDA**

---

**RE: Approval to conduct your research**

This communiqué serve to inform you that your request to conduct research at the following facilities in the sub-district of Tlokwe is approved based on the proof that you submitted to show that both the University and Department of Health have granted you approval

The above mentioned facilities will be notified but you can take this approval letter with you to the facilities

Contact details for facilities are as follows

Boiki Tlhapi: Acting Operational Manager Tloome  
:018 295 3352

Steve Tshwete: Operational Manager Ledimo  
: 018 295 6570

ACTING : PHC MANAGER  
K. MONYAMANE



Healthy Living for All

1

**Annexure G: Approval granted by the office of the clinical manager**



**health**

Department of  
Health  
North West Province  
REPUBLIC OF SOUTH AFRICA

110 Dreyerstrasse, 11  
Klerksfontein  
Driefs  
Private Bag X 200  
POTCHEFSTROOM  
2520

tel: 056 283 4416  
Fax: 056 772 2515  
Mshungu@nw.gov.za  
Secreat@nw.gov.za  
@nw.gov.za

OFFICE OF THE CLINICAL MANAGER  
POTCHEFSTROOM HOSPITAL

**TO: MS C OOSTHUIZEN AND MS M PRETORIUS**

**FROM: DR JMM SHAKUNG**

**DATE: 2014-05-15**

OFFICE OF THE CLINICAL MANAGER  
POTCHEFSTROOM HOSPITAL  
  
2014 -05- 15  
  
PRIVATE BAG X 938  
POTCHEFSTROOM 2520

**RE: APPROVAL GRANTED BY PSG COMMITTEE**

This serves to inform you that the PSG Committee has approved your research study on the Breast Milk Bank Implementation, Attitudes and Acceptability.

Kindly provide us with the written outcome upon completion of your research study.

Sincerely,

  
**DR JMM SHAKUNG**  
**CLINICAL MANAGER**



Healthy Living for All

## Annexure H: Consent form for participants



### Information sheet & consent form Stakeholder attitudes and acceptability on donating and receiving donated human breastmilk

Name of fieldworker:..... Tel nr: .....
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#### INFORMATION SHEET

**Study: Stakeholder attitudes and acceptability on donating and receiving donated human breastmilk.**

**Project leader:** Dr. Namukolo Covic

**Co-project leader:** Dr. Robin Dolman and Dr. Welma Lubbe

**Co-researchers:** Charlene Oosthuizen

Dear Participant

#### Who are we?

We are from the North-West University, Potchefstroom. We are doing a study involving mothers with babies between 6 and 12 months old, healthcare workers working with babies between 6 and 12 months old and the elderly. We want to collect information about the attitudes of participant towards the donation or receiving of donated breastmilk. Approval to do this study has been given by the Department of Health of the North-West Province. We have ethics approval from The North-West University Research and Ethics Committee.

#### Why do we want to do the research?

Potchefstroom has recently opened the first breastmilk bank in the North West Province. The North West Department of Health also plans to open more breastmilk banks across the province in the future, in an effort to reduce neonatal and post-natal morbidity and mortality for babies who cannot breastfeed.

The success and sustainability of a breastmilk bank is determined by numerous factors, including the support of the relevant health care workers as well as the community that the hospital serves.

We want to understand the attitudes towards human milk banks of doctors, nurses and dietitians that work with mothers of infants aged 0 to 12 months and mothers. This will provide valuable information to be incorporated into future training programs. Understanding the acceptability and attitudes of various members of the

community the hospital serves will enable the Department of Health and health care workers to develop appropriate educational material and messages for the community and other stakeholders.

**What does this research study entail?**

You will be asked to tell us:

- Participate in a focusgroup discussion; or
- Interview regarding your feelings around donated breastmilk

All information collected from you will be treated as confidential. Only the researchers will have access to it.

You are welcome to discuss with us any concerns that you may have.

**What will be expected of you to participate?**

You need to be a registered healthcare provider working with babies aged 0 to 12 months.

Or

You need to be a mother with babies aged 0 to 12 months

Or

You need to be elderly to represent grandmas

You need to be present on the day of the focus group or interviews.

Participation in the interview and focus group discussion is voluntary. You may withdraw yourself from the interview at any time without any consequences.

**Why should you participate in this study?**

If you participate it will help us know how to structure policies regarding donation and receiving of breastmilk in North West Province.

**What will the benefit be me to participate?**

There will be no specific benefit to you but we will share the results of our study with the Department of Health and this information will be useful in educating stakeholders on donation and receiving of donated breastmilk.

**Will any of the results be made public?**

Personal information including names or results from the interview will not be made public in a way that will identify you.

**Who can you contact if there are any queries?**

Feel free to contact Charlene Oosthuizen at Tel: 018-293 4648

## **Part 2: General Principles**

### **To the undersigned:**

You are invited to take part in the research project as described in Part 1. It is important that you read understand the following:

1. Participation is voluntary and no pressure however subtle may be enforced upon you to take part.
2. There is no specific benefit to you for participating in this study but the knowledge that is gained through the project might benefit babies in the community. You are not allowed to be bribed to take part in the project.
3. You are free, to at any time, without any reason, stop participation and you will by no means be negatively affected. You may also request that your data not be used further in the study.
4. By giving consent to take part in this project you are also giving consent that the data generated be used by the researchers for scientific purposes as they choose, providing that it be confidential and that your name or that of your child not be linked to any data.
5. By giving consent to take part in this project you are also giving consent that we are allowed to record you during the interview/ focus group discussion.
6. Medicine Control Board, Department of Health and/or any justifiably court may request access to the information to determine / insure the ethical responsibility of practices to the public.
7. You will be allowed to access your own data on request.
8. You are urged to at any stage address any questions regarding the project and procedures, to the Project leader or co-workers who will gladly answer your questions. They will discuss the project with you in full.
9. Signed consent is given in this case by the parent or legal guardian for participation in the project.
10. The project objectives are always secondary to the well-being of the participants and will at all times act in your child's best interest.
11. No project is allowed to start unless approved by the Ethical Committee. The Project head therefore must accept any negative effects that might be experienced throughout the execution of the project, and must report it in detail and immediately to the chairperson of the Ethics Committee. In case of unforeseen serious detrimental consequences the project will be terminated immediately.

**Part 3: Consent**

**Title of this study:**

Stakeholder attitudes and acceptability on donating and receiving donated human breastmilk

**Demographic information:**

Clinic/hospital attending: \_\_\_\_\_

Age: 15 -25\_\_ 25-35\_\_ 35-45\_\_ 45-55\_\_ 55-65\_\_ 75-85\_\_ >85\_\_

Are you a Mother\_\_\_\_\_ Grandmother\_\_\_\_\_ Healthcare professional\_\_\_\_\_

What are you highest educational level reached? \_\_\_\_\_

Are you employed? \_\_\_\_\_

I, the undersigned

\_\_\_\_\_

**Full names & Surname**

Have read and understand all the information pertaining to the study as discussed in Part 1 and Part 2 of this informed consent as well as heard the verbal communication. I initialed each page of Part 1 and Part 2. I was offered the chance to discuss some issues with the project leader and hereby declare that I am taking part in the project out of free will.

\_\_\_\_\_

2	0			-			-		
C	C	Y	Y		M	M		D	D

**Signature of Participant Parent/Guardian**

**Date**

Signed at

\_\_\_\_\_

**Place**

**Witnesses**

\_\_\_\_\_

2	0			-			-		
C	C	Y	Y		M	M		D	D

Signature of witness (translator, if applicable)

Date

Signed at

\_\_\_\_\_

Place

Name of fieldworker.....

Cell number.....

## **Annexure I: Example of translated transcripts used during data analysing process**

### **Focus group discussion: Day 1**

#### **Group: Mothers**

**F:** Between formula and breast milk which do you feel is a better choice for feeding infants and young children, why?

**P1:** I think its breast milk, at clinics and hospitals we are encouraged to breast feed.

**P2:** I also agree, because a child that is breastfed doesn't usually get ill. It is healthy.

**P3:** Me too, I agree it's so cheap you don't go shopping for it. It is ready to be used unlike formula milk. Breast milk is always ready when the child needs to be fed, unlike the formula.

**P4:** I think formula milk is also best, although it is so expensive. Children don't get sick from it.

**P1:** Breastfeeding the main reason again formulas are expensive and child support grants are not enough so breast milk have enough proteins for the child's body and the breast fed child don't get sick easily.

**F:** She says babies drinking formula milk don't get ill. What do you think about that?

**P1:** I still stand on my point that breast milk is the best and healthy, because it is the time you bond with your baby and it works out cheap you don't buy it. Sometimes you don't have money to buy formula so the child is going to suffer because there won't be milk to feed.

**P2:** I also think otherwise kids get sick because if you as a mother is sick you want to breastfeed knowing you are sick obvious you will make your child sick but I think if you breastfeed the child will get sick that much. Compared to formula milk as it comes in a tin and if we check tins have lots of chemicals that affects the formula so breast milk is healthy there is no need for the milk to be boiled or to pour lots of different things on it.

**P1:** It is true breast milk is healthy even mothers who are HIV positive can breastfeed if you have been given treatment so that you don't infect your child.

**P2:** Some times when it comes to the formula some people don't follow the instructions they just put in heaped spoons in boiling water and that is why it is not so healthy because there are careless mothers with formula milk.

**P1:** And if they see the milk is about to be finished in a tin they will start to reduce the scale and put small amount in a scoop. Breastfeeding is better because you just pick up the baby and feed it and the milk is the same temperature every time.

**P3:** And in winter it is so cold so you don't waste time cleaning the bottle you just give your child breast milk.

**F:** What do you think mothers can use to feed their children?

**P1:** I think breast milk as it is number one. To be honest formula milk not. As other ladies have already said some mothers are careless. You will sometimes find that they don't follow the instructions given on the tins according to the child's age. They just do as they want. Breast milk is always the same.

**P2:** You will be breastfeeding and at the same time you bond with your child. There are times you have to go somewhere and leave the child behind the option is to express and put the milk in something. Put the milk in the fridge and whoever is taking care of your baby will feed the child.

**F:** so if it happens that you are sick and you are told you cannot breastfeed what happens now?

**P1:** I think there are some mothers who have clean healthy breast milk so I think they can express and donate the milk to the kids that their parents cannot breast feed them.

**F:** How do you know it is safe?

All: They test it first.

**P1:** They don't just take it because I breastfeed so I can donate they check the milk first.

**P2:** When you discover late you are sick and pregnant you can give her donated milk. It is best for babies in incubators.

**P4:** Yes they need it just like donating blood.

**P1:** My baby grew inside an incubator and some ladies who were there with me waiting for our babies, they were struggling to produce milk and I had enough milk away in containers in the fridge and they stole it to feed their babies and the sister stopped us from doing that but explained to us that it is not a bad thing to do but it is dangerous because we don't know how healthy is that other persons milk.

**F:** Were you angry when they stole your milk?

**P1:** No I wasn't because I could hear their babies crying. Anyway I wasn't the one stealing for them.

**F:** How common do you think is breastfeeding in your community?

**P2:** It is common, it depends who it is. Usually young mother's life fast lives. It is not usual to find them breastfeeding. It is only older woman who do it. The young women are after the fun times.

**P3:** They like to compare with their friends. If one sees that their friend is on formula she is going to stop breastfeeding to show that she can also afford formula milk.

**P2:** It is sometimes common, sometimes it is not. In the older days it was common for the mother to breastfeed and also not common. Let's say for instance I went to town and I am a young mother and have a child with me. I would be complaining because there is lots of people. What would they say if they see me breastfeed? So they just think the best way is to bottle feed.

**P3:** I agree with you. Elderly people would say breastfeeding is controlled by ourselves and our believes they would say if you are around lots people you have to express a small amount on the ground before you can feed the child according to the tradition and believes of black people as they believe if you don't do so the child can get sick you should first take out some amount of milk then the baby won't get sick.

**F:** Is it your belief?

**P2:** Yes it is

**F:** Don't you think it's those beliefs that make mothers not to breastfeed?

**P1:** We hold on to unreasonable things, sometimes a mother has four months leave so they just breastfeed for a month or two or they don't breastfeed at all saying the 5<sup>th</sup> month I will be back at work so there is no need to breastfeed because soon I won't be breastfeeding anymore.

**P1:** Bear in mind they are still young, the other reason, they have boyfriends so they just want to get back to them like according to our culture you should mourn in a way of respect for your child when you breastfeed for about 3 – 4 months without sex so young mothers think 4 months is too much they can't wait for 4 months so it's best for them to bottle feed so that they have sex freely.

**P2:** but still in that way you can make your child sick.

**P1:** That is why I'm saying it's a belief I'm not breastfeeding and my child is still under 4 months and I'm busy with my boyfriend so what must I do? I must choose it is either I breastfeed or go with my boyfriend.

**P2:** Who looks after your child then?

**P1:** I do for a certain period according to our culture is said that if you breastfeed and sleep with your boyfriend sexually you are making your child sick so instead of breastfeeding the child I would rather not breastfeed at all and I will just buy NAN or Lactogen or whatever.

**F:** so if it's your husband in the house you have to do the same thing?

**P3:** According to our culture even if I'm married I have to go through the process of mourning for the child's sake at least for 3 – 4 months because you can't tell your husband that you can't have sex with him for 4 months that is where our culture comes. If I have just had my baby married or not I have to go away either at my parents' house or to my in-laws for a period of 3 – 4 months you leave your husband behind then after that period you can go back to your husband.

**F:** If I may ask ladies, do you think that it still exists these days?

**P1:** Not anymore life is too fast these days.

**P2:** And mothers these days they no longer want to breastfeed anymore. They have resorted to buy formula milk and that is why this is new fashion, if you don't breastfeed you bottle feed in fashioned bottles and it got lots of conditions to keep it and it should at all times be clean. for the sick babies die easily this days because their mothers don't have time to breastfeed they just bottle feed the way they want with NUK bottles you buy it from the chemist.

**F:** is there anyone of you who have heard of wet nursing to breastfeed someone's child?

**P3:** I have heard it from our parents (mother) not on this days. My mom used to breastfeed her sister's child when the mother was not around. But not in this days it is not safe anymore. It's dangerous.

**P1:** I have heard from our local clinic. I myself still have milk on my breast and my child is old and still now I have milk as if I'm still breastfeeding and that irritates me. I then went to the clinic and they said it's rare to find someone like me and they asked how about I donate breast milk, but you will have to go through some test. I then said I can't, I have my reasons. Firstly I won't donate breast milk it will be like I have a child as my body will produce. They said I will be taken to the hospital, but if they take milk on the first week I will have to go back again the following week and so on. So it will be like I have a baby and I don't.

**P2:** But still you say you still have milk on you.

**P1:** Yes but not like when I will be breastfeeding.

**F:** I understand but I want to know if you have to feed someone's baby in your breast.

**P2:** I know it in the olden days, not now.

**F:** What do you think of it?

**P2:** These days it is not good at all

**P1:** Because before you can feed someone's child they should know your status if you are sick or what. As there are lots of different illness as you can't just take someone's child and breast feed them.

**F:** So you don't trust it?

**P3:** Yes and on the other hand it got negative effects. I breast feed the child or if it is my child give the child to someone to feed the child there is something we call bond when you breast feed. So it means that person will bond with my child. I know what I'm talking about I did breast feed my child, so I know the child would look deep into my eyes and there is that connection between you and the child so if someone feeds my child warmth and bond between us will be taken by another woman. For me it is not right unless they give me milk from them and for me to breast feed my child myself.

**F:** So you don't agree with it?

**All:** Yes we don't agree with it.

**F:** any of you who have heard of giving someone breast milk?

**P2:** Yes, at the clinic they like the topic too much.

**F:** then if it is so can you explain it to me?

**P2:** what? Donation of milk? What I have heard while we sit there with our babies. Sister would ask if I would donate my milk like if I had enough milk. Some mothers struggle to have enough milk due to being sick and some reasons. They don't have enough to breastfeed their babies. How would you feel if you will be asked to express and your milk will be donated somewhere. I said I don't have a problem I can do it if breast milk is needed to feed a child.

**F:** Let me explain: if you haven't heard. Another way of donation with breast milk it will help those babies whose mothers cannot breastfeed them by that way you will be helping the child to get protein of a breast fed child that is needed in a baby's body. If you volunteer to donate there are questions that will be asked and some tests will be done to make sure the person is not weak or sick or have HIV AIDS virus. They will check all sort of illness. You will express then give the milk, it will be bottled then put it in a deep fridge. Temperature is high so that no germs can penetrate in the milk then after the milk will be boiled to check if the milk is safe. The milk is only given to those babies who really need it like premature babies. They will be given the milk for 14 days on top of what I have told you what do you think of that.

**P2:** I think it is a good idea so they said the baby needs the breast milk do that they can get proteins like the one that is breast fed.

Nothing bad if they have checked my milk and that of another woman. They are the same as long as they are clean. They are bottled breast milk so if they can donate it for my child because it is breast milk. No difference

**P3:** I also think it is good, we should sometimes have mercy for another person. I also support the donation. Part because if you can breast feed your child and watching another weak child whose mother cannot feed them it is painful so if you donate breast milk I don't see any wrong there, we should help each other.

**F:** do you think most mothers in our area will agree on giving their breast milk?

**P3:** Not all of them.

**F:** why are you saying so?

**P3:** If they are willing, yes. They will donate like for people who will be donating the milk. I think they should be explained to them that for what period of time she want to know for herself physically. How is she going to be like and for others not only her. There are some mothers out there like her who have lots of milk. Will she always have milk in her breast? She should always have breast pads so that she can prevent to wet her clothes. They should brief them of what will happen after. Like myself, I have fears for such thing. Since well I'm not breastfeeding, it would be easy if I had some child to feed when the milk is ready I can go to the baby and feed it and for other mothers they should brief them well of what will happen.

**P2:** I think mothers will be happy to donate if they can sit down and to be explained very well the main reason for the donation. Babies who need breast milk because most mothers are sick that is why we are asking for a donation so that we can reduce the number of mothers who cannot breastfeed.

**F:** Ladies, if you were breastfeeding I want to understand would you donate your milk and why?

**P2:** I would as I'm breastfeeding if they ask me to donate for a child I would as I have seen the need in the hospital for the babies who cannot breastfeed their sick. And some dies you can tell it so painful thinking you have the ability to donate your milk to save someone's life.

**P4:** My breast is too small I can't donate my baby is a boy and I don't have enough even for him alone. If I had enough milk I would say I will donate

**F:** So if you had enough milk you would donate?

**P4:** Yep and if my baby was a girl as girls don't eat as much as boys.

**P1:** Let's say I'm weak and sick and want to donate. So what is going to be done? I'm damaged, I'm no use but I wish to help. What will my help be to the babies?

**F:** You can help by spreading the message and tell people about the donation as you have the idea and knowledge that will be of good help to the babies. So ladies if you were breast feeding would you help in the form of donation?

(They all agreed and said a child is a child, if they need help they need to be helped.)

**P3:** If it could be explained well to the people and be given the right information about the donation every mother will like to donate for innocent little babies. I mean babies are God's angels and they should also check people's fears.

**F:** What difficulties do you think mothers will encounter if they have to give or accept donated milk?

**P3:** Firstly their breast, if I donate I would like to be a breastfeeding mom. For instance now I'm a size 34B and they express weekly from me. Soon I will be on 44 something.

**F:** What are some problems according to you? What problems will come up if we come from different homes?

**P2:** I think the problem will be maybe she won't have a connection with her child even if the baby gets the breast milk but not the mother's milk it will be someone else's milk. Again the mother will ask questions like I don't know the person who donated for my baby so they will be uncertain of such things.

**P3:** We black people have the tendency of saying English is not my language as something you never got from your mother. So if a child drinks someone's breast milk they will be confused.

**F:** So you think that will be the problem? According to your beliefs you think if the baby drinks someone's breast milk they will get that person's behaviour?

(They said yes, if the lady who has donated her milk if she was rude, useless person the baby will adapt her manners and behaviour.)

**P2:** I disagree with that if it was so what about the formula milk? Would they take cows' behaviour? I disagree because bonding starts when you are still pregnant and when they grow. If your child is out of line, don't blame the milk. The problem is on the parent for lack of discipline. Milk is milk. It gives protein and helps babies to grow if we have to talk about behaviour one of the formula tins they would cry like cows. I would say moms should stop putting their minds too much on beliefs

that will mislead them the child will end up being very sick or sometimes even dead all because of all this beliefs.

**F:** The other question: what do you think sangomas say or object on this and beliefs of other churches?

**P2:** I think because they are people with different beliefs they are going to disagree totally as they would say is not good to give someone's baby somebody's milk. They don't share same blood so they won't agree on that. They will be saying they won't feed their babies that's been shipped from where ever. They will see it as a bad thing.

**P1:** I think since well they are not going to agree with the donation some people do believe in sangomas and I bath and drink medicines that I get from a sangoma and I have to donate milk using such things. Won't it be bad? Won't it affect the child? She asks on behalf of traditional healers. I think they will disagree saying it is against ancestors. I really think they will totally disagree with the donation.

**F:** What do you think can be done to reduce that fear in people so that they can help by donating breast milk or to receive it for their babies?

**P2:** If they can be counselled so that they can be given the information and be given reasons and maybe something in practical like if you can come with a baby that needs breast milk and a baby that gets breast milk to show them how they differ. I think that fear in them will end or maybe if they can gather all the mothers, put them in a room with a screen showing the difference. Maybe papers to read, if there are mothers who cannot read they will believe by seeing to give them the information. And they should also be counselled not just fast, they should sit them down and explain to them so that they can understand to the fullest. So that you can say yes agreed on the terms not just to donate your milk and forget about it. No it doesn't work like that.

**F:** Ladies do you think the people who are busy with the project should be them who spread the information to the people?

**P2:** we can all spread the message to the people and the information I have I can tell all I know and still tell them for more information you can go to the clinic. It is our duty as a community. This is regarding our children's life, we have to help each other.

**F:** I would like to give you this brochure and look at them. This 3 are the same. This 2 are the same. Take a good look at them and then tell me after what do you ladies think about them. What you are looking at is brochures from the South African Breast Milk reserve it is for mothers to have the information.

(They are looking at the brochures)

**F:** if I may ask what you ladies are thinking about that brochures. What comes to mind?

**P1:** The one I have the first thing is no 3. It is scary. I don't know if it's a disease or what but when I read it, it says it's a disease.

**F:** Diseases where? On a child or parent?

**P1:** It looks like a disease on a premature baby. They say the baby's life in the first 2 weeks is critical. I think it's a premi that can't suck on their own and it fed a formula milk and they end up like this but I don't know what this is an intestine or a breast.

**F:** other ladies what do you think?

**P2:** It shows the way babies especially premi babies. How they really need to be fed breast milk. How important the milk is for the babies because it is also written here that a premi baby needs breast milk instead of formula milk. So that such diseases cannot affect the baby.

**P1:** and on nr 4 I can see the milk expresser, it's nicer. It is better than to milk yourself by hand, is it painful. And a baby on the front. But it looks like the baby is not healthy. If I look very well I don't know. What do other ladies think? Just look at the baby's hand, it looks very small. These are the babies who needs milk.

**P3:** See if ladies who will volunteer for breast milk donation see things like this they will feel pity and donate to avoid such things to happen to more babies as there is a need for breast milk. Sure if they can be given brochures like this they will know how important milk is for babies. Even if it can be that the baby is being fed by a cup at least there is a bond between a mother and the baby as she have put the baby on her chest. Breast milk according to me is the best.

**F:** Okay ladies. Charlene will explain more to you but I don't know because she is an English speaker. Will you understand her? Ladies is there any suggestions you would like to give that can be added on the brochure.

**P2:** maybe they can put a picture of a baby that drinks breast milk next to the one on nr3 so that people can see the difference between the two babies. The one that drinks formula milk and breast milk.

**F:** and other ladies what do you think can/ should be added to the brochure?

**P1:** I think the brochure have everything that is important. It only needed the one this lady pointed out. Besides remember earlier we were worried about the bond between the two. So now I can see that they can bond even if the baby is not sucking from the mother.

**P1:** Adding on that I just remembered in order for people to be interested in donating breast milk as it is scarce they will help if there would be something that will show for instance I breast feed for a couple of months because maybe the baby doesn't want the breast milk and you want to give it to the baby. They will be part even if you don't breast feed and you have enough milk how will you be affected. Maybe if there can be brochures for mothers who are at home not just for the ones in hospitals.

**F:** Ladies if I may ask when we wrap up. Is there any questions anyone would like to ask?

**P1:** Yes I was about to ask if you have stopped breastfeeding, is my breast milk safe to donate after a couple of years but your body still produces milk or should they test the milk first and is it safe to donate because I think it is not safe after a period of 5 years without breast feeding but still produces milk. Really I think it is not safe.

**P3:** Sister if I may ask after I donated will I just be okay or is there any medication that I have to take? How am I going to feel after the process, will there be any side effects or what?

**P2:** If I may ask for how long can a premature baby be breastfed?

**P3:** What about the kangaroo? How does it work? How are they fed via tube or straight from the breast?

**Dr Covic:** There is a difference between a premature baby and kangaroo mother care. Premature baby was born before time.

**F:** I will take this time to thank you ladies. We have come to the end of our group discussion for today.

## Annexure J: Coding themes and categories

Category 1	Category 2:	Category 3
Mothers	Elderly	Healthcare professionals
<b>Theme 1:</b>		
Breastfeeding vs Formula feeding		
<b>Sub -themes</b>		
<b>1.1 Benefits of breastfeeding</b>		
1.1.1 Convenience	1.1.1 Convenience	1.1.1 Convenience
1.1.2 Immune protection	1.1.2 Immune protection	1.1.2 Immune protection
1.1.3 Bonding	1.1.3 Bonding	1.1.3 Bonding
1.1.4 Affordability	1.1.4 Affordability	1.1.4 Affordability
1.1.5 Breastfed due to health education		
<b>1.2 Perceptions on formula feeding</b>		
1.2.1 Expensive	1.2.1 Expensive	1.2.1 Expensive
1.2.2 Risk of incorrect mixing	1.2.2 Risk of incorrect mixing	1.2.2 Risk of incorrect mixing
1.2.3 No immune protection		
1.2.4 Influenced by peer pressure	1.2.4 Influenced by peer pressure	1.2.3 Used due to returning to work
1.2.5 Used due to returning to work	1.2.5 Used due to returning to work	
1.2.6 Trendy or fashionable today	1.2.6 Trendy or fashionable today	

		1.2.4 Reason for malnutrition
<b>1.3 Perceptions on how common breastfeeding is</b>		
1.3.1 Less frequent among young mothers	1.3.1 Less frequent among young mothers	1.3.1 Less frequent among young mothers
<b>1.4 Attitudes, beliefs and perceptions based on cultural traditions</b>		
1.4.1 Should cease intercourse whilst breastfeeding		1.4.1 Not Breastfeeding due to lack of knowledge
1.4.2 Not safe if sleeping around		
1.4.3 Personality traits or behaviours can be carried over with breast milk	1.4.1 Personality traits or behaviours can be carried over with breast milk	
	1.4.2 Tradition to breastfeed	
	1.4.3 Superstitions regarding breastfeeding	
	1.4.4 Mixed feeding	
<b>Theme 2:</b>		
<b>Exposure to the concept of wet nursing</b>		
2.1 Heard about it	2.1 Heard about it	
2.2 Experienced it, or in family	2.2 Experienced it, or in family	
	2.3 Today not safe	
	2.4 Acceptable if related (known person but not unknown person)	

	2.5 Unacceptable, burden of transferring possible illness to recipient	
<b>Theme 3</b>		
<b>Breast milk donation or receiving</b>		
<b>Sub themes</b>		
<b>3.1 Perceived fears and obstacles</b>		
3.1.1 Not safe today due to diseases	3.1.1 Not safe today due to diseases	3.1.1 Not safe today due to diseases
3.1.2 Safety test procedures on donor and milk before considering it	3.1.2 Safety test procedures on donor and milk before considering it	
3.1.3 Expressing milk takes a lot of effort		3.1.2 Expressing milk takes a lot of effort
3.1.4 May cause bonding with donor		
3.1.5 May underfed own baby if donating		3.1.3 May underfed own baby if donating
	3.1.3 Don't know who donor is	
	3.1.4 Lack of knowledge on HMB procedures	3.1.4 Nutrients get lost during pasteurization process
3.1.6 Personality traits or behaviours can be carried over with breast milk		3.1.5 Personality traits or behaviours can be carried over with breast milk
3.1.7 Fear of negative side-effects after donation		
<b>3.2 General feelings</b>		

		3.2.1 Feels positive	
		3.2.2 There is a need for it	
<b>3.3 Suggestions to improve acceptability</b>			
3.3.1 Increase knowledge on HMB (What it is, How it works, importance of it)	3.3.1 Increase knowledge on HMB (What it is, How it works, importance of it)	3.3.1 Increase knowledge on HMB (What it is, How it works, importance of it)	
3.3.2 Ensure donors are in healthy status			
3.3.3 Advertise through TV, radio, pamphlets, talks	3.3.2 Advertise through clinics, churches and brochures	3.3.2 Advertise through posters and pamphlets, radio	
3.3.4 Counselling on subject	3.3.3 Test all milk properly	3.3.3 Reward donors	
	3.3.4 Label donated milk as with formula milk		3.3.4 Test for heritage and genes as well
			3.3.5 Don't misuse/abuse
			3.3.6 Rules and regulations should be in place
			3.3.7 Recruit more donors
			3.3.8 Make more doctors aware of it
			3.3.9 Follow up monthly with donors
			3.3.10 Consent form
			3.3.11 Criteria to who should receive donated milk
			3.3.12 Motivate paediatricians to use

Theme 4		
Opinions of community and traditional healers		
4.1 Mixed feelings, some will support some won't	4.1 Won't agree	
4.2 Will be more accepting after education	4.2 Should know donor milk is testes	

**Annexure K: HMBASA guidelines**

## Annexure L: Letter from co-coder



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22 October 2014

Dear Ms Oosthuizen

### Co-coding for masters study

Thank you for providing me the opportunity to act as co-coder on the data for your study titled: **Stakeholder attitudes and acceptability on donating and receiving donated human breast milk**. My findings correlated 100% with yours and I am therefore of the opinion that the data analysis is trustworthy.

Please refer to the comprehensive summary of my findings as provided and discussed with you on 22 October 2014.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Scruby'.

D: Belinda Scruby  
Senior lecturer: Anatomy

