

# Knowledge, attitudes and awareness regarding donor breast milk: a cross-sectional study of mothers in a high HIV-prevalent area

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**Background:** The use of donated expressed breast milk (DBM) is encouraged in South Africa, with donor milk banks and legislated policies and programmes available in hospitals serving populations with a high HIV prevalence. Concerns over poor attitudes amongst mothers towards DBM seem to persist.

**Methods:** A cross-sectional mixed-methods approach was used in a cohort of mothers of neonates in a regional hospital. Between April 2021 and January 2022, survey data on knowledge, awareness and attitudes towards DBM was collected. Qualitative data from open-ended questions were thematically analysed. Comparative analysis using independent sample *t*-tests and logistic regression to determine differences in variables and to understand associations related to knowledge was conducted.

**Results:** A total of 163 mothers with a mean (SD) age of 27.1 ± 6.3 years were included; 49.7% of mothers had post-high-school qualifications, 82.8% were unemployed and 87.0% received social security. Some 64.4% had inadequate knowledge of DBM. Awareness of DBM had the strongest association with better knowledge concerning DBM and AdjOR (25.25 95% CI 10.60–68.40; *p* < 0.001). Negative attitudes towards DBM were largely driven by a lack of knowledge regarding human immunodeficiency virus (HIV) screening of donor mothers and fears of HIV transmission when using DBM.

**Conclusion:** Lack of awareness concerning DBM was associated with poor knowledge of DBM, which may drive poor uptake of this critical nutritional source for at-risk neonates. Implementing targeted awareness programmes on DBM, which begin in the antenatal period and specifically address HIV screening of donor mothers, could address the poor uptake of DBM.

**Keywords:** donated expressed breast milk, HIV, breastfeeding, low birthweight, prematurity

## Introduction

Exclusive breast milk is the ideal nutritional source for optimal infant growth and neurodevelopment. However, when mothers cannot produce breast milk, the World Health Organization (WHO) recommends donated expressed breast milk (DBM) as the best alternative for infants with low birthweight (LBW) and/or who are premature.<sup>1</sup> The incidence of necrotising enterocolitis and septicaemia in LBW and premature infants has decreased with the usage of human milk, including DBM, as opposed to milk from non-human sources.<sup>2</sup> In these high-risk infants, feeding with donated expressed breast milk effectively prevents infectious diseases, enhances feeding tolerance, improves neurocognitive function and has other long-term health benefits.<sup>3</sup> Donated expressed breast milk is from a source other than the mother's own milk. It is usually pooled from several human donors and processed by a donor milk bank for use by a recipient who is not the mother's own infant.<sup>4</sup>

Donor mothers who have undergone screening for lifestyle habits and all infectious diseases, including human immunodeficiency virus (HIV), provide human milk, which is stored using established protocols. The use of DBM in neonatal intensive care units (NICUs) is seen as a temporary measure, while mothers are supported to establish their own breast milk supply. Therefore, DBM is part of the strategy to support and promote breastfeeding.<sup>5</sup> Promotion and the use of DBM also forms a component in the breastfeeding package of training and care. This is included in the Mother–Baby Friendly Hospital Initiative (MBFHI) and Kangaroo Mother Care launched by the

WHO and UNICEF in 1991.<sup>6</sup> In 2011, the South African Department of Health committed to promoting and supporting DBM in postnatal wards and NICUs to reduce neonatal morbidity and mortality.<sup>7</sup> The MBFHI programme has been implemented at most hospitals in SA, including those that serve populations with the highest HIV antenatal seroprevalence. Resources for in-hospital training to promote the benefits of breastfeeding should include promoting DBM through these MBFHI programmes. In most hospitals in South Africa (SA), these programmes are targeted at postnatal mothers (mothers who have already delivered their infants).<sup>8</sup>

KwaZulu-Natal (KZN) has the highest HIV infection rates in South Africa, and recommendations around breastfeeding in HIV-infected mothers have evolved over time from 2001 to 2017.<sup>9</sup> Breastfeeding within the context of the successful prevention of mother-to-child transmission of HIV (PMTCT) programme is now endorsed and promoted.<sup>7,8</sup> While the MBFHI and general breastfeeding awareness programmes and education target all postnatal mothers, it is not known whether mothers of high-risk neonates (defined as those requiring admission to NICU) are specifically targeted. These high-risk neonates include low birthweight infants, premature neonates and those whose HIV-infected mothers have unsuppressed HIV viral loads.<sup>10</sup> Many high-risk neonates benefit from the use of DBM. Despite the availability of established donor milk banks, concerns over attitudes towards using donated breast milk have been noted, and this occurs against a backdrop of low levels of exclusive breast-milk feeding in South Africa.<sup>10</sup>

The lack of awareness of the benefits and lack of knowledge of the acquisition, screening and storage methods of DBM have been identified as barriers to the acceptability of DBM.<sup>11</sup> There is a paucity of information specifically related to mothers of high-risk infants in high HIV-prevalent contexts, where the need for DBM is highest.<sup>12,13</sup> This study aimed to determine the awareness, knowledge and attitudes of hospitalised mothers of high-risk neonates towards DBM at a referral hospital where an established breast-milk bank is in existence, and there is a high HIV prevalence.

## Methodology

### Participants and study design

A mixed methodology cross-sectional study was conducted at the Mahatma Gandhi Memorial Hospital (MGMH), Durban, SA. This is a referral institution (receiving patients that a primary health care service has already assessed) with a 35-bedded NICU which admits high-risk neonates. The antenatal HIV seroprevalence in this district is 40%, and approximately 400 neonates are delivered each month. These neonates are managed in the postnatal wards, high-care nurseries or the NICU (F Khan, personal communication, July 2022). All mothers of neonates in these units are expected to receive and attend breastfeeding education programmes provided within the framework of the MBFHI. The donor breast-milk bank in this unit has been in operation since 2012. Standard operating procedures and policies based on provincial guidelines inform the use of donated expressed breast milk.<sup>8</sup> This study focuses specifically on the mothers of neonates who are hospitalised in the NICU.

### Data collection

All mothers of neonates who were admitted to the NICU (categorised as high-risk neonates) between August 1, 2021 and January 31, 2022 were eligible to participate in this study. The neonates admitted to NICU included premature neonates (< 36 weeks' gestation), small-for-gestation neonates and any neonate requiring supportive respiratory ventilation (invasive and non-invasive) or inotropic support. This maternal cohort was thus prospectively selected due to a higher than expected need for DBM than that of mothers of neonates who were not admitted to the NICU. All mothers whose babies were admitted were provided with paper-based information on the research study by nursing staff at admission. The primary investigator then actively recruited mothers opportunistically at scheduled bi-weekly meetings during the study period. Only mothers who provided written consent were then recruited to participate in the study.

### Data-collection tool

An investigator-developed survey instrument consisting of open and closed questions was developed and used to obtain the required data. All investigators participated in the development of the survey questionnaire. All investigators reviewed the questions asked through multiple rounds of iteration until consensus was determined on the final set and scoring systems to be used. This questionnaire was then piloted with a sample group of healthcare workers (nurses and doctors) and hospitalised mothers to ensure face validity. A review of the questions was done following the pilot (Appendix A is the final survey instrument developed).

Information on five core indications of DBM storage measures and one on infectious disease screening in DBM was assessed

to evaluate knowledge. A mother's willingness to recommend and donate DBM was assessed to evaluate her attitude. For knowledge and attitude questions, responses to each question were scored independently and then as composite scores. A score above 4/7 was considered as having adequate knowledge regarding DBM. For attitude scores, participants were categorised as having a positive attitude only if they answered yes to all questions in this section. Participants were considered ambivalent if they did not fall into the negative or positive category.

The demographic characteristics variables assessed in the questionnaire included maternal age and educational level. Socio-economic characteristics, namely employment status, eligibility for social welfare grants (a proxy for poverty/individual income levels) and access to indoor flushing toilets in the home (a proxy for family socioeconomic level) were also evaluated. Neonatal characteristics evaluated included: birthweight (kg), gestational age (classified as term or premature, < 36 weeks of gestation based on maternal history) and mode of delivery (normal vaginal delivery or Caesarean section).

### Data analysis

All data from the completed surveys were verified and then entered onto an Excel spreadsheet (Microsoft Corp, Redmond, WA, USA) by the primary investigator. Statistical analysis was performed using the R Statistical computing software of the R Core Team, version 3.6.3 (R Foundation for Statistical Computing, Vienna, Austria). The categorical variables were described as counts and percentage frequencies. Various comparative analyses were done to determine relationships between maternal demographic characteristics, clinical characteristics and prematurity with awareness of, knowledge and attitudes towards DBM. The chi-square or Fisher's exact test (small frequencies) was used for determining the association between categorical data. Logistic regression was further applied to determine the relationships of knowledge with attitudes to and awareness of DBM using odds ratios (OR), including 95% confidence intervals. Furthermore, the model diagnostics used the variance inflation factor (VIF) to test for multicollinearity and Cook's D to detect influential observations. The dependent variable used was adequate knowledge. Awareness and attitude were independent variables. All the inferential statistical analysis tests were conducted at 5% levels of significance ( $p < 0.05$ ).

The open-ended questions were transcribed and analysed by the principal investigator and an additional co-coder (second investigator KL), who read the transcripts of the open-ended questions on multiple occasions to familiarise themselves with the data. Specific categories of attitudes were analysed using a qualitative content analysis approach and, thereafter, using an inductive coding process, thematic analysis was used to determine patterns in these responses. The co-coders also coded the transcriptions independently to enhance rigour. The principal investigator and co-coder jointly compared and finalised the themes and labelled them. Consensus on the final themes was reached when all investigators agreed to categorise the quotes and the themes developed within each category.

### Ethical approval

Ethical approval for the study was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee

**Table 1:** Demographic characteristics of mother–neonatal pairs, *n* = 163 (%)

Demographic characteristics and number (%) of participants		
Characteristic		Number (%)
Highest educational grade ( <i>n</i> = 159)	Primary school	9 (5.7)
	High school	71 (44.7)
	Post-high school training	79 (49.7)
Employment status ( <i>n</i> = 163)	Unemployed	135 (82.8)
	Employed	28 (17.2)
Recipient of a social welfare grant ( <i>n</i> = 162)	Not receiving a welfare grant	21 (13.0)
	Receiving a welfare grant	141 (87.0)
Availability of an indoor flushing toilet ( <i>n</i> = 162)	Not available	70 (43.2)
	Available	92 (56.8)

(BREC/00002066/2020). All participants provided written consent for the study.

## Results

### Demographic characteristics

The data from a total of 163 eligible mothers of high-risk neonates were included in the analysis. The mean age and SD of mothers was 27.1 ± 6.6 years. Table 1 indicates the demographic characteristics of the recruited mothers and their infants. Of the included mothers, a high proportion, 44.7%, completed high school, and 49.7% had some post-high-school education. Only 17.2% were currently employed, and 87% indicated that they were receiving a social welfare grant. Just over half of the mothers, 56.8%, had flushing toilets in their homes. During the period of the study, for only 47 babies was DBM actively accessed from the total of 553 mothers who had their babies admitted to the unit in the study period. (F Khan, personal communication, June 2022). The HIV antenatal seroprevalence rate in the unit was 40.0%, and the proportion who were primigravid was 30.3%. Table 2 lists the clinical characteristics of all neonates of mothers enrolled in this study.

### Awareness of donor breast milk

Among all the participating mothers in the study, 55.8% indicated that they were unaware of DBM at the time of the survey.

**Table 2:** Clinical characteristics of neonates

Neonatal characteristics and number and percentages		
Characteristic		Number (%)
Mode of delivery ( <i>n</i> = 163)	Normal	83 (50.9)
	Caesarean	76 (46.6)
	Unknown	4 (2.5)
Gestational age ( <i>n</i> = 160)	Premature	71 (44.4)
	Term	89 (55.6)
Breastfeeding status ( <i>n</i> = 158)	Not breastfeeding	19 (12.0)
	Breastfeeding	139 (88.0)

The mean age (SD) of the babies of mothers sampled was 9.5 ± 18.6 days, with 46.6% having been born by Caesarean section. The mean birthweight was 2.4 ± 1.2 kg, and 44.4% were premature deliveries.

### Knowledge of donor breast milk

Table 3 lists participant responses to the seven knowledge questions that were assessed and the composite knowledge scores. Regarding knowledge on storage of DBM and the quality checks as well as infection screening of DBM, most mothers, 65.7% and 51.5% respectively, had inadequate knowledge to answer the questions. More than half of the mothers had inadequate knowledge of the five most common indications for DBM in this context. It was noted that 63.8% of mothers did not know that DBM could be used in mothers with a high HIV viral load. Over half, 59.5%, did not know that DBM could be used for abandoned infants, and 57% of mothers did not know DBM could be used for adopted babies. Only 46.6% of participants indicated that DBM could be used for premature babies.

On evaluating the composite knowledge score where all questions were assessed, 64.4% scored poorly, reflecting inadequate knowledge, and only 35.6% (*n* = 58) had a score to indicate adequate knowledge.

### Attitudes toward DBM

Among all participants, 69.3% and 73.6% would recommend or donate DBM, respectively. Attitudes towards DBM were categorised as either positive, ambivalent or negative based on the participant’s responses. It was noted that 67.5% were categorised as having a composite positive attitude (Figure 1).

Regarding seeking partner permission in this cohort, only 37.4% indicated that they would require such permission prior to accepting or donating DBM.

### Factors associated with knowledge levels of mothers on DBM

Table 4 lists the comparisons of levels of knowledge regarding the following: maternal demographics, neonatal clinical characteristics, and maternal attitudes as well as awareness levels. Of the mothers with adequate knowledge of DBM, 58.6% had

**Table 3:** Knowledge of donor breast milk among mothers<sup>1</sup>

Questions	Numbers and percentages of participants with adequate and inadequate knowledge for each knowledge question and composite knowledge scores	
	Adequate knowledge	Inadequate knowledge
1. Storage of DBM ( <i>n</i> = 128)	56 (34.4)	72 (65.7)
2. Quality of DBM ( <i>n</i> = 161)	77 (47.2)	84 (51.5)
3. Used by premature babies ( <i>n</i> = 163)	76 (46.6)	87 (53.5)
4. Used by mothers with HIV and high HIV viral loads ( <i>n</i> = 163)	59 (36.2)	104 (63.8)
5. Used by mothers who cannot breastfeed ( <i>n</i> = 163)	62 (38)	101 (61.9)
6. Used by abandoned babies ( <i>n</i> = 163)	66 (40.5)	97 (59.5)
7. Used by adopted babies ( <i>n</i> = 162)	69 (42.3)	93 (57)
Composite knowledge score	58 (35.6)	105 (64.4)

<sup>1</sup>The overall knowledge score was determined using questions on the storage and quality of DBM as well as the indications for DBM. Where a participant did not answer a question this was taken as having inadequate knowledge. A composite score above 4/7 was considered as having adequate knowledge regarding DBM.

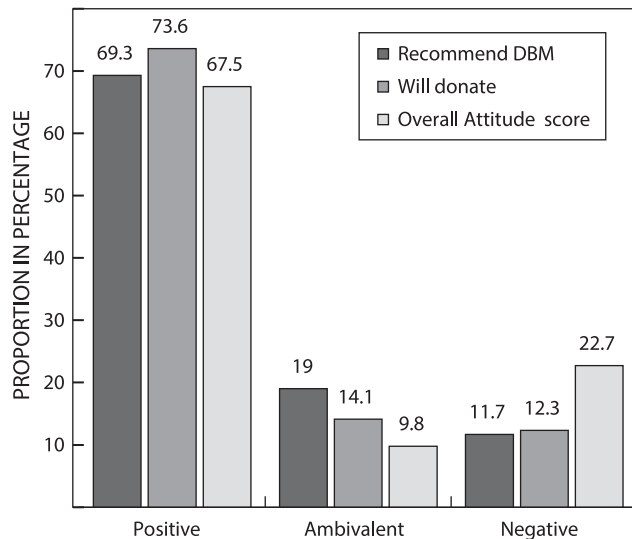


Figure 1: Attitudes towards donor breast milk.

post-high-school training. None of the maternal characteristics or neonatal characteristics differed between mothers with adequate knowledge and those with inadequate knowledge.

Specifically, breastfeeding and prematurity were not associated with having adequate knowledge.

Awareness of DBM was significantly associated with better levels of knowledge,  $p < 0.0001$ .

Lack of awareness of DBM was noted in 22.9% and 77.1% of participants who displayed adequate and inadequate knowledge, respectively. Of the mothers with adequate knowledge, 81% had a positive attitude compared with only 60% of those mothers with inadequate knowledge. Attitude toward DBM was significantly associated with knowledge levels,  $p = 0.013$ .

### Relationships among knowledge, awareness and attitudes to DBM

Table 5 summarises the logistic regression analysis undertaken. Without adjusting for attitude, the odds of participants being aware of DBM showed them to be 25 times more likely to have an adequate knowledge score (OR = 25.25,  $p < 0.001$ ). After adjusting for attitude, the odds of having adequate knowledge were 23 times higher for participants with an awareness of DBM when compared with those who were unaware (OR = 23.18,  $p < 0.001$ ).

Table 4: Comparison of participants with adequate and inadequate knowledge regarding maternal and neonatal characteristics, awareness and attitude levels to DBM

Maternal and neonatal characteristics and awareness and attitude levels, number (%)			
Maternal characteristics			
Highest educational grade:	Adequate knowledge (n = 58)	Inadequate knowledge (n = 105)	p-value
Primary school	2 (3.4)	7 (6.9)	0.204
High school	22 (37.9)	49 (48.5)	
Post-high-school training	34 (58.6)	45 (44.6)	
Employment status:			0.987
Unemployed	48 (82.8)	87 (82.9)	
Employed	10 (17.2)	18 (17.1)	
Child welfare support received:			0.800
Does not receive any welfare	7 (12.1)	14 (13.5)	
Receiving a welfare grant	51 (87.9)	90 (86.5)	
Indoor flushing toilet:			0.179
No	21 (36.2)	49 (47.1)	
Yes	37 (63.8)	55 (52.9)	
Neonatal characteristics			
Type of delivery			0.453
Normal delivery	28 (48.3)	55 (54.5)	
Caesarean	30 (51.7)	46 (45.5)	
Gestational age of baby			0.565
Term neonate	24 (41.4)	47 (46.1)	
Premature neonate	34 (58.6)	55 (53.9)	
Breastfeeding			0.663
No	6 (10.5)	13 (12.9)	
Yes	51 (89.5)	88 (87.1)	
Awareness levels			< 0.001
Not aware of DBM	10 (17.2)	81 (77.1)	
Aware of DBM	48 (82.8)	24 (22.9)	
Attitude levels			0.013
Negative attitudes	6 (10.3)	31 (29.5)	
Ambivalent	5 (8.6)	11 (10.5)	
Positive attitudes	47 (81.0)	63 (60.0)	

**Table 5:** Logistic regression analysis outcomes to determine the relationship between having adequate knowledge, and awareness and attitudes towards DBM

Adjusted and unadjusted odds ratios (OR) of participants with adequate knowledge of DBM		
Variables used in regression model	Unadjusted OR (CI, p-value)	Adjusted* OR (CI, p-value)
Awareness of DBM (yes versus no)	25.25 (10.60–68.40, $p < 0.001$ )	23.18 (9.55–64.15, $p < 0.001$ )
Attitude to DBM (ambivalent versus negative)	2.07 (0.37–10.23, $p = 0.378$ )	2.99 (0.38–22.14, $p = 0.286$ )
Attitude to DBM (positive versus negative)	4.63 (1.80–14.34, $p = 0.003$ )	3.12 (0.97–11.33, $p = 0.065$ )

\* Awareness of and attitude to DBM were variables used in the adjusted model.

With or without adjusting for awareness, participants with an ambivalent attitude had similar odds of having adequate knowledge compared with those with a negative attitude,  $p = 0.378$  and  $p = 0.286$ , respectively. On the other hand, participants with a positive attitude were almost five times more likely to have an adequate knowledge score when compared with those with a negative attitude (OR = 4.63,  $p = 0.003$ ). However, after controlling for awareness, it was found that those with a positive attitude did not have statistically significant differences in the knowledge scores when compared with those with a negative attitude ( $p = 0.065$ ).

**Thematic analysis of open comments**

Of 163 respondents, 92 provided open comments in the survey for qualitative analysis. Two major themes were identified in the analysis of these comments. The first major theme identified was categorised as ‘benefits of DBM to babies’ here, and the comments reflected that DBM helps the baby in some way. The second major theme identified was categorised as ‘hesitancy towards using DBM’, where the quote suggested the participant expressed some concern or fear regarding DBM. Within these major themes, we identified sub-themes. Table 6 illustrates the major themes and the sub-themes identified and their proposed relationships. The two sub-themes of the theme ‘benefits of DBM to babies’ included (i) DBM helps babies grow and (ii) DBM helps vulnerable babies. The major theme of hesitancy towards DBM included three sub-themes:

(i) fear of HIV transmission if using DBM, (ii) lack of trust in mothers who donate milk, and (iii) lack of knowledge on storage and supply of DBM. Fear of HIV transmission was the most dominant sub-theme. Selected quotes have been identified and listed to substantiate these sub-themes and themes.

**Discussion**

This study identifies and explores challenges in terms of mothers’ knowledge of DBM in a referral hospital that caters for mothers with a high HIV antenatal seroprevalence. Specifically, it focuses on mothers of high-risk neonates hospitalised in a NICU that is served by an established donor milk bank and where policies and programmes promoting breastfeeding are already in place.

The demographic characteristics of the maternal cohort sampled in this urban study reflect mothers from low socioeconomic backgrounds who are mainly unemployed and have high rates of HIV infection. DBM has been shown to have made a significant difference in respect of mortality and morbidity in babies who are at risk of prematurity, LBW and HIV infection.<sup>14</sup> A previous study on this topic largely focused on postnatal mothers whose babies were not in an ICU and were generally not at higher risk of the need for DBM.<sup>11</sup> Whilst the generally low rates of knowledge on DBM identified have been noted in previous studies across the world, a concern highlighted specifically in this study is that neither prematurity, LBW, high-risk deliveries nor high HIV seroprevalence rates were associated with higher levels of knowledge on DBM.<sup>15–17</sup> In addition, this study did not find any maternal demographic characteristics, including educational level, associated with higher knowledge levels. This is similar to other studies where no specific individual factors seem to be strongly associated with the uptake of knowledge on DBM.<sup>15–17</sup> In the absence of any specific individual factors that are associated with improved knowledge levels of mothers on DBM, the influence of external factors such as DBM maternal education and healthcare worker motivation in supporting DBM become important factors to be considered.

In addition to poor levels of knowledge, over half of the mothers sampled were unaware of DBM, and this lack of awareness and knowledge among many mothers possibly translates into an inability to make informed decisions when choosing an

**Table 6:** Major themes and sub-themes determined and selected quotes

Major theme	Sub-theme	Sample quote
Theme 1: Benefits to the baby of DBM	1.1 DBM helps babies grow	‘It’s good, it’s nutritious, and it’s of a high quality’ (P3)
	1.2 DBM helps vulnerable babies	‘Donor breast milk is a good thing because it helps mothers who want to feed their baby their breast milk but cannot’ (P43) ‘It’s very good and important for underweight babies and preterm’ (P149)
Theme 2: Hesitancy towards using DBM – having concerns and/or fear regarding DBM	2.1 Fear of HIV transmission if using DBM	‘I am confused if a donor is HIV positive, will the baby not be infected?’ (P23) ‘What if the mother’s HIV infection is still hidden?’ (P96) ‘How safe is it? Can you donate your milk if you are HIV positive?’ (P87)
	2.2 Lack of trust in mothers who donate milk	‘I don’t understand how you can feed your baby someone else’s milk?’ (P39) ‘I am worried if the donor is on toxic substances, will that not harm the baby?’ (P23)
	2.3 Lack of knowledge on storage and supply of DBM	‘Sometimes there is confusion regarding the milk becoming sour milk’ (P59) ‘I do not recommend it because I do not have enough knowledge on it’ (P82) ‘How safe is it? How long is it stored? Is it hygienic?’ (P79)



alternative to breast milk. It may partially explain the poor uptake of DBM reported.<sup>18,19</sup> Our study revealed that levels of awareness are related to knowledge, and this finding highlights the strong possibility that mothers are simply not being provided with either specific information or adequate training on DBM, leading to poor awareness and knowledge. Multiple studies have suggested that mothers' education is the key to the uptake of DBM, and poor healthcare worker (HCW) attitudes to DBM may contribute to poor uptake.<sup>12,20</sup> Whilst our study cannot speculate on HCW motivation, we postulate that in the context of an MBFHI hospital where processes are in place for general breastfeeding education to occur daily, our concern is that specific information regarding DBM is not being transmitted to mothers at all times, despite the average length of stay of mothers in the neonatal unit of 9.5 days. There have been calls to ensure awareness and education on DBM starts in the antenatal period.<sup>13</sup> While this is supported, the concern is that education on DBM specifically may not be included in the routine general breastfeeding education. For high-risk neonatal care, DBM has also been associated with reduced duration of hospital stay and improved maternal breastfeeding rates in neonatal intensive care units.<sup>21,22</sup> We thus recommend that general breastfeeding education be tailored to include knowledge of DBM for mothers admitted to the hospital with their high-risk babies in a NICU and use made of prolonged admission stays to accommodate this additional training time. In addition to improving awareness and knowledge, maternal attitudes to their role in DBM need exploration. A study conducted in China concerning the knowledge and attitudes of hospitalised mothers towards breast milk donation showed that the overall attitude towards breast milk donation was not positive.<sup>13</sup> Our study does not show that attitude is a major factor related to better knowledge of DBM, and this is similar to previous research in a different context.<sup>23</sup> However, in the current study, attitude levels reflected the general human nature and maternal psyche that were also identified in this cohort, where what benefits the baby is valued highly.<sup>11,15</sup> However, hesitancy to use DBM for one's own baby was also noted, in contrast to the benefits with which DBM is also associated. In exploring the hesitancy displayed towards DBM, and as noted in previous studies, one area related to fear of potential HIV transmission using DBM.<sup>13,20</sup> A call for transparency on sourcing of DBM and for information on HIV screening to be provided to educate mothers has been made previously.<sup>13,20</sup> We suggest that while DBM awareness and education should be specifically added to the general breastfeeding information and training provided, this DBM-specific training must focus specifically on the HIV screening that mothers who donate milk undergo and the low risks of HIV transmission with DBM. Active messaging must focus on this key element to improve knowledge, allay fears and break myths.

This study raises issues regarding the contrasting views concerning DBM as a benefit for neonates and the hesitancy to use DBM due to a lack of knowledge and fear regarding HIV transmission.

Our recommendations are as follows:

1. Education on breastfeeding should start during the antenatal period and continue throughout the entire hospitalisation of mothers of high-risk neonates.
2. This education on breastfeeding should include specific information on the indications for DBM and why it is the best alternative to mother's milk.

3. There must be an explicit explanation concerning the safety, screening and storage procedure for DBM and specifically how HIV is excluded by screening all donors.
4. Most mothers have a need to help their own infants and other babies; however, there are still concerns over the safety aspects of donated breast milk. Further qualitative studies are needed to explore the hesitancy and fear regarding DBM and how to overcome these.

### Limitations of the study

This study focused on one hospital site and included only hospitalised mothers. The availability of the investigator to carry out bi-weekly group meetings to recruit participants influenced the response rate to the survey questionnaires. A further limitation of the study is that antenatal HIV seroprevalence of all mothers delivering in the hospital during the study period was used as a proxy for HIV rates as we did not acquire the HIV status of individual participants. Further studies on mothers whose babies are recipients of donor milk in the unit are required.

### Conclusion

Poor uptake of DBM, despite an established donor milk bank on site, may be associated with the failure to ensure all high-risk mothers are made aware of and educated regarding DBM. This deficiency of knowledge may be exacerbating fears and concerns around DBM usage. Urgent steps are necessary to ensure that the Mother–Baby Friendly Hospital Initiatives incorporate education on DBM, especially for high-risk neonates. These programmes are tailored to focus on the HIV screening of potential donors specifically.

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## Appendix A: Survey questionnaires

### Form B1: English Survey

Please complete the following questions

Number	Question	Answer
D1	What is your age in years?	
D2	What is your highest level of education (please tick or circle your answer)	Primary school = 1; High school = 2; Post matric = 3
D3.1	Are you employed?	No = 0; yes = 1
D3.2	What type of work do you do?	(Fill in detail)
D4	How old is your baby in days?	
D5	What type of delivery did you have?	Normal vaginal delivery = 0 Caesarean section = 1
D6	Is your baby a premature baby?	No = 0; yes = 1
D7	What is the birthweight of your baby? (in kg)	
D8	Are you planning to apply for a SASSA grant for your baby?	No = 0; yes = 1
D9	How many rooms do you have at home?	
D10	Do you have a flushing toilet at home?	No = 0; yes = 1
D11	Is your baby taking breast milk or formula	Breast milk: No = 0; yes = 1 Formula milk: No = 0 yes = 1
K1	Have you ever heard of donor breast milk?	No = 0; yes = 1 If you answered no, skip the rest of the K questions and proceed to A1 If yes, proceed with all K questions
K2	Where is donated breast milk stored?	1 = milk banks; 2 = other
K3	What kind of babies qualify to receive donor breast milk? Please answer each question. K3A premature baby whose mother has insufficient milk: No = 0; yes = 1; I don't know = 3. K4B term baby whose mother has a high HIV viral load: No = 0; yes = 1; I don't know = 3 K5C cannot breast feed: No = 0; yes = 1; I don't know = 3 K6D abandoned baby: No = 0; yes = 1; I don't know = 3 K7E premature baby for adoption: No = 0; yes = 1; I don't know = 3 K8 Other reasons: please write here	
K9	Is donor breast milk the same quality as a mother's own breast milk?	No = 0; yes = 1
A1	Would you recommend for your friend /relative's baby to receive donor milk?	No = 0; yes = 1
A2	Would you recommend your friend/relative to donate their breast milk	No = 0; yes = 1
A3	Will you have to obtain permission from the baby's father if you want to use donor breast milk for your baby?	No = 0; yes = 1
Open 1	Tell us your feelings about DONOR BREAST MILK; ANY CONCERNS; ANY CONFUSION, or QUESTIONS: please write here 1 2 3	