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Breast milk donation: women's donor experience

ABSTRACT

OBJECTIVE: To describe the characteristics of donation behavior and identify reasons, beliefs and feelings relative to this practice, based on the reports of donor women. Personal and social-environmental aspects, which seem to affect donation behavior in donors and former donors, were also investigated.

METHODS: An exploratory, descriptive and cross-sectional study was carried out with women donors at two breast-milk banks within the public health system of the Brazilian Federal District. Data was collected from July to September 2005. The participants were 36 women, aged 14 to 33 years (average=24.78; SD=5.22), with different levels of schooling, 58.3% of which were first-time mothers. Data gathering was based on interviews carried out during home visits. In addition to descriptive statistical analyses of quantitative data, a qualitative data categorical analysis was also performed.

RESULTS: The most frequently reported reasons for donating breast milk were altruism and excess milk production. The most frequent time interval for donation was 13 days after delivery. Contact by phone with the milk bank was the most common means of communication used by the majority of participants (n=22) to obtain information that enabled the donating process.

CONCLUSIONS: Psychosocial aspects identified and the experience of donors can contribute to the empowerment of the formal and informal social donation-support network, in addition to serving as a driver for the implementation of technical and policy strategies in promoting future donation practices.

DESCRIPTORS: Milk Banks. Donor Selection. Milk, Human. Breast Feeding. Health Knowledge, Attitudes, Practice. Maternal and Child Health.

INTRODUCTION

In the last twenty years, the awareness of the importance of breastfeeding has increased considerably,^{13,14} as it can be evidenced by the indexing of scientific publications, which today include many related topics: the physiology of lactation, practices and benefits for the triad mother/baby/father, and the biological, psychological and social impact of breastfeeding on modern society.^{2,3} Donating breast milk is strongly related to breastfeeding itself, because it is when a woman has this life-cycle experience – the experience of being a mother, even when through adoption, and the experience of breastfeeding – that she can be a donor of this human product.

There is a shortage of scientific papers on breast milk donation.⁴ While researching scientific databases for breastfeeding, Alencar & Seidl,⁵ after looking up the topic

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in BVS/Breastfeeding, Lilacs, Medline and Fiocruz (online resources and the *Rede Brasileira de Bancos de Leite Humano* [REDEBLH – Brazilian Milk Bank Network]), between 2000 and 2005, using the keywords “doação” (“donation”) and “leite humano” (“human milk”), only identified one international paper and 14 abstracts presented in the Proceedings of the *III Congresso Brasileiro de Bancos de Leite Humano* [III Brazilian Human Milk Bank Conference], carried out in 2002.

In the only scientific full paper published on human milk donation, Azema & Callahan⁴ found that altruism was reported as a reason by a large part of the 103 women who were interviewed in the study. Other reasons mentioned were: excess milk production, knowing that another mother’s baby needed the milk, and knowing that the Human Milk Bank (HMB) needed the substance.

Since the HMB are centers that encourage and promote breastfeeding, donating breast milk is important. And because the HMB are non-for-profit organizations and do not sell their products, the role of the donor is essential in enabling the HMB to play their role of collecting and distributing human milk to meet the needs of receivers.²

By examining the selected publications,⁴ the goal was to initially identify the perception of women donor towards the donation of human milk. This study aimed at describing behaviors, beliefs and feelings behind human milk donation, by identifying donors’ individual and social and environmental features that could affect donation of milk.

METHODS

This is an exploratory descriptive and cross-sectional study in which interviews with breast milk donors and former donors were carried out.

This study was part of a broader study^a about women who donated breast milk in the Federal District, Central-West Brazil, from May 2005 to November 2006.

A pilot study was done with four women donors to assess the appropriateness of the data-gathering instrument created for the research and of the data gathering procedures (interviews conducted in the home environment).

The sample was a convenience sample and, in selecting and inviting participants, an attempt to achieve diversification was made by choosing participants with different levels of schooling, for instance, aiming at a sample with different characteristics in terms of social and demographic aspects.

Forty-eight women registered at two HMB of the public healthcare system of the Brazilian Federal District were invited in a telephone conversation to participate in the study. The researcher introduced herself by stating the institution she belonged to, the goals of the study and the ethical aspects involved, and all the data gathering procedures.

The criteria for being included in the sample were: frequent donations (weekly or fortnightly), occasional donations (women who decided to donate, but did not commit themselves to doing it frequently) or recent donations (women who asked to remove their names from the milk bank in the last thirty days). Women who had made their last donation more than 30 days ago were not included in the sample.

There were 12 reasons for refusal cited in the research: lack of time (five cases), unjustified reason (four cases) and refusal after scheduling (three cases). Therefore, 36 women participated in the study, representing 20.2% of the total number of 178 donors registered at two HMB. Twenty-seven were currently donating milk and nine were recent former donors.

Two interview techniques were used: 1) structured interviews (questions about age, place of birth, schooling, marital status, occupation, family income, prenatal care, number of prenatal appointments, number of pregnancies); and 2) semi-structured (open-ended and closed questions about the reasons for donating, prior donations, period of donation in weeks/months, measures to materialize the donation decision, perception of experience). In the case of former donors, two questions were added: reasons for stopping donating and total period of donation. The average time spent in the interviews was 60 minutes.

The reason why participants were interviewed at home was because they were breastfeeding and on maternity leave in most cases, in addition to the fact that collection was carried out by the HMB at the donor’s home, and this made it difficult for these women to be interviewed elsewhere.

While gathering the data, the interviews were disrupted on several occasions and the participant’s attention was reduced. The interruptions occurred due to the fact that the participant had to attend to her baby’s needs (crying, making noises, hunger, breastfeeding, among others), in addition to other sources of disruption (phone, visits, among others). The disruptions were expected since the interviews took place at the participant’s home. On the other hand, the domestic environment enabled the researcher to witness and observe *in loco* relevant aspects of the social and family environment of these women and did not affect the accuracy or quality of the answers obtained.

^a Alencar LCE. Doação de leite humano no Distrito Federal: aspectos psicossociais e experiências de mulheres doadoras [masters’ dissertation]. Brasília: Instituto de Psicologia da Universidade de Brasília; 2006.

Due to the demands resulting from the nature of this study, we attempted to ensure that information and/or guidance were provided based on the needs reported by participants, in terms of their doubts concerning breastfeeding and/or donating breast milk.

The statistical analysis of quantitative data included frequency measures, measures of dispersion and central tendencies, based on SPSS version 13.0.

For the qualitative data analysis, we used categorical analysis procedures.⁵ The interviews were fully transcribed. The open-ended questions were read horizontally, for all participants. The oral statements were analyzed and categorized based on content independently by two researchers, aiming at an agreement rate equal to or above 70% in identifying, naming and establishing the frequencies of the categories. Excerpts from participant's answers were selected as examples of categories.

This project received the approval of the Ethics and Research Committee of the State Health Secretariat of the Brazilian Federal District. Confidentiality was provided to all participants, who voluntarily signed and informed term of consent.

RESULTS

Participants were between 14 and 33 years old (mean=24.78; SD=5.22). In regard to place of birth, most of them had been born in the Federal District (n=20; 55.6%). On the question about what they thought of the donation experience, 33 participants (91.7%) said it was positive. The number of prenatal appointments varied from three to 30: eight women (22.2%) reported having had nine appointments and five (13.9%) reported having had ten. The sample distribution across other demographic data can be seen in Table 1.

When asked on the reasons that led them to donating their milk, altruism (donating in order to help other mother who are incapable of breastfeeding, voluntary action, not paid for) was the most mentioned reason by 33 participants.

"I donate milk to contribute with life, to contribute with premature children who are in hospital because... I keep thinking about the mothers who don't have any milk". (D20)

Excess milk production, beyond the needs of their baby, was the second most reported reason, and was mentioned by 22 participants, which was expected seeing that his biological feature is a necessary condition for donating.

"I donated because I had a lot of milk, and while I was breastfeeding my baby, my other breast was always leaking (...)"(former D6)

The prior experience category and/or not having been able to breastfeed or knowing that someone else was unable to, was defined as a driver for donation, mentioned by 19 participants.

"Because I was hospitalized for nine days and (...) in my room there were two mothers who didn't have any milk, so I saw their despair (...) their babies would cry of hunger and they would bring just a little... and they said that to put the baby to suck, suck, and the mothers cried more than the babies, and I was producing so much milk, and then a woman called me and asked me to pump milk (...) so she convinced me... I went, and then I started pumping milk every day and... every day I would pump a jar of mayo in the morning and one in the afternoon (...)" (D25)

The reason 'to avoid waste' – to make a better use human milk by avoiding loss and waste – was mentioned by 17 participants.

"Because, first, I think it's a waste, because when we're breastfeeding, so much milk is wasted when you take a shower; when you're giving one breast, the other is leaking, so when the other one is leaking, I collect it". (D26)

In regard to access to information about the importance of donating milk, – this category being defined by information made available by healthcare professionals and the media promoting understanding and valuing the practice of donation –, was considered essential to 17 participants, who felt motivated to donate because of this.

"...actually, I feel more confidence in the girls at the milk bank than in the pediatrician...they are more up-to-date, I've been to three other milk banks before coming to this one, I went to the Hospital M., the girl there, taught me, but I didn't know yet how to pump the milk, in the first week I already pumped enough milk". (former D7)

To another 17 participants self-esteem, defined as a personal positive feeling resulting from playing a socially significant role, was the strongest reason why they donated their milk.

"I think it makes you very happy to be able to help other babies... we don't even know them, we don't see other babies, but we know we are saving lives... they are so frail... so weak(...)" (D8)

The categories support of institutions such as hospitals, HMB, Fire Departments, and understanding the nutritional quality of human milk, were each mentioned by 16 participants as reasons why they became donors.

"after I called the fire department I felt they took the initiative and came, and gave all the support, they brought the glass, mask, and all of these things (...)" (D3)

Table 1. Social and demographic characteristics of participants. Federal District, Central-West Brazil, 2005. (N=36)

Characteristic	n	%
Marital status		
Married or in a partnership consensual consensual	28	77.8
Single, separated or divorced	8	22.2
Schooling		
Elementary school – incomplete	6	16.7
Elementary school – complete	2	5.6
Middle school – incomplete	7	19.4
Middle school – complete	8	22.2
University education – incomplete	4	11.1
University education – complete	9	25
Lives with		
Partner and child(ren)	26	72.2
Relatives	7	19.4
Other people besides partner, child(ren) and/or relatives	3	8.4
Number of pregnancies		
First	21	58.3
More than one	15	41.7
Number of children		
One	22	61.1
Two	11	30.6
More than two	3	8.3
Prenatal care		
Yes	36	100
No	0	0
Public healthcare network	23	63.9
Private healthcare network	13	36.1
Family income		
No income*	1	2.8
Less than 1 MW	2	5.6
1 to 2 MW	8	22.2
More than 2 to 5 MW	7	19.4
More than 5 to 10 MW	6	16.7
More than 10 SM	10	27.7
Didn't know	2	5.6
Occupation		
Independent worker	1	2.8
Unemployed	2	5.6
Registered worker	15	41.6
Unregistered worker	1	2.8
Student	2	5.6
Homemaker	15	41.6

MW: Minimum wage

*husband unemployed and homemaker wife

“(...) you get this feeling that (...) you’re throwing food away, it’s like you were throwing away a plate of food, so it’s for the love of our neighbor and for knowing that a mother will feel a bit more supported, that her child is getting food”. (former D4)

Seven of the participants considered that the emotional influence of an important person that encouraged the donation practice played an essential role in motivating them to donate.

“...first because my mother works there, so she turned to me and said that they needed it very much, any drop of milk that got there was welcome, so I called them and they came here to collect it, because this is a needy neighborhood”. (D21)

Table 2 provides the reasons for stopping, and the period of donation of the interviewees who were former donors. It was noticed that having returned to their daily routine (work, school) and reduction in the production of milk were the main reasons why they no longer donated.

When asked whether this was their first experience as donors, 30 women (83.3%) said yes. However, 15 (41.7%) had been pregnant before. In these cases, we investigated why they had not donated before. Some of the reasons why multiparae women had not donated before were the following: they were embarrassed and because of that they threw away excess milk, not knowing about milk donation at the time they had their first child (11 years ago); lack of information at the hospital where they gave birth for the first time; they wanted to donate, but did not take the initiative; had a lot of milk only in the beginning. The answers indicated that, possibly, some of these women had been potential donors in prior pregnancies, but had not had the opportunity of donating their milk for different reasons.

The time interval between the data of childbirth and the beginning of donation was varied and these dates were obtained in their charts at the milk banks involved in this study and during the interviews. The most frequent time interval for donation to take place was 13 days after childbirth. The average interval was 34 days (SD=31.26). Seventeen women reported having started donating milk within 20 days after delivery.

The behaviors adopted by the women, after deciding to donate, were expressed in their reports. Contacting the HMB over the phone was mentioned by 22 out of 36 participants in order to obtain information that favored the beginning of the practice.

“(...) I got no information on donation, they only told me I had to sterilize the jar, they were going to give me one... and after I sterilized it, I had to pump it with a mask on... a hair net (...), I couldn't use a little pump and they would come over to collect the milk, but then

since Hospital Y would never go (...) to collect it (...) I looked it up and called Hospital Z and (...) 'Hospital Z' started collecting it". (D27)

Behaviors such as: 1) visiting the HMB to obtain donor information; 2) calling the Fire Department; 3) looking for information (internet, other media or specific services) and; 4) receiving support from the maternity or hospital where she delivered (donation beginning during hospitalization), were also reported as actions to materialize the donation practice, after having made the decision to donate. The following reports provide example of each one of the four above-mentioned categories.

"...I went to 'Hospital A' with my husband, we went to the milk bank (...) we talked to the woman from the fire department...,I said "How can I donate here?" Then there were some people who didn't pay much attention to me... so I went up to her and said... "What do I have to do to donate milk here? I want to donate! I want to be a donor"...so she said "oh! It's right here (...)", then she gave me a little flyer explaining what I had to do and gave me the jars and said that every Monday they would go to my house to pick it up, and she told me that I had to put it in the freezer and all those things...". (D4)

"(...) I called the fire department because I thought they were the ones that called, then they told me to call the regional hospital in my city, so I picked up the phone and called them, and on the same day they picked it up at my house(...)". (former D7)

"Look, I got home from the maternity... and ... two or three days later I looked for information on how to donate on the internet, then I found the phone number of the hospital, which was very close to my mother's in 'A', then I called, and it was on the same week, she went there, explained to me what the procedure was, asked whether I really wanted to donate, she filled in my form, and I started, it was quick and easy". (D1)

"My breast was very full, it was hard and she couldn't suck it, the baby; then the milk bank at the hospital (Hospital C), the hospital where she was born went there and encouraged me, and after that I didn't stop donating (...)". (D13)

DISCUSSION

The results of this study address the donation of human milk from the point of view of donor women at two main HMB in the region, one of which is considered a reference in the Brazilian Federal District. The adopted methodology proved to be satisfactory, considering that this was a descriptive study, based on the experience of donor women.

The age bracket of the interviewees mirrored a young group, at reproductive age, and this was expected, see-

ing that most Brazilian women become mothers before age 30.⁸ There were three adolescents (14, 15 and 17 years of age) and two participants were 18 on the date of the interview, which corroborates the increase in prevalence of teenage pregnancy in Brazil. Most participants were pregnant for the first time, which indicates that the donation experience occurred at the same time as their first experience as a mother.

In regard to schooling and income, the group was made up of women of different social and economical levels. Assuming that schooling could influence in decision-making and maintaining the donation behavior, this variable was intentionally taken into consideration to diversify the sample in terms of social and economic aspects, in order to meet the goals of this study. However, the associations between social and economical status and aspects of the donation behavior were not investigated. This can be further explored in future studies of the database.

On the other hand, it is possible to state that altruism as the most common reason for human milk donation did not seem to be significantly influenced by social and economical variables because it was mentioned by the almost entirety of the sample. Therefore, for most women, the voluntary act associated to 'desire to help other people' seems to justify and favor making the decision to donate and donating, which is consistent with other studies about the donation of milk⁴ and of other human substances.^{7,9,10-12}

Another issue that also supplanted the biological reason (excess milk production as a necessary condition for donating) was the importance participants gave to other people – the newborn who was going to receive the donated milk, another mother, or their own child. In some cases, donation was connected to experiencing a significant emotional event during pregnancy, after delivery and/or puerperal period, and these events motivated and helped in understanding the importance of donating. The attitude of putting herself in the position of other mothers who were experiencing difficulties of this kind contributed to raising the awareness of these women.

Still, concerning the reasons for donating, the social influence, both from the family and from healthcare professionals, played an important role. Another issue refers to knowing about the quality and nutritional benefits of human milk which is a motivating factor for donation and a social and cultural aspect mirrored in the educational efforts in the last years promoting breastfeeding.¹

In regard to participant prenatal care, the data show that most women had an adequate number of appointments – from nine to ten –, which shows that, probably, there had been access to satisfactory healthcare actions and services during pregnancy, labor and puerperal period. Raising awareness to the importance of donating milk

Table 2. Categories of reasons why donation ceased and period of donation reported by former donors. Federal District, Central-West Brazil, 2005. (n=9)

Reason	Donation Period	Age of baby when donation ceased	Examples
Returning to daily activities: school and work	No information	–	"(...) I had to study, otherwise I would still be donating today". (former D1)
	4m5d	4m22d	"Only work, exactly on the day I went back to work I stopped donating because I can't do both things anymore....". (former D4)
	3m13d	3m28d	"I stopped because I went back to work(...) I already had to pump milk for A(...) he stays home(...) and he stills feeds on my milk (...) I wasn't able of pumping milk for the bank and for A". (former D5)
Reduced milk production	2m18d	4m3d	"I stopped because there was little milk, and (...) one reason is that my baby takes a lot of milk, so what I collect from the other breast, I feed it to her later on, and I have a lot of milk, and she's big, she takes a lot, a lot, a lot, she cries". (former D6)
	3m20d	4m26d	"It became less frequent because he took more milk, so that stopped me from pumping milk to donate (...).The lack of milk (...) of excess". (former D7)
	1m18d	2m	"The most important because of my baby, it was drying out (...) I was afraid the milk would dry out, that there was only enough for her, she was taking a lot, (...) I noticed I wasn't filling up as much as before(...)". (former D9)
	4m13d	5m20d	"Because I was producing less... there was only enough for my son". (former D3)
Donated for a long enough period	3m 22d	4m 3d	"(...)I thought it was enough... I had donated enough... so I thought it would be better to stop ...time too...". (former D2)
Pumping increased milk production and caused pain to the breasts	1m12d	3m6d	"It's because I pumped it, they filled up you know, and I had backaches (...) so I stopped because of the pain, and because I have very large breasts and after I had my baby my breast became bigger, they were carking, they were so full, they were becoming full of stretch marks (...)". (former D8)

can take place in privileged moments such as prenatal care, delivery and puerperal period. It is assumed that the women, who received information and orientation on breastfeeding, and possibly on donating human milk, may have developed a greater ability to identify their potential as a donor by assessing their own milk production. In addition, they may have better understood the importance of donating in terms of public health.

Therefore, we conclude that quality and humane educational actions during prenatal care, at maternities and nurseries, are essential in capturing milk donors. It was noticed that most multiparae women who were having the experience for the first time reflected on the possibility of having been donors in previous experiences. Donation not having taken place in previous pregnancies may have resulted from personal characteristics (lack of information or initiative), in addition to flaws in the institutional support process network, such as lack of information to clarify potential questions on donating human milk.

Another issued that emerged in this study was the period of donation, information obtained from former

donors. It was found that most women donated for a period between three to four months. The reasons for donation to stop were going back to work or school, in addition to reduced milk production. This period of time seems to be related to the duration of maternity leave in Brazil – 120 days.⁶ Assuming that this period is the average period of milk donation in Brazil, public entities – hospitals, HMB and Fire Departments – should display interest in optimizing this period, without neglecting, for obvious reasons, the ethical principles governing free will and autonomy. On the other hand, so these entities may act accordingly, it is important they receive specialized and political support through material and financial conditions in addition to the human resources necessary to fulfill their roles.

It is expected that the results found in this study are able to assist in implementing actions in consistency with public healthcare policies in Brazil in order to promote, protect, support and encourage breastfeeding and breast milk donation.^{1,2} Such policies shown constant concern with the application and/or appropriation of the results in studies in this field, both in drafting and reorganizing public policies.

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