

## Breast Milk Donation and Social Support: Reports of Women Donors<sup>1</sup>

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The study aimed to characterize the behavior of human milk donation and to describe the informal social and formal institutional support, according to reports from women donors. It is an exploratory, cross-sectional, descriptive study using domicile interviews based on structured and semi-structured scripts. The participants were 36 women enrolled in two human milk banks of the public health system of the Federal District. Statistical analysis of quantitative data and categorical content analysis of qualitative data were performed. Categories of reasons that most influenced the frequency of expressing were: food, time availability, negative emotions and fluid intake. The manual expressing technique was reported as predominant. The use of breast shells was cited by almost a third of the donors. Most frequent suggestions for improving institutional support were more attention and support from the milk banks for the donor. The study may serve as a stimulus for the implementation of technical and political strategies to encourage this practice.

Descriptors: Social Support; Milk, Human; Milk Banks; Gender and Health.

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## **Doação de leite humano e apoio social: relatos de mulheres doadoras**

O estudo objetivou caracterizar o comportamento de doação de leite humano e descrever o apoio social informal e institucional, segundo relatos de mulheres doadoras. Trata-se de estudo exploratório, descritivo, de corte transversal, com entrevista domiciliar baseada em roteiros estruturado e semiestruturado. Participaram 36 mulheres cadastradas em dois bancos de leite humano da rede pública de saúde do Distrito Federal. Foram realizadas análises estatísticas descritivas de dados quantitativos e categorial de conteúdo dos dados qualitativos. Categorias de motivos que mais influenciaram na frequência da ordenha: alimentação, disponibilidade de tempo, emoções negativas e ingestão de líquidos. A ordenha manual foi referida como técnica predominante. O uso da "conchinha" foi citado por quase um terço das doadoras. Sugestões mais frequentes para melhorar o apoio institucional foram maior atenção e apoio dos bancos de leite às doadoras. O estudo poderá servir de estímulo para implementação de estratégias técnicas e políticas que favoreçam essa prática.

Descritores: Apoio Social; Leite Humano; Bancos de Leite; Gênero e Saúde.

## **Donación de leche humana y apoyo social: relatos de mujeres donadoras**

El estudio objetivó caracterizar el comportamiento envuelto en la donación de leche humana y describir el apoyo social informal e institucional, según relatos de mujeres donadoras. Se trata de un estudio exploratorio, descriptivo, de corte transversal, con entrevista domiciliar basada en guiones estructurados y semiestructurados. Participaron 36 mujeres registradas en dos bancos de leche humana de la red pública de salud del Distrito Federal. Fue realizado el análisis estadístico descriptivo de los datos cuantitativos, y el categórico de contenido de los datos cualitativos. Las categorías de motivos que más influyeron en la frecuencia de la extracción de leche: alimentación, disponibilidad de tiempo, emociones negativas e ingestión de líquidos. La extracción de leche manual fue referida como técnica predominante. El uso de la "conchita" fue citado por casi un tercio de las donadoras. Sugerencias más frecuentes para mejorar el apoyo institucional fueron mayor atención y apoyo de los bancos de leche a las donadoras. El estudio podrá servir de estímulo para implementación de estrategias técnicas y políticas que favorezcan esa práctica.

Descriptores: Apoyo Social; Leche Humana; Bancos de Leche; Género y Salud.

## **Introduction**

In recent decades, the concept of social support has been the study target of several Brazilian and foreign researchers in the field of health<sup>(1-2)</sup>. An initial definition of the concept of social support indicates that it is "information that leads individuals to believe that they are cared for, loved, esteemed and that they belongs to a social network with mutual obligations"<sup>(2)</sup>.

Studies of social support focus the perception concerning the availability and the type of support received, also covering the satisfaction with it. Two

categories of support have prevailed in the literature: instrumental and emotional. The first category refers to the availability of help to assist the person in the management or resolution of practical situations or quotidian operation, with material or financial support or various day to day activities. Emotional support consists of behavior such as listening, providing attention or keeping company which contribute to the person feeling cared for and/or esteemed<sup>(1)</sup>.

Another interesting aspect concerns the sources

of social support. These may be informal (family, friends, people of religious groups) and formal (institutional, professional), however, they can also act in a complementary way. Therefore, it is necessary to consider these aspects in studies that investigate the types of support received by people in the different contexts of health, illness and vulnerability.

The concept of social support interfaces with that of the social network, which has also guided studies in the area of health. As an example, researchers have created social network maps of breastfeeding women<sup>(3)</sup>. The results indicated the presence of strong bonds between these women and people of the primary network such as friends, neighbors, their mother, or the father of the child, being those most involved with the mothers in the breastfeeding process. The authors concluded that the methodological framework of the social network can facilitate a comprehensive approach towards this theme in studies and professional interventions.

A question emerged in this study: how to structure, both formally and informally, social support for women donating breast milk? How does the woman perceive this support? Initially, it is important to note that the woman donor is in a time of life that may include adaptive aspects, possibly with stressful features: the recent experience of maternity; caring for the baby, often their first child; the donation being a continuous act over a period of time unlike blood donation which takes place in a single episode<sup>(4-5)</sup>.

Another issue relates to the fact that the practice of milk donation is consolidated from actions involving public institutions - the Human Milk Bank (HMB), the Fire Department (FD) -, implying regular relationships: contacts at home for collection and provision of necessary equipment such as jars for storage, masks and caps. From this perspective, HMBs have, in recent years, been made strategic elements in relation to the promotion and encouragement of breastfeeding and the donation of human milk, as well as representing driving centers of state policy, undergoing a series of ideological changes in their institutional practice, since the first unit deployed in the country in 1943<sup>(6)</sup>. Thus, it is clear that social support for the woman donor is related to public health policies, including HMB and the FD, as well as their families and individuals in their social bond. However, it has peculiarities that are not well understood, such as the perception of these women about the support received by these social actors<sup>(7-8)</sup>.

This study aimed to characterize the behavior of donation and to describe the informal social and formal

institutional support, identifying the level of satisfaction with the support received, according to reports from women donors enrolled at two milk banks in the public health system of the Federal District.

## Methods

This work is part of a larger study conducted by the first author<sup>(9)</sup>, under the guidance of the second author, which aimed to identify the motives, beliefs and feelings related to the practice of donation, from reports of women donors, and was conducted between May 2005 and November 2006<sup>(8)</sup>.

The project was first submitted to the Research Ethics Committee of the Health Secretariat of the Federal District. Upon approval, a pilot study was conducted with the aim of evaluating the adequacy of the interview script prepared for the research and data collection procedure proposed (interview in the domicile). Interviews were conducted on the basis of structured and semi-structured scripts, prepared for the study, containing questions relevant to the research objectives. The participants were 36 women enrolled in two HMBs of the public health system of the Federal District. The number of women represented 20.2% of the total 178 donors of the HMBs included in the study. Twenty seven women were current donors and nine recent former donors, based on the established criteria.

The descriptive statistical analysis of quantitative data included measures of frequency, dispersion and central tendency, using the software *Statistical Package for Social Sciences* (SPSS) version 13.0. Regarding the analysis of the qualitative data, analytical procedures for categorical content were used<sup>(10)</sup>.

The interviews were first transcribed in their entirety. Next, the open questions of all participants were read horizontally. The verbal reports were analyzed and categorized, based on their content by two independent researchers (the researcher and supervisor), seeking agreement of not less than 70% for the identification, naming and frequency of the categories. Excerpts from the reports of the participants in the study were selected as examples of the categories.

## Results

The age range of participants was between 14 and 33 years ( $m=24.78$ ;  $sd=5.22$ ). A key issue dealt with the frequency of extraction of milk by women participants, known by the technical name 'expressing'. It was observed that the majority ( $n=26$ ; 72.2%) of

the women expressed their milk more than once a day, 8.3% (n=3) reported expressing once a day and 19.4% (n=7) reported that the frequency was variable.

As to how breast milk was being expressed by the participants, it was observed that the technique of expressing manually prevailed over others (n=22; 61.1%), which meets the technical standards for human milk banks<sup>(11)</sup>. However, almost one third (n=11; 30.5%) reported the use of breast shells, which has not been recommended due to the possibility of negative consequences as regards the risk of microbiological contamination of the expressed milk. The use of the

manual or electric pump was reported for the remainder of participants (n=3; 8.4%). When asked if any factor interferes with expressing frequency, 83.3% (n=30) of respondents answered yes, some of them referring to more than one factor affecting this. Strictly speaking, this frequency was related to milk production. Table 1 shows the factors related to the frequency of expressing in categories, along with the classification of the influences as positive or negative on the aspects mentioned. From the reports, the consideration as to which factors could facilitate or prejudice milk production was made.

Table 1 - Positive and/or negative influences related to the frequency of expressing and milk production, according to reports from participants

Category	f	Type of influence	Example of reports
Ingestion of liquids	9	Positive and negative	<i>I think it is from the liquid you take, there were days that I took too much liquid, my chest filled a lot, and other days I cut down and then they were not so full and so that is it, right now, the day that I take a lot of liquid, then they fill a lot and can't stand (...), and then in the day I almost do not drink water (...) and then there is not so much (ex-D8).</i>
Diet	17	Positive and negative	<i>I felt when I ate less my breasts did not fill much, when I really ate a lot they leaked (ex-D1).</i>
Routines of the mother going out, contraceptive use and return to work	3	Negative	<i>(...) my going out, when I need to go out a lot, unbalances things a bit (D3). I think the pill contributed a lot because when I started taking the contraceptive pill my milk decreased (...) (D20). ... I realized that when I went back to work, it decreased (ex-D4).</i>
Baby feeding frequency	5	Positive and negative	<i>When my baby is healthy my breasts fill a lot... when he gets a cold my breasts do not fill much, they remain empty and it is difficult to get milk... every day, but when he's well, healthy, happy he leaves some as he is eating food... so there is enough milk for him and to donate, but when he gets sick he dries the breasts in just one minute (D6).</i>
Presence of negative emotions	10	Negative	<i>In a week, 15 days I realized that I was producing less... .. emotionally, sometimes fighting with the boys... I get angry... and then I felt a bit anxious and felt that I was not making the milk well (ex-D9).</i>
Availability of time	10	Positive and negative	<i>(...) sometimes the breast is full but I do not... have time to sit and relax a little bit to get the milk (...) (D9). Sometimes I take more at night (...) because I have more time (D14).</i>
Frequency of expressing	6	Positive	<i>(...) it is just start taking it and it starts producing lots and lots(...) (D27).</i>
Growth of the baby	4	Negative	<i>(...) the fact that my daughter's growing up and she needs more milk, she suckles more and it is more difficult to produce milk (D20).</i>
Period of the day	6	Positive	<i>(...) at night I produce more milk (D25).</i>
Physical fatigue and laziness	6	Negative	<i>If it was not for the physical exhaustion of the early hours of the morning I would be able to have taken more at that time, this is the period when she feeds less and when more milk accumulates (...) (ex-D4).</i>
Nothing interferes with production	5	Positive	<i>No, it stays the same, I want it to change, to express less (D23).</i>

Note: D = donor, ex-D = former donor

Regarding the frequency with which the HMBs would collect the milk from the domiciles of the women interviewed, 25 (69.4%) of them reported that this occurred weekly and 11 (30.6%) reported a fortnightly frequency. It is important to realize that, the frequency of HMB collection depends on the organizational aspects of the institution, such as the availability of transport and human resources for this task. When questioned about whether they knew what was happening with their milk, after donating it to the HMB, 16 (44.4%) of them reported that they did not know about the procedures performed, 12 (33.3%) were poorly informed and eight (22.2%) adequately informed, based on their reports. With regard to receiving information about the donation of human milk before the baby was born, 16 (44.4%) reported that they had received nothing. Nine

of them (25%) mentioned that this occurred during the prenatal period and six (16.7%) received information during previous pregnancies. On the occurrence of doubts at the beginning of the process of donation, the majority (n=24; 66.7%) reported hygienic and sanitary procedures required in the expressing process, such as carrying out the expressing, how to sterilize the materials to store the milk at home, how long the milk could stay in the shell, how to store the milk, where to put the milk after expressing, use of mask and cap, why the baby can not suckle on another woman donor.

When questioned about the presence of doubts about donation at the time of the survey, 29 (80.6%) women responded that they did not have any, and seven (19.4%) of them admitted that they still had doubts about donating, which are categorized in Table 2.

Table 2 - Presence of doubts about donation at the time of the survey, according to participants

Category	f	Examples reported
Processing of donated milk	4	<i>To know what happens, to know the whole process if the milk goes straight from the glass that we put it in, does it go straight to a child or if there is some other process that they do or if this milk goes somewhere else to some machine or something else that stores it there longer, even this process after it comes out of my house and arrives at the hospital, I have many doubts about because I do not really know what happens when it arrive (in HMB), how does that help the child after it leaves my house and goes to the child, who really needs it, who are they, who really gets this milk ? (...)</i> (D16).
Access of the beneficiary (child) to the donated milk	2	<i>(...) I'm so curious to know, to seek more information about donating milk, what will they do with the milk before it reaches the child, who are the children that receive the milk that is donated, is it because the mothers do not have milk, or that their milk is weak? Why does this donation exist? They take the milk to do what with that milk if every mother has, nature has given each one their own? (...)</i> (D27).
Operational issues about storage	1	<i>They send it to be frozen one week to another, but beyond this week how many days the milk can really stay frozen?</i> (D21).

Note. D = Donor

When asked about the support received from people in their family environment regarding the act of donation, 32 women (88.9%) responded affirmatively. From the

descriptions of the types of support received, the reports were categorized. Table 3 presents the categories, their frequency and examples that relate behavior considered by interviewees as support for donation.

Table 3 - Types of social support mentioned

Category	Definition	f	Example of reports
Perceived emotional support	Support through verbal encouragement to donate	19	<i>They say that it is beautiful the fact that you're helping other babies, not throwing away the milk, wasting it, just through words that (D7). My mother said (...) "daughter, donate, because you've already been through this and it is horrible for a child to spend the day or night hungry, so donate if you have it to give" (ex-D6).</i>

Continue...

Table 3 - Continuation

Category	Definition	f	Example of reports
Perceived instrumental or operational support	Help through concrete actions in practical aspects related to the donation: to seek containers, to help in expressing	9	<i>My husband helps me, (...)the baby is feeding on the breast then he comes with the glass and holds it there (...) I'm taking from the other breast, then he is holding the glass, then he'll put it in the fridge "oops already filled that glass!" (D25). ... my mother, any glass that she gets she reserved for milk (ex-D9).</i>
Both modes of support: emotional and instrumental		4	<i>(...) when our breasts are hardened they hurt a lot (...) my husband argued with me "you see you have to take the milk, get the milk, give massage because that will make your fever pass" (...) I took them, I massage my breasts and took the milk, but he always said "get the milk", when my son fed on one side he took the glass, put on the other and the milk was filling the glass (ex-D3).</i>
There is no clear expression of support		4	<i>He (the husband of the donor) was not very encouraging, but didn't say don't donate (...), he is neither very encouraging, nor against (...) (D22).</i>

Note: D = donor, ex-D = former donor

When invited to describe the support received from the institutions involved in the donation process (HMB and/or FD), 36.4% (n=12) of respondents answered that they did not feel supported by either of these services. Conversely, 30.3% (n=10) reported having received support from HMB and 21.2% (n=7) from the FD and HMB. Regarding the satisfaction of participants with the support received by people in their social life and by the institutions responsible, 91.7% (n=33) and 58.3% (n=21) reported being satisfied, respectively. In relation to institutional support, ten women (27.8%) reported dissatisfaction and five (13.9%) reported being partially satisfied. The following reports illustrate the satisfaction with the institutional support received;

*I think the girls who come to pick up the milk ... give support, they seem to be close to us ... every time they come they ask how I am, (...) the question of quarantine (...) I can't leave the house much and so whenever they came they would ask how I was doing and if I was okay and they would give some tips, their support was very gratifying (D8).*

One report illustrates the partial level of satisfaction.

*I think they should have more support... more incentive... for people to donate... there are many people who don't have any initiative to donate, so I think if they could be encouraged more... for us to donate, to look for some way, I do not know how, to encourage more people, sometimes people can donate, they want to donate but they don't know how, there is very little information and they end up not donating (D22).*

Concerning dissatisfaction with institutional support, the following report is illustrative.

*No, I do not consider as a support no, I think they have their interests that are in the milk but to support us, they do not support, in my opinion. I am satisfied with the milk donation, but not with their support (D11).*

The participants were unanimous in reporting that they had not received a visit from a BLH worker from where they were donors or are donating their milk, in addition to the visits to collect milk stored by donors. To improve the support of the HMBs and FD for women donors, the participants made a series of suggestions, when instigated by the researcher, categorized in Table 4.

Table 4 - Suggestions from participants for improving institutional assistance to the donors

Category	f	Examples of reports
Greater attention and support of the institution (HMB) to donors	14	<i>I think it would encourage them more if they came to talk, from time to time to visit ... I think a conversation ... would give an incentive for those who had already stopped due to being discouraged (...) (D12).</i>
Information campaigns in the media about milk donation	4	<i>(...) I think it should have more divulgation (...) I think it should also have work... orienting people about donating (...) I think that this shouldn't be something that we have doubts about and have to search, I think it should be information that comes to us. This awareness has not been developed (...) the first awareness that they are doing a lot of, is that of "breastfeed, breastfeed, breastfeed", but the other of "donate if it is necessary, helps" does not have, I believe that if you do not have this it will be increasingly difficult (D3).</i>

Continue...

Table 4 - Continuation

Category	f	Examples of reports
Benefits for donors	3	<i>(...) I saw the news saying that the HMB in a hospital had no milk to donate, look for the numbers... a couple of times I've seen in DF/TV, then (...) to increase this donation they have to encouraging not only with campaigns... with some benefit (...), could already be doing some sort of campaign (...) some sort of benefit for the women (...) a benefit for the woman a benefit to the baby (ex-D5).</i>
Provide guidance on appropriate procedures for collection and storage of milk (at the domicile)	3	<i>(...) I believe that at this time there should be a person from HMB (...) teaching even if the mother already knows how to collect the milk, but she would be there watching the way the mother is collecting the milk, but how that would be, truly, when she's there alone at home between four walls, is she wearing the mask, is she using the cap, has she washed her hands? (Ex-D3).</i>
Material and/or financial aid from government	2	<i>(...) I think there should be more of an incentive such as from the governors, from the government even (...) I think they should help, encouraging, "the mother who donates we help, we contribute with a diaper or we contribute with something" (...) in food (...) some help... financial... this encouragement perhaps, I think they would never say that milk was lacking in the bank, because people would feel encouraged and would donate the milk (D2).</i>
Provision of information about donating during pregnancy/prenatal care	2	<i>(...) that should have more meetings with people, that should have more guidance during the pregnancy period of the person (...) there, inside the hospital, when the person is going to have the baby ... major guidance because if you have better orientation you have more possibility to donate milk (...) more support, more clarification ... (D17).</i>
Visits of the donors to the HMBs to understand the process of pasteurization	2	<i>(...) invite the donors... so they can watch the (...) process of pasteurization of the milk, when they are going to use (...) then we are around... feeling that there... the effect of your donation, it would be very important, I personally would love... being there to see, meeting the children that are getting the milk, the mothers... promoting this meeting (...) would greatly increase our desire to be helping, increasing a lot ... (D27).</i>

Note: D = donor, ex-D = former donor

Faced with the question requesting an evaluation of the experience of donating, 33 participants (91.7%) said that it was positive. Of the 27 participants who were donating milk, 18 (66.7%) stated that they intended to continue donating while they had an excess of milk.

## Discussion

One of the main purposes of this study was to achieve some understanding of the theme of human milk donation, from reports of women donors. Therefore, we included two HMBs considered coverage centers in the region, one of which stood out as a reference in the Federal District.

It can be hypothesized that many potential donors have their intentions frustrated, not being able to put into practice their role as a donor. It is pertinent to suggest that the routine of collection and the relationship between HMBs-donor are being rethought in the light of issues raised by participants. Despite the reports of satisfaction with the institutional support received, suggestions made by them speak of the need to enhance technical support, to receive and to monitor the donors<sup>(12)</sup>, particularly with regard to educational aspects and attention to the woman which may even increase the time of donation and quality of milk collected. In this sense, the use of breast shells emerges – a method that seems to favor

the process of expressing - but that has not been recommended according to technical standards<sup>(11)</sup>.

The process of taking the decision to donate can be influenced by the kind of assistance received, whether it is humanized or not, and the valorization of autonomy, highlighting that adequate communication has a fundamental effect on this process. Another important point, mentioned earlier, that deserves to be discussed in the present study is the method of expressing. It is preferable that the collection of human milk is made by hand expressing manually, an electric or manual pump may also be used, because the quality of human milk collected, that is to be pasteurized, directly depends on the hygienic and sanitary procedures applied during the expressing<sup>(11)</sup>.

In the group of women who reported expressing more than once a day, the method of manual expressing was prevalent, however, half the participants in this group reported using the breast shell to extract their milk. Focusing on the total sample, almost one third of participants said that they make use of the breast shell. This type of method makes the situation worrisome, because the preference for this object is related, according to the interviewees, to practicality, comfort and time saving, eliminating the use of the cap and mask. This characterizes a probable lack of information

about the proper procedures recommended in the scientific literature<sup>(11)</sup>.

It can be suggested, as an educational measure, that information is provided to the donor by the formal support network on the risks that may cause contamination of raw, expressed human milk, especially when collected in breast shells. This could contribute significantly to avoid unnecessary expenses for the HMBs because efforts are undertaken in the course of the stages through which human milk passes before being consumed. It is important that the HMBs receive financial input, as well as human resources, in order to provide time to attend to the demands of the donors. It is suggested that preventive actions are implemented, through continuous monitoring of these women, at least at the time the HMBs makes the first domicile collection.

As for factors that interfere with milk production, it was noted that the aspects most cited by donors, such as fluid intake, type of diet, presence of negative emotions, frequency of expressing and suckling of the baby, are mentioned in the literature<sup>(7,13)</sup> as factors influencing the increase or decrease in milk production, indicating agreement between these responses and the scientific evidence. However, contraceptive use, the mother going out and the return to labor activity could be considered subjective variants that every woman faces in her everyday life. Situations such as lack of available time, physical exhaustion and laziness to express milk are those cited categories that deserve to be further studied, since expressing manually demands a lot of care that takes time and, depending on the tasks of the volunteers, may limit the practice of donation. This explains the fact that many women included in this study stated that they could donate their milk more often, but did not. From this perspective, educational activities could be implemented by HMBs, first, listening to the mothers and then educating them about the difficulties, offering support and guidance for coping with them. This might contribute to closer bonds between the HMBs and the donors, and perhaps reduce the difficulties of the mothers and contribute to increase the frequency of expressing<sup>(13)</sup>.

The precariousness of information for the donor on the processing and fate of the milk donated to the HMB is evident. As a result, it is suggested that, through educational work by the HMBs with the donors of human

milk, the treatment given to raw human milk and the main destinations that will receive the pasteurized milk, are explained. To make discussions with women during the prenatal period, to invite them to visit the HMB while still pregnant, to take them to visit the maternity ward, to show them who the consumers of donated human milk are, and to invite them to observe, at the location, the steps that the raw, donated human milk passes through up to the moment it is consumed, are some suggestions proposed by the women interviewed and could be implemented by the HMBs.

It is believed that the first visit by HMB professionals to the donor's domicile is important to clarify any possible doubts that the donor may have. To offer humanized support, to explain how to identify excess milk, or to suggest that they make a visit to the HMB to be examined by a technically skilled professional can serve as elements that contribute to reduce difficulties, doubts and waivers in the act of donation<sup>(4,7)</sup>. It is considered that the performance of visits by the HMB workers, outside the days on which collections are made, could ease the doubts arising from the practice of donation and ensure that the donated human milk meets the requirements determined by the technical standards. However, for this to occur, it is important that the HMBs receive technical and political support, prioritizing financial and human resources so that these suggestions can be put into practice.

## Conclusion

Considering the results, it was concluded that humanized institutional care, permeated by the actions of encouragement and improvements in the communication process about donation<sup>(12)</sup>, associated with social support from people significant to the donor, could help to strengthen the human milk donation network, facilitating the loyalty of these volunteers should they become pregnant again. Another possibility is that these donors engage in the role of multiplier within their social relationships, disseminating information and values that promote the engagement of new women donors.

Moreover, the improvement of institutional/organizational processes and the training of human resources engaged in this area may increase the quality of the network of milk banks and partner organizations, aiming to improve the responses of these institutions to the demands of interested people, especially women human milk donors.



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