

## Confronting HIV-positive mothers about the act of not breastfeeding\*

### Enfrentamento de puérperas HIV positivas relacionado ao ato de não amamentar

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\* Extracted from a Master's thesis presented to the Health Sciences Graduate Program, State University of Maringá.

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#### ABSTRACT

The objective of this study was to learn the feelings and difficulties of women with the human immunodeficiency virus (HIV) in face of not breastfeeding and the care offered to them. Thirty-six women/mothers with HIV and under follow-up at an STD/Aids outpatient clinic were interviewed. A qualitative study was conducted, using the Collective Subject Discourse method, which was represented by means of five discourses. The most relevant results show that the study participants suffer as a result of not being able to breastfeed their children and the lack of individualized care, especially regarding breast issues. The discourses evidenced beliefs that demystify the symbolism of breastfeeding, which strengthens these women to accept the fact that they cannot breastfeed. In conclusion, the care for this specific group must be individualized so as to assist them, especially, with their emotional conflicts in the non-breastfeeding process, as well as with their breast problems.

**Descriptors:** Acquired Immunodeficiency Syndrome; Breast Feeding; Infectious Disease Transmission, Vertical; Nursing Care; HIV.

#### RESUMO

O objetivo do estudo foi conhecer os sentimentos e as dificuldades de mulheres portadoras do vírus da imunodeficiência adquirida (HIV) frente à não amamentação e à assistência oferecida. Foram entrevistadas 36 mulheres/mães portadoras do HIV com acompanhamento no ambulatório de DST/aids. Estudo qualitativo que utilizou o método do Discurso do Sujeito Coletivo, representado por meio de cinco discursos. Os resultados mais relevantes apontam que as participantes da pesquisa sofrem com a impossibilidade de não amamentar seus filhos e com a falta de um cuidado individualizado, especialmente, relativos aos problemas nas mamas. Crenças foram evidenciadas nos discursos que desmistificam o simbolismo do aleitamento, o que fortalece as puérperas para aceitar o fato de não poderem amamentar. Conclui-se que o cuidado a esse grupo específico deve privilegiar uma assistência individualizada que auxilie, especialmente, nos conflitos emocionais no processo da não amamentação, assim como nos problemas mamários.

**Descritores:** Síndrome de Imunodeficiência Adquirida; Aleitamento Materno; Transmissão Vertical de Doença Infecciosa; Cuidados de Enfermagem; HIV.

## INTRODUCTION

From the initial onset of the epidemic in 1980, until June 2012, Brazil recorded 656,701 cases of acquired immunodeficiency syndrome (AIDS), with an incidence rate of 20.2 cases per 100,000 inhabitants in 2011. With the exception of the Southeast Region, all other regions recorded an increase in incidence in this period, going from 27.1 to 30.9 cases per 100,000 inhabitants in the South Region of Brazil<sup>(1)</sup>.

For both genders, the most frequently affected age group is 25-49-year-olds. The gender ratio (number of cases in men divided by the number of cases in women) in 1989 was 6 men for every 1 woman; 22 years later, this had changed to 1.7 men for every 1 woman. Moreover, women are not only becoming more frequently infected, but are also becoming infected at an earlier age compared to men<sup>(1)</sup>.

The growth of the AIDS epidemic in recent years, especially among women, has drawn attention to a new challenge related to the control of vertical transmission (VT) of human immunodeficiency virus (HIV)<sup>(2)</sup> resulting from increased numbers of HIV infections in pregnant women<sup>(3)</sup>.

Worldwide, VT (mother to child) is the leading cause of pediatric HIV infections (over 90% of cases)<sup>(4)</sup>. However, in countries such as South Africa, where the HIV prevalence is high, there is a paucity of data on the effectiveness of national programs to prevent vertical transmission<sup>(5)</sup>.

To eliminate VT is one of the main priorities today in the field of public health<sup>(6)</sup>. In the United States, routine prenatal testing for HIV, rapid HIV testing during labor, antiretroviral (ARV) therapy of the mother and infant, as well as formula feeding and thus absence of breastfeeding, have been credited as factors responsible for the reduction in VT, although the author of one previous study specified that the country has undergone criticisms related to the guideline of women not breastfeeding<sup>(7)</sup>. Nonetheless, the risk of VT of HIV is reduced to about 0.1% with viral suppression during

childbirth and postpartum, child prophylaxis, and avoidance of breastfeeding<sup>(8)</sup>.

In Brazil, between the years 2003 to 2012, an increase of 26.3% was found in the detection rate in pregnant women; in 2012, the HIV detection rate among pregnant women reached 2.4 cases per 1,000 live births. Of note, the South region was the only region with a higher detection rate than the national data, with a coefficient of 5.8 per 1,000 live births<sup>(3)</sup>.

The contagion from mother to child can occur during pregnancy, at birth, or while breastfeeding<sup>(9)</sup>. It is possible to avoid VT by up to 99% if the diagnosis is fast and the pregnant woman receives treatment with ARV drugs<sup>(9)</sup>.

Transmission of HIV through breastfeeding has been discussed since 1991. There are no questions about the presence of the virus in human milk or about its infective potential, with this mode of transmission being responsible for 14% of VT cases of HIV-1 in pregnant women with chronic infection. The fact that the mother uses ARV does not control the elimination of HIV-1 in her milk<sup>(2,10)</sup>. Thus, the exclusion of breastfeeding by infected women reduces the risk of child contamination by up to 20%<sup>(11)</sup>, and the numbers of HIV infections attributed to nursing mothers not taking ARV drugs range from 129,000 to 194,000 cases worldwide<sup>(4,12)</sup>. However, an African study analyzing breast milk showed no correlation between immunological markers, disease progression, and the composition of breast milk, suggesting that it would still be the best indication for infant feeding<sup>(13)</sup>.

Several studies have reported that HIV-infected women are discouraged from breastfeeding because of the risk of VT of HIV to their children through the breast milk<sup>(14-18)</sup>.

In the United States, although absence of breastfeeding has been a standard recommendation for 30 years in order to avoid the TV of HIV, many infected women have still chosen to breastfeed their children<sup>(7)</sup>. Some authors have reported that the women experience several problems as a result of not being able to provide their children breast milk, including psychological

suffering and breast problems, along with cultural and social problems<sup>(11.19)</sup>.

Considering these scenarios, the purpose of this study was to assess and determine the experiences of women living with HIV when instructed not to breastfeed, including the aspects related to the assistance offered at this time.

## METHODS

This is a qualitative study using the discourse of the collective subject (DCS) as its methodological framework.

The DCS is a way to make a subject speak in first person, but representing a collectivity. This method consists of analyzing the verbal material collected and extracting the methodological figures of each report, including the Key Expressions (KEX) identified by parts of the testimonies, which reveal the essence of the subjects' statements or part thereof; the Central Ideas (CI), which synthesize in the form of a linguistic expression the meaning of the discourses of the KEX; and the Anchor (AC), which inspires a theory of social representation that appears in the testimonies as a belief professed by the author of the discourse in a more generic way. Thus, the grouping of the KEX that originated the CI or AC also originates one or more DCS; these are the four methodological figures that comprise the method. The DCS, which is built and written in the first person singular, becomes a representation of the collectivity<sup>(20)</sup>.

The CI consists of linguistic names or expressions that reveal and describe in a concise and precise manner the meaning present in the testimonies. The CI describes the meaning using the words of the interviewee without an interpretation. The CIs are developed by the researcher after listening to the interviewee's discourse using terms that "strongly" indicate them. A criterion that justifies the CI is needed. From there, the researcher summarizes what has been justified. The CIs serve to group the discourse and there may be more than one CI in the same speech; all of these should be considered separately and included in the categorization process<sup>(21)</sup>.

The final process of the DCS technique is to prepare the synthesis; using a single discourse written in the first person singular, KEX that have CIs or similar ACs are gathered<sup>(21)</sup>.

As the DCSs are being built, the system is put together for interpreting reality by the participants and the relationships they establish in the social context, and their behaviors and practices become highlighted<sup>(21)</sup>.

In this process for building the DCS, the social scenarios are enriched by the Social Representations in which the practices are organized. It is through this collective mirror that the researcher has in his hands a wealth of information that will help him in putting together the health care plan<sup>(21)</sup>.

The study was performed from November 2009 to May 2010 at the STD/AIDS clinic in the city of Maringá, Paraná, Brazil, which provides services for the population of 30 municipalities within the State's 15th Health Region.

During the study period, 78 women were reported as pregnant and living with HIV, and were invited to participate in the study. The final study sample consisted of 36 pregnant women who came to the clinic during the study period and agreed to participate in the survey.

The following guiding question was used to collect data: "Speaking of breastfeeding, what is your feeling of not being able to breastfeed and how were you oriented about this?" An interview was held, which was necessary for the individual to freely express her thinking and to allow the collection of discourses of the subjects for representing the collectivity<sup>(20)</sup>. The interviews were recorded with a digital recorder, transcribed, and erased after their use. In order to keep the participants anonymous, the subjects were identified with the letter M followed by the interview order number. All participants signed a written consent form after receiving information about the research at the beginning of the interviews and after having any questions answered.

The analysis and organization of the data were performed using the *Qualiquantisoft*<sup>®</sup>, and the Discourse of the Collective Subject proposed by Lefèvre and

Lefèvre<sup>(20)</sup>. The research project was approved by the Research Ethics Committee of Maringá State University under decision 537/2009.

## RESULTS

### Characterization of the subjects

Of the 36 women interviewed, most were in the age group between 16 to 41 years, with the average age being 28 years. Most were married or in stable relationships, having finished grade school, of low income, without paid work, brown-colored skin, and professed a religion.

**Table 1:** Understanding the prohibition of breastfeeding. Maringá, PR, Brazil, 2010.

<b>Theme - Understanding the prohibition of breastfeeding</b>
(M03, M04, M11, M16, M17, M18, M20, M23, M26, M34).
<b>Discourse of the Collective Subject</b>
I looked at her and felt happy to have her, and I thought "There are so many mothers who are able to breastfeed but choose not to!" I cannot! So although I am unable to breastfeed her, just the fact that she is here was a joy for me and my husband, and if this is the best way for her to survive, I am thankful. Not being able to breastfeed was not a highly difficult thing for me. Furthermore, I did not have milk. To this day, I have never missed it. I thought about the desire that I had, but no, I did not breastfeed her, and it was not going to hurt her. Sometimes, I thought about it being good for her, but while doing this is good for her, I could be harming her, right? I was sad, you know. However, since it was for the good of the baby, I did not worry about it too much! I had the privilege of my child being healthy, and that is enough for me—that is the most important thing. If you breastfeed, the infant is in danger to get the disease. We get a little upset, but we have to get it in our head. I personally did have a hard time with it, it is all a matter of conscience, you have to work it into your psychological being. If you know you cannot, you cannot. Why suffer when it will only hurt yourself?

**Table 2:** Undoing the maternal symbolism of breastfeeding and accepting the reality, Maringá, PR, Brazil, 2010.

<b>Theme - Undoing the maternal symbolism of breastfeeding and accepting the reality</b>
(M00, M06, M07, M08, M11, M12, M15, M17, M22, M26, M28, M29, M32, M35)
<b>Discourse of the Collective Subject</b>
I was very concerned because I had heard that breast milk is important for the infant and that maternal bonding is established through it. I kept thinking, "How will this all work out then?" I will not be able to breastfeed, and anyone who gives her a bottle she will think is her mother." Every time I was giving her a bottle, I tried to hold her close to me and looked her in the eyes, because that is what is important, right? My baby only got a bottle, but a bottle given with love is worth more than breastfeeding without love. It was great being able to feed my baby even though I used a bottle. I did not miss not breastfeeding and I thanked God, because at least my breasts did not sag early. For me, I think there is no difference between breastfeeding or not; it is all the same. Everyone says the best thing in life is to breastfeed your baby. That is what some say, right? That breastfeeding brings you closer to your child and so on—but I do not know about that. There is even a plus side to the bottle, because if I went out I could leave her with someone and she could still nurse. I could make it for her. So it is good. People said that I did not have the motherly spirit, that I was not going to breastfeed because I was afraid of sagging breasts. I heard a lot of nonsense! They said that an infant that breastfeeds is healthier and that I was depriving my daughter of that.

**Table 3:** Suffering because of already breastfeeding. Maringá, PR, Brazil, 2010.

<b>Theme - Suffering because already breastfed (M00, M21, M24, M30)</b>
<b>Discourse of the Collective Subject</b>
I breastfed my other children, but this infant I cannot breastfeed. This hurts me. It is a difficult situation of not being able to breastfeed. To see your child come out of you, and you cannot give them your milk? I had milk, and I still have today! It's a very sad situation. It is as if I were not a complete mother. I nursed my first baby girl, but him, no. Not that I am depriving him, but to me, it is a strange situation in relation to my first child, having very good milk, breast milk, and not being able to give it to him. For my first child, I was only able to give little, because I did not have much milk, understand? Now, for this one, to be able to at least nurse for a week, you know? I even had postpartum depression because of this. I really could not deal with it. Having breastfed the other for 11 months, seeing the little one there, and I was bursting with milk. It really bothered me! My daughter needed that. This time, I had an overabundance and could not give it. It was something that was really hard for me. I even had to go to a psychologist to work it over in my head because I could not understand it.

**Table 4:** Suffering from the socio-affective aspect of breastfeeding. Maringá, PR, Brazil, 2010.

<b>Theme - Suffering from the socio-affective aspect of breastfeeding</b>
(M2, M3, M4, M6, M9, M10, M13, M14, M17, M18, M21, M24, M27, M29, M30, M32, M34)
<b>Discourse of the Collective Subject</b>
I do not even take him to the public health clinic for his appointment. My husband takes him; that way, I do not have to see all the other mothers nursing their babies. I cannot take watching that! Seeing everyone breastfeeding, and I am the only one not? Wow, I had to leave. I did not even want to see it. The other children cried and their mothers fed them right there. My baby had to wait. I could not stand to see that. Consequently, I asked for a room change, so they put me together with people who had the same problem as I. I confess I was sad, yes. Seeing those mothers breastfeed and I could not. Even more so when everyone asked why I could not. I had to lie. I said I did not have any milk. My milk did not come in. I had to invent a story, each time saying something else; but the truth is, I had so much milk! Then I would say that I had a problem in my blood and could not breastfeed. I suffered a lot with that, there. I spent my postpartum lying. I lied each time someone asked me. I sank into depression because I was so nervous about having to lie! I even said that I did not like breastfeeding. "I do not want to! I do not even like it." People criticized me for not breastfeeding! Being there with your milk going to waste, and not being able to breastfeed; it is really hard! It is weird. Makes you feel sorry for the infant. Anyway, only those who have been through it can understand. It is complicated! It is like you are missing a piece, a part of us as a mother, an obligation that you have and yet you cannot fulfill it for your child. It is like a punishment for him, imagine that!? You have an infant and you cannot breastfeed! Even though you do not breastfeed, your baby has that instinct to suckle. They root around next to us, nestle up to us with their little heads, and we see them and get really sad knowing that we put a child in the world but we cannot breastfeed them. It is a very sad thing.

**Table 5:** Theme: breast care. Maringá, PR, Brazil, 2010.

<b>Theme - Breast care</b>
(M00, M01, M02, M03, M04, M05, M06, M07, M08, M09, M10, M11, M17, M18, M21, M24, M25, M26, M27, M28, M31, M32, M33, M35)
<b>Discourse of the Collective Subject</b>
I was instructed to not breastfeed. They offered me milk for six months. I had a lot of breast milk. My breasts were full and they leaked night and day. It was sad not to be able to breastfeed. They were so full it felt like they were on fire. At the hospital the doctor said that if I gave my breast milk, the baby could get the virus. So they gave me an injection for my milk not to come in. I left the hospital with the whole breasts bound so that they would not be stimulated. After I got home I took off the bandage as I could not stand it squeezing me; I felt suffocated. I had a lot of milk! Not just had, I still have! In the afternoon my breasts become sore, they hurt! They told me to wear something tight over my breasts and apply ice compresses. I put ice packs on my breasts to help me dry my milk. At home, however, my breasts filled with milk and became so hard. I did not bind them because the bandage gave me an allergy. For my first pregnancy, they did not do anything, but for this one they did. In São Paulo, there is a human milk bank that pasteurizes the milk in these cases, but I was already so afraid that I did not use it. They did not give me the medication. I knew I was going to take cabergoline, but they did not have it in stock. They did a lot of ice compresses, and bound me, but I became engorged with milk anyway. It hurt very badly and I almost got to the point of passing out; that was how much pain I was in. I ended up being hospitalized for treatment. The doctor advised me to take very hot water showers and bind my breasts, but it did not help. I also felt really sick taking the pills.

## DISCUSSION

Women with HIV infection in the advanced stage of the disease begin to experience changes in their daily lives because of their diagnosis, such as restrictions of activities around the home and job losses, in addition to losses related to physical impairment, which in turn may create or increase feelings of anxiety and/or depression. Moreover, they often experience a sense of uselessness because of not being able to perform certain normal day-to-day activities<sup>(22)</sup>. Hence, it is essential for health care professionals to understand how these mothers

experience pregnancy in this context, especially regarding the inhibition of lactation.

In recent years, studies have focused on the TV of HIV, breast milk composition in mothers with HIV infection, and ARV therapy during the prenatal care, delivery, and postpartum periods; these are extremely important issues that have all contributed to its reduced incidence worldwide.

However, researches focused on the feelings of mothers related to the fact of not being able to breastfeed are limited, both at the national and international levels.

### Discourse of the Collective Subject

The DCS represented by the theme described in Table 1 depicts the understanding that the women had in relation to being prevented from the act of breastfeeding while the CI being *a way to have a healthy child*. Thus, it can be said that the most effective interventions for this fact to be understood were the orientations given during prenatal care, and unsatisfactory results in the inhibition of breastfeeding were seen when there was no such conduct<sup>(23)</sup>.

The maternal actions in terms of breastfeeding are determined by a personal view and personal experiences, and because of this, the perception and meaning of the act of breastfeeding are further influenced by social, cultural, and family issues<sup>(24)</sup>.

The belief of maternal symbolism is seen somehow as a deconstruction, and these women came to consider bottle-feeding their children as an acceptable experience, and through unique and positive expressions, they reconstructed a new paradigm of care based on love and attention despite having to offer a bottle.

This experience is in contrast to that reported in a previous study conducted in São Paulo, Brazil where the act of not breastfeeding was reportedly considered painful and emotionally draining<sup>(24)</sup>.

On the other hand, for the women in the present study who had already had a breastfeeding experience, to not be able to repeat the act was perceived as negative. As seen in Table 3, the collective discourse of these women describes not breastfeeding as being perceived as denial of the child, leading to psychological and moral suffering, and thereby strengthening the perception of powerlessness and anger; thus, the CI was built around the fact that it was very difficult to not be able to nurse the current baby after having nursed another child. For a woman who has already experienced breastfeeding, it becomes more difficult to accept that, for her new child, she cannot express this act of love, and this is combined with the feeling of helplessness, guilt, and incompetence.

Moreover, it can be observed that not breastfeeding was in certain ways considered proof of forgiveness for these women, a possibility to continue on with life, or a way to feel a part or totally detached from the decision process about their infant's feeding<sup>(24)</sup>. Apart from breastfeeding, other complex issues during the experience of pregnancy while being HIV carriers were not discussed and reported during prenatal care.

An important aspect to be highlighted in this discourse was the suffering of seeing other women breastfeeding and for the HIV infected women not to be able to do the same (Table 4). Experiencing motherhood without the ability to breastfeed and seeing others breastfeeding may generate a feeling of sadness and anguish in these women. Many women do not talk about their diagnosis and are afraid that not breastfeeding will reveal their HIV-positive status to others. Because of this, they also avoid questions or prepare a made-up answer that explains the fact that they are not breastfeeding<sup>(25)</sup>.

In this study, social expectations were found to put these women in embarrassing situations, causing them to try to come up with socially acceptable excuses to justify not breastfeeding<sup>(24)</sup>. Further, in this group of women, the act of not breastfeeding generated feelings of guilt and sadness, and emotional and technical support not only for relieving the pain in their breasts, but also for their psychological well-being, is hence needed<sup>(24,25)</sup>. Therefore, health professionals should be aware of some options to assist these mothers, such as keeping them in private rooms to protect them from the inevitable interrogation by other pregnant women and from the torture of witnessing this so-called "act of love" from other mothers, as well as preparing them for this possibility.

In addition, the suffering that women go through in relation to taking care of their engorged breasts due to the impossibility of breastfeeding is substantial (Table 5). Based on the discourse attitudes, this appears to reflect the lack of knowledge of these women in understanding or carrying out the correct care.

A previous study on HIV-infected pregnant women in Fortaleza, Brazil revealed that the use of drugs and the bandaging of the breasts in these women during the postpartum period was only performed in a limited way, and the women performed empirical practices to relieve their discomfort<sup>(11)</sup>. Bandaging of the breasts, despite being recommended, is viewed by some women as exposing their figure, thereby making them feel excluded and discriminated against, and some consider this a highly punitive action<sup>(24)</sup>.

In this study, the recommendation of bandaging showed varied responses, causing one woman to feel suffocated, as well as allergies, and because of this, these women did not value the practice. A way to avoid these situations would be an ethical engagement by the health services professional, because many women with HIV infection undergo prenatal care, delivery, and postpartum without receiving the attention needed by taking into account the differences between them and other mothers<sup>(19,24)</sup>.

Promoting health is not centered only on preventing VT, but also on developing physical, social, and emotional balances of these women and children.

## CONCLUSION

Currently, the subject of breastfeeding among HIV-positive mothers is still controversial, as shown by the results of the present study. Some countries encourage and guide the suppression of breastfeeding, while others, for financial reasons or unavailability of other forms of feeding, prioritize and encourage its continuation in such

cases. Moreover, ARV therapy during the prenatal care, delivery, and postpartum period, as well as for prophylaxis of the infant after birth, are carried out in some countries that guide mothers to start and continue breastfeeding.

In this study, which reflects the reality of a city in Southern Brazil, the results showed the feelings and difficulties of HIV-positive mothers in terms of not breastfeeding. Our findings provide the option for health professionals who provide care for HIV-positive women during pregnancy, childbirth, and postpartum, to get to know the issues that permeate the inhibition of lactation, since they go much beyond the physiological issues of VT, and our results demonstrate the emotional and physical issues to which these mothers are exposed. The nurse's role in caring for mothers infected with HIV needs to include a reflection on the quality of the care given to these women so as to ensure considerate, effective, and individualized care focused on human rights and not just knowledge of technical issues. This individualized and kind care of health services could help prevent unnecessary emotional harm to these women with regard to them not being able to breastfeed.

Given the problems raised, there is a need for future work that considers the transmission of the HIV virus through breast milk after using new treatments with ARVs, as well as more effective actions for inhibiting lactation. The role of human milk banks is important for ensuring that these mothers are able to offer human breast milk to their infants.

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Received: 05/01/2013.

Accepted: 09/10/2014.

Published: 03/31/2015.