HIV-SEROPOSITIVE WOMEN: UNDERSTANDING, FEELINGS AND EXPERIENCE BEFORE MOTHERHOOD

Mulheres soropositivas para o HIV: compreensão, sentimentos e vivência diante da maternidade

Mujeres seropositivas al VIH: Comprensión, sentimientos y vivencia frente a la maternidad

Original Article

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ABSTRACT

Objective: To understand the feelings of HIV-carrier women, emphasizing the significance of being pregnant, the inability to breastfeed and the living relating the means used to suppress lactation. **Methods:** A descriptive research with qualitative benchmark, conducted in an obstetric referral secondary hospital with 12 HIV-seropositive mothers in the immediate postpartum period in the city of Fortaleza-CE, Brazil, during September and October 2009. Data was collected in the form of semi-structured interview, recorded with prior consent, the statements being then analyzed and grouped by thematic analysis technique. **Results:** The results made it possible to understand the burden of feelings like sadness, surprise, despair and self-prejudice regarding the disclosure of diagnosis and concern for the child's health. The impossibility of breastfeeding led to frustration and denial to hide the disease. **Conclusion:** Women were in affective and social conflict due to uncertainty over the disease transmission to the child and the social stigma of being HIV-positive.

Descriptors: Breastfeeding; HIV/Transmission; Prejudice.

RESUMO

Objetivo*: Compreender os sentimentos das mulheres portadoras de HIV, enfatizando o significado de estarem grávidas, a impossibilidade de amamentarem, bem como a vivência relacionada aos procedimentos utilizados para inibição da lactação.* **Métodos***: Pesquisa descritiva, com referencial qualitativo, realizada em um hospital de nível secundário em referência obstétrica, com 12 mães soropositivas, no período de puerpério imediato, na cidade de Fortaleza-CE, Brasil, nos meses de setembro e outubro de 2009. Os dados foram coletados sob a forma de entrevista semiestruturada, gravada pós-consentimento, cujos depoimentos analisados e agrupados receberam análise temática.* **Resultados***: Os resultados possibilitaram compreender a sobrecarga de sentimentos como tristeza, surpresa, desespero e autopreconceito relativos à descoberta do diagnóstico e à preocupação com a saúde do filho. A impossibilidade de amamentação foi causa de frustração e negação para se esconder a doença.* **Conclusão:** *As mulheres estavam em conflito afetivo e social devido à incerteza sobre a transmissão da doença para o filho e ao estigma social de serem portadoras do vírus.*

Descritores: *Aleitamento Materno; HIV/Transmissão; Preconceito.*

RESUMEN

Objetivo: *Comprender los sentimientos de las mujeres portadoras de VIH, identificando el significado del hecho de estar embarazadas, la imposibilidad de amamantar así como la vivencia relacionada a los procedimientos utilizados para inhibir la lactancia.* **Métodos:** *Investigación descriptiva con referencial cualitativo realizada en un hospital de nivel secundario en referencia obstétrica, con 12 madres seropositivas en el periodo del puerperio inmediato en la ciudad de Fortaleza-CE, Brasil, en los meses de septiembre y octubre de 2009. Los datos fueron recogidos a través de entrevista semi-estructurada, grabada pos-consentimiento cuyos relatos fueron analizados, agrupados y recibieron el análisis temático.*

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Resultados: *Los resultados posibilitaron la comprensión de la sobrecarga de sentimientos como tristeza, sorpresa, desespero y el auto-perjuicio respecto el diagnóstico y a la preocupación con la salud del hijo. La imposibilidad de amamantar fue causa de frustración y negación para ocultar la enfermedad.* **Conclusión:** *Las mujeres estaban en conflicto afectivo y social debido la incertidumbre de la transmisión de la enfermedad para el hijo y el estigma social de ser portadora del virus.*

Descriptores: *Lactancia Materna; VIH; Perjuicio.*

INTRODUCTION

As a consequence of the heterosexual component of HIV transmission, there is an increasing occurrence of HIV infection/AIDS among women of reproductive age, which marks the feminization process and the resulting vertical transmission of the virus, making children a more vulnerable group to infection. The estimated number of people living with HIV/AIDS worldwide is around 33.2 million. In Brazil, they are estimated to be 630,000 people[1-3].

Concerning the transmission between genders, there has been a significant change from the beginning of the pandemic to the present day. In Ceará, the male/female ratio was 12 in the beginning of the epidemic in 1987. By October 2010, a rate of 2.5 men for each woman was found[4].

From the year 2000 on, there has been an increase in knowledge of HIV cases throughout the country, both in pregnant women and vertical transmission cases, since notification became compulsory. In Ceará, 1,210 HIV-positive pregnant women and 154 cases of vertical transmission have been confirmed between 1996 and 2009[4].

Facing the increasing number of reported cases and the importance of quality service being provided to the customer in the self-care process, arose an imminent need to move and empower professionals to handle situations relative to the infection or the disease itself[5].

One of the tools used by health professionals as a strategy to assist customers seeking support and guidance on the anti-HIV testing was the counseling. This must be incorporated into the routines of the services offered by the health system and be developed collectively and/or individually[6]. This tool provides an understanding of the client's subjectivity and representations about his health, giving him the opportunity to reflect and decide on the preventive measures, regardless of his HIV status[7].

For women, motherhood is regarded as a sign of life and hope, however, in front of so much conflict emerged from seropositive status, it starts to be seen as a disastrous event, for being linked to a rapidly progressive and devastating disease, with uncertain prognosis. Therefore, the woman in this period needs to receive emotional support to deal with the new condition of life, in order to prevent and reduce the vertical transmission[8].

Vertical transmission is the route of transmission from mother to child. The virus can be transmitted during pregnancy, during labor, in the moment of childbirth and during puerperium, through breast milk. Breastfeeding accounts for 7% to 22% additional risk of transmission. The probability of transmission without the use of AZT is about 25.5%, but in pregnant women and their children who have used the therapeutic plan, the probability decreases to 8.3%. Early detection of HIV-positive women in prenatal care, with introduction of AZT to the pregnant woman from the 14th week on, after clinical and laboratory evaluation, as well as for the mother and all newborns exposed to HIV, for a six-week period, are strategies that aim to reduce the vertical transmission to less than 2%[5,9].

The experience of breastfeeding is a milestone for the woman in her mother's condition; however, in the face of HIV infection, it configures itself as a threat to her child's health, changing concepts culturally constructed during life. Based on that, the women were asked the following questions: What does it mean, for a woman, the discovery of being HIV-positive and pregnant? What does the inability to breastfeed your child represent?

From this perspective, this study becomes relevant, as it enables the recognition of biological, social and emotional difficulties that women with HIV need to confront to ensure their place in society, and especially their role as mothers.

Thus, this research aims to understand the feelings of women with HIV, emphasizing the significance of being pregnant and unable to breastfeed, as well as the experience relating the procedures used for the inhibition of lactation.

METHODS

Descriptive research of a qualitative nature, as it enables the understanding of subjective aspects of the social phenomenon that involves the experience of motherhood after HIV diagnosis. Apprehending the meanings attributed to this situation requires an understanding of the subjectivity of the action expressed through language, scaled by mechanisms that go beyond language, often determined by sociocultural and ideological aspects[10].

The study was performed in the city of Fortaleza, capital of the Ceará State, northeastern Brazil, which features a great social inequality and counts on tourism as one of its main sources of income. The city boasts strong touristic attractions and receives around 2 million visitors per year[11].

The research was carried out at a clinic for sexually transmitted diseases of a secondary level referral hospital, in the months of September and October 2009. The participants were 12 HIV-positive women in the postpartum period, selected according to the following criteria: to have given birth to a child at least six months prior to the survey and have minimum age of 18 years. Exclusion criterion was the presence of mental illness that might interfere in the participant's consent, as well as in data collection. The study used saturation of the findings as the criterion to define the period of data collection.

The respondents agreed to participate in the survey, by signing the Free Informed Consent Form. Interviews were recorded, using a semi-structured script containing identification, socioeconomic and demographic data such as age, education, marital status, occupation, income and four guiding questions: 1- How did you feel when you discovered being infected by HIV? 2- How did you feel when you discovered being pregnant as a HIV-carrier? 3- What was your reaction to the information that you could not breastfeed? 4- How did you feel in relation to the procedure of compressive bandaging meant to avoid breastfeeding?

In addition to the interview, a simple observation was carried out for the apprehension of non-verbal aspects of behavior at the time of interview, recording the findings in a field diary.

For the analysis of the statements, literal transcription of speech, exhaustive reading and rereading were performed, using content analysis[12]. The basic steps that compose the content analysis are summarized in: pre-analysis, material exploration, and inference and understanding[13,14].

Pre-analysis consists of extracting the nuclei of records obtained during successive and careful reading, favoring an ordering of the material by compliance with the exhaustiveness, homogeneity and relevance rules. The exploration stage is performed by clipping from the choice of units of meaning properly listed, mapping, classifying, coding and adding the material into categories or thematic areas of significance. And the last phase, inference and understanding, allows going beyond the message issued, seizing the essentiality of 'speech'[13,14].

Data interpretation was based on the conceptual frameworks about seropositive status and feelings unveiled after the discovery of such a condition associated with motherhood. The meanings seized in the reports were also grounded in social and affective aspects attributed by women to the breastfeeding inability. For the understanding of meanings, feelings and experiences of HIV-positive women facing motherhood, the following themes were identified: feelings experienced by the discovery of seropositive status; feelings related to being pregnant and living with HIV, meaning of the impossibility of breastfeeding, and experience with procedures for inhibition of lactation.

The study followed the ethical precepts, in accordance with Resolution 196/96[15], and has been approved by the Ethics Committee in Research of UNIFOR, under opinion number 283/2009, in compliance with the basic principles of bioethics: autonomy, beneficence, non-maleficence and justice, among others. For the guarantee of anonymity, the interviewees were identified by the letter "P" from postpartum, followed by the number of the interview (1-12).

RESULTS AND DISCUSSION

Characterization of the participants

The study group consisted of 12 HIV-infected postpartum women, with mean age of 26.3 years, ranging between 19 and 38 years. Regarding education, five had incomplete primary education, one had complete primary education and six had complete secondary level. It was noticed that 50% of women were literate and 50% had complete secondary level; however, despite this level of educational, there is a deficiency observed in the acquisition of knowledge and information about health and how to take care of themselves.

With regard to marital status, three women were married, four were living in a stable union and five were single. Most did not currently live with the partners who transmitted them the virus. Family income ranged from R$200.00 to R$930.00. Regarding occupation, only three developed profitable activities and the others were housewives.

The data obtained allowed to identify that the socioeconomic status did not interfere or contributed to awaken the women regarding their real health status, as well as did not prepare them to deal with social issues arising from the new serological status. When confronted to the diagnosis and realizing that has been contaminated by her partner, for example, the woman feels betrayed and often breaks up the relationship, moved by revolt against the one who, in her opinion, was responsible for her illness.

In the following section, the themes constructed from the testimony are unveiled.

Feelings experienced with the discovery of HIV-seropositive status

This theme refers to the understanding of the feelings experienced by women when they discover to be seropositive. They reported feeling sadness because the disease has no cure, bringing insecurity about the future. Associated with that, came the depression and anxiety, due

to the sudden discovery, without any previous preparation. These meanings were perceived from the nuclei of meanings expressed in the following reports:

> *I felt terrible, I was devastated, very sad [....]. I didn't want to accept, did not believe it. (P11)*
>
> *[....] I was very sad. I was very scared to pass it to my son. (P3)*
>
> *I suffered a lot due to my daughter. Took all the medicine not to pass the virus to her. I felt sadness and a little bit of every bad thing. (P6)*
>
> *Gosh! [...] One never waits for such bad news! It completely changes our life. (P1)*
>
> *[...] I was astonished. I couldn't feel the ground, I couldn't believe... I went home, looked at the test many times until I could realize it was true. It's like living wasn't worth anymore, 'cause I had plans and now they're destroyed. (P5)*

The understanding of postpartum women with HIV was based on a variety of feelings: sadness, horror, surprise, disbelief and depression, all of them mixed with the fear of the unknown. It was noticed that the moment of diagnosis is the most striking and critical, because many feelings arise so conflicting. Under this circumstance, all plans are deconstructed and the woman finds herself helpless in this new reality.

Accordingly, other authors[16-18] report in their studies that the fear of the unknown leads to escape, to not recognize the situation. Denial is one of the main mechanisms of psychological defense before an unpleasant and undesired situation. Diagnosis causes a strong impact in people's lives and an experience of high emotional intensity. The concept of vulnerability supervenes issues related to inequality and gender violence, which make HIV/Aids epidemics to spread faster mainly among the women.

Other studies[19,20] have also corroborated this research by demonstrating that the HIV-positive serologic *status* in the woman experiencing maternity develops a feeling expressed as suffering, uncertainty towards the disease in the future, fear of stigma, self-blame and extreme emotional distress, determined by the sense of despair.

Some women showed feelings of revolt in the interview, for feeling betrayed by the former partner, and blame, for feeling responsible for transmission to new partners. They revealed their feelings when stated that:

> *My first husband was a carrier of the virus, he was under treatment but he never told me about it. He used to say he'd seen a doctor, but nothing was wrong. When I came to know, I got depressed, I cried a lot. I looked at my present husband and felt guilty. Nobody knows about it, just me and my husband. (P8)*
>
> *At that moment, I was so angry for being betrayed, because my former husband knew he was a carrier and didn't warn me at all. (P9)*

From the results of the present study, it is evidenced a feeling of revolt against the former partner's disrespect, frequently leading to separation when the women realizes the partner was intentionally doing harm to her, exposing her to situations of vulnerability. In agreement with this research, a study[16] demonstrated that most of the women are infected by the stable partner.

Given this findings, it becomes clear that, even if free of symptoms, after the disclosure of being HIV-positive those women share their lives with the ghost of the disease and the guilt, besides the imminent fear of being surprised by death.

Feelings related to being pregnant and living with HIV

This theme reveals the feelings experienced by HIV-positive women in puerperium towards their children's health. The feelings recorded herein were represented by concern about the child's health, specially in regard to the transmission and prognosis of the disease. That can be seen in these statements:

> *I only thought about him, just wanted his health. To me, it didn't matter whatever happened. (P1)*
>
> *I wasn't thinking of me, nor thinking of my health. All I thought about was my son, I was scared I could pass it to him. (P3)*
>
> *I used to wear a condom, but I sometimes didn't wear it, my bad! I was in fear, I knew he could die from the same disease I had. (P12)*

They emphasize the protection to their newborn. The fear of infecting the kids, as well as the ignorance about their future HIV serologic status, were represented with feelings of guilt and fear, for feeling indirectly responsible for the illness or death of the child. Lack of information on the disease often leads to an exacerbated interpretation of the disease. This reflects the ignorance of the possibilities for effective prevention of vertical transmission, existing from the advances in antiretroviral therapy[21].

This type of interpretation was reiterated in another study[22], demonstrating that, within the context of HIV and pregnancy, a major concern of women with their lifetime remains relative to surveillance of growth and development of children, that is, to the execution of the maternal role.

Other studies corroborate the findings in the present research when highlighting among the women, the overprotection, the concern about the son's health and the fear of transmitting the virus to the child, relegating

the maintenance of her own health to a lower level of priority[21,23]; besides the various feelings, such as guilt and impotence[24].

In the statements of women investigated in this research, who realized being HIV-positive during pregnancy, there was a sensation of fear and loss, providing a deep suffering with strong emotional and social impact. Comparing to feelings of the woman who finds her seropositive status regardless of pregnancy, the situation where that status is discovered during pregnancy exceeds with so much suffering and much stronger an emotional impact.

In a woman's life, the desire to have a child results from the need to feel complete, the desire to experience the power and productivity of your body. Having a child means the characterization of being a woman and, within a specific context of HIV-positive status, the realization of this desire is feared. From there on, different negative feelings permeate the reality of these women[25].

According to other studies[24,26], HIV-positive mothers fear the vertical transmission, what causes great emotional distress. The condition of being a mother with HIV is seen by these women as an extra challenge for her maternal role, as obstacles to be faced are much more difficult, given that, in addition to their health care, there is a concern with the son's health, which makes them feel 'supermoms'.

This study also observed the representation of these feelings by the superficial knowledge of the disease and fear of death. For some women, the feelings of death, depression, madness, despair and anger were shown vehemently.

> *It's bad, it's upsetting. I wish I'd die. (P2)*
>
> *Despair. Because I thought of the baby, what would it be of him? If I had transmitted it to him, what would it be like? I thought a lot about death. If I eventually die, who would stay? Who would look after him? (P4)*
>
> *I got depressed, almost crazy. Not really for me, but for the kid. Why did God give a child in the condition I'm in? (P5)*

It was evidenced[22] that the women in this serologic condition express uncertainties towards their own health, which brings closer the fear of death, persistent in all their thoughts and feelings.

The situation exposed through the statements in the present research revealed that, even for the women who aspired a 'miracle' regarding their child's serologic status, the main motivations were the maintenance of health and life, as hope for the experience of a healthy maternity.

Meaning of the impossibility of breastfeeding and experience with procedures for inhibition of lactation

The representation of maternity is closely linked to the act of breastfeeding. Even in the face of the slight mothers' knowledge about the benefits of breastfeeding, they do understand the importance of this practice for the health of their children. The reports below show their position about it:

> *I was very sad because the mother's wish is to breastfeed. We know that by doing that, we're taking good care and we feel that the child misses that milk, but we can't give it to him. (P3)*
>
> *I was sad that I couldn't give him the milk from my breast. A sentimental thing, for not being able to hold the son in my breast, 'cause that is something that would be good for him. (P7)*

This study's result revealed that the understanding of the woman in puerperium was also based on the negative meaning of the impossibility to breastfeed. The act of breastfeeding is considered by these women as a symbol of maternity. There was an ambiguity of feelings experienced by the women/mothers under the sad obligation to not breastfeed, a duty that permeates their social role and is confronted with the knowledge of the numerous advantages of breastfeeding for the health of babies.

It was found in this study, as in another study[27], that the impossibility of breastfeeding, due to the risk posed, causes great suffering to mothers with HIV, which confessed their desire to breastfeed, however, despite of accepting the abstinence as a benefit condition to the child.

The importance of breastfeeding is embedded into society, being common the explicit charge of this act from someone who has become a mother[28]. The literature[29] reveals that breastfeeding is an essential component for the mother role and, when dissociated, brings feelings of mutilation of the social role of being a mother.

Such conception meant a feeling of self-prejudice expressed by the impossibility of breastfeeding. Due to the intuitive speculation of the society, the mother finds herself in the dilemma of preserving her identity against the possible discrimination from her social group, evidenced by the following reports:

> *When people asked me, I used to say: 'No, she doesn't want my milk' or 'I don't have milk' or 'I ran out of milk' or 'she is being fed with other milk'. (P5)*
>
> *I look at him and feel sorry. I see other children feeding from their mom and feel like that... However, if it is in sake of his health, I find comfort. People asked me why I am not breastfeeding and I make up some excuse. (P6)*
>
> *When people asked me, I used to say that I had taken too much anti-inflammatory drugs and my milk was over, but they were still curious, they didn't buy it. (P7)*

Given this impossibility, despite knowing it is meant for the child's well-being, it was noticed that most women

in the study reported feeling frustration and sadness. Within this context, they reported unpleasant and embarrassing situations experienced before charges from the society.

The second conception attributed to the impossibility of breastfeeding was marked by an uneasiness when forced to hide their condition, fearing discrimination and prejudice against their serological status. The manner found to escape the social requirements was the omission of the real reasons for the abstinence from breastfeeding.

An investigation carried out with a group of HIV-positive women pointed out that the fact of not breastfeeding could, on one hand, denounce the serological status of women and, on the other, represent the noncompliance with their social role as expected by society[30].

Within the understanding of the impossibility of breastfeeding, women were about procedures employed by health services to inhibit that practice. It was perceived that the breast bandaging procedure was not used routinely. This situation was perceived by the following reports:

> *I didn't do bandaging in breast. What is it? They just told me my breast was dry. (P3)*
>
> *They didn't do bandaging. I don't know what it is. I don't even have a clue what it is. I took some pills in the maternity ward to make my milk dry. (P4)*
>
> *That was not done, I just took some pills to dry the milk. (P5)*
>
> *I didn't do bandaging. I took two pills after leaving the delivery room. (P7)*

The majority of women (n = 10) interviewed in this study did not perform breast bandaging and reported not knowing this inhibitory technique, stating they have made use of drugs to inhibit lactation. Both women who reported having the procedure done claimed painful sensations, physical discomfort, embarrassment, discrimination, suffocation and uneasiness.

This corroborates a previous research[31] that defined the use of the procedure as punishing and painful, with a high level of rejection and refusal.

Currently, no doubts remain about the presence of the HIV vírus in the breast milk and its infectant potential, responsible for 14% of the HIV-1 vertical transmission cases, when the pregnant woman is in the cronic infection stage. Besides, the use of antiretroviral drugs by the mother does not control the elimination of HIV-1 through the milk[9].

In accordance with new recommendations of the Ministry of Health[9] for prophylaxis of vertical transmission in the puerperium, in relation to the suspension of breastfeeding and lactation inhibition, the first choice is on the use of pharmacological inhibitors immediately after birth (Cabergoline 1.0 mg orally), leaving the breast bandaging as a second option. This recommendation is due to the high frequency of breast abscesses and the high rates of inhibition failure in warm climates.

All these recommendations should be incorporated by the healthcare services aiming to assist women with HIV, from the very knowledge of their HIV status until the postpartum period, making it imperative the interdisciplinary support of the health team, with emphasis on health education. Health education is required to the human being because he is an unfinished being[32]. It is the responsibility of health professionals to share knowledge with women so they can empower self-care, becoming able to take proper care of themselves and their newborn child at home, protecting them from the infection.

To achieve an affective education, capacitation and involvement of the health professionals are required, seeking a better quality of life for the HIV-positive mothers and their babies. The professionals need to be qualified to inform these women in an effective way about the barriers that may arise, acting in valorization of life as a transforming agent, promoting the humanization of assistance to postpartum women[33,34].

In an attempt to foster the proper organization of the service, the management activity is essential, aiming to maintain the flowcharts and work routines that ensure suitable conditions of approach to HIV carriers, especially to pregnant and postpartum women. Professionals' technical training and adequate technical management of labor are important, for these can contribute to enhancing the effectiveness of activities aimed at the organization of services in order to improve the quality of care and thus contribute to the reduction of HIV vertical transmission and control of HIV/Aids[35].

The socialization of the impossibility of breastfeeding has shown that it involves ambivalent feelings. Women sometimes feel castrated by denying their son the richest flavor given to maternity, that is, breastfeeding; they sometimes see their unconditional love motivate them to overcome and cooperate with treatment. The statements also allow to make a diagnosis which expresses the professionals' limited effectiveness in recognizing the mother's disquietude and in fostering education strategies that could calm their anxieties and inform them of recent possibilities regarding increased lifetime provided by the retroviral drugs.

Although it is not the goal of this research to cause generalizations, it was perceivable by the end of the study that the number of participants was limited to a better understanding of breast bandaging. Another fact observed

during the data collection was the unavailability of assistant nurses to contribute to the generation of scientific research.

FINAL CONSIDERATIONS

It can be considered that the seropositive status activates fears and raises deep marks on the woman, especially when she is expecting a child. The participants were apparently healthy and showed no evident symptoms, however, the concreteness of the diagnosis triggered numerous personal, social, and family challenges.

The concern reported by the interviewed mothers referred to avoid transmitting the virus to their child. Therefore, they fulfilled all prescribed prophylactic measures, especially abstinence from breastfeeding, despite their desire to breastfeed. From this reality, they reported facing divergent and conflicting situations generated by the social charges, representing singular moments in their lives that leave them emotionally weakened.

The complexity of the results points to the importance of listening to the feelings of the seropositive women, considering that it is certainly the best strategy that health care professional, including nurses, can use to understand them and help them face the situation they are in, in addition to targeting and conducting actions aimed at the mother's and child's welfare.

It is the health professionals' place to provide welcoming care to HIV-positive women and an emphatic argument to justify before the society the fact that they are not breastfeeding, ensuring the confidentiality of their HIV status.

Yet another strategy stands out: the formation of educational groups, among carriers of the virus, on the HIV and the impossibility of breastfeeding, aiming to prepare them to deal with conflicting situations associated with not breastfeeding and the exchange of experiences among them. It is essential that these are conducted by a multi and interprofessional team.

Given the findings in this study, it is recommended greater attention by the managers and health workers to HIV positive pregnant and postpartum women, in order to rethink their practice and jointly propose an organization that ensures the proper functioning of the labor process towards the achievement of the desired results.

After those questions, it may be understood that this research provides comprehension of the subjective aspects experienced by women with HIV, favoring adherence to non-breastfeeding, which will directly contribute to the reduction of vertical transmission.

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