#### ORIGINAL ARTICLE

# PERCEPTIONS OF PREGNANT WOMEN LIVING WITH HIV ABOUT BREASTFEEDING

Janainna Ferreira e Silva<sup>1</sup>; Ezequiel Almeida Barros<sup>2</sup>; Milena da Silva Soares<sup>3</sup> Romila Martins de Moura Stabnow Santos<sup>4</sup>; Ana Cristina Pereira de Jesus Costa<sup>5</sup> Livia Maia Pascoal<sup>6</sup>; Marcelino Santos Neto<sup>7</sup>; Floriacy Stabnow Santos<sup>8</sup>

**Highlights:** (1). HIV-positive pregnant women experience motherhood with the impossibility of breastfeeding. (2). HIV-positive pregnant women are hopeful that their child can live without the disease. (3). The impossibility of breastfeeding can lead to fear, frustration and anguish.

## PRE-PROOF

(as accepted)

This is a preliminary and unedited version of a manuscript that has been accepted for publication in Contexto & Saúde. As a service to our readers, we are providing this initial version of the manuscript as accepted. The article will still undergo review, formatting and approval by the authors before being published in its final form.

## http://dx.doi.org/10.21527/2176-7114.2024.48.14273

#### How to cite:

Ferreira e Silva J, Barros EA, Soares M de S, Santos RM de S, Costa ACP de J, Pascoal LM. et al. Perceptions of pregnant women living with HIV about breastfeeding. Rev. Contexto & Saúde, 2024;24(48): e14273

<sup>&</sup>lt;sup>1</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. https://orcid.org/0000-0002-0044-6606

<sup>&</sup>lt;sup>2</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. https://orcid.org/0000-0003-4825-7449

<sup>&</sup>lt;sup>3</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. https://orcid.org/0000-0001-6814-6995

<sup>&</sup>lt;sup>4</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. https://orcid.org/0000-0003-0407-0412

<sup>&</sup>lt;sup>5</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. http://orcid.org/0000-0001-7757-8183

<sup>&</sup>lt;sup>6</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. http://orcid.org/0000-0001-7757-8183

<sup>&</sup>lt;sup>7</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. https://orcid.org/0000-0002-6105-1886

<sup>&</sup>lt;sup>8</sup> Federal University of Maranhão (UFMA). Imperatriz/MA, Brazil. <a href="http://orcid.org/0000-0001-7840-7642">http://orcid.org/0000-0001-7840-7642</a>

## **ABSTRACT**

The objective of this study was to know the perception of pregnant women living with HIV about breastfeeding. This is a cross-sectional qualitative study carried out in a reference maternity hospital in Imperatriz (MA) between August 2020 and July 2021 with 28 pregnant women through recorded and transcribed individual interviews. Data analysis was based on Minayo's thematic content analysis. Initially, we sought to identify meanings about Exclusive Breastfeeding based on the Theory of Social Representations to know the ways of coping with the reality of women who are not able to breastfeed. Regarding the feelings expressed, it was noticed that most women reported the feeling of sadness, anguish and fear, mainly because they recognized the importance of breast milk for the baby and believed that the moment of feeding the baby produced a bond between mother and child. Some women reported that they see this impossibility in a positive way because of previous negative experiences with breastfeeding. The interviewees confirmed that they had been instructed by health professionals about the impossibility of breastfeeding. This study brings a reflection on the social representations of HIV-positive pregnant women regarding motherhood and the impossibility of breastfeeding.

**Keywords:** HIV seropositivity. Pregnancy. Breastfeeding. Nursing.

## INTRODUCTION

The increasing number of HIV/AIDS cases among women of childbearing age has been a matter of concern. In Brazil, in 2020, 32,701 new cases of HIV were diagnosed, and the sex ratio was 28 infected men for every 10 women. This is a disturbing figure because about 7,814 of these cases occurred among pregnant women<sup>1</sup>, a population that suffered an increase in the detection rate in the last decade, what can be related to prenatal screening. Furthermore, between 2000 and June 2021, 141.02 cases of the cases reported in Brazil were pregnant women, of whom 37.4% lived in the Southeast, 29.5% in the South, 18.3% in the Northeast, 8.9% in the North and 5.9% in the Midwest<sup>1</sup>.

The Ministry of Health points out that the HIV detection rate in pregnant women in Brazil has been showing an increasing trend in recent years, which draws attention to a new challenge regarding the control of vertical transmission (VT) of HIV<sup>2</sup>. The risk of VT during pregnancy is about 35%, during delivery 65%, and during breastfeeding 22%; it is, thus, fundamental to instruct women about the importance of adherence to Antiretroviral Therapy (ART) and prenatal follow-up<sup>3</sup>.

Because some women cannot breastfeed their children, they may suffer additional conflicts, such as psychological distress, fear, stigma and social discrimination<sup>4</sup>. It is important to know how these women face this situation of not being able to breastfeed their children in order to collaborate to improve health care in the context of this reality.

According to the HIV Clinical Monitoring Report, the 90-90-90 target proposed for the year 2020 calls for 90% of the total infected people in the country being diagnosed, 90% of people living with HIV (PLHIV) who know their status being on ART, and 90% of PLHIV on ART achieving suppression of the Viral Load (VL). By 2019, the percentages were 89% of diagnoses, 65% of PLHIV on ART, and 65% with suppressed VL<sup>5</sup>.

In this sense, the targets are associated, respectively, with increased access to health services and, consequently, diagnosis, access to ART drugs, and acceptance and adherence to therapy, in addition to the quality of care offered to HIV patients<sup>6</sup>.

When pregnancies are planned, adequate prenatal care is provided, interventions are properly performed at delivery, and there is no breastfeeding, the risk of vertical transmission of HIV is reduced to less than 2%. However, if this planning and follow-up are not adequate, this risk increases to 15% to 45%<sup>7</sup>.

Breastfeeding, when not contraindicated, represents the ideal and complete food for infants and exclusive breastfeeding should take place until six months of age of the baby because it brings benefits to the mother and favors the maternal-infant bond<sup>8</sup>. The impossibility of breastfeeding, therefore, often generates feelings of anguish and fear in women living with HIV (WLHIV)<sup>5</sup>.

The feeding of children of of MLHIV until the sixth month of age must be done usig supplementation with infant milk formula, whose free distribution is guaranteed by the Unified Health System (SUS) in Brazil through Ordinance GM/MS n. 2.313 of

December 19, 2002. Moreover, if the disease is diagnosed after exposure to breast milk, breastfeeding must be immediately suspended and the child needs to be followed-up<sup>9</sup>.

In view of the specificities that the HIV/AIDS epidemic presents among the different population segments, it is necessary to incorporate coping strategies appropriate to the situational context in which this population is inserted <sup>10</sup>. Therefore, it is essential to know the perceptions and coping strategies of pregnant women with HIV in order to assist in the construction of actions to effectively improve the quality of care for these women.

In view of the importance of knowing the representational universe of women with HIV, their desires, fears, difficulties, attitudes, and feelings built in the face of the impossibility of breastfeeding, since motherhood and breastfeeding are intertwined as a social role<sup>11</sup>, the present study aimed to know the perception of pregnant women living with HIV about breastfeeding.

# MATERIALS AND METHODS

Cross-sectional qualitative study carried out in a reference maternity hospital in the area of care for high-risk pregnant women. It is a Specialized Care Service (SCS) of the Regional Maternal and Child Hospital (HRMI) of Imperatriz (MA), a reference maternity hospital in the macro-region that provides care to HIV-positive women. The study was conducted between August 2020 and July 2021.

The study included women of any age, non-drug users, in any gestational period, diagnosed with HIV, attended at the SAE during the study period, coming from any city. The exclusion criteria were women who had cognitive or language problems that could hinder the communication with the researchers. The study included 28 pregnant women who agreed to participate in the study.

Data collection took place at the hospital, after prenatal consultations, when the women were invited to participate in the study. The interviews took place in a private room and were audio recorded on a cell phone with the authorization of the participants. The interview was conducted by a single researcher.

The interview took place with the help of the following guiding questions: How did you learn that you had HIV and how was it to receive this diagnosis? Do you know what Exclusive Breastfeeding is and for how long the child should be breastfed? Have

you breastfed and for how long? Were you instructed not to breastfeed during this pregnancy? What feelings did you have when you knew you would not be able to breastfeed? Do you know why you will not be able to breastfeed? Have you ever breastfed or wished to breastfeed? Do you use medications to treat HIV? For how long have you used them? Which are the medications?

The interviewees' medical records were also consulted to collect sociodemographic data and information on the medications used by the women. The description of the results includes a general characterization of the speeches and also quotations of the main speeches collected.

Data analysis was based on the content analysis proposed by Minayo<sup>12</sup> divided into three stages: ordering, classification and analysis. The analysis allowed the identification of four thematic categories: The impact of the discovery of HIV seropositivity in the context of pregnancy; History of previous breastfeeding and knowledge about breastfeeding; The impossibility of breastfeeding and coping with the situation; HIV treatment.

The theoretical framework of this study was the Theory of Social Representations, based on the idea that in any society individuals share representations, opinions, beliefs, values, which are external to these individuals, and the understanding of the process of knowledge construction is common sense, making it possible to conclude that the study of a representation presupposes the investigation of what individuals think, why they think this way, and how they think 13. In other words, it is an indispensable phenomenon to explain the cognitive processes and social interactions that guide and organize the attitudes and the communications 14. Therefore, we sought to identify the meanings attributed to Exclusive Breastfeeding based on the Theory of Social Representations to know the ways of coping with the reality of women who are not able to breastfeed.

The study complied with the ethical precepts and was approved by the Ethics and Research Committee of the Federal University of Maranhão under Opinion n. 2.496.047. To respect the right to anonymity, the pregnant women are identified with the letter P (pregnant woman) and listed from 01 to 28.

# **RESULTS**

The study included 28 pregnant women living with HIV aged between 18 and 40 years, of whom 19 were brown (67.8%), 8 black (28.6%) and 1 white (3.6%), 16 (57.2%) were married or lived in a stable union, 12 (42.8%) were single, 1 (3.6%) was illiterate, 5 (17.8%) had up to 8 years of schooling and 22 (78.6%) had up to 12 years of schooling.

Regarding the economic situation, the majority (23: 82.1%) did not have own income and said to be housewives; 22 (78.6%) were multiparous; 7 (25.0%) had experienced a previous abortion; 6 (21.4%) lived in Imperatriz; and 22 (78.6%) lived in in surrounding municipalities.

Regarding the medications used, 19 (68.2%) used Tenofovir + Lamivudine (2 in 1) and Raltegravir; 1 (3.5%) used Tenofovir + Lamivudine (2 in 1), Atazanavir and Ritonavir; 1 (3.5%) used Tenofovir + Lamivudine (2 in 1) and Nevirapine; 1 (3.5%) Tenofovir + Lamivudine (2 in 1) and Dolutegravir; 1 (3.5%) used Tenofovir + Lamivudine (2 in 1) and Efavirenz; 3 (10.7%) had not started treatment; and in the case of 2 (7.1%), the medications were not identified.

# The impact of the discovery of HIV seropositivity in the context of pregnancy

The study participants characterized the moment of discovery of the diagnosis of HIV seropositivity as a moment that brought a negative impact on them, which caused shock, much crying, nervousness, anguish, feelings of denial, fear and despair. However, many women said that those feelings passed, and that most of the time they even forget they had the infection. They also reported the fear of transmitting the virus, especially to their children.

- [...] I did four tests to be sure, and it was a shock, because no one expects something like this [...]. (P01)
- [...] I almost died, I cried a great deal, I was desperate. I cried but only in that moment, and then the feeling passed, and I had to move on, for me it doesn't matter, to be honest I only remember that I have it because I take the medicines every day [...]. (P03)
- [...] I was a little nervous, but that anguish I felt, it was only at that moment, it was momentary, thank God [...]. (P07)

- [...] I crashed, it was hard, very hard, until today I'm still processing, I think a lot about my child, just that, I ask God the baby is born healthy [...]. (P17)
- [...] I got scared, I got nervous, I felt anguish [...]. (P20)
- [...] the great fear is to pass it on to one of my children; I feel worried; I will do everything so that they do not get this from me [...]. (P24)
- [...] very sad, I wasn't expecting this, because I prevented myself, and in the first pregnancy, that's where everything happened, and that's where I felt helpless [...]. (P26)
- [...] very sad, I felt helpless [...]. (P27)

The participants also reported that the disease was detected mainly through rapid tests during the gestational period. However, some women also said that they found out through the partner's initial diagnosis or during routine examinations.

- [...] through my husband, he was feeling sick, he was having fever, then he got tested and received a positive diagnosis, then mine was also positive[...]. (P03)
- [...] I found out by chance, I just took a test out of curiosity and then I received the diagnosis [...]. (P04)
- [...] it was in this pregnancy, I did the rapid test and it was positive [...]. (P05)
- [...] through my ex-husband. He never had the guts to tell me, I trusted him blindly; I was very young, then there came a point when his mother contacted my mother and commented that there could be this possibility, but she already knew he was positive [...]. (P12)
- [...] I went to the doctor, and said: doctor it seems that I have some kind of disease, because my belly is growing and I am thin, then he said, let's find out now. Then when the ultrasound hit, he said I was pregnant [...]. (P22)
- [...] I found out by chance [...]. (P23)
- [...] I discovered it in a campaign that took place in my city [...]. (P28)

Most interviewees reported that the pregnancy was unplanned and occurred due to carelessness or failure of the contraceptive method used, bringing a feeling of surprise and anxiety. Furthermore, among the women who said to have planned the pregnancy, only one who already had the diagnosis prior to pregnancy underwent preconception follow-up with health professionals.

[...] I won't say that my pregnancy was planned, because I didn't know. And I never avoided, I never took pills [...]. (P08)

- [...] it was a huge mistake, man, it wasn't supposed to happen, it wasn't planned [...]. (P10)
- [...] it wasn't planned, yeah, I didn't want it [...] (P11)
- [...] I think that because every woman wants to be a mother and I had already seen some cases there in the health complex of seropositive people, and they got pregnant [...]. (P13)
- [...] no, I would never get pregnant, but, I do not know if it is because of anxiety or what it was, I just know on I ended up pregnant in a trip, but I had taken the morning-after pill and I even took a contraceptive pill [...]. (P14)
- [...] yes, I knew I was HIV positive, but my partner wanted the pregnancy too [...]. (P15)
- [...] what caused me to get pregnant? I messed up. [...]. (P16)
- [...] no, I was careless, I was not taking medicine, I was avoiding it only with condoms, then it happened [...]. (P18)
- [...] It was a mistake [...]. (P21)
- [...] this pregnancy was not planned, but it is also desired, because it was an unexpected event in fact, It was because I wasn't taking the measures to avoid it [...]. (P26)
- [...] I was being followed up in another city, and the doctor there gave me the the medications everything right, then when I was undetectable I started trying, my husband also takes the medication [...]. (P28)

# History of previous breastfeeding and knowledge about breastfeeding

We sought to investigate, initially, the knowledge the women had about the meaning of Exclusive Breastfeeding (EBF). Most of the interviewees answered with simply yes or no answers, and the women who shrugged off this question associated it with the act of offering breastfeeding, receiving milk donation or the fact that they could not offer breast milk to their children.

- [...] ah, the girl explained it to me, is it breastfeeding [...]? (P3).
- [...] that we are able to breastfeed, or not? I don't know [...]! (P4)
- [...] Exclusive? No, I imagine it is exclusive in the sense that it is excluded? Because I've been told that I can't breastfeed, I think that's it [...]. (P18)
- [...] not exactly, I think that's basically what we get, right, from other people [...]. (P26)

Then, the real meaning of EBF was explained and the women were asked which period they believed that the mother should offer only breast milk to the baby. Most of

them answered that this exclusive offer should occur within the first six months of the baby's life, but some women said that it should occur as far as the baby desired the breast milk, and until when the mother felt comfortable offering breast milk.

- [...] I already had one, for me up to six months is already good enough [...]. (P3).
- [...] oh, a couple of years [...]. (P6)
- [...] just the six months, that's enough [...]. (P7)
- [...] I have no idea, I don't know [...]. (P9)
- [...] I think that until she feels comfortable breastfeeding, it's ok [...]. (P17)
- [...] as long as the baby wants it, I gave it until the age of two to my other son [...]. (P25)

In addition, we sought to know the experience of women who had already gone through the experience of breastfeeding their previous children. Most of them said that the experience was positive and breastfeeding was maintained from three months to two years. It was possible to notice, in their speeches, that the mothers had had different experiences with each child.

- [...] I breastfed until she was a year and two months old. I can't explain it either, but it was good [...]. (P2)
- [...] it was a unique experience, I think every mother says that; that it is a unique experience and it really is [...]. (P3).
- [...] all four of them, the experience was very good, some were breastfed until three months, others until four months, but never until six months, I would give them porridge [...]. (P7)
- [...] four months, because there in the hospital they still made me collect the milk. The other one who was alive, after the doctor told me to stop, I stopped, she was one year old. Well, I loved to see her while breastfeeding [...]. (P8)
- [...] I breastfed, it was good, the older he did not like breast milk, he was only breastfed until he was four months old, but the second was breastfed for eight months, and the girl was not breastfed for long, because she did not latch on well [...]. (P19)
- [...] all the other three; the younger one was difficult to breastfeed; I had to hand express and put the milk in the bottle so she could drink it. The oldest, up to eight months old, which was when I found out that I was pregnant with the other, the middle girl who I only breastfed up to three months old, she only wanted the bottle and the youngest with a few days of birth, newborn, she already rejected it, she did not want it at all [...]. (P24)

## The impossibility of breastfeeding and coping with the situation

It was observed in the women's statements that most of them had been advised by the health team that they should not offer breast milk to the baby. Regarding feelings, during the interviews, it was possible to notice that the feeling of sadness was present in most women. They believed that breastfeeding was an important component that validates motherhood, but apparently they accepted the fact. There were also patients who viewed this impossibility in a positive way, in view of previous experiences.

- [...] I'm not going to lie, it's good and it's bad, bad for the child and good for the mother, because it is something you give, but I didn't feel very well, it hurts my breast, it has a very strong smell, but until now I keep thinking, will this child be attached to me? because what creates the bond between the child and the mother is breastfeeding [...]. (P3).
- [...] I feel sad, you know? I was shaken, but then it felt better with time, you have to get used to it, right, what can we do [...]? (P8)
- [...] I have already been instructed, but I never had this wish, I never thought about it, I never had this wish that many women have and dream with that, but in my case, it does not affect me in any way [...]. (P12)
- [...] yes I have been, the information about breastfeeding was passed on to me. I felt bad, to be true, because in my head breastfeeding is like a bond that you create with the baby, but it is for his sake [...]. (P17)
- [...] I've heard this, it's ok, if it is safe for him and keeping him safe, this is what matters [...]. (P24)

Furthermore, regarding the knowledge about the reason why breastfeeding is not possible, the interviewees were able to associate HIV infection with the possibility of vertical transmission to their children. The fear of other people finding out the reason was also observed in the speeches, since the women kept the diagnosis concealed from other family members.

- [...] it is to avoid that the child gets the disease [...]. (P1)
- [...] yes, because of the transmission; the same thing with milk is blood, then the same thing I can't have a normal birth, it has to be cesarean, the same thing is with milk [...]. (P4)
- [...] I know, it is because it passes the virus to my baby, and it is risky like this here to be born with the virus [...]. (P8)

When asked about the desire to breastfeed, if it were possible, most of the interviewees said that they had the desire to offer breast milk and would breastfeed if it did not pose risks to the baby's health. Two women said they did not have this desire, and they did not know or did not think about it, and four did not answer the question.

- [...] if I could, I would, but since I can't, I prefer that my son be born healthy and that he doesn't take it [...]. (P1)
- [...] I had no desire even with the other children, much less now that it is not possible [...]. (P7)
- [...] my last pregnancy was not planned, so there was no time for me to reason, and as soon as I found out, two days later I had to stop, so there was no time for me to think about all this [...]. (P15)
- [...] I think had the desire, but there is no way, so I have to accept [...]. (P28)

## **HIV** treatment

It was found that the study participants were using the antiretroviral drugs that are part of the treatment of the infection. Different adherence periods were informed, ranging from two months to six years. Also, through the statements during the interview, it was possible to note that the patients did not know the name of the drugs they used.

- [...] every day, it's been 5 to 6 years, they have weird names, I couldn't tell now you the names [...]. (P3).
- [...] yes, since May 2015. I don't know the name [...]. (P4)
- [...] I've been take it for about six years. I don't know the name of the medication [...]. (P7)
  - [...] I am, let me see, 2017, 2018, 2019, 2020. 5 years. I don't know, very complicated names to say [...]. (P8)

## DISCUSSION

According to the Ministry of Health, it is estimated that there are about 327,000 WLHIV in Brazil, and the age group most affected is from 30 to 34 years<sup>1-5</sup>, what is different from the findings of the present study, in which the age group of 20 to 25 years prevailed. Thus, it is observed that these women are in full reproductive age and,

consequently, there is an increased risk of VT, requiring the screening and provision of guidance to these women in a timely manner, even during prenatal care<sup>15</sup>.

A cross-sectional study conducted in Brazil in a 13-year time window pointed out that more than 300,000 people were affected by HIV and more than 50% of these individuals were black or brown<sup>1</sup>. In the present study, most women were brown. In addition, data from the Hospital Information System (HIS) indicate that brown people have a higher rate of hospitalization and death due to HIV in the Northeastern region of Brazil<sup>16</sup>.

When associated with unfavorable economic conditions, the risk of exposure to sexually transmitted infections (STIs) increases among black people, which is one of the vulnerabilities observed in this population. This happens because in these conditions people seek health services less frequently and have lower access to information. Black women are the ones who suffer the greatest impact of the disease, experiencing a higher mortality rate<sup>17</sup>.

As for marital status, most women were married or lived in a stable union. It was observed that WLHIV who were within a relationship reported receiving greater emotional support and encouragement and assistance regarding health-related issues<sup>18</sup>.

It was also identified that most of the women interviewed had attended high school. This differs from data of the national literature, which highlights the low level of education of pregnant women living with HIV<sup>3,10</sup>. On the other hand, the international literature shows higher levels of education in this public: a study carried out in Spain showed that 75.2% of HIV-infected women had secondary education<sup>19</sup>. This fact can be explained by the fact that European countries have better planning and investments in the educational area<sup>20</sup>.

During the study, 23.3% of women reported previous experiences of abortion. It is important to remember that abortion is a process that can be caused by multiple factors and should not be associated only with HIV infection<sup>21</sup>. Therefore, it is not possible to specify the causes that led to abortions in the interviewed patients.

A study carried out in the city of São Paulo among WLHIV compared with women who did not have the infection found a higher prevalence of induced abortion among women who had the diagnosis of HIV. However, both groups presented similar arguments, such as non-planning of pregnancy, lack of desire for motherhood, and in the case of WLHIV, the diagnosis was an important factor in this decision<sup>22</sup>.

Regarding work activity in the studied public, in Brazil, despite labor protection, WLHIV still face prejudice, stigma, and taboos in the work environment. However, when they are welcomed, bosses and co-workers also make up the individual's social support and relieve the strain in relation to the diagnosis<sup>23</sup>.

For WLHIV, it is important to discuss the methods that can be used for family and reproductive planning in order to address not only ways to prevent infecting the partner, but also other methods that can be concomitantly used to avoid pregnancy. Professional guidance that ensures the autonomy of the subjects with regard to their sexual practices and reproductive decisions is ideal<sup>24</sup>.

It is observed that many women do not share the diagnosis with family members, only with those closest to them, usually the mother. The negative impact that the discovery of HIV represented in the lives of these women was evident. Thus, because the nursing team is closer to the patient, it is also responsible for embracing and and providing health education in order to reduce the emotional burden generated by the lack of information<sup>5</sup>.

In relation to breastfeeding, the impossibility to breastfeed due to the risk of transmitting the infection to the baby generates a feeling of insecurity, fear and anguish in mothers. These women recognize the role of breastfeeding in the development of the mother-child bond<sup>5</sup>. The possibility of transmitting the disease to the child is a factor that generates conflicts and fear<sup>25</sup>.

In this sense, the contraindication of breastfeeding usually goes against the wishes and intentions of the mother. Thus, it is important that professionals provide the embracement during the process of women's suffering. In this perspective, the social representations related to breastfeeding as a symbol of motherhood should be very well understood, aiming to bring positive feelings to the mother, while highlighting the risks of exposing the baby to the illness<sup>26</sup>.

The impossibility of offering their own breast milk can also trigger feelings of fear, guilt, sadness and anxiety among HIV-positive women. It has been reported that these women may see themselves as incomplete and devalued, and even exhibit self-prejudice in some situations<sup>27</sup>.

In a study carried out in a hospital located in the sub-county of Kisumu, Kenya, symptoms indicative of depression were detected at three moments: 28 to 38 weeks of gestation, six weeks after giving birth, and five to seven months after giving birth.

During this follow-up, it was observed that 80% of the study participants had symptoms indicative of depression in the third trimester of pregnancy, such as concern about VT, anxiety, stress, embarrassment with the diagnosis, sadness, but there was a decrease in prevalence to 43% at six weeks postpartum, and 36% at five to seven months postpartum<sup>28</sup>.

Another important aspect is that there is a social expectation about breastfeeding, exposing WLHIV to questions about the reason why they are not offering milk to the child. Thus, mothers go through embarrassing situations that generate shame, and they need to make up justifications for not exposing their diagnosis<sup>27</sup>. In this sense, social representations may seem contradictory, considering that seropositivity is not an impediment for women to fulfill the dream of being mothers, although they will not breastfeed their babies.

Furthermore, the mothers fear creating a gap between them and the child because they do not breastfeed the child, since this moment helps to promote the mother-child bond and is socially marked as a characteristic that validates motherhood. Thus, there is a feeling of guilt for not being able to nourish the child with breast milk and the distance from "feeling like a mother"<sup>29</sup>. However, it is known that it is not only the offer an adequate diet to the baby; a safe and loving emotional environment is also essential, and this can be achieved through affection, warmth, proximity, eye contact between the dyad. After all, this environment will become the primary socializing experience of their lives<sup>30</sup>.

In view of the aforementioned feelings, it can be argued that the impossibility of breastfeeding increases the psychological vulnerability of the mother, who needs an environment with greater support. Therefore, health professionals, family members and the community play a vital role in providing emotional support, for example, through Non-Governmental Organizations (NGOs) and support agencies such as Sociedade Viva Cazuza, Instituto Vida Nova, and others<sup>30</sup>.

The discovery of seropositivity is usually marked as a difficult moment, especially when it occurs during pregnancy. The person experiences as a punishment, bringing fear, anguish and guilt for the possibility of transmitting the disease to the child. At this moment, fear is the feeling often shown. Women fear for their health and the risk of VT to their children, and also the affliction generated by the need to disclose the diagnosis to family members<sup>31</sup>.

Motherhood associated with the diagnosis of HIV seropositivity also produces fear about the child's future. This social representation can make women feel incompetent as mothers, either because of the fear of not being present in the raising of children due to the evolution of the infection or because of the fear of the possible situations of prejudice that the children may eventually go through<sup>32</sup>.

The process of suppressing breast milk production can also have negative repercussions, both mental and physical, being a form of social representation of the problem that surrounds seropositivity. A study showed that the lack of information about breast care in the postpartum period resulted in complaints of discomfort, pain, breast engorgement, and breast edema<sup>31</sup>.

Regarding treatment, ART is indicated for all seropositive patients, regardless of the presence of symptoms. The initial regimen recommended for pregnant women is the combination of Lamivudine and Tenofovir (TDF/3TC), because besides the effectiveness, it is available in a single dose, favoring therapeutic adherence, together with Raltegravir (RAL)<sup>2</sup>.

As a limitation of this study, the findings found in the present study bring results restricted to the institution and sample studied, so that the data cannot be generalized to other populations in different contexts.

## CONCLUSION

It is concluded that even today with so many transformations in the technological, scientific, political and social areas, WLHIV still experience pregnancy, motherhood and the impossibility of breastfeeding, which can lead to negative feelings such as fear, frustration, guilt, sadness, anguish – mainly because they recognize the importance of breast milk for the baby and believe that the moment of feeding the baby produces a bond between the the mother and the child – as well as feelings of faith and hope that their child has the possibility of living without the disease.

Despite the lack of knowledge of the majority of the women about the meaning of exclusive breastfeeding, when asked about the desire to breastfeed, many declared to have this desire and that they would offer breast milk if it was not contraindicated.

It was also observed that the health service offered clarification about the impossibility of breastfeeding and the reasons for this instruction. The interviewees

confirmed that they received guidance and were able to explain, in simple words, the reason for the contraindication.

It is worth mentioning that it is important that health professionals carry out educational activities focused on the issue of the impossibility of breastfeeding in this situation of risk of HIV infection. The health team assists with a care plan for coping and embracing the women, and also family and reproductive planning.

# **ACKNOWLEDGEMENTS**

This study was funded by the Coordination for the Improvement of Higher Education Personnel (CAPES).

We thank the Federal University of Maranhão. PIBIC/CNPq/FAPEMA/UFMA 2020-2021 AGEUFMA NOTICE n. 013/2020

## **REFERENCES**

- 1 Brasil. Ministério da Saúde. Boletim Epidemiológico Secretaria de Vigilância em Saúde. Ministério da Saúde. Semana epidemiológica 52. Número Especial; Dez. 2021. [acesso em 2022 dez 15]; ISSN 1517 1159. Disponível em: https://www.gov.br/saude/pt-br/centrais-deconteudo/publicacoes/boletins/epidemiologicos/especiais/2021/boletim-epidemiologico-especial-hiv-aids-2021.pdf
- 2 Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Protocolo Clínico e Diretrizes Terapêuticas para Manejo da Infecção pelo HIV em Adultos Brasília, 2018. [acesso em 10 jun 2021]; Disponível em: https://www.gov.br/aids/pt-br/centrais-de-conteudo/pcdts/2013/hiv-aids/pcdt\_manejo\_adulto\_12\_2018\_web.pdf/view
- 3 Trindade LNM, Nogueira LMV, Rodrigues ILA, Ferreira AMR, Corrêa GM, Andrade NCO. HIV infection in pregnant women and its challenges for the prenatal care. Rev. Bras. Enferm. 2021 [acesso em 17 mar 2021]; 74(supl. 4):e20190784. Disponível em: http://dx.doi.org/10.1590/0034-7167-2019-0784
- 4 Souza FLP, Clark LM, Lelis BDB, Dusso MIS, Leite AM. Sentimentos e significados: HIV na impossibilidade de amamentar. Rev. enferm. UFPE on line. 2019 [acesso em 18 mar 2021]; 13:e241854. Disponível em:10.5205/1981-8963.2019.241854
- 5 Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. Relatório de Monitoramento Clínico do HIV 2020/— Brasília, 2020 [acesso em 16 mar 2021]; Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/relatorio\_monitoramento\_clinico\_hiv\_2020.pdf
- 6 Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. Protocolo Clínico e Diretrizes Terapêuticas para Atenção Integral às Pessoas com Infecções Sexualmente Transmissíveis (IST)/— Brasília, 2020 [acesso em 16 mar 2021]; Disponível em: https://www.gov.br/aids/pt-br/centrais-de-conteudo/pcdts/2022/ist/pcdt-ist-2022\_isbn-1.pdf/view

- 7 Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. Relatório de Monitoramento Clínico das Gestantes Vivendo com HIV/— Brasília, 2019 [acesso em 24 mar 2021]; Disponível em:
- http://www.aids.gov.br/system/tdf/pub/2016/67093/relatorio\_de\_monitoramento\_clinico\_das\_g estantes\_vivendo\_com\_hiv\_-\_dezembro\_2019\_002.pdf?file=1&type=node&id=67093&force=1
- 8 Brasil. Ministério da Saúde. Secretaria de Atenção Primaria à Saúde. Departamento de Promoção da Saúde. Guia alimentar para crianças brasileiras menores de 2 anos. Brasília: Ministério da Saúde, 2019 [acesso em 05 jul 2021]; Disponível em: http://189.28.128.100/dab/docs/portaldab/publicacoes/guia\_da\_crianca\_2019.pdf
- 9 Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Protocolo Clínico e Diretrizes Terapêuticas para Manejo da Infecção pelo HIV em Crianças e Adolescentes Brasília, 2018 [acesso em 21 jul 2021]; Disponível em: http://www.aids.gov.br/system/tdf/pub/2016/64833/pcdt\_infantil\_04\_2019\_web.pdf?file=1&typ e=node&id=64833&force=1
- 10 Silva CM, Alves RS, Santos TS, Bragagnollo GR, Tavares CM, Santos AAP. Panorama epidemiológico do HIV/aids em gestantes de um estado do Nordeste brasileiro. Rev Bras Enferm [Internet], 2018 [acesso em 17 mar 2021]; 71(supl1): 613-21. Disponível em: https://www.scielo.br/j/reben/a/ztwvxH8Q5FBpqnQW6V6PCCH/abstract/?lang=pt
- 11 Giordani RCF, Piccoli D, Bezerra I, Almeida CCB. Maternidade e amamentação: identidade, corpo e gênero. Ciênc. saúde colet. 2018 [acesso em 17 mar 2021]; 23 (8):2731-2739. Disponível em: https://doi.org/10.1590/1413-81232018238.14612016
- 12 Minayo MCS (org.). Pesquisa Social. Teoria, método e criatividade. 18º edição. Pág 27. Editora Vozes. Petrópolis. 2001 [acesso em 27 out 2022].
- 13 Bertoni LM, Galinkin AL. Teoria e métodos em representações sociais. In: Mororó LP, Couto MÊS, Assis RAM, orgs. Notas teórico-metodológicas de pesquisas em educação: concepções e trajetórias [online]. Ilhéus, BA: Editus. 2017 [acesso em 08 jun 2019]; 101-122. Disponível em: http://books.scielo.org/id/yjxdq/epub/mororo-9788574554938.epub.
- 14 Moscovici S. Representações Sociais: investigação em psicologia social. 3ª ed. Petrópolis (RJ): Vozes; 2003. [acesso em 17 mar 2021].
- 15 Bick MA, Ferreira T, Sampaio CO, Padoin SMM, Paula CC. Perfil de gestantes infectadas e crianças expostas ao HIV atendidas em serviço especializado do sul do Brasil. Rev. Bras. Saude Mater. Infant. 2018 [acesso em 24 mar 2021]; 18(4):791-801. Disponível em: https://doi.org/10.1590/1806-93042018000400007
- 16 Souza Júnior EV, Cruz DP, Caricchio GMN, Jesus MAS, Boery RNSO, Boery EN. Aspectos epidemiológicos da morbimortalidade pelo vírus da imunodeficiência humana no nordeste brasileiro. Rev. Pesqui. (Univ. Fed. Estado Rio J., Online). 2021 [acesso em 17 mar 2021]; 13:144-149. Disponível em: https://pesquisa.bvsalud.org/controlecancer/resource/pt/biblio-1147708?src=similardocs
- 17 Fernandes RAC, Barbosa Filho EA, Vieira ACS. Mulheres que vivem com HIV/Aids: narrativas sobre violências em forma de cotidiano. O Social em Questão Ano XXV nº 52 Jan a Abr/2022. [acesso em 17 jul 2023]; 25(52): 253-274. Disponível em: https://www.maxwell.vrac.puc-rio.br/56387/56387.PDF

- 18 Padoin SMM, Marchi MC, Santos WM, et al. A influência da situação conjugal no suporte social em pessoas infectadas pelo HIV: estudo transversal. Revista de Enfermagem do Centro-Oeste Mineiro. 2018 [acesso em 24 ago 2021]; 8:e2485. Disponível em: http://dx.doi.org/10.19175/recom.v7i0.2485.
- 19 Hernando V, Alejos B, Montero M, Pérez-Elias Maj, Blanco JR, Giner L, et al. Reproductive history before and after HIV diagnosis: a cross-sectional study in HIV-positive women in Spain. Med[Internet]. 2017[cited 2017 Apr 21];96(5):e5991. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5293456/.
- 20 Moraes CSV. O ensino médio e as comparações Internacionais: Brasil, Inglaterra e Finlândia. Educ. Soc., Campinas, v. 38, nº. 139, p.405-429, abr.-jun., 2017 [acesso em 16 jul 2023].

  Disponível

  em: https://www.scielo.br/j/es/a/VH8WwHPbLVZsDCTyytDCJvQ/?format=pdf&lang=pt
- 21 Ferreira AVSG, Rocha BAM, Castro ACO, Piedade PHM, Botelho CAO, Botelho Junior CAO. Prevalência de gestantes diagnosticadas com HIV no "teste da mamãe" do Estado de Goiás no ano de 2005 a Setembro de 2016. Brazilian Journal of Health Review. 2021 [acesso em 24 ago 2021]; 4(2):7026-7040. Disponível em: https://www.brazilianjournals.com/index.php/BJHR/article/download/27449/21746
- 22 Pinho AA, Villela WV, Barbosa RM, Monteiro SS. Aborto entre mulheres vivendo e não vivendo com HIV/AIDS usuárias de serviços públicos de saúde no município de São Paulo: prevalência, contextos e motivos. Revista Brasileira de Saúde Materno Infantil. 2020 [acesso em 24 ago 2021]; 19(4):837-849. Disponível em: https://doi.org/10.1590/1806-93042019000400006.
- 23 Santos VF, Pedrosa SC, Aquino PS, Lima ICV, Cunha GH, Galvão MTG. Suporte social de pessoas com HIV/Aids: Modelo da Determinação Social da Saúde. Revista Brasileira de Enfermagem. 2018 [acesso em 11 ago 2021]; 71 (suppl 1):625-630. Disponível em: https://doi.org/10.1590/0034-7167-2017-0346.
- 24 Brasil. Ministério da Saúde. Secretaria de Ciência, Tecnologia, Inovação e Insumos Estratégicos em Saúde. Secretaria de Vigilância em Saúde. Protocolo Clínico e Diretrizes Terapêuticas para Prevenção da Transmissão Vertical do HIV, Sífilis e Hepatites Virais. Ministério da Saúde, Secretaria de Ciência, Tecnologia, Inovação e Insumos Estratégicos em Saúde, Secretaria de Vigilância em Saúde. 2. ed. rev. Brasília: Ministério da Saúde, 2022. [acesso em 15 jul 2023]; Disponível em: http://bvsms.saude.gov.br/bvs/publicacoes/protocolo\_clinico\_hiv\_sifilis\_hepatites.2.ed.rev.pdf
- 25 Lima CN, Rêgo HCLJ, Moraes LP. Aleitamento materno: a visão de puérperas soropositivas para hiv e htlv quanto a não amamentação. Nursing (São Paulo). 2019 [acesso em 13 ago 2021]; 22 (248): 2583-2586. Disponível em: https://pesquisa.bvsalud.org/portal/resource/pt/biblio-980662.
- 26 Sousa TNF, Costa TAM, Silva LCS. A vivência das mulheres portadoras de HIV e o processo de não amamentação. SAÚDE & CIÊNCIA EM AÇÃO. 2020 [acesso em 18 fev 2022]; 6(2): 98-122. Disponível em: https://revistas.unifan.edu.br/index.php/RevistaICS/article/download/809/539.
- 27. Silva FN, Raton LD, Miranda FP. Significados para puérperas soropositivas diante da impossibilidade de amamentar. Enfermagem Brasil. 2018 [acesso em 20 fev 2022]; 17(4):386-393. Disponível em: https://portalatlanticaeditora.com.br/index.php/enfermagembrasil/article/view/1676/3886.

- 28 Tuthill EL, Maltby AE, Odhiambo BC, Akama E, Pellowski JÁ, Cohen CR, Weiser SD, et al. "I Found Out I was Pregnant, and I Started Feeling Stressed": A Longitudinal Qualitative Perspective of Mental Health Experiences Among Perinatal Women Living with HIV. AIDS and Behavior. 2021 [acesso em 21 fev 2022]; 25(12):4154-4168. Disponível em: 10.1007/s10461-021-03283-z
- 29 Alvarenga WA, Nascimento LC, Leal CL, Fabbro MRC, Bussadori JCC, Melo SSS, et al. Mães vivendo com HIV: a substituição do aleitamento por fórmula láctea infantil. Revista Brasileira de Enfermagem. 2019 [acesso em 24 fev 2022]; 72(5):1153-1160. Disponível em: https://doi.org/10.1590/0034-7167-2017-0880.
- 30 Souza NO. A Impossibilidade de Amamentar em Gestantes Portadoras do HIV: Uma Revisão de Literatura. TCC, Programa de Residência em Enfermagem Obstétrica, Universidade Federal de Minas Gerais, Belo Horizonte, 2015.
- 31 Silva LBS, Silva CLC, Santos JMF, Gama MLS, Silva YNS, Melo GB. Vivência De Mulheres Portadoras De Hiv/Aids Sobre O Período Gravídico-puerperal. Caderno de Graduação-Ciências Biológicas e da Saúde-UNIT-ALAGOAS. 2019 [acesso em 24 ago 2021]; 5(2):83-93. Disponível em: https://periodicos.set.edu.br/fitsbiosaude/article/view/5988/3336.
- 32 Silva CB, Motta MGC, Bellenzani R. Maternidade e HIV: desejo reprodutivo, sentimentos ambivalentes e cuidado (não) ofertado. Revista Brasileira de Enfermagem. 2019 [acesso em 11 ago 2021]; 72(5):1378-1388. Disponível em: http://dx.doi.org/10.1590/0034-7167-2018-0063.

Submitted: April 6, 2023

Accepted: September 18, 2023

Published: March 27, 2024

#### **Authors' contributions:**

Janainna Ferreira e Silva: Conceptualization; Data curation; Formal analysis; Investigation; Writing – original draft.

Ezequiel Almeida Barros: Data curation; Formal analysis; Writing – review & editing.

Milena da Silva Soares: Data curation; Investigation; Writing – original draft.

Romila Martins de Moura Stabnow Santos: Data curation; Writing – original draft.

Ana Cristina Pereira de Jesus Costa: Formal analysis; Resources; Writing – review & editing.

Livia Maia Pascoal: Formal analysis; Resources; Writing – review & editing.

Marcelino Santos Neto: Conceptualization; Methodology; Visualization; Writing – review & editing.

Floriacy Stabnow Santos: Conceptualization; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Visualization; Writing – review & editing.

All authors approved the final version of the manuscript.

Conflict of interest: There is no conflict of interest.

Financed: Universidade Federal do Maranhão. PIBIC/CNPq/FAPEMA/UFMA 2020-2021 EDITAL AGEUFMA Nº 013/2020.

# **Corresponding author:**

Floriacy Stabnow Santos

Universidade Federal do Maranhão - Centro de Ciências de Imperatriz

Campus Avançado Bom Jesus - Av. da Universidade, S/N, Bairro Dom Afonso Felipe Gregory

Imperatriz/MA. Brasil - CEP: 65.915-240

E-mail: <u>floriacy.stabnow@ufma.br</u>

## **EDITORS:**

Associate editor: Dr. Giuseppe Potrick Stefani

Editor-in-Chief: Dr. Adriane Cristina Bernat Kolankiewicz

This is an open access article distributed under the terms of the Creative Commons license

