

**FEELINGS OF WOMEN WITH THE HUMAN IMMUNODEFICIENCY VIRUS IN
THE FACE OF THE IMPOSSIBILITY OF BREASTFEEDING****SENTIMENTOS DE MULHERES PORTADORAS DO VÍRUS DA
IMUNODEFICIÊNCIA HUMANA DIANTE DA IMPOSSIBILIDADE DE
AMAMENTAR****SENTIMIENTOS DE MUJERES INFECTADAS CON EL VÍRUS DE LA
INMUNODEFICIENCIA HUMANA ANTE LA IMPOSIBILIDAD DE LA
LACTANCIA MATERNA**

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ABSTRACT

Objective: To know the feelings of pregnant women living with Human Immunodeficiency Virus (HIV) when facing the impossibility of breastfeeding. **Method:** Qualitative study based on Content Analysis, with 17 HIV-positive pregnant woman in a high-risk prenatal clinic. **Results:** Participants were aged of 18 and 41 years. Five thematic categories emerged: The discovery of HIV; The revelation of the impossibility of breastfeeding; The professional approach to the topic; The family relationship and, Adherence to treatment. Feelings such as deep sadness, despair, hopelessness and segregation are revived with the discovery of the impossibility of breastfeeding. Family Relationships are challenging; there is dissatisfaction with the service provided, given the insensitivity of professionals and secrecy. Concern about their unborn child's health contributed to treatment adherence. **Conclusions:** The knowledge of the impossibility of breastfeeding rescued feelings experienced at the time of the revelation of seropositivity and which were aggravated by family relationships and lack of support. **Descriptors:** Nursing; Women's Health; HIV; Breast Feeding; Emotions

RESUMO

Objetivo: Conhecer os sentimentos de gestantes que convivem com o vírus da imunodeficiência humana (HIV) diante da impossibilidade de amamentar. **Método:** Estudo qualitativo fundamentado na Análise de Conteúdo, com 17 gestantes soropositivas, em um ambulatório de pré-natal de alto risco. **Resultados:** As participantes tinham entre 18 e 41 anos. Emergiram cinco categorias temáticas: A descoberta do HIV; A revelação da impossibilidade de amamentar; A abordagem profissional sobre o tema; A relação familiar e, Adesão ao tratamento. Sentimentos de tristeza profunda, desespero, desesperança e segregação, são reavivados com a descoberta da impossibilidade de amamentar. As relações familiares são desafiadoras; há insatisfação com os serviços, quanto a insensibilidade dos profissionais e sigilo. A preocupação com o filho contribuiu para a adesão ao tratamento. **Conclusões:** O conhecimento da impossibilidade de amamentar resgatou sentimentos vivenciados por ocasião da revelação da soropositividade e foram agravados pelas relações familiares e falta de suporte.

Descritores: Enfermagem; Saúde da Mulher; HIV; Aleitamento Materno; Emoções

RESUMEN

Objetivo: Conocer los sentimientos de las embarazadas que viven con el virus de la inmunodeficiencia humana (VIH) ante la imposibilidad de lactancia materna. **Método:** Estudio cualitativo fundamentado en los Analisis de Contenido, con 17 embarazadas seropositivas, en un ambulatorio de prenatalidad de alto riesgo. **Resultados:** Las participantes tenían entre 18 y 41 años. Surgieron cinco categorías temáticas: El descubrimiento del VIH; La revelación de la imposibilidad de lactancia; El enfoque profesional sobre el tema; La relación familiar y, Adhesión al tratamiento. Sentimientos de profunda tristeza, desespero, falta de esperanza y exclusión, son vividos otra vez con la descubierta de la imposibilidad de lactancia. Las relaciones familiares son de mucho reto; hay insatisfacción con los servicios en relación a la insensibilidad de los profesionales y secreto. La preocupación con el hijo contribuyó para la adhesión al tratamiento. **Conclusiones:** El conocimiento de la imposibilidad de amamentar rescató sentimientos vividos en el momento de la revelación de la seropositividad y que fueron agravados por las relaciones familiares y la falta de apoyo.

Descriptorios: Enfermería; Salud de la Mujer; VIH; Lactancia Materna; Emociones

INTRODUCTION

The World Health Organization (WHO) recommends breastfeeding (BF) for two years or more, based on the positive results of breastfeeding on the health of the child and the breastfeeding mother, as well as the economic impact provided by this practice.¹ Breastfeeding is a natural strategy of bonding, affection, protection and nutrition for children. It also constitutes the most sensitive, economical and effective intervention to reduce child morbidity and mortality, in addition to its impact on promoting the integral health of the mother/child binomial.²

The act of breastfeeding involves feelings that permeate desire, preparation, concern and insecurity regarding satiety and the amount of milk ingested by the baby. In recent years, there has been an incentive for women to breastfeed, so, in addition to their desire to breastfeed, it is expected by society that they do so. Despite the benefits, its recognition and the increasing awareness of the importance of breastfeeding, there are situations in which it is not recommended, such as in the case of mothers infected by the human immunodeficiency virus (HIV) or the T-virus. human lymphotropic (HTLV1 and HTLV2).²

Women living with HIV/AIDS are not exempt from expectations, feelings and desires, at the same time as they live with the reality of not being able to breastfeed and the need to explain the reasons for not breastfeeding. These women have knowledge about the impacts and benefits of breastfeeding, contributing to the negative feelings of not being able to offer the best for their child.³

The impacts and benefits of breastfeeding have been widely studied, however, more studies are needed to address the feelings of women living with HIV/AIDS when faced with the impossibility of breastfeeding. It is understood that, by listening to these women's reports about their feelings and psycho-emotional needs, it will be possible to contribute to more qualified and specialized planning and assistance, and also, with their strengthening and empowerment, seeking to meet the demands and needs by preventing this practice.

In view of the above, the objective of the study is to understand the feelings of pregnant women living with HIV when faced with the impossibility of breastfeeding.

METHOD

Qualitative study carried out through interviews from March 2016 to November 2017, at the high-risk prenatal outpatient clinic of the Jenny de Andrade Faria

Institute, annex to the Hospital das Clínicas of the Federal University of Minas Gerais/Ebserh. The study included 17 pregnant women registered with the service, aged 18 or over, carrying the HIV virus, who were aware of the impossibility of breastfeeding and had at least two consultations at the service. They were randomly invited on the day of the consultation.

The interviews took place face-to-face after clarifications about the study and the consent and signing of the Free and Informed Consent Form (TCLE), in a meeting room, seeking to guarantee a calm and reserved environment. They were carried out with the help of a semi-structured script, audio-recorded, and transcriptions carried out by the researcher/interviewer. This phase was considered closed when the repetition of speeches was noticed, that is, when no new information or theme was recorded, thus determining the saturation point.⁴

Content Analysis was used as a methodology. This consists of a set of communications analysis techniques and uses systematic and objective procedures for describing the content of messages. Its development is organized into three chronological poles: 1. Pre-analysis; 2. Exploitation of the material; and 3. Treatment of results, inference and interpretation. The first pole corresponds to

the organization of the analysis, that is, the choice of documents, the elaboration of hypotheses and objectives. Then, the material is explored where the decisions made previously are applied, and finally, the results obtained undergo validation tests and are subsequently interpreted.⁵

The research met the requirements requested in Resolution No. 466/2012, No. 510/2016, No. 580/2018 and was approved by the Research Ethics Committee of the Federal University of Minas Gerais (COEP UFMG) on March 19, 2015, Certificate Submission for Ethical Assessment (CAAE): 39699614.1.0000.5149. Participants were identified only with their initials, seeking to guarantee anonymity.

RESULTS

The 17 study participants were between 18 and 41 years old and were 16 weeks or more pregnant. They were infected with HIV through heterosexual intercourse, either by their partner or through sexual abuse. When invited to participate, the women readily accepted, however, during the interviews, feelings were noticed that went far beyond the impossibility of breastfeeding, sadness and hurt that came from the diagnosis of the disease permeating their lives.

Data analysis allowed the identification of five thematic categories: The discovery of HIV; The revelation of the

impossibility of breastfeeding; The professional approach to the topic; Relationship with family and adherence to treatment.

The discovery of HIV

In this category, participants reported their feelings at the time of discovering the virus. For some, HIV infection was already known before the current pregnancy, however, there were those in whom the diagnosis was made during prenatal consultations.

That was difficult for me. But I think for everyone at that time, I think it was very difficult. They are still prejudiced today, imagine in 1999.(E12)

So, in the first pregnancy tests I took.[...] So, it was a blessing from God, right!? Firstly this pregnancy for me! Because if it weren't for the pregnancy, I would never take a test to find out. (E3)

When pregnant with the first girl.[...] It was very sad, right. (E1)

Some participants reported having contracted the virus after suffering sexual violence or through contamination by their partner, through unprotected sex:

I dated a boy, then after a year, when we got engaged, he told me he was HIV positive and the test confirmed it.(E4)

I knew when I was raped by my stepfather.(E10)

The women presented feelings of deep sadness, despair and death at the time of the diagnosis, as portrayed in the following statements:

The first feeling you have is that you are going to die. No, I'm going to die, I'm not going to grow old! [...] (E13)

I was in shock, just crying. Do you know when a person says that someone in their family has died? That's how I ended up.(E16)

Our! Will to die. Very desperate. In fact, my penny hasn't even sunk in yet.(E14)

The revelation of the impossibility of breastfeeding

It can be seen here that the discovery of not being able to breastfeed once again had a negative impact on the lives of these women. This knowledge was mainly motivated by her curiosity, when seeking information about pregnancy and childbirth in HIV-positive women. Some reported having received the information during prenatal consultations:

I have always been very curious and researched on the internet to find out what it was like, what the birth possibilities would be.[...] So then I found out that I couldn't breastfeed. (E4)

I'm seeing the infectious disease specialist and he said to me: There's one more thing, you can't breastfeed.(E3)

The discovery of the impossibility of breastfeeding caused women feelings of sadness, hopelessness and separation:

I was sad, my eyes filled with water to cry. I was holding myself back from crying.(E16)

Our! It's terrible, it's very bad[...] wow. I think the first contact you have with your child is breastfeeding. It's priceless, it's very tasty. (E13)

A little upset, right? Because I hear it a lot, my mother says that the best milk for a child is the mother's milk.(E7)

Some women expressed concern about not offering breast milk, believing it to be the ideal food that provides protection for the child. However, they understand that artificial feeding is appropriate for these cases, despite expressing apprehension about its financial cost.

And then I thought, breast milk is healthy, my boys are all healthy. There are mothers who give breast milk and give NAN ®. My milk was so strong that I didn't need or give anything.(E3)

I was more worried about the milk being expensive and about her health too. Because breastfeeding is sorely missed.(E17)

We know that breastfeeding is a wonderful thing, protective and everything. Thank God you have supplementation. Babies grow, develop well and are healthy.(E9)

One participant did not show concern about not being able to breastfeed, as she had not experienced breastfeeding in previous pregnancies:

So I don't give milk either[...] what they like is a bottle. (E2)

A professional approach to the topic

In this category, the lack of preparation of health professionals to inform women – couples about seropositivity, as well as about not breastfeeding, was evident. Participants expressed a lack of empathy and sensitivity on the part of professionals providing care:

The person who informed me was Dr. C.[name], obstetrician. She didn't know that I didn't know, so she started talking. Then I thought I was going to die. There isn't much guidance at the health center, we search the internet ourselves. (E13)

[...] when it comes to nurses, because there are some who slip up, they arrive and say in front of everyone: - you're not going to breastfeed, are you? Give her the breast, she's hungry. (E11)

The relationship with the family

The participants demonstrated how representative family ties are for them. Some suffered prejudice, others, afraid of exposure, only told their parents and siblings and still others preferred to maintain secrecy, without sharing the feelings they experienced with the discovery. Women who did not reveal this to their family members were looking for justifications to explain why they did not breastfeed.

My two sisters, my aunt and my mother know, but my mother, she went and was angry with me![Gets emotional when speaking]. She's... prejudiced [crying]. (E2)

And my mother keeps talking to my brothers, my nieces not to be close... like she isolated me.(E2)

At first, every time I went to the bathroom my grandmother came and cleaned it with alcohol, and his mother(mother-in-law) too [...] (E6)

And my sister, who is a nurse, is even afraid to be close to me.(E3)

[...]. It's not even something to tell your family about. I don't tell anyone. (E16)

There were those who had not yet told their family and were thinking about what they said in light of the reality of not breastfeeding:

"It's complicated, no one in my family knows about HIV, just my father and my sister."(E5)

"And I keep thinking, what am I going to tell my family? Because they saw how much I enjoyed breastfeeding her."[previous pregnancy]. (E9)

"I said it was because I had anemia, I was taking a lot of vitamins, a lot of medicine and I wouldn't have milk."(E13)

Adherence to treatment

The interviewees revealed good adherence to treatment and the couple's complicity. Concern for the fetus being generated contributed to better acceptance of treatment:

"I even carry the medicine in my bag. If you take the medicine it will go down[viral charge]. I took the test on the 14th, now it is not detected." (E3)

"I use antiretroviral medication and he uses it too. It's one reminding the other and that way, we live normally."(E13)

"I didn't want to take medicine. I only took it during pregnancy and then I stopped."(E15)

DISCUSSION

The Primary Care Network plays a fundamental role so that, ideally, HIV diagnosis occurs before conception, reducing the chances of mother-to-child and sexual transmission for couples who have different serum levels, ensuring that sexual

practice occurs safely, without fear. and guilt. In this sense, the Ministry of Health highlights that “Primary Care is the preferred entry point into the SUS network, being responsible for welcoming people living with HIV and promoting linkage and co-responsibility for attention to their health needs”.⁶

Reproductive counseling aims to inform, guide and provide a safe space, allowing choices regarding conception and contraception to be made. It is recommended that professionals approach this topic gradually, in comprehensive care for people with HIV of reproductive age.⁶

The present study shows that regardless of the way in which HIV infection was informed to these women, the prevailing feeling was that of death, followed by deep sadness and despair. The discovery of the virus involves negative effects, such as great suffering, low levels of self-esteem and social support, in addition to worsening mental health, due to situations of embarrassment and rejection by other people.⁷

A study carried out with the aim of interpreting the feelings and meanings that women living with HIV/AIDS attribute to the impossibility of breastfeeding and motherhood revealed that after the diagnosis, women panicked because they did not accept treatment and reflected on the people who died as a result of the disease.⁸

The understanding for the participants in the present study that breast milk is an essential and complete food is explicit. Concern about the impossibility of breastfeeding was also associated with bonding, immunological protection and the financial cost of the formula. For these women, breastfeeding represents being a good mother, as it is an important instrument used by society to analyze the performance of maternal responsibility.

The knowledge that breastfeeding should be avoided was also discovered through the use of technology, however, little is still explored about how such information is achieved by women. The advancement of technology has enabled transformations in economic, social and cultural life⁹, so, motivated by curiosity, mothers obtained information about breastfeeding through quick searches. A study whose objective was to identify barriers to optimal nutrition in children under 6 months of age exposed to HIV in Kenya revealed that, due to the high cost of infant formula, many parents switched to cow's milk. And, the unstable availability of water is another factor that influences mixed breastfeeding.¹⁰

Research carried out in 2017 that investigated the feelings of HIV-positive women about not breastfeeding corroborates the findings of this study, which found that breastfeeding was a dream for mothers, but

due to HIV status, it was not possible to achieve it. Furthermore, they attributed breastfeeding as more important than childbirth, as it promoted the bond between mother and child.¹¹ Another study, whose objective was to investigate the decision not to breastfeed by African women with HIV, showed that for many, breastfeeding it was related to being a good mother, since culturally this is a highly valued practice. In this way, women who did not breastfeed began to be seen in social circles as HIV positive.¹²

The unpreparedness and lack of sensitivity of professionals to inform these women about the impossibility of breastfeeding were frequently mentioned during the interviews. The approach of professionals in these moments must target guidance, health care and confidentiality, always ensuring ethics, without letting their beliefs and prejudices appear. Revealing a positive result is a complex process, therefore health interventions must reflect an understanding of the numerous factors that affect the environment around HIV, including culture and beliefs, as well as life circumstances, psychosocial issues, mental health and clinical status.¹³

According to an integrative literature review study that sought to highlight the main care for HIV-positive pregnant women during prenatal care, childbirth and the postpartum period, revealed that in 30.7% of

the studies, professionals did not have the training to deal with the reality and complexities of HIV/AIDS. Furthermore, they presented communication difficulties and lack of clarity in language, significantly interfering with the quality of assistance provided to the user.¹⁴

Prejudice and stigma are present in family relationships, when the interviewees reported withdrawal and fear of being infected, when they were informed of their seropositivity. These reports confirm the findings of a study that sought to understand the experiences of HIV-positive mothers: these women feel excluded from the social environment and abandoned by their families, and may become insecure about caring for their children, requiring follow-up and support from a multidisciplinary team.¹⁵

The support of friends, neighbors, the family of origin and the husband's family appears in a study, which sought to portray the experience of motherhood while suffering from HIV. The same study also presents the restriction of support, with the husband appearing sometimes as support, sometimes in a conflictive relationship, with a lack of support, dialogue, separation and absence.¹⁶ Narrative review study that sought to identify in scientific production the sources and repercussions of social support for pregnant women with HIV, reveals that the main sources of social support for these women are: participation in

vertical transmission prevention programs and/or community associations, reception from the health team, health education, family, partner, friends and faith in God.¹⁷

Research whose objective was to investigate what motivates HIV-positive women to get pregnant despite knowing the risks of vertical transmission revealed that the possibility of HIV carriers suffering discrimination is still high, since family members reproduce negative metaphors and stigmas, encouraging mothers to self-isolate, confirming the findings of the present study.¹⁸

The fear of social exposure is a notable factor for these women and must be addressed during counseling sessions with the user, partner and their family members. The general population should also be a target for improving information actions about the disease, as a way of promoting, preventing and reducing the prejudices that still exist towards patients with HIV.

The importance of antiretroviral treatment is emphasized to women during prenatal care, as well as routine exams and consultation with an infectious disease doctor to monitor the viral load. The participants in this study mentioned pregnancy as a motivating factor for adherence to treatment, which can be characterized as protection, care and bonding between mother and baby. Another motivating factor for treatment may be

related to the feeling of pain, guilt and remorse for having put your child's life in danger.¹⁵ The care relationship was also represented between HIV-positive partners, where one helps the other in maintaining treatment, reminding each other about the daily use of medication.

The national survey “Nascer no Brasil”, carried out in 2012, identified that 74.9% of HIV-positive pregnant women received combined antiretroviral therapy (ART) during pregnancy.¹⁹ The Clinical Protocol and Therapeutic Guidelines for Prevention of Vertical Transmission of HIV, Syphilis and Viral Hepatitis of 2019 recommends that ART be continued even after birth, regardless of the value of the viral load and that, even if the mother uses antiretroviral (ARV), it is not possible to control the elimination of HIV through milk, thus not being able to guarantee the protection against vertical transmission.²⁰ The present study revealed that some mothers interrupted ART after giving birth, attributing care during pregnancy to adherence to treatment.

The inclusion of people in the care support network for HIV-positive women, whether they are partners, family or friends, should be considered as a contribution to their health care and also a factor that enhances adherence to treatment. Furthermore, a good support network can

alleviate negative feelings after the diagnosis.

CONCLUSIONS

This study revealed that feelings when learning about the impossibility of breastfeeding are almost as difficult and strong as when discovering seropositivity. Aggravating factors include the fact that the revelation took place carelessly and without the necessary emotional support. This situation is accentuated by the lack of support from family members.

The vulnerability of women living with HIV in society is highlighted, as well as the fragility of the available assistance network. In view of the above, greater investment is urgently needed in the training of professionals, thus contributing to humanized and networked assistance in maternal and child care, highlighting the importance of educational actions and other strategies such as qualified listening and relevant guidance.

The results of the study can contribute to improving the quality and humanization of care and to meeting the specific needs of this population. They can also contribute to encouraging family ties and reflecting on the assistance provided by health professionals, especially nurses, at different levels of care. These practices help women to enhance their care for themselves and their children.

This study was limited to a women's health clinic, a reference for high-risk prenatal care, making it necessary to investigate other scenarios, seeking to address different realities, including women who are in a vulnerable situation and do not access services of health. Studies are also needed to investigate the needs of these women in the health care network, the conditions of stay in the maternity ward during labor and birth, the professionals who provide care to this population, among others.

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