

# Meanings of breastfeeding interruption due to infection by human T cell lymphotropic virus type 1 (HTLV-1)

Sentidos da interrupção da amamentação devido infecção pelo vírus linfotrópico de células T humanas do tipo 1 (HTLV-1)

Karina Franco Zihlmann<sup>1</sup>

Maria Cristina Mazzaia<sup>2</sup>

Augusta Thereza de Alvarenga<sup>3</sup>

## Keywords

HTLV-1; Vertical transmission; Public health; Sexually transmitted diseases; Breastfeeding

## Descritores

HTLV-1; Transmissão vertical; Saúde pública; Doenças sexualmente transmissíveis; Amamentação

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## Corresponding author

Karina Franco Zihlmann  
Rua Silva Jardim, 136,  
11015-020, Santos, SP, Brazil.  
karina.zihlmann@unifesp.br

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## Abstract

**Objective:** Understand the meanings of breastfeeding inhibition to prevent vertical transmission among women living with HTLV-1 (WLHTLV).

**Methods:** A qualitative research with participant observation and in-depth interviews was undertaken, using a pretested thematic script, analyzed by means of Bardin's thematic content analysis. The participants were 13 people - 11 women and two men - over 18 years of age, diagnosed with HTLV-1 and without co-infections. The study was undertaken at a private room in a specialized center in São Paulo between June/2006 and April/2008, where the researcher worked, so that she was familiar with and had access to the users. The subjects were selected by convenience, during the participant observation. The subjects' reports were recorded, transcribed and analyzed in search of senses and meanings to elaborate the categories. Excerpts were presented, identified by fictitious names.

**Results:** Breastfeeding inhibition is a complex decision that is even more difficult in a context in which the health team does not know this infection.

**Conclusion:** The lack of knowledge on HTLV-1 in the hospital context is a risk for the vertical transmission of this virus and entails significant emotional consequences. The health team needs information and education for comprehensive care and welcoming of WLHTLV's specific needs.

## Resumo

**Objetivo:** Compreender os sentidos da inibição da amamentação como prevenção da transmissão vertical entre mulheres vivendo com HTLV-1 (MVHTLV).

**Métodos:** Trata-se de pesquisa qualitativa com observação participante e entrevistas em profundidade, por meio de roteiro temático, pela análise de conteúdo temática de Bardin, pré-testado e realizados com 13 pessoas - 11 mulheres e dois homens - maiores de 18 anos, diagnosticados com HTLV-1 e sem co-infecções, entre Junho/2006 a Abril/2008, em sala reservada de centro especializado em São Paulo, onde atuava a pesquisadora, psicóloga, com familiaridade e acesso aos usuários. A seleção dos sujeitos ocorreu por conveniência durante a observação participante. Os relatos dos sujeitos foram gravados, transcritos e analisados na busca dos sentidos e significados para elaboração das categorias e, foram apresentados trechos destes, identificados por nomes fictícios.

**Resultados:** A inibição da amamentação é uma decisão complexa dificultada em um contexto de desconhecimento dessa infecção pela equipe de saúde.

**Conclusão:** O desconhecimento do HTLV-1 no contexto hospitalar se torna um risco para a transmissão vertical desse vírus, além de consequências emocionais significativas. Indica-se a necessidade de informação e formação da equipe de saúde para um cuidado integral e o acolhimento das necessidades específicas de MVHTLV.

<sup>1</sup>Departamento de Gestão e Cuidado em Saúde, Universidade Federal de São Paulo, Santos, SP, Brazil.

<sup>2</sup>Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

<sup>3</sup>Faculdade de Saúde Pública, Universidade de São Paulo, São Paulo, SP, Brazil.

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## Introduction

HTLV-1 causes an infection that is unknown to most health professionals and is neglected in public health,<sup>(1-4)</sup> as its true epidemiological dimension is only estimated, considering that, between 10 and 20 million people have been infected around the world.<sup>(5)</sup> It is relevant that most people are asymptomatic (about 95% of the cases), do not know their serological status and can infect their partner or children.<sup>(3-7)</sup>

Zihlmann et al.<sup>(3)</sup> appoint the invisibility of HTLV in Brazil and around the world, raising a discussion about the influence of the hegemonic healthcare model that considers the low risk of illness as a justification for neglecting this endemic condition. Thus, the lack of knowledge about HTLV-1 entails implications for care practice, prevents the identification of infected patients and perpetuates the infection in society.

The infection by HTLV-1 is mixed up with the infection by HIV, but each entails different illnesses and demands distinct treatments, as the infection by HTLV-1 does not respond to antiretroviral drugs. The reasons why few people evolve to diseases associated with HTLV-1 are yet unknown, the most common of which are adult T-cell leukemia/lymphoma (LTTA) and HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP).<sup>(7)</sup>

The infections by HIV and HTLV-1 have identical transmission forms,<sup>(7)</sup> but epidemiological data appoint that the main transmission form of HTLV-1 is through breastfeeding. Therefore, the main form to prevent the vertical transmission of HTLV-1 is the interruption of breastfeeding.<sup>(8,9)</sup>

In Brazil, few epidemiological studies exist on the endemic condition of HTLV-1. The great heterogeneity of prevalence rates in the serological screening of blood bank donors in large Brazilian urban areas is known, the highest prevalence being found in the cities of São Luiz do Maranhão (10/1,000 donors), Salvador (9.4/1,000 donors), followed by Belém (9.1/1,000 donors).<sup>(6)</sup>

Until recently, Japan presented high vertical transmission rates of HTLV-1 but, through public policy actions that established prenatal serum

screening among pregnant women and the interruption of breastfeeding for seropositive patients, the vertical transmission rate dropped from 20% to approximately 3%.<sup>(10)</sup>

In Brazil, few studies exist on the prevalence of HTLV-1 among pregnant women. In a study developed in Salvador, a rate of 0.88 % of the pregnant women from the low socioeconomic level was indicated.<sup>(11)</sup> Between 2002 and 2006, a study was developed in Campo Grande, revealing a prevalence rate of 0.13% of HTLV 1/2 among pregnant women.<sup>(12)</sup>

The duration of the breastfeeding interferes in the vertical transmission risk. If breastfeeding cannot be avoided for socioeconomic reasons, however, a maximum of six months is recommended.<sup>(13,14)</sup> The most accepted recommendation - including in Brazil - is the interruption of breastfeeding to prevent the vertical transmission.<sup>(7)</sup>

One of the few disclosure actions on HTLV-1 in Brazil took place in 2003: the Recommendation Guide on the Management of HTLV.<sup>(7)</sup> Preventive actions to cope with HIV/Aids,<sup>(15)</sup> such as prenatal testing or access to formula milk, do not attend to specific demands of people living with HTLV (PLHTLV), and are rarely extended to women living with HTLV (WLHTLV).

Concerning HTLV-1, the identification of infected persons in the family network is a crucial problem and, in these cases, secondary actions to prevent the risk of vertical transmission of the virus need to be considered (especially during breastfeeding). These issues are challenges the public policies should face with caution, as reported in Zihlmann.<sup>(16)</sup> Therefore, to cope with the vertical transmission prevention of this virus (through the interruption of breastfeeding), we need to reflect on the place of breastfeeding in our society and the possible effects of interrupting breastfeeding for the stakeholders.

As from the 19<sup>th</sup> century, breastfeeding started to be considered as a shared social good, or as an attribute that characterizes motherhood and women's identity, within an essential conception of importance in the health area. Nowadays, the relation breastfeeding/weaning can take the form of a clash between health and illness, representing a task that

needs to be undertaken with pleasure and abnegation, as the health professional's success. In that context, the health actions are intended to inform the women about the advantages of breastfeeding, making them responsible for the future outcomes, in a top-down and authoritative care model. That logic intends to modulate women's behavior in favor of breastfeeding, blaming them for weaning as a form of health problem for their children.

Nursing professionals are currently the main boosters of this process, exercising power established in the health spheres and contributing to disseminate knowledge that has been validated as scientific. Overall, however, these orientations are limited to physiological aspects and ignore the women's social and psychological universe. In the past decade, the traditional biological reductionism has been progressively replaced by a new focus on the woman as a subject, beyond the idealization surrounding breastfeeding in the social imaginary.<sup>(17)</sup>

In view of the lack of studies that investigate the emotional aspects and meanings of the inhibition of breastfeeding in WLHTLV, we can draw parallels with the reports of women living with HIV/Aids who also inhibited breastfeeding. In addition, it should be kept in mind that experiencing a pregnancy in this context is a complex emotional experience loaded with biased feelings. Therefore, healthcare needs to be based on the humanization perspective, beyond a mere prophylactic practice.<sup>(18)</sup>

Some studies appoint that, for women living with HIV/Aids, being pregnant is equivalent to "being healthy". When the infant is born, the impossibility to breastfeed turns into a first "symptom" of HIV in the eyes of society.<sup>(19)</sup> For Moreno et al.,<sup>(20)</sup> the inhibition to breastfeed among women living with HIV/Aids is considered something punishing and painful (especially the bandaging of the breasts). In that sense, the women revealed that they did not consider themselves complete and valued as mothers and that, although this action served to protect their infant's health, they felt guilty and afraid of being socially judged.

For the pregnant women living with HIV/Aids, the mother's milk gains a new meaning and breastfeeding turns into a threatening act for their child's

integrity.<sup>(21)</sup> Therefore, in the context of HIV/Aids infection, the inhibition of breastfeeding requires a symbolic redefinition that makes it difficult to exercise the maternal role and articulates a loss experienced in a melancholic and blameful manner, which the woman elaborates little by little, based on strategies intended to avoid anguish.<sup>(22)</sup>

What would the WLHTLV's experience be like concerning the orientation not to breastfeed?

Therefore, the objective in this article is to understand the meanings of inhibiting breastfeeding as a way to prevent the vertical transmission among women living with HTLV-1 and, in addition, to present related situations on experiences of actually interrupting breastfeeding.

## Methods

The study is part of a research entitled "From the invisibility to the visibility of the subject living with the HTLV-1 infection/disease and the place of the reproductive decisions in the webs of knowledge and care".<sup>(16)</sup> In this qualitative study,<sup>(23)</sup> participant observation and in-depth interviews, by means of a pretested thematic script,<sup>(24)</sup> using Bardin's thematic content analysis,<sup>(25)</sup> were applied to 13 people - 11 women and two men - over 18 years of age, diagnosed with HTLV-1 and without co-infections, between June/2006 and April/2008, at a private room in a specialized center in São Paulo, where the researcher, a psychologist, worked, so that she was familiar with and had access to the users. The subjects were selected by convenience during the participant observation.<sup>(24)</sup> The subjects' reports were recorded, transcribed and analyzed in search of senses and meanings for the elaboration of the categories. Excerpts were presented, identified by means of fictitious names.

Two thematic analysis categories were constructed:<sup>(25)</sup> The diagnosis of HTLV and the emotional implications of the need to inhibit breastfeeding and situations experienced at the maternity hospital in the postpartum period: the drama of inhibiting breastfeeding as the first symptom of an infection unknown to the health team.

Approval for the study was obtained from COEP/FSP under 297/06 and COEP/*Instituto de Infectologia Emilio Ribas* 34/06. After receiving orientations, the interviewees signed an Informed Consent Form, in compliance with resolution 466/12.

## Results and Discussion

### The diagnosis of HTLV and the emotional implications of the need to inhibit breastfeeding

*Not breastfeeding was like a bomb. We get that expectation, right? I think I won't have that contact with the child, right? Because you're the only one who can breastfeed. That news that I won't be allowed to breastfeed really touched me and my husband. He thought it would negatively affect the baby. But I think she (daughter) won't miss something she never had! (Maria, 27 years, married, asymptomatic).*

*It was sad not to be allowed to breastfeed but, on the other hand, I felt relieved to know that was part of the care for my daughter not to have the HTLV (Ana, 27 years, married, symptomatic).*

In these women's statements, we can observe an emotional discourse, loaded with expectations on motherhood and breastfeeding. These overwhelming statements indicate that the act of breastfeeding would provide an irreplaceable and special bond, besides being an act they consider intrinsic in the maternal role. That means that WLHTLV anchor their female and maternal identity in the breastfeeding process, in accordance with an idealized and socially shared discourse.

They also reveal a clash between emotion and reason. If, on the one hand, idealizations continue to exist on the act of breastfeeding, on the other, the experts' information on the vertical transmission risk serve as a reference framework for decision making that is intended to guarantee the infant's health. In that sense, the inhibition of breastfeeding is a decision that grants them the feeling that they regain control over the situation.<sup>(14)</sup> We can recognize that these women try to accomplish a rationalization process that may, or may not, facilitate

an elaboration process. The statements illustrate that this is not a response to a simple orientation by the health team, but also a position that requires involvement from the women, as well as support from their family network.

### Situations experienced in the postpartum period at the maternity hospital: the drama of inhibiting breastfeeding as the first symptom of an infection unknown to the health team

Different difficulties were reported in relation to the postpartum situation. The health team's attitude is highlighted which, when discovering what the HTLV-1 infection is, welcoming the woman and family's singular needs. In Maria's report, the appropriate welcoming at the maternity hospital and the preparation of the health team are observed.<sup>(16)</sup> Her statement illustrates the relief for having been allocated to a separate room as, for her and her husband, besides having to cope with the need to inhibit the breastfeeding, the most difficult was to cope with the questioning look of other people and give explanations. She felt relieved for not having to watch other women breastfeed.

*I stayed at a separate room. Nobody came in asking. It would be very hard to see other women breastfeed. But there was one nurse\* who came in and asked "Why don't you like to breastfeed?". And I had to explain what HTLV was. Ah, not being allowed to breastfeed was hard, right? (gets emotional) And when she (the daughter) cried, my breast filled. Then my breasts were bandaged so as not to have contact with her. But who really suffered was her father. But it was difficult that everyone was asking "oh dear, she's so big, does she drink a lot?" Everyone asking, my neighbors. Not in my house, because I told them (about the HTLV) (Maria, 27 years, married, asymptomatic).*

In the hospital context, different actors participate, who may or may not serve as facilitators of the inhibition process of breastfeeding. A first actor is the health team and, although the majority showed to be prepared to cope with the situation, one team member was surprised at the situation and inquired about the reasons not to breastfeed. The professional mentioned not only demonstrates a critical pos-

ture towards the inhibition process of breastfeeding, but also illustrates a total lack of knowledge on the patient's specific medical situation. It is highlighted that, although the interviewees refer to nursing professionals, it was not clarified whether the nursing professional mentioned was the nurse or another member of the nursing team (see footnote).

Maria's discourse also reveals the role of the other patients' looks, as Maria mentioned difficulty to see (another woman breastfeeding) and to be seen (inhibiting the breastfeeding), putting the inhibiting of breastfeeding in the position of core signifier in the expression of her condition as a WLHTLV.

As for the companions and relatives, the experiences are similar to those reported by women living with HIV/Aids,<sup>(19)</sup> that is, what is observed in the anticipation of the situation through information for key figures in the family, preparing them for moments of commotion and suffering. Concerning the visitors - another actor in the hospital scenario - a list of apologies is constructed to justify the breastfeeding inhibition. This conduct is intended to avoid evidencing the infection by HTLV-1, in view of the fear of prejudice and stigmatization. In that context, the importance is observed of pregnant women's taking an active stance towards the generalized ignorance about HTLV-1. The situations reported reveal that the hospital setting can be a risky environment, that is, women in this condition experience invisibility for the health area, as reported by Zihlmann.<sup>(16)</sup>

Other participants reported on situations in which the health teams ignored the HTLV-1 and took an inappropriate stance. Maria Rita's report is dramatic and revealed the health team's pressures for her to breastfeed, even after having explained

\*Foot note: In the interviewees' statements, the term "nurse" is frequently observed to designate an interlocutor during the hospitalization. It is not clear or impossible to distinguish, however, based on the statements, whether that person is truly a nursing professional or the particularity of her function. For the sake of analysis, we consider that the interviewee's discourse indicated that, from her perspective, that person was a nursing professional, independently of other attributes. Even if the interlocutor does not come from the nursing area, she was identified as such by the interviewee and held responsible for this care during the hospitalization. This identification may indicate that the interviewee revealed her viewpoint on the importance and central role of this professional's engagement in the context appointed in this study. Therefore, for the sake of this article, the use of the term "nurse" will follow the considerations proposed.

that she was seropositive to HTLV-1. This interviewee told that she had been diagnosed (in the eighth month of pregnancy) with HTLV-1 and that the infectious disease specialist at the specialized referral center had instructed her not to breastfeed, providing a formal statement for that diagnosis. In her report, Maria Rita revealed that the conversation with the health team of the maternity hospital was tense and that she was confronted with disbelief in her information:

*The nurse\* brought her (the child) to breastfeed, then I said "I won't breastfeed!" The nurse\* said "why won't you breastfeed? You've got milk". I said "I've got milk, but I can't breastfeed, I was instructed by the infectious disease specialist". The obstetrician said "Yes you can breastfeed!". The nurse\* said "you can breastfeed, I've talked to the physician and there's no problem". I said "No! I see a specialist and he advised me not to breastfeed, because when I got here, at this hospital, nobody knew about the topic HTLV, why would I trust you now?" (Maria Rita, 27 years, asymptomatic).*

It should be reminded that Maria Rita had her daughter in 2007, in the city of São Paulo, which is considered the region with the best access to health in the country.<sup>(26)</sup> This report does not only illustrate a situation of the team's lack of preparation to deliver care to WLHTLV, but also reveals the risk this unpreparedness can entail. This means that there exists a risk when the hospital ignores these subjects' specific needs and does not acknowledge them as subjects with rights. It should be highlighted that the final consequence is the perpetuation of this infection in our midst.<sup>(3,7)</sup>

Maria Rita also reported that her rights were infringed as, even without any infectious-contagious condition, the patient would still have the right to decide whether she wants to breastfeed or not. The following expert discusses these aspects:

*I explained it to the nurse\*, but she nevertheless insisted. She put the baby here at my breast. I said I won't breastfeed! She said "I'll teach you how to breastfeed". Then I took the baby off my breast. Do you think I didn't want to breastfeed? Why did this have to be like that? (Maria Rita, 27 years, asymptomatic).*

This patient's posture was firm, as she felt safe as a result of the information and support received at the specialized center. The continuation of her report shows that she had to ask the infectious disease specialist's help as the health team did not consider anything she said was valid.

*I said "is there milk here for my daughter? If not, someone should bring it". Then they said "you can't bring other milk! It's the first breast milk she needs". I had to call the infectious disease specialist on my mobile phone. Dr. J. managed to calm me down and then I passed my phone to the hospital pediatrician, who was waiting at my side. Afterwards, the pediatrician said "it's best not to breastfeed" (Maria Rita, 27 years, asymptomatic).*

Finally, this case revealed that the patient bonded with the team at the specialized center, and was not merely "informed/advised". We can infer that this bond strengthened her to cope with an inconceivable situation, all the more when we consider the sensitiveness of her circumstances.<sup>(16)</sup>

As a study limitation, we observed that the interviewees' discourse frequently contains the term "nurse" to designate an interlocutor during the hospitalization. It is not clear or impossible to distinguish, however, based on the discourse, whether that person is truly a nursing professional or even the particularity of her function. Therefore, this identification may indicate the central role of this professional's engagement in the context appointed in this study.

## Conclusion

The interruption of breastfeeding as a way to prevent the vertical transmission of infectious-contagious diseases is a complex decision. Among WLHTLV, however, this experience comes with additional particularities and anguish, especially due to the aggravating factor of the general ignorance on this infection. The reports presented reveal a gap in health professionals' education, that is, our study unveiled the need for public policies that enhance the visibility of HTLV. Preparing the pregnant or parturient woman in advance is con-

sidered fundamental in order to help her to play a protagonist role, especially in a context of neglect of her specific needs. Therefore, diagnosing the infection by HTLV-1 in prenatal care is fundamental to guarantee the appropriate conduct of the vertical transmission prevention process. This research can contribute to dissemination on the subject, besides allowing reflection on the need for the construction of integral health care, which, after all, can allow the welcoming of PVHTLV's complex needs.

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## Collaborations

Zihlmann KF, Alvarenga AT and Mazzaia MC contributed to the conception of the project, analysis and interpretation of the data, writing of the article, relevant critical review of the intellectual content and final approval of the version for publication.

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