

# FEELINGS OF SEROPOSITIVE WOMEN TOWARDS NON-BREASTFEEDING

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## SENTIMENTOS DE MULHERES SOROPOSITIVAS ACERCA DA NÃO AMAMENTAÇÃO

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## SENTIMIENTOS DE MUJERES SEROPOSITIVAS SOBRE EL NO AMAMANTAMIENTO

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**Objective:** to know the feelings of HIV- and HTLV-positive women towards non-breastfeeding. **Method:** qualitative research based on the Theory of Social Representations, carried out with 134 women assisted at IST/AIDS and HTLV Reference Centers, in the city of Salvador, Bahia, Brazil. A descriptive survey and interactive dynamics were used to produce the information. Data were examined through thematic content analysis. **Results:** the interviewees revealed feelings of sadness, fear, anger, guilt, and uncertainty regarding the decision of not to breastfeed. This decision was anchored in the intent to protect the child from being contaminated with the acquired immunodeficiency virus and/or human T-lymphotropic virus. **Conclusion:** the feelings of the interviewees towards non-breastfeeding are permeated by conflicts arising from socio-culturally established patterns regarding breastfeeding. In professional practice, nurses have the possibility to intervene in the situation of non-breastfeeding by supporting the women in their decision.

**Descriptors:** Maternal and child health. Breastfeeding. Nursing. HIV. HTLV.

*Objetivo:* conhecer os sentimentos de mulheres soropositivas para o HIV e HTLV sobre a não amamentação. *Método:* pesquisa qualitativa, fundamentada na Teoria das Representações Sociais, realizada com 134 mulheres atendidas em Centros de Referências para IST/aids e HTLV, na cidade de Salvador, Bahia, Brasil. Para produção das informações foram utilizadas o survey descritivo e a dinâmica interativa. Foi utilizada a análise de conteúdo temática. *Resultados:* as entrevistadas revelaram sentimentos de tristeza, medo, raiva, culpa e incerteza diante da decisão de não amamentação. Essa decisão esteve ancorada no desejo de evitar a contaminação do seu filho para o vírus da imunodeficiência adquirida e/ou para o vírus T-linfotrópico humano. *Conclusão:* os sentimentos das entrevistadas acerca da não amamentação estão permeados por conflitos oriundos de padrões socioculturalmente estabelecidos com relação à amamentação. Na prática profissional, enfermeiras têm a possibilidade de intervir na situação da não amamentação apoiando a mulher na sua decisão.

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*Descritores: Saúde materno-infantil. Amamentação. Enfermagem. HIV. HTLV.*

*Objetivo: conocer los sentimientos de mujeres seropositivas para el VIH y el HTLV, sobre el no amamantamiento. Método: investigación cualitativa, basada en la Teoría de las Representaciones Sociales, realizada con 134 mujeres atendidas en Centros de Referencias para el IST/sida y HTLV, en la ciudad de Salvador, Bahía, Brasil. Para la recolección de datos se utilizó el survey descriptivo y la dinámica interactiva, además del análisis de contenido temático. Resultados: las entrevistadas revelaron sentimientos de tristeza, miedo, rabia, culpa e inseguridad delante de la decisión de no amamantar. Esa decisión se basó en el deseo de evitar la contaminación de su hijo con el virus de la inmunodeficiencia adquirida y/o para el virus T-linfotrópico humano. Conclusión: los sentimientos de las entrevistadas sobre el no amamantamiento, están permeados por conflictos oriundos de patrones establecidos socioculturalmente con relación al amamantamiento. En la práctica profesional, las enfermeras tienen la posibilidad de intervenir en la situación del no amamantamiento apoyando a la mujer en su decisión.*

*Palabras clave: Salud materno-infantil. Amamantamiento. Enfermería. VIH. HTLV.*

## Introduction

Seropositivity for acquired immunodeficiency virus (HIV) and human T-lymphotropic virus (HTLV) contraindicates breastfeeding because of the additional risk of vertical transmission<sup>(1-2)</sup>. Vertical transmission of the virus through lactation is an important risk factor, either by known biological factors or by social factors<sup>(3-4)</sup>. The impasse of breaking with social, cultural, and emotional issues that imply difficulties to women who are impeded to breastfeed in order to keep the baby healthy represents a challenge for many areas of knowledge, especially health<sup>(1,5)</sup>.

The risk of contamination and vertical transmission of the virus through breast milk makes it necessary that breastfeeding cease to be seen only as a source of life and health, but also as a source of illness and death. Cessation of breastfeeding is necessary in case of HIV or HTLV infection, despite the many advantages of breast milk such as antibodies, nuclear cells, and other protective factors to the newborns, these viruses infect the human milk<sup>(5)</sup>.

HIV is responsible for the development of acquired immunodeficiency syndrome (AIDS) in humans<sup>(4)</sup> and HTLV I can lead people to develop diseases such as adult T-cell leukemia/lymphoma (ATL) and HTLV-I-associated myelopathy/tropical spastic paraparesis (HAM/TSP). In turn, HTLV II causes HAM/TSP-like neurological diseases and granular lymphocyte leukemia and has also been isolated or detected

in patients with chronic lymphocytic leukemia with neutropenia, prolymphocytic leukemia, cutaneous lymphoma, Sézary's syndrome, exfoliative dermatitis, chronic fatigue syndrome and sudden neurodegenerative disorders<sup>(3,6-7)</sup>.

Thus, the advent of HIV and HTLV infections causes the promotion, protection, and support of breastfeeding to gain a new meaning, in which not only the vertical transmission must be considered, but above all the subjectivity of HIV-positive women. This is a moment when construction-deconstruction-reconstruction of the meanings and representations is necessary, not only on the part of the women who will be impeded of breastfeeding but also on the part of the health professionals who can help these women to cope with the experience of seropositivity and non-breastfeeding.

Thus, the following guiding question was raised: What are the feelings expressed in the social representations of women towards non-breastfeeding? In order to answer this question, the following objective was proposed: to know the feelings of HIV- and HTLV-positive women towards non-breastfeeding.

## Method

This is a qualitative research based on the Theory of Social Representations developed with 134 HIV- or HTLV-infected women assisted

at a State Reference Center for STI/AIDS and a Reference Center for HTLV, respectively, located in the Municipality of Salvador, Bahia, Brazil. The data presented here are part a larger research financed by the CNPq.

Women were personally invited to participate in the study while they were in the waiting room of the units, waiting for their own consultation and/or the consultation for their children, in different days and times, from August 2008 to April 2009. Inclusion criteria were: being registered in the unit, what implied a diagnosis of HIV or HTLV seropositivity; being over 18 years of age; and having become pregnant at some time in life.

The number of participants was small because the number of HTLV-positive women was taken as a parameter, and this was the less known universe among the participants. Thus, equivalence with HIV positive people was sought. It was decided that women who did not periodically attend the Reference Centers were to be excluded.

Among participants, there were 70 HIV-seropositive (HIV SP) and 64 HTLV-seropositive (HTLV SP) women. The age of HIV SP women ranged from 18 to 54 years, and of SP HTLV women ranged from 22 to 86 years. In general, the majority of participants had Incomplete Elementary School, was unemployed, self-declared black skin, and informed to live in a consensual union.

The information obtained through the descriptive survey, containing questions on knowledge about HIV/AIDS, HTLV, feelings towards seropositivity and non-breastfeeding, and attitudes and behaviors regarding non-breastfeeding, are presented in this article. At that moment, the participants were exposed to a hypothetical situation through an Interactive Dynamics (ID), specially prepared for this study, and were able to express their opinions and feelings on the object studied.

The information obtained from the open questions of the survey and of the ID were analyzed through thematic content analysis. The

statements were analyzed based on the units of records corresponding to each question, and thematic words and sentences were extracted from these statements to compose the thematic categories by their occurrence and co-occurrence. Three categories emerged from the mainstreaming of data, that is, from the information that was close by similarity and/or complementation, which will be presented and discussed below.

The women had their speeches identified with an Arabic number corresponding to the order in which the interview took place, followed by the acronym for their seropositive status, either for HIV or HTLV (example: Woman 22 HIV SP or Woman 33 HTLV SP).

The development of the study adhered to national and international standards of ethics in research involving humans.

## Results

After analyzing the content of the speeches, it was possible to know the social representations revealed and expressed in the feelings, organized in themes, and, consequently, the three following categories: "Between the desire to breastfeed and the desire to preserve life"; "What I see in my body: feelings about physical-organic changes in the face of non-breastfeeding"; "The obscurity before the window of life: the challenge of social prejudice".

These categories made it possible to understand that the socially constructed representations of HIV and HTLV of the informants influenced their decision not to breastfeed due to the contamination of their breast milk, even though breastfeeding was constructed as a form of affirmation of motherhood. This decision was objectified through tears that rolled over their faces, allowing them to externalize the feeling of sadness, anguish, guilt, fear, and anger when their children cried and they could not feed them with the milk that flowed from their breasts because it was contaminated by viruses.

*Between the desire to breastfeed and the desire to preserve life*

According to the report of the participants, non-breastfeeding poses a conflict between the desire to breastfeed and the desire to maintain the health of their children generated by the condition of seropositivity for HIV or HTLV. Breastfeeding was an unfulfilled dream, a repressed desire, suffocated due to their seropositivity. This fact can be explained by the representations that they attribute to breastfeeding as being more important than childbirth and a moment of happiness.

*[...] mothers want to breastfeed the child, but we cannot do that. (Woman 24 HIV SP).*

*I was sorry [...] not be able to breastfeed [...] it was a dream I had to breastfeed, but in that case, I had to be content not to pass the disease on to my daughter. (Woman 17 HIV SP).*

*It's complicated [...] I think that the contact in breastfeeding is even more important than childbirth. (Woman 21 HTLV SP).*

The conflict increased when the children cried and they felt the breast overflowing with milk that would not be used because it was carrying a virus considered fatal, especially when they did not have the artificial milk to be offered.

*[...] when I looked at my breast [...] seeing that milk, I wanted to breastfeed, but I couldn't give it to him, I would even get desperate, there were times that I gave in to cry. (Woman 33 HIV SP).*

*[...] sometimes I wanted to give him my milk [...] once, the milk he was taking did not come, this happened twice, I got mad and be hungry [...] I said: I'm going to take [...] and I'm going to give my son my milk. Then a friend of mine [...] said: do not do this, you know that you run the whole risk if you give it to him [...] (Woman 32 HIV SP).*

During the application of the ID, women showed feelings of sadness, fear, guilt, uncertainty, frustration, and anger because of the impossibility of breastfeeding.

*When I did not breastfeed, I was very sad. [...] (Woman 3 HIV SP).*

*[...] I got sad [...] I wish my daughter had been breastfed. (Woman 28 HTLV SP).*

*[...] I was so sad! [...] Because what I wanted was to breastfeed. (Woman 32 HTLV SP).*

*When I did not breastfeed my son I suffered a great deal [...] seeing that I had milk and I could not give it to my boys [...] I was much distressed. (Woman 9 HIV SP).*

*[...] not being able to breastfeed is a frustration. We know that, in the end, something is missing. (Woman 8 HIV SP).*

*What I see in my body: feelings about physical-organic changes in the face of non-breastfeeding*

According to the interviewees, the physical-organic changes present in their own bodies gave objectivity to the puerperal condition. However, they stressed a daily feeling of sadness, suffering, and pain due to the impossibility of breastfeeding.

*Back in the maternity ward, when I just had the baby, they gave me an injection to dry the milk, but it does not dry that soon. My breasts became really enormous. I had a fever, it was horrible [...] until it dried [...] it was very painful indeed. (Woman 9 HIV SP).*

Besides receiving medication to suppress lactation in the maternity, other measures to relieve breast discomforts were used, by the interviewees, in an attempt to inhibit production. However, these measures also caused physical and psychological pain.

*In order to dry the milk [...] I would take off the milk, every morning I would use a warm compress [...] and I also received medication, but it did not work, the milk dried only when I came back home. There in the maternity, they told me to use the compress of ice to avoid it to barden and that I should continue to take off the milk. (Woman 3 HIV SP).*

*[...] It gets bloated, it's unbearable, you have fever, I had a fever and cold [...] then my husband bought it [a kind of oil], I greased it, I took the comb, it hurt a lot [...] it would come out, dripping, dribbling [...] I was like this for three days and then it dried up. (Woman 5 HIV SP).*

*I felt so sad when she bandaged my breast [...] a huge pain. I even tried to stop it! (Woman 32 HIV SP).*

For the interviewees, being a mother is a natural event for women, it is normal and natural for a woman to breastfeed her child, especially if she is healthy, as shown in the following speech:

*[...] in my opinion, this is normal, it's natural because every child has to be nursed [...] when the mother is healthy, it is important to give the milk. (Female 29 HIV SP).*

Thus, the recognition that it is normal for a woman to breastfeed and that the breast milk

brings benefits to the health of the child had motivated some women to choose to breastfeed, although knowing their serological status. Thus, the desire to breastfeed overcomes the risks that contaminated milk can cause to the infant organism, as the following speeches illustrate:

*[...] for me this is normal, it's natural because every child has to be nursed [...]* (Female 29 HIV SP).

*I myself know a [mother] who got the HIV virus, and got pregnant [...] the children were born without the virus [...] but she nursed the children even knowing [of the seropositivity] [...] so she knew, but even so she did not give up breastfeeding. She nursed them up to they grew up [...] I do not know if the children got the virus or not.* (Woman 15 HIV SP).

### *The obscurity before the window of life: the challenge of social prejudice*

Failure to breastfeed due to seropositivity forced women to create situations to justify the non-breastfeeding before society, so as not to suffer the prejudice and discrimination of being HIV positive. Above all, they did that out of lack of courage to reveal their status as seropositive to family members and/or closer people.

*[...] my mother comes and says [...] breastfeed your child girl! [...] I have not told her that I am HIV positive. My sister is the one who knows. I get sad but what can I do? When my mother asked me, I told her that the milk dried and I'm not going to breastfeed him and I do not want to, then she said she was very sad [...] but I have not had yet the courage to tell my mother.* (Woman 2 HIV SP).

*[...] the people kept asking why I was not nursing [...] I would want to cry because I couldn't tell the truth. I said they had not told me anything.* (Woman 10 HIV SP).

In the invented situations, the women claimed, especially, being affected by a kind of health problem, as it appears in the speeches:

*[...] when people asked me why I was not breastfeeding, I would say that it was because I had a lung problem. I denied it, I was ashamed to tell [...]* (Woman 4 HIV SP).

In this group of women, the justifications were diversified: I do not want to, I cannot, I do not have milk, my milk is weak, it is not good, it dried up, my milk has problems, I am taking medicine, I have a health problem, I have problems with my blood, I am sick, I have anemia, hepatitis, puerperal infection, I do not

like to breastfeed, milk has not been produced, and my breasts can become flaccid.

## Discussion

The study presented limitations regarding the restriction to one locality – once the representations expressed in the feelings are of seropositive women being treated in the city of Salvador –, as well as to methodological aspects - the results produced with a qualitative approach are not generalizable. The results, however, pointed to new scientific knowledge that can be incorporated in the planning of care to be provided by nursing professionals to HIV and HTLV positive women who have newborn children. Furthermore, it is fundamental to know the feelings of these mothers experiencing the impossibility to breastfeed due to the contamination of their milk, based on the social representations seized from common sense and its signification systems. In this way, nursing professionals will be able to think/act and propose congruent and individualized care, consistent with what it means to be a woman, mother, HIV-positive and unable to breastfeed the child.

The feelings of sadness, fear, guilt, uncertainty, and anger expressed by mothers towards the experience of not breastfeeding contribute to the construction and interpretation of social reality. The understanding of this daily life is possible based on the comprehension of mental constructions of people, originated from daily life and the experience of the phenomenon/reality common to a social group<sup>(8)</sup>. In the present study, representations help to understand how women feel before the impossibility of breastfeeding since they have to deal with seropositivity.

The feelings expressed in the women's representations about non-breastfeeding showed that although aware of their serological status, they hold fast to the dream and the desire to breastfeed. However, not breastfeeding to preserve the child's health forced them to stifle such desire. Therefore, non-breastfeeding mothers experienced motherhood by denying

breast milk to their child. This, in some situations, can be delicate and embarrassing before other women and society, as well as painful and a source of suffering<sup>(9)</sup>. This can mean losing the dream of putting into practice the maternal skills and affections symbolically represented by the act of breastfeeding.

The dissolution of the dream of breastfeeding brings on psychological suffering because it is as if the mother denied the food considered ideal and diffused in the media as “the best medicine for the health of the child”<sup>(10)</sup>. This situation highlights only the milk of women who can breastfeed, leaving aside those who are unable to do it, such as HIV SP and HTLV SP women.

Breastfeeding promotion campaigns point to breastfeeding as desirable and ideal for maintaining the health of children, assigning to women the responsibility to promote breastfeeding<sup>(10)</sup>. In society, motherhood has been valued and instituted as the responsibility/duty of women, contributing to the imagery of breastfeeding as a sociocultural and historical process. Motherhood has also been based on socially constructed characteristics that refer to affectivity (feelings such as tenderness and affection) and favor the mother-child bond<sup>(11)</sup>.

Such representations of motherhood are also centered on a socially produced view, still in the eighteenth and nineteenth centuries, related to the social construction of which the biological condition of women confers them the desire of motherhood. Such thinking overlooks issues involving the psychological, cultural, social, and historical dimensions<sup>(12)</sup>.

As social representations are elaborated in the scope of the communications between groups, articulating elements of the relation of the individual with the world and with the group, they have repercussions on the social interactions and social changes, initiated with the content elaborated by a person who undergoes social, cultural, political, and historical transformations<sup>(11)</sup>.

The three systems that induce representations – diffusion, propagation, and propaganda –, analyzed by Moscovici, correspond to the

creation of stereotypes and conducts through communication<sup>(12)</sup>. Regarding the representation of breastfeeding as a symbol of motherhood, this is linked to the diffusion system, because the information is not addressed to a specific group, but to a plurality of groups, and the message about an object is organized in an undifferentiated way, ignoring the social differences and not provoking changes of attitude<sup>(13-14)</sup>. Therefore, the fact that there are other women who cannot breastfeed, simply because they do not want to or because they have contraindications, such as HIV and HTLV seropositivity, is forgotten.

Research shows that abstinence from breastfeeding due to HIV infection has caused women to feel sadness, for the reason that they did not have breastfed their children and, on the other hand, happiness because they did not contaminate their children with the virus<sup>(9,10,15-16)</sup>. Other feelings, such as suffering, frustration, fear, and anguish were also voiced by women in the face of non-breastfeeding. However, some women understand non-breastfeeding as normal, either from past experiences not very pleasant or simply because it meant a benefit to the child, in this case, non-contamination by the virus. In addition, having received help to feed the child minimizes the anxiety, uncertainty, and fear concerning the food to be offered to the child in place of breast milk.

Thus, it was evident that, when there was a change in the context of activation of the social representation of the object, that is, of the contamination of the breast milk and non-breastfeeding, the conduct before this representation occurred less painfully. This is because the uncanny became familiar, and the abstract became concrete. The concept has become an image capable of visibly reproducing an idea<sup>(13)</sup>, which can be identified based on cultural and normative criteria, outlined from the figurative nucleus through the naturalization of an abstract element materialized in elements of reality through classification and naming<sup>(14)</sup>.

The non-breastfeeding caused physical and organic changes that were both visible and felt in the female body, especially breast changes,



feelings of sadness, suffering, and pain. There were reports of pain, fever, and cold causing this period to be experienced by women with distress and suffering, demonstrating the inability of health professionals to deal with these issues.

Thus, by having their breasts bandaged, women faced emotional disorders that affected them in their different dimensions: physical, psychic, social, and cultural. They expressed several feelings that triggered internal conflicts, arising from social constructions about being a mother/woman. They include the embarrassment of the visibility of non-breastfeeding that the bandage provokes before family members and society as much as the consequent fear of the possibility of having their serological condition discovered. They include the discomforts and pains in the breasts resulting from the bandaging and also the aesthetic concern with the body, due to the relation of the breasts with being a woman<sup>(5,9)</sup>. These representations seen in these feelings are often overlooked by professionals, compromising the care to those women who live with the impossibility of breastfeeding.

By socially justifying non-breastfeeding, seropositive women suffer doubly – because they are not breastfeeding and because of the negative judgment against seropositivity. When they are afraid of stigma and social discrimination, they hide their serostatus, even from their own family. A seropositive woman may also feel embarrassment when she feels explicitly or implicitly demanded by health professionals, family members, and friends to give the reason for such behavior since in most cases these people are unaware of the seropositive status of the woman and take into account only the duty to breastfeed. However, social demands place them in embarrassing situations, ignoring aspects such as pain for the impediment of breastfeeding and the social punishment they have to bear. Therefore, they create socially accepted excuses to justify not breastfeeding<sup>(5,17)</sup>.

To do so, women used explanations related to maternal condition (lung problems, blood sugar), low milk production (I do not have milk, I produce too little milk, my milk dried up) or

they argued that they simply did not want to breastfeed, or did not know the reason they were forbidden to breastfeed. Among the reasons related to the newborn, only breast refusal was mentioned. Thus, in order to avoid such embarrassment, women have used common-sense claims which are not scientifically justified nor acceptable.

In order to the care of health professionals be efficiently established, it is necessary to develop skills to deal with women living with the condition of seropositivity and with the newborn, based on the needs presented and socially represented by them. This must aim to guarantee the preservation of the women's personal issues, offering them, above all, support and guidance in this unique and difficult situation<sup>(9)</sup>.

Thus, for the purpose of ensuring the prevention of vertical transmission, it is necessary to follow women since the pre-conception assistance, in order to know the serological condition of the expectant mother, as well as to invest in educational campaigns that affect preventive care. Pre- and post-testing counseling are also essential for prenatal care, which requires the building of mutual trust<sup>(18)</sup>. Hence, in the puerperium, the new mother will be conditioned and sensitized by the need to avoid breastfeeding. Therefore, advertising is a form of communication of a group that offers a cleaved view of the world, whose dynamics is inscribed in conflicting social relations, emphasizing them and accentuating social differences<sup>(12,14,19)</sup>.

Thus, “[...] appropriate environments must be created to reduce the stigma and discrimination”<sup>(18; 753)</sup> to which these women are exposed, having as “[...] assistance strategy, the lived and dialogued encounter, mediated by listening, empathy and inter-subjectivity, that develops from the understanding of the way of being of the human”<sup>(5; 82)</sup>.

The need to invest in new principles of rationality, allowing access to the space of representations, meanings, new possibilities for interpersonal interaction, and recognition of the world, is thus acknowledged. This new rationality requires that professional aptitude in the field of

health should include the ability to observe and listen, reworking concepts, descriptions, and taxonomies based on speeches and gestures<sup>(20)</sup>.

As social representations are interactive constructions objectified and anchored in situations experienced in the daily life, they originate with individuals belonging to a group, whose nature is relational, supported in the psycho-cognitive field of each one. Developed and shared within these social groups, social representations gain new meanings and knowledge, passing transformations over time<sup>(21)</sup>.

## Conclusion

Non-breastfeeding, for the investigated group, is represented as a conflicting act between the desire to breastfeed, fostered by the social construction of motherhood, and to keep the child healthy, free from vertical transmission of HIV or HTLV. The feelings of sadness, guilt, anger, and frustration arising from the decision not to breastfeed cause suffering that afflicts the body and mind of women. By anchoring and objectifying non-breastfeeding as something hard and difficult to conceive in their cognitive systems, women re-signify the representations of non-breastfeeding through conflicting feelings for coping with seropositivity.

The feelings of the investigated women evidenced the need to reflect on the practice of breastfeeding as an act of protection and love recommended by health professionals since not all women can adopt this practice. For them, not breastfeeding can be an act of protection and love that requires overcoming and causes suffering. In their professional practice, nurses have the possibility to intervene in the situation of non-breastfeeding by incentivizing/supporting the women in their decision.

We conclude that the feelings towards non-breastfeeding are permeated by conflicts from socio-culturally established patterns of breastfeeding. In professional practice, nurses have the possibility to intervene in the situation of non-breastfeeding by supporting the women in their decision.

## Collaborations

1. conception, design, analysis, and interpretation of data: Marizete Argolo Teixeira and Mirian Santos Paiva;

2. writing of the article and critical review of intellectual content: Marizete Argolo Teixeira, Mirian Santos Paiva, Pablo Luiz Santos Couto, Jeane Freitas Oliveira and Rafael Moura Coelho Pecly Wolter;

3. Final approval of the version to be published: Marizete Argolo Teixeira, Mirian Santos Paiva, Pablo Luiz Santos Couto, Jeane Freitas Oliveira and Rafael Moura Coelho Pecly Wolter.

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