

ORIGINAL ARTICLE

FEELINGS AND MEANINGS: HIV IN THE IMPOSSIBILITY OF BREASTFEEDING

SENTIMENTOS E SIGNIFICADOS: HIV NA IMPOSSIBILIDADE DE AMAMENTAR

SENTIMIENTOS Y SIGNIFICADOS: EL VIH EN LA IMPOSIBILIDAD DE LA LACTANCIA MATERNA

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ABSTRACT






**Objective:** to interpret the feelings and meanings that women living with HIV / AIDS attribute to the impossibility of breastfeeding and motherhood. **Method:** this is a qualitative, descriptive, exploratory and phenomenological study, by means of recorded unstructured interviews with six postpartum women living with HIV. Data was analyzed after description; reduction and the phenomenological interpretation. **Results:** three categories were raised: << From self-contempt to denial: the phenomenon of protecting the child from himself >>; << HIV and social stigma >>; << From information to knowledge: support networks >>. **Conclusion:** denoted feelings of anguish, fear, self-contempt, denial of one's own health condition, isolation and loneliness due to fear of social prejudice. In addition, they attribute the HIV virus directly to AIDS, with its extreme complications, and relate the possibility of death and leaving their children alone. On the contrary, it is revealed that, after knowing the treatment conditions, they feel safer and hopeful. It has been reported that on emotional support in difficult times, they seek faith and the prospect of living to care for their children and see them grow up healthy. **Descriptors:** HIV; Breast Feeding; Maternal and Child Health; Interview; Psychological; Women's Health; Nursing.

RESUMO

**Objetivo:** interpretar os sentimentos e significados que as mulheres que vivem com HIV/Aids atribuem à impossibilidade de aleitamento e à maternidade. **Método:** trata-se de estudo qualitativo, descritivo, exploratório, fenomenológico, por meio de entrevistas não estruturadas gravadas, com seis puérperas, que vivem com HIV. Analisaram-se os dados após a descrição; redução e a interpretação fenomenológica. **Resultados:** levantaram-se, três categorias: << Do autodesprezo à negação: o fenômeno de proteger o filho de si >>; << HIV e o estigma social >>; << Da informação ao conhecimento: redes de apoio >>. **Conclusão:** denotou-se, sentimentos de angústia, medo, autodesprezo, negação da própria condição de saúde, isolamento e solidão devido ao receio do preconceito social. Nota-se que, além disso, atribuem o vírus do HIV diretamente à Aids, com suas extremas complicações, relacionam a possibilidade de vir a óbito e deixar seus filhos sozinhos. Revela-se em contraponto que, após o conhecimento das condições de tratamento, sentem-se mais seguras e esperançosas. Relatou-se que sobre o apoio emocional nas horas difíceis, buscam na fé e na perspectiva de viver para cuidar dos filhos e vê-los crescer saudáveis. **Descritores:** HIV; Aleitamento Materno; Saúde Materno-Infantil; Entrevista Psicológica; Saúde da Mulher; Enfermagem.

RESUMEN

**Objetivo:** interpretar los sentimientos y significados que las mujeres que viven con el VIH / SIDA atribuyen a la imposibilidad de la lactancia materna y la maternidad. **Método:** este es un estudio cualitativo, descriptivo, exploratorio y fenomenológico, mediante entrevistas grabadas no estructuradas, con seis mujeres puérperas, que viven con el VIH. Los datos fueron analizados después de la descripción; reducción y la interpretación fenomenológica. **Resultados:** se plantearon tres categorías: << Del autodesprecio a la negación: el fenómeno de proteger al niño de sí mismo >>; << VIH y el estigma social >>; << De la información al conocimiento: redes de apoyo >>. **Conclusión:** denota sentimientos de angustia, miedo, autodesprecio, negación de la propia condición de salud, aislamiento y soledad debido al miedo al prejuicio social. Además, atribuyen el virus del VIH directamente al SIDA, con sus complicaciones extremas, y relacionan la posibilidad de muerte y dejar a sus hijos solos. Por el contrario, se revela que, después de conocer las condiciones del tratamiento, se sienten más seguros y esperanzados. Se ha informado que en apoyo emocional en tiempos difíciles, buscan fe y la posibilidad de vivir para cuidar a sus hijos y verlos crecer sanos. **Descriptor:** VIH; Lactancia Materna; Salud Materno-Infantil; Entrevista Psicológica; Salud de la Mujer; Enfermería.

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## INTRODUCTION

Acquired Immunodeficiency Virus (HIV) is known to cause progressive destruction of the immune system, making it unable to fight off infections and disease. Thus arise the so-called "opportunistic infections", which are infections that take advantage of the fragility of the organism; Acquired Immunodeficiency Syndrome (AIDS) refers to the most advanced stages of HIV infection, ie, when more than 20 opportunistic infections or cancers related to the virus occur.<sup>1</sup>

Since 1933, AIDS has been classified as a pandemic, and the first cases described in the literature occurred in the United States (US) in the early 1980s. It is reported that, at this time, there was no complete knowledge as to the cause of the disease, as it was supposed to be related to the compromise of cellular immunity related to risky sexual behaviour and homosexual relations.<sup>2-3</sup>

It is noted that in that same decade, Brazil was also hit by an HIV epidemic that, at first, affected homo and bisexual men and hemophiliacs and, later, injecting drug users. Since then, there has been a change in the epidemiological profile of people with HIV, the feminization of this epidemic, that is, the rapid increase in cases among women, with high rates of seropositive pregnant women being cataloged, a factor considered to be a public health problem through the possible vertical transmission of HIV.<sup>3-4</sup>

AIDS has been controlled with the introduction of antiretroviral therapy or HAART (highly active antiretroviral therapy) to make survival of HIV-positive individuals possible and currently about 36.9 million people worldwide live with the virus. In addition, efficient treatment to control the disease and improve the quality of life is shown, as well as to decrease the transmission rate of the virus.<sup>5</sup>

Between 2000 and 2017, 108,134 infected pregnant women were reported in Brazil, which reflects an alert situation and requires specific care. Approximately 65% of vertical transmission (VT) occurs during labor or delivery itself; 35% occur in the intrauterine environment, often in the last weeks of pregnancy, and the rate of VT during breastfeeding is between 7% and 22%, renewing itself with each exposure.<sup>2-6</sup>

It is described that one of the policies adopted by the World Health Organization (WHO) for TV prophylaxis are programs that recommend the use of antiretrovirals by mothers, the use of injectable Zidovudine (AZT) for women in labor and delivery and AZT oral solution for the newborn. In this regard, the WHO also recommends that mothers not breastfeed their children and not donate milk.<sup>7</sup>

Inhibition of lactation can be achieved soon after delivery with mechanical and

pharmacological measures. The mechanical measures in performing the breast compression (bandaging) are versatile, because this measurement alone is successful in up to 80% of cases, when maintained for a period of seven to ten days. However, breast manipulation and stimulation should be avoided and, in cases of difficulties in programming this measure, pharmacological suppression may be adopted using the lactation inhibitor.<sup>8</sup>

Breast milk is known to have a fundamental biological and emotional influence on the health of both mothers and children. Moreover, pregnancy is an important event that brings many expectations about the lives of these women, as many of them consider it a full way to fulfill the role of mother.

Although inhibition of lactation is a very effective measure for decreasing rates of vertical transmission of HIV; The following question arises: How do mothers living with HIV feel that they cannot breastfeed their children?

The research is justified by the importance of care with the postpartum in aspects related to emotional balance to deal with the new factors mother / child, family life and social relations, since the disease without cure and loaded with prejudice involves continuous treatment, with the possibility of complications related to immunosuppression, as well as complex situations associated with socio-emotional aspects. Thus seeking subsidies for a properly instrumented and integral attention to the carriers of the virus.

## OBJECTIVE

- To interpret the feelings and meanings that women living with HIV / AIDS attribute to the impossibility of breastfeeding and motherhood.

## METHOD

This is a qualitative, descriptive, exploratory, descriptive, phenomenological study. In Phenomenology, one wishes not to explain but to describe the phenomenon in its essence, that is, to understand it from the perspective of the individual perceptions of each being. Thus all acts, gestures, habits, any human action have meaning. Consciousness is understood, through intentionality, as attributing meaning to objects.<sup>9-10</sup>

Included in the study population, puerperal women living with HIV, registered at the Ambulatory School (AMBES), STD / AIDS treatment service and viral hepatitis of Passos-MG.

Six of the nine registered women were willing to participate in the interview. One refused to participate, another had no cognitive ability to answer for herself and another was under 18 years old.

Inclusion criteria were mothers who live with HIV who had their childbirth between 2015 and 2018, and those who were younger than 18 years old were excluded.

For data collection, unstructured interviews were conducted individually with each woman, with the guiding questions: “How did you feel when you found out you could not breastfeed your child?”; “Have you suffered any kind of prejudice from family or society?”; “Do you have negative thoughts loneliness, fear? What helps when you have bad feelings?”.

Data was collected from June to August 2018, after the agreement of the subjects, using the Free and Informed Consent Term (FICT), which was evaluated and approved by the Research Ethics Committee for Human Beings, Resolutions No. 466/12, and 510/16 of the National Health Council - Ministry of Health, according to CAAE No. 83141817.8.0000.5525 of the Minas Gerais State University. A letter was sent to the coordinating nurse of AMBES requesting authorization to conduct the research, which was authorized.

Participants were invited to be part of this study and, on occasion, the objectives of this study were explained and all were assured of the confidentiality of the data, anonymity as well as the right to interrupt their participation in the study, any time if they wished. It is revealed, in order to maintain the confidentiality of the identification, that the mothers were represented as M 101, M 102 and so respectively.

The interview speeches were initially recorded and later transcribed, read and interpretatively organized in the light of phenomenology in order to describe and reduce the phenomenon through the perspective of each individual's human perceptions and experiences.

The interviews with the six women made it possible to discover the essence of the phenomenon. Data was analyzed following the steps: description and phenomenological transcription of the interviews; the reduction, that is, organization and union of the statements in unity of meaning; distribution into categories and the phenomenological interpretation.

It becomes the fundamental phenomenological description because the habitual look does not allow to highlight the phenomenon itself, so, in this approach, the researcher considers their life experiences in their universe, a question of their own, allowing them to understand the phenomenon which is sought.<sup>11</sup>

Three categories emerged that denote the feelings and meanings related to the daily experiences of women living with HIV: “From self-contempt to denial: the phenomenon of protecting their children from themselves”; “HIV and social stigma”; “From information to knowledge: support networks”.

## RESULTS

### ◆ From self-contempt to denial: the phenomenon of protecting one's child from oneself

The women felt desperate at the moment of discovery of the diagnosis, in panic because they did not accept the symptoms and the possibilities of treatment. One reflected on cases of people who died in the suffering of AIDS. Children were thought of and how they would be alone if they died. There was a feeling of sadness, fear and frustration and yet they do everything to take care and protect their children from health.

*I feel terrible, the worst person in the world, a pain that only those who pass by can understand [...]. I'm afraid, I'm afraid of dying and leaving my child alone, I'm afraid of suffering in my death, of getting worse and dying little by little, because there are people who die like this. (M 101)*

*I felt horrible; when I found out, it felt like my world fell, that the ground was going to end; I was afraid [...]. I was afraid to die, I felt dirty [...]. (M 103)*

*I don't think about it much, I don't brood, I live normal, there are days I don't even remember. But moving it hurts, causes pain. (M 105)*

*I felt sad, scared, thinking, "How do I tell people?" Because I gave mamma to the other children, I thought, "How was I going to do it?". (M 102)*

*I felt sad because every mother likes to give mama. (M 104)*

### ◆ HIV and social stigma

In the testimonies, it is noticed the discrimination for the removal. It is mentioned that there are people who, when they know they have the disease, move away and thus prefer to keep the diagnosis confidential.

*No one knows about my illness, nor does my mother. (M 101)*

*My family, my sisters, I do manicure work, my sisters asked me if I had not caught this disease in a long time and knew the diagnosis, if I had their fingernails and other people's nails cut with pliers and transmit the disease to their others. I said that this was a very big sin, that it was inhuman, that is not because I have the disease that I will pass on to others, this is sin! (M 105)*

*My mother didn't talk to me at first; now she helps me, accepted and saw that she had no danger; my husband already knows and supports me. One time I was talking to a neighbor, she didn't know I was HIV-positive, my sister-in-law is dating a guy who got out of jail, who has the virus too, the neighbor asked me: "How does the 'person' have Courage to date / kiss someone who has AIDS? If it were me, I wouldn't drink in the same glass". (M 103)*

### ◆ From information to knowledge: support networks



According to the interviews, it is shown that although the mothers knew they could not breastfeed due to the instructions received, all of them showed, at a first moment of the diagnosis, little knowledge about the treatment, giving superficial or misleading information; however, as they lived with the treatment, they felt safer because they understood the functionality of the drugs.

*Before, who was afraid of dying, I felt dirty; now I have accepted the disease. I take my strength from him (son), I think I now have to take care of him and give him the best. (M 103)*

*[...] My current husband knows about the disease, I really wanted to give him a child because he didn't have it yet, and this baby was the best thing that ever happened to me, I draw my strength in God. (M 106)*

It is explained that the psychological and emotional support to seropositive women, in some situations, goes beyond the power of convincing and informing about the disease, because it is necessary to understand individually the characteristics of decision making and to plan a special conduct.

*I know this disease is to build the name of the Lord; I know it's not to my bad, I even stopped taking the medicine a while because I wanted God to heal me, I believe it, but then I got worse, I came here at the clinic, they told me that I couldn't run out of medicine because this is how if I get the flu I can get worse, get in and die, so I talked to God and I thought I could keep taking the medicine that it wouldn't stop me from receiving God's cure [...] this disease was to glorify the name of him, of my Lord [...]. He will heal me yet because I will give my testimony in the church and I will take the exams and it will not come to anything. How will you explain if there is no cure for doctors? (M 105)*

Regarding the reception of women about the guidance provided by health professionals, it is reported that all interviewees reported receiving support and guidance from the team, also claiming that they had never suffered any kind of prejudice from the professionals of the unit.

Thus, it is shown that the Nursing team has an essential role with regard to health education, HIV and treatment, improving the quality of life of carriers, in order to minimize the side effects of medications. Finally, it is understood that the welcoming of the team helped to better cope with the situation.

*I always received information from the team, always very clear and explained. (M 101)*

*They always supported me. (M 103)*

*They always helped me, explained everything right. (M 105)*

## DISCUSSION

Breastfeeding gives babies a healthier start to life. Through breastfeeding, cognitive

development is boosted and acts as a first vaccine for babies. Child and mother's risk of infections and illness is reduced, lowering health care costs and creating healthier families.<sup>12</sup>

In addition, breastfeeding is considered as a natural destination for women, and it is normal and natural to breastfeed their children. It is due to the reflection on the breaking of the dream and the honor of putting into practice the maternal affective skills represented socioculturally by the act of breastfeeding, psychological suffering, as it is as if the mother denied the food considered perfect for full growth and development of the child.<sup>8,13</sup>

Through breastfeeding campaigns, breastfeeding is referred to as desirable and ideal for maintaining the health of children, giving women the responsibility to comply with this practice. Thus, the woman ends up not taking into account the impossibility of some mothers being able to breastfeed precisely because breast milk can cause harm to the child. This can cause emotional discomfort and guilt in these mothers, as they cannot breastfeed and then "fail" to contribute to the beneficial aspects of breastfeeding the baby.<sup>3</sup>

These women suffer at first for not breastfeeding and then for condemning HIV-positive serology in the face of fear of stigma and social discrimination. Thus, it becomes possible to realize that social charging puts them in awkward situations.<sup>13</sup>

It is reflected that an individual not only adapts biologically to different kinds of demands and pressures, but also needs to adjust psychologically and emotionally. Despite the changing profile of people living with HIV / AIDS, psychological maladaptation to diagnosis is strongly referenced to prejudice, stigma and discrimination, making patients feel anguish, fear, shame, anxiety and depression.<sup>14-6</sup>

Stigmatization and discrimination related to people with HIV / AIDS are strongly related to the gender profile related to the onset of the disease epidemic. Given this situation, many mothers suffer on their own and do not talk about serological conditions even to the closest people in their social cycle. They are afraid of losing their friends, family and children.<sup>16</sup>

It is warned that the non-acceptance of their own health condition leads to defensive processes such as denial, and people who discover to be carriers of chronic diseases reverberate emotional mechanisms of dependence on those closest to them, or denial of their own health condition, since, in situations of chronic illness due to lack of adaptation, they resort to unconscious defensive strategies of denial to avoid suffering, fear and despair.<sup>17-9</sup>

Defensive motherhood becomes an emotional process in which mothers seek to protect their children from themselves when they feel self-disgust and self-loathing. Mothers focus their efforts on children, despite assuming favorable attitudes towards the future of their children, placing themselves in the background of care and segmenting the treatment of infection from its implications. It is known that this is an issue that demands attention from the professional team, since denial can lead to attitudes such as abandoning treatment or compromising the mother's self-care.<sup>18</sup>

By the effect of behavior, it interferes directly with psychological well-being, and thus the individual can cope with various demands or pressures. In this sense, it is inferred that adjustment is a process whereby a living organism maintains the balance between its needs and the circumstances that influence the satisfaction of those needs, thus connected to values, since one cannot think of adjustment without being sensitive to good and evil or right and wrong.<sup>14</sup>

It was possible to realize in an analysis performed that, for people living with HIV, the feeling of not being able to do anything because of the virus is greater among patients who do not have a treatment support. This finding establishes the fact that the presence of a treatment advocate increases the patient's sense that they are capable of performing any task, which facilitates adjustment to HIV.<sup>14</sup>

Thus, when a pregnant woman knows and believes in the form of treatment and the importance of her children being healthy, with the use of measures to prevent vertical transmission, the mother's self-care rates may increase. It is noteworthy that there is perseverance in overcoming and facing the obstacles to continue living, with the purpose of taking care of the children and seeing them growing healthy, proving to be a very significant factor regarding the motivation to continue the treatment.

Maternity strengthens and, in a certain way, when one perceives a feeling of self-forgiveness and free of self-loathing, the desire to continue life and to take care of the children, indirectly promoting self-care and admitting a new position towards the disease. It becomes the figure of the child a reason to rethink his health situation in life, reflecting a stimulus to resist bad times and even to find an innovative sense for life.<sup>16,18</sup>

Moreover, religion and faith were shown to be a great system of emotional support and coping from a new perspective. Emotional coping strategies that are triggered together with religion are associated with affection, God, love, care, help, strength and forgiveness, hope, pleasant feelings of well-being and comfort, and also place

in God the trust of better days for them and their families.<sup>16</sup>

## CONCLUSION

From the testimonies, it was observed the impact on the change of life of these women, which impacted after the birth of the child due to the impossibility of breastfeeding.

In the situation in which they find themselves during the postpartum period, feelings of anguish, fear, self-contempt, denial of their own health condition, isolation and loneliness due to the fear of social prejudice. It is noteworthy that, in addition, they attribute the HIV virus directly to AIDS, with its extreme complications, relate the possibility of death and leaving their children alone.

On the contrary, it is revealed that, after knowing the treatment conditions, they feel safer and hopeful. It is stated that, on the emotional support during difficult times, they seek in faith and the perspective of living to take care of their children and see them grow up healthy.

Thus, these processes were shown as axes that guided the production of care, in the structuring dimensions of services provided. It is understood that the attention offered by the Nursing team to mothers and family members, with guidance, support, accurate information, encouragement to bond with the baby, participation in care and learning to identify the needs of mothers and family in this situation of not being able to breastfeed, can expand humanized and welcoming care in the various institutional settings. For this reason, it is considered important to rethink and reorganize the intersectoral actions that affect the care of women living with HIV.

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