



SEROPOSITIVE RECENT MOTHERS TO HIV: HOW ARE EXPERIENCING NOT BREASTFEEDING

PUÉRPERAS SOROPOSITIVAS PARA O HIV: COMO ESTÃO VIVENCIANDO A NÃO AMAMENTAÇÃO

PUÉRPERAS SOROPOSITIVAS PARA EL VIH: CÓMO ESTÁN VIVIENDO LA NO LACTANCIA MATERNA

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ABSTRACT

Objective: to know how recent mothers with seropositive to the Human Immunodeficiency Virus are experiencing or have experienced the guidance of not breastfeeding. **Method:** this is a descriptive and exploratory study, with qualitative approach, developed with six recent mothers in a Specialized Service to HIV/aids, in a city of Rio Grande do Sul/RS. The construction of the data was through semi-structured interview and after the transcription they were submitted to thematic analysis. The study was approved by the Committee of Ethics in Research, opinion 006 2010. **Results:** two categories were identified: 1. Difficulty of coping with the condition of not breastfeeding, 2. Not breastfeeding: a gesture of love for her son. **Conclusion:** feelings of sadness and anguish were present in the reports, however, the decision not to breastfeed is attached to the protection and love for the baby. The nurses who work with pregnant women and recent mothers with HIV need to prepare for such a thing, because the Nursing Care aims to promote health and happiness, even in the most difficult and complex situations. **Descriptors:** Nursing; Breastfeeding; HIV.

RESUMO

Objetivo: conhecer como puérperas soropositivas para o Human Immunodeficiency Vírus estão vivenciando ou vivenciaram a orientação de não amamentar. **Método:** estudo exploratório e descritivo, de abordagem qualitativa, desenvolvido com seis puérperas em um Serviço de Assistência Especializada ao HIV/AIDS, em uma cidade do Rio Grande do Sul/RS. A construção dos dados foi mediante entrevista semiestruturada, após a transcrição, foram submetidas à análise temática. O estudo foi aprovado pelo Comitê de Ética em Pesquisa, parecer 006 2010. **Resultados:** identificaram-se duas categorias: 1. Dificuldade de enfrentamento da condição de não amamentação, 2. Não amamentação: um gesto de amor pelo filho. **Conclusão:** sentimentos de tristeza e angústia estiveram presentes nos relatos, entretanto, a decisão de não amamentar está atrelada à proteção e amor pelo bebê. Os enfermeiros que atuam com gestantes e puérperas soropositivas precisam se preparar para tal, pois o Cuidado de Enfermagem visa promover a saúde e a felicidade, mesmo nas situações mais difíceis e complexas. **Descritores:** Enfermagem; Aleitamento Materno; HIV.

RESUMEN

Objetivo: conocer como puérperas seropositivas para el Human Immunodeficiency Vírus están viviendo o vivieron la orientación de no amamentar. **Método:** estudio exploratorio y descriptivo, de abordaje cualitativo, desarrollado con seis puérperas en un Servicio de Asistencia Especializada al VIH/sida, en una ciudad de Rio Grande do Sul/RS. La construcción de los datos fue mediante entrevista semi-estructurada, después de la transcripción, fueron sometidas a análisis temático. El estudio fue aprobado por el Comité de Ética en Investigación, parecer 006 2010. **Resultados:** se identificaron dos categorías: 1. Dificultad de enfrentamiento de la condición de no amamentamiento, 2. No amamentamiento: un gesto de amor por el hijo. **Conclusión:** sentimientos de tristeza y angustia estuvieron presentes en los relatos, entre tanto, la decisión de no amamentar está vinculada a la protección y amor por el bebé. Los enfermeros que actúan con gestantes y puérperas seropositivas precisan prepararse para tal, pues el Cuidado de Enfermería visa promover la salud y la felicidad, mismo en las situaciones más difíciles y complejas. **Descriptores:** Enfermería; Lactancia Materna; VIH.

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INTRODUCTION

The Vertical transmission (VT) of Human Immunodeficiency Virus (HIV) represents the most common form of perinatal contamination, since the year 2006 is with percentages of exposure above 85%.¹ The transmission rates can reach 20%, every 100 children born of infected mothers, 20 may become HIV-positive, however, with prevention actions, the incidence can be reduced to less than 1%.^{1,2} In addition, to realize being positive for HIV represents a moment of intense variation of feelings for the woman, since the denial of the diagnosis, bypassing several conflicts, until the acceptance and mobilization efforts to balance physical and emotional conditions, as well as the control of the disease and its consequences.³

The relevance of the study is in the opportunity to broaden and consolidate the nursing care, bearing in mind the proposal of guidance to the recent mothers with seropositive to HIV in front of the impact generated by the inability to breastfeed, as well as to assist them in this confrontation.

Brazil was one of the first developing countries to set measures to prevent VT.⁴ A study in northwestern Ethiopia, demonstrates that in this country more than 90% of cases of pediatric acquired immunodeficiency syndrome (aids) are related to VT, evidencing ineffective or non-existent treatment performed by the seropositive pregnant woman to HIV in underdeveloped countries.⁵

The lack of attention and perception of women as citizen with rights, including sexual and reproductive rights, together with the lack of knowledge of these rights and disrespect them by the health professionals, especially in the first two decades of the epidemic of AIDS, reflected the precarious assistance given to women in Brazil. Then in June 2000, the Ministry of Health (MH) developed the Humanization Program in Prenatal and Birth (HPPB), which aims to incorporate of elements such as reproductive rights respect and the humanization of health services⁶.

It is highlighted the importance of the role of the nurse and the responsibility in this issue. Thus, through the nursing consultation, in addition to performing the clinical evaluation, to provide appropriate guidelines and to request examinations⁷, the nurse performs the advice, grounded in clinical knowledge and human sensitivity, develops the capacity of intently listening, strengthening the bond with the woman and

while maintaining a posture that promotes ties of trust, in pursuit of integral attention to health.⁸

It is essential that health professionals conduct the attendance so that the recent mother can feel safe in the monitoring by a team of health and, in particular, to rely on recommendations about care during the puerperal process. To elaborate strategies of approach with the reality of those mothers, evaluating what difficulties the mother/family is finding, becomes essential and fundamental to the work of professionals, especially nurses.⁹

Given the above, this study aims to:

- know how recent mothers with seropositive to the Human Immunodeficiency Virus are experiencing or have experienced the guidance of not breastfeeding.

METHOD

This is an exploratory, descriptive study of qualitative approach for providing particular situation overview, and it can be considered as the first step of a broader search, since, as a result of its results, can be organized strategic plans of action and, thus, the work can contribute to changing the investigated reality.¹¹

The survey was conducted in a Specialized Assistance Service (SAS) to HIV/aids, in a city located in the western boundary of Rio Grande do Sul, in the period from March to July of 2010. The inclusion criteria were: to be seropositive recent mother for HIV and to have experienced the guidance of not breastfeeding due to the risk of vertical transmission of the virus. The seropositive recent mothers for HIV were excluded because for some reason, they were not attending to the health service, to take the drugs personally. Thus, subjects totaled six seropositive recent mothers to HIV.

For the treatment and interpretation of data, it was used the thematic content analysis that "involves a bundle of relationships and can be graphically presented through a word, of a phrase, of a summary."¹² This analysis aims to obtain the systematization and description of the messages' content and it consists of three steps: pre-analysis, exploration of the material and treatment with interpretation of the results obtained.¹² After the analysis, it was established two categories: Difficulty of coping with the condition of not breastfeeding and Not breastfeeding: a gesture of love for her son.

Ethical and legal precepts involving the research with human beings were considered, as the resolution 196/96 of the National Council of Health.¹³ So, it was previously distributed the Free and Informed Consent

Statement (FICS) for survey's respondents, being in two copies, one for the participant and one for the researcher. The anonymity of the participants was kept and they were identified by the letter "I" (Interviewee), followed by a numeric digit, as interview order (I1, I2, I6). The research project has been approved by the Research Ethics Committee of the Federal University of Pampa (UNIPAMPA)/RS, as Opinion nº 006/2010.

RESULTS

From the analysis emerged two categories: *Difficulty in coping with the condition of not breastfeeding* and *Not breastfeeding: a gesture of love for her son*, listed below:

♦ Difficulty in coping with the condition of not breastfeeding

Feeling guilty is one of the main feelings experienced by women because they face the possibility or the risk of transmitting a serious pathology and momentarily without cure, bringing to his son the same limitations to which they are subjected. That sentiment reflects the existing portion of a possible stigma, experienced and expressed in the following lines:

[...] It just hurts because they are looking at you with mistrust, then you stay like and now what are they going to talk [...] (I6).

[...] so they look different at you, they treat you different, it is different [...] (I3).

The presence of a possible pre-trial regarding the impossibility that these women have in breastfeeding generates an immense discomfort as it can be observed in the reports above, which was also evidenced by non-verbal language during the interviews. The recent mothers interviewed were uncomfortable when reporting their experience of not breastfeeding. The clipping of speech, following below demonstrates the concern with the pre-trial before the condition of a recent mother living with HIV, situation that they will probably feel discrimination from their children.

[...] I talk a lot with his mother ... (stumbling). I'm afraid, I try to hide as much as possible to my daughters to one day they do not talk to them. The kids have not the fault [...] (I5).

Another observation noted in the reports refers to the difficulty faced by these women, as regards the need for omission of seropositivity, which is closely correlated with breastfeeding because they feel "obliged" to omit the real reason why they are advised against breastfeeding:

[...] Difficult (laughs), because the first time, when I found out, I had that shock, I just thought I couldn't breastfeed, there when she was born, they were in the room. Oh, why don't you breastfeed? And I like: because I don't have milk. They (nursing professionals) gave me medicine to dry my chest (I6).

[...] It is so you know, it hurts because you don't know what to say to the person. That hurts! It is bad also because the powder milk dries too, but as they say, life is like that (I1).

[...] So I was thinking to say that I have hepatitis, that we can't breastfeed with hepatitis (I3).

The feelings reported by recent mothers reflect the difficulty in tackling the condition of not breastfeed their children, what is evident also in the following reports:

[...] For me it was hard because I didn't know I had, I knew it with my third child [...] (I2).

[...] For me it was hard not to breastfeed. She was coming with the hands on the breasts, and I couldn't breastfeed (I4).

[...] It has been very difficult, because since I was a kid we play with dolls, we think like that, then I grow, I have a son, I breastfeed, I will change, I'm going to take care [...] (I5).

The emotional suffering triggered by not breastfeeding provides painful and conflicting feelings, as reported by some interviewees. At the time of discovery of the inability to breastfeed, some recent mothers feel reduced as to their role as wife and mother in society. When comparing with other breastfeeding mothers usually express feelings of nonconformity and sadness:

[...] The experience is bad. It's bad to see all the mothers breastfeeding, and we cannot [...] (E3).

[...] Sometimes I wonder why others may breastfeed and I can't? (I3).

Other issues emerge from these statements, as impotence before HIV contamination, as well as numerous limitations, like the one of not being able to breastfeed, among others. These issues can be highlighted in the following reports:

[...] I cried with anger, for her father and at the same time I cried of anger because I couldn't breastfeed, that hurt me (I1).

[...] She looked for the breast to breastfeed and I couldn't give (I2).

Feelings of sadness and despair also were reported by women, reflecting the anguish that exists, by being advised against practicing breastfeeding, which, besides offering the ideal food for the baby, is one of the most intense emotional relationships

between the mother and the child. Here, some reports:

[...] Then, the worst sad mothers' day (baby cries in the background), I couldn't breastfeed, it's sad, to have milk and can't give them (I2).

[...] Horrible, it is bad to have a kid that you really expected and you cannot breastfeed, for me it is bad. So, when I discovered that I couldn't breastfeed, I was desperate, I went into depression, I was just on the bed (I4).

♦ Not breastfeeding: a gesture of love for her son

The manifestations of love and zeal for the child can be found in the following reports, in which the interviewed gives their reason and motivation to carry out anti-retroviral treatment to their children, as well as seeks to follow the guidelines to prevent vertical transmission, as to not breastfeeding:

[...] I live for them, I get up every day for them, for me to be able to give a better life for them. If God wants it will be fine (I3).

[...] I feed, always, I do my exams right, for me to have strength to see them growing (I6).

In the context of HIV, according to the reports collected from participants, the way in which seropositive mothers can demonstrate their dedication and love for their children contrasts to the idealized image, many times, by most people, who understand that breastfeeding, as well as represent a gesture of love and affection for the child, it is also essential for their biological growth. The possibility to gestate and view the birth of a baby free of the disease, that both saddens and worries, makes them feel happy when thinking on possible and expected seronegativity, which can be observed in the following reports:

[...] The important thing for me is to see him healthy, being healthy, having no risk, only that makes me happy! (I1).

[...] I in my thinking, it is the only gesture of love that I can prove to my baby not breastfeeding, for him not to run any risk (I4).

The gesture of love and dedication with the son seems to be linked to the fact that seropositive mothers feel committed to not transmit the virus to the baby, seeming to find in not breastfeeding how to fulfil this determination, reinforcing the understanding that, in the condition of seropositivity for HIV, the gesture of love that can be offered, with the intention of preserving the health of the child, would be the inhibition of lactation, as it can be seen in the reports that follow:

[...] It is a gesture of love not breastfeed because with my new kid, all the tests I did, I had no problem (I3).

[...] not breastfeeding is to give love, because you won't give the virus to your baby (I5).

DISCUSSION

Breastfeeding is an action advocated for the healthy development of the baby, since it provides several benefits for both the mother and the son. It is recognized as the most complete and indicated to feed the newborn.¹⁴ But this incentive is contraindicated, when it is related to the mother's seropositivity for HIV, which awakens the woman the desire to protect the child, even if it means not offering breast milk.

The inhibition of lactation, conduct advocated by the Ministry of Health to prevent mother-to-child transmission of HIV, provide that risks are avoided between 7% to 22%, due to the exposure of newborns at the time of feeding, i.e. when the child comes into contact with contaminated breast milk. This behavior is associated with the provision of infant formula until six months to children subjected to such methods of inhibition.¹⁵

In addition to the biological factors involved in condition of breastfeeding, there are also the psychosocial factors, i.e. those involving maternal identity existed and how the woman faces the denial imposed by presence of seropositivity for HIV. The seronegativity perspective of the son is faced with several obstacles, including the physical, social and emotional, because society is still rigid in relation to issues involving women seronegative for HIV, that decide to get pregnant.¹⁶⁻⁸

The recent mothers interviewed were uncomfortable when reporting their experience of not breastfeeding because the possibility of mother-to-child transmission in addition to the stigma still present denotes that the woman opt for motherhood, in the presence of seropositivity for HIV, is generally regarded as an act of irresponsibility for them.¹⁷⁻¹⁹

In this context, the fear that society becomes aware of the diagnosis, due to the possibility of stigmatization and culpability, makes the recent mothers with HIV to avoid revelation of their serological condition for fear of being judged¹⁶⁻¹⁸. Still, not breastfeeding can raise suspicions of friends, neighbors and/or family, exposing the woman eventually to social stigmatization.¹⁹

As regards the time of discovery of the impossibility of breastfeeding, it should be

noted that, sometimes, the woman may feel frustrated about her role as wife and mother in contemporary society, especially when comparing with breastfeeding women. This fact can generate feelings of dissatisfaction and sadness, since breastfeeding corresponds to a previously established cultural and social determination, making it an act surrounded by ideologies and stigma imposed by society.¹⁷

Feelings of sadness and despair also arose in the women's reports, reflecting the anguish that exists, by the fact of being advised against the practice of breastfeeding, because the fact that they are giving birth and discovered having HIV brings changes of psychological origin, since HIV contamination still has no cure.¹ This situation causes the increase in expectations about possible contamination of the son as well as causing sensations of fear, insecurity and anguish.¹⁸ Such afflictions are present also with regard to the physical suffering of these women as a consequence of such inhibition.

It is emphasized the importance of understanding of the psycho-biologic issues with pregnancy upon the diagnosis of contamination by the HIV virus. The hard confrontation of not breastfeeding occurs as a result of this experience being interconnected to aspects of clinical origin, as well as social and psychological aspects. Such aspects trigger suffering that entwines the fact that HIV is still a pathology accompanied by social stigmas relating to inferiority and death, which leads to susceptibility to the countless prejudices.²⁰

In contradiction, the idea that exists about seropositivity for HIV, that is, the imaginary that pregnant women and recent mothers infected there was only death and, consequently, the abandonment of the child, the risk of vertical transmission undergoes to change in the way to be seen and understood by these women on the occasion of the birth of the baby, due to the symbolism and "status" that motherhood brings.¹⁸

In many situations, these women end up considering the possibility of having a healthy son as the reason to adhere to antiretroviral therapy, developing the strength to resist to preventions determined by the disease, as well as demonstrations of the medication in the organism. For these women, the use of medicine will provide the possibility of taking care of the son, to see him growing and possibly remain him healthy until the discovery of the cure of the disease.¹⁷

In this construct, to understand the feelings that surround pregnancy in the context of HIV is of extreme complexity,

because the understanding of the expression "gesture of love" won several meanings when it comes of the subjectivity of the verb "to love". So, in this context, the term gains the sense of seeking, offer satisfaction, which can be of various natures, such as the relationship with not breastfeeding and baby protection against the HIV virus, and about the relationship with society that will consider as positive their attitude of love and preservation of the baby health.¹⁸

FINAL REMARKS

In contemporary times there is incentive to breastfeeding however, we must not forget that there are seropositive women to the HIV virus which are advised breastfeeding. This fact directly affects the social identity of women, that is, her image as a mother within society. This conflicting situation triggered by not breastfeeding affects, besides the woman herself, the son that will demand to live with the possible charges and inner conflicts caused by inhibition of lactation, and the assessment of risks and benefits that not breastfeeding provides.

It is realized that the woman affected by HIV identifies in the act of not breastfeeding revealing the condition of being sick. Also, the methods for the inhibition confirm the serological status and their inability to breastfeed, impeding pursuing their biological and cultural determination, which contributes to the difficulty of acceptance and compliance with this guidance. In front of this complication, the encouragement found by these women to the drug treatment and not breastfeeding, seems to be the assessment of the risks and benefits for the baby.

The important decision to not breastfeeding, according to the reports of interviewed, denotes the maternal instinct that leads these women to avoid their child to purchase a pathology, which seems to designate so many stigmas. Through the categories listed and studied, it can be understood the reasons that determine the difficulty of coping with the condition not to breastfeed her child, as well as the understanding that these women have about inhibition. As noted, the act of not breastfeeding is linked to a gesture of love offered to their children, since, avoiding breastfeeding, will also be inhibiting the vertical transmission of HIV.

It should be noted, too, the question of the subject as being, in part, of difficult approach, in the context in which women are, therefore, in its entirety, the reports were of sadness by mentioning the inability to

breastfeed her child. It is believed that the subject can generate significant impact on opinions formed by society and health professionals, because there are feelings that arise with different intensities, when it comes to HIV and its manifestations, and these feelings become even more intense when they are connected to the vertical transmission. It is considered of the utmost importance that new studies be conducted on the issue of not breastfeeding, and its relation to perinatal transmission, considering not only the act of not breastfeeding with regard to prevention of diseases, but all changes that involves the life of these women.

Health professionals, particularly nurses who work with pregnant women and recent mothers seropositive for HIV, need to prepare for all this and they need to know the reality of these women, as well as their social-historical process. Thus, in the current days, Nursing Care cannot be restricted to clinical aspects, it needs to promote health and happiness, even in the most difficult and complex situations, valuing and respecting the human being.

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