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RESEARCH

As percepções das mulheres portadoras de HIV/AIDS perante a impossibilidade de amamentação

Perceptions of the bearers of HIV/AIDS before the inability to breastfeeding

Percepciones mujeres portadoras de VIH / SIDA ante la imposibilidad de lactancia materna

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ABSTRACT

Objective: To understand the perceptions of living with HIV / AIDS face impossibility of breastfeeding. **Method:** This is a descriptive, exploratory qualitative study conducted in a Day Hospital, reference the state of Santa Catarina in 2012. The sampling technique used was the semi-structured interview as open Minayo¹. **Results:** The study subjects showed predominant age group was between 27-38 years. The experience of not breastfeeding was for women experience painful and emotionally draining, and created a way to satisfy the idealized symbolic breastfeeding by them during the act of breastfeeding, replacing the physiological significance of breastfeeding. **Conclusion:** Thus, the nurse needs beyond compliance with protocols regarding the inhibition of lactation, understand and encourage breastfeeding symbolic, created by women, in addition to the biological, the emotional, social and cultural conditions that surround the woman. **Descriptors:** Breastfeeding, nursing, acquired immune deficiency syndromes.

RESUMO

Objetivo: Conhecer as percepções das portadoras de HIV/aids perante impossibilidade de amamentação. **Método:** Trata-se de estudo qualitativo descritivo e exploratório realizado em um Hospital Dia, de referência no estado de Santa Catarina, em 2012. A técnica de coleta utilizada foi à entrevista semi-estruturada aberta conforme Minayo¹. **Resultados:** Os sujeitos de pesquisa apresentaram faixa etária predominante foi entre 27 a 38 anos. A experiência de não amamentar, foi para as mulheres uma experiência penosa e emocionalmente desgastante, e criaram um modo de satisfazer a amamentação simbólica idealizada da por elas durante o ato de amamentar, substituindo o significado da amamentação fisiológica. **Conclusão:** Deste modo, a enfermagem precisa além do cumprimento de protocolos a respeito da inibição da lactação, compreender e estimular a amamentação simbólica, criada pelas mulheres, além dos aspectos biológicos, os emocionais, sociais e culturais que circundam a mulher. **Descritores:** Amamentação, enfermagem, síndromes de imunodeficiência adquirida.

RESUMEN

Objetivo: Conocer las percepciones de los que viven con el VIH/SIDA imposibilidad frente a la lactancia materna. **Método:** Se trata de un estudio cualitativo, descriptivo, exploratorio realizado en un Hospital de Día, referencia al estado de Santa Catarina en 2012. La técnica de muestreo utilizada fue la entrevista semi-estructurada como abierto Minayo¹. **Resultados:** Los sujetos del estudio mostraron grupo de edad predominante fue entre 27 a 38 años. La experiencia de la lactancia materna no fuera por las mujeres experimentan dolor y emocionalmente agotador, y creó una forma de satisfacer la lactancia simbólica idealizada por ellos, en sustitución de la importancia fisiológica de la lactancia materna. **Conclusión:** La enfermera necesita más allá de cumplimiento de los protocolos con respecto a la inhibición de la lactancia, entender y fomentar la lactancia materna simbólica, creado por las mujeres, además de los, las condiciones emocionales, sociales y culturales biológicos que rodean la mujer. **Descriptor:** Lactancia, ancianos, síndromes de inmunodeficiencia adquirida.

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INTRODUCTION

According to data from the Ministry of Health (MOH), the infection of the Human Immunodeficiency Virus (HIV) evolves in an accelerated manner, so that the spread over females has reached large proportions, especially in the age range of 25 to 39 years. Currently, the diagnosis of maternal infection by HIV in prenatal stages foresees reduction in probability of vertical transmission of viruses. The treatment of HIV-positive pregnant women increases by up to a 70% chance of the baby being born without the virus ².

The Ministry of Health states that the greatest number of cases of vertical HIV transmission (approximately 65 %) occurs in the period of labor and delivery, and the remaining 35% occur after intrauterine, especially in the last few weeks of pregnancy, and there is the additional risk of post-partum transmission by means of breastfeeding. The breastfeeding presents transmission risks that increase with each breastfeeding suction, raising up to between 7% and 22 % ³.

It is known that breastfeeding brings many advantages for both the mother and the newborn; however, the risk of vertical transmission of HIV is approximately 14% and increases if the maternal infection is acute and recent ⁴.

The nursing professionals should address these women through assistance that can accommodate and advise them on the management of their lives, in that their condition of HIV-carrier does not modify social conviviality, work, family, care and future of the children. The attention in the clinical management of infection should be expanded to an integral care of these women ⁵.

Despite the advantages of breastfeeding, in the cases of HIV-infected mothers it is inadvisable to breastfeed, since presence and infectivity in human milk is proven. It is recommended to provide breast milk to children of HIV positive women, if it is pasteurized, a procedure that turns inactive the HIV inactive. This practice is not distributed in the whole of the national territory. ³ The scope of the study was to identify the perceptions of living with HIV/AIDS when faced with the recommendation of not breastfeeding. Parting from the obtained results, we expect to contribute to the discussions on the process of not breastfeeding, in the light of perceptions of women living with HIV/AIDS.

In the state of Santa Catarina the incidence of new cases in the last ten years was 38 cases per 100,000 ⁶ , and in the city of Frankston the frequency of new cases in the years 2011 and 2012 was 4 cases per year ⁷.

METHOD

This study was qualitative descriptive-exploratory, as Minayo¹ performed in a Day Hospital in the state of Santa Catarina during the year 2012, were identified eight women, 03 women were excluded from the study because they refused to sign the informed consent form, having the final sample of 05 women. For purposes of confidentiality and anonymity for the identification of each interviewee the marks M1, M2, and so on, were used.

The objective of the study was to identify the perceptions of women living with HIV/AIDS given the impossibility of breastfeeding, for data-collecting semi-structured interviews were used along a questionnaire to identify data and socioeconomic characterization. For the understanding of the perception of women living with HIV/AIDS before the inability to breastfeed, up the guiding question was: *What is the perception of bearers of HIV/AIDS towards the impossibility of breastfeeding?*

The data collected were subjected to content analysis and resulted in four categories: the feeling in relation to the impossibility of breastfeeding; embarrassment of measures of inhibition of lactation; the feeling of punitive housing assembly; the imaginary in breastfeeding symbolisms.

The research project was approved by the Research Ethics Committee of the State University of Santa Catarina (Process no. 211/2011), according to the norms of Resolution no. 196/96.

RESULTS AND DISCUSSION

Sample Characterization

The women studied were in the age range of 27 to 38 years. As for schooling, only one had elementary school, one had incomplete secondary education and two had complete high school education, and only one had incomplete higher education. With regard to family income, two women have from 1 to 2 minimum salaries, two have as monthly income 2 to 3 minimum salaries, and only one has no fixed monthly income, because it is a student dependent on the country.

The low education level is related to the occupation with a lower income which causes a lower socioeconomic status. It is possible to view the difficulty of the interviewees in maintaining their economic status, beliefs and values, self-esteem, life projects, and social and cultural situation, when their positive serology was discovered in their places of work.⁸ We note that the Ministry of Health as being adult phase, in which they legally are

able to decide for themselves and generate their children ³, precisely references this age range:

In relation to the diagnosis of the disease of HIV/AIDS, we realized in research that four women received the diagnosis during the routine consultations of prenatal care for low risk. Only one woman presented result of negative examination for disease HIV/AIDS during pre-birth, but this woman had her son identified seropositive some months after the birth, being then included into the study, through the identification of vertical transmission via breastfeeding.

To receive the information of the disease HIV positive during the prenatal stage touches on several conflicting feelings, especially when the result is indeterminate. ² Study conducted with pregnant women during the prenatal phase has assigned the realization of anti-HIV test as a form of care and protection for the child, an expression of love, the test represents the possibility of preventing the transmission of HIV to their children ⁹.

By two of the women in this research the disease HIV/AIDS was identified during the first pregnancy. A second pregnancy happened by failure of contraceptive methods. They feared a new pregnancy because of the risk of disease transmission.

During the assistance to women living with HIV/AIDS, guidelines on family planning should prioritize also the methods of contraception, such as the choice of the most cost effective method and the correct use of the same, being that an unwanted pregnancy may bring many social and emotional problems with it. ¹⁰ The use of condoms, both female and male, serve as a contraceptive method preventing both a pregnancy as well as the re-infection of the virus. Currently there are many cases of non-use or improper use of contraceptive methods resulting in unexpected or unwanted pregnancy, coming to meet the reports of research, where the women mention failure of contraceptive methods.

In relation to the high-risk prenatal phase all six women had prenatal consultations and received guidance on the vertical transmission of HIV/AIDS. The prenatal care for pregnant women with HIV/AIDS should be differentiated in some aspects in relation to the prenatal normative, mainly in taking care of the fetus and the use of anti-retroviral drugs. The consultations are held monthly until the 7th month, biweekly from the seventh to the ninth month and weekly in the last month until delivery, performing the total of six consultations during the entire pregnancy. ¹¹

As the trajectory of birth, all women underwent cesarean delivery, being that two women performed tubal ligation after the birth of their sons. When one thinks about prevention of perinatal transmission of HIV, the cesarean section is a more appropriate way of childbirth, even though studies have demonstrated that the type of delivery will depend on the viral load of the woman. ¹²⁻¹³ When indicated elective cesareans should be performed in 38 or 39 weeks of gestation, thus avoiding the labor and the contact of the fetus with vaginal or cervical secretions ¹².

As findings of the survey revealed, five of the women contracted the disease HIV/AIDS of their partners, through sexual intercourse, these four maintained a stable union, while one acquired the virus in a foregoing sexual relationship.

The increasing number of new cases among women, especially those married or with fixed partners, originated the phenomenon known as "feminization of the epidemic", a term used to show the female vulnerability to exposure with the virus. Thus, many women were

infected in fertile age and by consequence, the children constituted an also growing group for HIV infection through vertical transmission ¹⁴.

The feeling about the impossibility of breastfeeding

In relation to the feelings of not being able to breastfeed, all the women said they have a lot of desire to practice lactation, but were aware of the risk of vertical transmission of HIV/AIDS disease. This is confirmed in the following reports:

This is great ... more practical, a feeling of actual breastfeeding, how can I say, even the child is more calm, does not have as much colic as with the Nan milk, that is far more complicated, until the child gets used to it, with breast milk it is more easily (M1)

"As to that I am sad ... I never gave breast but I am sad for not being able to". (M2)

The HIV-positive mothers who have adequate follow-up in the prenatal phase, showed to be aware of the recommendation of not breastfeeding, due to the risk of HIV transmission through breast milk. ¹⁴ It is believed that this clear guidance of the importance of not lactation is due to the fact that prenatal care is carried out differently by the qualified multidisciplinary team that composes the municipal service, prenatal care for high risk.

Many women have expressed their satisfaction with the fact that the newborn remain quiet, healthy, by convenience and by enjoying the closeness and caring for the child. ¹⁵

The survey showed that only one woman allowed the grandmother to breastfeed her daughter, because she also was in lactation period with enough milk to feed both her daughter and granddaughter.

"(...) as I worked out of the house I breastfed them almost only in the evening, and in the last daughter I could not breastfeed because of my disease ... my mother who had my little sister breastfed my daughter". (M5)

In Brazil a woman with HIV is oriented to not breastfeed her child, and neither is there a Breast Milk Bank (BLM) to donate breast milk. They are also advised on the risks of breastfeeding crossover. The woman with HIV/AIDS receives a free infant formula during the time of lactation of the child. The breastfeeding crossover occurs in many cases, due to a lack of understanding and clarification, understanding that it is the best for their children, not knowing that the child may contract diseases, the mothers feel less guilty for being unable to breastfeed, but providing their kids have breast milk, even being of another person ⁸.

In relation to the feelings of the women regarding the impossibility of breastfeeding, all the women mentioned a painful experience and punitive. As reports:

"A very great sadness, anguish, guilt, because I know how it is to breastfeed and I could not do this with her, she wept and I wept along ... because it was my fault not being able to give the breast to calm down". (M1)

"There is a pain inside of everyone, because in this way, it is maternal instinct ... " . (M3)

The countless restrictions suffered by HIV+ mothers, in particular the pregnant women who decide to continue with the pregnancy after the diagnosis, make the decision of not to breastfeed their babies manages lamentations and feelings of powerlessness and frustration.¹⁶ however, not breastfeeding, involves the possibility of keeping your baby healthy, which implies a biological, social, cultural and emotional aspects¹⁴.

Embarrassment of measures of inhibition of lactation

When questioned about the techniques geared to inhibit lactation, four women showed feelings of suffering, pain, helplessness and embarrassment upon the technique of mechanical restraint. Only one woman expressed tranquility in following the conduct to inhibit lactation upon the bandaging of the sinuses. As speech below:

"(...) I bandages as I was told, but all the same I had no milk, so I took them out as for nobody to see that I was bandaged, feeling pain, shame". (M4)

The mothers who live with the inability to breastfeed, conduct identified by bandaging the sinuses considered painful and punitive by women, is mitigated by the possibility to maintain the healthy baby¹⁴.

When questioned about following the orientation of mechanical containment and use of medication to inhibit lactation, three women followed the guidelines, while two women did not accept the method of bandaging of breasts, by fear of being discovered by friends and family and by discomfort generated by the bandaging. We also identified a woman who had aesthetics concerns about by bandaging, reason for her non-adherence to the technique.

The bandaging is a procedure adopted as routine in all the health care services, according to recommendations of the Ministry of Health and should always be based on free and informed consent of puerperal women. Clarification to the woman on this procedure is very important. The need to review the practice of breast bandaging and other non-biological aspects must be considered.⁸

A survey carried out in groups of a specialized Self-Help clinic in Ceará, showed that the majority of participants fear social rejection and prefer to forget the diagnosis, because they do not bear so much indifference of society.¹⁷

The imaginary in breastfeeding symbolic

All of the women researched adhered to the recommendation of not breastfeeding, because they do not want to run the risk of vertical transmission of the disease HIV/AIDS for their children, recognizing the risks of HIV infection in breastfeeding. Even to the mothers who know that the milk is contaminated by the virus, the beliefs of the benefits of breastfeeding, the impediment of breastfeeding for the well-being of the baby does not release the woman's feeling of sadness and of not having the freedom to choose, being that the only alternative offered is not to breastfeed.² Two women have reported no loss of affective bond triggered by the fact that it could not breastfeed her child, because physiological strapped to breastfeeding by an imaginary symbolic breastfeeding.

"No, not lost ... I kept the baby in the early months more closely, as close as possible". (M2)

"Not ... whenever I ... lactate into the bottle, I always held her near the chest sometimes I weeded the blouse for her to perceive the smell, I never stayed away from her, never". (M5)

They were also highlighted other forms of symbolic breastfeeding cited by women to offer the bottle beside the body, withdrawal of Ashley's mother for children to be skin to skin and perceive the smell of the mother.

It is necessary to recall the fact that these alternative methods of nourishing the baby do not deny mother nor child of skin to skin contact, caresses and attentions.¹⁸ contrary to what many authors mention as the loss of the affective bond by the inability to breastfeed, these mothers showed us that they do not feel they have lost at any moment the affective bond with their babies and yes feel an unconditional love for them, and giving them strength to continue living and struggling for life.

The affective loss is perceived by the mother as being for both, the mother and child, involving the absence of concrete experience to breastfeed for the mother and for the child to be breastfed.² The mothers infected with the virus experience the motherhood by denying the breast, losing the dream of putting into practice their skills and their motherly affections represented by act of breastfeeding.

The feeling of punitive housing assembly

With respect to the feelings that arise in the nursery, four women reported embarrassment and often felt pressured by other mothers to practice breastfeeding during the hospitalization period.

"They did not ask any questions, but they (other mothers) kept looking, ... having to take it ... administer a syringe is sad and having milk and not being able to give ... worst of all is this business of having to hide and say that I had no milk". (M1)

It was difficult, it hurt, hurt to see mothers giving breast, where I knew that I could not give breast. People see incentives of breastfeeding in various programs, but nobody talks about not breastfeeding ... I'm afraid of transmitting to my daughter ... I got my husband when I worked in a nightclub ... I have been working as a call girl for 10 years, and never got any disease, but with my husband I did. (M5).

The system of housing together is in principle an incentive to local breastfeeding, as there the puerperal women living with HIV/AIDS experience the inability to breastfeed observing this practice in other mothers staying in the same room, whereas most of the other times it becomes a painful situation⁵.

Coming to meet the research carried out by Batista and Silva⁵ where the interviewed mothers reported having the same feeling of fear during the period of institutionalization, often feels pressured by people to practice breastfeeding. Thus, these women feel constrained by not breastfeed, especially in these housings, where this practice is stimulated in most of the mothers.

The mothers express embarrassment at being accused of not breastfeeding their children. They realize that the levying of relatives and friends, who do not understand their condition, causes them anguish facing the impossibility of breastfeeding².

CONCLUSION

We identified that the researched women have in their majority low schooling, together with low income and contracted the disease HIV/AIDS from spouse during sexual relation, validating the existing profile of this population (women with HIV/AIDS) in national and international studies. Frequently, feelings of sadness, insecurity and abandonment accompany the pain of being unable to breastfeed. Pointing out that the majority of women reported suffering during the period of institutionalization, caused by the fact of being housed with breastfeeding women, aggravating the feelings of sadness, pain and guilt. Coupled to this constant fear of discovery of diagnosis by not breastfeeding and by mechanical containment of the breasts. This confirms the need of providing private rooms for these women, in the way of a readjustment of rooming in hospital institutions for this segment of the population. Thus avoiding embarrassing situations and punitive feelings.

What attracted most attention in this study was the fact that all of the women create a device to meet the need to breastfeed. For this they develop an imaginary breastfeeding symbolic, expressed in the act of breastfeeding by removing the clothes for the child to feel their touch, their smell, in short a motherly presence, as well as skin-to-skin contact without devaluing the artificial feeding. Thus all procured a symbolic manner to suppress the bond lost by the impossibility of normal physical breastfeeding.

It is essential that the health professionals if ownership of these devices, to meet the needs of these women's health, valuing and respecting these acts in search of the meaning of being a mother-woman-carrier of HIV/AIDS. It is then the alert for healthcare professionals, who through attitudes and cozy humanized, can facilitate the relationship and dialog with these women, thereby relieving the pain and suffering of not breastfeeding for that same feel secure, in this cycle of life, finding support in your family, friends and health professionals.

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