ORIGINAL ARTICLE

Problems with the puerperal breast revealed by HIV-infected mothers*

PROBLEMAS COM A MAMA PUERPERAL REVELADOS POR MÃES SOROPOSITIVAS

PROBLEMAS PUERPERALES EN LAS MAMAS DE MADRES SEROPOSITIVAS

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ABSTRACT

Given the recommendation not to breast-feed their infants, HIV-positive women may experience breast problems. The aim of the study was to gain knowledge regarding breast health as revealed by HIV+ women before the non-breast-feeding. This qualitative study was performed with 15 mothers with HIV/ AIDS in Fortaleza, Brazil. Recorded interviews were transcribed and analyzed. The mothers revealed problems with their breasts following childbirth, such as engorgement and pain in the breasts. They revealed that they received instruction in the course of prenatal care not to breastfeed; however, there was no further instruction or care in the postpartum period. The use of lactation inhibitors and bandaging (binding) of the breast were reduced. Health professionals should adopt appropriate measures to guide HIV- positive parturient women. Health services need to broaden strategies to minimize the current emotional problems resulting from non-breast-feeding, as well as the discomfort in the puerperal breast.

KEY WORDS

HIV.
Acquired Immunodeficiency Syndrome.
Breast feeding.
Quality assurance, health care

RESUMO

Em virtude da recomendação de não amamentar, a mulher soropositiva para o HIV poderá enfrentar problemas mamários. Objetivou-se conhecer situações vivenciadas e reveladas por mulheres HIV positivas, diante da não-amamentação. Estudo qualitativo, com 15 mulheres com HIV/Aids, realizado em ambulatório de um hospital referência em Fortaleza, Ceará. Entrevistas gravadas tiveram seus conteúdos transcritos e analisados. As mães revelaram problemas com as mamas após o parto, como o ingurgitamento e dores neste local. Informaram ter recebido orientação no pré-natal para não amamentar, mas não houve continuidade do cuidado no pós-parto. Foi reduzido o uso de inibidores da lactação e enfaixamento das mamas. Para orientar as puérperas soropositivas, os profissionais de saúde devem adotar medidas adequadas. Também os serviços de saúde necessitam ampliar estratégias para minimizar os problemas emocionais decorrentes da não-amamentação, bem como do desconforto na mama puerperal.

DESCRITORES

HIV.
Síndrome de Imunodeficiência Adquirida.
Aleitamento materno.
Garantia da qualidade dos cuidados de saúde.

RESUMEN

En virtud de la recomendación de no amamantar, la mujer seropositiva al HIV podrá sufrir problemas mamarios. Se planteó el objetivo de conocer situaciones vivenciadas y referidas por mujeres HIV positivas frente al hecho de no poder amamantar. El estudio fue de carácter cualitativo, con quince mujeres con HIV/AIDS, realizado en el Ambulatorio de un hospital referencial en Fortaleza, Ceará, Brasil. Las entrevistas fueron grabadas, y sus contenidos, transcriptos y analizados. Las madres refirieron problemas con las mamas después del parto, como ingurgitación y dolores en la zona. Informaron haber recibido orientación en la etapa prenatal para no amamantar, más no hubo continuidad del cuidado en la etapa posparto. El uso de inhibidores de la lactación y el fajado de las mamas fue escaso. Para orientar a las puérperas seropositivas, los profesionales de la salud deben adoptar medidas adecuadas. De igual modo, los servicios de salud necesitan ampliar estrategias para minimizar los problemas emocionales derivados del no amamantar, así como para la incomodidad de la mama puerperal.

DESCRIPTORES

VIH.
Síndrome de Immunodeficiencia Adquirida.
Lactancia materna.
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INTRODUCTION

The epidemic of AIDS in Brazil presents a rapid growth among women. This phenomenon is described as *feminization* of the epidemic. Current data confirm that the ratio between men and women changed from 30/1 at the beginning of the 1990s to 1.4/1 in 2007, evidencing growth and the leveling to near one male case for each female case[1].

Despite anti-retroviral therapy, freely distributed in Brazil, and tests performed during prenatal exams to detect the virus as a measure to avoid vertical transmission, cases of the disease have increased among individuals younger than 13 years of age. Eight-six percent of the current cases were transmitted through vertical exposure during pregnancy, at birth or during breastfeeding[2].

Vertical transmission (VT) can occur during pregnancy, at birth or during breastfeeding. If no intervention is implemented during pregnancy, the rate of transmission can reach 14 to 25%. As studies report, the use of Zidovudina® (AZT) during pregnancy can reduce the transmission of HIV in 67.5% of cases during pregnancy, birth or breastfeeding. Every year, around 700,000 babies are infected in the world and more than half of these infections occur during breastfeeding[3].

In Brazil, mothers infected with HIV are educated to replace breastfeeding with formula as a strategy to prevent HIV. Statistical data indicate that replacing breastfeeding with formula reduces the odds of contaminating the child by 20% after birth. Hence, mothers infected with HIV have to be monitored and educated about the pathology of the disease's potential alterations during pregnancy, as well as risks posed to their health and that of their babies. Specialized care and orientation should be offered to women during pregnancy, labor and after birth about the early implementation of prophylactic measures to the newborn right after birth to minimize the HIV's vertical transmission[4].

A safe option for mothers to offer their own milk to their children, given the risk of transmission through breastfeeding, is pasteurizing their milk. This technique consists of warming the milk at a temperature of 62.5ºC for 30 minutes[2,4]. However, this option has not been adopted or largely offered in Brazil.

HIV positive women can face a variety of problems, mainly physical, economic and psychological, in view of the impossibility of breastfeeding. According to the literature, the impossibility of breastfeeding leads HIV positive mothers to feel guilt, frustration, suffering, impotency and unfulfilled desires[5]. Additionally, many of them face financial problems, which can delay or hinder adequate prenatal follow-up[6]. Coupled with these, due to the disease, women experience fear, shame, stigma, prejudice and isolation[7]. Moreover, after birth, when not properly educated, infected women can have breast problems such as: engorgement, mastitis, breast abscess, blockage of milk ducts and galactocele[8].

According to the Ministry of Health and given the recommendation to avoid breastfeeding, healthcare services should offer lactation inhibitors right after childbirth and women should apply bandages to their breasts as a prophylactic and preventive measure[2]. Women should also receive emotional support because they are being deprived of their right to breastfeed and perform an act that involves a complex interaction between mother and child[8-9]. Women should be educated about the importance of their clinical and gynecological follow-up as well as that of their children during the time needed to define their serological situation. At the same time adherence to AZT treatment in the case of newborns should be reinforced[2].

Some concerns emerged given the factors mentioned before and the experience in delivering care to these women, such as: *How are the health services educating HIV positive mothers about feeding their children in the first days of life? Do HIV infected women have breast problems postpartum? Are the Ministry of Health recommendations to reduce VT being followed, given the exclusion of breastfeeding?*

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Given these considerations and the scarcity of literature about the theme, the results of this study will enable health services to evaluate the strategies adopted so far concerning HIV-positive pregnant and puerperal women, with a view to adopt preventive measures and early treatment of these women's physical and emotional discomfort.

OBJECTIVE

To know situations, prenatal and after birth, experienced by women infected with HIV, due to the orientation not to breastfeed.

METHOD

This is a descriptive and exploratory study with qualitative approach. This type of study describes a deepened perspective of facts and phenomena of a certain reality[10].

Fifteen women infected with HIV participated in the study. The inclusion criterion was having children younger than two years born while under the diagnosis of HIV infection and agreement to participate in the study. The number of participants was defined by the saturation of information, that is, repetition of data, which answered the authors' concerns and met the study's objectives.

The outpatient clinic of the Hospital São José of Infectious Diseases was the setting of this study between March

and June 2005. The facility is a center of excellence for HIV/AIDS in Fortaleza, CE, Brazil.

The interviews were carried out in a private area and followed a semi-structured script that focused on the situations related to *non-breastfeeding* and strategies adopted to prevent and treat breast problems during the puerperal period. We also aimed to uncover the women's knowledge concerning recommendations about the exclusion of breastfeeding given HIV infection.

Data collection was mediated by recorded interviews based on the following guiding question: *What orientation did you receive concerning breastfeeding and how to care for your breasts after your child's birth?*

To analyze the set of the participants' reports, the methodological referential composed[11] of three phases was adopted: Pre-analysis – organization and systematization of ideas; b) Exploration of material, corresponding to the systematic transformation of raw data through clipping, aggregation or enumeration with a view to achieve representation of content or its expression and, consequently, understanding of the text; and c) treatment of results, inference and interpretation. The reports were interpreted and categorized by inference of similar content. Three thematic categories emerged: 1) Breastfeeding or not: how the health services oriented the mothers; 2. Strategies of prevention and treatment of breast problems in HIV positive mothers; 3) Suffering for not breastfeeding and engorged breasts.

Complying with the standards that regulate research with human subjects, the study was approved by the Research Ethics Committee at the Hospital (Protocol nº 38/2005). All women signed a Free and Informed Consent Form and were informed of potential risks and benefits and also of the study's social relevance. The letter *M* followed by the number of the interview (1 to 15) was used to ensure the participants' confidentiality.

RESULTS AND DISCUSSION

Brief information about the participants is presented to enable better understanding of the different issues set out in the course of the study.

Of the 15 women infected with HIV participating in the study, three had two children younger than 24 months at the time. None of them refused to answer the individual interview. The characteristics of the interviewed mothers are described as follows:

The average age was 29.1 years old; none of them had graduated from college; ten had incomplete primary school and the remaining had completed primary school and incomplete secondary school. Twelve women reported having stable relationships and two were single. One informed her partner had recently died due to AIDS. The *per capita* income varied from R$ 52,00 to R$ 420,00 (average=R$ 86,60[a]). One of the participants did not have a monthly income at the time and received donations from relatives.

The participants reported during the interviews how they were or were not educated in health services about breastfeeding and care they should perform to prevent and treat breast problems during the puerperal period. The reports indicated several problems due to inappropriate structure and organization of health services, which probably did not comply with the recommendations of the STD/AIDS National Program of the Brazilian Ministry of Health concerning care delivery to this population.

Following, the categories that emerged from the reports of the interviewed women are presented:

Breastfeeding or not: how the health services oriented the mothers

Breastfeeding by mothers infected with HIV is counter indicated by the STD/AIDS Brazilian Program and by International agencies because they consider that the additional risk of contamination of newborns through breast milk is about 5 to 25%[1,12-14]. According to their recommendations, women should be educated, from the time of conception about the risks of contamination though the breast milk during counseling provided by health services to HIV-infected individuals.

According to the report of the majority of mothers participating in this study, they were educated to avoid breastfeeding after childbirth during prenatal consultations, especially those who had a previous diagnosis of HIV. Others, however, were educated concerning it after the baby's birth. The reports illustrate the situation:

> The physician said during the prenatal... that I couldn't breastfeed (M1);

> I received (orientation), that he couldn't breastfeed, have no contact whatsoever with my breast, I could only feed him formula (M14).

A mother informed she had not received orientation about the risks of breastfeeding her child after birth. She was only informed about the type of labor she had to opt to have her child, as follows:

> ...I didn't know... 'cause they had not explained me this part of breastfeeding, I thought that the only thing was that I couldn't have my child through normal birth. I though it had to be a c-section, but I didn't know that I could not breastfeed (M3).

According to one study, many women have their children without having attended prenatal appointments. During this period, the coverage of HIV testing is below 40%. Therefore, for the majority of women with HIV, the only opportunity to have access to counseling, to HIV testing, orientation about breastfeeding and chemoprophylaxis

[a] N.T. Equivalent to 48 U.S. Dollars in January 2010.

treatment to avoid vertical transmission is during labor and the puerpueral period[9].

The European Collaborative Study disseminated data at the beginning of 2005 indicating that caesarian delivery can reduce VT of the HIV-1 even in patients with viral loads below 1,000 copies/mL. According to this proposal, the C-section could be recommended to these women regardless of their viral load. Such measures, however, were not universally accepted, indicating elective C-section only for women with viral loads above 1,000 copies/mL, which was ratified in November 2005 by the Task Force Health Service of US Department of Health and Human Services[13] and by the STD/AIDS National Program in Brazil. As observed, the decision concerning the best type of birth for pregnant women with HIV is not definitely decided. However, complying with recommendations that aggregate the larger number of opinions, the viral load should be controlled during the prenatal period, though the decision is made only after 38 weeks of pregnancy and has to take into account whether the woman presents chorion and the stage of labor in which the patient arrives at the obstetrical unit[15].

In the face of the possibility of reducing maternal-infant transmission during the puerperal period, the Ministry of Health recommends informing puerperas infected with HIV about the risks of infection through breastfeeding and educating them to obtain and prepare formula and other foods. During prenatal counseling, women should be informed of preventive care for puerperal breasts[4].

The reports indicate that the infected women were not appropriately informed about the exclusion of breastfeeding in the case of HIV infection. Situations in which appropriate monitoring of women with HIV was hindered were demonstrated by a study carried out in Ceará, Brazil[9].

Access to counseling is a right of pregnant, parturient and puerperal women. Consequently, it is the duty of health professionals and managers to facilitate it and provide conditions to integrate it into the service's routine. This action can be achieved by qualifying and training human resources[9].

Strategies of prevention and treatment of breast problems in seropositive mothers

After a child is born, the concentration of the hormones oxytocin and prolactin, responsible for the letdown reflex and for producing milk in the mammary glands, increase in women's blood. When there is no sucking or the milk does not flow out, breasts become swollen and congested, which can favor an excess of milk and consequent engorgement[16]. It can be aggravated in the case of women infected with HIV, when breastfeeding is counter indicated[4].

A preventive strategy is for the health services to provide orientation to avoid an excessive flow of milk to breasts through the early use of drugs, so to inhibit lactation, and the application of bandages.

Some women are educated in procedures preventing engorgement as the following report shows:

> I had no problem at all, I took a shot to dry my milk (M8)
>
> …they explained everything, what I should do (M9)
>
> …they said to use ice, massage. The physician told me during the prenatal that I could not breastfeed (M1).

Even when properly educated, when excess milk is not removed, engorgement might occur. Engorgement means that the woman had problems establishing the self-regulation of the lactation physiology[17]. This difficulty, especially in HIV positive women, implies an excess of milk accumulated in the breasts, which leads to engorged breasts, according to these reports:

> It became engorged! So, I milked with the device (pump), but it really engorged and I got sick [she refers to mastitis] (M10);
>
> ...I massaged with ice [refers to the application of iced compress], which helped a lot and I took the baby out of my side, because he would get agitated just with the smell of it… (M11).

Self-care such as the use of a pump is a non-recommended measure. However, in the face of the evident sign of engorgement and due to the impossibility of removing the milk through breastfeeding the newborn, the mothers opted for the used of different strategies to alleviate the discomfort.

As recommended, a woman with a HIV diagnosis should have her lactation inhibited right after birth. Such an initiative can be facilitated by the use of mechanical and pharmacological measures to inhibit lactation. Mechanical measures consist of carefully compressing the breasts (bandages) without restricting breathing and consequently causing maternal discomfort. According to the literature, this single measure is successful in 80% of cases when it is maintained for a period of seven to ten days, avoiding manipulation and stimulation of breasts. In the case of a difficulty in implementing this measure, one can adopt pharmacological suppression with the use of lactation inhibitors[4,9].

However, as a qualitative study[18] with infected mothers revealed, the bandage technique is perceived as a punitive and painful act. Hence, this technique is recommended to mothers but has to be monitored to evaluate potential discomfort.

Suffering for not breastfeeding and engorged breasts

Despite their knowledge about the benefits of breastfeeding, mothers infected with HIV are instructed not to breastfeed due to the risks of contaminating the child through the breast milk. However, the exclusion of breastfeeding leads to personal conflicts, a process reported as *psychological suffering*. Such suffering can be motivated by two aspects: the first occurs when the mother has a previous experience

in breastfeeding and, therefore, recalls her previous experiences. The second originates from propaganda that addresses the theme *breast milk is the best remedy for your child's health*. These situations lead women infected with HIV to experience psychological suffering.

Nonetheless, when early suspension of breastfeeding is performed after birth, many women present clinical breast problems and more frequently present engorgement, which is characterized by excess of milk in the entire mammary gland when there is the letdown reflex, verified 48 to 72 hours after birth.

When there is no leakage or escape for the accumulated milk, there may be signs and symptoms such as: swollen, hardened breasts, hyperthermia and hyperemia [16], causing discomfort and pain. These situations were identified in the mothers' reports:

> Ah, I suffered a lot...I did crazy things, milked it with the pump and almost died of pain…(M 11).

> ...it got really swollen, engorged, so I only tied the bra… (M1)

> I didn't breastfed at all. It was horrible because I had too much milk and I didn't know why. They didn't explain this breastfeeding thing to me…(M3).

In cases of engorgement, a relief massage applied by the woman herself to let the milk flow, could be a self-care strategy adopted. However, this option is not provided to infected women. Hence, in case of engorgement the suggestion is to apply *relief massage* to the breasts and discard the expressed milk or it can be offered to the newborn, if there is the possibility of pasteurizing the milk.

Infected women should receive, in addition to emotional support, orientation about milking to alleviate the compression of breast alveoli, avoiding in this way intense pain and risk of mastitis[16].

Because this group of women cannot breastfeed, they experience guilty and sorrow and emotional support is required to alleviate *heartaches* in addition to breast pain[8-18].

It is undeniable that HIV affects the social life of women because the fact that they cannot breastfeed, oftentimes, announces they are HIV positive, leading to some restrictions, not only due to the pathology, but also due to the social stigma HIV carriers have to face[18-19].

FINAL CONSIDERATIONS

As observed, HIV positive women experienced situations, due to the fact they could not breastfeed their children, which could have been eased. The information concerning the fact they could not breastfeed is indicated during the prenatal period according to the Ministry of Health's recommendations. However, some women reported lack of knowledge concerning the care to be performed for puerperal breasts after birth as preventive and treatment measures.

Moreover, as observed in the reports, the use of lactation inhibitors and/or applying bandages to breasts is very limited, which led to discomfort and pain. After the third day postpartum, those who did not breastfeed their children experienced the letdown reflex and used manual milking, pump milking and iced compressions. All these women based these procedures on knowledge they acquired in their community or local culture.

In the view of these different situations, the professional negligence for not providing appropriate care stands out due to the reported lack of knowledge and discontinuity of care after childbirth. Because they were parturient women with risk and due to the requirement of special care for newborns, the health services should use strategies to monitor maternal/infant health. As a preventive strategy, women with HIV should receive orientation from services about how to avoid excessive production of milk with the use of early lactation inhibitors as well as mechanical measures such as the application of bandages on the breasts. However, the use of bandages should be explicated beforehand and patients should receive instruction afterwards to avoid pain and the feeling of punishment.

In addition to physical pain, the fact that women are deprived of their right to breastfeed can have psychological repercussions. Hence, health professionals should also offer emotional support. For that, is necessary to enlarge care, especially in terms of humanization. From this perspective, empathy between the professional and the mother is expected, increased with close ties between them and consequently more acceptance and awareness of these women.

Professionals try, through this kind of behavior, to understand the patients' fears and anxieties and seeks to employ communication skills in a clear and concise way, in which the mother feels valued and heard by professionals, feels free to talk regardless of her condition or previous behaviors, so she can find support that is so important in this moment.

It is known that breastfeeding is a biological attribute of women. Given this reality, one of the expectations of this study is the possibility to contribute to the understanding of this practice as an action shared with health professionals and all those who, somehow, are sensitive to its importance.

However, we highlight the following: professionals should pay attention to an emerging situation, that is, numerous women (mothers-to-be) are being infected with HIV and require care, especially from nurses. This care includes attentive listening and emotional support to free them from their feelings of guilt for not breastfeeding. These women should also be informed about the preventive and treatment measures to avoid problems with puerpueral breasts. From this perspective, it is possible to provide them comfort and security, both physical and emotional.

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