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WOMEN'S CONCEPTION ABOUT LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS AND IMPOSSIBILITY OF BREASTFEEDING

CONCEPÇÃO DE MULHERES SOBRE VIVÊNCIA COM VÍRUS DA IMUNODEFICIÊNCIA HUMANA E IMPOSSIBILIDADE DE AMAMENTAR

CONCEPCIÓN DE MUJERES SOBRE VIVIR CON VIRUS DE LA INMUNODEFICIENCIA HUMANA E IMPOSIBILIDAD DE AMAMANTAR

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Objectives: to discuss women's conception about living with the human immunodeficiency virus and the impossibility of breastfeeding. Method: descriptive, exploratory study, with a qualitative approach, conducted with 12 women in a university hospital in Rio de Janeiro, Brazil. Data collection, through individual and semi-structured interviews, occurred between June 2017 and March 2018. The data were analyzed using the methodological framework of content analysis. Results: most participants were diagnosed during prenatal care and delivery. They recognized the benefits of breastfeeding and followed the recommendation not to breastfeed. Conclusion: the participants recognized the benefits of breastfeeding and, even if sad and frustrated at the impossibility of breastfeeding, transcended these feelings to protect their child, reaffirming the role attributed by society and culture and gender asymmetries related to reproduction and motherhood.

Descriptors: Nursing. Women's Health. Breast Feeding. Postpartum Period. Aids Serodiagnosis.

Objetivos: discutir a concepção de mulheres sobre a vivência com o vírus da imunodeficiência humana e a impossibilidade de amamentar. Método: estudo descritivo, exploratório, com abordagem qualitativa, realizado com 12 mulheres em um hospital universitário no Rio de Janeiro, Brasil. A coleta de dados, por meio de entrevista individual

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e semiestruturada, ocorreu entre junho de 2017 e março de 2018. Os dados foram analisados mediante a utilização do referencial metodológico da análise de conteúdo. Resultados: a maioria das participantes foi diagnosticada no pré-natal e no parto. Elas reconheceram os benefícios da amamentação e seguiram a recomendação de não amamentar. Conclusão: as participantes reconheceram os benefícios da amamentação e, mesmo que tristes e frustradas diante da impossibilidade de amamentar, transcenderam esses sentimentos, por proteção ao filho, reafirmando o papel atribuído pela sociedade e pela cultura e as assimetrias de gênero relacionadas à reprodução e maternidade.

Descritores: Enfermagem. Saúde da Mulher. Aleitamento Materno. Período Pós-parto. Sorodiagnóstico da Aids.

Objetivos: discutir la concepción de mujeres sobre vivir con el virus de la inmunodeficiencia humana y la imposibilidad de amamantar. Método: estudio exploratorio descriptivo, con enfoque cualitativo, con 12 mujeres en hospital universitario de Río de Janeiro, Brasil. Recopilación de datos a través de entrevistas individuales y semiestructuradas, entre junio de 2017 y marzo de 2018. Datos analizados por el marco metodológico del análisis de contenido. Resultados: la mayoría de los participantes fueron diagnosticados durante el prenatal y parto. Reconocieron los beneficios de la lactancia materna y siguieron la recomendación de no amamantar. Conclusión: los participantes reconocieron los beneficios de la lactancia materna y, aunque tristes y frustradas ante la imposibilidad de la lactancia materna, trascendieron estos sentimientos para proteger al niño, reafirmando el papel atribuido por la sociedad y la cultura y las asimetrías de género relacionadas con la reproducción y maternidad.

Descriptores: Enfermería. Salud de la Mujer. Lactancia Materna. Período Posparto. Serodiagnóstico del SIDA.

Introduction

Human immunodeficiency virus (HIV) is one of the leading causes of death among adults worldwide. There are approximately 37.9 million people living with HIV[1]. In Brazil, in 2017, 42,420 new cases of HIV and 37,791 cases of AIDS were diagnosed[2].

Of the total number of cases recorded since 1980, the highest concentration is in the ages between 25 and 39 years, in a total of 169,932 (68.6%) cases in men and 77,812 (31.4%) cases in women[2]. The increased number of HIV/AIDS cases among women of childbearing age brings as one of its consequences the possibility of vertical transmission intrauterine, intrapartum or while breastfeeding, when the additional risk is from 7% to 22% per exposure, that is, with each nursing [3-4]. If preventive measures are not used, about 15% through 45% of these babies are more likely to be exposed to the infection[2,5].

The World Health Organization, from 2016, has recommended that women living with HIV should breastfeed for at least six months and can continue for up to 24 months, provided that they are using antiretroviral therapy, regardless of CD4lymphocyte count[6]. This approach is based on the various benefits of breastfeeding, regarding nutritional and emotional aspects, as well as on the prevention of childhood infectious diseases, reduction of leukemia, sudden infant death syndrome and obesity[7].

In Brazil, breastfeeding is not recommended in women living with HIV[3]. Therefore, health professionals working in prenatal consultations need to inform about the risks of breastfeeding and the inevitable suppression of lactation, guiding the need for artificial breastfeeding, in order to avoid the influence of economic and social factors on the choice of the infant eating[3,7].

Not breastfeeding can be frustrating, since being unable to offer the breast often goes against the wishes of the nursing mother, since the woman who does not breastfeed does not correspond to the socially idealized model, because she does not offer her child the best nutrition[8]. This situation may generate feelings such as guilt, frustration and anguish towards reality, reinforcing the importance of the role of nurses and other professionals in the embracement and follow-up of this woman.

In view of the above, the following objective was formulated for the study: to discuss women's conception about living with the human immunodeficiency virus and the impossibility of breastfeeding.

Method

Descriptive, exploratory research, with qualitative approach. In order to identify the target population, the acquisition process included the analysis of medical records. After this procedure, 14 postpartum women were invited to participate in the study. Of them, one refused and the other did not meet the eligibility criteria. Altogether, 12 postpartum women living with HIV, aged over 18 years, hospitalized in the rooming-in with born-alive child(ren). Women underage, those who gave birth to a stillborn child or who did not have emotional conditions to participate in the research were excluded. All participated voluntarily, by signing the Informed Consent Form.

The scenario was the maternity rooming-in of a university hospital located in the North Zone in the city of Rio de Janeiro. The scenario was chosen because the hospital was a reference for the treatment of HIV/AIDS.

Data collection occurred from June 2017 to March 2018, and ended with the data saturation criterion. The technique used was the individual and semi-structured interview. The guide, elaborated and validated by the group of researchers, with closed and open questions, aimed to obtain socioeconomic and reproductive characteristics, as well as information related to breastfeeding and HIV.

The interviews were conducted at the puerperal women's beds, in the absence of companions or some member from the health team, in order to ensure the participants' privacy. They lasted an average of 30 minutes, being recorded in MP3, with prior authorization, and fully transcribed. In order to guarantee women's anonymity, identification codes were adopted using the letter P followed by increasing ordinal numbering (P1 through P12), according to the order of the interviews. Importantly, the transcribed interviews will be under the responsibility of the main researcher for a period of five years.

The research was approved by the Research Ethics Committee of the Universidade Federal do Estado do Rio de Janeiro (UNIRIO) under Opinion n. 1.029.129. The ethical aspects were respected according to Resolution n. 466/2012 of the National Health Council of the Ministry of Health.

For data analysis, the methodological framework of Content Analysis[9] was used according to the following steps: pre-analysis, exploration of the material, treatment of results, inference and interpretation. The transcription and organization of the interviews were performed, which allowed exploring the material and the coding process. There emerged 159 thematic units regarding the thematic axis – diagnosis of HIV seropositivity, knowledge about infection and vertical transmission, (un) awareness knowledge of the serological situation of the partner and family, feelings about the act of (not) breastfeeding, previous breastfeeding experiences and support network –, which constituted the thematic category of this manuscript: *Knowledge about HIV and the impossibility of breastfeeding*.

Results

The women were between 20 and 36 years old. Six self-reported as Blacks and the others, as *pardas*. Regarding the place of residence, six lived in the city of Rio de Janeiro, three in Baixada Fluminense and the other three in Região dos Lagos. One of them had Angolan nationality and the others, Brazilian. Regarding marital status, eight lived in a stable union with their partners and four did not live with their partners. The time women in a stable union lived together with their partners ranged from two to twelve years. Regarding education, eight completed secondary school and four completed primary school. Concerning occupation, seven were in the labor market, two were unemployed and three were housekeepers. Family income ranged from three to six minimum wages.

In relation to sexual and reproductive history, four were prims and the others were multiparous, with two or three children. One underwent an induced abortion. Regarding

the use of contraceptives, all of them reported using the male condom eventually. Regarding the beginning of prenatal care, eight reported having started in the first trimester and seven did not plan pregnancy.

Among the 12 participants, 8 became pregnant and were aware of the diagnosis of HIV seropositivity. As for the others, the result was revealed in the current pregnancy, during prenatal care or delivery, through the rapid test performed in the maternity.

> *I did not know I had this disease. I did it* [rapid test] *in prenatal care and it was negative. So I just found out now.* (P3).

> *I was shocked when I did the prenatal test and it was positive. I looked at my husband and I was very, very angry with him.* (P9).

Among the eight interviewees who were already aware of their serological status, two had their diagnosis revealed during routine prenatal tests of previous pregnancies.

> *I found out in my first pregnancy, in prenatal care.* (P1).

> *I found out 13 years ago when I was pregnant with my first child.* (P6).

Of them, four participants discovered HIV seropositivity through the rapid test offered in the Basic Health Units, because they presented some sign or symptom that could suggest infection or even by the woman's own risk behavior, according to the following statements:

> *I found out two and a half years ago in a rapid test in a Basic Unit. After the condom broke, a few months later, I felt like doing the test. It was positive.* (P4).

> *There was a lump on my neck. Then I went to the doctor, and he asked me for some tests, the HIV came up.* (P10).

Regarding the feeling expressed by the women interviewed after receiving the diagnosis, fear was manifested in the interviews of nine women. This fear would be of death, of sharing this result with other people and of the vertical transmission of HIV to the child, as in the following fragments:

> *I looked at my kids and thought that I could die any minute, that I was not going to see it grow up. And the one who was going to be born? Who was going to look after him?* (P8).

> *I was afraid of dying and not being able to look after my son* [...] *I was afraid of my family's prejudice, but there was a time I would have to tell them.* (P6).

The results revealed that 11 participants revealed the result to the partner.

> *My partner knows, so do my kids and my mom.* (P3).

> *When I got the news, I told him right away, I did not want to hide it.* (P6).

In relation to sharing the diagnosis with the family, only one woman stated that she had not revealed her seropositivity, as she expressed in the interview:

> *That is why I do not want a companion* [...] *no one knows. My husband knows, but he is not a carrier. The worst part is that you cannot tell the people who live with you. You feel like crying and not being able* [...] *you keep making up stories.* (P1).

In relation to revealing the diagnosis to intimate people, such as close friends and relatives, nine participants stated that, after confiding the situation, they could count on some kind of support.

> *My mother, godmother and in-laws know. They give us a lot of support.* (P4).

> *My mother-in-law supports me very much, both psychologically and physically. She helped a lot, also looking after my son.* (P1).

The results indicate that the 12 participants were aware of the various forms of HIV transmission, mainly through the sexual route. Among the reports, there emerged blood transfusion, blood-contaminated material, use of drugs with shared syringes, tattoos in inappropriate places, possibility of using non-sterilized material and breastfeeding. The following excerpts are illustrative:

> *The virus is transmitted by breastfeeding, sex without a condom, blood transfusion. It is a disease that messes with immunity.* (P1).

> *Through the mother's milk, manicure material, non-sterilized needles and unprotected sex.* (P11).

All participants stated that the only type of exposure to the virus was sexual and believed that this was the way they were contaminated, as follows:

> *I think I got it during the intercourse because the father of my second daughter was a drug user, you know? And I did not use condom with him either. (*P2).

> *I think I got it from an old boyfriend who is already dead. I heard years later that he died from Aids*. (P11).

All interviewees stated that they were aware of the risk of HIV transmission through unprotected sexual contact. These women stated that they did not use condoms regularly, as evidenced below.

> *As he does not like wearing condoms and not to make him upset, I do not insist*. (P4).

> *You cannot always use it. When I have it at home, I use it, but when I do not, I have sex with it or not*. (P8).

> *I have never used a condom, because my partners never wanted to wear it, and I never insisted either. I am guilty too*. (P12).

Ten participants had monogamous relationships. Of them, eight remained with the partners who, according to them, were responsible for the transmission of the virus.

> *We have been together for many years, I like him. When I heard, I was very angry, I felt betrayed, but I am not going to leave him*. (P9).

Two study participants broke up with the partner and currently live other relationships with partners who do not have HIV.

> *After I found out he passed me it, it was over. I could not take it, too much pressure*. (P6).

> *It was not my current husband who passed it on to me, it was the father of my eldest son. I broke up with him*. (P2).

The eight women who were aware of the diagnosis of HIV seropositivity before becoming pregnant immediately sought the health service to start prenatal care, because they were aware of the risks of vertical transmission and the prophylactic measures that should be used. They stated that they received this information in prenatal follow-up of previous or current pregnancies and in the health services where they were followed up.

> *My viral load was low. There was no problem at all, they decided it would be a normal delivery, but they could have c-sectioned if it was high*. (P5).

The results showed that, among all the information received in the prenatal follow-up of previous or current pregnancies, all participants were aware of the impossibility of breastfeeding.

> *I cannot breastfeed him, because my milk has my disease. (P7).*

Concerning the desire to breastfeed and its impossibility due to the infection, feelings such as frustration and sadness stood out.

> *I felt very much like it, it is unique. Breast milk is very important for the child*. (P4).

> *But it is every mother's dream, right? To breastfeed your baby. It is sad*. (P2).

Three women stated that they had had previous experiences of breastfeeding their elder children and reported feeling anguish and frustration at the impossibility of breastfeeding this new baby.

> *I breastfed my two elder children and it was great, it was very good! I had no problem breastfeeding, it was very good!* (P2).

> *When you have never breastfed, I think it is easier, because you have never had that good feeling of breastfeeding. Now, when you have already breastfed, it is worse*. (P8).

One of the participants stated she had never wanted to breastfeed before. Nonetheless, when she became aware of her impossibility of breastfeeding her child, she reported feeling sadness.

> *I had already decided with my husband that I would not breastfeed, but when I found out I was HIV positive and could not, I felt bad about not having a choice*. (P3).

The embarrassment was another feeling mentioned by three women, because they were being criticized by family members and people in their social life for not being able to offer the mother's breast to their children.

> *Everyone kept asking, they thought I did not want to breastfeed because I was mean, but only I knew why I could not breastfeed*. (P1).

> *It was hard to convince the family, because they kept asking. I started inventing diseases. They said I had to breastfeed*. (P11).

The fact of witnessing breastfeeding experienced by other women, in the rooming-in scenario, it brought equal suffering to women who are facing this drama.

As much as I want the best for him, it is something you see everyone breastfeeding. And sometimes he does not want to sleep, you have keep fooling him, back and forth, because you can breastfeed him like them. (P1).

Despite recognizing the benefits of breastfeeding and wishing to breastfeed, all stated that they would adopt all necessary care and follow the recommendations regarding the prophylaxis of vertical transmission of HIV, especially in relation to breastfeeding, in order to protect the health and integrity of their children.

I think it is bad, but what can I do? It is the best for him, not nursing is better for him. As far as possible and impossible, I am going to make sure he is okay. (P8).

I understand why, but we long for it, right? First, I think about doing the best for him. He has nothing to do with what we go through. (P4).

As a way to compensate for the feeling of guilt and frustration for not breastfeeding and performing what they believe is an essential part of motherhood, six participants stated that they would reinforce their care as a way to compensate for that feeling.

He does not drink my milk, but I feed him, I am the one who looks after him, I give him the bottle. I am doing this for his own good, that is what matters. (P7).

I am going to do my best for him and give him a lot of affection. I know not giving him milk from my breast is the best thing for him. (P6).

Discussion

The socioeconomic characteristics found are similar to those of other studies related to women living with HIV[10-13]. The most susceptible are those with low schooling, Blacks or *pardas*, live in a stable union and have low family income.

Regarding obstetric history, a Spanish study[14] revealed a similar result, pointing out that the majority was multiparous, had children, did not plan pregnancy and eventually used condoms as a contraceptive method.

The discovery of HIV-positive diagnosis was divergent for the interviewees. For some, the result was revealed in the current or past pregnancy during prenatal care or delivery. For others, it occurred during the performance of tests or because they presented some sign or symptom that could suggest infection.

Pregnancy is a period of physical, hormonal, psychological and social changes and, as such, develops in a social and cultural context. The same occurs in the puerperium, because the arrival of a child brings several changes to the woman's life and in the way she perceives herself and the world. This situation can arouse anxieties, fears and insecurity in the face of this new stage of life[15].

For women who were aware of their seropositivity during pregnancy, the feelings that were raised in the revelation of this diagnosis, such as sadness, denial of the disease itself, fear of death and transmission of the virus to the future child, the disclosure of the diagnosis to people living together and the anguish of being unable to breastfeed, were similar to those reported in other studies[16-17].

The results of this research indicate that the access of women to the diagnosis of HIV infection occurred mostly during prenatal care, a fact that reinforces the importance of this follow-up and professional training to deal with this problem[12]. In prenatal consultations, women should undergo rapid HIV testing and/or HIV serology at the first consultation and in the third trimester of pregnancy[3].

For the participants who discovered the diagnosis of HIV through rapid tests performed in the Basic Health Units, as soon as they learned of the pregnancy, they quickly sought the health unit to perform prenatal consultations and prevent the risks of vertical transmission.

This situation highlights the importance of nurses and other health professionals regarding the open and sensitive listening in gynecological consultations, in order to observe vulnerabilities and offer rapid tests for the detection of HIV, syphilis, hepatitis B and C. Primary care is a favorable field for the development of STIs/HIV counseling[3].

Regarding the sharing of the diagnosis, most participants revealed their diagnosis to the partners. Those with a steady partner remained in the relationship after the diagnosis of seropositivity, even though they were aware that the man was responsible for the infection.

For these women, the diagnosis of HIV revealed the infidelity of the partner associated with the diagnosis of HIV, which was also found in a study[18] about the experience of sexuality of people living with HIV. The author interviewed men and women who discovered the HIV diagnosis associated with infidelity behaviors and ended their relationships after serological discovery.

Most participants said they had revealed their diagnosis to family and close friends and received the necessary support. A study conducted in Pelotas (RS)[17] pointed out that this decision is not easy, since sharing this situation with other people can distance them from social coexistence, as it is still an infection strongly marked by prejudice and stigma. The fear of social isolation, the distancing from friends and family and the loss of employment often cause silence about the serological condition, which also contributes to the non-access to the resources available in the health network[19].

Most of them did not plan pregnancy, even though they were aware of the diagnosis of HIV seropositivity. This situation evidences the inappropriate use of condoms and the non-use of other contraceptive methods. This study reiterates that power inequalities in stable relationships between couples often determine the difficulty of women in negotiating condom use with their partner, making them more exposed to risk. A study[20] corroborated this fact by identifying that most pregnant women interviewed were aware of their HIV serological status and became pregnant without planning.

Participants were aware of the forms of vertical transmission of HIV before becoming infected, especially sexual, and of the prophylactic measures they should adopt during pregnancy. The latter was informed during prenatal consultations. A study[20] corroborated this result when it revealed that the participants knew all forms of HIV transmission, including the impossibility of breastfeeding. However, another study[17] diverged from this result, pointing out that the participating pregnant women had a large knowledge deficit about vertical transmission of HIV. This situation reignites the role of nurses in the implementation of health education actions, as a way to reflect on gender and health issues, demystifying myths and stereotypes about the infection.

A study conducted in Pará, with the objective of knowing the postpartum woman's view of non-breastfeeding[15], confirms the results of this research when it reveals that the fact that women do not breastfeed distances them from the normality patterns of motherhood and the popular imaginary of its expectations, causing intense psychic and moral suffering, especially in those women who had the possibility of breastfeeding their children in previous pregnancies. Nevertheless, the study[16] conducted in Bahia with HIV-positive women draws attention when affirming the decision of some of them to breastfeed their children, despite their serological status. The motivation is based on the benefits of breastfeeding for the child's health, overcoming the risks of HIV transmission.

This situation reinforces the recommendation of the World Health Organization[6], when it stated that women who live with HIV and are on antiretroviral therapy can breastfeed exclusively up to six months of life. This reveals that if the woman is in assiduous use of antiretroviral therapy, the risk of HIV transmission is 0.5%[6]. International studies have revealing results regarding minimum risks of vertical transmission in women living with HIV and who breastfed their newborns[4,21].

Although all women in this study considered the benefits of breastfeeding, they stated that they understood the risks and did not intend to breastfeed. One factor that promotes this great adherence of HIV-positive women to preventive measures of vertical transmission is the concern to protect the child, because breast milk becomes a risk to the health of the newborn. Therefore, they understand that the protection at this moment is not to breastfeed.

Nurses need to know and understand the experiences and social context of women to support their actions and provide care. This means that the attention to HIV-positive women must go beyond the biological and reproductive aspects, paying attention to subjectivity, with a

view to understanding the multiple meanings of pregnancy and breastfeeding for each one.

The study presented limitations regarding the reduced number of participants. However, the results showed an overview of the challenges, which are part of the daily life of health professionals, especially nurses, who occupy an extremely relevant role in the care with women living with HIV in the pregnancy-puerperal cycle.

Conclusion

This study allowed concluding that the participants recognized the benefits of breastfeeding and, even if sad and frustrated at the impossibility of breastfeeding, they transcended these feelings to protect their child, reaffirming the role attributed by society and culture. This role was added to the various situations experienced by women, which reinforce gender asymmetries related to reproduction and motherhood, evidencing their vulnerabilities.

Finally, the conclusions reinforce the need for reflection on the ways of thinking and acting that enable the construction of new attitudes, with a view to individualized and comprehensive care, articulated with other health services based on women's embracement.

Collaborations:

1 – conception, design, analysis and interpretation of data: Cláudia Lima de Oliveira, Maria Beatriz de Assis Veiga;

2 – writing of the article and relevant critical review of the intellectual content: Selma Villas Boas Teixeira, Leila Rangel da Silva and Cristiane Rodrigues da Rocha;

3 – final approval of the version to be published: Selma Villas Boas Teixeira and Ana Paula Assunção Moreira.

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