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EXPERIENCE OF WOMEN DIAGNOSED WITH HIV/AIDS DURING PREGNANCY

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ABSTRACT
The study describes how women diagnosed with HIV during the prenatal experience the diagnosis and pregnancy. It is exploratory, descriptive, qualitative research conducted in a municipal institution Juazeiro health, between December 2012 and February 2013. Participant's five women, after approval by the Research Ethics Committee. Information was collected through semi-structured interviews and data were analyzed by content analysis technique. The results showed three categories: Prenatal as a strategy for screening of HIV infection; Reactions to the discovery of diagnostic and support after the discovery of HIV. In addition, showed that knowledge of the diagnosis caused negative impact on the lives of participants, leading them to analyze their personal plans, with the support of family, friends and / or service that accompany them. Finally, the diagnosis is still permeate stigma and prejudice. The prenatal consultations have become exceptional moments for the nursing interventions, ensuring a humane and comprehensive assistance.

Keywords: Women's health. HIV. Pregnant women.

INTRODUCTION

Infection with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), pandemic disease, is a major public health problem in Brazil and in the world, that generates human suffering, social, economic, cultural and political impacts[1].

A few years after the emergence of this epidemic, there was a significant increase in the number of women with HIV/AIDS, including those in childbearing-age. In Brazil, in 2011 14 388 cases of AIDS in women were reported, compared to 1984, when 11 cases were reported, in which there is evidence of the feminization process of the epidemic[2].

Regarding the pregnant population, 69,500 cases of HIV infection were reported in Brazil, from 2000 to 2012. In 2012, until the month of June, 3,426 cases were reported, of which 627 (18.3%) are in the Northeast region, and of these 99 (15.8%) are in the state of Ceará[2].

Given the evidence of increased HIV infection in women, there was need to draw strategies for and prevention of this infection in this group, especially the increase in testing coverage, antiretroviral therapy and prophylaxis for the prevention of vertical transmission (VT)[1].

In Brazil, the discovery of HIV seropositivity in women is mainly due to the appearance of opportunistic diseases in them or in their partner, and as result of serodiagnosis during prenatal consultations[3].

This discovery usually causes suffering to women, especially when it occurs during pregnancy, for women with HIV experience motherhood with dichotomy, since they have a disease still without cure (death) and are experiencing motherhood (life)[1]. Also because pregnancy and motherhood reflect social expectations related to health, happiness and life [4].

Living in this context, woman with HIV can experience various situations permeated with fear, prejudice, suffering and stigma. In addition, there is fear in the disclosure of diagnosis, barriers to work and shortage of encouraging social networks to motherhood, sexual and reproductive changes[1,4].

In this sense, these women may develop inappropriate strategies to confront this condition, such as overprotection and fear for the child, denial and concealment of disease[5].

Therefore, there are many elements that encompass the nursing care in the context of

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HIV/AIDS, and pregnancy is an important time for planning care, involving strategies that enable the reduction of VT, as well as the recognition of several other needs of specific care.

Therefore, the nurse, when monitoring HIV-positive pregnant women, aims, with their actions, to strengthen the bond with the patient, and to promote a humane, comprehensive and ethical care. Nurse should remember that the bond and the trust placed by the patient in the health care provider will make a difference in relation to the understanding of the disease and treatment adherence, enabling the positive coping, providing greater acceptance and tranquility by women[6].

Based on this, the research question was delimited as: What is the experience of women diagnosed with HIV during prenatal care regarding the diagnosis and pregnancy? Interest about the subject arouse from the experience of the researchers as to care for pregnant women with HIV, where we saw the need to know the experiences of this population regarding the diagnosis of infection and pregnancy, thus enabling the discovery of essential elements for nursing care.

The aim of this research is to approach nursing professionals to healthcare for this group, basing the performance of appropriate actions to the needs of these women. Finally, this study aimed to describe how women diagnosed with HIV during the prenatal experience the diagnosis and pregnancy.

METHODOLOGY

This is an exploratory-descriptive qualitative study, since its main function is to investigate the issues in depth, evaluating the emotional and intentional factors implicit in the positions and behaviors of respondents[7].

The research *locus* was a municipal health institution of Juazeiro do Norte, Ceará, Brazil. We chose this scenario it is a reference service in infectious diseases, in outpatient and specialized level for care in sexually transmitted diseases (STDs), HIV and AIDS, for assisting a large number of users, which enabled access to research participants.

For delimitation of women who would compose the investigation, we defined the following inclusion criteria: women enrolled in the infectious diseases service as pregnant women from 2010 to 2012, diagnosed with HIV during pregnancy, 18 years old or older, and that expressed agreement to participate in the research**.**

In this sense, 12 women were pre-selected, but only 05 participated. The reasons for exclusion were: not being available during the home visit, presenting risk to the researchers, denying participation in the study and living in distant city, making it impossible the approach by the researchers.

The risk to the researchers mentioned above refers to the possibility of interaction with HIV-positive woman, user of illicit drugs and alcohol, which can affect their behavior during the interview. Thus, this risk was considered and the researchers decided to exclude this research participant.

Data collection was held from December 2012 to February 2013, as this period enabled the approach of selected women in their homes.

We used as a semi-structured interview as data collection instrument. This interview was conducted during home visits, by the nurse and the social worker of the institution. We chose this approach because most of the women who met the research criteria were not scheduled to visit in the service during the data collection period. Therefore, we carried out the pre-test of the interview script with a research subject, and the script proved to be adequate.

The research followed the rules of Resolution No. 196/96 of the National Health Council[8], being approved by Opinion No. 173,852 of the Research Ethics Committee of the Regional University of Cariri - URCA. During the data collection period, it was requested the authorization of the research subjects through the Informed Consent Form - ICF, ensuring confidentiality of respondents, whose anonymity of the participants was guaranteed with the use of code names of precious stones.

Data were examined through content analysis, and were organized in accordance with the following steps: pre-analysis, material exploration and treatment of results, inference and interpretation[7].

The *corpus* consisted of five interviews, and the sentence was selected as a recording unit and the paragraph as context unit. After analyzing the reports, eight categories of analysis emerged. However, the three most significant will be presented: Prenatal as a strategy for screening HIV infection; Experiencing the discovery of diagnosis and; Support after the discovery of HIV.

RESULTS AND DISCUSSION

The five women with HIV in the research were aged 22-39 years old. Regarding marital status, at the time of data collection, two women lived with a partner, one was married, one was divorced and one was a widow. All participants reported not working and dedicated themselves to look after their children and home. Regarding education, two have finished high school, two completed primary school and one had not completed elementary school.

Regarding family income, one of them had from a minimum wage (R$ 622.00) to a minimum wage and a half (R$ 933.00), and another participant indicated having no family income. The number of children per woman ranged from one to six, and three women had one child, one woman had six children and one woman had two children. After the serodiagnosis, these women reproduced, and two of these had one child, one had two children, and two women had a child and were pregnant at the time of interview.

In relation to the discovery of HIV infection, all women discovered during pregnancy, and they discovered serodiagnosis between the third and sixth month of pregnancy. All participants underwent prophylaxis of VT, as recommended by the Ministry of Health. In addition, all of them underwent surgical abdominal mode of delivery (cesarean section).

Prenatal as a strategy for screening HIV infection

This category shows how the participants found the serodiagnosis for HIV and how they believe that the infection occurred. The five participants found the serodiagnosis during pregnancy, through the completion of the HIV testing, guided by health professionals (nurse and doctor) during prenatal consultations.

> I found out I had this disease during those consultations that you go in pregnancy, in the health unit. The nurse told me to do this test to find out, and the result showed I was had this (Jade).

> I knew the result there, in the lab, I did the test when I was pregnant, the doctor asked, then the result arrived (Pearl).

This finding confirms the results of other studies that show the importance of prenatal care in tracking HIV infection, in which women found to be positive for HIV during pregnancy and postpartum period and this moment appeared in the records of the reasons for the request for HIV serology[9,10,11].

As for the time of diagnosis of HIV infection, study in a university hospital of Santa Maria, Rio Grande do Sul, with a total of 176 pregnant women with HIV, observed that 44.7% (n=62) of patients were diagnosed during the current pregnancy, 27.7% (n= 39) out of pregnancy, 24.8% (n=34) in previous pregnancies and in 2.8% (n=4) this information was unknown[11].

These data reinforce the need for screening of HIV, by requesting the HIV test as recommended by the Ministry of Health to start VT prophylactic measures[3].

It is noteworthy that in addition to the pregnant woman herself diagnosis, prenatal care can be a means to reveal the diagnosis of this woman's partner and therefore the need for him to also undergo multi-professional monitoring. Prenatal is also important as a strategy to qualify the advising regarding the prevention measures to be adopted by the couple[1].

Also in this context, we ask these women about how they believe the contamination occurred, and all reported that was through sexual intercourse.

> [...] I was infected through sexual intercourse, between me and him, he was my first husband, it was from him, there can be other way[...] at school they used to say to use condom, but I thought that only prostitutes cold be infected (Ruby).

> It was through sex, it's the only explanation, through sex really [...] before I know I was HIV positive I wanted to get pregnant, so I did not use condoms [...] we used to use condoms at first, then we stopped using, but I could not get pregnant for a year. That was when he discovered he was with HIV (Sapphire).

We noticed that the transmission of the virus occurred, for these women, through unprotected sexual intercourse, and some reasons were given for such action, such as the desire to get pregnant and the notion of invulnerability, given the belief that only the sex workers would be vulnerable to infection, which leads to the notion of risk groups of the beginning of the HIV/AIDS epidemic.

Similar data were obtained for study in Santa Maria, Rio Grande do Sul, in which most of the pregnant women were infected through sex with HIV-positive partners, and some intravenous drug users. At the same time, in many of these cases, diagnosis occurred in pregnant women with a regular partner and apparently without risk factors for exposure. This finding shows the vulnerability of women that, even in stable unions, can be contaminated by their partners[11,12].

Research performed with six pregnant women with HIV investigated their feelings about their own infection, about motherhood and the baby, after the discovery of HIV status, and found that women felt the need to justify the form of infection. They sought to explain that were infected by a stable partner who did not have multiple partners[13]. So, we noticed in this study that the transmissibility of the virus is related to stable contexts and seems to represent an acceptable sexual behavior, attached to social standards expected to a "respectful woman".

In Fortaleza, Ceará state capital, study showed that in a total of 64 HIV positive female participants, 47 (73.4%) reported having sexual partner, with 45 (95.5%) of these in a closed relationship. And the main source of contamination of the women surveyed was their stable partner, highlighting the exposure of monogamous women to bigamist partners, accounting for 42 (65.6%)[14].

Therefore, it is necessary that health professionals are qualified to guide these women about the prevention of HIV transmission, showing them the importance of taking care of themselves, despite being in a stable relationship. This group of women exposed to the virus in this manner contributes to the change in the distribution of HIV infection, in which the feminization is an important phenomenon in the epidemic[15].

Experiencing the discovery of diagnosis

This category describes how women experienced the discovery of HIV seropositivity and also the changes that have occurred in their lives after this moment.

When faced with the confirmation of serodiagnosis, women had mixed reactions. Essentially, the discovery caused a negative impact on their lives, leading to sadness, despair, anguish, fear, associating the infection to a sense of destruction and death, leading them to analyze their personal plans.

> [...] I felt totally destroyed, my dreams, my plans of life, it's a dream for any woman, any girl, to build her family, to have her home, her children, her husband [...] when I discovered, the only thing I could do was to cry (Ruby).

> When I discovered, the world fell on my head, I was desperate [...] when I think of the diagnosis, the sadness arises (Pearl).

Another study also showed similar reactions in reports of pregnant women with HIV, which resulted in difficulty in accepting and believing in the diagnosis, attempted suicide, depression accompanying the occasion, isolation and shame, thus presenting a critical time in their lives, being a painful experience for them[1,5,17].

We found that the reactions that emerged with the serodiagnosis were more intense due to the fact that HIV/AIDS is a disease that has no cure and that the fear of abandoning their children with their death.

> The moment I found out, for me I would not even spend so much time with my son, because I've seen scenes that mothers soon died and left their children, for me this was going to happen to me (Ruby).

The fear of death arises because they are facing a disease that is not only unknown to them, but also incurable, despite having treatment and a chronic status. The concern is on the child's development, and under the care of who this child will be. They deal with a guilty for putting the child in such situation and depriving children of their presence and aid in the future[1].

Consubstantially, study performed with six pregnant women in prenatal monitoring in order to analyze the coping and perceptions regarding the outcome of positive HIV test, showed that

the reactions triggered with the diagnosis were associated with the perception of invulnerability to HIV by women, which initially provoked feelings of indignation, remorse, sadness and even indifference[17].

However, over time, women realized that they can have a normal life with HIV, performing the proper treatment. So they started to accept the disease in their day-to-day and showed that feel more peaceful now when thinking about their HIV status.

> When I found out, I don't know, so many things happens in our head, I was very sad [...] today when I think of diagnosis, you know, it is more quiet, but before I wanted to die, HIV was death for me (Sapphire).

Research indicates that as living with HIV, infected women realize they can live like other people and start rearranging their lives. They keep busy with household chores, with the other children, with the partner, and end up taking the focus away from the disease[16,17]. This may be associated with the fact that they know that there are other people experiencing the same situation (pregnant and with HIV) and/or who are facing worse situations and make comparison with their lives.

However, with the discovery of HIV, all women reported changes in their family and social relations, which helped to intensify the negative impact of the diagnosis on their lives. However, positive changes were also identified with the discovery, facing the financial aspect, due to illness aid that contributes for these women to bear family expenses, and in the marital relationship, since the disease strengthened love ties between couples, leading to greater complicity.

> [...] There are many people who are prejudiced; there were people who started talking about me in the very health unit, spreading out information. They were prejudiced toward me, it hurts (tears in her eyes) (Pearl).

> It changes so many things with the diagnosis because, well, it's something that can't be transmitted easily, but many people have prejudice, this is what really changes, the prejudice that people have (Sapphire).

> [...] It changed my financial aspect, because my illness aid helps me now to, at least, have my food, my house (Jade).

HIV seropositivity exposes women to social prejudice and stigma of being a carrier of a disease with no cure[1,5,17]. Discrimination, social rejection perceived by women, observed in this study, confirms the cultural aspects found in the literature on the topic, noting that living with the infection generates fear of prejudice and discrimination[4]. In addition to social prejudice, women may also suffer self-prejudice and self-punishment that deprives them of a healthy sex life and of being a confident mother[4,17].

All this may lie in the omission and concealment of seropositivity by women, and also of any other objects and actions that can be associated to it, such as drugs, tests and doctor visits[4], interfering with the care provided to them.

Support after the discovery of HIV

All women interviewed reported having received some support after the discovery of HIV, citing the family, friends and the service as important to face this condition.

> I had the support of the outpatient people, I used to talk to the nurse, with the people there, they told me things (about the disease) (Jade).

> I have always had support from my family, I relied in them, I sought the service just to do the treatment itself and to learn more about this disease, but it is my family who gives support. My family knows the diagnosis (Sapphire).

These reports reveal the importance of family support for this new phase of life of these women. For in the context of pregnancy, women need to make decisions, such as about giving medication to the newborn, and need to socialize their anguish, on, for example, the fact of not breastfeeding, use of medications, and other matters that affect the lives of these pregnant women[18].

In this way, being accepted by the family, having somebody to help to raise children and to perform the treatment gives them support. Health service and health workers who assist them are also supporting elements for these women[1,4].

As well as family support, the support of professionals is also essential. During the experience in the service, we realize that these professionals are working hard to provide a better quality of life and health for these women,

showing the degree of commitment. This was evidenced in the reports, which highlighted the importance of multidisciplinary care to cope with the disease.

Thus, professionals need to be trained to advise pregnant women efficiently about the difficulties they may encounter, relying on logical and understandable arguments, acting on the value of life as a transforming agent, thus promoting the humanization of care to these women[2,6,17]

However, there were women who reported not seeking support in the family, this being associated with the fear of suffering prejudice by relatives and also in the search of not taking suffering for the family, as shown in the statements below. Thus, the concern about the confidentiality of the serodiagnosis compromises the quality of life of these women[4,17].

> The doctors, my husband and God are the only ones who know my diagnosis. In my family no one knows, I did not say, because they were not going to help me, they would suffer along with me, so I said I will not tell, as long as I can run after and seek my health, I will not tell them (Ruby).

> I did not go after my family, no! I did not tell my family, the only one who knows is her father, no one else (Emerald).

We realize the importance of the partner's support, or the child's father in the lives of these women, which corroborates study that showed the husband, or the child's father, as the person most mentioned by pregnant women when asked about the support after diagnosis. As the one who hears complaints, shares feelings, pays attention, answers questions, besides being the financial provider.

But holding to faith and God was perceived as the main support for these women, and it finds correspondence with the statement that women believe that God is in control of their lives, that they can trust in Him and receive strength to continue living and expect Him to cure, if it is His will[20].

> Primarily, the support I had was from there, of the infectious diseases ward, they supported me a lot, no, in first place the support was from God, for me to endure. I've been going to evangelical church, I have strengthened myself in faith (Pearl).

> [...] I held to faith, to religion (Ruby).

Faith is seen as something that allows the continuity of a healthy life, even in face of HIV infection[17,19]. In this study and as found as in other literature[17], the belief in a religious entity enables these people to cope living with the exposed baby and their families, as well as social and professional environment.

FINAL CONSIDERATIONS

It can be seen that the context of discovery of HIV is still permeated by stigma, bias, and concerns about AIDS and virus, thus resulting in difficulties for women living with this condition. In this sense, since all study participants met the diagnosis for HIV during pregnancy, pre-natal consultations have become exceptional moments for the nursing interventions, to listen to them and guide them in caring for their health, their baby and educational guidelines and actions aimed at to the recommendations to reduce VT, such as the early initiation of VT chemoprophylaxis, use of injectable antiretroviral during childbirth, use of syrup for the newborn, in addition to the warranty and referral for monitoring the exposed child after birth.

It is evident, then, the importance of the dimension that is given to the professional-client relationship, especially the nursing care, as participants in the pursuit of health promotion in a building reality of relationships, health, life. Thus, care to this group requires sensitiveness, ethics and group work capacity that can encourage responsible decisions in these delicate care spheres.

Finally, this research was limited as to the number of participants (five). It is proposed, therefore, the performance of research that can involve more women who were diagnosed with HIV during pregnancy, in search of evidence not only for nursing care, but for the comprehensive health care of that parcel of the population.

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VIVÊNCIA DE MULHERES DIAGNOSTICADAS COM HIV/AIDS DURANTE A GESTAÇÃO

RESUMO
O estudo objetivou descrever como as mulheres diagnosticadas com HIV durante o pré-natal vivenciam o diagnóstico e a gestação. Trata-se de pesquisa exploratório-descritiva, qualitativa, realizada em uma instituição municipal de saúde de Juazeiro do Norte, entre dezembro de 2012 e fevereiro de 2013. Participaram cinco mulheres, após aprovação do Comitê de Ética em Pesquisa. As informações foram coletadas através de entrevista semiestruturada e os dados obtidos foram analisados pela técnica de Análise de Conteúdo. Os resultados indicaram três categorias: O pré-natal como estratégia para o rastreamento da infecção pelo HIV; Reações diante da descoberta do diagnóstico e; Apoio após a descoberta do HIV. E mostraram que o conhecimento do diagnóstico causou impacto negativo na vida das participantes, levando-as a analisar seus planos pessoais, com o apoio de familiares, amigos e/ou serviço que as acompanham. Enfim, o diagnóstico ainda encontra-se permeado de estigma e preconceito. As consultas de pré-natal tornaram-se momentos excepcionais para a atuação da enfermagem, garantindo uma assistência humanizada e integral.

Palavras-chave: Saúde da mulher. HIV. Gestantes.

EXPERIENCIA DE LAS MUJERES DIAGNOSTICADAS CON VIH/SIDA DURANTE EL EMBARAZO

RESUMEN
El estudio tuvo el objetivo de describir cómo las mujeres diagnosticadas con el VIH durante el prenatal viven el diagnóstico y el embarazo. Se trata de una investigación exploratoria-descriptiva, cualitativa realizada en una institución municipal de salud de Juazeiro do Norte, entre diciembre de 2012 y febrero de 2013. Participaron cinco mujeres, después de la aprobación por el Comité de Ética en Investigación. Las informaciones se recogieron a través de entrevistas semiestructuradas y los datos obtenidos fueron analizados por la técnica de Análisis de Contenido. Los resultados mostraron tres categorías: El prenatal como estrategia para el rastreo de la infección por el VIH; Reacciones delante del descubrimiento del diagnóstico y; Apoyo tras el descubrimiento del VIH. Además señalaron que el conocimiento del diagnóstico causó impacto negativo en la vida de los participantes, llevándolas a analizar sus planes personales, con el apoyo de familiares, amigos y/o servicios que las acompañan. Por último, el diagnóstico sigue permeado de estigma y prejuicios. Las consultas prenatales se convirtieron en momentos excepcionales para las intervenciones de enfermería, garantizando una atención humanizada e integral.

Palabras clave: Salud de la mujer. VIH. Mujeres embarazadas.

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