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SOCIAL REPRESENTATIONS OF WOMEN WHO LIVE WITH THE HUMAN IMMUNODEFICIENCY VIRUS AND WANT TO CONCEIVE

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ABSTRACT

Objective: to know the social representations that involve the desire to conceive of women living with the Human Immunodeficiency Virus.

Methods: exploratory-descriptive study with qualitative approach, carried out with 21 women who were at the Professor Alberto Antunes University Hospital (Alagoas/Brasil) and at the Salgadinho Medical Care Unit, reference centers for people living with the Human Immunodeficiency Virus/AIDS, in the period from May to June/2016. The data was collected through a semi-structured and audio-recorded interview technique, submitted to content analysis from Bardin's perspective. The Theory of Social Representations was used as theoretical reference.

Results: it was evidenced in the study that the social representations of women living with the Human Immunodeficiency Virus that have the desire to conceive is still experienced in a dramatic way by women, causing the appearance of several feelings that cause an internal conflict in them. The feelings arising from the representations evidenced in the studies were: fear, frustration, impotence, guilt, sadness, uncertainty, apprehension, anguish, depression and rejection.

Conclusion: the representations created throughout life history interfere with reproductive decisions. For women living with the Human Immunodeficiency Virus, the decision to conceive, or not, is influenced by the possible risk of vertical transmission, the inability to breastfeed, the treatment, and the social and moral aspects that would affect them and their children.

DESCRIPTORS: Pregnancy. Human Immunodeficiency Virus. Nursing. Family Power. Qualitative Research.

REPRESENTAÇÕES SOCIAIS DE MULHERES QUE VIVEM COM O VÍRUS DA IMUNODEFICIÊNCIA HUMANA E DESEJAM ENGRAVIDAR

RESUMO

Objetivo: conhecer as representações sociais que envolvem o desejo de engravidar de mulheres que vivem com o Vírus da Imunodeficiência Humana.

Métodos: estudo exploratório-descritivo com abordagem qualitativa, realizada com 21 mulheres que se encontravam no Hospital Universitário Professor Alberto Antunes (Alagoas/Brasil) e no Posto de Atendimento Médico Salgadinho, centros de referência para pessoas que vivem com Vírus da Imunodeficiência Humana/aids, no período de maio a junho/2016. Informações coletadas mediante técnica de entrevista semiestruturada e áudio-gravada, submetidas à análise de conteúdo na perspectiva de Bardin. Utilizou-se como referencial teórico a Teoria das Representações Sociais.

Resultados: foi evidenciado no estudo que as representações sociais das mulheres que vivem com o Vírus da Imunodeficiência Humana e desejam engravidar, ainda é vivenciado de forma dramática pelas mulheres, acarretando o surgimento de vários sentimentos que causam um conflito interno nas mesmas. Os sentimentos decorrentes das representações evidenciados nos estudos foram: medo, frustração, impotência, culpa, tristeza, incerteza, apreensão, angústia, depressão e rejeição.

Conclusão: as representações criadas ao longo da história de vida interferem nas decisões reprodutivas. Para as mulheres que vivem com o Vírus da Imunodeficiência Humana a decisão de engravidar, ou não, é influenciada pelo possível risco da transmissão vertical, a impossibilidade de amamentar, o tratamento, além dos aspectos sociais e morais que afetariam elas e seus filhos.

DESCRIPTORIOS: Gravidez. Vírus da Imunodeficiência Humana. Enfermagem. Poder familiar. Pesquisa qualitativa.

INTRODUCTION

With the drastic increase in the prevalence of the Human Immunodeficiency Virus (HIV) infection among women, and as the great majority of them are of reproductive age, the risk of vertical transmission of the virus is a major concern. Studies have shown that the vertical transmission rate of HIV when the mother receives no treatment is around 20-45%; however, with the advent of combined antiretroviral therapy, the transmission rates have been below 2%.¹⁻²

Pregnancy in the presence of HIV should be considered of high risk and the clinical surveillance should be a constant. Some complications are directly related to secondary infections and immune deficiencies. Discomforts due to pregnancy-related changes are more pronounced in women living with HIV, such as fatigue, nausea and vomiting, dyspnea and headache, in addition, the HIV infection in pregnancy is related to the appearance of complications such as: spontaneous miscarriage, malformations, intrauterine growth retardation, preterm birth, intrauterine fetal death.³

Despite the current and diverse changes in the role of women in society, pregnancy and motherhood continue to be one of the traditional defining aspects of this gender. It is known that the woman is inserted in a social context that has always been dominated by countless stigmas, marked by limitations and taboos, which have been maintained from traditional family values. These aspects are even more pronounced when it comes to a woman living with HIV/AIDS and, above all, who have the desire to be a mother in this circumstance.⁴

In this context, women living with HIV in expressing their desire to conceive should be embraced, informed about their state of health, current treatments and the risk of perinatal complications. Thus, the preconceptional counseling for their empowerment in decision making is necessary, since the desire to become pregnant is followed by different physical, psychological, social, political, and institutional dilemmas.⁵

Overcoming these dilemmas, in addition to generating fewer impacts, can demonstrate to them that each individual can experience different sensations, internal conflicts and the most diverse fears about the diagnosis. However, when there is an effective listening and embracement by the professionals, this can cause a transformation in their lives, helping them learn to live with the infection

and then reorganize their perceptions and goals, thus giving continuity to the process of life.⁴⁻⁵

In this perspective, the study allows the recognition of the particularities of the desire to conceive of women living with HIV, as well as their representations, repercussions and feelings, to better understand the reality of what is experienced by them, as well as the difficulties to guarantee their place in society and especially, their role as a mother. Thus, the improvement of health care has contributed to provide important information to he professionals in this area, in the construction of strategies for the qualification of the care provided to women living with HIV/AIDS and who want to conceive, enabling them to exercise their reproductive choices in a conscious way.

From the previous questioning, the following guiding question has emerged: what are the social representations of women living with HIV facing the desire to conceive? Thus, the present study aimed to investigate the social representations that involve the desire to become pregnant of women living with HIV.

METHOD

This is a descriptive, exploratory study with a qualitative approach, carried out in two specialized services in the care of people living with HIV/AIDS in the city of Maceió/Alagoas. The scenarios of the study were the Dia Hospital, located at the Professor Alberto Antunes University Hospital of the Federal University of Alagoas (HUPAA/UFAL) and at the Salgadinho Medical Care Unit (PAM), a reference for patients with Sexually Transmitted Infections-STI/HIV/AIDS. Twenty-eight women, who met the criteria for inclusion, were approached: fertile women, aged between 18 and 45 years old, diagnosed as HIV positive and at the time of data collection were at the research sites. However, of these, seven refused to participate in the study, leaving 21 women, of whom there was no withdrawal. The exclusion criteria were: pregnant women, those who had a tubal ligation, emotional issues and previous trauma related to the topic referred to during the interview.

The data collection was performed between May and August 2016 by two researchers, who had no connection with the study scenarios. It was done through the technique of individual interview, using as a collection instrument a script of semi-structured questions, divided into two parts: the first part

with questions related to sociodemographic data (age, origin, marital status, schooling, profession/occupation, address) of the participants, and the second with questions related to the object of study (When and how did you receive the diagnosis of HIV/AIDS?, What does this discovery mean to your life? How do you coexist with the diagnosis? Do you have the desire to be pregnant? Before you find out you have the virus, what were the feelings about pregnancy? And now what has changed in relation to those feelings of before? What feelings do you have now, living with the virus?).

The process of connecting with the participants happened initially in the visit to the respective study scenarios, by receiving information about the days of medical consultations, mainly, of the gynecologists and their schedules. Thus, the recruitment of women was performed by convenience and at the moment of waiting for the consultation, and they were approached and invited to a reserved place to respond to the interview, signing the Free and Informed Consent Term. The interviews were audio-recorded, with duration ranging from 15 to 30 minutes.

The collected data were transcribed in full and analyzed according to the Bardin's Content Analysis technique.⁶ This analysis began with the listening and transcription of the answers. Subsequently, the referent-nuclei (usually nouns or pronouns) were determined in function of their structuring discourse power and their strong referential value from the point of view of content and not just frequency of occurrence. Then the text was divided into propositions, which are phrases in their elementary form that qualify and explain the referent-nuclei. Then, there was the determination of the referent-nuclei, which implies the rewriting of the propositions in a simplified form through the categories that represent the content. The delimitation of the number of interviewees was performed by saturation of information, that is, when no new information was obtained and the answers became repetitive.

It was used as theoretical reference of this study the Theory of Social Representations, which represents a form of common sense knowledge, which seeks to understand and communicate the beliefs, images, symbols, values, and attitudes shared collectively and consciously in a group, society or culture. That is, it is an indispensable phenomenon to explain cognitive processes and social interactions, which guides and organizes behaviors and communication.⁷⁻⁸

This study was developed according to the Resolution No. 466 of December 12, 2012; the research project was submitted to the Ethics Committee of the Federal University of Alagoas and approved on 04/14/2016 by the Research Ethics Committee with CAAE No. 5319016.5.0000.5013. After approval, the data collection was initiated, in which the subjects were clarified about the purpose of the research, being guaranteed their spontaneous participation, anonymity through pseudonyms (name of flowers), the possibility of interrupting the interview at any time according to their will and respect for them and the data collected, without inducement or embarrassment.

RESULTS

The presentation of the results of this study was divided into three moments: the first one refers to the characterization of the research participants; the second refers to the social representations that involve the desire to conceive; and the third to the social representations facing the concretion of motherhood.

Characterization of the research participants

The study consisted of 21 HIV-infected women, 12 of whom were interviewed at the Salgadinho PAM and nine at the Hospital *Dia*, with age ranging from 19 to 36 years old, with an average age of 26 years old. Most of the interviewees (15) lived in the capital of the State of Alagoas, and six lived in cities located in the countryside. As for schooling, (13) attended incomplete elementary school, five had completed high school, one was in elementary school, one was in high school and only one was in higher education. In relation to the practice of a paid activity, only six had a job, the other (15) declared themselves housewives, not exercising any paid activity.

Regarding their marital status, eight were married, five lived in a stable union, one was divorced and seven were single. As for the number of children, nine had one child, nine had more than a child, and three had no children. It is worth mentioning that 11 of the 21 women interviewed have a history of abortion. Regarding the time of discovery of seropositivity, two were diagnosed less than one year ago, 11 were diagnosed between one and three years ago, six were diagnosed more than five years ago, and one did not know how to report. As to the stage of life in which the diagnosis

was received, ten women were in adult life (fertile age), seven during gestation, three at the childbirth and one in childhood (vertical transmission). When questioned about the desire to become pregnant after the HIV diagnosis, 14 stated that they want to have children, and seven said they did not want to have any more children.

Social representations involving the desire to conceive

In the study, both women who were never pregnant and those who already had children expressed the desire to be mothers as a natural feeling, being represented as one of the greatest dreams of their lives, according to the following speeches:

the feeling was what? Being able to buy a house for me, a car, a family, build a family and have a child, I did not think I would have it [HIV], but now it's harder for me to have a child, I guess. (Orchid);

oh, before I found out, it was a desire like that, to have my house, to have my husband, to have my son, not only a son, two children, right (Rose).

Pregnancy in women living with HIV is still seen by the society as "contraindicated," as can be seen in the speeches below:

[...] I wanted to have others "laughs", but they say you cannot, right, because of HIV, you cannot get pregnant. Well, I listen to the people saying, right, I do not know (Palm);

[...] I have it, but they say that the person cannot, because it can pass to the child and to the partner of the person, then there is this doubt (Lavender);

Concerning the desire to conceive in the face of HIV, the fear of vertical transmission appeared almost as a constant among the reports:

it changed, right, the fear, the risk of me wanting to be a mother and the child being born contaminated with this problem (Palm);

It's because I'm afraid of... like these things of mine and my husband's too, then we want to have a child, we want a child, but we're afraid to pass it on to the child, do you understand? That's it (Angelica);

[...] it's like I said, I always wanted to be a mother, I always had that desire and when I received this diagnosis, what I really felt was fear, right, fear of my son or my daughter being born with the same problem as me, but in relation to the desire I had to be a mother, it has never changed, I always wanted to have it, do you understand? But I feared, I was very afraid that the child would be born with the same problem, because I know the difficulties e/ she would have to go through and also there is the issue

of prejudice? In addition to the medication issue and everything, and to be always having to be tested, there is the issue of prejudice, because it is not all people who accept it (Jasmine).

The possibility of HIV to be transmitted to the child in a new gestation also appears as one of the strongest arguments that justify the definitive desire not to conceive, after the discovery of the diagnosis, through the desire to perform the tubal ligation:

I do not want to get pregnant anymore, what I wanted to do was to operate because I wanted them to take everything, I did not want them to leave it because I have no desire to have more children, not after one of these (Hydrangea).

For the younger participants who were not yet mothers, the serological condition did not change the desire to be a mother; however, they say it is more difficult:

I do, but, due to the disease I think it's difficult for me to get pregnant, but not now because I have to dedicate myself to my studies to have something in my life to be able to have a child, to have responsibilities with my son (Orchid);

I have it, I raised it, but after I became HIV-positive [...] because it gave me more the idea of raising a human being bringing with him all that awareness, this history that I have of life, through a dialogue with that child that in the future is going to become a man or will become a woman... conscientize, educate with responsibility, not that I have had this education with responsibility, but some things end up becoming taboos in the old traditional family and today we can break much more. So, this need to experience motherhood in view of this maturity, this teaching for the future (Glorious);

[...] I think HIV cannot disrupt the desire of a woman to want to be a mother, do you understand? Because there is all the care for the baby, I think I'm going to be a mother, a normal child, like a mother who is not HIV-positive, do you understand? It is just to be careful [...] I know that the care not to pass on to the baby is not to breastfeed, to be a normal birth, to be a cesarean, and to be at least every six months, until the age of ten, being tested, to see if he will have it [...] the doctor told me so (Rose).

However, for those women who underwent pregnancy prophylaxis, it was characterized as a poor experience due to the side effects of the medication:

my problem was [...] I was allergic to the medicine at the beginning, it was very strong, it was a lot of medicines that I would take because I discovered it at six months already, there was little time, there was a lot

of medicines, then I got intoxicated with one of them. I got sick, I was really, really ugly, I looked like an animal (Lavender);

[...] I'm afraid because I suffered too much, a lot of things, a lot of medicines, and then go through everything again, then I do not know, but deep within it has (Acacia).

In addition to that, being pregnant and having HIV generates psychological conflicts that can lead to the woman's illness, as can be seen in the following speech:

I accidentally got pregnant, but I got pregnant. [...] It was..., it was not good not because it was then that I became sicker, I was depressed, I became very sick (Lys).

It was also observed in the reports that the impossibility of breastfeeding brings a negative feeling to the exercise of the desire to conceive, since breastfeeding is considered by these women as a symbol of motherhood, as evidenced in the speeches:

[...] if I were to get pregnant, I would like to breastfeed, you know, because I have already breastfed my son. It's a, I do not know, I feel like it, it's that thing that you feel about breastfeeding, but with this thing I have, that problem, then I know I'm not going to harm a child, do you understand? Then I have to give the milk that is not from the breast, other than the problem I have (Angelica);

In the first moment there was a feeling of rejection, the fact of not being able to breastfeed was already a relation of rejection with the child that I did not want to have [...] my desire, my dream, was to have a healthy breastfeeding, to have that relationship with the child of feeling, of exchange of energy. Today I will not be able to have it, so this from the beginning it was kind of shocking (Glorious).

Social representations due to the concretion of motherhood

The situations experienced in the puerperium interfere with the decisions of women to have or no more children. In their speeches, the isolation and the postpartum depression in the hospital environment are evidenced, according to the reports:

When I heard it, I was going to try to kill myself, right there at the Açúcar Hospital. I tried to kill myself [...] I would even jump out a window, [...] a the woman said do not do it, a lot of people started coming close to me, doctors, they all stayed close to me to talk right with me, there ready, I was calm and held myself (Sunflower);

I stayed in the corner bed, I did not want to stay close to everyone, I stayed, I chose the bed in the corner, I said: 'Look, doctor, put me there in the corner.' I was away from almost everyone (Hydrangea).

The emotional instability of the puerperium interferes in the relationship of the binomial; the women reported the feeling of rejection, fear and guilt after the birth of the child:

I felt something bad, I did not want her. I felt that girl was not my daughter when I had her, that she is not my daughter [...] So, I was not feeling love for her (Sunflower);

I rejected her, I was afraid she would be [trembling voice] and judge me later in the future (Tulip).

The interviewees related the non-breastfeeding with a sense of denial of the child, as well as a psychological suffering linked to the perception of impotence:

I was not feeling well, not being able to breastfeed the children, my children. I said: 'Look, my first I breastfed, and why these two I cannot breastfeed?' I see the people breastfeeding and I do not, then I get sad because I could not (Sunflower);

It is not easy! I could not breastfeed my son, my daughter I breastfed and he I did not have the pleasure of breastfeeding, I was there receiving serum without being able to hold it (Hydrangea);

I arrived at the maternity hospital, my son could not be breastfed, could not suck at the breast [sad voice] there were people in the room with me who were not carriers, they had other illnesses, but they were not carriers, they kept asking why doesn't your child breastfeed? (Hydrangea).

With the concretion of the maternity and the arrival of the child, they were also evidenced feelings of happiness, love and strength to live. Positive feelings regarding motherhood are present in mothers who receive the negative result of their son's serology; they feel happy for having generated a healthy child, even with the advent of the disease.

So I was glad I had him and he did not have the disease. Thank God, he had the follow up and everything went well, so it was good for me (Iris).

I'm only living because of my son, who is only three years old and needs me. If it were not for my daughter I do not think I would be here anymore, I did not even want to live anymore, even take medicine to kill myself I've already tried (Hydrangea).

Oh, it's such a feeling of... realization of a dream, right, feeling that God truly exists, that God has done the impossible in my life through her. Until then, I called her Victoria, because it was a victory in my life and I thank God a lot, the feeling I have is gratitude [...] (Jasmine).

The motherhood of women living with HIV is also surrounded by feelings of anxiety and uncer-

tainty about their survival time, observed through discourses of fear of dying and not being able to raise their children.

Feeling that I have about him, that I think I'm going to die and I know I'll leave him... [cry] (Calla Lily).

My fear was to die, but with time it was passing (Lavender).

DISCUSSION

The meanings that women attribute to the gestation reflect the social and cultural expectations that arise in the social imaginary, as well as the objective and subjective conditions experienced, determining the decision to have children or not. Regarding the social representations, the definition of the roles of men and women in our society still relates the desire to have children to women, placing them as guilty for having generated a child with the virus and forgetting the relation of motherhood with ties of family relationship with her husband and the discovery of society.⁹

Faced with the discovery of the HIV diagnosis, women were fragile and afraid of exercising their reproductive desires, in which the decision making became more complicated. People's conception of HIV/AIDS is not limited to the biomedical knowledge about the infection, but it also includes different possibilities: the social constructs of the disease, represented by strong stigma, related to traditional beliefs about the moral nature of health, illness and human suffering.¹⁰

Knowing about the HIV seropositivity, particularly because of the possibility of transmitting the virus to the child, generates conflicts regarding the exercise of motherhood.¹¹ It can be seen that the serological condition of these women causes them to have a greater concern about the health of the child. In this way, the realization of the desire to conceive is put as something distant by the fear.

For women who had children before the HIV diagnosis and did not become pregnant afterwards, the decision not to have more children is justified because of the fear of transmitting the virus to their offspring at a later pregnancy. In addition, the fear of transmitting the virus to children is due to the extent of the difficulties faced by women living with HIV, such as prejudice, use of antiretroviral therapy, side effects of the medications, medical consultations and tests. They care about offering the best for their children and do not want to cause them any harm.

Thus, the literature corroborates this study showing that the prejudices rooted in society and

the lack of guidance and support from health professionals, in addition to the adverse effects of the antiretroviral therapy, lead women not to cultivate the desire to be mothers. In this perspective, the symbolic register of maternity related to social representations, often when not worked within the understanding and values by professionals, can modify a woman's desire to be a mother because she understands that she may be putting her baby at risk and exposing them to illness.^{7,9,12}

The renounce of conceiving again, after being diagnosed during pregnancy, denotes the strong emotional conflict that HIV causes about a woman's reproductive decisions. Accordingly, a study conducted in 13 Brazilian capitals found that the willingness to perform the tubal sterilization is greater in women who were diagnosed with HIV during the prenatal care than in those who had previously been diagnosed.¹²

However, in younger participants, living with HIV does not change the desire to be a mother, as seen in their speeches. The manifestation of the will to be a mother after the knowledge of the positive diagnosis, by the maturity and responsibility built after this discovery, since for her the will to be a mother was not present before. The possibility of motherhood strengthens a woman's self-esteem, as the miracle of life, the greatest expression of existence, challenges the mystery of illness and her own body.¹³

It was evidenced that one of the other motivations that supports the desire to become pregnant after the HIV diagnosis is the knowledge of the prophylactic measures of the maternal-fetal transmission. A study showed that the mechanisms to prevent mother-to-child transmission light up women's expectations of having a healthy child, as the treatment can reduce the risk of transmitting the HIV virus to the baby by 2% or less. In this sense, the social representations may seem illusory and even contradictory, since science proves that the seropositivity does not prevent women from fulfilling the dream of being mothers.

Although the use of antiretroviral drugs significantly reduces the risk of infection, providing some tranquility for the pregnant woman, there is still a negative feeling that these medications may have potential adverse effects on the pregnant woman and the fetus. When the diagnosis is received during pregnancy, the gestational process tends to be an experience based on distress, bringing tension and insecurity, both in relation to HIV transmission, and regarding the use of medications.¹³⁻¹⁴

Regarding the impossibility of breastfeeding, in this study, the woman who experienced pregnancy and breastfeeding before the diagnosis of HIV reported an ambiguity of feelings due to the possibility of a new pregnancy and the sad task of not breastfeeding her future children. The experience of breastfeeding represents a milestone for the woman in motherhood. However, due to the HIV infection, it poses a threat to their child's health by modifying culturally constructed concepts throughout life.¹⁵

In the interviewed women the frustration, incompetence and denial of the impossibility of breastfeeding were evident. In addition to these feelings, women idealize breastfeeding and symbolize it as the only way to bond with their child. This social representation does not only refer to HIV but involves physical, social, economic, political and cultural factors, since the act of breastfeeding is socially expected and stimulated, given the benefits of exclusive breastfeeding for both mother and baby. In addition, it should be observed that the social representations regarding breastfeeding do not always conform to the reality of the concepts and truths that the social actors make of it, since the bond of the binomial can be constructed independently of the breastfeeding process.^{8,15}

To ease these feelings, it is important to clarify and guide the woman about other ways of developing the bond between the binomial, such as: lullaby, bathing, caressing, looking, among other things. And demonstrate that the act of breastfeeding can be replaced, in this context, by the bottle, as well as the natural milk by the artificial one, without feeling guilty for not breastfeeding the child.¹³

With the concretion of the maternity, the interviewees related the non-breastfeeding act to a sense of denial of the child. The social representation of these mothers is anchored in expressions such as "I feel sad," which represent the symbolism and meaning of the impossibility of breastfeeding, because in the cultural sphere they feel that they cannot perform their role as a mother completely. For the woman who has already experienced breastfeeding, it is even more difficult to accept that for this child she cannot express her act of love, coupled with feelings of impotence, guilt and incompetence. Experiencing motherhood without the right to breastfeed and witness the breastfeeding of other people generates feelings of sadness and anguish in women.¹⁶

An important aspect highlighted in the study is the feeling of sadness when seeing other women breastfeeding in the hospital and not being able to

do the same, besides the social demands that put them in an embarrassing situation, when questioned about why these women are not breastfeeding.

The puerperium is a time of great emotional instability, especially in the face of an HIV diagnosis. In the first week postpartum, a woman can go from a state of euphoria to a depressed state very quickly, some causes for this are the hormonal changes, the length of hospitalization, the suppression of breastfeeding, the maternity idea and the uncertainty about the baby's diagnosis.¹⁷

The psychic overload remains after the child's birth, due to the uncertainty of the baby's diagnosis, permeated by feelings of rejection, fear and guilt. The process of motherhood of mothers with HIV/AIDS is a situation of vulnerability, aggravated by feelings of guilt, anxiety and uncertainty, due to the child's exposure to the virus. The feeling of guilt comes from the involvement of an innocent being with the HIV infection. And there is also the fear that other people will find her guilty for the infection of the child, being a form of social representation of the problematic that permeates HIV/AIDS.⁹

On the other hand, the participants indicated that the motherhood has brought new meaning to their lives regarding how to live with HIV, and their children represent an incentive and a reason to live. The results corroborate a study in which women revealed that being mothers brought into their lives the congregation of an ideal, a future project, the possibility of continuity of existence. Moreover, this same study shows that the most of women say that the love for their children is the great incentive for the struggle for their lives, and the adherence to treatments is performed by the desire to stay as long as possible with their offspring.^{12,18}

Some of these women relate pregnancy and the child to religiosity, because they believe they have been seen by God, because the child was born healthy, since motherhood represents for them an opportunity to live with different ideals, involved by perseverance and trust in life.¹² A study has found the relevance of religiosity and spirituality in the lives of women living with HIV as a coping strategy, as well as helping to promote life expectancy. It also highlights the importance of health professionals addressing these issues during care.¹⁹

The fear of death due to the fact that they face a disease seen as lethal, despite having a chronic status, causes women to think about the future, the development of their children, the care of whom they will be, and what can be made in the sense of having a better quality of life, because it is these

feelings that can determine the way of living and influencing in society, a social representation imposed by women who care about the way of birth and quality of life for their children.^{7,9}

With the birth, new conflicts emerge, such as fear of being ill and dying during the development phase of their child, leaving them helpless, causing concern about who will replace their mother's position. As death permeates the lives of these women, if they had the opportunity to choose, their deaths would occur in the period after the adolescence of their children, because at this stage they would be independent and self-sufficient, not delegating their care to third parties.²⁰

These feelings are common in every disease, whose treatment is ineffective in the sense of healing, overloaded with meaning, considering it more serious than it really is, and thus identifying it as death itself. AIDS has become something other than a disease, a myth that suggests and symbolizes an illusory truth accepted by people, which plays a significant role in their behavior.¹⁰

Understanding the meanings and representations of women living with HIV attributes the experience of motherhood and instigates the involvement of health professionals to have an expanded view of care and to consider all the elements of the context involved.²¹ In addition, health professionals should be aware of the family and affective repercussions arising from the condition of living with HIV and how it can influence the behavior of these women, including adherence to treatment, and it should therefore provide comprehensive care that can meet their bio psychosocial needs.²² Finally, it can be seen that for the woman living with HIV, the possible risk of transmission, the non-breastfeeding, treatment and its consequences, and the perception of impotence before the condition presented, besides the social and moral aspects that would affect the children, influence the decision to conceive.⁹

Thus, it is necessary a model of care that values the feelings expressed by women who wish to conceive in the face of the HIV diagnosis, and a reassessment of the ethical and professional posture of all those involved in the care of women with respect to their sexual and reproductive rights. The woman who wish to experience maternity should be embraced by health professionals, among them the nurse, who must be available and qualified to provide care and guidance in a humanized way, respecting their doubts, feelings and future decisions and providing them with comprehensive care. As well as being seen as promoter agents, capable of

overcoming the fulfillment of the women's desire and the need for specific treatment, psycho-emotional preparation and responsibility.²³⁻²⁴

The study, however, presented some limitations regarding the difficulty of approaching women, because it is a subject about which prejudice and stigma on the part of society already exists; and the study scenarios did not have an appropriate place for the interview, making many of the women afraid to respond to the interview form and memory bias. However, the researchers tried to minimize these problems through effective listening and embracement, demonstrating how much their testimonies could help in the construction of a reflection and change of the forms of care on the topic.

CONCLUSION

This study allowed a reflection on the social representations of women living with HIV regarding their desire to conceive and the exercise of motherhood. Despite transformations in the scientific, technological, social and political spheres, pregnancy and motherhood are still experienced by women living with HIV in a dramatic way, causing the appearance of different feelings that cause them internal conflicts. The feelings that involve the desire to conceive and the realization are: fear, frustration, impotence, guilt, sadness, uncertainty, apprehension, anguish, depression and rejection. Some of these feelings relate to social representations of HIV/AIDS present in society.

The knowledge by health professionals of the social representations regarding the desire to become pregnant of women living with HIV makes it possible to provide comprehensive care, focused mainly on the psychosocial aspects of women, in order to identify their feelings and doubts, helping their sexual and reproductive health decisions, since social and cultural elements impact women's decision-making, including their desire to become pregnant.

Thus, it is the responsibility of health professionals to provide care in a humane way, contributing to soften the feelings of women who wish to conceive and who are mothers during an HIV infection. In particular, nurses, who must be trained to carry out the family planning of this population, and have the sensitivity to provide comprehensive care that takes into account the physical, psychological/emotional, cultural and social dimension of these women.

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