

# Maternity perception by pregnant women living with HIV

Thelma Spindola<sup>1</sup>  
 Karla Temístocles de Brito Dantas<sup>2</sup>  
 Natália Fernanda Vitipó Cadavez<sup>3</sup>  
 Vinícius Rodrigues Fernandes da Fonte<sup>4</sup>  
 Denize Cristina de Oliveira<sup>5</sup>

## Maternity perception by pregnant women living with HIV

**Objective.** Identify the perceptions of pregnant women living with HIV about motherhood and understand the expectations and feelings experienced by these women. **Methodology.** Study with descriptive design and qualitative approach, carried out with 10 pregnant women living with HIV who attend the prenatal service of a university hospital in Rio de Janeiro, Brazil. The participants answered a semi-structured interview. Data were analyzed using the content analysis technique. **Results.** Pregnant women in their descriptions revealed that motherhood gives them different perspectives on the present and future. They see it as a good thing, a responsibility to care for the child, and consider bearing a child to be a gift. **Conclusion.** For pregnant women living with HIV, motherhood is a positive experience in their lives. Nurses must be sensitive to the needs of this group and aware of their role in health care and preventing any possible complications that may affect the mother and her baby.

**Key words:** HIV; pregnancy; obstetric nursing.

## Percepción de la maternidad por la gestante que vive con HIV

**Objetivo.** Identificar la percepción de las gestantes que viven con el VIH sobre la maternidad y conocer las expectativas y los sentimientos vivenciados por estas mujeres. **Metodología.** Estudio con diseño descriptivo y abordaje cualitativo, realizado con 10 gestantes que viven con el VIH y que asisten al servicio de prenatal de un hospital universitario en Rio de Janeiro – Brasil. Las participantes respondieron a una entrevista semiestructurada. Los datos fueron analizados con la técnica de análisis de contenido. **Resultados.** Las gestantes revelaron en sus descripciones, que la maternidad tiene diferentes perspectivas relacionadas con el presente y el futuro. Asumen como algo bueno, la responsabilidad y el cuidado del niño, y el dar a luz a un niño como un regalo. **Conclusión.** Para las mujeres embarazadas que viven con VIH la maternidad es una experiencia positiva en sus vidas. Los enfermeros deben ser sensibles a las demandas de atención de

- 1 Nurse, Ph.D. Associate Professor, University of the State of Rio de Janeiro (UERJ), Rio de Janeiro, Brazil. email: tspindola.uerj@gmail.com
- 2 Nurse, Specialist. UERJ, Rio de Janeiro, Brazil. email: karlatemistocles@bol.com
- 3 Nurse, Specialist. UERJ, Rio de Janeiro, Brazil. email: nataliacadavez@hotmail.com
- 4 Nurse, Specialis, Master's candidate. UERJ, Rio de Janeiro, Brazil. email: vinicius-fonte@hotmail.com
- 5 Nurse, Ph.D. Full professor, UERJ, Rio de Janeiro, Brazil. email: dcoliveira@gmail.com

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este grupo, conscientes de su papel en el fomento de la salud y de la prevención de posibles complicaciones que puedan afectar tanto a la madre como al bebé.

**Palabras clave:** VIH; embarazo; enfermería obstétrica.

### Percepção da maternidade pela gestante que vive com HIV

**Objetivo.** Identificar a percepção das gestantes que vivem com o HIV sobre a maternidade e conhecer as expectativas e os sentimentos vivenciados por essas mulheres. **Metodologia.** Estudo com desenho descritivo e abordagem qualitativa, realizado com 10 gestantes que vivem com o HIV e que são acompanhadas no serviço de pré-natal de um hospital universitário no Rio de Janeiro – Brasil. As participantes responderam a uma entrevista semiestruturada. Os dados foram analisados com a técnica de análise de conteúdo. **Resultados.** As gestantes revelaram em suas descrições, que a maternidade assume diferentes perspectivas relacionadas ao presente e futuro. Assumem como algo bom, a responsabilidade e cuidado com o filho, sendo uma dádiva gerar uma criança. **Conclusão.** Para as mulheres grávidas que vivem com HIV a maternidade é uma experiência positiva em suas vidas. Os enfermeiros devem ser sensíveis às demandas de atenção desse grupo, conscientes de seu papel na atenção à saúde e prevenção de possíveis complicações que possam afetar a mãe e o seu bebê.

**Palavras chave:** HIV; gravidez; enfermagem obstétrica.

## Introduction

Improved life expectancy and quality of life among people living with human immunodeficiency virus (HIV) requires specific care by health professionals, including the nurses who perform support activities in the three levels of health care. The desire to have children in a safe and risk-free manner can now be realized due to scientific and social achievements, whereas in the early days of the epidemic it was denied and condemned by society for exposing the child to harm. With the advent of antiretroviral therapy (ART), prenatal care, and the adoption of clinical management, the risk of vertical transmission is now less than 1%. Proper guidance and assistance to the health of carriers of the virus guarantee autonomy when deciding to become pregnant, thereby decoupling the feelings of fear and concern about the gestation of a healthy child. The experience of pregnancy and motherhood gives life and meaning to the ambitions of women living with HIV, and culturally rooted feelings in this instinctive practice arise in the social imaginary as expectations for health,

happiness, and continuity of life, family, and species.<sup>1</sup>

Although some women living with HIV desire to become pregnant, others neither desire nor plan pregnancy at certain times of life. The recommended use of condoms during sexual intercourse, regardless of whether the partner is HIV positive, is not necessarily a common practice in the life of these women, and may or may not be associated with contraception.<sup>2</sup> Given the reality of being an HIV-positive pregnant woman, and the range and intensity of feelings inherent in this moment in life, this study focused on the guiding questions: How do HIV-positive pregnant women perceive motherhood? What are the expectations and the feelings experienced by HIV positive pregnant women?

The objective of the study is: identify the perception of HIV-positive pregnant women about motherhood and understand their expectations and feelings.

The relevance of this research is linked to the fact that there is a significant number of HIV-positive women, especially pregnant women, who may transmit the virus to their child if they are not oriented and monitored in a timely manner by health professionals. Nursing, part of the multidisciplinary team that assists pregnant women living with HIV, plays a predominant role in guiding the health of women and counseling their adherence to the recommendations for preventing vertical transmission. An understanding of motherhood for HIV-positive pregnant women can contribute to the improvement of nursing care for women in all its complexity, during pregnancy, childbirth, and postpartum.

## Methodology

A descriptive design and qualitative approach was used. The setting was the prenatal service of a university hospital in Rio de Janeiro, Brazil, which specializes in services for people living with HIV and acquired immunodeficiency syndrome (AIDS). The participants were pregnant women with HIV regardless of the gestational period, who knew their HIV status, were aged 18 years old or more, in prenatal care in that institution. Those who were hospitalized with psychiatric comorbidities and sensory impairment (hoarseness and deafness) were excluded.

Data collection was carried out from January to April 2012, after the completion of a routine visit to the prenatal outpatient clinic, through application of the semi-structured interview technique, with questions related to social and obstetric characterization and the object of study. Interviews were conducted in private offices, with the aid of an audio recorder. Ten testimonies of pregnant women living with HIV were recorded, and on realizing that the information became repetitive, we decided to end this stage. Sampling saturation is the suspension of adding new participants when the data obtained begins to show, in the researcher's evaluation, an apparent repetitiveness.<sup>3</sup> Data were analyzed with the use

of the content analysis technique, in the form of thematic analysis.<sup>4</sup>

The analysis process consists of the transcription of the recorded audio followed by reading and rereading of interviews, and preparation of provisional hypotheses about the studied object and the content of the analyzed text. We established registration units (RUs) and subsequently grouped them in meaning units (MUs). The meaning units were then organized according to empirical criteria, resulting in categories that were named, quantified, and presented in cursive description.<sup>5</sup> The statements were identified with the letter I, referring to the word interview, followed by the participation number assigned to the interviewee (I number). The ethical and legal aspects of research involving human beings were respected, following the resolution in force No.196 / 96 of the National Health Council of Brazil, through the favorable opinion of the Research Ethics Committee of the Gafree and Guinle University Hospital, under the No.98 / 2011 and the signature of the Free and Informed Consent form by the participants.

## Results

From the interview analysis process, 219 RUs and six categories emerged, divided as follows: 1) Different perspectives of pregnant women living with HIV related to present and future (82 RUs and 37.4%); 2) Motherhood in the conception of pregnant women living with HIV (45 RUs and 20.5%); 3) Fear versus overcoming (30 RUs and 13.7%); 4) Revelation versus support (28 RUs and 12.8%); 5) Accepting pregnancy (21% RUs and 9.7%); and 6) Failure to breastfeed (13% RUs and 5.9%). The pregnant women interviewed were aged between 21 and 37 years old, averaging 28.2 years. As for the socio-economic history, six lived with a partner and four didn't; seven had less than 12 years of schooling; eight were living on a monthly family income ranging between one and two minimum wages (US\$ 181.73 - US\$ 363.47). Regarding their obstetric history, four women were nulliparous and were

in their first pregnancy; three were primiparous and secundiparous; one was primiparous and tertiparous; one was multiparous and tertiparous; and one was multiparous and quadriparous. All children of the respondents were alive and none were HIV positive. Two respondents (E4 and E7) were found to be carrying the virus during the prenatal exams of the current pregnancy.

### **Different perspectives of pregnant women living with HIV related to present and future**

During the interviews, it was found that HIV-positive pregnant women present various perspectives on motherhood, the most frequent of which was the hope for a healthy child and the capacity to care for it in the future. [...] *I hope that all happens well and everything goes right, that it be just like my first daughter's [...] this is what I pray to God [...]* (E6); [...] *I hope to do well in this pregnancy [...]* (E10). Some mothers considered as an expectation for the future restoration of their health and the discovery of a cure for AIDS: [...] *Improving, because it's being difficult, there is nothing, only medication only medication, there's no progress with this disease, so I hope that things get better in the future [...]* (E8); [...] *That our life expectancy improves. [...] That some medication to cure appears [...]* (E9).

Some women expressed as expectation the hope to take care of themselves first, to thus be able to care for their children in the future; others, the hope to live long to be able to care for their children: [...] *I'll take care of myself, so that I can raise my child. [...]* (E4); [...] *That I keep treating myself and that I live longer. To raise my children [...]* (E6). Some participants expressed the hope that the child will not carry the virus: [...] *My son has nothing, God willing, he has nothing [...]* (E1); [...] *I hope my son does not have the virus [...]* (E2). When asked about their future prospects, the mothers externalized the desire that their children be happy, be born healthy, have a healthy development and a normal life like any other child: [...] *That they [children] have a healthy, happy development, and a childhood*

*unlike mine [...]* (E3); [...] *I hope my children grow up, give me grandchildren, have a diploma and have a healthy life [...]* (E9). Interviewees E2 and E3 were the only ones who considered the fact that living with the virus does not interfere with future expectations: [...] *It has to have the same care whether or not it has the virus [...]* (E2); [...] *Normal, because I've already lived with this problem [with HIV] for a long time [...]* *The only thing I will not be able to do is feed my son, I'll have to change diapers, bathe, take care, take to school, do everything that a mother does [...]* (E3).

### **HIV-positive women's conception of motherhood**

The ten women interviewed demonstrated in their words that even though they live with HIV, they consider motherhood a positive experience in their lives: [...] *Being a mother is a very good thing, it's hard to explain [...]* (E1); [...] *For me it is the most important thing in my life at this time [...]* (E10). Some pregnant women ascribed certain meanings to motherhood in their accounts, as seen in these excerpts: [...] *Being a mother is a gift of God, not everyone can be a mother, not every woman can get pregnant, so if God gave me this child it is because it will bring me great happiness, no matter what she will bring good into my life in spite of this difficulty [the virus] [...]* (E4).

According to the pregnant woman E6, the meaning of motherhood is taking responsibility. E2 and E3 believe that being a mother is caring for the children: [...] *For me, it is the responsibility [...]* (E6); [...] *It is the baby's protection, whether it is HIV positive or not [...]* (E2); [...] *It is raising my child, giving it everything it can have, such as a good education, good development and structure, not only of income but also psychological [...]* *giving attention and affection. [...]* *Also, taking time to look after my children, play with them and see them develop. [...]* (E3). Only one participant (E10) highlighted in her speech that motherhood will result in greater care when compared to that of a woman not carrying the virus: [...] *It is going*

*to be complicated because I think the care will be greater, the work will be more [...] (E10).*

### **Fear versus overcoming**

The most obvious fear was in relation to transmitting HIV to the child, as the following report illustrates: [...] *I am a little afraid to transmit the disease [HIV] to my child during pregnancy [...] (E5).* Measures for coping with and overcoming the risk of transmission were based on a foundation of strength and motivation in the adoption of self-care measures during pregnancy: [...] *I take every possible care and hope my child does not have the virus [...] (E2); [...] I'm taking the same precautions with this second pregnancy so that my daughter does not have the virus [...] (E3).* The pregnant woman (E10), who was not on HAART, hinted at her fear regarding side effects of the medication. However, she reported that would overcome them because of the pregnancy: [...] *As soon as I had the diagnosis of pregnancy it was horrible, I cried, cried and cried, because I my only thought was: My God, what am I going to do now, I do not want to take the medicine because I didn't take it before, and I'll feel very ill, I will have the reactions, I do not want to, but what can I do? [...] (E10).*

In analyzing the interviews, it was possible to observe that concern to protect the baby so that it is born without the disease was also related to the fear that the children would suffer prejudice and discrimination in society, as the following report makes clear: [...] *I want my son not to have the disease, because it is very difficult, many people do not understand [...] there's still has a lot of prejudice [...] it's hard for us who are adults, imagine for a child [...] (E6).*

### **Revelation versus support**

Of the women interviewed, a large part made it clear in their speech that they only revealed their HIV-positive status to those closest to them. [...] *My family did not know, just my mother, my companion, and the doctors [...] (E1); [...] My partner is the only one who knows, and I do not intend to tell anyone else [...] (E7); [...] I told my*

*mom, my dad, my brother [...] of course I will not talk to my neighbors or my friends - nobody needs to know that [...] (E9).* On the other hand, some pregnant women said they did not hide from anyone the fact that they are HIV positive. [...] *I do not hide it from anyone [...] (E2); [...] everyone knows [...] (E6).* On the question of support, some women said they received support only from the people closest to them, since only they know about their diagnosis. There also exists a lack of acceptance: [...] *My parents support me a lot [...] My ex-husband too [...] (E3); [...] I received support from some co-workers, such as my boss [...] (E5); [...] Only my partner, because he is the only one who knows [...] (E7); [...] In my family there are many people who do not accept [...] (E2).*

### **Accepting pregnancy**

Whether they learned they were HIV-positive before or after becoming pregnant, as well as whether or not they had experienced motherhood already, did not affect the women's motivations for wanting to bear a child, as the following accounts show: [...] *I always wanted to be a mother [...] (E4); [...] Every woman wants to be a mother, that 's what I think [...] (E9).* However, as the interviews progressed, it was found that there some women never had the desire to be a mother, or lost interest after discovered that they were HIV-positive: [...] *I never had a big desire to be a mother [...] (E7); [...] Well, actually, before I found out I was HIV positive I really wanted to be a mother. After I found out the possibility was zero [...] (E10).*

Some pregnant women pointed out in their speech that they had not been planning to get pregnant at this time. Some blame their own carelessness or problems with the condom: [...] *It was an accident, well, not an accident, an irresponsibility, because I knew I could get pregnant and still had sex without a condom [...] (E3) ; [...] I was not planning for now [...] (E4); [...] I did not plan, I always use a condom, the condom broke, and I took the morning after pill [...] (E6).* For some women, it is not easy

to find themselves pregnant being HIV-positive, especially in an unplanned pregnancy, but some show in their accounts an attempt to overcome, to seek acceptance for the pregnancy: [...] *It will be welcome [...]* (E4); [...] *I'm like this, still accepting myself [...]* (E6).

### Impossibility of breastfeeding

Through the analysis of the interviews some participants showed themselves aware of, but uncomfortable with this condition. The following excerpts express this negative feeling: [...] *I already knew I was HIV-positive and was already aware that I could not breastfeed. At first I was a little stirred up about it, but then I thought that if I breastfed my son he would more affected. I would feed my ego, but would damage his health [...]* (E3). One of the participants explained in her speech that the fact of not breastfeeding will require greater care, showing a sense of concern over her limitations: [...] *The fact of not being able to breastfeed will be complicated [...] because I think that more care will be necessary [...]* (E10). In addition, during the analysis of the interviews it was noticeable that some participants expressed fear of prejudice related not being able to breastfeed: [...] *My mother-in-law does not know that I have the virus and when she asked me why I was not breastfeeding my first child I said he was allergic to milk. Now she doesn't ask anymore [...]* (E3); [...] *I feel uncomfortable to say, society does not accept it, that's the only thing that bothers me (not being able to breastfeed) [...]* (E9).

## Discussion

Our results corroborate those of other studies by identifying that pregnant women living with HIV have feelings of fear which they attempt to overcome, and that these are linked to their prospects during motherhood. They externalized fear of vertical HIV transmission during pregnancy, the side effects of medication, prejudice about the disease, and at the same time voiced feelings

of overcoming through self-care, confidence in adhering to their therapy, and attempting to overcome prejudice and the diagnosis of HIV recently discovered prenatally, even if absorbing this is not an easy task.<sup>1,6-10</sup> Studies have shown that although HIV-positive pregnant women have reported experiencing a normal pregnancy, peculiar situations are evidenced in the daily life of pregnant women who acquired this infection.<sup>8,11</sup> Many adopt defensive postures and denial in order to minimize the suffering and fear caused by stigma and a chronic illness.

Research has been verifying that, although many women living with HIV want to have children, they do not always have them in a planned way, placing sero-discordant partners in a position of vulnerability.<sup>1,6,7</sup>

Clearly, social and cultural pulls permeate the lives of women, influencing them to experience motherhood; the construct of this role configures in the social imaginary their self-realization as women, and the possibility of continuing their life and that of their family. In the case of pregnant women living with HIV, pregnancy has played a motivational role, in which the child becomes a reason for living and overcoming the adversity of living with an incurable and stigmatizing disease.<sup>1,6-7</sup> In contrast, the desire to become pregnant brings the fear of pregnancy, as evidenced in the interviews, insofar as different perspectives were portrayed regarding the uncertain future and the possibility of vertical transmission. Feelings such as hope that all progresses well in the pregnancy, being able to have a child, being capable of taking the medication, witnessing the healing of AIDS, having a long life, having a "normal" life, and raising a healthy child are also commonly found in other studies.<sup>8,9,12</sup>

Faced with the possibility of vertical transmission, most pregnant women living with HIV are engaged, adhering to their treatment and attending their appointments; learning about the disease, its evolution, and the manifestation of signs and symptoms; and changing their lifestyle in order to encourage the promotion of health.<sup>1</sup> The child

therefore becomes the strength and encouragement to overcome the obstacles of living with HIV, thus benefiting the physical and mental health of the pregnant women.<sup>7</sup> It is known that, despite all the effort made in monitoring and adhering to treatment, the risk of vertical transmission has not been eliminated; it has diminished considerably, to around 0-2%, provided that some therapeutic recommendations are followed. The routine adopted in Brazil includes: the administration of antiretroviral therapy during pregnancy, labor, and delivery; prioritization in the performance of cesarean delivery when the mother only used zidovudine monotherapy (AZT) or presents, in the last trimester of pregnancy, an unknown viral load above 1000 copies / ml; AZT administration to the newborn for 42 days; replacement of breastfeeding by artificial milk.<sup>13</sup>

Due to the risk of transmitting HIV to their baby, pregnant women are faced with the need to adopt the recommended prophylactic measures, because if they refuse or do not follow prescribed treatment, they endanger the health of their child. It is through this dyad that the vast majority of pregnant women accept adhering to treatment in order to evade the possible guilt of transmitting the virus to their baby.<sup>8</sup> Studies indicate that prevention of vertical transmission has been the main motivating factor in adherence to antiretroviral therapy; however, denial of diagnosis, fear of being discovered by others, and the side effects of medication are factors limiting this.<sup>14-15</sup> In some cases, treatment is abandoned after the delivery, due to fact the mother no longer carries a potential risk of infecting her baby.<sup>11</sup> However, adherence to treatment is further encouraged by the fear of dying and not being able to care for their child, besides subjecting them to the prejudice that they may suffer if the child is infected by vertical transmission. The guilt for putting the child at "risk" strengthens bonding and attachment practices, and leads to the development of overprotective attitudes.<sup>9</sup> The study shows that women who have experienced another pregnancy while HIV positive are more confident in caring for their children and worry about other activities of daily life such as work and commitments.<sup>12</sup>

Although the study participants consider that being a mother living with HIV does not change the care they need to provide their children, there were those who externalized the fact of not being able to breastfeed as something that differed them from sero-negative mothers. Studies show that pregnant women, although aware of the issue, revealed concern and fear of discrimination in relation to its limitation, mainly because some people would question them about not breastfeeding.<sup>1,8</sup> It was also observed that mothers who live with HIV experience conflicts and ambiguous feelings when discouraged from breastfeeding, because while suffering with a desire to engage in breastfeeding, they feel positive in preserving the health of the child. Thus, as a coping mechanism, they accept the situation. The fact of not being able to breast-feed is configured, in their minds, as a limiting factor in the formation of mother-infant attachment, even though there are other forms and gestures of affection that should be encouraged, such as speaking, touching, eye contact, and singing.<sup>16</sup> Although there is still no cure, according to the views of pregnant women scientific research has brought important contributions regarding the issue of HIV-positive pregnant women. International studies have shown that breastfeeding is no longer being contraindicated, as long as the mother and the child use antiretroviral therapy throughout the period of lactation. It is believed that the benefits of breast milk for strengthening the immune system, in addition to the prevention of malnutrition and diarrheal and respiratory diseases, justify its use until the child is 12 months of age.<sup>17-19</sup> The mortality rates for the disease during the first year of life and difficulties of acquiring the artificial formulas and drinking water are some reasons that favor the promotion and practice of breastfeeding. However its applicability is controversial, with national authorities still to decide on the best method.<sup>20</sup>

The multidisciplinary team plays a leading role in the care of pregnant women living with HIV, and is experienced with the treatment of prophylaxis of vertical transmission. Nursing contributes

to health education, providing support for self-care, and monitoring prenatal and childcare consultations because it offers care from both a technical-medical and a human perspective. In order to provide quality and humanized care, it is important to hear the perspective of pregnant women living with HIV. The act of listening and understanding the perceptions, feelings, and meanings that pregnant women bring from their constructs of social, cultural, and moral life is central to assessing vulnerabilities and building a care plan. The formation of a patient-nurse bond, through a trust relationship, favors the expression of doubts and anxieties that allows the professional to enter their intimate life, intended to facilitate reflection and overcoming of difficulties in order to adopt safe practices and the promotion of quality of life.<sup>21,22</sup>

The study found that being a mother and living with HIV involves various feelings, conflicts, and hardships imposed by their condition, in which a positive outlook for the future is quite desirable. However, there exists a belief that motherhood associated with HIV is surrounded by uncertainties, anxieties, and fears. Pregnant women, in this study, expressed that living with HIV does not change the concept of what being a mother is. On the contrary, they all considered that motherhood is a positive experience in their life, making it clear that the process of becoming a mother is little different to that of a sero-negative female. This study offers support for nursing staff in their work with pregnant women living with HIV, by highlighting that these women experience feelings of uncertainty, fear, and anxieties about the possibility of vertical transmission. As a result, they strive to comply with their treatment and adopt healthy lifestyles in order to avoid transmitting the virus to the child and to maintain a satisfactory quality of life to accompany its development.

It is essential that health care providers involve women of reproductive age and encourage the diagnostic testing for HIV. Women who already live with the virus should be included in the reproductive health care system so that

contraceptive methods can be made available to those that do not wish to become pregnant, besides the use of condoms. Those who express a desire to become pregnant should be guided and advised by a multidisciplinary team.

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