

## FEELINGS AND EXPECTATIONS OF PREGNANT WOMEN LIVING WITH HIV: A PHENOMENOLOGICAL STUDY

SENTIMENTOS E EXPECTATIVAS DA GESTANTE VIVENDO COM HIV: UM ESTUDO FENOMENOLÓGICO

SENTIMIENTOS Y EXPECTATIVAS DE ESTAR EMBARAZADA CON VIH: UN ESTUDIO FENOMENOLÓGICO

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### ABSTRACT

AIDS is a chronic disease increasing dramatically among the female population, especially amongst those women in their reproductive years, which can be seen in the increase of mother-to-child transmission of HIV cases. The objective of this research was to identify the feelings and expectations of such pregnant women about the disease and pregnancy from a phenomenological perspective. Five pregnant women living in Foz do Iguaçu, Brazil and being monitored at the HIV/AIDS Specialized Service were selected as study subjects. Their accounts were collected through semi-structured interviews, which were recorded by digital media. Two Thematic Units were identified after the transcription and analysis of the discourses, namely, "The reality of prejudice, discrimination and stigmatization against pregnant women living with HIV" and "Emergent hope and expectations in a HIV pregnancy". Despite prejudice, the pregnant women participating in the study had not lost hope neither in the treatment nor in the future. Several forms of expressing their problems were observed and the acceptance of being pregnant made them feel strong enough to face the situation.

**Keywords:** Pregnant Women; HIV Infections; Existentialism.

### RESUMO

Atualmente a AIDS encontra-se como uma doença crônica que avança drasticamente pela população feminina, especialmente em mulheres em idade reprodutiva, o que contribui para a ocorrência da transmissão vertical. O objetivo desta pesquisa foi compreender os sentimentos e expectativas de gestantes com HIV sobre a doença e a gestação, a partir de um olhar fenomenológico. Foram sujeitos do estudo cinco gestantes em acompanhamento no Serviço de Atendimento Especializado em HIV/AIDS, residentes em Foz do Iguaçu, Brasil. A coleta dos discursos ocorreu mediante entrevistas semiestruturadas, as quais foram gravadas por meio digital. Após a transcrição e análise foi possível encontrar duas unidades temáticas, a saber, "preconceito, discriminação e estigmatização como realidade de gestantes vivendo com HIV" e "esperanças e expectativas emergentes da gestação com HIV". Apesar do contexto de preconceito, as gestantes não perderam esperança em relação ao tratamento e futuro com o HIV. Observaram-se diversas formas de expressão sobre os problemas enfrentados pelas gestantes, sendo que a aceitação da gravidez evidenciou o motivo existente de superação sobre o diagnóstico da doença.

**Palavras-chave:** Gestantes; Infecções por HIV; Existencialismo.

### RESUMEN

Actualmente, el SIDA se presenta como una enfermedad crónica que avanza drásticamente en la población femenina, especialmente en mujeres en edad reproductiva, lo cual contribuye a su transmisión vertical. El objetivo de esta investigación fue entender los sentimientos y expectativas de las mujeres embarazadas con VIH sobre la enfermedad y el embarazo, desde la perspectiva fenomenológica. Los sujetos del estudio fueron cinco mujeres embarazadas que vivían en Foz de Iguazú, Brasil y estaban controladas en el Servicio de Atención Especializada en VIH / SIDA. La recogida de los discursos se produjo a través de entrevistas semi-estructuradas grabadas por medios digitales. Después de la transcripción y análisis se encontraron dos unidades temáticas: prejuicio, discriminación y estigmatización como realidad de las mujeres embarazadas con Sida y esperanzas y expectativas derivadas del embarazo con Sida. A pesar del contexto de prejuicios, estas mujeres no perdieron la esperanza en el tratamiento y en el futuro con el Sida. Se observaron diversas formas de expresar los problemas que enfrentan y al aceptar el embarazo muestran la voluntad de superar el diagnóstico de la enfermedad.

**Palabras clave:** Mujeres Embarazadas; Infecciones por VIH; Existencialismo.

## INTRODUCTION

The evolution of the AIDS epidemic, especially the feminization of the disease in the mid-nineties, brought a challenge to mother and child care, i.e. the control of vertical transmission (VT). Currently, a significant portion of diagnoses among women occurs during pregnancy and constitutes a complication. This situation requires specialized care provided by health professionals as well as the attention of policy-makers. Public policies should be proposed and implemented in order to ensure this group proper care and to reduce maternal and child mortality as well as vertical transmission (VT).<sup>1,2</sup>

AIDS is nowadays considered a chronic disease and its incidence increases dramatically amongst the female population. During the eighties this group accounted for approximately 10% of the reported cases.<sup>3</sup> The increase in the incidence of the condition amongst women means an increase in VT, viral transmission from mother to infant during pregnancy, labour, delivery or breastfeeding. Previous studies have demonstrated that positive serology is detected in the HIV testing carried out during ante natal care.<sup>2,4</sup>

For these reasons, counselling and HIV testing in antenatal care are extremely important as they ensure women's right to receive information and treatment with antiretroviral drugs which in most cases prevents transmission.<sup>5</sup>

However, after being diagnosed as HIV positive, pregnant woman may experience fear, anxiety and even physiological changes generated by the lack of information. Thus, pregnant women with HIV should receive the antiretroviral therapy (ART) and psychological and social support by a multidisciplinary team.<sup>2</sup>

ART significantly reduces HIV viral load to undetectable levels. Therefore, an early diagnosis will ensure better results in the control of mother-to-child infection.<sup>2</sup>

Women receiving antiretroviral treatment are prejudiced against or lack information about the use of medications which may lead to indecision about proceeding with the treatment. Some women with HIV hide their condition so they can *get pregnant* (authors' emphasis). They are often usually present in prevention programs of mother-to-child transmission and then absent for treatment follow-up.<sup>6</sup>

In Brazil, the Expert Care Service (SAE) on HIV/AIDS aims at providing comprehensive, quality and professional care in order to ensure adherence to treatment, as well as prevention and control of sexually transmitted diseases (STDs) and AIDS.<sup>2</sup>

The Department of Health advises that infected pregnant women should be informed about the risks of transmission during pregnancy and breastfeeding and that they should be guided on the importance of clinical and gynaecological monitoring throughout the pregnancy and postpartum.<sup>7</sup>

Women living with HIV have the right to decide whether to get pregnant or not. Such choice may generate tensions given the risk of vertical transmission. Therefore, future pregnant

women should receive more information on the use of medicines and care of new-borns to make a conscious decision.<sup>8,4</sup>

It is thus important to understand what a human being under such circumstances feels.<sup>9</sup> As the focus of this research is on women the authors would like to point out that they are socially seen as carers, especially in the family group.<sup>10</sup>

Given the above, the objective of this research was to identify the feelings and expectations of pregnant women with HIV about the disease and pregnancy, from a phenomenological perspective.

## METHODOLOGY

This is a phenomenological qualitative research based on Maurice Merleau-Ponty's philosophy of perception. Phenomenology seeks the return to human experiences and as such, perception and understanding attempt to approach the lived body<sup>11</sup>, in this case, the research subject.

Five pregnant women diagnosed with HIV monitored in SAE of Foz do Iguaçu, in the state of Paraná, participated in the study. They were married, aged between 20 and 35 years old, and had been diagnosed from one month to ten years before research began.

Data was collected from February to March 2011 through semi-structured interviews digitally recorded. The researcher who carried out the interviews had previously adjusted to the routine of the participants, established contact and invited them to take part in the study. The interviews lasted between 30 and 90 minutes. The interview script was discussed with the authors and two guiding questions were then formulated (What does it feel like being pregnant? and: What are your expectations for pregnancy and for your child? ).

The interviews were analysed through phenomenological methods consisting of description, reduction and understanding.<sup>12</sup> Phenomenological description is the transcript of the interviews as much detailed as possible; reduction is the finding of units of meaning in the interviews narratives after each interview has been thoroughly read; finally, understanding is the stage in which researchers seek to grasp the phenomenon studied and experienced by the bodies (research subjects).<sup>12</sup>

The study was approved by the Research Ethics Committee of the State University of Western Paraná (protocol No. 183/2010). The pregnant women's participation in the study was voluntary and made effective only after them signing the term of informed consent. In order to ensure their anonymity identification was made with the letter G followed by an Arabic number (G1, G2, G3, G4 and G5).

## RESULTS

All participants were married, aged between 20 and 35 years. Personal characteristics were as follows: G1 (35 years old,

diagnosed 10 years previously, mother of three boys); G2 (31 years old, diagnosed six years previously, the mother of two girls); G3 (38 years old, diagnosed four years previously, the mother of a couple); G4 (20 years old, diagnosed two years previously, no children); and G5 (21 years old, learned of the diagnosis during pregnancy, no children).

Two themes emerged from the data: "prejudice, discrimination and stigmatization: the reality of pregnant women living with HIV" and "hopes and expectations of HIV-positive mothers", both being discussed below.

## DISCUSSION

It is worth mentioning that none of the emerging themes predominated over the other since the pregnant women mentioned both of them in their accounts. Furthermore, phenomenological research not only considers the repetition of discourses but also looks for congruence relations, differences and idiosyncrasies.

### PREJUDICE, DISCRIMINATION AND STIGMATIZATION: THE REALITY OF PREGNANT WOMEN LIVING WITH HIV

Ignorance about the disease, prejudice and discrimination against HIV carriers are the main characteristics of the condition. HIV is often considered as cause and effect of social relationships. It has brought prejudice and social stigma that associates its diagnosis with disability and social segregation.<sup>14</sup>

Lack of knowledge about the disease is largely responsible for difficult or unpleasant situations people affected by sexually transmitted diseases such as HIV face in their daily lives. The population in general has developed prejudiced and discriminatory stances increasing anxiety around the issue.<sup>15</sup> Such is the experience of one of the interviewees:

*Some people I run into are very open minded; others aren't (G1).*

AIDS epidemic spread rapidly, requiring prompt organization of social and psychological resources to face a problem of such magnitude. The crisis challenged the society's ability to deal with a disease full of meanings and at the same time gave way to panic, denial, intolerance and discrimination against those affected by the disease.<sup>16</sup>

Many of such people go through life alone and silently, limiting to their access to protection, health care and promotion; feeling compelled to hide their HIV status due to fear of exposure, prejudice and discrimination produced by the stigma

attached to the condition.<sup>16</sup> The sexual discrimination is the most common form of gender-associated stigma.<sup>17</sup>

Stigma is a mark of discredit associated with a person and it is a powerful social control signal used to marginalize and dehumanize individuals that show undervalued attributes in a given social context.<sup>17</sup>

Stigma associated with HIV-positive individuals and its perverse consequences involve discrimination in public and private spaces, hostility, segregation, exclusion and/or self-exclusion,<sup>18</sup> as follows:

*Health care is good [...] let's put it in that way. But it's hard having to come here. The moment you get in, everyone knows what you are here for. But we have to face it (G5).*

*But you see, here they treat people well. But in health care [...] it is not new that people are prejudiced against you [...] because I said nothing [about being HIV positive]. People used to come to me and say [...] "You have to take care of yourself, prevent it, or you can get infected". That was when I realised that he was [prejudiced] (G1).*

*Today when I say that I am HIV positive, people look at me: – "But that's not true" because society's idea of a HIV positive is another one. Is it that one of a weak person, a sick person, an ugly person? I'm not, I'm beautiful, I like myself, I love myself as I am. And people who are prejudiced against us, HIV positives, I pity them. Because I consider it the meanest feeling you can have for someone. I say: I pity that guy, and all these prejudiced people, I pity them because they are misinformed, they are ignorant (G2).*

A stigmatization process can start during antiretroviral treatment, which requires several monitoring visits leading to absences and delays to work and other social activities. This mainly happens early in the treatment or when in clinical and serological complications. Such situations demonstrate the link between diagnosis and AIDS stigmatization followed by discrimination.<sup>17</sup>

Advances in drug therapy mean improvement in the quality of life a step away from lethality. However, the epidemic still reigns and living with HIV and AIDS still claims human suffering resulting from stigma, prejudice and discrimination.<sup>16</sup>

Effective responses that minimize stigma and discrimination against HIV and AIDS can happen from various sectors. Communication and education for the construction of new concepts and ideas related to the phenomenon can indicate new ways to learn about change processes. Social movements, cultural changes, as well as social equality and inequality; action and intervention based on fair policies can also be one of the responses to the problem. Finally, legal measures that guaran-

tee the rights of people living with HIV/AIDS, to redress or contest discriminatory acts should be implemented.<sup>16</sup>

The following discourse is centred on actions geared towards reduction of stigmatization processes:

*They [those who discriminate] are so ignorant that they end up being still more ignorant. Because they do not seek help, do not seek information. There is the internet, posters, there is a lot of material out there; you don't get information only if you don't want to. And we need to put an end to prejudice. We, being at this side of the fence, suffer a lot from it. I've suffered a lot before; now I don't suffer any longer (G2).*

The answer to the hostility and eradication of stigma and discrimination is not an easy one. It requires efforts to the understanding and the designing of effective actions. Individual actions reflect ideas and beliefs embedded in economic, political and social structures. It is necessary to give way to a compassionate, creative and liberating frame of mind in order to meet the challenges and to lessen the suffering of the individual.<sup>18</sup>

In the context of AIDS pandemic it is important to respect differences and question prejudices, fears and taboos.<sup>20</sup> Actions should be based on understanding, on the promotion of egalitarian behaviours regarding sexuality and collaborate to improve the way we live and how we relate to each other.<sup>16</sup>

## HOPES AND EXPECTATIONS OF HIV-POSITIVE MOTHERS

These HIV-positive women seek a new direction in life overcoming the hardships imposed by their condition.<sup>20</sup> Such stance can be observed in the following quote:

*Where is it written that you aren't going to make it? The only thing you can't beat is death; we can manage the rest (G3).*

The decision to get pregnant is determined by the meaning that a woman gives to maternity, taking into account the conditions experienced at some point in her life. It can change what having a child means to her, thinking about its benefits, gains and losses and the difficulties she will be facing.<sup>20</sup> Regardless of one's health status, different circumstances lead to different paths given one's experiences, as can be observed below:

*Pregnant women are all alike, whether she's ill or not, the expectations are the same. It changes things ... (G3).*

Motherhood has such a strong meaning to these women that not even the possibility of transmitting the virus to the

foetus can change their mind.<sup>20</sup> The wish to be a mother is stronger than the problems faced throughout life:

*I had already decided it; because I had always wanted a child [...] I have nothing to complain about till the end of the pregnancy (G4).*

Mothers with HIV focus their life on the uninfected child, which symbolizes the continuity and the hope to overcome their fears.<sup>20</sup> The child can be the motivator that helps them to face the challenges imposed by the disease:

*It will all go away. I know, the minute I see my child's face, I will not remember the pain I was feeling in the back, in the legs, I won't remember anything. I'm sure that when I see the baby I'll forget everything; (G2).*

For them, positive pregnancy experiences were an important source of support and hope to carry on living and taking care of their own health.<sup>20</sup>

The participants accepted their pregnancy and asked for a healthy baby. Even if it is an unplanned pregnancy, the child becomes a motivating force, giving them reason to fight the disease.<sup>8</sup> Pregnant women with HIV want their children to be healthy and do not want to transmit the virus.<sup>20</sup>

In the words of one of the participants, being a mother is to protect the child:

*I'd like everything to work out fine. I'm doing everything right because when I take the test, I want them to [...] [say] your child does not have it; it's a healthy baby (G3).*

In order to prevent vertical transmission the mother should adhere to the treatment offered by the health system to reduce the risk of transmitting the virus. A mother living with HIV will adhere more easily to treatment if she has been informed about the seriousness of the disease and about the possibilities of the child being infected.<sup>21</sup> The search for treatment is described in the following statement:

*Low immunity would be due to the pregnancy, right? Leaving the pregnancy aside I will still have a low immunity because of the disease. So I will have to carry on doing the same I'm doing now that I'm pregnant, I'll have to continue with it after pregnancy. Immunity will still be low, [...] I only have to take care of myself and wait for the baby to be born (G5).*

Antiretroviral treatment drugs reduce the chances of mother-to-child transmission, factor that influences their deci-

sion to carry on with the pregnancy and to stay health hoping that the new-born baby will be HIV negative.<sup>8</sup>

Pregnant women should carry on health advice serenely and have an opportunity to express their feelings. Psychological support helps to prevent VT because such interventions provide relief from anxiety and have an impact on the child's development.<sup>22</sup>

Pregnant women recognize that treatment and prevention are important to avoid future problems:

*I don't waver and imagine the possibility of the baby being a carrier. No. And if it happens it is because I had to go through it, but it will not happen, I know it will not. Because I did everything right (G2).*

*For us, mothers, it will be worthy. All I went through was worthy, those bad medications that I was taking, you know? The clinic knows it will be worth to know that the baby has nothing. I tried to make something that worked, then this is the mother's hope, and, of course, get some more time, some more years to raise the child (G3).*

*I came back because I got pregnant. Then I said to myself: – "No, now it's time to wake up." I mean, so God does not want me to die, He wants me to live and so gave me another child; it's like everything is God's wish, nothing comes without it. Then I came back because of the child (G3).*

*Even now, I can't imagine. I know they will make a battery of tests when the baby is born, right? I have been told all that will happen (G2).*

The participants revealed their ability to overcome adversity and traumatic situations that distort the meaning of motherhood with HIV infection and decide to value life and have faith and hope.<sup>20</sup>

AIDS coping strategies of a religious nature are associated with affection. Pregnant women make adjustments to deal with their seropositivity through religion, seeking in God's figure love, care, help, strength, forgiveness, and well-being.

The support of religion brings hope conveying a feeling of comfort and has an impact on coping with HIV/AIDS.<sup>20</sup>

These pregnant women struggle for survival backed by a religious belief that can also turn into an alternative to cope with the disease.<sup>20</sup>

For these women, the unborn child is the motivation for them to rethink their life and to withstand the bad times. Religiousness resurfaced by the wish for a child gives meaning to their life and helps the construction of a female identity.<sup>20</sup> This coping strategy minimizes problems and it gives hope to these women, as can be read below:

*But I have this feeling, you know, that something is going to happen, something has to happen. Doctors say it won't, but God says yes. Something will happen to me, you know? (G3).*

*If I didn't have God, without Him, I wouldn't be here anymore. You wouldn't have known me. The question was really suicide, get it all over with. I would have done it, you know, child or no child; I was going to put an end to it all but it would not be a life great solution. Because then I'd make other people suffer, you know? (G3).*

Faith is a life support that helps these women to withstand the uncertainties of being pregnant and HIV positive. Their faith in God gave them the confidence to face the difficulties imposed by the disease and hope for better days for them and their children:<sup>20</sup>

*But my faith, my hope is to give the baby my breast and say: you can have as much as you like (G3).*

*You can have anything if you have faith. You have to have faith, to fight, to have grit; you have to have courage too, because if you are weak, you do not win. So that's what I want to say to you; my single regret is that I carry this, but I still have hope, ah! still have it (G3).*

Spirituality is a comfort that helps them to bear the pain of being HIV positive; it makes them believe in quality of life due to treatment and, in the hope of a miracle, that God may transform their lives completely.<sup>20</sup>

## CONCLUSION

The interviews conveyed the experiences of the women with HIV, their acceptance of the limitations imposed by the disease and showed how they dealt with the stigma surrounding HIV. Despite the prejudice, such pregnant women did not lose faith and hope.

The testimonies of the mothers-to-be recorded the different feelings emerged during pregnancy. They demonstrated that the participants sought the well-being of their children, longing for a healthy pregnancy and a safe delivery. The authors observed the different forms they used to express the problems they faced. Acceptance of pregnancy was the reason why they wanted to overcome the disease.

Pregnant women believe in the treatment and the possibility of their children being born healthy. The desire of motherhood increases their expectations about the care, which prevents complications from the infection.

Despite the prejudice and discrimination experienced, women find ways to cope with their daily challenges.

The study participants accepted the pregnancy, mainly because the desire to become a mother was stronger than anything else they could feel. The treatment was then accepted, as the only way to protect their children from a HIV infection.

The researchers identified feelings of strength, will, and determination to overcome the problems which transcend the difficulties encountered throughout pregnancy. The fear of harming the child – symbol of perseverance, wishes and hopes – is faced and reignites their desire to carry on living in order to care for their children and to protect them.

The method used in this research helped the authors to identify the feelings and the expectations of pregnant women living with HIV. It contributed to disprove the popular belief that women living with HIV/AIDS cannot bear a child. A phenomenological approach revealed the different aspects of the participants' struggle, fight and recovery through the feelings generated by their life experiences. The research limitations were the size of the population studied, making it difficult to make generalizations based on the elements surfaced during the interviews.

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