

# Psychological phases of pregnant women with HIV: a qualitative study in a hospital

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## Abstract

There has been a paradigm shift regarding the prognosis of Human Immunodeficiency Virus infection, changing it from death to a chronic condition, but the infection still implies a review of the life of women who are living with this virus. The objective of this article is to present the psychological phases which pregnant women go through after knowing about their infection. A clinical-qualitative study was carried out, applying individual interviews, with an intentional sample, using the theoretical saturation criterion. Three evolutionary psychological phases emerged from the analysis: emotional confusion; existential doubt; functional ambiguity. The news of the presence of the virus brings intense emotions triggering defense mechanisms, especially, against the strong fear of vertical transmission. It is, thus, fundamental for health teams to broaden the understanding of this experience so significant for pregnant women and their families.

**Keywords:** Acquired immunodeficiency syndrome. Pregnancy. Bioethics. Qualitative research.

## Resumo

### Fases psicológicas de gestantes com HIV: estudo qualitativo em hospital

Houve mudança de paradigma quanto ao prognóstico da infecção pelo vírus da imunodeficiência humana, passando da morte para problema crônico, mas ainda hoje a infecção implica revisão de vida da mulher que convive com a doença. O objetivo deste artigo foi apresentar as fases psicológicas pelas quais passam as gestantes após descobrirem a contaminação. Foi realizado estudo clínico-qualitativo a partir de entrevistas individuais, e a amostra foi intencional e fechada pelo critério de saturação teórica. Após análise qualitativa de conteúdo, foram estabelecidas três fases psicológicas evolutivas: confusão emocional, dúvida existencial e ambigüidade funcional. A notícia do teste positivo desencadeia emoções intensas e mecanismos de defesa, sobretudo devido ao medo de transmissão vertical. Dessa forma, é fundamental que equipes de saúde ampliem a compreensão sobre esta vivência tão significativa para gestantes e seus familiares.

**Palavras-chave:** Síndrome de imunodeficiência adquirida. Gravidez. Bioética. Pesquisa qualitativa.

## Resumen

### Fases psicológicas de embarazadas con VIH: estudio cualitativo en un hospital

Hubo un cambio de paradigma con respecto al pronóstico de la infección por Virus de la Inmunodeficiencia Humana, pasando de la muerte a un problema crónico, pero aún hoy la infección implica la revisión de la vida de la mujer que convive con la enfermedad. El objetivo de este artículo fue presentar las fases psicológicas por las que pasan las embarazadas luego de descubrir la contaminación. Se realizó un estudio clínico-cualitativo, a partir de entrevistas individuales y la muestra fue intencional y cerrada por el criterio de saturación teórica. Luego del análisis cualitativo de contenido, se establecieron tres fases psicológicas evolutivas: confusión emocional, duda existencial y ambigüedad funcional. La noticia del test positivo desencadena emociones intensas y mecanismos de defensa, sobre todo debido al temor a la transmisión vertical. De esta forma, es fundamental que los equipos de salud amplíen la comprensión sobre esta vivencia tan significativa para las embarazadas y sus familiares.

**Palabras clave:** Síndrome de inmunodeficiencia adquirida. Embarazo. Bioética. Investigación cualitativa.

Aprovação CEP-Unicamp CAAE 0447.0.146.000-06

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Declararam não haver conflito de interesse.

Parallel to the growth of cases of human immunodeficiency virus (HIV) infection among heterosexual individuals, the contamination of women of reproductive age has also increased. Thus, public health authorities began to pay closer attention to the rates of mother to fetus transmission of the virus from (vertical transmission)<sup>1,2</sup>, from one of three routes: the gestational period, labor or breastfeeding<sup>3,4</sup>.

In this context, health care services began to concentrate efforts to apply the protocols for prophylaxis of vertical transmission in seropositive pregnant women, according to a recommendation of the Ministério da Saúde-MS (Ministry of Health) observed in the study by Kupek and Oliveira<sup>1</sup>. These efforts were driven by investments to detect situations of iniquity and deficiencies in the application of protocols, generating subsidies to enhance assistance<sup>5</sup>. Investigations on virus contamination through vertical transmission allowed the researchers to observe the main risk factors for these cases: non-performance of the HIV test in gestation and the lack of knowledge of the serology result before delivery<sup>6</sup>.

It is important to bring to light the psychological and social implications of pregnancy in women living with HIV. There are restrictions, especially regarding reproductive issues<sup>7</sup> - for example, not being able to breastfeed the child, which can provoke feelings of guilt, impotence and frustration<sup>8</sup>. It is observed that when the discovery of the pregnancy coincides with the diagnosis of the infection, pregnancy becomes emotionally unstable<sup>9</sup>. This instability is mainly a consequence of social constructions on contamination, marked by discrimination and stigmatization<sup>10</sup>.

Due to historical and sociological factors related to the global aids epidemic, the syndrome became socially stigmatized. The disease was associated with promiscuous behaviors, the use of illicit drugs and homosexuality, also referring, at least initially, to death, physical degradation and loss of civil rights<sup>11,12</sup>. Thus, infected pregnant women began to live with significant symbolic losses, as well as with affective and material difficulties<sup>13</sup>. The relevance of the theme is even more evident when one observes that psychological fantasies of social exclusion can make it difficult to adhere to preventive measures, penalizing virus carriers and increasing the negative experience of bias<sup>11</sup>.

For the pregnant woman, recognizing herself as infected by the virus implies the need to redefine the value of her own life and that of the fetus being generated, as well as the meanings of interpersonal relationships and even their own death<sup>14</sup>. Thus, having knowledge of their positive serology

during pregnancy, the woman suffers an intense psychological impact<sup>15</sup>. In addition, the public health system in Brazil presents deficiencies in the application of the protocol of care with pregnant women<sup>11</sup>, which causes insufficient serological tests for this population<sup>2</sup>.

Although the prognosis of HIV has changed in recent decades, from death to a chronic clinical problem, still today the couple living with the disease should review their position, especially regarding reproductive health<sup>16</sup>. That is, it's necessary that the motherhood experience of these women be associated with self-care, the recovery of self-esteem from the social role of caregiver and the desire to live<sup>17</sup>.

This study, conducted in a university hospital, discusses the psychological meanings attributed by pregnant women to their own experiences as carriers of the virus, in order to understand if these meanings are organized in stages. Thus, the article proposes a theory based on psychological, potentially evolutionary phases which pregnant women would go through after the diagnosis of the disease. The findings are expected to assist the health professional in the tasks of receiving and approaching this population.

## Methods

### Participants

This exploratory-descriptive and clinical-qualitative study<sup>18</sup> specifies generic qualitative methods and values existential, clinical and psychodynamic attitudes. The intentional sample consisted of nine pregnant women, being closed by the criterion of theoretical saturation<sup>19,20</sup>.

### Instruments

A structured semi-directed script with open questions was used to guide individual interviews. The interviews began with the following trigger question, in the form of an invitation: *"I would like you to tell me what it was like for you to be diagnosed with HIV, considering the moment of your pregnancy."*

### Data collection

For the data collection, the technique of semi-directed interview of open questions was used, with observation and accurate listening of the study subjects<sup>18</sup>. The interviews occurred at times previously

set with the women, in a private space, to guarantee the privacy and consequent validity of the reports. The place chosen was the Ambulatório de Pré-Natal Especializado-PNE (Specialized Prenatal Outpatient Clinic) of the Centro de Atenção Integral à Saúde da Mulher-CAISM (Center for Comprehensive Care for Women's Health), of the State University of Campinas (São Paulo, Brazil), where pregnant women with positive serology for HIV are clinically followed up.

### Data analysis

The interviews were recorded with a voice recorder and transcribed literally for later qualitative analysis of the contents<sup>21</sup>. This type of analysis includes the following steps: reading of the corpus, for refined perception of the latent content of the underlying discourse; identification of nuclei of meanings throughout the corpus, classified in thematic units for the debate; and validation of the results, which, in the present study, occurred in meetings of the Clinical-Qualitative Research Laboratory of the State University of Campinas (Unicamp), in the peer review system. Appropriate methods of qualitative studies have been used, such as the recognition of polysemy, that is, the various symbolic senses of human experience, and the emic perspective, which leads researchers to the affective-intellectual effort to see from whom the perspective of the subject.

### Ethical considerations

The project was duly approved by the Comitê de Ética em Pesquisa - CEP (Research Ethics Committee) of the Unicamp School of Medical Sciences. All participants were informed about the research, signing the informed consent form voluntarily.

### Results

Nine pregnant women, aged between 22 and 31 years, collaborated with the investigation, presenting asymptomatic at the time of the interview. As for obstetric history, there were two women in their first pregnancy, three women in their second pregnancy and four who had been pregnant more than three times. At the time of the interview, two were pregnant for less than 20 weeks, five were between 20 and 29 weeks, and two were pregnant for more than 36 weeks. All were diagnosed with AIDS at the beginning of gestation, as soon as they began prenatal care in the service.

In the following sections, we present clippings from which we can see the evolution - not necessarily in chronological order - of three major psychological phases that follow the diagnosis of HIV during pregnancy. It was observed that gestation was loaded with emotions and fantasies, leading the woman to develop emotional defense mechanisms against adverse self-perceptions, such as the impression of being contaminated by "bad things" or dread. Feelings of joy and inner renewal, often idealized for gestation, are overshadowed by the fear of stigmatization and discrimination, as well as the ideations associated with the finitude of life.

From the analysis of the interviews, categories appeared that point to great personal questions. An immediate consequence of the infection diagnosis during pregnancy is the knowledge of the dual presence within the body: that of a child that will come to the world and that of a virus that persecutes both mother and child.

### What am I feeling? The phase of emotional confusion

"What I'm feeling": this seems to be the first question the interviewees ask themselves. At this stage, the confirmation of HIV infection in pregnancy confuses feelings, "taking the ground from under the feet" of pregnant women, who lose the framework that shaped the particular world of the new mother. The perception of the internal renewal and the gratifying generation of life becomes something unnameable, not imagined, that stuns and distresses:

*"When I got to know, it was very difficult, a very strong impact, I never expected or suspected that I had... My world collapsed right there in front of me, I lost my ground" (E7);*

*"I never expected this to happen to me, because it changes everything, my world fell apart" (E2).*

Anxiety becomes dominant when women cannot or are unable to talk about the problem with the people around them. Literature records that when they are forced to hide the diagnosis for fear of prejudice and rejection, they become emotionally overwhelmed, feelings of despair being frequent<sup>22</sup>: *"I was desperate, afraid to tell to my partner ... Fear of my family finding out..." (E8).*

The interviewees were eager to speak, hesitating to verbalize the words "aids" and "HIV" and attributing human senses to them. The focal problem arises, related to the moral necessity of communicating

the diagnosis to others - a moment of transient disorganization, experienced as a personality shredder.

Women report the fear of being rejected, fearing the prejudice of the people around them, as pointed out in the literature<sup>23</sup>. This fear often causes infected women to resort to self-protection strategies against stigma, hiding the problem in their social circle, still amid the confusion of feelings. The inheritance of prejudice against population segments, the notion of "risk groups" and misconceptions about forms of contamination generate fantasies associated with HIV in the consciousness of people. A vicious circle is created, which intensifies the feeling of exclusion, worrisome for its potential to undermine adherence to treatment:

*"I called my partner ... I only told him and I intend to keep this, not to tell anyone else ... I do not trust my family, they are prejudiced, I do not feel safe speaking"* (E1);

*"Before society I feel bad, I try to talk to people and it's like I'm a freak, a walking virus, something like that"* (E2).

In this speech the interviewee reveals the great difficulty in accepting seropositivity, adopting the defensive mechanism of denial, a common primitive resource in the face of bad news. Components of guilt and self-condemnation accompany the clinical condition, exacerbating psychic distress in the face of the real threat of HIV to one's own life and life: *"I said it was a lie, that I didn't have it, that it was not possible"* (E4); *"I thought about giving the baby away to my family, I do not want to live with everyone pointing and saying that his mother has HIV ..."* (E3).

#### **What am I gestating: life or death? The phase of existential doubt**

In the second psychological phase, there are doubts of an existential nature, and the impact of the diagnosis causes intense and peculiar emotional reactions in the woman. Leaving the condition of purely gestating, death and life are mixed, and the patient comes to live with the ambivalence of affections - the strange state of gestating opposing entities: *"I asked how long I would have to live"* (E1).

By indicating that life is at risk, the diagnosis threatens dreams and "contaminates" a whole universe of meanings and desires<sup>24</sup>. Anxiety is referred to as a sign of catastrophe, of physical and spiritual disintegration: *"At first I thought I would look ugly, very thin, sick, bad..."* (E1).

Distorted fantasies about disabilities and risks to a baby's integrity are common. These thoughts are articulated and trigger other anxieties, linked to the abandonment of the child; the mother imagines herself as the provider of the child, but unable to see them grow. As a consequence, the woman fears for the child's helplessness and for her own end<sup>24</sup>: *"It meant that my life was over..."* (E3).

Gestation involves complex psychological demands, routine readaptation and reorganization of the roles played in the family, and although the discovery of the infection involves several fears in this readaptation, there are reports that it is possible to feel satisfaction for motherhood:

*"The only thing that motivated me was to hold my daughter... Nothing else made sense at the time"* (E7);

*"What I have to do is to take care of myself and think of the baby that's coming..."* (E4).

Again, life-threatening ideations populate the thinking of women, associating AIDS with the inexorable compromise of life. Even so, the pregnant woman struggles for the right to life, stimulated by the revitalization represented by the child that develops in her womb.

#### **What am I transmitting: love or disease? The phase of functional ambiguity**

The third step refers to the functional role of pregnancy. In this psychological phase, the woman feels a little more resolute, but the creative/procreative function is expressed by ambiguous thoughts. Dreams under construction are hampered by the new clinical condition, and the generation of life is also perceived as a risk of contamination of the disease. What was valued in life - transmitting love and life - becomes ambiguous: *"After all, what am I transmitting?"*

Interviewees report intense fear of passing the disease on to the baby, even though they know that with antiretroviral therapy, the chance of infecting them is minimal. The intensity and confusion of the emotions they experience represent the ambivalence between loving and transmitting such a terrible virus to the child: *"Does the baby have it too? will he be born with or without it? I'm afraid to pass it on to him and later he will not accept me"* (E1).

The ambiguity is most evident in the feelings associated with infection and the sense of possible close closeness to the child and the affection for life in expansion. Culturally, motherhood creates responsibility for another life, whatever the physical

condition of the woman. And in this case, the contradiction arises, because, with responsibility for the child, there is a probability of contaminating them. Then ideas of death are manifested:

*"I thought about having an abortion if my pregnancy were less advanced"* (E1);

*"I do not want to have any more children, I'm afraid of what will happen to them... If I can avoid it, why should I take the risk?"* (E2).

The fear of transmitting the virus to the child is evidently the greatest concern of pregnant women. In this phase, intensely painful experiences of "loss in life" lead to feelings of hopelessness towards the child.

## Discussion

In the theorizing, three moments were presented - not always linearly arranged - experienced by pregnant women with HIV. These three moments are marked by different feelings and questions: emotional confusion ("What am I feeling?"); existential doubt ("What am I gestating: life or death?"); and functional ambiguity ("What am I conveying: love or illness?"). The psychological phases have the characteristics: a relationship of interdependence, non-linearity, progress in advances and retreats, and rapid succession.

The intense fear related to the disease's contagion and the life of the child requires that health professionals better discuss the issue<sup>25</sup>, since assimilating HIV infection and pregnancy is an arduous emotional task since there are simultaneous feelings of life and death in the mind of the patient<sup>26</sup>. In the case of pregnant women living with the virus, prejudice and discrimination directly affect family life and motherhood<sup>10</sup>. Despite these negative factors, however, courage and feelings of happiness prevail over the son who is going to come to the world.

Pregnancy is experienced by these women as a moment of subjective redefinition since it is necessary to recognize at the same time as mother and carrier of the virus - therefore, as a transmitter of life and of the limitations to life, with all the consequences of this condition that requires great mental energy.

As the results show, the diagnosis obliges the woman to use defense mechanisms, such as denial, isolation, and devaluation of herself. It is essential that health professionals have better knowledge about the emotional and social situation of these

pregnant women so that they can use specific approach strategies<sup>26</sup>.

As said, the feelings and perceptions of these pregnant women can be classified in three phases: the first one, of initial confusion of feelings; the second, the perception of ambiguities; and the third, of the woman's doubt as to what will be passed on to her son. Realizing the development of these phases, which highlight aspects of the emotional structure of the HIV carrier, the health professional will be able to decide on the most appropriate reception. Discussions such as the one proposed here should serve as a tool to adapt therapeutic proposals to these women and their families, favoring adherence to treatment and minimizing the possibility of vertical transmission of HIV.

This proposal for a three-step classification should not be generalized *a priori*. The psychological phases suggested by this investigation can only be generalized *a posteriori*, depending on the similarities of the cases presented here with other clinical situations.

## Final considerations

The management of the clinical situations that involve these pregnant women can be improved with knowledge, by the reception and care team, of the psychological phases involved. Three of these phases were observed in this study. The experiences reported by them allowed us to observe that emotional confusion, existential doubt, and functional ambiguity are the result of the specific instability of this clinical situation, which implies hormonal, organic, physiological, psychological, behavioral and social changes.

This study highlights the psychological aspects of women who find themselves seropositive during pregnancy. Fear of vertical transmission and the threat to the child's life are part of their emotional universe, as the literature and the results of this study point out. The birth is usually idealized and related to positive feelings, but when there is the possibility of contamination of the baby by the virus, the anguish is felt by the mother herself. Therefore, it is a question of orienting them to redefine subjectivity in order to organize themselves as mothers of children with a potential risk of HIV contamination.



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### Participation of the authors


Nara Regina Bellini participated in the design and planning of the research project, in the collection and analysis of data, and in the writing of the manuscript. Rodrigo Almeida Bastos contributed in the analysis of the data, in the writing of the manuscript and in the critical revision. Carla Maria Vieira, in the analysis of the data and in the writing of the manuscript. Claudinei José Gomes Campos contributed in the design and planning of the research project and in the drafting of the manuscript. Egberto Ribeiro Turato participated in the design and planning of the research project, in the analysis of the data, in the writing of the manuscript and in the critical review.

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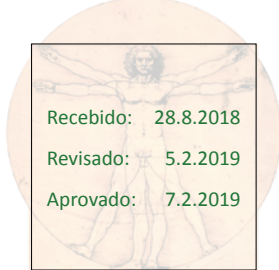
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Recebido: 28.8.2018

Revisado: 5.2.2019

Aprovado: 7.2.2019

## Annex

### Thematic script Psychosocial meanings of HIV diagnosis for pregnant women

I would like you to tell me a little bit about what it was like to be diagnosed with HIV during pregnancy.

Reactions to the diagnosis and the experience of aspects of seropositivity.

1. What did it mean for you to receive the diagnosis during pregnancy? How long have you had this diagnosis?
2. Did you tell anyone? Who? And what was the reaction of the person(s)?
3. What was it like to face the family after the exam result? What happened in your family relationship?
4. Did you have information about HIV transmission and prevention before you knew you were HIV positive?
5. Did you know the possibility of transmitting the virus to the baby? What did you know? How did you get to know about this?
6. How have your your plans and your project of life been affected?
7. How has the the relationship been in the marriage? Has there been any change?
8. What about your sexuality? How was it before before and how has the sexual desire been after the result? Tell me more about it.
9. In the face of society (even people not having to know about your diagnosis), how do you feel about being with people?
10. At that moment, what does motherhood mean to you? How will your relationship with this child be? Explain this better.
11. What are your thoughts about the impediment to breastfeeding?
12. Is there anything you like to say about pregnancy and the discovery of the HIV?