

# CUIDADO É FUNDAMENTAL

UNIVERSIDADE FEDERAL DO ESTADO DO RIO DE JANEIRO • ESCOLA DE ENFERMAGEM ALFREDO PINTO

RESEARCH

DOI: 10.9789/2175-5361.2018.v10i2.334-342

## Representações sociais de mulheres frente a descoberta do diagnóstico do HIV

Women social representations in face to HIV diagnosis disclosure

Mujeres de las representaciones sociales cara a diagnóstico de VIH del descubrimiento

*Ana Luiza de Souza Faria Lobo<sup>1</sup>; Amuzza Aylla Pereira dos Santos<sup>2</sup>; Laura Maria Tenório Ribeiro Pinto<sup>3</sup>; Sueli Terezinha Cruz Rodrigues<sup>4</sup>; Larissa Jucá Dantas Barros<sup>5</sup>; Marília Gabriela Teixeira Lima<sup>6</sup>*

### How to quote this article:

Lobo ALSF; Santos AAP; Pinto LMTR; et al. Women social representations IN face to HIV diagnosis disclosure. Rev Fund Care Online. 2018 abr/jun; 10(2):334-342. DOI: <http://dx.doi.org/10.9789/2175-5361.2018.v10i2.334-342>

### ABSTRACT

**Objective:** The study's goal has been to describe the social representations of women while facing their HIV diagnosis disclosure. **Methods:** It is a descriptive-exploratory study with a qualitative approach, which was carried out with 21 participating women who were in two referral centers for people bearing HIV/AIDS. Data were collected from May to June 2016. It was used the Social Representation Theory as theoretical basis, and the data were analyzed using the Content Analysis technique based upon the Bardin perspective. **Results:** It has been demonstrated the social representations of women regarding to the discovery of HIV diagnosis. The diagnosis of HIV is received with great impact by the woman who shows different feelings at that time, such as anxiety, fear, sadness, fear, surprise, incredulity, injustice and shame. **Conclusion:** There is a complex social representation that creates impact on the way of life and living of women bearing HIV, such as guilt, isolation, stigmatization and prejudice.

**Descriptors:** Pregnancy; HIV; nursing.

<sup>1</sup> Nursing Undergraduate student of the Nursing and Pharmacy School at Universidade Federal de Alagoas, Maceió, Alagoas, Brazil. E-mail address: ana\_lobo@gmail.com.

<sup>2</sup> Doctor's student of the Health Sciences Postgraduate Program, Professor of Nursing School at Universidade Federal de Alagoas, Maceió, Alagoas, Brazil. E-mail address: amuzzasantos@bol.com.br.

<sup>3</sup> Master's student of the Nursing Postgraduate Program at Universidade Federal de Alagoas, Maceió, Alagoas, Brazil. E-mail address: lauratenorio@hotmail.com.

<sup>4</sup> Master's Degree in Nursing, Professor of Nursing School at Universidade Federal de Alagoas, Maceió, Alagoas, Brazil. E-mail address: suelirodrigues@hotmail.com.

<sup>5</sup> Nursing Undergraduate student of the Nursing and Pharmacy School at Universidade Federal de Alagoas, Maceió, Alagoas, Brazil. E-mail address: larissa\_jdb@hotmail.com.

<sup>6</sup> Nursing Undergraduate student of the Nursing and Pharmacy School at Universidade Federal de Alagoas, Maceió, Alagoas, Brazil. E-mail address: mariliagabriela0305@hotmail.com.

## RESUMO

**Objetivo:** descrever as representações sociais de mulheres diante do recebimento do diagnóstico de HIV. **Método:** Estudo descritivo, exploratório com abordagem qualitativa, realizado com 21 mulheres que se encontravam em dois centros de referência para pessoas que vivem com HIV/aids. Os dados foram coletados de maio a junho de 2016. Utilizou-se como referencial teórico a Teoria das Representações Sociais, e os dados foram analisados por meio da técnica de análise de conteúdo na perspectiva de Bardin. **Resultados:** Demonstraram as representações sociais das mulheres frente à descoberta do diagnóstico do HIV. O diagnóstico do HIV é recebido com grande impacto pela mulher que apresenta sentimentos distintos no momento da descoberta, como: angústia, medo, tristeza, terror, surpresa, incredibilidade, injustiça e vergonha. **Conclusão:** Existe uma complexa representação social que gera impacto no modo de viver e conviver das mulheres que vivem com HIV, como a culpabilização, isolamento, estigmatização e preconceito.

**Descritores:** Gravidez. HIV. Enfermagem

## RESUMEN

**Objetivo:** describir las representaciones sociales de las mujeres a ser diagnosticados con HIV. **Método:** estudio cualitativo descriptivo, exploratorio, con 21 mujeres que no tuvieron mayor en dos centros de referencia para las personas que viven con el VIH / SIDA. Los datos fueron recolectados entre mayo y junio de 2016. Se utilizó como referencia teórica de la teoría de la Representación Social, y la fecha se analizaron mediante la técnica de análisis de contenido de Bardin perspectiva. **Resultados:** Demostrado las representaciones sociales de las mujeres con respecto al descubrimiento de diagnóstico de VIH. El diagnóstico de VIH es recibido con gran impacto para la mujer que tiene diferentes sentimientos en el momento del descubrimiento, como la ansiedad, el miedo, la tristeza, el miedo, la sorpresa, la incredulidad, la injusticia y la vergüenza. **Conclusión:** Hay un complejo de la representación social crea Que impacto en la forma de vida y la vida de las mujeres que viven con el VIH, como la culpa, aislamiento, estigmatización y prejudice.

**Descritores:** Embarazo. VIH. Enfermería

## INTRODUCTION

The HIV is a retrovirus that causes progressive immune dysfunction in the body, primarily by the decline in CD4 T lymphocyte levels. These lymphocytes are highlighted by the defense of the organism, from the moment they are reached, leave the individual vulnerable to other infections and opportunistic diseases, which take advantage of weakened immune system to manifest, in this context, the Human Immunodeficiency Virus (HIV) can cause Acquired Immunodeficiency Syndrome (AIDS).<sup>1</sup>

The period of HIV infection until the manifestation of AIDS can last for a few years, usually the virus carrier is asymptomatic, however, from the moment he discovers the seropositivity to the virus can present important disorders in the psychosocial scope.<sup>2</sup>

It is estimated that there are 35 million people bearing HIV/AIDS around the world. Since the beginning of the AIDS epidemic in Brazil in 1980, its rapid expansion has been observed, which was formerly concentrated in vulnerable

populations such as injecting drug users, sex workers, gays, transvestites and transsexuals. Over the years, however, a progressive change has been observed in its epidemiological profile with increasing involvement of heterosexuals, women, low-income individuals and the elderly.<sup>3,4</sup>

According to Furtado *et al.* (2016), AIDS has become one of the biggest public health problems in the world due to its harmful, heterogeneous and unstable nature.<sup>5</sup> Araújo *et al.* (2014) further corroborates the aforementioned statement and adds that HIV/AIDS has become the first modern pandemic with instability and volatility, presenting essential characteristics, acting in various social groups and economic classes, affecting all inhabited continents.<sup>6</sup> Due to these characteristics, there has been a change in the tendency of the infection pattern of the disease, with interiorization, pauperization and feminization.

According to the HIV/AIDS Epidemiological Bulletin for 2015, in Brazil, from the beginning of the AIDS epidemic in 1980 to June 2015, 798,366 AIDS cases were reported in the country, and out of that number 278,960 were women. At some point in history there has been an increase in HIV/AIDS cases in women (1980-2003); however, recent data show that in the last 10 years there has been a decline in cases in this public. Nonetheless, it is inherent to point out that despite this decrease there are important regional differences in relation to the number of cases, highlighting the North, Northeast and South regions with a higher number of infected women.<sup>7</sup>

In Alagoas State from January 1990 to June 2014, according to data from the *Sistema de Informação de Agravos de Notificação (SINAN)* [Notification of Injury Information System], 4,567 cases of AIDS were registered and women represent a total of 1,587 cases. According to Júnior *et al.* (2014), these data reaffirm what has been occurring in recent years in Brazil, in which HIV transmission is increasingly present among the heterosexual population, represented by the large number of women being diagnosed daily, including in Alagoas.<sup>3</sup>

In Maceió city, according to the data provided by the Municipal Health Department of Maceió, from 2007 to 2016, 1,802 cases of AIDS were registered, the city with the highest number of AIDS cases in Alagoas State. Regarding the HIV, 542 cases were diagnosed, out of which 216 were female.<sup>8</sup> A study carried out in a reference center in Maceió city indicated a high prevalence of HIV vertical transmission, corresponding to a rate of 6.6%.<sup>9</sup>

The regular notification of HIV infection cases from the confirmation of diagnosis came into force through Ministerial Ordinance No. 1,271/14, which lists the diseases of compulsory notification throughout the national territory. People bearing HIV in clinical and laboratory follow-up and diagnosed prior to the publication of the aforementioned ordinance may be notified as they attend the health services network.<sup>10,11</sup>

HIV among women is a public health problem that deserves attention with regard to prevention and health promotion strategies, as well as understanding the content of the feminization of AIDS, which includes questions related to the history of the disease in women, to socio-cultural relations of gender and the productions of meaning in their daily lives.<sup>12</sup>

According to Nascimento *et al.* (2013), the increasing number of women infected with the HIV virus involves the biological, social and cultural characteristics that are related to women's vulnerability. The idea of vulnerability in the context of AIDS is exposed by Rocha, Vieira and Lyra (2013) as a link between individual behavior, the social environment, human rights and public policies. The same is accentuated by issues of gender inequality, race inequality, social inequality and economic inequality.<sup>13,14</sup>

Furthermore, some women do not have access to information about sexuality and reproductive health, limiting control over their own bodies and making decisions about their sexuality in a safe way. Usually, they feel inhibited and powerless to negotiate condom use with their partner, fearful of generating suspicion of infidelity; and refusing the sexual relationship if the intimate partner refuses to use the condom is even more difficult.<sup>15</sup>

Seropositivity produces invaluable impacts, in which each individual can experience different sensations, internal conflicts and the most diverse fears about the diagnosis. In women, it causes a transformation in their lives, leading to a significant de-structuring in several aspects, making it necessary to learn to cope with the infection and then reorganize their perceptions and goals, thus giving continuity to the life process.<sup>16</sup>

These women bearing HIV "need shelter and listening, in the face of social prejudice and their own feelings, which are often conflicting and painful, covered by tension, insecurity, and fear."<sup>16</sup>

Moreover, the receipt of a positive HIV diagnosis causes, in the first moment, a change of great impact in all aspects of human life, changing the structure of its personality, its contacts with the world and its values. Regarding the women, it involves situations of fragility, such as pregnancy and maternity, making this moment even more complex.<sup>2</sup>

Despite the diverse and current social changes that have taken place in relation to the role of women, pregnancy and maternity remain one of the traditional aspects of this gender definition. Society has always been dominated by innumerable stigmas, especially in relation to women, marked by limitations and taboos, mainly through traditional family values. These aspects are further accentuated when it comes to an HIV-infected woman and, above all, the desire to be a mother.<sup>16</sup>

These paradigms cause emotional dysfunctions and alter the structure of women who suffer discrimination from different contexts. Consequently, a woman who is already experiencing an extremely delicate moment, constantly

burdened by psychological stress for nurturing the desire to become pregnant, of being a mother living with HIV, goes through a moment of emotional vulnerability, needing adequate support, and guidance according to their needs. Therefore, a reception, an effective listening, must be present in the adequate and qualified care to this population.<sup>16</sup>

## METHODS

It is a descriptive-exploratory study with a qualitative approach. According to Medeiros (2012), this research modality allows us to understand the symbolic and particular universe of experiences, behaviors, emotions and feelings experienced, as well as to understand about organizational functioning, social movements, cultural phenomena and interactions between people, their social groups and the institutions.<sup>17</sup>

Social Representations Theory was used as theoretical basis, representing a form of common sense knowledge that seeks to understand and communicate the beliefs, images, symbols, values and attitudes shared collectively and consciously in a group, society or culture. In other words, it is an indispensable phenomenon to explain cognitive processes and social interactions, which guides and organizes behaviors and communications.<sup>18,19</sup>

Representations are "complex phenomena always activated and in action in the social life". Therefore, studying social representations about HIV/AIDS means understanding how groups and individuals think and relate to this phenomenon in its totality and dynamism.<sup>19</sup>

The research was carried out in two specialized care services toward individuals bearing HIV/AIDS in the municipality of Maceió/AL: *Hospital Dia*, located at the *Professor Alberto Antunes University Hospital of the Universidade Federal de Alagoas (HUPAA/UFAL)* and Block I of the Medical Service *Salgadinho - PAM Salgadinho*.

Data collection was carried out from May to June 2016, through an individual interview, using as a collection tool a script of semi-structured questions. Inclusion criteria were the following: women of childbearing age, over 18 years old, who at the time of the data collection were at the research sites.

The interviews were performed in a reserved place, with the women being selected by convenience and waiting for the consultation. The script was divided into two parts, as follows: the first with questions related to the socio-demographic data of the participants and the second with questions related to the object of study.

The interviews were recorded with the use of a cellular device and transcribed in their entirety, thus enabling access to descriptive data of the subject's own language, as well as identifying non-verbal language information such as facial expressions, gestures and change the voice tone.

The information collected from the interviews was submitted to the Content Analysis technique based upon

the Bardin perspective, seeking to understand the subject's thinking through the content expressed in the text, in the transparent design of written language and in the context of the proposed analysis, through the use of the following steps: Pre-analysis; Material exploration; Results treatment; Inference and interpretation.<sup>20,21</sup>

Ethical criteria involving researches with human beings were respected according to the Resolution No. 466/12 from the National Health Council of the Health Ministry, which refers to research involving human beings. The participants were clarified about the objectives of the study and signed the Free and Informed Consent Term. The project was approved by the Research Ethics Committee from the *Universidade Federal de Alagoas*, under the Legal Opinion No. 5319016.5.0000.5013.

## RESULTS AND DISCUSSION

### Social representations of the diagnosis disclosure

The diagnosis disclosure is received by women with great impact, constituting a critical and significant moment. Women were asked about the meaning of HIV status in their lives. There were feelings of anguish, noticed by the pauses, crying and difficulty to answer the questioning.

*Wow... [crying] [pause] I cannot believe it yet [crying] (TULIPA).*

*Boy... I had no ground, right? Because it was very strong (VIOLETA).*

*I do not like to say no... because it changed my life, it practically turned inside out (crying) (ALFAZEMA).*

*... it was shocking, because like this... without ground, with nothing like I was going to overcome this problem (ACÁCIA).*

*[...] when something bad happens, people talking about death, I do not feel well inside... my aunt told me [...] I thought I was going to die right there... when she said I had AIDS (GIRASSOL).*

It is known that the discovery of the diagnosis of HIV/AIDS is a moment of change in the life of the individual, changing their way of life, relationships and life in society, especially in relation to the context of family and friends, who has greater proximity. In the confrontation with the new reality, this moment is accompanied by anxiety, uncertainty, insecurity, and fear of the situation unknown to the individual.<sup>21</sup>

The imminent death representation is present at the time of diagnosis, as evidenced in the *GIRASSOL* speech, in which that positive result meant its fatal sentence. This discourse, in addition to being derived from the social representations created since the onset of AIDS, reflects the lack of information of some people regarding the difference between the HIV virus and AIDS.

Understanding the significance of the HIV discovery by women in this study was characterized by negative feelings, such as fear, sadness, terror, surprise, unbelief, injustice and shame. According to Gonçalves *et al.* (2013, p. 284), he reports that "the moment of diagnosis is the most critical and shocking, since several feelings arise in a conflictive way."<sup>12</sup> Some of these feelings were addressed in the following speeches:

*At the time, the person is very sad, knowing that they only have it, you never expect to have it (BROMÉLIA).*

*Very good, no, it was a shock, right? Worse than a shot, right? (GARDÊNIA).*

*Wow, it was like the heaven was falling on my head when I got to know it [...] (JASMIM).*

*[...] for me to date has not dropped the plug know, but this for me I do not even know how to explain right is such a serious thing that ... terrible! I do not wish it to anyone (COPO DE LEITE).*

*It was a shock that I took in my life, I wanted to kill myself, depression, those kinds of things came through my mind (PAPOULA).*

These negative feelings are a worrying factor as they can trigger a stressful situation that influences the maintenance of the physical and mental health and social behavior of people bearing HIV. The stress also contributes to other diseases manifestation, then indicating that the psychological aspects are related to clinical psychosomatic symptoms.<sup>22</sup>

Having HIV/AIDS has always been related to taboos, stigma and prejudice. The historical course exposes the relation of HIV/AIDS to behaviors not accepted by society, said to be impure, insane, promiscuous and marginalized.<sup>23</sup> According to Teodorescu and Texeira (2015), in the emergence of AIDS, the Brazilian media reproduced the denominations of the HIV/AIDS epidemic. American press and published reports naming it as "a disease that afflicts homosexuals", "gay cancer" or "gay plague."<sup>24</sup> Consequently, society began to reproduce these denominations, which continue currently, as demonstrated through the discourses of women, who related HIV/AIDS to certain risk groups:

*Because so this disease to me at first I understood it like my father did not even tell me, it was like the monkeys and gays disease, that only people who had this problem were gay, because they had relationships like that, but then I began to understand over time as the doctors explain it (JASMIM).*

*Not believing, because I thought it would never happen, because I'm not from going out with one person and another, because that's what I thought it only could happen in people who "lived" choose people with HIV, and have happened it was a shock to me (LAVANDA).*

Conversely, the characteristics of the epidemic have completely changed. At the beginning, the most affected groups were the following: homosexual men, injecting drug users and individuals who received blood transfusion and blood products. In recent years, the epidemic has taken on a different profile, with the heterosexual public as the main route of transmission, which has continued to the present day, with a considerable increase in women affected by this infection.<sup>25</sup>

With regard to social representations associated with HIV infection, it is perceived that they are the result of the first information passed by the media that presented AIDS as a serious disease, of rapid, unknown and lethal evolution. Oliveira (2013) adds saying that AIDS was the first morbidity in which biomedical, symbolic and social construction took place simultaneously, highlighting the problematic of the relationships established between the process of symbolization and the adoption of daily practices and behaviors.<sup>26</sup>

The study by Gomes, Silva and Oliveira (2011), indicated that the perpetuation of the concept of risk group, makes the women believe that they are immune to HIV contamination. As it was evidenced in the participants who showed surprises before the diagnosis, since they did not expect to have the disease because they thought their relationships were monogamous and stable.<sup>27</sup>

It is worth emphasizing that in stable relationships, where there is trust between partners, condom use is judged to be unnecessary, due to the supposed safety that this type of relationship brings about the risk of HIV infection.<sup>27</sup>

Some of the interviewees showed a sense of indignation, because they feel betrayed by either their current or former intimate partner.

*It was shocking because I did not know whom I was with, so I thought that in my first husband I was married the first time (ÍRIS).*

*[...] the psychologist reported that he had died of HIV and I had to take (PALMA).*

*I was in love with a person and this person had this problem [HIV] for 7 years and he did not tell me anything (JASMIM).*

*I really liked the person, I did not expect him to be able to do something like that with me, because I really liked him [...] by that time I hated, I cried (JASMIM).*

*I think it's a very unfair thing, especially when you know and I do not want to do with anyone what they did to me (JASMIM).*

*I knew this person and with a little time this person got sick, only to me I was sick, but I was sick of something else it was not happening in my head that it was because of that [HIV] [...] I was shocked, because to my understanding they were cheating on me, lying to me, they knew everything and I did not know anything (COPO DE LEITE).*

So, once more when talking about women with fixed partners, it is worth questioning gender relations, referring to the differences between the roles of men and women in society. Thus Bazani, Silva and Rissi (2011) in their study, that the history of women is permeated by their submission to man, and the unequal opportunities that always favor them, still this submission of women in relation to their partners in their relationships increases vulnerability to infection.<sup>28</sup>

Furthermore, many women establish a relationship of emotional or financial dependence with their partners, making it difficult to perceive their own vulnerability or maintaining this relationship even after the diagnosis of the partner.<sup>28</sup> It is mentioned below:

*With this problem the man who just wants to live with me is only truly himself when I put it on my head that I am going to tell him. So, the man who wants to live with me is just those who have this problem [...] in the bedroom alone I cry because of these problems, I'm so sad (GIRASSOL).*

In this way, the direct relationship of vulnerability, the woman's submission by the partner and the strong affectivity is evidenced, making it difficult for her to make a decision when she discovers that she has infected herself with HIV through her intimate partner.

Within the social representations, regarding the use of the condom, to the negotiation of the use of the same with partner, arises as difficult, because culturally from a traditional marriage, the risk of contamination is not expected, since marriage in the social imaginary is configured as a loyalty relationship. However, in cases where there is distrust, the woman often fails to convince

her partner about condom use, because it is still something immoral within the old customs.<sup>29</sup>

In this study, it was noticed that the woman revealing the condition of being infected by HIV to the society opens the way to the possibility of suffering prejudices, be it of the partner, family or friends. She is judged as a person marked by a serious, transmissible, potentially dangerous disease, making it difficult to form new affective bonds, in other words, socialization problems.

Moreover, "the stigma surrounding HIV/AIDS promotes serological silencing as a way of protection, not to suffer discrimination and prejudice, which may potentiate the evolution of the disease, also implying noncompliance with treatment."<sup>30: 1982</sup> A concealment of having the virus was also put by the interviewees along with the denial of seropositivity, a mechanism of defense in the early phase of the discovery, often related to not seeking help and the use of antiretroviral therapy, as can be seen from the following statements:

*I do not know what time it was when I got a little disheartened from life, but I also take my normal, quiet life, I pretend I do not have it (PALMA).*

*[...] I try not to think, I've already walked away, I spent some time without taking medication (ÍRIS).*

*No, for me normal, I was pretending that I did not even have it, that's why I never dedicated myself to seeking a treatment; I surrendered to the hand of God (PALMA).*

The discovery of seropositivity proved to be a critical moment, marked by anguish and fear, not only because of the insecurity of having a disease without cure, but also because of the fear of abandonment and rejection, leading women to the need to conceal the diagnosis for their personal identity and the maintenance of relationships in the family or social environment.<sup>31</sup>

According to Galvão *et al.* (2011), one of the important factors to facilitate the achievement of results favorable to therapeutics is the adequate communication between patients and professionals in the healthcare process, providing information in order to increase the knowledge of patients to encourage adherence to the therapeutic regimen.<sup>32</sup>

### Living with the serological condition

With regard to living with HIV seropositivity, some women have shown concern and difficulty in getting involved in new relationships, especially if the partner is seronegative. The feeling of guilt for probably being responsible for transmitting the virus to new partners was also reported.

*I tell him that if he cares, I do not know what and he gets angry and just as I blame myself for knowing he has this problem, I'm blaming myself (JASMIM).*

*I'm not going to be living with a person that I tell this person that I have this problem, nobody will want to stay with me, no, no [...] if the person is going to live with another one, him or her has to say that the person has this problem, because not everyone accepts it (LAVANDA).*

*I was dating a person [...] I said it does not work because he wanted to take it more seriously, I said no, it's not like we're going to do it, let's stop right here (LAVANDA).*

*When it comes to the idea of what I am HIV positive and now how will my life be after that, how will I relate to people, how I will be able to have a relationship with other partners (GLORIOSA).*

The study by Oliveira *et al.* (2015) corroborates the findings of the study, showing that HIV seropositivity makes the woman feel dangerous to the sexual partner, which can trigger fear of transmitting HIV, anguish, guilt and anxiety in the infected spouse, interfering with sexuality. Additionally, he adds that HIV seropositivity poses a constant physical and psychological threat, which undermines social relations, because at each encounter, the fear of the unknown arises, leading to denial and fear for an opening of a new world. The fear of investing in new relationships is expressed as another repercussion of HIV, which is due to the prejudice of many people.<sup>29</sup>

Another relevant point that emerged during the analysis of the interviews was the prejudgment by the society, making difficult the process of acceptance and confrontation of seropositivity.

*[...] I think nobody, no human being wants to have news that has HIV, because it's not the fact that you have the disease, it's the fact that you see that people will reject you understood, people have prejudice, because they are people who do not even know how HIV transmits to people (ROSA).*

*[...] I am not much in commenting to everyone, because of prejudice, not everyone accepts it (MARGARIDA).*

*My family does not know and neither of his because it was going to be a shock to them, because they already have a lot of problems, they already have their problems, right, we'll live, when I go to the doctor, I will not tell where I'm going (GARDÊNIA).*

*[...] because I see that I'm sick, but I do not know what the problem is, then when I see that I'm sick, I'm afraid to get close to me when my mouth breaks, I cannot talk to anyone, is to live with what ... with nothing "I cry" (HORTÊNCIA).*

*No one knows what my problem is, then I wonder if Jesus would let anything happen to me and I get to internalize, how will my reaction be with the people (HORTÊNCIA).*

*Is something so serious that we feel so oppressed because we cannot talk to anyone, cannot, because today there is a lot of prejudice (COPO DE LEITE).*

It is noted that most women only relate to seropositivity for those they consider more intimate, since they are afraid of social judgment. The problem worsens when these women suffer humiliation and prejudice within their own family nucleus, as has been reported:

*And the only person in my family that knows is my aunt, my husband and a sister-in-law of mine, nobody else knows about my family, because everyone has prejudice to half the family, I do not tell, I tell nobody, because it is not easy (HORTÊNCIA).*

*Only that I have a brother that he did not, he was kind of like me [...] he would come to my mother's house he would take a pot to drink water, he would drink there was a glass like that in the cupboard on the counter and he would not take it he would take a pot to drink water... then I called him and I talked to him because I knew he was doing it because he was prejudiced with me, that from that day on I would give value to those who gave value for me, and today I do not give value to him (ROSA).*

The discrimination suffered by these patients is very evident, revealing the need for advancement in the education of the population with regard to virus infection. The person with HIV must be seen by all, regardless of whether the woman and the child born to HIV are entitled to equal care and treatment free of prejudice.<sup>31</sup>

The HIV/AIDS seropositivity has altered the life quality of affected women, both at personal and at professional levels. Examples are, respectively, a decrease in self-esteem and difficulty in getting a job. It is worth mentioning that most of the changes made by women were related to the side effects of antiretroviral drugs.

*No, after I found out I did not have any more love in my life, I'm not the person I was before I lived with it, I'm not that person anymore I was happy, today I'm not (HORTÊNCIA).*

*There are days that I do not want to talk to anyone, I do not want to hear anyone's voice [...] and another thing I got fat because of the medicine [...] I do not like to look at myself in the mirror [...] It is though, it is for the person to cry the whole life, without conditions, terrible "sniffing", I do not wish it even to my enemy (COPO DE LEITE).*

*I feel the remedies were so strong that I cannot work afterwards, because there's an hour that gives something in my mind, like it's like this... like it's a mental problem, there's a time for a business so my head I do not know what I'm doing by so much thinking (COPO DE LEITE).*

*No one will want me to work them, by the time I get sick, someone will help me, take me hospital and when he finds out that I have HIV, what will be the reaction of my boss, they will soon put me out without my rights, because what the people have most is prejudice, right? (HORTÊNCIA).*

The women interviewed showed resistance to the situation, reinforcing their loneliness and isolation from the work world. According to Silva, Moura and Pereira (2013), the HIV/AIDS epidemic in women's daily lives encompasses biological, social, psychological and religious issues. Among these, it is emphasized, in the psychological sphere, the fears that are installed in the daily life of women based on the diagnosis of HIV, among them, self-fearing, discrimination, prejudice, physical suffering and finitude. It is added that fear arises from misinformation about the disease or from inadequate information, coupled with the repercussions of contagion within the family, on discrimination and prejudice at work.<sup>21</sup>

The proportion of women bearing HIV/AIDS that does not work may be related to the health state compromised by infection and by opportunistic diseases as well. Therefore, the assistance to the woman with HIV requires of the nursing implementation of individualized care and with extent for the family.<sup>21</sup>

In the biological field, it is necessary to monitor the evolution of the infection and institute, along with the woman, preventive measures that can avoid reinfection, involvement by opportunistic diseases, as well as encourage adherence to drug therapy. Considering this, an important device should be pondered, the use of the nursing care systematization that allows the collection of information, elaboration of nursing diagnoses, care plan, prescription and constant evolution of the state of women's health.<sup>21</sup>

This reality signals toward the nursing care in the area, which should have actions that may influence the improvement of these women life quality. Women bearing HIV/AIDS should be included in society, carry out productive activities and enjoy routine that includes leisure. Encouraging women's social and economic integration is aimed at avoiding "civil death". It is necessary to stay active, to take care of their

children and their family. Consequently, the women will be able to live better with the seropositivity issue.<sup>21</sup>

## CONCLUSIONS

This study demonstrated that the diagnosis of HIV is received with great impact by the woman who presents different feelings at the moment of discovery, such as: anguish, fear, sadness, terror, surprise, incredibility, injustice and shame. These negative feelings are a reflection of the existing social representations on the topic.

The results showed the complex social representation and its impact on the living and living conditions of women bearing HIV, as evidenced by the guilt, isolation, stigmatization, prejudice faced by them, which lead to a change in the way of living.

The study showed the need for professionals able to provide assistance to this public who are able to look fully taking into account the particularities and subjectivities of each woman. In addition to the psychological dimension, the social representations generate more impacts.

In order to break the myths and taboos about the disease, it is relevant the realization of health education in the community about the topic, as it has been seen that society still lacks information about HIV/AIDS.



## REFERENCES

1. Abbas AK, Lichtman AH. *Imunologia Básica: Funções e distúrbios do sistema imunológico*. 2 ed. Rio de Janeiro: Elsevier, 2007.
2. SCHAEFER AS. Mudanças que ocorrem na vida da mulher portadora do HIV/AIDS após o diagnóstico. *Revista Eletrônica da Univar*. 2013;1(9): 14-6.
3. Júnior CA, Ferreira S MS, Albuquerque VWT, Silva JÍBW. Avaliação da qualidade de vida de mulheres com diagnóstico de HIV/AIDS em Maceió, Alagoas, Brasil. *O Mundo da Saúde, São Paulo*. 2014; 38(4): 448-61.
4. Tokano DV, Dessunti EM. Centro de testagem e aconselhamento: características dos usuários e prevalência de infecção pelo HIV. *Cienc Cuid Saude*. 2015; 4(14): 1537-45.
5. Furtado FMSF, Santos JAG, Loredanna S, Araújo E, Saldanha AAW, Silva J. Percepção de docentes de enfermagem sobre o cuidado: uma construção heideggeriana. *Rev. esc. enferm. USP, São Paulo*. 2016; 50 (Supl): 74-80.
6. Araújo OD, Nery IS, Monteiro CFS, Moura MEB. Representações sociais de mulheres profissionais do sexo. *Ciência, Cuidado e Saúde*. 2014; 13(4): 714-21.
7. Brasil. Ministério da Saúde. *Boletim Epidemiológico – HIV/AIDS*. Brasília: Ministério da Saúde, 2015a.
8. Levandowski DC, Pereira MD, Dores SD, Ritt GC, Schuck LM, Sanches IR. Experiência da gravidez em situação de seropositividade para o VIH: Revisão da literatura brasileira. *Análise Psicológica*. 2014 Set;32(3):259-77.
9. Rodrigues STC, Vaz MJR, Barros SMO. Transmissão vertical do HIV em população atendida no serviço de referência. *Acta paul. enferm. São Paulo*. 2013; 26 (2): 158-64.
10. Brasil. Ministério da Saúde. *Protocolo Clínico e Diretrizes Terapêuticas- Prevenção da Transmissão Vertical de HIV, Sífilis e Hepatites Virais*. Brasília: Ministério da Saúde, 2015b.
11. BRASIL. Ministério da Saúde. Portaria N° 1.271, de 6 de junho de 2014.
12. Gonçalves C, Weber B, Roso AR. Compartilhamento do diagnóstico do HIV/AIDS: um estudo com mulheres. *Mudanças-Psicologia da Saúde*. 2013; 21(2):1-7.
13. Nascimento CS, Nery IS, Pereira LC, Rodrigues IS, Bezerra MM, Gomes IS. Desejo de maternidade frente ao diagnóstico de síndrome da imunodeficiência adquirida. *Revista Baiana de Enfermagem, Salvador*. 2013 27 (3): 239-48.
14. Rocha S, Vieira A, Lyra J. Silenciosa conveniência: mulheres e Aids. *Rev. Bras. Ciênc. Polít., Brasília*. 2013; 11 92): 119-41.
15. Moura ERF, Lima DMC, Silva RM. Aspectos sexuais e perspectivas reprodutivas das mulheres com HIV / AIDS. *Mudanças com a soropositividade. Rev Cubana enfermer, Cidade de Habana*. 2012; 28(1): 1-8.
16. Camillo SO, Silva LO, Cortes JM, Maiorino FT. O desejo de ser mãe frente à infecção por HIV/AIDS. *Revista de Enfermagem do Centro-Oeste Mineiro, América do Norte*. 2015; 5(1): 1-7.
17. Medeiros M. Pesquisas de abordagem qualitativa. *Rev. Eletr. Enf. 2012*; 14(2): 224-9.
18. Moscovici S. *Representações Sociais: investigação em psicologia social*. 3. ed. Petrópolis: Vozes, 2003.
19. Jodelet D (org). *As representações sociais*. Rio de Janeiro: Ed UERJ, 2001.
20. Bardin L. *Análise de Conteúdo*. São Paulo: Edições 70, 2011.
21. Silva LMS, Moura MAV, Pereira MLD. Cotidiano de mulheres após contágio pelo hiv/aids: Subsídios norteadores da assistência de enfermagem. *Texto Contexto Enferm, Florianópolis*. 2013; 22 (2): 335-42.
22. Carvalho SM, Paes GO. A influência da estigmatização social em pessoas vivendo com HIV/AIDS. *Cad Saúde Coletiva*. 2011 Abr;19(2):157-63.
23. Vargens OMC, Rangel TS. A. Análise reflexiva sobre os aspectos sociais do HIV/AIDS: feminização, discriminação e estigma. *Online Brazilian Journal of Nursing*. 2012; 11(1): 1-9.
24. Teodorescu LL, Teixeira PR. *Histórias da AIDS no Brasil: 1983-2003, volume II: respostas governamentais à epidemia de AIDS*. Brasília, DF: Ministério da Saúde, 2015.
25. Araújo CLF, Aguiar OS, Santos GKA. A testagem anti-HIV nos serviços de ginecologia do município do Rio de Janeiro. *Esc Anna Nery*. 2014; 18(1): 82-9.
26. Oliveira DC. Construção e transformação das representações sociais da aids e implicações para os cuidados de saúde. *Revista Latino-Am de Enfermagem*. 2013; Fev 1;21(Spe):276-86.
27. Gomes AMT, Silva EMP, Oliveira DC. Representações sociais da AIDS para pessoas que vivem com HIV e suas interfaces cotidianas. *Revista Latino-Am Enfermagem*. 2011; 19(3): 1-8.
28. Bazani AC, Silva PM, Rissi MR. A vivência da maternidade para uma mulher soropositiva para o HIV: um estudo de caso. *Saúde & Transformação Social*. 2011; 29(1): 45-55.
29. Henrich HG, Kern FA. A Questão de Gênero na Relação com a AIDS: a maternidade em foco. *Textos & Contextos, Porto Alegre*. 2015; 14(2): 450 – 62.
30. Oliveira ADF, Vieira MCA, Silva SPC, Mistura C, Jacobi CS, Lira MOSC. Repercussões do HIV no cotidiano de mulheres vivendo com AIDS. *Revista de Pesquisa: Cuidado é Fundamental*. 2015; 7(1):1975-1986.
31. Renesto HMF, Falbo AR, Souza E, Vasconcelos MG. Enfrentamento e percepção da mulher em relação à infecção pelo HIV. *Rev. Saúde Pública*. 2014; 48(1): 36-42.
32. Galvão MTG, Cunha GH, Lima IV. Mulheres que geram filhos expostos ao vírus da imunodeficiência humana: representações sociais da maternidade. *Rev. Eletr. Enf.* 2014; 16(4): 804-11.

Received on: 06/10/2016

Reviews required: No

Approved on: 07/02/2017

Published on: 10/04/2018

**Author responsible for correspondence:**

Amuzza Aylla Pereira dos Santos

Avenida Lourival Melo Mota, s/n, Cidade Universitária

Tabuleiro dos Martins, Maceió/AL, Brazil

ZIP Code: 57072-900

E-mail address: amuzzasantos@bol.com.br

Telephone: +55 (082) 98897-9745