LIVING WITH HIV IN TIMES OF FEMINIZATION OF AIDS
VIVER COM HIV EM TEMPOS DE FEMINIZAÇÃO DA AIDS
VIVIR CON EL VIH EN LOS TIEMPOS DE LA FEMINIZACIÓN DE LA SIDA

Samya Raquel Soares Dias¹, Raisa Leocádio Oliveira², Francisco Braz Milanez Oliveira³, Maria Eleite Batista Moura⁴, Inez Sampaio Nery⁵, Fernanda Valéria Silva Dantas Avelino⁶

ABSTRACT

Objective: understanding the coping and the daily life of women with positive serodiagnosis for HIV/AIDS.

Method: a descriptive, exploratory study of a qualitative approach with women living with HIV/AIDS. Data were produced in a Specialized Care Service through consensual approach and recorded interview. The research project was approved by the Research Ethics Committee CAAE: 07582912.9.0000.5214. Results: it was clear the impact of the discovery of HIV/AIDS, compliance to antiretroviral therapy, negative feelings and coping with HIV status. Conclusion: the coexistence of women with the infection has peculiarities with regard to coping strategies they use, so it is up to nursing staff assist in this process. Descriptors: HIV; Acquired Immunodeficiency Syndrome; Nursing.

RESUMO

Objetivo: compreender o enfrentamento e a vivência cotidiana de mulheres com sorodiagnóstico positivo para o HIV/AIDS. Método: estudo descritivo, exploratório, de abordagem qualitativa com mulheres vivendo com HIV/AIDS. Os dados foram produzidos em um Serviço de Atendimento Especializado por meio da abordagem consentida e entrevista gravada. O projeto de pesquisa teve aprovação do Comitê de Ética em Pesquisa CAAE: 07582912.9.0000.5214. Resultados: foi esclarecido o impacto da descoberta da infecção por HIV/AIDS, adesão à terapia antirretroviral, sentimentos negativos e enfrentamento a essa condição sorológica. Conclusão: a convivência das mulheres com a infecção apresenta peculiaridades no que diz respeito a estratégias de enfrentamento que utilizam, assim, cabe a equipe de enfermagem auxiliar nesse processo. Descriptors: HIV; Síndrome de Imunodeficiência Adquirida; Enfermagem.

RESUMEN

Objetivo: entender la confrontación y las experiencias cotidianas de las mujeres con diagnostico positivo para el VIH/SIDA. Método: un estudio descriptivo, exploratorio con enfoque cualitativo con las mujeres que viven con el VIH/SIDA. Los datos se produjeron en un Servicio de Atención Especializada a través del enfoque consensual y entrevista grabada. El proyecto de investigación fue aprobado por el Comité de Ética en la Investigación CAAE: 07582912.9.0000.5214. Resultados: estaba claro que el impacto del descubrimiento del VIH/SIDA, el cumplimiento a la terapia antirretroviral, los sentimientos negativos y enfrentamiento a este estado de VIH. Conclusión: la coexistencia de las mujeres con la infección tiene peculiaridades en cuanto a las estrategias que utilizaran para hacer frente, por lo que corresponde al personal de enfermeria ayudar en este proceso. Descriptors: VIH; Síndrome de Inmunodeficiencia Adquirida; Enfermería.
INTRODUCTION

The first cases of HIV date from the 1980s, from that, AIDS has become a major problem of public health pandemic.1 Went by just over 3 decades, the presence of the HIV virus still generates different reactions, especially in relation to psychosocial aspects that require discussion beyond the biophysiological issues widely researched and published.2

According to the Epidemiological Bulletin AIDS/STD in 2012 there were 39,185 reported cases of AIDS in Brazil, and this number has remained stable over the past 5 years. The highest detection rate was observed in the South Region, 30,9 per 100,000 inhabitants, followed by the North (21,0), Southeast (20,1), Midwest (19,5) and Northeast (14,8).3

Before the multidimensionality of HIV/AIDS, now lives up the feminization process, heterosexual, pauperization, internalization, youth type and even the aging of AIDS cases in the world. HIV/AIDS have always risen in public health discussions, but with the feminization of the epidemic process of these discussions gained other proportions. Since the infection initially had prevalence in specific groups, and these, homosexuals, drug users and sex workers.

The literature describes several factors that relate to the feminization process of AIDS, namely: socio-economic conditions and impaired emotional ties, religious beliefs, stigma, use of legal and illegal drugs, sexual behavior, prostitution, violent situation, women in union stable, prisoners or living in quilombo (a type of African small communities in Brazil).4

Allied to the feminization process, discusses women's vulnerability, which is marked by the subordination of women to male desire in unequal gender relations, in order to determine conflictive relations in their own sexuality; as a woman takes the passivity regarding the decision making.4-2

Thus, it is worth considering gender relations as determinants in the health of women, as they influence their behavior towards self-care.2

In this context, more and more women are contracting HIV, and more cases are described in people with low income and in small towns. Worldwide, 17,3 million women aged 15 and older are living with HIV. This represents about 50% of people infected.5 For this purpose, living with the HIV virus includes more vivid aspects of emotions, feelings and probably subjective thoughts that seem to be linked. Studies have revealed evidence of emotions that are experienced worldwide in the context of HIV infection: anger, disgust, fear, surprise, guilt and sadness. There are other emotions, among them, shame, contempt and guilt.1

Researchers have sought to understand the universe of symbols and meanings that permeate this process, so as to promoting better care for people living with the virus. This requires, in question of the magnitude of the problem, more researches that seek to improve the production and distribution of the approached theme: How is it for a woman to live with the HIV virus?

This study is justified to seek a better understanding of issues related to HIV status, meanings and experiences of women living with the virus, thus contributing to improve the quality of life of women affected by HIV/AIDS. The objective is to understand the coping and the daily life of women with positive serodiagnosis for HIV/AIDS.

METHOD

It is a descriptive, exploratory study of a qualitative approach using the life history method, which is a procedure that uses the narrative of the life of the subject to the interviewer, as it was lived by himself, focusing on his convergences and divergences in his social condition, cultural and praxis, as well as the socio-structural relationships and historical dynamics.6

The study subjects were HIV-positive women under specialist care in a Specialized Care Service (SAE) in Teresina (PI). The sample size was due to the saturation of the speech of the interviewees. The inclusion of participants followed the following criteria: have resulted from serological reagent test for HIV or not having developed the syndrome; females, older than or equal to 18; be natural and domiciled in Teresina Piauí state capital; have physical, mental and psychological conditions to attend the interview; and acquiesce in the study.

As exclusion criteria there were women who had no follow-up or did not attend the outpatient at SAE during the period of data collection.

The data was produced by consensual approach and interview recorded with women living with HIV/AIDS before or after medical or nursing consultation in morning and afternoon shifts as previous outpatient schedule for return visits. On site, the interview was conducted in a private setting. Data collection was conducted in November and December 2012 and a sample of seven women.
RESULTS AND DISCUSSION

The reports of the study participants guided their experience with the HIV virus. So the following themes have been raised, which are: Being positive: the impact of the discovery; Use of antiretroviral therapy and compliance to treatment; Feelings against the HIV/AIDS; and women's experiences in fighting HIV/AIDS.

Characterization of the participants

Participants were seven women aged 28-64. Regarding self-reported color, two said they were white, two black and three dark skin. Regarding marital status three were single, a widow, a divorcee, a married and in a stable relationship. When asked about their religion, six referred Catholic and one Evangelical. Regarding the income, four of the participants received a salary and three women two salaries.

Concerning education, most had low education, three had elementary school incomplete, one with complete elementary school, two with complete high school and one was attending college. Two of the participants reported not working currently, the other two are domestic, one is cook, and one is administrative assistant and one retired. Regarding the evolution of the disease, two of them were in the asymptomatic phase, three in symptomatic phase and two have already developed AIDS. As for the time of diagnosis, six of them are under four years of infection and has 12 years of evolution of the disease. Four of them had active sexual partners, while three reported having sexual partners.

Being HIV-positive: the impact of the discovery

The discovery of HIV/AIDS is connected to a series of feelings that impact most women, making one and the same unpleasant moment. It was evidenced in the speeches of the participants the impact of the diagnosis of infection awakens in women. As revealed in the following lines:

I found out, my God, I no lie, no I got the point I despair. (E2)

For me it was a “thud” because we never expected ... my will was disappearing in the first place. (E4)

Almost die in fear, I was afraid even she sent me here, just the other day I came here, did not mean I was all confused. (E6)

I felt like it was not with me, as was passing the same as if I had died and had come back, seeing the people around my body and I dead there, I felt like I’d undead. (E7)

The discovery proved to be a sensitive time, triggering a series of feelings as seen in the reports above. It awakens a strong emotional charge that, without preparation, can even cause damage to patient care.

Knowing the positive diagnosis for HIV surprises many individuals who do not identify as vulnerable to contagion. Among them, a study relented students health which showed a perception of invulnerability, the reference to multiple sexual partners, use of alcoholic beverages before intercourse, and the discontinuous use or no use of condoms. 8

Feelings of shock have been reported, sadness, despair, fear, denial. These feelings are related to the fact that the disease has no cure, which causes insecurity about the future. And, related to the sudden discovery without prior preparation, linked to the lack of it. Impacts the plans already made for them to find themselves facing a new reality. 9

The discovery of diagnosis the woman is a delicate and important moment because the woman imposes a transformation of consciousness about themselves and about life. This moment triggers feelings as anxiety, sadness and fear, and the fear of abandonment and rejection.10

Confirmation of seropositivity most often is interpreted as finitude of life and inability to have a future. The presented emotions are related to feelings experienced in extreme situations imposed by life, though the intensity may be higher due to subjective interpretations of the subject about the concept socially shared about AIDS.

The existence of misconceptions in society about HIV/AIDS and the modes of transmission result in a life surrounded by stigmas, which almost becomes extremely stressful and difficult. Women living with HIV may encounter hostility and rejection, even the closest people; still at risk of losing their jobs, their families or important social relationships. 2

A very strong feeling of many people who find themselves opposite the virus infection is the fear of death, as is evidenced in the
speeches of the deponents. This is a growing feeling when faced with the disease and its consequences. 7

When asked about the discovery of HIV, there were different reactions as the discovery of diagnostic women E1, E2, E4, E6 and E7 show the negative impact of the discovery. But one of them was not so unaffected by the result:

I was not surprised at this, leave the hospital very well, immediately ordered this paper to take the examination, I made particular and in 24 hours I received the examination. (E3)

One study attributes these divergent reactions the fact that some women already expect a positive outcome and not others. As many have long suspected closely or had diagnostic confirmation of companion as well as recognize their vulnerability key behavior for HIV infection. 8 Others, however, do not understand and do not perceive themselves at risk in the face of HIV/AIDS and consider it far from their reality.

♦ Use of antiretroviral therapy and treatment compliance

It emphasizes the importance of compliance to antiretroviral therapy in fighting the infection. For those who adhere properly observe the evolution and improvement in their quality of life. As evidenced in the speeches:

After I started taking the medicines... has improved as well, because the weakness decreased, only it is kidney pain, pain in the head, stomach pain, it's not every day but we often feel. (E2)

Now that I'm taking direct, ready! I do not feel like throwing up not or do not want to take, I'm taking normal. (E1)

The antiretroviral therapy and access to treatment, reflected in the survival of people living with HIV infection and turned into a chronic disease, taking the aspect of the disease considered highly lethal. 1

Adherence to therapy is a dynamic and multifactorial process that includes physical, psychological, social, cultural and behavioral, and requires shared decisions and co-responsible between the person living with HIV, the health team and the social network. 11

The importance of the side effects of therapy as a factor that hinders treatment compliance was observed. As shown by the deponents E5 and E1.

Reaction when I started taking medication, almost died. (E5)

I spent now a year without taking medicine, so I'm feeling this pain here, I do not know what it is, week before last, this month I had a relapse, I was very weak, poor appetite, could not even walk, I started taking the medicine, I was already taking there, then improved.... I stopped taking because I was very sick, because I was not taking right. (E1)

Daily use of antiretroviral therapy might cause adverse reaction and cause an undesirable effect in patients. In these cases, depending on the type and frequency of events, patients eventually stop taking the drugs, causing flaws in the action of the same 12, as with the E1 woman.

It is essential that patients know the characteristics of the disease and is cleared by the team as the goal of antiretroviral therapy, and thus participate in the decision to start it with understanding the importance of making continues and correct the drug in order to achieve adequate virologic suppression of replication. 11-2

In this context, it highlights the importance of the multidisciplinary team that attends these patients for clarification and ways to approach therapy and its side effects, as well as the suitability of the body to the drug.

♦ Feelings when facing HIV/AIDS

Among the feelings that permeate living with HIV, depression is the most reported. As the following statements:

I get so depressed, sometimes I cry. (E1)

I have depression today and got this virus. (E7)

Depression in HIV positive can take place by various factors, affects the physical well-being, mood, perception of how that person views the world, the reality around you and how you feel about yourself and study when comparing the presence of depression symptoms between genders, we found statistically significant differences between men and women carriers of the disease, whereas women showed symptoms of more severe intensity of depression than men. 13

And sometimes through ignorance or prejudice, people fail to seek psychiatric help when they have symptoms of depression. Thus, for longer suffer discrimination by seropositivity prefer to save rather than face another stigmatized disease that is depression. 1

This shows that there are many factors that can trigger depression, so that the multidisciplinary team should observe and intervene in its progression, providing better care to the individual.

The disclosure of positive HIV status is a challenge that many women still cannot win. 9 One of the main factors is the fear of suffering...
prejudice from family, friends and the society itself.

Because we know that prejudice is great that people pretend to like us, but they never accept the problem you have. (E7) I’m afraid to suffer prejudice because I’ve heard, I’ve heard a person came up to me and said that he suffered prejudice in the beginning. (E4) I’m afraid so, because I think how they will react, it will have some prejudice, because there are people who have, I’d rather be on my own. (E5)

I suffered prejudice in the time it was sick even if the staff was talking, talking, and I have a friend who is a neighbor told her, her husband, daughter and boyfriend of her daughter, ai felt we went to the restaurant in the evening in Christmas, i thought my boyfriend was not with prejudice and not her husband, but she I thought I was. (E6)

It is understood that the person with HIV/AIDS suffer discrimination and prejudice, comes into emotional conflict from different fields, has feelings of guilt, rejection, fear, sadness, shame and responsibility for contamination and be contaminated. This is because patients undergo adaptations and likewise all the people who live with them when they have knowledge of HIV status, which leads to mental suffering. 1

For not having cure, HIV infection awakens in people a lifetime of questioning, bringing out the feeling of death and fear of it. As described by E5 woman.

Will I last many years? Will I see my grand daughter? These things pass on my mind. (E5)

Studies show the frequency of desire to face death with HIV/AIDS in older. The same also reported prejudice, discrimination and many negative feelings that permeate these experiences. Also show feelings and experiences related to revolt and indignation, shame and suffering, beyond the fear of death. 14-2

♦ Women’s experiences in the fight against HIV/AIDS

The impact of the discovery is not involved with positive feelings, but over time, many women find ways to challenge these feelings and promote a better quality of life for themselves, for example the deponents E1, E2, E3 and E6.

My mother and my aunt support me, they are two mothers. (E1)

Then, it is so, I hold myself in him and he in me ... and now I see that I have no reason to kill me at all (E2).

My family is great, my family, Mom, lift the mood, my daughter spirits lifted. I have an older son who is 40 years old he said, Mom, I do not want anyone to say that the lady is sick, because for me she is not sick. (E3)

Now it no longer, she comes to me for consultations here, she who accompanies me. (E6)

The challenge of sharing seropositivity is not experienced by all, but by who managed to overcome it was evidenced good personal achievements, with regard to the family, the spouse’s figure, children, parents and uncles as support the fight against HIV.

Family support becomes critical to emotional recovery, promoting them as positive coping measure on the disease. 15

There were obtained in the study positive reports about the family support as a differentiator to combat the disease. 9 Thus, it is shown the fundamental role of the family in facing women living with HIV, it should still be considered the negative influence that it brings these women.

In counterpoint to many people living with HIV prefer secrecy and confrontation because they fear the reaction of family for fear of prejudice and rejection by the stigma created to infection by the company since its discovery. 16-5

Another coping strategy evidenced in this research was to religiosity.

I went to a meeting with God, a retreat and you do not talk to anyone, alone in her place because it is an encounter with God, so I went to talk to God, I felt him hit my shoulder; daughter you’re healed, in Jesus’ name, do not want more. (E3)

Same one God to conform us ... I think God prepared me, sent me a blessing for me to prepare me for the pain I went through, I’m going through, but I did not convey to them what I’m feeling ... That moment God gives you a chance and taking care because you never know, we think that is rich in health, you think you’re rich health outside, but inside you do not know, that was what happened to me. (E4)

So life, if it continues living up to 100 years. (E2)

Facing the diagnosis, the negativity he wakes created by the stigma the disease arises religion as support, representing great emotional support. And their faith, a way of explaining the world tied to hope, provides overcome and endure daily existence. Thus, religious belief was also highlighted as a fulcrum for providing strength to the care and self-care. 17
In this context, health professionals must be alert and open to the social factor of the individual, being a religious one. And it is for her function to understand how religion is interfering with the illness experiences, in order to seek to anguish of users, and thus help to strengthen their autonomy.

**FINAL NOTES**

This study provided a better understanding about the experience of women with HIV/AIDS. It was shown the negative impact caused by the confrontation to the diagnosis that most often occurred without emotional preparation.

Woman in current feminization process for psychosocial issues we see facing a stigmatizing infection that triggers many negative feelings. Thus, it is the multidisciplinary team holistic care of these women in order to reduce these feelings from coping strategies. Thus, as coping strategies identified in this study, it can be described compliance to antiretroviral therapy, family support and religiosity.

It is hoped that this study will contribute to the systematization and humanization of nursing care, better address the health teams that serve this population in terms of its difficulties, possibilities and individuals. In order to provide a more humanized care and focused on their needs, making it possible to understand how to live with HIV/AIDS and its impacts on women's lives.

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Corresponding Address
Samya Raquel Soares Dias
Rua Jornalista Vieira Chaves, Quadra 255, casa 14
Bairro Dirceu II
CEP 64078-270 --- Teresina (PI), Brazil