

Changes in The Quotidian of Women Living With Hiv: Ambulatorial Analysis, Rio De Janeiro State, Brazil

Mudanças no Cotidiano de Mulheres Vivendo Com Hiv: Análise Ambulatorial, Rj, Brasil

Cambios en el Cotidiano de Mujeres que Viven con el Vih: Análisis Ambulatorio, Rj, Brasil

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ABSTRACT

Objective: The study's purpose has been to scrutinize the changes in women's daily life, as well as to investigate how they stand after the diagnosis of HIV/AIDS and the introduction of Antiretroviral Therapy (ART).

Methods: It is a descriptive and prospective study with a qualitative approach. Semi-structured interviews were performed with twenty-two HIV positive women, who were enrolled in the immunology ambulatory of a university hospital located in the *Rio de Janeiro* city. This research was approved by the Research Ethics Committee (CAAE: 45955315.0.0000.5285). **Results:** Most women dealt positively with the changes in their daily lives after discovering the disease, looking for a way of life with quality, although they still show some difficulties in that regard. Concerning the ART, there was struggle in its beginning, however, as the time went by the adaptations occurred mainly with the family support. **Conclusion:** It is essential to provide better support towards women during both HIV diagnosis and treatment, so that they can improve their coping strategies.

Descriptors: Hiv, Therapeutics, Women, Family, Coping.

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RESUMO

Objetivo: Investigar as mudanças no cotidiano e analisar o enfrentamento de mulheres após o diagnóstico do HIV/aids e a introdução da Terapia Antirretroviral (TARV). **Método:** Estudo descritivo e prospectivo de natureza qualitativa. Realizadas entrevistas semiestruturadas com vinte e duas mulheres HIV positivas, matriculadas no ambulatório de imunologia de um hospital universitário do Rio de Janeiro. Aprovado pelo Comitê de Ética CAAE: 45955315.0.0000.5285. **Resultados:** A maioria das mulheres enfrentou positivamente as mudanças no seu cotidiano após a descoberta da doença, buscando viver com qualidade, embora ainda apresentem dificuldades na retomada de suas vidas. Com relação à TARV houve dificuldade em seu início, no entanto com o passar do tempo ocorreram adaptações principalmente com o apoio da família. **Conclusão:** É fundamental que haja um maior apoio as mulheres durante o diagnóstico e tratamento do HIV, para que possam elaborar melhor suas estratégias de enfrentamento.

Descritores: HIV, Terapêutica, Mulheres, Família, Enfrentamento.

RESUMEN

Objetivo: Investigar los cambios en la rutina y hacer un análisis del enfrentamiento de mujeres tras el diagnóstico del VIH/sida y la introducción de la Terapia Antirretroviral (TARV). **Método:** Estudio descriptivo y prospectivo de naturaleza cualitativa. Se realizaron entrevistas semiestructuradas con veintidós mujeres VIH positivas, matriculadas en el ambulatorio inmunológico de un hospital universitario de Río de Janeiro. Aprobado por el Comité de Ética CAAE: 45955315.0.0000.5285. **Resultados:** La mayoría de las mujeres enfrentó positivamente los cambios en su cotidiano después del descubrimiento de la enfermedad, buscando vivir con calidad, aunque todavía presentan dificultades en la reanudación de sus vidas. En cuanto a la TARV hubo dificultad en su inicio, sin embargo con el paso del tiempo ocurrieron adaptaciones principalmente con el apoyo de la familia. **Conclusión:** El apoyo a las mujeres durante el diagnóstico y tratamiento del VIH es fundamental, para que puedan elaborar sus estrategias de enfrentamiento.

Descriptores: VIH, Terapêutica, Mujeres, Família, Adaptación Psicológica.

INTRODUCTION

Human Immunodeficiency Syndrome (AIDS) is considered a serious public health problem in Brazil and worldwide. The *Sistema de Informação de Agravos de Notificação (SINAN)* [Information System of Aggravation Notification] reported 842,710 cases of AIDS in Brazil from 1980 to June 2016, of which 548,850 (65.1%) were male and 293,685 (34.9%) were female.¹ Between 1980 and 2002, there was an increase in the number of women diagnosed with AIDS; from 2003 to 2008, the ratio of the genders remained 15 cases to men for every 10 cases to women, from 2009 there was a steady reduction in cases involving women. In the last ten years, the rate of AIDS cases in women has dropped from 15.8 cases/100 thousand citizens in 2006 to 12.7 cases/100 thousand citizens in 2015.¹

The feminization of such epidemic in Brazil occurred in a clear and rapid manner from 1980 to 2000, where women were believed to be immune to the risk of virus contamination, and the different vulnerability conditions to which women were exposed remained unchecked, which increased the risk of developing AIDS.^{2,3}

Discussions about women's sexual and reproductive rights should include the issue of HIV. Female emancipation has occurred in several aspects such as economic, for instance, but in the social and gender context they present greater vulnerability³ since many still elaborate behaviors and attitudes with support in sexual affective experiences that bring the representation of marriage, the stable union, fidelity and love as a protective factor and allied to the low level of schooling that can hinder access to information.^{2,3}

By facing the diagnosis, women have their personal, family and social universe immersed in a wide process of modifications, ranging from the biological to the psychological, which also includes the religious field in all its dimensions. Fear is a constant in the lives of these women and involves prejudice, discrimination, family rejection, domestic violence, suffering, and death.³

The objective of this work was to scrutinize the changes in women's daily life, as well as to investigate how they stand after the diagnosis of HIV/AIDS and the introduction of Antiretroviral Therapy (ART). Furthermore, to analyze the coping strategy used towards the changes that the diagnosis and introduction of ART may cause in women's quotidian.

METHODS

It is a descriptive and prospective study with a qualitative approach, which worked with the world of meanings, motives, aspirations, beliefs, and values through the interviewees' speeches.⁴ Data collection was done through a semi-structured interview performed with twenty-two HIV in the use of ART, who were enrolled in the immunology ambulatory of a university hospital in the *Rio de Janeiro* city. The participants were identified with the letter W and a random number.

The inclusion criteria of the women in the study were as follows: to be enrolled in the immunology ambulatory; to be HIV positive; over 18 years old; being on ART at the time of the interview; accept to participate in the research through the signing of the Informed Consent Form (ICF). This research was carried out according to Resolution 466/2012. The interviews were performed in private practice with a duration of up to 40 min/interview, having been recorded and transcribed in full. The study was submitted to the Research Ethics Committee from the *Universidade Federal do Estado do Rio de Janeiro (UNIRIO)* and approved under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 45955315.0.0000.5285.

The analysis of the data was performed through the technique of content analysis that according to Bardin⁵ presents three phases, as follows: pre-analysis: readings without discarding any part, guaranteeing the general abstraction of the material; material exploration: parts of the speech segments and the categorization and treatment of information.⁵ Therefore, the research performed all

phases of the proposed content analysis process and identified in the interviewees' speeches the topics that were most approached, which then resulted in the following two thematic categories: difficulties and abandonment of ART; family and social inclusion.

RESULTS AND DISCUSSION

Through this study, it was viable to trace the women's profile during the interviews, with the majority being between 28 (twenty-eight) and 61 (sixty-one) years old; being brown race, having between eight and eleven years of education. Twelve interviewees identified themselves as single, three married, four as common-law marriage, one divorced and two widowed. In the sample, there was a predominance of the Catholic and Evangelical religion. Nonetheless, five interviewees claimed to be Spiritists and two said they had no religion. The results of the 2010 Demographic Census from the *Instituto Brasileiro de Geografia e Estatística (IBGE)* [Brazilian Institute of Geography and Statistics] indicate that the Brazilian population is formed by the following in regards to religion: 64% Roman Catholic Apostolic, 22.2% Evangelicals, 4% Spiritists, 0.3% *Umbanda* and *Candomblé*, 2.7% of other Religions, and 8% without Religion.⁶

Concerning the labor activities, services such as: domestic work, general services auxiliary, commerce and sewing, were the most cited, determining an income above a minimum wage and a half, and some did not know how to report their income.

During the interview, when the participants were asked about the changes that occurred in their daily life after the HIV positive diagnosis and how they did stand about it, then the first thematic category came about: Difficulties and abandonment of ART.

Difficulties and abandonment of ART

Acceptance of medication is a dynamic process involving many factors, including physical, psychological, social, cultural and behavioral aspects. This requires shared and co-responsibility between the person living with HIV, the staff and the social network.⁷

In 1996, Law 9,313/96 guaranteed the free distribution of antiretroviral drugs by the *Sistema Único de Saúde (SUS)* [Brazilian Unified Health System]. The care policy has increasingly extended early access to the diagnosis, treatment, and follow-up of People Living with HIV (PLHIV). Approximately 65,000 individuals start ART

each year. From the beginning of the epidemic event in 1980 to December 2015, 303,353 deaths were identified, which resulted in AIDS deaths, with most cases (60.3%) in the Southeast region.¹

Abandonment of ART may occur in parallel with the abandonment of clinical follow-up, including non-attendance, testing, and any other action related to self-care.⁷ It is understood that each individual may present a different response with respect to use of ART and this can also be related to the feeling of living with a disease that does not yet present a cure, but only treatment.

By abandoning a therapeutic treatment, it was possible to understand that the patient has real reasons to make such a decision, and these reasons may be related to their daily life, living conditions, family and affective relationships, work, among other aspects specifically related to HIV/AIDS. These reasons can be verified in the interviewee's speech:

Not because I wanted to, but it was because I lived far away, sometimes I could not get the medicine, so I ended up not taking it, I stayed a month without taking the medicine and this caused me pneumonia, understood. (W47)

Although antiretroviral therapy is a free treatment in Brazil, it is known that there are many patients in a situation of vulnerability and these can make it difficult to comply with the treatment as explained by the interviewee above, because they do not have the financial condition to seek the remedy in a certain locality can be considered as a barrier to treatment adherence.

It is observed in the following statements that the beginning of the treatment was difficult for some patients due to different situations, such as the adaptation to the new disease situation and the side effects of the drug that took them some time to abandon the treatment. Nevertheless, this abandonment was momentary and soon resumed the therapy because it was considered important for the improvement of their health condition.

I never took the medicine before, and to tell you the truth, I started taking the medicine a year ago. I would take a week and stop. (W40)

I quit earlier because I was sick of taking medicine. (W13)

Antiretroviral therapy aims to reduce the morbidity and mortality of people living with HIV/AIDS, allowing a

better expectation and quality of life but does not eradicate the infection by the virus.⁸ The lack of adherence to therapy is considered an obstacle to effective treatment and its consequences can be numerous, reaching from the disease health process to the socioeconomic conditions of the patients.

AIDS is considered a chronic disease that has in adherence to the treatment the essence for the quality of life of the patient, however, several factors such as drug side effects, fear and insecurities should be considered throughout the process. These factors alone or together can lead to depression and hopelessness leading to the abandonment of therapy.³ During the interviews, some patients expressed feelings that came together with the initiation of ART as reported below:

It's horrible, it's really bad, I do not have any sensation, just in time to take it down here in my throat, that's why it gives me discouragement, sometimes sadness just hits, and depression. (W31)

One of the important tools in the approach to PLHIV is to know and understand their psychosocial conditions.³ In addition to physical health, their socio-emotional and sexual life are also affected.⁹ The health professional's understanding of this universe at the beginning of ART can contribute to patient compliance. Approaches to listening and guidance are important at this stage of treatment. Nonetheless, it is fundamental that the professional performance is throughout the process because many of the interviewees reported not receiving the support they needed during all phases of treatment.

Other factors also influence adherence to treatment and may be related to different aspects such as: efficacy of the prescribed regimen, adverse effects, dosages incompatible with the daily activities of the patient, a large number of tablets, drug interactions, loss of motivation over time or need for food restriction.⁷ The following statements show such factors that influence the adhesion of ART.

I vomit and I take another one, then always when I take it, I have to get fruits, a candy for me to eat, otherwise, it does not stop in my stomach. (W34)

I just would go away. It took a week and left. I would start to nauseate, vomited a lot. (W40)

When a person presents a certain disease is meant to use medication during treatment, which is not different from HIV/AIDS. The immediate onset of ART is recommended,

however, medications may have side effects, which are a difficulty for the continuation of treatment, since many patients present symptoms that intensify with the use of therapy and that make it difficult to perform correctly.⁷

When participants were asked about the changes that occurred in their daily lives after a positive HIV diagnosis, the answers addressed the challenges faced in resuming personal life and the emotional support given by the family. Thus, a new thematic category came about.

Family and social inclusion

The PLHIV choose the family as social support that contributes to the physical, emotional and mental balance of the individual.¹⁰ The family represents the first space of dialogue and social coexistence to which the PLHIV is submitted. In addition to being considered one of the main support matrices and composing the universe of the patient's senses and values. The family within the field of HIV/AIDS consolidates as an important base of resistance because it provides the necessary support to overcome the daily obstacles of this population.¹⁰

Family support for a diagnosis such as HIV/AIDS is one of the factors of great importance for coping with the disease. The discovery of HIV establishes a woman's transformation of consciousness about herself and her life.¹¹ In this context having the support of the family helps her find the strength to overcome the difficulties of that moment. As expressed through the following statements:

In the family no one has changed, everyone has treated me well; in the beginning, it was very hard for me, you know, very hard, I sometimes thought about killing myself. (W27)

I do think nothing has changed, so my family has not changed with me, everyone keeps treating me normally, even more carefully. (W31)

The fact that the family does not change the living after the diagnosis, favors the welcoming and strengthens positive actions while facing the syndrome. Hopelessness, the desire to die and suffering are recurrent feelings in this group, and it is up to the family to collaborate, so the negative thoughts are eliminated and replaced by surpassing actions and the will to live with quality.

HIV/AIDS has a serious impact on society and the economy, especially in the marketplace, both formal and informal, also on workers, their families, and

dependents, both public and private employers. The stigma, discrimination, and threat of job loss experienced by PLHIV are barriers faced by them, which increases the vulnerability of these workers and might hinder the acquisition of social benefits.^{12,13} The following statements explain situations in the labor field involving the diagnosis of HIV.

No, at work no one knows, just the office members, even though they know because of my reaction, so I had to move away. (W34)

When I was working at a company, the boss told me, let's say we are going to ask for exams and it appears, then what I am going to do, to keep you working here. (W47)

It is observed that many women mask the diagnosis in the work environment due to the fear of suffering some kind of either prejudgment or discrimination, although Law No. 12.984/2014 defines as a crime discrimination against PLHIV, punishable by imprisonment and fine those who deny employment or work to PLHIV, either exclude or dismiss their position or job, implement segregation in the work environment, among other discriminatory behaviors even with protective measures, not revealing their serum positivity is an attempt to keep the job.^{14,15}

The fact that they are inserted in a work activity strengthens their self-esteem by the feeling of usefulness diverting the PLHIV from negative thoughts.¹¹ Being included in the labor market contributes to the quality of life of women living with HIV/AIDS.

The World Health Organization (WHO) defines the quality of life as "conditions that may affect the individual's perception, feelings and behaviors related to their daily functioning, including, but not limited to, their health condition and medical interventions".¹⁶ The following statements reveal the respondents' standpoint regarding the changes in quality of life after HIV diagnosis:

It is better, yes, I think I've matured a lot in regards to all this. The disease scares those who do not know and do not understand. It does not stop me from doing anything. My husband is a blessing, thanks God; it seems that after all this happened, the blessings in my life have just multiplied. (W35)

I stopped going out at night, I stopped hanging out, I stopped drinking. I tried to take better care of myself, to love me more. (W48)

he reports indicate that with the diagnosis some women have undergone positive changes in their lives, with respect to their quality of life and self-care. Therefore,

it is understood that each person reacts and faces in a different way what a disease without a cure can bring as a change to their life. Some PLHIV after diagnosis has undergone positive changes in their daily life habits, as well as relationships with family and friends, valuing each day.⁹

Thus, it is understood that the disease encompasses other aspects of life, in other words, it involves social issues, which many people still do not understand, understanding HIV/AIDS only with regards to the clinic, forgetting everything that which surrounds the syndrome and which transpose other important aspects of human life. These difficulties can be noted through the following statements:

It has changed because I used to be happier, I was more cheerful, I had more pleasure in taking care of myself. Now, I already take a step back because I'm going to have to tell the person that I'm sick, and not all guys are empathetic. (W47)

Oh! It has changed, I became a bit more cranky. I was clean because I had nothing. Now, I think I'm not clean, I have a 'stain'. (W34)

A particular perception of life before and after the diagnosis was prominent, which goes beyond a path towards the meaning of life. Feelings are outstretched, obstacles seem insurmountable, but the environment might be the differential in the subject's life. The diagnosis always has a great impact on the woman's life, it generates a shock of physical, emotional and social nature. The way in which the coping strategies will take place depends on several factors, among them the woman's personality and socio-family framework.⁹ When facing the diagnosis, the woman experiences feelings of uncertainty and insecurity leading to a moment of crisis in her life.³

CONCLUSIONS

Through this research, it was to feasible know the universe of women living with HIV/AIDS and how much this feminine universe differs from the others in several aspects. The woman is still seen as a sensitive and fragile being by the society. Nevertheless, based on the findings that were shown here, it was possible to understand how the coping strategies were implemented by them vis-à-vis the disease diagnosis and antiretroviral therapy initiation. The women interviewed presented different behaviors and reactions towards the changes that HIV/AIDS brought to their lives. Some reacted positively looking for life quality. However, others have experienced the prejudgment that involves such disease, which has caused a wide disruption in their lives. What made them experience different feelings like death and the hopelessness of better days. The family environment

was an important source of support, as many reported to be feeling welcomed and not discriminated by their peers. The fear of discovering the disease was also addressed by some people, as in the workplace for instance, by facing the fear of suffering some kind of prejudice.

The introduction of ART proved to be difficult because it was a new situation from which they had to adapt, but as the time went by, there were positive changes in that regard.

Therefore, it is important to keep studying this topic, since it is through questioning and analysis of the answers that solutions can be found to make coping with HIV/AIDS somewhat less difficult for women.

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