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RESEARCH

Repercussões do HIV no cotidiano de mulheres vivendo com AIDS

Effects of HIV in daily life of women living with AIDS

Efectos del HIV en la vida diaria de mujeres viviendo con SIDA

Ariela Dias de Freitas Oliveira ¹, Michelle Christini Araújo Vieira ², Susanne Pinheiro Costa e Silva ³, Claudelí Mistura ⁴, Caren da Silva Jacobi ⁵, Margaret Olinda de Souza Carvalho e Lira ⁶

ABSTRACT

Objective: Understand the impact of HIV in everyday life of women living with AIDS. **Method:** A qualitative study involving 11 women attending a center of information on STD/HIV/AIDS and Viral Hepatitis in a city in northeastern semiarid, with data collected by semi-structured interview and interpreted by content analysis. **Results:** It was evident that the everyday life of women with HIV/AIDS suffers repercussions in the sexuality, by the reduction in sexual relations, discoveries of new forms of pleasure by couple and increase in personal and social responsibility after diagnosis. Moreover, there was the emergence of negative and positive feelings and the search for ways of coping of disease. **Conclusion:** It is concluded the necessity and importance of nursing to direct health interventions for these women, demonstrating the possibilities of pleasure, satisfaction with life and living with the disease. **Descriptors:** Sexuality, Woman, HIV, Nursing.

RESUMO

Objetivo: Compreender as repercussões do HIV no cotidiano de mulheres vivendo com AIDS. **Método:** Pesquisa qualitativa com a participação de 11 mulheres usuárias de um centro de Informações em DST/HIV/AIDS e Hepatites Virais de uma cidade do semiárido nordestino, com dados coletados por entrevista semiestruturada e interpretados por análise de conteúdo. **Resultados:** evidencia-se que o cotidiano de mulheres com HIV/aids sofre repercussões no que refere a sexualidade, pela redução das relações sexuais, descobertas de novas formas de prazer pelo casal e aumento da responsabilidade pessoal e social após o diagnóstico. Além disso, ocorreu o surgimento de sentimentos negativos e positivos e a busca por formas de enfrentamento da doença. **Conclusão:** Conclui-se a necessidade e importância da enfermagem direcionar ações em saúde para essas mulheres, demonstrando as possibilidades de prazer, satisfação com a vida e de convivência com a doença. **Descritores:** Sexualidade, Mulheres, Soropositividade para o HIV, Atividades cotidianas.

RESUMEN

Objetivo: Comprender el impacto del VIH en la vida cotidiana de las mujeres que viven con el SIDA. **Método:** Estudio cualitativo que participaron 11 mujeres que acudieron a una información de salud sobre las ITS/VIH/SIDA y la hepatitis viral en una ciudad en el noreste semiárido, con datos recogidos por entrevista semi-estructurada e interpretada por el análisis de contenido. **Resultados:** Se hizo evidente que la vida cotidiana de las mujeres con VIH/SIDA sufre repercusiones en materia de sexualidad, a través de la reducción de las relaciones sexuales, descubrimientos de nuevas formas de placer por pareja, y el aumento de la responsabilidad personal y social después del diagnóstico. Además, ocurrió el surgimiento de sentimientos negativos y positivos y la búsqueda de formas de lidiar con la enfermedad. **Conclusión:** Se concluye que la necesidad y la importancia de la enfermería dirigir las intervenciones de salud para estas mujeres, demostrando las posibilidades del placer, satisfacción con la vida y convivencia con la enfermedad. **Descriptor:** Sexualidad, Mujeres, VIH, Enfermería.

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INTRODUCTION

The sexually transmitted diseases (STDs) considered one of the most common public health problems worldwide, worrying the scientific community and Governments. Among these, gives emphasis to the infection by the human immunodeficiency virus (HIV) causes aids, which attacks the immune system, making people more prone to acquire opportunistic diseases.¹

In Brazil, the estimate is of 36 thousand new cases of AIDS per year, with increasing incidence rates, and in the Northeast, from 2001 to 2011, there was a rise of 7.5 to 13.9 cases per 100 thousand inhabitants and in the State of Bahia, there was a rise of 6.4 in 2000 to 12.6 in 2011.²

Although the largest number of reported cases of AIDS between men, currently there approximates the difference between the sexes, with 1.7 cases in men to each woman.³ by the year 2012 the country ever had 656,701 reported cases of the disease.² and the form of HIV transmission in women occurs predominantly via sexual intercourse, and in 2012 86.8% of registered cases were heterosexual relations with people infected with HIV.³

This finding extends the possibility of transmission of HIV during pregnancy, childbirth and the puerperium, identified as Vertical Transmission (TV). Among the States of the Northeast region, Bahia presents the biggest TV in the Northeast.² It is in this context that the Ministry of health has been investing in prevention of TV during prenatal care, intending to reach the goal of 100% coverage of HIV testing in pregnant women until 2015.²

Society and health services face some factors that influence the vulnerability of women to HIV infection, such as drug use, early sexual life early, low adherence to the use of condoms, the greater proportion of history of STD and sexual violence among women living with HIV/aids. The high proportion of women infected by their partners fixed drives demand for prevention strategies for this portion of the population, in which the regular use of condoms is hampered by gender relations, affection, and desire.⁴

Study shows that after the diagnosis of aids, women face personal difficulties, social and family because they live the anguish of silence, to hide your diagnosis trying to keep the marital relationship, the contact with family or getting pregnant. With the revelation of the diagnosis, can experience prejudice, rejection, family and domestic violence.⁵

Other research shows that the maintenance of affective-sexual relationships of people with HIV is associated with better quality of life, although sexuality is something quite compromised by impact of HIV seropositivity and the emotional and social consequences as social isolation, deterioration of interpersonal relationships and low self-esteem.⁶

Important changes can occur in the lives of infected individuals, emerging new needs for their understanding, coping, and expanding those that already exist.⁶ fear of HIV transmission to the partner and the maintenance of safe sex is also present.⁷

In this way, live with HIV can contribute to the isolation of the people, which are being rejected by family and feature afraid to face prejudice, leaving them susceptible to other problems, such as loss of employment and dependency in the family.⁸

Although the literature come addressing about the quality of life of women living with AIDS, under various aspects, including topics such as sexuality, treatment, involvement with drugs, abortion and TV. Despite this research, address some of the aspects mentioned, it considered relevant to investigate on the impact that the presence of this disease causes in women's lives in a reality of a region characterized by gender inequality with greater women's exposure to HIV/AIDS. From this, it was objective of the present study: understanding the impact of HIV on the daily life of women living with AIDS.

METHOD

Qualitative research developed from May to June 2010, into a center of Information on STD/HIV/AIDS and viral hepatitis (CIDHA) of a semi-arid Northeast city, located in the State of Bahia, with the participation of 11 women living with HIV/aids.

To select the participants applied inclusion criteria: be in monitoring in CIDHA, having more than 18 years, maintain, or have maintained intercourse after HIV infection.

Data collection occurred through semi-structured interview, individually and with open-ended questions in placeholder in CIDHA. The interviews recorded on audio and transcribed in full. The issues covered information about the repercussions of aids diagnosis and living with the disease.

The data analyzed by Content Analysis, following the three stages of organization, whether they are pre-analysis, exploration of the material and the processing and interpretation of data. In the first step, the information is organized according to facilitate analysis. On Monday, are the exploration of the material, the encoding, and the formulation of data collected. In the third, the data controller, gathering the data according to the Division of the theme categories, which are discussed as a theoretical support.⁹

The research approved by the Committee of ethics in research under the 1780/2010 number of Integral Medicine Institute Professor Fernando Figueira de Recife/PE. All women signed an informed consent in two ways, getting a copy in possession of the researcher and another with the participants of the survey. Been complied with other ethical precepts of the resolution 196/1996.¹⁰

It should be noted that the anonymity of participants guaranteed, being women participants identified by the letter M followed by a numeral in ascending order from one to 11.

RESULTS E DISCUSSION

Group of 11 women participating in the survey, with time of diagnosis between one to 12 years. The form of contagion was exclusively by sexual intercourse, and for five women, through transmission of ex-husbands, for two by spouses, an ex-boyfriend, a, in extramarital relationships and two reported not knowing how the transmission, because they are sex workers and don't have regular partner.

In the period of the survey, only three women had regular partner, infected by them. About the seropositivity science, the discovery occurred in different modes, four women found being HIV seropositive after receiving diagnosis of the companion, led him to seek assistance; four discovered during prenatal care; two were informed by relatives of the partner he was infected, leading them to take test and prove the diagnosis; one of the women discovered seropositivity in presenting symptoms, requiring health monitoring.

From these experiences of women participants of the survey, it identified that the impact of HIV/AIDS on women's daily life can understood through the categories: Sexuality of women living with AIDS, ambiguity of feelings and the combat against HIV/aids by the woman.

Sexuality of women living with AIDS

The discovery of HIV seropositivity is a traumatic experience and can cause distress largely associated with the fear of death, stigma, and prejudice. For women interviewed occurred changes in your sexuality, among them decreased sex drive and the frequency of relations or rejection by partner.

Changed once, at the time of the pleasure I changed more. When I will have, the pleasure is already almost out of grace and before I was happier, I was more active, I am not going to lie. I liked today do not like anymore, but I do. (M1)

Did many programs and come out to various places to make them and much has changed today, before used to do a lot more. (M2)

He does not kiss on mouth, no affection no, it is just so behind and ready, I do not like it. (M3)

Have difficulty having intercourse, I think if it was not for that, I would not have this disease that is why I am not in the mood. (M5)

Women to know their way of HIV transmission was sexual, create a stigma against sex, losing libido and demonstrating a sense of guilt and repentance for oversight on prevention. Sexuality is an issue compromised by HIV seropositivity and the emotional and social consequences associated with this diagnosis.⁶

Taking as reference the science of diagnosis, the sexual act was unlinked affect occurs. However, for women, sexual intercourse goes beyond the physical contact, with subjective meanings and longings as feel valued and attractive, important aspects to start a sexual relationship.

In this sense, infers that the link with the partner needs to strengthen through dialogue, coupled with mutual respect and affection in order to achieve the balance Board, providing a pleasurable relationship and satisfaction of the physical and emotional needs of both.

Despite the negative effects of seropositivity for HIV, there are women who sought work psychological aspects, managed to reverse them, improving sexual performance through new discoveries made by the couple after diagnosis of HIV. Knowledge about your health condition coupled with the strengthening of affective ties made these women rediscover their sexuality.

Changed a lot, now I feel like I'm dearly loved, and my current partner every time he says: I love you, you're the woman of my life. (M6)

I thought it was going to change a little, or else he wouldn't want me, but it was quite the opposite, got better and he told me he still accepts me the way I am. (M4)

We are having a spicier relationship, a relationship hot, more loving and that until then had not. (M7)

On the testimonials of women Note that face sex with naturalness after seropositivity for HIV can make emerge the pleasure as a truth manifested in the couple's sex life, providing these, sexual and affective experiences never before proved.

With the increased incidence of HIV infections, the conviviality of couples with different serologies comes becoming common, which reveals the possibility of support of the affective-sexual relationships with the presence of HIV, since this is a fundamental aspect for the quality of life of this people.⁶

In this way, share the diagnosis with your partner is crucial to the fight against the disease, because it makes it possible to express the anxieties and insecurities, as well as solicit or receive emotional support and care, promoting the discovery of new sexual experiences.¹¹

Women also highlighted that the personal and social responsibilities have increased after diagnosis of HIV positive. The virus infection had in the emergence responsibility on yourself takes care of themselves as a means to ensure its longevity, depending on the care they dispense themselves. Responsibility with the other arises as a way to prevent the spread of HIV and protect the partner of the illness.

It is a responsibility, because you have to take that medicine, you have to have medical follow-up, have to be careful because it may develop other diseases. (M5)

Today I feel responsible, use a condom to pass to other people, and talking about it is hard. After I got the blessed (aids), I warn. (M8)

If you have that disease you have to protect that person who you like, it is a responsibility. (M9)

The aids effect on female sexuality represented by self-care, women started to enhance and ensure more for health and partners. It reveals that one of the aspects of sexuality, sexual intercourse, modified, because they use a condom and make regular use of medication and over the years, the presence of the virus in the daily routine has become imperceptible.

The changes in the daily lives of women related to self-care after diagnosis of HIV, showing the desire to live, in spite of chronic illness with which will have to live with. The role of nursing in dealing with women with HIV/aids involves guidelines that focus on the achievement of healthy habits of life and leisure and accountability by the care of the self and the other.¹²

Another point is that the serum disagreement on HIV/AIDS demands of couples, dealing with difficulties related to intimacy, front the possibility of transmission of HIV to the spouse a great skater. In these cases, points out the necessity of interdisciplinary teams to persons with HIV/aids and their partners, in order to offer full assistance to serodiscordant sexuality.⁷

Before testimony can said these women's sexuality has reached. For some, there have been improvements in their marital relationships with the structuring of responsibilities, however, most interviewed revealed that sexuality HIV carriers is anchored in the sexual act itself, which was adversely affected.

For repercussions may modified, it is necessary a work aimed at this audience, so come and demonstrate the possibilities that exist to provide pleasure and satisfaction, in addition to demystify some taboos still prevalent. Address the issue HIV/aids among women is delicate, since debate requires raising issues related to marriage, maternity, sexuality, the relationship of gender and other intimate aspects.

Ambiguity of feelings in women living with AIDS

Among the repercussions caused by the diagnosis of HIV positive is the emergence of feelings that permeate the lives of these women, like trust, anger, fear, and guilt.

The trust considered the basis of some affective relationships, a preponderant factor in the success or failure of relationships and trust in fellow facilitated the revelation of the diagnosis, as described by M4 that lives with HIV/AIDS for 11 years:

Trust is something you have to say gradually, not immediately, because you have to conquer. He earned trust and I said about the disease for him, and he accepted the way I am. (M4)
Who does have the partners trust each other! (M8)

The presence of trust in relationships considered essential to ensure that women could have fullness in their emotional entanglements, once an extended relationship requires a level of intimacy and knowledge between the couple, the course of this process, the security that a partner forwarded to another.

Another sentiment evidenced in the testimonials of women was the grudge by its partners due to them having it transmitted HIV or do not accept your condition, representing the frustration by the lack of support they expected to have to his companions.

If I feel love, I feel no more, I feel is mad at him, because he gave me this. (M9)
After I knew changed, I was disgusted to kiss his mouth, had relationship, but no kissing. (M4)

I want to have relationship with him and he does only when he wants then I get very upset, angry. He will not kiss, not even an affection at all; is the hatred that I have of him. (M3)

The feeling of anger by the participants was associated transpired at implications of seropositivity in their daily lives, among them, the non-acceptance of the situation of health and loss of confidence in the partner, when they were contaminated with it, passing the demonstrate an aversion to sex with this person.

Study reveals that the marital relationship institutionalized refers to the guarantee of safe sex, whereas the relation known and you will not post the spouse at risk. This thought implies in not adopting the use of condom by the couple. In addition, the time of relationship is important for the development of confidence in the partner. In this way, the longer the time of closeness, the lower the requirement for condom use.¹³

Fear already reported by women triggered from the diagnosis of HIV. This fear quite present in the lives of these women can be related to ignorance of the ways of transmission of the virus and discrimination or the possibility of its new health condition be discovered by society.

I am afraid to infect others, afraid to kiss, even though it does not pass, I am afraid, I am very silly still. (M10)

Fear of not accepting person, afraid to spend, to be pointed: "Was that the guilty." (M11)

Because at the time of the relationship I have fear of the other person know what I have. You get that fear that he finds out one day and do something against you. (M4)

Often, the trial society front to people with HIV/aids comes with discrimination, because they see as epicenes in their sexual relations, which would justify its contamination with HIV. Study showed that HIV seropositivity makes the person feel as someone dangerous to sexual partner, and can trigger fear of transmitting HIV, anxiety, guilt and anxiety in infected spouse, interfering on sexuality.⁷

In addition, the seropositivity for HIV constitutes a constant threat both physical and psychological, which harms social relations, Yes, every meeting, there is fear of the unknown, leading to denial and fear for an opening of a new world. The fear of investing in new relationships expressed as another impact of HIV, which happens due to the prejudice of many people.

You know that the bias is very large, if you open your mouth to speak: "I am a carrier of the HIV virus," think of taking your hand grip, a kiss on the cheek here, and then I'm afraid. (M6)

I do not think I will find another partner, because if you have to speak up and nobody is going to want someone just like me, I think everybody wants someone healthy. (M1)

When I step out on the street and these people are as "Hey Brunett Babe" I speak not rolls, I cannot. I have some flirting, but I am still in my little corner. (M8)

In this study, it noted that communicate the status of the HIV carrier to society opens pathways to possibility of suffering prejudice or partner be singled out as a person marked by something bad, usually associated with death, leading his wife to fear of socializing.

The stigma that surrounds aids promotes the serological silencing as a protection mode, not to suffer discrimination and prejudice, which can enhance the evolution of the disease, implying also on non-adherence to treatment. HIV infection transcends the biological dimension reflecting socially in the life of the person who has aids. The main repercussions highlighted by the prejudice and discrimination that these people suffer, which may be obtained from the family, social or professional environment.¹⁴

The guilt manifested itself after diagnosis, when they began to reflect about the behavior that had in the past, if "self-condemned" for his health situation, as outburst of M9:

I feel that if I have a relationship with someone else I will put her disease as well and let it sit. Oh my god! I got involved with this. How silly I was, and now what's it going to be? (M9)

The fault is the demonstration of repentance of women for not having protected against the virus, being that this sentiment impairs their social relations and their mental health. The repercussions on living with HIV/aids highlighted by guilt, which reflects the perception of responsibility to take care not only of themselves but also of companions who does not have the affliction in order not to pass it on to people considered innocent.

It is worth mentioning that when this feeling considered an obstacle to social and personal activities, one can approach it through therapies that aim to reflection and minimization of fault, for the acceptance of his health condition.

The combat against HIV/aids by woman

The confrontation of HIV for women shows that some seek to support bases to support the illness, like religion or the acceptance of the diagnosis as another illness that demand attention.

I am expecting a work of God. He is so wonderful that I do not know I have faith that something good can happen. I ask God for strength not to drop me into depression. (M10)

I live with the virus like the flu, take a pill, and I am cure. I know there is not a cure, but we have to try to take care and I take care of myself too. (M6)

Women believe that religion can help them overcome the barriers imposed by the disease, with the discovery of the will to live, the redefinition of personal relationships, the perception of the meaning of life, the reevaluation of opinion about death. Religiosity seems to benefit the fight against disease, because they provide feelings and comfort, a feeling of strength, facilitating the acceptance of the disease and relief from fear.

The spiritual comfort from religiosity minimizes the biopsychosocial impact of HIV infection. Nursing to come across with the religious dimension of women should recognize it as an ally in the therapy process, considering it during the planning of assistance, with a view to improvement of quality of life according to the reality of this women.¹²

Women with HIV/aids face unique challenges as disease-related stress and aids adaptation. Health professionals need to be aware of existing individuality in the case of each woman with HIV, encouraging the use of stress-fighting resources to aid in adaptation, which can slow disease progression and improve quality of life.¹⁵

Still, much work needs to be done in order to advance not only in anti-retroviral drugs therapies, but encourage the promotion of psychological support and the breadth of psychosocial stress, since this can be a threat to mental and behavioral health of women with HIV/aids.¹⁵ thus, there is the need to meet the circumstances of life, efforts, social and spiritual support, self-esteem and perceived quality of life, i.e. the context of confronting the health condition in order to improve resilience strategies.¹⁶

Some women face treatment as essential to maintaining your health. They learn to live with the disease creating coping strategies, ranging from acceptance of their condition to focus their attention on other aspects, seeking to forget the presence of HIV.

Face to face, face even. You have to watch your back, always prevent taking the medication, and the more I conform will have more years of life. (M4)

I face well, hell; I might even want to get a new partner. The person gets scared, but still wants a new experience. (M11)

The follow-up of drug treatment for women who accept the disease represents the will to live and the creation of life prospects for the future. Study asserts that in order to achieve a greater lifetime women adhere to treatment through a behavior that involves adaptation, psychological adjustment, and appropriate care during HIV infection, preventing any living conditions that affect adhesion.¹⁷

Changes in life habits aimed at improvement of quality of life after diagnosed HIV-positive to HIV through the overcoming of losses caused by infection.¹² one way to rebuild the life project after infection by HIV/aids in the perception of women involves the establishment of new romantic relationships. Often, the desire to start new relations anchored the women's posture against the treatment, because it aims to be able to share with the new partner happy times or difficult.

The process of confronting the new health conditions of women with HIV/AIDS directly linked to the expression of their health situation without fears and prejudices that will reflect directly on possible relationships that they may have. Although some of the interviewed revealing, the desire of having new companions, in their speeches watched himself fears and uncertainties.

CONCLUSION

This study made it possible to know the impact that HIV/aids cause women met in a center of reference. According to the literature, it noted that there are no significant differences of the repercussions that women who not accompanied by experience.

The presence of HIV/aids has on women's sexuality in general negative way, leading them not want to have sex. The disease weakens the relationship with the partner, which may even host women's repudiation. On the other hand, this study may obtain statements, which revealed that the illness strengthened the affective relationship of the couple, through new discoveries to sexuality. In these couples, the women presented a sense of

responsibility with the treatment, expressed by take care of herself and her partner, preventing the transmission of HIV when he was a great skater.

From this, it believed that health care professionals should encourage the couple to create new ways of dealing with their sexuality. Dialogue on this theme may not be easy, requiring professionals to rebuild your opinion about couples who have HIV, to offer an open conversation, free of prejudices.

Another aspect highlighted by the research was the emergence of feelings like trust, anger, and fear, guilt, awakened in women after diagnosis of HIV positive. Confidence in the partner facilitated the revelation of the diagnosis and the emergence of support in this crisis. Already the rage, fear and guilt, negatively affect the lives of these women, interfering in the acceptance of the disease, in their psychological conditions and following their lives.

On these occasions, it is necessary forwarding of women with HIV/aids to the multidisciplinary team to work the negative feelings, the possible discrimination and if possible, address the relationship of the couple.

The combat against HIV/aids by the woman permeated by strategies designed to endure the pain of being a carrier of this disease. Religiosity, acceptance of the condition of illness and focus on other activities were ways found by participants of this research to tackle HIV and whole load of prejudice and stigma that permeates this disease.

The debunking of taboos that exist about contagion, the disruption of their own prejudices, fears, and minimization of heat causes the woman to develop courage to start a new relationship, in which she seeks support to live with the disease. From this, health professionals should encourage women to begin new relationships after HIV infection, guiding them on the prevention of the transmission of the virus and the importance of follow-up treatment.

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