

Life changes among women with the Acquired Immune Deficiency Syndrome*

Alterações na vida de mulheres com Síndrome de Imunodeficiência Adquirida em face da doença

Alteraciones en la vida de mujeres con Síndrome de Inmunodeficiencia Adquirida frente a la enfermedad

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ABSTRACT

Purpose: To describe life changes among women with acquired immune deficiency syndrome. **Methods:** The study was conducted in Fortaleza, CE with 10 women from December 2004 to March 2005. Data were collected through taped interviews regarding women oral history of their physical alterations, changes in daily life and life-style, and experiences with sexuality. **Results:** Data were organized by themes. Women verbalized difficulties and conflicts regarding the need to hide the diagnosis of acquired immune deficiency syndrome because of prejudice and shame, constant expectation of death, alterations of their body, life-style change, altered sexuality, feeling guilty, stigma and prejudice regarding the disease. **Conclusions:** The findings suggest that women considered the stigmatization changes. There is a need for health care services that promote support to women with acquired immune deficiency syndrome and their family to cope with the diagnosis and its management.

Keywords: Acquired Immunodeficiency Syndrome. Women's health; Prejudice.

RESUMO

Objetivo: Aprender as alterações vivenciadas pelas mulheres portadoras de Síndrome Imunodeficiência Adquirida em decorrência da infecção. **Métodos:** Realizado em Fortaleza-CE, no período de dezembro de 2004 a março de 2005 com dez mulheres, utilizando-se entrevista gravada na modalidade de história oral temática, abrangendo alterações físicas; mudanças no cotidiano e no estilo de vida; e vivenciando a sexualidade. **Resultados:** Os dados foram organizados em temáticas e as mulheres relataram dificuldades e conflitos tais como: a necessidade de ocultar o diagnóstico por medo de preconceito, vergonha, a relação constante com a morte, as alterações no corpo, as mudanças no estilo de vida, a sexualidade alterada, as culpas auto-atribuídas, o estigma e a discriminação enfrentados. **Conclusão:** As mulheres consideram as mudanças estigmatizantes e recomendou-se que os serviços promovam um ambiente de apoio para essas mulheres e sua família, mediante desenvolvimento de estratégias passíveis de ajudá-las no enfrentamento do vírus da imunodeficiência humana/Aids. **Descritores:** Síndrome de imunodeficiência adquirida; Saúde da mulher; Preconceito.

RESUMEN

Objetivo: Aprender las alteraciones experimentadas por las mujeres portadoras del Síndrome de Inmunodeficiencia Adquirida como consecuencia de infección. **Métodos:** Realizado en Fortaleza-CE, en el período de diciembre de 2004 a marzo de 2005 con diez mujeres, utilizando entrevista grabada en la modalidad de historia oral temática, abarcando: alteraciones físicas, cambios en lo cotidiano y en el estilo de vida, y, experimentando la sexualidad. **Resultados:** Los datos fueron organizados en temáticas y las mujeres relataron dificultades y conflictos tales como: la necesidad de ocultar el diagnóstico por miedo de prejuicio, vergüenza, la relación constante con la muerte, las alteraciones en el cuerpo, los cambios en el estilo de vida, la sexualidad alterada, las culpas auto-atribuidas, el estigma y la discriminación enfrentados. **Conclusión:** Las mujeres consideran que los cambios estigmatizan y se recomendó que los servicios promuevan un ambiente de apoyo para esas mujeres y su familia, mediante desarrollo de estrategias que puedan ayudarlas en el enfrentamiento del virus de la inmunodeficiencia humana/SIDA.

Palabras clave: Síndrome de inmunodeficiencia adquirida; Salud de la mujer; Prejuicio.

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INTRODUCTION

The third decade of the Acquired Immunodeficiency Syndrome (AIDS) epidemic shows a growing commitment of individuals and includes scarce financial resources, low level of education and an increase in the number of cases in women and adolescents. Moreover, there is the steady growth in the number of cases in cities with a small population. These situations justify the fact that the human immunodeficiency virus/AIDS is more associated with poverty, women, adolescence and the countryside in Brazil.

In particular, the increase in the number of AIDS cases in women is a cause for concern, as it means the possibility of children becoming infected by vertical transmission, as a result of the virus being transmitted from mother to child during pregnancy, at the time of birth or through breastfeeding.

As seen in reality, although the AIDS epidemic has grown among women, few studies have helped to improve, in a broader dimension, receptiveness and care for women with this syndrome, as well as the clinical treatment of the infection in this group⁽¹⁾. As shown in the literature, women, especially those who do not use drugs and those with only one partner, did not see themselves as vulnerable to the disease. However, according to what has been revealed by statistical data in the last decade, there has been an increase in the number of sexually transmitted cases reported among women⁽²⁾.

In addition to this, seropositive individuals reported stigmas experienced due to AIDS, a great part resulting from information that involve prohibited sexuality, fear of the imaginary, taboos and the imminence of death, among other things⁽³⁾. Furthermore, infected individuals are still rejected by health services, deprived of employment and housing, avoided by friends and colleagues or prevented from entering certain countries⁽⁴⁾.

In this sense, AIDS has revealed the importance of respecting differences and questioning prejudices, fears and taboos in view of this diversity. The AIDS problem is not restricted to information or the lack thereof, once, as observed, it challenges the field of science, technology, education, gender, class and social groups, among other things⁽⁵⁾.

Individuals with HIV/AIDS face a set of specific problems. Many have to live with the stigma and discrimination, especially in countries with high prevalence, where HIV reaches a great number of individuals. In general, when reporting about their infected state/condition, individuals are reticent, thus helping to increase feelings of isolation⁽⁶⁾.

For those with this disease, the diagnosis is always a shock and leads to traumas of a physical, emotional and social nature. Because of all this, there are all types of reactions. Yet, the way one will react to these changes depends on several factors, among which are one's personality and social and family context⁽⁷⁾.

Upon discovering the diagnosis, women with AIDS

experience feelings of uncertainty and insecurity. Such feelings also cause them to experience a moment of crisis.

By working with participatory care in a health-disease situation, questions about AIDS enabled this investigation, followed by other important purposes, such as the contribution to the unfolding of this issue of key academic-humanitarian interest. The present study aimed to understand the changes experienced by women infected with AIDS.

METHODS

The present study is characterized as qualitative, descriptive and exploratory. The place of study was a public hospital infirmary specialized in infectious contagious diseases in the city of Fortaleza, CE, Brazil, between December 2004 and March 2005.

A total of ten women with AIDS participated, whose inclusion criteria were as follows: to have been admitted to a hospital unit; to be aged 18 years or older; to have a confirmed diagnosis of AIDS; and to consent to voluntarily participate in the different research stages. The number of participants was determined by saturation of information, i.e. data repetition, in addition to its meeting the questions and objective of this investigation.

The method of thematic oral history, proposed by Meihy⁽⁸⁾ and Correa⁽⁹⁾, was employed and a recorded, semi-structured interview was used for data collection. This method provides resources for the researcher to clarify and obtain opinions about this issue, enabling women to be free to report their life experiences.

The interview guide was comprised of guiding questions about personal identification, clinical data, discovery of diagnosis, life with the disease, physical changes resulting from the infection, sexuality, feelings and situations experienced. Interviews were concluded with the recurrence of data, which were found to be satisfactory to meet the proposed objectives.

The process of change of oral reports into written records was adopted for data analysis, according to the following sequence of review of interview: transcription; transformation into text; transcreation; and review by interviewee⁽⁸⁻⁹⁾.

Bardin's methodological framework⁽¹⁰⁾ was adopted to treat the information obtained, as it describes the content analysis with a technique of investigation that aims to describe, systematically and quantitatively, the content manifested by communication. This is comprised of three stages: organization and systematization of ideas; material exploration, corresponding to the systematic change of crude data in the text, per section, cluster and enumeration, aiming to reach a representation of its content or expression and, as a result, the understanding of the text; and treatment of results, inference and interpretation. Reports were analyzed and categorized by inference to similar contents, with the following categories being

formed: Physical changes; Changes in routine and lifestyle; and Experiencing sexuality.

The present investigation is part of a broader research project whose formal process followed the norms of the *Comissão Nacional de Ética em Pesquisa* (National Research Ethics Committee). Initially, the proposed study was sent to the hospital's *Núcleo de Assistência, Ensino e Pesquisa de Enfermagem* (Nursing Research, Teaching and Care Center) for its Nursing team to be well familiarized with it. Next, the project was authorized by the *Direção Geral do Hospital* (General Management of Hospital) and approved by the institution's Research Ethics Committee, under protocol 033/2004.

An Informed Consent Form was signed by all women, as recommended by the legal precepts of Resolution 196/96⁽¹¹⁾. In order to keep secrecy and anonymity, each woman was named after a flower.

RESULTS

According to data found, women with AIDS participating in the study follow the epidemic profile, i.e. they are young, they work as housewives, they have been infected by stable partners, they live in impoverished households and they have a low level of education (Figure 1). These women did not see themselves as vulnerable to HIV, especially because they were faithful and dedicated to their home and family. The majority only became aware of the infection as a result of the discovery of their partners' seropositivity.

As shown by daily routine, living with AIDS causes changes in the lifestyle of many women. These changes can occur from transformations in the physical body, changes in sexual and social relationships or in other aspects. Such situations were observed in this study and reported as follows, according to the issues identified:

Physical changes

As observed in the present study, changes in the body resulting from the disease greatly upset these women and affected their self-image and self-esteem. Based on the following reports,

these statements were confirmed:

[...] I noticed changes in my body, which got weaker, with bruises and marks, and now I feel very bad for this [...] (Orchid).

[...] I'm sick the whole time, I've lost a lot of weight and this change in my body bothers me. I'd like to recover my normal body [...] (Rose).

[...] My body's changing. I look thin and weird and people begin to make comments. I only know that I'm already rejected and harmed at work like this [...] (Daisy).

For these women, the situation becomes worse, because, in addition to having to live with the awareness of their AIDS status, the disease may be followed by physical changes in the body that mark and characterize this disease even further. At the same time, weight loss causes them to feel listless and the skin spots reveal the presence of AIDS, the certainty of condemnation.

Changes in routine and lifestyle

The daily life of women in the study was affected by the discovery of AIDS. Many had to leave their jobs, restrict their activities to the home and stop doing pleasant activities, due to manifestations of the advanced stages of the disease. These losses were also associated with physical impairment and contributed to increase feelings of anguish and depression. Sometimes, they feel useless as they cannot perform certain activities, which had been considered part of their routine until then. Based on the following reports, these statements can be understood:

[...] before the diagnosis, I liked to go out. Now, I don't go anywhere, and if I weren't so strong, I would've lost my will to live as well [...] (Jasmine).

[...] after I found out about this disease, it was all over, I don't feel like doing anything, but to lie down. My life sucks now, I only take pills, I don't feel like doing anything in life anymore [...] (Hydrangea).

[...] my life's changed, I got sadder, disheartened, I don't believe I can

Table 1. Characterization of women with AIDS, Fortaleza, CE, Brazil, 2005.

Name	Age	Marital status	Time of diagnosis (years)	Category of exposure*	Occupation	Reason for hospitalization
Rose	28	Single	4	Sexual	Housewife	Furunculosis
Orchid	21	Single	18	Blood-related	Housewife	Therapeutic adequacy
Daisy	20	Single	1	Sexual	Housewife	Fever of unknown origin
Wake-robins	30	Married	2	Sexual	Maid	Headache
Violet	26	Married	2	Sexual	Manicurist	Herpes Zoster
Jasmine	29	Single	3	Sexual	Farmer	Kaposi sarcoma
Hydrangea	34	Separated	1	Sexual	Seamstress	Visual changes
Bromeliad	39	Married	3	Sexual	Maid	Facial cellulitis
Poppy	49	Widowed	7	Blood-related	Maid	Tuberculosis
Petunia	50	Separated	15	Sexual	Seamstress	Pneumonia

* In the present study, the following were considered: sexual = heterosexual; blood-related = blood transfusion.

live a happy life anymore. I like to live around many people and what makes me happy is to be among friends, playing, talking, smiling. But, now, I'm shunned by others, they don't approach me. It's very hard to be in a place where people don't want your presence, so I prefer to be alone [...] (Poppy).

Living with the disease caused these women to undergo changes in their employment status. Leaving work was observed, in addition to limitations to perform household chores. Such situations represented a moment of deep crisis and social stress and caused significant losses for those who live with AIDS, as revealed by the following reports:

[...] since I found out about the disease, I've been worried all the time, now I know I can get sick at any moment and won't be able to work [...] (Wake-robin).

[...] now, I only live at home, I've quit working because I used to wash other people's clothes and then they began to feel afraid to be infected and stopped asking for my services [...] (Bromeliad).

In addition, there was a change in routine that resulted in regular health surveillance and permanent care to try to maintain one's well-being. This constant care usually causes them to feel irritated, as they feel different from other people, who do not need to live under such stress and the condition of being stigmatized due to their infectious disease.

Experiencing sexuality

When the issue of sexuality is approached and women become aware of the risk of their transmitting the disease to another person, as well as the risk of their being re-infected, this possibility bothers these women, causing them to abstain from sex and any type of relationship, as shown by the following reports:

[...] just to know that I can transmit this disease to someone else makes me feel bad. That's why, after I found out I had it, I didn't want to have a relationship with anyone [...] (Rose).

[...] I'm really afraid of infecting someone else [...] (Bromeliad).

[...] since I found out about my diagnosis, I haven't felt like going out with anyone. I don't want to spread this disease [...] (Daisy).

According to what some women reported, they were guided on safe sex practice. However, they mentioned distrust in male condoms and, despite the guidance, preferred to avoid any romantic and sexual involvement out of fear of infecting their partner:

[...] I've already been instructed on safe sex practice. Still, I don't want to do it. I'm afraid, even with the condom, and don't want others to

have this disease I have [...] (Jasmine).

[...] even though I was instructed, during the consultations, on sexual relations and preventive measures that can be adopted, I rejected all sexual practices to be safe [...] (Hydrangea).

In the speech of one of the patients, infected as a child, she reported a lack of interest in having a relationship with someone. This woman was against a sexual life, as shown in the following report:

[...] I feel upset knowing that I can infect other people. If this ever happened, I'd cry a lot and apologize. I feel really bothered by this situation [...] (Orchid).

This patient was found to feel insecure about the issue and, throughout the interview, mentioned being afraid of infecting others. According to what was observed, she had not been guided on safe sex practice. Her fears and tension towards this issue were so great that she avoided speaking about this and expressed her feelings by crying.

DISCUSSION

The AIDS diagnosis is a threat to the physical body and it has often been impossible to assess its repercussions in terms of the depth and level of implications in women's lives. As observed in the literature, the body represents one of the key dimensions in the experience of living with AIDS⁽¹²⁾.

AIDS causes varied symptoms, from constitutional manifestations, such as diarrhea, fever and weight loss, to opportunistic diseases. However, one of the symptoms that most affects patients is weight loss, viewed as a worsening of their health condition and imminence of death⁽¹³⁾.

In addition, body changes resulting from the disease cause a series of problems and insecurities, once they represent the certainty of the end for these women. This is comparable to a slow "deterioration". Moreover, in terms of physical changes due to the majority of women in the study being young, there is a concern about body aesthetics, which, in their case, begins to differ from the standards required by society. There is also the concern that thinness, characterized by the scarce subcutaneous fat development or nutritional loss, shows that they have HIV/AIDS.

In addition to the disease symptomatology, physical appearance reveals in these women the condition of being infected with the virus. These changes cause innumerable consequences, such as loss of employment, a fact that contributes to worsen the clinical picture and to raise one's awareness of their dependence on others to seek their own survival and that of their children⁽¹⁴⁾.

In view of the reports resulting from the disease and the changes in routine and lifestyle, women explained how their life had been since finding out about the disease. They reported

how everything had changed and how they had stopped doing what used to be routine, such as daily life activities, leisure and relationships. In summary, these women do not live as intensely as they used to.

Apart from the changes in lifestyle, changes in their way of being and in the feelings experienced were observed. Sadness, disappointment and hopelessness start to be present in their routine, causing them to be isolated and sometimes depressed. These feelings and emotions are corroborated by a study that aimed to identify feelings experienced by women with AIDS, after receiving the confirmation of diagnosis⁽¹⁵⁾.

By speaking of their lives before and after finding out about the virus, amid tears, they expressed the feelings involved with living with AIDS and reported significant changes in their lives: they stopped performing activities considered routine until then and restricted their lives to their homes. These situations may indicate a path to self-prejudice and the limitation of abilities and attitudes needed to face the problems affecting their health.

Leaving work and being exposed to discrimination cause problems, not only of an economic, but also of a psychological nature. For a woman infected with HIV, work symbolizes a type of personal achievement and fulfillment of the desire to fight for life, the moment when she is disconnected from the context of the disease⁽¹²⁾.

Associated with the different losses resulting from the infection, this disease causes infected women to be marginalized, stigmatized and labeled as “incapable” by society.

In addition to the different situations related to changes of routine and lifestyle, such as the difficulty to live with a stigmatized and incurable chronic disease, loss of employment, loss of enjoyment during leisure time and impaired domestic activities, among other circumstances, women also revealed feelings of fear, insecurity and indignation in their routine, causing them to be isolated and lonely. These feelings and values are considered by them as a response to the new reality experienced in the different spaces of society.

The issue of sexuality is directly associated with the disease, because it is the most frequent cause of transmission and also because of the culture of marital fidelity. For some women, sex was experienced as a form of pleasure and as a way to see themselves as attractive, in contrast to old-fashioned cultural reasons that considered sex to be linked to reproduction. In certain times and cultures, pleasure was repressed, once it was considered sinful or morally wrong⁽¹⁶⁾.

Currently, sex is part of people's routine, not limited to conception only, once human pleasure is independent from reproduction. Sex also involves organic aspects, with biopsychosocial factors being associated with it⁽¹⁶⁾.

Apart from the purposes of reproduction and search for sexual pleasure, sexuality also includes the need for love and well-being. It involves knowing oneself as an individual and the

reactions and feelings resulting from the interaction with the other.

As observed, living with the disease causes these women to suffer and to feel ashamed and afraid, once they are aware they could transmit the disease to other people. At the same time, these feelings lead them to avoid any type of sexual involvement, preferring sexual abstinence to the risk of transmitting the infection. This type of behavior and awareness shown by them can lead one to think that they develop a critical sense and respect other people's health. In view of this observation, a more effective participation of these women could be a great advance to problem resolvability in public health services, especially those related to sexuality.

The fact that these women have been, almost exclusively, infected by sexual contact causes them to feel afraid and ashamed and to experience strong lack of interest in sexual activities, abstaining from sexual relations⁽¹²⁾.

Fear creates a source of stress in the history of life of these women, especially because it interferes with their quality of life. As a result, some even lose their “sexual appetite” or feel less sexy.

When faced with a diagnosis of seropositivity to HIV, women consider themselves to be AIDS victims, through a relationship with their partners in which they see themselves as innocent and betrayed, almost never as participants or cooperators of a type of relationship. Despite these feelings, inequalities in relationships between partners prevent them from having a reaction of indignation and effective rupture from a culturally acceptable pattern of relationship with these partners⁽¹³⁾.

Among single women, there are reports of the fear felt when informing their new partner about the diagnosis. They mentioned the fear of being abandoned as a result of the infection, because, by deciding to have a romantic relationship, they face the fear of being rejected by the other, when he learns about her diagnosis. In addition, they face the difficulties in negotiating the use of a condom.

The fear of not being accepted by their partner or even the risk of losing him causes certain women with AIDS to use a resource frequently used by men as regards sexual life: silence. Not revealing their condition of seropositivity is their weapon against male power. At the same time, especially when beginning a new relationship, they will face additional difficulties resulting from mutual unwillingness to use condoms⁽¹³⁾.

In agreement with this thought, nurses are those responsible for identifying the appropriate moment and maintain a bond with the patient to talk about the exercise of her sexuality. To achieve this, they are in charge of counseling the patient on the choice of contraceptive methods, the implications of a sexual relation without a condom and their social responsibility. Moreover, they should also emphasize the importance of a sexual and affective relationship, contributing to their self-esteem and quality of life⁽¹⁷⁾.

In view of what has been shown, professionals need to provide specific care to these women, who are exposed to several problems, not only due to their finding out about the diagnosis, but also due to the different issues and aspects involved with living with AIDS. Among these aspects, inherent in the disease, is the issue of sexuality, frequently mentioned by patients as a source of stress, interfering with these women's quality of life.

CONCLUSIONS

Throughout the present study, the relevance of approaching and understanding the changes experienced by women with AIDS, due to this disease, was found. Thus, touched by this issue, nurses will be able to contribute to the improvement of nursing care for those infected with HIV. As previously explained here, different changes in the life of these women were observed, which were mainly associated with physical body changes; changes in routine, resulting from impositions on them to live better with the disease; and unpleasant experiences of expression of one's sexuality.

In addition, these results enabled researchers to conclude that the different stigmas experienced prevented women from living in a natural way, free from any form of discrimination, once this is a right that should be respected, especially when dealing with people who already experience several negative

feelings, as a result of living with the infection.

Understanding the complexity of the issues related to the spread of AIDS in women is not a simple task, because it involves the stereotype of a shameful disease, strongly associated with morally and socially undervalued connotations.

This shame follows women with AIDS and intensifies their feelings. During interviews, there were moments of great emotion, both for the women narrating their experience and for the researcher, who listened to them and shared this situation of reliving difficult and tense moments.

In view of this perception, the creation of services that promote an environment of support for these women and their families, using strategies aimed at helping them to face the changes imposed by AIDS, was thought to be crucial.

Health professionals are responsible for becoming aware of this issue and clarify different aspects for these women. To achieve this, they must provide personalized care, once the inequalities experienced by them are diverse. A bond between client and professional should be considered, so that trust enables them to provide due care, attempting to improve the patient's quality of life.

It is hoped that the purpose of the present study has been achieved, although other studies will be able to clarify the ways in which health service professionals should perform and how women could use their cultural and social potential to face this disease and to achieve preventive means.

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