

Caring for women with HIV/AIDS: an interactionist analysis from the perspective of female healthcare professionals



Cuidando de mulheres com HIV/AIDS: uma análise interacionista na perspectiva de mulheres profissionais de saúde

Cuidando a mujeres con VIH/SIDA: análisis interaccionista desde la perspectiva de mujeres profesionales de salud

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ABSTRACT

The aim of this study was to know the meanings attributed by female health professionals to the process of caring for women with HIV, considering their vulnerability in the context of feminization of HIV/AIDS. It is a qualitative study based on the grounded theory method and symbolic interactionism, conducted in two public maternity hospitals in Rio de Janeiro, from November 2009 to April 2010. Data were collected by means of semi-structured interviews with twelve female health professionals. The core category that emerged was "Speaking as a Professional and Thinking about Caring", which focused on the meaning of care, and the integration of two categories, the first being the concerns of being a woman/professional caring for women with HIV and the second being the meanings of professional care provided to women with the virus. It was concluded that the professionals still maintained the former perception of HIV/AIDS, contributing to increased gender vulnerability to HIV, discrimination and prejudice.

Descriptors: Women's health. Acquired immunodeficiency syndrome. Health vulnerability. Gender identity.

RESUMO

Este estudo buscou conhecer os significados atribuídos por mulheres, profissionais de saúde, ao processo de cuidar de mulheres com HIV, considerando a vulnerabilidade no contexto da feminização do HIV/AIDS. Estudo qualitativo baseado nos pressupostos da Grounded Theory e do Interacionismo Simbólico, realizado em duas maternidades públicas do Rio de Janeiro, de novembro de 2009 a abril de 2010. Para coleta de dados utilizou-se a entrevista semiestruturada. Foram entrevistadas doze mulheres profissionais de saúde. Como categoria central emergiu "Falando como Profissional e Pensando no Cuidar", cujo foco foi o significado do cuidado, integrando duas categorias: a primeira traduz as inquietações do ser mulher/profissional cuidando de mulheres com HIV, e a segunda traz os significados dados por essas profissionais ao cuidado prestado às mulheres com o vírus. Conclui-se que as profissionais ainda trazem consigo a antiga visão do HIV/AIDS, contribuindo para o aumento da vulnerabilidade de gênero para o HIV, discriminação e preconceito.

Descritores: Saúde da mulher. Síndrome de imunodeficiência adquirida. Vulnerabilidade em saúde. Identidade de gênero.

RESUMEN

Este estudio buscó conocer los significados atribuidos por mujeres profesionales de salud, al cuidado de mujeres con VIH, teniendo en cuenta la vulnerabilidad en el contexto de la feminización del VIH/SIDA. Estudio cualitativo basado en la Grounded Theory y el interaccionismo simbólico, realizado en dos maternidades gubernamentales, en Río de Janeiro, desde noviembre/2009 hasta abril/2010. Los datos fueron obtenidos a través de entrevista semiestructurada. Se entrevistó a doce mujeres profesionales de salud. "Hablando como profesional y Pensando en el Cuidado" surgió como categoría central, cuyo foco fue el significado del cuidado, con la integración de dos categorías: la primera refleja las preocupaciones de ser una mujer/professional que cuida a mujeres con VIH, la segunda trae los significados del cuidado profesional prestado a las mujeres con el virus. Se concluye que los profesionales conservan la antigua percepción del VIH/SIDA, contribuyendo a aumentar la vulnerabilidad de género, la discriminación y prejuicios.

Descritores: Salud de la mujer. Síndrome de inmunodeficiencia adquirida. Vulnerabilidad en salud. Identidad de género.

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■ INTRODUCTION

HIV/AIDS is a pandemic that, over the years, has presented changes in its social and epidemiological profile. In spite of these changes, carriers of the virus still suffer prejudice and are labelled by society as individuals who were condemned for breaking social rules⁽¹⁾. Women already suffer prejudice related to their gender, so HIV carriers are doubly judged.

This occurs because society still reproduces the symbols it attributed to AIDS in the 1980s, which, in turn, carry representations supported in the concept of “plague” that punishes transgressors of morality and respectability⁽¹⁻²⁾.

In terms of social and epidemiological changes, researchers indicate growth of this pandemic in financially under-privileged population groups in cities of the interior, and women, chiefly due to gender vulnerability, resulting in the feminization of HIV/AIDS⁽³⁻⁴⁾.

The sex ratio, which was 40 men to every woman with AIDS in 1983, reached 1.7 men to every woman in 2010⁽⁶⁾. Some authors explain that due to gender vulnerability some women cannot convince their partners to use condoms, and, due to their submission, they accept their partner's imposition when they decide not to adopt this method⁽²⁻⁶⁾.

When it comes to gender, there is unequal treatment in terms of political, social, financial and cultural aspects, which generates unequal relationships of power and rights, and differences in obtaining access to material and symbolic assets⁽⁷⁾.

This inequality in relationships of power is also present in feminine sexuality, constructed from the perspective of gender as impure and passive, exerted from the feeling of love rather than desire with a maternal focus^(4,8-10). Women must also face the antitheses of pure and eternal love, as the idea of women negotiating the use of condoms or sex has always been considered the attitude of prostitutes. This lack of power to negotiate the use of condoms increases their vulnerability to HIV^(2,11).

There are different perspectives to analyse and interpret this phenomenon. In this study, the chosen perspective was symbolic interactionism.

Symbolic interactionism influences the meanings that female healthcare professionals attribute to the process of caring for HIV-positive women, as it conceives “society” as an entity that consists of interacting individuals based on sharing senses or meanings in the form of common understanding and expectations⁽¹²⁾.

The construction of the meaning of AIDS and the elaboration of its common knowledge were parallel to medical

coding⁽¹⁾. Consequently, society produces meanings supported on the idea of a contagious, incurable and mortal disease. Furthermore, AIDS was associated to groups considered discriminated and marginalized⁽¹⁻²⁾.

In the interactionist perspective, human beings act in relation to things based on the meanings these things have for them, and this is also the case with HIV/AIDS⁽¹²⁾. As this disease is burdened with taboos and prejudice, it leads to the idea of transgression of social standards.

Integration occurs through memories and prior information we acquire on a given subject. When we retrieve them in our minds, we also retrieve the symbols attributed to them, the opinions we have and the opinions that others expressed on that subject, as the meaning of things is also derived from social integration⁽¹²⁾.

For this reason, the research question of this study was: what is the meaning attributed by female healthcare professionals when caring for HIV-positive women? It is believed that healthcare professionals have knowledge on the biological and social implications of AIDS and adopt a gender perspective. Thus, this research is justified by these healthcare professionals, who care for these women, and who attribute to themselves a gender identity and recognize the same risk in themselves or for themselves.

The aim of this study was to acquire knowledge on the meanings attributed by female healthcare professionals to the process of caring for women with HIV, considering vulnerability in the context of feminization of HIV/AIDS.

■ METHODOLOGY

This is a quantitative study based on the grounded theory method and symbolic interactionism⁽¹³⁾. It originated from a dissertation⁽¹⁴⁾ conducted in two municipal maternity hospitals in Rio de Janeiro.

Data were collected from November 2009 to April 2010. These units were chosen because they are benchmark maternity hospitals for expectant mothers with HIV and due to the certainty of finding female healthcare professionals providing care for HIV-positive women.

Inclusion criteria were female healthcare professionals with a minimum age of 18 years, who have worked with HIV-positive women for at least one year. These criteria sought to ensure that these professionals had already provided care for HIV-positive women and that they had had time and opportunity to act and react socially in relation to this care. Exclusion criterion was female healthcare professionals with HIV. A total of 12 women/professionals met these criteria, constituting study subjects, which included physicians, nurses and nursing technicians and

aides. The final number of interviewees was defined by information saturation⁽¹³⁾.

Participation was voluntary and all subjects signed an informed consent statement. Interviews were coded using Arabic algorithms in ascending order of participation.

The adopted research method was semi-structured interviews, which were recorded in MP3 format and fully transcribed for analysis. These interviews were conducted on a time and date chosen by the participants. The guiding question for the interviews, after creating a setting between interviewees and interviewer, was based on the meaning of caring for women with HIV.

Interviews were analysed according to the grounded theory steps: a) codes, when the researcher examines data by using substantive coding; b) categorization, when coded data are compared and grouped into categories; c) concept building, when the researcher identifies the core problems of the social scene by using data as they are obtained; d) concept development, when the emerging theory is expanded and densified by comparing the developed categories to interrelate them, and when additional data is sought and specifically collected to develop hypotheses or core category properties by means of selective/theoretical samples; e) concept modification and integration, when the researcher compares concepts conveyed during the study to discover their relationship, and when conveyed concepts are again compared with data for assessment⁽¹³⁾.

In compliance with Resolution 466/2012 of the National Health Council⁽¹⁵⁾, research was approved by the Research and Ethics Committee of the Municipal Health and Civil Defence Secretariat of Rio de Janeiro (#191/09).

■ RESULTS AND DISCUSSION

To acquire knowledge on the meanings attributed by female healthcare professionals when caring for HIV-positive women, and considering vulnerability in the context of feminization of HIV/AIDS, it was necessary to identify the meanings of HIV/AIDS for these professionals. These meanings emerged according to several concepts that the virus and disease represent for each participant of this research.

The need to identify the meanings of HIV/AIDS for participants is important because, according to the interactionist perspective, these professionals are confronted with the situation defined as *caring for women with HIV*. At that moment, they are also confronted with symbols, perspectives, group references and their own past experiences. They observe themselves in the situation and take the place of others in that situation. They

eventually adopt a set of concepts that will be manipulated and used to give meaning to and make sense of objects and define their actions⁽¹³⁾.

Concepts attributed to HIV/AIDS have changed from their former characteristics, such as its association with adultery, former risk groups, promiscuity and drug abuse, to the current expectations, such as solidarity and quality of life. These characteristics originate from the history of the virus, past experiences with other patients, the social cycle with its conceptions, the work environment, educational background, and others. These aspects helped to understand how professional women see themselves within this process and attribute meanings to this care.

The interviews and the transcription and analysis processes showed that these women, when they spoke as professionals, incorporated the entire theoretical discourse that involves the physiopathological and/or social aspects of HIV/AIDS, resulting in the core category *“Speaking as a Professional and Thinking about Care”*. In this category, the focus was *“providing meaning to care”* (Figure 1).

Data analysis produced two categories: *“Being professionals caring for HIV-positive women”* and *“Attributing meanings to care for HIV-positive women”*. In these categories, women/professionals talked about providing care in two dimensions: i) when they perceived themselves as healthcare professionals who cared for women with HIV/AIDS and worried about themselves, the care provider; and ii) when they thought about the women and worried about issues related to HIV-positive women, the receiver of care.

Being professionals caring for HIV-positive women

Some participants indicated uneasiness during the provision of care by expressing fear of accidents with biological material. Others mentioned their concerns for others; the “other” being the child that is born of a woman with HIV, or the actual woman. These concerns formed three sub-categories: *“Fearing accidents with biological material”*, *“Concern for the child”* and *“Concern for the feelings of women as mothers”* (see Figure 1).

Fearing accidents with biological material

Participants believed they were vulnerable to the risk of HIV infection due to their profession. Some recalled their experiences and expectations when confronted with a work accident with biological material during their professional lives.

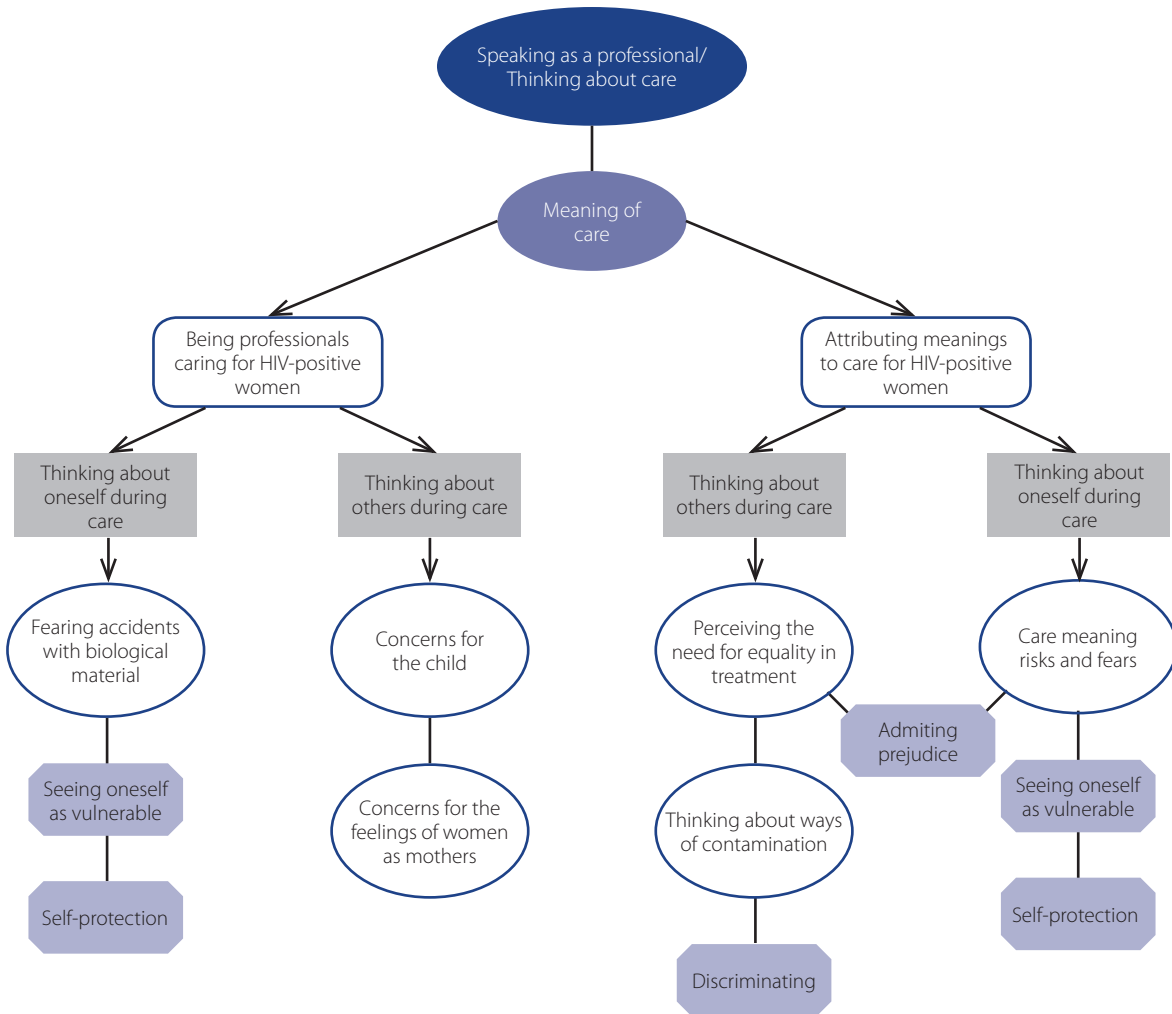


Figure 1. Speaking as a professional/Caring for others.

I think I am because of my profession, because I am afraid, because I have already cut myself, [...] I've had two accidents. (E02)

[...] I had to undergo antiretroviral therapy for a while, a year, and then I was tested and everything was fine [...] It was a rough period, because I vomited all the time, lost four kilos, it was a month, but I did not manage to keep up with the entire treatment, for all that time [...] (E12)

The interviewees, due to a classical issue of gender, do not consider themselves sexually vulnerable to HIV, only professionally vulnerable. Consequently, their fear of accidents with biological material is so expressive that it appears in various categories.

Once women are diagnosed with HIV, they are confronted with the social and moral implications of being HIV-seropositive and start to fear abandonment on a dai-

ly basis⁽¹⁶⁾. Fear of accidents with biological material is triggered by the idea that they will be judged if they are HIV-seropositive and subsequently abandoned by friends, family members and partners^(2,16).

Concern for the child

Interviewees spoke about their concerns for the health of children that must anxiously await positive or negative results for seroconversion. They expressed concern for the future of children by acknowledging the existence of prejudice and discrimination from their friends and fellow students. These same children may also grow up without their mothers, as these professionals believed their mothers would have short life spans. These concerns are the results of the meanings attributed to HIV, such as discrimination, prejudice, death and others.

The person is prone [...] and then they have a baby that basically depends on luck. [...] We, who work with health-care [...] from the moment an opportunist disease emerges, they feel bad. (E03)

When it comes to children [...] what will it be like at school, with his classmates, there is still so much discrimination, isn't there? (E10)

These statements show a lack of preparation of professionals, considering that there are protocols with measures that significantly diminish the risk of vertical contamination. However, this lack of preparation is not always caused by lack of information, but by prejudice constructed on the meanings that each individual attributes to HIV⁽²⁾.

The fear of exclusion and discrimination is described in a study in which parents of children with HIV reported they concealed the serological condition from friends and some family members. As these children need medication, only very close family members took care of them, such as parents or grandparents, and they had little social interaction to prevent suspicion⁽¹⁷⁾.

The fact that the interviewees showed concern for the future of these children and the death of their mothers is due to the strong and stigmatized image of an incurable disease that debilitates and kills in a short time, despite advancements in treatment⁽¹⁶⁾.

Concern for the feelings of women as mothers

This sub-category addressed the fact that women with HIV do not breastfeed, and their concerns. The healthcare professionals showed evident concern for the conflicting feelings of women when they wanted to breastfeed and were unable to. It is a conflict that also affects professionals as they tend to place themselves in this same situation.

It's also something that really bothers me [...] it's that this mother cannot breastfeed, and sometimes she wants to breastfeed, do you know what I mean? [...] (E01)

It's [...] quite sad. To want to breastfeed your baby and not being able to. (E02)

Participants showed concern for the feelings of these women because they cannot breastfeed their babies, although they were aware that this is a protective measure for the newborn child. However, this concern is maintained because of the meanings that women attribute to breast-

feeding, considering that, in addition to the health benefits, breastfeeding also carries a symbolic meaning that is understood by women as being an act of love⁽¹⁶⁾. The contraindication of breastfeeding can be interpreted as being deprived of fully experiencing maternity^(16,18).

Studies with women that were diagnosed as HIV-positive during pregnancy showed that the impossibility of breastfeeding affects women in several ways^(16,18). Moreover, the fact that they cannot breastfeed is a constant reminder of HIV in their organism. By not breastfeeding in order to protect their babies, they expose themselves to the risk of discrimination, as people close to them eventually suspect they are infected and distance themselves from these mothers⁽¹⁸⁾.

Attributing meanings to care for HIV-positive women

In this category, the professionals also spoke about care for women with HIV in two dimensions. These dimensions formed the three sub-categories that defined caring for women with HIV (see Figure 1).

Perceiving the need for equality in treatment

The interviewees emphasized the need for equality in treatment, without labelling and without discriminating, and the importance of providing support for these women by checking medical records to know if their families and partners are aware of their condition, the number of prenatal consultations, HIV treatment, its prevention for the newborn baby and their behaviour in relation to infection.

You start the inquiries [...] in fact, the first approach is ours, of the nursing unit [...] we talk to her, and ask things like, whether it's her first child, do you know what I mean? (E11)

We don't have to discriminate really, do we? (E08)

When they asked themselves about the meaning of caring for women with HIV, some stated that they perceived the need for equality for all patients, regardless of their serological condition. This need is comprehended by the participants because they have witnessed, heard statements or acted in a discriminatory way with HIV-positive women^(2,11,18).

The HIV/AIDS medical history helps make AIDS a disease marked by stigmas and prejudice. As the emergence of this disease was connected to risk groups, a so-called family woman would never be exposed to HIV, a virus that

affects transgressors of social standards^(1,19). The HIV-positive women are labelled as promiscuous or as drug users, both of which are considered unacceptable behaviour by society, thus generating discrimination and exclusion⁽¹⁾.

Thinking about ways patients are contaminated

During the interviews, the participants stated that they have different experiences depending on the medical history of each female patient.

It's actually quite tough, because every woman has a history, right [...] They are very different experiences [...] (E03)

I think...how they were contaminated, that they know the risks, right? Oh, the younger ones, as I said, are often street girls, they've been with several men. (02)

They also stated different care experiences, depending on the manner in which women were infected with the virus. That is, providing care for a woman with HIV can have different meanings depending on how she acquired the virus. Women are either considered "guilty" or "unfortunate". This shows how HIV/AIDS carriers, especially women, are still labelled, judged and condemned by society, including by healthcare professionals of the same gender⁽²⁾.

According to the interactionist perspective, when healthcare professionals observe these women, they resort to the symbols attributed to HIV/AIDS in the 1980s, and they apply past experiences and define their action, their feelings and meanings. These symbols are still burdened with prejudice and label women that carry the virus as prostitutes, as if HIV infection was a punishment for their so-called promiscuous behaviour^(2,3,8-9,19).

Care meaning risks and fear

According to the participants, caring for women with HIV means running risks and they consequently reinforce protection measures. Others emphasized the importance of maintaining the same care for all women, for preventive measures and to avoid discrimination. They stated that risks are also present in the healthy appearance of an HIV carrier and the fact that these women do not have the evident signs that would otherwise call the attention of these professionals does not exempt them of these risks.

Because care, the way I treat them, is the same for all of them. One of them is declared, with positive results. What about those that aren't? (E03)

Look, it's like this, [...] extra attention, right? [...] But I advise them [...] I try not to get that way [...] and label, right? (E09)

More care, more risks [...] for us [...] Sometimes she is so young and poses a risk and she doesn't look like she would [...] understand? (E02)

The healthcare professionals present the discourse of non-discrimination, but they also have social customs and values that influence the provided care⁽²⁾. When they perceive the need for equality in treatment, they admit that there may be prejudice when caring for women with HIV, as a consequence of their actions and reactions.

By attributing a sense of "extra attention", "risks and fear" to this care, these professionals are once again expressing their fears of having accidents with biological material and acting in a discriminatory and prejudiced manner⁽²⁾. When this occurs, they reproduce in women with HIV the same judgements they fear confronting if they were HIV-seropositive^(2,16).

In spite of the technical and scientific knowledge and the discourse of equal treatment, statements showed a distanced and mechanistic care that is influenced by prejudice and discrimination. For these professionals, this care represents a health risk instead of the possibility to exercise humanized care based on comprehensiveness.

■ FINAL CONSIDERATIONS

Analysis of the meanings attributed by female healthcare professionals when providing care for HIV-positive women, considering gender vulnerability in the context of feminization of HIV/AIDS, showed that HIV/AIDS is associated to deep-rooted stigmas that, to this day, determine the profile of HIV carriers and influence the meaning of care for healthcare professionals.

It was consequently concluded that although these professionals are aware of the changes to the social and epidemiological profile and have technical and scientific knowledge of the HIV/AIDS prevention and treatment process, the meaning of care for women with HIV is defined within a process of social interaction. These women suffer the influence of concepts, meanings and symbols that healthcare professionals bring from their social context. These professionals act and react with their daily lives, with all the reproductions or alterations, depending on the manner in which these professionals define the situation to themselves.

Changes are translated into the deconstruction of taboos and stigmas of AIDS so that society can view the

HIV carrier as a woman that deserves the same dignity and respect as any other, which does not justify different feelings and approaches during care. The transformation of these symbols must also occur in relation to the image and consequence of the disease, considering that treatment is effective and is significantly reducing the morbidity and mortality rate of AIDS in Brazil and around the world.

It should be observed that this study did not consider the meanings of care for the mother-child. Although the interviewees mentioned their concerns for the newborn child, the focus of their statements was the provision of care for women. This could be a limitation of the study and the development of studies on the mother-child in this same perspective is therefore recommended.

This research provided the grounds to stimulate reflection of all healthcare professionals, especially women, in relation to the professional discourse, which is academically constructed, and care practices, which suffer the influence of the social interactions experienced during an entire lifetime.

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