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Coping and perception of women with HIV infection

ABSTRACT

OBJECTIVE: To analyze women's perceptions and coping regarding the discovery of an HIV infection.

METHODS: A qualitative study in an HIV/AIDS Specialist Helpdesk in Recife, PE, Northeastern Brazil, from January to September 2010, involving eight women living with asymptomatic HIV aged between 27 and 37 years, without criteria for diagnosis of AIDS infected through intercourse and monitored by the service for at least one year. Forms were used to characterize the clinical situation and semi-structured interviews to understand perceptions and feelings related to personal trajectory after diagnosis and different ways of facing the diagnosis in family and social life. Content analysis was performed as suggested by Bardin.

RESULTS: The thematic category that emerged was stigma and discrimination. The women had life trajectories marked by stigma, which was perceived as discrimination after the diagnosis and in the experiences of everyday life. The revelation of the infection was perceived as limiting to a normal life, leading to the need to conceal the diagnosis. The discriminatory attitudes of some health care professionals, non-specialist in HIV/AIDS, had a negative impact on future experiences in other health services. Besides the effects of institutional stigma, the perception of women was that the service did not include dedicated space for the expression of other needs beyond the disease, which could help in fighting the infection.

CONCLUSIONS: Living with HIV was strongly linked to stigma. The results show the importance of strengthening educational approaches and emotional support at the time of diagnosis in order to facilitate coping with the condition of seropositivity.

DESCRIPTORS: Women. HIV Infections, psychology. Acquired Immunodeficiency Syndrome. Psychosocial Impact. Qualitative Research.

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Received: 4/15/2013
Approved: 9/26/2012

INTRODUCTION

Advances in the area of treating AIDS have led to reducing the morbimortality, and the chronic nature of the disease, as well as to improvements in quality of life. This has changed the situation of women living with HIV/AIDS and brought new challenges.^a In Brazil, between 1980 and June 2011, there have been around 210 thousand women living with HIV, with the trend increasing in women in the South, North and Northeast of the country.^b The profile of reported AIDS cases is characterized by economic inequality and low levels of schooling, which implies less access to consumer goods and services and to information.^{5,a}

Due to a variety of advances in diagnosing and treating AIDS, the World Health Organization (WHO) has now included it in the category of chronic conditions which are treatable and clinically manageable. After infection, efforts need to be turned to preventing full blown AIDS developing, with monitoring by a specialist service.⁵

Reducing the emotional and social impacts of diagnosis has been highlighted as basic element in adherence to future treatment plans and living with HIV.⁸

Discovering she is positive means the woman's view of herself and of her life changes. The expectations and suffering on diagnosis can be transformed through experience and as she acquires better understanding of the disease.⁸ Approaches should be sensitive not only to prevention but also to understanding how women deal with their everyday life after diagnosis with HIV/AIDS and the adjustments needed to face this new reality.¹¹

There are several frameworks for dealing with infection. In the area of health care, the most widely used concept is that of vulnerability, which emerged as a possibility of broadening interpretations of the AIDS epidemic. Delor & Hubert⁴ present their matrix, constructed based on research conducted with HIV/AIDS positive individuals in Belgium in the 1990s. The results were analyzed on three levels: social trajectory, interaction and social context.⁴

Mann et al,^c presented a methodology using three levels: individual, social and programmatic. In Brazil, Ayres et al,² trying to broaden the concept proposed by Mann et al, included living with HIV, producing a model in which the unit of analysis is the individual-collective. In this study, the focus was on the individual level, looked at more in-depth by Paiva et al^d using the psycho-social dimensions, which considers

individuals' subjectivity in everyday life after infection and the resources available to each individual to deal with infection with HIV/AIDS.

Foe Paiva et al,^e attention needs to move away from the narrow perspective of disease to valuing life stories and conditions, as health care practices, from the point of view of human interactions, are falling short of meeting the needs of the individual. Viewing people as active subjects within their reality, gifted with power, values and beliefs, respecting individual differences and relationships established with others at each time, this dimension emphasizes perceptions at the time of diagnosis and resources used in family relationships to live with this new reality.

Perceptions can be understood as part of how the individual constructs their reality.¹⁰ They are individual and are closely related to collectively established meanings, as disease goes beyond merely biological aspects. They involve the collective values and knowledge which permeates reference groups, mainly the family network at a specific place and time. The focus on subjectivity may contribute to reconstructing these practices, above all, in providing a space for listening, and offering the possibility of changing the distant and impersonal relationship that often prevails in day-to-day health care.

The aim of this study was to analyze the perceptions and ways of coping in women regarding discovering HIV infection.

METHODS

A qualitative study conducted in the HIV/AIDS Specialized Care Service in the *Instituto de Medicina Integral Prof. Fernando Figueira* (IMIP), in Recife, PE, Northeastern Brazil, between January and September 2010. Subjects were selected by convenience. Eight women participated in the study, all living with HIV,^e asymptomatic, without clinical or laboratorial (CD4 > 350 mm³) diagnosis of AIDS,^d (aged over 25 years, heterosexual, infected through sexual relations and having been monitored by the service for at least a year. Bearing in mind that this is a chronic infection and that HIV can be managed, the study prioritized asymptomatic women in an effort to get closer understanding of the resources used in coping and readjusting to deal with the infection.

^a Joint United Nations Programme on HIV/AIDS. Women and HIV/AIDS: Confronting the Crisis. Geneva; 2008 [cited 2009 May 22]. Available from: <http://www.unfpa.org/hiv/women>

^b Boletim Epidemiológico de DST/Aids. Brasília (DF): Ministério da Saúde; 2011;8(1).

^c Mann J, Tarantola, DJM, Netter TW, organizadores. A AIDS no mundo. Rio de Janeiro: Relume Dumará: ABIA:IMS/UERJ; 1993.

^d Paiva V. Prevenção Positiva? Abordagem psicossocial, emancipação e vulnerabilidade. In: Raxach JC, Maksud Ivia, Pimenta C, Terto Jr V. Prevenção Positiva: estado da arte. Rio de Janeiro: Associação Brasileira Interdisciplinar de AIDS; 2009. (Coleção ABIA Políticas Públicas, 8)

^e Ministry of Health. National STD and AIDS Program. Criteria to define AIDS cases in adults and childre. Brasília (DF); 2004. (Séries Manuais, 60).

Before the data were collected, we got closer to the area of research in order to understand the dynamics of the service and identify the best form to invite participants to join in. The latest CD4 tests and notes on medical records were consulted to identify eligible women.

After identification, on the days they came to collect their test results, the women were individual invited to participate. This took place in a private area, where the objectives and characteristics of the study were also explained to them. An interview was scheduled with those who agreed to participate. The interviews were semi-structured, and the sample size was defined by saturation.

The interviews took place in a reserved private room and lasted, on average, 50 minutes, using two guiding questions: "How did you feel when you discovered you had HIV?" and "What changes occurred in your life after this discovery?". The script included sociodemographic characteristics, characteristics of the infection by HIV, perceptions and feelings related to diagnosis and day-to-day experiences within the organization and family dynamics. The interviews were recorded, then transcribed in full.

It was decided to use Bardin's content analysis,³ which involved three stages: (1) pre-analysis: reading without rejecting any parts, ensuring overall understanding of the material; (2) exploiting the material: separating and categorizing excerpts; (3) analyzing the data.^{3,10}

The ethical principles of the Declaration of Helsinki were followed, as were those of the National Health Council Resolution 196/1996. The study was approved by the Human Research Ethics Committee of the *Instituto de Medicina Integral Prof. Fernando Figueira* (Process 1,598/2009). The statements were codified using the letter M followed by a number attributed to each woman. The participants signed a consent form.

RESULTS AND DISCUSSION

The analysis of the characteristics of the women (Table) reflects the sociodemographic profile of the HIV/AIDS epidemic in women in Brazil. The majority had fewer than seven years of schooling, were not in the formal job market and their monthly income was below one minimum wage.⁵

With the exception of one, all of them reported experiencing domestic abuse in within their family and from partners. After diagnosis, four of them remained with their partners, having been infected through that relationship. Two believed they had been infected in previous relationships, their current partners being seronegative. Two remained single. The families were composed mainly of the women, their partners and children. These women had, on average, two children each. One had a child who was seropositive. None of the women had participated in governmental or non-governmental social assistance groups.

One thematic category, with three subcategories, emerged by the process of interpretative construction of the statements, namely:

Stigma and discrimination

The process of stigmatization and its repercussions on the trajectories of these women is notable. The stigma is treated as an attribute for which its bearer is socially disqualified and disapproved. It stems from social and historical processes and, therefore, is subject to change.⁷ However, in the case of AIDS, the association of infection with "risk groups" remains in the social imagination, leading the women in this study to experience isolation and judgment.

Sub-category A: The need to conceal the infection

Being diagnosed with HIV was perceived as a turning point in their lives, capable of disordering their being

Table. Sociodemographic characteristics, time and place of diagnosis of asymptomatic HIV positive. Recife, PE, Northeastern Brazil, 2011.

Subject	Age (years)	Race	Religion	Occupation	Schooling (years)	Household income (R\$)	Place of diagnosis	Time since diagnosis (years)	CD4
M1	30	White	Evangelic	Teacher	8 to 10	600.00	ESF	3	770
M2	32	White	Catholic	Housewife	1 to 3	400.00	ESF	3	820
M3	27	White	Catholic	Shop assistant	8 to 10	400.00	ESF	2	1500
M4	26	Mixed race	Catholic	Shopkeeper	4 to 7	600.00	Maternity unit	2	651
M5	28	Black	Evangelic	Housewife	4 to 7	134.00	ESF	2	917
M6	30	Mixed race	None	Cleaner	1 to 3	250.00	ESF	5	445
M7	31	White	Catholic	Housewife	4 to 7	600.00	Public Hospital	6	628
M8	35	Black	None	Housewife	1 to 3	350.00	ESF	8	420

ESF: Family health care strategy

and their relationships, as well as making it difficult to adjust to life in society. This was accompanied by the need to deal with uncertainty and suffering of the disease being, as yet, incurable, added to which was the weight of moral judgment and concern to hide it at all costs in order to remain socially acceptable.

“I was scared of dying, of getting sick, scared by not knowing who would treat me well, who would distance themselves from me. I didn’t want anyone to know. Ever. Even after I died.” (M3)

As they did not have any physical signs of the disease, the women manipulated information about their “defect”, deciding when, to whom, where and why to reveal or conceal it. This situation proved to be exhausting for those who had lived with HIV for only a short time. The feelings of guilt and shame were more intense and they frequently internalized the negative responses and reactions of others, which resulted in self- or introverted-stigmatization.^{6,7}

“I had this trauma inside me, this guilt, I didn’t know where from and I couldn’t be alright. I suffered a lot. A lot.” (M6)

Reserve regarding the condition of being HIV positive and isolation were common attitudes, and sources of suffering, for the women, who constantly feared discrimination. Revealing the stigmatizing attribute made the difference the center of others’ attention. Revealing their condition could signify the end of relationships, prevent them from establishing new ones and limit opportunities, as confirmed in other findings.^{1,9,15} M7 and M8, who had lived with the disease for longer, reported that it there were tricks which helped concealment and in social co-existence, making use of beliefs about AIDS and motherhood.

“My family does not think that I have it, because I had my daughter, and she is normal and healthy, nothing wrong with her.” (M7)

“We know that those who do not have it don’t bother to learn about it. Everyone thinks that, that people with AIDS can’t have children [...]” (M8)

Stereotypes associated with AIDS are highlighted as elements of social vulnerability remaining in the imagination of communities. This means that they only recognize people with HIV when they are in the final stage, weak, with signs of the disease. Thus, they are far from viewing HIV/AIDS as chronic and something that can be managed and lived with.¹⁶

Sub-category B: Difficulties living with the disease

The family, by deliberate choice, was not told of the diagnosis. The only woman who decided to reveal her positive status to her family reported their suffering and

disbelief regarding her condition, as she did not have any of the characteristics they associated with AIDS. This impeded the formation of family support.

“If I had been lying in a hospital, if I had lost weight, with marks on my skin, [...] Then they would have believed. But I have HIV, I don’t have AIDS, I’m ok, nobody believes it, nobody asks how I’m doing.” (M1)

For the majority, revealing the infection to the family could have aggravated the already existing violent context and resulted in abandonment and loss of financial support. The trajectories of two of the women were marked by acts of exclusion from the immediate family unit (mother, father and siblings), who began to avoid her and avoid daily contact, separating domestic utensils and verbally abusing her. This issue may be linked to persisting beliefs about HIV transmission through social co-existence, as has been seen in other studies.^{1,15}

“[...] at home, there is a separate chair, I’m the only one who uses it. My clothes are washed separately, one spoon, one fork, and one plate. My sister has even said: Mom, this is criminal, she has to move out.” (M8)

Being excluded by the family due to having AIDS is colored by values, norms and behavior which have been internalized as unacceptable in the primary socialization process, of which the family is the primary agent.¹⁵ As there are distinctions in reactions to the stigma of AIDS according to gender, women are frequently blamed for infection and are more vulnerable to violent reactions.¹¹

Concealment ceases to be necessary when the individual perceives that they and their condition can be accepted by those around them, creating a protective circle which allows them to salvage their social acceptance and strengthen their resources to live with the infection.^{6,8} This situation existed in the trajectories of two participants, and did not involve immediate family. M1, a teacher, revealed her infection to work colleagues, and M2 was supported by a friend who did voluntary work with individuals living with AIDS.

When such a protective circle does not form, the individual becomes certain that there is a division between their world and that of “normal people”, constituting a type of “social apartheid”.^{7,9} In the women’s perceptions, this hinders them in establishing relationships based on equality and forming support networks, thus, often imposing isolation on them.

“[...] there are few people who accept it. [...] You’re here talking with me and everything, but would you really want me working in your house?” (M4)

The women feel that stigma in different areas is a significant limiting factor in their chances of leading

a normal life and they have to face it alone. Stigma means that inequalities appear acceptable and excusable, creating a social hierarchy of the stigmatized and the non-stigmatized, feeding social inclusion. We are dealing with a social construction, roles in interaction, but the consequences affect actual individuals.⁶

Sub-category C: Stigma within the health care services

The health care professional's attitude on receiving, listening to and treating the users and meeting their demands, the quality of educational and emotional support provided and valuing the individual's perspective; these are all important elements in reducing the impact of a HIV diagnosis. In Brazil, many women discover they are infected during routine antenatal care in primary care units, or when giving birth in maternity units, when they are offered an HIV test.¹¹

The entire diagnosis process is accompanied by counseling, and should involve active, individualized listening, centered on the individual. It should fulfill the ethical requisites involved in HIV testing: voluntary accept the test and confidentiality regarding the result, as well as providing emotional support and necessary education.¹³

The women perceive that there is a distancing in their dealings with health care professionals within non-specialized HIV/AIDS services. Diagnosis was communicated objectively, and the professionals showed no interest in their personal histories or lives. On some occasions, it was observed that important information on HIV/AIDS transmission were lacking or were negligently provided.

“The doctor went straight to the point when he opened the result and said: Oh! It's positive. He didn't try to explain anything, explain what was happening.” (M6)

A HIV test was requested without previously acquiring permission, and the confidentiality of the result was not respected.

“I found out through my sister [...] I think the doctor should be obliged to call me and talk with me. It's not right, the exam belongs to me, it's my health, and she gave it to my sister.” (M5)

Some attitudes and practices with a negative impact were noted after the women were informed of their diagnosis.

“I was discriminated against in the maternity unit, they put me in a room along. And the nurses looked at me strangely [...] they are scared of you, when you have HIV.” (M4)

Health care professionals are part of social groups and may have social representations of AIDS and of infected individuals which coincide with the popular image, and are incorporated into their practice. Sometimes they even disregard scientific knowledge.^{11,14}

“They told me I couldn't have a relationship, the nurse went there to the health center, the community worker and the doctor. Then he arrived there: you can't have a relationship with that guy [...] you can't have a relationship with that guy, he could catch it, you can't be with him.” (M6)

The women were reluctant to be identified, especially when they knew that they might meet people they knew, friends, neighbors or relatives, to whom they had not revealed their diagnosis, in these centers.

“I can't go to my health center, I can't take my girls there [...] because people aren't prepared for that, there they'll just discriminate against me and give me grief: ah! What's her name there with HIV.” (M5).

One of the biggest challenges for primary health care teams is broadening the way they look at the subject receiving care, to include family and community. Looking at the social-historical process of family organization, domestic spaces and care were centered around women, their fear of having the infection revealed and not establishing a trusting relationship with the health care professionals came to limit health care for the family and for their children.

Within specialized HIV/AIDS services, the risk of revelation constitutes an institutional stigma.^{7,9}

“It's torture to me, to come here, I come terrified that someone I know will see me come in. [...] it's so small, it's terrible for you to escape.” (M5)

This institutional stigma may act as an obstacle to adhering to HIV/AIDS specialist services and to continuity of actions, contributing to vulnerability to developing full blown AIDS.^{13,f} The specialist service appeared as an important source of support for the women, providing explanations about infection, treatment possibilities and emotional support. This helps them to accept their diagnosis and calms the initial fear of AIDS. However, the women emphasized the lack of a space in which to express other needs, apart from issues concerning the disease itself, although they did not consider this to be part of the health care professionals' remit, and even justified the lack.

“The appointment is like this, [...] they ask how I'm feeling, look at the tests and then write patient with

⁶The United Nations Joint Program for HIV/AIDS. Worldwide coalition about women and AIDS. Supporting individuals who care for others in the struggle against AIDS. Geneva; 2005 [cited 20 Apr 2009]. (La realidad, 5). Available from: http://data.unaids.org/publications/irc-pub07/jc1279-gcwa-5_es.pdf

no complaints, but I was full of complaints, I was full of problems.” (M4)

“I won’t talk to the Dr. about my problems, he’s so good to me and I don’t want to worry him.” (M5)

Lack of attention to psycho-social aspects is, partly, the result of excessive segmentation of the patient and of exaggerated interventionism, effects of changes in contemporary medicine towards more technological sophistication. In contrast, the practices are seriously limited when it comes to responding effectively to an individual’s complex health needs. Considering the presence of a subject face to face with the other is a daily challenge for health care professionals.¹⁶

CONCLUSIONS

The content that emerged from this study was a cross-section of a life trajectory and cannot be treated as definitive. In the context of a life marked by economic

and social difficulties, finding out they were HIV positive was shown to be a critical moment, marked by suffering and fear, not only insecurity of having an incurable disease, but also fear of abandonment and rejection. This led to the need to conceal the diagnosis in order to preserve their personal identity and to maintain family or social relationships.

The form and context in which non-specialized health care services deal with diagnosis indicates fragility in their actions, above all in the lack of care and in important ethical aspects, and calls for further investigation into the relationship with primary care. Specialized services represented an important source of support for the women, explaining technical aspects of the disease and enabling them to adjust their beliefs and knowledge of AIDS. However, those women suffered from institutional stigma and from the lack of space to air their difficulties beyond the disease itself. Stigmatization is an obstacle in a situation incapable of responding to the complex health needs of these women.

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