



PSYCHO-AFFECTIVE PERCEPTIONS OF WOMEN WITH 50 YEARS OR MORE ON AIDS

PERCEPÇÕES PSICOAFETIVAS DE MULHERES COM 50 ANOS OU MAIS ACERCA DA AIDS PERCEPCIONES PSICOACTIVAS DE MUJERES CON 50 AÑOS O MÁS SOBRE EL SIDA

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ABSTRACT

Objective: catch on the feelings experienced by women aged 50 or over who are living with HIV/AIDS and compare them with women without this kind of diagnosis. **Method:** it is an exploratory and descriptive research carried out in two public institutions in Fortaleza-CE, Brazil. The study included 44 women, 22 diagnosed with HIV/AIDS and 22 without this diagnosis. We used semi-structured interview and the non-systematic observation. The semi-structured interview was organized in two parts; the first with social and demographic data and the second with guiding questions relating to this thematic. The data were submitted to thematic content analysis. The study was approved by the Ethics Research Committee of the *Hospital São José*, for Infectious Diseases in city of Fortaleza-CE, Brazil, with the CAAE n° 0021.0.042.000-09; under protocol n° 018/2009. **Results:** in the analysis of interviews, the category Psycho-affective perceptions emerged and, as well as its subcategories. AIDS is represented as a disease that mistreats, generates suffering and causes the death. Moreover, the interaction with this disease is permeated by distress, stigmata. **Conclusion:** it is essential the development of spaces of listening in health services and the qualification of nurses, so that the orientation on HIV/AIDS can be practiced effectively. **Descriptors:** women's health; HIV; acquired immune deficiency syndrome.

RESUMO

Objetivo: apreender os sentimentos vivenciados por mulheres com 50 anos ou mais com HIV/AIDS e compará-los com as mulheres sem esse tipo de diagnóstico. **Método:** pesquisa exploratória e descritiva, desenvolvida em duas instituições públicas, em Fortaleza-CE, Brasil. Participaram do estudo 44 mulheres, 22 com diagnóstico de HIV/AIDS e 22 sem esse diagnóstico. Foram utilizadas a entrevista semiestruturada e a observação assistemática. A entrevista foi organizada em duas partes, a primeira com dados sociodemográficos e a segunda com questões norteadoras relativas à temática. Os dados foram submetidos à análise de conteúdo temática. O estudo teve o projeto de pesquisa previamente aprovado pelo Comitê de Ética em Pesquisa do Hospital São José de Doenças Infecciosas, em Fortaleza-CE, com o CAAE n°. 0021.0.042.000-09; sob protocolo n°. 018/2009. **Resultados:** na análise das entrevistas, emergiu a categoria Percepções psicoafetivas e suas subcategorias. A AIDS é representada como doença que maltrata, gera sofrimento e ocasiona a morte. O convívio é permeado de angústia e estigmas. **Conclusão:** é indispensável o desenvolvimento de espaços de escuta nos serviços de saúde e a capacitação de enfermeiros, para que a orientação quanto ao HIV/AIDS possa ser praticada de forma efetiva. **Descritores:** saúde da mulher; HIV; síndrome da imunodeficiência adquirida.

RESUMEN

Objetivo: comprender los sentimientos que experimentan las mujeres de 50 años o más con el HIV / SIDA y compararlas con las mujeres sin un diagnóstico. **Método:** estudio exploratorio y descriptivo, realizado en dos instituciones públicas, en Fortaleza, Brasil. El estudio incluyó a 44 mujeres, 22 con y 22 sin diagnóstico de HIV / SIDA. Se utilizó una entrevista semiestructurada y la observación sistemática. La entrevista fue organizada en dos partes, con los datos demográficos primera y segunda con preguntas guía relacionada con el tema. Los datos fueron sometidos a análisis de contenido temático. El estudio fue el proyecto de investigación previamente aprobado por el Comité de Ética del Hospital de Enfermedades Infecciosas de São José, en Fortaleza-CE, con el CAAE. 0021.0.042.000-09, en virtud del protocolo. 018/2009. **Resultados:** en las entrevistas, emergió la categoría y sus subcategorías Percepciones psicoactivas. SIDA se representa como una enfermedad que maltrata genera sufrimiento y causa la muerte. La vida está impregnada de ansiedad y estigma. **Conclusión:** es fundamental desarrollar espacios de escucha en los servicios de salud y la formación de las enfermeras de orientación sobre el HIV/SIDA. **Descritores:** salud de la mujer; HIV; síndrome de inmunodeficiencia adquirida.

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INTRODUCTION

In Brazil, the beginning of the AIDS epidemic occurred with large concentrations of cases in big urban centers, especially, in the South and Southeast regions of Brazil, affecting mainly males with higher socioeconomic status, belonging to the transmission categories of homosexual and bisexual, besides patients with hemophilia, receivers of blood and blood products, users of intravenous drugs and sex workers, considered as "risk groups".¹⁻²

Thus, preventive practices directed to the "risk groups" and individual behaviors produced gaps that facilitated the spreading in other parts of the population, among which stood out women and, more recently, people over 50 years old, culturally seen as 'sexless' subjects and devoid of desire for making sex.³

Changes in the way of life of the population, which begins to live more fully, intensifying social relations, motivate exposures to the risks before assigned to individuals of younger age groups, including exposure to HIV infection, giving rise to the challenge of establishing policies public and strategies that ensure the life quality of these individuals.

With regard to women older than 50 years old, it could be started from the understanding that, beyond the 'aging' of the pandemic, there is a trend towards its feminization, with a significant decrease of the ratio between men and women.

It is understood that, because of scientific advances, in an attempt to itemize or extinguish the HIV/AIDS, which increases the chance of survival with quality, it has been reflected on stigmas, behaviors and fears caused by this disease in women aged 50 years or more. Such reflections raise questions as: Who are these women? What are the repercussions of HIV/AIDS in their lives? How to position themselves with regard to this disease?

It is believed that the answers to these questionings will enable knowledge about the vulnerabilities to which are exposed the women aged 50 and over who live with HIV/AIDS; knowledge necessary to the designing of public health policies and strategies which contribute to the improvement of life quality of these people.

Based on the aforementioned, this study aims:

- Catch on the feelings experienced by women aged 50 or more with HIV/AIDS and to

compare them with women without this kind of diagnosis.

METHODOLOGY

This is an exploratory and descriptive research, with qualitative approach, developed in city of Fortaleza-CE, Brazil, in an outpatient for attendance of females with HIV/AIDS, from a reference hospital for treatment against AIDS of that state, and in coexistence group of elderly of a Social Urban Center - *Centro Social Urbano* (CSU).

44 women monitored in such services participated in this research, they were interviewed from September to November 2009. Of these, 22 women were diagnosed with HIV/AIDS (Group A) and 22 had no diagnosis of HIV/AIDS (Group B), in the speeches, we attributed the letter C to represent women with a diagnosis of AIDS and the letter S for women without this kind of diagnosis.

We considered as inclusion criteria for the research subjects of the Group A: being female; being 50 years of age or older; having a diagnosis of infection by HIV/AIDS; and be monitored by the specialized outpatient in HIV/AIDS of the institution of reference. With regard to the subjects of the Group B, females aged 50 or older were included; with no diagnosis of infection by HIV/AIDS; and participants of coexistence group of elderly - CSU. We excluded women with health changes that prevented communication, as well as those who did not meet all inclusion criteria.

For production of data, we used the techniques of semi-structured interview and the non-systematic observation. The semi-structured interview was organized in two parts; the first with social and demographic data and the second with guiding questions relating to this thematic. We used the non-systematic observation to complement the analysis of the interviews.

The interviews were submitted to the technique of thematic content analysis. Content analysis is a technique that provides the best way of investigation and treatment of the obtained messages, since, due to the advantages, it enables catch on the subjective ideas of interviewees, linked to their beliefs, values, and the opinions in everyday their actions.⁴

With possession of data, they were organized in accordance with the following steps: Pre-analysis, exploration of material, treatment of results, inference and interpretation. The use of this technique consists in the explicitness and

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systematization of the content of messages and the expressions of this content.⁴

As mentioned, the corpus consisted of 44 interviews, being selected the phrase as record unit and the paragraph as the context unit. It should be noted that the study was approved by the Ethics Research Committee of the *Hospital São José*, for Infectious Diseases, in Fortaleza-CE, Brazil, under protocol n° 018/2009. The subjects were informed about the theme and the objectives of our research. Furthermore, they signed a Free and Informed Consent Form (FICF), as required by the Resolution n° 196/96 of the Brazilian National Health Council / Brazilian Ministry of Health.⁵

RESULTS

● Psycho-affective perceptions.

The units of analysis demonstrated how subjects expressed their psycho-affective

Table 1. Distribution of frequencies, percentages and chi-square of the category and subcategories of psycho-affective perceptions, according to the groups with (WD) and without a diagnosis (ND) of HIV/AIDS. Fortaleza, Brazil, 2009.

Subcategory	WD	%	ND	%	Total	%	X ²
Fear	154	49,3	17	13,2	171	38,9	–
Death and HIV/AIDS	14	4,5	0	0	14	3,1	–
Situations of support and/or helplessness	144	46,2	111	86,8	255	58	–
Total	312	100	128	100	440	100	9,375 (p = 0,00)

Note.: p < 0,05

● Psycho-affective perceptions anchored in fear (death, prejudice and discrimination)

The fear of dying accompanies the human being throughout its life. Nevertheless, the emergence of a new disease with a high mortality rate, charged with stigmata of pain and suffering, already rooted in common sense, makes that this fear takes different meanings. In such cases, death becomes a real and constant threat.

Allied to these issues, the AIDS (HIV) is still an incurable disease, which makes that the idea of death takes the meaning of a sentence:

Yes, there is a difference. The difference is that I no longer feel joy, I think of dying anytime. Leaving my children alone [...]. (C4)

Some diagnosed women reported being encouraged to keep their seropositivity condition in secret, either explicitly, by their family members and health services workers, or implicitly, extracted from the media or the common sense. It should be inferred that it can act as an obstacle to the realization of individual and social vulnerability, interfering

perceptions about death, prejudice, HIV/AIDS, poverty and abandonment. We have found 440 units of analysis in the two groups, of these, 172 were related to situations of support and 127 for the fear of prejudice and discrimination - together - they represented 67.9% of the total. Then, there was the subcategory referring to situations of helplessness, with 19% of the total of thematic units.

When applying the chi-square statistical test, with significance level of 5%, it was shown that the comparison between in the two groups showed no statistical differences.

in how these women prevent and relate to each other:

Sometimes, children hide it, do not say this and such, do not disclose [...] And what does the AIDS' movement? Nothing! It says: We have to hide it. There is another thing that the service does, during the counseling, right? Do not tell it to anyone! [...]. (C7)

Besides the stigmata of pain, suffering and contagion inherent to the presence of HIV/AIDS, the fact of being an STD, makes it a disease loaded of cultural discrimination, translated into simplistic classification that touts its presence as a premise for labels of promiscuity and obscenity:

[...] The people think we are crazy, when we get it [...]. (C9)

Other women with no diagnosis reported:

There is still a lot of prejudice of the other side. Knowing that the person is that way, they withdrawn themselves, think it's a disease, which we take like this, with the wind, but that is not so. (S8)

● Psycho-affective perceptions anchored in death and HIV/AIDS

In this category, we tried to group the speeches that referred directly to HIV/AIDS as

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a synonym for death, with all the emotional load of loss, and often it (death) is seen as a solution to the pain involved in the process of feeling sick and abandoned:

AIDS is death to me. [...] I have no family, I have no one. (Crying) Sometimes, I even think about doing that (Suicide) [...].(C11)

It was found a direct association only in the group of women with a diagnosis of HIV/AIDS, revealing that the coexistence with the disease and another patient, with all its nuances, emerges on deeply the idea of approaching death, of others and itself:

I've been to many funerals of people who died from this disease [...]. (C21)

One of the speeches was very impressive by their ability to translate how strong are the negative feelings of fear, anguish and pain which involve individuals with HIV/AIDS:

I feel the death [...]. (C17)

The strong feature of contagion of the disease appears thickly, stating how these individuals feel responsible for virus transmission, allowing the understanding that they carry within them the death in potential.

The common sense knowledge disseminated by instruments that affect all social classes, as the spoken media, allows the association of HIV/AIDS with death, being frequent to use like reasons the speeches with examples of people who had space in the media, due to its life and by its death:

Why it came up with me? That one boy, one Cazuzza, was not? Cazuzza is gone, He died. I think [...] They say it was AIDS, I don't know [...]. (C14)

● **Psycho-affective perceptions anchored in situations of support and / or helplessness**

This subcategory has grouped 58% of thematic units (255) of the category, with 144 of group women with a diagnosis and 111 of group with no diagnosis, indicating the relevance of certain conditions of support or helplessness in life of these social actors.

Grouping the speeches that addressed situations of support and helplessness in a single subcategory was a deliberation that emerged from the reflection of how these situations are separated by a pretty fine line. The family who supports that is the same who does not hearing the implicit appeals of comprehension. The family, institution essential for that the feeling of loneliness and abandonment not get hold of the individual, is the same institution that does not understand the anguish hosted at the soul core:

[...] My family never despised me. [...] I was abandoned because of the virus. [...] All my

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kids gave me everything I like, they gave me joy. And it is the same for my daughters and my boys. (C22)

The women of the group with diagnosis noted the importance of support networks for people who are living with HIV/AIDS. It is noticeable the difference in terms of information of women who are linked to these groups, in comparison to those who do not have social links with specific groups, such information are on the disease itself and the exercise of citizenship, the right of every human being, regardless of its condition:

[...] It's called [...] movement of Positive Citizens Women. It is a movement of national level and it is present in all Brazilian states. (C21)

The women of the group with no diagnosis still narrated problems of loneliness, helplessness:

Currently [...] I live like this, participating of the group, because I do not like to stay alone at home, just because I have problem of loneliness, did you know? (S14)

The support network for people living with HIV/AIDS (called, in Brazil, of PVHA) encompasses public health services and a set of actions undertaken by organizations of the civil society. In the field of health services, we should cite Hospitals-Day Services, Specialized Care Services in HIV/AIDS (named of SAE), Centers for Testing and Counseling (named of CTA), besides all the coverage offered by the Brazilian Unified Health System - *Sistema Único de Saúde (SUS)*.⁶

In addition to these investments, we should highlight the strategies of educational nature and the promotion of several events with preventive purposes, in order to gather forces to minimize the exposure of the population to the risk factors, and, thereby, decrease the number of individuals with HIV.⁷

DISCUSSION

Regarding the perceptions anchored in the fear and the fact that the women, aged 50 years or more, ensuring that there is no cure for AIDS, it is evident that people with HIV/AIDS hope and, sometimes, even wish for death, sure that it will arrive shortly. It also be inferred that such women "agree that death is better than the coexistence with AIDS".⁸

The fear of prejudice and discrimination is attached to the disease. This theme arose between women from both groups, being strongest among those who were experiencing, daily, situations which exposed them to the fear of abandonment and loneliness.

With regard to death, there is a relationship with people of public life, with highlight in the media and who died from infection by HIV/AIDS, which reinforces the belief that there is no cure, probably because they believe that the higher socioeconomic status could guarantee them the access to healing, if there was it. Still, no matter the time elapsed since the death of these people, because the image that associated AIDS and death keeps inhabiting the popular imagination to the present day.⁷

Relating this approach to the aging, the biological cycle for the human being is consisted of several steps which are socially and culturally constructed. The various societies construct different practices and representations on the old age, social position of the elderly in the community and in their families, as well as the treatment that should be excused to them by youth.⁹

Family and health professionals play a role of great importance in the movement of self-care, of discovery, of diagnosis and acceptance of the disease, besides the understanding that, despite the possibility that some changes occur for that they adapt to their new status, the life quality can be maintained.¹⁰

Within the civil society there are actions developed through regular activities, such as: legal assistance, psychological support, groups of adherence to the treatment, home care and hospital visitation, income generation activities, coexistence centers and others. The work of Civil Society Organizations - *Organizações da Sociedade Civil* (CSOs) has facilitated the social inclusion of the people who are living with HIV/AIDS and their subsequent improvement in the life quality, as well as the articulation in terms of local community resources.⁶

In this context, emphasizing the life quality, patients with HIV/AIDS should be counseled about healthy feeding and sleep, both with regular hours, as they have positive effects in the prevention of opportunistic infections and, consequently, in the life quality of the patient. Exercises and sport activities are also recommended, since there is no specific contraindication. With regard to the emotional aspect, this cannot be despised; assistance and emotional support from professionals are indicated too. Since, a better explanation on the disease and its evolutionary phases help to reduce anxieties and reassure the patient.¹¹

Thus, understanding the concerns of women who are facing, all at once, the agony

of aging in a society that seeks to make gods the youth and, being carriers of a disease with a high rate of morbidity and mortality, with an immense load of prejudice, is the only way to provide adequate support in the confrontation of this emotional load.

CONCLUSION

The social representations obtained in this study allowed the identification of subjective aspects of the feminine being, in the context of infection by HIV/AIDS, especially, for the seizure of a biopsychosocial being who is involved by its historical, social and cultural determinations.

AIDS is represented as a disease that mistreats, generates suffering and causes the death. Moreover, the interaction with the same is permeated by distress, stigmata, social and economic difficulties, disruption of affective bonds, guilt and fear.

Despite so many difficulties, it was also seized that, among women diagnosed with HIV/AIDS, there are gains as the retirement and their insertion into groups of support networks, in which it is addressed the valorization of the individual, regardless of their health condition, expanding the social circle and participation in leisure activities to which, previously, they had no access.

It is essential, then, to qualify health professionals who provide care for this population, especially, the nurses, for that the guidance regarding STDs/HIV/AIDS for the elderly can be practiced in their care in an effective and solver manner, in order that the vulnerabilities outlined in this study are attenuated.

It is suggested that, in the attendance from the health professionals to the population in question, the sexual history of their elderly patients is addressed, questioning the matters related to the sexual issues, such as: sexual activity, number of sexual partners, use of condom and history of STDs, as well as blood transfusions or use of intravenous drugs, allowing the subject to extensive expression of their feelings.

Thus, studies involving issues such as infection by HIV/AIDS in people older than 50 years should be widely encouraged, in order to subsidize the development of actions and prevention programs, justified for several reasons, among them, the changes in sexual habits which were not preceded by incentives for prevention in a population who does not perceive itself as vulnerable - particularly woman who, historically and culturally, presents itself with a disadvantage with

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regard to the gender issues and the lack of studies which show the risks and vulnerabilities to which these individuals are exposed.

envelhecimento. Rio de Janeiro: Fiocruz; 2004. p.11-24.

REFERENCES

1. Rodrigues Júnior AL, Castilho EA. A epidemia de aids no Brasil, 1991-2000: descrição espaço-temporal. Rev Soc Bras Med Trop [Internet]. 2004 Aug [cited 2012 Aug 12];37(4):312-7. Available from: http://www.scielo.br/scielo.php?script=sci_ar ttext&pid=S0037-86822004000400005&lng=en. <http://dx.doi.org/10.1590/S0037-86822004000400005>.
2. Ministério da Saúde (BR) [Internet]. Epidemiologia aids, 2008 [cited 2011 Dec 13]. Available from: <http://www.aids.gov.br/data/Pages/LUMISD3352823ITEMID80FBE363C51842AAA02B89ED8003A071PTBRIE.htm>.
3. De La Torre-Ugarte-Guanilo MC. Vulnerabilidade feminina ao HIV: metassíntese [dissertation]. São Paulo (SP): Escola de Enfermagem, Universidade de São Paulo; 2008.
4. Bardin L. Análise de conteúdo. Lisboa: Edições; 2008.
5. Ministério da Saúde (BR). Conselho Nacional de Saúde. Manual operacional para comitês de ética em pesquisa. Brasília (DF): Ministério da Saúde; 2002.
6. Ministério da Saúde (BR) [Internet]. Rede de Apoio e Serviços de Saúde [cited 2010 Feb 13]. Available from: <http://www.aids.gov.br/data/Pages/LUMIS9F5EF77CPTBRIE.htm>.
7. Lúcio IML, Bastos MLA, Veríssimo RCSS, Lopes MLC, Ferreira FAS. Analysis of studies with a focus on counseling and testing centers for HIV: characteristics and contributions. Rev enferm UFPE on line [Internet]. 2012 Jan [cited 2012 Mar 07];6(2):444-53. Available from: <http://www.ufpe.br/revistaenfermagem/index.php/revista/article/view/2270>.
8. Lima DA. A mulher com idade igual ou superior a 50 anos e a epidemia de aids: percepção e ações de moradoras de uma comunidade de baixa renda [dissertation]. São Paulo (SP): Escola de Enfermagem da Universidade de São Paulo; 2006.
9. Minayo MCS, Coimbra Junior CEA. Entre a liberdade e a dependência: reflexões sobre o fenômeno social do envelhecimento. In: Minayo MCS, Coimbra Júnior CEA, organizadores. Antropologia, saúde e

10. Vieira CP, Lopes MHBM, Shimo AKK. Sentimentos e experiências na vida das mulheres com câncer de mama. Rev Esc Enferm USP [Internet]. 2007 [cited 2012 Mar 07];41(2):311-6. Available from http://www.scielo.br/scielo.php?script=sci_ar ttext&pid=S0080-62342007000200020&lng=en&nrm=iso.
11. Barroso L, Carvalho C, Araújo T, Galvão M. Self-care of a woman with AIDS: a model of nursing care. Online Brazilian Journal of Nursing [Internet]. 2006 Aug [cited 2012 Feb 1];5(2):[about 5 p.]. Available from: <http://www.objnursing.uff.br/index.php/nursing/article/view/289>.

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