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Quality of life and nursing diagnoses of women with AIDS

Qualidade de vida e diagnósticos de enfermagem de mulheres com AIDS

Calidad de vida y diagnósticos de enfermería de mujeres con AIDS

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ABSTRACT:

Aim: To evaluate the quality of life and the nursing diagnoses of women with AIDS.
Methods: Cross-sectional study involving 70 women with AIDS in outpatient follow-up. The sociodemographic and clinical form and the Brazilian version of the World Health Organization Quality of Life - HIV instrument were used for data collection. Nursing diagnoses were determined according to NANDA-I Taxonomy II. The analysis was performed using the Software Statistical Package for Social Sciences (SPSS) version 18.
Results: The majority of women were 18 to 59 years old (98.6%), heterosexual (97.2%) and had an undetectable viral load (54.3%). They presented intermediate quality of life in all domains of the scale and 14 nursing diagnoses were found, especially the Pattern of Ineffective Sexuality, Fear and Death Related Anxiety.
Conclusion: Women with AIDS presented intermediate quality of life, requiring integral and holistic nursing care.

Keywords: Quality of life; HIV; Nursing diagnosis.

RESUMO:

Objetivo: Avaliar a qualidade de vida e os diagnósticos de enfermagem de mulheres com aids.
Métodos: Estudo transversal, envolvendo 70 mulheres com aids em acompanhamento ambulatorial. Para coleta de dados utilizaram-se o formulário sociodemográfico e clínico e a versão brasileira do instrumento *World Health Organization Quality of Life - HIV*. Os diagnósticos de enfermagem foram determinados de acordo com a Taxonomia II da NANDA-I. Realizou-se análise através do *Software Statistical Package for Social Sciences*® (SPSS) versão 18.
Resultados: A maioria das mulheres tinha de 18 a 59 anos (98,6%), era heterossexual (97,2%) e com carga viral indetectável (54,3%). Apresentaram qualidade de vida intermediária em todos os domínios da escala e foram encontrados 14 diagnósticos de enfermagem, destacando-se o Padrão de Sexualidade Ineficaz, Medo e a Ansiedade Relacionada à Morte.
Conclusão: Mulheres com aids apresentaram qualidade de vida intermediária, necessitando de cuidado de enfermagem integral e holístico.

Palavras-clave: Qualidade de vida; HIV; Diagnóstico de enfermagem.

RESUMEN:

Objetivo: Evaluar la calidad de vida y los diagnósticos de enfermería de mujeres con sida.
Métodos: Estudio transversal, involucrando a 70 mujeres con sida en seguimiento ambulatorial. Para la recolección de datos, se utilizó el formulario sociodemográfico y clínico y la versión brasileña del instrumento *World Health Organization Quality of Life* - VIH. Los diagnósticos de enfermería se determinaron de acuerdo con la Taxonomía II de la NANDA-I. Se realizó análisis a través del *software Statistical Package for Social Sciences*® (SPSS) versión 18.

Resultados: La mayoría de las mujeres tenían entre 18 y 59 años (98,6%), era heterosexual (97,2%) y con carga viral indetectable (54,3%). Presentaron calidad de vida intermedia en todos los campos de la escala y se encontraron 14 diagnósticos de enfermería, destacándose el Patrón de Sexualidad Ineficaz, Miedo y la Ansiedad Relacionada con la Muerte.

Conclusión: Mujeres con sida presentaron calidad de vida intermedia, necesitando de atención de enfermería integral y holística.

Palabras clave: Calidad de vida; VIH; Diagnóstico de enfermería

INTRODUCTION

Individual, emotional, cultural and social factors, as well as the impact of the diagnosis and treatment of the disease, can affect the quality of life of people with chronic diseases.(1) In women, quality of life may be more impaired when compared to men, since they are more prone to risk and stress.(2) Men have higher socioeconomic levels, which may facilitate living with chronic diseases, while women have a much greater social burden, since it is culturally their duty to take care of their home and children, work and contribute to family income.(3)

Quality of life is a subjective expression that encompasses the social, environmental and spiritual domains, and has been studied in people living with HIV/ AIDS (PLWHA) since antiretroviral therapy (ART) has led to increased survival of these patients.(4,5) In this context, the nurse professional plays an important role in providing care to PLWHA. In order to identify health-related problems and conduct interventions in a holistic way, the nursing process is available, which is composed of the history, nursing diagnosis, planning, implementation and evaluation.(6) Among these stages of the process, the nursing diagnosis represents a clinical judgment about a human response to health conditions and life processes, or a vulnerability to such an individual, family, group or community response.(7)

The determination of nursing diagnoses in specific populations can point out the main health problems, anticipating alterations, in order to promote means so that the nursing care is directed to the existing real aggravations. However, despite the advantages of using the nursing process, there are still difficulties in implementing it in practice.(8) In view of the above, this study aimed to evaluate the quality of life and the nursing diagnoses of women with AIDS.

METHODS

A cross-sectional and quantitative study, developed from January to July 2013. The research was carried out at the infectology outpatient clinic of a reference University Hospital, in Fortaleza, Ceará, Brazil. Inclusion criteria were women with AIDS, older

than 18 years and using ART. Pregnant women, mentally ill persons and inmates in prisons were excluded.

The sample was scaled to estimate the mean scores of the domains of the PLWHA quality of life assessment instrument, with 95% of confidence that the estimation error did not exceed 5%, considering that the mean of these scores is about 13.7 with a standard deviation of 3.8 [9,10], and that there were 150 female patients followed at the outpatient clinic during the study period, a sample of 70 women with AIDS was estimated.

Data were collected through interviews in a private environment. Patients were invited to participate in the study when they attended the service for care. Data collection was done using two instruments, the Sociodemographic and Clinical Form for PLWHA and the World Health Organization Quality of Life HIV instrument (WHOQOL-HIV bref), validated in Brazil.[11]

The WHOQOL-HIV bref consists of 31 questions divided into six domains: I. Physical, II. Psychological, III. Level of independence, IV. Social relations, V. Environment, VI. Spirituality / religion / beliefs. The questions are scored on a five-point Likert scale. The domains scores were studied in three levels of quality of life: inferior (4-10 points), intermediate (10.1-14.9) and superior (15-20). [10]

After data collection, the nursing diagnoses were determined according to NANDA-I Taxonomy II. Thus, the items in each domain of the WHOQOL-HIV bref instrument were correlated with the defining characteristics of NANDA-I nursing diagnoses. Data analysis was performed using the Statistical Package for Social Sciences (SPSS) version 18. The descriptive variables were expressed as mean, median, standard deviation and distribution of uni and bivariate frequencies. A value of $p<0.05$ was considered statistically significant. To evaluate the internal consistency of the responses to the WHOQOL-HIV bref items, the Cronbach's alpha coefficient was used, where the values represent: weak internal consistency (<0.70), good internal consistency (0.70-0.90), or high consistency (> 0.90).

The development of the study met the national and international standards of research ethics involving human subjects.

RESULTS

Most of the women were aged between 18 to 39 years (51.4%), non-white (61.4%), heterosexual (97.2%), living with a partner (48.6%), had two children (58.6%) and 70.0% were Catholic. The monthly family income was lower than two minimum wages (52.9%), lack of employment was 52.9% and 41.4% had complete primary education. Most had an average of HIV/AIDS diagnosis time of more than five years (82.9%), they had been using ART for more than 12 months (78.6%), they had taken one to three tablets per day (61.4%), undetectable viral load (54.3%) and CD4 + T lymphocyte count greater than 200 cells/mm³ (84.3%).

The mean scores of the WHOQOL-HIV bref domains showed that most women had an intermediate perception about quality of life (Table I). The global Cronbach's alpha was 0.857, demonstrating good reliability of the instrument of quality of life applied in the study.

[Table I. Distribution of quality of life scores of the World Health Organization Quality of Life (WHOQOL-HIV bref) (n = 70)]

Domains of WHOQOL-HIV bref	Mean ± SD*	Medium	Minimum	Maximum	Cronbach's alpha
I. Physical	14.1 ± 3.1	14.0	6.0	20.0	0.446
II. Psychological	14.6 ±3.0	15.2	7.2	19.2	0.553
III. Level of independence	13.4 ±2.6	14.0	5.0	19.0	0.607
IV. Social relations	14.9 ±2.5	15.0	9.0	20.0	0.695
V. Environment	13.9 ±2.2	14.5	6.0	18.5	0.765
VI. Spirituality / religion / believes	14.0 ±3.8	14.0	7.0	20.0	0.356

SD - Standard deviation

Fourteen nursing diagnoses were identified according to NANDA-I Taxonomy II from the WHOQOL-HIV bref domains (Table II).

[Table II. Nursing diagnoses of women with AIDS in antiretroviral therapy according to NANDA-I taxonomy II and WHOQOL-HIV bref domains (n = 70)]

Domains of WHOQOL-HIV Bref	Nursing diagnoses	n (%)
I. Physical		
	Impaired comfort	32 (45.7%)
	Sleep deprivation	32 (45.7%)
	Fatigue	27 (38.6%)
II. Psychological		
	Impaired memory	31 (44.3%)
	Situational low self-esteem	19 (27.1%)
	Anxiety	27 (38.6%)
	Impaired mood regulation	27 (38.6%)
III. Level of independence		
	Impaired walking	10 (14.3%)
	Activity intolerance	21 (30.0%)
IV. Social relations		
	Impaired social interaction	22 (31.4%)
	Ineffective sexuality pattern	39 (55.7%)
V. Environment		
	Deficient diversional activity	35 (50.0%)
VI. Spirituality / religion / believes		
	Fear	37 (52.9%)
	Death anxiety	41 (58.6%)

In the Physical domain of the WHOQOL-HIV bref, 32 women (45.7%) stated that physical pain prevented them from carrying out their daily activities. From this, Impaired comfort was a nursing diagnosis related to the treatment regimen and symptoms of the disease, characterized by dissatisfaction with the situation and symptoms of suffering. Thirty-two patients reported no satisfaction with sleep (45.7%).

So, we identified the nursing diagnosis Sleep deprivation, related to the prolonged discomfort (physical and psychological) and treatment regimen, characterized by fatigue and drowsiness. It is noteworthy that this diagnosis was more common in women with an HIV positive diagnosis' time of more than five years (71.9%) (p = 0.025).

In addition, 28 respondents (38.6%) said they did not have enough energy to develop daily activities. Thus, it was found the nursing diagnosis Fatigue, related to the physiological condition (disease), characterized by impaired ability to maintain habitual routines and insufficient energy. This diagnosis was more present in Catholic women (55.6%) than in other religions (44.4%) (p=0.037), and was also more prevalent in patients with an HIV positive diagnosis time of more than five years (70.4%) (p = 0.028).

In the Psychological domain, 31 women (44.3%) verbalized difficulty of concentrating, being diagnosed Impaired memory, related to distractions in the environment, characterized by forgetfulness. Among the women with AIDS, 19 (27.1%) reported an inability to accept physical appearance, being diagnosed Situational low self-esteem, related to the alteration of the body image and history of rejection, characterized by self-negative verbalizations. This diagnosis was more common in women who reported brown skin color (78.9%) than in those who reported being white (21.1%) (p = 0.048).

Negative feelings, moodiness, anxiety and depression were reported by 27 women (38.6%). Thus, two nursing diagnoses were found: Anxiety, related to stressors and important change (health condition), characterized by anxiety, apprehension and fear, and Impaired mood regulation, related to anxiety, chronic illness and impaired social function, characterized by hopelessness. The diagnosis of Impaired mood regulation was more present in women who lived with less than five people at home (70.4%) compared to those who lived with more than five people (29.6%) (p = 0.011).

Regarding to the Level of independence domain, ten participants (14.3%) claimed that they could not move, and the diagnosis of Impaired walking was found, characterized by impaired ability to travel distances. This nursing diagnosis was more prevalent in women with an HIV positive diagnosis' time of more than five years (60.0%) (p = 0.038). Also, 21 interviewed (30.0%) declared dissatisfaction with the ability to perform daily activities, being diagnosed Activity intolerance, related to generalized weakness, characterized by discomfort to exertion and fatigue. This diagnosis occurred more frequently in Catholics (52.4%) than in other religions (47.6%) (p = 0.035), and was also common among those interviewed with HIV positive diagnoses over five years (66, 7%) (p = 0.019).

In the Social relations domain, 22 women (31.4%) did not feel accepted by the people they knew. Nursing diagnosis was identified Impaired social interaction, related to the absence of significant people, characterized by dissatisfaction with social involvement. This diagnosis occurred more in women who lived with up to five people (68.2%) (p = 0.012).

Thirty-nine participants (55.7%) were dissatisfied with their sexual life, being diagnosed as having an Ineffective sexuality pattern, related to insufficient knowledge of alternatives as well as skills related to sexuality, characterized by a change in

sexual behavior. This diagnosis was more common in brown patients (71.8%) (p = 0.024).

In the Environment domain, 35 patients (50.0%) reported having few leisure activities, identifying the nursing diagnosis Deficient diversional activity, related to insufficient recreation activities, characterized by boredom. In the domain Spirituality / religion / believes, 37 women (52.9%) reported fear of the future. We identified the diagnosis Fear, related to the phobic stimulus and separation of the support system, characterized by fear sensation.

Concern with death occurred in 41 participants (58.6%). It was identified the nursing diagnosis Death anxiety, due to the confrontation with the terminal illness, uncertainty of the prognosis and imminent perception of death, characterized by fear of death and thoughts related to death and dying. This diagnosis was more prevalent in Catholic women (80.5%) (p = 0.023), with one or two children (46.3%) (p = 0.047) and less educated, with 46.3% of them with elementary school (p = 0.009).

DISCUSSION

Stand out in this study women with AIDS in childbearing age, low schooling and precarious socioeconomic conditions, agreeing with other articles.[12-13] It was observed a longer survival of PLWHA compared to the initial years of the epidemic. This is due to the introduction of ART in Brazil, which led to a 33% reduction in the mortality of people with AIDS.[14,15]

Undetectable viral load and CD4 + T lymphocyte count greater than 200 cells/ mm^3 were found in most patients. Studies have shown that individuals with a CD4 + T lymphocyte count greater than 200 cells/ mm^3 and undetectable viral load are more likely to abandon ART. Therefore, it is emphasized the regular evaluation of health parameters, above all, in order to prevent diseases and promote the health of PLWHA[15,16]

Regarding to the mean scores of the WHOQOL-HIV bref instrument, the results corroborated with another study, in which, for most domains, the mean scores indicated an intermediate perception about quality of life. [10] Stood out a lower mean lower in the domain Level of independence, inferring that women with AIDS had changes in mobility and daily activities as well as dependence on treatments and interference in work capacity. This may be associated with lifestyle modification after the diagnosis of positive anti-HIV serology, introduction of ART, and prejudice as well as stigma. [10] The domain Level of independence was associated with the use of drugs, and it was explained by the dependence of medication and less work capacity due to health changes. [17]

Intermediate scores in the Physical and Psychological domains agreed with the literature, since there is a clear association between quality of life and the use of ART, both by improving the immunological capacity and by deconstructing the idea of death when the disease is diagnosed. However, drug therapy is also associated with adverse effects that interfere with PLWHA quality of life. [16,18]

The intermediate perception of the quality of life presented in the Environment domain, which represents physical security, housing, finances, access to health and social assistance, capacity to acquire information and to learn new skills, leisure, physical

environment as well as transportation, converged with another research held in an African country. These results may be associated with the low level of schooling and per capita income of PWLHA, which leads to an unfavorable socioeconomic situation, limiting the domestic environment, financial resources, accessibility and quality of health as well as social assistance.[19]

Prejudice and exclusion by family members and friends of PLWHA are associated with the low levels of mean scores in the Social relations domain. (17) However, in this research, the best mean scores were obtained in this domain, indicating that the women evaluated probably had the support of family, friends and partners. The favorable family environment is capable of providing security, protection and financial support, and can have a positive impact on the quality of life of the individuals.[15]

In the evaluation of the Spiritual domain, the average of intermediate scores can be justified by the fact that most women professed some religion. Therefore, another research affirms that religious well-being contributes to a sense of comfort that facilitates living with HIV and promotes individuals' capacity for resilience. [13]

A total of 14 nursing diagnoses were identified, highlighting Ineffective sexuality pattern, Fear and Death anxiety. These findings are in line with another study that assessed PLWHA quality of life and also identified these three diagnoses, among others. [20]

The nursing diagnosis Ineffective sexuality pattern can be justified by fear of transmitting the virus to the sexual partner, fear of rejection, trauma from having acquired HIV through sexual intercourse with a trusted partner, or remorse for prostitution, homosexuality, and infidelity. Another study ensures frequent disturbances in the sexual activities of PLWHA. [21]

The diagnoses Death anxiety and Fear may occur because PLWHA are more vulnerable to psychological disorders. [3] The lack of social support, stigmatization, prejudice and marginalization to which people with HIV/AIDS are subjected are risk factors to anxiety and fear. [15] The lack of information on the chronicity of HIV/AIDS, the use and benefits of ART, and the fear of death due to the disease still have no cure, contribute to the occurrence of these diagnoses in PLWHA.

Also, the diagnoses Sleep deprivation, Fatigue, Impaired walking and Activity intolerance were more prevalent in women diagnosed as HIV positive for more than five years. This study points out that people in the more advanced stage of the disease are more prone to sleep disorders, fatigue and difficulty of performing daily activities due to the side effects of ART and disease-related anxiety. [22]

The occurrence of the nursing diagnoses Situational low self-esteem and Ineffective sexuality pattern in brown women can be justified by social inequalities and racism. There are difficulties in the access to health by PLWHA, revealing discriminatory situations in care and the presence of racism. The difficulty of brown and black people in accessing health services causes suffering, individual vulnerability and low self-esteem. [23] Moreover, due to the non-accessibility of health care, this population may not develop empowerment, presenting problems related to sexuality and reproductive health.

Impaired mood regulation and Impaired social interaction were common in women who lived with up to five people at the same house. People living with HIV/AIDS are more likely to have mood disorders, depression, and social isolation because of fear, stigma and discrimination. Thus, family social support is a positive reinforcement in the search for better conditions to cope with the disease. [24] Finally, the diagnosis of Death anxiety was more present in patients who had one or two children. This finding is justified by the fear that PLWHA have to die and leave their children economically or emotionally helpless. [25]

CONCLUSION

Women with AIDS had intermediate perceptions about quality of life for most WHOQOL-HIV bref domains. Among the 14 nursing diagnoses identified, it is highlighted Ineffective sexuality pattern, Fear and Death anxiety.

The limitation of the study was the non-implementation of the complete nursing process, since the patients' returns occurred every four months, and many did not return at the correct date, making it difficult to follow up. In addition, despite the scale of quality of life used in the study enable the formulation of nursing diagnoses, it is possible to say that this fact restricts the diagnoses, requiring the collection of sociodemographic and clinical data to increase the understanding of the life context of the women with AIDS, which was carried out in this research.

However, because studies on nursing diagnoses of PLWHA are scarce, this research may direct nursing interventions to improve the quality of life of women with AIDS, providing subsidies for holistic health care.

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