Correlations in the quality of life of people with HIV/AIDS in the Amazon region

Correlações na qualidade de vida de pessoas com HIV/AIDS na região amazônica

Correlaciones de la calidad de vida de personas con el VIH/SIDA en la región amazónica

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Abstract

Objective: To evaluate the quality of life of people living with HIV/AIDS (PLWHA) and undergoing outpatient follow-up at a university hospital in the Amazon region (Belém, PA).

Methods: This was a cross-sectional descriptive study. Data were collected in November and December 2019 using a form with sociodemographic variables and the specific WHOQOL-HIV Bref instrument. Sociodemographic variables were analyzed using descriptive statistics. The inferential analysis of the WHOQOL-HIV Bref instrument was performed using the Spearman correlation test between the quality-of-life domains.

Results: A total of 208 patients were interviewed. They were born with male biological sex (66.3%), heterosexual (67.3%), and aged 36-55 years (57.2%). The highest mean score was found in the spiritual domain (17.1±2.8) and the lowest in the independence-level domain (4.2±2.8). In general, moderate positive correlations were observed; only the correlation between the independence level and spirituality domains was not statistically significant ($p>0.05$).

Conclusion: The results suggest that social and religious support, employment, and access to health services can improve the quality of life of PLWHA in the Amazon region. More research on the quality of life of PLWHA is necessary to improve public policies equitably and equally in Brazil, especially in the Brazilian Amazon where a continuous increase in the number of PLWHA has occurred.

Resumo

Objetivo: Avaliar a qualidade de vida de pessoas que vivem com HIV/AIDS (PVHA) e fazem seguimento ambulatorial em um hospital universitário na região amazônica (Belém, PA).

Métodos: Este foi um estudo descritivo transversal. Os dados foram coletados em novembro e dezembro de 2019 aplicando um formulário com variáveis sociodemográficas e usando o instrumento específico WHOQOL-HIV *Bref*. As variáveis sociodemográficas foram analisadas usando estatística descritiva. A análise inferencial do instrumento WHOQOL-HIV *Bref* foi realizada usando o teste de correlação de *Spearman* entre os domínios da qualidade de vida.

Resultados: Foram entrevistados 208 pacientes, sendo 66,3% nascidos com o sexo biológico masculino, 67,3% heterossexuais e 57,2% com faixa etária de 36-55 anos. O maior escore médio foi encontrado no domínio espiritual (17,1±2,8) e o menor no domínio nível de independência (4,2±2,8). Em geral, foram observadas correlações moderadas positivas; só a correlação entre os domínios nível de independência e espiritual não foi estatisticamente significante (p>0,05).

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Conclusão: Os resultados sugerem que os apoios social e religioso, emprego e acesso a serviços de saúde podem melhorar a qualidade de vida de PVHA na região amazônica. São necessárias mais pesquisas sobre a qualidade de vida de PVHA para aprimorar as políticas públicas igualitariamente e equanimemente no Brasil, especialmente na Amazônia Brasileira que tem tido um aumento contínuo no número de PVHA.

Resumen

Objetivo: Evaluar la calidad de vida de personas que viven con el VIH/SIDA (PVVS) y que realizan seguimiento ambulatorio en un hospital universitario de la región amazónica (Belém, estado de Pará).

Métodos: Se trató de un estudio descriptivo transversal. Los datos se recopilaron en noviembre y diciembre de 2019 mediante la aplicación de un formulario con variables sociodemográficas y la utilización del instrumento específico WHOQOL-HIV *Bref*. Se utilizó la estadística descriptiva para analizar las variables sociodemográficas. El análisis inferencial del instrumento WHOQOL-HIV *Bref* se realizó con la prueba de correlación de *Spearman* entre los dominios de la calidad de vida.

Resultados: Se entrevistaron 208 pacientes, de los cuales el 66,3 % era de sexo biológico masculino, el 67,3 % era heterosexual y el 57,2 % estaba dentro del grupo de edad de 36 a 55 años. La puntuación promedio más alta fue en el dominio espiritual (17,1±2,8) y la más baja en el dominio nivel de independencia (4,2±2,8). En general, se observaron correlaciones moderadas positivas. La única correlación que no fue estadísticamente significativa fue entre el dominio nivel de independencia y espiritual (p>0,05).

Conclusión: Los resultados sugieren que el apoyo social y religioso, el empleo y el acceso a los servicios de salud pueden mejorar la calidad de vida de PVVS en la región amazónica. Es necesario realizar más estudios sobre la calidad de vida de PVVS para mejorar las políticas públicas de forma igualitaria y ecuánime en Brasil, especialmente en la Amazonia brasileña que presenta un aumento continuo del número de PVVA.

Introduction

The emergence of acquired human immunodeficiency syndrome (AIDS) in the 1980s is related to the contagion of groups of people through sexual contact and sharing of needles and syringes containing illicit substances. This period was marked by great suffering as the disease is serious and fatal, with a strong psychological impact on the bearers.[1]

During a historical period, the HIV/AIDS epidemic was erroneously associated with men who had sexual relations with other men (MSM), fueling stereotypes (such as *gay plague* or *gay cancer)* originating from North American culture.[2] However, we have observed a significant change in the profile of infected people in the Brazilian context in recent decades, with emphasis on heterosexual transmission of the disease. According to data from the Ministry of Health, the growing number of cases related to heterosexual transmission (which affects both men and women) is what draws the most attention, although a notable equivalence exists in the HIV/AIDS transmission rates between MSM and heterosexual men.[3]

This phenomenon reflects a marked change in the dynamics of the HIV/AIDS epidemic in the country, highlighting the need for prevention and awareness strategies. These strategies must effectively address the new epidemiological reality, including sexual education measures, regular testing, and access to prevention methods such as the use of condoms for all people and pre-exposure antiretroviral therapy to reduce the transmission, spread of HIV/AIDS, and promote an effective response to the epidemic.[3]

The advent and use of antiretroviral medications have an important role in controlling AIDS, quality of life (QoL), and survival of people living with HIV (PLWHA). Zidovudine was the first antiretroviral drug used in the world to treat people with HIV. Then, protease inhibitors emerged. This period was marked by clinical studies of antiretroviral combinations around the world. The era of antiretroviral therapy (ART) was characterized by the continued development of new classes of antiretroviral drugs to combat HIV infection.[4]

Antiretroviral therapy significantly increased the survival of PLWHA and the QoL theme became part of several studies. Despite the great social relevance of QoL, it presents theoretical-methodological inaccuracies making its evaluation difficult.[5-7] Although viral suppression remains an important target, it should not be the priority objective in the HIV care cascade as many PLWHA continue to have a poor quality of life, significantly worse than that of the general population although they are virologically suppressed.[8]

To end inequalities and promote well-being, the Joint United Nations Program on HIV/AIDS (UNAIDS) has decided that new strategies must be adopted, based on a more holistic and people-centered approach beyond the current framework of

testing-centered response, treatment, and viral suppression.[9]

The use of QoL assessment instruments, *i.e.,* constructs containing items grouped by affinities is one of the ways to measure well-being in PLWHA. Currently, two types (generic and specific) of instruments are used to assess QoL in PLWHA.[8] Generic instruments allow comparing different diseases but they may not adequately capture QoL aspects relevant to PLWHA (such as HIV-related stigma or specific side effects related to antiretroviral medications). Differently, specific instruments for QoL are designed to respond to changes related to the illness. However, they face challenges of comparison with other diseases.[10]

Thus, the objective of the present study was to evaluate the QoL of PLWHA who receive ART in the outpatient clinic of a university hospital in the Amazon region. The results can be used to propose health promotion measures in conjunction with other professional categories, helping PLWHA to understand and improve the affected areas, thus promoting an improvement in QoL.

Methods

This descriptive and cross-sectional study was developed in the outpatient service of the Hospital Universitário João de Barros Barreto (SAE/HUJBB; managed by Empresa Brasileira de Serviços Hospitalares, EBSERH; Belém, PA). The service was specialized in the care of PLWHA and followed a population of 450 PLWHA when the study was performed. The sampling was probabilistic (simple random type), including patients who went to SAE/HUJBB to obtain antiretroviral medications and were awaiting a medical appointment with an infectologist in the period Nov-Dec 2019.

The criteria for inclusion of participants were as follows: PLHA of both sexes and over 18 years of age who were being treated with antiretroviral medications. Patients with cognitive impairment who did not understand the questionnaires administered and/or incorrectly completed questionnaires were excluded from the study.

To calculate the sample size, the expected percentage of QoL loss was not estimated. Then, we assumed the value of 50% which maximizes the sample size in epidemiological studies, allowing us to reach conservative values. Taking an acceptable sampling error of 5% and a confidence level of 95%, we obtained a sample of 208 patients.

The researcher used two instruments to record the collected data. The first instrument consisted of a structured form with objective and subjective questions containing sociodemographic variables. The questions that could cause doubts to the participants were transcribed in two versions; one of them was written simply and objectively for people with a lower level of understanding.

The second instrument (WHOQOL-HIV Bref) was developed by the WHO (2003) and was culturally adapted and validated for Brazilian Portuguese in 2007.[11] The WHOQOL-HIV Bref instrument is specific for assessing QoL in PLWHA. Its abbreviated version is composed of 29 facets, 31 questions, and the following six domains: physical, psychological, independence level, social relationships, environment, and spirituality. All questions were objective, and a *Likert*-type response scale (1-5; 1: worst level; 5: best level of QoL) was used. However, seven items (3, 4, 5, 8, 9, 10, and 31) had an inverted response pattern (1: best level; 5: worst level of QoL).[12]

After the collection was completed, the data were entered into an Excel 2010 (Windows 7) spreadsheet and subjected to consistency analysis using double entry. After comparing the two typed spreadsheets, the data was checked, corrected (in cases of inconsistency), and exported to the Statistical Package for the Social Sciences (v. 20.0) program.

Sociodemographic variables were analyzed using descriptive statistics. Regarding the WHOQOL-HIV Bref instrument, it was checked whether all questions were filled out correctly. Afterward, the inverted-scale questions were inverted, *i.e.,* items 3, 4, 5, 8, 9, 10, and 31 had their original scores (1, 2, 4, and 5) recoded (5, 4, 2, and 1). Thus, the domain scores were calculated by adding the scores of the *n* questions that make up each domain and dividing

the sum by the number of questions in the domain. The result was multiplied by 4, being represented on a 4-20 scale.

As an official stratification does not exist for the score values on the WHOQOL-HIV Bref scale, a classification of scores on this scale was adopted based on what has been used in the literature. The scores were then classified into three categories: low (4.0-9.9), medium (10.0-14.9), and high (15.0-20.0) QoL.[13,14]

Finally, the non-parametric Spearman correlation test was used to correlate the WHOQOL-HIV Bref domains, as the facets of the WHOQOL-HIV Bref did not present a normal distribution (verified using the Kolmogorov Smirnov test). The following values of Spearman's ρ were considered: 0.00-0.30: weak correlation, >0.30-0.50: moderate correlation, and >0.50: strong correlation. A significance level of 5% ($p \leq 0.05$) was adopted for the statistical test.[15]

This study was submitted to the Ethics and Research Committee of the Evandro Chagas Institute (Opinion: 3.518.094; CAAE: 13425119.0.0000.0019) and approved. At the same time, the study was assessed by the HUJBB Research Ethics Committee (Opinion: 3.599.171; CAAE: 13425119.0.3001.0017) and also approved.

Results

A total of 208 PLHA followed in SAE/HUJBB were interviewed and 138 of them were male. Table 1 shows the sociodemographic description of the study participants.

Table 2 shows the scores of the WHOQOL-HIV Bref instrument identifying the most "affected" QoL domains. Four of the six domains evaluated had high QoL. The highest mean score was found in the spiritual domain (17.1±2.8) and the lowest in the independence level domain (14.2±2.8).

In the correlation analysis between the six WHOQOL-HIV Bref domains, generally positive moderate correlations were observed. Only the correlation between the independence level and spiritual domains was not statistically significant ($p>0.05$).

Table 1. Sociodemographic characteristics of people living with HIV and/or AIDS followed at the outpatient clinic

Variables	n(%)
Birth sex	
Masculine	138(66.3)
Feminine	70(33.7)
Sexual orientation*	
People of the same sex	35(16.8)
People of different sex	140(67.3)
People of both sexes	31(14.9)
No answer	2(1)
Gender identity	
Man	133(63.9)
Woman	72(34.6)
Transsexual woman	3(1.4)
Cross-dresser	0(0)
Transsexual man	0(0)
Age (years)	
≤35	60(28.8)
36-55	119(57.2)
Above >55	29(13.9)
Education	
Illiterate	3(1.4)
Incomplete primary	52(25)
Complete primary	22(10.6)
Incomplete secondary	30(14.4)
Complete secondary	75(36.1)
Incomplete higher	17(8.2)
Complete higher	9(4,3)
Marital status*	
Single	131(63)
Married	34(16.3)
Stable union	31(14.9)
Divorced	3(1.4)
Widower	7(3.4)
Individual monthly income (SM)*	
≤1	126(60.6)
1-3	51(24.5)
>3	9(4.3)

SM: minimum wage; *Not everyone responded (n<208)

Table 2. Assessment of quality-of-life scores in different domains

Domains	Mean (SD)	Minimum	Maximum	1st quartile	Median	2nd quartile
Physical	15.9(3.2)	6.0	20.0	14.0	17.0	18.0
Psychological	15.5(2.5)	4.8	20.0	14.4	16.0	17.6
Independence level	14.2(2.8)	7.0	20.0	12.3	14.0	16.0
Social relationships	15.8(2.7)	8.0	20.0	14.7	16.0	17.3
Environmental	14.6(2.1)	8.0	19.5	13.5	14.5	16.0
Spiritual	17.1(2.8)	5.0	20.0	16.0	18.0	19.0

SD: Standard deviation

The highest correlations were observed between the independence level and physical domains as well as between the environment and social relationships domains (ρ=0.58) (Table 3).

Table 3. Correlations between the domains of the WHOQOL HIV Bref instrument

Domains	Physical	Psychological	Independence level	Social relationships	Environmental	Spiritual
Physical	1.00	0.44*	0.58*	0.36*	0.41*	0.23*
Psychological		1.00	0.29*	0.45*	0.51*	0.54*
Independence level			1.00	0.32*	0.30*	0.02
Social relationships				1.00	0.58*	0.35*
Environmental					1.00	0.38*
Spiritual						1.00

* p<0.05

Discussion

After the advent of ART, the natural history of HIV infection took on new directions. However, studies on the QoL of this population in Brazil are few, especially in the Amazon region, although ART has provided significant changes in the lives of PLWHA (who now live with a chronic disease).

The study of QoL in PLWHA is important to monitor the impact of the disease or the progress of HIV/AIDS infection as it can be used to know if there are hindering factors in the adherence to the antiretroviral treatment. It can be clinically useful to identify the most affected aspects or dimensions of QoL and monitor how changes occur during the natural history, in addition to allowing measurement of treatment results with the use of new antiretroviral drugs.

Regarding the analysis of sociodemographic variables, a predominance of males was observed compared to females. This agrees with the Ministry of Health's estimates of the HIV/AIDS epidemic in Brazil indicating that men are more affected.[3] This gender disparity in HIV/AIDS incidence is multifaceted and reflects an intersection of factors, including different risk behaviors, gender inequalities, and issues related to migration and population mobility. This discussion further highlights the importance of gender-specific prevention and education strategies to promote protective behaviors and strengthen equal access to health services, effectively tackling the spread of HIV/AIDS in Brazil.

Noting sexual orientation and gender identity is important. These factors must be considered when evaluating the QoL of PLWHA, as highlighted in a study performed with MSM and transgender women in Argentina.[16] Heteronormativity (considering heterosexuality as a sexual behavioral standard) contributes to marginalizing LGBTQIAPN+ identities and can lead to double discrimination for LGBTQIAPN+ PLWHA, negatively impacting their well-being and QoL.[17] Therefore, recognizing and incorporating sexual orientation and gender identity in research, public policy, and care practices are essential to ensure that the individual needs of PLWHA are met in an appropriate and diversity-sensitive manner. Furthermore, this more inclusive approach contributes to combating stigma and promoting a supportive environment that respects and values the diversity of gender identities and sexual orientation, thus improving the QoL of PLWHA.

Educational level and individual monthly income are also other relevant aspects to consider regarding the QoL of PLWHA. Education is a factor that can positively influence QoL as it is associated with greater knowledge about the disease, greater adherence to treatment, and less exposure to risk situations.[6] Monthly income can also directly affect QoL as it is related to the ability to meet basic needs and enjoy goods and services that contribute to physical, mental, and social well-being.[17] In this sense, public policies aimed at PLWHA must consider the social and economic factors, thus promoting the educational and professional inclusion of this population. Thus, improving not only the physical and mental health of PLWHA but also their autonomy, self-esteem, and social participation would be possible.

As for marital status, single people had a higher prevalence in this study. A study conducted in Iran analyzed the main factors that influence the QoL of PLWHA and revealed that married individuals tend to have better QoL compared to single ones.[18] However, another study suggested that marital status is not a significant determinant of PLWHA's QoL, and other

aspects, such as social support and treatment adherence, are more relevant.[13] Then, the diversity and complexity of PLWHA's affective relationships must be considered, not only their marital status. Thus, it would be possible to better understand how these relationships influence the QoL of PLWHA and how to promote appropriate psychosocial interventions for this population.

The spirituality domain had the highest mean score found on the WHOQOL-HIV Bref scale. Similar results were found in studies conducted in Brazil and Nigeria.[19,20] This fact can be partially explained as the populations of the present study and the studies mentioned above were predominantly religious. However, recognizing that spirituality is personal and diverse is fundamental, as it is shaped by individual and cultural beliefs.[21] These results also remind the need for patient-centered care approaches, respecting and accommodating different spiritual beliefs, when necessary, as components of holistic care and promoting the QoL of these individuals.

The lowest mean values on the WHOQOL-HIV Bref scale were found in the independence level and environmental domains. These results were similar to those from a Brazilian study.[19] Another investigation found the lowest results in the environmental and social relation domains. Differently, a study that evaluated the QoL of PLWHA in a Spanish population revealed the lowest results in the spiritual domain.[20,22] In the different populations studied, these differences may reflect sociocultural and economic characteristics, as well as individual and contextual factors that influence the QoL of PLWHA in addition to clinical and epidemiological aspects. Thus, developing intervention strategies would be possible considering the different macroscopic aspects that influence QoL.

The present study found significant correlations between the WHOQOL-HIV Bref domains. Previous research also found similar results, indicating positive and significant correlations between the WHOQOL-HIV Bref domains,[19,20] whereas other studies found positive correlations only between domains without reaching statistical significance.[22] These findings suggest that the WHOQOL-HIV Bref domains are interrelated, and improvement or worsening in one domain can affect the others. Thus, multidimensionally evaluating the QoL of PLWHA is important, developing interventions that promote balance and harmony between domains.

The highest correlations were observed between the independence level and physical domains. These findings are consistent with previous research that found similar results between the same domains.[20,22] These results reinforce the importance of a better understanding of the relationship between the ability to independently perform daily activities and physical health. They also emphasize the need for intervention strategies to improve people's autonomy and thus improve QoL, especially in the physical aspect of the populations studied. In addition, a strong correlation was observed between the environmental and social relationship domains, indicating that environmental conditions can influence the quality of social relationships.[23]

One of the limitations of the present study was that it was performed in a single reference center for monitoring PLWHA in the metropolitan region of Belém. Furthermore, the adoption of a cross-sectional study can also be considered a limitation, as data collection was performed at a single moment. Differently, the assessment in longitudinal studies is performed in at least two different moments. A second assessment could highlight some change in the perception of the QoL of PLWHA. Although some limitations were identified, they do not affect the results obtained nor the importance of the topic, considering the scarcity of studies on the subject and the possibility of reflecting on the results obtained and the QoL of PLWHA in the Amazon region.

Conclusion

Social and religious support, having a job, and access to health services can improve the quality of life of people living with human immunodeficiency virus and acquired immunodeficiency syndrome in the Amazon region. Interventions to improve the

quality of life of people living with HIV can be more specific, assertive, and effective with a comprehensive and multidimensional view. More research on the quality of life of people living with HIV/AIDS is needed to improve public policies with equality and equanimity in Brazil, especially in the Brazilian Amazon.

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Collaborations

Vera SO, Paes AL, and Chaves TS contributed to the study design, analysis and interpretation of data, writing of the manuscript, relevant critical review of intellectual content, and approval of the final version to be published.

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