

# Quality of life and associated factors in people living with HIV/AIDS

Qualidade de vida e fatores associados em pessoas vivendo com HIV/AIDS

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## Keywords

Quality of life; HIV; HIV infections; Acquired immunodeficiency syndrome; Public health nursing; Questionnaires

## Descritores

Qualidade de vida; HIV; Infecções por HIV; Síndrome de imunodeficiência adquirida; Enfermagem em saúde pública; Questionários

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## Abstract

**Objective:** To evaluate quality of life and the associated factors in people living with HIV/AIDS.

**Methods:** A cross-sectional study was performed with 146 people with HIV, receiving outpatient treatment. The instruments used were: a questionnaire for socioeconomic, demographic, epidemiological and clinical evaluation and the WHOQOL-HIV *BREF* scale for the quality of life evaluation. A descriptive analysis and a stepwise forward multiple linear regression test were performed.

**Results:** There was a predominance of male gender, lower educational level, and people who were asymptomatic. The Level of Independence and Environment domains had the worst scores. Having a paid occupation, the income *per capita*, having a religion, a longer time since diagnosis, and adherence to treatment were positively associated with quality of life. A homo-affective relationship, having been stigmatized or suffered prejudice, the presence of psychosocial symptoms, and having acquired opportunistic infections were predictors associated with a poorer quality of life.

**Conclusion:** Quality of life had associated predictors and compromise in two areas of the scale.

## Resumo

**Objetivo:** Avaliar a qualidade de vida em pessoas vivendo com HIV/AIDS e os fatores associados.

**Métodos:** Estudo transversal, realizado com 146 pessoas com HIV em tratamento ambulatorial. Os instrumentos utilizados foram: questionário para avaliação socioeconômica, demográfica, epidemiológica e clínica e a escala WHOQOL HIV-*bref* para avaliação da qualidade de vida. Foi realizada análise descritiva e empregado o teste de Regressão linear múltipla com modelagem *stepwise forward*.

**Resultados:** Houve prevalência do sexo masculino, baixa escolaridade e assintomáticos. Os domínios Nível de independência e Meio ambiente tiveram os piores escores. Ter ocupação remunerada, renda *per capita*, possuir religião, maior tempo de diagnóstico e adesão ao tratamento associaram-se positivamente à qualidade de vida. Relação homoafetiva, ter sofrido estigma ou preconceito, presença de sintomas psicossociais e ter adquirido infecções oportunistas foram preditores associados à pior qualidade de vida.

**Conclusão:** A qualidade de vida apresentou preditores associados e comprometimento em dois domínios da escala.

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**Conflicts of interest:** none to declare.

## Introduction

There are currently over 35 million people living with the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) worldwide.<sup>(1)</sup> The conquest of access to treatment, adherence to the antiretroviral therapy, the expansion of the diagnosis identification, and the chronic nature of the disease have created impacts on the quality of life of these people, leading to an increase in the survival time, a decrease in morbidity and mortality, an increase in the life expectancy, and a redefinition of future projects.<sup>(2)</sup>

In this context, the possibility of a longer life is not directly linked to a good quality of life, because HIV infection also implies changes related to coping with the HIV serostatus, such as the regular use of antiretroviral therapy, self-perception and the clinical stage of the disease, bodily changes, personal income, occupation, victimization due to discrimination and prejudice, lack of social support, and depressive symptoms.<sup>(3-5)</sup>

As a broad World Health Organization (WHO) concept, quality of life is the individuals' perception of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.<sup>(6)</sup> It is a comprehensive evaluation of the individuals' perceptions of a number of domains.

In recent years, in response to the struggle of coping with AIDS, interest has increased in evaluating the quality of life in people with HIV, based on the human needs affected by the chronic nature of the disease, progressing from clinical and laboratory outcomes (CD4, viral load and opportunistic infections), to the bioethical and socio-cultural dimensions.

To this end, the aim of this study was to evaluate quality of life and the associated factors in people living with HIV/AIDS.

## Methods

This was a cross-sectional, exploratory study with a quantitative approach, conducted with 146 people

living with HIV/AIDS who were receiving care in a specialized care center of an integrated health center in the state of Piauí, in the Northeastern region of Brazil.

The inclusion criteria for the study were: individuals of both genders, older than or equal to 18; positive HIV-serologic test result, with or without the development of the syndrome; use of antiretroviral therapy; being at the specialized care service at the time of data collection; residency in Teresina (PI); having physical, mental and psychological capacity to participate in the interview; and, agreeing to participate in the study. The exclusion criteria were: individuals deprived of their freedom, or those with cognitive difficulties.

The selection of participants was accidental, when they went to the service for medical care in a private place, before the start of the consultation. Data were collected through interviews, from August to December of 2013, by administering a questionnaire for socioeconomic, demographic, epidemiological and clinical evaluation, and an instrument previously translated and validated in Brazil, the World Health Organization Quality of Life (WHOQOL) HIV-BREF scale, used to measure parameters of quality of life specifically for people living with HIV/AIDS.

For data analysis, the Statistical Package for the Social Sciences (SPSS), version 19.0 for Windows, was used. To characterize the study population (univariate analysis), a descriptive analysis was performed using means and standard deviations for the quantitative variables, and proportions for qualitative variables.

The socioeconomic, demographic, epidemiological and clinical variables related with HIV were presented through univariate distributions of frequencies and descriptive measures. The WHOQOL-HIV-BREF reliability was analysed using the Cronbach's alpha. The calculation of scores was performed by following the syntax proposed by the WHOQOL Group. In the final model of the analysis, the socioeconomic, demographic, epidemiological and clinical variables were dichotomized and transformed into dummy variables by means of multiple linear regression, by adopting the stepwise

forward modeling with a statistical significance set at 5% ( $p \leq 0.05$ ) and a 95% confidence interval.

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

## Results

The socioeconomic and demographic characteristics of the sample evidenced a prevalence of males (63.7%), a mean age of 38.4 years (standard deviation 12.1), lower educational level (43.8%), single (74.7%), non-practicing any religion (57.5%), with a paid occupation (71.2%), personal income between one and two minimum wages, and distribution of per capita income lower than the minimum wage, in a setting of up to four people per household (67.8%). The predominant type of relationship was heterosexual (86.3%). In the clinical analysis, there was a prevalence of asymptomatic cases (44.5%), with time since diagnosis between two and eight years (64.4%), presence of adherence-related issues (78.8%), absence of opportunistic infections (65.8%), presence of psychosocial symptoms - such as fear, anxiety, depression (76.0%), and having been stigmatized or suffered prejudice (61.6%), as shown in table 1.

In the WHOQOL-HIV-BREF dimensions, the most affected domains were: Level of independence (55.1) and Environment (59.2). The Psychological domain (67.9) had a better evaluation of quality of life, followed by the Spirituality, religion and personal beliefs (65.7) and social relations (65.0) domains, as shown in table 2.

The final multiple regression model of the determinants that significantly differ within the quality of life domains are presented in table 3. In the six domains, those which mostly explained the quality of life were Social relationships (40.4%) and Environment (40.1%).

In the multivariate analysis, the predictors contributing to increased quality of life scores in the physical domain, in order of influence of the adjusted linear regression coefficient ( $\beta$ ) were: income per capita higher than three minimum wages ( $\beta = 11.93$ ;

**Table 1.** Sample characteristics according to socioeconomic, demographic, epidemiological and clinical variables

Variables	n(%)	Mean ( $\pm$ SD)
Gender		
Male	93(63.7)	
Female	53(36.3)	
Age group (years old)		38.4 $\pm$ 12.1
$\leq 39$	89(61.0)	
$\geq 40$	57(39.1)	
Education		
Elementary	64(43.8)	
Secondary	56(38.4)	
Higher education and Graduation	26(17.8)	
Marital status		
Single/separate/ divorced/ widow(er)	109(74.7)	
Married/civil union	37(25.3)	
Religion		
Practicing	62(42.5)	
Not practicing	84(57.5)	
Paid occupation		
Formal and informal work	104(71.2)	
Unemployed/retired	42(28.8)	
Personal income (R\$)		1.185.7 $\pm$ 1.725
No income to <1 MW*	50(34.3)	
1-2 MW	78(53.4)	
>3 MW	18(12.3)	
Income <i>per capita</i> (R\$)		832.4 $\pm$ 152.2
< 1 MW*	87(59.6)	
1-3 MW	47(32.2)	
>3 MW	12(8.2)	
People living in the same household		3.8 $\pm$ 2.3
$\leq 4$	99(67.8)	
>4	47(32.2)	
Type of affective relationship		
Heterosexual	126(86.3)	
Homo-affective	20(13.7)	
HIV infection stage		
Asymptomatic	65(44.5)	
Symptomatic	35(24.0)	
AIDS	46(31.5)	
Time since the infection was diagnosed (years)		
$\leq 1$	33(22.6)	
2-8	94(64.4)	
$\geq 8$	19(13.0)	
Adherence to treatment		
Correctly adheres	31(21.2)	
Adherence issues	115(78.8)	
Opportunistic infections		
Yes	52(35.6)	
No	96(65.8)	
Psychosocial symptoms		
Yes	111(76.0)	
No	35(24.0)	
Has been stigmatized/suffered prejudice		
Yes	90(61.6)	
No	56(38.4)	
Total	146(100.0)	

\*The MW when the study was performed was R\$678.00; SD - Standard deviation; MW - Minimum Wage

$p = 0.035$ ) and one to three minimum wages ( $\beta = 7.80$ ;  $p = 0.020$ ). The physical domain included evaluation

**Table 2.** Distribution of the quality of life scores in the domain of the *World Health Organization Quality of Life (WHOQOL) HIV-BREF*

WHOQOL HIV-BREF Domains	Mean	SD	Minimum	Maximum	Median	Cronbach's Alpha
Physical	62.5	20.3	12.5	100.0	62.5	0.80
Psychological	67.9	17.8	5.0	100.0	70.0	0.78
Level of independence	55.1	15.5	18.8	87.5	56.3	0.79
Social relationships	65.0	19.3	6.3	100.0	62.5	0.81
Environment	59.2	17.6	25.0	100.0	59.4	0.78
Spirituality, religion and personal beliefs	65.7	23.1	6.3	100.0	68.8	0.82
Global	64.1	20.1	12.5	100.0	62.5	0.82

SD - Standard Deviation

of energy and fatigue in the performance of physical activity, pain and/or physical limitation, tiredness or limitation for social engagement, and symptoms of people living with HIV/AIDS. The predictors that decreased the scores in this domain were bisexual orientation ( $\beta=-15.94$ ;  $p=0.002$ ), psychosocial symptoms such as fear and/or anxiety ( $\beta=-15.26$ ,  $p<0.001$ ) and homosexual orientation ( $\beta=-11.04$ ;  $p=0.002$ ). The regression model with the adjusted determination coefficient ( $r^2_a$ ) explained 24.6% of the variance in that domain.

The regression model that used the Psychological domain as the dependent variable explained 28.3% of the variance in that domain; it evaluated positive and negative feelings; cognition, through memory capacity and concentration; self-esteem; body image and appearance. The variable that contributed the most to positively explain it, in order of influence, was: having a per capita income greater than three minimum wages ( $\beta=11.9$ ;  $p=0.016$ ). In contrast, the predictors that negatively influenced quality of life in this domain were the presence of psychosocial feelings ( $\beta=-7.64$ ;  $p=0.005$ ), and having been stigmatized or experienced prejudice ( $\beta=-7.16$ ;  $p=0.020$ ).

As for the Level of independence, which evaluated physical mobility, activities of daily living, working capacity and dependence on medications and treatments, the predictors positively associated with a better quality of life were, in order of influence: having a per capita income greater than three minimum wages ( $\beta=11.05$ ;  $p=0.010$ ) or a per capita income of one to three minimum wages ( $\beta=6.95$ ;  $p=0.07$ ), and practicing a religion ( $\beta=5.48$ ;  $p=0.017$ ). Having a bisexual sexual orientation ( $\beta=-10.95$ ;  $p=0.004$ ), having been stigmatized or experienced prejudice ( $\beta=-6.57$ ;  $p=0.007$ ), and being homosexual ( $\beta=-5.72$ ;  $p=0.017$ ) were

negatively associated, thereby reducing the quality of life in this domain.

The predictors associated with a better quality of life in the Social relationships domain, which evaluated affective and sexual relationships, social inclusion and social support received from friends and family, were: length of HIV infection greater than eight years ( $\beta=14.45$ ;  $p=0.011$ ) and having a paid occupation ( $\beta=12.71$ ;  $p=0.007$ ). In this domain, having been stigmatized or suffered prejudice were associated with a poorer quality of life ( $\beta=-14.47$ ,  $p<0.001$ ).

The Environment domain evaluated the aspects related to physical safety and security, home environment, financial resources, quality of health and social care, information technology, leisure, physical environment and transport. The predictors positively associated with a better quality of life were: per capita income greater than three minimum wages ( $\beta=23.87$ ;  $p<0.001$ ), per capita income of one to three minimum wages ( $\beta=12.25$ ;  $p<0.001$ ), treatment adherence ( $\beta=9.29$ ;  $p=0.005$ ) and having a paid occupation ( $\beta=6.94$ ;  $p=0.02$ ). Having been stigmatized/suffered prejudice ( $\beta=-6.62$ ;  $p=0.019$ ) and a history of sexually transmitted infection or opportunistic infection ( $\beta=-6.18$ ;  $p=0.035$ ) decreased the quality of life in this domain.

Regarding the Spirituality domain, religion and personal beliefs, which evaluated aspects related to forgiveness and guilt over living with HIV/AIDS, and concern for the future and death, the regression model explained 23.6% of the variance. Only the occupation variable ( $\beta=9.24$ ;  $p=0.049$ ) was positively associated with quality of life. Presence of psychosocial feelings ( $\beta=-21.83$ ;  $p=0.004$ ) decreased the quality of life in this domain.

**Table 3.** Multiple linear regression analysis to identify predictors of quality of life, according to domains of the *World Health Organization Quality of Life (WHOQOL) HIV-BREF*

WHOQOL HIV-BREF Domain	$\beta^*$	CI95%	p-value	r <sup>2a</sup> **
Physical				0.246
Constant	89.87	73.42-8.53	<0.001	
Income <i>per capita</i> (1-3 MW)	7.80	1.22-14.37	0.020	
Income <i>per capita</i> (>3 MW)	11.93	0.83-23.03	0.035	
Homosexual orientation	-11.04	-17.83 -4.25	0.002	
Bisexual orientation	-15.94	-25.76 -6.11	0.002	
Presence of psychosocial symptoms	-15.26	-22.33 -8.20	<0.001	
Psychological				0.283
Constant	91.31	79.90-102.73	<0.001	
Income <i>per capita</i> (>3 MW)	11.90	2.25-21.56	0.016	
Has been stigmatized/suffered prejudice	-7.64	-12.98 -2.29	0.005	
Presence of psychosocial symptoms	-7.16	-13.18 -1.14	0.020	
Level of independence				0.288
Constant	49.97	43.40-56.55	<0.001	
Income <i>per capita</i> (1-3 MW)	6.95	1.95-11.95	0.007	
Income <i>per capita</i> (>3 MW)	11.05	2.68-19.41	0.010	
Practicing a religion	5.48	1.01-9.96	0.017	
Homosexual orientation	-5.72	-10.64 -0.80	0.023	
Bisexual orientation	-10.95	-18.40 -3.51	0.004	
Has been stigmatized/suffered prejudice	-6.57	-11.27 -1.86	0.007	
Social relationships				0.404
Constant	55.10	43.31-66.89	<0.001	
Employed	12.71	6.59-18.82	0.007	
Time since HIV diagnosis (>8 years)	14.45	6.11-22.79	0.011	
Has been stigmatized/suffered prejudice	-14.47	-20.04 -8.30	<0.001	
Environment				0.401
Constant	53.55	46.73-60.37	<0.001	
Income <i>per capita</i> (1-3 MW)	12.25	6.48-18.02	<0.001	
Income <i>per capita</i> (>3 MW)	23.87	14.68-33.06	<0.001	
Employed	6.94	1.09-12.79	0.020	
STI and HIV-associated opportunistic diseases	-6.18	-11.92 -0.44	0.035	
Adherence to treatment	9.29	2.80-15.77	0.005	
Has been stigmatized/suffered prejudice	-6.62	-12.15 -1.10	0.019	
Spirituality, religion and personal beliefs				0.236
Constant	76.19	64.44-87.95	<0.001	
With occupation	9.24	0.03-18.45	0.049	
Presence of psychosocial symptoms	-13.05	-21.83 -4.26	0.004	

\*Adjusted linear regression coefficient; \*\*Adjusted coefficient of determination; CI95% - 95% Confidence Interval; MW - Minimum Wage; STI - Sexually Transmitted Infection

## Discussion

The study had limitations such as the non-probabilistic sample size and the cross-sectional design, which did not enable the establishment of cause and effect relationships. The results, however, provided new scientific knowledge about the behavior of people living with HIV in Brazil, thereby supporting planning of health promotion and quality of life, especially in the Northeast of the country.

Socioeconomic, demographic, epidemiological and clinical data of 146 study participants evidenced a significant prevalence of males (63.7%),

with a mean age of 38.4 years. This characterization is similar to other Brazilian studies: male gender, aged 30-39 years, lower educational level, income between one to two minimum wages, exposure through heterosexual intercourse, time since diagnosis of 2-8 years, asymptomatic stage of infection, and problems related to antiretroviral therapy adherence.<sup>(4-7)</sup>

Other studies corroborate these findings: in South Africa, there was prevalence of cases among males (54.5%), with lower educational levels (48.2%) and young adults with a mean age of 36.2 years, which is typical of underdeveloped and developing countries.<sup>(8)</sup> In China, the majority of participants (92%) also did not practice a religion<sup>(9)</sup> In Nigeria, the region with the second highest number of people living with HIV/AIDS, the results diverged, indicating a greater prevalence of married women or women with stable unions.<sup>(10)</sup>

According to the quality of life domains, the individuals presented good scores in most domains, thereby emphasizing the Psychological (67.9) and Spirituality, religion and personal beliefs (65.7) domains, and worst average scores in the Environment (59.2) and Level of independence (55.1) domains. In Brazilian<sup>(3,6)</sup> and international<sup>(10,11)</sup> studies, the Environment and Level of independence domains also had lower scores compared to other quality of life domains.

Considering the comparative analysis between the evaluation of quality of life and the studied variables, the multiple regression analysis results indicate that having a paid occupation, per capita income, having a religion, longer time since diagnosis, and treatment adherence were positively associated with quality of life. Homo-affective relationships, having been stigmatized or suffered prejudice, presence of psychosocial symptoms, and having acquired opportunistic infections were predictors associated with a poorer quality of life in the WHOQOL-HIV BREF domains.

If per capita income and occupation are considered as a labor force, they showed statistically positive differences regarding all domains. Thereby, higher scores were identified among those who have

been or are somehow included in the labor market and among those whose proportion of gross income distribution, considering the wage of all people living in the same household, was higher than one minimum wage per person.

In other research in the area, employment or retirement, income above one minimum wage, and higher levels of education were associated with higher quality of life scores.<sup>(3)</sup> A study evaluating employability and adherence to antiretroviral therapy showed that employed people were 27% more likely to adhere to antiretroviral therapy than unemployed people.<sup>(12)</sup>

Considering the influence of the use of antiretrovirals, most of the sample had problems with treatment adherence regarding the scheme, doses and schedules. Adherence is a determining predictor of quality of life, viral suppression, and decreased risk of opportunistic infections. Given the changes in morbidity and mortality, studies have shown the positive impact of adherence to antiretroviral therapy on the quality of life.<sup>(5,13,14)</sup>

Permeated by feelings of guilt, loneliness and fear of death, participants who exercised spirituality by means of faith or religious beliefs achieved better coping with the HIV serostatus, encouragement and ability to work. Spirituality and religion improve health, quality of life, and help people living with HIV to cope with stress from stigma and discriminatory practices.<sup>(15)</sup>

Facing the chronic AIDS phenomenon, the redefinition of living with HIV in participants with a longer time since diagnosis enables acceptance, adaptation and conformity to the disease, thereby providing opportunities to complete projects, social inclusion, affective and sexual relationships, and even higher treatment adherence. Similar results show that higher CD4 levels, an undetectable viral load, and increased time length of antiretroviral therapy increased quality of life.<sup>(5)</sup>

Considering the representations of the disease in the lives of participants, there were statistically significant differences in all six domains, with the presence of psychosocial symptoms and having been stigmatized and/or suffered prejudice. Studies performed in southern India showed the prev-

alence of severe forms of depression and stigma in people with HIV, 12 and 27.1%, respectively. They also found an association between anxiety, depression and stigma and a poorer quality of life.<sup>(16-18)</sup> In Nigeria, a high prevalence of depression (23.1%) was identified in women 30-39 years old, single, with suicidal thoughts or attempts.<sup>(19)</sup> In Brazil, a cross-sectional study revealed a high prevalence of depressive symptoms (61%) and a poorer quality of life associated with a lower socioeconomic status, lower educational level, and presence of stigma.<sup>(4)</sup>

With increasing survival, actions to prevent and manage comorbidities have assumed an important role in the agenda of affirmative public policies. One study evaluating mortality from opportunistic infections showed a decrease of: 75.3% in the mortality rate for *Pneumocystis carinii* pneumonia, 82.8% from tuberculosis, 80.5% from Kaposi's sarcoma, and 70.8% from non-Hodgkin's lymphoma. In contrast, cancer mortality has increased by 12.7 times, lung cancer being the most common (13.6%), followed by lip malignancies, oral and pharynx cavity (10%), and stomach cancer (10%).<sup>(2)</sup>

Since the occurrence of the first HIV infection cases in the world, homo-affective relations have represented an important, key, vulnerable group with a significant influence on quality of life.<sup>(20)</sup>

## Conclusion

People living with HIV/AIDS have a poorer quality of life in the Level of independence and Environment domains. The predictors negatively associated with it were homo-affective relationship, having been stigmatized or suffered prejudice, presence of psychosocial feelings, and a history of a sexually transmitted or opportunistic infection.

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## Collaborations

Oliveira FBM and Moura MEB state that they contributed to the project design, data analysis and interpretation, writing of the article, critical review of the relevant intellectual content and final approval of the version to be published. Araújo TME and Andrade EMLR contributed to writing of the article and final approval of the version to be published.

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