

Quality of life of people living with HIV treated in public health services

Qualidade de vida de pessoas vivendo com HIV atendidas em serviços públicos de saúde

Calidad de vida de personas viviendo con VIH atendidas en servicios públicos de salud

*Hellen Pollyanna Mantelo Cecilio^I; Daniela Sousa Oliveira^{II}; Sergio Corrêa Marques^{III};
Thémistoklis Apostolidis^{IV}; Denize Cristina de Oliveira^V*

ABSTRACT

Objective: to describe the profile and evaluate the quality of life of people living with HIV treated in public health services. **Methods:** in this cross-sectional, quantitative study of 281 people living with HIV treated in public health services in the municipalities of Rio de Janeiro and Niteroi, data were collected using a socioeconomic and clinical instrument and the WHOQOL-HIV brief questionnaire, and analyzed by descriptive statistics, with research ethics committee approval. **Results:** the sample comprised mainly men, with income of up to two minimum wages and a positive perception of their health. Most facets of quality of life were positively assessed, with the highest averages in the psychological, social relations, spirituality, religion and personal beliefs domains, and the lowest, in the environmental domain. **Conclusion:** the profile of people living with HIV corroborates national data, and the assessment of quality of life was more positive than in other studies. **Descriptors:** Quality of life; HIV; HIV seropositivity; nursing.

RESUMO

Objetivo: descrever o perfil e avaliar a qualidade de vida de pessoas vivendo com HIV atendidas em serviços públicos de saúde. **Métodos:** estudo transversal, quantitativo com 281 pessoas vivendo com HIV atendidas em serviços públicos de saúde nos municípios do Rio de Janeiro e Niterói. Os dados foram coletados por meio de instrumento de dados socioeconômicos e clínicos e do WHOQOL-HIV *brief*, analisados por estatística descritiva, após aprovação do Comitê de Ética em Pesquisa. **Resultados:** a amostra foi composta majoritariamente por homens, renda de até dois salários mínimos e percepção positiva da saúde. A qualidade de vida foi positivamente avaliada na maioria das facetas, as maiores médias foram nos domínios: psicológico, relações sociais, espiritualidade, religião e crenças pessoais e a menor no domínio meio ambiente. **Conclusão:** o perfil das pessoas vivendo com HIV corrobora, os dados nacionais e a avaliação da qualidade de vida foi mais positiva do que em outros estudos. **Descritores:** Qualidade de vida; HIV; soropositividade para HIV; enfermagem.

RESUMEN

Objetivo: describir el perfil y evaluar la calidad de vida de personas viviendo con VIH atendidas en servicios públicos de salud. **Métodos:** estudio transversal, cuantitativo, junto a 281 personas viviendo con VIH, atendidas en servicios públicos de salud en los municipios de Río de Janeiro y Niterói. Se han recolectado los datos mediante un instrumento de datos socioeconómicos y clínicos y del WHOQOL-HIV *brief*, analizados por estadística descriptiva, después de la aprobación del Comité de Ética en Investigación. **Resultados:** la muestra se compuso mayoritariamente de hombres, con ingresos de hasta dos salarios mínimos y percepción positiva de la salud. Se evaluó positivamente la calidad de vida en la mayoría de las facetas, los promedios más altos en los dominios: psicológico, relaciones sociales, espiritualidad, religión y creencias personales y el más bajo en el dominio medio ambiente. **Conclusión:** el perfil de las personas que viven con VIH corrobora con los datos nacionales y la evaluación de la calidad de vida fue más positiva que en otros estudios. **Descritores:** Calidad de vida; VIH; seropositividad para VIH; enfermería.

INTRODUCTION

Data from UNAIDS (HIV/AIDS) have indicated that there are 36.7 million people living with (HIV) Human Immunodeficiency Virus in 2017 worldwide, including adults and children. In 2016 there were 1.8 million new cases of HIV infection and one million deaths related to the Acquired Immunodeficiency Syndrome (AIDS) worldwide; in Latin America, an estimated 1.8 million people are living with HIV, registering 36,000 deaths and 97,000 new infections. There is a 48% reduction in deaths between 2005 and 2016 due to the increased access to the antiretroviral therapy (ART)¹.

^INurse. PhD student Nursing, Rio de Janeiro State University, Brazil. E-mail: pollymantelo@gmail.com

^{II}Nurse. PhD student in Nursing, Assistant Professor. Bahia State University, Brazil. E-mail: oliverdany@gmail.com

^{III}Nurse. PhD. Adjunct Professor, Rio de Janeiro State University, Brazil. E-mail: sergiocmarques@uol.com.br

^{IV}Psychologist. PhD. Aix-Marseille Université, Laboratoire de Psychologie Sociale. Aix-en-Provence, France. E-mail: themistoklis.apostolidis@univ-amu.fr

^VNurse. PhD. Full Professor. Rio de Janeiro State University. Rio de Janeiro, RJ, Brazil. E-mail: dcouerj@gmail.com

^{VI}Thanks to CNPq for funding – Process 485797/2013-5.



Currently, the Brazilian epidemic is focused on key populations such as gays, men who have sex with men, transvestites and transsexuals, people who use drugs and sex workers. The age group with the highest concentration of cases is between 25 and 39 years old, men and women, 53.6% being men. The data indicates an increase in cases in men aged from 15 to 29 years old, 20 to 24 years old and 60 years old and over and fall in cases in men aged between 35 to 39 years old and 40 to 44 years old².

In the current context, it remains a global epidemic that continues to pose challenges at the political and everyday levels of people living with HIV, such as: increase in the number of people infected; poverty, discrimination and stigma; access to health services; maintaining employment relationships; relationships with health professionals; experience of sexuality; changes in body and perception of self-image; difficulties with social support and family relationships, which interfere in the evaluation of the quality of life of these people³⁻⁵.

Understanding the quality of life from a broad concept, which incorporates physical and psychological health, social relations and the environment and the level of independence; this study aimed at describing the profile and evaluating the quality of life of people living with HIV, who are treated in public health services.

LITERATURE REVIEW

In the analysis of the evolutionary history of the HIV epidemic, the quality of life is perceived in two moments, one before and after the advent of ART, highlighting the psychosocial interface with the possibility of living with a chronic condition⁶. After ART, the World Health Organization (WHO) included AIDS in the category of chronic conditions as a treatable and clinically manageable disease, taking into account the advances in the natural history of the infection, the possibility of monitoring progression and advances in antiretroviral drugs^{3,7}.

Although there are several definitions, for the WHO, quality of life reflects the individuals' perception that their needs are being met or that they are being denied opportunities to achieve happiness and self-accomplishment, regardless of their state of physical health or social and economic conditions⁸. Based on this conceptualization, instruments for the evaluation of quality of life were developed from a cross-cultural perspective, among them the WHOQOL-HIV brief, composed of facets that evaluate the different aspects of the quality of life, distributed in six domains: physical, psychological, level of independence, social relationship, environment and spirituality, religion and personal beliefs⁹.

The physical domain contains facets that evaluate the quality of life related to pain and discomfort, sleep and rest, energy and fatigue; the psychological evaluates positive and negative feelings, memory, concentration, self-esteem, body image and appearance; the level of independence includes questions about mobility, daily activities, dependence on treatment and drugs, and ability to work; the social relationship domain evaluates the social relations, social support and sexual activity; the environment evaluates the quality of life in relation to safety, housing, financial resources, health care, leisure and transportation; the domain spirituality, religion and personal beliefs evaluates the forms of spirituality, whether or not practiced through religions, and for those who are not affiliated with the religion or spiritual dimension, it refers to beliefs or codes of behavior⁹.

METHODOLOGY

A cross-sectional study was carried out with a quantitative cut-off, using non-probabilistic sampling of convenience, based on information provided by the health services about the number of people being followed up. The sample consisted of 281 people living with HIV, 101 in Niteroi and 180 in the city of Rio de Janeiro.

Individuals were invited to participate according to their presence in the health services in the periods established for collecting the data, until completing the number defined in each municipality. Whenever denials or withdrawal occurred, new individuals were invited to replace the previous ones, until the sample was totalized, and the first ones were selected to accept voluntarily participating in the study.

The inclusion criteria of the participants were: to have positive serology for HIV; to be in follow-up at the selected service; to be waiting for consultation, information or examinations during the period of data collection; to be aged over than or equal to 18 years old; to be in clinical and psychological conditions that would enable their participation. As an exclusion criterion, individuals who declared themselves as illiterate, with significant visual impairment or lack of clinical condition were replaced, due to the need for reading and interpretation to answer the self-administered questionnaires.

The data collection was performed between March and October 2016 in a Specialized HIV/AIDS Care Service in Niteroi and in three Municipal Health Centers in the city of Rio de Janeiro. The data were collected through the socioeconomic and clinical data instrument and WHOQOL-HIV brief^{8,9}.

The data were analyzed using the SPSS software[®]. The first stage of the analysis was configured in the description of the frequencies and categorization of socioeconomic and clinical variables; the second step consisted of the



calculation of the scores of the six domains of quality of life performed by means of simple average, grouping the questions corresponding to each domain⁸. For the interpretation of the quality of life scores, the following classification was used: averages above 15 were considered as superior evaluation of the quality of life, averages between 10 and 14.99 as intermediate evaluation and, means less than 10 as inferior evaluation¹⁰.

The requirements set for Resolution No. 466/12 of the National Health Council of Brazil, which deals with research involving human beings, were respected, and all the pertinent approvals were obtained. The Free and Informed Consent Term was made available to all the participants, ensuring confidentiality and anonymity.

RESULTS AND DISCUSSION

Profile of the group studied

The socioeconomic and clinical characteristics of the participants are presented in Table 1. The sample consisted mainly of men (68.7%), corroborating national data indicating 65% of the cases in males¹¹. Almost all of the participants were economically productive, with 43.8% of the cases between 18 and 38 years old and 48.7% of the cases between the ages of 39 and 59 years old, with an average of 41.1 years old (standard deviation \pm 12.7 years). Studies show that most of the cases of HIV infection are in the age groups of 15 to 39 years old², highlighting the age group from 30 to 39 years old^{3,12-15}.

In relation to schooling, 74.7% declared having elementary education¹⁶, and 25.3% higher education. As found in other studies, most people living with HIV have low levels of education, a study found that only 6% has higher education¹⁷ and another one, that 80.2% has up to seven years of study¹⁸. The marital situation had a similar distribution among the participants who reported living with a partner (50.5%) or without a partner (49.5%). Other studies^{3,19} also indicated the majority with a partner, demonstrating that the seropositivity situation does not present as an impediment to lasting affective relationships, although it indicates difficulty in maintaining a fixed partner and the fear of sharing the diagnosis in the face of exposure to situations of prejudice and discrimination.

Regarding the employment situation, the majority (62.3%) declared themselves as employed and 17.8% unemployed. This unemployment rate is probably more related to the situation of the country at the moment of data collection, characterized by an economic crisis with high unemployment rates, high inflation and dissatisfaction with the policy²⁰, than with the situation of seropositivity. A study²¹ conducted with people living with HIV had 12.7% unemployed and 9.2% retired; however, another study¹⁵ presented 15.9% of unemployed people, 24.8% retired and 23.6% employed.

Regarding income, even considering that the choice of the health units was intentional to guarantee the socioeconomic variability of the sample, the percentage of people with incomes of up to two minimum wages is higher. This situation corroborates national and international data that make poverty an important contribution to increasing vulnerability to HIV infection²². In addition, the low income found confirms data from the interior of the state of Rio de Janeiro, where 37.4% of people live with up to three minimum wages in Macaé³ and half of those interviewed live with up to two minimum wages in Rio das Ostras¹³, as well as those interviewed in Paraiba, where the majority lives with up to two minimum wages¹⁵.

Regarding religious orientation, when compared to the other options, the group of Catholics represented 31.4%, therefore, minority; nevertheless, when compared to the group of evangelicals, without religion or other religions they were majoritarian. The data of this study corroborate the results found in studies carried out in Fortaleza/CE¹² and in João Pessoa/PB¹⁵ that pointed out the Catholic majority; however, it contests the affirmation that the state of Rio de Janeiro has the smallest number of Catholics in the country and also, contrary to the national data that indicate a tendency to the decrease of Catholics, whose percentages ranged from 63.8% to 50% from 2010 to 2016, while evangelicals increased from 24% to 29% in the same period²³.

Regarding the exposure mode to HIV, although the homosexual relationship was the main exposure mode to the virus (43.1%), the heterosexual relations also contributed to the sexual transmission (40.2%), as found in a study with men in the Northeast¹² and in the South¹⁹. Attention is also drawn to data from Africa, where 53.5% and 35.6% of the people interviewed do not know how they have been infected^{24,25}. The low percentage of blood transmission is observed, especially for injectable drugs (0.7%), corroborating data from the state of Rio de Janeiro²⁶. UNAIDS believes that gays, men who have sex with men, transgender people, sex workers, their clients and people who use injectable drugs are the key populations¹, because these populations are often subject to stigmatizing punitive or political laws and are more likely to be exposed to HIV. National data indicate that men who have sex with men constitute the key population that accounts for most new cases of HIV infection².

TABLE 1: Characterization of people living with HIV. Rio de Janeiro and Niterói – Brazil, 2016. (n = 281)

Variables	f (%)
Gender	
Male	193 (68.7)
Female	88 (31.3)
Age group (in years)	
18 to 38	123 (43.8)
39 to 59	137 (48.7)
60 and over	21 (7.5)
Schooling	
Elementary education	210 (74.7)
Higher education	71 (25.3)
Marital status	
With partner	142 (50.5)
Without partner	139 (49.5)
Employment situation	
Employed	175 (62.3)
Retired/others	56 (19.9)
Unemployed	50 (17.8)
Income in “Reais”	
Up to R\$ 1734 (2 minimum wages)	159 (56.6)
R\$ 1735 and over	122 (43.4)
Religious orientation	
Catholic	88 (31.4)
No religion	74 (26.3)
Evangelical	65 (23.1)
Other religions	54 (19.2)
Exposure to HIV	
Homosexual relationship	121 (43.1)
Heterosexual relationship	113 (40.2)
Blood transmission	45 (16)
Injectable drugs	2 (0.7)
Sexual orientation	
Heterosexual	144 (51.2)
Homosexual/Bisexual	137 (48.8)
HIV diagnosis time	
Up to 24 months (2 years)	28 (10)
From 25 to 72 months (2 years and 1 month to 6 years)	77 (27.4)
From 73 to 168 months (6 years and 1 month to 14 years)	88 (31.3)
169 months and over (14 years and 1 month and over)	88 (31.3)
Use of ART	
Yes	265 (94.3)
No	16 (5.7)
Changes in relation to ART (n = 265)	
There was not or there is not changes	139 (52.5)
There was or there is changes	126 (47.5)
Stage of infection	
Without symptoms	252 (89.7)
With symptoms	29 (10.3)
Consider yourself ill	
No	234 (83.3)
Yes	47 (16.7)
Health perception	
Positive	233 (82.9)
Negative	48 (17.1)

This proposal partially corroborates this study, since most of the participants declared themselves to be male, 48.8% declared themselves as homosexual or bisexual, and 51.2% as heterosexual. These results differ from those found in Macaé³ and in João Pessoa¹⁵, whose majority declared themselves as heterosexual. Regarding the time of HIV diagnosis, more than half (62.6%) reported diagnosis for over six years, similar to that found in João Pessoa¹⁵ and different from Rio das Ostras¹³, in which 68% were diagnosed less than four years ago.

The results show a higher use of ART in this sample (94.3%), since in the studies carried out in the state in recent years, 77% of the interviewees used antiretroviral therapy in Macaé³ and 74% in Rio das Ostras¹³; in addition, in recent studies in Africa, 80% of the respondents used ART in Nigeria²⁴ and 72.9% in Burkina Faso²⁵. The increased use of ART is certainly related to the WHO recommendation for the earlier initiation of the treatment – T-CD4+ count from 350 to 500 cells per cubic millimeters –, as of 2013, in the face of evident of clinical benefits²⁷.

Regarding people using ART, just over half (52.5%) indicated that they did not have or had changes related to the medication, diverging from the data in which 80% of the people reported having those changes³, pointing to the lower toxicity of the ART currently used in Brazil. The participants reported not perceiving themselves as patients (83.3%), and this may be due to the fact that 89.7% of them stated that they did not present infection-related symptoms even when living with HIV. However, a study in Nigeria found that even 26.9% of the people in the symptomatic stage and 53.3% of those who had AIDS, 70.3% did not consider themselves to be ill²⁴.

The positive perception of health observed in 82.9% of the participants can be justified by a tendency to naturalize the living with HIV, being perceived as adaptation and acceptance of the seropositivity, as observed in other studies^{28,29}. The good perception of health was also found in other studies, being positive for 88.8% of the people interviewed in Nigeria²⁴ and 63.7% in Burkina Faso²⁵.

Evaluation of quality of life

In all facets and domains measured by WHOQOL-HIV *bref*, a positive evaluation was observed, since 78.9% positively evaluated their quality of life and 68.9% declared satisfaction with their health. This overall positive position was higher than the findings in the state of Rio de Janeiro, where the frequencies were 65.7% and 66% for positive quality of life and 55% and 50% for health satisfaction in Macaé³ and Rio das Ostras¹³, respectively. These notes corroborate the idea of some authors that the possibility of chronicity, with the introduction of ART and, above all, living with the virus for a long time without manifestations of the disease, provide a more positive perception of life and quality of life³⁰.

The results of the evaluation of quality of life are presented in Table 2, reflecting the positioning of people living with HIV on the domains of quality of life.

TABLE 2: Distribution of the scores among WHOQOL-HIV domains *bref*. Rio de Janeiro and Niterói – Brazil, 2016.

Domains of WHOQOL-HIV <i>bref</i>	Simple average	(±) sd	Multiplied average	(±) sd
Self-assessment of QoL	3.87	0.83	15.49	3.34
Psychological	3.81	0.70	15.24	2.82
Spirituality, religion and personal beliefs	3.75	0.93	14.99	3.74
Social relationship	3.74	0.83	14.96	3.34
Physical	3.68	0.86	14.72	3.45
Level of independence	3.67	0.76	14.68	3.07
Environment	3.37	0.64	13.50	2.57

For people living with HIV in this study, the self-assessment of quality of life presented an average of 15.49, indicating a higher evaluation. The psychological domain had the highest average (15.24) and the lowest standard deviation, indicating a higher evaluation. The other domains – Physical, Level of Independence, Social Relationship, Environment and Spirituality, religion and personal beliefs – allude to the intermediate evaluation¹⁰, with averages between 10 and 14.99. The averages found in all the domains in this study are higher than those found in the interior of the state of Rio de Janeiro^{3,13}.

The results of the facets corresponding to the domains of quality of life are in Table 3.

TABLE 3: Distribution of the participants' answers to the WHOQOL-HIV facets *bref.* Rio de Janeiro and Niterói – Brazil, 2016.

Aspects of Quality of Life		(1)VN(*)	(2)Negative	(3)Average	(4)Positive	(5)VP(**)
Self-Assessment of QoL	Q1 (G1) (280)	4	7	48	144	77
	Quality of Life	1.4%	2.5%	17.1%	51.4%	27.6%
Psychological Domain	Q2 (G4) (280)	11	24	52	126	67
	Satisfaction with health	3.9%	8.6%	18.6%	45%	23.9%
Domain Spirituality religion and personal beliefs	Q6 (F4.1) (279)	10	11	40	122	96
	Enjoys life	3.6%	3.9%	14.4%	43.7%	34.4%
Social Relationship Domain	Q11 (F5.3) (281)	11	30	59	125	56
	Can concentrate	3.9%	10.7%	21%	44.5%	19.9%
Domain Physical	Q15 (F7.1) (280)	8	22	56	91	103
	Accepts physical appearance	2.9%	7.8%	20%	32.5%	36.8%
Domain Level of Independence	Q24 (F6.3) (278)	12	18	44	107	97
	Satisfied with oneself	4.3%	6.5%	15.8%	38.5%	34.9%
Domain Environment	Q31 (F8.1) (279)	14	30	40	154	41
	Negative feelings	5%	10.8%	14.3%	55.2%	14.7%
Domain Environment	Q7 (F24.2) (279)	11	5	28	100	135
	Life has meaning	3.9%	1.8%	10%	35.8%	48.5%
Domain Environment	Q8 (F52.2) (277)	34	40	30	47	126
	Responsibility condition	12.3%	14.4%	10.8%	17%	45.5%
Domain Environment	Q9 (F53.2) (281)	30	44	51	43	113
	Fear of the future	10.7%	15.7%	18.1%	15.3%	40.2%
Domain Environment	Q10 (F54.1) (281)	43	37	39	40	122
	Concern about death	15.3%	13.2%	13.9%	14.2%	43.4%
Domain Environment	Q27 (F14.4) (279)	12	7	78	98	84
	Satisfied with friends' support	4.3%	2.5%	28%	35.1%	30.1%
Domain Environment	Q26 (F15.3) (276)	24	23	70	99	60
	Satisfied with sexual life	8.7%	8.3%	25.4%	35.9%	21.7%
Domain Environment	Q25 (F13.3) (281)	12	9	61	115	84
	Satisfied with personal relations	4.3%	3.2%	21.7%	40.9%	29.9%
Domain Environment	Q17 (F51.1) (279)	10	23	58	105	83
	Accepted by people	3.7%	8.2%	20.8%	37.6%	29.7%
Domain Environment	Q3 (F1.4) (281)	8	32	49	44	148
	Physical Pain hampers	2.8%	11.4%	17.4%	15.7%	52.7%
Domain Environment	Q4 (F50.1) (277)	27	47	41	44	118
	Physical problem bothers	9.7%	17%	14.8%	15.9%	42.6%
Domain Environment	Q14 (F2.1) (280)	6	24	86	100	64
	Enough energy day by day	2.1%	8.6%	30.7%	35.7%	22.9%
Domain Environment	Q21 (F3.3) (281)	14	53	71	95	48
	Satisfaction with sleep	5%	18.9%	25.3%	33.7%	17.1%
Domain Environment	Q5 (F11.3) (279)	42	86	58	62	31
	Needs treatment	15.1%	30.8%	20.8%	22.2%	11.1%
Domain Environment	Q22 (F10.3) (280)	12	25	46	115	82
	Daily activity capacity	4.3%	8.9%	16.4%	41.1%	29.3%
Domain Environment	Q23 (F12.4) (278)	13	18	52	120	75
	Capacity to work	4.7%	6.5%	18.6%	43.2%	27%
Domain Environment	Q20 (F9.1) (280)	4	9	33	86	148
	Capable of moving around	1.4%	3.2%	11.8%	30.7%	52.9%
Domain Environment	Q12 (F16.1) (281)	19	21	72	135	34
	Feels safe daily life	6.8%	7.5%	25.6%	48%	12.1%
Domain Environment	Q13 (F22.1) (281)	16	26	105	106	28
	Healthy physical environment	5.7%	9.3%	37.4%	37.6%	10%
Domain Environment	Q16 (F18.1) (280)	31	67	116	32	34
	Enough money	11.1%	23.9%	41.4%	11.4%	12.2%
Domain Environment	Q18 (F20.1) (279)	15	27	82	95	60
	Availability of information	5.4%	9.7%	29.3%	34.1%	21.5%
Domain Environment	Q19 (F21.1) (281)	16	39	90	91	45
	Leisure opportunities	5.7%	13.9%	32%	32.4%	16%
Domain Environment	Q28 (F17.3) (280)	13	27	56	103	81
	Satisfied with the habitation	4.6%	9.6%	20%	36.9%	28.9%
Domain Environment	Q29 (F19.3) (280)	18	33	52	106	71
	Access to health services	6.4%	11.7%	18.6%	37.9%	25.4%
Domain Environment	Q30 (F23.3) (281)	42	64	71	74	30
	Satisfied with transportation	14.9%	22.8%	25.3%	26.3%	10.7%

(*) Very Negative (**) Very Positive

The psychological domain obtained the highest average among the domains and the lowest standard deviation, corroborating that found in Teresina/PI¹⁴. This finding indicates a higher quality of life for people living with HIV, similar to that found in Nigeria²⁴ and in São José/SC³¹. On the other hand, it differs from the results in Macaé³, Rio das Ostras¹³, Mossoró/RN³², South Africa³³ and Cambodia³⁴, classified as intermediate.

This domain contains five facets and the first corresponds to how much the individual enjoys life, and 78.1% of the participants responded with a very positive evaluation. It is important to highlight that within the state, 21.1% of people reported taking advantage of very little or nothing of life¹³, a large percentage when compared to this study, in which only 7.5% considered not enjoying life. The second facet questions about the ability to concentrate and 64.4% perceived themselves as able to concentrate. Still, the facets related to the acceptance of physical appearance and satisfaction with themselves, obtained, respectively, 69.3% and 73.4% of positive responses. The facet related to negative feelings revealed that 69.9% of the participants do not present such feelings frequently. When compared to the interior of the state, 59% in Rio das Ostras¹³ reported not having negative feelings often, however, in Macaé³, 71% of people reported these negative feelings frequently.

The domain spirituality, religion and personal beliefs have four facets and presented average borderline between intermediate and superior, being the second highest average between the domains. The classification as intermediate corroborates the findings in Macaé³, in Rio das Ostras¹³, in South Africa³³ and in Cambodia³⁴. The data in Nigeria²⁴ and São José³¹ obtained higher evaluation, and in Mossoró³² it had an average lower than ten, suggesting a lower quality of life evaluation. The first facet evaluated how much life has meaning, being positive to 84.2%. The second facet questioned the accountability attributed by the condition of living with HIV, revealing not to bother 62.5% of the participants. The third questioned the fear of the future, which revealed not to be a problem for 55.5% of the people and the last one, concern about death, pointing out that 57.6% of people have no concern in this regard.

The social relationship domain contains four facets and presented the third highest average, suggesting an intermediate evaluation, however, very close to the limit for the superior evaluation. The data from South Africa³³ and from Nigeria²⁴ pointed to a superior evaluation of the quality of life and the studies in Macaé³, Rio das Ostras¹³, São José³¹ and Cambodia³⁴ intermediate evaluation. In Fortaleza¹² the highest average was obtained, different from that reported in São Paulo/SP¹⁰, revealing that people living with HIV have a better quality of life in the physical and psychological domains than the others; and worse in the social relationship domain, which may reflect situations of stigma, prejudice and discrimination, which seems not to be observed in this study. The first facet evaluates the support received by friends, which was perceived as positive by 65.2% of the people. The second questions about the satisfaction with the sexual life, indicating satisfaction for 57.6% of the participants, similar to that found in Rio das Ostras¹³, in which 51% were satisfied and contrary to that found in Macaé³, with dissatisfaction to 67.9%. The third and fourth facets evaluate, respectively, satisfaction with personal relations and acceptance by people they know, being evaluated positively by 70.8% and 67.3% of people living with HIV.

The physical domain has four facets and has had an intermediate evaluation, similar to the findings in South Africa³³, Cambodia³⁴, and in Brazil, in Fortaleza¹² and Mossoró³². The results from São José³¹ and Nigeria²⁴ indicated scores suggestive of superior evaluation. The first facet investigates the presence of pain, which can accompany some evolutionary conditions of the disease and interfere in the quality of life; however, the majority (68.4%) reported that physical pain does not prevent the performance of activities. The second question about physical discomforts as a result of the infection, showing that for 58.5% it is not a negative issue. The next facet evaluates the availability of energy for daily life, noting that 60.4% reported having enough energy, revealing a higher percentage than other studies, being 51.1% in Macaé³ and 53% in Rio das Ostras¹³. For the fourth facet, related to sleep, 50.9% reported satisfaction, indicating a less positive perception of quality of life, since 49.1% negatively evaluated this facet.

The level of independence domain assesses four facets and was classified as an intermediate similar to those found in South Africa³³ and Cambodia³⁴ and in other Brazilian cities, such as Macaé³, Rio das Ostras¹³, Fortaleza¹² and Mossoró³²; the findings from Nigeria²⁴ and from São José³¹ presented superior evaluation. The first facet questions the need for medical treatment and only 33.3% evaluated it positively, similar to the data from the interior of the state of Rio de Janeiro^{3,13}. The facet that evaluates performance in daily activities was positive for 70.4% of the participants; the facet that evaluates the capacity for work was positive for 70.2% and the mobility capacity was well evaluated by 82.2%.



The environment domain presents eight facets related to living conditions. This domain presented the lowest average, although still classified as intermediate, reaffirming the findings of several studies^{3,13,24,31,32,34}. The first facet questions how safe the participants feel in daily life, which was answered positively by 60.1%. The following evaluates how healthy is the physical environment, related to climate, pollution, among others, proving to be healthy for 47.7% of the people interviewed. The third facet questions the availability of money to meet the needs, which according to the findings of the variable income pointed out that for 76.5% of the people, money is insufficient, corroborating the negative findings to 89.3% of the participants in Macaé³ and 87% in Rio das Ostras¹³. Related to the availability of information, 55.6% answered positively to this fourth facet. The fifth facet evaluated the opportunity to perform leisure activities, which was positive for 48.4% of the participants. Regarding the place of residence, 65.7% answered that they were satisfied or very satisfied, and 63.3% reported satisfaction with their access to health services. However, the facet about satisfaction with transportation was evaluated negatively by 63% of the people.

CONCLUSION

Quality of life was positively evaluated by people living with HIV, especially in the areas of psychological, spiritual, religious, and personal beliefs and social relationships. The highlight of the positive evaluation in psychosocial dimensions shows the importance of interpersonal relations and the social support network to guarantee better levels of quality of life, especially in a chronic health condition, which involves stigma, prejudice and exclusion as major challenges to be faced.

It is recognized as a limitation of this study its performance as a convenience sample, which restricts the possibility of generalization; however, it was pointed out that it was composed of people living with HIV, attended in public health services, in cities with different sociodemographic characteristics, which guaranteed social, economic and educational level variability. In summary, the socioeconomic and clinical characteristics of the sample are similar to those observed in adults living with HIV in Brazil and in other countries, as shown in the results: male majority, in work activity, divided between low and middle income and using ART.

REFERENCES

1. Unaid. Guia de terminologia do UNAIDS. Genebra (Swi): UNAIDS; 2017.
2. Ministério da Saúde (Br). Secretaria de Vigilância em Saúde. Departamento de DST, Aids e Hepatites Virais. Boletim Epidemiológico Aids e DST. Brasília (DF): Secretaria de Vigilância em Saúde; 2015.
3. Costa TL. Representações sociais do HIV/Aids e da qualidade de vida: um estudo entre pessoas que vivem com o agravo em contexto de interiorização [tese de doutorado]. Rio de Janeiro: Universidade do Estado do Rio de Janeiro; 2012.
4. Oliveira DC. Qualidade de vida e construções simbólicas de pessoas que vivem com HIV/aids no Rio de Janeiro. Projeto Edital Universal 2013 do CNPq; 2013.
5. Oliveira DC, Spindola T, Gomes, AMT, Marques SC, Formozo GA, Campos LA. Construções simbólicas do tratamento de pessoas que vivem com o HIV/AIDS entre enfermeiros. Rev. enferm. UERJ [Internet] 2015 [cited 2018 Sep 18]; 23(5):596-602. DOI: <https://doi.org/10.12957/reuerj.2015.13191>
6. Seidl EMF, Zannon CMLC, Tróccoli BT. Persons living with HIV/AIDS: coping, social support and quality of life. Psicol. Reflex. Crit. [Internet]. 2005 [cited 2018 Sep 18]; 18(2): 188-95. DOI: <http://dx.doi.org/10.1590/S0102-79722005000200006>
7. Alencar TMD, Nemes MIB, Velloso MA. Transformações da “aids aguda” para a “aids crônica”: percepção corporal e intervenções cirúrgicas entre pessoas vivendo com HIV e Aids. Ciênc. saúde coletiva (Online). 2008 [cited 2018 Sep 18]; 13(6):1841-9. DOI: <http://dx.doi.org/10.1590/S0104-42302009000200028>
8. Organização Mundial da Saúde. Departamento de Saúde Mental e Dependência Química. Instrumento WHOQOL-HIV: sintaxe. Genebra (Swi): OMS; 2002.
9. Fleck MPA, Leal OF, Louzada S, Xavier M, Chachamovich E, Vieira G, Santos L, Pinzon V. Development of the Portuguese version of the OMS evaluation instrument of quality of life. Rev. Bras. Psiquiatr. [Internet]. 1999 [cited 2018 Sep 18]; 21(1):19-28. DOI: <http://dx.doi.org/10.1590/S1516-44461999000100006>
10. Santos ECM, França Junior I, Lopes F. Quality of life of people living with HIV/AIDS in São Paulo, Brazil. Rev. saúde pública (Online). 2007 [cited 2018 Sep 18]; 41(supl. 2):64-71. <http://dx.doi.org/10.1590/S0034-89102007000900011>
11. Ministério da Saúde (Br). Secretaria de Vigilância e Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico Aids e DST. Brasília (DF): Secretaria de Vigilância em Saúde; 2014.
12. Cunha GH, Fiuza MLT, Gir E, Aquino OS, Pinheiro AKB, Galvão MTG. Quality of life of men with AIDS and the model of social determinants of health. Rev. latinoam. enferm. (Online). 2015 [cited 2018 Sep 18]; 23(2):183-91. DOI: <http://dx.doi.org/10.1590/0104-1169.0120.2541>
13. Hipolito RL. Qualidade de vida das pessoas que vivem com o HIV/Aids no município de Rio das Ostras [tese de doutorado]. Rio de Janeiro: Universidade do Estado do Rio de Janeiro; 2015.



14. Oliveira FBM, Moura MEB, Araújo TME, Andrade EMLR. Quality of life and associated factors in people living with HIV/AIDS. *Acta Paul. Enferm.* (Online). 2015 [cited 2018 Sep 18]; 28(6):510-6. DOI: <http://dx.doi.org/10.1590/1982-0194201500086>
15. Silva ACO. Qualidade de vida de pessoas vivendo com HIV/aids e sua associação com aspectos sócio-demográficos, clínicos, psicoemocionais e adesão ao tratamento [tese de doutorado]. Ribeirão Preto; Universidade de São Paulo, 2013.
16. Senado Federal (Br). Lei de diretrizes e bases da educação nacional. Brasília (DF): Coordenação de Edições Técnicas; 2017.
17. Leadebal ODCP, Medeiros LB, Lins RSM, Chaves RB, Monroe AA, Nogueira JA. Cuidado às pessoas vivendo com AIDS: enfoque nas ações de educação em saúde. *Rev. enferm. UERJ* [Internet] 2017 [cited 2018 Sep 18]; 25:e9524. DOI: <https://doi.org/10.12957/reuerj.2017.9524>
18. Castrighini CC, Reis RK, Neves LAS, Galvão MTG, Gir E. Prevalence and epidemiological aspects of HIV/tuberculosis coinfection. *Rev. enferm. UERJ* [Internet]. 2017 [cited 2018 Sep 18]; 25:e17432. DOI: <http://dx.doi.org/10.12957/reuerj.2017.17432>
19. Passos SMK, Souza LDM. An evaluation of quality of life and its determinants among people living with HIV/AIDS from Southern Brazil. *Cad. Saúde Pública* (Online). 2015 [cited 2018 Sep 18]; 31(4):800-14. <http://dx.doi.org/10.1590/0102-311X00000514>
20. Cardoso Junior JC. O Brasil na encruzilhada: apontamentos para uma reforma do Estado de natureza republicana, democrática e desenvolvimentista. *Cadernos do Desenvolvimento* [Internet]. 2017 [cited 2018 Sep 18]; 12(20):99-133. Available from: <http://www.cadernosdodesenvolvimento.org.br/ojs-2.4.8/index.php/cdes/article/view/31/pdf>
21. Reis RK, Santos CB, Dantas RAS, Gir E. Quality of life, sociodemographic factors and sexuality of people living with HIV/AIDS.. *Texto contexto enferm* [Internet]. 2011 [cited 2018 Sep 18]; 20(3):565-75. DOI: <http://dx.doi.org/10.1590/S0104-07072011000300019>
22. Parker R. Unintended consequences: evaluating the impact of HIV and AIDS on sexuality research and policy debates. *Cad. Saúde Pública* (Online). 2009 [cited 2018 Sep 18]; 25(supl. 2):S251-8. DOI: <http://dx.doi.org/10.1590/S0102-311X2009001400007>
23. Coutinho RZ, Miranda-Ribeiro P. Religion, religiosity and sexual initiation during adolescence: lessons from a systematic literature review of a half-century of research. *Rev. bras. estud. popul* [Internet]. 2014 [cited 2018 Sep 18]; 31(2):333-65. DOI: <http://dx.doi.org/10.1590/S0102-30982014000200006>
24. Akinboro AO, Akinyemi SO, Olaitan PB, Raji AA, Popoola AA, Awoyemi OR, Ayodele OE. Quality of life of Nigerians living with human immunodeficiency virus. *Pan African Medical Journal* [Internet]. 2014 [cited 2018 Sep 18]; 18(234). DOI: <http://dx.doi.org/10.11604/pamj.2014.18.234.2816>
25. Bakiono F, Ouédraogo L, Sanou M, Samadoulougou S, Guigemdé PWL, Kirakoya-Samadoulougou F, Robert A. Quality of life in people living with HIV: a cross-sectional study in Ouagadougou, Burkina Faso. *Springerplus* [Internet]. 2014 [cited 2018 Sep 18]; 3(372). DOI: <http://dx.doi.org/10.1186/2193-1801-3-372>
26. Secretaria Municipal de Saúde do Rio de Janeiro. Boletim epidemiológico DST/aids. Rio de Janeiro (RJ): Secretaria Municipal de Saúde; 2013.
27. Unaid. 90-90-90 uma meta ambiciosa de tratamento para contribuir para o fim da epidemia de AIDS. Genebra (Swi): UNAIDS; 2015.
28. Gomes AMT, Silva EMP, Oliveira DC. Social representations of AIDS and their quotidian interfaces for people living with HIV. *Rev. latinoam. enferm.* (Online). 2011 [cited 2018 Sep 18]; 19(3): [8 telas]. DOI: <http://dx.doi.org/10.1590/S0104-11692011000300006>
29. Hipolito RL, Oliveira DC, Gomes AMT, Costa TL. Social representations of quality of life in HIV/AIDS: the role of time since diagnosis. *Rev. enferm. UERJ* [Internet]. 2014 [cited 2018 Sep 18]; 22(6):753-9. DOI: <https://doi.org/10.12957/reuerj.2014.12840>
30. Souto BGA. O HIV, seu portador e o tratamento anti-retroviral: implicações existenciais. São Carlos: EdUFSCar; 2008.
31. Silva J, Bunn K, Bertoni RF, Neves OA, Traebert J. Quality of life of people living with HIV. *AIDS Care* [Internet]. 2013 [cited 2018 Sep 18]; 25(1):71-6. DOI: <http://dx.doi.org/10.1080/09540121.2012.686594>
32. Silva JG, Morgan DA, Melo FCM, Santos IK, Azevedo KPM, Medeiros HJ, Knackfuss MI. Level of pain and quality of life of people living with HIV/AIDS pain and quality of life in HIV/AIDS. *AIDS Care* [Internet]. 2017 [cited 2018 Sep 18]; 29(8):1041-8. DOI: <https://doi.org/10.1080/09540121.2016.1274013>
33. Cronje JH, Williams M, Steenkamp L, Venter D, Elkonin D. The quality of life of HIV-infected South African university students: Experiences with the WHOQOL-HIV-Bref. *AIDS Care* [Internet]. 2017 [cited 2018 Sep 18]; 29(5):632-5. <http://dx.doi.org/10.1080/09540121.2016.1234688>
34. Yang Y, Thai S, Choi J. An evaluation of quality of life among Cambodian adults living with HIV/AIDS and using antiretroviral therapy: a short report. *AIDS Care* [Internet]. 2016 [cited 2018 Sep 18]; 28(12):1546-50. DOI: <http://dx.doi.org/10.1080/09540121.2016.1192100>