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SELF-EVALUATING THE QUALITY OF LIFE OF PEOPLE LIVING WITH HIV

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ABSTRACT

Objective: To analyze the self-evaluation of quality of life (QOL) of people living with HIV. **Methodology:** This is a descriptive, cross-sectional and quantitative study carried out with 150 users of a Specialized Care Service (SCS) on HIV located in the Capital of the State of Pernambuco. QoL was assessed from the WHOQOL HIV Bref instrument, divided into six domains: physical, psychological, social relations, environment, level of independence and spirituality. Statistical analysis was performed using SPSS 18.0 software. We used mean and standard deviation and tests such as Kolmogorov Smirnov, Friedman and Wilcoxon. **Results:** age extremes ranged from 18 to 69 years-old, with a median of 37.5 years-old. There was a predominance of women (65.3%) and people with no secondary education completed (60%). The domains of QoL that achieved better results were: psychological, physical and social relationships, with self-evaluation averages of very good quality of life of 16.69; 16.67 and 15.67, respectively. It is emphasized that a better self-perception of the QoL indicates better conditions in the domains evaluated. **Conclusion:** Factors that negatively affect QoL contribute to increasing the vulnerability of people living with HIV and, considering the structuring points of living conditions, it is clear that progress in health promotion policies must be made.

Keywords: Quality of life. Health promotion. HIV. Acquired Immunodeficiency Syndrome.

INTRODUCTION

Human immunodeficiency virus (HIV) still represents one of the world's major public health problems nowadays because of its epidemic character. According to the Joint United Nations Program on HIV/AIDS (UNAIDS) in 2017, there were approximately 36.9 million people living with HIV worldwide and 21.7 million using antiretroviral therapy (ART)(1). In Brazil, 17,248 new cases were reported from January to June 2018, 5.4% more than the amount reported in the same period of the previous year(2).

In this context, it should be pointed out that ART is made available throughout Brazil by the Unified Health System, making the country daring and pioneering in the continuous fight against the HIV epidemic. The Logistic Control System for Medicines (SICLOM), used throughout the national territory, which supports the logistics and distribution of these drugs, functions as a tool to evaluate adherence to medications(3).

It is well known that ART has provided a significant decrease in mortality rate, favoring reduction of viral load and increase in CD4 + T lymphocyte levels, resulting in a lower incidence of HIV transmission, reducing morbidity and mortality, health spending and promoting better quality of life (QOL) to people living with HIV(4).

Knowing the QOL of people living with HIV is recognized as a fundamental, necessary and urgent process, since the presence of the infection and the complications associated with the disease have a negative effect on the lives of these people. In this way, health professionals, by understanding the self-assessment of QoL of people living with HIV, are able to carry out interventions that permeate the essential pillars to sustain a healthy life, besides offering a social and psychological support that minimizes the negative effects of disease on QOL.

The concept of QoL is based on beliefs and

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values derived, in part, from the expected results in the promotion, prevention, protection and maintenance of health, being understood by domains involving social, physical, psychological and environmental aspects, not limited to the current situation of the subject, and must be inserted in the individuality and sustained in the long term(5).

With the increasing number of HIV cases and with strong impacts, especially in developing countries, a new challenge arises for public policies and health services: understanding and intervening in factors that are related to QoL, following the social, to meet the needs demanded by society(6).

It is also worth mentioning that, over more than three decades of fighting for HIV, in recent years, there has been an increase in the interest in assessing the QOL of people living with HIV in response to the human needs affected by the phenomenon of chronicity of the disease, ranging from clinical and laboratorial outcomes, ranging from consultations with multi-professional staff, examinations and clinical repercussions of opportunistic infections, bioethical and sociocultural dimensions(7,8).

The analysis of the QoL of people living with HIV in Brazil becomes increasingly important, since the epidemic in the country currently occurs at a time when accumulated scientific knowledge is used to control infection worldwide. Thus, measuring the QoL of people living with HIV from the perception of them keeps the practice of integral and holistic care for these groups, which has been tested by the indicators of evaluation of responses to public policies(9).

In response to the struggle to cope with HIV, it is imperative to look at the QoL self-evaluation of people living with HIV as a human need. Discussing issues that give rise to debates to improve the well-being of these people is a tool capable of stimulating the paradigm shift that is sometimes associated with confirmation of the diagnosis. For this purpose, the present construct aims to analyze the self-evaluation of the quality of life of people living with HIV.

MATERIAL AND METHOD

This is a descriptive cross-sectional study with a quantitative approach, developed in Recife, Pernambuco, Brazil, in 2016, in a Specialized Care Service (SAE) in HIV, located in the Capital of the state of Pernambuco.

The sample consisted of 150 individuals and it was decided to use the non-probabilistic sampling technique for convenience. Data collection occurred between February and August of 2016, before or after the medical appointment, and it was performed through individual interviews, in the clinic's own rooms, which provided privacy for the interviewee and the interviewer.

For the eligibility criteria, patients with a positive HIV diagnosis were included, who were 18 years-old or older and they were followed up clinically in the service under study and inserted in SICLOM. Subsequently, pregnant women, individuals with cognitive impairment recorded on the chart or who interfered with the interviewee's communication were excluded.

To obtain the data, the interview was guided by a structured questionnaire, prepared by the research team, considering the sociodemographic variables (sex, age group, schooling, income and occupation).

In order to evaluate QoL, the World Health Organization Quality of Life evaluation instrument for HIV-infected persons, WHOQOL-HIV-Bref, created and validated by the World Health Organization (WHO)), composed of 31 questions divided into six domains: physical, psychological, social relations, environment, level of independence and spirituality/religion/personal beliefs(10).

While answering it, the individual was told to think about their QOL in the last two weeks. The responses have a Likert scale format ranging from one to five points. All scores linearly reflect QOL, with score 1 being indicative of low and negative QOL perception and 5 indicating high and positive perception. Facets negatively formulated as pain and discomfort, negative feelings, dependence on medication, death and dying were reversed, according to official WHO document. The scores of each domain are multiplied by 4, so the scores of each domain vary from 4 to 20 points, in that the higher the score, the better the self-assessment of the QoL(10).

The data was stored in the Microsoft Excel 2016 spreadsheet, which was exported to the *Statistical Package for the Social Sciences* (SPSS) version 18.0 for statistical analysis.

Descriptive analysis was used for socioeconomic characterization. Mean and standard deviation were calculated for the scores of the WHOQOL-HIV-Bref domains. The normality of the score was assessed by the Kolmogorov Smirnov test. In cases in which the normality of the score was not indicated, the Friedman test was applied to evaluate if there was difference of the score between the domains. When a domain with greater discrepancy of the score was verified, the Wilcoxon test was performed between the domains, two by two, in order to evaluate in which domains the patients had similar/different qualities.

To compare the classification of self-perception of QoL in each domain, the *Kruskall-Wallis* test was applied. *Spearman*'s correlation test was used to measure the degree of influence of the domains on self-classification of QoL. The level of significance was set at 5%.

The study complied with Resolution No. 466/2012 of the National Health Council and was submitted to the Research Ethics Committee of the Hospital Complex of HUOC/PROCAPE and approved with the opinion 1,112,733.

All participants received information about the purpose and nature of the study and signed the Informed Consent Term (TCLE). For those who did not know how to sign the name, the fingerprinting of their thumb was performed.

RESULTS

The socioeconomic profile of the sample studied (table 1) shows that the age range ranged from 18 to 69 years-old, with a higher percentage of 40 to 59 years-old, expressed by 39.3% (n = 59) of the participants, a mean of 37.21 years-old, standard deviation of 10.77 years and median of 37.5 years-old. There was a predominance of females (65.3%, n=98) and educational level of one to eight years (86.6%, n = 130).

Regarding the family income, 61.3% (n=92) of the respondents reported having a monthly income of up to one minimum wage and 56.7% (n=85) had no formal/informal employment relationship.

Table 1. Description of socioeconomic characteristics of people living with HIV. Recife, PE, Brazil, 2017

Variable	Absolute frequence	Relative frequence
Sex		
Male	98	65,3
Female	52	34,7
Age group		
18 to 28 years-old	35	23,3
29 to 39 years-old	55	36,7
40 to 59 years-old	59	39,3
60 years-old or older	1	0,7
Scholarship (in years of study)		
Illiterate	3	2,0
1 – 4 years	65	43,3
5 – 8 years	65	43,3
≥ 9 years	17	11,4
Family income		
Up to 1 minimum wage *	92	61,3
More than 1 up to 2 minimum wages	34	22,7
More than 2 and less than 4 minimum wages	21	14,0
More than 4 minimum wages	3	2,0
Employment relationship		
Yes	65	43,3
No	85	56,7

* Minimum wage amount at the time of the study: 880.00 reals.

Table 2 shows the descriptive analysis of the QoL score according to the evaluated domains of the WHOQOL-HIV Bref instrument. It is verified that the domains in which people living with HIV reached, on average, better results were: psychological (mean = 14.02); physical (mean = 13.98) and independence (mean = 13.79). The domain with the lowest performance presented was environmental (mean = 11.96).

It is also observed that the distribution comparison test was significant (p-value <0.001), indicating that there is a difference in the QoL of the domains evaluated in the study population. Regarding the two-by-two comparison, it was identified that the level of QoL in the physical, psychological, independence and social relations domains is similar.

Table 2. Distribution of the classification of the WHOQOL-HIV Bref scores according to the domains evaluated. Recife, PE, Brazil, 2017

Domain evaluated	Mean	Standard deviation	IC(95%)	p-value[1]
Physical	13,98[a]	3,63	13,40 - 14,56	<0,001
Psychological	14,02[a]	3,23	13,50 - 14,54	
Independence	13,79[a]	2,60	13,37 - 14,21	
Social relations	13,38[a]	3,95	12,74 - 14,02	
Environment	11,96[b]	2,96	11,49 - 12,44	
Spiritual	12,28[b]	4,31	11,58 - 12,98	

[1] p-value of the Friedman test (if p-value <0.05 the score distribution differs between the evaluated domains).
[a]The level of QoL in the domains: physical, psychological, independence and social relations is similar.
[b]The level of QoL in environmental and spiritual domains is similar.
The two-by-two comparison was made by the Wilcoxon test.
IC = Confidence Interval.

Table 3 shows the descriptive analysis of the scores of the WHOQOL-HIV Bref domains according to the classification of the QoL self-perception. It was observed that in all domains evaluated, the higher the degree of self-classification, the higher the score of the instrument. Thus, a better self-perception of QoL indicates better physical, psychological, independence, social, environmental and spiritual conditions.

The comparison test of the distribution of WHOQOL-HIV Bref scores between the groups was significant for all domains evaluated (p-value <0.001).

Table 3. Distribution of the mean and standard deviation of the WHOQOL-HIV Bref domain scores according to the quality of life classification. Recife, PE, Brazil, 2017

Domain evaluated	Mean of classification of self-perception of quality of life					p-value
	Very bad	Bad	Neither bad nor good	Good	Very good	
Physical	10,14±2,27	11,33±2,74	12,43±3,49	15,37±2,91	16,67±2,97	<0,001
Psychological	9,83±3,05	10,77±3,18	12,94±2,86	15,24±2,38	16,69±1,90	<0,001
Independence	12,57±1,81	10,93±2,52	13,06±2,96	14,68±1,72	15,29±1,87	<0,001
Social relations	10,00±1,73	9,33±3,44	12,83±3,62	14,42±3,54	15,67±3,75	<0,001
Environment	10,71±1,89	10,00±2,50	10,72±3,04	12,69±2,62	14,48±1,80	<0,001
Spiritual	9,57±3,41	10,27±4,77	11,57±4,37	13,03±3,91	14,05±4,27	0,013

[1]p-value of Kruskall-Wallis test (if p-value < 0,05 the distribution of the score differs between self-perceived quality of life groups).

Table 4 shows the correlation analysis between the self-classification score of the QL and the score of the domains evaluated in the WHOQOL-HIV Bref. All of them were significantly relevant for increasing self-classification of QOL (p-value <0.001), with the psychological domain being the most influential (ρ = 0.603), followed by the physical domain (ρ = 0.556), environment (ρ = 0,480) social (ρ = 0.461), independence (ρ = 0.452) and spiritual (ρ = 0.289).

Table 4. Correlation analysis between the self-classification of the quality of life with the score of the domains evaluated in the WHOQOL-HIV Bref. Recife, PE, Brazil, 2017.

Domain evaluated	P	p-value[1]
Physical	0,556	<0,001
Psychological	0,603	<0,001
Independence	0,452	<0,001
Social relations	0,461	<0,001
Environment	0,480	<0,001
Spiritual	0,289	<0,001

ρ = Spearman correlation coefficient.
p-value of the Spearman correlation significance test.

DISCUSSÃO

The socioeconomic profile according to national trends and other surveys conducted in the country: female prevalence, low income/schooling, and increasing vulnerability of the non-young population(11,12).

The results show that, among the domains of QoL, according to WHOQOL-HIV Bref, the psychological and the physical stand out as the best evaluated, which highlights the interrelationship between psychosocial and clinical factors in living with HIV. These domains refer, respectively, to positive feelings, body image, appearance, self-esteem, memory and concentration, therapeutic adherence, energy, mobility, sleep, daily life activities and work capacity(10).

A good self-evaluation of the psychological factor of a person living with HIV points to the maintenance of good mental health and it is able to minimize the barriers that are anchored in a society still stigmatizing. In this scenario, a network of psychosocial and spiritual support, which provides a clinical treatment - composed of a multi-professional team -, adequate medication and laboratory, from the moment of the discovery of the diagnosis, contributes markedly to the better perception of the QoL of these people(13).

It is also added that the psychological and environmental dimensions reflect the psychosocial support networks of a person living with HIV, besides being related to the provision of a humanized care that is able to care for the subject in its entirety, evaluation of the factors mentioned above is also determinant for a satisfactory QOL(12).

The domain of social relations was the third most influential on the QoL of the studied population. In view of this, it is important to bring one of the greatest challenges of people living with HIV, stigmatization. Within this scenario, family and social support can be presented as an indispensable support network, including assessing the vulnerability of a person living with HIV to illness. According to Silva and Tavares (2015) social relations play a decisive role in the health care of people living with HIV, particularly in adherence to ART, which may require changes in routine and daily habits of life, and also to strengthen self-confidence(14).

Regarding the environmental domain, it had a worse score; however, it was one of the most influential on QoL. The poor performance of this score may not only be related to the condition of positive serology for HIV but also to structuring conditions of life, since the environmental dimension refers to financial resources, health care quality, infection information, among other resources and social facilities(6,15).

Identifying situations of greater environmental vulnerability contributes to the decision-making of professionals and managers regarding the necessary rearrangements to intervene on this problem, through actions and integration strategies between the health services to strengthen the care of people living with HIV within a network perspective(16).

People living with HIV can suffer from social isolation, discrimination and marginalization due to the stigmatization that permeates the history of the disease. In this study, the social relations domain was the fourth most impacting in QoL, but this distribution does not happen homogeneously among the different regions of the country. A survey conducted in Pelotas, Rio Grande do Sul, showed that the lower the social support offered to a person living with HIV, the lower their perception of QoL, when it is compared to the other five domains(11).

The domain of independence, which assesses issues related to mobility, daily life activities, dependence on medications or treatments and skills to work, is related to the need for access to anti-retrovirals and information that reinforces the relevance of their adherence as part of a good QoL, so that activities of daily living and work can be carried out without impediments or damages (17). In our study, the mentioned domain was classified by the majority of participants as being very good, reaching an average of 15.29.

However, the pharmacological adherence of people living with HIV is still a challenge for Brazil, since the continuous and daily taking of a drug requires dedication and commitment(18).

Although the domain of spirituality has proved to be the least impacting on QOL, it is well known that the support of many religious systems is relevant to coping with the disease. In addition to religious practices, spirituality encompasses beliefs and perceptions of the meaning of life, a phenomenon also linked to psychological health(19).

According to the results, the way people living with HIV perceive their disease, that is, self-perception is an important predictor of QoL. Therefore, it is suggested that health professionals stimulate the use of coping strategies, acceptance, distraction and instrumental support, and less use of behavioral disengagement and positive reinterpretation, in order to reduce the negative effects that may interfere in perception of the disease, reflecting an unsatisfactory QOL(18).

To improve the perception of QoL, whether due to better physical, psychological, independence, social, environmental and spiritual relations, it is fundamental to perform a multi-professional team that uses the coping strategies mentioned above. Hence, the focus of disease-centered care gives way to focusing on people-centered care.

At this juncture, health professionals play a unique role in maintaining QoL of people living with HIV, since in the context of health care, nurses play a key role in the development of educational interventions that promote health and the improvement of QoL, by the sharing and construction of knowledge in a joint and non-vertically integrated manner(20).

Thus, the results found and studies of this nature, besides providing the possibility to sensitize health professionals directly linked to the care of people living with HIV, may subsidize health care interventions that will help improve QoL in the different segments of this population, positively affecting the improvement of ART adherence(10).

It is perceived that HIV can have many impacts on individuals' lives. Confronting a new chronic condition, which is still stigmatizing, has been one of the challenges faced by people living with HIV, with repercussions, especially in the domains of QoL(21-22). Thus, investing in public policies that strengthen the promotion, protection and rehabilitation of health constitute an essential pillar for the empowerment and autonomy of the people, improvement in QoL and health concretization as a constitutional right.

Considering these considerations, nurses' understanding of this dynamics can contribute to their actions, especially care, therapeutic and educational, being more pertinent to the life and daily life of PLWHA, reflecting the improvement of QoL.

The study presented as limitations the sample number was not probabilistic and the cross-sectional design, which did not allow to establish cause and effect relationships. The results added new scientific knowledge about the behavior of people living with HIV in Brazil, subsidizing the planning of health promotion actions that focus on QoL improvements, especially in the Northeast of the country.

CONCLUSION

It was intended to increase the knowledge about predictors of QoL in the context of HIV, especially highlighting the important role of self-evaluation of factors that may compromise a satisfactory QoL. Thus, it can be seen that QoL has a polysemic notion and therefore serves as a parameter for assessing health levels and living conditions of a population against different domains that may compromise it.

In the case of people living with HIV, in this construct, it was observed that, in general, the self-assessment of the QoL was satisfactory, with impairment in the environmental domain. Therefore, it is necessary to invest in health policies that can subsidize the planning of actions to promote health and quality of life.

Through the discussions, it is clear that the health system needs to advance the inter-sectoriality of public policies, so that we can go beyond cure or treatment of diseases and prevention of diseases, strengthening health promotion. In the collective sphere, the essence of a multi-professional and interdisciplinary team is emphasized in order to overcome the fragmentation of care and to strengthen the empowerment of the individuals, thus conferring the autonomy of citizens so that they can be shared by health care.

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AUTOAVALIAÇÃO DA QUALIDADE DE VIDA DE PESSOAS VIVENDO COM HIV

RESUMO

Objetivo: Analisar a autoavaliação da qualidade de vida (QV) de pessoas vivendo com HIV**. Metodologia:** trata-se de estudo descritivo, transversal e quantitativo, realizado com 150 usuários de um Serviço de Assistência Especializada (SAE) em HIV localizado na Capital do estado de Pernambuco. A QV foi avaliada a partir do instrumento WHOQOL HIV Bref, dividido em seis domínios: físico, psicológico, relações sociais, ambiente, nível de independência e espiritualidade. A análise estatística foi feita pelo programa computacional SPSS 18.0. Foram aplicados média e desvio padrão e utilizados testes como Kolmogorov Smirnov, Friedman e Wilcoxon. **Resultados:** os extremos de idade variaram entre 18 e 69 anos, com mediana de 37,5 anos. Houve predominância de mulheres (65,3%) e de pessoas sem o ensino médio concluído (60%). Os domínios da QV que atingiram melhores resultados foram: psicológico, físico e relações sociais, com médias de autoclassificação de muito boa qualidade de vida de 16,69; 16,67 e 15,67 respectivamente. Salienta-se que uma melhor autopercepção da QV indica melhores condições nos domínios avaliados. **Conclusão:** os fatores que atingem negativamente a QV contribuem para aumentar as vulnerabilidades das pessoas vivendo com HIV e, considerando os pontos estruturantes das condições de vida, fica claro que é preciso avançar nas políticas de promoção da saúde.

Palavras-chave: Qualidade de vida. Promoção da saúde. HIV. Síndrome da Imunodeficiência Adquirida.

AUTOEVALUACIÓN DE LA CALIDAD DE VIDA DE PERSONAS VIVIENDO CON VIH

RESUMEN

Objetivo: analizar la autoevaluación de la calidad de vida (CV) de personas viviendo con VIH**. Metodología:** se trata de un estudio descriptivo, transversal y cuantitativo, realizado con 150 usuarios de un Servicio de Asistencia Especializada (SAE) en VIH ubicado en la Capital del estado de Pernambuco-BR. La CV fue evaluada a partir del instrumento WHOQOL HIV Bref, dividido en seis dominios: físico, psicológico, relaciones sociales, ambiente, nivel de independencia y espiritualidad. El análisis estadístico fue hecho por el programa computacional SPSS 18.0. Fueron aplicados promedio y desviación estándar y utilizadas pruebas como *Kolmogorov Smirnov*, *Friedman* y *Wilcoxon*. **Resultados:** los extremos de edad variaron entre 18 y 69 años, con promedio de 37,5 años. Hubo predominancia de mujeres (65,3%) y de personas sin la enseñanza secundaria concluida (60%). Los dominios de la CV que alcanzaron mejores resultados fueron: psicológico, físico y relaciones sociales, con promedios de autoclasificación de muy buena calidad de vida de 16,69; 16,67 y 15,67 respectivamente. Se señala que una mejor autopercepción de la CV indica mejores condiciones en los dominios evaluados. **Conclusión:** los factores que alcanzan negativamente la CV contribuyen para aumentar las vulnerabilidades de las personas viviendo con VIH y, considerando los puntos estructuradores de las condiciones de vida, queda evidente que es necesario avanzar en las políticas de promoción de la salud.

Palabras clave: Calidad de vida. Promoción de la salud. VIH. Síndrome de Inmunodeficiencia Adquirida.

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