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Evaluating the quality of life of people living with HIV/AIDS: integrative review

Avaliação da qualidade de vida de pessoas vivendo com HIV/AIDS: revisão integrativa

Evaluación de la calidad de vida de personas que viven con VIH/SIDA: revisión integradora

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ABSTRACT

Objective: to analyze studies on evaluating the quality of life of people living with HIV in Brazil, by integrative literature review. **Method:** this integrative review included 22 scientific articles published from 2011 to 2019. **Results:** the instruments most used to assess quality of life were the WHOQOL-HIV bref and the HAT-QOL. The highest-scoring domains were trust in the doctor, psychology and spirituality, while the lowest scores related to the environment and confidentiality concerns. Exposing the diagnosis has adverse impacts on both quality of life and conditions of life and health. **Final considerations:** quality of life is a multidimensional, subjective construct with direct implications for the health and treatment of people living with HIV. Accordingly, in order to develop public policies and improve conditions of life, it is essential to understand the factors that impact on its assessment.

Descriptors: Quality of Life; Evaluation Acquired Immunodeficiency Syndrome; HIV.

RESUMO

Objetivo: analisar estudos referentes à avaliação da qualidade de vida de pessoas vivendo com HIV no Brasil, por meio de uma revisão integrativa da literatura. **Método**: trata-se de revisão integrativa que incluiu 22 artigos científicos publicados no período de 2011 a 2019. **Resultados**: os principais instrumentos utilizados na avaliação da qualidade de vida foram o WHOQOL-HIV *bref* e o HAT-QOL. Os domínios com maiores escores na avaliação foram confiança no médico, psicológico e espiritualidade; as piores avaliações relacionavam-se com os domínios meio ambiente e preocupação com o sigilo. A exposição do diagnóstico impacta negativamente para a qualidade de vida bem como as condições de vida e saúde. **Considerações finais**: a qualidade de vida é um construto multidimensional e subjetivo com implicação direta na saúde e tratamento das pessoas vivendo com HIV, portanto, compreender os fatores que impactam sua avaliação é primordial na elaboração de políticas públicas e melhores condições de vida.

Descritores: Qualidade de Vida; Avaliação; Síndrome de Imunodeficiência Adquirida; HIV.

RESUMEN

Objetivo: analizar estudios sobre la evaluación de la calidad de vida de las personas que viven con el VIH en Brasil, mediante revisión integradora de la literatura. **Método:** esta revisión integradora incluyó 22 artículos científicos publicados entre 2011 y 2019. **Resultados:** los instrumentos más utilizados para evaluar la calidad de vida fueron el WHOQOL-HIV bref y el HAT-QOL. Los dominios de mayor puntuación fueron la confianza en el médico, la psicología y la espiritualidad, mientras que las puntuaciones más bajas se relacionaron con el medio ambiente y las preocupaciones de confidencialidad. Exponer el diagnóstico tiene impactos adversos tanto en la calidad de vida como en las condiciones de vida y salud. **Consideraciones finales:** la calidad de vida es un constructo subjetivo multidimensional con implicaciones directas para la salud y el tratamiento de las personas que viven con el VIH. En consecuencia, para desarrollar políticas públicas y mejorar las condiciones de vida, es fundamental conocer los factores que inciden en su evaluación.

Descriptores: Calidad de Vida; Evaluación; Síndrome de Inmunodeficiencia Adquirida; VIH.

INTRODUCTION

Studies on HIV/AIDS are meaningful due to the consequences and global impacts of the infection at the political, economic and social levels. From the beginning of the epidemic until the end of 2018, 74.9 million people were infected with HIV, and an estimated 37.9 million people are living with HIV worldwide[1]. In Brazil, from the first cases until June 2019, 966,058 cases were recorded, with 43,941 new cases of HIV infection in 2018 alone, thus maintaining the average of 39,000 new cases in the last five years[2].

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The current configuration of HIV infection shows a profile of heterosexualization, feminization, impoverishment and internalization of the epidemic, which is closely associated with the profound Brazilian social inequality[3]. Despite the magnitude of the infection in the national scenario, there was a decrease in the rate of AIDS detection - from 21.7/100,000 in 2012 to 17.8/100,000 in 2018 - as a result of policies of early treatment for everyone infected, regardless of their viral load[2].

More than three decades after its discovery, HIV/AIDS presents a new clinical and epidemiological configuration, leaving the association with the presence of imminent death in the past and beginning to figure as a chronic disease. It is important to highlight the role played by antiretroviral therapy (HAART) in increasing the life expectancy of people living with HIV and, consequently, in changing the way how such health condition is looked at[4].

Despite the recognition that increased survival time positively influences people's lives, it is understood that this factor alone is not directly related to improvement in the quality of life (QOL) of people living with HIV, since the diagnosis implies changes in various aspects of life, such as sexual, emotional and social aspects[5,6].

According to the World Health Organization (WHO), QOL can be defined as "*an individual's 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*"[7:28]. Thus, QOL of people living with HIV is identified as a multifactorial element, associated with functional, physical, economic, emotional, and social aspects, spirituality, personal beliefs and the environment, involving the subjective experience of HIV, as well as comprehensive health care. Studies developed on the theme show that individuals find different ways to adapt to and live with the changes occurring in their lives, which also influences the way of assessing QOL[4,8,9].

It is important to emphasize that, in an attempt to understand QOL, care must be taken not to reduce the concept only to objective and subjective factors, since this construct involves the constant interrelationships between all the elements that compose this universe[10].

In this context, it is considered relevant to investigate what scientific productions indicate in relation to the assessment of QOL of people living with HIV. Therefore, the objective was to analyze studies related to the evaluation of the quality of life of people living with HIV in Brazil, through an integrative literature review.

METHOD

This study consists in an integrative review, a method that synthesizes information available in the literature in a systematic and orderly manner, aiming to construct a consistent set of meanings that can relate empirical and theoretical findings[11]. The stages in this study were developed from the phases: theme identification; question formulation; survey of studies; selection of studies; data collection; evaluation of studies; data analysis; interpretation of findings; discussion of results; and, finally, the presentation of the integrative review[11].

In order to strictly comply with the aforementioned steps, the main theme in this study was defined as "QOL assessment of people living with HIV", and the following guiding question: what is the QOL assessment of people living with HIV/AIDS in Brazil today? was used.

To answer the question, the Virtual Health Library (VHL) was utilized by selecting the Nursing Database (BDENF), the Latin American and Caribbean Health Sciences Literature (LILACS), the Scientific Electronic Library Online (SCIELO) and the National Library of Medicine (PUBMED). The databases were selected in an attempt to capture all the studies published by Brazilian researchers. A combination of Boolean descriptors and operators was used: "AIDS" OR "HIV" OR "acquired immunodeficiency syndrome" AND "quality of life". The inclusion criteria were full articles, in Portuguese, available for free and indexed in the aforementioned databases. As an exclusion criterion, dissertations and theses were rejected. The elected publication period was from 2011 to 2019 in order to update the information on the theme. All articles that met the inclusion criteria were analyzed.

In order to organize the information, an electronic spreadsheet was designed in Microsoft Office Excel®, containing the following information: title, authors, year of publication, journal, objective, type of study, sample, instrument for assessing QOL, and results.

After evaluating the studies by using an adapted instrument[11], those whose research design did not fit the objective of this review, as well as those with low methodological quality, were excluded. The analysis of the selected studies and the synthesis of the data extracted from the articles were performed in a descriptive manner, making it possible to observe, analyze, describe and classify the data.

RESULTS

The initial sample consisted of 10,248 articles found on the selected databases. When inserting the inclusion criteria previously established, the number of articles was reduced to 166. Sixty-nine publications showing duplicates on the databases and 37 other articles that were not related to the object of study were excluded. Thus, the abstracts of 60 articles were read. Then, 35 articles were fully read, and 22 were selected for analysis and discussion. The details of the study selection process, according to PRISMA[12] recommendations, are shown in Figure 1.

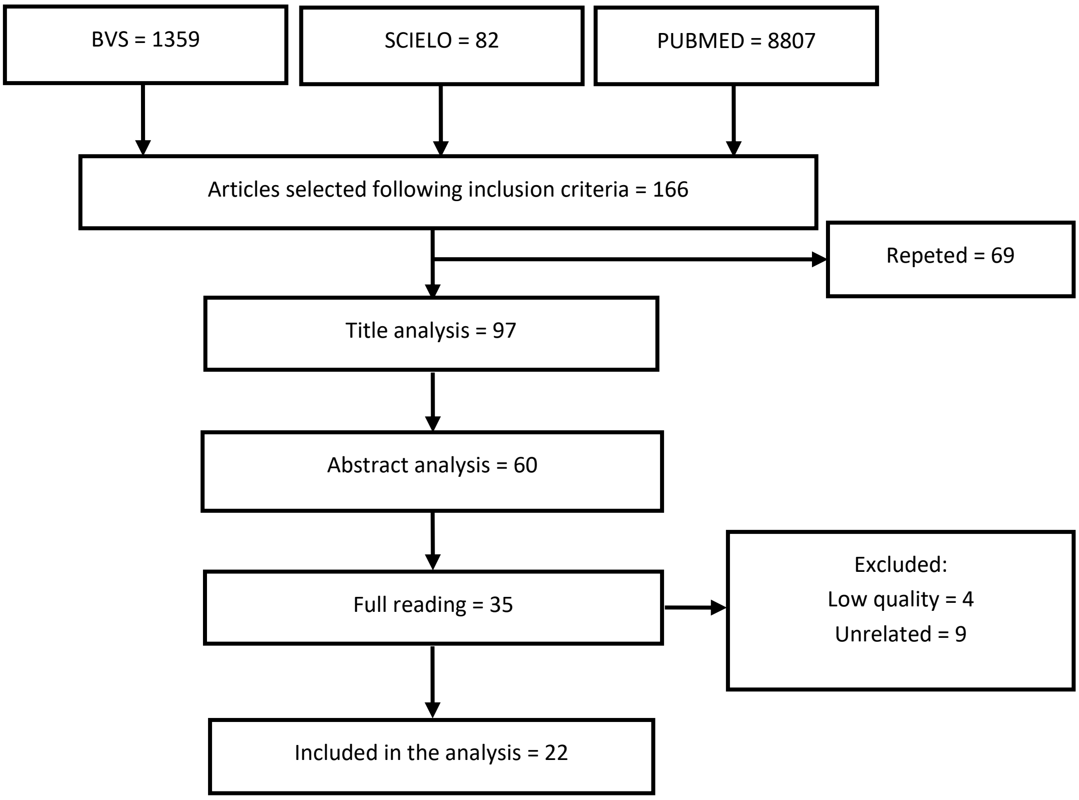

FIGURE 1: Selection of articles from databases, 2011 to 2019. Rio de Janeiro, Brazil, 2020.

Among the 22 selected articles, 13 (59%) were published in specific nursing journals, three (14%) in psychology journals, and the other six (27%) in medical or public health journals. The selected articles are shown in Figure 2.

Regarding the instruments for evaluating QOL, 14 (64%) articles used WHOQOL, seven (32%) used HAT-QOL, and one (4%) article made a comparison between WHOQOL and HAT-QOL, thus utilizing the two instruments.

HAT-QOL consists of nine dimensions, namely: provider trust; medication worries; overall function; life satisfaction; HIV mastery; sexual function; health worries; financial worries; and disclosure worries[5]. WHOQOL, in turn, is composed of six domains, namely: physical health; psychological; level of independence; social relationships; environment; and spirituality, religion and personal beliefs (SRPB)[13]. When analyzing the socioeconomic data in the selected studies, the predominance of low income and poorer education among the participants related to the lowest QOL scores was noteworthy in the samples[5,13-16,20]. A close association between these variables and QOL domains environment, psychological, health and medical treatment worries was observed.

Another important variable for analyzing QOL was gender. In some studies, the sample was composed only of females[13,21,26] or only of males[25]; others investigated females and males randomly[5,14-20,22-24,26-32]. The studies reported the lowest QOL scores for females, and the poorest education, the lowest income, economic and emotional dependence on their partners, difficulty in negotiating condom use, fear of rejection, sexual violence and lack of autonomy concerning their own bodies were the main predictors for this group[13,15,30].

Author, year	Title	Instrument/ Sample	State where data were collected
REIS et al, 2011[5]	Quality of life, sociodemographic and sexual aspects of people living with HIV/AIDS	HAT-QOL 229	São Paulo
GASPAR et al, 2011[13]	Quality of life of women living with HIV/AIDS in a city in São Paulo state	WHOQOL 106	São Paulo
LOPES et al, 2011[14]	Quality of life of over-50-year- old HIV-positive patients	HAT-QOL 86	Rio Grande do Sul
FERREIRA et al, 2012[15]	Quality of life of HIV/AIDS patients and its relationship with CD4+ lymphocytes, viral load and time of diagnosis	WHOQOL 205	Minas Gerais
MEDEIROS et al, 2012[16]	Religiosity and quality of life in people with HIV	WHOQOL 90	Paraíba
SILVA et al, 2013[3]	Quality of life in the context of HIV/AIDS: a comparative study with the general population	WHOQOL 561 without HIV 286 with HIV	Paraíba
MEDEIROS et al, 2013[17]	Biopsychosocial determinants that predict quality of life in people living with HIV/AIDS	WHOQOL 90	Paraíba
BORBA et al, 2014[18]	Comparative study on the performance of WHOQOL-HIV *bref* and HIV/AIDS - target quality of life in assessing the quality of life of individuals living with HIV/AIDS	HAT-QOL and WHOQOL 60	Santa Catarina
OLIVEIRA FILHO et al, 2014[19]	Quality of life of people living with HIV/AIDS	WHOQOL 30	Paraíba
OKUNO et al, 2014[20]	Quality of life of elderly patients living with HIV/AIDS	HAT-QOL 201	São Paulo
BELLINI et al, 2015[21]	Quality of life of women with HIV	WHOQOL 40	São Paulo
GALVÃO et al, 2015[22]	Quality of life and adherence to antiretroviral medication in people with HIV	HAT-QOL 45	Ceará
OLIVEIRA et al, 2015[23]	Quality of life and associated factors in people living with HIV/AIDS	WHOQOL 146	Piauí
OKUNO et al, 2015[24]	Quality of life, socioeconomic profile, knowledge and attitude about sexuality of "people who live" with the Human Immunodeficiency Virus	HAT-QOL 201	São Paulo
CUNHA et al, 2015[25]	Quality of life of men with AIDS and the model of social determination of health	WHOQOL 138	Ceará
TEIXEIRA et al, 2015[26]	Quality of life assessment of women living with HIV	WHOQOL 41	Paraná
SOARES et al, 2015[27]	Quality of life of people living with HIV/AIDS treated at the specialized service in Vitória (ES), Brazil	HAT-QOL 177	Espírito Santo
HIPOLITO et al, 2017[28]	Quality of life of people living with HIV/AIDS: temporal, sociodemographic and perceptive health relations	WHOQOL 100	Rio de Janeiro
CALIARI et al, 2018[29]	Quality of life of elderly people living with HIV/AIDS in outpatient care	HAT-QOL 81	Minas Gerais
CECILIO et al, 2018[30]	Quality of life of people living with HIV	WHOQOL 281	Rio de Janeiro
SILVEIRA et al, 2019[31]	Psychometric properties of WHOQOL-HIV *bref* to assess quality of life	WHOQOL 226	Minas Gerais
CECILIO et al, 2019[32]	Quality of life of people living with HIV treated in public health services	WHOQOL 281	Rio de Janeiro

FIGURE 2: Articles selected for analysis in the study. Rio de Janeiro, Brazil, 2020.

Among the seven articles that used HAT-QOL, the highest scores shown were in the domains of provider trust[5,14,22,27,29] and medication worries[20,24,29]. The lowest scores were in the domains of disclosure worries[5,20,22,24,29] and financial worries[14,27].

The studies using HAT-QOL showed that different sociodemographic factors are responsible for a better or worse QOL assessment, such as gender, age, white color, education, income, time of diagnosis, as well as the practice of physical activity and sexuality. Thus, they concluded that living and health conditions directly affect QOL assessment, which can be affected by public policies aimed at social inclusion, respecting differences and understanding the specificities of the chronicity of living with HIV/AIDS[5,14,20,22,24,27,29].

The highest scores reported in the articles using WHOQOL were in the psychological[15,17,23,25,30,32] and SRPB[3,13,16,21,28,31] domains. The lowest scores were in the environment[3,13,16-18,21,28,30-32] and level-of-independence domains[23,25].

The studies using WHOQOL showed that living conditions directly influenced the QOL assessment of people living with HIV. They also indicated that the psychosocial aspects interfered negatively in QOL, especially, when these people had already gone through situations of stigma and prejudice, when they had a same-sex relationship, or because they faced opportunistic diseases. In short, the studies confirmed the need to understand QOL as an expanded and multifactorial concept, with strategies that permeate the health sector[3,13,15-19,21,23,25-26,28,30-32].

The study comparing the QOL assessment as measured by HAT-QOL and WHOQOL suggested that both instruments behave in a similar way in the QOL assessment of people living with HIV, being recognized as valid and reliable instruments for the Brazilian population[18].

DISCUSSION

Discussions concerning the QOL construct in health care should not only contribute to reflection and criticism, but should also be considered a proposition instituted by discourses and practices in order to develop and improve protocols and policies[33]. Understanding QOL as a result of individual perceptions based on human experience also implies the concept of basic human needs, which needs to be expanded to a discussion in a less biological and normative, but more social and universal dimension[34].

In the AIDS context, the concern with the QOL concept refers to a movement within human and biological sciences in the sense of valuing broader parameters than just symptom control, mortality reduction or increased life expectancy[35]. Thus, when discussing QOL broadly, it is necessary to understand it as a dynamic and changeable process that includes continuous interactions between individuals and the environment; therefore, socioeconomic, demographic, cultural, psychological and spiritual conditions constitute intrinsic factors in QOL assessment. Low levels of education and income lead to precarious living conditions, social, cultural and economic vulnerabilities, difficulties in accessing health services and the lack of knowledge about one’s health status and treatment, thus reflecting negatively on QOL assessment.

In the context of individuals’ personal and social vulnerabilities to HIV, social strategies and policies aimed at ensuring rights and these social groups’ inclusion in society in an autonomous manner and with respect to differences are important.

Although the relationship between health and QOL dates from the beginning of social medicine, in the 18th and 19th centuries[36], scientific studies using the QOL construct in health care importantly increased as from the 1990s, in view of the need to understand QOL and its relations with biological, social and cultural issues[37].

With this regard, some instruments were created with the purpose of measuring the complexity that involves QOL assessment, either from specific instruments for the health care field or from those that use health as an intervening indicator for QOL[36]. Among the instruments developed, WHOQOL, designed by a group of health specialist researchers from WHO, makes it possible to compare data from an international and cross-cultural perspective. Subsequently, it was adapted for people living with HIV, being widely used by Brazilian researchers. Another instrument, the HIV/AIDS Quality of Life (HAT-QOL), was developed with the aim of specifically evaluating QOL of people living with HIV and the characteristics and impacts of the AIDS epidemic on these individuals’ AQOL. Although there are other instruments, these have gained greater prominence in Brazilian research.

Regarding the QOL assessment domains presented by the instruments, in the physical domain, there is a disagreement between the studies using WHOQOL-HIV *bref*. Higher scores in this domain may be related to the evolution HIV/AIDS treatment and HAART, which has enabled not only increased survival, but also the reduction of opportunistic infections and hospitalizations. This can influence better QOL assessment[13], as therapeutic measures provide individuals with a decrease in symptoms and promote functional capacity maintenance, in addition to favoring their self-image, providing people living with HIV with a “healthy” appearance, thus influencing their self-esteem and other QOL dimensions[24,26].

It can be inferred that studies with lower scores in this domain have identified changes resulting from HIV in functional capacity, HIV-related symptoms or HAART-related side effects. HAART can cause side effects, such as nausea, vomiting and the lipodystrophy syndrome, which can lead to noticeable physical changes and possible effects on the psychological and social dimensions of QOL[38]. Other factors perceived as negative for this dimension are the presence of opportunistic diseases, high viral-load levels and low CD4+ T lymphocyte levels[23].

Lower scores were also identified in the environment domain in studies using WHOQOL-HIV *bref*[13,16]. The possible implications are related to the vulnerabilities and social inequalities described. In addition, as a health problem, HIV infection reflects on the population's health, imposing the need for therapies and new habits, which generates increased costs for this social group. This information also emerged in the studies using HAT-QOL[5,14], as was shown the financial-worries domain.

With this regard, another facet that implicates the environment domain is the inclusion of people living with HIV in health care services. In Brazil, the IST/AIDS Program is considered a world reference in the distribution of HAART and treatment for this population. Some studies show a positive assessment by users of the care services specialized in HIV/AIDS, an assessment that is anchored on relationships with health professionals, especially doctors, and on the free distribution of medicines[17,38].

Provider trust[5,14] was one of the domains with the highest scores, thus showing the doctor's importance in the treatment of people living with HIV. Positive and trusting interpersonal relationships between doctors and patients favor the latter's acceptance of their serological condition and adherence to the prescribed treatment[14].

The medication-worries domain, assessed by HAT-QOL, obtained the second highest score among the selected articles[5]. HAART is considered an essential factor in maintaining QOL of people living with HIV, as it provides for symptom reduction and/or control, prolongs the latent stages of infection and reduces the possibility of one's becoming ill[13]. Drug treatment can have a positive influence on QOL of individuals, as well as a negative one, as it generates the need for changes in habits, such as the regular use of antiretrovirals and adaptation of the routine of people living with HIV[5,15].

The domain showing the lowest scores in HAT-QOL was disclosure worries[5,14]. This fact is associated with the social impacts that HIV/AIDS bring to individuals' lives. Research[5,14,23] points to stigma and discrimination as a relevant and negative factor for QOL of people living with HIV. Stigma and discriminatory attitudes generate feelings such as anguish, anxiety and fear, causing impacts on the psychological dimension of QOL and decreased self-esteem, in addition to the adoption of withdrawn behaviors and social isolation to hide the diagnosis. This omission occurs at all levels of social relationships, thus causing people living with HIV to assume tense and withdrawal behaviors so as not to show any factors that could reveal HIV positive serology[5,20,22,24]. This behavior, in addition to influencing the domain of social relationships, can influence the subject's acceptance of and adherence to treatment.

In the fight against stigma and discrimination, studies[5,14,26] point out the different social networks for inclusion of people living with HIV as a great strategy for damage reduction. Their social support, trust and empathy are established to help in addressing issues inherent to HIV, in addition to favoring adherence and strengthening social bonds by promoting the empowerment of people living with HIV as social actors.

Therefore, studies aimed at discussing and updating issues related to living with HIV/AIDS are always timely and appropriate. This is because QOL assessment, being an individual and social construction, simultaneously receives influences from the current health conditions in the lives of people living with HIV - presence of symptoms, adverse effects or opportunistic infections - as well as from the moment experienced in the context of health and social policies, such as access to health services, tests and medications, employment opportunities, housing conditions, transportation, among others. Thus, QOL of people living with HIV must be constantly assessed and the impacts, both negative and positive, should serve as indicators for the reformulation of public policies and improvement in living conditions.

FINAL CONSIDERATIONS

Studies seeking to learn about factors that intervene in QOL of people living with HIV, such as research with the QOL construct, are meaningful, as they favor the identification of the aspects that interfere in QOL and favor the construction of strategies to reduce damage to that social group. Policies and actions that aim to reduce inequalities and vulnerabilities of population groups and that can interfere in HIV prevention, combat and treatment actions are essential.

The instruments for measuring QOL provide means to capture individuals' well-being and their perception of their lives. It is noteworthy, however, that such instruments are constructed by quantitative means, where different domains have the same score, which can generate a false view of an eminently positive and/or negative QOL. The studies selected as a sample in this integrative review have mostly positive means; nevertheless, domains with negative evaluation scores and others with maximum evaluation means were observed, thus generating a final means tending to a positive QOL evaluation. QOL is a multidimensional, subjective and individual construct, with interconnection between its domains. Thus, the construction of an analysis that seeks to identify all the factors influencing QOL individually and their relationships promotes a better understanding of QOL and favors the development of strategies aimed at specific domains and with a final influence for QOL of people living with HIV.

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