

## 19 - QUALITY OF LIFE IN INDIVIDUALS WITH HIV / AIDS: INTEGRATIVE LITERATURE REVIEW

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### INTRODUCTION

The interest in the theme of quality of life in health stems, above all, from the definition of health advocated by the World Health Organization (WHO), as a state of complete physical, mental and social well-being, and not simply as absence of disease. Thus, health-related quality of life is a concept that focuses on the patient's subjective assessment and is necessarily related to the impact of health status on the individual's ability to live fully. It should be noted that quality of life is one of the most used subjective aspects in the assessment of the impact of chronic diseases and can be used as a parameter for decision-making regarding the treatment and approval of new therapeutic regimens (MEIRELLES et al. 2010).

Among these chronic diseases, the Acquired Immunodeficiency Syndrome (AIDS) stands out, which demands a growing concern with the quality of life, due to the increased life span provided by the use of antiretroviral therapy and the search for health systems, as well as prevention and control methods and strategies to facilitate adjustment and increase the well-being of people with HIV / AIDS (CRUZ et al., 2015).

It is in this sense that the importance of studies in the area of quality of life in the context of AIDS is inserted, since the development of research in this area may result in changes in care practices, improve the relationship between doctor and patient, based on broader perception of the disease process that locates priorities and improves physician's understanding and patient confidence, and contributes to the consolidation of new paradigms of the health-disease process (OLIVEIRA et al. 2017).

With regard to research, the tools employed to assess quality of life will contribute to providing information on how the HIV / AIDS process impedes patient well-being in various areas of their lives, which may be directed to the health policies that aim to improve the quality of life of this population (SEIDL et al., 2004).

Based on the above, the present study was conducted, which aimed to characterize the scientific production about the quality of life in individuals with HIV / AIDS, in online journals, from 2014 to 2018.

### MATERIALS AND METHODS

To achieve the proposed objectives, the integrative literature review was selected as a research method, which is used to understand a deeper phenomenon, based on previous studies, which allows the gathering of data from different modalities of study design, research and the expansion of the conclusions (CATUNDA et al, 2016).

In order to carry out this review, the following methodological steps were demarcated: identification of the research theme or question; sampling (selection of articles); categorization of studies; definition of information taken from revised publications; evaluation of selected studies; interpretation of results; and presentation of research results (CATUNDA et al, 2016; GOUVEA et al, 2016).

To take forward the research steps presented here and considering that a study in the integrative literature review mode is guided by a question or hypothesis, this work was guided by the following guiding question: What is the characterization of the national scientific production about of quality of life in individuals with HIV? It should be emphasized that, with the research questions, we proceeded to survey the literary corpus to be analyzed, through the Virtual Health Library (VHL) website, through the descriptor: "Quality of life and HIV".

This literature comprised scientific articles published in the databases: Latin American and Caribbean Health Science Information Literature (LILACS) and the International Health Science Literature (MEDLINE). The following inclusion criteria were adopted: articles published from 2014 to 2018, in Portuguese, which included in their titles and / or summaries aspects related to quality of life in individuals with HIV / AIDS and were made available in full, free of charge, online. This last criterion was adopted in order to evaluate the literature more accessible to health professionals.

Subsequently, all criteria related to the proposed objectives were selected with criteria. After a thorough reading of the titles and abstracts, twenty-two studies met the established inclusion criteria. The selected articles were read in full and analyzed according to the objectives proposed for the study. In the next moment, the data were grouped according to the titles of the publications selected for the study.

Data collection was performed during August 2019, using an instrument that contained the following variables: title, database, year, journal, type of research, objectives and conclusion of the studies. In the next phase, the data obtained through the compiled material (from the excerpts extracted from the publications) were grouped according to the objective proposed for the study.

### RESULTS AND DISCUSSION

The study consisted of twenty-two publications that dealt with the theme quality of life in individuals with HIV / AIDS, as shown in Table 1 below.

Table 1 - Bibliographic description of the analyzed studies - 2014 to 2018

Article title	Year of publication / journal
Quality of life of people living with HIV / AIDS: effects of the perception of the disease and coping strategies (6).	2016 <i>Psicologia: Teoria e Pesquisa</i>
Quality of life of people living with HIV / AIDS (9).	2014 <i>Revista Baiana de Enfermagem</i>
Sexual orientation and quality of life of people living with HIV / AIDS. (4).	2017 <i>Rev Bras Enferm</i>

Quality of life and associated factors in people living with HIV / AIDS. (10).	2015 Act Paulista de Enfermagem
An evaluation of quality of life and its determinants among people living with HIV / AIDS from Southern Brazil (11).	2015 Cad Saúde Pública
Quality of life and people living with AIDS: relationship with sociodemographic and health aspects (12).	2014 Rev Latino-am Enfermagem
Quality of life of elderly patients living with HIV / AIDS (13).	2014 Cad Saúde Pública
Quality of Life Evaluation of Elderly People Living with HIV / AIDS According to HAT-QoL. Int Arch Med: Epidemiol (14).	2016 Int Arch Med: Epidemiol
Social representations of the quality of life of people living with HIV / AIDS (15).	2018 Texto Contexto Enfermagem
Levels of anxiety, perceived stress and social support in people living with HIV / AIDS. (16).	2016 Psicol Teor Pesq
Psychosocial factors associated with adherence to treatment and quality of life in people living with HIV / AIDS in Brazil (17).	2014 J. bras. psiquiatr
Prevalence and factors associated with paternity intention among men living with HIV / AIDS in Fortaleza, Ceará. (18).	2015 Texto Contexto Enferm
Quality of life of people living with HIV / AIDS treated by the specialized service in Vitória-ES, Brazil (19).	2015 Ciênc. saúde coletiva
Quality of life of people living with HIV / AIDS: temporal, sociodemographic and health perception relationship (20).	2017 Revista Latino-Americana de Enfermagem
Difficulties of living with HIV / AIDS: barriers to quality of life. (21).	2017 Acta Paulista de Enfermagem
Sexual orientation and quality of life of people living with HIV / AIDS (22).	2017 Revista Brasileira de Enfermagem
Social representations of the quality of life of people living with HIV / AIDS (23).	2018 Texto Contexto Enferm
Quality of life of people living with HIV / AIDS treated by the	2015

In this sense, the thematic analysis method made it possible to categorize, interpret and group similar data. From this cluster, two thematic categories emerged: Theme I: Evaluation of the quality of life related to HIV / AIDS; Theme II: Strategies used to improve the quality of life in individuals with HIV / AIDS, who presented the synthesis of knowledge contemplated in the literature.

#### THEME I: HIV/AIDS-related quality of life assessment

According to the studies covered in Theme I, expressed in the table above, it is found that the assessment of quality of life in relation to AIDS can be performed by generic or specific instruments. Given the large number of researches that address the issue, we can say that the quality of life of people with HIV / AIDS has been a major concern of health professionals. Thus, with the literature available today, researchers can verify what is the real impact of the disease in a multidimensional aspect.

Concerning the generic instruments, which cover the common and important aspects of Health and that can be used to evaluate and compare the quality of life in different health conditions and subpopulations, it was concluded that the studies used these instruments: WHOQOL-Old ; WHOQOL-bref (or abbreviated WHOQOL); WHOQOL-100 (OLIVEIRA et al., 2016; MOURA et al., 2016; COSTA et al., 2014; OKUNO et al., 2014). They also point out that such instruments are useful in comparing different diseases or the general population with no reported health problem, but are not sensitive to detect changes or differences in the health condition of a specific clinical population. To this end, it is particularly important to employ specific quality of life assessment tools, which include questions relevant to the health problem in question, namely.

Among these specific instruments, we highlight the WHOQOL-120 HIV, which was elaborated by WHO, translated and validated in Brazil and is used as a specific instrument to assess the quality of life of individuals with HIV / AIDS. This questionnaire has six domains that represent the most significant manifestations of quality of life, such as: physical, psychological, level of independence, social relations, environment, spirituality / religiosity and personal beliefs (ERCP). Each domain is made up of facets, minor manifestations of quality of life, totaling 29 - five specific to people with HIV / AIDS (PLWHA) and one about overall quality of life. There are 120 questions that must be answered on the Likert scale, which defines the intensity (ZIMPEL et al., 2007).

Importantly, its abbreviated version is WHOQOL HIV bref, which consists of 31 questions divided into six domains: physical; psychological; level of independence; social relationships; environment; spirituality (ZIMPEL et al., 2007).

The physical domain consists of the following items: pain and discomfort, energy and fatigue, sleep and rest, symptoms; The psychological domain involves positive and negative feelings, cognition, self-esteem, body image and appearance; the level of independence includes mobility, activities of daily living, dependence on treatment and fitness for work; The social relationships domain involves: personal relationships, social support, sexual activity, and social inclusion; in the environment domain, the items physical security, housing, finances, health and social care, information, leisure; physical environment and transportation; and the domain spirituality relates the items spirituality, religion, forgiveness and guilt, concerns about the future and death (HIPOLITO et al., 2017).

It is noteworthy that the great differential of the WHOQOL-120 HIV specific instrument and its abbreviated version, WHOQOL HIV bref, refers to the fact that it involves the spiritual dimension of the patient, which is often not contemplated. Such importance is highlighted in a study (18), designed to assess the quality of life of women with HIV / AIDS, using the WHOQOL - HIV bref and its association with sociodemographic variables, in which the authors found that, Of the six domains covered by the instrument, the one with the highest average score, ie, the best performance, was the domain of spirituality. This result was also verified in another research (HIPOLITO et al., 2017). They observed that the spirituality domain was the one with the highest average score among all individuals participating in the research. In this domain, aspects related to forgiveness and guilt for living with HIV / AIDS and concern for the future and death were evaluated.

Another specific instrument to assess the quality of life of patients with HIV / AIDS was pointed out in another study, which refers to HIV / AIDS - Quality of Life - HAT-QoL, whose domains were developed entirely from suggestions from patients

with HIV / AIDS (Souza et al., 2017). It is therefore a specific quality of life questionnaire for these patients, which ensures the inclusion of relevant domains.

This instrument consists of 42 questions, divided into nine domains: general activity (eight items), sexual activity (three items), concern about infection secrecy (five items), health concern (five items), financial concern (four items), HIV awareness (three items), life satisfaction (eight items), medication issues (four items) and physician trust (three items) (GALVÃO et al., 2004). The answers obtained by applying this instrument are configured on a Likert scale with five options, ranging from 1 (all the time) to 5 (no part of the time) (CALVETTI, 2014).

It is important to highlight that, in a study conducted to translate into Brazilian Portuguese, culturally adapt and evaluate the psychometric properties (validity and reliability) of a quality of life questionnaire (HIV / AIDS-Targeted Quality of Life Instrument), HAT-QoL, specific for HIV-infected patients, it was observed that the Brazilian Portuguese version of this instrument was comprehensible and easy to apply. This proved the success of cultural adaptation (SOUZA et al., 2017). The results obtained through this research suggest that the instrument has good construct validity and excellent reliability.

Corroborating this assertion, it was revealed that the questionnaire, in its Brazilian version, is practical, easy to apply and presented satisfactory reproducibility and validity. The results obtained by this study suggest that it can be used to assess quality of life in patients with HIV / AIDS (CALVETTI, 2014).

Another study conducted in 2004 highlights that the HAT-QoL scale is useful for the population of women with HIV, noting a significant impairment in their quality of life, especially in the following areas: financial concerns; health concerns; concern about secrecy about infection and sexual activity. These results may have occurred, perhaps, because these women live with situations that lead them to economic and social precariousness (GALVÃO et al., 2004).

From this perspective, it is understood that HAT-QoL should be used to assess the quality of life in the population with HIV / AIDS in Brazil, so that it is possible to make a longitudinal assessment and a judgment of the need for the domains sexual function, acceptance, HIV, professional confidence, and medication concerns. This is justified because patients who live with this disease often face situations of discrimination, segregation, lack of financial and social resources, disruptions in affective relationships and problems with sexuality, which is why we need a close look at the aspect of quality of life assessment.

In addition to the aforementioned instruments used to assess the quality of life of the population with HIV / AIDS, the study by OLIVEIRA et al., 2017, points to the theory of social representations as another means of carrying out this assessment. Such theory allows us to grasp a wealth of figurative elements, such as: cognitive, ideological, normative, related to beliefs, values, attitudes, opinions, images, among others. In this sense, this study, through this instrument, could verify that the quality of life for HIV-positive people was represented in elements whose characteristics are subjective as objective: work, housing, support, friendship, happiness, God and family.

These representations are in accordance with the concept advocated by the World Health Organization, in which quality of life refers to how individuals perceive their position in life, in the context of the culture and value system in which they live and in relation to your goals, expectations, standards and concerns.

Given the above, it should be emphasized that, currently, there are several instruments to assess the quality of life in AIDS, however the specific ones for this disease should be commonly chosen, since they allow a concentrated evaluation in a particular aspect, where they are considered more accurate and sensitive to small differences in the quality of life of this population.

#### THEME II: Strategies Used to Improve Quality of Life in Individuals with HIV / AIDS

The articles on Theme II, shown in Table 3, highlight the strategies that can be employed to improve the quality of life of patients with HIV / AIDS, which is contemplated in the studies, such as how individuals perceive their position in life, in the context of the culture and value system in which he lives in relation to his goals, perspectives and standards.

PEREIRA et al., 2016 report that as treatment progressed with antiretroviral use, opportunistic infections declined, and survival rates increased. Given the change in the trajectory of HIV infection to chronic disease, due to lack of cure, improving the quality of life of individuals living with HIV / AIDS has become one of the main purposes of clinical practice. Thus, numerous strategies contribute to the construction of the perception of quality of life in these individuals (QUEIROZ et al., 2016; DOMINGUES et al., 2018).

In a survey, it was concluded that, to improve the quality of life of HIV-infected children, therapeutic adherence is required for maximum reduction and constancy of viral load, which leads to better immune function and, consequently, to better immunity, a better quality of life (PEREIRA et al., 2016). Another study corroborates the mentioned aspects and states that adherence to treatment of individuals with HIV and quality of life must occur simultaneously, and adherence is a stimulus to treatment (MARTINS et al., 2016).

It is noteworthy that religiosity was contemplated as a coping strategy in the context of this chronic disease. The relationship between religiosity and the psychological, social and environmental domains of quality of life refers to the role of religiosity as a driver of psychological well-being and social and structural support for people affected by disease and other clinical conditions. Thus, the relevance of the social support peculiar to many religious systems, which help in times of suffering in the context of HIV seropositivity, is emphasized, where often the low participation of the family and the little social support network contribute to the "social death" of the person (DOMINGUES et al., 2018).

Another research aimed to know the feeling of the person with HIV / AIDS regarding facial lipoatrophy, and the meaning of having performed facial filling (OLIVEIRA et al., 2017). Such disorder is caused by antiretroviral therapy, which causes intense changes in the face. Thus, a treatment suggested and made available by the Unified Health System (SUS) is polymethyl methacrylate for skin filling. It was verified, in the study, the increase of the quality of life of the people who had this treatment, not only in the physical dimension, but also in the psychosocial and emotional aspects that the polymethyl methacrylate filling has promoted in their lives, besides minimizing the stigmas and the self-stigma that are created around AIDS patients.

Thus, there is a need to provide comprehensive care, not only biological, but also enhancing the implementation of collective strategies aimed at discussing and working the health-disease process in the AIDS epidemic (MEDEIROS et al., 2017). In this context, AMARAL et al., 2016 allude that health professionals should enable the health team to plan integral care, including the biopsychosocial and spiritual dimensions of individuals (OLIVEIRA et al., 2017).

The communication of health professionals with preventive approach stands out as the main tool to reach the understanding of individuals and favor the change of their practices, believing in the need of assistance in spaces favorable to the promotion of health education, in which they can be heard, firstly, thus improving the quality of life (SOARES et al., 2016).

Based on this understanding, it is observed that there are several strategies aimed at quality of life, since these patients need holistic care, focusing on biopsychosocial and spiritual needs.

## FINAL CONSIDERATIONS

Health-related quality of life is an important adjunct to clinical indicators in assessing patient health. This assessment is even more relevant in patients with chronic diseases, where cure of the disease is not possible. Among these diseases, HIV infection stands out, which has become an important focus of interest in the research area regarding the assessment of quality of life, as it is considered a simple and effective measure for available treatment regimens.

From this perspective, as already mentioned, the study conducted an integrative literature review about the quality of life in individuals living with HIV / AIDS, highlighting two categories: 'Evaluation of the quality of life related to HIV / AIDS' and 'Strategies used to improve quality of life in individuals with HIV / AIDS'.

Regarding the category "Evaluation of HIV / AIDS-related quality of life", the study showed that, currently, there are several instruments to assess the quality of life in AIDS, however the specific ones for this disease should be commonly chosen, since they enable a concentrated assessment of a particular aspect, and are considered more accurate and sensitive to small differences in the quality of life of this population. These instruments include WHOQOL-120 HIV, WHOQOL HIV brief and HAT-QoL.

Regarding the category "Strategies used to improve quality of life in individuals with HIV / AIDS", it was found that the main strategies employed to improve the quality of life of individuals living with HIV / AIDS are: adherence to treatment, which will provide maximum reduction and constancy of viral load; polymethyl methacrylate treatment for skin filling; comprehensive care, including biopsychosocial and spiritual dimensions; social support from religious systems and the use of communication by health professionals with a preventive approach.

In this sense, it was observed that the development of studies related to the area of quality of life for this population can support humanized care practices, based on a broad perspective of the health-disease process, which encompasses the biopsychic and spiritual dimensions. Therefore, it is necessary to develop specific instruments that help health professionals to assess the quality of life of individuals living with HIV / AIDS, in order to identify the main problems that this population faces, in order to develop strategies aimed at promoting of the quality of life.

It is hoped, therefore, that this research can provide information compiled in order to subsidize new investigations that contemplate the interrelation of quality of life with individuals living with HIV / AIDS. This information should be more widely disseminated to managers, health professionals, students and researchers

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#### QUALITY OF LIFE IN INDIVIDUALS WITH HIV / AIDS: INTEGRATIVE LITERATURE REVIEW

Acquired Immunodeficiency Syndrome (AIDS) demands a growing concern with quality of life due to the increased life span provided by the use of antiretroviral therapy and the search for health systems, as well as prevention and control methods. strategies to facilitate adjustment and increase the well-being of people with HIV / AIDS. This study aimed to characterize and compile the scientific production about the quality of life in individuals with HIV / AIDS, in online journals, from 2014 to 2018. This is an integrative literature review, performed on the Virtual Library website. in Health, in the Latin American and Caribbean Health Information Literature and International Health Science Literature databases. The descriptor used was "Quality of Life and HIV", with a sample composed of twenty-two publications, selected according to given criteria. Two thematic categories were identified - "HIV / AIDS-related quality of life assessment"; and "Strategies used to improve quality of life in individuals with HIV / AIDS". It was observed that the development of studies in the area of quality of life for this population can support humanized care practices, based on a broad perspective of the health-disease process.

Descriptors: Quality of Life; AIDS serodiagnosis; HIV antigens.

#### QUALITÉ DE VIE DES PERSONNES VIVANT AVEC LE VIH / SIDA: EXAMEN INTÉGRAL DE LA LITTÉRATURE

Le syndrome d'immunodéficience acquise (SIDA) exige une préoccupation croissante en matière de qualité de vie en raison de la longévité accrue offerte par l'utilisation d'un traitement antirétroviral, la recherche de systèmes de santé, ainsi que de méthodes de prévention et de contrôle. stratégies visant à faciliter l'adaptation et à accroître le bien-être des personnes vivant avec le VIH / sida. Cette étude visait à caractériser et à compiler la production scientifique sur la qualité de vie des personnes vivant avec le VIH / sida, dans des revues en ligne, de 2014 à 2018. Il s'agit d'une analyse documentaire intégrative réalisée sur le site Web de la bibliothèque virtuelle. in Health, dans les bases de données sur la santé en Amérique latine et dans les Caraïbes et sur la littérature internationale sur les sciences de la santé. Le descripteur utilisé était «Qualité de vie et VIH», avec un échantillon composé de vingt-deux publications, sélectionnées selon des critères donnés. Deux catégories thématiques ont été identifiées - «Évaluation de la qualité de la vie liée au VIH / sida»; et «Stratégies utilisées pour améliorer la qualité de vie des personnes vivant avec le VIH / sida». Il a été observé que le développement d'études dans le domaine de la qualité de vie pour cette population peut soutenir des pratiques de soins humanisés, basées sur une perspective globale du processus santé-maladie.

Descripteurs: Quality of Life; Sérodiagnostic du SIDA; Antigènes du VIH.

#### CALIDAD DE VIDA EN PERSONAS CON VIH / SIDA: REVISIÓN INTEGRATIVA DE LA LITERATURA

El Síndrome de Inmunodeficiencia Adquirida (SIDA) exige una preocupación creciente con la calidad de vida debido al aumento de la vida útil proporcionada por el uso de la terapia antirretroviral y la búsqueda de sistemas de salud, así como métodos de prevención y control. estrategias para facilitar el ajuste y aumentar el bienestar de las personas con VIH / SIDA. Este estudio tuvo como objetivo caracterizar y compilar la producción científica sobre la calidad de vida en personas con VIH / SIDA, en revistas en línea, de 2014 a 2018. Esta es una revisión de literatura integradora, realizada en el sitio web de la Biblioteca Virtual. en Salud, en las bases de datos de Literatura de Información en Salud de América Latina y el Caribe y de Literatura en Ciencias de la Salud Internacional. El descriptor utilizado fue "Calidad de vida y VIH", con una muestra compuesta por 22 publicaciones, seleccionadas de acuerdo con los criterios dados. Se identificaron dos categorías temáticas: "evaluación de la calidad de vida relacionada con el VIH / SIDA"; y "Estrategias utilizadas para mejorar la calidad de vida en personas con VIH / SIDA". Se observó que el desarrollo de estudios en el área de calidad de vida para esta población puede apoyar las prácticas de atención humanizada, basadas en una perspectiva amplia del proceso de salud-enfermedad.

Descriptores: Calidad de Vida; Serodiagnóstico de SIDA; Antígenos del VIH.

#### QUALIDADE DE VIDA EM INDIVÍDUOS COM HIV/AIDS: REVISÃO INTEGRATIVA DA LITERATURA

A síndrome da imunodeficiência adquirida (AIDS), demanda uma preocupação crescente com a qualidade de vida, em virtude do aumento do tempo de vida proporcionado pela utilização da terapia antirretroviral e à busca pelos sistemas de saúde, além de métodos de prevenção e de controle e de estratégias para facilitar o ajustamento e aumentar o bem-estar dos portadores HIV/AIDS. Nesse estudo objetivou-se caracterizar e compilar a produção científica acerca da qualidade de vida em indivíduos com HIV/AIDS, em periódicos online, no período de 2014 a 2018. Trata-se de uma revisão integrativa da literatura, realizada no site da Biblioteca Virtual em Saúde, nas bases de dados da Literatura Latino Americana e do Caribe de Informação em Ciências da Saúde e da Literatura Internacional em Ciências da Saúde. O descritor utilizado foi "Qualidade de vida and HIV", com amostra composta por vinte e duas publicações, selecionadas segundo critérios determinados. Identificaram-se duas categorias temáticas - "Avaliação da qualidade de vida relacionada ao HIV/AIDS"; e "Estratégias utilizadas para a melhoria da qualidade de vida em indivíduos com HIV/AIDS". Pôde-se observar que o desenvolvimento de estudos, na área de qualidade de vida, para essa população pode subsidiar práticas assistenciais humanizadas, pautadas numa perspectiva ampla do processo saúde-doença.

Descritores: Qualidade de Vida; Sorodiagnóstico da AIDS; Antígenos HIV.