

Determinants of quality of life in people with HIV: an integrative review

Os determinantes da qualidade de vida em pessoas com HIV: uma revisão integrativa

Los determinantes de la calidad de vida en personas con VIH: una revisión integrativa

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ABSTRACT

Objective: to examine the determinants affecting the quality of life of people with HIV by a review of original research. **Method:** this integrative literature review surveyed publications on determinants of quality of life in HIV patients drawn from the PubMed, Scopus, CINAHL, CUIDEN and PsycINFO databases during April 2018. **Results:** 22 studies published from 2012 to 2016 were identified. The review found the determinants of these people's quality of life to be dispersed (42 variables): social support appeared in 36.3%, stigma in 31.8%, depression in 31.8%, and adherence in 22.7%. **Conclusion:** multiple determinants affect the quality of life of people with HIV, and there is consensus that social support, stigma, depression and adherence are determinants.

Descriptors: HIV infections; quality of life; nursing; epidemiologic factors.

RESUMO

Objetivo: analisar os determinantes que afetam a qualidade de vida de pessoas com HIV, a partir da revisão de pesquisas originais. **Método:** revisão integrativa da literatura com busca de produção sobre os determinantes da qualidade de vida de pacientes com HIV nas bases de dados PubMed, Scopus, CINAHL, CUIDEN e PsycINFO, realizada em abril de 2018. **Resultados:** foram identificadas 22 pesquisas, publicadas no período de 2012 a 2016. Detectou-se dispersão dos determinantes (42 variáveis) da qualidade de vida dessas pessoas. O apoio social (36,3%), o estigma (31,8%), a depressão (31,8%) e a adesão (22,7%) apareceram na revisão. **Conclusão:** existem múltiplos determinantes que afetam a qualidade de vida das pessoas com HIV, havendo consenso nos determinantes de apoio social, estigma, depressão e adesão.

Descritores: Infecções por HIV; qualidade de vida; enfermagem; fatores epidemiológicos.

RESUMEN

Objetivo: analizar los determinantes que afectan la calidad de vida de las personas con VIH, a través de la revisión de investigaciones originales. **Método:** revisión bibliográfica integral, buscando producción sobre los determinantes de la calidad de vida en pacientes con VIH, en las bases de datos PubMed, Scopus, CINAHL, CUIDEN y PsycINFO, realizada durante abril de 2018. **Resultados:** un total de 22 artículos incluidos se incluyeron en la revisión. Se observó que existe una gran dispersión de determinantes relacionados a la calidad de vida (42 variables diferentes). El apoyo social (36,3%), el estigma (31,8%), la depresión (31,8%) y la adhesión (22,7%) son los que más frecuentemente aparecieron durante la revisión. **Conclusión:** existen múltiples determinantes que afectan a la calidad de vida de las personas con VIH, existiendo un consenso sobre los determinantes relativos al apoyo social, el estigma, la depresión y la adherencia.

Descriptores: Infecciones por VIH; calidad de vida; enfermería; factores epidemiológicos.

INTRODUCTION

There is currently an upward trend in the number of individuals living with Human Immunodeficiency Virus (HIV), with an increase of over 8 million people in just 14 years. In addition, that same year, due to causes related to Acquired Immunodeficiency Syndrome (AIDS), 1.2 million people died¹.

The United Nations Joint Program on HIV/AIDS (UNAIDS) report presented in 2015 shows a 42% drop in disease-related deaths compared with 2004, the year when the highest number of deaths was reached². On the one hand, the number of individuals infected with HIV each year continues to be numbered in millions³. In this sense, anti-retroviral therapy does not completely eliminate HIV from the body, forcing the patient to continue treatment for the rest of his life⁴.

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In this perspective, the current treatment of the patient with HIV is effective only if he adheres to anti-retroviral treatment. However, these medications are not free from short- and long-term side effects⁵. The side effects experienced by the patient are not limited only to those produced by the anti-retroviral treatment. When he becomes a chronic patient, he experiences serious emotional deterioration. Thus, a person with HIV goes through a series of changes in their life, related to both the medication and the virus itself, which can put their quality of life at risk.

There is a current mainstream that holds that the patient is a holistic being. In exploring the situation of the HIV patient in this current context, the need to ensure that this person maintains an acceptable quality of life becomes fundamental. Logically, to be able to intervene on the quality of life of people living with HIV, it will be necessary to define in advance what the factors are which affect the quality of life of these individuals and how they can act on them.

We can find several review articles that precede this work. An example is that presented in 2010, in which the author concludes that the relationship between the quality of life of the patient with HIV and the indicators on clinical parameters and treatment adherence are not very consistent. Furthermore, the author stresses that it is essential to deepen the scientific field on the quality of care and the management of HIV diagnosis and treatment, due to the lack of studies found⁶.

Therefore, this review becomes relevant because individuals with HIV have an impaired quality of life, but there is shortage of works that treat it in a multidimensional way and that collect all the variables that affect quality of life. This fact makes it difficult to perform interventions that improve the quality of life of seropositive patients.

The following research question was observed: *What are the determinants that affect the quality of life of individuals with HIV?* Thus, this study aimed to analyze the determinants which affect the quality of life of individuals with HIV, based on the review of original research.

METHODOLOGY

For the elaboration of this work, an integrative review was performed, following some of the recommendations for the publication of systematic reviews or meta-analyses of the Preferred Report Items for Systematic Reviews and Meta-Analyses (PRISMA)⁷.

A survey of published bibliographic material was conducted throughout April 2018. The National Library of Medicine search engine of the United States (PubMed), the multiple bibliography search engine from Elsevier (Scopus) and the Cumulative Index for Nursing and Allied Health Literature (CINAHL) were used due to their relevance in the current bibliographic panorama. In addition, we searched in the Index Foundation's bibliographic database (CUIDEN), since it is a nursing-specific database, and in the American Psychological Association (PsycINFO) database, as it is a specific international search engine for psychology and sociology (branches of knowledge that also focus on individuals' quality of life).

In the first instance, the descriptors in Health Sciences (*Descritores em Ciências da Saúde*, DeCS) which could facilitate access to related articles on quality of life in patients with HIV were searched on the regional portal of the Virtual Health Library (*Biblioteca Virtual em Saúde*, BVS). The following descriptors were found: *HIV*, *Qualidade de vida* (Quality of life) and *Criança* (Child). In addition, the term nursing was added to reduce the search only for documents addressing the subject of nursing field. The different results obtained were analyzed and the articles were selected based on the following inclusion criteria: articles published between 2012 and 2018 to obtain the most up-to-date results possible, to have access to the full texts, to studies conducted in adult population and finally, to original research articles.

Articles that did not contemplate nursing, bibliographic reviews, studies conducted on children population, articles which only presented the abstract, dealt with the quality of life of patients with HIV and with some type of co-infection were excluded, since co-infection could interfere with the results

A total of 2,006 articles were obtained. After including the date filter (last 7 years), results were reduced to 294 documents, of which 8 were repeated and 5 did not have access to the full text. Of the 281 resulting articles, after reading their titles and abstracts, only 22 complied with the review characteristics to be performed⁸⁻²⁹. As shown in Figure 1, a flowchart is observed of this process in its entirety.

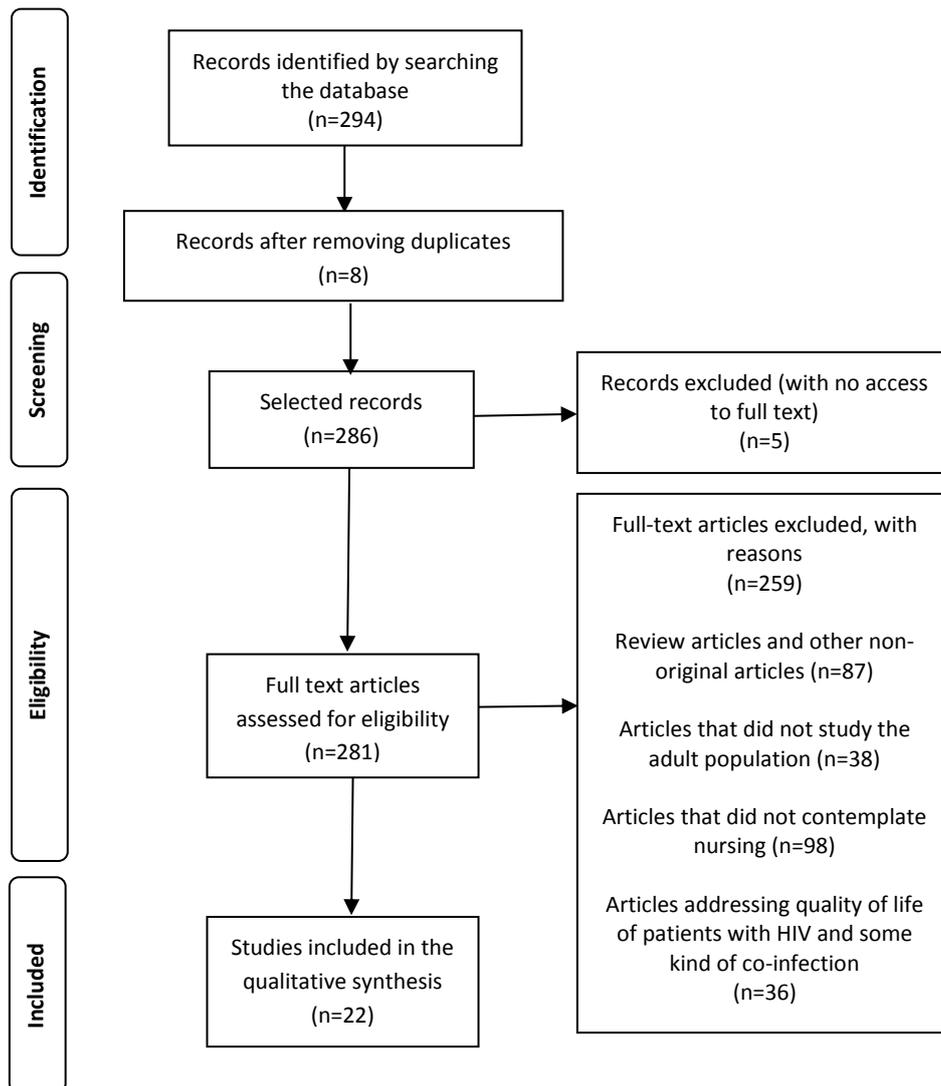


FIGURE 1: Bibliographic review flowchart

RESULTS AND DISCUSSION

22 articles that met all the selection criteria performed⁸⁻²⁹ were analyzed. In all cases, quantitative and descriptive design was used, except for one, which proposed a qualitative-quantitative methodology²⁸. There is a high frequency of cross-sectional studies, a total of 18 articles representing 81.8% of all documents studied^{8,9,13-27,29}.

Regarding the sample size, an average of N=238 (SD=212) was observed, ranging from 34²⁸ to 809¹¹ individuals.

Regarding origin, it was observed that there is a certain heterogeneity. Even so, it is necessary to emphasize that the countries with greater importance in the present work are: Brazil^{20,21,24-26,28,29}, USA^{10,15,18,19}, China^{8,12,14,22} and Thailand^{23,27}, as they account for almost 80% of the review.

After a detailed analysis of all identified articles, it can be observed that the total of the variables identified in all of them add up to 42 different determinants, which are related to quality of life.

Many of these determinants appear in more than one of 22 selected articles. This is the case with the *social assistance* determinant of quality of life, which is the most often identified result^{8,9,11-15,23}, appearing in 8 articles (36.3%). Then come *depression*^{8,9,12,13,17,18,19} and *stigma*^{8,9,12,14-16,26}, with 7 articles (31.8%). *Adherence* is another determinant of the quality of life of individuals living with HIV and was identified in a total of 5 articles (22.7%)^{19-22,26}.

Other determinants that, although to a lesser extent, also appeared in the papers included in this review, would be *age*^{15,16,25,27}, *comorbidity*^{15,18,28,29}, *education*^{16,17,23,24}, *income*²³⁻²⁶ and *work situation*^{23,25-27}, in 4 articles (18.2%). The determinant of *coping*^{11,15,23} was identified as a determinant of quality of life of individuals with HIV in 3 of the works (13.6%). Regarding *race*^{24,25}, *symptoms*^{10,18}, *stressful events*^{11,19}, *treatment*^{14,27}, *drug use*^{14,22}, *genre*^{16,24} and *elapsed time since diagnosis*^{25,26}, they were identified as determinants related to quality of life in only 2 articles (9%).

The determinants of the quality of life of seropositive individuals who appeared in only one article (4.5%) are the following: *avoidance*²², *family functioning*⁹, *physical care*⁹, *positive permanence*⁹, *CD4 levels*¹⁴, *marital status*¹⁶, *perception of situation control*²⁴, *healthy lifestyle habits*²⁵, *pain*¹⁷, *mobility*¹⁷, *viral load*²¹, *self-efficacy*²², *spiritual well-being*²³, *hospitalizations by AIDS phase*²⁴, *body changes*²⁴, *clinical condition*²⁴, *self-perception of the disease*²⁴, *physical activity*²⁵, *socioeconomic level*²⁵, *form of infection knowledge*²⁵, *religiosity*²⁶, *psychosocial symptoms*²⁶, *revealing of theseological status*²⁷ and *general health*²⁷.

As shown in figures 2 and 3, these main results can be observed from each of the articles included in the review.

The limitations observed during the conduct of this study have been mainly related to the great variability of the determinants found. This is largely due to the multidimensional nature of the concept of quality of life. The limitation would have been saved by focusing the review on only one aspect of quality of life but, in this case, the overall view that the study wanted to offer would have been lost. The option it could be due to the fact that the determinants related to the quality of life of individuals with HIV should be conditional on the sociodemographic area should also be evaluated.

Another limitation the study may present is that the results obtained may not be fully reliable, since some determinants are studied by different variables in the analyzed studies (for example, the clinical condition is measured as such in some studies² while in others it is measured by CD4 levels¹⁴ or through the viral load presented by the patient)²¹. It is therefore appropriate to analyze the reliability of the different mechanisms in place in future studies to determine quality-of-life variables.

Comparing the results offered by this review and those provided by other previous comments, we can see how there is a certain dissonance. In one of the oldest reviews found³⁰ we note that the resulting determinants are limited access to health care due to the lack of resources, stigma, mental health problems, drug use and domestic violence. Another article from the same year states that the main factors associated with quality of life are the phase of infection in which the person is found, biological parameters such as viral load, CD4 and lipodystrophy. Subsequently, we found another review in which adherence, religiosity and spirituality, clinical parameters, social support, psychiatric comorbidity, and sociodemographic variables are identified as determinants⁶. In their review study, other writers identified that the factors most associated with quality of life are CD4, gender and age³¹. Finally, the most recent article found that a review of the factors related to the quality of life of patients with HIV determines that the most frequent and consistently associated ones are the following: employment, immune status, presence of symptoms, depression, social support, and adherence³², which largely coincides with the four determinants identified by this review as most related to quality of life (social support, depression, stigma and adherence). Depression accounts for up to 53% of quality of life variability⁹, social support up to 24%¹¹, stigma up to a 64%¹⁵ and adherence to treatment up to 27.2%¹⁹, according to the bibliography reviewed. These numbers are consistent with the findings from other similar studies which addressed these determinants related to quality of life in individuals with HIV, both in the general population^{30,32} and in more specific groups such as women in rural areas³³.

These determinants that appear most closely related to quality of life require professionals who care for individuals with HIV, especially nurses, to have a specific profile that facilitates the understanding of the uniqueness of the health process these people go through, based on the preparation of humanitarian and emotional skills to address the determinants that affect the quality of life of individuals with HIV. This is recognized by more experienced nursing professionals caring for this type of patient³⁴, although they also require a large volume of care protocols, tailored to the specific regional or cultural realities of each locality, which improve the motivation of the professionals and the safe care of these patients³⁵.

Regarding the discussion of the results obtained, we say that 42 determinants that affect the quality of life of individuals with HIV were identified in the entire bibliography reviewed⁸⁻²⁹, namely: remain positive, cope well, perceive the situation, self-efficacy, maintain a good working situation and economic income, high socioeconomic and educational levels, knowledge about the form of HIV infection, spiritual well-being, physical care, maintaining a good clinical condition, overall health, low viral load and high levels of CD4, healthy life habits, social support, good family

functioning, good treatment and adherence, being older, living in a nuclear family, being a religious person, being black, being male, revealing HIV status, longer time since diagnosis, maintaining an attitude of avoidance, presence of comorbidity, hospitalizations for AIDS, drug use, depression, psychosocial symptoms, stigma, poor self-perception of the disease, presence of stressful events, experienced symptoms, pain, difficulty or lack of mobility and the presence of body changes.

Authors	Place	Result	Conclusion
Li X, et al. 2015. ⁸	China	The biggest symptomatology was associated with higher levels of stigma and less social support. Depressive symptoms were also associated with lower quality of life.	Stigma, social support and depressive symptoms are the main factors associated with quality of life in people with HIV.
Holtz C., et al. 2014. ⁹	Mexico	Family, emotional support, physical care and positive permanence were positively associated with quality of life. Stigma, depression and escape were negatively associated, and they explain 53% of the variability.	Efforts are needed to reduce stigma and to improve support networks for people with HIV, especially in rural areas. Stigma is a frequent barrier in seeking health support.
Sousa HK., et al. 2014. ¹⁰	USA	A substantial variation in quality of life variance (96.2%) is explained by the rate of change in the symptoms.	There is a strong connection between the number of symptoms experienced and quality of life. Proper management of the symptoms will have a huge benefit.
Nahas G., et al. 2015. ¹¹	Canada	Social support explains a 24% variation in quality of life. The following aspects are significantly related to quality of life: social support, number of stressful events and their intensity.	Results suggest that adequate social support has a partial mediating effect between stressful events and the quality of life of patients living with HIV.
Rao, D et al. 2012. ¹²	China	Social support as a mediator of the stigma on depression and quality of life.	Improving social support must be an important goal in interventions aimed at reducing the effect of stigma on health and on quality of life.
Hou, W. et al. 2014. ¹³	Taiwan	The effects of depression on quality of life were mitigated by the addition of social support, although it remained relevant. Social support was associated with quality of life.	Social support is a partial mediator of the relation between depression and quality of life.
Wu, X. et al. 2015. ¹⁴	China	Perceived stigma worsens quality of life and social support improves it. Low stigma scores, high support score against drug use, and high CD4 counts predict a variation in quality of life of 49%.	Perceived stigma, social support, CD4 count, internalized and family stigma, drug abuse, and anti-retroviral therapy are related to the quality of life of patients with HIV.
Slater, LZ et al. 2013. ¹⁵	USA	Age, social support and dealing with problems were associated with a better quality of life. Social stigma and emotion-centered coping were related to a poorer quality of life, and represented a 64% variance.	Positive influence of social support on patients' quality of life and a negative effect of medical comorbidities, of stigma and emotional struggle.
Nazik, E. et al. 2013. ¹⁶	Turkey	The quality of life mean index was higher in patients aged 36-45 years old, women and individuals from nuclear families.	It would be recommendable for families and caregivers to receive some type of training. Support and/or education on the treatment of a loved one suffering from a stigmatized disease.
Narsai P., et al. 2016. ¹⁷	South Africa	Those with a higher education level were more likely to have a better quality of life and did not experience pain/discomfort. Mobility is related to a better quality of life.	Interventions are needed to reduce the prevalence of pain/discomfort and to increase the ability to participate in normal activities, in order to increase the quality of life of people with HIV.
Gaynes, et al. 2015. ¹⁸	USA	Only 18% of the patients had a major depressive disorder. The individuals with psychiatric comorbidity reported worse health and quality of life.	Depressive disorders are associated with a greater severity of the disease and a deterioration in the patient's quality of life.

FIGURE 2: Features of reviewed articles⁸⁻¹⁸ in April 2018.

Authors	Place	Result	Conclusion
Corless, IB. et al. 2013. ¹⁹	USA	Stressful events are associated with patient adherence to treatment. Strong relation between treatment adherence and quality of life, explaining a 27.2% variation in quality of life.	Routine assessment of treatment concerns and stressful events may promote a better quality of life and higher adherence.
Galvão, M.T., et al. 2015. ²⁰	Brazil	There was a significant relation between adherence and the dimensions of quality of life related to concerns about the medication and to trusting the dispensing team.	Treatment adherence was inadequate in a large number of study subjects. As for quality of life, it was compromised in most of the dimensions of the scale.
Oliveira e Silva, A.C., et al. 2014. ²¹	Brazil	Adherence and an undetectable viral load improve quality of life.	Adherent individuals have a better quality of life than those who do not adhere to treatment. It is important to act on the patients' adherence to improve their quality of life.
Huang L., et al. 2013. ²²	China	Self-efficacy, adherence and drug use were significantly related to quality of life.	Self-efficacy in treatment and adherence to medication are predictors of quality of life. Programs are needed to improve patient self-efficacy.
KhumsaenN., et al. 2012. ²³	Thailand	A 42.7% variation in quality of life was related to education level, monthly income, social support, spiritual well-being and coping, adaptation, age and living with a relative.	Programs to improve quality of life must focus on promoting spiritual well-being. Incorporating social support systems should improve quality of life.
Costa LT., et al. 2014. ²⁴	Brazil	The variables which influence quality of life are the following: gender, education, work, income, hospitalizations for AIDS, body changes, clinical condition and self-perception of the disease.	It is important to promote active listening to people living with HIV. It would be necessary to include variables management within the therapeutic approach of the patient with HIV.
Pinto Okuno M.F., et al. 2015. ²⁵	Brazil	The characteristics related to higher quality of life are the following: physical activity, longer time since diagnosis, socioeconomic level, schooling, employment, knowledge of the form of infection and being a white male under 60 years old.	Guidance on forms of infection, treatment and evolution of the pathology, as well as social and psychological support, can increase the quality of life of individuals with HIV.
Milanez OFB., et al. 2015. ²⁶	Brazil	Occupation, income, religious practice, time since diagnosis and treatment adherence were positively associated with quality of life. The following were reported negatively: opportunistic infections and homoaffective relationship after suffering.	Quality of life presents associated predictors which have been identified. Professionals should preferably act to reduce stigma and psychosocial symptoms.
Bunjoungman ee P. 2014. ²⁷	Thailand	Work situation is related to the quality of life of physical and mental health. Individuals who revealed their HIV status had a better quality of life.	Publishing serological status, having a good overall health rating by nursing, and being employed were positive predictors for health.
Lemos, LL. et al. 2012. ²⁸	Brazil	The repercussion of co-infection showed a loss to the economic, sexual and furtive domains of quality of life.	Co-infection existence causes changes in the quality of life of individuals with HIV. Repercussions can be mitigated with health-promoting interventions.
Neves, LAS. et al. 2012. ²⁹	Brazil	Quality of life of individuals with HIV who had co-infection with tuberculosis was decreased in all fields of study.	Strategies need to be developed to reduce the epidemiological impact of one disease on the other.

FIGURE 3: Features of reviewed articles¹⁹⁻²⁹ in April 2018.

It would be necessary to classify the variables included in the review articles according to whether the impact on quality of life is positive or negative. Thus, the determinants that are positively related to quality of life are the following: staying positive, coping, perception of the situation, self-efficacy, maintaining a good work situation and economic income, high socioeconomic and educational levels, knowing the way for the HIV infection, spiritual well-being, physical care, maintaining a good clinical condition, general health, low viral load and high levels of CD4, healthy living habits,

social support, good family functioning, good treatment performance and adherence, being older, living in a nuclear family, being a religious person, being black, being male, spreading HIV status and longer time since diagnosis.

The determinants that negatively affect quality of life are the following: maintaining an attitude of avoidance, presence of comorbidity, hospitalizations for AIDS, drug use, depression, psychosocial symptoms, stigma, poor self-perception of the disease, presence of stressful events, experienced symptomatology, pain, difficulty or lack of mobility and presence of body changes.

In addition, we can classify the identified variables as modifiable and as non-modifiable according to the possibility or not of action¹¹. In total, 5 of the 42 determinants identified (11.9%) are considered unmodifiable and are as follows: age, race, gender, marital status and religion. The rest of the variables obtained, 37 in total, are modifiable variables (88.1%).

The wide variability of the variables identified in the review and the low coincidence among the determinants observed by the different existing reviews indicate that it is not yet clear which determinants intervene in this concept. However, some consensus can be seen on variables such as depression^{8,9,12,13,17,18,33}, social support^{8,9,11-15,23}, stigma^{8,9,12-14,20,33}, and adherence^{19-22,26}.

CONCLUSION

Quality of life is a multidimensional concept that is influenced by a large number of factors. Due to the number of variables identified and the low coincidence between them, it is concluded that it is not yet clear what the determinants are that affect the quality of life of individuals with HIV.

According to the results obtained in this review, the most consensual are the following: social support, depression, stigma and adherence. It is important to periodically evaluate the variables which affect the quality of life of individuals with HIV so nurses can intervene by improving their quality of life. Moreover, socially, it would be convenient to create programs that reduce stigma in relation to this group of people.

Further investigation into the determinants of the quality of life of individuals with HIV is needed in order to gain more specific, consensual and up-to-date knowledge on the subject.

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