

Influences of social support on the adherence of HIV/AIDS patients to their therapeutic regimen: an integrative review

Influência do suporte social na adesão ao regime terapêutico por pessoas com HIV/aids: revisão integrativa

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ABSTRACT

Objective: to analyze scientific evidence about the influence of social support on the adherence to the therapeutic regimen by people with HIV/AIDS. **Methods:** integrative review on the databases CINAHL, MEDLINE, Web of Science and SCOPUS, based on the acronym PICO, where P: person living with HIV/AIDS; I: social support; C: adherence to the therapeutic regimen. **Results:** 364 were found and 19 were selected. Research showed that a lack of social support from nurses and other health workers, significant others/family, neighbors, friends and community leads to a decrease or to the non-adherence to the therapeutic regimen. **Conclusion:** people who live with HIV/AIDS and perceive they have effective social support, have fewer depressive symptoms and risk behaviors, in addition to a better adherence to the therapeutic regimen. **Contributions to practice:** this study contributes for health workers, especially nurses who care for HIV/AIDS patients, to recognize the relevance of increasing their knowledge about social network support, in order to involve these networks in the care planning and improve adherence to the therapeutic regime, improving mental health.

Descriptors: HIV; Acquired Immunodeficiency Syndrome; Social Support; Treatment Adherence and Compliance; Nursing Care.

RESUMO

Objetivo: analisar a evidência científica sobre a influência do suporte social na adesão ao regime terapêutico por pessoas que vivem com HIV/aids. **Métodos:** revisão integrativa realizada nas bases de dados CINAHL, MEDLINE, Web of Science e SCOPUS, com base no acrônimo PICO, sendo P: pessoa vivendo com HIV/aids; I: suporte social; C: adesão ao regime terapêutico. **Resultados:** obtiveram-se 364 artigos e 19 foram selecionados. Evidenciaram que a ausência de suporte social por parte dos profissionais de saúde, particularmente do enfermeiro, da família/pessoa significativa, vizinhos, amigos e comunidade resulta na diminuição ou não adesão ao regime terapêutico. **Conclusão:** as pessoas que vivem com HIV/aids e têm percepção do suporte social e da sua efetividade, apresentam menos sintomas depressivos e comportamentos de risco, e maior adesão ao regime terapêutico. **Contribuições para a prática:** contribui para que os profissionais de saúde, em especial os enfermeiros que prestam cuidados a pessoas com HIV/aids, reconheçam a relevância de aprofundar o conhecimento sobre as redes de suporte social, de modo a envolvê-las no planejamento de cuidados para melhor adesão ao regime terapêutico e enriquecimento da saúde mental.

Descritores: HIV; Síndrome da Imunodeficiência Adquirida; Apoio Social; Cooperação e Adesão ao Tratamento; Cuidados de Enfermagem.

Introduction

The lack of social support from society and health services, especially on the part of nurses, can be an important obstacle for the adherence to a therapeutic regimen on the part of people affected by the Human Immunodeficiency Virus (HIV) infection⁽¹⁻²⁾.

Adherence to the therapeutic regimen is, therefore, an important determinant of quality of life and survival in people who live with HIV/Acquired Immunodeficiency Syndrome (AIDS). The World Health Organization defines adherence to therapeutic regimens as the degree to which a person's behavior corresponds to the recommendations of a health professional. Factors that affect adherence can be related with four dimensions: the person, the disease, the relationship between health professional and person, and the management of treatment⁽³⁾.

For those who live with HIV/AIDS, adherence to the therapeutic regimen is essential, as it improves their health and is crucial for the successful management of the disease. On the other hand, inadequate adherence to treatment is associated with increased morbidity and mortality; viral resistance; limited future options of treatment; increased risk of HIV transmission; and onset of neurocognitive disorders⁽⁴⁾.

The construct "social support" emerged more prominently in the literature in psychology and related areas in the 1970s. The first works in this regard were extremely important, as they pointed out the influence of social interaction over the wellbeing and health of people. They pointed out that, throughout one's life, social support is built through the relationships established with relatives, work colleagues, people in the community, and, in case of special needs, professional support. These studies attempted to understand how the lack or instability of social support could increase vulnerability to disease, and how social support could prevent stressful situations from causing mental and physical harm to individuals. Perceived social support, that is, the perception that one has support available to them, even if this support is not effectively present,

is more important for health than actual social support⁽⁵⁻⁶⁾.

Scientific evidence suggests a direct relationship between tangible social support, for example, a health worker or a relative, and the adherence to the therapeutic regimen⁽⁷⁾. Social support has also been understood as a means of improving adherence to a therapeutic regimen. A study showed that, in accordance with these results, the perception of family support stood out among other factors related to adherence. It had a positive correlation with the dispensing of medication from the pharmacy, showing that, the higher the perception of adequate family support, the greater the adherence⁽²⁾.

Among people who live with HIV/AIDS, those who are professionally active, have social support, and live in countries with low or high income have a higher probability of adhering to the antiretroviral therapy⁽⁸⁾. Several social variables, in addition to the use of substances such as methamphetamines, cocaine, alcohol and tobacco, are associated with lower adherence to the therapeutic regimen. The same is true for the scarcity of structured social and clinical support programs⁽⁹⁾. This evidence is supported by another study, which analyzed a sample of 411 people living with HIV/AIDS. The participants were approached during their follow-up visits. Their mean age was 43.7 years, with a minimum of 19 and a maximum of 80 years. 65.5% were women and 78.1% had the lowest educational level. Almost 78% received antiretroviral treatment less than 10 years ago. 3.41% reported poor adherence and 28% excellent adherence to the drug regimen. Factors related to poor adherence were: age below 40 years and inability to meet basic needs. It was found that, to improve adherence to the antiretroviral treatment in this sample, health workers should increase the counseling provided to younger people, providing more financial and social support⁽³⁾.

Social and family support is a significant factor associated with the adherence to the drug regimen. Social and affective support were pointed out as means to improve adherence. It was also noted that, given

the complexity of the issue, constant investigations in the field are necessary⁽¹⁰⁾.

Therefore, and recognizing the relevance of this topic, our goal was to analyze scientific evidence about the influence of social support on the adherence to the therapeutic regimen by people with HIV/AIDS.

Methods

This is an integrative review, which searched for evidence regarding the study object. It was carried out in six stages: identification of the problem and construction of the research question; search in literature (selection of inclusion and exclusion criteria); data collection; evaluation; analysis and interpretation; presentation of results and conclusions⁽¹¹⁾.

The investigation question was elaboration according to the PICO strategy. This acronym stands for Patients/Problem, Interest, and Context. In this case, the P stood for person living with HIV/AIDS; the I for social support; and the C for therapeutic regimen adherence. Starting with this premise, the guiding question was: What is the influence of the social support on the adherence to the therapeutic regimen by people living with HIV/AIDS?

To identify relevant studies that could answer the research question formulated, we started by defining the search question and selecting databases. We used the Medical Subject Headings (MeSH) glossary from the National Library of Medicine to identify the most appropriate terms for each descriptor in the search expression. These descriptors were combined using the Boolean operators AND and OR, and the first search expression was exclusively formed by terms from the MeSH: (Viruses, Human Immunodeficiency) OR (HIV) OR (Immunodeficiency Virus, Human) AND ((Treatment Adherence and Compliance) OR (Therapeutic Adherence) OR (Treatment Adherence) AND (Social Support)). The MeSH glossary was used again to enrich the search expression, adding terms in natural language, synonyms, and words hierarchically related to the MeSH terms from the initial expression.

The search for articles was carried out using the databases Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) via EBSCOhost, Web of Science (WOS), and SCOPUS, from September to October 2023.

Inclusion criteria were comprised by original articles that involved people with HIV/AIDS, evaluated the effect of social support in the adherence to the therapeutic regime, and were available in full, in English or Portuguese. We considered articles published from 2016 to 2023, the seven years prior to this study, in order to analyze the most recent evidence on the topic.

The article selection process is described in Figure 1, a flowchart of the selection and identification of the studies according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)⁽¹²⁾. This process involved two investigators to minimize bias and ensure that no major studies were excluded. After this early selection, the full texts were evaluated to exclude any that did not meet the inclusion criteria. The reasons for the exclusions have been indicated.

Records from researches found were exported into a Microsoft Excel® database, in which the following information was stored: identification, year of publication, place of study, methodological characteristics, main results, and conclusions.

The level of evidence of studies was classified as: Level I - systematic review or meta-analyses of randomized controlled clinical trials; Level II - well-designed randomized controlled clinical trials; Level III - well-designed, non-randomized clinical trials; Level IV - well-designed cohort and case-control studies; Level V - systematic reviews of descriptive and qualitative studies; Level VI - descriptive or qualitative studies; and Level VII - opinion of authorities and/or reports⁽¹³⁾.

Results

19 articles that fit the predetermined selection

criteria were included. Figure 1 shows the PRISMA flowchart regarding the three states of article selection: identification, selection, and inclusion.

The studies were carried out in several continents, such as Africa, Asia, South America, and North America. Figure 2 shows the authors, year, country, type of study, level of evidence, and main results.

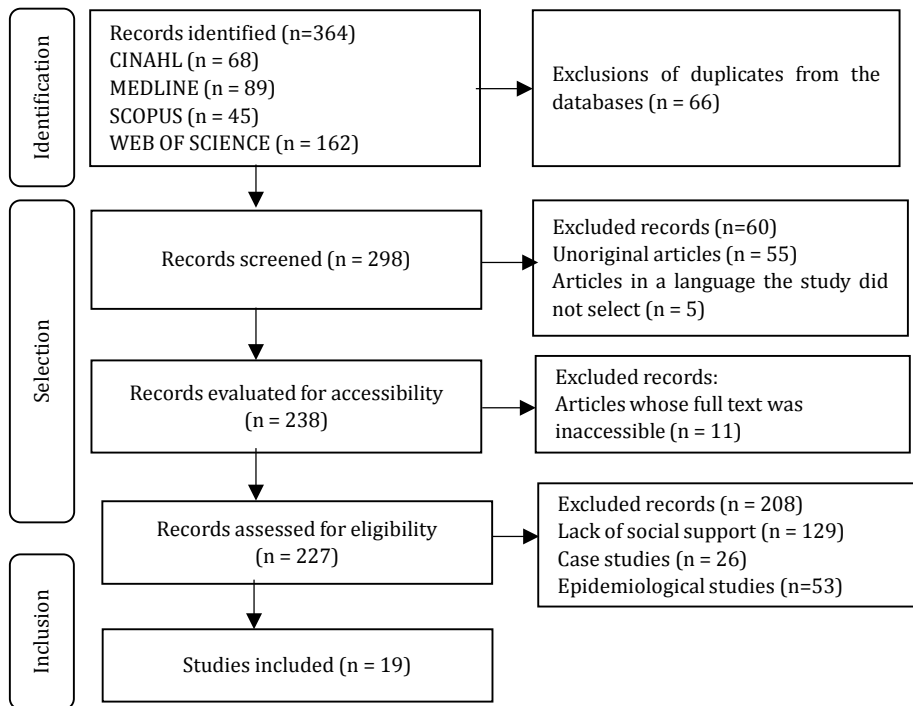


Figure 1 – Flowchart of the process of identification, selection and inclusion of studies, adapted from PRISMA. Funchal, Portugal, 2023

Authors/Year/ Country	Type of study/ Level of evidence	Main results
Lifson et al (2023) ⁽¹⁴⁾ Ethiopia	Randomized Clinical Trial II	A sample of 1,799 participants received individual health education, counseling, and social support. After 12 months of intervention, participants showed better emotional/informational and tangible support, a lower score in depression symptom assessments, and a lower negative self-perception due to HIV. A significant effect of the social support started at 36 months, showing a better social and emotional state, informational support, and reduction of depressive symptoms, with a consequent improvement in the adherence to the antiretroviral treatment.
Madundo et al (2023) ⁽¹⁵⁾ Tanzania	Quantitative cross-sectional VI	Sample of 272 participants. More than one third (42%) lived with their families, one third (33%) lived alone, and 24% lived with a partner or spouse. Results showed that more than half of the sample (56%) presented a good level of social support, which was associated with a better adherence to the therapeutic regime.
Rutakumwa et al (2023) ⁽¹⁶⁾ Uganda	Qualitative cross-sectional VI	The 17 participants showed that the lack of family social support led, allegedly, to depression, with a negative impact on the adherence to therapeutic regimen, stigmatization, and discrimination, in addition to non-disclosure when in serodiscordant relationships. The study also found economic causes/poverty, but their role was less significant, or moderated by the family social support.
Abebe; Tegegne (2022) ⁽¹⁷⁾ Ethiopia	Retrospective cohort IV	Data was obtained from a sample of 220 participants. Results showed that predictor variables for therapeutic regimen adherence and treatment continuity were: female participants, living in urban areas, living with partners, who disclosed their disease, used their cell phones to aid their memories, were well-educated, were employed, had social support, and went to follow-up consultations.

(the Figure 2 continue in the next page...)

Strother et al (2022) ⁽¹⁸⁾ Liberia	Quantitative cross-sectional VI	There was a high prevalence of non-adherence in the 185 participants. Results also showed that participants with low levels of informative support and high levels of stigma were less likely to adhere to the therapeutic regimen than those who had good levels of social support.
Villiera et al (2022) ⁽¹⁹⁾ Malawi	Mixed: quantitative and qualitative VI	The sample of 385 participants reported that the factors which led to a poor adherence to the therapeutic regimen were: lack of family social support, pressure at school, and inadequate support on the part of tutors and parents. Undergoing treatment for a longer period, enrollment in clubs, psychosocial support from health professionals, and self-improvement techniques improved therapeutic regimen adherence.
Berhe et al (2022) ⁽²⁰⁾ Ethiopia	Qualitative cross-sectional VI	For the 423 participants in this study, the result regarding perceived social support was 30.7, 47.2 and 22.1%, with low, moderate and high levels of perceived social support, respectively. Women, participants with low educational levels, and lack of knowledge about HIV/AIDS were variables significantly associated with the perceived social support. One in three participants did not perceive a lot of social support, which had a negative association with the adherence to the therapeutic regimen.
He et al (2021) ⁽²¹⁾ China	Observational prospective cohort IV	Of the sample of 521 participants, 18.2% reported non-adherence to the therapeutic regimen, 70.8% of whom were male. 58.8% had a partner who did not live with HIV/AIDS, and more than half had been diagnosed with the virus for more than a year. A bivariate analysis showed that a spouse who was not infected and provided greater social support was a predictor of better adherence to the therapeutic regimen.
Abadiga et al (2020) ⁽²²⁾ Ethiopia	Quantitative cross-sectional VI	In the sample of 311 participants, the level of drug regimen adherence was low when compared to recommendations from the World Health Organization (73.1%). However, having knowledge about the HIV and its treatment, strong family/social support, no adverse reactions to drugs, no chronic comorbidities, and having revealed the serological status to one's family was significantly associated to an increase in the probability of adherence to the medication regimen.
Gebreagziabher; Woldemariam (2020) ⁽²³⁾ Ethiopia	Quantitative cross-sectional VI	Of a sample of 339 participants, 74.6% adhered to the therapeutic regimen. Those who received social support were 2.7 times more likely to adhere to the therapeutic regimen. Factors related as predictors of therapeutic regimen adherence were living in an urban area, social support, having revealed the HIV, and not having depression.
Oliveira et al. (2020) ⁽²⁴⁾ Brazil	Quantitative cross-sectional VI	The 168 participants of the sample presented satisfactory levels of social support. Social support factors were stratified, showing as sources of emotional support: family members who do not live with the person living with HIV/AIDS; friends; neighbors; and health professionals. The mains sources of instrumental support were: family members who do not reside with the participant; friends; neighbors; and health professionals. Although the results of social support were satisfactory regarding the results of therapeutic regimen adherence, more than half the sample showed insufficient adherence.
Ceylan et al (2019) ⁽²⁵⁾ Turkey	Quantitative cross-sectional VI	Of the 158 participants in the sample, approximately 61% adhered well to the therapeutic regimen, while 37.9% showed moderate adherence. There was a significant association between having social support and adherence to the therapeutic regimen. The absence/presence of social support resources, the duration of the illness, the duration of treatment, and being informed about the drug regimen were statistically associated with adherence to the therapeutic regimen.
Mao et al (2019) ⁽²⁶⁾ China	Randomized clinical trial II	The sample included 319 participants. The study examined the longitudinal relationship between depression, social support from various sources, and adherence to the therapeutic regimen. There were negative associations between depression and adherence to the therapeutic regimen over time. On the other hand, a mediator effect of the social support perceived by the spouse/partner or children was associated with better results in the adherence to the drug regimen.
Li et al (2018) ⁽²⁷⁾ China	Non-randomized clinical trial III	The sample of 277 participants benefited from social support intervention program (health education, stress management, and social interactions) for one year. After the intervention, there were statistically significant differences in the total score and in the score of subjective perception regarding the adherence to the therapeutic regimen before and after the intervention. There was a statistically significant correlation between the total score of the social support and the use of said social support, leading to different scores of adherence to the therapeutic regimen.

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Tegegne et al (2018) ⁽²⁸⁾ Ethiopia	Prospective, quantitative VI	In a sample of 792 participants, those who received social support from their families (76%) adhered better to the therapeutic regimen. Participants with cell phones, females, those who had revealed they had the disease to family and relatives, and those who received social support from others, were more likely to adhere to the therapeutic regime recommended by the health professionals.
Arnold et al (2017) ⁽²⁹⁾ United States	Randomized clinical trial II	396 participants took part in an intervention with four individual counseling sessions. When participants could show their serological state, especially to others who also lived with HIV, they managed to receive support to continue their treatment, so they could receive care for longer and be connected to social resources made to help them. Participants with weaker social support did not have such a good performance. Some were close to death due to problems non-adherence to the therapeutic regimen.
Rouhaniet al (2017) ⁽³⁰⁾ Uganda	Qualitative cross-sectional VI	61 participants were interviewed and four topics emerged, showing how social support affected the test and the adherence to the therapeutic regimen in an environment for refugees: information support helped them undergo HIV tests; emotional support helped them deal with the situation after being diagnosed with HIV; instrumental support helped adhering to the therapeutic regimen; and once diagnosed with HIV, those infected provided emotional and informational support to encourage others to do the test.
Cardona-Duque et al (2017) ⁽³¹⁾ Colombia	Quantitative cross-sectional VI	From a sample of 70 participants, 57.1% reported poor adherence to the therapeutic regimen and 77.1% had low perception of social support. High levels of depression tripled low adherence to the therapeutic regimen, while high levels of perceived social support made it five times worse.
Pedrosa et al (2016) ⁽³²⁾ Brazil	Quantitative cross-sectional VI	In the sample of 215 participant, the social, emotional, and instrumental support means were satisfactory, and were not influenced by sex, educational level, marital status, and time of antiretroviral therapy. Those diagnosed for less than three years received more instrumental support than those who received a diagnosis more than three years ago. Neighbors, bosses, and health workers provided less social support. Social support was satisfactory, especially from friends and family who did not live with the person with HIV/AIDS. People receiving satisfactory social support from these last elements showed better adherence to the therapeutic regimen.

Figure 2 – Studies selected for the research. Funchal, Portugal, 2023

Discussion

Considering the findings of this review, it becomes clear that social support, be it emotional or instrumental, is extremely important for adherence to a therapeutic regimen.

The most common sources of social support were health workers^(14,24-27,29,32), support from partners^(17,21,26), social support from family^(17,22-24,26,28-32), from friends^(24,29-30,32), and from neighbors^(24,32).

The evidence found agrees with other studies that document social support. In addition to strengthening adherence to the therapeutic regimen, it also has an indirect effect in reducing stress, depressive symptoms, stigmatization, and social isolation in people living with HIV/AIDS. Furthermore, social support is an important factor in disease prevention, health promotion, adherence to the therapeutic regimen, and

the disease recovery processes⁽³³⁻³⁴⁾.

Interventions via individualized informational and psychological support provided by community professionals for people with the disease had a positive impact on the emotional health of these people, leading to a better adherence to the therapeutic regimen⁽¹⁴⁾. The adherence to the antiretroviral therapy was higher in people living with HIV/AIDS who were monitored, for the first 12 months after the beginning of therapy, by a multiprofessional health team that included primary care nurses and pharmacists. The highest levels of adherence to the therapeutic regimen were found in people with the social support of specialists, especially nurse case managers, social workers, and primary care nurses (7.5, 5.4 and 9.7%, respectively), but also mental health specialists (6.5%)⁽³⁵⁾, corroborating these findings.

The integration of interventions to provide

psychosocial support, and a change from individual counseling to family-centered counseling improves the adherence of people with HIV⁽³⁶⁻³⁷⁾.

People who share the serological status of HIV with their relatives or partners can be motivated to follow the treatment and take their medication correctly, and to attend appointments. On the other hand, hiding their status can make it more difficult to achieve the necessary social support⁽³⁸⁾. Revealing ones' serological state not only reduces the risk of transmitting the disease, but also increases the opportunities for receiving/providing social and spiritual support, improves access to treatment, gives more opportunity to discuss and implement programs, and reduces the likelihood of HIV sexual transmission⁽³⁹⁾.

Some studies^(16,19,21,26) reported that many people living with HIV/AIDS, particularly adults and the elderly, perceive low levels of social support, which results in a lower quality of life. These people present increased psychological suffering, risk behaviors, low adherence to therapy, and high exposure to additional psychosocial susceptibilities — they are, without a doubt, vulnerable populations⁽⁴⁰⁾. Furthermore, if there is no social support, especially from their family environment and on the part of health workers, these people become exposed to several stressful situations, job loss and financial challenges. These are associated with a high risk of developing psychological disorders such as depression, anxiety, guilt, and loneliness. These findings are in accordance with data cited by other authors⁽⁴¹⁻⁴³⁾.

There is still a strong stigma surrounding HIV/AIDS. People who live with it are more vulnerable to a lack of social support and low self-esteem. For many people who live with the disease, any type of social support is limited or non-existent, which can predispose them to psychological disorders such as depression and anxiety, which have negative repercussions on the adherence to a therapeutic regimen. Multiple factors can interact, leading to high rates of low adherence to a therapeutic regimen⁽⁴⁴⁻⁴⁵⁾.

A research that analyzed the structure of the

social networks of people who live with HIV investigated how important it is for health workers to know the social support networks of these persons. They carried out an exploratory, descriptive, qualitative study. In said study, maps were elaborated to enable an understanding of the networks of people who live with HIV and AIDS. Furthermore, the uniqueness of this experience was reiterated, showing the complexity of affective, social, and institutional relationships established, in addition to how they influence and are influenced by daily life and the circumstances of co-existence. Bonds were created to address the needs of these individuals, showing the importance of a well-structured support network to guarantee quality of life, adherence to a therapeutic regimen, and the well-being of these people⁽⁴⁶⁾.

It is paramount to further develop research in this field, given the importance of the contributions given by social support to self-care and the adherence to the therapeutic regimen, improving quality of life and reducing feelings of impotence in the face of the disease. When compared to other chronic diseases, HIV/AIDS patients face more challenges to adhere to their therapy due to several psychological and social implications. Each person has unique motivations to follow treatment or not. They are influenced by several factors, such as the complexity of therapeutic regimens, side effects, personal habits, illegal drug use, depression, lack of social support, comorbidities, and other individual complications. Managing adherence requires a holistic approach that considers all these aspects.

Study limitations

This study is limited by the fact that many of its findings were related to the African context, which has its unique peculiarities related to the population and the health system. Furthermore, few clinical trials with different samples and methodologies could be found. It is also noteworthy that most researches included in this study had small samples, and, in some cases, the

specific role of nurses or other health workers could not be identified. This may have contributed to some form of bias in the results found.

Contributions to practice

The findings of this study can contribute for health workers, especially nurses, to further their knowledge about social support networks of people with HIV/AIDS through efficient communication, in order to involve these networks in their care planning to improve adherence to the therapeutic regimen and strengthen the mental health of these persons. The results may also contribute for the development of actions to raise the awareness of the population about how important social support is, as a tool to help people with HIV/AIDS to adhere to therapeutic regimens, and for investment in health policies that consider social support as a preventive therapeutic technique for people with HIV/AIDS.

Conclusion

This study found that people with HIV/AIDS who perceive they have an effective social support have a better adherence to their therapeutic regimen. It also showed that there is a bidirectional relationship between social support, mental health, and adherence to a therapeutic regimen. On the other hand, people with less social support tend to be isolated and, thus, to manifest more depressive symptoms. This is in line with the perception that low social support can be an independent predictor of depressive symptoms. Psychosocial aspects, such as anxiety, stress, and social support, play a significant role in the quality of life of people with HIV/AIDS, calling attention to their relevance for public health.

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Authors' contribution

Project design, analysis and interpretation of data, writing of the article, final approval of the version to be published, and agreement to be responsible for all aspects related with precision of integrity of any part of the manuscript, ensuring they will be investigated and resolve appropriately: Sousa GMF, Padilha JMCS, Abreu WJCP.

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