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# Psychosocial factors involved in adherence to the treatment of HIV / AIDS in adults: integrative literature review

Factores psicosociales implicados en la adherencia al tratamiento del VIH / SIDA en adultos: revisión integrativa de la literatura  
Fatores psicossociais envolvidos na adesão ao tratamento do HIV/AIDS em adultos: revisão integrativa da literatura

## ABSTRACT

**Objective:** identify in the literature the psychosocial factors involved in adhering to the treatment of HIV / AIDS in adult patients. **Methods:** This is an integrative literature review using the SciELO, PubMed and Lilacs databases and including Brazilian articles published between 2014 to 2019, followed by the PICO strategy to identify the psychosocial factors associated with adherence to HIV / AIDS treatment in adults. The bibliographic search took place in May 2020. **Results:** 118 articles were found and after reading in full, five articles were selected that corresponded to the guiding question. Emotional aspects, social relationship and professional attention were identified as influential psychosocial factors in the process of adherence to drug treatment of HIV/AIDS in adults. **Conclusions:** We conclude that the social representation of HIV / AIDS is associated with cultural prejudices that exposes the person to emotional and social vulnerabilities, affecting their decision regarding therapeutic adherence.

**DESCRIPTORS:** Human immunodeficiency virus; Acquired immunodeficiency syndrome; Medication adherence; Psychosocial impact.

## RESUMEN

**Objetivo:** El propósito de esta revisión integradora es identificar en la literatura los factores psicosociales involucrados en la adherencia al tratamiento del VIH / SIDA en pacientes adultos. **Métodos:** se trata de una revisión integradora de la literatura utilizando las bases de datos SciELO, PubMed y Lilacs e incluyó artículos brasileños publicados entre 2014 y 2019, seguida de la estrategia PICO para identificar los factores psicosociales asociados con la adherencia al tratamiento del VIH / SIDA en adultos. La búsqueda bibliográfica se realizó en mayo de 2020. **Resultados:** Se encontraron 118 artículos y luego de su lectura completa se seleccionaron 5 artículos que correspondían a la pregunta orientadora. Los aspectos emocionales, la relación social y el cuidado profesional fueron identificados como factores psicosociales influyentes en el proceso de adherencia al tratamiento farmacológico del VIH / SIDA en adultos. **Conclusiones:** Concluimos que la representación social del VIH / SIDA está asociada a prejuicios culturales que exponen a la persona a vulnerabilidades emocionales y sociales, afectando su decisión sobre la adherencia terapéutica.

**DESCRIPTORES:** Virus de inmunodeficiencia humana; Síndrome de inmunodeficiencia adquirida; Cumplimiento de la medicación; Impacto psicosocial.

## RESUMO

**Objetivo:** identificar na literatura os fatores psicossociais envolvidos na adesão ao tratamento do HIV/AIDS em pacientes adultos. **Método:** trata-se de uma revisão integrativa da literatura utilizando as bases de dados SciELO, PubMed e Lilacs e incluídos artigos brasileiros publicados entre 2014 a 2019, seguiu-se a estratégia PICO para identificar os fatores psicossociais associados à adesão ao tratamento do HIV/AIDS em adultos. A busca bibliográfica ocorreu em maio de 2020. **Resultados:** foram encontrados 118 artigos e após a leitura na íntegra foram selecionados 5 artigos que correspondiam a questão norteadora. Identificou-se os aspectos emocionais, relação social e atenção profissional como influentes fatores psicossociais no processo de adesão ao tratamento medicamentoso do HIV/AIDS em adultos. **Conclusões:** a representação social do HIV/AIDS está associada a preconceitos culturais que expõe a pessoa a vulnerabilidades emocionais e sociais, afetando sua decisão na adesão terapêutica.

**DESCRIPTORES:** Vírus da imunodeficiência humana; Síndrome de imunodeficiência adquirida; Adesão à medicação; Impacto psicossocial.

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**INTRODUCTION**

The human immunodeficiency virus (HIV) affects immune function, impairing defense systems and preventing natural action against common infections. The disease can progress to acquired immunodeficiency syndrome (AIDS), when there are severe manifestations of the disease, such as opportunistic infections, neoplasms and other pathologies that generate direct damage to the organs.<sup>1,2</sup>

According to the global statistics of the Joint United Nations Program on HIV/AIDS (UNAIDS) in 2019 there were 37,9 million adults living with HIV, with 1,7 million new infections and more than 700 thousand AIDS-related deaths.<sup>3</sup>

For WHO, there are vulnerable population groups such as people deprived of their liberty, users of alcohol and other drugs, sex workers, gays and men who have sex with men. This portion

of the population is inserted in social settings and contexts that expose the social determination of the HIV/AIDS epidemic and other sexually transmitted infections (STIs). These groups often need to break the barriers of prejudice in order to have access to diagnosis and possibly due treatment.<sup>2</sup>

Despite its chronic evolutionary character, HIV is potentially controllable with the therapeutic regimen, which is indicated with immediate onset for all people living with HIV/AIDS (PLWHA).<sup>2</sup> Antiretroviral therapy (ART) is able to cause viral suppression by preventing progression to AIDS.<sup>1,2</sup>

In Brazil, ART is provided universally and free of charge by the Unified Health System (Sistema Único de Saúde - SUS) through federal law No. 9.313 of 1996, which provides for the Drug Distribution Policy of the National STI/AIDS Program.<sup>4</sup> In the cou-

entry, there is also a constant improvement of specialized care services (SAE) in SUS and in clinical protocols that also include behavioral changes that involve psychological, social and cultural aspects in the therapeutic process.<sup>5</sup>

In an attempt to combat the epidemic by the year 2030, in 2015, the goal 90 90 90 was established, which consists of three pillars: 90% of all people living with HIV know; 90% PLWHA receive ART continuously; 90% of all people using ART have viral suppression.<sup>6</sup>

The goal related to medication adherence has become a challenge for health organizations, since therapeutic decisions must be co-responsible, aiming at the autonomy of PLWHA, offering sufficient knowledge about the benefits of adherence to treatment. However, it is essential that there is also an understanding that there are psychosocial aspects, risks and vulne-

rabilities involved in the decision to adhere to treatment.<sup>1,6</sup>

A Brazilian study carried out with 1.784 adults between 18 and 76 years of age diagnosed with HIV found that 98,4% were in regular use of ART, in which 83,4% reached an undetectable viral load in the last 12 months. However, when questioning psychosocial aspects, 75,5% had a need to hide the diagnosis of social life and 47.9% reported having mental health problems related to living with HIV. Regarding socioeconomic characteristics, 72,9% had high school or professional education and 46,5% reported not being able to meet their basic life needs.<sup>7</sup>

Despite constant innovations in diagnostic strategies and treatment expansion in health organizations with the objective of reducing the incidence of the disease and providing a better quality of life for PLWHA, the challenge of adhering to ART remains to be seen, which permeate aspects that transcend assistance clinic. In this sense, the objective of this study was to review in the literature the psychosocial factors involved in adherence to the treatment of HIV/AIDS in adult patients.

## METHODS

It is an integrative literature review

following the steps of determining the objective; establishment of the research question; definition of the inclusion and exclusion criteria for productions; determining the information to be extracted from the selected studies; evaluation of included studies; interpretation of results and synthesis of knowledge. To structure the research question, the PICO strategy was adopted, represented by: population (P), interest (I), comparison (C) and outcome/outcomes (O), constructing the guiding question: What are the factors (O) psychosocial (I) involved in adherence to the treatment (C) of HIV/AIDS of the adult patient (P).<sup>8</sup>

The bibliographic search was carried out in May 2020, using the databases The Scientific Electronic Library Online (SciELO), PubMed and Latin American and Caribbean Literature in Health Sciences (Lilacs) through the search strategy (hiv) AND (medication adherence) AND year cluster: ("2014" OR "2018" OR "2019" OR "2015" OR "2017" OR "2016").

The inclusion criteria were scientific articles from original Brazilian researches, published between 2014 and 2019, which presented, in the titles or abstracts, references about adherence to the use of antiretrovirals or adherence to drug treatment of HIV. Exclusion

criteria were monographs, theses, dissertations, review articles, articles that did not correspond to the theme studied and/or the research question, which involved pregnant women, children or adolescents in the sample.

In order to verify whether the articles met the inclusion and exclusion criteria, the evaluation was carried out following the order: (1) titles of all identified studies; (2) summaries of studies in the previous phase; (3) complete reading of the selected texts. After excluding articles that did not meet the inclusion criteria. The entire selection process was carried out in the presence and agreement of two researchers.

The evaluation of the articles regarding the level of scientific evidence, followed the classification by type of study of the Oxford Center For Evidence-based Medicine according to Chart 1.

## RESULTS

118 articles were identified from the search in the databases. After reading the titles, 28 articles were selected for the abstracts. Of these, 9 articles were read in full and 4 articles were excluded for not responding to the guiding question and inclusion criteria. At the end, 5 articles made up the corpus of

Chart 1. Levels of evidence by type of study.

| NE* | TIPOS DE ESTUDO  |
|-----|--|
| 1A  | Revisões sistemáticas e metanálises de ensaios clínicos comparáveis. Estudos controlados randomizados bem delineados com desfecho clínico relevante. |
| 1B  | Estudos controlados randomizados com estreito intervalo de confiança.  |
| 1C  | Resultados do tipo "tudo ou nada". Estudo de série de casos controlados.   |
| 2A  | Revisão sistemática homogênea de estudos de coorte (com grupos de comparação e controle de variáveis).   |
| 2B  | Estudo de coorte com pobre qualidade de randomização, controle ou sem acompanhamento longo, estudo de coorte transversal.                            |
| 2C  | Resultados de pesquisas (observação de resultados terapêuticos ou evolução clínica).   |
| 3A  | Revisão sistemática homogênea de estudos de caso com grupo-controle.   |
| 3B  | Estudos de caso com grupo-controle.  |
| 4   | Relatos de caso e série sem definição de caso controle.  |
| 5   | Opinião de autoridades respeitadas ou especialistas. Revisão da literatura não sistemática.  |

Source: Adapted from Oxford Center Evidence-Based Medicine. Prepared by the authors. Subtitle: \*NE- Evidence level (Nível de Evidência)

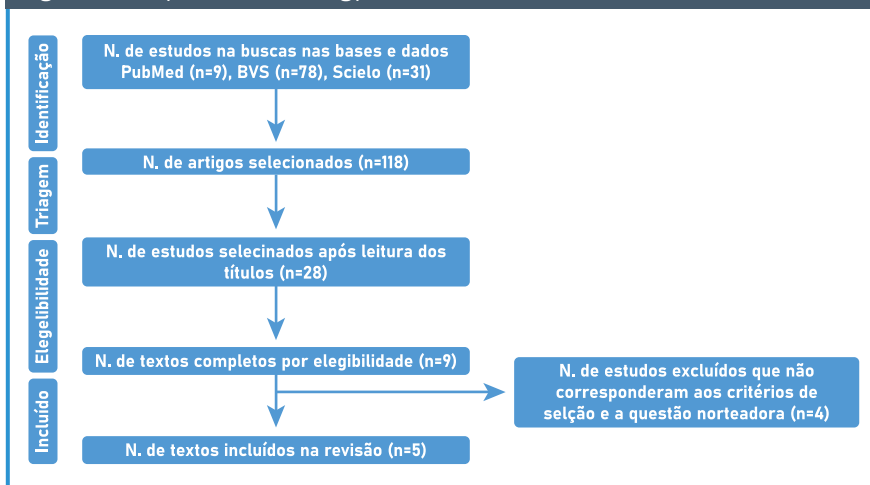
the work. Figure 1 shows the flowchart of strategy for selecting studies according to PRISMA.<sup>10</sup>

For analysis and synthesis of publications, a synoptic table was prepared with a summary of the level of eviden-

ce, study, authors; goal; sample of the study and synthesis of the main results related to the guiding question according to table 2. From the analysis it was found that all articles included are published in national journals, one in a journal focusing on health sciences, one focusing in public health and three in nursing journals.

As for the region of realization, one was held in the South, one in the Midwest and three in the Southeast. Regarding the design, two were quantitative and three qualitative. The total sample studied consisted of 293 respondents aged between 18 and 52 years. The positive and negative psychosocial factors related to adherence to the treatment of adult HIV/AIDS patients identified are shown in Table 3.

Figure 1. Study selection strategy flowchart.



Source: Prisma, 2015. Adapted by the authors.

Chart 2. Summary table of studies included in the Integrative Review

| NE | ESTUDO   | AUTORES  | OBJETIVOS   | AMOSTRA (N) | RESULTADOS   |
|----|--|--|---|-------------|--|
| 2C | Avaliação da adesão ao tratamento antirretroviral de pessoas vivendo com HIV. Saúde e pesquisa, 2018.11                  | Primeira, MR; Santos, EEP; Züge SS; Magnano, TSBS; Paula, CC; Padoim SMM.    | Avaliar a adesão ao tratamento antirretroviral de pessoas que vivem com HIV através do "Cuestionario para la Evaluación de la Adhesión al Tratamiento Antirretroviral" (CEAT-VIH) | 179         | Foi identificado que 46,4% apresentaram grau de adesão baixa ou insuficiente, 56,4% deixou de fazer uso da TARV por um ou mais dias, 79,3% deixaram de fazer uso por se sentir triste ou deprimido.  |
| 2A | Interações sociais e a adesão à terapia antirretroviral de pessoas vivendo com HIV/AIDS. Rev Mineira de Enferm., 2017.12 | Freitas, MIF; Bonolo, PF; Miranda, WD; Guimarães, MDC.                       | Compreender a influência das interações sociais na terapia antirretroviral em pacientes em início de tratamento.  | 30          | Identificou-se que as relações familiares, com parceiros e amigos íntimos auxiliam a manutenção medicamentosa e o apoio profissional colabora com a continuidade do tratamento.  |
| 2C | Adesão à terapia antirretroviral e suas representações para pessoas vivendo com HIV/AIDS. Esc. Anna Nery, 2014.13        | Paschoal, EP; Santo, CCE; Gomes, AMT; Santos, El; Oliveira, DC; Pontes, APM. | Analisar o processo de adesão à terapia antirretroviral e suas representações sociais para pessoas que vivem com HIV/AIDS.  | 30          | Como elemento facilitador a adesão da TARV apoio familiares 3,4%, apoio e orientação profissional 9,7%. Os fatores que dificultam o processo de adesão a TARV como falta de amor à vida, desinteresse, pensamentos suicidas, sofrimento fizeram parte de 7,4% dos participantes, a necessidade de esconder socialmente 4,2%. |

# artigo

Costa, L.F.; Medeiros, R.J.; Paungartner, L.M.; Luft, T.D.; Santos, A.P.; Paiva, T.S.; Fernandes, M.T.C.;  
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|    |   |   |  |    |   |
|----|---|---|--|----|---|
| 3B | Terapia com antirretrovirais: grau de adesão e a percepção dos indivíduos com HIV/Aids. Acta Paul de Enferm., 2018.14   | Freitas, JP; Sousa, LRM; Cruz, MCMA; Caldeira, NMVP; Gir E. | Apreender os aspectos relacionados ao grau de adesão de pessoas vivendo com HIV/AIDS aos antirretrovirais.   | 40 | O apoio familiar constitui um aspecto facilitador para o enfrentamento da doença e estimulação para a adesão medicamentosa. No entanto, experiências negativas com parceiros íntimos e falta de apoio familiar impactaram negativamente na adesão medicamentosa. Condições socioeconômicas desfavoráveis para a não adesão medicamentosa constituiu 18,5% dos entrevistados |
| 3B | Será que esse remédio vai valer a pena mesmo? Estudo antropológico sobre a adesão às terapias antirretrovirais entre grupos de mútua ajuda de pessoas vivendo com HIV/aids. Saúde soc., 2014.15 | Picelli, I; Diaz-Bermudez, XP.                              | Compreender o funcionamento e os potenciais benefícios dessas tecnologias para a vivência com o vírus, em particular para adesão à medicação antirretroviral | 14 | A ajuda mútua praticada em grupos terapêuticos auxilia no enfrentamento da nova condição de saúde e na manutenção do tratamento.  |

Chart 3. Psychosocial Factors Involved in Adhering to HIV/AIDS Treatment for Adult Patients.

| ESTUDOS   | FATORES PSICOSSOCIAIS ENVOLVIDOS NA ADESIÃO                    |
|---|--|
| Freitas, MIF et al.; 2017<br>Paschoal, EP et al.; 2014<br>Freitas, JP et al.; 2018<br>Picelli, I et al.; 2014 | Aspectos Positivos   |
|   | Apoio familiar e/ou de parceiros                               |
|   | Orientação profissional  |
|   | Grupos de ajuda mútua  |
|   | Apoio religioso  |
|   | Autoestima   |
|   | Redes sociais de apoio   |
| Picelli I; 2014<br>Freitas JP; 2018<br>Paschoal PE; 2014<br>Primeira MR; 2017                                 | Aspectos Negativos   |
|   | Depressão ou tristeza e suicídio                               |
|   | Medo de morrer   |
|   | Rejeição familiar e/ou de parceiros íntimos e medo de abandono |
|   | Condições socioeconômicas desfavoráveis                        |
|   | Carência de apoio emocional                                    |
|   | Representação social da terapia antirretroviral                |
|   | Preconceito  |
|   | Baixa autoestima   |
| Uso de álcool e outras drogas   |  |

Source: prepared by the authors.

## DISCUSSION

The assessment of the impact of the HIV virus on people's health and quality of life has been the subject of stu-

dies since its discovery. Currently, with the increase in life expectancy among people living with AIDS, research on quality of life has become more relevant due to the search for more com-

prehensive health assessment instruments, that is, involving psychological, social and structural factors.<sup>16</sup> This study reinforced that the social representation of HIV/AIDS is associated with cultural prejudices that expose PLWHA to emotional and social vulnerabilities, affecting their decision to adhere to therapy.

Emotional support can represent the security that there are people that the user can turn to when needed, consists of behaviors such as listening and listening or keeping company, which contributes to the person feeling cared for and/or appreciated, whether in the family and social, in health services, which also contributes to the management and adherence to treatment.<sup>12-15</sup>

A cross-sectional study conducted in Paraná, found that when PLWHA receive emotional support, the chances of adherence increase by up to 7,9%, the study suggests that the greater the emotional support, the better the adherence to treatment and, consequently, the lower the viral load.<sup>17</sup> For Freitas and authors (2018), family emotional support for coping with the new condition is relevant at different times in the lives of PLWHA, both for the acceptance of the diagnosis and for the



perception of the need to start the treatment and conduct it consistently.<sup>14</sup>

A survey conducted in Paraíba, showed that 58% of the participants (36), who underwent psychological monitoring, had late adherence to treatment, showing that these individuals need professional psychological monitoring to achieve future adherence to ART.<sup>18</sup> Fear, discrimination and social rejection are considered a barrier for young adults living with HIV/AIDS.<sup>19</sup>

The constant fear of public exposure and social rejection puts PLWHA in psychological distress, causing him to have cautious attitudes such as: abandoning the treatment, hiding the condition and/or the medication, abandoning the drug treatment because it may call attention and because some need to be stored in the refrigerator, which hinder their treatment.<sup>13</sup> Regarding the confidentiality of the seropositivity diagnosis, a study showed that 51,3% (119) of the participants kept the information secret or told a maximum of five people.<sup>17</sup>

Sometimes they see the need for limited social reorganization to expose therapeutic progress to trusted friends and intimate partners. In this sense, a weakened or even broken support network impairs therapeutic adaptation in the individual's and family's routine, and offers greater risk of negative emotional feelings, generating the idea of the inevitable loneliness and the lack of meaning to continue drug treatment.

In a survey conducted in southern Brazil, young adults expressed negative experiences of stigma and discrimination when their diagnosis was revealed to some colleagues and family members. And, therefore, the acceptance of the diagnosis does not always occur on the part of young adults, but even in the face of emotional and psychological upheavals arising from facing the diagnosis, they showed concern with their treatment, as it is related to the prolongation and quality of life.<sup>19</sup>

**Primeira MR  
et al. (2018)  
suggests investing  
in attention to  
psychosocial  
aspects, involving  
the social support  
network of this  
population, since it  
has a fundamental  
role in mitigating  
the consequences  
of stressful events,  
insufficient  
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Family participation in the therapeutic routine proved to be one of the main factors that positively impact the decision to adhere to medication. Family support contributes to the recovery of medication, overcomes difficulties related to treatment and strengthens the affective bond. However, there may be negative attitudes by family members and/or partners due to limited knowledge and accompanied by social prejudices that cause emotional distress that favor drug abandonment.<sup>11-15,19</sup>

In addition, although access to treatment is free in Brazil, the income deficit can be a barrier to satisfaction with perceived social support, economic precariousness can negatively impact access to health services, for example, when PLWHA need to move from their cities to have access to specialized services located in larger municipalities.<sup>19,20-21</sup> Difficulty is also identified in the study by Freitas and authors (2018).<sup>14</sup>

Primeira MR et al. (2018) suggests investing in attention to psychosocial aspects, involving the social support network of this population, since it has a fundamental role in mitigating the consequences of stressful events, insufficient support from the social and family environment seems to affect negatively adherence, leading the patient to depression and hopelessness.

The incentive by the health professional was also a facilitating aspect in adhering to treatment.<sup>11-15</sup> Patients are often open to professionals and it can be said that adherence to antiretroviral therapy is positively influenced by interactions with the care offered by professionals as a basis for feeling safe.<sup>12</sup> Faced with a diagnosis or clinical conditions involved, the professional must consider the emotional suffering it can generate for the individual and the family, requiring specialized attention that favors the bond between the user and the health service. The active listening practiced in the assistance is able to identify the context in which the PLWHA is inserted, facilitating the formulation of an

individual therapeutic plan and the re-adjustment of the routine, reducing the risks of psychosocial fragility.<sup>12</sup>

A study showed that doctors and nurses are the main stimulators for adherence to medication therapy.<sup>13</sup> Since the doctor acts with his training of curative character and the nurse, he is trained to take care through health education, active listening and prevention.<sup>22</sup> Health services are essential for treatment adherence to develop strategies such as: case studies, interdisciplinary workshops and adherence groups that aim to improve treatment adherence by welcoming the patient and making him/her the main subject of this process of change.<sup>13</sup> A survey conducted in Brasilia with 99 volunteers demonstrated good/adequate adherence to HIV treatment with 75% of the volunteers, and 87% of the interviewees had a good relationship with the doctor.<sup>23</sup>

Groups are an alternative for health production, reinforcing a support network that articulates with the guidelines obtained in health services, in a study identified that groups encourage the maintenance of commitment to PLWHA medication, in addition to the people who attending mutual aid groups have managed to encourage themselves to resume professional careers.<sup>15</sup>

One of the attributions of the Family Health Strategy (FHS), the gateway for users, is to carry out health education actions for the prevention of health problems and health promotion in the area covered by each team, which also corresponds to the school territory, place where educational actions

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can be carried out through the Health at School Program (Programa Saúde na Escola - PSE).<sup>1,24</sup> In the qualitative study by Paiva and authors, the planning of educational practices for the prevention of HIV/AIDS carried out with students from a public school in the southern region was analyzed, the authors suggest that the actions should provide opportunities for reflection and criticism of the subject, collaborating the education of schoolchildren, thus breaking the traditional clinical model of education.<sup>25</sup>

These findings reinforce the need for comprehensive and multidisciplinary care, so that patients feel supported in their difficulties. The assistance offered by professionals is an important factor in adhering to treatment, especially in the beginning, when patients have to face psychosocial barriers.

## CONCLUSION

The psychosocial representations of PLWHA are present as aspects that stimulate, but that can also mean impediments to adherence to ART. Family and social interactions are the most important interactions for the process of accepting treatment for people living with HIV and AIDS.

The results also revealed the need for health professionals to understand representations about HIV/AIDS, especially in relation to the importance of the representativeness of the patient's social relationships. The evidence shows that fear of discrimination is at risk for adherence to antiretroviral treatment. ■

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