

## Antiretroviral therapy adherence and functional health literacy of adults living with HIV/AIDS\*

### Adesão à terapia antirretroviral e letramento funcional em saúde de adultos que vivem com HIV/aids

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#### ABSTRACT

**Objective:** to analyze the association between antiretroviral therapy adherence and functional health literacy among adults living with HIV/AIDS. **Methods:** a cross-sectional study with 69 patients from a specialized HIV/AIDS care service. The Questionnaire for Assessing Antiretroviral Therapy Adherence the Test of Functional Health Literacy short version were used. Descriptive and inferential analyses were employed. In the analysis, the Chi-square test was used to verify the association between functional literacy levels and classification of antiretroviral therapy adherence, and Fisher's exact test was used to determine associations between therapy adherence classification and independent variables. **Results:** insufficient antiretroviral therapy adherence (76.8%) and adequate functional health literacy (63.8%) were identified. There was no significant association between antiretroviral therapy adherence and sociodemographic variables or functional literacy levels. However, an association was identified between antiretroviral therapy adherence and self-rated health ( $p=0.012$ ). **Conclusion:** there was no association between antiretroviral therapy adherence and functional health literacy levels among adults living with HIV/AIDS, but adherence was associated with self-rated health. **Contributions to practice:** the findings may guide nurses in adapting educational approaches and identifying specific patients who may require additional support or personalized strategies.

**Descriptors:** Antiretroviral Therapy; Highly Active; HIV; Acquired Immunodeficiency Syndrome; Medication Adherence; Health Literacy.

#### RESUMO

**Objetivo:** analisar associação entre adesão à terapia antirretroviral e letramento funcional em saúde de adultos que vivem com HIV/aids. **Métodos:** estudo transversal com 69 pacientes de serviço de assistência especializada em HIV/aids. Utilizou-se o Questionário para Avaliação da Adesão ao Tratamento Antirretroviral e o *Test of Functional Health Literacy Short version*. Empregou-se análise descritiva e inferencial. Na análise, utilizou-se teste Qui-quadrado para verificação da associação entre níveis de letramento funcional e classificação da adesão à terapia antirretroviral e teste Exato de Fisher para associações entre classificação da adesão à terapia com variáveis independentes. **Resultados:** identificou-se adesão à terapia antirretroviral insuficiente (76,8%) e letramento funcional em saúde adequado (63,8%). Não houve associação significativa entre adesão à terapia antirretroviral e variáveis sociodemográficas e níveis de letramento funcional. Contudo, identificou-se associação entre adesão à terapia antirretroviral e autoavaliação da saúde ( $p=0,012$ ). **Conclusão:** não houve associação entre adesão à terapia antirretroviral e níveis de letramento funcional em saúde de adultos que viviam com HIV/aids, porém a adesão foi associada à autoavaliação em saúde. **Contribuições para a prática:** os achados podem direcionar enfermeiros a necessidade de adaptação de abordagens educativas e identificação de pacientes específicos que podem precisar de suporte adicional ou estratégias personalizadas.

**Descriptores:** Terapia Antirretroviral de Alta Atividade; HIV; Síndrome da Imunodeficiência Adquirida; Adesão à Medicação; Letramento em Saúde.

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## Introduction

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) continues to be a global public health problem, with millions of people affected by this condition<sup>(1)</sup>. Between 1980 and 2024, 1,165,599 cases of AIDS were detected in Brazil, with a 35.7% decrease in the detection rate between 2012 and 2020. This decrease was influenced, in part, by the COVID-19 pandemic, which overloaded healthcare services, interrupted or reduced regular testing, and decreased healthcare seeking, resulting in fewer new cases being identified and reported during this period. However, there was a 2.5% increase in the number of cases between 2022 and 2023, with the most significant growth (33.1%) in northeastern Brazil<sup>(2)</sup>.

Although antiretroviral therapy (ART) is effective in reducing mortality and controlling HIV, treatment adherence remains a persistent challenge. This is because adherence is influenced by factors such as social stigma, financial barriers, access to healthcare, and treatment regimen complexity<sup>(3)</sup>. This is a continuous and combined treatment of medications that act at different stages of the virus replication cycle, with the aim of reducing viremia, preventing progression to AIDS, and improving patients' quality of life<sup>(4)</sup>. In 2022, 73.1% of Brazilians living with HIV were on treatment, but only 65.4% achieved viral suppression, which may be a result of weak therapeutic regimen adherence<sup>(5)</sup>.

Therapy adherence can be influenced by functional health literacy, defined as the ability to obtain, process, interpret, and understand health information, and to use reading, numeracy, visual, and writing skills to enable appropriate decision-making regarding one's own health<sup>(6)</sup>. This skill is not limited to the ability to read or write, but involves critical understanding of health-related information, such as treatment adherence<sup>(7)</sup>. This competence, therefore, becomes an essential social determinant for the effectiveness of complex therapies so that adherence is di-

rectly influenced by patients' level of understanding about their treatment<sup>(8)</sup>.

The analysis of the relationship between functional health literacy and ART adherence becomes relevant for promoting more effective educational strategies<sup>(9)</sup>. Nurses play a strategic role in identifying individual barriers to adherence, promoting health education strategies, and providing guidance on appropriate therapy management. In this process, ongoing interaction between nurses and patients contributes to strengthening literacy and improving treatment understanding and, consequently, adherence<sup>(10)</sup>.

Despite advances in access to treatment and public health policies, there are still gaps in the scientific literature specifically addressing this association in adults living with HIV/AIDS, especially in northeastern Brazil. This study seeks to fill this gap by exploring the association between different levels of literacy and ART adherence. Based on this analysis, we aimed to provide support for the creation of more appropriate educational and care strategies, aiming to improve treatment adherence and, consequently, the quality of life of people living with HIV.

This study aimed to analyze the association between antiretroviral therapy adherence and functional health literacy among adults living with HIV/AIDS.

## Methods

This is a cross-sectional study, carried out at the specialized HIV/AIDS care service of the *Hospital das Clínicas* of the *Universidade Federal de Pernambuco*, Recife, Brazil, from June to October 2021. The study followed STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) recommendations.

The study population consisted of adult healthcare service users with a confirmed diagnosis of HIV and AIDS. Sample selection began with review of 122 medical records of users who attended medical appointments over the five-month period of data collection. The sample was delimited after consid-

ering 84 users actively involved in the service. The calculation was based on sample size estimation for a finite population, using the formula:  $n = z^2 \cdot p \cdot q \cdot N / d^2 \cdot (N-1) + z^2 \cdot p \cdot q$ , adopting a 95% confidence level, a 5% margin of error, and an expected prevalence of strict ART adherence of 22.6%, as per a previous study<sup>(11)</sup>. The calculation resulted in a minimum sample of 65 participants.

Participants were selected by purposive sampling. People between 20 and 59 years old were included, as this was the age range served by the outpatient clinic and self-reported literacy. People with mental disorders or use of psychoactive medications that compromised cognitive abilities, as verified in medical records, and users with a period of ART use of less than one month, due to the short period for adherence assessment, were excluded. After applying the criteria, 69 users participated in the study.

For data collection, patients were approached in the outpatient waiting room and invited to participate in the study. Upon acceptance, an interview was conducted in a private setting. A sociodemographic and emotional questionnaire was used to collect the following variables: age; religion; self-reported race; sexual orientation; marital status; number of children; household composition; profession/occupation; individual and family income; education; time since diagnosis and treatment; health perception; viral load test results; and history of hospitalizations or emergency room visits.

The Questionnaire for Assessing Antiretroviral Therapy Adherence (In Portuguese, *Questionário para Avaliação da Adesão ao Tratamento Antirretroviral*) was used to assess ART adherence. The instrument had 17 items, with responses on a five-point Likert scale, which assess five competencies of therapy adherence: treatment compliance; behaviors and history of non-adherence; doctor-patient communication; personal beliefs/expectations about treatment; and satisfaction with treatment. The overall adherence index ranges from 17 to 85 points, with a higher score indicating greater treatment adherence. Insufficient adherence is classified as results below the 80<sup>th</sup> per-

centile, and strict adherence is classified as results equal to or above this percentile<sup>(12)</sup>.

To assess functional health literacy, we used the Test of Functional Health Literacy short version (S-TOFHLA), adapted to the Brazilian context. The S-TOFHLA measures the ability to read and understand common information in healthcare settings, such as medication labels and consultation instructions. The test consisted of two parts: a numeracy test (numerical competence), which assessed the interpretation of information about medications and laboratory tests; and a textual comprehension test, which involved filling in the gaps in two texts related to exam preparation and user rights in the Brazilian Health System. Each part of the test has a maximum score, and literacy is classified into three levels: inadequate (0-53 points), limited (54-67 points), and adequate (68-100 points)<sup>(13)</sup>. The maximum time for the numeracy assessment should be ten minutes and for the textual comprehension assessment a maximum of seven minutes, with interruption if a participant exceeds these times.

Data were entered into EpiInfo version 3.5.4 and exported to SPSS version 21.0 for statistical analysis. The Kolmogorov-Smirnov test was used to verify the normality of continuous variables, and non-normal distribution was identified. Categorical variables were presented as absolute and relative frequencies, and continuous variables as minimum, maximum, median, and interquartile range (IQR). In the inferential analysis, the Chi-square test was used to verify the association between literacy levels and ART adherence classification. Fisher's exact test was used to analyze the associations between therapy adherence classification and sociodemographic variables, HIV/AIDS infection profile, functional health literacy levels, and viral load. A significance level of 5% was considered.

The study was approved by the *Universidade Federal de Pernambuco* Research Ethics Committee, under Opinion 4,666,470/2021 and Certificate of Presentation for Ethical Consideration 44668821.3.0000.5208. All participants signed and received a copy of the Informed Consent Form.

## Results

The sample was predominantly composed of male participants (77.9%), self-identified as brown (54.4%), homosexual (47%), single (63.2%), without a stable sexual partner (54.7%), and aged 50 to 59 years (33%), with an average age of 42.6 years ( $\pm 10.94$ ). The majority of participants were Catholic (53.7%), attended school for 10 to 12 years (26.1%), and were employed (32.3%), with a personal income of up to one minimum wage (34.5%) and a family income of one minimum wage (25%). Regarding housing, those who shared a home with family or friends (82.6%) and had no children (58%) prevailed.

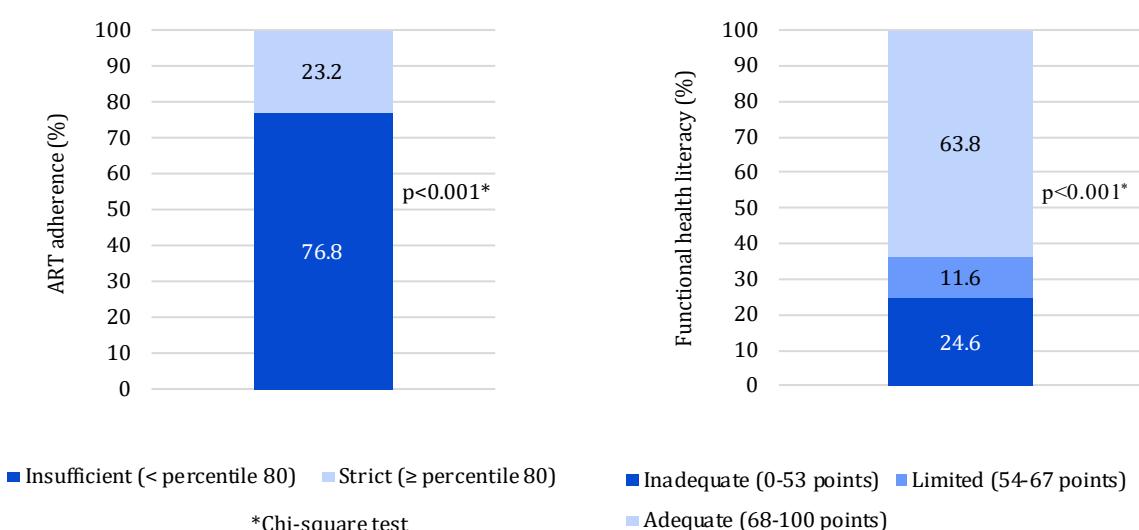
In the context of HIV infection, the majority of participants (50%) had been living with the virus for more than 10 years, with an undetectable viral load (83.9%). Concerning self-rated health, the predominant classification was good (47.8%), followed by fair (43.5%) and poor (8.7%). As for lifestyle habits, the majority (77.9%) did not smoke, did not use illicit drugs (88.2%), and did not consume alcoholic beverages (52.2%). Furthermore, they did not require hospitalization or emergency care (94.9%).

Concerning functional health literacy, the textual comprehension skill had a median of 64.0 (IQR = 35.50),

with values ranging from nine to 72. In numerical competence, the median was 9.42 (IQR = 10.50), with values ranging from zero to 28. The global functional literacy index, which combines both skills, had a median of 81.0 (IQR = 39.50), with values ranging from nine to 100.

ART adherence assessment identified that the competence related to treatment compliance had a median of 14.0 (IQR = 4.0), with a range between six and 15.0. Regarding behaviors and history of non-adherence, the median was 19.0 (IQR = 2.5), with values ranging from nine to 20.0. Doctor-patient communication competence had a median of 14.0 (IQR = 2.5) and a range between eight and 15.0. Personal beliefs and expectations about treatment had a median of 22.0 (IQR = 4.5), with values between nine and 25.0. Satisfaction had a median of nine (IQR = 1.0), with a range between two and ten. The overall ART adherence index had a median of 77.0 (IQR = 9.0), with a minimum of 41.0 and a maximum of 85.0.

In this study, participants with insufficient ART adherence and adequate functional health literacy prevailed. The Chi-square test identified a statistically significant difference between ART adherence classifications and literacy levels (Figure 1).



**Figure 1** – Classification of antiretroviral therapy adherence, functional health literacy levels of adults living with HIV/AIDS, and statistical significance. Recife, PE, Brazil, 2021

Sociodemographic variables did not have a statistically significant association with the overall therapy adherence index scores (Table 1).

**Table 1** – Analysis of the association between overall antiretroviral therapy adherence index scores and sociodemographic variables (n=69). Recife, PE, Brazil, 2021

Variables	Overall ART adherence rate*		p-value†
	Insufficient n (%)	Strict n (%)	
Gender identity			
Man	39 (73.6)	14 (26.4)	
Woman	10 (71.4)	4 (28.6)	1.000
Travestite	1 (100.0)	–	
Sexual orientation			
Heterosexual	19 (67.9)	9 (32.1)	
Homosexual	24 (77.4)	7 (22.6)	0.788
Bisexual	5 (71.4)	2 (28.6)	
Color			
White	11 (73.3)	4 (26.7)	
Brown	27 (73.0)	10 (27.0)	1.000
Black	12 (75.0)	4 (25.0)	
Education years (years)			
4 to 6	8 (72.7)	3 (27.3)	
7 to 9	12 (85.7)	2 (14.3)	0.195
10 to 12	14 (77.8)	4 (22.2)	
Marital status			
Single	30 (69.8)	13 (30.2)	
Married/common-law relationship	16 (80.0)	4 (20.0)	0.361
Divorced	5 (100)	–	
Work situation			
Employed	13 (61.9)	8 (38.1)	
Unemployed	13 (92.9)	1 (7.1)	
Self-employed	10 (62.5)	6 (37.5)	0.195
Odd job	3 (100)	–	
Social benefits	9 (81.8)	2 (18.2)	
Personal income (minimum wage)			
< 1	12 (85.7)	2 (14.3)	
1	14 (73.7)	5 (26.3)	
>1	7 (70.0)	3 (30.0)	0.624
>2	3 (60.0)	2 (40.0)	
≥3	4 (57.1)	3 (42.9)	
Family income (minimum wage)			
<1	4 (100)	–	
1	10 (90.9)	9 (9.1)	
>1	7 (77.8)	2 (22.2)	0.596
2	5 (83.3)	1 (16.7)	
>2	6 (66.7)	3 (33.3)	

\*ART: antiretroviral therapy; †Fisher's exact test

There was no significant association between the overall ART adherence index score and levels of functional health literacy, viral load, time since diagnosis, time on treatment, tobacco use, or illicit drug use. However, the overall ART adherence index score showed a statistically significant association with self-rated health (Table 2).

**Table 2** – Analysis of the association between overall antiretroviral therapy adherence scores and functional health literacy levels, viral load, and HIV/AIDS infection profile (n=69). Recife, PE, Brazil, 2021

Variables	Overall ART adherence index*		p-value†
	Insufficient n (%)	Strict n (%)	
Functional health literacy			
Inadequate	13 (76.5)	4 (23.5)	
Limited	6 (75.0)	2 (25.0)	1.000
Adequate	32 (72.7)	12 (27.3)	
Viral load			
Undetectable	40 (76.9)	12 (23.1)	0.266
Detectable	6 (60.0)	4 (40.0)	
Diagnosis time (years)			
≤ 1	5 (62.5)	3 (37.5)	
≤ 10	18 (72.0)	7 (28.0)	0.196
>10	27 (81.8)	6 (18.2)	
Treatment time (years)			
≤ 1	5 (62.5)	3 (37.5)	
≤ 10	20 (74.1)	7 (25.9)	0.614
>10	22 (78.6)	6 (21.4)	
Self-rated health			
Poor/a little poor	6 (100)	–	
Average/could be better	26 (86.7)	3 (13.3)	0.012
Good	19 (57.6)	14 (42.4)	
Tobacco use			
Yes	12 (80.0)	3 (20.0)	0.742
No	38 (71.7)	15 (28.3)	
Illicit drug use			
Yes	7 (87.5)	1 (12.5)	0.316
No	43 (71.7)	17 (28.3)	

\*ART: antiretroviral therapy; †Fisher's exact test

## Discussion

This study identified a predominance of adequate functional health literacy in the sample, but insufficient ART adherence. International literature shows different results and indicates that adults with lower literacy levels are more likely to miss medication doses<sup>(14)</sup>. This contrast suggests that, although participants demonstrated sufficient functional competence to understand basic health information and necessary treatment, other dimensions of this competence, such as critical and communicative skills, may be more relevant determinants of treatment adherence in the study sample. The results reinforce, therefore, the need to consider aspects beyond literacy, recognizing that subjective, relational, and contextual factors also influence care management for people living with HIV/AIDS.

Regarding therapy adherence competencies, those related to treatment adherence and communication with healthcare professionals showed reasonable levels. Thus, it is suggested that most participants were able to communicate adequately with their doctors and understand health instructions. However, the presence of non-adherence behaviors and variations in personal beliefs about treatment may indicate that, despite satisfactory communication, individual factors, such as treatment expectations and perceived benefits, still play an important role in medication continuity<sup>(15)</sup>. Barriers to adherence were identified as side effects, low medication self-efficacy, low social participation, disbelief in the benefits of treatment, and lack of a supportive environment<sup>(16-17)</sup>. These findings reinforce the idea that understanding clinical guidelines represents only an initial component in the process of therapeutic adherence. Converting this knowledge into ongoing action requires individualized strategies that integrate the cognitive, emotional, and motivational dimensions of care, aiming to bridge the gap between prescriptive knowledge and the effective implementation of adherence behaviors.

Adequate functional health literacy among stu-

dy participants can be explained by the educational profile of the sample, as the majority had between 10 and 12 years of education, a factor that may favor the understanding of information related to treatment and health in general<sup>(18)</sup>. A systematic review with meta-analysis identified that higher educational levels positively influence health literacy<sup>(19)</sup>. However, it is a multidimensional phenomenon that transcends functional competence and includes the ability to interpret complex information, assess risks, and make autonomous decisions in a health context<sup>(20)</sup>. Formal education, although contributing to basic literacy, does not in itself ensure the ability to critically apply knowledge in the daily life of healthcare. This critical and reflective perspective becomes especially relevant in the face of complex treatments, such as Art, which requires not only understanding of clinical guidelines, but also conscious judgment on the implications of the therapeutic regime and the consequences of strict non-compliance. Thus, even people with greater education can benefit from support strategies that promote the continuous strengthening of health literacy in their multiple dimensions<sup>(18)</sup>.

The results for functional health literacy skills indicated that, although most participants demonstrated adequate comprehension skills for health-related texts and information, there was variation in the sample for numerical competence. A study conducted in Indonesia suggests that this heterogeneity may reflect differences in education levels and prior experience with health information, factors that directly influence the ability to adequately interpret guidance from healthcare professionals and informational materials<sup>(21)</sup>. In the context of HIV/AIDS treatment, numerical competence is relevant, as ART adherence often requires understanding dosing schedules, calculating schedules, dose intervals, and interpreting laboratory tests, such as viral load and CD4 lymphocyte counts. The observed variation in textual and numerical comprehension skills reveals that, while some participants demonstrated skill in handling these types of information, others may face substantial difficulties.

People with limited basic math skills may face silent but significant barriers to treatment management, even when they understand textual information. Therefore, health interventions must consider not only verbal literacy but also numerical literacy, promoting more accessible and personalized communication strategies that take into account the educational and sociocultural profile of patients. This demonstrates the importance of assessing functional health literacy skills in the care pathway of patients using ART, as they can guide professionals to patients' specific information needs.

The significant association between insufficient therapy adherence and participants' self-rated health status corroborates the results of a Brazilian study that identified an association between negative self-rated health and lower levels of adherence<sup>(22)</sup>. This may be related to a lack of deeper understanding of the benefits of treatment and the perception that, in the absence of immediate symptoms, continued medication use becomes unnecessary. This perspective may be influenced by a lack of critical health skills, which would allow patients to understand the need for long-term treatment and not just as a response to acute symptoms. A lack of a critical approach to understanding health and treatment can result in failures in commitment to therapy, especially in chronic settings<sup>(23)</sup>. Insufficient adherence, therefore, cannot be attributed solely to the functional understanding of information, but reflects a broader limitation in patients' ability to integrate complex health knowledge into their personal experience, which highlights the need for interventions that strengthen critical skills and promote a broader and autonomous vision of chronic treatment management.

Socioeconomic factors, such as education and income, play an important role in treatment adherence. People with low income or unemployment tend to have more difficulty adhering to ART, which was corroborated by the data from this study and widely recognized in the literature<sup>(24)</sup>. Low therapy adherence was found to be associated with low education levels,

poor health status, and low engagement in care and literacy<sup>(25)</sup>. Furthermore, patients' life context can be an additional factor of vulnerability, especially when associated with the social stigmatization of HIV/AIDS and lack of adequate social support<sup>(26)</sup>.

In this study, there was no statistically significant association between ART adherence and the variables functional health literacy and viral load. Significant associations between these variables were found in another Brazilian study<sup>(9)</sup>. Regarding viral load, despite insufficient treatment adherence, viral load was undetectable (plasma levels below the quantification threshold) in most study participants. This finding reinforces the importance of health education and ongoing monitoring strategies, which should focus on adherence and overcoming psychological and behavioral barriers. Implementing approaches such as counseling and motivational interviewing can be important strategies for promoting more sustainable behavioral change and improving adherence<sup>(27)</sup>.

While adequate functional health literacy is important, it must be complemented by strategies that address critical and communicative dimensions, as well as interventions focused on emotional, psychological, and socioeconomic determinants that directly impact ART adherence. A clinical trial found that individual counseling sessions based on motivational interviewing resulted in a significantly twofold increased likelihood of treatment adherence and reduced distrust<sup>(28)</sup>. These findings reinforce that promoting adherence does not depend exclusively on the transmission of information, but on building bonds, acknowledging individual vulnerabilities, and valuing patients as an active subject in the care process.

Health education, guided by qualified professionals, such as nurses, is essential to ensure that patients not only understand the need for treatment adherence but also feel empowered to make positive decisions and motivated to follow through over time, which promotes better health outcomes for people living with HIV/AIDS.

## Study limitations

A limitation of this study is the small sample size selected from only one specialized HIV/AIDS care service, which may limit the generalizability of the findings. Furthermore, the lack of multivariate logistic regression analysis limits the robustness of inferences about associations between the variables studied. The outcome variables were assessed at a single point in time and may not reflect changes in adherence and literacy in studies that include follow-up of this sample. Furthermore, there was no laboratory collection for CD4 cell counts, which made it impossible to assess the association with this important immunological variable, recognized as relevant in the context of HIV infection. These limitations highlight the need for future studies with larger samples, multivariate analyses, and the inclusion of laboratory markers.

## Contributions to practice

This study advances knowledge on the topic, as although there are studies investigating the prevalence of ART adherence, those testing its association with functional health literacy are still limited. Further studies are needed to investigate this association in different cultural and regional contexts. By exploring this relationship, the impact on antiretroviral therapy adherence can be understood by identifying gaps in the understanding of therapeutic guidelines and the need for more personalized educational strategies. The findings can guide nurses in adapting educational approaches and identifying specific patients who may require additional support or personalized strategies.

## Conclusion

No statistically significant association was identified between ART adherence and functional health literacy among adults living with HIV/AIDS. Adherence was classified as insufficient and associated with

self-rated health, while literacy level was considered adequate. These findings indicate the complexity of factors that influence therapeutic adherence and reinforce the importance of comprehensive approaches in the monitoring of people living with HIV/AIDS. For nursing practice, it is important to consider the level of functional health literacy and self-rated health status when planning interventions to improve ART adherence.

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## Authors' contributions

Data conception and design or analysis and interpretation; Manuscript writing or critical review of relevant intellectual content; Final approval of the version to be published; Responsibility for all aspects of the text in ensuring the accuracy and integrity of any part of the manuscript: Santos RDS, Sá GGM, Guedes TG. Manuscript writing or critical review of relevant intellectual content; Final approval of the version to be published; Responsibility for all aspects of the text in ensuring the accuracy and integrity of any part of the manuscript: Gonçalves CMOB, Moraes KL, Coriolano-Marinus MWL, Monteiro EMLM.

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