

# Access barriers to health services for adolescents with HIV/AIDS

**RESUMO** | Objetivo: analisar as evidências na literatura nacional e internacional acerca das barreiras de acesso à saúde de adolescentes que vivem com o vírus da imunodeficiência humana e/ou Síndrome da Imunodeficiência Adquirida. Método: revisão integrativa sem restrição de anos de publicações, conduzida nas bases Science Direct, Web of Science, CINAHL, Scopus, PubMed, LILACS, Biblioteca Virtual em Saúde, EMBASE e MEDLINE. Utilizou-se duas estratégias de busca com os descritores: Adolescent, Health Services Accessibility, Acquired Immunodeficiency Syndrome e HIV. Resultados: identificaram-se 7.371 estudos, destes selecionaram-se 92 para leitura na íntegra, e quatro artigos compuseram a amostra final. As principais barreiras de acesso foram, medo do reconhecimento, falta de empatia no atendimento e pouca flexibilidade de horários dos serviços. Conclusão: o medo, estigma e a discriminação interferem no acesso aos serviços de saúde de adolescentes negativamente na vida dos jovens em questão, prejudicando-os na sua proteção e na possibilidade de se manterem saudáveis.

**Descritores:** HIV; Síndrome da Imunodeficiência Adquirida; Adolescente; Acesso aos Serviços de Saúde.

**ABSTRACT** | Objective: to analyze the evidence in the national and international literature about barriers to accessing health care for adolescents living with the human immunodeficiency virus and/or Acquired Immunodeficiency Syndrome. Methods: integrative review without restriction of years of publications, conducted in Science Direct, Web of Science, CINAHL, Scopus, PubMed, LILACS, Virtual Health Library, EMBASE and MEDLINE databases. Two search strategies were used with the descriptors: Adolescent, Health Services Accessibility, Acquired Immunodeficiency Syndrome and HIV. Results: 7371 studies were identified, 92 were selected for full reading, and four articles made up the final sample. The main barriers to access were fear of recognition, lack of empathy in care and little flexibility in service hours. Conclusion: fear, stigma and discrimination interfere with access to health services for adolescents negatively in the lives of the young people in question harming them in their protection and in the possibility of staying healthy.

**Keywords:** HIV; Acquired immunodeficiency syndrome; Adolescent; Access to Health Services.

**RESUMEN** | Objetivo: analizar la evidencia en la literatura nacional e internacional sobre las barreras de acceso a la atención de salud de los adolescentes que viven con el virus de la inmunodeficiencia humana y / o el síndrome de inmunodeficiencia adquirida. Métodos: revisión integradora sin restricción de años de publicaciones, realizada en las bases de datos Science Direct, Web of Science, CINAHL, Scopus, PubMed, LILACS, Virtual Health Library, EMBASE y MEDLINE. Se utilizaron dos estrategias de búsqueda con los descriptores: Adolescente, Accesibilidad a los Servicios de Salud, Síndrome de Inmunodeficiencia Adquirida y HIV. Resultados: Se identificaron 7371 estudios, se seleccionaron 92 para lectura completa y cuatro artículos conformaron la muestra final. Las principales barreras de acceso fueron el miedo al reconocimiento, la falta de empatía en la atención y la poca flexibilidad en los horarios de atención. Conclusión: el miedo, el estigma y la discriminación interfieren negativamente en el acceso a los servicios de salud de los adolescentes en la vida de los jóvenes en cuestión, perjudicando su protección y la posibilidad de mantenerse saludables.

**Palabras claves:** HIV; Síndrome de inmunodeficiencia adquirida; Adolescente; Acceso a los servicios de salud..

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## INTRODUCTION

Adolescents constitute a population considered vulnerable to sexually transmitted infections, due to factors: psychological, biological, social and economic. However, research indicates that this population, even after years of campaigns on prevention, transmission of the human immunodeficiency virus (HIV) and sexually transmitted infections, still has doubts about the subject and resistance to condom use. (1)

Bearing in mind that the main forms of HIV infection include transmission through unprotected sex, sharing sharps and vertical transmission (2) when relating this disease to adolescence, many concerns emerge. This happens, when considering adolescence as a period marked by the manifestation of sexuality, and by the frequent adoption of risky behaviors, mobilized by the search for identity, acceptance in social groups and independence, making these young people more exposed to contamination. Such behaviors lead adolescents to face various problems such as unwanted pregnancy, alcohol and drug use, juvenile delinquency, sexual exploitation, prostitution and greater exposure to illness from hepatitis and HIV infection and the acquired immunodeficiency syndrome (AIDS). (3)

For the World Health Organization, adolescence is the period between 10 and 19 years of age. This stage or phase of human development is punctuated by numerous physical, psychological and behavioral changes, which makes it essential to take a cautious look at this population in order to avoid the transmission of infections. (4)

From a public health point of view, the size of the world population of adolescents is very expressive, since they constitute one third of the total world population and concentrate half of HIV infections. Data reveal that most young people today become sexually active long before the age of 15. (5)



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Between 2007 and 2019, the Notifiable Diseases Information System notified 300,496 cases of HIV infection in Brazil, 746 in the age group between 10 and 14 years and 17,169 between 15 and 19 years. In addition, there was an increase in the incidence of HIV in adolescents, especially males and in the age group between 15 and 19 years. (6)

For the health care of this population, primary health care is one of the gateways to services for the treatment of HIV/AIDS for adolescents. (7) The Family Health Strategy program has a fundamental role in offering comprehensive and longitudinal care to people living with HIV/AIDS, promoting disease prevention, early diagnosis and treatment. (8)

However, in cases where health services do not have good coordination or management in their system, barriers to access for adolescents will arise, represented by inadequate opening hours, long distances from the home to services, delay in service, queues, judgment of health workers, stigma and fear. (9)

Considering such weaknesses in the system and the difficulties in accessing services for the treatment of HIV/AIDS in adolescents, in the present study, we sought to analyze the scientific evidence available through a review of national and international literature, focusing on the barriers faced by this population in health monitoring.

Thus, the present study aims to analyze the national and international literature on barriers to health access by adolescents living with HIV/AIDS.

## METHODS

This is an integrative literature review, which consists of a method that allows the synthesis and analysis of data to develop a more comprehensive explanation of a specific phenomenon, based on the synthesis or analysis of the findings of the studies, with the

purpose of identifying possible gaps in scientific knowledge. (10) For the preparation of this study, the recommendations contained in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist were used. (11)

To carry out this review, the following steps were implemented: elaboration of the guiding question, establishment of inclusion and exclusion criteria, literature search, data collection, categorization of studies, critical analysis of included studies, discussion of results and presentation of the integrative review. (11)

To formulate the research problem, the strategy of the acronym PICO was used, in which P (Population): adolescents with HIV/AIDS; I (Phenomenon of interest): accessibility to health services; Co (Context): primary health care, arriving at the following guiding question: What barriers to accessibility to primary health care services are faced by adolescents with HIV/AIDS?

Data were collected from January to May 2021, by two researchers concomitantly, as a strategy to reduce possible biases. The selected databases were: Latin American and Caribbean Literature on Health Sciences (LILACS), Online System for Medical Literature Analysis (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), SCOPUS, Web of Science, PubMed, Virtual Health Library (VHL), Embase and Science Direct.

To search the databases, the following descriptors controlled and indexed in DeCS and MeSH were used: "Accessibility to Health Services", "Adolescents", "HIV", "Acquired Immunodeficiency Syndrome". Two search strategies were made with the help of the Boolean operators "AND" and "OR" as follows: Adolescent AND Health Services Accessibility AND Acquired Immunodeficiency Syndrome; e Adolescent AND Health Services Accessibility AND HIV.

It is noteworthy that for each database a search strategy was developed, so that the established PICO acronym was contemplated. The following inclusion criteria were used: articles published



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in Portuguese, English and Spanish, available in national and international literature, without restriction of years of publications, but which addressed the age group of adolescence from 10 to 19 years, as recommended by the World Health Organization. The following

were excluded: duplicate articles in the databases, which did not answer the research question, letters to the editor, review studies, opinion articles, comments, essays and previous notes.

Initially, literature searches were carried out in the databases by two independent reviewers, in order to evaluate the primary studies according to the previously established inclusion and exclusion criteria. After identifying the primary studies, they were critically analyzed in terms of titles and abstracts through reflection on the objective, eligibility and exclusion criteria. When the researchers considered the information available in the title and abstract to be insufficient, they proceeded to read the article in its entirety.

After the identification of the studies in the bases, reflection on the title, abstracts and reading in full, a standardization was carried out, organized through the creation of a spreadsheet in Microsoft Excel® for each base of the articles selected at this stage, containing the following information: Article number, manuscript title, objective, study design, year of publication, name of the journal, and the following question: This study reports which barriers to accessibility to primary health care services are faced by adolescents with HIV/AIDS? What are the barriers?

The articles selected for the final sample were analyzed qualitatively and descriptively, named by ordinal numbers followed by a letter, analyzed by four experts in order to expand the reflection and discussion of the theme. Studies were also classified and evaluated according to the level of evidence from highest to lowest, presented by Roman numerals: I - Evidence from syntheses of cohort or case-control studies, II - Evidence derived from a single cohort study or case-control, III - Evidence obtained from metasynthesis or synthesis of descriptive studies, IV - Evidence from descriptive or qualitative studies, V - Evidence from expert

opinion. (12)

The articles selected for the final sample had their references analyzed, so that the articles that composed them were submitted to the reading of their titles and abstracts and, if the eligibility criteria were met, they were included in the present study.

**RESULTS**

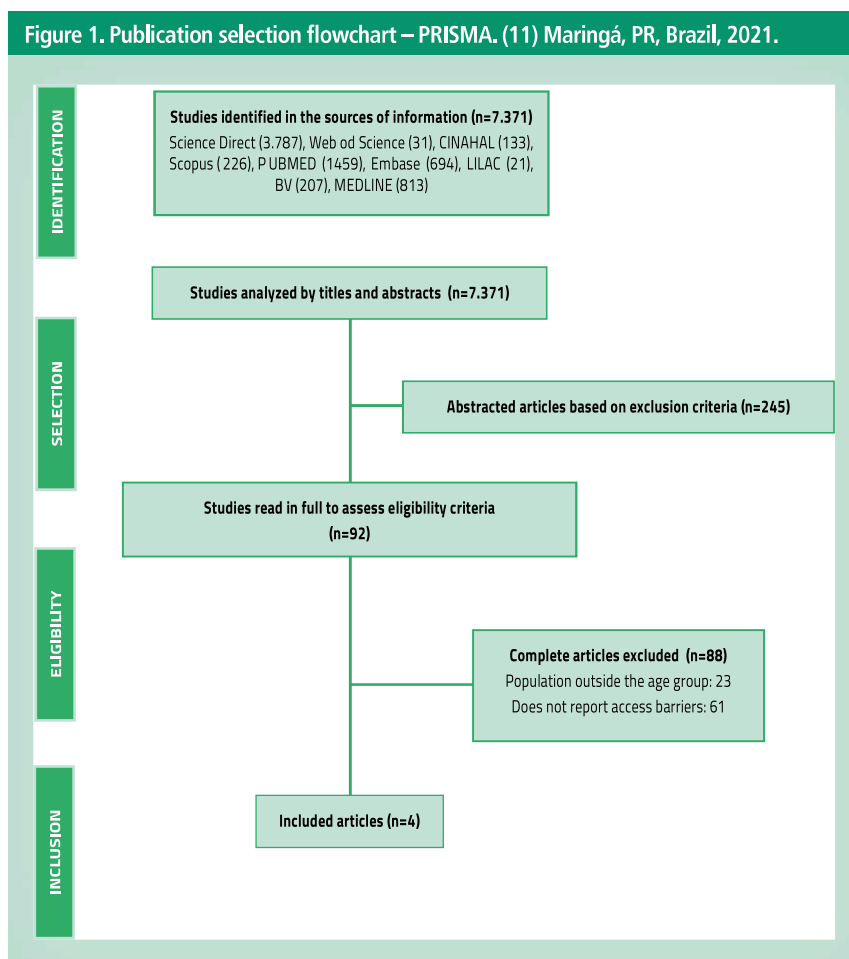
In the database searches, 7,371 studies were identified, whose titles and abstracts were subjected to careful reading. Of these, 92 were selected for reading in full and, from the reading, a total of four articles were reached that made up the final sample.

A total of 183 articles were also analyzed, listed in the references of the works selected for the final sample, however, no article was added to this sample because it did not respond to the objective of this study. In order to favor the visualization of the methodological course of the selection of studies, a flow diagram was built based on the recommendations contained in the PRISMA (11) exposed in Figure 1.

The results of this review showed articles published in English and predominantly in international journals, of which only one was from the African continent, three of them had free content and one had two access models: open or restricted. The themes of publication of his articles addressed: sexual and reproductive health and rights, disadvantaged and vulnerable families. Two publications presented the specific theme, directed to HIV/AIDS, addressing the dimensions: impact, social planning, policies, interventions, consequences and infection behaviors.

Regarding the place of development of the studies, three of those selected were from Zambia and the other was from Kenya. (13-16) As for the design of the studies found, three were qualitative with a methodology based on semi-structured interviews, and one used

Figure 1. Publication selection flowchart – PRISMA. (11) Maringá, PR, Brazil, 2021.



SOURCE: Authors, 2021.

Figure 2. Description of articles selected for integrative review. Maringá, PR, Brazil, 2021.

Identifica-tion/Year/ Country	Data-base	LE	Methods	Access barriers to health services
1A 2013 <sup>(13)</sup> Zâmbia	CINAHL	IV	Qualitative study with semi-structured interviews. Eight focus group measurements were carried out with 58 adolescents, 21 parents and 24 health professionals.	Fear of being recognized. Little privacy. Lack of empathy from professionals. Unfriendly environment. Lack of specialized services. There are no dialogues about sexuality between parents, guardians and adolescents.

mixed methods. In order to present the characteristics of the articles selected for this review in a more didactic way, the information was organized in Figure 2.

The development sites of the studies selected for the final sample were restricted to the African continent, a fact attributed to geographic and epidemiological factors. Some contextual aspects highlighted in the study included: high numbers of HIV prevalence, high numbers of viral load counts in infected people, health interventions by non-governmental organizations.

The findings of this study reveal that the greatest dissatisfaction of users is related to the quality of care provided by health professionals, the management of services, access and infrastructure of health institutions, aimed at serving this public. Considering these data, the barriers identified will be presented in three thematic axes, for better understanding and reflection.

## DISCUSSION

In terms of limitations of the study, there is a small number of articles present in the national and international literature about barriers to access to health for adolescents with HIV and restricted to the African reality, however, it should be noted that all articles available in open or restricted format were analyzed.

The importance of this review is emphasized to identify the main barriers to access to health for adolescents living with HIV/AIDS. Through the identification of these barriers, it is possible to draw up action plans in order to reduce the negative impacts caused by HIV/AIDS and to promote a more humanized care and treatment.

Access to health is an important aspect of citizenship and is related to the level of quality of care offered and the appropriate interventions available to respond to the needs of young people,

2A 2014(14) Zâmbia	CINAHL	IV	Qualitative study with semi-structured interviews. Eight adolescents were carried out, with 111 focus groups, 21 guardians and 38 caregivers.	<ul style="list-style-type: none"> <li>Lack of flexibility in hours.</li> <li>Need to miss class to go to the health service.</li> <li>Health professionals lack empathy.</li> <li>Specialized services are poorly incorporated into basic health services.</li> <li>They suffer discrimination in schools.</li> </ul>
3A 2017(15) Quênia	SCOPUS	IV	Qualitative study with semi-structured interviews, carried out with 24 adolescents and 14 caregivers.	<ul style="list-style-type: none"> <li>There are punishments, judgments.</li> <li>Information on HIV services is lacking.</li> <li>Long lines, long wait times.</li> <li>Employees don't stick to schedules.</li> <li>Transport and nutrition expenses.</li> <li>Lack of partnerships between schools and services.</li> </ul>
4A 2019(16) Zâmbia	MEDLINE	IV	Mixed methods study. Combination study and qualitative cross-sectional with focus group studies, each with 6 to 9. In addition to interviews with 47 adolescents.	<ul style="list-style-type: none"> <li>Fear of being recognized.</li> <li>Fear of revealing the serology to friends.</li> <li>Health workers do not have communication and reception skills.</li> <li>Records are poorly maintained.</li> <li>Going to the health service makes them late for school.</li> <li>They suffer disrespectful treatment</li> </ul>

SOURCE: Authors, 2021.

ple, families and communities. Access concerns several categories or levels, which cover aspects such as geographic accessibility, availability, feasibility and acceptability, and which can lead to the creation of a set of barriers in each of them. (17)

In order to have excellence in health care, it is necessary to develop an attentive look at some characteristics that were the target of complaints, such as difficulty, slowness in scheduling appointments and long waiting lines. Adequate care for this population must take into account the precepts of ambience, that is, of infrastructure that

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includes a welcoming, comfortable, bright, calm environment that offers privacy. (18)

Barriers of intangible aspects were mentioned in the analyzed studies, related to the emotional conditions of professionals who provide care to adolescent clients living with HIV/AIDS, which is one of the determining factors for user dissatisfaction. In order to achieve the expected objective, providing the resolution of the user's problem, it is essential that professionals make use of an adequate vocabulary, without judgments and that they have as a motto for their actions, attentive listening, capable of perceiving what he really needs to offer advice directed to the demands presented. (19)

The National Humanization Policy, implemented by the Unified Health System, aimed to build a policy aimed at the qualification of health services, providing quality and resolution in care, considering, for that, the adoption of ethical conducts and attitudes, by its service providers. (20)

Ethical and empathic behaviors must be practiced by health professionals. Scientific knowledge associated with the way in which the user is treated can mean adherence or not to care for their health. From this perspective, the treatment given to the patient should include actions such as greeting, calling the patient by name, looking into the eyes, performing the welcoming in an individualized way, transmitting trust, security, respecting intimacy, beliefs and desires, providing transparent information to patients and families. (8)

The lack of flexibility in health care was an important finding in international studies. In Brazil, to try to minimize the damage related to this problem, the National Policy of Primary Care recommends that the health unit establish a continuous service between the morning and afternoon periods, advocating that there is also the possibility of ins-

tituting alternative schedules, in order to provide care to the entire population without distinction.(21)

Inadequate infrastructure also proved to be one of the difficulties in the



The National Humanization Policy, implemented by the Unified Health System, aimed to build a policy aimed at the qualification of health services, providing quality and resolution in care, considering, for that, the adoption of ethical conducts and attitudes, by its service providers



search for HIV treatment and prevention services, as they are geographically located very far from the homes of adolescent users. The reduced number of institutions that serve this population negatively interferes with the access

of young people to services, who have the expense of transport and food during the journey, causing inequalities and the abandonment of treatment and diagnosis to increase. (22)

Therefore, there is a need to optimize the application of health resources, so that public money guarantees resources to solve the population's health needs. It is therefore proposed to expand primary health care and develop integrated networks, improving the management and efficiency of health providers. (23)

The articulation between health teams and schools contributes to the consolidation of health promotion practices, disease prevention and monitoring of students' health. The school, for adolescents, is the most advisable place for health education practices, as it provides the development of actions with the collaboration of different actors such as students, parents, educators and health professionals. (24)

In this context, it is extremely important to ensure the existence and strengthening of the link between services in the support network. The health professional, with the support of the educators, will play the role of coordinator and advisor of activities to promote health and prevent sexually transmitted diseases such as HIV, among others, contributing to school and community development. (24)

The studies showed that a portion of young people with HIV resent the discrimination they suffer in society, especially in schools, where they suffer constraints not only from their peers, but also from teachers.

The lack of knowledge related to HIV in schools, which persists over time, is due to factors such as: the biomedical model of sex education, in which the concern is focused on the clinical aspects of the disease (25); precariousness of health services, which does not adequately welcome and guide young people; other ways used by

young people to obtain information on the subject, such as the media, internet and exchanges of experiences among adolescents themselves. (26)

Health professionals are important agents for the discontinuation of this phenomenon of misinformation about HIV. In this way, these actors are responsible for a paradigm shift, seeking to implement new models of innovative educational practices that address the socio-political context in which young people are inserted and that promote reflection and dialogue on this topic. (9)

Fear due to the stigma of the disease stood out as a barrier to access to health services by adolescents and young people with HIV, in the analyzed studies. This negative feeling towards the disease is part of the daily reality of those diagnosed with the HIV virus and, also, for those who have affective or sexual contact with the person who has the virus/disease. (27)

The impact of stigmatization on carriers translates into undesirable effects, as they foster negative assessments of themselves and a feeling of self-rejection. Research attests to feelings of guilt, shame, fear, anger, and refusal to accept the diagnosis, with the poten-

tial for the development of depression, anxiety and social exclusion, isolation and low self-esteem, compromising treatment adherence. In young people, it can cause school dropout, interfering with quality of life or viral load itself. (28)

In Brazil, the content of official campaigns aimed at adolescents has always occurred with little information related to HIV/AIDS, and without using appropriate language for this age group. The information was designed to disseminate epidemiological data, but not with the aim of educating and preventing the spread of the disease to groups in the categories of gender, social class, race/ethnicity, generations, indigenous peoples, young people, the elderly, according to their way of living. (29)

The difficulty encountered in reaching adolescents and young people in raising awareness about HIV must be overcome by the health professional and, for that, it is necessary to innovate, and to leave common sense in the way of carrying out health education. Integrative strategies have been developed to improve communication about HIV/AIDS, promoting reflections among young people and dialogue between

their families.(1)

## CONCLUSION

Of the perceived barriers, the unfavorable environment for the private care of adolescents with HIV/AIDS, the lack of preparation of professionals and the inadequate opening hours for the care of the public, are the causes of non-continuity of treatment. The school, although it has been highlighted as a place that promotes discrimination, has also proved to be an important scenario for the development of health education, focusing on the prevention of sexually transmitted diseases, including HIV/AIDS.

Stigma and discrimination negatively interfere in the lives of young people with HIV, harming them in the possibility of staying healthy, for fear of looking for services and for methods that reduce the risk of infection. This literature review contributed to the understanding of barriers to access to health services by adolescents with HIV/AIDS, construction of subsidies that assist in the care practice of professionals, and providing comprehensive, humanized care.

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