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RESEARCH

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Perceptions of nurses regarding the absence of adolescents living with HIV in primary health care

Percepções de enfermeiras sobre a ausência de adolescentes vivendo com HIV na atenção primária à saúde

Percepciones de enfermeras sobre la ausencia de adolescentes que viven con VIH em la atención primaria de salud

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ABSTRACT

Objective: to describe nurses' perceptions regarding the absence of adolescents living with the Human Immunodeficiency Virus in primary health care. **Method:** qualitative research carried out with five nurses working in Basic Health Units in a Municipality of Alagoas, Brazil. Interviews were carried out, subjected to category thematic content analysis and interpreted from the perspective of health promotion. **Results:** the emerging categories indicate that the absence of these adolescents is anchored in the lack of knowledge about the severity of the disease, the presence of a feeling of shame and fear of having their diagnosis revealed by professionals to the community and their parents, as well as neglect of their health, starting from the conception of its distance from death, as well as its proximity. **Final considerations and implications for practice:** there is a need for powerful actions, using different means of communication, to promote behavioral changes in adolescents diagnosed with Human Immunodeficiency Virus.

Keywords: Adolescent; HIV; Primary Care Nursing; Primary Health Care; Health Promotion.

RESUMO

Objetivo: descrever as percepções de enfermeiras sobre a ausência de adolescentes vivendo com o Vírus da Imunodeficiência Humana na atenção primária à saúde. **Método:** pesquisa qualitativa realizada com cinco enfermeiras atuantes em Unidades Básicas de Saúde, em um município de Alagoas, Brasil. Foram realizadas entrevistas, submetidas à Análise de Conteúdo Temática, na modalidade categorial, e interpretadas a partir da perspectiva da promoção da saúde. **Resultados:** as categorias emergentes indicaram que a ausência desses adolescentes está relacionada à falta de conhecimento sobre a gravidade da doença, na presença dos sentimentos de vergonha e medo de exposição do diagnóstico pelos profissionais à comunidade e seus pais, bem como a negligência com a própria saúde, partindo da concepção do seu distanciamento em relação à morte, bem como pela sua proximidade. **Considerações finais e implicações para a prática:** portanto, existe necessidade de ações potentes, utilizando diversos meios de comunicação, para a promoção da saúde, desenvolvidas pela Enfermagem da atenção primária, com vistas a mudanças comportamentais nos adolescentes com diagnóstico de Vírus da Imunodeficiência Humana.

Palavras-chave: Adolescente; Atenção Primária à Saúde; Enfermagem de Atenção Primária; HIV; Promoção da Saúde.

RESUMEN

Objetivo: describir las percepciones de enfermeras sobre la ausencia de adolescentes que viven con el Virus de la Inmunodeficiencia Humana en la atención primaria de salud. **Método:** investigación cualitativa realizada con cinco enfermeras que trabajan en Unidades Básicas de Salud, en un municipio de Alagoas, Brasil. Se realizaron entrevistas, que fueron sometidas a Análisis de Contenido Temático, en la modalidad categorial, e interpretadas desde la perspectiva de la promoción de la salud. **Resultados:** las categorías emergentes indicaron que la ausencia de estos adolescentes está relacionada con la falta de conocimiento sobre la gravedad de la enfermedad, la presencia de sentimientos de vergüenza y miedo a la exposición del diagnóstico por parte de los profesionales ante la comunidad y sus padres, así como con la negligencia hacia su propia salud, basada en la concepción de su distanciamiento respecto a la muerte, así como por su cercanía. **Consideraciones finales e implicaciones para la práctica**: por lo tanto, existe la necesidad de acciones contundentes, utilizando diversos medios de comunicación, para la promoción de la salud, desarrolladas por la Enfermería de la atención primaria, con miras a promover cambios conductuales en adolescentes diagnosticados con el Virus de la Inmunodeficiencia Humana.

Palabras-clave: Adolescente; VIH; Enfermería de Atención Primaria; Atención Primaria de Salud; Promoción de la Salud.

INTRODUCTION

Human Immunodeficiency Virus (HIV) infection in adolescents represents a serious public health problem that, despite efforts to control and prevent it, has increased significantly worldwide. According to United Nations statistics, in 2022, there were approximately 39 million people living with HIV worldwide, including 1.7 million children and adolescents between the ages of zero and 14.[1] Approximately 210,000 female adolescents and 140,000 male adolescents were infected sexually that year.[2] In Brazil, approximately 489,594 cases of HIV were reported between 2007 and June 2023, of which 114,593 (23.4%) occurred in young people between the ages of 15 and 24.[3]

The emotional, behavioral, and physical changes that occur at this stage of life, when not closely monitored by parents, guardians, and health professionals, can culminate in early and unprotected sexual practices. These behaviors can make adolescents more vulnerable to Sexually Transmitted Infections (STIs), such as HIV, highlighting the need for strategies and/or strengthened youth health screening to address these issues in various settings, aiming to minimize these adolescents' exposure not only to health issues but also to social vulnerabilities.[4]

In Brazil, the Adolescent Health Program (PROSAD), created in 1989, pioneered proposals to address problems such as teenage pregnancy, alcohol, other drugs, and STIs. It is the main instrument for implementing the National Policy for Comprehensive Adolescent Health Care in Primary Care (PC).[5] Primary Health Care (PHC) is the main entry point, articulator of the care process, and coordinator of care within the Unified Health System (SUS). However, the lack of monitoring of people living with HIV, especially adolescents, highlights the need for improved care flow and network functionality.

In many municipalities, especially those located far from large urban centers, as is the case with this research site, adolescents living with HIV are not monitored directly in PHC settings, but are conducted exclusively in specialized outpatient clinics located in regional reference cities.[6] Municipal health networks lack dedicated services for specialized medical consultations, nor for the dispensing of Antiretroviral Therapy (ART), which is also provided outside the municipality. Therefore, diagnosed adolescents are referred to other levels of care, highlighting a limitation of PHC in providing comprehensive care to this population.

In the PHC setting, nurses play an essential role in care management, promoting health through education, guidance, counseling, and technical procedures aimed at protecting these young people, which can significantly contribute to a better quality of life for these adolescents.[7,8] Despite advances, this group remains largely absent from PHC services, lacking access to Basic Health Units (UBS) or the Family Health Strategy (ESF), especially when compared to other groups. These young people do not utilize these health services, a situation exacerbated by HIV infection.[9] Understanding the reasons for this low adherence is essential. Thus, the question arises: What is nurses' perception of the absence of adolescents with HIV in PHC? This study aimed to describe nurses' perceptions of the absence of adolescents living with HIV in PHC.

METHOD

This is a descriptive, exploratory, qualitative study that met the Consolidated Criteria for Reporting Qualitative Research (COREQ) criteria. It was conducted in Health Centers/Basic Health Units in the municipality of Santana do Mundaú, Alagoas, Brazil, located in the Zona da Mata region, with a Human Development Index (HDI) of 0.519 (considered low). Eight nurses participated, corresponding to the total number of health services in the municipality's primary care network, constituting a convenience sample. All invited professionals consented to participate.

The participating nurses met the following inclusion criteria: at least two years of experience in primary care, active employment with the Municipal Health Department, current or previous experience in providing care to adolescents, and availability to participate in interviews. Initial contact occurred via telephone, during which prior information was provided and interviews were scheduled. During the in-person meetings, the Informed Consent Form (ICF) was read and subsequently signed, followed by the beginning of the interviews.

Data were collected between September and October 2023 through semi-structured interviews, guided by a script that addressed the participants' characteristics and background (including age, gender, marital status, time since graduation, and specialization qualifications), as well as a guiding question: What is your perception of the lack of adolescents diagnosed with HIV in primary care?

The interviews were conducted by the lead researcher, a nurse with a PhD in Nursing and extensive experience in qualitative research, accompanied by two nursing students who assisted with organizational activities. The interviews were recorded, lasting approximately 50 minutes on average, and conducted individually in a private space, according to the interviewees' preferences. The recordings were transcribed verbatim, checked and validated by the interviewees, and then submitted for analysis.

Data systematization followed the precepts of Bardin's Thematic Content Analysis methodological framework, which guided the organization of the message content, allowing categories to emerge.[10] During pre-analysis, the textual corpus of the interviews was organized through skimming, aiming to familiarize oneself with the content produced. Subsequently, in the material exploration stage, the recording units that were relevant to understanding the phenomenon under study were selected and coded.

It is worth noting that the categories were grouped using the qualitative analysis software NVivo®12, which enabled further exploration of the data.[11] Finally, the results were processed, inferences were made, and interpretations were made, based on the perspective of health promotion, understood as a process of empowerment for improving health and increasing control

over it. This perspective derives from the concept that individual needs are only met to the extent that individuals understand their demands. Health promotion is a promising strategy for addressing problems affecting the population, based on the redefinition achieved through health education, the dissemination of information, and the strengthening of vital skills.[12] Scientific literature, both national and international, was consulted, which allowed for a more in-depth discussion of the findings.

The research was approved by the Research Ethics Committee (CEP) of the Maurício de Nassau University Center, in Maceió (AL), under Opinion No. 6,271,671, in accordance with the determinations established by Resolution No. 510/2016, of the National Health Council (CNS).[13] To guarantee the anonymity of the nurses, alphanumeric coding was used (E1, E2, E3, E4, E5, E6, E7 and E8) in which the letter E corresponds to "Nurse", and the numbers correspond to the order of the interviews.

RESULTS

The professionals interviewed were female, cisgender, and heterosexual, between the ages of 30 and 48. Four of them were married, had graduated between three and 34 years, and all had specialized in Family Health or related fields for between two and 30 years. The professionals' perceptions were presented according to the following categories:

Adolescents' lack of knowledge about the severity of the disease

Despite the dissemination of information about HIV on television, online, and in schools, the nurses reported that, in their perception, adolescents are unaware of the severity of the disease. Therefore, those who test positive may not be seeking care at primary care units (UBS) and, consequently, not adhering to treatment.

> *Adolescents with HIV don't seek care at Basic Health Units because they don't know about the disease or understand its severity.* [...] *I treated a teenager who had lesions on his genitals. After testing, he was diagnosed with HIV.* [...] *When I talked to him about the results, I realized he was unaware of his condition.* (E2)

> *Although this topic is discussed online, in schools, and on TV, I get the impression that adolescents know nothing about the disease.* [...] *Even after being diagnosed, they don't understand its severity and, therefore, don't seek care at Basic Health Units* [...]. *Today, there are treatments that allow patients to lead normal lives. Even so, without follow-up and guidance, the risk of abandonment is high.* (E5)

Adolescents' shame and fear of having their diagnosis revealed

The nurses' statements reveal that adolescents diagnosed with HIV do not seek care at primary care services near their homes, preferring to receive care in other municipalities. This is due to feelings of shame and fear of having their health condition exposed to family, friends, and the community where they live, even though the nurses advise them on the ethical and legal aspects of patient disclosure.

> *In our area, we have adolescents who are HIV-positive, but they prefer to seek treatment in other municipalities* [...] *they do this to avoid exposing themselves or to protect their families from embarrassing situations* [...]. *They think that if they receive their treatment here at the unit, everyone will know* [...] *even if I explain the existence of professional ethics and affirm that I will not disclose or expose it, they prefer to hide it or seek other municipalities*. (E1)

> *When adolescents are HIV-positive, they do not seek care at the basic unit because they feel ashamed and afraid of exposing themselves.* [...] *they are afraid to come and talk to the doctor and nurse and have their diagnosis revealed in the community, even to their parents.* [...] *they prefer to seek care in distant municipalities.* (E3)

> *Adolescents are afraid to come to the basic unit because they think someone will comment on or spread their condition to the community* [...]. *Confidentiality, as well as professional ethics, prohibit this type of behavior.* (E4)

Neglect of adolescents with their treatment

Even though professionals conduct educational activities about the disease, the belief that there is no risk of death or that it is imminent causes adolescents with HIV to neglect their treatment. As a result, according to nurses, they do not attend primary care for appointments and do not use the medications prescribed for their treatment.

> *They neglect their own care* [...] *they think they're not at risk of death or they've already internalized the idea that they're going to die and end up giving in to the disease. No matter how much we (health professionals) explain and provide appropriate guidance, some adolescents with HIV don't take treatment seriously, don't seek care at the primary care unit, and end up harming themselves.* (E7)

> *Sometimes, even though we explain the severity of the disease, as well as the importance of treatment and ongoing monitoring, they don't take it seriously. I once treated an adolescent who was diagnosed with HIV* [...]. *I explained the disease to him and referred him to start treatment. However, he didn't come to his first appointments and didn't use antiretrovirals.* [...] *Later, during a home visit, I met with him and spoke with him again, explaining the severity of the disease.* [...] *After that, he started coming for his treatment and attending his appointments.* (E8)

DISCUSSION

Nurses cited a lack of knowledge about the disease among adolescents diagnosed with HIV as one of the reasons they do not seek care or receive proper treatment. This lack of knowledge among young people is seen as a serious social and health problem, given that they are experiencing the beginnings of their sexual lives and are exposed to risky behaviors and the spread of the disease. Even though these adolescents have already tested positive for the disease, misunderstandings persist, as a study conducted in Côte d'Ivoire with 210 adolescents infected with HIV revealed. This study revealed that they had insufficient knowledge about the infection, its transmission, and the treatment process.[14]

Despite the widespread dissemination of information about the disease in schools, on television, and on the internet, adolescents' access to it remains difficult, especially in rural areas and/or those with low HDI, which is consistent with the context of this study. A study confirms that living with HIV in poverty or in areas far from large urban centers can negatively impact access to information about the disease, the search for health services, and adherence to treatment.[15]

Health education in the school environment is an important strategy for disseminating information among adolescents in rural areas and/or regions with low HDI, and is mostly carried out by nurses and other health professionals. Through dialogical pedagogical practices, sensitive to the specificities of the age group and the sociocultural context of the students, nurses contribute to the development of critical knowledge about self-care and condom use, strengthening the autonomy of individuals and expanding access to quality information, thus ensuring comprehensive care.[16]

Despite the scenario already presented, in Brazil, access to the internet and cell phones has grown significantly, as confirmed by the Continuous National Household Sample Survey (PNAD) in the Information and Communication Technology (ICT) module, conducted in 2023 by the Instituto Brasileiro de Geografia e Estatística (IBGE). This survey indicated that internet access in rural areas increased from 78.1% to 81.0%, with cell phones being the main access device, representing 96.7%.[17]

In this scenario, social media is part of adolescents' daily lives because it promotes quick access to global information. A study indicated that, although social media offers a diverse range of topics, adolescents are increasingly consuming content focused on personal growth, entertainment, games, entrepreneurship, academic support, and general education.[18] In this sense, health services linked to PHC can create and feed social media with relevant information, aiming to educate and disseminate information aimed at promoting health at both the individual and collective levels.

In China, in 2014, "Lihui Space" was created, a platform for disseminating knowledge about HIV. By September 2021, it had reached 100,008 users, 724,000 views, and 2,295 posts, all from reliable sources, reaching primarily adolescents and young adults.[19] From this perspective, it is urgent to expand assertive strategies, especially on social media, to disseminate information that strengthens knowledge, promotes reflection, and encourages behavior change among adolescents.

The increased knowledge of these young people regarding this disease, despite being only one dimension that influences adherence, not only in treatment but also in prevention strategies, significantly impacts their perception of the disease, giving them autonomy and control over their health, positively favoring treatment adherence, as well as their access to health services, especially those comprising primary care. A study conducted in Malang, Indonesia, with 763 adolescents, showed an increase in their knowledge after completing an online activity based on lectures (webinar) and a live event, which took place over seven weeks. This provided them with reflection and a change in their perception and attitudes regarding the disease, reducing transmission rates.[20]

Another element highlighted in the oral history of nurses working in primary care is shame. This feeling is identified in the literature as a barrier to combating the spread of HIV among adolescents and adults, preventing these individuals from being diagnosed or treated in health services, highlighting their concern with the social stigma surrounding this disease.[21]

In addition to causing adolescents diagnosed with HIV to withdraw from primary care settings, this feeling negatively impacts their mental health and may even be associated with depressive symptoms. A study conducted in Uganda with 98 adolescents diagnosed with HIV examined the relationship between shame and mental illness, indicating an association between this feeling and depressive symptoms, hopelessness, loneliness, and low self-concept.[22] This context confirms the complexity of this phenomenon due to its intertwining with issues that affect not only the physical but also the mental health of these adolescents, reinforcing the need for a holistic approach to this issue.

Mental health problems associated with shame can be exacerbated when this feeling combines with adolescents' fear of having their diagnosis revealed by healthcare professionals to their parents. Concern about professional confidentiality emerges in the scientific literature as a predictor of seeking healthcare services, as well as adherence to ART treatment, due to the fear present in these young people's minds of experiencing discrimination, stigma, and social exclusion.[23] It is important to reiterate that HIV is one of the most stigmatizing infections, characterized by the generation of moral condemnation and public blame, the latter being associated primarily with immorality and promiscuity.

Despite the conceptualization of stigma, it presents itself as a disqualifying, segregating, and devaluing attribute, leading individuals to develop inhibiting behaviors, a negative self-image, and isolation, reinforcing the stigma they suffer. These constructs strengthen social relations based on power and control, creating barriers that compromise stigmatized individuals' access to basic conditions for survival, ratifying social inequalities.[24] In this context, it is also important to emphasize

how HIV is intertwined with other social markers, highlighting, among other problems, stigma as a major barrier to seeking medical care in health services, leading to non-adherence to ART and neglect in other aspects of health.

Regarding professional confidentiality regarding a positive HIV diagnosis, its breach is guided by legislation and literature, and it is the duty of professionals to notify the parents or guardians of adolescents. The Code of Professional Nursing Ethics (CEPE), in its article 82, §4, emphasizes the maintenance of professional secrecy as long as the minor has the capacity to make informed decisions, except in situations that may cause harm or risk.[25] Furthermore, the Manual of the Brazilian Society of Pediatrics (SBP), which guides adolescent consultations, reinforces that, in the event of a positive HIV serostatus, parents or guardians, as well as intimate partners, must be notified.[26] It is worth noting that communicating this diagnosis requires professionals to provide clarification to both adolescents and parents about the nuances of the disease, treatment, and the importance of family support for better adherence and quality of life.

Negligence in treatment implementation and maintenance by adolescents diagnosed with HIV was another factor highlighted by nurses. One of the factors associated with this public's lack of care concerns their perception of their health, believing that, because they are young, even if they have a positive diagnosis for the disease, they do not present a significant risk of death, which makes it difficult for them to monitor their health and adhere to ART.[27]

Globally, non-adherence to ART is the leading cause of treatment failure, affecting 64% of HIV-infected adolescents, resulting in direct physical health implications.[28] Low or no adherence to ART leads to the failure of basic treatment regimens, necessitating the establishment of rescue therapeutic strategies that require a larger number of pills. Furthermore, non-adherence to medication favors the spread of drug-resistant viruses, damages the immune system, and leads to progression to Acquired Immunodeficiency Syndrome (AIDS), increasing the risk of opportunistic infections.[29] Given the above, a lack of a clear understanding of the risks of this disease can encourage these young people to continue risky behaviors and spread the virus.

Beyond the perception of a reduced risk of death with a positive HIV diagnosis, in many cases, adolescents disregard seeking care and treatment because they associate their illness with the imminent threat of death. For many years, due to its high incidence, prevalence, and severity, HIV was associated with deaths; however, with technological and treatment advances, the life expectancy of patients who follow treatment correctly, especially adolescents, has increased significantly. A North American study showed that those who correctly use ART, seek health monitoring, and change their lifestyle habits, compared to young people without HIV, who have a life expectancy of 76.3 years for men and 81.7 years for women, had projected life losses, in years, averaging six and 10.4 years for men and women, respectively.[30]

Despite this, in society, a diagnosis of this disease is seen as a death sentence, leading adolescents to distrust their care and treatment. Confirming this perception, another study conducted in Ghana with 12 adolescents revealed that, after discovering their positive HIV diagnosis, some of them reported feelings of hopelessness about achieving their dreams and a desire to give up on life, characterized by suicidal ideation.[31]

This scenario reinforces not only the importance of PHC as a gateway to health services, but also its role in controlling and preventing the spread of this disease among adolescents, especially in regions far from large urban centers, where these constitute the main health facilities available to the population. It is important to highlight that, since 2014, following the Brazilian Ministry of Health's proposal to reorganize the decentralized care model for people living with HIV, it has been recommended that PHC include rapid testing, comprehensive care for asymptomatic individuals starting ART, and routine examinations. For more complex cases, such as symptomatic individuals, pregnant women, children, and co-infected individuals, referrals to specialized care services are made, demonstrating better operationalization of cases based on individual risk stratification.[32]

Consequently, it is essential to implement strategies that can foster the connection between adolescents living with HIV in PHC, with a view to promoting comprehensive care and assistance. To this end, welcoming and active outreach are important strategies for strengthening adolescents' trust in nurses and other health professionals, who play a role in ensuring this population's right to access health services by reducing social and institutional barriers. In a review study focused on seeking experiences of care for adolescents in PHC, it was shown that adequate reception stood out as an instrument for generating bonds, which, associated with qualified listening, allows nurses to understand the particularities and demands of adolescents, thus improving the care provided.[33]

Regarding reception, international literature highlights some attitudes that compromise this process with adolescents, such as authoritarian attitudes, threatening tones, and disciplinary practices that do not encourage dialogue, thus hindering adolescents' adherence to primary care activities.[34] In this sense, adequate reception provided to adolescents diagnosed with HIV, as well as comprehensive health education, are powerful tools for building bonds and trust. Therefore, the behaviors adopted by nurses working in this setting are valued, encouraging care-seeking and treatment adherence.

Regarding the active identification of adolescents diagnosed with HIV, it is essential to highlight the role of Community Health Agents (CHWs) within primary care. The work of these professionals is recognized as extremely important, as it enhances users' access to services, in addition to facilitating the dissemination of information aimed at health promotion and disease prevention.[35] When working in an assigned area, in a territory where they reside, these professionals face a paradoxical role within the team, especially when they encounter adolescents living with HIV, as they are close people and whom

they have accompanied, for the most part, since childhood, and their professional practice is permeated by aspects related to territoriality and privacy.[35] Given this context, the CHA needs to understand their role in caring for these adolescents, so that they can act assertively, encouraging the adherence of this public and fostering reflection on the disease in their territory through health education.

This study presents relevant contributions by addressing nurses' perceptions, highlighting significant and contextual elements that remain underexplored in the scientific literature. Furthermore, the originality of the research is highlighted by its articulation of the psychosocial aspects and the practices of these professionals in PHC. Thus, the study advances both theoretically, as it allows for a broader understanding of the barriers that permeate the access and retention of adolescents living with HIV in PHC, and in practice, offering support for the development of assertive, welcoming, and affective strategies.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Nurses' perceptions regarding the exclusion of adolescents diagnosed with HIV from primary care were systematized into three categories. The first revealed this population's lack of knowledge about the severity of the disease, even in the face of widespread dissemination of information. The second highlighted the presence of shame in attending these care settings, as well as the fear of breaching professional confidentiality before the community and their families. Finally, the third identified two distinct perceptions among this population: one anchored in the notion that their health condition could not worsen and the other, the imminence of death as a result of their diagnosis.

The results of this research indicate the need for a change in the perception of this disease among adolescents diagnosed with HIV, favoring increased seeking of primary care and better treatment adherence. To this end, it is urgent to expand information dissemination strategies for this population, not only through the most popular social media and apps due to limited access, but also in schools, community centers, churches, and other spaces where these young people can be found, in order to reach adolescents in rural areas and poorer regions. Furthermore, the importance of welcoming not only this population but also their family members or guardians is reinforced, with a focus on creating and maintaining bonds, clarifying doubts, and promoting active listening.

The limitations of this study include the small sample of nurses from primary care units in a specific municipality, which restricts the analysis to the perceptions of a small number of professionals. Furthermore, the research was conducted in a single setting, not considering other realities, such as those in rural areas or different urban areas, which could have provided a more comprehensive and in-depth view of the factors that influence the absence of adolescents with HIV in primary care.

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DATA AVAILABILITY RESEARCH

The contents underlying the research text are included in the article.

CONFLICT OF INTEREST

No conflict of interest.

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