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Ethical reflections on the health care of HIV patients

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Abstract

This study analyzed ethical aspects in the therapeutic follow-up of patients with HIV via a systematic literature review conducted by searching the PubMed, LILACS and MEDLINE databases, using descriptors in English and Portuguese language, with 169 publications from 2011 to 2021. To avoid bias, the Prisma guidelines were used and the recommendations established by the Grading of Recommendations Assessment, Development and Evaluation system were considered to classify the level of evidence. The well-being of HIV patients is associated with the level of interpersonal relationships, quality of treatment and personal beliefs. Stigmatization and fear of the dissemination of the disease in the groups in which they live are the main reasons for distress. Support to patients during the diagnosis and treatment of the disease are fundamental, so that they can better apply their coping strategies.

Keywords: Acquired immunodeficiency syndrome. HIV. Ethics.

Resumo

Reflexões éticas na atenção à saúde de pacientes com HIV

Neste trabalho, pretendeu-se analisar aspectos éticos no seguimento terapêutico de pacientes com HIV mediante revisão sistemática de literatura, realizada por meio de pesquisas nas bases PubMed, LILACS e MEDLINE, usando descritores em inglês e português, com 169 publicações de 2011 a 2021. Para evitar viés, foi utilizado o método Prisma e consideradas as recomendações estabelecidas pelo sistema Grading of Recommendations Assessment, Development and Evaluation para classificação do nível de evidência. O bem-estar de pacientes com HIV está associado ao nível de relações interpessoais, qualidade do tratamento e crenças pessoais. A estigmatização e o medo da divulgação da doença nos grupos em que convivem são os principais motivos de aflição. Com isso, é fundamental um maior apoio aos pacientes durante o diagnóstico e tratamento da doença, para que possam elaborar melhor suas estratégias de enfrentamento.

Palavras-chave: Síndrome de imunodeficiência adquirida. HIV. Ética.

Resumen

Reflexiones éticas en la asistencia sanitaria a pacientes con VIH

Este trabajo propone analizar los aspectos éticos en el seguimiento terapéutico de pacientes con VIH a través de una revisión sistemática de la literatura en las bases de datos PubMed, LILACS y MEDLINE, utilizando descriptores en inglés y portugués, lo que resultó en 169 publicaciones entre 2011 y 2021. Para evitar sesgos se utilizó el método Prisma y, para clasificar el nivel de evidencia, se consideraron las recomendaciones establecidas por el sistema Grading of Recommendations Assessment, Development and Evaluation. El bienestar de los pacientes con VIH estuvo asociado al nivel de relaciones interpersonales, calidad del tratamiento y creencias personales. El estigma y el miedo a propagar la enfermedad en los grupos con los cuales conviven fueron los principales motivos de preocupación. Por lo tanto, es fundamental brindar un mayor apoyo a los pacientes durante el diagnóstico y tratamiento de la enfermedad para que puedan desarrollar mejor sus estrategias de afrontamiento.

Palabras clave: Síndrome de inmunodeficiencia adquirida. VIH. Ética.

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The human immunodeficiency virus (HIV) causes a sexually transmitted infection (STI) that can also be contracted via infected blood and vertically, that is, the mother can transmit the virus to the child during pregnancy. The first case of HIV infection recorded in Brazil occurred in 1980, in São Paulo/SP; the disease became a reason for social exclusion of patients. As the Unified Health System (SUS) was yet to be established, patients ended up helpless, without proper care, and afraid of disclosing their condition to the people they lived with [1,2].

According to DataSUS, from 1980 to 2020, 764,381 cases were registered across the country, most in the state of São Paulo (243,229), and the least in Acre (1,068). The largest number of infected individuals is aged between 20 and 34 years (440,105), with a lower incidence in the group over 80 years (1,067). These data show that, although there is a prevalence of cases in young people, which may be related to these individuals' social and sexual habits, all people are subject to HIV infection, regardless of gender and age, requiring only contact with one of the ways of transmitting the virus [3].

An HIV-infected patient will not necessarily have a compromised immune system, and may not manifest symptoms and/or develop acquired immunodeficiency syndrome (AIDS). HIV infection symptoms usually appear around a month or two after contact with the virus, manifesting as fever, headache, dysphagia, diarrhea, cough, night sweats, and joint pain. Diagnosis is based on blood or oral fluid collection, with detection of antibodies with laboratory or rapid tests [1].

SUS presents advances and innovations, with new national guidelines and local experience, characterizing primary health care (PHC) as responsible for maintaining and expanding the treatment, diagnosis and monitoring of individuals with HIV. A good physician-patient relationship is extremely important for a secure bond during therapy and care, however, some individuals fear the breach of medical confidentiality, which would result in their exposure and consequent stigmatization by society [4,5].

The Code of Medical Ethics (CEM) determines that the professional must welcome and aid with due care, regardless of the clinical condition of the person being assisted, and the health professional is prohibited from disclosing information about the patient even if it is public knowledge. Thus, it is essential that these professionals demonstrate the ethical principles that are instructed to follow, in order to provide their patients with the safety and comfort necessary to guarantee the continuity of treatment [6].

This study aims to reflectively analyze the exercise of ethics in the health care of patients with HIV.

Method

This research consists of a systematic review of the literature on ethical reflections in healthcare for HIV patients. The search took place in February 2021 in the PubMed, MEDLINE and LILACS databases, in addition to the others listed in the Virtual Health Library (VHL). The descriptors "HIV," "acquired immunodeficiency syndrome" and "medical ethics" were searched in the title, abstract or subject sections, and articles published between 2011 and 2021 were selected. Portuguese and English language were used to expand the search potential.

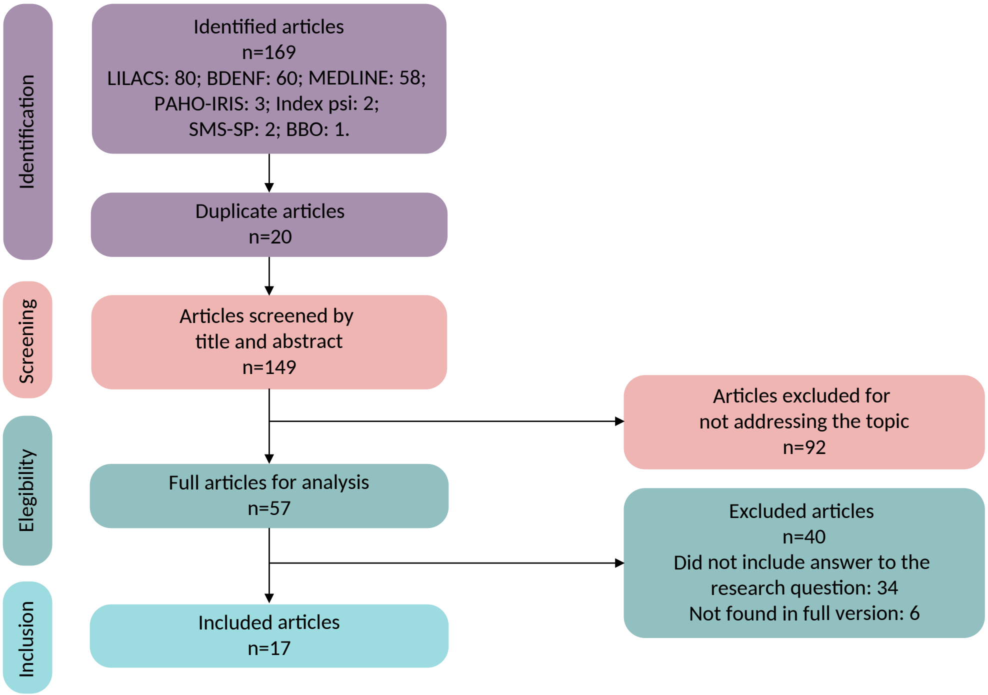
The articles excluded were those unrelated to the search characteristics, that were unrelated to bioethics, that were published before 2011, and that were not found in full.

Scientific evidence was classified only considering the recommendations established by the Grading of Recommendations Assessment, Development and Evaluation (Grade) system [7]. In total, 169 articles were selected, taken from the MEDLINE, LILACS, PAHO-IRIS and Index Psi databases, and means regarding confidentiality, patients' quality of life and self-care were addressed. The impact of spirituality and religion on the disease treatment process was also analyzed.

To avoid the risk of bias, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Prisma) [8] flowchart and checklist was chosen to guide the review. This instruction was developed in Canada, in 2005, from the review of a 1996 recommendation guide known as the Quality of Reporting of Meta-analyses (Quorum).

Using the previously established inclusion criteria, 169 articles were identified, of which 20 were duplicates. Thus, 149 articles were screened by title and abstract, excluding 92 for not addressing the topic, resulting in 57 studies for complete analysis. From eligibility, 34 articles that did not include the answer to the research question were excluded, and another six because they were not found in their full version, totaling 17 articles included (Figure 1).

Figure 1. Flowchart of the phases of identification, screening, eligibility and inclusion of articles on ethical reflections in the health care of HIV patients



Results

By evaluating the 17 publications included according to the Grade system, eight articles were classified with a high level of confidence and two with a low level of confidence. Chart 1 summarizes this classification, along with the characteristics of the studies reported.

Chart 1. Description of articles included in the review

Identification	Study method	Level of Evidence Grade	Main results
Marques and collaborators; 2020[9]	Quantitative cross-sectional study	High	The importance of accepting HIV patients for treatment is highlighted.
Dawson L; 2019[10]	Analytical study	Moderate	This study demonstrates that individuals who received more assistance had better results in HIV treatment.
Salvadori, Hahn; 2019[5]	Integrative review	High	Data analysis confirmed that fear of stigma, prejudice and discrimination ultimately determine the health-disease process.
Staff, Monteiro; 2018[11]	Qualitative study	High	The study demonstrates the difficulties of HIV-positive women and how important adequate care is.

continues...

Chart 1. Continuation

Identification	Study method	Level of Evidence Grade	Main results
Melo, Maksud, Agostini; 2018 [4]	Literature review	Low	Studies show that health policies are important in the treatment of seropositive patients, as well as the relevance of ethically-based medical care.
Leal, Lou; 2018 [12]	Qualitative research	Low	AIDS mortality occurs due to the various vulnerabilities to which patients are exposed, and the importance of qualifying the health care of seropositive individuals was pointed out.
Silva and collaborators; 2016 [13]	Descriptive, exploratory study	High	The influence of sex education programs at school and of qualification in medical care for HIV-positive patients is evaluated.
Coakley and collaborators; 2019 [14]	Qualitative research	High	The survey assessed the prominent role of parents and health professionals in raising awareness of young people's sexual health and preventing sexually transmitted diseases.
Schairer and collaborators; 2019 [15]	Literature review	Moderate	The molecular epidemiology of HIV for public health research poses significant ethical issues that continue to evolve as technologies and patient care improve.
Venables and collaborators; 2019 [16]	Qualitative research	High	Studies have shown that prejudice against HIV-positive patients and the lack of structure and medical ethics make it difficult to seek treatment.
Saura and collaborators; 2019 [17]	Qualitative study	High	The study demonstrates the need for primary care professionals to provide support and qualified care for seropositive patients, as those who were more oriented and supported had better treatment results.
Silva and collaborators; 2018 [18]	Descriptive, qualitative research	High	Unveil the perception of nurses working in family planning regarding vulnerability to sexually transmitted infections (STIs) and greater assistance to seropositive patients.
Ribeiro and collaborators; 2013 [2]	Descriptive search	High	The research characterized adolescents with HIV/AIDS and their special health needs.
Odero and collaborators; 2019 [19]	Qualitative research	Moderate	The study analyzed public HIV care centers and indifference in patient care.
Pereira, Tavares; 2013 [20]	Descriptive research with a qualitative approach	High	The study aims to analyze the development of a multiprofessional residency preceptorship at the Specialized HIV/AIDS Outpatient Clinic.
Sehnem and collaborators; 2018 [21]	Qualitative research	Moderate	The difficulties faced by patients with HIV and the weakening of their social relationships were identified.
Souza and collaborators; 2019 [1]	Descriptive and prospective study of a qualitative nature	High	The study investigated the changes in the daily life and the confrontation of women after the diagnosis of HIV/AIDS.

The report by Marques and collaborators[9] described the profile and evaluated the quality of life of people living with HIV treated in public health services, making it possible to show that these patients' quality of life is directly linked to interpersonal relationships, quality of treatment and personal beliefs. Therefore, support from the general population, health professionals and the family is an important aspect of the fight against HIV.

In his analytical study, Dawson[10] showed through exclusion criteria that individuals who received more assistance from health professionals in the treatment achieved more positive results in the treatment. In addition, it should be considered that HIV-positive individuals are responsible for protective measures and, consequently, for transmission. Thus, Dawson[10] showed that an almost effective recovery from the disease after treatment exists and that the lower the viral load, the lower the chance of transmission, which reinforces the importance of qualified care and good instructions on this pathology.

The researchers Salvadori and Hahn[5], through a systematic review, aimed to identify how confidentiality has been addressed in the care of people with HIV/AIDS. Their study selected 19 national and international scientific journals, published between 2010 and 2015, in open access databases, and confirmed that the fear of stigma, prejudice and discrimination determines the health-disease process. The studies showed that the stigmatization of the disease permeates the lives of HIV-positive people, who constantly suffer from the possibility of the diagnosis being disseminated by the people with whom they live.

In addition, it was found that discrimination exists even among health professionals and that the breach of confidentiality usually leads the patient to abandon treatment. Therefore, preserving the privacy and confidentiality of people with HIV/AIDS is the duty of professionals and represents a challenge in the information age.

Cajado and Monteiro[11], in a study carried out through interviews addressing the difficulties of women with HIV, describe the entry of these patients into a social movement after the diagnosis and analyze their self-care practices. The research findings indicated the need to encourage reflection on the ethics of care from a feminist perspective, in the context of the social movement of HIV-positive women, given the predominance of social and gender inequalities evidenced in the research. Therefore, specialized and effective care for HIV-positive women is necessary, since in addition to the problem of the pathology, this population faces a gender-related vulnerability.

In the article by Melo, Maksud and Agostini[4], new guidelines and Brazilian experiences are mentioned that have given PHC a greater role in the topic of HIV/AIDS policies. The care component of such policies used to be developed with a focus on specialized services, showing that health policies are important for the treatment of people with HIV due to the demand for this type of care.

The guidelines and recommendations are thus contextualized to also encourage the follow-up of these patients within PHC, making a comparison between this and specialized care. In addition, the moral and ethical challenges faced are also highlighted, concluding expanding the possibilities of access and the quality of care in PHC for individuals with HIV/AIDS in Brazil is necessary.

To highlight the difficulties experienced by seropositive patients, Leal and Lui[12] carried out a study to understand the perception of members of the Municipal AIDS Mortality Committee in Porto Alegre/RS regarding the consequences of this participatory institution in improving care for people living with HIV/AIDS. The study was qualitative and used a case study method, demonstrating that AIDS mortality occurs by multicausal factors related to the patient's situations of vulnerability in all dimensions. Therefore, the need for medical care and good public administration for these individuals' survival was suggested, in order to also improve the quality of care services for this condition.

Silva and collaborators[13], through a descriptive-exploratory study on the knowledge of adolescent students at a public school in the city of Natal/RN about transmission, prevention and risk behaviors in relation to STI/HIV/AIDS, showed significant rates of ignorance in relation to these factors and elucidated some risk behaviors that make the young population vulnerable to the aforementioned diseases. It was concluded that sex education programs in schools are necessary to encourage adolescents to have safe and healthy sexual behavior.

Qualitative research by Coakley and collaborators[14] proved the importance of the role of parents and health professionals in providing guidance on the sexual life of young people in HIV prevention. The need to welcome and accept patients with HIV is essential for them to seek treatment and have better survival.

Based on the literature review by Schairer and collaborators[15], significant ethical issues continue to evolve with the improvement of technology and patient treatment, highlighting the relevance of medical ethics in developing treatment options for seropositive patients and in their reception by health professionals.

According to Venables and collaborators[16], prejudice against HIV-positive patients and the deficit in the practice of medical ethics by health professionals make it difficult to seek treatment. As a result, the number of HIV infections and deaths increases, in addition to promoting this population's social exclusion; they face numerous psychological problems due to the stigmatization imposed by society. The sample study carried out by Saura and collaborators[17] shows the need for primary care professionals to know the influence of psychosocial processes on seropositive patients.

Silva and collaborators[18] revealed the perception of nurses working in family planning regarding the population's vulnerability to STIs and HIV with a descriptive and qualitative research carried out in a university hospital. STIs are still considered "diseases of the other," and their spread is influenced by gender inequalities. Traditional family planning actions did not prove to be sufficient for the use of preventive measures, requiring greater support for patients with STIs to influence the search for and continuation of treatment.

Paula and collaborators[22] reported the experience of guaranteeing the ethical aspects involved in the stage of data collection from adolescents with HIV/AIDS. These patients' difficulties and reports of experiences about breach of confidentiality were raised, in addition to evaluating ethical principles in health care. Ina qualitative research, Odero and collaborators[19] analyzed public care centers for HIV patients, finding indifference in the care given to these individuals, and, consequently, issues in the treatment, confirming that the lack of medical ethics is a factor directly linked to patients' abandoning the search and permanence in the treatment.

The development of preceptorship of multiprofessional residency at a specialized HIV/AIDS outpatient clinic was addressed in a descriptive and qualitative study. It was found that the ethical and cultural issues that constitute the principles of the current National Health Policy in Brazil are in deficit regarding the care of patients with HIV[20]. The study by Sehnem and collaborators[21] analyzed the experiences of adolescents living with HIV/AIDS regarding sexuality and the implications for health education, seeking to know the health professionals' perspectives towards this population.

Souza and collaborators[1], in a descriptive and prospective study of qualitative nature, investigated women's changes in daily living and experience after being diagnosed with HIV/AIDS, in addition to the introduction of antiretroviral therapy. The study found that most women positively faced the changes in their daily lives after the discovery of the disease, seeking to live with quality, although they still have difficulties in resuming their lives. Therefore, greater support for these patients during the diagnosis and treatment of the disease is essential so that they can better develop their coping strategies.

Discussion

Professional conduct, supported by ethical precepts, stimulates the demand for health services and increases the therapeutic adherence of HIV-positive individuals. The physician-patient relationship can positively impact these patients' quality of life, since it contributes to a better clinical understanding and, consequently, to the proper institution of treatment, solving the users' problem and providing them with well-being[9].

In this context, based on the analysis of the studies presented here, more satisfactory results were verified in relation to treatment when health professionals provided greater assistance to patients and complied with professional secrecy, thus confirming the importance of a specialized reception and qualified care, which clearly results in winning the patient's trust, in greater adherence to treatment and, finally, in promoting the autonomy of HIV-positive individuals[10].

However, despite the importance of the interpersonal relationship mentioned in several studies, most authors report the difficulty that respondents feel in trusting professionals, especially with regard to maintaining confidentiality and applying ethical principles in general. Furthermore, it was also found that the disclosure of confidential information induces the patient to abandon treatment[22].

Still in this regard, negative results in relation to the search for and adherence to treatment are associated with the patients' fear of having their clinical data leaked and, consequently, suffering some type of stigma, prejudice or discrimination[5]. According to Salvadori and Hahn[5], prejudice and discrimination against people with HIV also come from health professionals, so that the fear of suffering such impacts makes many not seek health services. Marques and collaborators[9] found that, due to the social conflicts that HIV-positive individuals suffer, these individuals suffer considerable impacts on their self-esteem, triggering withdrawn and isolation behaviors.

The lack of ethical principles causes most seropositive patients to not seek or remain in treatment[19], thus highlighting the relevance of such principles both for effective therapeutic adherence and for the patients' quality of life[15]. Professionals must protect the confidentiality of the diagnosis to solidify the interpersonal bond, increasing the incentive to monitor HIV-positive individuals within PHC, defending ethical principles and improving their conduct to achieve better results[4].

Silva and collaborators[13], in a descriptive-exploratory study, showed that adolescents from a public school had low levels of knowledge about the transmission, prevention and treatment of AIDS. Therefore, guardians, teachers and health professionals are crucial in the provision of guidance and in raising this age group's awareness of the disease, aiming at a better control of infection rates[14].

Finally, despite all the difficulties faced by HIV-positive individuals, Souza and collaborators[1] note that most women responded positively to changes in their lives after being diagnosed. However, another study still points to the indispensable duty of promoting ethical reflections and strategies with a focus on female individuals[11].

Final considerations

The quality of life of HIV patients is related to interpersonal relationships, and the support of the general population, health professionals and the family in coping with the disease is relevant. Trust in the health professional contributes to the adherence to treatment, more belief in the disease process and self-esteem elevation. The fear of suffering prejudice is considered one of the main reasons for resistance to treatment. PHC plays a key role in expanding access and quality of care for HIV-infected patients, enabling closer monitoring of physical and mental comorbidities triggered by the disease.

Thus, focus should be not only on patient follow-up, but also on primary prevention via sex health education, especially aimed at young people, who are experiencing increasing infection rates.

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Research