RCMOS – Revista Científica Multidisciplinar O
Saber. ISSN: 2675-9128. São Paulo - SP.
Ano VII, v.1 2026 | submissão: 09/10/2026 | aceito: 16/10/2026 | publicação: 21/10/2026

Beyond diagnosis: humanized care and social determinants in HIV management — an experience report

Além do diagnóstico: cuidado humanizado e determinantes sociais no manejo do HIV — um relato de experiência

Más allá del diagnóstico: atención humanizada y determinantes sociales en el manejo del VIH — un relato de experiencia

Andréa Terra Calil Macedo – Universidade Federal de Pelotas, atcmacedo@yahoo.com.br
Gabriela Siqueira Dibe Avila – Universidade Federal de Pelotas, gabidibe12@gmail.com

Abstract:
This study analyzes medical practice in the care of people living with HIV, aiming to reflect on key challenges regarding treatment adherence, the physician-patient relationship, and the impact of social stigma on healthcare. It is a descriptive study—specifically an experience report—based on critical reflection regarding the longitudinal medical care of people living with HIV. The experiences analyzed demonstrate that, although antiretroviral therapy has transformed HIV into a controllable chronic condition, maintaining health and quality of life depends directly on empathetic listening, the establishment of trusting relationships, and multidisciplinary support, particularly when facing emotional and socioeconomic barriers. The study concludes that empathy, confidentiality, and the dispelling of prejudice are essential elements for quality care and treatment adherence, complementing the biomedical approach to the care of people living with HIV.

Keywords: HIV; Humanized Care; Physician-Patient Relationship; Social Stigma; Treatment Adherence.

Resumo:
Este estudo analisa a prática médica no acompanhamento de pessoas vivendo com HIV, ele busca refletir sobre os principais desafios relacionados à adesão ao tratamento, à relação médico-paciente e ao impacto do estigma social no cuidado em saúde. Trata-se de um estudo descritivo, do tipo relato de experiência, baseado na reflexão crítica sobre o acompanhamento médico longitudinal de pessoas vivendo com HIV. As vivências analisadas evidenciam que, embora a Terapia Antirretroviral tenha transformado o HIV em uma condição crônica controlável, a manutenção da saúde e da qualidade de vida está diretamente relacionada à escuta acolhedora, ao estabelecimento de vínculos de confiança e ao suporte multiprofissional, especialmente diante de barreiras emocionais e socioeconômicas. Conclui-se que a empatia, o sigilo e a desmistificação do preconceito constituem elementos essenciais para a qualidade do cuidado e para a adesão ao tratamento, complementando a abordagem biomédica no acompanhamento das pessoas vivendo com HIV.

Palavras-chave: HIV. Assistência Humanizada. Relação Médico-Paciente. Estigma Social. Adesão ao Tratamento

Resumen:
Este estudio analiza la práctica médica en el seguimiento de las personas que viven con el VIH y busca reflexionar sobre los principales desafíos relacionados con la adherencia al tratamiento, la relación médico-paciente y el impacto del estigma social en la atención de salud. Se trata de un estudio descriptivo, de tipo relato de experiencia, basado en la reflexión crítica sobre el seguimiento médico longitudinal de las personas que viven con el VIH. Las vivencias analizadas evidencian que, aunque la terapia antirretroviral ha transformado el VIH en una

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condición crónica controlable, el mantenimiento de la salud y de la calidad de vida está directamente relacionado con la escucha acogedora, el establecimiento de vínculos de confianza y el apoyo multiprofesional, especialmente ante barreras emocionales y socioeconómicas. Se concluye que la empatía, la confidencialidad y la desmitificación de los prejuicios constituyen elementos esenciales para la calidad de la atención y la adherencia al tratamiento, complementando el enfoque biomédico en el seguimiento de las personas que viven con el VIH.

Palabras clave: VIH. Atención humanizada. Relación médico-paciente. Estigma social. Adherencia al tratamiento.

1. Introduction

Advances in diagnosis, treatment and, especially, antiretroviral therapy have profoundly changed the clinical course of human immunodeficiency virus (HIV) infection. Expanded access to antiretroviral medicines has made HIV a manageable chronic condition, enabling people living with the virus to achieve longer life expectancy and better health. The World Health Organization (WHO) emphasizes that, although there is still no cure for HIV infection, access to diagnosis, treatment and appropriate care enables people living with HIV to lead long and healthy lives (WHO, 2025). In Brazil, antiretroviral medicines are provided free of charge through the Unified Health System (SUS), and treatment is essential to preserve immune function, reduce the occurrence of opportunistic diseases and improve quality of life and life expectancy (BRASIL, 2026).

Despite significant biomedical advances, the experience of living with HIV extends beyond the clinical and pharmacological dimensions of infection. HIV remains associated with historical processes of stigmatization, prejudice, misinformation and discrimination, which can affect access to and continued engagement with health services. UNAIDS recognizes HIV-related stigma and discrimination as major barriers to access to services, diagnosis, treatment and continuity of care. Furthermore, discriminatory experiences within health services themselves may lead people living with HIV to avoid or delay seeking care (UNAIDS, 2026).

In this context, stigma must be understood not only as a social issue external to health services, but also as a phenomenon that can have tangible consequences for the care process. Discriminatory practices may hinder care-seeking, interfere with communication between service users and professionals and contribute to disengagement from health services. WHO emphasizes that providing services free from stigma and discrimination is essential to ensure equitable, quality care for people living with HIV (WHO, 2024). Thus, building a physician-patient relationship based on respect, listening and confidentiality becomes an important component of quality follow-up care.

In addition to the challenges associated with stigma, adherence to antiretroviral treatment is another central aspect of HIV care. As HIV is a chronic condition, follow-up involves maintaining treatment and ongoing contact with health services over time. Individual, social and economic factors, as well as factors related to service organization, can influence continuity of care in this process. WHO recommendations reinforce the importance of adherence support strategies and integrated care that also addresses mental health and other chronic conditions that may accompany aging among people living with HIV (WHO, 2025).

Against this background, medical practice must move beyond an exclusively biomedical perspective and incorporate a comprehensive, person-centered approach that is sensitive to the different factors shaping the experience of living with HIV. Quality care depends not only on the availability of medicines, but also on building trusting relationships, respecting autonomy, ensuring confidentiality and reducing discriminatory practices in health services. In this respect, the relationship established between physician and patient plays an important role in developing welcoming care and identifying barriers that may interfere with treatment continuity.

This study therefore aims to reflect on medical practice in the follow-up of people living with HIV, emphasizing the professional-patient relationship, challenges related to long-term treatment adherence and the importance of humanized care strategies. It thus seeks to understand how professional practice can contribute not only to clinical control of infection, but also to the development of welcoming, ethical care based on trust and free from stigma and discrimination.

2 Methodology

This is a descriptive study, specifically an experience report, focused on critical reflection on professional practice and ongoing clinical follow-up of people living with HIV within healthcare services.

This report was developed by systematizing everyday experiences in medical care, using a structured guide for self-assessment and reflection on professional development, routine consultations, dilemmas of treatment adherence, the impact of social stigma and guidelines for humanizing care. As this is a reflective analysis of the authors' own professional practice, observations were organized in a continuous narrative to connect biomedical clinical management with the socioemotional dimensions encountered in everyday service delivery.

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3 Results and discussion

Everyday healthcare experience reveals that a welcoming initial reception and active listening are fundamental to building a strong, non-hierarchical therapeutic relationship. In the follow-up of people living with HIV, the needs presented during consultations extend well beyond the assessment of laboratory tests, such as CD4 lymphocyte counts and viral load. Frequently reported concerns include fear of the future, anxiety about the diagnosis, uncertainty about disclosing their status to family members or partners, and fear of discrimination in social and work settings. In this context, clear, accessible communication is an important clinical tool. Discussing up-to-date information on the concept of undetectable = untransmittable (U=U), according to which people living with HIV who maintain an undetectable viral load do not transmit the virus sexually, can help reduce diagnosis-related insecurities while promoting a better understanding of treatment and quality of life.

Observations of everyday practice also show that irregular treatment adherence is not necessarily related to a lack of information about medication. In several situations observed, treatment discontinuation was associated with emotional factors, such as psychological distress, difficulties accepting the diagnosis and fear of abandonment, as well as social and economic barriers. Stigma also persists in subtle or explicit forms, manifesting in some patients' fear of being identified when attending specialized services and, in certain situations, in inappropriate practices by healthcare professionals. These include the unnecessary use of personal protective equipment that would not be used with other patients, lack of privacy and judgments about personal life. Socioeconomic difficulties, such as a lack of resources to travel to health services, can also affect regular attendance at appointments and medication collection.

The lessons drawn from everyday practice therefore demonstrate the importance of coordination among different professionals and areas of care, including psychology, nursing and social work. This experience shows that humanized care requires systematically addressing prejudice within health services themselves, ensuring the privacy and confidentiality of information and reducing bureaucratic barriers that hinder access and continuity of follow-up. Treating HIV today means recognizing each patient's autonomy and individual characteristics, understanding that respect, nonjudgmental listening and empathy help strengthen the therapeutic relationship, treatment continuity and the quality of care provided.

Final considerations

Medical practice in caring for people living with HIV demonstrates that therapeutic success depends on an ongoing balance between scientific and technical rigor and human sensitivity. Although pharmacological advances ensure virological control and the preservation of physical health, sustained adherence and patients' well-being are profoundly influenced by the quality of the reception and support they receive in health services.

Building a relationship based on trust, respect for privacy and listening free from moral judgment proves as decisive for treatment continuity as prescribing antiretrovirals. It is concluded that humanizing medical practice in this context requires looking beyond serological status, seeing the individual as a whole and ensuring the right to dignified, empathetic care that promotes autonomy and quality of life.

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