

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

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**Highlights:** (1) Professionals' and managers' conceptions about HIV influence healthcare. (2) Institutional routines are disconnected from the needs of women with HIV. (3) Health professionals consider preventive actions as ineffective in health services.

PRE-PROOF

(as accepted)

This is a preliminary, unedited version of a manuscript that was accepted for publication in Revista Contexto & Saúde. As a service to our readers, we are making this initial version of the manuscript available, as accepted. The article will still be reviewed, formatted and approved by the authors before being published in its final form.

<http://dx.doi.org/10.21527/2176-7114.2026.51.15670>

How to cite:

Kleinubing RE, Schek G, Padoin SMM, Paula CC, Langendorf TF. Healthcare for women with HIV: an analysis from institutional ethnography. Rev. Contexto & Saúde. 2026;26(51):e15670

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## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

### ABSTRACT

**Objective:** To analyze the institutional context of the Primary and Specialized Healthcare Network in the healthcare of women with Human Immunodeficiency Virus (HIV). **Method:** This qualitative participatory research was conducted with 11 healthcare professionals and managers from municipal and federal healthcare services in a municipality in southern Brazil. Data were collected through focus groups and participant observation. The data were triangulated for analysis, and the discussion was mediated by interpretation in light of Institutional Ethnography. **Results:** The results were based on the discursive constructions of professionals and managers, and their observation notes. Three categories were then created: (1) trivialization of HIV infection and devaluation of women's health needs, (2) institutional routines versus the needs of these women, and (3) disarticulation of the Primary and Specialized Healthcare Network. **Conclusion:** Healthcare is shaped, organized, and institutionalized under the influence of healthcare professionals' understanding of HIV, and it appears to meet the demands of local services in a disjointed way, different from what these women need.

**Keywords:** HIV. Institutional organization. Healthcare networks.

### INTRODUCTION

At the end of the 20<sup>th</sup> century, the model of care for people with the Human Immunodeficiency Virus (HIV) reflected the epidemiological pattern that marked the beginning of the epidemic, with acute characteristics, high mortality, and restricted to groups considered to be at risk. Due to the high number of hospitalizations and deaths resulting from Acquired Immunodeficiency Syndrome (AIDS), clinical follow-up has become complex. Then, it has also become the exclusive domain of specialized services <sup>1</sup>, but a care network for this population does not exist.

Thus, after more than three decades, the HIV epidemic remains a significant global health problem <sup>2</sup>. Over the years, the Unified Health System (*Sistema Único de Saúde - SUS*) in Brazil has sought to incorporate new actions in response to the epidemic, anchored in evidence-based practice <sup>3</sup>.

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

Among the scientific and technological advances, highly active antiretroviral therapy (HAART) has modified morbidity and mortality indicators. Between 2012 and 2022, there was a 26.5% decrease in mortality <sup>4</sup>, making HIV infection a chronic condition <sup>5</sup>. This made it possible to direct health care to Primary Health Care (PHC) services, thereby decentralizing specialized services' activities. These decentralization experiences are at different stages of implementation in Brazilian municipalities. Its function is to expand its link with health services and optimize actions related to health education and adherence to ARVT, becoming a promising path to confront HIV infection <sup>6</sup>.

The decentralization of care for people with HIV is a recent policy. It required reorganizing services, using the PHC unit as a basis for action. This has made the implementation of care in the Health Care Network (HCN) and PHC a complex task (in the current Brazilian health care model) regarding the structural characteristics of these services <sup>7</sup>.

Considering the model of care for chronic conditions, establishing a link between health professionals and service users promotes the comprehensiveness and continuity of care as attributes of PHC. These attributes are determining aspects in the adherence, retention, and linkage of people with HIV to the services of RAS <sup>5</sup>.

Regarding the pregnancy-postpartum period of women with HIV, prevention actions in these services are still insufficient (e.g., low adherence to HIV testing), even considering PHC as the entry point in SUS (*Sistema Único de Saúde*) <sup>8</sup>. To include care services for this population, it is necessary to overcome difficulties such as low prenatal coverage, sometimes conflicting interactions between health professionals and female users <sup>9</sup>, and assurance/flexibility in access to services in this network <sup>1</sup>.

From this perspective, understanding how healthcare for women with HIV is organized and institutionalized within health services is important. For this purpose, Institutional Ethnography contributed to this study. This is a theoretical framework that allows for the analysis of the institutional context within a broader perspective, giving visibility to both the professional practices developed in these spaces and the relationships processed at their base. Institutional ethnography allows researchers to explore the institutional context, based on the experiences, problems, and concerns of people. From this, the ethnographic exploration of

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

institutional processes is carried out via systematic analysis of the different social, institutional, and dominant forces that shape, delimit, and organize the forms of work<sup>10</sup>.

Thus, the research question was as follows: What is the institutional context of the Primary and Specialized Healthcare Network in providing healthcare to women with HIV in a municipality in southern Brazil? Therefore, the objective of this research was to analyze the institutional context of the Primary and Specialized Health Care Network in the health care of women with HIV in a municipality in southern Brazil.

### **METHOD**

This participant-type qualitative research was<sup>11</sup> approved by the Ethics Committee (EC) of the Universidade Federal de Santa Maria (Opinion: 1.635.237) with the participants' consent documented in the Free and Informed Consent form. The field phase of the research was conducted between June and August 2017. For this study, the research database was used, and the rereading/reinterpretation of this data was based on the theoretical framework of Institutional Ethnography. This procedure was approved by the EC above (Opinion: 6.615.517; CAAE: 57042216.0.0000.5346) in 2024.

In participant-type research, subjects and cultures are the sources of knowledge, fostering the progressive subject-subject relationship within the subject-object, researcher-educator, and popular group relationships. The understanding of social reality is collaboratively constructed through this interaction, *i.e.*, the articulation between scientific and popular knowledge fosters the critical construction of a third, new, and transformative knowledge<sup>11</sup>.

The institutional settings analyzed are located in a small municipality in southern Brazil. This municipality has 49 PHC services, which are divided into 25 Family Health teams (FHT), 23 Primary Care teams (PCT), and 1 Prison Primary Care team (PPCT).

Regarding specialized services, there is a municipal agency where people with HIV receive clinical care through consultations, examinations, treatments, and guidance about the virus. This service aims to integrate health services; the other institution (a referral teaching hospital for care in the area of infectious diseases) is federal.

Participant recruitment was carried out from a list of possible locations (for participant observation) and healthcare professionals to form a Focus Group (FG)<sup>12</sup>, thus being selected

## **HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY**

by convenience. As inclusion criteria, professionals with the following characteristics were selected: to be active in PHC services (and in a specialized agency) and to develop health care actions for women with HIV. The exclusion criteria indicated the following professionals: those who are contracted and belong to the municipality's permanent staff, or who were absent from work during the data collection period. The locations for participant observation were chosen because they are services that provide care to women with HIV.

To begin the field phase, participants were contacted via an invitation letter (containing the objectives and suggestions for date, time, and location to develop FG), which was read aloud in person at the service centers. Data collection followed the four phases of participant research: (1) institutional and methodological setup of participatory research, (2) preliminary and provisional study of the zone and population under study, (3) placement of problems considered priorities, and (4) programming and execution of an action plan<sup>11</sup>.

### **1. Institutional and methodological setup of participatory research**

The structure and functioning of the services (accessibility and use) were observed (45 h), as well as the care provided to women when possible. The observation technique was proposed to capture behaviors and events.

We emphasize that the participant-type observation was carried out by the doctoral student, who had no direct relationship with the services. On these occasions, the researcher acted not only as an observer of the object of study, but also as the other elements involved in the phenomenon<sup>11</sup>. Thus, obtaining a situational diagnosis of the access of women with HIV to municipal services (the research setting) was possible through informal conversations. To present the observation notes, the "NO code" was used, followed by the corresponding health service.

### **2. Preliminary and provisional study of the area and population under study.**

Alongside participant observation, four FG meetings were held with health professionals and managers from PHC services and those municipal and federal specialized services (11 participants). Regarding the operational aspects, the coordination team (the doctoral student moderator and two observers) was responsible for conducting the meetings.

## **HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY**

They were all nurses trained in data collection using both a qualitative approach and the FG technique.

During the meetings, the coordination team used a field diary (a tool for recording the researcher's data) where visits to the research field were noted. The FG's meeting moments included the following: opening of the session, introductions of the participants to each other, clarification on both the dynamics of the discussions and *the setting* (group contract), debate, summary of the previous moments, and closing.

Since this was a participant-type research project, the topic guides were previously structured and revised at each meeting to ensure they met the participants' needs. These guidelines addressed the access of women with HIV to health services; the participants acted in them by pointing out the strategies used to promote access, facilities, difficulties encountered, and other information (Health Care Networks, care pathway, and construction of care flows for this population).

The meetings lasted ~2 h. Regarding the location, date, and time of each meeting, the moderator sought to establish agreements with the participants' availability, without interfering with service provision or participants' daily routines. To organize the environment, the seats were arranged in a circular pattern, aiming for a wide view between participants, the moderator, and observers, also facilitating face-to-face eye contact.

To preserve anonymity, the FGN (Focus Group Note) code was used, followed by the codes M (meetings 1, 2, 3, or 4) and P (participant numbers 1-11), resulting in FGN.M1.P1 (*e.g.*). A digital recorder was used to record the meetings, and a field diary was used to note the observers' impressions during and after each FG meeting.

### **3. Presentation of problems considered as priorities**

The priority issue to be discussed was defined during the first FG meeting.

### **4. Programming and execution of an action plan**

From the perspective of Institutional Ethnography, the institution was defined as the spaces where social and work relations occurred. Such relationships are not abstract, but mediated by *texts*, which are the main elements of the activities developed in the institutional

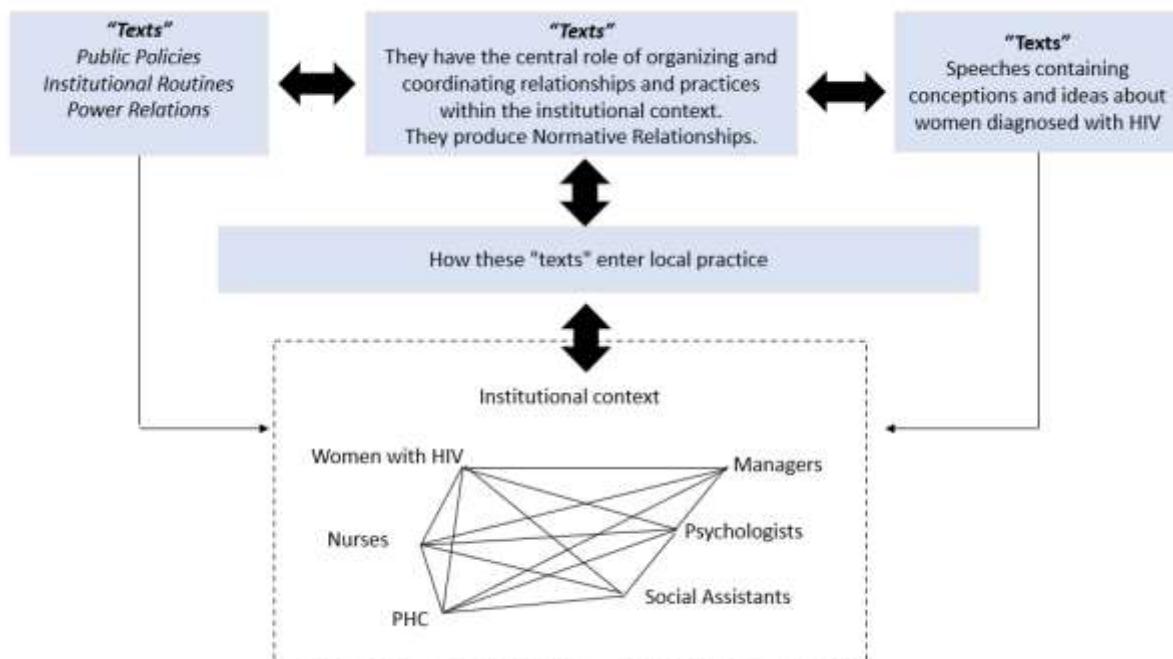
## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

context<sup>10</sup>. In the context of the present study, the *texts* are represented by public policies, institutional routines, power relations, and some forms of discourse about women living with HIV.

In Institutional Ethnography, *texts* must be activated, whereas the human factor is the main facilitator of the *text*'s ability to coordinate actions and make things happen specifically. After activation, the *texts* formalize sequences of actions, coordinating what can be said and done within the institutional context. Thus, they assume the role of standardizing and normalizing social relations and work activities, being able to formulate a process of institutional organization that is superior and independent of people<sup>10</sup>.

Data triangulation was developed as a technique for analysis through the organization and reading of the texts. Content analysis was used for data processing<sup>13</sup>, with pre-analysis (organization), exploration of results content (reading of *texts*), and discussion mediated by interpretation in light of Institutional Ethnography. Figure 1 shows the concepts of Institutional Ethnography used in this study.

**Figure 1:** Theoretical framework for analysis to understand the organization of professional practices in the care of women with HIV (Santa Maria, RS, Brazil; 2024).



Source: The authors, 2024.

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

### RESULTS

The FG consisted of a total of eight professionals, including nurses, psychologists, and CHAs (Community Health Agents) who worked in assistance and/or management. Next, the categories comprised of the participants' discursive constructions and notes from participant observation are presented.

#### **Trivialization of HIV infection and devaluation of women's health needs**

In the context of Institutional Ethnography, the different forms of discourse about a given phenomenon must be analyzed and incorporated by professionals to organize their work. Thus, the researcher should give voice to the participants in the research, seeking to understand their conceptions and perceptions of situations experienced, relating them to the complex networks in the institutional organization.

From this perspective (after questioning how women with HIV are perceived), three healthcare professionals reported a change in the behavior of people who stopped worrying about the risks of HIV transmission after a few years.

*It seems that young people today don't have that concern. I've heard about it, I've read about it... People think: there is treatment; then I won't die of HIV. (P4)*

*It seems like it's a peaceful matter; they accept it; there's treatment; it was referred [to the specialized federal service]; treatment continues. I think it's a change in behavior that's happening, and I don't know if we, as professionals, are able to keep up. (P3)*

*I think we're more worried than they are, and this shouldn't be trivialized. (P8)*

While professionals and managers reproduce discourses that trivialize HIV among people (and that this attitude could become dangerous), the adoption of measures capable of contributing to a change in the attitude of these people has not been evidenced.

*The [infectious diseases] clinic does not distribute supplies for prevention and promotion of health, such as condoms, lubricating gels, or explanatory leaflets. Regarding educational activities with the target population and the community, there was a group, led by a nurse, that was offered to adult patients with HIV (it was not a specific group of pregnant women or women who had been pregnant with HIV), but no further meetings were held. (NO: specialized federal service)*

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

The conceptions and discourses about women with HIV produced by the professionals who participated in this study contribute to institutionalizing practices that frequently devalue the health needs of these women. Based on the notes (obtained through participant observation), it was evident that women often felt uncomfortable discussing their clinical condition and pregnancy with HIV infection, showing interest in receiving psychological support. However, no action was taken even after requesting.

*The pregnant woman seemed uncomfortable when talking about the fate of her pregnancy. There was no referral for psychological counseling. The resident spoke with a social assistant, but nothing was done as she wasn't the one who assisted the woman. (NO: specialized federal service)*

*During the consultation, the user said she needed psychological support. At that moment, the doctor recommended that she seek out the service's psychologist, as she was unsure if referring her to a psychiatrist would be necessary (for medication). However, the doctor had neither referred the patient to the service's psychologist nor discussed the case with her by late morning. Furthermore, the user did not receive a formal referral for psychological care nor was she directed to the service's psychologist. (NO: specialized municipal service)*

### **Institutional routines versus the needs of women with HIV**

The routines established in healthcare services follow technical instructions for executing specific tasks. They are based on protocols and systematically describe the steps necessary to provide care. The protocols and routines in Institutional Ethnography must be analyzed, as the human factor is the main determinant of whether they should be included in the practices developed by professionals.

According to the statements of three professionals (who were interviewed and work in PHC services), the institutional routines are not different in the care for people with HIV.

*There is no such distinction. I don't have this; I don't know if anyone else does... even because it is a Basic Unit. There is no difference. (P4)*

*She's a user like any other who goes to work... I don't think there's a specific action for that audience; at the moment, there isn't. (P7)*

*Actually, the service or action is general, isn't it? Some issues require a different approach, questioning due to their particular nature, but specific action... there, we don't have any differentiation. (P6).*

It is possible to show that institutional routines are pre-established to meet the general needs of the population. They are not changed when women with HIV receive care. From this

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

perspective, some professionals see the need to make certain routines more flexible to make access as easy as possible for women with HIV.

*One day, I go for prenatal care, the next day I go for a check-up, and the next day I don't; I do who knows what. I think this makes access more difficult. E.g., a mother who has HIV has one day off per week, which is Tuesday, but she goes to the clinic on that day, and the nurse only does well-child checkups. She will then look for another Unit or [the specialized federal service]. (P4)*

From the perspective of the women served at the services, we highlight that the institutional routines established there contribute to exclusion, especially regarding the choice of delivery method, as shown in the following observation note. It was also possible to show some established institutional routines within the services (which only some staff members know), thus contributing to a fragmented assistance process.

*The medical resident welcomed the pregnant woman, who was in the final stages of pregnancy, and guided labor (which could be a normal delivery, as the pregnant woman's health was stable). However, she stated that the delivery would be a cesarean section (as it is standard practice to prevent vertical transmission of HIV), and it would occur in the 38th week. Given that it was a surgical procedure, the pregnant woman was not asked about her preference for the type of delivery, nor how she felt about the upcoming delivery. (NO: specialized federal service)*

*Within the hospital's service, transfers between outpatient clinics are made by doctors via a computerized system. The nursing staff in the outpatient clinic is unfamiliar with this process [...]. (NO: specialized federal service)*

### **Disarray in the support network for women with HIV**

Since the PHC services are the entry point for care for women with HIV, they should maintain follow-up care within their local PHC system, even if referred to specialized services. However, the professionals refer to the network's organizational structure as being disjointed, *i.e.*, the referral and counter-referral of services do not happen correctly.

*Generally, people end up becoming linked to specialized services and do not remain in primary care. Even so, I have also worked on the front lines, and I saw the difficulty professionals had in obtaining information from specialized services and even getting that counter-referral. (P2)*

*It's complicated. The pregnant woman with HIV goes and stays [at the specialized federal service]; she remains there throughout her entire pregnancy. And where does she go back to? So, she should also be monitored here at the clinic during her pregnancy, because this should be her home. (P3)*

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

*The doctor agreed to allow the observer to be present during the interviews, but reported that pregnant women diagnosed with HIV only see him twice, after which they are transferred to [the specialized federal service]. (NO: PHC)*

The professionals' statements highlighted the lack of information records in patients' medical charts, reporting a lack of coordination between referral and counter-referral services, despite the existence of a public policy *text* that refers to the regulation and coordination of activities developed within the institutional context as a line of care. This makes it difficult to provide care and support to women with HIV and their children.

*We have a problem with the service here. Doctors don't put anything in the medical record, including test results. So sometimes the patients end up walking back and forth. To avoid this, everything would have to be written down in the patient's medical record. (P3)*

*The resident doctor also reported during the consultation: "What a pity that you're receiving care [at the specialized municipal service], there's nothing written in your medical record, I'll have to call to find out how you're taking your medication." (NO: specialized federal service)*

*The discrepancy in information reveals the difficulty users face in accessing information at different points of care, and points to the need to equip and empower professionals on issues involving HIV, humanization, and welcoming users in services. (NO: specialized municipal services)*

*It's an illusion to think that people are only being helped by referral services. If a child with HIV has any stomach pain, she goes to the clinic. And the doctor doesn't even know if the child has HIV or not. So what, there's nothing written. In a little while, he'll give a medication that the child shouldn't even take. (P4)*

## DISCUSSION

In Brazil, actions to prevent HIV infection and reduce the risks associated with vertical transmission have become more evident, mainly due to the availability of universal treatment<sup>14</sup>. Specific services were also created to provide early diagnosis strategies and decentralize care, so that PHC becomes the foundation of best practices. They include prevention, diagnosis, teamwork, and evidence-based clinical management of HIV<sup>15</sup>. This restructuring is still insufficient to ensure comprehensive care only in PHC, even though it has been positively evaluated<sup>16</sup>.

**HEALTH CARE FOR WOMEN WITH HIV:  
ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY**

Given these new scenarios, professionals working in services for people with HIV regularly need to make decisions that will impact on the lives and development of this segment of the population. Thus, the context of services provided requires a careful look to better understand the social and institutional relationships that limit, shape, and organize the care provided.

In the theoretical framework of Institutional Ethnography, there are elements to coordinate and regulate the activities developed within the institutional context. They were designed and interconnected to standardize and regulate both social relations and work activities in a superior and people-independent process of institutional organization. The speeches about a given phenomenon are elements that can determine the organization of services<sup>10</sup>.

The research data points to a professional speech that considers HIV infection as something that has been trivialized by society. As a result (in the professionals' perception), people stopped taking adequate precautions to avoid transmission. Some authors suggest that biomedical advances associated with HAART (in public policies) fuel a social discourse that HIV infection can be controlled, which has made it chronic. However, considering the dependence on access to ART, questioning this speech is necessary to ensure the chronicity of the infection<sup>1,17</sup>.

Despite the speech trivializing HIV, we highlight that institutionalized actions for promotion and prevention of HIV transmission to disseminate relevant health information to the population were not observed (in the context of the services investigated). Enthusiasm regarding the chronicity of HIV can affect public policies and the organization of services. In other words, there has been a reduction in collective actions promoting health and preventing HIV. In contrast, approaches linked to medicalization and individualization grew<sup>18</sup>.

To meet the specific needs of population groups with distinct approaches applied at various levels, health professionals and managers must be supported in planning and implementing prevention actions. Such actions should contribute (through incentives for behavioral changes in individuals and communities) to increasing information and awareness of the risk of HIV exposure, aiming for a reduction.

## HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY

A study conducted in Thailand highlighted successful experiences implemented there regarding actions to prevent HIV transmission. Civil society campaigns to promote the use of condoms, a program from the Ministry of Public Health (to prevent the spread of HIV in high-risk populations), and a universal program (to prevent the mother-to-child transmission) are among them<sup>19</sup>.

The institutional routines established in the services are another important aspect to be discussed. In Institutional Ethnography, routines are a focus of attention, especially because they are often considered objective ways of constructing and organizing institutional practices where care relationships are processed. These routines can exclude the personal point of view, taking on a translocal or extralocal character, producing dominant relations that override the local realities of people and work<sup>10</sup>.

Studies have shown that the quality of life of HIV patients treated in public services is directly linked to interpersonal relationships and the quality of care received from professionals<sup>20</sup>, highlighting the importance of routines that include the patients' point of view and effective care.

In the present study, we highlight that the routines developed in PHC services are not directed towards people with HIV. These results are consistent with a study conducted in a capital city in southern Brazil. This study showed that healthcare for people with HIV in the context of PHC is provided through spontaneous demand (but not through programmatic actions to offer and ensure health services and actions with management appropriate to the individual needs of each person with HIV). This study also revealed that healthcare for people with HIV is characterized by medical attention that contributes little to raising community awareness about prevention and early diagnosis, despite the potential of PHC services<sup>21</sup>.

We reiterate that adopting the sharing of specialized services with PHC would make it possible to expand diagnosis (as well as access to ART at the appropriate time)<sup>22</sup>, considering the individual decision about the reproductive process in this context.

In the present study, some institutional routines that exclude the perspective of women with HIV on certain occasions (especially decisions about the reproductive process and childbirth) were observed. A study conducted in Porto Alegre sought to report the childbirth experiences of 20 women with HIV. This study highlighted that these women's choices or

## **HEALTH CARE FOR WOMEN WITH HIV: ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY**

preferences regarding childbirth appeared to be of lesser importance compared to the technical procedures to prevent vertical transmission, with adherence to antiretroviral therapy being the focus of the consultations. Thus, the wishes of women in labor were not considered by the professionals, with medical decisions and women's passivity prevailing<sup>23</sup>.

Regarding the healthcare network for women with HIV, PHC services are the entry point, and HIV testing is one of their first strategies. Thus, the possibilities for accessing services have been expanded, and the care practices of the Specialized Centers have been decentralized<sup>21</sup>.

A study conducted in Rio de Janeiro analyzed the recent experience of decentralizing care for people with HIV in primary care, highlighting the advanced implementation of rapid testing. However, difficulties in counseling, diagnostic disclosure, and confidentiality management were noted, particularly relative to community health agents and residents of neighborhood<sup>7</sup>.

Thus, we highlight the importance of programmatic actions that could ensure the provision of health services aimed at adequate care for people with HIV. Equipping those receiving care with the tools for self-care (through individual consultations, relationship building, and home visits) is an important tool to bring users closer to the health service<sup>21</sup>.

We emphasize the importance of an articulated care network to serve people with HIV. For this population, the Care Pathway helps organize the network, identifying possible ways to care for and monitor people, prioritizing the most rational and effective routes, bringing management and care closer together, operating based on therapeutic projects, and considering the users' perspective<sup>24</sup>. Furthermore, formulating strategies to maintain care for people with HIV is necessary; follow-up after initial consultations is among them, adapting care to individual needs<sup>25</sup>.

For the healthcare network to become articulated and meet the health needs of women with HIV, it must be based on values of justice, rights, respect, and equity<sup>26</sup>.

### **FINAL CONSIDERATIONS**

Healthcare practices for women with HIV are shaped, organized, and institutionalized under the influence of healthcare professionals' and administrators' understanding of HIV. From

**HEALTH CARE FOR WOMEN WITH HIV:  
ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY**

the professionals' perspective, living with HIV has become trivialized by women. Few preventive measures were observed in these services, as professionals consider them ineffective given the current trivialization environment. Some institutional routines seem disarticulated and poorly aligned with the care needs of women with HIV.

Analysis of institutional contexts can contribute to health management, encouraging innovative processes with a better reorganization of the care flow and articulation between services. This implies assistance, as articulation between services is an essential strategy for both the proper management of maternal infection and the prevention of vertical transmission of HIV.

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**HEALTH CARE FOR WOMEN WITH HIV:  
ANALYSIS FROM THE PERSPECTIVE OF INSTITUTIONAL ETHNOGRAPHY**

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**HEALTH CARE FOR WOMEN WITH HIV:  
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Submitted: February 15, 2024

Accepted: August 28, 2025

Published: January 2, 2026

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<b>All authors approved the final version of the text</b>
<b>Conflict of interest:</b> There is no conflict of interest.
<b>Financing:</b> There was no funding.
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<b>Editor-in-chief:</b> Adriane Cristina Bernat Kolankiewicz. PhD

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