

**PERCEPTIONS OF PEOPLE LIVING WITH HIV/AIDS ABOUT THE CARE
OFFERED IN PRIMARY CARE****PERCEPÇÕES DE PESSOAS QUE VIVEM COM HIV/AIDS SOBRE O CUIDADO
OFERECIDO NA ATENÇÃO BÁSICA****PERCEPCIONES DE PERSONAS QUE VIVEN CON VIH SOBRE LA ATENCIÓN
OFRECIDA EN LA ATENCIÓN BÁSICA**

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ABSTRACT

Objective: to know the perceptions of people living with HIV about the care offered to them in Primary Care. **Method:** a descriptive-exploratory study, with a qualitative approach, developed in a Specialized Care Service in HIV/AIDS, with 16 participants. Semi-structured interviews were used, analyzed by the assumptions of content analysis. **Results:** data were organized into three categories - Primary Care: an underestimated scenario for HIV care delivery; Fear of breach of confidentiality: obstacle to seeking care in Primary Care; Controversial perspective of comprehensive care without the participation of Primary Care. **Conclusions:** it was found that the participants consider Primary Care as a good service; however, they did not seek care related to HIV in this scenario. The fear of breach of confidentiality is a barrier to seeking care in Primary Care and they have a controversial perception about comprehensive care, believing that a single service is capable of meeting health needs.

Descriptors: Care; HIV; Basic Attention.

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RESUMO

Objetivo: conhecer as percepções de pessoas que vivem com HIV sobre o cuidado que lhes é oferecido na Atenção Básica. **Método:** estudo descritivo-exploratório, de abordagem qualitativa, desenvolvido em um Serviço de Assistência Especializada em HIV/Aids, com 16 participantes. Utilizaram-se entrevistas semiestruturadas, analisadas pelos pressupostos da análise de conteúdo. **Resultados:** os dados foram organizados em três categorias – Atenção Básica: um cenário subestimado para prestação de cuidados em HIV; Medo de ruptura do sigilo: obstáculo para buscar cuidados na Atenção Básica; Perspectiva controversa de cuidado integral sem a participação da Atenção Básica. **Conclusões:** verificou-se que os participantes consideram a Atenção Básica como um bom serviço, todavia não buscavam cuidados relacionados ao HIV nesse cenário. O medo de ruptura do sigilo é uma barreira para buscar cuidados na Atenção Básica e possuem uma percepção controversa sobre o cuidado integral, acreditando que um único serviço é capaz de suprir as necessidades em saúde.

Descritores: Cuidado; HIV; Atenção Básica.

RESUMEN

Objetivo: Conocer las percepciones de las personas que viven con el VIH sobre la atención que se les ofrece en Atención Primaria. **Método:** estudio descriptivo-exploratorio, con enfoque cualitativo, desarrollado en un Servicio de Atención Especializada en VIH / SIDA, con 16 participantes. Se utilizaron entrevistas semiestructuradas, analizadas por los supuestos del análisis de contenido. **Resultados:** los datos se organizaron en tres categorías: Atención primaria: un escenario subestimado para la prestación de atención del VIH; Miedo a la violación de la confidencialidad: obstáculo para buscar atención en atención primaria; Perspectiva controvertida de la atención integral sin la participación de la Atención Primaria. **Conclusiones:** se encontró que los participantes consideran la Atención Primaria como un buen servicio, sin embargo, no buscaron atención relacionada con el VIH en este escenario. El miedo a la violación de la confidencialidad es una barrera para buscar atención en Atención Primaria y tienen una percepción controvertida sobre la atención integral, ya que creen que un solo servicio es capaz de satisfacer las necesidades de salud.

Descriptores: Cuidado; VIH; Atención básica.

INTRODUCTION

Knowing the users' perception of the care offered by the Health Care Network (HCN) is relevant to strengthen the actions developed to improve the quality of life, especially when it comes to chronic diseases.¹

In this premise, the Human Immunodeficiency Virus (HIV) appeared in Brazil in 1980 and, since then, a significant number of people have been infected. These became the target audience for health

actions, since the country's last epidemiological bulletin revealed 43,941 new cases of HIV, totaling 966,058 cases detected between 1980 and June 2019.²

Regarding the care developed for people living with HIV (PLHIV), it is known that the Unified Health System (SUS) reorganized the flow of care after the disease took on chronic characteristics, as well as the traditional model, in which care was restricted to Specialized Assistance Services (SAS), indicating failures, signaling the need for coordination between

the HCN services, with a focus on comprehensive care.^{3,4}

Subsequently, the Ministry of Health prioritized the sharing of care in the HCN. Thus, in addition to the SAS, Primary Care (PC) became part of the care network for PLHIV.³ Therefore, developing shared actions became fundamental for the advancement of care for PLHIV, ensuring greater bond and access to the health system.⁴

In this sense, PC, through health promotion and disease prevention actions, plays a decisive role in comprehensive care for PLHIV, as it has proximity, contact and links with the population.⁴

Furthermore, PC had its potential expanded, received investments and was recognized by health managers as a valuable scenario in the care of PLHIV. It started offering rapid tests, post-diagnosis counseling, requesting complementary and follow-up tests, risk stratification, monitoring of stable asymptomatic patients, prophylaxis for opportunistic infections, immunization, starting antiretroviral therapy and early detection of therapy failure.⁵

Consequently, PLHIV have experienced a health care model that advocates articulation in the HCN. With that, the interest of the scientific community arises in unveiling the care developed for PLHIV in PC. From this perspective, a

study revealed that, in general, SUS users positively evaluate the actions developed by PC.¹ However, they have a fragmented view of care and illness, as they believe that comprehensive care is carried out by a single service, which arouses the need for further research to better understand this phenomenon.⁶

This study is justified because, in the literature, there are gaps in the care offered to PLHIV, since recent studies have been conducted under the eyes of people who do not live with HIV¹ and health professionals^{3,7}, not giving the opportunity to PLHIV to expose their perceptions about the care offered by PC, its potentialities and developments in the HCN.

In addition, the National Agenda for Health Research Priorities suggests that unveiling health actions and services at PLHIV and their perceptions of the care offered is a scientific priority, which requires reflection and analysis of topics such as access, attachment and shared care.⁸

Therefore, the object of this investigation was the care offered by PC, aiming to know the perceptions of PLHIV about the care offered to them in PC.

METHOD

Descriptive and exploratory research, with a qualitative approach, developed in

the SAS on HIV/AIDS of a municipality in Zona da Mata Mineira. This scenario was chosen because it welcomes a large number of PLHIV, facilitating proximity to these users. The motivating questions for this study were: Do PLHIV seek care in PC? How do PLHIV perceive the care developed in PC?

In May 2016, there was an ambience to get to know the service routine and establish a relationship with potential participants. Data collection was carried out between June and October 2016. Eighteen subjects were individually approached at the time of screening, which was carried out before attending the service, in a reserved room. Users were invited to participate in the study and spontaneously revealed their HIV diagnosis. Then, they were clarified as to the motivations, risks and benefits of the study.

This study is a non-probability convenience sampling, composed of 16 participants who met the eligibility criteria.⁹ The recurrence of the data defined the number of participants, and three more interviews were carried out after this finding.¹⁰ PLHIV of both genders, over 18 years old and residing in neighborhoods covered by the Basic Health Unit (UBS) were included in this study. Two participants were excluded, one for not living in a neighborhood with FHS and another for refusing to participate.

Subsequently, data were collected after consenting and signing the Free and Informed Consent Form, through a semi-structured interview, conducted in a comfortable and private environment, lasting from 32 to 57 minutes and with audio recording on digital media. The first stage of the interview consisted of personal data (age, gender and time of diagnosis) and the second, by the questions: What health services did you seek after confirmation of the diagnosis? Did you contact PC for follow-up? What is your perception about the care offered in PC? What reasons make you seek care in PC? What are the reasons that hinder the search for care in PC?

Anonymity of participants was ensured, coding them by the initials of their names. Next, the interviews were transcribed and stored in a database of Word for Windows program. The participants received feedback from the interviews and, after agreeing with the content, they followed the analytical path.

Data were analyzed using the assumptions of content analysis, consisting of the stages: pre-analysis, exploration of the material and treatment of the results with inferences and interpretations.¹¹ After the transcription and analysis of the interviews, the participants' perceptions were grouped into thematic units and categories.

The research was carried out after approval by the Research Ethics Committee of the Federal University of Juiz de Fora, under the consubstantiated opinion n° 1.5570.0022. The ethical principles set out in Resolution no. 466/12 of the National Health Council, which regulates research with human beings, were respected.¹²

RESULTS AND DISCUSSIONS

Sixteen people participated in this study, being eight female and eight male. The age group ranged between 27 and 70 years, with a diagnosis time between 7 months and 20 years.

From the speeches, three categories emerged -Primary Care: an underestimated scenario for HIV care delivery; Fear of breach of confidentiality: obstacle to seeking care in Primary Care; Controversial perspective of comprehensive care without the participation of Primary Care.

Primary Care: an underestimated scenario for HIV care delivery

This category was constructed from the fragments of the interviews that addressed the reasons that led PLHIV to seek care in PC and their perceptions about

the care offered. As for the reasons, the participants reported that they sought PC care when needs related to acute, chronic non-transmissible and preventive conditions arose, considered by them as simpler, in comparison with the actions developed in other HCN services, underestimating the potential of PC:

I go to the clinic because of the flu or something silly. (R.P.F.)

I go to the clinic for simple things, like diabetes control. (A.M.C.M.)

I go to the clinic to do pressure control, preventive tests, exams, exchange prescriptions, common things. (J.M.O.L.)

Participants named PC as a “clinic” and, when asked about their perceptions regarding the care offered by it, they reiterated that this is a qualified scenario, offering good care, but did not seek it to meet HIV-related needs:

I like the service at the clinic, but I do not go to things related to HIV. (M.A.F.)

The clinic is very good, I like the staff and the service, but I go for a routine exam or some referral to a doctor, but not for the virus. (E.L.)

PC comprises the level of health closest to people's daily lives.⁶ Therefore, it should be the first way of inserting its users in the HCN, providing an attention ordered by the resolution and acceptance of the users' health needs.⁴

It appears that PLHIV access PC, but that it is not recognized by them as a scenario enabled to meet the needs related to HIV. Although little recognized in the face of its possibilities of action, the PC, in developing the perspective of integrality, has disclosed successful experiences regarding the implementation of the management of HIV infection.³

Although there is no recent study on the perception of PLHIV regarding the care offered by PC, it can be said that, in general, SUS users positively evaluate PC services. Cross-sectional study carried out with more than 65 thousand users reported that 78.9% of them considered the service provided by the PC good or very good.¹

It is noteworthy that PLHIV are attended in PC for other reasons, which are not directly related to HIV. However, it is important that PC meets individual and collective needs in relation to HIV, consolidating the principle of comprehensiveness.⁴ Thus, the search for PC exclusively to meet needs related to chronic non-communicable diseases underestimates the varied attributions of PC in the care of PLHIV. Therefore, care is expected to be shared, establishing information flow and allowing PC teams to be trained, performing their duties to provide qualified and resolute care established by the HCN.¹³

It is considered that actions of health promotion and HIV prevention are widespread and that the diagnosis of new cases and the monitoring of diagnosed users are in progress. However, these processes are recent, surrounded by controversy and still little studied, although there are policies and guidelines that legitimize PC's competencies in the provision of care to PLHIV.¹⁴

The challenge is to overcome the paradigm that the actions developed by PC are simplistic, which, in this study, was materialized in the speeches of the participants. Therefore, health has multiple determinants and conditions and the improvement of its conditions depends on several factors, of which a large part are addressed by PC.⁴

Although PC does not play a leading role in the care of PLHIV, participants recognize it as a qualified service in the provision of acute, chronic and preventive care, except for HIV care. Thus, it is inferred that the underestimation of PC's potentialities can be overcome with the articulation between HCN and disclosure of PC's attributions. It should be noted that this fact is not related to the absence of guidelines, since shared care in HIV/AIDS is a practice encouraged and provided for in the normative scope of PC.

Fear of breach of confidentiality: obstacle to seeking care in PC

This category came up with the question about the reasons that hindered the search for care in PC. Subsequently, subjectivities and feelings related to the fear of having their diagnosis revealed by PC professionals identified themselves in the interviews, being the main factor that discourages the search for assistance at this level of care.

It is noteworthy that the participants did not narrate personal experiences that materialized the breach of confidentiality in PC, but considered this scenario as a potential for breaking the confidentiality of the diagnosis.

I am afraid they will tell someone (PC professionals). I don't want anyone from there (PC) to know. (VVP)

There are people who would not keep a secret about what we have, so I am afraid to look for the clinic. (MAF)

Secrecy is understood as an essential aspect of HIV/AIDS care, especially in the context of PC. When it is not well established among professionals and users, bonding and the search for care become impaired.³ It is understood that confidentiality is the prerogative of the ethical commitment of the health professional, and it is essential that PLHIV

are informed that confidentiality and privacy are the rights of users.^{4,13}

The breach of secrecy occupies a barrier, creating a setback for users' access to health services. Soon, health professionals have an ethical mission with society and must respect the fundamental guiding principles of the care relation, as the professionals' commitment to ensure ethical care will define the user's choice for the service that best arouses their trust.^{5,15}

In this sense, a cross-sectional study, conducted with 156 participants with HIV, revealed that the concern with confidentiality is a constant in the scenario of care for PLHIV and is related to stigma and discrimination. In addition, the concern with the breach of confidentiality may make it impossible to link and retain PLHIV in the different health services.¹⁵

Because PC is a service close to the users' daily lives, they believe that this factor contributes to the breach of confidentiality.^{4,13} Some participants highlighted that the proximity of PC to their realities was something that increased the fear and insecurity of having their diagnosis revealed.

The neighborhood is very small, everything is close to the clinic and it is easy to find out what I have. (ES)

I never looked for the clinic, because they are known people, everyone knows each other. (MAF)

While getting treatment close to home brings advantages to the user, such as avoiding traveling great distances to take care of health and receiving comprehensive care, on the other hand, proximity can be a problem in the view of PLHIV, bringing potential risks, such as rupture of the diagnosis confidentiality.⁴

Based on the principle of territorialization, PC is organized with a high degree of proximity to the population and their living conditions. Thus, the literature points to the fear of PLHIV in having the diagnosis revealed to the community, based on the sharing of information and decisions between the team. This makes territoriality a tool for care possibilities, but also a potential source of exposure, stigma and prejudice.¹⁷

The development of a bond with the user is the main potential of PC. Despite the challenges faced, when it manages to break the barriers of prejudice and fear felt by patients, it becomes an important instrument for promoting the health of the individual, since, by offering physical and emotional support, it contributes to the quality of life.¹⁸

The trust conveyed by professionals from the PC team to PLHIV contributes to establishing the bond and adhering to treatment. There is a need for educational processes for PLHIV and for the PC team, reaffirming the binomial (right/duty)

regarding the confidentiality of the diagnosis.

Controversial perspective of comprehensive care with no participation of PC

This category was constructed from the inquiries of the participants about which health services they had sought after the confirmation of the HIV diagnosis and whether they sought the PC to perform follow-up. The findings revealed that the SAS was the service chosen by the participants after confirmation of the diagnosis. This situation converges with the flow of care management in HIV/AIDS.

As soon as I discovered my diagnosis, I looked for SAS. (MAF)

When I found out I had this disease, I came here right away [SAS]. (EL)

Knowledge about the search for care after the diagnosis of HIV/AIDS is essential to understand the main barriers that permeate the search for care in PC. In addition, it is important that the duties of each service are well defined and widely publicized.

SAS aims to provide quality care to PLHIV, with the premise of developing care articulated with other points of the HCN, since a single service does not have

all the resources necessary to meet the demand in health and contribute to legitimize integral care.¹⁴

In this sense, both SAS and PC are responsible for continuous care, in which PLHIV must undergo a timely diagnosis, link to a health service, retention through monitoring, periodic examinations, adherence to treatment and load suppression in order to achieve quality of life.¹³

Therefore, the search for SAS after diagnosis cannot be considered an action that disturbs the principles and objectives of the cascade of continuous HIV care, as this service has important attributions in the HCN; however, it should not be understood as the only qualified scenario to offer care to PLHIV.

In this sense, investments were made so that PC became a qualified service for the care of PLHIV, offering, in addition to promotion and prevention actions, tests for diagnosis, reception and monitoring.⁴ In the municipality of the study, the regulation establishes that PC is able to carry out post-test counseling, rapid diagnostic tests, in addition to shared monitoring with SAS.¹⁵

When asked whether, after diagnosis, they sought PC to perform follow-up, the participants reported they did not and emphasized satisfaction with the care provided by the SAS, characterizing it as complete and of quality. The attributes of

this service generated an illegitimate feeling of integrality in the care, given that they attended the SAS, but sought the PC in search of care related to acute, chronic non-communicable conditions and preventive actions, as previously mentioned.

I didn't look for the clinic, because everything I need I have at the SAS, I have a nutritionist, dentist, doctor, psychologist, here is a complete unit. (MAF)

I have never sought other health services for HIV, as the service here (SAS) is of quality. (FEV)

After I discovered the diagnosis, I was followed up here (SAS) and did not look for another service to take care of HIV. (BMT)

I don't go to the clinic because of this virus, because, here at SAS, they welcomed me and the assistance is very good, I have everything here. (VVP)

It is noteworthy that this study did not aim to learn about perceptions about SAS, but these appeared in a supplementary way, when the participants justified the reason why they did not seek PC for follow-up. Satisfaction with SAS is present in the literature, but the concept of full service and without limitations is controversial. In this logic, a cross-sectional study evaluated the satisfaction of PLHIV with the SAS and pointed out a high degree of satisfaction with the services provided, but acknowledged that there are negative points regarding information, support, continuity, cooperation and organization of services.¹⁹

In this study, it is noticed that the participants are retained in a single point of the HCN, which contributes to the centralization of care, limiting the perception of PLHIV about the qualities of care offered by PC. It is understood that the care network for HIV/AIDS is established and PC is an indispensable component.^{4,5,13} However, this has weaknesses and does not yet lead the flow of care and management of PLHIV. As obstacles, the disproportion of services offered by PC to the number of inhabitants, insufficient communication in the services of different technological densities of the HCN and the need to prepare professionals to meet the demands related to HIV are pointed out.²⁰

In this scenario, new global goals were proposed for 2020, such as the 90-90-90 commitment, to which Brazil is a signatory. These goals represent 90% of PLHIV diagnosed, under treatment and with an undetectable viral load. Among the strategies to achieve goals, a greater participation of the PC stands out.¹³ In this transition process, the PC has responsibility to PLHIV, offering care that includes the diagnostic test and the monitoring of asymptomatic and stable users in the first line of treatment.^{4,13}

Thus, the accessibility and use of PC enhance early diagnosis and, consequently, the appropriate management of HIV infection, favoring the development of a

bond between professionals and PLHIV, which has a positive impact on the perception of these users. However, investment in access must be intensified by public policies and implemented by professionals, so that PC can become resolute.²⁰

It is inferred that there is a need to strengthen PC to consolidate care for PLHIV, through the training of health professionals, better allocation of financial resources and evaluation of shared management strategies for HIV/AIDS care.

CONCLUSION

The study made it possible to know the perception of PLHIV about the care offered to them in PC. It was found that they considered it as a good service; however, they did not seek care related to HIV in this scenario, underestimating its potential.

In addition, the fear of PLHIV of breach of confidentiality is a barrier to seeking care in PC and still have a controversial perception about comprehensive care, believing that their needs were already met in a single health service.

The results signaled important reflections, since PC was perceived as a limited scenario in the development of care for PLHIV, even in the face of advances in

public policies. Therefore, the results of this research fill an existing gap and contribute to changes in the care model offered in this scenario, grounded in the concept of transformation based on the perception of PLHIV. Thus, PC can be perceived and used, contributing significantly to health goals and indicators.

Short-term actions are suggested, as already recommended by health policies to qualify the care for PLHIV and modify their perceptions. Such actions must be guided by qualified people management, an educational process reflecting the professional ethical precepts, competencies and attributions of the care network, demystifying the belief that comprehensive care can be achieved in a single service.

As a limitation of this study, the fact that data collection was carried out in the SAS is presented, which, at a given moment, caused PLHIV to express their perceptions about the SAS, even though this is not the objective. In addition, the absence of previous research that presented the perception of PLHIV about the care offered to them in PC prevented the results of this study from being compared and the incongruities to be discussed in depth.

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