Barriers to access HIV post-exposure prophylaxis: a case study

Barreiras de acesso à profilaxia pós-exposição ao HIV: estudo de caso

Barreras de acceso a la profilaxis post exposición al VIH: estudio de caso

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How to cite:
Queiroz AA, Mendes IA, Dias S. Barriers to access HIV post-exposure prophylaxis: a case study. Acta Paul Enferm. 2022;35:eAPE039007634.

DOI
http://dx.doi.org/10.37689/acta-ape/2022AO0076349

Keywords
HIV infections; Acquired immunodeficiency syndrome; Post-exposure prophylaxis; Barriers to access of health services

Descritores
Infecções por HIV; Síndrome de imunodeficiência adquirida; Profilaxia pós-exposição; Barreiras ao acesso aos cuidados de saúde

Descriptores
Infecciones por VIH; Síndrome de inmunodeficiencia adquirida; Profilaxis posexposición; Barreras de acceso a los servicios de salud

Submitted
March 29, 2021

Accepted
June 21, 2021

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Associate Editor (Peer review process):
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Abstract

Objective: To explore barriers to access HIV post-exposure prophylaxis perceived by users and professionals.

Methods: This is an exploratory, qualitative study. The research participants were medical professionals and nurses involved in the prophylaxis protocol in Reference Centers and prevention users, totaling 10 participants, a sample defined by data saturation. The recorded interviews were transcribed and later processed by the Descending Hierarchical Classification and by similitude analysis.

Results: Five classes were obtained: Information; Access centralization; Service flow; Interpersonal relationships in healthcare services; Difficulties and barriers. There are several factors that hinder access to prevention, which permeate knowledge, reception and dissemination of information. With the advent of the COVID-19 pandemic, many of these problems are aggravated and increase the vulnerability of possible users of prophylaxis.

Conclusion: Access to HIV post-exposure prophylaxis faces challenges and barriers, ranging from lack of knowledge about prophylaxis, which makes it impossible to pursue it, to the centralization of healthcare services and stigmas that permeate the structures of healthcare services.

Resumo

Objetivo: Explorar as barreiras de acesso à Profilaxia Pós-Exposição ao HIV percebidas por usuários e profissionais.

Métodos: Pesquisa exploratória com abordagem qualitativa. Os participantes da pesquisa foram profissionais médicos e enfermeiros envolvidos no protocolo da profilaxia em Centros de Referência e usuários da prevenção, totalizando 10 participantes, amostragem definida por saturação de dados. As entrevistas gravadas foram transcritas e posteriormente processadas pela Classificação Hierárquica Descendente e por análise de Similitude.

Resultados: Foram obtidas cinco classes: Informação; Centralização de acesso; Fluxo de atendimento; Relações interpessoais nos serviços de saúde e Dificuldades e Barreiras. Existem diversos fatores dificultadores no acesso à prevenção, que perpassam conhecimento, acolhimento e divulgação de informações. Diante do advento da Pandemia de COVID-19 muitos desses problemas se agravam e aumentam a vulnerabilidade de possíveis utilizadores da profilaxia.

Conclusão: O acesso à profilaxia pós-exposição ao HIV encontra desafios e barreiras, que vão desde o desconhecimento sobre a profilaxia, o que impossibilita sua busca, à centralização dos serviços de saúde e estigmas que permeiam as estruturas dos serviços de saúde.

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Conflicts of interest: nothing to declare.

Resumen

Objetivo: Explorar las barreras de acceso a la Profilaxis Post Exposición al VIH percibidas por usuarios y profesionales.

Métodos: Investigación exploratoria con abordaje cualitativo. Los participantes de la investigación fueron profesionales médicos y enfermeros involucrados en el protocolo de profilaxis en Centros de Referencia y usuarios de la prevención, totalizando 10 participantes, muestreo definido por saturación de datos. Se transcribieron las entrevistas grabadas y posteriormente procesadas por la Clasificación Jerárquica Descendente y por medio de análisis de Similitud.

Resultados: Se obtuvieron cinco clases: Información; Centralización de acceso; Flujo de atención; Relaciones interpersonales en los servicios de salud y Dificultades y Barreras. Hay diversos factores que dificultan el acceso a la prevención, que sobrepasan conocimiento, acogida y divulgación de informaciones. Ante el surgimiento de la Pandemia de COVID-19, muchos de esos problemas se agravan y aumentan la vulnerabilidad de posibles utilizadores de la profilaxis.

Conclusión: El acceso a la profilaxis post exposición al VIH encuentra desafíos y barreras, que van desde el desconocimiento sobre la profilaxis, lo que imposibilita su búsqueda, a la centralización de los servicios de salud y estigmas que permean las estructuras de los servicios de salud.

Introduction

In 2014, in a joint action to combat AIDS as a threat to public health by 2030, the Joint United Nations Program on HIV/AIDS (UNAIDS) launched the 90-90-90 targets so that, by 2020, 90% of people living with the Human Immunodeficiency Virus are aware of their positive serological status for the virus, 90% of those diagnosed with HIV have access to antiretroviral treatment, and that 90% of people undergoing treatment have an undetectable viral load.[1]

By analyzing the completeness of the goal, [2] we see in HIV post-exposure prophylaxis (PEP) a meeting point for these indicators: when meeting the PEP protocol, users (many of them highly vulnerable) are adhered to the system and referred for treatment, if necessary.[3]

The implementation of PEP in the Unified Health System (SUS – *Sistema Único de Saúde*) as part of the cascade of care for the prevention of HIV infection took place in 2015. However, since 1990 this technology has been used in a timely manner, especially in case of accidents with materials contaminated or potentially contaminated. Later, it was gradually expanded to cases of sexual violence (1998) and then to any type of sexual exposure (2011).[3]

Despite this, there is still a lack of knowledge about PEP by the population and professionals. Populations vulnerable to infection control are those potentially focused on this strategy, but for this they must be properly instructed by the healthcare service. Recent research indicates that serodiscordant couples undergoing treatment are unaware of the option of adhering to PEP as a prevention option[4] and men who have sex with men (MSM) do not identify risk situations for exposure to the virus.[5]

Thus, this study aims to explore the barriers to access HIV PEP perceived by users and professionals.

Methods

This is an exploratory research, with a qualitative approach based on the Discourse of the Collective Subject method, where the speeches were organized and tabulated through key expressions that allowed the identification of central ideas, so collective thinking could be captured and grouped into categories.[6]

The study was carried out with professionals from the Basic Health Unit who developed activities with the Counseling and Testing Center (CTC) or Emergency Care Units (ECU) operating for at least one year. Professionals who were on leave, on vacation and who did not work with the PEP protocol were excluded.

Among users were included those who, at some point, had already used the service to access PEP, were using prophylaxis during this period or in the subsequent follow-up. People deprived of freedom were excluded due to the intrinsic differences in care within the prison system.

The interviews took place, after signing the Informed Consent Form, between June and August 2019, in the two services that provide PEP in Ribeirão Preto (SP): the ECU and the CTC in a private room at the institution, guided by a script semi-structured, composed of three open questions, which addressed: previous experience with PEP,

perceived difficulties in accessing it and what would be the ways to reduce or eliminate these difficulties. The sample consisted of 6 users and 4 professionals. The interviews lasted an average of 30 minutes, were recorded and transcribed in full for analysis, the participants were interviewed until data saturation was reached.

For data processing, the lexical-type analysis technique was used, with the aid of IRaMuTeQ.[7,8] For textual analysis, the Descending Hierarchical Classification (DHC) method was defined, in which texts are classified according to their respective words and the set of them is divided by the frequency of reduced forms.[9] Subsequently, the organization of keywords taken from interviewees' speeches and identification of central ideas that complemented the findings of DHC and allowed delimiting the statements into definitive classes was carried out.[8]

Furthermore, similarity analysis was used, graphically representing the structure of a set of elements with which linguistic research is related, distinguishing the common parts of the specificities of the codified variables.[10]

The recommendations for the development of research with human beings were complied with, and the project was approved by the Institutional Review Board of *Escola de Enfermagem de Ribeirão Preto* (CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 08198819.2.0000.5393) (Opinion 3.280.490).

Results

The IRAMUTEQ software recognized the division of the corpus into 178 elementary text units from 208 text segments. Thus, 3,794 occurrences were registered, accounting for 60.91% of the total corpus, a value that allows its assessment, but indicates a low level of content on the part of the interviewees, who even within this reality had little ownership of the theme (Figure 1).

Class 1: Information

This class, the first to be formed, demonstrates the beginning of users' path to PEP, portraying their first contacts with prevention and how they learned about it. Ignorance directly affects access, causing users to seek services that do not provide the prophylaxis. Search for PEP, in different settings, causes many participants to miss the optimal access time (2 hours) or even give up seeking it. During the reports, it is constant that the main source of information does not come from the healthcare service or professionals, but from their peers who have already used PEP, which does not exempt the interviewees from a situation of trial and error, when seeking more information, services and support from the healthcare service.

Class 2: Access centralization

This class behaved as a deepening of one of the listed barriers: the centralization of access to PEP.

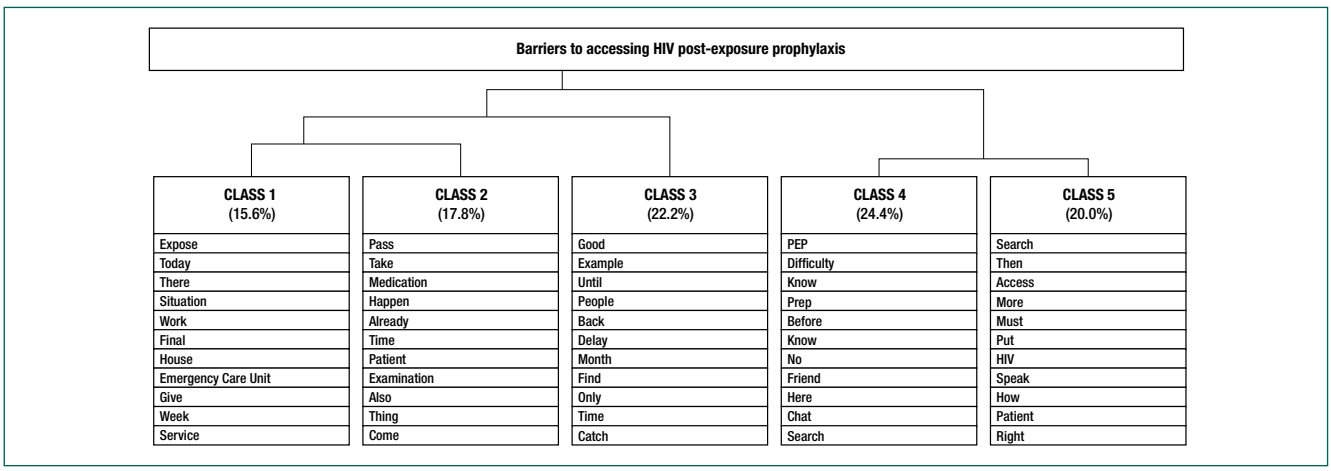

Figure 1. Dendrogram

Although available in two types of services, users and professionals point out the difficulty in their daily activities. The ECU, due to its structure and scope of service, is constantly overcrowded, with long waits and little privacy so that many participants choose (or are indicated to) seek specialized service. This situation even jeopardizes the effectiveness of PEP, as the Expert Center operates during business hours and searching for the ECU outside that time window can force individuals beyond the 72 hours of PEP functionality.

Class 3: Service flow

The contents in this class appear as transversal to the previous classes, bringing together the barriers of the service when attending to those patients who obtain information (Class 1) about services and access to it (Class 2). Then, constructing the experience of access to prophylaxis is an arduous process that often encourages users to give up.

Class 4: Interpersonal relationships in healthcare services

This class is closely related to class 5, and reveals a particular aspect of the findings: the way interpersonal relationships permeate the navigation through the health system, until reaching the desired service. In fact, they can even overwhelm the clinical protocols, since even following the recommendations, users may encounter embarrassing situations, neglect or violence, creating a hostile environment that hinders access of new users and adherence of current users. In a third sphere, the fear of the other's gaze on their decision to attend the specialized healthcare service is perceived. HIV stigma is still one of the greatest barriers to any form of prevention, so making these environments welcoming goes beyond making environments pleasant, but truly transforming them as a prevention strategy.

Class 5: Difficulties and barriers

This class is formed from a bifurcation of the previous one, revealing how basic aspects (information) influence the entire experience of accessing PEP and presents itself as its main difficulty. Professionals see how structural details end up driving people away. When seeking to avoid the stigma of going to a treatment center for infectious diseases, individuals go to the ECU and are unable to access, being referred to the CTC. This path, mediated by the stigma to HIV and its services, makes the process more time-consuming and puts the effectiveness of PEP at risk. When asked about how this process could be improved, users and professionals converged to point out the help of technologies to disseminate information and mediate the first access to the healthcare service, focusing on agility in the exchange of information and privacy.

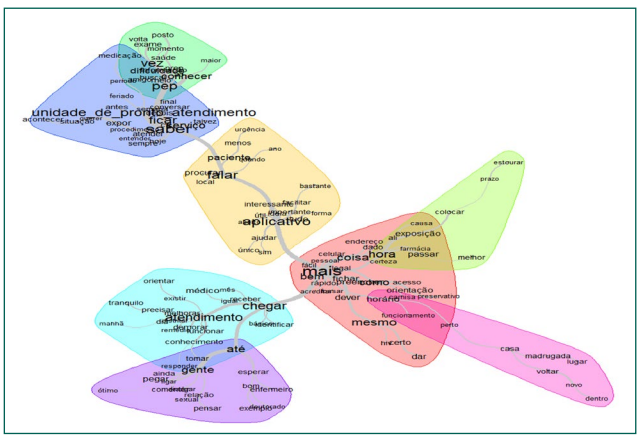

Figure 1. Similitude analysis

For similarity analysis (Figure 2), we were able to perceive nuclei of ideas formed from shared experiences. The first of these nuclei, in the upper left quadrant, points out as the first barrier to access the difficulty in knowing PEP, and from it we see its consequences. The ECU appears in the reports as an alternative to non-ordinary hours (term: period and holiday) not as a solution to the search, but as a step in the process, in which people are informed (term: to know) where seek care and PEP (term: medication).

From there, the corpus converges to a point that deals with two issues: the concern that PEP is an urgent situation and how technological strategies could help to solve the difficulties pointed out (term: application).

Seeking to overcome these difficulties, participants point out routes for improvement: increase agility and thus reduce access time to PEP, as highlighted by the terms: more, faster, time, and dead-

line. Inform the access points to PEP, prioritizing those closest to the people, making their access easier (terms: location, near, and home). Finally, even after arriving at the healthcare service, the service still represents a barrier and reflects the need for guidance and care (term: service, doctor and conversation).

Discussion

There are several barriers to access PEP, perceived by its users and professionals, which permeate knowledge, reception and dissemination of information. With the COVID-19 Pandemic, many of these problems worsen and increase the vulnerability of potential users.

In healthcare services, considerations relating to the resilience and adaptive capacity of the built environment are central to managing the challenges of supply constraints, alternative forms of service delivery and broad continuity of operations. Previously linked to the impacts of climate change, the concepts have recently been reassigned to COVID-19, which reveals the need for maturity in the health sectors for the progressive development of essential practices and strategies associated with organizational resilience.[11]

In times of crisis, it should be recognized that the future of research and practice in various domains of resilience and adaptation will be defined by the quantification of socioeconomic indicators and also by the qualification of human experience in all its capacities for ingenuity, empathy and moral responsibility.[12] As demonstrated in our results, even though PEP has clear and well-established protocols in the care network, the human factor presents itself as an even greater barrier.

Professionals and users agree that there is a gap between the service and the community it seeks to assist, sometimes depending on interpersonal connections to enable this access. Accurate and transparent communication of healthcare services with the community is essential and challenging in emergencies because it determines public trust in authorities over rumor and misinformation.

The COVID-19 pandemic reveals how socio-structural problems are recurrent in HIV services, which must be continuously worked on to strengthen them and ensure quality care that meets the UNAIDS goals.

Among these socio-structural aspects, the structural homophobia that pervades several, if not all, instances of the service, stands out. This factor not only affects the lives of people in the LGBTQIA+ community, it also undermines the service that fails to assist one of its most vulnerable audiences and, by and large, contributes to an unequal society.

In light of global shifts in financing investments for key populations most affected by HIV (e.g., the Global Fund's emphasis on sexual orientation and gender identity in its investment strategy), the importance of parallel efforts to reduce barriers access to HIV-related services is a global trend with local effects. Directed efforts to alleviate this inequality in access to evidence-based HIV prevention interventions for MSM are urgently needed to successfully contain the HIV epidemic in this population. For example, community-based social marketing campaigns targeting social media and peer health education strategies have shown promise in expanding HIV testing, treatment and knowledge among younger MSM.[13]

The few evidence-based interventions that are specific to these men prove inadequate, and scaling up existing HIV interventions alone is likely to be insufficient, social factors such as homophobia impede the acceptance of HIV prevention services, especially among this group. Disparities in incidence and access to prevention services among MSM will persist unless prevention services are tailored to specific needs, strategies that promote resilience are supported, and efforts to reduce barriers to access are developed and financed. Efforts and goals to eradicate HIV will only be possible through structural interventions that address homophobia and discrimination – including policies that decriminalize homosexuality – must be implemented and prioritized.[13]

Advocacy, targeting discriminatory laws, policies and practices, has also proven effective in removing barriers to HIV services, while evidence

of ensuring law enforcement is increasing. There is evidence of the impact of these types of human rights programs for people living with HIV and key vulnerable populations, ranging from reduced risk behavior to even reduced incidence. Furthermore, this evidence clearly points to the need for better training of health professionals to reduce stigma and programs that promote legal education and advocacy.[14]

But few adequately funded human rights programs address discrimination operating on a national scale. Often "stigma and discrimination" programs are small or emphasize stigma but ignore discriminatory laws, policies and practices. They have messages that urge everyone to act together to end stigma, while ignoring systematic mechanisms such as the judiciary that can identify and hold those who commit discrimination accountable.[15] Individualizing the problem, pointing as culprits to patients who seek PEP for exposing themselves, or professionals for homophobic attitudes, is a simplification of the problem that does not reach its roots and, consequently, moves away from a solution.

To truly achieve zero discrimination in healthcare settings, governments and the health sector need to recognize problems, such as those highlighted in this research, and change them with concrete actions. Integrating legal assistants into health facilities, creating ombudsmen, combined with independent monitoring and civil society advocates, would begin to make concrete that the services are truly zero discrimination. Achieving the "end of AIDS" is also about meeting health-related sustainable development goals, and requires a commitment to affordable, acceptable, and quality care for all.[16]

Our results, even coming from local services, are reflections of larger and structural problems, as mentioned above. The analysis of this reality, and the exploration of how it is connected to different areas of activity, also allows us to reflect on how the response to these problems does not depend on isolated attitudes, but on intersectoral actions.

In the context of sexual and reproductive health and rights and issues related to HIV, special attention should be given to people living with HIV, sex workers, transgender people, MSM, people who use drugs and people deprived of liberty, with additional attention to key adolescents and young populations. However, in the Brazilian reality, these are the people with the greatest difficulty in accessing healthcare services.

In recent material, WHO[16] recommends that national levels work with the criminal justice system and civil society partners to amend national laws and policies that have been proven to prevent people from accessing the services they need; reinforcing that joint and synergistic actions are needed to achieve change.

Most countries in the European Region have developed and started to implement comprehensive sexual and reproductive health strategies. They have been introduced since 1994, following the recommendations and Program of Action of the International Conference on Population and Development, organized by UNFPA in Cairo, Egypt. They often include intersectoral actions, especially with respect to interventions in the education and youth sector, including the prevention of sexual violence.[16,17]

A recurring theme in the interviews was the lack of automation in the process of accessing PEP, which is still bureaucratic and analogical. When looking for eHealth or mHealth strategies on the topic, a recent review[18] showed that there are very few initiatives dedicated exclusively to PEP, as most applications address generic aspects of HIV. Objective and content analyzes show that these apps are very similar to traditional strategies (booklets and websites) in that they use little or none of the wide range of tools that a smartphone can offer.[19]

In Singapore,[12] Government authorities provide daily information in the mainstream media, using Telegram and WhatsApp groups with doctors in the public and private sectors where more detailed clinical and logistical information is shared and authorities use websites to debunk misinformation that circulates.

The literature on prevention shows that changing individual behaviors is linked to community mobilization and changes in intersubjective con-

texts.[20] In the use of any of the preventive methods, it would be important – in the context of prevention policy – to develop actions aimed at community mobilization and promoting public debate about prevention, dimensions that are still little explored.

Conclusion

Access to PEP is hampered by the lack of knowledge about prophylaxis (which makes its search impossible), the centralization of healthcare services and stigmas that permeate the structures of healthcare services. Bureaucratic aspects, such as centralization of prophylaxis in specific centers, create physical barriers that prevent people from starting it in time, in addition to contributing to intangible barriers, such as widespread prejudice among professionals and service users and even public policies. These findings point to problems and, consequently, solutions that go beyond punctual and individualistic actions. Although they are complementary and important, they do not cover the real problems. Changing the structures of HIV services is necessary to combat the stigma that services carry, streamline them and bring them closer to communities.

Acknowledgments

This study is part of a doctoral thesis by Artur Acelino Francisco Luz Nunes Queiroz, which is financed through a graduate grant from the CNPq (Brazilian National Council for Scientific and Technological Development - (*Conselho Nacional de Desenvolvimento Científico e Tecnológico*).

Collaborations

Queiroz AAFL, Mendes IAC and Dias S collaborated with the project design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and final approval of the version to be published.

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