

I'm not a threat: A qualitative study on the mental health's aspects of women living with HIV in Brazil

Não sou uma ameaça: Um estudo qualitativo sobre aspectos de saúde mental de mulheres que vivem com HIV no Brasil

No soy una amenaza: Un estudio cualitativo sobre los aspectos de salud mental de mujeres que viven con VIH en Brasil

Received: 04/24/2024 | Revised: 05/02/2024 | Accepted: 05/03/2024 | Published: 05/05/2024

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Abstract

This study aimed to analyze aspects of the mental health of women living with Human Immunodeficiency Virus (HIV) in Brazil. To this end, was carried out qualitative research, anchored in the theoretical framework of Interpretive Anthropology, from January to March 2022, based on interviews with ten women living with HIV of reproductive age and undergoing treatment in a specialized public service in São Paulo, Brazil. Thematic Analysis was adopted as a methodological reference. Three thematic categories emerged from the data: Perception of the received care and its impact on mental health; Feelings related to living with HIV; and Perception of social stigma of HIV. The results showed that the mental health of women living with HIV was directly related to perceived health care, the information they receive, the way communication is established, and the bonds built in care. Feelings of fear, guilt and loneliness related to living with HIV and social stigma are elements that promote psychological suffering for these women. Sensitive and open strategies are essential to providing effective support and improving the lives of women living with HIV.

Keywords: HIV; Mental health; Gender discrimination; Gender inequality.

Resumo

Este estudo teve como objetivo analisar aspectos da saúde mental de mulheres que vivem com o Vírus da Imunodeficiência Humana (HIV) no Brasil. Para tanto, foi realizada pesquisa qualitativa, ancorada no referencial teórico da Antropologia Interpretativa, no período de janeiro a março de 2022, a partir de entrevistas com dez mulheres vivendo com HIV em idade reprodutiva e em tratamento em serviço público especializado de São Paulo, Brasil. A Análise Temática foi adotada como referencial metodológico. Dos dados emergiram três categorias temáticas: Percepção do cuidado recebido e seu impacto na saúde mental; Sentimentos relacionados ao viver com HIV; e Percepção do estigma social do HIV. Os resultados mostraram que a saúde mental das mulheres que vivem com HIV esteve diretamente relacionada à percepção do cuidado em saúde, às informações que recebem, à forma como a comunicação é estabelecida e aos vínculos construídos no cuidado. Sentimentos de medo, culpa e solidão relacionados ao convívio com HIV e o estigma social são elementos que promovem sofrimento psíquico para essas mulheres. Estratégias sensíveis e abertas são essenciais para fornecer apoio eficaz e melhorar a vida das mulheres que vivem com o VIH.

Palavras-chave: HIV; Saúde mental; Discriminação de gênero; Desigualdade de gênero.

Resumen

Este estudio tuvo como objetivo analizar aspectos de la salud mental de mujeres que viven con el Virus de Inmunodeficiencia Humana (VIH) en Brasil. Para ello, se realizó una investigación cualitativa, anclada en el marco teórico de la Antropología Interpretativa, de enero a marzo de 2022, a partir de entrevistas a diez mujeres viviendo con VIH en edad reproductiva y en tratamiento en un servicio público especializado en São Paulo, Brasil. Se adoptó como referencia metodológica el Análisis Temático. De los datos surgieron tres categorías temáticas: Percepción de la atención recibida y su impacto en la salud mental; Sentimientos relacionados con vivir con VIH; y Percepción del estigma social del VIH. Los resultados muestran que la salud mental de las mujeres que viven con VIH estuvo directamente relacionada con la atención médica percibida, la información que reciben, la forma en que se establece la comunicación y los vínculos construidos en la atención. Los sentimientos de miedo, culpa y soledad relacionados con vivir con VIH y el estigma social son elementos que promueven el sufrimiento psicológico de estas mujeres. Las estrategias sensibles y abiertas son esenciales para brindar apoyo efectivo y mejorar las vidas de las mujeres que viven con el VIH.

Palabras clave: VIH; Salud mental; Discriminación de género; Desigualdad de género.

1. Introduction

Mental health care has increasingly gained recognition as an essential component of comprehensive care due to its impact on individuals' lives, especially in the context of chronic diseases, such as Human Immunodeficiency Virus (HIV) (Arruda & Coutinho, 2021; Pinto & Fleury Seidl, 2022). In addition to the pathophysiological particularities of the condition, it is important to highlight psychosocial aspects, which elements impact (and how) mental health, such as the relationship between care provided by health professionals and the mental health of Women Living with HIV (WLHIV), a vulnerable population that faces unique challenges (Gomes et al., 2019).

WLHIV face an intersection of stigmas related to health status and gender, which can have a significant impact on mental health. In addition to the stigma surrounding HIV, these women may face discrimination and prejudice due to their gender, further increasing the psychological burden (Lima et al., 2021; Lima & Narchi, 2020; Paquiela et al., 2023).

Although the relationship between the care provided by health professionals and the mental health of WLHIV is an important topic, research exploring the relationship between the care offered by health professionals and the mental health of WLHIV is still limited, among the aspects that can impact their mental health.

In this context, this study aimed to analyse aspects of the mental health of WLHIV in Brazil. The main challenges faced by this population, gaps in existing research and possible intervention strategies that can be implemented to promote the mental health and well-being of these women will be considered.

2. Methodology

This is Qualitative Research, anchored in the theoretical framework of Interpretive Anthropology (IA) of Geertz, (2001). The methodological orientation that supported the study was Qualitative Thematic Analysis, proposed by Minayo (2014). The analytical process followed the steps described by the author, starting with the transcription process, which is deepened with immersion readings in the text. The definition of thematic nodes aimed to synthesize the identification of ideas contained in the texts that made up the corpus. Based on the analysis, the formation of categories was organized, based on similar text segments and the qualitative thematic analysis (Minayo, 2014).

The eligibility criteria for the participants were: being a woman in reproductive age, aged between 15 and 49 years old (WHO, 2009); being HIV positive; being monitored by the Specialized Public Service; residing in the state of São Paulo, Brazil. 18 women were approached, individually and in person, while waiting for care at the health service. Of these, eight refused to participate due to unavailability of time to carry out the interview. When invited to participate in the study, the interviewer introduced herself as a researcher, providing her credentials to them, the guiding questions for the interview, the objectives of the project and the main researcher's professional and personal motivations. Upon acceptance, the participants

chose the day and time for the interview. The sample was composed through convenience and there were no dropouts throughout the research.

Ten interviews were carried out between February 2022 and February 2023, with an average duration of 53 to 70 minutes, audio recorded, transcribed, and validated by the participants after transcription. The interviews were carried out in a semi-structured model according Minayo et al. (2018). The following questions were presented: 1- How did health professionals welcome you in the diagnosis result? 2- How does the care offered by health professionals influence your treatment? 3- What were your feelings when you discovered your seropositivity? 4- How do you perceive social behavior regarding the topic of HIV and how does this affect you emotionally?

At the time of the interview, before it began, the women signed a form consenting to their participation in the research, in accordance with the ethical guidelines. All interviews took place in a private room at the health service unit, only in the presence of the participant and the interviewing researcher, without the need for repetition. Immediately after each interview, the researcher recorded field notes. Data collection ended when the content of the last interviews carried out no longer altered the understanding of the phenomenon under investigation (Nascimento et al, 2018).

It's important to add that in qualitative research, data collection and analysis are simultaneous. The interviews were transcribed for later re-reading and analysis, based on the adopted methodological framework (Minayo et al., 2018). The analysis method consisted of exhaustive in-depth reading of data, seeking to identify the cores of meaning that made up the communication, so that their presence and frequency were relevant to the objective of the study. The analysis steps consisted of in-depth reading of the material; pre-analysis, phase in which the objectives of the study were revisited, comparing them with the collected material; from immersion, coding; and finally, in the treatment and interpretation of results based on the theoretical framework. The content of the interviews was grouped according to thematic similarity, resulting in categories (Minayo, 2014). The names of the participants were replaced to preserve anonymity, using sequential alphanumeric identifiers.

As support for data analysis, the use of the Iramuteq software, version 0.7 alpha 2, was adopted. Associated with the in-depth reading process, the use of the software analytical test made it possible to validate the thematic categories produced. Based on the analysis of the classes created and the words described in the software, relevant words were highlighted in the textual corpus (Barbosa et al., 2022; Camargo & Justo, 2016), which, based on the evaluation of the contexts, highlighted by the software, allowed the application of precepts inherent to the use Minayo's (2014) methodological framework.

It's followed the international ethical guidelines of the Declaration of Helsinki and the legal procedures for studies involving human beings required in the country in which the research was carried out. The research was evaluated and approved by the research ethics committee of the São Paulo Municipality Health Secretary.

3. Results

From the analysis of the interviews, three thematic subcategories were derived from the data: Perception of the received care and its impact on mental health; Feelings related to living with HIV; and Perception of social stigma of HIV.

In the first category, "Perception of received care and its impact on mental health", words such as consultation, converse, welcome, manner and doctor as starting points for in-depth analysis of the texts. Such words, but not only these, allowed observation of the textual contexts that supported the understanding of the elements of assistance, which have an impact on the emotional aspect of WLHIV.

The data indicate that the perception of the care offered by health professionals when providing care has a direct impact on how WLHIV deal with seropositivity throughout their lives.

Interpersonal relationships in which a bond was established between the woman and the professional, in which the woman felt welcomed and in which the communication established was kind and respectful, the impact on mental health was

positive, promoting feelings of security, tranquility and sensation of affection, especially in challenging circumstances such as the time when women were diagnosed with seropositivity. The excerpts illustrate this result, with emphasis on thematic nodes such as welcoming and effective communication:

“The Nurse was a fundamental part of my history and so he is a person that I will never truly forget (emotion in their voice), he provided us with the help we needed, the support we needed, he sat down and talked, explained, he supported us, he welcomed us at that moment.” (E1)

On the other hand, reports of professional care anchored by moral judgments, based on social stigma and in which violent communication was established resulted in psychological suffering in addition to impacting the (dis)continuity of treatment. The perception of a lack of empathy and acceptance by professionals directly affected adherence to treatment, leading to a lack of interest in maintaining clinical follow-up and abandonment of follow-up:

“She treats us as if we were the proliferation of this thing, you know? It's like you're irresponsible, you're not careful and that's why you're the way you are. After the day she yelled at me in her office just because I didn't bring my vaccination card... I came again, I think, only once more. Because if I have to see her again, I won't come here anymore.” (E4)

“He treated me so badly...if I hadn't had these people: my daughter, my friend, this strength, God, I don't know what I would have done, I left here destroyed, the way he treated me was horrible. I have never felt so mistreated. That hurt me so much, so much, because it was my first contact with a doctor on this issue and it took me to rock bottom.” (E9)

In the second category, “Feelings related to living with HIV”, words such as depression, anxiety, guilt, sadness, and crisis appeared frequently in the in-depth analysis of the texts. Such words allowed the observation of the textual contexts that supported the understanding of the emotional aspects that originate from the moment HIV is discovered, and how such discovery influences the lives of WLHIV over the years.

Negative feelings related to living with HIV were elements that promoted psychological suffering for WLHIV. Fear was frequently reported by participants, especially in relation to their own death and viral transmission. The fear of death permeated the imagination of WLHIV, contributing to worsening mental health and affecting their life routine:

“I no longer slept, my cell phone woke up almost every half hour to let me know I was alive, I slept with the TV on because I was afraid that I don't know, no, no (I stutter) I wouldn't wake up.” (E3)

The fear of viral transmission was another facet of fear reported by the participants, related to family emotional relationships and the feeling of being a possible transmitter of the infection to loved ones:

“...It was difficult, it was depressing, I suffered a lot, I had no appetite. Then I didn't want to take the medication... but I was very afraid because I was afraid of passing it on to my son, I was afraid of him having it too.” (E10)

In addition to fear, the feeling of guilt deserves to be highlighted in the statements of the participating women. Blaming oneself for the infection itself led to mental suffering, emerging in the statements as causing common disorders such as anxiety and depression.

“I would simply get up, feed my baby, take a bath and sleep. 10, 15, 20 baths a day (shaking voice), which was the only thing that calmed me down, I had a lot of anxiety attacks and during my anxiety attack I would either clean or take a shower.” (E1)

Loneliness was a notable feeling in some statements and appeared associated with other negative feelings, fear and guilt, especially related to the decision to reveal or not the diagnosis and the reaction of their partners:

“He started to treat me indifferently, he no longer made a point of pleasing me or anything, we stopped talking, he moved away from me, he completely moved away from me. And I started feeling very lonely.” (E10)

In the third category, “Perception of the social stigma of HIV”, words such as talking, prejudice, telling, transmission and threat permeated the speeches of WLHIV, when analysing the reflections of the perception of social stigma on their experiences.

The perception of social stigma and the way people position themselves was another element that promoted psychological suffering in the interviewees. In the speeches, in addition to negative feelings related to confronting social stigma, coping tactics stood out. The excerpts illustrate the feeling of shame, the prejudice experienced in everyday life, the trauma perceived in response to humiliating situations and social coping strategies and how to deal with the infection itself:

“There was a guy I got involved with [...] he found out about my diagnosis [...] He replied that he had the right to know, because he had taken a risk by sleeping with me. [...] I said that we had never hook up without a condom. He said that's not the only way to get infected, at that time I got stressed, I left crying a lot [...] (E5)

4. Discussion

Living with HIV is extremely challenging, and when we associate this reality with being a woman, we see the challenges increase. The social vision that stigmatizes those who live with the virus, marking them as transgressors, practitioners of conduct that is not consistent with moral standards, has been present since the beginning of the infection. The experience of stigmatization, permeated by prejudice and discrimination, can have harmful effects on the health of people living with HIV (Lima et al., 2021; Lourenço et al., 2018; Nascimento et al., 2019; Silva et al., 2021).

Empathetic reception, from the time of diagnostic disclosure should be a primary concern in care practice. Humanized care by the multidisciplinary health team is essential in the composition of the support network for WLHIV. This practice is essential in promoting mental health, which is why the attention of professionals must be focused on fully accepting the demands presented, going beyond the biological aspects of the infection, welcoming and valuing the emotional aspects presented (Cavalcante et al., 2021; Muniz & Brito, 2022).

Building a bond between health professionals and those receiving care has important impacts on adherence to treatment and improvements in the quality of life of WLHIV (Cavalcante et al., 2021; Lima et al., 2021; Muniz & Brito, 2022). The actions of the health team build a welcoming and safe environment, ensuring that the individual is fully cared for, respecting their health and disease process (Fonseca & Pires Perez, n.d.; Lima et al., 2022).

However, the literature shows that WLHIV lack sensitivity and openness to dialogue with health professionals, which makes it difficult to establish bonds and, consequently, to adhere to treatment. These actions contribute to the removal of these people from health services and contribute to the feeling of abandonment. The affective dimension in the relationship between

health professional and user is important, considering the humanization process as a dialogue that allows and encourages integration between technical care and the user's life projects (Amaral et al., 2023; Gomes et al., 2019; Lima et al., 2022).

This demonstrates that health teams that deal with WLHIV need to be attentive to the biological, psychological, clinical, and social demands of women who live with HIV/AIDS, thus taking into account the feelings and sociocultural particularities of each woman (Silva et al., 2018).

Since HIV is an infection that remains pandemic and has no cure, as well as being strongly associated with stigma, prejudice, and discrimination, it is not uncommon for WLHIV to receive such a diagnosis and be permeated by negative feelings and even denial of the serological condition. In this context, both family and health team support are essential for maintaining the mental health of WLHIV, with the aim of reducing rates of emotional disorders, such as depression (Hernandes et al., 2019; Santos et al., 2019). Although HIV-related mortality decreased, stigmatization is still frequent up to these days. This perception is present when the woman receives the diagnosis, causing a confrontation between life and death.

WLHIV have their daily lives affected by the constant fear of transmitting the virus to their family members. This is due to a lack of knowledge about how HIV contamination occurs and social stigma, which makes these women feel isolated and guilty (Lima et al., 2021, 2022).

The data collected corroborates the findings that WLHIV are afraid of revealing their serological status to their partners, because there are many social stigmas surrounding seropositivity in women, who often, when revealing their diagnosis, are labelled as promiscuous. Thus, WLHIV are afraid of transmitting the virus and telling their partner about the diagnosis, fearing being rejected or abandoned (Juliano et al., 2022).

The feeling of guilt regarding the discovery of serological status reflects the social stigma faced by WLHIV, who are socially suggested to have “risky behaviors” due to their seropositivity. However, the data analyzed counter this social stigma, given that the majority of WLHIV were infected by their sexual partner, in a stable heterosexual relationship at the time of infection (Cardoso, 2021; Moura, 2020).

5. Final Considerations

The mental health of WLHIV was directly related to the perceived health care, the information they receive, the way communication is established, and the bonds built in care. Feelings of fear, guilt and loneliness related to seropositivity, HIV infection and the disclosure of the diagnosis and social stigma are elements that promote psychological suffering for WLHIV. Sensitive and open strategies are essential to provide effective support and improve the lives of these women.

By understanding the importance of sensitive and integrated care for WLHIV, this study contributes to greater awareness of the psychosocial needs of these women, in addition to providing valuable insights for clinical practice and the development of public policies that promote comprehensive care and mental health of those women.

The themes that emerged from the analyzes that originated the thematic categories deserve further research whose focus is to understand the meanings of the contexts indicated by the women. Mental health issues are highlighted nowadays, especially after the Covid 19 pandemic. Understanding the effects of psychosocial health on the emotional and social experiences of people living with HIV can contribute to the development of focused soft technology tools in promoting adherence to treatment, improving quality of life, promoting health and the consequent qualification of care.

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