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Repercussions of Human Immunodeficiency Virus diagnosis and perspectives on treatment

Repercussões do diagnóstico do Vírus da Imunodeficiência Humana e perspectivas acerca do tratamento

Repercusiones del diagnóstico del Virus de la Inmunodeficiencia Humana y las perspectivas a cerca del tratamiento

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ABSTRACT

Objective: To analyze the repercussions of Human Immunodeficiency Virus (HIV) diagnosis and the perspectives on the treatment in people attending a testing and counseling center. **Methods:** A qualitative research was carried out using analysis of narratives of 28 people living with HIV treated at a testing and counseling center in Pinheiro, Maranhão, Brazil. From February to June 2019, semi-structured interviews were carried out using sociodemographic questions about diagnosis and treatment. **Results:** Post-diagnosis impact and treatment perspectives were categories that emerged from the analyses. The narratives showed the ways in which the HIV diagnosis can reflect on the individual's life, especially regarding social and economic issues and the confrontation of stigma and prejudice related to the infection. Although important for the maintenance of health, antiretroviral therapy can face obstacles due to the challenges that affect the research participants. **Conclusion:** Distancing from family and friends, the feeling of exclusion, the greater concern with health and the difficulty in earning an income represent the greatest repercussions after diagnosis. Thus, treatment is considered a measure to promote health and prevent the progress of infection, but it can be affected by several issues, including financial ones.

Descriptors: HIV; Diagnosis; Psychosocial Impact; Qualitative Research.

RESUMO

Objetivo: *Analisar as repercussões do diagnóstico do Vírus da Imunodeficiência Humana (HIV) e as perspectivas acerca do tratamento em pessoas atendidas em um centro de testagem e aconselhamento.* ***Métodos:*** *Realizou-se uma pesquisa qualitativa, por meio da análise de narrativas de 28 pessoas que vivem com HIV atendidas em um centro de testagem e aconselhamento de Pinheiro, Maranhão, Brasil. Durante o período de fevereiro a junho de 2019, aplicaram-se entrevistas semiestruturadas contendo questões sociodemográficas, sobre o diagnóstico e o tratamento.* ***Resultados:*** *Os impactos pós-diagnóstico e as perspectivas sobre o tratamento apresentaram-se como as categorias emergentes das análises. As narrativas demonstraram as formas como o diagnóstico do HIV pode refletir na vida do indivíduo, principalmente quanto às questões social e econômica e quanto ao enfrentamento de estigmas e preconceitos relativos à infecção. A terapia antirretroviral, ainda que importante para a manutenção da saúde, pode sofrer empecilhos devido aos desafios que acometem os participantes da pesquisa.* ***Conclusão:*** *O afastamento de familiares e amigos, o sentimento de exclusão, a maior preocupação com a saúde e a dificuldade de obter renda representam as maiores repercussões no pós-diagnóstico. assim, o tratamento é considerado uma medida de promoção à saúde e impedimento de avanço da infecção, podendo ser afetado por diversas questões, dentre elas a financeira.*

Descritores: *HIV; Diagnóstico; Impacto psicossocial; Pesquisa Qualitativa.*

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RESUMEN

Objetivo: *Analizar las repercusiones del diagnóstico del Virus de la Inmunodeficiencia Humana (VIH) y las perspectivas del tratamiento de personas asistidas en un centro de pruebas para el diagnóstico y consejería.* ***Métodos:*** *Se realizó una investigación cualitativa a través del análisis de narrativas de 28 personas que tienen el VIH y que son asistidas en un centro de pruebas de diagnóstico y consejería de Pinheiro, Maranhão, Brasil. Se aplicaron entrevistas semiestructuradas con preguntas sociodemográficas, el diagnóstico y el tratamiento durante el período entre febrero y junio de 2019.* ***Resultados:*** *Los impactos pos-diagnóstico y las perspectivas sobre el tratamiento se presentaron como las categorías emergentes de los análisis. Las narrativas demostraron las formas como el diagnóstico de VIH puede influenciar en la vida del individuo, en especial sobre los aspectos social y económico y sobre el enfrentamiento de los estigmas y perjuicios de la infección. La terapia antirretroviral, aunque sea importante para la manutención de la salud, puede tener objeciones debido a los desafíos que acometen los participantes de la investigación.* ***Conclusión:*** *El alejamiento de los familiares y los amigos, el sentimiento de exclusión, mayor preocupación con la salud y la dificultad de una renta representan las mayores repercusiones del pos diagnóstico. De esa manera, se considera el tratamiento como una medida de promoción de la salud y barrera para el avanzo de la infección que puede ser afectado por distintos aspectos, entre ellos, el financiero.*

Descriptores: *VIH; Diagnóstico; Impacto Psicosocial; Investigación Cualitativa.*

INTRODUCTION

The availability of sophisticated tests for the detection of the Human Immunodeficiency Virus (HIV) and the increased survival of people living with HIV, as a result of antiretroviral therapy, are evidence of advances in attention and care provided to these people. In 2019, an estimated 38 million people were living with HIV worldwide. At the end of June 2020, 26 million of these people had access to treatment(1).

Despite legal support and the expansion of care in Brazil, this population group is the target of stigma and repercussions arising from its diagnosis(2,3). This can be seen when erroneous ideas are conveyed about the ways in which the virus is transmitted, about behaviors considered to be risky, and the stereotypes related to people with HIV (“sick”, “contagious” or “irresponsible”)(4). A survey carried out between April and August 2019 by UNAIDS – a United Nations program that seeks solutions to tackle AIDS – with 1,784 people living with HIV found that 46.3% of the participants felt that they were the target of discriminatory or speculative comments and 25.3% reported having been victims of verbal harassment, thus indicating that this population group still lives with repercussions that arise from the diagnosis of the infection(5).

This problem, associated with the fact that it is a chronic infection, makes the diagnosis of HIV a milestone in the trajectory of individuals, especially in terms of psychosocial, family, financial and cultural aspects. Discrimination and judgment from family and friends result in weaknesses in social interactions, as well as in isolation of people living with HIV(5). This can even influence that some of them choose to omit the diagnosis from people close to them as a way to face the infection and avoid prejudice(6).

In the international scenario, there is evidence that health organizations adopt the strategy of mass testing and early treatment in order to diagnose quickly and reduce the risk of transmission through the immediate initiation of treatment. Thus, it is expected that the dissemination of the positive effects of this strategy will reflect in the mitigation of associated stigma, thereby contributing to the indication that the diagnosis and treatment make the promotion of health of people living with HIV possible(7).

Despite the relevance of the advances achieved, the discovery of the infection still has important repercussions for the lives of people with HIV(1,5-7). Thus, it is interesting to direct attention so that there is an investigation of these repercussions and perspectives regarding the treatment of the infection. Thus, the present study aims to analyze repercussions of the diagnosis of the Human Immunodeficiency Virus (HIV) and perspectives on treatment among people assisted at a testing and counseling center.

METHODS

A qualitative study was carried out using the method of narrative analysis, a research method that allows capturing stories and life experiences of the subject interviewed in addition to their relationship with the social, cultural and historical contexts in which they are inserted(8). The study was carried out following the consolidated criteria for reporting qualitative research (COREQ) and methodological guidelines for the synthesis of qualitative research(9,10).

The study was carried out at the Testing and Counseling Center (TCC) located at the Center for Medical Specialties in the municipality of Pinheiro, Maranhão, Brazil. TCC serves the local population and people from other municipalities in the Baixada Maranhense, a geographic microregion with about 20,000 km² covering 21 municipalities.

Data were collected from February to June 2019 from people waiting for an appointment or receiving their antiretroviral medication. People living with HIV over 18 years of age, of both sexes, who agreed to participate in the research, were included. Exclusion criteria were: people with HIV under 18 years of age and/or with severe neurocognitive alterations that hindered the application of the research instruments. Thus, a convenience sample of 28 people living with HIV was used.

The semi-structured interview followed a questionnaire with questions on the sociodemographic and economic characterization of the participants: sex, age, race/color, education, marital status, municipality of residence and monthly income. Additionally, it contained questions about diagnosis and treatment: “Has your life changed after the diagnosis of the infection? In what sense?”; “Do you think the treatment is important? Why?”; and “What do you see as something that most hinders the treatment?”.

With interviews conducted individually by trained researchers and lasting 25 minutes on average, there was no need to record them, but simultaneous transcriptions of the participants’ narratives were carried out. Thus, after data collection, the narratives were analyzed based on two categories: post-diagnosis impact and treatment perspectives.

An informed consent form was read before the beginning of the interviews so that participants could reflect on their willing to participate. All those who agreed to sign the consent form were anonymized using coded numbers for identification. The study previously respected all ethical aspects of field research and was approved by the Research Ethics Committee of the Federal University of Maranhão, under Approval No. 2.984.868/2018.

RESULTS AND DISCUSSION

Twenty-eight people living with HIV participated in the study. Their age ranged between 26 and 67 years, 15 were women (53.57%), 17 (60.71%) were self-declared *Pardos* (mixed-race Brazilians), 18 (64.28%) had less than eight years of study, 25 (89.28%) lived without a partner and 22 (78.57%) lived in other municipalities in the Baixada Maranhense or in municipalities outside the region.

As for economic status, 19 (53.20%) participants had a monthly income of less than 1 minimum wage, 12 (42.85%) were part of the Economically Active Population (EAP) as self-employed and 11 (39.28%) were unemployed.

These results contribute to the identification of the epidemiological profile of the infection, to the strengthening of surveillance systems, to the provision of greater attention to people with these characteristics, and to health promotion(11,12). Thus, economic conditions can have a decisive impact on the lives of people living with HIV since safe treatment involves adequate and good quality food in addition to financial resources for transport to the health service and expenses with extra medications that may be necessary(13).

Furthermore, the impact on professional life is often influenced by stigma, such as the fear of contagion and the idea that people living with HIV have less work capacity and limitations imposed by infection and treatment. In this context, people with the infection give up their jobs or resort to informal jobs, resulting in low wages, economic instability, limited access to health services and less social and legal support(14).

During the process of analyzing the narratives, two categories emerged: post-diagnosis impact and treatment perspectives. These are presented next.

Post-diagnosis impact

When asked about the HIV diagnosis, participants provided information about life changes after the discovery of the infection. Prejudice and distance from family and friends were highlighted. Thus, the participants reported suffering discrimination due to their health condition:

> *“Yes, life has changed for the worse because of prejudice, especially from family members.” (P1)*
>
> *“I feel excluded and I suffer prejudice from society.” (P23)*
>
> *“Some things changed for the worse, because I didn’t have support from family and friends.” (P15)*
>
> *“I feel discriminated against, but I’m also more humanized with others.” (P3)*

Stigma and prejudice are challenging factors in the routine of people living with HIV and can result in distancing from family and friends(15). There are also links between stigma and social issues, such as gender(16) and feelings of inferiority and incapacity when relating to other people, which are the result of the influence of prejudice on self-perception(17).

In addition to affecting self-esteem, this scenario impairs the feeling of inclusion of people living with HIV, contributing to isolation, loss of social and emotional support and fear of interpersonal interaction(15,16). What can be seen is that the negative attributions linked to HIV refer to the 1980s, when the virus was beginning to be studied(18,19).

Another aspect found in the present study was the greater attention to health after diagnosis. For participants, there is a fear of acquiring other infections or concern for finding themselves more fragile. Therefore, this fear led them to abandon old habits:

> *"I'm worried about my health and now I have to take medication forever." (P8)*
>
> *"I began to have a feeling of fragility." (P11)*
>
> *"My health got more vulnerable." (P18)*
>
> *"My life has changed because before I liked to party, to go out and now I don't think I can anymore." (P12)*
>
> *"I decreased the intake of alcohol and now I live with few people." (P21)*
>
> *"I don't go out to run my errands anymore." (P27)*

Associated with these feelings of fragility and vulnerability is the change in lifestyle, such as the decrease in the intake of alcoholic beverages. Based on similar narratives found in a study carried out in Bahia with 11 women living with HIV, there is evidence that self-care, proper use of medication and personal and social responsibilities with the partner, including condom use, were among the main repercussions after the discovery of the infection(20).

These changes are fundamental for the success of the treatment, contributing to the effectiveness of the drugs and to the prevention of comorbidities and co-infections(21). On the other hand, the feeling of vulnerability can trigger the renunciation of activities that were previously considered pleasurable or routine and affect the idea of life expectancy and the ability to make short and long-term plans(22).

For other participants in the current study, the diagnosis also culminated in changes in mood and behavior. These manifested through sadness, irritability, and a decrease in interest in socializing with other people or in sexual relations:

> *"Life isn't the same anymore. I'm afraid of having health issues, I feel different from others and I no longer have the ambition to be with other people." (P6)*
>
> *"Life got worse. I got saddened and very angry." (P17)*
>
> *"I have less interest in sexual relations. I'm afraid of being violated by my partner because of the disease." (P20)*

HIV infection is considered a triggering factor for the onset of psychiatric disorders or the exacerbation of pre-existing conditions, such as depressive symptoms. People living with HIV are more susceptible to depression due to different mechanisms: direct effect of infection; adverse effects of antiretroviral therapy; and socio-behavioral challenges that come with the diagnosis, such as stigma, discrimination and fear of death(1-3).

Depressive symptoms may be associated with the progression of the infection, with the decline of immune function and with failure in adhering to treatment. In this population group, depression tends to manifest through somatic symptoms, such as irritability, low willingness to work, loss of libido, fatigue or affective-cognitive symptoms, which include sadness, pessimism and feelings of failure and guilt(23).

Although less frequent, there were some narratives in the study that highlighted a positive impact after diagnosis. In that regard, the diagnosis enabled greater health care and the search for quality of life, as shown below:

> *"It changed for the better because I now consider every day a new opportunity." (P5)*
>
> *"I'm more thoughtful in life." (P9)*
>
> *"I started to take better care of myself." (P10)*

Based on reports such as those mentioned above, a study with HIV patients in 2016 in Rio de Janeiro observed the impact of resilience on coping with infection and adherence to treatment(7). Continuous monitoring of health in general promotes the health of these people, because by making more use of resources for self-care it is possible to prevent opportunistic infections and late discovery of diseases(24).

Treatment perspectives

The possibility of antiretroviral therapy increasing survival was presented as the main justification for participants to understand treatment as important in addition to improvements in quality of life and health status. They also considered the therapy to be beneficial for strengthening immunity and controlling co-infections:

> *"To live longer and not get sick." (P1)*
>
> *"To increase longevity." (P2)*
>
> *"To have quality of life, improve immunity." (P3)*
>
> *"I want to keep my health good and not get sick for any reason." (P8)*
>
> *"My health condition improved, before the medication I felt weak, ill, then everything improved." (P10)*

These narratives demonstrate that acknowledging the need to use medication and its health benefits is a fundamental step towards adherence to treatment in the experience of people with HIV(25). The subjective, psychosocial and social dimensions influence the way these people observe and adhere to the treatment. Thus, it is important that there are interventions conducted by health professionals to influence people living with HIV to improve knowledge and self-care(26).

An integrative review corroborates this finding by revealing that the interprofessional approaches of health professionals improve the chances of successful therapy. One way in which this can happen is through in-depth explanations about the possible adverse effects and also the benefits, thus ensuring adherence by people living with HIV(27).

Family support is also very important both for the acceptance of the diagnosis and for the treatment. The absence of this support results in negative reactions to the HIV diagnosis, which can cause people living with the infection to leave this important social circle and impair therapy follow-up(28).

The association between quality of life and family support should be considered in the care of those who have the infection, as some dimensions can benefit from specific aspects of family support(29). Thus, this support can have positive effects that range from influencing the maintenance of treatment, coping with the disease and promoting the health of people living with HIV:

> *"My children encourage me to take better care of my health." (P20)*
>
> *"I have more family support to face the disease." (P22)*
>
> *"Family support is an important factor for therapeutic adherence." (P26)*

The participants in the present study pointed out the factors that most hinder the treatment: the distance from where they live to the TCC and the expenses with commute. Considering that most of the people assisted at this center are residents of other municipalities in the Baixada Maranhense and even municipalities outside the region, frequent visits to the health service can hence become a hindrance as individuals need to pay for the inter-municipal travel to receive medication and attend consultations with the health team. This can be worse as most respondents have a monthly income limited to less than the minimum wage:

> *"The lack of money, the difficulty in coming to get the medication." (P8)*
>
> *"It's hard to get the medicine, I don't live here and I don't always have the money to come." (P15)*

Financial instability and lack of employment are significant factors for the irregular use of medications and non-adherence to therapy(26). An Ethiopian study showed that people living with HIV and living far from urban centers, in rural communities, present more challenges in adherence to treatment due to, among other factors, the long distance to health services(29).

It should be noted that most of the interviewees in the present research have less than eight years of study. In addition to influencing professional occupation, low levels of education can also compromise obtaining and understanding information about the infection and access to better resources for coping with the serological condition(28). The difficulty encountered in having to take the medication daily also appears in the reports. In addition, mood swings and lack of interest were also evident:

> *"Lack of interest." (P5)*
>
> *"It gets in the way of having to take medication every day." (P19)*

> *“Sadness, sometimes I can’t get interested in anything.” (P26)*

Reports like this are consistent with another study, which shows that interruption of the regular use of medications can be associated with moments of sadness, irritability and stress. The need to take medication daily can be a challenge, especially for younger people who have their routine changed due to strict medication schedules, restriction of activities and adverse effects(20).

For other interviewees in this study, there are difficulties related to the TCC itself, such as occasional visits to the site without receiving the medication or even failed attempts to contact the team by phone, as seen in the following reports:

> *“The usual lack of medicines, we come here and we don’t get them.” (P1)*
>
> *“They don’t answer the TCC phone.” (P7)*

The present study had limitations such as the lack of characterization of the clinical status of the research participants and the failure to specify the type of antiretroviral therapy they use. Another limitation is related to the degree of veracity of the narratives, but we tried to get as close as possible to the reality of the participants, explaining in detail the importance of the research.

FINAL CONSIDERATIONS

This study identified post-diagnosis repercussions and perspectives on treatment from the point of view of people living with HIV. It was observed that the participants’ reflections represent a series of challenges and reconfigurations in the family, psychological, socio-behavioral and financial spheres.

The distance from family and friends, the feeling of exclusion, the greater concern with health and the difficulty in earning an income stood out as important changes in post-diagnosis life. In addition, it was observed that treatment is considered an important measure for maintaining health and preventing the progress of the infection. However, therapeutic adherence can be affected by different issues, such as mood swings, distance from the treatment site, financial problems and participants’ lack of interest.

CONFLICTS OF INTEREST

The authors declare there are no conflicts of interest.

CONTRIBUTIONS

Ana Eliza de Carvalho Fonseca and **Paola Trindade Garcia** contributed to the conception and design of the study; the acquisition, analysis and interpretation of data and the writing and revision of the manuscript. **Ana Beatriz Barbosa Lima Nascimento** and **Renata Cristina dos Santos Oliveira** contributed to the conception of the study; the acquisition, analysis and interpretation of data and the writing and revision of the manuscript. All the authors approved the final version of the manuscript and are responsible for its content, accuracy and integrity.

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