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RESEARCH

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LIFE CONDITIONS OF PEOPLE LIVING WITH HIV IN A CITY OF THE STATE OF RIO DE JANEIRO, BRAZIL

Condições de vida de pessoas vivendo com HIV em um município do estado do Rio de Janeiro, Brasil
Condiciones de vida de las personas que viven con el VIH en un municipio del estado de Río de Janeiro, Brasil

Maria Inês Ferreira¹ 

Fabiana Barbosa Assumpção de Souza² 

ABSTRACT

Objective: investigate the implications for the life conditions of people living with HIV in a city of the State of Rio de Janeiro, Brazil. **Method:** cross-sectional, descriptive, and qualitative study. Data collection was conducted through interviews, and the findings were subjected to the content analysis technique. The sample comprised people living with HIV that were approached at the time they attended the specialized assistance service, and a sample of 20 participants was defined by saturation technique. **Method:** cross-sectional, descriptive, and qualitative study. Data collection was conducted through interviews, and the findings were subjected to the content analysis technique. The sample comprised people living with HIV that were approached at the time they attended the specialized assistance service, and a sample of 20 participants was defined by saturation technique. **Result:** categories emerged based on the topics addressed in the interview related to quality of life (food condition, physical activity, leisure, religion, and satisfaction with sexual life) and the experience of living with HIV. **Conclusion:** : people living with HIV in antiretroviral treatment can enjoy good living and the preventing potential factor is the fear of experiencing situations of stigma and discrimination.

DESCRIPTORS: HIV seropositivity; Public policies; Health-related quality of life.

¹Federal University of the State of Rio de Janeiro, Rio de Janeiro, Rio de Janeiro, Brazil.

²Arthur Sá Earp Neto University Center, Petrópolis, Rio de Janeiro, Brazil.

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Corresponding Author: Maria Inês Ferreira m.inesferreira@unirio.edu.br

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RESUMO

Objetivo: : discorrer sobre as condições de vida das pessoas vivendo com HIV em um município do estado do Rio de Janeiro, Brasil. **Método:** estudo do tipo transversal, descritivo, de natureza qualitativa. A coleta de dados foi através de entrevistas, sendo os achados submetidos à técnica de análise de conteúdo. A amostra foi composta por pessoas vivendo com HIV que eram abordados no momento que compareciam ao serviço de assistência especializada, sendo definida uma amostra de 20 participantes por técnica de saturação. **Resultado:** emergiram categorias com base nos temas abordados na entrevista relacionados à qualidade de vida (condição de alimentação, atividade física, lazer, religião e satisfação com a vida sexual) e à experiência de viver com HIV. **Conclusão:** as pessoas vivendo com HIV, em tratamento antirretroviral, podem usufruir de boas condições de vida tendo como principal fator impeditivo o medo de vivenciar situações de estigma e discriminação.

DESCRITORES: Soropositividade para HIV; Políticas públicas; Qualidade de vida relacionada à saúde.

RESUMEN

Objetivos: conocer las implicaciones para las condiciones de vida de las personas que viven con el VIH en un municipio del Estado de Río de Janeiro, Brasil. **Método:** estudio de tipo transversal, descriptivo, de naturaleza cualitativa. La recolección de datos se realizó a través de entrevistas, y los hallazgos fueron sometidos a la técnica de análisis de contenido. La muestra se compuso por personas que viven con el VIH que fueron abordadas en el momento en que vinieron al servicio de asistencia especializada, y se definió una muestra de 20 participantes por la técnica de saturación. **Resultados:** emergieron categorías basadas en los temas abordados en la entrevista relacionados con la calidad de vida (condición alimentaria, actividad física, ocio, religión, y satisfacción con la vida sexual) y la experiencia de vivir con VIH. **Conclusión:** las personas que viven con el VIH en tratamiento antirretroviral pueden disfrutar de buenas condiciones de vida y salud, y el principal impedimento y el temor de experimentar situaciones de estigma y discriminación.

PALABRAS CLAVE: Seropositividad para VIH; Políticas públicas; Calidad de vida relacionada con la salud.

INTRODUCTION

After 40 years of the beginning of the AIDS pandemic, the World Health Organization (WHO) has set goals aiming to end the disease as a threat to public health by 2030, but to achieve them, it is necessary the involvement of all countries with the implementation of assertive and consistent public policies. To this end, in addition to ensuring access and adherence to antiretroviral therapy (ART), it is necessary to promote improved living and health conditions for People Living with HIV (PLHIV), health equity, and well-being with broad access, without stigma or prejudice, and with financial security.¹⁻³

As ART provides viral suppression, life expectancy increases, and longer life expectancy leads to metabolic changes, loss of neurocognitive functions, aging, and others that can impact activities of daily living and interfere with quality of life.⁴ In order for PLHIV not to get sick, besides medication, they must have good living conditions, which involve physical, mental, spiritual, psychological, and emotional well-being, social relationships, access to health care, education, housing, food, and the adoption of healthy habits.⁵

Healthy eating, very important for promoting quality of life, can be simple, tasty, rich, and diverse, and still offer what our body needs. Dedicating time and putting our hands in the dough is an important step to always have real food on the table. In order to increase people's autonomy in their food choices, it is essential to have access to reliable and

consistent information, respecting the population's identity and food culture.⁶⁻⁷

Physical activity, also essential for quality of life, should be integrated into Primary Care (Atenção Básica - AB), which has infrastructure, equipment, and qualified professionals for its promotion through the Academia da Saúde Program.⁸

For the leisure activity, it is intrinsic to leave home to socialize. Therefore, during the Covid-19 pandemic, many people, even with isolation orientation, took the risk and went out, while others stayed at home for a long time, which may have interfered with their life routine, which, added to HIV, may also have triggered psychological and social changes and provoked feelings that lead to social isolation as a consequence of negative stereotypes, discriminatory and prejudiced labels imposed by society.⁹⁻¹¹ The approach of social and family issues, satisfaction with health, and the condition of living with seropositivity over time may represent a reworking of the life processes of PLHIV.¹²

The spiritual dimension is considered an important part of the process of illness and healing. However, there is resistance in valuing the religious dimension because it is a field marked by the domination of a hierarchy that has historically shown itself to be authoritarian and dogmatic, which makes people withdraw and not find meaning.¹ Moreover, a dualistic vision that separates the "world of matter" from the "world of spirit" has made it illegitimate to consider the religious dimensions of human life in the investigation of the genesis of diseases and in the search for therapeutic

measures, which leads professionals, professors, and researchers not to bring religious knowledge and experiences into the scientific debate.¹³

The quality of sexual life is one of the pillars of quality of life, and sexuality may be affected by the fear of infecting partners or acquiring other sexually transmitted infections.¹⁴ The social representation of the sexual life of PLHIV may undergo changes after the diagnosis of HIV, because what used to be based on freedom and sexual desire, today may represent something regulated and limited, which compromises the quality of life, preventing them from exercising their sexuality in a pleasurable and full way.¹⁵

There is a serious problem that persists since the beginning of the HIV/AIDS pandemic, which negatively interferes in the results of ART, which is stigma and prejudice.¹⁶ Most PLHIV have experienced at least some situation of discrimination throughout their lives, which has proven to be a major obstacle to initiation and adherence to treatment, in addition to having a negative impact on social relationships, an important and worrisome picture of the daily discrimination situations to which PLHIV are exposed in Brazil. For this reason, many PLHIV cannot disclose their diagnosis even to fixed partners.¹⁷ Factors such as prejudice and stigma rooted in society may lead many PLHIV to hide their diagnosis and, above all, stay away from health services, which prevents the access to treatment and, consequently, makes it impossible to reach the bold global goal of ending the AIDS epidemic by 2030.¹⁸ In this sense, it is essential that interventions in Mental Health are offered, not only for users, but also involving family and community, in a holistic and humanized way. Furthermore, the stimulus to political and social engagement is also important to break with narratives marked by suffering, fear, stigmatization, and silencing. Diagnosis, affection, sex, intimacy, and HIV should intertwine, producing diverse effects on self-care, on the safety of sexual practices, on identity, and on the construction of new sexual and loving relationships.

This study is justified by the importance of knowing and giving visibility to public policies aimed at promoting and improving the living conditions of PLHIV. In addition, it is justified by allowing to reflect on the implications related to living with HIV, such as facing stigmas and prejudices, which interfere drastically in adherence to ART and hinder the achievement of the WHO goal of ending the AIDS pandemic as a public health problem by 2030.

Given the above, this study aims to discuss the living conditions of people living with HIV in a city in the state of Rio de Janeiro, Brazil.

METHODS

This is a cross-sectional, descriptive, qualitative study.

The selection of participants was carried out in the period between July and August 2022 by approaching users living in the field municipality of the research, at times when they attended the specialized care service on HIV/AIDS for withdrawal of medication, medical appointments and collection of tests. The inclusion criterion was to be at least 18 years old at the time of data collection and to be residents of the municipality where the research was carried out; the exclusion criterion was not to be clinically and/or cognitively able to answer the research questions. The sample was defined by saturation, i.e., when the data obtained started to present redundancy or repetition, being closed with a number of 20 participants.

Data collection was carried out through interviews recorded by a cell phone application (Super Recorder) and transcribed by the researchers, the participants being identified by numbers (P1, P2, and so on), thus guaranteeing anonymity. The findings were organized, categorized and analyzed based on the Content Analysis technique assumed by Bardin, ensuring the methodological rigor necessary for the interpretation of data of a subjective nature.

The research is in accordance with the principles of the National Health Council Resolution (CNS) No. 510/2016 and was approved by the Research Ethics Committee (CEP) Hospital Universitário Gaffrée e Guinle da UNIRIO, filed under CAAE No. 4604.6621.2.0000.5258, Opinion Number: 4.733.239, on May 25, 2021.

RESULTS

Regarding the characterization of the sociodemographic profile of the participants of this study, 20 PLHIV were interviewed, predominantly male, homogeneously distributed among all age groups, mostly white, single, heterosexual, with higher education, in formal working conditions, living in their own homes and using the bus as a means of transportation.

Chart 1 – Aspects related to quality of life

ISSUES ADDRESSED	CATEGORIES	FREQUENCY
Nutrition	Consider eating well	18
	Don't consider eating well	02
Physical activity	Do not do any physical activity	12
	Do physical activity	8
Leisure	Prefer to stay home	18
	Like to leave home for leisure	2
Professed religion	Do not profess religion	10
	Profess religion	10
Sexual life	Refer satisfaction	11
	Refer dissatisfaction	9

Source: : Own elaboration.

The categories with the respective frequencies of responses are presented in the tables below.

Regarding food, the category "consider food good" was expressed by the majority, showing that PLHIV try to see food as health care.

When I found out I had HIV and started treatment, I started to take care of myself more, to have a good diet. I try to make my own food, cook with olive oil, eat a lot of greens, vegetables, healthier foods. (P17)

It is known that PLHIV with access and adherence to ART have a longer life expectancy and, with longer life, can develop diseases such as hypertension, diabetes, among others, including those related to aging, which makes health promotion actions necessary, among them healthy eating. Getting involved in food preparation is an important step to always have real food on the table and to offer everything the body needs.⁵⁻⁶

The lack of time to prepare their own food, the lack of financial conditions, and the lack of correct information were the justifications presented for those who do not consider food good.

I think that the fact that I work, in the rush, I end up not eating well [...] it is for practicality. (P14)

I would like to eat better, but sometimes I lack money. (P16)

There are many foods that I have allergies, for example, I do not eat bananas, tomatoes, milk, cheese, pork... this disturbs my eating and I end up restricting my food a lot. (P2)

The lack of time associated with modern life is perhaps today one of the main factors that prevent people from making good choices when it comes time to eat. In this sense, it is essential to have access to reliable and consistent information, respecting the identity and food culture of the population, because the adoption of healthy eating habits is not just an individual choice. Autonomy during food choices is necessary, as well as the guarantee of financial security and equity in health, identifying and meeting the essential needs of the person. It is necessary to overcome the barrier of ignorance with correct information, make the person aware of the need to change the paradigm of eating behavior, and identify individual difficulties, relying on multiprofessional support.³⁻⁷

Regarding the practice of physical exercises, the feeling of laziness, not liking to exercise, and the difficulties imposed by the Covid-19 pandemic were statements that emerged to justify the category "do not practice physical exercises," according to the statements below.

Sedentary pure and simple. I know I need it, but what about laziness? (P5)

I know it is for my health, but I don't like it (P17)

I used to swim twice a week [...], I only stopped now because of the pandemic. (P4)

Considering the importance of physical activity, services that provide care to PLHIV need to involve the PCU so that it is possible to develop a multidisciplinary approach with greater participation and autonomy of users, as a way to ensure comprehensive care that develops actions to promote health. An excellent strategy is to include PLHIV in the Academia da Saúde program, which works in public spaces where physical activities are offered to the population.⁵⁻⁸

Regarding leisure activities, the vast majority expressed their liking to stay at home, according to the following statements.

I really like to stay at home watching TV or on the internet. (P1)

Staying at home, playing with my dog and my son is a leisure time for me. (P5)

I hardly go out of the house, I do nothing, I feel like a prisoner of HIV. (P20)

Leisure activities are considered an opportunity to leave home. In this research, the statement of staying at home so expressively may be related to the isolation imposed by the Covid-19 pandemic that interfered with the life routine of many people or, also, to clinical, psychological and social changes triggered by HIV that can cause feelings of low self-esteem, fear, loneliness and, consequently, social isolation. To improve the living conditions of PLHIV who suffer such maladjustments, it is necessary to have an efficient multidisciplinary team with the technical capacity and prepared to welcome, listen, and help in the process of reintegration and reworking of life processes.⁹⁻¹²

In the category "They like to leave home", meeting friends, traveling, and doing religious activities emerged in the findings as a form of leisure.

I love to go out with friends, have a coffee with a friend, have lunch at another's house... (P7)

I like to go out for evangelism. (P9)

I like to travel, I go whenever I can. (P19)

Regarding religion, the statements below justify the category "no religion":

The important thing is to have faith [...] to attend church, for me, it is not necessary. (P13)

I believe that religion works as an escape for the human being [...] and makes us have a moral guilt that makes no sense. (P08)

The spiritual dimension has always been linked to religious practices and continues to be present in all social strata. However, much of the resistance in valuing religion is due to the perception

that it is a field marked by the domination of a hierarchy that has historically shown itself to be authoritarian and dogmatic, which makes people move away. Moreover, in the field of science, there is a dualistic vision that has made the consideration of religious dimensions illegitimate. Thus, professionals, teachers, and researchers feel constrained to bring into scientific debate the religious knowledge and experiences that are often fundamental in their private lives.¹³

The category "profess religion" was represented by the following statements in this study:

I am Catholic and I attend [...]. I never had difficulties with the Catholic Church, on the contrary, it was always a great partner for me. (P3)

I am a Spiritist, Kardecist and I frequent it. Religion gives you a support, you know? Each one has to find his own way to continue, to give his best, trying to evolve, this is the function, we came to evolve.

I am a practicing religious. In difficult moments, without answers, it is the connection with God that sustains us. (P19)

The maintenance of good mental health, together with a psychosocial and spiritual support network, in addition to adequate treatment, from the moment of the discovery of the diagnosis, contributes markedly to the improvement of the living conditions and health of PLHIV.¹² It is important to know how to identify individually the desire of the person in this sense and with which religion the same identifies (or does not identify with any), and be very careful not to force the PLHIV to accept any particular religion, especially with a guarantee of healing. Spirituality needs to offer comfort with tranquility and lightness.

When approached about satisfaction with their sex life, the categories "satisfied" and "Dissatisfied" emerged. The statement of dissatisfaction with sex life was quite expressive in the survey.

"I feel very dissatisfied because after I discovered HIV I get very stuck, I am not comfortable in the relationship, I am afraid of passing the virus to him." (P5)

I feel dissatisfied because I can't relate to anyone anymore and being alone is very bad. (P9)

The quality of sexual life is one of the pillars of quality of life. The social representation of sex life, especially for women living with HIV, has undergone changes after the diagnosis, especially in the experience with serodifferent partners. The relationship, previously based on freedom and sexual desire, due to the fear of transmitting the infection, may become something regulated and limited, which compromises the self-esteem and quality of life of these women, preventing them from exercising their sexuality in a pleasurable and full way.¹⁴⁻¹⁵ In this sense, it is essential to have a space for the couple's care, rethinking the forms of intervention in the health-disease process and in the care strategies regarding sexual life.

The fear of transmitting the infection can affect the satisfaction of PLHIV with sexuality in an intense way, to the point that, even knowing that undetectable CV prevents the transmission of HIV, there is still insecurity, as observed in the speech below.

Today I live a little more tranquil because I have been undetectable for 4 years, but even so it gives me insecurity and that makes me unsatisfied. (P15)

That is why it is so important to have broad access to quality services, in which support and essential information is provided by multiprofessional teams, so that PLHIV can fully exercise their sexuality, safely and calmly.

To fully exercise your sexuality, it is not necessary to open the diagnosis to anyone, if you don't want to, as long as you don't put other people at risk. Having good adherence to treatment and the viral load being undetectable, the possibility of transmitting the

Chart 2 – Aspects related to the experience of living with HIV

THEMES ADDRESSED	CATEGORIES	FREQUENCY
Experience of living with HIV	Live Well with HIV	12
	Don't live well with HIV	8
Prejudice Situations	Never suffered prejudice	17
	Have suffered prejudice	3

Source: Elaborated by the author

virus ceases to exist. Therefore, it is essential that PLHIV appropriates the meaning of the slogan "Undetectable = Untransmissible", which can, along with the use of condoms to prevent other sexually transmitted infections, be the "light at the end of the tunnel" for a safe, full and happy life.

DISCUSSION

About the experience of living with HIV, two categories emerged: "Live well with HIV" and "Not live well with HIV".

In the first category, relevant aspects were pointed out, such as the importance of promoting self-care, seeing life positively, facing the disease and the treatment with normality, among others, as observed in the statements below.

When I knew I had HIV, the choice was live or die, and I chose to live. I live very well with HIV (P3)

In some aspects my life even improved. I started to take care of myself more, to worry more about me, about who I am involved with, I started to see life in a different way, more positively. (P6)

HIV changed my way of seeing life, I started to take care of myself more, I became more attentive to my health, my quality of life improved (P14)

It is just another chronic disease, normal life. (P19)

To improve the living conditions of PLHIV, besides public policies to expand access to ART, other aspects (social, family, etc.) must also be considered, because they can represent a reworking of life processes.¹² In general, due to the impact of AIDS on society, it is common to think that the HIV infection prevents the person from living well, having quality of life and being happy. However, the statements above show that each individual has his or her own way of coping, including improving self-care conditions and living more positively. This is what is expected by health teams who provide care to PLHIV, and not only expect the reduction of CV to the undetectable level (life is not reduced to a test result), but that PLHIV can enjoy good living conditions and health.

In the category "Do not live well with HIV" emerged speeches related to prejudice experienced by PLHIV, loneliness, limitation of life by fear of exposure, among other impacting.

Very difficult. Sometimes I cry alone because I keep thinking about people's acceptance if they know, I am afraid of suffering prejudice, sometimes even from family. (P2)

My life became very limited mainly because of the secrecy. Even in relation to work it is difficult for me to ask to leave to go to the doctor, I need to do exams, get medicine

It is very difficult because of this secret, I am a hostage of this (P4)

A prison, I am hostage of this secret, HIV took away all my freedom. (P20)

It is observed that the problem circulates around secrecy. Discrimination has been shown to be a major obstacle to treatment initiation and adherence, in addition to having a negative impact on social relationships in the family, community, and work environments, among others, an important and worrisome portrait of the daily discrimination situations to which PLHIV are exposed in Brazil.¹⁷ This negatively affects people's lives, since it is contradictory to live well when one is held hostage by a secret that prevents life in all its fullness.

The study also sought to investigate possible situations of prejudice experienced by the participants and, from the findings, two categories emerged: those who reported never having suffered prejudice (the vast majority) and those who reported having already suffered prejudice.

Among those who reported "Never having suffered prejudice" it is noteworthy that it was unanimous that total confidentiality of the diagnosis was maintained.

Qwq21I never suffered this kind of prejudice because I keep it a secret. (Q12)

My parents died without knowing. If I had opened it to everybody, I am sure that I would have suffered some kind of prejudice. (P11)

Among those who reported having suffered prejudice, affirmations of indirect situations emerged, even with confidentiality preserved, according to the statements below.

[...] at my work, once in a while I hear some jokes about people who have HIV and I keep quiet, but I don't make it known that I have the virus. (P09)

[...] I have heard people speaking in a prejudiced way about people with HIV without knowing my condition, like: beautiful on the outside, but rotten inside, among other things. (P20)

Affirmations of direct situations also emerged, as in the following statements:

"I don't hide from anyone that I have HIV, everyone knows, but I've been judged a lot because of that among other trans people and by my family, I've cried a lot, I've suffered a lot." (P06)

"Once there was an accident at work with a patient who bit me and I realized that the nurse was only worried about the patient, that I had contaminated him, and not a bit about me. There was all this whispering around the hospital and it really bothered me. I was hurt, I could have torn my finger off, but nobody cared, not even the CAT did, so in that situation I felt like a victim of prejudice. (P17)

These findings support the WHO's goal of ending prejudice and discrimination, which are so damaging to the lives of PLHIV and a serious problem that has persisted since the beginning of the HIV/AIDS pandemic.³⁻¹⁶ Most PLHIV have experienced at least some form of discrimination throughout their lives. Discrimination has proven to be a major obstacle to treatment initiation and adherence, in addition to having a negative impact on social relationships in the family, community, and work environments, among others.¹⁷

CONCLUDING REMARKS

Among the aspects related to good living conditions, the research showed that food is seen as a form of health care, having as difficulties, the lack of time to prepare their own food, the lack of financial conditions and lack of correct information. In this sense it is necessary to offer autonomy during the food choices of PLHIV and, for such, it is necessary to overcome the barrier of ignorance with correct information, sensitize the person so that there is a change of paradigm of eating behavior and identify individual difficulties counting, for such, with multidisciplinary support.

The findings showed that the practice of physical exercises needs to be encouraged because the discouragement, the feeling of laziness, the fact of not liking the gym, and the isolation imposed by the Covid-19 pandemic interfere negatively. It is necessary to involve the PCU and insert PLHIV in the Academia da Saúde program that works in public spaces where physical activities are offered to the population.

Regarding leisure, it was evident that PLHIV have a preference for staying at home, requiring individual assessment

to identify whether it is really a desire or a consequence of some emotional distress arising from the condition of living with HIV or the isolation imposed by the Covid-19 pandemic.

Religion was expressed more as an exercise of spirituality and not as religiosity, being necessary then to stimulate the PLHIV as long as they wish, because spirituality cannot be forced and, when desired, needs to offer comfort with tranquility and lightness.

The satisfaction with sexuality was expressive in the findings, however appears hampered by the fear that the PLHIV have of transmitting the infection to the sexual partner and the imposition of the secrecy of the diagnosis. That is why it is so important the broad access to quality services, in which support and essential information is provided by multidisciplinary teams, so that the PLHIV can know all forms of prevention and fully exercise their sexuality, safely and peacefully.

The research showed that PLHIV have the possibility to live well with HIV as long as they have access to ART and have their basic needs met. However, the fear of experiencing situations of stigma and prejudice was expressed as the biggest factor preventing the quality of life being necessary actions of public policies to eliminate prejudice and discrimination.

RESULTS

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