

# Difficulties of living with HIV/Aids: Obstacles to quality of life

Dificuldades do viver com HIV/Aids: Entraves na qualidade de vida

Giselle Juliana de Jesus<sup>1</sup>

Layze Braz de Oliveira<sup>1</sup>

Juliano de Souza Caliar<sup>1</sup>

Artur Acelino Francisco Luz Queiroz<sup>1</sup>

Elucir Gir<sup>1</sup>

Renata Karina Reis<sup>1</sup>

## Keywords

HIV; Acquired immunodeficiency syndrome; Quality of life; Patient care; Adaptation, psychological

## Descritores

HIV; Síndrome de imunodeficiência adquirida; Qualidade de vida; Assistência ao paciente; Enfrentamento

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## Abstract

**Objective:** To identify and explore the dimensions of the difficulties faced by people living with HIV/Aids in the disease management.

**Methods:** A qualitative, descriptive, exploratory study was developed in Specialized Care Services, with 26 patients. The recorded interviews were transcribed, and then processed and analyzed by means of descending hierarchical classification. Findings were based on the collective subject discourse.

**Results:** Five classes were obtained: "Intrafamiliar prejudice and its impact on coping with the disease"; "Social prejudice: macro environment impacts"; "Difficulties in managing the risk of HIV/Aids transmission and its implications on partnerships", "Maintenance of high rates of HIV/Aids treatment adherence: qualifying the service" and "Quality of life promotion for people living with HIV/Aids".

**Conclusion:** The difficulties experienced go far beyond the disease, with central, intimate aspects, and are linked to prejudice, which hinders their personal, professional and affective development, expanding into abstract macro-concepts such as quality of life.

## Resumo

**Objetivo:** Identificar e explorar as dimensões das dificuldades enfrentadas por Pessoas Vivendo com HIV/Aids no manejo da doença.

**Métodos:** Estudo descritivo, exploratório, de abordagem qualitativa desenvolvido em Serviços de Atendimento Especializado, com 26 pacientes. As entrevistas gravadas foram transcritas e posteriormente, processadas analisadas pela Classificação Hierárquica Descendente. Os achados foram fundamentados no Discurso do Sujeito Coletivo.

**Resultados:** Obteve-se cinco classes: "O preconceito intrafamiliar e seu impacto no enfrentamento da doença"; "Preconceito social: os impactos do macroambiente"; "As dificuldades em gerenciar o risco de transmissão do HIV/Aids e as implicações em parcerias", "A manutenção de altas taxas de adesão ao tratamento do HIV/Aids: qualificando o serviço" e "Promovendo a qualidade de vida em pessoas vivendo com HIV/Aids".

**Conclusão:** As dificuldades experienciadas vão muito além da doença, tomando aspectos íntimos, centrais ligadas ao preconceito, que impede seu desenvolvimento pessoal, profissional e afetivo expandindo-se a macro-conceitos abstratos como qualidade de vida.

## Corresponding author

Giselle Juliana de Jesus  
Bandeirantes Avenue, 3900,  
14040-902, *Campus* Universitário,  
Ribeirão Preto, SP, Brazil.  
giselle.nana@usp.br

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<sup>1</sup>Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, Ribeirão Preto, SP, Brazil.

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## Introduction

In Brazil, up to 2015, 830,000 cases of people living with HIV infection (PLWHA) were recorded, a finding that places the country in a prominent position for the pandemic in Latin America, being the only one that still showed an increase in the number of new infections in the last decade, of about 11%.<sup>(1)</sup>

With the therapeutic advances and the introduction of new classes of antiretrovirals in the last decades, the context of this infection progresses from fatal disease to a chronic condition. However, this improvement in treatment is presented as a challenge for patients and healthcare professionals who, in this new context of chronicity, should face HIV infection not as a death sentence, but as a potential obstacle to their quality of life. The measurement of this construct in PLWHA provides information on the aspects that permeate this problem, and reveal the interfaces of living with HIV/AIDS in the current context.<sup>(2)</sup>

People living with HIV face several difficulties when they try to achieve a satisfactory quality of life, from interruptions of their life history; disruption of interpersonal and occupational relationships, which can lead to social isolation; to problems with sexuality and social relationships, which can compromise their mental and physical health. Adapting to these changes can sometimes be challenging, requiring an approach that reconciles the particularities related to HIV, and the subject's perception in his/her biopsychosocial context.<sup>(3)</sup>

Currently, living with HIV requires more than only treating the disease, because PLWHA daily have to deal with transdisciplinary problems involving depression symptoms, stigma, discrimination, and adverse effects related to the therapy regimen.<sup>(4)</sup>

Based on these problems, the objective of this study was to identify and explore the dimensions of the difficulties faced by people living with HIV/Aids in the management of the disease.

## Methods

This was a descriptive, exploratory study with a qualitative approach based on the collective subject discourse method, in which the speeches (empirical data of a verbal nature) are organized and tabulated through key expressions that allow the identification of the central ideas, so that collective thinking can be apprehended and grouped into categories.<sup>(5)</sup>

The subjects participating in the study were PLWHA, followed in two HIV/Aids Specialized Care Services (SAE, as per its acronym in Portuguese) of a large city in the Northwest region of the state of São Paulo, Brazil. The participants were chosen through convenience sampling, provided that they met the pre-defined criteria: awareness of the HIV seropositivity, age greater than or equal to 18 years, and to be clinically followed as an outpatient in the services chosen. Institutionalized patients or those living in support houses were excluded.

The convenience sample consisted of 26 PLWHA. Data were collected from May to August 2015, using data saturation as the criterion for completing the collection. To begin the collection, there was a previous contact with the institution, and the participants were invited to integrate the research while they were in the waiting room, waiting for consultations with healthcare professionals.

Data were collected through semi-structured interviews, in a reserved room of the institution. The interviews were guided by a script, previously validated by experts, with two guiding questions about the difficulties of living with HIV/Aids and their relation with quality of life, with an average duration of 40 minutes. The statements were recorded and fully transcribed for analysis.

For data processing, the lexical type analysis technique was used, with the help of the software IRaMuTeQ (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*).<sup>(6)</sup> A *p* value of 0.05 was adopted; thus, for every  $p \leq 0.05$ , the test is considered significant, and the word is considered pertaining to the class determined in the software. The same has been emphasized in studies using a qualitative approach, by the use of

statistical techniques to help researchers grasp the social construct, and create classes of analysis based on the apprehension and identification of units of meaning.<sup>(7,8)</sup> It is noteworthy that the use of the software is not an absolute data analysis method, but a procedural tool that facilitates and helps interpret the findings.<sup>(9)</sup>

For the textual analysis, the descending hierarchical classification (DHC) method was defined, in which the texts are classified according to their respective words and their set is divided by the frequency of the reduced forms.<sup>(10)</sup> Thus, classes of text segments were obtained, which were called “pre-class”. Later, the organization of key expressions from the interviewed speeches, and the identification of central ideas complementing the DHC findings were performed, and allowed the delimitation of statements in definite classes.<sup>(8)</sup>

The recommendations for the development of studies with human beings were followed, with the project being approved by the Ethics Committee of the Ribeirão Preto College of Nursing (protocol no. 16740).

## Results

The mean age of the 26 people living with HIV/Aids who participated in this study was 50 years, with 13 being male and 13 female. The mean time since diagnosis was 10 years, and 22 of them had a monthly income of one to two minimum wages, and education level of less than 8 years.

Regarding the statements, the software recognized the corpus separation in 449 elementary context units (ECU), from 26 initial context units (ICU) with utilization of 85.75% of the initial corpus. Based on the DHC, the more relevant words present in the statements and their relationship with the research object were analyzed, to form the “pre-classes”. Then, based on the collective subject discourse method, the identification of “key expressions” was performed, and they were quantified to facilitate the identification of central ideas, which

allowed the creation of definite classes, as shown on the following dendrogram (Figure 1).

The arrangement of classes reveals that the material has been consecutively divided into three axes: the first one related to quality of life (class 5), the second linked to the importance of health services to the PLWHA’s quality of life (class 4), and the third encompassing the other classes (classes 1, 2 and 3), related to the various confrontations that these individuals experience on a daily basis. Each class was named according to the content it presents, represented by the words, interpretation of its thematic convergence, and identification of the central idea associated with it as it appears in the dendrogram (Figure 1).

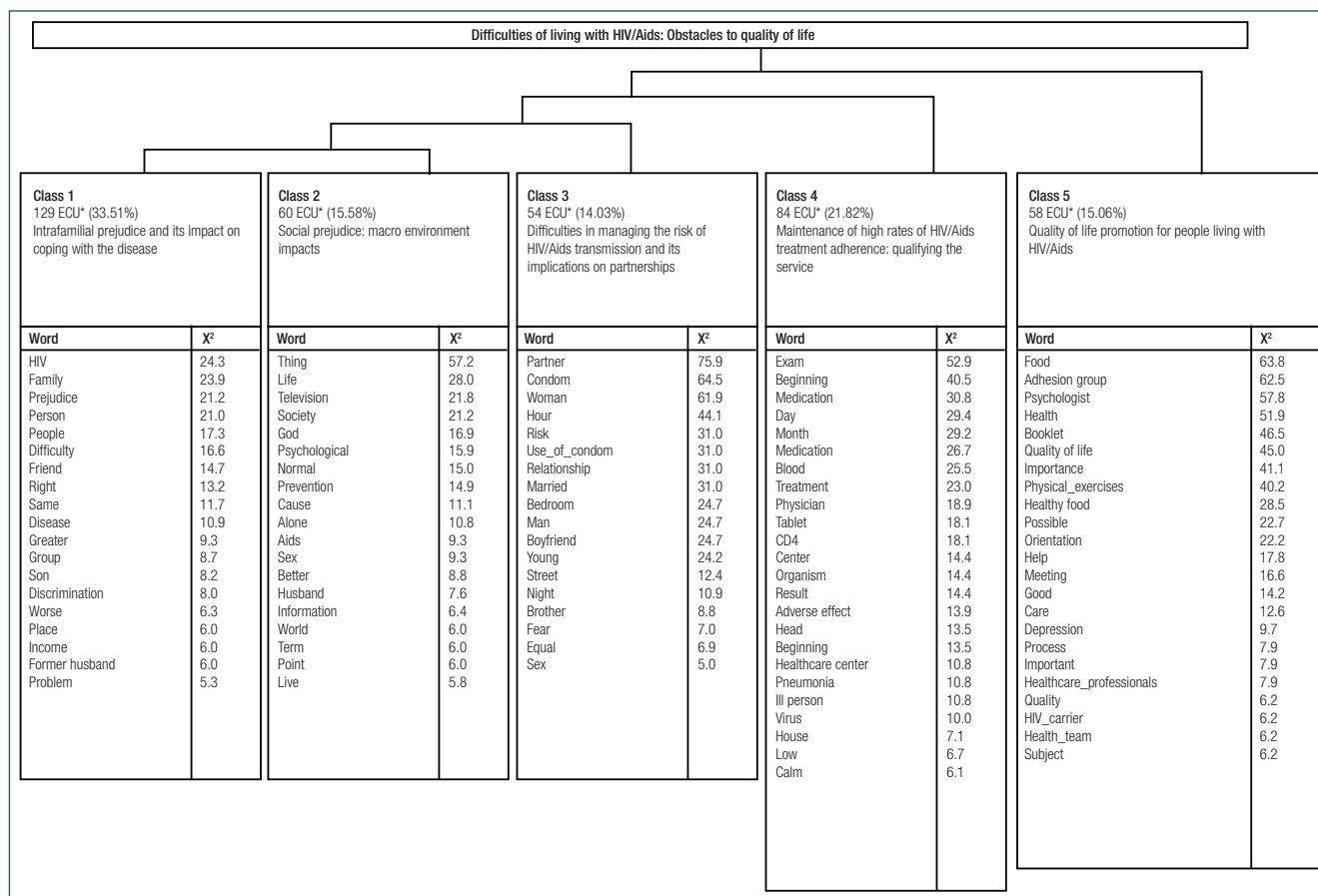
### Class 1. Intrafamilial prejudice and its impact on coping with the disease

This class includes a large number of words, suggesting that the subjects know about the theme or, at least, have experience with it. The greatest difficulties faced by these subjects are in the intra-family environment, experiencing prejudice from close family members. In the statements, the key expressions, as well as the words, were condensed in the nucleus “family, children and friends”. This triad is considered by the participants as an important support base, and when it is not present, it has greater negative repercussions that directly affect the process of living with the disease, making it more tiring.

Failure to recognize the importance of family members in the care for the member living with HIV suggests the lack of promising perspectives in living with HIV, because family support is essential for these patients, especially at early diagnosis, when they need support in recognizing the disease, and in the search for specialized care, encouragement for self-care, and emotional support.

### Class 2. Social prejudice: macro environment impacts

This class complements the previous one, because its contents transcend the difficulties and prejudices experienced in the family environment, extending them to the civil society. The lower concentration



Note: ECU – Elementary Context Unit

**Figure 1.** Thematic structure about difficulties of living with HIV/Aids

of words in this class suggests that this object, although close to the participants, does not impact as much as the prejudice, or the intrafamilial stigma. Thus, the score given to prejudice and/or stigma against the disease in family life seems to be higher than in social life.

In the civil society, their experiences include stigmas and lack of information about the infection, treatment and perspectives of care. Among these, lack of information directly affects the search by PLWHA for a better quality of life, because the HIV prognosis is not known before the beginning of the treatment, and indirectly, because its relations become permeated by prejudice of people who see them as “contaminated” or “condemned”, limiting their social support. This isolation can be observed in the key expressions contained in this class, in which the participants emphasize: “*at work I do not tell anyone that I have HIV*”.

### Class 3. Difficulties in managing the risk of HIV transmission and its implications in partnerships

In spite of complementing the previous class, the words belonging to these classes stood out for their more personal and intimate character, because their contents address sexual partnerships and love relationships. This class highlights the fragility that permeates the affective and sexual intimacy of people living with HIV/AIDS. The key expressions identified “*I am alone; always alone; without anyone,*” point towards feelings of isolation and loneliness.

Those experiencing a relationship report difficulties in negotiating the use of condoms with the partner, with a resistance to its use by men and women being mentioned, which can indicate unprotected and high-risk sexual practices. The most mentioned words highlight problems in the affective-sexual life that can lead individ-

uals and their partners to physical, psychic and social damages.

#### **Class 4. Maintenance of high rates of HIV/Aids treatment adherence: qualifying the service**

Categorized by the physical, social and psychological changes and difficulties experienced by the interviewees during the stages of diagnosis and treatment of HIV infection, the most evoked words reveal the positive and negative influences coming mainly from drug treatment, interfering with their self-care and quality of life. This axis moves away from subjective and emotional contents, and is anchored in real objects about the therapeutic treatment of HIV.

The central ideas about adherence to treatment take over, in a symbolic and concrete way, as well as the difficulty in clinical follow-up, participation in the adherence group, number of tablets, and their adverse effects.

The success of highly active antiretroviral therapy for AIDS (HAART) depends on the maintenance of high rates of patient adherence to drug treatment. Analyzing how the factors associated with this adherence are perceived by PLWHA is crucial for the improvement of health policies and practices aimed at improving the treatment effectiveness.

#### **Class 5. Quality of life promotion in people living with HIV/Aids**

This class, as well as the contents that it entails, involves all the others and points out that despite advances in the treatment of HIV and the increase in life expectancy, the implementation of actions promoting quality of life still presents gaps. In the statements, the most evoked words refer to the need to build comprehensive care that meets the needs of people living with HIV/AIDS.

Quality of life is the central axis of this class, and its elements are varied and show a plurality of sub-items that can make up this construct, varying from concrete (food, physical exercises, and adherence group) to abstract representations (health, company, guidance and help).

Understanding this complexity is an increasing need of healthcare professionals, especially the nursing team, due to their functions as caregivers and health educators; and also as creators and users of light technologies for interventions on PLWHA's quality of life.

## **Discussion**

The impact of living with a chronic disease that still carries a lot of stigma and prejudice is the greatest obstacle between these individuals and their quality of life, impacting their micro and macro environment, and directly interfering in their coping capacity. In an attempt to manage their quality of life, it was observed that PLWHA have different strategies to manage and confront the disease, depending on the environment, the degree of intimacy, or the importance of their relationships, and their own capacity in this management, which make them assign different scores to different situations.

In the family environment, hiding the serological status as a primary coping strategy was common. This is due to the search for social support in an attempt to keep family harmony, because families are afraid of acquiring the infection and losing their social prestige in their communities.<sup>(11)</sup>

Living with this stigma in such an intimate environment as the family impairs PLWHA social support, reducing their emotional coping, and forcing them to search for coping strategies in extra-family environments. Family support is one of the most important forms of social support for people in situations of vulnerability, being an important protective factor for the development of psychosocial disorders such as depressive symptoms and suicidal thoughts.<sup>(7,12)</sup>

When the family environment is insufficient, or unable to meet their demands, PLWHA sought support in society in general, represented here as a network of individuals and institutions that had no family relationship with the participants. The participants' statements, and the way the words be-

haved in the classes, point to a situation of helplessness, in which individuals do not have social or emotional support. This lack of support is associated with more severe symptoms resulting from HIV infection, such as fatigue, malaise, numbness, and body changes (e.g. weight gain).<sup>(13)</sup>

This constant reassertion of placing them as sick and marginalized individuals, by their own families and/or society, affects self-esteem. This effect, associated with the internalization of stigma and prejudice, can trigger a progressive isolation reaction, as a way to protect against future prejudice, culminating in negative psychological conditions such as anxiety and depression. Another characteristic of the study participants was being older (<50), which makes them more likely to have less social support and develop mental health problems.<sup>(12,14)</sup>

The perception by PLWHA of health services as an obstacle to their quality of life is an alarming finding. The constant procedures, considered routine for professionals, become symbolic and representative images of the disease. It is not always that these professionals pay attention to the comorbidities accompanying the process of disease chronification and population aging, which leads PLWHA to take several medications and require various care specialties. The understanding by the professionals that these therapeutic and technical actions can reinforce negative feelings in their patients corroborates the importance of a humanized care, which is not impositive, but rather empowering.<sup>(15,16)</sup>

The configuration of health services and policies in Brazil focused on PLWHA allows for few changes that fit the specific needs of this population, and this involves changes in the therapy regimen, service time options, influence of socio-cultural factors that take the patient away from the service (in the case of the LGBT population), and bring losses in various aspects of their quality of life. European countries that have invested in this flexibility already show better rates of life expectancy and quality of life in PLWHA.<sup>(17-19)</sup>

Quality of life is a multidimensional variable, and can be affected by several aspects. In the present study, the several difficulties of coping are directly related to this variable. Thus, in addition to identi-

fying the main difficulties of living with HIV, it is necessary to implement interventions that support the development of coping strategies.<sup>(20)</sup>

The great focus of the health team on biomedical processes and hard technologies is a problem that affects not only PLWHA but virtually all health settings today. The requirement for diagnosis, effectiveness of interventions and treatment through increasingly sophisticated techniques, and with more noticeable evidence (CD4 count, viral load or body mass index) become a demand of professionals and patients, who use the technological advances as the only therapeutic option, neglecting psychosocial problems. Therefore, more abstract constructs are underestimated, and become an even more difficult goal to achieve.<sup>(21)</sup>

The use of light technologies provides support for the development of educational processes in different population segments. These tools aim to increase the efficiency of information acquisition in educational contexts; and the integration of this technology in teaching and learning has showed a positive impact on the affective and cognitive domains.<sup>(22)</sup>

Faced with the challenge and importance of the generation of technological innovations developed specifically for PLWHA, it is opportune to implement actions that are based on such technologies for interventions in gaps related to coping.<sup>(22)</sup>

The limitations of this study are related to its cross-sectional design, which limits the comprehensiveness of the results to the universe of the participants and their sample, consisting of only two health institutions. The expansion of research fields and participants could broaden the findings, deepening the issues addressed, and allowing the stratification by gender, age group or sexual orientation.

## Conclusion

The difficulties faced by people living with HIV infection are presented throughout their statements as obstacles to a final objective: quality of life. The main difficulties cited are the prejudice experienced in the

family and in the social context; managing affective and sexual partnerships; managing treatment and quality of life achievement. The statements, their central nuclei, and key expressions point out that the experience of HIV/AIDS behaves as a spiral of barriers between people living with HIV infection and their quality of life. These barriers have personifications and concrete elements, which are based on prejudice and stigma as a common branch. These barriers are anchored in a network of “intimate and essential contacts”, among which family members seem to have a more negative impact, and cover other forms of social, intimate and affective-sexual support.

### Collaborations

Jesus GJ, Oliveira LB, Caliar JS, Queiroz AAFL, Gir E and Reis RK declare that they contributed to the project design, data analysis and interpretation, article writing, relevant critical review of its intellectual content, and final approval of the version to be published.

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