



# Perceptions about the quality of life of people living with HIV<sup>a</sup>

*Percepções acerca da qualidade de vida de pessoas vivendo com HIV*

*Percepciones sobre la calidad de vida de personas que viven con VIH*

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## ABSTRACT

**Objective:** to understand the meaning of quality of life attributed by people living with HIV. **Method:** a qualitative approach study carried out with people living with HIV, in the Specialized Care Services in a large city in the interior of São Paulo. Data were processed by the IRaMuTeQ software and the analysis was based on the Discourse of the Collective Subject technique. **Results:** after the analysis of the statements, four main classes emerged: Difficulties faced in the treatment; Stigma and lowering of self-esteem; Health as center of quality of life; and Living with expectations. **Conclusion:** The meaning of quality of life was understood by people living with HIV through several factors that permeate life, and may suffer positive or negative influences. The positive aspects included healthy lifestyle habits, and the negative aspects were related to stigma, prejudice, and difficulty in adhering to treatment.

**Keywords:** Quality of Life; HIV; Social Stigma; Qualitative Research.

## RESUMO

**Objetivo:** compreender o significado de qualidade de vida atribuído pelas pessoas vivendo com HIV. **Método:** estudo de abordagem qualitativa realizado com pessoas vivendo com HIV, nos Serviços de Atendimento Especializado em um município de grande porte no interior de São Paulo. Os dados foram processados pelo software IRaMuTeQ e a análise foi embasada na técnica do Discurso do Sujeito Coletivo. **Resultados:** após a análise das falas emergiram quatro classes principais: Dificuldades enfrentadas no tratamento; Estigma e diminuição da autoestima; Saúde como centro da qualidade de vida e; Viver com expectativas. **Conclusão:** O significado de qualidade de vida foi compreendido pelas pessoas vivendo com HIV por diversos fatores que permeiam a vida, podendo sofrer influências positivas ou negativas. Os aspectos positivos incluíram hábitos de vida saudável, e os aspectos negativos relacionaram-se ao estigma, preconceito e a dificuldade de adesão ao tratamento.

**Palavras-chave:** Qualidade de Vida; HIV; Estigma Social; Pesquisa Qualitativa.

## RESUMEN

**Objetivo:** comprender el significado de calidad de vida atribuido por las personas que viven con el VIH. **Método:** un estudio de enfoque cualitativo realizado con personas que viven con el VIH en los Servicios de Atención Especializada en una gran ciudad del interior de São Paulo. Los datos se procesaron utilizando el software IRaMuTeQ y el análisis se basó en la técnica de Discurso del Sujeto Colectivo. **Resultados:** después del análisis de las declaraciones, surgieron cuatro clases principales: dificultades enfrentadas en el tratamiento; Estigma y disminución de la autoestima; La salud como centro de calidad de vida; y Vivir con expectativas. **Conclusión:** el significado de calidad de vida fue entendido por las personas que viven con el VIH bajo varios factores que impregnan la vida y pueden sufrir influencias positivas o negativas. Los aspectos positivos incluían hábitos de vida saludables, y los aspectos negativos estaban relacionados con el estigma, los prejuicios y la dificultad para adherir al tratamiento.

**Palabras clave:** Calidad de Vida; VIH; Estigma Social; Investigación Cualitativa.

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## INTRODUCTION

Quality of life (QOL) is a complex multidimensional subjective construct. In this way, it is essential to understand the theoretical framework that involves the definition so that valid researches are possible.<sup>1</sup>

Therefore, following internationally accepted definitions is essential. The concept of QOL defined by the World Health Organization states that it is the "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".<sup>2:1405</sup> Measuring the subjective aspects linked to QOL has been an alternative commonly used for health assessments of people who experience a chronic condition.<sup>3</sup>

Despite being a well-worked theme in the literature, research that investigates QOL are an important tool to assess the impact of health treatments, such as adherence to antiretroviral treatment.<sup>4</sup> Furthermore, living with HIV is in the fourth decade of the epidemic and the treatment has undergone important advances such as the definition of non-transmissibility in the face of undetectable viral load.<sup>5</sup>

These new implications may interfere with the quality of life of people living with HIV (PLHIV), which may justify further research on the subject. Furthermore, it is necessary to build and validate new scales to assess the quality of life of PLHIV, given that instruments for this purpose are more than 10 years old<sup>6</sup> in the sense that there is a need to develop new instruments that contemplate the medical advances added to the treatment.

Despite advances in prevention and treatment related to HIV infection, the issue remains an important public health problem that deserves different perspectives, as there is still no cure.<sup>7</sup> Approximately 37.9 million people live with HIV in the world, concentrating in poorer regions and with structural problems in health services. In Latin America alone, the number of infected people is estimated at 1.9 million. In this region, Brazil is one of the countries that deserves special attention due to the persistent high rates of new infections.<sup>8</sup> Thus, addressing issues related to the quality of life of PLHIV may contribute to improving the understanding of a complex and multifaceted phenomenon.<sup>9</sup>

The QOL of this population is not only related to the possibility of a long life, but it can be negatively influenced by concerns about confidentiality and financial concerns.<sup>10</sup> Qualitative studies using the Theoretical Framework of Social Representations have endeavored to clarify these issues and bring light about the problem. The authors characterized QOL linked to positive aspects regarding good nutrition and health care, however prejudice is still present.<sup>11,12</sup>

Therefore, it is deduced that are relevant studies that deepen the investigations in understanding the positive and negative aspects related to the QOL of PLHIV. The results of research of this nature may guide individual and collective health actions to improve QOL, such as actions of interventions capable of influencing positive changes.

In this sense, since QOL is a multidimensional construct and used as a tool to measure the impact of treatment on patients,

nursing, by identifying aspects that interfere with it, will contribute to its improvement through the promotion of an integral approach to health with practices successful in the management of HIV infection, such as the elaboration of care strategies, prevention of health problems, and retention of the individual in the treatment service. This holistic view must focus on the identification of factors that can interfere with QOL of PLHIV, thus contributing to a more humanized and targeted care.<sup>13</sup>

Given the above, considering that the QOL construct includes several concepts, this study aimed to understand the meaning of QOL attributed by PLHIV.

## METHODOLOGY

This is a qualitative study, extracted from a doctoral thesis,<sup>14</sup> based on the technique of the Discourse of the Collective Subject (DCS), conducted with PLHIV under clinical outpatient monitoring in the city of Ribeirão Preto, São Paulo, Brazil. The DCS technique allows the recognition of thoughts, representations, beliefs and values of a sample of the community on a given subject.<sup>15</sup>

This study was developed at the Specialized Care Services (SCS) in a city in the interior of São Paulo, Brazil in 2016. It is part of a larger project for the construction and validation of a scale to assess the quality of life of PLHIV.

The elaborating of this study sought to meet the checklist of recommendations from the Consolidated Criteria for Reporting Qualitative Research (COREQ).<sup>16</sup>

Participants in this study were people who met the following inclusion criteria: age 18 years or older, diagnosed with HIV for at least six months, with knowledge of the same and who were being followed up at the service. Individuals in confinement (prisoners and institutionalized) were excluded. There was no refusal to participating in the study.

The sample of 26 people was by convenience. For the initial contact, each participant was approached individually by the researchers, the research objectives were presented and, if the participant showed interest, an interview was scheduled. The initial contact was made while they waited for the medical appointment. During the data production period, an average of 16 people was attended per day in specialized medical consultations. It is noteworthy that all interviews were conducted in a private room, at the health service itself, in order to promote privacy.

The interviews lasted an average of 30 minutes. A semi-structured questionnaire was used to obtain sociodemographic data, and a guiding question: What is QOL for you? The instrument was developed by the authors specifically for this study. After its construction, it was assessed by a committee of experts who proposed changes to improve the quality of data production. The specialists had experience in the subject and method used.

The interviews were conducted by two nurses previously trained for this activity. The participants' speeches were recorded with the aid of a multimedia recorder, transcribed in full to Word for Windows and subsequently identified from E1 to E26, maintaining the anonymity of the interviewees.

The number of participants was defined through saturation of the content of the speeches.<sup>17</sup> As the main subjects were repeated in the interviews, such as maintaining health for quality of life and perceptions of stigma, saturation was noticed and the production of data was ended.

The content was processed and analyzed using the lexical analysis technique, the Descending Hierarchical Classification, by means of the IRaMuTeQ software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*).<sup>18</sup>

The study was approved by the Municipal Health Department of the municipality and by the Research Ethics Committee of Escola de Enfermagem de Ribeirão Preto at the Universidade de São Paulo (EERP/USP) under CAAE 50811815.7.0000.5393, n° 060/2016. All participants signed the Free and Informed Consent Form.

## RESULTS

Twenty-six people participated in this study, most of them male 18 (69.0%), aged between 20 and 77 years old and average of 43 years old. The average time of diagnosis was 08 years, and ranged from 01 to 29 years.

The IRaMuTeQ recognized the separation of the corpus into 222 text segments (TS), 164 of which (73.87%) were used. In addition, 2,713 occurrences of words were recorded (616 distinct from each other and 321 occurring only once). The segments used were divided into four classes of senses. The meanings

of the classes were obtained from the descending Hierarchical Classification. Thus, Class 1 corresponded to 26% of TS, Class 2 corresponded to 14.6% of TS, Class 3 corresponded to 34.1% of TS, and Class 4 to 25% of TS (Figure 1).

The naming of each class occurred through the contents of the statements, according to their respective divisions and weights in each group. Thus, they were named: 1 - Difficulties faced in the treatment; 2 - Stigma and lowering of self-esteem; 3 - Health as center of QOL and 4 - Living with expectations.

A dendrogram was prepared containing the classes and the most prominent words, considering frequency and chi-square.

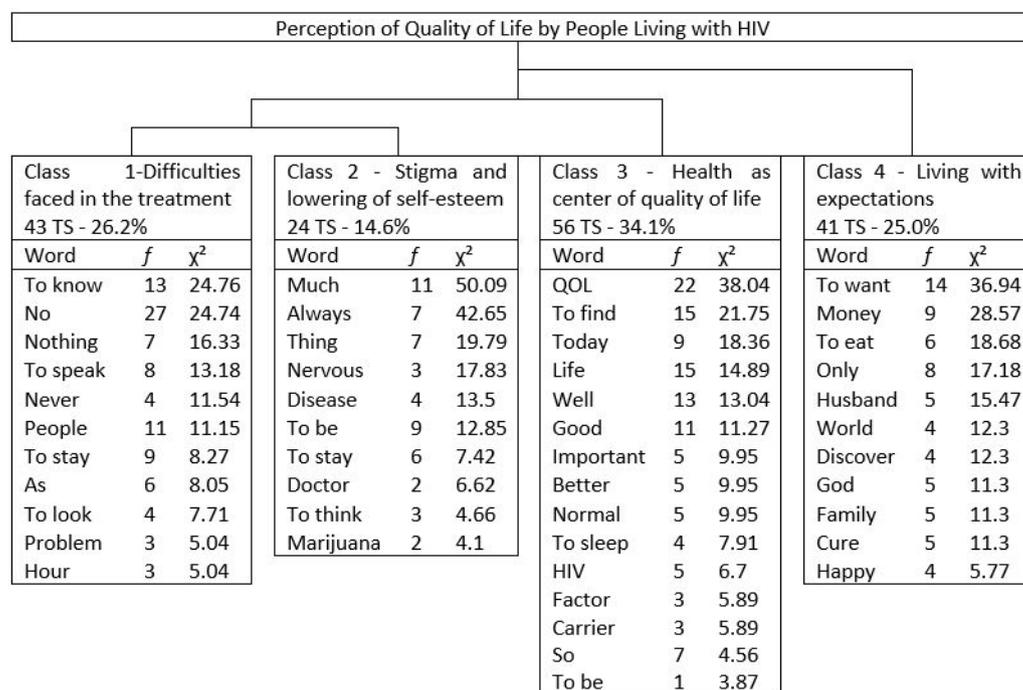
### Class 1 – Difficulties faced in the treatment

Here, on the one hand, it is possible to observe that PLHIV face difficulties in their daily lives. We highlight those related to general health status, maintaining adequate weight and having a medical professional guiding health care, as follows:

*I know we have to lose weight (E2).*

*It means having health, but we don't have it, oh I don't know (E5).*

*I wasn't much of a person who would keep going to the doctor, but now I have continuous medical monitoring. I am always taking a blood test to see how my viral load is doing, how my health is doing, whether I have anemia or diabetes. I take vaccines (E20).*



**Figure 1.** Class Dendrogram, Ribeirão Preto, SP, Brazil, 2020.

\*f: frequency by text segments

Source: IRAMUTEQ, adapted by the authors.

The QOL according to the participants' discourse is limited to isolated elements related to the general health status, such as maintaining the ideal weight, unspecified health conditions and access to health services, such as attending a medical consultation. Although the aspects listed here are positive, it is limited to physical well-being and maintaining the stability of diseases such as diabetes.

### **Class 2 – Stigma and lowering of self-esteem**

This class considers stigmatization as a negative determinant of QOL. This situation can be observed in the reports of individuals who demonstrate that this condition interferes negatively in their health situation.

*For me, the problem I had with this disease, I even thought about doing something bad with me (E1).*

*I think it is more prejudice than the disease itself. I would give anything, everything to have the health I had back. It changes in relation to prejudice, it is a disease that I know I would not find another boyfriend (E6).*

*People's quality of life is destroyed, it destroys everything. We cannot have that love we had with our partner because we are afraid of transmitting the infection on to others (E8).*

*Because it is a very hard thing, you end up very low-spirited, and I have always been high-spirited (E26).*

The decrease in self-esteem stimulated by stigma can weaken the positive situations related to QOL of these people, such as establishing new affective relationships. The barriers created by stigma can still influence the daily lives of these people, interfering in activities that before seemed simple, but have become complex and difficult to be carried out due to the "mark" they carry.

### **Class 3 – Health as center of quality of life**

In this class, participants highlight HIV as a central determinant of QOL. The implications of this determination are to consider only aspects related to physical health and other relevant aspects are not pointed out, as shown in the reports:

*Today I have HIV, so for me quality of life is having health, which today I no longer have, I find myself limited in relation to everything. But if you asked me some time ago, some years ago, maybe I would tell you other meanings (E6).*

*I think that quality of life is related to several factors that permeate life since health issues, which is fundamental, but also other factors (E13).*

*I think it is to eat well if you take good care in my case to do the treatment right and avoid drugs and avoid alcohol (E15).*

*Having a quality of life means having a good diet, avoiding drugs, avoiding alcohol, avoiding smoking, practicing physical activity, which I am not practicing, the rest I have*

*been doing all right in addition to sleeping well so we can rest our bodies, that is what I see (E20).*

*I think there was no quality of life because I was weak today I think I have a good quality of life that today I have an appetite, healthy diet, I am lively, I sleep a little, I sleep seven eight hours and when I wake up I'm already fine so I think that's a quality of life already (E21).*

QOL was associated with good general health, the participants emphasized the diagnosis of HIV in relation to other conditions or situations such as physical well-being, adequate nutrition, non-involvement with the use of psychoactive substances such as alcohol and other drugs and an adequate adherence to antiretroviral treatment.

### **Class 4 – Living with expectations**

Other aspects observed were the feelings of PLHIV related to hope and motivation. The hope is that the cure for HIV will be discovered and they can be treated and cured. Motivation is observed among those people who are inserted in the work context. Family issues are also highlighted in the statements as components of the support and pursuit of happiness framework.

*God willing, find a cure, because I don't want to keep it for the rest of my life, I intend, God willing, to still see if a cure can be found (E2).*

*My quality is to find a cure and to take care of my family, to take care of my only mother, only thing that I have, the only one, to find a cure, is the only thing, that is my desire (E8).*

*Being happy, my family, wife and children, money does not bring happiness, money is good. So, quality of life is being happy to go where I want with my wife, to eat what I want, to watch my television, I love my television, my animals (E9).*

*Working with joy, because it helps too, not only for you, but the environment where you are (E10).*

*For me it is working, you going after your goals, your projects, your living with the family (E16).*

In this class, optimism emerges as a positive aspect in the QOL of these people, as it opens up possibilities to reestablish and strengthen their family relationships and to have positive thoughts about treatment and hopes for a cure. The collective speeches presented build a narrative that can be translated as a reunion of the PLHIV with him/herself and his/her function as a social subject inserted in a context, be it of work, family or affective.

## **DISCUSSION**

This investigation contributed to understand the meaning of QOL for PLHIV, through reports on their perception and experience after diagnosis. The results included that the comprehension of QOL for this population is related to four main thematic classes

which involve the difficulties experienced in the treatment: facing the stigma and lowering of self-esteem; living with the hope that something will happen; and having health as the focus of QOL. These data are in line with other national studies.<sup>19</sup>

In relation to the difficulties experienced in the treatment, discourses emerge containing elements that involve sedentary lifestyle and fear of being overweight. Research has shown that comorbidities are a major problem experienced after the introduction of ART, since HIV infection can increase the risk of cardiovascular diseases when combined with some health and lifestyle factors.<sup>20,21</sup> Furthermore, a survey identified that the main difficulties in adhering to ART are socio-economic issues related to family support.<sup>22</sup> Evidence from a study in Zambia reinforces that poverty and unemployment are important barriers to adherence to antiretroviral treatment.<sup>23</sup>

Another meaning attributed by PLHIV to QOL was the stigma experienced. A study pointed out that suffering from stigma can cause feelings of guilt and inferiority, which can lead to mental illness and social isolation.<sup>24</sup> In addition, depressive symptoms are important predictors of QOL.<sup>25</sup> Furthermore, an international study has indicated that increased stigma reduces QOL.<sup>26</sup>

Even so, it is highlighted that the stigma had an impact on sexuality, since the statements presented concerns about the transmissibility of HIV to the sexual partner. A similar situation was described in a study that showed the fear of infecting the partner with HIV, in addition to the interference in sexual disposition caused by antiretroviral drugs.<sup>27</sup>

The importance of identifying feelings that interfere with self-esteem is emphasized, since they can affect adherence to treatment. A study carried out in the interior of São Paulo, with 331 PLHIV, verified the presence of the feeling of low self-esteem in this population.<sup>28</sup> In this sense, it is necessary to promote appropriate interventions for this population, as self-esteem is a protective factor against symptoms of depression, as identified in a study of Namibia.<sup>29</sup>

It is noticed that optimistic behaviors are correlated with the perception of healthier habits, positive experiences, clinical follow-up and good family experience. It is noteworthy that such findings differ from a study that used the Life Orientation Test (LOT-R) tool, which had as result low optimism scores from the interviewees.<sup>30</sup>

The speeches of the participants also demonstrated that the positivity to face the infection as well as the new challenges experienced was related to family support and hope. Living with hope for PLHIV helps to face the infection and favors living more intensely despite the difficulties imposed by the course of the disease and treatment.<sup>31</sup> In fact, hope has been identified as an interference factor in the quality of life of PLHIV.<sup>32,33</sup>

Having a good family relationship was associated with a feeling of happiness. A study conducted in a municipality in the interior of São Paulo, positively highlighted the role of the family in supporting HIV treatment.<sup>22</sup>

Regarding work-related expectations, positive feelings for its accomplishment are demonstrated as well as the yearning to

reach plans projected through it. Similar conclusions were found in a survey conducted with 122 people, which aimed to assess the perception of the ability of PLHIV to work.<sup>34</sup>

This discussion is endorsed by the central role of the professional nurse in the development of viable strategies to promote the QOL of PLHIV. Initiatives by nurses (professors) with undergraduate nursing students are reported based on positive results in promoting the health of PLHIV using educational technologies. Educational actions contributed to better acceptance of the diagnosis and involved health professionals in the service in which they were implemented.<sup>35</sup> In fact, nurses have the potential to implement strategies aimed at PLHIV, which may generate results capable of influencing the improvement of the quality of life.

## CONCLUSION

The meaning of QOL is understood by PLHIV by factors that can influence positively or negatively. The positive aspects include healthy lifestyle habits; while the negative aspects are related to stigma, prejudice and difficulty in adhering to treatment, therefore, unfavorable for a desirable QOL.

It is noteworthy that the assessment of QOL is an important tool for the individual approach regarding the relevant aspects that need to be unveiled in each individual and can be used in the clinical practice of nurses. In this sense, this study contributes to nursing by awakening the importance of holistic care so that intervention strategies can be designed and implemented based on the identification of positive and negative factors pointed out by PLHIV.

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