

Social representations of the quality of life of the young people living with HIV

Representações sociais da qualidade de vida de jovens que vivem com HIV

Representaciones sociales de la calidad de vida de jóvenes que viven con VIH

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ABSTRACT

Objectives: to analyze the social representations of the quality of life of the young people living with HIV. **Methods:** qualitative survey, based on the Social Representations Theory, with 24 young people living with HIV, monitored in specialized services in Rio de Janeiro, through semi-structured interviews, and the analysis supported by the software IRAMUTEQ. **Results:** multidimensionality of the quality of life was observed unfolding the implications of living with HIV/aids concerning the familiar and social support network, time of diagnosis, healthcare services, antiretroviral therapy, and prejudice expressions. **Final Considerations:** a conceptual synthesis of quality of life is observed when it is associated with healthy lifestyle habits, interpersonal relationships, and health services and professional practices. **Descriptors:** Quality of Life; HIV; Adult Young; Social Perception; Nursing.

RESUMO

Objetivos: analisar as representações sociais da qualidade de vida para jovens que vivem com HIV. **Métodos:** pesquisa qualitativa, fundamentada na Teoria de Representações Sociais, com 24 jovens que vivem com HIV, acompanhados em serviços especializados do Rio de Janeiro, por meio de entrevistas semiestruturadas e análise apoiada no software IRAMUTEQ. **Resultados:** a multidimensionalidade da qualidade de vida foi observada revelando as implicações do viver com HIV/aids em relação à rede de apoio familiar e social, momento do diagnóstico, atendimento dos serviços de saúde, terapia antirretroviral e expressões de preconceito. **Considerações Finais:** Observa-se uma síntese conceitual da qualidade de vida ao ser associada a hábitos de vida saudáveis, às relações interpessoais e aos serviços de saúde e práticas profissionais.

Descritores: Qualidade de Vida; HIV; Adulto Jovem; Percepção Social; Enfermagem.

RESUMEN

Objetivos: analizar las representaciones sociales de la calidad de vida para jóvenes que viven con VIH. **Métodos:** investigación cualitativa, fundamentada en la Teoría de Representaciones Sociales, con 24 jóvenes que viven con VIH, acompañados en servicios especializados de Rio de Janeiro, por medio de entrevistas semiestructuradas y análisis apoyado en el software IRAMUTEQ. **Resultados:** la multidimensionalidad de la calidad de vida ha sido observada revelando las implicaciones del vivir con VIH/Sida en relación a las redes de apoyo familiar y social, momento del diagnóstico, atención a los servicios de salud, terapia antirretroviral y expresiones de prejuicio. **Consideraciones Finales:** se observa una síntesis conceptual de la calidad de vida al ser relacionada a hábitos de vida saludables, a las relaciones interpersonales y a los servicios de salud y prácticas profesionales.

Descriptor: Calidad de Vida; VIH; Adulto Joven; Percepción Social; Enfermería.

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INTRODUCTION

The infection caused by the human immunodeficiency virus (HIV) tackles approximately 37.9 million people in the world, and it is estimated at around 1.7 million new cases⁽¹⁾ in 2019, still representing a big issue in public health.

Brazil has annually registered an average of 39 thousand new cases of aids in the last five years⁽²⁾. According to the Ministry of Health, between 2008 and 2018, there was an increment in the detection rate among young people of the male gender from 15 to 29 years of age. Regarding the age range, studies showed that the epidemic profile of aids presents a growing process of youthfulness, even with prevention campaigns⁽²⁻³⁾. Young people constitute an important social group, with a high susceptibility to HIV infection, due to the psychosocial vulnerability that they predispose adopting behaviors of exposition, such as early sexual life, lack of an appropriate prevention, multiple sexual partners, use of drugs — all associated to the invulnerability feeling⁽⁴⁻⁶⁾.

In general, young people are defined as those in the age range from 15 to 29 years old⁽⁷⁾ though it may be understood as a stage of life in which the transition between childhood and adulthood lives occurs. This idea of youth linked to the transition process between the stages or age range has been subjected to criticism, bearing in mind that youth constitutes a category in permanent historical and social construction, in a process of constant changes⁽⁸⁻⁹⁾.

Living with HIV in the youth represents a complex situation that encompasses several factors, making it essential to recognize the biological, organizational, political, cultural, individual, and social aspects that permeate the lives of young people with HIV/aids⁽¹⁰⁾. Healthcare becomes essential, though the difficulties related to the discrimination and stigmatization by the disease may be huge obstacles and undermine their health condition⁽¹¹⁾.

The access to antiretroviral therapy (ART) made possible longer survival and a Better quality of life (QOL) to people that live with HIV, thus attributing a chronic illness character to AIDS⁽¹²⁾. However, the infection by HIV must be faced as a potential obstacle to the quality of life, due to the several aspects that involve living with HIV⁽¹³⁾, especially from the group of young people. Thus, it is necessary the understanding of perceptions and representations of this group regarding the QOL, to support health promotion strategies⁽¹⁴⁾.

The WHO defines QOL as a “perception of the individuals about their position in the life, within a context of culture and in the system of values in which they live, and about their expectation, their patterns, and their concerns,” then constituting a subjective and multidimensional concept⁽¹⁵⁾.

Thus, to understand the different aspects that impact the QOL, studies show that the infection by HIV affects several domains of QOL of people living with HIV, due to the implications of the disease, once it engages, social, religious, and cultural aspects, in addition to drug therapy⁽¹⁶⁻¹⁷⁾. Regarding to QOL of the young people that live with HIV, studies indicate that the psychosocial and physic domains are the most affected^(18,19).

Another study that analyzed the QOL of people living with HIV confirmed that socioeconomic variables associate with domains of quality of life between people that live with HIV. The variable “gender” showed significant statistical association with psychological, social

relations, environment and spirituality, religion, and personal beliefs of QOL domains, always showing the highest average for males. The variable “age” came up associated to the domain spirituality, religion, and personal beliefs, in which the participants with age between 18 and 38 years old had an average score of QOL lower to the age range from 39 to 59 years old in this domain, showing a vulnerability of the younger age group⁽²⁰⁾.

In this context, the use of the concept of social representations, defined as “a socially elaborate and shared form of knowledge, with a practical aim that contributes for the construction of a common reality to a social group,” making possible the understanding of QOL and the ways constructed by young people to see and think QOL⁽²¹⁾, interfering in their practices of self/heteroprotection.

This study may contribute to the understanding of the attitudes of this group in the face of its health condition for the practice of healthcare and nursing, and the planning of public policies. Also, the lack of scientific investigations about the quality of life associated with HIV/aids in youth. Then, the leading question was defined: What is the social representation of life to the young people living with HIV?

OBJECTIVES

To analyze the social representations of the quality of life for young people living with HIV.

METHODS

Ethical aspects

The present survey was developed in a Master’s dissertation and is part of a multicentric survey named “The quality of life and their symbolic construction among people living with HIV/ Aids in the State of Rio de Janeiro,” coordinated by an advisor and here denominated master project. The rules established by the Resolution N° 466/12 of the National Council of Health were followed, which provides for the guidelines and rules that regulate research involving human beings, having been approved by the Research Ethics Committee of the Municipal Health Secretariat of Rio de Janeiro and by the Research Ethics Committee of UERJ. The participants read and signed the Informed Consent Form (ICF).

Type of study

It is a descriptive study, with a qualitative approach, based on the Theory of Social Representations, which enables the understanding of the reality common to a social group⁽²²⁾.

Study setting

The survey was developed in five Specialized HIV/Aids Care Services (SCS): three in the municipality of Rio de Janeiro and two in the municipalities of Rio das Ostras and Macaé.

Data source

The participants of this study are young that live with HIV, under therapy at SCSs chosen for the study.

The following inclusion criteria were considered for the composition of an intentional sample: have between 18 and 29 years old; have positive serology for HIV; be at SCS in the moment of the collection of data; be literate; and have cognitive conditions to participate in the study.

Of the total of 110 participants in the master project, 24 met the inclusion criteria for this study. The studied sample was composed of 24 participants distributed as the following: 4 participants from Rio de Janeiro, 10 from Macae, and 10 from Rio das Ostras. The sample composition of the master project was delimited by the data saturation criterion.

Collection and organization of data

The data collection was carried out with the assistance of two instruments: a questionnaire of socioeconomic and clinical data and a semi-structured interview script.

At first, the participant filled up the socioeconomic questionnaire, and then a second data was schedule according to the participants' return and availability to conduct the interview. The interviews were conducted in a separate room, at the health service units where they were monitored; they were recorded in a digital device, after participants' consent, and the content was transcript in full afterward. The interview lasted around 25 to 80 minutes.

After the collection, two databases were built: one with socioeconomic and clinical variables, on the software SPSS; and another one having the transcription of the interviews, on the software Word. Aiming to preserve the identity of the participants, their identifications were alphanumeric, using the abbreviation "Entr" (interview) followed by the number representing the order it occurred (For example, Entr_0001). This identification modality was adopted in the data collection instruments and the construction of the two databases.

Data analysis

Descriptive statistical analysis of the questionnaire was performed using Excel software, using descriptive statistics. Interviews were analyzed through the technique of lexical analysis, supported by the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaire* (IRAMUTEQ). The software is free, developed by the open-source logic, and anchored in the environment of the R software in the *python* language. It was elaborated in 2009, in France, and introduced in Brazilian surveys from 2013, having been tested by the Laboratory of Social Psychology of Communication and Cognition at the Federal University of Santa⁽²³⁾.

This software allows the performance of different types of statistical analysis about text corpus. In this study, the descending hierarchical classification (DHC) was used, in which the text segments (TS) are classified according to their respective vocabularies, and their set is divided according to the frequency of the reduced forms (words without their ending), aiming to obtain classes of text segments with similar vocabulary and with different vocabularies related to the other classes of the same analysis⁽²³⁾.

The results of this analysis are presented in a dendrogram that illustrate the relationships between classes, the reduced forms, and the variables associated to each class with their frequency and qui-squared values (χ^2). The software still provides text segments (TS) statistically associated to each class, allowing its description and appointment⁽²³⁾.

In this study, the analysis corpus was composed of 24 interviews, separated by a command line including the identification number of the interviewed and the chosen variables for the study, which are: home location, gender, age range, education, employment, marital status, personal income, religion, time of diagnostic, transmission type, use of ART, time of use of ART, sexual orientation, condom use, health status perception, health evaluation. Subsequently, the entire file was reviewed, aiming to correct digit and punctuation mistakes, standardizing the abbreviations and uniting compound words — for example, the term "quality of life" was included with the combination of characters by *underline*, thus being recognized as a single word by the software.

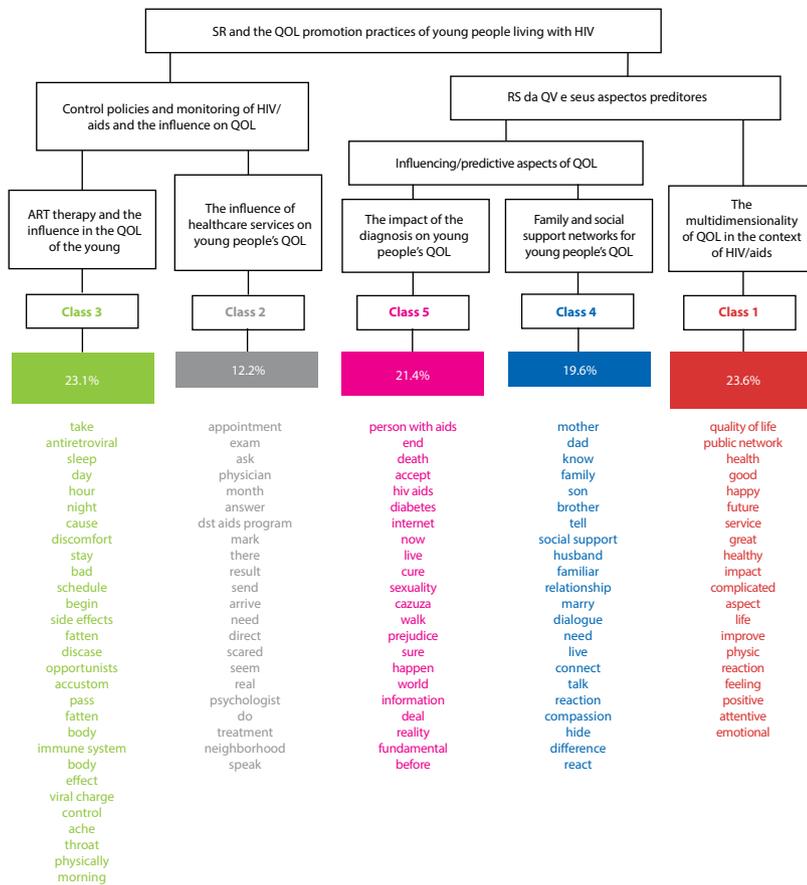
Then, the questions were suppressed, keeping only the complete answers and referred to the question. The file was saved in OpenOffice format with encoded text, according to the software's guidelines⁽²³⁾. On the software IRAMUTEQ, the analysis of the duly prepared corpus was carried out.

RESULTS

Sociodemographic definition of the participants reveals that the most part is of the male gender, corresponding to 66.7% of the samples. Regarding the age range, 54.1% of the participants are in the age range from 21 to 24 years. Concerning marital status, 54.2% claimed not having a partner. About religious orientation, 33.3% declared Christians. About education, 50% reported had completed high school or incomplete higher education. Regarding personal income, 37.5% of the participants did not have personal income, 29.1% presented an income up to R\$1,000.00, representing 66.6% of the sample. Concomitantly, 50% of the participants claimed unemployed. The clinical characterization and health practices show that, concerning sexual orientation, 37.5% of the participants claim to be heterosexual. Regarding the time of diagnosis, this was less than four years for 66.6% of participants; the use of ART was less than or equal to six months (45.4%); with transmission by heterosexual contact (37.5%); using condoms continuously (45.8%). About the asses of one's own health, 45.8% of the participants do not consider themselves sick, and 50% evaluate their health status as good or very good.

Lexical analysis of the interviews resulted in 1,665 TSs, of which 1,501 were used in the analysis, representing 90% of the total corpus, a number considered satisfactory. Five classes were created resulted from DHC, which contains the representational content of the QOL of the group of young people living with HIV.

The result of the lexical analysis is represented in the class dendrogram, which shows the relationship between the classes according to the sequence of divisions suffered, in addition to the profile of each class, as shown in Figure 1.



Note: SR – Social Representations; QOL – Quality of Life; HIV – Human Immunodeficiency Virus; AIDS – Acquired Immunodeficiency Syndrome; ART – Antiretroviral.

Figure 1 – Dendrogram of distribution of classes generated by the IRAMUTEQ software, Rio de Janeiro, Rio de Janeiro, Brazil, 2019

The corpus that includes the total of interviews received the name “Social representation and the practices of promotion of QOL of young people living with HIV,” which originated two subcorpus. The first is called “Social representation of the QOL and its predictive aspects,” which encompasses Class 1 (23.6%), “The multidimensionality of quality of life in the context of HIV/AIDS,” Class 4 (19.6%), “Family and social support networks for the quality of life of young people,” and Class 5 (21.4%), “The impact of the diagnosis on the quality of life of young people.” The second textual block was called “Control policies and monitoring of HIV/AIDS and the influence on the quality of life” and includes Class 2 (12.2%), “the influence of healthcare services on the quality of life of young people,” and Class 3 (23.1%), “the antiretroviral therapy and the influence in the quality of life of the young people.”

The details of the representational content of QOL included in the classes will be presented according to the order of division of the descending hierarchical analysis, shown in the dendrogram (Figure 1).

Class 1: The multidimensionality of the quality of life in the context of HIV/AIDS

Class 1 has 355 TSs, which comprises 23.6% of the total of TSs analyzed. It was the first class generated after the binary division of corpus, and it is the biggest analysis class showing its importance.

The young group profile of this class refers to those that live in a big city (χ^2 142.94), in Rio de Janeiro (χ^2 142.94), of male gender (χ^2 115.65), employed (χ^2 37.73), with income between R\$ 1,000.00 and R\$ 2,000.00 (χ^2 50.44), with a homosexual orientation (χ^2 106.45), HIV transmission by homosexual contact (χ^2 138.24), and with the diagnostic time between 6 and 14 years (χ^2 39.26).

The words with the highest value of association with the class are *quality of life, public network, health, good, happy, future, service*. In this class, we observe that the perception of the quality of life is linked to the habits of life considered healthy, such as good nutrition, physical exercise, sleeping the necessary hours, performing leisure activities - habits that are related to health promotion practices, considered as defining quality of life.

For me, leisure, fun, my family, my husband, improve my quality of life. (Entr_1069; female gender; 21 years; complete high school; one year of diagnosis)

The most important factor for the quality of life of people with AIDS today is to prevent, maintain a healthy life, do physical activity. Eating is also very good, because there are things you eat that will not be good to you. It's practicing physical activity, I really like swimming and hiking, my next focus is to hang gliding. (Entr_0164; male gender; 26 years; complete high school, four years of diagnosis)

In this context, the public network is inserted as a set of support services for health maintenance, since it makes possible the access to the necessary healthcare, such as the medical monitoring of the multidisciplinary team, and the access to (ART) treatment, factors considered to enhance the QOL.

Currently, the main thing is medical monitoring, which contributes to my quality of life. Without medical supervision, you cannot follow. (Entr_1083; male gender; 28 years; complete higher education; two years of diagnosis)

The public network can influence the quality of life and adherence to antiretroviral therapy, especially with regard to the receptive treatment of the STD/AIDS program. (Entr_1083; male gender; 28 years; complete higher education; two years of diagnosis)

In this class, it is identified a wide perception of QOL, contributing to a positive sense of it.

Understanding the factors influencing QoL for young people contributes to the effectiveness of care strategies for this group.

Class 4: Family and social support networks for young people's quality of life

Class 4 is constituted of 294 TSs, meaning 19.6% of the total TSs analyzed. The profile of the group of young people in this class refers to those that attended elementary school (χ^2 21.26),

do not use ARV (χ^2 11,62), and claims Christian religion, and others (χ^2 9.14).

The main words associated with the class are *mother, father, know, friend, family, son, brother, tell, social support*, and others. In this class, there is an emphasis on the representational content of QOL in the context of the relationships established with the family, with friends, and with other people in social life.

The relationship with the family influences my quality of life, because if my family were not on my side, supporting me, I would not have the strength to fight on a daily basis. Family support was what gave me strength. (Entr_3015; male gender; 25 years; complete elementary school; nine years of diagnosis)

Quality of life is when you have a good relationship, not only with a sexual partner, but with your father, your mother, your child, your brothers, your friends and the people around you. (Entr_1084; female gender; 22 years; complete high school; two years of diagnosis)

It is noticed that HIV influences social and family relationships, and it represents a potential impact on the QOL of the participants.

In contrast, the negative representational content is also present in the class and is related to the disclosure of the diagnosis, given the fear of prejudice and rejection linked to the disease. This feeling leads young people to hide or restrict information about the serology positive HIV from some people, to avoid suffering from withdrawal situations, which influences the way to perceive the quality of life.

We never know the person's reaction and it's complicated. HIV/Aids has not changed my relationship with friends, because nobody knows and I do not intend to tell, because I am afraid that the person will see me with prejudice. (Entr_1072; female gender; 24 years; incomplete high school; diagnosis time not informed)

In the past, it was kind of scary. Everyone will know that I have HIV/Aids, everyone will walk away from me, but I am having very good social support. Yes, without a doubt, you can be sure that the social support of the social cycle is important. (Entr_3066; male gender; 22 years; incomplete higher education; one month of diagnosis)

The decision to hide the serological condition both to the group of friends and to the family is linked to negative perception associated with Aids. That said, Young people have no other option than hide the diagnosis, which ends up impacting health promotion and, consequently, QOL.

Class 5: The impact of the diagnosis on the quality of life of young people

Class is constituted of 322 TSs, which represents 21.4% of the total of TSs analyzed. The profile of the group of young people of this class refers to retiree (χ^2 3,66), with income higher to R\$ 2,001.00 (χ^2 3.51), and the city of the collection is Rio das Ostras (χ^2 3,34).

The main words associated with Class 5 are *people with aids, end, death, mind, accept, HIV/Aids, diabetes, internet, now, live*, among others. Participants express the memories of the HIV/Aids impacts in their daily lives, which influence the QOL. More

positive representational content is perceived, permeated by changes in the social representations of HIV/Aids in terms of coping with the diagnosis, enabling a better QOL.

When I saw the result, in the past, my God, the world fell on my head, but today it is normal. I access to information on the internet. Currently, the quality of life of people with AIDS contains more vitamins. (Entr_0075; male gender; 20 years; complete high school; one year of diagnosis)

For me, the worst has already happened. Currently, HIV/Aids for me is a common chronic disease. (Entr_1083; male gender; 28 years; complete higher education; two years of diagnosis)

The process of acclimating of Aids and its diagnosis, observed in the last years, provided a Better acceptance and adaptation to seropositivity condition among the young people, reflecting in actions of maintenance and promotion of the QOL.

Class 2: The influence of healthcare services on the quality of life of young people

Class 2 is constituted of 183 TSs, which comprises 12.2% of the total of TSs analyzed, being the lowest class of the analysis. The profile of the typical group of the young people of this class refers to the female gender (χ^2 15.2), heterosexual (χ^2 19.52), Catholics (χ^2 12.96), which way of transmission was heterosexual (χ^2 19.52), considered sick (χ^2 22.04), evaluate their health as good or very good (χ^2 33.74), live in small or medium-sized cities (χ^2 8.39), the collection city was Macae (χ^2 24.6).

The main words associated to Class 2 were *appointment, exam, come, ask, physician, month, answer, DST/Aids Program*.

I believe that this implies in the quality of life, because I know that I am well, I take the exams and I see that everything is fine with me. Contact with health professionals also implies taking antiretroviral drugs, because I attend the STD/Aids program and they explain everything to me; if I have any questions, I speak, and they explain to me, I will come home with another thought. (Entr_1091; female gender; 24 years; incomplete high school; five years of diagnosis)

It may be an improvement in the STD/Aids program, the infrastructure. Currently, you take an exam today, and you will get the results in two months, and you have to arrive very early. (Entr_0016; male gender; 26 years; incomplete higher education; nine years of diagnosis)

In this class it is noticed that the assistance provided to the participants, added to a satisfactory response of the resources available in the health services, reveals a positive representational content of QOL. However, elements corresponding to a more negative perception were noted, linked to the delay in exam results.

Class 3: The antiretroviral therapy and its influence in the quality of life of the young people

Class 3 is constituted of 347 TSs, which comprises 23.1% of the total of TSs analyzed, being the second biggest class. The profile of the group of young people refers to people that live

in a medium-sized city (χ^2 52.94), Macae (χ^2 85.99), of female gender (χ^2 73.46), unemployed (χ^2 23.08), with income up to R\$ 1,000.00 (χ^2 16.99), with heterosexual orientation, HIV transmission via heterosexual relationship (χ^2 57.81), and with a time of diagnosis of up to six years (χ^2 19.33).

The main words associated with this class are: take, antiretroviral, sleep, day, hour, night, cause, discomfort, stay, bad. You can see that medication has a positive symbolic value in the participants' report due to the possibility of suppressing symptoms, stabilizing the disease, and preventing opportunistic pathologies, favoring a better prognosis, which is positively expressed in the perception of the quality of life.

The influence of antiretroviral on my quality of life, as I said, the antiretroviral only serves me not to make me sick, it only makes me feel good. My viral load is undetectable, and the cd4 goes up because of it. (Entr_1069; female gender; 21 years old; complete high school; one year of diagnosis)

What makes my quality of life better is having to take correctly the antiretroviral, because I don't get sick, it doesn't change anything, everything is quite normal. What makes the quality of life worse is not taking the antiretroviral, because I keep feeling a lot of things. (Entr_1091; female gender; 24 years; incomplete high school; five years of diagnosis)

It is noticed that the use of ART therapy is recognized as a health care modality. In this context, participants express the need for behaviors incorporation adaptive to ART, as well as the abandonment of unhealthy and harmful behaviors to keep the body stable.

Many difficulties, because you have to adapt to antiretroviral. You need to have a schedule, be regulated and it's very complicated. (Entr_0016; male gender; 26 years; incomplete higher education; nine years of diagnosis)

I used to spend the night outside the house, drank and without food sometimes, and I didn't worry much about anything. Currently, I'm more homely, I don't drink anymore after I started treatment. (Entr_1069; female gender; 21 year; complete high school; one year of diagnosis)

The survey identified that young people showed worries with side effects, mainly due to the possibility of changes in physical appearance and self-image.

And I thought that the antiretroviral would make me fat, that I would get fat, and I was terrified of taking the antiretroviral. I thought: "At 20, I'm going to get fat, I'm going to be whale". (Entr_1075; female gender; 22 years; complete high school; five years of diagnosis)

The first thing I got scared of was people who were already here, I saw people who already had side effects stamped on their faces, it made me crazy, that I didn't want to take antiretroviral to have that appearance because of lipodystrophy. (Entr_1069; female gender; 21 years; complete high school; one year of diagnosis)

It is observed that side effects may influence the adherence to ART therapy and, consequently, negatively impacts the QOL.

DISCUSSION

It is noticed that the constitutive content of the social representation of the quality of life of the group of young people living with HIV is coherent with the multidimensional concept of the QOL, which encompasses the economic, lifestyle, health conditions, housing, personal satisfaction, social environment contexts, among others⁽²⁴⁾. This is also related to the perception that individuals have of their position in life, regarding their objectives, expectations, patterns, and concerns⁽²⁵⁾.

This multidimensionality of the QOL was observed in the set of lexical classes that reveals the relationships and the implications of living with HIV/Aids in the family and social support networks, with the moment of the diagnostic, health services, and antiretroviral therapy. There are several individual perceptions of the QOL in Class 1, revealing its specifications in terms of healthy lifestyle habits, such as good nutrition, physical exercise, sleeping the necessary hours, and performing leisure activities.

The life of the group of young people that lives with HIV is marked by the need for successive adaptations in daily life, which includes the relationship with the body, with peers, family, and the development of sexuality⁽²⁶⁾. The ART therapy is revealed as a challenge in this process of multiple adaptations, since it is a permanent presence in the daily life of the group, giving materiality to the disease and being able to reflect on the body and body self-image. ART therapy is understood as a positive predictor of the quality of life, mainly for improving immunity, controlling the viral load, and slowing the progression of the disease⁽²⁷⁾. However, it imposes the need of permanent healthcare, not negotiable, since it is indispensable for the survival and, consequently, for the improvement of the quality of life of people living with HIV⁽²⁸⁾.

Young people living with HIV/Aids may have a body image compromised due to clinical alterations caused by the infection, side effects caused by the ART therapy, and the stigma associated with the disease⁽²⁹⁾. The perception of the body image is defined as an image related to the dimension and shape of the body, parts that constitute this image, and also the feeling related to this characteristic, including affective, cognitive, perceptive, and behavioral components⁽³⁰⁾. In general, studies on body image point out damages related to the dissatisfaction and distortion of the physical shape, being strongly influenced by sociocultural factors, especially in adolescence⁽³¹⁻³²⁾. For example, a study carried out with adolescents showed that despite the male gender had presented higher prevalence for distortion of body image, it had a light grade whereas the female group had a higher prevalence in moderate and severe grades, a more serious situation since it is commonly associated with the development of eating disorders. Gender does not seem to have been determinant for the presence of the body image distortion, though the severity of the distortion seems to be more common among female school-age⁽³³⁾.

In this context, the health sector is a similar quality of life enhancer, contributing to the coexistence of the disease⁽³⁴⁻³⁵⁾. The care provided by health services and the relationships with health professionals is indicated as aspects that impact the QOL of the people living with HIV. This is because the QOL of this group involves, in addition to drug therapy, social, religious, behavior, and cultural aspects, requiring the offer of comprehensive, humanized,

and decisive care, compatible with the needs of people living with HIV, from infection prevention to health recovery⁽³⁶⁻³⁷⁾.

Living with HIV and its implications go beyond the physical and biological threats. It is also observed psychologic and social difficulties, which are factors that influence the living with this condition. The stigma and prejudice experienced, or even the fear of experiencing them, may cause social and family isolation, compromising the support social network and health monitoring^(34,38).

The process of stigmatization, real or imagined, started with the emergence of AIDS and its association with homosexual groups and those using drugs, and has been maintained ever since, but with different configurations. For Goffman⁽³⁹⁾,

while the stranger is in front of us, evidence may arise that it has an attribute that makes it different from others that are in a category in which it could be included, even being of a less desirable species [...]. Thus, we stop considering it a common and total creature, reducing it to a damaged and diminished person. Such a characteristic is stigma, especially when its discredit effect is very large [...]

Despite the epidemiological changes observed in the context of HIV and Aids, prejudice is still an element that permeates the life of people living with HIV. The core of prejudice and stigmatization is revealed not only in daily life but also in the fear of experience in such situations. This way, the everyday social relationships are subjects to this marker, being influenced by this practice, which is anchored in the perceptions, still in force, of social risk groups, depreciated, and in the association of seropositivity with risk behaviors⁽⁴⁰⁾.

Social support positively influences the QOL of the group of young people living with HIV with regard to coping with stress related to the illness process. The support that came from the relatives and friends during the course of the disease is essential, bearing in mind the confronting situations of discrimination and stigmatization by young people, since the diagnosis⁽⁴¹⁻⁴³⁾. Thus, to improve the QOL of this group, greater emphasis should be placed on improving social support⁽⁴⁴⁾.

The diagnosis of seropositivity is one of the factors that negatively impact the perception of the QOL of young people. Diagnosis constitutes a divisor between a normal life and living with a chronic, infectious, and still incurable disease^(34,45). However, living with the disease, people adapt; and, with that, the perception of the quality of life is changing, assuming greater positivity⁽³⁴⁾.

The study carried out with people living with HIV points out that the social representation of the quality of life is structured based on a positive evaluation of QOL itself and, still, in the dimensions of the physic-body care, self-care, and care of the next, as part of a satisfactory QOL⁽²⁸⁾. Another systematic review study revealed that the social representation of the quality of life of people living with the harm is constituted by the following elements: information and prevention, prejudice and stigmatization, the suffering caused by HIV, construction, and change of social representation of Aids, quality of life, and support structures. Results of both studies carried out with the adult population when compared to those found in this survey, confirm the representational content of the QOL related to the daily life of living with HIV, with some nuance of greater acclimating of the disease in this study and less reference

to the elements of memory of the beginning of the epidemic⁽⁴⁶⁾.

Study limitations

A limitation of this study was the sample predominantly male, avoiding an analysis encompassing the female specificity about the quality of life. A second limitation refers to an intentional sample adopted, not allowing the use of results for comparison with other groups.

Contributions to the fields of Nursing, Health or Public Policy

Understanding the QOL of people that live with HIV is relevant for contributing to the planning, monitoring, and care practices aimed at this group, considering the specificity of the ways to understand its QOL in the context of chronicity of the disease and the care involved.

FINAL CONSIDERATIONS

This study made it possible to know the contents of the social representation of the quality of life for the young people living with HIV, allowing the understanding of the meanings attributed by the group to its actions, based on the contexts in which they are produced. It is considered that understanding the determinants of the practices of the young people is essential for the success of the prevention and vulnerability reduction practices.

Thus, it was identified that QOL for Young people is anchored in the health and well-being as structured elements of the representation. However, the threat of loss of health or feel sick, and the situations experienced in daily life imposed by HIV result in suffering and generate feelings that negatively influence the perception of QOL.

The content of social representation of the quality of life for the young group expresses in a multidimensional perception of this quality, including the identification of the role of family and social support networks as promoters of quality of life; the positive and negative impacts of the diagnostic of quality of life; the recognition of the care provided by health services, and the access to ARTs as promoters of young people's quality of life. In contrast, ART therapy side effects, self-image disorders as well as the perception of stigma and discrimination directed at young people are associated with a negative perception of QOL.

Therefore, despite recognizing that the seropositive diagnostic is a factor that negatively impacts the QOL, the context of the interpersonal relationships, and the health service and professional support show as relevant representational elements to determine a better quality of life. This study highlights few physical manifestations as a constitutive element of the representation of QOL, which reinforces the notion that psychosocial aspects in the context of illness are important and positively or negatively impact the perception of the quality of life in everyday life.

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