Quality of life and adherence to antiretroviral medication in people with HIV

Qualidade de vida e adesão à medicação antirretroviral em pessoas com HIV

Marli Teresinha Gimeniz Galvão[1]
Larisse Lima Soares[2]
Samyla Citó Pedrosa[1]
Maria Luciana Teles Fiuza[1]
Larissa de Araújo Lemos[1]

Abstract

Objectives: To assess and correlate the quality of life and adherence to antiretroviral therapy in people with HIV.

Methods: A cross-sectional study was performed with 45 outpatients with HIV. The instruments used were: a questionnaire to assess adherence to antiretroviral therapy (CEAT- HIV), and a scale for assessing quality of life in people with HIV (HAT-QoL). A descriptive analysis was performed and the Spearman's linear correlation test was used.

Results: Quality of life was compromised in the dimensions related to overall function; sexual function; health, disclosure and financial worries; and HIV mastery. Poor adherence prevailed in 51.3% of participants. The correlation between the scores of the scales was statistically significant in the dimensions of medication concerns and provider trust.

Conclusion: The quality of life was compromised in six dimensions of the scale and adherence scale was inadequate in most people with HIV.

Resumo

Objetivos: Avaliar e correlacionar a qualidade de vida e a adesão à terapia antirretroviral em pessoas com HIV.

Métodos: Estudo transversal, desenvolvido com 45 pessoas com HIV em tratamento ambulatorial. Os instrumentos utilizados foram: questionário para avaliação da adesão ao tratamento antirretroviral (CEAT-VIH) e escala para avaliação da qualidade de vida em pessoas com HIV (HAT-QoL). Foi realizada análise descritiva e empregado o teste de correlação linear de Spearman.

Resultados: A qualidade de vida mostrou-se comprometida nos domínios relacionados às atividades gerais; sexuais; preocupação com a saúde, com o sigilo, com questões financeiras; e conscientização sobre o HIV. Houve predomínio da adesão inadequada em 51,3% dos participantes. A correlação entre os escores das escalas mostrou significância estatística nos domínios relacionados à medicação e confiança no profissional.

Conclusão: A qualidade de vida apresentou comprometimento em seis domínios da escala e a adesão encontrou-se inadequada na maioria das pessoas com HIV.

Corresponding author
Larissa de Araújo Lemos
Alexandre Baraúna street, 1115, Rodolfo Teófilo, Fortaleza, CE, Brazil. Zip Code: 60430-160.
lariss_araujo@hotmail.com

[1]Universidade Federal do Ceará, Fortaleza, CE, Brazil.
[2]Secretaria de Saúde de Madalena, Madalena, CE, Brazil.
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Introduction

In the 1990s, Brazil adopted the policy of universal access to antiretroviral therapy, with free distribution to all people living with HIV; its strategies were aimed at preventing new cases of infection and controlling the aggravations of the epidemic, which resulted in the reduction of morbidity and mortality associated with HIV infection and hospitalization occurrence, thereby increasing life expectancy.[1]

AIDS has become a chronic disease, due to advances in therapeutics, characterized by a significant increase in life expectancy, resulting in the need for assessing the quality of life of affected people. With the increasing survival of people living with HIV, due to the therapeutic advances in the area, concerns have turned to quality of life, which is becoming an important criterion for assessing the effectiveness of health care treatments and interventions.[2]

Understanding the quality of life of these people is essential, considering the chronic progression of HIV infection, the possibility of treatment, longer survival, living with a stigmatizing condition, and the fact that it is incurable to date, with uncountable biopsychosocial consequences that impact on quality of life.[3]

The technological advances and the reduction of the number of daily pills of antiretroviral therapy, such as the combination of medications, have facilitated adherence to treatment. The times of medication administration and the adverse effects caused by medications can be taken into consideration when adherence is assessed, because it is difficult to maintain these routines for long periods, which can influence the treatment success. Also, changes in the quality of life may be related to the extension of the time of the antiretroviral treatment.[4]

In this context, the aim of this study was to assess and correlate the quality of life and adherence to antiretroviral therapy in people with HIV and to correlate the scores of quality of life and adherence.

Methods

This was a cross-sectional, exploratory study with a quantitative approach, developed in the Clinic of Infectious Diseases, University Hospital Walter Cantídio at the Federal University of Ceará, with people admitted to the service who met the following inclusion criteria: having the HIV diagnosis formally registered in their chart; age $\geq$ 18 years of age, and having initiated outpatient follow up less than one year before. Exclusion criteria were: individuals in a situation of deprivation of freedom, with cognitive impairment, or pregnancy.

The participants were recruited through convenience sampling, as they attended the service. Data were collected from September of 2011 to April of 2012. Data were obtained when people living with HIV attended their medical consultations, in a private place before the start of the consultation.

According to the data provided by the hospital, 65 people started health monitoring in the service in 2012. The number included in the study was 45 people with HIV with antiretroviral therapy prescription, representing approximately 70% of all those assisted in the study period. Two people refused to participate.

The questionnaires used for data collection were: a questionnaire for sociodemographic and clinical assessment, a questionnaire to assess adherence to antiretroviral therapy (CEAT-HIV),[5] and a scale for assessing quality of life in people with HIV (HAT-QoL).[6]

The questionnaire for sociodemographic and clinical assessment contained variables related to personal identification, economic, social and educational status, clinical and epidemiological data on the disease, such as laboratory tests and duration of treatment.

The CEAT-HIV is an instrument, validated in Brazil, with 20 items to identify the degree of adherence to antiretroviral therapy in people with HIV infection.[5] For the analysis, the scores were clustered into two groups, classified as good/adequate and strict adherence (raw score ≥75) and inadequate/poor/ insufficient adherence (raw score ≤74).

The HAT-QoL is a scale, validated in Brazil, with 42 items divided into nine dimensions, namely: overall function, sexual function, disclosure worries, health worries, financial worries, HIV mastery,

life satisfaction, medication concerns and provider trust. The sum of the scores in each dimension was studied in an analogous similar scale of zero to 100 points. Values close to or equal to zero correspond to poorer quality of life, and numbers closer to 100 indicate better quality of life.[6] The cutoff used in this study was 75 points.

The sociodemographic and clinical variables related to HIV were presented through univariate frequency distributions and descriptive measures. To describe the contents of the HAT-QoL dimensions, the means, standard deviation and percentiles were used. The CEAT-VIH scale was synthesized through the outcome indicator as adequate or inadequate adherence. The Spearman's linear correlation test was used to assess the correlations between the scores of the scales. The level of significance for all statistical analyses was 5% ($p \leq 0.05$).

The development of the study met national standards of ethics in research involving human beings.

Results

During the development of the study, during assessment of medication adherence, six of the 45 total participants were not using antiretrovirals because of treatment abandonment or inadequacy of the medications. Thus, 39 people were assessed who were in fact under antiretroviral therapy. However, it was deemed necessary to include them in the quality of life assessment, because they would return to treatment as soon as they recognized the importance of continuous use of the medications, or when the medication scheme was readjusted. Thus, we assessed the quality of life of 45 people, and adherence to antiretroviral therapy of 39 people.

There was a predominance of males (66.6%), aged between 18 - 39 years (62.3%), who were single (73.3%), with ≥ 10 years of education (73.3 %), and who were employed (66.6%). Regarding economic status, 62.2% reported less than or equal to two minimum wages (at the time of the study, the minimum wage was R$ 622.00, equivalent to US$ 311.00/month). Among those using antiretroviral therapy at the time of the interview (n=39), 77.8%

were using up to three pills a day. With regard to CD4+ T lymphocytes count, 51.1% had more than 500 cells / mm³ (Table 1).

Table 1. Sociodemographic and clinical characteristics of the 45 people living with HIV

Characteristic	n(%)
Age group (years)	
18-39	28(62.3)
≥40	17(37.7)
Gender	
Male	30(66.6)
Female	15(33.4)
Education (years)	
≤9	12(26.7)
≥10	33(73.3)
Marital status	
Married/ common law	12(26.7)
Single/widow(er)	33(73.3)
Family income (minimum wages*)	
≤2	28(62.2)
>2	17(37.8)
Occupational status	
Employed	30(66.6)
Unemployed	15(33.4)
Category of exposure	
Sexual	40(88.9)
Blood	5(11.1)
Number of pills a day	
≤3	35(77.8)
≥4	10(22.2)
CD4+ (cell/mm³)	
≤500	22(48.9)
>500	23(51.1)

*At the time of the study, the minimum wage was R$ 622.00, equivalent to US$ 311.00/month

Regarding the assessment of medication adherence through CEAT-HIV, 51.3% had inappropriate levels of adherence to treatment, indicating incorrect and/or disrupted use of medications.

As for the quality of life assessment using the HAT-QoL, out of the nine dimensions, six had mean scores below 75 points, demonstrating impairment in quality of life, namely: overall function (70.9), sexual function (68.1), disclosure worries (38.8), health worries (62.7), financial worries (55.3) and HIV mastery (71.1) (Table 2).

Table 2. Descriptive measures of the dimensions of the quality of life assessment scale (HAT-QoL)

Dimensions	Items	n	Mean (± SD)	P50	Maximun	Minimun	P25	P75	P75-P25
Overall function	7	45	70,9(±22.7)	75.0	100	7.1	53.6	89.3	35.7
Sexual function	3	45	68,1(±22.8)	62.7	100	0.0	58.3	83.3	25.0
Disclosure worries	5	45	38,8(±26.3)	35.0	100	0.0	20.0	55.0	35.0
Health worries	5	45	62,7(±26.0)	65.0	100	5.0	45.0	85.0	40.0
Financial worries	4	45	55,3(±29.6)	56.3	100	0.0	31.3	75.0	43.8
HIV mastery	3	45	71,1(±23.1)	75.0	100	16.7	40.0	91.7	41.7
Life satisfaction	8	45	79,1(±21.9)	81.3	100	0.0	68.8	93.8	25.0
Medication concerns	4	39	79,8(±20.0)	87.5	100	37.5	68.8	100	31.2
Provider trust	3	45	91,3(±17.4)	100.0	100	0	83.3	100	16.7

SD – standard deviation; P50 – 50th percentile; P25 – 25th percentile; P75 – 75th percentile

The correlations between the dimensions scores of the HAT-QoL and CEAT-HIV were weak; they were statistically significant between the dimensions related to medication concerns (p=0.0056) and provider trust (p=0.0278), indicating that people with a better quality of life in these areas also had adequate adherence to the use of antiretroviral medications (Table 3).

Table 3. Correlations of scores on the quality of life assessment scale (HAT-QoL) and the questionnaire to assess adherence to antiretroviral therapy (CEAT-HIV)

HAT-QoL Dimensions	Correlation with CEAT-VIH* scoring
Overall function	(r=0.0680; p=0.6808)
Sexual function	(r=-0.0106; p=0.9490)
Disclosure worries	(r=-0.1420; p=0.3884)
Health worries	(r=-0.1953; p=0.2335)
Financial worries	(r=0.1518; p=0.3562)
HIV mastery	(r=-0.0235; p=0.8869)
Life satisfaction	(r=0.2869; p=0.0766)
Medication concerns	(r=0.4354; p=0.0056)
Provider trust	(r=0.3523; p=0.0278)

* Spearman's linear correlation

Discussion

The sample size was a study limitation, since the participants were required to have initiated outpatient follow up less than one year before the study, as an inclusion criterion; the remaining patients who were monitored for more than one year were not included in the study, a situation that resulted in a reduced number of subjects in the sample.

Concerning the contribution of this study's results, the knowledge produced about the impaired quality of life and poor adherence to antiretroviral therapy enables planning of strategies based on the needs of these patients to improve adherence and quality of life, and to establish care for this group of people living with HIV, contributing to improved care practice and health monitoring.

In this study, there was a predominance of men, aged 18-39 years. The different social roles of men and women have negative influences on the quality of life, primarily in women infected with the virus. HIV in the childbearing age can produce significant losses, both in social and economic areas.[7] The prevalence of male participants in this study corroborates several previous studies.[3,7-9]

Regarding education, the present study had a significant number of people who had completed high school, different from that found in the literature, which points to lower schooling, with incomplete primary education predominating.[4] People with secondary or higher education may have greater access to information related to HIV infection and, therefore, better internal and external resources to live with their HIV status.

A previous study demonstrated that a significant portion of people living with HIV is in a socially vulnerable condition, living in poverty, with low income and education.[4] Low family income impacts extreme poverty situations, because it is associated with difficulty accessing treatment, which can make it harder to live with HIV, thereby negatively impacting quality of life.[7] Although the income of the participants in this study was slightly higher than that found in the literature, that individuals were still financially limited.

People living with HIV who were living in a common law relationships had a better quality of

life related to satisfactory social support.[7] However, the predominance of single people in this study can justify the below average quality of life level in the HIV mastery dimension.

A worsened condition of the immune system, represented by a low CD4+ T cell count, high viral load levels and progression to AIDS, was not associated with a lower quality of life. The use of antiretroviral therapy was associated with better physical function, both in men and women, which evidences its positive influence on the quality of life of people living with HIV.[10]

Concerning adherence to antiretroviral therapy, a Chilean study showed that most people living with HIV using antiretroviral medications had inadequate levels of adherence, namely, 68.0% of the subjects were considered nonadherent to therapy,[11] corroborating the findings of this study. However, the treatment time may result in different levels of adherence. As cautioned by the researchers, people living with HIV on treatment for less time are more likely to not adhere to treatment when compared to those who have been under treatment for longer,[4] as observed in the present study, in which the recent treatment proved to be a predisposing factor for poor adherence to antiretroviral therapy.

In a study performed in Thailand, 31.4% of subjects had poor adherence to treatment, mainly due to neglect of the antiretroviral therapy, fear of stigma, and the possibility of disclosure of their HIV status through the use of such medications.[12] This was a situation also revealed in this study, when it was found that the most compromised dimension of quality of life was related to disclosure worries.

One study highlighted the multidimensional nature of interference with quality of life, such as working conditions and income, life satisfaction, disclosure of the disease and social support, and situations of emotional stress caused by the disease, such as discrimination and poverty, which represent a negative impact on the quality of life of people living with HIV.[13] These findings are impaired in this study, in most cases, thereby confirming the compromised quality of life in this population.

In Brazil, studies in different regions that used the HAT-QoL found similar impairments in the di-

mensions of quality of life, such as overall function, sexual function, financial worries and disclosure worries, suggesting that people living with HIV have similar concerns regardless of their geographic location,[6,14] corroborating the findings of this study. In this respect, regardless of where the person is, it was observed that the impacts on quality of life are similar, causing health, financial and disclosure worries, and in relation to general aspects of life, depicted by the low scores in these dimensions, which may be related to the impact of the diagnosis, with a concern about becoming ill and adapting to a new reality.

Conclusion

People living with HIV recently starting the treatment had inadequate levels of adherence to antiretroviral medications, demonstrating disrupted or incorrect use. Quality of life was impaired in six dimensions of the scale used. It is possible that people living with HIV in the first year of treatment had impaired quality of life and adherence because they were adapting to a new condition of life.

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Collaborations
Galvão MTG; Fiuza MLT and Lemos LA contributed to the project design, study execution, writing of the research paper and final approval of the version to be published. Soares LL and Pedrosa SC contributed to the execution of the research and writing of the article.

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