Quality of life, adherence and clinical indicators among people living with HIV

Qualidade de vida, adesão e indicadores clínicos em pessoas vivendo com HIV

Calidad de vida, adherencia e indicadores clínicos en personas que viven con el VIH

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Abstract

Objective: To evaluate the association between quality of life and adherence to antiretroviral treatment.

Methods: Cross-sectional study conducted in an outpatient clinic for infectious disease in a university hospital located in the state of Rio Grande do Sul, Brazil. The sample consisted of 156 participants with HIV who answered questions related to social, demographic and clinical characterization, evaluation of adherence to antiretroviral treatment (CEAT-HIV), and quality of life (HAT-QoL). Statistical analyzes were performed, including logistic regression to verify associations.

Results: The quality of life domains that affect adherence positively were those related to general function, medication concerns and confidence in the health professional. The domain that affected adherence negatively was related to concerns about confidentiality. It was observed that the highest means of quality of life were associated with strict adherence (adequate). Strict adherence promotes viral suppression and increases the defense cells in the body. However, negative results in these clinical indicators impair quality of life domains, especially those related to health concerns, medication concerns, and sexual function.

Conclusion: Quality of life, associated with adherence and clinical indicators generate a cycle, in which the different results of each one suffers the interference of the others.

Resumo

Objetivo: Avaliar a associação entre a qualidade de vida e a adesão ao tratamento antirretroviral.

Métodos: Estudo transversal, desenvolvido em serviço ambulatorial de doenças infecciosas em hospital universitário, localizado no interior do Rio Grande do Sul, Brasil. A amostra constitui-se de 156 participantes com HIV que responderam a questões de caracterização social, demográfica, clínica, de avaliação da adesão ao tratamento antirretroviral (CEAT-VIH), e de qualidade de vida (HAT-QoL). Foram realizadas análises estatísticas, entre elas a regressão logística para verificar associações.

Resultados: Os domínios da qualidade de vida que interferem positivamente na adesão foram os relacionados à função geral, preocupações com a medicação e confiança no profissional de saúde. O domínio que interferiu de forma negativa na adesão foi relacionado com as preocupações com o sigilo. Observou-se que as médias mais elevadas dos domínios de qualidade de vida estão relacionadas com a adesão estrita (adequada). A adesão estrita promove a supressão viral e o aumento das células de defesa no organismo. No entanto, resultados negativos nesses indicadores clínicos prejudicam os domínios de qualidade de vida, principalmente os relacionados à preocupação com a saúde, preocupações com a medicação e função sexual.

Conclusão: A qualidade de vida, associada à adesão e aos indicadores clínicos geram um ciclo, em que os diferentes resultados de cada um admitem a interferência entre si.

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Resumen

Objetivo: Evaluar la relación entre la calidad de vida y la adherencia al tratamiento antirretroviral.

Métodos: Estudio transversal, desarrollado en servicio ambulatorio de enfermedad infecciosas en hospital universitario, ubicado en el interior del estado de Rio Grande do Sul, Brasil. La muestra consistió en 156 participantes con VIH que respondieron preguntas de caracterización social, demográfica, clínica, de evaluación de adherencia al tratamiento antirretroviral (CEAT-VIH) y de calidad de vida (HAT-QoL). Se realizaron análisis estadísticos, entre ellos regresión logística para verificar relaciones.

Resultados: Los dominios de calidad de vida que interfieren positivamente en la adherencia fueron los relacionados con la función general, preocupaciones con la medicación y confianza en el profesional de la salud. El dominio que interfirió de forma negativa en la adherencia estuvo relacionado con la preocupación por el secreto profesional. Se observó que los promedios más elevados de los dominios de calidad de vida están relacionados con la adherencia estricta (adecuada). La adherencia estricta promueve la supresión viral y el aumento de las células de defensa en el organismo. Sin embargo, resultados negativos de estos indicadores clínicos perjudican los dominios de calidad de vida, principalmente los relacionados con la preocupación por la salud, preocupación por la medicación y función sexual.

Conclusión: La calidad de vida, relacionada con la adherencia e indicadores clínicos, generan un ciclo, en el cual los diferentes resultados de cada uno permiten la interferencia entre sí.

Introduction

Human immunodeficiency virus (HIV) infection is now considered a chronic health condition with potential endemic disease control through the implementation of high-activity antiretroviral therapy (ART).[1] Endemic disease control is the objective of national and international guidelines in response to the HIV epidemic, seeking to achieve the 90-90-90 Target proposed by the Joint United Nations Program on HIV/AIDS[2]

This Target calls for concentrating efforts so that by 2020 about 90% of people infected with HIV are aware of their diagnosis. Also, that 90% of these are on antiretroviral therapy (ART) and that 90% of people receiving ART have viral suppression, which is related to the prevention of HIV transmission.[2]

In order to facilitate the achievement of these goals, the Brazilian Ministry of Health (MS) has developed the "Clinical Protocol and Therapeutic Guidelines for the Management of HIV Infection in Adults" to provide up-to-date technical content and recommendations for prevention of transmission, treatment of infection and improvement of quality of life (QoL) of people living with HIV. This document recommends, based on current public health policies, association to health services, retention in these services for continuous follow-up and adherence to treatment.[3]

In order to achieve the longevity expected with appropriate use of ART, treatment adherence must remain adequate over the years, resulting in viral suppression of people living with HIV.[4-12] Viral suppression after this treatment should be associated with a QoL similar to people who do not live with HIV.[3] Thus, there are aspects of the lives of people living with HIV that negatively affect QoL, leading to high morbidity and mortality and increased costs.[9,13-15]

Assessing adherence and therapeutic possibilities related to QoL is indispensable for the elaboration of treatment strategies for people living with HIV. However, the literature lacks evidence on the evaluation and correlation between quality of life and treatment adherence, considering the clinical indicators of viral suppression. In this sense, the objective of the study was to evaluate the association between QoL and adherence to antiretroviral therapy and its effect on clinical indicators.

Methods

The cross-sectional study was conducted in the outpatient clinic for infectious diseases of a university hospital in southern Brazil. The study population consisted of 156 participants with HIV, all over 15 years old and on ART for at least three months.[3]

Data collection, instruments and variables

Data was collected between July 2016 and November 2017, through an interview held in a private room. The study sample was selected by randomization. The characterization data in-

cluded personal, educational and social data, income, and clinical indicators (Viral Load and CD4+ T Lymphocytes) from the last exam prior to the interview date. Participants answered a scale for evaluation of quality of life called *HIV/AIDS - targeted quality of life* (HAT-QoL), which was translated, adapted and validated for use in Brazil. This scale has 34 questions distributed in nine domains that include general functions (GENFUNC) related to everyday life, life satisfaction (LIFESAT), health concerns (HEALTHCON), financial concerns (FICON), acceptance of positive HIV serology (ACHIV), confidence in the health professional (CONPRO) and sexual function (SEXFUNC). It is a Likert-type scale with scores ranging from 0 to 100 for each QoL domain.[16] Based on this score, low QoL was identified by scores below 50 points, and high QoL by scores of 75 points or more.

The *Cuestionario para la Evaluación de la Adhesión al Tratamiento Antiretroviral* (CEAT–VIH) was used for the evaluation of adherence to antiretroviral therapy, in the version translated, adapted and validated for use in Brazil.[17] The questionnaire contains 20 questions addressing compliance with treatment, factors that influence adherence, interaction between health professional and user, beliefs about the effort required for treatment and evaluation of side effects. The score is obtained by summing the items and it ranges from 17 to 89 points. Based on this score, the degree of adherence to antiretroviral therapy will be classified as "strict", "fair" and "low or inadequate adherence".[12]

Statistical analysis

The database was produced using Epi Info 7.0 software and analyzes were performed using SPSS 21.0 software. The variables related to the social and demographic questionnaires and QoL domain scores were described by absolute and relative frequency, mean and standard deviation. The bivariate analyzes, which had the purpose of evaluating the relationship between treatment adherence and quality of life, were conducted with the chi-square test or the Fisher's exact test, adopting 95% confidence levels ($p<0.05$). Logistic linear regression and binary regression with a 95% Confidence Interval were performed to assess the influence between dependent and independent variables. Binary regression was used to assess the impact of clinical indicators, considering a 95% confidence interval.

Ethics

The study was approved by the Research Ethics Committee, protocol 1.538.216

Results

The participants (n = 156) were between 18 and 73 years old, with a mean age of 42.54 years. The study population was predominantly female (57.1%) and white (65.4%) (black 18.6%, brown 13.5%, yellow and indigenous 1.3% respectively). More than half of the participants were residents of the same city of the service (53.9%), lived with a spouse or partner (50.6%) (single 25.6%, separated/divorced 14.1%, widowed 9.6%) and had between 0 and 6 children. Regarding education, the mean number of years of schooling was 8.7 years, ranging from 0 to 16 years. The majority did not have an employment bond (60.9%) and their monthly income was between no income and R$7,000, with a mean of R$1,430.79. The predominant route of infection was sexual transmission (71.2%), and the other forms of HIV infection were unknown (22.4%), drug injection (2.6%), blood transfusion (1.9%) and maternal transmission (1.9%).

As for clinical indicators, CD4+ T lymphocytes (n=131) ranged from 0 to 2165, with a mean of 537 cells. Viral Load (HIV copies/milliliter of blood) (n=130) varied between viral suppression (zero copies) and 214,669 copies/millimeter of blood, with a mean of 3291.39 copies/millimeter of blood.

In the QoL assessment, the areas related to Confidentiality Concerns (CONCON) and Financial Concerns (FINCON) presented the lowest mean scores, indicating low QoL: 47.40

Table 1. Evaluation of QoL mean scores on HAT-QoL according to degree of adherence to antirretroviral treatment CEAT-VIH (n=156)

QoL domain	Mean QoL scores		Degree of adherence					
			Low adherence		Insufficient adherence		Strict adherence	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
GENFUNC	68.38	24.11	41.67	11.79	64.08	24.73	78.10	19.70
LIFESAT	75.52	22.75	34.38	22.10	72.82	23.67	82.60	17.82
HEALTHCON	67.11	30.47	62.50	35.36	64.38	31.42	72.79	28.11
FICON	49.20	36.02	16.67	23.57	47.25	36.48	54.41	34.89
MEDCON	84.20	21.23	50.00	14.14	81.65	23.45	90.69	13.00
ACHIV	64.74	34.45	31.25	44.19	62.38	35.33	70.83	31.59
CONCON	47.40	31.63	30.00	42.43	49.17	31.17	44.51	32.48
CONPRO	74.79	22.76	66.67	11.79	71.20	23.19	82.35	20.46
SEXFUNC	80.69	33.91	12.50	17.68	79.13	35.67	86.52	27.14

SD – standard deviation. GENFUNC: General function; LIFESAT: Life satisfaction; HEALTHCON: Health concerns; FICON: Financial concerns; MEDCON: Medication concerns; ACHIV: Acceptance of HIV; CONCON: Confidentiality concerns; CONPRO: Confidence in the professional; SEXFUNC: Sexual function

Table 2. Influence of quality of life domains (HAT-QoL) on adherence to antiretroviral therapy (CEAT-VIH) (n=156)

Domain	Non-standard coefficients		t	95% Confidence interval	
	B	Standard model		Lower Limit	Upper Limit
(Constant)	58.81	2.95	19.89	52.97	64.65
GENFUNC	0.08	0.02	2.90	0.02	0.14
MEDCON	0.14	0.03	4.29	0.08	0.21
CONCON	- 0.05	0.02	- 2.62	- 0.09	- 0.01
CONPRO	0.09	0.02	3.59	0.04	0.14

GENFUNC: General function; MEDCON: Medication concerns; CONCON: Confidentiality concerns; CONPRO: Confidence in the professional. Logistic regression

and 49.20 points, respectively. The domains with the highest mean scores were Life Satisfaction (LIFESAT), Sexual Function (SEXFUNC), and Medication Concerns (MEDCON), with respectively 75.52, 80.69, and 84.20 points (Table 1).

Regarding the degree of adherence, 1.3% were classified with low adherence (inadequate), 66% with insufficient adherence and 32.7% with strict adherence (adequate). Among the values obtained as adherence scores, the mean was 81.59 points, with a minimum of 47 points, maximum of 97 points and standard deviation of 8.77.

The highest means of quality of life are related to strict (adequate) adherence, demonstrating that the higher the QOL level of people living with HIV, the greater their adherence to treatment (Table1).

The evaluation of the impact of QoL domains on treatment adherence showed that the domains General Function (GENFUNC), Medication Concerns (MEDCON), and Confidence in the Professional (CONPRO) had a positive influence on adherence, while the domain Confidentiality Concern (CONCON) had a negative influence on this outcome (Table 2).

Figure 1 shows the relationship between the QoL domains that are statistically associated with adherence, the influence of QoL on clinical indications, and the influence of clinical indicators on QoL Therefore, health is a cycle that should not be broken in the relationship between QoL and adherence.

The cycle demonstrates that strict adherence increases the chance of an undetectable viral load by 148% and fair adherence increases this chance by 74% when compared to patients with low adherence. Compared to patients with low adherence, strict adherence increased the chance of a CD4+ T lymphocytes count greater than 500/mm^3 by 225% and fair adherence increased this chance by 62.5%. The impact of clinical indicators on QoL was verified. A viral load greater than 50 copies/ml is associated with significant reduction in HEALTHCON scores ($p = 0.05$), by up to 12.58 points, MEDCON scores by up to 10.72 points ($p = 0.01$) and SEXFUNC scores by up to 10.45 points ($p = 0.05$).

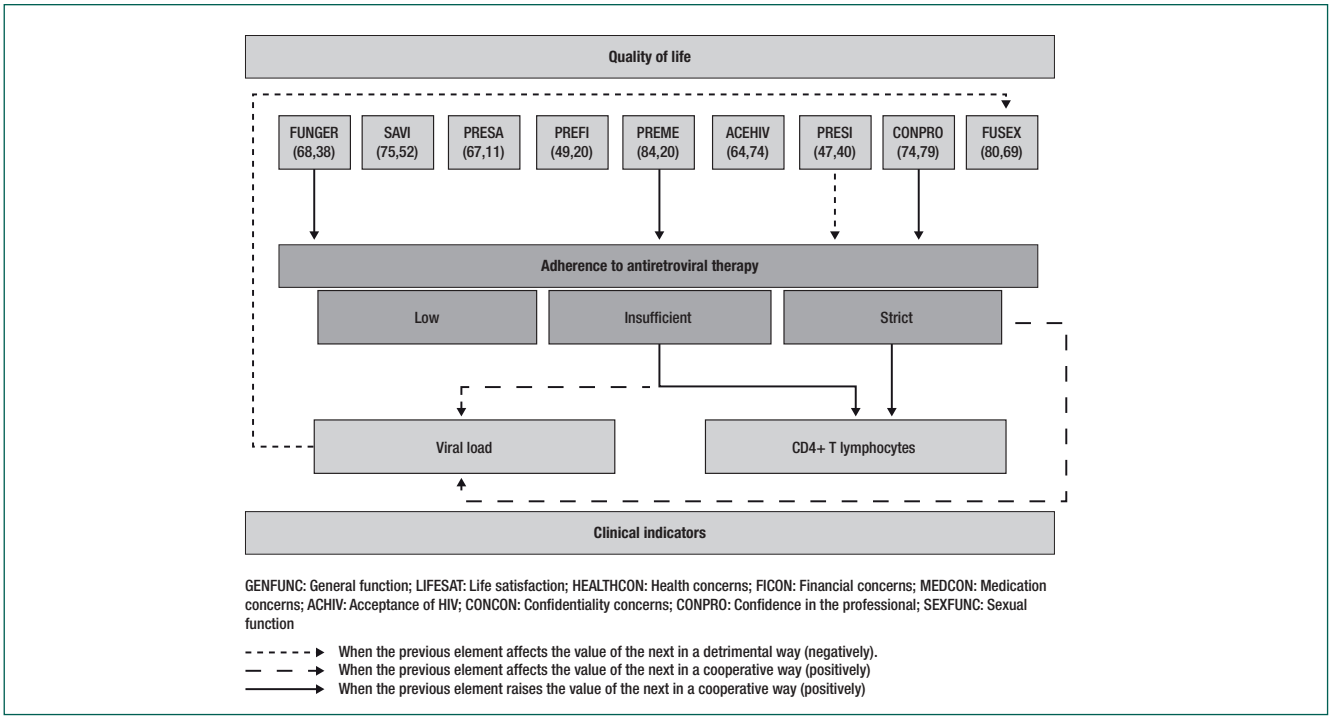

Figure 1. Quality of life cycle of people living with HIV on antiretroviral therapy

Discussion

Among the domains that indicated low QOL, CONCON was the one with the lowest mean. This concern is present in different contexts in Brazil, and it does not present better means outside the national context.[6,14,15,18-25]

Concern about confidentiality refers to the non-disclosure of diagnosis and is mainly related to stigma and discrimination. This concern occurs among both older and younger adults. Issues related to breach of confidentiality may impair proper treatment if patients are afraid of stigma and prejudice, compromising the administration of ART in environments with people outside their circle. Concern about confidentiality is also related to most vulnerable financial situations.[13,15,20]

The domain FICON is associated with low QoL. Factors related to social vulnerability such as unemployment, low income and low level of education may be related to a decline in QoL and might affect self-care.[6,14,15,18-24,26]

In contrast, the domain LIFESAT had a high score (75.52), which is similar only to two other studies.[15,22] High scores in this domain may be associated with employment or retirement (fixed income). It may also be associated with better conditions for enjoying life, feeling in control of life, and using work as a moment for socialization.[15,20]

The domain related to sexual function (SEXFUNC) presented good results in this research (80.69). This shows that having a sexually active life and having a steady partner or being married are important for having good scores in this domain. The risk of transmission of the virus makes people with HIV afraid to engage in sexual relationships. In addition to the concern about transmitting the virus, this domain may be hampered by lack of trust and difficulty negotiating condom use with partners.[19]

The domain of medication concern (MEDCON) varied between 79.80 and 88.72 points in national territory.[15,19,20,24] International research have also found high scores in Zimbabwe (86.70) and India (91,38).[14,25] In this domain, the research participants considered that the use of ART took little time and had no severe side effects that could affect their daily routine.

The findings show that QoL must be constant evaluated. Despite the variation of the scores veri-

fied in all the studies cited, both national and international, domains that cover financial concerns and breaches of confidentiality were observed in almost all the studies. [6,14,15,18-26]

Regarding the adherence assessment, there is some variation in the results of strict adherence, showing the diversity of services and population samples in the different states of the country.[4-6,9,10,27] This leads to the reflection that, even though the health policy for treatment is the same in the entire national territory, the structure of services and the cultural aspects of the populations studied may affect adherence patterns.

Similar to Brazil, other countries have also used the CEAT-HIV to assess and classify treatment adherence; however, no other international study has exceeded the percentage of strict adherence found in this research (32%).[7,8,11,12] This result is a reflection of Brazil's health system and its universal policy for controlling the HIV epidemic.

Brazilian studies using the QoL assessment scale of the WHO and the CEAT-HIV adherence scale showed statistically significant correlations between the variables of these scales. There were associations with the domains related to physical, spiritual and psychological aspects, level of independence, social relationships and the environment. These studies demonstrated that these domains contribute to treatment adherence of people living with HIV, and that people that don't follow treatment have the worst mean QoL scores.[9,12,28,29]

The evidence supporting the domains related to medication concern (MEDCON) and confidence in the professional (CONPRO), which are related to QOL, were statistically significant when correlated with the adherence score,[24] corroborating the findings of this study.

Therefore, health professionals should know their clients' QoL in order to understand the aspects of QoL that interfere with adherence. As a favorable outcome of treatment adherence, patient's clinical condition will improve, with increase in CD4+ T lymphocyte and reduction (suppression) of viral load, resulting in positive effects on QoL.[6]

Health professionals should be prepared to intervene, when possible, in the most compromised domains of quality of life. Thus, stigma and discrimination can be discussed within a team, and financial problems and fears related to limited income can be analyzed and clarified by other professionals such as the social worker. These evaluations and referrals can be done by the nurse.

Another recommendation refers to the need to promote the bond between professional and user, which leads to a confidence that is essential for the success of treatment, as it may reflect on acceptance of prescribed care. Correct use of ART is associated with the acceptance of the prescription and the bond with the health professional.

The assessment of quality of life and adherence can be incorporated into the health care of this population. QoL can be verified even before the beginning of therapy, promoting specific care in domains that may predict non-adherence. The assessment of QoL and adherence must be continuous, in the same was as routine laboratory tests.

The evaluation in a single moment (cross-sectional) without the possibility of intervening in the evaluated issues is a limitation of this study.

Conclusion

The results of this study show that the quality of life of people with HIV is compromised mainly by the confidentiality and financial concerns. On the other hand, confidence in the professional promotes adherence, helping to improve the living conditions of people living with HIV. It was also demonstrated that viral loads greater than 50 copies per cubic decimeter of blood compromise quality of life domains and that the relationship between quality of life and adherence promotes good clinical results.

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Collaborations

Primeira MR, Santos WM, Padoin SMM and Paula CC state that they participated in the study design, data analysis and interpretation, writing of the manuscript, review of critical content and approval of the final version to be published.

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