

Quality of life of people living with HIV/AIDS treated by the specialized service in Vitória-ES, Brazil

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Abstract *The aim of this study is to establish the factors that influence the quality of life of people living with HIV/AIDS being treated at a specialized public service. The participants answered the questionnaire on sociodemographic conditions, issues related to HIV and daily habits. The quality of life was analyzed using the HIV/AIDS-targeted quality of life (HAT-QoL) instrument with 42 items divided into 9 fields: General Activity, Sexual Activity, Confidentiality Concerns, Health Concerns, Financial Concerns, HIV Awareness, Satisfaction with Life, Issues related to Medication and Trust in the Physician. Bivariate and multiple linear regressions were performed. Of the participants, 53.1% were women and had a mean age of 42 years. In analyzing the quality of life, the HAT-QoL domain with the lowest average was Financial Concerns (39.4), followed by Confidentiality Concerns (43.2), Sexual Activity (55.2) and Health Concerns (62.88). There was an association between the variables: not being gainfully employed ($p < 0.001$), being mulatto or black ($p = 0.045$) and alcohol consumption ($p = 0.041$) with the worst quality of life scores. Inadequate socioeconomic and health conditions had a negative impact on the quality of life of people with HIV/AIDS.*

Key words HIV, Quality of life, Health services

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Introduction

More than 30 years since the discovery of the first case of HIV / AIDS in the world, the Acquired Immunodeficiency Syndrome (AIDS) is still considered a major problem for public health. Despite scientific advances and investments for control and therapy, there is a continuous growth of the infection in the population. Only in Brazil are recorded, on average, 35,000 new cases of AIDS per year^{1,2}.

Worldwide, it is estimated that in 2012 there were 35.3 million people between men, women and children infected with HIV. Only in 2012, 2.3 million people were infected with HIV and 1.6 million died from AIDS, mostly due to inadequate access to treatment and attention services³. In Brazil, since the identification of the first case of AIDS, from 1980 until June 2012, 656,701 cases were identified, with more than 253,706 deaths, which have the underlying cause defined as "diseases by the HIV virus." The disease is concentrated in sub-populations aged 20 to 59 years, with 11 years of study and a gender ratio of 1.7 men for every woman with AIDS².

Advances in antiretroviral therapy (ART) led to a reduction in morbidity and mortality from AIDS, and population studies show improvement in survival of patients with this disease, having at 25, a median life expectancy of 32.5 years from the moment they start the treatment⁴.

In 1996, in a pioneering and innovative way, Brazil signed the law guaranteeing universal free access to medicines for people with HIV / AIDS^{5,6}. This technological development has changed the profile of the epidemic in the sense of its chronicity, providing opportunities to individuals with HIV / AIDS to live better with the disease. That is, the antiretroviral therapy (ART) enabled the transformation of a syndrome that previously was culturally perceived as a result of a death foretold, in a disease with prospects of chronicity⁷.

This therapy has provided considerable benefits to its user, such as increased survival, decrease in hospitalizations and the occurrence of opportunistic complications and mortality associated with HIV / AIDS⁸. The Ministry of Health points out that ten years after the implementation of this policy in Brazil, 180,000 people were already receiving treatment in the country and there was a 34% reduction in mortality and morbidity in 70% of AIDS cases, considering only the period between 1996 and 2002.

With the improvement in life expectancy of these people, the quality of life becomes an im-

portant tool for evaluating the health of these individuals⁹. The variation in the Brazilian population's quality of life has created various social strata in which they operate vulnerable subgroups to HIV / AIDS, increasingly associated with the impoverishment process. This fact has contributed to situations of abandonment of treatment, worsening of the disease and, consequently, increased spending on treatment of complications of people living with HIV / AIDS¹⁰.

Little research has been conducted that evaluated the quality of life of people living with HIV / AIDS in Brazil. Thus, the present study investigated the quality of life associated with socio-demographic conditions, issues related to HIV, health habits of people living with HIV / AIDS assisted in the public reference service in Vitoria (ES), Brazil.

Methodology

This is an exploratory quantitative study of cross-sectional analytical cut, held in the public health service provided to people living with HIV/AIDS, STD / AIDS Reference Center, which operates since 1992 in Vitoria (ES), Brazil.

Around 1,500 people living with HIV / AIDS are accompanied by the STD / AIDS Reference Centre, and on this basis, the sample size (n) was calculated by a Simple Random Sample, with a total of 177 patients, margin of error of 7% and a 95% confidence level. The sample selection was random, since they were attended to by the service. Included were patients with a confirmed diagnosis of HIV infection, above 18 years of age and who agreed to participate in the study.

Data collection was held for four months in 2012, after a pilot study in which all variables were tested.

The quality of life data were collected by a validated HAT-QoL instrument, prepared by Holmes and Shea¹¹, originally written in English, but translated and validated in Brazil by Galvão *et al.*¹². This instrument was selected to be specific for assessing the quality of life of people living with HIV / AIDS, and has good psychometric properties, good internal consistency and evidence of construct validity. The HAT-QoL has 42 items divided into nine domains: General Activity, Sexual Activity, Secrecy concerns, Health Concerns, Financial Concerns, Awareness about HIV, Satisfaction with Life, Issues related to medication and Confidence in the doctor. The response for all items is obtained through a Likert

scale that contains: all the time, most of the time, some of the time, a short time and no part of the time. For each question, only an option is written down that corresponds to that which best characterizes the last four weeks experienced by the patient. The scores are calculated according to the answers and range from one to five, with one representing a worst state and five in a better state or condition. The scores obtained in each domain are transformed into an index-weighted from 0-100, and the closer the index is to 100, the better the quality of life¹².

The data relating to sociodemographic questions, issues related to HIV and habits were obtained through a structured questionnaire, developed specifically for this study. The sociodemographic variables include: nationality, age, gender, race, marital status, education, employment status and family income. Related to HIV and habits are: viral load, CD4 count, date of diagnosis of HIV infection mode, use of antiretroviral therapy, smoking habits, alcohol consumption, drug use and condom use before and after the diagnosis of the disease.

Descriptive analyzes were performed for the sociodemographic characterization of the population, through measures of central tendency (single frequency, mean and median) and measures of dispersion (standard deviation). The sample involved in the research set normal probability distributions, verified by the Kolmogorov and Smirnov tests ($p = 0.100$), and the hypotheses were verified with the help of parametric statistics. The region for the rejection or not any of these hypotheses considered a significance level of 0.05. Statistical analysis of variance (ANOVA) and multiple linear regression tests with elimination of non-significant variables were performed. The selection of independent variables for the multiple linear regression models was performed according to a stepwise model. After adjusting the multiple linear regression models, with a 95% confidence interval, the p - values were estimated. All statistical analyzes were performed using the SPSS version 17.0 software.

The study was approved by the Ethics in Research Committee with human beings of the Paulista State University, Araçatuba Dental School and performed with the understanding and written consent from each participant.

Results

Of the 177 study participants, more than half of the sample were women (53.1%), with a mean age of 42 years. Most were mixed (61.6%) and was not in a steady relationship (48.6%). As for education, 53.1% had eight years or less of schooling and 7.3% could not read and write. Of the respondents, 20.3% were not employed and 63.8% had a monthly income of one to two minimum wages (Table 1).

Regarding the tests, 78.2% had CD4 counts greater than 350 cells / mm³, and 61.6% of undetectable viral load. As for the time of discovery of HIV diagnosis, 35.0% said they had more than 10 years, and 86.4% of patients were between 20 to 50 years when they received the result. The contamination was via heterosexual relationship in 55.9% of the respondents and 53.1% said they did not know how they contracted the virus. Most patients were ART users (77.4%). Of the

Table 1. Sociodemographic characteristics of people living with HIV / AIDS assisted at the HIV / AIDS Reference Center, Vitoria, Brazil. 2012.

Variables	Frequency	%
Gender		
Feminine	94	53.1
Masculine	83	46.9
Race		
White	30	16.9
Black	38	21.5
Brown	109	61.6
Marital status		
Single	86	48.6
Married	27	15.3
Widowed	13	7.3
Common Law	31	17.5
Separated/Divorced	20	11.3
Education		
Illiterate	13	7.3
8 or < years of study	94	53.1
9 to 11 years of study	51	28.8
12 or > years of study	19	10.7
Work link		
Employed	141	79.7
Unemployed	36	20.3
Family income		
Less than 1 MS	18	10.2
1 to 2 MS	113	63.8
3 to 4 MS	33	18.6
More than 4 MS	10	5.7
None	3	1.7

patients, 77.4% did not smoke, 67.2% did not consume alcohol and 95.5% of patients said they did not make use of illicit drugs. Regarding the use of condoms during sexual intercourse, 67.8% said they always use and 6.8% said they never use, even after the discovery of contamination.

In assessing the QoL, the domain with the lowest average was Financial concern (39.4), followed by Concern with secrecy (43.2), Sexual activities (55.2) and Health concerns (62.88). And the highest averages were: Confidence in the doctor (96.18) and Issues related to medication (86.54) (Table 2).

The results of the bivariate analysis between the mean values of the HAT-QoL domains with the sociodemographic variables, issues related to HIV, and health habits, can be seen in Tables 3 and 4.

In the multiple linear regression model for the Financial concern domain, it was associated with higher variable scores: higher level of education and do not smoke, while not having a work link was associated with lower scores (Table 5).

In the Secrecy concern domain, older age was positively associated with better scores, while the fact that being brown or black had a negative association. There was a negative association to the Sexual activity domain, not having a work link and alcohol consumption.

In the analysis of the Health concern domain, being male, have less age and not using illicit drugs were associated with higher scores on the QoL.

Discussion

Most patients attending the STD / AIDS Reference Center in Victoria were of poor income and

had little schooling, as seen in the literature that HIV infection has greater weight on the disadvantaged and the socially marginalized¹³.

Another important aspect is in relation to contamination for heterosexual relationships, which is in agreement with the epidemiological profile of HIV for a few years now: heterosexuals and women, internalization and pauperization¹⁴⁻¹⁶.

In the analysis of the scores of the quality of life domains, the results showed that the lowest averages are: Financial concerns, Secrecy concerns, Sexual activity and Health concerns, results that corroborate the findings of other studies using the HAT-QoL scale^{11,12,17}.

The obtained average rate (39.4), in the Financial concern domain probably was due to the low per capita income of the respondents, which hinders the survival of the individual. This finding may indicate that income, in addition to deterring its value linked to living conditions and services, may influence the health status, which further hinders their integration into the work force¹⁸. People living with HIV / AIDS who have no work links have a worse quality of life than those that work, and this is also observed in another study¹⁰. Therefore, the chronic disease brings new changes, including issues related to occupation, and employment does not only have the importance of financial benefit, but is also a form of social and emotional integration, and identity^{19,20}.

The participants in this study, with regards to concern with secrecy, were even affected in the demand for health care because these patients stopped going to the doctor or other health professionals for fear of having to report that they have the HIV virus and suffer prejudice on account of the unpreparedness of the professional²¹. Therefore, concern about confidentiality is a

Table 2. HIV / AIDS assisted in the HIV / AIDS Reference Center, Vitoria, Brazil. 2012.

Domains	Average	SD	Alpha Cronbach's
Financial concern	39.40	33.94	0.67
Concerns about the confidentiality of infection	43.25	27.38	0.71
Sexual Activity	55.24	38.70	0.71
Health concerns	62.88	19.41	0.65
Awareness about HIV	74.99	32.40	0.62
General activity	75.86	24.46	0.64
Satisfaction with life	78.54	27.99	0.61
Issues related to medication	86.84	18.06	0.69
Confidence in the doctor	96.18	13.56	0.70

Table 3. Bivariate analysis of standardized scores of the HAT-QoL domains according to sociodemographic variables of people living with HIV / AIDS assisted in the HIV / AIDS Reference Center, Vitoria, Brazil, 2012.

Variables	General Activity	Sexual Activity	Secrecy Concern	Health Concern	Financial Concern
Age					
18-34	81.8	65.4	35.1	55.6	48.4
35-44	76.4	59.5	41.2	61.8	30.7
45-70	71.8	45.2	49.8	68.0	42.2
P value	0.109	0.014	0.017	0.004	0.021
Gender					
Feminine	72.0	45.8	39.0	58.8	33.1
Masculine	80.2	65.8	47.7	67.4	46.4
P value	0.025	0.001	0.041	0.003	0.009
Race					
White	72.3	59.9	55.5	64.8	44.4
Black	76.3	52.8	40.2	63.5	42.1
Brown	76.6	54.7	40.9	62.1	37.0
P value	0.692	0.740	0.026	0.773	0.491
Marital Status					
Single/ Common Law	80.2	54.8	45.2	62.9	38.8
Married	74.0	70.0	46.2	66.4	38.3
Widowed	63.0	12.8	36.5	61.1	43.7
Separated/Divorced	74.1	50.4	48.7	64.5	45.1
P value	0.114	0.000	0.216	0.687	0.900
Education					
Illiterate	62.6	50.6	42.6	66.1	18.3
8 or < years of study	76.8	50.5	44.3	61.7	37.3
9 years or more of study	75.1	57.7	42.6	62.7	42.4
P value	0.162	0.079	0.921	0.683	0.015
Work link					
Employed	84.4	69.7	36.7	64.4	46.7
Unemployed	67.9	41.8	49.2	61.4	32.5
P value	0.000	0.000	0.002	0.296	0.005
Family income					
Less than 1 MS	57.0	41.6	52.5	56.1	18.0
1 to 2 MS	77.0	53.1	41.0	63.8	39.2
3 to 4 MS	83.7	68.6	47.2	66.2	53.5
More than 4 MS	84.4	55.0	36.0	61.0	49.0
P value	0.002	0.146	0.684	0.557	0.006

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very common situation among these individuals, which happens because of the fear of being seen as a carrier of a disease still very stigmatized by society. This makes having a double life, because only a few people from their friendships are chosen to know of their serological condition¹⁵.

Life with HIV / AIDS leads to changes in the sexual activity of people, and the conditions under which they find themselves due to infection lead to fear of sexual intercourse, which makes for avoiding relationships, even having sexual desires²².

This implies commitment in the sexual activity domain on the quality of life, and the fact that having no work links and alcohol consumption further strengthened to a worse quality of life.

The fear of being abandoned and rejected by the partner is an aspect due to the seropositivity of HIV, and is present in the lives of individuals with HIV / AIDS²³. The possibility of maintaining emotional-sexual relationships is a key aspect in the lives of individuals with HIV / AIDS that contributes to a better QoL. The partner is an important source of emotional support, which can

Table 3. continuation

Variables	HIV Awareness	Satisfaction with Life	Issues related to medication	Confidence in doctor
Age				
18-34	67.7	81.8	84.2	92.6
35-44	70.8	77.2	88.6	97.7
45-70	83.2	77.7	86.6	96.7
P value	0.021	0.687	0.476	0.157
Gender				
Feminine	69.0	72.0	85.1	94.9
Masculine	81.7	85.8	88.7	97.5
P value	0.009	0.001	0.184	0.198
Race				
White	82.5	75.6	92.3	98.9
Black	76.9	81.8	87.2	99.1
Brown	72.2	78.1	85.1	94.4
P value	0.285	0.644	0.158	0.089
Marital Status				
Single/ Common Law	73.8	80.0	88.0	97.9
Married	85.5	82.2	82.8	97.2
Widowed	64.7	64.9	89.8	91.6
Separated/Divorced	77.9	76.8	85.9	90.8
P value	0.312	0.425	0.722	0.177
Education				
Illiterate	69.9	76.0	78.8	93.6
8 or < years of study	71.6	78.7	86.6	96.7
9 years or more of study	79.5	76.2	89.1	96.2
P value	0.325	0.663	0.335	0.834
Work link				
Employed	77.9	85.3	88.7	95.9
Unemployed	72.2	72.2	85.0	96.3
P value	0.246	0.002	0.167	0.839
Family income				
Less than 1 MS	72.2	60.5	89.5	92.1
1 to 2 MS	74.1	80.2	87.1	96.9
3 to 4 MS	81.3	82.7	86.3	97.4
More than 4 MS	76.8	94.4	85.0	96.6
P value	0.572	0.003	0.931	0.123

be expressed by the care and help in performing daily activities, monitoring the consultations stimulus for maintenance treatment, and social support from family, friends and partners associated with a better QoL²⁴.

The concern with health domain investigates the concern of respondents in living with the virus and its consequences, and the self-assessment in relation to health, knowledge of laboratory parameters and the concern with a prognosis of death, situations that possibly prevent the well-being¹². From this perspective, in the present study, the year of HIV diagnosis was associated with this domain for the reason that people with

recent discovery of the infection do not accept the fact of the disease, which leads to discouragement with life and with health care, which implies low scores. In the multiple regression, the fact of not using illicit drugs had a positive association in this domain, which demonstrates the individual's care with their health and well-being.

Despite the impact of HIV / AIDS in the psychological health and social relationships of infected individuals, as well as life satisfaction, the use of ART led to a positive effect on the health, providing the deconstruction of the idea of death arising from the diagnostic of the carrier of HIV / AIDS and the construction of better prospects

Table 4. Bivariate analysis of standardized scores of the HAT-QoL domains according to variables related to HIV and the habits of people living with HIV / AIDS assisted in the HIV / AIDS Reference Center, Vitoria, Brazil, 2012.

Variables	General Activity	Sexual Activity	Secrecy Concern	Health Concern	Financial Concern
CV					
Undetectable	77.4	53.9	46.1	65.2	39.3
< 10000	73.9	56.9	42.8	62.6	44.1
> 10000	74.2	59.0	38.3	60.6	38.3
P value	0.689	0.757	0.290	0.399	0.796
CD4					
< 200	57.4	59.2	47.2	72.2	29.8
From 200 to 350	72.9	60.4	43.3	54.1	39.8
> 350	76.0	55.6	43.4	63.7	39.5
P value	0.039	0.722	0.915	0.006	0.680
Year of HIV discovery					
Less than 1 year	72.7	52.0	31.2	41.2	39.1
From 1 to 5 years	80.3	63.7	39.5	65.5	42.6
More than 5 years	78.0	58.1	42.0	66.0	40.2
P value	0.155	0.089	0.146	0.003	0.774
Contamination mode					
Heterosexual relationship	71.4	49.3	41.7	59.6	36.0
Homosexual relationship	84.9	68.5	46.6	67.0	50.6
Drug use	100.0	100.0	80.0	45.0	0
Blood transfusion	69.5	0	57.5	70.0	44.0
Mother to child	100.0	50.0	70.0	77.5	84.5
P value	0.043	0.026	0.370	0.146	0.065
Use of HAART					
Yes	76.3	54.7	45.4	63.3	39.7
No	74.0	57.0	35.8	61.2	38.1
P value	0.600	0.742	0.053	0.547	0.797
Abandoned use of HAART					
Yes	64.0	49.4	53.7	57.1	22.0
No	80.6	55.9	43.0	65.5	46.0
P value	0.000	0.406	0.048	0.029	0.000
Smokes					
Yes	75.1	63.5	39.6	62.7	25.9
No	76.0	52.8	44.3	62.9	43.3
P value	0.978	0.025	0.721	0.519	0.602
Consumes alcoholic beverages					
Yes	77.7	65.3	38.6	60.4	33.2
No	74.9	50.3	45.5	64.0	42.3
P value	0.474	0.015	0.117	0.242	0.094
Use of illicit drugs					
Yes	71.8	50.8	55.0	43.7	26.6
No	76.0	55.4	42.6	63.7	40.0
P value	0.638	0.745	0.215	0.004	0.277

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for life¹⁵. With the advent of ART, living with HIV / AIDS allowed for rethinking and reframing HIV infection, deconstructing the idea of death to a more human perspective, in which the individual lives better every day with HIV, allowing the

reconstruction of professional projects and emotional life, with the insertion in the labor market and the establishment of affective-sexual links⁷.

The results showed sociodemographic and clinical characteristics of these individuals sim-

Table 4. continuation

Variables	HIV Awareness	Life satisfaction	Issues related to medication	Confidence in doctor
CV				
Undetectable	78.9	81.6	88.3	97.7
< 10000	68.8	82.1	90.7	96.3
> 10000	70.3	70.0	79.8	91.8
P value	0.196	0.062	0.016	0.059
CD4				
< 200	79.6	60.5	82.6	98.1
From 200 to 350	63.4	73.0	80.7	91.0
> 350	75.4	78.5	86.4	96.0
P value	0.096	0.058	0.145	0.112
Year of HIV discovery				
Less than 1 year	61.3	70.3	78.7	86.5
From 1 to 5 years	70.0	79.6	86.5	94.5
More than 5 years	77.6	84.6	89.2	96.9
P value	0.294	0.126	0.447	0.098
Contamination mode				
Heterosexual relationship	69.8	74.9	83.3	95.1
Homosexual relationship	87.7	88.1	90.2	96.7
Drug use	100.0	81.0	81.0	100.0
Blood transfusion	100.0	100.0	94.0	100.0
Mother to child	100.0	94.0	100.0	100.0
P value	0.046	0.167	0.096	0.891
Use of HAART				
Yes	77.5	80.8	88.4	97.8
No	66.2	70.5	81.3	90.6
P value	0.051	0.040	0.028	0.003
Abandoned use of HAART				
Yes	61.4	65.6	83.0	97.9
No	82.3	85.8	90.1	97.7
P value	0.000	0.000	0.075	0.930
Smokes				
Yes	79.1	73.1	83.7	98.7
No	73.7	80.1	87.7	95.4
P value	0.816	0.930	0.064	0.103
Consumes alcoholic beverages				
Yes	75.4	78.5	85.1	95.8
No	74.7	78.5	87.6	96.3
P value	0.897	0.993	0.379	0.810
Use of illicit drugs				
Yes	61.5	55.3	68.7	89.6
No	75.6	79.6	87.6	96.4
P value	0.229	0.016	0.003	0.162

ilar to other surveys conducted with Brazilian people living with HIV / AIDS^{10,12,20}. There are some limitations in this study, such as the voluntary participation of respondents, which may have had more individuals concerned with their health and higher education. The study is of

cross-sectional nature, which precludes causal inferences. Due to the nature of the study of anonymity, it is not possible to collect any information about those who did not answer the questionnaire completely. The instrument of quality of life, though it may be validated in Portuguese,

Table 5. Multiple linear regression for the quality of life variable of people living with HIV / AIDS assisted in the HIV / AIDS Reference Center, Vitoria, Brazil. 2012.

HAT-Qol quality of life domains	Explanatory variables	B	P value
Financial Concern (0.462)	Presents 9 years or more of studies	10.430	0.002
	Non smoker	19.784	0.002
	No work link	-15.601	0.004
Concern with secrecy (r = 0.311)	More advanced age	7.534	0.007
	Is brown or black	-5.684	0.045
Sexual Activity (r = 0.318)	No work link	-19.943	0.001
	Consumes alcoholic beverages	-12.758	0.041
Health Concern (0.437)	Is of the masculine gender	10.289	0.001
	Does not use illicit drugs	20.722	0.006
	Is 18 to 34 years of age	3.890	0.046

B = coefficient of the regression model, r= coefficient of determination.

and the educational level of the respondents may have had answers in which participants answered even without understanding the question.

Despite these limitations, the study shows that there are many factors that influence the quality of life of people living with HIV / AIDS, and socioeconomic and inadequate health conditions negatively influence the quality of life of these individuals. From these results, the need to implement public policies for social inclusion that promote better living conditions is evident,

greater access to health services and the formal labor market, to foster the scope of citizenship and a better QoL for people living with HIV / AIDS.

Understanding the quality of life of these people is critical, considering the chronic course of infection, the possibility of treatment and longer survival and living with a stigmatizing, transmitted, incurable disease so far, with numerous biopsychosocial consequences that impact the quality of life.

Collaborations

GB Soares, CAS Garbin, TAS Rovida and AJI Garbin also participated in all stages of the preparation of the article.

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