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Quality of life of people living with HIV/AIDS in São Paulo, Brazil

ABSTRACT

OBJECTIVE: To assess quality of life of people living with HIV/AIDS.

METHODS: Cross-sectional study conducted in an AIDS outpatient service based on consecutive sampling during the second half of the year 2002. There were selected 365 men and women aged 18 years or older who were attended by the infectious disease physician. Sociodemographic and recent drug use variables and data on clinical conditions were obtained using a questionnaire and quality of life was analyzed using WHOQOL-bref.

RESULTS: Scores of the four domains (physical, psychological, social relationships and environment) were very similar. There were statistically significant differences in mean scores for the environment domain according to skin color, with blacks and *pardos* having lower scores. Women also had the lowest scores for the psychological and environmental domains. Higher income was significantly associated to higher scores in all domains of quality of life, except for the social relationships domain. Subjects with CD4⁺ cell counts below 200 cells/mm³ had lower scores for the physical domain. In all domains significantly lower scores were seen for those receiving psychiatric treatment or with an indication for such treatment.

CONCLUSIONS: Despite differences in sex, skin color, income, and mental and immunological status, people living with HIV/AIDS have better (physical and psychological) quality of life than other patients but lower quality in social relationships domain. The latter domain could reflect stigmatization and discrimination associated to the difficulties of disclosing their HIV status in social settings and for a safe sex life.

KEY WORDS: Acquired immunodeficiency syndrome, psychology. Quality of life. Life style. Socioeconomic factors. Cross-sectional studies.

INTRODUCTION

From 1980 to June 2006, 433,067 AIDS cases were notified in Brazil. Between 1995 and 2004, the disease incidence rate increased from 14.1 to 19.7 per 100,000 inhabitants while its mortality rate decreased from 8.7 to 6.2 per 100,000 inhabitants.* This case/death dissociation can be attributable to the introduction of highly active antiretroviral therapy (HAART)** and, starting

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** Ministério da Saúde. The sustainability of universal access to antiretroviral medicines in Brazil. Brasília; 2005 [Accessed on 3/31/2006]. Available at: http://www.aids.gov.br/data/documents/storedDocuments/%7BB8EF5DAF-23AE-4891-AD36-1903553A3174%7D/%7B6AB55CB8-AD0A-42C7-BE9C-1E86CFE66F40%7D/Cons._nacional_sustainability.doc

from 1996, its universal free distribution to around 170,000 HIV-infected people in Brazil. As survival of infected people increases, the focus shifts to their quality of life.

The term quality of life is applied in everyday language and in several different areas of knowledge and work. Quality of life has recently been scientifically defined and it has been employed as synonymous of health status, functional status, psychological well-being, life happiness, need satisfaction and assessment of one's own life.*

Studies on people living with HIV/AIDS have used the term health-related quality of life (HRQOL)^{5,7,**} to assess the impact of health on social activities and mobility focusing whether there are or not signs and symptoms and effects of new drugs or health interventions.⁷ HRQOL assessment does not include aspects such as the level of satisfaction with one's own life, especially regarding to income, housing conditions, employment, environment, sexuality, among others.

Published studies on quality of life of people living with HIV/AIDS in Brazil^{4,10-11} used a variety of questionnaires.

The purpose of the present study was to assess quality of life scores of people living with HIV/AIDS.

METHODS

A cross-sectional study based on a non-probabilistic consecutive sample of patients attending an AIDS service called "Casa da Aids" was conducted between September 23 and December 18, 2002. Casa da Aids is a specialized university service located in downtown city of São Paulo that, at the time of the study, had enrolled 4,000 patients.

Eligible patients were those living with HIV/AIDS, 18 years or older, who attended periodical consultations with an infectious disease specialist. Patients attending visits for diagnosis confirmation or who had a medical status that prevented their participation were excluded.

The estimated sample size was 385 subjects based on previous studies, 95% confidence level and 2% standard error of mean.^{1,5} The first six patients coming in for their periodical visit with the infectious disease specialist, at the three different visit hours and in all days of the week during the study period, were invited to participate. Of

392 patients invited, 365 accepted to participate, 25 refused and two did not complete all interviews.

Sociodemographic and recent drug use information were obtained through a self-administered questionnaire and data related to medical status, such as HIV exposure category and signs and symptoms in the last three months, were collected from medical records.

Quality of life was assessed using the WHOQOL-bref^{2,4,13} questionnaire applied by trained interviewers. The WHOQOL-bref is an easy-to-use instrument developed by the World Health Organization (WHO) and validated in Brazilian Portuguese.²

The WHOQOL-bref comprises 26 items whose answers should refer to situations occurring within two weeks prior to the interview and is divided into four domains: physical health, psychological health, social relationships, and environment. The physical health domain measures pain and discomfort; energy and fatigue; sleep and rest; mobility; daily life activities; dependence on medications or treatments; and work capacity. The psychological health domain measures positive feelings; thinking, learning, memory and concentration; self-esteem; bodily image and appearance; negative feelings; spirituality, religion and personal beliefs. The social relationships domain includes personal relationships; social support; and sexual activity. And the environment domain measures physical safety and security; home environment; financial resources; health and social care: accessibility and quality, opportunities for acquiring new information and skills; participation in and opportunities for recreation and leisure activities; physical environment (pollution, noise, traffic, climate and transport).***

The equation suggested by WHO² was applied to overall estimation of each domain with scores ranging between four and 20. Data statistics were means, standard deviations, minimum and maximum values, and medians. Kolmogorov-Smirnov test was used to assess normality of distributions.

For the analysis of potential differences between mean scores of quality of life, t-Student or Mann-Whitney tests and variance analysis or Kruskal-Wallis test were applied when needed. For the sake of result interpretation, scores between 4 and 10 were considered as low level; between 10 and 14.9 as intermediate level; and between 15 and 20 as high level.**** Multiple comparisons of means were performed using Tukey's HSD (honestly significant differences) test.

* Seidl EMF. Pessoas que vivem com HIV/AIDS: configurando relações entre enfrentamento, suporte social e qualidade de vida [doctorate thesis]. Brasília: Instituto de Psicologia da UNB; 2001.

** Tostes MA. A qualidade de vida de mulheres com a infecção pelo vírus da imunodeficiência adquirida [doctorate thesis]. Rio de Janeiro: Universidade Federal do Rio de Janeiro; 1998.

*** Fleck MPA Versão em português dos instrumentos de avaliação de qualidade de vida (WHOQOL) 1998. Porto Alegre: UFRGS; 1998 [Accessed on 1/10/2001]. Available at: <http://www.ufrgs.br/psiq/whoqol.html>

**** Souza RC. Qualidade de vida de pessoas egressas de instituições psiquiátricas: o caso de Ilhéus/BA [master's dissertation]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da USP; 2000

The study protocol was approved by the ethics committees of Faculdade de Medicina and Faculdade de Saúde Pública of Universidade de São Paulo. Interviews and medical record consultations were carried out after subjects had read and signed the free informed consent form.

RESULTS

Mean age of 365 interviewees was 39.3 years (SD = 9.1 years), about half were male and 40% were single. More than half of them self-referred as white, 31% as mulatto, and 98% as black. Median income was R\$ 600.00, and 15% of interviewees reported having no income (Table 1).

Median CD4+ cell count was 343 cells/mm³.

Mean time elapsed since they knew their HIV-positive status was five years, and 315 interviewees (86.5%) were on antiretroviral therapy (ARVs). Most subjects have neither indication for psychiatric care nor were being followed up for any psychiatric conditions three months prior to the interview (Table 1).

Table 2 shows scores of quality of life domains. It can be noted that mean scores were similar in all domains.

Table 3 shows sociodemographic information and mean scores of quality of life domains and their respective mean differences.

Comparison of mean raw scores of quality of life in men and women showed a statistically significant difference in the environment and psychological health domains with lower scores for women in both domains.

A statistically significant difference between score means was found for skin color in the environment domain. Multiple comparisons using Tukey test showed white subjects had better scores than *pardo* and black.

These comparisons also revealed significant differences in the physical health domain: lower scores were seen among subjects who did not attend school or completed middle school education compared to those with higher education. In the environment domain, there were similar differences and lower scores were seen among those with middle school education or no education and higher scores were found among those with higher education.

Tukey's multiple comparisons multiple for income (in minimum monthly wages, MMW) in the physical health domain revealed lower scores for those with no income or income up to three MMWs compared to those with income equal to or greater than five MMWs. In the social relationships domain, there was a statisti-

Table 1. Distribution of the population studied (number and percent) according to sociodemographic and clinical and epidemiological characteristics. São Paulo, Southeastern Brazil, 2002.

Variable	N	%
Sex (N=365)		
Male	230	63.0
Female	135	37.0
Skin color (N=365)		
White	206	56.4
<i>Pardo</i>	112	30.7
Black	32	8.8
Asian	3	0.8
Native	12	3.3
Individual income (N=363)		
No income	55	15.1
Up to 1 MMW	18	4.9
1.1 to 3 MMWs	112	30.8
3.1 to 5 MMWs	74	20.4
5.1 to 7 MMWs	37	10.2
7.1 to 9 MMWs	18	4.9
9.1 MMWs and more	49	13.5
Psychiatric care (N=364)		
Yes	57	15.7
No	307	84.3
Other symptoms (N=364)		
Yes	154	42.3
No	210	57.7
Time elapsed since HIV diagnosis (N=363)		
< 2 years	78	21.5
2 to 5 years	105	28.8
5.1 to 8 years	109	29.9
8.1 to 21 years	72	19.8
CD4+ cell/mm ³ (N=363)		
< 200	75	20.5
200 to 350	111	30.5
> 350	177	49.0

MMW: monthly minimum wage

Table 2. Distribution of means and standard deviations and range of raw scores obtained from the quality of life questionnaire (WHOQO-bref). São Paulo, Southeastern Brazil, 2002.

Domain	Mean (SD)	Minimum–Maximum
Physical health	14.6 (2.8)	6.2 - 20.0
Psychological health	14.9 (2.8)	6.0 - 20.0
Social relationships	14.2 (3.6)	4.0 - 20.0
Environment	13.5 (2.3)	6.0 - 20.0

Raw score ranging between 4 and 20
SD: standard deviation

Table 3. Distribution of the population studied according to sociodemographic characteristics and quality of life scores. São Paulo, Southeastern Brazil, 2002.

Explanatory variable Sociodemographic	N	%	Physical health	Mean quality of life scores (SD)		
				Psychological health	Social relationships	Environment
Sex						
Male	230	63.0	14.8(2.7)	15.2(2.7)	14.3(3.5)	13.8(2.3)
Female	135	37.0	14.3(2.8)	14.4(2.9)*	14.1(3.8)	12.9(2.2)**
Skin color						
White	206	56.4	14.8(2.9)	15.1(2.8)	14.4(3.6)	13.9(2.3)***
Mulatto	112	30.7	14.2(2.7)	14.5(3.0)	13.8(3.7)	13.1(2.3)***
Black	32	8.8	14.7(2.4)	15.3(2.2)	14.0(3.8)	12.4(2.6)
Asian	3	0.8	16.3(1.7)	16.6(2.3)	16.0(2.7)	14.3(2.7)
Native	12	3.3	13.9(2.8)	14.7(2.4)	14.8(2.8)	12.4(2.3)
Individual income						
No income	55	15.1	14.2(2.7)***	14.5(2.0)	13.9(2.0)	12.7(2.1)***
Up to 1 MMW	18	4.9	12.4(2.9)***	13.0(3.1)	13.4(4.2)	11.7(2.8)***
1.1 to 3 MMWs	112	30.8	14.1(2.8)***	14.6(2.8)	13.5(4.1)***	12.9(2.3)***
3.1 to 5 MMWs	74	20.4	14.7(2.4)***	14.8(2.6)	14.6(2.8)	13.6(2.0)***
5.1 to 7 MMWs	37	10.2	15.5(2.6)***	15.5(3.4)	14.9(3.6)	14.2(2.2)***
7.1 to 9 MMWs	18	4.9	15.1(2.9)***	16.1(2.0)	15.0(2.2)	14.8(2.2)***
9.1 MMWs and more	49	13.5	16.0(2.6)***	15.9(2.5)	15.5(3.2)***	15.1(1.7)***
Schooling						
Did not attend school	5	1.3	11.3(2.1)*	12.6(3.3)*	12.0(3.1)*	11.6(1.5)*
Elementary education	149	41.0	14.3(2.6)	15.0(2.6)	14.6(3.2)	13.2(2.2)
Middle school education	108	29.8	14.9(2.5)	14.8(3.0)	13.7(4.3)	13.3(2.5)
Higher education	101	27.9	15.0(3.1)***	15.1(2.8)***	14.3(3.2)***	14.3(2.3)***

* p<0.05; ** p<0.01; *** Tukey
MMW – Monthly minimum wage
SD: standard deviation

Table 4. Distribution of the population studied according to clinical and epidemiological characteristics and quality of life scores. São Paulo, Southeastern Brazil, 2002.

Explanatory variable Clinical and epidemiological	N	%	Physical health	Mean quality of life scores (SD)		
				Psychological health	Social relationships	Environment
Psychiatric care						
Yes	57	15.7	13.0(3.1)**	13.1(2.6)**	12.5(4.4)**	12.7(2.2)*
No	307	84.3	14.9(2.6)**	15.3(2.6)**	14.5(3.4)**	15.3(2.6)*
Other symptoms						
Yes	154	42.3	14.2(2.7)*	14.6(2.8)	13.9(3.9)	13.3(2.3)
No	210	57.7	14.9(2.8)*	15.2(2.8)	14.4(3.4)	13.6(2.3)
Time elapsed since HIV diagnosis						
< 2 years	78	21.5	14.6(3.1)	15.1(3.0)	14.0(4.0)	13.4(2.3)**
2 a 5 years	105	28.8	15.1(2.8)	15.3(2.8)	14.8(3.5)	14.0(2.3)**
5.1 to 8 years	109	29.9	14.3(2.5)	14.5(2.7)	13.9(3.4)	13.3(2.2)
8.1 to 21 years	72	19.8	14.4(2.7)	14.9(2.7)	14.0(3.7)	13.6(2.4)
CD4+ cell/mm ³						
< 200	75	20.5	14.0(2.9)**	14.5(3.0)	14.1(3.9)	13.5(2.4)
200 to 350	111	30.5	14.5(2.9)**	15.0(2.8)	14.2(3.4)	13.4(2.4)
> 350	177	49.0	15.0(2.6)**	15.1(2.6)	14.3(3.7)	13.5(2.2)

* p<0.05; ** Tukey
SD: standard deviation

Table 5. Distribution of the population studied (number and percent) according to illicit drug use and quality of life scores. São Paulo, Southeastern Brazil, 2002.

Explanatory variable Illicit drug use	N	%	Mean quality of life scores (SD)			
			Physical health	Psychological health	Social relationships	Environment
Marijuana						
Yes	30	8.2	14.7(3.3)	14.7(3.2)	13.9(4.0)	13.5(2.4)
No	335	91.8	14.6(2.7)	15.0(2.8)	14.2(3.6)	13.5(2.3)
Inhaled cocaine						
Yes	9	2.5	14.0(3.3)	14.5(2.3)	12.4(4.7)	12.4(3.4)
No	356	97.5	14.6(2.8)	15.0(2.8)	14.3(3.6)	13.5(2.3)

* Mann-Whitney $p < 0.05$

SD: standard deviation

cally significant difference only for those with income between one to three MMWs and those with income equal to or greater than nine MMWs.

In the environment domain, the same pattern was seen in those with lower income (lower than 3 MMWs or no income) who had lower scores of quality of life.

Clinical and epidemiological characteristics of subjects are presented in Table 4 as well as mean scores of quality of life domains along with their respective mean differences.

There were no statistically significant differences between quality of life domains and current use of ARVs, age, marital status, living with a partner, having had sex within one month prior to the interview, HIV infection route and cigarette smoking within one month prior to the interview.

Subjects who had indication for or were receiving psychiatry care within three months prior to the interview had significantly lower mean scores of quality of life in all domains.

Those who did not have any general signs and symptoms within three months prior to the interview had higher mean scores in the physical health domain.

There were no statistically significant differences in mean scores in the psychological health, social relationships and environment domains according to CD4+ cell count. Those with >350 CD4+ cells/mm³ in any domain had higher mean scores compared to other groups.

The variable time elapsed since HIV diagnosis indicated that subjects who knew their HIV status for two to five years had mean higher scores than those who knew it less than two years in the environment domain. There were statistically significant differences in mean scores of quality of life according to marijuana and inhaled cocaine use within three months prior to the study (Table 5).

DISCUSSION

People living with HIV/AIDS who attended Casa da AIDS in 2002 had quality of life scores in the physical and psychological health domains close to the high level (between 15 and 20) while their scores in the social relationships and environment domains fell in the intermediate level (between 10 and 14.9). In Belo Horizonte* and Taiwan^{1,4} studies, lower results were found in the physical and psychological health domains with scores in the intermediate level. These differences can be partly explained by the diversity of the samples studied. Subjects of the present study were on ARVs for a long time while those studied in Belo Horizonte had recently started treatment. The sample of the Taiwan study was younger and had a greater proportion of men (96%) than Casa da AIDS sample and some interviewees were living in a shelter supported by a religious institution. Owing to non-random recruiting of subjects, the present study findings cannot be generalized to other specialized services. However, the consecutive sampling method used in this study has been considered one of the best non-probabilistic approaches.⁵

In the validation study of WHOQOL-bref in Brazil, Fleck et al² verified that patients from different clinical specialties (outpatients and inpatients from internal medicine, psychiatric surgery, and gynecology) in a university hospital in Porto Alegre (southern Brazil) had scores in the intermediate level (between 10 and 14.9) in the physical and psychological health and environment domains. Scores of the social relationships domain fell within the high level (between 15 and 20). Comparatively to Casa da AIDS patients, only the control group (non-patients) of Fleck et al² study had scores within the high level in the physical and psychological health domains. On the other hand, concerning the social relationships domain, the subjects of the present study had higher scores compared only to psychiatric patients. In regard to the environment domain, AIDS patients had

* Campos LN. Qualidade de vida e prevalência de ansiedade e depressão em pacientes portadores do HIV/Aids antes do início da terapia anti-retroviral. [master's dissertation] Belo Horizonte: Universidade Federal de Minas Gerais; 2004.

lower scores compared to clinical and control patients in Fleck et al² study.

In short, people living with AIDS have better quality of life, i.e., physical and psychological health, than other patients but worse quality of life in the social relationships domains. This latter can reflect stigma and discrimination associated to difficulties to disclose their HIV status in social settings (work, family, and friends) and for a comfortable sex life. The study findings indicate that distinctive features of people living with HIV/AIDS can negatively affect issues in the social relationships domains (personal relationships, social support and sexual activity).

Few studies for the assessment of quality of life of people living with HIV/AIDS^{3,6,8,*} have used the WHOQOL-bref^{1,4,**} while others, which are not comparable to the present study, used different instruments (MOS, SF-36, HAT-QoL). Besides, the WHOQOL group developed the WHOQOL-100 and WHOQOL-HIV instruments, which have not been yet validated in Portuguese, at the time of the present study. Even considering the methodological limitations of this analysis, it is important to contrast the present study findings with those from studies on quality of life and HIV/AIDS.

Starace et al¹² in a validation study of WHOQOL-HIV comprising 134 Italian men and women, reported lower scores in the environment domain. It is worth noting that this questionnaire consists of questions from WHOQOL-100 instrument in addition to 35 specific questions for people living with HIV/AIDS, making a total of 135 questions and seven domains. In this study,¹² higher scores were found in the level of independence domain, followed by psychological health, beliefs of people living with HIV/AIDS (fear of disease progression, fear of being left alone as disease progresses, feeling uncomfortable in the presence of other people with HIV), physical health, social relationships and spirituality domains. In the present study, when compared to men, women were found to have lower scores lower in the psychological health and environment domains.

In a study investigating women living with HIV/AIDS conducted in three cities of the state of São Paulo, Paiva et al⁹ reported the following factors as harmful to their quality of life: “changes in sexual and affective life due to difficulties to disclose their diagnosis; ongoing daily negotiation for condom use; fear of rejection; and hard decisions concerning their desire to have a family”.

According to Tostes,** negative impacts on quality of life of people living with HIV/AIDS seem to be more profound in women because they have lower earnings and schooling; they are financially dependent on their partners; they are overwhelmed with home chores and caring for their children and other relatives; their socioeconomic condition deteriorates as disease progresses; and because the majority was infected by their (current or former) partners, which could arouse feelings of great sorrow, anger, and disappointment.

As women try to meet all their home, family and work commitments, they may disregard their health care and prioritize all other activities.*** In other words, gender inequalities have an impact on women's quality of life.

With respect to time elapsed since HIV diagnosis, owing to free access to more powerful ARVs in the mid-1996, it is possible there has been a lower impact on the environment domain in this group. This group most likely learned their HIV status when HIV drugs were less effective.

It is also possible that those who knew their HIV status for less than two years had the lowest scores because they were still trying to conform to a new life situation, which had a negative impact on issues dealt in the environment domain, as Campos* described. The present study documents quality of life scores and their variation measured by an instrument validated in Brazil, WHOQOL-bref, which provides an opportunity to apply it to people living with HIV/AIDS and therefore indicate priority intervention areas. The study sample is representative of patients attending visits with infectious disease specialists at Casa da AIDS with few losses and refusals. There were no differences in sociodemographic characteristics of interviewees and of those refusing to participate in the study (data not shown).

Since it is a university reference service, significant differences in quality of life scores found among black (black and *pardo*), women, people with lower income and schooling and those with indication for or receiving psychiatric care are suggestive of social inequalities. Hence the study findings cannot be generalized to other services in São Paulo and other regions. Samples based on reference university services usually comprise patients with better health and life conditions and overestimation of quality of life scores can be expected. In contrast, lower scores can be expected in marginalized populations and those attending services with less resources.

* Campos LN. Qualidade de vida e prevalência de ansiedade e depressão em pacientes portadores do HIV/Aids antes do início da terapia anti-retroviral. [Master's dissertation] Belo Horizonte: Universidade Federal de Minas Gerais; 2004.

** Tostes MA. A qualidade de vida de mulheres com a infecção pelo vírus da imunodeficiência adquirida [doctorate thesis]. Rio de Janeiro: Universidade Federal do Rio de Janeiro; 1998.

*** Vulnerability and care of women living with HIV/AIDS (WLWHA) in Sao Paulo, Brazil. [Accessed on 8/30/2007]. Available at: <http://www.iasociety.org/Default.aspx?pagelD=11&abstractId=4073>

As the WHOQOL instrument measures quality of life within two weeks prior to the interview, information provided is a snapshot which minimizes potential recall bias. AIDS patients have good quality of life in the physical and psychological health domains but face difficulties in the social relationships and environment domains. The inclusion of quality of life assessment through standardized instruments in medical follow-up can help to identify the most crucial domains in these patients' life and allow to providing more specific and better care.

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