Revista da Sociedade Brasileira de Medicina Tropical

Journal of the Brazilian Society of Tropical Medicine Vol.:52:e20180157: 2019

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doi: 10.1590/0037-8682-0157-2018

Short Communication

Quality of life of people with HIV/AIDS – the influence of social determinants and disease-related factors

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Abstract

Introduction: This study assessed the quality of life (QoL) of people with HIV/AIDS. **Methods:** This cross-sectional epidemiological study was conducted at a specialized HIV/AIDS health facility of the Brazilian Public Health Service. Data were collected using the HIV/AIDS-Targeted Quality of Life (HAT-QoL) instrument. **Results:** The study included 109 participants. Among the many significant statistical associations found in the study, the variables that had a greater effect on the domains assessed by the instrument were educational level, occupation, financial situation, ethnicity, and symptomatology. **Conclusions:** Sociodemographic factors and HIV/AIDS-related aspects were influential in the QoL of people living with HIV/AIDS.

Keywords: Quality of life. HIV. Unified Health System.

HIV gained notoriety in the 1980s, a period characterized by a feeling of anguish originating from the realization that this was a severe and lethal disease caused by sexual transmission and use of illicit drugs. This understanding placed a heavy psychological burden on people affected by this disease. Forty years later, estimates indicate that AIDS is still a major challenge to public health¹.

With the arrival of antiretroviral therapies (ART) and their subsequent improvement, AIDS has become a chronic disease characterized by a significantly greater life expectancy, thus requiring the reevaluation of the quality of life (QoL) of people affected by it. In addition, the greater survival rate of HIV carriers has raised awareness regarding the importance of focusing more on QoL assessments, which can provide important criteria for evaluating the effectiveness of treatments and interventions in the health field^{2,3}

In this context, the goal of this study was to assess the QoL of people living with HIV/AIDS and to identify the associated

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ORCID: 0000-0001-5069-8812 Received 18 April 2018 Accepted 30 August 2018 sociodemographic factors and HIV-related aspects. This was an exploratory cross-sectional study using a quantitative approach. The target population was HIV-positive patients enrolled in a health facility specialized in sexually transmitted diseases, in an average-sized town located in Northwest São Paulo. We included patients aged 18 years or older, who had been tested positive for HIV and agreed to participate in the study. We excluded illiterate patients, individuals with cognitive difficulties, and those who were incarcerated.

Participants were recruited by convenience sampling as they came into the health facility for treatment. Data collection spanned eight months, and the questionnaire was administered in a private location, before the medical appointment.

The research instrument used was the HIV/AIDS-Targeted Quality of Life (HAT-QoL) instrument, developed by Holmes and Shea⁴ originally in English, and translated and validated in Brazil by Soárez et al.⁵. This instrument was selected because it was created specifically for assessing the QoL of people with HIV/AIDS, in addition to presenting adequate psychometric properties, satisfactory internal consistency, and evidence of construct validity. The HAT-QoL comprises 34 items that assess nine domains: general activity (GA), sexual activity (SA), confidentiality concerns (CC), medication issues (MI), health concerns (HC), financial concerns (FC), HIV acceptance (HA),

satisfaction with life (SL), and provider trust (PT). Responses to items are rated on a 5-point Likert scale with the following options: always, most of the time, sometimes, rarely, and never. Patients selected only one option per question, which best represented how they had lived over the past four weeks. Scores range from one to five; a score of one represents the worst situation, and five corresponds to the best situation or condition. Later, the scores obtained in each domain are converted into indexes with weights ranging from zero to 100, where indexes closer to 100 indicate a better QoL.

In addition to variables assessed by the HAT-QoL, our study also analyzed sociodemographic variables, such as age, gender, educational level, marital status, occupation, perception of financial situation, ethnicity, and sexual orientation. Further, the following HIV-related variables were evaluated: method of contamination, symptoms or opportunistic infections in the past months, CD4 count, and viral load.

Descriptive analysis was used to characterize the variables through measures of central tendency and dispersion. Regarding the standardized scores of the HAT-QoL domains, comparisons among the categories of the sociodemographic or clinical variables were performed using Student's t-test or ANOVA and complemented by Tukey's test when necessary. In addition, a linear multiple regression model was performed. These procedures have been commonly adopted in the corresponding research literature and were also justified because of the reasonably large number of individuals in the groups compared. Statistical analyses were performed at a significance level of 5%.

The study was approved by the Ethics Committee on Human Research and carried out with the understanding and written consent of each participant.

A total of 109 patients were interviewed, 56% of whom were men. Subjects' age ranged from 18 to 74 years, with a mean of 45.7 years. The majority declared that they were white (59%), heterosexual (83%), and not in a stable relationship (37%). With regards to education, 45% had completed only elementary school. In addition, 56% were unemployed, and 81% believed their financial situation was equal to or better than that of the average person. Regarding HIV-related data, the majority (74%) disclosed that they had been infected through sexual contact, and were taking three tablets or fewer (58%) as part of ART.

Regarding the assessment of the HAT-QoL domains, the lowest scores were obtained in the FC and CC domains, whereas the highest score, remarkably, was for PT (**Table 1**).

Table 2 indicates that women had a worse QoL index for the SL domain than men. Concerning the education variable, individuals with a university education presented a positive impact on the HC, FC, MI, and HA domains, according to statistical associations. Regarding employed participants, higher mean scores were observed for the GA domain and lower ones for the CC domain (**Table 2**).

In relation to the multivariate analysis by the linear logistic regression model (**Table 3**), individuals with HIV symptoms had a negative association in most of the domains of the HAT-QoL. Domains that presented the lowest scores were GA, SL, HC, MI, CC, and SF.

TABLE 1: Descriptive statistics of scores for quality of life domains.

Domain	Items	M (SD)	Mdn (Q1; Q2)
General activity	6	67 (25)	71 (50; 88)
Satisfaction with life	4	67 (29)	69 (44; 94)
Health concerns	4	64 (35)	75 (38; 100)
Financial concerns	3	47 (37)	42 (8; 83)
Medication issues	5	74 (30)	85 (60; 100)
HIV acceptance	2	59 (39)	63 (25; 100)
Confidentiality concerns	5	46 (33)	40 (20; 80)
Provider trust	3	82 (25)	100 (67; 100)
Sexual activity	2	64 (40)	88 (25; 100)

M: mean, SD: standard deviation, Mdn: median, Q: quartile.

The population analyzed in this study was composed primarily of individuals who were male, heterosexual, had white skin, primary level of education, and were unemployed. This structural and epidemiological characterization of the individuals surveyed is similar to that of other studies^{1,4-6}, and these data are considered to be important for public health service since it can help develop actions and health plans to fight against HIV/AIDS.

The predominance of heterosexual men in the present research may be a factor that has an effect on QoL. This phenomenon may be explained by the stigma of hegemonic masculinity, which drives these men to hold on to their so-called masculine habits reinforcing their habitual pattern of reckless actions. This situation makes them vulnerable to contracting HIV, as well as resistant to accepting the disease and adhering to treatment⁷.

Socially speaking, ever since the HIV/AIDS epidemic appeared, its stigma has been associated with the image of prostitutes, drug addicts, and men who have sex with other men (MSM). This segregation has resulted in heterosexual men not being openly represented. The consequence is that this group has been left out of HIV/AIDS prevention efforts^{1,8}. In this regard, understanding the masculine gender, particularly within a health context, must take into account its broad and universal condition. This is important because even after implementation of the National Policy for the Integral Attention of Men's Health, the conditions for coping with the disease still remain insufficient⁷.

Analysis of the HAT-QoL instrument indicated that the lowest means were related to the FC and CC domains. These results corroborate those found in other studies that have also used the HAT-QoL instrument 5,9,10.

With regards to FC, its importance may be explained by the low purchasing capacity of the study participants, considering that an unprivileged socioeconomic level may negatively impact an individual's life and survival. Regarding the CC domain, results are similar to those reported by Soares et al., who observed the apprehension of individuals infected with HIV when seeking health services, originated from their fear

TABLE 2: Analysis of standardized scores of HAT-QoL domains, according to sociodemographic variables and HIV-related factors of disease carriers.

Categories	GA	SL	НС	FC	MI	HA	CC	PT	SF
Age⁺									
18 -39 (n=35)	68 (25)	65 (28)	57 (40)	49 (36)	70 (31)	59 (38)	45 (33)	74 (30)	74 (30)
≥ 40 (n=74)	66 (26)	67 (30)	67 (33)	46 (37)	76 (30)	59 (40)	47 (33)	85 (22)	85 (22)
p value	0.656	0.678	0.167	0.728	0.357	0.912	0.736	0.052	0.052
Gender									
F (n=48)	61 (24)	58 (29)	62 (36)	45 (35)	74 (25)	54 (42)	45 (34)	84 (22)	84 (22)
M (n=61)	71 (26)	73 (28)	66 (35)	48 (38)	74 (34)	63 (37)	47 (33)	80 (27)	80 (27)
p value	0.051	0.007*	0.579	0.669	0.997	0.214	0.701	0.466	0.466
Educational level									
Primary (n=49)	63 (25)	64 (31)	^a 56 (36)	a 34 (34)	a 69 (33)	^a 53 (39)	47 (35)	87 (20)	87 (20)
Secondary (n=44)	66 (26)	67 (29)	^{ab} 65 (34)	^b 58 (37)	^b 76 (28)	a 58 (40)	44 (31)	80 (26)	80 (26)
Tertiary (n=16)	80 (20)	74 (24)	^b 85 (29)	^b 59 (31)	b 84 (28)	^b 80 (31)	53 (35)	74 (32)	74 (32)
p value	0.053	0.452	0.014*	0.002*	0.002*	0.049*	0.650	0.155	0.155
Marital status									
Single (n=40)	69 (25)	70 (28)	59 (36)	51 (38)	75 (29)	55 (40)	45 (33)	79 (27)	79 (27)
Married (n=39)	66 (27)	63 (30)	68 (34)	45 (35)	72 (32)	63 (37)	48 (35)	78 (27)	78 (27)
Div. or widowed (n=30)	65 (24)	66 (30)	66 (36)	45 (38)	75 (31)	59 (41)	45 (32)	90 (18)	90 (18)
p value	0.784	0.509	0.537	0.714	0.714	0.677	0.878	0.109	0.109
Occupation									
Employed (n=48)	72 (24)	73 (27)	69 (33)	51 (36)	75 (31)	63 (37)	37 (33)	78 (30)	78 (30)
Unemployed (n=61)	62 (26)	62 (30)	60 (37)	44 (37)	73 (30)	56 (41)	54 (32)	85 (20)	85 (20)
p value	0.048*	0.055	0.192	0.312	0.683	0.333	0.008*	0.164	0.164
Financial Situation									
Work (n=21)	49 (24)	45 (32)	32 (34)	13 (18)	54 (38)	45 (39)	37 (30)	87 (19)	87 (19)
Equal or better (n=88)	71 (24)	72 (26)	72 (31)	55 (35)	79 (26)	63 (38)	49 (34)	81 (26)	81 (26)
p value	<0.001*	<0.001*	<0.001*	<0.001*	0.008*	0.058	0.141	0.213	0.213
Ethnicity									
White (n=64)	69 (25)	64 (28)	69 (33)	52 (36)	80 (24)	59 (38)	48 (33)	82 (23)	82 (23)
Brown/black (n=45)	63 (26)	70 (30)	57 (39)	39 (37)	65 (36)	59 (41)	44 (33)	82 (27)	82 (27)
p value	0.220	0.358	0.071	0.070	0.013*	0.949	0.511	0.957	0.957
Sexual orientation									
Heterosexual (n=90)	67 (25)	66 (30)	63 (36)	46 (37)	74 (29)	57 (39)	45 (33)	83 (24)	83 (24)
Homo/bisexual (n=19)	67 (29)	68 (27)	67 (34)	51 (36)	71 (36)	69 (37)	52 (36)	77 (29)	77 (29)
p value	0.929	0.838	0.708	0.616	0.611	0.226	0.447	0.327	0.327
Origin of HIV Infection	0.020	0.000		0.0.0	0.01.		••••	0.02.	0.02.
Sexual (n=81)	65 (26)	65 (30)	63 (37)	48 (36)	73 (31)	63 (39)	45 (33)	81 (25)	81 (25)
Blood (n=12)	76 (23)	83 (14)	64 (36)	42 (38)	81 (30)	50 (37)	58 (32)	94 (11)	94 (11)
Unknown (n=16)	67 (25)	63 (27)	70 (30)	47 (40)	70 (30)	48 (42)	42 (36)	78 (29)	78 (29)
p value	0.365	0.118	0.794	0.895	0.895	0.288	0.402	0.202	0.202
Symptoms	0.303	0.110	0.734	0.000	0.000	0.200	0.402	0.202	0.202
No (n=85)	71 (24)	71 (27)	70 (33)	51 (37)	78 (28)	62 (39)	49 (34)	83 (26)	83 (26)
			42 (35)	32 (31)		` '		78 (22)	
Yes (n=24)	51 (22) <0.001 *	50 (32) 0.002 *	42 (35) <0.001 *	32 (31) 0.019 *	58 (32) 0.003 *	48 (39) 0.128	37 (30) 0.109	78 (22) 0.406	78 (22)
p value T-CD4**	~U.UU1"	0.002	~U.UU I	0.019	0.003	0.120	0.109	0.400	0.406
	70 (25)	67 (22)	63 (36)	50 (27)	66 (27)	10 (11)	43 (22)	82 (20)	82 (20)
≤350 (n=22)	70 (25)	67 (32)	63 (36)	50 (37)	66 (37)	49 (44)	43 (32)	82 (28)	82 (28)
> 350 (n=87)	66 (26)	66 (28)	64 (36)	46 (37)	76 (28)	62 (38)	47 (34)	82 (24)	82 (24)
p value V.L.***	0.455	0.924	0.892	0.711	0.284	0.192	0.626	0.990	0.990
	04 (07)	66 (00)	60 (05)	40 (07)	70 (04)	64 (40)	E4 (0E)	00 (05)	00 (05)
≤ 50 (n=75)	64 (27)	66 (30)	69 (35)	48 (37)	76 (31)	61 (40)	51 (35)	82 (25)	82 (25)
> 50 (n=34)	73 (21)	68 (28)	53 (36)	45 (37)	70 (30)	56 (38)	36 (28)	82 (26)	82 (26)
p value	0.929	0.929	0.929	0.929	0.929	0.929	0.929	0.929	0.929

GA: General activity, **SL:** Satisfaction with life, **HC:** Health concerns, **FC:** Financial concerns, **MI:** Medication issues, **HA:** HIV acceptance, **CC:** Confidentiality concerns, **PT:** Provider trust, and **SA:** Sexual activity. * Significance level set at 5% (t-test when comparing two categories, and ANOVA when comparing three). Mean of Educational level accompanied by equal letters in the same domain are not significantly different (Tukey's test: p>0.05). *in years, **cells/mm³ and ***copies/mL

TABLE 3: Multiple linear regression for quality of life variables of people living with HIV/AIDS.

Domains	Explanatory Variable	В	p-value	95%CI		\mathbb{R}^2
				LL	UL	
General activity						
	Constant	50,47	<0,001	39,14	61,81	0,232
	Higher education (primary)	12,32	0,046	0,22	24,43	
	Financial situation (worse)	17,37	0,003	6,16	28,58	
	Symptoms (no)	-16,61	0,002	-27,18	-6,04	
	Viral level (≤50)	12,74	0,007	3,52	21,96	
Satisfaction with life						
	Constant	42,65	<0,001	28,66	56,64	0,23
	Gender (F)	13,66	0,008	3,64	23,67	
	Financial situation (worse)	23,61	<0,001	10,76	36,47	
	Symptoms (no)	-12,82	0,043	-25,19	-0,44	
lealth concerns						
	Constant	14,30	0,278	-11,72	40,31	0,31
	Age*	0,57	0,025	0,07	1,07	
	Higher education (primary)	22,47	0,009	5,68	39,25	
	Financial situation (worse)	31,03	<0,001	15,99	46,08	
	Symptoms (no)	-19,09	0,009	-33,27	-4,90	
inancial concerns						
	Constant	14,69	0,058	-0,53	29,92	0,26
	Higher education (primary)	15,40	0,016	2,92	27,88	
	Ethnicity (white)	-12,60	0,046	-24,98	-0,23	
	Financial situation (worse)	38,79	<0,001	23,32	54,25	
Medication issues						
	Constant	66,52	<0,001	52,53	80,51	0,20
	Financial situation (worse)	20,10	0,004	6,44	33,76	
	Ethnicity (white)	-13,87	0,011	-24,49	-3,25	
	Symptoms (no)	-14,81	0,026	-27,80	-1,82	
IIV acceptance						
	Constant	55,51	<0,001	47,64	63,38	0,05
	Higher education (primary)	24,96	0,018	4,43	45,49	
Confidentiality concerns						
	Constant	42,99	<0,001	33,20	52,77	0,14
	Occupation (employed)	20,06	0,001	7,89	32,23	
	Symptoms (no)	-16,09	0,031	-30,70	-1,49	
	Viral level (≤50)	-14,06	0,032	-26,85	-1,26	
Provider trust						
	Constant	76,55	<0,001	70,78	82,32	0,08
	Div. or widowed (single)	12,91	0,015	2,53	23,30	
	Origin (sexual)	16,12	0,033	1,31	30,94	
Sexual activity						
-	Constant	61,08	<0,001	49,42	72,74	0,16
	Gender (F)	17,80	0,015	3,54	32,07	
	Symptoms (no)	-29,96	<0,001	-47,04	-12,87	

Reference classes are shown in parentheses; **B:** coefficient of the regression model; **CI:** confidence interval; **LL:** lower limit; **UL:** upper limit.

of being discriminated, resulting from the stigma caused by the disease. As a consequence, many adopt a life of duplicity, in which they keep their immunologic condition a secret from friends and family, and also neglect self-care.

According to statistical analyses, we observed that the female participants presented the worst means in the SL domain. The diagnosis of HIV/AIDS leads to harmful psychosocial consequences for both genders, which negatively affects the individual's QoL 11, because of the stigma and prejudice associated with HIV/AIDS. However, the impact of this domain on women may be associated with situations of financial, physical, and emotional dependence on a partner or family member. This is likely to affect their living conditions even more severely. Furthermore, women's concerns about pregnancy and the inherent risk and danger of HIV to the health of the fetus, particularly vertical transmission, contributes to a lower QoL index in this domain¹⁰. The path traversed by women in the history of HIV/AIDS demands the consolidation of health measures and actions covering a broader context, ultimately to achieve a more complete inclusion of diverse situations. This scenario of social vulnerability reveals obstacles that still need to be faced, which are generated by factors such as public health, AIDS, gender disparities, and social inequality¹².

In this study, the educational level variable was noteworthy and showed statistical differences regarding several domains of the HAT-QoL. This finding corroborates the results from other studies^{4,9,10}, thus indicating that the higher the educational level, the better the QoL. Individuals with a higher level of education gained from access to knowledge and different sources of information have a better understanding of the impact of certain determinants on their own health. Therefore, individuals' discernment and comprehension of these intrinsic and extrinsic factors may facilitate their acceptance of the disease and resignation towards their serologic condition¹³.

In addition, inclusion in the workforce affected patients' health condition and QoL indexes. Having a job helped them build social, emotional, interpersonal, and identity skills⁹, as well as consolidating financial aspects of their lives. Regarding this issue, the influence of the financial situation on people living with HIV/AIDS cannot be separated from their QoL, a finding corroborated by other studies in which the same research instrument was administered¹⁰.

According to multivariate analysis, the presence of AIDS symptomatology was the major influencing factor in most of the HAT-QoL domains and generated lower QoL scores. This same finding was corroborated by a study conducted by Akinboro et. al¹⁴, which highlighted that the symptomatic condition of the disease interferes in individuals' level of dependence to perform everyday tasks, thus severely impacting their QoL. Another factor related to this situation is non-adherence to ART, signaling neglect for self-care that results in the emergence of AIDS symptomatology. In this case, their survival prospects change from disease chronicity to one of preordained death^{8,15}.

The social disparity that is found especially in developing countries contributes to the marginalization of people with HIV/AIDS, who are usually victims of prejudice and discrimination.

The stigma around this disease is underpinned by a strong cultural base that cannot be disassociated from individuals and that sets into motion a cyclical action leading to the segregation of this vulnerable group, and adverse effects on their QoL^{9,10}.

The limitations of the study are inherent to the methodology of a cross-sectional epidemiological study; therefore, it is not possible to infer the causality of the results. Furthermore, the low educational level of the subjects could have led to bias and a confused interpretation of the alternatives of the HAT-QoL instrument. Nonetheless, the findings of the present study are important in understanding how sociodemographic factors influence the living conditions of people with HIV/AIDS. Clearly understanding these determinants lends evidence to the need for implementing public policies that will not only act on the clinical aspects of HIV/AIDS but also contribute to reform these determining factors, so that there is QoL beyond basic survival for these patients.

Considering the factors associated with sociodemographic and HIV/AIDS-related aspects, we can conclude that the domains that most strongly influenced the QoL of participants were educational level, financial situation, and the symptomatology of the disease. The HAT-QoL scale proved to be consistent for analyzing the QoL in this population, highlighting several representative relationships between the variables of the study and the domains of the instrument.

Acknowledgments: We would like to express our deepest appreciation to the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* (CAPES) for providing the masters scholarship grant.

Conflicts of interest: The authors declare that they have no conflict of interests.

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