RESEARCH PAPER

Assessment of quality of life and its associated factors among people living with HIV/AIDS

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Abstract

Introduction: Acquired immunodeficiency syndrome (AIDS) has evolved from a mysterious illness to a global pandemic which has infected tens of millions of people. Assessing health-related quality of life (HQOL) is useful for documenting the patients' perceived burden of chronic disease, tracking changes in health over time, assessing the effects of treatment and quantifying the return on health care investment. The study aimed to assess the quality of life and its associated factors in patients with HIV/AIDS.

Material and methods: It was a hospital-based observational study conducted at the anti-retroviral therapy centre of the civil hospital, Nashik District. A total of 100 participants with confirmed HIV/AIDS were included. The WHOQOL-HIV BREF instrument was used to assess the quality of life of people living with HIV/AIDS (PLHAs). Multivariate logical regression was used to study the factors affecting the quality of life of PLHAs.

Results: The mean scores of HQOL was highest in the domain of spirituality (15.99) followed by the physical domain (14.71), level of independence (14.45), social relationships (14.04), psychological domain (13.26), and environment (13.04), and the overall perception of quality of life and general health perception's scores were 13.28 and 12.84.

Conclusions: These findings highlight the need for enhanced socio-psychosocial support and a better environment for improving the health-related quality of life among PLHAs.

Introduction

Acquired immunodeficiency syndrome (AIDS) has evolved from a mysterious illness to a global pandemic which has infected tens of millions people [1]. Human immunodeficiency virus (HIV)/AIDS places an increasing burden on the health of the population, and causes further socio-economic problems for individuals, families, communities, NGOs and governments in many countries [2, 3]. However, the recent advance in knowledge about the disease, better diagnostic methods, new treatments and strengthened HIV programs have provided great hope for HIV-positive people to live a long life [4]. In 2009, the National AIDS Control Organization (NACO) reported that there were 211 anti-

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retroviral therapy (ART) centers providing ART treatment free of cost to over 200 000 PLHAs. ART can prolong the life span of PLHAs. However, there is no cure for HIV. HIV is increasingly considered a chronic disease. For a person living with HIV, this means having to cope up with a range of HIV-related symptoms for the entire life. Symptoms may be related to the infection itself, comorbid illnesses or iatrogenic effects from HIV-related medications.

Many HIV patients struggle with numerous social problems such as stigma, discrimination, poverty, depression, substance abuse, and cultural beliefs which can affect their quality of life (QOL) not only in the physical health aspect, but also from the mental and social health point of view and causes numerous problems [5]. The World Health Organization (WHO) has defined QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns" [6].

Assessing health-related quality of life (HRQOL) is useful for documenting the patients' perceived burden of chronic disease, tracking changes in health over time, assessing the effects of treatment and quantifying the return on health care investment [7].

Many instruments for measuring QOL have been developed and described [8]. The WHO, in turn, has invested in the approach to QOL, having constructed the Quality of Life Assessment Group (The WHOQOL Group) for this. This initiative culminated in the creation of a generic QOL assessment instrument called the WHOQoL-100, developed in a multi-centric manner, with trans-cultural potential. Considering the particularities of living with AIDS, the WHOQOL-HIV was created, based on the above-mentioned instrument [9]. They have further developed its brief version (WHOQOL-HIV BREF) which contains a total of 31 questions divided into 6 domains and a general facet.

The aim of the study was to assess the quality of life of patients with HIV/AIDS using the WHOQOL-HIV BREF scale and to study the factors associated with the quality of life of people living with HIV/AIDS (PLHAs).

Material and methods

Type of study: Hospital-based observational study.

Study settings: The study was conducted at the anti-retroviral therapy (ART) centre of the civil hospital of a "Y" grade (Tier II) city of India.

Sample size: 100.

Sampling technique: Convenience sampling was used. The consecutive participants satisfying the eligibility criteria and willing to participate were enrolled until the desired sample size was achieved.

Selection criteria: inclusion criteria – 1) confirmed cases of HIV/AIDS, 2) age 18 years or above, irrespective of gender, 3) willing to participate; exclusion criteria – 1) the presence of any obvious co-morbid conditions not associated with HIV/AIDS, 2) documented cases of co-existing psychi-

atric morbidity, 3) suffering from other systemic/metabolic/endocrinal disorder.

Study design: The project proposal was approved by ICMR STS 2016. The study proposal was submitted to the Institutional Ethical Committee (IEC) and research was carried out after its approval. Permission from Maharashtra State AIDS Control Society (MSACS) was obtained. User agreement with the WHO was signed to use its Questionnaire WHOQOL-HIV BREF.

Before collecting data of patients from the ART, permission from the Civil Surgeon was taken.

Written informed consent was obtained. The respondents were informed about the objectives, purpose of the study and other relevant information of the study. Privacy and confidentiality were strictly maintained throughout. All other ethical issues were handled appropriately.

Research instrument: WHOQOL-HIV BREF scale

The questionnaire was originally developed by adopting the "31 items World Health Organization Quality of Life HIV BREF (WHOQOL-HIV BREF) instrument". It is a multidimensional, conceptualized, generic, 31-item QOL instrument. It covers the respondent's perception of the overall quality of life within six broad domains: physical, psychological, level of independence, social, environmental and spiritual. There is also a general facet that measures the overall QOL and general health perceptions. The Physical domain describes 4 facets: pain and discomfort, energy and fatigue, sleep and rest, and symptoms related to HIV. The Psychological domain describes 5 facets: positive feelings, concentration, self-esteem, bodily image and appearance, and negative feelings. The Level of independence domain describes 4 facets: mobility, activities of daily living, dependence on medication and treatment, and work capacity. The Social relationships domain describes 4 facets: personal relationships, social support, sexual activity, and social inclusion. The Environment domain describes 8 facets: 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/leisure activities, physical environment, and transport. The Spirituality, religion and personal beliefs domain describes 4 facets: personal beliefs, forgiveness and blame, concerns about the future, and death and dying [10].

Demographic and clinical information

The socio-demographic and health variables collected were: gender; age; education level; work; average family income; place of residence; time since diagnosis of HIV seropositivity; clinical condition (asymptomatic/symptomatic/AIDS converted); ART use; duration of ART use; CD4 count, presence of opportunistic infections, etc.

Table 1. Socio-demographic characteristics of study participants (*N* = 100)

Variables/Categories	Frequency (% same as frequency)
Sex	
Male	54
Female	46
Age	
≤ 30 years	19
31-40 years	43
41-50 years	21
51-60 years	11
> 60 years	6
Residence	
Urban	45
Rural	50
Slum	5
Marital status	
Single	12
Married	74
Living as married	01
Separated	02
Divorced	05
Widow	06
Occupation	
Profession	16
Semi-professional	02
Clerk, shop owner, farmer	31
Skilled worker	12
Semiskilled worker	03
Unskilled worker	22
Unemployed	14

Table 1. Cont.

Variables/Categories	Frequency (% same as frequency)
Education	
Illiterate	23
Primary	29
Secondary	28
University graduates	13
Post-graduates	7
Average monthly income	
< 5000	33
5000-10000	42
10 000-15 000	6
15 000 or above	19
Religion	
Hindu	92
Muslim	4
Buddha	3
Jain	1
Loss of job	
Yes	14
No	86
Presently employed or not	
Yes	79
No	21

Mode of data collection

The socio-demographic, clinical and quality of life data were obtained using the questionnaire by the personal interview method.

Statistical analysis

Descriptive statistical analysis of the socio-demographic and health questionnaire data was performed with the aid of the Statistical Package for the Social Sciences (SPSS) 20.0. For the analysis of the data from the WHOQOL-HIV BREF scale, the WHO user manual for the WHOQOL-HIV BREF scale was used for calculating the domain scores.

Generalized linear multivariate linear regression was used to test the association between the quality of life of PLHAs and various socio-demographic and disease-related factors.

Results

Sample characteristics

Table 1 shows the socio-demographic characteristics of the study participants. Of the 100 participants, more than half the respondents were male (54%). They were mostly (43%) between 31 and 40 years of age. Half of them were residing in rural areas and only 5% of them came from urban slums. Most of them were married (74%) and there was a much lower percentage of separated (2%) and divorced (5%). Patients were from all kinds of occupations ranging from farmers and laborers to teachers and engineers. 14% of them were unemployed or suffered loss of a job. The average monthly income of 42% of them was only Rs 5000-10 000 and 33% of them earned less than Rs 5000. Almost one quarter of respondents were illiterate (23%) and much fewer of them have a post-graduate level of educational qualification (7%). Most study participants were from the Hindu religion (92%).

Table 2 shows disease- and treatment-related characteristics of the study participants. Only 15% of the respondents have not shared their serostatus with anyone and families of 77% of them were well acquainted with their serostatus. The majority of the respondents had been infected with this virus for a long time (more than 6 years). Only 2% of them

Table 2. Disease- and treatment-related characteristics of study participants (*N* = 100)

Variables/Categories	Frequency (%)
Serostatus is known to	
Nobody	15
Spouse only	5
Family only	77
Family and friends	3
Time since diagnosis of HIV	
≤ 1 year	23
2-5 years	27
6-10 years	40
> 10 years	10
Antiretroviral medication	
≤ 1 year	28
2-5 years	26
6-10 years	38
> 10 years	6
Not started	2
CDC stage of HIV infection	
Asymptomatic	55
Symptomatic	25
AIDS converted	20
Current CD4 count (cells/mm³)	
< 200	22
200-500	53
> 500	25
Opportunistic infections	
Yes	8
No	92
Side effects of drugs	
Yes	20
No	80

Table 3. Mean scores for overall quality of life and general health perceptions and for six domains (*N* = 100)

Domains	Mean (±SD)
Physical	14.71 (3.32)
Psychological	13.26 (3.32)
Level of independence	14.45 (3.08)
Social relationships	14.04 (3.07)
Environment	13.04 (2.78)
Spirituality/religion	15.91 (2.77)
Overall perception of HQOL	13.28 (3.97)
Overall general health perception	12.84 (4.45)

The mean scores of health-related quality of life (HQOL) was highest in the domain of spirituality (15.99) followed by the physical domain (14.71), level of independence (14.45), social relationships (14.04), psychological domain (13.26), environment (13.04) and the overall perception of quality of life and general health perception's scores were 13.28 and 12.84.

Generalized linear multivariate linear regression was used to test the association between the quality of life of PLHAs and various socio-demographic and disease-related factors.

For this analysis, the 6 domain scores of the WHOQOL-HIV BREF scale were taken as the dependent variables and the independent variables considered were socio-demographic (age, gender, education, marital status, place of residence, income, loss of job) and the HIV disease-related characteristics (clinical stage of HIV, years since diagnosis, years since ART, side effects, CD4 count, presence of opportunistic infections).

Tables 4A and 4B show the association of various socio-demographic and HIV disease characteristics with the quality of life of PLHAs. A significant association was found between the physical domain of QOL and presence of opportunistic infections. Domain 3 (Level of independence) showed a significant association with educational status and the number of years since ART was started. Also, the presence of side effects due to ART showed a significant association with the domain of social relationships. The environmental factors were significantly associated with the marital status. The number of years since ART was started was also associated with the spirituality/religion domain.

Discussion

This study demonstrated the importance of social demographic variables for quality of life for people dealing with HIV/AIDS. The largest portion of respondents affected were between 31 and 40 years of age and this finding is congruent with the report of Imam *et al*. [11] and Giri *et al*. [12].

The majority of the study participants were male, similar to the findings of report by Yadav *et al*. [13] and Giri *et al*. [12]. Most of them were from rural areas, which is similar to the study of Anusuya *et al*. [14] in Chennai.

were not receiving antiretroviral treatment. Most of them were asymptomatic (55%) in the CDC stage of HIV infection and 20% AIDS converted. The majority of them (53%) had a current CD4 count of more than 200 but less than 500. Most of them had no opportunistic infection at all. Only 8% of them showed infection of pulmonary tuberculosis, fungal infection and oral thrush. Some of them even suffered from side effects of drugs (20%) such as giddiness, headache, nausea, vomiting, stomach ache, rashes, and ulcers.

Mean scores of quality of life in different domains

Table 3 shows the mean scores for the overall perception of quality of life, general health perceptions and six domains.

Table 4A. Generalized linear multivariate linear regression showing the association between socio-demographic factors affecting quality of life of people living with HIV/AIDS

Sr. No.	Independent variable	Dependent variable	*p*-value	Statistical significance
1	Age	D-1	0.119	NS
		D-2	0.676	NS
		D-3	0.460	NS
		D-4	0.222	NS
		D-5	0.550	NS
		D-6	0.786	NS
2	Gender	D-1	0.811	NS
		D-2	0.750	NS
		D-3	0.326	NS
		D-4	0.367	NS
		D-5	0.330	NS
		D-6	0.604	NS
3	Education	D-1	0.254	NS
		D-2	0.397	NS
		D-3	0.018	Statistically significant
		D-4	0.426	NS
		D-5	0.447	NS
		D-6	0.323	NS
4	Loss of job	D-1	0.416	NS
		D-2	0.673	NS
		D-3	0.887	NS
		D-4	0.391	NS
		D-5	0.834	NS
		D-6	0.822	NS
5	Income	D-1	0.052	NS
		D-2	0.095	NS
		D-3	0.092	NS
		D-4	0.983	NS
		D-5	0.518	NS
		D-6	0.758	NS
6	Residence	D-1	0.057	NS
		D-2	0.964	NS
		D-3	0.052	NS
		D-4	0.731	NS
		D-5	0.338	NS
		D-6	0.069	NS
7	Marital status	D-1	0.458	NS
		D-2	0.068	NS
		D-3	0.499	NS
		D-4	0.051	NS
		D-5	0.039	Statistically significant
		D-6	0.370	NS

D-1 – Physical, D-2 – Psychological, D-3 – Level of independence, D-4 – Social relationships, D-5 – Environment, D-6 – Spirituality/Religion

Table 4B. Generalized linear multivariate linear regression showing the association between HIV disease-related factors affecting quality of life of people living with HIV/AIDS

Sr. No.	Independent variable	Dependent variable	p-value	Statistical significance
1	Clinical stage of HIV	D-1	0.458	NS
		D-2	0.268	NS
		D-3	0.668	NS
		D-4	0.397	NS
		D-5	0.065	NS
		D-6	0.658	NS
2	Years since diagnosis	D-1	0.390	NS
		D-2	0.061	NS
		D-3	0.471	NS
		D-4	0.650	NS
		D-5	0.781	NS
		D-6	0.998	NS
3	Years since ART	D-1	0.108	NS
		D-2	0.217	NS
		D-3	0.018*	Statistically significant
		D-4	0.235	NS
		D-5	0.057	NS
		D-6	0.004*	Statistically significant
4	Side effects	D-1	0.262	NS
		D-2	0.411	NS
		D-3	0.533	NS
		D-4	0.018*	Statistically significant
		D-5	0.068	NS
		D-6	0.640	NS
5	CD4 count	D-1	0.517	NS
		D-2	0.402	NS
		D-3	0.671	NS
		D-4	1.000	NS
		D-5	0.518	NS
		D-6	0.271	NS
6	Presence of opportunistic infections	D-1	0.009*	Statistically significant
		D-2	0.112	NS
		D-3	0.075	NS
		D-4	0.074	NS
		D-5	0.166	NS
		D-6	0.939	NS

*Statistically significant, NS – Not significant

The socioeconomic and demographic characteristics of respondents of this study indicate that most of them were of low socio-economic status. This finding is consistent with several other studies of similar nature of various developing countries [15-18]. Almost one quarter of them were illiterate, which is similar to the findings of Anusuya *et al*. [14].

A majority of our patients were found to be asymptomatic in the present study, which is in agreement with the study by Bakiono *et al*. [19].

Table 5 shows the comparison of domain scores of WHOQOL-BREF in various studies with the present study. In the present study, the global score of quality of life was 85.41.

Table 5. Comparison of the quality of life domain scores of various studies with the present study

Domains	Mean (±SD)			
	Present study	Imam *et al.* [11]	Anusuya *et al.* [14]	Liping *et al.* [21]
Physical	14.71 (3.32)	12.41(3.03)	13.27	14.99
Psychological	13.26 (3.32)	11.63(2.62)	12.88	14.25
Level of independence	14.45 (3.08)	12.21 (2.28)	14.40	–
Social relationships	14.04 (3.07)	12.98 (2.41)	11.63	13.22
Environment	13.04 (2.78)	11.80 (1.77)	12.91	13.31
Spirituality/religion	15.91 (2.77)	13.37 (3.21)	14.67	–
Overall perception of HQOL	13.28 (3.97)	11.85 (3.74)	–	–
Overall general health perception	12.84 (4.45)	12.54 (3.70)	–	–

It is a slightly higher mean score than what was found in Burkina by Bakiono *et al.* [19]. A study conducted in Ethiopia by Deribew *et al.* [20] found a higher mean score of 91.9.

Liping *et al.* [21] reported that factors such as age, education, WHO clinical stage, ART adherence and CD4 count were significantly associated with various domains of QOL. In the present study, factors significantly associated with QOL were educational status, marital status, number of years since ART, side effects of ART and presence of opportunistic infections.

Conclusions

As HIV disease is among the most devastating of illnesses, having multiple and profound effects on all aspects of life, the evaluation of QOL is very important. A rise in the standard of living of people alone will not be enough to achieve happiness; there should be improvement in quality of life also. These findings highlight the need for enhanced socio-psychosocial support and a better environment for improving the health-related quality of life among PLHAs. It can be attained by offering comprehensive and integrated services to the PLHAs including primary medical care, substance abuse treatment, financial assistance, housing, food, child care and social sensitization. It is also important to underline the role of consultation-liaison psychiatry in the diagnosis and treatment of HIV and AIDS. Stress management interventions for HIV-infected persons are a promising approach to facilitate positive adjustment.

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Conflict of interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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