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Quality of life of people living with HIV/AIDS attending antiretroviral therapy center at a tertiary care center

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Abstract

Introduction: Human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) is a serious healthcare challenge globally. Morbidities caused by inefficient immune system potentially reduce quality of life (QoL) of HIV patients. The introduction of highly active antiretroviral therapy has transformed this deadly disease into a chronic manageable illness, with focus shifting from fighting the virus to ensuring good quality of life. To assess the quality of life of people living with HIV/AIDS (PLWHA) and the factors influencing it.

Material and methods: An institutional-based cross-sectional study was carried out among 207 PLWHA, aged more than 18 years, attending antiretroviral therapy (ART) center at a tertiary care center in India between July and September 2023. WHOQOL-HIV BREF questionnaire was used, and statistical analysis was performed with SPSS version 26.0. The association between QoL and various factors was tested using ANOVA and Student's *t*-test.

Results: This study showed that PLWHA had better QoL in physical domain (mean score of 15.9 ± 2.2), while lowest QoL mean score was noted in social relationship domain (11.8 ± 1.4). Participants with higher educational qualifications, those who were taking ART for more than 10 years, patients who were self-motivated to take ART, and those without any opportunistic infections had higher mean scores in all 6 domains of QoL.

Conclusions: The low QoL mean score in social relationship domain is an indication of the persisting stigma related to HIV/AIDS among PLWHA. Proper awareness and counselling of patients and caretakers can help improve PLWHA QoL.

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Key words: HIV, PLWHA, ART center, WHOQOL-HIV BREF, quality of life.

Introduction

Since the human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) epidemic in the United States during the 1980s, it has been a serious healthcare global challenge. In India, first known HIV cases were diagnosed in 1986 [1]. According to the World Health Organization (WHO), there were 39 million people living with HIV worldwide at the end of 2022, and

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based on the estimates of the National AIDS Control Organization (NACO), the adult HIV prevalence (age range, 15-49 years) in 2021 was 0.21% [2]. During their lifetime, people living with HIV/AIDS (PLWHA) are facing challenges with a variety of HIV-related symptoms [3]. The wide range of morbidities secondary to a weakened immune system, significantly reduces quality of life (QoL) in every domain. QoL is a multidimensional construct generally defined as a subjective assessment of a person's overall sense of well-being, and includes aspects, such as happiness and satisfaction with life as a whole [4].

The scenario has improved dramatically since the introduction of highly active antiretroviral therapy (HAART) in 1996 and its availability worldwide. It increased life expectancy of infected individuals, and it changed the notion of HIV/AIDS from a deadly disease to a chronic manageable illness. In order to make sure that PLWHA are leading a satisfied life, the focus shifted from fighting the virus to ensuring good QoL.

Since there are not many studies worldwide on QoL of PLWHA, the present study investigated the impact of various socio-demographic factors on QoL of these patients as well as to identify the most affected domain of daily life. This study was conducted among PLWHA (aged > 18 years) attending antiretroviral therapy (ART) center of McGann Teaching District Hospital, Shimoga Institute of Medical Sciences, Shivamogga, Karnataka, India, to assess their QoL. The findings and conclusions obtained will help building an insight to improve HIV/AIDS-positive patients QoL.

Material and methods

This epidemiological study was conducted among PLWHA attending the ART center at McGann Teaching District Hospital, Shimoga Institute of Medical Sciences, Shivamogga, Karnataka, India, from July 2023 to September 2023. All patients aged > 18 years, attending the ART center who provided a written informed consent were included. Patients were approached and explained about the objectives of the study in local language (Kannada). Target study population was calculated according to previous 3 years' average records of PLWHA attending the ART center in our institution, which was 450. Data were collected every working day of the study duration from 10:30 AM to 12:30 PM, considering a greater number of patients during these 2 hours and time allotted by the authorities for research work. Convenient sampling method was used.

The protocol was approved by the Institutional Ethics Committee of Shimoga Institute of Medical Sciences, Shivamogga, Karnataka, India, prior to the start of the study.

Data were collected during face-to-face interviews, with an average interview's duration of 20 minutes per patient. To maintain patient confidentiality, interviews were performed in a separate area. Baseline characteristics of participants were collected using pre-tested semi-structured questionnaire, which included socio-demographic and clinical characteristics. Socio-economic status (SES) was assessed with a modified Kuppuswamy scale.

QoL was evaluated using World Health Organization Quality of Life (WHOQOL)-HIV BREF instrument. This questionnaire includes 31 questions distributed into 6 domains, such as physical (4 questions), psychological (5 questions), level of independence (4 questions), social relationship (4 questions), environment (8 questions), spirituality (4 questions), and overall general health (2 questions). Respondents answered each question using a 5-point Likert-type scale. Higher scores generally indicate better QoL, therefore scores of negatively directed questions were reversed purposefully. Average scores of all items in each domain were multiplied by 4, to convert domain scores to the range of 4 to 20, for comparability with the scoring pattern of WHOQOL-100.

Statistical analysis

Collected data were entered and analyzed using SPSS version 26.0. The association between QoL domain scores with socio-demographic and clinical characteristics of the participants was analyzed using one-way analysis of variance (ANOVA test) and Student's *t*-test. A p-value < 0.05 was considered statistically significant.

Results

In this study, majority (46.8%) of the participants were in the 20-40 years age group. Out of the 207 study participants, 138 (66.7%) were males, while 68.6% were married. Regarding education, most of the respondents (85.9%) reported a secondary school or below, and 63.7% of the study sample belonged to upper lower class of SES. In terms of ART, 26.1% of the subjects have been taking ART for more than 10 years. Majority (70.5%) of the subjects were self-motivated to take the treatment, while 17 patients were suffering from opportunistic infections. The socio-demographic and clinical characteristics of the participants are shown in Table 1.

The mean of transformed scores (along with standard deviation) ranging from 4 to 20 across the 6 domains of QoL is presented in Table 2. Physical domain of QoL revealed a maximum score of 15.9 ± 2.2, whereas social relationship domain showed a minimum score of 11.8 ± 1.4.

The association between QoL domain scores with socio-demographic and clinical characteristics of the participants is presented in Table 3. We observed that participants with higher educational qualifications, those who were taking ART for more than 10 years, patients who were self-motivated to take ART, and those without any opportunistic infections, had higher mean scores in all 6 domains of QoL and this association was found to be statistically significant ($p < 0.05$). With respect to gender, males had higher scores compared with females across all the domains, and there was a significant association with physical, psychological, level of independence, and social relationships domains of QoL.

Discussion

HIV/AIDS has been a global healthcare challenge for more than past four decades. The incompetent immune system leads to a number of morbidities, thereby causing a significant reduction in QoL of PLWHA. The introduction of HAART has increased the life expectancy, with focus shifting from fighting the virus to ensuring a good QoL of PLWHA.

This institutional-based cross-sectional study included 207 participants, with 138 of males and majority (46.8%) belonged to 20-40 years age group, consistent with findings of other studies [5-8]. A large proportion (63.7%) of our patients placed themselves in upper lower class of SES, and were married (68.6%). Only 29 (14.1%) subjects were graduates, and 63.3% of patients were on ART for more than 5 years, with majority (70.5%) being self-motivated to take ART. Seventeen (8.2%) PLWHA were suffering from one or more opportunistic infections at the time of study. Similar findings were observed in other research [5, 9-11].

In this study, the mean QoL domain score showed maximum in physical domain (15.9 ± 2.2), followed by the level of independence, spirituality, psychological, and environmental domains of QoL. The minimum score was reported in social relationship domain (11.8 ± 1.4). Comparable results were observed in a study conducted among PLWHA in Coastal South of India [9] as well as in another study from the center of excellence in HIV care in India [5]. Since the study sample consisted of patients with age ranging from 18 to 76 years, there were differences in QoL in each domain according to the age group. Our analysis clearly showed that younger age groups had significantly better QoL scores in physical, psychological, level of independence, and social relationship domains. This finding can be easily ascribed to the better physical strength and nutrition as well as better access to the community of younger patients.

In our research, males had significantly better QoL scores in the physical, psychological, level of independence, and social relationship domains. Nojomi *et al.* [12] observed similar findings with respect to gender, whereas some studies have shown no significant differences between two genders [13, 14]. Higher QoL scores in this study among males can be attributed to the fact that most parts of India are having a patriarchal society, with women having less accessibility to all facilities, and that includes better nutrition, education, travelling, employment, and healthcare, which inversely affects their QoL. Marital status did not affect QoL in any of the six domains. Other studies reported different observations, with significantly higher QoL scores among married individuals, indicating better support from the spouses and family members [9, 12, 15].

Patients with higher educational qualification showed better QoL scores in all the study's domains, with a *p*-value of less than 0.05. This could be attributed to better awareness regarding the disease and its natural course, knowledge about the treatment, its availability, and complications. These patients attend counselling sessions with social workers

Table 1. Socio-demographic and clinical characteristics of the participants

Characteristics	*n* (%)
Gender	
Male	138 (66.7)
Female	69 (33.3)
Age (years)	
< 20	19 (9.17)
20-40	97 (46.8)
41-60	68 (32.8)
> 60	23 (11.1)
Marital status	
Married	142 (68.6)
Not married	65 (32.4)
Socio-economic scale	
Upper middle	13 (6.2)
Middle/lower middle	46 (22.2)
Lower/upper lower	132 (63.7)
Lower	16 (7.7)
Education status	
Illiterate	11 (5.3)
Primary school	69 (33.3)
Secondary school	98 (47.3)
Graduate	29 (14.1)
Duration of ART	
< 5 years	76 (36.7)
5-10 years	77 (37.2)
> 10 years	54 (26.1)
Motivation to take ART	
Self-motivated	146 (70.5)
Compulsion	61 (29.5)
Opportunistic infections	
Present	17 (8.2)
Absent	190 (9.8)

ART – antiretroviral therapy

Table 2. Transformed scores of the 6 domains of quality of life (QoL)

QoL domains	Transformed score, mean (SD)
Physical	15.9 (2.2)
Psychological	13.1 (1.6)
Level of independence	13.9 (1.8)
Social relationships	11.8 (1.4)
Environmental	12.6 (1.7)
Spirituality	13.5 (2.1)

Table 3. Association between quality of life and socio-demographic and clinical characteristics of the participants

Characteristics	WHOQOL-HIV BREF domains					
	Physical mean (SD)	Psychological mean (SD)	Level of independence mean (SD)	Social relationship mean (SD)	Environmental mean (SD)	Spirituality mean (SD)
Gender						
Male	16.6 (2.1)	13.8 (2.1)	12.9 (2.8)	12.5 (1.9)	12.8 (1.4)	12.8 (1.4)
Female	14.1 (2.4)	13.1 (2.1)	12.1 (2.1)	11.1 (1.3)	12.4 (1.6)	13.1 (1.5)
p-value	0.001	0.001	0.005	0.001	0.287	0.186
Age (years)						
< 20	16.8 (1.9)	13.7 (1.7)	13.9 (2.0)	13.2 (1.8)	12.9 (1.5)	12.7 (1.6)
20-40	16.2 (1.6)	12.3 (1.8)	13.7 (1.8)	12.6 (1.6)	12.6 (1.4)	12.6 (1.6)
40-60	15.4 (1.8)	12.1 (2.1)	13.2 (1.8)	11.8 (2.2)	12.5 (1.9)	12.3 (1.2)
> 60	14.6 (2.1)	12.0 (1.7)	12.2 (2.1)	11.1 (2.0)	12.1 (2.0)	12.0 (2.0)
p-value	0.001	0.008	0.007	0.004	0.182	0.087
Marital status						
Married	15.2 (1.8)	12.8 (3.0)	13.5 (1.4)	12.8 (1.6)	12.6 (2.2)	12.8 (1.4)
Not married	15.4 (1.8)	12.4 (2.1)	13.8 (1.8)	13.7 (2.0)	12.9 (2.6)	12.2 (1.9)
p-value	0.446	0.276	0.334	0.086	0.198	0.334
SES						
Upper middle	16.9 (1.5)	13.5 (1.7)	14.1 (1.0)	13.5 (1.5)	13.3 (1.3)	12.9 (1.6)
Middle	16.4 (2.1)	12.8 (1.8)	13.7 (1.8)	12.7 (1.8)	12.8 (1.4)	12.5 (1.6)
Upper lower	15.6 (1.8)	12.6 (2.1)	13.6 (1.8)	11.6 (2.0)	12.2 (1.9)	12.3 (1.2)
Lower	14.9 (1.1)	12.5 (1.7)	12.9 (2.1)	11.4 (1.6)	12.4 (2.0)	12.1 (2.0)
p-value	0.002	0.016	0.009	0.014	0.122	0.091
Education						
Illiterate	15.0 (1.8)	12.5 (1.7)	12.1 (1.1)	10.5 (1.20)	11.5 (1.2)	12.0 (1.8)
Primary	15.0 (1.6)	12.7 (1.8)	12.8 (1.7)	11.1 (2.0)	12.2 (1.8)	12.6 (1.7)
Secondary	15.6 (2.2)	12.7 (2.0)	13.6 (1.8)	11.8 (1.6)	12.5 (2.0)	13.0 (2.0)
Graduate	16.2 (1.1)	13.6 (1.3)	14.5 (1.1)	12.8 (1.2)	13.5 (1.5)	13.8 (1.2)
p-value	0.002	0.002	0.002	0.003	0.001	0.004
Duration of ART						
< 5 years	14.8 (1.9)	12.1 (1.8)	12.8 (1.8)	11.1 (1.9)	11.9 (2.1)	12.1 (3.1)
5-10 years	15.5 (1.6)	12.7 (1.6)	13.4 (1.3)	11.8 (2.0)	12.4 (2.4)	12.5 (2.1)
> 10 years	16.1 (1.4)	13.3 (1.6)	14.2 (2.2)	12.2 (3.0)	13.3 (2.7)	13.4 (1.7)
p-value	0.004	0.002	0.001	0.003	0.002	0.004
Motivation to take ART						
Self-motivated	16.5 (1.7)	13.7 (2.4)	14.1 (1.4)	11.9 (2.0)	12.8 (1.1)	13.8 (2.0)
Compulsion	14.8 (2.0)	12.4 (2.6)	12.9 (1.9)	10.6 (1.6)	11. 5 (1.7)	12.6 (1.20)
p-value	0.001	0.002	0.004	0.003	0.002	0.001
Opportunistic infections						
Absent	16.6 (1.8)	14.1 (1.9)	14.4 (1.1)	12.2 (1.2)	13.0 (1.5)	13.9 (1.2)
Present	14.5 (2.6)	12.8 (2.1)	13.1 (2.5)	10.8 (2.8)	11.9 (2.1)	12.5 (2.0)
p-value	0.001	0.003	0.002	0.003	0.005	0.003

ART – antiretroviral therapy, SES – socio-economic status

in the ART center more regularly than the less educated participants. Moreover, they adhere to follow-up schedules and get the investigations done time-bound, which all account for better control of the disease process, better sense of well-being, and thereby better QoL. Another finding from this study is that participants with higher socio-economic scores had better QoL scores in all the domains. The analysis showed that the participants reported significantly better scores in physical, psychological, level of independence, and social relationship domains. Other studies also suggested that higher SES scores indicated better QoL [9, 16, 17].

Our study demonstrated that PLWHA who were self-motivated to take ART reported better QoL scores in all 6 domains of QoL than those who were obliged to take medications. These findings indicate patient knowledge about the long-term nature of ART, trust in the treatment process, and understanding the importance of adherence to ART. Similar findings were noted by Arjun *et al.* [9].

The current study also revealed that PLWHA who have received ART for a longer time showed significantly better QoL in all domains. Patients who were on ART for more than 10 years had better QoL mean scores. These can be due to the side effects experienced at the beginning of ART, and the fact that patients who were diagnosed with the disease long ago have already accepted the idea of life-long nature of the disease and treatment, and adapted to the lifestyle they have to follow. A study conducted by Handajani *et al.* [18] in Indonesia indicated that better QoL domain scores were observed among PLWHA receiving ART for a longer duration. Some other studies from different parts of the world provided similar results [19-21]. In other similar studies, lower QoL domain scores were reported among PLWHA receiving ART for a shorter duration [22, 23]. This can be attributed to the fact that almost all newly diagnosed PLWHA are struggling with mental stress and challenges to adjust to the treatment and its burdens. Similarly, participants with no opportunistic infections had significantly better QoL in all domains compared with those suffering from one or more opportunistic infections at the time of the study or in the past. Opportunistic infections, whether minor or major, definitely affect the patient both physically and mentally, which is reflected in the QoL.

Limitation of the study

For the study, subjects were recruited by convenient sampling from all 18 years or older PLWHA attending ART clinic of a tertiary care center. Hence, the study results might not represent the general population. The questionnaire used had 31 questions with 5 options as answers for each question, which made it difficult to narrow down the answer, as few patients complained during feedback after the interview. Also, most of these questions were regarding the feeling of the patient, which could have changed in terms of mental status of the patient during the interview.

Conclusions

The study demonstrates the importance of assessing the QoL of PLWHA, to understand their day-to-day life struggles and challenges. A lower mean QoL score in the social relationship domain point to the persisting stigma towards the disease and affected people. Proper awareness programs using digital media and similar platforms can be implemented for improving this problem. The QoL domain scores of PLWHA are higher among males, younger age groups, and participants with higher SES. Those with higher educational qualifications showed remarkably better QoL scores in all domains. Patients on ART for more than 10 years, those who were self-motivated to take ART, and subjects without any opportunistic infections, reported higher scores in all 6 domains of QoL. Providing counselling sessions and motivating patients for proper follow-up and adherence to ART can help improve their QoL.

Disclosures

1. Institutional review board statement: This study was approved by the Institutional Ethics Committee of Shimoga Institute of Medical Sciences, Shivamogga, Karnataka, India, with approval number of SIMS/IEC/838/2022-23.
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4. Conflicts of interest: None.

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